CENTRE FOR COMMUNITY-DRIVEN RESEARCH

Personal Experience, Expectations and Knowledge (PEEK)

People diagnosed with:

Bladder cancer

Volume 5 (2022), Issue 2

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Summary of results

Executive summary

There were 44 participants with bladder cancer, and 5 carers to people with bladder cancer in the study from across Australia. The majority of participants lived in major cities, they lived in all levels of economic advantage. Most of the of participants identified as Caucasian/white. Most of the participants had trade or high school qualifications, and most were employed either full time or part time, or were retired. Approximately a quarter of the participants were carers to family members or spouses.

Physical activities were not limited for participants in this study, and emotional problems rarely interfered with work or other activities.

Participants in this study had an average of two symptoms before diagnosis, and the most common symptoms were blood in urine and needing to pass urine often.

This is a group that had health conditions other than bladder cancer to deal with, most often sleep problems, arthritis or scoliosis, and anxiety,

This is a patient population that had blood in their urine leading to diagnosis which they recalled clearly. Most participants sought medical attention after noticing symptoms and were diagnosed after their general practitioner referred them to a specialist.

This is a cohort that were mostly diagnosed with bladder cancer following experiencing symptoms. On average, this group had four diagnostic tests for bladder cancer, they were diagnosed by a urologist in a specialist clinic. The cost of diagnosis was not a burden to them and their families. They were mostly diagnosed with urothelial carcinoma, and stage I. This is a group that had no emotional support at the time of diagnosis. This is a cohort that did not have any conversations about biomarker/genomic/gene testing, and had no knowledge of their biomarker status.

This is a study cohort that had no knowledge of bladder cancer before they were diagnosed. This patient population described prognosis in terms of no evidence of disease or in remission, or in relation to monitoring their condition with tests, scans, or regular follow up appointments.

This is a patient population that had discussions about multiple treatment options.

This is a study cohort that took into account the advice of their clinician as part of many considerations when making decisions about treatment.

Within this patient population, participants had not changed decision making over time, this was because they had always taken the advice of their clinician.

When asked about their personal goals of treatment or care participants most commonly described wanting to be cancer free, avoid recurrence or increase longevity

This is a group that were cared for by a urologist, and had access to a general practitioner to treat their condition.

Almost two-thirds of this cohort had private health insurance, mostly treated as private patients treated in the private hospital system. This is a group that did not have trouble paying for healthcare appointments, prescriptions, and paying for basic essentials. Their monthly expenses due to bladder cancer were not a burden.

The work status of participants in this study did not change due to bladder cancer. Carers and family did not have to change employment status.

Participants had surgery, and drug treatments for bladder cancer. The most common treatments were transurethral resection of bladder tumour and Bacillus Calmetter-Guérin.

This is a group that did not have discussion about clinical trials, though would consider taking part if there was a suitable one for them.

This is a patient population that described mild side effects as symptoms such as fatigue or lethargy. This is a study cohort that described severe side effects as symptoms such as pain.

This is a patient population which described adhering to treatment as per the advice of their specialist, as long as prescribed, or as long as treatment is working. This is a study cohort that needed to see evidence of stable disease or no disease progression. If treatment worked, it would mean that they could do everyday activities and return to normal life.

Participants in this study had very good knowledge about their condition, were good at coping with their condition, were very good at recognizing and managing symptoms, and were very good at adhering to treatment.
Participants were given information about treatment options, disease management, and disease cause from health care professionals, and searched for treatment options, disease causes, and disease management, most often. This is a group who accessed information from non-profit, charity or patient organisations most often.

This is a patient population that access information primarily through the internet, a health charity, or from other patient's experiences.

This is a study cohort that found information from health charities, other people's experiences, and what to expect from the disease, side effects and treatments as being most helpful.

Participants commonly found no information unhelpful, and information from their GP as unhelpful.

This is a group that preferred talking to someone plus online information. This is a study cohort that generally felt most receptive to information after the shock of diagnosis.

Most participants described receiving an overall positive experience with health professional communication, which was holistic, two way and comprehensive. For those that had a negative experience it was mostly communication was dismissive, a one way conversation.

The participants in this study experienced good quality of care, and good coordination of care. They had a good ability to navigate the healthcare system, and experienced moderate communication from healthcare professionals.

This is a patient population described not receiving and care or support. For those that did have support, it was from charities, their hospital or clinic, or from online support groups.

This is a patient population that experienced a negative impact on quality of life largely due to the side effects of treatment or symptoms of conditions that they need to manage

This is a study cohort that experienced at least some impact on their mental health and to maintain their mental health they noted the importance of family and friends, the importance of exercise, and mindfulness or meditation in maintaining their mental health.

Within this patient population, participants described being physically active, and the importance keeping a normal routine, and managing their stoma or incontinence in order to maintain their general health.

Participants in this study had felt vulnerable especially during or after treatments, and when first diagnosed and the first few months after diagnosis. To manage vulnerability, they practised self-help (resilience, acceptance, staying positive) to manage the feeling of vulnerability

This cohort most commonly felt there was a positive impact on their relationships, with relationships strengthened, and that people were well-meaning and supportive.

Section 1

Introduction and methods

Section 1 Introduction and methodology

Patient Experience, Expectations and Knowledge (PEEK) is a research program developed by the Centre for Community-Driven Research (CCDR). The aim of PEEK is to conduct patient experience studies across several disease areas using a protocol that will allow for comparisons over time (both quantitative and qualitative components). PEEK studies give us a clear picture and historical record of what it is like to be a patient at a given point in time, and by asking patients about their expectations, PEEK studies give us a way forward to support patients and their families with treatments, information and care.

This PEEK study in bladder cancer includes 44 people diagnosed with bladder cancer throughout Australia. In addition, 5 carers or family members to people with bladder cancer took part.

Bladder cancer occurs more frequently in men and those over 60 years of age. In 2021 there were and estimated 3,066 new cases of bladder cancer in Australia, approximately 2,400 of these were men; the median age was 76.3 years. There were an estimated 653 deaths from bladder cancer in Australia in 2021, it is the 9th most common cause of death from cancer[2]. The five year survival during the period 2031 to 2017 was 55%. In Australia, at the end of 2016, there were 8165 people living with bladder cancer.

There was a decrease in 5 year survival from 68% in 1982 – 1987, to 53% in 2009-2013, the reasons for this are not clear and cannot be explained by an increase in age at diagnosis which has only modestly increased in this time period[1,4] . However, there was a decrease in age-standardised mortality rate from 5.4 per 100,000 in 1982 to 3.8 per 100,000 in 2017, this is due to a reduction of overall incidence.

Section 2

Demographics

Section 2 Demographics

Participants

There were 43 people with bladder cancer, and 5 carers of people with bladder cancer who took part in this study. There were 5 participants (10.42%) with Stage 0, 14 participants (29.17%) with Stage I, 10 participants (20.83%) with Stage II, 10 participants (20.83%) with Stage III, 4 participants (8.33%) with stage IV bladder cancer, and 5 carers (10.42%).

Demographics: Participants with bladder cancer

There were 43 people with bladder cancer that took part in this study, 17 were females (39.53%).

Participants were most commonly from New South Wales (n=20, 46.51%), Victoria (n=11, 25.58%), and South Australia (n=5, 11.63%). Most participants were from major cities (n=30, 69.77%), and they lived in all levels of advantage, defined by Socio-economic Indexes for Areas (SEIFA) (www.abs.gov.au) with 26 participants (60.47%) from an area with a high SEIFA score of 7 to 10 (more advantage), and 20 participants (41.67%) from an area of mid to low SEIFA scores of 1 to 6 (less advantaged).

There were 18 participants (41.86%) that had completed university to at least an associate degree. There were 19 participants (44.19%), who were employed either full time or part time.

Approximately a quarter of participants were carers to family members or spouses (n=11,25.58%), most commonly carers to Children (n=5, 11.63%).

Demographics: Participants that are carers to people with bladder cancer

There were 5 carers to people with bladder cancer that took part, all were carers to males with bladder cancer. Carers most commonly lived in metropolitan areas (n=3, 60.00%), and were from NSW (n=2, 40.00%), or Victoria (n=2, 40.00%). The majority of carers were in either full or part time work (n=4, 80.00%).

Other health conditions

Participants were asked about health conditions other than bladder cancer that they had to manage. Participants could choose from a list of common health conditions and could specify other conditions.

The majority of participants had at least one other condition that they had to manage (n=38, 90.48%), the maximum number reported was 9 other conditions, with a median of 2.00 other conditions (IQR = 3.00). The most commonly reported health conditions were sleep problems (n=17, 40.48%), and anxiety (n=17, 40.48%), followed by arthritis or scoliosis (n=16, 38.10%), and depression (n=11, 26.19%).

Participants were asked a follow up question about their quality of life from these other conditions. Quality of life was rated on a Likert scale from one to seven, where one is “Life was very distressing” and seven is “Life was great”. Median quality of life is presented where five or more participants reported the symptom.

Quality of life from other conditions ranged from 3.00 (life was a little distressing) to 5.00 (life was good).

Baseline health

The Short Form Health Survey 36 (SF36) measures baseline health, or the general health of an individual. The SF36 comprises nine scales: physical functioning, role functioning/physical, role functioning/emotional, energy and fatigue, emotional well-being, social function, pain, general health, and health change from one year ago. The scale ranges from 0 to 100, a higher score denotes better health or function.

SF36 Physical functioning scale measures health limitations in physical activities such as walking, bending, climbing stairs, exercise, and housework. On average, physical activities were not limited for participants in this study.

SF36 Role functioning/physical scale measures how physical health interferes with work or other activities. On average, physical health sometimes interfered with work or other activities for participants in this study.

SF36 Role functioning/emotional scale measures how emotional problems interfere with work or other activities. On average, emotional problems never interfered with work or other activities for participants in this study.

SF36 Energy/fatigue scale measures the proportion of energy or fatigue experienced. On average, participants were sometimes fatigued.

The **SF36 Emotional well-being** scale measures how a person feels, for example happy, calm, depressed or anxious. On average, participants had good emotional well-being.

The **SF36 Social functioning** scale measures limitations on social activities due to physical or emotional problems. On average, social activities were slightly limited for participants in this study.

The **SF36 Pain** scale measures how much pain, and how pain interferes with work and other activities. On average, participants had mild pain.

The **SF36 General health** scale measures perception of health. On average, participants reported average health.

The **SF36 Health change** scale measures health compared to a year ago. On average, participants reported that their health is about the same as a year ago.

Participants felt they were a burden on their family, due to the mental or emotional strain.

Most participants felt there was some cost burden which was from the costs of treatments, and gap payments for public or private health.

The participants in this PEEK study had moderate levels of anxiety in relation to their condition.

Participants would like future treatments to be more accessible particularly equitable, timely and includes access in rural locations, and for there to be more open and informed discussions about treatments.

This is a study cohort that would like information to be more accessible and easy to find, and also to include all treatment options available to them. Many participants were happy with the information they had about their condition.

Participants in this study would like future communication to be more transparent and forthcoming, and delivered with more empathy.

Participants would like future treatments to include access to appropriate real-world support services. Many participants were happy with the care and support they received.

This patient population was grateful for healthcare staff, and for low cost or free medical treatments through the government.

It was important for this cohort to control, pain, nausea and vomiting, and diarrhoea. Participants in this study would consider taking a treatment for more than ten years if quality of life is improved with no cure.

Participants' message to decision-makers was to raise community awareness, and that they were grateful for the healthcare system and the treatment they had received.

This is a patient population that wished they had known what to expect from their condition especially the symptoms, and side effects of medication. They also wished they had been more assertive in relation to understanding treatment options and discussions about treatment

The aspect of care or treatment that participants in this study would most like to change is to have is they would have like more time and personalised attention with specialists.

Section 3

Symptoms and diagnosis

Section 3: Symptoms and diagnosis

Experience of symptoms before diagnosis

Participants were asked in the questionnaire which symptoms they had before diagnosis, they could choose from a set list of symptoms and could then specify other symptoms not listed.

There were 3 participants (6.98%) that had no symptoms before diagnosis. Participants had a maximum of 6 symptoms, and a median of 2.00 (IQR=2.00).

Symptoms before diagnosis

The most common symptoms before diagnosis were blood in urine (n=33, 76.74%), needing to pass urine often (n=16, 37.21%), lower abdominal/stomach or back pain (n=14, 32.56%), and burning feeling when passing urine (n=12, 27.91%).

Participants were asked a follow up question about their quality of life while experiencing these symptoms. Quality of life was rated on a Likert scale from one to seven, where one is “Life was very distressing” and seven is “Life was great”. Median quality of life is presented where five or more participants reported the symptom.

The median quality of life was between 3.00 and 4.50, for all of the symptoms listed in the questionnaire, this is in the “Life was a little distressing” to “Life was average to good” range. The symptoms with the worst quality of life were needing to pass urine often, and a burning feeling when passing urine.

Symptoms leading to diagnosis

In the online questionnaire, participants were asked to select every symptom that they had at diagnosis. In the structured interview, participants were asked to describe the symptoms that actually *led* to their diagnosis.

The majority participants described symptoms leading to a diagnosis in a clear way (n=43, 87.76%). There were 4 participants (8.16%) that described symptoms leading to diagnosis but not with a clear recollection, and there were 2 participants (4.08%) that described having no symptoms.

The most common symptom leading to diagnosis was having blood in urine (n=35, 71.43%), this was followed by pain in the bladder region (n=4, 8.16%), and having frequent or prolonged urinary tract infections (n=3, 6.12%). There were 7 participants (14.29%) that described changes in urinary habits which did not lead to diagnosis, however recognised the importance in hindsight.

Symptoms leading to diagnosis: Seeking medical attention

Participants described when they sought medical attention after noticing symptoms. There were 37 participants (75.51%) that described having symptoms and seeking medical attention relatively soon. There were 8 participants (16.33%) that described having symptoms and not seeking medical attention initially, and 4 participants (8.16%) that described not having any symptoms before diagnosis

Symptoms leading to diagnosis: Description of diagnostic pathway

Participants were most commonly referred directly to a specialist from their general practitioner which led to their diagnosis (n=30, 61.22%), and this was followed by being diagnosed by their general practitioner due to concerns about symptoms (n=10, 20.41%). There were 6 participants (12.24%) that described being diagnosed after being admitted into the emergency department or hospital, and 3 participants (6.12%) that were diagnosed by their general practitioner following routine check-up or incidental finding.

Time from symptoms to diagnosis

Participants were asked to give the approximate date of when they first noticed symptoms of bladder cancer and the approximate date of diagnosis with bladder cancer. Where enough information was given, an approximate duration from first noticing symptoms to diagnosis was calculated.

Duration was calculated for 42 participants. There were 12 participants (28.57%) that were diagnosed less than 1 month of noticing symptoms, 13 participants (30.95%) diagnosed 1 to 3 months from noticing symptoms, 6 participants (14.29%) that were diagnosed 3 to 6 months of noticing symptoms, and 11 participants (26.19%) that were diagnosed 6 months or more after noticing symptoms.

Time from diagnostic test to receiving a diagnosis

Participants were asked in the online questionnaire how long they waited between diagnostic tests and getting a diagnosis.

Participants were most commonly diagnosed less than a week after diagnostic tests (n = 12, 27.91%). There were 11 participants (25.58%) that were diagnosed less than between 1 and 2 weeks after diagnostic tests, 10 participants (23.26%) diagnosed between 2 and 3 weeks, 10 participants (23.26%) diagnosed more than four weeks after diagnostic testing.

Diagnostic tests

Participants were asked in the questionnaire which diagnostic tests they had for their diagnosis with bladder cancer. They could choose from a set list of diagnostic tests, and could then specify other tests not listed. The number of tests per participant were counted using both tests from the set list and other tests specified.

Participants reported between 1 to 6 diagnostic tests (median=4.00, IQR=2.00). The most common tests were cystoscopy and biopsy (n=37, 86.05%), urine tests (n=32, 74.42%), ultrasound scans (n=29, 67.44%), and CT scans (n=27, 62.79%).

Diagnosis provider and location

Participants were asked in the online questionnaire, which healthcare professional gave them their diagnosis, and where they were given the diagnosis.

The majority of participants received their diagnosis by a urologist (n=33, 76.74%). There were 8 participants (18.60%) that received their diagnosis from a general practitioner.

Participants were most commonly given their diagnosis in the specialist clinic (n=19, 44.19%), this was followed by the hospital (n=14, 32.56%), and the general practice (GP) (n=7, 16.28%).

Year of diagnosis

Participants were diagnosed between 2004 to 2022. There were 18 participants (42.86%) that were diagnosed in the last three years.

Bladder cancer diagnosis

The majority of participants were diagnosed with urothelial carcinoma (n=25, 58.14%), followed by squamous cell carcinoma (n=4, 9.30%). There were 3 participants (6.98%) that were diagnosed with adenocarcinoma, and 3 participants (6.98%), diagnosed with transitional cell carcinoma. There were 9 participants (20.93%) who were not sure about the type they were diagnosed with.

Bladder cancer stage

There were 43 people with bladder cancer who took part in this study. There were 5 participants (11.63%) with Stage 0, 14 participants (32.56%) with Stage I, 10 participants (23.26%) with Stage II, 10 participants (23.26%) with Stage III and 4 participants (9.30%) with stage IV bladder cancer.

Bladder cancer spread

Participants noted in the online questionnaire if the cancer had spread, and where it had spread to. There were 7 participants (16.28%) that noted that the cancer had spread. The most common site of spread were lymph nodes (n=4, 9.30%).

Bladder cancer recurrence

Almost half of the participants noted that they had a bladder cancer recurrence (n=21, 48.84%), there were 17 participants (39.53%) that had not had a recurrence and there were 5 participants that were not sure (11.63%).

Understanding of disease at diagnosis

Participants were asked in the structured interview how much they knew about their condition at diagnosis. Most participants described having no understanding about the condition at diagnosis (n=32, 65.31%), this was followed by knowing very little about the condition (n=13, 26.53%), and having a good understanding (n=3, 6.12%). The most common reason for having limited knowledge was from doing research through the diagnostic process (n=7, 14.29%).

Emotional support at diagnosis

Participants were asked in the online questionnaire how much emotional support they or their family received between diagnostic testing and diagnosis.

There were 10 participants (23.26%) who had enough support, 5 participants (11.63%) that had some support but it wasn't enough, and 28 participants (65.12%) had no support.

Out of pocket expenses at diagnosis

Participants noted in the online questionnaire the amount of out-of-pocket expenses they had at diagnosis, for example doctors' fees, and diagnostic tests.

There were 14 participants (32.56%) who had no out of pocket expenses, and 15 participants (34.88%) who did not know or could not recall. There were 3 participants (6.98%) that spent $1 to $250, 3 participants (6.98%) that spent between $251 to $500, 2 participants (4.65%) that spent $501 to $1000, and 6 participants (13.95%) that spent more than $1000.

Burden of diagnostic costs

In the follow-up question about the burden of costs at diagnosis, for 30 participants who had out of pocket expenses.

For 28 participants (73.68%) the cost was slightly or not at all significant. For 6 participants (15.79%) the out-of-pocket expenses were somewhat significant, and for 4 participants (10.53%), the burden of out-of-pocket expenses were moderately or extremely significant.

Genetic tests and biomarkers

Participants answered questions in the online questionnaire about if they had any discussions with their doctor about biomarkers, genomic and gene testing that might be relevant to treatment. If they did have a discussion, they were asked if they brought up the topic or if their doctor did.

Most commonly, participants had never had a conversation about biomarkers, genomic, or gene testing that might be relevant to treatment, (n=39, 90.70%). There were 3 participants (6.98%) who brought up the topic with their doctor, and a single participant (2.33%) whose doctor brought up the topic with them.

Participants were then asked if they had had any biomarker, genomic or gene testing. If they had testing, they were asked if they had it as part of a clinical trial, paid for it themselves or if they did not have to pay for it. Those that did not have the test were asked if they were interested in this type of test.

The majority of participants did not have any genetic or biomarker tests but would like to (n=32, 74.42%). There were 9 participants (20.93%) who did not have these tests and were not interested in them, and a single participant (2.33%) that had biomarker tests.

Biomarker status

All participants (n=43, 100%) were not sure about any markers that they have in relation to bladder cancer.

Understanding of prognosis

Participants were asked in the structured interview to describe what their current understanding of their prognosis was. Participants most commonly described their prognosis in relation to having no evidence of disease or that they are in remission (n=28, 57.14%), and in relation to monitoring their condition with tests, scans, or regular follow up appointments (n=28, 57.14%). There were 12 participants (24.49%) that described prognosis in relation to probable recurrence/cycle of recurrence, 10 participants (20.41%) that described prognosis in relation to tumour grade or stage, and 7 participants (14.29%) described prognosis in relation to a specific timeframe that they have been disease free.

Section 4

Decision-making

Section 4 summary

Discussions about treatment

Participants were asked to recall what treatment options they were presented with and how they felt about such options. The most common description was being presented with multiple treatment options, and this was described by 34 participants (69.39%). This was followed by being presented with one treatment option only (n=14, 28.57%).

Discussions about treatment (Participation in discussions)

In relation to participant in discussions about treatments, of the participants that were presented with multiple treatment options, 10 participants (20.41%) described taking part in the decision-making process, and the same number described not participating in the decision making process (n=10, 20.41%). There were 6 participants (12.24%) that described discussing multiple options, however they felt there was only one viable option. Of the participants presented with one option, they most commonly described being told what to do with out any discussion (n=5, 40.20%).

Considerations when making decisions

Participants were asked in the structured interview what they considered when making decisions about treatment. The most reported theme was taking the advice of their clinician, and this was described by 23 participants (46.94%). There were 15 participants (30.61%) that considered being cancer free, avoiding recurrence, or longevity, and 12 participants (24.49%) that described taking side effects into account. Other considerations included taking ease of administration into account (n=8, 16.33%), quality of life (n=7, 14.29%), costs (n=5, 10.20%), and impact on family and dependents (n=5, 10.20%).

Decision-making over time

Participants were asked if the way they made decisions had changed over time. There were 28 participants (57.14%) that felt the way they made decisions about treatment had not changed over time, and 20 participants (40.82%) that described decision making changing.

Where participants had not changed their decision making over time, this was because they have always taken the advice of clinicians (n=11, 22.45%), or had always been informed and assertive (n=7, 14.29%). Where participants had changed the way they make decisions, this was primarily in relation to becoming more informed or more assertive (n=13, 26.53%).

Personal goals of treatment or care

Participants were asked what their own personal goals of treatment or care were. The most common response was wanting to be cancer free, avoid recurrence or increase longevity (n=20, 40.82%), and this was followed by wanting to improve their quality of life or return to normality (n=15, 30.61%). Other themes included wanting to minimise or avoid side effects (n=10, 20.41%), bladder preservation (n=8, 16.33%), wanting to be supported/reassured/informed by their healthcare team (n=6, 12.24%), and not having personal goals as they are guided by their doctor (n=5, 10.20%).

Section 5

Treatment

Section 5: Experience of treatment

Access to healthcare professionals

Participants noted in the online questionnaire the healthcare professionals they had access to for the treatment and management of their condition.

Almost all participants had access to a urologist (n=41, 97.62%), and a general practitioner (GP) (n=40, 95.24%) A total of 26 participants (61.90%) noted that they had access to a nurse for their bladder cancer, there were 14 participants (33.33%) that had a stoma nurse, 17 participants (40.48%) that had a registered nurse, and 7 participants that had a nurse care coordinator (16.67%)

There were 13 participants (30.95%) treated by a physiotherapist, 8 participants (19.05%) treated by a Counsellor or had psychological support, and 5 participants (11.90%) treated by a dietician.

Health care system

In the online questionnaire, participants were asked questions about the healthcare system they used, about private insurance and about whether they were treated as a public or private patient.

The majority of participants had private health insurance (n=27, 64.29%). Throughout their treatment, there were 16 participants (38.10%) that were treated mostly as a private patient, 19 participants (45.24%) were mostly treated as a public patient, and there were 7 participants (16.67%) that were equally treated as a private and public patient.

Throughout their treatment, there were 19 participants (45.24%) that were treated mostly in the private hospital system, 17 participants (40.48%) were mostly treated in the public system, and there were 6 participants (14.29%) that were equally treated in the private and public systems.

Affordability of healthcare

Participants were asked a series of questions about affordability of healthcare in the online questionnaire. The first question was about having to delay or cancer healthcare appointments because they were unable to afford them. Almost all the participants never or rarely had to delay or cancel appointments due to affordability (n = 40, 95.24%).

The next question was about the ability to fill prescriptions. Almost all of the participants never or rarely were unable to fill prescriptions (n=41, 97.62%).

The third question was about the affordability of basic essentials such as such as food, housing and power. There were 38 participants (90.48%) that never or rarely had trouble paying for essentials, and 2 participants (4.76%) that sometimes found it difficult, and 2 participants (4.76%) often or very often found it difficult to pay for basic essentials.

The final question was about paying for additional carers for themselves or for their family, no participants had paid for additional carers.

Cost of condition

In the online questionnaire, participants estimated the amount they spend per month due to their condition, including doctors' fees, transport, carers, health insurance gaps and complementary therapies. Where the response was given in a dollar amount, it is included below.

The most common amount was $50 or less (n=9, 21.43%), followed by between $51 to $100 (n=7, 16.67%), and $101 to $250 (n=5, 11.90%). There were 2 participants (4.76%), that spent $501 or more a month.

Burden of cost

As a follow up question, for participants that had monthly expenses due to their condition, participants were asked if the amount spent was a burden.

The amount spent was a slightly or not at all significant burden for 36 participants (85.71%), somewhat significant for 4 participants (9.52%), and moderately or extremely significant burden for 2 participants (4.76%).

Changes to employment status

Participants were asked, in the online questionnaire, if they had any changes to their employment status due to their condition. Participants were able to choose multiple changes to employment.

Work status for 7 participants (16.67%) had not changed since diagnosis, and 18 participants (42.86%) were retired or did not have a job. There were 4 participants (9.52%) had to quit their job, 6 participants (14.29%) reduced the number of hours they worked, and 2 participants (4.76%) that accessed their superannuation early. There were 5 participants (11.90%) that took leave from work without pay, and 10 participants (23.81%) that took leave from work with pay.

Changes to carer/partner employment status

Participants were asked, in the online questionnaire, if they had any changes to the employment status of their care or partner due to their condition. Participants were able to choose multiple changes to employment.

Most commonly, participants had partners or carers that did not change their work status due to their condition (n=27, 64.29%). There was a single participant (2.38%) whose partner reduced the number of hours they worked, and 2 partners, (4.76%) that quit their job.   No partners participants took leave without pay, and there were 2 partners (4.76%) that took leave with pay.

Reduced income due to condition

Participants noted in the online questionnaire details about and changes to income due to the bladder cancer diagnosis.

Approximately a third of the participants (n=12, 28.57%) indicated in the online questionnaire that they had a reduced family income due to their condition.

Estimated reduction monthly income

As a follow up question, participants were asked if their family or household income had reduced due to their condition. Most commonly, participants monthly income was reduced by more than $1000 per month (n=5, 11.90%), or reduced by between $501 to $1000 per month (n=4, 9.52%).

Summary of treatment

Participants noted in the online questionnaire the different treatments, they had since diagnosis with their condition.

All participants were treated for bladder cancer. There were 40 participants (95.24%) that had surgery, 20 participants (47.62%) that had chemotherapy and 24 participants (57.14%) that had Bacillus Calmetter-Guérin (BCG), 3 participants had radiotherapy (7.14%), and a single participant had immunotherapy (2.38%)

Summary of surgery

In the online questionnaire, participants noted the number of operations (excluding biopsies) that they had for their condition.

There were 40 participants (95.24%) that had surgery for their condition (excluding biopsies). There were 16 participants (38.10%) that had one operation, 9 participants (21.43%) that had two operations, 4 participants (9.52%) that had three operations, and 11 participants (26.19%) that had four or more operations.

Most common types of surgery

Participants completed a series of questions about surgery, including type of surgery, quality of life, and effectiveness of surgery.

There were 40 participants (95.24%) that had surgery for their condition. The most common type of surgery was transurethral resection of bladder tumour (TURBT) (n=,30, 71.43%), followed by radical cystectomy (n=19, 45.24%), and urostomy (n= 15, 35.71%).

Quality of life and effectiveness of surgery

Quality of life was rated on a Likert scale from one to seven, where one is “Life was very distressing” and seven is “Life was great”. Effectiveness of treatment was rated on a five-point scale where one is ineffective, and five is very effective. Values are calculated where there was adequate data available (five or more participants).

Median quality of life from surgery ranged from 2.00 to 5.00, in the life was distressing to good range. The median effectiveness of all surgery was between 3.50 to 5.00, in the moderately to very effective range.

On average, quality of life from transurethral resection of bladder tumour (TURBT) was in the 'life was a little distressing' range (median=3.00, IQR = 1.00), and was found to be moderately effective to effective (median=3.50, IQR=2.75).

On average, quality of life from radical cystectomy was in the 'life was distressing' range (median=2.00, IQR=1.00), and was found to be very effective (median=5.00, IQR=0.00).

On average, quality of life from urostomy was in the 'life was good' range (median=5.00, IQR=1.00), and was found to be very effective (median=5.00, IQR=0.00).

Summary of drug treatments

Participants completed a series of questions about drug treatments, including type of treatment, quality of life, and effectiveness of treatment.

There were 20, participants (47.62%) that had chemotherapy. The most common types of chemotherapy were MVAC chemotherapy (methotrexate, vinblastine, doxorubicin/ Adriamycin, and cisplatin), (n=5, 11.90%), and Gemcitabine with cisplatin n=5,11.90%). There were 24 participants (57.14%) that had Bacillus Calmetter-Guérin (BCG).

Median quality of life from drug treatments ranged from 1 to 4, in the life was very distressing to good range. The median effectiveness of all surgery was between 2.5 to 4, in the somewhat effective to effective range.

On average, quality of life from Bacillus Calmetter-Guérin (BCG) was in the 'life was a little distressing to average' range (median=3.50, IQR=2.00), and was found to be somewhat to moderately effective (median=2.50 , IQR=3.25).

On average, quality of life from methotrexate, vinblastine, doxorubicin/Adriamycin, and cisplatin was in the 'life was average' range (median=4.00, IQR=2.00), and was found to be effective (median=4.00, IQR=1.00).

On average, quality of life from gemcitabine with cisplatin was in the 'life was very distressing' range (median=1.00, IQR=2.00), and was found to be effective (median=4.00, IQR=1.00).

Clinical trials discussions

In the online questionnaire, participants were asked if they had discussions with their doctor about clinical trials, and if they did, who initiated the discussion.

There was a total of 10 participants (23.81%) that had discussions about clinical trials, 5 participants (11.90%) had brought up the topic with their doctor, and the doctor of 5 participants (11.90%) brought up the topic. The majority of participants had not spoken to anyone about clinical trials (n=32, 76.19%).

Clinical trial participation

As a follow up question, participants were asked if they had taken part in a clinical trial, and if they had not taken part if they were interested in taking part.

There were 5 participants (11.90%) that had taken part in a clinical trial, 21 participants (50.00%) that would like to take part in a clinical trial if there was a suitable one, and 16 participants, that have not participated in a clinical trial and do not want to (38.10%).

Description of mild side effects

In the structured interview, participants were asked how they would describe the term ‘mild side effects’. The most common description of ‘mild side effects’ was a specific side effect as an example (n=36, 73.47%). This was followed by describing ‘mild side effects’ as those that can be self-managed (n=10, 20.41%), those that do not interfere with daily life (n=9, 18.37%), and as those that have a short duration or are reversable (n=7, 14.29%).

Of those who described a specific side effect, the most commonly described side effects were fatigue or lethargy (n=11, 22.45%%), mild pain or aches (n=7, 14.29%) and nausea (n=6, 12.24%). Other side effects described by fewer than 5 participants, included hair loss, stoma bag/irritation/leaks, emotion/mental impact, and cystitis/UTIs.

Description of severe side effects

In the structured interview, participants were asked how they would describe the term ‘severe side effects’. The most common description of ‘severe side effects’ was a specific side effect as an example (n=34, 69.39%). Other descriptions of ‘severe side effects’ included those that impact everyday life/ability to conduct activities of daily living (n=9, 18.37%), and those that are long lasting (n=6, 12.24%). There were 6 participants (12.24%) that were unable to describe severe side effects as they had not experienced them.

Of those who described a specific side effect, the most commonly described side effects were pain (n=18, 36.73%), the emotional or mental impact of the condition, (n=7, 14.29%), and pain when urinating (n=5, 10.20%). Other side effects described by fewer than 5 participants, included fatigue, nausea, fever or infection, and incontinence.

Adherence to treatment

Participants were asked in the structured interview what influences their decision to continue with a treatment regime. The most common themes described were adhering to treatment as per the advice of their specialist/as long as prescribed (n=20, 40.82%), and adhering to treatment as long as treatment is working (n=16, 32.65%). This was followed by adhering to treatment as long as side effects are tolerable (n=12, 24.49%%), adhering to treatment for a specific amount of time (n=11, 22.45%), and 7 participants (14.29%) described not giving up on any treatments.

Where participants stated a specific amount of time to adhere to a treatment, the most common amount of time was two to three weeks.

What needs to change to feel like treatment is working

Participants were asked to describe what needs to change to feel like treatment is effective. The most common response from 24 participants (48.89%) was needing to experience evidence of stable disease/no disease progression. There were 14 participants (28.57%) that reported needing to experience a reduction in physical signs/reduced side effects, and 13 participants (26.53%) needed to see specific symptom reduction. The most common specific symptoms were nausea, aches and pains, fatigue and lethargy, and muscle cramping.

What would it mean if treatment worked

Participants were asked what it would mean to them if their treatment worked. The most common response from 16 participants (32.65%) was treatment allowing them to do everyday activities/ return to normal life. There were 12 participants (24.49%) that reported treatment working as having a positive impact on their mental health, 8 participants (16.33%) described treatment leading to a reduction in symptoms/side effects, and 8 participants (16.33%) described treatment allowing them to engage more with social activities and family life. Other participants described that treatment would allow them to keep their bladder (n=6, 12.24%), and allow them to do more exercise (n=6, 12.24%).

Section 6

Information and communication

Section 6: Information and communication

Access to information

In the structured interview, participants were asked what information they had been able to access since they were diagnosed. The most common type of information accessed by 41 participants (83.67%) was the internet in general, this was followed by accessing information through a bladder cancer charity (n=32, 65.31%), and through other patient's experience (n=24, 48.98%). Other participants described accessing information from books, pamphlets and newsletters (n=16, 32.65%), through treating clinician (n=13, 26.53%), through international sources (n=13, 26.53%), through Facebook and/or social media (n=9, 18.37%), and through journals (research articles) (n=8, 16.33%).

Where participants mentioned specific health charities, these were most commonly BEAT Bladder Cancer Australia (n=19, 38.78%), Cancer Council (n=18, 36.73%), and Bladder Cancer Awareness Australia (n=5, 10.20%).

Information that was helpful

In the structured interview, participants were asked to describe what information they had found to be *most* helpful. The most common type of information found to be helpful by 16 participants (32.65%) was information from health charities. There were 14 participants (28.57%) that described information from other people's experiences as helpful, and 14 participants (28.57%) that described hearing what to expect (e.g. from disease, side effects, treatment) as being helpful. Other types of information described as being helpful included treatment options (n=10, 20.41%), talking to their doctor or specialist (n=8, 16.33%), information specific to their condition (n=8, 16.33%), and information about stoma management or from their stoma nurse (n=7, 14.29%).

Information that was not helpful

In the structured interview, participants were asked if there had been any information that they did not find to be helpful. There were 22 participants (44.90%) that responded that no information was not helpful, and 7 participants (14.29%) that were confident in deciding if something is not helpful (or not credible). The most common type of information found to be unhelpful by 9 participants (18.37%) was from their GP or specialist, this was followed by worse case scenarios (n=5, 10.20%), and a lack of information in general, and lack of community awareness as not helpful (n=5, 10.20%).

Information preferences

Participants were asked whether they had a preference for information online, talking to someone, in written (booklet) form or through a phone App. Overall, the most common theme was talking to someone plus online information (n=17, 34.69%), followed by talking to someone (n=14, 28.57%), online (n=14, 28.57%), and written information preference (n=11, 22.45%).

The main reasons for a preference for online information were accessibility, being able to digest information at their own pace, and finding personalised or relevant information. The main reasons for talking to someone as a preference were being able to ask questions, get personalised or relevant information, and feeling supported. The main reason for written material as a preference was being able to refer back to it.

Timing of information

Participants in the structured interview were asked to reflect on their experience and to describe when they felt they were most receptive to receiving information. The most common time that participants described being receptive to receiving information after the shock of diagnosis (n=18, 36.73%), this was followed by participants describing being receptive to information from the beginning when diagnosed (n=13, 26.53%), after the start of treatment (n=9, 18.37%), and continuously throughout their experience or bit-by-bit so that it is digestible (n=9, 18.37%). Other participants described being receptive to information after they have had time to learn about condition/thought about questions to ask their healthcare professional (n=7, 14.29%), and a month after diagnosis (n=5, 10.20%).

Healthcare professional communication

Participants were asked to describe the communication that they had had with health professionals throughout their experience. The most common theme was that participants described having an overall positive experience (n=22, 44.90%). There were 13 participants (26.53%) that described an overall positive experience, with the exception of one or two occasions, 9 participants (18.37%) that had an overall negative experience and 4 participants (8.16%) that had an overall negative experience.

Healthcare professional communication (Rationale for response)

Participants described reasons for positive or negative communication with healthcare professionals.

Participants that had positive communication, described the reason for this was because of holistic, two-way, supportive and comprehensive conversations (n=18, 36.73%), and this was followed by participant describing good communication with no particular reason given (n=17, 34.69%).

The main reasons for negative communication was limited communication that was not supportive, or empathetic (n=10, 20.41%), that information about treatment being withheld or given too late (n=8, 16.33%), and was limited in relation to their understanding of the condition (n=6, 12.24%)

Partners in health

The Partners in Health questionnaire (PIH) measures an individual's knowledge and confidence for managing their own health. The Partners in Health comprises a global score, 4 scales; knowledge, coping, recognition and treatment of symptoms, adherence to treatment and total score. A higher score denotes a better understanding and knowledge of disease.

The **Partners in Health questionnaire (PIH)** measures an individual's knowledge and confidence for managing their own health.

The **Partners in health: knowledge** scale measures the participants knowledge of their health condition, treatments, their participation in decision making and taking action when they get symptoms. On average, participants in this study had very good knowledge about their condition and treatments.

The **Partners in health: coping** scale measures the participants ability to manage the effect of their health condition on their emotional well-being, social life and living a healthy life (diet, exercise, moderate alcohol and no smoking). On average, participants in this study had a good ability to manage the effects of their health condition.

The **Partners in health: treatment** scale measures the participants ability to take medications and complete treatments as prescribed and communicate with healthcare professionals to get the services that are needed and that are appropriate. On average participants in this study had a very good ability to adhere to treatments and communicate with healthcare professionals.

The **Partners in health: recognition and management of symptoms** scale measures how well the participant attends all healthcare appointments, keeps track of signs and symptoms, and physical activities. On average participants in this study had very good recognition and management of symptoms.

The **Partners in health: total score** measures the overall knowledge, coping and confidence for managing their own health. On average participants in this study had a good overall knowledge, coping and confidence for managing their own health.

Information given by health professionals

Participants were asked about what type of information they were given by healthcare professionals, information about treatment options (n=38, 80.85%), disease management (n=23, 48.94%), disease cause (n=22, 46.81%), and physical activity (n=16, 34.04%) were most frequently given to participants by healthcare professionals, and, information about complementary therapies (n=3, 6.38%), how to interpret test results (n=3, 6.38%) and, hereditary considerations (n=0, 0.00%) were given least often.

Information searched independently

Participants were then asked after receiving information from healthcare professionals, what information did they need to search for independently. The topics participants most often searched for were treatment options (n=28, 59.57%), disease cause (n=26, 55.32%), disease management (n=21, 44.68%) and, how interpret test results (n=18, 38.30%) were most frequently searched for independently and, information about physical activity (n=13, 27.66%), clinical trials (n=10, 21.28%), and hereditary considerations (n=7, 14.89%) were searched for least often.

Information gaps

The largest gaps in information, where information was neither given to patients nor searched for independently were hereditary considerations (n=40, 85.11%) and clinical trials (n=33, 70.21%).

The topics that participants did not search for independently after receiving information from healthcare professionals were treatment options (n=22, 46.81%) and disease Cause (n=12, 25.53%).

The topics that participants were given most information from both healthcare professionals and searching independently for were treatment options (n=16, 34.04%) and disease management (n=12, 25.53%).

The topics that participants searched for independently after not receiving information from healthcare professionals were how to interpret test results (n=17, 36.17%), and disease cause (n=14, 29.79%).

Most accessed information

Participants were asked to rank which information source that they accessed most often, where 1 is the most trusted and 4 is the least trusted. Across all participants, information from Non-profit organisations, charity or patient organisations and the hospital or clinic where treated. Information from Pharmaceutical companies were least accessed.

My Health Record

My Health Record is an online summary of key health information, an initiative of the Australian Government. There were 16 participants (33.33%) had accessed My Health Record.

Of those that had accessed My Health Record, there were 11 participants (68.75%) who found it to be poor or very poor, 4 participants (25.00%) who found it acceptable, and 1 participant (6.25%) who found it to be good or very good.

Section 7

Care and support

Section 7: Experience of care and support

Care coordination

A Care Coordination questionnaire was completed by participants within the online questionnaire. The Care Coordination questionnaire comprises a total score, two scales (communication and navigation), and a single question for each relating to care-coordination and care received. A higher score denotes better care outcome.

The **Care coordination: communication** scale measures communication with healthcare professionals, measuring knowledge about all aspects of care including treatment, services available for their condition, emotional aspects, practical considerations, and financial entitlements. The average score indicates that participants had moderate communication with healthcare professionals.

The **Care coordination: navigation** scale navigation of the healthcare system including knowing important contacts for management of condition, role of healthcare professional in management of condition, healthcare professional knowledge of patient history, ability to get appointments and financial aspects of treatments. The average score indicates that participants had good navigation of the healthcare system.

The **Care coordination: total score** scale measures communication, navigation and overall experience of care coordination. The average score indicates that participants had moderate communication, navigation and overall experience of care coordination.

The **Care coordination: care coordination global measure** scale measures the participants overall rating of the coordination of their care. The average score indicates that participants scored rated their care coordination as good.

The **Care coordination: Quality of care global measure** scale measures the participants overall rating of the quality of their care. The average score indicates that participants rated their quality of care as good.

Experience of care and support

In the structured interview, participants were asked what care and support they had received since their diagnosis. This question aims to investigate what services patients consider to be support and care services. The most common theme was that participant did not receive any support (n=18, 36.73%). This was followed by receiving support through charities (n=15, 30.61%), hospital and clinical setting (including nurse support) (n=14, 28.57%), online, phone or social media peer support (n=12, 24.49%), and face-to-face peer support (n=8, 16.33%). There were 5 participants (10.20%) that described not needing any help or support.

Section 8

Quality of life

Section 8: Quality of life

Impact on quality of life

In the structured interview, participants were asked whether they felt that their condition had affected their quality of life. Overall, there were 14 participants (28.57%) that described a negative impact on quality of life, 12 participants (24.49%) that reported some negative impact on quality of life, and 12 participants (24.49%) that described a mix of positive and negative impacts on quality of life. Other participants described no impact on quality of life (n=10, 20.41%), an overall positive impact on quality of life (n=8, 16.33%, and a minimal impact on quality of life (n=8, 16.33%).

The most common themes in relation to a negative impact on quality of life were due to the side effects of treatment or symptoms of conditions that they need to manage (n=18, 36.73%), the mental and emotional impact of their condition (n=16, 32.65%), emotional strain on family or partner/change in relationship dynamics (n=14, 28.57%), intimacy problems (n=11, 22.45%), the need to plan for toilets or to manage stoma (n=10, 20.41%), and reduced capacity for physical activity (n=8, 16.33%).

The most common theme in relation to a positive impact on quality of life was that it brings people together (n=9, 18.37%)

Impact on mental health

In the structured interview, participants were asked if there had been an impact on their mental health. There were 38 participants (77.55%) who gave a description suggesting that overall there was some impact on their mental health and 10 participants (20.41%) who gave a description suggesting that overall there was no impact on mental health.

Regular activities to maintain mental health

In the structured interview, participants were asked what they needed to do to maintain their emotional and mental health. The most common way that participants reported managing their mental and emotional health was describing the importance of family and friends (n=19, 38.78%). Other participants described the importance of physical exercise (n=11, 22.45%), mindfulness and/or meditation, consulting a mental health professional (n=9, 18.37%), and maintaining social, lifestyle changes, and hobbies (n=7, 14.29%). There were 11 participants (22.45%) that described no activities to maintain mental health.

Regular activities to maintain health

In the structured interview, participants were asked what were some of the things they needed to do everyday to maintain their health? The most common ways that participants reported managing their health were; being physically active (n=11, 22.45%), keeping busy or keeping a normal routine (n=11, 22.45%), and managing their stoma or incontinence (n=11, 22.45%). Other ways to maintain health were complying with treatment (n=7, 14.29%), socialising with friends and/or family (n=7, 14.29%), maintaining a healthy diet (n=6, 12.24%), and the importance of self care e.g. more rest, support for housework etc. (n=5, 10.20%). There were 7 participants (14.29%) that described no activities to maintain health.

Experience of vulnerability

In the structured interview, participants were asked if there had been times that they felt vulnerable. There were 42 participants (85.71%) who gave a description suggesting that overall they had experiences of feeling vulnerable, and 2 participants (4.08%) who gave a description suggesting that overall they did not have feelings of being vulnerable.

In relation to when participants felt most vulnerable, the most common theme was feeling vulnerable during or after treatments (n=25, 51.02%). There 13 participants (26.53%) that described feeling vulnerable when first diagnosed, first few months after diagnosis, while experiencing side effects from treatment or symptoms from condition (n=10, 20.41%), because of interactions with the medical team (n=8, 16.33%), and 8 participants (16.33%) described feeling vulnerable when having sensitive discussion (diagnosis, treatment decision). Other participants described feeling vulnerable when thinking about disease course/incurable condition (n=5, 10.20%), being vulnerable when they have a loss of independence, e.g in hospital, recovering from surgery (n=5, 10.20%), and when first sent home after being hospitalised without the care/availability healthcare professionals (n=5, 10.20%).

Methods to manage vulnerability

In the structured interview, participants described ways that they managed feelings of vulnerability. Participants described using self help methods such as resilience, acceptance, and staying positive to manage the feeling of vulnerability (n=12, 24.49%), support from family and friends to manage the feeling of vulnerability (n=7, 14.29%), and being supported by nurse or treatment team to manage the feeling of vulnerability (n=6, 12.24%).

Impact on relationships

In the structured interview, participants were asked whether their condition had affected their personal relationships. Overall, there were 17 participants (34.69%) that described that overall, there was a positive impact on relationships. Other participants described a mix of a positive and a negative impact (n=11, 22.45%), a negative impact on relationships (n=9, 18.37%), no impact on relationships (n=8, 16.33%), and an impact on relationships that was neither positive nor negative (n=3, 6.12%)

The most common themes in relation to having a positive impact on relationships were relationships within the family being strengthened (n=22, 44.90%), and people being well-meaning and supportive (n=10, 20.41%). The most common themes in relation to having a positive impact on relationships were relationships suffering, that is people not knowing what to say or do and withdrawing from relationships (n=9, 18.37%), and dynamics of relationships change due to anxiety, exacerbations and/or physical limitations of condition (n=7, 14.29%).

Burden on family

In the structured interview, participants were asked whether they felt that their condition placed additional burden on their family. Overall, there were 22 participants (44.90%) that felt there was an additional burden, 20 participants (40.82%) that reported no additional burden, and 6 participants (12.24%) that felt they were not a burden on their family but anticipate this will change in the future.

For people that felt they were not a burden on their family, the most did not give any specific reasons for this (n=14, 28.57%). The main reason that participant described their condition not being a burden in general was that they were very independent and did not need any help (n=8, 16.33%). The most common reasons for feeling that they were a burden on their family was the mental/emotional strain placed on their family (n=12, 24.49%), the extra household duties and responsibilities that their family must take on (n=5, 10.20%), and that the burden was temporary or only during treatment (n=5, 10.20%).

Cost considerations

In the structured interview, participants were asked about any significant costs associated with having their condition. There were 25 participants (51.02%) that described some cost burden and 22 participants (44.90%) who described no cost burden.

Where participants described a cost burden associated with their condition, it was most commonly in relation to the cost of treatments, including repeat scripts (n=12, 24.49%). Other cost burdens were in relation to gap payments (public or private) (n=10, 20.41%), specialist appointments (n=9, 18.37%), and the cost of diagnostic tests and scans (n=8, 16.33%). There were 14 participants (28.57%) that described no cost burden and that nearly everything was paid for through the health system, 12 participants (24.49%) described that there was no cost burden, even if costs exist, and 7 participants (14.29%) that described no cost burden and that nearly everything was paid for through private health insurance.

Fear of progression

The Fear of Progression questionnaire measures the level of anxiety people experience in relation to their conditions. The Fear of Progression questionnaire comprises a total score, between 12 and 60, with a higher score denoting increased anxiety. The **Fear of Progression** questionnaire measures the level of anxiety people experience in relation to their conditions. On average fear of progression score for participants in this study indicated moderate levels of anxiety.

Section 9

Expectations and messages to decision-makers

Section 9: Expectations of future treatment, care and support, information and communication

Expectations of future treatment

Participants were asked in the structured interview what their expectations of future treatments are. The most common theme was that future treatments will be accompanied by more information about available treatments and treatment pathways (n=13,26.53%), and this was followed by future treatment will be more accessible particularly equitable, timely and includes access in rural locations (n=12,24.49%).

Other participants would like future treatments to have less cost burden (n=10, 20.41%), to have more options, and/or will be targeted (n=9, 18.37%), to have fewer or less intense side effects (n=7, 14.29%), to be more effective (n=5, 10.20%), to prevent loss of bladder or will improve bladder replacements (n=5, 10.20%), to be administered in a less invasive and more dignified way (n=5, 10.20%), and to include emotional and mental support (n=5, 10.20%)

Expectations of future information

Participants were asked in the structured interview if there was anything that they would like to see changed in the way information is presented or topics that they felt needed more information. The most common theme was that participants have no recommendations or they are satisfied with the information currently available (n=13, 26.53%). There were 9 participants (18.37%) that described that future information should be more accessible/easy to find, and 9 participants (18.37%) that described that future information should include all treatment options available to them.

Other participants described that future information will provide more details about mental health and emotional support (n=6, 12.24%), will help to inform the community and decision-makers about their condition (raise awareness) (n=6, 12.24%), will describe what to expect, especially with respect to side effects and treatment outcomes (n=6, 12.24%), will provide more details about where to find available services (n=5, 10.20%), and will be more targeted to specific types or stages (n=5, 10.20%).

Expectations of future healthcare professional communication

Participants were asked in the structured interview what they would like to see in relation to the way that healthcare professionals communicate with patients. The most common theme was that participants expected future information will be more transparent and information more forthcoming (n=14, 28.57%). Other themes about expectations of future communication included that future communication will be more empathetic (n=11, 22.45%), will allow people more time to meet with their clinician to talk about all that they need to talk about (n=9, 18.37%), will include better communication between healthcare professionals, and better coordination of appointments (n=7, 14.29%), and will include discussions about mental and emotional health (n=6, 12.24%).

There were 7 participants (14.29%) that had no recommendations or that they experienced good communication.

Expectations of future care and support

Participants were asked in the structured interview whether there was any additional care and support that they thought would be useful in the future, including support from local charities. The most common theme was that participants had no recommendations or were satisfied with care received (n=15, 30.61%), and this was followed by 13 participants (26.53%) that described the expectation that future care and support will include more access to support services. Other expectations include, future care and support will include being able to connect with other patients through peer support (support groups, online forums) (n=9, 18.37%), will include more information and awareness of the condition (n=8, 16.33%), and will include mental health or emotional support (n=7, 14.29%).

What participants are grateful for in the health system

Participants were asked in the structured interview what aspects of the health system that participants are grateful for. The most common theme was that participants were grateful for healthcare staff (n=22, 44.90%), and this was followed by 14 participants (28.57%) that described that participants were grateful for low cost or free medical treatments through the government, and 13 participants (26.53%) were grateful for timely access to treatment. Other participants were grateful for access to private healthcare or private insurance (n=10, 20.41%), and grateful for the entire health system (n=7, 14.29%).

Symptoms and aspects of quality of life

Participants were asked to rank which symptoms/aspects of quality of life would they want controlled in a treatment for them to consider taking it, where 1 is the most important and 11 is the least important. The most important aspects reported were pain, nausea and vomiting and, diarrhoea. The least important were hair loss and, mouth ulcers.

Values in making decisions

Participants were asked to rank what is important for them overall when they make decisions about treatment and care, where 1 is the most important and 8 is the least important. The most important aspects were “"How safe the medication is and weighing up the risks and benefits"”, and “"The severity of the side effects"”. The least important were “"Ability to follow and stick to a treatment regime"” and “"The financial costs to me and my family"”.

Values for decision makers

Participants were asked to rank what is important for decision-makers to consider when they make decisions that impact treatment and care, where 1 is the most important and 5 is the least important. The most important values were “Quality of life for patients”, and “All patients being able to access all available treatments and services”. The least important was “Economic value to government and tax payers”.

Time taking medication to improve quality of life

Participants were asked in the online questionnaire, how many months or years would you consider taking a treatment, provided it gave you a good quality of life, even if it didn’t offer a cure.

The most commonly participants would use a treatment for more than 10 years for a good quality of life even if it didn’t offer a cure (n = 17, 36.17%), followed by less than a year (n=14, 29.79%), and between 1 and 5 years (n=12, 25.53%).

Messages to decision-makers

Participants were asked, “If you were standing in front of the health minister, what would your message be in relation to your condition?” The most common message was to help raise community awareness (n=16, 32.65%). This was followed by that they are grateful for the healthcare system and the treatment that they received (n=11, 22.45%), to invest in screening or early detection (n=7, 14.29%), to improve access to support and care (n=7, 14.29%), and to be compassionate and empathetic (n=6, 12.24%).

Section 10

Advice to others in the future: The benefit of hindsight

Section 10: Advice to others in the future

Anything participants wish they had known earlier

In the structured interview, participants were asked if there was anything they wish they had known earlier. The most common responses were that participants wished they had known what to expect from their condition (e.g. symptoms, side effects of medication) (n=11, 22.45%), and they wished they had known to be more assertive in relation to understanding treatment options and discussions about treatment (n=11, 22.45%). Other themes included participants described that there is nothing that they wished they new earlier (satisfied) (n=9, 18.37%), and wished they had know the early signs and symptoms of the condition (n=7, 14.29%).

Aspect of care or treatment they would change

In the structured interview, participants were asked if there was any aspect of their care or treatment they would change. The most common theme was that they would have liked more time and personalised attention with specialists (n=10, 20.41%). There were 8 participants (16.33%) who would not change any aspect of treatment or care without giving a reason, and 8 participants (16.33%) who would not change any aspect of treatment or care because they were satisfied with care and treatment received. Other participants would have liked to have had a better understanding of their condition (n=6, 12.24%), and would have liked more support for side effects of treatment (n=5, 10.20%).

Section 1

Introduction and methods

Section 1 Introduction and methodology

Patient Experience, Expectations and Knowledge (PEEK) is a research program developed by the Centre for Community-Driven Research (CCDR). The aim of PEEK is to conduct patient experience studies across several disease areas using a protocol that will allow for comparisons over time (both quantitative and qualitative components). PEEK studies give us a clear picture and historical record of what it is like to be a patient at a given point in time, and by asking patients about their expectations, PEEK studies give us a way forward to support patients and their families with treatments, information and care.

This PEEK study in bladder cancer includes 44 people diagnosed with bladder cancer throughout Australia. In addition, 5 carers or family members to people with bladder cancer took part.

Bladder cancer occurs more frequently in men and those over 60 years of age. In 2021 there were and estimated 3,066 new cases of bladder cancer in Australia, approximately 2,400 of these were men; the median age was 76.3 years. There were an estimated 653 deaths from bladder cancer in Australia in 2021, it is the 9th most common cause of death from cancer[2]. The five year survival during the period 2031 to 2017 was 55%. In Australia, at the end of 2016, there were 8165 people living with bladder cancer.

There was a decrease in 5 year survival from 68% in 1982 – 1987, to 53% in 2009-2013, the reasons for this are not clear and cannot be explained by an increase in age at diagnosis which has only modestly increased in this time period[1,4] . However, there was a decrease in age-standardised mortality rate from 5.4 per 100,000 in 1982 to 3.8 per 100,000 in 2017, this is due to a reduction of overall incidence.

Introduction

Bladder cancer occurs more frequently in men and those over 60 years of age[1]. In 2021 there were and estimated 3,066 new cases of bladder cancer in Australia, approximately 2,400 of these were men; the median age was 76.3 years[2,3]. There were an estimated 653 deaths from bladder cancer in Australia in 2021, it is the 9th most common cause of death from cancer[2]. The five year survival during the period 2031 to 2017 was 55% [3]. In Australia, at the end of 2016, there were 8165 people living with bladder cancer[3].

There was a decrease in 5 year survival from 68% in 1982 – 1987, to 53% in 2009-2013, the reasons for this are not clear and cannot be explained by an increase in age at diagnosis which has only modestly increased in this time period[1,4] . However, there was a decrease in age-standardised mortality rate from 5.4 per 100,000 in 1982 to 3.8 per 100,000 in 2017[1], this is due to a reduction of overall incidence.

Personal Experience, Expectations and Knowledge (PEEK)

Patient Experience, Expectations and Knowledge (PEEK) is a research program developed by the Centre for Community-Driven Research (CCDR). The aim of PEEK is to conduct patient experience studies across several disease areas using a protocol that will allow for comparisons over time (both quantitative and qualitative components). PEEK studies give us a clear picture and historical record of what it is like to be a patient at a given point in time, and by asking patients about their expectations, PEEK studies give us a way forward to support patients and their families with treatments, information and care.

The research protocol used in PEEK studies is independently driven by CCDR. PEEK studies include a quantitative and qualitative component. The quantitative component is based on a series of validated tools. The qualitative component is the result of two years of protocol testing by CCDR to develop a structured interview that solicits patient experience data and provides patients with the opportunity to provide advice on what they would like to see in relation to future treatment, information and care. The structured interview has also been designed so that the outcomes of PEEK studies can inform policy, research, care, information, supportive care services and advocacy efforts.

Participants

To be eligible for the study, participants needed to have been diagnosed with bladder cancer, have experienced the healthcare system in Australia, be 18 years of age or older, be able to speak English, and be able to give consent to participate in the study. Recruitment commenced 1 April 2022 and was completed by 30 July 2022.

Ethics

Ethics approval for this study was granted (as a low or negligible risk research study) by the Centre for Community-Driven Research Ethics Committee (Reference CS_Q4_03).

Data collection

Data for the online questionnaire was collected using Zoho Survey (Zoho Corporation Pvt. Ltd. Pleasanton, California, USA, www.zoho.com/survey). Participants completed the survey from 1 April 2022 to 30 July 2022.

There were five researchers who conducted telephone interviews and used standardised prompts throughout the interview. The interviews were recorded and transcribed verbatim. Identifying names and locations were not included in the transcript. All transcripts were checked against the original recording for quality assurance.

Interview data was collected from 1 April 2022 to 30 July 2022.

Online questionnaire (quantitative)

The online questionnaire consisted of the 36-Item Short Form Health Survey (SF36) (RAND Health)[5], a modified Cancer Care Coordination Questionnaire for Patients (CCCQ)[6], the Short Fear of Progression Questionnaire (FOP12)[7], and the Partners in Health version 2 (PIH)[8]. In addition, investigator derived questions about demographics, diagnosis, treatment received and future treatment decisions making were included.

Structured Interview (qualitative)

Interviews were conducted via telephone by registered nurses who were trained in qualitative research. The first set of interview questions guided the patient through their whole experience from when symptoms were noticed up to the present day.

Questionnaire analysis

Statistical analysis was conducted using R included in the packages “car”, “dplyr” and “ggplot2” (R 3.3.3 GUI 1.69 Mavericks build (7328). The aim of the statistical analysis of the SF36, CCCQ, FOP12, and PIH responses was to identify variations by disease stage, gender, location of residence, education status and socio-economic status. Scales and subscales were calculated according to reported instructions[5-8].

The Location of participants was evaluated by postcode using the Australian Statistical Geography Maps (ASGS) Remoteness areas accessed from the Australian Bureau of Statistics[9].

The level of socio-economic status of participants was evaluated by postcode using the Socio-economic Indexes for Areas (SEIFA) accessed from the Australian Bureau of Statistics[10].

For comparisons by disease stage , a one-way analysis of variance (ANOVA) analysis was conducted. A Tukey HSD test was used post-hoc to identify the source of any differences identified in the one-way ANOVA test. Where the assumptions for the one-way ANOVA were not met, a Kruskal-Wallis rank sum test on care was conducted with post-hoc pairwise comparisons using Wilcoxon rank sum test. When the assumption of equal variances were not met, a Welch one-way test was used with post-hoc pairwise t-tests with no assumption of equal variances.

For all other comparisons between groups, a two-sample t-test was used when assumptions for normality and variance were met, or when assumptions were not met, a Wilcoxon rank sum test with continuity correction was used. Questions where participants were asked to rank preferences were analysed using weighted averages. Weights were applied in reverse, the most preferred option was given the largest weight equal to the number of options, the least preferred option was given the lowest weight of 1.

Structured interviews analysis

A content analysis was conducted using conventional analysis to identify major themes from structured interviews. Text from the interviews were read line-by-line by the lead researcher and then imported into NVivo 8 (QSR International)/MaxQDA. Each question within the interview was individually analysed. Initial categories and definitions were identified and registered in NVivo 8 (QSR International)/MaxQDA. The minimum coded unit was a sentence with paragraphs and phrases coded as a unit.

A second researcher verified the codes and definitions, and the text was coded until full agreement was reached using the process of consensual validation. Where a theme occurred less than 5 times it was not included in the study results, unless this result demonstrated a significant gap or unexpected result.

Data analysis and final reporting was completed in June 2021.

Position of this study

A search was conducted in Pubmed (April 7, 2022) to identify studies of bladder cancer with patient reported outcomes, or patient experience conducted in the past five years in worldwide (Table 1.1). Meta-analysis studies, studies with children, studies conducted in developing countries, population studies, and studies of less than five participants were excluded. There were 99 studies identified of between 8 and 1796 liver cancer participants.

There were 10 studies that interviewed between 10 and 30 people with bladder cancer. There were 3 studies that were focused on treatment[11-13], 2 studies that were focused on health related quality of life[14,15], and a single study each focused on diagnosis[16], education[17], decision making[18], healthcare services[19]

There were 7 studies where 10 to 57 people with bladder cancer took part in focus groups, two of these studies included interviews and are described above. There were 3 studies that were focused on healthcare service[20-22], and a single study each focused on treatment[23], and lifestyle[24]

There were 65 studies that were focused on treatment[5,9,10,25-86], 6 studies that were focused on Health related quality of life[87-89], 3 studies that were focused on Lifestyle[90-92], 2 studies that were focused on diagnosis[93,94], 2 studies that were focused on costs to patients[95,96], 2 studies that were focused on complementary therapy[97,98], and a single study each focused on healthcare services[99], decision making[100], and education[101]

In this PEEK study, 44 people with bladder cancer were interviewed and completed questionnaires, in addition to 5 carers of people with bladder cancer. PEEK is a comprehensive study covering all aspects of disease experience from symptoms, diagnosis, treatment, healthcare communication, information provision, care and support, quality of life, and future treatment and care expectations.

Table 1.1: PEEK position

First Author, Year	Location	Number of participants	Data collection	Focus	PEEK SECTION							
					2: Health status, co-morbidities	3: Diagnosis experience	4: Decision making	5: Treatment, healthcare system use	6: Information, communication and self-management	7: Care, support and navigating healthcare system	8: Quality of life, mental health, relationships	9 Expectations, preferences and messages
McMullen (2019)[23]	USA	57 (5 carers)	Focus group	Treatment			X	X	X			
Gupta (2021)[13]	USA	22 (3 partners)	Interviews/ focus groups	Treatment							X	
Rammant (2019)[11]	Belgium	30	Interview	Treatment	X	X		X			X	
Yi (2022)[12]	Korea	9	Interview	Treatment							X	
Garg (2018)[20]	USA	20	Focus group	Healthcare service			X	X		X	X	
Lee (2020)[21]	USA	19	Focus group	Healthcare service					X			
Koo (2017)[22]	USA	12	Focus group	Healthcare service			X	X			X	
Jordan (2022)[19]	USA	10	Interview/ focus group	Healthcare service			X		X	X		
Rutherford (2017)[14]	Australia	26	Interview	Health related quality of life	X	X						
Heyes (2020)[15]	Australia	8	Interview	Health related quality of life						X	X	
Tan (2020)[102]	UK	20 interview, 213 quest.	Interviews/ questionnaire	Diagnosis	X	X					X	
Schroeck (2020)[16]	USA	22	Interview	Diagnosis					X			
Wulff-Burchfield (2021)[17]	USA	16	Interview	Education					X			
Banerjee (2021)[24]	UK	14	Focus group	Lifestyle				X			X	
Klein (2021)[18]	USA	13	Interview	Decision making			X					X
Witjes (2022)[25]	Multi-national	709	Questionnaire	Treatment	X	X						
Bajorin (2021)[26]	Multi-national	709	Questionnaire	Treatment	X	X						

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Kelly (2019)[27]	UK	709	Questionnaire	Treatment	X	X						
Mason (2018)[28]	England	673	Questionnaire	Treatment	X	X						
Necchi (2020)[29]	Multi-national	530	Questionnaire	Treatment	X	X						
Vaughn (2018)[30]	Multi-national	519	Questionnaire	Treatment	X	X						
Huddart (2020)[31]	UK	485	Questionnaire	Treatment	X	X						
Cox (2020)[32]	UK	472	Questionnaire	Treatment	X							
Clements (2022)[33]	USA	411	Questionnaire	Treatment	X	X						
Westhofen (2022)[34]	Germany	407	Questionnaire	Treatment	X	X						
Kukreja (2018)[35]	USA	383	Questionnaire	Treatment		X						
Masiero (2021)[9]	Italy	382	Questionnaire	Treatment	X	X						
Wijburg (2021)[10]	Netherlands	348	Questionnaire	Treatment	X							
Hupe (2018)[36]	Germany	324	Questionnaire	Treatment	x	x						
Cerruto (2017)[37]	Italy	319	Questionnaire	Treatment	X	X						
Becerra (2020)[38]	USA	302	Questionnaire	Treatment	X	X						
Frees (2017)[39]	Germany	250	Questionnaire	Treatment	X	X						
Volz (2022)[40]	Germany	246	Questionnaire	Treatment	X	X						
Asanad (2021)[41]	USA	198	Questionnaire	Treatment	X	X						
Check (2020)[42]	USA	192	Questionnaire	Treatment	X	X	X	X				
Grimm (2019)[43]	Germany	178	Questionnaire	Treatment	X	X						
Normann (2020)[44]	Norway	173	Questionnaire	Treatment	X	X						

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Kijima (2019)[45]	Japan	154	Questionnaire	Treatment	X	X						
Loh-Doyle (2020)[46]	USA	151	Questionnaire	Treatment		X						
Kern (2021)[47]	USA	146	Questionnaire	Treatment	X	X						
Siracusano (2018)[48]	Italy	145	Questionnaire	Treatment	X	X						
Rehme (2022)[49]	Germany	143	Questionnaire	Treatment	X							
Kretschmer (2020)[50]	Germany	134	Questionnaire	Treatment	X	X						
Westerman (2020)[51]	USA	132	Questionnaire	Treatment	X	X						
Gellhaus (2017)[52]	USA	128	Questionnaire	Treatment	X	X						
Mastroianni (2022)[53]	Italy	116	Questionnaire	Treatment	X							
Danielsson (2018)[54]	Sweden	113	Questionnaire	Treatment	X	X						
Tan (2019)[55]	UK	104	Questionnaire	Treatment	X	X						
Schulz (2019)[56]	Germany	103	Questionnaire	Treatment	C	X						
Siracusano (2018)[57]	Italy	103	Questionnaire	Treatment	X	X						
Kretschmer (2017)[58]	Germany	100	Questionnaire	Treatment	X	X						
Kitamura (2020)[59]	Japan	99	Questionnaire	Treatment	X	X						
Rammant (2022)[60]	USA	99	Questionnaire	Treatment	X				X	X	X	
Dellabella (2018)[61]	Italy	95	Questionnaire	Treatment	X							
Mostafid (2020)[62]	UK	82	Questionnaire	Treatment	X	X						
Taarnhøj (2021)[63]	Denmark	79	Questionnaire	Treatment	X	X					X	

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Fuschi (2021)[64]	Italy	78	Questionnaire	Treatment	X	X						
Cerruto (2018)[65]	Italy	77	Questionnaire	Treatment	X	X						
Abozaid (2022)[66]	UK	76	Questionnaire	Treatment	X	X						
Tostivint (2021)[67]	France	73	Questionnaire	Treatment	X	X						
Siracusano (2019)[68]	Italy	73	Questionnaire	Treatment	X	X						
Volz (2021)[5]	Germany	72	Questionnaire	Treatment	X	X						
Cheng (2021)[69]	USA	58	Questionnaire	Treatment	X	X						
González-Padilla (2021)[70]	Spain	56	Questionnaire	Treatment	X	X						
Kaye (2020)[71]	USA	54	Questionnaire	Treatment	X	X						
Mastroianni (2021)[72]	Italy	51	Questionnaire	Treatment	X	X						
Catto (2021)[73]	UK	50	Questionnaire	Treatment	X							
Huddart (2017)[74]	UK	45	Questionnaire	Treatment	X	X						
Liedberg (2022)[75]	Sweden	44	Questionnaire	Treatment		X						
Biardeau (2020)[76]	France	40	Questionnaire	Treatment	X	X						
Rose (2021)[77]	USA	39	Questionnaire	Treatment	X	X						
Ziegelmueller (2020)[78]	Germany	35	Questionnaire	Treatment	X	X						
Bosschieter (2019)[79]	Netherlands	28	Questionnaire	Treatment	X	X						
Frees (2018)[80]	Canada	27	Questionnaire	Treatment	X			X				
Ebbing (2018)[81]	Germany	27	Questionnaire	Treatment	X	X						

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Pattou (2022)[82]	France	23	Questionnaire	Treatment	X	X						
Feuerstein (2019)[83]	USA	16	Questionnaire	Treatment	X	X					X	
Hockman (2020)[84]	USA	13	Questionnaire	Treatment				X	X	X		
Tuderti (2020)[85]	Italy	11	Questionnaire	Treatment	X	X						
Miyake (2022)[86]	Japan	10	Questionnaire	Treatment	X	X						
Catto (2021)[87]	UK	1796	Questionnaire	Health related quality of life	X	X						
Yu (2019)[88]	UK	1160	Questionnaire	Health related quality of life	X	X		X		X		
Tsai (2021)[89]	Taiwan	343	Questionnaire	Health related quality of life	X							
Draeger (2018)[103]	Germany	301	Questionnaire	Health related quality of life						X	X	
Suppanuntaroek (2020)[104]	Japan	205	Questionnaire	Health related quality of life	X	X						
Taarnhøj (2020)[105]	Denmark	78	Questionnaire	Health related quality of life	X	X						
Chung (2019)[99]	Canada	586	Questionnaire	Healthcare service	X	X			X	X	X	
Gopalakrishna (2017)[90]	USA	472	Questionnaire	Lifestyle	X	X		X				
Gopalakrishna (2018)[91]	USA	459	Questionnaire	Lifestyle	X	X		X				
Chung (2020)[92]	Canada	235	Questionnaire	Lifestyle	X	X		X				
Lauridsen (2022)[106]	Denmark	104	Questionnaire	Lifestyle	X							
Kukreja (2022)[93]	USA	488	Questionnaire	Diagnosis		X						
Smith (2019)[94]	USA	304	Questionnaire	Diagnosis		X					X	

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Ehlers (2021)[95]	USA	226	Questionnaire	Costs to patients				X				
Casilla-Lennon (2018)[96]	USA	138	Questionnaire	Costs to patients	X	X		X				
Hussain (2021)[97]	UK	117	Questionnaire	Complementary therapy	X	X						
Silverdale (2019)[98]	UK	38	Questionnaire	Complementary therapy	X	X						
Li (2019)[100]	USA	211	Questionnaire	Decision making			X					
Mohamed (2020)[101]	USA	25	Questionnaire	Education				X	X			

Abbreviations and terminology

ASGS	The Australian Statistical Geography Standard from the Australian Bureau of Statistics, defines remoteness and urban/rural definitions in Australia
CCDR	Centre for Community-Driven Research
dF	Degrees of Freedom. The number of values in the final calculation of a statistic that are free to vary.
f	The F ratio is the ratio of two mean square values, used in an ANOVA comparison. A large F ratio means that the variation among group means is more than you'd expect to see by chance.
HER2	Human epidermal growth factor receptor 2
FOP	Fear of Progression. Tool to measure anxiety related to progression
IQR	Interquartile range. A measure of statistical dispersion, being equal to the difference between 75th and 25th percentiles, or between upper and lower quartiles.
p	Probability value. A small *p*-value (typically ≤ 0.05) indicates strong. A large *p*-value (> 0.05) indicates weak evidence.
PEEK	Patient Experience, Expectations and Knowledge
PIH	Partners in Health
SD	Standard deviation. A quantity expressing by how much the members of a group digger from the mean value for the group/
SEIFA	Socio-Economic Indexes for Areas (SEIFA) ranks areas in Australia according to relative socio-economic advantage and disadvantage. This is developed by the Australian Bureau of Statistics.
SF36	Short Form Health Survey 36
t	t-Statistic. Size of the difference relative to the variation in your sample data.
Tukey HSD	Tukey's honestly significant difference test. It is used in this study to find 10significantly different means following an ANOVA test.
W	The W statistic is the test value from the Wilcoxon Rank sum test. The theoretical range of W is between 0 and (number in group one) x (number in group 2). When W=0, the two groups are exactly the same.
X^2	Chi-squared. Kruskal-Wallis test statistic approximates a chi-square distribution. The Chi-square test is intended to test how likely it is that an observed distribution is due to chance.

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Section 2

Demographics

Section 2 Demographics

Participants

There were 43 people with bladder cancer, and 5 carers of people with bladder cancer who took part in this study. There were 5 participants (10.42%) with Stage 0, 14 participants (29.17%) with Stage I, 10 participants (20.83%) with Stage II, 10 participants (20.83%) with Stage III, 4 participants (8.33%) with stage IV bladder cancer, and 5 carers (10.42%).

Demographics: Participants with bladder cancer

There were 43 people with bladder cancer that took part in this study, 17 were females (39.53%).

Participants were most commonly from New South Wales (n=20, 46.51%), Victoria (n=11, 25.58%), and South Australia (n=5, 11.63%). Most participants were from major cities (n=30, 69.77%), and they lived in all levels of advantage, defined by Socio-economic Indexes for Areas (SEIFA) (www.abs.gov.au) with 26 participants (60.47%) from an area with a high SEIFA score of 7 to 10 (more advantage), and 20 participants (41.67%) from an area of mid to low SEIFA scores of 1 to 6 (less advantaged).

There were 18 participants (41.86%) that had completed university to at least an associate degree. There were 19 participants (44.19%), who were employed either full time or part time.

Approximately a quarter of participants were carers to family members or spouses (n=11,25.58%), most commonly carers to Children (n=5, 11.63%).

Demographics: Participants that are carers to people with bladder cancer

There were 5 carers to people with bladder cancer that took part, all were carers to males with bladder cancer. Carers most commonly lived in metropolitan areas (n=3, 60.00%), and were from NSW (n=2, 40.00%), or Victoria (n=2, 40.00%). The majority of carers were in either full or part time work (n=4, 80.00%).

Other health conditions

Participants were asked about health conditions other than bladder cancer that they had to manage. Participants could choose from a list of common health conditions and could specify other conditions.

The majority of participants had at least one other condition that they had to manage (n=38, 90.48%), the maximum number reported was 9 other conditions, with a median of 2.00 other conditions (IQR = 3.00). The most commonly reported health conditions were sleep problems (n=17, 40.48%), and anxiety (n=17, 40.48%), followed by arthritis or scoliosis (n=16, 38.10%), and depression (n=11, 26.19%).

Participants were asked a follow up question about their quality of life from these other conditions. Quality of life was rated on a Likert scale from one to seven, where one is “Life was very distressing” and seven is “Life was great”. Median quality of life is presented where five or more participants reported the symptom.

Quality of life from other conditions ranged from 3.00 (life was a little distressing) to 5.00 (life was good).

Baseline health

The Short Form Health Survey 36 (SF36) measures baseline health, or the general health of an individual. The SF36 comprises nine scales: physical functioning, role functioning/physical, role functioning/emotional, energy and fatigue, emotional well-being, social function, pain, general health, and health change from one year ago. The scale ranges from 0 to 100, a higher score denotes better health or function.

SF36 Physical functioning scale measures health limitations in physical activities such as walking, bending, climbing stairs, exercise, and housework. On average, physical activities were not limited for participants in this study.

SF36 Role functioning/physical scale measures how physical health interferes with work or other activities. On average, physical health sometimes interfered with work or other activities for participants in this study.

SF36 Role functioning/emotional scale measures how emotional problems interfere with work or other activities. On average, emotional problems never interfered with work or other activities for participants in this study.

SF36 Energy/fatigue scale measures the proportion of energy or fatigue experienced. On average, participants were sometimes fatigued.

The **SF36 Emotional well-being** scale measures how a person feels, for example happy, calm, depressed or anxious. On average, participants had good emotional well-being.

The **SF36 Social functioning** scale measures limitations on social activities due to physical or emotional problems. On average, social activities were slightly limited for participants in this study.

The **SF36 Pain** scale measures how much pain, and how pain interferes with work and other activities. On average, participants had mild pain.

The **SF36 General health** scale measures perception of health. On average, participants reported average health.

The **SF36 Health change** scale measures health compared to a year ago. On average, participants reported that their health is about the same as a year ago.

Participants

There were 43 people with bladder cancer, and 5 carers of people with bladder cancer who took part in this study. There were 5 participants (10.42%) with Stage 0, 14 participants (29.17%) with Stage I, 10 participants (20.83%) with Stage II, 10 participants (20.83%) with Stage III, 4 participants (8.33%) with stage IV bladder cancer, and 5 carers (10.42%). (Table 2.1, Figure 2.1).

Table 2.1: Participants

Participant type	Number (n=48)	Percent
Stage 0	5	10.42
Stage I	14	29.17
Stage II	10	20.83
Stage III	10	20.83
Stage IV	4	8.33
Carer	5	10.42

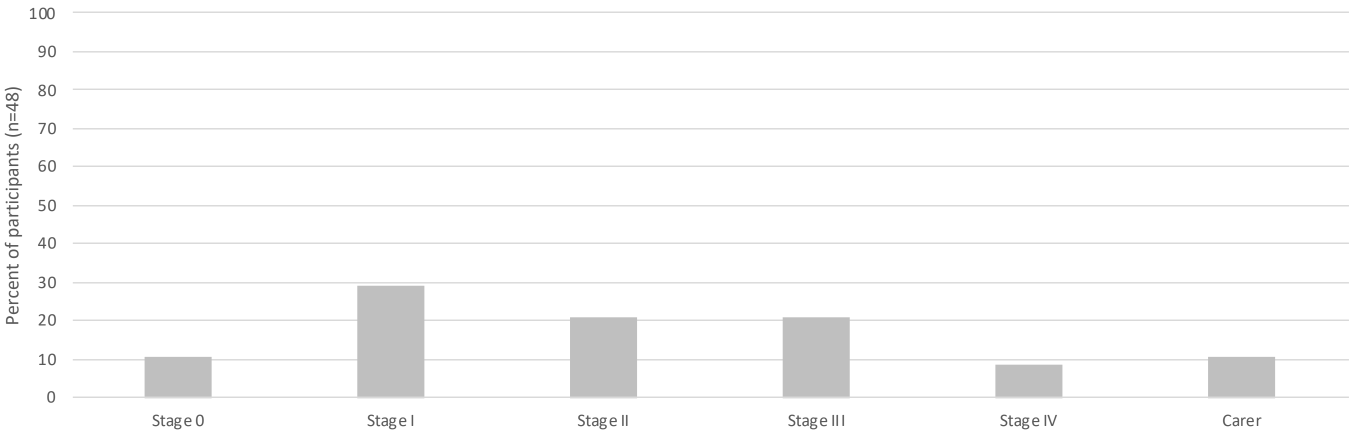


Figure 2.1: Participants

Demographics

Participants with bladder cancer

There were 43 people with bladder cancer that took part in this study, 17 were females (39.53%).

Participants were most commonly from New South Wales (n=20, 46.51%), Victoria (n=11, 25.58%), and South Australia (n=5, 11.63%). Most participants were from major cities (n=30, 69.77%), and they lived in all levels of advantage, defined by Socio-economic Indexes for Areas (SEIFA) (www.abs.gov.au) with 26 participants (60.47%) from an area with a high SEIFA score of 7 to 10 (more advantage), and 20 participants (41.67%) from an area of mid to low SEIFA scores of 1 to 6 (less advantaged).

There were 18 participants (41.86%) that had completed university to at least an associate degree. There were 19 participants (44.19%), who were employed either full time or part time.

Approximately a quarter of participants were carers to family members or spouses (n=11,25.58%), most commonly carers to Children (n=5, 11.63%). The demographics of participants are listed in Table 2.2.

Participants that are carers to people with bladder cancer

There were 5 carers to people with bladder cancer that took part, all were carers to males with bladder cancer. Carers most commonly lived in metropolitan areas (n=3, 60.00%), and were from NSW (n=2, 40.00%), or Victoria (n=2, 40.00%). The majority of carers were in either full or part time work (n=4, 80.00%).

Table 2.2: Demographics

Demographic	Definition	Number (n=43)	Percent	Number (n=5)	Percent
Gender	Female	17	39.53	0	0.00
	Male	26	60.47	5	100.00
Location	Major Cities of Australia	30	69.77	3	60.00
	Inner Regional Australia	10	23.26	0	0.00
	Outer Regional or remote Australia	3	6.98	2	40.00
State	Australian Capital Territory	3	6.98	0	0.00
	New South Wales	20	46.51	2	40.00
	Northern Territory	0	0.00	0	0.00
	Queensland	1	2.33	1	20.00
	South Australia	5	11.63	0	0.00
	Tasmania	1	2.33	0	0.00
	Victoria	11	25.58	2	40.00
	Western Australia	2	4.65	0	0.00
Socio-Economic Indexes for Areas (SEIFA)	1	1	2.33	1	20.00
	2	2	4.65	2	40.00
	3	3	6.98	0	0.00
	4	1	2.33	0	0.00
	5	6	13.95	0	0.00
	6	4	9.30	0	0.00
	7	4	9.30	0	0.00
	8	7	16.28	1	20.00
	9	7	16.28	0	0.00
	10	8	18.60	1	20.00
Race/ethnicity	Caucasian/White	40	93.02	4	80.00
	Asian	2	4.65	0	0.00
	Indigenous Australian	1	2.33	1	20.00
Education	Less than high school degree	3	6.98	0	0.00
	High school degree or equivalent	6	13.95	3	60.00
	Some college but no degree	6	13.95	0	0.00
	Trade	10	23.26	1	20.00
	Associate degree	2	4.65	0	0.00
	Bachelor degree	7	16.28	1	20.00
	Graduate degree	9	20.93	0	0.00
Employment	Retired	19	44.19	1	20.00
	Employed, working full time	14	32.56	3	60.00
	Employed, working part time	5	11.63	1	20.00
	Currently receiving Centrelink support	2	4.65	0	0.00
	Full/part time carer	2	4.65	0	0.00
	Disabled, not able to work	1	2.33	0	0.00
	Full/part time study	1	2.33	0	0.00
	Not employed, looking for work	1	2.33	0	0.00
Carer status	I am not a carer	32	74.42	3	60.00
	Children	5	11.63	2	40.00
	Parents	3	6.98	1	20.00
	Grandchildren	2	4.65	0	0.00
	Grandparents	1	2.33	0	0.00

Other health conditions

Participants were asked about health conditions other than bladder cancer that they had to manage. Participants could choose from a list of common health conditions and could specify other conditions.

The majority of participants had at least one other condition that they had to manage (n=38, 90.48%), the maximum number reported was 9 other conditions, with a median of 2.00 other conditions (IQR = 3.00) (Table 2.3, Figure 2.2). The most commonly reported health conditions were sleep problems (n=17, 40.48%), and anxiety (n=17, 40.48%), followed by arthritis or scoliosis (n=16, 38.10%), and depression (n=11, 26.19%) (Table 2.4, Figure 2.3).

Participants were asked a follow up question about their quality of life from these other conditions. Quality of life was rated on a Likert scale from one to seven, where one is “Life was very distressing” and seven is “Life was great”. Median quality of life is presented where five or more participants reported the symptom.

Quality of life from other conditions ranged from 3.00 (life was a little distressing) to 5.00 (life was good).

Table 2.3: Number of other health conditions

Number of other conditions	Number (n=42)	Percent	Number (n=5)	Percent
No other conditions	5	11.90	3	7.14
1 to 2	19	45.24	0	0.00
3 to 4	13	30.95	1	2.38
5 to 6	4	9.52	1	2.38
7 or more	2	4.76	0	0.00

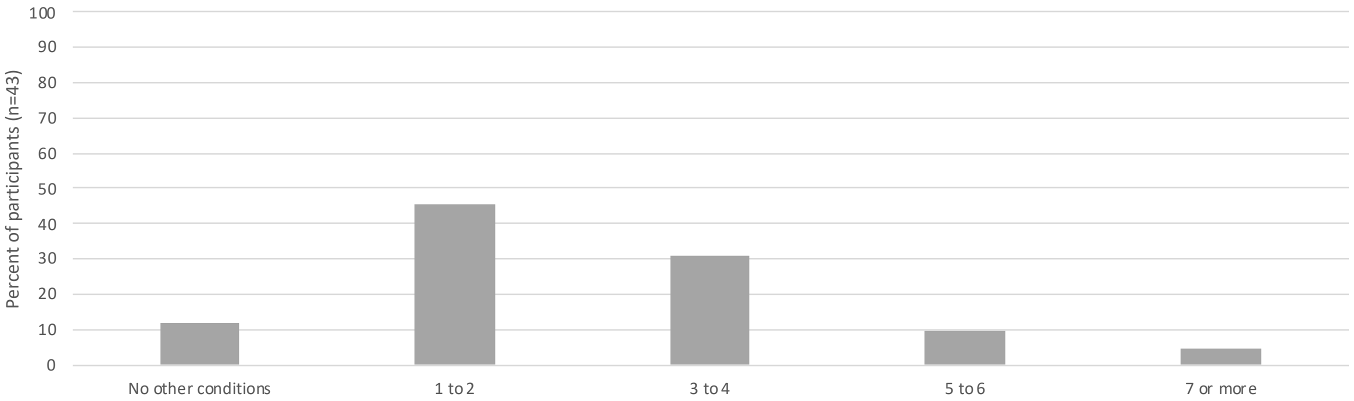


Figure 2.2: Number of other health conditions

Table 2.4: Other health conditions

Other conditions	Number (n=42)	Percent	Number (n=5)	Percent	Median	IQR
Sleep problems	17	40.48	1	20.00	4.00	1.00
Anxiety	17	40.48	2	40.00	4.00	2.00
Arthritis or scoliosis	16	38.10	1	20.00	4.50	1.50
Depression	11	26.19	1	20.00	4.00	1.50
Hypertension	10	23.81	1	20.00	5.00	1.50
Asthma	7	16.67	0	0.00	5.00	1.50
Chronic pain	7	16.67	1	20.00	3.00	1.00
Diabetes	4	9.52	0	0.00	NA	NA
Arrhythmias	4	9.52	0	0.00	NA	NA
Heart attack	4	9.52	0	0.00	NA	NA
Angina	2	4.76	0	0.00	NA	NA
Chronic Obstructive Pulmonary Disease (COPD)	2	4.76	1	20.00	NA	NA
Chronic heart failure	1	2.38	0	0.00	NA	NA
Other conditions or illnesses	13	30.95	2	40.00	NA	NA

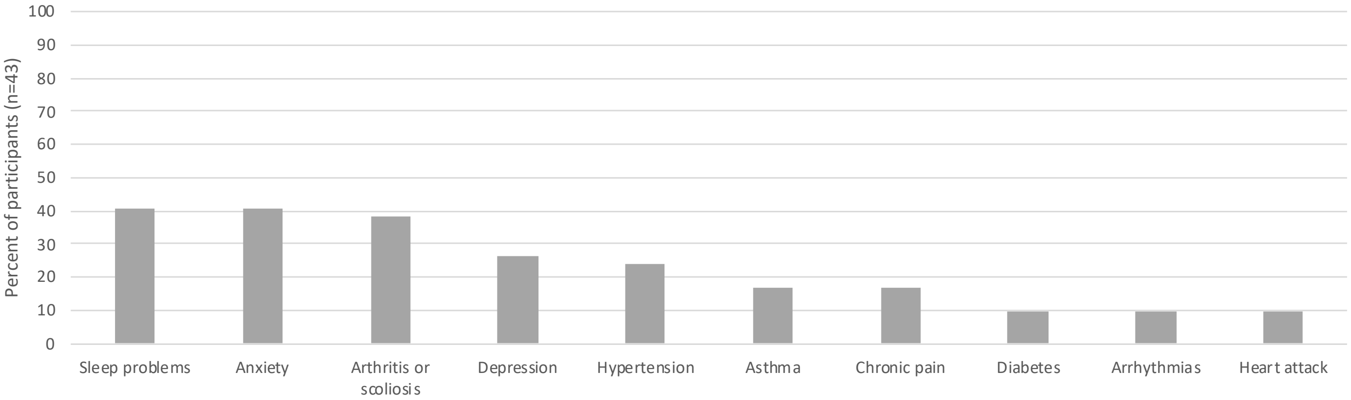


Figure 2.3: Other health conditions (% of all participants)

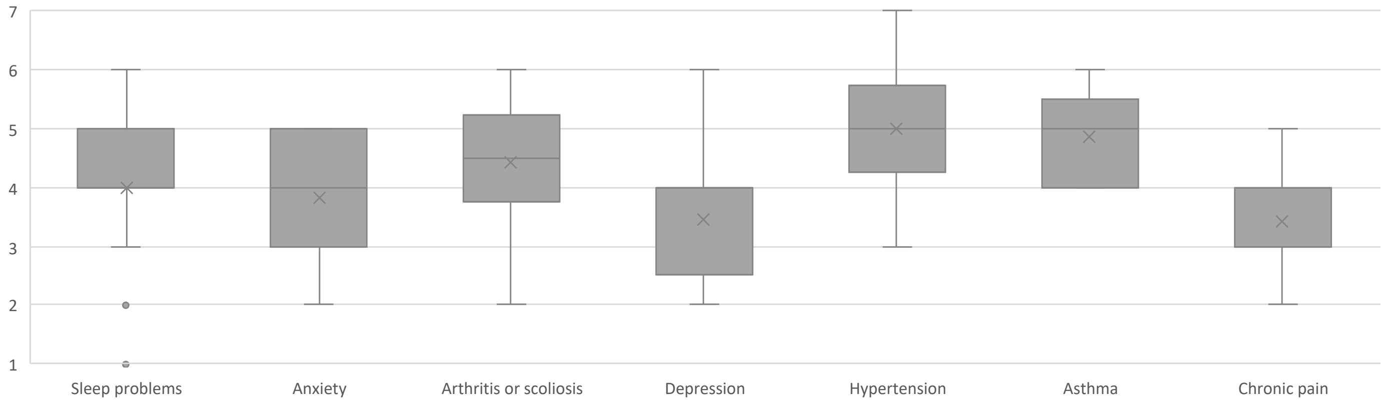


Figure 2.4: Other health conditions quality of life

Subgroup analysis

Subgroup analysis are included throughout the study and the subgroups are listed in Table 2.5.

Comparisons were made by Stage. There were 19 participants (44.19%) with Early bladder cancer(Stages 0 and I), 10 participants (23.26%) with Invasive bladder cancer (Stage III), and 14 participants (32.56%) with Advanced bladder cancer (Stage IV).

Comparisons were made by type of participant, there were 43 participants (89.58%) with bladder cancer and, 5 participants (10.42%) that were a carer to someone with bladder cancer.

Comparisons were made by gender, there were 17 female participants (35.42%), and 31 male participants (64.58%).

Comparisons were made by education status, between those with trade or high school qualifications (n=29, 60.42%), and those with a university qualification (n=19, 39.58%).

The location of participants was evaluated by postcode using the Australian Statistical Geography Maps (ASGS) Remoteness areas accessed from the Australian Bureau of Statistics. Those living in regional or remote area (n=15, 31.25%) were compared to those living in a metropolitan area(n=33, 68.75%).

Comparisons were made by socioeconomic status, using the Socio-economic Indexes for Areas (SEIFA) (www.abs.gov.au), SEIFA scores range from 1 to 10, a higher score denotes a higher level of advantage. Participants with a mid to low SEIFA score of 1-6 (n=20, 41.67%) compared to those with a higher SEIFA score of 7-10 (n=28, 58.33%).

Table 2.5: Subgroups

Subgroup	Definition	Number (n=48)	Percent
Stage (n=43)	Early (Stages 0 and I)	19	44.19
	Invasive (Stage III)	10	23.26
	Advanced (Stage IV)	14	32.56
Participant type	Person with bladder cancer	43	89.58
	Carer to someone with bladder cancer	5	10.42
Gender (n=48) (Of person with bladder cancer)	Female	17	35.42
	Male	31	64.58
Education(n=48) (Of person with bladder cancer)	Trade or high school	29	60.42
	University	19	39.58
Location(n=48) (Of person completing questionnaire)	Regional or remote	15	31.25
	Metropolitan	33	68.75
Socioeconomic status(n=48) (Of person completing questionnaire)	Mid to low status	20	41.67
	Higher status	28	58.33

Baseline health

The Short Form Health Survey 36 (SF36) measures baseline health, or the general health of an individual. The SF36 comprises nine scales: physical functioning, role functioning/physical, role functioning/emotional, energy and fatigue, emotional well-being, social function, pain, general health, and health change from one year ago. The scale ranges from 0 to 100, a higher score denotes better health or function.

Summary statistics for the entire cohort are displayed alongside the possible range of each scale in Table 2.6, for scales with a normal distribution, the mean and SD should be used as a central measure, and median and IQR for scales that do not have a normal distribution.

The overall scores for the cohort were in the highest quintile for **SF36 Physical functioning** (median=85.00, IQR=20.00), and **SF36 Role functioning/emotional** (median=83.33, IQR=66.67), indicating very good physical functioning, very good emotional role functioning,

The overall scores for the cohort were in the second highest quintile for **SF36 Emotional well-being** (mean=66.92, SD=16.48), **SF36 Social functioning** (median=62.50, IQR=50.00), and **SF36 Pain** (median=77.50, IQR=25.00), indicating good emotional well-being, good social functioning, mild pain,

The overall scores for the cohort were in the middle quintile for **SF36 Role functioning/physical** (median=50.00, IQR=75.00), **SF36 Energy/Fatigue** (mean=52.71, SD=17.59), **SF36 General health** (mean=56.35, SD=18.76), and **SF36 Health change** (median=50.00, IQR=25.00), indicating moderate physical role functioning, moderate energy, moderate general health, about the same as a year ago

SF36 Physical functioning scale measures health limitations in physical activities such as walking, bending, climbing stairs, exercise, and housework. On average, physical activities were not limited for participants in this study.

SF36 Role functioning/physical scale measures how physical health interferes with work or other activities. On average, physical health sometimes interfered with work or other activities for participants in this study.

SF36 Role functioning/emotional scale measures how emotional problems interfere with work or other activities. On average, emotional problems never interfered with work or other activities for participants in this study.

SF36 Energy/fatigue scale measures the proportion of energy or fatigue experienced. On average, participants were sometimes fatigued.

The **SF36 Emotional well-being** scale measures how a person feels, for example happy, calm, depressed or anxious. On average, participants had good emotional well-being.

The **SF36 Social functioning** scale measures limitations on social activities due to physical or emotional problems. On average, social activities were slightly limited for participants in this study.

The **SF36 Pain** scale measures how much pain, and how pain interferes with work and other activities. On average, participants had mild pain.

The **SF36 General health** scale measures perception of health. On average, participants reported average health.

The **SF36 Health change** scale measures health compared to a year ago. On average, participants reported that their health is about the same as a year ago.

Table 2.6: SF36 summary statistics

SF36 scale (n=48)	Mean	SD	Median	IQR	Possible range	Quintile
Physical functioning	78.96	20.45	85.00	20.00	0 to 100	5
Role functioning/physical	56.25	39.11	50.00	75.00	0 to 100	3
Role functioning/emotional	64.58	39.74	83.33	66.67	0 to 100	5
Energy/Fatigue*	52.71	17.59	55.00	27.50	0 to 100	3
Emotional well-being*	66.92	16.48	68.00	24.00	0 to 100	4
Social functioning	65.89	26.89	62.50	50.00	0 to 100	4
Pain	71.51	21.34	77.50	25.00	0 to 100	4
General health*	56.35	18.76	60.00	30.00	0 to 100	3
Health change	58.33	24.91	50.00	25.00	0 to 100	3

*Normal distribution, use mean and SD as central measure. Possible range 0-100

SF36 by bladder cancer stage

Comparisons were made by Stage. There were 19 participants (44.19%) with early bladder cancer(Stages 0 and I), 10 participants (23.26%) with invasive bladder cancer (Stage III), and 14 participants (32.56%) with advanced bladder cancer (Stage IV).

A one-way ANOVA test was used when the assumptions for response variable residuals were normally distributed and variances of populations were equal (Table 2.7). When the assumptions for normality of residuals was not met, a Kruskal-Wallis test was used (Table 2.8). Post hoc pairwise comparisons using Wilcoxon rank sum test was used to identify the source of any differences identified in the Kruskal -Wallis test (Table 2.9).

A Kruskal-Wallis test indicated a statistically significant difference in the **SF36 Physical functioning** scale between groups, $\chi2(2) = 7.50$, $p = 0.0235$. Wilcoxon rank sum tests between groups indicated that participants in the early bladder cancer subgroup (median = 90.00, IQR = 15.00) was significantly higher compared to participants in the advanced bladder cancer subgroup (median = 72.50, IQR = 38.75 p=0.0770).

SF36 Physical functioning scale measures health limitations in physical activities such as walking, bending, climbing stairs, exercise, and housework. On average, participants in the early bladder cancer subgroup scored higher than participants in the advanced subgroup. This indicates that physical activities were not limited for participants in the early bladder cancer subgroup and were slightly limited for participants in the advanced subgroup.

Table 2.7: SF36 by bladder cancer stage summary statistics and one-way ANOVA

SF36 scale	Group	Number (n=43)	Percent	Mean	SD	Source of difference	Sum of squares	dF	Mean Square	f	p-value
Energy/fatigue	Early	19	44.19	53.16	15.83	Between groups	697.00	2	348.40	1.09	0.3470
	Invasive	10	23.26	59.50	17.07	Within groups	12804.00	40	320.10		
	Advanced	14	32.56	48.57	20.89	Total	13501.00	42	668.50		
Emotional well-being	Early	19	44.19	68.00	16.17	Between groups	28.00	2	13.87	0.05	0.9470
	Invasive	10	23.26	70.00	16.57	Within groups	10263.00	40	256.57		
	Advanced	14	32.56	68.29	15.41	Total	10291.00	42	270.44		
General health	Early	19	44.19	56.58	18.93	Between groups	362.00	2	181.20	0.54	0.5850
	Invasive	10	23.26	56.50	18.42	Within groups	13328.00	40	333.20		
	Advanced	14	32.56	50.36	17.15	Total	13690.00	42	514.40		

Table 2.8: SF36 by bladder cancer stage summary statistics and Kruskal-Wallis test

SF36 scale	Group	Number (n=43)	Percent	Median	IQR	C^2	dF	p-value
Physical functioning	Early	19	44.19	90.00	15.00	7.50	2	0.0235*
	Invasive	10	23.26	85.00	8.75			
	Advanced	14	32.56	72.50	38.75			
Role functioning physical	Early	19	44.19	50.00	62.50	2.81	2	0.2457
	Invasive	10	23.26	87.50	50.00			
	Advanced	14	32.56	25.00	75.00			
Role functioning emotional	Early	19	44.19	66.67	66.67	0.74	2	0.6919
	Invasive	10	23.26	100.00	66.67			
	Advanced	14	32.56	100.00	33.33			
Social functioning	Early	19	44.19	75.00	43.75	0.91	2	0.6341
	Invasive	10	23.26	75.00	56.25			
	Advanced	14	32.56	62.50	43.75			
Pain	Early	19	44.19	77.50	11.25	3.85	2	0.1460
	Invasive	10	23.26	85.00	20.00			
	Advanced	14	32.56	67.50	41.88			
Health change	Early	19	44.19	50.00	25.00	0.71	2	0.7003
	Invasive	10	23.26	50.00	25.00			
	Advanced	14	32.56	62.50	25.00			

*Statistically significant at $p<0.05$

Table 2.9: SF36 by bladder cancer stage Wilcoxon rank sum tests between groups p values

SF36 scale	Subgroup	Early	Invasive
Physical functioning	Invasive	0.6420	-
	Advanced	0.0310*	0.0770

*Statistically significant at $p<0.05$

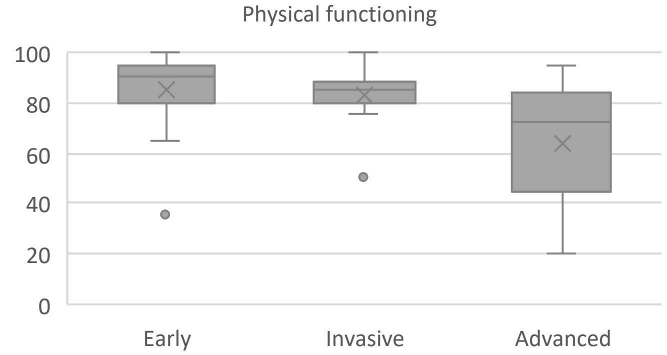


Figure 2.5: Boxplot of SF36 Physical functioning by bladder cancer stage

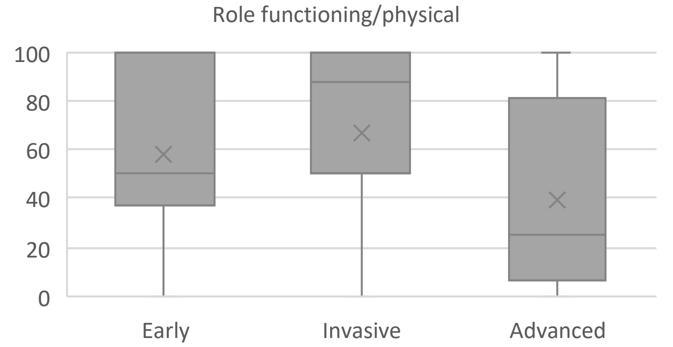


Figure 2.6: Boxplot of SF36 Role functioning/physical by bladder cancer stage

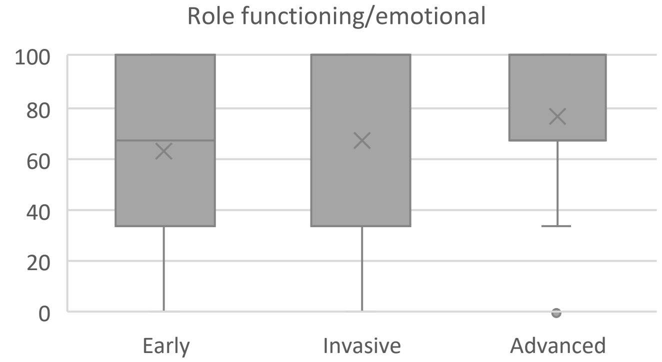


Figure 2.7: Boxplot of SF36 Role functioning/emotional by bladder cancer stage

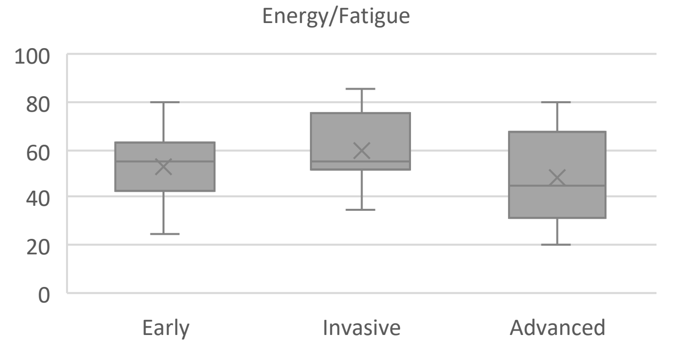


Figure 2.8: Boxplot of SF36 Energy/fatigue by bladder cancer stage

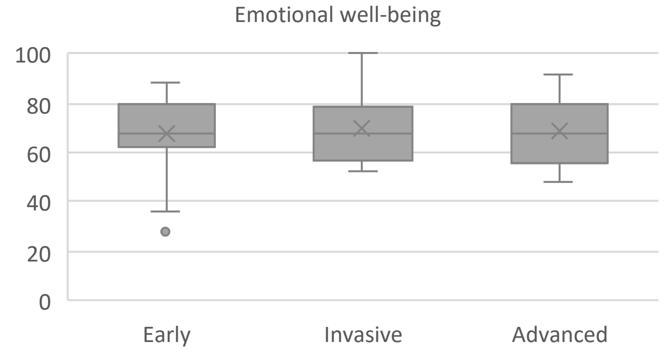


Figure 2.9: Boxplot of SF36 Emotional well-being by bladder cancer stage

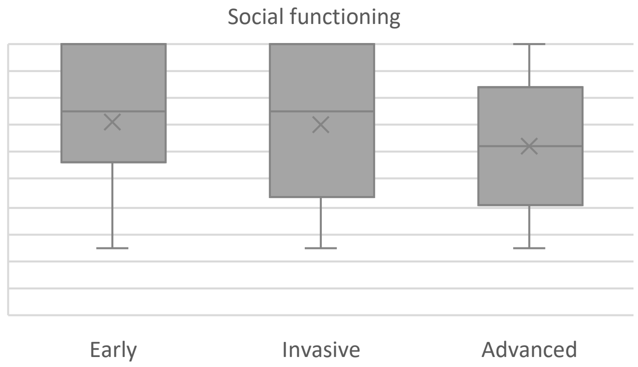


Figure 2.10: Boxplot of SF36 Social functioning by bladder cancer stage

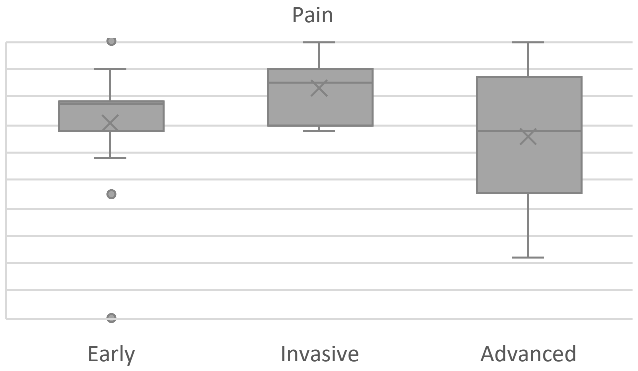


Figure 2.11: Boxplot of SF36 Pain by a bladder cancer stage

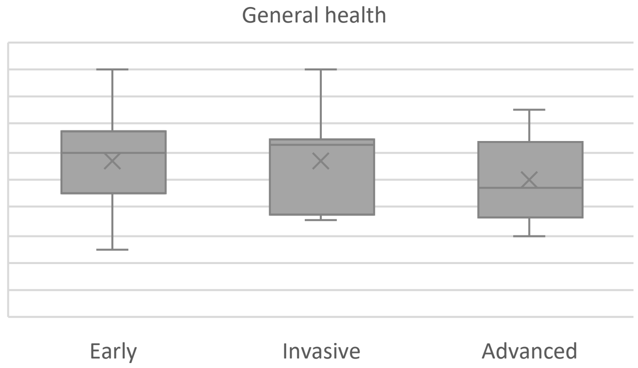


Figure 2.12: Boxplot of SF36 General health by bladder cancer stage

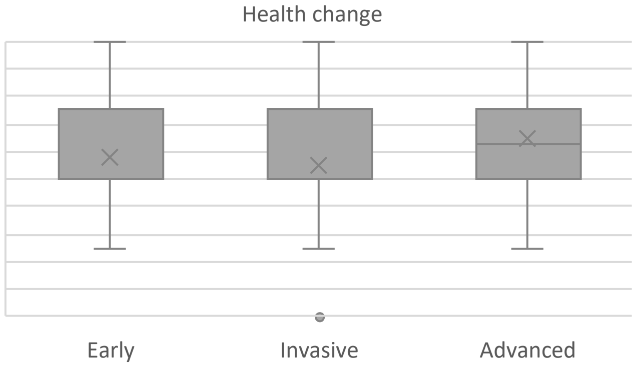


Figure 2.13: Boxplot of SF36 Health change by bladder cancer stage

SF36 by participant type

Comparisons were made by type of participant, there were 43 participants (89.58%) with bladder cancer and, 5 participants (10.42%) that were a carer to someone with bladder cancer.

A two-sample t-test was used when assumptions for normality and variance were met (Table 2.10), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 2.11).

A two sample t-test indicated that the mean score for the **SF36 Emotional well-being** scale [t(46) = 2.10 , p = 0.0416] was significantly higher for participants in the Mid to low status subgroup (Mean = 68.56, SD = 15.65) compared to participants in the Higher status subgroup (Mean = 52.80, SD = 18.42.)

SF36 Emotional well-being scale measures how a person feels, for example happy, calm, depressed or anxious**.** On average, participants in the patient subgroup scored higher than participants in the carer subgroup. This indicates that participants in the patient subgroup had good emotional well-being, and participants in the carer subgroup had fair emotional well-being.

Table 2.10: SF36 by participant type summary statistics and T-test

SF36 scale	Group	Number (n=47)	Percent	Mean	SD	T	dF	p-value
Energy/Fatigue	Patient	43	89.58	53.14	17.93	0.49	46	0.6237
	Carer	5	10.42	49.00	15.57			
Emotional well-being	Patient	43	89.58	68.56	15.65	2.10	46	0.0416*
	Carer	5	10.42	52.80	18.42			

*Statistically significant at p<0.05

Table 2.11: SF36 by participant type summary statistics and Wilcoxon test

SF36 scale	Group	Number (n=48)	Percent	Median	IQR	W	p-value
Physical functioning	Patient	43	89.58	85.00	20.00	59.50	0.1057
	Carer	5	10.42	100.00	15.00		
Role functioning/physical	Patient	43	89.58	50.00	75.00	81.00	0.3663
	Carer	5	10.42	75.00	0.00		
Role functioning/emotional	Patient	43	89.58	100.00	66.67	156.50	0.0771
	Carer	5	10.42	33.33	33.33		
Social functioning	Patient	43	89.58	75.00	50.00	158.50	0.0824
	Carer	5	10.42	50.00	0.00		
Pain	Patient	43	89.58	77.50	22.50	132.00	0.4117
	Carer	5	10.42	67.50	10.00		
General health	Patient	43	89.58	60.00	27.50	51.00	0.0576
	Carer	5	10.42	70.00	20.00		
Health change	Patient	43	89.58	50.00	25.00	130.50	0.4247
	Carer	5	10.42	50.00	0.00		

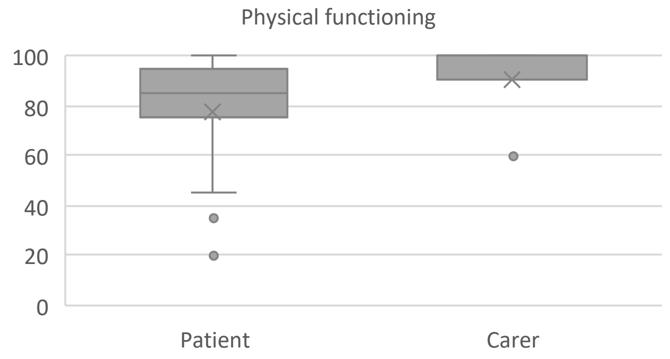


Figure 2.14: Boxplot of SF36 Physical functioning by participant type

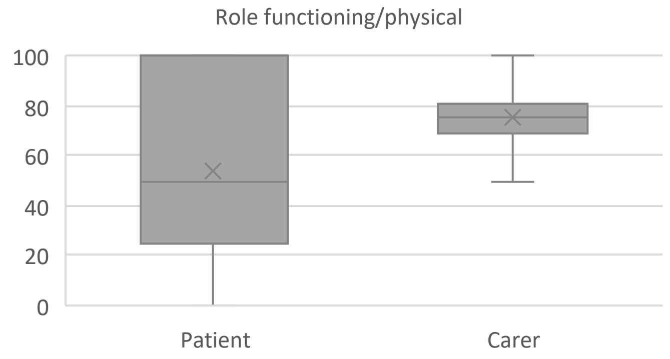


Figure 2.15: Boxplot of SF36 Role functioning/physical by participant type

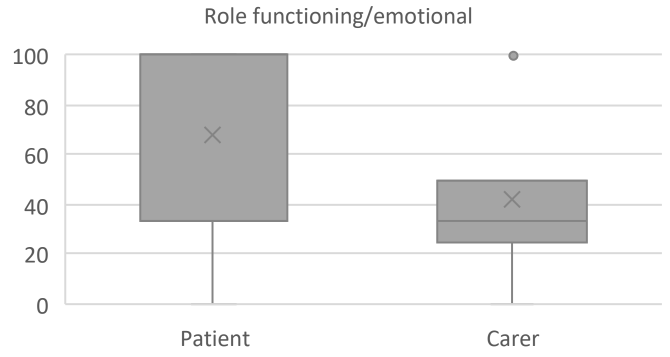


Figure 2.16: Boxplot of SF36 Role functioning/emotional by participant type

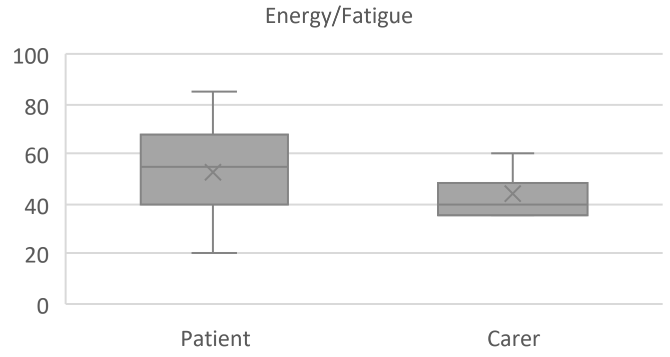


Figure 2.17: Boxplot of SF36 Energy/fatigue by participant type

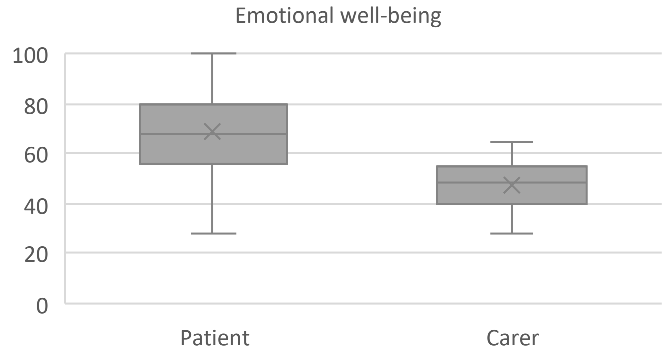


Figure 2.18: Boxplot of SF36 Emotional well-being by participant type

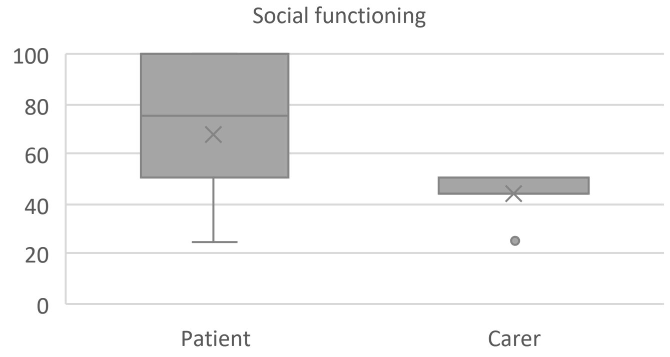


Figure 2.19: Boxplot of SF36 Social functioning by participant type

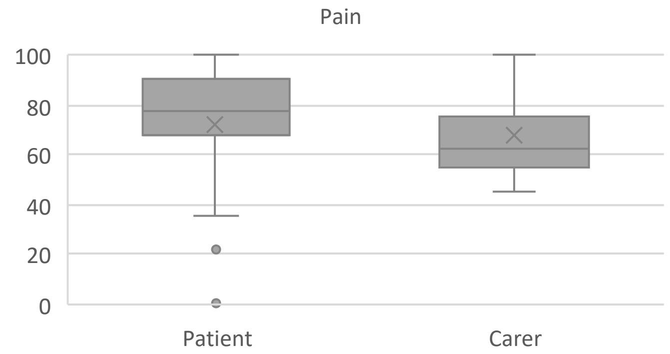


Figure 2.20: Boxplot of SF36 Pain by a participant type

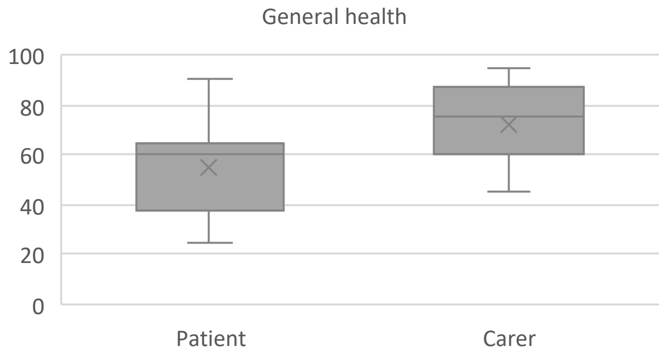


Figure 2.21: Boxplot of SF36 General health by participant type

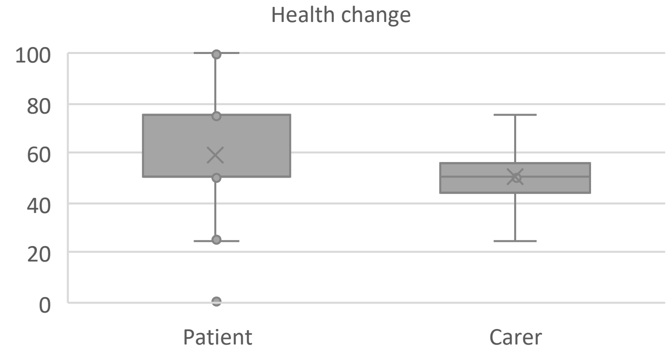


Figure 2.22: Boxplot of SF36 Health change by participant type

SF36 by Gender

Comparisons were made by gender, there were 17 female participants (35.42%), and 31 male participants (64.58%).

A two-sample t-test was used when assumptions for normality and variance were met (Table 2.12), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 2.13).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the **SF36 Physical functioning** scale [W = 337.00, p = 0.0449] was significantly higher for participants in the female subgroup (Median = 90.00, IQR = 11.25) compared to participants in the male subgroup (Median = 80.00, IQR = 35.00).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the **SF36 Social functioning** scale [W = 339.50, p = 0.037] was significantly higher for participants in the female subgroup (Median = 81.25, IQR = 37.50) compared to participants in the male subgroup (Median = 62.50, IQR = 37.50).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the **SF36 General health** scale [W = 345.50, p = 0.029] was significantly higher for participants in the female subgroup (Median = 65.00, IQR = 12.50) compared to participants in the male subgroup (Median = 45.00, IQR = 30.00).

SF36 Physical functioning scale measures health limitations in physical activities such as walking, bending, climbing stairs, exercise, and housework. On average, participants in the female subgroup scored higher than participants in the male subgroup. This indicates that physical activities were not limited for participants in the female subgroup, and were slightly limited for participants in the male subgroup.

SF36 Social functioning scale measures limitations on social activities due to physical or emotional problems. On average, participants in the female subgroup scored higher than participants in the male subgroup. This indicates that social activities were not limited for participants in the female subgroup, and slightly limited for participants in the male subgroup.

SF36 General health scale measures perception of health. On average, participants in the female subgroup scored higher than participants in the male subgroup. This indicates that participants in the female subgroup had good health, and participants in the male subgroup had average health.

Table 2.12: SF36 by Gender summary statistics and T-test

SF36 scale	Group	Number (n=48)	Percent	Mean	SD	T	dF	p-value
Energy/Fatigue	Female	17	35.42	59.06	18.00	1.76	45	0.0858
	Male	31	64.58	49.68	17.03			
Emotional well-being	Female	17	35.42	72.00	18.13	1.62	45	0.1112
	Male	31	64.58	63.87	15.23			

Table 2.13: SF36 by Gender summary statistics and Wilcoxon test

SF36 scale	Group	Number (n=48)	Percent	Median	IQR	W	p-value
Physical functioning	Female	17	35.42	90.00	11.25	337.00	0.0449*
	Male	31	64.58	80.00	35.00		
Role functioning/physical	Female	17	35.42	100.00	56.25	320.00	0.0981
	Male	31	64.58	50.00	50.00		
Role functioning/emotional	Female	17	35.42	100.00	66.67	306.50	0.1613
	Male	31	64.58	66.67	66.67		
Social functioning	Female	17	35.42	81.25	37.50	339.50	0.0373*
	Male	31	64.58	62.50	37.50		
Pain	Female	17	35.42	78.75	15.00	330.50	0.0618
	Male	31	64.58	67.50	20.00		
General health	Female	17	35.42	65.00	12.50	345.50	0.0287*
	Male	31	64.58	45.00	30.00		
Health change	Female	17	35.42	50.00	25.00	282.00	0.4285
	Male	31	64.58	50.00	37.50		

*Statistically significant at p<0.05

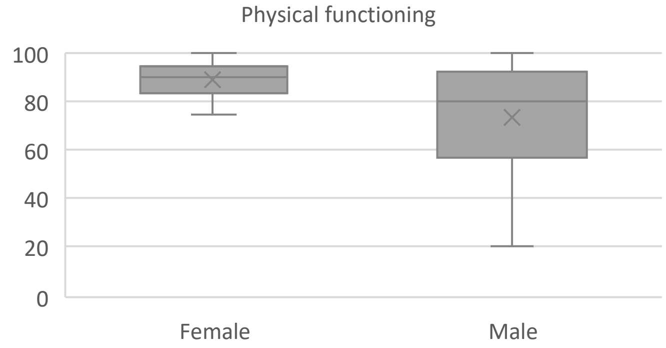


Figure 2.23: Boxplot of SF36 Physical functioning by Gender

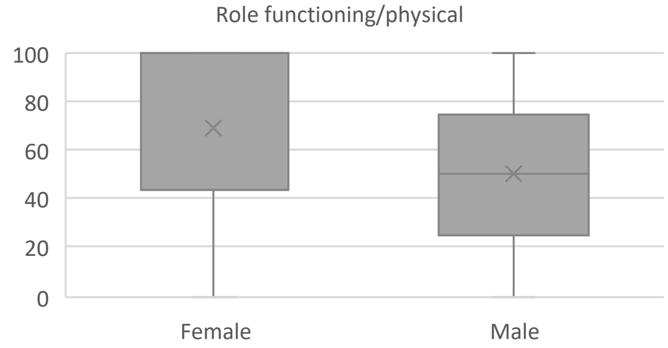


Figure 2.24: Boxplot of SF36 Role functioning/physical by Gender

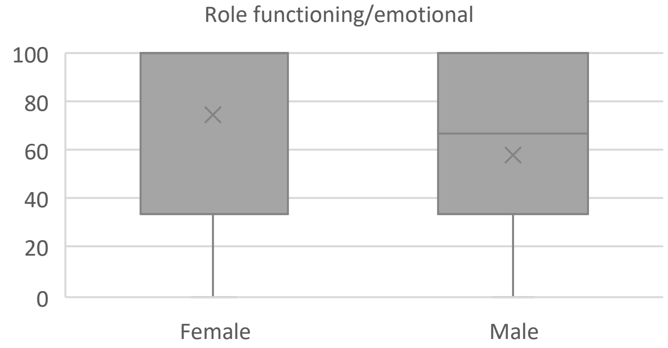


Figure 2.25: Boxplot of SF36 Role functioning/emotional by Gender

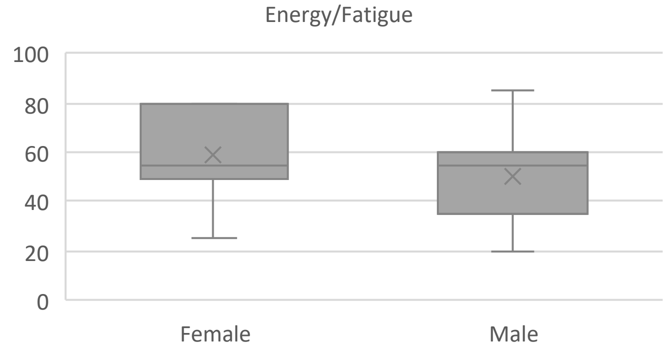


Figure 2.26: Boxplot of SF36 Energy/fatigue by Gender

Figure 2.27: Boxplot of SF36 Emotional well-being by Gender

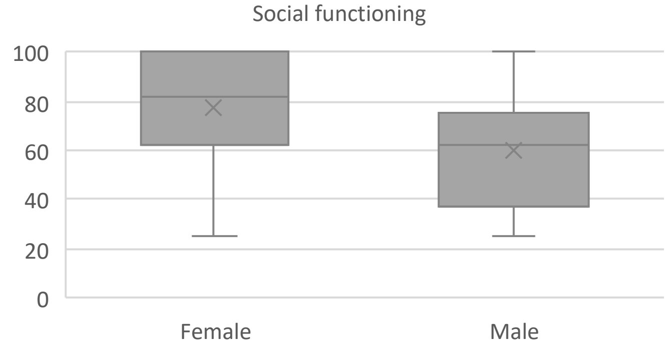


Figure 2.28: Boxplot of SF36 Social functioning by Gender

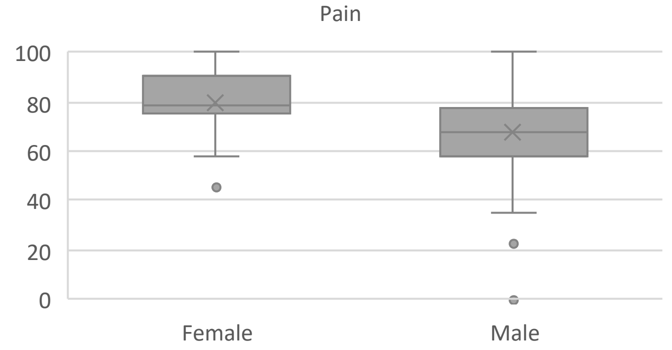


Figure 2.29: Boxplot of SF36 Pain by a Gender

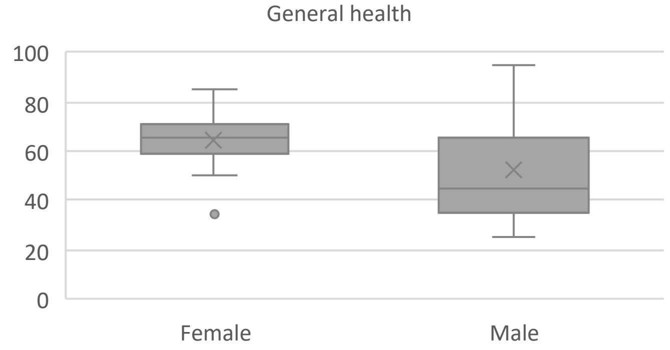


Figure 2.30: Boxplot of SF36 General health by Gender

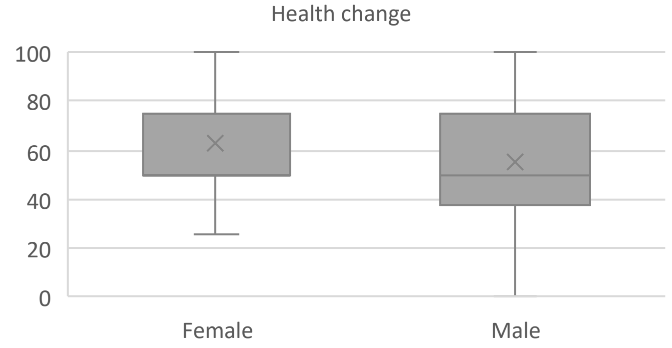


Figure 2.31: Boxplot of SF36 Health change by Gender

SF36 by education

Comparisons were made by education status, between those with trade or high school qualifications (n=29, 60.42%), and those with a university qualification (n=19, 39.58%).

A two-sample t-test was used when assumptions for normality and variance were met (Table 2.14), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 2.15).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the **SF36 Physical functioning** scale [W = 169.00, p = 0.043] was significantly lower for participants in the trade or high school subgroup (Median = 80.00, IQR = 40.00) compared to participants in the university subgroup (Median = 85.00, IQR = 10.00).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the **SF36 Energy/fatigue** scale [W = 163.00, p = 0.031] was significantly lower for participants in the trade or high school subgroup (Median = 40.00, IQR = 25.00) compared to participants in the university subgroup (Median = 55.00, IQR = 18.75).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the **SF36 Pain** scale [W = 137.50, p = 0.006] was significantly lower for participants in the trade or high school subgroup

(Median = 67.50, IQR = 32.50) compared to participants in the university subgroup (Median = 78.75, IQR = 20.00).

SF36 Physical functioning scale measures health limitations in physical activities such as walking, bending, climbing stairs, exercise, and housework. On average, participants in the university subgroup scored higher than participants in the trade or high school subgroup. This indicates that physical activities were not limited for participants in the university subgroup, and were slightly limited for participants in the trade or high school subgroup.

SF36 Energy/fatigue scale measures the proportion of energy or fatigue experienced. On average, participants in the university subgroup scored higher than participants in the trade or high school subgroup. This indicates that participants in the university subgroup were sometimes fatigued, and participants in the trade or high school subgroup were often fatigued.

SF36 Pain scale measures how much pain, and how pain interferes with work and other activities. On average, participants in the university subgroup scored higher than participants in the trade or high school subgroup. This indicates that participants in the university subgroup had mild pain, and participants in the trade or high school subgroup had moderate pain.

Table 2.14: SF36 by education summary statistics and T-test

SF36 scale	Group	Number (n=48)	Percent	Mean	SD	T	dF	p-value
Emotional well-being	Trade or high school	29	60.42	65.10	16.97	-0.80	45	0.4254
	University	19	39.58	69.11	15.99			

Table 2.15: SF36 by education summary statistics and Wilcoxon test

SF36 scale	Group	Number (n=48)	Percent	Median	IQR	W	p-value
Physical functioning	Trade or high school	29	60.42	80.00	40.00	169.00	0.0432*
	University	19	39.58	85.00	10.00		
Role functioning/physical	Trade or high school	29	60.42	50.00	75.00	215.00	0.3048
	University	19	39.58	75.00	68.75		
Role functioning/emotional	Trade or high school	29	60.42	66.67	66.67	210.00	0.2345
	University	19	39.58	100.00	66.67		
Energy/Fatigue	Trade or high school	29	60.42	40.00	25.00	163.00	0.0315*
	University	19	39.58	55.00	18.75		
Social functioning	Trade or high school	29	60.42	62.50	25.00	243.50	0.7045
	University	19	39.58	62.50	50.00		
Pain	Trade or high school	29	60.42	67.50	32.50	137.50	0.0063*
	University	19	39.58	78.75	20.00		
General health	Trade or high school	29	60.42	55.00	30.00	209.00	0.2576
	University	19	39.58	62.50	18.75		
Health change	Trade or high school	29	60.42	50.00	25.00	210.00	0.2446
	University	19	39.58	50.00	25.00		

*Statistically significant at p<0.05

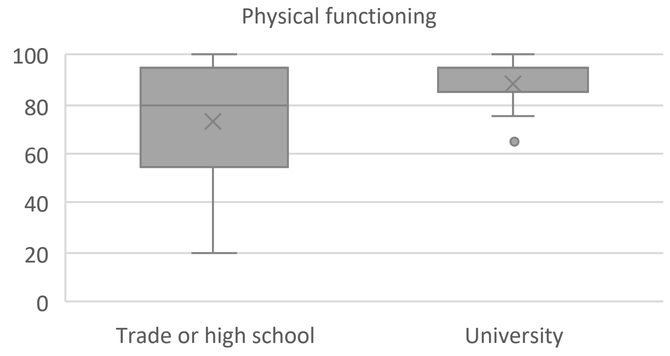


Figure 2.32: Boxplot of SF36 Physical functioning by education

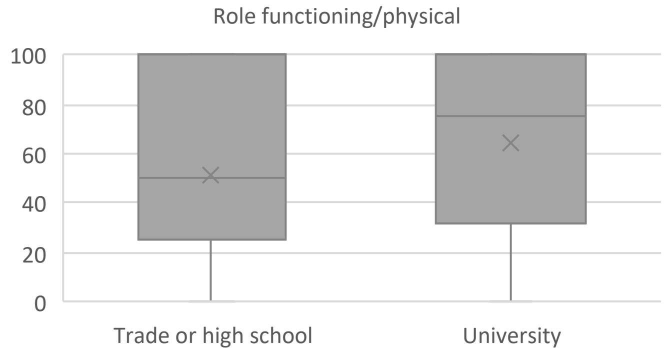


Figure 2.33: Boxplot of SF36 Role functioning/physical by education

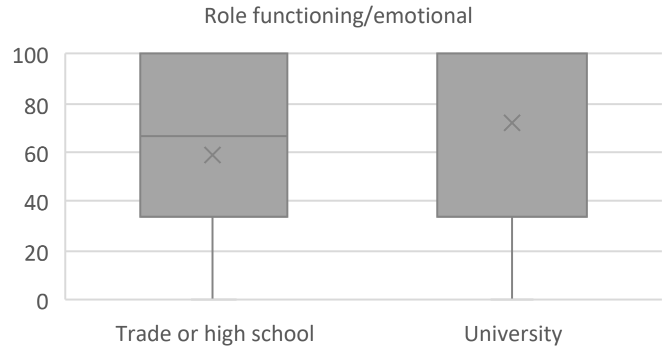


Figure 2.34: Boxplot of SF36 Role functioning/emotional by education

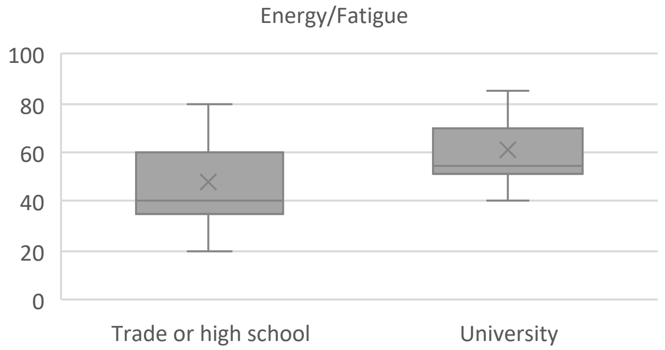


Figure 2.35: Boxplot of SF36 Energy/fatigue education

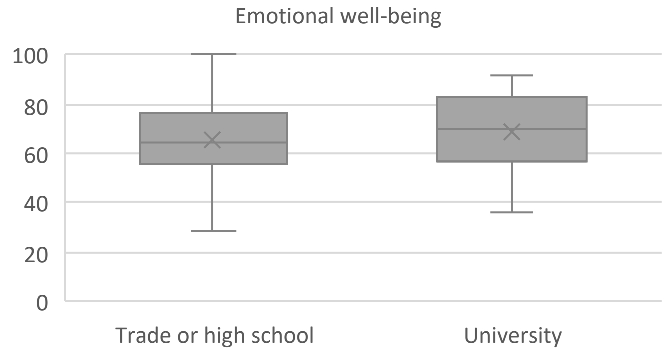


Figure 2.36: Boxplot of SF36 Emotional well-being by education

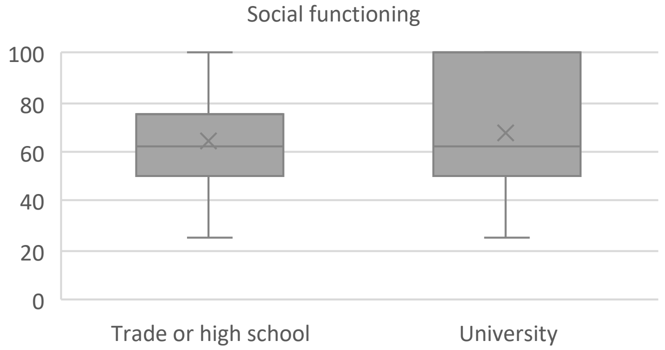


Figure 2.37: Boxplot of SF36 Social functioning by education

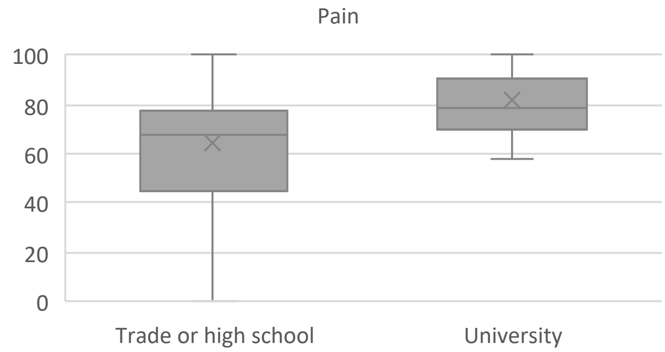


Figure 2.38: Boxplot of SF36 Pain by a education

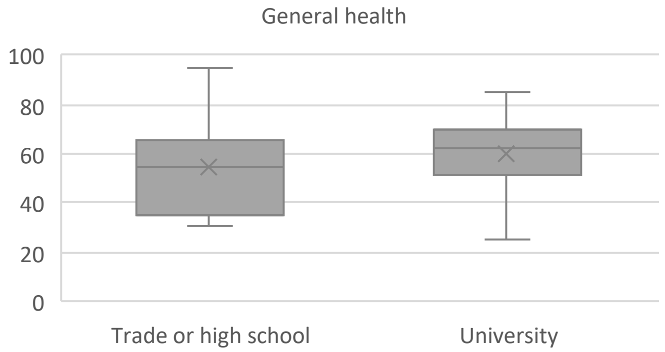


Figure 2.39: Boxplot of SF36 General health by education

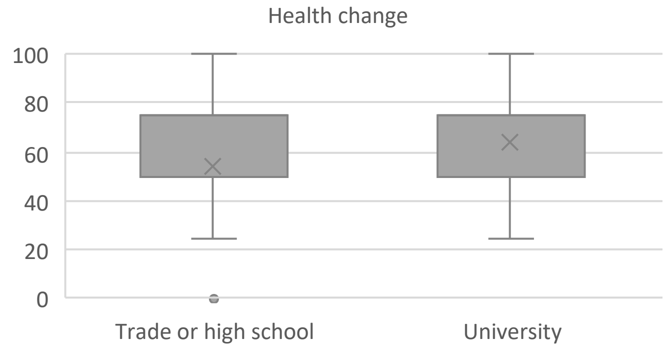


Figure 2.40: Boxplot of SF36 Health change by education

SF36 by location

The location of participants was evaluated by postcode using the Australian Statistical Geography Maps (ASGS) Remoteness areas accessed from the Australian Bureau of Statistics. Those living in regional or remote area (n=15, 31.25%) were compared to those living in a metropolitan area(n=33, 68.75%).

A two-sample t-test was used when assumptions for normality and variance were met (Table 2.16), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 2.17).

No significant differences were observed between participants by **location** for any of the SF36 scales.

Table 2.16: SF36 by location summary statistics and T-test

SF36 scale	Group	Number (n=48)	Percent	Mean	SD	T	dF	p-value
Energy/Fatigue	Regional or remote	15	31.25	49.33	17.10	-0.93	45	0.3549
	Metropolitan	33	68.75	54.53	18.07			
Emotional well-being	Regional or remote	15	31.25	61.33	20.71	-1.53	45	0.1337
	Metropolitan	33	68.75	69.13	13.87			

Table 2.17: SF36 by location summary statistics and Wilcoxon test

SF36 scale	Group	Number (n=48)	Percent	Median	IQR	W	p-value
Physical functioning	Regional or remote	15	31.25	85.00	15.00	266.50	0.5491
	Metropolitan	33	68.75	82.50	21.25		
Role functioning/physical	Regional or remote	15	31.25	75.00	62.50	263.50	0.5885
	Metropolitan	33	68.75	50.00	81.25		
Role functioning/emotional	Regional or remote	15	31.25	33.33	83.33	206.00	0.4109
	Metropolitan	33	68.75	83.33	66.67		
Social functioning	Regional or remote	15	31.25	62.50	62.50	243.50	0.9444
	Metropolitan	33	68.75	62.50	40.63		
Pain	Regional or remote	15	31.25	77.50	22.50	287.00	0.2817
	Metropolitan	33	68.75	67.50	32.50		
General health	Regional or remote	15	31.25	60.00	27.50	239.00	0.9909
	Metropolitan	33	68.75	60.00	31.25		
Health change	Regional or remote	15	31.25	75.00	25.00	314.50	0.0754
	Metropolitan	33	68.75	50.00	50.00		

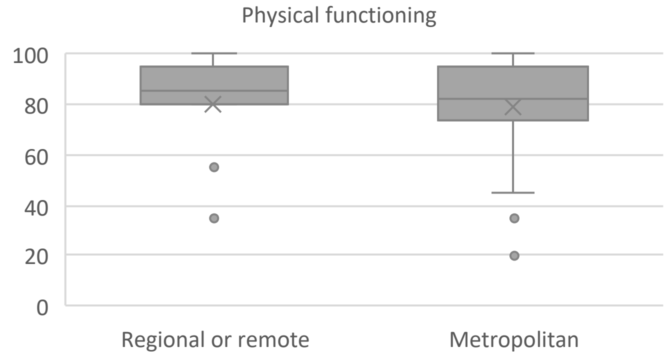


Figure 2.41: Boxplot of SF36 Physical functioning by location

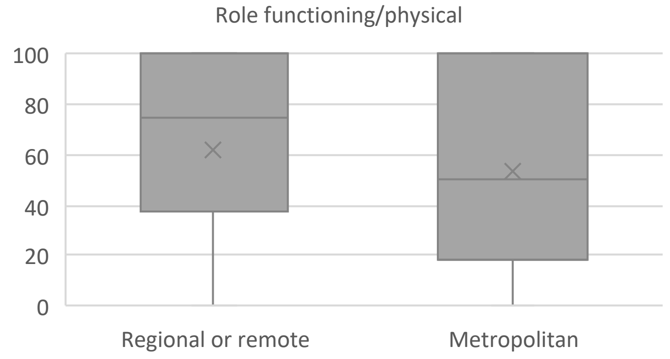


Figure 2.42: Boxplot of SF36 Role functioning/physical by location

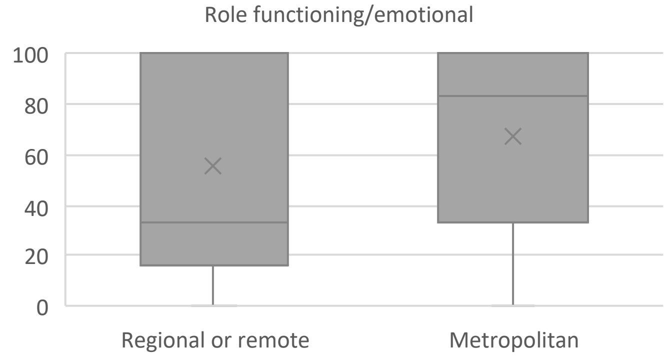


Figure 2.43: Boxplot of SF36 Role functioning/emotional by location

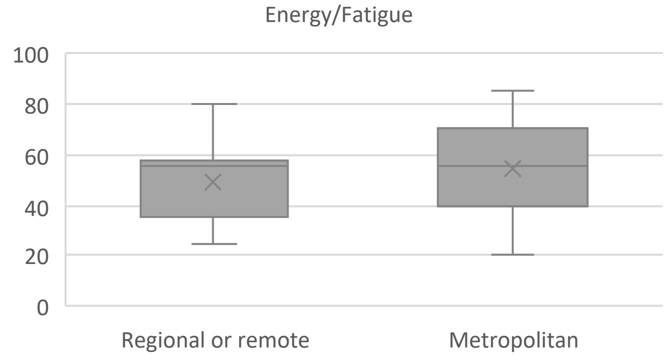


Figure 2.44: Boxplot of SF36 Energy/fatigue by location

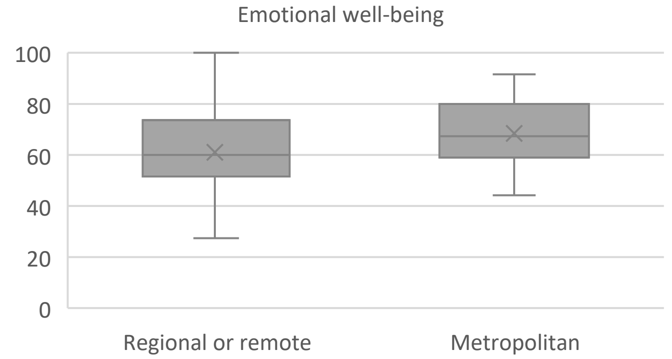


Figure 2.45: Boxplot of SF36 Emotional well-being by location

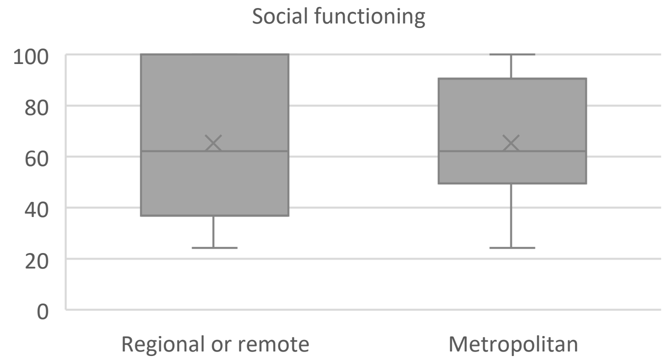


Figure 2.46: Boxplot of SF36 Social functioning by location

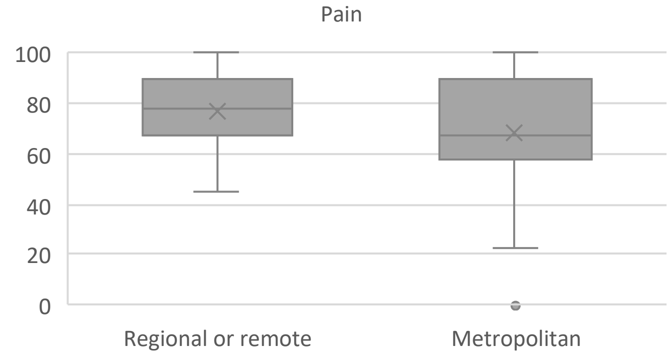


Figure 2.47: Boxplot of SF36 Pain by a location

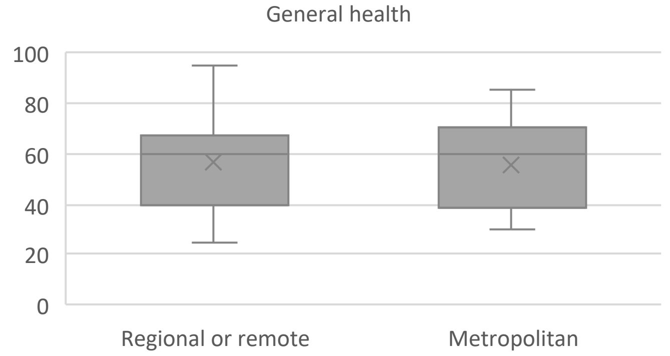


Figure 2.48: Boxplot of SF36 General health by location

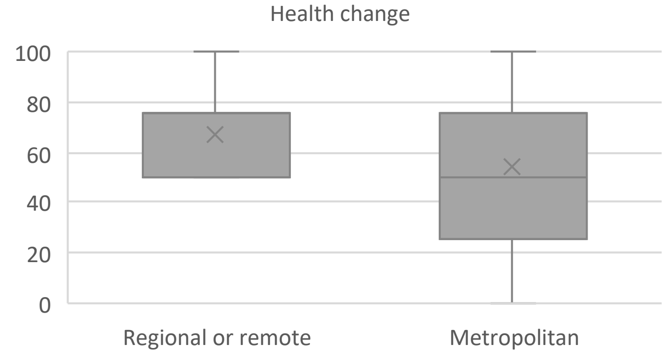


Figure 2.49: Boxplot of SF36 Health change by location

SF36 by socioeconomic status

Comparisons were made by socioeconomic status, using the Socio-economic Indexes for Areas (SEIFA) (www.abs.gov.au), SEIFA scores range from 1 to 10, a higher score denotes a higher level of advantage. Participants with a mid to low SEIFA score of 1-6, Mid to low status (n=20, 41.67%) compared to those with a higher SEIFA score of 7-10, Higher status (n=28, 58.33%).

