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%).