CENTRE FOR COMMUNITY-DRIVEN RESEARCH

Personal Experience, Expectations and Knowledge (PEEK)

People diagnosed with:

Hormone receptor positive breast cancer

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Summary of results

Executive summary

There were 52 participants with hormone receptor positive breast 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, aged mostly between 45 and 64. More than half of the participants had completed some university, and most were employed either full time or part time. Half of the participants were carers to family members or spouses.

Physical health and emotional problems interfered with work and other activities for participants in this study.

Approximately half had symptoms before diagnosis, and approximately half have ongoing symptoms from breast cancer or breast cancer treatments. Before diagnosis, they most commonly had breast lumps, and fatigue. The most common current symptoms were sleep problems, weight and muscle changes, thinking and memory problems, anxiety, fatigue and pain that all contributed to poor quality of life.

This is a group that had health conditions other than breast cancer to deal with, most often anxiety, sleep problems, and depression.

This is a patient population that did not experience symptoms and were diagnosed by having breast cancer screening. Of those that did have symptoms, on finding a breast lump, they sought medical attention and were diagnosed by their GP following referral to imaging studies.

This group had some knowledge of their condition before diagnosis, mostly because of their professional background or because they researched it during the diagnostic period. They understood their prognosis in terms of there being no evidence of cancer.

This is a cohort that were mostly diagnosed with breast cancer without experiencing symptoms. On average, this group had three diagnostic tests for breast cancer, they were diagnosed by a specialist doctor. The cost of diagnosis was somewhat of a burden to them and their families. They were mostly diagnosed with invasive breast cancer, and stage II or III. This is a group that did not have enough emotional support at the time of diagnosis, they did have enough information. This is a cohort that had conversations about biomarker/genomic/gene testing, and had knowledge of their biomarker status.

This is a group that were presented with multiple options and approached to managing their condition, and took part in making decisions about their treatment.

This is a study cohort that took side effects into account the of many considerations when making decisions about treatment.

Within this patient population, near equal numbers of participants had changed decision making over time and hadn’t changed over time, in both cases, this was linked to being informed and assertive.

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

They were cared for by a medical oncologist, and it usually took less than an hour to travel to medical appointments.

Over 80% of this cohort had private health insurance, they were mostly private patients in the private health 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 breast cancer were somewhat of a burden.

Participants in this study had to quit, reduce hours, or take leave from work. Carers and family did not have to change their employment status. The loss of family income was a burden.

Participants had surgery, drug treatments, and radiotherapy for breast cancer. They on average used one allied health service, one complementary therapy and made two lifestyle changes.

A third of this cohort had conversations about clinical trials. The majority of participants would take part in a clinical trial if there was a suitable one for them.

This is a patient population that described mild side effects as symptoms such as fatigue, pain and hair loss, they also described them as those which can be self-managed and do not interfere with daily life.

This is a study cohort that described severe side effects as symptoms such as pain, nausea, impact mental and emotional health or sleep. They also described severe side effects as those that impact everyday life and the ability to conduct activities of daily living.

This is a patient population which described an amount of time they were willing to adhere to a treatment before giving up, or would continue treatments on the advice of their doctor. This is a study cohort that needed to see symptom reduction to feel that treatment is working. If treatment was working, it would mean that they could do everyday activities and return to a 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 physical activity from health care professionals, and searched for treatment options, interpreting test results, 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, and health charities.

This is a study cohort that found information about what to expect from the disease, side effects and treatments as being most helpful.

Participants commonly found no information unhelpful, and information from other people's experience as unhelpful.

This is a group that preferred to get their information from a combination of resources, most commonly talking to someone plus online information. This is a study cohort that generally felt most receptive to information from the beginning, at diagnosis.

Most participants described receiving an overall positive experience with health professional communication (some with a few exceptions) which was holistic, two way and comprehensive. Despite having good communication, it was limited by time, and their understanding.

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

This is a patient population that felt that they did not receive any care and support, for those that did, it was from their hospital or treatment clinic.

This is a patient population that experienced a negative impact on quality of life largely due to emotional and mental strain on their partners, children, and themselves.

Life was a average for this group, due to having breast cancer. The symptoms that most impact quality of life of this group are pain, fatigue, and cognitive problems.

This is a study cohort that experienced at least some impact on their mental health and to maintain their mental health they used coping strategies such as mindfulness and meditation, and physical exercise.

Within this patient population, participants described being physically active, and the importance of self-care, in order to maintain their general health.

Participants in this study had felt vulnerable especially during the diagnostic process, and during or after treatments. To manage vulnerability, they relied on their own resilience, acceptance, and being positive.

This cohort most commonly felt there was a mix of positive and negative impacts on their relationships, with some relationships strengthened, and others described family and friends withdrawing from relationships because they don't know what to say or do .

Half of the Participants in this study felt they were a burden on their family, due to the extra responsibilities that had to take on, and the other half of participants were not a burden as they didn't need any help and remained independent.

Almost all participants felt there was some cost burden which was from the costs of treatments, tests and scans, and also from having to take time off work.

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

Participants would like future treatments to have fewer or less intense side effects.

This is a study cohort that would like more information about symptoms and side effect management and control.

Participants in this study would were mostly happy with their communication with healthcare providers, but suggested that future communication could be more transparent, forthcoming, and empathetic.

Participants would like future treatments to include more access to support services.

This patient population was grateful for the healthcare staff, and the entire health system, both public and private.

It was important for this cohort to control memory loss and cognitive function, fatigue, and pain. 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 improve access to support and care.

This is a patient population that wished they had known what to expect from their condition especially the disease trajectory and disease biology. They also wished they had been more proactive in asking for information.

This is a patient group that were satisfied with the care received and would not change it, though they wish they had a better understanding of their condition.

Section 1

Introduction and methods

Section 1 Introduction and methodology

The estimated incidence of breast cancer in Australia was over 19,000 cases, and it was the most diagnosed cancer in women, and the most diagnosed cancer overall [1]. There were over 3000 deaths from breast cancer in 2019, and this was the second most common cause of death from cancer for women, and the fourth most common overall. Over three quarters of breast cancers are diagnosed at stage I or stage II[1]. Approximately 55% of women aged 50 to 74 participated in breast cancer screening in the 2015 to 2016 period[1].

The five-year survival from breast cancer (2011 to 2015) was 90.8%, survival when diagnosed at stage I is almost 100%, however, when diagnosed at stage IV, the survival is 32%[1].

Hormone-receptor positive breast cancers are sensitive to oestrogen or progesterone, approximately 70% of breast cancers are hormone-receptor positive[2]. Adjuvant treatment with tamoxifen is recommended, followed by an addition five years for pre or peri-menopausal women, and an additional five years with tamoxifen or an aromatase inhibitor for post-menopausal women[2].

A PubMed search was conducted on 4 October 2021 to identify studies reporting patient experience, patient reported outcomes, and quality of life studies in the Australian hormone-receptor positive breast cancer community. Studies conducted more than five years ago were excluded, and studies that included multiple types of breast cancers that did not report hormone-receptor positive breast cancers separately (as a subgroup) were excluded. There were 12 studies identified of between 26 and 4891 participants. There was only one study identified that interviewed participants or used qualitative methods, this study was focused on endocrine therapy.

This PEEK study includes 52 people diagnosed with hormone-receptor positive breast cancer throughout Australia, including a qualitative structured interview and quantitative questionnaire. This study in hormone-receptor positive breast cancer is therefore the largest mixed method study reported in an Australian population. In addition, 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.

Section 2

Demographics

Section 2 Demographics

Breast cancer stage

In this PEEK study, a total of 52 participants with hormone receptor positive breast cancer were recruited into the study. There were two participants (3.85%) with Stage 0, 17 participants (32.69%) with Stage I, 21 participants (40.38%) with Stage II, 10 participants (19.23%) with Stage III, and two participants (3.85%) with Stage IV.

Demographics

Participants were most commonly from New South Wales (n = 18, 34.62%), Queensland (n = 14, 26.92%), and Victoria (n = 9, 17.31%). Most participants were from major cities (n = 41, 78.85%), and they lived in all levels of advantage, defined by Socio-economic Indexes for Areas (SEIFA) (www.abs.gov.au) with 34 participants (65.38%) from an area with a high SEIFA score of 7 to 10 (more advantage), and 18 participants (34.62%) from an area of mid to low SEIFA scores of 1 to 6 (less advantaged).

There were 33 participants that had completed university to at least an associate degree (63.46%). There were 21 participants who were employed either full time (40.38%), or part time (n =5, 9.62%).

Half of the participants were carers to family members or spouses (n = 26, 50.00%), most commonly carers to children (n = 19, 36.54%).

Other health conditions

The majority of participants had at least one other condition that they had to manage (n = 48, 92.31%), the maximum number reported was 9 other conditions, with a median of 3.00 (IQR = 3.25) other conditions. The most commonly reported health condition was anxiety (self or doctor diagnosed) (n = 31, 59.62%), followed by sleep problems or insomnia (n = 29, 55.77%), depression (self or doctor diagnosed) (n =19, 36.54%), and arthritis (n = 16, 30.77%).

Baseline health

SF36 Physical functioning scale measures health limitations in physical activities such as walking, bending, climbing stairs, exercise, and housework. On average, physical activities were slightly 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 almost 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 moderate pain.

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

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

Section 3

Symptoms and diagnosis

Section 3: Symptoms and diagnosis

Symptoms leading to diagnosis

The most common symptom leading to diagnosis was having a lump or lumps in their breast (n=26, 50.00%), this was followed by being vigilant about having breast check-ups due to their family or personal medical history (n=7, 13.46%), breast pain (n=5,9.62%), and breast skin changes such as puckering, dimpling, a rash or redness of skin (n=5, 9.62%).

Symptoms leading to diagnosis: Seeking medical attention

There were 25 participants (48.08%) that described having symptoms and seeking medical attention relatively soon. There were 14 participants (26.92%) that described being diagnosed through screening without experiencing symptoms, and 13 participants (25.00%) described having symptoms and not seeking medical attention initially.

Symptoms leading to diagnosis: Description of diagnostic pathway

Participants were most commonly diagnosed through a population screening program (n=19, 36.54%), and this was followed by being diagnosed by their general practitioner due to concerns about symptoms (following imaging studies) (n=17, 32.69%), and being referred directly to a specialist from their general practitioner which led to their diagnosis (n=16, 30.77%).

Time from symptoms to diagnosis

Duration was calculated for 22 participants (30 participants had no symptoms before diagnosis), there were three participants (13.64%) that were diagnosed less than 1 month of noticing symptoms, six participants (27.27%) diagnosed 1 to 2 months from noticing symptoms, four participants (18.18%) that were diagnosed 3 to 6 months of noticing symptoms, and five participants (22.73%) that were diagnosed more than 6 months of noticing symptoms

Time from diagnostic test to receiving a diagnosis

Participants were most commonly diagnosed less than one week after diagnostic tests (n=21, 40.38%), followed by being diagnosed between 1 and 2 weeks (n=16, 30.77%)

Diagnostic tests

Participants reported between 1 and 5 diagnostic tests (median = 3.00 , IQR = 1.00). The most common tests were mammogram (n = 47, 90.38%), breast ultrasound (n = 47, 90.38%), fine needle aspiration (n = 25, 48.08%), and core biopsy (n = 40, 76.92%)

Diagnosis provider and location

More than half of the participants were given their diagnosis by a specialist doctor (n=31, 59.62%), and there were 21 participants (40.38%) given the diagnosis by a general practitioner (GP)

Participants were most commonly given their diagnosis in the general practice (GP) (n = 17, 32.69%), this was followed by the specialist clinic (n = 14, 26.92%), and the hospital (n = 8, 15.38%)

Breast cancer diagnosis

The majority of participants were diagnosed with invasive breast cancer (n = 30, 57.69%), followed by invasive lobular breast cancer (n = 10, 19.23%) and ductal carcinoma in situ (DCIS) (n=7, 13.46%)

Breast cancer stage

In this PEEK study, a total of 52 participants with hormone receptor positive breast cancer were recruited into the study. There were two participants (3.85%) with Stage 0, 17 participants (32.69%) with Stage I, 21 participants (40.38%) with Stage II, 10 participants (19.23%) with Stage III, and two participants (3.85%) with Stage IV.

Understanding of disease at diagnosis

Most participants described having limited knowledge about the condition at diagnosis (n=30, 57.69%), this was followed by having no knowledge (n=11, 21.15%), and having had a good knowledge (n=9, 17.31%). The most common reasons for having limited knowledge was from having a family history of the condition (n=9, 17.31%), having a friend or acquaintance with the condition (n=8, 15.38%), having a medical, research or relevant professional background (n=8, 15.38%), and researching the condition during the diagnostic process (n=5, 9.62%). The most common reason for having good knowledge of the condition at diagnosis was having a medical, research or relevant professional background (n=9, 9.62%).

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 15 participants (28.85%) who had enough support, 11 participants (21.15%) that had some support but it wasn't enough, and 26 participants (50.00%) had no support.

Information at diagnosis

Participants were asked in the online questionnaire how much information they or their family received at diagnosis. There were 29 participants (55.77%) who had enough information, 21 participants (40.38%) that had some information but it wasn't enough, and two participants (3.85%) had no information.

Costs 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 19 participants (36.54%) who had no out of pocket expenses, and 12 participants (23.08%) who did not know or could not recall. There were eight participants (15.38%) that spent Less than $500,, and 13 participants (25.00%) that spent more than $1000.

Burden of diagnostic costs

For 13 participants (39.39%) the cost was slightly or not at all significant. For 12 participants (36.36%) the out-of-pocket expenses were somewhat significant, and for eight participants (24.24%), the burden of out-of-pocket expenses were moderately or extremely significant.

Genetic tests and biomarkers

Most commonly, participants had never had a conversation about biomarkers, genomic, or gene testing that might be relevant to treatment, (n = 16, 30.77%). There were 14 participants (26.92%) who brought up the topic with their doctor, and 22 participants (42.31%) whose doctor brought up the topic with them.

Half of the participants did not have any genetic or biomarker tests but would like to (n = 26, 50.00%). There were five participants (9.62%) who did not have these tests and were not interested in them, and a total of seven participants (13.46%) that had biomarker tests

Biomarker status

All participants knew the status for at least one biomarker (n = 52, 100%). All participants knew their ER status (n=52, 100%), and most participants knew their PR status (n = 42, 80.77%). There were 15 participants (28.85%) that knew their HER2 status and seven participants (13.46%) that knew their BRCA status.

Current symptoms

Almost half of the participants had symptoms to deal with at the time of completing the questionnaire (n = 24, 46.15%). Participants had between four and 13 symptoms (mean = 4.10, SD = 4.69).

The most common current symptoms, and those where more than 40% of the participants experienced the symptom were; sleep problems (n = 23, 44.23%), weight and muscle changes (n = 23, 44.23%), thinking and memory problems (n = 22, 42.31%), anxiety/anxious mood (n=21, 40.38%), fatigue (n = 23, 44.23%), and pain(n = 23, 44.23%).

The median quality of life was between 2.00 and 3.00, for all of the symptoms listed in the questionnaire, this is in the "Life was distressing" to "Life was a little distressing" range.

Understanding of prognosis

Participants most commonly described their prognosis in relation to no evidence of disease or that they are in remission (n=23, 44.23%). There were 22 participants (42.31%) that described a positive prognosis in relation managing their condition with treatment. Other participants described prognosis in relation to statistics such as five year survival rates (n=19, 36.54%), in relation to probable recurrence/cycle of recurrence (n=16, 30.77), and in relation to monitoring their condition without treatment until there is an exacerbation or progression (n=6, 11.54%).

Section 4

Decision-making

Section 4 summary

Discussions about treatment

The most common description was being presented with multiple treatment options, and this was described by 43 participants (82.69%). This was followed by being presented with one treatment option only (n=8, 15.38%).

Discussions about treatment (Participation in discussions)

In relation to participant in discussions about treatments, there were 23 participants (44.23%) that described that they participated in decision making or had informed discussions, and 21 participants (40.38%) that described that they did not take part in decision making, and nine participants (17.31%) that described feeling that they were told what to do with little or no discussion.

Considerations when making decisions

The most reported theme was taking side effects into consideration and this was described by 24 participants (46.15%). There were 17 participants (32.69%) described taking efficacy of treatment into account, and 15 participants (28.85%) described taking the advice of their clinician. Other considerations included quality of life (n=9, 17.31%), impact on family and dependents (n=8, 15.38%), survival benefit (n=8, 15.38%), ease of administration (n=7, 13.46%), and the ability to work (n=5, 9.62%).

Decision-making over time

Participants were asked if the way they made decisions had changed over time. There were 27 participants (51.92%) that felt the way they made decisions about treatment had not changed over time, and 25 participants (48.08%) that described decision making changing.

Where participants had not changed their decision making over time, this was this was because they have had always been informed and assertive (n=7, 13.46%), or always taken the advice of clinicians (n=6, 11.54%). Where participants had changed the way they make decisions, it was primarily because they had become more informed or more assertive over time (n=17, 32.69%), or because they were more focused on quality of life or the impact of side effects (n=6, 11.54%).

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 or avoid recurrence (n=23, 44.23%), and this was followed by wanting to minimise or control side effects (n=20, 38.46%). Other themes included wanting quality of life or return to normality (n=9, 17.31%), and wanting to see improvements in mental or emotional health (n=5, 9.62%).

Section 5

Treatment

Section 5: Experience of treatment

Main provider of treatment

The most common provider of treatment and care were medical oncologists (n = 26, 50.00 %), followed by specialist surgeons (n = 15, 28.85%).

There were 13 participants (25.49%) that travelled for less than 15 minutes, 23 participants (45.10%) that travelled between 15 and 30 minutes, nine participants (17.65%) that travelled between 30 and 60 minutes, two participants (3.92%) that travelled between 60 and 90 minutes, and four participants (7.84%) that travelled more than 90 minutes.

Access to healthcare professionals

Almost all participants had access to a medical oncologist (n = 49, 94.232%), and a specialist surgeon (n = 49, 94.23%) for the treatment and management of breast cancer. There were 43 participants (82.69%) that had a radiation oncologist, 43 participants (82.69%) that had a general practitioner (GP), and 42 participants (80.77%) had a breast care nurse, and 30 participants (57.69%).

There were 30 participants (57.69%) cared for by a oncology or chemotherapy nurse, 28 participants (53.85%) treated by a physiotherapist and, 25 participants (48.08%) with a pharmacist. Almost half of the participants had a lymphoedema practitioner to care for their condition (n = 24, 46.15%).

Health care system

The majority of participants had private health insurance (n = 41, 80.39%). The majority of participants were not asked if they wanted to be treated as a public or private patient (n = 31, 60.78%), however, they were asked if they had private health insurance (n = 44, 86.27%).

Throughout their treatment, there were 29 participants (56.86%) who were treated as a private patient, 13 participants (25.49%) were mostly treated as a public patient, and there were nine participants (17.65%) who were equally treated as a private and public patient.

Throughout their treatment, there were 25 participants (49.02%) who were treated mostly in the private hospital system, 11 participants (21.57%) were mostly treated in the public system, and there were 15 participants (29.41%) who were equally treated in the private and public systems.

Affordability of healthcare

Almost all the participants never or rarely had to delay or cancel appointments due to affordability (n = 48, 94.12%).

Almost all of the participants never or rarely were unable to fill prescriptions (n = 47, 92.16%).

There were 45 participants (88.24%) that never or rarely had trouble paying for essentials such as such as food, housing and power., and four participants (7.84%) that sometimes found it difficult.

There were 8 participants (15.69%) that paid for additional carers carers for themselves or for their family due to their condition.

Cost of condition

Participants estimated the amount they spend per month due to their condition, including doctors' fees, transport, carers, health insurance gaps and complementary therapies. The most common amount was between $101 to $250 (n = 15, 29.41%), followed by between $251 to $500 (n = 8, 15.69%). There were four participants (7.84%), who spent $1001 or more a month.

The amount spent was an extremely significant or moderately significant burden for 12 participants (23.53%), somewhat significant for 12 participants (23.53%), and slightly or not at all significant for 27 participants (52.94%).

Changes to employment status

Work status for 10 participants (19.61%) had not changed since diagnosis, and eight participants (15.69%) were retired or did not have a job. There were eight participants (15.69%) that had to quit their job, 15 participants (29.41%) reduced the number of hours they worked, and three participants (5.88%) that accessed their superannuation early. There were 11 participants (21.57%) that took leave from work without pay, and 10 participants (19.61%) who took leave from work with pay.

Changes to carer/partner employment status

There were 11 participants (21.57%), without a main partner or carer. Most commonly, participants had partners or carers that did not change their work status due to their condition (n = 24, 47.06%). There were four participants (7.84%) whose partners reduced the numbers of hours they worked, and no partners of participants had to quit their job. The partners of two participants (3.92%) took leave without pay, and there were 10 partners (19.61%) who took leave with pay.

Reduced income due to condition

More than half of the participants (n = 27, 52.94%) indicated in the online questionnaire that they had a reduced family income due to their condition.

Most commonly, participants were not sure about the amount their monthly income was reduced by (n = 8, 15.69%), or reduced by between $1001 to 2500 per month (n = 8, 15.69%).

For nine of these participants (33.33%) (40.74%), the burden of this reduced income was extremely or moderately significant, for 7 participants (25.93%) the burden was somewhat significant, and for seven participants (40.74%), the burden was slightly or not all significant .

Treatments overview

There were 46 participants (88.46%) that had surgery, 48 participants (92.31%) that had drug treatments, and 42 participants (80.77%) that had radiotherapy. The majority of participants had used allied health (n=40, 76.92%), complementary therapies (n=40, 76.92%), and, made lifestyle changes(n=45, 86.54%).

Surgical treatments

There were 46 participants (88.46%) that had surgery for breast cancer. The most common type of surgery was lumpectomy (n=30, 57.69%), followed by mastectomy (n=19 , 36.54%). There were 14 participants (26.92%) that had breast reconstruction, 10 participants (19.23%) had re-excision following lumpectomy, and nine participants (17.31 %) had surgery to remove ovaries.

Drug treatments

There were 48 participants (92.31%) that had drug treatments. The most common types of drug treatments were tamoxifen (n=23, (45.1%), letrozole n=18, (35.29%) and, anastrozole (n=8, 15.69%).

Radiotherapy

There were 40 participants (76.92%) that had radiotherapy to the primary cancer site, and four participants (7.69%) that had radiotherapy to a secondary cancer site.

Allied health

The most common allied health service used was physiotherapy (n = 31, 60.78%), followed by psychology (n = 18, 35.29%), and occupational therapist (n = 7, 13.73%). There were six participants (11.76%) that saw a dietician, and six participants (11.76%) that saw a social worker.

Lifestyle changes

The most common lifestyle change used was exercise (n = 43, 84.31%), followed by diet changes (n = 28, 54.90%), and quit or cut back on alcohol (n = 27, 52.94%)

Complementary therapies

The most common complementary therapies used were supplements (n = 25, 49.02%), and mindfulness or relaxation techniques (n = 25, 49.02%), and massage therapy.

Clinical trials

There was a total of 17 participants (33.33%) that had discussions about clinical trials, 4 participants (7.84%) had brought up the topic with their doctor, and the doctor of 13 participants (25.49%) brought up the topic. The majority of participants had not spoken to anyone about clinical trials (n = 34, 66.67%).

There were seven participants (13.73%) that had taken part in a clinical trial, 32 participants (62.75%) that would like to take part in a clinical trial if there was a suitable one, and 12 participants, who have not participated in a clinical trial and do not want to (23.53%).

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
to describe them with specific examples (n=27, 51.92%). There were 25 participants (48.08%) that described mild side effects as those that do not interfere with daily life, and 19 participants (36.54%) that described mild side effects as those that can be self-managed.

Of those who described a specific side effect, the most commonly described side effects were fatigue (n=7, 13.46%), mild pain or aches (n=6, 11.54%), and hair loss.

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=30, 57.69%). Other descriptions of ‘severe side effects’ included those that impact everyday life/ability to conduct activities of daily living (n=26, 50.00%), those that require medical intervention (n=5, 9.62%).

Of those who described a specific side effect, the most commonly described side effects were pain (n=11, 21.15%), the emotional and mental impact (n=7, 13.46%), those that impact on sleep (n=5, 9.62%), and nausea (n=5, 9.62%).

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 for a specific amount of time (n=20, 38.46%), and as per the advice of their specialist/as long as prescribed (n=19, 36.54%). Other participants described adhering to treatment as long as side effects are tolerable (n=15, 28.85%), and not giving up on any treatment (n=15, 28.85%).

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 (46.15%) was needing to see an improvement in specific symptoms, and this was followed by 19 participants (36.54%) that reported needing to experience an improvement in side effects in general, and needing evidence of stable disease or no disease progression (n= 12, 23.08%). There were 12 participants (23.08%) that described needing to have a balance between benefits and potential side effects, and 11 participants (21.15%), that reported that it was difficult to know if the treatment was working and that they needed evidence.

Where participants need to see improvements in specific side effects, the most noted side effects were aches and pain, and hot flushes.

What it would mean if treatment worked

Participants were asked to describe what it would mean to them, if their treatment worked. The most common response from 25 participants (48.08%) was allowing them to return to everyday activities or return to normal life. Other participants described that it would have a positive impact on their mental health (n=13, 25.00%), that it would allow them to work (n=9, 17.31%), get enough sleep (n=6, 11.54%), and do more exercise (n=5, 9.62%).

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 40 participants (76.92%) was the internet in general. There were 29 participants (55.77%) that described accessing from a specific health charity, 24 participants (46.15%) accessed information primarily through other patient's experience. Other types of information accessed included books, pamphlets and newsletters (n=21, 40.38%), from Facebook or social media (n=17, 32.69%), nursing staff (n=17, 32.69%), and their treating clinician (n=14, 36.992%), and through journals and research articles (n=13, 25.00%).

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 20 participants (38.46%) was information about what to expect (e.g. from disease, side effects, treatment). There were 17 participants (32.69%) that described talking to their doctor or specialist as being helpful, and 11 participants (21.15%) that described other people's experiences as being helpful. Other types of information described as being helpful included information from health charities (n=10, 19.23%), and and information that is specific to their condition and sub-types (n=5, 9.62%).

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 19 participants (36.54%) that responded that no information was not helpful. The most common type of information found to be unhelpful by 13 participants (25.00%) was other people's experiences. There were eight participants (15.38%) that described other people giving advice or opinions as unhelpful, and the same number that described worst case scenarios and negative information as unhelpful (n=8, 15.38%). Other participants described information from their GP or specialist as unhelpful (n=7, 13.46%), and information from sources that are not credible as not helpful (not evidence-based) (n=6, 11.54%).

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, most participants had a preference for a combination of information sources (n=44, 8.63%), all of these combinations included online information. There were five participants (9.62%) only had a preference for talking to someone, and four participants (7.69%) only had a preference for written (booklets). Participants commonly had a preference for talking to someone plus a written form of information (either app, internet or booklet) (n=33, 63.47%), and a total of 15 participants (n=15, 28.84%) that had a preference for information in the written form only (either app, internet or booklet).

The main reasons for a preference for online information were accessibility, and being able to digest information at their own pace. The main reason for talking to someone as a preference was being able to ask questions, and getting information that was relevant or personalised.

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 was from the beginning when diagnosed (n=20, 38.46%), this was followed by participants describing being receptive to information after the shock of diagnosis (n=13, 25.00%), continuously throughout their experience (n=9, 17.31), and after treatment (n=7, 13.46%).

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=32, 61.54%). There were 16 participants (30.77%) that described an overall positive experience, with the exception of one or two occasions, and four participants (7.69%) that had an overall negative experience.

Participants that had positive communication, described the reason for this was because of holistic, two-way, supportive and comprehensive conversations (n=17, 32.69%).

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: 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 very good overall knowledge, coping and confidence for managing their own health.

Information given by health professionals

information they were given by healthcare professionals. Information about treatment options (n=46, 88.46%), physical activity (n=26, 50.00%), disease management (n=25, 48.08%) and, hereditary considerations (n=22, 42.31%) were most frequently given to participants by healthcare professionals, and, information about how to interpret test results (n=10, 19.23%), complementary therapies (n=9, 17.31%) and, clinical trials (n=7, 13.46%) 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=29, 55.77%), how to interpret test results (n=27, 51.92%), disease management (n=25, 48.08%), and disease cause (n=24, 46.15%) were most searched for by participants, and information about psychological and social support (n=12, 23.08%) and, clinical trials (n=10, 19.23%) were searched for least often.

Information gaps

The largest gaps in information, where information was neither given to patients nor searched for independently were clinical trials (n = 37, 71.15%), dietary information (n = 27, 51.92%), complementary therapies (n = 27, 51.92%) and psychological and social support (n = 26, 50.00%).

The topics that participants most commonly did not search for independently after not receiving information from healthcare professionals were treatment options (n = 21, 40.38%) and physical activity (n = 16, 30.77%).

The topics that participants were given most information from both healthcare professionals and searching independently for were how to interpret test results (n = 22, 42.31%), and disease Cause (n = 19, 36.54%).

The topics that participants most commonly searched for independently after not receiving information from healthcare professionals were treatment options (n = 25, 48.08%) and disease management (n = 12, 23.08%).

Most accessed information

Across all participants, information from non-profit organisations, charity or patient organisations was most accessed followed by information from the hospital or clinic where being treated. Information from Pharmaceutical companies was least accessed.

My Health Record

My Health Record is an online summary of key health information, an initiative of the Australian Government. There were 12 participants (23.53%) had accessed My Health Record, 39 participants (76.47%) had not.

Of those that had accessed My Health Record, there were seven participants (58.33%) that found it to be poor or very poor, and four participants (33.33%) that found it acceptable.

Section 7

Care and support

Section 7: Experience of care and support

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 good 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 good 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 very 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 very 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 help (n=18, 34.62%). This was followed by receiving support through the hospital and clinical setting (n=14, 26.92%), through charities (n=11, 21.15%) and face-to-face peer support (n=8, 15.38%). There were six participants that described not needing any help (11.54%).

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 27 participants (51.92%) that described a negative impact on quality of life, 11 participants (21.15%) that described a minimal impact on quality of life, and six participants (11.54%) that described an overall positive impact on quality of life. There were four participants (7.69%) that reported no impact on quality of life, and the same number that reported a mix of positive and negative impact.

The most common themes in relation to a negative impact on quality of life were the emotional strain on family/change in dynamics of relationships with partners (n=16, 30.77%), family/change in dynamics of relationships with children (n=12, 23.08%), the mental and emotional impact (n=8, 15.38%), intimacy problems (n=5, 9.62%), and reduced social life (n=5, 9.62%). Other reasons for a negative impact on quality of life were from side effects or physical symptoms such as reduced physical activity (n=10, 19.23%), fatigue (n=7, 13.46%), and the impact of side effects from treatment (especially menopause) (n=5, 9.62%).

The most common theme in relation to a positive impact on quality of life was giving perspective on what is important (n=5, 9.62%).

Impact on mental health

In the structured interview, participants were asked if there had been an impact on their mental health. There were 50 participants (96.12%) who gave a description suggesting that overall there was some impact on their mental health and two participants (3.85%) who gave a description suggesting that overall there was no impact on mental health.

In the structured interview, participants were asked what they needed to do to maintain their emotional and mental health. The most common ways that participants reported managing their mental and emotional health was using mindfulness or meditation (n=25, 48.08%), physical exercise (n=19, 36.54%), and consulting a mental health professional (n=16, 30.77%). Other ways to maintain mental health were remaining social and enjoying hobbies (n=13, 25.00%), and the importance of family and friends (n=13, 25.00%). There were five participants (9.62%) 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 by being physically active (n=25, 48.08%), and the importance of self-care (n=24, 46.15%). There were 16 participants (30.77%) that described understanding their limitations, ten participants (19.23%) that described the importance of complying with treatment, and eight participants (15.38%) that described maintaining a healthy diet. There were eight participants (15.38%) 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 47 participants (90.38%) who gave a description suggesting that overall they had experiences of feeling vulnerable, and five participants (9.62%) 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 themes were feeling vulnerable during or after treatments (n=19, 36.54%), and feeling vulnerable during the diagnostic procedure (n=19, 36.54%). There were 11 participants (21.15%) that described feeling vulnerable because of interactions with their medical team, and eight participants (15.38%) described feeling vulnerable during the surgical procedure.

Methods to manage vulnerability

In the structured interview, participants described ways that they managed feelings of vulnerability. Participants described self-help, such as resilience, acceptance and staying positive to manage the feeling of vulnerability (n=16, 30.77%). Others described support from their nurse or treatment team (n=10, 19.23%), and support from their family and friends (n=8, 15.38%) to manage their vulnerability. There were five participants (9.62%), that were unsure of how to manage their vulnerability.

Impact on relationships

In the structured interview, participants were asked whether their condition had affected their personal relationships. Overall, there were 13 participants (25.00%) that described no impact on relationships, and the same number that described a mix of positive and negative impacts on relationships. Other participants reported a positive impact on relationships (n=12, 23.08%), and a negative impact on relationships (n=9, 17.31%).

The most common themes in relation to having a positive impact on relationships were because of people being well-meaning and supportive (n=11, 21.15%), and from family relationships being strengthened (n=10, 19.23%). The most common theme in relation to having a negative impact on relationships were because of people not knowing what to say or do and withdrawing from relationships (n=16, 30.77%).

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 26 participants (50.00%) that felt there was an additional burden, and 26 participants (50.00%) that reported no additional burden.

The main reason that participant described their condition not being a burden in general was that they and remained independent and did not need any help (n=10, 19.23%). For participants that felt they were a burden on their family, the main reason was the extra household duties and responsibilities that their family must take on (n=14, 26.92%). There were six participants (9.62%) that described that the burden on their family was only temporary or during treatment .

Cost considerations

In the structured interview, participants were asked about any significant costs associated with having their condition. There were 48 participants (92.31%) that described some cost burden and four participants (7.69%) that 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=43, 82.69%). Other cost burdens were in relation to taking time off work (n=24, 46.15%), the cost of specialist appointments (n=20, 38.46%), the cost of diagnostic tests and scans (n=20, 38.46%), family members needing to take time off work (n=7, 13.46%), and the cost of parking and travel to attend appointments, including accommodation (n=5, 9.62%). There were seven participants (13.46%) that described no cost burden and that nearly everything was paid for through the health system or private coverage.

Experience of anxiety related to disease progression

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 that future treatments would have fewer or less intense side effects (n=27, 51.92%), would have less cost burden (n=17, 32.69%), would be more effective (n=14, 26.92%), and more accessible, (n=8, 15.38%). Other participants would like future treatments to be accompanied with more information about treatment and treatment pathways (n=8, 15.38%), and more open and informed discussions (options, side effects etc) (n=8, 16.00%).

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 the expectation that future information will have detailed information about symptom and side effect control) (n=16, 30.77%), and this was followed by more information about services (n=13, 25.00%). Other participants described wanting future information to be more accessible (n=11, 21.15%), to provide details about holistic treatments (n=6, 11.54%), specific to type and stage (n=6, 11.54%), and to age or life stage (n=5, 9.62%). There were six participants (11.54%) that recommended information include personalised records of diagnosis and treatments, and 11 participants (22.00%) that had no recommendations and were satisfied with the information currently available.

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 had no recommendations and they had experienced good communication (n=29, 55.77%). Other themes about expectations of future communication included that communication will be more transparent and forthcoming (n=16, 30.77%), and that communication will be more empathetic (n=11, 21.15%).

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 future care and support support will include more access to appropriate, real-world support services (n=34, 65.38%). Other expectations include long term condition management (n=7, 13.46%), mental health and emotional support (n=6, 11.54%), being able to connect with other patients through peer support (support groups, online forums) (n=6, 11.54%). There were 11 participants (21.15%) with no recommendation as they were satisfied with the care and support received.

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 themes were that participants were grateful for the healthcare staff (n=17, 32.77%), and the entire health system (Includes having access to good healthcare and having options) (n=16, 30.77%). Other participants were grateful for access to private healthcare/private insurance (n=15, 28.85%), timely access to treatment (n=13, 25.00%), low cost treatment and medical care through the government (n=12, 23.08%), and timely access to diagnostics (n=6, 11.54%).

Symptoms and aspects of quality of life

The most important aspects reported were memory loss and cognitive function, fatigue, pain problems with movement and strength, and effects on bones and joints. The least important was fertility.

Values for decision makers

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”.

Values in making decisions

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 “The ability to include my family in making treatment decisions” and “The financial costs to me and my family”.

Time taking medication to improve quality of life

Almost half of participants (n = 25, 49.02%) would use a treatment for more than ten years for a good quality of life even if it didn’t offer a cure.

Most effective form of medicine

Participants most commonly responded that they thought that IV and pill were equally effective (n = 21, 41.18%), followed by not being sure.

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 messages were to improve access to support and care (n=26, 50.00%), and to that treatments need to be more affordable (n=13, 26.00%). Other messages included the need to invest in research (n=9, 17.31%), the need for timely access to treatments (n=9, 17.31%), to understand the financial implications (and provide financial support) (n=8, 15.38%), the need to be compassionate and empathetic (n=6, 11.54%), the need for holistic treatments (n=6, 11.54%), invest in screening and early detection (n=6, 11.54%), better treatment access in rural and remote communities (n=6, 11.54%), and support for side effects and symptoms including long term follow up and support (n=6, 11.54%).

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 response was that participants wished they had known what to expect from their condition, particularly symptoms and side effects of treatment (n=22, 42.31%). Other themes included participants wished they had known to be more assertive in relation to understanding treatment options and discussions about treatment (n=10, 19.23%), and they wished that they had sought medical attention or attended screening sooner (n=5, 9.62%). There were eight participants that did not describe anything that they wished they had known (n=10, 19.23%).

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 themes were that they would not change any aspect of treatment or care without giving a reason (n=13, 25.00%), and that they would not change any aspect because they were satisfied with their care or treatment (n=9, 17.31%). Other themes include changing or stopping treatment sooner (n=4, 7.69%), and having a better understanding of their condition (n=4, 7.69%).

Section 1

Introduction and methods

Section 1 Introduction and methodology

The estimated incidence of breast cancer in Australia was over 19,000 cases, and it was the most diagnosed cancer in women, and the most diagnosed cancer overall [1]. There were over 3000 deaths from breast cancer in 2019, and this was the second most common cause of death from cancer for women, and the fourth most common overall. Over three quarters of breast cancers are diagnosed at stage I or stage II[1]. Approximately 55% of women aged 50 to 74 participated in breast cancer screening in the 2015 to 2016 period[1].

The five-year survival from breast cancer (2011 to 2015) was 90.8%, survival when diagnosed at stage I is almost 100%, however, when diagnosed at stage IV, the survival is 32%[1].

Hormone-receptor positive breast cancers are sensitive to oestrogen or progesterone, approximately 70% of breast cancers are hormone-receptor positive[2]. Adjuvant treatment with tamoxifen is recommended, followed by an addition five years for pre or peri-menopausal women, and an additional five years with tamoxifen or an aromatase inhibitor for post-menopausal women[2].

A PubMed search was conducted on 4 October 2021 to identify studies reporting patient experience, patient reported outcomes, and quality of life studies in the Australian hormone-receptor positive breast cancer community. Studies conducted more than five years ago were excluded, and studies that included multiple types of breast cancers that did not report hormone-receptor positive breast cancers separately (as a subgroup) were excluded. There were 12 studies identified of between 26 and 4891 participants. There was only one study identified that interviewed participants or used qualitative methods, this study was focused on endocrine therapy.

This PEEK study includes 52 people diagnosed with hormone-receptor positive breast cancer throughout Australia, including a qualitative structured interview and quantitative questionnaire. This study in hormone-receptor positive breast cancer is therefore the largest mixed method study reported in an Australian population. In addition, 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.

Introduction

The estimated incidence of breast cancer in Australia was over 19,000 cases, and it was the most diagnosed cancer in women, and the most diagnosed cancer overall [1]. There were over 3000 deaths from breast cancer in 2019, and this was the second most common cause of death from cancer for women, and the fourth most common overall. Over three quarters of breast cancers are diagnosed at stage I or stage II[1]. Approximately 55% of women aged 50 to 74 participated in breast cancer screening in the 2015 to 2016 period[1].

The five-year survival from breast cancer (2011 to 2015) was 90.8%, survival when diagnosed at stage I is almost 100%, however, when diagnosed at stage IV, the survival is 32%[1].

Hormone-receptor positive breast cancers are sensitive to oestrogen or progesterone, approximately 70% of breast cancers are hormone-receptor positive[2]. Adjuvant treatment with tamoxifen is recommended, followed by an addition five years for pre or peri-menopausal women, and an additional five years with tamoxifen or an aromatase inhibitor for post-menopausal women[2].

Hormone therapy increases overall survival, decreases risk recurrence, and decreases risk of contralateral breast cancer[2,3]. However, risks from hormone treatment include menopausal symptoms, additional risks from tamoxifen included endometrial cancer, deep vein thrombosis or pulmonary embolism, and uterine cancer, additional risks from aromatase inhibitors include heart disease, and osteoporosis[2,4]

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 hormone receptor-positive breast 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 2021 and was completed by 31 October 2021.

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 2021 to 31 October 2021.

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 2021 to 31 October 2021.

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, age, education, year of diagnosis, location of residence, 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 and year of diagnosis, 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 PubMed search was conducted on 4 October 2021 to identify studies reporting patient experience, patient reported outcomes, and quality of life studies in the Australian hormone-receptor positive breast cancer community. Studies conducted more than five years ago were excluded, and studies that included multiple types of breast cancers that did not report hormone-receptor positive breast cancers separately (as a subgroup) were excluded.

There were 12 studies identified of between 26 and 4891 participants. There was only one study identified that interviewed participants or used qualitative methods, this study was focused on endocrine therapy[11].

There were 11 studies that collected patient experience/patient reported data by questionnaire. There were seven drug clinical trials of between 152 and 4891 participants[12-20], two studies of between 119 and 172 participants that was focused on endocrine therapy[21,22], and two studies of between 26 and 31 participants that was focused on symptoms and side effects[23,24].

This PEEK study includes 52 people diagnosed with hormone-receptor positive breast cancer throughout Australia, including a qualitative structured interview and quantitative questionnaire. This study in hormone-receptor positive breast cancer is therefore the largest mixed method study reported in an Australian population. In addition, 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

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
Sousa et al, 2018 [11]	Australia	32	Interviews	Endocrine therapy				x	x	x	x	
Pagani et al 2020[12], Ribi et al 2020[13], Saha et al 2017[14].	International	4891	Questionnaire	Drug clinical trial	x							
Bines et al, 2021 [15].	International	4808	Questionnaire	Drug clinical trial								
Tutt et al, 2021[16]	International	1836	Questionnaire	Drug clinical trial	x							
Ribi et al, 2019 [17]	International	956	Questionnaire	Drug clinical trial	x							
Fasching et al, 2020 [18]	International	726	Questionnaire	Drug clinical trial	x	x						
Timmins et al, 2021 [19]	Australia	159	Questionnaire	Drug clinical trial	x							

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
Cinieri et al, 2017 [20]	International	152	Questionnaire	Drug clinical trial	x							
Tucker et al, 2021 [21]	Australia	172	Questionnaire	Endocrine therapy	x	x						
Tucker et al, 2016 [22]	Australia	119	Questionnaire	Endocrine therapy	x	x					x	
Baker et al, 2018 [23]	Australia	31	Questionnaire	Symptoms and side effects	x	x						
Pearson et al, 2019 [24]	Australia	26	Questionnaire	Symptoms and side effects	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.
ER	Estrogen-receptor
PR	Progesterone-receptor
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 6significantly 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

Breast cancer stage

In this PEEK study, a total of 52 participants with hormone receptor positive breast cancer were recruited into the study. There were two participants (3.85%) with Stage 0, 17 participants (32.69%) with Stage I, 21 participants (40.38%) with Stage II, 10 participants (19.23%) with Stage III, and two participants (3.85%) with Stage IV.

Demographics

Participants were most commonly from New South Wales (n = 18, 34.62%), Queensland (n = 14, 26.92%), and Victoria (n = 9, 17.31%). Most participants were from major cities (n = 41, 78.85%), and they lived in all levels of advantage, defined by Socio-economic Indexes for Areas (SEIFA) (www.abs.gov.au) with 34 participants (65.38%) from an area with a high SEIFA score of 7 to 10 (more advantage), and 18 participants (34.62%) from an area of mid to low SEIFA scores of 1 to 6 (less advantaged).

There were 33 participants that had completed university to at least an associate degree (63.46%). There were 21 participants who were employed either full time (40.38%), or part time (n =5, 9.62%).

Half of the participants were carers to family members or spouses (n = 26, 50.00%), most commonly carers to children (n = 19, 36.54%).

Other health conditions

The majority of participants had at least one other condition that they had to manage (n = 48, 92.31%), the maximum number reported was 9 other conditions, with a median of 3.00 (IQR = 3.25) other conditions. The most commonly reported health condition was anxiety (self or doctor diagnosed) (n = 31, 59.62%), followed by sleep problems or insomnia (n = 29, 55.77%), depression (self or doctor diagnosed) (n =19, 36.54%), and arthritis (n = 16, 30.77%).

Baseline health

SF36 Physical functioning scale measures health limitations in physical activities such as walking, bending, climbing stairs, exercise, and housework. On average, physical activities were slightly 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 almost 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 moderate pain.

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

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

Participants

In this PEEK study, a total of 52 participants with hormone receptor positive breast cancer were recruited into the study. There were two participants (3.85%) with Stage 0, 17 participants (32.69%) with Stage I, 21 participants (40.38%) with Stage II, 10 participants (19.23%) with Stage III, and two participants (3.85%) with Stage IV (Table 2.2, Figure 2.1).

Table 2.1: Participants

Participants and diagnosis	Number (n=52)	Percent
Stage 0	2	3.85
Stage I	17	32.69
Stage II	21	40.38
Stage III	10	19.23
Stage IV	2	3.85

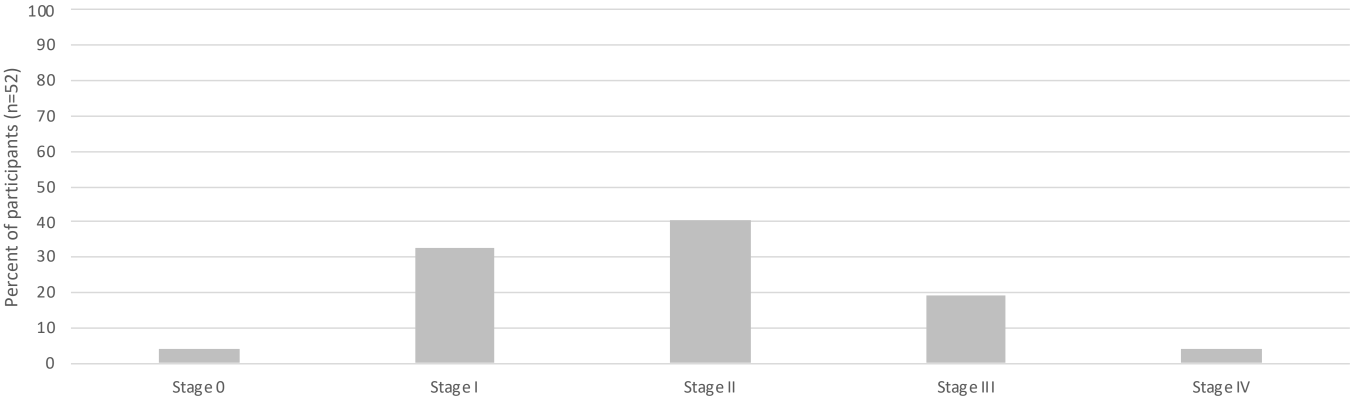


Figure 2.1: Participants

Demographics

There were 52 people with that took part in this study. Participants were aged from 25 to 74 years of age, most were aged between 45 and 64 years (n = 28 ,75.00%).

Participants were most commonly from New South Wales (n = 18, 34.62%), Queensland (n = 14, 26.92%), and Victoria (n = 9, 17.31%). Most participants were from major cities (n = 41, 78.85%), and they lived in all levels of advantage, defined by Socio-economic Indexes for Areas (SEIFA) (www.abs.gov.au) with 34 participants (65.38%) from an area with a high SEIFA score of 7 to 10 (more advantage), and 18 participants (34.62%) from an area of mid to low SEIFA scores of 1 to 6 (less advantaged).

There were 33 participants that had completed university to at least an associate degree (63.46%). There were 21 participants who were employed either full time (40.38%), or part time (n =5, 9.62%).

Half of the participants were carers to family members or spouses (n = 26, 50.00%), most commonly carers to children (n = 19, 36.54%). The demographics of participants are listed in Table 2.2.

Table 2.2: Demographics

Demographic	Definition	Number (n=52)	Percent
Age	25 – 44	8	15.38
	45 – 54	21	40.38
	55 – 64	18	34.62
	65 – 74	5	9.62
Location	Major Cities of Australia	41	78.85
	Inner Regional Australia	7	13.46
	Outer Regional or remote Australia	4	7.69
State	Australian Capital Territory	2	3.85
	New South Wales	18	34.62
	Northern Territory	0	0.00
	Queensland	14	26.92
	South Australia	3	5.77
	Tasmania	0	0.00
	Victoria	9	17.31
	Western Australia	6	11.54
Socio-Economic Indexes for Areas (SEIFA)	1	0	0.00
	2	0	0.00
	3	2	3.85
	4	6	11.54
	5	4	7.69
	6	6	11.54
	7	5	9.62
	8	12	23.08
	9	10	19.23
	10	7	13.46
Race/ethnicity	Caucasian/White	48	92.31
	Other	4	7.69
Education	High school degree or less	11	21.15
	Some college but no degree	6	11.54
	Trade	2	3.85
	Associate or Bachelor degree	21	40.38
	Graduate degree	12	23.08
Employment	Currently receiving Centrelink support	2	3.85
	Employed working full time	13	25.00
	Employed working part time	21	40.38
	Full/part time carer	5	9.62
	Not employed looking for work	3	5.77
	Retired	11	21.15
	Other	2	3.85
Carer status	I am not a carer	26	50.00
	Children	19	36.54
	Parents	4	7.69
	Spouse	3	5.77
	Other	3	5.77

Other health conditions

Participants were asked about health conditions, other than hormone receptor positive breast 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 = 48, 92.31%), the maximum number reported was 9 other conditions, with a median of 3.00 (IQR = 3.25) other conditions (Table 2.3, Figure 2.2). The most commonly reported health condition was anxiety (self or doctor diagnosed) (n = 31, 59.62%), followed by sleep problems or insomnia (n = 29, 55.77%), depression (self or doctor diagnosed) (n =19, 36.54%), and arthritis (n = 16, 30.77%) (Table 2.4, Figure 2.3).

Table 2.3: Number of other conditions

Number of other conditions	Number (n=52)	Percent
No other conditions	4	7.69
1 to 2	17	32.69
3 to 4	16	30.77
5 to 6	11	21.15
7 or more	4	7.69

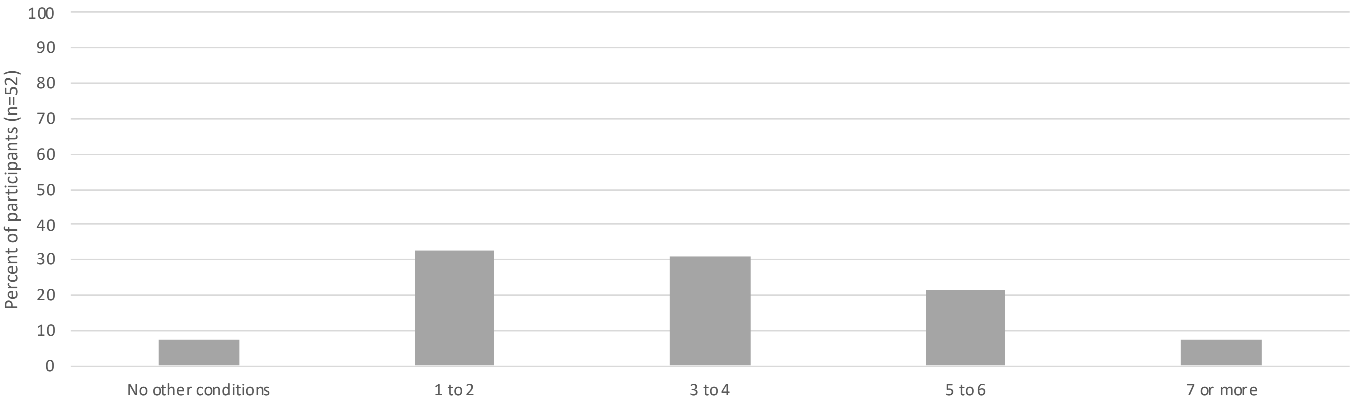


Figure 2.2: Number of other conditions

Table 2.4: Other health conditions

Other conditions	Number (n=52)	Percent
Anxiety (Self or doctor diagnosed)	31	59.62
Anxiety (that you diagnosed) yourself	17	32.69
Anxiety (that a doctor diagnosed)	27	51.92
Sleep problems or insomnia	29	55.77
Depression (Self or doctor diagnosed)	19	36.54
Depression (that you diagnosed yourself)?	12	23.08
Depression (that a doctor diagnosed)	13	25.00
Arthritis	16	30.77
High cholesterol	15	28.85
Chronic pain	10	19.23
Hypertension	8	15.38
Atrial fibrillation or arrhythmias	4	7.69
Cancer (other than breast)	4	7.69
Number of participants with other conditions (conditions not listed above)	21	40.38

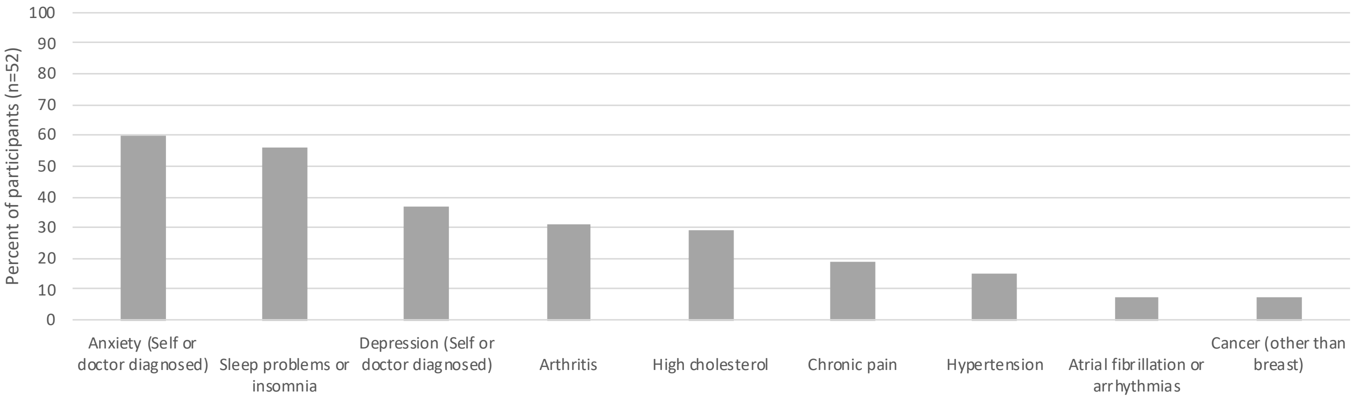


Figure 2.3: Other health conditions (% of all participants)

Subgroup analysis

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

Comparisons were made by breast cancer **stage**, there were 19 participants (36.54%) with *Stage 0 and I* cancer, 21 participants (40.38%) *with Stage II*, and 12 participants (23.08%) with *Stage III and IV.*

Participants were grouped according to **age,** with comparisons made between participants *Aged 25 to* 54 (n=29, 55.77%) and participants *Aged 55 to 74* (n=23, 44.23%).

Comparisons were made by **education** status, between those with trade or high school qualifications, *Trade or high school* (n=19, 36.54%), and those with a university qualification, *University* (n= 33, 63.46%).

Participants were grouped according to the year of breast cancer diagnosis, with 10 participants (19.23%) *Diagnosed in 2016 or before,* 16 participants (30.77%) *Diagnosed in 2017 to 2019*, and 26 participants (50.00%) *Diagnosed in 2020 or 2021.*

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/rural areas, *Regional or remote* (n=11, 21.15%) were compared to those living in a major city, *Metropolitan* (n=41, 78.85%).

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=158, 34.62%) compared to those with a higher SEIFA score of 7-10, *Higher status* (n=34, 65.38%).

Table 2.5: Subgroups

Subgroup	Definition	Number (n=52)	Percent
Breast cancer stage	Stage 0 and I	19	36.54
	Stage II	21	40.38
	Stage III and IV	12	23.08
Age	Aged 25 to 54	29	55.77
	Aged 55 to 74	23	44.23
Education	Trade or high school	19	36.54
	University	33	63.46
Year of diagnosis	Diagnosed in 2016 or before	10	19.23
	Diagnosed in 2017 to 2019	16	30.77
	Diagnosed in 2020 or 2021	26	50.00
Location	Regional or remote	11	21.15
	Metropolitan	41	78.85
Economic status	Mid to low status	18	34.62
	Higher status	34	65.38

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 Role functioning/emotional** (median = 83.33, IQR = 66. 67), indicating emotional function that almost never interferes with work and other activities.

The overall scores for the cohort were in the second highest quintile for **SF36 Physical functioning** (median = 75.00, IQR = 25.00), **SF36 Emotional well-being** (median = 72.00, IQR = 21.00), **SF36 Social functioning** (median = 75.00, IQR = 37.50), **SF36 General health** (mean = 60.48, SD = 17.55), indicating good physical function, good emotional well-being, good social functioning, and good general health.

The overall scores for the cohort were in the middle of the scale for **SF36 Role functioning/physical** (median = 50.00, IQR = 100.00), **SF36 Energy/Fatigue** (mean = 43.56, SD = 18.19), **SF36 Pain** (median = 57.50, IQR = 32.50), and **SF36 Health change** (median = 50.00, IQR = 50.00), indicating physical function that moderately interferes with work and other activities, moderate levels of energy, moderate pain, and health that is much the same as a year ago.

Comparisons of SF36 have been made based on **stage** (Tables 2.7 to 2.9, Figures 2.4 to 2.12), **age** (Tables 2.10 to 2.11, Figures 2.13 to 2.21), **education** (Tables 2.12 to 2.13, Figures 2.22 to 2.30), **year of diagnosis** (Tables 2.14 to 2.15, Figures 2.31 to 2.39), **location** (Tables 2.16 to 2.17, Figures 2.40 to 2.48), and **socioeconomic status** (Tables 2.18 to 2.19, Figures 2.49 to 2.57).

SF36 Physical functioning scale measures health limitations in physical activities such as walking, bending, climbing stairs, exercise, and housework. On average, physical activities were slightly 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 almost 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 moderate pain.

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

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

Table 2.6: SF36 summary statistics

SF36 scale (n=52)	Mean	SD	Median	IQR	Possible range	Quintile
Physical functioning	76.83	16.66	75.00	25.00	0 to 100	4
Role functioning/physical	48.56	43.28	50.00	100.00	0 to 100	3
Role functioning/emotional	67.31	38.77	83.33	66.67	0 to 100	5
Energy/Fatigue*	43.56	18.19	45.00	30.00	0 to 100	3
Emotional well-being	70.15	16.57	72.00	21.00	0 to 100	4
Social functioning	67.55	25.28	75.00	37.50	0 to 100	4
Pain	60.10	22.36	57.50	32.50	0 to 100	3
General health*	60.48	17.55	60.00	25.00	0 to 100	4
Health change	46.63	28.45	50.00	50.00	0 to 100	3

*Normal distribution, use mean and SD as central measure.

SF36 by stage

Comparisons were made by breast cancer **stage**, there were 19 participants (36.54%) with *Stage 0 and I* breast cancer, 21 participants (40.38%) *with Stage II*, and 12 participants (23.08%) with *Stage III and 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 Emotional well-being** scale between groups, $\chi^2(2) = 6.3538$,p = 0.0417. Wilcoxon rank sum tests between groups indicated that participants in the *Stage 0 and I* subgroup (median =80, IQR = 18), scored significantly higher than participants in the *Stage III and IV* subgroup (median =56, IQR = 24, p = 0.0440).

A Kruskal-Wallis test indicated a statistically significant difference in the **SF36 Social functioning** scale between groups, $\chi^2(2) = 6.5106$,p = 0.0386. Wilcoxon rank sum tests between groups indicated that participants in the *Stage 0 and I* subgroup (median =75, IQR = 31.25), scored significantly higher than participants in the *Stage III and IV* subgroup (median =56.25, IQR = 31.25, p = 0.0400).

SF36 Emotional well-being scale measures how a person feels, for example happy, calm, depressed or anxious**.** On average, participants in the *Stage 0 and I* subgroup scored higher than participants in the *Stage III and IV* subgroup. This indicates that participants in the *Stage 0 and I* subgroup had good emotional well-being, and participants in the *Stage III and IV* subgroup had fair emotional well-being.

SF36 Social functioning scale measures **l**imitations on social activities due to physical or emotional problems**.** On average, participants in the *Stage 0 and I* subgroup scored higher than participants in the *Stage III and IV* subgroup. This indicates that social activities were slightly limited for participants in the *Stage 0 and I* subgroup, and moderately limited for participants in the *Stage III and IV* subgroup.

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

SF36 scale	Group	Number (n=52)	Percent	Mean	SD	Source of difference	Sum of squares	dF	Mean Square	f	p-value
Energy/fatigue	Stage 0 and I	19	36.54	48.68	16.06	Between groups	1902.00	2	950.90	3.114	0.0533
	Stage II	21	40.38	45.00	18.51	Within groups	14965.00	49	305.40		
	Stage III and IV	12	23.08	32.92	17.77	Total	16867.00	51			
Pain	Stage 0 and I	19	36.54	66.84	23.83	Between groups	2191.00	2	1095.50	2.303	0.1110
	Stage II	21	40.38	60.00	22.67	Within groups	23308.00	49	475.70		
	Stage III and IV	12	23.08	49.58	15.98	Total	25499.00	51			
General health	Stage 0 and I	19	36.54	60.26	17.52	Between groups	138.00	2	68.90	0.217	0.8060
	Stage II	21	40.38	62.14	18.81	Within groups	15575.00	49	317.90		
	Stage III and IV	12	23.08	57.92	16.44	Total	15713.00	51			

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

SF36 scale	Group	Number (n=52)	Percent	Median	IQR	C^2	dF	p-value
Physical functioning	Stage 0 and I	19	36.54	85.00	27.50	5.51	2	0.0636
	Stage II	21	40.38	80.00	15.00			
	Stage III and IV	12	23.08	70.00	7.50			
Role functioning physical	Stage 0 and I	19	36.54	75.00	100.00	5.77	2	0.0558
	Stage II	21	40.38	50.00	75.00			
	Stage III and IV	12	23.08	0.00	75.00			
Role functioning emotional	Stage 0 and I	19	36.54	100.00	33.33	4.20	2	0.1223
	Stage II	21	40.38	100.00	33.33			
	Stage III and IV	12	23.08	33.33	100.00			
Emotional well-being	Stage 0 and I	19	36.54	80.00	18.00	6.35	2	0.0417*
	Stage II	21	40.38	72.00	16.00			
	Stage III and IV	12	23.08	56.00	24.00			
Social functioning	Stage 0 and I	19	36.54	75.00	31.25	6.51	2	0.0386*
	Stage II	21	40.38	75.00	25.00			
	Stage III and IV	12	23.08	56.25	31.25			
Health change	Stage 0 and I	19	36.54	25.00	25.00	4.60	2	0.1004
	Stage II	21	40.38	50.00	25.00			
	Stage III and IV	12	23.08	25.00	25.00			

*Statistically significant at $p<0.05$

Table 2.9: SF36 by stage one-way post hoc Wilcoxon rank sum test

SF36 scale		Stage 0 and I	Stage II
Emotional well-being	Stage II	0.4280	-
	Stage III and IV	0.0440*	0.0980
Social functioning	Stage II	0.5400	-
	Stage III and IV	0.0400*	0.0800

*Statistically significant at $p<0.05$

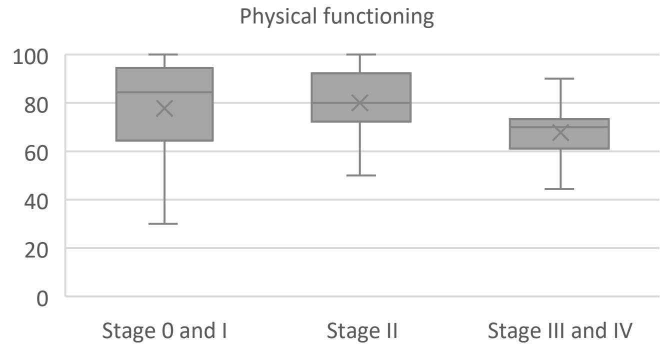


Figure 2.4: Boxplot of SF36 Physical functioning by stage

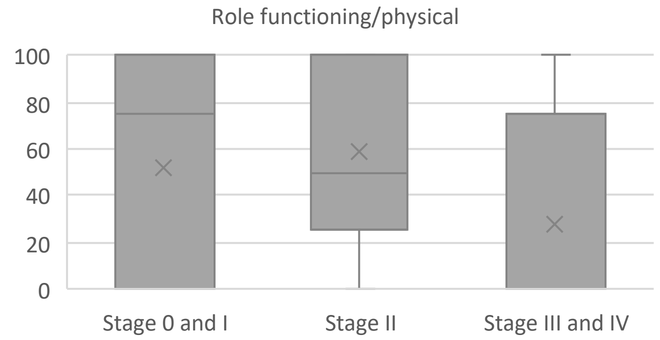


Figure 2.5: Boxplot of SF36 Role functioning/physical by stage

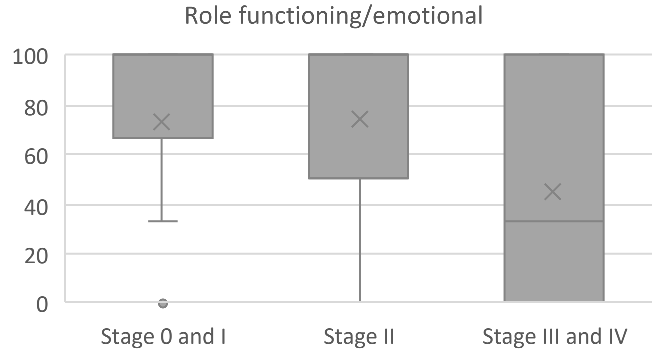


Figure 2.6: Boxplot of SF36 Role functioning/emotional by stage

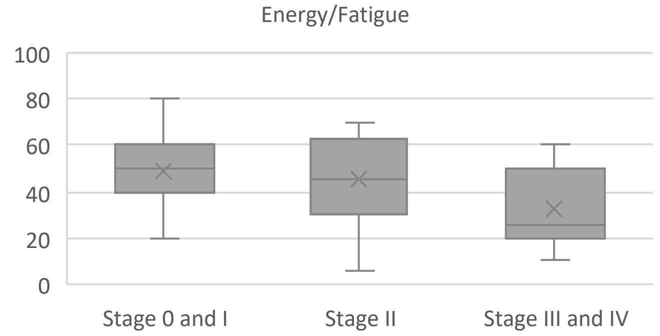


Figure 2.7: Boxplot of SF36 Energy/fatigue by stage

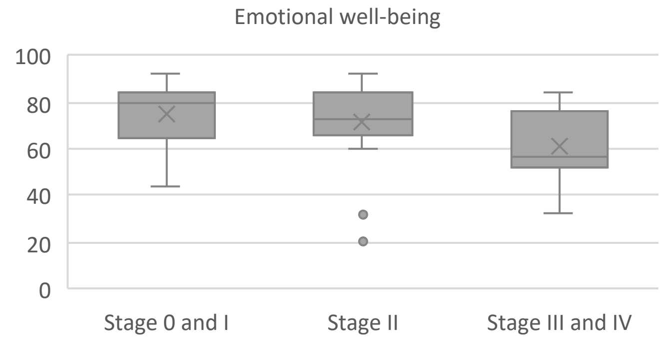


Figure 2.8: Boxplot of SF36 Emotional well-being by stage

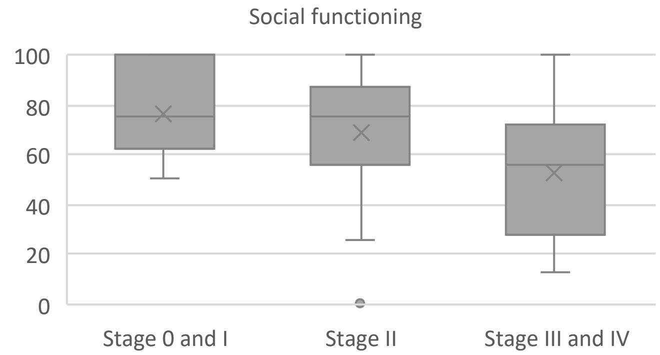


Figure 2.9: Boxplot of SF36 Social functioning by stage

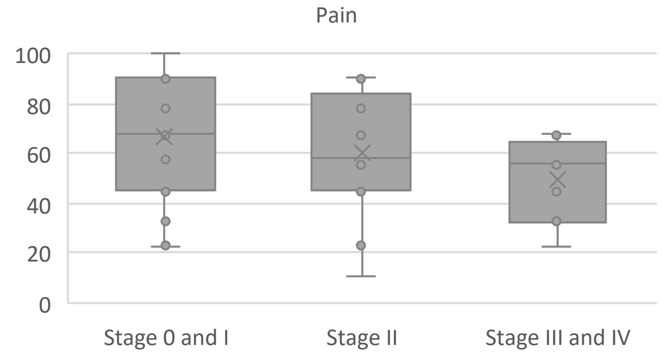


Figure 2.10: Boxplot of SF36 Pain by a stage

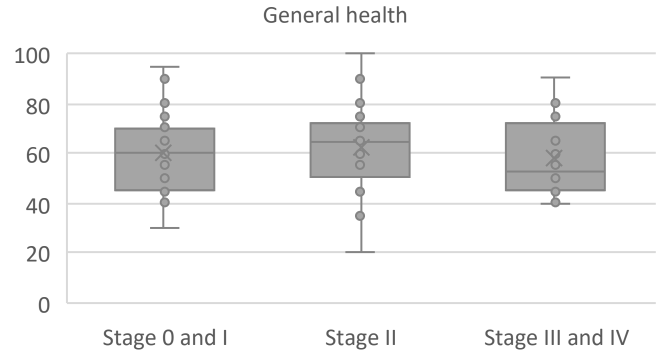


Figure 2.11: Boxplot of SF36 General health by stage

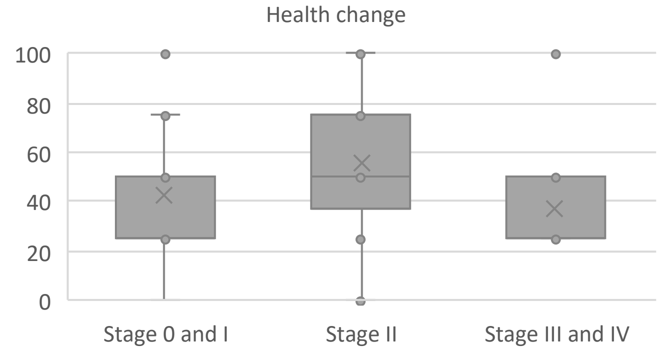


Figure 2.12: Boxplot of SF36 Health change by stage

SF36 by age

Participants were grouped according to **age,** with comparisons made between participants *Aged 25 to 54* (n=29, 55.77%) and participants *Aged 55 to 74* (n=23, 44.23%).

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).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the SF36 Social functioning scale [W = 222.00, p = 0.0377*] was significantly lower for participants in the Aged 25 to 54 subgroup (Median = 62.50, IQR = 25.00) compared to participants in the Aged 55 to 74 subgroup (Median = 75.00, IQR = 31.25).

SF36 Social functioning scale measures **l**imitations on social activities due to physical or emotional problems. On average, participants in the *Aged 55 to 74* subgroup had a higher score for social functioning compared to *Aged 25 to 54*, however, social activities were slightly limited for both groups.

Table 2.10: SF36 by age summary statistics and T-test

SF36 scale	Group	Number (n=52)	Percent	Mean	SD	T	dF	p-value
Energy/Fatigue	Aged 25 to 54	29	55.77	40.00	20.35	-1.61	50	0.1140
	Aged 55 to 74	23	44.23	48.04	14.20			
General health	Aged 25 to 54	29	55.77	60.69	17.96	0.10	50	0.9244
	Aged 55 to 74	23	44.23	60.22	17.42			

Table 2.11: SF36 by age summary statistics and and Wilcoxon test

SF36 scale	Group	Number (n=52)	Percent	Median	IQR	W	p-value
Physical functioning	Aged 25 to 54	29	55.77	75.00	20.00	325.00	0.8819
	Aged 55 to 74	23	44.23	75.00	27.50		
Role functioning/physical	Aged 25 to 54	29	55.77	25.00	75.00	244.50	0.0891
	Aged 55 to 74	23	44.23	75.00	87.50		
Role functioning/emotional	Aged 25 to 54	29	55.77	66.67	66.67	246.50	0.0858
	Aged 55 to 74	23	44.23	100.00	33.33		
Emotional well-being	Aged 25 to 54	29	55.77	72.00	28.00	297.00	0.5043
	Aged 55 to 74	23	44.23	72.00	20.00		
Social functioning	Aged 25 to 54	29	55.77	62.50	25.00	222.00	0.0377*
	Aged 55 to 74	23	44.23	75.00	31.25		
Pain	Aged 25 to 54	29	55.77	57.50	22.50	301.50	0.5567
	Aged 55 to 74	23	44.23	67.50	38.75		
Health change	Aged 25 to 54	29	55.77	50.00	50.00	360.00	0.6178
	Aged 55 to 74	23	44.23	50.00	25.00		

*Statistically significant at p<0.05

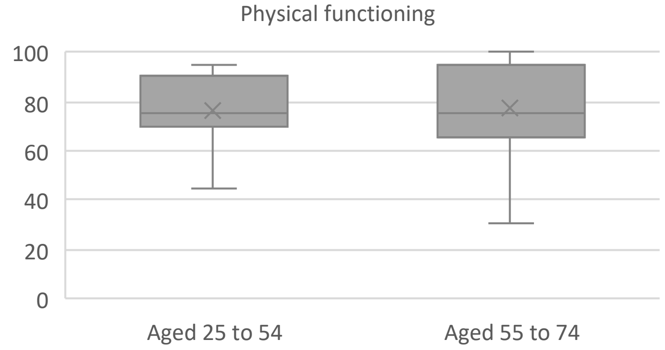


Figure 2.13: Boxplot of SF36 Physical functioning by age

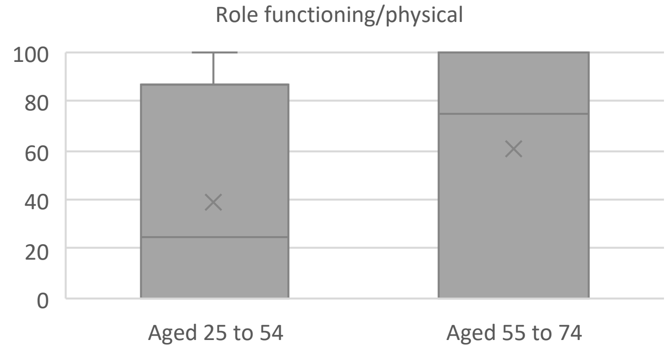


Figure 2.14: Boxplot of SF36 Role functioning/physical by age

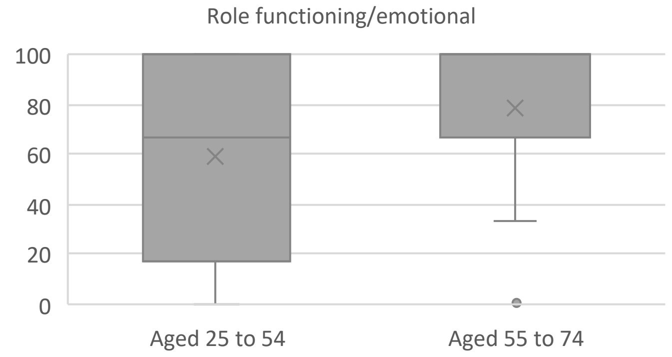


Figure 2.15: Boxplot of SF36 Role functioning/emotional by age

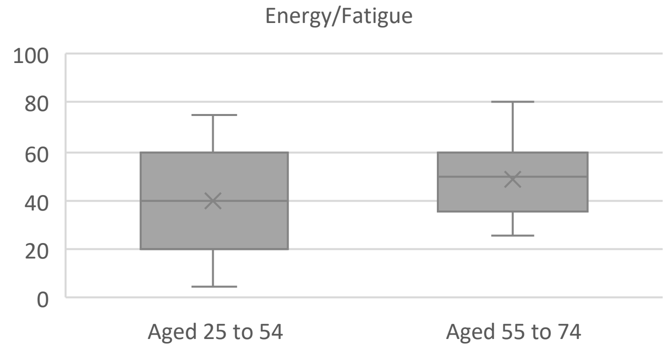


Figure 2.16: Boxplot of SF36 Energy/fatigue by age

Figure 2.17: Boxplot of SF36 Emotional well-being by age

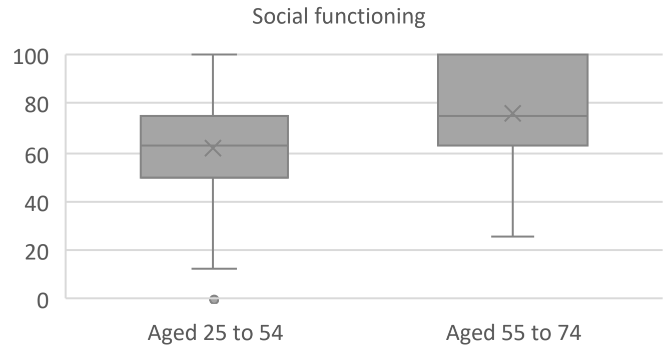


Figure 2.18: Boxplot of SF36 Social functioning by age

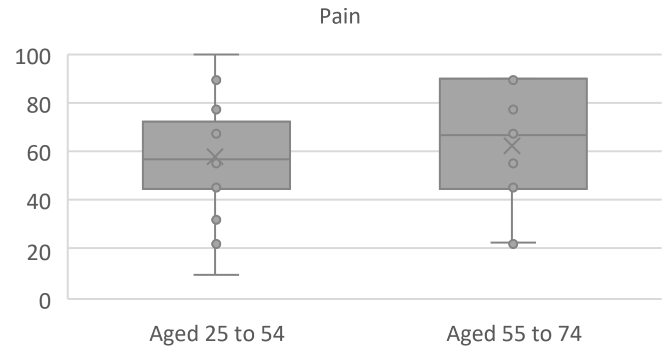


Figure 2.19: Boxplot of SF36 Pain by a age

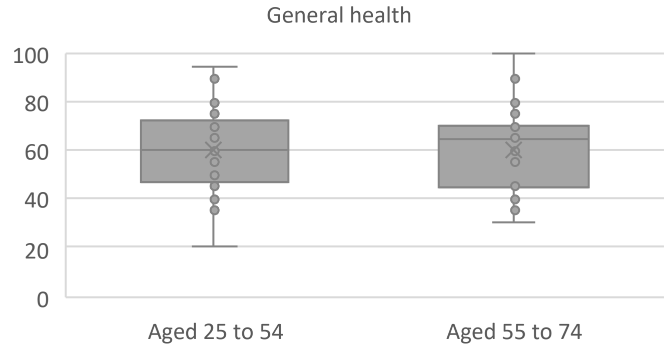


Figure 2.20: Boxplot of SF36 General health by age

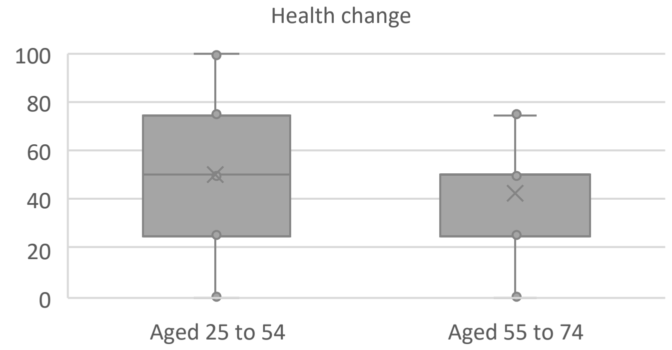


Figure 2.21: Boxplot of SF36 Health change by age

SF36 by education

Comparisons were made by **education** status, between those with trade or high school qualifications, *Trade or high school* (n=19, 36.54%), and those with a university qualification, *University* (n= 33, 63.46%).

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).

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

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

SF36 scale	Group	Number (n=52)	Percent	Mean	SD	T	dF	p-value
Physical functioning	Trade or high school	19	36.54	75.26	18.52	-0.51	50	0.6123
	University	33	63.46	77.73	15.72			
Energy/Fatigue	Trade or high school	19	36.54	43.42	18.93	-0.04	50	0.9677
	University	33	63.46	43.64	18.04			
General health	Trade or high school	19	36.54	62.11	17.90	0.50	50	0.6174
	University	33	63.46	59.55	17.56			

Table 2.13: SF36 by education summary statistics and Wilcoxon test

SF36 scale	Group	Number (n=52)	Percent	Median	IQR	W	p-value
Role functioning/physical	Trade or high school	19	36.54	25.00	100.00	311.50	0.9763
	University	33	63.46	50.00	100.00		
Role functioning/emotional	Trade or high school	19	36.54	100.00	66.67	323.50	0.8457
	University	33	63.46	66.67	66.67		
Emotional well-being	Trade or high school	19	36.54	72.00	22.00	293.00	0.7020
	University	33	63.46	76.00	20.00		
Social functioning	Trade or high school	19	36.54	75.00	37.50	275.50	0.4690
	University	33	63.46	75.00	25.00		
Pain	Trade or high school	19	36.54	57.50	28.75	285.00	0.5900
	University	33	63.46	57.50	32.50		
Health change	Trade or high school	19	36.54	25.00	25.00	226.00	0.0851
	University	33	63.46	50.00	50.00		

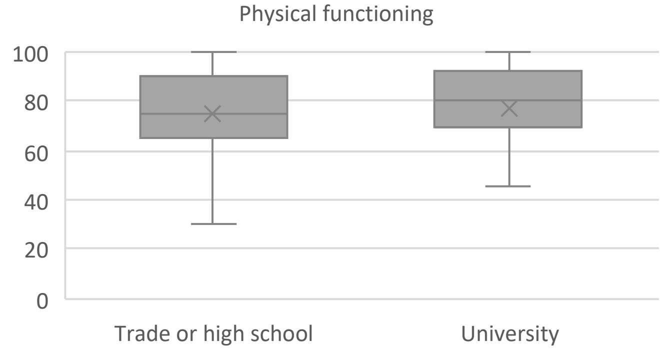


Figure 2.22: Boxplot of SF36 Physical functioning by education

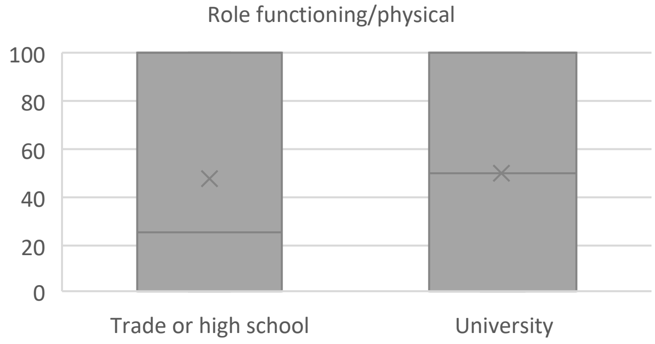


Figure 2.23: Boxplot of SF36 Role functioning/physical by education

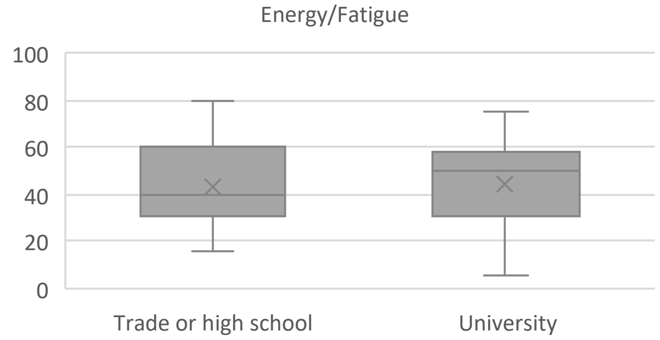


Figure 2.24: Boxplot of SF36 Role functioning/emotional by education

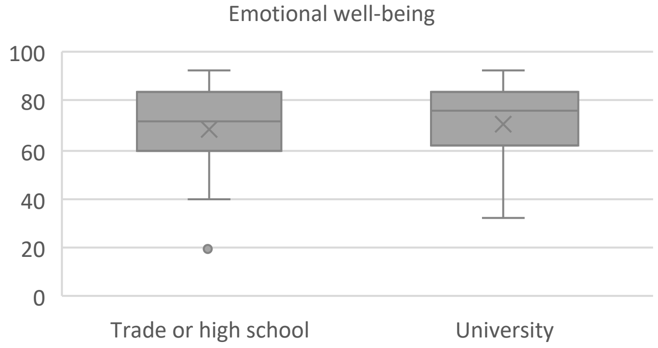


Figure 2.25: Boxplot of SF36 Energy/fatigue by education

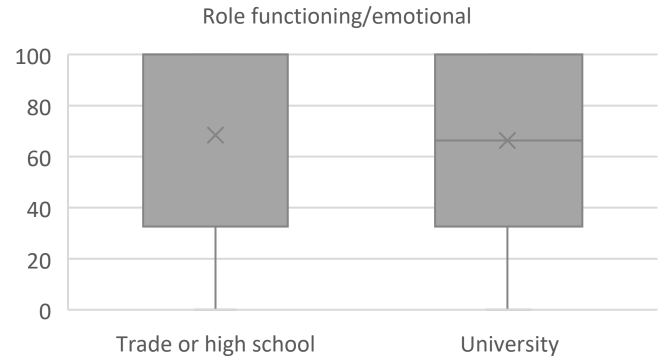


Figure 2.26: Boxplot of SF36 Emotional well-being by education

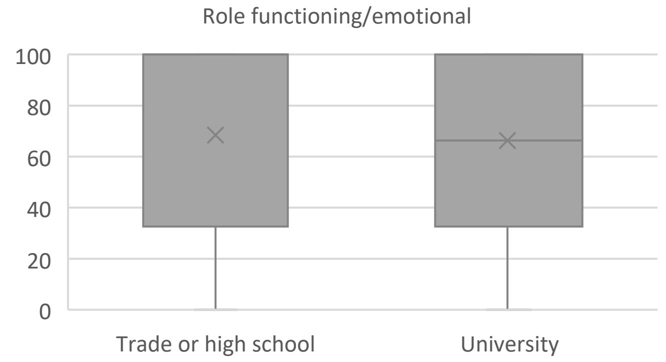


Figure 2.27: Boxplot of SF36 Social functioning by education

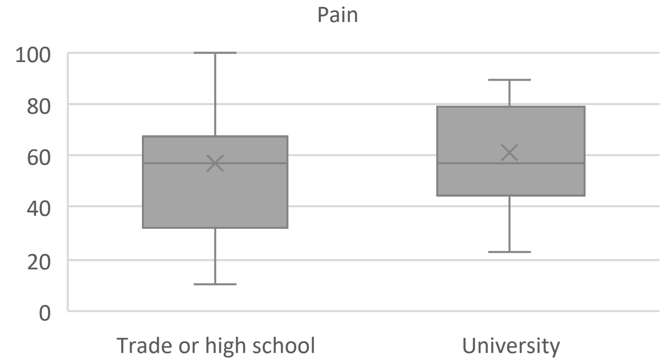


Figure 2.28: Boxplot of SF36 Pain by a education

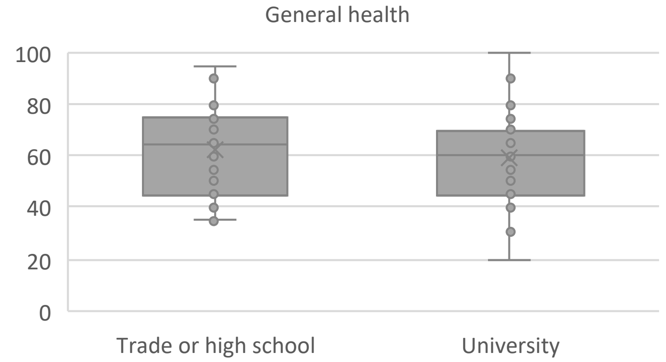


Figure 2.29: Boxplot of SF36 General health by education

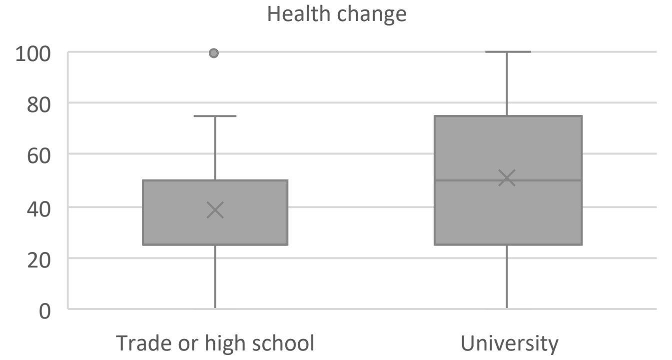


Figure 2.30: Boxplot of SF36 Health change by education

SF36 by year of breast cancer diagnosis

Participants were grouped according to the **year of breast cancer diagnosis**, with 10 participants (19.23%) *Diagnosed in 2016 or before,* 16 participants (30.77%) *Diagnosed in 2017 to 2019*, and 26 participants (50.00%) *Diagnosed in 2020 or 2021.*

A one-way ANOVA test was used when the assumptions for response variable residuals were normally distributed and variances of populations were equal (Table 2.14). When the assumptions for normality of residuals was not met, a Kruskal-Wallis test was used (Table 2.15).