A two-sample t-test was used when assumptions for normality and variance were met (Table 2.18), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 2.19).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the **SF36 Role functioning emotional** scale [W = 175.00, p = 0.0287] was significantly lower for participants in the mid to low status subgroup (Median = 33.33, IQR = 100.00) compared to participants in the higher status subgroup (Median = 100.00, IQR = 50.00).

SF36 Social functioning scale measures **l**imitations on social activities due to physical or emotional problems**.** On average, participants in the higher status subgroup scored higher than participants in the mid to low status subgroup. This indicates that social activities were not limited for participants in the higher status subgroup, and limited for participants in the mid to low status subgroup.

Table 2.18: SF36 by socioeconomic status summary statistics and T-test

SF36 scale	Group	Number (n=48)	Percent	Mean	SD	T	dF	p-value
Energy/fatigue	Mid to low status	20	41.67	49.25	18.08	-1.21	45	0.2324
	Higher status	28	58.33	55.56	17.34			
Emotional well-being	Mid to low status	20	41.67	65.20	19.81	-0.51	45	0.6133
	Higher status	28	58.33	67.70	13.94			

Table 2.19: SF36 by socioeconomic status summary statistics and Wilcoxon test

SF36 scale	Group	Number (n=48)	Percent	Median	IQR	W	p-value
Physical functioning	Mid to low status	20	41.67	80.00	28.75	212.50	0.2157
	Higher status	28	58.33	85.00	17.50		
Role functioning physical	Mid to low status	20	41.67	50.00	50.00	196.50	0.1055
	Higher status	28	58.33	75.00	75.00		
Role functioning emotional	Mid to low status	20	41.67	33.33	100.00	175.00	0.0287*
	Higher status	28	58.33	100.00	50.00		
Social functioning	Mid to low status	20	41.67	62.50	46.88	229.00	0.3744
	Higher status	28	58.33	75.00	50.00		
Pain	Mid to low status	20	41.67	67.50	23.13	203.50	0.1497
	Higher status	28	58.33	77.50	22.50		
General health	Mid to low status	20	41.67	42.50	35.00	217.50	0.2611
	Higher status	28	58.33	60.00	15.00		
Health change	Mid to low status	20	41.67	50.00	25.00	278.50	0.8562
	Higher status	28	58.33	50.00	37.50		

*Statistically significant at p<0.05

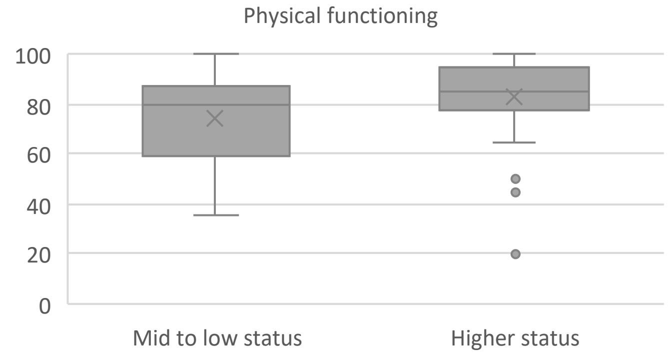


Figure 2.50: Boxplot of SF36 Physical functioning by socioeconomic status

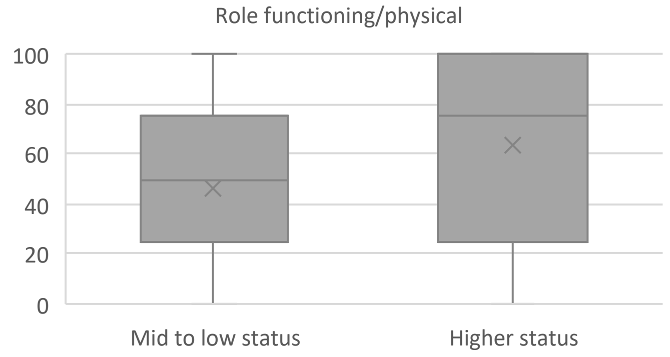


Figure 2.51: Boxplot of SF36 Role functioning/physical by socioeconomic status

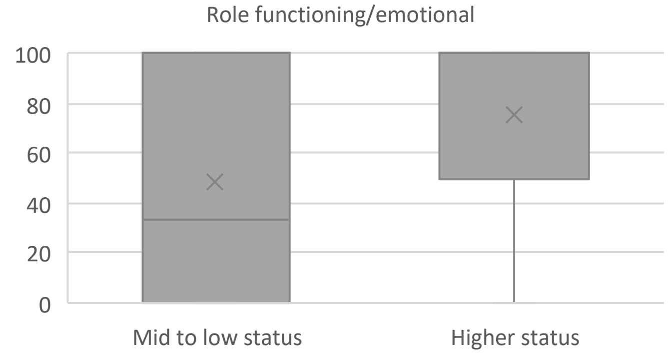


Figure 2.52: Boxplot of SF36 Role functioning/emotional by socioeconomic status

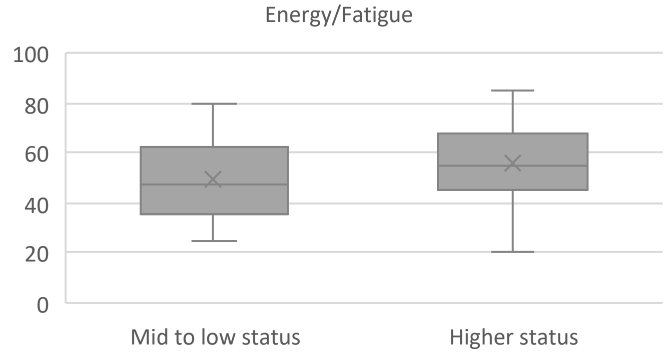


Figure 2.53: Boxplot of SF36 Energy/fatigue by socioeconomic status

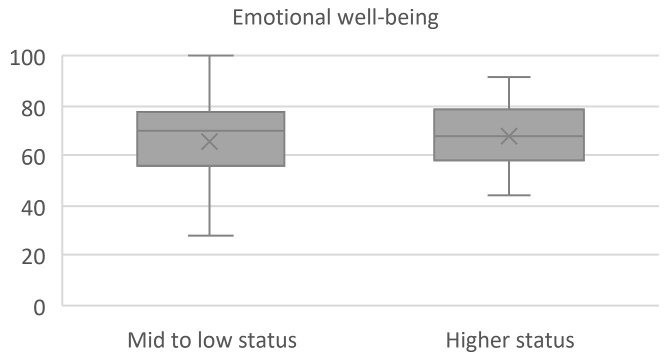


Figure 2.54: Boxplot of SF36 Emotional well-being by socioeconomic status

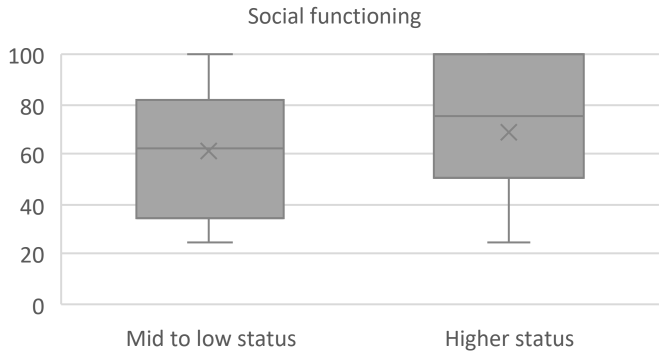


Figure 2.55: Boxplot of SF36 Social functioning by socioeconomic status

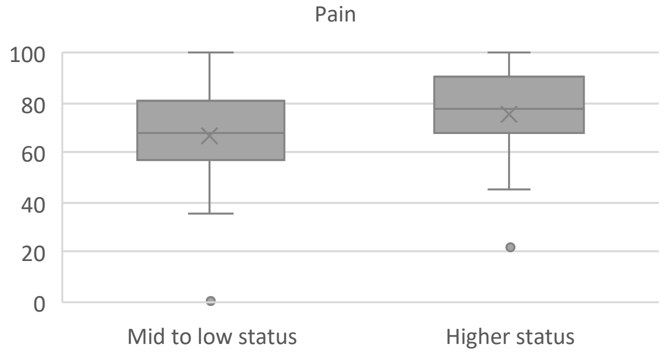


Figure 2.56: Boxplot of SF36 Pain by a socioeconomic status

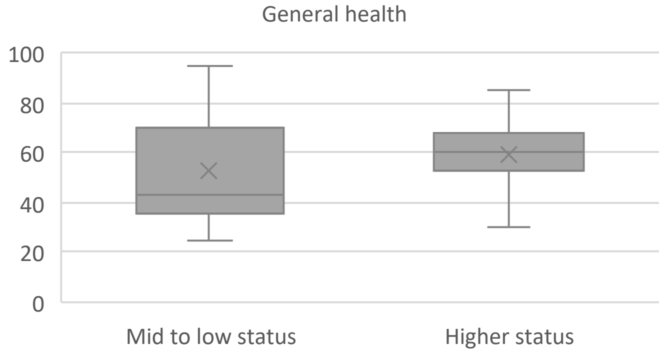


Figure 2.57: Boxplot of SF36 General health by socioeconomic status

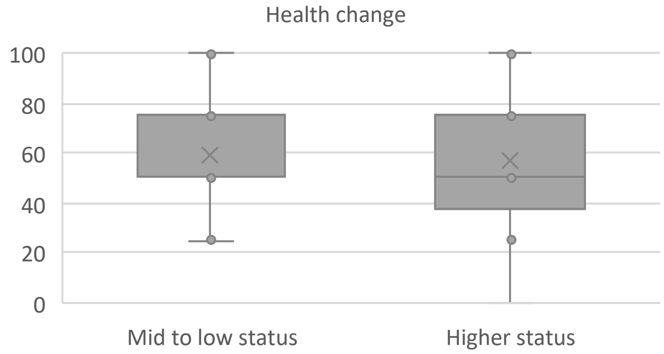


Figure 2.58: Boxplot of SF36 Health change by socioeconomic status

Section 3

Symptoms and diagnosis

Section 3: Symptoms and diagnosis

Experience of symptoms before diagnosis

Participants were asked in the questionnaire which symptoms they had before diagnosis, they could choose from a set list of symptoms and could then specify other symptoms not listed.

There were 3 participants (6.98%) that had no symptoms before diagnosis. Participants had a maximum of 6 symptoms, and a median of 2.00 (IQR=2.00).

Symptoms before diagnosis

The most common symptoms before diagnosis were blood in urine (n=33, 76.74%), needing to pass urine often (n=16, 37.21%), lower abdominal/stomach or back pain (n=14, 32.56%), and burning feeling when passing urine (n=12, 27.91%).

Participants were asked a follow up question about their quality of life while experiencing these symptoms. Quality of life was rated on a Likert scale from one to seven, where one is “Life was very distressing” and seven is “Life was great”. Median quality of life is presented where five or more participants reported the symptom.

The median quality of life was between 3.00 and 4.50, for all of the symptoms listed in the questionnaire, this is in the “Life was a little distressing” to “Life was average to good” range. The symptoms with the worst quality of life were needing to pass urine often, and a burning feeling when passing urine.

Symptoms leading to diagnosis

In the online questionnaire, participants were asked to select every symptom that they had at diagnosis. In the structured interview, participants were asked to describe the symptoms that actually *led* to their diagnosis.

The majority participants described symptoms leading to a diagnosis in a clear way (n=43, 87.76%). There were 4 participants (8.16%) that described symptoms leading to diagnosis but not with a clear recollection, and there were 2 participants (4.08%) that described having no symptoms.

The most common symptom leading to diagnosis was having blood in urine (n=35, 71.43%), this was followed by pain in the bladder region (n=4, 8.16%), and having frequent or prolonged urinary tract infections (n=3, 6.12%). There were 7 participants (14.29%) that described changes in urinary habits which did not lead to diagnosis, however recognised the importance in hindsight.

Symptoms leading to diagnosis: Seeking medical attention

Participants described when they sought medical attention after noticing symptoms. There were 37 participants (75.51%) that described having symptoms and seeking medical attention relatively soon. There were 8 participants (16.33%) that described having symptoms and not seeking medical attention initially, and 4 participants (8.16%) that described not having any symptoms before diagnosis

Symptoms leading to diagnosis: Description of diagnostic pathway

Participants were most commonly referred directly to a specialist from their general practitioner which led to their diagnosis (n=30, 61.22%), and this was followed by being diagnosed by their general practitioner due to concerns about symptoms (n=10, 20.41%). There were 6 participants (12.24%) that described being diagnosed after being admitted into the emergency department or hospital, and 3 participants (6.12%) that were diagnosed by their general practitioner following routine check-up or incidental finding.

Time from symptoms to diagnosis

Participants were asked to give the approximate date of when they first noticed symptoms of bladder cancer and the approximate date of diagnosis with bladder cancer. Where enough information was given, an approximate duration from first noticing symptoms to diagnosis was calculated.

Duration was calculated for 42 participants. There were 12 participants (28.57%) that were diagnosed less than 1 month of noticing symptoms, 13 participants (30.95%) diagnosed 1 to 3 months from noticing symptoms, 6 participants (14.29%) that were diagnosed 3 to 6 months of noticing symptoms, and 11 participants (26.19%) that were diagnosed 6 months or more after noticing symptoms.

Time from diagnostic test to receiving a diagnosis

Participants were asked in the online questionnaire how long they waited between diagnostic tests and getting a diagnosis.

Participants were most commonly diagnosed less than a week after diagnostic tests (n = 12, 27.91%). There were 11 participants (25.58%) that were diagnosed less than between 1 and 2 weeks after diagnostic tests, 10 participants (23.26%) diagnosed between 2 and 3 weeks, 10 participants (23.26%) diagnosed more than four weeks after diagnostic testing.

Diagnostic tests

Participants were asked in the questionnaire which diagnostic tests they had for their diagnosis with bladder cancer. They could choose from a set list of diagnostic tests, and could then specify other tests not listed. The number of tests per participant were counted using both tests from the set list and other tests specified.

Participants reported between 1 to 6 diagnostic tests (median=4.00, IQR=2.00). The most common tests were cystoscopy and biopsy (n=37, 86.05%), urine tests (n=32, 74.42%), ultrasound scans (n=29, 67.44%), and CT scans (n=27, 62.79%).

Diagnosis provider and location

Participants were asked in the online questionnaire, which healthcare professional gave them their diagnosis, and where they were given the diagnosis.

The majority of participants received their diagnosis by a urologist (n=33, 76.74%). There were 8 participants (18.60%) that received their diagnosis from a general practitioner.

Participants were most commonly given their diagnosis in the specialist clinic (n=19, 44.19%), this was followed by the hospital (n=14, 32.56%), and the general practice (GP) (n=7, 16.28%).

Year of diagnosis

Participants were diagnosed between 2004 to 2022. There were 18 participants (42.86%) that were diagnosed in the last three years.

Bladder cancer diagnosis

The majority of participants were diagnosed with urothelial carcinoma (n=25, 58.14%), followed by squamous cell carcinoma (n=4, 9.30%). There were 3 participants (6.98%) that were diagnosed with adenocarcinoma, and 3 participants (6.98%), diagnosed with transitional cell carcinoma. There were 9 participants (20.93%) who were not sure about the type they were diagnosed with.

Bladder cancer stage

There were 43 people with bladder cancer who took part in this study. There were 5 participants (11.63%) with Stage 0, 14 participants (32.56%) with Stage I, 10 participants (23.26%) with Stage II, 10 participants (23.26%) with Stage III and 4 participants (9.30%) with stage IV bladder cancer.

Bladder cancer spread

Participants noted in the online questionnaire if the cancer had spread, and where it had spread to. There were 7 participants (16.28%) that noted that the cancer had spread. The most common site of spread were lymph nodes (n=4, 9.30%).

Bladder cancer recurrence

Almost half of the participants noted that they had a bladder cancer recurrence (n=21, 48.84%), there were 17 participants (39.53%) that had not had a recurrence and there were 5 participants that were not sure (11.63%).

Understanding of disease at diagnosis

Participants were asked in the structured interview how much they knew about their condition at diagnosis. Most participants described having no understanding about the condition at diagnosis (n=32, 65.31%), this was followed by knowing very little about the condition (n=13, 26.53%), and having a good understanding (n=3, 6.12%). The most common reason for having limited knowledge was from doing research through the diagnostic process (n=7, 14.29%).

Emotional support at diagnosis

Participants were asked in the online questionnaire how much emotional support they or their family received between diagnostic testing and diagnosis.

There were 10 participants (23.26%) who had enough support, 5 participants (11.63%) that had some support but it wasn't enough, and 28 participants (65.12%) had no support.

Out of pocket expenses at diagnosis

Participants noted in the online questionnaire the amount of out-of-pocket expenses they had at diagnosis, for example doctors' fees, and diagnostic tests.

There were 14 participants (32.56%) who had no out of pocket expenses, and 15 participants (34.88%) who did not know or could not recall. There were 3 participants (6.98%) that spent $1 to $250, 3 participants (6.98%) that spent between $251 to $500, 2 participants (4.65%) that spent $501 to $1000, and 6 participants (13.95%) that spent more than $1000.

Burden of diagnostic costs

In the follow-up question about the burden of costs at diagnosis, for 30 participants who had out of pocket expenses.

For 28 participants (73.68%) the cost was slightly or not at all significant. For 6 participants (15.79%) the out-of-pocket expenses were somewhat significant, and for 4 participants (10.53%), the burden of out-of-pocket expenses were moderately or extremely significant.

Genetic tests and biomarkers

Participants answered questions in the online questionnaire about if they had any discussions with their doctor about biomarkers, genomic and gene testing that might be relevant to treatment. If they did have a discussion, they were asked if they brought up the topic or if their doctor did.

Most commonly, participants had never had a conversation about biomarkers, genomic, or gene testing that might be relevant to treatment, (n=39, 90.70%). There were 3 participants (6.98%) who brought up the topic with their doctor, and a single participant (2.33%) whose doctor brought up the topic with them.

Participants were then asked if they had had any biomarker, genomic or gene testing. If they had testing, they were asked if they had it as part of a clinical trial, paid for it themselves or if they did not have to pay for it. Those that did not have the test were asked if they were interested in this type of test.

The majority of participants did not have any genetic or biomarker tests but would like to (n=32, 74.42%). There were 9 participants (20.93%) who did not have these tests and were not interested in them, and a single participant (2.33%) that had biomarker tests.

Biomarker status

All participants (n=43, 100%) were not sure about any markers that they have in relation to bladder cancer.

Understanding of prognosis

Participants were asked in the structured interview to describe what their current understanding of their prognosis was. Participants most commonly described their prognosis in relation to having no evidence of disease or that they are in remission (n=28, 57.14%), and in relation to monitoring their condition with tests, scans, or regular follow up appointments (n=28, 57.14%). There were 12 participants (24.49%) that described prognosis in relation to probable recurrence/cycle of recurrence, 10 participants (20.41%) that described prognosis in relation to tumour grade or stage, and 7 participants (14.29%) described prognosis in relation to a specific timeframe that they have been disease free.

Experience of symptoms before diagnosis

Participants were asked in the questionnaire which symptoms they had before diagnosis, they could choose from a set list of symptoms and could then specify other symptoms not listed.

There were 3 participants (6.98%) that had no symptoms before diagnosis. Participants had a maximum of 6 symptoms, and a median of 2.00 (IQR=2.00) (Table 3.1, Figure 3.1).

Table 3.1: Number of symptoms per participant

Number of symptoms per participant	Number (n=43)	Percent
No symptoms	3	6.98
1 to 2	26	60.47
3 to 4	12	27.91
5 to 6	2	4.65

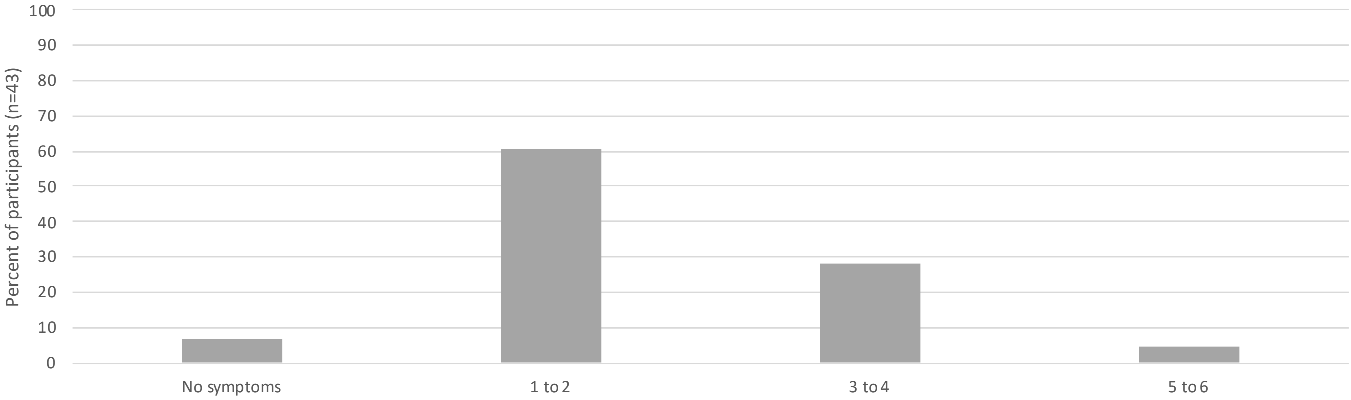


Figure 3.1: Number of symptoms per participant

Symptoms before diagnosis

The most common symptoms before diagnosis were blood in urine (n=33, 76.74%), needing to pass urine often (n=16, 37.21%), lower abdominal/stomach or back pain (n=14, 32.56%), and burning feeling when passing urine (n=12, 27.91%) (Table 3.2, Figure 3.2).

Participants were asked a follow up question about their quality of life while experiencing these symptoms. Quality of life was rated on a Likert scale from one to seven, where one is “Life was very distressing” and seven is “Life was great”. Median quality of life is presented where five or more participants reported the symptom.

The median quality of life was between 3.00 and 4.50, for all of the symptoms listed in the questionnaire, this is in the “Life was a little distressing” to “Life was average to good” range. The symptoms with the worst quality of life were needing to pass urine often, and a burning feeling when passing urine (Table 3.2, Figure 3.3).

Table 3.2: Symptoms before diagnosis

Symptom	Number (n=43)	Percent	Quality of life	
			Mean	SD
No symptoms	3	6.98	NA	NA
Blood in urine	33	76.74	4.00	3.00
Need to pass urine often	16	37.21	3.00	2.50
Lower abdominal/stomach or back pain	14	32.56	4.00	1.75
Burning feeling when passing urine	12	27.91	3.00	3.00
Problems emptying bladder	11	25.58	4.50	1.00
Other symptoms	4	9.30	NA	NA

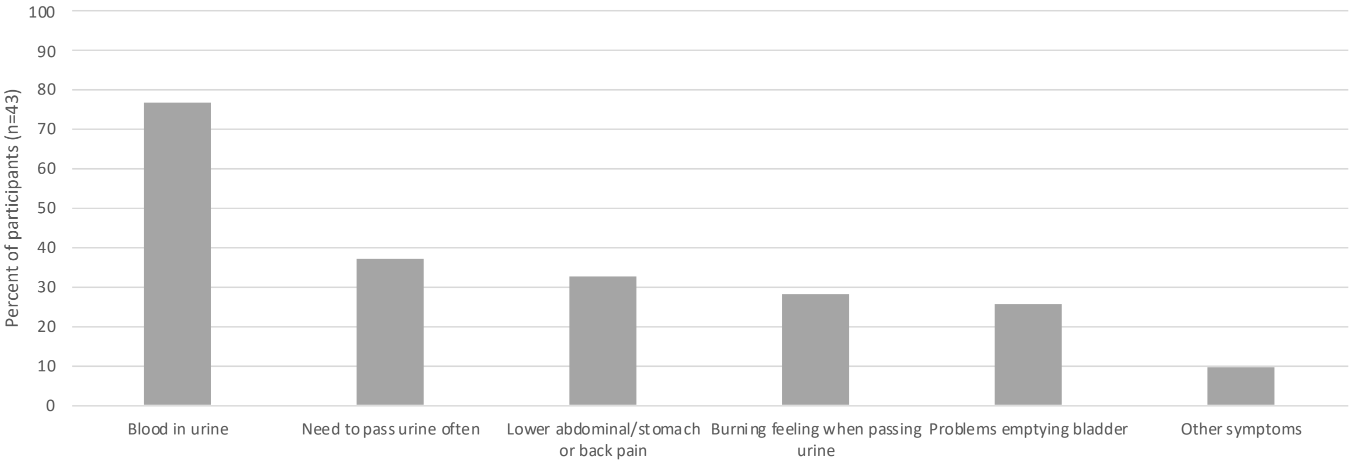


Figure 3.2: Symptoms before diagnosis

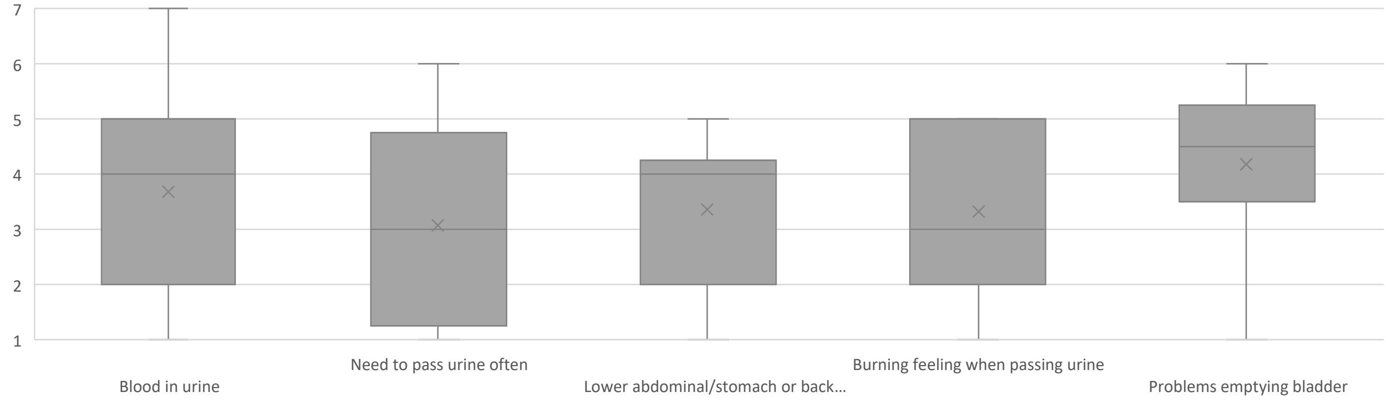


Figure 3.3: Quality of life from symptoms before diagnosis

Symptoms leading to diagnosis

In the online questionnaire, participants were asked to select every symptom that they had at diagnosis. In the structured interview, participants were asked to describe the symptoms that actually *led* to their diagnosis.

The majority participants described symptoms leading to a diagnosis in a clear way (n=43, 87.76%). There were 4 participants (8.16%) that described symptoms leading to diagnosis but not with a clear recollection, and there were 2 participants (4.08%) that described having no symptoms.

The most common symptom leading to diagnosis was having blood in urine (n=35, 71.43%), this was followed by pain in the bladder region (n=4, 8.16%), and having frequent or prolonged urinary tract infections (n=3, 6.12%). There were 7 participants (14.29%) that described changes in urinary habits which did not lead to diagnosis, however recognised the importance in hindsight.

Participant describes having blood in urine, which led to their diagnosis

Mine was so simple. There's only one day in the whole of my pre diagnosis prior to me seeing a doctor. It's a matter of hours from first noticing. I had never noticed any pain, any sensation, any thing whatsoever. I woke up one morning to help a friend in a business to drive a truck for them. And I'm a PROFESSION,but I have a heavy vechicle licence, and I want to do a pee when I woke up in the morning. And I went to urinate and I thought, Oh, it feels like I'm passing a lot of water, like a lot of fluids. And I looked down and I just saw a stream of what looked like pure blood flowing out of my body. And I absolutely freaked out.
Participant 001_2022AUBLC

About 25 years ago, I had an autoimmune disease which was treated with steroids and the chemo drug cyclophosphamide, and I always knew that was a risk of cyclophosphamide. Bladder cancer. So I had some when I wasn't sure, I had some a little bit of blood loss. Well, it's just pink. And I thought, oh, that's not sure if that's from the bladder or not, so. But I thought, Oh, I better get that checked pretty quickly. But I'd had

uterine polyps a couple of years before that. So first I went to the just spoke to the gynae and she said, Oh, we're going to have a pelvic ultrasound and that showed up the bladder tumours. So yeah, it was a haematuria that, that alerted me to it and I didn't really ignore it because I knew that it was a risk it already has.
Participant 019_2022AUBLC

Basically, it was blood in my pee. And at the time I was doing quite a bit of race walking and competitive long distance walking, and I put it in as being just things shaking too much basically. And I did ignore the symptoms for about six months before I did talk with my GP.
Yeah. Yeah. Yeah. Yeah. I mean, the main symptoms were the blood in the urine and then it developed into clots. And it's that point that I knew something was wrong like that. So I didn't know whether it was kidney infection or whatever. So I waited about a week. I went to the GP and it was, you know, then he just put me through a lot of tests. He was okay then.
Participant 023_2022AUBLC

Um, not really, because my first major symptom was blood in my urine, which I acted on immediately. So. So I didn't really have anything where, you know, I thought, oh, that could have been a problem. I was completely healthy, you know, I wasn't even feeling tired. So. So I didn't really. There wasn't anything that I ignored.
Participant 032_2022AUBLC

Um, I had, um, blood in my urine. I had a AF heart condition and, um, I was put on blood thinners. And with that, the blood started showing up in me urine. I thought it was from the blood thinners cause in the, the blood and urine and um, I went and seen just me GP because, and after a couple of weeks and he, he sent me for my test and he sent me for a CT scan and he called me back the next day. Um, because we got the results of the scan and um, they found a four and a half centimetre tumour in me bladder. And from there, I went to the urologist. I think it was about a week later and. He organised me to have a two. TURBT. An incision to get the tumour removed.
Participant 044_2022AUBLC

Participant describes changes in urinary habits, which did not lead to diagnosis, however recognised the importance in hindsight

Yes, mainly just slightly slight changes in, uh, voiding as in like, um, yeah, I really only noticed in retrospect. So I would say my bladder not quite emptying with the first sort of empty and then I would kind of think, oh yeah, just, um, you know, use like my sphincter again. And a bit more would empty as if there was something holding back the rest of the urine. So that certainly but not to the point where it, it rang alarm bells. And I suppose that was really the only thing. Yeah. Until the morning that I had haematuria.
Participant 010_2022AUBLC

Yeah, I'm 72 now from the age of about 35. I've had bladder problems. Well, I'd been going to the toilet regularly at night, three or four times, sometimes five times a night. And then it escalated about seven years ago. I was going all the time and I never saw anyone about it because it didn't cause me any pain, just the lack of sleep. And then I was playing golf six years ago, in May 2006, and I went to the toilet at the golf and I just started peeing blood. And I immediately went to HOSPITAL in CITY and they did a scan, a CT scan I think it was, and they said I had some sort of tumour there that there was, they weren't sure whether it was bladder cancer or whatever. So they booked me in for cystoscopy and straight away, which was done I think within about a week. And they came back and said tthe biopsy that said that I had high grade bladder cancer. Can't remember the size of the cancer. I think it was a couple of centimetres, maybe two.
Participant 021_2022AUBLC

Yes. Let me have a look. What? My local doctor, my local GP. He had been monitoring my blood and urine from March last year. He didn't, he was a little bit concerned and mentioned there was a little blood in the urine and I didn't really think too much about it, but he just kept calling me back. And then I was also mention to him that I was needing to go to the toilet to urinate quite a lot in the night, and that had been probably going on for quite some years. And when he heard that, he referred me to get a pelvic ultrasound in LOCATION.
Participant 043_2022AUBLC

My husband has been a frequent urinater for years. And we always thought that was, you know, prostate linked. And he's had he had all the checks, all the the scans and none of the time came on. And the last big last scans were two years ago before COVID. Yes. And the only other symptom then that we got him tested on was about a month before he got his diagnosis. He had some urine and some blood in his urine. Okay. Okay. And then he had it the second day, and he only told me on the second day, and I said to him, Well, you need to go and get checked. And within a week, he had the doctor's appointment. He had the ultrasound.
Carer 004_2022AUBLC

Participant describes having pain in bladder region, which led to their diagnosis

PARTICIPANT Okay. I had absolutely no symptoms. But one morning, early December of 2017, I woke up with severe, right sided pain, which I thought was renal colic. So I kind of thought that I had renal stones and that was the only symptoms that I had. I had no blood in the urine or anything like that. So it came as quite a surprise

INTERVIEWER Okay. Anything else

PARTICIPANT No, just the pain. Just the pain. So I went to my local doctor and I had to seek a scan. And that's when they recommended that. I see a specialist.
Participant 039_2022AUBLC

So it started off fairly suddenly. So I was actually heading away for a weekend with friends and someone else was driving, us sitting in the backseat. And I had pains in my back just beneath my rib cage sort of kicks that are going to kidney location. And I did actually, it was it was of a, sort of severity where I actually called, you know, a nurse on call and asked for advice, you know, if I should do anything in particular or what kind of pain management or I should look at. Anyway, they suggested that I went and saw a GP, so I did that the following morning. It was Saturday morning, and they just prescribed a particular pain medication, which I can't remember at the time that the oncologist had actually, actually told me later that it was the completely wrong thing to be prescribing for someone with kidney pain. Anyway, I was only away for the weekend and as we were coming home by the Sunday. I was actually at school reunion anyway, and I avoided a couple of things because it seemed too much pain. And on the way, as we were driving. On the way home on a Sunday afternoon, I got the, I got my friend to just drop me at the hospital that emergency at the hospital, too, so we could start having a look at that. Yeah. And so, so the cancer itself was in the ureter and it had occluded the ureter so. And so I was just getting kidney pain from pressure because of the occluded ureter.
Participant 041_2022AUBLC

Just the frequent urination he never had never presented with any blood in the urine. And then probably about eight months after that had been going on, he then had very extreme pelvic pain that sent him kind of in a bowl on the ground, huddled in pain. And that was what escalated him to the emergency department
Carer 002_2022AUBLC

Participant describes having frequent or prolonged urinary tract infections, which led to their diagnosis

Okay. The first the very first symptom, I realised what it was, was a very fine speck of blood on the toilet paper the size of a pinhead. And I just thought, oh. Women's problems. And I never saw it again for months. Then I started to have urinary tract infections. And I went to the Doctor several times and she gave me antibiotics. And really didn't seem to do much except clear it up.
Participant 003_2022AUBLC

Yeah, it was August 20, 21, like late, like 2020. I started to get like what I thought were UTIs that, you know, that I could go to the toilet and that. But every time they did, a pathology, there was no bugs in it.
Participant 004_2022AUBLC

Yes, certainly. I was seeing my GP about, uh, urinary tract infections. I had the typical sort of symptoms of that my GP started looking at that. In fact, he looked at it for many months and he never mentioned bladder cancer at all. But I found out later about that.
Participant 029_2022AUBLC

Table 3.3: Symptom recall

Symptom recall	All participants		Early		Invasive		Advanced		Person with bladder cancer		Carer		Female		Male	
	n=49	%	n=20	%	n=10	%	n=14	%	n=44	%	n=5	%	n=17	%	n=32	%
Participant describes symptoms leading to diagnosis in a clear way (strong recall)	43	87.76	19	95.00	10	100.00	10	71.43	39	88.64	4	80.00	15	88.24	28	87.50
Participant describes symptoms leading to diagnosis but does not provide a clear recollection	4	8.16	1	5.00	0	0.00	2	14.29	3	6.82	1	20.00	2	11.76	2	6.25
Participant describes having no symptoms before diagnosis	2	4.08	0	0.00	0	0.00	2	14.29	2	4.55	0	0.00	0	0.00	2	6.25

Symptom recall	All participants		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=49	%	n=29	%	n=19	%	n=15	%	n=33	%	n=20	%	n=28	%
Participant describes symptoms leading to diagnosis in a clear way (strong recall)	43	87.76	26	89.66	16	84.21	14	93.33	28	84.85	18	90.00	24	85.71
Participant describes symptoms leading to diagnosis but does not provide a clear recollection	4	8.16	1	3.45	3	15.79	1	6.67	3	9.09	1	5.00	3	10.71
Participant describes having no symptoms before diagnosis	2	4.08	2	6.90	0	0.00	0	0.00	2	6.06	1	5.00	1	3.57

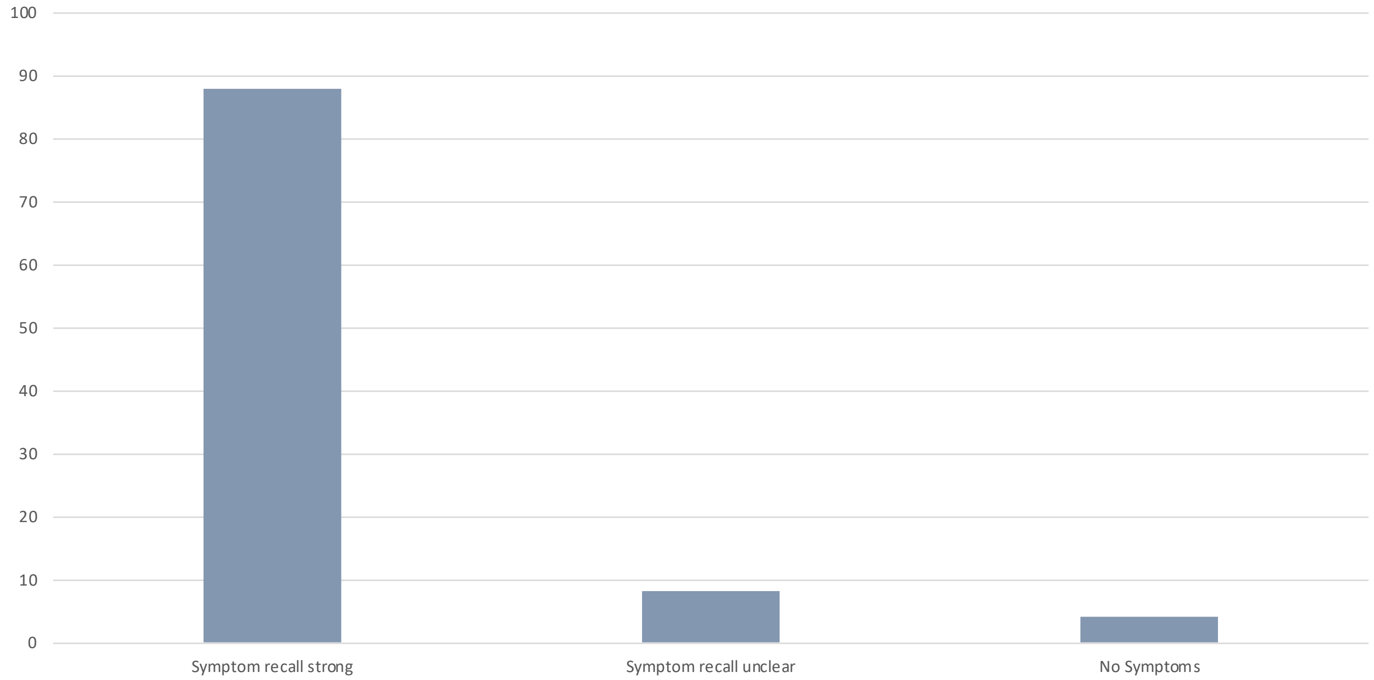


Figure 3.4: Symptom recall

Symptom recall	Reported less frequently	Reported more frequently
Participant describes symptoms leading to diagnosis in a clear way (strong recall)	Advanced (Stage IV)	Invasive (Stage III)
Participant describes symptoms leading to diagnosis but does not provide a clear recollection	-	Carer to someone with bladder cancer

Table 3.4: Symptom recall– subgroup variations

Table 3.5: Symptoms leading to diagnosis

Symptoms leading to diagnosis	All participants		Early		Invasive		Advanced		Person with bladder cancer		Carer		Female		Male	
	n=49	%	n=20	%	n=10	%	n=14	%	n=44	%	n=5	%	n=17	%	n=32	%
Participant describes having blood in urine, which led to their diagnosis	35	71.43	**17**	**85.00**	8	80.00	**7**	**50.00**	32	72.73	**3**	**60.00**	12	70.59	23	71.88
Participant describes changes in urinary habits, which did not lead to diagnosis, however recognised the importance in hindsight	7	14.29	3	15.00	1	10.00	1	7.14	5	11.36	**2**	**40.00**	3	17.65	4	12.50
Participant describes having pain in bladder region, which led to their diagnosis	4	8.16	0	0.00	0	0.00	3	21.43	3	6.82	1	20.00	2	11.76	2	6.25
Participant describes having frequent or prolonged urinary tract infections, which led to their diagnosis	3	6.12	2	10.00	0	0.00	1	7.14	3	6.82	0	0.00	2	11.76	1	3.13

Symptoms leading to diagnosis	All participants		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=49	%	n=29	%	n=19	%	n=15	%	n=33	%	n=20	%	n=28	%
Participant describes having blood in urine, which led to their diagnosis	35	71.43	21	72.41	13	68.42	11	73.33	23	69.70	15	75.00	19	67.86
Participant describes changes in urinary habits, which did not lead to diagnosis, however recognised the importance in hindsight	7	14.29	5	17.24	2	10.53	2	13.33	5	15.15	2	10.00	5	17.86
Participant describes having pain in bladder region, which led to their diagnosis	4	8.16	2	6.90	2	10.53	0	0.00	4	12.12	0	0.00	4	14.29
Participant describes having frequent or prolonged urinary tract infections, which led to their diagnosis	3	6.12	3	10.34	0	0.00	1	6.67	2	6.06	2	10.00	1	3.57

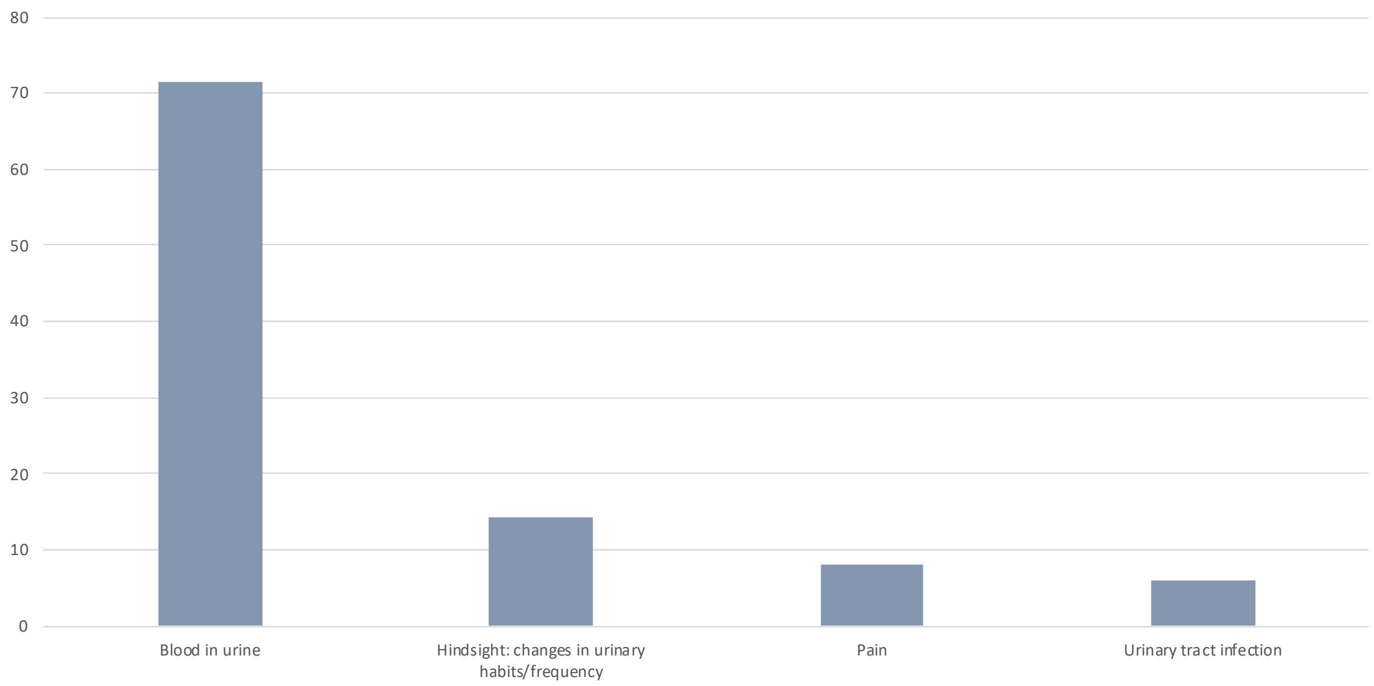


Figure 3.5: Symptoms leading to diagnosis

Table 3.6: Symptoms leading to diagnosis – subgroup variations

Symptoms leading to diagnosis	Reported less frequently	Reported more frequently
Participant describes having blood in urine, which led to their diagnosis	Advanced (Stage IV) Carer to someone with bladder cancer	Early (Stages 0 and I)
Participant describes changes in urinary habits, which did not lead to diagnosis, however recognised the importance in hindsight	-	Carer to someone with bladder cancer

Symptoms leading to diagnosis: Seeking medical attention

Participants described when they sought medical attention after noticing symptoms. There were 37 participants (75.51%) that described having symptoms and seeking medical attention relatively soon. There were 8 participants (16.33%) that described having symptoms and not seeking medical attention initially, and 4 participants (8.16%) that described not having any symptoms before diagnosis.

Participant describes having symptoms and seeking medical attention relatively soon

Yeah, sure. I had a frequency of of urination going to the toilet and and it was sudden onset. And I when this first happened, I was immediately concerned and I went to my general practitioner. And he started doing, you know, blood tests and all those sorts of things. And I said to him could it be cancer, and he laughed it off. Sadly, that's what it was. So. So my first comment is, my first comment is, well, certainly with this GP at the GP level, they had no he had no understanding. And he was an old he was not a young doctor, the GP. He had no understanding of looking for that, you know, the signs of potential bladder cancer. Participant 008_2022AUBLC

Sure. I was very fortunate. Everything panned out is as good as you know, you'd want for for a quick diagnosis and until the, You know, that tumour removal, actually. So that morning I woke up, went a toilet and noticed that it was very evident. It certainly wasn't frank Haematuria was just a different bloodstain. And so I thought, hmm, that's interesting. Went and had something to drink and thought, I'll check, check the next time I go to the toilet. Of course. And the next void was also quite bloodstained. So I thought, this is not good. I'll ring my GP which I did. Or ring a GP, I just thought he gave he'll do so and get booked in to see the GP later that afternoon and. She checked my urine and said, okay, what we might do is. I get you an ultrasound. So in the same, I think. Yeah, that's right. So an ultrasound I booked for next day went and had that done. And I remember as I was having it done, I asked them. I asked the ultrasoundographer. You know how it looked. And she said, Oh, you better check with your GP about that. So I knew something was up and I took the scans home. Participant 010_2022AUBLC

Um. As soon as I had the bleed, I went into the doctors, um, he sent me for an ultrasound and a blood test.

And the results came back. That there was a lesion on my bladder.
Participant 027_2022AUBLC

PARTICIPANT Okay. I had absolutely no symptoms. But one morning, early December of 2017, I woke up with severe, right sided pain, which I thought was renal colic. So I kind of thought that I had renal stones and that was the only symptoms that I had. I had no blood in the urine or anything like that. So it came as quite a surprise.

INTERVIEWER Okay. Anything else?

PARTICIPANT No, just the pain. Just the pain. So I went to my local doctor and I had to seek a scan. And that's when they recommended that. I see a specialist.
Participant 039_2022AUBLC

Participant describes having symptoms and not seeking medical attention initially

Yes, I can. I can't put a date to it. Right. Let's say sometime in maybe late 2015, early 2016, I remember reporting to my GP that I had noticed a little bit of blood in my urine and he gave me a, you know, little bottle to take home and said, well, if it happens again, pee in to this to this sort of thing. And I think about 18 months elapsed before it got to the point where I went back again and said, I really do have a bit of blood.
Participant 006_2022AUBLC

Basically, it was blood in my pee. And at the time I was doing quite a bit of race walking and competitive long distance walking, and I put it in as being just things shaking too much basically. And I did ignore the symptoms for about six months before I did talk with my GP.
Participant 019_2022AUBLC

Yeah. Um, blood in urine. I think I was perimenopausal. Um, so I assumed it was spotting. Um, I didn't think it was anything unusual. Um, what. What took me to the doctor was the hot flushes and the, um, uncontrolled emotion. So I was crying at the drop of a hat.
Participant 022_2022AUBLC

Participant describes having no symptoms or not noticing any symptoms before diagnosis

I didn't have any symptoms. I went for my normal prostate blood tests and it showed an anomally when I did an ultrasound, it showed up in an ultrasound. Okay. Participant 031_2022AUBLC

Well, the interesting thing was that I was asymptomatic and I had had a bit of a history of urinary tract infections, but I had no blood in the urine or pain or anything to indicate that I was something was going on in my bladder. In fact, it was just purely by chance that I was diagnosed. I changed doctors and started up with a new doctor and she had a look at my history and the medications I was on, and she could see that I was using a particular gel that eventually it's vaginally applied and she was a bit concerned about the long term use of it. And so what she asked me to do was to go and have a abdominal ultrasound because she was a bit concerned about what was happening to the uterus and she wanted to get checked to make sure there was no adverse effects on the uterus. So I just went off to have an ultrasound of the abdominal area and that's when it was picked up. So I was actually a very lucky girl because if my doctor hadn't asked me to do that, it could have progressed for quite a while before symptoms developed.
Participant 036_2022AUBLC

My local doctor, my local GP. He had been monitoring my blood and urine from March last year. He didn't, he was a little bit concerned and mentioned there was a little blood in the urine and I didn't really think too much about it, but he just kept calling me back. And then I was also mention to him that I was needing to go to the toilet to urinate quite a lot in the night, and that had been probably going on for quite some years. And when he heard that, he referred me to get a pelvic ultrasound in LOCATION.
Participant 043_2022AUBLC

Table 3.7: Seeking medical attention

Seeking medical attention	All participants		Early		Invasive		Advanced		Person with bladder cancer		Carer		Female		Male	
	n=49	%	n=20	%	n=10	%	n=14	%	n=44	%	n=5	%	n=17	%	n=32	%
Participant describes having symptoms and seeking medical attention relatively soon	37	75.51	15	75.00	8	80.00	11	78.57	34	77.27	3	60.00	13	76.47	24	75.00
Participant describes having symptoms and not seeking medical attention initially	8	16.33	4	20.00	2	20.00	0	0.00	6	13.64	2	40.00	2	11.76	6	18.75
Participant describes having no symptoms or not noticing any symptoms before diagnosis	4	8.16	1	5.00	0	0.00	3	21.43	4	9.09	0	0.00	2	11.76	2	6.25

Seeking medical attention	All participants		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=49	%	n=29	%	n=19	%	n=15	%	n=33	%	n=20	%	n=28	%
Participant describes having symptoms and seeking medical attention relatively soon	37	75.51	20	68.97	16	84.21	11	73.33	25	75.76	15	75.00	21	75.00
Participant describes having symptoms and not seeking medical attention initially	8	16.33	6	20.69	2	10.53	3	20.00	5	15.15	3	15.00	5	17.86
Participant describes having no symptoms or not noticing any symptoms before diagnosis	4	8.16	3	10.34	1	5.26	1	6.67	3	9.09	2	10.00	2	7.14

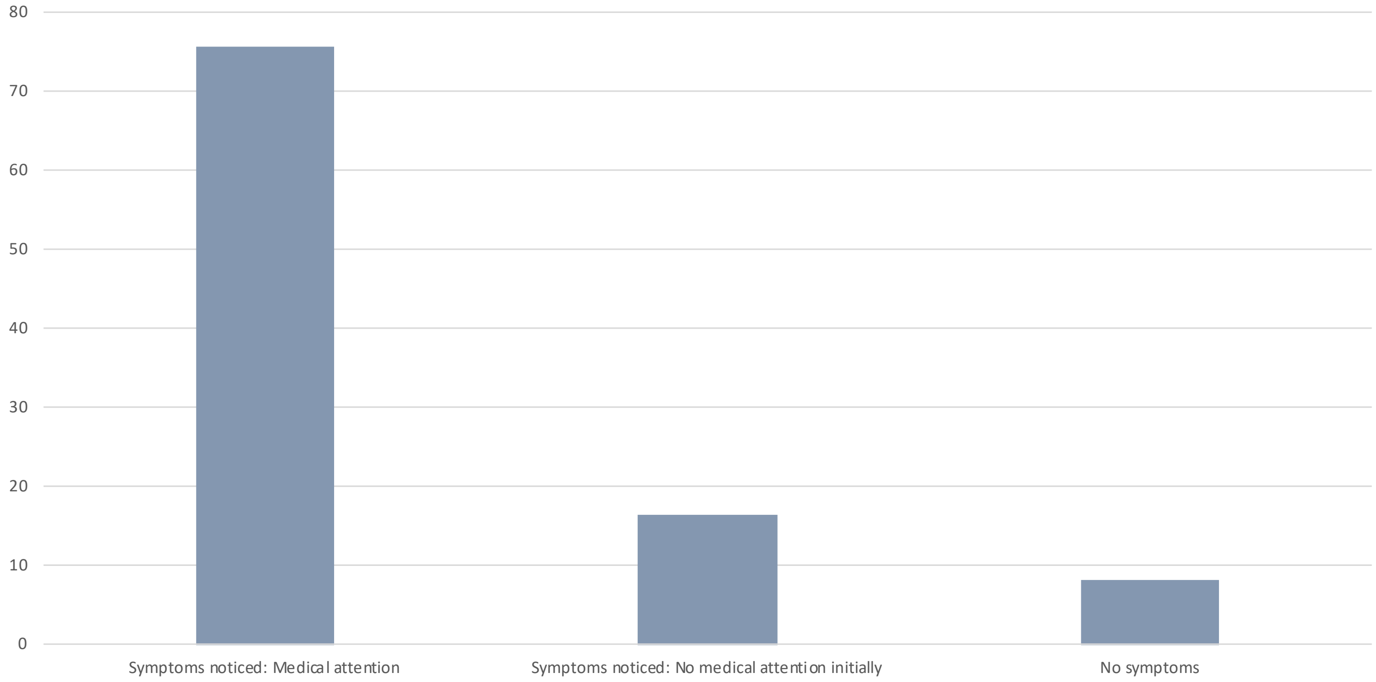


Figure 3.6: Seeking medical attention

Table 3.8: Seeking medical attention – subgroup variations

Seeking medical attention	Reported less frequently	Reported more frequently
Participant describes having symptoms and seeking medical attention relatively soon	Carer to someone with bladder cancer	-
Participant describes having symptoms and not seeking medical attention initially	Advanced (Stage IV)	Carer to someone with bladder cancer

Symptoms leading to diagnosis: Description of diagnostic pathway

Participants were most commonly referred directly to a specialist from their general practitioner which led to their diagnosis (n=30, 61.22%), and this was followed by being diagnosed by their general practitioner due to concerns about symptoms (n=10, 20.41%). There were 6 participants (12.24%) that described being diagnosed after being admitted into the emergency department or hospital, and 3 participants (6.12%) that were diagnosed by their general practitioner following routine check-up or incidental finding.

Participant describes being referred directly to a specialist from their general practitioner which led to their diagnosis

Um, I started having a show of, uh, you know, a little bit of blood. So I, over a period of time I went to the GP with samples and they had it tested and said, Oh yeah, there was a little bit, but it'll be alright, it's probably an infection and gave me some antibiotics and then it got a little bit worse. So I went back again and this time he said, I want you to go and have a MRI at oh no an ultrasound at the local X-ray place and also make an appointment with a urologist in your area. And yeah, so I made the appointment and I got the results back saying that I had a tumour and I went back to the doctor and the doctor rang straight away to the urologist and they got me seen to that day. And then a couple of weeks later I went back, I went in the hospital and they found two tumours and high grade

cancer cells, but it was still only stage one, so I got it early. And so since then I've had 13 cystoscopy and one flexible. And then I've had, uh, 18 BCG.
Participant 007_2022AUBLC

Oh, well, I went made an appointment for the doctor and got the I think the next day I took a sample and she looked at it and said, Oh, it's a infection. But then she sent it off and found it. It wasn't an infection. Mm hmm. And then I think I had to have an ultrasound. Yep. And then she referred me to a urologist.
Participant 013_2022AUBLC

Okay. So I was. I had an ultrasound and then was quickly sent to a urologist. So the urologist then informed me that I had bladder cancer.
Participant 026_2022AUBLC

Okay. Yeah. Well, the first thing I went to, I went to my GP and and explained the symptoms to him, which didn't really need much explanation because was sort of blood in the urine. And so the first, the first test was actually conducted. He sent me to he referred me to a urologist and urologist. Then he conducted a test with a camera. I don't know what it's called.
Participant 034_2022AUBLC

Participant describes being diagnosed by their general practitioner due to concerns about symptoms

So went to the GP. We started talking about how HRT. Like the help with the hot flushes. And I, um, through the conversation with the I happened to mention the spotting. Let's do a few tests before we talk about hormone replacement. And that led to me having a urine test, and theyl found gross hematuria. And then I was directed to have an ultrasound. And at that point, they found a, um, a four centimetre tumour at the top of my bladder.
Participant 022_2022AUBLC

Well, I had it took me a while to be diagnosed because being a female and being young for blood, I was only 49. I had blood in my urine. I went to the GP, they said it was a UTI, gave me antibiotics, came back, the blood came back. About two weeks later it went back to the the GP. They tried a different set of antibiotics. Then the blood came back and went back to the GP and they tested my urine and she said, Oh, it's just microscopic blood, you know, it's nothing, don't worry about it, go home, you know, live your life, everything's okay. Then the blood came back again and went back to the GP and you know, I said, you know, this is, you know, pattern which is, you know, there's something wrong. So then I thought that it was going to be a gynaecological problem and she wanted to send me for an ultrasound of the uterus. But then we decided to see if I could do the bladder at the same time. And when I had an ultrasound of the bladder, they saw the tumour straight away. So it did take a while. Frustrating process. It was very frustrating. So I have to say that the GP side of it was very poor and I'm lucky to be alive because it took so long to diagnose.
Participant 032_2022AUBLC

PARTICIPANT: He actually got not his normal doctor. He got them because many doctors in that room. And he said, Oh, Phil, I never have you in he never ever have you in my office. And he. Said. You. Could have a UTI. You know what? I'm going to waste your money and I'm going to send you through all these tests.

INTERVIEWER Good on him, Okay, so what happened? Okay. So. Any. Any idea what those tests were off the top of your head?

PARTICIPANT: He sent him for a CT scan, blood tests and urine tests.
Carer 001_2022AUBLC

Participant describes being diagnosed after being admitted into the emergency department or hospital

So it started off fairly suddenly. So I was actually heading away for a weekend with friends and someone else was driving, us sitting in the backseat. And I had pains in my back just beneath my rib cage sort of kicks that are going to kidney location. And I did actually, it was it was of a, sort of severity where I actually called, you know, a nurse on call and asked for advice, you know, if I should do anything in particular or what kind of pain management or I should look at. Anyway, they suggested that I went and saw a GP, so I did that the following morning. It was Saturday morning, and they just prescribed a particular pain medication, which I can't remember at the time that the oncologist had actually, actually told me later that it was the completely wrong thing to be prescribing for someone with kidney pain. Anyway, I was only away for the weekend and as we were coming home by the Sunday. I was actually at school reunion anyway, and I avoided a couple of things because it seemed too much pain. And on the way, as we were driving. On the way home on a Sunday afternoon, I got the, I got my friend to just drop me at the hospital that emergency at the hospital, too, so we could start having a look at that. Yeah. And so, so the cancer itself was in the ureter and it had occluded the

ureter so. And so I was just getting kidney pain from pressure because of the occluded ureter.
Participant 041_2022AUBLC

Yeah, I'm 72 now from the age of about 35. I've had bladder problems. Well, I'd been going to the toilet regularly at night, three or four times, sometimes five times a night. And then it escalated about seven years ago. I was going all the time and I never saw anyone about it because it didn't cause me any pain, just the lack of sleep. And then I was playing golf six years ago, in May 2016, and I went to the toilet at the golf and I just started peeing blood. And I immediately went to HOSPITAL in CITY and they did a scan, a CT scan I think it was, and they said I had some sort of tumour there that there was, they weren't sure whether it was bladder cancer or whatever. So they booked me in for cystoscopy and straight away, which was done I think within about a week. And they came back and said tthe biopsy that said that I had high grade bladder cancer. Can't remember the size of the cancer. I think it was a couple of centimetres, maybe two.
Participant 021_2022AUBLC

Well, I just said I had blood in my urine. Um, and then in 2016, I took the wife for a cruise and I noticed there was blood in my urine again. And this was first in November 2016. I went to a hospital emergency or whatever it was, and they said, Sorry, NAME, you got bladder cancer. And they said it's. Well, I had all three types adenocarcinoma, CIS and papillary. Three different cancers in the bladder.
Participant 042_2022AUBLC

Participant describes being diagnosed by their general practitioner following routine check-up or incidental finding

The PSA tests. I would have I would have had every year and the prostate and that all been negative above one. And that was the only one. And I said they sent me off to get my prostate ultrasound. And while she was rummaging around with the ultrasound, she found the anomalies in the bladder instead.
Participant 031_2022AUBLC

Well, the interesting thing was that I was asymptomatic and I had had a bit of a history of urinary tract infections, but I had no blood in the urine or pain or anything to indicate that I was something was going on in my bladder. In fact, it was just purely by chance that I was diagnosed. I changed doctors and started up with a new doctor and she had a look at my history and the medications I was on, and she could see that I was using a particular gel that eventually it's vaginally applied and she was a bit concerned about the long term use of it. And so what she asked me to do was to go and have a abdominal ultrasound because she was a bit concerned about what was happening to the uterus and she wanted to get checked to make sure there was no adverse effects on the uterus. So I just went off to have an ultrasound of the abdominal area and that's when it was picked up. So I was actually a very lucky girl because if my doctor hadn't asked me to do that, it could have progressed for quite a while before symptoms developed.
Participant 036_2022AUBLC

Table 3.9: Diagnostic pathway

Diagnostic pathway	All participants		Early		Invasive		Advanced		Person with bladder cancer		Carer		Female		Male	
	n=49	%	n=20	%	n=10	%	n=14	%	n=44	%	n=5	%	n=17	%	n=32	%
Participant describes being referred directly to a specialist from their general practitioner which led to their diagnosis	30	61.22	**15**	**75.00**	**5**	**50.00**	**6**	**42.86**	26	59.09	**4**	**80.00**	**13**	**76.47**	17	53.13
Participant describes being diagnosed by their general practitioner due to concerns about symptoms	10	20.41	3	15.00	**4**	**40.00**	2	14.29	9	20.45	1	20.00	2	11.76	8	25.00
Participant describes being diagnosed after being admitted into the emergency department or hospital	6	12.24	1	5.00	1	10.00	**4**	**28.57**	6	13.64	**0**	**0.00**	1	5.88	5	15.63
Participant describes being diagnosed by their general practitioner following routine check-up or incidental finding	3	6.12	1	5.00	0	0.00	2	14.29	3	6.82	0	0.00	1	5.88	2	6.25

Diagnostic pathway	All participants		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=49	%	n=29	%	n=19	%	n=15	%	n=33	%	n=20	%	n=28	%
Participant describes being referred directly to a specialist from their general practitioner which led to their diagnosis	30	61.22	16	55.17	**14**	**73.68**	9	60.00	21	63.64	12	60.00	18	64.29
Participant describes being diagnosed by their general practitioner due to concerns about symptoms	10	20.41	6	20.69	3	15.79	3	20.00	6	18.18	4	20.00	5	17.86
Participant describes being diagnosed after being admitted into the emergency department or hospital	6	12.24	4	13.79	2	10.53	2	13.33	4	12.12	2	10.00	4	14.29
Participant describes being diagnosed by their general practitioner following routine check-up or incidental finding	3	6.12	3	10.34	0	0.00	1	6.67	2	6.06	2	10.00	1	3.57

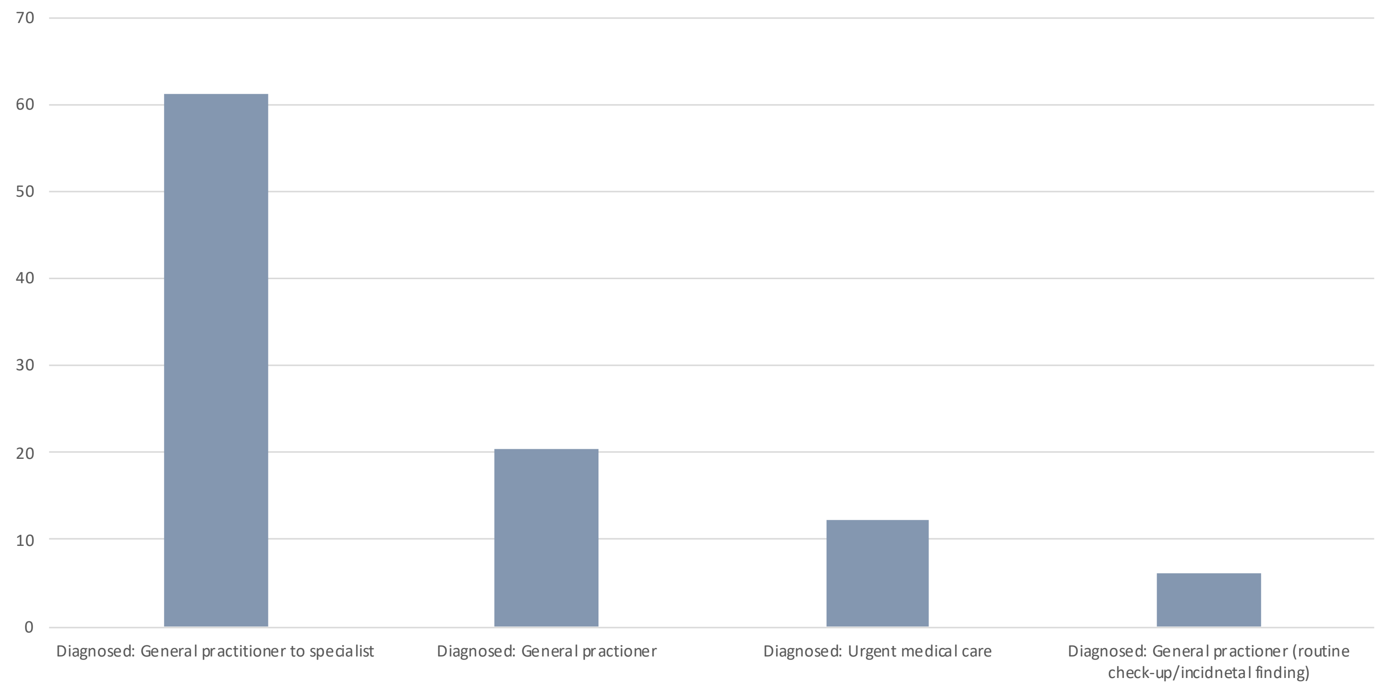


Figure 3.7: Diagnostic pathway

Table 3.10: Diagnostic pathway – subgroup variations

Diagnostic pathway	Reported less frequently	Reported more frequently
Participant describes being referred directly to a specialist from their general practitioner which led to their diagnosis	Invasive (Stage III) Advanced (Stage IV)	Early (Stages 0 and I) Carer to someone with bladder cancer Female University
Participant describes being diagnosed by their general practitioner due to concerns about symptoms	-	Invasive (Stage III)
Participant describes being diagnosed after being admitted into the emergency department or hospital	Carer to someone with bladder cancer	Advanced (Stage IV)

Timing of diagnosis

Time from symptoms to diagnosis

Participants were asked to give the approximate date of when they first noticed symptoms of bladder cancer and the approximate date of diagnosis with bladder cancer. Where enough information was given, an approximate duration from first noticing symptoms to diagnosis was calculated.

Duration was calculated for 42 participants. There were 12 participants (28.57%) that were diagnosed less than 1 month of noticing symptoms, 13 participants (30.95%) diagnosed 1 to 3 months from noticing symptoms, 6 participants (14.29%) that were diagnosed 3 to 6 months of noticing symptoms, and 11 participants (26.19%) that were diagnosed 6 months or more after noticing symptoms (Table 3.11, Figure 3.8).

Time from diagnostic test to receiving a diagnosis

Participants were asked in the online questionnaire how long they waited between diagnostic tests and getting a diagnosis.

Participants were were most commonly diagnosed less than a week after diagnostic tests (n = 12, 27.91%). There were 11 participants (25.58%) that were diagnosed less than between 1 and 2 weeks after diagnostic tests, 10 participants (23.26%) diagnosed between 2 and 3 weeks, 10 participants (23.26%) diagnosed more than four weeks after diagnostic testing (Table 3.12, Figure 3.9).

Table 3.11: Time from symptoms to diagnosis

Time from symptoms to diagnosis	Number (n=42)	Percent
Less than 1 month	12	28.57
1 to 3 months	13	30.95
3 to 6 months	6	14.29
6 months or more	11	26.19

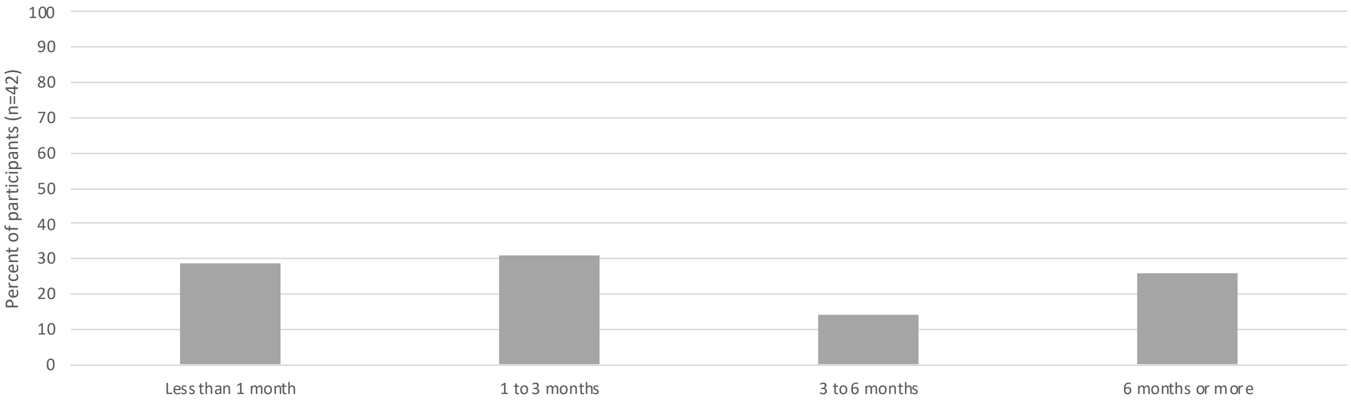


Figure 3.8: Time from symptoms to diagnosis

Table 3.12: Time from diagnostic test to diagnosis

Time from diagnosis test to diagnosis	Number (n=43)	Percent
Less than 1 week	12	27.91
Between 1 and 2 weeks	11	25.58
Between 2 and 3 weeks	10	23.26
4 weeks or more	10	23.26

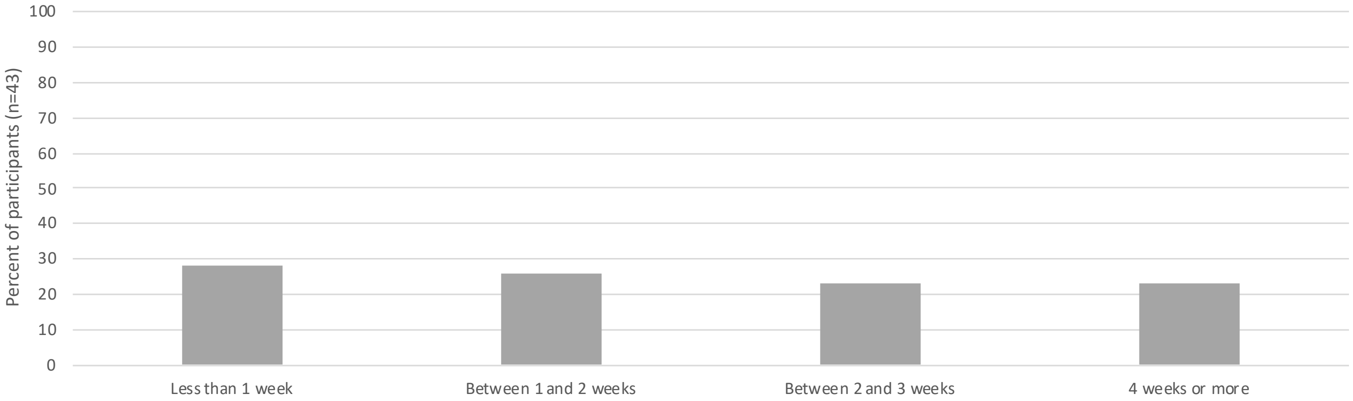


Figure 3.9: Time from diagnostic test to diagnosis

Diagnostic tests

Participants were asked in the questionnaire which diagnostic tests they had for their diagnosis with bladder cancer. They could choose from a set list of diagnostic tests, and could then specify other tests not listed. The number of tests per participant were counted using both tests from the set list and other tests specified.

Participants reported between 1 to 6 diagnostic tests (median=4.00 , IQR=2.00) (Table 3.13, Figure 3.10). The most common tests were cystoscopy and biopsy (n=37, 86.05%), urine tests (n=32, 74.42%), ultrasound scans (n=29, 67.44%), and CT scans (n=27, 62.79%) (Table 3.14, Figure 3.11).

Table 3.13: Number of diagnostic tests

Number of diagnostic tests per participant	Number (n=43)	Percent
1 to 2	9	20.93
3 to 4	18	41.86
5 to 6	16	37.21

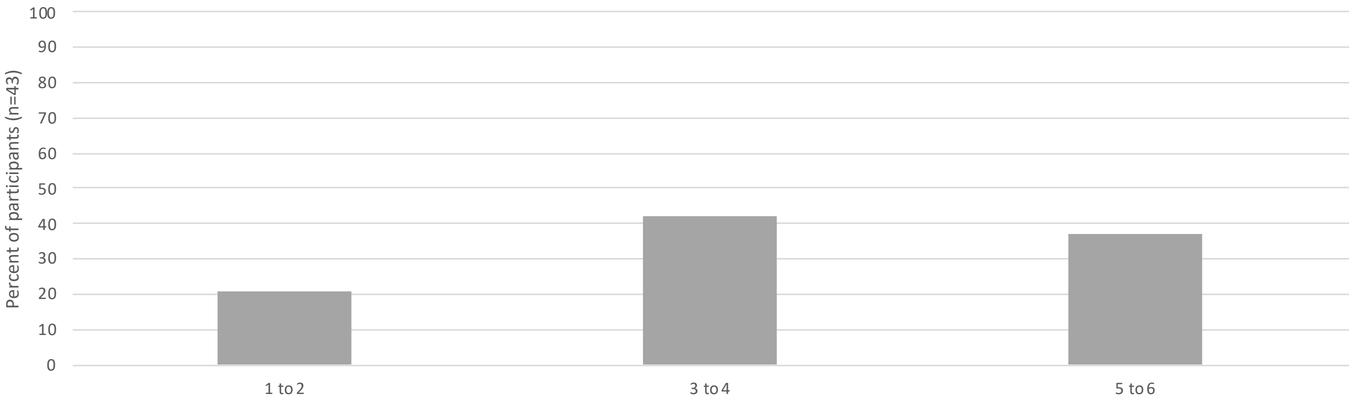


Figure 3.10: Number of diagnostic tests

Table 3.14: Diagnostic tests

Diagnostic tests	Number (n=43)	Percent
Cystoscopy and biopsy	37	86.05
Urine tests	32	74.42
Ultrasound scans	29	67.44
CT scans	27	62.79
Blood tests	24	55.81
Physical examination	13	30.23

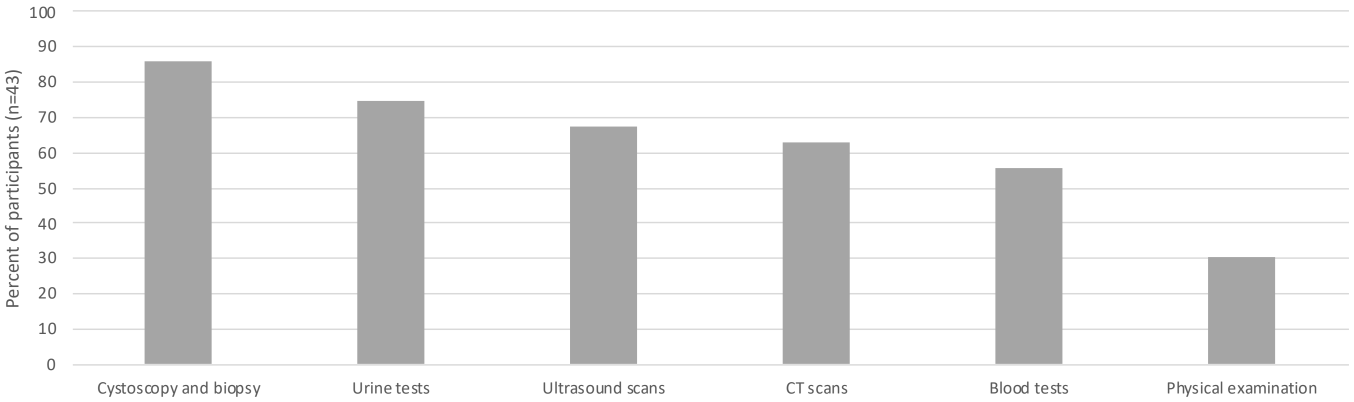


Figure 3.11: Diagnostic tests

Diagnosis provider and location

Participants were asked in the online questionnaire, which healthcare professional gave them their diagnosis, and where they were given the diagnosis.

The majority of participants received their diagnosis by a urologist (n=33, 76.74%). There were 8 participants (18.60%) that received their diagnosis from a general practitioner (Table 3.15, Figure 3.12).

Participants were most commonly given their diagnosis in the specialist clinic (n=19, 44.19%), this was followed by the hospital (n=14, 32.56%), and the general practice (GP) (n=7, 16.28%) (Table 3.16, Figure 3.13).

Table 3.15: Diagnosis provider

Health professional gave diagnosis	Number (n=43)	Percent
General practitioner (GP)	8	18.60
Urologist	33	76.74
Other	1	2.33
Surgeon	1	2.33

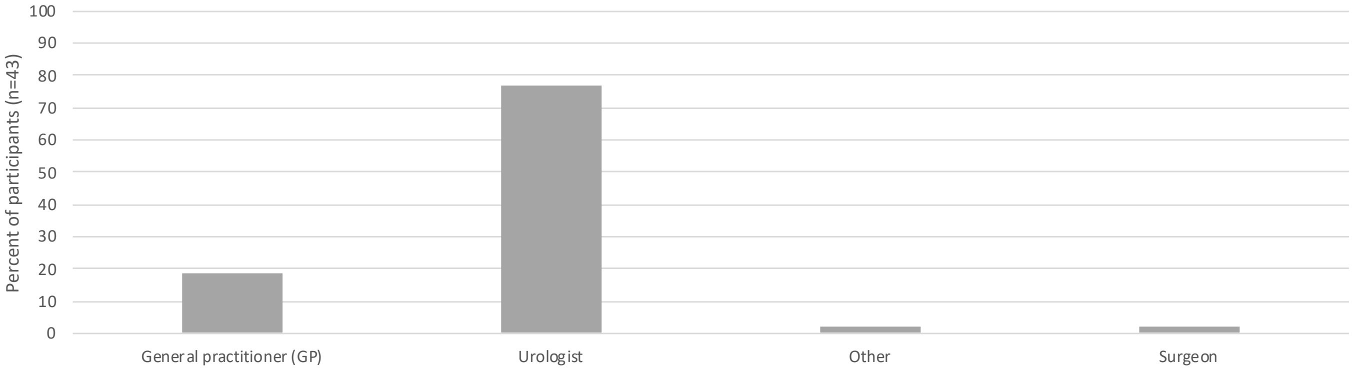


Figure 3.12: Diagnosis provider

Table 3.16: Diagnosis location

Location of diagnosis	Number (n=43)	Percent
Specialist clinic	19	44.19
Hospital	14	32.56
General practice (GP)	7	16.28
Other	3	6.98

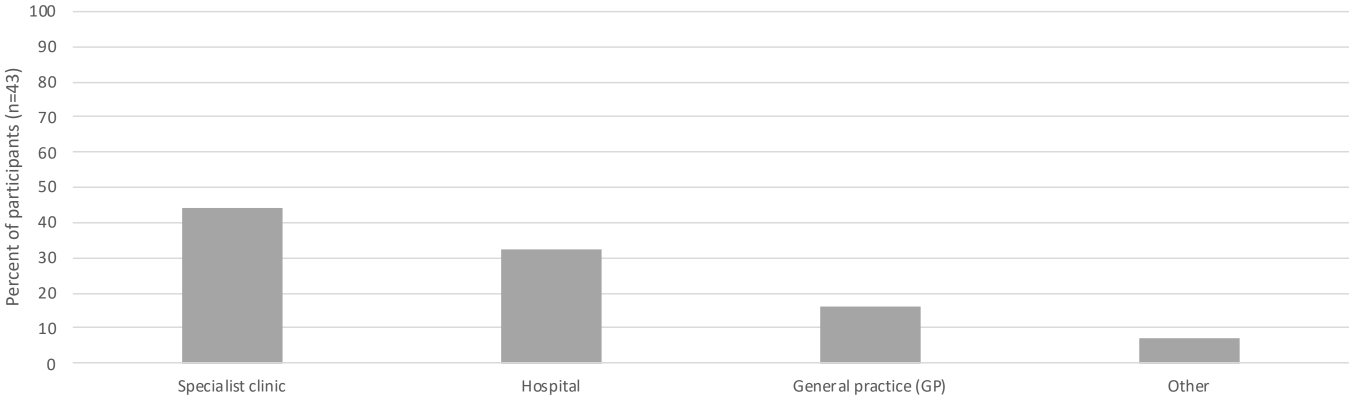


Figure 3.13: Diagnosis location

Year of diagnosis

In the online questionnaire, participants noted the approximate date of diagnosis, the year of diagnosis is presented in Table 3.17, Figure 3.14.

Participants were diagnosed between 2004 to 2022. There were 18 participants (42.86%) that were diagnosed in the last three years.

Table 3.17: Year of diagnosis

Year of diagnosis	Number (n=42)	Percent
2021 to 2022	18	42.86
2015 to 2019	21	50.00
Before 2015	3	7.14

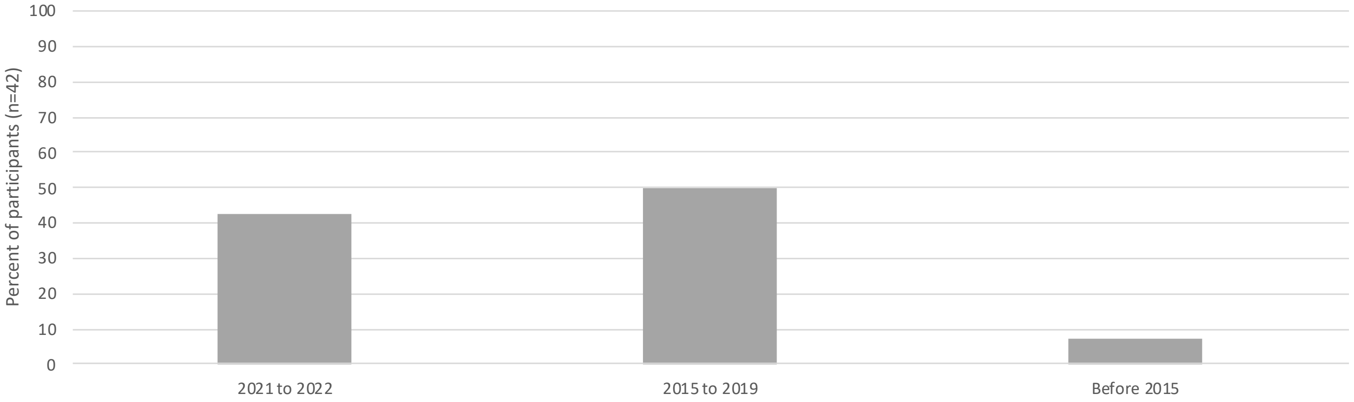


Figure 3.14: Year of diagnosis

Bladder cancer diagnosis, stage and spread

Bladder cancer diagnosis

The majority of participants were diagnosed with urothelial carcinoma (n=25, 58.14%), followed by squamous cell carcinoma (n=4, 9.30%). There were 3 participants (6.98%) that were diagnosed with adenocarcinoma, and 3 participants (6.98%), diagnosed with transitional cell carcinoma. There were 9 participants (20.93%) who were not sure about the type they were diagnosed with (Table 3.18, Figure 3.15).

Bladder cancer stage

There were 43 people with bladder cancer who took part in this study. There were 5 participants (11.63%) with Stage 0, 14 participants (32.56%) with Stage I, 10 participants (23.26%) with Stage II, 10 participants (23.26%) with Stage III and 4 participants (9.30%) with stage IV bladder cancer (Table 3.19, Figure 3.16).

Bladder cancer spread

Participants noted in the online questionnaire if the cancer had spread, and where it had spread to. There were 7 participants (16.28%) that noted that the cancer had spread. The most common site of spread were lymph nodes (n=4, 9.30%) (Table 3.20, Figure 3.17).

Bladder cancer recurrence

Almost half of the participants noted that they had a bladder cancer recurrence (n=21, 48.84%), there were 17 participants (39.53%) that had not had a recurrence and there were 5 participants that were not sure (11.63%) (Table 3.21, Figure 3.18).

Table 3.18: Type of bladder cancer

Diagnosis	Number (n=43)	Percent
Urothelial carcinoma	25	58.14
Squamous cell carcinoma	4	9.30
Adenocarcinoma	3	6.98
Transitional cell carcinoma	3	6.98
Other	2	4.65
Not sure	9	20.93

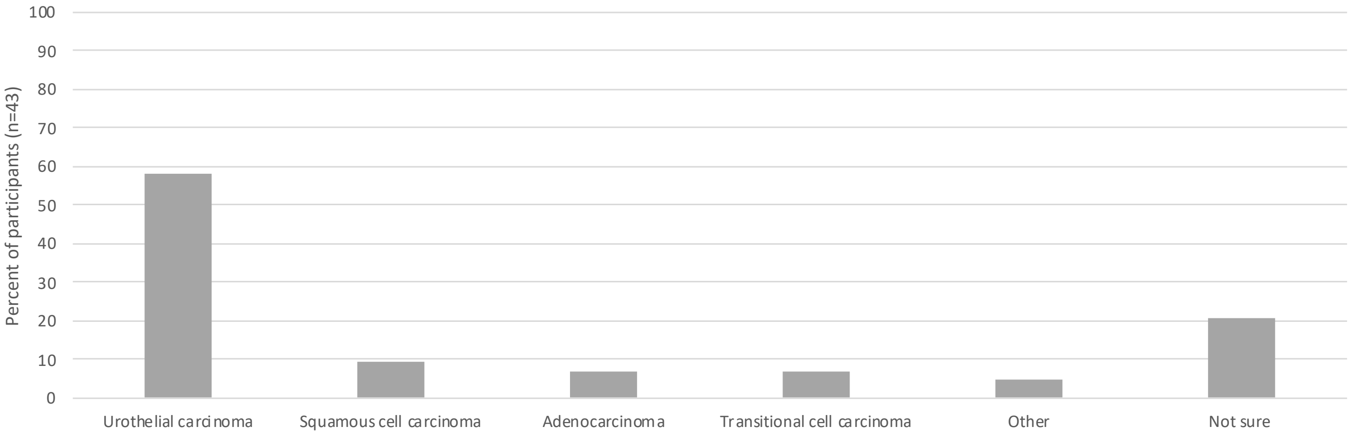


Figure 3.15: Type of bladder cancer

Table 3.19: Bladder cancer stage

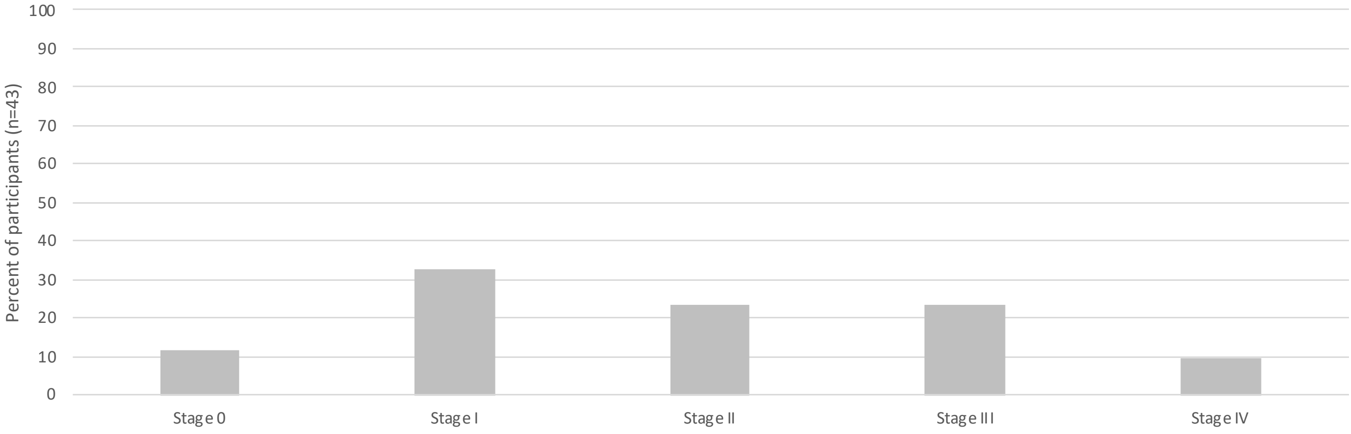


Figure 3.16: Bladder cancer stage

Bladder cancer stage	Number (n=48)	Percent
Stage 0	5	11.63
Stage I	14	32.56
Stage II	10	23.26
Stage III	10	23.26
Stage IV	4	9.30

Table 3.20: Bladder cancer spread

Cancer spread	n=43	%
Not applicable, bladder cancer has not spread	36	83.72
Lymph nodes	4	9.30
Other distant sites	3	6.98

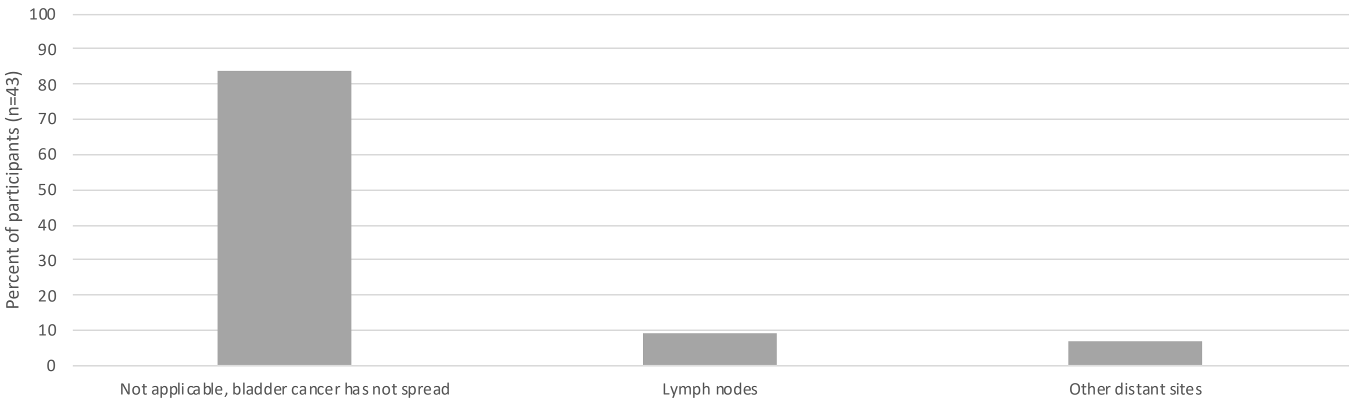


Figure 3.17: Bladder cancer spread

Table 3.21: Bladder cancer recurrence

Recurrence since diagnosis	N=43	%
Yes	21	48.84
No	17	39.53
Not sure	5	11.63

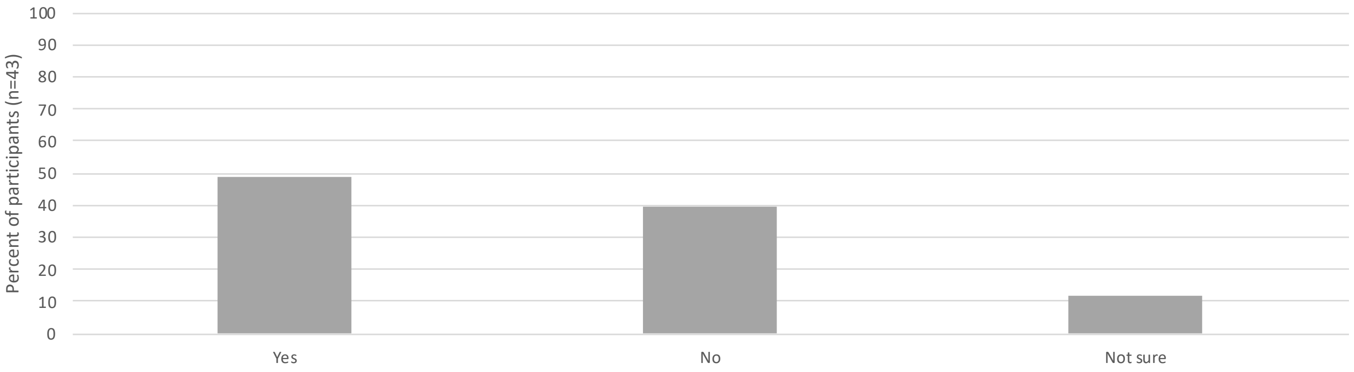


Figure 3.18: Bladder cancer recurrence

Understanding of disease at diagnosis

Participants were asked in the structured interview how much they knew about their condition at diagnosis. Most participants described having no understanding about the condition at diagnosis (n=32, 65.31%), this was followed by knowing very little about the condition (n=13, 26.53%), and having a good understanding (n=3, 6.12%). The most common reason for having limited knowledge was from doing research through the diagnostic process (n=7, 14.29%).

Participant describes having no understanding of condition at diagnosis

Nothing. To be honest, I didn't even, like a lot of people, realise there was such a thing. It's not one of the common talked about cancers like bowel or breast or anything like that.
Participant 014_2022AUBLC

I'd never heard of it and never heard of bladder cancers, never heard of bladder cancer in my life. My wife is a registered nurse and has been in aged care for 25 years. Goes, what the hell are you doing with bladder cancer? Cause that's an old man's disease. And, you know, everybody said, you know, everyone queried me along the way. Were you a smoker and did you work in heavy industry or with chemicals or toxins

and that kind of stuff? I said, No, no, no, no, no. I sit behind a desk all day and have and have for 30 years. I'm a pen pusher or keyboard person. So that was a bit bizarre that I didn't fit the archetype for that thing, being 52 and non-smoker and an office worker. I don't sort of fit the demographic for this.
Participant 017_2022AUBLC

I never heard of it. Didn't even know it existed. All I know is that when I went to the toilet playing golf, I just saw the blood coming out and went, This is something wrong? That's what I thought, because I remember playing football when I was in my twenties and a couple of blokes started peeing blood. It was because I got hit in the kidneys. I thought immediately I had a kidney problem or something, or the kidney infection or something. And they told me that there's a, there's a tumour on your bladder when they did the C.T. scan. I'd never heard of it, to be honest. Heard nothing about it. Okay. But I've done a bit of research since then, obviously, from the on the Internet, as most people do.
Participant 021_2022AUBLC

Dead set nothing. Didn't know. Didn't even know you could get bladder cancer. And, and even, even then the word, the word cancer in any form whatsoever didn't exist. It was, it was not talked about. Um. The wording was possible carcinoma and that was it.
Participant 040_2022AUBLC

Participant describes knowing very little about the condition at diagnosis

Well, firstly, nothing. And it didn't hit. There was no it it without being impolite. It was just like, you know, going to a shop and buying something, you know, the doctors said, no, this is what will happen to you. There was no I did ask because I did some research on the Internet. I did ask should there be a multi-disciplinary approach? And he didn't take kindly to that suggestion, which I believe is what, you know, the bladder cancer, bladder cancer support groups suggest, etc.. So I didn't I well, just on the job, the shock was this, you know, that I think the two main causes are smoking and, and working with paints, industrial factories, etc.. Yeah. And I've never done either. Yeah. I never you know, I'm not I'm not 100% healthy, but I've never smoked in my life and I've never worked in factories. So it was a great it was a great shock to me. And I think it was a surprise to the to the urologist.
Participant 008_2022AUBLC

Absolutely nothing. I found myself getting online and stumbled across the Bladder Cancer Awareness Support Group, which I joined really quickly. And I reached out to the founders of that group, one of which is a doctor and her sister. They had lost their dad to bladder cancer nine years previously and they channelled their grief into setting up a support group in Melbourne. And it was there that I asked a lot of my questions because there were people that were much further into their bladder cancer journey than what we were. So that was my area I went to to ask questions and get more information, get support from people.
Carer 002_2022AUBLC

When I was diagnosed. Okay. So. I suppose it all came to late 2019 oh. I knew it was serious at that. At that stage it was given the actual category I'd been diagnosed at. Yeah. There was every Yeah. That something had to be done very quickly to ensure that it wasn't spreading elsewhere to, to the body. And at that time, they turned around and said, look, we would suggest having the bladder resected and prostate resected. And yeah. And along with any other lymph nodes that are around there. To see exactly how far gone. So it's there was no chance for me to have any immunotherapy or any other type of treatment. And it had basically advanced so quickly and I suppose four or five months to to the time. Yeah. And they said, well we need to take your bladder out.
Participant 035_2022AUBLC

Participant describes knowing about the condition at diagnosis

PARTICIPANT: My knowledge? Yeah, well, my background is nurse. So, like so, I knew about it.

INTERVIEWER: Okay.

PARTICIPANT: But yet. Yeah the things I knew about it's nasty one and deliberately peed on and a fostering think about it a lot. I had a bladder cancer, and said, my god, that is old mans disease. You know, I never smoked . I'm female. Why bladder cancer? Anyway, that's what I thought.
Participant 015_2022AUBLC

Um. I was. Fairly well informed in terms of the nature of the cancer, how serious it was. The everybody stressed how dangerous and the operation is, but essentially was to have it. So that was that really. So I don't think it was there was no doubt about what I had to do. So none of it was a surprise.
Participant 034_2022AUBLC

Table 3.22: Understanding of disease at diagnosis

Understanding of disease at diagnosis	All participants		Early		Invasive		Advanced		Person with bladder cancer		Carer		Female		Male	
	n=49	%	n=20	%	n=10	%	n=14	%	n=44	%	n=5	%	n=17	%	n=32	%
Participant describes having no understanding of condition at diagnosis	32	65.31	12	60.00	10	100.00	6	42.86	28	63.64	4	80.00	10	58.82	22	68.75
Participant describes knowing very little about the condition at diagnosis	13	26.53	7	35.00	0	0.00	5	35.71	12	27.27	1	20.00	5	29.41	8	25.00
Participant describes knowing very little about the condition at diagnosis but notes they began researching the condition before or throughout the diagnostic process	7	14.29	5	25.00	0	0.00	1	7.14	6	13.64	1	20.00	3	17.65	4	12.50
Participant describes knowing very little about the condition at diagnosis but no specific reason for the level of knowledge	2	4.08	0	0.00	0	0.00	2	14.29	2	4.55	0	0.00	1	5.88	1	3.13
Participant describes knowing very little about the condition at diagnosis but notes they have a family history of the condition	1	2.04	0	0.00	0	0.00	1	7.14	1	2.27	0	0.00	0	0.00	1	3.13
Participant describes knowing very little about the condition at diagnosis but knew that it was serious	1	2.04	0	0.00	0	0.00	1	7.14	1	2.27	0	0.00	0	0.00	1	3.13
Participant describes knowing very little about the condition at diagnosis but notes that doctor explained it to them during the diagnostic process	2	4.08	2	10.00	0	0.00	0	0.00	2	4.55	0	0.00	1	5.88	1	3.13
Participant describes knowing about the condition at diagnosis	3	6.12	1	5.00	0	0.00	2	14.29	3	6.82	0	0.00	1	5.88	2	6.25
Participant describes knowing about the condition at diagnosis as they has began researching the condition before or throughout the diagnostic process	1	2.04	0	0.00	0	0.00	1	7.14	1	2.27	0	0.00	0	0.00	1	3.13
Participant describes knowing about the condition as they have a medical, research or relevant professional background	1	2.04	1	5.00	0	0.00	0	0.00	1	2.27	0	0.00	1	5.88	0	0.00
Participant describes knowing/not knowing about the condition but no specific reason for the level of knowledge	1	2.04	0	0.00	0	0.00	1	7.14	1	2.27	0	0.00	0	0.00	1	3.13
Other/no response	1	2.04	0	0.00	0	0.00	1	7.14	1	2.27	0	0.00	1	5.88	0	0.00

Understanding of disease at diagnosis	All participants		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=49	%	n=29	%	n=19	%	n=15	%	n=33	%	n=20	%	n=28	%
Participant describes having no understanding of condition at diagnosis	32	65.31	20	68.97	11	57.89	12	80.00	19	57.58	13	65.00	18	64.29
Participant describes knowing very little about the condition at diagnosis	13	26.53	7	24.14	6	31.58	3	20.00	10	30.30	6	30.00	7	25.00
Participant describes knowing very little about the condition at diagnosis but notes they began researching the condition before or throughout the diagnostic process	7	14.29	3	10.34	4	21.05	2	13.33	5	15.15	2	10.00	5	17.86
Participant describes knowing very little about the condition at diagnosis but no specific reason for the level of knowledge	2	4.08	1	3.45	1	5.26	0	0.00	2	6.06	1	5.00	1	3.57
Participant describes knowing very little about the condition at diagnosis but notes they have a family history of the condition	1	2.04	1	3.45	0	0.00	0	0.00	1	3.03	1	5.00	0	0.00
Participant describes knowing very little about the condition at diagnosis but knew that it was serious	1	2.04	1	3.45	0	0.00	0	0.00	1	3.03	1	5.00	0	0.00
Participant describes knowing very little about the condition at diagnosis but notes that doctor explained it to them during the diagnostic process	2	4.08	1	3.45	1	5.26	1	6.67	1	3.03	1	5.00	1	3.57
Participant describes knowing about the condition at diagnosis	3	6.12	2	6.90	1	5.26	0	0.00	3	9.09	1	5.00	2	7.14
Participant describes knowing about the condition at diagnosis as they has began researching the condition before or throughout the diagnostic process	1	2.04	1	3.45	0	0.00	0	0.00	1	3.03	0	0.00	1	3.57
Participant describes knowing about the condition as they have a medical, research or relevant professional background	1	2.04	0	0.00	1	5.26	0	0.00	1	3.03	0	0.00	1	3.57
Participant describes knowing/not knowing about the condition but no specific reason for the level of knowledge	1	2.04	1	3.45	0	0.00	0	0.00	1	3.03	1	5.00	0	0.00
Other/no response	1	2.04	0	0.00	1	5.26	0	0.00	1	3.03	0	0.00	1	3.57

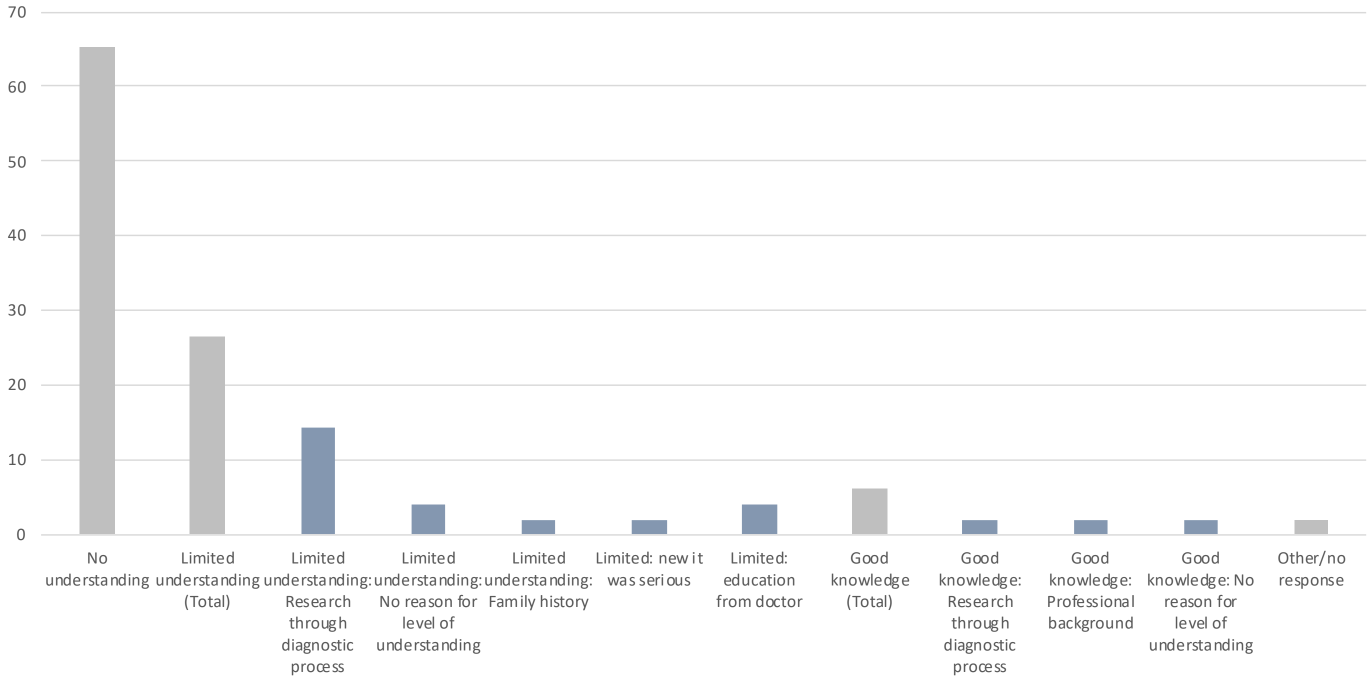


Figure 3.19 Understanding of disease at diagnosis

Table 3.23: Understanding of disease at diagnosis – subgroup variations

Understanding of disease at diagnosis	Reported less frequently	Reported more frequently
Participant describes having no understanding of condition at diagnosis	Advanced (Stage IV)	Invasive (Stage III) Carer to someone with bladder cancer Regional or remote
Participant describes knowing very little about the condition at diagnosis	Invasive (Stage III)	

Emotional support at diagnosis

Participants were asked in the online questionnaire how much emotional support they or their family received between diagnostic testing and diagnosis.

There were 10 participants (23.26%) who had enough support, 5 participants (11.63%) that had some support but it wasn't enough, and 28 particiants (65.12%) had no support (Table 3.24, Figure 3.20).

Table 3.24: Emotional support at diagnosis

Emotional support at diagnosis	Number (n=43)	Percent
Enough support	10	23.26
Some support but it wasn't enough	5	11.63
No support	28	65.12

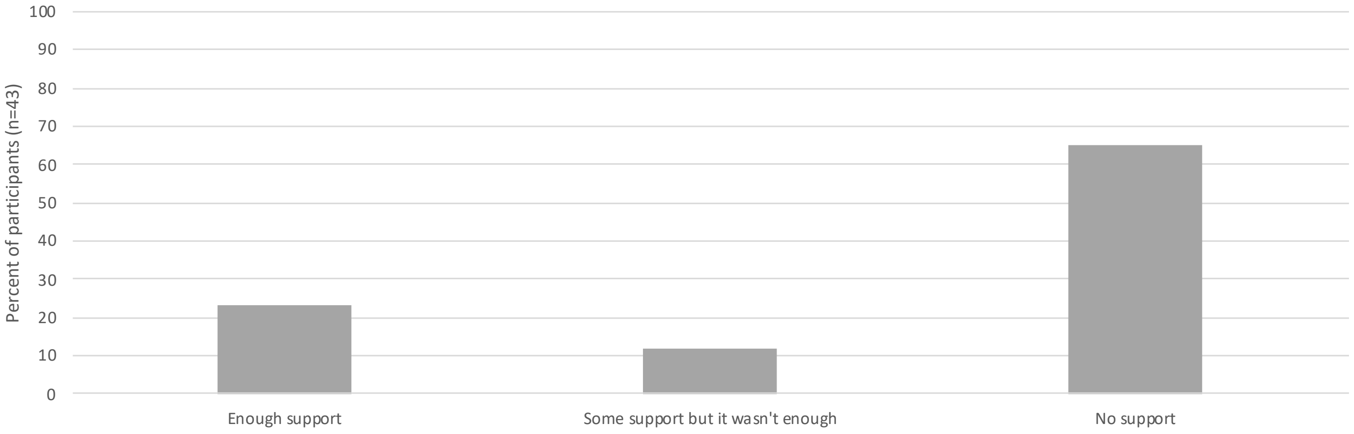


Figure 3.20: Emotional support at diagnosis

Costs at diagnosis

Out of pocket expenses at diagnosis

Participants noted in the online questionnaire the amount of out-of-pocket expenses they had at diagnosis, for example doctors' fees, and diagnostic tests.

There were 14 participants (32.56%) who had no out of pocket expenses, and 15 participants (34.88%) who did not know or could not recall. There were 3 participants (6.98%) that spent $1 to $250, 3 participants (6.98%) that spent between $251 to $500, 2 participants (4.65%) that spent $501 to $1000, and 6 participants (13.95%) that spent more than $1000 (Table 3.25, Figure 3.21).

Burden of diagnostic costs

In the follow-up question about the burden of costs at diagnosis, for 30 participants who had out of pocket expenses.

For 28 participants (73.68%) the cost was slightly or not at all significant. For 6 participants (15.79%) the out-of-pocket expenses were somewhat significant, and for 4 participants (10.53%), the burden of out-of-pocket expenses were moderately or extremely significant (Table 3.26, Figure 3.22)

Table 3.25: Out of pocket expenses at diagnosis

Out of pocket expenses for diagnostic tests	Number (n=43)	Percent
$0	14	32.56
$1 to $250	3	6.98
$251 to $500	3	6.98
$501 to $1000	2	4.65
More than $1000	6	13.95
Not sure/can't remember	15	34.88

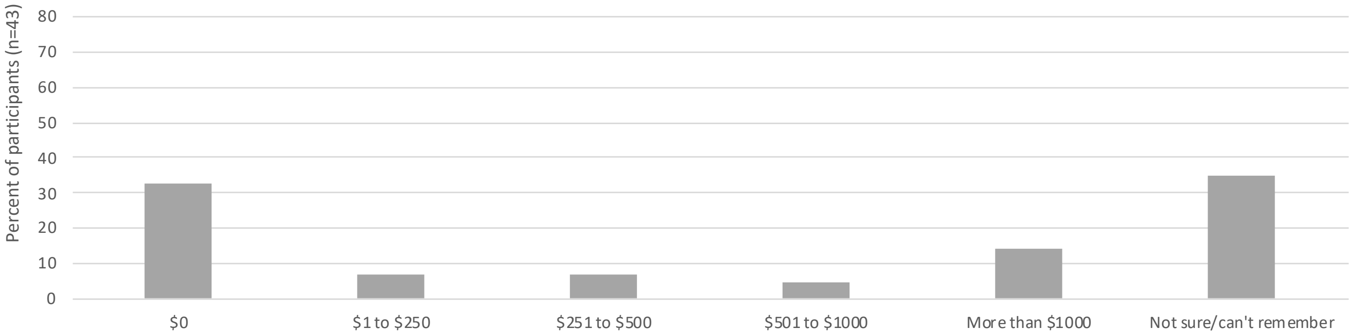


Figure 3.21: Out of pocket expenses at diagnosis

Table 3.26: Burden of diagnostic costs

Burden of diagnostic costs	Number (n=38)	Percent
Not at all significant	18	47.37
Slightly significant	10	26.32
Somewhat significant	6	15.79
Moderately significant	3	7.89
Extremely significant	1	2.63

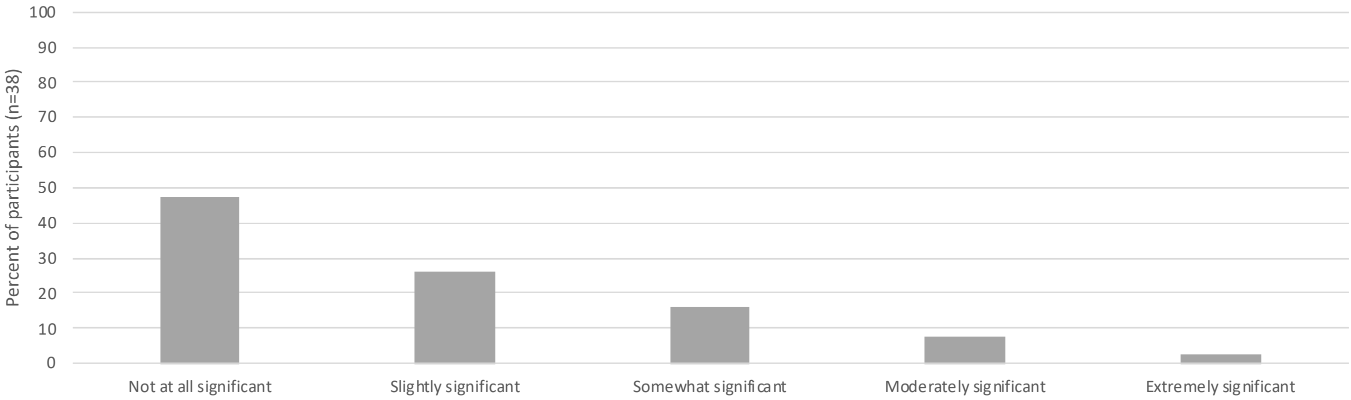


Figure 3.22: Burden of diagnostic costs

Genetic tests and biomarkers

Participants answered questions in the online questionnaire about if they had any discussions with their doctor about biomarkers, genomic and gene testing that might be relevant to treatment. If they did have a discussion, they were asked if they brought up the topic or if their doctor did.

Most commonly, participants had never had a conversation about biomarkers, genomic, or gene testing that might be relevant to treatment, (n=39, 90.70%). There were 3 participants (6.98%) who brought up the topic with their doctor, and a single participant (2.33%) whose doctor brought up the topic with them (Table 3.27, Figure 3.23).

Participants were then asked if they had had any biomarker, genomic or gene testing. If they had testing, they were asked if they had it as part of a clinical trial, paid for it themselves or if they did not have to pay for it. Those that did not have the test were asked if they were interested in this type of test.

The majority of participants did not have any genetic or biomarker tests but would like to (n=32, 74.42%). There were 9 participants (20.93%) who did not have these tests and were not interested in them, and a single participant (2.33%) that had biomarker tests (Table 3.28, Figure 3.24).

Biomarker status

All participants (n=43, 100%) were not sure about any markers that they have in relation to bladder cancer.

Table 3.27: Discussions about biomarkers

Discussions about biomarkers	Number (n=43)	Percent
Participant brought up the topic with doctor for discussion	3	6.98
Doctor brought up the topic with participant for discussion	1	2.33
Participant had no discussion about this type of test	39	90.70

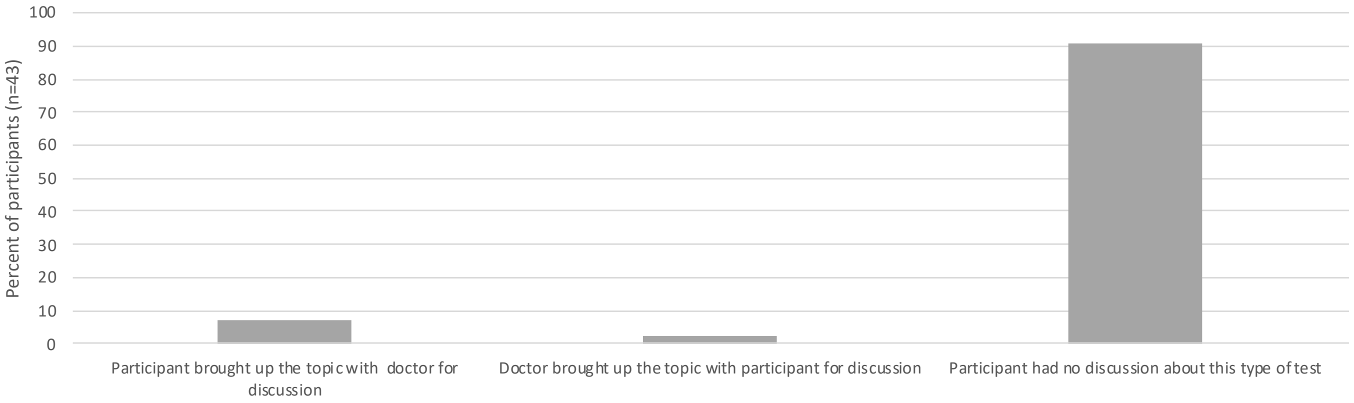


Figure 3.23: Discussions about biomarkers

Table 3.28: Experience of genetic tests and biomarkers

Experience of genetic tests and biomarkers	Number (n=43)	Percent
Participant had this test and did not have to pay out of pocket for it	1	2.33
Participant had this test athrough a clinical trial	1	2.33
Participant had this type of test and paid for it	0	0.00
Participant did not have this test and is not interested in it	9	20.93
Participant did not have this test but would like to	32	74.42

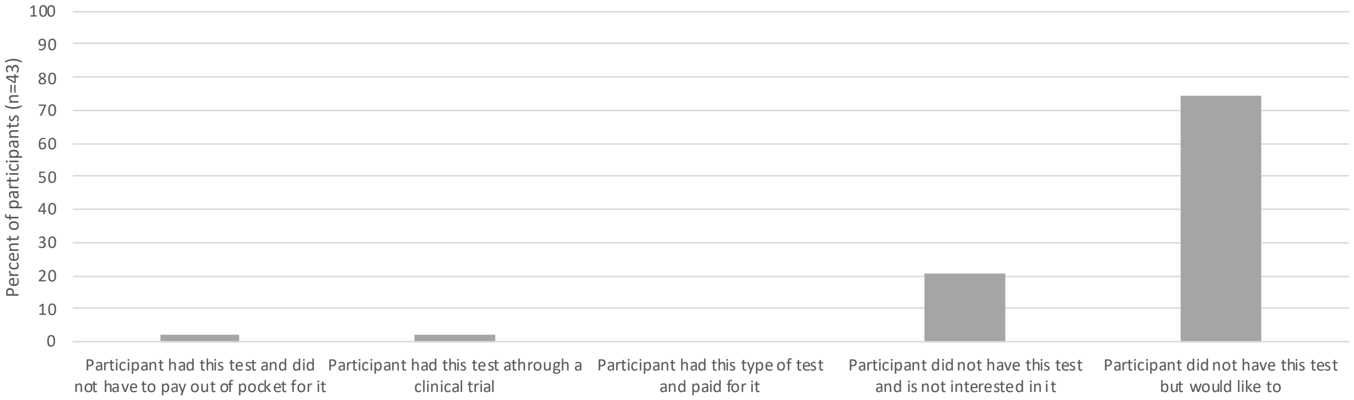


Figure 3.24: Experience of genetic tests and biomarkers

Understanding of prognosis

Participants were asked in the structured interview to describe what their current understanding of their prognosis was. Participants most commonly described their prognosis in relation to having no evidence of disease or that they are in remission (n=28, 57.14%), and in relation to monitoring their condition with tests, scans, or regular follow up appointments (n=28, 57.14%). There were 12 participants (24.49%) that described prognosis in relation to probable recurrence/cycle of recurrence, 10 participants (20.41%) that described prognosis in relation to tumour grade or stage, and 7 participants (14.29%) described prognosis in relation to a specific timeframe that they have been disease free.

Participant describes prognosis in relation to no evidence of disease or that they are in remission

Okay. Um. Medically, I don't know. At the moment I've been given an all clear and certainly the specialist that treated me fairly confident that I've had a result as good as I can expect and as good as they can expect. Um, so we're sort of basically we're happy about that. Um, so from that point of view, I'm not really too concerned about whether I get a return of the cancer or not. Um, so my primary concern has been really just learning to live with the results of the operation, which is, you know, nearly lost me back. Hmm.
Participant 034_2022AUBLC

Well, the last prognosis is that, um, they did a cystoscopy and biopsies, they did a fair few biopsies. And, uh, the surgeon came in and seen me and said that he couldn't see any cells, so any cancer cells. So that was good. And then I've been to my urologist since, and he says that the bladder itself is all clear, but he's worried about, he's worried about the, the tubes and the kidneys.
Participant 007_2022AUBLC

Um, well, I finished our BCG in January this year. I had a cystoscopy a couple of months later, cystoscopy, and everything was clear at the moment. I'll have another test probably in about three months time. And, yeah, I think at the moment it's it's I'm in remission, but at the moment there are no signs of the cancer, which is okay.
Participant 024_2022AUBLC

Participant describes prognosis in relation to monitoring their condition with tests, scans, or regular follow up appointments

Well, I just get monitored with a CAT scan every six months and blood tests. And to all intents and purposes, he's got it all. It's cured at the moment. So it's just monitoring to make sure it doesn't come back. But given that everything is taken, the urethra, uh, top part of the ureters, bottom part sorry. And full radical hysterectomy and everything. And I think 23 lymph nodes were negative, which was that's all we took out. So it looks pretty clear and it's meant to have over 80% cure rate if you get it that early. So, yeah, I'm hopeful that it's cured.
Participant 018_2022AUBLC

Yeah, basically a blood blood test and urine test once a year to see for any markers.
Participant 019_2022AUBLC

Mine is very, very good. I think the bladder cancer was non-invasive and I've been on a number of treatments, including a trial drug, and I'm now over two years past the original remove or removal of the tumour and undergoing sort of routine and follow ups.
Participant 029_2022AUBLC

My current outlook. Now, I am now on six monthly reviews with my oncologist, uh, my surgeon still just, uh, that I've gone to doing a phone check-up with me every three months just to see how things are going. But that pretty well handed it over to the oncologist, um, there's been no, no change as far as anything in, uh, yeah, there's no other tumours visible or my blood are all coming back at this stage. Yeah, yeah, yeah.
Participant 035_2022AUBLC

Yeah, well, what my current outlook is. I mean, the when I'd had the operation I had the operation on the 17th of September. Doctor NAME came in the following day or the day after to say that as far as they were concerned, the cancer, they'd got rid of it by removing the bladder of the cancer and cancer free, were his words. And I would have to, I dodn't have to have any radiation or chemotherapy or anything at all. It was all really done quite quickly. But I have to have C.T. scans every six months for five years. And in fact, I'll have my first one in a couple of weeks time in May.
Participant 043_2022AUBLC

Participant describes prognosis in relation to probable recurrence/cycle of recurrence

Yeah. Yeah. So I had another cystoscopy a few weeks back and that was the second one. So I was diagnosed about June last year. And so this was the second cystoscopy that I'd had. And it came back all clear. And in fact, the oncologist remarked that it was odd that they didn't even take a biopsy of just some tissue that might have looked a bit suspect. He said if I didn't even do a biopsy, it means you're very, very clear. So that was good to hear and, oh look, it's once it's happened, it can happen any time. So it's just a matter of having to live with the knowledge that it could happen again because it happened the first time. So it's not like I'm cured.
Participant 030_2022AUBLC

PARTICIPANT: Oh, yes. Um, I, I had BCG, um, basically for the last couple of years, and then I got to the point where I just couldn't handle the BCG any longer. The side effects seem to be getting worse and worse. And my urologist was obviously checking, doing, cystoscopy every three months and every six months. And in the end, his recommendation was that I'd done well to stick it out as long as I had and basically to stop the BCG, which is what I did.

INTERVIEWER: So is the current outlook reasonable yet?

PARTICIPANT: Quite, quite reasonable. I belong to a group that's called Beat, B E A T , and it's run by a urologist that's based in Sydney. And I am aware through going, ther'e a Zoom meeting once a month, I'm aware with that that there's definitely the possibility of the cancer coming back and. At the

moment I am cancer free. I had a cystoscopy in December and nothing was there, but I am aware that potentially it could come back. And my urologist has said just to have a cystoscopy once a year. But given that the initial one was a high grade, I discussed it with him and said, could I make it more often? And he said, that's entirely up to me. So I was elected at this point to have a cystoscopy every nine months. And I would have to say I get very anxious before each one because I am. Aware that it can just come back and and can also it can be that the kidneys become affected and what have you. And I don't want it to get out of control before I find out about it.
Participant 036_2022AUBLC

Yeah, sorry. Definitely. So it's pretty good at the moment because he's had some treatment and the last cystoscopy showed nothing has going back. And however when we went to the oncologist. He said that because it's high grade cancer, it's just a matter of when it comes back because it will come back. So it's just a matter of now just catching it early and preserving his bladder.
Carer 003_2022AUBLC

Participant describes prognosis in relation to tumour grade or stage

Well they sort of thinking that it it's okay the prognosis because it's still just sitting on the lining of of the bladder. So it's not invasive at this stage. I'm just trying to get rid of it.
Participant 004_2022AUBLC

Mine is very, very good. I think the bladder cancer was non-invasive and I've been on a number of treatments, including a trial drug, and I'm now over two years past the original remove or removal of the tumour and undergoing sort of routine and follow ups.
Participant 029_2022AUBLC

My prognosis is good. I had a radical cystectomy in 2017. Once I went, once I got referred to the urologist and they found the tumour. They even then still thought that this would be one of the low grade cases. But once they did the TURBT and had pathology done on the tumour, they realised that it was very aggressive and high grade and muscle invasive. So everything moved really quickly. I think I had the TURBT on the 10th of May and waited a week for the results and then I had a radical cystectomy already in June where they removed my bladder and I now have a neo bladder. So everything went really quickly. Like no time to think, no time to act. Let's just get this out and hope that it hasn't spread.
Participant 032_2022AUBLC

Participant describes prognosis in relation to a specific timeframe that they have been disease free

My outlook. Oh, yeah, yeah, yeah. Okay. My current is, uh, is clear for two years.
Participant 016_2022AUBLC

PARTICIPANT: Very good now.

INTERVIEWER: What does very good mean?

PARTICIPANT: So I should say excellent. I mean, I've been told repeatedly by my urologist that this. If my type of cancer was going to come back. It's generally within the first 12 months.

INTERVIEWER: And how long? When were you diagnosed?

PARTICIPANT: I was diagnosed in late, early, early 2016, January 2016. And I had the operation and everything out in March 2016.
Participant 022_2022AUBLC

Participant describes prognosis in relation to the specific medical interventions they need to manage their condition

Or he said to me, Oh, it's just a low grade bladder cancer. We just have to keep an eye on. Okay. Take them off as they come up. And I actually spoke with a friend of my sister's who's a physician, and she's a good friend. And I said and she kept on saying to me, Have you had BCG? Have you had BCG? And I started to ask my surgeon, am I gonna have BCG. And he just said one day, why do you have this obsession about BCG? I said I'm not actually, I'm not. I don't know anything about this, but this doctor just said to me, she keeps on asking me if I had BCG and he said, no, no, BCG isn't for your sort of bladder cancer.
Participant 001_2022AUBLC

I just have another operation and that five months time or in July or by July, I suppose to have another operation.
Participant 013_2022AUBLC

Well, I had a series of BCG treatments in January and February, and I went back at the end of March to have a flexible cystoscopy and they found the third he found is still some tumours there. So I need to go back

in July and have an operation to have them removed. And he didn't say what the next step was, but I'm assuming I'll have more BCG treatment.
Participant 023_2022AUBLC

Participant describes prognosis in relation to statistics such as five year survival rates

Well, I just get monitored with a CAT scan every six months and blood tests. And to all intents and purposes, he's got it all. It's cured at the moment. So it's just monitoring to make sure it doesn't come back. But given that everything is taken, the urethra, uh, top part of the ureters, bottom part sorry. And full radical hysterectomy and everything. And I think 23 lymph nodes were negative, which was that's all we took out. So it looks pretty clear and it's meant to have over 80% cure rate if you get it that early. So, yeah, I'm hopeful that it's cured.
Participant 018_2022AUBLC

Very not much. All I know from my readings because. Once I got diagnosed, I started reading a lot all the research articles from Universities and Cancer Council, Victoria and America and UK. And with my treatment, it's actually there are two types of treatments surgery or radiation, and it's almost the same. There's about 67% survival, five year survival rate. Okay. And my my radiation doctor also said, yeah, it's around this much. Okay. 65 to 70%. But he says, I mean, my outlook looks good.
Participant 028_2022AUBLC

PARTICIPANT: It's unusual. I'm talking to the urologist. They say it's unusual for a for a bladder cancer to metastasise and then slow down. So I had my secondaries in the lung and I had surgery done on my right lung it to remove part of the lower lobe. And there are two spots there looking at or two growths their looking at about know about a centimetre in diameter in my left lung, but, they're very static. They're just sitting there doing nothing and they're in a position that's awkward to biopsy. They assume that it's the metastasised bladder cancer. But they're just sitting there doing nothing which which they say is unusual. Of course, when I found out I had a metastasised bladder cancer, I went and googled, you know that. What is it, a, which which put it had something like 5% chance of survival. So after five years of prep. Which left me psychologically kind of screwed up for a little while, I mean. I'm not sure what you're supposed to how you're supposed to process that information.
Participant 041_2022AUBLC

Table 3.29: Understanding of prognosis

Understanding of prognosis	**All participants**		**Early**		**Invasive**		**Advanced**		**Person with bladder cancer**		**Carer**		**Female**		**Male**	
	n=49	**%**	**n=20**	**%**	**n=10**	**%**	**n=14**	**%**	**n=44**	**%**	**n=5**	**%**	**n=17**	**%**	**n=32**	**%**
Participant describes prognosis in relation to no evidence of disease or that they are in remission	28	57.14	11	55.00	5	50.00	9	64.29	25	56.82	3	60.00	10	58.82	18	56.25
Participant describes prognosis in relation to monitoring their condition with tests, scans, or regular follow up appointments	28	57.14	**14**	**70.00**	5	50.00	7	50.00	26	59.09	**2**	**40.00**	9	52.94	19	59.38
Participant describes prognosis in relation to probable recurrence/cycle of recurrence	12	24.49	4	20.00	3	30.00	4	28.57	11	25.00	1	20.00	4	23.53	8	25.00
Participant describes prognosis in relation to tumour grade or stage	10	20.41	4	20.00	**0**	**0.00**	**5**	**35.71**	9	20.45	1	20.00	4	23.53	6	18.75
Participant describes prognosis in relation to a specific timeframe that they have been disease free	7	14.29	3	15.00	2	20.00	**0**	**0.00**	5	11.36	**2**	**40.00**	2	11.76	5	15.63
Participant describes prognosis in relation to the specific medical interventions they need to manage their condition	3	6.12	2	10.00	1	10.00	0	0.00	3	6.82	0	0.00	1	5.88	2	6.25
Participant describes prognosis in relation to statistics such as five year survival rates	3	6.12	1	5.00	1	10.00	1	7.14	3	6.82	0	0.00	0	0.00	3	9.38

Understanding of prognosis	**All participants**		**Trade or high school**		**University**		**Regional or remote**		**Metropolitan**		**Mid to low status**		**Higher status**	
	n=49	**%**	**n=29**	**%**	**n=19**	**%**	**n=15**	**%**	**n=33**	**%**	**n=20**	**%**	**n=28**	**%**
Participant describes prognosis in relation to no evidence of disease or that they are in remission	28	57.14	18	62.07	9	47.37	10	66.67	17	51.52	12	60.00	15	53.57
Participant describes prognosis in relation to monitoring their condition with tests, scans, or regular follow up appointments	28	57.14	15	51.72	12	63.16	10	66.67	17	51.52	11	55.00	16	57.14
Participant describes prognosis in relation to probable recurrence/cycle of recurrence	12	24.49	5	17.24	**7**	**36.84**	**2**	**13.33**	10	30.30	4	20.00	8	28.57
Participant describes prognosis in relation to tumour grade or stage	10	20.41	6	20.69	4	21.05	2	13.33	8	24.24	3	15.00	7	25.00
Participant describes prognosis in relation to a specific timeframe that they have been disease free	7	14.29	4	13.79	3	15.79	**4**	**26.67**	3	9.09	3	15.00	4	14.29
Participant describes prognosis in relation to the specific medical interventions they need to manage their condition	3	6.12	0	0.00	3	15.79	0	0.00	3	9.09	0	0.00	3	10.71
Participant describes prognosis in relation to statistics such as five year survival rates	3	6.12	2	6.90	1	5.26	0	0.00	3	9.09	0	0.00	3	10.71

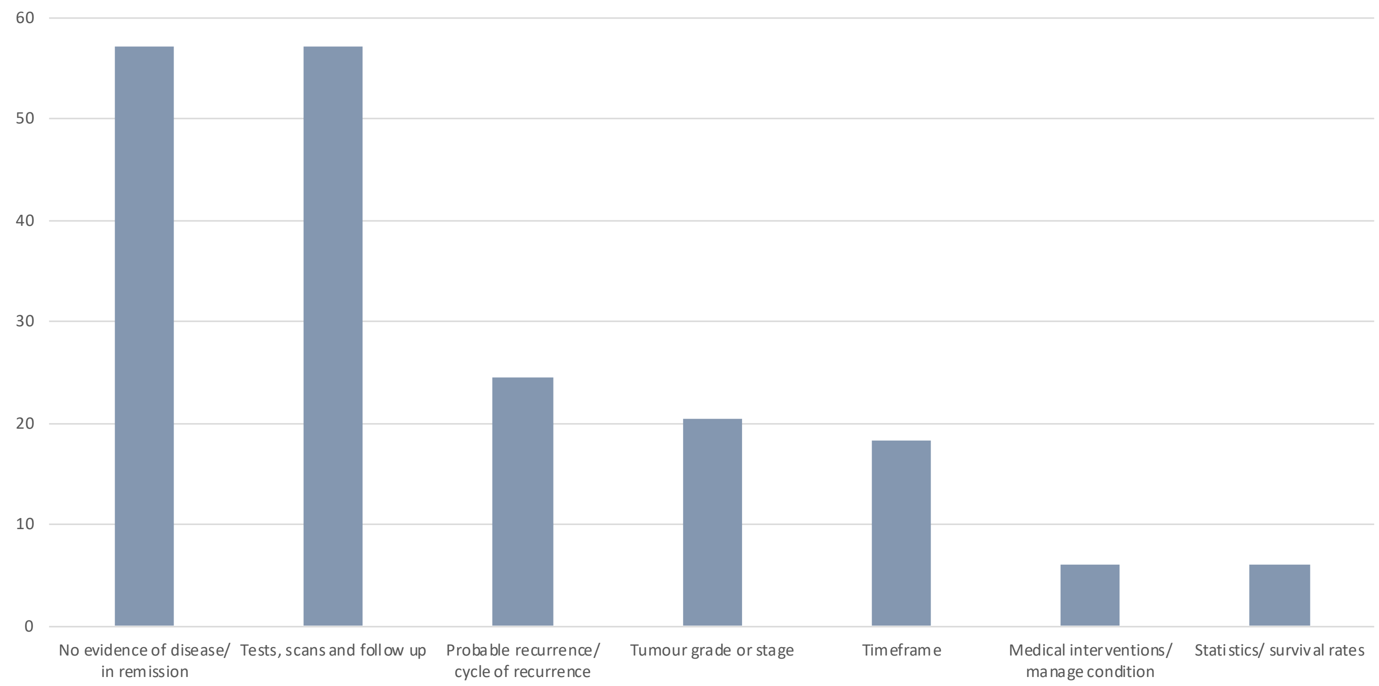


Figure 3.25: Understanding of prognosis

Table 3.30: Understanding of prognosis – subgroup variations

Understanding of prognosis	Reported less frequently	Reported more frequently
Participant describes prognosis in relation to monitoring their condition with tests, scans, or regular follow up appointments	Carer to someone with bladder cancer	Early (Stages 0 and I)
Participant describes prognosis in relation to probable recurrence/cycle of recurrence	Regional or remote	University
Participant describes prognosis in relation tumour grade or stage	Invasive (Stage III)	Advanced (Stage IV)
Participant describes prognosis in relation to a specific timeframe that they are expected to live	Advanced (Stage IV)	Invasive (Stage III) Carer to someone with bladder cancer

Section 4

Decision-making

Section 4 summary

Discussions about treatment

Participants were asked to recall what treatment options they were presented with and how they felt about such options. The most common description was being presented with multiple treatment options, and this was described by 34 participants (69.39%). This was followed by being presented with one treatment option only (n=14, 28.57%).

Discussions about treatment (Participation in discussions)

In relation to participant in discussions about treatments, of the participants that were presented with multiple treatment options, 10 participants (20.41%) described taking part in the decision-making process, and the same number described not participating in the decision making process (n=10, 20.41%). There were 6 participants (12.24%) that described discussing multiple options, however they felt there was only one viable option. Of the participants presented with one option, they most commonly described being told what to do with out any discussion (n=5, 40.20%).

Considerations when making decisions

Participants were asked in the structured interview what they considered when making decisions about treatment. The most reported theme was taking the advice of their clinician, and this was described by 23 participants (46.94%). There were 15 participants (30.61%) that considered being cancer free, avoiding recurrence, or longevity, and 12 participants (24.49%) that described taking side effects into account. Other considerations included taking ease of administration into account (n=8, 16.33%), quality of life (n=7, 14.29%), costs (n=5, 10.20%), and impact on family and dependents (n=5, 10.20%).

Decision-making over time

Participants were asked if the way they made decisions had changed over time. There were 28 participants (57.14%) that felt the way they made decisions about treatment had not changed over time, and 20 participants (40.82%) that described decision making changing.

Where participants had not changed their decision making over time, this was because they have always taken the advice of clinicians (n=11, 22.45%), or had always been informed and assertive (n=7, 14.29%). Where participants had changed the way they make decisions, this was primarily in relation to becoming more informed or more assertive (n=13, 26.53%).

Personal goals of treatment or care

Participants were asked what their own personal goals of treatment or care were. The most common response was wanting to be cancer free, avoid recurrence or increase longevity (n=20, 40.82%), and this was followed by wanting to improve their quality of life or return to normality (n=15, 30.61%). Other themes included wanting to minimise or avoid side effects (n=10, 20.41%), bladder preservation (n=8, 16.33%), wanting to be supported/reassured/informed by their healthcare team (n=6, 12.24%), and not having personal goals as they are guided by their doctor (n=5, 10.20%).

Discussions about treatment

Participants were asked to recall what treatment options they were presented with and how they felt about such options. The most common description was being presented with multiple treatment options, and this was described by 34 participants (69.39%). This was followed by being presented with one treatment option only (n=14, 28.57%).

Participant describes being presented with multiple options/approaches

I had the Dr. NAME neurologist here in LOCATION and he's awesome. He's set down this and he was straight up and down. My wife was with me and he said, It is stage two and it's hitting stage three. It's muscle invasive and it's high and that whatever it is, it's serious. And he said, ah, I don't think you're an option for BCG. So he said, What we'll have to do is take it completely and the prostate. And he said either have the stoma or have the neo bladder. But I, and I chose the stoma after discussion with him. And then. Yeah, okay. So my wife was in on it from day one. My, my, my, my partner.
Participant 038_2022AUBLC

PARTICIPANT Um, he told me that, um, when of course it was high grade. Um, it was a bit scary at the time when I had the TURBT and had been removed. He gave me the option of having treatment BCG or he said, you could get oh, I had to have a second TURBT. And he said if it came back that it was in the muscle. He said, you'll have to get your bladder removed like straight away. And if it's not, he basically said you can start your treatment of having the BCG treatment. And he said that was a bit scary, like only being diagnosed a month and then telling me I had to get my bladder removed. Well I didn't realise it was, I didn't think it was that serious, you know what I mean? Like 'cause you don't feel sick at the time, you know? I mean, there's except for having like the blood in urine, I felt okay, you know? I mean, like, I feel I didn't feel like I had cancer. Does that make sense?

INTERVIEWER Yeah. Yeah. Was definitely a shock.

PARTICIPANT It was, yeah. And then I had the, um, the second TURBT and he, he thought then because it hadn't invaded the, um, the wall of the bladder, he said we should go ahead with the, um, the BCG treatment and. Yeah. And, and he said, well, he did give me the option. He said, you can either go get your bladder removed or you could, or he suggested to go for the treatment of the BCG and see if that worked.
Participant 044_2022AUBLC

With the doctor? Yeah. Okay. We really didn't offer many different options. He said, okay, we need to do this and then we need to do that and then we need to do this. And there was no, no real options given. Oh, well, I guess before they removed the bladder, they did say we could choose to not remove it, but he wouldn't have a good prognosis for five years.
Carer 005_2022AUBLC

Participant describes being presented with one option/approach

Well, basically he just said that, well, get in and check it on a regular, you know, semi-regular basis sort of thing. And COVID was a disruptive force, I've got to say that, it didn't quite go to plan because of that. Pretty good. I've got to say that I didn't have too many issues with it did delay things at times but not to any great extent put it that way. It was only weeks, not months. And so, yeah, and I think that the discussion side of it probably. He spoke to me more as I, at the hospital rather than go back and see him. Whether I was 100% clear on everything. I would not say that I was. Normally when I go and see a specialist, I do take my wife with me, I mean she worked in the hospital system, which she can generally interpret something that I haven't quite picked up on as clearly. So I sort of yeah, I wouldn't say I was 100% clear of what was going to happen initially, but he spoke to me about the BCG and what should happen with that. And I didn't have any well, basically when I got down to that, that was another issue. But. Yeah. That's, that's basically what we spoke about.
Participant 011_2022AUBLC

Um, basically, I was diagnosed by I got referred to a urologist. He sent me for a couple of tests and come back with bladder cancer. Yeah. And then it was just cystoscopy and stuff like that at the start. And. Okay.
Participant 033_2022AUBLC

Okay. Well, I was in HOSPITAL when I was diagnosed, and when I woke up from the anaesthetic, the surgeon was trying to talk to me and I wasn't really around properly. So she, he, you know, broke the news and not a bit surprising, you know, totally surprised. And she also rang my wife. And Yeah. So that it was in a lot of discovery then of, of uh, they provide, they provide very good information to me, booklets etc. from the Cancer Foundation about it. And the pointed me towards a lot of reading. Now they were open to *discuss it as much as I wanted. And I also, when I stayed in hospital for a night, um, there was another surgeon that came around and talked about the, what had happened and what the process was likely to be from there on. They very good. I never went back to my, I didn't go back to my GP for probably quite a few weeks after and discussed with her what was happening. A new GP that was at this point. Participant 029_2022AUBLC*

Table 4.1: Discussions about treatment

Discussions about treatments	All participants		Early		Invasive		Advanced		Person with bladder cancer		Carer		Female		Male	
	n=49	%	n=20	%	n=10	%	n=14	%	n=44	%	n=5	%	n=17	%	n=32	%
Participant describes being presented with multiple options/approaches	34	69.39	13	65.00	7	70.00	10	71.43	30	68.18	4	80.00	9	52.94	25	78.13
Participant describes being presented with one option/approach	14	28.57	7	35.00	3	30.00	3	21.43	13	29.55	1	20.00	8	47.06	6	18.75
Other/no response	1	2.04	0	0.00	0	0.00	1	7.14	1	2.27	0	0.00	0	0.00	1	3.13

Discussions about treatments	All participants		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=49	%	n=29	%	n=19	%	n=15	%	n=33	%	n=20	%	n=28	%
Participant describes being presented with multiple options/approaches	34	69.39	22	75.86	11	57.89	11	73.33	22	66.67	13	65.00	20	71.43
Participant describes being presented with one option/approach	14	28.57	6	20.69	8	42.11	4	26.67	10	30.30	6	30.00	8	28.57
Other/no response	1	2.04	1	3.45	0	0.00	0	0.00	1	3.03	1	5.00	0	0.00

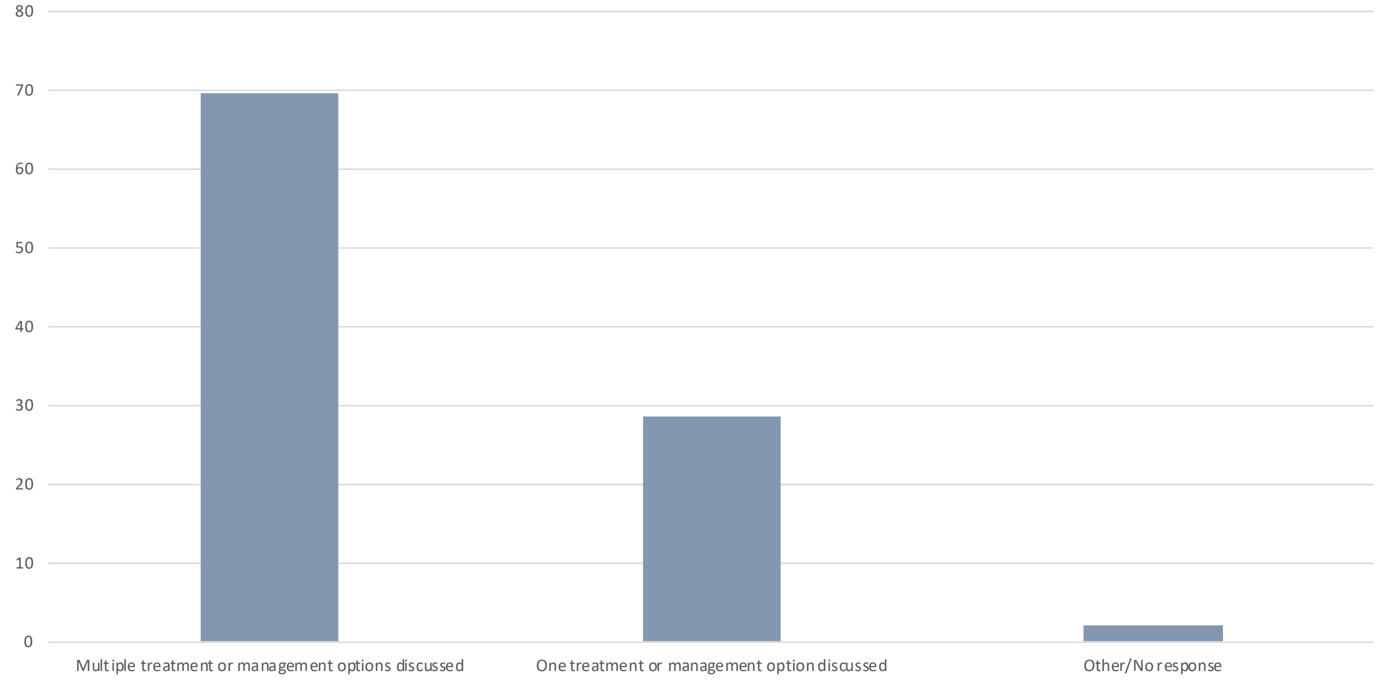


Figure 4.1: Discussions about treatment

Table 4.2: Discussions about treatment – subgroup variations

Discussions about treatments	Reported less frequently	Reported more frequently
Multiple treatment or management options discussed	Female University	Carer to someone with bladder cancer
One treatment or management option discussed	-	Female University

Discussions about treatment (Participation in discussions)

In relation to participant in discussions about treatments, of the participants that were presented with multiple treatment options, 10 participants (20.41%) described taking part in the decision-making process, and the same number described not participating in the decision making process (n=10, 20.41%). There were 6 participants (12.24%) that described discussing multiple options, however they felt there was only one viable option. Of the participants presented with one option, they most commonly described being told what to do with out any discussion (n=5, 40.20%).