No significant differences were observed between participants by **year of breast cancer diagnosis** for any of the SF36 scales.

Table 2.14: SF36 by year of breast cancer diagnosis summary statistics and one-way ANOVA

SF36 scale	Group	Number (n=XXX)	Percent	Mean	SD	Source of difference	Sum of squares	dF	Mean Square	f	p-value
Energy/fatigue	Diagnosed in 2016 or before	10	19.23	51.00	19.97	Between groups	693.00	2	346.60	1.05	0.3580
	Diagnosed in 2017 to 2019	16	30.77	41.25	19.10	Within groups	16174.00	49	330.10		
	Diagnosed in 2020 or 2021	26	50.00	42.12	16.86	Total	16867.00	51			
Pain	Diagnosed in 2016 or before	10	19.23	61.75	27.94	Between groups	34.00	2	17.20	0.033	0.9670
	Diagnosed in 2017 to 2019	16	30.77	59.84	23.14	Within groups	25465.00	49	519.70		
	Diagnosed in 2020 or 2021	26	50.00	59.62	20.40	Total	25499.00	51			
General health	Diagnosed in 2016 or before	10	19.23	56.00	13.70	Between groups	499.00	2	249.30	0.803	0.4540
	Diagnosed in 2017 to 2019	16	30.77	58.44	20.55	Within groups	15214.00	49	310.50		
	Diagnosed in 2020 or 2021	26	50.00	63.46	16.96	Total	15713.00	51			

Table 2.15: SF36 by year of breast cancer diagnosis summary statistics and Kruskal-Wallis test

SF36 scale	Group	Number (n=XXX)	Percent	Median	IQR	C^2	dF	p-value
Physical functioning	Diagnosed in 2016 or before	10	19.23	80.00	28.75	0.54083	2	0.7631
	Diagnosed in 2017 to 2019	16	30.77	75.00	12.50			
	Diagnosed in 2020 or 2021	26	50.00	77.50	27.50			
Role functioning physical	Diagnosed in 2016 or before	10	19.23	75.00	100.00	1.164	2	0.5588
	Diagnosed in 2017 to 2019	16	30.77	62.50	81.25			
	Diagnosed in 2020 or 2021	26	50.00	25.00	93.75			
Role functioning emotional	Diagnosed in 2016 or before	10	19.23	100.00	25.00	1.7961	2	0.4074
	Diagnosed in 2017 to 2019	16	30.77	66.67	66.67			
	Diagnosed in 2020 or 2021	26	50.00	66.67	58.33			
Energy/fatigue	Diagnosed in 2016 or before	10	19.23	47.50	30.00	1.4527	2	0.4837
	Diagnosed in 2017 to 2019	16	30.77	47.50	27.50			
	Diagnosed in 2020 or 2021	26	50.00	45.00	28.75			
Social functioning	Diagnosed in 2016 or before	10	19.23	75.00	31.25	0.90329	2	0.6366
	Diagnosed in 2017 to 2019	16	30.77	75.00	40.63			
	Diagnosed in 2020 or 2021	26	50.00	75.00	21.88			
Health change	Diagnosed in 2016 or before	10	19.23	50.00	25.00	4.618	2	0.09936
	Diagnosed in 2017 to 2019	16	30.77	62.50	50.00			
	Diagnosed in 2020 or 2021	26	50.00	25.00	25.00			

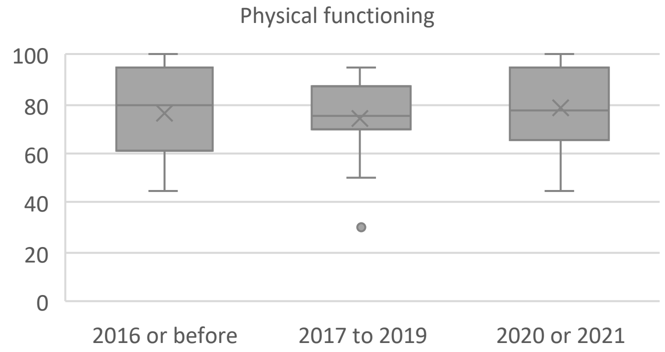


Figure 2.31: Boxplot of SF36 Physical functioning by year of breast cancer diagnosis

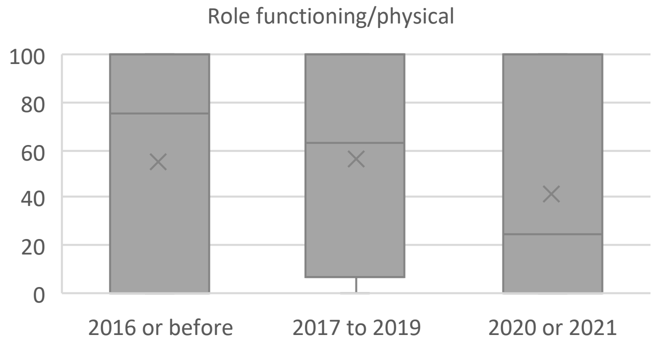


Figure 2.32: Boxplot of SF36 Role functioning/physical by year of breast cancer diagnosis

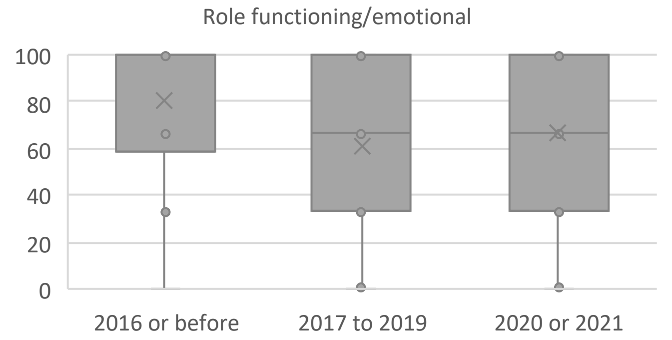


Figure 2.33: Boxplot of SF36 Role functioning/emotional by year of breast cancer diagnosis

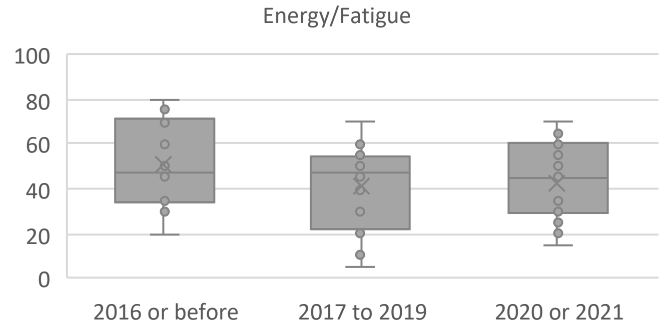


Figure 2.34: Boxplot of SF36 Energy/fatigue by year of breast cancer diagnosis

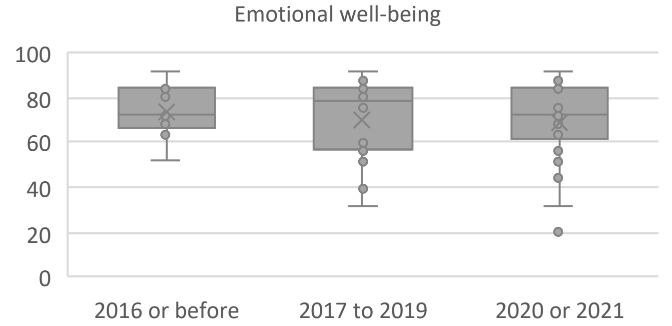


Figure 2.35: Boxplot of SF36 Emotional well-being by year of breast cancer diagnosis

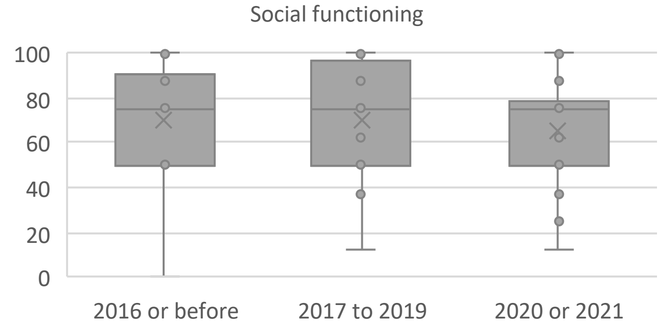


Figure 2.36: Boxplot of SF36 Social functioning by year of breast cancer diagnosis

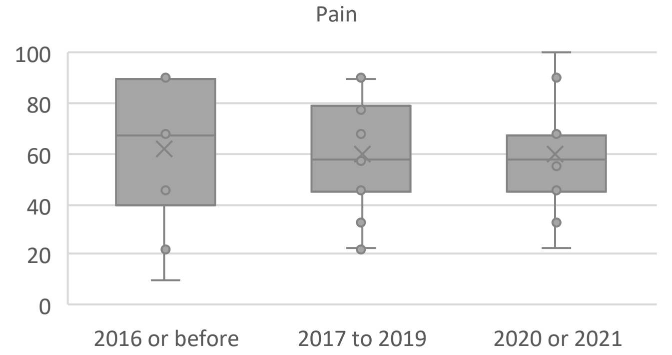


Figure 2.37: Boxplot of SF36 Pain by a year of breast cancer diagnosis

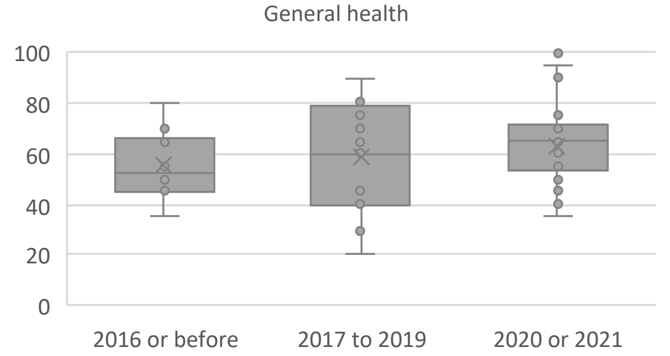


Figure 2.38: Boxplot of SF36 General health by year of breast cancer diagnosis

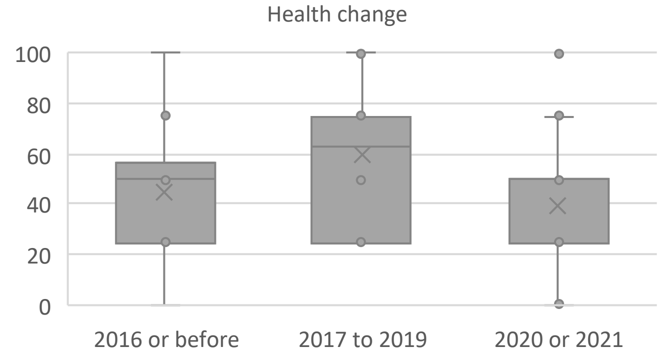


Figure 2.39: Boxplot of SF36 Health change by stage

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/rural areas, *Regional or remote* (n=11, 21.15%) were compared to those living in a major city, *Metropolitan* (n=41, 78.85%).

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).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the **SF36 Role functioning physical scale** [W = 315.50, p = 0.0365*] was significantly higher for participants in the *Regional or remote* subgroup (Median = 100.00, IQR = 50.00) compared to participants in the *Metropolitan* subgroup (Median = 25.00, IQR = 75.00).

SF36 Role functioning/physical scale measures how physical health interferes with work or other activities. On average, participants in the *Regional or remote* subgroup scored higher than participants in the *Metropolitan* subgroup. This indicates that physical health never interfered with work or other activities for participants in the *Regional or remote* subgroup, and often interfered for participants in the *Metropolitan* subgroup.

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

SF36 scale	Group	Number (n=52)	Percent	Mean	SD	T	dF	p-value
Energy/Fatigue	Regional or remote	11	21.15	48.18	17.50	0.95	50	0.3473
	Metropolitan	41	78.85	42.32	18.37			
General health	Regional or remote	11	21.15	61.82	19.01	0.28	50	0.7791
	Metropolitan	41	78.85	60.12	17.37			

Table 2.17: SF36 by location summary statistics and Wilcoxon test

SF36 scale	Group	Number (n=52)	Percent	Median	IQR	W	p-value
Physical functioning	Regional or remote	11	21.15	90.00	27.50	282.50	0.2022
	Metropolitan	41	78.85	75.00	25.00		
Role functioning/physical	Regional or remote	11	21.15	100.00	50.00	315.50	0.0365*
	Metropolitan	41	78.85	25.00	75.00		
Role functioning/emotional	Regional or remote	11	21.15	100.00	33.33	271.50	0.2718
	Metropolitan	41	78.85	66.67	66.67		
Emotional well-being	Regional or remote	11	21.15	68.00	16.00	218.00	0.8745
	Metropolitan	41	78.85	76.00	24.00		
Social functioning	Regional or remote	11	21.15	75.00	43.75	264.50	0.3807
	Metropolitan	41	78.85	75.00	37.50		
Pain	Regional or remote	11	21.15	57.50	17.50	222.50	0.9548
	Metropolitan	41	78.85	57.50	32.50		
Health change	Regional or remote	11	21.15	25.00	25.00	191.50	0.4344
	Metropolitan	41	78.85	50.00	50.00		

*Statistically significant at p<0.05

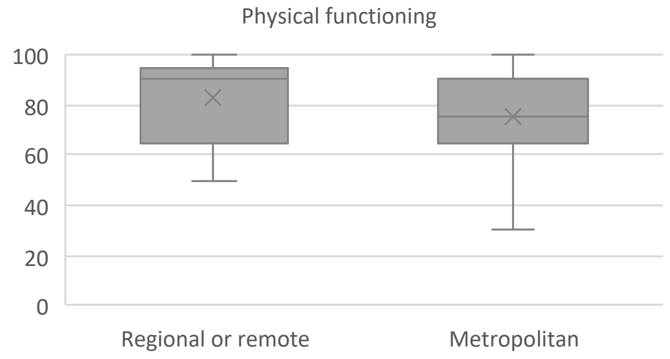


Figure 2.40: Boxplot of SF36 Physical functioning by location

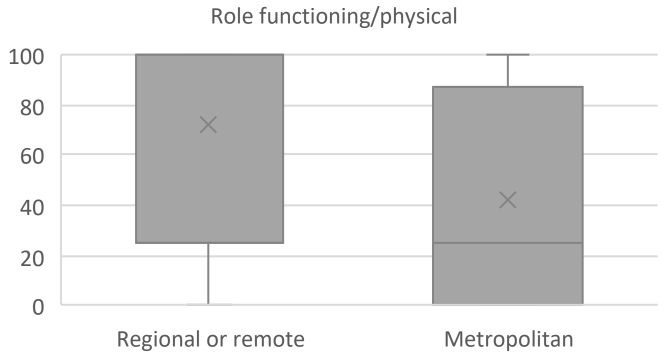


Figure 2.41: Boxplot of SF36 Role functioning/physical by location

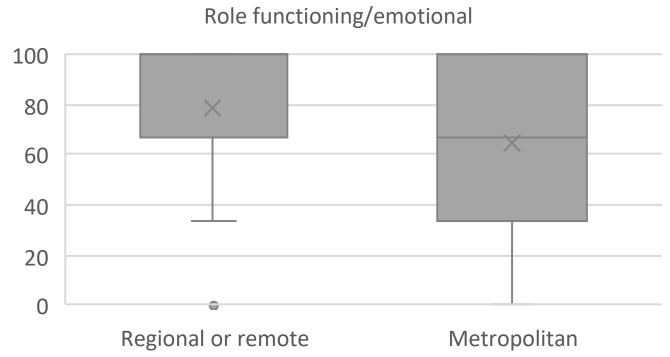


Figure 2.42: Boxplot of SF36 Role functioning/emotional by location

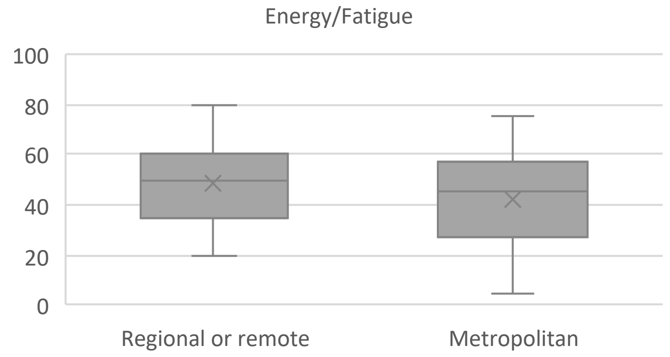


Figure 2.43: Boxplot of SF36 Energy/fatigue by location

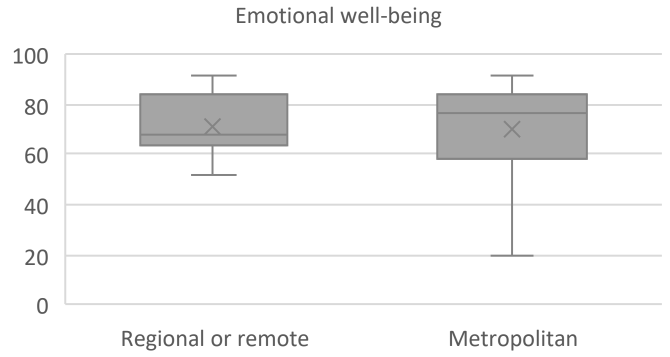


Figure 2.44: Boxplot of SF36 Emotional well-being by location

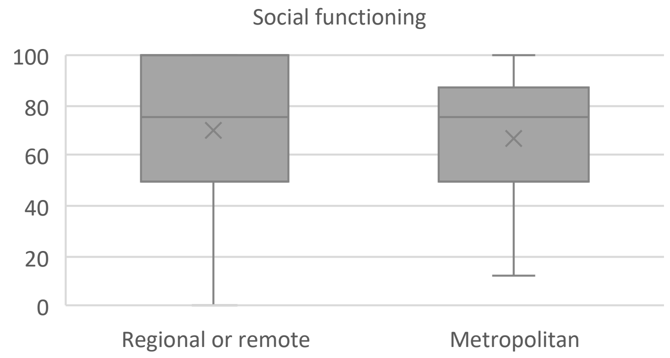


Figure 2.45: Boxplot of SF36 Social functioning by location

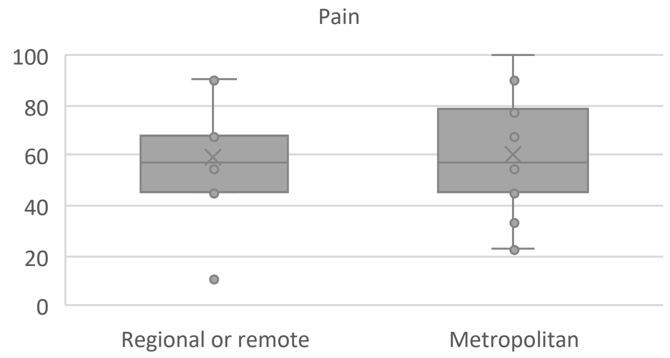


Figure 2.46: Boxplot of SF36 Pain by a location

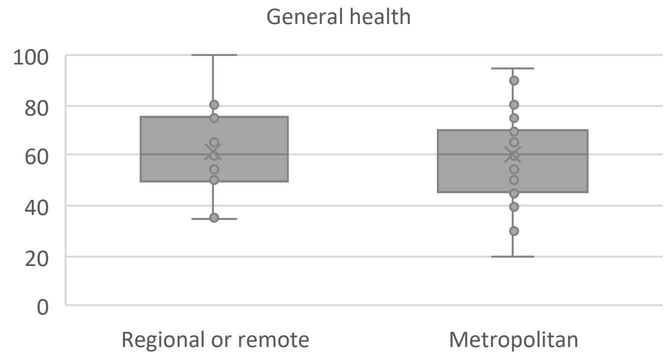


Figure 2.47: Boxplot of SF36 General health by location

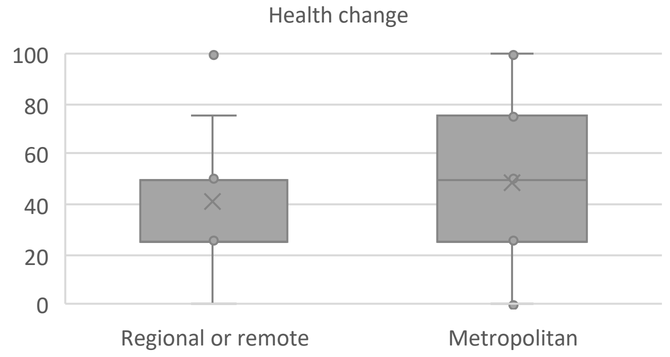


Figure 2.48: Boxplot of SF36 Health change by location

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=158, 34.62%) compared to those with a higher SEIFA score of 7-10, *Higher status* (n=34, 65.38%).

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).

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

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

SF36 scale	Group	Number (n=52)	Percent	Mean	SD	T	dF	p-value
Energy/Fatigue	Mid to low status	18	34.62	44.72	16.76	0.33	50	0.7405
	Higher status	34	65.38	42.94	19.11			
General health	Mid to low status	18	34.62	59.17	18.73	-0.39	50	0.6985
	Higher status	34	65.38	61.18	17.15			

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

SF36 scale	Group	Number (n=52)	Percent	Median	IQR	W	p-value
Physical functioning	Mid to low status	18	34.62	75.00	25.00	265.50	0.4382
	Higher status	34	65.38	77.50	20.00		
Role functioning/physical	Mid to low status	18	34.62	50.00	100.00	314.00	0.8804
	Higher status	34	65.38	37.50	100.00		
Role functioning/emotional	Mid to low status	18	34.62	100.00	33.33	346.00	0.4128
	Higher status	34	65.38	66.67	66.67		
Emotional well-being	Mid to low status	18	34.62	80.00	20.00	357.50	0.3234
	Higher status	34	65.38	72.00	26.00		
Social functioning	Mid to low status	18	34.62	75.00	34.38	313.50	0.8912
	Higher status	34	65.38	75.00	34.38		
Pain	Mid to low status	18	34.62	57.50	22.50	257.00	0.3448
	Higher status	34	65.38	62.50	45.00		
Health change	Mid to low status	18	34.62	50.00	50.00	335.00	0.5681
	Higher status	34	65.38	50.00	25.00		

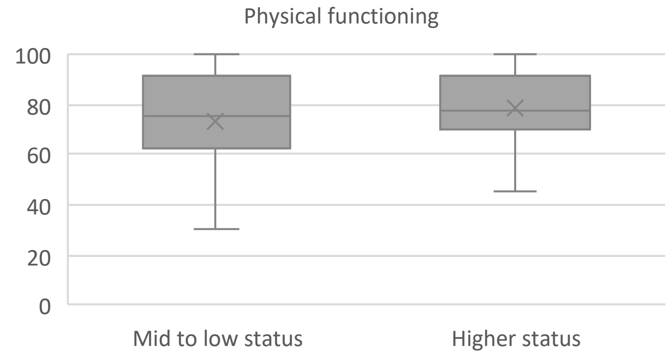


Figure 2.49: Boxplot of SF36 Physical functioning by socioeconomic status

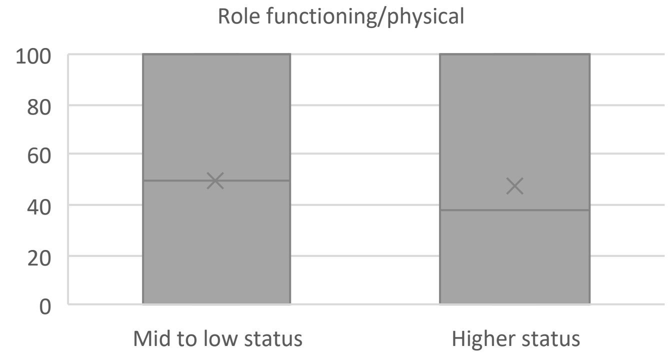
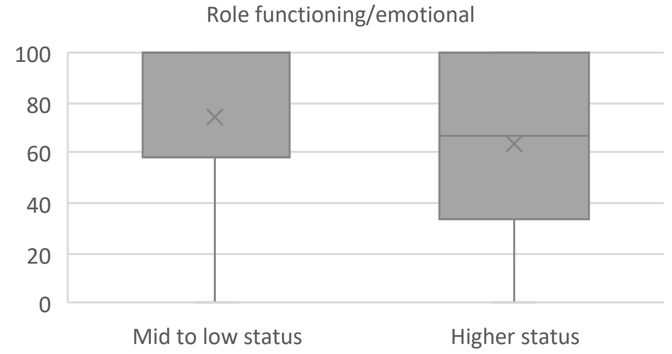


Figure 2.50: Boxplot of SF36 Role functioning/physical by socioeconomic status



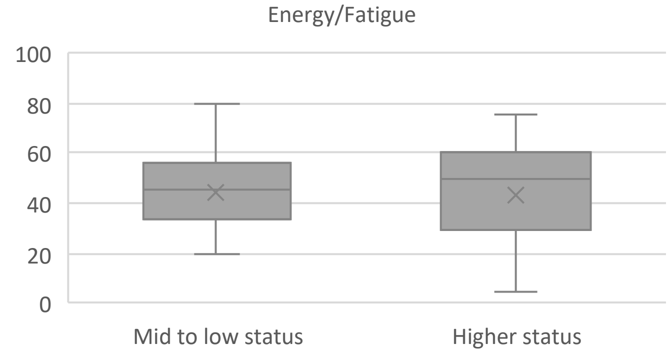


Figure 2.51: Boxplot of SF36 Role functioning/emotional by socioeconomic status

Figure 2.52: Boxplot of SF36 Energy/fatigue by socioeconomic status

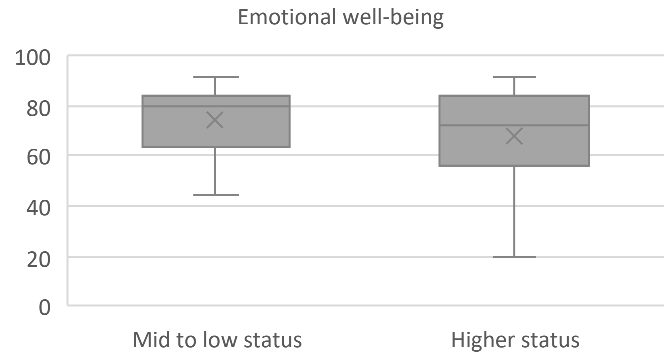


Figure 2.53: Boxplot of SF36 Emotional well-being by socioeconomic status

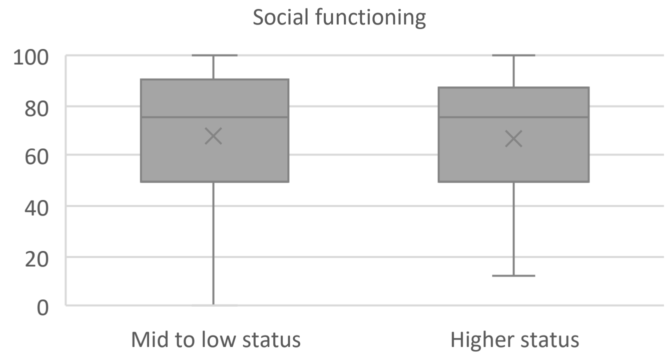


Figure 2.54: Boxplot of SF36 Social functioning by socioeconomic status

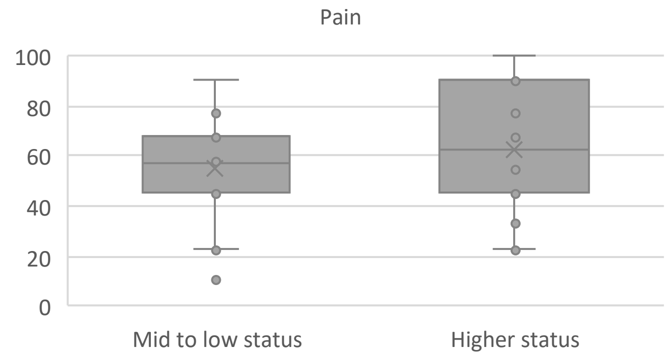


Figure 2.55: Boxplot of SF36 Pain by a stage socioeconomic status

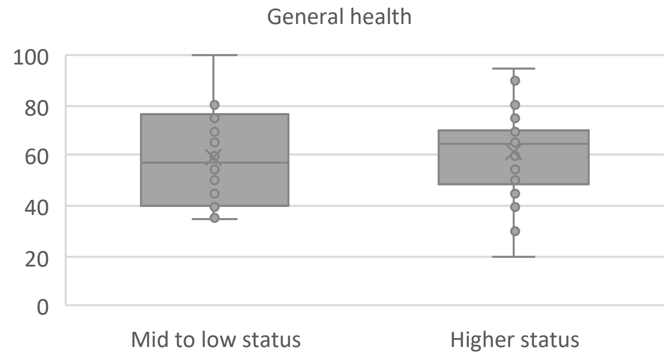


Figure 2.56: Boxplot of SF36 General health by socioeconomic status

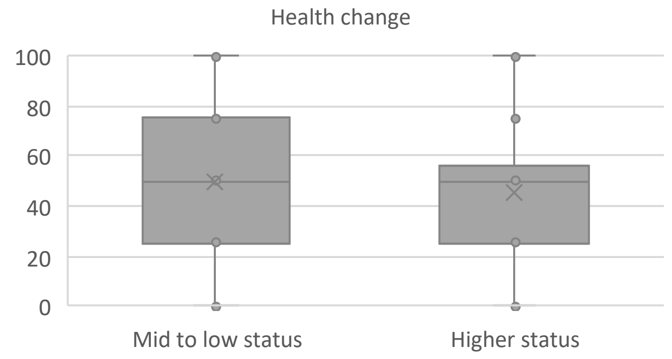


Figure 2.57: Boxplot of SF36 Health change by socioeconomic status

Section 3

Symptoms and diagnosis

Section 3: Symptoms and diagnosis

Symptoms leading to diagnosis

The most common symptom leading to diagnosis was having a lump or lumps in their breast (n=26, 50.00%), this was followed by being vigilant about having breast check-ups due to their family or personal medical history (n=7, 13.46%), breast pain (n=5,9.62%), and breast skin changes such as puckering, dimpling, a rash or redness of skin (n=5, 9.62%).

Symptoms leading to diagnosis: Seeking medical attention

There were 25 participants (48.08%) that described having symptoms and seeking medical attention relatively soon. There were 14 participants (26.92%) that described being diagnosed through screening without experiencing symptoms, and 13 participants (25.00%) described having symptoms and not seeking medical attention initially.

Symptoms leading to diagnosis: Description of diagnostic pathway

Participants were most commonly diagnosed through a population screening program (n=19, 36.54%), and this was followed by being diagnosed by their general practitioner due to concerns about symptoms (following imaging studies) (n=17, 32.69%), and being referred directly to a specialist from their general practitioner which led to their diagnosis (n=16, 30.77%).

Time from symptoms to diagnosis

Duration was calculated for 22 participants (30 participants had no symptoms before diagnosis), there were three participants (13.64%) that were diagnosed less than 1 month of noticing symptoms, six participants (27.27%) diagnosed 1 to 2 months from noticing symptoms, four participants (18.18%) that were diagnosed 3 to 6 months of noticing symptoms, and five participants (22.73%) that were diagnosed more than 6 months of noticing symptoms

Time from diagnostic test to receiving a diagnosis

Participants were most commonly diagnosed less than one week after diagnostic tests (n=21, 40.38%), followed by being diagnosed between 1 and 2 weeks (n=16, 30.77%)

Diagnostic tests

Participants reported between 1 and 5 diagnostic tests (median = 3.00 , IQR = 1.00). The most common tests were mammogram (n = 47, 90.38%), breast ultrasound (n = 47, 90.38%), fine needle aspiration (n = 25, 48.08%), and core biopsy (n = 40, 76.92%)

Diagnosis provider and location

More than half of the participants were given their diagnosis by a specialist doctor (n=31, 59.62%), and there were 21 participants (40.38%) given the diagnosis by a general practitioner (GP)

Participants were most commonly given their diagnosis in the general practice (GP) (n = 17, 32.69%), this was followed by the specialist clinic (n = 14, 26.92%), and the hospital (n = 8, 15.38%)

Breast cancer diagnosis

The majority of participants were diagnosed with invasive breast cancer (n = 30, 57.69%), followed by invasive lobular breast cancer (n = 10, 19.23%) and ductal carcinoma in situ (DCIS) (n=7, 13.46%)

Breast cancer stage

In this PEEK study, a total of 52 participants with hormone receptor positive breast cancer were recruited into the study. There were two participants (3.85%) with Stage 0, 17 participants (32.69%) with Stage I, 21 participants (40.38%) with Stage II, 10 participants (19.23%) with Stage III, and two participants (3.85%) with Stage IV.

Understanding of disease at diagnosis

Most participants described having limited knowledge about the condition at diagnosis (n=30, 57.69%), this was followed by having no knowledge (n=11, 21.15%), and having had a good knowledge (n=9, 17.31%). The most common reasons for having limited knowledge was from having a family history of the condition (n=9, 17.31%), having a friend or acquaintance with the condition (n=8, 15.38%), having a medical, research or relevant professional background (n=8, 15.38%), and researching the condition during the diagnostic process (n=5, 9.62%). The most common reason for having good knowledge of the condition at diagnosis was having a medical, research or relevant professional background (n=9, 9.62%).

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 15 participants (28.85%) who had enough support, 11 participants (21.15%) that had some support but it wasn't enough, and 26 participants (50.00%) had no support.

Information at diagnosis

Participants were asked in the online questionnaire how much information they or their family received at diagnosis. There were 29 participants (55.77%) who had enough information, 21 participants (40.38%) that had some information but it wasn't enough, and two participants (3.85%) had no information.

Costs 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 19 participants (36.54%) who had no out of pocket expenses, and 12 participants (23.08%) who did not know or could not recall. There were eight participants (15.38%) that spent Less than $500,, and 13 participants (25.00%) that spent more than $1000.

Burden of diagnostic costs

For 13 participants (39.39%) the cost was slightly or not at all significant. For 12 participants (36.36%) the out-of-pocket expenses were somewhat significant, and for eight participants (24.24%), the burden of out-of-pocket expenses were moderately or extremely significant.

Genetic tests and biomarkers

Most commonly, participants had never had a conversation about biomarkers, genomic, or gene testing that might be relevant to treatment, (n = 16, 30.77%). There were 14 participants (26.92%) who brought up the topic with their doctor, and 22 participants (42.31%) whose doctor brought up the topic with them.

Half of the participants did not have any genetic or biomarker tests but would like to (n = 26, 50.00%). There were five participants (9.62%) who did not have these tests and were not interested in them, and a total of seven participants (13.46%) that had biomarker tests

Biomarker status

All participants knew the status for at least one biomarker (n = 52, 100%). All participants knew their ER status (n=52, 100%), and most participants knew their PR status (n = 42, 80.77%). There were 15 participants (28.85%) that knew their HER2 status and seven participants (13.46%) that knew their BRCA status.

Current symptoms

Almost half of the participants had symptoms to deal with at the time of completing the questionnaire (n = 24, 46.15%). Participants had between four and 13 symptoms (mean = 4.10, SD = 4.69).

The most common current symptoms, and those where more than 40% of the participants experienced the symptom were; sleep problems (n = 23, 44.23%), weight and muscle changes (n = 23, 44.23%), thinking and memory problems (n = 22, 42.31%), anxiety/anxious mood (n=21, 40.38%), fatigue (n = 23, 44.23%), and pain(n = 23, 44.23%).

The median quality of life was between 2.00 and 3.00, for all of the symptoms listed in the questionnaire, this is in the “Life was distressing” to “Life was a little distressing” range.

Understanding of prognosis

Participants most commonly described their prognosis in relation to no evidence of disease or that they are in remission (n=23, 44.23%). There were 22 participants (42.31%) that described a positive prognosis in relation managing their condition with treatment. Other participants described prognosis in relation to statistics such as five year survival rates (n=19, 36.54%), in relation to probable recurrence/cycle of recurrence (n=16, 30.77), and in relation to monitoring their condition without treatment until there is an exacerbation or progression (n=6, 11.54%).

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=38, 73.08%). All other participants (n=14, 26.92%) described having no symptoms.

The most common symptom leading to diagnosis was having a lump or lumps in their breast (n=26, 50.00%), this was followed by being vigilant about having breast check-ups due to their family or personal medical history (n=7, 13.46%), breast pain (n=5,9.62%), and breast skin changes such as puckering, dimpling, a rash or redness of skin (n=5, 9.62%).

Participant describes having lump(s) in the breast, which led to their diagnosis

I didn't really have anything like that. I just found a lump and went to the doctor a couple days later. So I found a lump. In my left breast, I have been working in a job for SHOP so I thought maybe I just had a box hit me in the chest or something. So I waited a day or so. When it didn't go away or didn't bruise or anything. I made a doctor's appointment. I went to the doctor about two days after that. Participant 020_2021AUHRP

I went to the GP because of my lump. She sent me for a mammogram. Participant 012_2021AUHRP

Yeah, look, I don't recall any symptoms at all. It's simply a purely sound the lump by chance. I, it was winter, and I had a really hot shower before going to bed, went to bed, and then kind of cooked myself a little bit, I was quite hot, and then put my hand under my top and just scratched and just scratched my left breast, and then that's when I because it was sort of itchy. And then that's when I found the lump. Participant 013_2021AUHRP

Participant describes having no symptoms, and being diagnosed through screening

Yes, so the BreastScreen van was in our town and I just had turned 50 the month before I went. I made an appointment and went down only because it was here. Otherwise, I probably wouldn't have. Participant 006_2021AUHRP

PARTICIPANT: No, none.
INTERVIEWER: None, okay.
PARTICIPANT: None. I had absolutely no idea because my cancer wasn't a lump. It's a spreader. Participant 026_2021AUHRP

Okay. I used to get my two-yearly breast mammogram. I'm pretty body aware, and I didn't notice anything. There was no lump as such. I just went off to my BreastScreen LOCATION screening, but because of COVID, my screen was put off almost one year to the day. Participant 032_2021AUHRP

I just went for a routine mammogram. Then got recalled when they noticed some changes on that one. Went then to Breast Screen in town and had a repeat mammogram and then a biopsy, ultrasound. When they then discovered yes, I had a tumor. Then I went to see the surgeon, and he on looking at the mammogram, then sent me for an MRI, and they subsequently found a second tumor. Participant 050_2021AUHRP

Participant describes having family, or personal medical history that made them vigilant about breast screening, which lead to their diagnosis

I didn't have any actually I've been part of the breast screen for clinic for about eight years prior because my mum passed away. She was diagnosed at 41. So I really fought for my doctor to give me that referral because I was like, I had it in my head doesn't get breast cancer around the same time. So it was a bit of a fight. But I think I got there a couple of years later with her and she referred me on so yeah, it was just a routine. I was having routine MRIs that they found it. Participant 048_2021AUHRP

My sister had breast cancer at a young age as well, so I was getting a mammogram, that was one thing. In terms of the diagnosis for this one, because it was in inflammatory breast cancer, it came up like an infection, so it was really red and hot and swollen and all that sort of thing. I went to the doctor initially, and she put me on a course of antibiotics but also ordered a scan for that week. 052_2021AUHRP

Yeah, I was just having a usual yearly mammogram because my mum had breast cancer and I've had implants that 14 years ago.
041_2021AUHRP

Participant describes having breast skin changes including (puckering, dimpling, a rash or redness of skin)

I hesitate to even call it a rash. I had a patch of dry skin on one side of my breast that I thought was dry skin or maybe a fungal infection. It seemed to come and go a bit, so I didn't think a lot of it. I had a skin check with my GP and so I got her to have a look and she didn't really think it was anything either, but gave me some forms to go off and get scanned and I didn't get around to doing that.
INTERVIEWER: Was that the only sign? Sorry.
PARTICIPANT: That was the only sign and everyone all the way through has said it never looks like any of the typical breast cancer rashes that we're told about, there was no nipple change, there wasn't the orange pill. There was none of that. There was a real question around whether it was ever actually related or not, but I had the lumpectomy it's gone away. I think it probably was. I should have taken some pictures and written it up. [chuckles] Participant 011_2021AUHRP

For me, it was orange peel appearance on the breast and my nipple started to invert, but it was actually only after a friend posted something on Facebook while I was working overseas. I looked and went, ah, because I lost a lot of weight in the previous 12 months. I put it down to wrinkly bits and changes because of that. Then I had a look and went, okay, probably not. That was my first indication. Although the few years previously I had had multiple mammograms because I have a family history, unfortunately. Participant 018_2021AUHRP

Yes, sure. I was diagnosed in August of 2019, but I had felt a lump back in May. I noticed dimpling of that breast, which though I wasn't particularly alarmed, I had my suspicions as to what that might indicate. They were the signs that sparked my wish to go to the doctors to get ultrasound or whatever, a mammogram. At the same time I was having back pain, by late July I was getting back pain, but at the time I didn't realize that the two were linked. I was literally at the same doctor's appointment, I was flagging with him the lump and the need to probably not go and get an x-ray, but to go and get some physio. The lump, first initially I was aware of it by that mid to late May. Participant 051_2021AUHRP

Table 3.1: Symptom recall

Symptom recall	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participant describes symptoms leading to diagnosis in a clear way (strong recall)	38	73.08	13	68.42	15	71.43	10	83.33	20	68.97	18	78.26	14	73.68	24	72.73
Participant describes having no symptoms	14	26.92	6	31.58	6	28.57	2	16.67	9	31.03	5	21.74	5	26.32	9	27.27

Symptom recall	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participant describes symptoms leading to diagnosis in a clear way (strong recall)	38	73.08	4	40.00	12	75.00	22	84.62	8	72.73	30	73.17	15	83.33	23	67.65
Participant describes having no symptoms	14	26.92	6	60.00	4	25.00	4	15.38	3	27.27	11	26.83	3	16.67	11	32.35

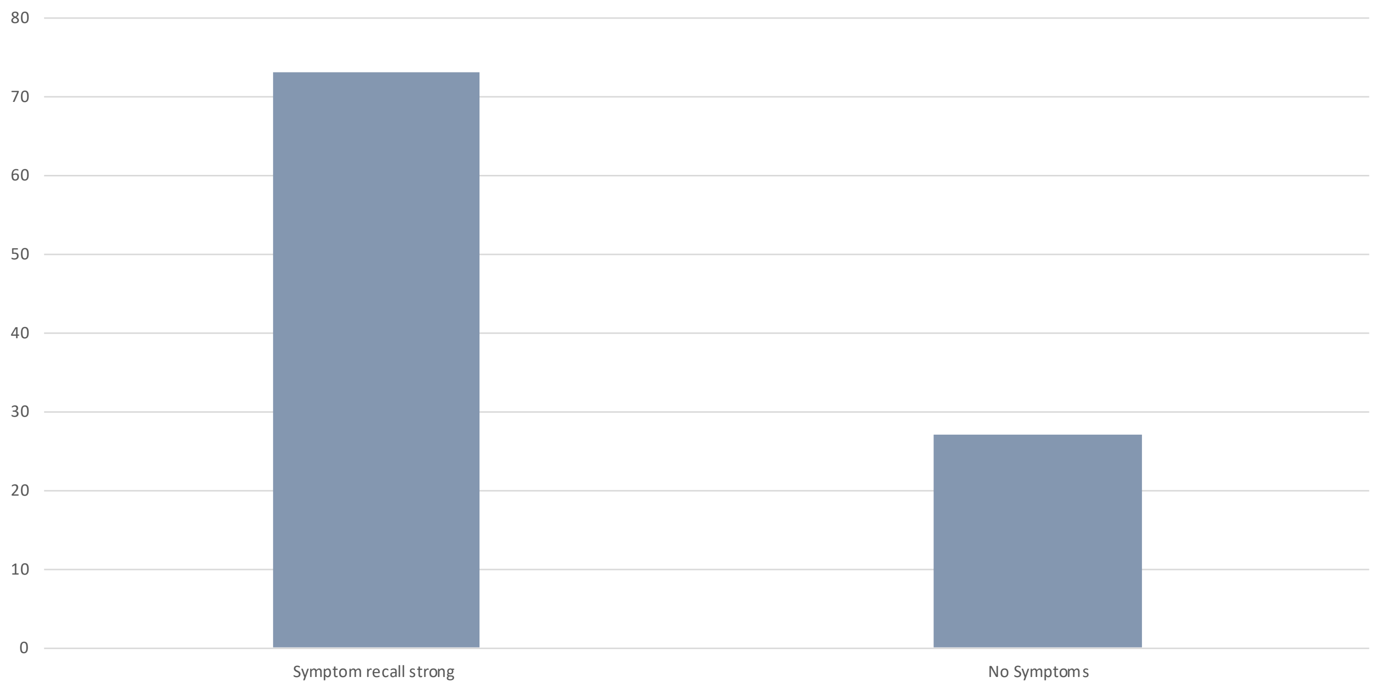


Figure 3.1: Symptom recall (percent of all participants)

Table 3.2: Symptom recall -subgroup variations

Symptom recall	Reported less frequently	Reported more frequently
Participant describes symptoms leading to diagnosis in a clear way (strong recall)	Diagnosed in 2016 or before	Stage III and IV Diagnosed in 2020 or 2021 Mid to low status
Participant describes having no symptoms	Stage III and IV Diagnosed in 2020 or 2021 Mid to low status	Diagnosed in 2016 or before

Table 3.3: Symptoms leading to diagnosis

Symptoms leading to diagnosis	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participant describes having lump(s) in the breast, which led to their diagnosis	26	50.00	10	52.63	10	47.62	6	50.00	15	51.72	11	47.83	10	52.63	16	48.48
Participant describes having no symptoms, and being diagnosed through screening	14	26.92	6	31.58	6	28.57	**2**	**16.67**	9	31.03	5	21.74	5	26.32	9	27.27
Participant describes having family, or personal medical history that made them vigilant about breast screening, which lead to their diagnosis	7	13.46	4	21.05	2	9.52	1	8.33	2	6.90	5	21.74	3	15.79	4	12.12
Participant describes having breast pain), which lead to their diagnosis	5	9.62	1	5.26	2	9.52	2	16.67	3	10.34	2	8.70	3	15.79	2	6.06
Participant describes having breast skin changes including (puckering, dimpling, a rash or redness of skin), which lead to their diagnosis	5	9.62	3	15.79	0	0.00	2	16.67	3	10.34	2	8.70	2	10.53	3	9.09

Symptoms leading to diagnosis	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participant describes having lump(s) in the breast, which led to their diagnosis	26	50.00	4	40.00	8	50.00	14	53.85	**4**	**36.36**	22	53.66	9	50.00	17	50.00
Participant describes having no symptoms, and being diagnosed through screening	14	26.92	**6**	**60.00**	4	25.00	**4**	**15.38**	3	27.27	11	26.83	**3**	**16.67**	11	32.35
Participant describes having family, or personal medical history that made them vigilant about breast screening, which lead to their diagnosis	7	13.46	**3**	**30.00**	1	6.25	3	11.54	2	18.18	5	12.20	3	16.67	4	11.76
Participant describes having breast pain), which lead to their diagnosis	5	9.62	0	0.00	3	18.75	2	7.69	0	0.00	5	12.20	2	11.11	3	8.82
Participant describes having breast skin changes including (puckering, dimpling, a rash or redness of skin), which lead to their diagnosis	5	9.62	0	0.00	1	6.25	4	15.38	1	9.09	4	9.76	1	5.56	4	11.76

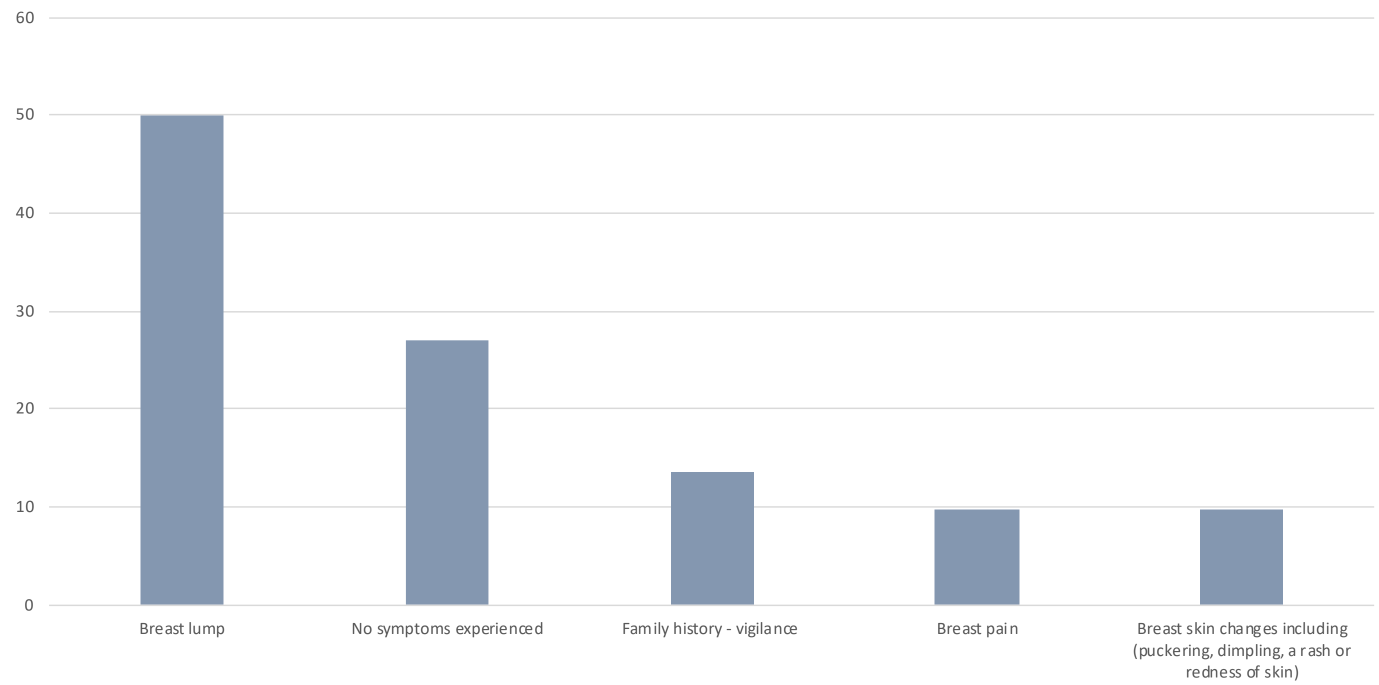


Figure 3.2: Symptoms leading to diagnosis (percent of all participants)

Table 3.4: Symptoms leading to diagnosis – subgroup variations

Symptoms leading to diagnosis	**Reported less frequently**	**Reported more frequently**
Participant describes having lump(s) in the breast, which led to their diagnosis	Regional or remote	-
Participant describes having no symptoms, and being diagnosed through screening	Stage III and IV	Stage II Diagnosed in 2016 or before
Participant describes having family, or personal medical history that made them vigilant about breast screening, which lead to their diagnosis	-	Trade or high school

Symptoms leading to diagnosis: Seeking medical attention

Participants described when they sought medical attention after noticing symptoms. There were 25 participants (48.08%) that described having symptoms and seeking medical attention relatively soon. There were 14 participants (26.92%) that described being diagnosed through screening without experiencing symptoms, and 13 participants (25.00%) described having symptoms and not seeking medical attention initially.

Participant describes having symptoms and seeking medical attention relatively soon

Yes, so then. So it was pretty scary, because the lump was quite big. So I went straight into a GP, a medical practice the next morning and saw a GP just got their first thing for when they opened for a GP. And he then was it gave me a referral to the hospital to get some scans done. Participant 013_2021AUHRP

I didn't really have anything like that. I just found a lump and went to the doctor a couple days later. So I found a lump. In my left breast, I have been working in a job for COMPANY so I thought maybe I just had a box hit me in the chest or something. So I waited a day or so. When it didn't go away or didn't bruise or anything. I made a doctor's appointment. I went to the doctor about two days after that. Participant 020_2021AUHRP

Okay, so I, I found the lump in my breast. When I was having a shower went to the GP, I'd never had a mammogram in the past I was 44. Participant 034_2021AUHRP

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

Well, that's not how it happened. And for me, I was just having a routine mammogram. I had no symptoms. Participant 001_2021AUHRP

I didn't have any. It was just a mammogram. Participant 024_2021AUHRP

No signs or symptoms whatsoever. I was booked in for a two-yearly mammogram and they recalled me because I wanted to have a better look to make sure everything was fine. Ha-ha-ha. Participant 039_2021AUHRP

Participant describes having symptoms and not seeking medical attention initially, but recognising the importance of those symptoms in hindsight

With me, it was quite a large lump that had been there for probably 20 years or more and had been investigated many times, and was always found just to be breast tissue. When I was in the shower, it was sore, which was just before Christmas last year. I thought, "Oh, I wonder why that's sore, I must have bumped it." Didn't think too much more about it. It still continued to be sore, so probably about a few weeks later, I decided I better go and see the doctor. By the time I got into the doctor, I'd canceled a couple of appointments. It's very hard to get into a doctor when you're in a rural area with limited doctors. Participant 017_2021AUHRP

Yes, I did feel a lump. I felt a lump but I'm not obese and I'm probably quite-- I eat healthy and I exercise. I didn't think much of it. I just thought, "Oh, I'll get that checked out," but my parents were sick and I put them first. Participant 021_2021AUHRP

One day, I was sitting on a couch with like, I was just a bit premenstrual and my boobs are a bit sore. And I just thought, you know, that's a usual thing. But I had taken my bra off, and I just pushed my left hand across my right breast, just to sort of give them a bit of support when I was sitting there, and I'm pajamas, and I found a lump. But it felt like the mastitis, like it felt like the same way my breasts had felt when I got mastitis, but just without the infective, like bits going on. So I sort of didn't think anything of it because I was 32. And, you know, it was just before my period, and maybe it was just lumpy, you know, premenstrual breast, that kind of thing. So I didn't really think anything of it. And then the next month, I felt it again. Same, same still trying for a baby bit premenstrual, we're just like, whatever. And then the following months, I felt it earlier in the month. So I was like, Okay, well, we'll go and get that investigated. Participant 033_2021AUHRP

Table 3.5: Seeking medical attention

Seeking medical attention	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participant describes having symptoms and seeking medical attention relatively soon	25	48.08	10	52.63	**7**	**33.33**	**8**	**66.67**	13	44.83	12	52.17	**7**	**36.84**	18	54.55
Participant describes having no symptoms or not noticing any symptoms before diagnosis	14	26.92	6	31.58	6	28.57	**2**	**16.67**	9	31.03	5	21.74	5	26.32	9	27.27
Participant describes having symptoms and not seeking medical attention initially, but recognising the importance of those symptoms in hindsight	13	25.00	3	15.79	**8**	**38.10**	2	16.67	7	24.14	6	26.09	**7**	**36.84**	6	18.18

Seeking medical attention	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participant describes having symptoms and seeking medical attention relatively soon	25	48.08	4	40.00	8	50.00	13	50.00	**4**	**36.36**	21	51.22	10	55.56	15	44.12
Participant describes having no symptoms or not noticing any symptoms before diagnosis	14	26.92	**6**	**60.00**	4	25.00	**4**	**15.38**	3	27.27	11	26.83	**3**	**16.67**	11	32.35
Participant describes having symptoms and not seeking medical attention initially, but recognising the importance of those symptoms in hindsight	13	25.00	**0**	**0.00**	4	25.00	9	34.62	**4**	**36.36**	9	21.95	5	27.78	8	23.53

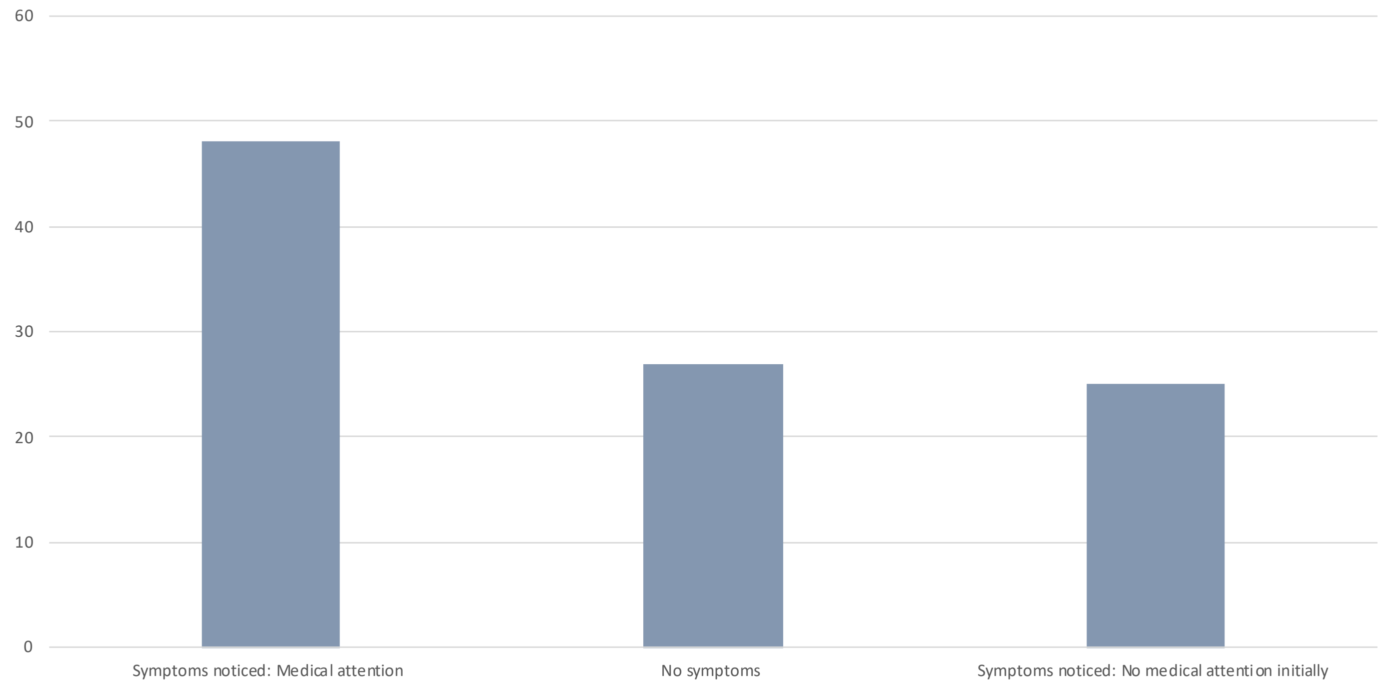


Figure 3.3: Seeking medical attention (percent of all participants)

Table 3.6: Seeking medical attention – subgroup variations

Seeking medical attention	Reported less frequently	Reported more frequently
Participant describes having symptoms and seeking medical attention relatively soon	Stage II Trade or high school Regional or remote	Stage III and IV
Participant describes having no symptoms or not noticing any symptoms before diagnosis	Stage III and IV Diagnosed in 2020 or 2021 Mid to low status	Diagnosed in 2016 or before
Participant describes having symptoms and not seeking medical attention initially, but recognising the importance of those symptoms in hindsight	Diagnosed in 2016 or before	Stage II Trade or high school Regional or remote

Symptoms leading to diagnosis: Description of diagnostic pathway

Participants were most commonly diagnosed through a population screening program (n=19, 36.54%), and this was followed by being diagnosed by their general practitioner due to concerns about symptoms (following imaging studies) (n=17, 32.69%), and being referred directly to a specialist from their general practitioner which led to their diagnosis (n=16, 30.77%).

Participant describes being diagnosed through a population screening program

Well, that's not how it happened. And for me, I was just having a routine mammogram. I had no symptoms. Because it was my routine, biannual mammogram, so I booked it. My GP is fairly proactive here. He will, he will remind me when I'm due. Participant 001_2021AUHRP

PARTICIPANT: On my two-yearly mammogram.
INTERVIEWER: Who organized that for you?
PARTICIPANT: You get a reminder to say that you're due for your two-yearly mammogram and then it's up to you to ring up and make an appointment. It was when I first got the letter, it was maybe August or something of last year when we were going through that first crappy lockdown COVID crap. I thought, "Oh, no, I'm not going anywhere yet. I'm not going to a breast screen place to get tested yet. I'll put it off." I mentally put it off and then I did make the appointment when I felt safer to do so. I think the breast screen places were pretty much shut down anyway. Participant 010_2021AUHRP

Okay. I was having regular mammograms every two years because I'm-- How old am I now? I'm 52 and I have them in, I think the odd years. Anyway, it doesn't matter. I don't have routine mammograms anymore. Anyway, it was a routine mammogram. I did that because that's what you do and I'd always go along and you'd get a letter a few weeks later saying, "Yes, it's all good". This time I got a phone call. That was, the phone call was here. "We just want to have a bit of a look at your right breast again". They did, and they also have a look at my left breast. They did a mammogram, they did an ultrasound and they did a pine needle aspiration, I think it's called. Great big, long thing they stick in and they might've done something with the lymph nodes as well.

…So the outcome of that was I have a day at the breast screen, lots of nice people who were basically preparing me for a diagnosis of breast cancer. They didn't say, "You have breast cancer", but it was all, "This looks very suspicious". They did it nicely, but by the time I left, I was fairly confident I had breast cancer. I had to wait for a week for an appointment with them, which with hindsight was something that was wrong. The pathology reports were all date of the day after the test. I was told "Come back in a week", which I did and by the time I come back in a week, they had made a series of appointments with me. My GP knew about it. It was looked after well, but that delay was not good for my mental health. Participant 039_2021AUHRP

Participant describes being diagnosed by their general practitioner due to concerns about symptoms (following imaging studies)

Okay. I just went to my normal GP and they felt the lump. She didn't think too much of it, but she sent me to a women's imaging center to have more invas-- which I've had before but a more invasive, like a mammogram and a ultrasound. I did that one week and then they called me and I had to go back from the ultrasound and have a fine needle aspiration.
Then while I had the fine needle, they went out of the room and checked the cells that they'd taken while I still was there. They warned me that might happen. They came back and did like a core biopsy where they dug a little bit deeper. From that, I went back to the GP and she diagnosed me. Participant 009_2021AUHRP

Okay, because it was a Saturday, that I found that. I didn't think it was worth trying to turn up at a public hospital to get a mammogram that day. I reckon they just would've turned us away. I waited until Monday morning and I rang my GP. I had a bit of trouble with the receptionist because it was still COVID and they were still mostly only doing telehealth. I said to the receptionist, she's saying, "She's not going to want you to come in." I said, "I am coming in. You tell her I have found a lump in my right breast on Saturday and I need it checked." Anyway, went into the GP and she went. "Yes, you need an mammogram and an ultrasound." She walked straight back out to the receptionist with me and she said to me, "Just sit down there for a minute." She said, "You're not leaving until I find someone who'll do a mammogram today because," she said, "if I send you with a referral, they'll just laugh it off and you won't get one for three months." She said it's just too important. Participant 030_2021AUHRP

I went to the doctor initially, and she put me on a course of antibiotics but also ordered a scan for that week. While I was still on my antibiotics, I went for a mammogram first off, and in the mammogram, she said, "Oh, it's just a bit of mastitis and some fibroids, because I already have fibroids in the other breast.
When I had the ultrasound I think that's when she found it. She didn't say anything to me during that, but she was a bit quiet. I was called in the next day, to my GP, and she said that since she told me that it's highly likely that it is breast cancer. Participant 052_2021AUHRP

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

Yep, so my GP just did a breast exam. And she felt the lump as well. I was then referred to get an ultrasound. And then, when the results of that came back, I was referred to HOSPITAL, which was two and a half hours away from where I lived for a biopsy. And I had that at around 11:30 one day by 12:30. Lunchtime the next day, the doctor had rung me and given me the results. Participant 020_2021AUHRP

Then I went to my local doctor. This is a different doctor. I went to a new doctor,, and as soon he felt it, because he was a surgeon for seven, eight years, he said, "I'll say why didn't you come sooner?" I was just devastated. He sent me straight away for ultrasound, mammograms, and biopsies, and he said to me that if "They deny of those-- Because sometimes they'll say, 'We don't want to do the biopsies.' you ring me there and then." because he said "I wanted to have all of them. The three options, and if you don't have all of those--" because he said, "I really want to sure to make sure." because he said, "They might not be cancer, but it might be." That's when I went had all my scans done. Participant 029_2021AUHRP

The doctor, I saw the same GP that I'd seen for the original lump, same lump, two months earlier. I think he and I both agreed that the lumps were of concern. He sent me off for an ultrasound, and he also suggested that maybe it'd be worth looking in to see a breast specialist surgeon. Because if again we didn't see anything on the investigations, then at least she could explain why this kept on happening. In hindsight, I think he knew better. He knew more than he was giving away. The ultrasound definitely showed breast cancer or very suspicious stuff. I saw the breast specialist literally within a day after getting the ultrasound. She pretty much diagnosed me on the spot, seeing the ultrasound and examining me. Participant 051_2021AUHRP

Table 3.7: Diagnostic pathway

Diagnostic pathway	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participant describes being diagnosed through a population screening program	19	36.54	6	31.58	7	33.33	6	50.00	11	37.93	8	34.78	9	47.37	10	30.30
Participant describes being diagnosed by their general practitioner due to concerns about symptoms (following imaging studies)	17	32.69	6	31.58	7	33.33	4	33.33	8	27.59	9	39.13	5	26.32	12	36.36
Participant describes being referred directly to a specialist from their general practitioner which led to their diagnosis	16	30.77	7	36.84	7	33.33	2	16.67	10	34.48	6	26.09	5	26.32	11	33.33

Diagnostic pathway	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participant describes being diagnosed through a population screening program	19	36.54	6	60.00	5	31.25	8	30.77	5	45.45	14	34.15	7	38.89	12	35.29
Participant describes being diagnosed by their general practitioner due to concerns about symptoms (following imaging studies)	17	32.69	3	30.00	6	37.50	8	30.77	5	45.45	12	29.27	5	27.78	12	35.29
Participant describes being referred directly to a specialist from their general practitioner which led to their diagnosis	16	30.77	1	10.00	5	31.25	10	38.46	1	9.09	15	36.59	6	33.33	10	29.41

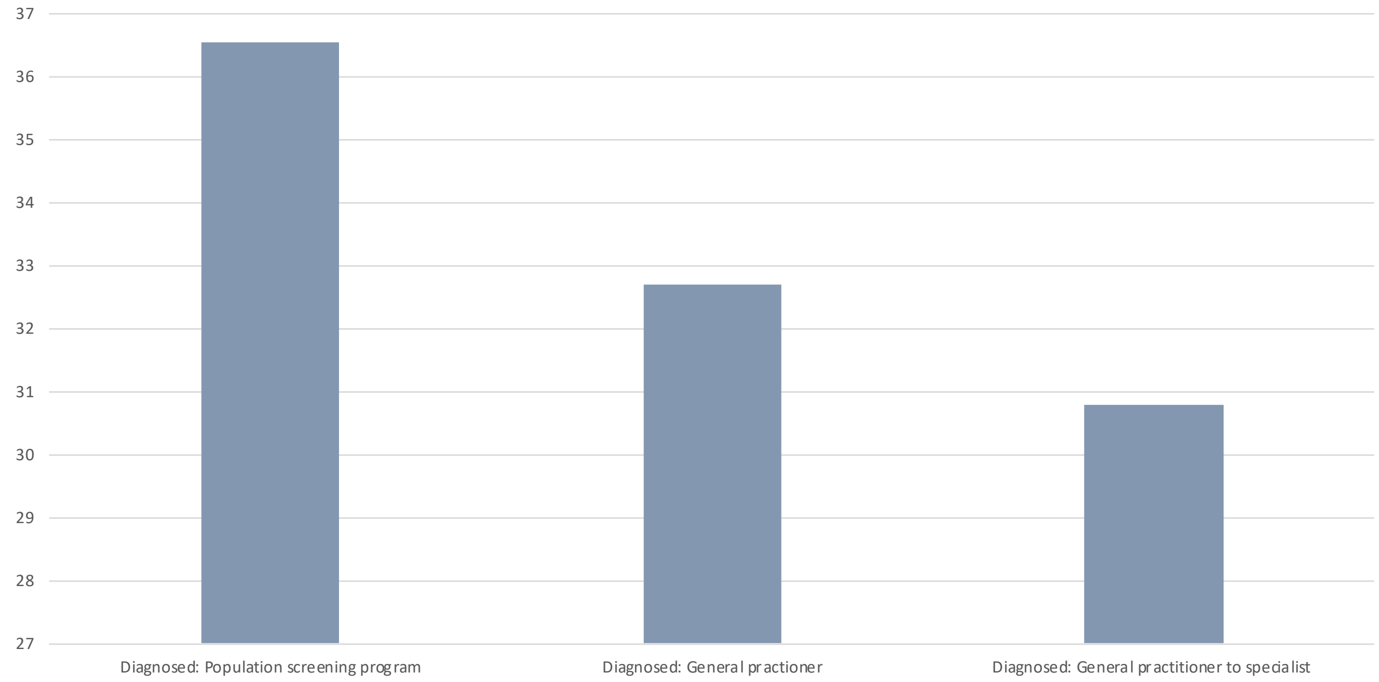


Figure 3.4: Diagnostic pathway (percent of all participants)

Table 3.8: Diagnostic pathway – subgroup variations

Diagnostic pathway	Reported less frequently	Reported more frequently
Participant describes being diagnosed through a population screening program	-	Stage III and IV Trade or high school Diagnosed in 2016 or before
Participant describes being diagnosed by their general practitioner due to concerns about symptoms (following imaging studies)	-	Regional or remote
Participant describes being referred directly to a specialist from their general practitioner which led to their diagnosis	Stage III and IV Diagnosed in 2016 or before Regional or remote	-

Timing of diagnosis

Time from symptoms to diagnosis

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

Duration was calculated for 22 participants (30 participants had no symptoms before diagnosis), there were three participants (13.64%) that were diagnosed less than 1 month of noticing symptoms, six participants (27.27%) diagnosed 1 to 2 months from noticing symptoms, four participants (18.18%) that were diagnosed 3 to 6 months of noticing symptoms, and five participants (22.73%) that were diagnosed more than 6 months of noticing symptoms (Table 3.9, Figure 3.5).

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 one week after diagnostic tests (n=21, 40.38%), followed by being diagnosed between 1 and 2 weeks (n=16, 30.77%) (Table 3.10, Figure 3.6).

Table 3.9: Time from symptoms to diagnosis

Time from symptoms to diagnosis	n=22 (with symptoms before diagnosis)	Percent
Less than 1 month	3	13.64
1 to 2 months	6	27.27
3 to 6 months	4	18.18
More than 6 months	5	22.73
Incomplete data	4	18.18

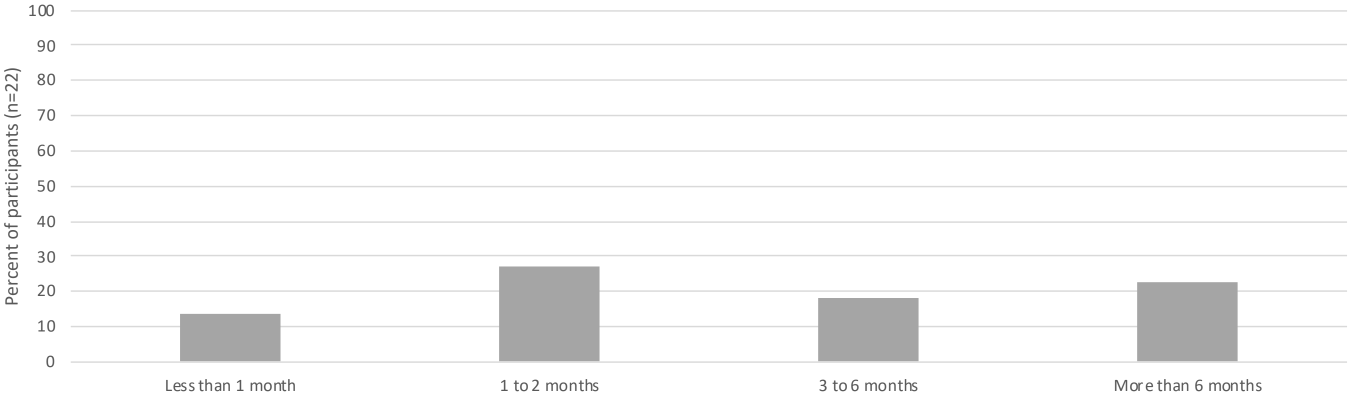


Figure 3.5: Time from symptoms to diagnosis

Table 3.10: Time from diagnostic test to diagnosis

Time from diagnosis test to diagnosis	Number (n=52)	Percent
Diagnosed immediately at the consultation	4	7.69
Less than 1 week	21	40.38
Between 1 and 2 weeks	16	30.77
Between 2 and 3 weeks	2	3.85
Between 3 and 4 weeks	1	1.92
4 weeks or more	7	13.46
Not specified	1	1.92

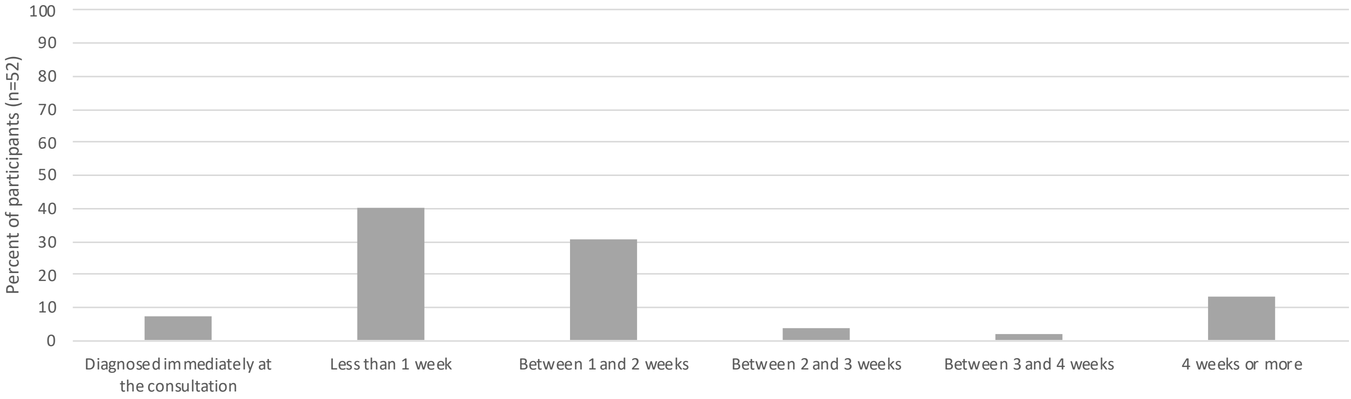


Figure 3.6: Time from diagnostic test to diagnosis

Diagnostic tests

Participants were asked in the questionnaire which diagnostic tests they had for their diagnosis with condition. 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 and 5 diagnostic tests (median = 3.00 , IQR = 1.00) (Table 3.11, Figure 3.7). The most common tests were mammogram (n = 47, 90.38%), breast ultrasound (n = 47, 90.38%), fine needle aspiration (n = 25, 48.08%), and core biopsy (n = 40, 76.92%) (Table 3.12, Figure 3.8).

Table 3.11: Number of diagnostic tests

Number of diagnostic tests per participant	Number (n=52)	Percent
1 to 2	7	13.46
3	29	55.77
4 to 5	16	30.77

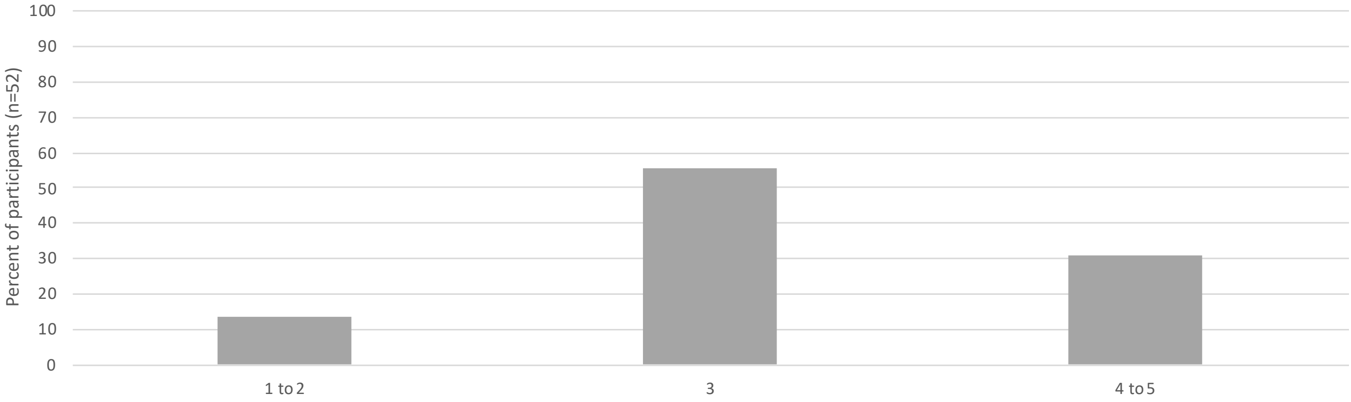


Figure 3.7: Number of diagnostic tests

Table 3.12: Diagnostic tests

Diagnostic tests	Number (n=52)	Percent
Mammogram	47	90.38
Breast ultrasound	47	90.38
Fine needle aspiration (A thin needle is used to take tissue from the breast lump)	25	48.08
Core biopsy (A wider needle is used to remove a piece of tissue)	40	76.92
Other	4	7.69

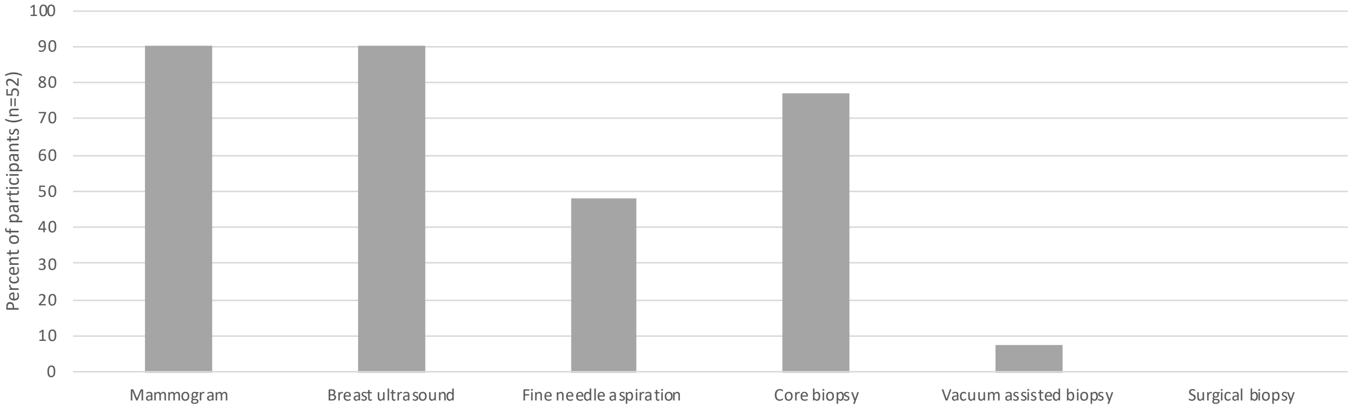


Figure 3.8: Diagnostic tests

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.

More than half of the participants were given their diagnosis by a specialist doctor (n=31, 59.62%), and there were 21 participants (40.38%) given the diagnosis by a general practitioner (GP) (Table 3.13, Figure 3.9).

Participants were most commonly given their diagnosis in the general practice (GP) (n = 17, 32.69%), this was followed by the specialist clinic (n = 14, 26.92%), and the hospital (n = 8, 15.38%) (Table 3.14, Figure 3.10).

Table 3.13: Diagnosis provider

Health professional gave diagnosis	Number (n=52)	Percent
General practitioner (GP)	21	40.38
Specialist doctor	31	59.62

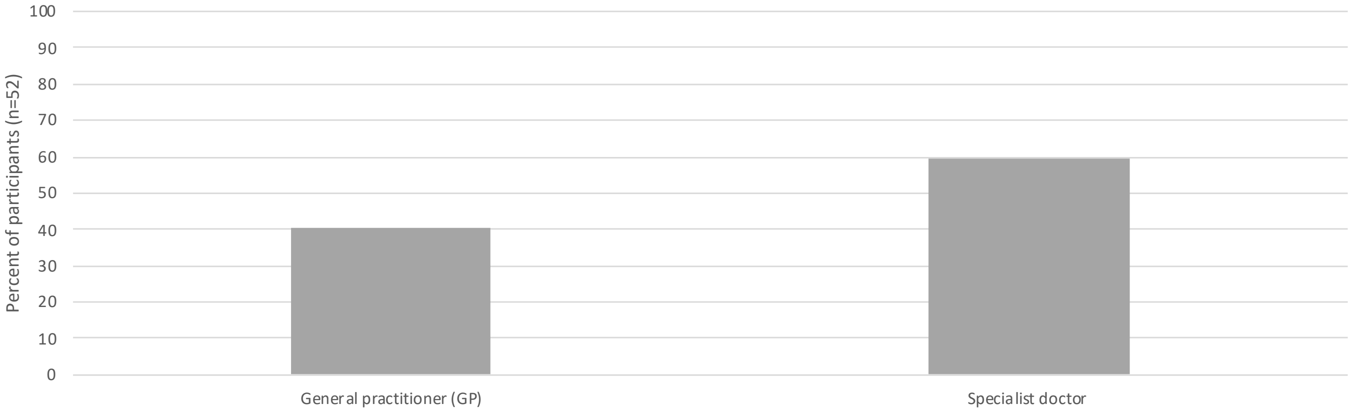


Figure 3.9: Diagnosis provider

Table 3.14: Diagnosis location

Location of diagnosis	Number (n=52)	Percent
General practice (GP)	17	32.69
Specialist clinic	14	26.92
Hospital	8	15.38
Breastscreen/imaging centre	8	15.38
By telephone	5	9.62

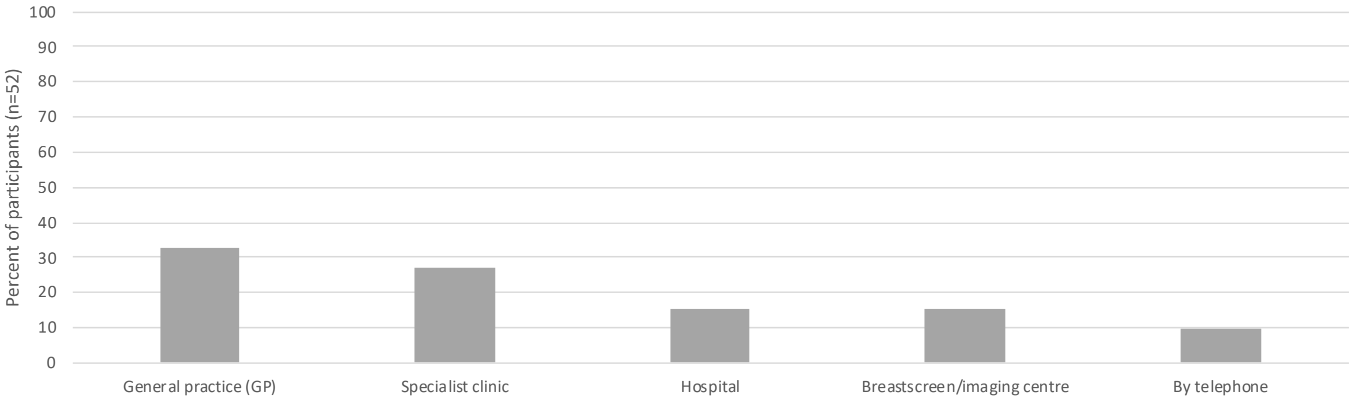


Figure 3.10: Diagnosis location

Breast cancer diagnosis, and stage

Breast cancer diagnosis

The majority of participants were diagnosed with invasive breast cancer (n = 30, 57.69%), followed by invasive lobular breast cancer (n = 10, 19.23%) and ductal carcinoma in situ (DCIS) (n=7, 13.46%) (Table 3.15, Figure 3.11).