Participant describes being presented with multiple options: Participated in the decision-making process

Okay. It's a beginning. When they find that tumour. Uh, yeah, they. They said, all right, I'm sure. I just wanna. It's a low, low grade. It was big, but low grade. And my urologist said it was so lucky. It was a low grade, and I'll see you next year. But I thought, yeah, *it is. He said it was a low grade, so don't worry. We'll do a check-up in 12 months time. But from my knowledge in COUNTRY there even there was low grade, they would do check up in like every three months for a while. Just make sure it's okay. So I thought a 12 month, leave it for 12 month is too long. And I ask the doctor if it's if you do that, you don't mind. For my peace of mind, can you do the analysis? This could be doing a check-up in like I. No, no, no. Actually the first time she said I would do the another cystoscopy in a six month time and okay I did another cystoscopy in September 2018 and it was come back clear okay so then he said okay then this year, next year, you don't need to do anything for 12 months. But I said for peace of mind, I can do it in a six month check-off and he did a cystoscopy check-up six months and actually, he find a high grade. So it was really lucky I did a six month check-up.*

INTERVIEWER: Okay? Yeah. Okay. Yeah. Then what sort of discussions did you have about treating it.

PARTICIPANT: So that after that is okay? And he said, Oh, unfortunate, right? Um, how did that. Uh, the high grade. It was a high grade. It's no good. So she said a BCG is a standard of treatment for this tumour. Uh, thne he, he introduced me to BCG.
Participant 015_2022AUBLC

Where the main choices were to have either an ileal conduit like radical cystectomy and pelvic clearance with urostomy, I had to have a urostomy whatever way we went wasn't eligible to have a neo bladder because I had to take the urethra out. So that was easy choice. I didn't have to worry about that. And then the other option was a reservoir that sits in under the skin. You probably know that those and then you put a catheter in to empty them. And I thought, Oh yeah, I can probably manage that. That'd be right, because then everything's hidden. But then he told me that to make so you need to use a lot more bowel to make the capacity a reasonable size. And that means that that bit of bowel can then not absorb all the things that it used to when it was bowel. So you get quite low in magnesium and all sorts of electrolytes. And I remember having a patient coming in all the time who had had a similar piece of bowel taken out for something else, and we were forever topping up her magnesium and she just couldn't get electrolytes right. And I thought, I'm not doing that. So he said, look, the simplest is just a stoma. Ileal conduit stoma a bag. And you know, easy, so that was sort of decided in a way because of my knowledge in those areas, I guess. Yeah. So, you know, ideally I thought it'd be nice to have it hidden away and you could just empty it when you wanted to. But it sounded like there's too many medical issues with that. Yeah, just made it plain and simple. Just have a bag on, and you empty it and that's it.
Participant 018_2022AUBLC

So I don't have one doctor. I mean, I have a GP who sent me to the hospital for a cystoscopy. And the hospital told me that I have cancer. And they said that the treatment for me is surgery to remove the bladder. And I said, well, is there more other options for me? And they said, you can try radiation, but we do not recommend it for your age because you're not very old and you can handle the surgery. And with surgery that it cannot come back because you don't have a bladder, but with radiation that can come back and also with radiation, maybe not now, but maybe in few years, the radiation itself can cause cancer. So I said, okay, then I go for surgery, but I can I still talk to them, I still get some more information for radiation. So I was not given very clear information that in my case, radiation, radiation was equally successful. So then I told them, do you need more me to continue? … So I just wanted to be aware that, you know, the main difference was radiation versus surgery and both have pros and cons. And I really wanted to be completely, very clearly informed. But because both treatments have got risk, it's not that one is right or wrong. It's what you are prepared to pay, what risk you want to take.
Participant 028_2022AUBLC

Okay. So the options that are available to me, they strongly suggested having the bladder removed and a stoma put in. I yeah. I asked about, you know, the possibility of a neobladder right now at that time they said, look they, they basically said, they didn't do the neobladders all that much here in Australia and they weren't being able to, to give that is an option for me.
Participant 035_2022AUBLC

No, it was pretty, pretty quick, to be honest. It was it was just in there. I did I'm on the pension. So really a lot of this stuff has cost me a bit of money, but I couldn't afford to really go and see Dr. NAME in his private rooms there all the time because it's, you know, saying three times it cost me a fair bit of money, a couple of hundred bucks a visit. And so I saw he has these registrars work for him and you see them and that's free for pensioners. And they were fairly quick and to the point of pretty, you know, pretty good knowledge about it, you know, that it was really a fairly quick sort of summation of what had to be done. So that was basically, basically all I had I didn't or really the appointments only went for probably 5

minutes, maybe ten max. But you know, they were quite sympathetic it's something that we've got to do and we have to do is have a cystoscopy and worse comes to worse you lose your bladder, and I went, really? OK. That that hasn't come to fruition at this stage. Hopefully it doesn't in the future. So that's basically it for the treatment. It wasn't an hour interview or anything like that. It was just, tell me what I had, what had to be done, you don't have to have chemo. It's got to start next week. And that was it went in every day, every Wednesday for six weeks for the mitomycin. And that was basically it. So it wasn't anything not nothing like I had when I had both my knees replaced at that was a real, uh, consultations went forever. But that's about it. Just get in, have a look, see if we can get it and go from there. I suppose if I had to have a, I can't remember what they called a bladder replacement or was that a call that that would have been a bit more thorough or a bit more in-depth? That hasn't come to pass at this stage. I've got to say, Dr.. Excuse me. I've got to say Dr. NAME, it's been fantastic, really. He's a terrific bloke. The times I've seen him and we get along with him pretty well.
Participant 021_2022AUBLC

Participant describes being presented with multiple options: Did not participate in the decision-making process

Um, well, I had a phone call with a urologist after the cytology came back positive, and he said the treatment was going to be a trans urethral resection of the tumour. Um, after that, he said. When I was in hospital, I'd need another one in about four weeks time, which I had. And in the meantime, I was referred to an oncologist. And. Um. I guess my discussion with the oncologist is probably a bit sketchy because I couldn't have anyone with me when I went in. I'm trying to absorb it all. Basically, he just was going, because I had been on treatment for an autoimmune disease. He told me I wasn't suitable to have BCG, which was the treatment of choice. But even if I was suitable, there was a shortage so they couldn't have given it to me anyway. So the treatment was just gemcitabine at the end of his cycle treatment for six weeks. And then I would have, um, either he or the urologist said I'd have them cystoscopy after each a lot of treatment to see what the response was. Um, I, I believe in a letter to the GP and he said to the GP that we discussed having a cystectomy as a treatment of choice, but I don't believe that was the case.
Participant 002_2022AUBLC

So when we got, so the first, when I first went in and had tumours removed, obviously they were sent off for a biopsy. And it came back as non-muscle, a high grade non-muscle invasive bladder cancer. So. Um. Then I went in three weeks later and the next night it was non-muscle invasive at that point. It was a high grade tumour, cancer. Then when I went back in for another resection of the bladder. A trans urethral resection of the bladder. They then sent that off for a biopsy and that came back clear. So nothing the cancer cells hadn't metastasised into the muscle wall or anything like that. So after that the treatment option? Well, we didn't really, she said. But the treatment we would do is the BCG treatment, which was the tuberculosis vaccine, directly instilled into the bladder. Nothing else was really talked about other than. You know, she said, look, it's a 50% effective vaccine. If it doesn't work, it's potential bladder removal. But at this stage, this is just what happened, what the route that she thought would be best to go, because we got it sort of reasonably early, I guess it was classed a sT1. So even though there were three tumours about ten mil, it was still classed as an early, sort of finding. So I didn't feel the need to go down the radio or chemo route.
Participant 014_2022AUBLC

As soon as I was diagnosed with, um, sent straight to a urologist. And at this point was where he basically told me what it was. And he didn't really want to to mess around. So he didn't wan,t he didn't want me to go through chemo or radiotherapy. He thought the best option was to go straight to the operation to see what was going on.
Participant 027_2022AUBLC

Participant describes being presented with multiple options: They were told what to do without discussion

As I said, the first two, they cut out stuff. The next three were clear. Then I was on the BCG treatment and I got so sick from that that I had to, you know, I was in so much terrible pain from that that I had to I had to discontinue the BCG, which I know is a risk. But, but I couldn't. And, and he just kept saying that's the gold standard, that's the treatment for, you. And so there was no there was no discussion of other options or. Or. Or anything.
Participant 008_2022AUBLC

Just I can't really remember an actual discussion about the actual any treatments. They were just saying, oh, this is what we're going to do regarding this procedure. And then we'll then we'll go for the next procedure and we'll work out from there, from

there on. And it was just like they must have had steps that they had to follow, you know? I mean.
Participant 031_2022AUBLC

Very little, really. Dr. NAME is a highly skilled surgeon, urologist, and he, he just was pretty, matter of fact, and told me what the what it was and what would have to be done. He mentioned a neobladder, but he said he didn't think that that that would be the best option for me, probably because of my age and the fact that it grown into the muscle.
Participant 043_2022AUBLC

With the doctor? Yeah. Okay. We really didn't offer many different options. He said, okay, we need to do this and then we need to do that and then we need to do this. And there was no, no real options given. Oh, well, I guess before they removed the bladder, they did say we could choose to not remove it, but he wouldn't have a good prognosis for five years.
Carer 005_2022AUBLC

Participant describes being presented with multiple options: however, there was only one viable option

Um, so when I was first diagnosed and as I said, my GP told me that I had cancer and then my urologist followed up with a call and, mind you it was the middle of COVID. So all of my appointments were done via the phone, via phone. Um, but basically I didn't really have too many treatment options as far as I was aware. My urologist told me that chemotherapy or radiation or any of those forms of treatment would not be effective. The only way forward was to have part of my bladder removed.
Participant 009_2022AUBLC

All of these fundamentally tw,o two sources of conversation really in terms of surgery. And the first one was the cancer, which is the oncologist, the oncologist, who obviously was aware of the surgery. But he said that the cancer itself really had no other treatment. He said the only option was to not have it, not have to simply I couldn't have radio therapy because it was in the wrong places, too deep and too difficult. Anyway, so he said basically said, if you have it, you probably got, you know, up to another five years of life expectancy. If you don't have it, you'll probably get between six months and a year. If you're lucky. That was the oncologist saying those sentiments were basically reflected in the uro-surgeons sent to the, the primary resection the guy who actually removed the bladder. And he, he basically said that, I would say you can either take a punt and hope that you last six months or 12 months, he said, or you can have the operation and hopefully you can have up to another five years, he said. But apart from that, he said that this everything goes well, he said. But this operation is fraught with complications. And he said in many ways complications are more of a danger than the operation itself.
Participant 034_2022AUBLC

With the doctor? Yeah. Okay. We really didn't offer many different options. He said, okay, we need to do this and then we need to do that and then we need to do this. And there was no, no real options given. Oh, well, I guess before they removed the bladder, they did say we could choose to not remove it, but he wouldn't have a good prognosis for five years.
Carer 005_2022AUBLC

Participant describes being presented with multiple options: Changed clinician as they were not satisfied with discussion, lack of empathy and/or options presented

The first specialist I saw only talked about the gold standard is that we should rip everything out. And he wouldn't, he was immovable, but I'm also immovable, so I refused. … I will, I refused to cooperate with the surgery and insisted on a referral to an oncologist. So at that point they offered me what they call the tri modal option. So bladder salvage, which is what my main focus was on bladder salvage. So I didn't want to go down the road to surgery. … Okay. Well, once I got to the oncologists, they said that they felt that they could preserve my bladder and so they recommended it. And how does the chemotherapy dose dense? In fact, it was called. And I also saw a radio and oncology radiologist as well. And so the treatment that was recommended was the track to weekly for four sessions, followed by, I think it was 30 sessions of radiotherapy.
Participant 020_2022AUBLC

Well, I knew there was two types. All right. Bladder cancer. Okay. So basically. They talked a little bit about Neo. What they call it the one where you got the they make the bladder bag inside your body and they go to neo, whatever it's called. Then they talk about the one that's outside your body. Yeah, but I did my own research, mainly because the doctors they, they're very fast and they don't, don't spend much time explaining it. So you really because of I've had. As you know, I've told you already 4 cancers. So, you know, they're. I actually went to a private doctor to, to get my. And what was that one? That was a prostate. Yeah. So, you know, I paid a private

urologist to tell me about the prostate operation and stuff. And when he quoted me $25,000 for the operation, I said, I'll oh, I'll take the public one. He didn't want to know me after that because I went after I went through the public operation for the removal of the prostate. I want to talk to him again. And his secretary wouldn't let me talk to him. Oh, you just you chose the public operation, so sorry. No, our policy is we don't get involved after that. He was happy to take my money beforehand, and I would have paid money paid him again to afterwards. But he did want to know me, so I thought that was very lousy. But as far as bladder cancer, it's something that is, you know, you treat like a number.
Participant 042_2022AUBLC

No, I'm waiting. I could have started if I'd gone private. Probably in the next week or two. I'm hoping is to start in the next week or two. With public if the public takes too long, then I'll hand out my credit card and go back to the private sector. But again, it would probably be something after I believe I've entered a boy's club. Um, and therefore I just say I'm getting gouged every way I turn for out of pocket expenses. And I thought, no, I'm going for something that's fairly standard protocol, BCG. It's not rocket science. They rinse and repeat, you know, six times in a to do a three in a three and then spending what they say they should plateau or whatever. Um, so from my perspective, I've gone, I'll go public. If the wait list is too long, then yes, I'll jump back into the private queue and pay. But I just thought I can just say this is a bit of a boys club. So yeah.
Participant 017_2022AUBLC

Participant describes being presented with multiple options: Wanted more discussion/options

PARTICIPANT So there was no consideration of any assistance to help going to public systems. So if this is where you're angling or just the type of treatment that he was, I can I do private, I can help you privately. I can control the outcome privately and everything I do is private. And I said, what if I wanted to do public? He said, Yeah, you can go down that path. At no stage was there any option that he could assist me in that path that since come to light when I've gone and got an independent referral to public which circumvented back very, very quickly to him. And I don't quite know how that was done because it should not have happened. But anyway, he goes, Oh, well now I always said I could treat you as a public, a private patient, a public hospital, which was a direct lie because this guy.

INTERVIEWER: Was specific to let your say BCG told the truth.

PARTICIPANT Yeah. So that kind of stuff. So he pretty much said Explain what BCG was and said, you know, it's immunotherapy. You have six treatments a couple of hours in the bladder. You go into a into a facility. It happens to be the same building he's in. They do it under like a day, not a day surgery, but like a clinical sort of thing. Nurse put it in, you get it in, you sit there and you go and you do that for six weeks. So that was all fairly well explained. He was very, very hesitant to talk about any sexual side effects of any type of thing, including, you know, what would happen if you lose your bladder. Urologist don't tend to want to talk too much about that upfront because it does impact your treatments and what you may or may not want to have done and how long you pursue with one treatment or another. Because I've since joined a bladder beat bladder support group. Um, so, you know, I've been to a couple of meetings, including one last night, which was all about BCG. Why do I say this? Because I'm now well informed and my wife has been miraculous at doing lots of online research to kind of go. Most of my intelligence has come from my wife and her research or the beat bladder website, BEAT cancer website or their support group and certainly not my urologist. He has given me the bare basics necessary to take you to the next step with a provider of his choice.
Participant 017_2022AUBLC

The urologist really just went through that they would have a look and confirm it was cancer. And that I would have probably BCG treatment. Mm yes. And he gave me a bit of information, but I didn't realise at that time how much or what to expect totally. You know, at that time I was hoping that. It would be, for want of a better term cured. Treated and I could just carry on as normal. It did indicate that if the BCG worked, I could have a follow up cystoscopy as I think it was. But I'm not sure if it's every six months or every three months for a while, and then it would go to six months. And so that was pretty much the discussion at that time. Um, yes. And then as I say I had the cystoscopy that doctor did that cystoscopy it removed tumours and it was high grade non-invasive.
Participant 003_2022AUBLC

Participant describes being presented with multiple options: No reason provided

It was a radical cystectomy, and an ileal conduit to that was what was offered. So chemotherapy was offered. First, you have to do chemotherapy first for

three, four cycles, and then a radical cystectomy would be would be ordered within after four weeks of chemo finishing. Okay. And what was it?
Carer 004_2022AUBLC

And really wasn't at diagnosis with the urologist. It was probably after confirmation. So he went in and had a scope done. It was see that I found a about a 5 cm centimetre tumour in the bladder wall which they removed and it went off for testing. It was when that test results come back that we then discussed a treatment plan which was initially with the urologist, but then we were referred on to an oncologist because to tackle my husband's bladder cancer, they were going to do a combination of chemotherapy and bladder removal. So, yeah, the oncologist was the one that discussed the treatment options with
Carer 002_2022AUBLC

Participant describes being presented with one option/approach: They were told what to do without discussion

Um, well, I was told that I would have BCG and nothing else, wasn't told about anything.
Participant 007_2022AUBLC

And really, it was only that I have BCG therapy. So and that that that has a I wasn't really aware that it had a sort of set Schedule. But yeah, I was told that BCG is the gold standard treatment source for my high grade non-muscle invasive bladder cancer. And so that's, you know, it wasn't really any of the discussion. I don't recall there being a discussion about cystectomy unless I blocked that out. Well, but I think I think it's fair that most urologists would recommend BCG before going straight to it cystectomy with, with Non-Muscle invasive.
Participant 010_2022AUBLC

And basically, I'll still remember, he said, you have to have your bladder out. If you don't, you've got six months. Not very um, yeah. And I basically said, no way you're not taking my bladder out.
Participant 023_2022AUBLC

Participant describes being presented with one option/approach: Participated in the decision-making process

And like, you know, like they I felt that they discussed, you know, whatever questions we had. I mean, I think I was in a bit of denial at some stage. Um, whatever questions my kids had, they, you know, went through it all and reassured. And so I was really quite pleased with, see, um. With the preparation. Yeah.
Participant 039_2022AUBLC

When I was first diagnosed, he didn't I wasn't really you know, I think I had already done research. So I kind of knew what, what might be discussed with me. But they decided that, that I didn't have to have any other treatment at that time, that they would just remove the cancer and do regular cystoscopy. So I think I had a cystoscopy every three months, just so.
Participant 026_2022AUBLC

Table 4.3: Discussions about treatment (Participation in discussions)

Discussions about treatment (Participation in discussions)	All participants		Early		Invasive		Advanced		Person with bladder cancer		Carer		Female		Male	
	n=49	%	n=20	%	n=10	%	n=14	%	n=44	%	n=5	%	n=17	%	n=32	%
Participant describes being presented with multiple options: Participated in the decision-making process	10	20.41	5	25.00	2	20.00	3	21.43	10	22.73	**0**	**0.00**	2	11.76	8	25.00
Participant describes being presented with multiple options: Did not participate in the decision-making process	10	20.41	4	20.00	**1**	**10.00**	**5**	**35.71**	10	22.73	**0**	**0.00**	2	11.76	8	25.00
Participant describes being presented with multiple options: They were told what to do without discussion	8	16.33	4	20.00	1	10.00	2	14.29	7	15.91	1	20.00	3	17.65	5	15.63
Participant describes being presented with multiple options: however, there was only one viable option	6	12.24	3	15.00	1	10.00	1	7.14	5	11.36	1	20.00	2	11.76	4	12.50
Participant describes being presented with multiple options: Changed clinician as they were not satisfied with discussion, lack of empathy and/or options presented	3	6.12	1	5.00	1	10.00	1	7.14	3	6.82	0	0.00	0	0.00	3	9.38
Participant describes being presented with multiple options: Wanted more discussion/options	3	6.12	1	5.00	2	20.00	0	0.00	3	6.82	0	0.00	2	11.76	1	3.13
Participant describes being presented with multiple options: No reason provided	3	6.12	1	5.00	0	0.00	0	0.00	1	2.27	2	40.00	1	5.88	2	6.25
Participant describes being presented with one option/approach: They were told what to do without discussion	5	10.20	3	15.00	1	10.00	0	0.00	4	9.09	1	20.00	3	17.65	2	6.25
Participant describes being presented with one option/approach: Participated in the decision-making process	3	6.12	0	0.00	1	10.00	2	14.29	3	6.82	0	0.00	2	11.76	1	3.13

Discussions about treatment (Participation in discussions)	All participants		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=49	%	n=29	%	n=19	%	n=15	%	n=33	%	n=20	%	n=28	%
Participant describes being presented with multiple options: Participated in the decision-making process	10	20.41	5	17.24	4	21.05	3	20.00	6	18.18	2	10.00	7	25.00
Participant describes being presented with multiple options: Did not participate in the decision-making process	10	20.41	8	27.59	2	10.53	2	13.33	8	24.24	4	20.00	6	21.43
Participant describes being presented with multiple options: They were told what to do without discussion	8	16.33	3	10.34	5	26.32	2	13.33	6	18.18	3	15.00	5	17.86
Participant describes being presented with multiple options: however, there was only one viable option	6	12.24	5	17.24	1	5.26	2	13.33	4	12.12	3	15.00	3	10.71
Participant describes being presented with multiple options: Changed clinician as they were not satisfied with discussion, lack of empathy and/or options presented	3	6.12	2	6.90	1	5.26	1	6.67	2	6.06	1	5.00	2	7.14
Participant describes being presented with multiple options: Wanted more discussion/options	3	6.12	2	6.90	1	5.26	2	13.33	1	3.03	2	10.00	1	3.57
Participant describes being presented with multiple options: No reason provided	3	6.12	2	6.90	1	5.26	0	0.00	3	9.09	1	5.00	2	7.14
Participant describes being presented with one option/approach: They were told what to do without discussion	5	10.20	3	10.34	2	10.53	0	0.00	5	15.15	1	5.00	4	14.29
Participant describes being presented with one option/approach: Participated in the decision-making process	3	6.12	1	3.45	2	10.53	2	13.33	1	3.03	2	10.00	1	3.57

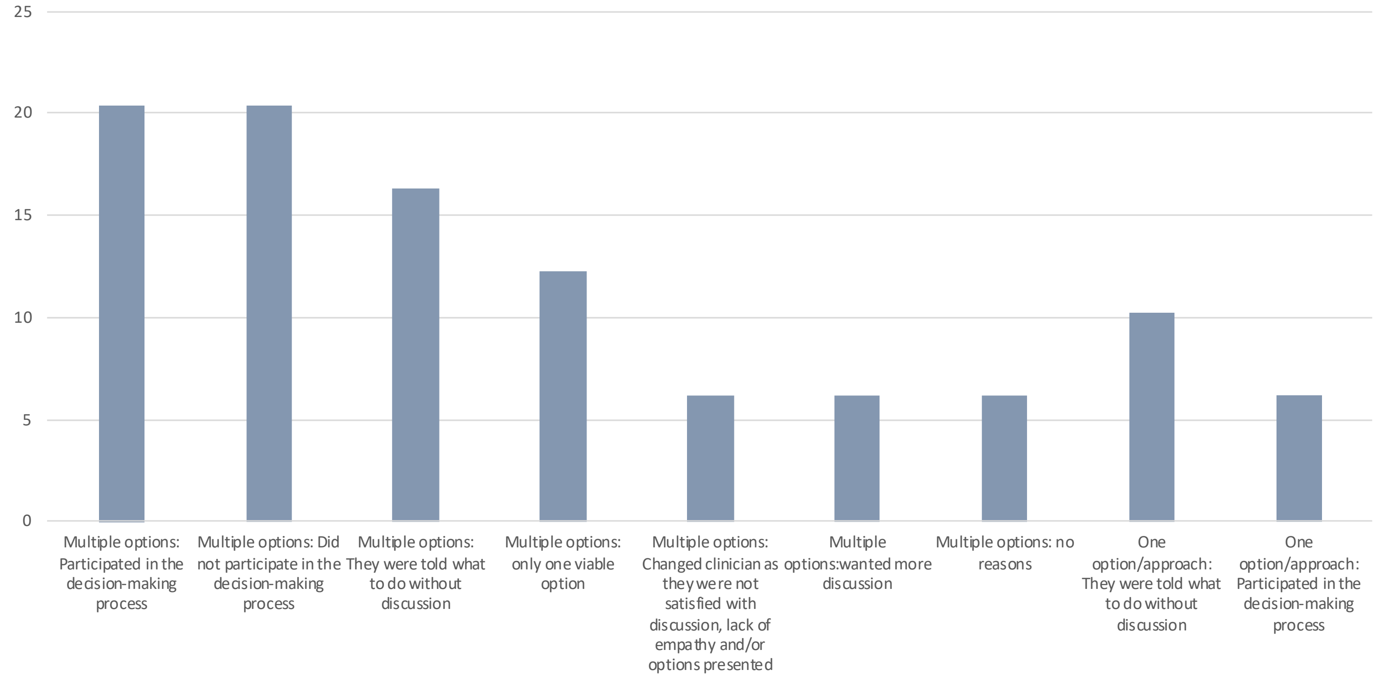


Figure 4.2: Discussions about treatment (Participation in discussions)

Table 4.4: Discussions about treatment (Participation in discussions) – subgroup variations

Discussions about treatment (Participation in discussions)	Reported less frequently	Reported more frequently
Participant describes being presented with multiple options: Participated in the decision-making process	Carer to someone with bladder cancer Mid to low status	-
Participant describes being presented with multiple options: Did not participate in the decision-making process	Invasive (Stage III) Carer to someone with bladder cancer	Advanced (Stage IV)

Considerations when making decisions

Participants were asked in the structured interview what they considered when making decisions about treatment. The most reported theme was taking the advice of their clinician, and this was described by 23 participants (46.94%). There were 15 participants (30.61%) that considered being cancer free, avoiding recurrence, or longevity, and 12 participants (24.49%) that described taking side effects into account. Other considerations included taking ease of administration into account (n=8, 16.33%), quality of life (n=7, 14.29%), costs (n=5, 10.20%), and impact on family and dependents (n=5, 10.20%).

Participant describes taking the advice of their clinician into account when making decisions about treatment (Total)

I just mainly do what the urologist tells me to. Oh. Because it. Because I've had no one. No. No one's ever spoken to me about it. So if I'm, you know, I've got to take faith that he knows what he's doing and he can get rid of it. Well, I don't know whether you'll ever get rid of it, but. Yeah. Put it in remission.
Participant 007_2022AUBLC

But then I just do what they tell me. Okay. You know, I haven't played the role. It's even. I just do it. So they

set up the surgery, I just fill out the form and go to the hospital.
Participant 013_2022AUBLC

It was, I guess, trust in my medical team, my brainiacs I called them, my brainiacs, and just the logic behind it. Like everything they explain to me made sense.
Participant 022_2022AUBLC

Participant describes taking being cancer free, avoiding recurrence, or longevity into account when making decisions about treatment (Total)

Um. I suppose the treatment you're hoping that you'll get it, well a cure. Really hope that you will get a cure so that life can continue on. So my treatment really pretty much I've done whatever the doctors have told me, I've been fairly careful to follow through with all my appointments and all the check-ups. I was hoping that I wouldn't have to have the bladder removal. I got a second opinion on that. Oh my daughter in law works for an insurance company who have a scheme where family members can have a second opinion from a group called Best Doctors. So before I actually went through the bladder removal operation, I was in touch with them and was eligible for this service. And they went through. They speak to your doctors, all your treatment people, and agreed that radical cystectomy was my best option. Not what you want to hear. So I, I don't want to die yet.
Participant 003_2022AUBLC

Life expectancy. Yes. Um. The pros and cons of undergoing surgery. And how it's going to impact on my life. The recovery time. Mainly life expectancy. By having it go down, however. And I take the advice of the doctor.
Participant 038_2022AUBLC

Um, you know, just, um, DOCTOR came up to me and he said, you could have more treatment or you can get your bladder removed. And of course, I had been it had reoccurred. I think it was three or four times. Three times, I think over the three years. But two and a half years. I so well, if he offered me more treatment of that, I'll be sitting here in six months time and we could be having this discussion again. And I didn't want to, um, I didn't want the cancer to become invasive and then, you know, for the rest of my body. So I made the decision of going ahead and get me bladder removed.
Participant 044_2022AUBLC

Participant describes taking side effects into account when making decisions about treatment (Total)

The main one is the is the side effects. A lesser one, but still relevant is, is the finances the cost? And I suppose the third one less important is the distance to travel. I mean, that doesn't worry me because I don't, I, I only do a bit of casual work now so it doesn't affect me. I can, you know, I'm going to a different hospital in CITY now, which is not anywhere near where I live, but that doesn't worry me. The main one is the side effects and the second one would be the finances.
Participant 008_2022AUBLC

Um, what the treatments I need, I, I'm a PROFESSION. I tend to want to know what the treatment actually is and what, what the benefits and side effects of the treatment are, particularly to lifestyle. And initially when I looked at the, the big decision was not, not to do BCG because it's pretty much standard treatment and um, you know, you do that. But the trial was another issue. Whether I do the trial or do it became a major thing to consider how much of my time and how much I'd actually go through in doing the trial. Because the, the trial has three pages of side effects, possible side effects starting at one in one in ten, which is, you know, nausea and, and all that sort of thing. And going through to one in a thousand of you dying and things like that. So it's things to be to be heart issues or lung issues or all those sort of things. So you have to really weigh those up. So I was very I was pleased to get a lot of support from my son in, in looking at that with me and then also with my doctor. And I was able to go back to the, the professor who was leading the trial. And he's a very down to earth sort of guy as well. And discuss, you know, in real terms, what does that mean when they say you got to 100, one, 100 chance of having issues with lung and the fact that the, the drug can actually attack many or the side effects to any tissues in your body that now what does that actually mean and how likely are those sorts of things. And it I was very supportive of all that.
Participant 029_2022AUBLC

Side effects. The big one. Yeah. And then the effect it will have on the cancer. Long term, long term prognosis, I guess.
Carer 005_2022AUBLC

Participant describes taking ease of administration into account when making decisions about treatment (Total)

Well location. We wanted it because I wasn't able to go with him again. There was only one person in the day room, the treatment room. So location was really

important for us. That was a big factor, that he didn't have to go too far to have chemotherapy. We did ask the question about having chemotherapy at home, but because we were public patients, that wasn't an option for us.
Carer 002_2022AUBLC

Well, the main the main one is the treatment I had is very invasive. I'm a little bit apprehensive about it. As I said, I'm facing it again now. So, yeah, I would say that my mind is the same. I'm still. It's very invasive and then, and it's sometimes painful.
Participant 012_2022AUBLC

Look, I guess what I was told, what I was going to have to get done. And how are we going to be administered. It was a bit daunting in the beginning. You know, obviously, you know, it's all administered through a catheter. So which is, you know. So I was a bit worried. But then after a couple of sessions, it was fine. And I just thought, you know, whatever is, you know, I'm not the specialist, my urologist is the specialist. So I'm just really relying on their advice and, you know, for them to tell me what needs to be done.
Participant 024_2022AUBLC

Participant describes taking cost into account when making decisions about treatment (Total)

Um, cost to a point. We can afford it. Do we need to spend? I've got top private health, pay a fortune in Medicare, Medicare levies. So I'm going, why do I need to keep digging into my pocket for cancer? So that's a consideration. It's not a deal breaker. The other thing I was going to say was second opinion. We're getting a second opinion at this stage on the 10th of May from a very respectable urologist just to kind of. And it might also be another way to get into the public system to him, given that he also operates in the public system. And we do lots of research. Well, considering you know what my options are.
Participant 017_2022AUBLC

Yeah. You know, and so I walked out of there thinking, I never want to see him again. I'm saying to my husband, Did you not find him? You know, that he had no empathy for you. Did you not find that he you know, and then he talked about money as if it was almost guilting us into you should not even be thinking because I asked the question about, well, what are out-of-pocket pockets going to be because we've got private health insurance. And it was like, oh, you don't ask me that. You have to talk to my secretary about it. I said, But you must know what you are. I said, Yes, I'll talk to your secretary about it. But you must know what you're out of pocket. And it was like verbatim, I'm telling you. Well, if you want to give less to your children in their will, for your husband's health, that would be a good idea. So that's why I totally disliked him. Oh, yeah, that's.
Carer 004_2022AUBLC

Um. The cost. Mm hmm. The risk? The risk of having it done or not having it done, time off work.
Participant 016_2022AUBLC

Participant describes taking quality of life into account when making decisions about treatments (Total)

Probably earlier. When I first started, it was about lifestyle. All my lifestyle is, is active. I'm actually a skydiver. If I had surgery, I would have probably had to stop that. If you have a if you have a bag hanging off you, you can't really jump out of a plane and not have problems. So that was my primary focus, was to maintain my lifestyle as it was.
Participant 020_2022AUBLC

Um, to, to get the cancer out of me. You get to get it. Get back to where I was.
Participant 033_2022AUBLC

Um, what the treatments I need, I, I'm a PROFESSION. I tend to want to know what the treatment actually is and what, what the benefits and side effects of the treatment are, particularly to lifestyle. And initially when I looked at the, the big decision was not, not to do BCG because it's pretty much standard treatment and um, you know, you do that. But the trial was another issue. Whether I do the trial or do it became a major thing to consider how much of my time and how much I'd actually go through in doing the trial. Because the, the trial has three pages of side effects, possible side effects starting at one in one in ten, which is, you know, nausea and, and all that sort of thing. And going through to one in a thousand of you dying and things like that. So it's things to be to be heart issues or lung issues or all those sort of things. So you have to really weigh those up. So I was very I was pleased to get a lot of support from my son in, in looking at that with me and then also with my doctor. And I was able to go back to the, the professor who was leading the trial. And he's a very down to earth sort of guy as well. And discuss, you know, in real terms, what does that mean when they say you got to 100, one, 100 chance of having issues with lung and the fact that the, the drug can actually attack many or the side effects to any tissues in your body that now what does that actually mean and how likely are

those sorts of things. And it I was very supportive of all that.
Participant 029_2022AUBLC

Participant describes taking the potential impact on their family or dependents into account when making decisions about treatment (Total)

Well, how really it was going to affect the rest of my life. Um, what was the best option for both myself and my family?
Participant 027_2022AUBLC

Well, the first thing was, what do I need to do to give me the best chance of living? So that was number one. And basically my decision was have this surgery and, you know, hopefully everything's contained and you will live or not have this surgery. And the prognosis was not good. So that was my number one thought. I also had school age children. One of them was doing their final year of school. So that was sort of a consideration as well. I selected or elected to have a neobladder, one, because I was young and a good candidate for a neobladder, two, because, you know, if everything went well and worked well, it gave me just that little bit more normality. Because while I don't have a bladder, my neobladder is inside of me. It's made out of a piece of my bowel. I operate it just like a regular person operates their bladder. So that was you know, that was that was an important decision for me that, you know, I don't have anything external. If you were to look at me, you would not know I've had this surgery.
Participant 032_2022AUBLC

The things, I suppose. Firstly, yeah, it's myself and my family. The things that I think of first and foremost, how it impacts me and how it can have whatever potential treatment is going to impact my family going forward.
Participant 035_2022AUBLC

Participant describes taking the advice of family and friends into account when making decisions about treatment (Total)

Oh, look, I really just have to go with what? You know, they tell me what they what they recommend. I discuss it with m,y I mean, discuss it with the family and my husband. But we all go. We. Just think we have to go with what they're recommending, which I don't know enough about it, you know?
Participant 004_2022AUBLC

Probably the main thing was that I'm in a men's shed. I've got a couple of guys out there that have had cancer that has actually gone to their lungs. So I knew by discussion with them on these issues, if it didn't get rid of the cancer at the right time. So I sort of you know by reading and researching and actually being able to talk to people that are in that situation. I knew that probably better out sooner rather than later I didn't postpone anything I did it as soon as practical, mainly because I, you know, I, my, my main mantra is I've got my youngest grandson is nine. And I'd like to be here when they grow up, you know, not in the adults, but as long as I can, if they're old enough to realise what's happened, you know, I would like to be there for that to.
Participant 011_2022AUBLC

Participant describes taking bladder preservation into account when making decisions about treatment (Total)

Um. I suppose the treatment you're hoping that you'll get it, well a cure. Really hope that you will get a cure so that life can continue on. So my treatment really pretty much I've done whatever the doctors have told me, I've been fairly careful to follow through with all my appointments and all the check-ups. I was hoping that I wouldn't have to have the bladder removal. I got a second opinion on that. Oh my daughter in law works for an insurance company who have a scheme where family members can have a second opinion from a group called Best Doctors. So before I actually went through the bladder removal operation, I was in touch with them and was eligible for this service. And they went through. They speak to your doctors, all your treatment people, and agreed that radical cystectomy was my best option. Not what you want to hear. So I, I don't want to die yet.
Participant 003_2022AUBLC

Probably earlier. When I first started, it was about lifestyle. All my lifestyle is, is active. I'm actually a skydiver. If I had surgery, I would have probably had to stop that. If you have a if you have a bag hanging off you, you can't really jump out of a plane and not have problems. So that was my primary focus, was to maintain my lifestyle as it was.
Participant 020_2022AUBLC

Participant describes being given only one treatment option, they could have treatment or risk progression or death (Total)

Well, there seemed to be in the literature suggested that there was only one immunotherapy treatment

because it wasn't chemotherapy, it was immunotherapy. And there's really only one tried and tested. Apart from clinical trials, it's not really anything else currently available. So there wasn't an option. It was either BCG or nothing, really.
Participant 030_2022AUBLC

Look, we haven't really had to make too many decisions about treatment because we've always had BCG available. I know that isn't the same for everybody, and he hasn't needed to go to a different type of treatment. So really, that was just always the obvious choice and the only choice we've had to make.
Carer 003_2022AUBLC

Table 4.5 Considerations when making decisions

Considerations when making treatment decisions	All participants		Early		Invasive		Advanced		Person with bladder cancer		Carer		Female		Male	
	n=49	%	n=20	%	n=10	%	n=14	%	n=44	%	n=5	%	n=17	%	n=32	%
Participant describes taking the advice of their clinician into account when making decisions about treatment (Total)	23	46.94	**7**	**35.00**	**6**	**60.00**	**9**	**64.29**	22	50.00	**1**	**20.00**	9	52.94	14	43.75
Participant describes taking the advice of their clinician into account as part of multiple aspects that they consider when making decisions about treatment	10	20.41	3	15.00	2	20.00	**5**	**35.71**	10	22.73	**0**	**0.00**	3	17.65	7	21.88
Participant describes taking the advice of their clinician into account as the only thing that they consider when making decisions about treatment	13	26.53	4	20.00	**4**	**40.00**	4	28.57	12	27.27	1	20.00	6	35.29	7	21.88
Participant describes taking being cancer free, avoiding recurrence, or longevity into account when making decisions about treatment (Total)	15	30.61	6	30.00	**2**	**20.00**	**6**	**42.86**	14	31.82	**1**	**20.00**	**3**	**17.65**	12	37.50
Participant describes taking being cancer free, avoiding recurrence, or longevity into account as part of multiple considerations when making decisions about treatment	11	22.45	3	15.00	**1**	**10.00**	**6**	**42.86**	10	22.73	1	20.00	**2**	**11.76**	9	28.13
Participant describes taking being cancer free, avoiding recurrence, or longevity into account as the only thing that they consider when making decisions about treatment	4	8.16	3	15.00	1	10.00	0	0.00	4	9.09	0	0.00	1	5.88	3	9.38
Participant describes taking side effects into account when making decisions about treatment (Total)	12	24.49	3	15.00	2	20.00	4	28.57	9	20.45	**3**	**60.00**	**2**	**11.76**	10	31.25
Participant describes taking side effects into account as part of multiple aspects that they consider when making decisions about treatment	11	22.45	3	15.00	**1**	**10.00**	4	28.57	8	18.18	**3**	**60.00**	**1**	**5.88**	10	31.25
Participant describes taking side effects into account as the only thing that they consider when making decisions about treatment	1	2.04	0	0.00	1	10.00	0	0.00	1	2.27	0	0.00	1	5.88	0	0.00
Participant describes taking ease of administration into account when making decisions about treatment (Total)	8	16.33	3	15.00	1	10.00	2	14.29	6	13.64	**2**	**40.00**	**1**	**5.88**	7	21.88
Participant describes taking ease of administration into account as part of multiple aspects that they consider when making decisions about treatment	6	12.24	3	15.00	1	10.00	1	7.14	5	11.36	1	20.00	1	5.88	5	15.63
Participant describes taking ease of administration into account as the only thing that they consider when making decisions about treatment	2	4.08	0	0.00	0	0.00	1	7.14	1	2.27	1	20.00	0	0.00	2	6.25
Participant describes taking quality of life into account when making decisions about treatments (Total)	7	14.29	1	5.00	1	10.00	**5**	**35.71**	7	15.91	**0**	**0.00**	1	5.88	6	18.75
Participant describes taking quality of life into account as part of multiple aspects that they consider when making decisions about treatment	7	14.29	1	5.00	1	10.00	**5**	**35.71**	7	15.91	**0**	**0.00**	1	5.88	6	18.75
Participant describes taking quality of life into account as the only thing that they consider when making decisions about treatment	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
Participant describes taking cost into account when making decisions about treatment (Total)	5	10.20	3	15.00	1	10.00	**0**	**0.00**	4	9.09	1	20.00	1	5.88	4	12.50
Participant describes taking cost into account as part of multiple aspects that they consider when making decisions about treatment	5	10.20	3	15.00	1	10.00	**0**	**0.00**	4	9.09	1	20.00	1	5.88	4	12.50
Participant describes taking cost into account as the only thing that they consider when making decisions about treatment	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
Participant describes taking the potential impact on their family or dependents into account when making decisions about treatment (Total)	5	10.20	1	5.00	1	10.00	2	14.29	4	9.09	1	20.00	1	5.88	4	12.50
Participant describes taking the potential impact on their family or dependents into account as part of multiple aspects that they consider when making decisions about treatment	5	10.20	1	5.00	1	10.00	2	14.29	4	9.09	1	20.00	1	5.88	4	12.50
Participant describes taking the potential impact on their family or dependents into account as the only thing that they consider when making decisions about treatment	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
Participant describes taking the advice of family and friends into account when making decisions about treatment (Total)	3	6.12	2	10.00	0	0.00	1	7.14	3	6.82	0	0.00	1	5.88	2	6.25
Participant describes taking the advice of family and friends into account as part of multiple aspects that they consider when making decisions about treatment	3	6.12	2	10.00	0	0.00	1	7.14	3	6.82	0	0.00	1	5.88	2	6.25
Participant describes taking the advice of family and friends into account as the only thing that they consider when making decisions about treatment	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
Participant describes taking bladder preservation into account when making decisions about treatment (Total)	3	6.12	2	10.00	0	0.00	0	0.00	2	4.55	1	20.00	1	5.88	2	6.25
Participant describes taking bladder preservation into account as part of multiple aspects that they consider when making decisions about treatment	3	6.12	2	10.00	0	0.00	0	0.00	2	4.55	1	20.00	1	5.88	2	6.25
Participant describes taking bladder preservation into account as the only thing that they consider when making decisions about treatment	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
Participant describes being given only one treatment option, they could have treatment or risk progression or death (Total)	3	6.12	0	0.00	1	10.00	1	7.14	2	4.55	1	20.00	0	0.00	3	9.38
Participant describes being given only one treatment option, they could have treatment or risk progression or death	3	6.12	0	0.00	1	10.00	1	7.14	2	4.55	1	20.00	0	0.00	3	9.38

Considerations when making treatment decisions	All participants		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=49	%	n=29	%	n=19	%	n=15	%	n=33	%	n=20	%	n=28	%
Participant describes taking the advice of their clinician into account when making decisions about treatment (Total)	23	46.94	16	55.17	7	36.84	7	46.67	16	48.48	10	50.00	13	46.43
Participant describes taking the advice of their clinician into account as part of multiple aspects that they consider when making decisions about treatment	10	20.41	9	31.03	1	5.26	4	26.67	6	18.18	7	35.00	3	10.71
Participant describes taking the advice of their clinician into account as the only thing that they consider when making decisions about treatment	13	26.53	7	24.14	6	31.58	3	20.00	10	30.30	3	15.00	10	35.71
Participant describes taking being cancer free, avoiding recurrence, or longevity into account when making decisions about treatment (Total)	15	30.61	11	37.93	3	15.79	5	33.33	9	27.27	9	45.00	5	17.86
Participant describes taking being cancer free, avoiding recurrence, or longevity into account as part of multiple considerations when making decisions about treatment	11	22.45	10	34.48	1	5.26	5	33.33	6	18.18	9	45.00	2	7.14
Participant describes taking being cancer free, avoiding recurrence, or longevity into account as the only thing that they consider when making decisions about treatment	4	8.16	1	3.45	2	10.53	0	0.00	3	9.09	0	0.00	3	10.71
Participant describes taking side effects into account when making decisions about treatment (Total)	12	24.49	9	31.03	3	15.79	7	46.67	5	15.15	9	45.00	3	10.71
Participant describes taking side effects into account as part of multiple aspects that they consider when making decisions about treatment	11	22.45	9	31.03	2	10.53	6	40.00	5	15.15	8	40.00	3	10.71
Participant describes taking side effects into account as the only thing that they consider when making decisions about treatment	1	2.04	0	0.00	1	5.26	1	6.67	0	0.00	1	5.00	0	0.00
Participant describes taking ease of administration into account when making decisions about treatment (Total)	8	16.33	6	20.69	2	10.53	4	26.67	4	12.12	4	20.00	4	14.29
Participant describes taking ease of administration into account as part of multiple aspects that they consider when making decisions about treatment	6	12.24	4	13.79	2	10.53	4	26.67	2	6.06	4	20.00	2	7.14
Participant describes taking ease of administration into account as the only thing that they consider when making decisions about treatment	2	4.08	2	6.90	0	0.00	0	0.00	2	6.06	0	0.00	2	7.14
Participant describes taking quality of life into account when making decisions about treatments (Total)	7	14.29	5	17.24	2	10.53	3	20.00	4	12.12	4	20.00	3	10.71
Participant describes taking quality of life into account as part of multiple aspects that they consider when making decisions about treatment	7	14.29	5	17.24	2	10.53	3	20.00	4	12.12	4	20.00	3	10.71
Participant describes taking quality of life into account as the only thing that they consider when making decisions about treatment	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
Participant describes taking cost into account when making decisions about treatment (Total)	5	10.20	2	6.90	3	15.79	3	20.00	2	6.06	4	20.00	1	3.57
Participant describes taking cost into account as part of multiple aspects that they consider when making decisions about treatment	5	10.20	2	6.90	3	15.79	3	20.00	2	6.06	4	20.00	1	3.57
Participant describes taking cost into account as the only thing that they consider when making decisions about treatment	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
Participant describes taking the potential impact on their family or dependents into account when making decisions about treatment (Total)	5	10.20	4	13.79	1	5.26	2	13.33	3	9.09	4	20.00	1	3.57
Participant describes taking the potential impact on their family or dependents into account as part of multiple aspects that they consider when making decisions about treatment	5	10.20	4	13.79	1	5.26	2	13.33	3	9.09	4	20.00	1	3.57
Participant describes taking the potential impact on their family or dependents into account as the only thing that they consider when making decisions about treatment	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
Participant describes taking the advice of family and friends into account when making decisions about treatment (Total)	3	6.12	3	10.34	0	0.00	1	6.67	2	6.06	2	10.00	1	3.57
Participant describes taking the advice of family and friends into account as part of multiple aspects that they consider when making decisions about treatment	3	6.12	3	10.34	0	0.00	1	6.67	2	6.06	2	10.00	1	3.57
Participant describes taking the advice of family and friends into account as the only thing that they consider when making decisions about treatment	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
Participant describes taking bladder preservation into account when making decisions about treatment (Total)	3	6.12	2	6.90	1	5.26	0	0.00	3	9.09	2	10.00	1	3.57
Participant describes taking bladder preservation into account as part of multiple aspects that they consider when making decisions about treatment	3	6.12	2	6.90	1	5.26	0	0.00	3	9.09	2	10.00	1	3.57
Participant describes taking bladder preservation into account as the only thing that they consider when making decisions about treatment	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
Participant describes being given only one treatment option, they could have treatment or risk progression or death (Total)	3	6.12	1	3.45	2	10.53	0	0.00	3	9.09	0	0.00	3	10.71
Participant describes being given only one treatment option, they could have treatment or risk progression or death	3	6.12	1	3.45	2	10.53	0	0.00	3	9.09	0	0.00	3	10.71

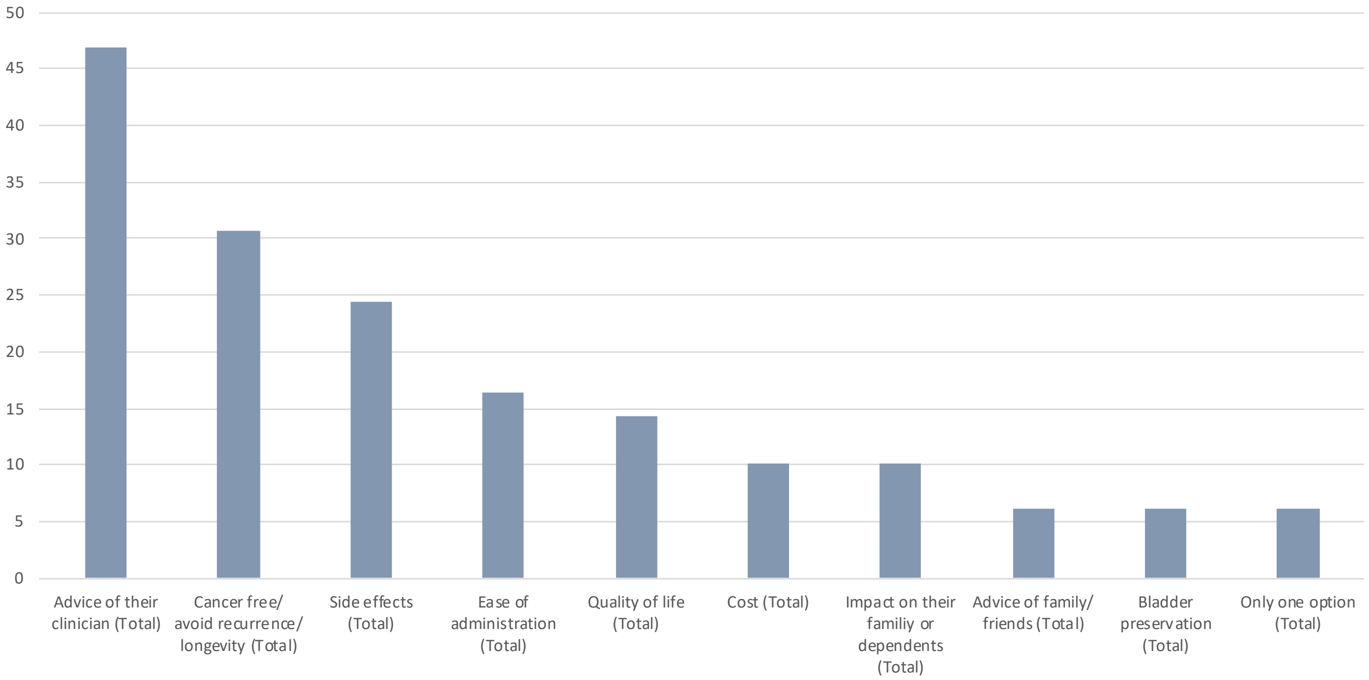


Figure 4.3 Considerations when making decisions

Table 4.6: Considerations when making decisions – subgroup variations

Considerations when making treatment decisions	Reported less frequently	Reported more frequently
Participant describes taking the advice of their clinician into account when making decisions about treatment (Total)	Early (Stages 0 and I) Carer to someone with bladder cancer University	Invasive (Stage III) Advanced (Stage IV)
Participant describes taking being cancer free, avoiding recurrence, or longevity into account when making decisions about treatment (Total)	Invasive (Stage III) Carer to someone with bladder cancer Female University Higher status	Advanced (Stage IV) Mid to low status
Participant describes taking side effects into account when making decisions about treatment (Total)	Female Higher status	Carer to someone with bladder cancer Regional or remote Mid to low status
Participant describes taking ease of administration into account when making decisions about treatment (Total)	Female	Carer to someone with bladder cancer Regional or remote
Participant describes taking quality of life into account when making decisions about treatments (Total)	Carer to someone with bladder cancer	Advanced (Stage IV)
Participant describes taking cost into account when making decisions about treatment (Total)	Advanced (Stage IV)	-

Decision-making over time

Participants were asked if the way they made decisions had changed over time. There were 28 participants (57.14%) that felt the way they made decisions about treatment had not changed over time, and 20 participants (40.82%) that described decision making changing.

Where participants had not changed their decision making over time, this was because they have always taken the advice of clinicians (n=11, 22.45%), or had always been informed and assertive (n=7, 14.29%). Where participants had changed the way they make decisions, this was primarily in relation to becoming more informed or more assertive (n=13, 26.53%).

Participant describes no change in decision-making over time as they have always taken advice of clinicians

Look, no, because I didn't know anything about it and as I say it's I'm more than happy to be guided by those that know more than I do.
Participant 014_2022AUBLC

I think I approach in the same way. Yeah. I'd like to see an evidence base for whatever treatment I'm going to choose and like read up on the research and that sort of thing. But I've always done that, so I think it's probably similar. I think where the change in my problem solving abilities would have come when I did a master's of research. And then you start looking, you look at things a different way after that. So yeah, that's probably more influenced me than anything else.
Participant 018_2022AUBLC

In terms of my health, even actually strengthen my position in terms of listening to professionals because it's working? Yeah.

Participant 024_2022AUBLC

Participant describes no change in decision-making over time and there is no particular reason noted

Yeah. No, I don't think so. I don't think much has changed, to be honest.
Participant 009_2022AUBLC

Oh, I think I might them the same way.
Participant 012_2022AUBLC

In the same way. Yeah, I'm okay. I'm quite still quite happy with the decision that we made.
Participant 027_2022AUBLC

Participant describes no change in decision-making over time as they have always been informed/assertive

No, no, no, no, no, no, no. I did research when I was on Internet research. I don't just rely on Dr Google though, but I try and get onto the different sites and the you know, that I'm one of the American and English bladder cancer sites and there was the Australian ones and tried to see what was the up to date technology and what they were doing and everything else. So I thought I was pretty well on top of our discussion and I had a pretty good understanding of where I was going with. Hmm. It still doesn't prepare you for the operation or anything. But, you know, it gives you a bit better understanding. Put it that way. Hmm. I've always been a pretty healthy person I've only had a knee replacement ten years ago. But and I thought that was fairly healthy, like helping me know I used to run marathons and I and I've actually been back out kayaking since.
Participant 011_2022AUBLC

Uh, I. I don't think it has changed, because it's just my just my personality. I don't take a decision until I have all the information. So I would have rather postponed my decision if I was unsure. But I would first be very clear that what are available options and then take the decision. So nothing has changed once I decided on.
Participant 028_2022AUBLC

No, I I've, I've always it always approach things in the same way. I think if you weren't either technically or structured in your thinking, putting all these things together would be terribly hard for some. But it's hard enough on your own. It's hard enough with a group of, you know, two or three people deciding what's the best thing to do. But if you all just seek and or not seek, but just trying to weigh up what to do, I think it'd be terribly hard to have that, you know, ability to read and try and understand, digest what it was all about.
Participant 029_2022AUBLC

Participant describes decision-making changing over time as they are more informed and/or more assertive

Possibly I would ask more questions. I would know the questions to ask now. What are the problems with this stuff as you don't know what questions to ask? I do believe that somewhere along the line it might be, you know, if you Google stuff, I do believe there is a sort of it could be a list. So when you go to a doctor, or when you go somewhere with something like this, you've got a list of questions. You know, what was the treatment? What if I don't have treatment? Do I need chemo? Do I need this? Knowing the questions to ask was probably one of the missing links kind of thing for me, I did ask questions. I took my partner with me whenever I was getting results yeah, I find that, it's trying to go into some mental lockdown, I didn't take issues in. And then when we'd come out, I'd remember some. And he would say, Oh, well, what about when he said this? Or What about when he said that? So that's the way to, to get your head around more information.
Participant 003_2022AUBLC

Now, I do a lot more research now. Yeah. Because I got a hell of a scare with the with the first diagnosis. So I did a lot more research and I take notes at the meetings, I go to, telephone calls or whatever, and then I do my own independent research. And if, if, if, if it's convenient, I go to the there's the bladder cancer support group meetings, which is where I how I came to hear your research project.
Participant 008_2022AUBLC

Yeah, I think I've probably found myself becoming more affirmative and more speaking out, being my own advocate, asking lots more questions. Yeah. I think are definitely.
Carer 002_2022AUBLC

Participant describes decision-making changing over time as they are more focused on quality of life or impact of side effects

PARTICIPANT: And I think just being more well-informed, I can consider more things before I make a decision. Like I took my sister with me to the consult I had a couple of weeks ago to, to the surgeon who's *going to do my cystectomy. And, of course, you know, at the end of it all, he says, well, if that is what I need to know, is whether or not you, you want me to do the operation for you. And by that point, I'd decided because, you know, you just want to feel the same similar thing about having a face to face consult. If you just want to get a good feel about whether or not you feel this is the person. Are you happy to do this for you? Um, yeah, but I, you know, I came to that decision fairly quickly and my sister commented later that I mean, she, I think she was on the same page, especially if it's easy for her to say that I should have it because not having as much of it is not having her. She had her reasons for saying have it because she she's looking at saving my life or as I'm sort of considering more things. But it's more simplistic to her that she did say. Um, for, for a family that doesn't make, make decisions quickly. You made that decision quickly. But yeah, I, I had made that decision probably several months beforehand because my bladder function has declined so much that it has impacted on my, my life to the point where if I go to CITY I have to make sure I have no fluid for, you know, don't drink anything for 12 hours beforehand, so that I don't have to stop. Um, so am I. I can barely hold 100 mLs in my bladder. Now.*

INTERVIEWER: That sounds like it makes things a lot more complicated. Yeah.

PARTICIPANT: Yeah. So that's what sort of helped me come to the as well as time and also my life revolving around three monthly, um, anaesthetics. And um, and then between those three months is in intra-cystical therapy, which is becoming so my bladder has barely ever had the chance to, to feel normal again. And then when it didn't feel normal again, you think, well, okay, this is the rest of my life, so you got to make a decision. And so it was pretty. Yeah, I think I was. In a way, I've been fortunate that I've been able to ease my way into this decision, whereas some people who find they're muscle invasive, I said straight away, they don't have that luxury.
Participant 010_2022AUBLC

Well, we are more comfortable with it now, I guess. Like we've just gotten used to how it goes and know what we're in for. Unfortunately, the last one, though, was really it affected him much more than the first. Yeah. So that was a lot more severe. So I guess like the next one we'll be a little bit more, concerned, and worried about what's coming up, what sort of reaction he'll have
Carer 003_2022AUBLC

Participant describes decision-making changing over time as they base decisions more on their experience and judgement

Yes, I do. I don't trust my urologist. We're making more independent decisions of the urologist. And initially I trusted the GP, went to the you know, you got a look, you go to a GP and they refer you to a urologist. You don't kind of go, I don't know, you just go to who he said, right. And even he wanted feedback, so how have you found him? Because he said, you know, I refer people to him. And I said, well, this is you know, I don't think he's, I think he's loose with the truth. I don't like his bedside manner. I'm not saying he's not a great surgeon. He's probably a great surgeon. But I don't like his I don't like the way he talks to me and I don't like the way he communicates to me. And therefore, that's why I'm looking to go an alternate path. So it does change my decision making. Based upon those experiences, if I gelled with him, like if I had a, you know, if we had rapport. There's no rapport there. That's my point. Yeah. Because I don't trust him.
Participant 017_2022AUBLC

Well, I would, I would say in the same way. I've recently joined a couple of support groups over Zoom by the cancer support group. And I've heard other people talking about how they've done loads of research and they've got second and third opinions and they've had all sorts of treatment, but they're still got the cancer. And also, I've heard people on those calls talk about having a neobladder and, and how actually difficult that is to manage. So to be honest, I say it's not ideal to have this new sort of body, if you like, but I feel that it was certainly the best option for me and I haven't had to have any other treatment and hopefully I won't have to have any other treatment.
Participant 043_2022AUBLC

Participant describes decision-making changing over time and there is no particular reason noted
Oh, yeah. I've change the way I make decisions. In how I do things. And yes, I do change.
Participant 037_2022AUBLC

It's changed.
Carer 005_2022AUBLC

Table 4.7: Decision-making over time

Decision-making over time	All participants		Early		Invasive		Advanced		Person with bladder cancer		Carer		Female		Male	
	n=49	%	n=20	%	n=10	%	n=14	%	n=44	%	n=5	%	n=17	%	n=32	%
Participant describes no change in decision-making over time (Total)	28	57.14	12	60.00	6	60.00	9	64.29	27	61.36	**1**	**20.00**	**7**	**41.18**	21	65.63
Participant describes no change in decision-making over time as they have always taken advice of clinicians	11	22.45	4	20.00	3	30.00	4	28.57	11	25.00	**0**	**0.00**	4	23.53	7	21.88
Participant describes no change in decision-making over time and there is no particular reason noted	7	14.29	3	15.00	1	10.00	2	14.29	6	13.64	1	20.00	1	5.88	6	18.75
Participant describes no change in decision-making over time as they have always been informed/assertive	7	14.29	3	15.00	2	20.00	2	14.29	7	15.91	**0**	**0.00**	1	5.88	6	18.75
Participant describes decision-making changing over time (Total)	20	40.82	7	35.00	4	40.00	5	35.71	16	36.36	**4**	**80.00**	**9**	**52.94**	11	34.38
Participant describes decision-making changing over time as they are more informed and/or more assertive	13	26.53	6	30.00	**1**	**10.00**	4	28.57	11	25.00	**2**	**40.00**	5	29.41	8	25.00
Participant describes decision-making changing over time as they are more focused on quality of life or impact of side effects	3	6.12	2	10.00	0	0.00	0	0.00	2	4.55	1	20.00	2	11.76	1	3.13
Participant describes decision-making changing over time as they base decisions more on their experience and judgement	3	6.12	0	0.00	1	10.00	2	14.29	3	6.82	0	0.00	1	5.88	2	6.25
Participant describes decision-making changing over time and there is no particular reason noted	3	6.12	0	0.00	1	10.00	1	7.14	2	4.55	1	20.00	1	5.88	2	6.25
Other/no response	1	2.04	1	5.00	0	0.00	0	0.00	1	2.27	0	0.00	1	5.88	0	0.00

Decision-making over time	All participants		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=49	%	n=29	%	n=19	%	n=15	%	n=33	%	n=20	%	n=28	%
Participant describes no change in decision-making over time (Total)	28	57.14	19	65.52	**8**	**42.11**	10	66.67	17	51.52	13	65.00	14	50.00
Participant describes no change in decision-making over time as they have always taken advice of clinicians	11	22.45	7	24.14	4	21.05	3	20.00	8	24.24	4	20.00	7	25.00
Participant describes no change in decision-making over time and there is no particular reason noted	7	14.29	6	20.69	**0**	**0.00**	**4**	**26.67**	2	6.06	4	20.00	2	7.14
Participant describes no change in decision-making over time as they have always been informed/assertive	7	14.29	5	17.24	2	10.53	**4**	**26.67**	3	9.09	4	20.00	3	10.71
Participant describes decision-making changing over time (Total)	20	40.82	10	34.48	**10**	**52.63**	5	33.33	15	45.45	7	35.00	13	46.43
Participant describes decision-making changing over time as they are more informed and/or more assertive	13	26.53	10	34.48	**3**	**15.79**	**2**	**13.33**	11	33.33	6	30.00	7	25.00
Participant describes decision-making changing over time as they are more focused on quality of life or impact of side effects	3	6.12	1	3.45	2	10.53	1	6.67	2	6.06	1	5.00	2	7.14
Participant describes decision-making changing over time as they base decisions more on their experience and judgement	3	6.12	2	6.90	1	5.26	1	6.67	2	6.06	1	5.00	2	7.14
Participant describes decision-making changing over time and there is no particular reason noted	3	6.12	1	3.45	2	10.53	1	6.67	2	6.06	1	5.00	2	7.14
Other/no response	1	2.04	0	0.00	1	5.26	0	0.00	1	3.03	0	0.00	1	3.57

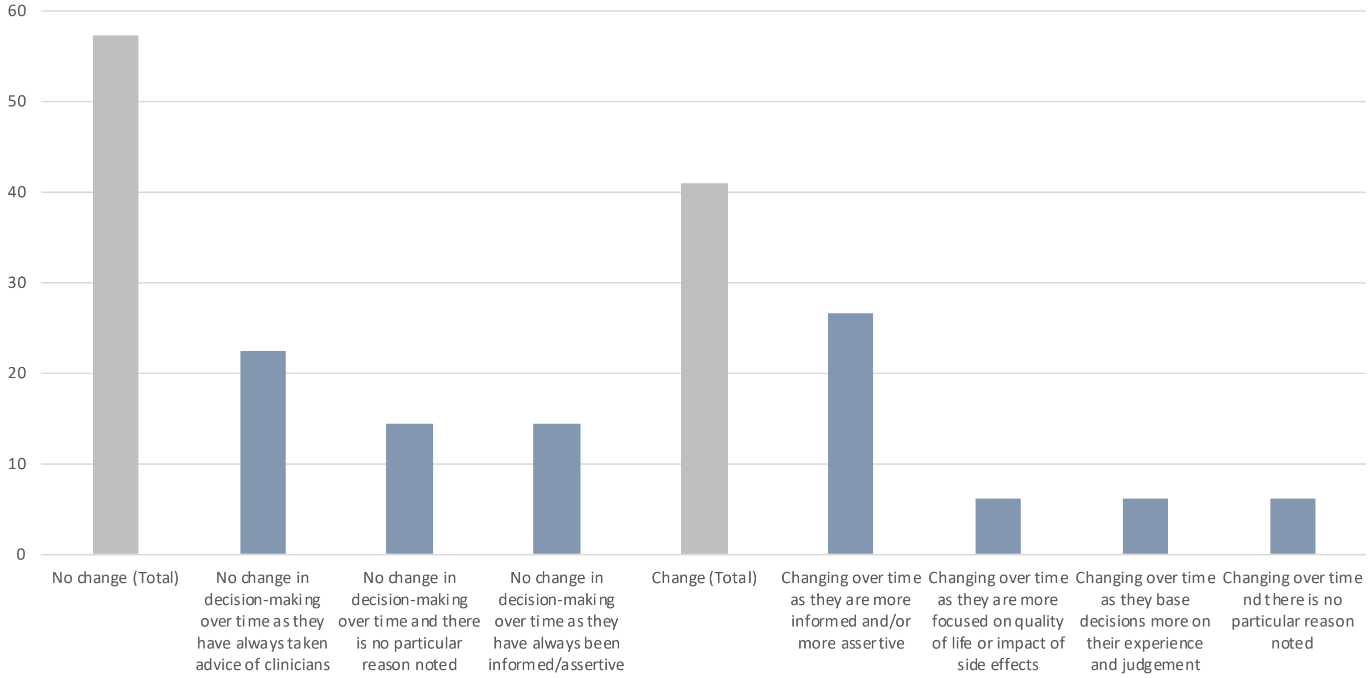


Figure 4.4: Decision-making over time

Table 4.8: Decision-making over time – subgroup variations

Decision-making over time	Reported less frequently	Reported more frequently
Participant describes no change in decision-making over time (Total)	Carer to someone with bladder cancer Female University	-
Participant describes decision-making changing over time (Total)	-	Carer to someone with bladder cancer Female University

Personal goals of treatment or care

Participants were asked what their own personal goals of treatment or care were. The most common response was wanting to be cancer free, avoid recurrence or increase longevity (n=20, 40.82%), and this was followed by wanting to improve their quality of life or return to normality (n=15, 30.61%). Other themes included wanting to minimise or avoid side effects (n=10, 20.41%), bladder preservation (n=8, 16.33%), wanting to be supported/reassured/informed by their healthcare team (n=6, 12.24%), and not having personal goals as they are guided by their doctor (n=5, 10.20%).

Participants describe wanting to be cancer free, avoid recurrence or increase longevity

My girls. Well. Uh, main one was just obviously try and keep my, keep my bladder. But the ultimate goal was to stay alive. I'm only 49, so I was. Whatever it takes. Um, you know, the fact that we, you know, because I've only got young children, I wanted to. Yeah, I want to see them finish school and achieve things. So that was my main goal was to stay alive. But then secondary to that was to keep my bladder. Um. I didn't really want to. Yeah. Have a, a bag or anything like that. So that was mainly it.
Participant 014_2022AUBLC

Oh, my goal was just to get rid of the cancer and those like, you know, not um, you know, if it's going to hurt, it's going to hurt. If it's going to be required for me to do things, I'll do it. It has to be done. So he had a very he had a very willing and accommodating patient. I'm also relatively young. For someone to have this. And so I think that made it, you know, I just you know, it was scary for me given how young I am, and just the not quite in common. And just so I was pretty, you know, the goal is simple. Just get rid of it, whatever it takes to do so.
Participant 024_2022AUBLC

Ah, well, of course the goal was to rid myself of the cancer for as long as possible. Obviously, the diagnosis, the prognosis is variable person to person. And depending on the type of cancer and the individuals that my expectation was that I could have a normal sort of life and, and somehow outlived the possibility of dying of bladder cancer.
029_2022AUBLC

Participant describes wanting to improve their quality of life or return to normality

I think I just have been through the whole thing, hoping and expecting to come out of it pretty much as I was before I went in, minus a couple of years of your life.
Participant 006_2022AUBLC

And what was my goal or the treatment? Yes, first firstly, my first the first and foremost was, was to be able to live and. Yeah. And to live a, aquiet life with some, some sort of quality attached to it, you know. Yeah. That was that was that never, ever going to be at the stage where we could turn and say, look, life is going to be normal again after this this happened. Um, but yeah, I was hoping that I would be able to lead a normal, active life.
Participant 035_2022AUBLC

PARTICIPANT: All I'd like to do is get, like I say, get back to about 80% of where I was, where I can actually do things without, without running out of breath. I realise with the operation there comes life changing elements, but at the end of the day it's a lot to be able to do stuff. With it without sort of having to rest every 20 minutes or so.
Participant 040_2022AUBLC

Participant describes wanting to minimise or avoid side effects of treatment for their condition

Okay. Well, I suppose my, my main goal at that point was to just keep my bladder. And, yeah, um, the further I got into the, um, this BCG therapy, the more you have, the more impact it has. Um, side effects wise. Um, so, yes. Then I. When it when it became, I think you maintenance dose is usually three. Your first induction is six. Six weekly doses. And then you have a break. And then when you have it again, it's three. So I got to the point with I can't remember how many along the line, but the third, the second or third dose, it has an a cumulative effect on your bladder up with those three weeks. And that was once when I just rang them up and say, look, I've still got haematuria and a lot of discomfort and I'm wondering whether I should be having the next dose. And they said, just leave it. And then I got to another point, which was, I think my very last go at BCG. It was unbearable. And I'm just. Yes. Very, very, very distressing to have it like it got 20 times to the toilet in the space of an hour. It's just so irritating. And I think at that point, too, I'd already had a recurrent so high grade. So it was obviously I'd become. Well, I'm assuming they use the word resistant to it, or it wasn't working for me anyway.
Participant 010_2022AUBLC

And the occupational therapist was really good too. She said to me, Are you just expecting to go back four days a week? I said, Oh, well, that was a plan. And she said, Well, that's really stupid, but you know, you're your own worst enemy. You need to go back one day a week and see how you go, and then two days a week, maybe for a couple of weeks and then build up

slowly and just see how you are. And, and I also, because I'd had 23 lymph nodes taken out, I went to see a lymphedema physio because I just wanted to get a baseline and make sure that if I got any leg swelling that she'd already seen me and to give me some exercises to make sure I didn't get lymphedema. And she said the same thing. She said, you're stupid, just going back straight away and, and you need to just grade it. So that was really helpful. And then it built up over a couple of months back to four days a week again. And so my goals were just getting back to work and managing to get through the day here was, you know, learning how to manage the bag and when to empty that sort of stuff and not have a leak. And, and then at home also done swimming and playing tennis this not that often but and walk the dogs all the time so and it's a bit scary start doing lifting, because the literature says you can get a hernia quite easily so I've done that slowly but now I come back to pretty much full strength again. I'm just a bit more careful now.
Participant 018_2022AUBLC

My personal goals is probably not to have treatment. Yeah, I don't. My body doesn't like. My body doesn't like. Artificial chemical stuff. So, so I react to a lot of things. I react to a lot of medications. And so it's a nightmare for me to be. To be trying to deal this way. It's bad enough if I have to go into hospital and what they want to give me and I argue because I'm going to react to it and know. Yes. So, so my goal is not is to monitor it and hopefully not to have to have treatment.
Participant 026_2022AUBLC

Participant describes wanting to preserve their bladder

Just to stay alive suppose at that time, just to stay alive. The main thing that I kept, well my main goal, my main goal is to retain my bladder. To not have a bag. That's my main goal.
Participant 001_2022AUBLC

I refused to cooperate with the surgery and insisted on a referral to an oncologist. So at that point they offered me what they call the tri modal option. So bladder salvage, which is what my main focus was on bladder salvage.
Participant 020_2022AUBLC

Um. Look, I think just the goals of going ahead was to stop the cancer from recurring really. And to avoid the need to have a radical cystectomy. I guess that was really the main. The main objective.
Participant 002_2022AUBLC

Participant describes no personal goals of treatment or care (no reason given)

There's been no. None.
Participant 008_2022AUBLC

PARTICIPANT: There's no it hasn't affected me at all. So I'm just, just planning for the next operation the rest of the year and then see what happens.

INTERVIEWER: And like any personal goals or treatment, like what you hope can achieve after the operation.

PARTICIPANT: No.
Participant 013_2022AUBLC

Participant describes wanting to be supported/reassured/informed by their healthcare team

Not. Certainly not. No, none of that. Certainly. I've talked about that with my wife. And, you know, what point would we give up BCG and just go for bladder removal? You know, if, if you know, if you're, you know, 12, 15 rounds of, you know, courses of BCG or whatever, you might go, are we kidding ourselves here? Because, you know, if you're two years into it and you still trying to solve this, maybe a bladder out would be a better outcome. But that has side effects. And we've talked about, you know, nerves, nerve saving surgery, if we had to get to that. Again, this has all been our own research, not really coming from the clinician himself, looked at, you know, blue light therapy for cystoscopy to have looked at. Are there any clinical trials have, you know, looked at all the various options. And again, that's all been my wife's work not really coming from the clinician himself he's very much of, well the next stage is BCG go off here, go see Dr. X and you know, they'll make that happen. And then I'll come back every three months and have a look and see in resect or whatever you need to do. And you know, it's all been very short term focussed, very like, let's just get past the next month, let's just get past the next month. You know, long term strategy, no long term options, no ever talk about survival options, that kind of stuff. Oh, he did explain, to be fair, he did explain, the difference is if I had muscle invasive what that meant in terms of immediate bladder loss, you know, those kind of things, the fact that, you know, he was going this is good news. You've got yes, you've got high grade between the two resections. He said it had come back and he had to, you know, go deeper and that's the

stuff. But he said it's still second histology came back as the same diagnosis, which was high grade non-muscle invasive. So he had explained what the other types could have been and what that would have meant for treatment. But in terms of mine he goes BCG is your next step.
Participant 017_2022AUBLC

That was that was that was six years ago. And all the cystoscopies have been then have been clear since then. They found, they did find something different. I should be about to say that they found and what I call it, that red my red marks on the bladder which they scraped. And set off the biopsy. But one thing they didn't tell me in in the March, in March when I had the urgent cystoscopy, they didn't tell me that the scab forms and once the scab falls off you can you can start peeing blood again, which happened about two weeks later after the cystoscopy happened in early April this year. And I just sort of I have got to come back. And I went to emergency. I spent 10 hours in emergency. They put a bloody catheter in me, which was agony. I had to have it taken out and, I just went home. I went home. I just said, I've got to go. I rang Dr NAME, and I saw Dr NAME. And he said, oh, that's the, that's the scab that forms. That happens quite regularly, quite often and you'll see blood for about a day or two. If they had to tell me that, you know, six, six weeks, two weeks prior, I wouldn't have spent 10 hours in emergency and had catheters put in me and all that sort of thing. So that's one thing he should, should have told me. Should have told me at the point when I had this could be a large issue. They definitely should have told me, you may, you may have some bleeding in a couple of weeks when we did the biopsy of the scab may cause you to bleed. So I just frankly, I just thought this is it that's going to come back. Could have come back. So my wife, she drove me to emergency 10 hours later. Because the doctors down there, they're only kids. You know, as I didn't like to say no, because I have this time we got to do this, we're going to see someone, all this sort of thing. And in the end, I just walked out. I spend so much time telling them, I just got to get going and I'll speak to my urologist tomorrow.
Participant 021_2022AUBLC

PARTICIPANT: My own goal is, was that I wanted the, the, the most appropriate treatment for my case because I that I somehow felt that the doctors there they want to influence you and that the. They would like to you to go to a particular have a particular treatment. But it may be best for you, but, sometimes, you know, the treatment, which is best for you, may not be so. You know what you want. So I just wanted to be aware that, you know, the main difference was radiation versus surgery and both have pros and cons. And I really wanted to be completely, very clearly informed. But because both treatments have got risk, it's not that one is right or wrong. It's what you are prepared to pay, what risk you want to take.
Participant 028_2022AUBLC

Participant describes no personal goals as they are guided by their doctor

Well, it was always I know the BCG is the standard of treatment and I wasn't any issue about it. And I would say that I was a scare already a little bit scared of the side effect. But anyway, well, doctor said if I need it and yeah. So I accepted the BCG treatment.
Participant 015_2022AUBLC

Well, not being aware of anything. I just was guided by the doctor.
Participant 027_2022AUBLC

Look, I, I actually probably didn't. I think I just put my trust into the urologist. Um, I knew there was neo bladders and things like that, but he kind of just said no. Um, you know, like, because it was muscle invasive, there was the bladder had to, there was no the ileal conduit was the correct way to go.
Participant 039_2022AUBLC

Table 4.9: Personal goals of treatment or care

Personal goals of treatment	All participants		Early		Invasive		Advanced		Person with bladder cancer		Carer		Female		Male	
	n=49	%	n=20	%	n=10	%	n=14	%	n=44	%	n=5	%	n=17	%	n=32	%
Participants describe wanting to be cancer free, avoid recurrence or increase longevity	20	40.82	7	35.00	**6**	**60.00**	5	35.71	18	40.91	2	40.00	**5**	**29.41**	15	46.88
Participant describes wanting to improve their quality of life or return to normality	15	30.61	6	30.00	**2**	**20.00**	**6**	**42.86**	14	31.82	**1**	**20.00**	6	35.29	9	28.13
Participant describes wanting to minimise or avoid side effects of treatment for their condition	10	20.41	3	15.00	3	30.00	**1**	**7.14**	7	15.91	**3**	**60.00**	2	11.76	8	25.00
Participant describes wanting to preserve their bladder	8	16.33	**6**	**30.00**	1	10.00	1	7.14	8	18.18	**0**	**0.00**	3	17.65	5	15.63
Participant describes no personal goals of treatment or care (no reason given)	6	12.24	3	15.00	1	10.00	2	14.29	6	13.64	**0**	**0.00**	2	11.76	4	12.50
Participant describes wanting to be supported/reassured/informed by their healthcare team	6	12.24	1	5.00	**4**	**40.00**	1	7.14	6	13.64	**0**	**0.00**	2	11.76	4	12.50
Participant describes no personal goals as they are guided by their doctor	5	10.20	1	5.00	1	10.00	2	14.29	4	9.09	1	20.00	3	17.65	2	6.25

Personal goals of treatment	All participants		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=49	%	n=29	%	n=19	%	n=15	%	n=33	%	n=20	%	n=28	%
Participants describe wanting to be cancer free, avoid recurrence or increase longevity	20	40.82	13	44.83	6	31.58	**9**	**60.00**	**10**	**30.30**	9	45.00	10	35.71
Participant describes wanting to improve their quality of life or return to normality	15	30.61	9	31.03	6	31.58	5	33.33	10	30.30	8	40.00	7	25.00
Participant describes wanting to minimise or avoid side effects of treatment for their condition	10	20.41	8	27.59	2	10.53	3	20.00	7	21.21	5	25.00	5	17.86
Participant describes wanting to preserve their bladder	8	16.33	4	13.79	4	21.05	1	6.67	7	21.21	**1**	**5.00**	7	25.00
Participant describes no personal goals of treatment or care (no reason given)	6	12.24	2	6.90	4	21.05	1	6.67	5	15.15	2	10.00	4	14.29
Participant describes wanting to be supported/reassured/informed by their healthcare team	6	12.24	3	10.34	3	15.79	**4**	**26.67**	2	6.06	3	15.00	3	10.71
Participant describes no personal goals as they are guided by their doctor	5	10.20	2	6.90	3	15.79	1	6.67	4	12.12	**0**	**0.00**	5	17.86

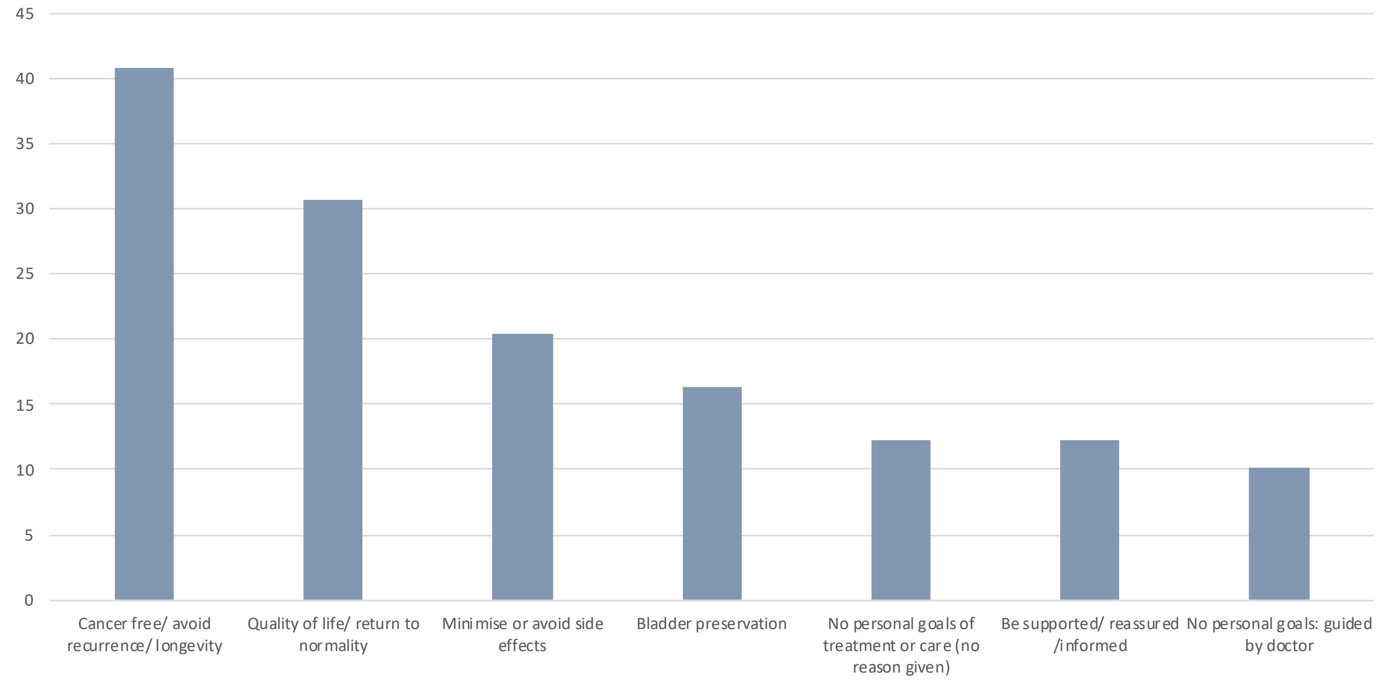


Figure 4.5: Personal goals of treatment or care

Table 4.10: Personal goals of treatment or care – subgroup variations

Personal goals of treatment	All participants		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=49	%	n=29	%	n=19	%	n=15	%	n=33	%	n=20	%	n=28	%
Participants describe wanting to be cancer free, avoid recurrence or increase longevity	20	40.82	13	44.83	6	31.58	**9**	**60.00**	**10**	**30.30**	9	45.00	10	35.71
Participant describes wanting to improve their quality of life or return to normality	15	30.61	9	31.03	6	31.58	5	33.33	10	30.30	8	40.00	7	25.00
Participant describes wanting to minimise or avoid side effects of treatment for their condition	10	20.41	8	27.59	2	10.53	3	20.00	7	21.21	5	25.00	5	17.86
Participant describes wanting to preserve their bladder	8	16.33	4	13.79	4	21.05	1	6.67	7	21.21	**1**	**5.00**	7	25.00
Participant describes no personal goals of treatment or care (no reason given)	6	12.24	2	6.90	4	21.05	1	6.67	5	15.15	2	10.00	4	14.29
Participant describes wanting to be supported/reassured/informed by their healthcare team	6	12.24	3	10.34	3	15.79	**4**	**26.67**	2	6.06	3	15.00	3	10.71
Participant describes no personal goals as they are guided by their doctor	5	10.20	2	6.90	3	15.79	1	6.67	4	12.12	**0**	**0.00**	5	17.86

Section 5

Treatment

Section 5: Experience of treatment

Access to healthcare professionals

Participants noted in the online questionnaire the healthcare professionals they had access to for the treatment and management of their condition.

Almost all participants had access to a urologist (n=41, 97.62%), and a general practitioner (GP) (n=40, 95.24%) A total of 26 participants (61.90%) noted that they had access to a nurse for their bladder cancer, there were 14 participants (33.33%) that had a stoma nurse, 17 participants (40.48%) that had a registered nurse, and 7 participants that had a nurse care coordinator (16.67%)

There were 13 participants (30.95%) treated by a physiotherapist, 8 participants (19.05%) treated by a Counsellor or had psychological support, and 5 participants (11.90%) treated by a dietician.

Health care system

In the online questionnaire, participants were asked questions about the healthcare system they used, about private insurance and about whether they were treated as a public or private patient.

The majority of participants had private health insurance (n=27, 64.29%). Throughout their treatment, there were 16 participants (38.10%) that were treated mostly as a private patient, 19 participants (45.24%) were mostly treated as a public patient, and there were 7 participants (16.67%) that were equally treated as a private and public patient.

Throughout their treatment, there were 19 participants (45.24%) that were treated mostly in the private hospital system, 17 participants (40.48%) were mostly treated in the public system, and there were 6 participants (14.29%) that were equally treated in the private and public systems.

Affordability of healthcare

Participants were asked a series of questions about affordability of healthcare in the online questionnaire. The first question was about having to delay or cancer healthcare appointments because they were unable to afford them. Almost all the participants never or rarely had to delay or cancel appointments due to affordability (n = 40, 95.24%).

The next question was about the ability to fill prescriptions. Almost all of the participants never or rarely were unable to fill prescriptions (n=41, 97.62%).

The third question was about the affordability of basic essentials such as such as food, housing and power. There were 38 participants (90.48%) that never or rarely had trouble paying for essentials, and 2 participants (4.76%) that sometimes found it difficult, and 2 participants (4.76%) often or very often found it difficult to pay for basic essentials.

The final question was about paying for additional carers for themselves or for their family, no participants had paid for additional carers.

Cost of condition

In the online questionnaire, participants estimated the amount they spend per month due to their condition, including doctors' fees, transport, carers, health insurance gaps and complementary therapies. Where the response was given in a dollar amount, it is included below.

The most common amount was $50 or less (n=9, 21.43%), followed by between $51 to $100 (n=7, 16.67%), and $101 to $250 (n=5, 11.90%). There were 2 participants (4.76%), that spent $501 or more a month.

Burden of cost

As a follow up question, for participants that had monthly expenses due to their condition, participants were asked if the amount spent was a burden.

The amount spent was a slightly or not at all significant burden for 36 participants (85.71%), somewhat significant for 4 participants (9.52%), and moderately or extremely significant burden for 2 participants (4.76%).

Changes to employment status

Participants were asked, in the online questionnaire, if they had any changes to their employment status due to their condition. Participants were able to choose multiple changes to employment.

Work status for 7 participants (16.67%) had not changed since diagnosis, and 18 participants (42.86%) were retired or did not have a job. There were 4 participants (9.52%) had to quit their job, 6 participants (14.29%) reduced the number of hours they worked, and 2 participants (4.76%) that accessed their superannuation early. There were 5 participants (11.90%) that took leave from work without pay, and 10 participants (23.81%) that took leave from work with pay.

Changes to carer/partner employment status

Participants were asked, in the online questionnaire, if they had any changes to the employment status of their care or partner due to their condition. Participants were able to choose multiple changes to employment.

Most commonly, participants had partners or carers that did not change their work status due to their condition (n=27, 64.29%). There was a single participant (2.38%) whose partner reduced the number of hours they worked, and 2 partners, (4.76%) that quit their job. No partners participants took leave without pay, and there were 2 partners (4.76%) that took leave with pay.

Reduced income due to condition

Participants noted in the online questionnaire details about and changes to income due to the bladder cancer diagnosis.

Approximately a third of the participants (n=12, 28.57%) indicated in the online questionnaire that they had a reduced family income due to their condition.

Estimated reduction monthly income

As a follow up question, participants were asked if their family or household income had reduced due to their condition. Most commonly, participants monthly income was reduced by more than $1000 per month (n=5, 11.90%), or reduced by between $501 to $1000 per month (n=4, 9.52%).

Summary of treatment

Participants noted in the online questionnaire the different treatments, they had since diagnosis with their condition.

All participants were treated for bladder cancer. There were 40 participants (95.24%) that had surgery, 20 participants (47.62%) that had chemotherapy and 24 participants (57.14%) that had Bacillus Calmetter-Guérin (BCG), 3 participants had radiotherapy (7.14%), and a single participant had immunotherapy (2.38%)

Summary of surgery

In the online questionnaire, participants noted the number of operations (excluding biopsies) that they had for their condition.

There were 40 participants (95.24%) that had surgery for their condition (excluding biopsies). There were 16 participants (38.10%) that had one operation, 9 participants (21.43%) that had two operations, 4 participants (9.52%) that had three operations, and 11 participants (26.19%) that had four or more operations.

Most common types of surgery

Participants completed a series of questions about surgery, including type of surgery, quality of life, and effectiveness of surgery.

There were 40 participants (95.24%) that had surgery for their condition. The most common type of surgery was transurethral resection of bladder tumour (TURBT) (n=,30, 71.43%), followed by radical cystectomy (n=19, 45.24%), and urostomy (n= 15, 35.71%).

Quality of life and effectiveness of surgery

Quality of life was rated on a Likert scale from one to seven, where one is “Life was very distressing” and seven is “Life was great”. Effectiveness of treatment was rated on a five-point scale where one is ineffective, and five is very effective. Values are calculated where there was adequate data available (five or more participants).

Median quality of life from surgery ranged from 2.00 to 5.00, in the life was distressing to good range. The median effectiveness of all surgery was between 3.50 to 5.00, in the moderately to very effective range.

On average, quality of life from transurethral resection of bladder tumour (TURBT) was in the 'life was a little distressing' range (median=3.00, IQR = 1.00), and was found to be moderately effective to effective (median=3.50, IQR=2.75).

On average, quality of life from radical cystectomy was in the 'life was distressing' range (median=2.00, IQR=1.00), and was found to be very effective (median=5.00, IQR=0.00).

On average, quality of life from urostomy was in the 'life was good' range (median=5.00, IQR=1.00), and was found to be very effective (median=5.00, IQR=0.00).

Summary of drug treatments

Participants completed a series of questions about drug treatments, including type of treatment, quality of life, and effectiveness of treatment.

There were 20, participants (47.62%) that had chemotherapy. The most common types of chemotherapy were MVAC chemotherapy (methotrexate, vinblastine, doxorubicin/ Adriamycin, and cisplatin), (n=5, 11.90%), and Gemcitabine with cisplatin n=5,11.90%). There were 24 participants (57.14%) that had Bacillus Calmetter-Guérin (BCG).

Median quality of life from drug treatments ranged from 1 to 4, in the life was very distressing to good range. The median effectiveness of all surgery was between 2.5 to 4, in the somewhat effective to effective range.

On average, quality of life from Bacillus Calmetter-Guérin (BCG) was in the 'life was a little distressing to average' range (median=3.50, IQR=2.00), and was found to be somewhat to moderately effective (median=2.50 , IQR=3.25).

On average, quality of life from methotrexate, vinblastine, doxorubicin/Adriamycin, and cisplatin was in the 'life was average' range (median=4.00, IQR=2.00), and was found to be effective (median=4.00, IQR=1.00).

On average, quality of life from gemcitabine with cisplatin was in the 'life was very distressing' range (median=1.00, IQR=2.00), and was found to be effective (median=4.00, IQR=1.00).

Clinical trials discussions

In the online questionnaire, participants were asked if they had discussions with their doctor about clinical trials, and if they did, who initiated the discussion.

There was a total of 10 participants (23.81%) that had discussions about clinical trials, 5 participants (11.90%) had brought up the topic with their doctor, and the doctor of 5 participants (11.90%) brought up the topic. The majority of participants had not spoken to anyone about clinical trials (n=32, 76.19%).

Clinical trial participation

As a follow up question, participants were asked if they had taken part in a clinical trial, and if they had not taken part if they were interested in taking part.

There were 5 participants (11.90%) that had taken part in a clinical trial, 21 participants (50.00%) that would like to take part in a clinical trial if there was a suitable one, and 16 participants, that have not participated in a clinical trial and do not want to (38.10%).

Description of mild side effects

In the structured interview, participants were asked how they would describe the term ‘mild side effects’. The most common description of ‘mild side effects’ was a specific side effect as an example (n=36, 73.47%). This was followed by describing ‘mild side effects’ as those that can be self-managed (n=10, 20.41%), those that do not interfere with daily life (n=9, 18.37%), and as those that have a short duration or are reversable (n=7, 14.29%).

Of those who described a specific side effect, the most commonly described side effects were fatigue or lethargy (n=11, 22.45%%), mild pain or aches (n=7, 14.29%) and nausea (n=6, 12.24%). Other side effects described by fewer than 5 participants, included hair loss, stoma bag/irritation/leaks, emotion/mental impact, and cystitis/UTIs.

Description of severe side effects

In the structured interview, participants were asked how they would describe the term ‘severe side effects’. The most common description of ‘severe side effects’ was a specific side effect as an example (n=34, 69.39%). Other descriptions of ‘severe side effects’ included those that impact everyday life/ability to conduct activities of daily living (n=9, 18.37%), and those that are long lasting (n=6, 12.24%). There were 6 participants (12.24%) that were unable to describe severe side effects as they had not experienced them.

Of those who described a specific side effect, the most commonly described side effects were pain (n=18, 36.73%), the emotional or mental impact of the condition, (n=7, 14.29%), and pain when urinating (n=5, 10.20%). Other side effects described by fewer than 5 participants, included fatigue, nausea, fever or infection, and incontinence.

Adherence to treatment

Participants were asked in the structured interview what influences their decision to continue with a treatment regime. The most common themes described were adhering to treatment as per the advice of their specialist/as long as prescribed (n=20, 40.82%), and adhering to treatment as long as treatment is working (n=16, 32.65%). This was followed by adhering to treatment as long as side effects are tolerable (n=12, 24.49%%), adhering to treatment for a specific amount of time (n=11, 22.45%), and 7 participants (14.29%) described not giving up on any treatments.

Where participants stated a specific amount of time to adhere to a treatment, the most common amount of time was two to three weeks.

What needs to change to feel like treatment is working

Participants were asked to describe what needs to change to feel like treatment is effective. The most common response from 24 participants (48.89%) was needing to experience evidence of stable disease/no disease progression. There were 14 participants (28.57%) that reported needing to experience a reduction in physical signs/reduced side effects, and 13 participants (26.53%) needed to see specific symptom reduction. The most common specific symptoms were nausea, aches and pains, fatigue and lethargy, and muscle cramping.

What would it mean if treatment worked

Participants were asked what it would mean to them if their treatment worked. The most common response from 16 participants (32.65%) was treatment allowing them to do everyday activities/ return to normal life. There were 12 participants (24.49%) that reported treatment working as having a positive impact on their mental health, 8 participants (16.33%) described treatment leading to a reduction in symptoms/side effects, and 8 participants (16.33%) described treatment allowing them to engage more with social activities and family life. Other participants described that treatment would allow them to keep their bladder (n=6, 12.24%), and allow them to do more exercise (n=6, 12.24%).

Access to healthcare professionals

Participants noted in the online questionnaire the healthcare professionals they had access to for the treatment and management of their condition.

Almost all participants had access to a urologist (n=41, 97.62%), and a general practitioner (GP) (n=40, 95.24%) A total of 26 participants (61.90%) noted that they had access to a nurse for their bladder cancer, there were 14 participants (33.33%) that had a stoma nurse, 17 participants (40.48%) that had a registered nurse, and 7 participants that had a nurse care coordinator (16.67%)

There were 13 participants (30.95%) treated by a physiotherapist, 8 participants (19.05%) treated by a Counsellor or had psychological support, and 5 participants (11.90%) treated by a dietician (Table 5.1, Figure 5.1).

Table 5.1: Access to healthcare professionals

Healthcare professional	Number (n=42)	Percent
Urologist	41	97.62
Medical Oncologist	16	38.10
Radiation Oncologist	5	11.90
Other specialist	4	9.52
Geneticist	1	2.38
General Practitioner (GP)	40	95.24
Palliative care	1	2.38
Registered Nurse	17	40.48
Stoma nurse	14	33.33
Nurse Care Coordinator	7	16.67
Physiotherapy	13	30.95
Counselling or psychological support	8	19.05
Dietician	5	11.90
Naturopath	1	2.38
Chiropractor	1	2.38

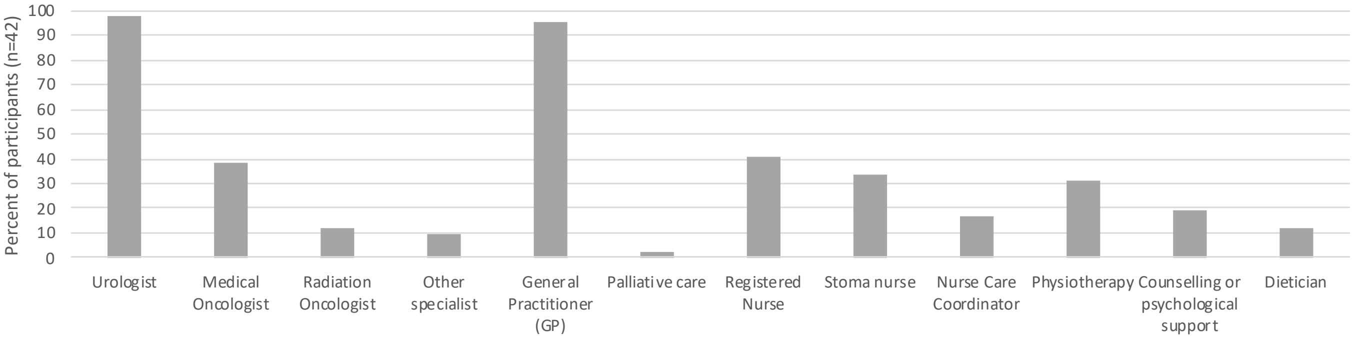


Figure 5.1: Access to healthcare professionals

Health care system

In the online questionnaire, participants were asked questions about the healthcare system they used, about private insurance and about whether they were treated as a public or private patient (Table 5.2, Figures 5.2 and 5.3).

The majority of participants had private health insurance (n=27, 64.29%). Throughout their treatment, there were 16 participants (38.10%) that were treated mostly as a private patient, 19 participants (45.24%) were mostly treated as a public patient, and there were 7 participants (16.67%) that were equally treated as a private and public patient.

Throughout their treatment, there were 19 participants (45.24%) that were treated mostly in the private hospital system, 17 participants (40.48%) were mostly treated in the public system, and there were 6 participants (14.29%) that were equally treated in the private and public systems.

Table 5.2: Health care system

Health care services	Response	Number (n=42)	Percent
Private health insurance	No	15	35.71
	Yes	27	64.29
Throughout your treatment in hospital, have you most been treated as a public or a private patient	Equally as a public and private patient	7	16.67
	Private patient	16	38.10
	Public patient	19	45.24
Which hospital system have you primarily been treated in	Both public and private	6	14.29
	Private	19	45.24
	Public patient	17	40.48

Figure 5.2: Health insurance

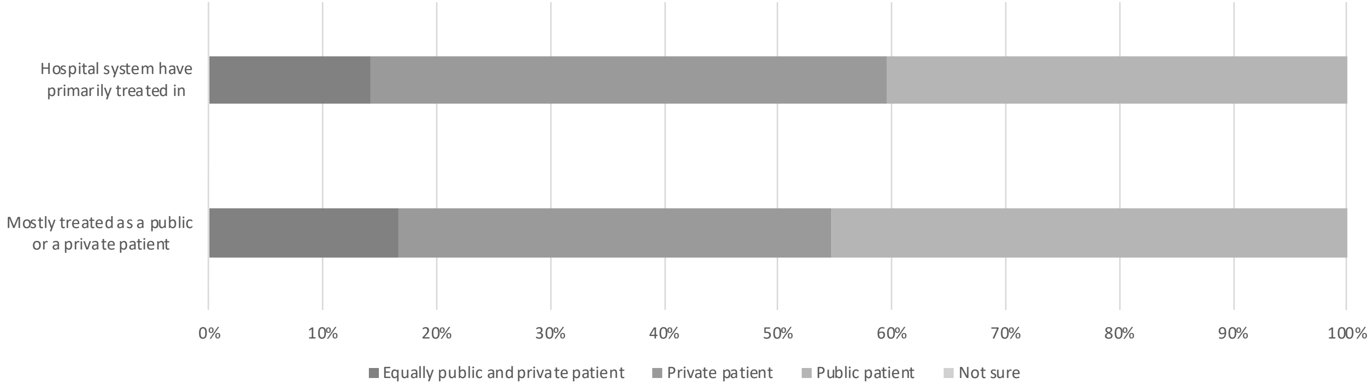


Figure 5.3: Hospital system

Affordability of healthcare

Participants were asked a series of questions about affordability of healthcare in the online questionnaire (Table 5.3, Figure 5.4).

The first question was about having to delay or cancer healthcare appointments because they were unable to afford them. Almost all the participants never or rarely had to delay or cancel appointments due to affordability (n = 40, 95.24%).

The next question was about the ability to fill prescriptions. Almost all of the participants never or rarely were unable to fill prescriptions (n=41, 97.62%).

The third question was about the affordability of basic essentials such as such as food, housing and power. There were 38 participants (90.48%) that never or rarely had trouble paying for essentials, and 2 participants (4.76%) that sometimes found it difficult, and 2 participants (4.76%) often or very often found it difficult to pay for basic essentials.

The final question was about paying for additional carers for themselves or for their family, no participants had paid for additional carers.

Table 5.3: Affordability of healthcare

Health services and insurance	Response	Number (n=42)	Percent
Delay or cancel healthcare appointments due to affordability	Never	38	90.48
	Rarely	2	4.76
	Sometimes	1	2.38
	Often	1	2.38
	Very often	0	0.00
Did not fill prescriptions due to cost	Never	40	95.24
	Rarely	1	2.38
	Sometimes	1	2.38
	Often	0	0.00
	Very often	0	0.00
Difficult to pay for basic essentials	Never	31	73.81
	Rarely	7	16.67
	Sometimes	2	4.76
	Often	2	4.76
	Very often	0	0.00
Pay for additional carers for self or family	Yes	0	0.00
	No	42	100.00

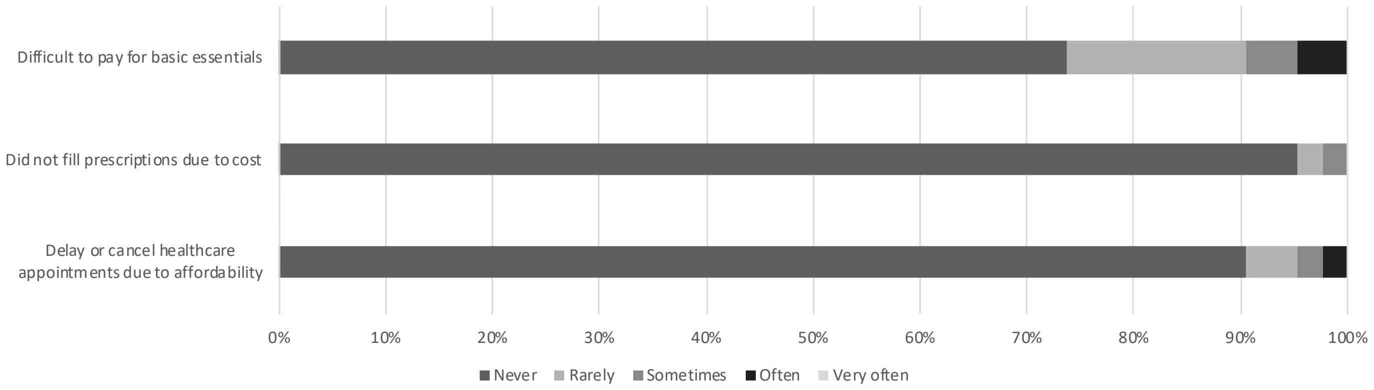


Figure 5.4: Affordability of healthcare

Cost of condition

In the online questionnaire, participants estimated the amount they spend per month due to their condition, including doctors' fees, transport, carers, health insurance gaps and complementary therapies. Where the response was given in a dollar amount, it is included below (Table 5.4, Figure 5.5).

The most common amount was $50 or less (n=9, 21.43%), followed by between $51 to $100 (n=7, 16.67%), and $101 to $250 (n=5, 11.90%). There were 2 participants (4.76%), that spent $501 or more a month.

Burden of cost

As a follow up question, for participants that had monthly expenses due to their condition, participants were asked if the amount spent was a burden (Table 5.5, Figure 5.6).

The amount spent was a slightly or not at all significant burden for 36 participants (85.71%), somewhat significant for 4 participants (9.52%), and moderately or extremely significant burden for 2 participants (4.76%) (Table 5.10, Figure 5.9).

Table 5.4: Estimated monthly out of pocket expenses due to condition

Estimated monthly out of pocket expenses	Number (n=42)	Percent
$0	7	16.67
$50 or less	9	21.43
$51 to $100	7	16.67
$101 to $250	5	11.90
$251 to $500	5	11.90
$501 or more	2	4.76
Not sure	7	16.67

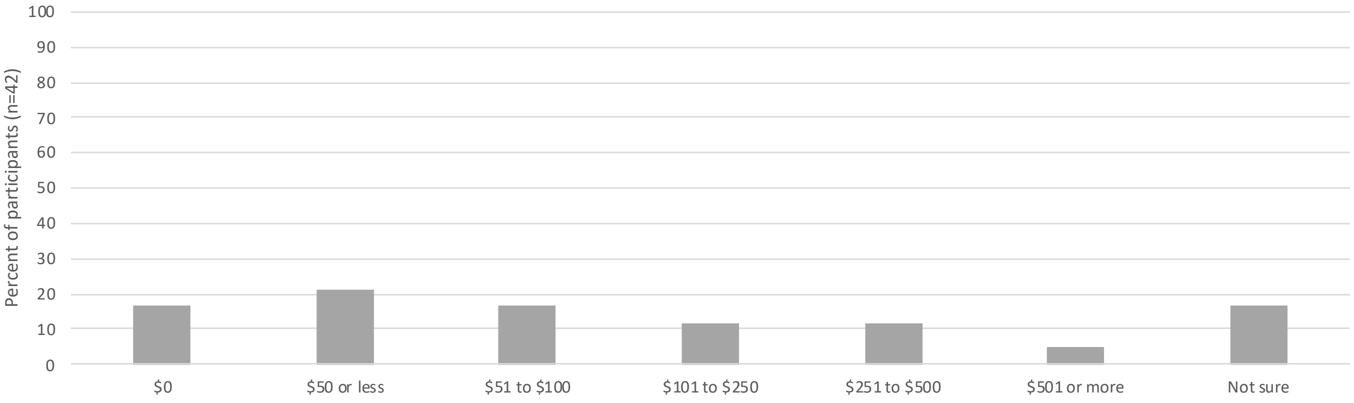


Figure 5.5: Estimated monthly out of pocket expenses due to condition

Table 5.5: Burden of out-of-pocket expenses due to condition

Burden of out of pocket expenses	Number (n=42)	Percent
Extremely significant	1	2.38
Moderately significant	1	2.38
Somewhat significant	4	9.52
Slightly significant	16	38.10
Not at all significant	20	47.62

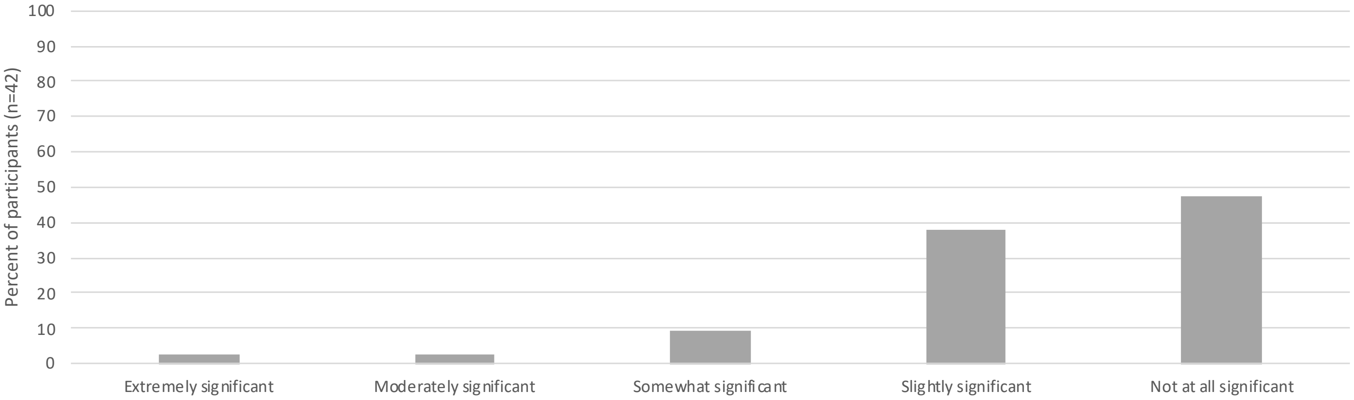


Figure 5.6: Burden of out-of-pocket expenses due to condition

Changes to employment status

Participants were asked, in the online questionnaire, if they had any changes to their employment status due to their condition. Participants were able to choose multiple changes to employment (Table 5.6, Figure 5.7).

Work status for 7 participants (16.67%) had not changed since diagnosis, and 18 participants (42.86%) were retired or did not have a job. There were 4 participants (9.52%) had to quit their job, 6 participants (14.29%) reduced the number of hours they worked, and 2 participants (4.76%) that accessed their superannuation early. There were 5 participants (11.90%) that took leave from work without pay, and 10 participants (23.81%) that took leave from work with pay.

Changes to carer/partner employment status

Participants were asked, in the online questionnaire, if they had any changes to the employment status of their care or partner due to their condition. Participants were able to choose multiple changes to employment. (Table 5.7, Figure 5.8).

Most commonly, participants had partners or carers that did not change their work status due to their condition (n=27, 64.29%). There was a single participant (2.38%) whose partner reduced the number of hours they worked, and 2 partners, (4.76%) that quit their job. No partners participants took leave without pay, and there were 2 partners (4.76%) that took leave with pay.

Table 5.6: Changes to employment status

Changes in work status due to condition	Number (n=42)	Percent
Work status has not changed	7	16.67
Retired or did not have a job	18	42.86
Had to quit job	4	9.52
Reduced number of hours worked	6	14.29
Leave from work without pay	5	11.90
Leave from work with pay	10	23.81
Accessed Superannuation early due to condition	2	4.76

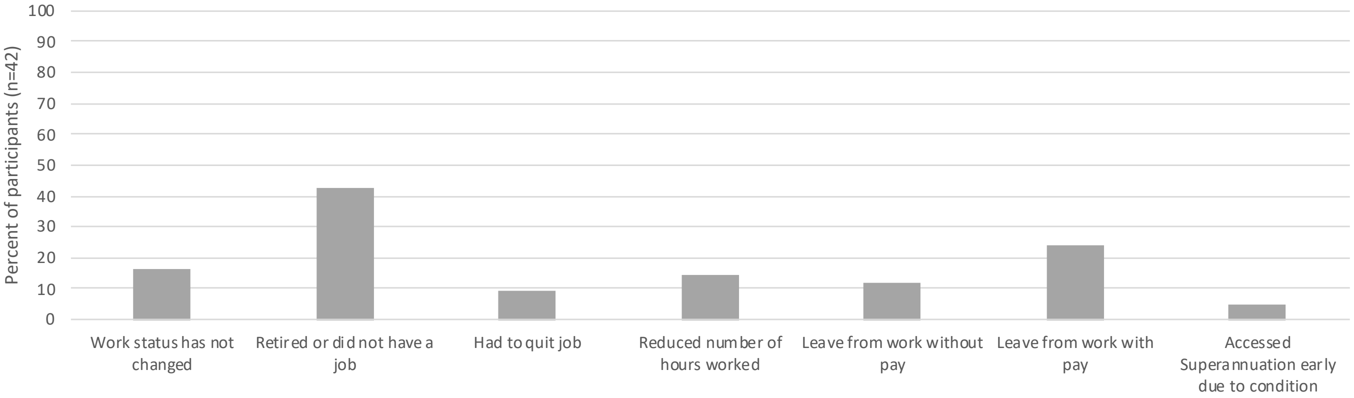


Figure 5.7: Changes to employment status

Table 5.7: Changes to care/partner employment status

Changes to care/partner employment status	Number (n=42)	Percent
Work status has not changed	27	64.29
Retired or did not have a job	10	23.81
Had to quit job	2	4.76
Reduced number of hours worked	1	2.38
Leave from work without pay	0	0.00
Leave from work with pay	2	4.76

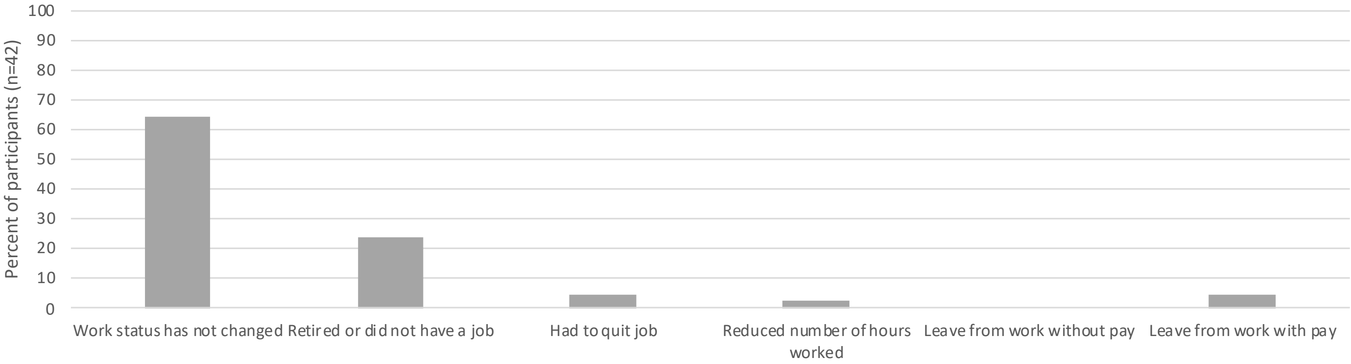


Figure 5.8: Changes to care/partner employment status

Reduced income due to condition

Participants noted in the online questionnaire details about and changes to income due to the bladder cancer diagnosis.

Approximately a third of the participants (n=12, 28.57%) indicated in the online questionnaire that they had a reduced family income due to their condition.

Estimated reduction monthly income

As a follow up question, participants were asked if their family or household income had reduced due to their condition. Where a dollar amount was given, it is included below (Table 5.8, Figure 5.9).

Most commonly, participants monthly income was reduced by more than $1000 per month (n=5, 11.90%), or reduced by between $501 to $1000 per month (n=4, 9.52%).

Table 5.8: Estimated monthly loss of income

Estimated monthly loss of income	Number (n=42)	Percent
$0	28	66.67
$500 or less	3	7.14
$501 to $1000	4	9.52
$1001 or more	5	11.90
Not sure	2	4.76

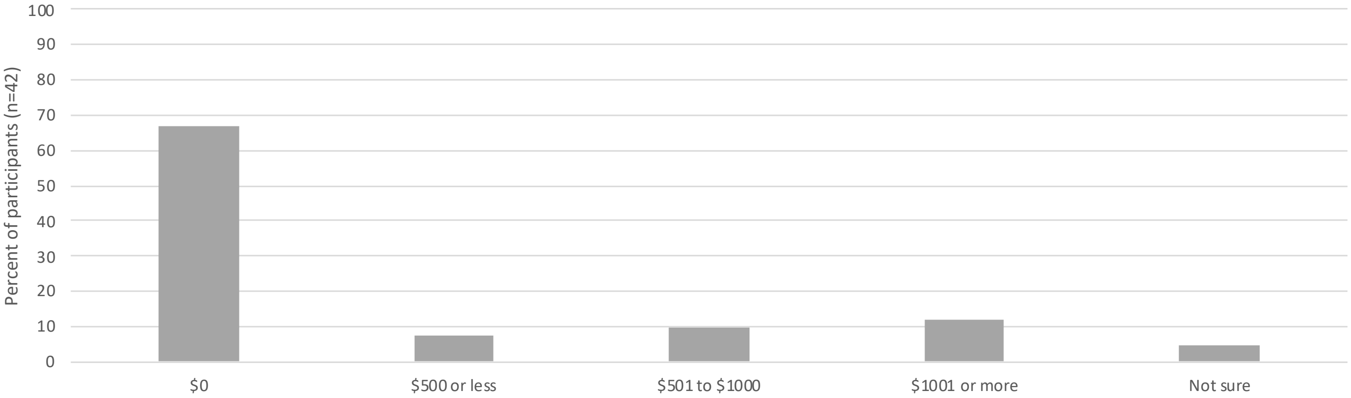


Figure 5.9: Estimated monthly loss of income

Summary of treatment

Participants noted in the online questionnaire the different treatments, they had since diagnosis with their condition (Table 5.9, Figure 5.10).

All participants were treated for bladder cancer. There were 40 participants (95.24%) that had surgery, 20 participants (47.62%) that had chemotherapy and 24 participants (57.14%) that had Bacillus Calmetter-

Guérin (BCG), 3 participants had radiotherapy (7.14%), and a single participant had immunotherapy (2.38%)

Table 5.9: Summary of treatment

Treatments overview	Number (n=42)	Percent
No treatment	**0**	**0.00**
Surgery	**40**	**95.24**
Transurethral resection of bladder tumour (TURBT)	30	71.43
Radical cystectomy	19	45.24
Urostomy	15	35.71
Bladder reconstruction	4	9.52
Urinary diversion	2	4.76
Surgery for metastases	2	4.76
Partial cystectomy	1	2.38
Fistula repair	1	2.38
nephrostomy stents	1	2.38
Stoma moved	1	2.38
Ureter reattachment	1	2.38
Chemotherapy	20	47.62
MVAC chemotherapy (Methotrexate, vinblastine, doxorubicin/adriamycin, and cisplatin)	5	11.90
Gemcitabine with cisplatin	5	11.90
Mitomycin with fluorouracil (5FU)	3	7.14
CMV chemotherapy (Cisplatin, methotrexate, vinblastine)	2	4.76
Gemcitabine and Docetaxel	2	4.76
Cisplatin	1	2.38
5 FU	1	2.38
Gemcitabine	1	2.38
Gemcitabine and mitomycin	1	2.38
Carboplatin and etoposide	1	2.38
Carboplatin	1	2.38
Gemcitabine with carboplatin	1	2.38
Carboplatin with either paclitaxel or docetaxel	0	0.00
Cisplatin with fluorouracil (5FU)	0	0.00
Immunotherapy	**1**	**2.38**
Pembrolizumab	1	2.38
Bacillus Calmetter-Guérin (BCG)	**24**	**57.14**
Radiotherapy	**3**	**7.14**

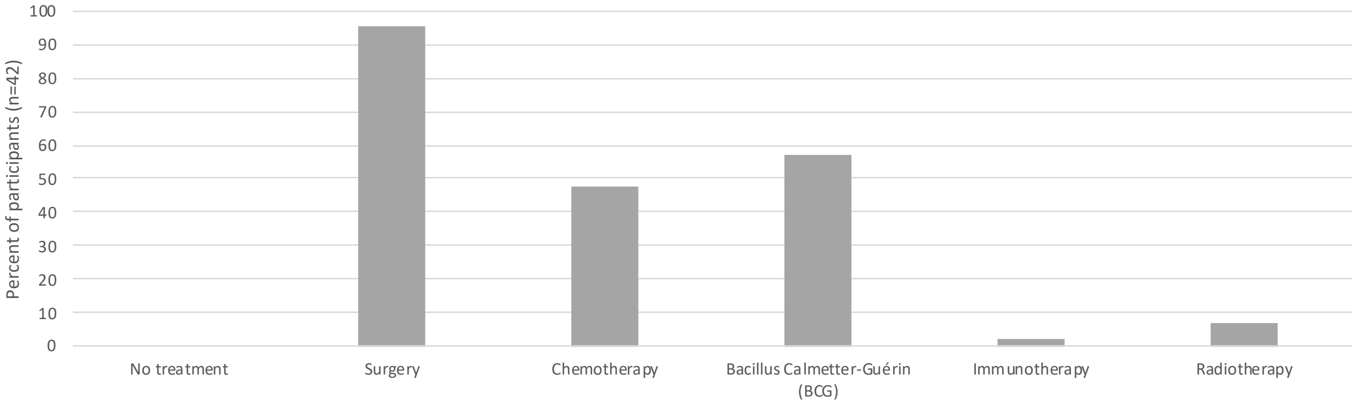


Figure 5.10: Summary of treatment

Summary of surgery

In the online questionnaire, participants noted the number of operations (excluding biopsies) that they had for their condition (Table 5.10, Figure 5.11).

There were 40 participants (95.24%) that had surgery for their condition (excluding biopsies). There were 16 participants (38.10%) that had one operation, 9 participants (21.43%) that had two operations, 4 participants (9.52%) that had three operations, and 11 participants (26.19%) that had four or more operations.

Table 5.10: Number of surgeries

Number of operations (excluding biopsy)	Number (n=42)	Percent
0	2	4.76
1	16	38.10
2	9	21.43
3	4	9.52
4 or more	11	26.19

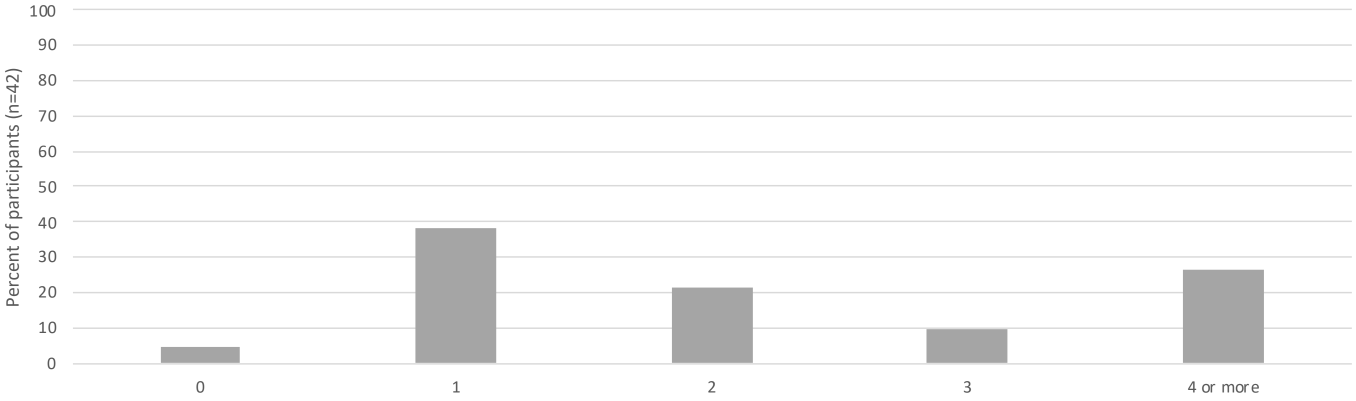


Figure 5.11: Number of surgeries

Surgical treatments

Most common types of surgery

Participants completed a series of questions about surgery, including type of surgery, quality of life, and effectiveness of surgery. A summary of the surgery, quality of life and effectiveness is presented in Table 5.11.

There were 40 participants (95.24%) that had surgery for their condition. The most common type of surgery was transurethral resection of bladder tumour (TURBT) (n=,30, 71.43%), followed by radical cystectomy (n=19, 45.24%), and urostomy (n= 15, 35.71%) (Figure 5.12).

Quality of life and effectiveness

Quality of life was rated on a Likert scale from one to seven, where one is “Life was very distressing” and seven is “Life was great”. Effectiveness of treatment was rated on a five-point scale where one is ineffective, and five is very effective. Values are calculated where there was adequate data available (five or more participants).

Table 5.11: Details of surgeries

Median quality of life from surgery ranged from 2.00 to 5.00, in the life was distressing to good range (Figure 5.13). The median effectiveness of all surgery was between 3.50 to 5.00, in the moderately to very effective range (Figure 5.14).

On average, quality of life from transurethral resection of bladder tumour (TURBT) was in the 'life was a little distressing' range (median=3.00, IQR = 1.00), and was found to be moderately effective to effective (median=3.50, IQR=2.75).

On average, quality of life from radical cystectomy was in the 'life was distressing' range (median=2.00, IQR=1.00), and was found to be very effective (median=5.00, IQR=0.00).

On average, quality of life from urostomy was in the 'life was good' range (median=5.00, IQR=1.00), and was found to be very effective (median=5.00 , IQR=0.00).

Surgery		**Transurethral resection of bladder tumour (TURBT)**		**Radical cystectomy**		**Urostomy**	
		n=30	**%**	**n=19**	**%**	**n=15**	**%**
Number (n=42)		30	71.43	19	45.24	15	35.71
Year of surgery	2020-2022	18	64.29	9	50.00	7	50.00
	2018-2019	4	14.29	4	22.22	4	28.57
	2017 or before	6	21.43	5	27.78	3	21.43
Side effects	No complications or side effects	Not collected		Not collected		2	13.33
	Sexual problems					9	60.00
	Urine leakage					7	46.67
	Infections					4	26.67
	Stoma related problems					3	20.00
	Bowel problems					2	13.33
	Extra surgery to fix problems with urostomy					2	13.33
	Hernia					2	13.33
	Kidney stone					1	6.67
Hospital stay	Day surgery	6	20.00	0	0.00	Not collected	
	Overnight	17	56.67	0	0.00		
	2-6 days	6	20.00	2	10.53		
	7-13 days	1	3.33	10	52.63		
	14-20 days	0		3	15.79		
	21 days or more	0		4	21.05		
Cost	$0	17	56.67	11	57.89	Not collected	
	$1-$500	4	13.33	2	10.53		
	$501-$1000	4	13.33	1	5.26		
	>$1000	3	10.00	4	21.05		
	Not sure	2	6.67	1	5.26		
Monthly cost	$0	Not collected		Not collected		4	26.67
	$10 -$20					8	53.33
	$21-$50					1	6.67
	$51-$60					2	13.33
		Median	**IQR**	**Median**	**IQR**	**Median**	**IQR**
Quality of life		3.00	1.00	2.00	1.00	5.00	1.00
Effectiveness		3.50	2.75	5.00	0.00	5.00	0.00

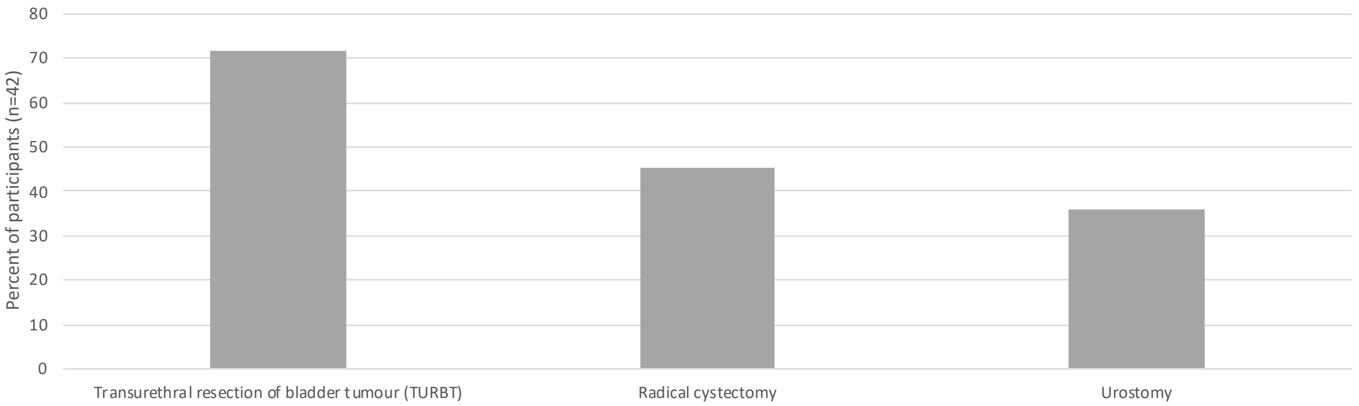


Figure 5.12: Surgery for bladder cancer

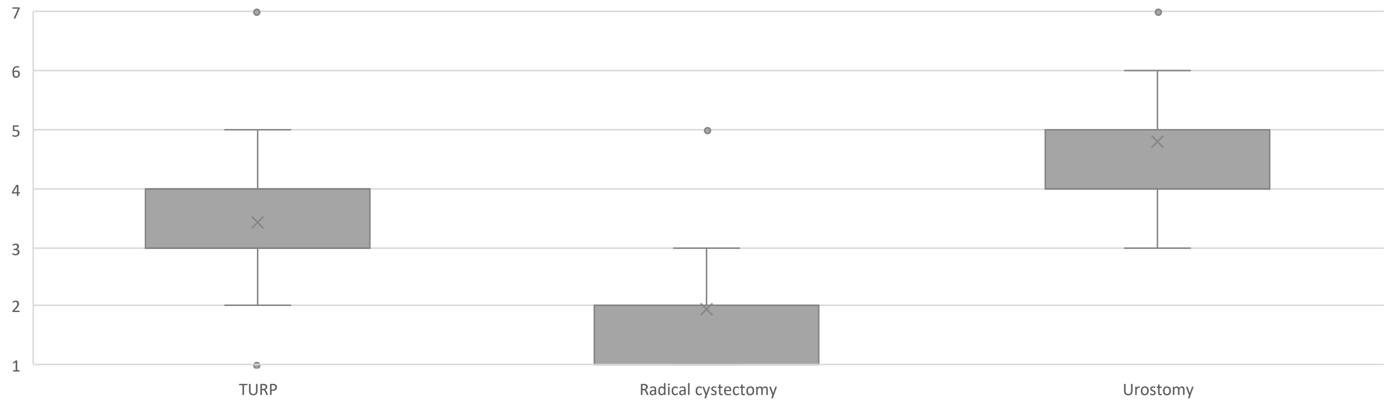


Figure 5.13: Quality of life from surgery

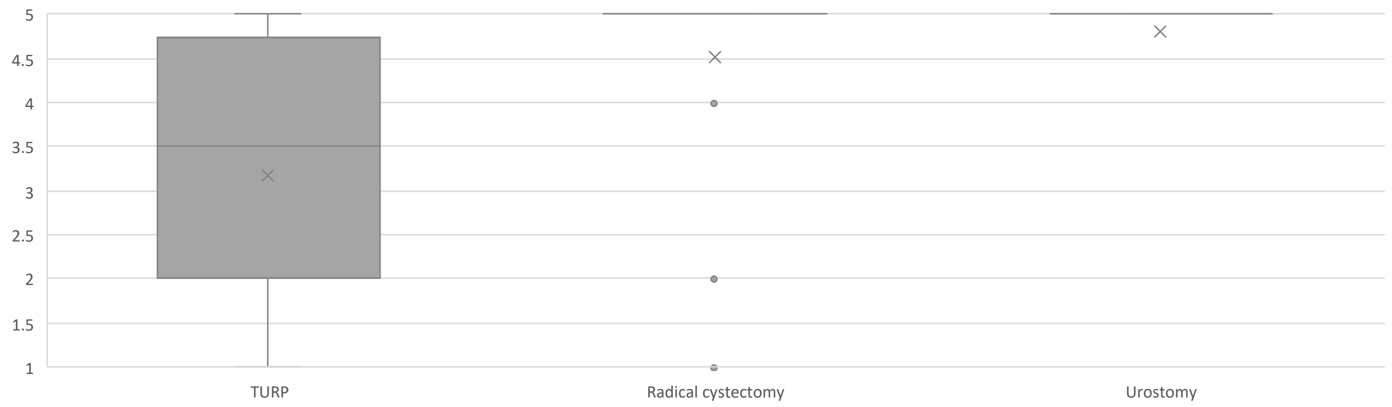


Figure 5.14: Effectiveness of surgery

Summary of drug treatments

Participants completed a series of questions about drug treatments, including type of treatment, quality of life, and effectiveness of treatment.

There were 20, participants (47.62%) that had chemotherapy. The most common types of chemotherapy were MVAC chemotherapy (methotrexate, vinblastine, doxorubicin/ Adriamycin, and cisplatin), (n=5, 11.90%), and Gemcitabine with cisplatin n=5,11.90%). There were 24 participants (57.14%) that had Bacillus Calmetter-Guérin (BCG) (Figure 5.15).

Median quality of life from drug treatments ranged from 1 to 4, in the life was very distressing to good range (Figure 5.16). The median effectiveness of all surgery was between 2.5 to 4, in the somewhat effective to effective range (Figure 5.17).

On average, quality of life from Bacillus Calmetter-Guérin (BCG) was in the 'life was a little distressing to average' range (median=3.50, IQR=2.00), and was found to be somewhat to moderately effective (median=2.50 , IQR=3.25).

On average, quality of life from methotrexate, vinblastine, doxorubicin/adriamycin, and cisplatin was in the 'life was average' range (median=4.00, IQR=2.00), and was found to be effective (median=4.00 , IQR=1.00).

On average, quality of life from gemcitabine with cisplatin was in the 'life was very distressing' range (median=1.00, IQR=2.00), and was found to be effective (median=4.00 , IQR=1.00).

Table 5.12: Detailed summary of drug treatments taken by 5 or more participants (where complete data was available)

Drug treatments (5 or more participants)		Bacillus Calmetter-Guérin (BCG)		Methotrexate, vinblastine, doxorubicin/adriamycin, and cisplatin		Gemcitabine with cisplatin	
		n=24	%	n=5	%	n=5	%
Treatment status	No, it is ongoing	3	12.50	0	0.00	0	0.00
	Yes, I completed BCG as planned	16	66.67	5	100.00	4	80.00
	Yes, I stopped BCG because it wasn't working	3	12.50	0	0.00	0	0.00
	Yes, I stopped BCG early due to side effects	2	8.33	0	0.00	1	20.00
Place treatment given	In-patient at hospital	3	12.50	0	0.00	0	0.00
	Out-patient at hospital or clinic	21	87.50	5	100.00	5	100.00
Time taking treatment	2 months or less	6	25.00	1	20.00	1	20.00
	3-4 months	6	25.00	4	80.00	4	80.00
	1 year	5	20.83	0	0.00	0	0.00
	1.5 -2 years	4	16.67	0	0.00	0	0.00
	3-4 years	3	12.50	0	0.00	0	0.00
	$0	10	41.67	4	80.00	3	60.00
Monthly expenses	$1 to $50	6	25.00	0	0.00	1	20.00
	$51 to $100	3	12.50	0	0.00	0	0.00
	$101 or more	2	8.33	0	0.00	1	20.00
	Not sure	3	12.50	1	20.00	0	0.00
		Median	IQR	Median	IQR	Median	IQR
Quality of life		3.5	2	4	2	1	2
Effectiveness		2.5	3.25	4	1	4	1

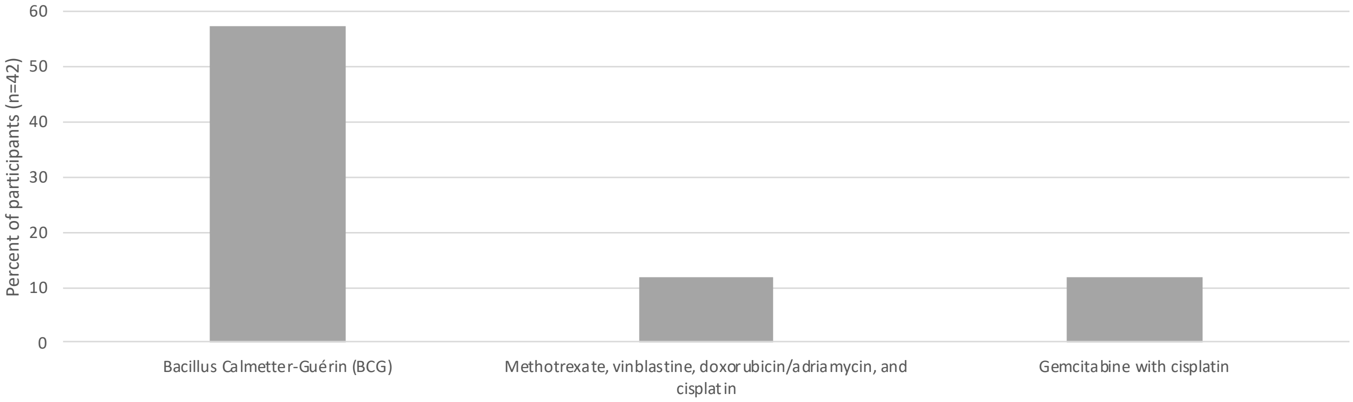


Figure 5.15: Drug treatments

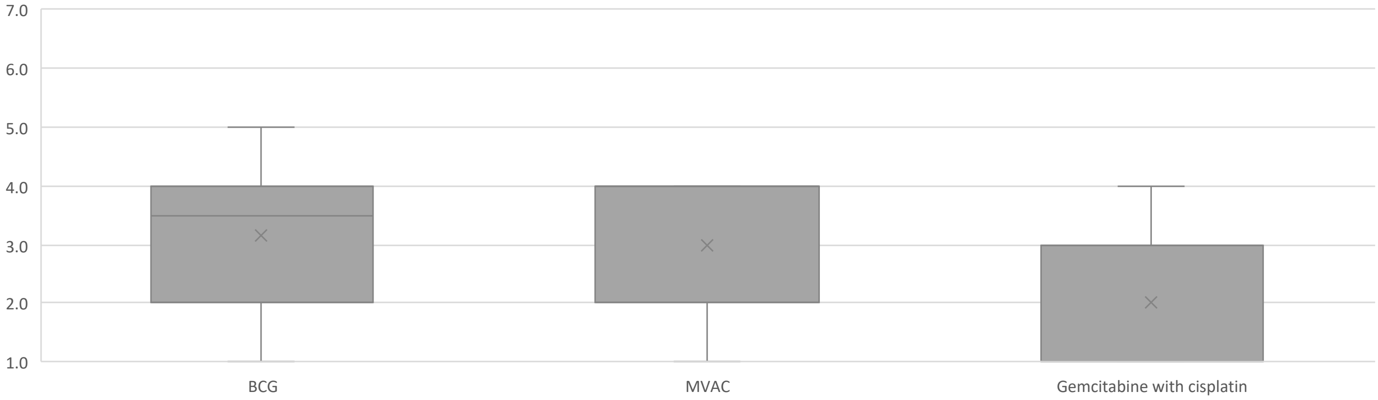


Figure 5.16: Quality of life from drug treatments

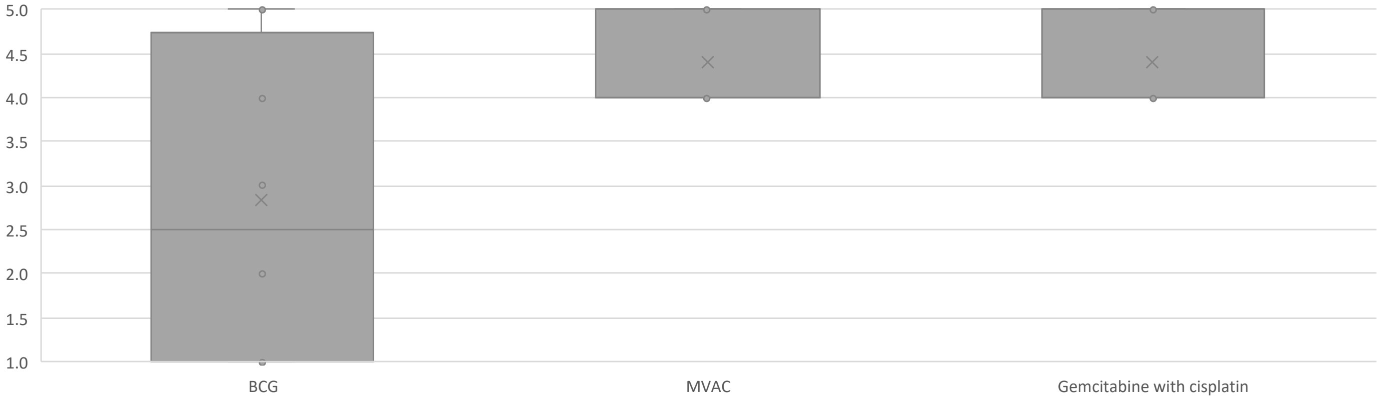


Figure 5.17: Effectiveness of drug treatments

Clinical trials

Clinical trials discussions

In the online questionnaire, participants were asked if they had discussions with their doctor about clinical trials, and if they did, who initiated the discussion (Table 5.13, Figure 5.18).

There was a total of 10 participants (23.81%) that had discussions about clinical trials, 5 participants (11.90%) had brought up the topic with their doctor, and the doctor of 5 participants (11.90%) brought up the topic. The majority of participants had not spoken to anyone about clinical trials (n=32, 76.19%).

Clinical trial participation

As a follow up question, participants were asked if they had taken part in a clinical trial, and if they had not taken part if they were interested in taking part (Table 5.14, Figure 5.19).

There were 5 participants (11.90%) that had taken part in a clinical trial, 21 participants (50.00%) that would like to take part in a clinical trial if there was a suitable one, and 16 participants, that have not participanted in a clinical trial and do not want to (38.10%).

Table 5.13: Clinical trial discussions

Clinical trial discussions	Number (n=42)	Percent
Participant brought up the topic of clinical trials doctor for discussion	5	11.90
Doctor brought up the topic of clinical trials for discussion	5	11.90
Participant has ever spoken to me about clinical trials	32	76.19

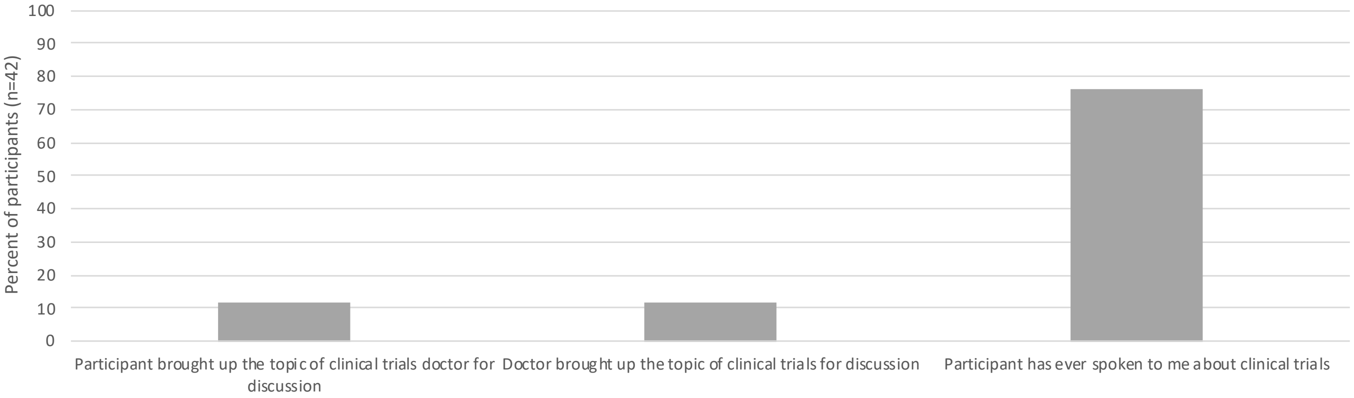


Figure 5.18: Clinical trial discussions

Table 5.14: Clinical trial participation

Clinical trial participation	Number (n=43)	Percent
Has not participated in a clinical trial and does not want to	16	38.10
Has not participated in a clinical trial but would like to if there is one	21	50.00
Has participated in a clinical trial	5	11.90

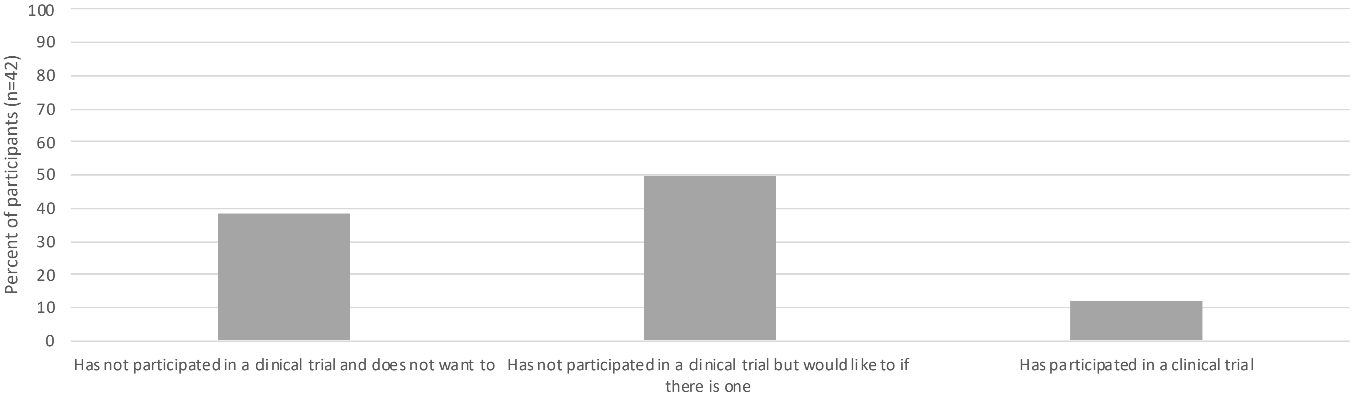


Figure 5.19: Clinical trial participation

Description of mild side effects

In the structured interview, participants were asked how they would describe the term ‘mild side effects’. The most common description of ‘mild side effects’ was a specific side effect as an example (n=36, 73.47%). This was followed by describing ‘mild side effects’ as those that can be self-managed (n=10, 20.41%), those that do not interfere with daily life (n=9, 18.37%), and as those that have a short duration or are reversable (n=7, 14.29%).

Of those who described a specific side effect, the most commonly described side effects were fatigue or lethargy (n=11, 22.45%%), mild pain or aches (n=7, 14.29%) and nausea (n=6, 12.24%). Other side effects described by fewer than 5 participants, included hair loss, stoma bag/irritation/leaks, emotion/mental impact, and cystitis/UTIs.

Participant provides a specific side effect as an example: Aches/pain

The blood in the urine didn't hurt. No. I think that I didn't have any soreness. You know, through passing. urine or any of that. It was only the, the visible sign of the blood was a bit disconcerting, but didn't hurt. The pain after the cystoscopy, the ones that hurt was quite excruciating. On the first day. Um, just managed with Panadol then and it was very sore. And all the other ones were sore. So the first one wasn't sore. But the other, the other ones were, how many others did I have, I've lost track. In February, that was and July and then October. Those three was more painful. But it was the second one was the most painful. And then the other two after that hurt, but not as extreme. Really, pretty much. I just went to bed and put a hot water bottle on my tummy. And things like that to try

and, I took Panadol. So it was only a few days. After probably two days, I was able to sort of do stuff still a little bit cramped, you know.
Participant 014_2022AUBLC

Maybe just low energy levels sort of thing? You know, I mean, no obvious pain or discomfort or, or if you don't notice it, I think it's mild or if you notice it some times its mild, but if its constantly there then, that's obviously something more severe and more acute.
Participant 024_2022AUBLC

Participant provides a specific side effect as an example: Fatigue/lethargy

And it's something that's uncomfortable but doesn't stop you from doing things. You know, the prime example of that is being, you know, tired having or being a bit lethargic. Mm hmm. The hot sweats, you know? You know, again, uncomfortable. Um, you know, not. Not to. Not too bad. The hair loss. That's, that was a side effect of the chemo. Um, and I would say that, I mean, for me, it was mild because it just was what it was. I couldn't change it. So it wasn't that big of a deal. Didn't stop me going there for anything.
Participant 022_2022AUBLC

Participant provides a specific side effect as an example: Stoma bag/irritation/leaks

Oh, just the irritation of having a bag and, you know, and having a pee in a bag and not use it the normal way. I don't know if any of that sort of is the irritation that comes from the frustration that comes from initially not being as agile. Um, not being able to do the things that you used to do before the operation, but I would say, really, these are my, my effects, my after effects and side effects have been so mild really that I wouldn't even count them as effects. Okay. Just get on with it.
Participant 034_2022AUBLC

Participant describes mild side effects as those that can be self-managed

Probably something probably something manageable. But then when it comes to major, that's something that I can't manage at home.
Participant 033_2022AUBLC

Originally, it was just incontinence, that was the only mild, mild side effects and, you know, it was getting really bad at one stage. Yeah, initially it was pretty mild. You know, it was only a matter of a pad on, if I was going out, if I was in the, the house, I didn't worry too much, but if I was going out I had to put a pad on, in case of leakages, and wearing dark coloured clothes to instead of light coloured.
Participant 011_2022AUBLC

Oh, well, some just some irritation in the bladder when you go into the toilet. Like a bit like cystitis, I guess. Um, but it's not really bad. I mean, I. I take, um, Panadol or Nurofen sometimes, but, um. That's all. Yeah. So Only enough to just take Panadol, and then it was not too bad at all. So that's what.
Participant 025_2022AUBLC

Participant describes mild side effects as those that do not interfere with daily life

Mild side effects, I would determine. I would say that they are you know, you notice them, but they don't impact your day to day life. They're in a bit of a bit of a nuisance, but they don't stop you from doing anything that you want to do or could do before.
Participant 032_2022AUBLC

Mild I would think of as a potential irritations. Things that don't stop you going about what you ordinarily would. It's a more yeah. More an awareness and possibly a slight caution for, you know, to, not provoke them or not, you know, irritate. No. I would say mild is just something you're aware of, but it doesn't prevent, you know, impacts your day to day behaviour. I would say.
Participant 041_2022AUBLC

Okay. I guess mild side effects are something that didn't affect too much with his day to day existence. And that might be something like the, the loss of his hair. Well, it was a bit depressing. It wasn't the major things. And so that was probably a mild side effect.
Carer 005_2022AUBLC

Participant describes mild side effects as those that have a short duration or are reversable

So mild would be just, I guess, a slight a slight discomfort, maybe a small fever for a day or something like that.
Participant 014_2022AUBLC

Well, the weight loss I suppose because it didn't take long to put it back on again.
Participant 027_2022AUBLC

Mild side effects. Okay. All right. So mild side effect is particularly for chemo. Okay. So I'll cover chemotherapy for the my mild side effects, I would,

> *quote, qualified as constipation. Okay. It's something that, you know, it's going to happen. But, you know, if you took the right tablet and drank lots of fluids. And yeah, eventually that that and that settled down by itself. The hair loss for me is a mild side effect. Didn't really bother me that I lost, lost hair. Just prior to treatment, I just had a very short haircut anyway, so whatever I lost, I knew was eventually going to come back. Um. What else? I mean, mild for me could be short term, but it could be annoying, but, you know, it's only going to be for a certain period of time. Yeah. Loss of taste, for example. Yeah, like loss of taste. For me, it was annoying when I was having that because it was, it was more of a mucking around with what I could eat or wanted to eat at the time. But again, I also knew once I got through chemotherapy that it would come back even if that was long term, boy it would be completely different. Yeah, that because they were short term and short term with only the course of chemotherapy that that period of time I can handle that part of it.*
> *Participant 035_2022AUBLC*

Table 5.15: Description of mild side effects

Description of mild side effects	All participants		Early		Invasive		Advanced		Person with bladder cancer		Carer		Female		Male	
	n=49	%	n=20	%	n=10	%	n=14	%	n=44	%	n=5	%	n=17	%	n=32	%
Participant provides a specific side effect as an example	36	73.47	16	80.00	9	90.00	7	50.00	32	72.73	4	80.00	11	64.71	25	78.13
Participant describes mild side effects as those that can be self-managed	10	20.41	6	30.00	1	10.00	3	21.43	10	22.73	0	0.00	5	29.41	5	15.63
Participant describes mild side effects as those that do not interfere with daily life	9	18.37	1	5.00	3	30.00	4	28.57	8	18.18	1	20.00	3	17.65	6	18.75
Participant describes mild side effects as those that have a short duration or are reversable	7	14.29	3	15.00	3	30.00	1	7.14	7	15.91	0	0.00	3	17.65	4	12.50

Description of mild side effects	All participants		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=49	%	n=29	%	n=19	%	n=15	%	n=33	%	n=20	%	n=28	%
Participant provides a specific side effect as an example	36	73.47	21	72.41	14	73.68	12	80.00	23	69.70	16	80.00	21	75.00
Participant describes mild side effects as those that can be self-managed	10	20.41	5	17.24	5	26.32	2	13.33	8	24.24	6	30.00	5	17.86
Participant describes mild side effects as those that do not interfere with daily life	9	18.37	7	24.14	2	10.53	3	20.00	6	18.18	1	5.00	4	14.29
Participant describes mild side effects as those that have a short duration or are reversable	7	14.29	4	13.79	3	15.79	3	20.00	4	12.12	3	15.00	4	14.29

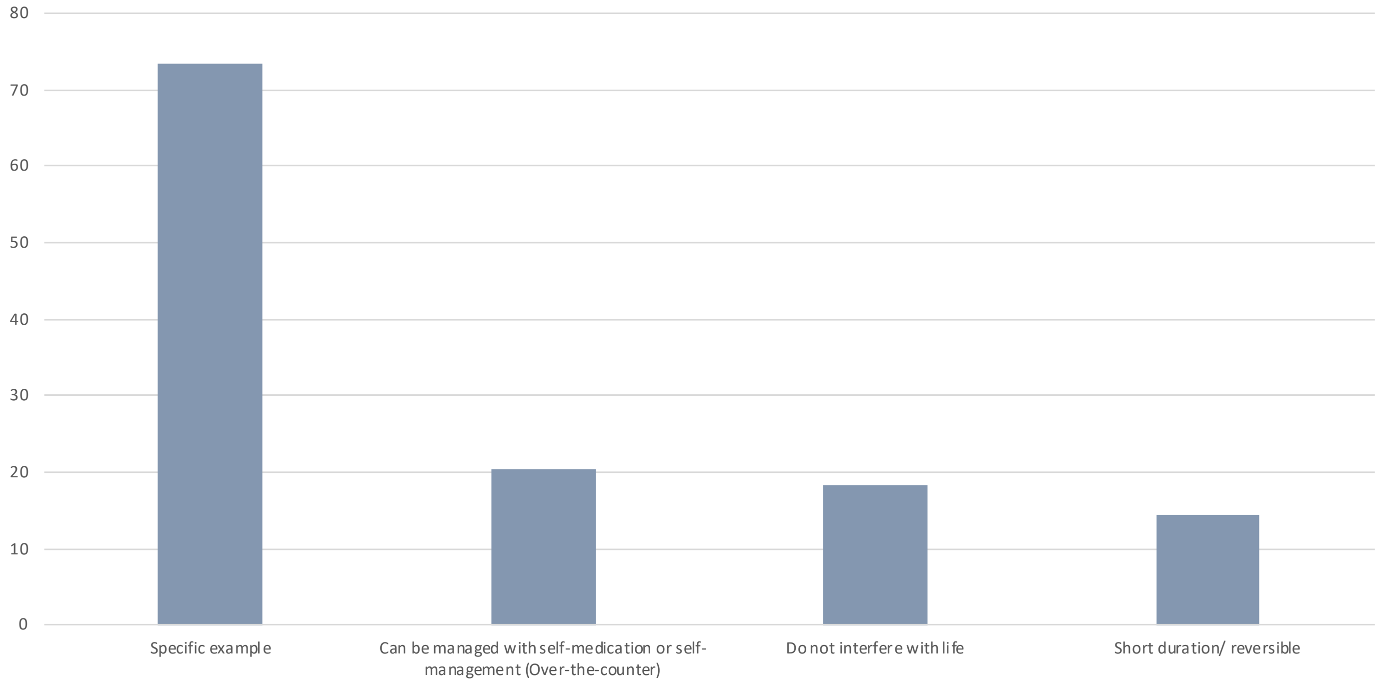


Figure 5.20: Description of mild side effects

Table 5.16: Description of mild side effects – subgroup variations

Description of mild side effects	Reported less frequently	Reported more frequently
Participant provides a specific side effect as an example	Advanced (Stage IV)	Invasive (Stage III)
Participant describes mild side effects as those that can be self-managed	Invasive (Stage III) Carer to someone with bladder cancer	
Participant describes mild side effects as those that do not interfere with daily life	Early (Stages 0 and I) Mid to low status	Invasive (Stage III) Advanced (Stage IV)
Participant describes mild side effects as those that have a short duration or are reversable	Carer to someone with bladder cancer	Invasive (Stage III)

Table 5.17: Description of mild side effects (Specific side effects)

Description of mild side effects (Specific side effects)	All participants		Early		Invasive		Advanced		Person with bladder cancer		Carer		Female		Male	
	n=49	%	n=20	%	n=10	%	n=14	%	n=44	%	n=5	%	n=17	%	n=32	%
Participant describes mild side effects giving the specific example of Fatigue/lethargy	11	22.45	3	15.00	4	40.00	2	14.29	9	20.45	2	40.00	3	17.65	8	25.00
Participant describes mild side effects giving the specific example of Aches/pain (general)	7	14.29	5	25.00	2	20.00	0	0.00	7	15.91	0	0.00	1	5.88	6	18.75
Participant describes mild side effects giving the specific example of nausea	6	12.24	2	10.00	1	10.00	1	7.14	4	9.09	2	40.00	2	11.76	4	12.50
Participant describes mild side effects giving the specific example of Hair loss	4	8.16	0	0.00	2	20.00	1	7.14	3	6.82	1	20.00	1	5.88	3	9.38
Participant describes mild side effects giving the specific example of Stoma bag/irritation/leaks	4	8.16	2	10.00	0	0.00	2	14.29	4	9.09	0	0.00	1	5.88	3	9.38
Participant describes mild side effects giving the specific example of Emotion/mental impact	3	6.12	1	5.00	0	0.00	1	7.14	2	4.55	1	20.00	1	5.88	2	6.25
Participant describes mild side effects giving the specific example of Cystitis/UTIs	3	6.12	2	10.00	1	10.00	0	0.00	3	6.82	0	0.00	2	11.76	1	3.13

Description of mild side effects (Specific side effects)	All participants		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=49	%	n=29	%	n=19	%	n=15	%	n=33	%	n=20	%	n=28	%
Participant describes mild side effects giving the specific example of Fatigue/lethargy	6	20.69	4	21.05	3	20.00	7	21.21	3	15.00	5	17.86		
Participant describes mild side effects giving the specific example of Aches/pain (general)	3	10.34	4	21.05	3	20.00	4	12.12	5	25.00	4	14.29		
Participant describes mild side effects giving the specific example of nausea	4	13.79	2	10.53	2	13.33	4	12.12	2	10.00	3	10.71		
Participant describes mild side effects giving the specific example of Hair loss	4	13.79	0	0.00	2	13.33	2	6.06	0	0.00	2	7.14		
Participant describes mild side effects giving the specific example of Stoma bag/irritation/leaks	3	10.34	1	5.26	2	13.33	2	6.06	2	10.00	0	0.00		
Participant describes mild side effects giving the specific example of Emotion/mental impact	2	6.90	1	5.26	2	13.33	1	3.03	1	5.00	1	3.57		
Participant describes mild side effects giving the specific example of Cystitis/UTIs	1	3.45	2	10.53	2	13.33	1	3.03	2	10.00	2	7.14		

Figure 5.36: Description of mild side effects (Specific side effects)

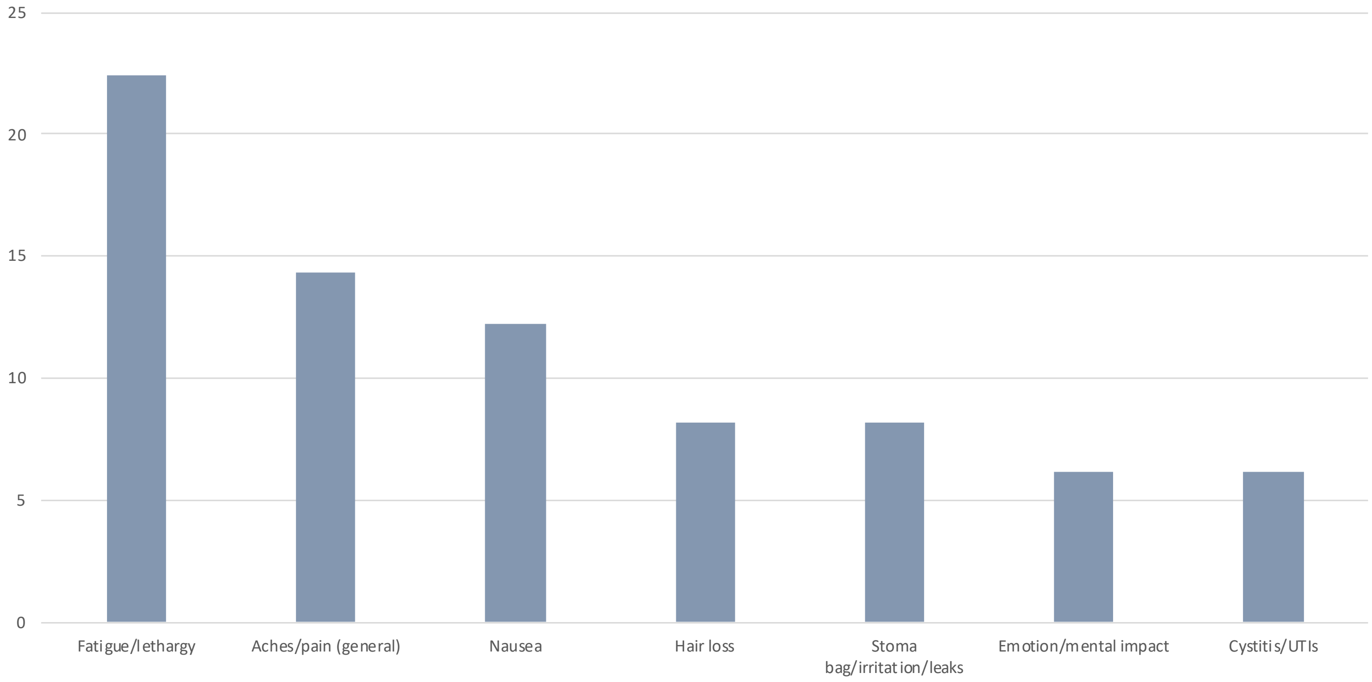


Table 5.21: Description of mild side effects (Specific side effects) – subgroup variations

Description of mild side effects (Specific side effects)	Reported less frequently	Reported more frequently
Participant describes mild side effects giving the specific example of Fatigue/lethargy	-	Invasive (Stage III) Carer to someone with bladder cancer
Participant describes mild side effects giving the specific example of Aches/pain (general)	Advanced (Stage IV) Carer to someone with bladder cancer	Early (Stages 0 and I) Mid to low status
Participant describes mild side effects giving the specific example of nausea	-	Carer to someone with bladder cancer

Description of severe side effects

In the structured interview, participants were asked how they would describe the term ‘severe side effects’. The most common description of ‘severe side effects’ was a specific side effect as an example (n=34, 69.39%). Other descriptions of ‘severe side effects’ included those that impact everyday life/ability to conduct activities of daily living (n=9, 18.37%), and those that are long lasting (n=6, 12.24%). There were 6 participants (12.24%) that were unable to describe severe side effects as they had not experienced them.

Of those who described a specific side effect, the most commonly described side effects were pain (n=18, 36.73%), the emotional or mental impact of the condition, (n=7, 14.29%), and pain when urinating (n=5, 10.20%). Other side effects described by fewer than 5 participants, included fatigue, nausea, fever or infection, and incontinence.

Participant provides a specific side effect as an example: Aches/pain (general)

It was after the operation. I had a lot of pain. It took about six months to resolve all that. Participant 016_2022AUBLC

Participant provides a specific side effect as an example: Emotion/mental impact

I got a severe um, mental side effects that were just ongoing, especially at the chemotherapy. Um, but just this the stress and strain that you got mentally during that period of time from diagnosis through to your treatment phases and even ongoing. Yeah. As to how you going to cope with that. So it's the mental stress that the severe side effects
Participant 035_2022AUBLC

Participant provides a specific side effect as an example: Pain when urinating

I found it very difficult. I found it difficult to cope with. In the first few days of the after the tumour was removed, I found that very hard you know that it we tend to try and manage the pain and the particularly when I needed to urinate and when I couldn't when you know there's a small amount of urine in the in the bladder would, would cause a lot of pain. And there was no there's no there's no answer to it really. It just got to live through it somehow. Somehow or other.
Participant 029_2022AUBLC

Participant describes severe side effects as those that impact everyday life/ability to conduct activities of daily living

And severe side effects means that you're, you know, you're house bound. You can't do or enjoy anything that you want to do you're, you know, basically incapacitated and can't leave the house.
Participant 032_2022AUBLC

And how you would be severe would be not getting out of bed or something like that, I guess. Yeah. And not being able to function. Not being able to go and work.
Participant 014_2022AUBLC

So, yes, the BCG, like I couldn't cope with, because I ended up in my second round of BCG for 6 weeks. I ended up I couldn't work for three days after having the treatment where most people could go back to work the day after. So my body was screaming, stop doing this to me. And I didn't listen to it. So, you know, it ended up the side effects of the BCG were horrific for me. So I mean, the bladder cancer itself, when I had bladder cancer, it wasn't you know, I wasn't really noticing anything much anyway. So, you know, I think. I think it was more. Participant 026_2022AUBLC

Participants reported not experiencing any severe side effects

Well, I didn't have I never had any. I was very lucky. There was nothing. I mean, I guess if, if you were to say severe side effect would be the hair loss. But it wasn't. It was it was just an inconvenience. It wasn't anything really bad. Participant 020_2022AUBLC

I never really had any, any severe side effects at all now sort of but coming out of hospitals early in the hospital, seven days. And yeah, I sort of just kept walking and I think it was driving. Within four weeks, I went back to driving. Fine. And, and, um, yeah, you know, I just, um, I had a really positive attitude that it was going to be okay and no problem. But yeah, I had a few leaks with me bag, but I just get the hang of it and yeah, these things can happen. And yeah, I went and seen my stoma nurse and we change bags and yeah, I sort of wasn't going to let it get me down but, we can work through this and um, yeah, and it's been great. I haven't any problems at all with my bag and having any issues with it at all.
Participant 044_2022AUBLC

Participant identifies severe side effects as those that are long lasting

But certainly the severe side effects would be that very high level of pain and continuing pain. And, and also the just the the general discomfort in the bladder area.
Participant 008_2022AUBLC

It was after the operation. I had a lot of pain. It took about six months to resolve all that.
Participant 016_2022AUBLC

Severe ones would be things that impacted and were ongoing, I think be some things you can put up with for a little while, but I guess the severe ones would be the ones, also sort of went on for weeks, but they passed and then the ongoing pain I guess from the surgery is just was something that we didn't know to expect. I think that was that was something that wasn't spelled out to us. Yeah. Ongoing, the pain level would be.
Carer 005_2022AUBLC

Participant describes severe side effects as those that are life threatening or result in hospitalisation

Um. Well, I suppose with severe side effects. When I got the infection that I had to go into hospital for, um. I guess the other one was a few weeks ago when I felt chained to the bathroom for a couple of weeks. I suppose the rest you just deal with because. Otherwise you just deal with it really
Participant 002_2022AUBLC

Hospitalisation. Okay. Yeah. When it gets too severe, I end up in hospital. Because I can't manage that anymore.
Participant 033_2022AUBLC

Severe, I guess, not being able to breathe and having a fever, about 40. That's sort of more severe side of it to me. Um, pain wise. Pain that, um, would almost tempt me to want to take a pain relief pill. Like, I'm talking, like, oh [groans in pain], getting up in, like, that sort of level of pain of, oh [groans in pain again], ten out of ten, you know? Yeah. Like, unbelievable pain. Yeah. Oh. Yeah.
Participant 001_2022AUBLC

Participant identifies severe side effects as requiring medical intervention

Yeah. So it's things where, you know, I would say, certainly some of the aftermath would have gone into severe side effects. And in those situations, it's situations where you'd really like assistance. Situations where you think, I think particularly being alone, I think you'd really like someone else. You know, you need comfort, you need., and possibly medical assistance or medical opinion, at least severe side effects where I would have liked to have gone to air to have things appraised, but I had no manner of getting there. I guess then some. Yeah. Well, I'm not. Well, I'm not well enough to catch a taxi anywhere. Not. Not. Yeah. Not. I don't know. I think I think I hold out too long before trying to get assistance.
Participant 041_2022AUBLC

Also had to have I think they said it was atrial flutter and they gave me something to reverse that which I can't remember them vividly looking and saying is that flutter or fibrillation? I was trying to look at the monitor myself. I couldn't quite see it.
Participant 018_2022AUBLC

Participant identifies severe side effects as impacting their everyday life by being bed ridden

Uh, something that. Yeah, something that basically lays you up. You, you just feel like you can't do anything else because your mind is fully occupied.
Participant 006_2022AUBLC

Severe would be not getting out of bed or something like that, I guess. Yeah. And not being able to function. Not being able to go and work
Participant 014_2022AUBLC

And I probably could cope with it for a day. But I wouldn't want to cope with the ongoing and, you know, I don't know. Just trying to think how I feel about that. Had it gone on for days and days and days, it would have been extremely hard to cope with. You know, you can get laid up for a couple of days, and, you know, you curl up in a ball in bed and try and sort of lie still don't budge or don't move. And. Yeah. So the first that first day, it was very, very painful and I don't think I could have to coped. Well you have to cope, but I think. I might need something a bit stronger if it wasn't going. Yeah. Unless you overcome that.
Participant 003_2022AUBLC

Table 5.19: Description of severe side effects

Description of severe side effects	All participants		Early		Invasive		Advanced		Person with bladder cancer		Carer		Female		Male	
	n=49	%	n=20	%	n=10	%	n=14	%	n=44	%	n=5	%	n=17	%	n=32	%
Participant provides a specific side effect as an example	34	69.39	13	65.00	8	80.00	9	64.29	30	68.18	4	80.00	13	76.47	21	65.63
Participant describes severe side effects as those that impact everyday life/ability to conduct activities of daily living	9	18.37	4	20.00	2	20.00	3	21.43	9	20.45	0	0.00	5	29.41	4	12.50
Participants reported not experiencing any severe side effects	7	14.29	3	15.00	3	30.00	1	7.14	7	15.91	0	0.00	2	11.76	5	15.63
Participant identifies severe side effects as those that are long lasting	6	12.24	3	15.00	2	20.00	0	0.00	5	11.36	1	20.00	2	11.76	4	12.50
Participant describes severe side effects as those that are life threatening or result in hospitalisation	4	8.16	3	15.00	0	0.00	1	7.14	4	9.09	0	0.00	2	11.76	2	6.25
Participant identifies severe side effects as requiring medical intervention	4	8.16	3	15.00	0	0.00	1	7.14	4	9.09	0	0.00	2	11.76	2	6.25
Participant identifies severe side effects as impacting their everyday life by being bed ridden	3	6.12	3	15.00	0	0.00	0	0.00	3	6.82	0	0.00	1	5.88	2	6.25

Description of severe side effects	All participants		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=49	%	n=29	%	n=19	%	n=15	%	n=33	%	n=20	%	n=28	%
Participant provides a specific side effect as an example	34	69.39	20	68.97	14	73.68	11	73.33	23	69.70	13	65.00	20	71.43
Participant describes severe side effects as those that impact everyday life/ability to conduct activities of daily living	9	18.37	5	17.24	4	21.05	4	26.67	5	15.15	4	20.00	5	17.86
Participants reported not experiencing any severe side effects	7	14.29	2	6.90	4	21.05	2	13.33	4	12.12	3	15.00	4	14.29
Participant identifies severe side effects as those that are long lasting	6	12.24	2	6.90	4	21.05	4	26.67	2	6.06	3	15.00	3	10.71
Participant describes severe side effects as those that are life threatening or result in hospitalisation	4	8.16	1	3.45	3	15.79	0	0.00	4	12.12	3	15.00	3	10.71
Participant identifies severe side effects as requiring medical intervention	4	8.16	2	6.90	2	10.53	0	0.00	4	12.12	3	15.00	3	10.71
Participant identifies severe side effects as impacting their everyday life by being bed ridden	3	6.12	3	10.34	0	0.00	2	13.33	1	3.03	3	15.00	1	3.57

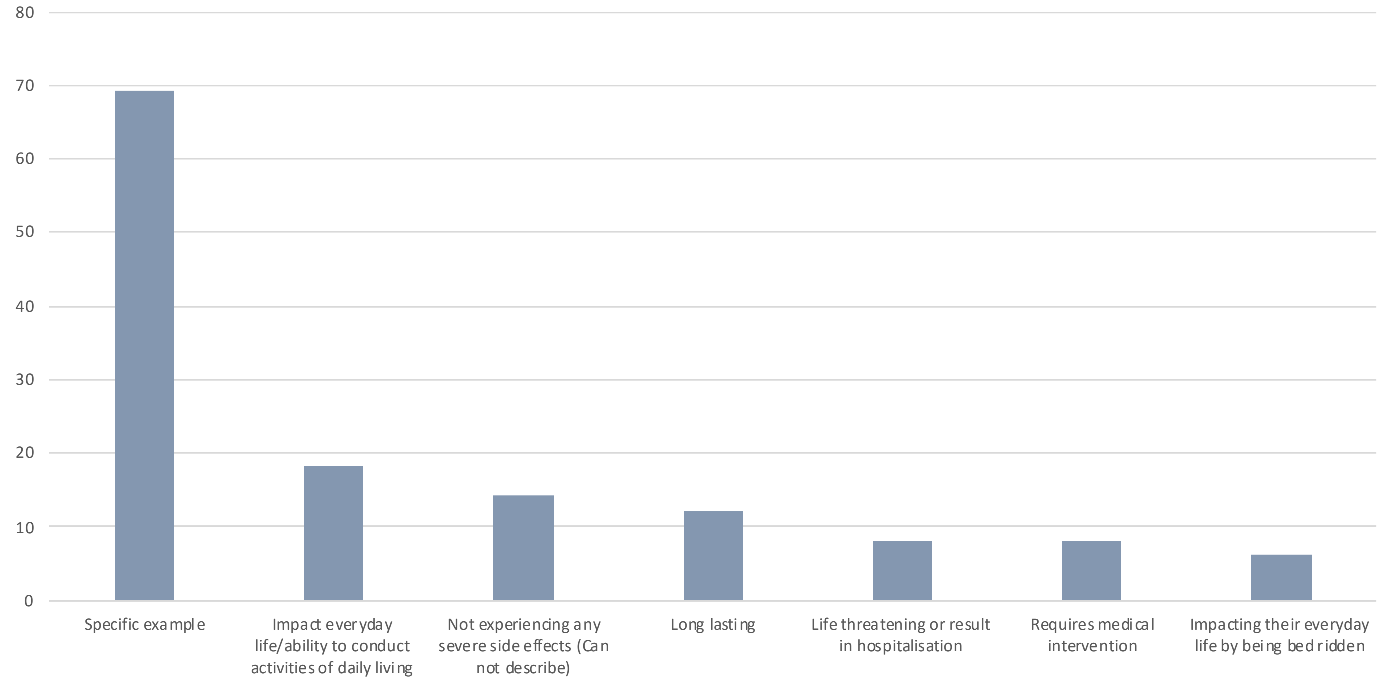


Figure 5.22: Description of severe side effects

Table 5.20: Description of severe side effects – subgroup variations

Description of severe side effects	Reported less frequently	Reported more frequently
Participant provides a specific side effect as an example	-	Invasive (Stage III) Carer to someone with bladder cancer
Participant describes severe side effects as those that impact everyday life/ability to conduct activities of daily living	Carer to someone with bladder cancer	Female
Participants reported not experiencing any severe side effects	Carer to someone with bladder cancer	Invasive (Stage III)
Participant identifies severe side effects as those that are long lasting	Advanced (Stage IV)	Regional or remote

Table 5.21: Description of severe side effects (Specific example)

Description of severe side effects (Specific side effects)	All participants		Early		Invasive		Advanced		Person with bladder cancer		Carer		Female		Male	
	n=49	%	n=20	%	n=10	%	n=14	%	n=44	%	n=5	%	n=17	%	n=32	%
Participant describes severe side effects giving the specific example of Aches/pain (general)	18	36.73	10	50.00	4	40.00	2	14.29	16	36.36	2	40.00	8	47.06	10	31.25
Participant describes severe side effects giving the specific example of Emotion/mental impact	7	14.29	3	15.00	0	0.00	3	21.43	6	13.64	1	20.00	2	11.76	5	15.63
Participant describes severe side effects giving the specific example of Pain when urinating	5	10.20	2	10.00	2	20.00	1	7.14	5	11.36	0	0.00	2	11.76	3	9.38
Participant describes severe side effects giving the specific example of Fatigue/lethargy	4	8.16	2	10.00	0	0.00	0	0.00	2	4.55	2	40.00	2	11.76	2	6.25
Participant describes severe side effects giving the specific example of Nausea or loss of appetite	4	8.16	0	0.00	0	0.00	1	7.14	1	2.27	3	60.00	0	0.00	4	12.50
Participant describes severe side effects giving the specific example of Fever/infection	4	8.16	4	20.00	0	0.00	0	0.00	4	9.09	0	0.00	3	17.65	1	3.13
Participant describes severe side effects giving the specific example of Incontinence that is not manageable	3	6.12	0	0.00	1	10.00	1	7.14	2	4.55	1	20.00	1	5.88	2	6.25

Description of severe side effects (Specific side effects)	All participants		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=49	%	n=29	%	n=19	%	n=15	%	n=33	%	n=20	%	n=28	%
Participant describes severe side effects giving the specific example of Aches/pain (general)	18	36.73	9	31.03	9	47.37	6	40.00	12	36.36	10	50.00	10	35.71
Participant describes severe side effects giving the specific example of Emotion/mental impact	7	14.29	6	20.69	1	5.26	2	13.33	5	15.15	3	15.00	2	7.14
Participant describes severe side effects giving the specific example of Pain when urinating	5	10.20	3	10.34	2	10.53	1	6.67	4	12.12	2	10.00	4	14.29
Participant describes severe side effects giving the specific example of Fatigue/lethargy	4	8.16	3	10.34	1	5.26	0	0.00	4	12.12	2	10.00	3	10.71
Participant describes severe side effects giving the specific example of Nausea or loss of appetite	4	8.16	3	10.34	1	5.26	1	6.67	3	9.09	0	0.00	2	7.14
Participant describes severe side effects giving the specific example of Fever/infection	4	8.16	2	6.90	2	10.53	0	0.00	4	12.12	4	20.00	4	14.29
Participant describes severe side effects giving the specific example of Incontinence that is not manageable	3	6.12	2	6.90	1	5.26	2	13.33	1	3.03	0	0.00	2	7.14

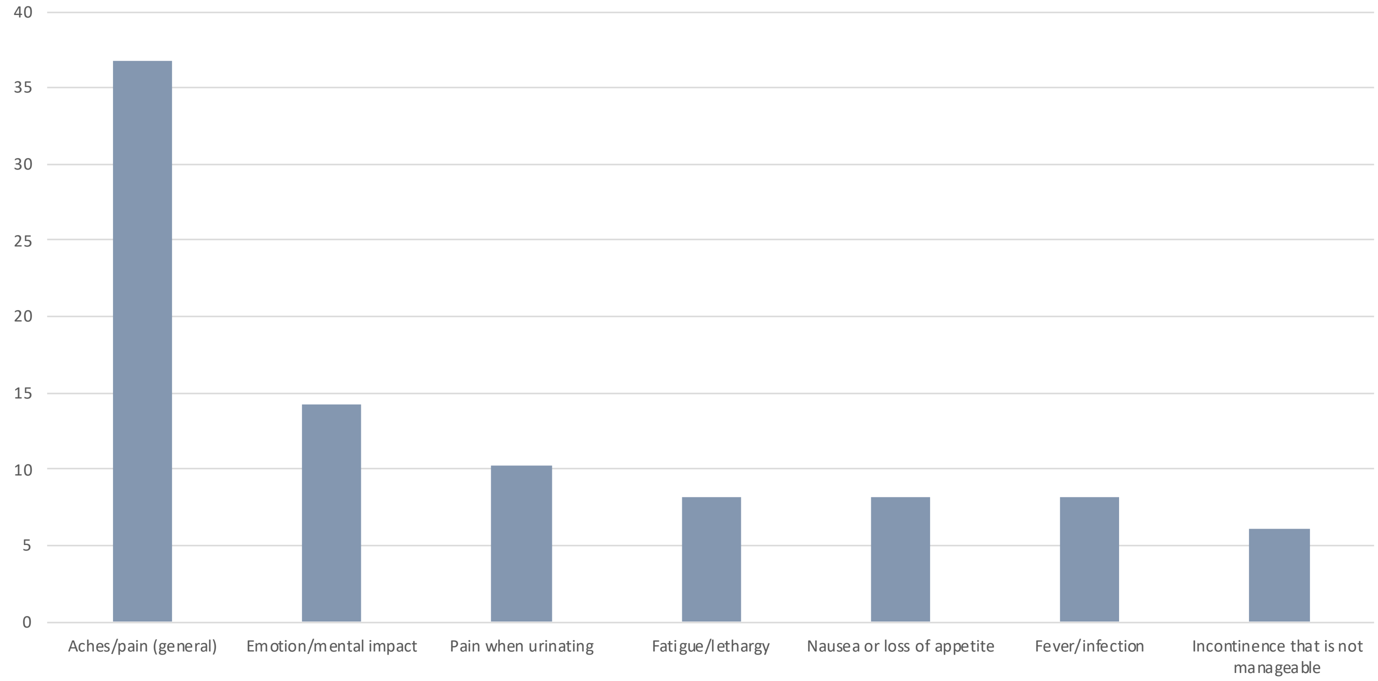


Figure 5.23: Description of severe side effects (Specific example)

Table 5.22: Description of severe side effects (Specific side effects)– subgroup variations

Description of severe side effects (Specific side effects)	Reported less frequently	Reported more frequently
Participant describes severe side effects giving the specific example of Aches/pain (general)	Advanced (Stage IV)	Early (Stages 0 and I) Female University Mid to low status
Participant describes severe side effects giving the specific example of Emotion/mental impact	Invasive (Stage III)	-
Participant describes severe side effects giving the specific example of Pain when urinating	Carer to someone with bladder cancer	-

Adherence to treatment

Participants were asked in the structured interview what influences their decision to continue with a treatment regime. The most common themes described were adhering to treatment as per the advice of their specialist/as long as prescribed (n=20, 40.82%), and adhering to treatment as long as treatment is working (n=16, 32.65%). This was followed by adhering to treatment as long as side effects are tolerable (n=12, 24.49%%), adhering to treatment for a specific amount of time (n=11, 22.45%), and 7 participants (14.29%) described not giving up on any treatments.

Where participants stated a specific amount of time to adhere to a treatment, the most common amount of time was two to three weeks.

Participant describes adhering to treatment as per the advice of their specialist/as long as prescribed

And I think I'd, I'd stick with it until I know as long as I was the doctor or specialist wa,s was saying it was what was wanting me to do it. I don't think I'd just stop partway.
Participant 025_2022AUBLC

Oh, no, I never do. If the doctor tells me to have something, you know, for a particular time, I just have it. I have issues with it. I will discuss, like with the with the steroid, you know, dexamethasone. They told me to take it so that with the with the on the day of chemotherapy, I was to take four tablets, then two tablets, then one tablet. So like I said, I got too restless and the reduced doses to two and one from 4 to 2. But I discussed with them and I didn't give up.
Participant 028_2022AUBLC

Uh, I am one of those sort of people that if they are told to take a tablet once a day, I take a tablet once a day. So I tend to be very compliant. Like at the at the moment I'm using eyedrops every 2 hours during the day and I'd say that's 80% of the time I'm putting it. And then on the 2 hours if not. Sometimes the other 20% might be an extra half hour here and there, but I do tend to be very compliant.
Participant 036_2022AUBLC

Participant describes adhering to treatment as long as treatment is working

Well. I really didn't have any much too much in the way of medication initially for. There's no medication except for the BCG, and the BCG. Well, it was quite obvious that it was just getting worse and worse. There's no you know, I could see it, the doctors and nurses could see it just wasn't working. Yeah. Yeah. They the doctors, the one that basically said, you know what? We'll, we'll see about the operation, you know. Which my urologist goes to a board, apparently down at the hospital. They sit down and have a discussion about and figure out who's next in line with who needs the treatments, the most urgently, or who's available for treatment, I suppose they don't do too many at any given time. And with COVID it made it a little bitter harder I think.
Participant 011_2022AUBLC

Yeah. Yeah, I'll say. Well, in my case, really, the only sort of new things that I can try are new types or different makes of the equipment on there have to live with, such as stoma bags and the some of the associated paraphernalia that comes with it. Um. I not really know to ask that, because what I've tried so far is was basically what I came out of the hospital with because it seems to work well. I'm staying with it. I've tried one other. And to and if these things, fail, it is quite messy. So you lose, you lose the sense of security. And so you tend to sort of in a shy away from things that haven't worked for you too well. So you can try things for very long if they don't work. So, you know, maybe once or twice if they don't work, I'll stick with the ones that do, which is common sense. Yeah, there are there are there are improvements that I look for because some of them are not particularly comfortable. And some of the, some of the support systems and the physical support systems belts and things could be improved. But that's a design thing really.
Participant 034_2022AUBLC

Like when I had the bleeding, I as I said before, I took the oregano oil and the flaxseed, though I did that helped me virtually within 24 hours I was much better. I was 90% better within 24 hours. So I think I because I improved so quickly, I, I only us,e only took that for about a week or two. Um. So that was pretty straightforward as far as the bladder cancer goes. Well, um, BCG, I think I had about 11. I might have had 11 infusions of that, but it wasn't helping. So that was, that was stopped. And as far as supplements go, I've been taking supplements now for probably, you know, two and a half, three years and. I don't think I've actually. I did have what do you call it? Medical cannabis there for a little while. But once I started the immunotherapy with KEYTRUDA, I stopped taking the medical cannabis because I read somewhere it could

interfere with the immunotherapy. So I didn't want to risk it, so I stopped taking that.
Participant 042_2022AUBLC

Participant describes adhering to treatment as long as side effects are tolerable

Oh, that's a good question. So, well with the BCG. I mean, I guess theoretically I've stuck with it regardless of knowing whether it's working or not, because proof is the long term non-recurrence of the of the thing. So in that in that sense, I stuck with it based on the evidence that it does improve with, with other things. So like I, if I don't think they're working or if I think the side effects are worse than the um, then yeah. What is it? The thing is worse than the treatment. The cure is worse than the treatment. I. I don't stick with it too long. Okay? I have to say I'm a bit, you know, I guess that's not working the CBD. I sort of well because you buy a little tube, it costs three or $400 and it lasts about a month. So you stick with it because you've paid a lot of money for it.
Participant 006_2022AUBLC

I give it a good go. I can, I can only, I can only point at chemotherapy where I meant to go through four cycles. I did have to stop it at three because I was so ill. I was in hospital, I was around and I said, well, look, it was done in consultation with the oncologist cause I said, what was going to be the benefit of me doing? You know, if I had to do a full cycle, what was the what was the benefit like? A cost benefit for me. So the oncologists were able to come back and say, look, most, most of the benefits that you've had are in the first couple of cycles, cycles 1 to 2 and potentially three. If you do cycle four, you might get an extra 10% top up. Uh, yeah, to be sure, to be sure type of thing. But um. So I made a, made a call on that and said, I don't want to do that because I didn't think I was having any real quality of life myself. By going through that. So, yeah, I would if somebody says me, here's a, here's a treatment that could well help, I would definitely give it, give it a go first.
Participant 035_2022AUBLC

Oh, I would. I would stick with whatever I could. Um, I actually the second load of chemo, after I had my kidney out, I got so sick I could only have three rounds. They had to stop the fourth round. Um, but, and I didn't want to stop, but I knew that the oncologist just said I couldn't take any more. Um, but no, I would. I would try anything and everything.
Participant 039_2022AUBLC

Participant describes adhering to treatment for a specific amount of time

The only thing I've had trouble with is some anti-inflammatories, and I, you know, play with my stomach and, make me sick, so those I stop fairly quickly. If I'm given something that reacts in that way, if it's something that doesn't alleviate whatever it is. I was trying to get rid of I persist with those for a while, you know, at least a couple of weeks.
Participant 022_2022AUBLC

Well, I think you need to stick with it for a while and it depends on what the side effects are. So is it just mild side effects? I'd stick with it till it was proven whether it was working or not working. If it was severe side effects and there was no improvement in the condition, I think I'd be asking questions to the specialist who described it, you know, to, to really get an idea of how long, you know, you need to be on this treatment because it's impacting your quality of life so severely. And it's not working. I'd want to know. So I would be asking questions I didn't know after a few weeks, I think. But they would obviously, I would ask them to set the expectation, you know, we should see some improvement in four weeks, six weeks. So if I got to that point in time and there was still nothing, then I would be asking questions.
Participant 032_2022AUBLC

Honestly, probably less than a month. Okay. But I would obviously consult my doctor first.
Participant 009_2022AUBLC

Well, you'd have to give it time to. To go a new treatment, at least probably three months.
Participant 027_2022AUBLC

Participant describes not giving up on any treatment

I've not given up on any treatments that I've had. I've never given up. And with the BCGs and like, I wanted to continue to BCG and after the week in hospital with the BCG process, it was it was left up to the care of an infectious diseases doctor. Whether or not I'd be able to continue. And he said that because I was I had age in my favour and fitness, that he said that I could continue on with it, that I was strong enough to fight. So I said, you know, do it again. I kept it on.
Participant 001_2022AUBLC

I'm a pretty good fighter. I'll stick with that until. Until the end. For as long or as long as I can. Okay? Yeah, yeah, I don't. I don't quit that easy.
Participant 033_2022AUBLC

I've never really given up on anything. I've just sort of seen it through and eventually sort of spoken to a GP about it. Yeah. I would take a ridiculously long time before I'd give up. On anything. Right. Possibly. I'm not sure if I'm just too, I don't think it's stubborn, I think, I think I just will continue to put up with something.
Participant 041_2022AUBLC

Participant describes not giving up on treatment as they have no other options/will continue despite side effects

Oh, I'd take the advice of my urologist. And it's like I don't know if I would if the urologist said, this is the one thing that's going to 100% improve your chances of reducing cancer recurring. And yeah, it's got some horrible side effects, but it's going to we just have done that many trials, we've got that much statistical evidence that it improves your chances of low to zero recurrence. I'd do it. I would not do it, like I wouldn't go against my urologist recommendation just because it was a bit sore.
Participant 030_2022AUBLC

Well, I have other, I didn't have a choice. Yeah. That there's, there's not, there's no choice of treatment. It. This is what. And you'll either have it or I don't have it. If I don't have it, then the chances are I'll end up having an cystectomy, which I don't want to have. So I'm really. It's not about giving up on a treatment, there just weren't any options.
Participant 002_2022AUBLC

Table 5.23: Adherence to treatment

Adherence to treatment	All participants		Early		Invasive		Advanced		Person with bladder cancer		Carer		Female		Male	
	n=49	%	n=20	%	n=10	%	n=14	%	n=44	%	n=5	%	n=17	%	n=32	%
Participant describes adhering to treatment as per the advice of their specialist/as long as prescribed	20	40.82	6	30.00	4	40.00	7	50.00	17	38.64	3	60.00	6	35.29	14	43.75
Participant describes adhering to treatment as long as treatment is working	16	32.65	7	35.00	3	30.00	4	28.57	14	31.82	2	40.00	6	35.29	10	31.25
Participant describes adhering to treatment as long as side effects are tolerable	12	24.49	2	10.00	3	30.00	3	21.43	8	18.18	4	80.00	4	23.53	8	25.00
Participant describes adhering to treatment for a specific amount of time	11	22.45	5	25.00	3	30.00	2	14.29	10	22.73	1	20.00	6	35.29	5	15.63
Participant describes not giving up on any treatment	7	14.29	2	10.00	2	20.00	2	14.29	6	13.64	1	20.00	1	5.88	6	18.75
Participant describes not giving up on treatment as they have no other options/will continue despite side effects	4	8.16	2	10.00	0	0.00	2	14.29	4	9.09	0	0.00	3	17.65	1	3.13

Adherence to treatment	All participants		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=49	%	n=29	%	n=19	%	n=15	%	n=33	%	n=20	%	n=28	%
Participant describes adhering to treatment as per the advice of their specialist/as long as prescribed	20	40.82	11	37.93	9	47.37	6	40.00	14	42.42	6	30.00	12	42.86
Participant describes adhering to treatment as long as treatment is working	16	32.65	10	34.48	5	26.32	2	13.33	13	39.39	7	35.00	10	35.71
Participant describes adhering to treatment as long as side effects are tolerable	12	24.49	8	27.59	4	21.05	5	33.33	7	21.21	2	10.00	8	28.57
Participant describes adhering to treatment for a specific amount of time	11	22.45	5	17.24	5	26.32	5	33.33	5	15.15	5	25.00	5	17.86
Participant describes not giving up on any treatment	7	14.29	5	17.24	2	10.53	1	6.67	6	18.18	2	10.00	4	14.29
Participant describes not giving up on treatment as they have no other options/will continue despite side effects	4	8.16	1	3.45	3	15.79	1	6.67	3	9.09	2	10.00	3	10.71

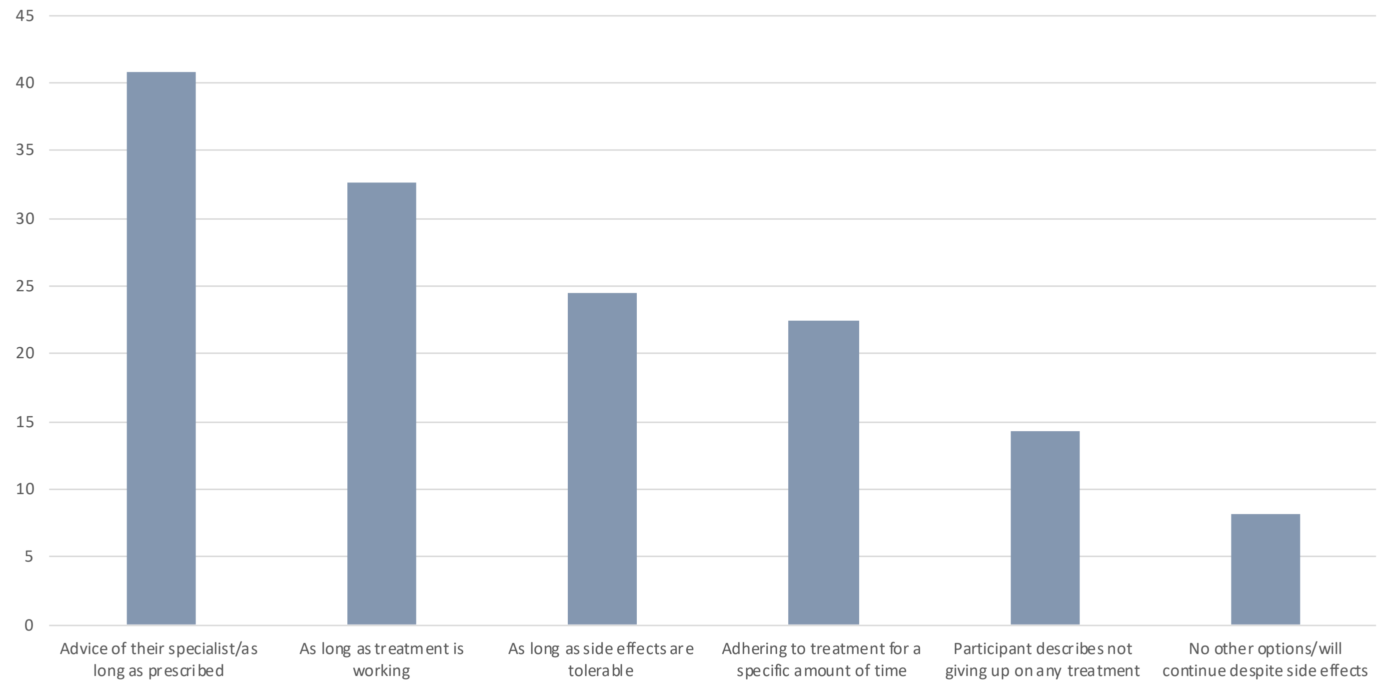


Figure 5.24: Adherence to treatment

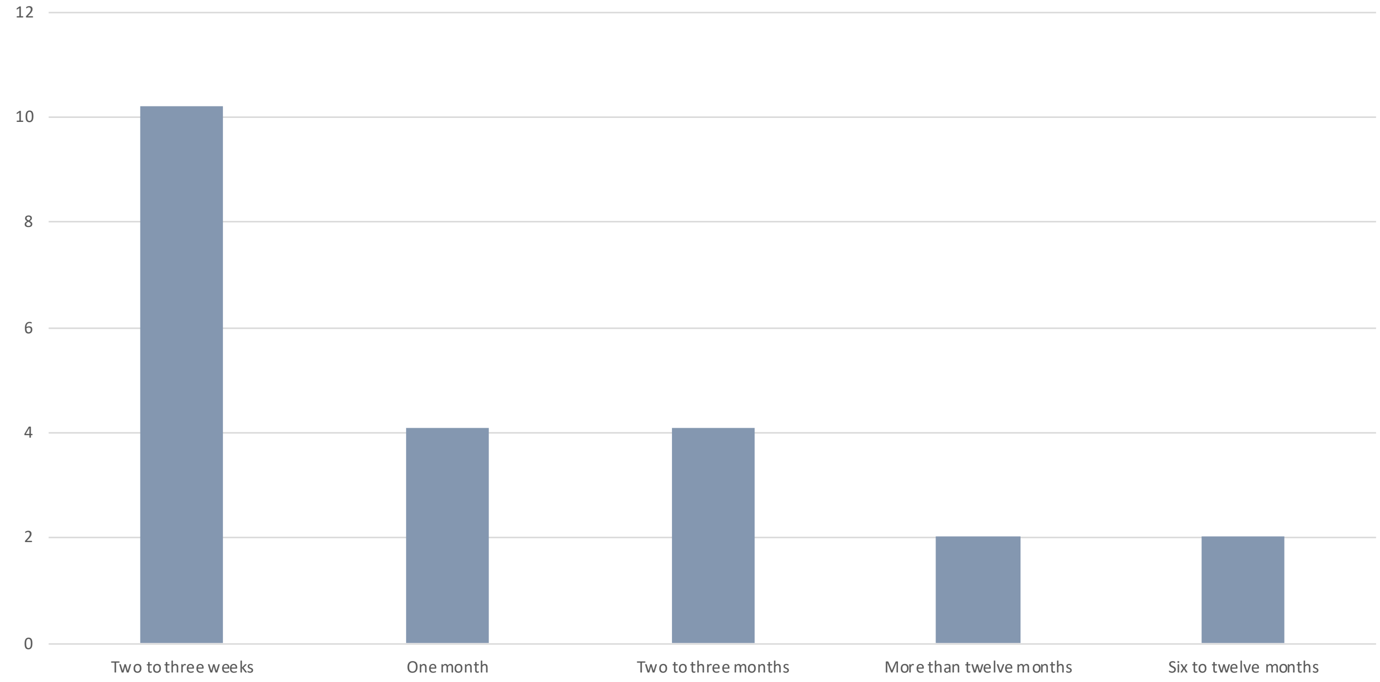


Figure 5.25: Adherence to treatment (Time to adhere to treatment)

Table 5.24: Adherence to treatment – subgroup variations

Adherence to treatment	Reported less frequently	Reported more frequently
Participant describes adhering to treatment as per the advice of their specialist/as long as prescribed	Early (Stages 0 and I) Mid to low status	Carer to someone with bladder cancer
Participant describes adhering to treatment as long as treatment is working	Regional or remote	-
Participant describes adhering to treatment as long as side effects are tolerable	Early (Stages 0 and I) Mid to low status	Carer to someone with bladder cancer
Participant describes adhering to treatment for a specific amount of time	-	Female Regional or remote

What needs to change to feel like treatment is working

Participants were asked to describe what needs to change to feel like treatment is effective. The most common response from 24 participants (48.89%) was needing to experience evidence of stable disease/no disease progression. There were 14 participants (28.57%) that reported needing to experience a reduction in physical signs/reduced side effects, and 13 participants (26.53%) needed to see specific symptom reduction. The most common specific symptoms were nausea, aches and pains, fatigue and lethargy, and muscle cramping.

Participants reported needing to experience evidence of stable disease/no disease progression

Okay. For me, it's just going. Having a cystoscopy after each round of BCG finished and not having any tumours in there. Having a clear bladder. No progression of the disease from in the last cancer I've had in the bladder has been a high grade non-muscle invasive cancer. So for it to be working, it means that it's either come back without being muscle invasive once again, or it hasn't progressed or I don't have anything. And so far there's been nothing since I've been having BCG. There's been no tumours.
Participant 001_2022AUBLC

I think the delay time between the procedure and saying getting results is the only one because it can be very stressful. You know, between having the procedure, the cystoscopy and then getting the results. Sometimes, you know, it's sort of I know it's hard because you can't get an appointment with the urologist sometimes, but, you know, it's a three or four weeks or something like, you know, sitting around wondering.
Participant 007_2022AUBLC

No, I don't get any of that. If anything, I get increased side effects. I've been told that that doesn't signify whether the treatment's working or not. The only way they know is when they go to check to see if there's any more recurrences.
Participant 002_2022AUBLC

Participants reported needing to experience a reduction in physical signs/reduced side effects

Well. Like I said, what I've got now is working. Put it that way. And then I don't have much issue with any of that. It's just a matter of regularly changing the bag on to every couple of days. Got a couple of minor things. Irritation I suppose from the different tapes and stuff that I've used at times, I've stop using a couple of different brands because I found that they were give me a bit of skin reaction. I've been pretty consistent what I'm using at the moment, and I've had no problems for about 3 months now, I think, so. Hmm. Yeah. It's only minor irritation now, but it's just because you've got to be, you don't need an infection on your stomach. So you got to keep putting that back on again. So you've got to be careful with them. You know, you don't get any, any major infection, put it that way. Yeah. You get a bit of redness, you're got to sort of treat it straight away.
Participant 011_2022AUBLC

Well, I don't know. That's the thing. I just when I was having the BCG, I didn't know really. I read about it and I was given information in pamphlets and things about what could happen with side effects. But mostly it didn't happen. And I thought at the time, I don't know whether this is working or not because I don't really feel any different.
Participant 025_2022AUBLC

I mean, you know, that maybe you just you, you feel better. You know, you don't you don't have that many side effects.
Participant 044_2022AUBLC

Participants reported needing to see specific symptom reduction

Of course it would have been worrying if I started weeing blood, weeing claret, weeing red wine again sort of thing. So yeah, that would have been a very quick indicator to go to emergency. But yeah, it was probably that was always the main symptom we were looking for all that. Yeah. It was the end result. During the BCG therapy. It. Yeah. You know, no new thingies growing on the wall of the bladder.
Participant 019_2022AUBLC

Yeah. So far. Yeah. So far, the only thing we've tackled as far as side effects is, is the breathing side of it. That's probably been the most debilitating. And I said it was probably a little bit too early into it to work out whether or not we need to change it or, we'll have a chat with the lung specialist in a couple of weeks. Um. I don't think there's a great deal that we can do about anything else.
Participant 040_2022AUBLC

I think typically particularly the treatment I've been having, has been from a pain management

perspective. And so I guess, I guess I've spoken to my GP or a couple of times to, no actually a number of, quite a number of times to the pain management specialist through the cancer centre. Because post surgery I was having a lot of pain that was quite poorly managed and so I had to get, you know, get, get increases in pain, pain relief. And yet I think, a,s as I mentioned before, I think I would have, I would have ordinarily just been putting up with this for a lot longer than I should have, except for the encouragement and assistance from a friend to actually join, join me in a telehealth appointment and try, trying to explain to the pain management specialist how much pain I actually really was in and how much it was impacting my life.
Participant 041_2022AUBLC

Table 5.25: What needs to change to feel like treatment is working

What needs to change to feel like treatment is working	All participants		Early		Invasive		Advanced		Person with bladder cancer		Carer		Female		Male	
	n=49	%	n=20	%	n=10	%	n=14	%	n=44	%	n=5	%	n=17	%	n=32	%
Participants reported needing to experience evidence of stable disease/no disease progression	24	48.98	12	60.00	3	30.00	6	42.86	21	47.73	3	60.00	12	70.59	12	37.50
Participants reported needing to experience a reduction in physical signs/reduced side effects	14	28.57	5	25.00	6	60.00	3	21.43	14	31.82	0	0.00	5	29.41	9	28.13
Participants reported needing to see specific symptom reduction	13	26.53	3	15.00	2	20.00	5	35.71	10	22.73	3	60.00	2	11.76	11	34.38

What needs to change to feel like treatment is working	All participants		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=49	%	n=29	%	n=19	%	n=15	%	n=33	%	n=20	%	n=28	%
Participants reported needing to experience evidence of stable disease/no disease progression	24	48.98	9	31.03	15	78.95	4	26.67	20	60.61	12	60.00	16	57.14
Participants reported needing to experience a reduction in physical signs/reduced side effects	14	28.57	7	24.14	6	31.58	5	33.33	8	24.24	5	25.00	9	32.14
Participants reported needing to see specific symptom reduction	13	26.53	10	34.48	3	15.79	4	26.67	9	27.27	3	15.00	8	28.57

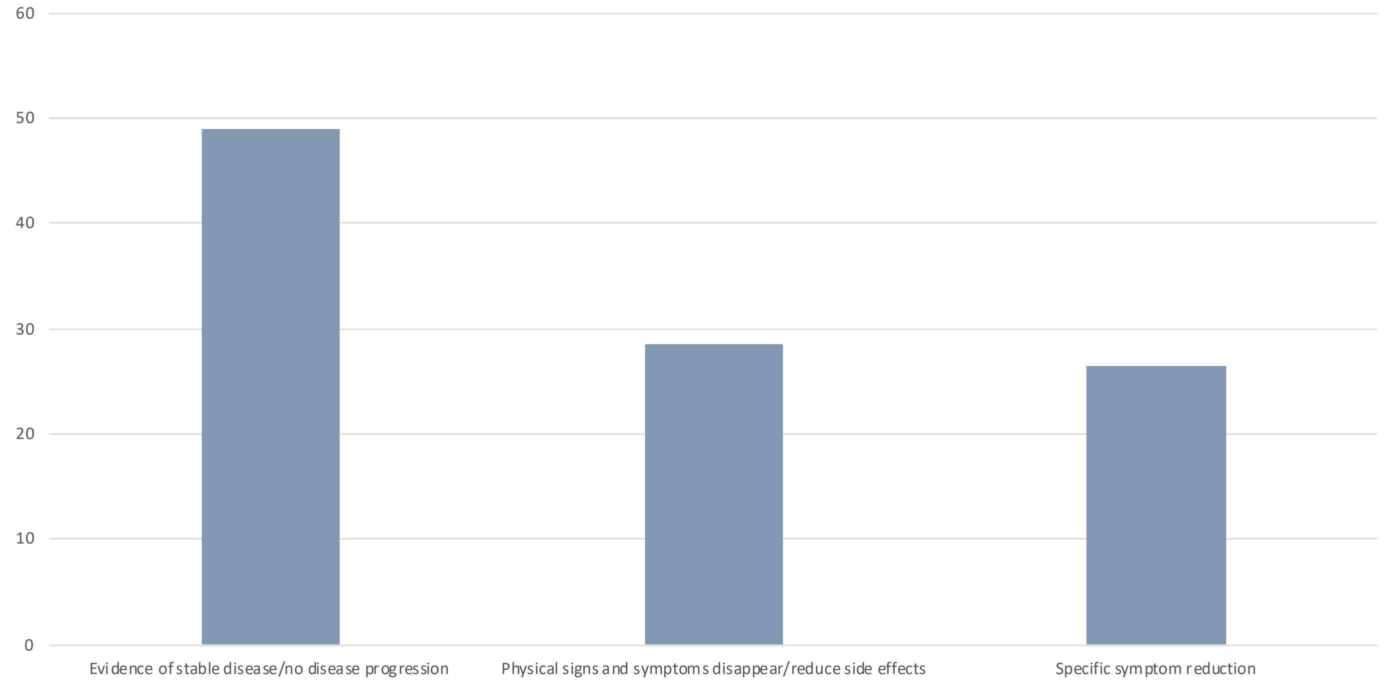


Figure 5.26: What needs to change to feel like treatment is working

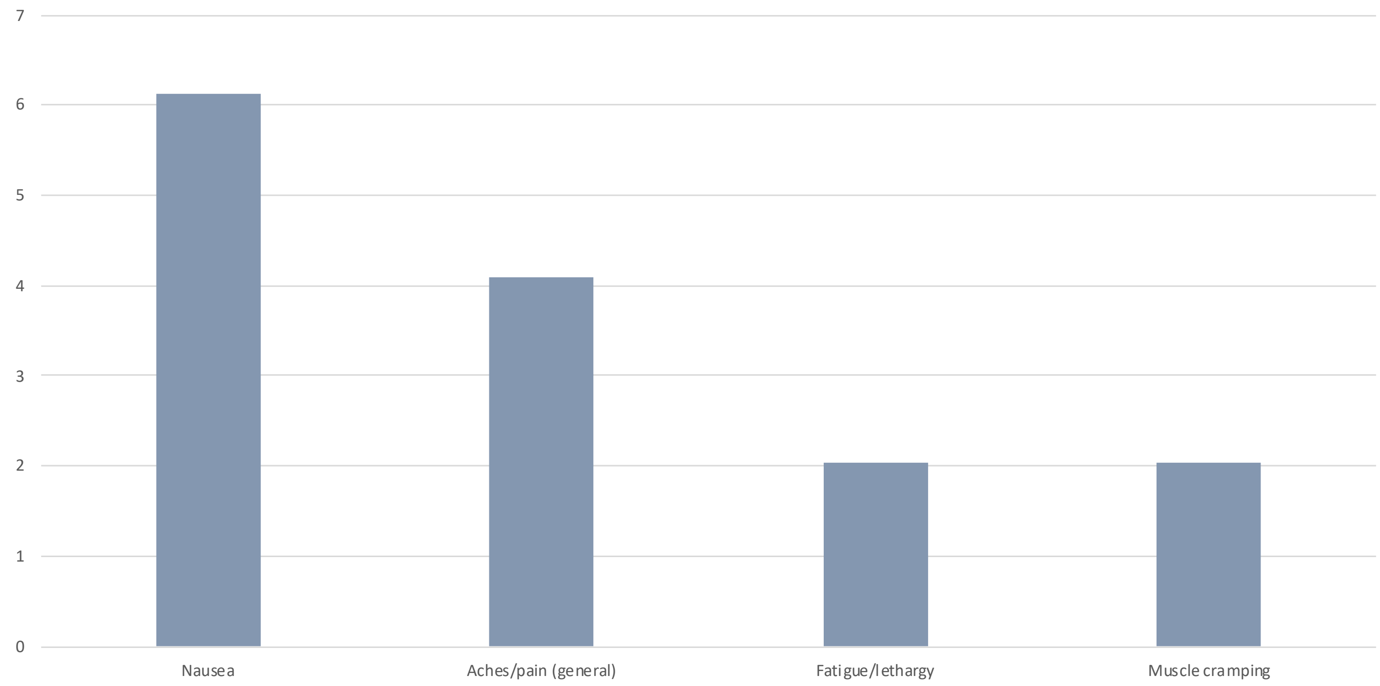


Figure 5.27: What needs to change to feel like treatment is working: specific symptoms

Table 5.26: What needs to change to feel like treatment is working – subgroup variations

What needs to change to feel like treatment is working	Reported less frequently	Reported more frequently
Participants reported needing to experience evidence of stable disease/no disease progression	Invasive (Stage III) Male Trade or high school Regional or remote	Early (Stages 0 and I) Carer to someone with bladder cancer Female University Metropolitan Mid to low status
Participants reported needing to experience a reduction in physical signs/reduced side effects	Carer to someone with bladder cancer	Invasive (Stage III)
Participants reported needing to see specific symptom reduction	Early (Stages 0 and I) Female University Mid to low status	Carer to someone with bladder cancer

What would it mean if treatment worked

Participants were asked what it would mean to them if their treatment worked. The most common response from 16 participants (32.65%) was treatment allowing them to do everyday activities/ return to normal life. There were 12 participants (24.49%) that reported treatment working as having a positive impact on their mental health, 8 participants (16.33%) described treatment leading to a reduction in symptoms/side effects, and 8 participants (16.33%) described treatment allowing them to engage more with social activities and family life. Other participants described that treatment would allow them to keep their bladder (n=6, 12.24%), and allow them to do more exercise (n=6, 12.24%).

Participant describes treatment allowing them to do everyday activities/ return to normal life

So in that case, it would be the anti-spasmodic medication that I was on. Okay. And I can, I can certainly give an example of that because as I said before, when I was just recently before, just in February, and it was suggested that I tried concurrently two different acting anti-spasmodic and they did work because for the three months previous to that, I felt very my bladder was very irritable. I couldn't go for long without emptying my bladder and to the point where I would have to pre-emptively empty my bladder so I wasn't caught unawares. I would occasionally have a spasm that I could not fight with muscles. And you would have to work hard just to make sure that I was not, and if I did happen to have an accident. So going out, it certainly affected my confidence in going out and whereas since I started the two anti-spasmodic for about, about two weeks. I felt a lot more secure in myself about going out and that I could control my bladder and the spasm wasn't as difficult to kind of combat
Participant 010_2022AUBLC

I'm assuming if they'd removed the tumours, I'd be able to carry on with life as I've been doing before I was diagnosed with cancer.
Participant 003_2022AUBLC

Um, I guess if I'd. Yeah, look, it was because until I sort of got an idea of what, what was going on and. Yeah. It was one of those things that really restricted what I did, even if not physically, at least mentally. And, you know, not going to do that because it's really going to hurt after. So it mightn't stop me doing, I don't know, working around the house or something like that. But I, I live on the surf coast in STATE and I'm still, still quite still surf quite often and it really. Yeah. Procrastination is part of the surfing thing, but it took me to a new level. I would just get so, I don't know if I could be bothered today
Participant 006_2022AUBLC

Yeah. No, no, that's okay. Like, just the fact that I can function on a day to day basis. Normally, still, like, I've had, I still have a half a bladder It's not huge, but, um, if it didn't work, then I would have a whole lifestyle change. Yeah. So I still live a very normal life.
Participant 009_2022AUBLC

Participant describes treatment working as having a positive impact on their mental health

Yeah, it would be. Yeah. Because one, you would feel that it's working. It would give you hope that, you know, your cancer is either going to go into remission. And, you know, so it would be great because you could do what you wanted. So you know, I think it would be a good thing.
Participant 032_2022AUBLC

Well, it gave me a lot of peace of mind to think that I didn't have to be continually thinking about, you know, this condition I have and whether it was going to get worse or, uh, at some point or just having to go so regularly for checks and into hospital. I just, it's all a bit of a drag, really. Um. So it would just it would be really peace of mind, I think.
Participant 025_2022AUBLC

PARTICIPANT Oh, it would be great if there was some solution to it because, for his quality of life and mental health quality.

INTERVIEWER What would he be? What would he be able to do if he had that solved?

PARTICIPANT Well, you don't have to panic about going away and go away more often and just start enjoying life.
Carer 001_2022AUBLC

Participant describes treatment leading to a reduction in symptoms/side effects

You know, and I guess that's with the medication that I'm on, I take a HRT tablet and that stops of, you know, it holds off the hot flushes. If I forget to take it for a couple of days, I start to feel like ohh. Can I get back on those drugs!
Participant 022_2022AUBLC

Well, I haven't got to that stage yet, but I suppose if, if it did, it was, you know, I mean, I'd hate to have to wear a bag or something like that. Yeah. You know, I'd feel very self-conscious of that or even embarrassed. Um, But, but I'm fortunate. I'm not in that, I'm not in that position at the moment and hopefully I won't be. But, you know, I know that the, the chance of recurrence is 75, 70, 80%. And I've read some of the articles, academic articles on this. So, you know, I'm, you know, I'm, I'm pragmatic that, you know, it may happen. My biggest fear is having to have the BCG treatment again, even, even now I realise it's, it's probably effective. Um, it's, you know, it's most invasive and the problem is you're awake when you have to be awake when they do it. Yeah. Now, if, if I was asleep or knocked out temporarily, I don't think you'd feel the pain. Or you might feel the pain later, but then you wouldn't feel the pain when they're doing it. Yeah. So it's very hard.
Participant 008_2022AUBLC

What? I mean, I'm very tired now, and, you know, I could plan to go and spend time with my kids on the coast or down the coast. But at the moment, I'll even just to go away for a few days ourselves and I go, well, you know, I've got two treatments and all that week.
Participant 004_2022AUBLC

Participant described treatment allowing them to engage more with social activities and family life

I just want to be able to support and help my, my children or my grandchildren. They're my main priority. And every day, I've got nine of them from 10 to 5 months of age. But every day I see, like they all live within 5 minutes of where I live. Five, 10 minutes. The four kids. Um, I just like to spend time with them, my friends, and go on holidays when I want to. Um. Yeah. Like, if I couldn't do that, I'd be. It'd be pretty devastating. I mean, it's just simple things in life. Just simple things.
Participant 039_2022AUBLC

Well, I well, if, if the treatment was working, I guess he would be less depressed about things. He would

feel able to join in family functions better. He'd be able to travel better. Travel is very difficult because of the pain threshold so, and discomfort so you know if, if there was something that could help those things. It would make life a lot easier.
Carer 005_2022AUBLC

So in that case, it would be the anti-spasmodic medication that I was on. Okay. And I can, I can certainly give an example of that because as I said before, when I was just recently before, just in February, and it was suggested that I tried concurrently two different acting anti-spasmodic and they did work because for the three months previous to that, I felt very my bladder was very irritable. I couldn't go for long without emptying my bladder and to the point where I would have to pre-emptively empty my bladder so I wasn't caught unawares. I would occasionally have a spasm that I could not fight with muscles. And you would have to work hard just to make sure that I was not, and if I did happen to have an accident. So going out, it certainly affected my confidence in going out and whereas since I started the two anti-spasmodic for about, about two weeks. I felt a lot more secure in myself about going out and that I could control my bladder and the spasm wasn't as difficult to kind of combat
Participant 010_2022AUBLC

Participant described treatment allowing them to keep their bladder

Well, what is the next step going to be like? Uh, you know, you have to have a surgery. You would not have to remove my bladder. It's going to be different for my life, I think.
Participant 015_2022AUBLC

Okay. If the BCG had worked and I hadn't got bladder cancer again, then I wouldn't have had to have my bladder removed, which has changed everything for me. So, you know, obviously that would have been better, but it's not the case. So then, you know, I'm not dead, so that's good.
Participant 026_2022AUBLC

Well, I haven't got to that stage yet, but I suppose if, if it did, it was, you know, I mean, I'd hate to have to wear a bag or something like that. Yeah. You know, I'd feel very self-conscious of that or even embarrassed. Um, But, but I'm fortunate. I'm not in that, I'm not in that position at the moment and hopefully I won't be. But, you know, I know that the, the chance of recurrence is 75, 70, 80%. And I've read some of the articles, academic articles on this. So, you know, I'm, you know, I'm, I'm pragmatic that, you know, it may happen. My biggest fear is having to have the BCG treatment again, even, even now I realise it's, it's probably effective. Um, it's, you know, it's most invasive and the problem is you're awake when you have to be awake when they do it. Yeah. Now, if, if I was asleep or knocked out temporarily, I don't think you'd feel the pain. Or you might feel the pain later, but then you wouldn't feel the pain when they're doing it. Yeah. So it's very hard.
Participant 008_2022AUBLC

Participant describes treatment allowing them to do more exercise

Yeah, yeah, definitely. Um, if I didn't have those side effects, um, I, I found myself far less active than what I should have been. I mean, if I can. If I could have found something that would have allowed me to get out into the fresh air more and to be able to do very limited walks, um, you know, some type of physical activity to help my body as well. That, that would have definitely been a big plus.
Participant 035_2022AUBLC

I wouldn't be able to do what I'm doing now. I wouldn't have to go out. I wouldn't be able to see the grandkids as much or I wouldn't be able to enjoy life as much as what I am. That's okay. I still want to feel not alone now that I'm 74 years of age and I'm still very cautious about it. And that's because the treatments actually buggered my dosage getting my vaccinations and all that done on that too. You know, it sort of put me behind the 8 ball with some of it. So that's about the main things it',s it's affected, you know, but I've been out a few weekends out in the kayak before the weather got a bit cooler. I'm looking forward to next spring and next spring and summer actually getting out in the kayak a bit more often. But I'm walking regularly, which I'm struggling to do prior, because I'd have to go somewhere where I can stop and have a squirt, maybe four or 500 metres, you know, very, very awkward. Then I was walking around my backyard, you know, and I've got a big back yard, but not that big. But at least I can go for walk down the street now and you know, whatever.
Participant 011_2022AUBLC

Participant describes treatment allowing them to be cancer free/cured/ live longer

Look forward to being around for quite a bit longer. Um. Yeah. If my life just get back to normal, get on, you know, enjoy life, enjoy life. And, um. Yeah. Work, work, family. All of that sort of thing.
Participant 016_2022AUBLC

PARTICIPANT If it wasn't doing this job, I wouldn't be here.

INTERVIEWER Yeah. Right.

PARTICIPANT There, There would be fear, there would be frustration. And in my case, there wouldn't be any life. Absolutely not.
Participant 038_2022AUBLC

Participant describes that they would keep trying new treatments, if their treatment did not work.

If it wasn't working. Let's try it, or maybe try something else, which I've done, or just change my diet. Probably not that I drink much, but I'll probably give up alcohol and just try to lead a more and more healthy lifestyle, more exercise. I find the best thing for me, for anything I've had in the past, is when I want to do my walking. I walk from my place around the SPORTGROUND, which I live next to and. It's better. Okay. I feel much, much better when I do that.
Participant 021_2022AUBL

When you look at alternative treatments, really, I mean, it's. But it's changing diet or another type of chemotherapy or having to actually get the, you know, your bladder removed and having a new bladder put in or a stoma. I mean, you just have to look at everything. Just ultimately you want to live. So that's the cancer, not going away just to try what the other options are. And there are others, you know, from what I'm aware of now, that seems to do as it progresses or if it gets worse. But. Yeah. So we just have go through the process.
Participant 024_2022AUBLC

In my words. Yeah, probably wouldn't be here. I probably wouldn't be here because the cancer would just keep spreading. So if we don't go through it and it doesn't work well, you go to the next, next option and you go the next option. But soon enough you are going to run out of options.
Participant 033_2022AUBLC

Table 5.27: What would it mean if treatment worked

What would it mean if treatment worked	All participants		Early		Invasive		Advanced		Person with bladder cancer		Carer		Female		Male	
	n=49	%	n=20	%	n=10	%	n=14	%	n=44	%	n=5	%	n=17	%	n=32	%
Participant describes treatment allowing them to do everyday activities/ return to normal life	16	32.65	8	40.00	3	30.00	**3**	**21.43**	14	31.82	2	40.00	6	35.29	10	31.25
Participant describes treatment working as having a positive impact on their mental health	12	24.49	3	15.00	3	30.00	3	21.43	9	20.45	**3**	**60.00**	5	29.41	7	21.88
Participant describes treatment leading to a reduction in symptoms/side effects	8	16.33	4	20.00	2	20.00	2	14.29	8	18.18	**0**	**0.00**	**5**	**29.41**	3	9.38
Participant described treatment allowing them to engage more with social activities and family life	8	16.33	5	25.00	**0**	**0.00**	1	7.14	6	13.64	**2**	**40.00**	4	23.53	4	12.50
Participant described treatment allowing them to keep their bladder	6	12.24	4	20.00	2	20.00	**0**	**0.00**	6	13.64	**0**	**0.00**	3	17.65	3	9.38
Participant describes treatment allowing them to do more exercise	6	12.24	3	15.00	**0**	**0.00**	3	21.43	6	13.64	**0**	**0.00**	**0**	**0.00**	6	18.75
Participant describes treatment allowing them to be cancer free/cured/ live longer	3	6.12	1	5.00	0	0.00	2	14.29	3	6.82	0	0.00	1	5.88	2	6.25
Participant describes that they would keep trying new treatments, if their treatment did not work.	3	6.12	0	0.00	2	20.00	1	7.14	3	6.82	0	0.00	0	0.00	3	9.38

What would it mean if treatment worked	All participants		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=49	%	n=29	%	n=19	%	n=15	%	n=33	%	n=20	%	n=28	%
Participant describes treatment allowing them to do everyday activities/ return to normal life	16	32.65	11	37.93	**4**	**21.05**	**7**	**46.67**	8	24.24	8	40.00	8	28.57
Participant describes treatment working as having a positive impact on their mental health	12	24.49	7	24.14	5	26.32	**6**	**40.00**	6	18.18	3	15.00	7	25.00
Participant describes treatment leading to a reduction in symptoms/side effects	8	16.33	6	20.69	2	10.53	2	13.33	6	18.18	4	20.00	5	17.86
Participant described treatment allowing them to engage more with social activities and family life	8	16.33	5	17.24	3	15.79	3	20.00	5	15.15	5	25.00	4	14.29
Participant described treatment allowing them to keep their bladder	6	12.24	2	6.90	4	21.05	**4**	**26.67**	2	6.06	4	20.00	2	7.14
Participant describes treatment allowing them to do more exercise	6	12.24	5	17.24	1	5.26	1	6.67	5	15.15	3	15.00	4	14.29
Participant describes treatment allowing them to be cancer free/cured/ live longer	3	6.12	2	6.90	1	5.26	1	6.67	2	6.06	1	5.00	1	3.57
Participant describes that they would keep trying new treatments, if their treatment did not work.	3	6.12	2	6.90	1	5.26	0	0.00	3	9.09	0	0.00	2	7.14

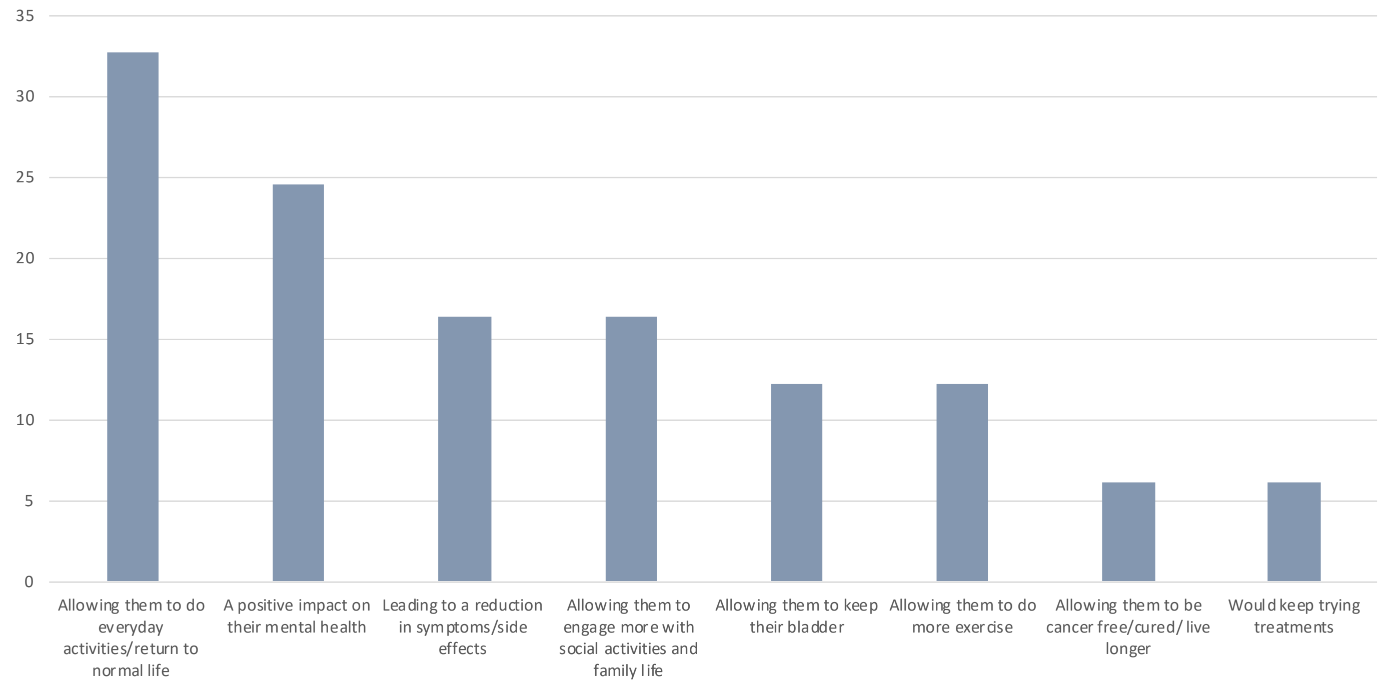


Figure 5.28: What would it mean if treatment worked

Table 5.28: What would it mean if treatment worked – subgroup variations

What would it mean if treatment worked	Reported less frequently	Reported more frequently
Participant describes treatment allowing them to do everyday activities/ return to normal life	Advanced (Stage IV) University	Regional or remote
Participant describes treatment working as having a positive impact on their mental health	-	Carer to someone with bladder cancer Regional or remote
Participant describes treatment leading to a reduction in symptoms/side effects	Carer to someone with bladder cancer	Female
Participant described treatment allowing them to engage more with social activites and family life	Invasive (Stage III)	Carer to someone with bladder cancer
Participant described treatment allowing them to keep their bladder	Advanced (Stage IV) Carer to someone with bladder cancer	Regional or remote
Participant describes treatment allowing them to do more exercise	Invasive (Stage III) Carer to someone with bladder cancer Female	-

Section 6

Information and communication

Section 6: Information and communication

Access to information

In the structured interview, participants were asked what information they had been able to access since they were diagnosed. The most common type of information accessed by 41 participants (83.67%) was the internet in general, this was followed by accessing information through a bladder cancer charity (n=32, 65.31%), and through other patient's experience (n=24, 48.98%). Other participants described accessing information from books, pamphlets and newsletters (n=16, 32.65%), through treating clinician (n=13, 26.53%), through international sources (n=13, 26.53%), through Facebook and/or social media (n=9, 18.37%), and through journals (research articles) (n=8, 16.33%).

Where participants mentioned specific health charities, these were most commonly BEAT Bladder Cancer Australia (n=19, 38.78%), Cancer Council (n=18, 36.73%), and Bladder Cancer Awareness Australia (n=5, 10.20%).

Information that was helpful

In the structured interview, participants were asked to describe what information they had found to be *most* helpful. The most common type of information found to be helpful by 16 participants (32.65%) was information from health charities. There were 14 participants (28.57%) that described information from other people's experiences as helpful, and 14 participants (28.57%) that described hearing what to expect (e.g. from disease, side effects, treatment) as being helpful. Other types of information described as being helpful included treatment options (n=10, 20.41%), talking to their doctor or specialist (n=8, 16.33%), information specific to their condition (n=8, 16.33%), and information about stoma management or from their stoma nurse (n=7, 14.29%).

Information that was not helpful

In the structured interview, participants were asked if there had been any information that they did not find to be helpful. There were 22 participants (44.90%) that responded that no information was not helpful, and 7 participants (14.29%) that were confident in deciding if something is not helpful (or not credible). The most common type of information found to be unhelpful by 9 participants (18.37%) was from their GP or specialist, this was followed by worse case scenarios (n=5, 10.20%), and a lack of information in general, and lack of community awareness as not helpful (n=5, 10.20%).

Information preferences

Participants were asked whether they had a preference for information online, talking to someone, in written (booklet) form or through a phone App. Overall, the most common theme was talking to someone plus online information (n=17, 34.69%), followed by talking to someone (n=14, 28.57%), online (n=14, 28.57%), and written information preference (n=11, 22.45%).

The main reasons for a preference for online information were accessibility, being able to digest information at their own pace, and finding personalised or relevant information. The main reasons for talking to someone as a preference were being able to ask questions, get personalised or relevant information, and feeling supported. The main reason for written material as a preference was being able to refer back to it.

Timing of information

Participants in the structured interview were asked to reflect on their experience and to describe when they felt they were most receptive to receiving information. The most common time that participants described being receptive to receiving information after the shock of diagnosis (n=18, 36.73%), this was followed by participants describing being receptive to information from the beginning when diagnosed (n=13, 26.53%), after the start of treatment (n=9, 18.37%), and continuously throughout their experience or bit-by-bit so that it is digestible (n=9, 18.37%). Other participants described being receptive to information after they have had time to learn about condition/thought about questions to ask their healthcare professional (n=7, 14.29%), and a month after diagnosis (n=5, 10.20%).

Healthcare professional communication

Participants were asked to describe the communication that they had had with health professionals throughout their experience. The most common theme was that participants described having an overall positive experience (n=22, 44.90%). There were 13 participants (26.53%) that described an overall positive experience, with the exception of one or two occasions, 9 participants (18.37%) that had an overall negative experience and 4 participants (8.16%) that had an overall negative experience.

Healthcare professional communication (Rationale for response)

Participants described reasons for positive or negative communication with healthcare professionals.

Participants that had positive communication, described the reason for this was because of holistic, two-way, supportive and comprehensive conversations (n=18, 36.73%), and this was followed by participant describing good communication with no particular reason given (n=17, 34.69%).

The main reasons for negative communication was limited communication that was not supportive, or empathetic (n=10, 20.41%), that information about treatment being withheld or given too late (n=8, 16.33%), and was limited in relation to their understanding of the condition (n=6, 12.24%)

Partners in health

The Partners in Health questionnaire (PIH) measures an individual's knowledge and confidence for managing their own health. The Partners in Health comprises a global score, 4 scales; knowledge, coping, recognition and treatment of symptoms, adherence to treatment and total score. A higher score denotes a better understanding and knowledge of disease.

The **Partners in Health questionnaire (PIH)** measures an individual's knowledge and confidence for managing their own health.

The **Partners in health: knowledge** scale measures the participants knowledge of their health condition, treatments, their participation in decision making and taking action when they get symptoms. On average, participants in this study had very good knowledge about their condition and treatments.

The **Partners in health: coping** scale measures the participants ability to manage the effect of their health condition on their emotional well-being, social life and living a healthy life (diet, exercise, moderate alcohol and no smoking). On average, participants in this study had a good ability to manage the effects of their health condition.

The **Partners in health: treatment** scale measures the participants ability to take medications and complete treatments as prescribed and communicate with healthcare professionals to get the services that are needed and that are appropriate. On average participants in this study had a very good ability to adhere to treatments and communicate with healthcare professionals.

The **Partners in health: recognition and management of symptoms** scale measures how well the participant attends all healthcare appointments, keeps track of signs and symptoms, and physical activities. On average participants in this study had very good recognition and management of symptoms.

The **Partners in health: total score** measures the overall knowledge, coping and confidence for managing their own health. On average participants in this study had a good overall knowledge, coping and confidence for managing their own health.

Information given by health professionals

Participants were asked about what type of information they were given by healthcare professionals, information about treatment options (n=38, 80.85%), disease management (n=23, 48.94%), disease cause (n=22, 46.81%), and physical activity (n=16, 34.04%) were most frequently given to participants by healthcare professionals, and, information about complementary therapies (n=3, 6.38%), how to interpret test results (n=3, 6.38%) and, hereditary considerations (n=0, 0.00%) were given least often.

Information searched independently

Participants were then asked after receiving information from healthcare professionals, what information did they need to search for independently. The topics participants most often searched for were treatment options (n=28, 59.57%), disease cause (n=26, 55.32%), disease management (n=21, 44.68%) and, how interpret test results (n=18, 38.30%) were most frequently searched for independently and, information about physical activity (n=13, 27.66%), clinical trials (n=10, 21.28%), and hereditary considerations (n=7, 14.89%) were searched for least often.

Information gaps

The largest gaps in information, where information was neither given to patients nor searched for independently were hereditary considerations (n=40, 85.11%) and clinical trials (n=33, 70.21%).

The topics that participants did not search for independently after receiving information from healthcare professionals were treatment options (n=22, 46.81%) and disease Cause (n=12, 25.53%).

The topics that participants were given most information from both healthcare professionals and searching independently for were treatment options (n=16, 34.04%) and disease management (n=12, 25.53%).

The topics that participants searched for independently after not receiving information from healthcare professionals were how to interpret test results (n=17, 36.17%), and disease cause (n=14, 29.79%).

Most accessed information

Participants were asked to rank which information source that they accessed most often, where 1 is the most trusted and 4 is the least trusted. Across all participants, information from Non-profit organisations, charity or patient organisations and the hospital or clinic where treated. Information from Pharmaceutical companies were least accessed.

My Health Record

My Health Record is an online summary of key health information, an initiative of the Australian Government. There were 16 participants (33.33%) had accessed My Health Record.

Of those that had accessed My Health Record, there were 11 participants (68.75%) who found it to be poor or very poor, 4 participants (25.00%) who found it acceptable, and 1 participant (6.25%) who found it to be good or very good.

Access to information

In the structured interview, participants were asked what information they had been able to access since they were diagnosed. The most common type of information accessed by 41 participants (83.67%) was the internet in general, this was followed by accessing information through a bladder cancer charity (n=32, 65.31%), and through other patient's experience (n=24, 48.98%). Other participants described accessing information from books, pamphlets and newsletters (n=16, 32.65%), through treating clinician (n=13, 26.53%), through international sources (n=13, 26.53%), through Facebook and/or social media (n=9, 18.37%), and through journals (research articles) (n=8, 16.33%).

Where participants mentioned specific health charities, these were most commonly BEAT Bladder Cancer Australia (n=19, 38.78%), Cancer Council (n=18, 36.73%), and Bladder Cancer Awareness Australia (n=5, 10.20%).

Participant describes accessing information through the internet in general

Um, I've unfortunately been best friends with Dr. Google. I do a lot of research on my own, um, because, honestly, I don't get much information from my care providers. Um, but basically I was just more looking for information on my type of cancer. Um, what? You know, the life expectancy after five years and, you know, all those kind of questions that you need to know to ease the mind.
Participant 009_2022AUBLC

Um, yeah. When I was first diagnosed, I just googled and went from there. Found a support group on social media, spoke to the Cancer, Cancer Council, and it just went from there.
Participant 033_2022AUBLC

Yeah. Yeah. I think that, you know, they, you know, they're always saying, you know, don't don't go searching information, you'll get wrong information and stuff. But I think that. I think that you have to do that anyway. I think that I think it's good to do that because at least, you know, you look at the worst case scenarios, you look at options, and you do learn a lot by just searching. Um. You know, because doctors don't tell you that much. And you know, they might give you a couple of pamphlets still, still don't answer your questions. So if you didn't do a bit of research yourself and I like to do the research and get my head around what the problem is and. But yeah, I know lots of people that don't like to do that. So so I think we just all do what we need to do.
Participant 026_2022AUBLC

Participant describes accessing information from a specific health charity

So my wife very quickly found this BEAT bladder cancer dot org website. I think it's an association that has been my primary source. They have everything laid out. They've got videos from urologists that explains all the things. Great online resources. Cancer Council STATE, which seems just a broader part of Cancer Council, have got great documents, really simple to read 50 page booklets on what it means to have bladder cancer, all the different types dealing with telling your kids, dealing with the sexual side or the impact on the sex life around those sort of things. We've also joined this support group that I've talked about, which is, again, an extension of the BEAT Bladder Cancer Association. And I've also joined a couple of different Facebook groups that are support groups where people post how they're going or challenges they're having or just what are people have done when this fork in the road, you know, getting that sort of again, that peer feedback from other people.
Participant 017_2022AUBLC

Mostly from the Internet. Um, mostly I'm answering this in reverse, mostly from Cancer Council literature, both here and, and some of the American stuff and the British stuff. So it's yeah, it's usually the internet that I find out information from.
Participant 006_2022AUBLC

PARTICIPANT: Yeah, I, I sought all sorts of information. I did find fairly early on them BCAN forum, which is, which is um, in America. But they they get people from all over the world sort of asking questions and and contributing. And that's reasonably good. Then at the end of 2019, I found the BEAT bladder cancer group and also the bladder Cancer Australia with another organisation. I think it's more based in Melbourne and the BEAT especially has been wonderful because they have, you know, much about BEAT?.

INTERVIEWER: No, I don't. Sorry.

PARTICIPANT: Okay. So BEAT is an organisation that was strung out as a family's losses. Their 45 year old mother died of bladder cancer. They she had two

young children, very similar. Very similar, although the children are a bit older. And I think she was a bit older than Jane McGrath, but certainly a similar scenario. And her husband then started a charitable organisation in her memory to to sponsor the recognition of bladder cancer because it's such an unknown cancer. And BEAT stands for bladder cancer Education, Awareness and Treatment. So and they started off with meetings at Macquarie University Hospital once a month. So I went to a couple of those and then of course COVID hit. So yeah, they changed to having Zoom meetings. And the good thing about that is, of course, once they spread, tried to spread, that the awareness of the existence of this group and people from all over Australia tuned in and joined and it's been very, very beneficial to all these people. They are, they're very, become a very cohesive, supportive group in every way it should be here.
Participant 010_2022AUBLC

Participant describes primarily accessing information through other patient's experience

Yeah. It's actually quite a lot. I suppose. When you have a medical condition, you tend to get close minded about it and the whole universe sort of circles around your own condition. But I imagine that that applies to every condition that you can think or, you know, some that from an itchy nose to a stubbed foot. The um, I don't think there's any real. Just try to think of that. Well. There is a tremendous wealth of knowledge that I have found in and my wife, found through the relevant associations of this condition. And I imagine all conditions having an association somewhere. It's usually buried as part of the council. The Cancer Council umbrella. There's a lot of different types of cancers and different types of associations with them, of course, and there's really so much information out there that you just can't handle it, or even if it's there, if you need it. And it has proved very useful. Particularly useful at the outset when you first, when you first contemplating whether to have the operation or not. Getting online to people that have had it is a big plus. It really does give you some inspiration. Both for then and later. And I think something that probably applies to all forms of cancer, you know, it's like bonding, I guess, and bonding that other people go through.
Participant 034_2022AUBLC

Mainly the bladder council. There was some information on that. The BEAT support group where they have as I said to you, they have guest speakers, in fact, just on Tuesday night was a fantastic guest speaker. It was a urologist from Macquarie University Hospital, I think, and he spoke for 40 minutes about BCG and I learnt so much about BCG, this far down the track. And then after. they've had a guest speaker, they've had a physiotherapist come that was also good that had the histologist come, a whole lot of things. And then they have a roundtable conversation where. Perhaps somebody that's new and they're on the Zoom meeting for the first time and are being told that they need to have their bladder removed and they want to ask who here has, had the bladder removed, and they'll get feedback from various members that have been through that experience. So that's been really good. But as I say, also really scary because you see the worst case scenarios and then, just Google. I've had, no I think I got given a bit of a one page leaflet from the urologist on bladder cancer that just talked about the treatment for BCG. But that's been it really it. The nurses were too busy to really talk to you at great length.
Participant 036_2022AUBLC

Well, we actually funny enough, my daughter came to me and she said, Mum, I found these girls in Melbourne whose father passed away from bladder cancer and they'd really like to talk to you. So, anyhow, long story short, they run a support service of Bladder Cancer Australia. And so we join that support group, and we have been out on a few functions with them and met quite a few different members. And we just came back from a retreat in February with them all. And it was really nice to hear everybody's stories and meet them. And their quality of life and what kind of treatments they've had and everyone was just so different.
Carer 001_2022AUBLC

Participant describes receiving information from books, pamphlets and newsletters

Really, the only information I mean, as I said, I was given pamphlets before the BCG treatment about what to expect. Um, but really the only information I've had is from looking on the internet . And I also am part of the Facebook group Bladder Cancer Awareness Group. So I joined up so pretty early, this about six months after I was diagnosed. So I haven't had any other information.
Participant 025_2022AUBLC

So my wife very quickly found this BEAT bladder cancer dot org website. I think it's an association that has been my primary source. They have everything laid out. They've got videos from urologists that explains all the things. Great online resources. Cancer Council STATE, which seems just a broader part of

Cancer Council, have got great documents, really simple to read 50 page booklets on what it means to have bladder cancer, all the different types dealing with telling your kids, dealing with the sexual side or the impact on the sex life around those sort of things. We've also joined this support group that I've talked about, which is, again, an extension of the BEAT Bladder Cancer Association. And I've also joined a couple of different Facebook groups that are support groups where people post how they're going or challenges they're having or just what are people have done when this fork in the road, you know, getting that sort of again, that peer feedback from other people.
Participant 017_2022AUBLC

The Cancer Council of course, I got a , which you'll know about, you know, the booklet they've got, which is very good. Um, there's a lot of stuff online, I believe, from reputable sources that, that I, uh, I read a lot of that stuff. They tell you the same sort of thing. So, and it doesn't, it doesn't say anything about, you, it says something about, you know, what the cancer is about and what stages and that sort of thing. So it doesn't really give you an answer for you how long, you know, you're going to be around. Yeah. The other thing which was important was I got an invite to join BEAT, B.E.A.T, bladder something I can't remember what it is called which is run by clinical and uh, other people. And it's a sort of self-help talk. Zoom. Zoom meetings.
Participant 029_2022AUBLC

Participant describes primarily accessing information through treating clinician

Um, basically the internet. But, um, you know, she just looking at what a stoma actually was. Um, we found out a lot of information from the actual specialist regarding the neobladder, because that is what he specialises in. More so than removal, than the stoma. But just looking at side effects and what the what the possibility. If I had to have radio radiotherapy or chemotherapy.
Participant 027_2022AUBLC

Uh, we got a whole heap of information. Um, but we did a bit of research on the net. Um. As far, as muscular invasive bladder cancer, when our urologist gave us a couple of pamphlets to read up on to start with. Um. And, uh. And then when we had our interview. With one of the nurses at the renal unit in the HOSPITAL, she gave us a lot more information abou. bladder cancer, and neo bladder and all that kind of stuff. So, we were, we were pretty sure at that point roughly about what was what was coming up.
Participant 040_2022AUBLC

Well, the information, the information that I received was from Doctor NAME, he gave me papers 2 papers, a few sheets of paper to explain what would happen and what the options were for this operation. Um, I didn't look on Google, but lots and lots of people do apparently, because I think that can be can probably cause more anxiety than it's worth, but then hopes. And he explained to me the options or what would have to happen.
Participant 043_2022AUBLC

PARTICIPANT In general, it just would have been the health professionals that gave us booklets, bladder cancer booklets. I sourced a lot of my information from my bladder cancer support group.

INTERVIEWER Online.

PARTICIPANT Online yes. That was the main thing, really. And asking the questions like I guess with the professionals when we're at appointments, I'd always write things down, put them in a book, write them down and take notes and. Yeah.
Carer 002_2022AUBLC

Participant describes accessing information primarily through international sources

Okay. So so basically the information I sought out since diagnosis was the Understanding Bladder Cancer booklet, which is a Cancer Council booklet. There really wasn't a lot of rest for bladder cancer for Australians. So, you know, there was no Australian website to go to. So we looked at the overseas websites. I mean I'm not sure when I, you know, in the few weeks I had to make this decision, I was up to joining a support group. But I mean, that's that's a fabulous resource. And looking back on it now, it would have been good if I'd known that there was one. Well, not not not face to face one, but it would have been good to have been able to think about asking some questions there. So basically the information I have sought out is, you know, information on neobladders and what other people do and how they manage with them.
Participant 032_2022AUBLC

I've got. I guess sort of a science background. So I would just look for medical journals and use those as the point of reference, and basic government stuff. And that's okay. And the American stuff. The British stuff for bladder of cancer is probably better than the American, and recommended by the urologist as well,

so that was good. Recommended such confirmed. And, generally speaking, there's only a few good reports, or journal articles on BCG in the last probably five years or ten years or whatever. Most of them are quite specific, but just general ones about the efficacy of BCG and stuff like that. There's some good ones, so I'd read those, understand what it was about as best I could, not getting too scientific about it, but just understanding likely success on how it works as best people can describe it.
Participant 030_2022AUBLC

Participant describes accessing information primarily through Facebook and/or social media

Um, yeah. When I was first diagnosed, I just googled and went from there. Found a support group on social media, spoke to the Cancer, Cancer Council, and it just went from there.
Participant 033_2022AUBLC

Just what's on Google and what's been on Facebook. My surgeon doesn't want me to use Facebook. He wants me to be on the bladder cancer sites. He said to me, they make people depressed and they make them more worried. And he's, that's your opinion. You know, he's just sort of against social media, but he's worried about it for me to hear everyone's negative stories about losing their bladders and things. And he said it's in his opinion, it's not good for your emotional well-being.
Participant 001_2022AUBLC

Mainly government. So it's just to try and get a bit of independence as opposed to, you know, I know the pharmaceutical companies develop the products and things, but this tends to make it more of a sales pitch. So I've gone to mainly independent organisations, cancer councils and things like that and government sponsored websites just to try and get a bit more of a, an independent view of it. And then yeah, as I say, a couple of the support groups that, that I'm on. One support group on the on Facebook, there's a sort of Australia-New Zealand bladder cancer support group just sort of saying, yeah, what other people have done and are doing and all of that.
Participant 014_2022AUBLC

Participant describes accessing information primarily through journals (research articles)

Um, well, I got very little from the hospital. I got all the information, that's true, Googling through medical journals, through the BEAT bladder cancer website and support group. Um. That's probably where I've got most of my information. The bladder, called BCAN , which is American based. Web site for this sort of thing. I've done a lot of, I am a HEALTHCARE PROFESSIONAL, so I do it to different medical journals to try and get urology journals to try and get whatever information is available.
Participant 002_2022AUBLC

Well, I like looking at them. Well, general searches on the Internet at the Mayo Clinic in America. Find the, their information is very good. I didn't know that they existed until I actually had a blood test. And the person who gave me a blood test, the pathology collector, had bladder cancer herself. She was the one who gave me the information about it. So then I looked up that group that the like the Bladder Cancer Society or whatever they are, what comes under the Cancer Council, whoever they are. Yeah. Um, uh, I've got access to some databases, so I've looked at some academic articles about BCG treatment and you know, because that gave me reassurance that a lot of people, not a lot, but quite a few people find it too difficult to continue BCG
Participant 008_2022AUBLC

I've got. I guess sort of a science background. So I would just look for medical journals and use those as the point of reference, and basic government stuff. And that's okay. And the American stuff. The British stuff for bladder of cancer is probably better than the American, and recommended by the urologist as well, so that was good. Recommended such confirmed. And, generally speaking, there's only a few good reports, or journal articles on BCG in the last probably five years or ten years or whatever. Most of them are quite specific, but just general ones about the efficacy of BCG and stuff like that. There's some good ones, so I'd read those, understand what it was about as best I could, not getting too scientific about it, but just understanding likely success on how it works as best people can describe it.
Participant 030_2022AUBLC

Table 6.1: Access to information.

Access to information	All participants		Early		Invasive		Advanced		Person with bladder cancer		Carer		Female		Male	
	n=49	%	n=20	%	n=10	%	n=14	%	n=44	%	n=5	%	n=17	%	n=32	%
Participant describes accessing information through the internet in general	41	83.67	17	85.00	9	90.00	12	85.71	38	86.36	3	60.00	14	82.35	27	84.38
Participant describes accessing information from a specific health charity	32	65.31	15	75.00	5	50.00	8	57.14	28	63.64	4	80.00	12	70.59	20	62.50
Participant describes primarily accessing information through other patient's experience	24	48.98	8	40.00	5	50.00	8	57.14	21	47.73	3	60.00	9	52.94	15	46.88
Participant describes receiving information from books, pamphlets and newsletters	16	32.65	4	20.00	3	30.00	7	50.00	14	31.82	2	40.00	7	41.18	9	28.13
Participant describes primarily accessing information through treating clinician	13	26.53	6	30.00	1	10.00	4	28.57	11	25.00	2	40.00	6	35.29	7	21.88
Participant describes accessing information primarily through international sources	13	26.53	6	30.00	3	30.00	4	28.57	13	29.55	0	0.00	4	23.53	9	28.13
Participant describes accessing information primarily through Facebook and/or social media	9	18.37	7	35.00	0	0.00	2	14.29	9	20.45	0	0.00	5	29.41	4	12.50
Participant describes accessing information primarily through journals (research articles)	8	16.33	4	20.00	0	0.00	2	14.29	6	13.64	2	40.00	3	17.65	5	15.63

Access to information	All participants		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=49	%	n=29	%	n=19	%	n=15	%	n=33	%	n=20	%	n=28	%
Participant describes accessing information through the internet in general	41	83.67	25	86.21	16	84.21	13	86.67	28	84.85	18	90.00	23	82.14
Participant describes accessing information from a specific health charity	32	65.31	19	65.52	12	63.16	10	66.67	21	63.64	13	65.00	18	64.29
Participant describes primarily accessing information through other patient's experience	24	48.98	14	48.28	10	52.63	5	33.33	19	57.58	10	50.00	14	50.00
Participant describes receiving information from books, pamphlets and newsletters	16	32.65	8	27.59	8	42.11	5	33.33	11	33.33	4	20.00	12	42.86
Participant describes primarily accessing information through treating clinician	13	26.53	8	27.59	5	26.32	5	33.33	8	24.24	6	30.00	7	25.00
Participant describes accessing information primarily through international sources	13	26.53	9	31.03	3	15.79	3	20.00	9	27.27	5	25.00	7	25.00
Participant describes accessing information primarily through Facebook and/or social media	9	18.37	4	13.79	5	26.32	4	26.67	5	15.15	4	20.00	5	17.86
Participant describes accessing information primarily through journals (research articles)	8	16.33	3	10.34	5	26.32	3	20.00	5	15.15	4	20.00	4	14.29

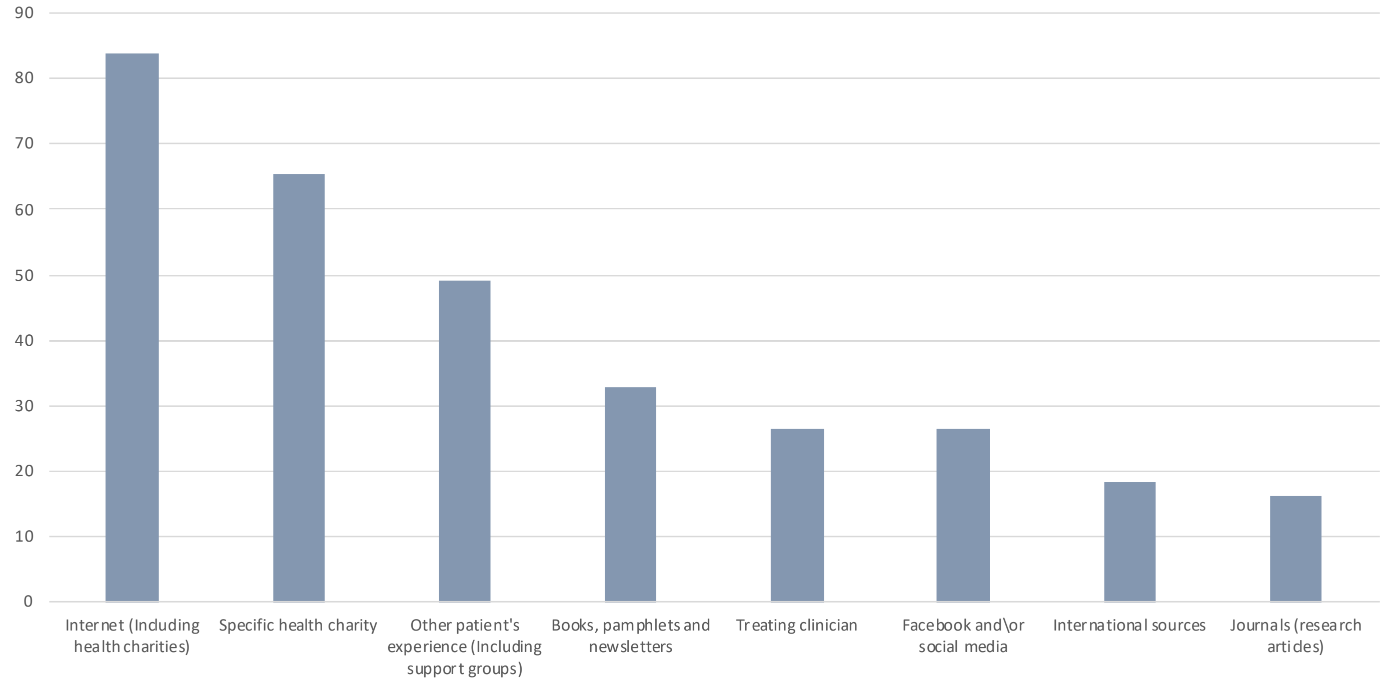


Figure 6.1: Access to information

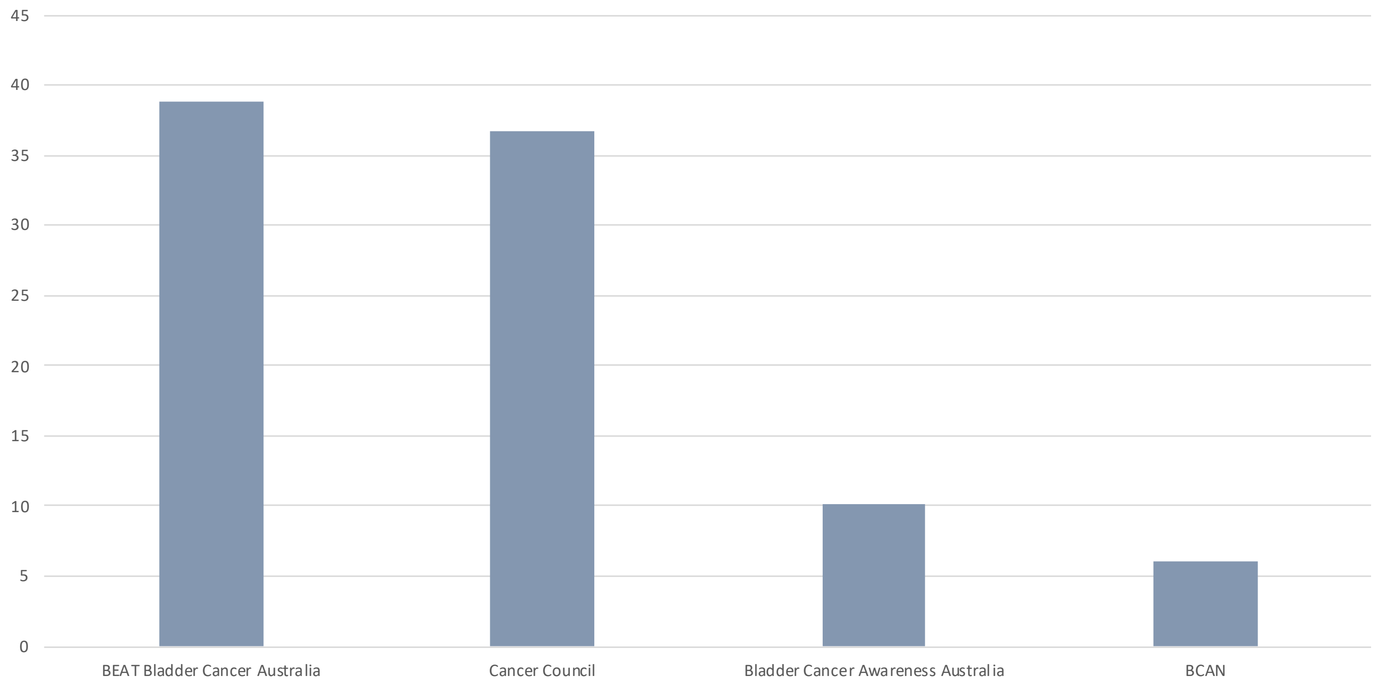


Figure 6.2: Specific charities

Table 6.2: Access to information – subgroup variations

Access to information	Reported less frequently	Reported more frequently
Participant describes accessing information through the internet in general	Carer to someone with bladder cancer	-
Participant describes accessing information from a specific health charity	Invasive (Stage III)	Carer to someone with bladder cancer
Participant describes primarily accessing information through other patient's experience	Regional or remote	Carer to someone with bladder cancer
Participant describes receiving information from books, pamphlets and newsletters	Early (Stages 0 and I) Mid to low status	Advanced (Stage IV) Higher status
Participant describes primarily accessing information through treating clinician	Invasive (Stage III)	Carer to someone with bladder cancer
Participant describes accessing information primarily through international sources	Carer to someone with bladder cancer University	-
Participant describes accessing information primarily through Facebook and/or social media	Invasive (Stage III) Carer to someone with bladder cancer	Early (Stages 0 and I) Female
Participant describes accessing information primarily through journals (research articles)	Invasive (Stage III)	Carer to someone with bladder cancer

Information that was helpful

In the structured interview, participants were asked to describe what information they had found to be *most* helpful. The most common type of information found to be helpful by 16 participants (32.65%) was information from health charities. There were 14 participants (28.57%) that described information from other people's experiences as helpful, and 14 participants (28.57%) that described hearing what to expect (e.g. from disease, side effects, treatment) as being helpful. Other types of information described as being helpful included treatment options (n=10, 20.41%), talking to their doctor or specialist (n=8, 16.33%), information specific to their condition (n=8, 16.33%), and information about stoma management or from their stoma nurse (n=7, 14.29%).

Participant describes health charities information as helpful

Um, I've just found just the booklets from the Cancer Council. I've just found that they have been excellent information sources. Um, but because it just depends like every, night, like I have random thought and they kind of answer my questions like, you know what I mean? Like there's always an answer somewhere on the Cancer Council website.
Participant 009_2022AUBLC

PARTICIPANT: Ah, probably the information from the BEAT support group. Mm hmm. Yep. Yeah. Okay. It is formal and informal because they have like they have the monthly get togethers where they'll often have, you know, an expert, but they also have discussion with other patients and things like that. And so that's been very useful. Yeah.

INTERVIEWER: So it's at the same time like for information but also for like support group, right?

PARTICIPANT: Correct. People who've been through what you've been through and can give you tips and encouragement. Support as well. Yep, yep, yep.
Participant 016_2022AUBLC

PARTICIPANT: Uh, I think BEAT bladder cancer, the support group has been. The most. I got the most information from and also from the people, the experience. I think that that's the most helpful one.

INTERVIEWER: So what type of information? Bladder cancer provide you? Yeah.

PARTICIPANT: Uh, it's more the mental side about it and how other people's journeys are.
Participant 005_2022AUBLC

Participant describes other people's experiences as helpful (Peer-to-peer)

Basically I think what I got from the forums from the Facebook pages. Hmm. And that's very helpful to me, to be honest. Putting your mind at rest and just sort of want to stay on top of it and understanding what's what's going to happen. You know what I'm going to go through
Participant 011_2022AUBLC

Well, I've received information. What has been the most helpful? Um. Well, I think, um. Well, I suppose back to the other question. So now I'm involved in the, in the support group. So, um, I mean, that's been very helpful to me, other people that, I mean, it's just been fabulous to meet other people that have, that no longer have their bladder and to meet other females that have neobladders. You know, and just be able and around my age. So that's been fabulous to to do that that's been incredibly helpful and to hear about their journey and and and discuss it, you know, compared to my journey. And so that's been that's been fabulous. Um. Um, you know, just reading some, you know, some more, some more information about bladder cancer and, and the different treatment has also been helpful. Even some of the information about clinical trials so that, you know, if it does recur, what's what's next, you know?
Participant 032_2022AUBLC

Possibly that I know that, you know, like, I rang a few people before I had my radical cystectomy and, you know, the guy said, you know, that they've, they've got through it, okay. And yeah, one guy goes climbing mountains and I know another guy ride motorbikes and he said that he got back on his bike, you know, like he's riding bikes. So after the, after the surgery, you can still yeah, I was worried about not being able to do a lot of the activities I used to do before, but yeah. So then I found that I've been able to do most of the things that I could do before my operation
Participant 044_2022AUBLC

Participant describes hearing what to expect (e.g. from disease, side effects, treatment) as being helpful

Basically I think what I got from the forums from the facebook pages. Hmm. And that's very helpful to me, to be honest. Putting your mind at rest and just sort of want to stay on top of it and understanding what's what's going to happen. You know what I'm going to go through
Participant 011_2022AUBLC

The plain English way that these documents have been written to kind of go, this is what it means. This is this is, you know, really, really simple to read. Like, I gave it to my 76 year old mother and said, read this. This will tell you all about what I've got, you know, really simple, digestible guide. So, like, all information about like, you know, what does it mean to be high grade or non-invasive? And, you know, what is BCG, talks about what is BCG, how its administered, you know, just all of that sort of broken down into. And it's you can almost see that when you read all this stuff and then the doctor goes, will be doing this. I'm going, Yeah, you're just following the textbook, you know, because it seems to me, for me at this point, it's a very textbook protocol. You can almost second guess what the doctor's going to say next, and yet you are just ticking off the next thing on the on the court, as you said, the decision tree type thing. I'm sure it gets trickier once we go to BCG and, you know, potential implications. But but right now, it seems to be, you know, even the fact that it says, you know, you're going to go and get a CT scan or probably do an ultrasound start. Yeah, tick, tick, tick. So it's been it's been very easy to follow it. It's almost like paint with numbers know. But it's that type of thing where, you know, I guess you're kind of following a recipe here. And it's it's I guess it's comforting to kind of know, well, he's not off the reservation with what he's doing. It seems to be very simple in terms of, you know, what he's prescribing is the next thing. This is the urologist lines up with the literature that I've been provided, but he didn't provide any of that directly. I think he provided one document, a link to a document, but he was very dismissive of, you know, the support group type things or the opinions of those guys. Yeah. The

only people that go into those, the ones that got the problems right and it's couldn't be further from the truth. In general it is people inspiring others with their experiences. That may be good or otherwise, but it's very inspirational and very uplifting. His view was when I was going, if people are going well, no one talks about it online. It's only people that aren't going well. Well, that's not actually true. Maybe you need to spend 5 minutes in these forums and understand they're not quite what you think they are. So he was a bit dismissive of that. So again, done most of my own research. He probably hates it because we quite often will send him a link to kind of something and go.
Participant 017_2022AUBLC

I think the Cancer Council booklet and also the the beat the two initial meetings where I found out about, you know, people with bags and other other other issues, what that actually meant with their daily life and their journeys, journeys with cancer. Some of them weren't able to receive BCG treatment at all because they were in states where it was in short supply and they went on to other other sorts of drugs. So their journey was much more complicated than my mine, mine was very much routine. It was, you know, standard treatment except for the trial drug. So I did it whilst I still get information from BEAT and they still get invited to a meeting. I haven't been attending those, although they've also done a couple of very good videos as well. So they're very, very good. So background information is good.
Participant 029_2022AUBLC

Participant describes information about treatment options as helpful

I've got a lot of information on I wouldn't call them alternative therapies, but on other treatment options like the tri modal option um, about other forms of surgery, So there's neobladder and the ileal conduit. So I looked into all that and it was all use. It was useful information which just made me more determined to live a normal life.
Participant 020_2022AUBLC

Well, the the notes that he gave me, they were just a few sheets, I've still got them here, I was looking at them. They just explain what will happen during the operation and how there's a couple of options that are available. The removal of the bladder. If the cancer is grown into the wall of the bladder or this neobladder, they make and and replace or or repair your existing bladder. And the information he gave me also explained how they take a piece of the small intestine and bring it through the abdomen, and then you have to to the urine goes into a bag. So that's that information seemed to me it was easy to understand. Well, it was written in plain English, let's put it like that. And I mean, he he didn't he didn't. The consultations I had with him were quite brief because he doesn't he's not a man who sort of talks a lot, but he gave me the information very clearly.
Participant 043_2022AUBLC

The studies, I find the most recent studies, in fact, that have been been being trialled and tested. I've found that to be the most informative, even more. And then that's how we've gone down to actually getting in touch with the radiation oncologist like we never thought. We never even thought that radiation was an option.
Carer 004_2022AUBLC

Participant describes talking to their doctor or specialist as helpful

PARTICIPANT: Look, I think that you just like I've had the same urologist for 18 years, and then I saw the head urologist at HOSPITAL. And then I had to because I had to do an operation that nobody knew how to do on me. And so then I had to see the head urologist at LOCATION because she knew more than anybody else on this particular thing. Now, she was brilliant. Like, I think that I gleaned more information from her in one consultation than what I had. From all the others. So, so I think you just get lucky. Maybe occasionally, and somebody who's good with, because doctors and not traditionally good with people. They do their thing, but they often don't know how to relate.

INTERVIEWER: In specifically, what information you found helpful from him or was it just, you know, ?

PARTICIPANT: Well, and I now think I should change to her, even though it will cost me a lot more money because she just explained everything, and asked questions and sounded like she gave a shit.
Participant 026_2022AUBLC

Well, I myself, I took it from the doctor because I thought, well, he knows what he's talking about and he's the one that's going to be doing the surgery and the post-operative treatment.
Participant 027_2022AUBLC

From the probably the two two source of interactions is the urologist surgeon who who did the operation. His information has been particularly valuable and

also the specialist stoma nurse. Her information has been absolutely wonderful.
Participant 034_2022AUBLC

Participant describes information specific to their condition (and sub-types) as helpful

Probably the most helpful is that it's a different if, if it's maintained in the outer wall of the bladder. It is 95% curable. If it gets if it gets into the inner layer, or it spreads that it has, it gets worse the further it goes in. That's grade T1 or T2 or whatever its called, then Two, three and four. I think I was grade three. I think he said two or three anyway. He said it was what you call it, not advanced. I've got the I forgotton whatever it was, wasn't superficial. Anyway, I put it that way.
Participant 021_2022AUBLC

The pieces of information that are helpful to me is understanding the diagnosis initially. To be able to say, yeah, if somebody says to you, look, you've been diagnosed with bladder cancer, T1, and I say, if, if a medical person says, you've got bladder cancer, the first thing you start thinking of, you're going to die. Your gonna die. And you're so confused. You have no idea what, what, what they're saying that. But I think a lot of that material would actually all standard says, Well, hey, look, these are the four stages that you have and that it's possible to have. Yeah. And if you if you have one of the lowest tears, that's great. You've got a lot more treatment options that are available. I get that. That helps put somebodies mind at ease. Yeah. Especially somebody that's just coming in and then they have very little. But just to have very little cancer there at all to, to be concerned about. But at the same time, if you if you've been diagnosed, it say at T3 or T2 say, well, okay, what does that mean? Yeah, well, what are the options available? What can we do with that level, that change. Yeah. And. Yeah. To keep it in layman's terms for someone as well. Because everything's a lot of stuff that's either written from the medical side of you. I mean, I'm comfortable with some of it, but I don't understand everything. Yeah, right. So it's also the way that something's written.
Participant 035_2022AUBLC

Probably more. About. Not not so much the treatment for it because it was going to be fairly, fairly obvious to start with. Um, but more, more. about potential secondary infections and, and whether or not it was it was muscular, invasive. But and then because it got into the lymph system, then it was like researching. How much, you know, what, what possibilities that presented. Um. And then it was like, well, okay, well, let's not be an ostrich and stick our heads in the sand. Um. Let's face it, we're dealing with a five year lottery here.
Participant 040_2022AUBLC

Participant describes information about stoma management or from their stoma nurse as being helpful

I suppose, really, that was, not very mind blowing, was about the bag and you know, the appliance that you use. And it was probably the most helpful. I think it took that little unknown away. You can't, there's no way i you haven't had it done, you could imagine. You know, how it all works and what it's all about. And so that was probably most helpful. Yeah. I'm trying to think a lot of it was just basic stuff, whether it was helpful or not..
Participant 003_2022AUBLC

Probably the, the company ostomy books that the stoma nurse gave me initially, you go on their sites and they have little videos of other people who had been through it. Those sort of things were helpful. And their booklets and stuff about, you know, about adjusting to a different sort of life. Probably the most helpful thing.
Participant 018_2022AUBLC

I guess what I got from the doctors. Um, yeah. Like and the stoma nurse, like, towards when I was having about to have the surgery. I am so the stoma nurse and I actually got her to put a bag, an appliance on my tummy. Um, and then I filled it with water when I was at home just to see how it felt. Um, yeah, so I did that. And so, like, I kind of was thinking about clothes that kind of, um, I thought, oh, can I wear, you know, my normal clothes, jeans and, and, you know, sports things, which I found that I can, of course. Yeah. Nothing changes, really
Participant 039_2022AUBLC

Participant describes information from international sources as being helpful

I think it is basically that there are different levels of bladder cancer. And don't be afraid to ask questions. A theme of a few of the patient groups from the U.S. and Canada was, don't be afraid to ask too many questions of a surgeon.
Participant 019_2022AUBLC

Which information has been the most helpful? Most helpful? Most helpful. You mean. I mean, it's been on on on Internet only. It's the, it's the, you know, the the

hospital websites which publish the patient information. Not like Google thing, you know, but the the does the proper cancer hospital information. Like Australian Cancer Council, Australia, the USA. I think I don't remember the name of that website and the UK also. So all I could say that the information is very clear and. But I will just add that all these hospitals, they have information for patients and they have information for physicians also, which is a bit high level. And I do tend to read the physician information also. Then I wanted more detail so I didn't understand everything, but I did understand more than what they give to patients.
Participant 028_2022AUBLC

Participant describes all or any information as being helpful

Any information going from having no information at all and not knowing what a dealing with? Yeah. So any information I could get through my research. You know, was helpful.
Participant 002_2022AUBLC

I think just all of it, really, because I'm the person I want to know. So to me, I think it was just all of it from start to finish. Yeah, I don't think there's I don't think there's never too much. There's no such thing as never too much information. That's how I felt
Carer 002_2022AUBLC

Table 6.3: Information that was helpful

Information that has been helpful	All participants		Early		Invasive		Advanced		Person with bladder cancer		Carer		Female		Male	
	n=49	%	n=20	%	n=10	%	n=14	%	n=44	%	n=5	%	n=17	%	n=32	%
Participant describes health charities information as helpful	16	32.65	8	40.00	3	30.00	**3**	**21.43**	14	31.82	2	40.00	5	29.41	11	34.38
Participant describes other people's experiences as helpful (Peer-to-peer)	14	28.57	6	30.00	**1**	**10.00**	5	35.71	12	27.27	**2**	**40.00**	5	29.41	9	28.13
Participant describes hearing what to expect (e.g. from disease, side effects, treatment) as being helpful	14	28.57	4	20.00	**4**	**40.00**	**6**	**42.86**	14	31.82	**0**	**0.00**	**7**	**41.18**	7	21.88
Participant describes information about treatment options as helpful	10	20.41	3	15.00	2	20.00	4	28.57	9	20.45	1	20.00	5	29.41	5	15.63
Participant describes talking to their doctor or specialist as helpful	8	16.33	3	15.00	2	20.00	3	21.43	8	18.18	**0**	**0.00**	4	23.53	4	12.50
Participant describes information specific to their condition (and sub-types) as helpful	8	16.33	3	15.00	2	20.00	3	21.43	8	18.18	**0**	**0.00**	2	11.76	6	18.75
Participant describes information about stoma management or from their stoma nurse as being helpful	7	14.29	2	10.00	**3**	**30.00**	2	14.29	7	15.91	**0**	**0.00**	4	23.53	3	9.38
Participant describes information from international sources as being helpful	3	6.12	2	10.00	1	10.00	0	0.00	3	6.82	0	0.00	0	0.00	3	9.38
Participant describes all or any information as being helpful	3	6.12	2	10.00	0	0.00	0	0.00	2	4.55	1	20.00	1	5.88	2	6.25

Information that has been helpful	All participants		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=49	%	n=29	%	n=19	%	n=15	%	n=33	%	n=20	%	n=28	%
Participant describes health charities information as helpful	16	32.65	11	37.93	5	26.32	**7**	**46.67**	9	27.27	**10**	**50.00**	**6**	**21.43**
Participant describes other people's experiences as helpful (Peer-to-peer)	14	28.57	7	24.14	6	31.58	**2**	**13.33**	11	33.33	5	25.00	8	28.57
Participant describes hearing what to expect (e.g. from disease, side effects, treatment) as being helpful	14	28.57	**5**	**17.24**	**9**	**47.37**	3	20.00	11	33.33	**3**	**15.00**	**11**	**39.29**
Participant describes information about treatment options as helpful	10	20.41	5	17.24	5	26.32	2	13.33	8	24.24	**2**	**10.00**	8	28.57
Participant describes talking to their doctor or specialist as helpful	8	16.33	5	17.24	3	15.79	**4**	**26.67**	4	12.12	4	20.00	4	14.29
Participant describes information specific to their condition (and sub-types) as helpful	8	16.33	4	13.79	4	21.05	1	6.67	7	21.21	**1**	**5.00**	7	25.00
Participant describes information about stoma management of from their stoma nurse as being helpful	7	14.29	4	13.79	3	15.79	1	6.67	6	18.18	3	15.00	4	14.29
Participant describes information from international sources as being helpful	3	6.12	1	3.45	2	10.53	1	6.67	2	6.06	1	5.00	2	7.14
Participant describes all or any information as being helpful	3	6.12	2	6.90	1	5.26	1	6.67	2	6.06	1	5.00	2	7.14

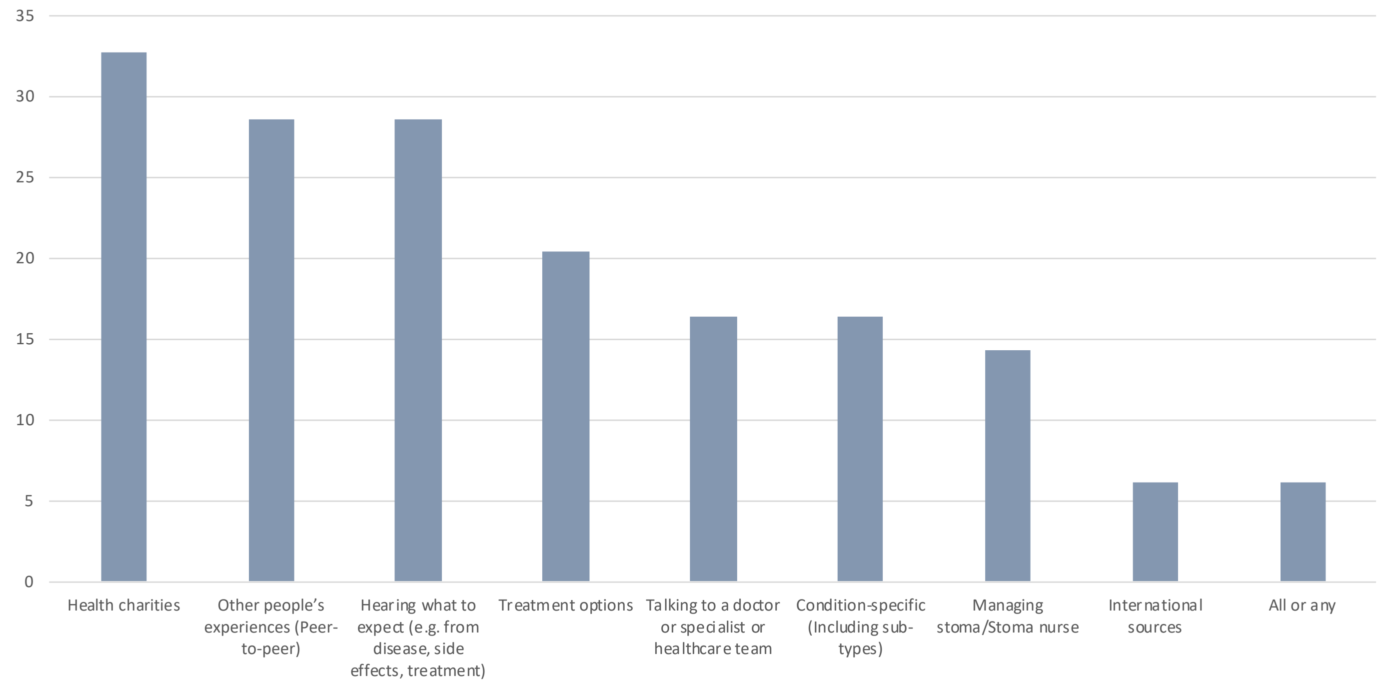


Figure 6.3: Information that was helpful

Table 6.4: Information that was helpful – subgroup variations

Information that has been helpful	Reported less frequently	Reported more frequently
Participant describes health charities information as helpful	Advanced (Stage IV) Higher status	Regional or remote Mid to low status
Participant describes other people's experiences as helpful (Peer-to-peer)	Invasive (Stage III) Regional or remote	Carer to someone with bladder cancer
Participant describes hearing what to expect (e.g. from disease, side effects, treatment) as being helpful	Carer to someone with bladder cancer Trade or high school Mid to low status	Invasive (Stage III) Advanced (Stage IV) Female University Higher status
Participant describes information about treatment options as helpful	Mid to low status	-
Participant describes talking to their doctor or specialist as helpful	Carer to someone with bladder cancer	Regional or remote
Participant describes information specific to their condition (and sub-types) as helpful	Carer to someone with bladder cancer Mid to low status	-
Participant describes information about stoma management of from their stoma nurse as being helpful	Carer to someone with bladder cancer	Invasive (Stage III)
Participant describes all or any information as being helpful	-	Carer to someone with bladder cancer

Information that was not helpful

In the structured interview, participants were asked if there had been any information that they did not find to be helpful. There were 22 participants (44.90%) that responded that no information was not helpful, and 7 participants (14.29%) that were confident in deciding if something is not helpful (or not credible). The most common type of information found to be unhelpful by 9 participants (18.37%) was from their GP or specialist, this was followed by worse case scenarios (n=5, 10.20%), and a lack of information in general, and lack of community awareness as not helpful (n=5, 10.20%).

Participant describes no information being not helpful

No. No. Everyone I've encountered has been, has given me the right information. Nothing that's been useless. No, nothing.
Participant 022_2022AUBLC

No, not really. I mean, it is all helpful information and you need to know everything
Participant 024_2022AUBLC

Well, I think everybody everybody's tried to do their best and, and I do believe that my health is my responsibility. So I'm not just relying on them. And so, so I don't know that anybody hasn't been helpful.
Participant 026_2022AUBLC

Participant describes the GP/specialist as being not helpful

Well, the first urologist gave me pictures of my bladder, but didn't explain it at all very clearly to me. And then he gave me printouts, which is flat out, obviously in English, but it's written in a very technical

language. So I didn't find that really helpful at all. In fact, I found nothing helpful from both urologists. Most of my nearly all my information is from my own research.
Participant 008_2022AUBLC

No, not really. I think probably the nurses. Keen to really push me to have the treatment every month because that's what their, they were told that I had to have. So they're putting a little bit of pressure on me to come back every month. And I but they were lovely. They were really nice, lovely, lovely people. But they were busy. They had people day that they were on chemo as well that they were having to look after. So I couldn't expect too much from them. The urology practise, I don't think there was a lot of support there really. I think once or twice, as I said to you, I phoned the nurse and she was helpful. But I think I really felt like I was on my own and I think what would have been really nice is to actually have. Gone and have coffee with some other people that had bladder cancer and that we're on BCG and and just maybe had someone that coordinated it and talked about it rather than a Zoom meeting, which was quite, quite good. But because there's about 23, 30 people on the Zoom meeting, often you didn't really get a chance to ask a question or you felt a bit intimidated anyway because you were on Zoom. So something like that would have been nice.
Participant 036_2022AUBLC

Look, I don't know if it's been unhelpful, but it's definitely been confronting at times. Like, as I said, the oncologist that we first spoke to has the bedside manner of, I don't know what a bull. Um. Sorry. Yeah, like. Just the way he put he was just, you know, and in a very confronting manner, I guess.
Carer 003_2022AUBLC

But what he's directly contradicted himself is, again, this may not be an answer to your question, but couple of things we picked up early on was absolute contradiction in what the what he just said. And then when we next met in what he said, he backflipped on, you know, when we provided challenges, he goes, you know, we should do this. You know, the safest thing is to do this. And my wife goes, hang on a moment, if you do that, you receding or whatever, you know, it's the cancer and it could seed into the kidney, he goes, yeah, you're right. So if you actually want to do the safest thing, do the following. All right. And my wife goes, yes, that's the point I'm trying to get at. Four weeks later, when you meet him, he goes, and remember how I told you we should do this? I'm thinking, bullshit. You did, you, she told you something else. We corrected you and then you agreed with our position. And now you're you, now you're replaying that position as your own. That's those types of things to me. Whereas he lost integrity with me. I'm sorry the trust eroded very quickly between patient and practitioner. Not again. I can't say he's not a great surgeon. I'm not qualified to do know anything that he does when I'm under the, on the bed, on the operating table. But in the clinical setting, he backflips and is a bit loose with the truth and things like that. Whether he knows he's doing it, I don't know. But it doesn't. You know, my wife and I just both pick up and go, you know, that, you know, you kind of fact check, fact check,hang on fact check. That's not right. That's not what you said last time or whatever, you know.
Participant 017_2022AUBLC

Participant describes feeling confident in deciding if something is not helpful (or not credible)

Not really. No, no. I mean, there's been a bit of rubbish on there and things that I've just disregarded. Yeah. Things on the rubbish. There's no, I don't believe in instant cures. And you know what of that kind of stuff out of this life that's really not medical. That's just rubbish. I'm not going to look at that.
Participant 001_2022AUBLC

Um. Uh, yeah, there's probably a fair bit, um, but you know, um, there's a lot of websites that provide information that you don't necessarily trust, but I've actually, I tend to only look at Australian websites or I tend to only really look at Cancer Council websites if I'm being honest.
Participant 009_2022AUBLC

All the different, you get different information from certain people about it. And saying that, you know, if you get it, you know, you're in a bit of trouble for that sort of thing. The only the only things I take notice of is the medical doctors, you know, urologists, not from reviews of people writing in or things that you see on YouTube. So it's mainly mainly misinformation about how bad, how dire things are from people who are not medical practitioners and things like that.
Participant 021_2022AUBLC

Participant describes information about worse case scenarios and negative information as being not helpful

Yes. I have to say, this is my opinion on diagnosis. When I, you know, one of the first websites you come across will be the Cancer Council. And you know,

straight up, it gives you the fact that this about five year survival rate for bladder cancer is 50%. And that sent me into a spin, if you know what I mean. And, you know, it might be true, but it's just, you know, it depends on the type of, you know, that survival rate depends on many, many factors. Yes. And. I just don't necessarily think it's helpful to have that kind of information upfront. Does that make sense?
Participant 016_2022AUBLC

Some of the very old studies on the Internet that, you know, gives people very less hope and, you know, and, you know, talks about, you know, the prognosis hasn't been good. And then when I've looked at the study data, I thought, oh, okay, thank God that's been that's an old one. But definitely the bladder cancer. And can I tell you the I found actually my daughter in law found the bladder cancer support survivor support group. So yeah, so that has been really fantastic in terms of getting emotional and and psychological support for me as a carer. That's been my main source of, of help.
Carer 004_2022AUBLC

Possibly the ones that went into detail about the different levels, but you didn't know what level we were at, so you didn't know which one was appropriate. It was a bit scary.
Carer 005_2022AUBLC

Participant describes a lack of information in general, and lack of community awareness as not helpful

Not that I remember. I think it was just a surprise at the time. There was only one resource with Australian authorshship and that would have been the Cancer Council of New South Wales. It was a 1 or 2 pages. Yeah. That was my only sort of memory of the time. Yeah. There's always stuff that isn't helpful, but nothing really that stuck out as being quack, quack medicine or quack therapies. No. Not everything I was asked about and read about has been helpful.
Participant 019_2022AUBLC

Oh, look, just not. Really. I was looking at my own clinical trials to see if there were any clinical trials, just more more confidence about whether or not there were clinical trials available or a little bit of information about the fact that they exist. They are not common, but they do happen. And I'll let you know if somebody had said to me, I'll let you know if there's any opportunity for your demographic, your, your current situation. I'll let you know. As opposed to saying, yeah, there are some out there and okay going on and was kind of the attitude which might have been the same message. I just misinterpreted it, but it would have been good to be part of a and it still might be good to be part of a clinical trial. Because I just think BCG is, as I said, it's good, but it's just not it's not a healthy option. Okay. Yeah. So I guess. Yeah, probably good for that.
Participant 030_2022AUBLC

PARTICIPANT I don't like that bladder cancer doesn't get the spotlight that a lot of other cancers get, like bowel cancer and breast cancer and ovarian cancer because it kills many people annually every year. And yet it doesn't, it's not under the radar. It doesn't get the spotlight that some of the other cancers do. And I don't think there should be any comparison when we're dealing with something that's, you know, it's so it's deadly. Cancer is deadly if it's not caught early.

INTERVIEWER Yeah, it's quite insidious, but no. And not many people do. Know about it. Yeah. Because it hasn't been as marketed or out in the open. Let's talk about.

PARTICIPANT Yep. Yep. So, yeah, I think a big thing for bladder cancer that's missing is, um. You know, promoting it on promoting it, on making people. A lot of people that we spoke to said, oh, my God, I didn't even know it was a thing. You could get cancer in your bladder like here you can you can.

INTERVIEWER You can get it anywhere.

PARTICIPANT You can get cancer anywhere. It's all about the cells, you know, just growing, multiplying and dividing and, you know. So, yeah, it's, um, I think if there's anything that's lacking in regards to bladder cancer, it's that it's just not out there like the other cancers are. And it needs to be. It's just as important.
Carer 002_2022AUBLC

Participant describes other people's experiences as being not helpful

Oh, I don't think so. Not, not, not, not helpless. As I said, a few of the a couple of the groups, they're all a bit way past where I am. And I just had to go. I don't need I don't want to hear about that at this stage. I don't I don't need to be Thinking about That yet.
Participant 004_2022AUBLC

Oh. Oh, I don't think so. There was one patient who said to me, It's much easier for people to have surgery because they don't have to sit having, you know, cystoscopy every six months and worrying about things. And I thought, oh, that's a person who hasn't had surgery. But that was just an unhelpful comment.

Participant 018_2022AUBLC

I think it would be from most of my friends and family who try to tell about their own experience. You know, some friend has a friend going to say, look, this is what works for him. You know, you should try this. And that's the worst thing somebody can do. You know, I mean, they don't know my full condition, so people will try to be helpful then. I think that's the worst. I don't think people should try to help a cancer patient and leave it. They should leave it to the doctors and specialists, you know?
Participant 028_2022AUBLC

Participant describes information that is not comprehensive as being not helpful

What was not helpful? Yeah. The total support. Because a urologist, they do the treatments, but they don't think about the human body and the mind. So that's something I really missed.
Participant 005_2022AUBLC

Um, initial, initial GP, I suppose. I don't know about that. He didn't really tell me much at all. Yeah, I can get from hospital onwards yet that they'd be open and honest, which I also do anyway. I also like to call a spade a shovel. And they were, you know, they, they told me straight. All good after that.
Participant 023_2022AUBLC

Table 6.5: Information that was not helpful

Information that has not been helpful	All participants		Early		Invasive		Advanced		Person with bladder cancer		Carer		Female		Male	
	n=49	%	n=20	%	n=10	%	n=14	%	n=44	%	n=5	%	n=17	%	n=32	%
Participant describes no information being not helpful	22	44.90	6	30.00	5	50.00	11	78.57	22	50.00	0	0.00	8	47.06	14	43.7
Participant describes the GP/specialist as being not helpful	9	18.37	5	25.00	2	20.00	1	7.14	8	18.18	1	20.00	4	23.53	5	15.6
Participant describes feeling confident in deciding if something is not helpful (or not credible)	7	14.29	6	30.00	1	10.00	0	0.00	7	15.91	0	0.00	2	11.76	5	15.6
Participant describes information about worse case scenarios and negative information as being not helpful	5	10.20	2	10.00	1	10.00	0	0.00	3	6.82	2	40.00	3	17.65	2	6.25
Participant describes a lack of information in general, and lack of community awareness as not helpful	5	10.20	2	10.00	0	0.00	1	7.14	3	6.82	2	40.00	0	0.00	5	15.6
Participant describes other people's experiences as being not helpful	3	6.12	2	10.00	1	10.00	0	0.00	3	6.82	0	0.00	2	11.76	1	3.13
Participant describes information that is not comprehensive as being not helpful	3	6.12	1	5.00	2	20.00	0	0.00	3	6.82	0	0.00	1	5.88	2	6.25

Information that has not been helpful	All participants		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=49	%	n=29	%	n=19	%	n=15	%	n=33	%	n=20	%	n=28	%
Participant describes no information being not helpful	22	44.90	13	44.83	8	42.11	3	20.00	18	54.55	7	35.00	14	50.0
Participant describes the GP/specialist as being not helpful	9	18.37	4	13.79	5	26.32	3	20.00	6	18.18	4	20.00	5	17.8
Participant describes feeling confident in deciding if something is not helpful (or not credible)	7	14.29	4	13.79	3	15.79	2	13.33	5	15.15	3	15.00	4	14.2
Participant describes information about worse case scenarios and negative information as being not helpful	5	10.20	3	10.34	2	10.53	3	20.00	2	6.06	3	15.00	2	7.14
Participant describes a lack of information in general, and lack of community awareness as not helpful	5	10.20	4	13.79	1	5.26	3	20.00	2	6.06	2	10.00	3	10.7
Participant describes other people's experiences as being not helpful	3	6.12	1	3.45	2	10.53	0	0.00	3	9.09	0	0.00	3	10.7
Participant describes information that is not comprehensive as being not helpful	3	6.12	2	6.90	1	5.26	2	13.33	1	3.03	2	10.00	1	3.57

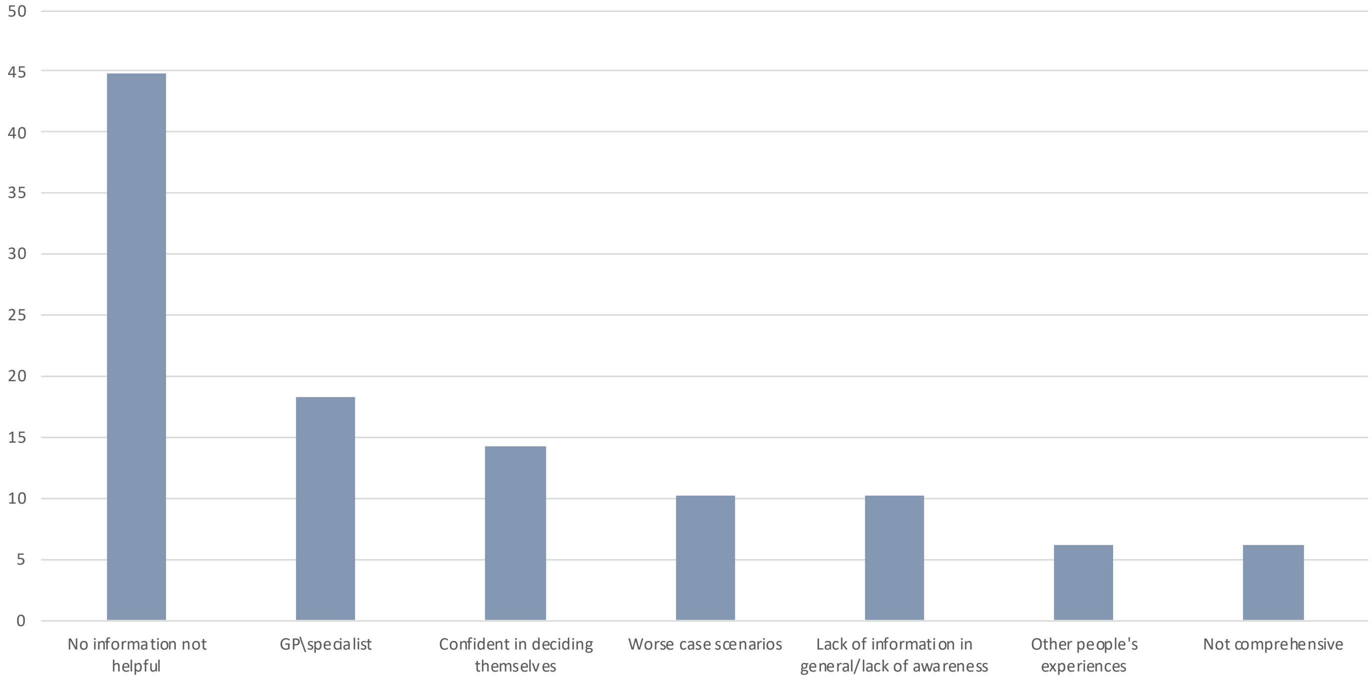


Figure 6.4: Information that was not helpful

Table 6.6: Information that was not helpful – subgroup variations

Information that has not been helpful	Reported less frequently	Reported more frequently
Participant describes no information being not helpful	Early (Stages 0 and I) Carer to someone with bladder cancer Regional or remote	Advanced (Stage IV)
Participant describes the GP/specialist as being not helpful	Advanced (Stage IV)	-
Participant describes feeling confident in deciding if something is not helpful (or not credible)	Advanced (Stage IV) Carer to someone with bladder cancer	Early (Stages 0 and I)
Participant describes information about worse case scenarios and negative information as being not helpful	Advanced (Stage IV)	Carer to someone with bladder cancer
Participant describes a lack of information in general, and lack of community awareness as not helpful	Invasive (Stage III) Female	Carer to someone with bladder cancer

Information preferences

Participants were asked whether they had a preference for information online, talking to someone, in written (booklet) form or through a phone App. Overall, the most common theme was talking to someone plus online information (n=17, 34.69%), followed by talking to someone (n=14, 28.57%), online (n=14, 28.57%), and written information preference (n=11, 22.45%).