Breast cancer stage

In this PEEK study, a total of 52 participants with hormone receptor positive breast cancer were recruited into the study. There were two participants (3.85%) with Stage 0, 17 participants (32.69%) with Stage I, 21 participants (40.38%) with Stage II, 10 participants (19.23%) with Stage III, and two participants (3.85%) with Stage IV (Table 3.16, Figure 3.12).

Table 3.15: Type of breast cancer

Diagnosis	Number (n=52)	Percent
Invasive breast cancer	30	57.69
Invasive lobular breast cancer	10	19.23
Ductal carcinoma in situ(DCIS)	7	13.46
Other	5	9.62

Figure 3.11: Type of breast cancer

Table 3.16: Breast cancer stage

Participants and diagnosis	Number (n=52)	Percent
Stage 0	2	3.85
Stage I	17	32.69
Stage II	21	40.38
Stage III	10	19.23
Stage IV	2	3.85

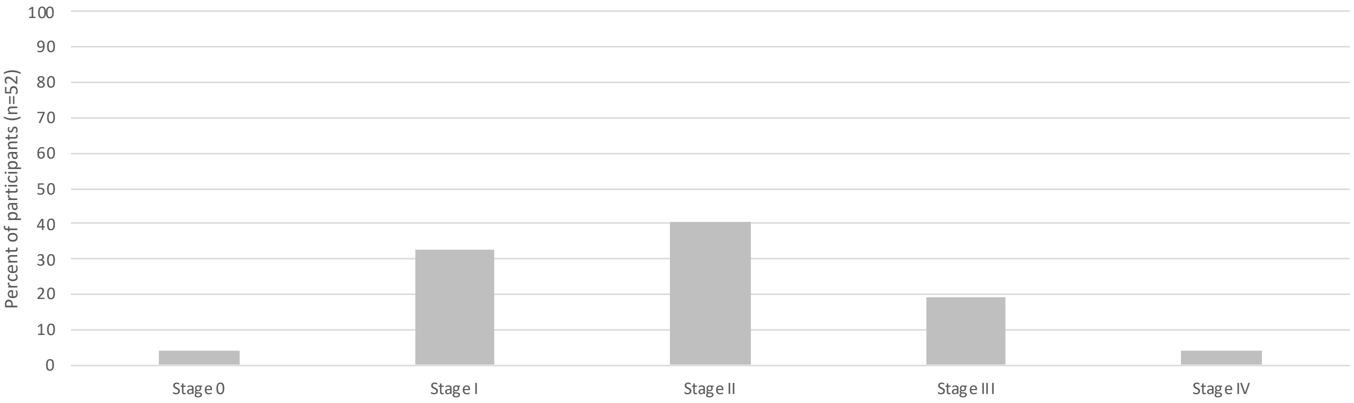


Figure 3.12: Breast cancer stage

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 limited knowledge about the condition at diagnosis (n=30, 57.69%), this was followed by having no knowledge (n=11, 21.15%), and having had a good knowledge (n=9, 17.31%). The most common reasons for having limited knowledge was from having a family history of the condition (n=9, 17.31%), having a friend or acquaintance with the condition (n=8, 15.38%), having a medical, research or relevant professional background (n=8, 15.38%), and researching the condition during the diagnostic process (n=5, 9.62%). The most common reason for having good knowledge of the condition at diagnosis was having a medical, research or relevant professional background (n=9, 9.62%).

Participant describes having limited knowledge from research through diagnostic process

They told me when I went back to see the breast surgeon that I had invasive ductal cancer. That's what the needle biopsy showed. I was given the impression that I had invasive ductal carcinoma. It was very, very small, very treatable. I would only need a lumpectomy. It was 7 mm. That's very tiny. Definitely did not need a mastectomy. She said definitely did not need a mastectomy. I would only require a lumpectomy. She was pretty positive that it wasn't in any lymph nodes. They gave me a lot of information. Asked me if I had questions. I was in shock aura. I didn't know what to ask. I really didn't know what to ask. She was just giving me information. Participant 010_2021AUHRP

Not a lot because I was in shock, to start off with because it was only about a week later I was in and I had surgery. It was quick bang, bang, bang in the hospital had the surgery and I had a lumpectomy. Participant 015_2021AUHRP

Not much, really, when I think about it. I didn't know that there were so many different varieties of breast cancer. I had no idea. Participant 032_2021AUHRP

Participant describes knowing a good amount about the condition at diagnosis e.g. understood diagnosis and aspects of treatment

A moderate amount. I'm medical, I'm a PROFESSION so I knew medical student level information about breast cancer from about 15 years ago. [chuckles] Relatively literate but not really up to date, that would be my summary. Obviously it's not something I'd done a lot of reading about in the last 10 years because it really hadn't been on my radar, but I had a reasonable understanding of most of the basics. Participant 005_2021AUHRP

Quite a bit, really, because I'm a registered nurse. I knew a reasonable amount. I knew the lumpectomies and mastectomies because I've worked on surgical wards for many years, and have looked after a lot of people who had mastectomies and lumpectomies. Is that what you mean? Participant 017_2021AUHRP

I'm actually a nurse. So I knew a fair bit and one of the wards I worked on, one of the surgeries they did was mastectomy. So I pretty much knew a fair bit about, like the early stages, as far as you know, the difference between lumpectomy and mastectomy. And I knew that basically, due to my age that they were going to do is really radical treatment rather than like, let's just wait and see. So I had that bit of bit of knowledge. But obviously, I've never haven't ever done any oncological nursing so that when we got to the next part, so the chemo, I didn't really know much about that. But I from the surgical point of view, I knew more than the average Joe Blow. Participant 033_2021AUHRP

Participant describes knowing nothing about the condition at diagnosis

Before diagnosis, I didn't know anything about a DCIS. I didn't know about breast cancer. But I didn't know about pre cancer. Participant 001_2021AUHRP

I didn't know anything about my condition at all. Not a thing. Participant 004_2021AUHRP

Not a lot, to be honest with you. For me, because of my age, not many people had spoken about it before. I've never really been educated on it, so nothing. Now I know everything about it, but yes, nothing at all really. Participant 008_2021AUHRP

Nothing really, I was pretty much in denial. The GP who wasn't my GP was just filling in got the report and just rang me and said, You need to come in today and I was like what? What for and I was thinking why I haven't been to the doctors, and then I remembered three weeks ago and he said, Now you need to come in. I said this to me and he goes, I can't you need to come in. I went about a week later. Okay. Participant 041_2021AUHRP

Table 3.17: Understanding of disease at diagnosis

Understanding of disease at diagnosis	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participant describes knowing very little about the condition at diagnosis	30	57.69	12	63.16	11	52.38	7	58.33	17	58.62	13	56.52	13	68.42	17	51.52
Participant describes knowing very little about the condition at diagnosis as they have a family history of condition	9	17.31	6	31.58	3	14.29	0	0.00	2	6.90	7	30.43	6	31.58	3	9.09
Participant describes knowing very little about the condition at diagnosis because of a friend or acquaintance with condition	8	15.38	4	21.05	0	0.00	4	33.33	4	13.79	4	17.39	1	5.26	7	21.21
Participant describes knowing very little about the condition at diagnosis as they have a medical, research or relevant professional background	8	15.38	1	5.26	5	23.81	2	16.67	6	20.69	2	8.70	3	15.79	5	15.15
Participant describes knowing very little about the condition at diagnosis without giving a reason for level of understanding	8	15.38	3	15.79	3	14.29	2	16.67	5	17.24	3	13.04	5	26.32	3	9.09
Participant describes knowing very little about the condition at diagnosis as they has began researching the condition before or throughout the diagnostic process	5	9.62	2	10.53	2	9.52	1	8.33	3	10.34	2	8.70	3	15.79	2	6.06
Participant describes knowing a good amount about the condition at diagnosis e.g. understood diagnosis and aspects of treatment	9	17.31	4	21.05	3	14.29	2	16.67	3	10.34	6	26.09	3	15.79	6	18.18
Participant describes knowing about the condition as they have a medical, research or relevant professional background	5	9.62	4	21.05	1	4.76	0	0.00	2	6.90	3	13.04	2	10.53	3	9.09
Participant describes knowing about the condition at diagnosis as they has began researching the condition before or throughout the diagnostic process	4	7.69	1	5.26	1	4.76	2	16.67	2	6.90	2	8.70	1	5.26	3	9.09
Participant describes knowing nothing about the condition at diagnosis	11	21.15	3	15.79	6	28.57	2	16.67	8	27.59	3	13.04	2	10.53	9	27.27

Understanding of disease at diagnosis	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participant describes knowing very little about the condition at diagnosis	30	57.69	5	50.00	8	50.00	17	65.38	6	54.55	24	58.54	12	66.67	18	52.94
Participant describes knowing very little about the condition at diagnosis as they have a family history of condition	9	17.31	2	20.00	3	18.75	4	15.38	3	27.27	6	14.63	5	27.78	4	11.76
Participant describes knowing very little about the condition at diagnosis because of a friend or acquaintance with condition	8	15.38	1	10.00	3	18.75	4	15.38	0	0.00	8	19.51	5	27.78	3	8.82
Participant describes knowing very little about the condition at diagnosis as they have a medical, research or relevant professional background	8	15.38	1	10.00	1	6.25	6	23.08	2	18.18	6	14.63	3	16.67	5	14.71
Participant describes knowing very little about the condition at diagnosis without giving a reason for level of understanding	8	15.38	2	20.00	2	12.50	4	15.38	3	27.27	5	12.20	1	5.56	7	20.59
Participant describes knowing very little about the condition at diagnosis as they has began researching the condition before or throughout the diagnostic process	5	9.62	2	20.00	1	6.25	2	7.69	1	9.09	4	9.76	3	16.67	2	5.88
Participant describes knowing a good amount about the condition at diagnosis e.g. understood diagnosis and aspects of treatment	9	17.31	1	10.00	3	18.75	5	19.23	3	27.27	6	14.63	2	11.11	7	20.59
Participant describes knowing about the condition as they have a medical, research or relevant professional background	5	9.62	0	0.00	2	12.50	3	11.54	2	18.18	3	7.32	1	5.56	4	11.76
Participant describes knowing about the condition at diagnosis as they has began researching the condition before or throughout the diagnostic process	4	7.69	0	0.00	2	12.50	2	7.69	1	9.09	3	7.32	2	11.11	2	5.88
Participant describes knowing nothing about the condition at diagnosis	11	21.15	4	40.00	4	25.00	3	11.54	1	9.09	10	24.39	3	16.67	8	23.53

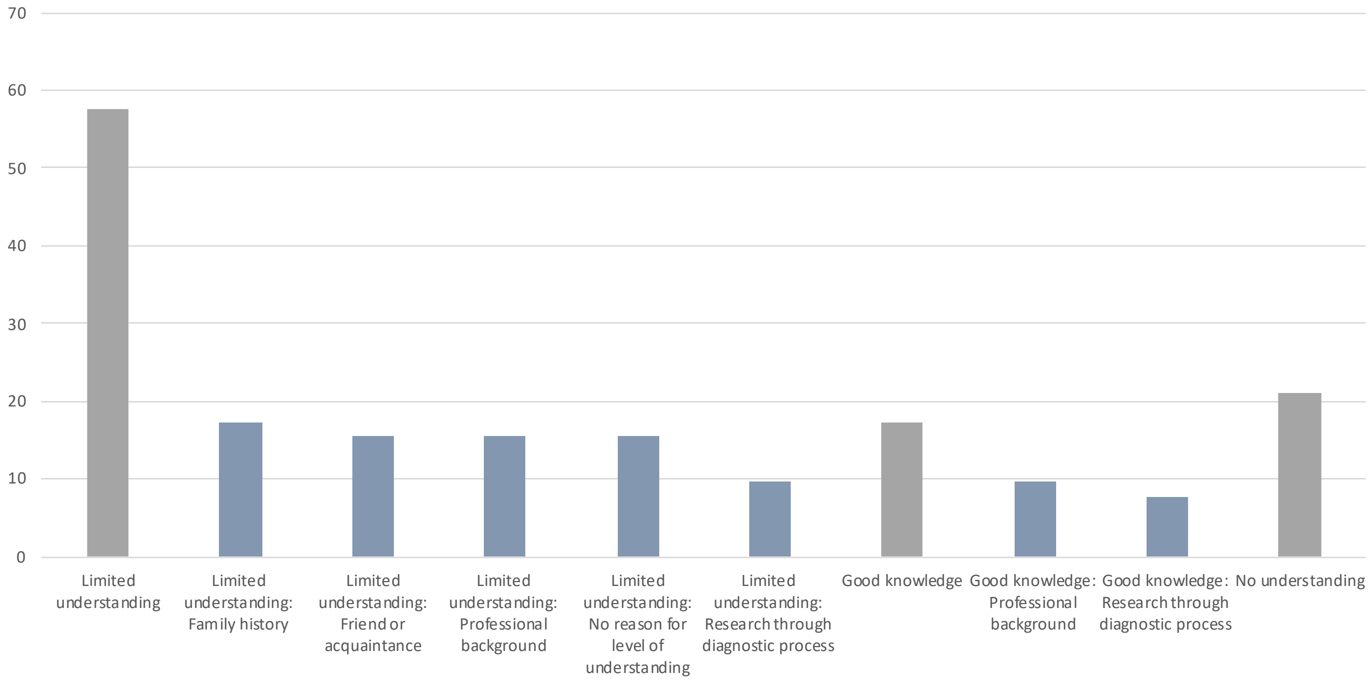


Figure 3.13 Understanding of disease at diagnosis (percent of all participants)

Table 3.18: Understanding of disease at diagnosis – subgroup variations

Understanding of disease at diagnosis	Reported less frequently	Reported more frequently
Participant describes knowing very little about the condition at diagnosis	-	Trade or high school
Participant describes knowing very little about the condition at diagnosis as they have a family history of condition	Stage III and IV Aged 25 to 54	Stage 0 and I Aged 55 to 74 Trade or high school Mid to low status
Participant describes knowing very little about the condition at diagnosis because of a friend or acquaintance with condition	Stage II Trade or high school Regional or remote	Stage III and IV Mid to low status
Participant describes knowing very little about the condition at diagnosis as they have a medical, research or relevant professional background	Stage 0 and I	-
Participant describes knowing very little about the condition at diagnosis without giving a reason for level of understanding		Trade or high school Regional or remote
Participant describes knowing very little about the condition at diagnosis as they has began researching the condition before or throughout the diagnostic process		Diagnosed in 2016 or before
Participant describes knowing about the condition as they have a medical, research or relevant professional background		Stage 0 and I
Participant describes knowing nothing about the condition at diagnosis	Trade or high school Regional or remote	Diagnosed in 2016 or before

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 15 participants (28.85%) who had enough support, 11 participants (21.15%) that had some support but it wasn't enough, and 26 participants (50.00%) had no support (Table 3.19, Figure 3.14).

Subgroup variations of more than 10% are listed in Table 3.20

Table 3.19: Emotional support at diagnosis

Emotional support at diagnosis	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Enough support	15	28.85	5	26.32	6	28.57	4	33.33	9	31.03	6	26.09	6	31.58	9	27.27
Some support but it wasn't enough	11	21.15	4	21.05	5	23.81	2	16.67	6	20.69	5	21.74	5	26.32	6	18.18
No support	26	50.00	10	52.63	10	47.62	6	50.00	14	48.28	12	52.17	8	42.11	18	54.55

Emotional support at diagnosis	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Enough support	15	28.85	2	20.00	5	31.25	8	30.77	4	36.36	11	26.83	7	38.89	8	23.53
Some support but it wasn't enough	11	21.15	3	30.00	1	6.25	7	26.92	4	36.36	7	17.07	3	16.67	8	23.53
No support	26	50.00	5	50.00	10	62.50	11	42.31	3	27.27	23	56.10	8	44.44	18	52.94

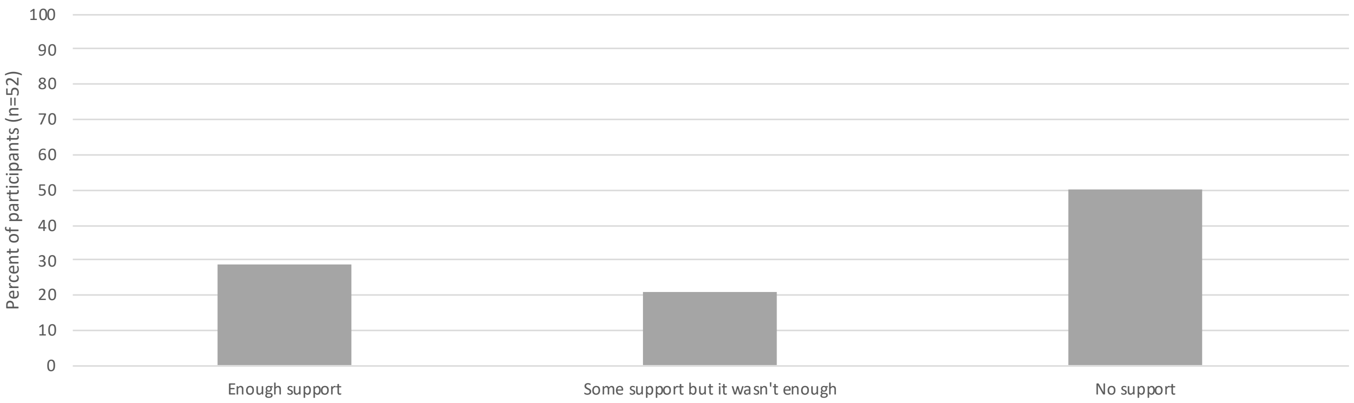


Figure 3.14: Emotional support at diagnosis

Table 3.20: Emotional support at diagnosis – subgroup variations

Emotional support at diagnosis	Less frequently	More frequently
Enough support	-	Mid to low status
Some support but it wasn't enough	Diagnosed in 2017 to 2019	Regional or remote
No support	Regional or remote	Diagnosed in 2017 to 2019

Information at diagnosis

Participants were asked in the online questionnaire how much information they or their family received at diagnosis.

There were 29 participants (55.77%) who had enough information, 21 participants (40.38%) that had some information but it wasn't enough, and two participants (3.85%) had no information (Table 3.21, Figure 3.15).

Subgroup variations of more than 10% are listed in Table 3.24

Table 3.21: Information at diagnosis

Information at diagnosis	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Enough information	29	55.77	7	36.84	13	61.90	9	75.00	18	62.07	11	47.83	11	57.89	18	54.55
Some information but it wasn't enough	21	40.38	11	57.89	7	33.33	3	25.00	11	37.93	10	43.48	7	36.84	14	42.42
No information	2	3.85	1	5.26	1	4.76	0	0.00	0	0.00	2	8.70	1	5.26	1	3.03

Information at diagnosis	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Enough information	29	55.77	5	50.00	9	56.25	15	57.69	5	45.45	24	58.54	10	55.56	19	55.88
Some information but it wasn't enough	21	40.38	5	50.00	6	37.50	10	38.46	5	45.45	16	39.02	6	33.33	15	44.12
No information	2	3.85	0	0.00	1	6.25	1	3.85	1	9.09	1	2.44	2	11.11	0	0.00

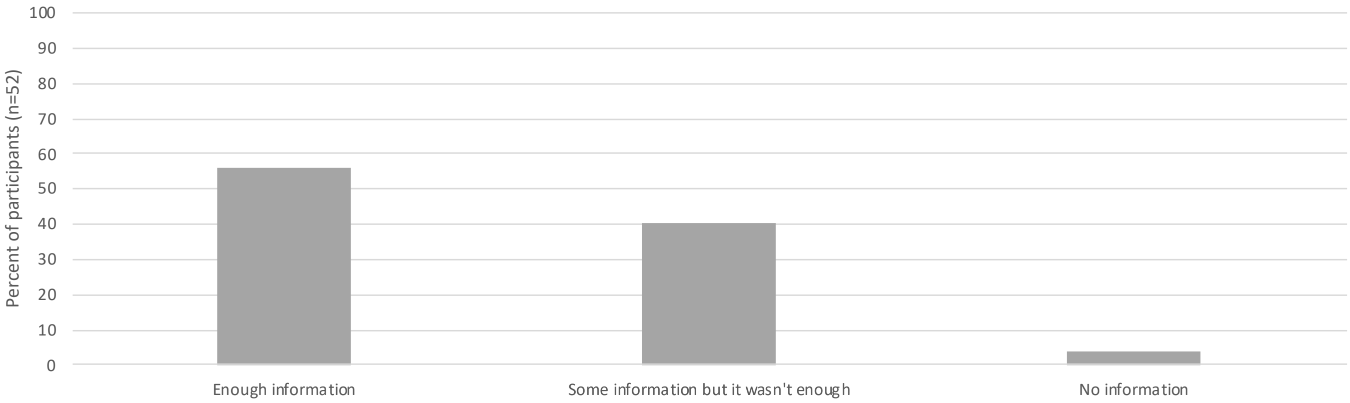


Figure 3.15: Information at diagnosis

Table 3.22: Information at diagnosis – subgroup variations

Information at diagnosis	Less frequently	More frequently
Enough information	Stage 0 and I Regional or remote	Stage III and IV
Some information but it wasn't enough	Stage III and IV	Stage 0 and I

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 19 participants (36.54%) who had no out of pocket expenses, and 12 participants (23.08%) who did not know or could not recall. There were eight participants (15.38%) that spent Less than $500,, and 13 participants (25.00%) that spent more than $1000 (Table 3.23, Figure 3.16).

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 13 participants (39.39%) the cost was slightly or not at all significant. For 12 participants (36.36%) the out-of-pocket expenses were somewhat significant, and for eight participants (24.24%), the burden of out-of-pocket expenses were moderately or extremely significant (Table 3.24, Figure 3.17).)

Table 3.23: Out of pocket expenses at diagnosis

Out of pocket expenses for diagnostic tests	Number (n=52)	Percent
$0	19	36.54
Less than $500	8	15.38
$500 to $1000	0	0.00
More than $1000	13	25.00
Not sure	12	23.08

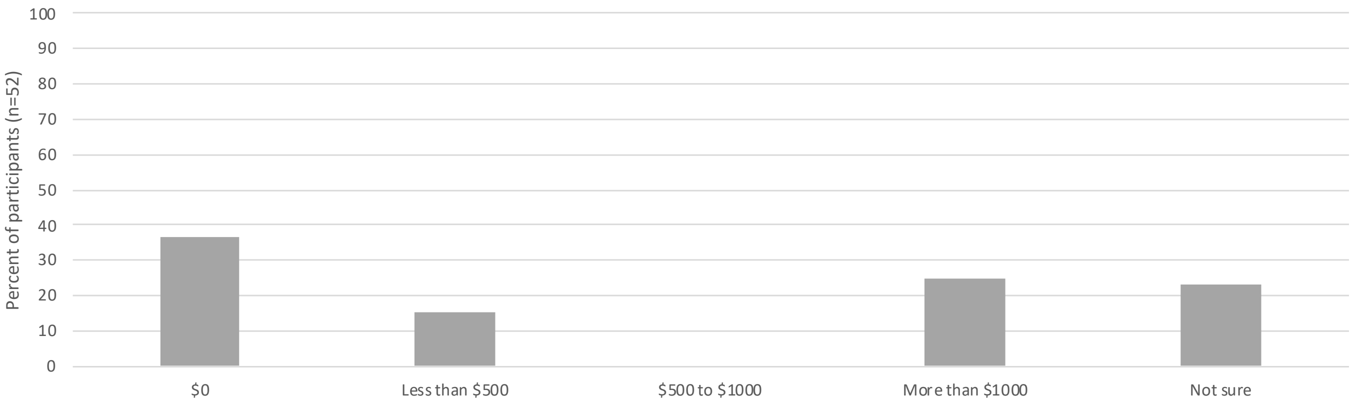


Figure 3.16: Out of pocket expenses at diagnosis

Table 3.24: Burden of diagnostic costs

Burden of diagnostic costs	Number (n=33)	Percent
Not at all significant	3	9.09
Slightly significant	10	30.30
Somewhat significant	12	36.36
Moderately significant	4	12.12
Extremely significant	4	12.12

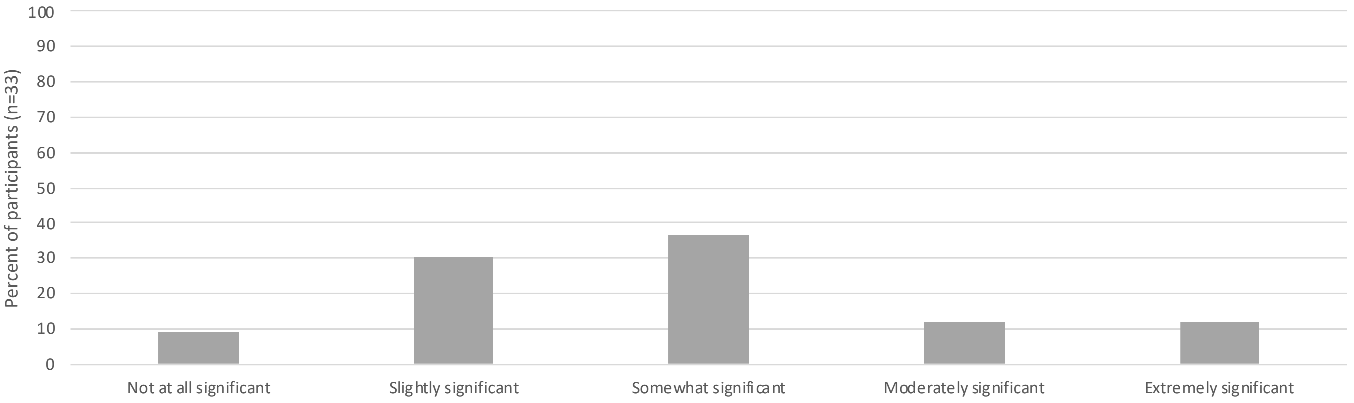


Figure 3.17: Burden of diagnostic costs

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 = 16, 30.77%). There were 14 participants (26.92%) who brought up the topic with their doctor, and 22 participants (42.31%) whose doctor brought up the topic with them (Table 3.25, Figure 3.18).

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.

Half of the participants did not have any genetic or biomarker tests but would like to (n = 26, 50.00%). There were five participants (9.62%) who did not have these tests and were not interested in them, and a total of seven participants (13.46%) that had biomarker tests (Table 3.26, Figure 3.19).

Table 3.25: Discussions about biomarkers

Discussions about biomarkers	Number (n=52)	Percent
Participant brought up the topic with doctor for discussion	14	26.92
Doctor brought up the topic with participant for discussion	22	42.31
Participant had no discussion about this type of test	16	30.77

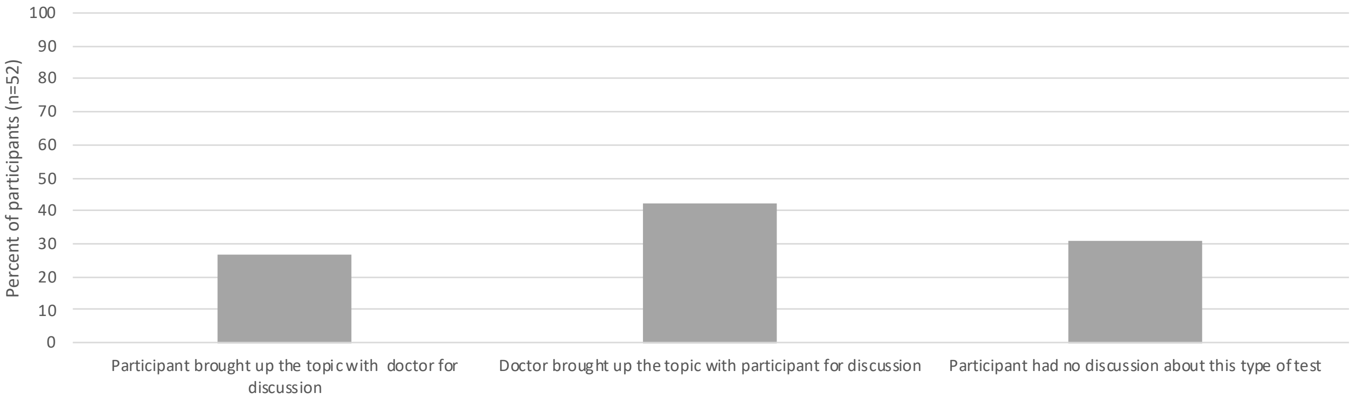


Figure 3.18: Discussions about biomarkers

Table 3.26: Experience of genetic tests and biomarkers

Experience of genetic tests and biomarkers	Number (n=52)	Percent
Participant had this test and did not have to pay out of pocket for it	14	26.92
Participant had this test athrough a clinical trial	3	5.77
Participant had this type of test and paid for it	4	7.69
Participant did not have this test and is not interested in it	5	9.62
Participant did not have this test but would like to	26	50.00

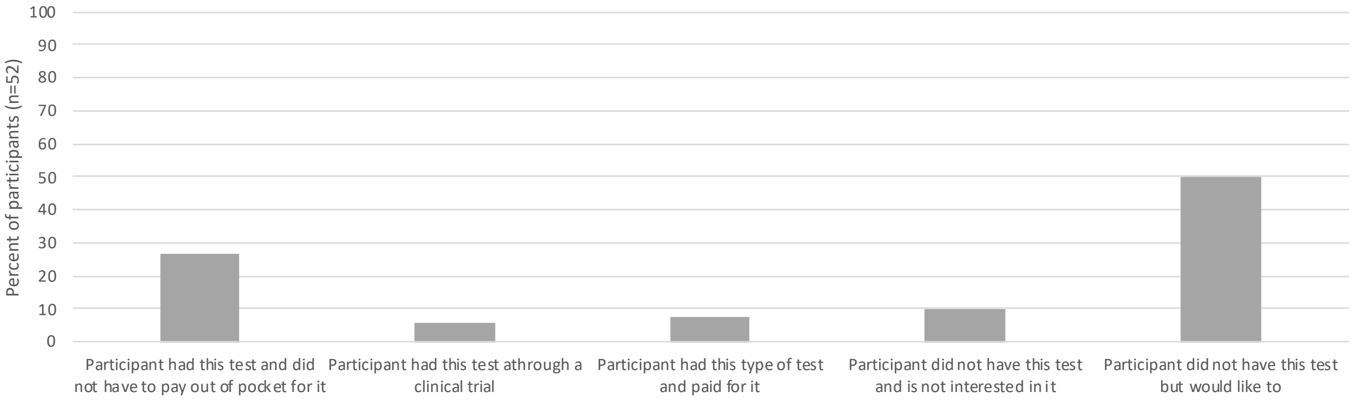


Figure 3.19: Experience of genetic tests and biomarkers

Biomarker status

All participants knew the status for at least one biomarker (n = 52, 100%). All participants knew their ER status (n=52, 100%), and most participants knew their PR status (n = 42, 80.77%). There were 15 participants (28.85%) that knew their HER2 status and seven participants (13.46%) that knew their BRCA status (Table 3.27, Figure 3.20).

Table 3.27: Biomarker status

Biomarkers status known	Number (n=52)	Percent
HER2	15	28.85
ER	52	100.00
PR	42	80.77
BRCA	7	13.46
PALB2	1	1.92

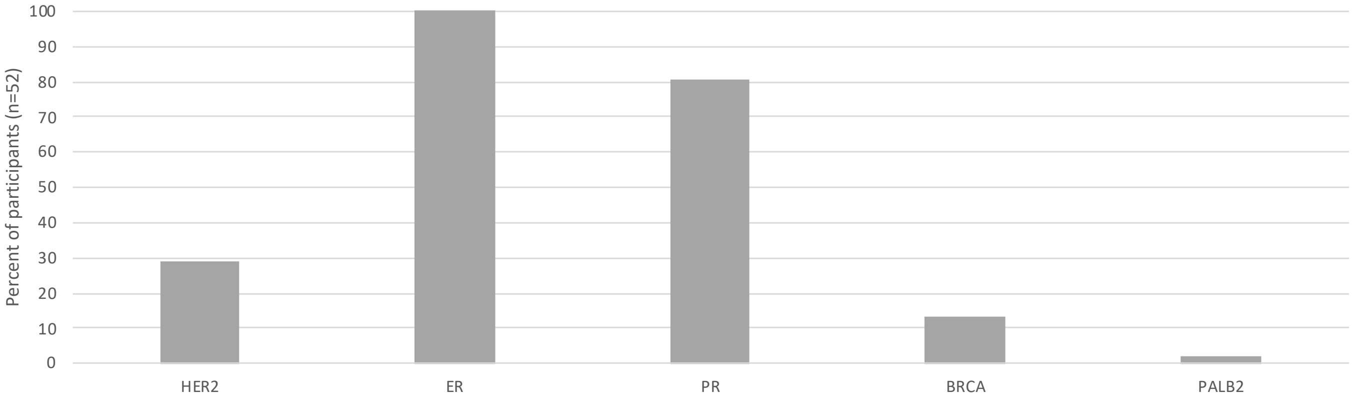


Figure 3.20: Biomarker status

Current symptoms

Number of current symptoms

Participants were asked in the questionnaire what symptoms they are currently dealing with, they could choose from a set lit of symptoms and could then specify other symptoms not listed.

Almost half of the participants had symptoms to deal with at the time of completing the questionnaire (n = 24, 46.15%). Participants had between four and 13 symptoms (mean = 4.10, SD = 4.69) (Table 3.28, Figure 3.21).

Type of current symptoms

The most common current symptoms, and those where more than 40% of the participants experienced the symptom were; sleep problems (n = 23, 44.23%), weight and muscle changes (n = 23, 44.23%), thinking and memory problems (n = 22, 42.31%), anxiety/anxious mood (n=21, 40.38%), fatigue (n = 23, 44.23%), and pain(n = 23, 44.23%) (Table 3.29, Figure 3.21).

Quality of life from current symptoms

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” (Figure 3.26). The median quality of life was between 2.00 and 3.00, for all of the symptoms listed in the questionnaire, this is in the “Life was distressing” to “Life was a little distressing” range.

The symptoms with the lowest quality of life were sleep problem, weight and muscle changes, and fatigue.

Table 3.28: Number of current symptoms

Number of symptoms before diagnosis	Number (n=52)	Percent
No symptoms	28	53.85
4 to 6	4	7.69
7 to 8	3	5.77
9 to 10	13	25.00
11 or more	4	7.69

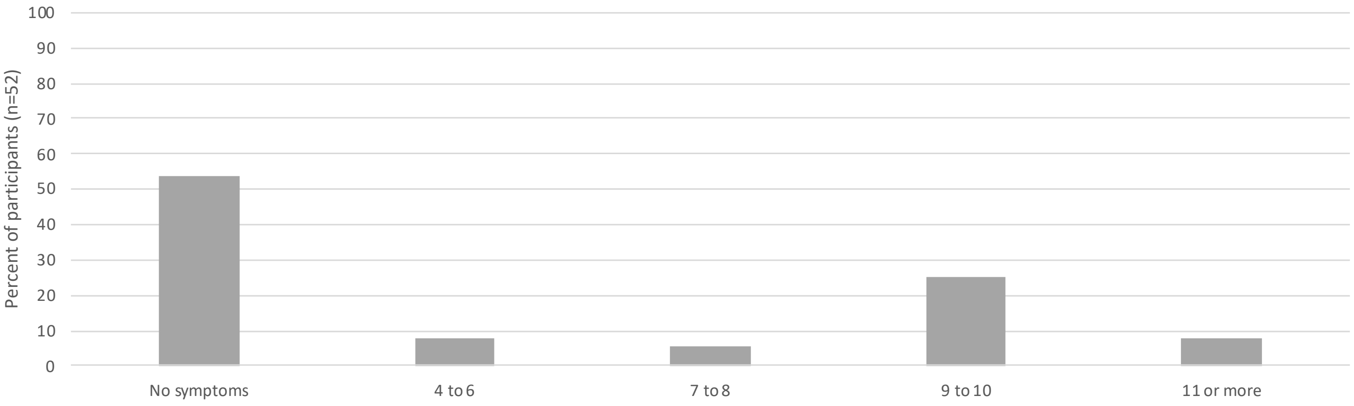


Figure 3.21: Number of current symptoms

Table 3.29: Type of current symptoms

Symptom	Number (n=52)	Percent	Quality of life	
			Mean	SD
No symptoms	28	53.85	NA	NA
Bladder problems	6	11.54	3.00	2.75
Sexual function/ability to have inimate relationships	20	38.46	2.00	2.00
Sleep problems	23	44.23	3.00	1.50
Weight and muscle changes	23	44.23	2.00	2.00
Thinking and memory problems	22	42.31	3.00	2.75
Bone problems	18	34.62	3.00	2.00
Depression/depressed mood	19	36.54	3.00	2.00
Anxiety/anxious mood	21	40.38	3.00	1.00
Fatigue	23	44.23	3.00	1.00
Pain	23	44.23	3.00	1.50

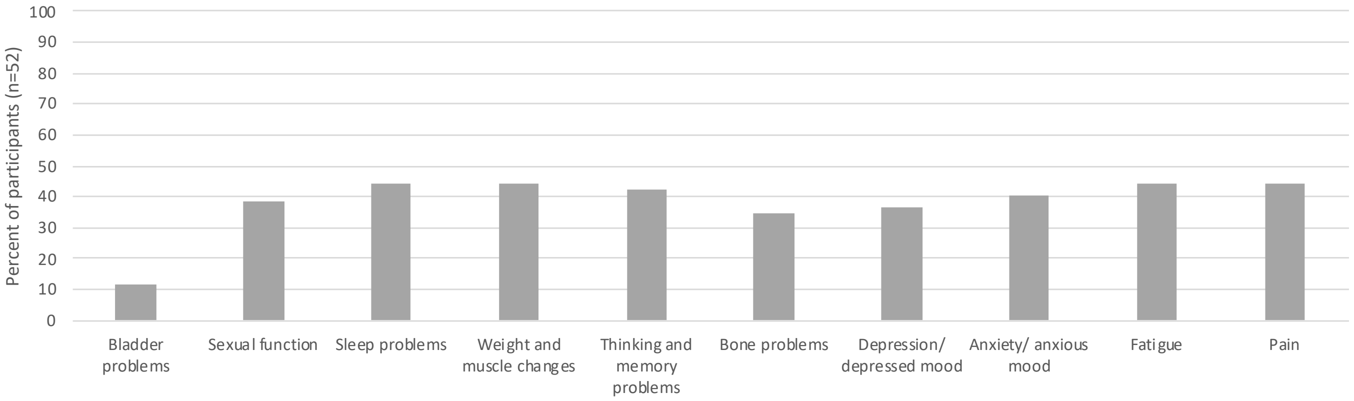


Figure 3.22: Type of current symptoms

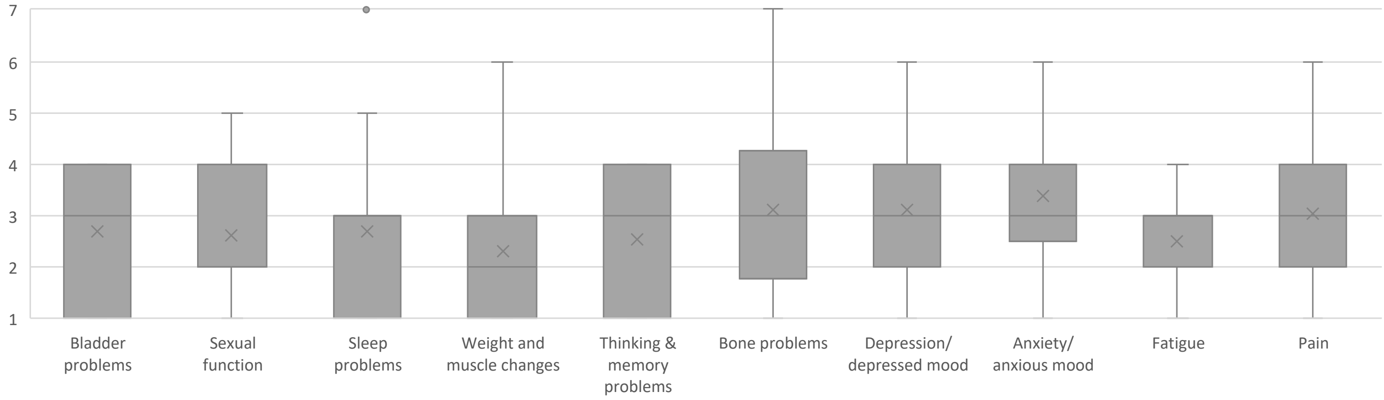


Figure 3.23: Quality of life from current symptoms

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 no evidence of disease or that they are in remission (n=23, 44.23%). There were 22 participants (42.31%) that described a positive prognosis in relation managing their condition with treatment. Other participants described prognosis in relation to statistics such as five year survival rates (n=19, 36.54%), in relation to probable recurrence/cycle of recurrence (n=16, 30.77), and in relation to monitoring their condition without treatment until there is an exacerbation or progression (n=6, 11.54%).

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

Yes, so I am technically free of cancer now, thankfully. I have finished my treatments six weeks ago now, end of radiation. Now it's just all the follow-ups. I've just literally started my hormone blockers yesterday. Participant 008_2021AUHRP

When I was having the radiation treatment, I saw a radiation oncologist, and she said, "Oh, you've got no cancer now." I thought that was a bit swift because it was only after my second day of the radiation treatment. No one's really said anything other than that. Participant 012_2021AUHRP

I'm four years clear in August. I've just had tissue expanders in March. All clear at the moment. Participant 024_2021AUHRP

I've never asked and they don't tell you. I'm not stage four. I guess what you'd say is that I've no evidence of disease, prognosis isn't anything that my specialists talked to me about. Participant 043_2021AUHRP

Participant describes prognosis in relation to it being positive: Manageable with treatment

Good question. I'm ERPR positive and I'm on hormone blockers for the next six years, I think. I've been on them already four or five. They don't really say a lot but they did tell me that if I didn't follow the protocols that I probably wouldn't be around in a couple of years. We tend to just do what you're told. Not that that always works because I'm sorry, the flow-on effects really don't make for a fun life, I can assure you. Participant 018_2021AUHRP

My surgeon contacted my oncologist and they did test, a whole heap of bloods and there was nothing. They were thinking that it might be, shall I say, fatty tissue? [laughs]. At this stage, I'm on tamoxifen for 10 years and I have six-monthly checkups with the oncologist and 12-monthly checkups with my surgeon. Participant 031_2021AUHRP

Yes. Again, I am one of these people, I actually feel guilty even telling people I have breast cancer because my journey has been so easy and simple compared to so many other people I've seen around me. I am reradiation. I have just started the tamoxifen, which I have not had very bad side effects. A little bit of lesions, but no other side effects. I've come through all the physical therapy. I'm swimming and running, so I would say it was more of a wake up call to a healthier lifestyle, than anything else. Participant 007_2021AUHRP

My prognosis should be good, but I'm taking Arimidex. Hopefully, because mine's hormone positive, so it's a receptor blocker. Participant 032_2021AUHRP

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

I would say it's pretty good. Mine was a low stage tumor so it's only a 1A but it was high grade, grade three, and it was treated with wide local excision and radiotherapy which means the risk of recurrence in the same site at five years is about 10%. Because it's a hormone-positive tumor, total risk of recurrence per year is 2%, and that doesn't seem to diminish after 20 years, which is the longest trial that's been done so far. Participant 005_2021AUHRP

Nobody can tell you categorically that you're in the clear. I don't know what my outlook is. The guy that did my radiology on oncologist, DOCTOR, he seems to think I have a good prospect. I didn't undergo chemo. I didn't want to do that, even though they recommended it, but when I was told it would only give me an 8% benefit or 6%, I think they said benefit. I thought well, I'm not going to undergo that for 6% extra chance. A 6%, what is it? Less mortality or something, I can't remember. Anyway, I wasn't going to go through that, so I went along with the radio-- I didn't even want to have radiation because after what my mother had been through. I'd seen the burns and the pain. Then I didn't know a lot about her disease. I did see that when I was young, how much pain and *the torture she went through. Then I was convinced, they told me times have changed and things are a lot better and radiation is a lot better and more targeted and less painful, so I went ahead and had the radiation done. As I said, my radiation oncologist seems to think that I've got a good chance of having a good outcome. Participant 035_2021AUHRP*

Yeah. So at the moment, they just tell you that they can only really tell you that the next five or 10 years, so it's all those percentages, which is really daunting, isn't it? So I've just finished chemo, probably not that long ago, so less probably about two months ago. And they've got another surgery to do, I just have another surgery just recently, like, probably three weeks, four weeks ago. And they've said that they've totally removed all the cancer now that they've accidentally but I didn't get clean margins to start off with after my double mastectomy. So they have to go back and do that. So now they're saying the, they're happy that they've got all the cancer that my chemo was sufficient. And that I think I've got a 94% survival rate for the next five years. And I think with hormone therapy and stuff, they're saying, you know, if I do that, too, obviously, it's an improve my longevity. Participant 048_2021AUHRP

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

Favorable. I think when the oncologist explained it to me, he said that they are getting it down to probably in the realm of potential 15% chance of recurrence. Participant 050_2021AUHRP

Not not, in the words of saying, Oh, look, they shouldn't come back and you should be fine. with breast cancer, they tend to just do mammogram, and ultrasound, you don't have scans or anything. So it's just like, if you keep taking the letrozole, it'll add an increase chance they all talk about this five year survival. No one really talks about 10, 15, 20 years and every all the literature you read is all five years or 10 years, nothing goes beyond that. Okay. Participant 041_2021AUHRP

Okay, it's a bit wishy-washy. I've actually had a -- my other breast removed. I had a prophylactic mastectomy. with malignant phalloides tumours it has a very high reoccurrence rate. It's up around the 25-30% within two years. Distant and local mets are also a big issue. So, yeah, it was sort of the prognosis, unless you do something is quite poor. Participant 003_2021AUHRP

Participant describes prognosis in relation to monitoring their condition without treatment until there is an exacerbation or progression

I'm scheduled for annual surveillance. I got told off for calling it screening, but it's surveillance now. No, actually there was nothing in the lymph nodes. They took a dye and a couple of lymph nodes out. They were clear. I did have to go back for a second surgery to make sure the margins were clear, but that was all good. The cancer itself was quite small, but there was quite a lot of calcium membrane situ around it more than I think anyone had anticipated. That was a bit freaky, but that's all gone.I had radiotherapy and I'm now on tamoxifen, but basically said it's a situation where the surgery is assumed to be pretty much curative, and the other things are relatively low-risk. Even though there's only a little bit of benefit on top of the surgery from doing them, it's worth doing. The additional benefits from chemotherapy would have been well outweighed by the side effects and therefore it wasn't recommended, which was quite a relief Participant 011_2021AUHRP

PARTICIPANT: I tell myself I'm all fine and I think it's so far so good. I had a raft of scans and tests and things towards the end of last year and I'm now only seeing a specialist once every six months.
INTERVIEWER: Okay.
PARTICIPANT: That's a good thing, I think. What else? Yes, I just hope I'm okay. I have regular tests and regular appointments and I don't think there's anything else I can do. Participant 039_2021AUHRP

Right now, I'm doing regular screening for, I should say, some cyst or lump that they found in my liver and my lungs and just a small area on my head which they believe that they're all benign but they are just watching what's happening with those. I've been told that the first three years I have a very high risk for the cancer coming back somewhere in my body, but that's also normal with a 50/50 chance of [unintelligible 00:09:54] survival. That's how it was described to me at the end of the treatment. Participant 049_2021AUHRP

Table 3.30: Understanding of prognosis

Understanding of prognosis	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participant describes prognosis in relation to no evidence of disease or that they are in remission	23	44.23	6	31.58	9	42.86	8	66.67	13	44.83	10	43.48	7	36.84	16	48.48
Participant describes prognosis in relation to it being positive: Manageable with treatment	22	42.31	9	47.37	9	42.86	6	50.00	9	31.03	14	60.87	10	52.63	13	39.39
Participant describes prognosis in relation to statistics such as five year survival rates	19	36.54	7	36.84	10	47.62	2	16.67	14	48.28	5	21.74	7	36.84	12	36.36
Participant describes prognosis in relation to probable recurrence/cycle of recurrence	16	30.77	7	36.84	6	28.57	3	25.00	9	31.03	7	30.43	6	31.58	10	30.30
Participant describes prognosis in relation to monitoring their condition without treatment until there is an exacerbation or progression	6	11.54	4	21.05	1	4.76	1	8.33	3	10.34	3	13.04	3	15.79	3	9.09

Understanding of prognosis	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participant describes prognosis in relation to no evidence of disease or that they are in remission	23	44.23	5	50.00	9	56.25	9	34.62	4	36.36	19	46.34	9	50.00	14	41.18
Participant describes prognosis in relation to it being positive: Manageable with treatment	22	42.31	4	40.00	8	50.00	12	46.15	5	45.45	18	43.90	8	44.44	15	44.12
Participant describes prognosis in relation to statistics such as five year survival rates	19	36.54	4	40.00	7	43.75	8	30.77	4	36.36	15	36.59	10	55.56	9	26.47
Participant describes prognosis in relation to probable recurrence/cycle of recurrence	16	30.77	4	40.00	5	31.25	7	26.92	5	45.45	11	26.83	7	38.89	9	26.47
Participant describes prognosis in relation to monitoring their condition without treatment until there is an exacerbation or progression	6	11.54	0	0.00	2	12.50	4	15.38	2	18.18	4	9.76	2	11.11	4	11.76

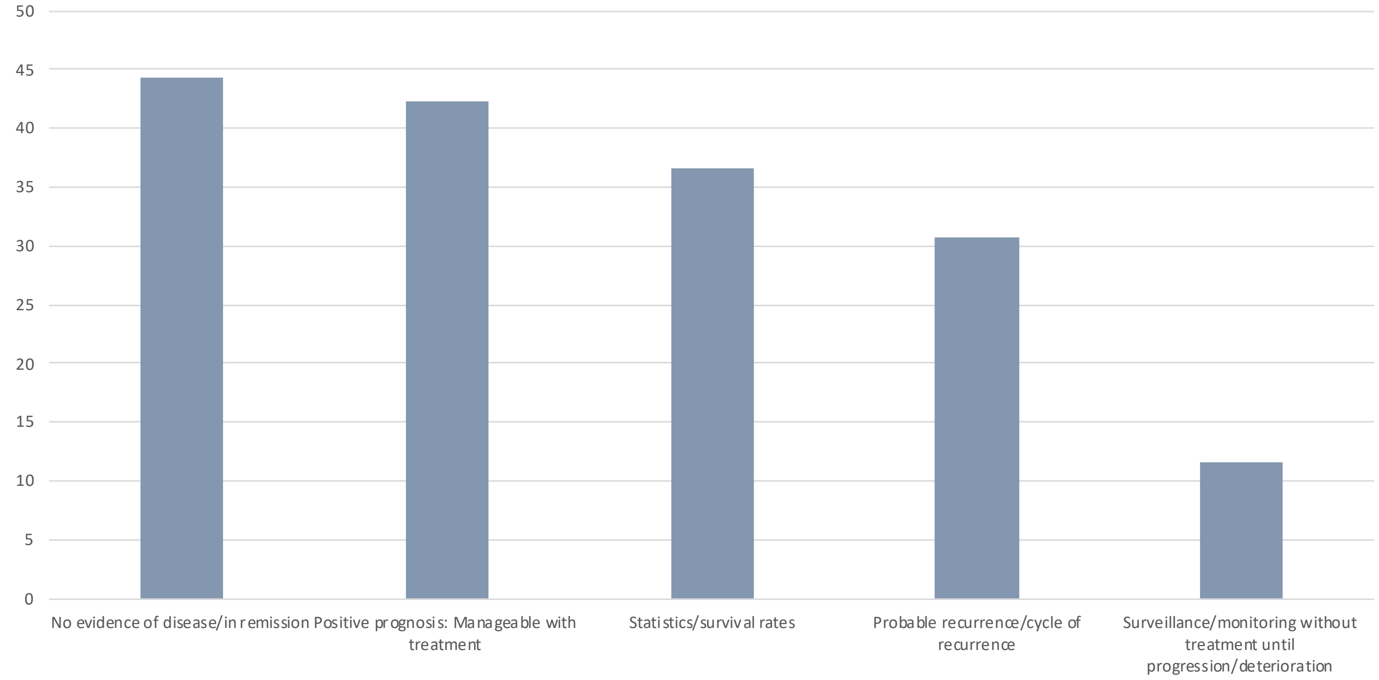


Figure 3.24: Understanding of prognosis (percent of all participants)

Table 3.31: Understanding of prognosis – subgroup variations

Understanding of prognosis	Reported less frequently	Reported more frequently
Participant describes prognosis in relation to no evidence of disease or that they are in remission	Stage 0 and I	Stage III and IV Diagnosed in 2017 to 2019
Participant describes prognosis in relation to it being positive: Manageable with treatment	Aged 25 to 54	Aged 55 to 74 Trade or high school
Participant describes prognosis in relation to statistics such as five year survival rates	Stage III and IV Aged 55 to 74 Higher status	Stage II Aged 25 to 54 Mid to low status
Participant describes prognosis in relation to probable recurrence/cycle of recurrence		Regional or remote
Participant describes prognosis in relation to monitoring their condition without treatment until there is an exacerbation or progression	Diagnosed in 2016 or before	

Section 4

Decision-making

Section 4 summary

Discussions about treatment

The most common description was being presented with multiple treatment options, and this was described by 43 participants (82.69%). This was followed by being presented with one treatment option only (n=8, 15.38%).

Discussions about treatment (Participation in discussions)

In relation to participant in discussions about treatments, there were 23 participants (44.23%) that described that they participated in decision making or had informed discussions, and 21 participants (40.38%) that described that they did not take part in decision making, and nine participants (17.31%) that described feeling that they were told what to do with little or no discussion.

Considerations when making decisions

The most reported theme was taking side effects into consideration and this was described by 24 participants (46.15%). There were 17 participants (32.69%) described taking efficacy of treatment into account, and 15 participants (28.85%) described taking the advice of their clinician. Other considerations included quality of life (n=9, 17.31%), impact on family and dependents (n=8, 15.38%), survival benefit (n=8, 15.38%), ease of administration (n=7, 13.46%), and the ability to work (n=5, 9.62%).

Decision-making over time

Participants were asked if the way they made decisions had changed over time. There were 27 participants (51.92%) that felt the way they made decisions about treatment had not changed over time, and 25 participants (48.08%) that described decision making changing.

Where participants had not changed their decision making over time, this was this was because they have had always been informed and assertive (n=7, 13.46%), or always taken the advice of clinicians (n=6, 11.54%). Where participants had changed the way they make decisions, it was primarily because they had become more informed or more assertive over time (n=17, 32.69%), or because they were more focused on quality of life or the impact of side effects (n=6, 11.54%).

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 or avoid recurrence (n=23, 44.23%), and this was followed by wanting to minimise or control side effects (n=20, 38.46%). Other themes included wanting quality of life or return to normality (n=9, 17.31%), and wanting to see improvements in mental or emotional health (n=5, 9.62%).

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 43 participants (82.69%). This was followed by being presented with one treatment option only (n=8, 15.38%).

Participant describes being presented with multiple options/approaches

The doctor at the breast clinic was very helpful in pushing me, that's the right word ahead to get that test done on that Friday and not have to wait a week or two for it. When I found DOCTOR, I got in to see her on the following Monday. She was absolutely lovely. She spoke to myself and my husband and said that she would be doing a lumpectomy. She would not be doing a mastectomy that she was hoping it would just be the one surgery. Depending on what she found, she wouldn't be removing the whole breast. If that was needed, that would be a second surgery. Yes, she just basically, well, there wasn't all that many options. It was well this is what will happen. You will have had the lumpectomy. They do some pathology while I was under anaesthetic to make sure they got it within the boundaries. She would be taking, well, she didn't know how many lymph nodes but she ended up taking two lymph nodes. As far as I can ascertain, there was no cancer had got out. DOCTOR organized for me to see the oncologist and she also organized for me to see the DOCTOR who was the radiation doctor that was looking after me when I had the radiation. Participant 004_2021AUHRP

INTERVIEWER: Then, what were the types of discussions you had with your clinicians about treatment options, when you first received that diagnosis?
PARTICIPANT: Well, surgery, and then radiation, and then we would discuss anything going on further.
INTERVIEWER: They said, "Surgery and radiation, that's what you need to do, and then anything from there, we can discuss further"?
PARTICIPANT: Yes. Then I was put on medication. Participant 038_2021AUHRP

There's only one specialist in LOCATION, so I just went to him and they more or less said all I really needed was radiation and estrogen blockers and that was it. There was no, really, other discussion. I just went with what they had because they said that the specialists, the oncologists, get together as a team and radiation people and they discuss what is your best treatment. Participant 006_2021AUHRP

Participant describes being presented with one options/approach

No conversation whatsoever. I was basically told I am getting a mastectomy. I wasn't asked. I was told, we have booked you in for a mastectomy because this is the only thing that's going to save your life. Participant 003_2021AUHRP

Well, in the first instance, it was the medical director who is a GP who was running the breast screening clinic and doing the counselling and the core biopsies and things like that. When she initially called me back and redid the mammogram and ultrasound and then the core biopsy, it was obvious to me, looking at the mammogram, that I obviously had a tumour that was malignant. So at that stage, I was advised that I would be referred to a surgeon. So and then it was left up to me that I wanted to go to the public on a private system. And so at that point, it was just really a case of knowing that I was being directed towards a surgical outcome for my tumours. Participant 019_2021AUHRP

And she was very open with the survival rate. Is that 100 percent for this type of cancer? So you do have to make some choices about getting rid of it. So she helped me through the originals. So going to go my journey. But the original conversation was about doing a lumpectomy and which is just a wide incision just on the side of the first. I had a quarter with model. From what I can gather, not everyone had a quarter that was probably the most unpleasant of all. I had a quiet and then she went and then I waited three days until my results. Participant 002_2021AUHRP

Table 4.1: Discussions about treatment

Discussions about treatment	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participant describes being presented with multiple options/approaches	43	82.69	16	84.21	18	85.71	9	75.00	24	82.76	19	82.61	16	84.21	27	81.82
Participant describes being presented with one option/approach	8	15.38	2	10.53	3	14.29	3	25.00	5	17.24	3	13.04	3	15.79	5	15.15

Discussions about treatment	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participant describes being presented with multiple options/approaches	43	82.69	6	60.00	16	100.00	21	80.77	9	81.82	34	82.93	16	88.89	27	79.41
Participant describes being presented with one option/approach	8	15.38	3	30.00	0	0.00	5	19.23	2	18.18	6	14.63	1	5.56	7	20.59

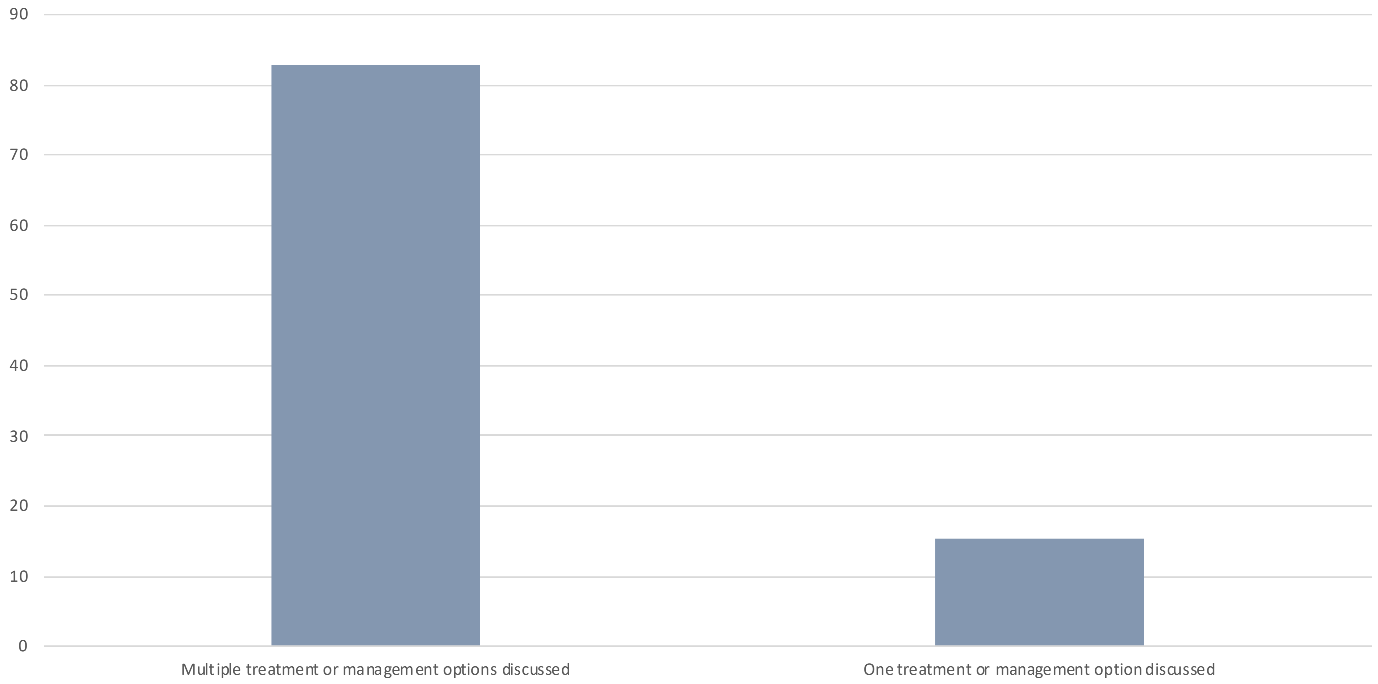


Figure 4.1: Discussions about treatment (percent of all participants)

Table 4.2: Discussions about treatment – subgroup variations

Discussions about treatment	Reported less frequently	Reported more frequently
Participant describes being presented with multiple options/approaches	Diagnosed in 2016 or before	Diagnosed in 2017 to 2019
Participant describes being presented with one option/approach	Diagnosed in 2017 to 2019	Diagnosed in 2016 or before

Discussions about treatment (Participation in discussions)

In relation to participant in discussions about treatments, there were 23 participants (44.23%) that described that they participated in decision making or had informed discussions, and 21 participants (40.38%) that described that they did not take part in decision making, and nine participants (17.31%) that described feeling that they were told what to do with little or no discussion.

Participant describes taking part in the decision making process

I went to the woman first, and she went through the report very carefully from top to toe and then explained to me what she felt needed to be done. She was very clear. I asked her what drugs she was going to use for the chemo. She told me and I thought, "Oh," because I was a PROFESSION. My immediate reaction was to jump up and say, "I'm not having that." Anyway. Then I realized, "Oh, come to think of it I've got my back to the wall and I'm not in a bargaining position." Anyway, I have to say, she handled my reaction extremely well. Then I asked her what the advantages of it were. I was absolutely shocked when she said there's 7% in chemotherapy. You could have knocked me over with a feather. I thought it mop up 85% or something like that. Anyway, and I said, "Oh do you really think it's worth it?" Well, she reckoned the margins were not good enough. They were less than 0.4 millimetres. She wasn't all that happy about it. She said that if she were me that she would definitely take the chemo. I said, "Okay." I said we were going to LOCATION to see all our children for Christmas. She said, "Oh, that will be fine." Then she *worked out a date that I could then fly back a day or two early so I could fit into her schedule and stuff. The guy the next day was terrible. The local guy was so bad I could not believe my ears. Participant 022_2021AUHRP*

PARTICIPANT: OK with me? I had a really great first surgeon and she was very thorough. She had the glass notepad that had pictures of everything from ductal to invasive on it. So she would refer to this piece of paper and draw and share exactly with the cancer bone and explain what ductal was. And then she had a little chart below and showed me how it was. Please tell me I'm being very simplistic that someone would try and keep it. Classically said, told me that ductal is like being a prisoner in a cage and sort of said, look, doctor, which is, you know, I think it was considered Zero grade cancer as it was for ductal do I'm not sure whether that might say,
INTERVIEWER: yes, it does. Yes, because yes, it does.
PARTICIPANT: And she was very open with the survival rate. Is that 100 percent for this type of cancer? So you do have to make some choices about getting rid of it. So she helped me through the originals. So going to go my journey. But the original conversation was about doing a lumpectomy and which is just a wide incision just on the side of the first. I had a quarter with model. From what I can gather, not everyone had a quarter that was probably the most unpleasant of all. I had a quiet and then she went and then I waited three days until my results. Participant 002_2021AUHRP

I feel I had quite a good collection of clinicians, I think they were really excellent. Initially, I had a conversation with a surgeon about whether we were going to look at wide local excision and radiotherapy or a mastectomy. I was fairly reticent on the radiotherapy side of things, mostly because of obviously my experiences in vascular surgery and we see the late complications of radiotherapy. Lymphedema of my upper limb was probably the most concerning thing because that would be career-ending. I was actually leaning towards the mastectomy and probably still am, to be honest [chuckles] but she talked me into a lumpectomy.
I had a good conversation with the radiation oncologist, he was lovely, that if you don't have a mastectomy, it's almost a no-brainer that you need to have it. The difficult one was chemo or not. I actually had I believe three or four conversations with my oncologist before excision, and then after we got the grade and everything, and I decided the genomics, whether or not to go ahead with that. That was a long process, a joint decision, and in fact, my consideration was I'd like to go ahead, even though she was like, "Well, you probably don't have to if you don't want to." I actually had quite a good set of people who listen and talk well. Participant 005_2021AUHRP

We had with the surgeon, the specialist, it was quite a long consultation for probably a good hour-and-a-half. My husband and I were in there and had lots of-- I had lots of questions written down. He was very patient and agreed to everything. For me, I think my initial-- I went in there. I think like lots of women do, they say, "Just take my breasts, take both the breasts and take them off."
He, in the nicest possible way didn't say, "No, we're not doing that," but I think he-- I needed more information from him to make a decision that worked for my type of breast cancer, which he did. I felt like he gave me all the options and was quite clear about it, too. Made me feel that why-- Yes, I don't need to remove this part of my body right now. Participant 009_2021AUHRP

Participant describes not taking part in the decision making process

I've done the Google search and I've talked to-- some of the doctors will tell you, others won't tell you much at all, to be honest. That's frustrating. You'll talk to one oncologist, he'll just say, "Just do what I ask you to do," type thing. Then you'll talk to a younger one and they'll give you a more honest approach to things. In my experience, the younger the oncologist you talk to, the more information you'll get and the more cutting-edge stuff they'll look at for you. Whereas the older oncologist just go with the standard, "That's just standard. That's just what we do." Participant 018_2021AUHRP

PARTICIPANT: I pretty much just wanted to know what were the steps that we needed to go through to treat this and it was a case of I had the mastectomy first and then recovered from that. Then we would go through chemotherapy and I would have four doses of, I can't remember the name of it, every three weeks, and then I would have weekly doses of paclitaxel, and I got to week six and I was having some pretty bad side effects, so they gave me a week's break, and then I went back and had week seven. Then they said, "No, we've got to stop because the side effects can become permanent if you don't stop early enough." Then I had to go back and have another surgery to have the lymph nodes removed from my armpit and then once I healed from that, it was a case of the radiation treatment to be starting.

INTERVIEWER: Yes. It was sort of, this is the treatment that you need to have done. There wasn't really like too much options given

PARTICIPANT: I'll couldn't have a lumpectomy because it was in the ducts and it was too big. Participant 025_2021AUHRP

I've got referred initially to a breast surgeon and my treatment changed about three or four times initially, I was having a lumpectomy and I was gonna have radiotherapy, then they cancel that. And they said, or no, we're thinking because they weren't sure if I was equivocal HER2 positive as well as the ER PR positive. If they said, Ah, maybe we can just clip the tumour and give you chemo and then we can just remove the tumour once it's gone and it's all good. And they booked me in for that. And then they said, No, we're cancelling that. Can you come in and see me and then he says, I need to have a mastectomy. It's just everywhere. And you just need to cut the whole thing off. And like really? Participant 041_2021AUHRP

Participant describes being told what to do without discussion

We went just bang, bang, bang. This is what we're doing. We didn't even discuss like a full mastectomy or anything. He just said partial, and I trusted him completely. Participant 027_2021AUHRP

It was definitely not a conversation, more of a this is what we're, this is what we're doing. You know, there was I wasn't really given any options. As far as treatment options, I was basically just told you will be coming in in two days for mastectomy and the lymph nodes. And then when I saw the oncologist, she was like, and we will be starting chemo on this date. And please don't have any more children was basically the conversation. Yeah. Yeah. Participant 033_2021AUHRP

It's just a year ago or so. I said I don't want to have a mastectomy and they were like, "You have to have a mastectomy." That was about it. Then they said, "You can have an immediate reconstruction." I went to a plastic surgeon for that and I said-- The one where they use your stomach to do it and they said, "You can't have that, you're too thin, you have to have the one with your back muscle" which I didn't really want. I feel I didn't want them to cut my nipple and stuff off and they just ignored it and did it anyway. I wouldn't really say there was a lot of discussion really. There was a lot of me saying, I don't want that and a lot of everybody else just ignoring me really. Participant 036_2021AUHRP

Table 4.3: Discussions about treatment (Participation in discussions)

Discussions about treatment (Participation in discussions)	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participant describes taking part in the decision making process (Total)	23	44.23	**11**	**57.89**	8	38.10	**4**	**33.33**	14	48.28	9	39.13	**6**	**31.58**	17	51.52
Participant describes taking part in the decision making process (Multiple options/approaches)	21	40.38	**10**	**52.63**	7	33.33	4	33.33	12	41.38	9	39.13	6	31.58	15	45.45
Participant describes taking part in the decision making process (One option/approach)	2	3.85	1	5.26	1	4.76	0	0.00	2	6.90	0	0.00	0	0.00	2	6.06
Participant describes not taking part in the decision making process (Total)	21	40.38	**5**	**26.32**	10	47.62	6	50.00	11	37.93	10	43.48	9	47.37	12	36.36
Participant describes not taking part in the decision making process (Multiple options/approaches)	17	32.69	**4**	**21.05**	**9**	**42.86**	4	33.33	9	31.03	8	34.78	8	42.11	9	27.27
Participant describes not taking part in the decision making process (One option/approach)	4	7.69	1	5.26	1	4.76	2	16.67	2	6.90	2	8.70	1	5.26	3	9.09
Participant describes being told what to do without discussion (Total)	9	17.31	3	15.79	3	14.29	3	25.00	5	17.24	4	17.39	3	15.79	6	18.18
Participant describes being told what to do without discussion (Multiple options/approaches)	5	9.62	2	10.53	2	9.52	1	8.33	3	10.34	2	8.70	2	10.53	3	9.09
Participant describes being told what to do without discussion (One option/approach)	4	7.69	1	5.26	1	4.76	2	16.67	2	6.90	2	8.70	1	5.26	3	9.09

Discussions about treatment (Participation in discussions)	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participant describes taking part in the decision making process (Total)	23	44.23	5	50.00	8	50.00	10	38.46	4	36.36	19	46.34	7	38.89	16	47.06
Participant describes taking part in the decision making process (Multiple options/approaches)	21	40.38	4	40.00	8	50.00	9	34.62	4	36.36	17	41.46	7	38.89	14	41.18
Participant describes taking part in the decision making process (One option/approach)	2	3.85	1	10.00	0	0.00	1	3.85	0	0.00	2	4.88	0	0.00	2	5.88
Participant describes not taking part in the decision making process (Total)	21	40.38	**2**	**20.00**	7	43.75	12	46.15	5	45.45	16	39.02	6	33.33	15	44.12
Participant describes not taking part in the decision making process (Multiple options/approaches)	17	32.69	**1**	**10.00**	**7**	**43.75**	9	34.62	4	36.36	13	31.71	6	33.33	11	32.35
Participant describes not taking part in the decision making process (One option/approach)	4	7.69	1	10.00	0	0.00	3	11.54	1	9.09	3	7.32	0	0.00	4	11.76
Participant describes being told what to do without discussion (Total)	9	17.31	2	20.00	**1**	**6.25**	6	23.08	2	18.18	7	17.07	3	16.67	6	17.65
Participant describes being told what to do without discussion (Multiple options/approaches)	5	9.62	1	10.00	1	6.25	3	11.54	1	9.09	4	9.76	3	16.67	2	5.88
Participant describes being told what to do without discussion (One option/approach)	4	7.69	1	10.00	0	0.00	3	11.54	1	9.09	3	7.32	0	0.00	4	11.76

Figure 4.2: Discussions about treatment (Participation in discussions)

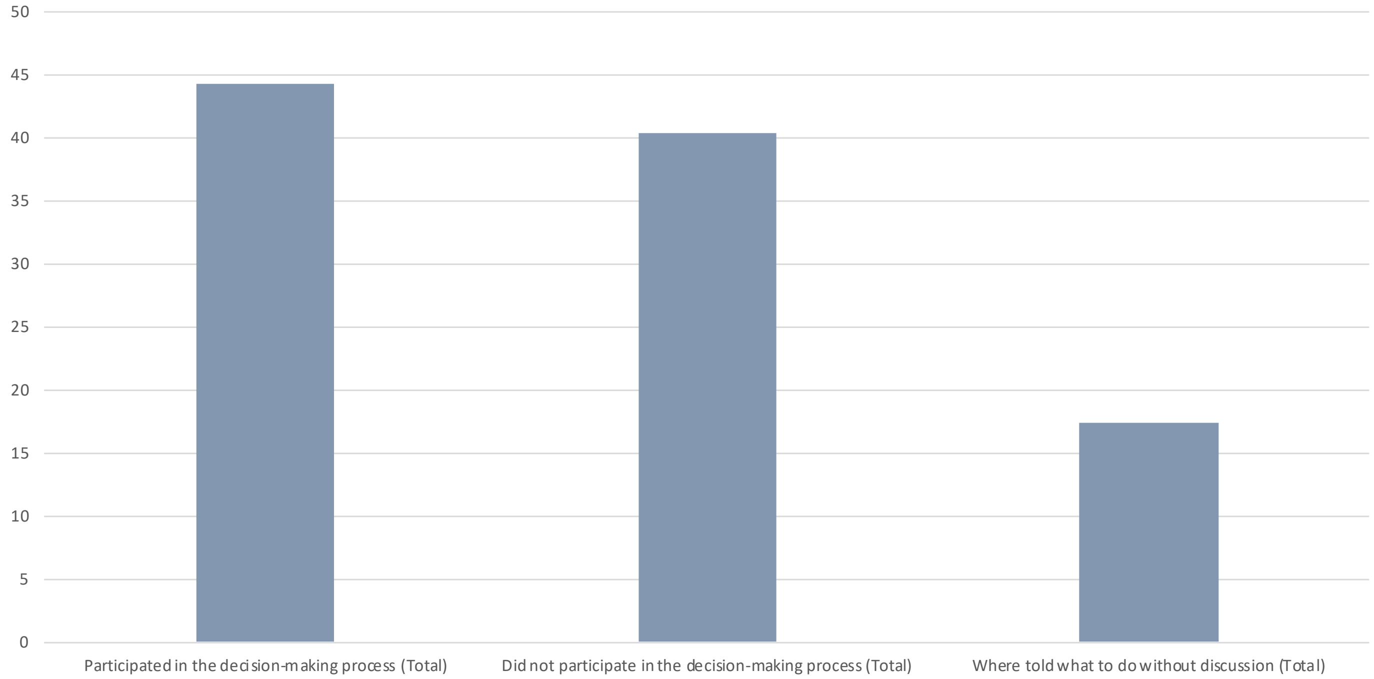


Table 4.4: Discussions about treatment (Participation in discussions) – subgroup variations (percent of all participants)

Discussions about treatment (Participation in discussions)	Reported less frequently	Reported more frequently
Participant describes taking part in the decision making process (total)	Stage III and IV Trade or high school	Stage 0 and I
Participant describes taking part in the decision making process (Multiple options/approaches)	-	Stage 0 and I
Participant describes not taking part in the decision making process (total)	Stage 0 and I Diagnosed in 2016 or before	-
Participant describes not taking part in the decision making process (Multiple options/approaches)	Stage 0 and I Diagnosed in 2016 or before	Stage II Diagnosed in 2017 to 2019
Participant describes being told what to do without discussion (total)	Diagnosed in 2017 to 2019	-

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 side effects into consideration and this was described by 24 participants (46.15%). There were 17 participants (32.69%) described taking efficacy of treatment into account, and 15 participants (28.85%) described taking the advice of their clinician. Other considerations included quality of life (n=9, 17.31%), impact on family and dependents (n=8, 15.38%), survival benefit (n=8, 15.38%), ease of administration (n=7, 13.46%), and the ability to work (n=5, 9.62%).