The main reasons for a preference for online information were accessibility, being able to digest information at their own pace, and finding personalised or relevant information. The main reasons for talking to someone as a preference were being able to ask questions, get personalised or relevant information, and feeling supported. The main reason for written material as a preference was being able to refer back to it.

Participant describes talking to someone plus online information as main preference

That's an interesting one. It depends on the type of information as to. How I'd like to receive it. If it's something that I'm looking for. Initially. I like to find it online. And the reason for that is. It's there, it's indelible and it's digestibility permanent. You can stare it for long as you like, and the words don't go away until you actually comprehend what you're looking at, which you don't get too much with talking because you can go in one ear and out the other by the next day, which it doesn't do online. But then having said that, there are other things where. A reaction to a question and answer can lead to another question which doesn't happen online. So in a case like that, it's better to have a personal conversation online. So it depends on the type of information that you're after. Sometimes, mostly. In fact, I think it's probably a combination of the two. For me anyway. It's best to look it up. Obviously online, get a broad, knowledge of what it is and then really talk to somebody about it on the same page swapping ideas. So that's good. The telephone is probably the last the last device, usually for expediency of time or distance. It serves the purpose providing what you need to know. This is fairly succinct. But it's no cause for index views is not really very useful or not useful as face to face chat or an online discussion.
Participant 034_2022AUBLC

And what I think I like to talk to people because I get the immediate opportunity to ask questions. But but I also don't mind online because I can do it at my own pace. Um, occasionally, like in appointments, whether someone is busy or whether you perceive that you don't want to take up too much of their time, that they might be busy but can sometimes affect. Yeah, that face to face. So it's going to be close, But probably as a main one, that face to face.
Participant 022_2022AUBLC

I don't have a preference, per se. I value listening to a professional, who has been working in the field for a number of ten, 20, 30 years and I would value whatever they say because I have a specialised knowledge, but so and I probably put more light on that than a lot of websites that you, although it might seem reputable you still doesn't know necessarily. So the trusted referral is always something that's, you know, the highest held in the highest regard by me but also online. Like there are so obviously sites I think it's a kind of what healthline or the cancer council or whatever they are. There are a few websites that you know are pretty reputable and it's also a very good source of diverse information, which is some you might not get necessarily from the people that you know. So it's is it hard. I value both equally, but I think you get different things out of them.
Participant 024_2022AUBLC

I think it's both because I mean, like the online information is not specific to your case. But when I talk to my radiation and chemotherapy doctors, they know my specific case and they can provide me information specific to me. So some level of information, general information on the Internet, but

specific information, I think it's better to talk to my treating doctor.
Participant 028_2022AUBLC

Participant describes talking to someone as main preference

Quite honestly, I think it would have been really good to be able to sit down and talk to somebody maybe over a cup of tea in a relaxed more and had a discussion. Have face to face with the urologists, have an oncologist that was more, um, had a better bedside manner maybe or more compassionate, um, or somebody that could coordinate it all. I had to do all the coordination myself between the urologists and oncologists, and that was really stressful when you're trying to deal with, you know, a condition like I, I was facing, um. While information online was helpful. I don't think there's anything that is better than having a conversation. A face to face conversation with somebody that actually understands and is compassionate and can answer your questions.
Participant 002_2022AUBLC

I think if you get information from talking to someone or from the, like from from the medical professionals. I think is probably the best because that's probably going to be the most accurate. And if you can go through with someone and had it and been through it and had their experiences, at least you know what you're up for. Uh, I think if I, if I could have my time again, I would have loved to have turned around and had a conversation with somebody about this. To know what I was going to be in store for. I would have still gone through the operation. But at least. You would have known what was coming. Up. What what the possible side effects were going to be, and what challenges were going to lie ahead. Hmm. You know, the fun stuff.
Participant 040_2022AUBLC

I'd much prefer to speak to people face to face. Just answer your question. Yes. Yeah, I'm I'm I'm not one for sitting on the Internet all day looking at stuff. I, I'd prefer to talk to someone face to face, like the doctor or the consultant and. Yeah. That's the way I like to to have things done. Like for example, there's a the LOCATION Stoma Association, they've got a support group. I met with them just a couple of weeks ago. They were able to have a face to face meeting the first time they've been able to have quite a long time. And I found that very helpful, just going along and talking to the nurses there and a couple of the patients as well. I found that really helpful and, you know, reassuring that, you know, on your own, the people that come out there to help
Participant 043_2022AUBLC

Participant describes online information as main preference

We've got yeah, we got you know, when the first time we went into the research in the rural urologists offices, obviously she gave us some some booklets and they generally give you a little bit of info and then point you. In the in the direction of various websites. I think I find that easy because you can sit down wherever you want, whether it's in your bed or on a lounge or in an office and. Go trawling through the Internet and finding what you can.
Participant 014_2022AUBLC

PARTICIPANT: Um. I like the online stuff because it's. They're readily accessible. I suppose if you got to talk to somebody, you got to ring them up. And then they gotta ring you back and god know what else. So it's a little bit of a little bit of.

INTERVIEWER: Yeah, I get that.

PARTICIPANT: We play phone tag for about three days and then you. Also.

INTERVIEWER: Get what you're aiming for.

PARTICIPANT: I think. But yeah, I prefer to go online because you can find the answer straight away.
Participant 037_2022AUBLC

PARTICIPANT: Probably online. My guess.

INTERVIEWER: Okay. Why is that?

PARTICIPANT: Because it's quick and easy to access. If you've got a question, you just go straight to it.

Carer 003_2022AUBLC

Participant describes written information as main preference

Probably written down information, whether it was, you know, on a piece of paper or we're on a flyer or on a website. Probably on a piece of paper would be better for my husband because just of his generation, first things written down and I think it's easy to take the mean if you can read it and reread it a few times.
Carer 005_2022AUBLC

I like the opportunity to talk to someone, but I like things written down. You know, sometimes you talk to someone, and you go away and you think, oh, did he say it was pink. Or did he say it was blue? Or did he say it was this? Or they said it was that. Whereas if it's written down, and then you can refer back to it. When your mind stops. Because your mind doesn't look the same when you're going through things like that at all. So it's almost a bit like it seizes up and can't absorb all the information that you would normally.
Participant 003_2022AUBLC

To grasp it to get a good understanding. So. So I think you do need everything. I think you need. You need to be able to talk to a doctor and you need to. Pamphlets are good. Like when? When I was. When I found out I had my bladder out. I needed the pamphlets because I needed to go back and relook at information to get my head around it and it can be good. And I still had to go online and look for information to understand more about it. But yes, I needed all three things I needed to be spoken to about it in the first place and have the pamphlets. And then I had to look further to find more information.
Participant 026_2022AUBLC

Table 6.7: Information preferences

Information preferences	All participants		Early		Invasive		Advanced		Person with bladder cancer		Carer		Female		Male	
	n=49	%	n=20	%	n=10	%	n=14	%	n=44	%	n=5	%	n=17	%	n=32	%
Participant describes talking to someone plus online information as main preference	17	34.69	4	20.00	6	60.00	7	50.00	17	38.64	0	0.00	7	41.18	10	31.25
Participant describes talking to someone as main preference	14	28.57	6	30.00	3	30.00	3	21.43	12	27.27	2	40.00	4	23.53	10	31.25
Participant describes online information as main preference	14	28.57	9	45.00	1	10.00	3	21.43	13	29.55	1	20.00	5	29.41	9	28.13
Participant describes written information as main preference	11	22.45	6	30.00	2	20.00	2	14.29	10	22.73	1	20.00	6	35.29	5	15.63

Information preferences	All participants		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=49	%	n=29	%	n=19	%	n=15	%	n=33	%	n=20	%	n=28	%
Participant describes talking to someone plus online information as main preference	17	34.69	9	31.03	8	42.11	4	26.67	13	39.39	6	30.00	11	39.29
Participant describes talking to someone as main preference	14	28.57	9	31.03	4	21.05	5	33.33	8	24.24	7	35.00	6	21.43
Participant describes online information as main preference	14	28.57	8	27.59	6	31.58	5	33.33	9	27.27	5	25.00	9	32.14
Participant describes written information as main preference	11	22.45	3	10.34	8	42.11	4	26.67	7	21.21	5	25.00	6	21.43

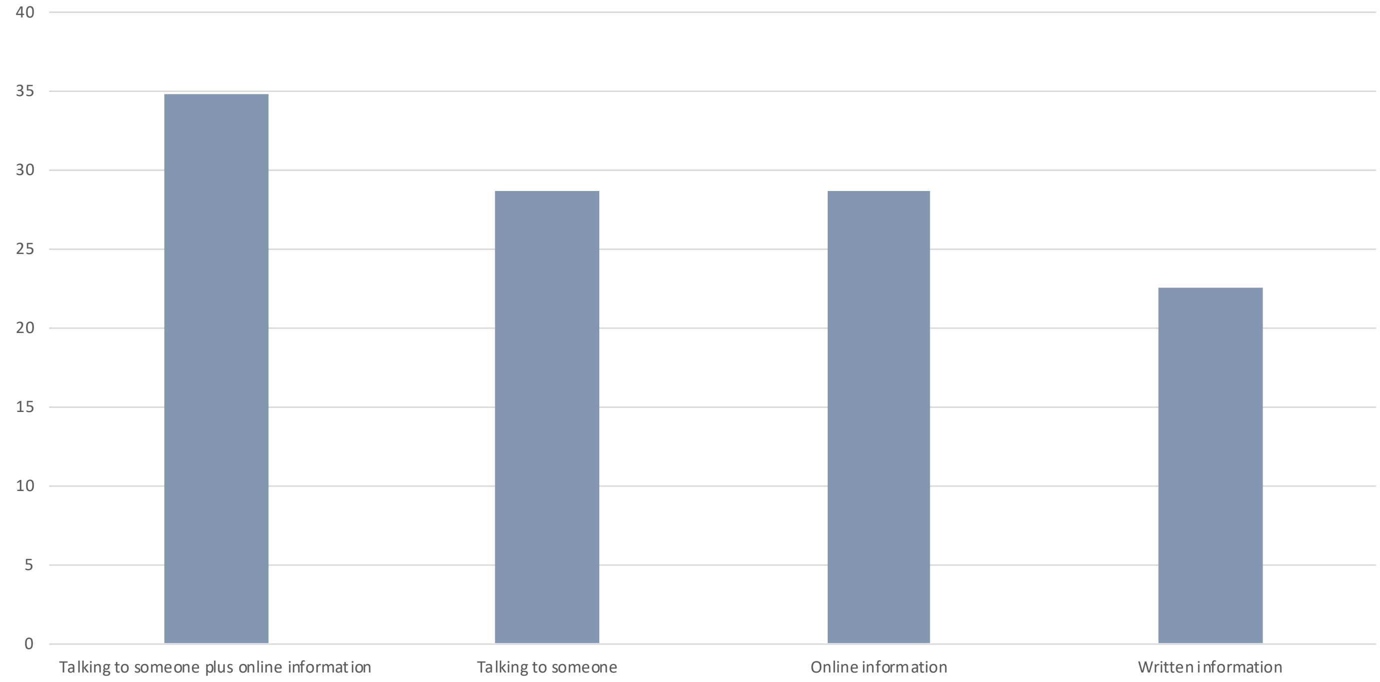


Figure 6.5: Information preferences

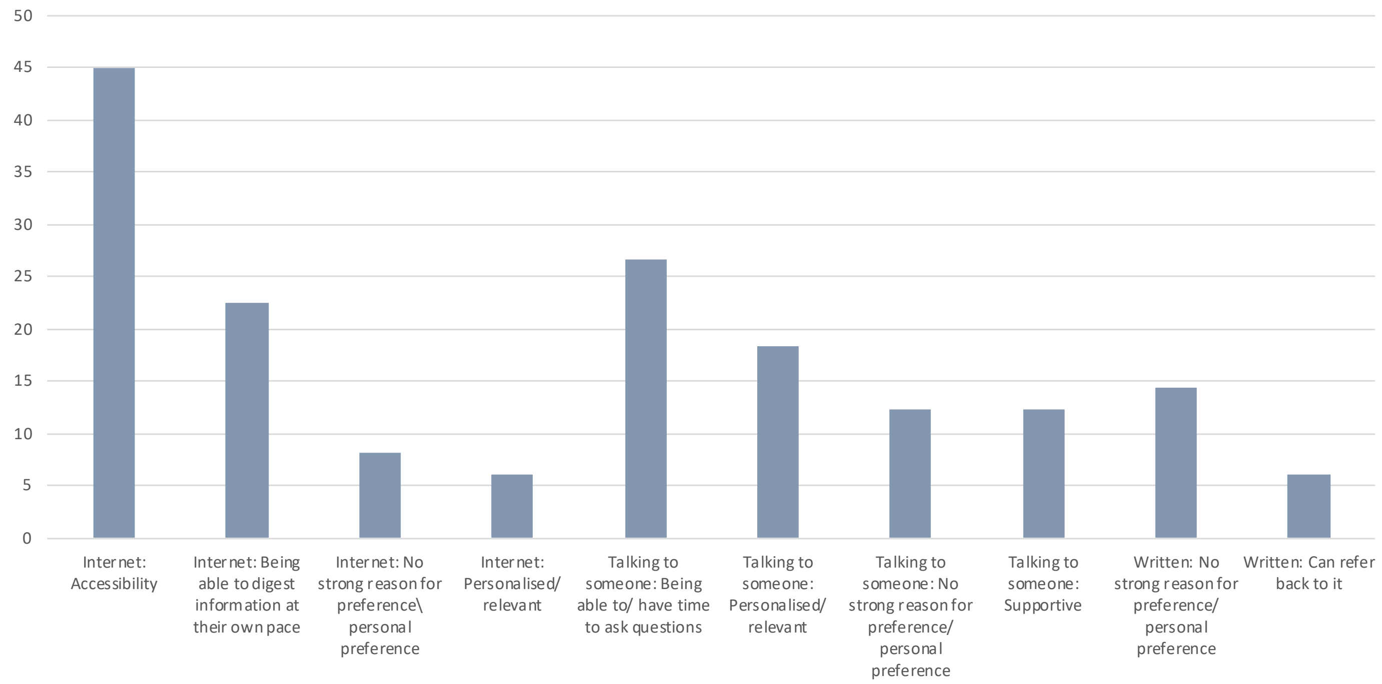


Figure 6.6: Reasons for information preferences by format

Table 6.8: Information preferences – subgroup variations

Information preferences	Reported less frequently	Reported more frequently
Participant describes talking to someone plus online information as main preference	Early (Stages 0 and I) Carer to someone with bladder cancer	Invasive (Stage III) Advanced (Stage IV)
Participant describes talking to someone as main preference	-	Carer to someone with bladder cancer
Participant describes online information as main preference	Invasive (Stage III)	Early (Stages 0 and I)
Participant describes written information as main preference	Trade or high school	Female University

Timing of information

Participants in the structured interview were asked to reflect on their experience and to describe when they felt they were most receptive to receiving information. The most common time that participants described being receptive to receiving information after the shock of diagnosis (n=18, 36.73%), this was followed by participants describing being receptive to information from the beginning when diagnosed (n=13, 26.53%), after the start of treatment (n=9, 18.37%), and continuously throughout their experience or bit-by-bit so that it is digestible (n=9, 18.37%). Other participants described being receptive to information after they have had time to learn about condition/thought about questions to ask their healthcare professional (n=7, 14.29%), and a month after diagnosis (n=5, 10.20%).

Participant describes being receptive to information after the shock of diagnosis

Probably around the time I, I think the sequence I think is I had my first cystoscopy to removed it and then I had another one and then he told me it was cancer. So have another look. And I think when he first spoke to me in the in his waiting rooms and told me it was cancer, I don't know how much I absorbed, to be honest. I was a bit, as you are, taken aback. It always happens to somebody else. But when he told when he sat down and talked to me after my second cystoscopy, when he sort of did a double check to make sure he had missed anything, I think that's when I started to take it in a bit more and think, okay, well, we can do this.
Participant 006_2022AUBLC

Um. Probably only just, excuse me, I'm loosing my voice a bit there. Well, after diagnosis initially it was just overwhelming. Yeah, you know, the mind just didn't function very well. And I've got to say, after the operation, more and more, I was in a definitely in a different zone with my mind, similar to what they say on COVID, I guess I was in a fog. I was treasurer, in my local men's shed and I had to end up resigning from that position. I just couldn't concentrate on it. No, I found it very, very difficult to, I could do things in short pieces, but I couldn't do it long term. I couldn't sit down and even reading, and I've been an avid reader all my life I would read ten pages or 20 pages. then I'd put the book down. Which, you know, I used

to read for hours once, was much more effective in that in that regard, you know, and that and that sort of thing. But I can I can read something for a while and do something else and then I can read something for a while again. Yeah. I can't concentrate on one thing for too long. Better, better now than what I was Christmas time sort of thing. Christmas time was a bit of a turning point for me with that I think.
Participant 011_2022AUBLC

PARTICIPANT: But when you first diagnosed with cancer, you can't take anything in because you can only hear the word cancer. And so you're not going to remember anything then. So, you know, on initial diagnosis you need, if they're going to give you all that information at that time, that's pointless because you're not going to you're not going to take it in. What did you ask me?

INTERVIEWER: Just when you are most receptive to receiving.

PARTICIPANT: Receiving the, receiving information. Yeah. Um. Well, you know, when you don't feel rushed like this, if you, if you in an appointment and you can sense that you're being rushed, they want to get you out, then you're not really taking anything in because you're feeling feeling rushed about it. Yeah. So, so I think it's important to, that they have the time, and I think it is important that they talk to you about it and give you information about it to take time to read because you're not going to remember what you get told.
Participant 026_2022AUBLC

Participant describes being receptive from the beginning (diagnosis)

I think, me, my process, because I'm a process person or list person or organised person. It all fell into context straight away. And I think there was a day of a day of tears, still tears in between. And during but a day of tears start with the first diagnosis. And that was onwards. Getting rid of this bastard. We're getting it fixed. There, it wasn't, it wasn't, oce or twice when sort of little tumours decided to regrow. Yes, we'd have tears in the day surgery area waiting to go home. But then we move on and do it.
Participant 019_2022AUBLC

Oh, gosh, it's hard to say. It's really hard to say because it feels like I've, even though it is all bladder cancer, it feels like I've had different cancers, if that makes sense. Because it's gone from low grade to, yeah, like even being a different type of bladder cancer. Going from the low grade to the high grade and the different treatment regimes and things. Oh. I don't know. I wanted more information at times than what I have given. But that's probably just me as well. You know I like to know what's going on
Participant 001_2022AUBLC

Yeah. I remember the anxious wait, getting the first biopsy. That was probably the hardest thing. I think were pretty receptive. And then there's that, you know, that four or five day wait to find out, you know, what type of cancer you've got because that when conjured up all sorts of things in that period, thought that four or five days that conjured up the worst case scenario that could happen. And, you know, anything from the best to the worst and probably. And I think once you've heard that diag that initial diagnosis of of what grade and muscle invasiveness or not you've got you probably. Well, to me that relaxed me considerably. Still got cancer. But that could be, you know, could be worse. Um, I was probably more receptive to take other things on board. Up until that point, my mind was just bothering with, Gee, you know, what does this mean? You know, because, you know, we just come back from a long holiday in COVID and we're planning the time it so our minds are spinning, going. Retirement looks like that's not going to happen. Am I going to make it to retirement? You know, I am. I see the kids hit their 21st , you know, that kind of crap that goes through your head, because we just didn't know enough about it initially. So, you know, we were bewildered, kind of lost, like going, how did I get here? And then you kind of get clarity as you start to read material and as you start to go to treatments. And it makes more sense. And then once you got your diagnosis. Okay, this may not be a death sentence. So if it is, it's not going to be in the next few years. Right. So.
Participant 017_2022AUBLC

Participant describes being receptive to information after treatment

I think in the beginning. You'll have the most eager. Your most eager to. To get the basic information. And I know your. When everything is under control, you have different needs of of information that it's more the long term. First, you go to short term, get the tumour out and then it's more information about the long term.
Participant 005_2022AUBLC

You know, probably after, after they removed the tumour, of the timing for reality, they removed the first tumour and they said that it was clear and it

hadn't spread. That was when I really started looking into it. I sort of didn't want to know that because I was scared before that. And then when I got the positive news after the first TURBT, and that's when I sort of feel more confident to understand more about what was going on.
Participant 024_2022AUBLC

Take in? Yeah. Not. Not really, no. My wife took a lot of notes and it pretty much. For me once I heard, you know, bladder removal was pretty much switched off. I didn't want to know at the time. I was very angry about it, though, and not to do with anybody else, but just me, and my wife took a lot of notes asked and most of the questions. And then afterwards we went back through it again. But being receptive to all, you know, eventually once everything was done. And like the doc. Once the doctors started giving you advice, you just followed their advice. And everything was fine, you know?
Participant 031_2022AUBLC

Participant describes being receptive to information continuously throughout their experience or bit-by-bit so that it is digestible

Uh, I think I'm always receptive to reading about it and any new treatments or strategies. I think I, I think I'm a lot calmer now with it because, you know, I haven't had I haven't had a, you know, procedure that's had to cut things out, etc., in the last 12 months. So, you know, suppose I'm in remission temporarily or whatever. Um. So, um. Um. Yeah. I don't know. Any time, I think.
Participant 008_2022AUBLC

Yeah, good question. That's, um, I suppose honestly, it's a gradual thing and I was very fortunate. I'm probably not a good one to ask this because I'm very fortunate in that I have a HEALTH PROFESSIONAL background, so I'm not quite as fazed by things as some people would be, and I'm very quick to look things up as well. I don't know if you don't know something, you google it, ASAP and um. Yeah, and I don't mind talking about anything medical reasons even if it if it is about myself. But certainly because I was as I said before, I didn't know anything about that. … . Um, so I would say. I probably learnt a lot in the first month and there and then from then on I'm mean I'm even learning things now because I'm still kind of looking through YouTube videos I haven't looked at before. And it's just there's a lot of information out there.
Participant 010_2022AUBLC

Participant describes being receptive to information after they have had time to learn about condition/thought about questions to ask their healthcare professional

Probably after the first appointment. I think the first appointment was a bit I don't want to say overwhelming because it wasn't that overwhelming, but it was probably the most confusing because it was the first time I'd heard lots of different terms that I didn't really understand.
Participant 022_2022AUBLC

PARTICIPANT: Um. I suppose now would be the best. Oh, yeah. Oh, I think so.

INTERVIEWER: Uh. Um. Okay. What's the reason? Why do you think you are more receptive to information now than in the past?

PARTICIPANT: Probably because I I've had more and more information, as you say, that more communication. More information. Give me a better view.
Participant 012_2022AUBLC

PARTICIPANT: Oh, well, you know, you don't really, because in those early days almost completely knocks you sideways. And I your, I mean, I had my son with me, or a friend, NAME, she's a friend . All I've for 25 years now. So. So. Yeah, see, it's basically you don't hear anything, and that's the trouble. You go to these appointments and most of it just goes flows out the window you know, so the problem with taking my son was that he was just as shocked as I was.. And you come out and you think. Well, yeah, well, what did he say?

INTERVIEWER: And if you ask your son to probably say something different than you.

PARTICIPANT: Yeah. And it's very hard because, I mean, sure, take a tape recorder in with you, you miss a lot of stuff, you know.

INTERVIEWER: That you know. So did it get any better? Now, now, when you sit down and talk to a medical professional, does it?

PARTICIPANT: Yes, because, again, when you when you get that diagnosis, you go home, you're thinking it over. Mm. You go to the Dr Google and and you can pre-arm yourself with questions you need to answer. And the Cancer Council helped me as well. And you need to ask, this that and the other. That's after the

fact, if you like. You know, I wish I'd asked that but it's too late. You know, you got your 20 minute window and that's it.
Participant 023_2022AUBLC

When I was trying to decide whether to go for surgery because the surgeon said, look, you've got those articles to read, and now you want to be you know, you want a surgical cure if you can. But I'm going to take the pathology to the surgical MDT and get all the opinions there of what would be recommended. Given the background of cyclophosphamide, because he hadn't come across it very often. And so he said, why don't we both make our own, you know, investigations? And then in bring me back after the MDT and that that's probably when I was the most clear of really researching and trying to work out which, which way to go. And then when he rang back and said, give overall opinion was radical cystectomy. I said, yeah, well, that's what I think too. So it was good that we both lined up on that because he recommended watching it, but, you know, would have been too nervous to go with that option.
Participant 018_2022AUBLC

Oh, from the moment, from the moment I knew that I had to decide whether I'm going to have an operation, this particular operation or not. That's the moment I knew I needed to find out about it. And I knew that was the moment I discovered how much information actually was out there. There is no shortage of information.
Participant 034_2022AUBLC

Participant describes being receptive to information a month after diagnosis

Yeah. I'm sorry. I'm just thinking. When I first got diagnosed. Absolutely. No, I cannot remember things. It was just lucky that I had a notepad and a pen and just literally wrote everything down that the specialist told me, because I would not have retained any information whatsoever. Um, I would probably say maybe about, I think it was about a month or two months after the diagnosis that I found that I was really retaining information better than what I first had and probably best during still since diagnosis.
Participant 009_2022AUBLC

Yeah, probably. You know what? I didn't do a lot of research at first because I was in shock and possibly a bit of denial. So, everyone else, like I know my sister was looking at stuff and probably my wife and probably some of the friends that I spoke to, but I myself was not even looking at stuff initially. You know, we got a booklet and. And I had a little bit of a look on the Internet, and I just sort of didn't want it because I was pretty worried, pretty scared and, when I saw that the 50% sort of margins or factors I was. Yeah. Had a pretty negative outlook on outlook initially of thinking. Well yeah, I'm probably going to be in that 50% where it doesn't, it doesn't work, which means I'd have to get my bladder out. Or worse still, I don't make it. So I reckon it took me about a month before I started delving in and doing a bit more reading and research and becoming bit more comfortable with it.
Participant 014_2022AUBLC

Table 6.9: Timing of information

Timing of information	All participants		Early		Invasive		Advanced		Person with bladder cancer		Carer		Female		Male	
	n=49	%	n=20	%	n=10	%	n=14	%	n=44	%	n=5	%	n=17	%	n=32	%
Participant describes being receptive to information after the shock of diagnosis	18	36.73	5	25.00	5	50.00	6	42.86	16	36.36	2	40.00	5	29.41	13	40.63
Participant describes being receptive from the beginning (diagnosis)	13	26.53	8	40.00	1	10.00	2	14.29	11	25.00	2	40.00	5	29.41	8	25.00
Participant describes being receptive to information after treatment	9	18.37	4	20.00	2	20.00	3	21.43	9	20.45	0	0.00	4	23.53	5	15.63
Participant describes being receptive to information continuously throughout their experience or bit-by-bit so that it is digestible	9	18.37	4	20.00	0	0.00	4	28.57	8	18.18	1	20.00	2	11.76	7	21.88
Participant describes being receptive to information after they have had time to learn about condition/thought about questions to ask their healthcare professional	7	14.29	4	20.00	2	20.00	1	7.14	7	15.91	0	0.00	3	17.65	4	12.50
Participant describes being receptive to information a month after diagnosis	5	10.20	2	10.00	0	0.00	1	7.14	3	6.82	2	40.00	1	5.88	4	12.50

Timing of information	All participants		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=49	%	n=29	%	n=19	%	n=15	%	n=33	%	n=20	%	n=28	%
Participant describes being receptive to information after the shock of diagnosis	18	36.73	14	48.28	4	21.05	9	60.00	9	27.27	10	50.00	8	28.57
Participant describes being receptive from the beginning (diagnosis)	13	26.53	6	20.69	7	36.84	2	13.33	11	33.33	3	15.00	10	35.71
Participant describes being receptive to information after treatment	9	18.37	3	10.34	5	26.32	1	6.67	7	21.21	2	10.00	6	21.43
Participant describes being receptive to information continuously throughout their experience or bit-by-bit so that it is digestible	9	18.37	6	20.69	3	15.79	3	20.00	6	18.18	5	25.00	4	14.29
Participant describes being receptive to information after they have had time to learn about condition/thought about questions to ask their healthcare professional	7	14.29	6	20.69	1	5.26	2	13.33	5	15.15	4	20.00	3	10.71
Participant describes being receptive to information a month after diagnosis	5	10.20	5	17.24	0	0.00	4	26.67	1	3.03	4	20.00	1	3.57

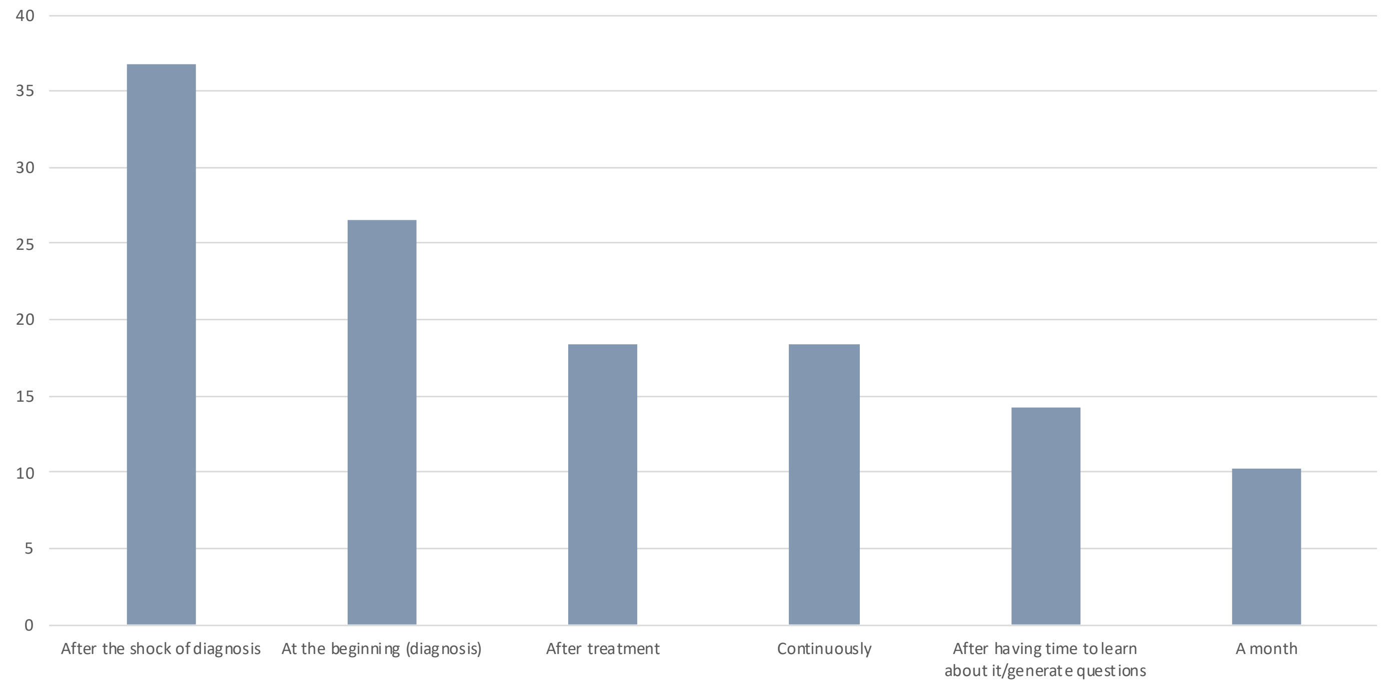


Figure 6.7: Timing of information

Table 6.10: Timing of information – subgroup variations

Timing of information	Reported less frequently	Reported more frequently
Participant describes being receptive to information after the shock of diagnosis	Early (Stages 0 and I) University	Invasive (Stage III) Trade or high school Regional or remote Mid to low status
Participant describes being receptive from the beginning (diagnosis)	Invasive (Stage III) Advanced (Stage IV) Regional or remote Mid to low status	Early (Stages 0 and I) Carer to someone with bladder cancer University
Participant describes being receptive to information after treatment	Carer to someone with bladder cancer Regional or remote	-
Participant describes being receptive to information continuously throughout their experience or bit-by-bit so that it is digestible	Invasive (Stage III)	Advanced (Stage IV)
Participant describes being receptive to information after they have had time to learn about condition/thought about questions to ask their healthcare professional	Carer to someone with bladder cancer	-
Participant describes being receptive to information a month after diagnosis	Invasive (Stage III) University	Carer to someone with bladder cancer Regional or remote

Healthcare professional communication

Participants were asked to describe the communication that they had had with health professionals throughout their experience. The most common theme was that participants described having an overall positive experience (n=22, 44.90%). There were 13 participants (26.53%) that described an overall positive experience, with the exception of one or two occasions, 9 participants (18.37%) that had an overall negative experience and 4 participants (8.16%) that had an overall negative experience.

Participants describes health professional communication as being overall positive

You know, I'm more than happy they have kept in touch with me. I've got a brilliant GP, you know, he'll ring me up and talk to me if he's got any issues. Well, if something comes up. The doctor down there, they've been very straightforward. He lists what, what's gotta to be done, and why it's got to be done. The guy that did the operation. So I feel I'm in pretty, pretty good hands. There's nothing hidden.
Participant 011_2022AUBLC

Yeah, it's really fantastic. They're followed me up often. It was a period of time where I wasn't doing my check-ups as often as I should, and they were calling me and making sure that they were getting me back on track, it has been fantastic.
Participant 024_2022AUBLC

Well, both the specialist and the GP were pretty informative. So. My specialist is available by email

or by phone if I need him. So yeah, they're pretty accessible.
Participant 027_2022AUBLC

Participants describes health professional communication as being overall positive, with the exception of one or two occasions

Yeah. Look, it was pretty good. I think the only letdown for NAME was, like I said to you, we did a lot of telehealth consultations and. To me, I just feel like. I don't know what I feel like. I feel like I feel let down that. Erm. That something so serious was treated medically over the phone. Yes, that's how I feel. I feel something like that. You need to be face to face. I think the patient needs to be seen physically by the doctor. I mean, I'm even talking after having his bladder removed, you know, like, how do you assess how someone is managing a stoma or wound care and all that kind of thing when you're doing it via telehealth? I'm not saying there weren't times we didn't go. We did, but not often enough.
Carer 002_2022AUBLC

It's been varied. GP Yeah, as I said, lucky to be alive. Um, my surgeon, absolutely fabulous. Uh, and the urology nurse and the hospital, absolutely fabulous. I can't fault them in any way. They're the reason that I'm alive and so well today and managing so well today. And I know if I had a problem, I could pick up the phone to any of them. And I would be taken seriously. And they would seem.
Participant 032_2022AUBLC

Oh, in the most part. Very good. I think I had one bad experience. That wasn't very difficult. I just got rid of him.
Participant 020_2022AUBLC

Participants describes health professional communication as being overall negative

Um. Well, the conversation. I actually like the urologist, but the conversations with him were pretty hit and miss because they took place over the phone at a time when I didn't know when to expect the call. I didn't have my questions ready or when I did have questions ready, we had children in the car, so it wasn't really appropriate conversation. So I think that that could have been better. The oncologist, he was in the private sector. The oncologist was in the public sector. He he has the manner where he doesn't make eye contact with you. So it's very hard to feel validated or understood. He told me that, you know, if I what was my problem? About having my bladder removed because if I had breast cancer, I would have lost the breast by now. So I found that really difficult. That was a real conversation stopper from my my part when I had went out with the nurse that was supposed to be the coordinator. She and another person sat with their backs to me and with the computer just after I'd had my first appointment sorting out appointments. But I may as well would not have been there. I felt really very much like in an inanimate part of the procedure. So that's been pretty ordinary. Arriving in the four appointments I rarely get greeted with hello, it's sort of name Medicaid card sort of, and it's all so regimented. It's a horrible experience.
Participant 002_2022AUBLC

Not very well at first. I just had to find it out myself. Just read the discharge instructions or the pathology report. They hardly tell you anything. They just expected that I knew. I didn't, actually. When I went, after the surgery, they didn't explain at all.
Participant 013_2022AUBLC

Well, as I said, it's very poor. I think that I think both urologists have different personalities, but very poor in their communication. And I feel like it's visiting a factory. You know, you're going in there and you meet them, you pay the bill and you go. And it's there's not, as I say, and the current urologist has a practise nurse and and she just keeps saying, you know, doctors are very busy. Doctors very busy is very important. And I don't think that's really appropriate. When you're a patient and particularly a private patient, you're paying a tremendous amount of money. Yeah, because even though I've got top private health funding, you get very little back. Um, so I think communication is the biggest, it's the biggest concern I have.
Participant 008_2022AUBLC

Participants describes health professional communication as being a mix of positive and negative

With my GP. Brilliant. Mm hmm. Um. But some of the other professionals could be better work.
Participant 040_2022AUBLC

Hmm. Boy, that's, that's hard because we see so many people during, to try and sort of say, well, okay, the last two years, have you put an overall thing on communication? Some people have, some people some areas are excellent, either in other areas that are hopeless. And again, then even gets down to the individuals. You know, and I've had surgeons that, uh, excellent communicators and they see you as a, as a person, not just not just a problem or a yeah or, or an up or an operation that they need to. Um, but that, that runs that whole gamut. Whenever you have you human interaction, you get the good, you get the bad. Um, overall, look, the majority of communication we're talking about? I would say. 60% good. Yeah. Yeah. Yeah.
Participant 035_2022AUBLC

Table 6.11: Healthcare professional communication.

Healthcare professional communication	All participants		Early		Invasive		Advanced		Person with bladder cancer		Carer		Female		Male	
	n=49	%	n=20	%	n=10	%	n=14	%	n=44	%	n=5	%	n=17	%	n=32	%
Participants describes health professional communication as being overall positive	22	44.90	7	35.00	6	60.00	8	57.14	21	47.73	1	20.00	6	35.29	16	50.00
Participants describes health professional communication as being overall positive, with the exception of one or two occasions	13	26.53	6	30.00	3	30.00	3	21.43	12	27.27	1	20.00	5	29.41	8	25.00
Participants describes health professional communication as being overall negative	9	18.37	6	30.00	1	10.00	1	7.14	8	18.18	1	20.00	6	35.29	3	9.38
Participants describes health professional communication as being a mix of positive and negative	4	8.16	1	5.00	0	0.00	2	14.29	3	6.82	1	20.00	0	0.00	4	12.50
Other/No response	5	10.20	1	5.00	0	0.00	2	14.29	3	6.82	2	40.00	0	0.00	5	15.63

Healthcare professional communication	All participants		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=49	%	n=29	%	n=19	%	n=15	%	n=33	%	n=20	%	n=28	%
Participants describes health professional communication as being overall positive	22	44.90	14	48.28	7	36.84	6	40.00	15	45.45	10	50.00	11	39.29
Participants describes health professional communication as being overall positive, with the exception of one or two occasions	13	26.53	7	24.14	6	31.58	3	20.00	10	30.30	4	20.00	9	32.14
Participants describes health professional communication as being overall negative	9	18.37	4	13.79	5	26.32	4	26.67	5	15.15	4	20.00	5	17.86
Participants describes health professional communication as being a mix of positive and negative	4	8.16	3	10.34	1	5.26	1	6.67	3	9.09	1	5.00	3	10.71
Other/No response	5	10.20	4	13.79	1	5.26	2	13.33	3	9.09	2	10.00	3	10.71

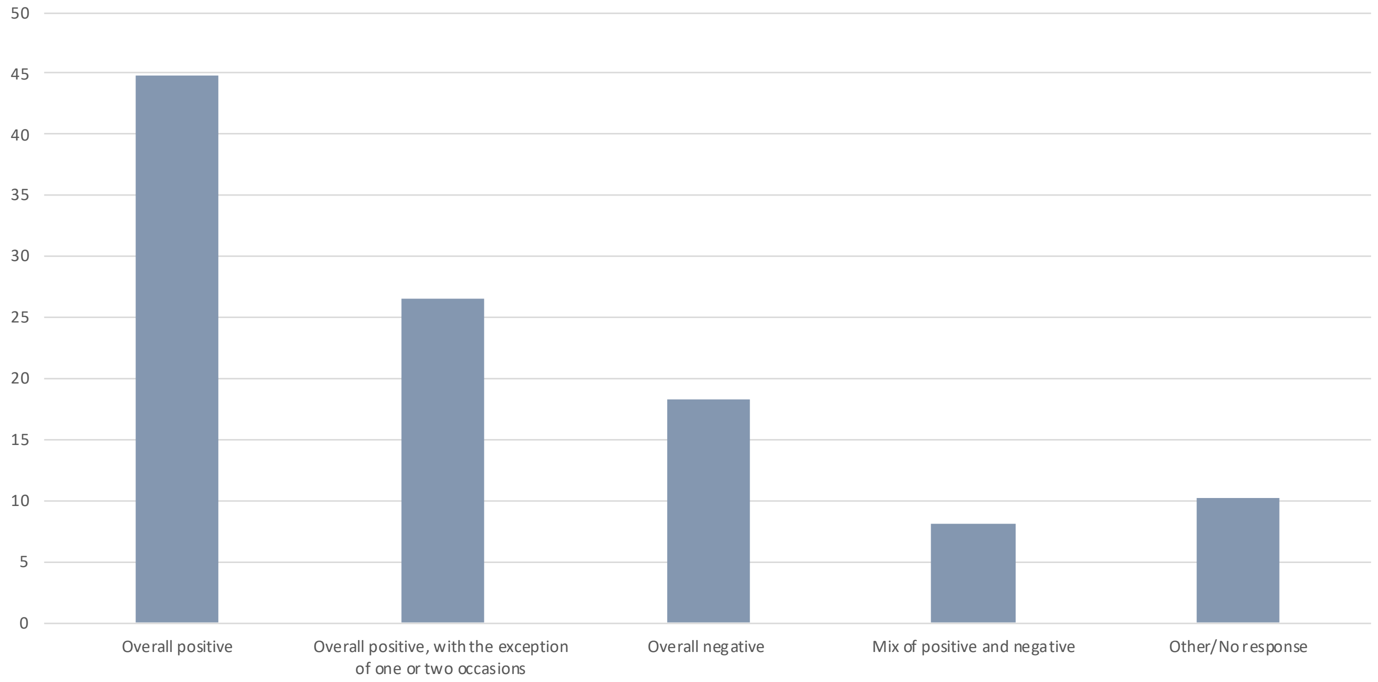


Figure 6.8: Healthcare professional communication

Table 6.12: Healthcare professional communication – subgroup variations

Healthcare professional communication	Reported less frequently	Reported more frequently
Participants describes health professional communication as being overall positive	Carer to someone with bladder cancer	Invasive (Stage III) Advanced (Stage IV)
Participants describes health professional communication as being overall negative	Advanced (Stage IV)	Early (Stages 0 and I) Female

Healthcare professional communication (Rationale for response)

Participants described reasons for positive or negative communication with healthcare professionals.

Participants that had positive communication, described the reason for this was because of holistic, two-way, supportive and comprehensive conversations (n=18, 36.73%), and this was followed by participant describing good communication with no particular reason given (n=17, 34.69%).

The main reasons for negative communication was limited communication that was not supportive, or empathetic (n=10, 20.41%), that information about treatment being withheld or given too late (n=8, 16.33%), and was limited in relation to their understanding of the condition (n=6, 12.24%)

Participant describes health professional communication as holistic (Two way, supportive and comprehensive conversations)

You know, I'm more than happy they have kept in touch with me. I've got a brilliant GP, you know, he'll ring me up and talk to me if he's got any issues. Well, if something comes up. Um. Yeah, and. Yeah. The doctor down there, they've been very straightforward. He lists. What? What's gotta to be done? And why it's got to be done. The guy that did the operation. So I feel I'm in pretty, pretty good hands. There's nothing hidden. It's also the ups and downs of doing
Participant 011_2022AUBLC

There's been really good despite the speciaists that I had were really honest and they told me that yeah he always told me that this time that doesn't work this time you know what will be considering you have to have your radical cystectomy. And he took it to a board. He said, I've got a panel of specialists. He said, like the the time before I had the gemcitabine. He said, Well, I took it to the board and because it hasn't become invasive yet, he said, that we'll try this gemcitabine. And he said, this is your last chance. He said, because if it keeps on, yeah. Like he was pretty honest. He said that they're worried about it spread like going through the wall your bladder and he said if it keeps coming back, you know, he said it is more highly likely because it's high grade that it will go through all of your bladder. So he was really honest about the treatment. Then he suggested, that I go and see the the other specialist who does the the operation. And he sort of referred me on to him, you know, really honest. And it was really good. You know, it was the first two years of the treatment I was with him.
Participant 044_2022AUBLC

Oh, wonderful. Absolutely wonderful. Look at the oncologist. He. He just told me to ring him if I've got any problems. That was when I was going through surgery and things like that. And he would say, don't wait to ring his room. So I had his pager number as well. And I could I knew I could ring. And also the cancer, where I was having the chemo, the charge nurse, I guess she was the one that ran the unit. She was always available. If you had any queries or questions, you could bring them up and then they would contact the oncologist for you.
Participant 039_2022AUBLC

Participant describes healthcare communication as good, with no particular reason given

Overall, probably. Good. I say not great. Not satisfactory, but good.
Participant 016_2022AUBLC

I'm so lucky. So all the way through the people I was put on to were fantastic, post-operative care, you know, just fantastic.
Participant 022_2022AUBLC

PARTICIPANT: 90% good. Yep.

INTERVIEWER: Okay. That's good.

PARTICIPANT: Because the God surgeon lost 10% or it'd be a 100%
Participant 019_2022AUBLC

Participant describes healthcare communication as good, yet hard to access or make appointments with healthcare professionals

Well, I've got a great GP so I can openly talk to her. And, yeah, my urologist is a super busy man. He's the he's not easy to. You know, I have found that I could have make appointments. He's easy to talk but, yeah, but it's a communication. It's good. If I got a question. Mainly I've talked to them, my GP, and she can see she can help me to get to the answer if I need to. She said like, um, you know, if

it takes a long time to get an appointment with urologists and she said she's going to talk to him directly and it's very helpful. So yeah, I've got a very good quality in communication at the moment. I think the specialist they are nice, but it is hard to communicate with them.
Participant 015_2022AUBLC

Pretty good. Once you do get a hold of the doctor, it's been pretty good. They're very helpful. I've still got the contact numbers for the nurse specialist at the urology and she's always been really helpful. I've still got the contact numbers for the stoma therapy nurses and I can pick up the phone any time and speak to them if I have any issues. But other than that, yeah, everything's pretty fine as long as you get to speak to a doctor. They're not easy to get hold of either.
Participant 031_2022AUBLC

Once you can get hold of them. Good. Getting hold of them isn't always easy. And I think if there's ever a weak link in the chain, that's it. The professionals are, surgeons particularly and are very difficult to get hold of.
Participant 034_2022AUBLC

Participant describes health professional communication as being dismissive (One way conversation)

PARTICIPANT I've only spoken to the urologist. I've only spoken to the urologist.

INTERVIEWER Yeah. And what's that been like, do you think, in terms of communication?

PARTICIPANT Uh. Oh, well, I don't I don't think it's that good because they just tell you, you know, with me, they just say, well, you know, we're going to do this, we're going to do that, and this is when we're going to do it.
Participant 007_2022AUBLC

Well, as I said, it's very poor. I think that I think both urologists have different personalities, but very poor in their communication. And I feel like it's visiting a factory. You know, you're going in there and you meet them, you pay the bill and you go. And it's there's not, as I say, and the current urologist has a practise nurse and and she just keeps saying, you know, doctors are very busy. Doctors very busy is very important. And I don't think that's really appropriate. When you're a patient and particularly a private patient, you're paying a tremendous amount of money. Yeah, because even though I've got top private health funding, you get very little back. Um, so I think communication is the biggest, it's the biggest concern I have. Yeah. With the health care treatment?
Participant 008_2022AUBLC

Um, very factual and uh, but not really giving options. It's just showing you what is the next step if you want to get rid of it.
Carer 005_2022AUBLC

Participant describes health professional communication as limited in relation to information about treatment being withheld or given too late

Well, I guess because it's gone on so long. I probably haven't had a lot of information. I don't seem to have got any further with knowing why or how, other than I have read that it's really hard to cure. They do recur. You know, sometimes it's really hard to get rid of so bladder cancer. So that's all I assume is the fact that I haven't got sick or anything is good is a bonus. And probably if I was feeling sick or anything, I would want to have more. Information, I guess.
Participant 025_2022AUBLC

Um, very factual and uh, but not really giving options. It's just showing you what is the next step if you want to get rid of it.
Carer 005_2022AUBLC

Um. With the the oncologist. I have Professor NAME. He's been fantastic. He's explained things. Very, very clearly. And he's giving me answers to questions that I trust. Um, I guess, um, in that he's sort of giving me a lot of hope for a successful treatment and so forth. And he's backed it up with reasons. If, for example, you know, you have non-muscle invasive cancer and it's this and it's that, you respond well to the BCG and blah, blah, blah, blah, blah, that sort of thing. So he's put me up into the high nineties at been successful in keeping my bladder and so forth, you know, those sorts of things. Um, so. Um. Yeah. Yeah. The, um. Yeah, I do trust what he's told me, I think above, you know, I like my surgeon, nd he's actually a really nice bloke and he's quite a funny guy. Yeah, but, um, at times I've wanted more answers and we've argued about things like, okay, part of my treatment is I had to get circumcised right, I know that sounds weird, but I, I wasn't circumcised when I was a child and the

nurses at the hospital actually said to me, Hey, um, the catheter is really were painful. And they said, I think you need to be, um, is there any reason you're not circumcised like these? You know, blah, blah, blah, blah. I should not just it wasn't done when I was a child they weren't doing at that time. It wasn't done routinely. And why the nurses said, yeah, it's, it's hard with the catheters, you know, maybe you should talk to your urologist about it. And I did, and he's like, no, I don't believe in it. I'm a conscientious objector, you know, I don't believe in doing these things. And I'm like, well, the nurses suggested it and it took a nurse to actually ring him up and give him a blast. You know, honestly, that's just me, you gutsy powerhouse. You, you know, she rang up and blasted him. Oh, really nurse, and you've made that diagnosis have you? And she's like, yes, I have. Yes, I have. I mean, he's come down to see me in the recovery and said, I don't like to admit it but she was right.
Participant 001_2022AUBLC

Participant describes health professional communication as limited in relation to their understanding of the condition

Um. I guess it's been I guess it's been good luck. It's hard. Like even when you were in hospital after major surgery, it's hard. It's hard to get information and it's hard to, to feel supported and, and living in the country. It's hard because you, you know, you can't get to help very quickly. Yes. And that you can't get to the hospital and the doctor that did the operation. So if you go to LOCAL HOSPITAL, nobody's going to have a clue and you just going to be worse off. So you'd rather not talk anymore. Well, damage can be caused by people who don't know anything. And and so, you know, I think that at the times that I've had, had things go wrong. It's been horrible to have to go to local hospitals because they've just got no clue of my actual problem. Whereas if I was in CITY obviously I'd be going to the hospital that the specialist was at and you'd be getting looked after by people who knew what was happening.
Participant 026_2022AUBLC

But, you know, the consultations are not all that long. But I've got to say, Doctor, in these consultations, the consultations with these registrars are very short, and sharp, because it'd be more people seeing him and seeing him. And that was a ten minute consultations. But the last consultation I had with Dr. NAME went for nearly an hour, sat me down and got me right through it, told me everything, and told me what to do to stopgoing to the toilet so much, if not all that sort of thing. So he's been a fantastic doctor and he's been brilliant. He's actually phoned me, as I said before, at home a few times to give me a progress on what, on what he thinks, And that everything's okay. The registrars have been okay, but the people are lining up to see them, left right and centre and my GP's they don't really, I have spoken to the GP a couple of times about it and they don't really know much about bladder cancer. They're not specialists, said that specialist Dr. NAME. The he's been pretty bloody good. I've seen him three times. As I said, it's very expensive. To see him for me. But he's good.
Participant 021_2022AUBLC

When you go to the nurse to change the dressing and the nurse says. Oh, I don't know what to do. Yeah. So you end up in theatre where you end up a theatre with your backpack still on your back, on your bed, when you're required to have some antibiotics before you go into surgery and they can't find your antibiotics.
Participant 005_2022AUBLC

Participant describes health professional communication as limited, with no particular reason given

The urologist now is really good that we have but yeah, the first urologist we had and the oncologist definitely not. I'd say it's been pretty poor
Carer 003_2022AUBLC

With my GP. Brilliant. Mm hmm. Um. But some of the other professionals could be better work.
Participant 040_2022AUBLC

Participant describes health professional communication as limited in relation to care coordination and conflicting information between healthcare professionals.

Well, the conversation. I actually like the urologist, but the conversations with him were pretty hit and miss because they took place over the phone at a time when I didn't know when to expect the call. I didn't have my questions ready or when I did have questions ready, we had children in the car, so it wasn't really appropriate conversation. So I think that that could have been better. The oncologist, he was in the private sector. The oncologist was in the public sector. He he has the manner where he doesn't make eye contact with you. So it's very hard

to feel validated or understood. He told me that, you know, if I what was my problem? About having my bladder removed because if I had breast cancer, I would have lost the breast by now. So I found that really difficult. That was a real conversation stopper from my my part when I had went out with the nurse that was supposed to be the coordinator. She and another person sat with their backs to me and with the computer just after I'd had my first appointment sorting out appointments. But I may as well would not have been there. I felt really very much like in an inanimate part of the procedure. So that's been pretty ordinary. Arriving in the four appointments I rarely get greeted with. Hello, it's sort of name Medicaid card sort of, and it's all so regimented. It's a horrible experience. Are the nurses very generally that give the treatment are empathetic, but they don't have the information and they can't get it to me because the specialist is not around when you have treatment. So when there was issues, all that information was coming third hand and there was a problem at one stage because the stent I had in was causing problems and impacting my bit, their ability to give me that treatment because of bleeding. And that was really difficult. And when I was in hospital, I was told was going to do theatre one minute, next minute. The other team was saying, no, you're not, and they couldn't agree on it. And then I was told I had to coordinate the conversation. So it was really, really, really difficult. So yeah, teh communication was what I thought was awful. I think it'd be really helpful to have somebody there that was like a case manager that could help you. My my GP tried to do that, but her all the communication she got was, you know, a week or two later in the form of the letter which didn't really answer the question.
Participant 002_2022AUBLC

Table 6.13: Healthcare professional communication (Rationale for response)

Healthcare professional communication (Rationale for response)	All participants		Early		Invasive		Advanced		Person with bladder cancer		Carer		Female		Male	
	n=49	%	n=20	%	n=10	%	n=14	%	n=44	%	n=5	%	n=17	%	n=32	%
Participant describes health professional communication as holistic (Two way, supportive and comprehensive conversations)	18	36.73	7	35.00	4	40.00	7	50.00	18	40.91	0	0.00	5	29.41	13	40.63
Participant describes healthcare communication as good, with no particular reason given	17	34.69	6	30.00	4	40.00	4	28.57	14	31.82	3	60.00	5	29.41	12	37.50
Participant describes healthcare communication as good, yet hard to access or make appointments with healthcare professionals	3	6.12	1	5.00	0	0.00	2	14.29	3	6.82	0	0.00	1	5.88	2	6.25
Participant describes health professional communication as being dismissive (One way conversation)	10	20.41	6	30.00	0	0.00	3	21.43	9	20.45	1	20.00	4	23.53	6	18.75
Participant describes health professional communication as limited in relation to information about treatment being withheld or given too late	8	16.33	6	30.00	1	10.00	0	0.00	7	15.91	1	20.00	5	29.41	3	9.38
Participant describes health professional communication as limited in relation to their understanding of the condition	6	12.24	3	15.00	2	20.00	1	7.14	6	13.64	0	0.00	4	23.53	2	6.25
Participant describes health professional communication as limited, with no particular reason given	4	8.16	0	0.00	1	10.00	2	14.29	3	6.82	1	20.00	0	0.00	4	12.50
Participant describes health professional communication as limited in relation to care coordination and conflicting information between healthcare professionals.	3	6.12	3	15.00	0	0.00	0	0.00	3	6.82	0	0.00	3	17.65	0	0.00

Healthcare professional communication (Rationale for response)	All participants		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=49	%	n=29	%	n=19	%	n=15	%	n=33	%	n=20	%	n=28	%
Participant describes health professional communication as holistic (Two way, supportive and comprehensive conversations)	18	36.73	9	31.03	8	42.11	3	20.00	14	42.42	5	25.00	12	42.86
Participant describes healthcare communication as good, with no particular reason given	17	34.69	12	41.38	5	26.32	7	46.67	10	30.30	8	40.00	9	32.14
Participant describes healthcare communication as good, yet hard to access or make appointments with healthcare professionals	3	6.12	2	6.90	1	5.26	0	0.00	3	9.09	2	10.00	1	3.57
Participant describes health professional communication as being dismissive (One way conversation)	10	20.41	4	13.79	6	31.58	2	13.33	8	24.24	3	15.00	7	25.00
Participant describes health professional communication as limited in relation to information about treatment being withheld or given too late	8	16.33	5	17.24	3	15.79	3	20.00	5	15.15	3	15.00	5	17.86
Participant describes health professional communication as limited in relation to their understanding of the condition	6	12.24	3	10.34	3	15.79	1	6.67	5	15.15	3	15.00	3	10.71
Participant describes health professional communication as limited, with no particular reason given	4	8.16	3	10.34	1	5.26	2	13.33	2	6.06	2	10.00	2	7.14
Participant describes health professional communication as limited in relation to care coordination and conflicting information between healthcare professionals.	3	6.12	1	3.45	2	10.53	1	6.67	2	6.06	1	5.00	2	7.14

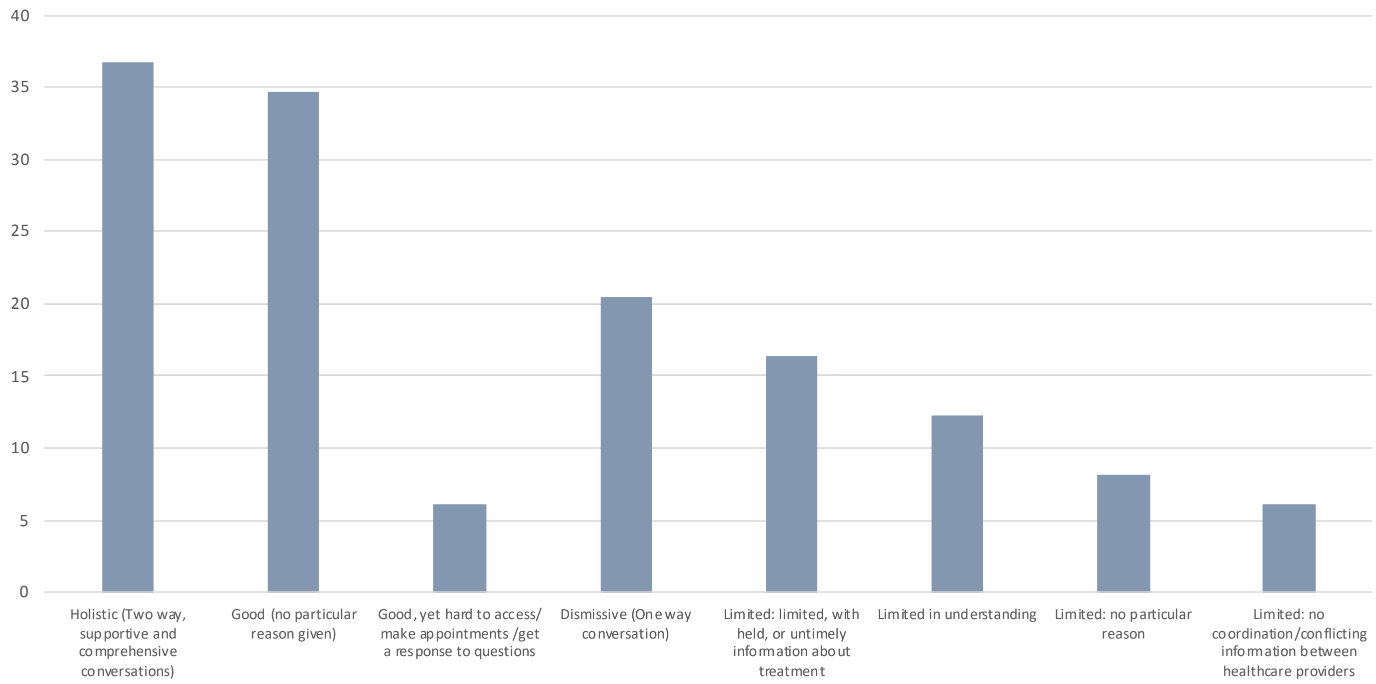


Figure 6.9: Healthcare professional communication (Rationale for response)

Table 6.14: Healthcare professional communication (Rationale for response) – subgroup variations

Healthcare professional communication (Rationale for response)	Reported less frequently	Reported more frequently
Participant describes health professional communication as holistic (Two way, supportive and comprehensive conversations)	Carer to someone with bladder cancer Regional or remote Mid to low status	Advanced (Stage IV)
Participant describes healthcare communication as good, with no particular reason given	-	Carer to someone with bladder cancer Regional or remote
Participant describes healthcare communication as good, yet hard to access or make appointments with healthcare professionals	-	
Participant describes health professional communication as being dismissive (One way conversation)	Invasive (Stage III)	University
Participant describes health professional communication as limited in relation to information about treatment being withheld or given too late	Advanced (Stage IV)	Early (Stages 0 and I) Female
Participant describes health professional communication as limited in relation to their understanding of the condition	Carer to someone with bladder cancer	Female

Partners in health

The Partners in Health questionnaire (PIH) measures an individual's knowledge and confidence for managing their own health. The Partners in Health comprises a global score, 4 scales; knowledge, coping, recognition and treatment of symptoms, adherence to treatment and total score. A higher score denotes a better understanding and knowledge of disease. Summary statistics for the entire cohort are displayed alongside the possible range of each scale in Table 6.15.

The overall scores for the cohort were in the highest quintile for **Partners in health: Knowledge** (median=27.00, IQR=5.00), **Partners in health: Recognition and management of symptoms** (median=21.00, IQR=4.50), **Partners in health: Adherence to treatment** (median=14.00, IQR=4.00), indicating very good knowledge, very good recognition and management of symptoms, and very good adherence to treatment.

The overall scores for the cohort were in the second highest quintile for **Partners in health: Coping** (mean=16.32, SD=4.86), **Partners in health: Total score** (mean=75.15, SD=13.51) indicating good coping, and good overall ability to manage their health

The **Partners in Health questionnaire (PIH)** measures an individual's knowledge and confidence for managing their own health.

The **Partners in health: knowledge** scale measures the participants knowledge of their health condition, treatments, their participation in decision making and taking action when they get symptoms. On average, participants in this study had very good knowledge about their condition and treatments.

The **Partners in health: coping** scale measures the participants ability to manage the effect of their health condition on their emotional well-being, social life and living a healthy life (diet, exercise, moderate alcohol and no smoking). On average, participants in this study had a good ability to manage the effects of their health condition.

The **Partners in health: treatment** scale measures the participants ability to take medications and complete treatments as prescribed and communicate with healthcare professionals to get the services that are needed and that are appropriate. On average participants in this study had a very good ability to adhere to treatments and communicate with healthcare professionals.

The **Partners in health: recognition and management of symptoms** scale measures how well the participant attends all healthcare appointments, keeps track of signs and symptoms, and physical activities. On average participants in this study had very good recognition and management of symptoms.

The **Partners in health: total score** measures the overall knowledge, coping and confidence for managing their own health. On average participants in this study had a good overall knowledge, coping and confidence for managing their own health.

Table 6.15: Partners in health summary statistics

Partners in health scale (n=47)	Mean	SD	Median	IQR	Possible range	Quintile
Knowledge	25.62	5.08	27.00	5.00	0 to 32	5
Coping*	16.32	4.86	16.00	8.00	0 to 24	4
Recognition and management of symptoms	19.87	3.58	21.00	4.50	0 to 24	5
Adherence to treatment	13.34	3.60	14.00	4.00	0 to 16	5
Total score*	75.15	13.51	76.00	15.50	0 to 96	4

*Normal distribution use mean and SD as measure of central tendency

Partners in health by bladder cancer stage

Comparisons were made by Stage. There were 18 participants (42.86%) with early bladder cancer (Stages 0 and I), 10 participants (23.81%) with invasive bladder cancer (Stage III), and 14 participants (33.33%) with advanced bladder cancer (Stage IV).

A one-way ANOVA test was used when the assumptions for response variable residuals were normally distributed and variances of populations were equal (Table 6.16). When the assumptions for normality of residuals was not met, a Kruskal-Wallis test was used (Table 6.17).

No significant differences were observed between participants by **bladder cancer stage** for any of the Partners in health scales.

Table 6.16: Partners in health by bladder cancer stage summary statistics and one-way ANOVA

Partners in health scale	Group	Number (n=42)	Percent	Mean	SD	Source of difference	Sum of squares	dF	Mean Square	f	p-value
Coping	Early	18	42.86	16.22	4.91	Between groups	7.80	2	3.883	0.15	0.8620
	Invasive	10	23.81	17.30	5.68	Within groups	1012.60	39	25.965		
	Advanced	14	33.33	16.43	4.91	Total	1020.40	41	29.848		

Table 6.17: Partners in health by bladder cancer stage summary statistics and Kruskal-Wallis test

Partners in health scale	Group	Number (n=42)	Percent	Median	IQR	C^2	dF	p-value
Knowledge	Early	18	42.86	25.50	7.75	3.04	2	0.2183
	Invasive	10	23.81	28.00	2.75			
	Advanced	14	33.33	27.00	2.75			
Recognition and management of symptoms	Early	18	42.86	21.00	4.25	0.54	2	0.7634
	Invasive	10	23.81	22.00	3.00			
	Advanced	14	33.33	20.50	3.75			
Adherence to treatment	Early	18	42.86	14.00	3.75	3.86	2	0.1453
	Invasive	10	23.81	16.00	0.75			
	Advanced	14	33.33	14.50	2.75			
Total score	Early	18	42.86	76.00	12.25	2.04	2	0.3615
	Invasive	10	23.81	84.00	12.75			
	Advanced	14	33.33	78.00	18.00			

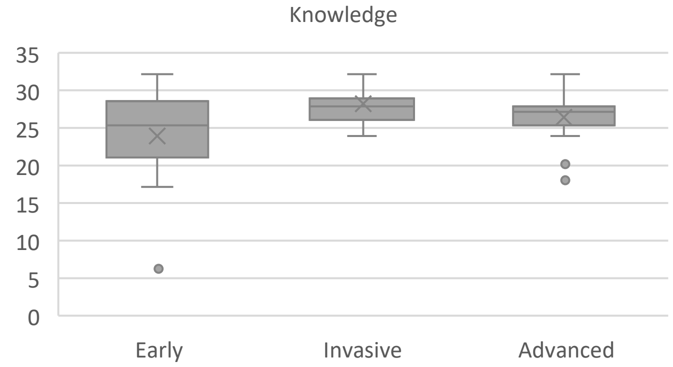


Figure 6.10: Boxplot of Partners in health: knowledge by bladder cancer stage

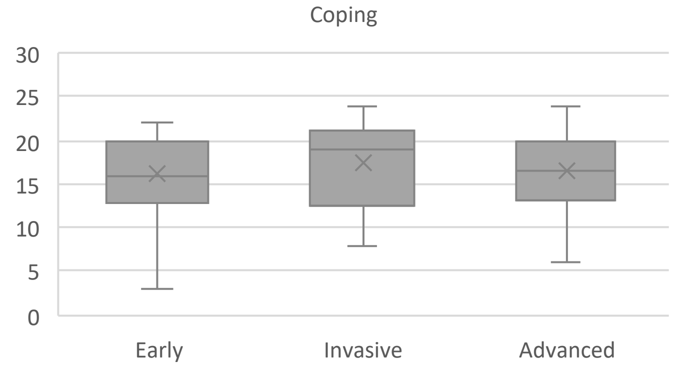


Figure 6.11: Boxplot of Partners in health: coping by bladder cancer stage

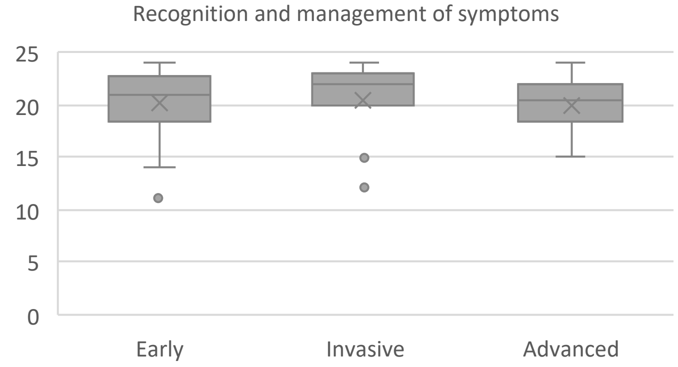


Figure 6.12: Boxplot of Partners in health: recognition and management of symptoms by bladder cancer stage

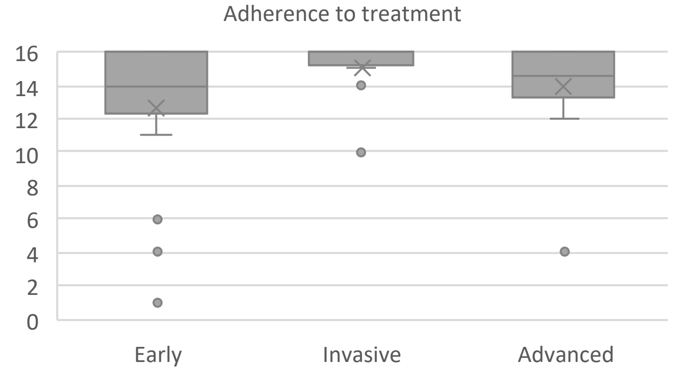


Figure 6.13: Boxplot of Partners in health: adherence to treatment by bladder cancer stage

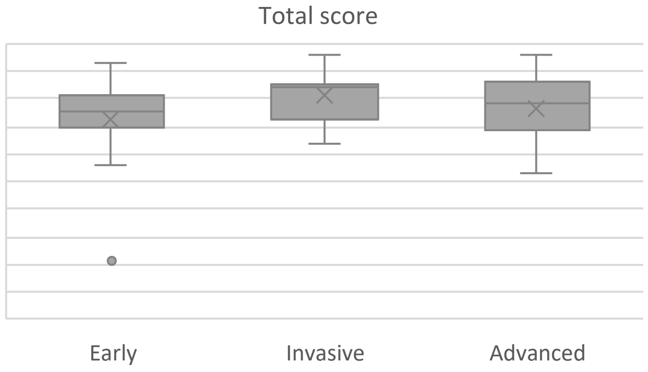


Figure 6.14: Boxplot of Partners in health Total score by bladder cancer stage

Partners in health by participant type

Comparisons were made by type of participant, there were 42 participants (89.36%) with bladder cancer and, 5 participants (10.64%) that were a carer to someone with bladder cancer.

A two-sample t-test was used when assumptions for normality and variance were met (Table 6.18), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 6.19).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the **Partners in health Adherence to treatment** scale [W = 182.00 , p = 0.0064] was significantly higher for participants in the patient subgroup (Median = 15.00, IQR = 2.75) compared to participants in the carer subgroup (Median = 11.00, IQR = 2.00).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the **Partners in health Total score** scale [W = 165.50 , p = 0.0383] was significantly higher for participants in the patient subgroup (Median = 78.00, IQR = 15.50) compared to participants in the carer subgroup (Median = 68.00, IQR = 4.00).

The **Partners in health: treatment** scale measures the participants ability to take medications and complete treatments as prescribed and communicate with healthcare professionals to get the services that are needed and that are appropriate. On average, participants in the patient subgroup scored higher than participants in the carer subgroup. This indicates that, treatment adherence was very good for participants in the patient subgroup, and good for participants in the carer subgroup.

The **Partners in health: total score** measures the overall knowledge, coping and confidence for managing their own health. On average, participants in the patient subgroup scored higher than participants in the carer subgroup. This indicates that overall knowledge, coping and confidence for managing their own health was very good for participants in the patient subgroup, and good for participants in the carer subgroup.

Table 6.18: Partners in health by participant type summary statistics and T-test

Partners in health scale	Group	Number (n=47)	Percent	Mean	SD	T	dF	p-value
Coping	Patient	42	89.36	16.55	4.99	0.93	45	0.3559
	Carer	5	10.64	14.40	3.36			

Table 6.19: Partners in health by participant type summary statistics and Wilcoxon test

Partners in health scale	Group	Number (n=47)	Percent	Median	IQR	W	p-value
Knowledge	Patient	42	89.36	27.00	5.00	134.00	0.3231
	Carer	5	10.64	25.00	4.00		
Recognition and management of symptoms	Patient	42	89.36	21.00	4.75	159.00	0.0632
	Carer	5	10.64	18.00	2.00		
Adherence to treatment	Patient	42	89.36	15.00	2.75	182.00	0.0064*
	Carer	5	10.64	11.00	2.00		
Total score	Patient	42	89.36	78.00	15.50	165.50	0.0383*
	Carer	5	10.64	68.00	4.00		

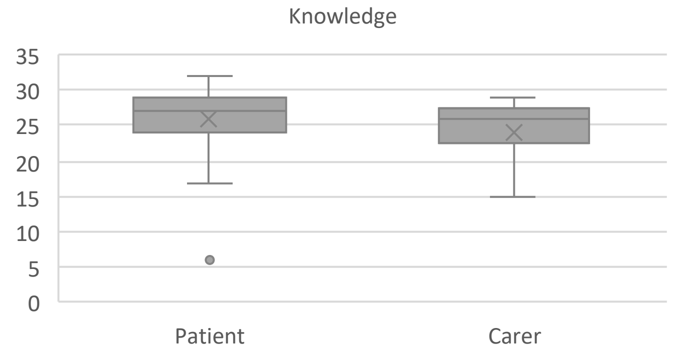


Figure 6.15: Boxplot of Partners in health: knowledge by participant type

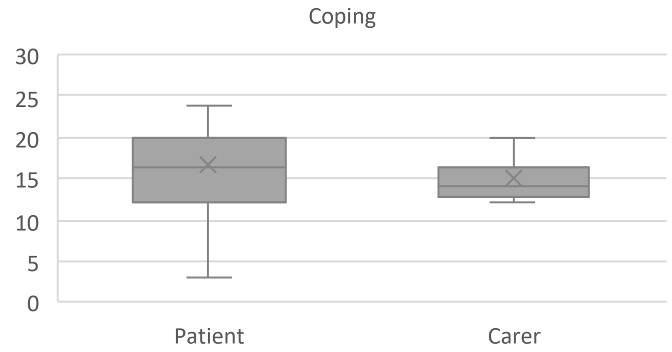


Figure 6.16: Boxplot of Partners in health: coping by participant type

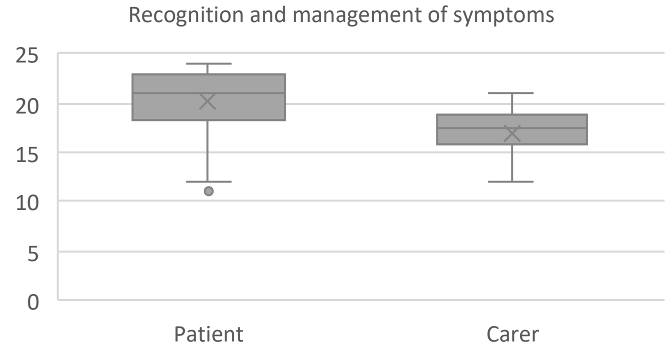


Figure 6.17: Boxplot of Partners in health: recognition and management of symptoms by participant type

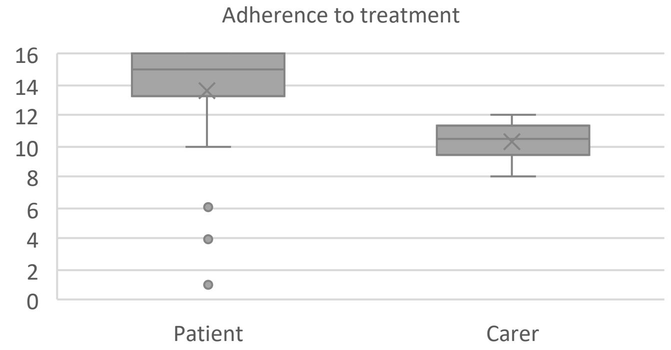


Figure 6.18: Boxplot of Partners in health: adherence to treatment by participant type

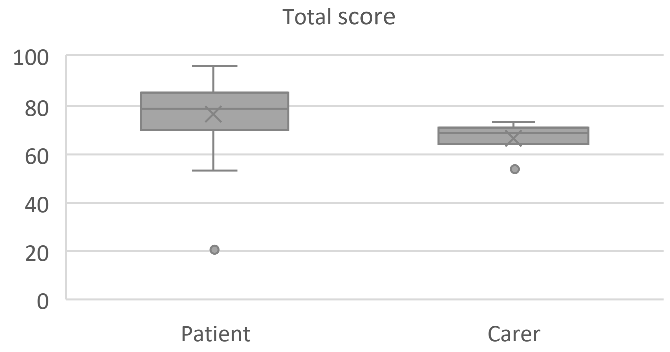


Figure 6.19: Boxplot of Partners in health Total score by participant type

Partners in health by gender

Comparisons were made by gender, there were 16 female participants (34.04%), and 31 male participants (65.96%).

A two-sample t-test was used when assumptions for normality and variance were met (Table 6.20), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 6.21).

No significant differences were observed between participants by **gender** for any of the Partners in health scales.

Table 6.20: Partners in health by gender summary statistics and T-test

Partners in health scale	Group	Number (n=47)	Percent	Mean	SD	T	dF	p-value
Coping	Female	16	34.04	17.69	4.77	1.40	45	0.1680
	Male	31	65.96	15.61	4.83			

Table 6.21: Partners in health by gender summary statistics and Wilcoxon test

Partners in health scale	Group	Number (n=47)	Percent	Median	IQR	W	p-value
Knowledge	Female	16	34.04	28.00	3.50	300.50	0.2407
	Male	31	65.96	27.00	5.00		
Recognition and management of symptoms	Female	16	34.04	21.50	2.75	288.50	0.3661
	Male	31	65.96	20.00	5.00		
Adherence to treatment	Female	16	34.04	15.00	2.00	293.00	0.3020
	Male	31	65.96	14.00	4.50		
Total score	Female	16	34.04	81.00	14.00	314.00	0.1411
	Male	31	65.96	73.00	14.00		

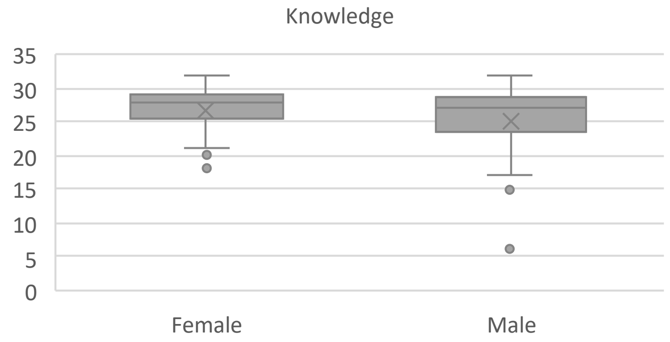


Figure 6.20: Boxplot of Partners in health: knowledge by gender

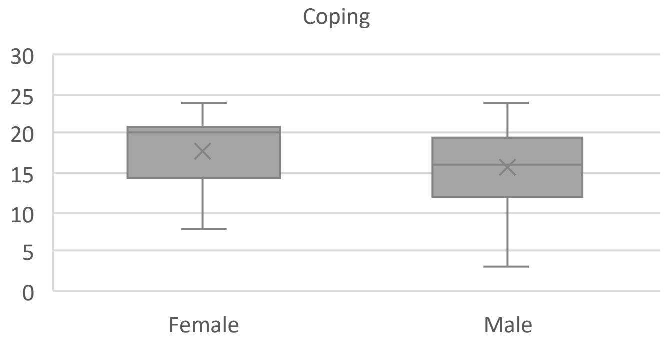


Figure 6.21: Boxplot of Partners in health: coping by gender

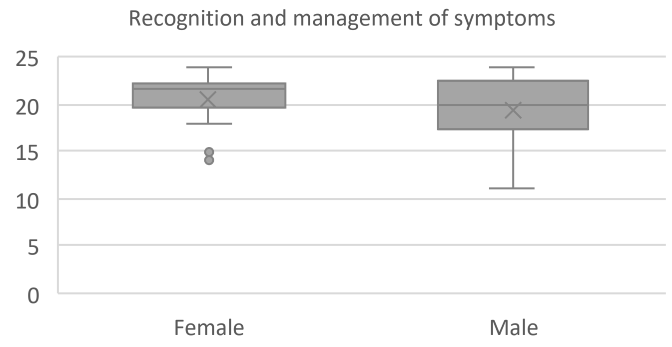


Figure 6.22: Boxplot of Partners in health: recognition and management of symptoms by gender

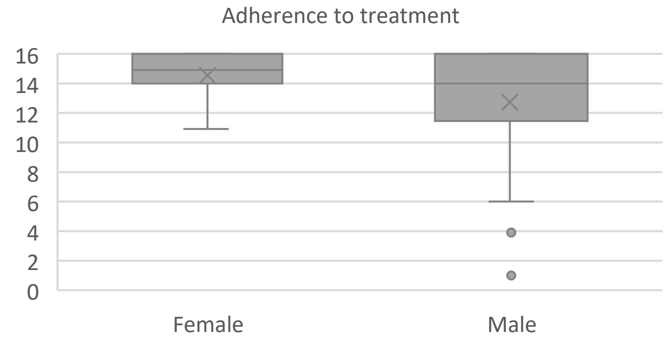


Figure 6.23: Boxplot of Partners in health: adherence to treatment by gender

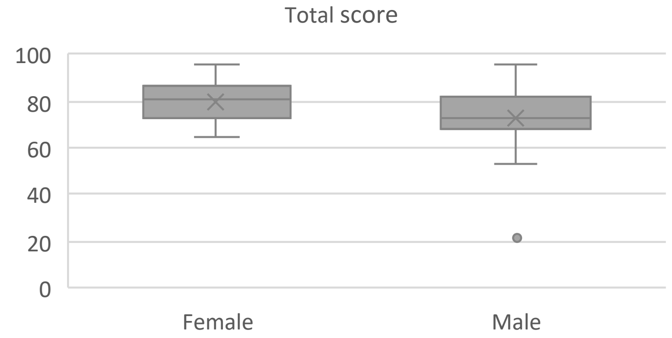


Figure 6.24: Boxplot of Partners in health Total score by gender

Partners in health by education

Comparisons were made by education status, between those with trade or high school qualifications (n=29, 61.70%), and those with a university qualification (n=18, 38.30%).

A two-sample t-test was used when assumptions for normality and variance were met (Table 6.22), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 6.23).

No significant differences were observed between participants by **education** for any of the Partners in health scales.

Table 6.22: Partners in health by education summary statistics and T-test

Partners in health scale	Group	Number (n=47)	Percent	Mean	SD	T	dF	p-value
Coping	Trade or high school	29	61.70	16.10	4.10	-0.38	45	0.7038
	University	18	38.30	16.67	6.00			

Table 6.23: Partners in health by education summary statistics and Wilcoxon test

Partners in health scale	Group	Number (n=47)	Percent	Median	IQR	W	p-value
Knowledge	Trade or high school	29	61.70	27.00	4.00	196.50	0.1593
	University	18	38.30	28.50	6.00		
Recognition and management of symptoms	Trade or high school	29	61.70	20.00	4.00	222.50	0.4026
	University	18	38.30	21.50	5.75		
Adherence to treatment	Trade or high school	29	61.70	14.00	4.00	228.00	0.4625
	University	18	38.30	15.00	2.75		
Total score	Trade or high school	29	61.70	76.00	14.00	222.50	0.4052
	University	18	38.30	79.50	19.00		

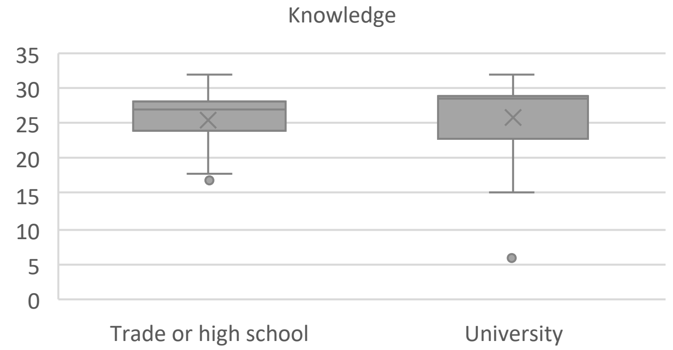


Figure 6.25: Boxplot of Partners in health: knowledge by education

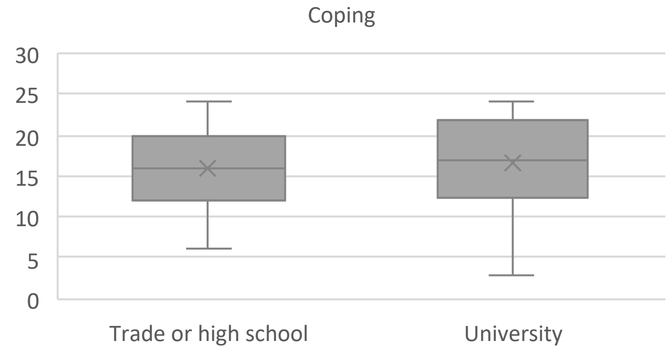


Figure 6.26: Boxplot of Partners in health: coping by education

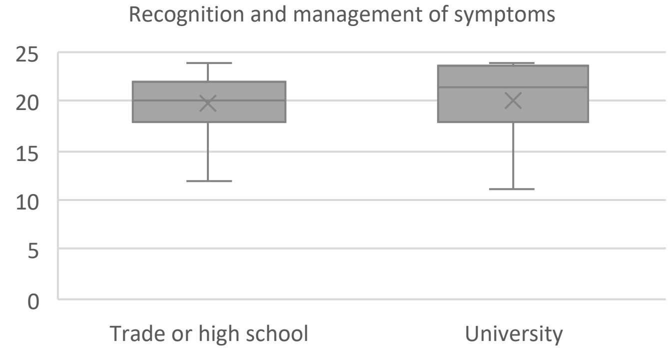


Figure 6.27: Boxplot of Partners in health: recognition and management of symptoms by education

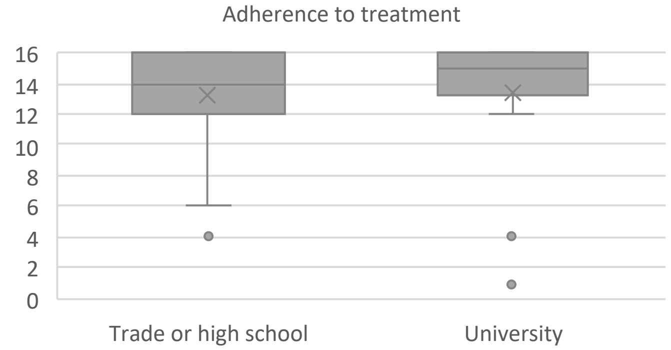


Figure 6.28: Boxplot of Partners in health: adherence to treatment by education

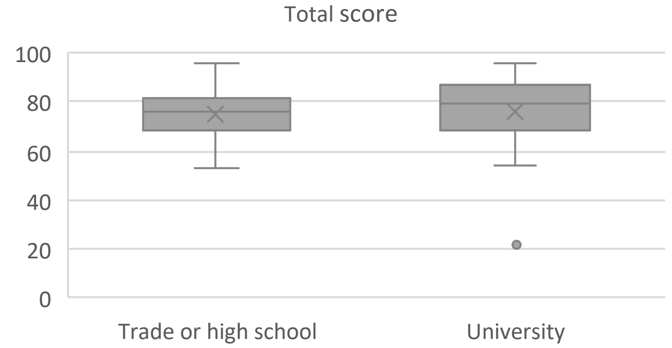


Figure 6.29: Boxplot of Partners in health Total score by education

Partners in health by location

The location of participants was evaluated by postcode using the Australian Statistical Geography Maps (ASGS) Remoteness areas accessed from the Australian Bureau of Statistics. Those living in regional or remote area (n=15, 31.91%) were compared to those living in a metropolitan area (n=32, 68.09%).

A two-sample t-test was used when assumptions for normality and variance were met (Table 6.24), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 6.25).

No significant differences were observed between participants by **location** for any of the Partners in health scales.

Table 6.24: Partners in health by location summary statistics and T-test

Partners in health scale	Group	Number (n=47)	Percent	Mean	SD	T	dF	p-value
Coping	Regional or remote	15	31.91	15.33	5.59	-0.95	45	0.3466
	Metropolitan	32	68.09	16.78	4.50			

Table 6.25: Partners in health by location summary statistics and Wilcoxon test

Partners in health scale	Group	Number (n=47)	Percent	Median	IQR	W	p-value
Knowledge	Regional or remote	15	31.91	26.00	5.00	208.00	0.4700
	Metropolitan	32	68.09	27.00	5.00		
Recognition and management of symptoms	Regional or remote	15	31.91	20.00	6.50	209.00	0.4836
	Metropolitan	32	68.09	21.00	4.00		
Adherence to treatment	Regional or remote	15	31.91	15.00	3.00	273.50	0.4365
	Metropolitan	32	68.09	14.00	4.00		
Total score	Regional or remote	15	31.91	71.00	17.50	211.50	0.5224
	Metropolitan	32	68.09	76.50	12.50		

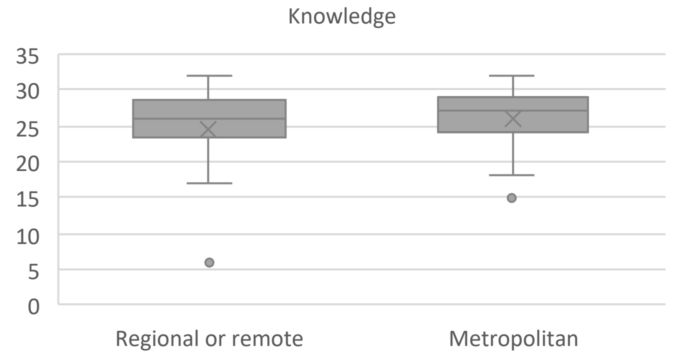


Figure 6.30: Boxplot of Partners in health: knowledge by location

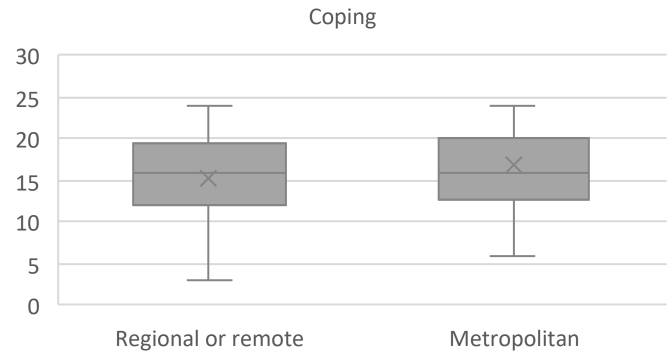


Figure 6.31: Boxplot of Partners in health: coping by location

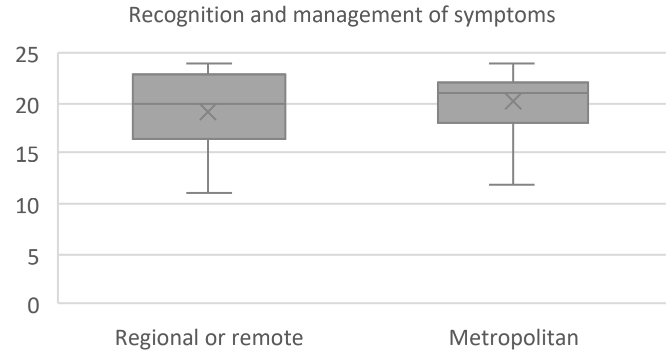


Figure 6.32: Boxplot of Partners in health: recognition and management of symptoms by location

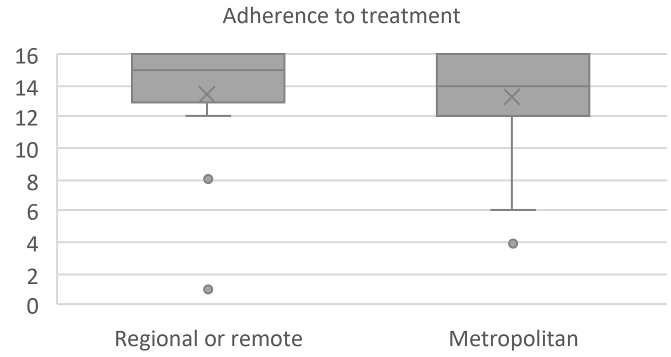


Figure 6.33: Boxplot of Partners in health: adherence to treatment by location

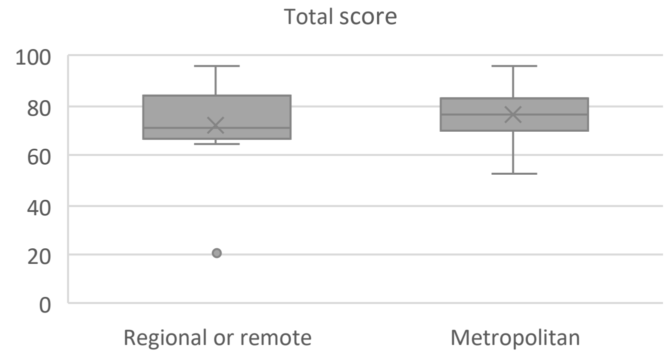


Figure 6.34: Boxplot of Partners in health Total score by location

Partners in health by socioeconomic status

Comparisons were made by socioeconomic status, using the Socio-economic Indexes for Areas (SEIFA) (www.abs.gov.au), SEIFA scores range from 1 to 10, a higher score denotes a higher level of advantage. Participants with a mid to low SEIFA score of 1-6 (n=20, 42.55%) compared to those with a higher SEIFA score of 7-10 (n=27, 57.45%).

A two-sample t-test was used when assumptions for normality and variance were met (Table 6.26), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 6.27).

No significant differences were observed between participants by **socioeconomic status** for any of the Partners in health scales.

Table 6.26: Partners in health by socioeconomic status summary statistics and T-test

Partners in health scale	Group	Number (n=47)	Percent	Mean	SD	T	dF	p-value
Coping	Mid to low status	20	42.55	15.25	4.83	-1.31	45	0.1974
	Higher status	27	57.45	17.11	4.81			

Table 6.27: Partners in health by socioeconomic status summary statistics and Wilcoxon test

Partners in health scale	Group	Number (n=47)	Percent	Median	IQR	W	p-value
Knowledge	Mid to low status	20	42.55	25.50	3.50	182.00	0.0585
	Higher status	27	57.45	28.00	4.00		
Recognition and management of symptoms	Mid to low status	20	42.55	19.50	5.25	186.00	0.0706
	Higher status	27	57.45	21.00	3.00		
Adherence to treatment	Mid to low status	20	42.55	14.00	4.25	232.50	0.4108
	Higher status	27	57.45	15.00	3.00		
Total score	Mid to low status	20	42.55	72.00	13.75	187.50	0.0774
	Higher status	27	57.45	80.00	15.00		

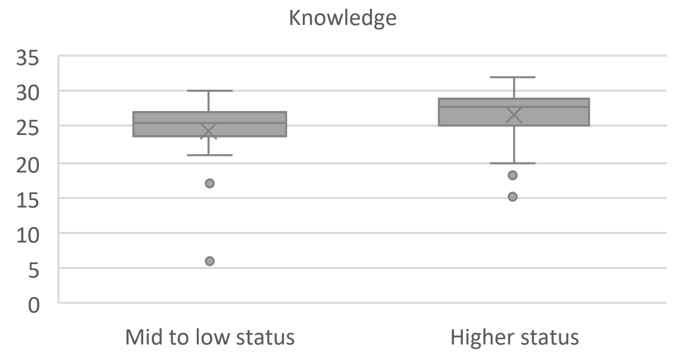


Figure 6.35: Boxplot of Partners in health: knowledge by socioeconomic status

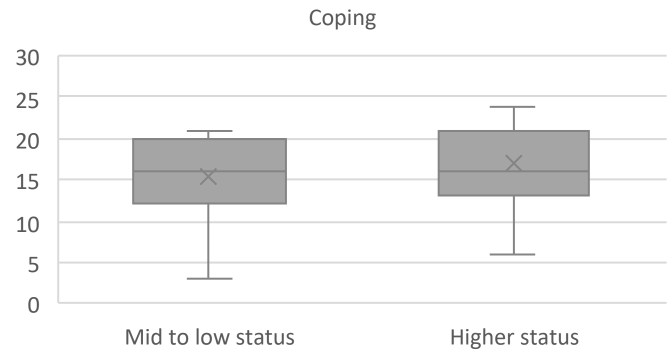


Figure 6.36: Boxplot of Partners in health: coping by socioeconomic status

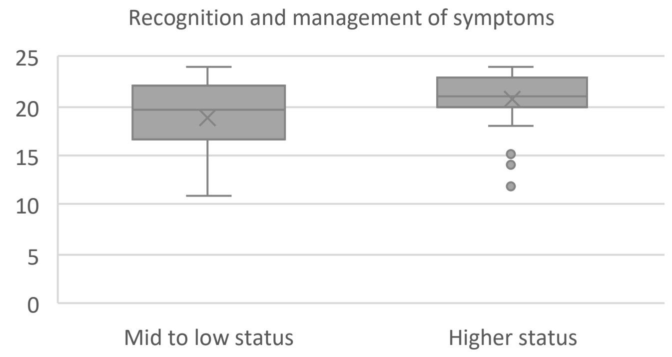


Figure 6.37: Boxplot of Partners in health: recognition and management of symptoms by socioeconomic status

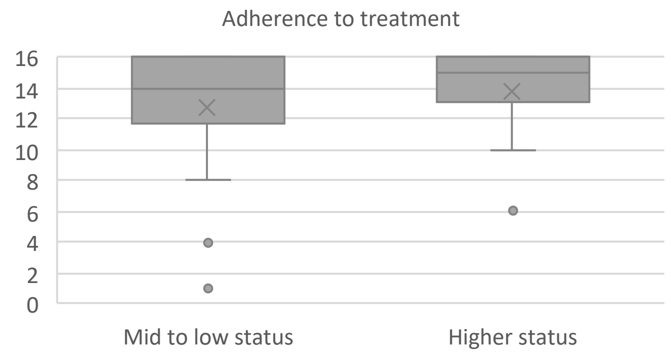


Figure 6.38: Boxplot of Partners in health: adherence to treatment by socioeconomic status

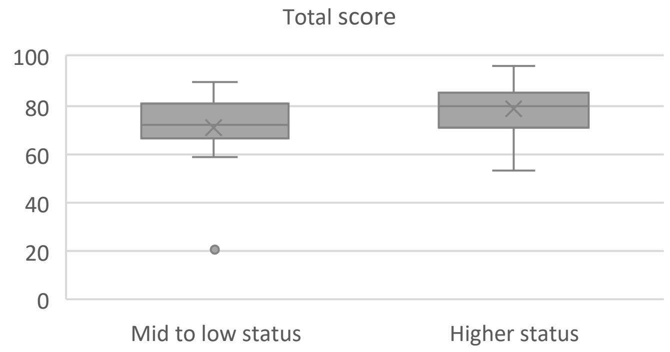


Figure 6.39: Boxplot of Partners in health Total score by socioeconomic status

Information given by health professionals

Information given by health professionals

Participants were asked about what type of information they were given by healthcare professionals, information about treatment options (n=38, 80.85%), disease management (n=23, 48.94%), disease cause (n=22, 46.81%), and physical activity (n=16, 34.04%) were most frequently given to participants by healthcare professionals, and, information about complementary therapies (n=3, 6.38%), how to interpret test results (n=3, 6.38%) and, hereditary considerations (n=0, 0.00%) were given least often (Table 6.28, Figure 6.40).

Table 6.28: Information given by health professionals

Information given by health professionals	n=47	Percent
Disease cause	22	46.81
Treatment options	38	80.85
Disease management	23	48.94
Complementary therapies	3	6.38
How to interpret test results	3	6.38
Clinical trials	5	10.64
Dietary information	12	25.53
Physical activity	16	34.04
Psychological/social support	8	17.02
Hereditary considerations, genes or genomic biomarker information	0	0.00
No information	0	0.00

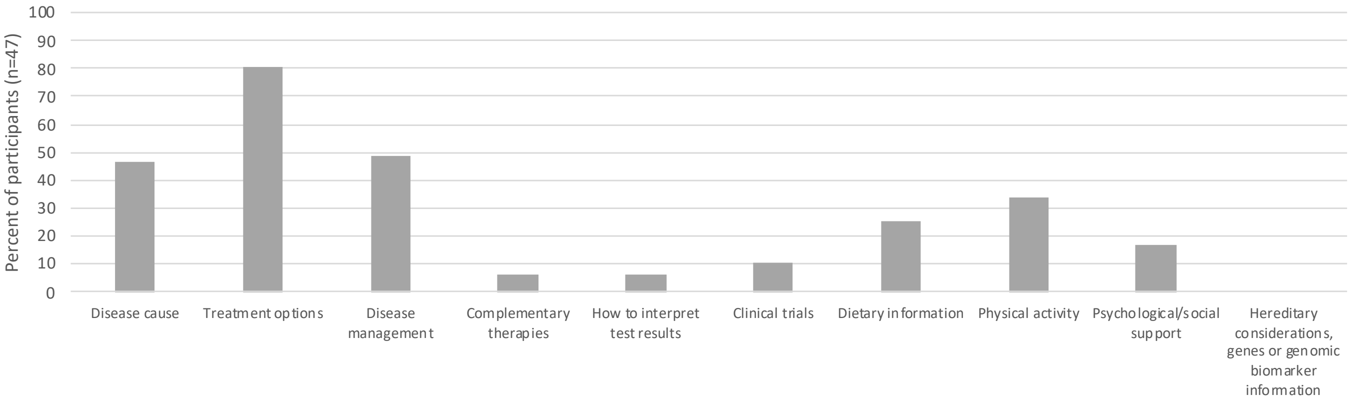


Figure 6.40: Information given by health professionals

Information searched independently

Participants were then asked after receiving information from healthcare professionals, what information did they need to search for independently. The topics participants most often searched for were treatment options (n=28, 59.57%), disease cause (n=26, 55.32%), disease management (n=21, 44.68%) and, how interpret test results (n=18, 38.30%) were most frequently searched for independently and, information about physical activity (n=13, 27.66%), clinical trials (n=10, 21.28%), and hereditary considerations (n=7, 14.89%) were searched for least often (Table 6.29, Figure 6.41).

Table 6.29: Information searched for independently

Information searched independently	n=47	Percent
Disease Cause	26	55.32
Treatment options	28	59.57
Disease management	21	44.68
Complementary therapies	14	29.79
Interpret test results	18	38.30
Clinical trials	10	21.28
Dietary	14	29.79
Physical activity	13	27.66
Psychological/ social support	14	29.79
Hereditary considerations	7	14.89
No information		

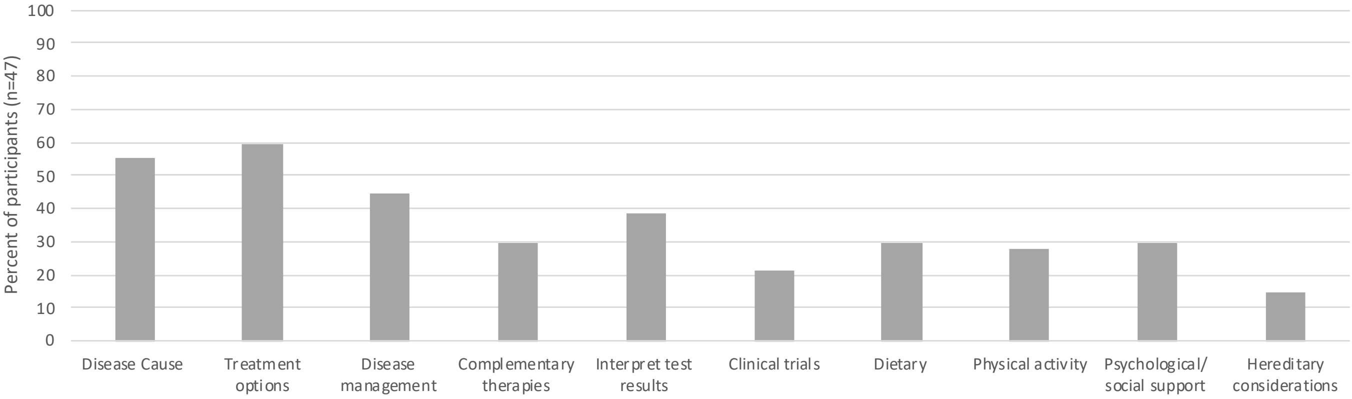


Figure 6.41: Information searched for independently

Information gaps

The largest gaps in information, where information was neither given to patients nor searched for independently were hereditary considerations (n=40, 85.11%) and clinical trials (n=33, 70.21%).

The topics that participants did not search for independently after receiving information from healthcare professionals were treatment options (n=22, 46.81%) and disease Cause (n=12, 25.53%).

The topics that participants were given most information from both healthcare professionals and searching independently for were treatment options (n=16, 34.04%) and disease management (n=12, 25.53%).

The topics that participants searched for independently after not receiving information from healthcare professionals were how to interpret test results (n=17, 36.17%), and disease Cause (n=14, 29.79%) (Table 6.30, Figure 6.42).

Table 6.30: Information gaps

Information topic	Not given by health professional, not searched for independently		Given by health professional only		Given by health professional, searched for independently		Searched for independently only	
	n=47	%	n=47	%	n=47	%	n=47	%
Disease Cause	11	23.40	10	21.28	12	25.53	14	29.79
Treatment options	3	6.38	16	34.04	22	46.81	6	12.77
Disease management	14	29.79	12	25.53	11	23.40	10	21.28
Complementary therapies	31	65.96	2	4.26	1	2.13	13	27.66
How to interpret test results	27	57.45	2	4.26	1	2.13	17	36.17
Clinical trials	33	70.21	4	8.51	1	2.13	9	19.15
Dietary information	24	51.06	9	19.15	3	6.38	11	23.40
Physical activity	22	46.81	12	25.53	4	8.51	9	19.15
Psychological/social support	27	57.45	6	12.77	2	4.26	12	25.53
Hereditary considerations	40	85.11	0	0.00	0	0.00	7	14.89

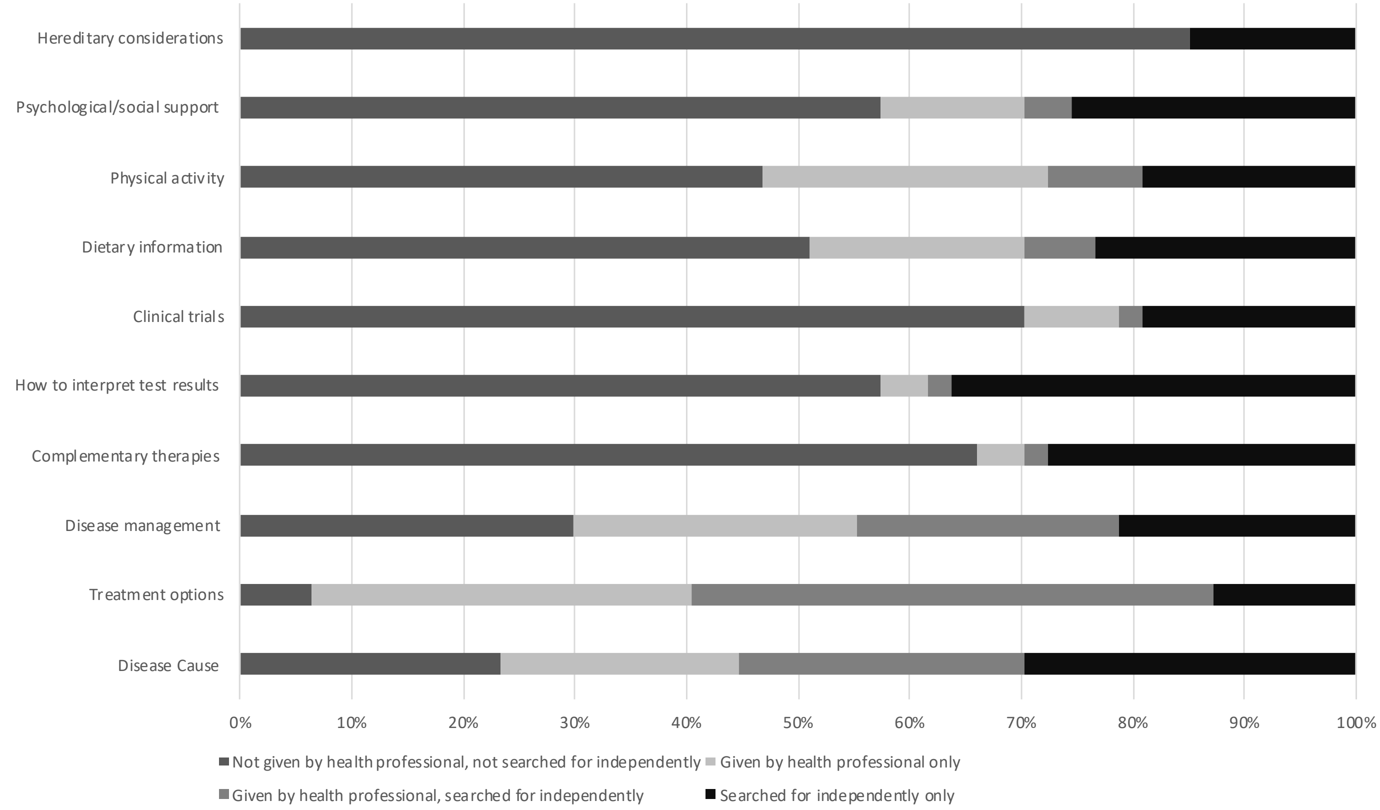


Figure 6.472: Information gaps

Most accessed information

Participants were asked to rank which information source that they accessed most often, where 1 is the most trusted and 4 is the least trusted. A weighted average is presented in Table 6.36 and Figure 6.48. With a weighted ranking, the higher the score, the more accessed the source of information.

Across all participants, information from Non-profit organisations, charity or patient organisations and the hospital or clinic where treated. Information from Pharmaceutical companies were least accessed.

Table 6.31: Most accessed information

Information source	Weighted average (n=47)
Non-profit organisations, charity or patient organisations	3.13
Government	2.57
Pharmaceutical companies	1.23
Hospital or clinic where being treated	3.06

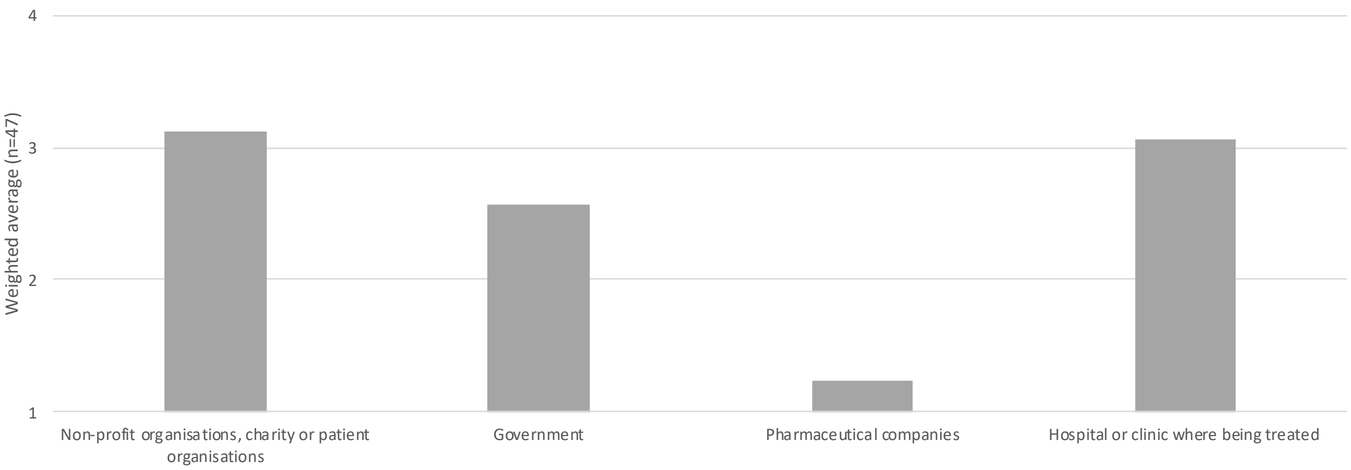


Figure 6.43: Most accessed information

My Health Record

My Health Record is an online summary of key health information, an initiative of the Australian Government. There were 16 participants (33.33%) had accessed My Health Record (Table 6.32. Figure 6.44).

Of those that had accessed My Health Record, there were 11 participants (68.75%) who found it to be poor or very poor, 4 participants (25.00%) who found it acceptable, and 1 participant (6.25%) who found it to be good or very good (Table 6.33, Figure 6.45).

Table 6.32: Accessed My Health Record

Accessed "My health record"	Number (n=48)	Percent
Yes	16	33.33
No	20	41.67
Not sure	8	16.67
Doesn't know what 'My Health Record' is	4	8.33

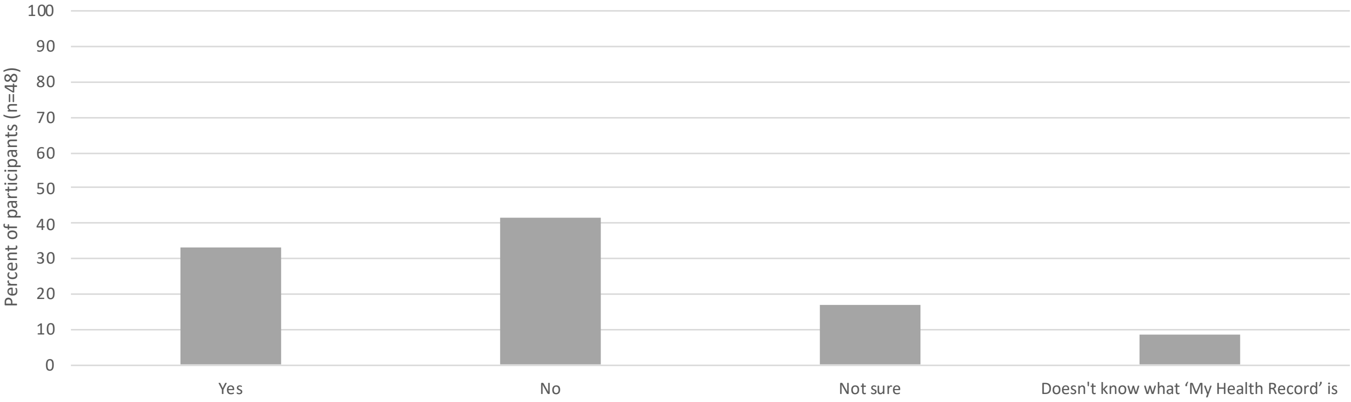


Figure 6.44: Accessed My Health Record

Table 6.33: How useful was My Health Record

How useful was "My health record"	Number (n=16)	Percent
Very poor	1	6.25
Poor	10	62.50
Acceptable	4	25.00
Good	0	0.00
Very good	1	6.25

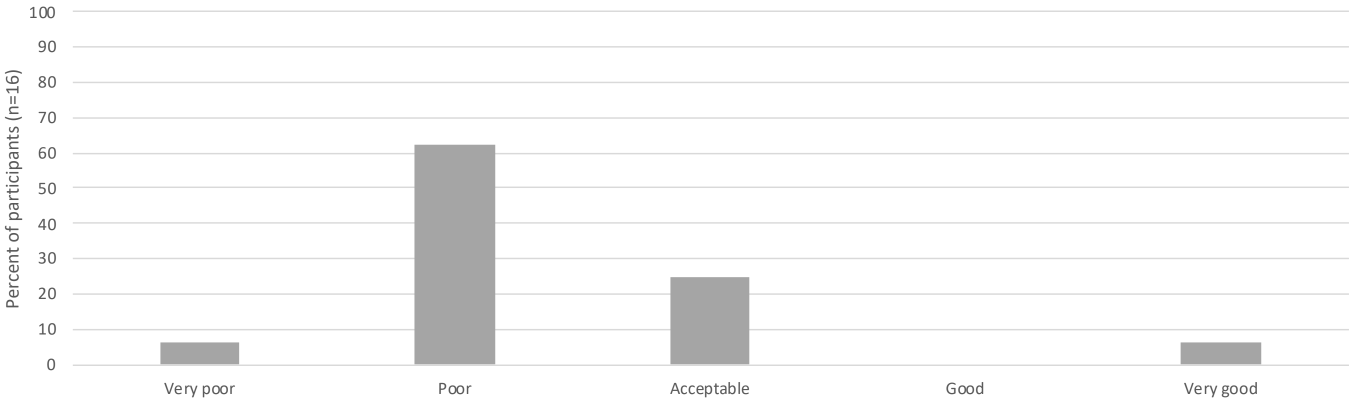


Figure 6.45: How useful was My Health Record

Section 7

Care and support

Section 7: Experience of care and support

Care coordination

A Care Coordination questionnaire was completed by participants within the online questionnaire. The Care Coordination questionnaire comprises a total score, two scales (communication and navigation), and a single question for each relating to care-coordination and care received. A higher score denotes better care outcome.

The **Care coordination: communication** scale measures communication with healthcare professionals, measuring knowledge about all aspects of care including treatment, services available for their condition, emotional aspects, practical considerations, and financial entitlements. The average score indicates that participants had moderate communication with healthcare professionals.

The **Care coordination: navigation** scale navigation of the healthcare system including knowing important contacts for management of condition, role of healthcare professional in management of condition, healthcare professional knowledge of patient history, ability to get appointments and financial aspects of treatments. The average score indicates that participants had good navigation of the healthcare system.

The **Care coordination: total score** scale measures communication, navigation and overall experience of care coordination. The average score indicates that participants had moderate communication, navigation and overall experience of care coordination.

The **Care coordination: care coordination global measure** scale measures the participants overall rating of the coordination of their care. The average score indicates that participants scored rated their care coordination as good.

The **Care coordination: Quality of care global measure** scale measures the participants overall rating of the quality of their care. The average score indicates that participants rated their quality of care as good.

Experience of care and support

In the structured interview, participants were asked what care and support they had received since their diagnosis. This question aims to investigate what services patients consider to be support and care services. The most common theme was that participant did not receive any support (n=18, 36.73%). This was followed by receiving support through charities (n=15, 30.61%), hospital and clinical setting (including nurse support) (n=14, 28.57%), online, phone or social media peer support (n=12, 24.49%), and face-to-face peer support (n=8, 16.33%). There were 5 participants (10.20%) that described not needing any help or support.

Care coordination

A Care Coordination questionnaire was completed by participants within the online questionnaire. The Care Coordination questionnaire comprises a total score, two scales (communication and navigation), and a single question for each relating to care-coordination and care received. A higher score denotes better care outcome. Summary statistics for the entire cohort are displayed alongside the possible range of each scale in Table 7.1.

The overall scores for the cohort were in the second highest quintile for **Care coordination: Navigation** (mean=25.43, SD=4.82), **Care coordination: Care coordination global measure** (median=8.00, IQR=3.50), **Care coordination: Quality of care global measure** (median=8.00, IQR=2.50) indicating good communication, good care coordination, and good quality of care

The overall scores for the cohort were in the middle quintile for **Care coordination: Communication** (mean=39.77, SD=9.52), **Care coordination: Total score** (mean=65.19, SD=13.06), indicating moderate communication, and moderate care coordination.

The **Care coordination: communication** scale measures communication with healthcare professionals, measuring knowledge about all aspects of care including treatment, services available for their condition, emotional aspects, practical considerations, and financial entitlements. The average score indicates that participants had moderate communication with healthcare professionals.

The **Care coordination: navigation** scale navigation of the healthcare system including knowing important contacts for management of condition, role of healthcare professional in management of condition, healthcare professional knowledge of patient history, ability to get appointments and financial aspects of treatments. The average score indicates that participants had good navigation of the healthcare system.

The **Care coordination: total score** scale measures communication, navigation and overall experience of care coordination. The average score indicates that participants had moderate communication, navigation and overall experience of care coordination.

The **Care coordination: care coordination global measure** scale measures the participants overall rating of the coordination of their care. The average score indicates that participants scored rated their care coordination as good.

The **Care coordination: Quality of care global measure** scale measures the participants overall rating of the quality of their care. The average score indicates that participants rated their quality of care as good.

Table 7.1: Care coordination summary statistics

Care coordination scale (n=47)	Mean	SD	Median	IQR	Possible range	Quintile
Communication*	39.77	9.52	40.00	13.50	13 to 65	3
Navigation*	25.43	4.82	25.00	6.50	7 to 35	4
Total score*	65.19	13.06	68.00	16.00	20 to 100	3
Care coordination global measure	7.09	2.08	8.00	3.50	1 to 10	4
Quality of care global measure	7.85	1.92	8.00	2.50	1 to 10	4

*Normal distribution use mean and SD as measure of central tendency

Care coordination by bladder cancer stage

Comparisons were made by Stage. There were 18 participants (42.86%) with early bladder cancer (Stages 0 and I), 10 participants (23.81%) with invasive bladder cancer (Stage III), and 14 participants (33.33%) with advanced bladder cancer (Stage IV).

A one-way ANOVA test was used when the assumptions for response variable residuals were normally distributed and variances of populations were equal (Table 7.2). When the assumptions for normality of residuals was not met, a Kruskal-Wallis test was used (Table 7.3). Post hoc pairwise comparisons using Wilcoxon rank sum test was used to identify the source of any differences identified in the Kruskal -Wallis test (Table 7.4).

A one way ANOVA test indicated a statistically significant difference in the Care coordination: Communication scale between groups, F(2, 39) = 5.18, p = 0.0101. Post hoc comparisons using the Tukey HSD test indicated that the mean score for participants in the early subgroup (mean = 36.22, SD = 7.92) was significantly lower compared to participants in the invasive subgroup (mean = 23.81, SD = 9.74 p=0.0171).

Post hoc comparisons using the Tukey HSD test indicated that the mean score for participants in the early subgroup (mean = 36.22, SD = 7.92) was significantly lower compared to participants in the advanced subgroup (mean = 43.57, SD = 8.06 p=0.0485).

A one way ANOVA test indicated a statistically significant difference in the Care coordination: Total score scale between groups, F(2, 39) = 4.84, p = 0.0133.

Post hoc comparisons using the Tukey HSD test indicated that the mean score for participants in the early subgroup (mean = 60.89, SD = 11.73) was significantly lower compared to participants in the invasive subgroup (mean = 74.30, SD = 12.95 p=0.0150).

The **Care coordination: communication** scale measures communication with healthcare professionals, measuring knowledge about all aspects of care including treatment, services available for their condition, emotional aspects, practical considerations, and financial entitlements. On average, participants in the invasive subgroup scored higher than participants in the early subgroup. This indicates that healthcare communication was good for participants in the Invasive subgroup, and average for participants in the Early subgroup.

The **Care coordination: communication** scale measures communication with healthcare professionals, measuring knowledge about all aspects of care including treatment, services available for their condition, emotional aspects, practical considerations, and financial entitlements. On average, participants in the advanced subgroup scored higher than participants in the early subgroup. This indicates that healthcare communication was good for participants in the advanced subgroup, and average for participants in the early subgroup.

The **Care coordination: total score** scale measures communication, navigation and overall experience of care coordination. On average, participants in the invasive subgroup scored higher than participants in the early subgroup. This indicates that communication, navigation and overall experience of care coordination was good for participants in the invasive subgroup, and average for participants in the early subgroup.

Table 7.2: Care coordination bladder cancer stage summary statistics and one-way ANOVA

Care coordination scale	Group	Number (n=42)	Percent	Mean	SD	Source of difference	Sum of squares	dF	Mean Square	f	p-value
Communication	Early	18	42.86	36.22	7.92	Between groups	733.80	2	366.9	5.176	0.0101*
	Invasive	10	23.81	45.80	9.74	Within groups	2764.10	39	70.9		
	Advanced	14	33.33	43.57	8.06	Total	3497.90	41			
Navigation	Early	18	42.86	24.67	5.28	Between groups	94.50	2	47.24	2.36	0.1080
	Invasive	10	23.81	28.50	3.92	Within groups	780.50	39	20.01		
	Advanced	14	33.33	26.00	3.59	Total	875.00	41			
Total score	Early	18	42.86	60.89	11.73	Between groups	1298.00	2	648.8	4.835	0.0133*
	Invasive	10	23.81	74.30	12.95	Within groups	5233.00	39	134.2		
	Advanced	14	33.33	69.57	10.32	Total	6531.00	41			
Care coordination global measure	Early	18	42.86	6.67	2.28	Between groups	13.79	2	6.895	1.677	0.2000
	Invasive	10	23.81	8.10	1.52	Within groups	160.33	39	4.111		
	Advanced	14	33.33	7.43	1.99	Total	174.12	41			

*Statistically significant at p<0.05

Table 7.3: Care coordination bladder cancer stage summary statistics and Kruskal-Wallis test

Care coordination scale	Group	Difference	Upper	Lower	p adjusted
Communication	Invasive - Early	9.58	1.49	17.67	0.0171*
	Advanced - Early	7.35	0.04	14.66	0.0485*
	Advanced - Invasive	-2.23	-10.72	6.26	0.7994
Total score	Invasive - Early	13.41	2.28	24.54	0.0150*
	Advanced - Early	8.68	-1.37	18.74	0.1022
	Advanced - Invasive	-4.73	-16.41	6.96	0.5900

*Statistically significant at p<0.05

Table 7.4: Care coordination bladder cancer stage one-way post hoc Wilcoxon rank sum test

Care coordination scale	Group	Number (n=42)	Percent	Median	IQR	C^2	dF	p-value
Quality of care global measure	Early	18	42.86	8.00	2.00	3.55	2	0.1695
	Invasive	10	23.81	9.50	1.75			
	Advanced	14	33.33	8.50	2.00			

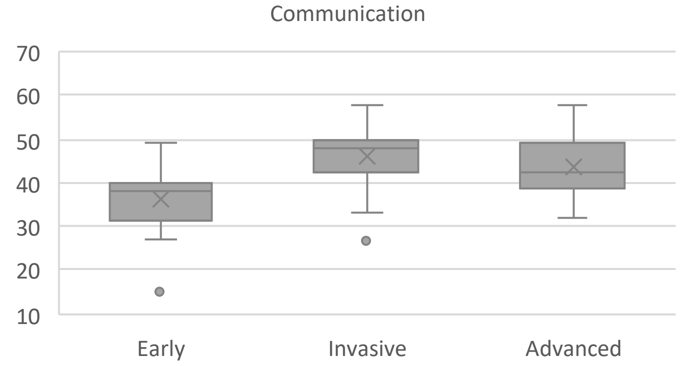


Figure 7.1: Boxplot of Care coordination: Communication bladder cancer stage

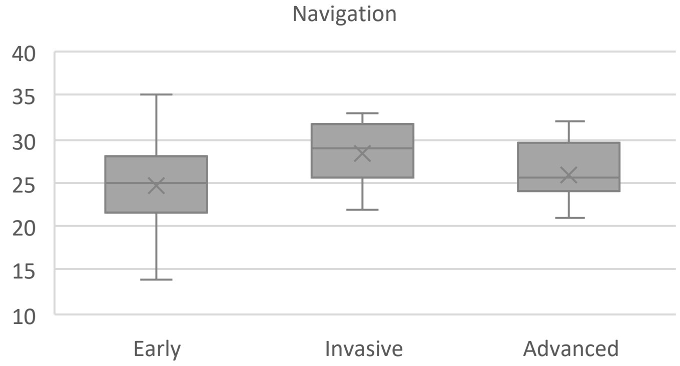


Figure 7.2: Boxplot of Care coordination: Navigation bladder cancer stage

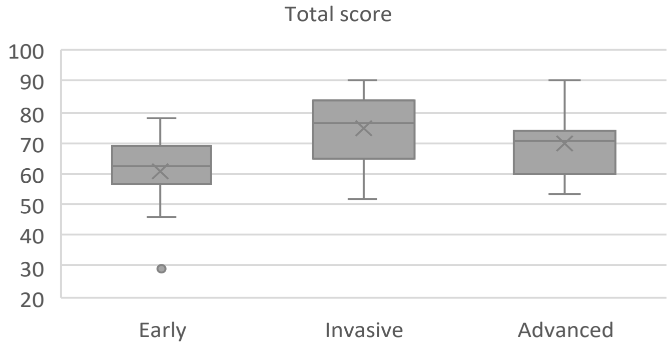


Figure 7.3: Boxplot of Care coordination: Total score bladder cancer stage

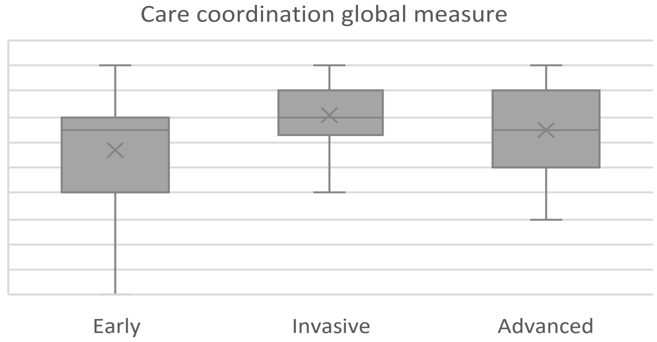


Figure 7.4: Boxplot of Care coordination: Care coordination global measure bladder cancer stage

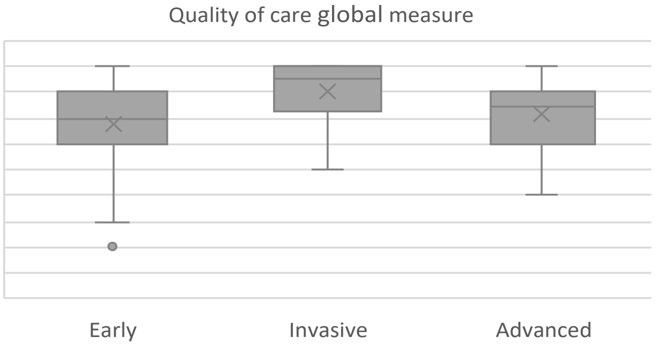


Figure 7.5: Boxplot of Care coordination: Quality of care global measure bladder cancer stage

Care coordination by participant type

Comparisons were made by type of participant, there were 42 participants (89.36%) with bladder cancer and, 5 participants (10.64%) that were a carer to someone with bladder cancer.

A two-sample t-test was used when assumptions for normality and variance were met (Table 7.5), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 7.6).

A two sample t-test indicated that the mean score for the **Care coordination Communicatio**n scale [t(45) = 2.63 , p = 0.0116] was significantly higher for participants in the patient subgroup (Mean = 40.95, SD = 9.24) compared to participants in the carer subgroup (Mean = 29.80, SD = 5.40.)

A two sample t-test indicated that the mean score for the **Care coordination Navigation** scale [t(45) = 2.62 , p = 0.0120] was significantly higher for participants in the patient subgroup (Mean = 26.02, SD = 4.62) compared to participants in the carer subgroup (Mean = 20.40, SD = 3.65.)

A two sample t-test indicated that the mean score for the **Care coordination Total score** scale [t(45) = 2.93 , p = 0.0053] was significantly higher for participants in the patient subgroup (Mean = 66.98, SD = 12.62) compared to participants in the carer subgroup (Mean = 50.20, SD = 3.96.)

Wilcoxon rank sum tests with continuity correction indicated that the median score for the Care coordination **Quality of care global measure scale** [W = 192.50 , p = 0.0023] was significantly higher for participants in the patient subgroup (Median = 9.00, IQR = 2.75) compared to participants in the carer subgroup (Median = 5.00, IQR = 0.00.

The **Care coordination: communication** scale measures communication with healthcare professionals, measuring knowledge about all aspects of care including treatment, services available for their condition, emotional aspects, practical considerations, and financial entitlements. On average, participants in the patient subgroup scored higher than participants in the carer subgroup. This indicates that healthcare communication was average for participants in the patient subgroup, and poor for participants in the carer subgroup.

The **Care coordination: navigation** scale measures the ability of a patient to navigate the healthcare system including knowing important contacts for management of condition, role of healthcare professional in management of condition, healthcare professional knowledge of patient history, ability to get appointments and financial aspects of treatments. On average, participants in the patient subgroup scored higher than participants in the carer subgroup. This indicates that healthcare navigation was good for participants in the patient subgroup, and average for participants in the carer subgroup.

The **Care coordination: total score** scale measures communication, navigation and overall experience of care coordination. On average, participants in the patient subgroup scored higher than participants in the carer subgroup. This indicates that communication, navigation and overall experience of care coordination was average for participants in the patient subgroup, and poor for participants in the carer subgroup.

The **Care coordination: Quality of care global measure** scale measures the participants overall rating of the quality of their care. On average, participants in the patient subgroup scored higher than participants in the carer subgroup. This indicates that, quality of care was very good for participants in the patient subgroup, and average for participants in the carer subgroup.

Table 7.5: Care coordination by participant type summary statistics and T-test

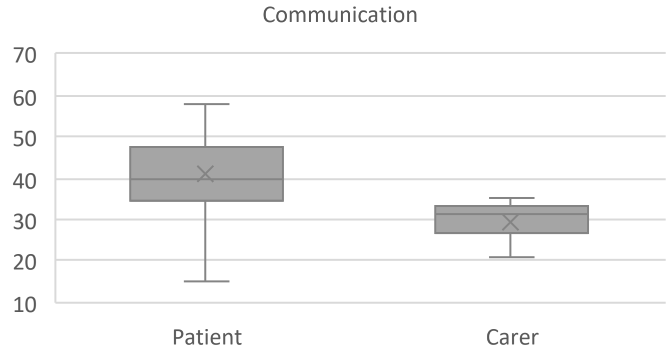
Care coordination scale	Group	Number (n=47)	Percent	Mean	SD	T	dF	p-value
Communication	Patient	42	89.36	40.95	9.24	2.63	45	0.0116*
	Carer	5	10.64	29.80	5.40			
Navigation	Patient	42	89.36	26.02	4.62	2.62	45	0.0120*
	Carer	5	10.64	20.40	3.65			
Total score	Patient	42	89.36	66.98	12.62	2.93	45	0.0053*
	Carer	5	10.64	50.20	3.96			

*Statistically significant at p<0.05

Table 7.6: Care coordination by participant type summary statistics and Wilcoxon test

Care coordination scale	Group	Number (n=47)	Percent	Median	IQR	W	p-value
Care coordination global measure	Patient	42	89.36	8.00	3.00	155.00	0.0836
	Carer	5	10.64	6.00	1.00		
Quality of care global measure	Patient	42	89.36	9.00	2.75	192.50	0.0023*
	Carer	5	10.64	5.00	0.00		

*Statistically significant at p<0.05



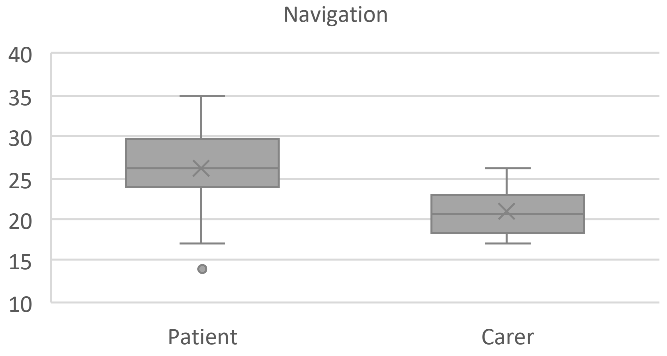


Figure 7.6: Boxplot of Care coordination: Communication participant type

Figure 7.7: Boxplot of Care coordination: Navigation participant type

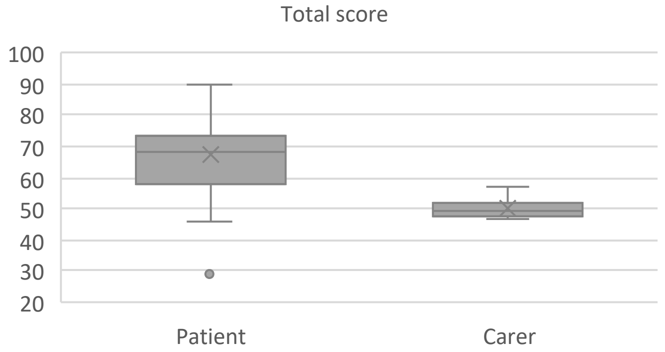


Figure 7.8: Boxplot of Care coordination: Total score participant type

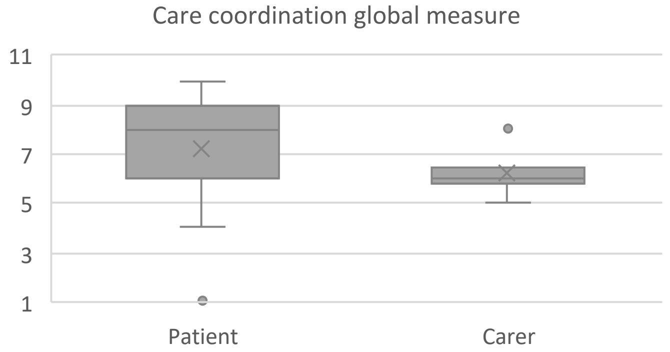


Figure 7.9: Boxplot of Care coordination: Care coordination global measure participant type

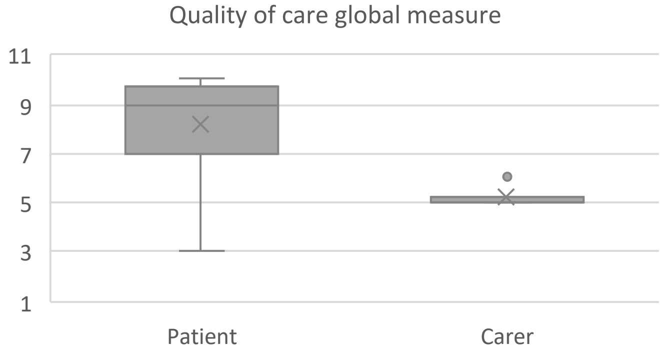


Figure 7.10: Boxplot of Care coordination: Quality of care global measure participant type

Care coordination by gender

Comparisons were made by gender, there were 16 female participants (34.04%), and 31 male participants (65.96%).

A two-sample t-test was used when assumptions for normality and variance were met (Table 7.7), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 7.8).

No significant differences were observed between participants by **gender** for any of the Care coordination scales.

Table 7.7: Care coordination by gender summary statistics and T-test

Care coordination scale	Group	Number (n=47)	Percent	Mean	SD	T	dF	p-value
Communication	Female	16	34.04	39.50	9.42	-0.14	45	0.8924
	Male	31	65.96	39.90	9.72			
Navigation	Female	16	34.04	26.31	4.53	0.90	45	0.3707
	Male	31	65.96	24.97	4.98			
Total score	Female	16	34.04	65.81	12.58	0.23	45	0.8178
	Male	31	65.96	64.87	13.50			

Table 7.8: Care coordination by gender summary statistics and Wilcoxon test

Care coordination scale	Group	Number (n=47)	Percent	Median	IQR	W	p-value
Care coordination global measure	Female	16	34.04	8.00	3.25	252.00	0.9366
	Male	31	65.96	7.00	3.00		
Quality of care global measure	Female	16	34.04	8.00	2.50	254.50	0.8910
	Male	31	65.96	8.00	2.50		

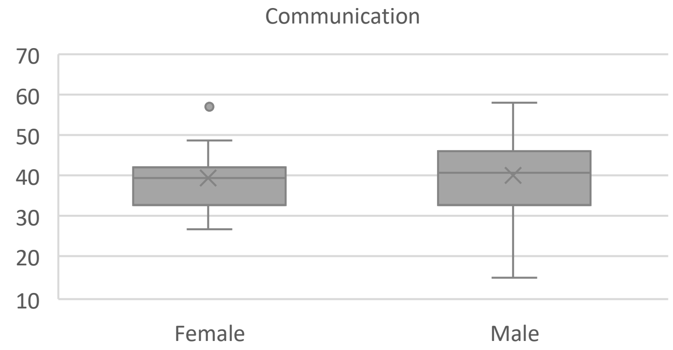


Figure 7.11: Boxplot of Care coordination: Communication gender

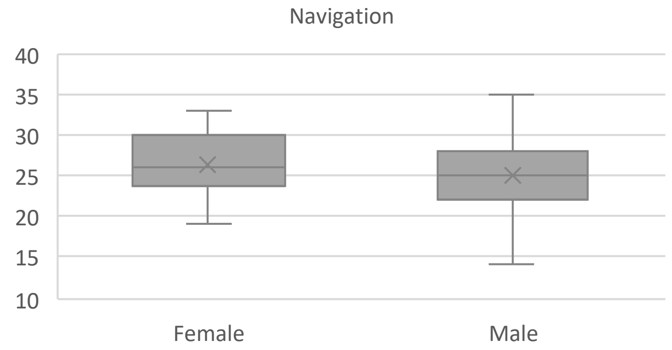


Figure 7.12: Boxplot of Care coordination: Navigation gender

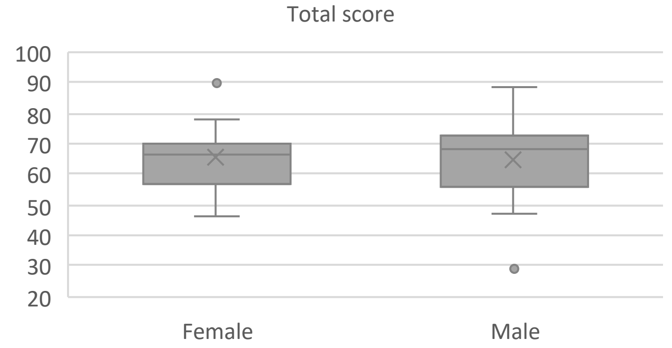


Figure 7.13: Boxplot of Care coordination: Total score gender

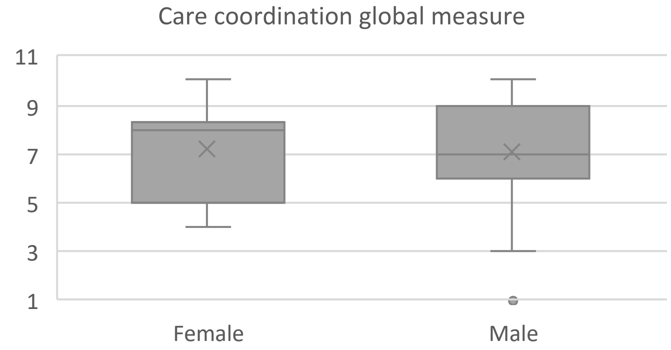


Figure 7.41: Boxplot of Care coordination: Care coordination global measure gender

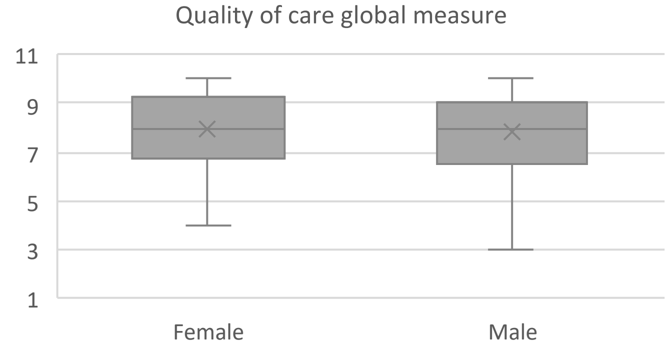


Figure 7.15: Boxplot of Care coordination: Quality of care global measure gender

Care coordination by education

Comparisons were made by education status, between those with trade or high school qualifications (n=29, 61.70%), and those with a university qualification (n=18, 38.30%).

A two-sample t-test was used when assumptions for normality and variance were met (Table 7.9), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 7.10).

No significant differences were observed between participants by **education** for any of the Care coordination scales.

Table 7.9: Care coordination by education summary statistics and T-test

Care coordination scale	Group	Number (n=47)	Percent	Mean	SD	T	dF	p-value
Navigation	Trade or high school	29	61.70	24.83	4.88	-1.08	45	0.2854
	University	18	38.30	26.39	4.70			
Total score	Trade or high school	29	61.70	65.45	11.38	0.17	45	0.8664
	University	18	38.30	64.78	15.75			
Care coordination global measure	Trade or high school	29	61.70	6.93	1.85	-0.64	45	0.5258
	University	18	38.30	7.33	2.45			

Table 7.10: Care coordination by education summary statistics and Wilcoxon test

Care coordination scale	Group	Number (n=47)	Percent	Median	IQR	W	p-value
Communication	Trade or high school	29	61.70	40	12	291.00	0.5181
	University	18	38.30	39.5	16.5		
Quality of care global measure	Trade or high school	29	61.70	8	2	253.00	0.8674
	University	18	38.30	8.5	3.5		

*Statistically significant at $p<0.05$

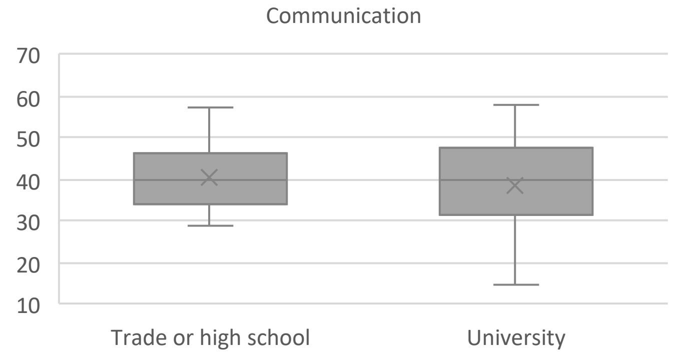


Figure 7.16: Boxplot of Care coordination: Communication education

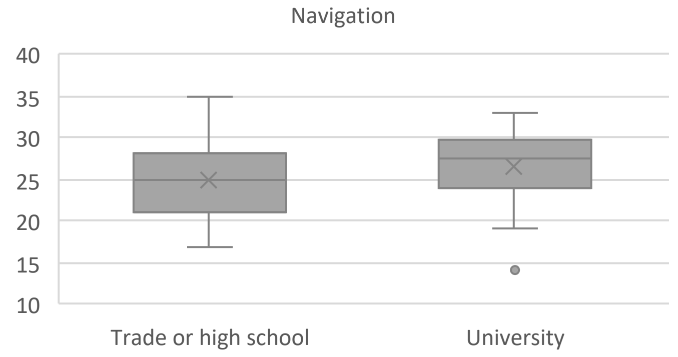


Figure 7.17: Boxplot of Care coordination: Navigation education

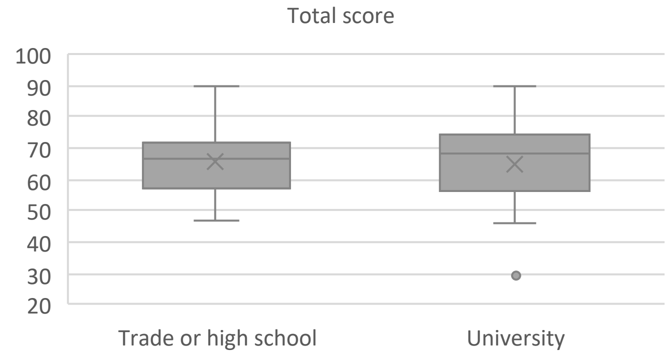


Figure 7.18: Boxplot of Care coordination: Total score education

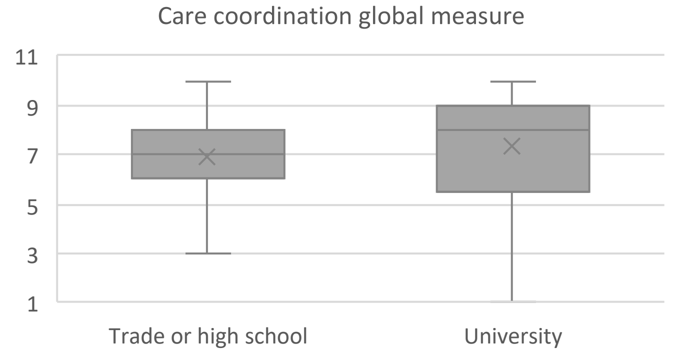


Figure 7.19: Boxplot of Care coordination: Care coordination global measure education

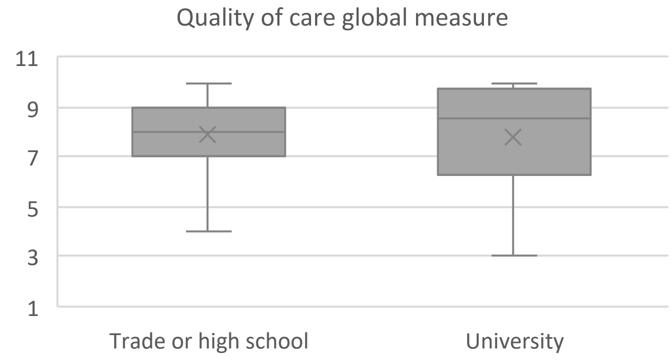


Figure 7.20: Boxplot of Care coordination: Quality of care global measure education

Care coordination by location

The location of participants was evaluated by postcode using the Australian Statistical Geography Maps (ASGS) Remoteness areas accessed from the Australian Bureau of Statistics. Those living in regional or remote area (n=15, 31.91%) were compared to those living in a metropolitan area (n=32, 68.09%).

A two-sample t-test was used when assumptions for normality and variance were met (Table 7.11), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 7.12).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the **Care coordination Care coordination global measure** scale [W = 141.00 , p = 0.0228] was significantly lower for participants in the regional or remote subgroup (Median = 7.00, IQR = 3.00) compared to participants in the metropolitan subgroup (Median = 8.00, IQR = 3.00.

The **Care coordination: Quality of care global measure** scale measures the participants overall rating of the quality of their care. On average, participants in the metropolitan subgroup scored higher than participants in the regional or remote subgroup. This indicates that, quality of care was good for participants in the metropolitan subgroup, and average for participants in the regional or remote subgroup.

Table 7.11: Care coordination by location summary statistics and T-test

Care coordination scale	Group	Number (n=47)	Percent	Mean	SD	T	dF	p-value
Communication	Regional or remote	15	31.91	37.27	10.38	-1.24	45	0.2217
	Metropolitan	32	68.09	40.94	9.02			
Navigation	Regional or remote	15	31.91	24.40	5.69	-1.00	45	0.3235
	Metropolitan	32	68.09	25.91	4.37			
Total score	Regional or remote	15	31.91	61.67	15.30	-1.28	45	0.2089
	Metropolitan	32	68.09	66.84	11.78			

Table 7.12: Care coordination by location summary statistics and Wilcoxon test

Care coordination scale	Group	Number (n=47)	Percent	Median	IQR	W	p-value
Care coordination global measure	Regional or remote	15	31.91	7.00	3.00	141.00	0.0228*
	Metropolitan	32	68.09	8.00	3.00		
Quality of care global measure	Regional or remote	15	31.91	8.00	3.50	178.00	0.1533
	Metropolitan	32	68.09	9.00	2.25		

*Statistically significant at p<0.05

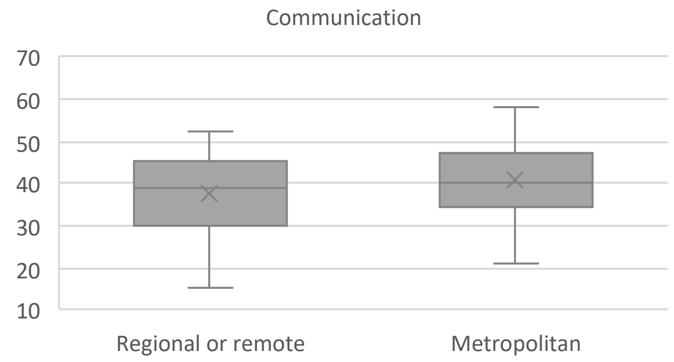


Figure 7.21: Boxplot of Care coordination: Communication location

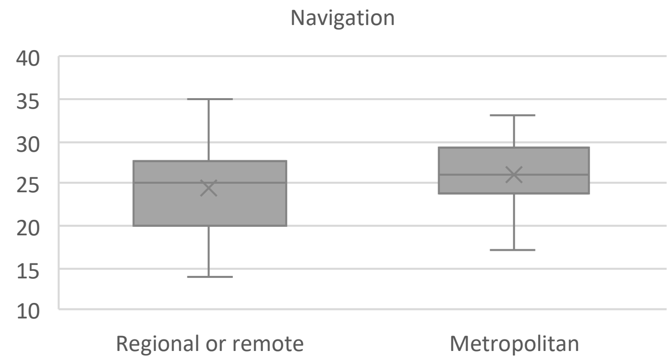
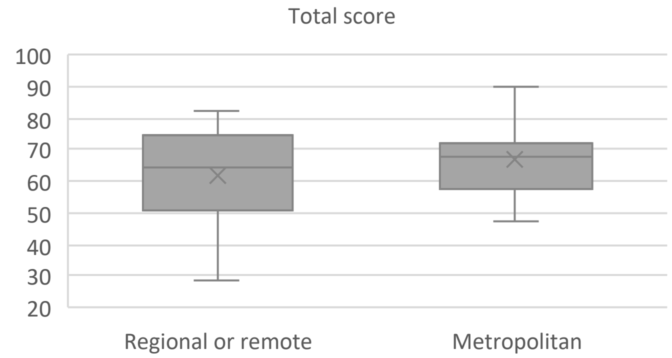


Figure 7.22: Boxplot of Care coordination: Navigation location



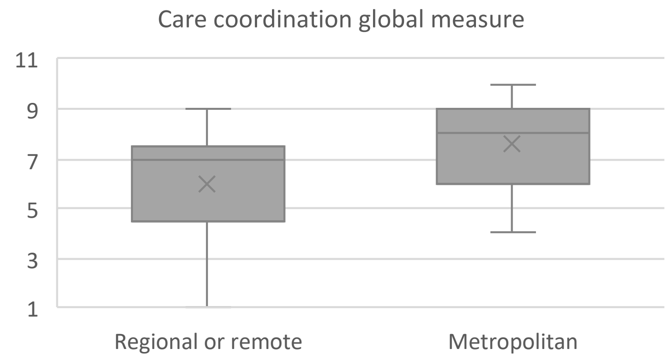


Figure 7.23: Boxplot of Care coordination: Total score location

Figure 7.24: Boxplot of Care coordination: Care coordination global measure location

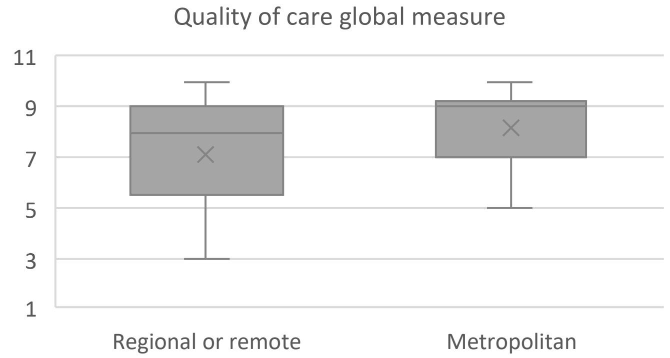


Figure 7.25: Boxplot of Care coordination: Quality of care global measure location

Care coordination by socioeconomic status

Comparisons were made by socioeconomic status, using the Socio-economic Indexes for Areas (SEIFA) (www.abs.gov.au), SEIFA scores range from 1 to 10, a higher score denotes a higher level of advantage. Participants with a mid to low SEIFA score of 1-6 (n=20, 42.55%) compared to those with a higher SEIFA score of 7-10 (n=27, 57.45%).

A two-sample t-test was used when assumptions for normality and variance were met (Table 7.13), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 7.14).

No significant differences were observed between participants by **socioeconomic status** for any of the Care coordination scales.

Table 7.13: Care coordination by socioeconomic status summary statistics and T-test

Care coordination scale	Group	Number (n=47)	Percent	Mean	SD	T	dF	p-value
Communication	Mid to low status	20	42.55	38.50	10.39	-0.78	45	0.4388
	Higher status	27	57.45	40.70	8.91			
Navigation	Mid to low status	20	42.55	25.00	5.42	-0.52	45	0.6080
	Higher status	27	57.45	25.74	4.41			
Total score	Mid to low status	20	42.55	63.50	14.42	-0.76	45	0.4510
	Higher status	27	57.45	66.44	12.09			
Care coordination global measure	Mid to low status	20	42.55	6.70	2.39	-1.09	45	0.2802
	Higher status	27	57.45	7.37	1.82			

Table 7.14: Care coordination by socioeconomic status summary statistics and Wilcoxon test

Care coordination scale	Group	Number (n=47)	Percent	Median	IQR	W	p-value
Quality of care global measure	Mid to low status	20	42.55	8.50	3.50	249.00	0.6536
	Higher status	27	57.45	8.00	2.00		

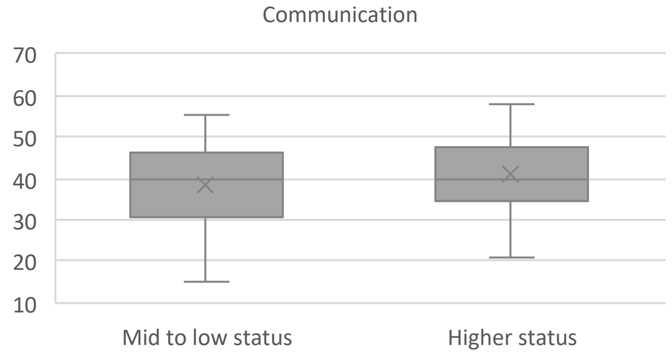


Figure 7.26: Boxplot of Care coordination: Communication socioeconomic status

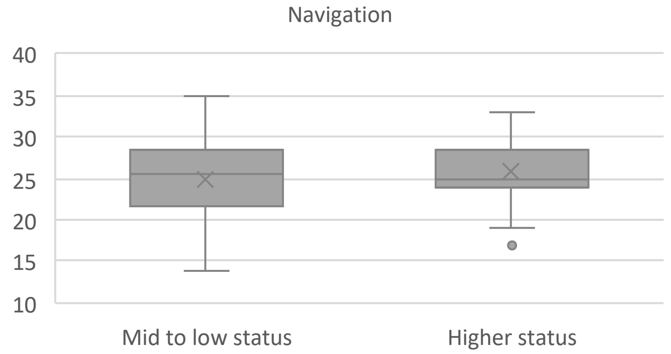


Figure 7.27: Boxplot of Care coordination: Navigation socioeconomic status

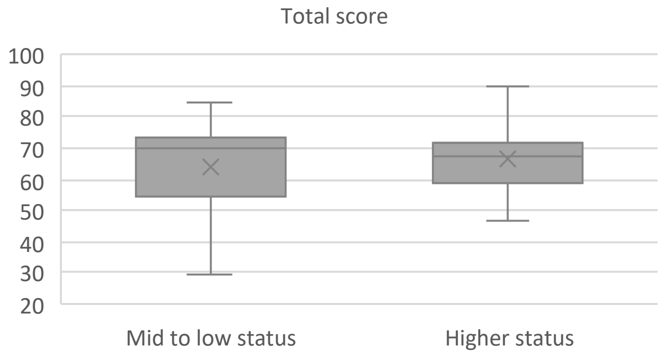


Figure 7.28: Boxplot of Care coordination: Total score socioeconomic status

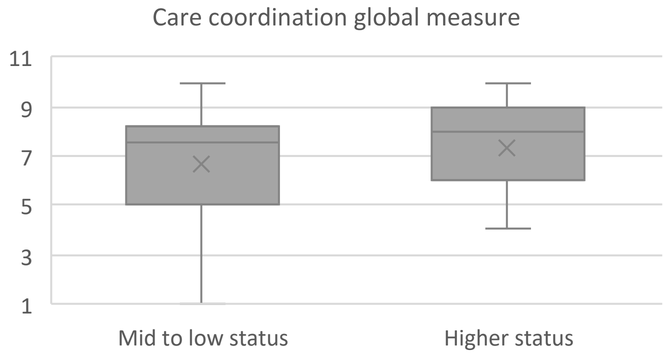


Figure 7.29: Boxplot of Care coordination: Care coordination global measure socioeconomic status

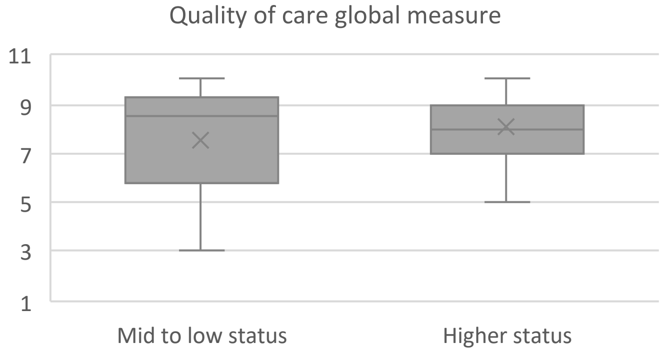


Figure 7.30: Boxplot of Care coordination: Quality of care global measure socioeconomic status

Experience of care and support

In the structured interview, participants were asked what care and support they had received since their diagnosis. This question aims to investigate what services patients consider to be support and care services. The most common theme was that participant did not receive any support (n=18, 36.73%). This was followed by receiving support through charities (n=15, 30.61%), hospital and clinical setting (including nurse support) (n=14, 28.57%), online, phone or social media peer support (n=12, 24.49%), and face-to-face peer support (n=8, 16.33%). There were 5 participants (10.20%) that described not needing any help or support.

Participant describes not receiving any support

No one. No one's even spoken about it.
Participant 007_2022AUBLC

No. Never been offered. Yeah. Yeah. No discussion from the surgeons.
Participant 008_2022AUBLC

No, because private patients don't get offered anything. If you're, like if I had gone to PUBLIC HOSPITAL, they might have offered something or seen to work or something, but not in the private. You really got to see things yourself and yeah, I mean and I don't really need it because I'm still working.
Participant 018_2022AUBLC

Participant describes receiving support through charities (General support and information)

We were we were put in touch with Palliative Care Australia. So we've had them pretty much, you know, from. Once he started palliative care in hospital, right through to coming home and even continuing now with my own grief counselling, bereavement counselling that my daughter, my youngest, just sort of had a dabble with some art therapy and music therapy through Palliative Care Australia. We were put in touch with health, community and health services. He also was offered a social worker in hospital, which he declined.
Carer 002_2022AUBLC

PARTICIPANT: Oh yes, support from BEAT. Also I had trouble. Well, this is a couple years ago. I had trouble with with a garden. And I had one Cancer STATE or Cancer Australia, not sure who, offered, offered a, um uh, well, I don't know whether it was 3 or $600, but they offered a one off come and clean up type of thing. I got to a gardener to come in and fix my garden for me.

INTERVIEWER: Excellent. Okay.

PARTICIPANT: All right. Look at that. That was about two years ago now.

INTERVIEWER: And now other important things like transport, maybe help with that.

PARTICIPANT: But that's that's part of the DVA. I used theiir transport. They transport the go to clinic all the time.

Participant 037_2022AUBLC

Well, the main support of that is basically from via Facebook and ZOOM some some of the bladder cancer groups. BEAT's been a big help they had an open forum, I was on a Zoom meeting I was on that last night they had a chap on, and I'm glad I didn't do it prior to the operation to be honest, he showed a few gory pictures. One of the urologist or gentleman's he's been in the field for quite a few years 40 years or something urology. There was a few, but answered questions and describing operations for various people. So I thought it was fairly good, I went down to a bladder cancer walk on Sunday and a walk in CITY, in Memory of The young lass that died with bladder cancer died from bladder cancer. And people there, it's a registered charity, BEAT they were very supportive. And, you know, all of the family members plus members of the medical association are medical, they were there. So, you know, just general chit chat and no one got too personal about anything, but it was a yes. Good supportive environment.
Participant 011_2022AUBLC

Participant describes receiving support through the hospital or clinical setting

No. Like I said, just like the government. Free counselling services at the hospital. Um, but I have more done my own research and found BEAT bladder cancer. I'm like, I've just come across them on Facebook page, which is obviously where all this interview is actually come from. That's how I heard about it. Um. But if I'm being honest, I've signed up for the support groups, but I've never once attended because I'm too anxious about it.
Participant 009_2022AUBLC

It was during the BCG therapy stage, the nurse did reach out with some very good information on what BCG therapy was and would be involved in it. And, they were always, every nurse and registrar was always excellent with explaining the process and making sure you knew what was going to happen that day when you went into a hospital and even had one of the sessions was on my birthday and the registrar offered to sing Happy Birthday right at the right time, but I said, no, thank you. Afterwards, there was none really by professionals. There was no care that really needed when I was at the hospital.
Participant 019_2022AUBLC

Yeah, I've found that they've been awesome. When I had a problem there maybe six months ago, I was having problems withwhere around the stoma. it was pretty red. And yeah, when seen the nurse and she told me to change the bag like daily instead of, you know, it was doing two or three days and things like that. So I've found that if I have any problems, I can ring her up, you know. And she's been great to ring up. I actually should, I save having to go into the hospital. I was taking pictures of me stoma and I'll send it to her and she was sending messages back and try this or try that. So didn't actually have to come to the hospital. So I was having like telephone consults with her. And I found it really good support.
Participant 044_2022AUBLC

Only the support group. Yeah, his GP has been very caring of him. So I think the GP having put everything in place. You know, my husband used to think, oh, I can see any doctor, you know. But now he's, he's really, realised that his GP is very important and also we've had to shop health care professionals. And when I said we've had to shop for care professionals, we've had to shop around for the ones that have empathy, the ones who have ethics, the ones who have time, and the ones who have your interests at heart. Those four elements is what we've had to shop for. Oh, and and then the other most important thing is our private health. You know, having a caring and empathetic private health insurer has been amazing.
Carer 004_2022AUBLC

Participant describes receiving support through peer support: Online, online/phone groups and social media

Well, the main support of that is basically from via Facebook and ZOOM some some of the bladder cancer groups. BEAT's been a big help they had an open forum, I was on a Zoom meeting I was on that last night they had a chap on, and I'm glad I didn't do it prior to the operation to be honest, he showed a few gory pictures. One of the urologist or gentleman's he's been in the field for quite a few years 40 years or something urology. There was a few, but answered questions and describing operations for various people. So I thought it was fairly good, I went down to a bladder cancer walk on Sunday and a walk in CITY, in Memory of The young lass that died with bladder cancer died from bladder cancer. And people there, it's a registered charity, BEAT they were very supportive. And, you know, all of the family members plus members of the medical association are medical, they were there. So, you know, just general chit chat and no one got too personal about anything, but it was a yes. Good supportive environment.
Participant 011_2022AUBLC

So I don't really know. I did I did go to a couple of those things, the bladder cancer forums. I have it at night, they do that once every month or two months, but that's the only thing I'll just. I've been on it twice, I think. Might have only been once, about a year ago. Apart from that, there's been nothing.
Participant 021_2022AUBLC

And think the only support I got is from this bladder cancer group. Oh, right. On Facebook. So that was very helpful. I if I had any question or, you know, just learning about other people's experiences, that was pretty good.
Participant 028_2022AUBLC

Participant describes receiving support through peer support: Face-to-face (or unspecified support group)

Well, this the support group we are a member of that is based in Melbourne. Bladder Cancer Australia. It was run by two young women that lost their father to bladder cancer a few years ago. So and then we've been, you know. They have meetings and Zoom meetings and we've just been down and had a conference in Melbourne just February. So it's, it's good to see people in person and be able to talk to them about their experiences. Participant 027_2022AUBLC

PARTICIPANT: Yes BEAT, B E A T.

INTERVIEWER: Yes. Are there other are there other groups that you've you've accessed any sort of community support from? If so, what kind of support and where from?

PARTICIPANT: No, no. There'd been nothing else that I could think of. I mean, I belong to a social group. It's called Progress, but it's got nothing to do with health. It's it's about fun, friendship and frivolity, basically. And it's we we organise a lot of retirees activities, days out, lunches, that sort of thing. And that has been a means of support for me, but not the community support health wise.Participant 036_2022AUBLC

Okay. So the psychiatric help or the psychological help that I've just recently gotten onto it was put into place two years ago by HOSPITAL and they, they put me down on their programme to have access to somebody to help me there. I've had access through to community groups, bladder cancer community groups. Um, that, yeah, we actively take part in and meet with and raise funds for.
Participant 035_2022AUBLC

Participant describes not needing and help or support

No, not really. And I haven't, I don't think I've needed it as such. You know I'm I'm still ,you know, not is a people sort of a surprise when I told them because I was oh you don't look sick and I don't I don't feel sick. It didn't get to that point of it being debilitating or anything like that. So I haven't required any. Community care or anything like that. Participant 014_2022AUBLC

No, I'm living normal lives. I'm lucky. Yes. Participant 015_2022AUBLC

Well, no, not really. I don't think because. As I say, I am fiercely independent. So, you know, like I had a major op and they told me I'd have to have three months of work and I'm like, Well, I don't think I will. So, you know, I said, I'll have a month and. And then I will work because I don't like sitting around doing nothing. And so I need to be busy. So. So yes, I didn't kind of really. Really need it. And when I'm you know, when I had the last op my son wanted to come and I'm like, you know, it might be a time when I feel good actually like to be just on my own when I feel shit. So I actually don't want people around. I'd rather just. Take my time to do what I'm going to do and manage.
Participant 026_2022AUBLC

Participant describes receiving support through a psychologist or counselling services

So the psychiatric help or the psychological help that I've just recently gotten onto it was put into place two years ago by HOSPITAL and they, they put me down on their programme to have access to somebody to help me there. I've had access through to community groups, bladder cancer community groups. Um, that, yeah, we actively take part in and meet with and raise funds for. Um. Well, what else? No, that that's probably that is. Yeah, I think we've covered up on most of that.
Participant 035_2022AUBLC

Table 7.15: Experience of care and support

Care and support received	All participants		Early		Invasive		Advanced		Person with bladder cancer		Carer		Female		Male	
	n=49	%	n=20	%	n=10	%	n=14	%	n=44	%	n=5	%	n=17	%	n=32	%
Participant describes not receiving any support	18	36.73	12	60.00	2	20.00	3	21.43	17	38.64	1	20.00	7	41.18	11	34.38
Participant describes receiving support through charities (General support and information)	15	30.61	4	20.00	2	20.00	7	50.00	13	29.55	2	40.00	5	29.41	10	31.25
Participant describes receiving support through the hospital or clinical setting	14	28.57	3	15.00	2	20.00	6	42.86	11	25.00	3	60.00	2	11.76	12	37.50
Participant describes receiving support through peer support: Online, online/phone groups and social media	12	24.49	3	15.00	4	40.00	4	28.57	11	25.00	1	20.00	3	17.65	9	28.13
Participant describes receiving support through peer support: Face-to-face (or unspecified support group)	8	16.33	1	5.00	2	20.00	3	21.43	6	13.64	2	40.00	2	11.76	6	18.75
Participant describes not needing and help or support	5	10.20	3	15.00	2	20.00	0	0.00	5	11.36	0	0.00	3	17.65	2	6.25
Participant describes receiving support through a psychologist or counselling services	3	6.12	1	5.00	0	0.00	1	7.14	2	4.55	1	20.00	1	5.88	2	6.25

Care and support received	All participants		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=49	%	n=29	%	n=19	%	n=15	%	n=33	%	n=20	%	n=28	%
Participant describes not receiving any support	18	36.73	8	27.59	10	52.63	5	33.33	13	39.39	8	40.00	10	35.71
Participant describes receiving support through charities (General support and information)	15	30.61	12	41.38	2	10.53	4	26.67	10	30.30	5	25.00	9	32.14
Participant describes receiving support through the hospital or clinical setting	14	28.57	10	34.48	3	15.79	4	26.67	9	27.27	6	30.00	7	25.00
Participant describes receiving support through peer support: Online, online/phone groups and social media	12	24.49	9	31.03	2	10.53	3	20.00	8	24.24	4	20.00	7	25.00
Participant describes receiving support through peer support: Face-to-face (or unspecified support group)	8	16.33	5	17.24	2	10.53	3	20.00	4	12.12	3	15.00	4	14.29
Participant describes not needing and help or support	5	10.20	1	3.45	4	21.05	2	13.33	3	9.09	2	10.00	3	10.71
Participant describes receiving support through a psychologist or counselling services	3	6.12	3	10.34	0	0.00	1	6.67	2	6.06	1	5.00	2	7.14

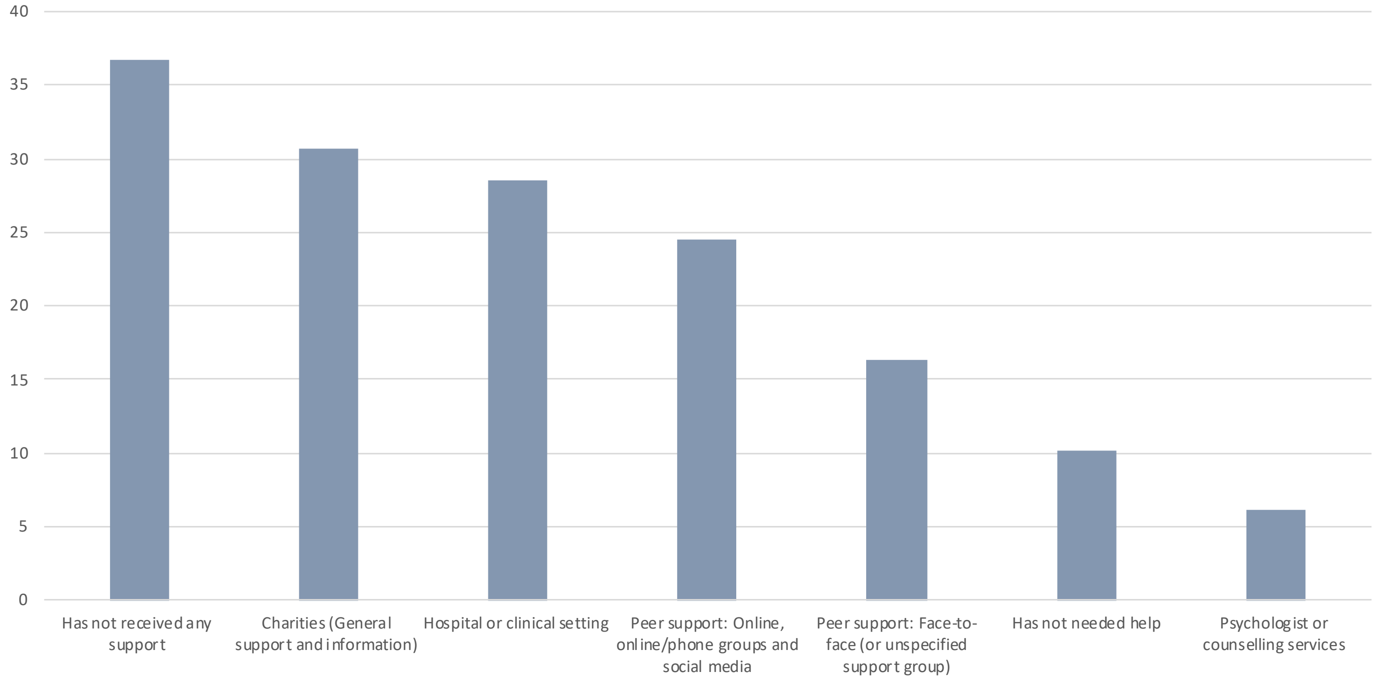


Figure 7.31: Experience of care and support

Table 7.16: Experience of care and support – subgroup variations

Care and support received	Reported less frequently	Reported more frequently
Participant describes not receiving any support	Invasive (Stage III) Advanced (Stage IV) Carer to someone with bladder cancer	Early (Stages 0 and I) University
Participant describes receiving support through charities (General support and information)	Early (Stages 0 and I) Invasive (Stage III) University	Advanced (Stage IV) Trade or high school
Participant describes receiving support through the hospital or clinical setting	Early (Stages 0 and I) Female University	Advanced (Stage IV) Carer to someone with bladder cancer
Participant describes receiving support through peer support: Online, online/phone groups and social media	University	Invasive (Stage III)
Participant describes receiving support through peer support: Face-to-face (or unspecified support group)	Early (Stages 0 and I)	Carer to someone with bladder cancer
Participant describes not needing and help or support	Advanced (Stage IV) Carer to someone with bladder cancer	University

Section 8

Quality of life

Section 8: Quality of life

Impact on quality of life

In the structured interview, participants were asked whether they felt that their condition had affected their quality of life. Overall, there were 14 participants (28.57%) that described a negative impact on quality of life, 12 participants (24.49%) that reported some negative impact on quality of life, and 12 participants (24.49%) that described a mix of positive and negative impacts on quality of life. Other participants described no impact on quality of life (n=10, 20.41%), an overall positive impact on quality of life (n=8, 16.33%, and a minimal impact on quality of life (n=8, 16.33%).

The most common themes in relation to a negative impact on quality of life were due to the side effects of treatment or symptoms of conditions that they need to manage (n=18, 36.73%), the mental and emotional impact of their condition (n=16, 32.65%), emotional strain on family or partner/change in relationship dynamics (n=14, 28.57%), intimacy problems (n=11, 22.45%), the need to plan for toilets or to manage stoma (n=10, 20.41%), and reduced capacity for physical activity (n=8, 16.33%).

The most common theme in relation to a positive impact on quality of life was that it brings people together (n=9, 18.37%)

Impact on mental health

In the structured interview, participants were asked if there had been an impact on their mental health. There were 38 participants (77.55%) who gave a description suggesting that overall there was some impact on their mental health and 10 participants (20.41%) who gave a description suggesting that overall there was no impact on mental health.

Regular activities to maintain mental health

In the structured interview, participants were asked what they needed to do to maintain their emotional and mental health. The most common way that participants reported managing their mental and emotional health was describing the importance of family and friends (n=19, 38.78%). Other participants described the importance of physical exercise (n=11, 22.45%), mindfulness and/or meditation, consulting a mental health professional (n=9, 18.37%), and maintaining social, lifestyle changes, and hobbies (n=7, 14.29%). There were 11 participants (22.45%) that described no activities to maintain mental health.

Regular activities to maintain health

In the structured interview, participants were asked what were some of the things they needed to do everyday to maintain their health? The most common ways that participants reported managing their health were; being physically active (n=11, 22.45%), keeping busy or keeping a normal routine (n=11, 22.45%), and managing their stoma or incontinence (n=11, 22.45%). Other ways to maintain health were complying with treatment (n=7, 14.29%), socialising with friends and/or family (n=7, 14.29%), maintaining a healthy diet (n=6, 12.24%), and the importance of self care e.g. more rest, support for housework etc. (n=5, 10.20%). There were 7 participants (14.29%) that described no activities to maintain health.

Experience of vulnerability

In the structured interview, participants were asked if there had been times that they felt vulnerable. There were 42 participants (85.71%) who gave a description suggesting that overall they had experiences of feeling vulnerable, and 2 participants (4.08%) who gave a description suggesting that overall they did not have feelings of being vulnerable.

In relation to when participants felt most vulnerable, the most common theme was feeling vulnerable during or after treatments (n=25, 51.02%). There 13 participants (26.53%) that described feeling vulnerable when first diagnosed, first few months after diagnosis, while experiencing side effects from treatment or symptoms from condition (n=10, 20.41%), because of interactions with the medical team (n=8, 16.33%), and 8 participants (16.33%) described feeling vulnerable when having sensitive discussion (diagnosis, treatment decision). Other participants described feeling vulnerable when thinking about disease course/incurable condition (n=5, 10.20%), being vulnerable when they have a loss of independence, e.g in hospital, recovering from surgery (n=5, 10.20%), and when first sent home after being hospitalised without the care/availability healthcare professionals (n=5, 10.20%).

Methods to manage vulnerability

In the structured interview, participants described ways that they managed feelings of vulnerability. Participants described using self help methods such as resilience, acceptance, and staying positive to manage the feeling of vulnerability (n=12, 24.49%), support from family and friends to manage the feeling of vulnerability (n=7, 14.29%), and being supported by nurse or treatment team to manage the feeling of vulnerability (n=6, 12.24%).

Impact on relationships

In the structured interview, participants were asked whether their condition had affected their personal relationships. Overall, there were 17 participants (34.69%) that described that overall, there was a positive impact on relationships. Other participants described a mix of a positive and a negative impact (n=11, 22.45%), a negative impact on relationships (n=9, 18.37%), no impact on relationships (n=8, 16.33%), and an impact on relationships that was neither positive nor negative (n=3, 6.12%)

The most common themes in relation to having a positive impact on relationships were relationships within the family being strengthened (n=22, 44.90%), and people being well-meaning and supportive (n=10, 20.41%). The most common themes in relation to having a positive impact on relationships were relationships suffering, that is people not knowing what to say or do and withdrawing from relationships (n=9, 18.37%), and dynamics of relationships change due to anxiety, exacerbations and/or physical limitations of condition (n=7, 14.29%).

Burden on family

In the structured interview, participants were asked whether they felt that their condition placed additional burden on their family. Overall, there were 22 participants (44.90%) that felt there was an additional burden, 20 participants (40.82%) that reported no additional burden, and 6 participants (12.24%) that felt they were not a burden on their family but anticipate this will change in the future.

For people that felt they were not a burden on their family, the most did not give any specific reasons for this (n=14, 28.57%). The main reason that participant described their condition not being a burden in general was that they were very independent and did not need any help (n=8, 16.33%). The most common reasons for feeling that they were a burden on their family was the mental/emotional strain placed on their family (n=12, 24.49%), the extra household duties and responsibilities that their family must take on (n=5, 10.20%), and that the burden was temporary or only during treatment (n=5, 10.20%).

Cost considerations

In the structured interview, participants were asked about any significant costs associated with having their condition. There were 25 participants (51.02%) that described some cost burden and 22 participants (44.90%) who described no cost burden.

Where participants described a cost burden associated with their condition, it was most commonly in relation to the cost of treatments, including repeat scripts (n=12, 24.49%). Other cost burdens were in relation to gap payments (public or private) (n=10, 20.41%), specialist appointments (n=9, 18.37%), and the cost of diagnostic tests and scans (n=8, 16.33%). There were 14 participants (28.57%) that described no cost burden and that nearly everything was paid for through the health system, 12 participants (24.49%) described that there was no cost burden, even if costs exist, and 7 participants (14.29%) that described no cost burden and that nearly everything was paid for through private health insurance.

Fear of progression

The Fear of Progression questionnaire measures the level of anxiety people experience in relation to their conditions. The Fear of Progression questionnaire comprises a total score, between 12 and 60, with a higher score denoting increased anxiety. The **Fear of Progression** questionnaire measures the level of anxiety people experience in relation to their conditions. On average fear of progression score for participants in this study indicated moderate levels of anxiety.

Impact on quality of life

In the structured interview, participants were asked whether they felt that their condition had affected their quality of life. Overall, there were 14 participants (28.57%) that described a negative impact on quality of life, 12 participants (24.49%) that reported some negative impact on quality of life, and 12 participants (24.49%) that described a mix of positive and negative impacts on quality of life. Other participants described no impact on quality of life (n=10, 20.41%), an overall positive impact on quality of life (n=8, 16.33%, and a minimal impact on quality of life (n=8, 16.33%).

The most common themes in relation to a negative impact on quality of life were due to the side effects of treatment or symptoms of conditions that they need to manage (n=18, 36.73%), the mental and emotional impact of their condition (n=16, 32.65%), emotional strain on family or partner/change in relationship dynamics (n=14, 28.57%), intimacy problems (n=11, 22.45%), the need to plan for toilets or to manage stoma (n=10, 20.41%), and reduced capacity for physical activity (n=8, 16.33%).

The most common theme in relation to a positive impact on quality of life was that it brings people together (n=9, 18.37%)

Participant describes an overall negative impact on quality of life

I've had to go, I've had it on, off sort of girlfriend on off relationship over the years and it definitely stuffed up like not stuffed up the relationship. But I mean we sort of kind of sort of seeing each other again. Oh, yeah. So yeah, the actual thing of having I guess there's been a few issues, some of us, by the psychological of me being I don't want to commit to marriage or something like that if I'm going to die. Yeah, I know that might sound weird or whatever, but I just, you know, it's like, I want to be alive and I don't want to be one of those guys getting married and then dying on the partner or, you know, that kind of thing or having someone have to look after me because I'm really terrible, you know, that kind of stuff. It's been a major psychological hit for me, I guess in that way, relationship wise. And when you're having treatments done of BCG, it's the toxic, cytotoxic, whatever it's called, or some of its toxic effects too. Yeah, you're supposed to take precautions as you I mean, sexual relations. And really it doesn't feel very sexy when you're having urinary tract infections and stuff going on up there and all the rest of it. And so I sort of, um, it's not the most fun feeling to have. And I've had some big operations who have had a catheter in for weeks at a time and stuff like that, um, within the hospital and that sort of thing. And it takes a while for that to sort of feel better.
Participant 001_2022AUBLC

Uh, the. I guess the inconvenience of having now is having a urinary diversion. Also being a bit more tired. Yeah. And then, you know, and you've always got in the back of your mind that the cancer will return.
Participant 016_2022AUBLC

I think it certainly did affect the quality of life while I was having the BCG. I was paranoid about having a getting a urinary tract infection because I knew, and had heard that if you urinary tract infection when you're on BCG, it can be quite problematic and quite hard to get rid of. And consequently, in all honesty, it did put me off sexual relationships considerably for some time over the BCG, but not, not too severely. But definitely it was in the back of my mind that I don't want to get a urinary tract infection. So that didn't really affect the family. The family are all grown up and doing their own thing now anyway. So and I'm not like looking after children or have any other commitments and I found I could fit it in if like if I had a social occasion to go to, I'd make sure that I had the BCG a day or two beforehand, so I still managed to have a social life. And the other thing that did affect me, apart from the side effects of the relationship, was travel. I tried to organise potentially to go overseas. My husband and I were looking at a trip overseas and I couldn't get health insurance, couldn't get travel insurance. Because they they deemed that because I was having BCG, obviously, for ongoing treatment for cancer. That's the way they saw it. And so they said that they would not cover me for bladder cancer or anything related to that. And my concern was if anything went wrong when I was overseas, that I wouldn't be covered. So we made the decision not to go overseas.
Participant 036_2022AUBLC

Because it affected us being diagnosed with it as well. And because it was in the middle of COVID, like right at the start of COVID. When I was first diagnosed then. Every you know. The last two years. It's like shit for everyone. We didn't want to go out anywhere. We didn't want to socialise with our other family members. We were invited to birthday parties. I didn't want to go. I didn't want to mix with anyone because

of the fear of catching something and then missing out on an operation or missing out on a check-up and things like that. So yeah, it affected our quality of life.
Participant 033_2022AUBLC

Participant describes some negative impact on quality of life

It caused a bit of stress within the family. But again, that was only the first 1 to 2 weeks in terms of my quality of life. No, because I've still got my bladder and it's just inconvenient having to go for surveillance now every 12 months. But that's all. It's just it's a mild inconvenience.
Participant 020_2022AUBLC

It only for the first three months I was a little bit. You know, didn't do too much and was a little bit, not depressed, but a bit concerned. But apart from that, it hasn't affected or hasn't affected my ability to, to play my golf and to go out and enjoy myself. Um, so that really hasn't affected my quality of life at all except for those first three months and March this year, March, February, March issue, when I thought the symptoms had returned, the symptoms show that it the cancer had returned. For those six, eight weeks. It was terrible. I couldn't sleep. Couldn't sleep at all.
Participant 021_2022AUBLC

It obviously does, but obviously does have an impact. It's not disastrous, but it does have an impact. The fact that I mean, I can still do most of the things I used to do, but there's some things that I can't. Family relations. There are some aspects of family relations, of course, that change
Participant 034_2022AUBLC

Participant describes an mix of positive and negative impacts on quality of life

PARTICIPANT It is it is strengthened my relationship with my wife. Without a doubt, we are far more intimate. We are far more connected. We are far more. Yeah. With my kids, they're young. I've got 10, 12 and 13. Am I going to die tonight? No Okay, good. I'll get back on my device. [Laughs] Yeah, you know, it's that kind of thing. You know, even I was running this morning, I was jogging. Now I, you know, I'm still able to do that with my son. And he goes, gosh, you're not keeping up, Dad. I'm going, no, I'm older than you, and I've got cancer. Then he goes cancer's in your bladder, not your legs. …

INTERVIEWER So you've got a good sense of humour.
PARTICIPANT Yeah, that's right. And, and grounding, very supportive family, very supportive friends. So I've lost the train of thought. What was the question? Okay, what was the question?

INTERVIEWER No, no, no. That's that's that's exactly right. It was related to that. But also, has it affected your quality of life as well?

PARTICIPANT When I had stents in which were partially to do with the bladder cancer resection and partly to do with the kidney stones, I felt like an old man. I couldn't run. I couldn't walk long distances. I hurt when I peed intensely, leading up to it, like getting those out last Thursday I said, I've just gone for a jog this morning for six ks. I feel like a new man. Don't get me wrong. I know I've got cancer. I'm not kidding myself, but it's not holding me back from doing anything like now. Now that those damn foreign objects are out of my bladder, I'm feel, I'm feeling $1,000,000 physically, but I'm not stupid enough to know that that's not going last right. So.
Participant 017_2022AUBLC

I think my set, I think my family are I mean, they're all incredibly supportive. I think it did affect them in that period of time. As I said, I had a daughter doing her final year of school, about to face the final exams and her mother's having this major surgery. And we don't know what the outcome is going to be. So there was a lot of stress, a lot of stress that that period of time. Now, five years on, my quality life is great. Most people wouldn't even know I've had this major surgery. I probably go to the toilet more often than a regular person. But, you know, a lot of, you know, 50 year old women go to the toilet a lot anyway. They, you know, I'm, you know, when it when I'm out, I'm cautious of how much liquid I've had just in case. So I suppose that's sort of a bit of a downside. You know, I have to get up in the middle of the night that a lot of people get up in the middle of the night that are my age. So, you know, I just never did before. But, you know, I do now. So I have to say, my quality of life is excellent. I count my lucky stars every day. And I think as a result of this experience, you know, my two girls and myself are just more accepting of things that are happening around us and, you know, and of other people. And, you know, if someone's grumpy towards you, you don't know what's going on in their life. You don't know, you know, because from the outside looking in at me, you would have had no idea that I was facing this. You know, I had this life threatening disease and I was facing these major decisions. So I

think we've all come to appreciate each day even more and that the time that we have with each other. So in some respects, I think it's changed everyone's outlook on life and maybe made us even better people.
Participant 032_2022AUBLC

Participant describes no impact on quality of life

No, it hasn't. I think that, um, you know, it's still pretty close and it's going really well. We've got 14 grandchildren
Participant 044_2022AUBLC

No, I don't think so. Our quality of life is still the same.
Participant 007_2022AUBLC

Participant describes an overall positive impact on quality of life

Yeah, that's right. I suddenly realised that, you know, these things are important and they take, they've taken a different course of interest in, in, you know, my activities and my health and what I'm doing and what tests and then what the outcomes are supposed to be and all that stuff. So it's only improved that way and the way we've been able to talk about things like, you know, wills and all that sort of stuff that you might say, God, they might not be interested in. You know, you put a bit more thought into those things, how you handle your affairs and get your face in check and particularly in another chance, like a terrible thing. But, you know, um, in, in your life, every, everybody has roles and mine to some extent has been technology. And so it's about, it's about, you know, what would happen if I wasn't here? How, how do the bills get paid and all the accounts and things that you have and emails and stuff to have, you know, how would we ever and would someone else, my wife or anybody else and untangle all this new things? But no, I don't think it's been any negative side of it all at all. There's, there's been a generally been a positive sort of a more realistic approach to life. Life doesn't go on forever.
Participant 029_2022AUBLC

Quality of life has improved because at the moment it has improved because I'm in remission.
Participant 008_2022AUBLC

Table 8.1: Impact on quality of life

Impact on quality of life	All participants		Early		Invasive		Advanced		Person with bladder cancer		Carer		Female		Male	
	n=49	%	n=20	%	n=10	%	n=14	%	n=44	%	n=5	%	n=17	%	n=32	%
Participant describes an overall negative impact on quality of life	14	28.57	**3**	**15.00**	**5**	**50.00**	4	28.57	12	27.27	**2**	**40.00**	**2**	**11.76**	12	37.50
Participant describes some negative impact on quality of life	12	24.49	**7**	**35.00**	2	20.00	**2**	**14.29**	11	25.00	1	20.00	4	23.53	8	25.00
Participant describes an mix of positive and negative impacts on quality of life	12	24.49	4	20.00	3	30.00	**5**	**35.71**	12	27.27	**0**	**0.00**	**6**	**35.29**	6	18.75
Participant describes no impact on quality of life	10	20.41	5	25.00	2	20.00	**1**	**7.14**	8	18.18	**2**	**40.00**	3	17.65	7	21.88
Participant describes an overall positive impact on quality of life	9	18.37	**6**	**30.00**	1	10.00	**1**	**7.14**	8	18.18	1	20.00	4	23.53	5	15.63
Participant describes a minimal impact on quality of life	8	16.33	**6**	**30.00**	**0**	**0.00**	**0**	**0.00**	6	13.64	**2**	**40.00**	**6**	**35.29**	**2**	**6.25**
Other/No response	7	14.29	1	5.00	2	20.00	3	21.43	6	13.64	1	20.00	**5**	**29.41**	2	6.25

Impact on quality of life	All participants		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=49	%	n=29	%	n=19	%	n=15	%	n=33	%	n=20	%	n=28	%
Participant describes an overall negative impact on quality of life	14	28.57	9	31.03	4	21.05	**2**	**13.33**	11	33.33	5	25.00	8	28.57
Participant describes some negative impact on quality of life	12	24.49	8	27.59	4	21.05	4	26.67	8	24.24	4	20.00	8	28.57
Participant describes an mix of positive and negative impacts on quality of life	12	24.49	7	24.14	5	26.32	**6**	**40.00**	6	18.18	4	20.00	8	28.57
Participant describes no impact on quality of life	10	20.41	6	20.69	4	21.05	**5**	**33.33**	5	15.15	5	25.00	5	17.86
Participant describes an overall positive impact on quality of life	9	18.37	7	24.14	2	10.53	**1**	**6.67**	8	24.24	4	20.00	5	17.86
Participant describes a minimal impact on quality of life	8	16.33	6	20.69	2	10.53	3	20.00	5	15.15	5	25.00	3	10.71
Other/No response	7	14.29	2	6.90	**5**	**26.32**	1	6.67	6	18.18	**0**	**0.00**	**7**	**25.00**

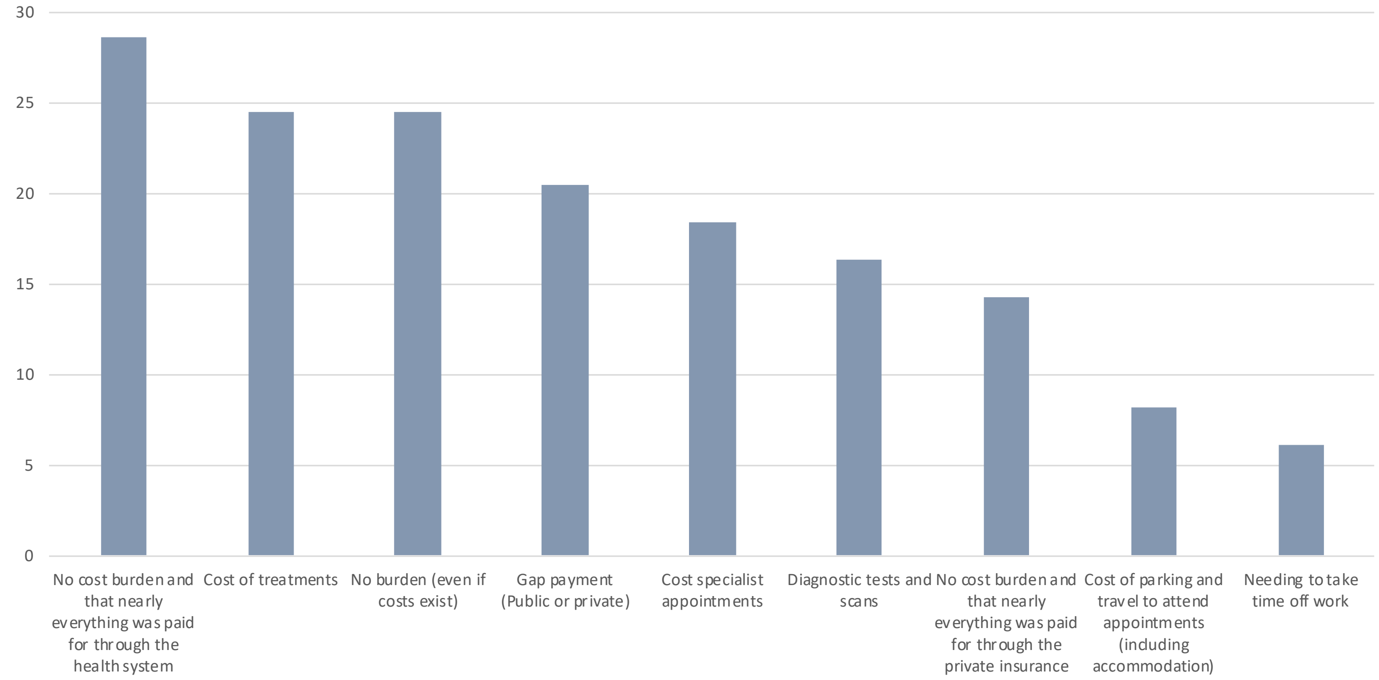


Figure 8.1: Impact on quality of life

Table 8.2: Impact quality of life – subgroup variations

Impact on quality of life	Reported less frequently	Reported more frequently
Participant describes an overall negative impact on quality of life	Invasive (Stage III)	Carer to someone with bladder cancer University
Participant describes some negative impact on quality of life	Carer to someone with bladder cancer Female	Invasive (Stage III)
Participant describes an mix of positive and negative impacts on quality of life	Invasive (Stage III)	Advanced (Stage IV)
Participant describes no impact on quality of life	-	Early (Stages 0 and I)
Participant describes an overall positive impact on quality of life	-	Invasive (Stage III)

Table 8.3: Impact on quality of life (Reasons)

Impact on quality of life (Reasons)	All participants		Early		Invasive		Advanced		Person with bladder cancer		Carer		Female		Male	
	n=49	%	n=20	%	n=10	%	n=14	%	n=44	%	n=5	%	n=17	%	n=32	%
Participant describes negative impact on quality of life due to the side effects of treatment or symptoms of conditions that they need to manage	18	36.73	5	25.00	2	20.00	9	64.29	16	36.36	2	40.00	6	35.29	12	37.50
Participant describes negative impact on quality of life due to the mental and emotional impact of their condition	16	32.65	3	15.00	5	50.00	4	28.57	12	27.27	4	80.00	4	23.53	12	37.50
Participant describes negative impact on quality of life as a result of emotional strain on family or partner/change in relationship dynamics	14	28.57	4	20.00	4	40.00	6	42.86	14	31.82	0	0.00	6	35.29	8	25.00
Participant describes negative impact on quality of life, but that it was only temporary	12	24.49	4	20.00	3	30.00	5	35.71	12	27.27	0	0.00	2	11.76	10	31.25
Participant describes negative impact on quality of life due to intimacy problems	11	22.45	6	30.00	0	0.00	3	21.43	9	20.45	2	40.00	4	23.53	7	21.88
Participant describes negative impact on quality of life due to the need to plan for toilets or to manage stoma	10	20.41	2	10.00	2	20.00	5	35.71	9	20.45	1	20.00	5	29.41	5	15.63
Participant describes negative impact on quality of life as a result of reduced capacity for physical activity	8	16.33	3	15.00	0	0.00	5	35.71	8	18.18	0	0.00	2	11.76	6	18.75
Participant describes negative impact on quality of life as they are unable to travel or need to adapt significantly in order to travel	3	6.12	0	0.00	0	0.00	1	7.14	1	2.27	2	40.00	1	5.88	2	6.25
Participant describes negative impact on quality of life due to reduced social interaction	3	6.12	1	5.00	0	0.00	1	7.14	2	4.55	1	20.00	1	5.88	2	6.25
Participant describes positive impact on quality of life as the diagnosis brings people together	9	18.37	3	15.00	2	20.00	3	21.43	8	18.18	1	20.00	5	29.41	4	12.50
Participant describes positive impact on quality of life as the diagnosis helps you realise what is important (giving perspective)	4	8.16	0	0.00	1	10.00	3	21.43	4	9.09	0	0.00	1	5.88	3	9.38

Impact on quality of life (Reasons)	All participants		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=49	%	n=29	%	n=19	%	n=15	%	n=33	%	n=20	%	n=28	%
Participant describes negative impact on quality of life due to the side effects of treatment or symptoms of conditions that they need to manage	18	36.73	11	37.93	7	36.84	7	46.67	11	33.33	9	45.00	9	32.14
Participant describes negative impact on quality of life due to the mental and emotional impact of their condition	16	32.65	9	31.03	7	36.84	7	46.67	9	27.27	7	35.00	9	32.14
Participant describes negative impact on quality of life as a result of emotional strain on family or partner/change in relationship dynamics	14	28.57	7	24.14	7	36.84	5	33.33	9	27.27	5	25.00	9	32.14
Participant describes negative impact on quality of life, but that it was only temporary	12	24.49	8	27.59	4	21.05	3	20.00	9	27.27	4	20.00	8	28.57
Participant describes negative impact on quality of life due to intimacy problems	11	22.45	7	24.14	4	21.05	2	13.33	9	27.27	5	25.00	6	21.43
Participant describes negative impact on quality of life due to the need to plan for toilets or to manage stoma	10	20.41	5	17.24	5	26.32	5	33.33	5	15.15	6	30.00	4	14.29
Participant describes negative impact on quality of life as a result of reduced capacity for physical activity	8	16.33	6	20.69	2	10.53	0	0.00	8	24.24	3	15.00	5	17.86
Participant describes negative impact on quality of life as they are unable to travel or need to adapt significantly in order to travel	3	6.12	2	6.90	1	5.26	2	13.33	1	3.03	2	10.00	1	3.57
Participant describes negative impact on quality of life due to reduced social interaction	3	6.12	2	6.90	1	5.26	1	6.67	2	6.06	2	10.00	1	3.57
Participant describes positive impact on quality of life as the diagnosis brings people together	9	18.37	6	20.69	3	15.79	1	6.67	8	24.24	3	15.00	6	21.43
Participant describes positive impact on quality of life as the diagnosis helps you realise what is important (giving perspective)	4	8.16	2	6.90	2	10.53	1	6.67	3	9.09	2	10.00	2	7.14

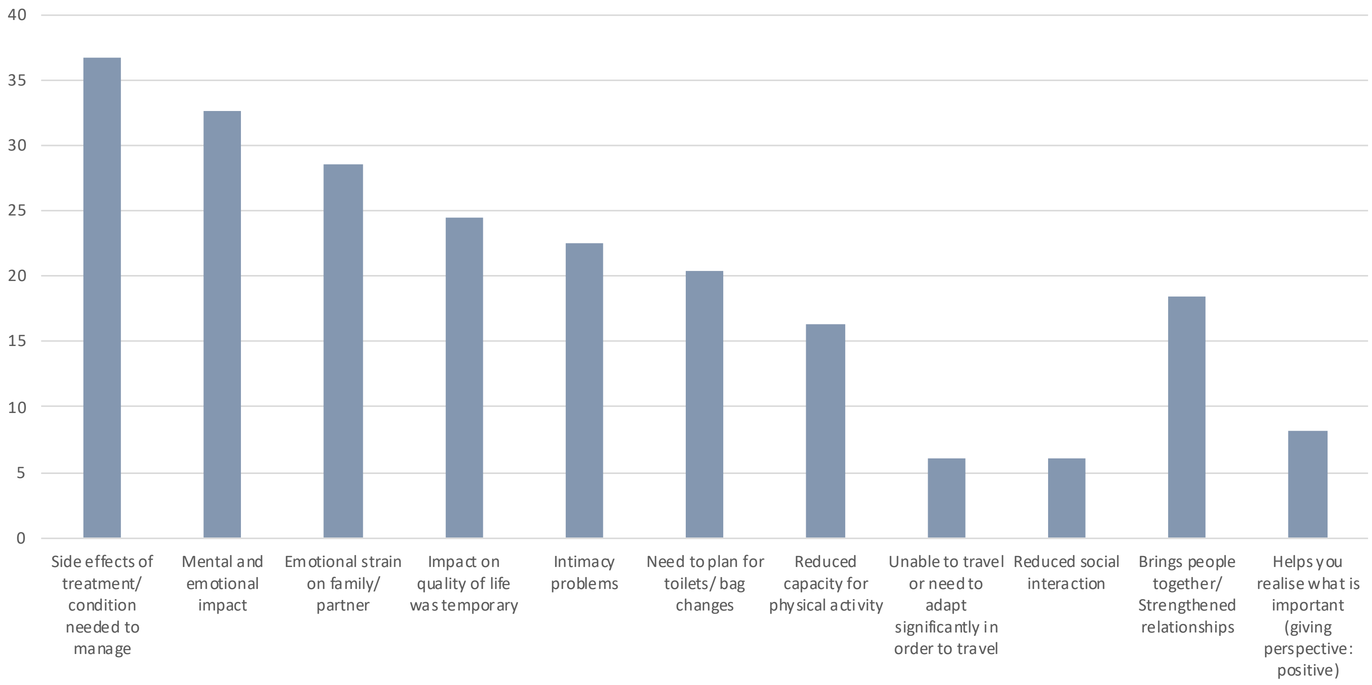


Figure 8.2: Impact on quality of life (Reasons)

Table 8.4: Impact on quality of life (Reasons)– subgroup variations

Impact on quality of life (Reasons)	Reported less frequently	Reported more frequently
Participant describes negative impact on quality of life due to the side effects of treatment or symptoms of conditions that they need to manage	Early (Stages 0 and I) Invasive (Stage III)	Advanced (Stage IV)
Participant describes negative impact on quality of life due to the mental and emotional impact of their condition	Early (Stages 0 and I)	Invasive (Stage III) Carer to someone with bladder cancer Regional or remote
Participant describes negative impact on quality of life as a result of emotional strain on family or partner/change in relationship dynamics	Carer to someone with bladder cancer	Invasive (Stage III) Advanced (Stage IV)
Participant describes negative impact on quality of life, but that it was only temporary	Carer to someone with bladder cancer Female	Advanced (Stage IV)
Participant describes negative impact on quality of life due to intimacy problems	Invasive (Stage III)	Carer to someone with bladder cancer
Participant describes negative impact on quality of life due to the need to plan for toilets or to manage stoma	Early (Stages 0 and I)	Advanced (Stage IV) Regional or remote
Participant describes negative impact on quality of life as a result of reduced capacity for physical activity	Invasive (Stage III) Carer to someone with bladder cancer Regional or remote	Advanced (Stage IV)
Participant describes positive impact on quality of life as the diagnosis brings people together	Regional or remote	Female

Impact on mental health

In the structured interview, participants were asked if there had been an impact on their mental health. There were 38 participants (77.55%) who gave a description suggesting that overall there was some impact on their mental health and 10 participants (20.41%) who gave a description suggesting that overall there was no impact on mental health.

Participant describes that there was at least some impact on mental health

I am on anti-depressants, which I never used to be on prior to going into having bladder cancer. So that's one thing that's come into play. Um. The other thing that that I have now, at long last, I've access to a, um, a psychiatrist psychologist that's been working with me to, uh, I suppose to unpack some of the issues, mentally mental issues that of sort of encountered, encountered since my surgery. Um, so yeah, it definitely has had impacts. Um, and I look, to be honest, I think it will continue to have an impact. So that is the need for me to have access to a mental health professional is probably much more, almost. My need for mental health professional is probably more than what I need an oncologist at the moment. Does that make sense?
Participant 035_2022AUBLC

Obviously because you're always sort of worried is it going to be all right? Is the bag going to be all right. And then. Well, you know, it's just a different way to just get on with it and I see patients a lot worse off than me.
Participant 018_2022AUBLC

Yes, it certainly has over time. You know, you don't get your bladder removed without a few major issues, but, you know, there's certainly over the years I have I have often chosen to seek some help to work through stuff. So that's something that I do. I do for myself whenever I need it. So I have a few different avenues of that and. And that's really helped me.
Participant 026_2022AUBLC

Um, you know, everyone has scan anxiety, so before you're about to have a major scan, no matter what, even five years on, everyone has major scan anxiety. You know, I think it's affected me that, you know, whereas before you had a pain in your knee, you would think, oh, you know, I must have done that when I was, you know, doing the latest work out or something. But now you think, oh, that pain wasn't there before. Why have I got that pain? I think it's very conscious of all the niggles in your body, whereas before you weren't. I wasn't that conscious of all the niggles in my body. Scan anxiety is a real thing. Everyone has it. I don't know anyone with any kind of cancer that doesn't feel anxious when they have the scan and then waiting for the results and then actually getting the result that everyone has it. It's, it's very stressful no matter how many years have gone by that you've been cancer free. So, you know, so I obviously never had that before. But you know, you know, you sometimes wake up and you think, oh, gosh, you know, what if, um. But I have to say, I try and just, you know, give my best possible life and continue to try and be healthy and, and keep moving forward.
Participant 032_2022AUBLC

Participant describes that there was no impact on mental health

I don't know. It hasn't affected me. Just carry on
Participant 013_2022AUBLC

Um, not mentally, really, because I was like, I was, but I didn't really. I never thought I was going to die from cancer. Um, again, I feel like I've had cancer for 5 minutes, and then if you know, it's gone. Yeah. Yep. So not mentally dismal.
Participant 022_2022AUBLC

I've always been very good with my mental, emotional health. I look after I think I look after it quite well. So I just needed something to focus on. So I focused on because I've been jumping out of aeroplanes for 25 years. And so I just got I guess more deeply into that as a, as a distraction. And yeah, so I didn't know it didn't affect my quality of life at all.
Participant 020_2022AUBLC

Table 8.5: Impact on mental health

Impact on mental health	All participants		Early		Invasive		Advanced		Person with bladder cancer		Carer		Female		Male	
	n=49	%	n=20	%	n=10	%	n=14	%	n=44	%	n=5	%	n=17	%	n=32	%
Participant describes that there was at least some impact on mental health	38	77.55	16	80.00	5	50.00	12	85.71	33	75.00	5	100.00	14	82.35	24	75.00
Participant describes that there was no impact on mental health	10	20.41	4	20.00	5	50.00	1	7.14	10	22.73	0	0.00	3	17.65	7	21.88
Other/No response	1	2.04	0	0.00	0	0.00	1	7.14	1	2.27	0	0.00	0	0.00	1	3.13

Impact on mental health	All participants		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=49	%	n=29	%	n=19	%	n=15	%	n=33	%	n=20	%	n=28	%
Participant describes that there was at least some impact on mental health	38	77.55	21	72.41	16	84.21	12	80.00	25	75.76	17	85.00	20	71.43
Participant describes that there was no impact on mental health	10	20.41	7	24.14	3	15.79	3	20.00	7	21.21	3	15.00	7	25.00
Other/No response	1	2.04	1	3.45	0	0.00	0	0.00	1	3.03	0	0.00	1	3.57

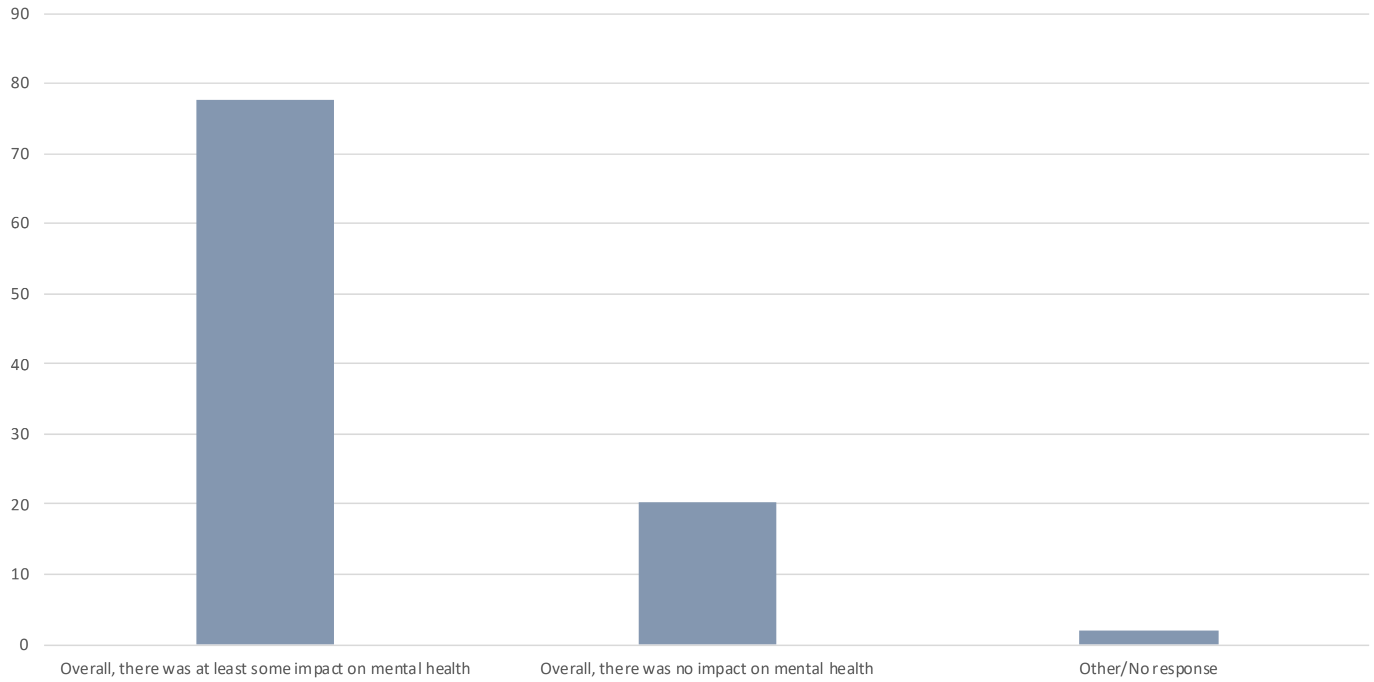


Figure 8.3: Impact on mental health

Table 8.6: Impact on mental health – subgroup variations

Impact on mental health	Reported less frequently	Reported more frequently
Participant describes that there was at least some impact on mental health	Invasive (Stage III)	Carer to someone with bladder cancer
Participant describes that there was no impact on mental health	Advanced (Stage IV) Carer to someone with bladder cancer	Invasive (Stage III)

Regular activities to maintain mental health

In the structured interview, participants were asked what they needed to do to maintain their emotional and mental health. The most common way that participants reported managing their mental and emotional health was describing the importance of family and friends (n=19, 38.78%). Other participants described the importance of physical exercise (n=11, 22.45%), mindfulness and/or meditation, consulting a mental health professional (n=9, 18.37%), and maintaining social, lifestyle changes, and hobbies (n=7, 14.29%). There were 11 participants (22.45%) that described no activities to maintain mental health.

Participant describes the importance of family and friends in maintaining their mental health

PARTICIPANT: You know? Yeah. I mean, I'm pretty, pretty strong and I just know that I'm going to do I've got to get up and I've got to do stuff and actually if anything. I've started to look after my physical and emotional health more than I was

INTERVIEWER: Go to yoga. You do your over 60s class.

PARTICIPANT Yes that right, I do yoga, I do my over 60s class. We walk, walk, well when we can with all this bloody rain

INTERVIEWER: Yeah, that's good. That's good for mental health.

INTERVIEWER: Yeah. Yeah. So when.

PARTICIPANT: I got a really good support network around me.

INTERVIEWER: Excellent.

PARTICIPANT: And my Friends and my neighbours, they were. Wonderful.
Participant 004_2022AUBLC

I'm just I think having a couple of close friends that I could talk to about it in my life and helped and I did a bit of exercise, I think helps you just, you know, working full time always distraction are good to, so it just keeps you busy and, you're not, dwelling on on negative things, which is there. But as I think at times, I definitely, and especially early on was very concerned and it would affect me sometimes when I'd think about it well, I'd often think about it, but again, didn't want to talk about it too much.
024_2022AUBLC

Well, I have. I have an amazing wife and three children. Um, well, he just told me so and, you know, a few close friends. So that was. Being able to be around them and talking to them was good.
Participant 027_2022AUBLC

Participant describes the importance of physical exercise

I try to walk exercise and that's the main thing. Yes, it did affect me very badly two, three years ago. But I mean, as I come closer each procedure that helps me, you know, obviously I get quite anxious about it. I get very anxious when I go, you know, into the procedure at the hospital or whatever it is.
Participant 008_2022AUBLC

Yes, not really. We do. We make sure that we exercise regularly. So every night we go home, we walk the dog for 20 to 30 minutes. And that's, that's definitely beneficial.
Participant 010_2022AUBLC

Going for a walk with NAME, I think that helps my mental health that we go walking for probably an hour and a half every morning. That, yeah, that bond I've built with NAME been really good for me. Mental health. And yeah, it's been a really good bond that we've got between ourselves. I'm just really lucky that he lives so close from. Yeah, we can yeah. Walk and we can talk. That's yeah.
Participant 044_2022AUBLC

Participant describes using mindfulness and/or meditation

Um, well, counselling or I actually ended up doing studies, so I ended up studying Mind-Body Medicine and so that was really beneficial for me. And that was, that was to help me deal with, with my health and my life and. So. And then I end up doing a journey practitioner course, which is really beneficial. So all of those things. So it means that I now wouldn't hesitate. If I feel like anything's getting on top of me, then I will deal with it. I'll either go and have a journey session with somebody or a book in some counselling or um.
Participant 026_2022AUBLC

Look, I did quite a lot of sort of self-hypnosis and listen to support the CDs, you know. Calming ones. And I can't even remember them all now moment, my sister sent me a whole load of, not quite meditation, but that kind of thing. You know, calming stuff. That was what I use more than anything. To try and keep myself calm. And it was looking back and it was quite, you know, at times when you when you. Go to bed, like most of us. The minute you lie down, everything goes round and round in your head. And you're trying to find a place for all and trying to sort of get your head to calm down. Yeah. So that that was difficult.
Participant 003_2022AUBLC

Participant describes no actions or activities to maintain mental health

I don't know. It hasn't affected me. Just carry on
Participant 013_2022AUBLC

PARTICIPANT: Um, I guess, uh, it might make me a bit more anxious. Um, and. No, no, I don't do anything. As in see anybody about it. No, no. Hmm. Okay.

INTERVIEWER: What are some of the things? Yeah. Go on.

PARTICIPANT: No, I just. I probably should. Go back to the GP and say, I have been feeling a bit anxious lately. So yeah, but I haven't. I find it hard to get into a GP.
Participant 025_2022AUBLC

Participant describes consulting a mental health professional

Uh, well it does a bit. Well, that has much, and the doctors mainly look after it. I've been to a psychiatrist and a psychologist and, uh, I'm still under them if I need them. At the moment. I'm travelling alright. But I've got some, uh, some, uh, antidepressants to keep me in focus on that.
Participant 007_2022AUBLC

I am on anti-depressants, which I never used to be on prior to going into having bladder cancer. So that's one thing that's come into play. Um. The other thing that that I have now, at long last, I've access to a, um, a psychiatrist psychologist that's been working with me to, uh. I suppose to unpack some of the issues, mentally mental issues that of sort of encountered, encountered since my surgery. Um, so yeah, it definitely has had impacts. Um, and I look, to be honest, I think it will continue to have an impact. So that is the need for me to have access to a mental health professional is probably much more, almost. My need for mental health professional is probably more than what I need an oncologist at the moment. Does that make sense?
Participant 035_2022AUBLC

PARTICIPANT: And then I had my surgery. And then when I was told that I didn't actually need chemotherapy, I. That's kind of and that was only probably about three months ago. Um, that was kind of when the will sell off. And now I'm suffering depression and anxiety. So yeah, it's taken a big toll. It's just taken about a year to actually come out.

INTERVIEWER: Mhm. How are you managing that. Um, those impacts.

PARTICIPANT: I'm sorry, I'm seeing counsellors regularly and I'm also, I've been prescribed with a low dose of antidepressants.
Participant 009_2022AUBLC

Participant describes using coping strategies such as remaining social, lifestyle changes and hobbies

Uh, I try a lot of things. Um. Try to go walking. Uh, try to do things I enjoy. Visiting friends, being outdoors. Um. Yeah. That kind of stuff.
Participant 005_2022AUBLC

So I like listening to music and then I go to music concerts and stuff like that. It's nice, walking on the beach with the dogs, you know? So yeah, the dogs can really be, so things like that. It's sometimes I go for swimming, but I have to, really it has to be managed quite carefully, it's a pain. But you know, and we've got a place LOCATION, a beach place. So we get down there and it's really nice. Yeah. So do those sort of things.
Participant 018_2022AUBLC

Yeah. Yeah, I know. I have this, um, I, I really, really feel it. Um, I did take up some hobbies just before by the cancer. Things are not done ever before, like painting and stuff like that and art and, and spending, spending time with, with friends, I suppose, and, uh, going that extra, extra mile as far as ringing people that, that's also communicating with people with that. That's also part of COVID as well, taking that extra time. Yeah, I don't think it's necessarily about bladder cancer. It does give you something to talk about. Of course, people will have a reason for ringing you as well and then asking how you are, which is um, from that point of view is actually a nice thing that, and you do the same with them. You appreciate your friends that have got, you know, a heart problem or some other problem.
Participant 029_2022AUBLC

Table 8.7: Regular activities to maintain mental health

Regular activities to maintain mental health	All participants		Early		Invasive		Advanced		Person with bladder cancer		Carer		Female		Male	
	n=49	%	n=20	%	n=10	%	n=14	%	n=44	%	n=5	%	n=17	%	n=32	%
Participant describes the importance of family and friends in maintaining their mental health	19	38.78	7	35.00	4	40.00	5	35.71	16	36.36	**3**	**60.00**	5	29.41	14	43.75
Participant describes the importance of physical exercise	11	22.45	6	30.00	**1**	**10.00**	2	14.29	9	20.45	**2**	**40.00**	5	29.41	6	18.75
Participant describes using mindfulness and/or meditation	11	22.45	5	25.00	2	20.00	4	28.57	11	25.00	**0**	**0.00**	**6**	**35.29**	5	15.63
Participant describes no actions or activities to maintain mental health	11	22.45	5	25.00	3	30.00	3	21.43	11	25.00	**0**	**0.00**	**6**	**35.29**	5	15.63
Participant describes consulting a mental health professional	9	18.37	2	10.00	1	10.00	**5**	**35.71**	8	18.18	1	20.00	2	11.76	7	21.88
Participant describes using coping strategies such as remaining social, lifestyle changes and hobbies	7	14.29	3	15.00	**3**	**30.00**	**0**	**0.00**	6	13.64	1	20.00	2	11.76	5	15.63

Regular activities to maintain mental health	All participants		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=49	%	n=29	%	n=19	%	n=15	%	n=33	%	n=20	%	n=28	%
Participant describes the importance of family and friends in maintaining their mental health	19	38.78	12	41.38	6	31.58	**4**	**26.67**	14	42.42	7	35.00	11	39.29
Participant describes the importance of physical exercise	11	22.45	5	17.24	5	26.32	3	20.00	7	21.21	3	15.00	7	25.00
Participant describes using mindfulness and/or meditation	11	22.45	7	24.14	4	21.05	4	26.67	7	21.21	6	30.00	5	17.86
Participant describes no actions or activities to maintain mental health	11	22.45	5	17.24	6	31.58	3	20.00	8	24.24	3	15.00	8	28.57
Participant describes consulting a mental health professional	9	18.37	7	24.14	2	10.53	3	20.00	6	18.18	5	25.00	4	14.29
Participant describes using coping strategies such as remaining social, lifestyle changes and hobbies	7	14.29	3	10.34	4	21.05	2	13.33	5	15.15	3	15.00	4	14.29

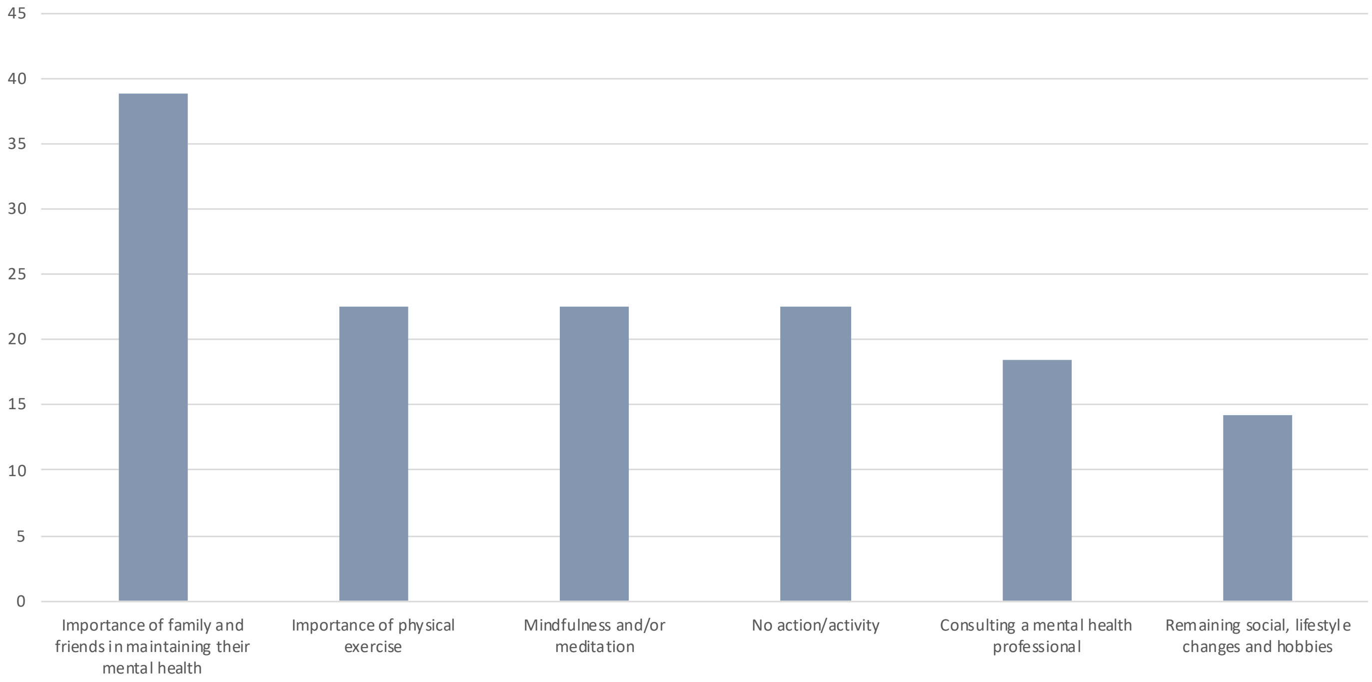


Figure 8.4: Regular activities to maintain mental health

Table 8.8: Regular activities to maintain mental health – subgroup variations

Regular activities to maintain mental health	Reported less frequently	Reported more frequently
Participant describes the importance of family and friends in maintaining their mental health	Regional or remote	Carer to someone with bladder cancer
Participant describes the importance of physical exercise	Invasive (Stage III)	Carer to someone with bladder cancer
Participant describes using mindfulness and/or meditation	Carer to someone with bladder cancer	Female
Participant describes no actions or activities to maintain mental health	Carer to someone with bladder cancer	Female
Participant describes consulting a mental health professional	-	Advanced (Stage IV)
Participant describes using coping strategies such as remaining social, lifestyle changes and hobbies	Advanced (Stage IV)	Invasive (Stage III)

Regular activities to maintain health

In the structured interview, participants were asked what were some of the things they needed to do everyday to maintain their health? The most common ways that participants reported managing their health were; being physically active (n=11, 22.45%), keeping busy or keeping a normal routine (n=11, 22.45%), and managing their stoma or incontinence (n=11, 22.45%). Other ways to maintain health were complying with treatment (n=7, 14.29%), socialising with friends and/or family (n=7, 14.29%), maintaining a healthy diet (n=6, 12.24%), and the importance of self care e.g. more rest, support for housework etc. (n=5, 10.20%). There were 7 participants (14.29%) that described no activities to maintain health.

Participant describes being physically active

PARTICIPANT: And I don't know. The pandemic's also thrown a bit of a spanner in the works about that too somethings that I'd like to do that I haven't done. When we're in lockdown, um, I walk, I suppose. Walking helps me as I walk about 12 Ks a day.

INTERVIEWER: It's really good. Yeah. And with your dog early on.

PARTICIPANT: The dog. Yeah. Yeah. I've got a dog and I also bought one for my sister as well and. Yeah, yeah. Get that one out as well for the same sort of two or three K for my dog, two, three K separately for hers. They don't walk all together.
Participant 001_2022AUBLC

I suppose I just. Yeah. Try and maintain a good level of fitness. And I'd like to say get enough sleep. But, I don't know, because I'm also one that will. Well, especially if I'm going to the toilet, three, four, five, six, even, sometimes seven times a night. It's very hard to get back to sleep afterwards. And sometimes I. Then I'm awake for quite a while. Yeah. So. Yes, definitely. Sleep deprivation is a big part, is what I would say has been the effect of this.
Participant 010_2022AUBLC

Participant describes keeping busy or keeping a normal routine

Exercise. Get out. Don't, don't just sit around thinking about things all the time. Yeah, exercise. I'm pretty lucky. I live, like, 5 minutes from the beach, so every day I go for walks on the beach. Just clear the head
Participant 033_2022AUBLC

Not at the moment just because the cancer has so far in remission, it's not affecting me at all. I do for my mental well-being. I've been trying to go to the gym once or twice a week. I've been walking, trying to do I can't do 10,000 a day, but I try and do 8000 a day. I'm finding that continuing working is good for my mental well-being. It makes me feel good about myself because I'm useful. And also the money's good. So I find mixing with friends and talking about all the other stuff and having fun really helps me as well. So I sort of try and just have a little those and keep myself in a positive frame as I can. It's all fallen, fallen down a little bit at the moment because of the operation. But up until then I was managing quite well. I thought, you know, remaining reasonably positive and getting on with life.
Participant 036_2022AUBLC

Um, I need to try and just get out of, in front of, you know, get myself, in a predicament that I can't get myself out like. So on a day to day basis, I make an effort of something as simple as getting out of bed, making the bed and getting dressed and going for a walk. And, you know, those kind of things. Like, I just need to try and set a routine for myself in order to tick off the boxes and say that I've done them. Because if I don't, I tend to get into a state that I can't get myself out of, and then I start thinking about everything that's happened. And then I start over thinking, what if the cancer is going to come back? You know, all those kind of questions. So yeah, on a day to day basis, I really have to take control and just move on with life.
Participant 009_2022AUBLC

Participant describes managing their stoma or incontinence

I still I still wear a pad as a precaution. Not every time. But, you know, if I'm not feeling well, I certainly wear a pad. You know, so just in case I get the sudden, you know, the urgency. But in general, I mean, as I said, I said in general, I ca,n I can hold off five or 10 minutes now, which I certainly couldn't do that three years ago, and that would be within 30 seconds. If that.
Participant 008_2022AUBLC

Well, I don't have to do too much basically. It's a matter of just making sure everything is kept clean and tidy. You know, I've got to rinse the bag out every morning or change your bag every couple of days, which is, you know, a little bit, you know, just a few wipes and a couple of tissues. You know, it's not really, you know I've got a separate bath mat and just a couple of different little things that, you know, I've just got to be aware of and just go on. You know, you make a few mistakes on the way, a few spillages. Most people I know that have been through it, they have the same issue. Yeah, but apart from that, yeah no dramas
Participant 011_2022AUBLC

Oh, just have to change a bag every two days now. Or, if I have this swim, I change it straight away. And so it's just really care the stoma. And I know a patient told me her husband got constant UTIs for the first six months when he was looking after his stoma and I thought, well, I'm probably lucky I'm a HEALTHCARE PROFESSIONAL and I've looked after those before because I'm very careful. So I haven't had any problems with UTIs at all, which has been good. But it

does change shape sometimes. And it's, you know, a bit ugly, you know, and somebody said to me, Oh, what have you called your stoma? We have to do that. [LAUGHS]. So I said, If I if I could call it anything, it would be, oh, what's her name? Ripley! Because she was in alien, you know, Sigourney Weaver. Oh yeah, she was that Alien. And I said, Oh, she was a really strong woman, but she was dealing with an alien and that's what it looks like. Yeah. So I better be call it that than anything other than a bit of a nuisance for which, I'm fond of it because it saved my life. So you have, you know, true feelings, but it is a bit of a nuisance, too. Yeah.
Participant 018_2022AUBLC

Participant describes the importance of complying with treatment

I can do everything I need to do. Okay. So it's just now it's just once every 12 months I have to go through surveillance. Apart from them? No, nothing
Participant 020_2022AUBLC

Nothing, really. I've just gone on as usual. The only thing I've done is Doctor NAME he said, you should try and do this, what do they call it? Urination rehab or retraining or something, you know, where I drink a lot of water and I got a hold off trying to build up my bladder capacity. So I've just been doing that. I did that for about two months now, have done it, didn't do too much while I had COVID. But so that's the only thing I've done. Try to increase my bladder capacity. So I'm not going to the toilet. During the day I can go 6 hours with out going to the toilet, it is only at night time when I go to sleep. So that's I've done that and that's really helped. Plus the tablet that he and tablet that he gave me, which has helped. So quality of life is at the moment, it's probably as good as I've had since I got diagnosed.
Participant 021_2022AUBLC

Nothing. It doesn't really does not doesn't really affect my life in any way at the moment, other than needing to make allowances for the three monthly cystoscopy and all the other tests that sit around that I have to plan those. And I have a diary where they're all planned. Um, other than that it has no impact on my life or ability to do the things that we want to do. I mean, travelling and that is sometimes a bit tricky when you've got things happening, but once every three months it's not too bad is the good, good catch in the middle where we can travel and do the things catch up that we need to do. There's a lot of other things that eat into those into that anyway, that ability.
Participant 029_2022AUBLC

Yeah, the carer activities, yes. Yeah. Um, and then, like, making sure that I'm there and. After every, you know, sort of BCG or, you know, investigations or surgeries. Yeah. So making sure that I'm there to, like, give him his pain meds and, you know, providing the food. Yeah, whatever, you know, I'm making taking on all the parenting. And so he can rest.
Carer 003_2022AUBLC

Participant describes socialising with friends and/or family

PARTICIPANT: And so the things I need to do, I need to. I stopped, I'd already stopped drinking to a certain extent. And I completely I stopped drinking, which I think now there's a lesson that I should have learnt about 40 years ago. But anyway, we get there eventually and what else?, just and I continue to do those stretching exercises and I try and exercise regularly. Was that the question I lost it a bit there?

INTERVIEWER: What are some of the things that you need to do on a regular basis

PARTICIPANT: Exercise, yeah exercise. I'm feeling I'm probably feeling a bit less cheerful this week because, because I haven't been able to go out of the house with COVID and I haven't really been able to exercise. But normally I would be you know, I'd be doing some exercises, keeping myself busy that way. I think I think I'm lucky that, and this was unplanned, but my family all live nearby and my son and daughter and their family. And I've got a sort of a reasonable group of mates, so they're not close friends. I haven't been to most of their houses, but you know, we catch up and we talk and sort of that mateship, stuff I guess.
Participant 006_2022AUBLC

Um, oh, God, I just get up in the morning and I like to, like, I like to have things. I can't stay home all day. I it would drive me insane. I either have to go for a walk with a friend or go out for coffee or baby, you know, look after my grandkids. Um, yeah. I like to have. I like to be able to do something every day. I don't think I've ever stayed. I mean, I don't like staying home, even if, even if it's only out for a couple of hours, at least you're outside. You're getting fresh air and talking to somebody.
Participant 039_2022AUBLC

Participant describes no activities to maintain health

Oh, nothing really, because I've been it's been off and on, has been there and I've treatment and it has gone away. And so it's sort of come, you know, nothing. Nothing sort of permanent.
Participant 012_2022AUBLC

Not much. Nothing I can remember specifically.
Participant 019_2022AUBLC

Participant describes maintaining a healthy diet

Yeah, so it definitely that has improved and that's something that's a daily thing. I've just had a bit of a look to see what helps bladder and urinary tract and all that crappy stuff. Um, excuse the pun and you know, there's some particular vitamins that are meant to help and sometimes take those and sometimes don't. But generally getting, you know, organic or locally grown fruit and veg is a better option than the Coles and Woolworths crap. So. Just little things like that that make me I'm sure it's psychosomatic up to a point. A part of it is real as well. But getting healthy as a healthy person.
Participant 030_2022AUBLC

Well, I'm I try and stay fit and healthy. So I walk. I do regular workouts. I eat well. Um. You know, I don't drink a lot. Um, I do still have the odd glass of wine, so. But I don't drink a lot. Um. Um. Um, you know, I try and drink lots of water because that's, that's good for you. Um. That's basically it.
Participant 032_2022AUBLC

Participant describes the importance of self care e.g. more rest, support for housework etc.

I'm more aware of. What's going on with my body. I think so. Um. And I'm trying to, you know, take better care.
Participant 027_2022AUBLC

I suppose I just. Yeah. Try and maintain a good level of fitness. And I'd like to say get enough sleep. But, I don't know, because I'm also one that will. Well, especially if I'm going to the toilet, three, four, five, six, even, sometimes seven times a night. It's very hard to get back to sleep afterwards. And sometimes I. Then I'm awake for quite a while. Yeah. So. Yes, definitely. Sleep deprivation is a big part, is what I would say has been the effect of this.
Participant 010_2022AUBLC

Get plenty of rest. Drink plenty of water. Reduce the amount of alcohol I drink. Mm. Eat more healthy food. Exercise more.
Participant 016_2022AUBLC

Table 8.9: Regular activities to maintain health

Regular activities to maintain health	All participants		Early		Invasive		Advanced		Person with bladder cancer		Carer		Female		Male	
	n=49	%	n=20	%	n=10	%	n=14	%	n=44	%	n=5	%	n=17	%	n=32	%
Participant describes being physically active	11	22.45	6	30.00	**1**	**10.00**	4	28.57	11	25.00	**0**	**0.00**	5	29.41	6	18.75
Participant describes keeping busy or keeping a normal routine	11	22.45	4	20.00	**1**	**10.00**	**5**	**35.71**	10	22.73	1	20.00	4	23.53	7	21.88
Participant describes managing their stoma or incontinence	11	22.45	4	20.00	2	20.00	**5**	**35.71**	11	25.00	**0**	**0.00**	3	17.65	8	25.00
Participant describes the importance of complying with treatment	7	14.29	2	10.00	**3**	**30.00**	1	7.14	6	13.64	1	20.00	3	17.65	4	12.50
Participant describes socialising with friends and/or family	7	14.29	3	15.00	**0**	**0.00**	2	14.29	5	11.36	**2**	**40.00**	3	17.65	4	12.50
Participant describes no activities to maintain health	7	14.29	**5**	**25.00**	2	20.00	**0**	**0.00**	7	15.91	**0**	**0.00**	2	11.76	5	15.63
Participant describes maintaining a healthy diet	6	12.24	3	15.00	1	10.00	2	14.29	6	13.64	**0**	**0.00**	3	17.65	3	9.38
Participant describes the importance of self care e.g. more rest, support for housework etc.	5	10.20	2	10.00	2	20.00	**0**	**0.00**	4	9.09	1	20.00	3	17.65	2	6.25

Regular activities to maintain health	All participants		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=49	%	n=29	%	n=19	%	n=15	%	n=33	%	n=20	%	n=28	%
Participant describes being physically active	11	22.45	5	17.24	5	26.32	2	13.33	8	24.24	3	15.00	7	25.00
Participant describes keeping busy or keeping a normal routine	11	22.45	7	24.14	3	15.79	**1**	**6.67**	9	27.27	5	25.00	5	17.86
Participant describes managing their stoma or incontinence	11	22.45	9	31.03	**2**	**10.53**	2	13.33	9	27.27	**7**	**35.00**	4	14.29
Participant describes the importance of complying with treatment	7	14.29	2	6.90	**5**	**26.32**	3	20.00	4	12.12	2	10.00	5	17.86
Participant describes socialising with friends and/or family	7	14.29	4	13.79	2	10.53	1	6.67	5	15.15	2	10.00	4	14.29
Participant describes no activities to maintain health	7	14.29	3	10.34	4	21.05	2	13.33	5	15.15	2	10.00	5	17.86
Participant describes maintaining a healthy diet	6	12.24	3	10.34	3	15.79	3	20.00	3	9.09	2	10.00	4	14.29
Participant describes the importance of self care e.g. more rest, support for housework etc.	5	10.20	3	10.34	2	10.53	**4**	**26.67**	1	3.03	3	15.00	2	7.14

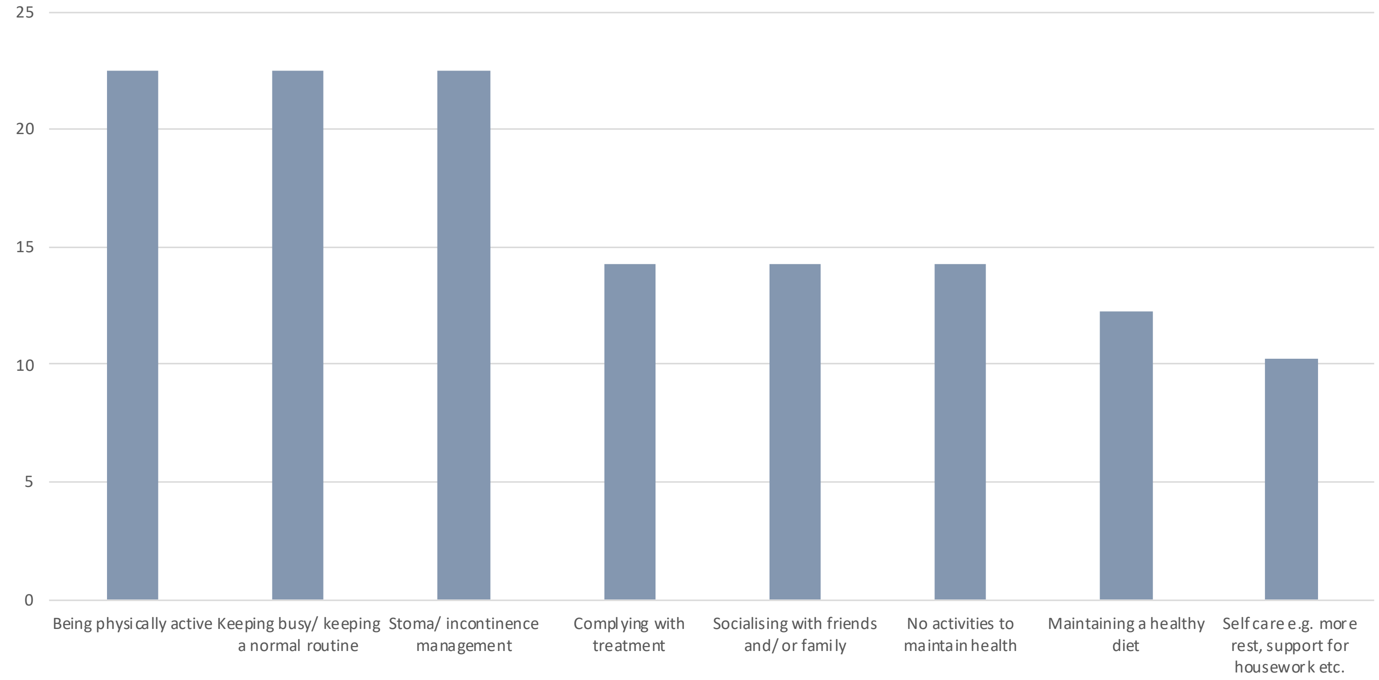


Figure 8.5: Regular activities to maintain health

Table 8.10: Regular activities to maintain health – subgroup variations

Regular activities to maintain health	Reported less frequently	Reported more frequently
Participant describes being physically active	Invasive (Stage III) Carer to someone with bladder cancer	-
Participant describes keeping busy or keeping a normal routine	Invasive (Stage III) Regional or remote	Advanced (Stage IV)
Participant describes managing their stoma or incontinence	Carer to someone with bladder cancer University	Advanced (Stage IV) Mid to low status
Participant describes the importance of complying with treatment	-	Invasive (Stage III) University
Participant describes socialising with friends and/or family	Invasive (Stage III)	Carer to someone with bladder cancer
Participant describes no activities to maintain health	Advanced (Stage IV) Carer to someone with bladder cancer	Early (Stages 0 and I)
Participant describes maintaining a healthy diet	Carer to someone with bladder cancer	-
Participant describes the importance of self care e.g. more rest, support for housework etc.	Advanced (Stage IV)	Regional or remote

Experience of vulnerability

In the structured interview, participants were asked if there had been times that they felt vulnerable. There were 42 participants (85.71%) who gave a description suggesting that overall they had experiences of feeling vulnerable, and 2 participants (4.08%) who gave a description suggesting that overall they did not have feelings of being vulnerable.

In relation to when participants felt most vulnerable, the most common theme was feeling vulnerable during or after treatments (n=25, 51.02%). There 13 participants (26.53%) that described feeling vulnerable when first diagnosed, first few months after diagnosis, while experiencing side effects from treatment or symptoms from condition (n=10, 20.41%), because of interactions with the medical team (n=8, 16.33%), and 8 participants (16.33%) described feeling vulnerable when having sensitive discussion (diagnosis, treatment decision). Other participants described feeling vulnerable when thinking about disease course/incurable condition (n=5, 10.20%), being vulnerable when they have a loss of independence, e.g in hospital, recovering from surgery (n=5, 10.20%), and when first sent home after being hospitalised without the care/availability healthcare professionals (n=5, 10.20%).

Participant describes being vulnerable during/after treatments

Vulnerable. I don't know if that's the right word. Only when I was in the hospital to begin. I've never been in hospital. Had had nothing done to me. I couldn't even wipe my own bum after the operation
Participant 022_2022AUBLC

I would probably most when I first got out of surgery. It was very hard the first week because you never you you, don't think you're going to get out of bed ever again, you know, and especially maybe the first three

or four days. And then when you do get out of the hospital, you don't think you're going to be able to drag it out of bed and injure your arse into a shower and then get yourself something to eat. And, you know, it's just it's just a struggle to get everything done.
Participant 031_2022AUBLC

Um. Probably the first four days after the surgery, very vulnerable where your being told what you have to do. He didn't want to do any of it. You have to do it because you know it's going to make the next day just a little bit easier. So probably then immediately after the surgery, when I came home and I had a catheter and I had to flush the catheter and manage all on my own. And, um, and. To give myself that clexane through injections, the blood thinning things. You know, you had to administer that yourself straight after the surgery. So, you know, you feel a bit vulnerable then because you think you are doing it right, you know? You know, you've got, you know, stitches and tubes. And so I think that was probably when I felt most vulnerable and then probably when they took out everything and I then had to use the neobladder on my own. I mean, I had support from the hospital, and if I knew if I had a problem, I could have called them. But that was probably, you know, during that period when I personally felt most vulnerable and I suppose, you know, initially after diagnosis as well.
Participant 032_2022AUBLC

Every time I was catheterized very vulnerable, I hated it. I hated it with a passion. And one time, they were going to get a man to do it and I was prepared to walk out, a male nurse. I just spat the dummy. I said, I can't do that. I was just that was just my limit of having a male nurse catheterize me for some reason. And it was silly, but it was just me at the time.
Participant 036_2022AUBLC

Participant describes being vulnerable when first diagnosed, first few months after diagnosis

Yes. Probably the first two weeks when I didn't really know what was going on. I just had this weird cancer. I felt quite vulnerable then. Then I started to gather information and report to people. Then once I, once that was over, the vulnerability went away. I just went back. Let's just deal with it.
Participant 020_2022AUBLC

Yeah, yeah, yeah, right. From well, right. From being diagnosed, I thought, well, you know, what the hell? And then I was pretty, um anxious and sensitive, often for weeks after. For even months probably. When you think about it.
Participant 027_2022AUBLC

Well, I was pretty vulnerable for about the first six months. … Really. Really, really, really frightening.
Participant 037_2022AUBLC

Participant describes being while experiencing side effects from treatment or symptoms from condition

One time in particular, I felt vulnerable was after my surgery I was having I had, that I was running on high temperatures as well that then managed to settle down my temperature using a particular type of drug which I can't remember the name of. But one of the side effects of the drug was it, it stopped me from being able to verbally communicate my thoughts to my thought. Processes were going all over the place. So while it was helping in one respect, I couldn't communicate properly to say, Hey, I think it could be. This particular thing is every time you give me this drug, this is happening to me. I couldn't communicate that. And at that stage, I felt vulnerable. Um, I, I was lucky. My, um, my eldest daughter came to visit me with a partner who is also a doctor. And I was struggling, I, I struggled to, to get my view across to them. I basically had to go so slowly and then NAME who is the doctor understood that it was something about a drug that was not quite right. And he, but he actually spoke to it to the team and said, what? What are you are you giving him? And, and yeah, lo and behold, that stopped. Yeah. And that was good. Yeah. Vulnerability. Yeah. That, that definitely I felt very vulnerable at that point. Um, vulnerability also comes into play once you come home and. You've been so used to having, you know, being looked after in the hospital and now all of a sudden you come back and it's just yourself or yourself and your life coping with the situation that you've got. Yeah. And at that time, I felt vulnerable because I didn't think we knew enough about how to cope with day to day issues. And yeah, so starting the therapy or what happens really if I'm not feeling well, where do I go to?
Participant 035_2022AUBLC

Oh, yes, absolutely. Yeah. Yeah. After especially initially when, you know, you don't know much about it. And within, I think two days of my having the first initial tumour removed and I was in hospital and my abdomen just kept blowing up and I'm about 53 kilos. And so I, my abdomen was blowing up with fluidity and to the point where I felt like, I just was commenting to my husband. I look like I'm 34 weeks

pregnant. This is ridiculous. What's going on? And then the same time, they'd taken my catheter out and they said, right, you need to void now. And what had happened was my bladder had ruptured. And so fluid as the fluid had leaked out of my bladder and into my peritoneal space to the point where. It was some even starting to be told by my lungs. And I was in a lot of pain that night. And I kept telling the nurses, this is not right. This is not right. I couldn't void, they put the catheter back in. Not much was draining
Participant 010_2022AUBLC

Oh, yeah, work up in recovery room? And I thought, well, that's good, pains under control. And then all of a sudden it hit me like a truck and I had no pain relief whatsoever because they hadn't set PCA up. Yeah, and that was horrible. Anyways, they got the. anesthetist and, and gave me something and knocked me out again, which was good, but that was really vivid. So that was pretty horrible. And also because I read my notes when I was in the ward, it's just you shouldn't. But it said something like, oh, pain relief or pain issues or something like that. Change of shift didn't have time to set PCA up or something along those lines. And I just thought, it's really poor. So probably in retrospect, I shouldn't have read my notes, but they were just sitting there. But that really annoyed me because I knew that the anesthetist already knew that it was a very painful operation, and she would have preferred to put a block in. But, you know. So, yeah, the attention to detail was pretty poor for that. So anyway, these things happen.
Participant 018_2022AUBLC

Participant describes being vulnerable when having sensitive discussion (diagnosis, treatment decision)

When I was first diagnosed and my doctor, my sorry, my specialist told me what my treatment was going to be and what my cancer was. But didn't give me an option. They didn't give me a say in my own treatment. I was very vulnerable in that time because I just had to kind of back down and say, yep, right. I said that, so I do it kind of thing.
Participant 009_2022AUBLC

Especially at the beginning of my when I was first diagnosed. And then when I was first diagnosed and then I was told it was more or less, you know, that I've got low grade. It's not a problem. It's just like, you know, just like getting skin cancers burn off, blah, blah. That went on for about two years. And then the cancer changed. And then I felt, you know, it changed into a different type with a much higher risk. And then I felt vulnerable and then again, at that point.
Participant 016_2022AUBLC

Right from the first time somebody says, sorry to tell you this old son, but you've got this very fatal cancer. That sort of makes you think a bit.
Participant 034_2022AUBLC

Participant describes being vulnerable because of interactions with the medical team

At the beginning I felt, well, yes, after the first procedure. And then I was sick at home. And then I got the invoice about two weeks later, which said for the first time I had cancer. I was very vulnerable then, you know. And I rang my GP straight away and said, I haven't been told it's, you know, he put on a brave face and said, oh, well, the surgeon had to send away the specimen to the laboratory, which I understand the process. Yeah, but. But I don't recall. I feel very vulnerable because living by yourself and all that, you know, you're at home, unwell, bleeding all night. Frankly, you know, I didn't know whether to call the hospital or not. Um, now, you know, it passed within about four or five days, that very acute phase. And so very scary. It was very distressing. Yes. And you're isolated and you don't, you know. And the surgeon, as I said, his response when I saw him a month later was, well, I told you, Mr. NAME, I told you this when you came out of surgery, I said, well, I don't remember that I was so sick. Between the anesthetic and the bleeding. I don't remember him saying that at all. Yeah. And I'm not I'm not saying he didn't say it. I'm just saying I didn't hear it.
Participant 008_2022AUBLC

PARTICIPANT: Oh, yes, absolutely. Yeah. Yeah. After especially initially when, you know, you don't know much about it. And within, I think two days of my having the first initial tumour removed and I was in hospital and my abdomen just kept blowing up and I'm about 53 kilos. And so I, my abdomen was blowing up with fluidity and to the point where I felt like, I just was commenting to my husband. I look like I'm 34 weeks pregnant. This is ridiculous. What's going on? And then the same time, they'd taken my catheter out and they said, right, you need to void now. And what had happened was my bladder had ruptured. And so fluid as the fluid had leaked out of my bladder and into my peritoneal space to the point where. It was some even starting to be told by my lungs. And I was in a lot of pain that night. And I kept telling the nurses, this is *not right. This is not right. I couldn't void, they put the catheter back in. Not much was draining*

INTERVIEWER: And then I got to interject, just so I don't miss anything yet, but I just want to focus on what they needed to do. Like what you need to do to address or overcome that vulnerability.

PARTICIPANT: Okay, so what I'm what I'm saying it saying then is that well, the nursing staff eventually listened to me and got a doctor and to see me, the doctor, I had to convince there was something wrong. And it was nine, 9:00 at night. She reluctantly sent me for a scan. And of course, the scan showed this had happened. So I felt a bit vindicated. But yeah, just to be listened to, to be examined properly. And I felt that was very, very, very remiss of especially the doctor. And she was to just a at that point she's a resident. She wasn't sure of my specialist and my also should have come in to see me after that, but she didn't. So because of that, I had to have a catheter, go home with a catheter and have it in for two weeks and manage it at home and have scans at my expense to check when it healed. So yeah to be, to b,e felt very vulnerable there in that you pay for you pay the health insurance, you pay for a specialist and then not even looking after you properly and you don't want to have to be your own advocate shouldn't have to be I mean, you might have family members, but in my family, I was the one with the medical knowledge, not my husband, not my sister. And all I could do is sort of say, hey, look, she's not usually a whinger. She's not.
Participant 010_2022AUBLC

Early, only the first two months. I thought, I thought you know, I might be in a lot of trouble. Yeah, especially when I was at one of the doctors before hospital. I asked him when I came out of the anesthetic and they came and saw me when I woke up. So I said how did it go and he said don't no mate. I went ok. He was a young bloke, and I said, Well, what's the consequences? He said. if worst comes to worst, you'll just have to just get another bladder. And he just walked away all the way. That was when I really freaked out.
Participant 021_2022AUBLC

Participant describes being vulnerable when thinking about disease course/incurable condition

Ah yeah. A number of times. I can't say, I can't say anything specifically but I think anyone and again I've mentioned some of my mates have had various cancers. I think everyone who goes through actually gets cancer suddenly, you know, like, you know, we all know we're going to die. But yeah, one day, one day. But suddenly they are that you're looking you're looking at a lot closer thinking, oh, okay, this is real. So yeah, I felt vulnerable just in that sort of up and down way that you do when you when you get the diagnosis.
Participant 006_2022AUBLC

I think everybody goes through this. Anyone who has. Cancer. It's a bad word. You know, I mean, there's a lot of fear attached with this word. And the truth is, you know, many people don't live through it, you know? I mean, it is. It's called a high, you know, death rate.
Participant 028_2022AUBLC

That's a very vulnerable place because you have no idea what's going to happen. I'm looking at my wife and kids going, it's actually easy for me because if I die, I'm dead. But with these guys, they're going to go on without me. So it was me having to lose my wife. It would be absolutely horrendous. So it's actually as hard, if not harder, on the partners or the families as it is to the person that's actually getting cancer, I think.
Participant 030_2022AUBLC

Participant describes being vulnerable when they have a loss of independence, e.g in hospital, recovering form surgery

Vulnerable. I don't know if that's the right word. Only when I was in the hospital to begin. I've never been in hospital. Had had nothing done to me. I couldn't even wipe my own bum after the operation.
Participant 022_2022AUBLC

Oh, Jesus. Definitely after the operation, um, it took me about six months to recover. And I didn't like that feeling of being helpless. Really. I've got stairs here, and I couldn't go up and down the stairs, well I could with help. I've got lovely neighbours who call in on me or whatever. I'm in a block of units sort of thing. My son's working full time, I didn't really want to, you know, sort of trouble him too much. You know, you tend to sort of, again be, I'm Mr Independent so you can do this or not want to help. But having to ask for it is very hard, you know.
Participant 023_2022AUBLC

I mean, after when I got home, after being in the hospital for three weeks during the recovery, obviously you can't do too much, you know, in there at home. There were there was certainly a period and probably for about three months that I felt I mean, I live on my own, but I've got family very close by. Um, but because I, I'm a grandmother, so I'm very hands on and I'm usually out and about doing lots of stuff and helping with the kids. I couldn't do any of that. I couldn't go out. I couldn't drive. And I felt really. I felt like a big part of me was missing. Because I just I'm not one for just sort of sitting and even reading. I was finding hard. Some days I felt a bit low. I found it very, very, it was really lovely that a nurse came to see me every second day because again, she was very helpful and comforting, but I certainly felt a big it was as if I'd lost part of myself, like both physically and mentally, because I couldn't do the things that I normally do. I'd lost a certain amount of independence and that was not pleasant, but I knew it was just a short term thing and that it would all come back.
Participant 043_2022AUBLC

Participant describes being vulnerable when first sent home after being hospitalised without the care/availability healthcare professionals

Um. Probably the first four days after the surgery, very vulnerable where your being told what you have to do. He didn't want to do any of it. You have to do it because you know it's going to make the next day just a little bit easier. So probably then immediately after the surgery, when I came home and I had a catheter and I had to flush the catheter and manage all on my own. And, um, and. To give myself that clexane through injections, the blood thinning things. You know, you had to administer that yourself straight after the surgery. So, you know, you feel a bit vulnerable then because you think you are doing it right, you know? You know, you've got, you know, stitches and tubes. And so I think that was probably when I felt most vulnerable and then probably when they took out everything and I then had to use the neobladder on my own. I mean, I had support from the hospital, and if I knew if I had a problem, I could have called them. But that was probably, you know, during that period when I personally felt most vulnerable and I suppose, you know, initially after diagnosis as well.
Participant 032_2022AUBLC

I guess I felt really vulnerable when I was first diagnosed and leading up to the surgery. I guess I, you know, you emotional and everything. Um, and I guess. I don't know. I guess when, when immediately post-op or whatever, when I just felt that I wasn't able to change the appliance and then you'd think, would I ever be able to? But just a few weeks later, when I got more strength, that's when I just made the decision. I had to do it myself. Yeah. So I guess leading up to the surgery and doing chemo was when you were most in after, after surgery and I guess when you came home from hospital the first few weeks was, it was challenging. Until I got, until I got the confidence to look after myself.
Participant 039_2022AUBLC

Participant describes being vulnerable waiting for test results/around follow up appointments

Like. Yeah. Well, again, this cancer is like every three months. Check-Up and treatment and every like if we do BCG six times every week, you have to take days off and I'm full time worker.
Participant 015_2022AUBLC

Yeah, probably a few weeks ago when I was waiting on some test results and some other things and just a few things colliding together. I felt pretty anxious and went and saw my GP, went and rang EAP from work and probably had a anxious time.
Participant 017_2022AUBLC

I guess before surgery. Hmm. When you're wondering when, if I'm going to wake up and. And yeah, I think that's really the only time I really thought what was going to happen leading up to the surgery. And even today, I'm coming up to CAT scan. I still have that niggling what happens if it has metastasized. So I'm very vulnerable then. And even just a little bit afterwards when I had sepsis, I felt very vulnerable there as well.
Participant 038_2022AUBLC

Table 8.11: Experience of vulnerability

Experience of vulnerability	All participants		Early		Invasive		Advanced		Person with bladder cancer		Carer		Female		Male	
	n=49	%	n=20	%	n=10	%	n=14	%	n=44	%	n=5	%	n=17	%	n=32	%
Participant gives a description suggesting that overall, they had experiences of feeling vulnerable	42	85.71	19	95.00	9	90.00	14	100.00	42	95.45	0	0.00	17	100.00	25	78.13
Participant gives a description suggesting that overall, they did not have feelings of being vulnerable	2	4.08	1	5.00	1	10.00	0	0.00	2	4.55	0	0.00	0	0.00	2	6.25
Other/No response	5	10.20	0	0.00	0	0.00	0	0.00	0	0.00	5	100.00	0	0.00	5	15.63

Experience of vulnerability	All participants		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=49	%	n=29	%	n=19	%	n=15	%	n=33	%	n=20	%	n=28	%
Participant gives a description suggesting that overall, they had experiences of feeling vulnerable	42	85.71	25	86.21	17	89.47	13	86.67	29	87.88	17	85.00	25	89.29
Participant gives a description suggesting that overall, they did not have feelings of being vulnerable	2	4.08	0	0.00	1	5.26	0	0.00	1	3.03	0	0.00	1	3.57
Other/No response	5	10.20	4	13.79	1	5.26	2	13.33	3	9.09	3	15.00	2	7.14

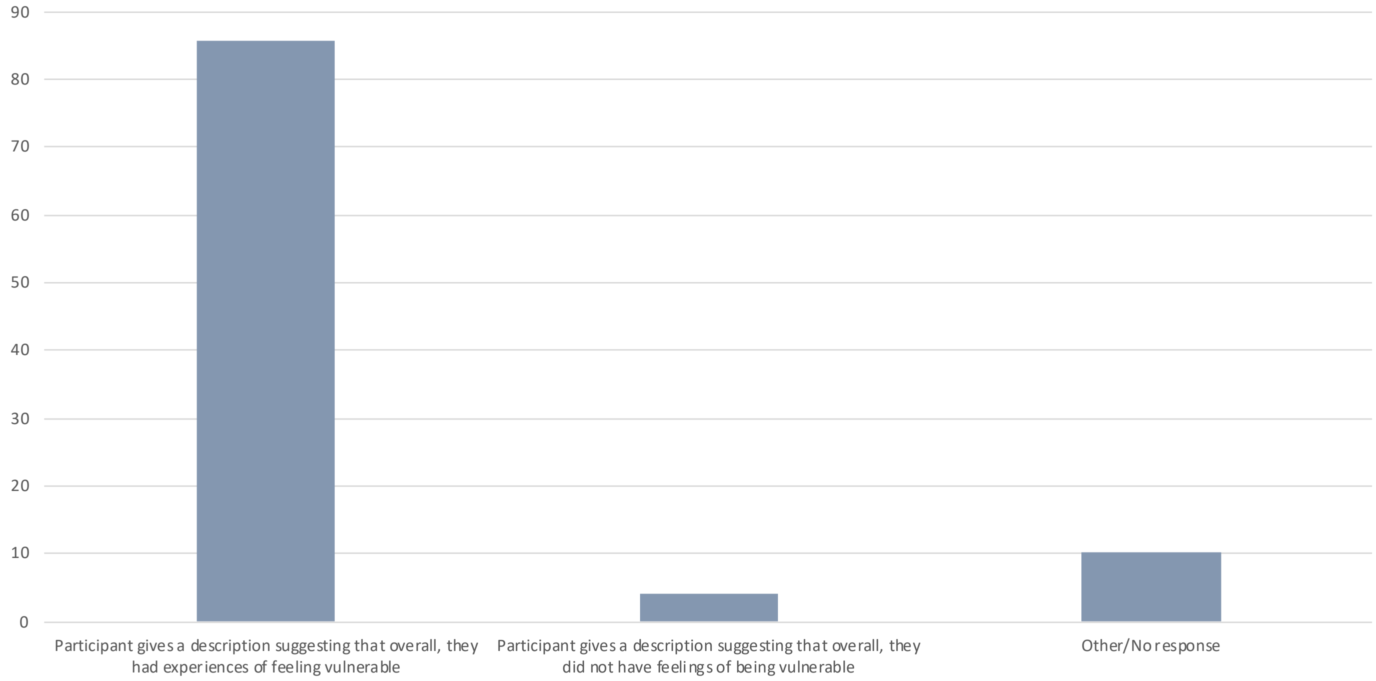


Figure 8.6: Experience of vulnerability

Table 8.12: Experience of vulnerability (details)

Experience of vulnerability	All participants		Early		Invasive		Advanced		Person with bladder cancer		Carer		Female		Male	
	n=49	%	n=20	%	n=10	%	n=14	%	n=44	%	n=5	%	n=17	%	n=32	%
Participant describes being vulnerable during/after treatments	25	51.02	11	55.00	4	40.00	10	71.43	25	56.82	0	0.00	12	70.59	13	40.63
Participant describes being vulnerable when first diagnosed, first few months after diagnosis	13	26.53	6	30.00	4	40.00	3	21.43	13	29.55	0	0.00	3	17.65	10	31.25
Participant describes being while experiencing side effects from treatment or symptoms from condition	10	20.41	5	25.00	0	0.00	5	35.71	10	22.73	0	0.00	4	23.53	6	18.75
Participant describes being vulnerable when having sensitive discussion (diagnosis, treatment decision)	8	16.33	5	25.00	0	0.00	3	21.43	8	18.18	0	0.00	4	23.53	4	12.50
Participant describes being vulnerable because of interactions with the medical team	8	16.33	4	20.00	2	20.00	2	14.29	8	18.18	0	0.00	4	23.53	4	12.50
Participant describes being vulnerable when thinking about disease course/incurable condition	5	10.20	1	5.00	2	20.00	2	14.29	5	11.36	0	0.00	0	0.00	5	15.63
Participant describes being vulnerable when they have a loss of independence, e.g in hospital, recovering form surgery	5	10.20	2	10.00	2	20.00	1	7.14	5	11.36	0	0.00	4	23.53	1	3.13
Participant describes being vulnerable when first sent home after being hospitalised without the care/availability healthcare professionals	5	10.20	0	0.00	0	0.00	5	35.71	5	11.36	0	0.00	3	17.65	2	6.25
Participant describes being vulnerable waiting for test results/around follow up appointments	4	8.16	3	15.00	0	0.00	1	7.14	4	9.09	0	0.00	1	5.88	3	9.38

Experience of vulnerability	All participants		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=49	%	n=29	%	n=19	%	n=15	%	n=33	%	n=20	%	n=28	%
Participant describes being vulnerable during/after treatments	25	51.02	13	44.83	12	63.16	5	33.33	20	60.61	9	45.00	16	57.14
Participant describes being vulnerable when first diagnosed, first few months after diagnosis	13	26.53	8	27.59	5	26.32	5	33.33	8	24.24	5	25.00	8	28.57
Participant describes being while experiencing side effects from treatment or symptoms from condition	10	20.41	7	24.14	3	15.79	2	13.33	8	24.24	5	25.00	5	17.86
Participant describes being vulnerable when having sensitive discussion (diagnosis, treatment decision)	8	16.33	5	17.24	3	15.79	3	20.00	5	15.15	4	20.00	4	14.29
Participant describes being vulnerable because of interactions with the medical team	8	16.33	4	13.79	4	21.05	3	20.00	5	15.15	3	15.00	5	17.86
Participant describes being vulnerable when thinking about disease course/incurable condition	5	10.20	4	13.79	1	5.26	3	20.00	2	6.06	2	10.00	3	10.71
Participant describes being vulnerable when they have a loss of independence, e.g in hospital, recovering form surgery	5	10.20	4	13.79	1	5.26	2	13.33	3	9.09	3	15.00	2	7.14
Participant describes being vulnerable when first sent home after being hospitalised without the care/availability healthcare professionals	5	10.20	2	6.90	3	15.79	1	6.67	4	12.12	1	5.00	4	14.29
Participant describes being vulnerable waiting for test results/around follow up appointments	4	8.16	3	10.34	1	5.26	1	6.67	3	9.09	2	10.00	2	7.14

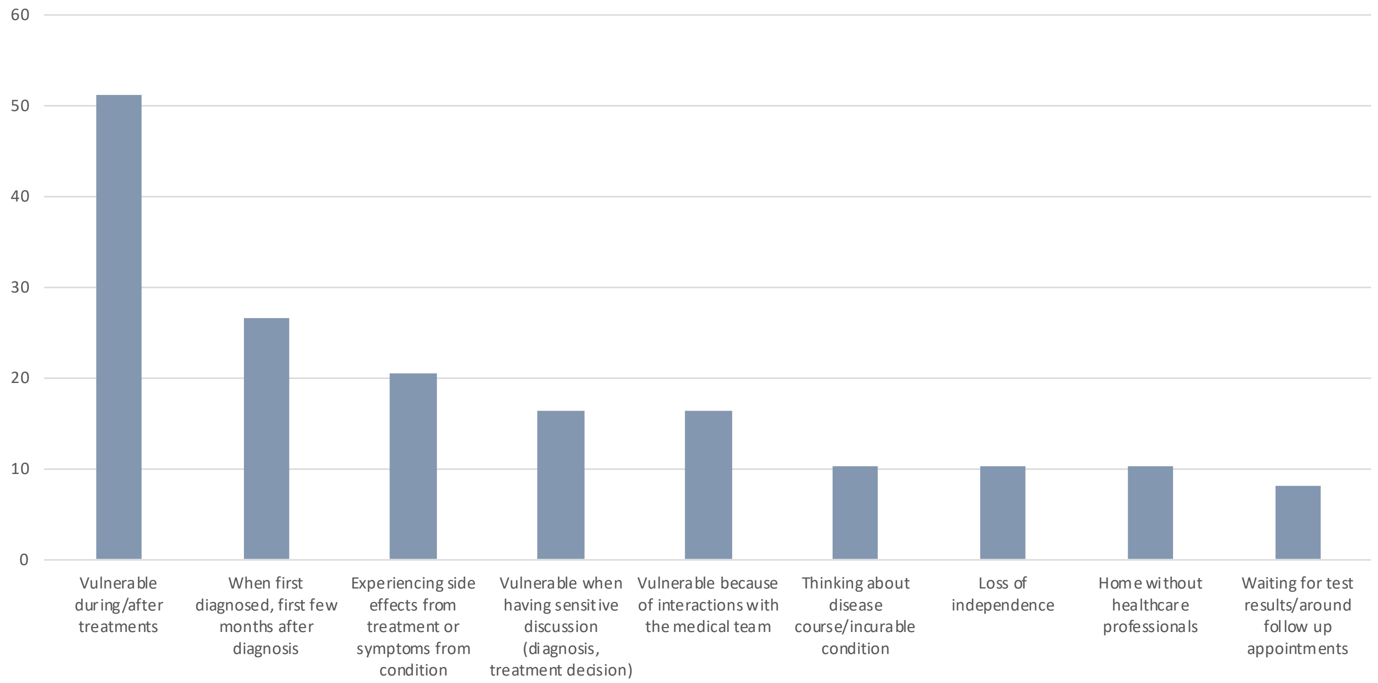


Figure 8.7: Experience of vulnerability (details)

Table 8.13: Experience of vulnerability (details) – subgroup variations

Experience of vulnerability	Reported less frequently	Reported more frequently
Participant describes being vulnerable during/after treatments	Invasive (Stage III) Carer to someone with bladder cancer Male Regional or remote	Advanced (Stage IV) Female University
Participant describes being vulnerable when first diagnosed, first few months after diagnosis	Carer to someone with bladder cancer	Invasive (Stage III)
Participant describes being while experiencing side effects from treatment or symptoms from condition	Invasive (Stage III) Carer to someone with bladder cancer	Advanced (Stage IV)
Participant describes being vulnerable when having sensitive discussion (diagnosis, treatment decision)	Invasive (Stage III) Carer to someone with bladder cancer	-
Participant describes being vulnerable because of interactions with the medical team	Carer to someone with bladder cancer	-
Participant describes being vulnerable when thinking about disease course/incurable condition	Carer to someone with bladder cancer Female	-
Participant describes being vulnerable when they have a loss of independence, e.g in hospital, recovering form surgery	Carer to someone with bladder cancer	Female
Participant describes being vulnerable when first sent home after being hospitalised without the care/availability healthcare professionals	Early (Stages 0 and I) Invasive (Stage III) Carer to someone with bladder cancer	Advanced (Stage IV)

Methods to manage vulnerability

In the structured interview, participants described ways that they managed feelings of vulnerability. Participants described using self help methods such as resilience, acceptance, and staying positive to manage the feeling of vulnerability (n=12, 24.49%), support from family and friends to manage the feeling of vulnerability (n=7, 14.29%), and being supported by nurse or treatment team to manage the feeling of vulnerability (n=6, 12.24%).

Participant describes self-help (resilience, acceptance, staying positive) to manage the feeling of vulnerability

Well, so not much. This is a very scary first time round and you don't know what's going on? And you just you just try and stay strong for your family, and you know I've got two kids. And I'm married and I don't think, um, I think is going to go through the motions a little bit and try to just stay strong, maybe it's a male thing, I dunno.
Participant 024_2022AUBLC

Well, I did it just by myself, you know. And as I said, I had, you know, a family. I had kids at school. Um, you know, I'd say just basically distract yourself with other things, I mean, that were great, helping me and looking after me. So you just distract yourself and you just want to be better every day because you're needed.
Participant 032_2022AUBLC

Oh, I didn't have to do too much. Just, you know, just took comfort in the fact that I'm old enough to live with it and without any regrets. You know, it's just a personal philosophy that helped me get through that bit. Hmm. In other words, I didn't really see it as a complete disaster. I just thought it was one of those things that happens either sooner or later. And I found my one sooner, so, you know, I'm one of the lucky ones.
Participant 034_2022AUBLC

Participant describes support from family and friends to manage the feeling of vulnerability

Okay. I think the best approach I took was I spoke about my fears to everybody. With my family, with my friends. I didn't hold back my feelings. And that helped me to overcome, you know, because, yeah, if you keep it inside, you know, then the worry only grows. And so I tried to talk to everybody, although, I mean, many of my friends, they meant well, but they only made me feel bad because they said, oh, don't worry, don't worry, you'll be fine. You're a strong man. And I think what a silly thing to say. You know, they don't know what I'm going through, you know?
Participant 028_2022AUBLC

In that situation, there wasn't anything else I could do in other situations. It's been. When I've been outside of the hospital, because every other time staff has been great in terms of support, in terms of. Vulnerability. Yeah. Talk. Talking. Picking up the phone and talking to a friend or family.
Participant 041_2022AUBLC

We talked. Yeah. We talked. My wife and I talked. Yeah. And then put it in to put it in context as we do.
Participant 019_2022AUBLC

Participant describes being supported by nurse or treatment team to manage the feeling of vulnerability

PARTICIPANT: Every time I was catherterised very vulnerable, I hated it. I hated it with a passion. And one time, they were going to get a man to do it and I was prepared to walk out, a male nurse. I just spat the dummy. I said, I can't do that. I was just that was just my limit of having a male nurse catherterise me for some reason. And it was silly, but it was just me at the time.

INTERVIEWER: Is is there anything that you think could be done to address that vulnerability?

PARTICIPANT: I think they were really respectful, but I did notice some were more respectful than others. I ended up having this one nurse who I really found very motherly and respectful, and in the end what they did was they very kindly allowed me to have her every time. And there was another one who was a bit more flippant. She'd get me to expose myself basically for the catherterisation, and then she'd turn around and she'd spend about 5 minutes preparing the solution. And there was only a curtain between me and the outside world. And although they were all very respectful of the curtains drawn, they wouldn't come in. I just didn't feel that I was private and, yet, this one that was quite motherly and nice, she would always get everything all ready until the last possible moment. Then she'd tell me to expose my, and that just felt better because she respected that. I didn't want to be lying like that for too long.
Participant 036_2022AUBLC

I mean, after when I got home, after being in the hospital for three weeks during the recovery, obviously you can't do too much, you know, in there at home. There were there was certainly a period and probably for about three months that I felt I mean, I live on my own, but I've got family very close by. Um, but because I, I'm a grandmother, so I'm very hands on and I'm usually out and about doing lots of stuff and helping with the kids. I couldn't do any of that. I couldn't go out. I couldn't drive. And I felt really. I felt like a big part of me was missing. Because I just I'm not one for just sort of sitting and even reading. I was finding hard. Some days I felt a bit low. I found it very, very it was really lovely that a nurse came to see me every second day because again, she was very helpful and comforting, but I certainly felt a big it was as if I'd lost part of myself, like both physically and mentally, because I couldn't do the things that I normally do. I'd lost a certain amount of independence and that was not pleasant, but I knew it was just a short term thing and that it would all come back.
Participant 043_2022AUBLC

Actually a nurse in CITY, who does phone consults. They would ring up and ask, how are you going, do I need anything? How I'm going with this. And then when we were, we were told, that in order to try and get rid of the UTIs, to use a catheter every day. She was, she was brilliant. Absolutely brilliant.
Participant 040_2022AUBLC

Participant describes that they are unsure how vulnerability can be managed to manage the feeling of vulnerability

Uh uh, you can't do much because you know you're there, you can't move, and they have to stick a needle in your back. So the only thing you can do. You're left in your room, on your own. You can start crying. Or then when they said when they gave it another try, and then the radiologist says, Ah, I think you go home without a bag and then you feel it's not working and that they are swearing and yes, they can. The only thing you can do is start crying.
Participant 005_2022AUBLC

Ah, well, there's not much. I just have to live with it. There's not much I can.
Participant 008_2022AUBLC

In that situation there wasn't anything else I could do.
Participant 041_2022AUBLC

Participant describes becoming informed about their condition, available treatment, and statistics to manage the feeling of vulnerability

Yeah, that's a good question. I think maybe in the first week it would have been nice if somebody could have sat me down and told me what it is, in essence, giving me lots of information about prognosis and treatment options. Had I had that information in the beginning, I wouldn't probably have felt I was just thinking.
Participant 020_2022AUBLC

I don't think I could say I did actively anything. I guess understanding what I was facing to be better informed and to know what the statistics likely were. I was only 49 and even I was 49 when I got diagnosed. And according to the statistics, I was on the very end of that sort of 40 to 49 year old bracket. And the percentage of Australian males that have this or that are diagnosed with bladder cancer in that age group is tiny. And you jump up to the sort of 72, 79 bracket, and that's where everybody sits like there's, hundreds of thousands of people, as opposed to a few of us in the 40 to 49. So straight away, I felt vulnerable because I was out of the ordinary. I wasn't the normal. I didn't fit the normal curve of the demographic. And so you feel vulnerable because you don't understand why there's no. Family history of it. There's no exposure through industrial or some form of employment previously that can sometimes trigger this. So there was no reason why I would have had it or should have had it. And here I was out of the normal. I'm not in demographic for this diagnosis, so I certainly felt vulnerable. With that knowledge and trying to understand why. Not necessarily, why me? But why did it happen? Yeah. Yeah. Which is a bit different. The one that he's like, oh, look, something's going to happen at some point, as it does to everybody. But why? Yeah. I would have thought a whole lot of other things that get be before and bladder cancer, etc.. It sounds like an old man.
Participant 030_2022AUBLC

Table 8.14: Methods to manage vulnerability

Methods to manage vulnerability	All participants		Early		Invasive		Advanced		Person with bladder cancer		Carer		Female		Male	
	n=49	%	n=20	%	n=10	%	n=14	%	n=44	%	n=5	%	n=17	%	n=32	%
Participant describes self-help (resilience, acceptance, staying positive) to manage the feeling of vulnerability	12	24.49	4	20.00	3	30.00	5	35.71	12	27.27	0	0.00	5	29.41	7	21.88
Participant describes support from family and friends to manage the feeling of vulnerability	7	14.29	3	15.00	2	20.00	2	14.29	7	15.91	0	0.00	0	0.00	7	21.88
Participant describes being supported by nurse or treatment team to manage the feeling of vulnerability	6	12.24	0	0.00	1	10.00	5	35.71	6	13.64	0	0.00	3	17.65	3	9.38
Participant describes that they are unsure how vulnerability can be managed to manage the feeling of vulnerability	4	8.16	3	15.00	0	0.00	1	7.14	4	9.09	0	0.00	2	11.76	2	6.25
Participant describes becoming informed about their condition, available treatment, and statistics to manage the feeling of vulnerability	3	6.12	1	5.00	1	10.00	1	7.14	3	6.82	0	0.00	0	0.00	3	9.38

Impact on relationships	All participants		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=49	%	n=29	%	n=19	%	n=15	%	n=33	%	n=20	%	n=28	%
Participant describes self-help (resilience, acceptance, staying positive) to manage the feeling of vulnerability	12	24.49	5	17.24	6	31.58	3	20.00	8	24.24	3	15.00	8	28.57
Participant describes support from family and friends to manage the feeling of vulnerability	7	14.29	5	17.24	2	10.53	2	13.33	5	15.15	3	15.00	4	14.29
Participant describes being supported by nurse or treatment team to manage the feeling of vulnerability	6	12.24	4	13.79	2	10.53	1	6.67	5	15.15	2	10.00	4	14.29
Participant describes that they are unsure how vulnerability can be managed to manage the feeling of vulnerability	4	8.16	2	6.90	2	10.53	1	6.67	3	9.09	2	10.00	2	7.14
Participant describes becoming informed about their condition, available treatment, and statistics to manage the feeling of vulnerability	3	6.12	2	6.90	1	5.26	2	13.33	1	3.03	2	10.00	1	3.57

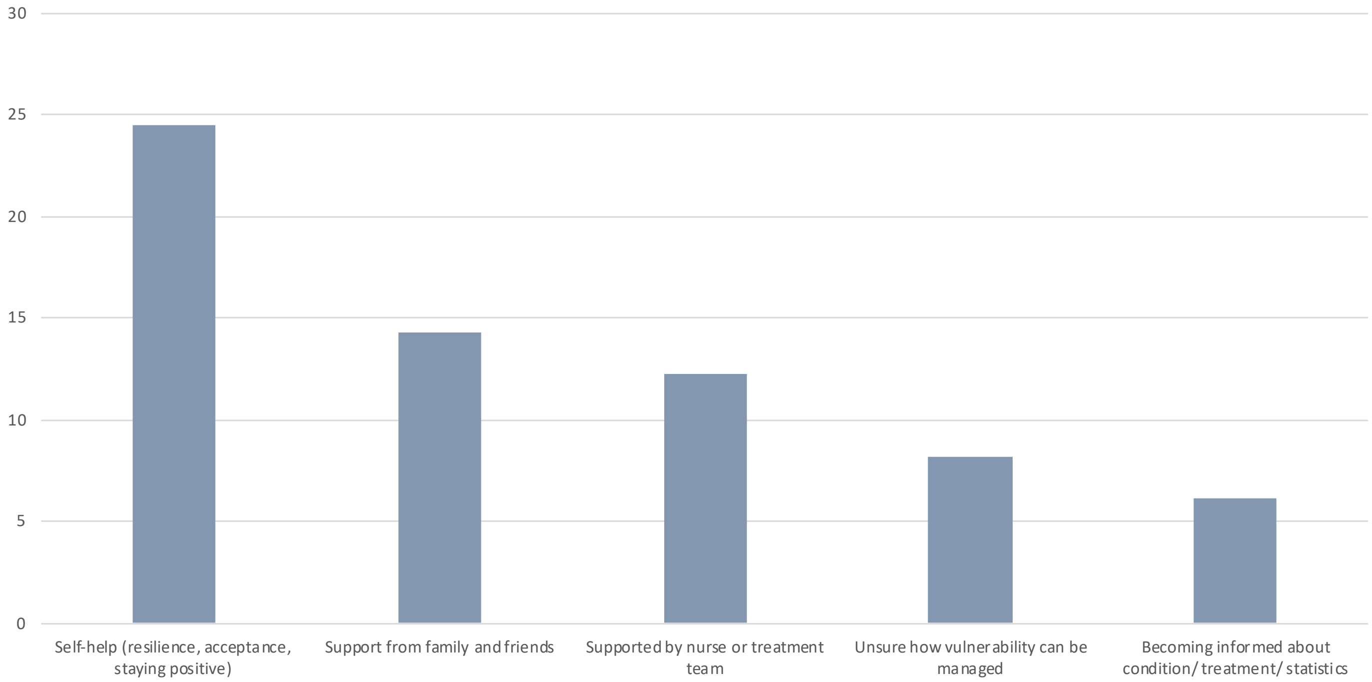


Figure 8.7: Methods to manage vulnerability

Table 8.15: Methods to manage vulnerability– subgroup variations

Impact on relationships	Reported less frequently	Reported more frequently
Participant describes self-help (resilience, acceptance, staying positive) to manage the feeling of vulnerability	Carer to someone with bladder cancer	Advanced (Stage IV)
Participant describes support from family and friends to manage the feeling of vulnerability	Carer to someone with bladder cancer Female	-
Participant describes being supported by nurse or treatment team to manage the feeling of vulnerability	Early (Stages 0 and I) Carer to someone with bladder cancer	Advanced (Stage IV)

Impact on relationships

In the structured interview, participants were asked whether their condition had affected their personal relationships. Overall, there were 17 participants (34.69%) that described that overall, there was a positive impact on relationships. Other participants described a mix of a positive and a negative impact (n=11, 22.45%), a negative impact on relationships (n=9, 18.37%), no impact on relationships (n=8, 16.33%), and an impact on relationships that was neither positive nor negative (n=3, 6.12%)

The most common themes in relation to having a positive impact on relationships were relationships within the family being strengthened (n=22, 44.90%), and people being well-meaning and supportive (n=10, 20.41%). The most common themes in relation to having a positive impact on relationships were relationships suffering, that is people not knowing what to say or do and withdrawing from relationships (n=9, 18.37%), and dynamics of relationships change due to anxiety, exacerbations and/or physical limitations of condition (n=7, 14.29%).

Participant described that overall, there was a positive impact on relationships

Um, I think it did, but not to me. I think it made some of my family and friends take stock of their situation. I don't think it so much affected their relationship as me. I think after a while they all got used to the idea. I know there was a few of the younger guys that you could you could really see when they you know, I'd be out surfing with them and I'd say, oh yeah, I had bladder cancer. So and it was a genuine shock. And then you'd see them a bit later and you could tell that they really thought, bloody hell, if it can happen to him. So I don't think it affected my relationship too much with most people, I think. I think probably my wife and I became closer, but, you know, normal. As we said recently, normal hostilities have almost resumed [LAUGHS].
Participant 006_2022AUBLC

No. Probably brought me a bit closer maybe with my sisters. Not that we were distant by any stretch, but yeah, we speak a lot more often now about it. Yeah. So in that regard, you're probably positive. And I've told, I've told the friends that I need to tell them and some of my, my clients that I work for. I've told them because of certain days I can't, you know, or if I can't be there because of the Thursday of my treatment, then, you know, I would give them I would say, look, this is where I'm at. Um. No, I don't think it's changed any. Certainly not professional relationships. And, um, you know, my relationship with my sisters is probably somewhat closer, even though we were quite reasonably close. We're probably better now. Probably more thoughtful for each other.
Participant 014_2022AUBLC

I have to say, I've been really lucky because while I had a very serious diagnosis and major surgery, I have come out the other side really well. If anything, it's brought my family closer together.
Participant 032_2022AUBLC

Participant described that overall, there was a mix of a positive and a negative impact

Well, friends. Uh, a couple. Yeah. Sometimes you go and talk to friends and they'll look straight at your stomach and you think, Oh, God, what are they looking to see. And my husband never noticed that. He said, oh, I don't think they do. And I said, well, you can, it's subtle. You can notice subtle things, but most of our friends are pretty good, and a couple of them just dropped meals around, even though they weren't meant to with COVID and that was that really nice and helpful and really because I'm just back on track and doing everything I pretty much used to. They don't worry too much. It's just, you know, back normal, but it kind of makes you feel a bit like you're the only one who's got this none of your friends have got it. So you feel a bit of an outsider.
Participant 018_2022AUBLC

Um. Yeah. Good question. Some people really step up and say all the right things. And some people are absolutely terrified of the C-word and don't know what to say. So they choose not to say anything at all. And to be honest, that's a bit disappointing. But for some people, that might have been exactly the right reaction that they wanted from their friends. But for me, it was people who I let know and I just think. Excuse my language, but, you know, I'd text somebody or call someone, that's really sucks, that's really horrible. I'm really sorry that's happened. Yeah, that's, that's all you're gonna need to hear, because there's nothing anyone can do about it. And it's very cliche, but anybody who said, oh, you're strong, you'll get through it. And so, yeah, I don't know if I will have no I can control some things, but there's a lot I can't control at this. So people who would say, you know, put on a brave face to be strong. Obviously, that doesn't help at all. So it was interesting to see who did step up to check in, see how things were going on a daily or weekly basis. Probably closer to my best mate than ever. So that was good. So it certainly improved some things. And it's a shame that takes the scare did it to make you talking a bit closer to people. Yeah.
Participant 030_2022AUBLC

Yes, definitely. Yeah. Yeah. Um, we definitely have expectations of how people might support you and react. And some people exceed those and some people, you know, don't like, you know. So you think that your immediate family might be really supportive and sometimes they're just not. So yeah, you just don't know how people are going to be, really. How they going to react and support. So yeah, that's just yeah,

I've definitely had some detrimental effects to my immediate family.
Carer 003_2022AUBLC

Participant described that overall, there was a negative impact on relationships

Yeah. Look, I've noticed some people sort of tend to shy away a bit from you once they hear that you've been diagnosed with terminal cancer. But oh, you know, all in all. I had to give up my job because I became too tired. You know, I couldn't, I sort of get tired and breathless pretty easily. And I was a finance broker before, and I used to. It was stressful job to some extent because, you know, I, I looked after difficult loans like people they've really been to their bank and got knocked back so they come to me as a specialist finance broker andwWant to keep the houses from being repossessed and all that sort of stuff. So I did. I did a lot of alternative type of loan lending or private lending and all that sort of stuff. Mortgage lending. So say people, their houses, you know, and sometimes I can't help everybody and it can get become stressful a bit, you know. But if I had a bit of a stressful job. So when they told me I was terminal, I thought bugger this, I might as well stop and smell the roses a bit, you know, and. I applied for a disability pension and was granted that. And yes, I was quite thankful for thatParticipant 042_2022AUBLC

Um. Probably a little bit. Not so much the family, maybe friends because he just doesn't tend to go out very much. In the beginning, he wouldn't go out at all. So I had, you know, we had unfortunately a big argument over it. And I said, well, you get in this car and you get in here now. You know, I was actually dragging him. I said, we're just going to a coffee shop. We have to get out of this house. you have to continue with your life.
Carer 001_2022AUBLC

PARTICIPANT Well, I also feel that, which I never felt when I had breast cancer or anything. A lot of people don't contact you when they find out like you don't. And with friends of friends that we've had for years. And I think they found it, I've heard from them.

INTERVIEWER Nothing. That's so weird. But that didn't happen with the breast or thyroid cancer.

PARTICIPANT Which was bizarre. thyroid cancer was you know, that was but with the breast cancer. No.

INTERVIEWER Was like everybody kept on going on. I can support it. Yeah. Yeah. But I have heard that before. It is a strange thing, isn't it? Maybe there are quite a lot of now.