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

I was a bit concerned about what effect radiation would have on your heart and the side effects of that, but I didn't have any. That was okay. That was the only thing I was more or less worried about. Participant 006_2021AUHRP

So, like side effects and then the short term effects as well as the long term effects there whether it whether the doctor thought it was necessary or not and why. What else? How it was sort of going to affect my lifestyle at the time. And the kind of support I could get to go through that. Treatment I suppose. Participant 020_2021AUHRP

Certainly, what are the benefits of the treatment? How much benefit I'm I likely to get from the treatment? Then on the other hand what are the side effects? The side effects and what they might do to my body. Participant 047_2021AUHRP

Participant describes taking efficacy into account when making decisions about treatment

Well, I guess, first and foremost, it's a risk-benefit assessment. We look at what is the benefit of the treatment in terms of recurrence, et cetera, and, obviously, removal of tumour, for example. Then, in terms of risk, I guess, we look at the acute risks, things *like surgery, et cetera, and then long-term, in particular, things that might catch up with you later. That is stuff like your cardiovascular health and bone densities and things. I guess ease of access is important too. Participant 005_2021AUHRP*

I think, first of all, at this point is, is efficacy. I'm very much guided by my oncologist with that, because I know that he's going to, you know, offer me the the option that's likely to be most effective, and obviously, side effects are a consideration. I fortunately, I'm in the position where I don't have to work if I don't need to, because I've got income protection. And although I'm still working at this point, but very much reduced my hours. So you know that the side effects. I think I would tolerate you know, the efficacy, I would put above the side effects that there was the side effects at this point, because I know that I can just spend full time at home if needed. My kids are all teenagers now and fairly independent. So you know, they don't need me as much and my husband's very supportive. So yeah, I guess I guess they're the they're the main ones. Participant 034_2021AUHRP

Certainly, what are the benefits of the treatment? How much benefit I'm I likely to get from the treatment? Then on the other hand what are the side effects? The side effects and what they might do to my body. Participant 047_2021AUHRP

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

I very much followed my-- I guess what I did is I followed the lead of my specialists. My specialists would recommend the course of action of treatment and then I'd go off and do some research and I pretty much felt comfortable with my team and what they were recommending. Participant 043_2021AUHRP

I just went with the experts. They're doing it all the time. If I need an operation, I've got to have an operation. I've had the lumpectomy and I had some lymph nodes taken out and I just accepted it. They told me I would have to have radiation treatment, so I had four weeks of radiation treatment, just to mop up any escaped cells, because when I was initially diagnosed with breast cancer, they told me I had invasive cancer. Participant 032_2021AUHRP

PARTICIPANT: I think probably the main things, to be honest, is the recommendation of the professionals that I'm seeing. [crosstalk]
INTERVIEWER: Oh, sorry. Go ahead.
PARTICIPANT: I was just happy that I'd found good people that knew a lot more about this than me, and that I trusted their judgment and would follow their advice pretty much. If I wasn't sure about something, I was happy to ask questions, but at the end of the day, "This is your specialty. I'm going to be guided by what you tell me if you think that." Participant 011_2021AUHRP

So, like side effects and then the short term effects as well as the long term effects there whether it whether the doctor thought it was necessary or not and why. What else? How it was sort of going to affect my lifestyle at the time. And the kind of support I could get to go through that. Treatment I suppose. Participant 020_2021AUHRP

Participant describes taking quality of life into account when making decisions about treatment

Well, I guess a lot of it is how it's going to make me feel really. I've had a lot of crises in my life, a lot of grief, and a lot of crises, so I'm very-- for want of a better-- I suppose fragile. I've just got to be really careful of my care. I have no compunction of changing doctors, for example, like the one I just told you. You can't go and see a doctor and come out crying every time, it's ridiculous. Participant 038_2021AUHRP

We talked through them all. And this is supposed to be the one I'm on is supposed to have the least amount of side effects? Yes, I asked the percentage of benefit. Because, you know, I've been told that about chemo, and chemo with 2%. And this medication is less than 4%. Could with considering quality of life with the side effects. But somewhere on the line, he said, and how having had breast cancer have a 50% chance of getting it again, taking this medication only have a 40% chance of getting it again, and I don't know how that works. But I'm just rolling with it. Participant 014_2021AUHRP

Obviously, quality of life. I think that maybe want you to do certain things in life, how much does that have an impact on you in daily living and is it worth it? Because at the moment, I've just started my hormone suppressing therapy. I'm struggling with-- I've just gone back to work and my bones, joint pain, and all that stuff is really impacting on me. I'm in that mindset of really researching a lot at the moment to determine is this really going to help me or is it going to impede on my life so much that I'm not going to enjoy life anymore? Participant 048_2021AUHRP

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

I think more than the impact on myself, my health, and my family, and what the outcomes are likely to be as well. Participant 037_2021AUHRP

Seems really quite obvious for me. That might help my family when a nine year old daughter. So she is first and foremost, she makes her mom. And my husband and her they do for me now helps them, to be honest with you. I remember first and foremost that to be honest with you want to really know what happened. And I'll just admit that it just took hours and hours of thought. This is not happening to me, that probably I never felt sorry for myself, but I just kind of went and I'll be really honest and I'll have to swear in front of you. Participant 002_2021AUHRP

It'll be probably the impact on my day-to-day life. Reason being was when I was due to start radiation treatment, they only gave me well, an afternoon's notice, and they weren't very cooperative at all. I can distinctly remember because my son had broken his big toe and we had to go to the main hospital service and get him fitted with a moon boot. As we were driving home, they rang and said, "Oh look, we need you in LOCATION tomorrow morning at nine o'clock to start your radiation treatment." At that stage it was one o'clock, two o'clock in the afternoon and I just said, "That is not possible. I'm three hours away, I've got three kids to factor in and organize. To give me an afternoon's notice just was terrible." They spoke to their supervisor and said, "Well, can you be here the next day?" They gave me a day then to get myself organized and get to LOCATION. That part of it I was really disappointed with in the sense that they should have really allotted than half a day ahead that I was going to be required to come to LOCATION. Participant 031_2021AUHRP

Participant describes taking the survival benefit into account when making decisions about treatment

Survival. [chuckles] That was pretty much it. Participant 025_2021AUHRP

Just survival rates. I mean I just do whatever is possible to be able to get a good outcome. Participant 046_2021AUHRP

Look, I live alone in Australia, I'm NATIONALITY. I needed something where I, A, felt in control B, that I could still take care of myself. I made decisions with low longevity in mind. I didn't want to alter my physical appearance. I know that sounds vain, but I did not want it to have considered affects me or anything like that. Those were some of my top consideration. Participant 007_2021AUHRP

Participant describes taking the ease of administration into account when making decisions about treatment

Side effects that impacts my life on a daily basis, and how invasive the treatment is, for example, I had my ovaries out because I didn't want to have the Zoladex injection. Participant 027_2021AUHRP

Well, I guess, first and foremost, it's a risk-benefit assessment. We look at what is the benefit of the treatment in terms of recurrence, et cetera, and, obviously, removal of tumour, for example. Then, in terms of risk, I guess, we look at the acute risks, things like surgery, et cetera, and then long-term, in particular, things that might catch up with you later. That is stuff like your cardiovascular health and bone densities and things. I guess ease of access is important too. In many ways, it's why I actually preferred three months of chemo done in the center to what is going to be 5 or 10 years of every month accessing the drugs and then taking it to your GP with an appointment to get injected for a long period of time. Participant 005_2021AUHRP

Well cost firstly, how long it will take? Because I work so that can be tricky doing that balance? Where the where that person is located? So do How far do I have to travel to see them? Their background and reputation and often that's word of mouth, talking to other people about who might have seen them or know of then. Then probably off my head the main things I think about. Participant 013_2021AUHRP

Participant describes taking the ability to work into account when making decisions about treatment

At the time I was working so time off from work. How to integrate whatever treatment I was having into work as well. That was probably the main thing. Participant 050_2021AUHRP

Well cost firstly, how long it will take? Because I work so that can be tricky doing that balance? Where the where that person is located? So do How far do I have to travel to see them? Their background and reputation and often that's word of mouth, talking to other people about who might have seen them or know of then. Then probably off my head the main things I think about. Participant 013_2021AUHRP

I guess, the long-term impacts and also the short-term inconveniences. For example, I've recently made a decision about surgery and my main reasoning for what I chose, was that it's a better longer-term solution and doesn't require follow-up surgeries as much. Long-term is just to me, a much better option. I also made a decision about not having radiotherapy unless it's absolutely necessary because of the inconvenience and also because of the lack of-- I guess because I don't want to be overtreated so the lack of necessity. The radiation oncologist wasn't certain that I would need it. I said, well, I don't want to have it then unless it's actually necessary. I don't want to have it just in case. I want an actual reasons for going through the effort of attending the hospital five days a week for weeks and missing huge amount of work and dealing with more side effects even after I've gone through chemo and surgery and everything else. In the case of that, the logistical side of things was a factor, but also, the side effects. The risk, versus reward. It didn't seem like it's a necessary thing to do especially considering all the side effects that come from it and the inconvenience of it and the loss of income and everything like that. Those are the main factors. The long-term advantages and the short-term inconveniences. Participant 044_2021AUHRP

Table 4.5 Considerations when making decisions

Considerations when making decisions	**All participants**		**Stages 0 and I**		**Stage II**		**Stages III and IV**		**Aged 25 to 54**		**Aged 55 to 74**		**Trade or high school**		**University**	
	n=52	**%**	**n=19**	**%**	**n=21**	**%**	**n=12**	**%**	**n=29**	**%**	**n=23**	**%**	**n=19**	**%**	**n=33**	**%**
Participant describes taking side effects into account when making decisions about treatment (Total)	24	46.15	**13**	**68.42**	9	42.86	**2**	**16.67**	13	44.83	11	47.83	8	42.11	16	48.48
Participant describes taking side effects into account as the only thing that they consider when making decisions about treatment	4	7.69	2	10.53	2	9.52	0	0.00	3	10.34	1	4.35	1	5.26	3	9.09
Participant describes taking side effects into account as part of multiple aspects that they consider when making decisions about treatment	20	38.46	**11**	**57.89**	7	33.33	**2**	**16.67**	10	34.48	10	43.48	7	36.84	13	39.39
Participant describes taking efficacy into account when making decisions about treatment (Total)	17	32.69	7	36.84	6	28.57	4	33.33	9	31.03	8	34.78	5	26.32	12	36.36
Participant describes taking efficacy into account as the only thing that they consider when making decisions about treatment	2	3.85	0	0.00	1	4.76	1	8.33	1	3.45	1	4.35	0	0.00	2	6.06
Participant describes taking efficacy into account as part of multiple aspects that they consider when making decisions about treatment	15	28.85	7	36.84	5	23.81	3	25.00	8	27.59	7	30.43	5	26.32	10	30.30
Participant describes taking the advice of their clinician into account when making decisions about treatment (Total)	15	28.85	5	26.32	6	28.57	4	33.33	7	24.14	8	34.78	7	36.84	8	24.24
Participant describes taking the advice of their clinician into account as the only thing that they consider when making decisions about treatment	8	15.38	2	10.53	2	9.52	**4**	**33.33**	5	17.24	3	13.04	3	15.79	5	15.15
Participant describes taking the advice of their clinician into account as part of multiple aspects that they consider when making decisions about treatment	7	13.46	3	15.79	4	19.05	**0**	**0.00**	2	6.90	5	21.74	4	21.05	3	9.09
Participant describes taking quality of life into account when making decisions about treatment (Total)	9	17.31	4	21.05	3	14.29	2	16.67	4	13.79	5	21.74	**7**	**36.84**	**2**	**6.06**
Participant describes taking quality of life into account as the only thing that they consider when making decisions about treatment	1	1.92	0	0.00	1	4.76	0	0.00	1	3.45	0	0.00	1	5.26	0	0.00
Participant describes taking quality of life into account as part of multiple aspects that they consider when making decisions about treatment	8	15.38	4	21.05	2	9.52	2	16.67	3	10.34	5	21.74	**6**	**31.58**	2	6.06
Participant describes taking the potential impact on their family or dependents into account when making decisions about treatment (Total)	8	15.38	3	15.79	2	9.52	3	25.00	3	10.34	5	21.74	3	15.79	5	15.15
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	2	3.85	0	0.00	0	0.00	**2**	**16.67**	1	3.45	1	4.35	0	0.00	2	6.06
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	6	11.54	3	15.79	2	9.52	1	8.33	2	6.90	4	17.39	3	15.79	3	9.09
Participant describes taking the survival benefit into account when making decisions about treatment (Total)	8	15.38	2	10.53	4	19.05	2	16.67	7	24.14	**1**	**4.35**	2	10.53	6	18.18
Participant describes taking the survival benefit into account as the only thing that they consider when making decisions about treatment	2	3.85	0	0.00	1	4.76	1	8.33	2	6.90	0	0.00	1	5.26	1	3.03
Participant describes taking the survival benefit into account as part of multiple aspects that they consider when making decisions about treatment	6	11.54	2	10.53	3	14.29	1	8.33	5	17.24	1	4.35	1	5.26	5	15.15
Participant describes taking the ease of administration into account when making decisions about treatment (Total)	7	13.46	2	10.53	4	19.05	1	8.33	4	13.79	3	13.04	2	10.53	5	15.15
Participant describes taking ease of administration 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 ease of administration into account as part of multiple aspects that they consider when making decisions about treatment	7	13.46	2	10.53	4	19.05	1	8.33	4	13.79	3	13.04	2	10.53	5	15.15
Participant describes taking the ability to work into account when making decisions about treatment (Total)	5	9.62	3	15.79	2	9.52	0	0.00	2	6.90	3	13.04	1	5.26	4	12.12
Participant describes taking their ability to work into account as the only thing that they consider when making decisions about treatment	4	7.69	3	15.79	1	4.76	0	0.00	1	3.45	3	13.04	1	5.26	3	9.09
Participant describes taking their ability to work into account as part of multiple aspects that they consider when making decisions about treatment	1	1.92	0	0.00	1	4.76	0	0.00	1	3.45	0	0.00	0	0.00	1	3.03

Considerations when making decisions	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participant describes taking side effects into account when making decisions about treatment (Total)	24	46.15	5	50.00	6	37.50	13	50.00	5	45.45	19	46.34	8	44.44	16	47.06
Participant describes taking side effects into account as the only thing that they consider when making decisions about treatment	4	7.69	0	0.00	2	12.50	2	7.69	1	9.09	3	7.32	1	5.56	3	8.82
Participant describes taking side effects into account as part of multiple aspects that they consider when making decisions about treatment	20	38.46	**5**	**50.00**	**4**	**25.00**	11	42.31	4	36.36	16	39.02	7	38.89	13	38.24
Participant describes taking efficacy into account when making decisions about treatment (Total)	17	32.69	4	40.00	4	25.00	9	34.62	3	27.27	14	34.15	7	38.89	10	29.41
Participant describes taking efficacy into account as the only thing that they consider when making decisions about treatment	2	3.85	0	0.00	1	6.25	1	3.85	0	0.00	2	4.88	0	0.00	2	5.88
Participant describes taking efficacy into account as part of multiple aspects that they consider when making decisions about treatment	15	28.85	**4**	**40.00**	**3**	**18.75**	8	30.77	3	27.27	12	29.27	**7**	**38.89**	8	23.53
Participant describes taking the advice of their clinician into account when making decisions about treatment (Total)	15	28.85	**1**	**10.00**	6	37.50	8	30.77	4	36.36	11	26.83	6	33.33	9	26.47
Participant describes taking the advice of their clinician into account as the only thing that they consider when making decisions about treatment	8	15.38	**0**	**0.00**	**5**	**31.25**	3	11.54	2	18.18	6	14.63	3	16.67	5	14.71
Participant describes taking the advice of their clinician into account as part of multiple aspects that they consider when making decisions about treatment	7	13.46	1	10.00	1	6.25	5	19.23	2	18.18	5	12.20	3	16.67	4	11.76
Participant describes taking quality of life into account when making decisions about treatment (Total)	9	17.31	**4**	**40.00**	**1**	**6.25**	4	15.38	2	18.18	7	17.07	4	22.22	5	14.71
Participant describes taking quality of life into account as the only thing that they consider when making decisions about treatment	1	1.92	0	0.00	1	6.25	0	0.00	0	0.00	1	2.44	1	5.56	0	0.00
Participant describes taking quality of life into account as part of multiple aspects that they consider when making decisions about treatment	8	15.38	**4**	**40.00**	**0**	**0.00**	4	15.38	2	18.18	6	14.63	3	16.67	5	14.71
Participant describes taking the potential impact on their family or dependents into account when making decisions about treatment (Total)	8	15.38	**4**	**40.00**	1	6.25	3	11.54	1	9.09	7	17.07	3	16.67	5	14.71
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	2	3.85	0	0.00	0	0.00	2	7.69	0	0.00	2	4.88	0	0.00	2	5.88
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	6	11.54	**4**	**40.00**	1	6.25	1	3.85	1	9.09	5	12.20	3	16.67	3	8.82
Participant describes taking the survival benefit into account when making decisions about treatment (Total)	8	15.38	**3**	**30.00**	2	12.50	3	11.54	1	9.09	7	17.07	3	16.67	5	14.71
Participant describes taking the survival benefit into account as the only thing that they consider when making decisions about treatment	2	3.85	1	10.00	0	0.00	1	3.85	1	9.09	1	2.44	1	5.56	1	2.94
Participant describes taking the survival benefit into account as part of multiple aspects that they consider when making decisions about treatment	6	11.54	2	20.00	2	12.50	2	7.69	**0**	**0.00**	6	14.63	2	11.11	4	11.76
Participant describes taking the ease of administration into account when making decisions about treatment (Total)	7	13.46	1	10.00	2	12.50	4	15.38	2	18.18	5	12.20	2	11.11	5	14.71
Participant describes taking ease of administration 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 ease of administration into account as part of multiple aspects that they consider when making decisions about treatment	7	13.46	1	10.00	2	12.50	4	15.38	2	18.18	5	12.20	2	11.11	5	14.71
Participant describes taking the ability to work into account when making decisions about treatment (Total)	5	9.62	1	10.00	1	6.25	3	11.54	2	18.18	3	7.32	3	16.67	2	5.88
Participant describes taking their ability to work into account as the only thing that they consider when making decisions about treatment	4	7.69	1	10.00	1	6.25	2	7.69	1	9.09	3	7.32	2	11.11	2	5.88
Participant describes taking their ability to work into account as part of multiple aspects that they consider when making decisions about treatment	1	1.92	0	0.00	0	0.00	1	3.85	1	9.09	0	0.00	1	5.56	0	0.00

Figure 4.3 Considerations when making decisions

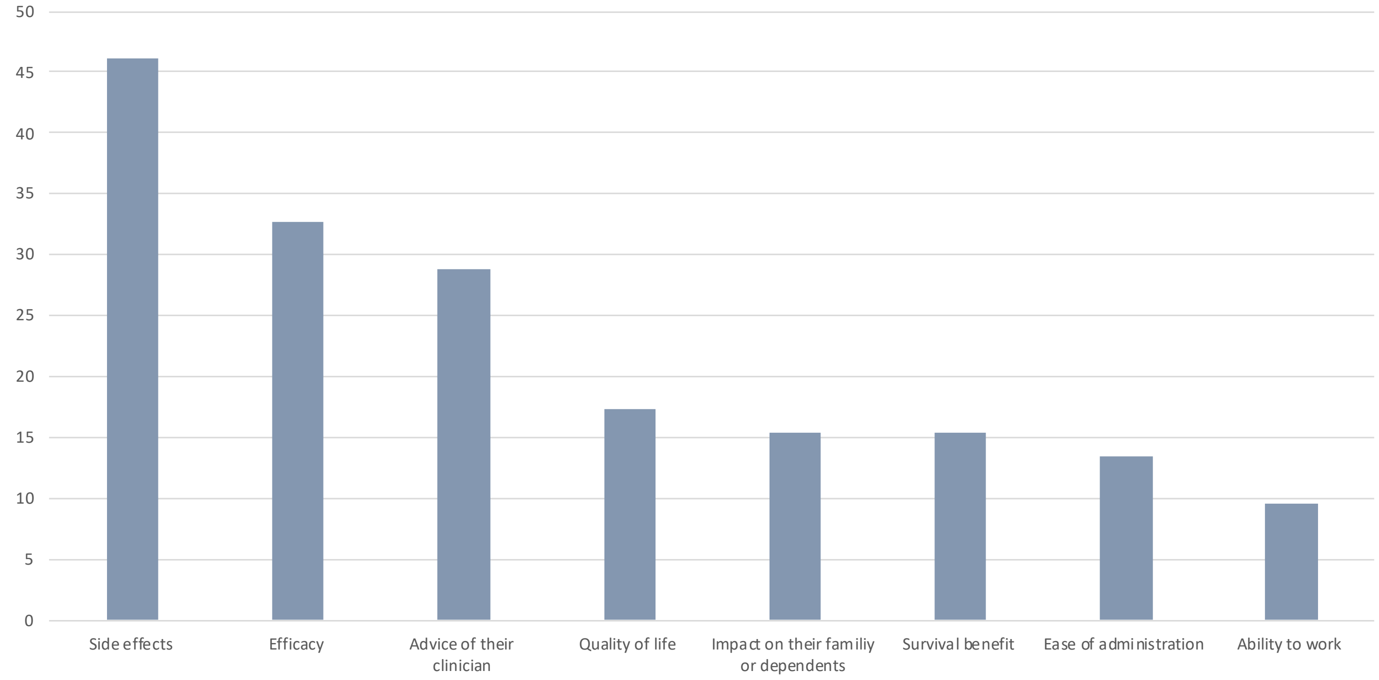


Table 4.6: Considerations when making decisions – subgroup variations (percent of all participants)

Considerations when making decisions	Reported less frequently	Reported more frequently
Participant describes taking side effects into account when making decisions about treatment (Total)	Stage III and IV	Stage 0 and I
Participant describes taking the advice of their clinician into account when making decisions about treatment (Total)	Diagnosed in 2016 or before	-
Participant describes taking quality of life into account when making decisions about treatment (Total)	University Diagnosed in 2017 to 2019	Trade or high school Diagnosed in 2016 or before
Participant describes taking the potential impact on their family or dependents into account when making decisions about treatment (Total)	-	Diagnosed in 2016 or before
Participant describes taking the survival benefit into account when making decisions about treatment (Total)	Aged 55 to 74	Diagnosed in 2016 or before

Decision-making over time

Participants were asked if the way they made decisions had changed over time. There were 27 participants (51.92%) that felt the way they made decisions about treatment had not changed over time, and 25 participants (48.08%) that described decision making changing.

Where participants had not changed their decision making over time, this was this was because they have had always been informed and assertive (n=7, 13.46%), or always taken the advice of clinicians (n=6, 11.54%). Where participants had changed the way they make decisions, it was primarily because they had become more informed or more assertive over time (n=17, 32.69%), or because they were more focused on quality of life or the impact of side effects (n=6, 11.54%).

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

No, I think the same way. I think I'm a pretty common sense sort of person. My husband and I have got a good relationship and we talk about lots of things and we chat about-- Bounce it off each other and see. I think I'm pretty calculated how I make deci-- Yes, I think I'm the same. Participant 009_2021AUHRP

I don't really know at the moment. Sorry. Decision-making's -- I'll put it this way, I generally don't like making very rapid decisions like I had to with this. I'm the sort of the person who likes to go away and think about things for a really long time, so that aspect hasn't changed. Participant 030_2021AUHRP

I think with health-based things, I've always been pretty good with making decisions. I've tried to implement that into my personal and normal life [chuckles] because I'm much more factual and logical about it all. Whereas I've become quite emotional with my personal life so I'm trying to take that really big positive and bring it into [chuckles] the other elements of my life. Participant 042_2021AUHRP

No, it hasn't changed because I am a clinical person myself. It's pretty black and white to me. Participant 027_2021AUHRP

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

I would approach it the same way. I always like to find who's the best at their job and I'll always listen to their advice. When you've got a cancer diagnosis, time is of the essence. You can't sit around thinking about what you're going to do for too long while the cancer is progressing. I was happy that everything was done in a very timely manner. I was incredibly impressed that they were appointments available for people like myself at the surgeon in less than a week. Participant 004_2021AUHRP

No. I think the specialists in that field, they know exactly what is best for you. Participant 006_2021AUHRP

I think that's probably how it's been. I would be guided by colleagues and professionals with the expertise in the areas of the problem. I don't think that's a new thing for me. Participant 011_2021AUHRP

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

I think I'd acknowledge that I'm braver than I thought I was to change the way I do it now. But I'll probably have more confidence in myself now that I know I can do the hard stuff. Participant 002_2021AUHRP

Maybe more to a -- I'm taking it to the Nth Degree now, I'm very, the more information I have, the more comfortable I feel. So yeah, I go and look for information and read medical studies, medical journals, that sort of thing. That's just the way my brain processes it. But I may have become hypervigilant about it. That's about the only thing. Yes, I've taken it to the Nth degree now Participant 003_2021AUHRP

Maybe more to a -- I'm taking it to the Nth Degree now, I'm very, the more information I have, the more comfortable I feel. So yeah, I go and look for information and read medical studies, medical journals, that sort of thing. That's just the way my brain processes it. But I may have become hypervigilant about it. That's about the only thing. Yes, I've taken it to the Nth degree no. Participant 003_2021AUHRP

I want to know more detail. I ask more questions these days. That would be about the only thing that I've changed. I want to know, what's that? Why is that? Yes, so it's to why, what, where, when type questions, yes. Participant 012_2021AUHRP

No, I think it's quite different. You know, it's -- when you come from a position of very little knowledge, you make decisions based on the advice that you get from the people who you feel that you can trust with their knowledge-base, experience, etc.. Excuse me, but I think as time goes on and you've experienced your surgery and by that stage you've gleaned a fair amount of information, you've done quite a bit of reading and research and I think that you become more enquiring, selective about the choices that you make, much more so than in the first instance. Participant 019_2021AUHRP

PARTICIPANT: I'll probably ask more questions now, which drives other medical people mad. [laughs] INTERVIEWER: It's good. You're advocating for yourself, which is great. Yes. Participant 039_2021AUHRP

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

That's a little bit hard to say because I haven't been faced with any major health decisions since the diagnosis. For instance, after going through all the treatment, I sort of think, "Shit, for the quality of life, would I do that again?" The answer is, I don't know. My youngest is 16, so it would depend on if the cancer came back, how old I was, how old my kids were, what the long-term prognosis was going to be. If it was going to be terminal regardless, well then, I'd opt for quality of life rather than longevity. I suppose it has changed in that I'd be a little bit more subjective as to the quality of life, I think. Participant 025_2021AUHRP

Yes, I think so. Yes, I approach them how they're going to make me feel, on all levels, physically, emotionally, and ethically, and morally, how are things going to make me feel. Participant 038_2021AUHRP

I think not the way I make them but maybe why I make them. Yeah. I feel I'm still considered and like all the information. But the side effects more than anything that I have focus on knowing what they can be like. Participant 045_2021AUHRP

Table 4.7: Decision-making over time

Decision-making over time	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participant describes no change in decision-making over time	27	51.92	9	47.37	11	52.38	7	58.33	17	58.62	10	43.48	8	42.11	19	57.58
Participant describes no change in decision-making over time and there is no particular reason noted	13	25.00	5	26.32	7	33.33	**1**	**8.33**	6	20.69	7	30.43	5	26.32	8	24.24
Participant describes no change in decision-making over time as they have always been informed/assertive	7	13.46	1	5.26	2	9.52	**4**	**33.33**	4	13.79	3	13.04	1	5.26	6	18.18
Participant describes no change in decision-making over time as they have always taken advice of clinicians	6	11.54	2	10.53	2	9.52	2	16.67	6	20.69	**0**	**0.00**	2	10.53	4	12.12
Participant describes decision-making changing over time	25	48.08	10	52.63	10	47.62	5	41.67	12	41.38	13	56.52	11	57.89	14	42.42
Participant describes decision-making changing over time as they are more informed and/or more assertive	17	32.69	**9**	**47.37**	6	28.57	**2**	**16.67**	7	24.14	**10**	**43.48**	6	31.58	11	33.33
Participant describes decision-making changing over time as they are more focused on quality of life or impact of side effects	6	11.54	3	15.79	2	9.52	1	8.33	3	10.34	3	13.04	2	10.53	4	12.12

Decision-making over time	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participant describes no change in decision-making over time	27	51.92	**3**	**30.00**	**11**	**68.75**	13	50.00	5	45.45	22	53.66	8	44.44	19	55.88
Participant describes no change in decision-making over time and there is no particular reason noted	13	25.00	2	20.00	3	18.75	8	30.77	**4**	**36.36**	9	21.95	3	16.67	10	29.41
Participant describes no change in decision-making over time as they have always been informed/assertive	7	13.46	1	10.00	3	18.75	3	11.54	1	9.09	6	14.63	3	16.67	4	11.76
Participant describes no change in decision-making over time as they have always taken advice of clinicians	6	11.54	**0**	**0.00**	**4**	**25.00**	2	7.69	**0**	**0.00**	6	14.63	1	5.56	5	14.71
Participant describes decision-making changing over time	25	48.08	**7**	**70.00**	**5**	**31.25**	13	50.00	6	54.55	19	46.34	10	55.56	15	44.12
Participant describes decision-making changing over time as they are more informed and/or more assertive	17	32.69	**5**	**50.00**	**3**	**18.75**	9	34.62	**5**	**45.45**	12	29.27	7	38.89	10	29.41
Participant describes decision-making changing over time as they are more focused on quality of life or impact of side effects	6	11.54	1	10.00	1	6.25	4	15.38	2	18.18	4	9.76	**4**	**22.22**	2	5.88

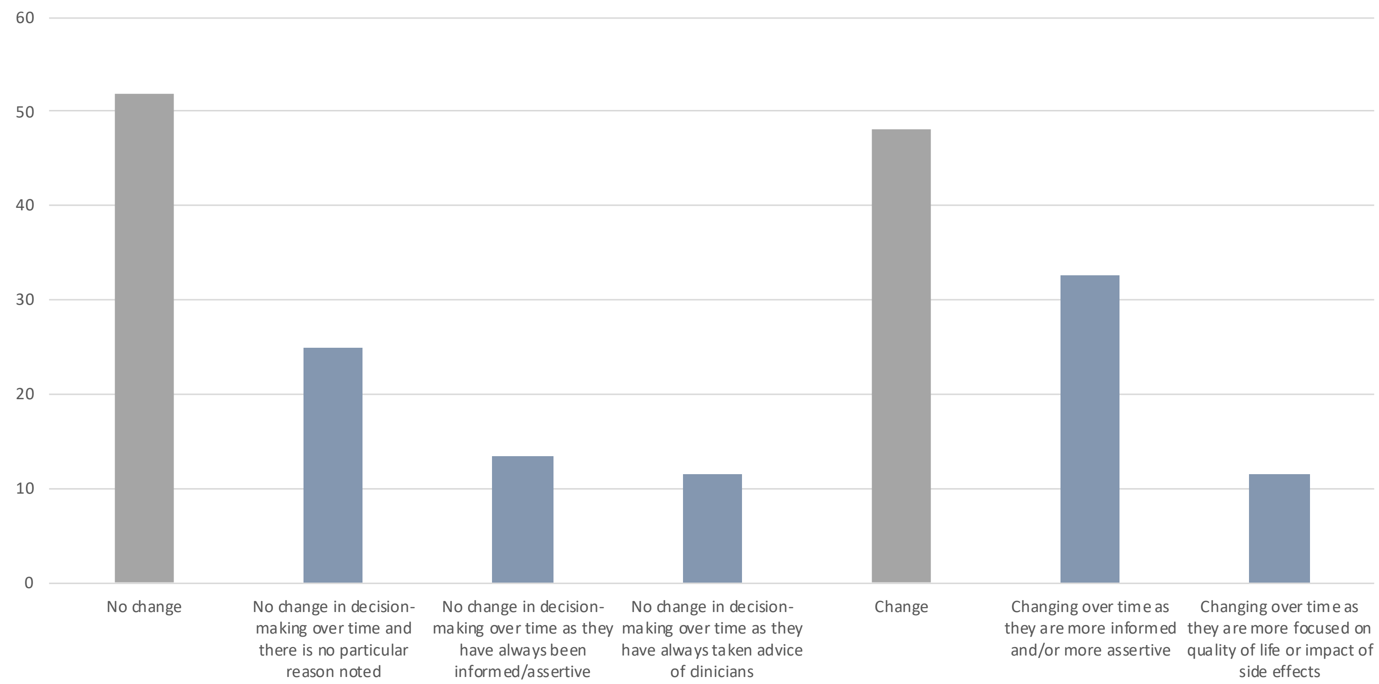


Figure 4.4: Decision-making over time (percent of all participants)

Table 4.8: Decision-making over time – subgroup variations

Decision-making over time	Reported less frequently	Reported more frequently
No change	Diagnosed in 2016 or before	Diagnosed in 2017 to 2019
Participant describes no change in decision-making over time and there is no particular reason noted	Stage III and IV	Regional or remote
Participant describes no change in decision-making over time as they have always been informed/assertive	-	Stage III and IV
Participant describes no change in decision-making over time as they have always taken advice of clinicians	Aged 55 to 74 Diagnosed in 2016 or before Regional or remote	Diagnosed in 2017 to 2019
Participant describes decision-making changing over time	Diagnosed in 2017 to 2019	Diagnosed in 2016 or before
Participant describes decision-making changing over time as they are more informed and/or more assertive	Stage III and IV Diagnosed in 2017 to 2019	Stage 0 and I Aged 55 to 74 Diagnosed in 2016 or before Regional or remote
Participant describes decision-making changing over time as they are more focused on quality of life or impact of side effects	-	Mid to low status

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 or avoid recurrence (n=23, 44.23%), and this was followed by wanting to minimise or control side effects (n=20, 38.46%). Other themes included wanting quality of life or return to normality (n=9, 17.31%), and wanting to see improvements in mental or emotional health (n=5, 9.62%).

Participant describes wanting to be cancer free, avoid recurrence, or increase longevity

In terms of goals, I guess, minimizing long-term problems related to the hormone therapy, so things like osteoporosis are quite concerning because effectively going into menopause at 36 is not great for cardiovascular health and bone density. They're not limiting me now but they'd be something I'm concerned about future-wise, but obviously, recurrence is also a bad thing [chuckles] because that's what weighs it against it, is not wanting to get a recurrence. Participant 005_2021AUHRP

My own personal goal was not to be diagnosed again. Again, I have recovered 100%. If you and I were going to go run, I'd probably win. I've been very, very fortunate to not have the side effects. I do not have to know which chemo I think would have really been the hardest part for me. Radiation was very simple for me. I had some redness. I had an infection, but it was a very simple process. Participant 007_2021AUHRP

Not really. I suppose the ongoing goals of discussions that I've had with my oncologist is to be healthy and be healthier to reduce the chance that it'll come back. Participant 037_2021AUHRP

My main goal was basically to just still be here. I didn't really go beyond that. I didn't think about, whether there was going to be any limitations or any of that sort of stuff. Just basically survival
Participant 050_2021AUHRP

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

My goals are to reduce actually the side effects because I'm still experiencing, which is my lung function, to get my lung function back to normal or as best I can, and the swelling and tenderness in my breast, to reduce that as much as possible. Also, in my left arm to get a full range of movement and strength back in my left arm. Participant 047_2021AUHRP

I guess at the moment because I was diagnosed three and a half years ago and since then I've had three surgeries, which have included ovary removal and hysterectomy reconstruction and stuff like that. I guess at the moment, my goal is to try and find a balance of working in the-- because of the modern aromatase inhibitor, I have pretty much zero estrogens. Just looking to be able to try and find a balance to live with the super surgical menopause that I'm in at the moment. Participant 043_2021AUHRP

My priorities as far as chemo went, I don't want to go through that and have all that poison through my body. I'm natural person, and I don't even like taking Panadol. For me, being told that they'd put all this poison in my body just freaks me out. Chemo was not an option as far as I was concerned. They had really had to talk me into getting radiation because I really didn't want that. They [sound cut] me into it. Sorry, I had the radiation done because I think it's given me more of a chance that I won't get recurring cancer in the same site. From my understanding, that's what the radiation does. It kills all the cancer cells that may be there in the area. Even that, radiation has left me with some legacies that I'm not happy with. It's been a long costly, long process to deal with the side effects of radiation. Participant 035_2021AUHRP

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

I didn't have any goals. I was just, "Let's get this done and I'll do what I've got to do to get through it. Participant 024_2021AUHRP

Up until then I'm fit and well, active, go to the gym regularly, working. Probably not the wisest move, but I had the first surgery on Friday and I was back in the gym on Monday morning, which I think there was a bit of denial. [laughs] this is not going to affect me, I'm free to get on with my life. Then I had to go back for the second surgery and then had some fluid accumulating, which did slow me down and was pretty tough probably for a month or so. Then that finally settled. I had radiotherapy and then since then really life is back to normal. Participant 011_2021AUHRP

I'm very much an accepting person, so my goal was to put my faith into the hands of my surgeon and the team. I just did as I was told, basically, because I don't believe you're fighting something, I believe that you've got to accept it and go with it. That's what I did. Participant 032_2021AUHRP

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

Oh, that's a hard one. It's just to get back on track and to spend more time with the family. It's been difficult anyway, hasn't it? With what's been happening. Participant 015_2021AUHRP

Early on, it just was very to me very clinical straight down the line, not meaning there weren't options, but it was just very matter of fact of the way they came across. They have to be you learn, you know, that that's a bit hard to kind of hear so. But yes, so the surgeon mentioned multiple options, but what he thought would be best given my situation, then definitely the things I wanted out of life or particular procedures that would suit what because I was only 39. So what might suit my lifestyle better as well. So we definitely did have that conversation. Participant 013_2021AUHRP

I just want to be back to normal. I know it sounds silly because that's probably what you get from everybody. I just want to be able to function better. I have terrible memory loss. I'm in constant pain all the time. I get terrible side effects from most of the medications I take. It's just wanting to get back. I'm slowly getting there, but it's just having that normality, the way I look, it's the way I function every day. It's sometimes a hard task. Getting back to even before last year, because as I said to you, I was always incredibly tired and I didn't realize why, and now I obviously know why. Previously, I'd had a lot of energy. I was such a people person, I was very outgoing and now I'm not getting out there as well because I don't like the way that I look, so just having that everyday normal functionality. Participant 008_2021AUHRP

My sexual health is huge. I think that's something I advocate for all the time. It's not about intimate. It's just me feeling like a woman. I didn't want to come out of my surgery being flat-chested. I wanted the reconstruction done through-- some part of it done straight away. I knew there was going to be a lot to lose. My nipples, but then I also understood that they have to go. I think just them hearing my side of it, just to have a little bit of compassion. I'm not just that job for them to do. That I'm a human and that those things are going to change my life dramatically. That was really important to me. That's my body you need to know how I felt about myself and stuff. Participant 048_2021AUHRP

Participant describes wanting to see Improvements in mental or emotional health

Now, there's not a lot of information as to what's going to happen when you come off them. Yeah, when you're young, like you just don't, nobody's able to say, you know, will I get my period back or, you know, will the perimenopausal symptoms disappear? Like, you know, Will I lose the weight that apparently tamoxifen doesn't make you put on but you speak to breast cancer victims they will tell you, it does make you put weight on like, yeah, you know, so will all that come off. It's just all that mental health, both body both questions that, you know, 10 years ago, they didn't have answers to I feel like I have more answers now. Participant 033_2021AUHRP

Well, I've only just gone back to work, that was a big thing. I'm pretty limited. I'm a swimming teacher, so in the water it limited me what I could do while I was going to the radiation and to heal from the surgery. That was a big thing to do that. I'm trying to get-- I like to exercise, but I feel a bit limited of what I can and can't do with my-- But I'm starting tomorrow actually doing some Pilates. I'm going to try something like that, which I hadn't done before because I feel like I want to strengthen my body and just for mind. They were some of my goals. I was a bit, with the hormone treatment, wasn't sure what that was going to do to me and how it's going to make me feel but I do feel like I've got myself in a good fight. I feel pretty good. Participant 009_2021AUHRP

No, my adoptive mother had reoccurrences of fibroadenoma and I always said to her, look, I'd rather have you flat and alive than with boobs and dead. So it was sort of like, I'd be the biggest hypocrite if I turned around and said -- for me it was never a vanity thing. I didn't want, necessarily, to look the way I'd looked before. I mean, it's sort of a weird thing because I'm sort of, 57. I've got grown up children. So for me, it wasn't a case of I need these to be able to function. It was sort of like they're purely decorative at this stage. I have a very understanding husband who had been through his own cancer journey and he goes, I want you alive. And that's the way I think I was sort of going. Look, I hate wearing bras. So I never have to wear a bra again. I also process things with humour a lot. I basically gave my name, gave him a farewell party. It's just the way I cope with horrible things. So to me, yeah it was more an issue of, look, I've just really got a really good life now. I want to be alive to enjoy it. So for me, it was more just about, yes, getting rid of it. And yes, I have other chronic health issues. So to me, another scar wasn't really a problem. I've already got meters and meters of scars all over my body from the rest that I've got. So that wasn't an issue. It's not like my…You're not that shallow. I was like, let's get rid of it. Participant 003_2021AUHRP

Table 4.9: Personal goals of treatment or care

Personal goals of treatment or care	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participant describes wanting to be cancer free, avoid recurrence, or increase longevity	23	44.23	6	31.58	11	52.38	6	50.00	12	41.38	11	47.83	8	42.11	15	45.45
Participant describes wanting to minimise or avoid side effects of treatment or symptoms of their condition	20	38.46	8	42.11	6	28.57	6	50.00	12	41.38	8	34.78	9	47.37	11	33.33
Participant describes wanting to improve quality of life, or return to normality	9	17.31	3	15.79	5	23.81	1	8.33	5	17.24	4	17.39	3	15.79	6	18.18
Participant describes no personal goals of treatment or care (no reason given)	8	15.38	5	26.32	1	4.76	2	16.67	4	13.79	4	17.39	2	10.53	6	18.18
Participant describes wanting to see Improvements in mental or emotional health	5	9.62	0	0.00	4	19.05	1	8.33	3	10.34	2	8.70	1	5.26	4	12.12

Personal goals of treatment or care	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participant describes wanting to be cancer free, avoid recurrence, or increase longevity	23	44.23	5	50.00	5	31.25	13	50.00	7	63.64	16	39.02	8	44.44	15	44.12
Participant describes wanting to minimise or avoid side effects of treatment or symptoms of their condition	20	38.46	5	50.00	4	25.00	11	42.31	5	45.45	15	36.59	6	33.33	14	41.18
Participant describes wanting to improve quality of life, or return to normality	9	17.31	1	10.00	4	25.00	4	15.38	2	18.18	7	17.07	4	22.22	5	14.71
Participant describes no personal goals of treatment or care (no reason given)	8	15.38	0	0.00	3	18.75	5	19.23	1	9.09	7	17.07	2	11.11	6	17.65
Participant describes wanting to see Improvements in mental or emotional health	5	9.62	1	10.00	3	18.75	1	3.85	1	9.09	4	9.76	0	0.00	5	14.71

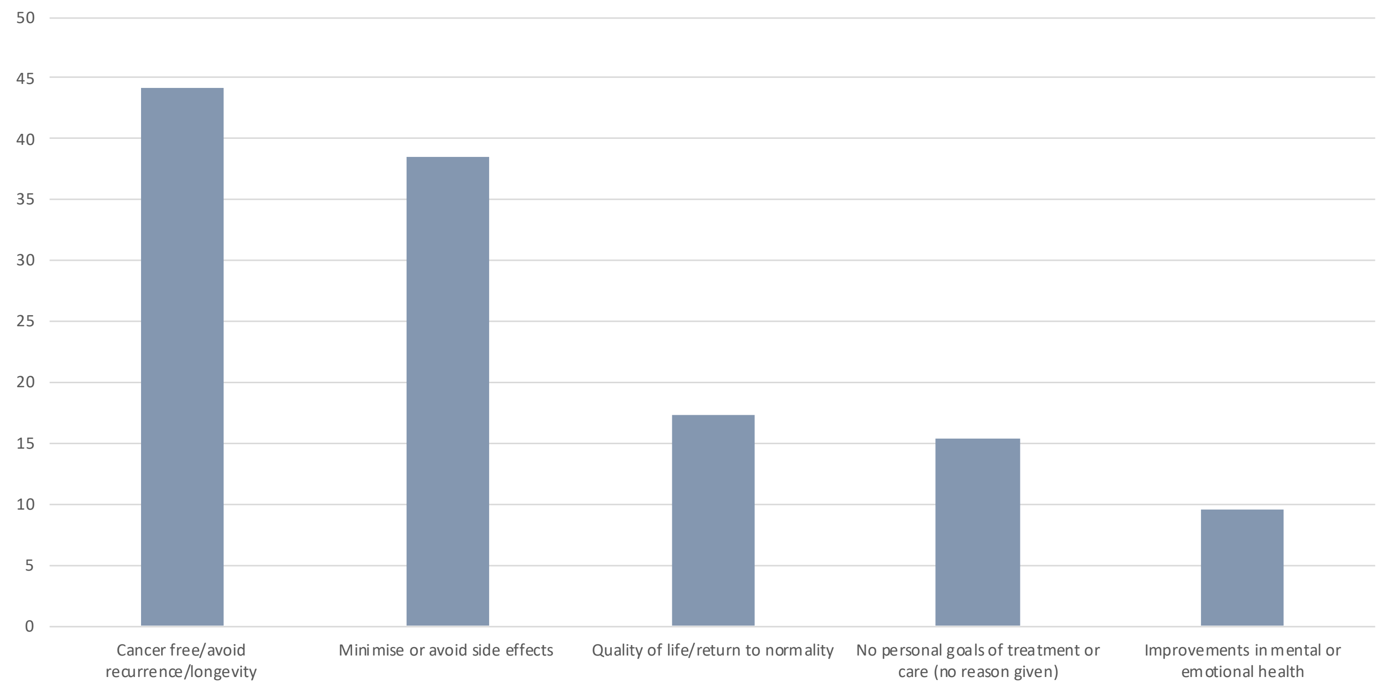


Figure 4.5: Personal goals of treatment or care (percent of all participants)

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

Personal goals of treatment or care	Reported less frequently	Reported more frequently
Participant describes wanting to be cancer free, avoid recurrence, or increase longevity	Stage 0 and I Diagnosed in 2017 to 2019	Regional or remote
Participant describes wanting to minimise or avoid side effects of treatment or symptoms of their condition	Diagnosed in 2017 to 2019	Stage III and IV Diagnosed in 2016 or before
Participant describes no personal goals of treatment or care (no reason given)	Stage II Diagnosed in 2016 or before	Stage 0 and I

Section 5

Treatment

Section 5: Experience of treatment

Main provider of treatment

The most common provider of treatment and care were medical oncologists (n = 26, 50.00 %), followed by specialist surgeons (n = 15, 28.85%).

There were 13 participants (25.49%) that travelled for less than 15 minutes, 23 participants (45.10%) that travelled between 15 and 30 minutes, nine participants (17.65%) that travelled between 30 and 60 minutes, two participants (3.92%) that travelled between 60 and 90 minutes, and four participants (7.84%) that travelled more than 90 minutes.

Access to healthcare professionals

Almost all participants had access to a medical oncologist (n = 49, 94.232%), and a specialist surgeon (n = 49, 94.23%) for the treatment and management of breast cancer. There were 43 participants (82.69%) that had a radiation oncologist, 43 participants (82.69%) that had a general practitioner (GP), and 42 participants (80.77%) had a breast care nurse, and 30 participants (57.69%).

There were 30 participants (57.69%) cared for by a oncology or chemotherapy nurse, 28 participants (53.85%) treated by a physiotherapist and, 25 participants (48.08%) with a pharmacist. Almost half of the participants had a lymphoedema practitioner to care for their condition (n = 24, 46.15%).

Health care system

The majority of participants had private health insurance (n = 41, 80.39%). The majority of participants were not asked if they wanted to be treated as a public or private patient (n = 31, 60.78%), however, they were asked if they had private health insurance (n = 44, 86.27%).

Throughout their treatment, there were 29 participants (56.86%) who were treated as a private patient, 13 participants (25.49%) were mostly treated as a public patient, and there were nine participants (17.65%) who were equally treated as a private and public patient.

Throughout their treatment, there were 25 participants (49.02%) who were treated mostly in the private hospital system, 11 participants (21.57%) were mostly treated in the public system, and there were 15 participants (29.41%) who were equally treated in the private and public systems.

Affordability of healthcare

Almost all the participants never or rarely had to delay or cancel appointments due to affordability (n = 48, 94.12%).

Almost all of the participants never or rarely were unable to fill prescriptions (n = 47, 92.16%).

There were 45 participants (88.24%) that never or rarely had trouble paying for essentials such as such as food, housing and power., and four participants (7.84%) that sometimes found it difficult.

There were 8 participants (15.69%) that paid for additional carers carers for themselves or for their family due to their condition.

Cost of condition

Participants estimated the amount they spend per month due to their condition, including doctors' fees, transport, carers, health insurance gaps and complementary therapies. The most common amount was between \$101 to \$250 (n = 15, 29.41%), followed by between \$251 to \$500 (n = 8, 15.69%). There were four participants (7.84%), who spent \$1001 or more a month.

The amount spent was an extremely significant or moderately significant burden for 12 participants (23.53%), somewhat significant for 12 participants (23.53%), and slightly or not at all significant for 27 participants (52.94%).

Changes to employment status

Work status for 10 participants (19.61%) had not changed since diagnosis, and eight participants (15.69%) were retired or did not have a job. There were eight participants (15.69%) that had to quit their job, 15 participants (29.41%) reduced the number of hours they worked, and three participants (5.88%) that accessed their superannuation early. There were 11 participants (21.57%) that took leave from work without pay, and 10 participants (19.61%) who took leave from work with pay.

Changes to carer/partner employment status

There were 11 participants (21.57%), without a main partner or carer. Most commonly, participants had partners or carers that did not change their work status due to their condition (n = 24, 47.06%). There were four participants (7.84%) whose partners reduced the numbers of hours they worked, and no partners of participants had to quit their job. The partners of two participants (3.92%) took leave without pay, and there were 10 partners (19.61%) who took leave with pay.

Reduced income due to condition

More than half of the participants (n = 27, 52.94%) indicated in the online questionnaire that they had a reduced family income due to their condition.

Most commonly, participants were not sure about the amount their monthly income was reduced by (n = 8, 15.69%), or reduced by between \$1001 to 2500 per month (n = 8, 15.69%).

For nine of these participants (33.33%) (40.74%), the burden of this reduced income was extremely or moderately significant, for 7 participants (25.93%) the burden was somewhat significant, and for seven participants (40.74%), the burden was slightly or not all significant .

Treatments overview

There were 46 participants (88.46%) that had surgery, 48 participants (92.31%) that had drug treatments, and 42 participants (80.77%) that had radiotherapy. The majority of participants had used allied health (n=40, 76.92%), complementary therapies (n=40, 76.92%), and, made lifestyle changes(n=45, 86.54%).

Surgical treatments

There were 46 participants (88.46%) that had surgery for breast cancer. The most common type of surgery was lumpectomy (n=30, 57.69%), followed by mastectomy (n=19 , 36.54%). There were 14 participants (26.92%) that had breast reconstruction, 10 participants (19.23%) had re-excision following lumpectomy, and nine participants (17.31 %) had surgery to remove ovaries.

Drug treatments

There were 48 participants (92.31%) that had drug treatments. The most common types of drug treatments were tamoxifen (n=23, (45.1%), letrozole n=18, (35.29%) and, anastrozole (n=8, 15.69%).

Radiotherapy

There were 40 participants (76.92%) that had radiotherapy to the primary cancer site, and four participants (7.69%) that had radiotherapy to a secondary cancer site.

Allied health

The most common allied health service used was physiotherapy (n = 31, 60.78%), followed by psychology (n = 18, 35.29%), and occupational therapist (n = 7, 13.73%). There were six participants (11.76%) that saw a dietician, and six participants (11.76%) that saw a social worker.

Lifestyle changes

The most common lifestyle change used was exercise (n = 43, 84.31%), followed by diet changes (n = 28, 54.90%), and quit or cut back on alcohol (n = 27, 52.94%)

Complementary therapies

The most common complementary therapies used were supplements (n = 25, 49.02%), and mindfulness or relaxation techniques (n = 25, 49.02%), and massage therapy.

Clinical trials

There was a total of 17 participants (33.33%) that had discussions about clinical trials, 4 participants (7.84%) had brought up the topic with their doctor, and the doctor of 13 participants (25.49%) brought up the topic. The majority of participants had not spoken to anyone about clinical trials (n = 34, 66.67%).

There were seven participants (13.73%) that had taken part in a clinical trial, 32 participants (62.75%) that would like to take part in a clinical trial if there was a suitable one, and 12 participants, who have not participated in a clinical trial and do not want to (23.53%).

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

to describe them with specific examples (n=27, 51.92%). There were 25 participants (48.08%) that described mild side effects as those that do not interfere with daily life, and 19 participants (36.54%) that described mild side effects as those that can be self-managed.

Of those who described a specific side effect, the most commonly described side effects were fatigue (n=7, 13.46%), mild pain or aches (n=6, 11.54%), and hair loss.

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=30, 57.69%). Other descriptions of ‘severe side effects’ included those that impact everyday life/ability to conduct activities of daily living (n=26, 50.00%), those that require medical intervention (n=5, 9.62%).

Of those who described a specific side effect, the most commonly described side effects were pain (n=11, 21.15%), the emotional and mental impact (n=7, 13.46%), those that impact on sleep (n=5, 9.62%), and nausea (n=5, 9.62%).

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 for a specific amount of time (n=20, 38.46%), and as per the advice of their specialist/as long as prescribed (n=19, 36.54%). Other participants described adhering to treatment as long as side effects are tolerable (n=15, 28.85%), and not giving up on any treatment (n=15, 28.85%).

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 (46.15%) was needing to see an improvement in specific symptoms, and this was followed by 19 participants (36.54%) that reported needing to experience an improvement in side effects in general, and needing evidence of stable disease or no disease progression (n= 12, 23.08%). There were 12 participants (23.08%) that described needing to have a balance between benefits and potential side effects, and 11 participants (21.15%), that reported that it was difficult to know if the treatment was working and that they needed evidence.

Where participants need to see improvements in specific side effects, the most noted side effects were aches and pain, and hot flushes.

What it would mean if treatment worked

Participants were asked to describe what it would mean to them, if their treatment worked. The most common response from 25 participants (48.08%) was allowing them to return to everyday activities or return to normal life. Other participants described that it would have a positive impact on their mental health (n=13, 25.00%), that it would allow them to work (n=9, 17.31%), get enough sleep (n=6, 11.54%), and do more exercise (n=5, 9.62%).

Main provider of treatment

Participants were asked in the online questionnaire who was the main healthcare professional that provided treatment and management of their condition.

The most common provider of treatment and care were medical oncologists (n = 26, 50.00 %), followed by specialist surgeons (n = 15, 28.85%) (Table 5.1, Figure 5.1).

Time to travel to main provider of treatment

Participants were asked in the online questionnaire how long they had to travel for to get to their appointments with their main treatment provider.

There were 13 participants (25.49%) that travelled for less than 15 minutes, 23 participants (45.10%) that travelled between 15 and 30 minutes, nine participants (17.65%) that travelled between 30 and 60 minutes, two participants (3.92%) that travelled between 60 and 90 minutes, and four participants (7.84%) that travelled more than 90 minutes (Table 5.2, Figure 5.2).

Table 5.1: Main provider of treatment

Main provider of treatment	Number (n=52)	Percent
Medical oncologist	26	50.00
Specialist surgeon	15	28.85
General practitioner (GP)	10	19.23
Other	3	5.77

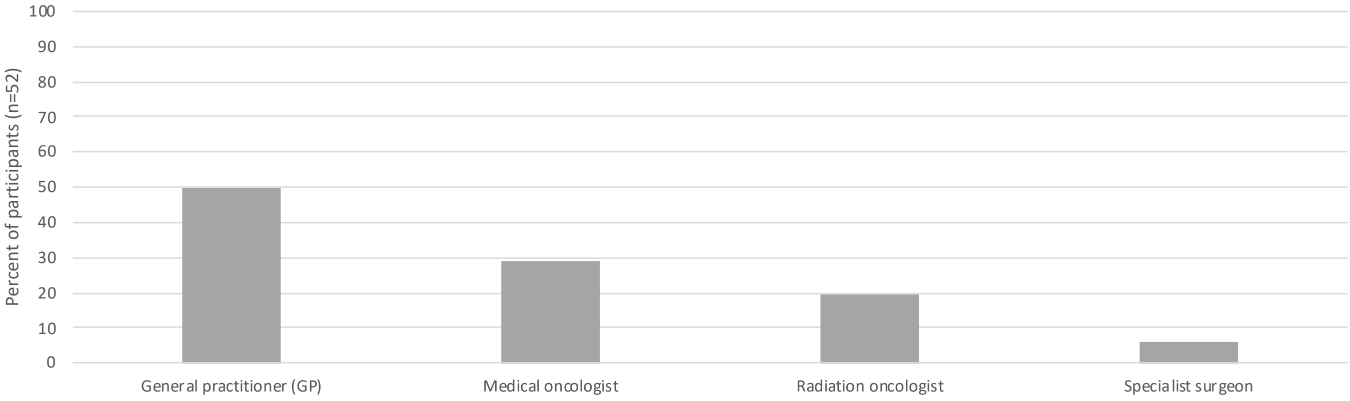


Figure 5.1: Main provider of treatment

Table 5.2: Time to travel to main provider of treatment

Main provider of treatment	Number (n=52)	Percent
Less than 15 minutes	13	25.49
Between 15 and 30 minutes	23	45.10
Between 30 and 60 minutes	9	17.65
Between 60 and 90 minutes	2	3.92
More than 90 minutes	4	7.84
Not applicable	1	

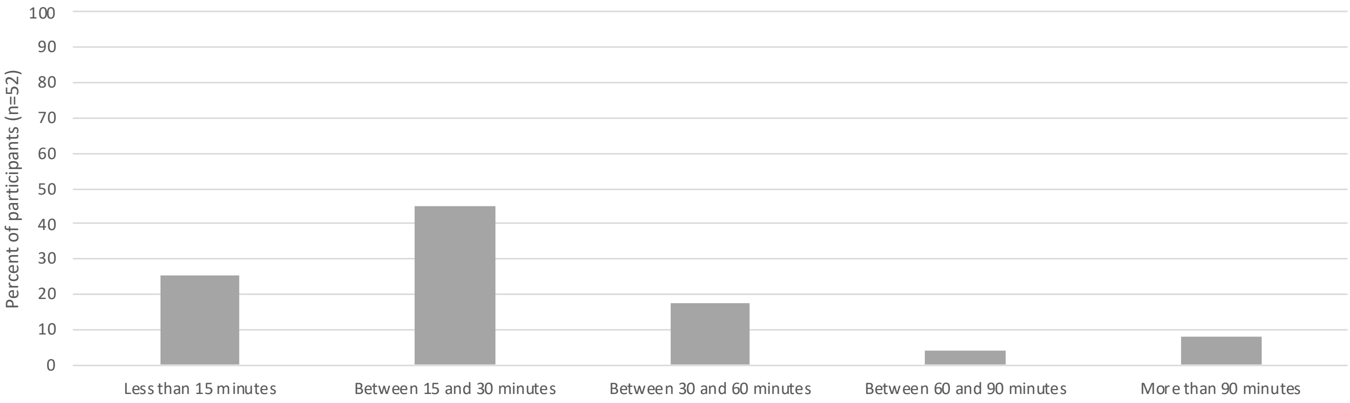


Figure 5.2: Time to travel to main provider of treatment

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 medical oncologist (n = 49, 94.232%), and a specialist surgeon (n = 49, 94.23%) for the treatment and management of breast cancer. There were 43 participants (82.69%) that had a radiation oncologist, 43 participants (82.69%) that had a general practitioner (GP), and 42 participants (80.77%) had a breast care nurse, and 30 participants (57.69%).

There were 30 participants (57.69%) cared for by a oncology or chemotherapy nurse, 28 participants (53.85%) treated by a physiotherapist and, 25 participants (48.08%) with a pharmacist. Almost half of the participants had a lymphoedema practitioner to care for their condition (n = 24, 46.15%). (Table 5.3, Figure 5.3).

Table 5.3: Access to healthcare professionals

Healthcare professional	Number (n=52)	Percent
Medical oncologist	49	94.23
Specialist surgeon	49	94.23
Radiation oncologist	43	82.69
General Practitioner (GP)	43	82.69
Breast care nurse	42	80.77
Oncology/chemotherapy nurse	30	57.69
Physiotherapist	28	53.85
Pharmacist	25	48.08
Lymphoedema practitioner	24	46.15
Genetic Counsellor	18	34.62
Exercise physiologist	17	32.69
Psychologist	17	32.69
Breast cancer care coordinator discharge planner or key worker	14	26.92
Dietitian/nutritionist	9	17.31
Counsellor	8	15.38
Chiropractor	6	11.54
Occupational therapist	4	7.69
Social worker	3	5.77
Osteopath	3	5.77
Social worker	1	1.92
Palliative care specialist	1	1.92
Other	7	13.46

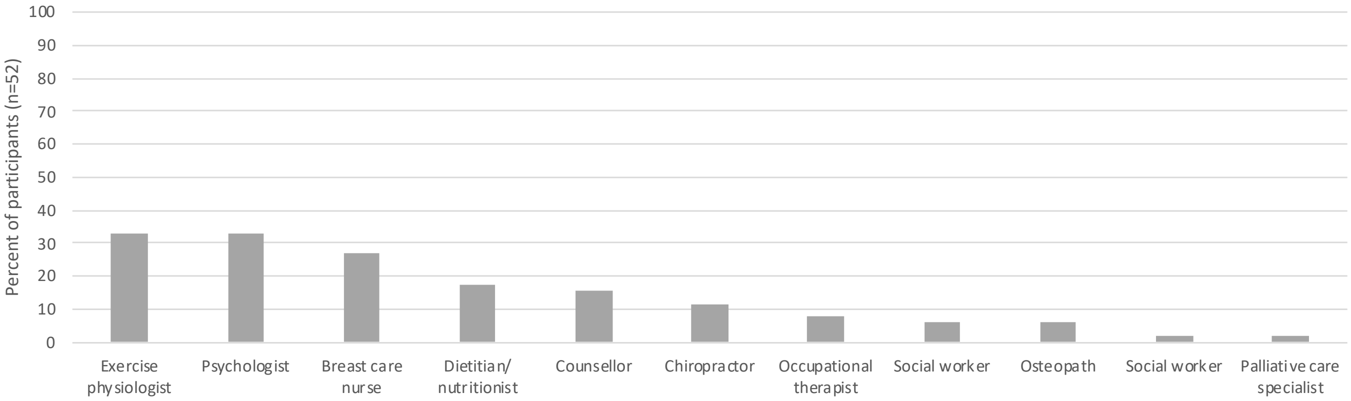


Figure 5.3: Access to healthcare professionals

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 5.4, Figures 5.5 and 5.6).

The majority of participants had private health insurance (n = 41, 80.39%). The majority of participants were not asked if they wanted to be treated as a public or private patient (n = 31, 60.78%), however, they were asked if they had private health insurance (n = 44, 86.27%).

Throughout their treatment, there were 29 participants (56.86%) who were treated as a private patient, 13 participants (25.49%) were mostly treated as a public patient, and there were nine participants (17.65%) who were equally treated as a private and public patient.

Throughout their treatment, there were 25 participants (49.02%) who were treated mostly in the private hospital system, 11 participants (21.57%) were mostly treated in the public system, and there were 15 participants (29.41%) who were equally treated in the private and public systems.

Table 5.4: Health care system

Health care services	Response	Number (n=51)	Percent
Private health insurance	No	10	19.61
	Yes	41	80.39
Asked whether you want to be treated as a public or private patient	No	20	39.22
	Yes	31	60.78
Asked whether you had private health insurance	No	7	13.73
	Yes	44	86.27
Throughout your treatment in hospital, have you most been treated as a public or a private patient	Equally as a public and private patient	9	17.65
	Private patient	29	56.86
	Public patient	13	25.49
Which hospital system have you primarily been treated in	Both public and private	15	29.41
	Private	25	49.02
	Public patient	11	21.57

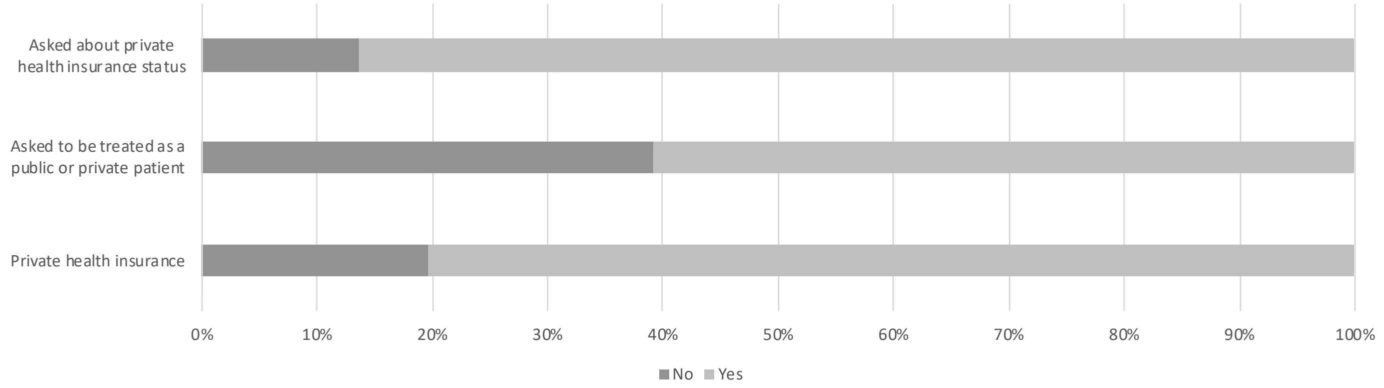


Figure 5.4: Health insurance

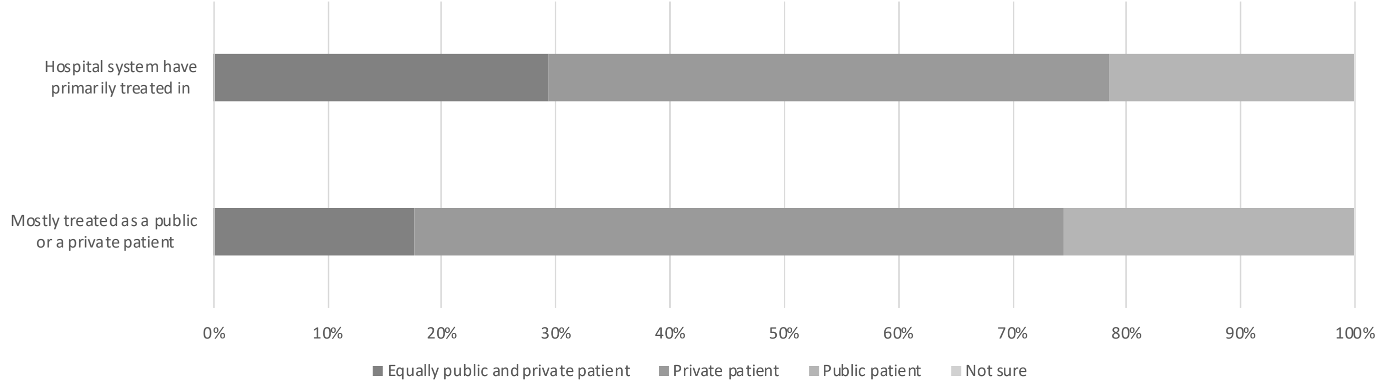


Figure 5.5: Hospital system

Affordability of healthcare

Participants were asked a series of questions about affordability of healthcare in the online questionnaire (Table 5.5, Figure 5.6).

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 = 48, 94.12%).

The next question was about the ability to fill prescriptions. Almost all of the participants never or rarely were unable to fill prescriptions (n = 47, 92.16%).

The third question was about the affordability of basic essentials such as such as food, housing and power. There were 45 participants (88.24%) that never or rarely had trouble paying for essentials, and four participants (7.84%) that sometimes found it difficult.

The final question was about paying for additional carers for themselves or for their family, there were 8 participants (15.69%) that paid for additional carers due to their condition.

Table 5.5: Affordability of healthcare

Affordability of healthcare	Response	Number (n=51)	Percent
Delay or cancel healthcare appointments due to affordability	Never	44	86.27
	Rarely	4	7.84
	Sometimes	1	1.96
	Often	1	1.96
	Very often	1	1.96
Did not fill prescriptions due to cost	Never	46	90.20
	Rarely	1	1.96
	Sometimes	4	7.84
	Often	0	0.00
	Very often	0	0.00
Difficult to pay for basic essentials	Never	35	68.63
	Rarely	10	19.61
	Sometimes	4	7.84
	Often	1	1.96
	Very often	1	1.96
Pay for additional carers for self or family	Yes	8	15.69
	No	43	84.31

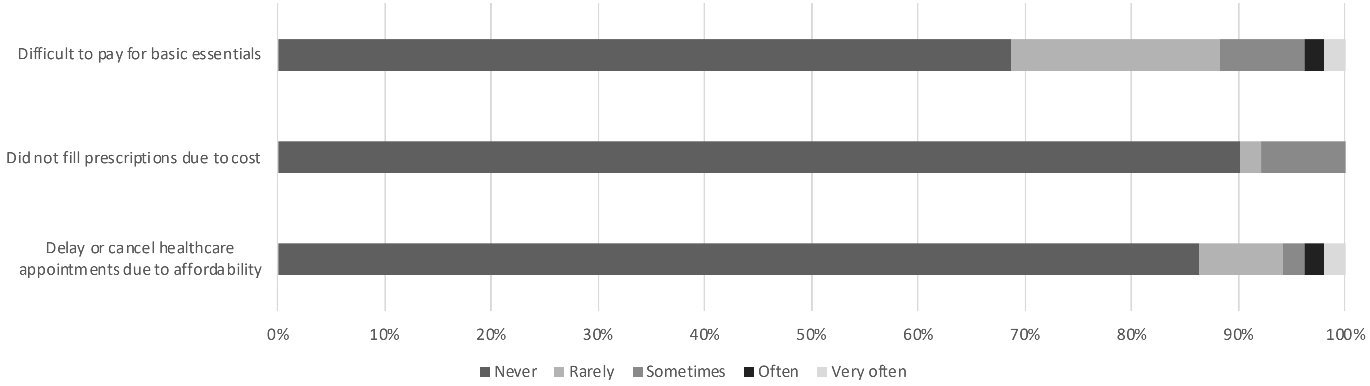


Figure 5.6: Affordability of healthcare

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 listed below (Table 5.6, Figure 5.7).

The most common amount was between $101 to $250 (n = 15, 29.41%), followed by between $251 to $500 (n = 8, 15.69%). There were four participants (7.84%), who spent $1001 or more a month.

Burden of cost

As a follow up question, for participants who had monthly expenses due to their condition, participants were asked if the amount spent was a burden (Table 5.7, Figure 5.8).

The amount spent was an extremely significant or moderately significant burden for 12 participants (23.53%), somewhat significant for 12 participants (23.53%), and slightly or not at all significant for 27 participants (52.94%).

Table 5.6: Estimated monthly out of pocket expenses due to condition

Estimated monthly out of pocket expenses	Number (n=51)	Percent
$0	3	5.88
$100 or less	7	13.73
$101 to $250	15	29.41
$251 to $500	8	15.69
$501 to $1000	4	7.84
$1001 or more	4	7.84
Not sure of amount	10	19.61

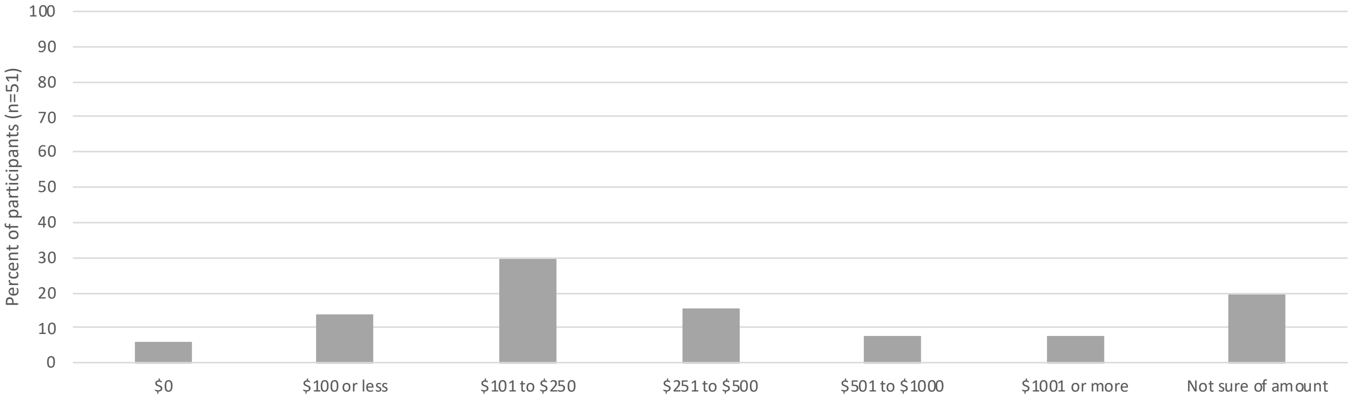


Figure 5.7: Estimated monthly out of pocket expenses due to condition

Table 5.7: Burden of out-of-pocket expenses due to condition

Burden of out of pocket expenses	Number (n=51)	Percent
Extremely significant	4	7.84
Moderately significant	8	15.69
Somewhat significant	12	23.53
Slightly significant	16	31.37
Not at all significant	11	21.57

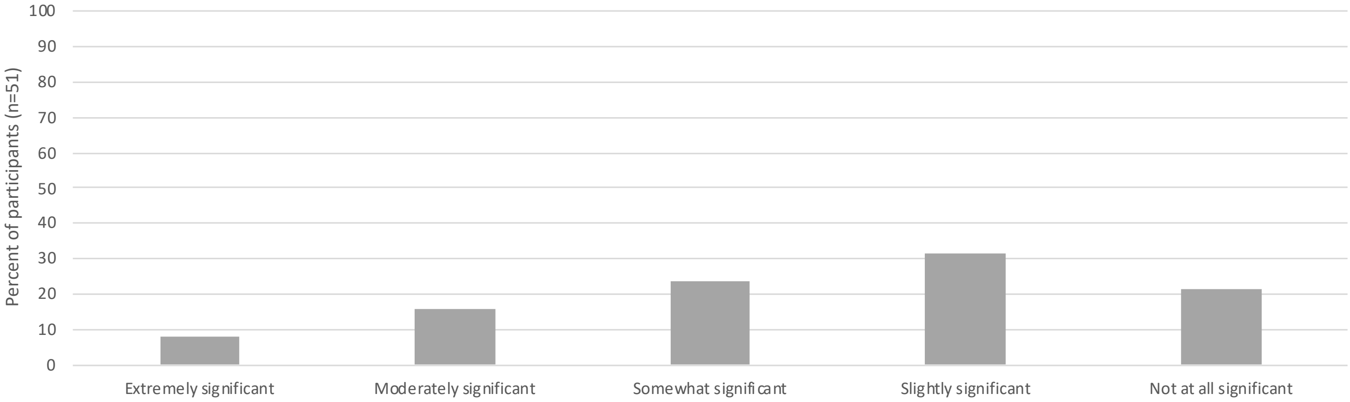


Figure 5.8: Burden of out-of-pocket expenses due to condition

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 5.8, Figure 5.9).

Work status for 10 participants (19.61%) had not changed since diagnosis, and eight participants (15.69%) were retired or did not have a job. There were eight participants (15.69%) that had to quit their job, 15 participants (29.41%) reduced the number of hours they worked, and three participants (5.88%) that accessed their superannuation early. There were 11 participants (21.57%) that took leave from work without pay, and 10 participants (19.61%) who 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 5.9, Figure 5.10).

There were 11 participants (21.57%), without a main partner or carer. Most commonly, participants had partners or carers that did not change their work status due to their condition (n = 24, 47.06%). There were four participants (7.84%) whose partners reduced the numbers of hours they worked, and no partners of participants had to quit their job. The partners of two participants (3.92%) took leave without pay, and there were 10 partners (19.61%) who took leave with pay.

Table 5.8: Changes to employment status

Changes in work status due to condition	Number (n=51)	Percent
Work status has not changed	10	19.61
Retired or did not have a job	8	15.69
Had to quit job	8	15.69
Reduced number of hours worked	15	29.41
Leave from work without pay	11	21.57
Leave from work with pay	10	19.61
Accessed Superannuation early due to condition	3	5.88

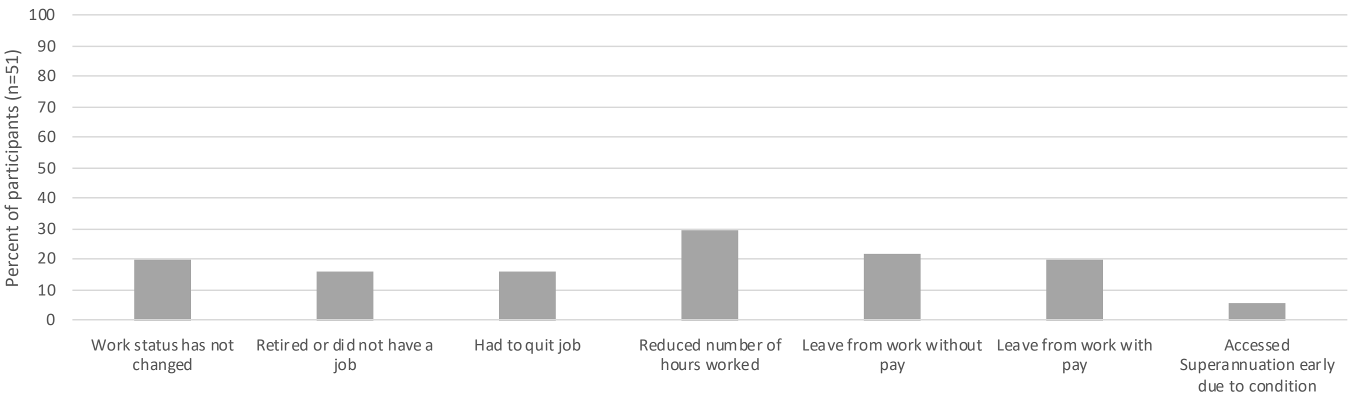


Figure 5.9: Changes to employment status

Table 5.9: Changes to carer/partner employment status

Changes to care/partner employment status	Number (n=51)	Percent
Does not have a partner/main carer	11	21.57
Work status has not changed	24	47.06
Retired or did not have a job	2	3.92
Had to quit job	0	0.00
Reduced number of hours worked	4	7.84
Leave from work without pay	2	3.92
Leave from work with pay	10	19.61

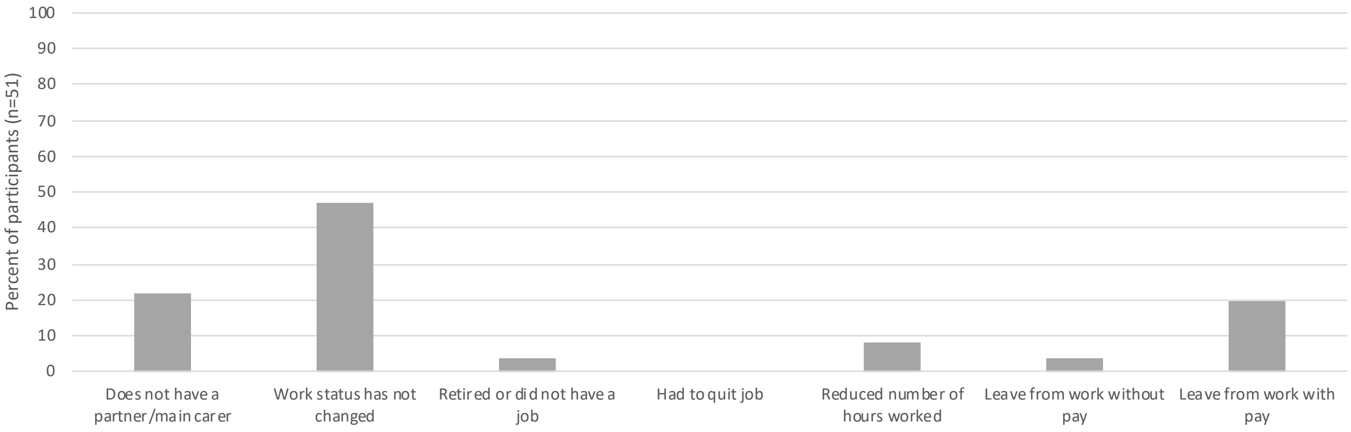


Figure 5.10: Changes to carer/partner employment status

Reduced income due to condition

More than half of the participants (n = 27, 52.94%) 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 listed below (Table 5.10, Figure 5.11).

Most commonly, participants were not sure about the amount their monthly income was reduced by (n = 8, 15.69%), or reduced by between $1001 to 2500 per month (n = 8, 15.69%).

Burden of reduced income

Participants were then asked if this reduced family or household income was a burden. (Table 5.11, Figure 5.12).

For nine of these participants (33.33%) (40.74%), the burden of this reduced income was extremely or moderately significant, for 7 participants (25.93%) the burden was somewhat significant, and for seven participants (40.74%), the burden was slightly or not all significant .

Table 5.10: Estimated monthly loss of income

Estimated monthly loss of income	Number (n=51)	Percent
$0	24	47.06
Less than $1000	3	5.88
$1001 to 2500	8	15.69
$2501 to 5000	8	15.69
More than $5000	2	3.92
Not sure/not specified	6	11.76

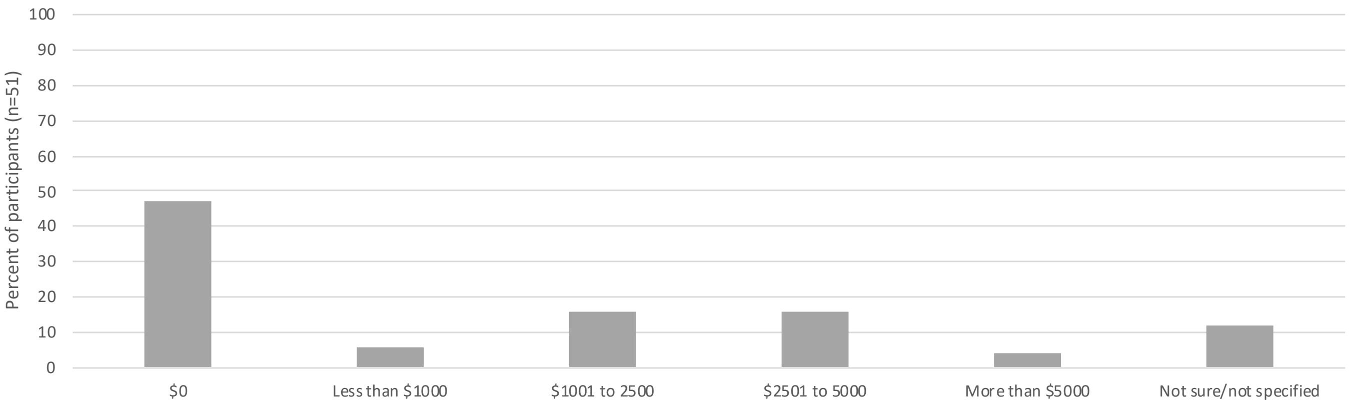


Figure 5.11: Estimated monthly loss of income

Table 5.11: Burden of reduced income

Burden of reduced income	Number (n=27)	Percent
Extremely significant	3	11.11
Moderately significant	6	22.22
Somewhat significant	7	25.93
Slightly significant	9	33.33
Not at all significant	2	7.41

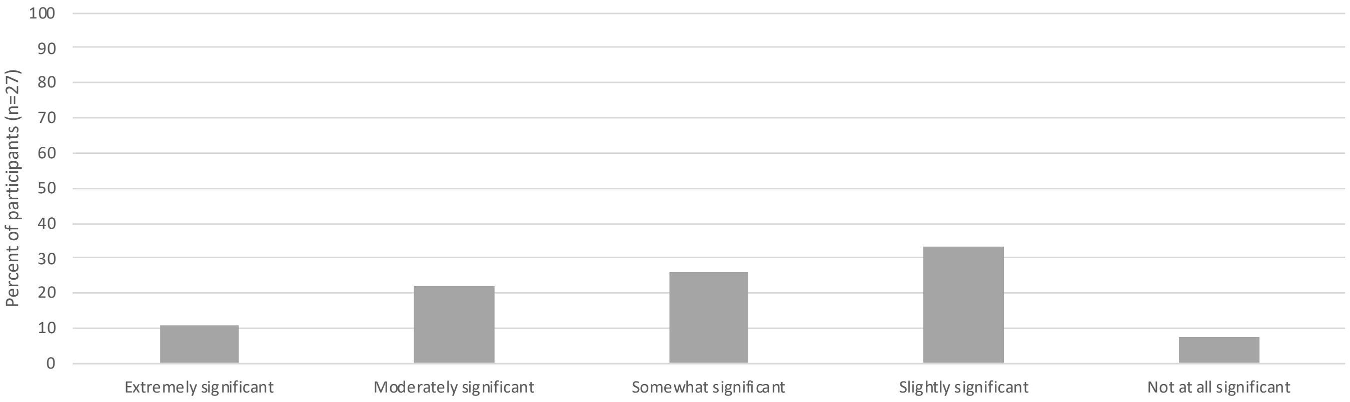


Figure 5.12: Burden of reduced income

Treatments overview

Participants noted in the online questionnaire the different treatments, allied health services, complementary therapies, and lifestyle changes they had since diagnosis with their condition (Table 5.12, Figure 5.13).

There were 46 participants (88.46%) that had surgery, 48 participants (92.31%) that had drug treatments, and 42 participants (80.77%) that had radiotherapy. The majority of participants had used allied health (n=40, 76.92%), complementary therapies (n=40, 76.92%), and, made lifestyle changes(n=45, 86.54%).

Table 5.12: Treatments overview

Treatments overview	Number (n=52)	Percent
No treatment	1	1.92
Surgery	46	88.46
Drug treatments	48	92.31
Radiotherapy	42	80.77
Allied health	40	76.92
Complementary therapies	40	76.92
Lifestyle Changes	45	86.54

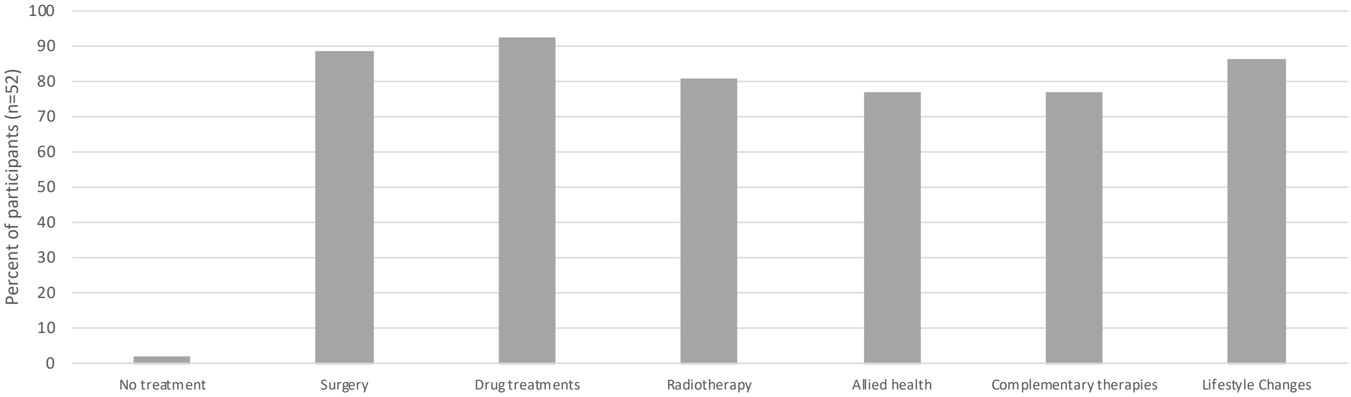


Figure 5.13: Treatments overview

Summary of surgery

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

There were 46 participants (88.46%) that had surgery for breast cancer (excluding biopsies). There were 17 participants (32.69%) that had one operation, 12 participants (23.08%) that had two operations, eight participants (15.38%) that had three operations, and nine participants (17.31%) that had four or more operations (Table 5.13, Figure 5.14).

Table 5.13: Number of surgeries

Number of operations (excluding biopsy)	Number (n=52)	Percent
0	6	11.54
1	17	32.69
2	12	23.08
3	8	15.38
4 or more	9	17.31

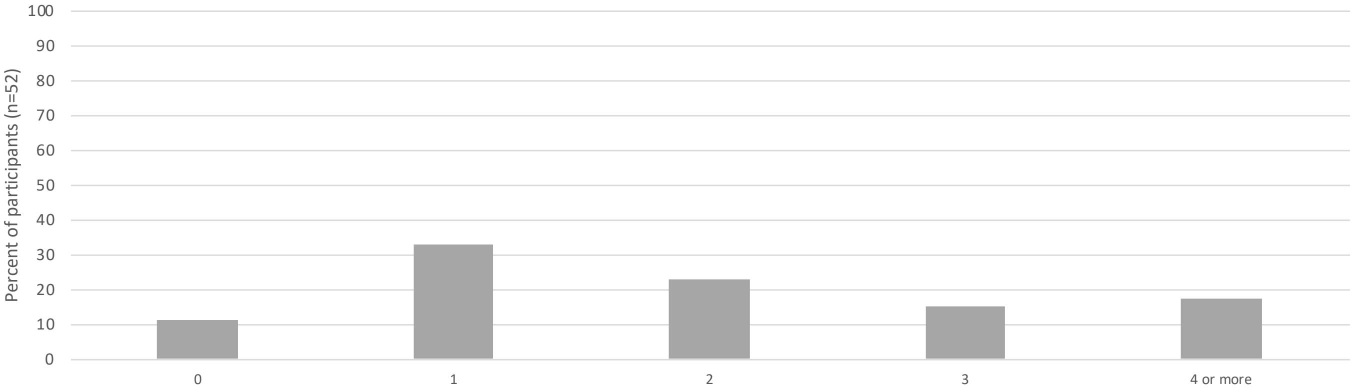


Figure 5.14: Number of surgeries

Surgical treatments

Participants completed a series of questions about surgery, including type of surgery, quality of life, effectiveness of surgery, and side effects. A summary of the surgery, quality of life and effectiveness is presented in Table 5.14.

There were 46 participants (88.46%) that had surgery for breast cancer. The most common type of surgery was lumpectomy (n=30, 57.69%), followed by mastectomy (n=19 , 36.54%). There were 14 participants (26.92%) that had breast reconstruction, 10 participants (19.23%) had re-excision following lumpectomy, and nine participants (17.31 %) had surgery to remove ovaries (Figure 5.15).

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 4.00 to 5.00, in the life was average to life was good range (Figure 5.16).The median effectiveness of all surgery was between 4.00 and 5.00, in the effective to very effective range (Figure 5.17).

On average, quality of life from lumpectomy was in the 'life was average' range (median = 4.00, IQR = 1.00), and was found to be effective to very effective (median = 4.50, IQR = 1.00).

On average, quality of life from re-excision following lumpectomy was in the 'life was a little distressing' range (median = 3.00, IQR = 1.50), and was found to be effective (median = 4.00, IQR = 0.00).

On average, quality of life from mastectomy was in the 'life was a little distressing' range (median = 3.00, IQR = 2.50), and was found to be effective (median = 4.00, IQR = 1.00).

On average, quality of life from breast reconstruction was in the 'life was distressing to a little distressing' range (median = 2.50, IQR = 1.75), and was found to be effective (median = 4.00, IQR = 1.75).

On average, quality of life from surgery to remove ovaries was in the 'life was average' range (median = 4.00, IQR = 0.00), and was found to be very effective (median = 5.00, IQR = 1.00).