PARTICIPANT You know, maybe because it is a bladder or. I don't know. I don't.
Participant 004_2022AUBLC

Participant described that overall, there no impact on relationships

No, not at all. Not one bit. As a matter of fact half of the people I know don't know about it, oh more than a half. Couple of mates know I've had it. It doesn't ever get brought up. And NAME, my wife, she has been fantastic. Yeah, we just got on as we have the last 30 years. So there's been no dramas there at all.
Participant 021_2022AUBLC

No, no, no. Because I've got a, um. A really close bond family. Like a circle and my close friends that have been here for us from day one. Yeah. No, I'd say not. No. When it comes to my children and my wife. No.
Participant 033_2022AUBLC

No, I don't think so.
Participant 044_2022AUBLC

Participant described that overall, there was an impact on relationships that was neither positive nor negative

Yeah. As we discussed before, like with, with my wife, with two daughters, they have also been impacted not not, not badly, but I've also had to be mindful that dad's had bladder cancer. Yeah. Uh, yeah. With friends. Not so much, because I can choose to, to sort of go. And I choose, if somebody wants to know about bladder cancer, I'm. I'm quite comfortable to talk to them about it and, and what what's happened to me and I, I don't try and hide that I have a stoma or anything like that. If somebody has a genuine question, I'm happy to talk and talk about it. Um, but. Yeah. It doesn't stop me from doing those things. I'm still able to go out and meet up with people and talk to other people.
Participant 035_2022AUBLC

Uh, not now. I think at the time, it definitely did. Um, but no, I think, I think because of the stage I am at, and that's, I'm sort of, well, three years down the track and trying not to think about any possibility of it re-occurring too much. At the moment I'm in quite a good position, so it's not really affecting my day to day life too much at all.
Participant 036_2022AUBLC

Table 8.16: Impact on relationships

Impact on relationships	All participants		Early		Invasive		Advanced		Person with bladder cancer		Carer		Female		Male	
	n=49	%	n=20	%	n=10	%	n=14	%	n=44	%	n=5	%	n=17	%	n=32	%
Participant described that overall, there was a positive impact on relationships	17	34.69	6	30.00	6	60.00	3	21.43	15	34.09	2	40.00	7	41.18	10	31.25
Participant described that overall, there was a mix of a positive and a negative impact	11	22.45	5	25.00	1	10.00	4	28.57	10	22.73	1	20.00	3	17.65	8	25.00
Participant described that overall, there was a negative impact on relationships	9	18.37	3	15.00	2	20.00	2	14.29	7	15.91	2	40.00	2	11.76	7	21.88
Participant described that overall, there no impact on relationships	8	16.33	5	25.00	1	10.00	2	14.29	8	18.18	0	0.00	3	17.65	5	15.63
Participant described that overall, there was an impact on relationships that was neither positive nor negative	3	6.12	1	5.00	0	0.00	2	14.29	3	6.82	0	0.00	2	11.76	1	3.13
Other/No response	1	2.04	0	0.00	0	0.00	1	7.14	1	2.27	0	0.00	0	0.00	1	3.13

Impact on relationships	All participants		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=49	%	n=29	%	n=19	%	n=15	%	n=33	%	n=20	%	n=28	%
Participant described that overall, there was a positive impact on relationships	17	34.69	9	31.03	8	42.11	4	26.67	13	39.39	4	20.00	13	46.43
Participant described that overall, there was a mix of a positive and a negative impact	11	22.45	8	27.59	3	15.79	4	26.67	7	21.21	8	40.00	3	10.71
Participant described that overall, there was a negative impact on relationships	9	18.37	6	20.69	3	15.79	5	33.33	4	12.12	4	20.00	5	17.86
Participant described that overall, there no impact on relationships	8	16.33	4	13.79	3	15.79	2	13.33	5	15.15	4	20.00	3	10.71
Participant described that overall, there was an impact on relationships that was neither positive nor negative	3	6.12	1	3.45	2	10.53	0	0.00	3	9.09	0	0.00	3	10.71
Other/No response	1	2.04	1	3.45	0	0.00	0	0.00	1	3.03	0	0.00	1	3.57

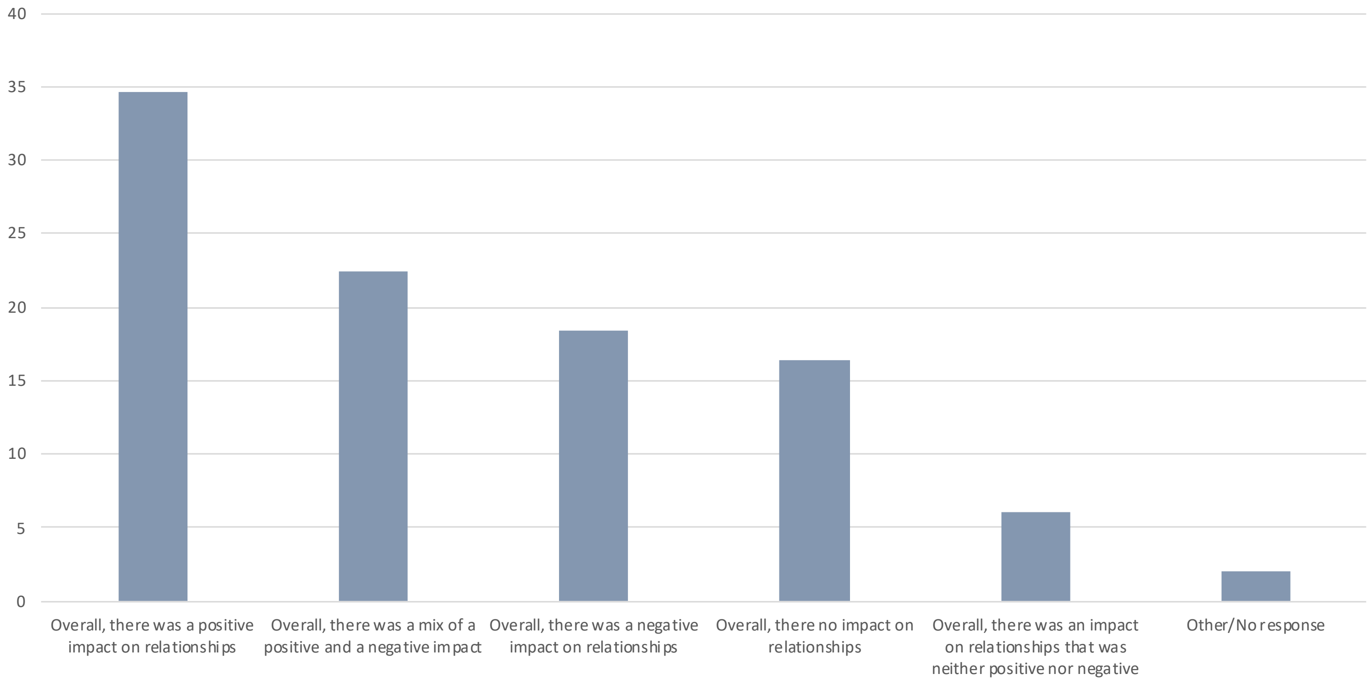


Figure 8.8: Impact on relationships

Table 8.17: Impact on relationships – subgroup variations

Impact on relationships	Reported less frequently	Reported more frequently
Participant described that overall, there was a positive impact on relationships	Advanced (Stage IV) Mid to low status	Invasive (Stage III) Higher status
Participant described that overall, there was a mix of a positive and a negative impact	Invasive (Stage III) Higher status	Mid to low status
Participant described that overall, there was a negative impact on relationships	-	Carer to someone with bladder cancer Regional or remote
Participant described that overall, there no impact on relationships	Carer to someone with bladder cancer	

Table 8.18: Impact on relationships (Reason for impact)

Impact on relationships (Reason for impact)	All participants		Early		Invasive		Advanced		Person with bladder cancer		Carer		Female		Male	
	n=49	%	n=20	%	n=10	%	n=14	%	n=44	%	n=5	%	n=17	%	n=32	%
Participant describes relationships with family being strengthened	22	44.90	9	45.00	6	60.00	5	35.71	20	45.45	2	40.00	8	47.06	14	43.75
Participant describes a positive impact on relationships, as people are well-meaning and supportive	10	20.41	3	15.00	1	10.00	5	35.71	9	20.45	1	20.00	5	29.41	5	15.63
Participant describes relationships suffering, that is people not knowing what to say or do and withdrawing from relationships	9	18.37	3	15.00	2	20.00	3	21.43	8	18.18	1	20.00	4	23.53	5	15.63
Participant describes that there was no impact on relationships	8	16.33	5	25.00	1	10.00	2	14.29	8	18.18	0	0.00	3	17.65	5	15.63
Participant describes relationship with family changing: dynamics of relationships change due to anxiety, exacerbations and/or physical limitations of condition	7	14.29	5	25.00	0	0.00	1	7.14	6	13.64	1	20.00	2	11.76	5	15.63
Participant describes an negative impact on relationships, due to intimacy challenges	3	6.12	0	0.00	1	10.00	2	14.29	3	6.82	0	0.00	0	0.00	3	9.38

Impact on relationships (Reason for impact)	All participants		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=49	%	n=29	%	n=19	%	n=15	%	n=33	%	n=20	%	n=28	%
Participant describes relationships with family being strengthened	22	44.90	15	51.72	7	36.84	7	46.67	15	45.45	10	50.00	12	42.86
Participant describes a positive impact on relationships, as people are well-meaning and supportive	10	20.41	5	17.24	5	26.32	2	13.33	8	24.24	4	20.00	6	21.43
Participant describes relationships suffering, that is people not knowing what to say or do and withdrawing from relationships	9	18.37	6	20.69	3	15.79	4	26.67	5	15.15	4	20.00	5	17.86
Participant describes that there was no impact on relationships	8	16.33	4	13.79	3	15.79	2	13.33	5	15.15	4	20.00	3	10.71
Participant describes relationship with family changing: dynamics of relationships change due to anxiety, exacerbations and/or physical limitations of condition	7	14.29	3	10.34	4	21.05	3	20.00	4	12.12	4	20.00	3	10.71
Participant describes an negative impact on relationships, due to intimacy challenges	3	6.12	3	10.34	0	0.00	2	13.33	1	3.03	3	15.00	0	0.00

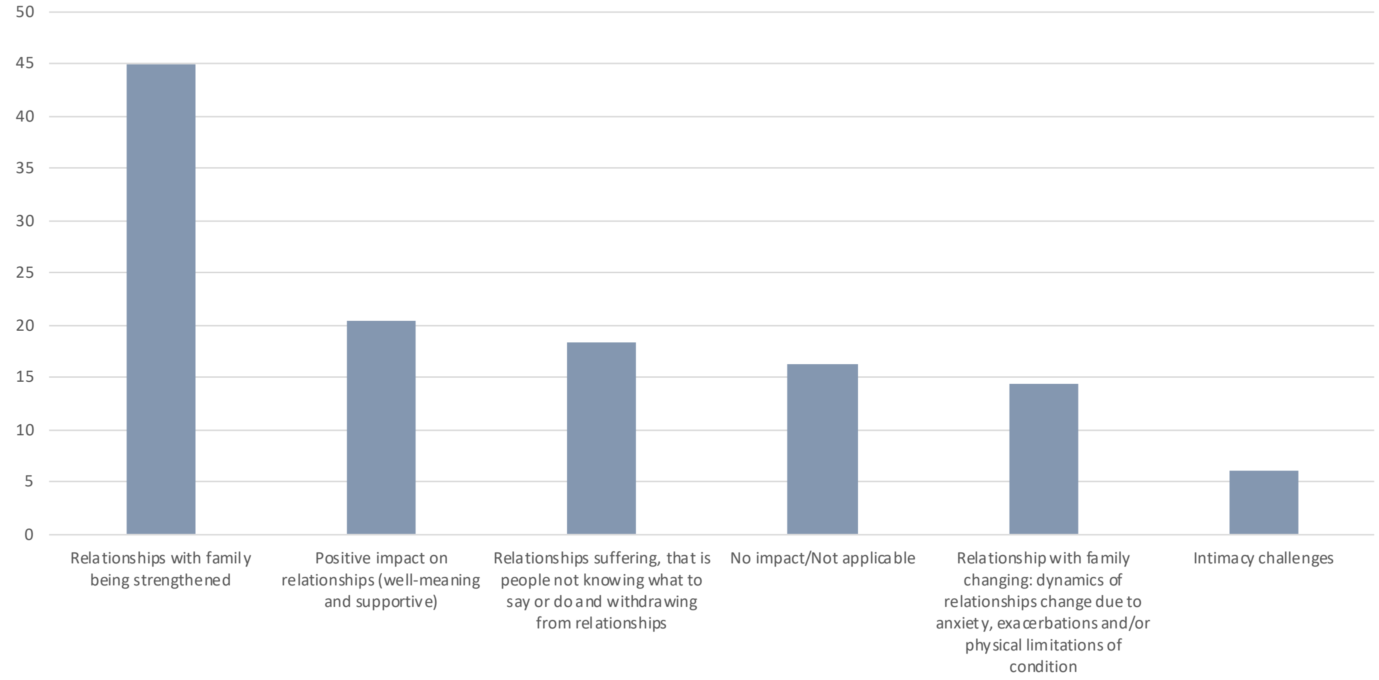


Figure 8.9: Impact on relationships

Table 8.19: Impact on relationships: Reason for impact – subgroup variations

Impact on relationships (Reason for impact)	Reported less frequently	Reported more frequently
Participant describes relationships with family being strengthened	-	Invasive (Stage III)
Participant describes a positive impact on relationships, as people are well-meaning and supportive	Invasive (Stage III)	Advanced (Stage IV)
Participant describes relationships suffering, that is people not knowing what to say or do and withdrawing from relationships	-	-
Participant describes that there was no impact on relationships	Carer to someone with bladder cancer	-
Participant describes relationship with family changing: dynamics of relationships change due to anxiety, exacerbations and/or physical limitations of condition	Invasive (Stage III)	Early (Stages 0 and I)

Burden on family

In the structured interview, participants were asked whether they felt that their condition placed additional burden on their family. Overall, there were 22 participants (44.90%) that felt there was an additional burden, 20 participants (40.82%) that reported no additional burden, and 6 participants (12.24%) that felt they were not a burden on their family but anticipate this will change in the future.

For people that felt they were not a burden on their family, the most did not give any specific reasons for this (n=14, 28.57%). The main reason that participant described their condition not being a burden in general was that they were very independent and did not need any help (n=8, 16.33%). The most common reasons for feeling that they were a burden on their family was the mental/emotional strain placed on their family (n=12, 24.49%), the extra household duties and responsibilities that their family must take on (n=5, 10.20%), and that the burden was temporary or only during treatment (n=5, 10.20%).

Participant describes that overall, there was a burden on their family

Oh, for sure. As I said before, my husband certainly it's a burden on him because I'm supposed to be helping him with the business. And so therefore he gets so

much. He has to work so much more. He'll often bring work home. And then with regard to my children, all live independently and only one in the same city that I live in. But it hasn't really impacted them yet. However, because I'm now booked to have my bladder removed. And it's such major surgery. Both the interstate children are flying up to see me one before and one afterwards. So, I mean, if anything, that's an impact.
Participant 010_2022AUBLC

Yeah, definitely. Definitely. You know, my wife has to be strong and I've got two young children and initially, you know. She had to sort of show a brave face, I guess, and. Um. You know, probably really put her in a not on awkward but just in a difficult position because you are facing mortality. I guess that's the first thing you think about is what if I die? Where are we at? So it is a burden. I feel. I felt I was a burden in that regard. I know my wife would say it wasn't, but, I felt that it was. It's because of the uncertainty and the potential. Yeah. Personality of the cancer.
Participant 014_2022AUBLC

It has it has been it has been particularly draining on my wife I think. It's not so bad now because it's, I've become a lot more self-sufficient since the recoveries has occurred. But I think that immediate post-op period is a bit of a, a bit of a demanding time for whoever it is that's going to be your carer.
Participant 034_2022AUBLC

Oh, I just feel that it was definitely a burden on my husband and I don't know what I would have done without him, to be honest, because he was the one that would come and pick me up after my BCG and he'd have the hot water bottle there and he'd fill it up and then he'd drive me home and be so concerned that he could see how uncomfortable I was. And I just don't know what I would have done without him. I felt quite reliant upon him and he found it very frustrating because he couldn't do anything to help. He wanted to try and take it away from me, but he couldn't. So it was quite stressful for him as well.
Participant 036_2022AUBLC

Participant describes that overall, there was not a burden on their family

No I didn't get any extra care. I've been very independent
Participant 002_2022AUBLC

I'm only having like a scan every six months and yeah, life is pretty normal. It's just, um. Yeah, I haven't got any extra, as I said the bag doesn't affect anything I do, everything so know it's no extra care that I have, but I'm staying pretty healthy.
Participant 044_2022AUBLC

No. Because I am self sufficient.
Participant 037_2022AUBLC

Participant describes that overall, there was not a burden on their family now but they anticipate this will change in the future

Not at the moment it's not? No, to be fair, it could be in the future, but no, not at the moment.
Participant 008_2022AUBLC

Not at the moment. I do worry down the track. When I was six years difference between NAME and myself, and if anything happens to be, she would have to care for me. So I'll worry about that. But. It's not a problem at the moment because I do all the changes myself and the bags come automatically with me. So yeah, so it's very different.
Participant 038_2022AUBLC

Well, luckily not in my case, because I have like as I said, so far, no side effects and no, no bad, you know, outcome. So I am still fit and healthy, so I am not a burden. But if I had the surgery and if I had to have the external stoma, then I would have been some limited in my abilities, you know, and maybe some burden on my family also. But right now, I don't think they have to do anything extra than before.
Participant 028_2022AUBLC

Table 8.20: Burden on family

Burden on family	All participants		Early		Invasive		Advanced		Person with bladder cancer		Carer		Female		Male	
	n=49	%	n=20	%	n=10	%	n=14	%	n=44	%	n=5	%	n=17	%	n=32	%
Participant describes that overall, there was a burden on their family	22	44.90	7	35.00	3	30.00	9	64.29	19	43.18	3	60.00	6	35.29	16	50.00
Participant describes that overall, there was not a burden on their family	20	40.82	11	55.00	5	50.00	2	14.29	18	40.91	2	40.00	8	47.06	12	37.50
Participant describes that overall, there was not a burden on their family now but they anticipate this will change in the future	6	12.24	2	10.00	2	20.00	2	14.29	6	13.64	0	0.00	2	11.76	4	12.50
Other/No response	1	2.04	0	0.00	0	0.00	1	7.14	1	2.27	0	0.00	1	5.88	0	0.00

Burden on family	All participants		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=49	%	n=29	%	n=19	%	n=15	%	n=33	%	n=20	%	n=28	%
Participant describes that overall, there was a burden on their family	22	44.90	17	58.62	5	26.32	9	60.00	13	39.39	11	55.00	11	39.29
Participant describes that overall, there was not a burden on their family	20	40.82	9	31.03	10	52.63	5	33.33	14	42.42	6	30.00	13	46.43
Participant describes that overall, there was not a burden on their family now but they anticipate this will change in the future	6	12.24	3	10.34	3	15.79	1	6.67	5	15.15	3	15.00	3	10.71
Other/No response	1	2.04	0	0.00	1	5.26	0	0.00	1	3.03	0	0.00	1	3.57

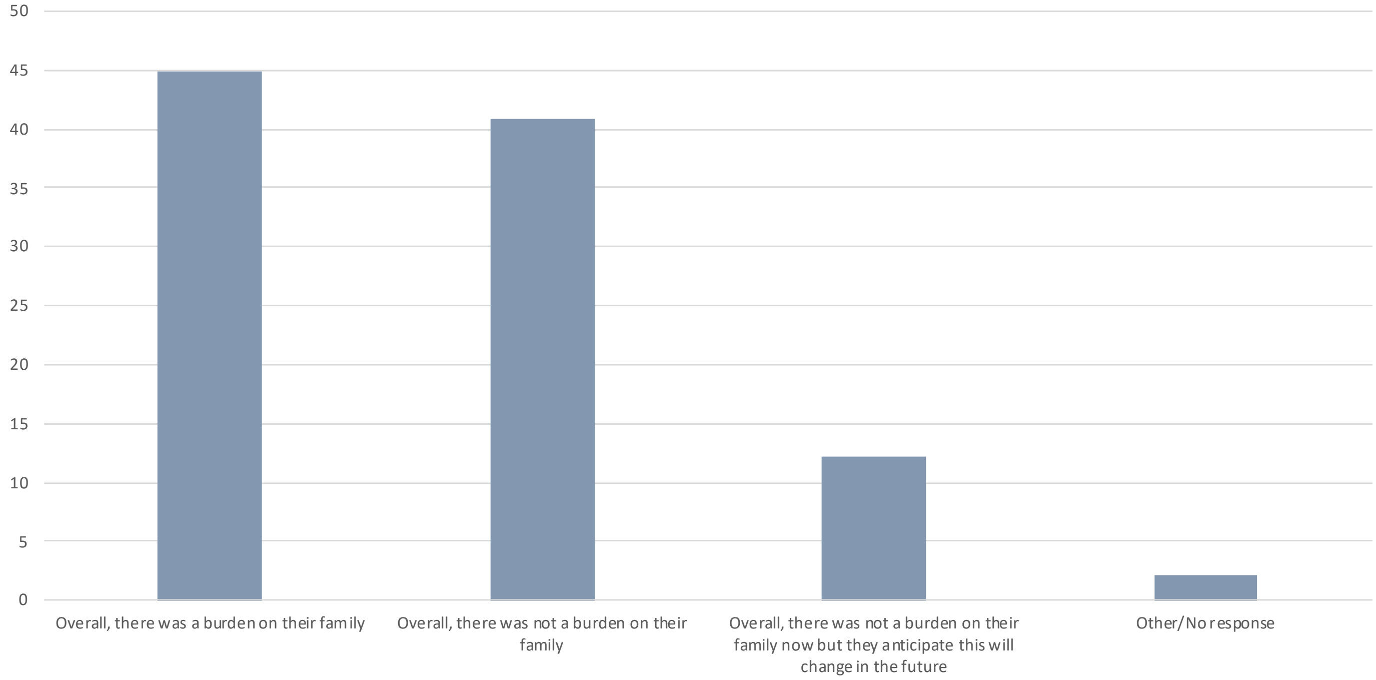


Figure 8.10: Burden on family

Table 8.21: Burden on family – subgroup variations

Burden on family	Reported less frequently	Reported more frequently
Participant describes that overall, there was a burden on their family	Invasive (Stage III) University	Advanced (Stage IV) Carer to someone with bladder cancer Trade or high school Regional or remote Mid to low status
Participant describes that overall, there was not a burden on their family	Advanced (Stage IV) Mid to low status	Early (Stages 0 and I) University
Participant describes that overall, there was not a burden on their family now but they anticipate this will change in the future	Carer to someone with bladder cancer	

Table 8.22: Burden on family (description)

Burden on family (description)	All participants		Early		Invasive		Advanced		Person with bladder cancer		Carer		Female		Male	
	n=49	%	n=20	%	n=10	%	n=14	%	n=44	%	n=5	%	n=17	%	n=32	%
Participant describes their condition not being a burden in general (No specific examples)	14	28.57	7	35.00	4	40.00	2	14.29	13	29.55	1	20.00	6	35.29	8	25.00
Participant describes the mental/emotional strain placed on their family	12	24.49	4	20.00	1	10.00	6	42.86	11	25.00	1	20.00	3	17.65	9	28.13
Participant describes their condition not being a burden, as they are very independent	8	16.33	4	20.00	3	30.00	1	7.14	8	18.18	0	0.00	3	17.65	5	15.63
Participant describes extra household duties and responsibilities that their family must take on	5	10.20	1	5.00	0	0.00	3	21.43	4	9.09	1	20.00	2	11.76	3	9.38
Participant describes their condition being a burden, but that it was temporary or only during treatment	5	10.20	2	10.00	1	10.00	2	14.29	5	11.36	0	0.00	3	17.65	2	6.25
Participant describes extra assistance needed getting to appointments	4	8.16	2	10.00	0	0.00	1	7.14	3	6.82	1	20.00	2	11.76	2	6.25
Participant describes their condition being a burden in general (No specific examples)	3	6.12	0	0.00	1	10.00	1	7.14	2	4.55	1	20.00	0	0.00	3	9.38

Burden on family (description)	All participants		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=49	%	n=29	%	n=19	%	n=15	%	n=33	%	n=20	%	n=28	%
Participant describes their condition not being a burden in general (No specific examples)	14	28.57	8	27.59	6	31.58	5	33.33	9	27.27	7	35.00	7	25.00
Participant describes the mental/emotional strain placed on their family	12	24.49	9	31.03	3	15.79	4	26.67	8	24.24	5	25.00	7	25.00
Participant describes their condition not being a burden, as they are very independent	8	16.33	2	6.90	5	26.32	1	6.67	6	18.18	2	10.00	5	17.86
Participant describes extra household duties and responsibilities that their family must take on	5	10.20	4	13.79	1	5.26	1	6.67	4	12.12	1	5.00	4	14.29
Participant describes their condition being a burden, but that it was temporary or only during treatment	5	10.20	2	6.90	3	15.79	1	6.67	4	12.12	3	15.00	2	7.14
Participant describes extra assistance needed getting to appointments	4	8.16	3	10.34	1	5.26	2	13.33	2	6.06	3	15.00	1	3.57
Participant describes their condition being a burden in general (No specific examples)	3	6.12	2	6.90	1	5.26	1	6.67	2	6.06	1	5.00	2	7.14

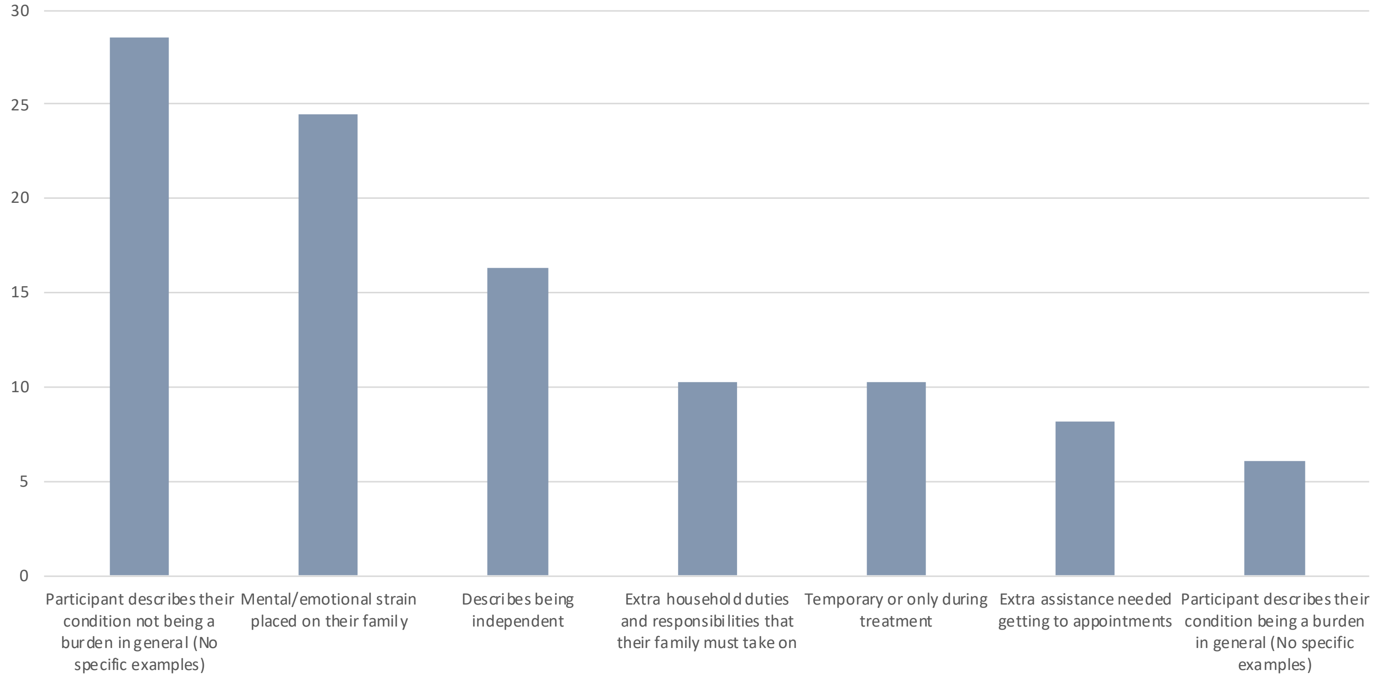


Figure 8.11: Burden on family (description)

Table 8.23: Burden on family (description)– subgroup variations

Burden on family (description)	Reported less frequently	Reported more frequently
Participant describes their condition not being a burden in general (No specific examples)	Advanced (Stage IV)	Invasive (Stage III)
Participant describes the mental/emotional strain placed on their family	Invasive (Stage III)	Advanced (Stage IV)
Participant describes their condition not being a burden, as they are very independent	Carer to someone with bladder cancer	Invasive (Stage III)
Participant describes extra household duties and responsibilities that their family must take on	Invasive (Stage III)	Advanced (Stage IV)
Participant describes their condition being a burden, but that it was temporary or only during treatment	Carer to someone with bladder cancer	-

Cost considerations

In the structured interview, participants were asked about any significant costs associated with having their condition. There were 25 participants (51.02%) that described some cost burden and 22 participants (44.90%) who described no cost burden.

Where participants described a cost burden associated with their condition, it was most commonly in relation to the cost of treatments, including repeat scripts (n=12, 24.49%). Other cost burdens were in relation to gap payments (public or private) (n=10, 20.41%), specialist appointments (n=9, 18.37%), and the cost of diagnostic tests and scans (n=8, 16.33%). There were 14 participants (28.57%) that described no cost burden and that nearly everything was paid for through the health system, 12 participants (24.49%) described that there was no cost burden, even if costs exist, and 7 participants (14.29%) that described no cost burden and that nearly everything was paid for through private health insurance.

Participant describes that there was some cost burden

I've thought at times. Wow. This is expensive, Like, some of the out-of-pocket expenses. Yeah. Um, and, ah, you. Yeah. I thought, wow, that's really, really expensive. And I've had other people saying to me, they're having cystoscopy, they've gotten out of pocket and, and there's lots of things and, but I've had several operations of like more than seven and a half

hours. Robotic surgeries and complicated things like that, which I've been I've paid out 5000 out of pocket for anesthetist yeah. For one operation and stuff like that for a really high profile anesthetist that did an awake intubation on me, you know what sort of stuff. So, um, it's been expensive and I've just though I could have bought a Harley [Laughs], you know, the cost of these couple of operations. I could have done this or that with the money rather having surgery. Damn.
Participant 001_2022AUBLC

PARTICIPANT It's mainly the, the testing at the beginning. All the different tests that you have to have. Um, I, the only ongoing fees I have with my urologist is when I see her in the, in her rooms because when I, when she does a cystoscopy now, she doesn't charge me any anything. I just, she just charges the, you know, the, the going rate, whatever. You know, the thing with the Medicare rebate, right. But it's the it is the other, you know, like the, you know, the the even the oncologist, you know, it's. Every, every hour, every month or so, there's another slug of another $160 here. And it, especially when you're on a fixed income, because, as I said, we're both retired now.
Participant 004_2022AUBLC

Well, the costs were very high, but, but I had private health insurance that covered some of it. But, you know, I've been saving money up for when I was, when, because you get sicker as you get older. So and I was able to meet the costs, but it wasn't easy.
Participant 008_2022AUBLC

I was lucky that my urologist because I'm just having a quick day surgery procedure. They said to me that I wouldn't be out of pocket for. I mean, I've had 23 cystoscopies now and several of them I've had to stay overnight for initially because of complications and apart from that, there's been medications. I have to pay for the BCG, pay for the, which is not exorbitant. That's medication, that medication. Then there's the anti-spasmodics an,d and the scans I had had to have as well although the some scans can be bulk billed like the CT scans checking metastases. So yeah, yeah. That sort of brings me to the present time. So I haven't I mean, I did have one, a, one of the anesthetists tried to charge me more than the, my health fund rebate and I queried that and they, he, he waved it on and as my specialist said to me, you know, of course there'll be out of pocket expense when you have a big operation and I can totally understand that. But he was um. Yeah. So it's bad enough that you got cancer, let alone having to pay so much every time since.
Participant 010_2022AUBLC

It's been a kerching, kerching, kerching along the whole way. I'm really, really surprised how expensive it's been already. I'm probably, you know, what, am I two months into this? And I'm probably at least 1500 dollars out of pocket already despite having the best medical coverage. The private sector are happy to gouge at all costs. Having said that, I've been challenging on the costs and they've been waving some of their gaps and things like that, which is good. But I've really had to kind of apply quite a bit of pressure to do that. But even my GP, nothing against my GP said he's brilliant. But because I have extended appointments I'm at least $50 out of pocket, every time I go see my GP and for a while there a couple of appointments a week, you know, for several weeks and you know, every one of those $50.
Participant 017_2022AUBLC

Participant describes that there was no cost burden

Look, I have I'm retired, so it doesn't affect work. I've got well, we've, we've got a reasonable pension so we can afford I think the BCG was costing me about $130 every what is it, six months. So you know that I there was no real cost imposition. There was a few times when I'm, I've got I have got private health insurance, too. You know, look, there were costs and but they were not anything to break the bank or even trouble me greatly. So I look, I realise I'm pretty privileged like that. I know some people must really struggle but I, you know it's, it hasn't been a huge burden.
Participant 006_2022AUBLC

I'm retired, so I'm 74 years of age. So it's not that that wasn't an issue at the time it wasn't an issue. Uh, problem being in some of them, you know, and then I've got, I have a half hour drive to go to a hospital and you can't get a car park or an hour's drive to go to the same doctor where I can get a car back enough. Yeah, yeah. There's a lot that are at the make, but apart from that. Yeah. No problems at all, realistically.
Participant 011_2022AUBLC

PARTICIPANT: Nothing. Nothing. I've got really good health insurance and there was barely any out of pocket along the way. It was really good. Yeah.

INTERVIEWER: Costs in terms of time of work for you or.

PARTICIPANT: It was 12 weeks, but I've got buckets of sick leave, you know, 700 hours or something. So that wasn't a problem at all
Participant 018_2022AUBLC

PARTICIPANT: So, um. Very lucky, really. Private health insurance. Mhm. Um, it afforded me the robotic surgery over open surgery. And my urologist didn't charge well that urologist that was doing the robotic surgery. He didn't charge me any out of pocket when he could have. The other surgeon did. And, um, it was, you know, because I had the private health insurance, I paid my excess for the year, um, the things that cost me still were the MRI's PET scans.
But, but most of the things that was covered. So I'm so lucky in that respect. My GP was bulk billing me all throughout. I happened to speak to a work colleague who had gone through bowel cancer the year before and he got me onto salary continuance. So I got onto that straight away and I had a three month wait period, but that was the three wait month period was basically all of the lead up to the operation. So I was able to get 75% of my wage after my operation.

INTERVIEWER: Okay, excellent. I was going to say, what is salary continuance?

PARTICIPANT: The continuance, it is an insurance is part of my superannuation. I didn't even, didn't even know I had it.
Participant 022_2022AUBLC

Well, I don't have any words for the cost. It's I have $0 costs. I just have to thank my country that they have this wonderful Medicare system that from beginning to end, everything is free
Participant 028_2022AUBLC

Well, I've been in the public system. I've never, never provided my credit card to anybody at any stage. So it's been absolutely zero. I've been reimbursed by the trial for any parking at the hospital. In terms of personal life. You know, I obviously spent a lot of hours, um, uh, doing tests and backwards and forwards to the hospital. I haven't, but I haven't regretted that in any, any way. Um, family life that hasn't been impacted. I'm retired, so there's no, there's no impact there.
Participant 029_2022AUBLC

Nothing. Hmm. I paid nothing. Hmm. And Department of Veterans Affairs cover for all servicemen. I guess they cover all costs for cancers and mental health issues. So if you've been in the Army, Navy or Airforce. So they will pay for it. So I was covered. I lost no money. I lost nothing. I had retired. Everything was great.
Participant 038_2022AUBLC

Table 8.24: Cost considerations

Cost considerations	All participants		Early		Invasive		Advanced		Person with bladder cancer		Carer		Female		Male	
	n=49	%	n=20	%	n=10	%	n=14	%	n=44	%	n=5	%	n=17	%	n=32	%
Participant describes that there was some cost burden	25	51.02	**14**	**70.00**	**3**	**30.00**	**5**	**35.71**	22	50.00	3	60.00	10	58.82	15	46.88
Participant describes that there was no cost burden	22	44.90	**6**	**30.00**	**6**	**60.00**	**8**	**57.14**	20	45.45	2	40.00	7	41.18	15	46.88
Other/No response	2	4.08	0	0.00	1	10.00	1	7.14	2	4.55	0	0.00	0	0.00	2	6.25

Cost considerations	All participants		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=49	%	n=29	%	n=19	%	n=15	%	n=33	%	n=20	%	n=28	%
Participant describes that there was some cost burden	25	51.02	16	55.17	9	47.37	9	60.00	16	48.48	**13**	**65.00**	12	42.86
Participant describes that there was no cost burden	22	44.90	11	37.93	10	52.63	**4**	**26.67**	17	51.52	**5**	**25.00**	**16**	**57.14**
Other/No response	2	4.08	2	6.90	0	0.00	2	13.33	0	0.00	2	10.00	0	0.00

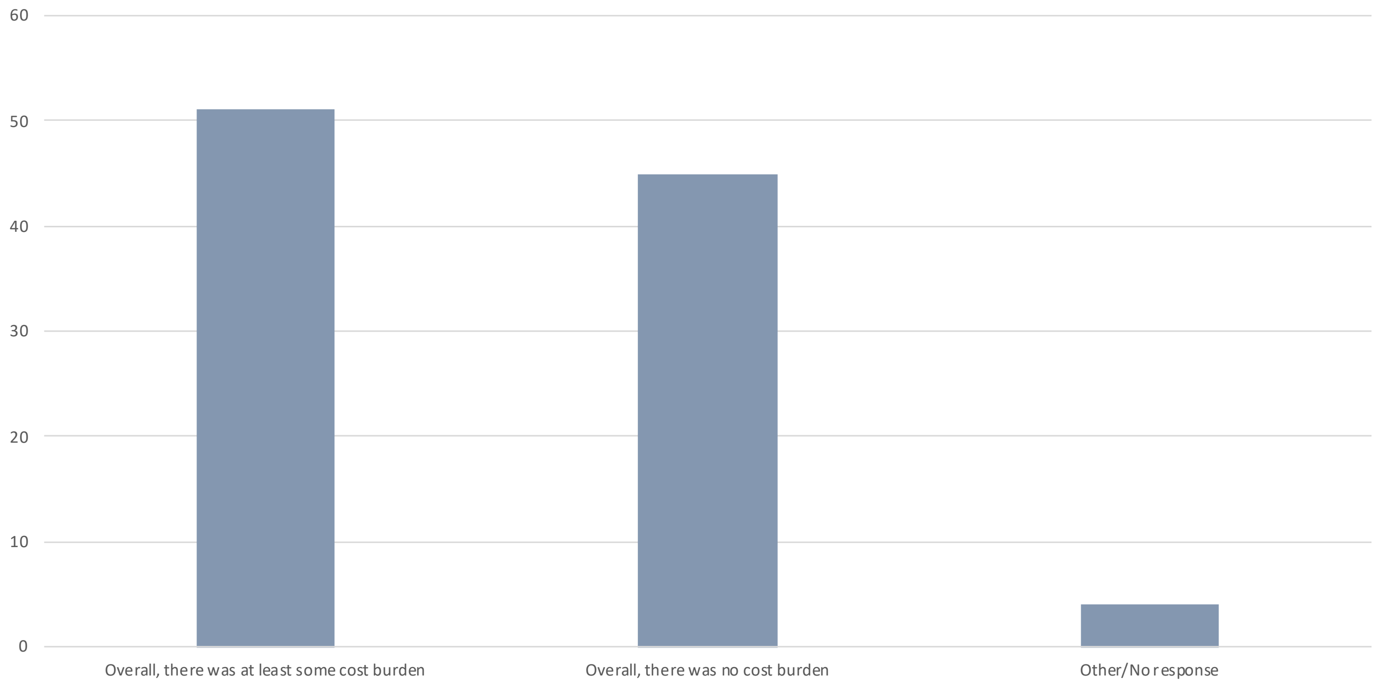


Figure 8.12: Cost considerations

Table 8.25: Cost considerations – subgroup variations

Cost considerations	Reported less frequently	Reported more frequently
Participant describes that there was some cost burden	Invasive (Stage III) Advanced (Stage IV)	Early (Stages 0 and I) Mid to low status
Participant describes that there was no cost burden	Early (Stages 0 and I) Regional or remote Mid to low status	Invasive (Stage III) Advanced (Stage IV) Higher status

Table 8.26: Cost considerations (Reasons for cost)

Cost considerations (Reasons for cost)	All participants		Early		Invasive		Advanced		Person with bladder cancer		Carer		Female		Male	
	n=49	%	n=20	%	n=10	%	n=14	%	n=44	%	n=5	%	n=17	%	n=32	%
Participant describes no cost burden and that nearly everything was paid for through the health system	14	28.57	**3**	**15.00**	**5**	**50.00**	4	28.57	12	27.27	**2**	**40.00**	**2**	**11.76**	12	37.50
Participant describes a cost burden in relation to the cost of treatments (including repeat scripts)	12	24.49	**7**	**35.00**	2	20.00	**2**	**14.29**	11	25.00	1	20.00	4	23.53	8	25.00
Participant describes that there was no cost burden, even if costs exist	12	24.49	4	20.00	3	30.00	**5**	**35.71**	12	27.27	**0**	**0.00**	**6**	**35.29**	6	18.75
Participant describes a cost burden in relation to gap payments (public or private)	10	20.41	5	25.00	2	20.00	**1**	**7.14**	8	18.18	**2**	**40.00**	3	17.65	7	21.88
Participant describes a cost burden in relation to the cost specialist appointments	9	18.37	**6**	**30.00**	1	10.00	**1**	**7.14**	8	18.18	1	20.00	4	23.53	5	15.63
Participant describes a cost burden in relation to diagnostic tests and scans	8	16.33	**6**	**30.00**	**0**	**0.00**	**0**	**0.00**	6	13.64	**2**	**40.00**	**6**	**35.29**	**2**	**6.25**
Participant describes that there was no cost burden, as nearly everything was paid for through private insurance	7	14.29	1	5.00	2	20.00	3	21.43	6	13.64	1	20.00	**5**	**29.41**	2	6.25
Participant describes a cost burden in relation to the cost of parking and travel to attend appointments (including accommodation)	4	8.16	2	10.00	0	0.00	1	7.14	3	6.82	1	20.00	1	5.88	3	9.38
Participant describes a cost burden in relation to needing to take time off work	3	6.12	1	5.00	0	0.00	2	14.29	3	6.82	0	0.00	1	5.88	2	6.25

Cost considerations (Reasons for cost)	All participants		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=49	%	n=29	%	n=19	%	n=15	%	n=33	%	n=20	%	n=28	%
Participant describes no cost burden and that nearly everything was paid for through the health system	14	28.57	9	31.03	4	21.05	**2**	**13.33**	11	33.33	5	25.00	8	28.57
Participant describes a cost burden in relation to the cost of treatments (including repeat scripts)	12	24.49	8	27.59	4	21.05	4	26.67	8	24.24	4	20.00	8	28.57
Participant describes that there was no cost burden, even if costs exist	12	24.49	7	24.14	5	26.32	**6**	**40.00**	6	18.18	4	20.00	8	28.57
Participant describes a cost burden in relation to gap payments (public or private)	10	20.41	6	20.69	4	21.05	**5**	**33.33**	5	15.15	5	25.00	5	17.86
Participant describes a cost burden in relation to the cost specialist appointments	9	18.37	7	24.14	2	10.53	**1**	**6.67**	8	24.24	4	20.00	5	17.86
Participant describes a cost burden in relation to diagnostic tests and scans	8	16.33	6	20.69	2	10.53	3	20.00	5	15.15	5	25.00	3	10.71
Participant describes that there was no cost burden, as nearly everything was paid for through private insurance	7	14.29	2	6.90	**5**	**26.32**	1	6.67	6	18.18	**0**	**0.00**	**7**	**25.00**
Participant describes a cost burden in relation to the cost of parking and travel to attend appointments (including accommodation)	4	8.16	3	10.34	1	5.26	2	13.33	2	6.06	2	10.00	2	7.14
Participant describes a cost burden in relation to needing to take time off work	3	6.12	2	6.90	1	5.26	0	0.00	3	9.09	1	5.00	2	7.14

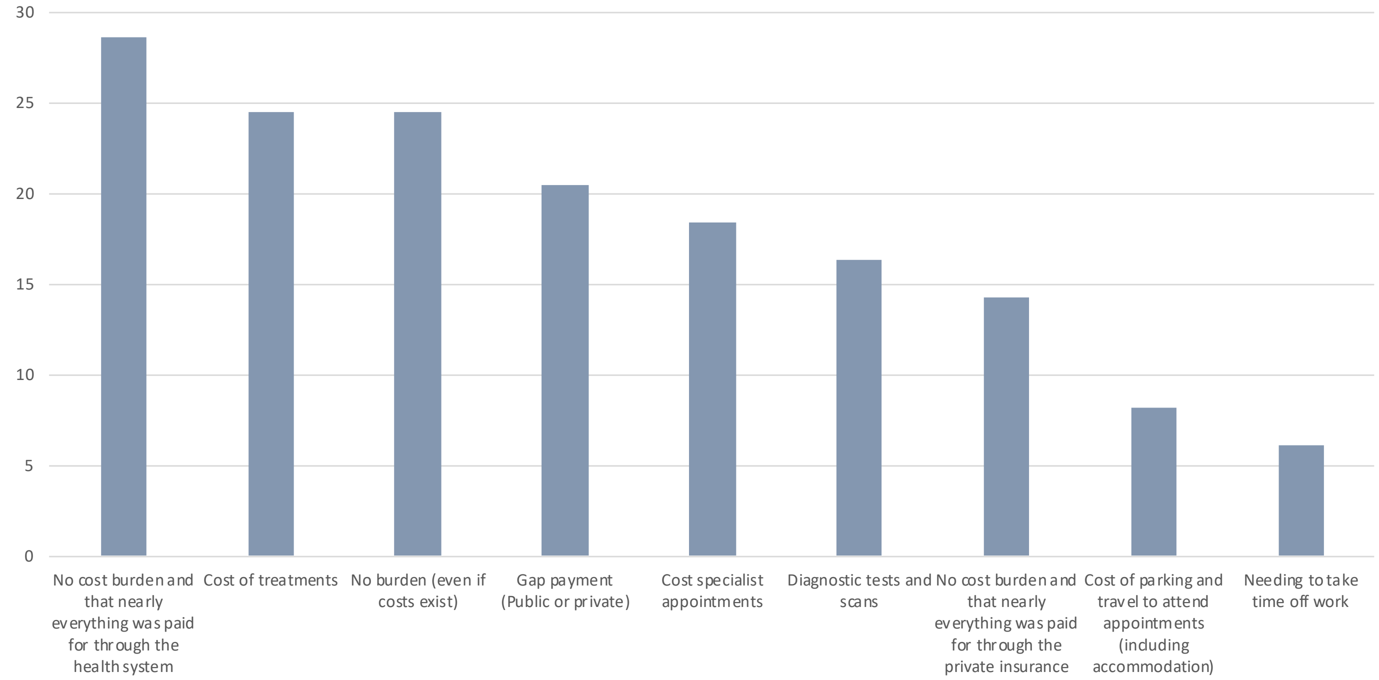


Figure 8.13: Cost considerations (Reasons for cost)

Table 8.27: Cost considerations (Reasons for cost)– subgroup variations

Cost considerations (Reasons for cost)	Reported less frequently	Reported more frequently
Participant describes no cost burden and that nearly everything was paid for through the health system	Early (Stages 0 and I) Female Regional or remote	Invasive (Stage III) Carer to someone with bladder cancer
Participant describes a cost burden in relation to the cost of treatments (including repeat scripts)	Advanced (Stage IV)	Early (Stages 0 and I)
Participant describes that there was no cost burden, even if costs exist	Carer to someone with bladder cancer	Advanced (Stage IV) Female Regional or remote
Participant describes a cost burden in relation to gap payments (public or private)	Advanced (Stage IV)	Carer to someone with bladder cancer Regional or remote
Participant describes a cost burden in relation to the cost specialist appointments	Advanced (Stage IV) Regional or remote	Early (Stages 0 and I)
Participant describes a cost burden in relation to diagnostic tests and scans	Invasive (Stage III) Advanced (Stage IV) Male	Early (Stages 0 and I) Carer to someone with bladder cancer Female
Participant describes that there was no cost burden, as nearly everything was paid for through private insurance	Mid to low status	Female University Higher status

Experience of anxiety related to disease progression

Fear of progression

The Fear of Progression questionnaire measures the level of anxiety people experience in relation to their conditions. The Fear of Progression questionnaire comprises a total score, between 12 and 60, with a higher score denoting increased anxiety. Summary statistics for the entire cohort are displayed in Table 8.10. The overall scores for the cohort were in the highest quintile for Fear of progression: Total score (mean=32.87, SD=8.66), indicating moderate levels of anxiety (Table 8.28).

The **Fear of Progression** questionnaire measures the level of anxiety people experience in relation to their conditions. On average fear of progression score for participants in this study indicated moderate levels of anxiety.

Table 8.28: Fear of progression summary statistics

Fear of progression (n=47)	Mean	SD	Median	IQR	Possible range	Quintile
Total score*	32.87	8.66	31.00	11.50	12 to 60	3

*Normal distribution use mean and SD as measure of central tendency

Fear of progression by bladder cancer stage

Comparisons were made by Stage. There were 18 participants (42.86%) with early bladder cancer (Stages 0 and I), 10 participants (23.81%) with invasive bladder cancer (Stage III), and 14 participants (33.33%) with advanced bladder cancer (Stage IV).

A one-way ANOVA test was used when the assumptions for response variable residuals were normally distributed and variances of populations were equal (Table 8.29).

No significant differences were observed between participants by **bladder cancer stage** for any of the Fear of progression scales.

Table 8.29: Fear of progression total score by bladder cancer stage summary statistics and one-way ANOVA

Fear of progression	Group	Number (n=42)	Percent	Mean	SD	Source of difference	Sum of squares	dF	Mean Square	f	p-value
Total score	Early	18	42.86	33.83	8.69	Between groups	164.30	2	82.13	1.30	0.2850
	Invasive	10	23.81	30.30	8.90	Within groups	2472.00	39	63.39		
	Advanced	14	33.33	29.57	6.06	Total	2636.30	41	145.52		

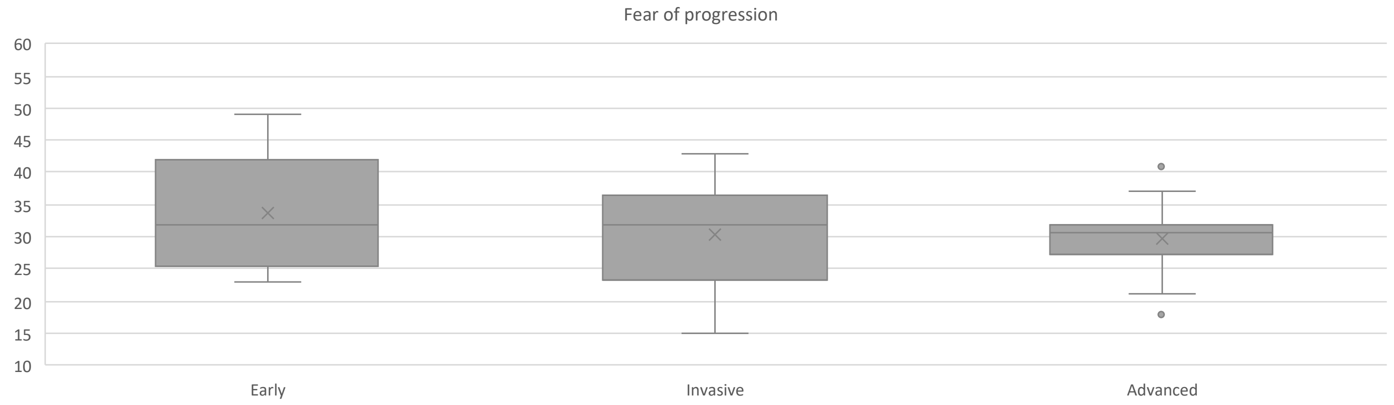


Figure 8.14: Boxplot of Fear of progression total score by bladder cancer stage

Fear of progression by participant type

Comparisons were made by type of participant, there were 42 participants (89.36%) with bladder cancer and, 5 participants (10.64%) that were a carer to someone with bladder cancer.

Assumptions for normality and variance were met, a two-sample t-test was used (Table 8.30).

A two sample t-test indicated that the mean score for the Fear of progression Total score scale [t(45) = -3.29 , p = 0.0020] was significantly lower for participants in the Mid to low status subgroup (Mean = 31.57, SD = 8.02) compared to participants in the Higher status subgroup (Mean = 43.80, SD = 6.06.)

The **Fear of Progression** questionnaire measures the level of anxiety people experience in relation to their conditions. On average, participants in the carer subgroup scored higher than participants in the patient subgroup. This indicates that participants in the carer subgroup had high levels of anxiety, and participants in the patient subgroup had moderate levels of anxiety.

Table 7.30: Fear of progression total score by participant type summary statistics and T-test

Fear of progression	Group	Number (n=47)	Percent	Mean	SD	T	dF	p-value
Total score	Patient	42	89.36	31.57	8.02	-3.29	45	0.0020*
	Carer	5	10.64	43.80	6.06			

*Statistically significant at p<0.05

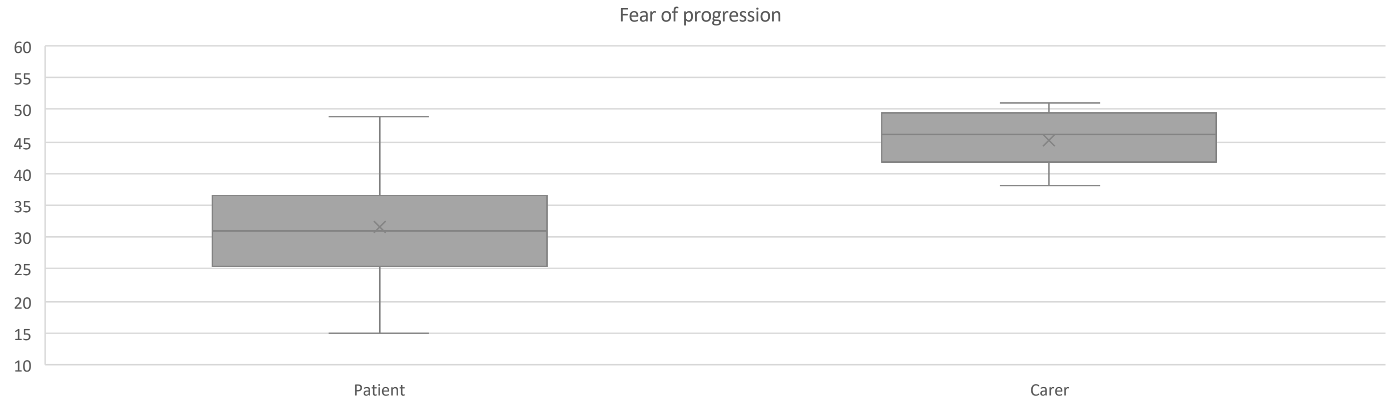


Figure 8.15: Boxplot of Fear of progression total score by participant type

Fear of progression by gender

Comparisons were made by gender, there were 16 female participants (34.04%), and 31 male participants (65.96%).

Assumptions for normality and variance were met, a two-sample t-test was used (Table 8.31).

No significant differences were observed between participants by **gender** for any of the Fear of progression scales.

Table 7.31: Fear of progression total score by gender summary statistics and T-test

Fear of progression	Group	Number (n=47)	Percent	Mean	SD	T	dF	p-value
Total score	Female	16	34.04	31.56	8.33	-0.74	45	0.4625
	Male	31	65.96	33.55	8.89			

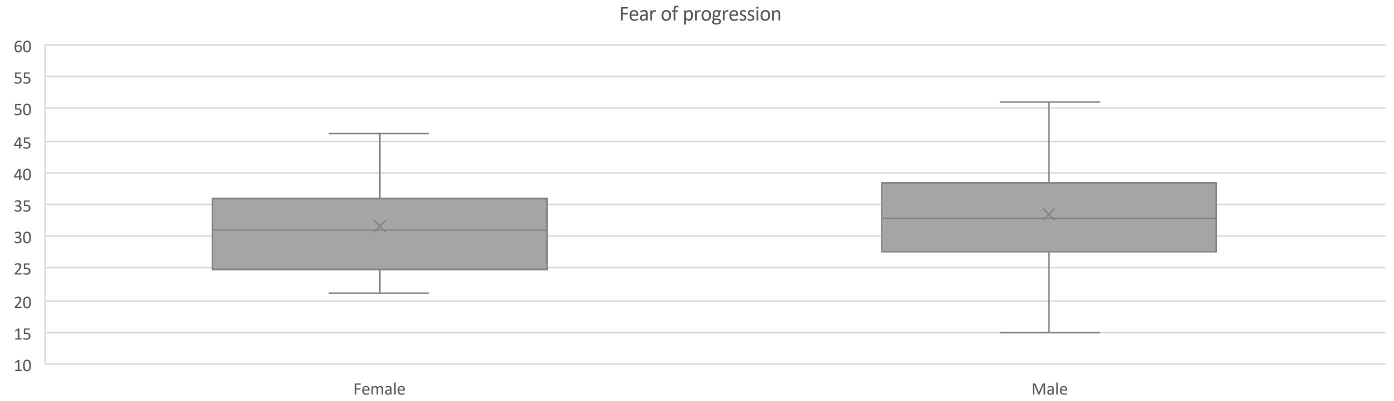


Figure 8.16: Boxplot of Fear of progression total score by gender

Fear of progression by education

Comparisons were made by education status, between those with trade or high school qualifications (n=29, 61.70%), and those with a university qualification (n=18, 38.30%).

Assumptions for normality and variance were met, a two-sample t-test was used (Table 8.32).

No significant differences were observed between participants by **education** for any of the Fear of progression scales.

Table 7.32: Fear of progression total score by education summary statistics and T-test

Fear of progression	Group	Number (n=47)	Percent	Mean	SD	T	dF	p-value
Total score	Trade or high school	29	61.70	33.52	8.91	0.64	45	0.5230
	University	18	38.30	31.83	8.39			

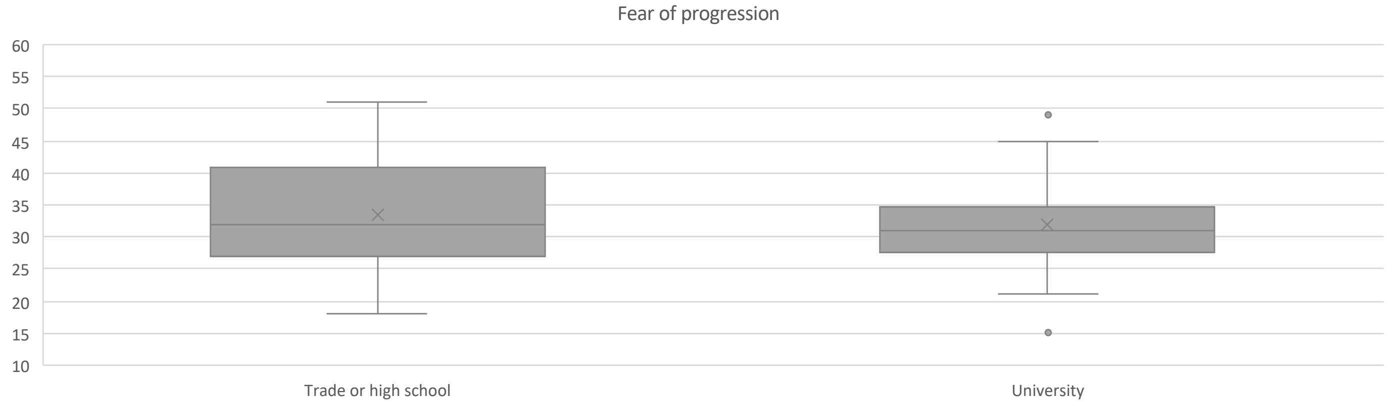


Figure 8.17: Boxplot of Fear of progression total score by education

Fear of progression by location

The location of participants was evaluated by postcode using the Australian Statistical Geography Maps (ASGS) Remoteness areas accessed from the Australian Bureau of Statistics. Those living in regional or remote area (n=15, 31.91%) were compared to those living in a metropolitan area (n=32, 68.09%).

Assumptions for normality and variance were met, a two-sample t-test was used (Table 8.33).

No significant differences were observed between participants by **location** for any of the Fear of progression scales.

Table 7.33: Fear of progression total score by location summary statistics and T-test

Fear of progression	Group	Number (n=47)	Percent	Mean	SD	T	dF	p-value
Total score	Regional or remote	15	31.91	35.80	8.74	1.61	45	0.1135
	Metropolitan	32	68.09	31.50	8.41			

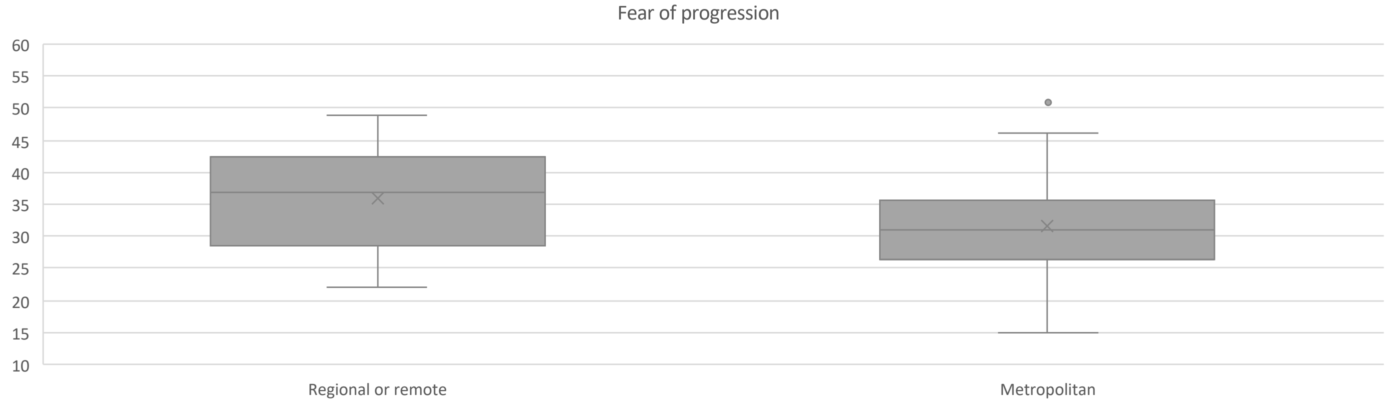


Figure 8.18: Boxplot of Fear of progression total score by location

Fear of progression by socioeconomic status

Comparisons were made by socioeconomic status, using the Socio-economic Indexes for Areas (SEIFA) (www.abs.gov.au), SEIFA scores range from 1 to 10, a higher score denotes a higher level of advantage. Participants with a mid to low SEIFA score of 1-6 (n=20, 42.55%) compared to those with a higher SEIFA score of 7-10 (n=27, 57.45%).

Assumptions for normality and variance were met, a two-sample t-test was used (Table 8.34).

No significant differences were observed between participants by **socioeconomic status** for any of the Fear of progression scales.

Table 7.34: Fear of progression total score by socioeconomic status summary statistics and T-test

Fear of progression	Group	Number (n=47)	Percent	Mean	SD	T	dF	p-value
Total score	Mid to low status	20	42.55	34.05	8.80	0.80	45	0.4285
	Higher status	27	57.45	32.00	8.62			

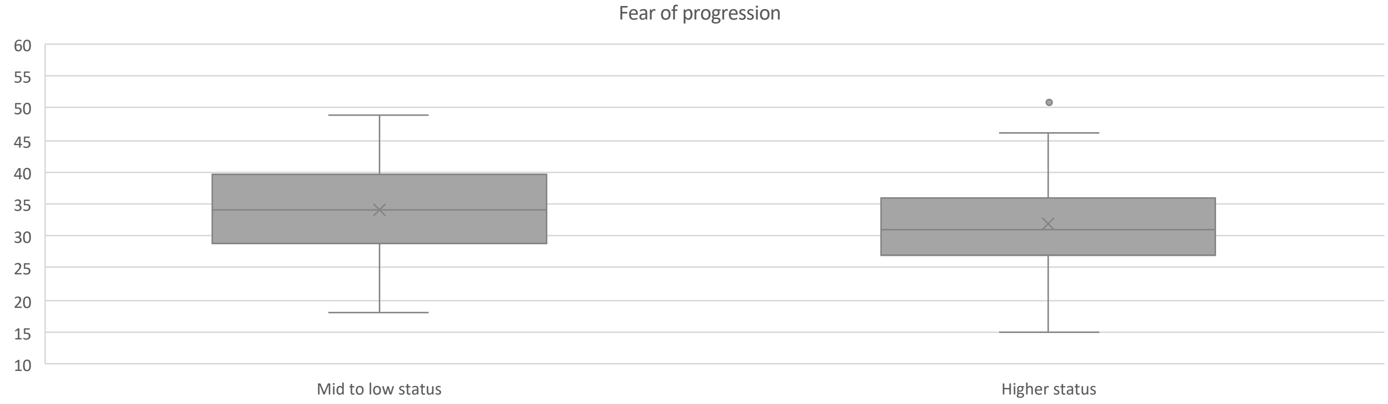


Figure 8.19: Boxplot of Fear of progression total score by socioeconomic status

Anxiety about treatment

An overview of responses to individual fear of progression questions is given in Table 8.35.

Fear of progression individual questions

On average, participants scored in the “Seldom” range for the following questions: “Has concerns about reaching professional and/or personal goals because of illness:” (median=2.00, IQR=2.00), “When anxious, has physical symptoms such as a rapid heartbeat, stomach ache or agitation” (median=2.00, IQR=1.00), “The possibility of relatives being diagnosed with this disease disturbs participant” (median=2.00, IQR=2.00), “Is disturbed that they may have to rely on strangers for activities of daily living” (median=2.00, IQR=2.00), “The thought that they might not be able to work due to illness disturbs participant” (median=2.00, IQR=2.00).

On average, participants scored in the “Sometimes” range for the following questions: “Becomes anxious thinking that disease may progress” (median=3.00, IQR=1.00), “Afraid of pain” (median=3.00, IQR=1.50), “Worried that at some point in time will no longer be able to pursue hobbies because of illness” (median=3.00, IQR=1.50), “Afraid of severe medical treatments during the course of illness” (median=3.00, IQR=1.50), “Worried that treatment could damage their body” (median=3.00, IQR=2.00), “Worried about what will become of family if something should happen to participant” (median=3.00, IQR=2.00).

On average, participants scored in the “Often” range for the following questions: “Is nervous prior to doctors appointments or periodic examinations” (median=4.00, IQR=1.50).

Table 8.35: Fear of progression individual questions

Fear of progression (n=47)	Median	IQR	Average response
Becomes anxious thinking that disease may progress	3.00	1.00	Sometimes
Is nervous prior to doctors appointments or periodic examinations	4.00	1.50	Often
Afraid of pain	3.00	1.50	Sometimes
Has concerns about reaching professional and/or personal goals because of illness:	2.00	2.00	Seldom
When anxious, has physical symptoms such as a rapid heartbeat, stomach ache or agitation	2.00	1.00	Seldom
The possibility of relatives being diagnosed with this disease disturbs participant	2.00	2.00	Seldom
Is disturbed that they may have to rely on strangers for activities of daily living	2.00	2.00	Seldom
Worried that at some point in time will no longer be able to pursue hobbies because of illness	3.00	1.50	Sometimes
Afraid of severe medical treatments during the course of illness	3.00	1.50	Sometimes
Worried that treatment could damage their body	3.00	2.00	Sometimes
Worried about what will become of family if something should happen to participant	3.00	2.00	Sometimes
The thought that they might not be able to work due to illness disturbs participant	2.00	2.00	Seldom

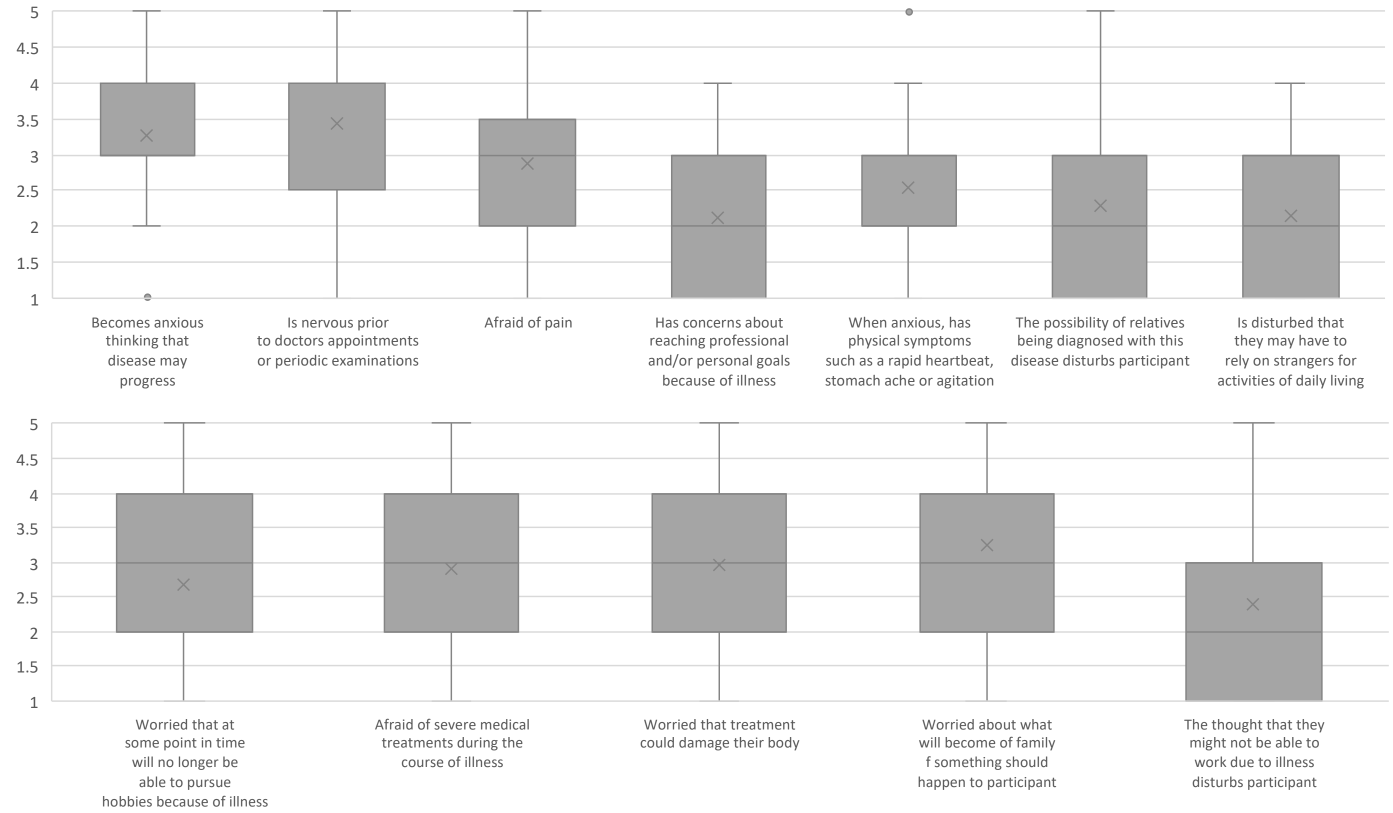


Figure 8.20: Fear of progression individual questions

Section 9

Expectations and messages to decision-makers

Section 9: Expectations of future treatment, care and support, information and communication

Expectations of future treatment

Participants were asked in the structured interview what their expectations of future treatments are. The most common theme was that future treatments will be accompanied by more information about available treatments and treatment pathways (n=13,26.53%), and this was followed by future treatment will be more accessible particularly equitable, timely and includes access in rural locations (n=12,24.49%).

Other participants would like future treatments to have less cost burden (n=10, 20.41%), to have more options, and/or will be targeted (n=9, 18.37%), to have fewer or less intense side effects (n=7, 14.29%), to be more effective (n=5, 10.20%), to prevent loss of bladder or will improve bladder replacements (n=5, 10.20%), to be administered in a less invasive and more dignified way (n=5, 10.20%), and to include emotional and mental support (n=5, 10.20%)

Expectations of future information

Participants were asked in the structured interview if there was anything that they would like to see changed in the way information is presented or topics that they felt needed more information. The most common theme was that participants have no recommendations or they are satisfied with the information currently available (n=13, 26.53%). There were 9 participants (18.37%) that described that future information should be more accessible/easy to find, and 9 participants (18.37%) that described that future information should include all treatment options available to them.

Other participants described that future information will provide more details about mental health and emotional support (n=6, 12.24%), will help to inform the community and decision-makers about their condition (raise awareness) (n=6, 12.24%), will describe what to expect, especially with respect to side effects and treatment outcomes (n=6, 12.24%), will provide more details about where to find available services (n=5, 10.20%), and will be more targeted to specific types or stages (n=5, 10.20%).

Expectations of future healthcare professional communication

Participants were asked in the structured interview what they would like to see in relation to the way that healthcare professionals communicate with patients. The most common theme was that participants expected future information will be more transparent and information more forthcoming (n=14, 28.57%). Other themes about expectations of future communication included that future communication will be more empathetic (n=11, 22.45%), will allow people more time to meet with their clinician to talk about all that they need to talk about (n=9, 18.37%), will include better communication between healthcare professionals, and better coordination of appointments (n=7, 14.29%), and will include discussions about mental and emotional health (n=6, 12.24%).

There were 7 participants (14.29%) that had no recommendations or that they experienced good communication.

Expectations of future care and support

Participants were asked in the structured interview whether there was any additional care and support that they thought would be useful in the future, including support from local charities. The most common theme was that participants had no recommendations or were satisfied with care received (n=15, 30.61%), and this was followed by 13 participants (26.53%) that described the expectation that future care and support will include more access to support services. Other expectations include, future care and support will include being able to connect with other patients through peer support (support groups, online forums) (n=9, 18.37%), will include more information and awareness of the condition (n=8, 16.33%), and will include mental health or emotional support (n=7, 14.29%).

What participants are grateful for in the health system

Participants were asked in the structured interview what aspects of the health system that participants are grateful for. The most common theme was that participants were grateful for healthcare staff (n=22, 44.90%), and this was followed by 14 participants (28.57%) that described that participants were grateful for low cost or free medical treatments through the government, and 13 participants (26.53%) were grateful for timely access to treatment. Other participants were grateful for access to private healthcare or private insurance (n=10, 20.41%), and grateful for the entire health system (n=7, 14.29%).

Symptoms and aspects of quality of life

Participants were asked to rank which symptoms/aspects of quality of life would they want controlled in a treatment for them to consider taking it, where 1 is the most important and 11 is the least important. The most important aspects reported were pain, nausea and vomiting and, diarrhoea. The least important were hair loss and, mouth ulcers.

Values in making decisions

Participants were asked to rank what is important for them overall when they make decisions about treatment and care, where 1 is the most important and 8 is the least important. The most important aspects were “"How safe the medication is and weighing up the risks and benefits"”, and “"The severity of the side effects"”. The least important were “"Ability to follow and stick to a treatment regime"” and “"The financial costs to me and my family"”.

Values for decision makers

Participants were asked to rank what is important for decision-makers to consider when they make decisions that impact treatment and care, where 1 is the most important and 5 is the least important. The most important values were “Quality of life for patients”, and “All patients being able to access all available treatments and services”. The least important was “Economic value to government and tax payers”.

Time taking medication to improve quality of life

Participants were asked in the online questionnaire, how many months or years would you consider taking a treatment, provided it gave you a good quality of life, even if it didn’t offer a cure.

The most commonly participants would use a treatment for more than 10 years for a good quality of life even if it didn’t offer a cure (n = 17, 36.17%), followed by less than a year (n=14, 29.79%), and between 1 and 5 years (n=12, 25.53%).

Messages to decision-makers

Participants were asked, “If you were standing in front of the health minister, what would your message be in relation to your condition?” The most common message was to help raise community awareness (n=16, 32.65%). This was followed by that they are grateful for the healthcare system and the treatment that they received (n=11, 22.45%), to invest in screening or early detection (n=7, 14.29%), to improve access to support and care (n=7, 14.29%), and to be compassionate and empathetic (n=6, 12.24%).

Expectations of future treatment

Participants were asked in the structured interview what their expectations of future treatments are. The most common theme was that future treatments will be accompanied by more information about available treatments and treatment pathways (n=13,26.53%), and this was followed by future treatment will be more accessible particularly equitable, timely and includes access in rural locations (n=12,24.49%).

Other participants would like future treatments to have less cost burden (n=10, 20.41%), to have more options, and/or will be targeted (n=9, 18.37%), to have fewer or less intense side effects (n=7, 14.29%), to be more effective (n=5, 10.20%), to prevent loss of bladder or will improve bladder replacements (n=5, 10.20%), to be administered in a less invasive and more dignified way (n=5, 10.20%), and to include emotional and mental support (n=5, 10.20%)

Participant describes the expectation that future treatment will be accompanied by more information about available treatments and treatment pathways

And goodness me, it would be nice to see more actually more research into bladder transplants for those people that haven't got them any more. It would be nice if there was a less confusing amount of information about immuno therapy and about trials, because looking for trials is is very complicated. So some an easier access to that. I still see an oncologist. I'm sure that they would be very helpful, but without actually going and taking their time up just for questions, it would be good to have something that I could get clear, information that I could trust. To find potential trials, look at new research coming out.
Participant 020_2022AUBLC

Well, I guess in an ideal world, you'd like someone to sit down and spend a lot of time going through what was available, what the risks were, and minimal costs and just really, really time spent making you fully aware of every choice you could have and what it would mean. I think I think that we I as I said to you earlier, if I this happened to me second time around, I would be almost demanding that I think of the cost, obviously, I can't demand that the information and the ability to discuss choices and to get information about choices would be would be really an advantage.
Participant 036_2022AUBLC

PARTICIPANT: From any new treatments, I'd like to see clearer communication as to the benefits and the potential side effects then. Yeah, I think that's number one. Number one. Okay.

INTERVIEWER: Is there anything else you'd like to add on?

PARTICIPANT: Well, hopefully the you know, the costs would be, you know, lower. You know, I'm really I'm realistic that that that's not going to happen.
Participant 008_2022AUBLC

Participant describes the expectation that future treatments will be more accessible particularly equitable, timely and includes access in rural locations

Honestly, that everything flowed pretty well from me um. And I know from a lot of people it's more the time frame, you know. People Want it fixed tomorrow, but it's just that they've got to deal with the system that's, you know, they're not the number one priority. But they are. But, you know, I guess from my point of view I just, you know, if there is a 40 year old with the same problem, to me, he would have a priority over me. You know, someone with a younger family or whatever. Like I said, I've a lot of got very, very good response and and yeah. Not no problems at all with anyone, you know. Hmm. I can't think of a thing that I would actually change. You know, the people were very, very good. You know.
Participant 011_2022AUBLC

Oh. With the BCG? Mm hmm. I think it should be available when, you know, when you're ready to when you need it. Because, you know, when I first was eligible for I think I had to wait six months, and it was probably COVID things, but. And then when I did get it, the treatment was interrupted by that month because I got three weeks into it and then I couldn't get any more. Stop for a month and then go back on it.
Participant 016_2022AUBLC

I suppose for me it's probably the way they're rolled out because if we talk bladder cancer, I'm at the pointy end where I've had everything removed it's but there's a lot of new treatments that should be available for somebody that's just been diagnosed that might be able to or should be able to have access to new treatments that way. Um, I think how bladder cancer patients have access to new treatments that, that sort of publicised. Um, yeah, I don't know how it could be publicised more widely through the medical profession. Yeah. But so that the patients that are

kept in the loop as we've actually got something that that is going to help with this particular type of bladder cancer.
Participant 035_2022AUBLC

Um, well, there was a shortage with the BCG and, you know, like, um, I found it really disappointing that, um, a lot of the people only get half treatment, half doses of, you know, half doses of the BCG. And I think, um, you know, disappointing that they, they told me that, and you wonder that if you actually got the full doses would it have worked? And I might not have had to have the radical cystectomy. I feel a little bit let down by, I don't know if its the medical and I know that there is a worldwide shortage is the BCG but um. Yeah let down by the medical pharmacies or whoever produces it that okay you know, why isn't there a supply of the BCG for bladder cancer patients. It just feels like that's a bit disheartening. Yeah. And I mean, it just feels like, you know, the didn't seem to be, um, they highlighted, you know, with a, with it, you know, like with it was a shortage of, of the BCG, which is, you know, like the help, you know, let people save lives really.
Participant 044_2022AUBLC

Participant describes the expectation that future treatment will have less cost burden

PARTICIPANT: Um. For me the costs, well, in an ideal world, I think that, we'd have no gap cover. For surgeons fees for cancer or some form of taxation benefits for people that are paying out large out-of-pocket amounts of money for medical treatment.

INTERVIEWER: Yeah. It's going to be extremely hard.

PARTICIPANT: Some sort of tax breaks that people do. I know they used to have. So the out-of-pocket expenses of Medicare like when that when it weren't covered after a certain amount, you could count on your tax. But that sort of I think it has gone, yes it has gone, my accountant said
Participant 001_2022AUBLC

PARTICIPANT: From any new treatments. I'd like to see clearer communication as to the benefits and the potential side effects then. Yeah, I think that's number one. Number one. Okay.

INTERVIEWER: Is there anything else you'd like to add on?

PARTICIPANT: Well, hopefully the you know, the costs would be, you know, lower. You know, I'm really I'm realistic that that that's not going to happen.
Participant 008_2022AUBLC

Probably just more if there was something that was going to be released, just maybe, probably more the, uh, the cost of things just to make it more easier for people to actually receive. Because I was lucky that most of mine was covered in, um, under my health care as well as Medicare. But I have had sleepless nights worrying about the potential financial impact of what future treatment would look like
Participant 009_2022AUBLC

Participant describes the expectation that future treatment will have more options, and/or will be targeted

Suppose what we'd like to see with regard to bladder cancer is that the bladder doesn't have to be removed because you don't have another one. And so therefore it's fairly alarming that there's been no progress really in terms of treatments to try to cure bladder cancer. I mean, everyone wants to cure every cancer, but this particular cancer can't even be cured by removing the tumour because it's a field cancer and new tumours will pop up. So it has that high recurrence rate. So there's that. And then also of course, because of that and because of the as I'm experiencing the ramifications of six years of treatment and biopsies, I need to have it removed. And there has been very little and I'm quoting in a YouTube PowerPoint I watched last night, I'm quoting an American, a sort of from America that there's been no progress in the last three decades in regard to how to how to create creating a bladder substitute and still using a piece of small bowel must not be many. So I would say some sort of I was thinking this morning, some sort of biomedical engineering kind of advance to to create to be able to install a new device that is not going to be rejected is something that will will be a good bladder substitute that you can connect to your utreters above and your urethra below. And that would help people progress on with a fairly normal life. It's not impacted by catherisation and and, you know, intermittent catheterisation and bags and, you know, loss of dignity and and etc., you know.
Participant 010_2022AUBLC

Well, I would have I would have liked to had some other options. Except for one. Yeah. Other than the one I have got. That's the main thing. But I haven't. I haven't talked to anyone else about that.
Participant 012_2022AUBLC

Oh, I'd like to see the development of them. Something to not be in BCG. I just don't think that. That it's such a chemical, even though it's a bacteria. Which by rights is natural. It's been a, you know, it's a, um, a lab grown bacteria sort of thing. I don't know. And natural it really is. But there's got to be something more stable. Not necessarily natural, but just something that's more targeted to addressing or solving the problem that is bladder cancer or cancer in general. BCG was found that was a tubuculosis vaccine and still is yet its use in bladder cancer like it's really strange and also aan help with, no, not like skin cancers. That's where it was first recognised as skin cancer probably. I think maybe that was it that people who had TB at least weren't susceptible to skin cancer. But there was some very strange correlation made. And its purpose is not to fix bladder cancer. It just so happens that it does so in a perfect world that actually have something it target bladder cancer. With minimal side effects. I mean, that's a perfect world and very difficult to find, but something that was actually fit for purpose, not just an accidental accident.
Participant 030_2022AUBLC

Participant describes the expectation that future treatments will have fewer or less intense side effects

Well, I think immunotherapy. I think we have pembrolizumab, KEYTRUDA, which is the the immunotherapy that we use for bladder cancer. And from the people I know that have been on it, the side effects are much better than, say, chemotherapy. So I would like to see more immunotherapy, more personalised immunotherapy. So I'm really looking at the the individual's tumour and what drug is best going to work for them so that they're not subjected to take drugs that, you know, will have no impact on that type of tumour and therefore they experience side effects for no reason.
Participant 032_2022AUBLC

Oh, I'd like to see the development of them. Something to not be in BCG. I just don't think that. That it's such a chemical, even though it's a bacteria. Which by rights is natural. It's been a, you know, it's a, um, a lab grown bacteria sort of thing. I don't know. And natural it really is. But there's got to be something more stable. Not necessarily natural, but just something that's more targeted to addressing or solving the problem that is bladder cancer or cancer in general. BCG was found that was a tubuculosis vaccine and still is yet its use in bladder cancer like it's really strange and also aan help with, no, not like skin cancers. That's where it was first recognised as skin cancer probably. I think maybe that was it that people who had TB at least weren't susceptible to skin cancer. But there was some very strange correlation made. And its purpose is not to fix bladder cancer. It just so happens that it does so in a perfect world that actually have something it target bladder cancer. With minimal side effects. I mean, that's a perfect world and very difficult to find, but something that was actually fit for purpose, not just an accidental accident.
Participant 030_2022AUBLC

Participant describes the expectation that future treatment will be more effective

I really don't know. Obviously more success in stopping recurrence of it. But, you know, that's I think that's a very hard thing for the doctors or for surgical procedures to control. And that's a lot of to do with just genetics and what's going on inside your body, in your cells. So maybe something.
Participant 024_2022AUBLC

I'd just really like something to work to get to stop the cancer's growing. So yeah, I don't have any issue with the treatments or how they've been administered, but it's just that they obviously haven't worked that well.
Participant 025_2022AUBLC

Um. Yeah, I, I it just seems there seems to be the trial that I did may lead in the future to some sort of new way of treating bladder cancer. But at at the moment, the BCG is I mean, it's been they've been doing it for 40 years or so. You know, like it seems that there hasn't really been any any great outcomes or any great changes in the way in which the the cancer is dealt with. It would be nice to see see some I don't know whether it's lack of research or maybe it's just the fact that BCG is is pretty effective. Um, I don't know.
Participant 029_2022AUBLC

Participant describes the expectation that future treatment will prevent loss of bladder or will improve bladder replacements

So I would like to see see that, you know, it would be great if they could make, you know, and I mean, I don't know how futuristic I'm allowed to be, but, you know, when you lose your bladder and I have the neobladder, which is made out of a piece of my bowel, but, you know, if I could do something where you can have a bladder, that really is the muscle that you had before. So you know that you don't have to learn how to to make it work. It would just work like a normal

bladder. That would be great. And also then, you know, not having to cut your bowel. Um. To make your bladder. They can open that like. Like a lab grown, cloned bladder made out of your cells or something. Um, you know, that would be. That would be wonderful, because then it would be a muscle and it would work in the same way that your, you know, your bladder did. And, you know, when they cut you about it's a major part of the operation and your bowel like being cut and it causes you know, it makes you not well for quite a few days until it all starts working again. And, you know, I'm not complaining. I have to say my surgery, thank goodness, went really, really smoothly. But I was still in hospital for 11 days. So, you know, if they could improve that and it's also a major operation that was, you know, eight and a half hours of surgery. So know it's a long time. So. So. Yeah, but I think, you know, if we could really start analysing tumours and finding treatments that work for the particular tumour, you had that personalised to you. That would be great. And then then the artificial bladder, because, you know, it's nice to know that the bladder is that that the cancer is out of your body and, you know, not just using a drug to treat it in the in the non-muscle invasively. They can just cut all the tumour out and it hasn't gone into the muscle. I think the drug immunotherapy is fine, but, you know, in the more serious cases, it's nice to know that the cancer is out.
Participant 032_2022AUBLC

What would you like to see from new treatment? Yeah. Well, be nice to be able to keep be nice to be able to keep your real bladder. Um, yeah. Look, um. Obviously. A cure would be nice. But, you know, I guess I'd like to see more empathy from doctors and specialists because a lot of that is lacking in the, um, particularly in the public system. And, and there's a bit of resentment, as I said earlier, when I went to a private doctor, and I chose the public operation. The private doctor didn't want to know me anymore. Even though I was prepared, even though I was prepared to pay out of my self funding, you know, he didn't want to receive me anymore, so I thought that was pretty lousy.
Participant 042_2022AUBLC

And goodness me, it would be nice to see more actually more research into bladder transplants for those people that haven't got them any more.
020_2022AUBLC

Participant describes the expectation that future BCG treatment will be administered in a less invasive and more dignified way

Uh, well, if we didn't have to, if the treatment didn't have to be shoved down my penis. So I'd think that'd be great. But I guess it's probably the best way because it's it's not a it's not a broad spectrum chemotherapy where it rattles your whole body or anything like that. Even with the chemo, they do a direct installation as well. So, you know, that's an uncomfortable feeling, having something going up the wrong way. And it has to be said, and you certainly leave your dignity at the door when you walk in. It's all on show. But, they've been doing this treatment for us for a fair while and it's probably one of the even now it's only 50% effective, the BCG. When it's effective, it's effective. It's either going to work on you or it's not. So I haven't had to have the radio or the chemotherapy. So if there was an easy way to put it in there. Yeah, but there's not because it's got good direct to it and it doesn't affect any other part of my body. I'm not getting an intravenous sort of injection or something that's coursing through my veins or, or a shot of radiation. So. I think for this method, it's probably the only way that I can do it. And, you know, look, the nurses are they're very good. They're not fumbling around. They know what they're doing, they do this a lot. So not not just with BCG, but they do these catheters and things all the time. So they're very practised and they're very the hygiene is second to none. They're oh, yeah. Each time they do it, the whole regime is very routine. Rather, the whole routine is, is second to none.
Participant 014_2022AUBLC

Right. Um, look, it would be great to, I guess, it would be great to have a more time efficient one as well as a treatment would be, because you know, every time you someone has a BCG, they have to be in there for a minimum of 2 to 3 hours. So, yeah, I guess that would be amazing if it just a little less time effective. And, um, yeah, with side effects would definitely be more amazing and. Like you mentioned before, if it was just like a pill or a tablet or injection, that would be fantastic.
Carer 003_2022AUBLC

Participant describes the expectation that future treatment will include emotional and mental support

I think I thought when you're having treatments, I think. You know, I don't I don't think I felt emotional support and and really that's what you need I reckon, to deal with treatment is support. And so I think more

needs to go into. Into that just, improving the experience, I guess. And. So that you don't feel like a number or you don't just you know, you don't feel like you don't really matter. It's, you know, it's called process.
Participant 026_2022AUBLC

On treatments. Yeah. Yeah, I suspect the availability of the robotic surgery. Mm hmm. Without the high cost overhead. Because I think if you don't have private insurance, you have to pay for it. Um. That would be handy for patients. What else? I think. I think and this is regarding patients that have already been diagnosed with cancer that right? So they may be the knowledge around support groups and where to get help.
Participant 022_2022AUBLC

When I was actually diagnosed like with the thing you sort of, you come out of the surgery and says, Oh, you've got bladder cancer. I felt there was no actual support, not unless you rang up yourself and followed up. I think there should, um, urologist or whoever is dealing with it should give you some numbers or, you know, support like that. I just feel like you're on your own after they sort of give you the diagnosis.
Participant 044_2022AUBLC

Participant describes the expectation that future treatment will be accompanied by more community awareness and early detection

New treatments. Yeah. Oh, yeah. I couldn't. I couldn't really say, um, it's catch it a lot earlier and, you know, not remove it would be so much better. And I just so much cheaper. Yeah. An early diagnosis.
Participant 031_2022AUBLC

It's the number one thing I think. I think more awareness of of of of the cancer. And like I say, May is bladder cancer month. So we're doing a couple of things. Different markets in public areas, I think. It's not, the treatment is there. And this is changing. Every, every time I look, it's changing. You know, like 20 years ago, I wouldn't have survived and here I am, it hasn't metastasised, I underwent chemo, so really I think the only thing I can think of that that sticks in my mind more than anything else I've brought up is GPs have to know that there's blood in your pee, check it, not just for don't just assume that it is a UTI to me that's the most education is. Because my GP, my new GP, the other one didn't know about BEAT cancer Australia. So. And I'm only using patients more. We're covering patients more to inform new patients are starting their journey that not to worry. There is no one where I could talk to them at the beginning. Now that I've been there. I believe there's a lot of us have got something to offer those who are just beginning the journey. Even if it's going to be a terminal result, you know, it's it's good to be able to talk to someone who's been there rather than a doctor or a nurse that. Does that make sense
Participant 038_2022AUBLC

Look, I think there's studies going on all the time. My my oncologist was over in America giving. And actually, I meant to ask him exactly what the new treatment is he's working on. Um, I do believe that there's studies going on and new drugs will all the time. I truly believe that. And as I said, my oncologist was in America giving a talk on what he's actually. Yeah. Yeah. So I guess just funding to to I'm, I think like there's not a lot of. A lot of there's not a lot of talk about bladder cancer.
Participant 039_2022AUBLC

Participant describes being uncertain about what to expect from future treatments/would defer to medical advice

PARTICIPANT I don't know. I don't know about that.

INTERVIEWER That's okay.

PARTICIPANT I never thought about that. No. I'm sorry. I don't know. I don't know.
Participant 007_2022AUBLC

Oh, I don't know.
Participant 013_2022AUBLC

PARTICIPANT: Well, almost. Okay. One treatment. I'm not on any. I'm not on any, uh, radiation, or chemo type therapy. So I can't really answer that question.
Participant 037_2022AUBLC

Table 9.1: Expectations of future treatment

Expectations of future treatments	All participants		Early		Invasive		Advanced		Person with bladder cancer		Carer		Female		Male	
	n=49	%	n=20	%	n=10	%	n=14	%	n=44	%	n=5	%	n=17	%	n=32	%
Participant describes the expectation that future treatment will be accompanied by more information about available treatments and treatment pathways	13	26.53	6	30.00	3	30.00	4	28.57	13	29.55	0	0.00	4	23.53	9	28.13
Participant describes the expectation that future treatments will be more accessible particularly equitable, timely and includes access in rural locations	12	24.49	5	25.00	3	30.00	3	21.43	11	25.00	1	20.00	4	23.53	8	25.00
Participant describes the expectation that future treatment will have less cost burden	10	20.41	5	25.00	1	10.00	2	14.29	8	18.18	2	40.00	4	23.53	6	18.75
Participant describes the expectation that future treatment will have more options, and/or will be targeted	9	18.37	3	15.00	1	10.00	5	35.71	9	20.45	0	0.00	4	23.53	5	15.63
Participant describes the expectation that future treatments will have fewer or less intense side effects	7	14.29	2	10.00	1	10.00	3	21.43	6	13.64	1	20.00	2	11.76	5	15.63
Participant describes the expectation that future treatment will be more effective	5	10.20	0	0.00	3	30.00	0	0.00	3	6.82	2	40.00	1	5.88	4	12.50
Participant describes the expectation that future treatment will prevent loss of bladder or will improve bladder replacements	5	10.20	1	5.00	1	10.00	3	21.43	5	11.36	0	0.00	3	17.65	2	6.25
Participant describes the expectation that future BCG treatment will be administered in a less invasive and more dignified way	5	10.20	3	15.00	0	0.00	1	7.14	4	9.09	1	20.00	1	5.88	4	12.50
Participant describes the expectation that future treatment will include emotional and mental support	5	10.20	2	10.00	2	20.00	1	7.14	5	11.36	0	0.00	3	17.65	2	6.25
Participant describes the expectation that future treatment will be accompanied by more community awareness and early detection	4	8.16	0	0.00	1	10.00	3	21.43	4	9.09	0	0.00	1	5.88	3	9.38
Participant describes being uncertain about what to expect from future treatments/would defer to medical advice	3	6.12	2	10.00	0	0.00	1	7.14	3	6.82	0	0.00	1	5.88	2	6.25

Expectations of future treatments	All participants		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=49	%	n=29	%	n=19	%	n=15	%	n=33	%	n=20	%	n=28	%
Participant describes the expectation that future treatment will be accompanied by more information about available treatments and treatment pathways	13	26.53	8	27.59	5	26.32	5	33.33	8	24.24	7	35.00	6	21.43
Participant describes the expectation that future treatments will be more accessible particularly equitable, timely and includes access in rural locations	12	24.49	9	31.03	2	10.53	4	26.67	7	21.21	6	30.00	5	17.86
Participant describes the expectation that future treatment will have less cost burden	10	20.41	6	20.69	4	21.05	4	26.67	6	18.18	5	25.00	5	17.86
Participant describes the expectation that future treatment will have more options, and/or will be targeted	9	18.37	5	17.24	4	21.05	2	13.33	7	21.21	3	15.00	6	21.43
Participant describes the expectation that future treatments will have fewer or less intense side effects	7	14.29	6	20.69	1	5.26	4	26.67	3	9.09	3	15.00	4	14.29
Participant describes the expectation that future treatment will be more effective	5	10.20	2	6.90	3	15.79	2	13.33	3	9.09	1	5.00	4	14.29
Participant describes the expectation that future treatment will prevent loss of bladder or will improve bladder replacements	5	10.20	3	10.34	2	10.53	1	6.67	4	12.12	1	5.00	4	14.29
Participant describes the expectation that future BCG treatment will be administered in a less invasive and more dignified way	5	10.20	3	10.34	2	10.53	2	13.33	3	9.09	1	5.00	4	14.29
Participant describes the expectation that future treatment will include emotional and mental support	5	10.20	3	10.34	1	5.26	1	6.67	3	9.09	3	15.00	1	3.57
Participant describes the expectation that future treatment will be accompanied by more community awareness and early detection	4	8.16	3	10.34	1	5.26	1	6.67	3	9.09	3	15.00	1	3.57
Participant describes being uncertain about what to expect from future treatments/would defer to medical advice	3	6.12	2	6.90	1	5.26	0	0.00	3	9.09	1	5.00	2	7.14

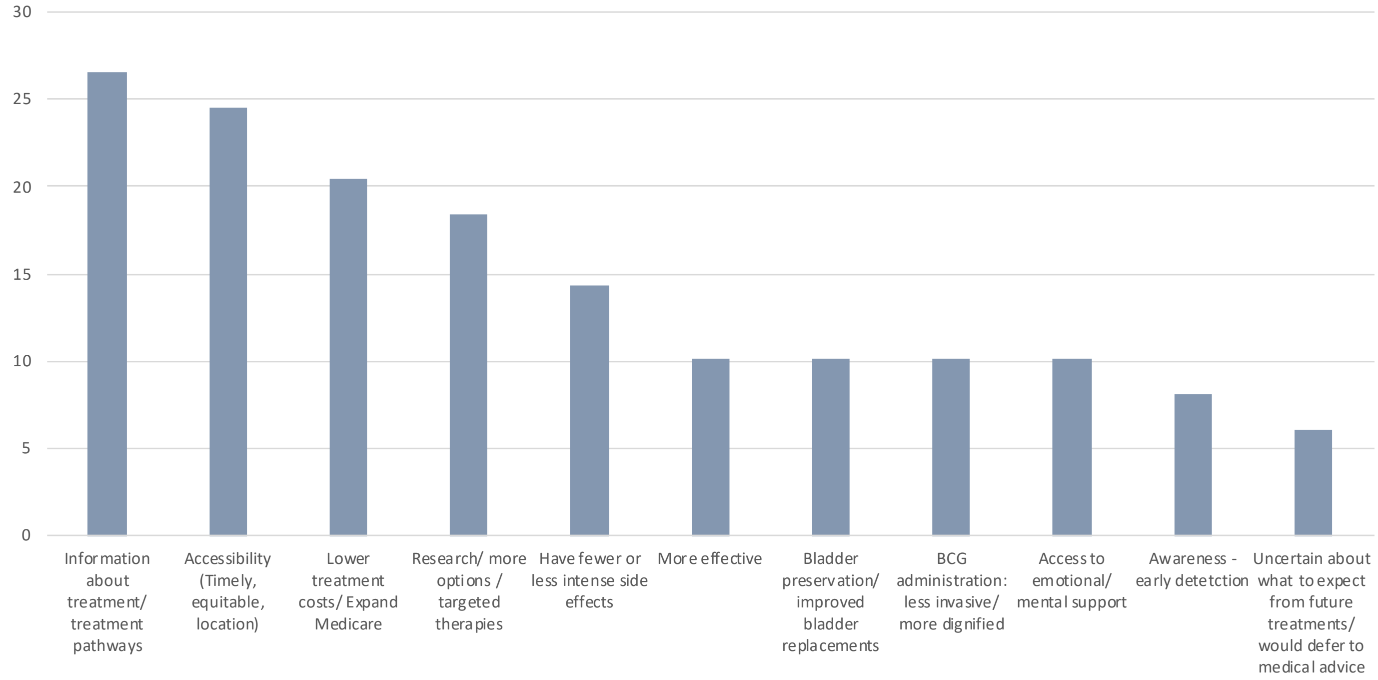


Figure 9.1: Expectations of future treatment

Table 9.2: Expectations of future treatment – subgroup variations

Expectations of future treatments	Reported less frequently	Reported more frequently
Participant describes the expectation that future treatment will be accompanied by more information about available treatments and treatment pathways	Carer to someone with bladder cancer	-
Participant describes the expectation that future treatments will be more accessible particularly equitable, timely and includes access in rural locations	University	-
Participant describes the expectation that future treatment will have less cost burden	Invasive (Stage III)	Carer to someone with bladder cancer
Participant describes the expectation that future treatment will have more options, and/or will be targeted	Carer to someone with bladder cancer	Advanced (Stage IV)
Participant describes the expectation that future treatments will have fewer or less intense side effects		Regional or remote
Participant describes the expectation that future treatment will be more effective	Early (Stages 0 and I) Advanced (Stage IV)	Invasive (Stage III) Carer to someone with bladder cancer
Participant describes the expectation that future treatment will prevent loss of bladder or will improve bladder replacements	Carer to someone with bladder cancer	Advanced (Stage IV)
Participant describes the expectation that future BCG treatment will be administered in a less invasive and more dignified way	Invasive (Stage III)	-
Participant describes the expectation that future treatment will include emotional and mental support	Carer to someone with bladder cancer	-

Expectations of future information

Participants were asked in the structured interview if there was anything that they would like to see changed in the way information is presented or topics that they felt needed more information. The most common theme was that participants have no recommendations or they are satisfied with the information currently available (n=13, 26.53%). There were 9 participants (18.37%) that described that future information should be more accessible/easy to find, and 9 participants (18.37%) that described that future information should include all treatment options available to them.

Other participants described that future information will provide more details about mental health and emotional support (n=6, 12.24%), will help to inform the community and decision-makers about their condition (raise awareness) (n=6, 12.24%), will describe what to expect, especially with respect to side effects and treatment outcomes (n=6, 12.24%), will provide more details about where to find available services (n=5, 10.20%), and will be more targeted to specific types or stages (n=5, 10.20%).

Participant has no recommendations/is satisfied with the information currently available

Well, that's an interesting question because I go back to BEAT Bladder Cancer Australia each month. We have a guest speaker. It's been on BCG treatment, it's been on sexual relationships, speaking on health. So nutrition, exercise, that type of topic is very helpful. And physiotherapist uh. When I had NAME in my case was absolutely awesome. She helped me afterwards and followed on from that as well.
Participant 038_2022AUBLC

No. I think, again, I went through the Cancer Council booklet and it's it's all good. It's all pretty. It it's got everything, you know, it's got all the options. It's all very well written, you know, and like somebody who knows zero about bladder cancer, they can know everything, you know, how to see their symptoms, what treatment options, what type of cancer, what support is there, what afterwards? You know, I think the Cancer Council is doing a brilliant job. Yeah. That that's such a good and helpful information booklet.
Participant 028_2022AUBLC

I think when you're going on this journey, I think. I think my urologist got it right. We just deal with things as presented and we try things. And I think we started on mitomycin because it wasn't as strong the BCG And so therefore that's what we started with as a first step and we just worked through the steps and more serious treatment as things don't work.
Participant 024_2022AUBLC

Participant describes the expectation that future information will be more accessible/easy to find

I think we could just go, but it is a bit of an overlap. We go back to that first two weeks when I'm in shock. It would have been nice to. Be made aware that all this information is available and not forced down my throat, that, you know, you're going to need to read all this. When you feel able to sit down and concentrate and and here it is. And if you have any questions, this is where you can get the answers from.
Participant 020_2022AUBLC

I had to ask people, do I had to dig a bit. You have to dig a little bit deep to find some of this information.

But. I just again, everything's sort of around BCG just because that's how it is and that's what it is. I know there are trials out there and I don't know if there's much information on. It probably is, and I just haven't found it. I was hungry for information. When I first got diagnosed and I'm less so now, I just sort of become part of life. And it's not quite like this anymore. But I think more information on alternatives would be really good alternative treatments.
Participant 030_2022AUBLC

I think a bomb needs to get put under the communication and information. You know, the it was just as a registered nurse who was a strong advocate for patients and, you know, providing information. I have found the whole thing has been really scarily missing. There just isn't that information available. There's no support. As I said, you in the cancer service, you don't even feel like a person. So yeah, I do. I think the whole thing needs to be re looked at. The main support I've had in through the BEAT Bladder Cancer Support Group, which is online and sending emails, I've sent a couple of times to try and get some information and I found that been really helpful. But in terms of the information that I've been offered voluntarily through and support through the hospital, there's there's really none.
Participant 002_2022AUBLC

Participant describes the expectation that future information will include all treatment options available to them

No the format doesn't really worry me. It can be black and white with headings or whatever it's, it's a clearer discussion of the treatment options at each stage or, or the different stages of the disease. And that's what I haven't. I mean, for example, the current urologist has difficulties, his communication style problems. He's doing, as I said, a flexible cystoscopy that was never, ever mentioned to me by the previous urologist. You know, you had to have the full cystoscopy every time. Yeah. So I mean, that's that's a that's that's a different that's a different treatment option, which the first I heard about it was when I went to the new urologist. I didn't go to him because of that. I just found that out from they gave me the option.
Participant 008_2022AUBLC

Well, going to the initial diagnosis, I'm like, a bit more, um. I mean, all I had was you got bladder cancer. Bladder is going to come out. Um, and then the ins and outs of the operation, you know, there was no options, you know, I mean, I wanted to explore more the, the BCG or or what ever it's called treatment, but that was, that wasn't on the table. Um, I mean, basically what I'm saying is if I could have kept my bladder, yeah, yeah, I would have, but I didn't have that option. The fact that that surgeon didn't give me that option, so was like going to have a second opinion or third opinion as you do
Participant 023_2022AUBLC

Yeah. So there was never any options presented. But I guess there was also there was never any discussion or presentation of what current research there was or even if there was like, you know, are there any clinical trials? What kind of procedures have either historically been used and are still used or what is new or what is. Yeah. And maybe that's seen as too overwhelming and confusing for the patient.
Participant 041_2022AUBLC

Participant describes the expectation that future information will provide more details about mental health and emotional support

Uh uh, I think more support groups, more personal care and mental support. That's the part I totally missed.
Participant 005_2022AUBLC

Well, we didn't know about any support groups. We didn't know anything about where you could get help for for financial reasons. We didn't know mental health. I think that should have been. You know people could say he was really depressed, but no one did anything about it.
Carer 001_2022AUBLC

I think a bomb needs to get put under the communication and information. You know, the it was just as a registered nurse who was a strong advocate for patients and, you know, providing information. I have found the whole thing has been really scarily missing. There just isn't that information available. There's no support. As I said, you in the cancer service, you don't even feel like a person. So yeah, I do. I think the whole thing needs to be re looked at. The main support I've had in through the BEAT Bladder Cancer Support Group, which is online and sending emails, I've sent a couple of times to try and get some information and I found that been really helpful. But in terms of the information that I've been offered voluntarily through and support through the hospital, there's there's really none. I think the one to get is breast cancer. Not that I wish that on anybody, but I believe it's so much more help and and services available for people with breast cancer. I don't I don't

know why, but the, I rang the Cancer Society to try and get some help and information and they couldn't even help me.
Participant 002_2022AUBLC

Participant describes the expectation that future information will help to inform the community and decision-makers about their condition (raise awareness)

No, look, As I said earlier, it's not one of those cancers that you don't hear much about. Yes. So anything would be would be some improvement. I did coincidentally hear a radio programme, I think about this time last year where they talked about it must have been Bladder Cancer Awareness Week. And I heard a few people, I stumbled on it. I didn't know it was going to happen. It was on the ABC and they were talking about it and you know, that sort of information was fantastic. I really listened to it and I was like, Wow, that's good to know that. And that's the sort of information that needs to come out. I think with all of these with these cancers, people are always feeling they're a bit in the dark. But there is information there with with the lesser known cancers, I find it's harder to dig out that information without getting into the really bad. You know what? This what happens.
Participant 006_2022AUBLC

Probably just, I think that I think BEAT bladder cancer has kind of already started it, but maybe because I didn't actually see them originally, but maybe like on bigger pages like the Cancer Council, I would really like to see more information about like maybe some prompts about questions to ask urologist and GP use and those kind of things. Just more tips and tricks of like what we could be asking rather than being overwhelmed with all this information and not being able to connect the dots or anything. So yeah, maybe just some of yeah. And just some every day. So I didn't actually know. I know this sounds stupid, but I didn't even know bladder cancer was a real thing. Like, I knew it was a thing, but like, I didn't know anyone that it affected. So maybe just trying to put it out to the world that we do need to be aware of other types of cancer. Um. Because I've been looked at differently, like I've lost half my bladder, but I still have both my boobs. Like I don't have breast cancer, but if I had breast cancer, I think people would look at me differently because it's more commonly known.
Participant 009_2022AUBLC

I think it's definitely not highlighted enough on, say, like TV adverts or radio adverts or newspaper adverts. It's not out there a lot. You don't know about it until you've got it. And it's not like breast cancer is front and centre at the moment for a lot of Australians and bowel cancer is front and centre for a lot of Australians. But bladder cancer, you never hear anything on it.
Participant 031_2022AUBLC

PARTICIPANT I'd love to walk into a toilet one day and see a sign on the door when we're talking about urine and blood in the urine. Those kind of signs need to be in toilets. Toilet cubicles. Not to say more awareness. More promoting it on. Yeah. Screening. Why can't we do screening? If there is any such thing, can we screen for bladder cancer? Like we do for bowel cancer and breast cancer.

INTERVIEWER Yeah. That's a good question.

PARTICIPANT And why haven't we got that up and running? Well, there's that. Anything, I guess, that can just. Allow us to have an early diagnosis, because I know if my husband was, you know, diagnosed early, it might have been a very different outcome. So it may not have been, but, you know it could have been.
Carer 002_2022AUBLC

Participant describes the expectation that future information will describe what to expect, especially with respect to side effects and treatment outcomes

I suppose the one thing that stands out that is not discussed is. Like with any area that that might affect your, your sexual life. That's one thing that is so often a no go zone. And yet, you know, it's a big part of our lives and it's not something you want to give up. So you shouldn't have to bring that subject up. And like I, you know, I have with all my specialist, because I'm an out there kind of woman, I have a bit of a medical background on my husband and I still, you know, certainly enjoy our sex life. So it's not something we before are happy to just, uh, of course, you know, my life and longevity is more important, but at the same time, if it can be spared and accommodated, then you, you want that to be considered and taken into account and sensitivity and all the rest. So that's something that is, as per usual, the last thing that people feel comfortable talking about. So the elephant in the room.
Participant 010_2022AUBLC

PARTICIPANT: There was very little information about recovery and things after recovery.

INTERVIEWER: You mean after the bladder removal?

PARTICIPANT: Yes, I had I had side effects in my body. And that's when my treatment really fell apart. To be honest, no one wanted to own the problem or to really help me out.
Participant 016_2022AUBLC

I think a break down in the post-operative, so again, part of the cancer, part of it the post-operative stages, what the impacts of the surgery can can mean both and separated maybe for some male and female. And from my perspective, um, like, there was a vaginal leakage, and I didn't know what that was. And when I went to, I went back to the urologist, and he said, oh, yeah, that can happen. That's, why wasn't something that I was told about? What does it mean, and how long is it going to last?

And for men and also women as well. Um, from a, um, from a sexuality perspective and, you know, intimate relationships and things like that, I think there needs to be more awareness around what the impacts of the operation, um, will preclude you from being able to do. But also tell you what you can continue to do. … And the how, you know, I think online again is good, but, um, it should be certainly something that's either if it's not offered by the urologist, then they should be directing to, you know, an appropriate sort of forum or group that can discuss.
Participant 022_2022AUBLC

Participant describes the expectation that future information will provide more details about where to find available services

And I think sometimes even a list with what, a list of what is there and how to contact them would be useful. Not everybody is able to sort of will access it if they don't have the facilities and symptoms, they don't know what it is knowing what's there sometimes. And knowing like a slide. And you know, it's easy to say, oh, go and speak to so-and-so. But you need to know what they provide. Is that what you're after? So I think some kind of list would be a start. And I do think the hospital is busy enough, I suppose, but wouldn't it would be nice if there was some way where you could, you could go easily call to get your information. Or a meeting place where you could be with people who have the same problems as you. So you can get how do they manage. Often a lot of the stuff I find out is by the group on Facebook, you know, all different things that are available. And yeah, I did go to a few of the sessions of the urostomy group where I got information there. But then, of course COVID shut everything down, and now that they've opened up again I think to this, every one of them, they only do it once every two months. And if I've got something else on, I can't go. I haven't been yet. Probably about two and a half years since I went to a meeting of them.
Participant 003_2022AUBLC

I suppose clinical trials is one thing that would be good to be better presented. You know, it's quite tricky to find that information out at the moment. And you know. Also, I suppose one thing that would be good to know is, you know, where you know is the best place to go that do a lot of radical cystectomy. You know, because you don't want to be in a hospital that does, you know, once a year or even worse, you want to be somewhere where they're doing them often.
Participant 032_2022AUBLC

I guess like the emotional support is sorely lacking. And like, as I said before, like if you when you get diagnosed, be handed like a brochure. And on bladder cancer and also, um, you know, where to get support, whether it be emotionally, financially, anything. You know, here's a phone number that you can call. Um. You know, that would be. That would be amazing. Like I said, we were lucky that we had a family member who's an oncologist that we were able to call and talk to. But I imagine most people don't have that. So, yeah, I think written information in a hardcopy at the time of diagnosis where you can take away and actually read it and process it later. It would be would be something that definitely should happen.
Carer 003_2022AUBLC

Participant describes the expectation that future information will be more targeted to specific types or stages

No, the format doesn't really worry me. It can be black and white with headings or whatever it it's. It's a clearer discussion of the treatment options at each stage or, or the different stages of the disease. And that's what I haven't. I mean, for example, the current urologist has difficulties, his communication style problems. He's doing, as I said, a flexible cystoscopy that was never, ever mentioned to me by the previous urologist. You know, you had to have the full cystoscopy every time. Yeah. So I mean, that's that's a that's that's a different that's a different treatment option, which the first I heard about it was when I went to the new urologist. I didn't go to him because

of that. I just found that out from they gave me the option.
Participant 008_2022AUBLC

Um, I felt like that because as NAME was in a muscular, that I thought it was well, the information was about the other sort, you know, so it wasn't relevant. I think it should have been divided into two groups
Carer 005_2022AUBLC

You know, I would love to be able to click on, you know. Click on. You know, what I love about the support group is that we, you know, this week, next week, next. So there's this month last month they did a you know, a specialist came on and talked about must non-muscle invasive bladder cancer. And I sat and listened to the whole thing and it wasn't relevant to me. But the fact that when I said to them, is it possible to have the next talk be about muscle invasive? And they put it on. So this next week, I'm going to hear all about, you know, and that would be so wonderful that someone could video that. And that I could click on to that that link so that I can say to anybody else who comes on and says, Listen, my husband just got diagnosed with muscle invasive bladder cancer, you know, instead of reading, can we listen to someone talking about it and what the options are for treatment and all that? That would be fantastic. Yeah, like that would have been so good for me if if there was, you know, not everyone. You know, I'm I'm a I'm a researcher, right? Like so I'm a person that will go on and read and all that. But my husband isn't. Whereas if I could have said to my husband, All you have to do is click on this person. This person is talking about muscle invasive bladder cancer. And this person's not only telling you about muscle invasive bladder cancer, but it's also telling you about the most recent research into your options of preservation, or surgical removal and gives you all this information there and and you can make your decision. And it doesn't need me to have to research it to give you the option, you know.
Carer 004_2022AUBLC

Participant describes the expectation that in future there will be enough time to discuss information with their healthcare professionals

I think. I think it's kind of like. When when they give you mass information, it's like they need to follow up in a few days time and and and care enough to go through it again. And answer your questions. Yeah. You know, the times that you're getting lots of information, you can't ask questions because you're just trying to grab. What's going on. And then you don't really feel like you can ring back and bother them and ask questions later.
Participant 026_2022AUBLC

It's a big game and it's a big question really, isn't it. I guess I think we could just go, but it is a bit of an overlap. We go back to that first two weeks when I'm in shock. It would have been nice to. Be made aware that all this information is available and not forced down my throat, that, you know, you're going to need to read all this. When you feel able to sit down and concentrate and and here it is. And if you have any questions, this is where you can get the answers from.
Participant 020_2022AUBLC

Table 9.3: Expectations of future information

Expectations of future information	All participants		Early		Invasive		Advanced		Person with bladder cancer		Carer		Female		Male	
	n=49	%	n=20	%	n=10	%	n=14	%	n=44	%	n=5	%	n=17	%	n=32	%
Participant has no recommendations/is satisfied with the information currently available	13	26.53	4	20.00	**5**	**50.00**	4	28.57	13	29.55	**0**	**0.00**	**2**	**11.76**	11	34.38
Participant describes the expectation that future information will be more accessible/easy to find	9	18.37	4	20.00	2	20.00	3	21.43	9	20.45	**0**	**0.00**	**6**	**35.29**	3	9.38
Participant describes the expectation that future information will include all treatment options available to them	9	18.37	3	15.00	1	10.00	**4**	**28.57**	8	18.18	1	20.00	4	23.53	5	15.63
Participant describes the expectation that future information will provide more details about mental health and emotional support	6	12.24	4	20.00	**0**	**0.00**	**0**	**0.00**	4	9.09	**2**	**40.00**	**4**	**23.53**	2	6.25
Participant describes the expectation that future information will help to inform the community and decision-makers about their condition (raise awareness)	6	12.24	2	10.00	**0**	**0.00**	3	21.43	5	11.36	1	20.00	2	11.76	4	12.50
Participant describes the expectation that future information will describe what to expect, especially with respect to side effects and treatment outcomes	6	12.24	4	20.00	2	20.00	**0**	**0.00**	6	13.64	**0**	**0.00**	**5**	**29.41**	1	3.13
Participant describes the expectation that future information will provide more details about where to find available services	5	10.20	2	10.00	**0**	**0.00**	1	7.14	3	6.82	**2**	**40.00**	3	17.65	2	6.25
Participant describes the expectation that future information will be more targeted to specific types or stages	5	10.20	3	15.00	**0**	**0.00**	**0**	**0.00**	3	6.82	**2**	**40.00**	**0**	**0.00**	5	15.63
Participant describes the expectation that in future there will be enough time to discuss information with their healthcare professionals	3	6.12	0	0.00	2	20.00	1	7.14	3	6.82	0	0.00	1	5.88	2	6.25

Expectations of future information	All participants		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=49	%	n=29	%	n=19	%	n=15	%	n=33	%	n=20	%	n=28	%
Participant has no recommendations/is satisfied with the information currently available	13	26.53	8	27.59	5	26.32	2	13.33	11	33.33	4	20.00	9	32.14
Participant describes the expectation that future information will be more accessible/easy to find	9	18.37	5	17.24	4	21.05	3	20.00	6	18.18	3	15.00	6	21.43
Participant describes the expectation that future information will include all treatment options available to them	9	18.37	4	13.79	5	26.32	3	20.00	6	18.18	4	20.00	5	17.86
Participant describes the expectation that future information will provide more details about mental health and emotional support	6	12.24	2	6.90	4	21.05	1	6.67	5	15.15	2	10.00	4	14.29
Participant describes the expectation that future information will help to inform the community and decision-makers about their condition (raise awareness)	6	12.24	5	17.24	1	5.26	2	13.33	4	12.12	3	15.00	3	10.71
Participant describes the expectation that future information will describe what to expect, especially with respect to side effects and treatment outcomes	6	12.24	3	10.34	3	15.79	2	13.33	4	12.12	1	5.00	5	17.86
Participant describes the expectation that future information will provide more details about where to find available services	5	10.20	2	6.90	3	15.79	1	6.67	4	12.12	2	10.00	3	10.71
Participant describes the expectation that future information will be more targeted to specific types or stages	5	10.20	4	13.79	1	5.26	4	26.67	1	3.03	4	20.00	1	3.57
Participant describes the expectation that in future there will be enough time to discuss information with their healthcare professionals	3	6.12	2	6.90	1	5.26	3	20.00	0	0.00	3	15.00	0	0.00

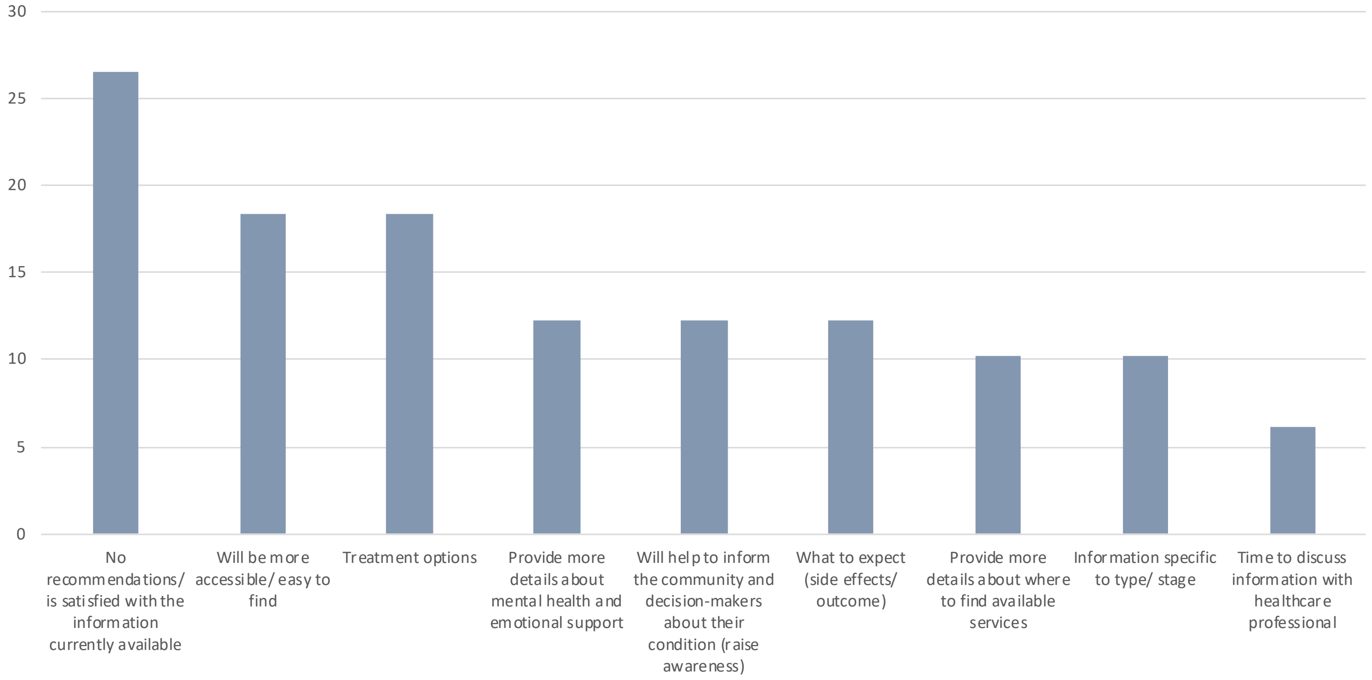


Figure 9.2: Expectations of future information

Table 9.4: Expectations of future information – subgroup variations

Expectations of future information	Reported less frequently	Reported more frequently
Participant has no recommendations/is satisfied with the information currently available	Carer to someone with bladder cancer Female Regional or remote	Invasive (Stage III)
Participant describes the expectation that future information will be more accessible/easy to find	Carer to someone with bladder cancer	Female
Participant describes the expectation that future information will include all treatment options available to them	-	Advanced (Stage IV)
Participant describes the expectation that future information will provide more details about mental health and emotional support	Invasive (Stage III) Advanced (Stage IV)	Carer to someone with bladder cancer Female
Participant describes the expectation that future information will help to inform the community and decision-makers about their condition (raise awareness)	Invasive (Stage III)	-
Participant describes the expectation that future information will describe what to expect, especially with respect to side effects and treatment outcomes	Advanced (Stage IV) Carer to someone with bladder cancer	Female
Participant describes the expectation that future information will provide more details about where to find available services	Invasive (Stage III)	Carer to someone with bladder cancer
Participant describes the expectation that future information will be more targeted to specific types or stages	Invasive (Stage III) Advanced (Stage IV) Female	Carer to someone with bladder cancer Regional or remote

Expectations of future healthcare professional communication

Participants were asked in the structured interview what they would like to see in relation to the way that healthcare professionals communicate with patients. The most common theme was that participants expected future information will be more transparent and information more forthcoming (n=14, 28.57%). Other themes about expectations of future communication included that future communication will be more empathetic (n=11, 22.45%), will allow people more time to meet with their clinician to talk about all that they need to talk about (n=9, 18.37%), will include better communication between healthcare professionals, and better coordination of appointments (n=7, 14.29%), and will include discussions about mental and emotional health (n=6, 12.24%).

There were 7 participants (14.29%) that had no recommendations or that they experienced good communication.

Participant describes the expectation that future communication will be more transparent and information more forthcoming

PARTICIPANT: I guess I like to know. The facts, I like to be told the facts. Even if they're not great, I've just got to know. Yeah. And, um. I guess just more disclosure, maybe. Um, I know I said I like to access information online, but maybe something in at the same time in writing when you actually physically see a doctor. But when you reach that clinic, when I left the clinic for the first time of bladder cancer or suspected may have bladder cancer. After I first saw my surgeon, I left with no information. Does that make sense? Nothing in writing.

INTERVIEWER: Nothing to go back to or anything.

PARTICIPANT: Nothing to refer back to or nothing to explain that you're going to have a T U R B T. All I remember was I sat in the surgeon's room. And he had this model of, like, a male torso or not to full torso, but just a urological system and that sort of male part. And he had the cystoscopy tube, and I said, oh where abouts will you be cutting me? Like to get the to get into the bladder? You go through my side or under my belly or whereabouts to go, and all of a sudden you get to sort of model thing out and starts showing, oh I put a tube through your penis and I put this camera up there and I'm just like, I remember I swore when he showed me this, I'm like you've got to be bleeping joking or something like that. And then I realised, opps, you know, opps what am I saying, I'm swearing at his doctor because I was in shock, you know? And it's just like there was nothing to sort of, um, I had if I hadn't asked that, if I hadn't said something, I wouldn't have known what I was having done. And yeah, so I guess to something to say, this is what you're going to have done. You might feel this way or it won't be painful. It may seem painful, but you'll be asleep or or something of that nature without having to ask for, you know, without asking it.

INTERVIEWER: Like you're not going to be expected to know.

PARTICIPANT: It's like I had weight loss surgery, which has been very successful as a whole, which I with the top surgeon in his field and you come out sort of with it, you know with a folder full of information about this is what you're going to have done and this is how it works and blah, blah, blah. These are the different options available and you know, you're fully armed with information and that's not something that generally is going to kill you or not like it's cancer, you know. So yeah, it's a bit different.
Participant 001_2022AUBLC

No. It just comes back to two reliable information sources. And I think easier access, easier access, more logical access to information about trials that would be important and treatment options.
Participant 020_2022AUBLC

Um, well, we've got to go back to the initial GP. I mean, I'm sorry, it sounds like an old echo, but yeah, the initial diagnosis, well, it wasn't diagnosed at the GP. He probably knew, but he passed me over to the urology. So I would have liked him to still come clean earlier with the a bit more warning. In a way, I knew in my head that something was wrong. So then would you think something like that, you, you, you, you basically go into or what if what that. It's you know, without knowing the facts. You know. I would have liked a clearer, a clearer timeline.
Participant 023_2022AUBLC

Yes. That look, you know, you've got non-invasive muscle bladder cancer. Click on this site and they're going to tell you this side is going to say, tell you what it is, what the treatments are. How many people have, you know, all the studies that have been done on it? This is what the studies have found. And. These are you know, these studies are telling you that this is the best way to go. All this is the studies are telling you

that there's multiple options. And. Any of these options have similar risks and benefits.
Carer 004_2022AUBLC

Participant describes the expectation that future communication will be more empathetic

I guess that health professionals can become a bit destigmatised, desensitised rather to it. And so for them, it's very matter of fact. And although, you know, we are friendly with my urologist, it's her job and she talks as very matter of fact, there's not a huge amount of compassion and warmth. And that's certainly no judgement. I mean, also some people don't have that. But, you know, she's a well, she's a leader in a field, there's no question about it, urology, but, she, you know she didn't deal with it very well. When I broke down and cried, I suppose she was like, oh, I don't have any tissues. She felt a bit uncomfortable. So I guess and that's been a thing in the medical industry. Is is compassion, I suppose. I mean, she is. But, you know, the desensitised to something that you just do day in day out in your routine. It, you know, she'll tell you all the facts and everything like that that doesn't have the, um the warmth, I suppose. I guess that they just need that training in to deal with, with compassion and humanity side of it.
Participant 014_2022AUBLC

Oh, yeah. Um, get rid of the pedestal if, in my case, urologist, get rid of your pedestal, you know, stand next to me, be in the trenches with me, you know, show some empathy. Um. Be balanced and be open and transparent.
Participant 017_2022AUBLC

PARTICIPANT: No, it's 90% of it. Excellent.

INTERVIEWER: Yeah. And that 10% though.

PARTICIPANT: Yeah. Yeah. Nurses. Reception staff. Yeah. Registrar's. All good Yeah.

INTERVIEWER: Okay.

PARTICIPANT: For one day when I did come back after a few months we were in day surgery and we were both having a cup of tea in our cubicle, routine would be, anaethetists and surgeon walk past in a hurry and then registrar walk will past, but he stopped and turned and came back. And said, I saw you guys were a bit upset. Do you guys want to talk about it? Yeah, that was good. I hope that guy. It's almost eight years ago. Hopefully he hasn't lost that if he's a qualified surgeon somewhere now.
Participant 019_2022AUBLC

Participant describes the expectation that future communication will allow people more time to meet with their clinician to talk about all that they need to talk about

Oh, yeah. They need to sit down and explain the diagnosis as soon as possible. Just explain and make sure you understand it and not have to find out for yourself... They assumed I knew what was going on... I had to wait for 3 hours in the out patients, and they just see you for 5 minutes...To be treated with respect I suppose...3 hours for nothing.
Participant 013_2022AUBLC

As I said before, just a little bit of a little bit of a consultation after after any procedure. You know I can't fault Dr NAME, I can't fault him at all for what he what he's told me and the lengths and explanations that he's given me and the consultations I've had with him. There's just a little bit of that. And as I said before, just after after any sort of treatment. Just be told what may or may not happen if everything's clear. So, you know, the first four or five cysctoscopies I had, the doctors, the doctors, one doctor, they're all different. The doctor came and said to me, fine, it's all clear. You know, you can, go home. When you when you come out of the anaesthetic, you know, when you when you're okay and that just you breathe easy, you know. But when they don't when they don't get any information after the procedure, that's when you go home with thinking, what if? you know? So that's the only thing I can think of about. Little bit of the information that should be given to you.
Participant 021_2022AUBLC

No, I was very lucky. You know, I had my urologist texting me when I got home and check in and see how I was going. I was really I had a really good relationship with my oncologist and urologist. So, but from others I hear of, you know, the empathy is just sometimes not there at all. And that's what people want. They want a little bit of empathy and they want someone that doesn't make them feel rushed and makes them feel like they can ask questions. Or if they can't, if they haven't got the time, you know, give them an avenue to ask the questions, whether it's through them still or via someone else.
Participant 022_2022AUBLC

Participant has no recommendations/experienced good communication

No, my communication has been very good.
Participant 012_2022AUBLC

I had a great I had a great experience the journey.
Participant 024_2022AUBLC

No, not really. I think the urologist, he is very approachable, my GP is good. Um. The nursing staff? Yeah. I don't think I could change anything.
Participant 027_2022AUBLC

Participant describes the expectation that future communication will include better communication between healthcare professionals, and better coordination of appointments

So I think it also needs to be coordinated. I think, you know, they talk about a multidisciplinary team that discusses your case. I think as a patient, you've got a right to be at that. So you can get a holistic view about what the what the thoughts are of the treating health professionals are and you become you need to be central to
Participant 002_2022AUBLC

I think. Yeah. Okay. So once it's established that you are. In a situation that will require continuing. Or. Potentially continuing care and visits and appointments. I guess. If there was some point of contact, some stuff, some single point of contact rather than the reception desk and asking to be put through urology. Or. Or, you know, put through a oncology. Well, you put through to the cancer centre, which I didn't know existed until sort of 5 years in. Yeah. A point of contact, but not just emergency, or asking to speak to a urology registrar because you don't think something's quite right after you've been sent home.
Participant 041_2022AUBLC

Oh, no, no. I'm happy with that. All, good, doctors. So. But. Yeah. Um. Yeah, it's actually in between oncologist and the urologist, if, well, I can talk with them in at one time. Same here. I could put it on the same table and I can talk with two doctors that together. It's much easier sometimes, I got to see separate. You know, sometimes the information they are not sharing, and I'm in the middle, and I have to ask them or so I have to have a cystoscopy before treatment. After treatment or you know, it depends on the on the sometimes the doctors, the oncologist after your utilisation. You're just asking me to ask the oncologists So, you know, I'm in the middle sometimes. He's like, if I we can see together, it's much easier. But yeah, yeah, yeah, yeah. Maybe difficult. You know, I understand that.
Participant 015_2022AUBLC

Participant describes the expectation that future communication will include discussions about mental and emotional health

PARTICIPANT: I think. Everybody looks at their own little territory. They don't look at the full person.

INTERVIEWER: Okay. Anything else?

PARTICIPANT: They are more on the mental side because everybody that's, I think, a nurse changes dressing. A surgeon does the cutting and the camera work, but. They don't see the human being and the impact it has on the human being.
Participant 005_2022AUBLC

Well, yes, I think they just need to be much more empathetic when they don't have to, you know, they don't know us, they don't have to cry or anything, but they could at least sit down and talk to you. As a human being. And I think they should refer you to Allied Health. You know, your social worker or psychologist or counsellor or whatever you want to call them. You know, it just seems to be a very one on one relationship. That is, there's no there's no cross disciplinary consideration. I mean, I even looked in the first I looked in his waiting room, there are no brochures there for any other health care. Allied Health? Nothing. The only brochures for the hospitals where he where he where he performs the surgeries and procedures.
Participant 008_2022AUBLC

PARTICIPANT Yeah, probably would be, as I said, day. Like, um, I don't know, they could direct you to, um.

INTERVIEWER Like support groups.

PARTICIPANT Or group or social, you know, like a social worker or someone, you know, like, and you could to actually, um, I don't know if they've changed the system. I actually spoke to his nurse after, after he had given me the diagnosis, I went into, like he told me the diagnosis and then his nurse they had a nurse there at the time after that and she sort of explained the situation, you know, where it was going to happen next after that. And I felt that that was really good that she actually I know he's busy with all these other patients and stuff like that. So I found it really helpful

that he had someone that was there to explain what was going to happen. But what she did, she explained to, you know, what was going to happen, you know, like where it was going to go from there. Okay. You know, and you know.
Participant 044_2022AUBLC

Participant describes the expectation that future communication will include better ability to make appointments with specialists and contact them between appointments

Yes. Because sometimes you can't actually get to speak to your urologists or anyone on the urology team except through at the time of an appointment. Yes. I'm not sure. Like the three monthly scheduled appointment. If you've got a problem outside of that time and you don't get to it's not easy to get to speak to anybody without making a lot of fuss.
Participant 016_2022AUBLC

Perhaps just a bit more information. Yeah. That's I don't have very long with the doctor when. After I've had the operations or anything sort of 5 minutes or something. So. Yeah. I don't know whether I should have a second opinion, but then trying to get into a different specialist would take another six months or something, or even more. So that's why I just think I'm lucky that I've got someone that is treating me.
Participant 025_2022AUBLC

Not really, no. I don't know. Once you do get hold of a doctor, the information is free flowing and they're not afraid to tell you they are. You know what you want to hear or what you need to hear. Sorry. Yeah. Getting a hold of them is the hardest part because they are a busy, busy bunch of people.
Participant 031_2022AUBLC

Participant describes the expectation that future communication will include developing a care plan with follow-up

I think the this probably like finding aftercare, the support. It was something that, you know, I had to do by myself or actually through the help of my daughter. In hospital, they give you you they show you have to you try to change the bag and put you into signing up for the STATE Stoma Association. But I don't recall that there was any, any clues on or any sort of information given as to, to mental health afterwards and support groups that wasn't mentioned.
Participant 043_2022AUBLC

I think. Yeah. Okay. So once it's established that you are. In a situation that will require continuing. Or. Potentially continuing care and visits and appointments. I guess. If there was some point of contact, some stuff, some single point of contact rather than the reception desk and asking to be put through urology. Or. Or, you know, put through a oncology. Well, you put through to the cancer centre, which I didn't know existed until sort of 5 years in. Yeah. A point of contact, but not just emergency, or asking to speak to a urology registrar because you don't think something's quite right after you've been sent home.
Participant 041_2022AUBLC

Table 9.5: Expectations of future healthcare professional communication

Expectations of future communication	All participants		Early		Invasive		Advanced		Person with bladder cancer		Carer		Female		Male	
	n=49	%	n=20	%	n=10	%	n=14	%	n=44	%	n=5	%	n=17	%	n=32	%
Participant describes the expectation that future communication will be more transparent and information more forthcoming	14	28.57	7	35.00	3	30.00	**2**	**14.29**	12	27.27	**2**	**40.00**	4	23.53	10	31.25
Participant describes the expectation that future communication will be more empathetic	11	22.45	4	20.00	**1**	**10.00**	4	28.57	9	20.45	**2**	**40.00**	**1**	**5.88**	10	31.25
Participant describes the expectation that future communication will allow people more time to meet with their clinician to talk about all that they need to talk about	9	18.37	**6**	**30.00**	**3**	**30.00**	**0**	**0.00**	9	20.45	**0**	**0.00**	**7**	**41.18**	**2**	**6.25**
Participant has no recommendations/experienced good communication	7	14.29	1	5.00	**3**	**30.00**	2	14.29	6	13.64	1	20.00	**0**	**0.00**	7	21.88
Participant describes the expectation that future communication will include better communication between healthcare professionals, and better coordination of appointments	7	14.29	**5**	**25.00**	1	10.00	1	7.14	7	15.91	**0**	**0.00**	4	23.53	3	9.38
Participant describes the expectation that future communication will include discussions about mental and emotional health	6	12.24	3	15.00	1	10.00	2	14.29	6	13.64	**0**	**0.00**	**4**	**23.53**	2	6.25
Participant describes the expectation that future communication will include better ability to make appointments with specialists and contact them between appointments	5	10.20	3	15.00	**0**	**0.00**	1	7.14	4	9.09	1	20.00	2	11.76	3	9.38
Participant describes the expectation that future communication will include developing a care plan with follow-up	3	6.12	0	0.00	1	10.00	2	14.29	3	6.82	0	0.00	2	11.76	1	3.13

Expectations of future communication	All participants		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=49	%	n=29	%	n=19	%	n=15	%	n=33	%	n=20	%	n=28	%
Participant describes the expectation that future communication will be more transparent and information more forthcoming	14	28.57	11	37.93	3	15.79	7	46.67	7	21.21	9	45.00	5	17.86
Participant describes the expectation that future communication will be more empathetic	11	22.45	8	27.59	3	15.79	3	20.00	8	24.24	4	20.00	7	25.00
Participant describes the expectation that future communication will allow people more time to meet with their clinician to talk about all that they need to talk about	9	18.37	4	13.79	4	21.05	2	13.33	6	18.18	2	10.00	6	21.43
Participant has no recommendations/experienced good communication	7	14.29	5	17.24	2	10.53	4	26.67	3	9.09	4	20.00	3	10.71
Participant describes the expectation that future communication will include better communication between healthcare professionals, and better coordination of appointments	7	14.29	2	6.90	5	26.32	1	6.67	6	18.18	2	10.00	5	17.86
Participant describes the expectation that future communication will include discussions about mental and emotional health	6	12.24	4	13.79	2	10.53	2	13.33	4	12.12	4	20.00	2	7.14
Participant describes the expectation that future communication will include better ability to make appointments with specialists and contact them between appointments	5	10.20	0	0.00	4	21.05	1	6.67	3	9.09	1	5.00	3	10.71
Participant describes the expectation that future communication will include developing a care plan with follow-up	3	6.12	1	3.45	2	10.53	1	6.67	2	6.06	1	5.00	2	7.14

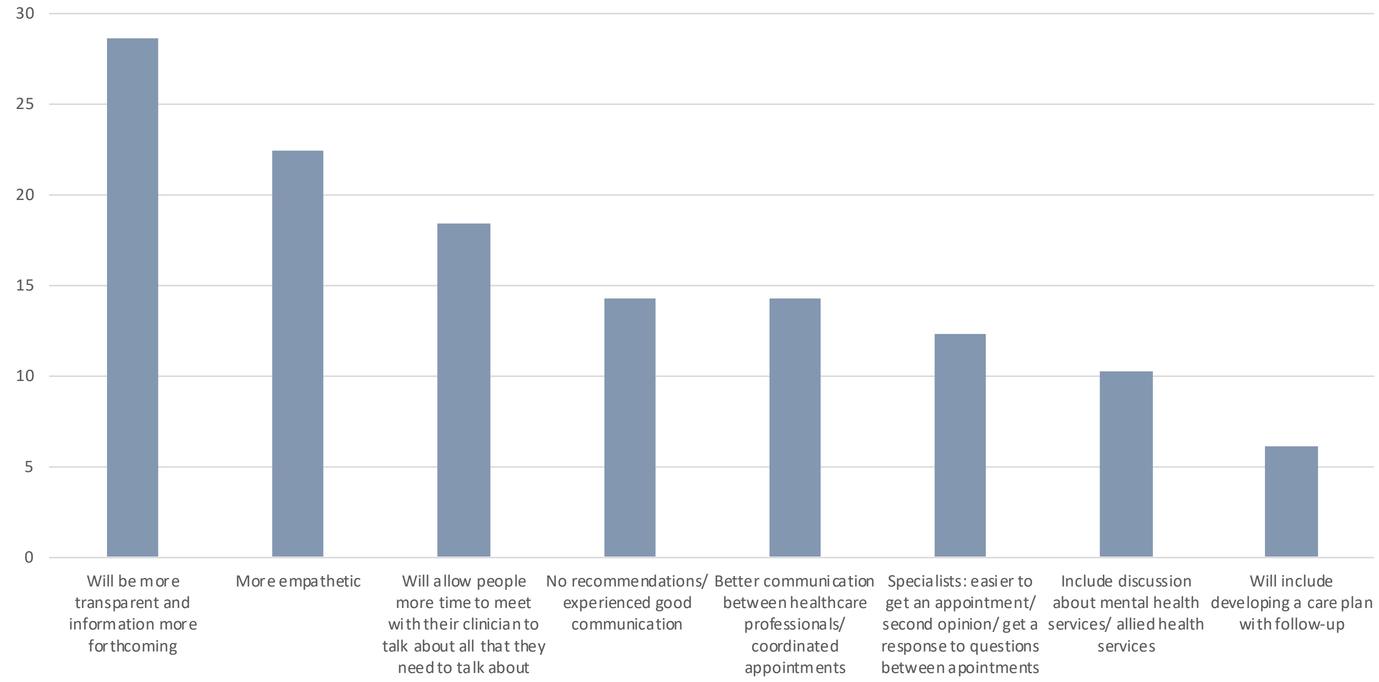


Figure 9.3: Expectations of future healthcare professional communication

Table 9.6: Expectations of future healthcare professional communication – subgroup variations

Expectations of future communication	Reported less frequently	Reported more frequently
Participant describes the expectation that future communication will be more transparent and information more forthcoming	Advanced (Stage IV) University Higher status	Carer to someone with bladder cancer Regional or remote Mid to low status
Participant describes the expectation that future communication will be more empathetic	Invasive (Stage III) Female	Carer to someone with bladder cancer
Participant describes the expectation that future communication will allow people more time to meet with their clinician to talk about all that they need to talk about	Advanced (Stage IV) Carer to someone with bladder cancer Male	Early (Stages 0 and I) Invasive (Stage III) Female
Participant has no recommendations/experienced good communication	Female	Invasive (Stage III) Regional or remote
Participant describes the expectation that future communication will include better communication between healthcare professionals, and better coordination of appointments	Carer to someone with bladder cancer	Early (Stages 0 and I) University
Participant describes the expectation that future communication will include discussions about mental and emotional health	Carer to someone with bladder cancer	Female
Participant describes the expectation that future communication will include better ability to make appointments with specialists and contact them between appointments	Invasive (Stage III) Trade or high school	University

Expectations of future care and support

Participants were asked in the structured interview whether there was any additional care and support that they thought would be useful in the future, including support from local charities. The most common theme was that participants had no recommendations or were satisfied with care received (n=15, 30.61%), and this was followed by 13 participants (26.53%) that described the expectation that future care and support will include more access to support services. Other expectations include, future care and support will include being able to connect with other patients through peer support (support groups, online forums) (n=9, 18.37%), will include more information and awareness of the condition (n=8, 16.33%), and will include mental health or emotional support (n=7, 14.29%).

Participant has no recommendations/is satisfied with care received

I think my group of people that have this condition of are as, well targeted for is any particular group. So I don't think in our case there's much it can be done, should be going to make life very much better. Apart from not having to have that kind of drastic operation in the first place. But if you've got to have it, it really is done quite well at the moment.
Participant 034_2022AUBLC

I think it's at the right place now there is information available. I know those charities are communicating with most health systems around Australia. And yes, I think the information is a lot easier to pass on and communicate.
Participant 019_2022AUBLC

Participant describes the expectation that future care and support will include more access to support services

What more can be done? I really appreciated the Cancer Council was their lawn mowing guy that came out. That was really nice. Um, yeah. So it's, you know, the country. I feel sorry for the country people because they, you know, they go three hour drive or four hour drive to come into the city for treatment. And then, you know, they got the Cancer Council, got a special, special lodge for the country people so they can, you know, stay there for the treatment, cancer treatment, which is nice. I feel sorry for the children when I was getting my radiation.
Participant 042_2022AUBLC

Well, I know, like there's some charities that support people with young patients, with families, you know, with meals and those kind of things. But for bladder cancer patients, I don't think there is anything specific like that, I'm not really sure what's available because it's not easy to find out. But, um. And I just, just in the public system. I think there's probably more things that are offered that might already exist, but I just don't know about them. But for me, I'm quite happy back at work and I don't think I need more things. And maybe, funneling into lymphedema services. If patients don't know about it so that if they've had a lot of lymph nodes out, that just for, you know prevention down the track, you know.
Participant 018_2022AUBLC

Um, I'd like to see a, some sort of a list of all the appliances and things available to people with a stoma. I mean, I do my order from this stoma society or whatever they called, and I have to do the research to find out what the hell is out there. I think there should be a a list of what what is good and what it's good for. We just just found a belt that has a little protective cover in it because he could never get comfortable with a seatbelt. Now, why we didn't get offered that from day one? I don't know, because it's brilliant.
Carer 005_2022AUBLC

Participant describes the expectation that future care and support will include being able to connect with other patients through peer support (support groups, online forums)

Okay, well, that's an interest. Yeah. What I'd like it's been rattling around in my brain for a couple of weeks now. What I would like to see a, probably a volunteer service where where people who have actually gone through the treatments can visit hospital, people who who've either had the operation or are going to have the operation. And we can all get together and talk and they can hear basically from the horse's mouth. What what treatment is like? Put their fears at ease. You can talk to a doctor. You can talk to any professionals. But to be honest, if you haven't actually go through it yourself, um, it doesn't really mean much to be. You know, I would love to see, you know, I would put my hand up in an instant to actually talk to someone about stoma treatment. I had a lovely stoma nurse. Yes. I didn't know what the hell this thing. Suddenly was going on the stomach and what the hell it was, you know? Yes. How to manage it, you know? You know, if I could go in and talk to someone,

say, well, it's not as bad as you think. Yeah. I've been doing this for a year. Yeah. What would you go. You talk to a crisis manager all the phone. You know, do you feel that they understand you feel depressed or whatever? Yeah. So if there was some sort of service that I could give back to someone who's going to do this if I can help someone. Yeah. Which is obviously why I'm talking to you as well.
Participant 023_2022AUBLC

I think again, this Facebook group was very good, so they organised a get togethers. We think that's what you need. You know, sometimes you need to meet face to face also.
Participant 028_2022AUBLC

Um, well, you know, I think it helps people to talk about it in a, you know, like a closed group of people on Facebook or one of these Inspire sites, you know? I think that helps a lot to talk about things. And there's one where there's men only, you know, they talk about sexual problems, this stuff, you know. Yeah. It's you know, it's. Yeah, I mean, that sort of thing is good. Um. I know we had a, you know, a session with the hospital where they spoke about chemotherapy and, you know, wigs and all that sort of stuff, you know, and using cosmetics to hide the skin rashes or whatever, you know, that was helpful to a certain extent.
Participant 042_2022AUBLC

Participant describes the expectation that future care and support will include more information and awareness of the condition

I would absolutely love some more charities around bladder cancer. Obviously, my cancer is relatively rare form of cancer of the cancer as well. So no one knew about it. So I think, again, just charities just to raise money for people that are going through everything, but also just to raise awareness of what it actually is and what the side effects of what the effects are. And yeah, because people don't understand that just something so simple can have such a major impact on your life.
Participant 009_2022AUBLC

I think maybe a little bit more, I think. Yeah. A bit more information earlier on. Might might have been a bit more beneficial. Yep. Um. So, like. Uh. From the, from the cancer centre. Because even to this point, there's a lot of people that have bladder cancer, but it's it for, for whatever reason, it's not widely known. I think it just needs to be more aware. More awareness out of and, you know, maybe GPs push, push it a little bit further because I mean, basically, what's that the the detection side of it. It's. Um. Just it's an ultrasound. I mean, it's nothing invasive about it. So there's no need for people to, to um cringe from it. So. Yeah. So maybe maybe a bit more maybe a bit more awareness that that bladder cancer actually exists?
Participant 040_2022AUBLC

I there's there's definitely not enough information out there on bladder cancer because I had no idea. How, how, how how is it that I know so much about without having without having had it or anyone had it? But how is it that I know so much about breast cancer and, you know, the pink ribbon? How is it that I know so much about prostate cancer? How is it that I know so much about Movember and mental health? You know how I'm. And how is it that I mean, nothing. Nothing, nothing, nothing. Zero. How is it that I know about prostate? I know no one in my family that have had it. But how is it that I knew nothing about bladder cancer? How I how that everything that I've had to find out has been through my own sourcing of information groups. How is it that you know. Well, that everything that I've had to find. Yeah. And now that I know that. So now I know that this month, May is Bladder Cancer Awareness Month. But I had to find that out until my husband found it, you know?
Carer 004_2022AUBLC

Participant describes the expectation that future care and support will include mental health/emotional support

I think mental support it should be in the in the package. Yeah. Like I have a nurse, a urologist, oncologist, mental support, a social worker or whatever.
Participant 005_2022AUBLC

Possibly. You know, when you get your diagnosis. A recommendation to go and talk to someone straight away would probably be very helpful. Not everyone wants to do it. You know, you people try and sort of tough it out or whatever. And I think that if if you had someone to talk to straight away, they can set some methods of dealing with such shock. Because, you know, you get this diagnosis and then you're just in a bit of a, a world of oblivion, almost. You just, really, I remember being quite vacant and just staring off into space. So I think as soon as you get a diagnosis or recommendation from, from the health professional and with direct links, go and speak to this person. Let's make a booking for you to go and see a counsellor straight away so you can start to deal with this and get some strategies in place.