Table 5.14 Summary of surgeries

Surgery		Lumpectomy		Re-excision following lumpectomy		Mastectomy		Breast reconstruction		Surgery to remove ovaries	
		n=30	%	n=10	%	n=19	%	n=14	%	n=9	%
Number (n=52)		30	57.69	10	19.23	19	36.54	14	26.92	9	17.31
Year of surgery	2020 to 2021	17	56.67	3	30.00	6	31.58	7	50.00	3	33.33
	2017 to 2019	9	30.00	5	50.00	10	52.63	5	35.71	4	44.44
	2016 or before	4	13.33	2	20.00	3	15.79	2	14.29	2	22.22
Side effects	I didn't experience any side effects	5	16.67	2	20.00	4	21.05	2	14.29	2	22.22
	Cough	0	0.00	0	0.00	1	5.26	0	0.00	0	0.00
	Feeling generally unwell	3	10.00	2	20.00	5	26.32	2	14.29	1	11.11
	Feeling hot and cold	2	6.67	1	10.00	2	10.53	1	7.14	1	11.11
	Feeling sick	4	13.33	2	20.00	3	15.79	1	7.14	1	11.11
	Pain	18	60.00	6	60.00	13	68.42	8	57.14	5	55.56
	Shivering	1	3.33		0.00	1	5.26	0	0.00	1	11.11
	Swelling or redness around your wound	15	50.00	6	60.00	8	42.11	4	28.57	0	0.00
	Other	5	16.67	2	20.00	3	15.79	5	35.71	0	0.00
		Median	IQR	Median	IQR	Median	IQR	Median	IQR	Median	IQR
Quality of life		4.00	1.00	3.00	1.50	3.00	2.50	2.50	1.75	4.00	0.00
Effectiveness		4.50	1.00	4.00	0.00	4.00	1.00	4.00	1.75	5.00	1.00

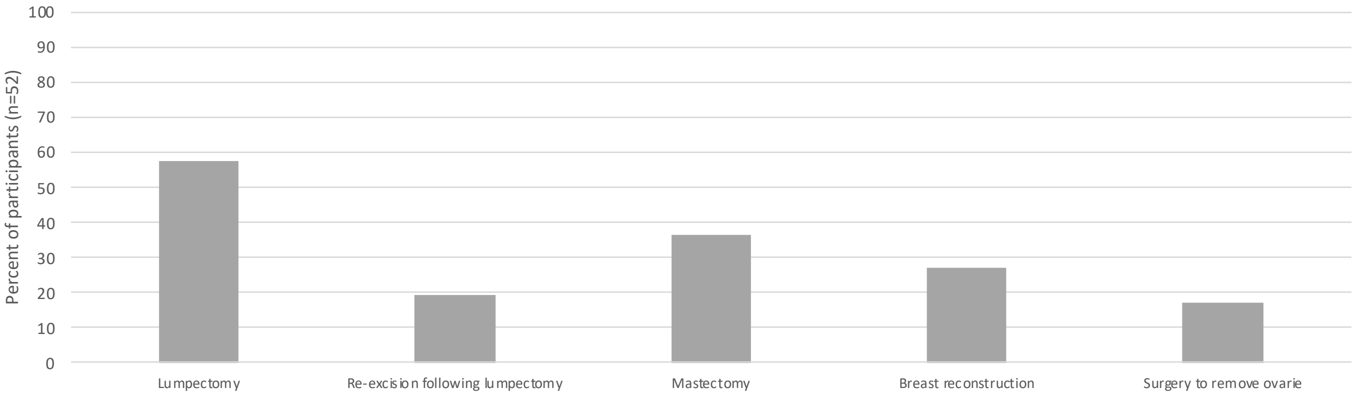


Figure 5.15: Summary of surgeries

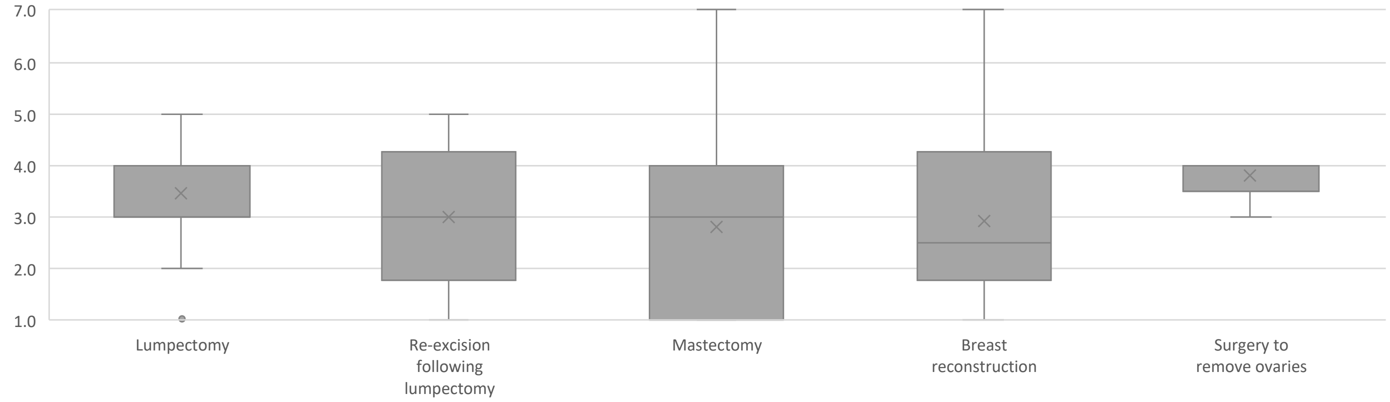


Figure 5.16: Quality of life from surgery

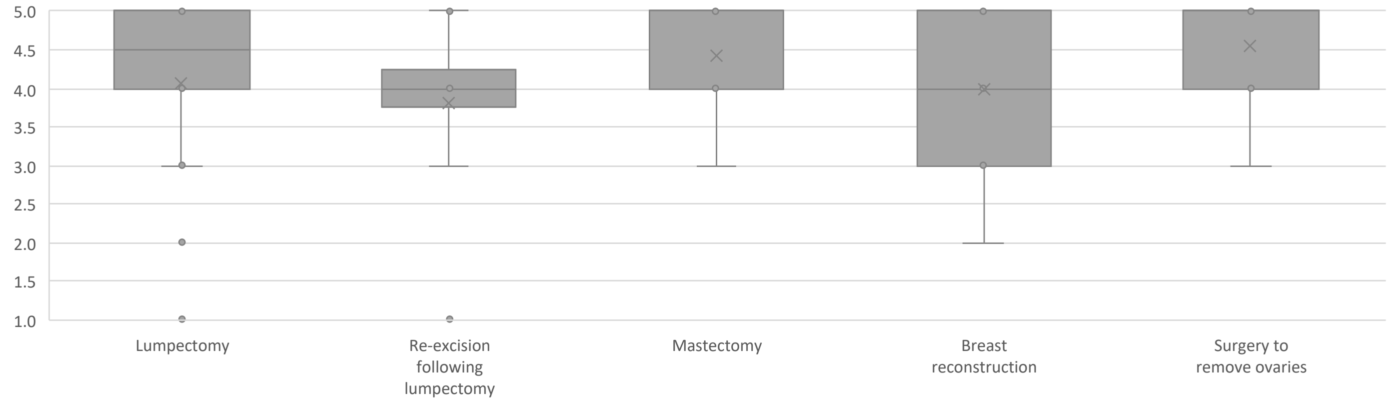


Figure 5.17: Effectiveness of surgery

Summary of drug treatments

Participants completed a series of questions about surgery, including type of surgery, quality of life, effectiveness of surgery, and side effects. A summary of the surgery, quality of life and effectiveness is presented in Table 5.15, and more detailed information including side effects is given in Table 5.16.

There were 48 participants (92.31%) that had drug treatments. The most common types of drug treatments were tamoxifen (n=23, (45.1%), letrozole n=18, (35.29%) and, anastrozole (n=8, 15.69%) (Figure 5.18).

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” (Figure 5.19). Effectiveness of treatment was rated on a five-point scale where one is ineffective, and five is very effective (Figure 5.20). Values are calculated where there was adequate data available (five or more participants).

Median quality of life from treatments ranged from 3.00 to 4.00, in the life was a little distressing to average range. Median effectiveness from treatments ranged from 3.00 to 5.00 in the moderately effective to very effective range.

On average, quality of life from tamoxifen was in the 'life was a little distressing' range (median = 3.00, IQR = 2.00), and was found to be effective (median = 4.00, IQR = 1.00).

On average, quality of life from letrozole was in the 'life was average' range (median = 4.00, IQR = 3.00), and was found to be effective (median = 4.00, IQR = 1.00).

On average, quality of life from anastrozole was in the 'life was average' range (median = 4.00, IQR = 1.50), and was found to be effective (median = 4.00, IQR = 0.00).

On average, quality of life from fluorouracil, epirubicin, cyclophosphamide and docetaxel was in the 'life was a little distressing' range (median = 3.00, IQR = 0.75), and was found to be effective (median = 4.00, IQR = 0.00).

On average, quality of life from doxorubicin, cyclophosphamide, and paclitaxel was in the 'life was a little distressing' range (median = 3.00, IQR = 0.00), and was found to be very effective (median = 5.00, IQR = 1.00).

On average, quality of life from exemestane was in the 'life was average' range (median = 4.00, IQR = 3.00), and was found to be moderately effective (median = 3.00, IQR = 2.50).

On average, quality of life from paclitaxel was in the 'life was average' range (median = 4.00, IQR = 1.00), and was found to be effective to very effective (median = 4.50, IQR = 1.25).

Table 5.15: Summary of drug treatments

Drug treatments	Number (n=52)	Percent	Median quality of life	IQR	Median effectiveness	IQR
Tamoxifen	23	45.10	3.00	2.00	4.00	1.00
Letrozole	18	35.29	4.00	3.00	4.00	1.00
Anastrozole	8	15.69	4.00	1.50	4.00	0.00
Fluorouracil, epirubicin, cyclophosphamide and docetaxel	7	13.73	3.00	0.75	4.00	0.00
Doxorubicin and cyclophosphamide, and paclitaxel	5	9.80	3.00	0.00	5.00	1.00
Exemestane	5	9.80	4.00	3.00	3.00	2.50
Paclitaxel	5	9.80	4.00	1.00	4.50	1.25
Denosumab	4	7.84	NA	NA	NA	NA
Docetaxel	4	7.84	NA	NA	NA	NA
Docetaxel and cyclophosphamide	4	7.84	NA	NA	NA	NA
Goserelin	4	7.84	NA	NA	NA	NA
Zoledronic acid	4	7.84	NA	NA	NA	NA
Exemestane and goserelin	2	3.92	NA	NA	NA	NA
Abemaciclib	1	1.96	NA	NA	NA	NA
Capecitabine	1	1.96	NA	NA	NA	NA
Carboplatin and gemcitabine	1	1.96	NA	NA	NA	NA
Carboplatin paclitaxel	1	1.96	NA	NA	NA	NA
Doxorubicin	1	1.96	NA	NA	NA	NA
Doxorubicin and cyclophosphamide	1	1.96	NA	NA	NA	NA
Fluorouracil, epirubicin, and cyclophosphamide	1	1.96	NA	NA	NA	NA
Fulvestrant	1	1.96	NA	NA	NA	NA
Palbociclib	1	1.96	NA	NA	NA	NA
Ribociclib	1	1.96	NA	NA	NA	NA

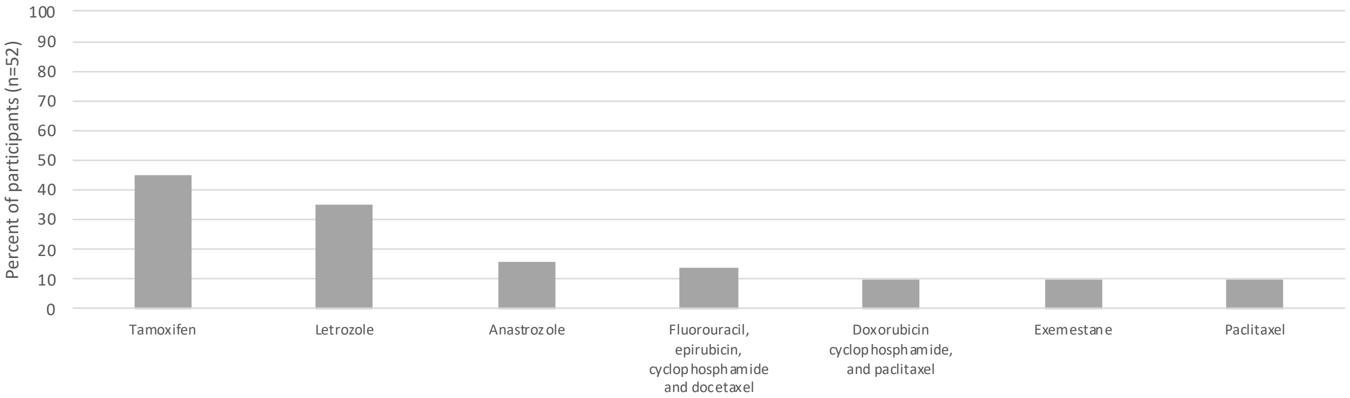


Figure 5.18: Summary of drug treatments

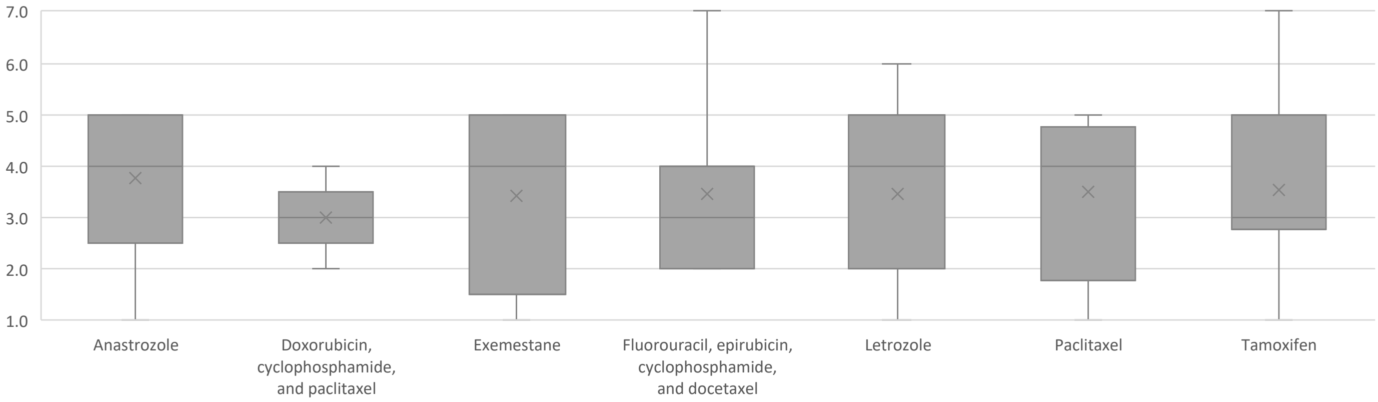


Figure 5.19: Quality of life from drug treatments (where complete data was available)

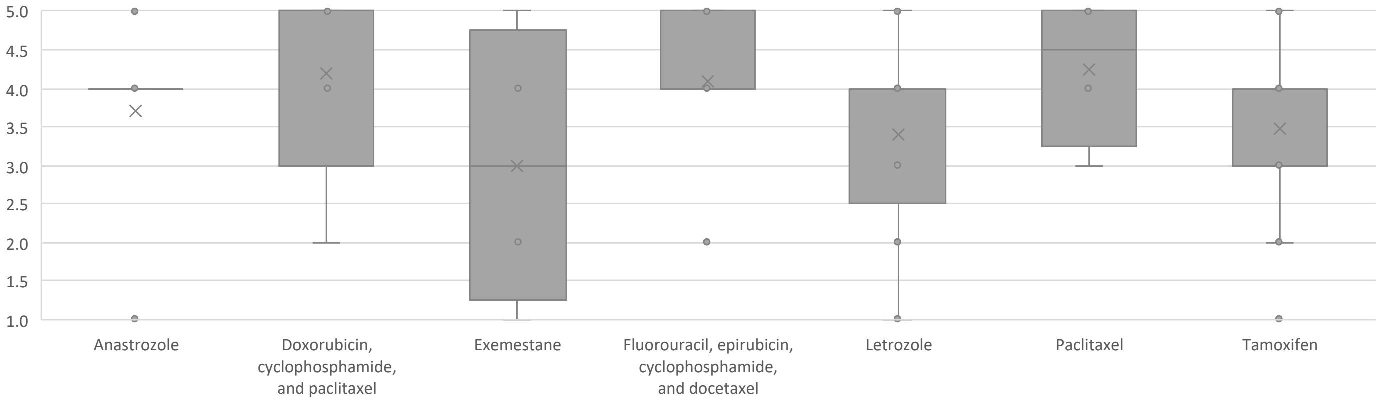


Figure 5.20: Effectiveness of drug treatments (where complete data was available)

Table 5.16: Details of drug treatments taken by more than five participants (where complete data was available)

Drug treatments (5 or more participants)		Tamoxifen		Letrozole		Anastrozole		Fluorouracil, epirubicin, cyclophosphamide and docetaxel		Doxorubicin and cyclophosphamide, and paclitaxel		Exemestane		Paclitaxel	
		n=23	%	n=18	%	n=8	%	n=7	%	n=5	%	n=5	%	n=5	%
Year of treatment	2021 -2020	23	44.23	18	34.62	8	15.38	7	13.46	5	9.62	5	9.62	5	9.62
	2019-2015	8	34.78	9	50.00	4	50.00	1	14.29	2	40.00	2	40.00	2	40.00
	Before 2015	10	43.48	5	27.78	3	37.50	3	42.86	3	60.00	3	60.00	2	40.00
Treatment status	Participant is taking as needed/prescribed	5	21.74	2	11.11	1	12.50	2	28.57	0	0.00	0	0.00	0	0.00
	Participant doesn't need to take it any more	9	39.13	9	50.00	6	75.00		0.00	1	20.00	4	80.00	0	0.00
	Participants stopped due to side effects or not working	3	13.04	0	0.00	1	12.50	1	14.29	1	20.00	0	0.00	1	20.00
	Participants finished treatment as planned	7	30.43	7	38.89	1	12.50	0	0.00	0	0.00	1	20.00	3	60.00
Side effects	No side effects	2	8.70	2	11.11	1	12.50	0	0.00	0	0.00	1	20.00	0	0.00
	Allergic reaction	2	8.70	1	5.56	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
	Blood clots	0	0.00	0	0.00	0	0.00	1	14.29	0	0.00	0	0.00	0	0.00
	Bone pain	1	4.35	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
	Changes to the lining of the womb and risk of developing cancer of the uterus	0	0.00	0	0.00	0	0.00	0	0.00	2	40.00	4	80.00	0	0.00
	Chemo brain (chemotherapy-related cognitive impairment)	4	17.39	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
	Diarrhoea	0	0.00	0	0.00	0	0.00	6	85.71	5	100.00	0	0.00	0	0.00
	Extra fluid in the body (fluid retention)	0	0.00	0	0.00	0	0.00	2	28.57	3	60.00	0	0.00	1	20.00
	Eye problems	13	56.52	4	22.22	2	25.00	4	57.14	0	0.00	1	20.00	0	0.00
	Hair loss	0	0.00	0	0.00	0	0.00	2	28.57	0	0.00	0	0.00	0	0.00
	Hand-foot syndrome	0	0.00	0	0.00	0	0.00	6	85.71	5	100.00	0	0.00	4	80.00
	Headache	0	0.00	0	0.00	0	0.00	4	57.14	0	0.00	0	0.00	0	0.00
	Hot flushes	8	34.78	6	33.33	3	37.50	0	0.00	0	0.00	2	40.00	0	0.00
	High blood cholesterol levels	19	82.61	12	66.67	6	75.00	0	0.00	0	0.00	4	80.00	0	0.00
	Infection risk (neutropenia)	0	0.00	1	5.56	0	0.00	0	0.00	0	0.00	1	20.00	0	0.00
	Injection-site reaction or pain	0	0.00	0	0.00	0	0.00	4	57.14	3	60.00	0	0.00	2	40.00
	Joint and muscle pain and stiffness	0	0.00	0	0.00	0	0.00	0	0.00	2	40.00	0	0.00	0	0.00
	Low platelets (thrombocytopenia)	16	69.57	14	77.78	6	75.00	6	85.71	0	0.00	5	100.00	0	0.00
	Low red blood cells (anaemia)	0	0.00	0	0.00	0	0.00	1	14.29	1	20.00	0	0.00	0	0.00
	Menopausal symptoms	0	0.00	0	0.00	0	0.00	1	14.29	2	40.00	0	0.00	1	20.00
	Mouth pain and soreness (mucositis)	0	0.00	0	0.00	0	0.00	3	42.86	3	60.00	0	0.00	2	40.00
	Nail changes	0	0.00	0	0.00	0	0.00	3	42.86	1	20.00	0	0.00	2	40.00
	Nausea and or vomiting	0	0.00	0	0.00	0	0.00	5	71.43	2	40.00	0	0.00	3	60.00
	Nerve damage (peripheral neuropathy)	0	0.00	2	11.11	3	37.50	5	71.43	3	60.00	0	0.00	1	20.00
	Redness and itching along vein	0	0.00	0	0.00	0	0.00	6	85.71	4	80.00	0	0.00	4	80.00
	Skin rash	0	0.00	0	0.00	0	0.00	1	14.29	1	20.00	0	0.00	0	0.00
	Skin that is more sensitive to the sun (photosensitivity)	0	0.00	0	0.00	0	0.00	3	42.86	1	20.00	0	0.00	0	0.00
	Taste and smell changes	0	0.00	0	0.00	0	0.00	2	28.57	1	20.00	0	0.00	0	0.00
	Tiredness and lack of energy (fatigue)	0	0.00	0	0.00	0	0.00	4	57.14	5	100.00	0	0.00	2	40.00
	Urine turning orange or red	0	0.00	0	0.00	0	0.00	6	85.71	5	100.00	0	0.00	4	80.00
	Vaginal changes	0	0.00	0	0.00	0	0.00	5	71.43	5	100.00	0	0.00	0	0.00
	Weak and brittle bones (osteoporosis)	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	3	60.00	0	0.00
	Other	0	0.00	2	11.11	1	12.50	0	0.00	0	0.00	1	20.00	0	0.00

Summary of radiotherapy

In the online questionnaire, participants answered a series of questions about their radiotherapy treatment, including treatment given, quality of life from treatment, side effects from treatment and how effective they thought the treatment was. Median quality of life, and effectiveness, and side effects are given in Table 5.17.

There were 40 participants (76.92%) that had radiotherapy to the primary cancer site, and four participants (7.69%) that had radiotherapy to a secondary cancer site (Figure 5.21).

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 radiotherapy to the primary cancer site was 3.00, in the life was a little distressing range (Figure 5.21). Median effectiveness of radiotherapy the primary cancer site was 4.00, in the effective range (Figure 5.22).

Table 5.17: Radiotherapy quality of life and effectiveness

Radiotherapy		Primary site		Secondary site	
		n=40	%	n=4	%
Number (n=52)		40	76.92	4	7.69
Year of treatment	2021 -2020	22	55.00	1	25.00
	2019-2015	15	37.50	2	50.00
	Before 2015	3	7.50	1	25.00
Treatment status	Treatment completed as planned	35	87.50	4	100.00
	Treatment ongoing	8	20.00	0	0.00
	Treatment stopped due to side effects or because it wasn't working	1	2.50	0	0.00
Side effects	Skin problems (red irritated swollen blistered sunburned tanned)	35	87.50	3	75.00
	Fatigue	27	67.50	3	75.00
	Nausea and vomiting	5	12.50	0	0.00
	Hair loss	4	10.00	0	0.00
	Stiff joints and muscles	4	10.00	0	0.00
	Swollen limbs	4	10.00	0	0.00
	Diarrhoea	3	7.50	0	0.00
	Loss of appetite and weight loss	3	7.50	0	0.00
	Discomfort when swallowing	1	2.50	1	25.00
	Sore mouth	1	2.50	0	0.00
	Sexual issues	1	2.50	0	0.00
	Other	7	17.50	1	25.00
		Median	**IQR**	**Median**	**IQR**
Quality of life		3.00	2.00	NA	NA
Effectiveness		4.00	1.00	NA	NA

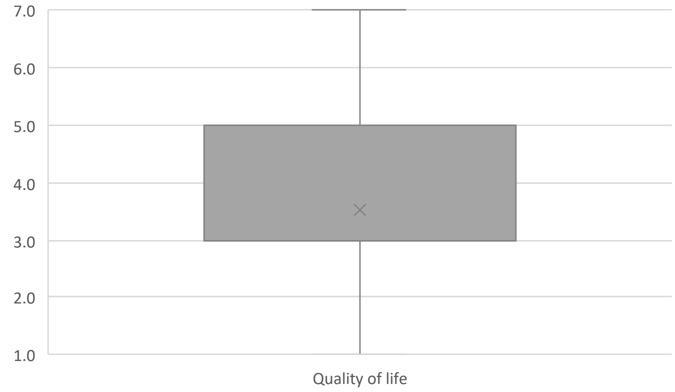


Figure 5.21: Quality of life from radiotherapy

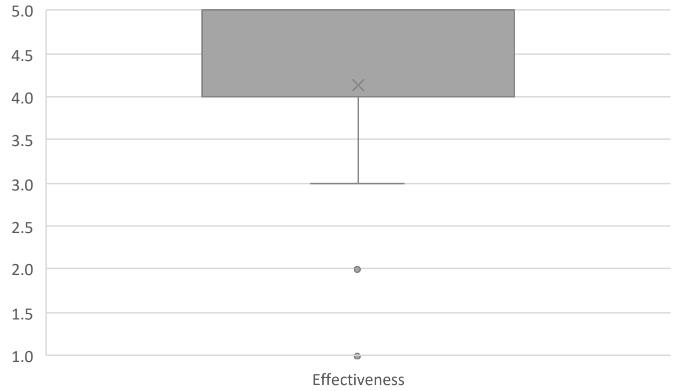


Figure 5.22: Effectiveness of radiotherapy

Allied health

Participants were asked about allied health services they used, the quality of life from these therapies, and how effective they found them.

Most participants used at least one type of allied health service (n = 40, 76.92%), and on average used one service (median = 1.00, IQR = 1.00).

The most common allied health service used was physiotherapy (n = 31, 60.78%), followed by psychology (n = 18, 35.29%), and occupational therapist (n = 7, 13.73%). There were six participants (11.76%) that saw a dietician, and six participants (11.76%) that saw a social worker (Table 5.18, Figure 5.23).

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” (Figure 5.24). Effectiveness of treatment was rated on a five-point scale where one is ineffective, and five is very effective (Figure 5.24(. Values are calculated where there was adequate data available (five or more participants).

On average, quality of life from physiotherapy 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 psychology was in the 'life was a little distressing' range (median = 3.00, IQR = 3.00), and was found to be effective (median = 4.00, IQR = 2.00).

On average, quality of life from occupational therapy was in the 'life was a little distressing' range (median = 3.00, IQR = 0.50), and was found to be effective (median = 4.00, IQR = 1.50).

On average, quality of life from dieticians was in the 'life was good' range (median = 5.00, IQR = 1.50), and was found to be effective (median = 4.00, IQR = 2.25).

On average, quality of life from social work was in the 'life was distressing' range (median = 2.00, IQR = 1.50), and was found to be moderately effective to effective (median = 3.50, IQR = 1.75).

Table 5.18: Allied health

Allied health	Number (n=51)	Percent	Median quality of life	IQR	Median effectiveness	IQR
Physiotherapist	31	60.78	4.00	2.00	4.00	1.00
Psychologist	18	35.29	3.00	3.00	4.00	2.00
Occupational therapist	7	13.73	3.00	0.50	4.00	1.50
Dietician	6	11.76	5.00	1.50	4.00	2.25
Social worker	6	11.76	2.00	1.50	3.50	1.75
Podiatrist	3	5.88	NA	NA	NA	NA
Speech pathologist or speech therapist	0	0.00	NA	NA	NA	NA
Neuropsychologist	0	0.00	NA	NA	NA	NA

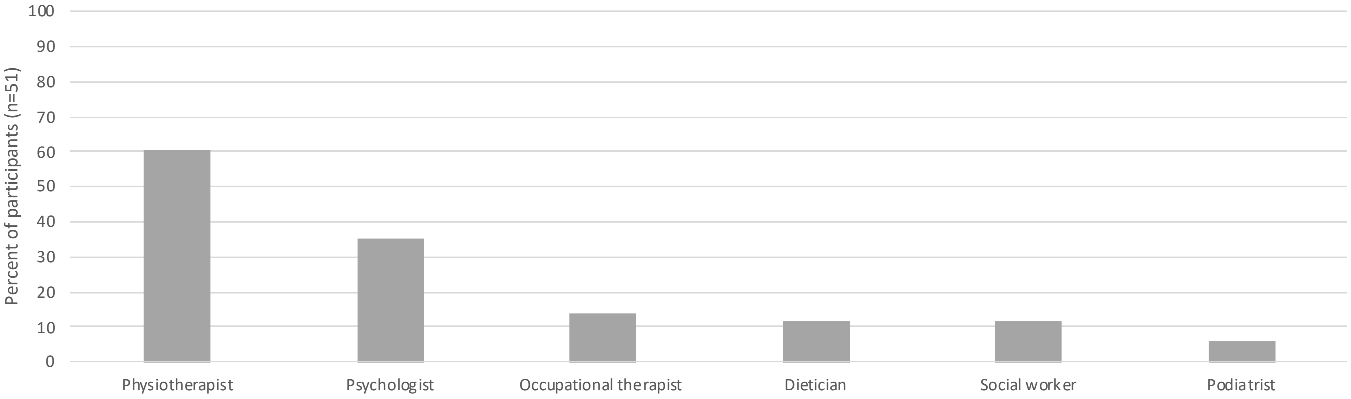


Figure 5.23: Allied health

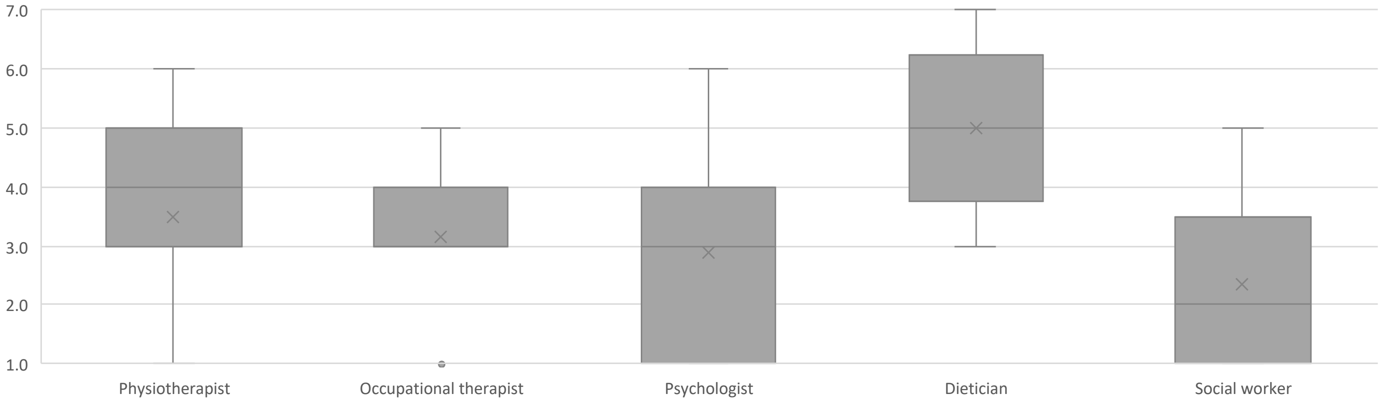


Figure 5.24: Quality of life from allied health

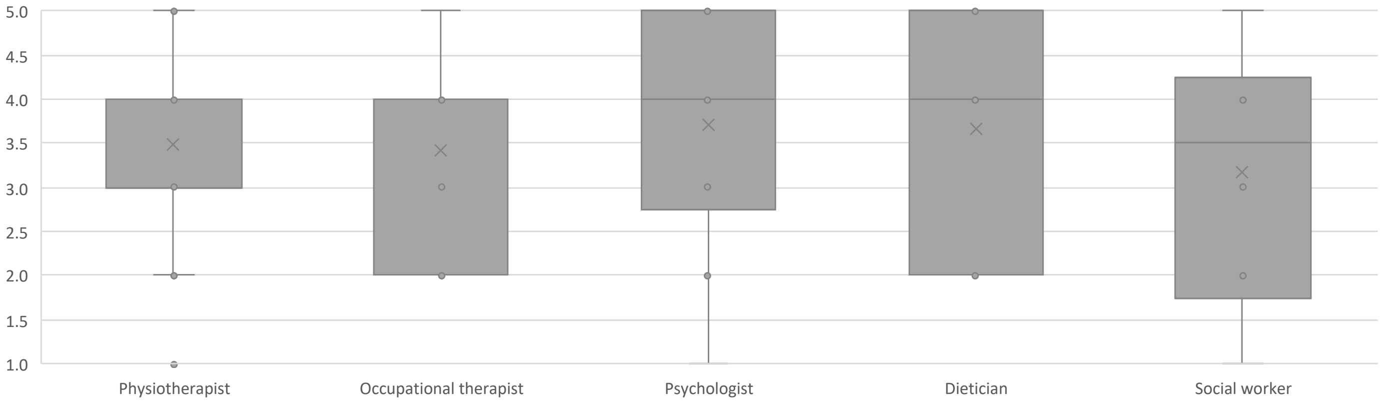


Figure 5.25: Effectiveness of allied health

Lifestyle changes

Participants were asked about any lifestyle changes they had made since diagnosis, the quality of life from these changes, and how effective they found them (Table 5.19).

Most participants used at made at least one lifestyle change (n = 45, 86.54%), and on average made two changes (median = 2.00, IQR = 2.00).

The most common lifestyle change used was exercise (n = 43, 84.31%), followed by diet changes (n = 28, 54.90%), and quit or cut back on alcohol (n = 27, 52.94%) (Figure 5.26).

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” (Figure 5.27). Effectiveness of treatment was rated on a five-point scale where one is ineffective, and five is very effective (Figure 5.28). Values are calculated where there was adequate data available (five or more participants).

On average, quality of life from Exercise was in the 'life was good' range (median = 5.00, IQR = 1.00), and was found to be effective (median = 4.00, IQR = 1.50).

On average, quality of life from Diet changes was in the 'life was average' range (median = 4.00, IQR = 2.00), and was found to be moderately effective (median = 3.00, IQR = 2.00).

On average, quality of life from reducing alcohol was in the 'life was good' range (median = 5.00, IQR = 1.00), and was found to be effective (median = 4.00, IQR = 1.00).

Table 5.19: Lifestyle changes

Lifestyle changes	Number (n=51)	Percent	Median quality of life	IQR	Median effectiveness	IQR
Exercise	43	84.31	5.00	1.00	4.00	1.50
Diet changes	28	54.90	4.00	2.00	3.00	2.00
Quit or cut back on alcohol (n=39)	27	52.94	5.00	1.00	4.00	1.00
Quit smoking (n=8)	0	0.00	NA	NA	NA	NA

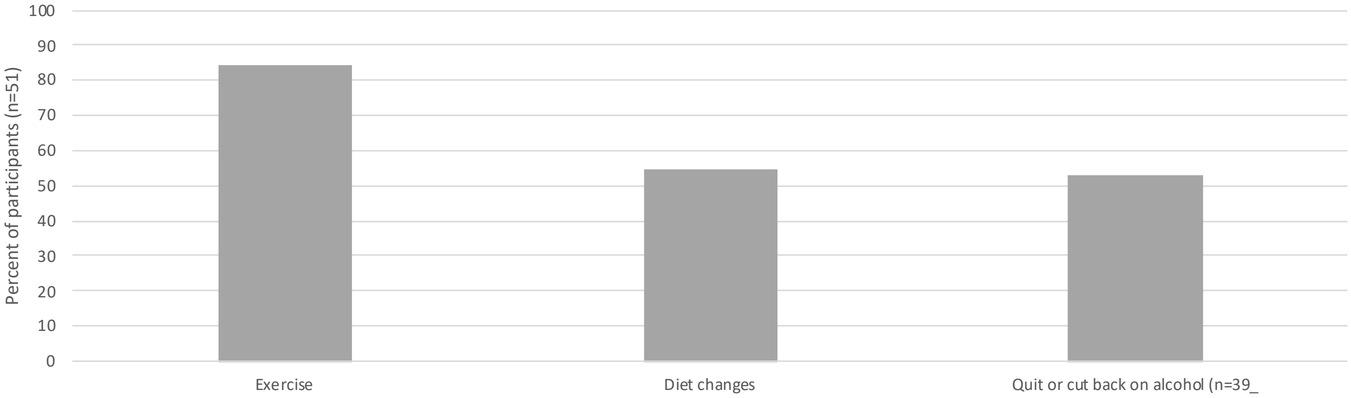


Figure 5.26: Lifestyle changes

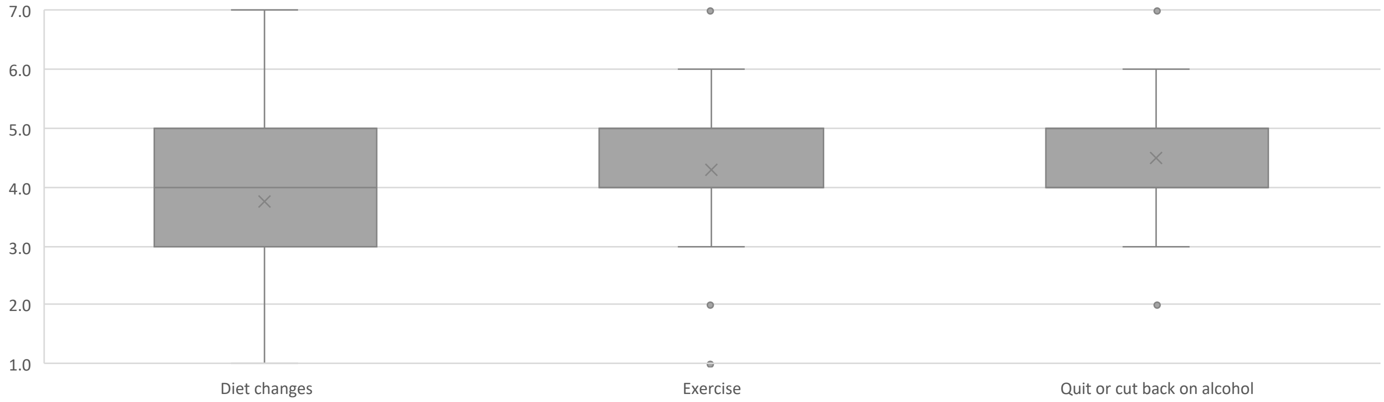


Figure 5.27: Quality of life from lifestyle changes

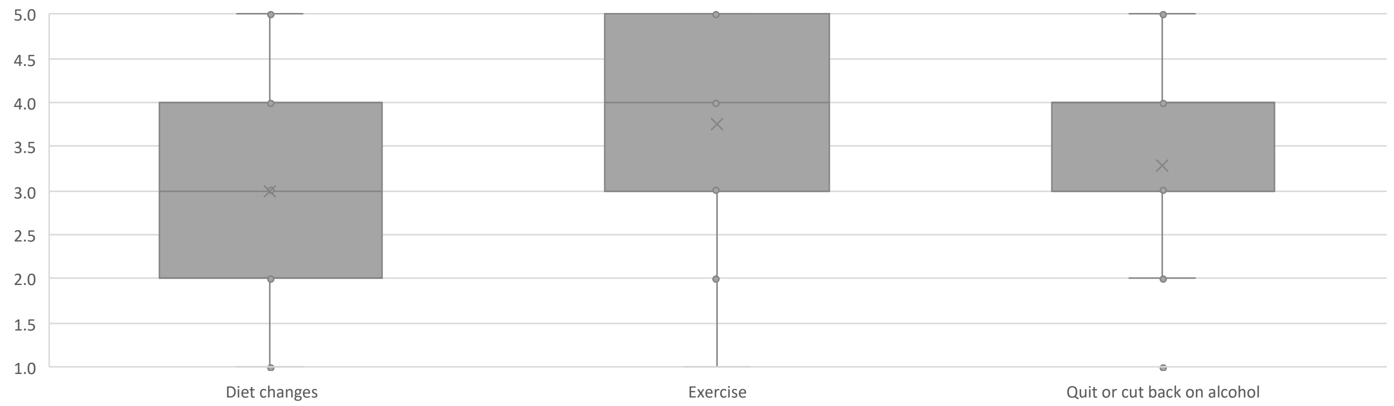


Figure 5.28: Effectiveness from lifestyle changes

Complementary therapies

Participants were asked about any complementary therapies they used to manage their condition, the quality of life from these changes, and how effective they found them (Table 5.20).

Most participants used at made at least one complementary therapy (n = 40, 76.92%), and on average used 1 therapies (median = 1.00, IQR = 1.00).

The most common complementary therapies used were supplements (n = 25, 49.02%), and mindfulness or relaxation techniques (n = 25, 49.02%), and massage therapy (n = 16, 31.37%) (Figure 5.29).

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” (Figure 5.30). Effectiveness of treatment was rated on a five-point scale where one is ineffective, and five is very effective (Figure 5.31). Values are calculated where there was adequate data available (five or more participants).

On average, quality of life from supplements was in the 'life was average' range (median = 4.00, IQR = 2.00), and was found to be moderately effective (median = 3.00, IQR = 1.00).

On average, quality of life from mindfulness or relaxation techniques was in the 'life was average' range (median = 4.00, IQR = 2.00), and was found to be effective (median = 4.00, IQR = 3.00).

On average, quality of life from massage therapy was in the 'life was average to good' range (median = 4.50, IQR = 2.00), and was found to be effective to very effective (median = 4.50, IQR = 1.00).

On average, quality of life from naturotherapy was in the 'life was a little distressing range' (median = 3.00, IQR = 3.00), and was found to be effective (median = 4.00, IQR = 1.00).

Table 5.20: Complementary therapies

Complementary therapies	Number (n=51)	Percent	Median quality of life	IQR	Median effectiveness	IQR
Supplements	25	49.02	4.00	2.00	3.00	1.00
Mindfulness or relaxation techniques	25	49.02	4.00	2.00	4.00	3.00
Massage therapy	16	31.37	4.50	2.00	4.50	1.00
Naturopath	5	9.80	3.00	3.00	4.00	1.00
Acupuncture	4	7.84	NA	NA	NA	NA
Homeopathy	1	1.96	NA	NA	NA	NA

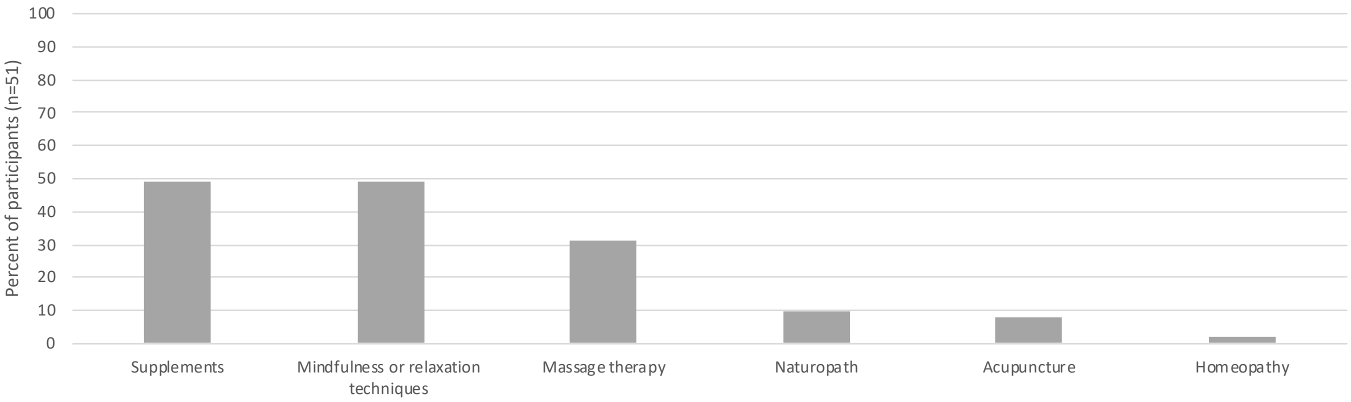


Figure 5.29: Complementary therapies

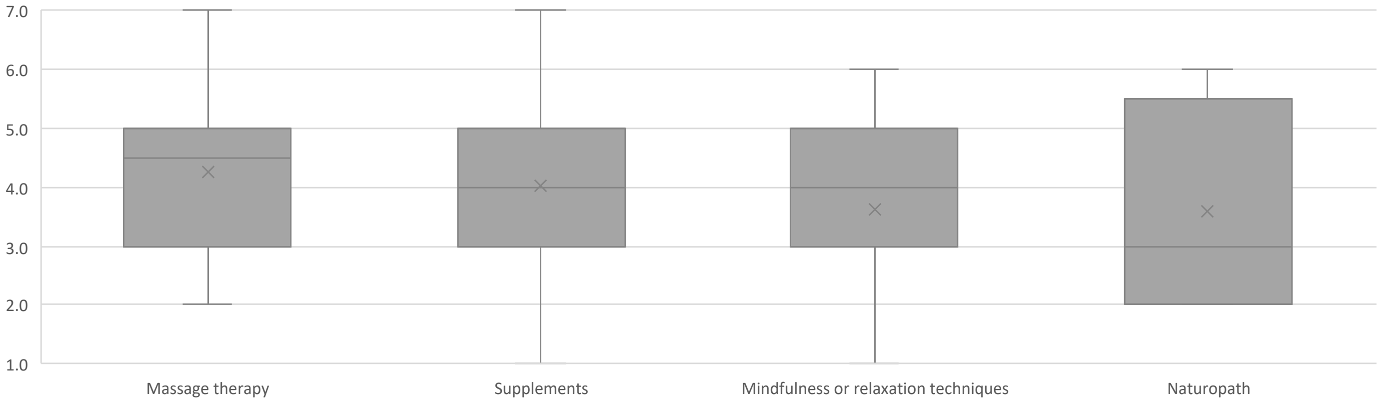


Figure 5.30: Quality of life from complementary therapies

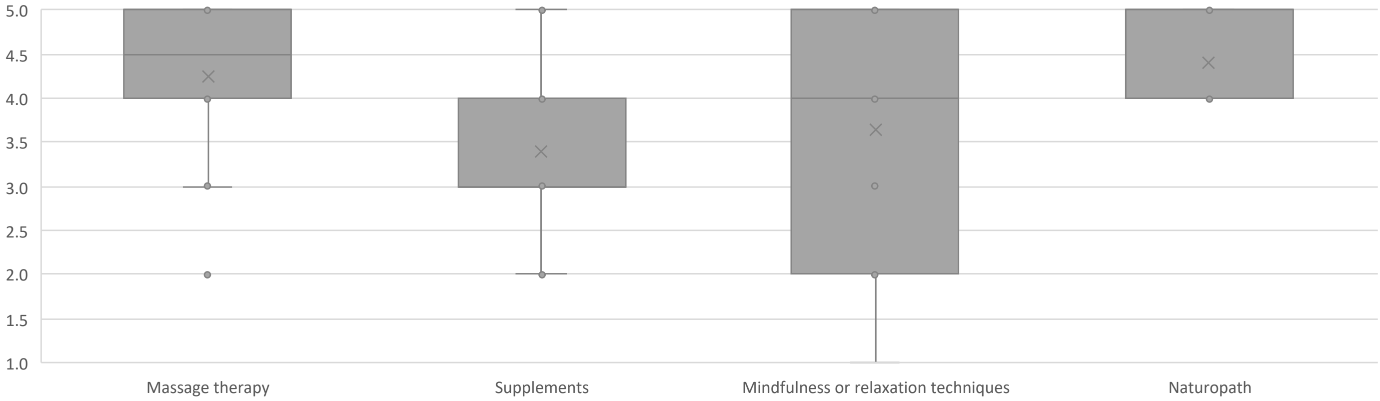


Figure 5.31: Effectiveness of complementary therapies

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 5.21, Figure 5.32).

There was a total of 17 participants (33.33%) that had discussions about clinical trials, 4 participants (7.84%) had brought up the topic with their doctor, and the doctor of 13 participants (25.49%) brought up the topic. The majority of participants had not spoken to anyone about clinical trials (n = 34, 66.67%).

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 5.22, Figure 5.33).

There were seven participants (13.73%) that had taken part in a clinical trial, 32 participants (62.75%) that would like to take part in a clinical trial if there was a suitable one, and 12 participants, who have not participated in a clinical trial and do not want to (23.53%).

Table 5.21: Clinical trial discussions

Clinical trial discussions	Number (n=51)	Percent
Participant brought up the topic of clinical trials doctor for discussion	4	7.84
Doctor brought up the topic of clinical trials for discussion	13	25.49
Participant has ever spoken to me about clinical trials	34	66.67

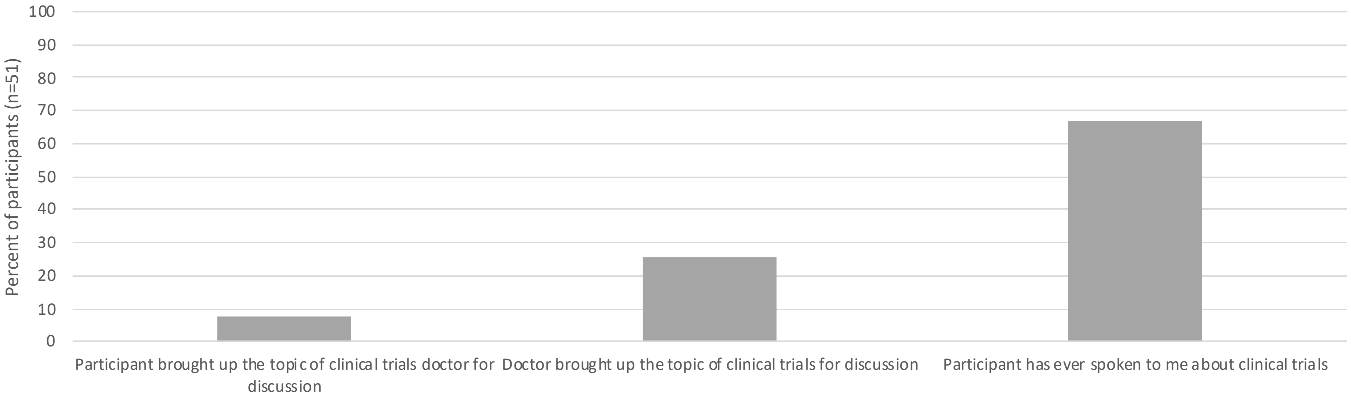


Figure 5.32: Clinical trial discussions

Table 5.22: Clinical trial participation

Clinical trial participation	Number (n=51)	Percent
Has not participated in a clinical trial and does not want to	12	23.53
Has not participated in a clinical trial but would like to if there is one	32	62.75
Has participated in a clinical trial	7	13.73

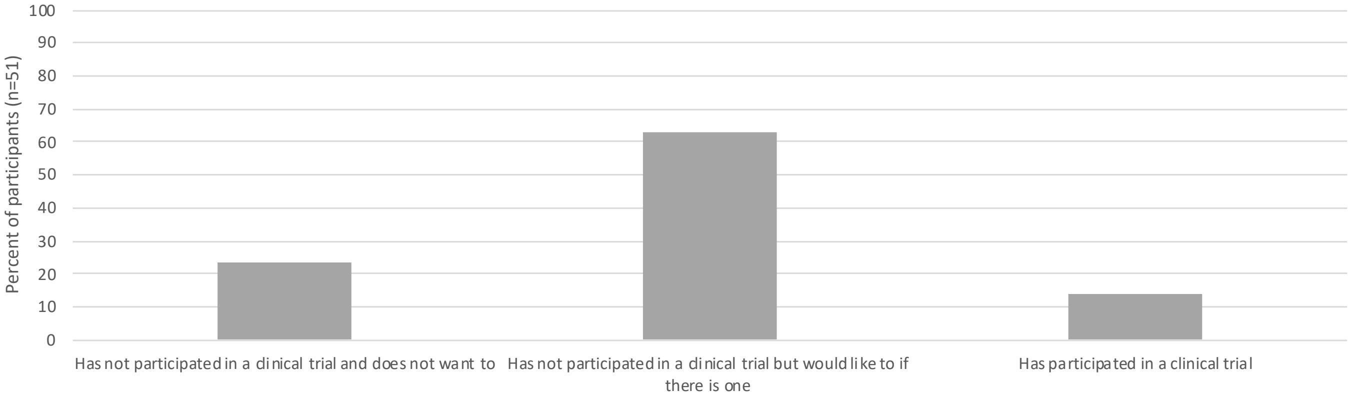


Figure 5.33: Clinical trial participation

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 to describe them with specific examples (n=27, 51.92%). There were 25 participants (48.08%) that described mild side effects as those that do not interfere with daily life, and 19 participants (36.54%) that described mild side effects as those that can be self-managed.

Of those who described a specific side effect, the most commonly described side effects were fatigue (n=7, 13.46%), mild pain or aches (n=6, 11.54%), and hair loss.

Participant provides a specific side effect as an example

Mild side effects would be neuropathy, nerve pain. Yes, dealing with the seroma. They're all fairly mild, You know, it's nothing that, sort of, really, really bad. Participant 003_2021AUHRP

They're all manageable because even, I guess, some people would consider hair loss as being significant but it didn't really bother me that much. I think it bothered my vacuum cleaner far more than it bothered me. The only one that's really adjusted how I function, which I would say is the definition of something that's not mild would be the hot flashes. Participant 005_2021AUHRP

The hair loss and stuff like that. I've been quite lucky to not have had too many side effects. I've actually been okay [chuckles] with that. Participant 042_2021AUHRP

Participant describes mild side effects as those that do not interfere with daily life

Okay. Mild side effects to me would be something that doesn't really interfere with my daily living, and I don't need to take any medication as far as Panadol or anything like that. That, to me, is a mild side effect. It's something that you know you can feel it, but it doesn't stop you doing anything. Participant 017_2021AUHRP

Well, I would say mild side effect is something that is perhaps a bit annoying but you're still functioning and able to operate as normal and do everything as normal. Participant 044_2021AUHRP

If it was mild, I could still carry out my daily activities maybe slightly reduced, but my self-care, my daily activities, and be able to continue the work, my work activities. Maybe some limitations, but still do most of the things I was doing previously in daily activities, social activities, and I guess, physically exercise and sports. Participant 047_2021AUHRP

Participant describes mild side effects as those that can be self-managed

Mild is the indigestion. Severe is the skin burn I'd say and fatigue is right up there, it's a shocker. I didn't realize the difference between fatigue and just being dead tired. Yeah. Oh, mild you can go and take Gaviscon and it fixes pain you can take Panadol and pretty much fix it. Burning skin it doesn't, you know, putting cream on does not stop that burning or itching. Participant 014_2021AUHRP

Oh, that's the minor things that you can go and take some Panadol and feel better from. Participant 030_2021AUHRP

Just a general annoyance, like something that you can fix. Does that make sense? You know, like, you know, the side effect of constipation is a mild side effects. And it's frustrating at the time, but you know, it's fleeting, and it goes away. Yes. Whereas, you know, your more in depth side effects for the ones that doesn't matter what you do, like the weight gain, you know, I could live on freaking lettuce leaves for ever and still not lose any weight. Participant 033_2021AUHRP

Table 5.23: Description of mild side effects

Description of mild side effects	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participant provides a specific side effect as an example	27	51.92	10	52.63	10	47.62	7	58.33	17	58.62	10	43.48	7	36.84	20	60.61
Participant describes mild side effects as those that do not interfere with daily life	25	48.08	9	47.37	12	57.14	4	33.33	12	41.38	13	56.52	10	52.63	15	45.45
Participant describes mild side effects as those that can be self-managed	19	36.54	7	36.84	6	28.57	6	50.00	8	27.59	11	47.83	10	52.63	9	27.27

Description of mild side effects	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participant provides a specific side effect as an example	27	51.92	4	40.00	12	75.00	11	42.31	2	18.18	25	60.98	6	33.33	21	61.76
Participant describes mild side effects as those that do not interfere with daily life	25	48.08	4	40.00	8	50.00	13	50.00	6	54.55	19	46.34	11	61.11	14	41.18
Participant describes mild side effects as those that can be self-managed	19	36.54	4	40.00	2	12.50	13	50.00	6	54.55	13	31.71	5	27.78	14	41.18

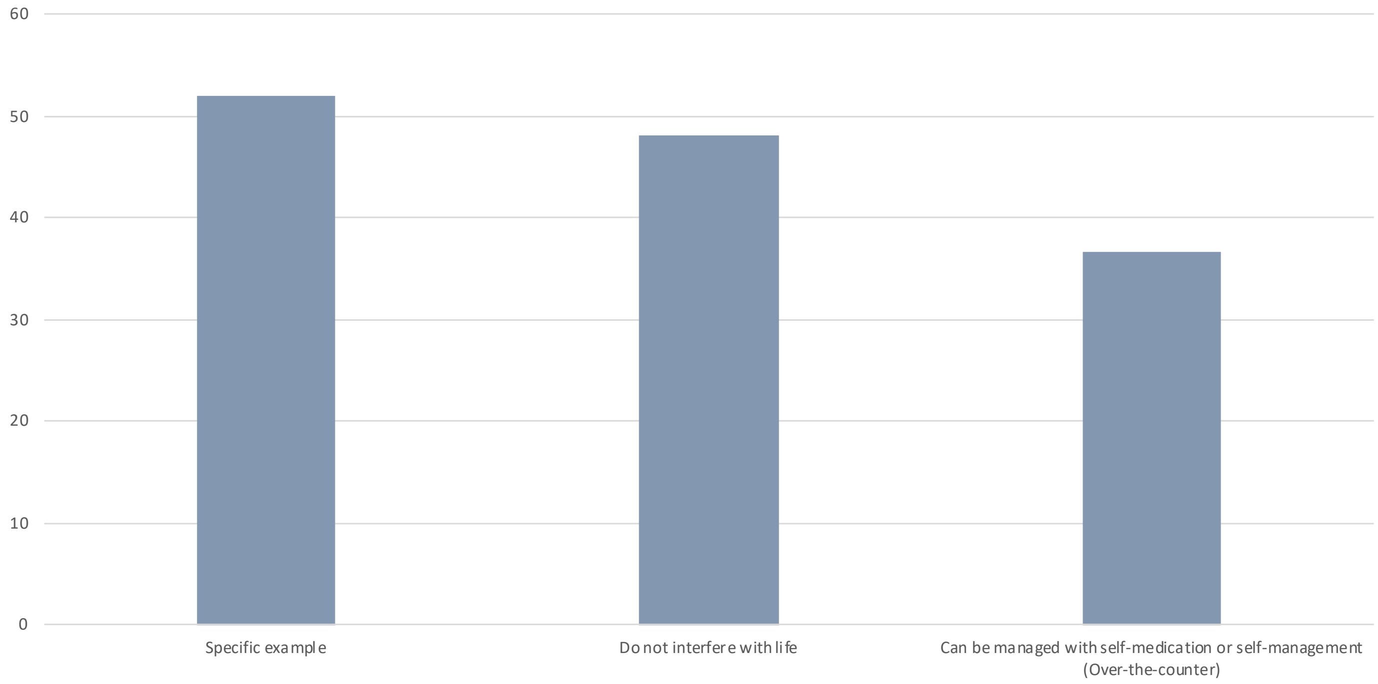


Figure 5.34: Description of mild side effects (percent of all participants)

Table 5.24: 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	Trade or high school Diagnosed in 2016 or before Regional or remote Mid to low status	Diagnosed in 2017 to 2019
Participant describes mild side effects as those that do not interfere with daily life	Stage III and IV	Mid to low status
Participant describes mild side effects as those that can be self-managed	Diagnosed in 2017 to 2019	Stage III and IV Aged 55 to 74 Trade or high school Diagnosed in 2020 or 2021 Regional or remote

Table 5.25: Description of mild side effects (Specific side effects)

Description of mild side effects (Specific side effects)	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participant describes mild side effects giving the specific example of Fatigue/lethargy	7	13.46	1	5.26	2	9.52	4	33.33	6	20.69	1	4.35	1	5.26	6	18.18
Participant describes mild side effects giving the specific example of aches/pain (general)	6	11.54	4	21.05	1	4.76	1	8.33	4	13.79	2	8.70	1	5.26	5	15.15
Participant describes mild side effects giving the specific example of hair loss	5	9.62	4	21.05	1	4.76	0	0.00	3	10.34	2	8.70	2	10.53	3	9.09

Description of mild side effects (Specific side effects)	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participant describes mild side effects giving the specific example of Fatigue/lethargy	7	13.46	1	10.00	4	25.00	2	7.69	0	0.00	7	17.07	2	11.11	5	14.71
Participant describes mild side effects giving the specific example of aches/pain (general)	6	11.54	1	10.00	1	6.25	4	15.38	0	0.00	6	14.63	1	5.56	5	14.71
Participant describes mild side effects giving the specific example of hair loss	5	9.62	0	0.00	3	18.75	2	7.69	0	0.00	5	12.20	2	11.11	3	8.82

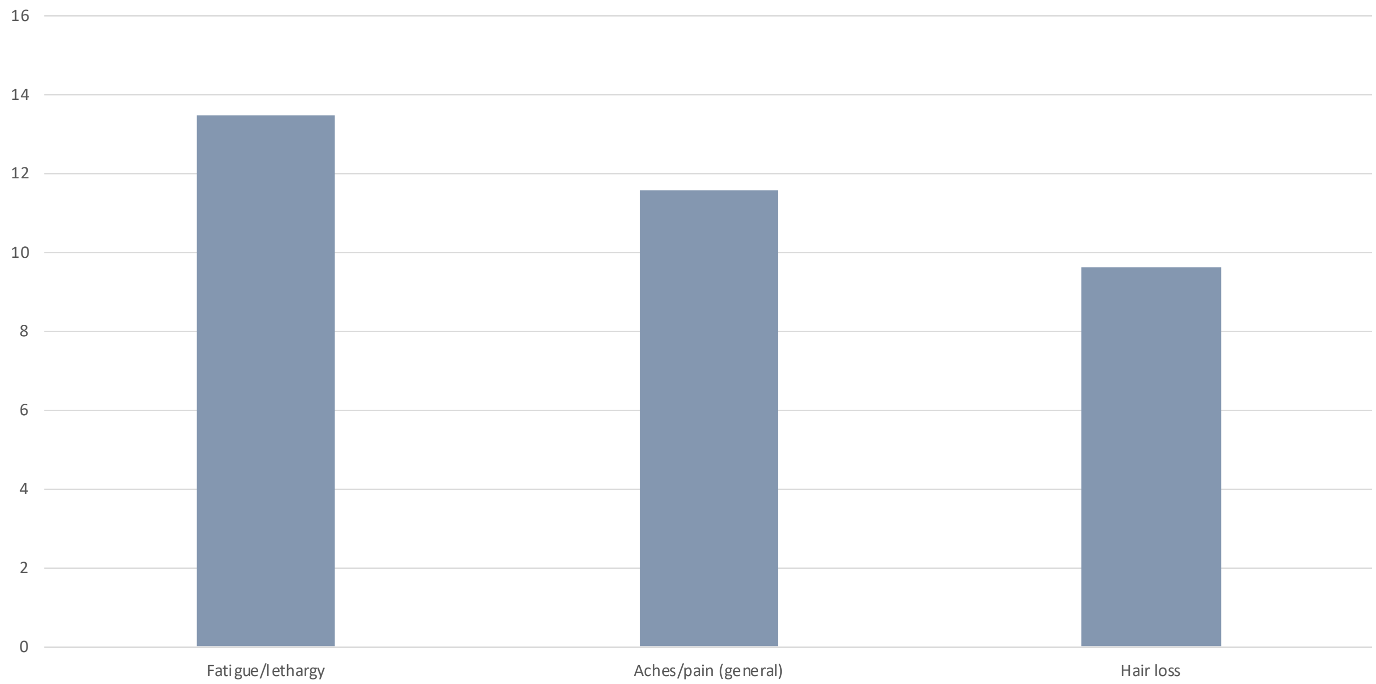


Figure 5.35: Description of mild side effects (Specific side effects) (percent of all participants)

Table 5.26: 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	Regional or remote	Stage III and IV Diagnosed in 2017 to 2019
Participant describes mild side effects giving the specific example of aches/pain (general)	Regional or remote	-
Participant describes mild side effects giving the specific example of hair loss	-	Stage 0 and I

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=30, 57.69%). Other descriptions of ‘severe side effects’ included those that impact everyday life/ability to conduct activities of daily living (n=26, 50.00%), those that require medical intervention (n=5, 9.62%).

Of those who described a specific side effect, the most commonly described side effects were pain (n=11, 21.15%), the emotional and mental impact (n=7, 13.46%), those that impact on sleep (n=5, 9.62%), and nausea (n=5, 9.62%).

Participant provides a specific side effect as an example of a severe side effect

The fluid accumulation post-surgery was uncomfortable and frustrating because I just wanted to get back to normal. That was probably what I found the toughest. Participant 011_2021AUHRP

When you feel so down and you cry because you're so fed up with feeling sore and in pain all the time. Participant 012_2021AUHRP

Severe is more to do with the upset stomach for me, the nausea. It was hard to handle. That would be my thing, and the uncomfortableness behind your arm and pins, sharp pins and needles all down the back, which has now gone. It's gone, but it took a good about five months to go. Participant 032_2021AUHRP

Participant describes severe side effects as those that impact everyday life/ability to conduct activities of daily living

Severe to me would be it would inhibit my daily living or my life as far as I wouldn't be able to go to work, and I wouldn't be able to go out to do the shopping, or it would interfere with my life, would be what I would class as severe. Participant 017_2021AUHRP

Severe side effects is where you basically couldn't do what you would normally do. Participant 020_2021AUHRP

They're the activities that stop, would really stop me from doing my daily living tasks, and stopped me from working, and socializing, not being able to do social activities. It's really impacting on those and I guess my physical activities. Participant 047_2021AUHRP

Participant describes severe side effects as those that require medical intervention

Severe side effects, something that really limits me being able to function or puts me in a situation where I need other medical intervention? Yes, that would be my idea of severe side effects. 003_2021AUHRP

Severe side effects, I guess where it is having much more impact on your daily life. It does have you thinking about changing or stopping the treatment. It takes a lot more care to manage. A lot more treatment to manage and it has an effect physically and emotionally on how you feel about A, if it's a physical pain type side effects, ongoing pain has an effect on your mood and mental health. Severe side effects can affect body image. Again, the amount of treatments that you need to manage those side effects. Participant 023_2021AUHRP

Yes, it's probably when you have to take the Endone that they prescribe for you. Participant 026_2021AUHRP

Table 5.27: Description of severe side effects

Description of severe side effects	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participant provides a specific side effect as an example of a severe side effect	30	57.69	12	63.16	**10**	**47.62**	8	66.67	17	58.62	13	56.52	**9**	**47.37**	21	63.64
Participant describes severe side effects as those that impact everyday life/ability to conduct activities of daily living	26	50.00	8	42.11	12	57.14	6	50.00	13	44.83	13	56.52	11	57.89	15	45.45
Participant describes severe side effects as those that require medical intervention	5	9.62	0	0.00	4	19.05	1	8.33	3	10.34	2	8.70	1	5.26	4	12.12

Description of severe side effects	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participant provides a specific side effect as an example of a severe side effect	30	57.69	**3**	**30.00**	**13**	**81.25**	14	53.85	**5**	**45.45**	25	60.98	9	50.00	21	61.76
Participant describes severe side effects as those that impact everyday life/ability to conduct activities of daily living	26	50.00	5	50.00	7	43.75	14	53.85	**7**	**63.64**	19	46.34	10	55.56	16	47.06
Participant describes severe side effects as those that require medical intervention	5	9.62	1	10.00	1	6.25	3	11.54	1	9.09	4	9.76	1	5.56	4	11.76

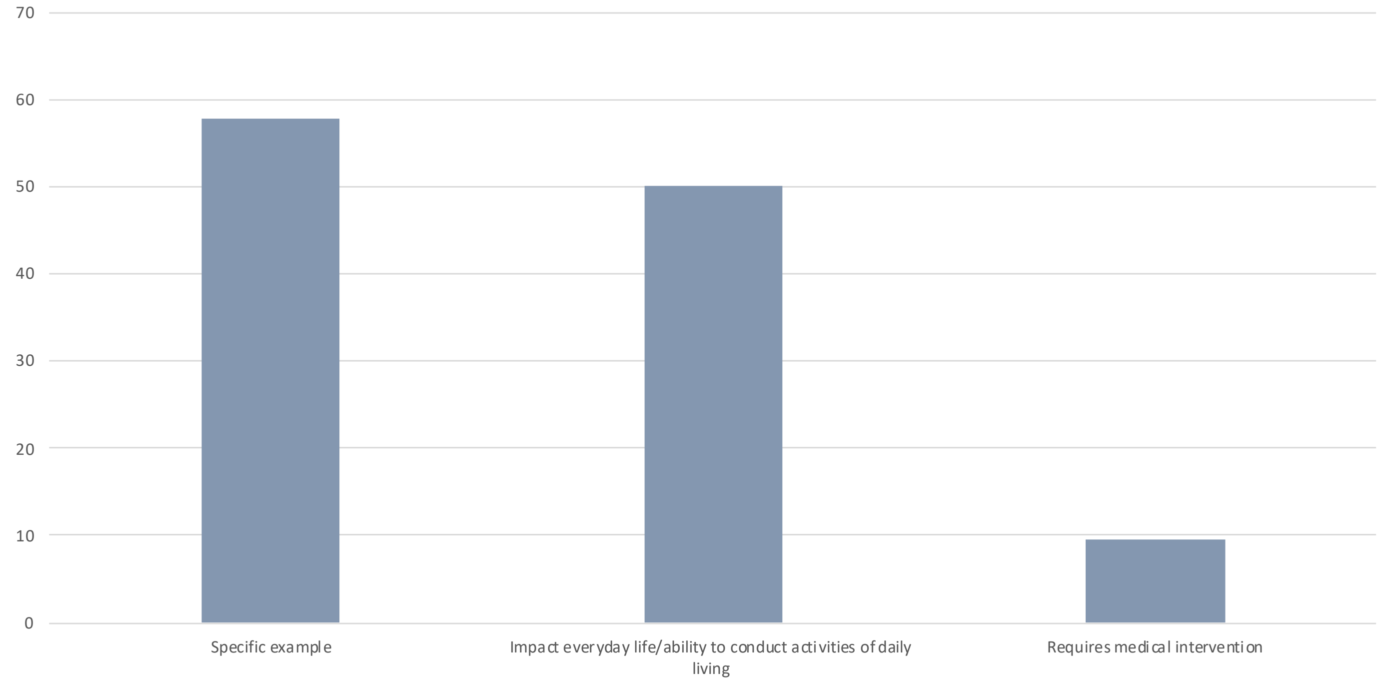


Figure 5.36: Description of severe side effects (percent of all participants)

Table 5.28: 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 of a severe side effect	Stage II Trade or high school Diagnosed in 2016 or before Regional or remote	Diagnosed in 2017 to 2019
Participant describes severe side effects as those that impact everyday life/ability to conduct activities of daily living	-	Regional or remote

Table 5.29: Description of severe side effects (Specific example)

Description of severe side effects (Specific example)	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participant describes severe side effects giving the specific example of aches/pain (general)	11	21.15	5	26.32	4	19.05	2	16.67	4	13.79	7	30.43	2	10.53	9	27.27
Participant describes severe side effects giving the specific example of the emotion/mental impact	7	13.46	1	5.26	4	19.05	2	16.67	3	10.34	4	17.39	3	15.79	4	12.12
Participant describes severe side effects giving the specific example of the impact on sleep	5	9.62	3	15.79	0	0.00	2	16.67	4	13.79	1	4.35	0	0.00	5	15.15
Participant describes severe side effects giving the specific example of nausea	5	9.62	2	10.53	2	9.52	1	8.33	4	13.79	1	4.35	4	21.05	1	3.03

Description of severe side effects (Specific example)	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participant describes severe side effects giving the specific example of aches/pain (general)	11	21.15	1	10.00	4	25.00	6	23.08	2	18.18	9	21.95	6	33.33	5	14.71
Participant describes severe side effects giving the specific example of the emotion/mental impact	7	13.46	0	0.00	4	25.00	3	11.54	1	9.09	6	14.63	3	16.67	4	11.76
Participant describes severe side effects giving the specific example of the impact on sleep	5	9.62	1	10.00	2	12.50	2	7.69	1	9.09	4	9.76	0	0.00	5	14.71
Participant describes severe side effects giving the specific example of nausea	5	9.62	0	0.00	2	12.50	3	11.54	1	9.09	4	9.76	1	5.56	4	11.76

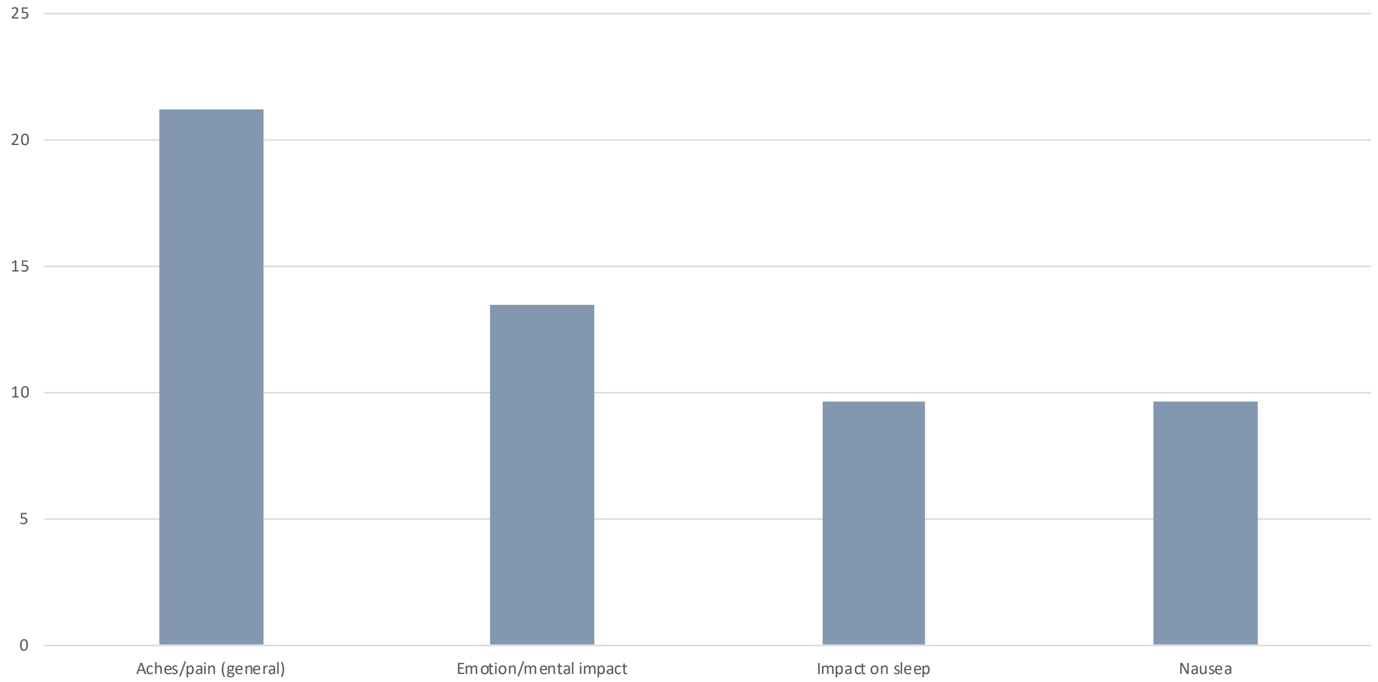


Figure 5.37: Description of severe side effects (Specific example) (percent of all participants)

Table 5.30: Description of severe side effects (Specific side effects)– subgroup variations

Description of severe side effects (Specific example)	Reported less frequently	Reported more frequently
Participant describes severe side effects giving the specific example of aches/pain (general)	Trade or high school Diagnosed in 2016 or before	Mid to low status
Participant describes severe side effects giving the specific example of the emotion/mental impact	Diagnosed in 2016 or before	Diagnosed in 2017 to 2019
Participant describes severe side effects giving the specific example of nausea	-	Trade or high school

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 for a specific amount of time (n=20, 38.46%), and as per the advice of their specialist/as long as prescribed (n=19, 36.54%). Other participants described adhering to treatment as long as side effects are tolerable (n=15, 28.85%), and not giving up on any treatment (n=15, 28.85%).

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

Participant describes adhering to treatment for a specific amount of time

Yes. I think that depends on what you're trying because I think you need to really understand the nature of treatment and what's going on behind it. There's not much point trying it for less than two weeks. I think that depends on the treatment really. Based on whether it's going to be something that should fix things quickly, or it takes a couple of weeks to work. Participant 005_2021AUHRP

I give something at least three months before I ask a question as to why isn't it doing what it's supposed to do. Participant 018_2021AUHRP

With the tablets, the first one I stuck with it for about three months. Then they put me on to the second one. I think I was on that for two months. Then they put me on the third one. Then by about two months when it was still giving me grief, that's when we had the conversation about long-term prognosis before I stopped taking them. I kept taking them. ...hen it was only in the last couple of months that I stopped. I pulled the sheets and I stopped taking them full stop. Participant 025_2021AUHRP

Participant describes adhering to treatment as per the advice of their specialist/as long as prescribed

Yeah, I stick with it. I follow the protocols. If it says, you know, you're going to have nausea, take this stuff to stop it. Yes, I will take it. And you know, if I'm going to go off something, it's going to be because I've discussed it with the doctor. Participant 003_2021AUHRP

I didn't, I never did that. So I was five years on the Tamoxofen. And because I said five years, I didn't want to go the extra time because that was all new too. By the end of my five years, I'm just playing with trying for 10 years. And I've had enough I think I had that five year goal in my head that they said I could stop, and I think I mentioned the Zoladex I got after speaking with the surgeon and how I was feeling it was decided that it was betterr not to take it anymore. Participant 045_2021AUHRP

I probably the required length, in consultation with the medical person I continued. After discussing with them, I continued for the recommended time. Participant 047_2021AUHRP

Participant describes adhering to treatment as long as side effects are tolerable

Me personally, probably a good couple of months I'll do it. Depends how bad the side effects were. If it made you throw up and feel like that, I think two months is a long time. Participant 009_2021AUHRP

Usually, I'll just keep sticking with it forever until I see the doctor again. Unless it's causing really bad side effects or something. Participant 036_2021AUHRP

I'd say I'd like to give it a good chance. I know sometimes too, when you're starting a new medicine you can have the side effects then they can sort of die down or you get used to it as well. I tend to stick with it. The only thing would be if the side effects outweigh the benefits. Yes, I do like to stick with some things. Participant 052_2021AUHRP

Participant describes not giving up on any treatment

I haven't really been in that position. I have surgery, radiotherapy. That's done. I started on tamoxifen and then that's been fine. I'll stick with that. I think the tough thing will be when someone suggests I don't need to take it anymore. At this point, I would be very anxious about stopping it. Participant 011_2021AUHRP

Right. And I've been on this letrozole for a while now, nearly a year. So yeah, I haven't given up I thought, I know I mean, a Facebook group where a lot of women go oh stuff this, I'm not doing it because any, when you look at the percentages, it's only a couple of percents that increases but I said she's going to take all the percent you can get on top of everything you know, to survive. Participant 041_2021AUHRP

I've never got to that point. I guess with tamoxifen I was getting side effects, but I always knew that I wanted to get onto an aromatase inhibitor because that was meant to be better for invasive lobular. I just cracked on through tamoxifen. I'm not at that point yet. Even if I stop my medication-- A lot of women talk about stopping tamoxifen or Aromasin because of the impact it's having on them being in menopause, but the fact is even if I stop taking those drugs now, I've had my gynae surgery. I have those side effects. I'm not at that stage. I think it's also difficult to try and differentiate. Is that side effect because I'm in menopause, is it because of the Aromasin, or is it because I'm getting older, or is it just because of the cancer or of all the treatment? Is it all of those things? It's really difficult to actually isolate what's what. Participant 043_2021AUHRP

Table 5.31: Adherence to treatment

Adherence to treatment	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participant describes adhering to treatment for a specific amount of time	20	38.46	7	36.84	9	42.86	4	33.33	12	41.38	8	34.78	10	52.63	10	30.30
Participant describes adhering to treatment as per the advice of their specialist/as long as prescribed	19	36.54	6	31.58	11	52.38	2	16.67	10	34.48	9	39.13	8	42.11	11	33.33
Participant describes adhering to treatment as long as side effects are tolerable	15	28.85	8	42.11	6	28.57	1	8.33	5	17.24	10	43.48	6	31.58	9	27.27
Participant describes not giving up on any treatment	15	28.85	3	15.79	7	33.33	5	41.67	10	34.48	5	21.74	2	10.53	13	39.39

Adherence to treatment	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participant describes adhering to treatment for a specific amount of time	20	38.46	3	30.00	8	50.00	9	34.62	3	27.27	17	41.46	8	44.44	12	35.29
Participant describes adhering to treatment as per the advice of their specialist/as long as prescribed	19	36.54	7	70.00	3	18.75	9	34.62	6	54.55	13	31.71	7	38.89	12	35.29
Participant describes adhering to treatment as long as side effects are tolerable	15	28.85	4	40.00	4	25.00	7	26.92	4	36.36	11	26.83	6	33.33	9	26.47
Participant describes not giving up on any treatment	15	28.85	1	10.00	7	43.75	7	26.92	4	36.36	11	26.83	8	44.44	7	20.59

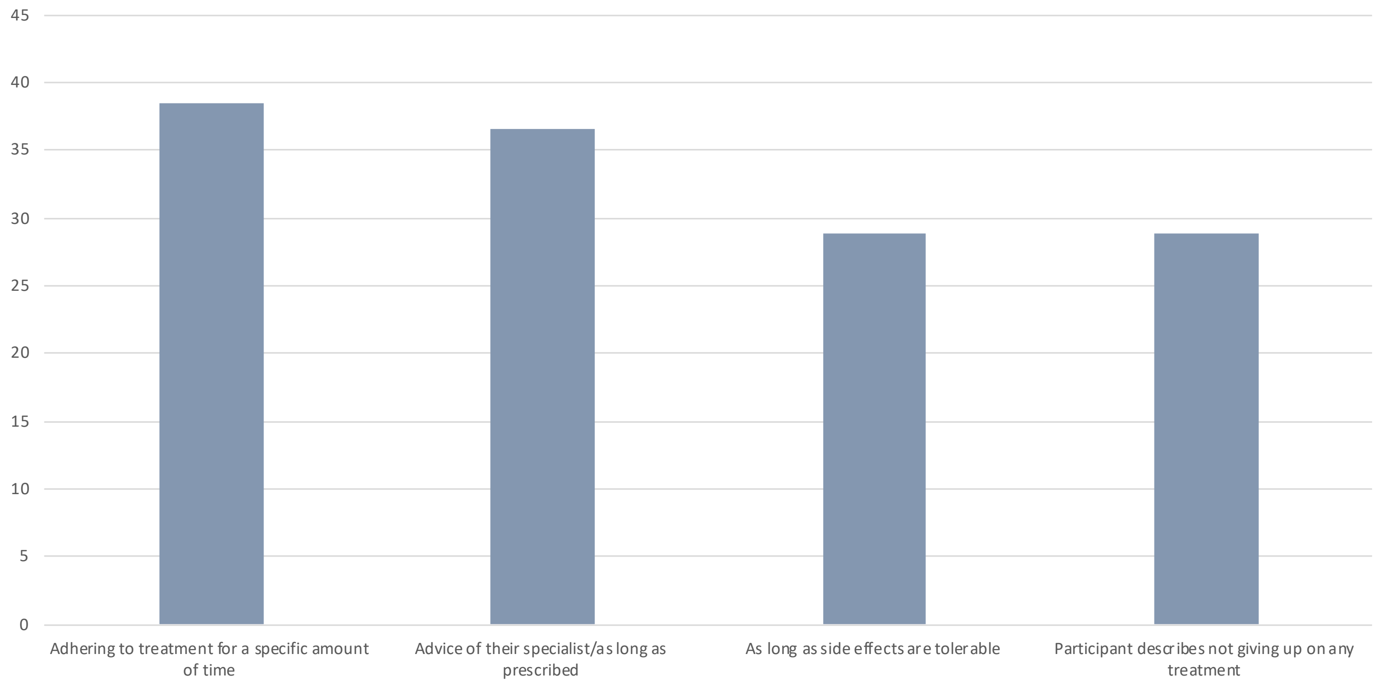


Figure 5.38: Adherence to treatment (percent of all participants)

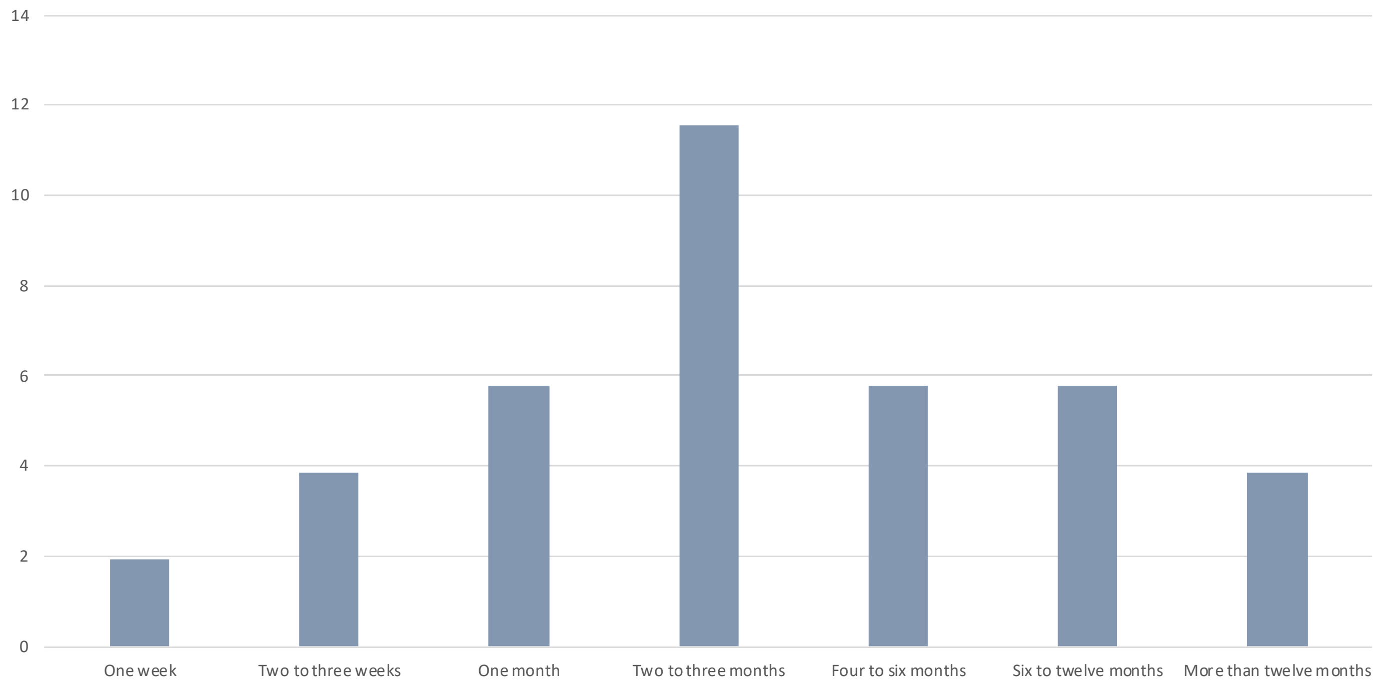


Figure 5.39: Adherence to treatment (Time to adhere to treatment) (percent of all participants)

Table 5.32: Adherence to treatment – subgroup variations

Adherence to treatment	Reported less frequently	Reported more frequently
Participant describes adhering to treatment for a specific amount of time	Regional or remote	Trade or high school Diagnosed in 2017 to 2019
Participant describes adhering to treatment as per the advice of their specialist/as long as prescribed	Stage III and IV Diagnosed in 2017 to 2019	Stage II Diagnosed in 2016 or before Regional or remote
Participant describes adhering to treatment as long as side effects are tolerable	Stage III and IV Aged 25 to 54	Stage 0 and I Aged 55 to 74 Diagnosed in 2016 or before
Participant describes not giving up on any treatment	Stage 0 and I Trade or high school Diagnosed in 2016 or before	Stage III and IV University Diagnosed in 2017 to 2019 Mid to low status

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 (46.15%) was needing to see an improvement in specific symptoms, and this was followed by 19 participants (36.54%) that reported needing to experience an improvement in side effects in general, and needing evidence of stable disease or no disease progression (n= 12, 23.08%). There were 12 participants (23.08%) that described needing to have a balance between benefits and potential side effects, and 11 participants (21.15%), that reported that it was difficult to know if the treatment was working and that they needed evidence.