Participant 014_2022AUBLC

Well, I think there should be more on the counselling or support side or even somebody just giving you a call. You know, when people are first diagnosed, maybe someone just to give them a call to say, you know, are you okay? Do you understand what it is.
Participant 010_2022AUBLC

Participant describes the expectation that future care and support will include specialist clinics or services where they can talk to professionals (in person, phone, online)

Yeah, I didn't really have any problems in my care. I imagine a lot of other people would have problems with attending appointments. Um, so. But then I know that I didn't avail at any stage, but I know that the LOCATION Hospital to have all sorts of support systems where you can, you know, they have a bus that will pick you up and take you for appointments, etc.. Um, I didn't, did, didn't have to avail myself of that because I either drove myself or my wife was able to and then my son was a back up on top of that again. So, um, I think those services are terribly important for some people, but that weren't for me. And then there was, there was the issue for me and for others was the issue, well, what happens if something goes wrong on Saturday night at 11:00? You know what, what, what, what what would other people do? Not me or what would I do? Um, so they. They also have a LOCATION hospital have a system there for dealing with that as well. Yeah. Um, I think that that's just so terribly important. Someone to ring and say. I'm, I'm cancer. I'm a, I'm a, I'm a bladder cancer patient, and I've got bleeding or whatever it might do. What should I do? They've got those services. They're terribly important. I didn't have to use any of them, but they did. Terribly important.
Participant 029_2022AUBLC

Um. I don't, I don't think. And maybe I, further on if my cancer recurs and and progresses may maybe I will need most I probably will need support of some sort but I just really think that. They need, I just said it just needs to be a look at the way that. a person diagnosed with cancer is treated right from the beginning. And about what? Communication and about having support. It's not even I don't even know what sort of support that someone that is prepared to talk to you, that has information and knowledge right from the beginning, rather than you just left in the dark, floundering into secretive, find your own information. And to coordinate your own care. I think all the as I have said in all the other times, that's the thing that's missing. Even, you know, to be, you know, when when I'm at the hospital there for most of the day, some days, you're not even offered a meal or something to eat. Um. You know, just just to have had that available would be really helpful. You know, the nurse would usually get me a cup of tea afterwards, but they're running to do that. And we feel really bad that when it's been so long since you've had any fluids. Yeah. You know, you're hanging out for a drink. You know, I think it'd be really good just to have that as part of the normal type, normal part of treatment, rather than then having to do it as a special request.
Participant 002_2022AUBLC

Participant describes the expectation that future care and support will include support for side effects of treatment

Um. No, the supply and all. That's pretty good. Probably because it's, I think, based on a. It's a semi-professional sort of thing. They've got, they've got paid workers and whatever in these organisations, but you know, that's a dollar thing as well because the Government subsidises it. You basically you've only got paid postage and it's probably people who can't afford the postage, you know, it's 15 bucks a month for most people in Australia. I think it's around that price. Yeah, some people probably struggle with that little bit of extra money. I'm very, very, very pleased that the government support them because I think if you bought it, I don't know the cost but buying as an individual would be, I know with the Americans struggle a lot because they've got to and they've got their supplies where I can abide by medical advice and do the changes and all the stuff as I should do them just they live probably a little bit more professionalism in that side of. Your not 100% in some cases, some people will explain, don't seem to be very confident what they're allowed to have and what they're not. They put a magazine out, but it's not it's not spelt out. If you're a newcomer coming in, it's not there in black and white for you or as clear as it probably could be, you know.

I know. I know. I can go back to a stoma nurse, but I don't believe I should be wasting her time on that sort of, you know, it's an admin thing, you know? Yeah. Not a Nursing thing, you know?
Participant 011_2022AUBLC

Yeah, definitely. More support. More, more talk about that. More awareness and being able to, you know, bring it out in the open and, and let people know that, you know, this life is going to be different. Post bladder removal, you know, knowing what to expect,

knowing how to deal with it, you know, even maybe support groups for something like that where people can go and they can talk about it. Because I know for us personally that being affected didn't affect their marriage, but it did affect intimacy and that affects the intimacy. If it's not there, that's how you relate to one another as well. Yeah, because it then starts to affect your mental attitude and how you're feeling about yourself as a person. So I feel like there's a whopping big hole there.
2_2022AUBLC

Um. No, the supply and all. That's pretty good. Probably because it's, I think, based on a. It's a semi-professional sort of thing. They've got, they've got paid workers and whatever in these organisations, but you know, that's a dollar thing as well because the Government subsidises it. You basically you've only got paid postage and it's probably people who can't afford the postage, you know, it's 15 bucks a month for most people in Australia. I think it's around that price. Yeah, some people probably struggle with that little bit of extra money. I'm very, very, very pleased that the government support them because I think if you bought it, I don't know the cost but buying as an individual would be, I know with the Americans struggle a lot because they've got to and they've got their supplies where I can abide by medical advice and do the changes and all the stuff as I should do them just they live probably a little bit more professionalism in that side of. Your not 100% in some cases, some people will explain, don't seem to be very confident what they're allowed to have and what they're not. They put a magazine out, but it's not it's not spelt out. If you're a newcomer coming in, it's not there in black and white for you or as clear as it probably could be, you know.

I know. I know. I can go back to a stoma nurse, but I don't believe I should be wasting her time on that sort of, you know, it's an admin thing, you know? Yeah. Not a Nursing thing, you know?
Participant 011_2022AUBLC

Table 9.7: Expectations of future care and support

Expectations of future care and support	All participants		Early		Invasive		Advanced		Person with bladder cancer		Carer		Female		Male	
	n=49	%	n=20	%	n=10	%	n=14	%	n=44	%	n=5	%	n=17	%	n=32	%
Participant has no recommendations/is satisfied with care received	15	30.61	7	35.00	4	40.00	3	21.43	14	31.82	1	20.00	5	29.41	10	31.25
Participant describes the expectation that future care and support will include more access to support services	13	26.53	4	20.00	2	20.00	5	35.71	11	25.00	2	40.00	3	17.65	10	31.25
Participant describes the expectation that future care and support will include being able to connect with other patients through peer support (support groups, online forums)	9	18.37	1	5.00	4	40.00	3	21.43	8	18.18	1	20.00	4	23.53	5	15.63
Participant describes the expectation that future care and support will include more information and awareness of the condition	8	16.33	4	20.00	0	0.00	2	14.29	6	13.64	2	40.00	3	17.65	5	15.63
Participant describes the expectation that future care and support will include mental health/emotional support	7	14.29	5	25.00	0	0.00	0	0.00	5	11.36	2	40.00	2	11.76	5	15.63
Participant describes the expectation that future care and support will include specialist clinics or services where they can talk to professionals (in person, phone, online)	3	6.12	1	5.00	2	20.00	0	0.00	3	6.82	0	0.00	1	5.88	2	6.25
Participant describes the expectation that future care and support will include support for side effects of treatment	3	6.12	1	5.00	0	0.00	0	0.00	1	2.27	2	40.00	0	0.00	3	9.38

Expectations of future care and support	All participants		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=49	%	n=29	%	n=19	%	n=15	%	n=33	%	n=20	%	n=28	%
Participant has no recommendations/is satisfied with care received	15	30.61	7	24.14	8	42.11	4	26.67	11	33.33	4	20.00	11	39.29
Participant describes the expectation that future care and support will include more access to support services	13	26.53	9	31.03	4	21.05	3	20.00	10	30.30	4	20.00	9	32.14
Participant describes the expectation that future care and support will include being able to connect with other patients through peer support (support groups, online forums)	9	18.37	4	13.79	5	26.32	4	26.67	5	15.15	4	20.00	5	17.86
Participant describes the expectation that future care and support will include more information and awareness of the condition	8	16.33	6	20.69	2	10.53	2	13.33	6	18.18	3	15.00	5	17.86
Participant describes the expectation that future care and support will include mental health/emotional support	7	14.29	5	17.24	2	10.53	4	26.67	3	9.09	3	15.00	4	14.29
Participant describes the expectation that future care and support will include specialist clinics or services where they can talk to professionals (in person, phone, online)	3	6.12	1	3.45	2	10.53	1	6.67	2	6.06	1	5.00	2	7.14
Participant describes the expectation that future care and support will include support for side effects of treatment	3	6.12	3	10.34	0	0.00	1	6.67	2	6.06	2	10.00	1	3.57

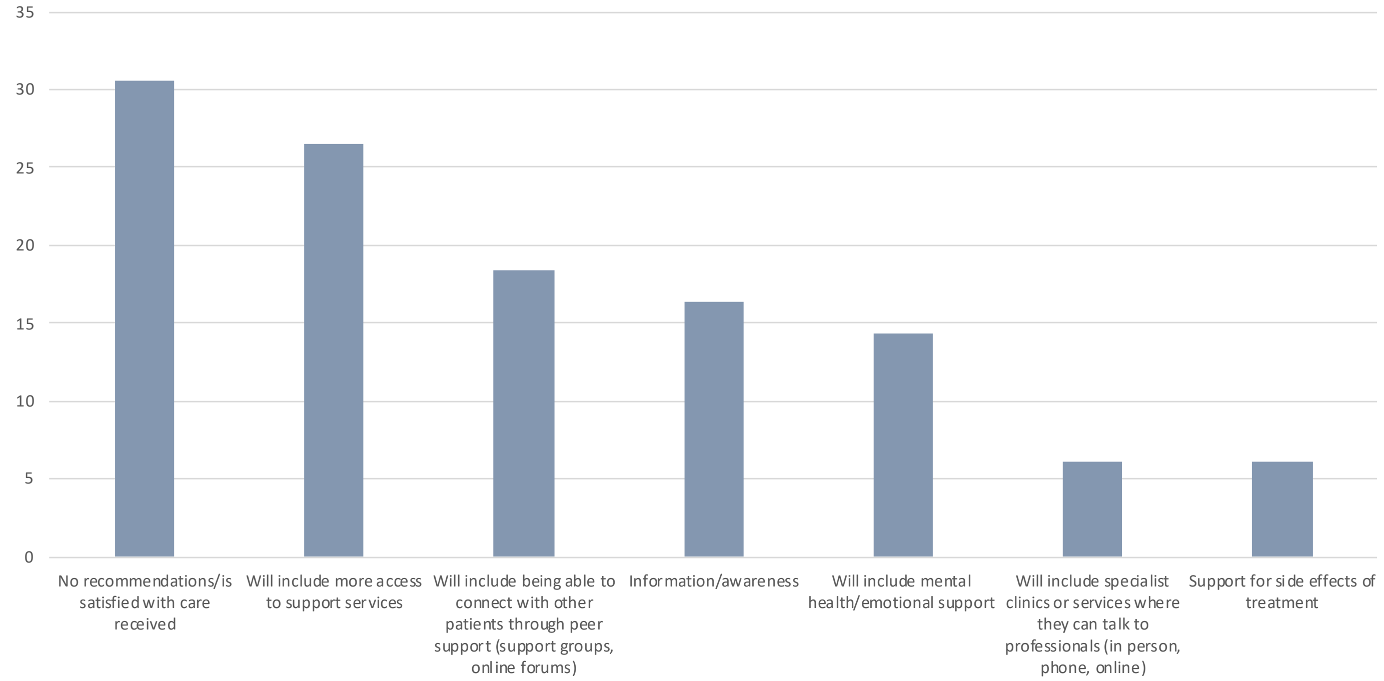


Figure 9.4: Expectations of future care and support

Table 9.8: Expectations of future care and support – subgroup variations

Expectations of future care and support	Reported less frequently	Reported more frequently
Participant has no recommendations/is satisfied with care received	Carer to someone with bladder cancer Mid to low status	University
Participant describes the expectation that future care and support will include more access to support services	-	Carer to someone with bladder cancer
Participant describes the expectation that future care and support will include being able to connect with other patients through peer support (support groups, online forums)	Early (Stages 0 and I)	Invasive (Stage III)
Participant describes the expectation that future care and support will include more information and awareness of the condition	Invasive (Stage III)	Carer to someone with bladder cancer
Participant describes the expectation that future care and support will include mental health/emotional support	Invasive (Stage III) Advanced (Stage IV)	Early (Stages 0 and I) Carer to someone with bladder cancer Regional or remote

What participants are grateful for in the health system

Participants were asked in the structured interview what aspects of the health system that participants are grateful for. The most common theme was that participants were grateful for healthcare staff (n=22, 44.90%), and this was followed by 14 participants (28.57%) that described that participants were grateful for low cost or free medical treatments through the government, and 13 participants (26.53%) were grateful for timely access to treatment. Other participants were grateful for access to private healthcare or private insurance (n=10, 20.41%), and grateful for the entire health system (n=7, 14.29%).

Participant is grateful for healthcare staff

Well, I guess, um, I'm grateful that I haven't had to pay for the medications and the chemo and the immunotherapy drugs. I'm not sure what they cost, but I'm sure they wouldn't have been cheap. I guess I was lucky to get in as quickly as I did. So, you know, I'm really grateful for that. And I am grateful for the nurses that are compassionate and kind and treat you like a person.
Participant 002_2022AUBLC

I'm just having. Oh, gee, I think. Yeah, I guess in the most part, having really empathic or empathetic specialists who are willing to answer questions and give clarity. Yeah. So I'm incredibly grateful to all of them.
Participant 020_2022AUBLC

I've been able to get access to some great medical specialists along the way, medical professionals, health professionals along the whole range, nursing staff all the way through the top up clinicians. So I feel grateful that I know there's other places that you can go to, don't have access to it.
Participant 035_2022AUBLC

Yeah, the oncology nurse at the HOSIPTAL. She was awesome. She was she like spoke to me two or three times before the operation. What was going to happen? Like explain the whole how long will it be in hospital for how long the operation was going to be for. And, you know, she found, I think her name was NAME. I found her really good. She explained everything like two or three times. So you knew what what procedure you were going to be happening to. You go to hospital. I think it was the day before the operation and she came in. I was having operation on Tuesday morning and she came up to me Monday afternoon and she explained, well, I went and seen her like I think it was two or three weeks before, a week beforehand I had had the pre-op and I went and had an interview with NURSES NAME and she explained the whole system what was going to happen, you know, like this will happen. You got to have a pick line and you'll stay overnight, you have a drip and then you have the operation would be 7 or 8 hours. And she said, you could end up in intensive care, but you said 9 times out of 10 you won't. But yeah, she she was really good. I found it. She explained the whole whole procedure
Participant 044_2022AUBLC

Participant is grateful for low cost/free medical treatments through the government

Oh yes, definitely. And I think yeah, I totally agree with that. The clinic that I go to, my local public hospital, which is a big one. Um to have that, the all the chemotherapy treatments have been wonderful. All I've had to pay for there is the medication which everyone should be able to afford. It was not prohibitive. And so, yeah, that's the main thing, I think. And, you know, there was no there's I like the fact that this I mean, I've paid to a health fund, but I like the fact that there's no demarcation between, you know, the rich and the poor there. It's just everyone. That's where you go for your chemotherapy. Yeah. Whereas things like radiotherapy, you know, there are private places you can have it sooner because you've got the money to pay for it. And that's what we all like to see our health system that treats people fairly no matter what the financial circumstances.
Participant 010_2022AUBLC

The hospital care. It was just incredible, really. Okay, like, I again had never experienced being hospitalised and it was a massive operation. Um, you know, um, just their care was incredible, like out of this world stuff out and nothing was ever too difficult. So, yeah, I found that to be really, really great. Um, I think the bulk billing, um, through my GP and for my CT scans and things like that, that's been really good. Um, yeah, I think they, they really help in that, um, you know, financial sense.
Participant 022_2022AUBLC

The main thing is the cost to you know and I know people, they lose their life savings in other countries. Once you have it, it's not a cheap treatment, you know, and if I had to pay I would be, you know, I have no more, you know, I don't know how to pay it. I don't have that money.
Participant 028_2022AUBLC

Participant is grateful for timely access to treatment

Oh, okay. Well, that's that's a no brainer because, after having come back from COUNTRY to be honest, if I'd have been there. And I'm not the I'm not the downtreading in my my country of origin, but I'd probably still be bloody waiting for the operation.
Participant 023_2022AUBLC

Yeah just the level of care and the speed that they've go me into surgeries and there are multiple times the nurses the doctors everyone's been amazing in the fact that I haven't paid for it. It's just, you know, it's it's unbelievable. So no, I wouldn't anything. Everything's been a fantastic.
Participant 024_2022AUBLC

Yeah, so I guess what I've been grateful for is because I know like during COVID and as I'm on this Facebook group in Australia even that there was limited access to BCG and we never experienced that. We were lucky. So if, if I'm aware that if you can't get access to BCG and it's chemo which comes with a whole other bunch of side effects. So I'm very grateful for that. But he does hope has always going to have access to BCG.
Carer 003_2022AUBLC

The fact that we have private medical insurance, I think I'm very grateful that that we have that ability to have it and we can get treated immediately. Immediately. Yes. That's incredible. Right. And and having a second opinion, you know, being able to go to HOSPITAL and have a relatively, you know, a reasonable timeframe to get a second opinion. I think that's been fantastic finding, you know, having. I think that there should be a patient database. This should be a patient influenced database of doctors. So, you know. So I should be able to go on my. Go on. Get on to saying that, you know, 3000 patients have have recommended this specialist or. You know, I said there

should be a database of of doctors and specialists and that that patients have actually rated.
Carer 004_2022AUBLC

Participant is grateful for access to private healthcare/private insurance

Oh, just all of it. God, you know. I think we're right. We're very, very lucky. And I mean, I am I am also fortunate enough that I can have private health care as well. I can afford private healthcare. For how much longer? I'm not sure of it
Participant 004_2022AUBLC

Oh, I'm very grateful to my GP and how quick she dealt with. I'm grateful for my urologist, very patient with me and very clearly explaining things. The nurses so far are very caring and supportive and. And yeah, there's an advantage of private health system you're in there with in no time, because on a Tuesday I went to my GP Wednesday ultrasound. The next Tuesday I was with my urologist and on Friday it was in theatre. So yeah. Yeah. You don't have much time to think. And two weeks later I was back again. Because there was a bit of cancer found in my ureter. Also, I have to go back again. Okay. And in hindsight, they should have put a stent in there, but that's always in hindsight then it wouldn't have. That's a lot of drama that came after that. But, uh, yeah. It's but the. The thing with the cancer, I, um. They can treat it, but not cure it. And that's my eye opener. And. Yeah. That's the hardest thing, I think.
Participant 005_2022AUBLC

I think I was very fortunate to be able to continue on with BCG because I understand that there were shortages and the powers that be within the hospital system made sure that there was always some for me, which was because I got quite anxious. I mean, even though I hated it, I knew that I had to have it and they were talking about shortages. And then at one point my urologist said, she said, Oh, we might stop you now. And I was like, No, that's not that's too soon. I don't want to stop now. And he said, Oh, well, that's up to you then. And he made sure that there was BCG available. So I think in other countries that may not have been the case, but I think the big thing was I am very, very lucky that I had private health insurance because I think to have gone to a general hospital might have been quite a different situation. I probably would have got a different nurse every time, probably got male nurses and maybe been told that the BCG was unavailable for me with. Whereas, I had the same people who were, you know, reliably in place every time I went, which was reassuring and the BCG was available. So yeah, I think Australia, it wasn't Medicare, it was my private insurance that gave me that support really. But living in Australia certainly helped.
Participant 036_2022AUBLC

Participant is grateful for the entire health system

Yeah just the level of care and the speed that they've go me into surgeries and there are multiple times the nurses the doctors everyone's been amazing in the fact that I haven't paid for it. It's just, you know, it's it's unbelievable. So no, I wouldn't anything. Everything's been a fantastic.
Participant 024_2022AUBLC

All, all of it. Yeah. I think we're very, very lucky here. M,y you look at America. Very different there. Yeah, we're very lucky, very, very fortunate here. And, um. Yeah. Looking back, I was grateful for all of that. I just wish that all of what he went through could have saved his life. That's all.
2_2022AUBLC

Oh, being grateful for it all, to be honest, it saved his life. So that's fine with me and some of the I mean, the chemotherapy nurses were just outstanding, they were just so empathetic and lovely.
Carer 005_2022AUBLC

Table 9.9: What participants are grateful for in the health system

What participants are grateful in the health system	All participants		Early		Invasive		Advanced		Person with bladder cancer		Carer		Female		Male	
	n=49	%	n=20	%	n=10	%	n=14	%	n=44	%	n=5	%	n=17	%	n=32	%
Participant is grateful for healthcare staff	22	44.90	8	40.00	6	60.00	6	42.86	20	45.45	2	40.00	9	52.94	13	40.63
Participant is grateful for low cost/free medical treatments through the government	14	28.57	6	30.00	5	50.00	3	21.43	14	31.82	0	0.00	5	29.41	9	28.13
Participant is grateful for timely access to treatment	13	26.53	7	35.00	2	20.00	2	14.29	11	25.00	2	40.00	5	29.41	8	25.00
Participant is grateful for access to private healthcare/private insurance	10	20.41	3	15.00	2	20.00	4	28.57	9	20.45	1	20.00	7	41.18	3	9.38
Participant is grateful for the entire health system	7	14.29	3	15.00	1	10.00	1	7.14	5	11.36	2	40.00	1	5.88	6	18.75

What participants are grateful in the health system	All participants		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=49	%	n=29	%	n=19	%	n=15	%	n=33	%	n=20	%	n=28	%
Participant is grateful for healthcare staff	22	44.90	12	41.38	9	47.37	7	46.67	14	42.42	9	45.00	12	42.86
Participant is grateful for low cost/free medical treatments through the government	14	28.57	8	27.59	6	31.58	4	26.67	10	30.30	4	20.00	10	35.71
Participant is grateful for timely access to treatment	13	26.53	7	24.14	6	31.58	5	33.33	8	24.24	6	30.00	7	25.00
Participant is grateful for access to private healthcare/private insurance	10	20.41	4	13.79	6	31.58	2	13.33	8	24.24	2	10.00	8	28.57
Participant is grateful for the entire health system	7	14.29	6	20.69	1	5.26	3	20.00	4	12.12	4	20.00	3	10.71

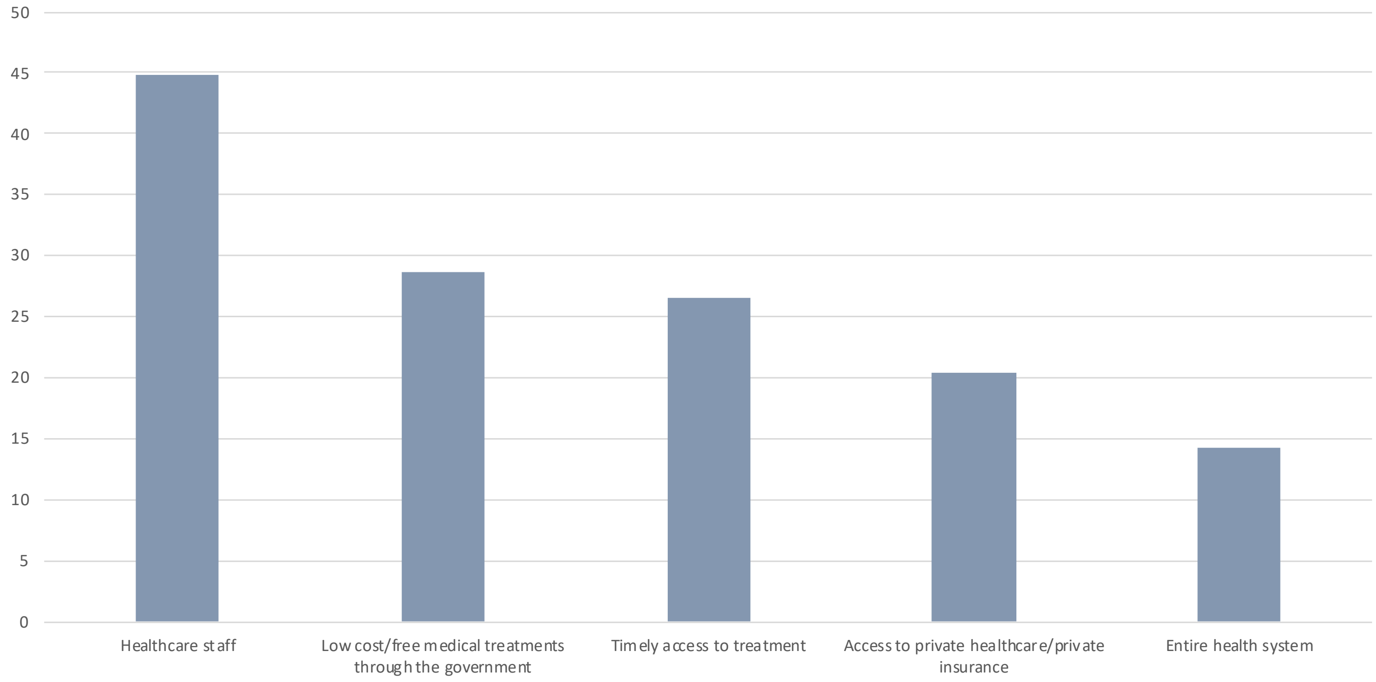


Figure 9.5: What participants are grateful for in the health system

Table 9.10: What participants are grateful for in the health system – subgroup variations

What participants are grateful in the health system	Reported less frequently	Reported more frequently
Participant is grateful for healthcare staff	-	Invasive (Stage III)
Participant is grateful for low cost/free medical treatments through the government	Carer to someone with bladder cancer	Invasive (Stage III)
Participant is grateful for timely access to treatment	Advanced (Stage IV)	Carer to someone with bladder cancer
Participant is grateful for access to private healthcare/private insurance	Male Mid to low status	Female University
Participant is grateful for the entire health system	-	Carer to someone with bladder cancer

Symptoms and aspects of quality of life

Participants were asked to rank which symptoms/aspects of quality of life would they want controlled in a treatment for them to consider taking it, where 1 is the most important and 11 is the least important. A weighted average is presented in Table 9.11, Figure 9.6. With a weighted ranking, the higher the score, the greater value it is to participants.

The most important aspects reported were pain, nausea and vomiting and, diarrhoea. The least important were hair loss and, mouth ulcers.

Table 9.11: Symptoms and aspects of quality of life

Symptoms and aspects of quality of life	Weighted average (n=42)
Pain	7.10
Nausea and vomiting	6.62
Diarrhoea	4.55
Tiredness and Fatigue	4.17
Loss of appetite	3.93
Constipation	3.40
Hair loss	3.24
Mouth ulcers	3.00

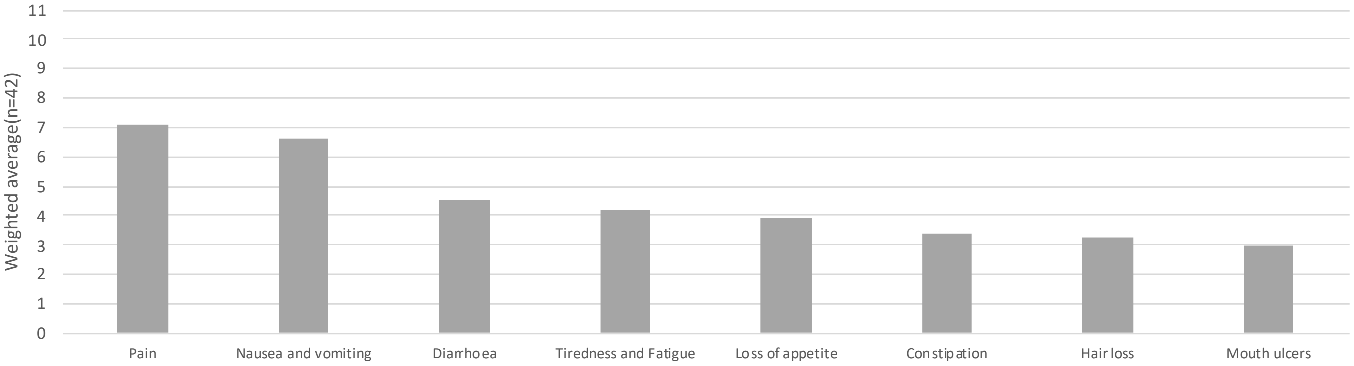


Figure 9.6: Symptoms and aspects of quality of life

Values in making decisions

Participants were asked to rank what is important for them overall when they make decisions about treatment and care, where 1 is the most important and 8 is the least important. A weighted average is presented in Figure 9.7. With a weighted ranking, the higher the score, the greater value it is to participants.

The most important aspects were “"How safe the medication is and weighing up the risks and benefits"”, and “"The severity of the side effects"”. The least important were “"Ability to follow and stick to a treatment regime"” and “"The financial costs to me and my family"”.

Table 9.12: Values in making decisions

Symptom	Weighted average (n=47)
How safe the medication is and weighing up the risks and benefits	7.00
The severity of the side effects	6.83
Time impact of the treatment on my quality of life	5.70
How the treatment is administered	3.55
How personalised the treatment is for me	4.19
The ability to include my family in making treatment decisions	3.53
Ability to follow and stick to a treatment regime	2.62
The financial costs to me and my family	2.57

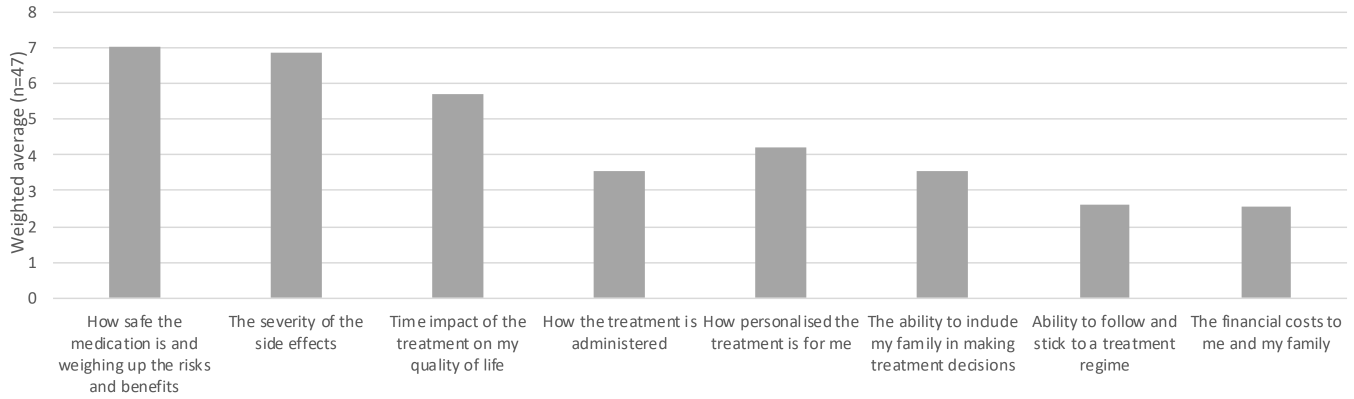


Figure 9.7: Values in making decisions

Values for decision makers

Participants were asked to rank what is important for decision-makers to consider when they make decisions that impact treatment and care, where 1 is the most important and 5 is the least important. A weighted average is presented in Figure 9.8. With a weighted ranking, the higher the score, the greater value it is to participants.

The most important values were "Quality of life for patients", and "All patients being able to access all available treatments and services". The least important was "Economic value to government and tax payers".

Table 9.13: Values for decision makers

Values for decision makers	Weighted average (n=47)
Economic value to government and tax payers	1.36
Economic value to patients and their families	2.57
Quality of life for patients	4.40
Compassion	2.91
All patients being able to access all available treatments and services	3.74

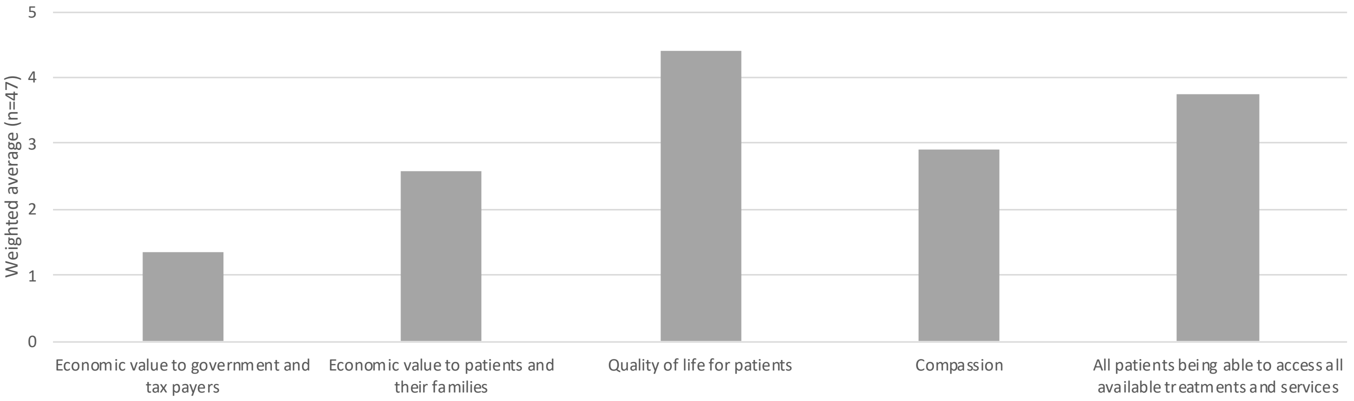


Figure 9.8: Values for decision makers

Time taking medication to improve quality of life

Participants were asked in the online questionnaire, how many months or years would you consider taking a treatment, provided it gave you a good quality of life, even if it didn't offer a cure.

The most commonly participants would use a treatment for more than 10 years for a good quality of life even if it didn't offer a cure (n = 17, 36.17%), followed by less than a year (n=14, 29.79%), and between 1 and 5 years (n=12, 25.53%) (Table 9.14, Figure 9.9).

Table 9.14: Time taking treatment to improve quality of life

Time taking medication to improve quality of life	Number (n=47)	Percent
Less than 1 year	14	29.79
1 to 5 years	12	25.53
5 to 10 years	4	8.51
More than 10 years	17	36.17

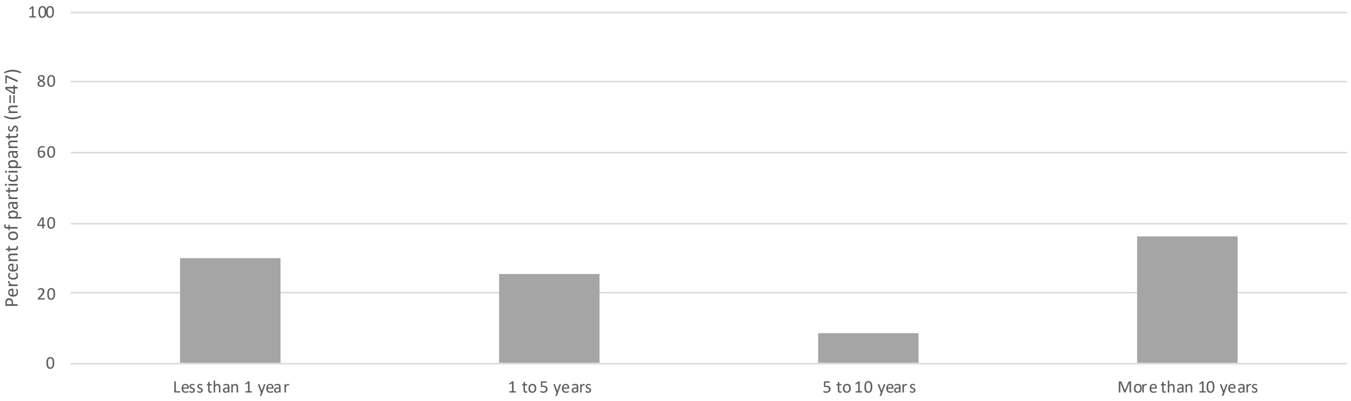


Figure 9.9: Time taking treatment to improve quality of life

Messages to decision-makers

Participants were asked, "If you were standing in front of the health minister, what would your message be in relation to your condition?" The most common message was to help raise community awareness (n=16, 32.65%). This was followed by that they are grateful for the healthcare system and the treatment that they received (n=11, 22.45%), to invest in screening or early detection (n=7, 14.29%), to improve access to support and care (n=7, 14.29%), and to be compassionate and empathetic (n=6, 12.24%).

Participant's message is to help raise community awareness

Oh, I would say. So I'm very thankful for all the treatment and care I've had. It's not, bladder cancer it's not massively common, but it's not uncommon, I think this 3000 cases a year. And I think an awareness campaign needs to be almost like a bowel cancer thing where. You know, you do a routine check or something like that just to see. Um. Because, you know, I got onto it early and I'm probably very lucky. Other people have probably thought, yeah, a bit of blood in urine will go away. And it did, you know, I had it for one day and then there's nothing I could have left it and thought nothing of it. Thought that my body had fixed itself. So if I was to talk to the Health Minister, I would decide an awareness. Not just of, you know, breast cancer and bowel cancer, but. You know, and heart disease. But of. Yeah. Are they all cancers, really? Yeah. I mean, I didn't even know about bladder cancer till I had it.
Participant 014_2022AUBLC

I think there needs to be more stoma nurses available, and I think that they need to be available 24/7. So whether there's a hotline or that sort of thing, and it probably doesn't warrant at the numbers of patients, but in comparison to other cancers and that sort of thing. But I think it's important to people that have experienced it to have easy access to a stoma nurse. I would probably. Now the Ostomy Association's pretty good. The fact that all of our supplies are covered by Medicare is excellent. Forgot to mention that, your supplies are really, really good. I pay something like $60 a year membership for the Ostomy Association. Then pay for delivery. And that's it. So very lucky in that respect. Hmm. Yeah. I think that's about that's what I you know, this stoma nurses the availability of stoma nurses. And the other thing is awareness. I mean, okay, I know that's not really relevant to the question of if I was standing in front of the health minister, that's what I'd be pushing for, for awareness. Like, it's Bladder Cancer Awareness Month and the only things I see coming out from bladder cancer organisations or charities.
Participant 022_2022AUBLC

Excuse me. To, um I guess they put more funding. You know, there's a lot of talk about funding certain kinds of cancers. So I suppose the message would be to to, fund bladder cancer. I'm not sure how how it's not really talked about. We hear about lung cancer. We hear about breast cancer. But there's not so much awareness of bladder cancer. So of us want him to do something to increase the awareness and also to, um, excuse me, to, to alert people to the symptoms of of

bladder cancer because they kind of creep up on you, you know, the obvious.
Participant 043_2022AUBLC

Participant's message is that they are grateful for the healthcare system and the treatment that they received

I'd have to shake his hand and say, well, pretty good at the moment. Yeah. Yeah. I certainly as I said this morning, a couple of negatives. But I think, you know, enables knowing that things are only minor irritation and more than you know you know, there's 5% of problems and 95% positivity. You know, you don't do much better than that most things in life
Participant 011_2022AUBLC

Oh, I have to tell you that I've been extremely satisfied with the system and with how I have been treated at HOSPITAL and I've been in other hospitals, which I regard to HOSPITAL as probably the best hospital I've ever been in, and I've been in a lot of hospitals with various injuries playing sport and that sort of thing. So. Yeah, I would have to say the treatment, I can't fault, except I have had a couple of minor things which I've already mentioned about the aftercare. When you are in a procedure in a bit of consultations after your procedure, it would would help that apart from that. You know, it's not a drama. When I've been in there and waited for seven or 8 hours to be done, I spent a day with people who have gone off their heads, about have to wait so long to get my head around it and that I've just got to sit there and wait, read the paper or something of it. Some people do have short tempers. I've seen medical staff go up to them and say, do you realise you have all this treatments for nothing. And that sort of shut them up pretty quick. So anyway, that treatment no dramas, it's been no problems at all really.
Participant 021_2022AUBLC

I'd say it's perfect, to be honest. That's just the way the system is designed. I mean, again, just based on my experience. Yes. Just everything's done methodical way. And the fact is, I didn't have to pay for pretty much any of it is just phenomenal. So I wouldn't change a thing. I think it's perfect.
Participant 024_2022AUBLC

Participant's message is to invest in research (including to find new treatments)

I think I would just go right to the root, which is to me, okay, it's not a sexy cancer, but you need to give it more funding. It's just it's just not it's not good enough that certain cancers that celebrities have are given far more money and far more airtime. It's it's got to be more funded and as in more research and just also picked up on at an earlier stage those things. I mean, especially with men, they tend to although men tend to ignore things like that. And unfortunately, as women, much as they might not ignore it, it tends to be more aggressive in women.
Participant 010_2022AUBLC

Okay. For the bladder cancer? Yeah. Yeah, please. Spend more money for research. We need a cure.
Participant 015_2022AUBLC

They created this specific bladder cancer centre and all research is being done with that. Also, they have a massive database, so all kinds of that kind of research and and do with that because lots of research is only short term. But if you have a big database, you can have data over 20 years or whatever. But they, they keep all the samples. Yeah. And you can study it for, for all kinds of things. And now you have to go for everything, everywhere and everybody. It would be handy if you have one stop. It's also there. When you enter there it's one stop and that's the end of the day. You know everything and make your plan and treatment.
Participant 005_2022AUBLC

Participant's message is to invest in screening/early detection

I don't know. I think I only what I'd said earlier that the the detection, early detection would be paramount. And that could save a lot of costs in the health system further down the line. And possibly also that Australia should look at um switching the market for BCG because um it nearly got wiped out. Uh, one of the years I was having it the whole, the. It's a, it's, it's grown from, I think from potato or something. It's the thing they treat tuberculosis with regularity.
Participant 006_2022AUBLC

Um. Hmm. If we were able to have more choices for types of treatment. Let's get them here. Let's have them here. Make them available. It's important and the other thing is, like I said to you earlier on, is um making bladder cancer one of the cancers is up there

with all the others. And I just, you know, screening. Can we get screening? Is there any available screening for early diagnosis of bladder cancer? If there is, why can't that be? You know, rolled out like the bowel cancer screening and the breast cancer screening. That's important. I think that's a big one. That's important if it is a possibility. Let's make it a possibility. Let's have bladder cancer screening if that's what it takes. Urine tests. I mean, urine test from a certain age. I don't know. Yeah. So those. Yeah, I think just. Just the. Anything that would help promote awareness and early diagnosis. Yes.
Carer 002_2022AUBLC

What would be my message to him? My message to him would be that, you know, make be educated and aware of the warning signs and and react. Because early diagnosis saves lives. So that would be my first message to him. And you know, the GP shouldn't be so hesitant. You know, when, when you keep getting blood to send you for an initial scan. And my second message would be that I've been really lucky that I've been able to afford my the cost of my treatment. But robotic surgery is, you know, said that treatment I had had had was really wonderful in speeding up my recovery. And, you know, we should look at making that available to all, not just the ones that can afford to pay the additional costs associated with it. Okay.
Participant 032_2022AUBLC

Participant's message is to improve access to support and care

I think they need more like, more information, more support, more access to doctors, and more access outside the regular scheduled appointments or to the whole team, the urology team.
Participant 016_2022AUBLC

Oh, that's a big one. Um, I think, that probably there needs to be more support because people with bladder cancer, what goes on in their homes when they're trying to deal with it is huge. And I think once, especially if they get into the situation where they have muscle invasive cancer, bladder cancer, which I was fortunate that I didn't, what goes on with that? As with any cancer, it's the needs to be more care offered, more in-home treatments and definitely more financial support to people in that situation. But I'm a little bit remote from all that because, my was all handled okay. But I would push for definitely more support in home, you know, because if you're on your own and you had muscle invasive and you were being on chemotherapy, I think it would be absolutely awful to have to try and cope with it on your own.
Participant 036_2022AUBLC

Participant's message is to be compassionate and empathetic

The staff in general. Thank you very much for doing an excellent job. Keep showing empathy and keep treating your patients as family members and friends and, surgeons, watch Patch Adams, read about Patch Adams.
Participant 019_2022AUBLC

PARTICIPANT: Well, now that's an interesting one. Firstly, I'd be really a I feel quite angry towards the authorities because they only take on the popular cancers, the popular ones that attract the funding. And so for the politicians to be popular, they give all the funding of research to things like brain cancer, breast cancer, cervical cancer, bowel cancer. And so I was really quite shocked when I found out that bladder cancer even existed. And even more shocked when I found that I really aren't very interested in it because it's not politically expedient for them to pay attention to it. So I'd probably tell him off.

INTERVIEWER: Hmm. I'm guess this is why the CCDR are doing this and why you're like this thing in to, like, the government know more about this, like the cancer they are not aware of.

PARTICIPANT: Yes. Yes. Because of end of day cancer's, cancer, when somebody gets it, they don't want to be either a group that feels cared for, a group that feels ostracised. They just want to know what's the best thing. And I think the way it's presented and through the press too, it's not presented very well at all. It's it's almost like bladder cancer. Is that the it's the the black sheep that you shouldn't talk about. I Mean, it's not obviously, but that's how we seem to present it.
Participant 020_2022AUBLC

No just that the system needs to have compassion and consideration for the people, that they're not numbers and as much as possible the systems support support them during their journey. To some people, that would be a daunting journey, understanding what's happening to them. So having having health professionals that can explain things in a layman's terms and set things out. I mean, I, I've had so many tests and things like that, I can understand where people would be completely bamboozled by, you

know, what they're got to do next week and whether they got it passed or whether they've got to, you know, psychologies or whatever, they've got to do that. The horrible thing for them and know it, you know, they need to have somebody following them. And if they get sick and they don't follow the you know, they they need to take a whole range of medicine and things like that. It's even worse.
Participant 029_2022AUBLC

Participant's message is to invest in professional development so that clinicians understand the condition

Uh, I guess mine would be more of that health education that patients need to go to tertiary centres to, you know, real experts in the field. And perhaps they need to train more of them because there's not that many. I don't actually know how many urology oncologists there are in Australia, but they're certainly concentrated in the big cities and your outcomes very much depend on who does your surgery. So I guess my message would be train more, more experts and educate people about signs and symptoms and perhaps have more comprehensive, holistic management within the hospitals. But I think really they do a pretty good job now. With what they do. Yeah. And he's sort of far removed from it probably doesn't really take much notice of the little plebs like us, but I guess more training of specialist surgeons. I guess we were lucky. Yeah. And it's a rare cancer, so they'd probably think it was a waste of money to put money into a rare cancer. I don't know.
Participant 018_2022AUBLC

I'd be saying to make sure that everybody is provided with the full information. I mean, I can only talk about my case ,and my case. In the end it was non-muscle invasive. It hasn't metastasised. So it is quite different to those other people. So for me it was a much more straightforward situation. And I suppose the other thing that I would try and get someone to to look at is to ensure that doctors follow up properly. I went through probably a couple of months to a doctor who was so busy, so busy turning over the patients that she, I think, was neglectful in providing me with the treatment or the information I needed. I was horrified when I discovered that I had bladder cancer after being going to her week after week after week and never got sent for any tests. Take take antibiotics and you know, blood in the urine. That is not normal and it wouldn't have hurt her to send me somewhere to get it checked, which is what the second doctor did. So I think the health professionals, doctors should be I'm assuming, they should be more aware of what what to, what to do for people who present with those symptoms. Not treat them like a hypochondriac.
Participant 003_2022AUBLC

Participant's message is to improve healthcare professional communication and information given to patients

No discrimination. There should be a lack of discrimination on services that are available to people with bladder cancer as opposed to any other cancer. That would be number one. Number two, get a training package together that would assist patients who have been diagnosed with bladder cancer to get the information from a not just a you know, there has to be an auditory as well as a visual presentation of what's happening to them. And what they should be expecting from, you know, depending on what their diagnosis is, they say they should be a they should be a visual and auditory presentation, not something that just to be read, to get all the best information and it needs to be regularly updated. And so that people have can make informed decisions about their choices of treatment, not to neglect alternate therapies, because right now, alternative therapies get no mention because there's no studies being done on who survives these alternative treatments.
Carer 004_2022AUBLC

I think they need more like, more information, more support, more access to doctors, and more access outside the regular scheduled appointments or to the whole team, the urology team.
Participant 016_2022AUBLC

Participant's message is to employ more healthcare professionals, especially specialists and nurses

Well, I think it would be to spend a lot less money on football stadiums and a lot more money on hospital equipment. I mean, that seems to be one of the weaknesses. Is that we seem to be short of doctors, nurses and medical equipment, for the size of the the population that we have, but it's still one of the best in the world and we're still some of the luckiest people. Minister, get rid of some of those useless people that you got in there costing a fortune and start spending some money on where it counts.
Participant 034_2022AUBLC

PARTICIPANT: Yep. We need more doctors in the outpatients, cause they were just run off their feet.

INTERVIEWER: Right a wait for 3 hours.

PARTICIPANT: And get your operation. All right. As a follow up, you have to wait and hang around. So if he had I think it's more doctors or better care after just for the follow up
Participant 013_2022AUBLC

Participant's message is that treatments need to be affordable

I think the fact that it's got to see, you know cancer full stop. Why why are people in this country with the healthcare system we have. Why are people required to to dig into their pocket? To solve cancer treatment in this country. Yeah. Yeah. That was the whole inequity thing, you know, the massive differences between public and private. Why is that the case in this country? When you talk about cancer, you're not talking about some discretional operation.
Participant 017_2022AUBLC

What would be my message to him? My message to him would be that, you know, make be educated and aware of the warning signs and and react. Because early diagnosis saves lives. So that would be my first message to him. And you know, the GP shouldn't be so hesitant. You know, when, when you keep getting blood to send you for an initial scan. And my second message would be that I've been really lucky that I've been able to afford my the cost of my treatment. But robotic surgery is, you know, said that treatment I had had had was really wonderful in speeding up my recovery. And, you know, we should look at making that available to all, not just the ones that can afford to pay the additional costs associated with it. Okay.
Participant 032_2022AUBLC

Participant's message is that they need to increase funding for specialist nurses

I think there needs to be more stoma nurses available, and I think that they need to be available 24/7. So whether there's a hotline or that sort of thing, and it probably doesn't warrant at the numbers of patients, but in comparison to other cancers and that sort of thing. But I think it's important to people that have experienced it to have easy access to a stoma nurse. I would probably. Now the Ostomy Association's pretty good. The fact that all of our supplies are covered by Medicare is excellent. Forgot to mention that, your supplies are really, really good. I pay something like $60 a year membership for the Ostomy Association. Then pay for delivery. And that's it. So very lucky in that respect. Hmm. Yeah. I think that's about that's what I you know, this stoma nurses the availability of stoma nurses. And the other thing is awareness. I mean, okay, I know that's not really relevant to the question of if I was standing in front of the health minister, that's what I'd be pushing for, for awareness. Like, it's Bladder Cancer Awareness Month and the only things I see coming out from bladder cancer organisations or charities.
Participant 022_2022AUBLC

Well, I'd say make it more aware. Mm hmm. And have an ostomy nurse: Sorry. Sorry. A stoma nurse. In every private hospital and public hospital in the state of STATE. Because I walk. If I were to walk from here. If I go from here to, let's say, to LOCTION, the treatment I get from a stoma nurse in LOCATION is not going to be the same as I get from a stoma nurse in this urban situation.
Participant 037_2022AUBLC

Table 9.15: Messages to decision-makers

Message to decision-makers	All participants		Early		Invasive		Advanced		Person with bladder cancer		Carer		Female		Male	
	n=49	%	n=20	%	n=10	%	n=14	%	n=44	%	n=5	%	n=17	%	n=32	%
Participant's message is to help raise community awareness	16	32.65	6	30.00	**2**	**20.00**	**6**	**42.86**	14	31.82	2	40.00	6	35.29	10	31.25
Participant's message is that they are grateful for the healthcare system and the treatment that they received	11	22.45	4	20.00	**5**	**50.00**	2	14.29	11	25.00	**0**	**0.00**	**2**	**11.76**	9	28.13
Participant's message is to invest in research (including to find new treatments)	10	20.41	4	20.00	2	20.00	3	21.43	9	20.45	1	20.00	5	29.41	5	15.63
Participant's message is to invest in screening/early detection	7	14.29	3	15.00	**0**	**0.00**	2	14.29	5	11.36	**2**	**40.00**	3	17.65	4	12.50
Participant's message is to improve access to support and care	7	14.29	2	10.00	1	10.00	3	21.43	6	13.64	1	20.00	4	23.53	3	9.38
Participant's message is to be compassionate and empathetic	6	12.24	2	10.00	2	20.00	2	14.29	6	13.64	**0**	**0.00**	**0**	**0.00**	6	18.75
Participant's message is to invest in professional development so that clinicians understand the condition	4	8.16	2	10.00	1	10.00	1	7.14	4	9.09	0	0.00	3	17.65	1	3.13
Participant's message is to improve healthcare professional communication and information given to patients	4	8.16	3	15.00	0	0.00	0	0.00	3	6.82	1	20.00	2	11.76	2	6.25
Participant's message is to employ more healthcare professionals, especially specialists and nurses	4	8.16	2	10.00	0	0.00	1	7.14	3	6.82	1	20.00	2	11.76	2	6.25
Participant's message is that treatments need to be affordable	3	6.12	1	5.00	0	0.00	2	14.29	3	6.82	0	0.00	2	11.76	1	3.13
Participant's message is that they need to increase funding for specialist nurses	3	6.12	0	0.00	1	10.00	2	14.29	3	6.82	0	0.00	1	5.88	2	6.25

Message to decision-makers	All participants		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=49	%	n=29	%	n=19	%	n=15	%	n=33	%	n=20	%	n=28	%
Participant's message is to help raise community awareness	16	32.65	11	37.93	4	21.05	6	40.00	9	27.27	8	40.00	7	25.00
Participant's message is that they are grateful for the healthcare system and the treatment that they received	11	22.45	7	24.14	4	21.05	3	20.00	8	24.24	5	25.00	6	21.43
Participant's message is to invest in research (including to find new treatments)	10	20.41	5	17.24	5	26.32	3	20.00	7	21.21	2	10.00	8	28.57
Participant's message is to invest in screening/early detection	7	14.29	5	17.24	2	10.53	3	20.00	4	12.12	2	10.00	5	17.86
Participant's message is to improve access to support and care	7	14.29	3	10.34	4	21.05	2	13.33	5	15.15	4	20.00	3	10.71
Participant's message is to be compassionate and empathetic	6	12.24	4	13.79	2	10.53	1	6.67	5	15.15	3	15.00	3	10.71
Participant's message is to invest in professional development so that clinicians understand the condition	4	8.16	1	3.45	3	15.79	0	0.00	4	12.12	1	5.00	3	10.71
Participant's message is to improve healthcare professional communication and information given to patients	4	8.16	2	6.90	2	10.53	2	13.33	2	6.06	4	20.00	0	0.00
Participant's message is to employ more healthcare professionals, especially specialists and nurses	4	8.16	2	6.90	2	10.53	1	6.67	3	9.09	2	10.00	2	7.14
Participant's message is that treatments need to be affordable	3	6.12	1	3.45	2	10.53	0	0.00	3	9.09	0	0.00	3	10.71
Participant's message is that they need to increase funding for specialist nurses	3	6.12	3	10.34	0	0.00	1	6.67	2	6.06	1	5.00	2	7.14

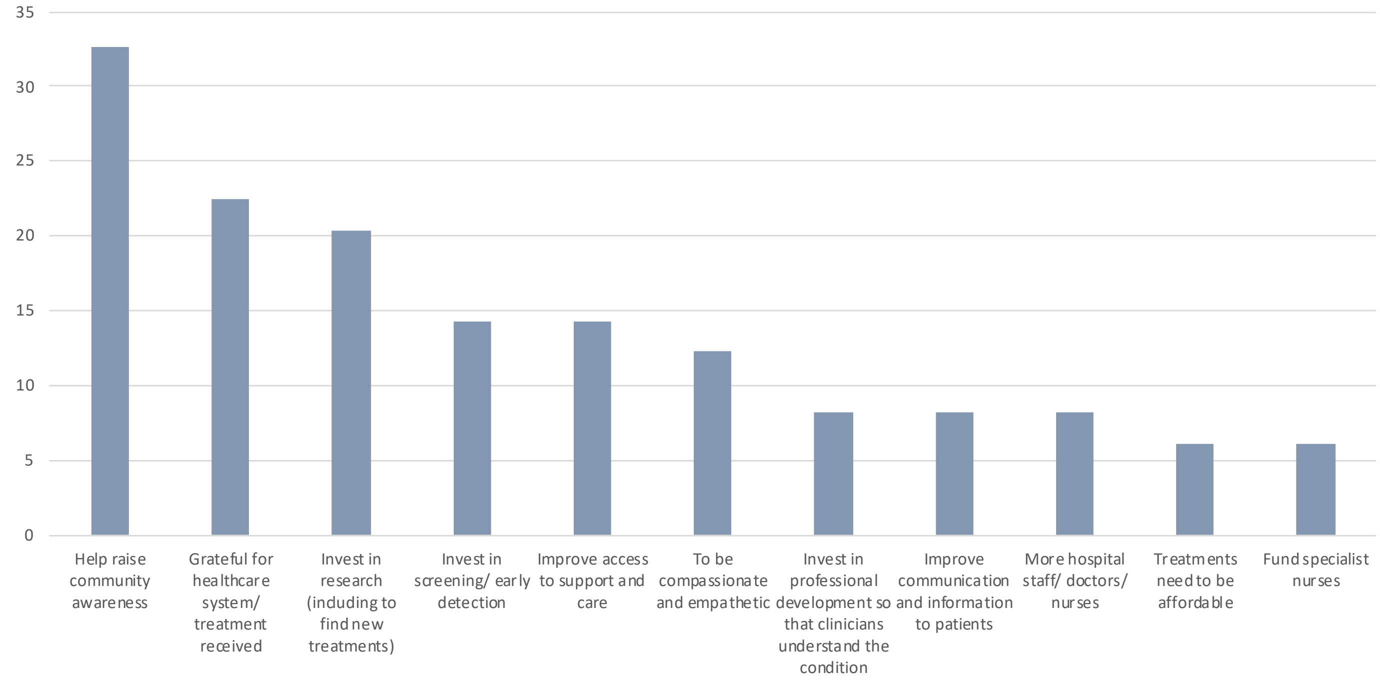


Figure 9.10: Messages to decision-makers

Table 9.16: Messages to decision-makers – subgroup variations

Message to decision-makers	Reported less frequently	Reported more frequently
Participant's message is to help raise community awareness	Invasive (Stage III) University	Advanced (Stage IV)
Participant's message is that they are grateful for the healthcare system and the treatment that they received	Carer to someone with bladder cancer Female	Invasive (Stage III)
Participant's message is to invest in research (including to find new treatments)	Mid to low status	-
Participant's message is to invest in screening/early detection	Invasive (Stage III)	Carer to someone with bladder cancer
Participant's message is to improve access to support and care	-	-
Participant's message is to be compassionate and empathetic	Carer to someone with bladder cancer Female	-

Section 10

Advice to others in the future: The benefit of hindsight

Section 10: Advice to others in the future

Anything participants wish they had known earlier

In the structured interview, participants were asked if there was anything they wish they had known earlier. The most common responses were that participants wished they had known what to expect from their condition (e.g. symptoms, side effects of medication) (n=11, 22.45%), and they wished they had known to be more assertive in relation to understanding treatment options and discussions about treatment (n=11, 22.45%). Other themes included participants described that there is nothing that they wished they new earlier (satisfied) (n=9, 18.37%), and wished they had know the early signs and symptoms of the condition (n=7, 14.29%).

Aspect of care or treatment they would change

In the structured interview, participants were asked if there was any aspect of their care or treatment they would change. The most common theme was that they would have liked more time and personalised attention with specialists (n=10, 20.41%). There were 8 participants (16.33%) who would not change any aspect of treatment or care without giving a reason, and 8 participants (16.33%) who would not change any aspect of treatment or care because they were satisfied with care and treatment received. Other participants would have liked to have had a better understanding of their condition (n=6, 12.24%), and would have liked more support for side effects of treatment (n=5, 10.20%).

Anything participants wish they had known earlier

In the structured interview, participants were asked if there was anything they wish they had known earlier. The most common responses were that participants wished they had known what to expect from their condition (e.g. symptoms, side effects of medication) (n=11, 22.45%), and they wished they had known to be more assertive in relation to understanding treatment options and discussions about treatment (n=11, 22.45%). Other themes included participants described that there is nothing that they wished they new earlier (satisfied) (n=9, 18.37%), and wished they had know the early signs and symptoms of the condition (n=7, 14.29%).

Participant wishes they had known what to expect from their condition (e.g. symptoms, side effects of medication)

PARTICIPANT: Oh. I wish I'd known about blood in urine. Mm hmm. And maybe what it looks like an actual representation of what it really looks like. Because for women with gynaecological, you know, we don't always put it down to that. But, you know, to say that it could present, like, a UTI or something like that. You know, so those that would have been good.

INTERVIEWER: Because you would have gone to the doctor sooner.

PARTICIPANT: Yes.

INTERVIEWER: Yes. Okay.

PARTICIPANT: Cause I didn't have any pain at all, so I didn't think about it, you know, potentially being as UTI, because that's what I, you UTI down to. But, um, also after, I think, um, I would like to have known a bit more about the bag before I met with the stoma nurse two days before the surgery. No. Actually, I met her one day before the surgery and she marked up my stomach and basically said, this is likely where you're bag's going to be. But it would have been good to meet with them beforehand. And I suggest this to people that I talk to now. Ask for an appointment with the stoma nurse, get a bag, half fill it with water, stick it on your stomach and walk around with it. Try it with clothes that you wear, all things that, you could, you know, you can trial beforehand just to get a feel for things. I would have liked to have had that.
Participant 022_2022AUBLC

Oh, I wish I'd known the side effects of the BCG. That was never explained to me. I was just told that, I was just told I'd be having that. And it was the gold standard. And that may well be that that is most probably true. It is the best treatment. But there was no discussion whatsoever about side effects at any stage.
Participant 008_2022AUBLC

But. Um. Yeah. I don't know. Just probably the extent of the incontinence and the ongoing effect of that.
Participant 027_2022AUBLC

Yes. I wished I'd had a list of potential questions to ask somebody so that I could have gone through those and thought about that. That is now available. And I wished that, that I could have spoken to somebody that was similar to me that had in the bladder. And it wasn't you know, I didn't know how to access that then, but it is now available via via by BEAT. I can I can put people in contact with, you know, people that have had in a similar situation and they can talk with everyone's permission, of course, face to face. And I didn't I didn't have that. And I would really like towards that would have really helped me if I could have sat down with somebody over the phone or over Zoom and, you know, said, you know, okay, you have any ability to tell me what your life is like? And it would have put my mind at ease and and I couldn't do that back then.
Participant 032_2022AUBLC

Participant wishes they had known to be more assertive in relation to understanding treatment options and discussions about treatment

Yeah. Look would it would have changed the public versus private path. But we might have still ended up in private, but we would have journeyed down the public first. Yeah. And yeah, that's probably money and probably just, you know, an estimate of what this would cost on an annual basis to to treat if you kept down the private part. As I said, my wife told me this morning, you know, credible number was 65,000, um, to, to treat bladder cancer over it's over its lifetime out of pocket, that is. Yeah. Now if you'd said to me that in January I got holy crap. Oh, we better go. We better find something sustainable here and go down this path. You still want the urgency to want the quality care, but, you know, the public system has probably better qualified people. Cause they have to deal with everything they see, everything the private people would just do with a niche thing. They might be really

good at what they do. But I only see, you know, only do bladders, only do kidney stones or whatever might be one to get really good at that. But the public system have really broad robust surgeons have to deal with a lot more.
Participant 017_2022AUBLC

Well, I would like to have probably more information on bladder cancer. So that I did get leaflets. But, you know, let's face it, we don't really read as much as we should do. So, you know, I mean, before we did the operation for you know, I would like to have a clearer idea, you know, what if I did have a choice? Basically, I do feel as though I didn't have a choice, you know? Yeah. If you don't do this, then that's, you know, there's no other alternative or whatever, you know. So I wont say I was railroaded into it. But I, you know, it's it's afterwards you think, well, I wish I had a bit more sort of, you know, information. Then, you know, maybe try this for that before, you know. If you know, you were going to have a leg off? Well, you know, before that, is there a treatment for, you know, before you take the leg off?
Participant 023_2022AUBLC

Yes. I think the first time when I was diagnosed, it's a very shocking time. And I again repeated, you know, I wasn't giving almost very little information, you know, that what kind of cancer it is and what are the treatment options? What are the pros and cons? I was just given a phone call. I looked at it, look, we've found you've got cancer. And I think you should go for surgery and. I mean, it should be a face to face meeting with all information like this council. I had to dig for this Cancer Council booklet and you know, okay, so I think when they give the diagnosis, if that is to have a face to face meeting sit down, give me all the written information as much as possible so that the person can immediately start thinking, you know, what, what, what's happening?
Participant 028_2022AUBLC

Participant describes that there is nothing that they wish they knew earlier (satisfied)

No. No, not really. I guess I'd want a treatment that's effective. And I would, um. There's been no other sort of treatments more effective apparently in my type of cancer than the BCG. Um. So, no, I'm happy that I've had the treatment that I've had.
Participant 001_2022AUBLC

Uh, no, probably. As I said earlier, I think probably knowing a bit less is probably better at the initial stage when you're gonna get an operation than that because, um, you know, my friend, I go walking with, and he's also in the same boat. His urologist said to him, You'll have a very poor standard to life once you get a stoma. And he said nothing's really changed for him, you know, apart from that little bit of extra time and effort that you've got to put in, um, managing it. Uh, but he's his doctor, in all was saying to him, you know, his standard of life, and I know mine's altered, but I don't think it's dropped. I've probably got to look at it differently. You know what? If I've lost a leg or an arm or something like that, I've got to look at life a little bit differently. But your life doesn't drop away because of that. It is going to change things a little bit. You know, Imight not be able to do some thing, you transferred over other items. You know what? When I had my knees done and I couldn't run any of the, I couldn't really run anymore. I just, I walk and I swim and I kyack, you know? Yeah. Yeah, I'll just. I'll just change tack a bit. Yeah. Just staying positive. Yeah. and I know some people that need help to stay positive. You know, I'm one of the lucky ones. I've got a good outlook on life.
Participant 011_2022AUBLC

Um, oh, no. It's been a process of learning and dealing with it, no I found that, um, this is something that you learn and you get to. It's a journey, isn't it? So as I said you see some people who've, you know, like, diagnosed and they got to get their bladder removed within three weeks. And yeah, it's just a process of everyone's different, you know, I'm, I'm pretty happy with the treatment with that.
Participant 044_2022AUBLC

Participant wishes they had know the early signs and symptoms of the condition

Well, I wish I did now. And to this day, I'm absolutely, totally convinced that my nocturia and very frequent urination from about age 35. Was was the reason that I got bladder cancer because I don't smoke, never had one cigarette in my life. I never work in areas where there's chemicals and things like that, which apparently is. So I didn't have any sort of risk factors for getting cancer. The I'm totally convinced that the fact that I was 30 years was 20 years, 30 years going to the toilet regularly at night. And I reckon that must have had something to do with the. So I didn't, I had no information or didn't even know, never even knew there was a bladder cancer. All I knew was that I thought I had prostate problems, which I had checked out when I was 45. And they said. He said, you haven't got prostate problems. That was when I was 45 and I had this PSA test on blood tests over the years, which was less than one. So I just thought I was unlucky and that I had this bladder frequency problem. If doctors had said, well, you know. I don't. I'm just totally

convinced that's the reason I got this bladder cancer. Totally convinced. It's the only thing I can think of. Just the I've had a bladder irritation. So for so many, many years. So just a little bit of information beforehand would have been was the doctors had said you should go and see urologist so-and-so, a doctor GP a few times about it. They should always this is you know, you'll get out of it. I'll just do the bladder retraining, one doctor advised me that can offer what is maybe a bit more information about risk factors and all that sort of thing.
Participant 021_2022AUBLC

Probably because I, I sort of had blood in the urine from, oh, maybe ten years ago or more than that. But at different stages, and then it would go away and. If I and I did go to that doctor once and have a CT scan and they said they couldn't find anything, that was maybe 2010, 2012 or something. So if I'd known that that's what it could have been, I think I would have been more vigilant in going, because I think when I when it was diagnosed, it had been there for quite a while, he said.
Participant 025_2022AUBLC

Oh, I mean. I wish I had of known what blood in your urine meant
Participant 040_2022AUBLC

Participant does not describe anything they wish they had known earlier (no reason given)

Oh, well, no, I don't think so.
Participant 012_2022AUBLC

No, not at all.
Participant 031_2022AUBLC

Participant wishes they had known to be more assertive through the diagnostic process

I wish I knew that UTIs were actually a symptom of cancer. Um, unfortunately, I was female. I was 24 at the time. I was having recurring UTIs and everyone just said, no, it's fine. Don't even worry about it. You're not male, you're not older, you don't actually meet the criteria of anything sinister. So yeah, I wish I just knew the side effects so I could maybe speak up more about my health and have, you know, just something that I could say, look, no, this is an issue, and it turned out to be cancer. And yeah, I was kind of surprised a lot of people.
Participant 009_2022AUBLC

Oh, diagnosis. Um, I guess. I don't think we could have picked it up any earlier because there was no blood in the urine the year before. Just three weeks wouldn't have made a difference. I guess. I guess we should have got a referral to a specialist in Newcastle earlier because he said he thought we should have had chemo two months before we did so. I mean, it might not make any difference, but it's all just. Yeah. Anyway, it is what it is.
Carer 005_2022AUBLC

Participant wishes they had known more about what support was available to them

Probably about the incontinence, about how severe the incontinence can be. And what kind of help that there is out there for incontinence
Carer 001_2022AUBLC

Um. Not really. Everything happened so quickly for me, but I certainly found it reassuring to to have to make the acquaintance of the support group that I was just talking about, the one that is run by Coloplast. Because when I was in the hospital, the stoma nurse, I mean the state hospital I was in was in the city, in HOSPITAL. I am not sure if you're familiar with CANCER CENTRE, but in in normal times I would have probably been put into LOCATION hospitals, which is quite close, but the stoma nurse in the in the city. He said I'm your stoma nurse now and you know if you need me help. And I tried to contact him a couple of times just because there was something little happening that was worrying me and I couldn't get hold of it because he's so busy. So I found that when I went to this support group run by Coloplast two of the people there were nurses from LOCATION stoma nurses and they said, I can make appointments to see them if if I need to. And that was really reassuring because I was the stoma nurse in the city obviously, and the private hospital is incredibly busy. And also the practicality of going to see him would be really not not that easy. So I found it really, really helpful to know that there's two nurses in LOCATION which is just like five minute drive away, that I can make appointments to see if I need to.
Participant 043_2022AUBL

Table 10.1: Anything participants wish they had known earlier

Wish they had known earlier	All participants		Early		Invasive		Advanced		Person with bladder cancer		Carer		Female		Male	
	n=49	%	n=20	%	n=10	%	n=14	%	n=44	%	n=5	%	n=17	%	n=32	%
Participant wishes they had known what to expect from their condition (e.g. symptoms, side effects of medication)	11	22.45	5	25.00	3	30.00	1	7.14	9	20.45	2	40.00	6	35.29	5	15.63
Participant wishes they had known to be more assertive in relation to understanding treatment options and discussions about treatment	11	22.45	3	15.00	4	40.00	3	21.43	10	22.73	1	20.00	3	17.65	8	25.00
Participant describes that there is nothing that they wish they knew earlier (satisfied)	9	18.37	4	20.00	2	20.00	3	21.43	9	20.45	0	0.00	2	11.76	7	21.88
Participant wishes they had know the early signs and symptoms of the condition	7	14.29	1	5.00	3	30.00	2	14.29	6	13.64	1	20.00	2	11.76	5	15.63
Participant does not describe anything they wish they had known earlier (no reason given)	4	8.16	2	10.00	1	10.00	1	7.14	4	9.09	0	0.00	2	11.76	2	6.25
Participant wishes they had known to be more assertive through the diagnostic process	4	8.16	2	10.00	1	10.00	0	0.00	3	6.82	1	20.00	2	11.76	2	6.25
Participant wishes they had known more about what support was available to them	3	6.12	1	5.00	0	0.00	1	7.14	2	4.55	1	20.00	2	11.76	1	3.13

Wish they had known earlier	All participants		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=49	%	n=29	%	n=19	%	n=15	%	n=33	%	n=20	%	n=28	%
Participant wishes they had known what to expect from their condition (e.g. symptoms, side effects of medication)	11	22.45	7	24.14	4	21.05	5	33.33	6	18.18	5	25.00	6	21.43
Participant wishes they had known to be more assertive in relation to understanding treatment options and discussions about treatment	11	22.45	6	20.69	5	26.32	2	13.33	9	27.27	2	10.00	9	32.14
Participant describes that there is nothing that they wish they knew earlier (satisfied)	9	18.37	3	10.34	5	26.32	0	0.00	8	24.24	2	10.00	6	21.43
Participant wishes they had know the early signs and symptoms of the condition	7	14.29	5	17.24	2	10.53	2	13.33	5	15.15	2	10.00	5	17.86
Participant does not describe anything they wish they had known earlier (no reason given)	4	8.16	2	6.90	2	10.53	2	13.33	2	6.06	3	15.00	1	3.57
Participant wishes they had known to be more assertive through the diagnostic process	4	8.16	3	10.34	1	5.26	4	26.67	0	0.00	2	10.00	2	7.14
Participant wishes they had known more about what support was available to them	3	6.12	2	6.90	1	5.26	1	6.67	2	6.06	2	10.00	1	3.57

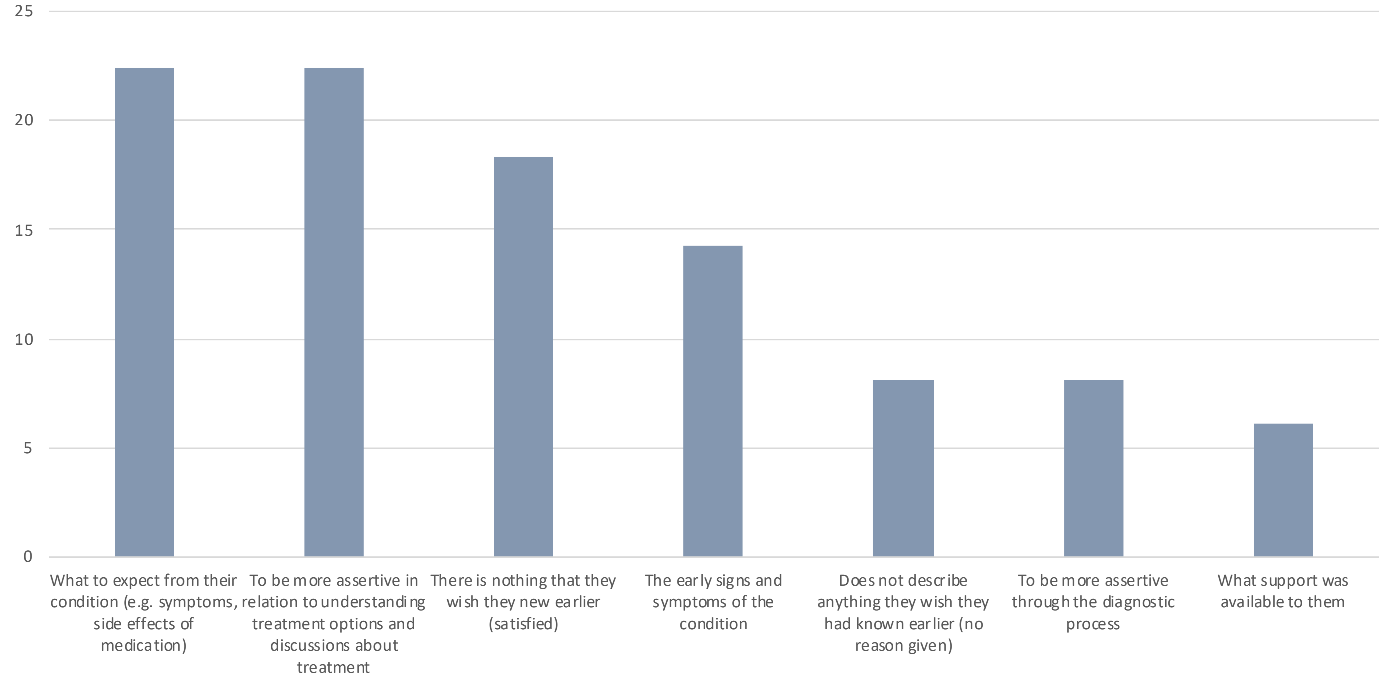


Figure 10.1: Anything participants wish they had known earlier

Table 10.2: Anything participants wish they had known earlier – subgroup variations

Wish they had known earlier	Reported less frequently	Reported more frequently
Participant wishes they had known what to expect from their condition (e.g. symptoms, side effects of medication)	Advanced (Stage IV)	Carer to someone with bladder cancer Female Regional or remote
Participant wishes they had known to be more assertive in relation to understanding treatment options and discussions about treatment	Mid to low status	Invasive (Stage III)
Participant describes that there is nothing that they wish they knew earlier (satisfied)	Carer to someone with bladder cancer Regional or remote	-
Participant wishes they had know the early signs and symptoms of the condition	-	Invasive (Stage III)

Aspect of care or treatment they would change

In the structured interview, participants were asked if there was any aspect of their care or treatment they would change. The most common theme was that they would have liked more time and personalised attention with specialists (n=10, 20.41%). There were 8 participants (16.33%) who would not change any aspect of treatment or care without giving a reason, and 8 participants (16.33%) who would not change any aspect of treatment or care because they were satisfied with care and treatment received. Other participants would have liked to have had a better understanding of their condition (n=6, 12.24%), and would have liked more support for side effects of treatment (n=5, 10.20%).

Participant would have liked more time and personalised attention with specialists

Um. I wouldn't change anything. I would love to have changed like the communication side of things with my doctor, but I don't think that was ever going to change. So yeah, probably just more being involved in my treatment plan and actually knowing what was going on. Like, for example, when I had my partial bladder removed, partial bladder removal, I was never told that they were going to be removing some of my lymph nodes around the bladder, around the pelvis or wherever it is. Um, and when he told me that they removed some lymph nodes and they said, keep it all, it looks fine, don't worry about it. But if I do come back cancerous, we're going to have to do chemotherapy. That really scared me because I didn't actually know that they had intentions of removing it, even though it's just a precaution. I would have, just like if they actually had a bit more communication with me, have, you know, exact step by step what was going to happen.
Participant 009_2022AUBLC

Well, the treatment is what the treatment is. So I can't really say I want to be treated. Clinically any different? I mean, the diagnosis is what it is and you follow the the recommended approach. It's just that how. You know, I look, I sound like a broken record. It's coming back just to the way that you want to just chooses to do, to communicate the the messaging of of what I'm dealing with and what my options are. It's very aloof, standard, standoffish and drip fed based upon what you need to know when you need to know it. And don't don't concern yourself with anything else right now other than what I've just told you.
Participant 017_2022AUBLC

Oh, the only thing I would change is that the clinics would be longer. In other words, the time spent with with the doctor or with the the carers, that's with your stoma nurse or your doctors, was allocated longer. But I know they've got the, they've got deadlines they've got to do and then god knows what else, the other patients to see, etc.. All that I'm saying is that you know the length of the consultation be longer.
Participant 037_2022AUBLC

Participant would not change any aspect of their care or treatment/satisfied with care and treatment received

No, not really. As I said, I, I, thank my lucky stars every day. I had excellent care and excellent and excellent treatment. And you know, anyone facing what I faced, you know, my urology nurse when I met her before my surgery explained to me that, you know, the first four days are not going to be good and you're just going to have to follow instructions and you just going to have to do it no matter what. And, you know, it was so very true. It would have been nice to speak to another patient that had been through that and, you know, explained to me that, you know, this is you know, this is very true and this is what's going to happen.
Participant 032_2022AUBLC

So they were, they were pretty good. Um, as I say, there was, I had a preferred nurse, um, because I thought she, she lent me more dignity because I felt very vulnerable having, you know, that being catherterised so often. And it did and it didn't seem to get me better, to be honest. So I didn't get immune to it really. Um, so, but I, I think overall they were tremendous. Really.
Participant 036_2022AUBLC

Only the ones I've already mentioned. But everything else has been amazing. Like, um, where he receives BCG and cystoscopy. Nope, that's all been fabulous.
Carer 003_2022AUBLC

Participant would not change any aspect of their care or treatment (no reason given)

No, not really. I don't know what I would change. I don't know what would make it any different.
Participant 003_2022AUBLC

Care or treatment? No. No, I wouldn't change anything.
Participant 033_2022AUBLC

Participant would have liked to have had a better understanding of their condition

Maybe just a bit more explanation.
Participant 013_2022AUBLC

Um. Probably wouldn't have been in a hurry to get out of hospital. Probably would argue that quite a bit. [CROSS TALK]. It's not that you really like that idea. And probably. Yeah. More information about, um. cathertorising. Um. Having to having to self cathertise would have been, would have been more helpful. I as said that it was the information that we got. From. Coloplast was was more helpful than what we got out of the health department.
Participant 040_2022AUBLC

No, I don't think I think I've been really well-cared for. No. I mean. I don't know what else they could have done or anyone could have done so. No. Nothing. Nothing more than perhaps a bit more information, but. That. Yeah. Yeah. About other options. But I don't know that there are many other options. Mhm.
Participant 025_2022AUBLC

Participant would have liked more support for side effects of treatment

PARTICIPANT: So and I've just talked to a 74 year old lady who was diagnosed with cancer and spoke to her before her operation and gave her some hints and tips and things like that.

INTERVIEWER: Excellent.

PARTICIPANT: She wanted to know before we went into hospital and I suggested the bag and she did all of those things. And I've spoken to her numerous times after her also. She's incredible, constantly positive and fantastic. But she she really liked the practical side of things and really appreciated having a bit of a heads up around that before she got through them. So really, I'm the more that that sort of stuff can happen, the better I think.
Participant 022_2022AUBLC

Because it's one of the I think if they remove your bladder, then you a nephro tube to as well. It's very invasive and it's, um, very discomfort. And you need to find practical ways to deal with it because it's just kept around your leg. And that's in the beginning you're afraid It will leak and it will drop off down there, fall off. And I was so unhappy that I designed my own. It's like a a like a lycra short, but I stitched pockets on it. And then I could put the the the bag I could put in there. So that gave me so much joy. But I couldn't find anything on the market like that, and I think lots of people would be helped with that as well, because when you have something strapped to your leg, it's it hurts at a certain stage. And with my Lycra shorts, when I put that in the pockets, I sticth on. Yeah. Then you're. Yeah. It's like, uh. Yeah, it's very comfortable and it gives you confidence. But that's something, uh, I share to a lot of people. But yeah, I think other people could benefit from something like that as well. And that's the experience. And when you talk to people, you can give that advice that there are other ways to deal with it. Yeah, and I never think there's so many things. Tips and tricks that could be way better explained than on an A4.
Participant 005_2022AUBLC

Well, when I was bleeding, I wish I knew about the Falxseed. But the flaxseed oil and the oregano, because I would have saved money, saved me 34 days of bleeding, you know. And that was definitely on the cards. Um, but again, as I said, the doctors didn't really want to know about it because that something they don't learn at university so that I'm one of those, you know
Participant 042_2022AUBLC

Participant would have stopped or changed treatment sooner

I keep coming back to say I didn't have private health. I got, I went through the public system. Sometimes I go through them myself, now. I go, well, if I'd had private health coverage, would that have made a difference to me? Would it? Would that have given me quicker access with. Without, without? Having an idea of what was actually happening to me at the time. I did not know because I still felt I still felt fine. And that's that's the insidious part about the whole process is that, yeah, this cancer is growing in you, but you feel there's nothing wrong. There's literally nothing wrong.
Participant 035_2022AUBLC

Not one. I survived. Yes. Yeah. So I wouldn't I wouldn't go down. As I said earlier, I wouldn't go down the same track as having BCG. But I'm seeing so many problems with that. I end up having it out anyhow. I'm quite happy to have the bladder removed that don't worry about it
Participant 038_2022AUBLC

Oh, no, as I said, you know, like you still think about whether they should have gone for the extra treatment or, you know, went have you bladder

removed like straight away as a sort of the decision. Yeah. Like you said, he was sitting there in the office with me and he said, which way you want to go with? You know, like you sit there within 10 minutes, you're gonna make a life changing decision.
Participant 044_2022AUBLC

Table 10.3: Aspect of care or treatment they would change

Anything to change about treatment or care	All participants		Early		Invasive		Advanced		Person with bladder cancer		Carer		Female		Male	
	n=49	%	n=20	%	n=10	%	n=14	%	n=44	%	n=5	%	n=17	%	n=32	%
Participant would have liked more time and personalised attention with specialists	10	20.41	6	30.00	1	10.00	1	7.14	8	18.18	2	40.00	3	17.65	7	21.88
Participant would not change any aspect of their care or treatment/satisfied with care and treatment received	8	16.33	2	10.00	2	20.00	3	21.43	7	15.91	1	20.00	3	17.65	5	15.63
Participant would not change any aspect of their care or treatment (no reason given)	8	16.33	4	20.00	2	20.00	2	14.29	8	18.18	0	0.00	2	11.76	6	18.75
Participant would have liked to have had a better understanding of their condition	6	12.24	2	10.00	3	30.00	1	7.14	6	13.64	0	0.00	3	17.65	3	9.38
Participant would have liked more support for side effects of treatment	5	10.20	2	10.00	1	10.00	2	14.29	5	11.36	0	0.00	3	17.65	2	6.25
Participant would have stopped or changed treatment sooner	4	8.16	2	10.00	0	0.00	2	14.29	4	9.09	0	0.00	0	0.00	4	12.50
Participant would have liked better communication with specialist	3	6.12	3	15.00	0	0.00	0	0.00	3	6.82	0	0.00	2	11.76	1	3.13

Anything to change about treatment or care	All participants		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=49	%	n=29	%	n=19	%	n=15	%	n=33	%	n=20	%	n=28	%
Participant would have liked more time and personalised attention with specialists	10	20.41	7	24.14	2	10.53	1	6.67	8	24.24	2	10.00	7	25.00
Participant would not change any aspect of their care or treatment/satisfied with care and treatment received	8	16.33	3	10.34	5	26.32	1	6.67	7	21.21	2	10.00	6	21.43
Participant would not change any aspect of their care or treatment (no reason given)	8	16.33	5	17.24	3	15.79	2	13.33	6	18.18	5	25.00	3	10.71
Participant would have liked to have had a better understanding of their condition	6	12.24	4	13.79	2	10.53	5	33.33	1	3.03	4	20.00	2	7.14
Participant would have liked more support for side effects of treatment	5	10.20	3	10.34	2	10.53	0	0.00	5	15.15	1	5.00	4	14.29
Participant would have stopped or changed treatment sooner	4	8.16	2	6.90	1	5.26	1	6.67	2	6.06	2	10.00	1	3.57
Participant would have liked better communication with specialist	3	6.12	3	10.34	0	0.00	1	6.67	2	6.06	1	5.00	2	7.14

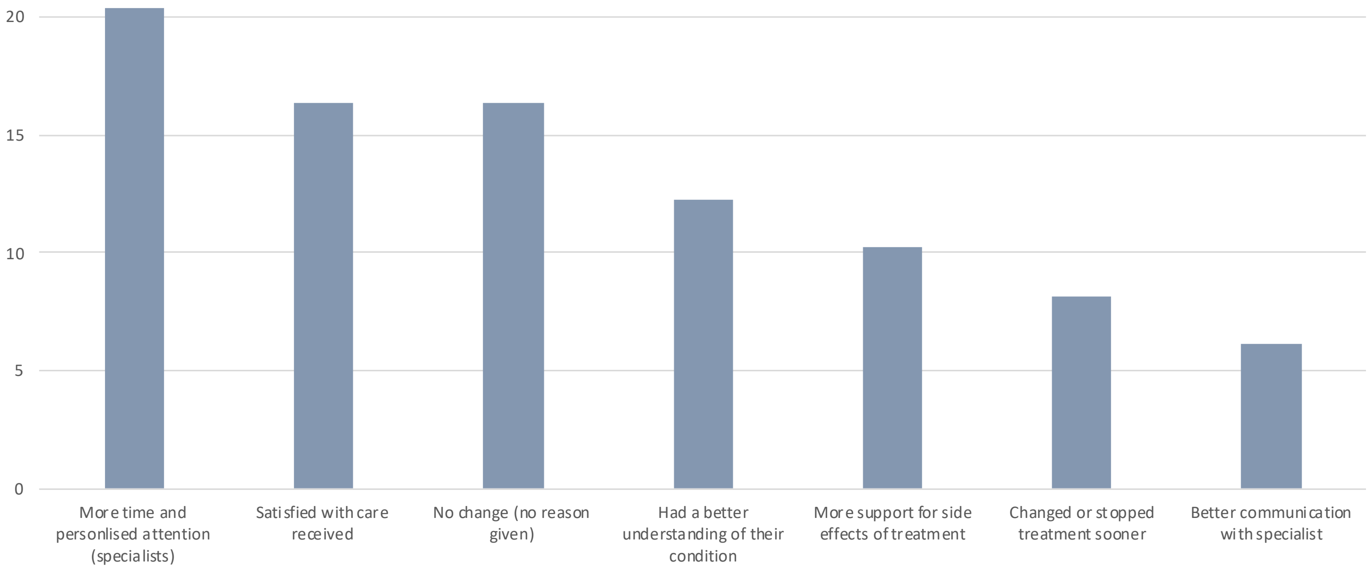


Figure 10.2: Aspect of care or treatment they would change

Table 10.4: Anything participants wish they had known earlier – subgroup variations

Anything to change about treatment or care	Reported less frequently	Reported more frequently
Participant would have liked more time and personalised attention with specialists	Invasive (Stage III) Advanced (Stage IV) Regional or remote Mid to low status	Carer to someone with bladder cancer
Participant would not change any aspect of their care or treatment/satisfied with care and treatment received		-
Participant would not change any aspect of their care or treatment (no reason given)	Carer to someone with bladder cancer	-
Participant would have liked to have had a better understanding of their condition	Carer to someone with bladder cancer	Invasive (Stage III) Regional or remote
Participant would have liked more support for side effects of treatment	Carer to someone with bladder cancer Regional or remote	-
Participant would have stopped or changed treatment sooner	-	-
Participant would have liked better communication with specialist	-	-

Section 11

Discussion

Introduction

Patient Experience, Expectations and Knowledge (PEEK) is a research program developed by the Centre for Community-Driven Research (CCDR). The aim of PEEK is to conduct patient experience studies across several disease areas using a protocol that will allow for comparisons over time (both quantitative and qualitative components). PEEK studies give us a clear picture and historical record of what it is like to be a patient at a given point in time, and by asking patients about their expectations, PEEK studies give us a way forward to support patients and their families with treatments, information and care.

This PEEK study in bladder cancer includes 44 people diagnosed with bladder cancer throughout Australia. In addition, 5 carers or family members to people with bladder cancer took part.

Incidence, prevalence and mortality

Bladder cancer occurs more frequently in men and those over 60 years of age[1]. In 2021 there were and estimated 3,066 new cases of bladder cancer in Australia, approximately 2,400 of these were men; the median age was 76.3 years[2,3]. There were an estimated 653 deaths from bladder cancer in Australia in 2021, it is the 9th most common cause of death from cancer[2]. The five year survival during the period 2031 to 2017 was 55% [3]. In Australia, at the end of 2016, there were 8165 people living with bladder cancer[3].

There was a decrease in 5 year survival from 68% in 1982 – 1987, to 53% in 2009-2013, the reasons for this are not clear and cannot be explained by an increase in age at diagnosis which has only modestly increased in this time period[1,4] . However, there was a decrease in age-standardised mortality rate from 5.4 per 100,000 in 1982 to 3.8 per 100,000 in 2017[1], this is due to a reduction of overall incidence.

Demographics

The demographic data we collect in the PEEK study helps us to understand how our PEEK participants compares to people in Australia, and with people that have bladder cancer.

In this PEEK study, the proportions of participants that lived in major cities and had non-school qualifications (certificate, diploma or degree), were all similar to that of the Australian population. There were higher proportions that lived in areas with higher socioeconomic status.[5-7] There were no participants from the Northern Territory, and there were a lower proportion of participants from Queensland, and Western Australia while a greater proportion from NSW, and Canberra compared to the proportion that live in each state[8].

Table 12.1: Demographics

Demographic	Australia %	Bladder cancer PEEK %
Live in major cities	71	69
Non-school qualification	65	63
Higher socioeconomic status (7 to 10 deciles)	40	58
New South Wales	32	46
Victoria	26	27
Queensland	20	4
South Australia	7	10
Western Australia	10	4
Tasmania	2	2
Northern Territory	1	0
Australian Capital Territory	2	6

Health status

In PEEK studies we collect information about other health conditions that participants manage, as well as health-related quality of life (with the SF36 questionnaire). The purpose of this is to have an idea of the general health of the participants in the study. We can also compare this data with the Australian population, and with other studies with bladder cancer participants.

Other health conditions

The majority of participants in this PEEK study had at least one other condition that they had to manage, and on average 2 other conditions. The most commonly reported health conditions were sleep problems and anxiety, followed by arthritis or scoliosis, and depression.

The National Health Survey was conducted in 2017 to 2018, it is an Australia wide survey conducted by the Australian Bureau of statistics. Almost half of the Australian population have one chronic condition[9]. Common chronic health conditions experienced in Australia in 2017-18 were: mental and behavioural conditions (20%), back problems (16%), arthritis (15%), asthma (11%), diabetes mellitus (5%), heart, stroke and vascular disease (5%), osteoporosis (4%), chronic obstructive pulmonary disease (COPD) (3%), cancer (2%), and kidney disease (1%)[9]. The Australian Bureau of statistics reports that 10% of Australians have depression or feelings of depression and 13.1% have an anxiety-related condition[9].

In this PEEK study, participants had higher levels of anxiety (40% compared to 13%), depression (26% compared to 10%), arthritis (38% compared to 15%), diabetes (10% compared to 5%), and asthma (17% compared to 5%) compared to the Australian population. High rates of anxiety in depression have been reported in other studies [10]

Baseline health

The Short Form Health Survey 36 (SF36) measures baseline health, or the general health of an individual[11]. The SF36 comprises nine scales: physical functioning, role functioning/physical, role functioning/emotional, energy and fatigue, emotional well-being, social function, pain, general health, and health change from one year ago. The scale ranges from 0 to 100, a higher score denotes better health or function[11].

Population norms for the SF36 dimensions in Australia were assessed in the 1995 National health survey, while this was conducted 25 years ago, it can give an indication of how the bladder cancer community in this PEEK study compares with the Australian population[12]. The bladder cancer PEEK participants on average had considerably lower scores for the SF36 Energy/Fatigue, SF36 Social functioning, and SF36 General health SF36 domains.

Participants in this PEEK study had scores within the moderate to very good range. In other studies, people with bladder cancer have displayed worse health-related quality of life compared to people with prostate cancer or colorectal cancer[13], and often reported problems with conducting usual activities. [10]. However, following surgery, bladder cancer did not affect health-related quality of life for those without symptoms [14].

In this PEEK study, Participants with advanced bladder cancer and males had worse physical function, participants with trade or high school qualifications had worse pain, males and those living in areas with mid to low socioeconomic status had worse social functioning, and males had worse general health.

Similar to this PEEK study, other studies have reported that people with advanced stage have poorer health related quality of life, and in contrast that males have better health related quality of life[15]. Other factors associated with poorer quality of life include old age, comorbidities, anxiety, poor emotional function, poor cognitive function, poor social support and poor self efficacy [10,13,15,16]

Key points

- **PEEK bladder cancer participants had high rates of depression and anxiety**
- **PEEK bladder cancer had an average of 2 other health conditions they needed to manage, most often sleep problems and arthritis or scoliosis**

Symptoms and risk factors

I'd never heard of it and never heard of bladder cancers, never heard of bladder cancer in my life. My wife is a registered nurse and has been in aged care for 25 years. Goes, what the hell are you doing with bladder cancer? Cause that's an old man's disease. And, you know, everybody said, you know, everyone queried me along the way. Were you a smoker and did you work in heavy industry or with chemicals or toxins and that kind of stuff? I said, No, no, no, no, no. I sit behind a desk all day and have and have for 30 years. I'm a pen pusher or keyboard person. So that was a bit bizarre that I didn't fit the archetype for that thing, being 52 and non-smoker and an office worker. I don't sort of fit the demographic for this.
Participant 017_2022AUBLC

Risk factors for bladder cancer include smoking, workplace exposure in the textile dyeing, petrochemical and rubber industries, diabetes, the chemotherapy drug cyclophosphamide, family history, and chronic inflammation of the bladder[17]. The most common symptom is haematuria, other less common symptoms include problems emptying bladder, dysuria, polyuria and abdominal or back pain[17].

There are higher age standardised mortality rates from bladder cancer for in those living in very remote areas of Australia compared with those that live in major cities, likewise, those in the most disadvantaged areas have higher age standardised incidence and mortality compared with those living in the most advantaged areas[1]. Migrants have a higher risk than Australian born[18], and Indigenous Australians have the same risk as other Australians[19].

In the PEEK study, information about symptoms and quality of life from symptoms before diagnosis are collected in the online questionnaire, and in the interview, participants talk about the symptoms that actually lead them to get a diagnosis. Taken together, we can get an insight into the number and type of symptoms participants get, the symptoms that impact quality of life, and the symptoms that prompt medical attention.

In this PEEK study, the most common symptoms before diagnosis were urine related such as blood in urine, needing to pass urine often and having a burning feeling when passing urine. Over 70% of participants went to sought medical advice after seeing blood in their urine. Pain in the abdomen or lower back was also a common symptom.

Mine was so simple. There's only one day in the whole of my pre diagnosis prior to me seeing a doctor. It's a matter of hours from first noticing. I had never noticed any pain, any sensation, anything whatsoever. I woke up one morning to help a friend in a business to drive a truck for them. And I'm a PROFESSION, but I have a heavy vechicle licence, and I want to do a pee when I woke up in the morning. And I went to urinate and I thought, Oh, it feels like I'm passing a lot of water, like a lot of fluids. And I looked down and I just saw a stream of what looked like pure blood flowing out of my body. And I absolutely freaked out.
Participant 001_2022AUBLC

Histological types

The most common type of bladder cancers are transitional cell carcinomas, accounting for more than 90% of cases. The remainder of bladder cancers are squamous cell carcinomas, adenocarcinomas and small cell carcinomas[20,21].

Stages of bladder cancer

Stage 0 bladder cancer is confined to the bladder lining, stage I has spread into the connective tissue, stage II is in the muscle of the bladder. Stage III has spread through the bladder and into the surrounding fat and may have spread to nearby organs and stage IV has spread throughout the body[9].

There are conflicting reports about the differences in the stage of presentation of the disease between men and women, some report no differences between men and women[22], while others report that women present with more advanced disease[23]. Women are more likely to die from the disease than men[24-26], one study reports that this only occurs in those older than 70, the younger patients have the same disease specific survival[22].

Recurrence and progression

So I had another cystoscopy a few weeks back and that was the second one. So I was diagnosed about June last year. And so this was the second cystoscopy that I'd had. And it came back all clear. And in fact, the oncologist remarked that it was odd that they didn't even take a biopsy of just some tissue that might have looked a bit suspect. He said if I didn't even do a biopsy, it means you're very, very clear. So that was good to hear and, oh look, it's once it's happened, it can happen any time. So it's just a matter of having to live with the knowledge that it could happen again because it happened the first time. So it's not like I'm cured.
Participant 030_2022AUBLC

Bladder cancer recurrence typically occurs within a year of definitive treatment[27]. Depending on type and stage of disease, recurrence occurs in approximately 50 to 70% cases, and will progress in 7-40% of cases[28].

In this PEEK study, almost half noted that they had a recurrence, and a quarter of participants described prognosis in relation to probable recurrence/cycle of recurrence

Diagnosis

There are inconsistencies in diagnostic pathways with many patients experiencing delays in diagnosis, and there are no Australian evidence-based guidelines for haematuria presentation[29,30]. The UK National Institute for Health and Care Excellence recommend investigating suspected bladder cancer in patients aged 45 and over with unexplained visible haematuria and in patients aged 60 and over who have unexplained non visible haematuria and either dysuria and raised white cell count[31]. The American Urology Association recommend cystoscopic evaluation for all patients with visible haematuria and aged 35 or older, and high risk patients over the age of 40 presenting with microscopic haematuria[32]. A patient cohort in an Australian hospital reported that the probability of bladder cancer in patients presenting with haematuria was less than 1% for patients under 45 years, 13% at age 65 and 26% at age 80, based on this the authors recommended an approach similar to the UK guidelines[29].

In this PEEK study, participants were asked to describe the symptoms that actually led to their diagnosis, as opposed to all the symptoms that they could recall. The most common symptom leading to a diagnosis of bladder cancer was blood in the urine followed by pain in the bladder region and 60% of the participants were diagnosed within 3 months of noticing symptoms. Early detection for bladder cancer is important, delayed diagnosis is associated with poor outcomes, investigations for patients with suspected bladder cancer include blood and urine tests, imaging studies and referral for urology review, and cystoscopy[27,32-34].

A worldwide systematic review of the haematuria assessment described that women compared with men had a longer wait for urology review, were referred to urology less often, had fewer imaging studies and fewer cystoscopy[29]. In addition, despite greater risk of disease, smokers had less comprehensive assessments compared to non-smokers[30]. Delays in diagnosis and treatment of bladder cancer are associated with poorer outcomes[35,36]. Patients with macroscopic haematuria are more likely to be referred to urology sooner than those with microscopic haematuria[37], and are diagnosed sooner[38]. However, between 15 and 20% of patients presenting with haematuria will have bladder cancer[29,39], general practitioners may not want to over-investigate the cause of haematuria for an unlikely cancer diagnosis, this may be a factor in the delays that patients have in referral to urology.[30]

A hundred participants that had visual hematuria and had subsequently been diagnosed with bladder cancer in Western Australia described the waiting times to diagnosis and treatment[40]. The median time from haematuria to surgery in this cohort was 69.5 days[40]. Delays commonly occurred due to lack of public awareness of symptoms of bladder cancer, patient fear and anxiety, delayed and non-referral from primary care, administrative delays and resource limitations[40].

Another study described that the delay between cystoscopy and getting results universally caused anxiety and stress[41]. In this PEEK study, the majority of participants did not have enough emotional support during the diagnostic period, and almost half of the participants waited more than two weeks to get their diagnosis following diagnostic tests.

Biomarkers

Biomarkers may be used to detect bladder cancer or recurrences[42]. The protein nuclear matrix protein 22 (NMP22) has lower specificity to detect bladder cancer compared to cytology, however, the presence of NMP22 was associated with recurrence[43,44]. UroVysion uses fluorescence in situ hybridisation (FISH) to detect chromosomal abnormalities, it is approved in USA to aid diagnosis and to monitor tumour recurrence[42]. Other methods of detection under investigation include analysis of microRNA, epigenetic changes and next generation sequencing[42]. There are some mutations that may be of prognostic value, FGFR3 in non muscle invasive bladder cancer (NMIBC) was shown to be associated with recurrence in a large study[45], however, two other studies found no association[46,47]. Next generation sequencing techniques have highlighted that TP53 mutations and CDKN2A mutations may have worse outcomes and PIK3CA and or PI3k/Akt mutations may be associated with better disease specific outcomes[48,49]. PD-L1 may be used to select patients for atezolizumab or pembrolizumab, and FGFR2 or FGFR3 mutations for FGFR-targeted therapy (erdafitinib)[50]

There are no routine biomarker tests currently recommended by the Royal College of Pathologists of Australasia, most bladder cancers can be identified by histological examination, immunohistochemistry may be useful in distinguishing between tumour types[51].

Almost all of participants in this PEEK study did not recall having discussions about biomarkers and the majority were interested in having this test. No participants could name a biomarker test result.

Understanding and knowledge

Knowledge about chronic disease before diagnosis varies between individuals. Some will gain information from family and friends with the condition, though it can result in misconceptions and misunderstandings[52,53]. Some people will seek out information about a possible diagnosis, or explore the reasons for symptoms, before receiving a final diagnosis[54,55] others, especially those who have symptoms for long periods before diagnosis, will gain information in terms of how to live with or adapt to symptoms they experience[56]. For some people, the first time they have heard of their chronic condition is when they are diagnosed[55]. At the time of diagnosis, it may be useful for the healthcare professional to talk about how much a patient knows about a condition so that appropriate information can be given, and correct misconceptions[55].

Participants in this PEEK study noted that they did not have enough emotional support when they were diagnosed. Almost all participants had limited or no knowledge or understanding of bladder cancer when they were diagnosed. In another study, the majority people with bladder cancer (68%) reported that they did not receive enough information at diagnosis [57]. A common theme throughout this PEEK study was a lack of awareness of the condition in the community, in addition to wanting more information about their condition, in particular, treatment options.

In another study, people with bladder cancer described poor communication from their doctors at the time of diagnosis, where unclear language (such as “tumour”, “carcinoma”, or “polyp”) were used leading to misunderstanding about diagnosis[58]. The use of more direct terms such as “cancer” was preferred[58]

Key points

- **The majority of participants had symptoms before diagnosis, these were mostly blood in urine or changes to urination habits.**
- **Lack of emotional support in a sometimes lengthy period from diagnostic tests to diagnosis**
- **Almost all had limited or no knowledge about bladder cancer when diagnosed.**

Decision making

So I don't have one doctor. I mean, I have a GP who sent me to the hospital for a cystoscopy. And the hospital told me that I have cancer. And they said that the treatment for me is surgery to remove the bladder. And I said, well, is there more other options for me? And they said, you can try radiation, but we do not recommend it for your age because you're not very old and you can handle the surgery. And with surgery that it cannot come back because you don't have a bladder, but with radiation that can come back and also with radiation, maybe not now, but maybe in few years, the radiation itself can cause cancer. So I said, okay, then I go for surgery, but I can I still talk to them, I still get some more information for radiation. So I was not given very clear information that in my case, radiation, radiation was equally successful. So then I told them, do you need more me to continue? … So I just wanted to be aware that, you know, the main difference was radiation versus surgery and both have pros and cons. And I really wanted to be completely, very clearly informed. But because both treatments have got risk, it's not that one is right or wrong. It's what you are prepared to pay, what risk you want to take. Participant 028_2022AUBLC

The decision-making process in healthcare is an important component in care of chronic or serious illness[59]. Knowledge of prognosis, treatment options, symptom management, and how treatments are administered are important aspects of a person's ability to make decisions about their healthcare[60,61], highlighting the importance of healthcare professional communication. In addition, the role of family members in decision making is important, with many making decisions following consultation with family[62].

Most participants in this PEEK study were presented with multiple treatments or multiple options, however in some cases there was only one viable option. Participants described the most important considerations in decision making as taking the advice of their doctor, being cancer free or avoiding recurrence, side effects, ease of administration, and quality of life.

The majority of participants in this PEEK study described that they did not take an active role in decision making about their treatment. In some cases, it was because they felt there was only one treatment option available to them, and in others, that they were told what to do without discussion. It is noteworthy that the most common theme when asked about what they would like to see in future treatments was more information about their treatment options, and it was the second most common theme for what they wanted to see in future information. In addition, the most common theme for future communication was that it should be more transparent and forthcoming.

In other studies, people with bladder cancer described being overwhelmed by the amount of information given when discussing treatment options, while others felt they did not get enough information, in addition, some advice was inconsistent between healthcare professionals [63]. Those that were more informed about their options where more satisfied with their treatment.[64,65]. One study described women including family in decision making whereas male participants were more likely to describe family in a non-supportive role[66]. In this PEEK study, approximately 10% took the impact on their family into account when making treatment decisions, and fewer took advice from family and friends when making treatment decisions.

In other studies, people with bladder cancer described both wanting to play an active role in decision making and others did not[41,63]. Those that wanted a more active role in decision making described seeking a second opinion, finding more information online, or talking to other people[63], in addition, they described feeling uncertain about their doctor's recommendation and whether it satisfied their own treatment goals[41]. Those that did not want to take an active role in decision making described a preference to defer decisions to their doctor, as their doctor knows best[41]. Almost half of the participants in this PEEK study took the advice of their clinician into account when making treatment decisions, a total of 26% only took the advice of their clinician when making decisions, while the remaining considered other factors.

Goals of treatment and decision-making

Confidence to take part in decision-making is increased by knowledge, being prepared with relevant questions for their consultation, and summaries of previous consultations and results[67,68]. Participants in this PEEK study had limited to no understanding of bladder cancer at the time of diagnosis, making initial decision making difficult. However, a quarter of participants noted that they had changed decision making over time as they had become more informed or assertive.

Participants in this PEEK study described their treatment goals as taking the advice of their doctor, being cancer free or avoiding recurrence, minimising side effects, ease of administration, and quality of life. In other studies, people considered disease recurrence, prolonging life, avoiding cystectomy, family, return to normality or work, convenience of treatment, recovery time from treatment, and quality of life when making decisions about treatment for bladder cancer[69,70]

Key points

- **Many participants did not feel that they took part in their treatment decision making**
- **Participation in treatment decision making may be increased with more transparent and forthcoming information about treatment options**

Treatment and healthcare provision

In this PEEK study, to get an insight healthcare access, information about access to healthcare professionals, health insurance, health system, and financial consequences from having bladder cancer are collected.

Access to health professionals

In this PEEK study, more than 76% of the participants were given their diagnosis by a urologist, and 19% were given their diagnosis by a general practitioner. Almost all participants had access to a urologist, and to a general practitioner, and 63% had access to a nurse.

A focus group of 20 people with bladder cancer in America described difficulties in finding a urologist, lack of continuity of care, difficulty in getting timely medical appointments as barriers to bladder cancer treatment, and having a single point of contact with either a nurse or patient navigator as a facilitator to care[69]. In addition, they described wanting treatment closer to home rather than traveling to major cities[69]. In this PEEK study, participants noted the difficulty in communicating with healthcare professionals between appointments and the difficulty in getting appointments with their specialist.

Affordability of healthcare

I've thought at times. Wow. This is expensive, Like, some of the out-of-pocket expenses. Yeah. Um, and, ah, you. Yeah. I thought, wow, that's really, really expensive. And I've had other people saying to me, they're having cystoscopy, they've gotten out of pocket and, and there's lots of things and, but I've had several operations of like more than seven and a half hours. Robotic surgeries and complicated things like that, which I've been I've paid out 5000 out of pocket for anaesthetist yeah. For one operation and stuff like that for a really high profile anaesthetist that did an awake intubation on me, you know what sort of stuff. So, um, it's been expensive and I've just though I could have bought a Harley [Laughs], you know, the cost of these couple of operations. I could have done this or that with the money rather having surgery. Damn.
Participant 001_2022AUBLC

Almost half of the Australian population have private health insurance with hospital cover[65]. This can be used to partially or completely fund stays in public or private hospitals. Between 2006 and 2016, the proportion of private health care funded hospitalisations in public hospitals rose from about 8% to 14%[65]. In this PEEK study, a higher proportion had private health insurance compared to the Australian population.

Participants in this PEEK study described the costs and loss of income they experienced due to having bladder cancer. In this PEEK study, approximately a two-thirds had private health insurance and participants were most commonly treated as private patients in private hospitals. Work status did not change for approximately 60% of participants, this was mostly because they were already retired at the time of diagnosis. Where work status did change, it was primarily having to take leave from work or reducing hours worked.
The majority of participants in this PEEK study had monthly out of pocket expenses, with 50% spending up to $250 a month. the costs were from paying for treatments, gap payments, and cost of specialist appointments. Over half of the participants described having at least some cost burdens, but for those without a cost burden this was primarily due to having everything paid for through the health system.

In other studies, people with bladder cancer described having financial difficulties as a result of their diagnosis. Reasons for financial difficulties included being unable to work, having a low income, or a lack of insurance[10,58]. People aged under 65, those on lower income, or without insurance reported more financial difficulties [10,13]. [71], and financial difficulties resulted in treatment delays in lower health related quality of life [71]

Treatment

Treatment decisions are based on tumour grade and stage. Treatment may include surgery, chemotherapy, radiotherapy or a combination of these[27], a multidisciplinary approach improves the use of multi-modal treatment[72]. Tumour recurrence frequently occurs within the first year of definitive treatment, and more than half of high grade tumours recur[73,74]. The majority of participants had surgery to treat bladder cancer, and more than half the participants had Bacillus Calmetter-Guérin (BCG) treatment, 20 participants (48%) had chemotherapy, and three participants (7%) had radiotherapy.

The first specialist I saw only talked about the gold standard is that we should rip everything out. And he wouldn't, he was immovable, but I'm also immovable, so I refused. … I will, I refused to cooperate with the surgery and insisted on a referral to an oncologist. So at that point they offered me what they call the tri modal option. So bladder salvage, which is what my main focus was on bladder salvage. So I didn't want to go down the road to surgery. … Okay. Well, once I got to the oncologists, they said that they felt that they could preserve my bladder and so they recommended it. And how does the chemotherapy dose dense? In fact, it was called. And I also saw a radio and oncology radiologist as well. And so the treatment that was recommended was the track to weekly for four sessions, followed by, I think it was 30 sessions of radiotherapy.
Participant 020_2022AUBLC

Surgery

Early bladder cancer are treated by Trans Urethral Removal of Bladder Tumour (TURBT). High risk early bladder cancer, invasive bladder cancer and locally advanced bladder cancer, the tumours are treated by cystectomy, urinary function is restored by procedures such as an ileal conduit, continent urinary diversion, or bladder reconstruction (neobladder)[75].

There is growing evidence of better outcomes for patients who undergo radical cystectomies in high volume hospitals. Following implementation of volume guidelines in the UK, there was a decrease in 30 and 90 day mortality[76]. In Australia, a review of radical cystectomy in Victoria reports of increased in-hospital mortality and prolonged intensive care unit admission in patients who had a radical cystectomy in a low volume hospital (less than 4 radical cystectomies per year) compared with those in a high volume hospital (more than 10 radical cystectomies per year)[77]. A review of NSW RCs reported that high volume centres (more than 6 radical cystectomies per year) had better disease specific survival than low volume centres (less than 3 radical cystectomies per year)[78]. A registry of radical cystectomies performed could be beneficial, it could detect quality improvements[77]. In addition, the number of RC performed by surgeon and hospital to ensure that bladder cancer patients are treated in medium to high volume centres. In Sweden a prospective database of radical cystectomies identified risk factors for complications[79].

Elderly patients experience higher complication rates, higher hospital readmissions and higher perioperative rates following radical cystectomy[80]. Alternatives need to be considered and more data is needed to determine which elderly patients will benefit from radical cystectomy in terms of complications, quality of life and survival[80].

Other treatments

Following the surgical removal of the tumour, non-invasive high grade tumours can be treated with BCG immunotherapy for prevention or delaying of recurrence[81-83]. This is given weekly for six weeks once the bladder has healed from surgery, maintenance schedules with BCG are not well defined[82,84]. Non-invasive low-grade tumours have a poor response to BCG[84].

Muscle invasive tumours and BCG failures should be treated with cystectomy with urinary diversion. Neoadjuvant chemotherapy may be used with large tumours to assist with resection, there is a 5% advantage at five years, however, those that do not respond have a worse outcome due to delaying surgery. Adjuvant chemotherapy should be administered for lymph node positive tumours and or for tumours that invade muscle or surrounding organs[84].

Post surgical follow up of bladder cancer patients usually consists of urine cytology, repeat CT and regular check cystoscopies. Recurrence usually occurs within 12 months and over 50% of high grade tumours recur[27].

Pembrolizumab can be used for locally advanced or metastatic disease in patients that have received platinum-based chemotherapy[85].. Avelumab as maintenance therapy for locally advanced or metastatic disease in patients that did not progress on first line platinum based chemotherapy[85].

Urinary diversions

Three systematic reviews of quality of life following neobladder or ileal conduct diversion suggests that those with a neobladder had a quality of life advantage over other methods of urinary diversions[86-88]

A meta-analysis of post-operative quality of life following continent and incontinent diversion showed no overall difference in overall quality of life, mental health and social health[89]. However, those that had incontinent diversion displayed improvements in physical health compared to continent diversions. Those that had a neobladder had better emotional function and body image compared to incontinent diversion. The long-term quality of life following continent or incontinent diversion was not clear.

A mixed methods study of cancer and non-cancer ostomy patients described the most common symptoms that influenced daily life, these were fatigue and/or sleep problems, leakages, pain, bladder or bowel complaints, physical activity, usual daily activities such as work, clothing, diet and relationships/sexual intimacy.[90]

A qualitative study of people that had undergone urinary diversion described that resumption of normal daily activities with no or limited restrictions on social and personal life, older age, and lower complications were associated with a better quality of life[91]. Those that had difficulty in the management of the ostomy, and those that had only a partial resumption of normal activities were more likely to have poorer quality of life[91].

In this PEEK study participants described a negative impact on quality of life from having a stoma or problems with incontinence, and they described information about stoma management or from their stoma nurse as helpful. Some participants described that bladder preservation was an important treatment goals, while others described a hope that in the future there will be treatments that either prevent bladder loss or that bladder replacements will be improved.

Allied health

And the occupational therapist was really good too. She said to me, Are you just expecting to go back four days a week? I said, Oh, well, that was a plan. And she said, Well, that's really stupid, but you know, you're your own worst enemy. You need to go back one day a week and see how you go, and then two days a week, maybe for a couple of weeks and then build up slowly and just see how you are. And, and I also, because I'd had 23 lymph nodes taken out, I went to see a lymphedema physio because I just wanted to get a baseline and make sure that if I got any leg swelling that she'd already seen me and to give me some exercises to make sure I didn't get lymphedema. And she said the same thing. She said, you're stupid, just going back straight away and, and you need to just grade it. So that was really helpful. And then it built up over a couple of months back to four days a week again. And so my goals were just getting back to work and managing to get through the day here was, you know, learning how to manage the bag and when to empty that sort of stuff and not have a leak. And, and then at home also done swimming and playing tennis this not that often but and walk the dogs all the time so and it's a bit scary start doing lifting, because the literature says you can get a hernia quite easily so I've done that slowly but now I come back to pretty much full strength again. I'm just a bit more careful now.
Participant 018_2022AUBLC

Allied health is important to manage the physical, emotional, practical and financial consequences of bladder cancer. The most common allied health professionals accessed by participants in this PEEK study were physiotherapists, counsellors or psychologists, and dieticians. In addition, a recurring theme throughout the study was the need for easier access or direct referral to emotional and mental support, however, only a third reported accessing counsellors or psychologists.

Lifestyle changes

Diet and exercise needs of people with cancer change throughout the course of their treatment and survivorship[92], and lifestyle changes may be made by individuals to improve treatment outcomes, improve quality of life and reduce recurrence risk factors[93]. In this PEEK study, participants described using physical exercise for both maintaining mental and physical health, as well as maintaining a healthy diet to manage their general health.

Other studies noted that people with bladder cancer making lifestyle changes such as diet and exercise, describing benefits to health-related quality of life[14,41,94]. People with bladder cancer were motivated to exercise to have better outcomes following surgery, to improve health, return to normality, resume playing sports, however, side effects, worry about leakage and comorbidities were a barrier to exercise. [95,96]

Complementary therapies

Complementary therapies include taking supplements, mindfulness and relaxation techniques, massage therapy and acupuncture and many others. Complementary therapies have been reported to be used by between 40% and 80% of people with cancer, with reports of improvements in stress or side effects of treatments[97-100].

Key point

- **Participants were in need of mental and emotional support, better access or information about how to access counsellors or psychologists may fill this unmet need.**

Clinical Trials

And goodness me, it would be nice to see more actually more research into bladder transplants for those people that haven't got them any more. It would be nice if there was a less confusing amount of information about immunotherapy and about trials, because looking for trials is is very complicated. So some an easier access to that. I still see an oncologist. I'm sure that they would be very helpful, but without actually going and taking their time up just for questions, it would be good to have something that I could get clear, information that I could trust. To find potential trials, look at new research coming out. Participant 020_2022AUBLC

Clinical trials are essential for development of new treatments. The benefits to participants include access to new treatments, an active role in healthcare, and closer monitoring of health condition. The risks to participants include new treatment may not be as effective, and side effects.

A search of the Australian New Zealand Clinical Trials Registry was conducted on 20 June 2022. The search included any study that included participants with bladder cancer, was conducted in Australia, and was open to recruitment in the last five years. A total of 23 studies were identified that had a target recruitment of between 12 and 1292 participants (average=395), there were 16 studies that were international, and 7 studies that were conducted exclusively with in Australia. There were 17 studies that included only bladder cancer participants, and 6 studies that listed bladder cancer in the inclusion criteria among other types of cancer. The most common types of studies were investigating drugs (n=19), other studies were investigating surgery (n=1), allied health (n=1), surveillance (n=1), and patient reported outcome questionnaires (n=1).

There were 18 studies conducted in New South Wales, 18 studies in Victoria, 12 in Queensland, 10 in Western Australia, and 6 in South Australia. There were no studies conducted in Tasmania, the Australian Capital Territory, or the Northern Territory.

In this PEEK study, 76% of participants had not discussed clinical trials, 12% had participated, however, and 50% were willing to participant in a clinical trial if there was one available to them.

Figure 12.1: Distribution of clinical trials for bladder cancer in Australia 2017-2022

Patient treatment preferences

Clinical guidelines that are aligned to patient preferences are more likely to be used and lead to higher rates of patient compliance.[101-103] Patient preferences and priorities vary across different health issues, preferences are associated with health care service satisfaction, they refer to the perspectives, values or priorities related to health and health care, including opinions on risks and benefits, the impact on their health and lifestyle[101,104].

To help inform patient preferences in the bladder cancer community, participants in this PEEK study discussed side effects, treatment administration, adherence to treatment. Participants in this PEEK study used examples to describe both mild and severe side effects. Examples of mild side effects included Fatigue, pain and nausea. Aches and pain were also used as an example of severe side effects, as was the emotional impact. Mild side effects were also described as those that can be self-managed, and don't interfere with life, and severe side effects as those that do interfere with everyday life.

In other studies, people with bladder cancer have described side effects and symptoms they experienced as a result of their bladder cancer or treatment for bladder cancer. The types of symptoms reported include; urinary symptoms (frequency, incontinence, urgency, leakage, blood, and pain), pain and discomfort (in particular pain in bladder, pelvic and abdominal area), gastrointestinal symptoms (dry mouth, reduced appetite, nausea, vomiting, diarrhoea,and constipation), general malaise and fatigue (in particular disrupted sleep from changes to bladder function), sexual problems (sexual function, interest in sex), and emotional and mental health problems (depression, embarrassment from changes to bladder function) [9,10,13,41,58,63,70,105].

People with bladder cancer have noted the overall burden of side effects and rated the most troublesome side effects as blood in urine, frequent urination, sting or burning during urination, urgency to urinate, restricted movement due to pain or stiffness, worry about leaking (especially during sex, bed wetting, unable to hold it in), blood following cystoscopy, pain or discomfort during urination, and reduced interest in sex [70]. In addition, people with bladder cancer have described the impact that changes to bladder function has on their daily lives, including disrupted sleep and always needing to know toilet locations[58,63]. In this PEEK study, the symptoms that participants most wanted to control were pain, nausea and vomiting, and diarrhoea.

Self-management

Self-management of chronic disease encompasses the tasks that an individual must do to live with their condition. Self-management is supported by education, support, and healthcare interventions. It includes regular review of problems and progress, setting goals, and providing support for problem solving[106]. Components of self-management include information, activation and collaboration[106].

Information

Um, I've just found just the booklets from the Cancer Council. I've just found that they have been excellent information sources. Um, but because it just depends like every, night, like I have random thought and they kind of answer my questions like, you know what I mean? Like there's always an answer somewhere on the Cancer Council website.
Participant 009_2022AUBLC

Information is a key component of health self-management[107,108]. The types of information that help with self-management includes information about the condition, prognosis, what to expect, information about how to conduct activities of daily living with the condition, and information about lifestyle factors that can help with disease management[107,108].

Participants in this PEEK study were most commonly open to information after they had gotten over the shock of their diagnosis, or right from the beginning. Others were receptive to information following treatment, continuously, or after they had a chance to learn about their condition so that they are able to ask questions. In another study, people with bladder cancer described a lack of appropriate information at diagnosis, for example their doctor not giving them a clear diagnosis that they could understand, or were given important information after procedures while still effected by drugs[58]

Participants were asked about what type of information they were given by healthcare professionals, information about treatment options, disease management, disease cause, and physical activity were most frequently given to participants by healthcare professionals, and, information about complementary therapies, how to interpret test results and, hereditary considerations were given least often. The topics participants most often searched for were treatment options, disease cause , disease management and, how interpret test results were most frequently searched for independently and, information about physical activity, clinical trials, and hereditary considerations were searched for least often.

In other studies, people with bladder cancer described the topics of information that were useful, this included; general information about cancer, side effects of treatment, managing side effects, treatment advantages and disadvantage, follow up schedule and tests, financial concerns, and what to expect [63,65,109]. In some studies, people with bladder cancer described situations were they did not receive enough information to be able to cope, this included information about complications after surgery and chemotherapy, self-care after surgery, what to expect from chemotherapy, and the amount of maintenance required following continent and incontinent diversions[63,65]

Participants in this PEEK study described preferences for talking to someone plus online information as main preference. The internet was described as accessible, and a source of data they could digest at their own pace. Talking to someone was valued as it allowed them to ask questions, and it was described as more personalised and relevant. Written information was a preferred source for some, as this was a resource that they could refer back to. In other studies, people with bladder cancer described getting information from the internet, other people with bladder cancer and support groups, bladder cancer charities, social media, videos, printed material, indicating that a wide range of formats are useful information sources[63,65]

Participants in this PEEK study described information that they found helpful, most often this was information from health charities. Others described information about what to expect, treatment options, and side effects, and other people's experiences as helpful. Information about treatment options, talking to their doctor, information specific to their stage, and information about stoma management was also described as helpful. Participants most commonly described that no information was not helpful, they also described being able to decide for themselves if information was credible or not. Information from their doctor, worse case scenarios, and a lack of information were all described as not helpful.

In this PEEK study, gaps in information provision were also identified. Information about treatment options, disease cause, and disease management were most frequently given to participants by healthcare professionals. Information about complementary therapies, hereditary, genes and biomarkers and interpreting test results were given least often. The largest gaps in information, where information was neither given to patients nor searched for independently were hereditary, genes and biomarkers, clinical trials and complementary therapies.

Participants in this PEEK study described what they would like to see in future information about bladder cancer. Topics included that information was more accessible and easy to find, that it includes all the treatment options available to them, and that information will include were to get emotional and mental support. In addition, participants wanted information about bladder cancer to reach the wider community, to increase awareness of their condition.

Activation (skills and knowledge)

Oh, yes. Um, I, I had BCG, um, basically for the last couple of years, and then I got to the point where I just couldn't handle the BCG any longer. The side effects seem to be getting worse and worse. And my urologist was obviously checking, doing, cystoscopy every three months and every six months. And in the end, his recommendation was that I'd done well to stick it out as long as I had and basically to stop the BCG, which is what I did.

Participant 036_2022AUBLC

Patient activation is the skills, knowledge, and confidence that a person has to manage their health and care; and is a key component to health self-management. Components of patient activation are support for treatment adherence and attendance at medical appointments, action plans to respond to signs and symptoms, monitoring and recording physiological measures to share with healthcare professionals, and psychological strategies such as problem solving and goal setting.

Patient activation is measured in the PEEK study using the Partners in Health questionnaire. The Partners in Health questionnaire measures an individual's knowledge and confidence for managing their own health. The Partners in Health comprises a global score, 4 scales; knowledge, coping, recognition and treatment of symptoms, adherence to treatment and total score. A higher score denotes a better understanding and knowledge of disease. [110]. Participants in this PEEK study had very good knowledge about their condition, were good at coping with their condition, were good at recognizing and managing symptoms, and were very good at adhering to treatment.

In other studies, people with bladder cancer described their motivations for adhering to treatment, therapy or surveillance schedules. Some described being motivated by feeling that they were taking care of themselves, support from family, support from healthcare professionals, and adhering to what their doctor prescribed for them[41 95,111]. People with bladder cancer described reasons for not adhering to treatment, therapy or surveillance because of side effects, and not seeing positive changes[70,95]. In this PEEK study, participants described adhering to treatment as per the advice of their clinician, as long as treatment is working, as long of side effects are tolerable, and for a specific amount of time (usually 2 to 3 weeks).

Communication and collaboration

Dead set nothing. Didn't know. Didn't even know you could get bladder cancer. And, and even, even then the word, the word cancer in any form whatsoever didn't exist. It was, it was not talked about. Um. The wording was possible carcinoma and that was it.
Participant 040_2022AUBLC

Dutch participants with Non Muscle Invasive Bladder Cancer (NMIBC) expressed that verbal and non-verbal communication was important to them, participants were less likely to ask questions if the medical professionals appeared to be busy, they preferred information that was clear and concise otherwise they worried[112]. An organised hospital implied to the participants professionalism and was confidence building[112]. In a number of other studies, people with bladder cancer described the importance of continuity of care with the same healthcare professionals, the importance of communication between healthcare professionals, convenient ways to make and keep track of medical appointments, and knowing who contact to get their needs met[41,58,63]. [70].

In this PEEK study, participants also described wanting to have more time with their healthcare providers, and the importance communication between healthcare professionals for continuity of care.

Collaboration is an important part of health self-management, the components of collaboration include healthcare communication, details for available information, psychosocial and financial support [107,108] Communication between healthcare professionals and patients can impact the treatment adherence, self-management, health outcomes, and patient satisfaction[113-116].

An expert panel identified the fundamental elements of healthcare communication that encourages a caring, trusting relationship for patient and healthcare professional that enables communication, information sharing, and decision-making[117].

Building a relationship with patient, families and support networks is fundamental to establishing good communication[117]. Healthcare professionals should encourage discussion with patients to understand their concerns, actively listen to patients to gather information using questions then summarising to ensure understanding[117]. It is important for healthcare professionals to understand the patient's perspective and to be sympathetic to their race, culture, beliefs, and concerns. It is important to share information using language that the patient can understand, encourage questions and make sure that the patient understands[117]. The healthcare professional should encourage patient participation in decision-making, agree on problems, check for willingness to comply with treatment and inform patient about any available support and resources[117]. Finally, the healthcare professional should provide closure, this is to summarise and confirm agreement with treatment plan and discuss follow up.

Communication and collaboration with healthcare professionals was measured in this PEEK study by the Care Coordination questionnaire. The Care Coordination questionnaire comprises a total score, two scales (communication and navigation), and a single question for each relating to care-coordination and care received. A higher score denotes better care outcome[118]. The participants in this study experienced good quality of care, and good coordination of care. They had a good ability to navigate the healthcare system, and experienced average communication from healthcare professionals.

Participants that noted having good communication with their healthcare professionals noted that this was because of two-way, holistic, supportive and comprehensive conversations. In other studies, people with bladder cancer described characteristics of good communication with healthcare professionals, these included; thorough explanations, transparent and direct, supportive, reassuring, appearing interested, and responding to needs[69,70]. In addition, good communication resulted in greater satisfaction with treatment choices, and adherence to therapy[64,65].

Negative communication was described as dismissive or one way conversations, information that was withheld or was not forthcoming. In other studies, people with bladder cancer described characteristics of poor communication with healthcare professionals, these included; being insensitive to intrusive procedures leading to embarrassment of patient, insensitive ways of delivering diagnosis or test results (for example via email), lack of time to discuss issues important to the patient[58,69]. Participants in this PEEK study described wanting future communication to be more transparent and forthcoming, delivered with more empathy, and to have more time to discuss issues important to them.

Well, basically he just said that, well, get in and check it on a regular, you know, semi-regular basis sort of thing. And COVID was a disruptive force, I've got to say that, it didn't quite go to plan because of that. Pretty good. I've got to say that I didn't have too many issues with it did delay things at times but not to any great extent put it that way. It was only weeks, not months. And so, yeah, and I think that the discussion side of it probably. He spoke to me more as I, at the hospital rather than go back and see him. Whether I was 100% clear on everything. I would not say that I was. Normally when I go and see a specialist, I do take my wife with me, I mean she worked in the hospital system, which she can generally interpret something that I haven't quite picked up on as clearly. So I sort of yeah, I wouldn't say I was 100% clear of what was going to happen initially, but he spoke to me about the BCG and what should happen with that. And I didn't have any well, basically when I got down to that, that was another issue. But. Yeah. That's, that's basically what we spoke about.
Participant 011_2022AUBLC

Care and support

Yeah, I've found that they've been awesome. When I had a problem there maybe six months ago, I was having problems with where around the stoma. it was pretty red. And yeah, when seen the nurse and she told me to change the bag like daily instead of, you know, it was doing two or three days and things like that. So I've found that if I have any problems, I can ring her up, you know. And she's been great to ring up. I actually should, I save having to go into the hospital. I was taking pictures of me stoma and I'll send it to her and she was sending messages back and try this or try that. So didn't actually have to come to the hospital. So I was having like telephone consults with her. And I found it really good support.
Participant 044_2022AUBLC

In the USA, a study that included thirty participants with Muscle Invasive Bladder Cancer discussed their unmet needs, medical needs were lacking during the post-operative period, pain, bowel dysfunction and support for stoma and catheters were most frequent unmet. During the survivorship period (6 to 72 months post operatively) participants most frequently needed ongoing support to adjust to functions of daily living[119].

In this PEEK study, participants were asked what care and support they had received since their diagnosis. This gives an insight into what services patients consider to be support and care services. Most commonly, participants described not receiving any support. In other studies, people with bladder cancer described the types of support they would have liked but did not have access to. People with bladder cancer described wanting more peer support, counselling, support to address problems with sexual function , information about services available, financial support, relationship support, and support to get to medical appointments. [58,65,109]. Participants in this PEEK also described they type of support that they wanted in the future, this included access to support and care in general, that they would like peer support, and that their will be more awareness of bladder cancer and what it is like to live with the condition.

Participants in this PEEK study that did receive support, described it in terms of support from organisations such as charities, from the hospital or clinic they were treated in, and peer support, both online and in person. In other studies, people with bladder cancer described the type of support they received and from whom they received the support. The types of support included support to make lifestyle changes, managing treatments and appointments, household duties, emotional comfort, providing information, providing support when coming recovering from treatments, information about services, and managing side effects and symptoms[63,69,109]. They received support from nurses and healthcare professionals, other people with bladder cancer, partners, family, and friends[58,63,69]

Well, the main support of that is basically from via Facebook and ZOOM some some of the bladder cancer groups. BEAT's been a big help they had an open forum, I was on a Zoom meeting I was on that last night they had a chap on, and I'm glad I didn't do it prior to the operation to be honest, he showed a few gory pictures. One of the urologist or gentleman's he's been in the field for quite a few years 40 years or something urology. There was a few, but answered questions and describing operations for various people. So I thought it was fairly good, I went down to a bladder cancer walk on Sunday and a walk in CITY, in Memory of The young lass that died with bladder cancer died from bladder cancer. And people there, it's a registered charity, BEAT they were very supportive. And, you know, all of the family members plus members of the medical association are medical, they were there. So, you know, just general chit chat and no one got too personal about anything, but it was a yes. Good supportive environment.
Participant 011_2022AUBLC

Anxiety associated with condition

I think the delay time between the procedure and saying getting results is the only one because it can be very stressful. You know, between having the procedure, the cystoscopy and then getting the results. Sometimes, you know, it's sort of I know it's hard because you can't get an appointment with the urologist sometimes, but, you know, it's a three or four weeks or something like, you know, sitting around wondering.
Participant 007_2022AUBLC

The rates of depression and anxiety are higher in people with chronic conditions compared to the general population. In a meta-analysis of 20 qualitative studies, it was reported that people with chronic conditions experienced anxiety or depression as either as independent of their chronic condition or as a result of, or inter-related with the chronic disease, usually however, anxiety and depression develops as a consequence of being diagnosed with a chronic disease[120].

In this PEEK study, anxiety associated with bladder cancer was measured by the fear of progression questionnaire. The Fear of Progression questionnaire comprises a total score, between 12 and 60, with a higher score denoting increased anxiety[121]. On average fear of progression score for participants in this study indicated moderate levels of anxiety. In addition, there were high rates of depression and anxiety in the PEEK bladder cancer participants.
In other studies, people with bladder cancer described having anxiety about their condition. Specific times when anxiety about condition noted were before treatment, before surveillance tests, and during the diagnostic period, however, once diagnosis is confirmed, some reported a reduction in anxiety[14,41,58]. People with bladder cancer described being anxieous about disease progression or returning, death, continence, and dealing with a urostomy[41,58,70]. People with progressive disease had higher stress levels [7]. Younger people with bladder cancer have described more fear compared to older people[69]

Quality of life

Because it affected us being diagnosed with it as well. And because it was in the middle of COVID, like right at the start of COVID. When I was first diagnosed then. Every you know. The last two years. It's like shit for everyone. We didn't want to go out anywhere. We didn't want to socialise with our other family members. We were invited to birthday parties. I didn't want to go. I didn't want to mix with anyone because of the fear of catching something and then missing out on an operation or missing out on a check-up and things like that. So yeah, it affected our quality of life.
Participant 033_2022AUBLC

In relation to quality of life, participants in this PEEK study described a mix of positive and negative impacts on quality of life, with more participants describing the negative impacts. Negative impacts were due to the management of side effects of treatment, the mental and emotional impact, the emotional strain on partners and family, and due to intimacy problems.

In other studies, people with bladder cancer have described the impact of their condition on quality of life. The impact of side effects, such as pain, cognitive function, urinary function, sexual function[58,69]. Changes to sexual function has been described as impacting quality of life in other studies. This is from loss of sexual function, loss of sexual interest, anxiety about leaks, and pain [58,63,70]. Changes to urinary function had an impact on day to day life, worry about incontinence or leakage, making some activities more difficult since access to toilets is essential, [9,10,58,63,70]. People with bladder cancer described difficulty in travel or taking holidays, unable to act spontaneously as they need to know that a toilet is nearby, and needing to urinate at night leading to disrupted sleep and fatigue[63,69].

People with bladder cancer have described the impact on their mental or emotional health, especially with respect to depression, embarrassment from change in urinary and bowel function, body image, and worry that they will die from bladder cancer. [9,10,14,63,69].Others described regret in not taking better care of their health[9].People with bladder cancer have described the negative impact on their ability to work, role in their family, social life, ability to enjoy physical activities, and their independence[9,10,58,63].

In terms of positive impacts of bladder cancer, participants in this PEEK study described a positive impact from bringing people together, and to make them realise what is important. Similarly, in another study, people with bladder cancer described a positive impact of bladder cancer on their quality of life. This was from a change in their outlook, and strength from surviving a major illness[63].

People with bladder cancer have described the impact of bladder cancer on relationships. Many have described loosing friends, that family and friends equate cancer with death and are too afraid to visit [58,63]. Partners of people with bladder cancer have described changes to their relationships, the effects of the changing moods and emotions of their partners, and the disruption of medical appointments and treatment and problems with urinary function was socially isolating. [58]

In this PEEK study, a common theme was that a relationships suffered because family and friends withdrew, not knowing what to do or say, and from family dynamics changing from the stress and emotional impact of bladder cancer. Others reported that relationships were strengthened by people who were well-meaning and supportive, and that it had strengthened relationships.

Coping with bladder cancer

I'm just I think having a couple of close friends that I could talk to about it in my life and helped and I did a bit of exercise, I think helps you just, you know, working full time always distraction are good to, so it just keeps you busy and, you're not, dwelling on on negative things, which is there. But as I think at times, I definitely, and especially early on was very concerned and it would affect me sometimes when I'd think about it well, I'd often think about it, but again, didn't want to talk about it too much.
024_2022AUBLC

In other studies, people with bladder cancer described how they coped with bladder cancer, or activities that they did to maintain their mental or physical health. People with bladder cancer described accepting or adapting to their condition being positive, and acknowledging that their health was better compared to others[9,58,65]. In addition, people with bladder described the importance of support from family and friends, and support from healthcare professionals[69] [14]. [9,58]. Others described being prepared when leaving home by knowing the location and accessibility of toilets, eating a healthy diet, bot smoking, and regular exercise[9,58,70,95,122]

Participants in this PEEK study described maintaining their mental health, and noted the importance of family and friends, the importance of exercise, using mindfulness or meditation techniques. Almost a quarter noted that they did not do anything to maintain mental health. Participants in this PEEK study described maintaining their general health by being physically active, keeping busy, managing their stoma or incontinence, and complying with treatment.

Oh, I just feel that it was definitely a burden on my husband and I don't know what I would have done without him, to be honest, because he was the one that would come and pick me up after my BCG and he'd have the hot water bottle there and he'd fill it up and then he'd drive me home and be so concerned that he could see how uncomfortable I was. And I just don't know what I would have done without him. I felt quite reliant upon him and he found it very frustrating because he couldn't do anything to help. He wanted to try and take it away from me, but he couldn't. So it was quite stressful for him as well.
Participant 036_2022AUBLC

Characterisation

There were 44 participants with bladder cancer, and 5 carers to people with bladder cancer in the study from across Australia. The majority of participants lived in major cities, they lived in all levels of economic advantage. Most of the of participants identified as Caucasian/white. Most of the participants had trade or high school qualifications, and most were employed either full time or part time, or were retired. Approximately a quarter of the participants were carers to family members or spouses.

Physical activities were not limited for participants in this study, and emotional problems rarely interfered with work or other activities.

Participants in this study had an average of two symptoms before diagnosis, and the most common symptoms were blood in urine and needing to pass urine often.

This is a group that had health conditions other than bladder cancer to deal with, most often sleep problems, arthritis or scoliosis, and anxiety,

This is a patient population that had blood in their urine leading to diagnosis which they recalled clearly. Most participants sought medical attention after noticing symptoms and were diagnosed after their general practitioner referred them to a specialist.

This is a cohort that were mostly diagnosed with bladder cancer following experiencing symptoms. On average, this group had four diagnostic tests for bladder cancer, they were diagnosed by a urologist in a specialist clinic. The cost of diagnosis was not a burden to them and their families. They were mostly diagnosed with urothelial carcinoma, and stage I. This is a group that had no emotional support at the time of diagnosis. This is a cohort that did not have any conversations about biomarker/genomic/gene testing, and had no knowledge of their biomarker status.

This is a study cohort that had no knowledge of bladder cancer before they were diagnosed. This patient population described prognosis in terms of no evidence of disease or in remission, or in relation to monitoring their condition with tests, scans, or regular follow up appointments.

This is a patient population that had discussions about multiple treatment options.

This is a study cohort that took into account the advice of their clinician as part of many considerations when making decisions about treatment.

Within this patient population, participants had not changed decision making over time, this was because they had always taken the advice of their clinician.

When asked about their personal goals of treatment or care participants most commonly described wanting to be cancer free, avoid recurrence or increase longevity

This is a group that were cared for by a urologist, and had access to a general practitioner to treat their condition.

Almost two-thirds of this cohort had private health insurance, mostly treated as private patients treated in the private hospital system. This is a group that did not have trouble paying for healthcare appointments, prescriptions, and paying for basic essentials. Their monthly expenses due to bladder cancer were not a burden.

The work status of participants in this study did not change due to bladder cancer. Carers and family did not have to change employment status.

Participants had surgery, and drug treatments for bladder cancer. The most common treatments were transurethral resection of bladder tumour and Bacillus Calmetter-Guérin.

This is a group that did not have discussion about clinical trials, though would consider taking part if there was a suitable one for them.

This is a patient population that described mild side effects as symptoms such as fatigue or lethargy. This is a study cohort that described severe side effects as symptoms such as pain.

This is a patient population which described adhering to treatment as per the advice of their specialist, as long as prescribed, or as long as treatment is working. This is a study cohort that needed to see evidence of stable disease or no disease progression. If treatment worked, it would mean that they could do everyday activities and return to normal life.

Participants in this study had very good knowledge about their condition, were good at coping with their condition, were very good at recognizing and managing symptoms, and were very good at adhering to treatment.

Participants were given information about treatment options, disease management, and disease cause from health care professionals, and searched for treatment options, disease causes, and disease management, most often. This is a group who accessed information from non-profit, charity or patient organisations most often.

This is a patient population that access information primarily through the internet, a health charity, or from other patient's experiences.

This is a study cohort that found information from health charities, other people's experiences, and what to expect from the disease, side effects and treatments as being most helpful.

Participants commonly found no information unhelpful, and information from their GP as unhelpful.

This is a group that preferred talking to someone plus online information. This is a study cohort that generally felt most receptive to information after the shock of diagnosis.

Most participants described receiving an overall positive experience with health professional communication, which was holistic, two way and comprehensive. For those that had a negative experience it was mostly communication was dismissive, a one way conversation.

The participants in this study experienced good quality of care, and good coordination of care. They had a good ability to navigate the healthcare system, and experienced moderate communication from healthcare professionals.

This is a patient population described not receiving and care or support. For those that did have support, it was from charities, their hospital or clinic, or from online support groups.

This is a patient population that experienced a negative impact on quality of life largely due to the side effects of treatment or symptoms of conditions that they need to manage

This is a study cohort that experienced at least some impact on their mental health and to maintain their mental health they noted the importance of family and friends, the importance of exercise, and mindfulness or meditation in maintaining their mental health.

Within this patient population, participants described being physically active, and the importance keeping a normal routine, and managing their stoma or incontinence in order to maintain their general health.

Participants in this study had felt vulnerable especially during or after treatments, and when first diagnosed and the first few months after diagnosis. To manage vulnerability, they practised self-help (resilience, acceptance, staying positive) to manage the feeling of vulnerability

This cohort most commonly felt there was a positive impact on their relationships, with relationships strengthened, and that people were well-meaning and supportive.

Participants felt they were a burden on their family, due to the mental or emotional strain.

Most participants felt there was some cost burden which was from the costs of treatments, and gap payments for public or private health.

The participants in this PEEK study had moderate levels of anxiety in relation to their condition.

Participants would like future treatments to be more accessible particularly equitable, timely and includes access in rural locations, and for there to be more open and informed discussions about treatments.

This is a study cohort that would like information to be more accessible and easy to find, and also to include all treatment options available to them. Many participants were happy with the information they had about their condition.

Participants in this study would like future communication to be more transparent and forthcoming, and delivered with more empathy.

Participants would like future treatments to include access to appropriate real-world support services. Many participants were happy with the care and support they received.

This patient population was grateful for healthcare staff, and for low cost or free medical treatments through the government.

It was important for this cohort to control, pain, nausea and vomiting, and diarrhoea. Participants in this study would consider taking a treatment for more than ten years if quality of life is improved with no cure.

Participants’ message to decision-makers was to raise community awareness, and that they were grateful for the healthcare system and the treatment they had received.

This is a patient population that wished they had known what to expect from their condition especially the symptoms, and side effects of medication. They also wished they had been more assertive in relation to understanding treatment options and discussions about treatment

The aspect of care or treatment that participants in this study would most like to change is to have is they would have like more time and personalised attention with specialists.

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Section 12

Next steps

Next steps

At the end of each PEEK study, CCDR identifies three key areas that, if improved, would significantly increase the quality of life and/or the ability for individuals to better manage their own health.

In relation to this community, these three areas are:

1. Community awareness: Raise community awareness about bladder cancer, the risks, symptoms, and what it is like for someone to live with bladder cancer
2. Information: A guide to treatment options by stage, a list of centres that perform specialised surgical techniques such as robotic surgery or neobladders, with prompt lists available for patients to drive questions for clinicians
3. Support: Holistic support for the side effects and symptoms of bladder cancer, in particular mental and emotional support from when diagnosed, sexual function, incontinence, and stoma management

2022PEEK study in DISEASE

Data collected in this PEEK study also provides a basis on which future interventions and public health initiatives can be based. Some of the 2022 metrics that the sector can work together to improve upon are provided in Table 12.1

Table 12.1 Bladder cancer 2022 Metrics

		2022 results		2018 results	
Measure	**Detail**	**Mean**	**Median**	**Mean**	**Median**
Baseline health (SF36)	Physical functioning	78.96	85.00	66.30	70.00
	Role functioning/physical	56.25	50.00	49.00	50.00
	Role functioning/emotional	64.58	83.33	66.00	100.00
	Energy/fatigue	52.71	55.00	52.20	55.00
	Emotional well-being	66.92	68.00	70.67	70.00
	Social functioning	65.89	62.50	66.25	62.50
	Pain	71.51	77.50	73.65	78.75
	General health	56.35	60.00	54.70	55.00
	Health change	58.33	50.00	49.00	50.00
Knowledge of condition and treatments (Partners in Health)	Knowledge	25.62	27.00	25.06	26.00
	Coping	16.32	16.00	16.48	16.00
	Recognition and management of symptoms	19.87	21.00	20.04	20.00
	Adherence to treatment	13.34	14.00	13.76	15.00
	Total score	75.15	76.00	75.34	74.00
Care coordination scale	Communication	39.77	40.00	38.68	37.50
	Navigation	25.43	25.00	27.26	28.50
	Total score	65.19	68.00	65.94	64.50
	Care coordination global measure	7.09	8.00	7.36	8.00
	Quality of care global measure	7.85	8.00	8.24	9.00
Fear of progression	Total Score	32.87	31.00	29.32	29.00
		Percent		**Percent**	
Accessed My Health Record	-		-	10%	-
Participants that had discussions about biomarkers/genetic tests	-		-	8%	-