Where participants need to see improvements in specific side effects, the most noted side effects were aches and pain, and hot flushes.

Participants reported needing to experience an improvement in a specific symptom

Yeah, I guess Yeah, I guess certainly being less stressful, which is probably a direct result of possibly feeling better, having more energy. For me, because of the weight gain, it would possibly be losing weight, but feeling good, not losing weight for the wrong reasons, like or through stress or something like that, but genuinely losing it, because maybe you are more, have more energy. So you're doing more active, you know, you're doing more walking or exercising more than what you have. I guess if you've got swelling in things reduce swelling, if there's any, you know, healing of scars, that's all things that that that are working, you know that your skin is not dry and flaky or or. Whats the word is when it's sort of cold and clammy. Like your hair is in good condition. Like it's not dried, it's not falling out. And healthy for skin in terms of feeds moisturizer, like retains the moisture. So all those combination of things, I think. And I think you know, your stress is directly related to how you're feeling. So I think if you're feeling better, and things are looking better, then you tend to not stress as much you're more calm. Yeah. Participant 013_2021AUHRP

Yes, a reduction in the side effects. The reduced number of hot flushes I experience in a 24-hour period. Or the management of pain. If I'm taking something for the management of pain I would expect the pain to reduce. Participant 027_2021AUHRP

My foot, I used to support stuff, sometimes my feet are feeling really good today, I won't go with the support stuff and I might be able to go two or three days without it and then it will come back, it'll get worse and, "Okay, I've got to put the support stuff on again." It just gives me a little break from it sometimes or not doing at all but it comes back and I know what I've got to do to start off again. Participant 004_2021AUHRP

Participants reported needing to experience an improvement in side effects in general

If there was a treatment to reduce the side effects and that'd be good depends how much it really impacts on quality of life because 4% doesn't sound like enough to make life unbearable, we'll see which one's most worthwhile. Yeah. Participant 018_2021AUHRP

I think when it comes to things like the hormone blockers, I think the reduction in side effects would be, for me, what really needs to change to make me happy to stay on the things. Participant 014_2021AUHRP

So it'd be a reduction in side effects, or I guess it would be something that I would go through if there was a, you know, an in an increased chance of a better lifestyle outcome at the end of it. So, that bone pain that you get from the treatment, does that prevent you from doing anything in your day to day. Participant 020_2021AUHRP

Participants reported needing to experience evidence of stable disease/no disease progression

Probably I'd like to see maybe with the radiation especially, a bit of a X-ray or a scan before and after and what it's done. Visually I can't see that. I don't see that. I don't know. I didn't ask to see that either. Whether they would have showed me that, I don't know. It's something visual. I'm a visual person. I know it's probably make you feel more paranoid about it coming back, but I think to when I go back in December and see the surgeon, I know he's probably not going to allow me to do it. I could ask for it. I'd like to have another MRI done of my breast and see something visual that it's not there. Participant 009_2021AUHRP

PARTICIPANT: Oh, that you're cancer free that you have a scan, of breast cancer patients don't unless they're symptomatic. They don't have scans, they just have mammography or ultrasounds they don't have CTs, like about cancer or pancreatic cancer, we don't have anything or you don't need any scans unless you symptomatic. And then I see so many women with breast cancer present with symptoms are yet sorry, it's gone to your bones Gone to your lungs. Okay. So that sort of is strange to me, but I guess there must be research that shows there's no need to unnecessary scan. For breast cancer patients

INTERVIEWER: So, if your not getting those scans, how do you know if the treatment's working?

PARTICIPANT: Exactly. I'm having a mammogram and ultrasound, so I'll know that it's not in my boob. Yeah, but unless you're a stage three or four, I doubt you're gonna have scans. Okay, right, I guess because it shouldn't really come back. But you know, there's different types of breast cancers, some are more aggressive than others. It just depends on all your scores and all that stuff we go into. So I guess you're not going to know you're just going to have to trust that your mammogram and see a good boob and your ultrasound on your lymph nodes. And that shows up. Participant 041_2021AUHRP

Well, for me, it's just knowing that the tumor is responding to it. The side effects are all manageable if I know that it's working. The side effects, a lot of them are great so I'll put up with it if I know that the tumour is shrinking. Participant 044_2021AUHRP

Participant describes needing to have a balance between benefits and potential side effects

Definitely a reduction in side effects. It does—In the groups that I'm in, the support groups that I'm in the women some women just refuse, they just think it's about quality of life, not quantity. I mean I haven't got to that stage fortunately but there's a lot of women out there that just, "No, I want quality of life." They won't and look I'm one of the lucky ones. I don't consider that I've got bad side effects from this medication at this stage. There are a lot of women that have atrocious side effects and I don't know how they freaking get up and function every day. Participant 010_2021AUHRP

A reduction in side effects would be good and knowing that what I'm taking is keeping or is helping me. I don't know. They say that taking this hormone therapy, I think my oncologist told me it was only 8%, but with chemo, it was 6%; this is 8%. It doesn't seem like a lot, but I'd rather put up with five years of mild symptoms if it's going to give me an 8% greater chance. If it's going to be severe like the first lot was, then I'd have to think about that again. I don't know if I'm going to continue it if the symptoms that I had from this last medication come again. Participant 035_2021AUHRP

I guess I'm not really going to know unless it worked. The only reason you know it hasn't worked is when you get the cancer back. I guess for me one of the key things I ask myself is, "If I stop doing this and my cancer came back, how would I feel?" That's one of the things that I try and think about. Is it too much? Is it too debilitating? Is it affecting my life to the point where it's just too much? I guess I'm not there at the moment. Participant 043_2021AUHRP

Participant reports that it is difficult to know that it is working/needs evidence

Yes, that's a hard one because I guess I couldn't understand why I needed to have chemo. I thought that that was a bit strange when I had a double mastectomy, my lymph nodes with CR, I didn't understand that. To me, you've gone through all this trauma of your body changing, and now you want me to do chemo and I lose my hair and all that stuff, and basically, I'm going to be off work. I think they need to sell it a bit better, I think, why? You need to have full disclosure and an understanding of why are they doing this, not because, "We just do this, because everyone that's in this category that has it." I think it needs to be really explained, research, evidence-based, and that's what we will do. When you have that cancer diagnosis, you start looking at research, you start hearing what other people are doing, what's out there, so they need to probably speak a little bit more like that as well. This is going to increase your probability or chances and whatever, but just, I don't know, having that more understanding. Participant 048_2021AUHRP

I don't know because with the cancer, I guess you can't tell if it's working or not. Sorry, I don't know. For the side effects, yes. When I was going to chemo, then anti-nausea tablets and stuff like yes that would work. Definitely that. I don't know whether the hormonal replacement therapy that I'm taking, is it working? I won't know. There are no markers that shows you that. There's no blood test I can take. I see that's the hard part of it. You don't know whether it's working or it's not. Until it comes back and you say, "Yes." I think that's the hard part. Participant 040_2021AUHRP

Well, with the cancer one you can't really tell, but with the side effects one, it's usually whether you get a significant improvement, or a mild improvement, or no improvement. Participant 036_2021AUHRP

Well, you don't really know, do you? I guess it's a bit of a hidden thing. You just got to hope that it's working. Participant 016_2021AUHRP

Table 5.33: What needs to change to feel like treatment is working

What needs to change to feel like treatment is working	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participants reported needing to experience an improvement in a specific symptom	24	46.15	8	42.11	11	52.38	5	41.67	10	34.48	14	60.87	8	42.11	16	48.48
Participants reported needing to experience an improvement in side effects in general	19	36.54	7	36.84	8	38.10	4	33.33	11	37.93	8	34.78	8	42.11	11	33.33
Participants reported needing to experience evidence of stable disease/no disease progression	12	23.08	5	26.32	4	19.05	3	25.00	7	24.14	5	21.74	3	15.79	9	27.27
Participant describes needing to have a balance between benefits and potential side effects	12	23.08	4	21.05	6	28.57	2	16.67	6	20.69	6	26.09	5	26.32	7	21.21
Participant reports that it is difficult to know that it is working/needs evidence	11	21.15	5	26.32	2	9.52	4	33.33	6	20.69	5	21.74	4	21.05	7	21.21

What needs to change to feel like treatment is working	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participants reported needing to experience an improvement in a specific symptom	24	46.15	6	60.00	8	50.00	10	38.46	5	45.45	19	46.34	5	27.78	19	55.88
Participants reported needing to experience an improvement in side effects in general	19	36.54	4	40.00	5	31.25	10	38.46	2	18.18	17	41.46	7	38.89	12	35.29
Participants reported needing to experience evidence of stable disease/no disease progression	12	23.08	1	10.00	5	31.25	6	23.08	4	36.36	8	19.51	6	33.33	6	17.65
Participant describes needing to have a balance between benefits and potential side effects	12	23.08	3	30.00	4	25.00	5	19.23	2	18.18	10	24.39	4	22.22	8	23.53
Participant reports that it is difficult to know that it is working/needs evidence	11	21.15	2	20.00	4	25.00	5	19.23	1	9.09	10	24.39	7	38.89	4	11.76

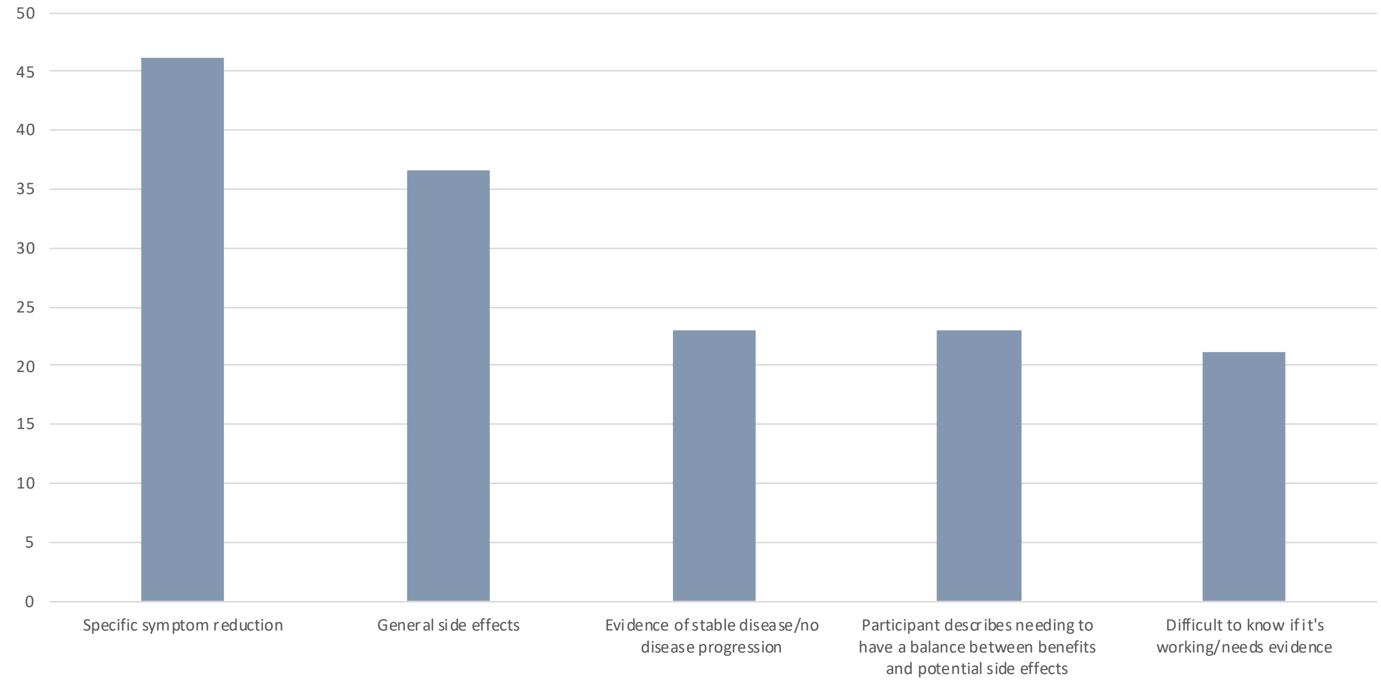


Figure 5.40: What needs to change to feel like treatment is working (percent of all participants)

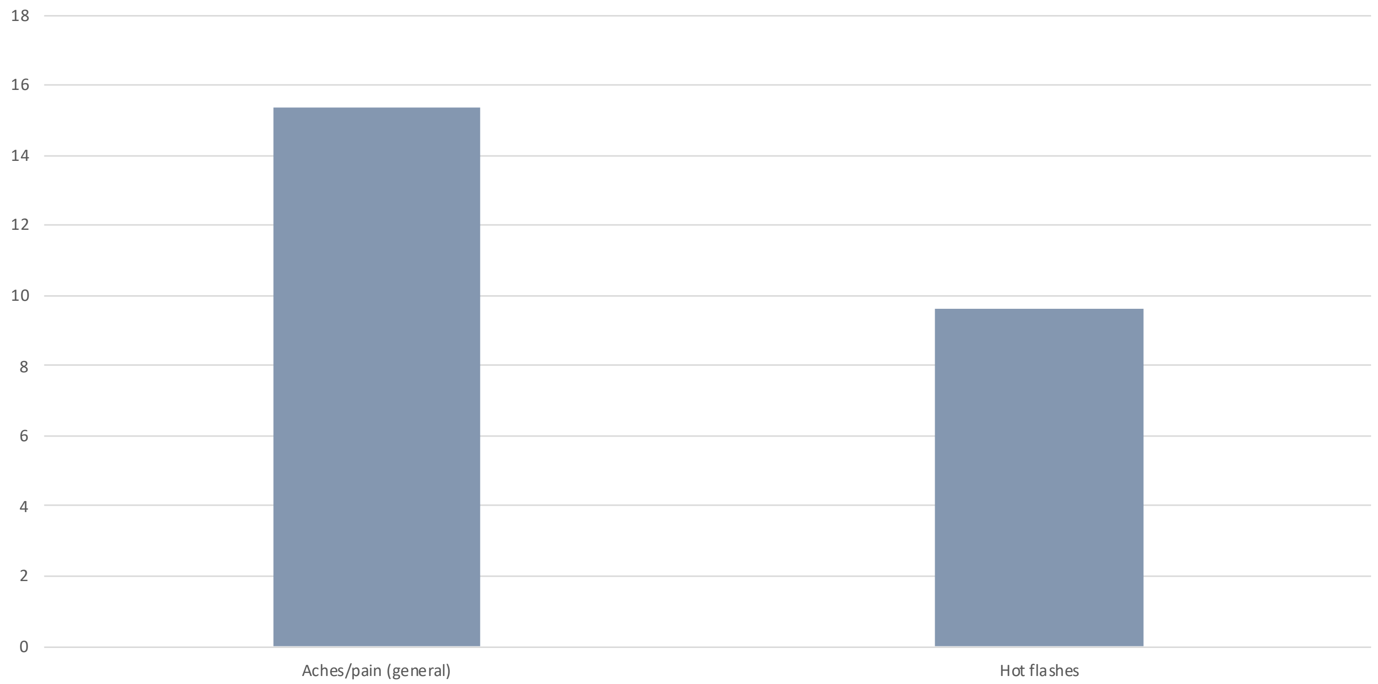


Figure 5.41: What needs to change to feel like treatment is working (specific symptoms) (percent of all participants)

Table 5.34: 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 an improvement in a specific symptom	Aged 25 to 54 Mid to low status	Aged 55 to 74 Diagnosed in 2016 or before
Participants reported needing to experience an improvement in side effects in general	Regional or remote	-
Participants reported needing to experience evidence of stable disease/no disease progression	Diagnosed in 2016 or before	Regional or remote Mid to low status
Participant reports that it is difficult to know that it is working/needs evidence	Stage II Regional or remote	Stage III and IV Mid to low status

What it would mean if treatment worked

Participants were asked to describe what it would mean to them, if their treatment worked. The most common response from 25 participants (48.08%) was allowing them to return to everyday activities or return to normal life. Other participants described that it would have a positive impact on their mental health (n=13, 25.00%), that it would allow them to work (n=9, 17.31%), get enough sleep (n=6, 11.54%), and do more exercise (n=5, 9.62%).

Participant describes treatment allowing them to do everyday activities/ return to normal life

I can go on living, get to work, I can travel, I can be active in sports, but if I had really bad side effects, I wouldn't be able to do that, or if the cancer comes back, I have to change my life to a deal with it. Participant 007_2021AUHRP

I guess just day-to-day living, cooking dinner, doing a little bit of housework, reading the newspaper, just get on with the basic things, being able to shower unassisted. For the first couple of days after each lot of chemo, I could've had a chair in the shower because I just felt so wobbly. Participant 039_2021AUHRP

I think being 41 years old, and every time I stand up, I feel like I'm 80, it's really hard. That would mean a lot to me to just feel normal again, I'm going to cry just thinking of it. Yes, because it really, you feel like that once the chemo is over, that you can start living again and get back to normal life, but you realize that your life's never going to be like that again. That's why I think I've struggled with the whole hormone therapy stuff and then they want to take out my ovaries and all that, I'm just refusing to do that, because there's a lot of research, you remove all those hormones totally, then you're already reducing someone's life sentence already, because your body made some of those hormones to function correctly to keep your organs and all that healthy, I do struggle with that a lot. Participant 048_2021AUHRP

Participant describes treatment working as having a positive impact on their mental health

For me, it's the impact and me emotionally, the chronic ongoing pain just get me down at times. I would say that compared to other people, my pain isn't really severe, but it's always there. It's things that I don't do that I used to really enjoy doing, cross stitching, that sort of thing, that my wrist doesn't really tolerate these days. My writing was never overly neat. These days, it's atrocious and ended actually. I can't for more than a few lines before my wrist starts getting really uncomfortable. Having never learned to touch stuff, I'm actually more comfortable typing than writing. [chuckles] The lymphedema for me has actually meant that I've had to change what I do work-wise. Of course, that is something that isn't ever going to go away. I just had to learn to live with that. Then alternative work that I've been really lucky to find. That's been a big side effect of it all. I forget that one sometimes. Participant 023_2021AUHRP

Probably, I think for mental support, I think often that's probably missed because it can be-- you do question how many chemicals you keep pumping and pumping into your body and it's like the tamoxifen, I know it's working even though my cancer count goes up and down. I feel that it is still working but sometimes, because I live in a warm part of Victoria, once full summer, late spring, summer, and autumn come along, I just perspire all the time. That sort of does impact what you then do and when you do things day to day, this sort of thing, it does change my routine quite a bit like I'll get up earlier and be outside early then come inside. I'll probably have a rest for a couple of hours around midday because then in the evening it's a lot cooler so I'm back outside. So you're outside for a lot longer but I think the mental support is probably a big one. Participant 031_2021AUHRP

If I had reduced side effects I'd probably more consistent in taking my medication. In that sense, I would actually then also, it would alleviate the feeling of worry and guilt. Even though you're making a decision to say, "I'm not going to take this medication," then you worry because you're not taking it. I think if the side effects were less, more patients would be inclined to take and deal with treatment. That's generally why most people stop any treatment whether it's radiation, chemotherapy, because the side effects are just not worth it. Participant 038_2021AUHRP

Participant describes treatment allowing them to return to work

I can go on living, get to work, I can travel, I can be active in sports, but if I had really bad side effects, I wouldn't be able to do that, or if the cancer comes back, I have to change my life to a deal with it. Participant 007_2021AUHRP

If you're on a treatment which makes you nauseous, yes, you can take something to help alleviate the nausea, but that to me just means another pill to mask the problem. I'd prefer them to try and find a solution with a medication that doesn't create those things in the first place. Having said that, yes, if you can take something that alleviates it so you can-- in my case I can't work full time because I can't stand on my feet for more than a short period of time. I just lost a job because my wrist doesn't work properly so because I can't do what needs to be done at a speed that needs to be done, I can't hold that job. It impacts on your ability to better your life. I don't have answers for that because I don't know. Participant 018_2021AUHRP

I guess, if it wasn't causing this fatigue and some of the major issues, then I probably wouldn't miss as much work and probably wouldn't need to ask as much assistance from people but as it is, I'm coping pretty well. I don't know. When I was having AC chemo, I missed a fair bit of work in the days afterward. For a few days afterward, immediately after I was stuck. If I didn't have that side effect, I wouldn't have missed work. Participant 044_2021AUHRP

Participant describes treatment allowing them to get enough sleep

Well, most of the stuff I'm taking at the moment is just for the menopause thing. I think all that would happen is I would sleep better. Otherwise, they don't stop me doing things that this is uncomfortable, something that's disgusting and gross. If that stops happening, I'll have to do a lot less that would be better. Participant 036_2021AUHRP

I think if we talk about the hot flashes, for one of them, [unintelligible 00:16:26] talk about, increasing my body heat means that I shouldn't be exercising in the heat of the day. I can't overheat because then that increases the hot flashes and that increases the side effects of those which can be quite uncomfortable. Obviously, at night time, too many of those can keep you awake, they wake you up, they make it very difficult to sleep. Obviously, sleep deprivation then impacts the rest of your day. If I was to see a reduction even by half of those symptoms, then I'd simply be taking the medication because it would definitely lead to obviously a better night's sleep and you're going to be [unintelligible] the next day. Participant 037_2021AUHRP

Sleep, that's easy. [laughs] Sleep through the night. I think that would be the main thing. Participant 005_2021AUHRP

Participant describes treatment allowing them to do more exercise

It just means I could be more mobile. I could hit my 10,000 steps a day. Well, not quite. Having the antidepressant didn't take the pain away. It just made it easier to push through. By four-five o'clock, I was still in agony. If I could get rid of the side effects, I'd still be taking the tablets. Participant 025_2021AUHRP

Oh, I almost couldn’t look after myself. In terms of, I couldn’t carry out my daily living tasks, so I couldn’t really go shopping. I couldn’t go out socially. I certainly couldn’t do any physical activity like sport or exercise. Couldn’t do any of that. Participant 047_2021AUHRP

I can go on living, get to work, I can travel, I can be active in sports, but if I had really bad side effects, I wouldn't be able to do that, or if the cancer comes back, I have to change my life to a deal with it. Participant 007_2021AUHRP

Table 5.35: What it would mean if treatment worked

What it would mean if treatment worked	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participant describes treatment allowing them to do everyday activities/ return to normal life	25	48.08	9	47.37	10	47.62	6	50.00	11	37.93	14	60.87	9	47.37	16	48.48
Participant describes treatment working as having a positive impact on their mental health	13	25.00	3	15.79	7	33.33	3	25.00	8	27.59	5	21.74	4	21.05	9	27.27
Participant describes treatment allowing them to return to work	9	17.31	5	26.32	3	14.29	1	8.33	6	20.69	3	13.04	2	10.53	7	21.21
Participant describes treatment allowing them to get enough sleep	6	11.54	4	21.05	1	4.76	1	8.33	3	10.34	3	13.04	0	0.00	6	18.18
Participant describes treatment allowing them to do more exercise	5	9.62	1	5.26	1	4.76	3	25.00	3	10.34	2	8.70	1	5.26	4	12.12

What it would mean if treatment worked	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participant describes treatment allowing them to do everyday activities/ return to normal life	25	48.08	7	70.00	6	37.50	12	46.15	6	54.55	19	46.34	11	61.11	14	41.18
Participant describes treatment working as having a positive impact on their mental health	13	25.00	2	20.00	7	43.75	4	15.38	2	18.18	11	26.83	3	16.67	10	29.41
Participant describes treatment allowing them to return to work	9	17.31	1	10.00	3	18.75	5	19.23	1	9.09	8	19.51	2	11.11	7	20.59
Participant describes treatment allowing them to get enough sleep	6	11.54	3	30.00	2	12.50	1	3.85	1	9.09	5	12.20	4	22.22	2	5.88
Participant describes treatment allowing them to do more exercise	5	9.62	2	20.00	2	12.50	1	3.85	1	9.09	4	9.76	3	16.67	2	5.88

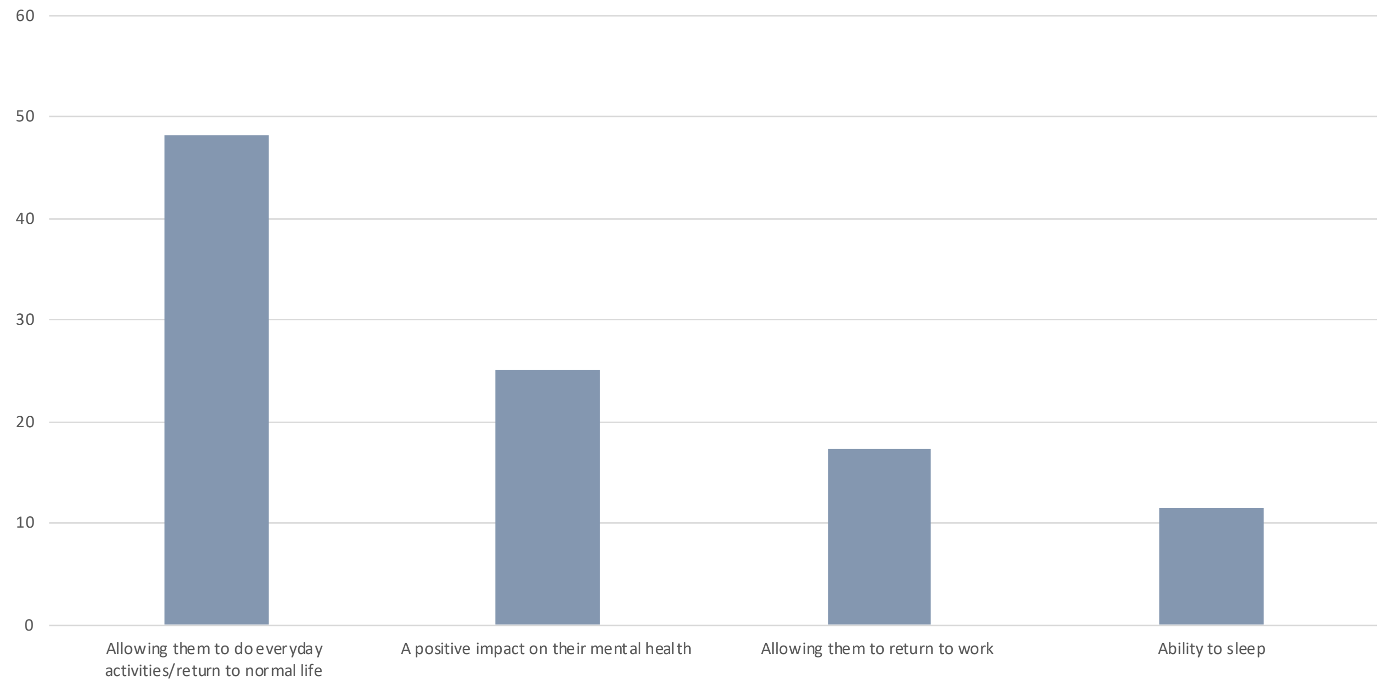


Figure 5.42: What it would mean if treatment worked (percent of all participants)

Table 5.36: What it would mean if treatment worked – subgroup variations

What it would mean if treatment worked	Reported less frequently	Reported more frequently
Participant describes treatment allowing them to do everyday activities/ return to normal life	Aged 25 to 54 Diagnosed in 2017 to 2019	Aged 55 to 74 Diagnosed in 2016 or before Mid to low status
Participant describes treatment working as having a positive impact on their mental health	-	Diagnosed in 2017 to 2019
Participant describes treatment allowing them to get enough sleep	Trade or high school	Diagnosed in 2016 or before Mid to low status
Participant describes treatment allowing them to do more exercise	-	Stage III and IV Diagnosed in 2016 or before

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 40 participants (76.92%) was the internet in general. There were 29 participants (55.77%) that described accessing from a specific health charity, 24 participants (46.15%) accessed information primarily through other patient's experience. Other types of information accessed included books, pamphlets and newsletters (n=21, 40.38%), from Facebook or social media (n=17, 32.69%), nursing staff (n=17, 32.69%), and their treating clinician (n=14, 36.992%), and through journals and research articles (n=13, 25.00%).

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 20 participants (38.46%) was information about what to expect (e.g. from disease, side effects, treatment). There were 17 participants (32.69%) that described talking to their doctor or specialist as being helpful, and 11 participants (21.15%) that described other people's experiences as being helpful. Other types of information described as being helpful included information from health charities (n=10, 19.23%), and and information that is specific to their condition and sub-types (n=5, 9.62%).

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 19 participants (36.54%) that responded that no information was not helpful. The most common type of information found to be unhelpful by 13 participants (25.00%) was other people's experiences. There were eight participants (15.38%) that described other people giving advice or opinions as unhelpful, and the same number that described worst case scenarios and negative information as unhelpful (n=8, 15.38%). Other participants described information from their GP or specialist as unhelpful (n=7, 13.46%), and information from sources that are not credible as not helpful (not evidence-based) (n=6, 11.54%).

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, most participants had a preference for a combination of information sources (n=44, 8.63%), all of these combinations included online information. There were five participants (9.62%) only had a preference for talking to someone, and four participants (7.69%) only had a preference for written (booklets). Participants commonly had a preference for talking to someone plus a written form of information (either app, internet or booklet) (n=33, 63.47%), and a total of 15 participants (n=15, 28.84%) that had a preference for information in the written form only (either app, internet or booklet).

The main reasons for a preference for online information were accessibility, and being able to digest information at their own pace. The main reason for talking to someone as a preference was being able to ask questions, and getting information that was relevant or personalised.

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 was from the beginning when diagnosed (n=20, 38.46%), this was followed by participants describing being receptive to information after the shock of diagnosis (n=13, 25.00%), continuously throughout their experience (n=9, 17.31), and after treatment (n=7, 13.46%).

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=32, 61.54%). There were 16 participants (30.77%) that described an overall positive experience, with the exception of one or two occasions, and four participants (7.69%) that had an overall negative experience.

Participants that had positive communication, described the reason for this was because of holistic, two-way, supportive and comprehensive conversations (n=17, 32.69%).

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: 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 very good overall knowledge, coping and confidence for managing their own health.

Information given by health professionals

information they were given by healthcare professionals. Information about treatment options (n=46, 88.46%), physical activity (n=26, 50.00%), disease management (n=25, 48.08%) and, hereditary considerations (n=22, 42.31%) were most frequently given to participants by healthcare professionals, and, information about how to interpret test results (n=10, 19.23%), complementary therapies (n=9, 17.31%) and, clinical trials (n=7, 13.46%) 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=29, 55.77%), how to interpret test results (n=27, 51.92%), disease management (n=25, 48.08%), and disease cause (n=24, 46.15%) were most searched for by participants, and information about psychological and social support (n=12, 23.08%) and, clinical trials (n=10, 19.23%) were searched for least often.

Information gaps

The largest gaps in information, where information was neither given to patients nor searched for independently were clinical trials (n = 37, 71.15%), dietary information (n = 27, 51.92%), complementary therapies (n = 27, 51.92%) and psychological and social support (n = 26, 50.00%).

The topics that participants most commonly did not search for independently after not receiving information from healthcare professionals were treatment options (n = 21, 40.38%) and physical activity (n = 16, 30.77%).

The topics that participants were given most information from both healthcare professionals and searching independently for were how to interpret test results (n = 22, 42.31%), and disease Cause (n = 19, 36.54%).

The topics that participants most commonly searched for independently after not receiving information from healthcare professionals were treatment options (n = 25, 48.08%) and disease management (n = 12, 23.08%).

Most accessed information

Across all participants, information from non-profit organisations, charity or patient organisations was most accessed followed by information from the hospital or clinic where being treated. Information from Pharmaceutical companies was least accessed.

My Health Record

My Health Record is an online summary of key health information, an initiative of the Australian Government. There were 12 participants (23.53%) had accessed My Health Record, 39 participants (76.47%) had not.

Of those that had accessed My Health Record, there were seven participants (58.33%) that found it to be poor or very poor, and four participants (33.33%) that found it acceptable.

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 40 participants (76.92%) was the internet in general. There were 29 participants (55.77%) that described accessing from a specific health charity, 24 participants (46.15%) accessed information primarily through other patient's experience. Other types of information accessed included books, pamphlets and newsletters (n=21, 40.38%), from Facebook or social media (n=17, 32.69%), nursing staff (n=17, 32.69%), and their treating clinician (n=14, 36.992%), and through journals and research articles (n=13, 25.00%).

Participant describes accessing information through the internet in general

I'm trying to get the words out. After I was diagnosed, I guess, like most people did, got online. Get on all the different types of chances that you have and treatment that you'd have. Or the usual treatment that you'd be given and general prognosis, I guess. Depending on the stage and all that sort of stuff. Participant 028_2021AUHRP

I haven't accessed much recently, but I used to always be on the internet. Asking any of the physicians or medical people I was seeing what they thought about my understanding of things. Participant 016_2021AUHRP

Oh, lots of googling which everyone tells you not to do that. Probably, at the surgeon with all the results and biopsy and things like that, when we went back, he explained everything, but I don't know. I went home, he gave me the whole report and all the ins and outs of everything, which of course I googled everything. I wanted to know what everything meant and all that sort of thing. Maybe I should have asked more questions at the time, but I probably- a little bit more information from him. I felt that they don't want to overload you with too much information either because they don't want to scare you. You got enough to deal with, but, I guess most of the information that I know now about breast cancer is probably from me doing my own research possibly. If that makes sense. What does my ER/PR+, HER2-negative-- At first, I'm like, well, what's that mean? That's me googling. What does ER/PR+ mean? What does HER2-negative mean? What does all these different, I guess the whole glossary terminology of what. That was me doing that myself. Participant 009_2021AUHRP

Participant describes accessing information from a specific health charity

At the prompting of BreastScreen LOCATION, they told me I should register with BCNA, and so I did that and I found that with a good resource. I also looked through information on reputable sites, reading studies and general information, whether they be Australian, British, American. I knew it was important to make sure it was coming from a well researched -- and I also find it interesting to read the stories of other women, of what they'd experienced and how they access things and what have you. Participant 019_2021AUHRP

Over time, I've found two or three websites that are my go to, so BCNA, the UK breast cancer site and the US breast cancer site. Those tend to be the ones that I will-- The websites that I look at for different things. I've looked up things like types of surgery, risk of lymphedema, side effects of chemo, side effects of radiation, long-term side effects of radiation, short-term side effects, recurrence, risk information, and signs and symptoms of recurrence and metastases, [silence] side effects of hormone therapy. These days as a side effect of hormone therapy, I'm osteopenic. I'm on Prolia, so, looking up different things about that. Participant 023_2021AUHRP

Just mostly about information on on treatment for young women and a lot of stuff about that mental health support and about post tamoxifen inflammation, mostly what I accessed, I went across to Melbourne for conference at the Breast Cancer Network that was pretty good. But yeah, that's really pretty much it. Okay. I tried not to research stuff like, yeah, beyond the extra little bit of support. Because it is like, it's just, it's such a rabbit warren of information that can be read so many different ways. And, you know, I growl at my patients when they Dr. Google stuff, so I've sort of really tried really hard not to be, to follow that path, even though sometimes you just can't help yourself. I have, like, when I was going through treatment, you know, you hear people talking about, oh, you know, will my white cell count was this my neutrophils was that. I purposely didn't sound mine out. Yeah. Cuz I was like, if I need to know, and they're worried about something, you know, they'll tell me. Okay. Participant 033_2021AUHRP

Participant describes primarily accessing information through other patient's experience

So there was just an ad in the paper for the annual sort of fundraiser luncheon in October. And I just went on for the first time, I didn't actually ring you know, and find out what it's about, I just turned up because I just thought that people be standing around for an hour or two, you know, maybe having some nibblies. And when it was a sit down, luncheon, and everyone was in pink, and I turned up in pants and a gray shirt. And was a bit overwhelmed, then I just straightaway obviously knew I was yeah, not, not not Yeah, newbie. And they came up and took me under their wings and had a cry, and yeah, set me down. Yeah. And then and then from then on, like I am still friends with some of them, you know, they just so from them, it was more like than the word of mouth sort of stuff. And that's gold, and you can't, you know, you can't put a price on that. Because they're the people that let me know about the the care plans, you know, the old chronic disease management plans, and things like that, that you didn't know about and what oh, I didn't know about that. And like no that in support, you know, we'd have because I wasn't working, I was going through all my treatment and stuff that has, you know, lunches once a month and have little dress ups and we'd bring a plate each and, and then with all the social things in between. And so, yeah, that was a wealth of information from that group.
Participant 013_2021AUHRP

The Breast Care Network has been really helpful. They've got a really helpful website that gives a lot of information. I've also joined a couple of Facebook pages of women who have also been suffering from breast cancer and being able to share the knowledge that they've gained, and also talking to my breast care nurse. I haven't seen her for a while, but when I was going through treatment, talking to my breast care nurse as well was quite helpful. The Australian government's cancer sites as well have a lot of good information. I get my information from what I consider reputable sources. I'd rather get them from people who know what they're talking about rather than the hearsay. Participant 037_2021AUHRP

I had a friend who put me in contact with the charity Pink Finss. They've given me a lot of support on a holistic level just with information, support packages, financial support, emotional support, support for the family, support group, just everything. They've really supported me a lot throughout the year. Then, I've also looked at all the support online from Breast Cancer Foundation, Cancer Council, McGraw Foundation, all that stuff. Obviously, looked at all the information from that. I only ever really looked at reputable sites and then just people's accounts of things, someone shared their experience, I didn't really go looking at random stuff that wasn't reputable. Then I just took people's experiences also with a grain of salt, knowing that everyone's different in how they respond and react. To me, knowledge is power. If I had the information there, then I could adapt it to fit me. Participant 042_2021AUHRP

Participant describes receiving information from books, pamphlets and newsletters

Well, I've just read the little books that I was sent home with that I got from Breastscreen.
Participant 015_2021AUHRP

I got an information pack at the hospital, from the nurses, before radiation started. There was about seven or eight booklets in it, so it discussed things like your carers, what they go through, and it discussed nutrition, and then just discussed the chemo and the radiation. I read through that. I found that I joined at the Jacaranda Lodge, and I think If COVID hadn't been in it, it would be better. COVID came and it stopped people from meeting face to face. It. was done over Zoom, which was fine. I've done that a couple of times, and it was fine. It's good when you go to the hospital and you meet other women who are going through it as well. Participant 032_2021AUHRP

I had all the information, like the pamphlets and all of those things from Breast Screen. I also got given some more, when I went for the chemotherapy. Then I didn't actually really, like I said, I didn't Google anything, look online, or do any of that stuff. That was it. Participant 050_2021AUHRP

Participant describes accessing information primarily through Facebook and/or social media

Then, and they had several meetings as well. So they did kind of everything, socialize formal meetings with guest speakers. Then there's also things like the encore program, YWCA encore programs, where that they had guest speakers and people who provided knowledge and information and that we had that exercise Yeah, just simply paying for hospitals and then, things like particular in terms of websites that I've learned, you know, the BCNA in particular have fantastic information, once was sort of put onto them in the first getting the, what they call like the care package was in them send you out a diary and this and that and we can track things that you're going through and lots of good information, lots of good fact sheets about pathology and lymphodema and, and *the care plans. And I found, particularly the bcna to be a lot and Cancer Council, website and booklets and things to be the main go to as incredible and what I needed. And then also Facebook pages that like close Facebook page through bcna, with different the different groups there, which I'm not really on anymore. But at the time, I found it quite helpful. Participant 013_2021AUHRP*

I've sought out information on the surgery and its side effects. I've sought information on whether to have a lumpectomy or mastectomy, sought information all about radiation, looked into that. Talked to other women on the breast, on the MyJourney site, I joined that. Talked to other women that had undergone it, just to put my mind at ease about having radiation, looked up everything I could about the hormone drug. Did a lot of research on what to use to stop my skin burning in radiation. Again, I talked to the girls that had already been through all this and they're on MyJourney, what is it like? It's a chat site through the MyJourney thing and you can talk to other girls about everything really, so that's been really helpful. The internet's been really helpful but I've stuck to all the profit.org cancer sites. I haven't looked at-- I ignore the websites that I don't feel look legitimate or real. What else did I look up? I read a lot about chemotherapy and looked all that up before I made my choice, did a lot of reading. A lot of research on practically everything that I had to undergo, I researched it before I gave a yes or no, I went ahead with whatever it was. Participant 035_2021AUHRP

Dr. Google, a lot. [laughs] A lot. I've also, spent a lot of time on Facebook forums, specifically closed ones for stage four breast cancer patients. There's one that's Australia and New Zealand-based. There's one that's international. I've more recently joined one for the older patients and one that's for stage four liver mets-- Breast cancer with liver Mets. Mums with stage four breast cancer, so a fair few different forums. I've got a brain trust of real time experience. That's been really useful. Google's been good. I've been tapping into things like PubMed and the like. The breast care nurse is terrific as well. My oncologist has just wealth of knowledge, and she gives me a lot of times, but I obviously, you don't have them on tap. The breast care nurse has been really great in terms of filling out some information that I think of later on. Participant 051_2021AUHRP

Participant describes receiving information through nursing staff

The hospital provides you with information, seminar type of things. When you first get diagnosed, they sit down with you and talk with you. The breast care nurses are very helpful. Through my dragon boating clubs, dragons of breast, I got information through them. The breast cancer network online. I've accessed a lot of those. I've done a lot of Google researches myself to ask questions. Talking to other people, other cancer survivors, and also Facebook groups have been very helpful. Participant 018_2021AUHRP

You get overwhelmed with it when you first get diagnosed. You get all your information and then you get bombarded by the Breast Care Network. I didn't actually read a lot of it. Does that make me bad? I don't know. If I wanted to look up something I'd look it up on the web or on the books they'd given me or pamphlets or whatever. Or I'd ask the breast care nurse. Participant 024_2021AUHRP

The Breast Care Network has been really helpful. They've got a really helpful website that gives a lot of information. I've also joined a couple of Facebook pages of women who have also been suffering from breast cancer and being able to share the knowledge that they've gained, and also talking to my breast care nurse. I haven't seen her for a while, but when I was going through treatment, talking to my breast care nurse as well was quite helpful. The Australian government's cancer sites as well have a lot of good information. Participant 037_2021AUHRP

Participant describes primarily accessing information through treating clinician

The breast cancer nurse put me on to The Breast Cancer Association, BCNA I want to say. Yes. That was a useful source of information. I had information from my specialist. I did a bit of Googling and I also have access to things like Medline databases, but I tried not to do that too much. Participant 011_2021AUHRP

Dr. Google. Probably just talking to the surgeon or the radiation oncologist or the oncologist. I think of things and make a list to ask them so I don't forget. I'm on a Facebook support group. Participant 014_2021AUHRP

A lot online. Now I know you've got to be very careful about the sources you go to. But there's been a lot through breast cancer network Australia. Just information that I was given through my health providers also tried to look at various PubMed studies. Which, you know, then I discussed with the oncologist. I was happy to ask my oncologist. And I knew that he knew what he was talking about. I guess there's *reading books, or the cancer survivors, and then links then to, you know, things, I guess, groups through social media, other people going through the same things, their stories, what they've tried. Participant 034_2021AUHRP*

Participant describes accessing information primarily through journals (research articles)

Okay, um, let's start at the beginning when I was told I had a Phyllodes tumour, the registrar at the hospital who told me wrote down cystosarcoma Phyllodes tumour on a Post-it note, gave it to me and said, that's what you've got. So that is all the information I was given. Everything I have found out about Phyllodes tumours since then, I've done off my own bat. And it's reading research studies, John Hopkins, Mayo Clinic, stuff in The Lancet. So peer reviewed medical journals is where I've been getting most of my information from and also, and also speaking to other women with the same problem. Participant 003_2021AUHRP

Look, mainly I guess internet, only looking things up on the internet, going into certain journals, Lancet journals. Seeing new studies that are being done, studies that have been done around the world, particularly in regards to tamoxifen and letrozole. Case studies they've done and different groups they've done and the outcome of someone taking this every day versus someone taking it every second day to someone just taking it once a week, what were the outcomes. That's quite interesting. Not much difference which I was quite surprised. Participant 038_2021AUHRP

Well, I pretty much read everything on the internet, and the breast cancer people gave you a lot of books and templates and things. Some of them were a bit out of date. Then because I can get access to some of the medical journals and stuff, the Lancet and things like that, so I can read up specific articles in Google Scholar and things. I can get medical journal articles, and so could have looked at some of them. A lot of it, that stuff was not actually particularly helpful. Then books and blogs and stuff. I've got to the point where I don't really read much anymore. A lot of it is about the same so a bit repetitive. Participant 036_2021AUHRP

Table 6.1: Access to information.

Access to information	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participant describes accessing information through the internet in general	40	76.92	15	78.95	16	76.19	9	75.00	20	68.97	**20**	**86.96**	15	78.95	25	75.76
Participant describes accessing information from a specific health charity	29	55.77	9	47.37	**14**	**66.67**	6	50.00	14	48.28	15	65.22	12	63.16	17	51.52
Participant describes primarily accessing information through other patient's experience	24	46.15	10	52.63	10	47.62	**4**	**33.33**	**10**	**34.48**	**14**	**60.87**	10	52.63	14	42.42
Participant describes receiving information from books, pamphlets and newsletters	21	40.38	**10**	**52.63**	7	33.33	4	33.33	12	41.38	9	39.13	7	36.84	14	42.42
Participant describes accessing information primarily through Facebook and/or social media	17	32.69	**9**	**47.37**	**4**	**19.05**	4	33.33	8	27.59	9	39.13	7	36.84	10	30.30
Participant describes receiving information through nursing staff	17	32.69	6	31.58	6	28.57	5	41.67	7	24.14	**10**	**43.48**	7	36.84	10	30.30
Participant describes primarily accessing information through treating clinician	14	26.92	6	31.58	4	19.05	4	33.33	7	24.14	7	30.43	5	26.32	9	27.27
Participant describes accessing information primarily through journals (research articles)	13	25.00	6	31.58	5	23.81	2	16.67	6	20.69	7	30.43	3	15.79	10	30.30

Access to information	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participant describes accessing information through the internet in general	40	76.92	**9**	**90.00**	**14**	**87.50**	**17**	**65.38**	**7**	**63.64**	33	80.49	14	77.78	26	76.47
Participant describes accessing information from a specific health charity	29	55.77	**8**	**80.00**	10	62.50	**11**	**42.31**	**8**	**72.73**	21	51.22	10	55.56	19	55.88
Participant describes primarily accessing information through other patient's experience	24	46.15	**6**	**60.00**	8	50.00	10	38.46	6	54.55	18	43.90	9	50.00	15	44.12
Participant describes receiving information from books, pamphlets and newsletters	21	40.38	**3**	**30.00**	7	43.75	11	42.31	**7**	**63.64**	14	34.15	9	50.00	12	35.29
Participant describes accessing information primarily through Facebook and/or social media	17	32.69	4	40.00	6	37.50	7	26.92	4	36.36	13	31.71	**8**	**44.44**	9	26.47
Participant describes receiving information through nursing staff	17	32.69	3	30.00	**3**	**18.75**	11	42.31	4	36.36	13	31.71	**4**	**22.22**	13	38.24
Participant describes primarily accessing information through treating clinician	14	26.92	**0**	**0.00**	4	25.00	**10**	**38.46**	3	27.27	11	26.83	**3**	**16.67**	11	32.35
Participant describes accessing information primarily through journals (research articles)	13	25.00	3	30.00	5	31.25	5	19.23	3	27.27	10	24.39	6	33.33	7	20.59

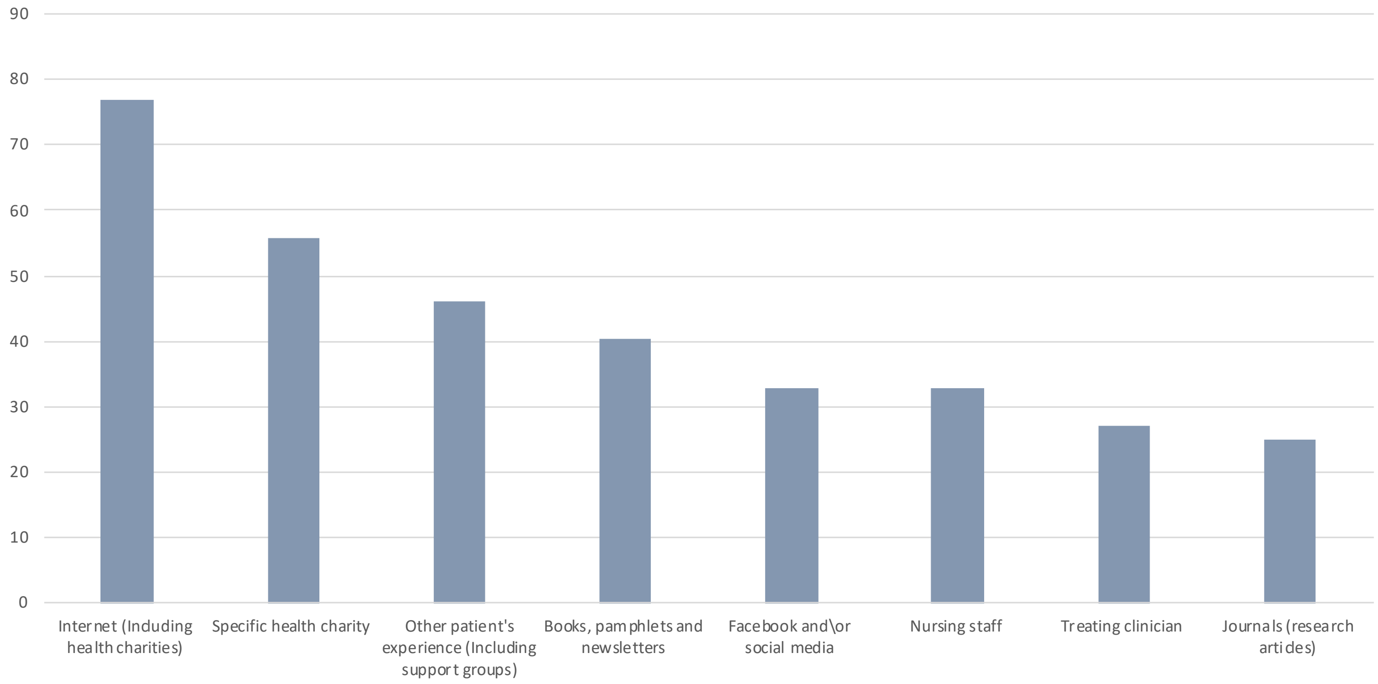


Figure 6.1: Access to information

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	Diagnosed in 2020 or 2021 Regional or remote Mid to low status	Diagnosed in 2017 to 2019 Metropolitan
Participant describes accessing information from a specific health charity	Diagnosed in 2020 or 2021 Regional or remote Mid to low status	Diagnosed in 2017 to 2019 Higher status
Participant describes primarily accessing information through other patient's experience	Regional or remote	Aged 55 to 74
Participant describes receiving information from books, pamphlets and newsletters	Stage II Diagnosed in 2016 or before Regional or remote Mid to low status	Stage 0 and I Diagnosed in 2017 to 2019
Participant describes accessing information primarily through Facebook and/or social media	Stage II Regional or remote	Stage 0 and I Diagnosed in 2017 to 2019
Participant describes receiving information through nursing staff	Regional or remote Mid to low status	Stage III and IV Higher status
Participant describes primarily accessing information through treating clinician	Diagnosed in 2016 or before Regional or remote Mid to low status	Stage III and IV
Participant describes accessing information primarily through journals (research articles)		Diagnosed in 2017 to 2019

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 20 participants (38.46%) was information about what to expect (e.g. from disease, side effects, treatment). There were 17 participants (32.69%) that described talking to their doctor or specialist as being helpful, and 11 participants (21.15%) that described other people's experiences as being helpful. Other types of information described as being helpful included information from health charities (n=10, 19.23%), and and information that is specific to their condition and sub-types (n=5, 9.62%).

Participant describes hearing what to expect (e.g. from disease, side effects, treatment) as being helpful

I guess knowing what's going to happen to me as I went through chemo and then radiation. Knowing what to expect. Participant 039_2021AUHRP

Whilst I was going through chemo, the most helpful information I received was from people who'd been through it before, what to expect, what sort of things ease the symptoms. Same with radiation, talking to people who'd been through it and getting information on the things that they do use to reduce the side effects and to get through it. Day-to-day, probably more my oncologist and the information that he *provides me around the expected side effects of the Tamoxifen and how I counteract those and what sort of things will reduce the impacts or reduce the likelihood of the cancer coming back. Participant 037_2021AUHRP*

A lot of it was just kind of more under like, you know, the information that gave us an understanding of what to expect and what the process was, you know, from, from where you were, what was the next step? And the step after that so far, so you knew where you're heading and that sort of stuff? Participant 020_2021AUHRP

Participant describes talking to their doctor or specialist as helpful

Probably having it explained to me exactly what the pathology actually meant. That was explained very well to say that the grade of the tumor and how fast it's growing and know what the implications are for having hormone-positive breast cancer as opposed to the negative one. That sort of thing was very helpful from the breast care nurse and the doctor and the oncologist even. They explained things very well. Participant 017_2021AUHRP

I would say actually talking to the oncologists, because I think the stuff that's given to me I think, because I already have medical knowledge it's written for people really with no medical knowledge and it's very thorough, but I know all that stuff. So yeah, so I although it's been good to have it and read it and go yep, yep, yep, yep. Yep, that's what I kind of knew. I haven't found it sort of particularly eye opening or useful. Participant 034_2021AUHRP

Probably the information that, as it's explained to me, either by the doctors or nursing staff, rather than reading it. They're able to provide it in a way that's more interactive, and I can ask follow up questions and things like that. Participant 050_2021AUHRP

Participant describes other people's experiences as helpful (Peer-to-peer)

Actually, I was going to support groups on Facebook and I found that more helpful to me than anything else. It's nice to actually speak to people that were going through it. Whilst, for instance, each breast cancer's obviously different but there are some that are similar and I found that the most helpful, to be honest, than any information written down. Participant 008_2021AUHRP

Honestly, I think a lot of the information that's been best for me is validation of some of my ailments if you like. That no, I'm not the only one that has this, despite the doctor saying, oh, that's not normal. Especially the breast cancer sites on Facebook and through the networks. You talk to other women who are on the same protocols and they'll go, oh yes, I've got that. It's like, "Okay, it's not just me. I'm not being difficult." This is a standard, the joint ache, the lack of being able to sleep, the insomnia is just crazy. All those things are normal. They're all going, "Yes, we've all got that. You're not weird. We're all doing this and this is what we try to do to deal with it." I think it's more about validation than anything else. Participant 018_2021AUHRP

Whilst I was going through chemo, the most helpful information I received was from people who'd been through it before, what to expect, what sort of things ease the symptoms. Same with radiation, talking to people who'd been through it and getting information on the things that they do use to reduce the side effects and to get through it. Day-to-day, probably more my oncologist and the information that he provides me around the expected side effects of the Tamoxifen and how I counteract those and what sort of things will reduce the impacts or reduce the likelihood of the cancer coming back. Participant 037_2021AUHRP

Participant describes health charities information as helpful

The cancer council booklet that I got was good. It was basic. It was to the point and you didn't have to be a rocket scientist to understand it. Actually, that had a glossary in the back of it of terms and wording that might be used and what does it mean. That was probably quite helpful. I don't know.
I think it's difficult when you're sitting in front of somebody when you're dealing with. I'd write down questions because I know I'd forget. Sometimes that's why it's good to have somebody else with you because they'll remember things that you don't remember to actually record the conversation. You walk out of there with so much information, so much new information and things that you didn't know anything about before that you think, "Oh, what did he say? Did he say this? Or did he say that? Or did you mean this or did you mean? Participant 009_2021AUHRP

What's been the most helpful? Yeah, in terms of going through myself, the BCNA fact sheets and booklets. Because you know the pathology gets your pathology, and it's like, you know, reading something in

Japanese, and they don't really I've got some results that they didn't really explain it in detail, or they might have mentioned things. And because you're basically you're in shock. And so you're not absorbing everything because you're still kind of behind on what they just told you. And so even this year, that's the pathology factsheet things that lymphoedema. Like I said, care plans. Fertility, because I'm a young information, hotline that you can ring, you know, they got counselors, they give you financial advice. And then like cancer council for that other more general broader, broader issues, about cancer and things in your community that might help. You know, they've got lots of health and well being things you can do courses, online webinars, all that sort of things. Participant 013_2021AUHRP

It actually depends on what treatment stage I was at. Sometimes, for me, I like- because I've dealt with so many, I felt there's so many different components and it can be so overwhelming that the way I hoped was only just concentrating on if it was my surgery, I'm only looking at the surgery. I'm not even thinking about chemo. I'm not even thinking about radiotherapy. I was just getting to that mindset first. A lot of it, especially like at the start, when they were looking for the diagnosis. The Breast Care Association and so my journey just books, I found a booklet there that I could flip through, look at it, write it. Now, I think they've got an online tool too, but it just asks lots of questions. From that, then I would try and find information. It'd be disadvantages of having a deep surgery compared with having an implant and those types of things. Whether I wanted to have an immediate. There's so many smaller decisions to make. Whether I wanted an immediate reconstruction or wait till later on. I guess I found that is the basis for that book. That would give me some knowledge that I could ask my health professionals to go from there. Participant 021_2021AUHRP

Participant describes information specific to their condition (and sub-types) as helpful

I think it's just the way that-- I'm trying to think, really. How it happens. It's a hormonal one, now I understand what it means. Just the type of cancer it is. I don't know if it's hormonal. Then I need to stay away from things that have high-concentration of progesterone. That kind of information that there was so much information as well so just be careful on what you see sometimes or you just get overwhelmed with it. Participant 040_2021AUHRP

The most helpful was looking at whether or not I should have radiation for the DCIS. Cause with DCIS many women have it, they don't know it. And they die with it, even without ever knowing where head it. And a lot of women with DCIS is over treated. And and, and so that's why I was hesitant in having it that the oncologist gave me the stats that say, Okay, if you don't have it, you've got a 20% chance of coming back. If you have radiation, it's less than 5%. And so in the end had to go with the evidence. And there are international studies, where longitudinal studies where they're tracking women who are not having treatments to try and work out whose DCIS takes off and becomes invasive and who doesn't. And the it's not out yet, they don't know yet. Participant 001_2021AUHRP

Table 6.3: Information that was helpful

Information that was helpful	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participant describes hearing what to expect (e.g. from disease, side effects, treatment) as being helpful	20	38.46	7	36.84	7	33.33	6	50.00	9	31.03	11	47.83	8	42.11	12	36.36
Participant describes talking to their doctor or specialist as helpful	17	32.69	7	36.84	6	28.57	4	33.33	10	34.48	7	30.43	5	26.32	12	36.36
Participant describes other people's experiences as helpful (Peer-to-peer)	11	21.15	5	26.32	3	14.29	3	25.00	5	17.24	6	26.09	3	15.79	8	24.24
Participant describes health charities information as helpful	10	19.23	1	5.26	6	28.57	3	25.00	5	17.24	5	21.74	5	26.32	5	15.15
Participant describes information specific to their condition (and sub-types) as helpful	5	9.62	3	15.79	1	4.76	1	8.33	2	6.90	3	13.04	1	5.26	4	12.12

Information that was helpful	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participant describes hearing what to expect (e.g. from disease, side effects, treatment) as being helpful	20	38.46	5	50.00	7	43.75	8	30.77	4	36.36	16	39.02	8	44.44	12	35.29
Participant describes talking to their doctor or specialist as helpful	17	32.69	4	40.00	3	18.75	10	38.46	6	54.55	11	26.83	6	33.33	11	32.35
Participant describes other people's experiences as helpful (Peer-to-peer)	11	21.15	4	40.00	3	18.75	4	15.38	3	27.27	8	19.51	5	27.78	6	17.65
Participant describes health charities information as helpful	10	19.23	2	20.00	4	25.00	4	15.38	2	18.18	8	19.51	4	22.22	6	17.65
Participant describes information specific to their condition (and sub-types) as helpful	5	9.62	1	10.00	1	6.25	3	11.54	1	9.09	4	9.76	1	5.56	4	11.76

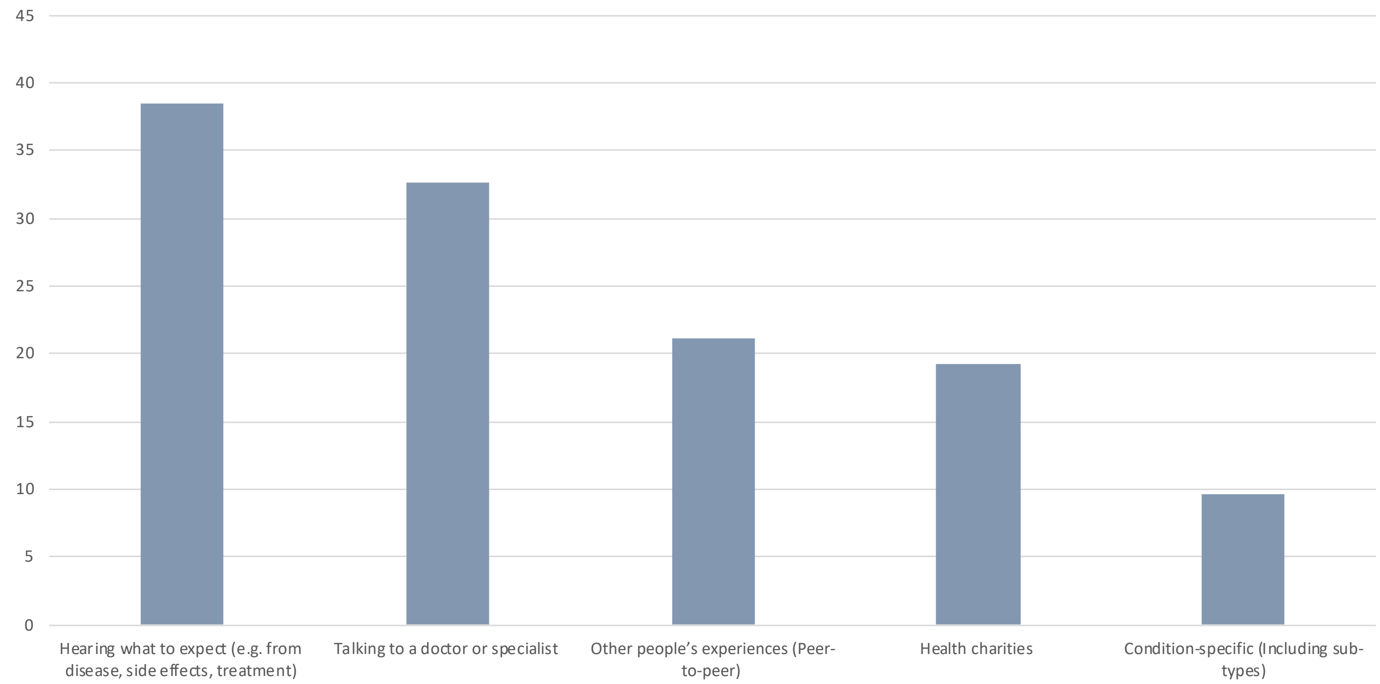


Figure 6.2: Information that was helpful

Table 6.4: Information that was helpful – subgroup variations

Information that was helpful	Reported less frequently	Reported more frequently
Participant describes hearing what to expect (e.g. from disease, side effects, treatment) as being helpful	-	Stage III and IV Diagnosed in 2016 or before
Participant describes talking to their doctor or specialist as helpful	Diagnosed in 2017 to 2019	Regional or remote
Participant describes other people's experiences as helpful (Peer-to-peer)	-	Diagnosed in 2016 or before
Participant describes health charities information as helpful	Stage 0 and I	-

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 19 participants (36.54%) that responded that no information was not helpful. The most common type of information found to be unhelpful by 13 participants (25.00%) was other people's experiences. There were eight participants (15.38%) that described other people giving advice or opinions as unhelpful, and the same number that described worst case scenarios and negative information as unhelpful (n=8, 15.38%). Other participants described information from their GP or specialist as unhelpful (n=7, 13.46%), and information from sources that are not credible as not helpful (not evidence-based) (n=6, 11.54%).

Participant describes no information being not helpful

Not as far as information...not really. Nothing unhelpful, no. Participant 017_2021AUHRP

Not really, like I mean, we were we were given a lot of information at appointments and stuff like that. It was relevant to what was being discussed, but it wasn't necessarily something that I research further on or something like that. Participant 020_2021AUHRP

Unhelpful? No, no, never been unhelpful. Participant 035_2021AUHRP

Participant describes other people's experiences as being not helpful

They run forums and then you get people constantly saying, "Oh, that made me so sick," or, "That made me," this or that. It's like, "You know, I don't really need to hear all that. I'm just going to go [unintelligible 00:31:42]." I think it can put ideas into your head. There's a medication and I have two injections a year called Prolia for osteoporosis. If you actually go online and read reviews about it, you'd never touch it. You never go within cooee of it because of the side effects. People have just gone on, "Oh, it's killed me," and blah, blah, blah, and it probably did. I gave it a shot anyway and I didn't have any side

effects. I've been on it for two years now. That was an example of going, "Okay, well just don't go onto forums because I don't think that's helpful." Participant 038_2021AUHRP

I will say, like some of the Facebook pages, some of them have been really helpful. Some of them have been very unhelpful as well, just because the people that you get on there, you obviously get some people who are less than helpful. Generally, I'd stay away from undocumented and unsupported sites. It's just not the sort of place that I would go to, to look for information. Participant 037_2021AUHRP

Yes, that Facebook group I joined. So many people had stopped their treatment and they knew this and they were trying this and all these natural things and I thought, "I'm getting out of here." Participant 006_2021AUHRP

Participant describes other people giving their advice or opinions as being not helpful

A lot of people would try and help you with suggestions to different alternative therapy. There are people that try and be supportive by telling you to be positive. Yes, positive energy, it'll make a difference. Yes, it might make a difference emotionally but it's not going to make a difference to the way I respond to my treatment and I guess, in terms of not making…It is sometimes hard to-- Also reading things that are out of date and a lot of what's online is still a few years old these days and a lot of stuff that is freely available. Participant 023_2021AUHRP

The doctors. You probably do way too much reading online in the beginning, and people say don't Google, but you're going to Google. I tend to once I've read things, I can generally discard what I think is stupid information, the stuff that goes, "You're all right, you've got cancer but you need to go, and just going use CBD oil and never see your doctor again." Or, "You just go and don't have any treatment or you become a vegan." Do you know how many times I've been told if I become a vegan, I'd never get cancer again? You've obviously heard that one before? Participant 030_2021AUHRP

"Journey, this journey." I did get upset one day and I said to a really good friend, I said, if you use that word one more time, I'm seriously going to punch you. Well, what do you mean? You're on a journey. I said journey means to me somewhere you go that you want to go, that you're enjoying. I said, "this shit storm is not a journey." I said, there's no such thing. People that aren't dealing with it, I know they mean well but because they're not there, they throw a throwaway line. "What doesn't kill you makes you stronger." Standard crap like that, I just look can go, yes, you're [unintelligible 00:39:57]. I won't go there because they don't mean it to be unkind, so I'm not about to be mean back. As I said, I just tend to, I'm not wasting my time on that one. I'll leave it alone and I just smile and go. "Yes, okay." Because when you're not in it and you're not doing it, it is hard to relate to. I often say to people now, especially since diagnosis and treatment, when I hear of someone who's-- I've lost a couple of friends in the last 18 months. I'll visit and I'll say to them, "There isn't anything I can say so I'm not going to. I'm just going to give you a hug and tell you I love you." Because there's nothing else you can do. To me, don't say anything if it's really a waste of time to say it, just do something. Tell someone you love them, give them a hug. That means more than a whole lot of words that really don't mean anything. Participant 018_2021AUHRP

Participant describes information about worse case scenarios and negative information as being not helpful

People? Yeah. Yeah. You know, everybody knows somebody who knows somebody who Oh, my God, she died. That's not very helpful. And I had said that to a few people who you know, so yeah, so I would say most of the unhelpful information has come from the general community. Yes. Yeah. So Facebook pages or those, they're always funs aren't they? Then I joined Facebook page for Western Australian breast cancer people and lasted on that for about six months and then went Oh, no more thank you! Participant 033_2021AUHRP

I think reading all about the tamoxifen really got me very upset. There's so many people with different side effects that I actually before I even got on it was just very much like I don't want to take it. I don't want anything to do with it. I've been lucky so far but I would say the rest of it, it had to have the surgery that was no issue. The radiation was very simple for me. It was really around the tamoxifen more than anything. I felt that there's a lot of people posting their experiences which is great but a friend of mine said, people only post a negative, they don't post the positive. Participant 007_2021AUHRP

I guess other people's horror stories. Participant 050_2021AUHRP

Participant describes the GP/specialist as being not helpful

No. I think the only thing that hasn't been helpful is, when you go in for all these tests before your operation, like the sentinel node and the radiation fade, you know, just a bit of a heads up. If they say to you, "Look, this is really an uncomfortable procedure, and maybe you should have a driver with you." The truth is, it took an hour and a half to get down here, you're bawling all the way home because it feels like hell, and you just think, "A heads up would have been nice." Participant 026_2021AUHRP

I mean, probably the main thing I did was ask for, going back to the previous question, was asking for a prophylactic mastectomy and I had to fight tooth and nail for that. Surgeons were more -- and other doctors are more interested in seeing whether I would like reconstruction done, than me wanting to take the risk of a possible reoccurrence in the other breast because they did find another fibroadenoma. In that one, again, I was not told about it. It was there for four years. And nobody bothers to tell me or my surgeon that I had another one growing in the other breast. So, the moment I found out that I had another fibroadenoma, which could turn nasty, I started fighting for getting mastectomy. Participant 003_2021AUHRP

Participant describes information from sources that are not credible as not helpful (Not evidence-based)

Only with the local oncologist who was just unbelievable. I could not believe how negative he was. Instead of sitting down and explaining things to me as she had done he leaned back against a wall or whatever and says joking, "What do you know about this?" I mean the breast cancer. I was just absolutely gobsmacked. I said, "I thought I was here to be told." Participant 022_2021AUHRP

Table 6.5: Information that was not helpful

Information that was not helpful	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participant describes no information being not helpful	19	36.54	7	36.84	8	38.10	4	33.33	10	34.48	9	39.13	11	57.89	8	24.2
Participant describes other people's experiences as being not helpful	13	25.00	4	21.05	6	28.57	3	25.00	9	31.03	4	17.39	5	26.32	8	24.2
Participant describes other people giving their advice or opinions as being not helpful	8	15.38	2	10.53	4	19.05	2	16.67	3	10.34	5	21.74	3	15.79	5	15.1
Participant describes information about worse case scenarios and negative information as being not helpful	8	15.38	3	15.79	3	14.29	2	16.67	4	13.79	4	17.39	3	15.79	5	15.1
Participant describes the GP/specialist as being not helpful	7	13.46	3	15.79	2	9.52	2	16.67	2	6.90	5	21.74	1	5.26	6	18.1
Participant describes information from sources that are not credible as not helpful (Not evidence-based)	6	11.54	2	10.53	2	9.52	2	16.67	2	6.90	4	17.39	0	0.00	6	18.1

Information that was not helpful	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participant describes no information being not helpful	19	36.54	3	30.00	7	43.75	9	34.62	4	36.36	15	36.59	5	27.78	14	41.1
Participant describes other people's experiences as being not helpful	13	25.00	3	30.00	6	37.50	4	15.38	4	36.36	9	21.95	7	38.89	6	17.6
Participant describes other people giving their advice or opinions as being not helpful	8	15.38	2	20.00	0	0.00	6	23.08	1	9.09	7	17.07	0	0.00	8	23.5
Participant describes information about worse case scenarios and negative information as being not helpful	8	15.38	1	10.00	2	12.50	5	19.23	4	36.36	4	9.76	4	22.22	4	11.7
Participant describes the GP/specialist as being not helpful	7	13.46	1	10.00	1	6.25	5	19.23	2	18.18	5	12.20	0	0.00	7	20.5
Participant describes information from sources that are not credible as not helpful (Not evidence-based)	6	11.54	1	10.00	3	18.75	2	7.69	1	9.09	5	12.20	3	16.67	3	8.82

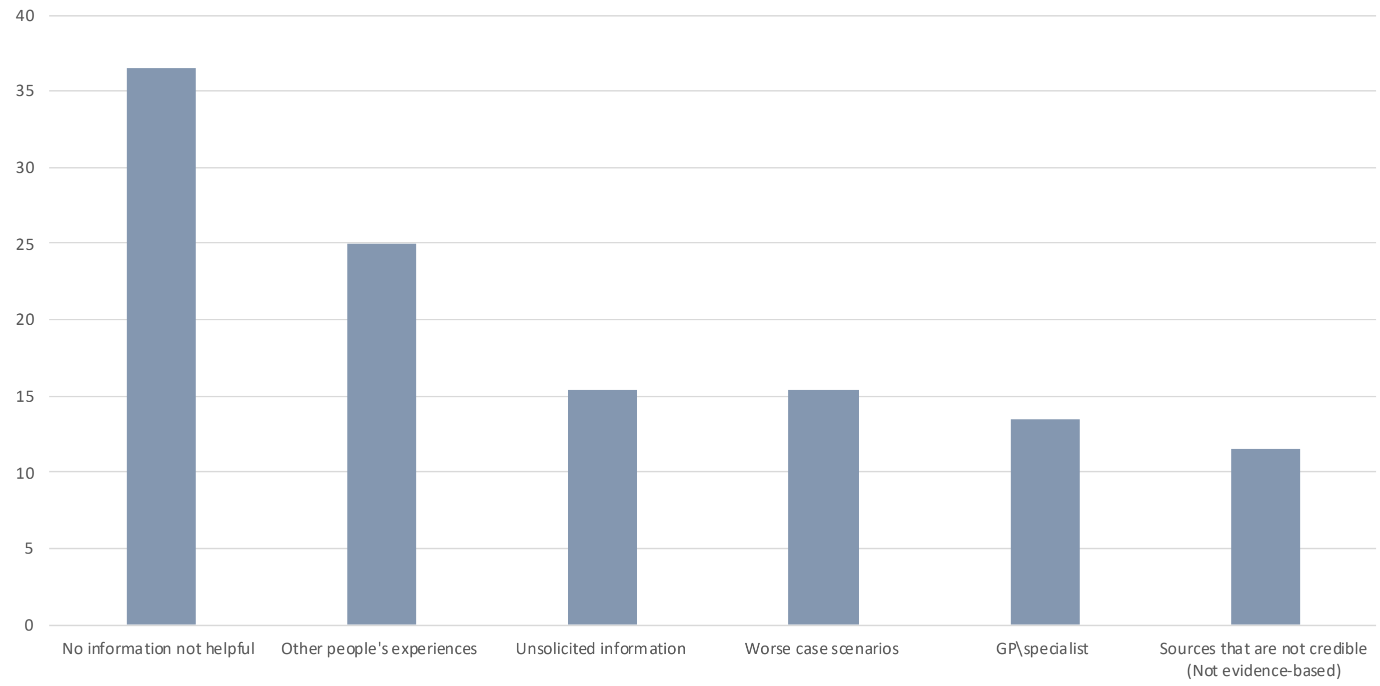


Figure 6.3: Information that was not helpful

Table 6.6: Information that was not helpful – subgroup variations

Information that was not helpful	Reported less frequently	Reported more frequently
Participant describes no information being not helpful	University	Trade or high school
Participant describes other people's experiences as being not helpful	-	Diagnosed in 2017 to 2019 Regional or remote Mid to low status
Participant describes other people giving their advice or opinions as being not helpful	Diagnosed in 2017 to 2019 Mid to low status	-
Participant describes information about worse case scenarios and negative information as being not helpful	-	Regional or remote
Participant describes the GP/specialist as being not helpful	Mid to low status	-
Participant describes information from sources that are not credible as not helpful (Not evidence-based)	Trade or high school	-

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, most participants had a preference for a combination of information sources (n=44, 8.63%), all of these combinations included online information. There were five participants (9.62%) only had a preference for talking to someone, and four participants (7.69%) only had a preference for written (booklets). Participants commonly had a preference for talking to someone plus a written form of information (either app, internet or booklet) (n=33, 63.47%), and a total of 15 participants (n=15, 28.84%) that had a preference for information in the written form only (either app, internet or booklet).

The main reasons for a preference for online information were accessibility, and being able to digest information at their own pace. The main reason for talking to someone as a preference was being able to ask questions, and getting information that was relevant or personalised.

Participant describes a preference for online information

I think online simply because it's right there right when you want it. There'll be times I'd be sitting in my living room and a question would pop in my head. You just walk back and you google it on the computer. Instantaneous information. Participant 007_2021AUHRP

Maybe the online information would be a preference because I said, "Go back and read over it." Read it again and evaluate things from it where if I was talking to somebody on things being personal, I might forget what- or not take in all the information that, like I said, actually maybe ask questions and make sure-- You don't always do- I don't think you always do that. Participant 009_2021AUHRP

Online because it's immediate gratification when you are worried about something, but I'm still old school *and I do like books and booklets. It would be nice to talk to someone, but I don't know who to contact. I'd say that would probably be my first. Well, maybe, first and foremost, online, and then to be able to access to talk to someone. Participant 012_2021AUHRP*

Participant describes a preference for booklets/pamphlets/newsletters

I am happy with any sort of information. I'm an avid reader, so yeah booklets or online stuff doesn't bother me. I research that way quite a lot. Talking to other people also helps. So I don't have a preferred method of information. Just information in general in any way, shape or form is good. Yeah. Participant 003_2021AUHRP

Maybe the booklets, because you can pick them up at any time and have a look, and then go back and check something. and have a look, and then go back and check something. Participant 015_2021AUHRP

I don't know, I quite like getting handouts because I can go back to them and reread them rather than searching the internet. It's probably not a good idea for me to search the internet all the time anyhow, you only find out a lot of negative stuff there. Yes, I quite like it when they give you the handouts, the pamphlets. They're very helpful. Participant 017_2021AUHRP

Participant describes a preference for talking to someone

I think talking to someone is probably the best because that you can ask the questions in that information tailored for you. But then having obviously, because you've got so much you might want to find out about having some online resources are always really useful, because then you can obviously follow up on any leads. And I mean, I'm lucky that I've got the ability to do a PubMed search and look at a journal article and understand what studies. So you know, that's obviously going straight to the evidence myself, and I'm more than happy to read a review article as well. And, and have that evidence summarize. So yeah, so online to me and like in person best, but then some resources online, I can follow up on. Participant 034_2021AUHRP

Certainly, talking to the specialist and the information they gave. Then I did find the network good for some general information. Participant 011_2021AUHRP

I prefer when it comes to my own treatment anyways, face to face. So that when you're processing it, you can ask a question directly and get a response. That's just my personal, and I think that's a generational thing. Participant 018_2021AUHRP

Participant describes a preference for phone apps

Okay, I think a combination. I like things that are written because it allows you to go back over them, and particularly when you're in those first couple of weeks of trying to sort things out. There's a lot of information going round in circles so it's nice to be able to re-read it. Whether that's online or it's an app, I think doesn't matter very much to me, it's much the same. In terms of talking to people, that's always useful but sometimes after you've actually had the opportunity to read and digest the information and then talk to a clinician afterwards. Participant 005_2021AUHRP

I'm attached to the...I like booklets, and I like to have something in my hand I can read and circle or whatever. Apps are always good as well. I think it's having the information and then having that person to talk to you about it. I think it has to be a combination. You're going to come up with questions and then having someone to talk it out and just clear our minds of whatever's going through our head at the time would be very beneficial. Because sometimes you might not see your specialist for a couple of weeks, and then it could be something that's really bothering you, and you haven't been able to get onto a breast care nurse. I loved the service, and the nurse that was working at therapy was fantastic. So many times like when I was going to go into hospital trying to call them for help, they just weren't there. No one answered, and you felt really alone and let down. Participant 048_2021AUHRP

Table 6.7: Information preferences

Information preferences	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participant describes talking to someone plus online information as main preference	15	28.85	7	36.84	5	23.81	3	25.00	7	24.14	8	34.78	3	15.79	12	36.36
Participant describes online plus written information as main preference	10	19.23	1	5.26	7	33.33	2	16.67	6	20.69	4	17.39	5	26.32	5	15.15
Participant describes talking to someone plus online, and written information as main preference	7	13.46	4	21.05	1	4.76	2	16.67	4	13.79	3	13.04	3	15.79	4	12.12
Participant describes talking to someone as main preference	5	9.62	2	10.53	2	9.52	1	8.33	3	10.34	2	8.70	1	5.26	4	12.12
Participant describes talking to someone plus online, and written information, plus apps as main preference	5	9.62	2	10.53	2	9.52	1	8.33	3	10.34	2	8.70	1	5.26	4	12.12
Participant describes talking to someone plus online information as main preference	5	9.62	1	5.26	3	14.29	1	8.33	3	10.34	2	8.70	2	10.53	3	9.09
Participant describes written information as main preference	4	7.69	2	10.53	1	4.76	1	8.33	3	10.34	1	4.35	3	15.79	1	3.03
Participant describes online plus written information as main preference	1	1.92	0	0.00	0	0.00	1	8.33	1	3.45	0	0.00	0	0.00	1	3.03
Participant describes talking to someone plus online information, plus apps as main preference	1	1.92	1	5.26	0	0.00	0	0.00	0	0.00	1	4.35	1	5.26	0	0.00

Information preferences	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participant describes talking to someone plus online information as main preference	15	28.85	3	30.00	4	25.00	8	30.77	4	36.36	11	26.83	3	16.67	12	35.29
Participant describes online plus written information as main preference	10	19.23	2	20.00	4	25.00	4	15.38	3	27.27	7	17.07	3	16.67	7	20.59
Participant describes talking to someone plus online, and written information as main preference	7	13.46	2	20.00	3	18.75	2	7.69	1	9.09	6	14.63	4	22.22	3	8.82
Participant describes talking to someone as main preference	5	9.62	1	10.00	3	18.75	1	3.85	0	0.00	5	12.20	1	5.56	4	11.76
Participant describes talking to someone plus online, and written information, plus apps as main preference	5	9.62	1	10.00	3	18.75	1	3.85	0	0.00	5	12.20	1	5.56	4	11.76
Participant describes talking to someone plus online information as main preference	5	9.62	1	10.00	1	6.25	3	11.54	1	9.09	4	9.76	4	22.22	1	2.94
Participant describes written information as main preference	4	7.69	0	0.00	1	6.25	3	11.54	0	0.00	4	9.76	1	5.56	3	8.82
Participant describes online plus written information as main preference	1	1.92	0	0.00	0	0.00	1	3.85	0	0.00	1	2.44	0	0.00	1	2.94
Participant describes talking to someone plus online information, plus apps as main preference	1	1.92	1	10.00	0	0.00	0	0.00	1	9.09	0	0.00	1	5.56	0	0.00

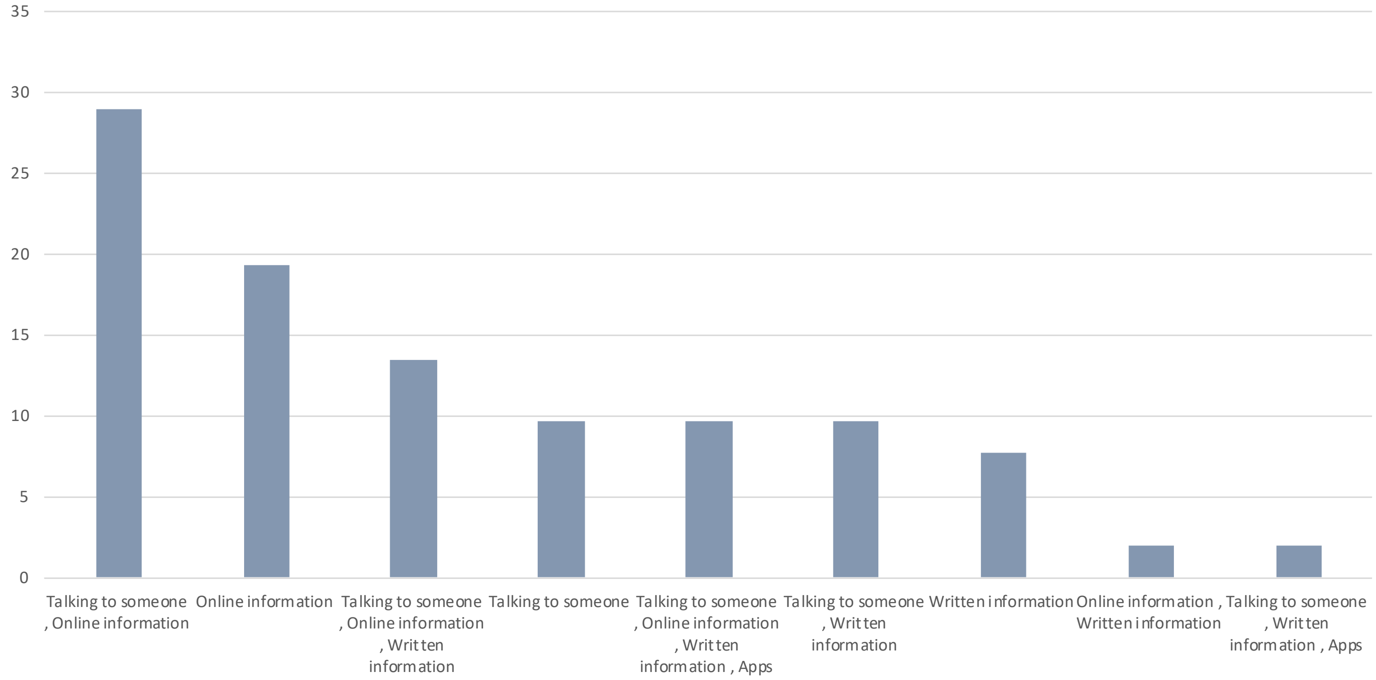


Figure 6.4: Information preferences

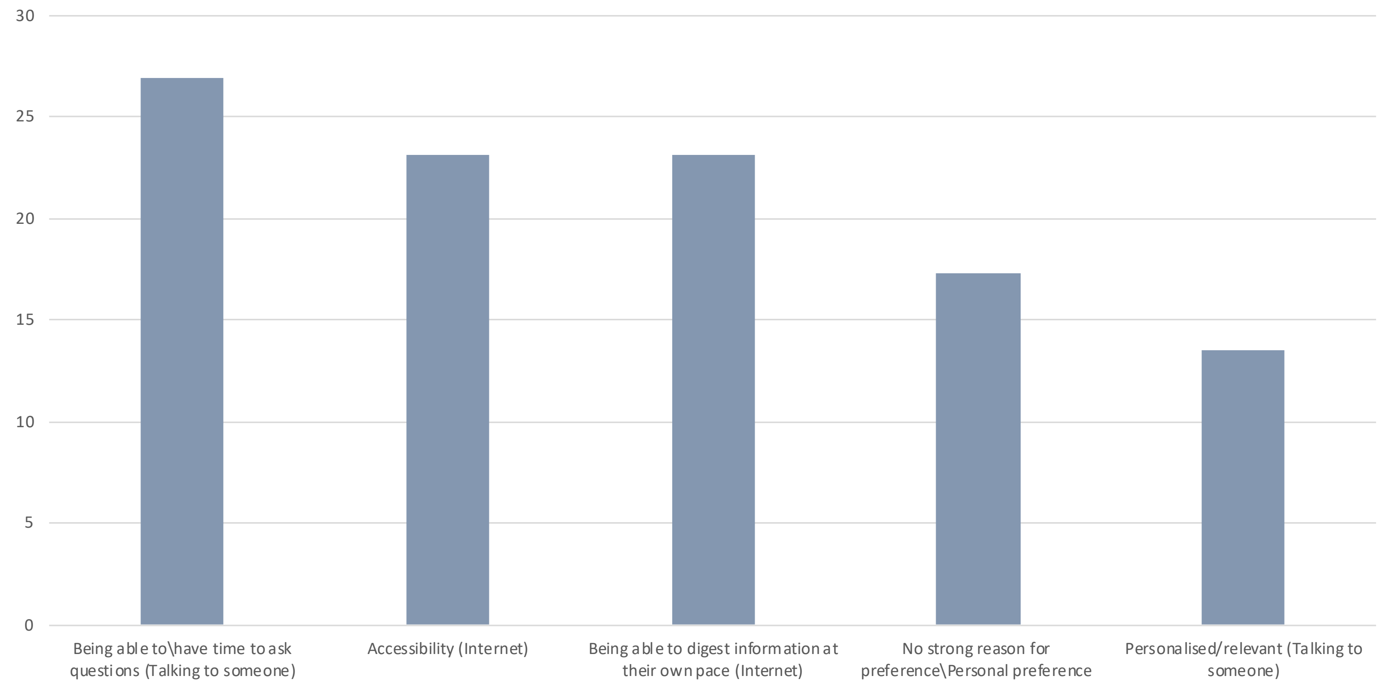


Figure 6.5: Reasons for information preferences by format

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	Trade or high school Mid to low status	
Participant describes online plus written information as main preference	Stage 0 and I	Stage II
Participant describes talking to someone plus online information as main preference		Mid to low status

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 was from the beginning when diagnosed (n=20, 38.46%), this was followed by participants describing being receptive to information after the shock of diagnosis (n=13, 25.00%), continuously throughout their experience (n=9, 17.31), and after treatment (n=7, 13.46%).

Participant describes being receptive from the beginning (diagnosis)

Virtually straight away? I think I cried for maybe about a minute and a half when they told me. And then yeah, basically shook myself off and thought, OK, let's deal with this And that's it. That's the way I am. I don't have -- I don't think I'm more receptive to information now or then, just any information is good. Participant 003_2021AUHRP

Well, even when I first went to the breast clinic, because I'd done a lot of research on the internet and I was reading the Cancer Council booklets and things, I thought I was pretty okay with what was going to happen, and even the nurse said, "Oh, you've done a lot of research on this as well." I said, "Yes." The signing of the paper about having the surgery and the sentinel node biopsy and then the clearance, I just think that little bit needs to be fully explained more to people. It just seemed to be brushed over when I think back, that's how I felt, it was brushed over. Participant 012_2021AUHRP

I think when I was first diagnosed, I was just soaking up everything and reading everything. I couldn't think of anything else, so I was really reading everything and searching the net, doing all of this stuff. Well, probably I still could-- That's what I do anyway. Yes, so probably at the start for me, and then as things settled down and then I was a bit more selective and able to look at things with a bit more depth and trained a bit more is what I would say. Participant 036_2021AUHRP

Participant describes being receptive to information after the shock of diagnosis

I don't really know. Well, my doctor, on the day of my diagnosis, she gave me a printout but I couldn't look at it. I wasn't ready then. Plus, it was at that stage where I just knew it was breast cancer, nothing much more. I think when I started chemo was when I was more receptible to start receiving the information. Participant 008_2021AUHRP

Um, from the start for me. So I was diagnosed on a Wednesday, and was side-swipped for the Thursday and the Friday from the shock of it and then after that I was just into research, and I don't know, we tend to go, well I did, went into this brave mode for all your family and friends that was in tears and panicking and you know, had already satrted my research and gone it's not that bad. It's okay, it's early it's fine. And then at the six week mark I think it's fianlly hit me, it's amazing. After those two days of shock, it was righto, lets do some learning. Participant 014_2021AUHRP

Oh, I guess when you when you really upset. So the initial diagnosis isn't there isn't a good time, because I know that you're just totally triggered, and you're not going to think logically. So I think probably those still, while it's quite raw, that you've had a little bit of time to process and calm down. And you're really, really got loads of questions. And you really, really need to know, I think that's probably the best time because if you leave it too long, people are going to go to the internet and find, you know, find it unhelpful, or certainly what I found, I found it extremely depressing. Participant 034_2021AUHRP

Participant describes being receptive to information continuously throughout their experience or bit-by-bit so that it is digestible

As I said before, I had to compartmentalize it. I was most receptive of the different information just before I was going to have the next procedure. Maybe I could finish the other stuff and then I'd go Okay, right. We've got radiotherapy. What do I need to do now? Participant 021_2021AUHRP

Pretty much all the way through because it's part of the journey. There was new information to deal with. Whether it was surgery, whether it was radiation, whether it was medication. All the way through. Participant 038_2021AUHRP

I've probably been quite receptive to receiving information the whole way through being all that, knowledge is power. Any piece of information could be beneficial to me or, God forbid, I have contact with someone else, it could be beneficial to them. I just generally like to gather as much as I can from everywhere. Participant 042_2021AUHRP

Participant describes being receptive to information after treatment

Probably once, I'd actually had that initial surgery. And once I knew that, this was the plan, like and had, like, lost that first element of absolute fear of what was going on. Once we were on a process of I've had the surgery. And then I've had the appointment, the oncologist and I knew that okays right from this day, this is what's happening. And this is happening for this long, then I was sort of, I feel like my brain was able to slow down a little bit and take stuff in then. Yeah. Whereas when you're initially diagnosed, it's such a whirlwind of information thrown at you in a short period of time. And I guess, as well, I mean, everything that happened to me happened in really quite quick succession. Whereas I've had a couple of girls that I grew up with that got diagnosed at later date. I don't feel like there's, to me, as an outsider, I didn't feel quite as rushed. But, you know, I also had that little bit more knowledge by that point, as well, because it was like already finished treatment and stuff. So watching their journey didn't feel quite as chaotic, as I felt like mine was but yeah, it's the outside looking in thing. Participant 033_2021AUHRP

I think it's a bit overwhelming at the beginning when you get diagnosed. I think probably more after my treatment, I'd be more inclined to go, "Oh, is that what I've--" I think after the treatment is finished then I found I was looking into what I'd actually had a bit more. Does that make sense? Participant 024_2021AUHRP

PARTICIPANT: Probably, I don't know, that's a hard one. I don't think it's-- I know I couldn't take anything in or read anything for at least a week after I was diagnosed. Following surgery, I just couldn't taste anything for maybe a week following surgery. That was probably the worst time for me, just post-diagnosis and post-surgery.
INTERVIEWER: After that, you can do a more effective receiving information?
PARTICIPANT: To contemplate reading the information and having it sink into my brain, yes. Participant 035_2021AUHRP

Table 6.9: Timing of information

Timing of information	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participant describes being receptive from the beginning (diagnosis)	20	38.46	11	57.89	5	23.81	4	33.33	12	41.38	8	34.78	6	31.58	14	42.42
Participant describes being receptive to information after the shock of diagnosis	13	25.00	5	26.32	4	19.05	4	33.33	9	31.03	4	17.39	4	21.05	9	27.27
Participant describes being receptive to information continuously throughout their experience or bit-by-bit so that it is digestible	9	17.31	3	15.79	3	14.29	3	25.00	5	17.24	4	17.39	5	26.32	4	12.12
Participant describes being receptive to information after treatment	7	13.46	1	5.26	3	14.29	3	25.00	6	20.69	1	4.35	3	15.79	4	12.12

Timing of information	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participant describes being receptive from the beginning (diagnosis)	20	38.46	6	60.00	7	43.75	7	26.92	3	27.27	17	41.46	6	33.33	14	41.18
Participant describes being receptive to information after the shock of diagnosis	13	25.00	0	0.00	6	37.50	7	26.92	2	18.18	11	26.83	3	16.67	10	29.41
Participant describes being receptive to information continuously throughout their experience or bit-by-bit so that it is digestible	9	17.31	0	0.00	5	31.25	4	15.38	0	0.00	9	21.95	4	22.22	5	14.71
Participant describes being receptive to information after treatment	7	13.46	2	20.00	1	6.25	4	15.38	2	18.18	5	12.20	3	16.67	4	11.76

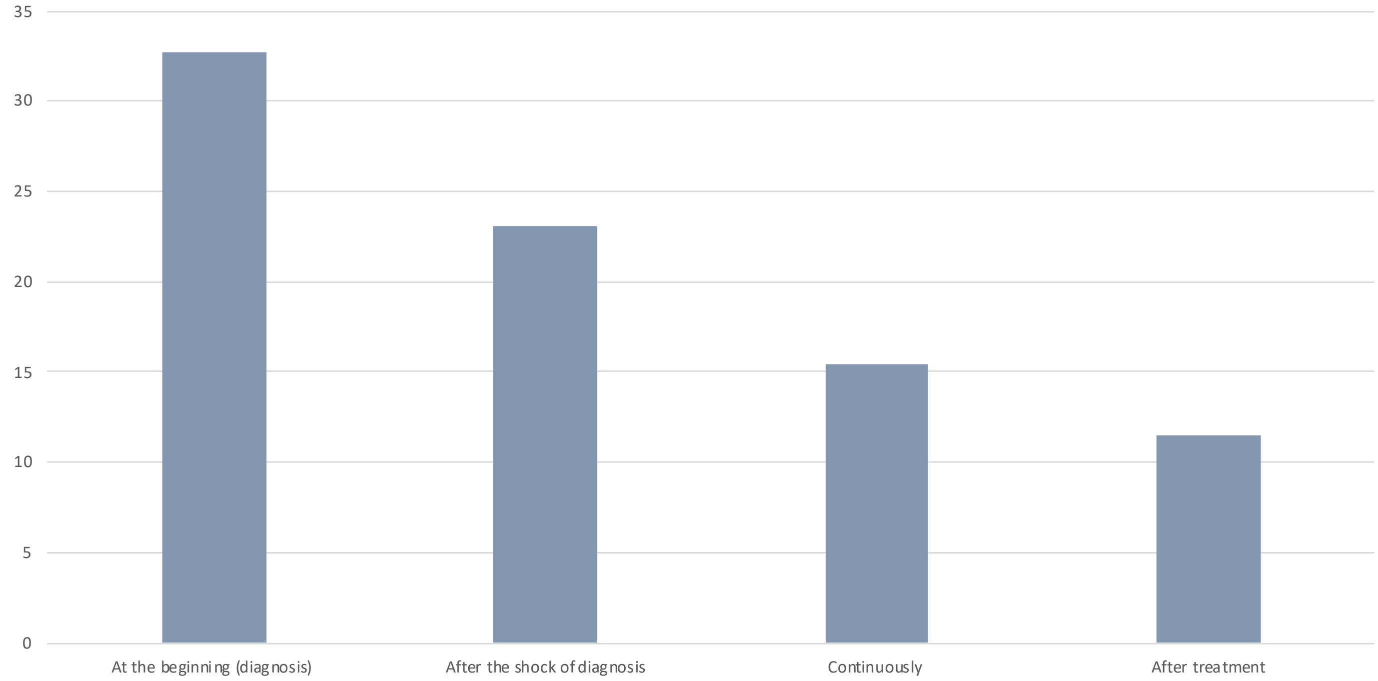


Figure 6.6: Timing of information

Table 6.10: Timing of information – subgroup variations

Timing of information	Reported less frequently	Reported more frequently
Participant describes being receptive from the beginning (diagnosis)	Stage II Diagnosed in 2020 or 2021 Regional or remote	Stage 0 and I Diagnosed in 2016 or before
Participant describes being receptive to information after the shock of diagnosis	Diagnosed in 2016 or before	Diagnosed in 2017 to 2019
Participant describes being receptive to information continuously throughout their experience or bit-by-bit so that it is digestible	Diagnosed in 2016 or before Regional or remote	Diagnosed in 2017 to 2019
Participant describes being receptive to information after treatment	-	Stage III and IV

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=32, 61.54%). There were 16 participants (30.77%) that described an overall positive experience, with the exception of one or two occasions, and four participants (7.69%) that had an overall negative experience.

Participant describes health professional communication as overall positive

Really good. I can't fault it. I feel I've been supported well. I've been given good information. I think I've been given plenty of time. Participant 051_2021AUHRP

It's been good. They've been really good. They've shared to me as much information as they can and, obviously, enlighten me to risk factors and possible side effects as best they can, and then they've, obviously, touch base with me and I've been able to share what's been happening. They've been able to help me with those issues as needed so that's been good. Participant 042_2021AUHRP

I've got a really good bunch of health care professionals that I work with. They're all very informative. Whenever I've had a question, it hasn't been like I couldn't pick up the phone and talk to them or email them and ask the questions that I've got. Participant 037_2021AUHRP

Participant describes health professional communication as overall positive, with the exception of one or two occasions

I think fairly good except for the initial diagnosis that didn't even come to my GP by the receptionist, which was just shocking, absolutely shocking. Overall, the information has been good. Participant 007_2021AUHRP

I've seen a lot. I wish to say that they were all of the more brilliant. A lot of them were. Some of them weren't so brilliant. Some of them, I wish they would have individualized, seeing me as an individual, not like tick the box sort of thing. Participant 021_2021AUHRP

The surgeon was really good. The oncologist was really good. I wasn't so impressed with the radiation oncologist. I've only had one blip with the oncologist, and I think she was just having a bad day. Participant 030_2021AUHRP

Participant describes health professional communication as overall negative

It's been somewhat fraught...I would not say it has been a positive experience with any of them to be honest. Participant 036_2021AUHRP

Good question. Very good question. I have found that it's not always very clear. In fact, I learned to take a good friend with me who is quite skilled at note taking and it also helping me take notes. I don't wish to be disrespectful, but a lot of times things were not very clear. I think that's probably to do with, in terms of me and lots of other patients, our lack of understanding of what's going on and how it all goes together and the pathway and that. I guess there's so much maybe information. I don't feel the communication that's particularly good. Participant 047_2021AUHRP

Well, I just feel like once I've had the surgery and the radiation, that's it, off you go, and then I've been with my GP. He's been looking after me. I don't think there's been any follow-up really that-- I beg your pardon, I've had two phone calls from a medical oncologist, but they were concerned about the numbness on my lips and tongue, but otherwise, she said when I spoke to her, "Normally we would hand you over to your doctor now, but we want to keep a check on this, so we'll have another appointment for you." Maybe I'm expecting too much or not really know what is the norm and help that people should get because I've always been healthy and not had a lot of dealings medically-wise for myself. Participant 012_2021AUHRP

Table 6.11: Healthcare professional communication.

Healthcare professional communication	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participant describes health professional communication as overall positive	32	61.54	12	63.16	14	66.67	**6**	**50.00**	**21**	**72.41**	**11**	**47.83**	**9**	**47.37**	23	69.7
Participant describes health professional communication as overall positive, with the exception of one or two occasions	16	30.77	5	26.32	6	28.57	**5**	**41.67**	**6**	**20.69**	**10**	**43.48**	**9**	**47.37**	7	21.2
Participant describes health professional communication as overall negative	4	7.69	2	10.53	1	4.76	1	8.33	2	6.90	2	8.70	1	5.26	3	9.09

Healthcare professional communication	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher statu	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participant describes health professional communication as overall positive	32	61.54	6	60.00	11	68.75	15	57.69	6	54.55	26	63.41	11	61.11	21	61.7
Participant describes health professional communication as overall positive, with the exception of one or two occasions	16	30.77	**1**	**10.00**	4	25.00	**11**	**42.31**	4	36.36	12	29.27	5	27.78	11	32.3
Participant describes health professional communication as overall negative	4	7.69	**3**	**30.00**	1	6.25	0	0.00	1	9.09	3	7.32	2	11.11	2	5.88

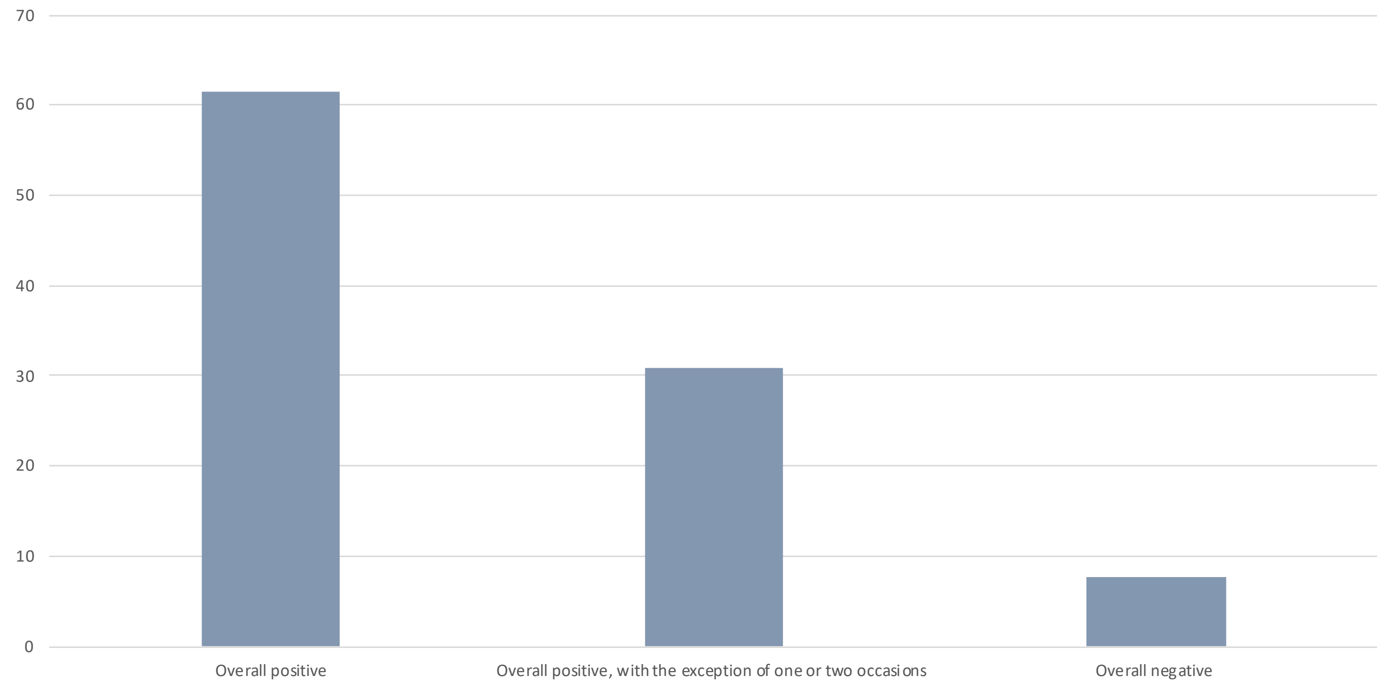


Figure 6.7: Healthcare professional communication

Table 6.12: Healthcare professional communication – subgroup variations

Healthcare professional communication	Reported less frequently	Reported more frequently
Participant describes health professional communication as overall positive	Stage III and IV Aged 55 to 74 Trade or high school	Aged 25 to 54
Participant describes health professional communication as overall positive, with the exception of one or two occasions	Aged 25 to 54 Diagnosed in 2016 or before	Stage III and IV Aged 55 to 74 Trade or high school Diagnosed in 2020 or 2021

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=17, 32.69%).

Participant describes health professional communication as holistic (Two way, supportive and comprehensive conversations)

If I've had any questions, I have a breast care nurse who's standing there answering questions. I went through, I guess a holistic provider with HOSPITAL. They were very well-practiced in everything that needed to be done. I think that probably was the most helpful having people I've asked the question through. Participant 007_2021AUHRP

Pretty like I have been pretty happy with anything that any doctor that I've seen everything's been explained in full if I had any questions you know, they'll happy to answer them whether that be during the appointment or later afterwards. I've never really had any issues in terms of that during the course of my treatment. Participant 020_2021AUHRP

My surgeon has always been really open to discussions and answering questions and to a great degree, she has been a go-to and my medical oncologist is also fabulous, in a different way. He is very good at using statistics for and against things to help with decision-making and doesn't push a decision overly in one direction. He'll gently encourage but he's not a you-must-do-this person, it's, "I suggest this because the research shows." My GP, hit and miss. Participant 023_2021AUHRP

Participant described healthcare communication as good, with no particular reason given

The specialists have been very good, each one of them from the surgeon to the oncologist and the radiotherapy. Participant 015_2021AUHRP

I found the communication really good. As I said, I wouldn't do any different. It's been fantastic. Participant 032_2021AUHRP

Mine has been very good. I have nothing negative there at all. Participant 017_2021AUHRP

Table 6.13: Healthcare professional communication (Rationale for response)

Healthcare professional communication (Rationale for response)	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participant describes health professional communication as holistic (Two way, supportive and comprehensive conversations)	17	32.69	7	36.84	6	28.57	4	33.33	9	31.03	8	34.78	4	21.05	13	39.39
Participant describes healthcare communication as good, with no particular reason given	15	28.85	5	26.32	7	33.33	3	25.00	10	34.48	5	21.74	7	36.84	8	24.24
Participant describes healthcare communication as good, yet limited in understanding	4	7.69	3	15.79	1	4.76	0	0.00	1	3.45	3	13.04	2	10.53	2	6.06
Participant describes healthcare communication as good, yet limited in time	3	5.77	2	10.53	1	4.76	0	0.00	1	3.45	2	8.70	1	5.26	2	6.06
Participant describes health professional communication as limited in relation to their understanding of the condition	3	5.77	0	0.00	2	9.52	1	8.33	1	3.45	2	8.70	2	10.53	1	3.03
Participant describes health professional communication as limited in relation health professionals not having a lot of time	3	5.77	1	5.26	1	4.76	1	8.33	2	6.90	1	4.35	1	5.26	2	6.06

Healthcare professional communication (Rationale for response)	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participant describes health professional communication as holistic (Two way, supportive and comprehensive conversations)	17	32.69	3	30.00	6	37.50	8	30.77	4	36.36	13	31.71	9	50.00	8	23.53
Participant describes healthcare communication as good, with no particular reason given	15	28.85	2	20.00	3	18.75	10	38.46	4	36.36	11	26.83	4	22.22	11	32.35
Participant describes healthcare communication as good, yet limited in understanding	4	7.69	1	10.00	0	0.00	3	11.54	2	18.18	2	4.88	2	11.11	2	5.88
Participant describes healthcare communication as good, yet limited in time	3	5.77	2	20.00	1	6.25	0	0.00	1	9.09	2	4.88	1	5.56	2	5.88
Participant describes health professional communication as limited in relation to their understanding of the condition	3	5.77	2	20.00	0	0.00	1	3.85	1	9.09	2	4.88	1	5.56	2	5.88
Participant describes health professional communication as limited in relation health professionals not having a lot of time	3	5.77	0	0.00	2	12.50	1	3.85	0	0.00	3	7.32	1	5.56	2	5.88

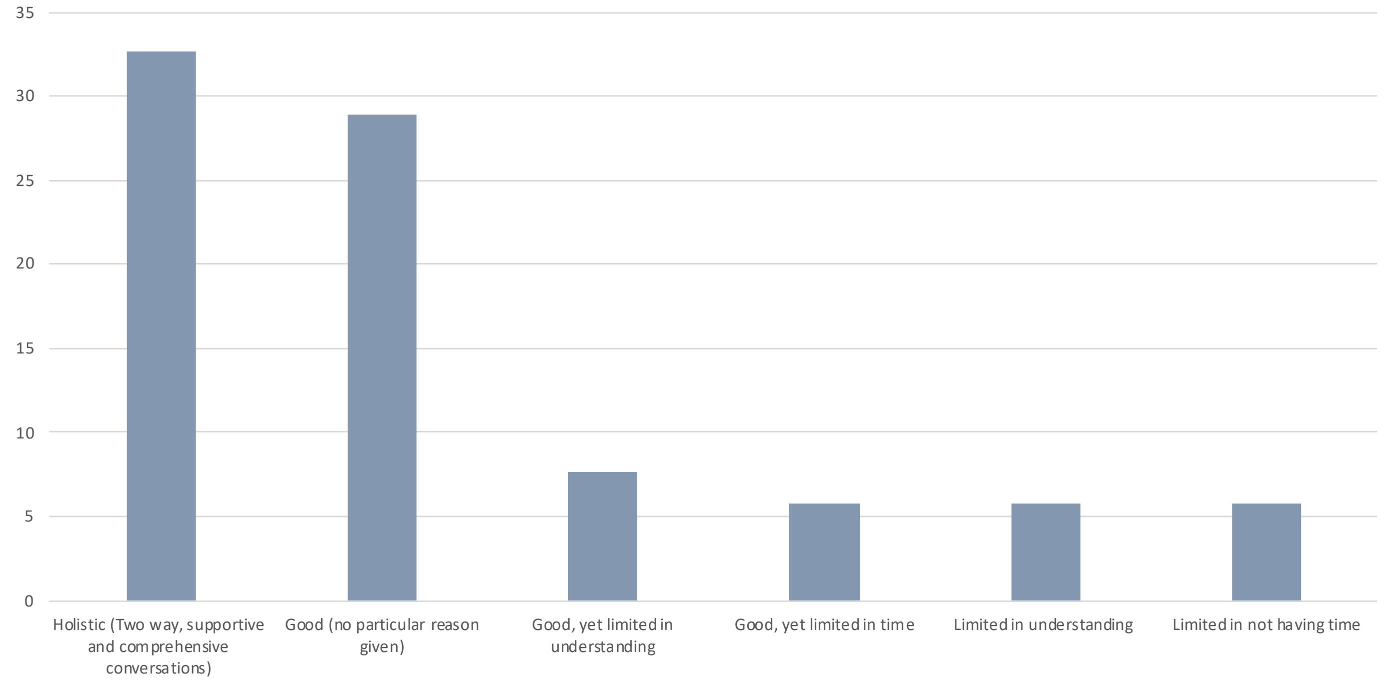


Figure 6.8: Healthcare professional communication (Rationale for response)

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)	Trade or high school	Mid to low status
Participant describes healthcare communication as good, with no particular reason given	Diagnosed in 2017 to 2019	

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.

Overall, the participants in this PEEK study had an average score for **Partners in health: Knowledge** (median = 29.00, IQR = 5.00), **Partners in health: Recognition and management of symptoms** (median = 21.00, IQR = 3.50), **Partners in health: Adherence to treatment** (median = 15.00, IQR = 2.00), **Partners in health: Total score** (mean = 80.86, SD = 9.38) in the highest quintile indicating very good knowledge, very good recognition and management of symptoms, and very good adherence to treatment.

The average score for the **Partners in health: coping** (median = 18.00, IQR = 9.00), was in the second highest quintile indicating good coping.

Comparisons of Partners in health have been made based on **stage** (Table 6.16, Figures 6.9 to 6.13), **age** (Tables 6.17 to 6.18, Figures 6.14 to 6.18), **education** (Tables 6.19 to 6.20, Figures 6.19 to 6.23), **year of diagnosis,** (Tables 6.21 to 6.22, Figures 6.24 to 6.28), **location** (Tables 6.23 to 6.24, Figures 6.29 to 6.33), and **socioeconomic status** (Tables 6.25 to 6.26, Figures 6.34 to 6.38).

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 very good overall knowledge, coping and confidence for managing their own health.

Table 6.15: Partners in health summary statistics

Partners in health scale (n=51)	Mean	SD	Median	IQR	Possible range	Quintile
Partners in health: knowledge	28.00	3.39	29.00	5.00	0 to 32	5
Partners in health: coping	17.22	4.80	18.00	9.00	0 to 24	4
Partners in health: recognition and management of symptoms	20.71	2.85	21.00	3.50	0 to 24	5
Partners in health: adherence to treatment	14.94	1.30	15.00	2.00	0 to 16	5
Partners in health: total score*	80.86	9.38	82.00	10.00	0 to 96	5

*Normal distribution use mean and SD as measure of central tendency

Partners in health by stage

Comparisons were made by breast cancer **stage**, there were 18 participants (35.29%) with *Stage 0 and I* breast cancer, 21 participants (41.18%) *with Stage II*, and 12 participants (23.53%) with *Stage III and IV.*

A one-way ANOVA test was used when the assumptions for response variable residuals were normally distributed and variances of populations were equal. When the assumptions for normality of residuals was not met, a Kruskal-Wallis test was used (Table 6.16).

No significant differences were observed between participants by **stage** for any of the Partners in health scales.

Table 6.16: Partners in health by stage summary statistics and Kruskal-Wallis test

Partners in health scale	Group	Number (n=51)	Percent	Median	IQR	C^2	dF	p-value
Knowledge	Stage 0 and I	18	35.29	27.00	5.00	2.15	2	0.3420
	Stage II	21	41.18	29.00	5.00			
	Stage III and IV	12	23.53	28.00	3.50			
Coping	Stage 0 and I	18	35.29	18.50	8.75	2.24	2	0.3255
	Stage II	21	41.18	19.00	6.00			
	Stage III and IV	12	23.53	15.00	7.50			
Recognition and management of symptoms	Stage 0 and I	18	35.29	21.00	2.75	0.06	2	0.9708
	Stage II	21	41.18	22.00	6.00			
	Stage III and IV	12	23.53	21.50	2.25			
Adherence to treatment	Stage 0 and I	18	35.29	15.50	1.75	1.18	2	0.5543
	Stage II	21	41.18	15.00	2.00			
	Stage III and IV	12	23.53	16.00	2.00			
Total score	Stage 0 and I	18	35.29	80.50	16.00	1.08	2	0.5841
	Stage II	21	41.18	84.00	10.00			
	Stage III and IV	12	23.53	80.00	5.75			

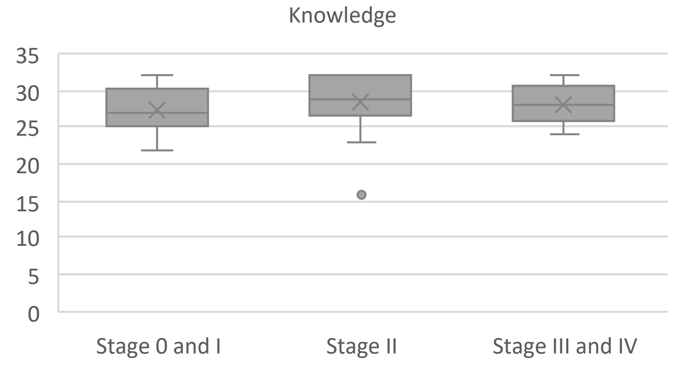


Figure 6.9: Boxplot of Partners in health: knowledge by stage

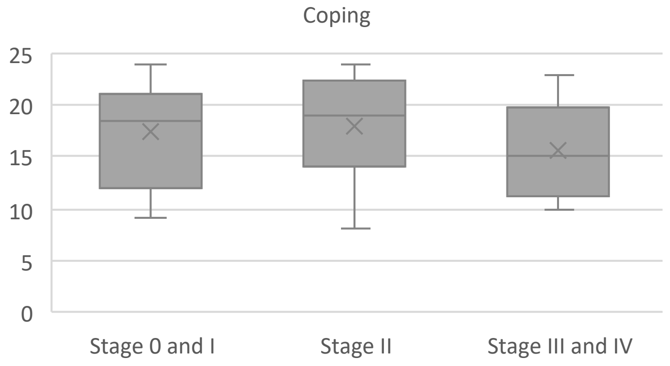


Figure 6.10: Boxplot of Partners in health: coping by stage

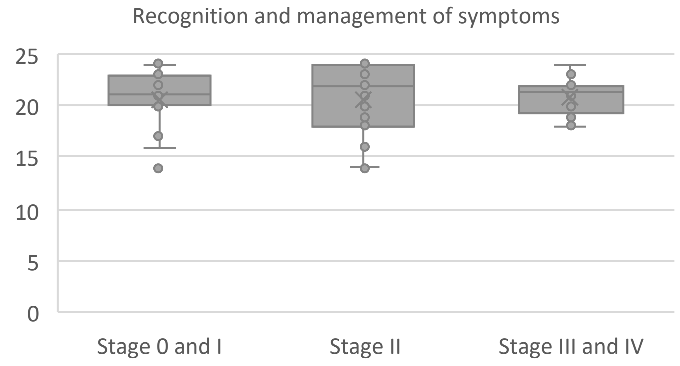


Figure 6.11: Boxplot of Partners in health: recognition and management of symptoms by stage

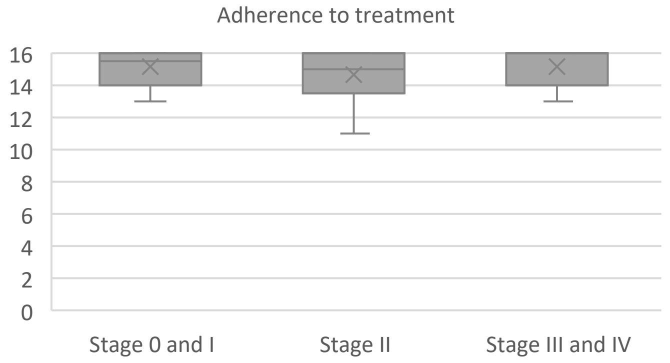


Figure 6.12: Boxplot of Partners in health: adherence to treatment by stage

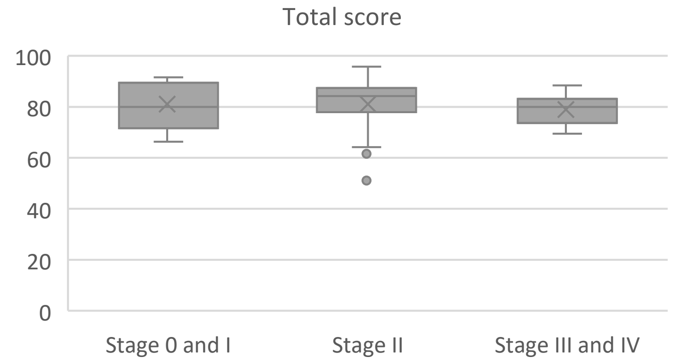


Figure 6.13: Boxplot of Partners in health Total score by stage

Partners in health by age

Participants were grouped according to **age,** with comparisons made between participants *Aged 25 to 54* (n=29, 56.86%) and participants *Aged 55 to 74* (n=22, 43.14%).

A two-sample t-test was used when assumptions for normality and variance were met (Table 6.17), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 6.18).

No significant differences were observed between participants by **age** for any of the Partners in health scales.

Table 6.17: Partners in health by age summary statistics and T-test

Partners in health scale	Group	Number (n=51)	Percent	Mean	SD	T	dF	p-value
Total score	Aged 25 to 54	29	56.86	79.83	9.67	-0.90	49	0.3707
	Aged 55 to 74	22	43.14	82.23	9.01			

Table 6.18: Partners in health by age summary statistics and Wilcoxon test

Partners in health scale	Group	Number (n=51)	Percent	Median	IQR	W	p-value
Knowledge	Aged 25 to 54	29	56.86	28.00	4.00	320.00	0.9923
	Aged 55 to 74	22	43.14	29.00	5.75		
Coping	Aged 25 to 54	29	56.86	16.00	8.00	240.00	0.1333
	Aged 55 to 74	22	43.14	19.50	5.25		
Recognition and management of symptoms	Aged 25 to 54	29	56.86	21.00	3.00	288.00	0.5574
	Aged 55 to 74	22	43.14	22.00	3.00		
Adherence to treatment	Aged 25 to 54	29	56.86	15.00	2.00	328.50	0.8543
	Aged 55 to 74	22	43.14	15.50	2.00		

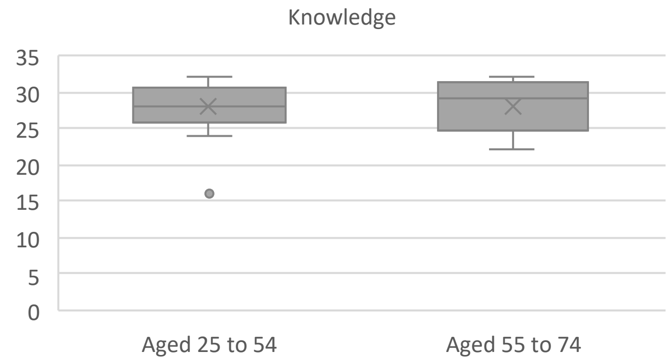


Figure 6.14: Boxplot of Partners in health: knowledge by age

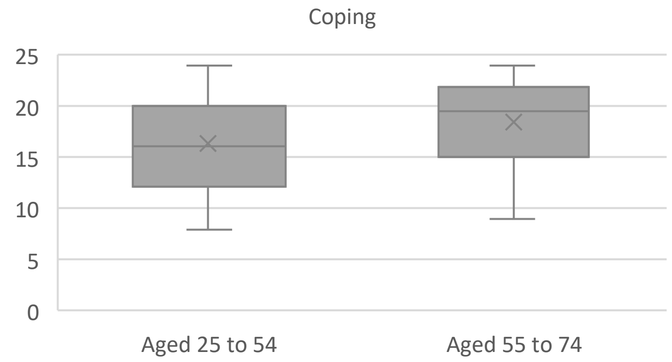


Figure 6.15: Boxplot of Partners in health: coping by age

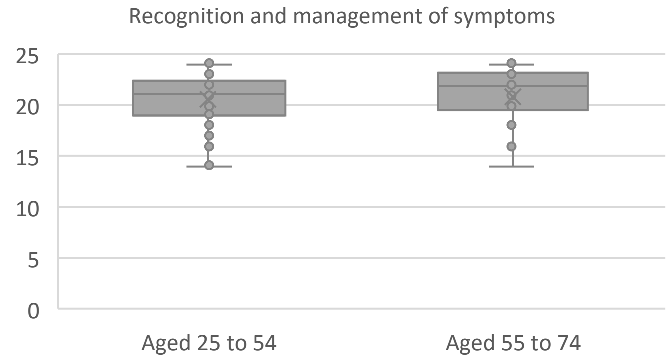


Figure 6.16: Boxplot of Partners in health: recognition and management of symptoms by age

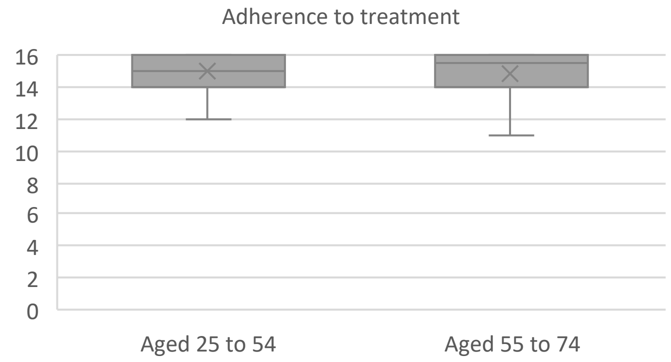


Figure 6.17: Boxplot of Partners in health: adherence to treatment by age

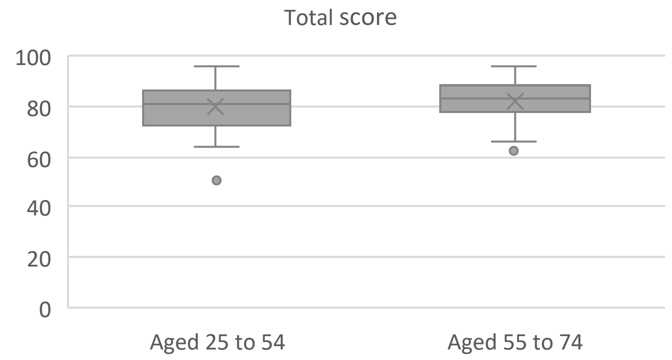


Figure 6.18: Boxplot of Partners in health Total score by age

Partners in health by education

Comparisons were made by **education** status, between those with trade or high school qualifications, *Trade or high school* (n=19, 37.25%), and those with a university qualification, *University* (n= 32, 62.75%).

A two-sample t-test was used when assumptions for normality and variance were met (Table 6.19), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 6.20).

No significant differences were observed between participants by **education** for any of the Partners in health scales.

Table 6.19: Partners in health by education summary statistics and T-test

Partners in health scale	Group	Number (n=51)	Percent	Mean	SD	T	dF	p-value
Coping	Trade or high school	19	37.25	16.84	5.49	-0.42	49	0.6730
	University	32	62.75	17.44	4.42			

Table 6.20: Partners in health by education summary statistics and Wilcoxon test

Partners in health scale	Group	Number (n=51)	Percent	Median	IQR	W	p-value
Knowledge	Trade or high school	19	37.25	28.00	6.00	311.50	0.8905
	University	32	62.75	29.00	4.50		
Recognition and management of symptoms	Trade or high school	19	37.25	20.00	6.00	283.50	0.6935
	University	32	62.75	22.00	3.00		
Adherence to treatment	Trade or high school	19	37.25	15.00	2.00	252.50	0.2865
	University	32	62.75	16.00	2.00		
Total score	Trade or high school	19	37.25	79.00	17.50	274.00	0.5646
	University	32	62.75	82.00	10.00		

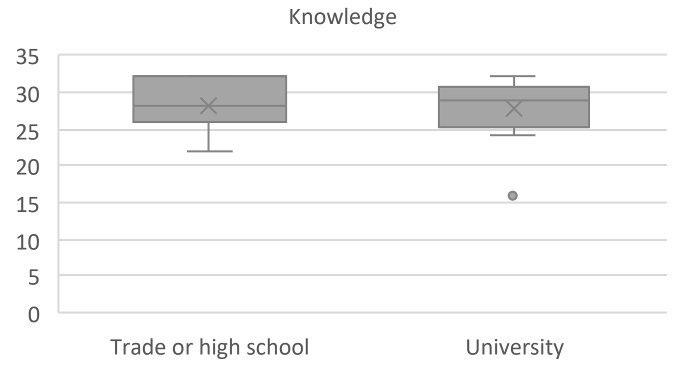


Figure 6.19: Boxplot of Partners in health: knowledge by education

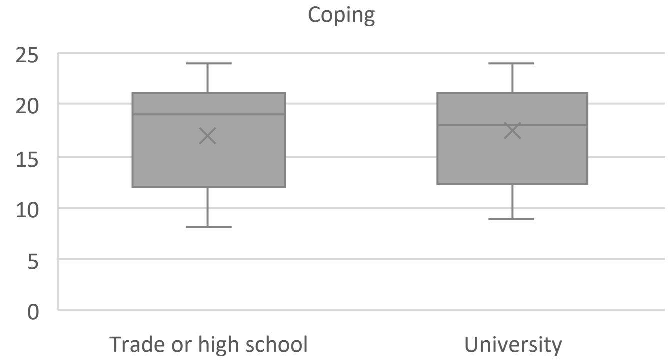


Figure 6.20: Boxplot of Partners in health: coping by education

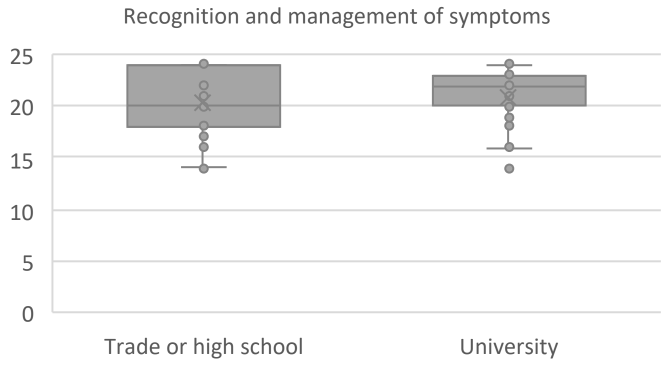


Figure 6.21: Boxplot of Partners in health: recognition and management of symptoms by education

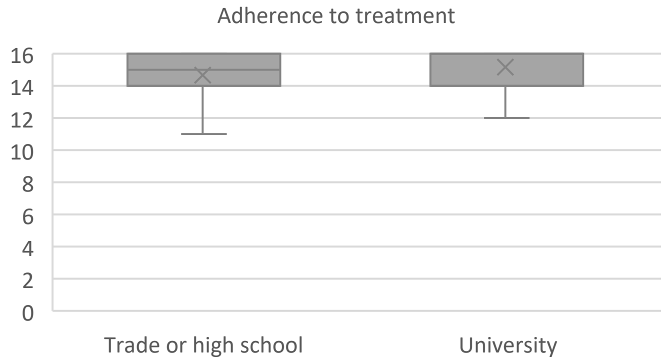


Figure 6.22: Boxplot of Partners in health: adherence to treatment by education

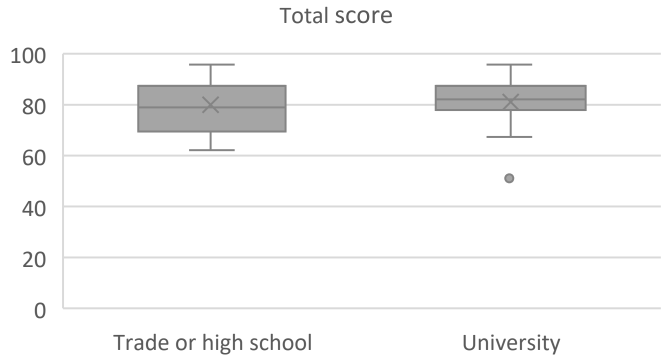


Figure 6.23: Boxplot of Partners in health Total score by education

Partners in health by year of breast cancer diagnosis

Participants were grouped according to the **year of breast cancer diagnosis**, with 9 participants (17.65%) *Diagnosed in 2016 or before,* 16 participants (31.37%) *Diagnosed in 2017 to 2019*, and 26 participants (50.98%) *Diagnosed in 2020 or 2021.*

A one-way ANOVA test was used when the assumptions for response variable residuals were normally distributed and variances of populations were equal (Table 6.21). When the assumptions for normality of residuals was not met, a Kruskal-Wallis test was used (Table 6.22).

No significant differences were observed between participants by **year of breast cancer diagnosis** for any of the Partners in health scales.

Table 6.21: Partners in health by year of breast cancer diagnosis summary statistics and one-way ANOVA

Partners in health scale	Group	Number (n=51)	Percent	Mean	SD	Source of difference	Sum of squares	dF	Mean Square	f	p-value
Total score	Diagnosed in 2016 or before	9	17.65	77.56	9.79	Between groups	125	2	62.34	0.701	0.501
	Diagnosed in 2017 to 2019	16	31.37	81.13	10.61	Within groups	4271	48	88.99		
	Diagnosed in 2020 or 2021	26	50.98	81.85	8.52	Total	4396	50			

Table 6.22: Partners in health by year of breast cancer diagnosis summary statistics and Kruskal-Wallis test

Partners in health scale	Group	Number (n=51)	Percent	Median	IQR	C^2	dF	p-value
Knowledge	Diagnosed in 2016 or before	9	17.65	45.00	10.00	1.68	2	0.4314
	Diagnosed in 2017 to 2019	16	31.37	48.50	11.00			
	Diagnosed in 2020 or 2021	26	50.98	46.00	10.50			
Coping	Diagnosed in 2016 or before	9	17.65	24.00	7.00	1.21	2	0.5461
	Diagnosed in 2017 to 2019	16	31.37	28.00	4.25			
	Diagnosed in 2020 or 2021	26	50.98	26.00	5.50			
Recognition and management of symptoms	Diagnosed in 2016 or before	9	17.65	70.00	15.00	1.48	2	0.4763
	Diagnosed in 2017 to 2019	16	31.37	77.00	12.75			
	Diagnosed in 2020 or 2021	26	50.98	73.50	18.50			
Adherence to treatment	Diagnosed in 2016 or before	9	17.65	7.00	3.00	0.41	2	0.8142
	Diagnosed in 2017 to 2019	16	31.37	8.50	1.25			
	Diagnosed in 2020 or 2021	26	50.98	9.00	1.00			

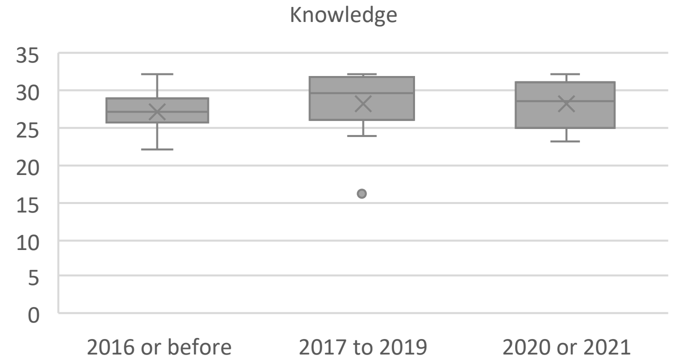


Figure 6.24: Boxplot of Partners in health: knowledge by year of breast cancer diagnosis

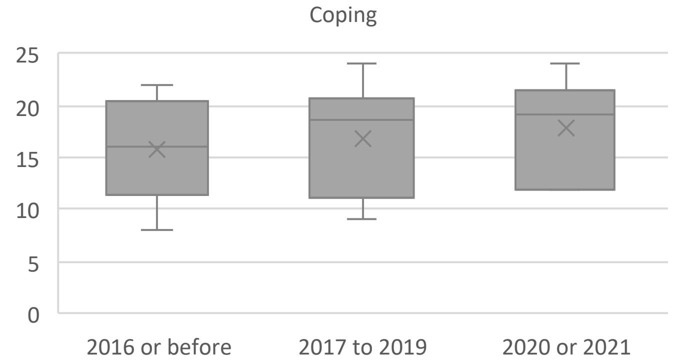


Figure 6.25: Boxplot of Partners in health: coping by year of breast cancer diagnosis

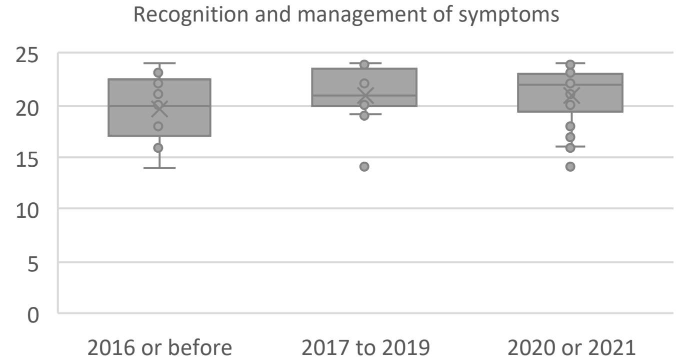


Figure 6.26: Boxplot of Partners in health: recognition and management of symptoms by year of breast cancer diagnosis

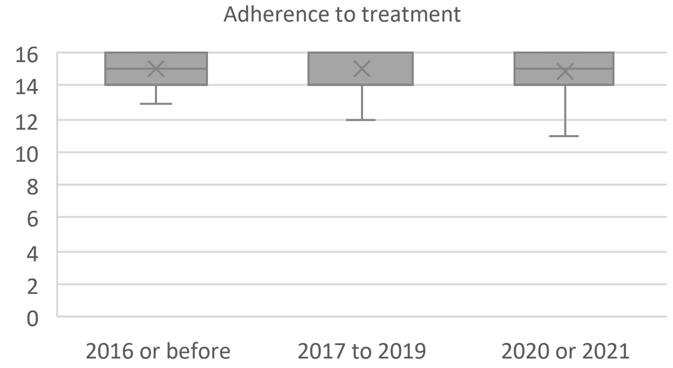


Figure 6.27: Boxplot of Partners in health: adherence to treatment by year of breast cancer diagnosis

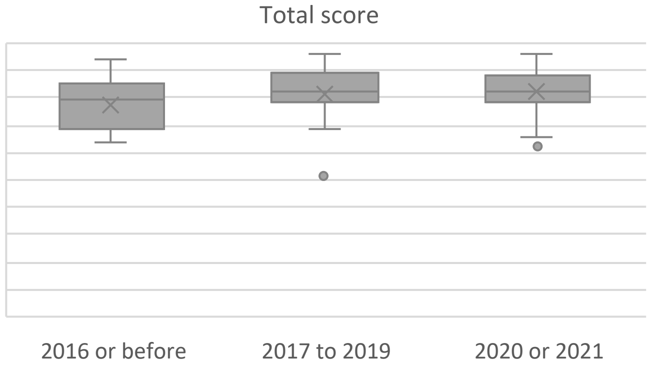


Figure 6.28: Boxplot of Partners in health Total score by year of breast cancer diagnosis

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/rural areas, *Regional or remote* (n=10, 19.61%) were compared to those living in a major city, *Metropolitan* (n=41, 80.39%).

A two-sample t-test was used when assumptions for normality and variance were met (Table 6.23), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 6.24).

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

Table 6.23: Partners in health by location summary statistics and T-test

Partners in health scale	Group	Number (n=51)	Percent	Mean	SD	T	dF	p-value
Total score	Regional or remote	10	19.61	81.36	9.66	0.20	49	0.8438
	Metropolitan	41	80.39	80.73	9.42			

Table 6.24: Partners in health by location summary statistics and Wilcoxon test

Partners in health scale	Group	Number (n=51)	Percent	Median	IQR	W	p-value
Knowledge	Regional or remote	10	19.61	28.00	7.00	213.50	0.8897
	Metropolitan	41	80.39	29.00	4.25		
Coping	Regional or remote	10	19.61	18.00	7.50	223.00	0.9541
	Metropolitan	41	80.39	18.50	8.25		
Recognition and management of symptoms	Regional or remote	10	19.61	22.00	5.00	249.50	0.5017
	Metropolitan	41	80.39	21.00	2.50		
Adherence to treatment	Regional or remote	10	19.61	15.00	1.00	235.00	0.7217
	Metropolitan	41	80.39	15.50	2.00		

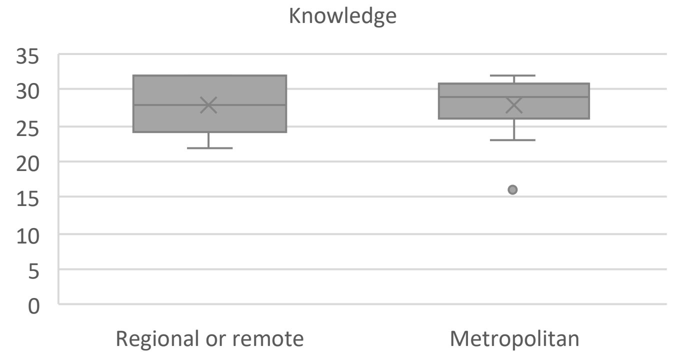


Figure 6.29: Boxplot of Partners in health: knowledge by location

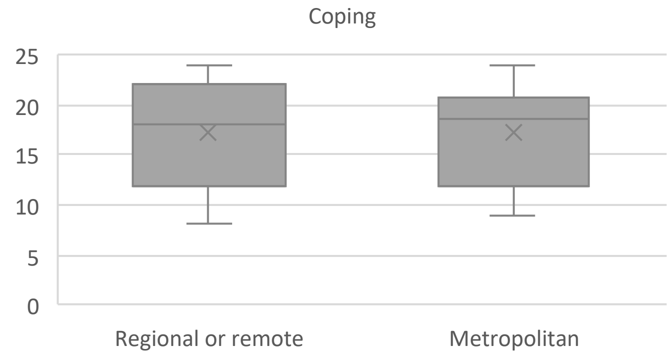


Figure 6.30: Boxplot of Partners in health: coping by location

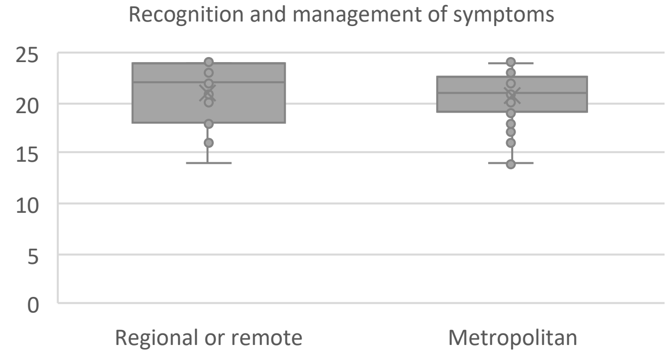


Figure 6.31: Boxplot of Partners in health: recognition and management of symptoms by location

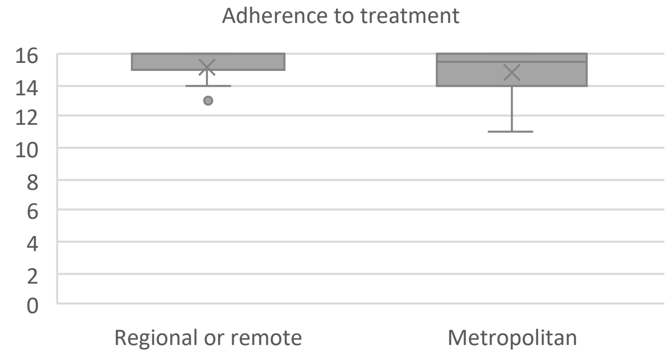


Figure 6.32: Boxplot of Partners in health: adherence to treatment by location

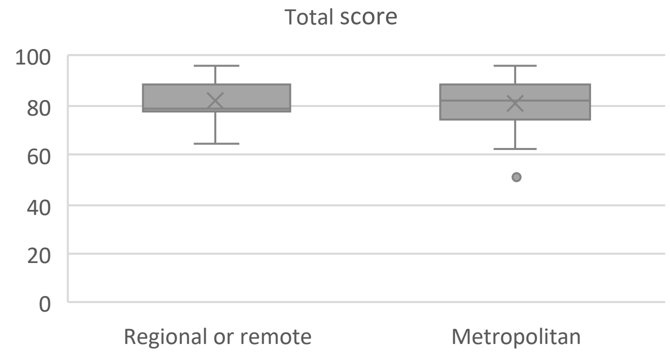


Figure 6.33: Boxplot of Partners in health Total score by location

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, *Mid to low status* (n=17, 33.33%) compared to those with a higher SEIFA score of 7-10, *Higher status* (n=34, 66.67%).

A two-sample t-test was used when assumptions for normality and variance were met (Table 6.25), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 6.26).

No significant differences were observed between participants by **socioeconomic status** for any of the Partners in health scales.

Table 6.25: Partners in health by socioeconomic status summary statistics and T-test

Partners in health scale	Group	Number (n=51)	Percent	Mean	SD	T	dF	p-value
Total score	Mid to low status	17	33.33	80.47	9.29	-0.21	49	0.8352
	Higher status	34	66.67	81.06	9.55			

Table 6.26: Partners in health by socioeconomic status summary statistics and Wilcoxon test

Partners in health scale	Group	Number (n=51)	Percent	Median	IQR	W	p-value
Knowledge	Mid to low status	17	33.33	28.00	5.00	260.00	0.5655
	Higher status	34	66.67	29.00	5.00		
Coping	Mid to low status	17	33.33	19.00	7.00	284.00	0.9280
	Higher status	34	66.67	18.00	9.00		
Recognition and management of symptoms	Mid to low status	17	33.33	22.00	4.00	312.50	0.6420
	Higher status	34	66.67	21.00	3.75		
Adherence to treatment	Mid to low status	17	33.33	15.00	2.00	256.50	0.4928
	Higher status	34	66.67	16.00	2.00		

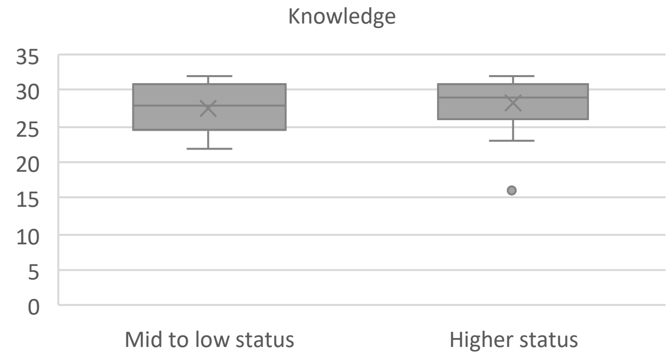


Figure 6.34: Boxplot of Partners in health: knowledge by socioeconomic status

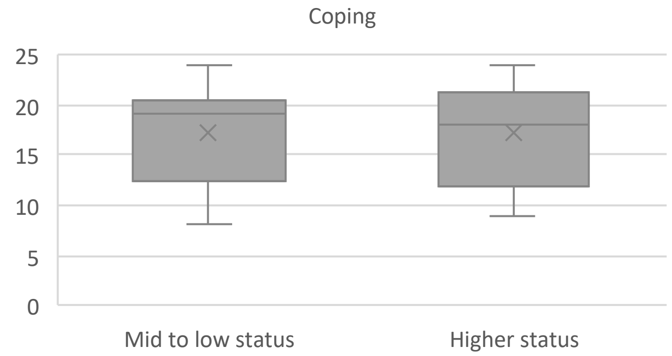


Figure 6.35: Boxplot of Partners in health: coping by socioeconomic status

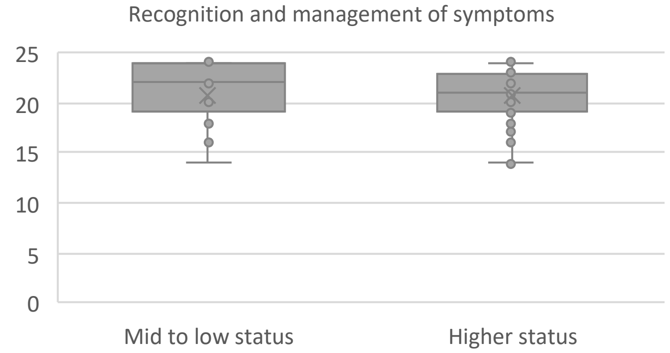


Figure 6.36: Boxplot of Partners in health: recognition and management of symptoms by socioeconomic status

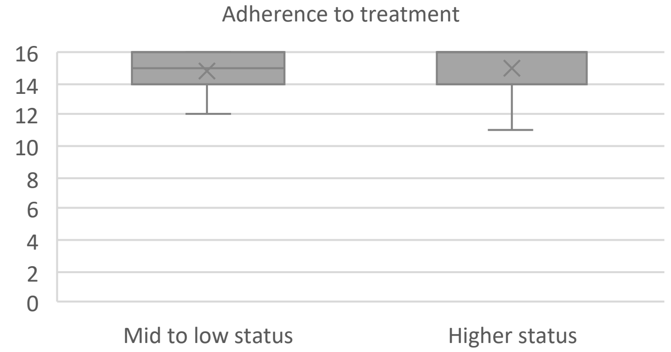


Figure 6.37: Boxplot of Partners in health: adherence to treatment by socioeconomic status

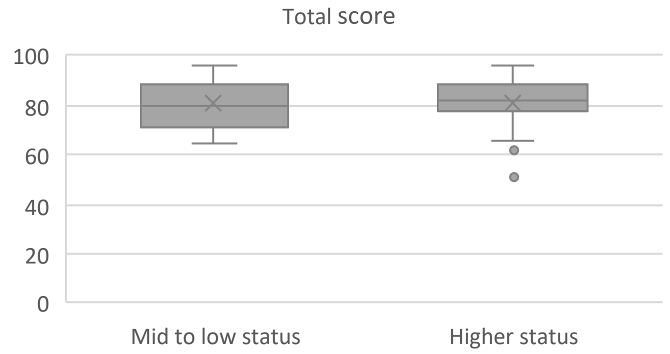


Figure 6.38: Boxplot of Partners in health Total score by socioeconomic status

Ability to take medicine as prescribed

Participants were asked about their ability to take medicines as prescribed. The majority of the participants responded that they took medicine as prescribed all the time (n = 32, 62.75%), and 18 participants (35.29%) responded that they took medicines as prescribed most of the time. (Table 6.27, Figure 6.39).

Table 6.27: Ability to take medicine as prescribed

Ability to take medicine and stick to prescription	n=51	%
All of the time	32	62.75
Most of the time	18	35.29
Sometimes	1	1.96
Rarely	0	0.00

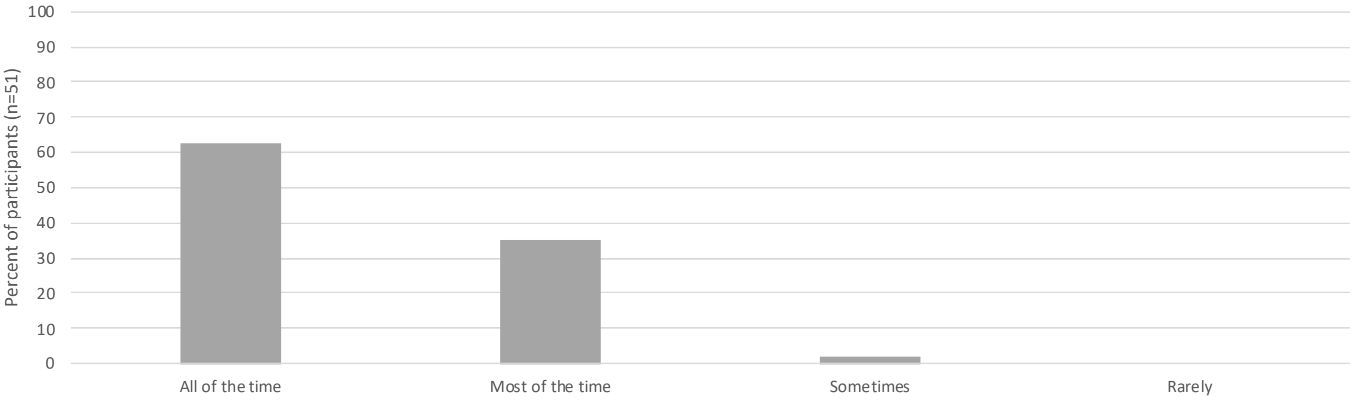


Figure 6.39: Ability to take medicine as prescribed

Information given by health professionals

Participants were asked about what type of information they were given by healthcare professionals. Information about treatment options (n=46, 88.46%), physical activity (n=26, 50.00%), disease management (n=25, 48.08%) and, hereditary considerations (n=22, 42.31%) were most frequently given to participants by healthcare professionals, and, information about how to interpret test results (n=10, 19.23%), complementary therapies (n=9, 17.31%) and, clinical trials (n=7, 13.46%) were given least often (Table 6.28, Figure 6.40).

Subgroup variations of more than 10% are listed in Table 6.29.

Table 6.28: Information given by health professionals

Information given by health professionals	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Disease Cause	15	28.85	5	26.32	5	23.81	**5**	**41.67**	9	31.03	6	26.09	6	31.58	9	27.27
Treatment options	46	88.46	16	84.21	19	90.48	11	91.67	27	93.10	19	82.61	15	78.95	31	93.94
Disease management	25	48.08	8	42.11	**13**	**61.90**	**4**	**33.33**	14	48.28	11	47.83	8	42.11	17	51.52
Complementary therapies	9	17.31	**1**	**5.26**	**6**	**28.57**	2	16.67	5	17.24	4	17.39	2	10.53	7	21.21
Interpret test results	10	19.23	**6**	**31.58**	4	19.05	**0**	**0.00**	6	20.69	4	17.39	2	10.53	8	24.24
Clinical trials	7	13.46	**0**	**0.00**	3	14.29	**4**	**33.33**	6	20.69	1	4.35	3	15.79	4	12.12
Dietary	12	23.08	**1**	**5.26**	**8**	**38.10**	3	25.00	9	31.03	**3**	**13.04**	**2**	**10.53**	10	30.30
Physical activity	26	50.00	**7**	**36.84**	**14**	**66.67**	5	41.67	16	55.17	10	43.48	**7**	**36.84**	19	57.58
Psychological/ social support	19	36.54	**5**	**26.32**	9	42.86	5	41.67	**15**	**51.72**	**4**	**17.39**	**5**	**26.32**	14	42.42
Hereditary considerations	22	42.31	**5**	**26.32**	7	33.33	**10**	**83.33**	**16**	**55.17**	**6**	**26.09**	7	36.84	15	45.45

Information given by health professionals	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Disease Cause	15	28.85	3	30.00	4	25.00	8	30.77	**5**	**45.45**	10	24.39	**3**	**16.67**	12	35.29
Treatment options	46	88.46	**7**	**70.00**	14	87.50	25	96.15	10	90.91	36	87.80	**14**	**77.78**	32	94.12
Disease management	25	48.08	5	50.00	9	56.25	11	42.31	**7**	**63.64**	18	43.90	8	44.44	17	50.00
Complementary therapies	9	17.31	2	20.00	**5**	**31.25**	2	7.69	1	9.09	8	19.51	2	11.11	7	20.59
Interpret test results	10	19.23	1	10.00	3	18.75	6	23.08	**4**	**36.36**	6	14.63	4	22.22	6	17.65
Clinical trials	7	13.46	2	20.00	**4**	**25.00**	1	3.85	2	18.18	5	12.20	2	11.11	5	14.71
Dietary	12	23.08	3	30.00	5	31.25	4	15.38	3	27.27	9	21.95	5	27.78	7	20.59
Physical activity	26	50.00	**3**	**30.00**	**10**	**62.50**	13	50.00	5	45.45	21	51.22	9	50.00	17	50.00
Psychological/ social support	19	36.54	**5**	**50.00**	5	31.25	9	34.62	4	36.36	15	36.59	6	33.33	13	38.24
Hereditary considerations	22	42.31	4	40.00	7	43.75	11	42.31	4	36.36	18	43.90	6	33.33	16	47.06

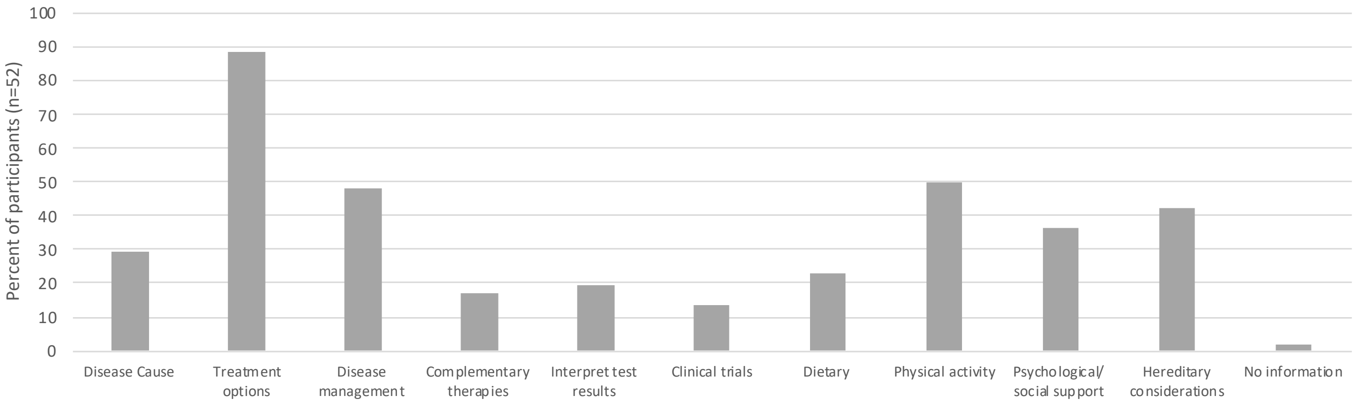


Figure 6.40: Information given by health professionals

Table 6.29: Information given by health professionals – subgroup variations

Information given by health professionals	Less frequently	More frequently
Disease Cause	Mid to low status	Stage III and IV Regional or remote
Treatment options	Diagnosed in 2016 or before Mid to low status	-
Disease management	Stage III and IV	Stage II Regional or remote
Complementary therapies	Stage 0 and I	Stage II Diagnosed in 2017 to 2019
Interpret test results	Stage III and IV	Stage 0 and I Regional or remote
Clinical trials	Stage 0 and I	Stage III and IV Diagnosed in 2017 to 2019
Dietary	Stage 0 and I Aged 55 to 74 Trade or high school	Stage II
Physical activity	Stage 0 and I Trade or high school Diagnosed in 2016 or before	Stage II Diagnosed in 2017 to 2019
Psychological/ social support	Stage 0 and I Aged 55 to 74 Trade or high school	Aged 25 to 54 Diagnosed in 2016 or before
Hereditary considerations	Stage 0 and I Aged 55 to 74	Stage III and IV Aged 25 to 54

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=29, 55.77%), how to interpret test results (n=27, 51.92%), disease management (n=25, 48.08%), and disease cause (n=24, 46.15%) were most searched for by participants, and information about psychological and social support (n=12, 23.08%) and, clinical trials (n=10, 19.23%) were searched for least often (Table 6.30, Figure 6.41).

Subgroup variations of more than 10% are listed in Table 6.31.

Table 6.30: Information searched for independently

Information searched independently	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Disease Cause	24	46.15	7	36.84	11	52.38	6	50.00	12	41.38	12	52.17	8	42.11	16	48.48
Treatment options	29	55.77	10	52.63	12	57.14	7	58.33	16	55.17	13	56.52	11	57.89	18	54.55
Disease management	25	48.08	9	47.37	9	42.86	**7**	**58.33**	14	48.28	11	47.83	**7**	**36.84**	18	54.55
Complementary therapies	20	38.46	**5**	**26.32**	10	47.62	5	41.67	13	44.83	7	30.43	7	36.84	13	39.39
Interpret test results	27	51.92	11	57.89	**8**	**38.10**	**8**	**66.67**	17	58.62	10	43.48	**7**	**36.84**	20	60.61
Clinical trials	10	19.23	4	21.05	3	14.29	3	25.00	4	13.79	6	26.09	5	26.32	5	15.15
Dietary	19	36.54	**5**	**26.32**	8	38.10	**6**	**50.00**	13	44.83	**6**	**26.09**	6	31.58	13	39.39
Physical activity	23	44.23	7	36.84	**12**	**57.14**	**4**	**33.33**	14	48.28	9	39.13	9	47.37	14	42.42
Psychological/ social support	12	23.08	4	21.05	5	23.81	3	25.00	9	31.03	**3**	**13.04**	4	21.05	8	24.24
Hereditary considerations	16	30.77	7	36.84	5	23.81	4	33.33	11	37.93	5	21.74	5	26.32	11	33.33

Information searched independently	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Disease Cause	24	46.15	5	50.00	8	50.00	11	42.31	5	45.45	19	46.34	8	44.44	16	47.06
Treatment options	29	55.77	6	60.00	9	56.25	14	53.85	6	54.55	23	56.10	9	50.00	20	58.82
Disease management	25	48.08	5	50.00	9	56.25	11	42.31	**4**	**36.36**	21	51.22	**6**	**33.33**	19	55.88
Complementary therapies	20	38.46	**6**	**60.00**	**8**	**50.00**	**6**	**23.08**	4	36.36	16	39.02	**10**	**55.56**	10	29.41
Interpret test results	27	51.92	**4**	**40.00**	**11**	**68.75**	12	46.15	**4**	**36.36**	23	56.10	9	50.00	18	52.94
Clinical trials	10	19.23	**0**	**0.00**	**5**	**31.25**	5	19.23	**1**	**9.09**	9	21.95	4	22.22	6	17.65
Dietary	19	36.54	**7**	**70.00**	5	31.25	7	26.92	5	45.45	14	34.15	7	38.89	12	35.29
Physical activity	23	44.23	**7**	**70.00**	7	43.75	9	34.62	5	45.45	18	43.90	8	44.44	15	44.12
Psychological/ social support	12	23.08	**4**	**40.00**	3	18.75	5	19.23	**1**	**9.09**	11	26.83	3	16.67	9	26.47
Hereditary considerations	16	30.77	3	30.00	5	31.25	8	30.77	**1**	**9.09**	15	36.59	5	27.78	11	32.35

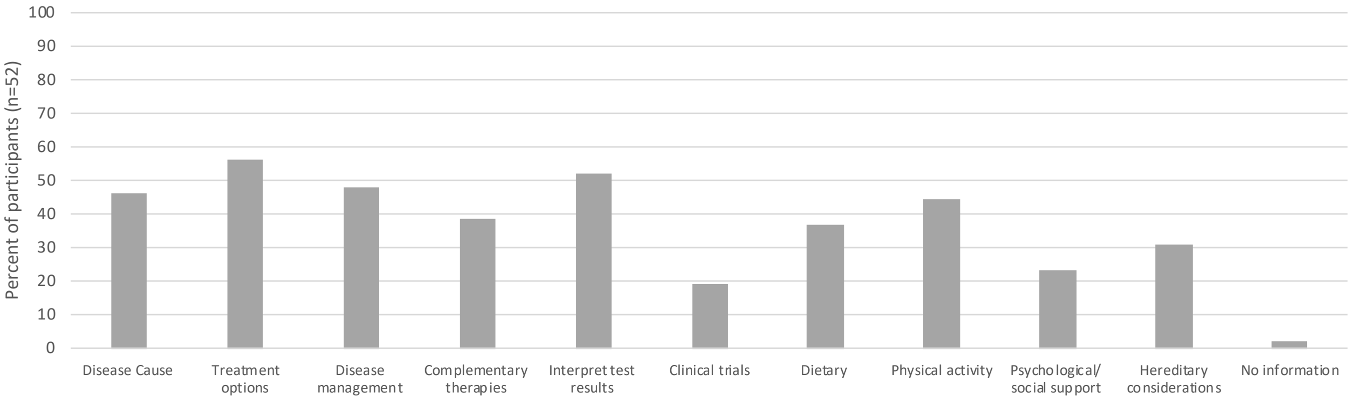


Figure 6.41: Information searched for independently

Table 6.31: Information searched for independently – subgroup variations

Information searched independently	Less frequently	More frequently
Disease management	Trade or high school Regional or remote Mid to low status	Stage III and IV
Complementary therapies	Stage 0 and I Diagnosed in 2020 or 2021	Diagnosed in 2016 or before Diagnosed in 2017 to 2019 Mid to low status
Interpret test results	Stage II Trade or high school Diagnosed in 2016 or before Regional or remote	Stage III and IV Diagnosed in 2017 to 2019
Clinical trials	Diagnosed in 2016 or before Regional or remote	Diagnosed in 2017 to 2019
Dietary	Stage 0 and I Aged 55 to 74	Stage III and IV Diagnosed in 2016 or before
Physical activity	Stage III and IV	Stage II Diagnosed in 2016 or before
Psychological/ social support	Aged 55 to 74 Regional or remote	Diagnosed in 2016 or before
Hereditary considerations	Regional or remote	-

Information gaps

The largest gaps in information, where information was neither given to patients nor searched for independently were clinical trials (n = 37, 71.15%), dietary information (n = 27, 51.92%), complementary therapies (n = 27, 51.92%) and psychological and social support (n = 26, 50.00%).

The topics that participants most commonly did not search for independently after not receiving information from healthcare professionals were treatment options (n = 21, 40.38%) and physical activity (n = 16, 30.77%).

The topics that participants were given most information from both healthcare professionals and searching independently for were how to interpret test results (n = 22, 42.31%), and disease Cause (n = 19, 36.54%).

The topics that participants most commonly searched for independently after not receiving information from healthcare professionals were treatment options (n = 25, 48.08%) and disease management (n = 12, 23.08%) (Table 6.32, Figure 6.42).

Table 6.32: 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=52	%	n=52	%	n=52	%	n=52	%
Disease cause	18	34.62	10	19.23	19	36.54	5	9.62
Treatment options	2	3.85	21	40.38	4	7.69	25	48.08
Disease management	14	26.92	13	25.00	13	25.00	12	23.08
Complementary therapies	27	51.92	5	9.62	16	30.77	4	7.69
How to interpret test results	20	38.46	5	9.62	22	42.31	5	9.62
Clinical trials	37	71.15	5	9.62	8	15.38	2	3.85
Dietary information	27	51.92	6	11.54	13	25.00	6	11.54
Physical activity	13	25.00	16	30.77	13	25.00	10	19.23
Psychological/social support	26	50.00	14	26.92	7	13.46	5	9.62
Hereditary considerations	21	40.38	15	28.85	9	17.31	7	13.46

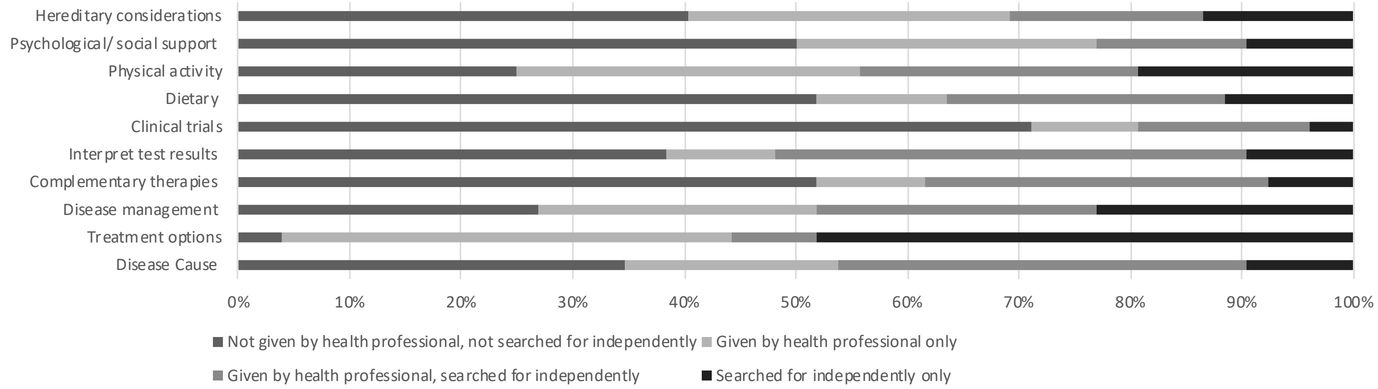


Figure 6.42: Information gaps

Most accessed information

Participants were asked to rank which information source that they accessed most often, where 1 is the most trusted and 5 is the least trusted. A weighted average is presented in Table 6.33 and Figure 6.43. 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 was most accessed followed by information from the hospital or clinic where being treated. Information from Pharmaceutical companies was least accessed.

Table 6.33: Most accessed information

Information source	Weighted average (n=51)
Non-profit organisations, charity or patient organisations	3.88
Government	3.20
Pharmaceutical companies	1.94
Hospital or clinic I am being treated in	3.22
Medical journals	2.76

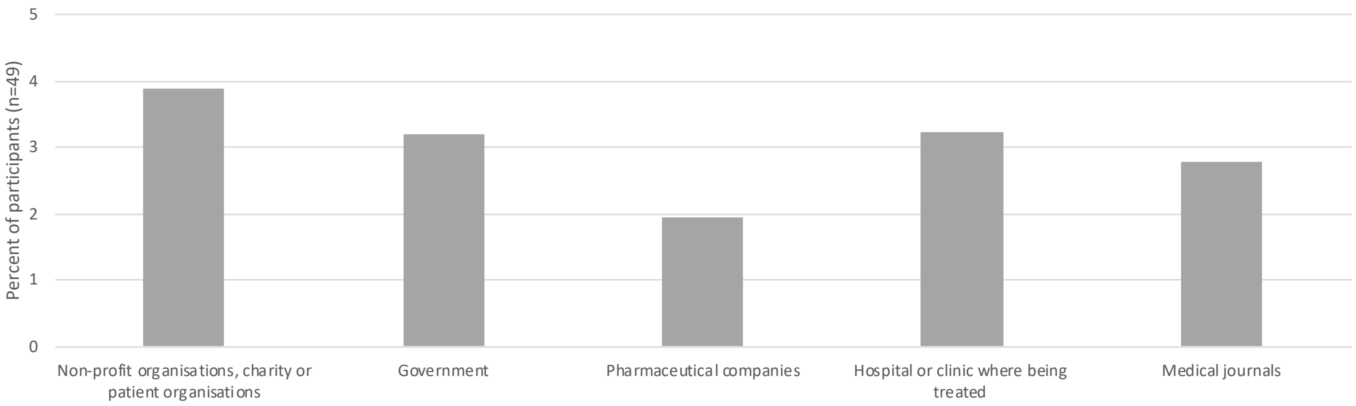


Figure 6.43: Most accessed information

My Health Record

My Health Record is an online summary of key health information, an initiative of the Australian Government. There were 12 participants (23.53%) had accessed My Health Record, 39 participants (76.47%) had not (Table 6.34. Figure 6.44).

Of those that had accessed My Health Record, there were seven participants (58.33%) that found it to be poor or very poor, and four participants (33.33%) that found it acceptable (Table 6.35, Figure 6.45).

Table 6.34: Accessed My Health Record

Accessed "My health record"	Number (n=51)	Percent
Yes	12	23.53
No	31	60.78
Not sure	6	11.76
Doesn't know what 'My Health Record' is	2	3.92

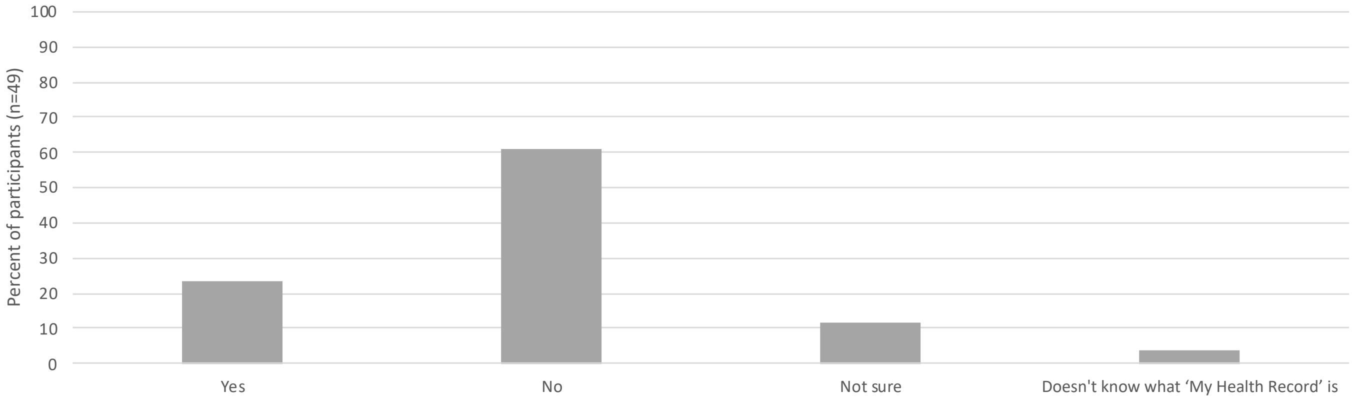


Figure 6.44: Accessed My Health Record

Table 6.35: How useful was My Health Record

How useful was "My health record"	Number (n=12)	Percent
Very poor	4	33.33
Poor	3	25.00
Acceptable	4	33.33
Good	1	8.33
Very good	0	0.00

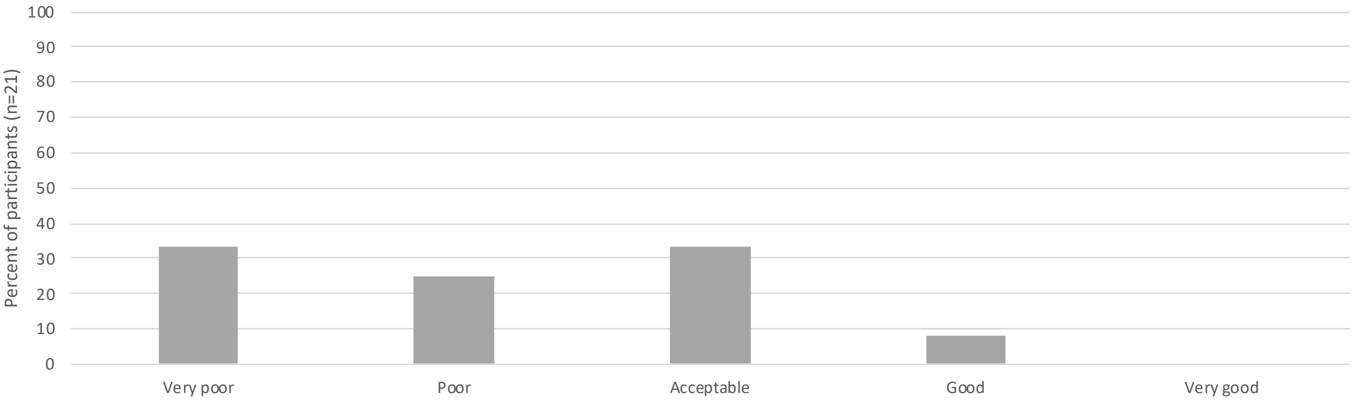


Figure 6.45: How useful was My Health Record

Section 7

Care and support

Section 7: Experience of care and support

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 good 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 good 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 very 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 very 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 help (n=18, 34.62%). This was followed by receiving support through the hospital and clinical setting (n=14, 26.92%), through charities (n=11, 21.15%) and face-to-face peer support (n=8, 15.38%). There were six participants that described not needing any help (11.54%).

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.

Overall, the participants in this PEEK study had an average score in the second highest quintile for the **Care coordination: Communication** (mean = 45.75, SD = 9.58), **Care coordination: Navigation** (mean = 26.86, SD = 4.55), and **Care coordination: Total score** (mean = 72.61, SD = 12.86), indicating good communication and navigation of the healthcare system.

Overall, the participants in this PEEK study had an average score in the highest quintile for the **Care coordination: Care coordination global measure** (median = 9.00, IQR = 2.50), and **Care coordination: Quality of care global measure** (median = 9.00, IQR = 2.00) indicating very good care coordination and quality of care.

Comparisons of Care co-ordination have been made based **stage** (Tables 7.2 to 7.3, Figures 7.1 to 7.5), **age** (Tables 7.4 to 7.5, Figures 7.6 to 7.10), **education** (Tables 7.6 to 7.7, Figures 7.11 to 7.15), **year of diagnosis** (Tables 7.8 to 7.9, Figures 7.16 to 7.20), **location** (Tables 7.10 to 7.11, Figures 7.21 to 7.25), and **socioeconomic status** (Tables 7.12 to 7.13, Figures 7.26 to 7.30).

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 good 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 good 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 very 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 very good.

Table 7.1: Care coordination summary statistics

Care coordination scale (n=51)	Mean	SD	Median	IQR	Possible range	Quintile
Communication*	45.75	9.58	46.00	10.00	13 to 65	4
Navigation*	26.86	4.55	27.00	6.50	7 to 35	4
Total score*	72.61	12.86	75.00	17.50	20 to 100	4
Care coordination global measure	8.12	1.90	9.00	2.50	1 to 10	5
Quality of care global measure	8.80	1.33	9.00	2.00	1 to 10	5

*Normal distribution use mean and SD as measure of central tendency

Care coordination by stage

Comparisons were made by breast cancer **stage**, there were 18 participants (35.29%) with *Stage 0 and I* breast cancer, 21 participants (41.18%) *with Stage II*, and 12 participants (23.53%) with *Stage III and 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).

No significant differences were observed between participants by **stage** for any of the Care coordination scales.

Table 7.2: Care coordination by stage summary statistics and one-way ANOVA

Care coordination scale	Group	Number (n=51)	Percent	Mean	SD	Source of difference	Sum of squares	dF	Mean Square	f	p-value
Communication	Stage 0 and I	18	35.29	45.17	10.19	Between groups	36.00	2	17.99	0.19	0.8280
	Stage II	21	41.18	45.38	10.49	Within groups	4556.00	48	94.91		
	Stage III and IV	12	23.53	47.25	7.33	Total	4592.00	50			
Navigation	Stage 0 and I	18	35.29	25.28	4.21	Between groups	71.30	2	35.64	1.777	0.1800
	Stage II	21	41.18	27.57	4.69	Within groups	962.80	48	20.06		
	Stage III and IV	12	23.53	28.00	4.49	Total	1034.10	50			
Total score	Stage 0 and I	18	35.29	70.44	13.79	Between groups	171.00	2	85.26	0.505	0.6070
	Stage II	21	41.18	72.95	14.23	Within groups	8102.00	48	168.78		
	Stage III and IV	12	23.53	75.25	8.64	Total	8273.00	50			

Table 7.3: Care coordination by stage summary statistics and Kruskal-Wallis test

Care coordination scale	Group	Number (n=51)	Percent	Median	IQR	C^2	dF	p-value
Care coordination global measure	Stage 0 and I	18	35.29	9.00	1.75	1.87	2	0.3924
	Stage II	21	41.18	9.00	3.00			
	Stage III and IV	12	23.53	8.00	2.00			
Quality of care global measure	Stage 0 and I	18	35.29	9.00	2.75	0.01	2	0.9971
	Stage II	21	41.18	9.00	2.00			
	Stage III and IV	12	23.53	9.00	1.25			

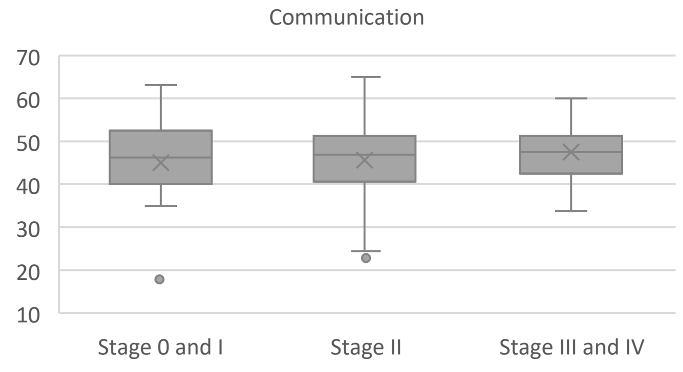


Figure 7.1: Boxplot of Care coordination: knowledge by stage

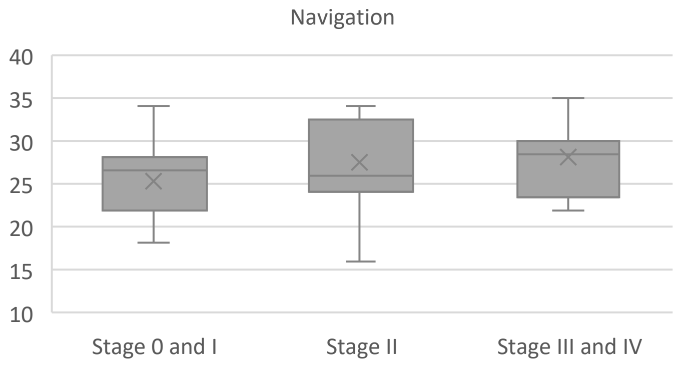
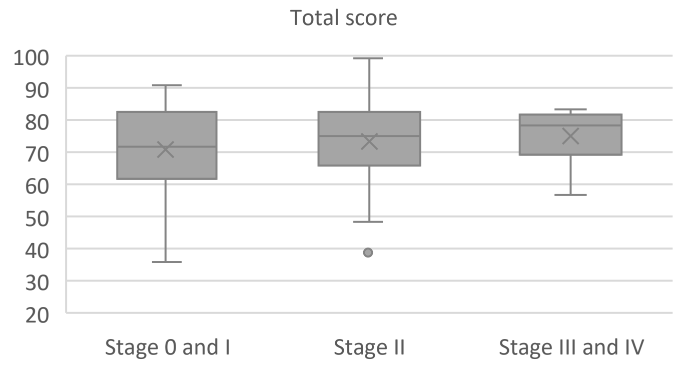


Figure 7.2: Boxplot of Care coordination: coping by stage



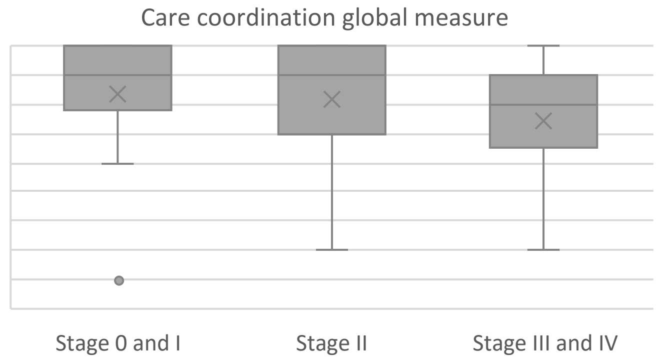


Figure 7.3: Boxplot of Care coordination: recognition and management of symptoms by stage

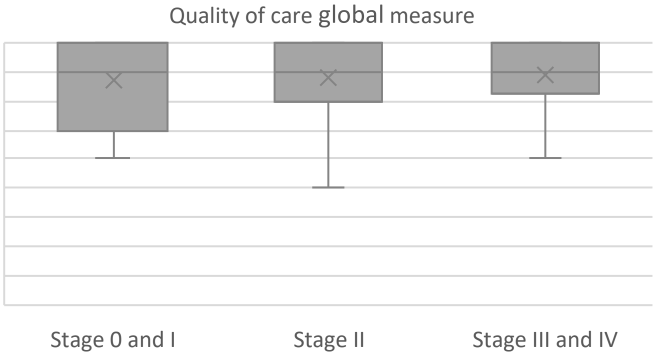


Figure 7.5: Boxplot of Care coordination Total score by stage

Figure 7.4: Boxplot of Care coordination: adherence to treatment by stage

Care coordination by age

Participants were grouped according to **age,** with comparisons made between participants *Aged 25 to* 54 (n=29, 56.86%) and participants *Aged 55 to 74* (n=22, 43.14%).

A two-sample t-test was used when assumptions for normality and variance were met (Table 7.4), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 7.5).

A two sample t-test indicated that the mean score for the Care coordination Communication scale [t(49) = 2.02 , p = 0.0491*] was significantly higher for participants in the *Aged 25 to 54* subgroup (Mean = 48.03, SD = 8.32) compared to participants in the *Aged 55 to 74* subgroup (Mean = 42.73, SD = 10.47.

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 *Aged 25 to 54* subgroup scored higher than participants in the *Aged 55 to 74* subgroup. This indicates that healthcare communication was good for participants in the *Aged 25 to 54* subgroup, and average for participants in the *Aged 55 to 74* subgroup.

Table 7.4: Care coordination by age summary statistics and T-test

Care coordination scale	Group	Number (n=51)	Percent	Mean	SD	T	dF	p-value
Communication	Aged 25 to 54	29	66.00	48.03	8.32	2.02	49	0.0491*
	Aged 55 to 74	22	34.00	42.73	10.47			
Navigation	Aged 25 to 54	29	66.00	27.28	4.90	0.74	49	0.4619
	Aged 55 to 74	22	34.00	26.32	4.09			
Total score	Aged 25 to 54	29	66.00	75.31	11.73	1.76	49	0.0849
	Aged 55 to 74	22	34.00	69.05	13.68			

*Statistically significant at p<0.05

Table 7.5: Care coordination by age summary statistics and Wilcoxon test

Care coordination scale	Group	Number (n=51)	Percent	Median	IQR	W	p-value
Care coordination global measure	Aged 25 to 54	29	66.00	9.00	2.00	384.50	0.2059
	Aged 55 to 74	22	34.00	8.00	2.75		
Quality of care global measure	Aged 25 to 54	29	66.00	9.00	2.00	345.00	0.6113
	Aged 55 to 74	22	34.00	9.00	2.00		

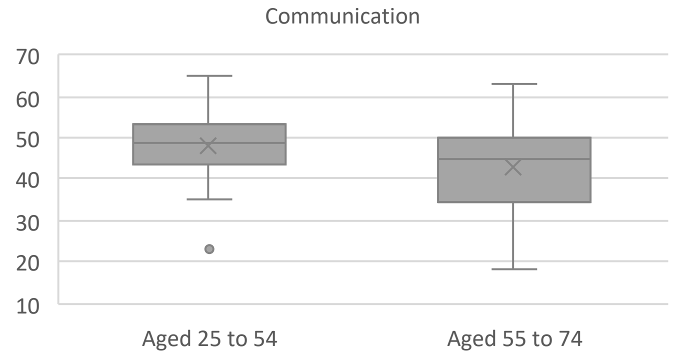


Figure 7.6: Boxplot of Care coordination: knowledge by age

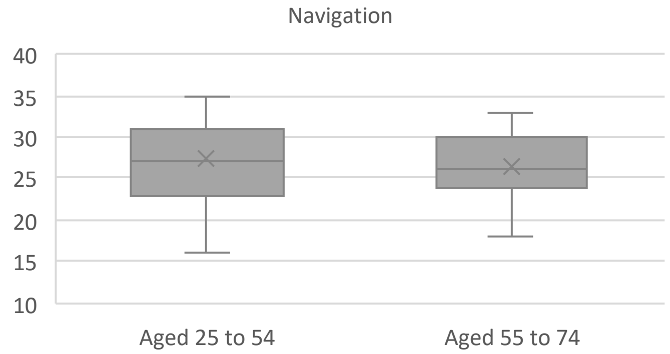


Figure 7.7: Boxplot of Care coordination: coping by age

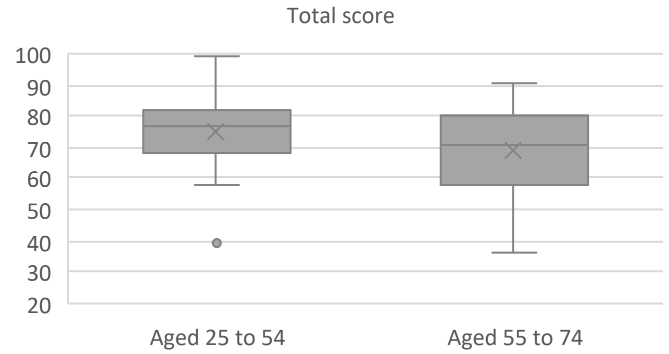


Figure 7.8: Boxplot of Care coordination: recognition and management of symptoms by age

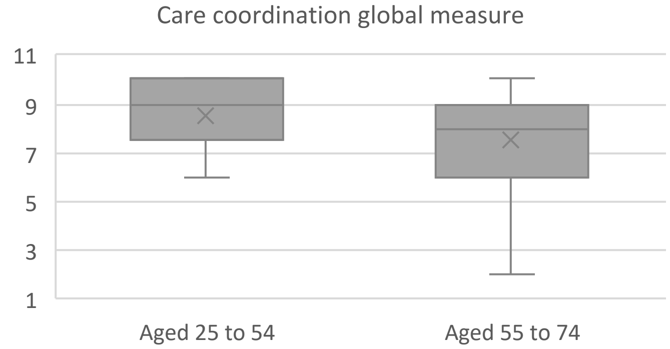


Figure 7.9: Boxplot of Care coordination: adherence to treatment by age

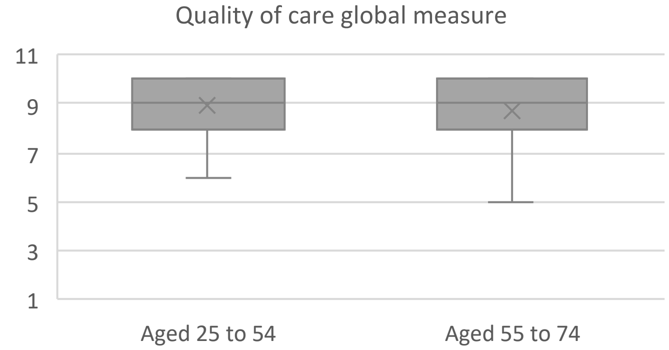


Figure 7.10: Boxplot of Care coordination Total score by age

Care coordination by education

Comparisons were made by **education** status, between those with trade or high school qualifications, *Trade or high school* (n=19, 37.25%), and those with a university qualification, *University* (n= 32, 62.75%).

A two-sample t-test was used when assumptions for normality and variance were met (Table 7.6), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 7.7).

No significant differences were observed between participants by **education** for any of the Care coordination scales.

Table 7.6: Care coordination by education summary statistics and T-test

Care coordination scale	Group	Number (n=51)	Percent	Mean	SD	T	dF	p-value
Navigation	Trade or high school	19	37.25	26.58	4.68	-0.34	49	0.7350
	University	32	62.75	27.03	4.53			
Total score	Trade or high school	19	37.25	69.89	13.83	-1.16	49	0.2497
	University	32	62.75	74.22	12.19			

Table 7.7: Care coordination by education summary statistics and Wilcoxon test

Care coordination scale	Group	Number (n=51)	Percent	Median	IQR	W	p-value
Communication	Trade or high school	19	37.25	46.00	12.50	260.00	0.3961
	University	32	62.75	47.00	12.50		
Care coordination global measure	Trade or high school	19	37.25	8.00	2.50	284.00	0.6975
	University	32	62.75	9.00	1.50		
Quality of care global measure	Trade or high school	19	37.25	9.00	2.00	287.50	0.7440
	University	32	62.75	9.00	2.00		

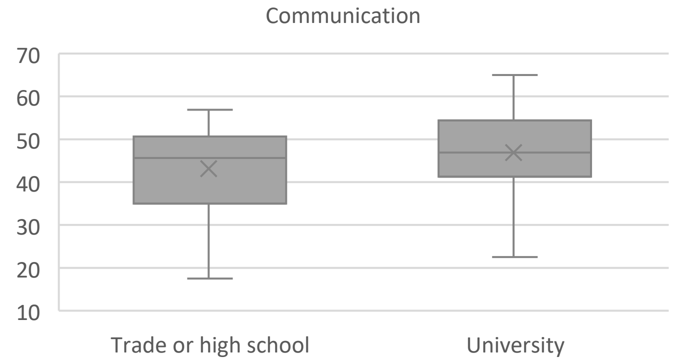


Figure 7.11: Boxplot of Care coordination: knowledge by education

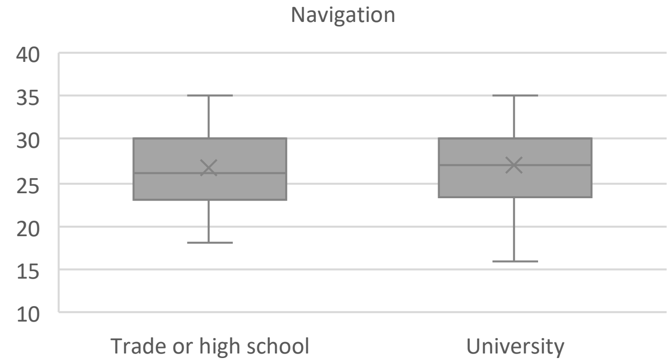


Figure 7.12: Boxplot of Care coordination: coping by education

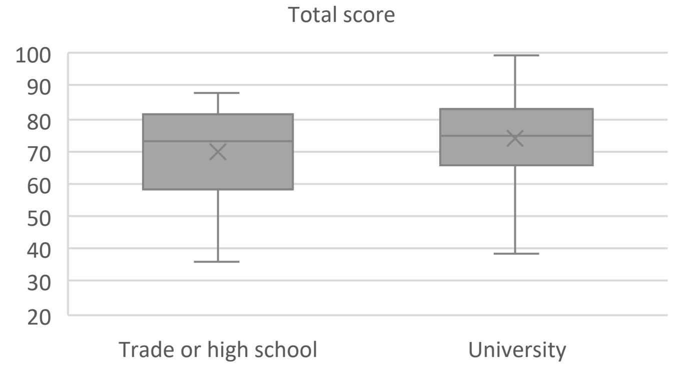


Figure 7.13: Boxplot of Care coordination: recognition and management of symptoms by education

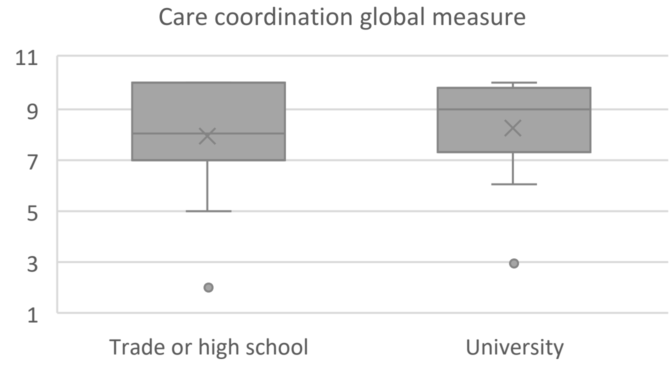


Figure 7.14: Boxplot of Care coordination: adherence to treatment by education

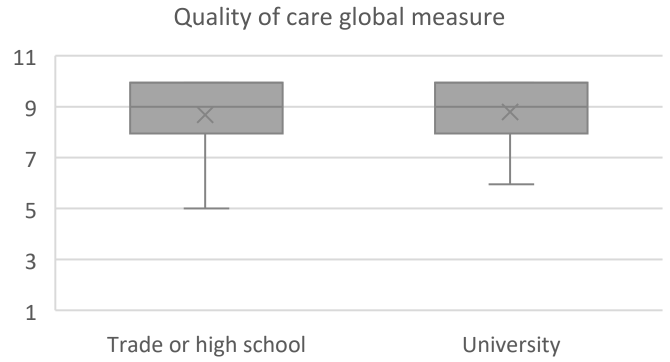


Figure 7.15: Boxplot of Care coordination Total score by education

Care coordination by year of breast cancer diagnosis

Participants were grouped according to the **year of breast cancer diagnosis**, with 9 participants (17.65%) *Diagnosed in 2016 or before,* 16 participants (31.37%) *Diagnosed in 2017 to 2019*, and 26 participants (50.98%) *Diagnosed in 2020 or 2021.*

A one-way ANOVA test was used when the assumptions for response variable residuals were normally distributed and variances of populations were equal (Table 7.8). When the assumptions for normality of residuals was not met, a Kruskal-Wallis test was used (Table 7.9).

No significant differences were observed between participants by **year of breast cancer diagnosis** for any of the Care coordination scales.

Table 7.8: Care coordination by year of breast cancer diagnosis summary statistics and one-way ANOVA

Care coordination scale	Group	Number (n=51)	Percent	Mean	SD	Source of difference	Sum of squares	dF	Mean Square	f	p-value
Communication	Diagnosed in 2016 or before	9	17.65	45.22	6.02	Between groups	16.00	2	7.92	0.083	0.9200
	Diagnosed in 2017 to 2019	16	31.37	46.56	12.10	Within groups	4576.00	48	95.33		
	Diagnosed in 2020 or 2021	26	50.98	45.42	9.14	Total	4592.00	50			
Navigation	Diagnosed in 2016 or before	9	17.65	25.89	4.54	Between groups	32.70	2	16.32	0.783	0.4630
	Diagnosed in 2017 to 2019	16	31.37	28.00	5.18	Within groups	1001.40	48	20.86		
	Diagnosed in 2020 or 2021	26	50.98	26.50	4.17	Total	1034.10	50			

Table 7.9: Care coordination by year of breast cancer diagnosis summary statistics and Kruskal-Wallis test

Care coordination scale	Group	Number (n=51)	Percent	Median	IQR	C^2	dF	p-value
Total score	Diagnosed in 2016 or before	9	17.65	70.00	15.00	1.87	2	0.3918
	Diagnosed in 2017 to 2019	16	31.37	77.00	12.75			
	Diagnosed in 2020 or 2021	26	50.98	73.50	18.50			
Care coordination global measure	Diagnosed in 2016 or before	9	17.65	7.00	3.00	0.81	2	0.6675
	Diagnosed in 2017 to 2019	16	31.37	8.50	1.25			
	Diagnosed in 2020 or 2021	26	50.98	9.00	1.00			
Quality of care global measure	Diagnosed in 2016 or before	9	17.65	8.00	2.00	4.81	2	0.0902
	Diagnosed in 2017 to 2019	16	31.37	10.00	1.00			
	Diagnosed in 2020 or 2021	26	50.98	9.00	1.75			

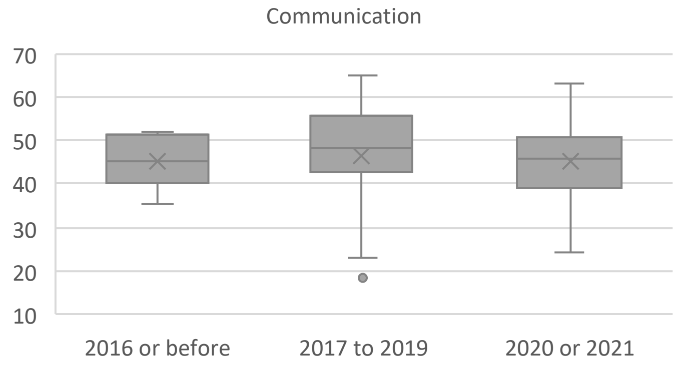


Figure 7.16: Boxplot of Care coordination: knowledge by year of breast cancer diagnosis

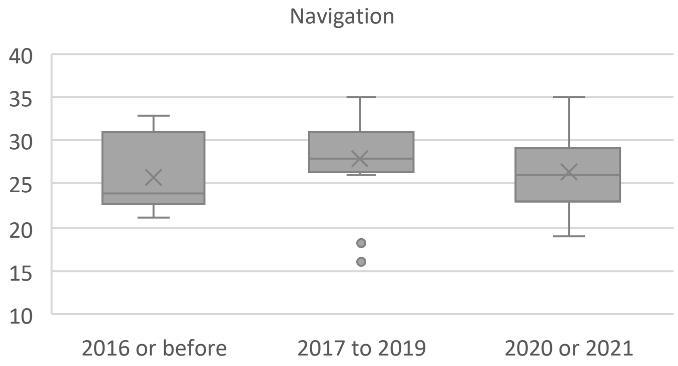


Figure 7.17: Boxplot of Care coordination: coping by year of breast cancer diagnosis

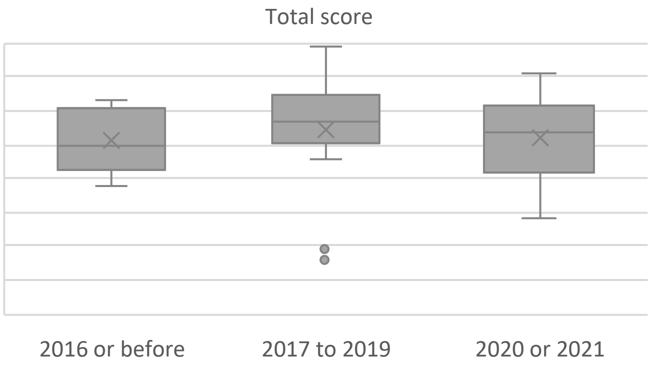


Figure 7.18: Boxplot of Care coordination: recognition and management of symptoms by year of breast cancer diagnosis

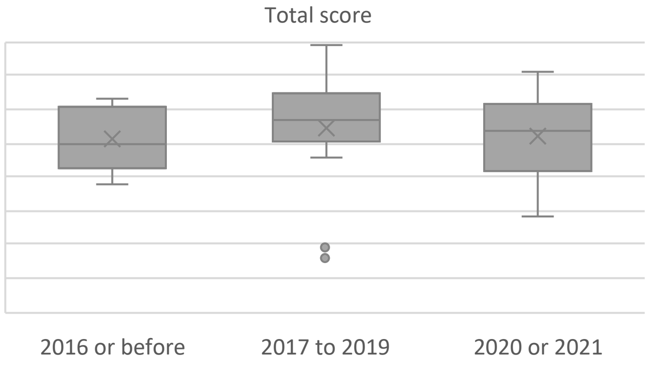


Figure 7.19: Boxplot of Care coordination: adherence to treatment by year of breast cancer diagnosis

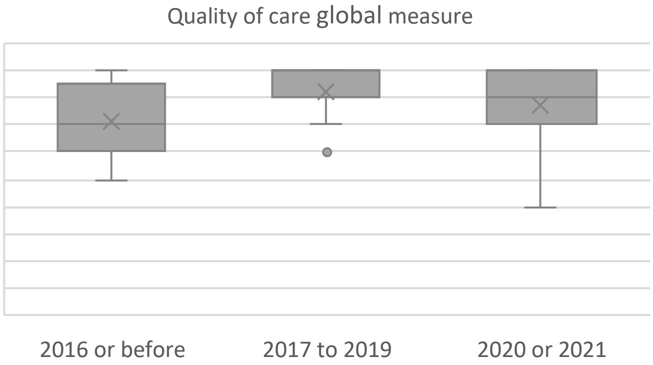


Figure 7.20: Boxplot of Care coordination Total score by year of breast cancer diagnosis

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/rural areas, *Regional or remote* (n=10, 19.61%) were compared to those living in a major city, *Metropolitan* (n=41, 80.39%).

A two-sample t-test was used when assumptions for normality and variance were met (Table 7.10), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 7.11).

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

Table 7.10: Care coordination by location summary statistics and T-test

Care coordination scale	Group	Number (n=51)	Percent	Mean	SD	T	dF	p-value
Communication	Regional or remote	10	19.61	45.82	10.20	0.03	49	0.9776
	Metropolitan	41	80.39	45.73	9.54			
Navigation	Regional or remote	10	19.61	26.55	3.86	-0.26	49	0.7968
	Metropolitan	41	80.39	26.95	4.76			
Total score	Regional or remote	10	19.61	72.36	11.83	-0.07	49	0.9442
	Metropolitan	41	80.39	72.68	13.27			

Table 7.11: Care coordination by location summary statistics and Wilcoxon test

Care coordination scale	Group	Number (n=51)	Percent	Median	IQR	W	p-value
Care coordination global measure	Regional or remote	10	19.61	9.00	2.50	265.00	0.2970
	Metropolitan	41	80.39	8.00	2.00		
Quality of care global measure	Regional or remote	10	19.61	9.00	1.00	263.50	0.3022
	Metropolitan	41	80.39	9.00	2.00		

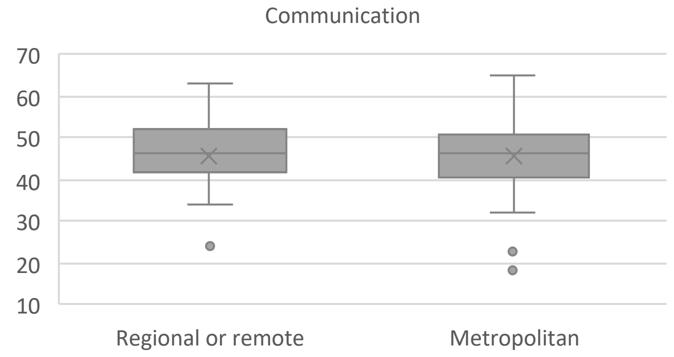


Figure 7.21: Boxplot of Care coordination: knowledge by location

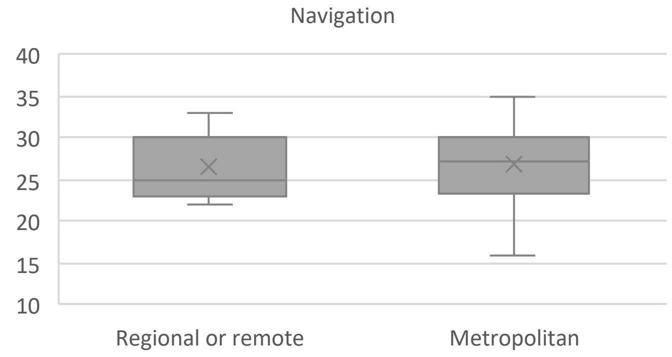


Figure 7.22: Boxplot of Care coordination: coping by location

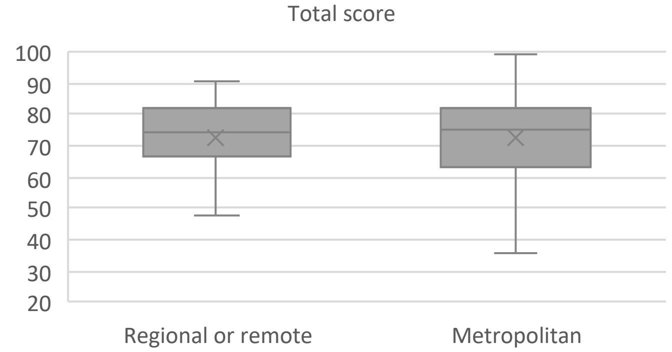


Figure 7.23: Boxplot of Care coordination: recognition and management of symptoms by location

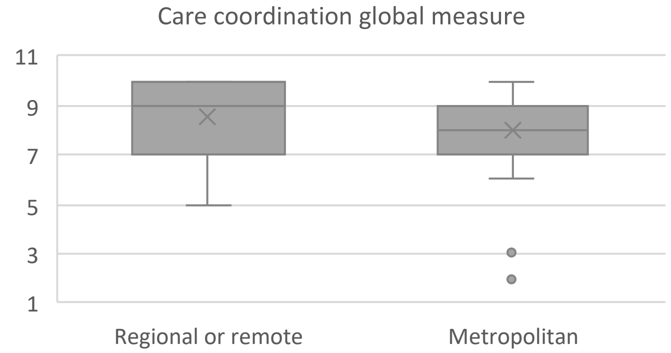


Figure 7.24: Boxplot of Care coordination: adherence to treatment by location

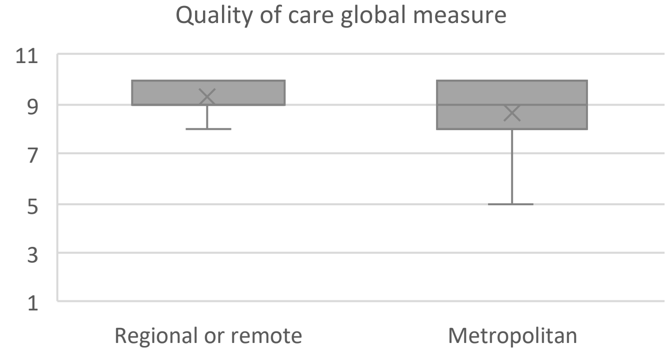


Figure 7.25: Boxplot of Care coordination Total score by location

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, *Mid to low status* (n=17, 33.33%) compared to those with a higher SEIFA score of 7-10, *Higher status* (n=34, 66.67%).

A two-sample t-test was used when assumptions for normality and variance were met (Table 7.12), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 7.13).

No significant differences were observed between participants by **socioeconomic status** for any of the Care coordination scales.

Table 7.12: Care coordination by **socioeconomic status** summary statistics and T-test

Care coordination scale	Group	Number (n=51)	Percent	Mean	SD	T	dF	p-value
Communication	Mid to low status	17	33.33	48.00	11.27	1.19	49	0.2385
	Higher status	34	66.67	44.62	8.58			
Navigation	Mid to low status	17	33.33	26.88	5.04	0.02	49	0.9829
	Higher status	34	66.67	26.85	4.36			
Total score	Mid to low status	17	33.33	74.88	14.91	0.89	49	0.3772
	Higher status	34	66.67	71.47	11.78			

Table 7.13: Care coordination by **socioeconomic status** summary statistics and Wilcoxon test

Care coordination scale	Group	Number (n=51)	Percent	Median	IQR	W	p-value
Care coordination global measure	Mid to low status	17	33.33	9.00	2.00	358.00	0.1613
	Higher status	34	66.67	8.00	2.00		
Quality of care global measure	Mid to low status	17	33.33	10.00	2.00	345.50	0.2410
	Higher status	34	66.67	9.00	2.00		

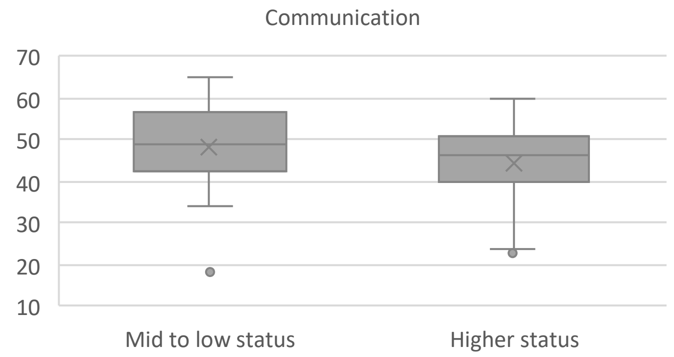


Figure 7.26: Boxplot of Care coordination: knowledge by socioeconomic status

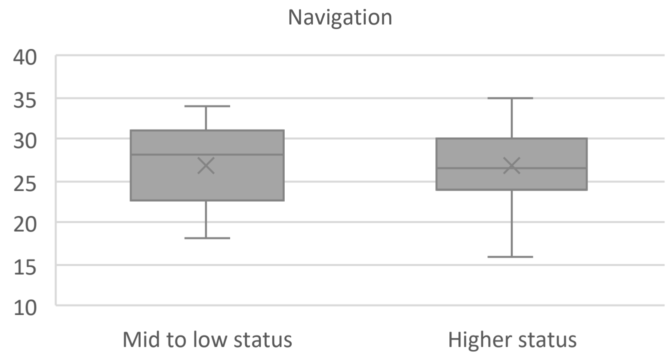


Figure 7.27: Boxplot of Care coordination: coping by socioeconomic status

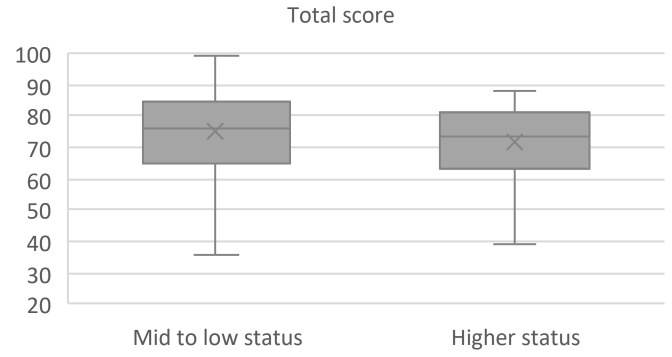


Figure 7.28: Boxplot of Care coordination: recognition and management of symptoms by socioeconomic status

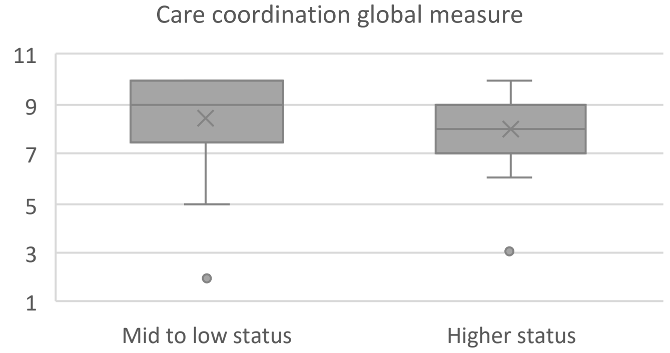


Figure 7.29: Boxplot of Care coordination: adherence to treatment by socioeconomic status

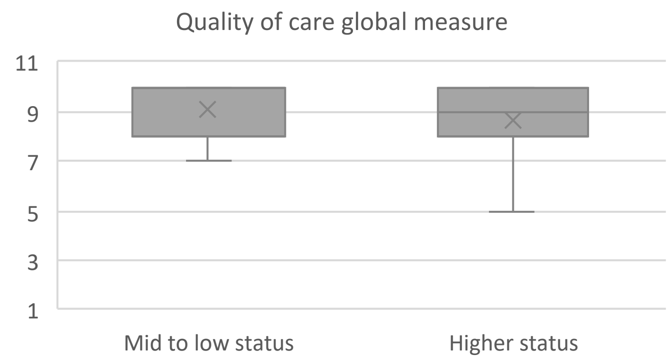


Figure 7.30: Boxplot of Care coordination Total score by socioeconomic status

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 help (n=18, 34.62%). This was followed by receiving support through the hospital and clinical setting (n=14, 26.92%), through charities (n=11, 21.15%) and face-to-face peer support (n=8, 15.38%). There were six participants that described not needing any help (11.54%).

Participant describes not receiving any support

No, nope. Nope. And I've asked for it. Participant 003_2021AUHRP

The public hospital said a McGrath breast care nurse will be in contact with you. And before I go home, and that was meant to be day surgery, I didn't see her I didn't go home and I didn't see her the next day and there was another breast lumpectomy patient as well breast cancer patient and she didn't see anyone either. And when I was discharged I was given her number if I, in case I'd needed her but I also felt that I'm only stage one probably other people that need her more or she busy with people that need her more than me so I didn't feel right contacting her and I thought now maybe in a couple of weeks she'll ring me anyway but nup.
INTERVIEWER: And yeah, have you had any community engagement?
PARTICIPANT: Nup. Participant 014_2021AUHRP

No. I actually wasn't eligible for home help when I had the mastectomy, because I was the wrong age and I'd had the operation in a private hospital. Participant 031_2021AUHRP

Participant describes receiving support from a hospital or clinical setting

I guess the only support I have is my GP has me on, I'm trying to think of the proper name of it, but some care plan. With that, I get five, I think it is, five treatments a year, and that's where I use the occupational therapist to do the lymphatic training. I get five treatments paid for, and then I pay for all the rest. That's the only government help that I have. Participant 004_2021AUHRP

Just when my GP would frequently check in on me. She would actually call me to check in on me quite often. Participant 008_2021AUHRP

The breast cancer nurse at my oncology unit was amazing. She told me about all the charities that were available, all the support that was available. If I wanted counseling it was available. She was my main go-to if I needed something to help with something, she was just a breast care nurse. Participant 024_2021AUHRP

It was there if I needed it. I remember one day when I was having radiation, I was a complete mess and I was just lying there crying. When I finished, the social worker came and sat down and had a cup of tea with me. I think I just gave myself a good virtual kick in the pants and got back on track. If I needed help, I'm sure that could have been arranged. Participant 039_2021AUHRP

Participant describes receiving support through charities

Not a lot. I think when I was going for radiation there was a community group who gave us a fuel voucher to get to and from hospital to help with the petrol side of things, but that's about it. Participant 018_2021AUHRP

And I think I've got a $500 thing from Cancer Council that went towards some bills that that, and I went to it a feel better program. Yep. And I went to an I did the life, the life program, that's the Cancer Council, the exercise program that they run that as well. So that's it's really. Participant 033_2021AUHRP

I've received some support from a charity called Mummy's Wish. They gave me a grocery voucher, which was really lovely and just the materials and things for my daughter. Look Good Feel Better Foundation. They sent me through that little pack that they sent your information. I know BCNA, one of the nurses just called me to check in and see how I was going. That was really good in terms of just mental health, particularly, at the beginning of things. That would be the three things. Participant 052_2021AUHRP

Participant describes receiving support through peer support (Face-to-face)

No. I've reached out to a couple of other mothers that have had breast cancer. So wait to see first of all, we should put a team together and walked around, look like we've done bikes and stuff like that. No, no. That's all the stuff. Participant 002_2021AUHRP

Yes, it was the early breast cancer group at the HOSPITAL. Even now, I'm a peer mentor. Peer mentors meet up regularly for coffee. We've become our own little support group as well. Participant 043_2021AUHRP

Breast care nurses, they put me in touch with some support groups, which were good, but weren't really good because I was always the youngest, [chuckles] and I went through a support group with the hospital where we used to live, and it was a cancer support group, and it's just to get you doing some exercise and they have guest speakers in that, and unfortunately, a lot of it was geared towards the older people, so 50, 60 plus. I didn't get a lot out of it that way, and it's hard because there's not necessarily a lot of people that I know of that have been my age and gone through it, but they did try, so that was really good. Participant 025_2021AUHRP

Participant describes not needing any support

Other than, like breast care nurse, and doctors. I haven't really thought anything outside of that, because I didn't really feel like I needed that. Participant Okay. 020_2021AUHRP

I'm trying to think what that would, what that would involve, but no, I don't think so. Because I haven't really needed it. Participant 034_2021AUHRP

No. I haven't really needed anything...My family is in LOCATION, but my sisters send care packages. Participant 011_2021AUHRP

Table 7.14: Experience of care and support

Experience of care and support	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participant describes not receiving any support	18	34.62	5	26.32	8	38.10	5	41.67	12	41.38	6	26.09	7	36.84	11	33.33
Participant describes receiving support from a hospital or clinical setting	14	26.92	7	36.84	6	28.57	**1**	**8.33**	6	20.69	8	34.78	7	36.84	7	21.21
Participant describes receiving support through charities	11	21.15	4	21.05	5	23.81	2	16.67	**3**	**10.34**	**8**	**34.78**	3	15.79	8	24.24
Participant describes receiving support through peer support (Face-to-face)	8	15.38	3	15.79	2	9.52	3	25.00	5	17.24	3	13.04	**1**	**5.26**	7	21.21
Participant describes not needing help	6	11.54	2	10.53	3	14.29	1	8.33	4	13.79	2	8.70	1	5.26	5	15.15

Experience of care and support	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participant describes not receiving any support	18	34.62	**5**	**50.00**	6	37.50	7	26.92	**5**	**45.45**	13	31.71	6	33.33	12	35.29
Participant describes receiving support from a hospital or clinical setting	14	26.92	3	30.00	5	31.25	6	23.08	2	18.18	12	29.27	6	33.33	8	23.53
Participant describes receiving support through charities	11	21.15	**1**	**10.00**	2	12.50	8	30.77	**4**	**36.36**	7	17.07	**6**	**33.33**	5	14.71
Participant describes receiving support through peer support (Face-to-face)	8	15.38	1	10.00	3	18.75	4	15.38	**0**	**0.00**	8	19.51	2	11.11	6	17.65
Participant describes not needing help	6	11.54	**0**	**0.00**	3	18.75	3	11.54	1	9.09	5	12.20	1	5.56	5	14.71

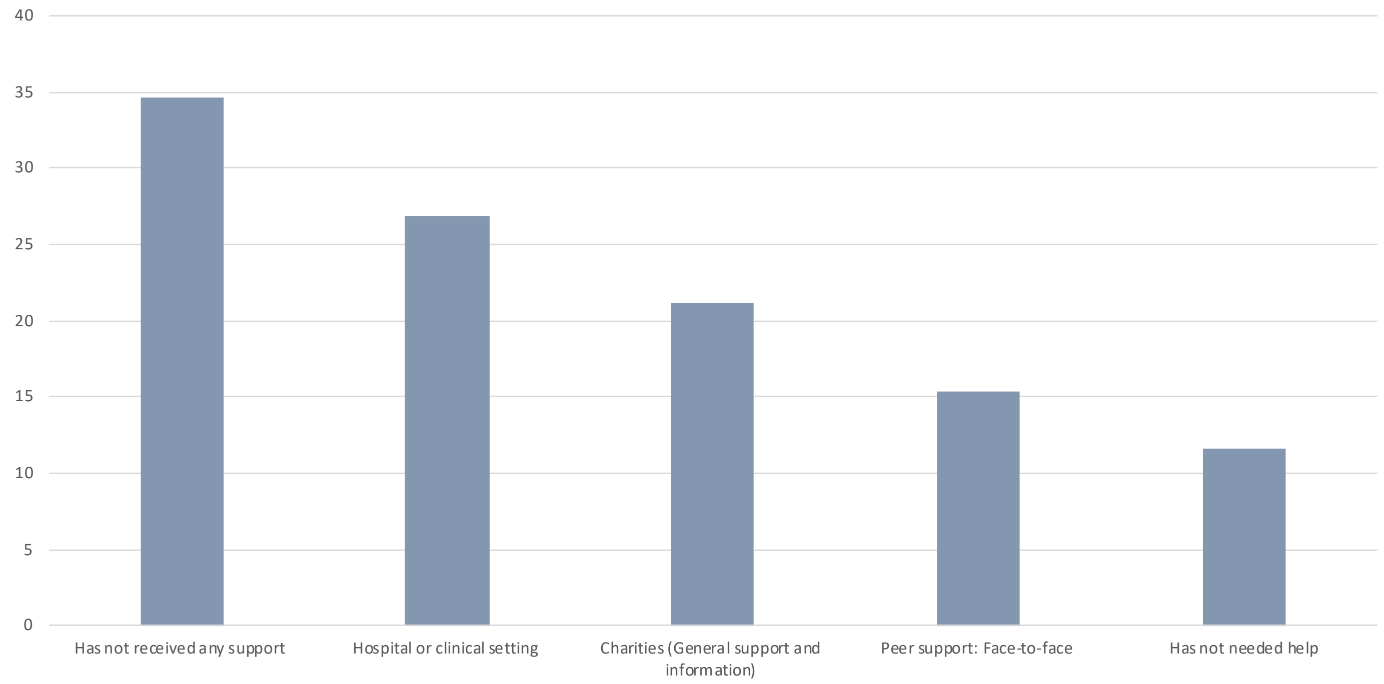


Figure 7.31: Experience of care and support

Table 7.15: Experience of care and support – subgroup variations

Experience of care and support	Reported less frequently	Reported more frequently
Participant describes not receiving any support	-	Diagnosed in 2016 or before Regional or remote
Participant describes receiving support from a hospital or clinical setting	Stage III and IV	
Participant describes receiving support through charities	Aged 25 to 54 Diagnosed in 2016 or before	Aged 55 to 74 Regional or remote Mid to low status
Participant describes receiving support through peer support (Face-to-face)	Trade or high school Regional or remote	-
Participant describes not needing help	Diagnosed in 2016 or before	-

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 27 participants (51.92%) that described a negative impact on quality of life, 11 participants (21.15%) that described a minimal impact on quality of life, and six participants (11.54%) that described an overall positive impact on quality of life. There were four participants (7.69%) that reported no impact on quality of life, and the same number that reported a mix of positive and negative impact.

The most common themes in relation to a negative impact on quality of life were the emotional strain on family/change in dynamics of relationships with partners (n=16, 30.77%), family/change in dynamics of relationships with children (n=12, 23.08%), the mental and emotional impact (n=8, 15.38%), intimacy problems (n=5, 9.62%), and reduced social life (n=5, 9.62%). Other reasons for a negative impact on quality of life were from side effects or physical symptoms such as reduced physical activity (n=10, 19.23%), fatigue (n=7, 13.46%), and the impact of side effects from treatment (especially menopause) (n=5, 9.62%).

The most common theme in relation to a positive impact on quality of life was giving perspective on what is important (n=5, 9.62%).

Impact on mental health

In the structured interview, participants were asked if there had been an impact on their mental health. There were 50 participants (96.12%) who gave a description suggesting that overall there was some impact on their mental health and two participants (3.85%) who gave a description suggesting that overall there was no impact on mental health.

In the structured interview, participants were asked what they needed to do to maintain their emotional and mental health. The most common ways that participants reported managing their mental and emotional health was using mindfulness or meditation (n=25, 48.08%), physical exercise (n=19, 36.54%), and consulting a mental health professional (n=16, 30.77%). Other ways to maintain mental health were remaining social and enjoying hobbies (n=13, 25.00%), and the importance of family and friends (n=13, 25.00%). There were five participants (9.62%) 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 by being physically active (n=25, 48.08%), and the importance of self-care (n=24, 46.15%). There were 16 participants (30.77%) that described understanding their limitations, ten participants (19.23%) that described the importance of complying with treatment, and eight participants (15.38%) that described maintaining a healthy diet. There were eight participants (15.38%) 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 47 participants (90.38%) who gave a description suggesting that overall they had experiences of feeling vulnerable, and five participants (9.62%) 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 themes were feeling vulnerable during or after treatments (n=19, 36.54%), and feeling vulnerable during the diagnostic procedure (n=19, 36.54%). There were 11 participants (21.15%) that described feeling vulnerable because of interactions with their medical team, and eight participants (15.38%) described feeling vulnerable during the surgical procedure.

Methods to manage vulnerability

In the structured interview, participants described ways that they managed feelings of vulnerability. Participants described self-help, such as resilience, acceptance and staying positive to manage the feeling of vulnerability (n=16, 30.77%). Others described support from their nurse or treatment team (n=10, 19.23%), and support from their family and friends (n=8, 15.38%) to manage their vulnerability. There were five participants (9.62%), that were unsure of how to manage their vulnerability.

Impact on relationships

In the structured interview, participants were asked whether their condition had affected their personal relationships. Overall, there were 13 participants (25.00%) that described no impact on relationships, and the same number that described a mix of positive and negative impacts on relationships. Other participants reported a positive impact on relationships (n=12, 23.08%), and a negative impact on relationships (n=9, 17.31%).

The most common themes in relation to having a positive impact on relationships were because of people being well-meaning and supportive (n=11, 21.15%), and from family relationships being strengthened (n=10, 19.23%). The most common theme in relation to having a negative impact on relationships were because of people not knowing what to say or do and withdrawing from relationships (n=16, 30.77%).

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 26 participants (50.00%) that felt there was an additional burden, and 26 participants (50.00%) that reported no additional burden.

The main reason that participant described their condition not being a burden in general was that they and remained independent and did not need any help (n=10, 19.23%). For participants that felt they were a burden on their family, the main reason was the extra household duties and responsibilities that their family must take on (n=14, 26.92%). There were six participants (9.62%) that described that the burden on their family was only temporary or during treatment .

Cost considerations

In the structured interview, participants were asked about any significant costs associated with having their condition. There were 48 participants (92.31%) that described some cost burden and four participants (7.69%) that 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=43, 82.69%). Other cost burdens were in relation to taking time off work (n=24, 46.15%), the cost of specialist appointments (n=20, 38.46%), the cost of diagnostic tests and scans (n=20, 38.46%), family members needing to take time off work (n=7, 13.46%), and the cost of parking and travel to attend appointments, including accommodation (n=5, 9.62%). There were seven participants (13.46%) that described no cost burden and that nearly everything was paid for through the health system or private coverage.

Experience of anxiety related to disease progression

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 27 participants (51.92%) that described a negative impact on quality of life, 11 participants (21.15%) that described a minimal impact on quality of life, and six participants (11.54%) that described an overall positive impact on quality of life. There were four participants (7.69%) that reported no impact on quality of life, and the same number that reported a mix of positive and negative impact.

The most common themes in relation to a negative impact on quality of life were the emotional strain on family/change in dynamics of relationships with partners (n=16, 30.77%), family/change in dynamics of relationships with children (n=12, 23.08%), the mental and emotional impact (n=8, 15.38%), intimacy problems (n=5, 9.62%), and reduced social life (n=5, 9.62%). Other reasons for a negative impact on quality of life were from side effects or physical symptoms such as reduced physical activity (n=10, 19.23%), fatigue (n=7, 13.46%), and the impact of side effects from treatment (especially menopause) (n=5, 9.62%).

The most common theme in relation to a positive impact on quality of life was giving perspective on what is important (n=5, 9.62%).

Participant describes positive impact on quality of life as the diagnosis helps you realise what is important (giving perspective)

I think you have a new-- When you say quality of life, you definitely have a different-- You see life through a different lens. I'm much more slower in some way, but I think much more slower and rightfully in a good way. Participant 021_2021AUHRP

I don't think it has. I think it actually-- This might seem really strange to you, but I think it's actually enhanced it because we've actually sat back and got a hell of a fright and thought, "You know what? There are more important things. Let's kick back, smell the roses, and nothing is-- the little things don't matter anymore." Participant 026_2021AUHRP

Participant describes negative impact on quality of life as a result of emotional strain on family/change in relationship dynamics (Partner)

My children are grown up, and it's just my husband and myself at home. I feel sorry for NAME because he's had to cope with my ups and downs and the pain that I've had. Other than that, no, I've tried to carry on as I normally would. Participant 012_2021AUHRP

Look, on the emotional side of things, that emotional strain, my husband is still struggling with that. He struggles physically with intimacy. He also struggles with the communication side of things. Just generally, if I get tired or if I have a conversation and halfway through the sentence, I forget what I'm talking about, or what that line of sentence is and such. Participant 031_2021AUHRP

I don't think so. I've probably done more since I've had breast cancer than I did before. I enjoy a lot more stuff. Participant 028_2021AUHRP

Participant describes negative impact on quality of life as a result of emotional strain on family/change in relationship dynamics (Children)

Yeah, I would say it has I think I no longer really trust my own body, you know, everyone just go through daily life just going or what does that ache and pain mean? Or what? You know, all that kind of thing. I think, you know, my kids were three and six at the time and they learned very quickly that mommy's get sick and sometimes mommies get very sick and I think that did affect especially my older boy who was six at the time he caught a few attachment issues for a good few years after that. And he's pretty good now at 17 but every now and again when we found out that I had to have hysterectomies, he was a bit freaked out about the whole thing because it had to work you know, cancer and that again, so here we go again. Participant 033_2021AUHRP

Initially, yes. I've got two daughters and a son, and they were obviously quite concerned and quite scared about what it meant to them, as well. I think the genetic testing that I had was able to put my daughters' minds at ease. If they think about birth control, or they think about any treatments, or they think about anything that they do, they now have to consider whether or not they should be having certain treatments given that my my cancer was so reactive to hormones, they need to make sure that they're aware of that, and they let their GPs know. Participant 037_2021AUHRP

Yes, I think it has. I think things have definitely changed and I think it definitely had an impact on my family but I think we're okay as well. We're getting through it, obviously, and, obviously, with COVID, it's made it a bit more difficult because I haven't been able to take the kids to the hospital. They haven't been able to visit me at any of them. They're dropping off. During lockdown and stuff for chemo, they weren't able to come in or they were able to visit me at the hospital when I had surgery. I think it has changed a lot for us, but I think we're also okay.
Participant 042_2021AUHRP

Participant describes negative impact on quality of life as a result of reduced capacity for physical activity

I'm a single person. It hasn't really affected my family, but it has certainly affected the quality of my life, in terms of I was a very active person, bush-walking and kayaking. I am very limited in my ability to get back into that. It's affected that. I'd love to be out doing a lot more physical activities and things and I can't. I'm much reduced in that and I'm a lot more tired. I'm not back at work, so there is that aspect of purpose in life. I'm having to think about whether actually-- I'm left with a big choice of, "I'm I actually able to go back to work or should I retire and just try and enjoy the however many years that I have left?" There's certainly some big-- It certainly affected my outlook on life in terms of that and my life's pathway of where I'm going. Participant 047_2021AUHRP

Definitely. I try for it to not to. I've always been someone who's a bit of a weirdo. When it comes to exercise, I have low tolerance and stuff, I get sore easily. With all my chemo and the drugs that I've been on, I find it really hard. I went for a half and hour walk last night, it was so nice. I was nearly crippled by the time I got back. My legs were so sore. I'm so stiff in my joints. The last time when I was in bed, I was just in tears because my legs were in so much pain. Even during my chemo, probably up until the third round, I was still on a treadmill. I was still able to go out, I was doing my exercises. Some days I'd feel the pain, but my body wasn't as sore. Now, all my joints are really bad. My bones ache really bad. I've obviously lost a lot of muscle strength. I'm finding it really hard to do any exercise. I've only just gone back to work the last three weeks and I'm only working two to three days a week and that's really physical. I'm just exhausted when I get home.
048_2021AUHRP

That's a tricky one. It's hard to just say yes or no. I feel my outlook has been better, I appreciate more. Quality of life through the different treatments has changed. When the trial was failing at the end of last year, quality of life was pretty poor. Xeloda wasn't fun because of the hand and foot, which really cut off or reduced my exercising opportunities because my feet were just really sensitive and hot and angry. I haven't been able to drive recently, so that's a bit tricky. Participant 051_2021AUHRP

Participant describes negative impact on quality of life as a result of the mental and emotional impact

I do think that, yes, it's affected my quality of life and certainly affects energy levels. I'm single, but I think in terms of affecting the family I know that they worry about me. Mom and Dad are early 90s, I wish that they didn't have to worry, but as parents, that's what you do. Now they've got two of us to worry about, having had breast cancer. Emotionally, yes, it's had an impact on quality of my mental health. Participant 023_2021AUHRP

I suppose there's still that element of vulnerability. Even though I've moved on, sometimes I go, "You've had cancer and cancer is a terminal illness. Whether I'm cancer free or not, it's irrelevant. At the end of the day, I have had a cancer diagnosis." That's the way I look at that. I don't dwell on it. I don't feel sorry for myself. I don't wallow. I don't whinge and whine but I've had cancer. Participant 027_2021AUHRP

Your temptation is just to brush it off and go, no. Given that I have lymphoedema, given that I have what I would say chronic low to moderate level pain, I do think that, yes, it's affected my quality of life and certainly affects energy levels. I'm single, but I think in terms of affecting the family I know that they worry about me. Mom and Dad are early 90s, I wish that they didn't have to worry, but as parents, that's what you do. Now they've got two of us to worry about, having had breast cancer. Emotionally, yes, it's had an impact on quality of my mental health. Participant 023_2021AUHRP

Participant describes negative impact on quality of life as a result of fatigue

I think in some aspects, yes. So far just going through treatment and not working. Then just being tired and also, just feeling soreness and things like that. We have tried to carry out things as much as we can, normally. I guess some of those aspects hasn't really changed things too much aside from just the fact that I do have it. Participant 052_2021AUHRP

Yeah, I still suffer from fatigue that affects my marriage as much as that the beginning he said he understood everything and he was quite careful with me and understood you know why I couldn't work as hard as I used to. But that changed and that would stand against me not being able to remember things and not being able to you know work seven days a week or whatever it was, caused quite a few problems. Participant 045_2021AUHRP

It has definitely affected relationships. I have dropped some friends due to the cancer diagnosis. I believe they just didn't know to deal with it or cope. I've also made some very good friends through the whole process. I did attempt going back to work a couple of times because my workplace did keep my job open for a while a little bit back prior to COVID for about four months. Then, when COVID happened, I went on move again due to my lung nodules. I just got back again earlier this year for another four months, but just on the fatigue, everything's got overwhelming. It has definitely affected our income, our ability to work, and losing our family home. Participant 049_2021AUHRP

Participant describes negative impact on quality of life as a result of intimacy problems

No. Probably intimacy with my husband it has because it puts you into menopause, but no, not with my children or anything. No. Participant 006_2021AUHRP

Yes, it's probably affected the quality of my life because I have a little bit of restriction from pain, and definitely it's reduced my quality of life with the hormone blockers, but not dramatically. It hasn't really affected my relationship apart from the intimate side of it, [chuckles] because of the hormone blockers, they tend to do lots of things to your body. I've got a very wonderful partner, very supportive partner. I'm incredibly lucky that way too. Participant 017_2021AUHRP

On the physical side of things, because of the hormone blockers and all of those sorts of things, it severely impacted my intimate side of things with my husband. It's very difficult because just things don't work the way that they used to, and that's not to say that we don't have a good relationship. We do, but the physical side of our relationship has been severely impacted. Participant 018_2021AUHRP

Well, hugely, hugely, yes. As I mentioned before, it's my shoulders I've had problems with my shoulders, so it's impacted me there. I can't even do my brow up, I can't go swimming on the beach because I've had a mastectomy, so I haven't got a site. Yes, I could probably go and buy swimming prosthesis but I haven't done that yet but whereas before I used to go down the beach, no problem. I can't do that at the moment not until I get a swimming prosthesis, so that's impacted on me. I don't feel-- I used to be a really happy-go-lucky out there, bright and bubbly person, I think I've lost a bit of that. I'm a little bit more contained, serious and concerned about-- even though I try not to think about it, I do think, I wonder whether I still got a long future or how it often comes up in your head. You think, "Has it all gone or will it come back?" Participant 035_2021AUHRP

Participant describes negative impact on quality of life due to reduced social interaction

Yeah, I don't want to go out anymore, really. I don't really like to go out. I do, because I have to go to work and that's my outlet. And I put on my face and do it. And the husband probably, don't know why he sticks around, but he does. So yeah, that I feel bad about that. Participant 041_2021AUHRP

Yes, it has. In some ways, it's given me an understanding of what my quality of life is but it does affect, yes, what I can do and what I can't do. I'm making decisions about what to do, I don't have the confidence to say, "I can go out and go and meet friends and do a day's music festival for instance, or something like that." Therefore it affects my quality of life with my family because we don't do all that, all things that we might ordinarily do with my husband, so yes. Participant 043_2021AUHRP

Well, yes, it's affected my quality of life, because the treatment has reduced my ability to do things, enjoy things, be social, work in the office. It's reduced me to staying at home where it's safe, especially, because of COVID. I don't want to catch COVID while I'm having cancer treatment. It has impacted me a lot in that sense, that I don't get to go out and enjoy myself as much because, A, I don't have the energy, and, B, it's not safe. Participant 044_2021AUHRP

Participant describes negative impact on quality of life as a result of side effects of treatment (menopause in particular)

It has affected my quality of life. One, getting around with vaginal atrophy is not a big fun. The medication, when I had the medication in the morning, I feel quite yuck for about an hour or so. I think it does make me feel harder and I think this hardness comes from insomnia so, yes, I don't have nearly the energy. I was always on the dose. I don't have that energy that I used to have. Some days, it's a bit unpredictable to plan ahead because I think, "I'll do this tomorrow," and then tomorrow comes and not feeling well, so, "I'm not going to do this." Yes, I've had in terms of my family. Participant 004_2021AUHRP

The scars have healed, should be a beautiful job on the scars. The tamoxifen, it's medical-induced menopause. I'm not quite at menopause yet. I just turned 50. This is going to be something that you go through and I recognize that it will change my sexual life and I just have to deal with that. Participant 007_2021AUHRP

It hasn't affected the quality of life of my family. No, the only thing is this business now, whinging about my knees, the joints. Other than that, really, no. Participant 022_2021AUHRP

Table 8.1: Impact on quality of life

Impact on quality of life	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participant describes an overall negative impact on quality of life	27	51.92	7	36.84	13	61.90	7	58.33	14	48.28	13	56.52	12	63.16	15	45.45
Participant describes an overall minimal impact on quality of life	11	21.15	6	31.58	3	14.29	2	16.67	8	27.59	3	13.04	3	15.79	8	24.24
Participant describes an overall positive impact on quality of life	6	11.54	2	10.53	1	4.76	3	25.00	2	6.90	4	17.39	2	10.53	4	12.12
Participant describes no impact on quality of life	4	7.69	1	5.26	3	14.29	0	0.00	3	10.34	1	4.35	1	5.26	3	9.09
Participant describes a mix of positive and negative impact on quality of life	4	7.69	3	15.79	1	4.76	0	0.00	2	6.90	2	8.70	1	5.26	3	9.09

Impact on quality of life	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participant describes an overall negative impact on quality of life	27	51.92	6	60.00	9	56.25	12	46.15	7	63.64	20	48.78	10	55.56	17	50.00
Participant describes an overall minimal impact on quality of life	11	21.15	3	30.00	4	25.00	4	15.38	1	9.09	10	24.39	3	16.67	8	23.53
Participant describes an overall positive impact on quality of life	6	11.54	1	10.00	0	0.00	5	19.23	1	9.09	5	12.20	0	0.00	6	17.65
Participant describes no impact on quality of life	4	7.69	0	0.00	1	6.25	3	11.54	1	9.09	3	7.32	1	5.56	3	8.82
Participant describes a mix of positive and negative impact on quality of life	4	7.69	0	0.00	2	12.50	2	7.69	1	9.09	3	7.32	4	22.22	0	0.00

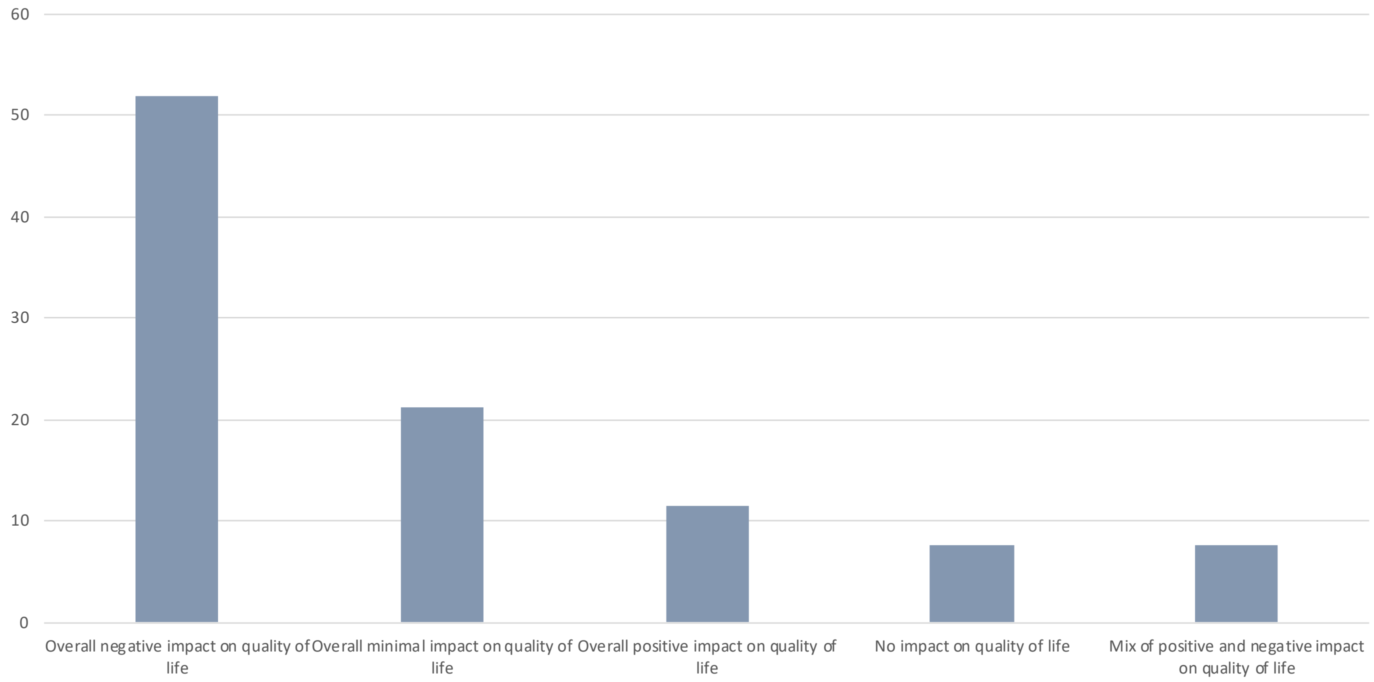


Figure 8.1: Impact on quality of life

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	Stage 0 and I	Trade or high school Regional or remote
Participant describes an overall minimal impact on quality of life	Regional or remote	Stage 0 and I
Participant describes an overall positive impact on quality of life	Diagnosed in 2017 to 2019 Mid to low status	Stage III and IV
Participant describes a mix of positive and negative impact on quality of life	-	Mid to low status

Table 8.3: Impact on quality of life (Reasons)

Impact on quality of life (Reasons)	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participant describes positive impact on quality of life as the diagnosis helps you realise what is important (giving perspective)	5	9.62	3	15.79	0	0.00	2	16.67	1	3.45	4	17.39	2	10.53	3	9.09
Participant describes negative impact on quality of life as a result of emotional strain on family/change in relationship dynamics (Partner)	16	30.77	5	26.32	8	38.10	3	25.00	**6**	**20.69**	**10**	**43.48**	7	36.84	9	27.27
Participant describes negative impact on quality of life as a result of emotional strain on family/change in relationship dynamics (Children)	12	23.08	3	15.79	6	28.57	3	25.00	5	17.24	7	30.43	**7**	**36.84**	5	15.15
Participant describes negative impact on quality of life as a result of reduced capacity for physical activity	10	19.23	5	26.32	4	19.05	**1**	**8.33**	4	13.79	6	26.09	5	26.32	5	15.15
Participant describes negative impact on quality of life as a result of the mental and emotional impact	8	15.38	4	21.05	4	19.05	**0**	**0.00**	3	10.34	5	21.74	4	21.05	4	12.12
Participant describes negative impact on quality of life as a result of fatigue	7	13.46	2	10.53	4	19.05	1	8.33	2	6.90	5	21.74	3	15.79	4	12.12
Participant describes negative impact on quality of life as a result of intimacy problems	5	9.62	2	10.53	3	14.29	0	0.00	1	3.45	4	17.39	**5**	**26.32**	0	0.00
Participant describes negative impact on quality of life due to reduced social interaction	5	9.62	2	10.53	1	4.76	2	16.67	3	10.34	2	8.70	1	5.26	4	12.12
Participant describes negative impact on quality of life as a result of side effects of treatment (menopause in particular)	5	9.62	2	10.53	2	9.52	1	8.33	4	13.79	1	4.35	2	10.53	3	9.09

Impact on quality of life (Reasons)	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participant describes positive impact on quality of life as the diagnosis helps you realise what is important (giving perspective)	5	9.62	0	0.00	1	6.25	4	15.38	1	9.09	4	9.76	2	11.11	3	8.82
Participant describes negative impact on quality of life as a result of emotional strain on family/change in relationship dynamics (Partner)	16	30.77	**2**	**20.00**	**7**	**43.75**	7	26.92	4	36.36	12	29.27	6	33.33	10	29.41
Participant describes negative impact on quality of life as a result of emotional strain on family/change in relationship dynamics (Children)	12	23.08	3	30.00	5	31.25	4	15.38	**4**	**36.36**	8	19.51	**7**	**38.89**	5	14.71
Participant describes negative impact on quality of life as a result of reduced capacity for physical activity	10	19.23	**4**	**40.00**	2	12.50	4	15.38	**5**	**45.45**	5	12.20	**8**	**44.44**	**2**	**5.88**
Participant describes negative impact on quality of life as a result of the mental and emotional impact	8	15.38	2	20.00	1	6.25	5	19.23	2	18.18	6	14.63	2	11.11	6	17.65
Participant describes negative impact on quality of life as a result of fatigue	7	13.46	1	10.00	2	12.50	4	15.38	**4**	**36.36**	3	7.32	4	22.22	3	8.82
Participant describes negative impact on quality of life as a result of intimacy problems	5	9.62	1	10.00	0	0.00	4	15.38	1	9.09	4	9.76	1	5.56	4	11.76
Participant describes negative impact on quality of life due to reduced social interaction	5	9.62	1	10.00	3	18.75	1	3.85	1	9.09	4	9.76	**4**	**22.22**	1	2.94
Participant describes negative impact on quality of life as a result of side effects of treatment (menopause in particular)	5	9.62	0	0.00	3	18.75	2	7.69	0	0.00	5	12.20	0	0.00	5	14.71

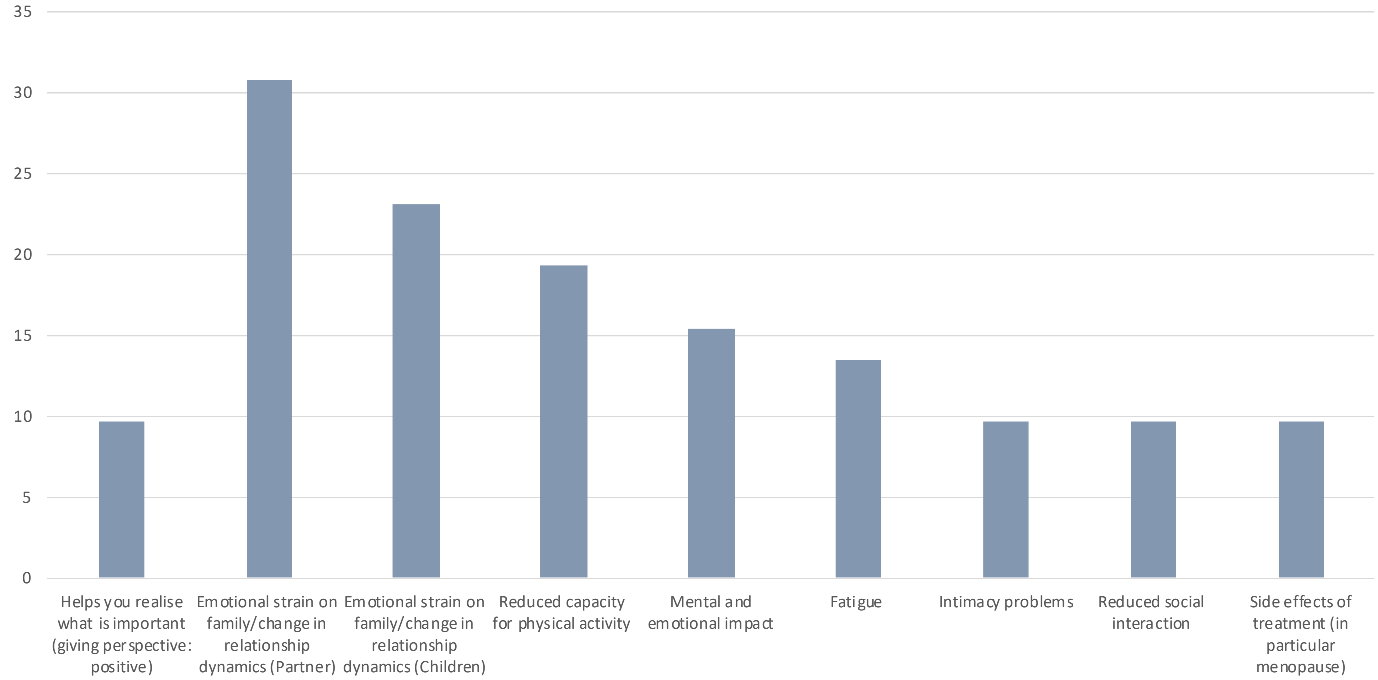


Figure 8.2: Impact on quality of life (Reasons)

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 as a result of emotional strain on family/change in relationship dynamics (Partner)	Aged 25 to 54 Diagnosed in 2016 or before	Aged 55 to 74 Diagnosed in 2017 to 2019
Participant describes negative impact on quality of life as a result of emotional strain on family/change in relationship dynamics (Children)	-	Trade or high school Regional or remote Mid to low status
Participant describes negative impact on quality of life as a result of reduced capacity for physical activity	Stage III and IV Higher status	Diagnosed in 2016 or before Regional or remote Mid to low status
Participant describes negative impact on quality of life as a result of the mental and emotional impact	Stage III and IV	
Participant describes negative impact on quality of life as a result of fatigue	-	Regional or remote
Participant describes negative impact on quality of life as a result of intimacy problems	-	Trade or high school
Participant describes negative impact on quality of life due to reduced social interaction	-	Mid to low status

Impact on mental health

In the structured interview, participants were asked if there had been an impact on their mental health. There were 50 participants (96.12%) who gave a description suggesting that overall there was some impact on their mental health and two participants (3.85%) who gave a description suggesting that overall there was no impact on mental health.

In the structured interview, participants were asked what they needed to do to maintain their emotional and mental health. The most common ways that participants reported managing their mental and emotional health was using mindfulness or meditation (n=25, 48.08%), physical exercise (n=19, 36.54%), and consulting a mental health professional (n=16, 30.77%). Other ways to maintain mental health were remaining social and enjoying hobbies (n=13, 25.00%), and the importance of family and friends (n=13, 25.00%). There were five participants (9.62%) that described no activities to maintain mental health.

Participant describes using mindfulness and/or meditation

Yeah, but I can do I could could do better. I mentioned that I was into the meditation. And that was really, really helpful. But then I just say with time you do the old life with TV and whatnot. Participant 013_2021AUHRP

Yeah, I like to do craft. Crochet or knit, I find that a bit meditating so I'll do that. I've got a new grandchild expected in January everything everything to celebrate and look forward to. Participant 014_2021AUHRP

I've taken up meditation for mindfulness and I do yoga the best I can at the moment with the wrist problems and whatnot, but I do what I can to stay flexible and mobile and keep my mind engaged. I've also gone back to reading a lot more. Participant 018_2021AUHRP

Participant describes the importance of physical exercise

Yes, it certainly does affect your mental and emotional health. I think for me a few things, physical activity when I can do it, and I think to a degree that was certainly helpful for me keeping as active as possible, physically. I guess for me the spiritual component. I'm a spiritual person and just using my spiritual-- The word is there. My spirituality has absolutely helped me to be centered and to not be anxious, or to be less anxious is probably a better word, and has given me some more peace and hope. Participant 047_2021AUHRP

Yes. It has impacted it somewhat. I do yoga and that is not just physical, but mentally and emotionally a benefit. The focus on breathing throughout yoga practice makes a big difference to my mental state, and my emotional state is very calm. Anytime that I'm feeling like I'm struggling a bit and need some zen, [chuckles] that's what I rely on yoga for. Participant 044_2021AUHRP

I'm not depressed, it hasn't affected me in that way. I'm not depressed, I'm just not as bright and bubbly as I was, I'm a little bit more serious. [chuckles] What do I do for my mental health? I get out there and do a lot of walking and I meditate. Participant 035_2021AUHRP

Participant describes consulting a mental health professional

I do walk regularly. I do know that helps. There are certain days that are worse than others. I've just started just last week antidepressants, and I've accessed a psychologist again because I had stopped that for seven months, I was doing pretty well. It just comes and goes, and I think with every-- you do get a lot of anxiety when you have a new pain or it's just something new, or when you have a scan coming up. That will be ongoing, speaking with other people, that will be ongoing. Participant 049_2021AUHRP

Yes. I recognized that I needed to see a psychologist. I obviously went and got that all sorted straight away, but it just took months before it could happen. I've got mindfulness journals, I try and do exercise when I can. Sometimes I'm really unmotivated [chuckles]. Participant 048_2021AUHRP

I'm seeing the psychologist. I do what I can. It's just talking, it's talking to my friends. I started a blog. It originally started for me to try and talk my feelings but it actually has ended up being a blog page where I'm now giving people an inside of a journey of cancer, especially with a young woman. That's helped me immensely as well. Participant 008_2021AUHRP

Participant describes using coping strategies such as remaining social, lifestyle changes and hobbies

Little things like that I think everybody that's with anything that trauma that you've been through, I think. Yes, I feel- and coping I like talking, walking, exercising, going to the beach, getting out and about, seeing people, don't isolate yourself. Then some days, if I feel "I just don't want to do much today," and I've learned now that tomorrow when I wake up, I'm going to feel better, and I do. I do. Participant 009_2021AUHRP

I'll try and distract myself and I read a lot and I knit and I sew and all those kinds of things and do the garden and what have you. I'll try to carry on as normal. Participant 012_2021AUHRP

I've had quite a bit of psychological help. I've joined breast cancer groups, The Dragon Boats Australia, to be with other women with the same problem so that you've got somewhere to feel comfortable and your new normal, I think is the best way to put it. You have to find the new normal and you have to build your life around the new normal. Participant 018_2021AUHRP

Participant describes the importance of family and friends in maintaining their mental health

Now that I'm feeling okay, I try to do a walk every day. For most days, go for a walk, have lunch with a friend. I haven't been able to visit family. From this weekend, yes. Participant 015_2021AUHRP

So I try, my outlook for the entire time was just to look for anything positive. I just felt like the minute I focused on the negative that it would start to take over. So I just kept positive about it all. And even now I'm still the same way. And I just found that being able to talk to family and friends about it made a lot easier. I really found just even even if it was only 15 minutes a day that I could manage like going for a walk or doing a bit of exercise that really helped. Participant 020_2021AUHRP

I would try, and I know that going for walk or being physically active actually does really help me. I guess trying to keep emotionally engaged with friends and family, but also recognizing that, for me, timeout is also important. As I said, I'm single, I live by myself, I need time by myself to recharge. Recognizing what my needs have been has been important. Participant 023_2021AUHRP

Participant describes no activities to maintain mental health

Look, initially, yes, it did. With time, I think with the first one, and with time, you feel like just get on with life. Plus, I had young children, so I just got on with it. It did, initially. I think there's always a fear of dying, the fear of re-occurrence. When I had to go and have my annual mammogram or ultrasound, that caused considerable amounts of anxiety. Participant 046_2021AUHRP

Yes, absolutely. As an ongoing thing, every year you go, and you've got to have your scans and the ultrasound, and that causes what we call scanxiety. You've got the anxiety in the lead up through those tests because it brings back all those memories of when you were diagnosed, and then you've got to wait to get the results from those tests and make sure that they haven't found anything additional and you don't have to go through it all again. On an annual basis, it really does, at that point of view, impact your mental health. It does take you a while. Obviously, I don't think you ever get over that anxiety and fear that it's going to come back. From a mental health perspective, you've always got that in the back of your mind, and it was a fear that you never had prior to breast cancer. Participant 037_2021AUHRP

No. Look, initially, I probably could have done with seeing somebody, but no, I'm fine. Participant 022_2021AUHRP

Table 8.5: Impact on mental health

Impact on mental health	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participant gives a description suggesting that overall, there was at least some impact on mental health	50	96.15	19	100.00	20	95.24	11	91.67	27	93.10	23	100.00	19	100.00	31	93.94
Participant gives a description suggesting that overall, there was no impact on mental health	2	3.85	0	0.00	1	4.76	1	8.33	2	6.90	0	0.00	0	0.00	2	6.06

Impact on mental health	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participant gives a description suggesting that overall, there was at least some impact on mental health	50	96.15	10	100.00	16	100.00	24	92.31	10	90.91	40	97.56	17	94.44	33	97.06
Participant gives a description suggesting that overall, there was no impact on mental health	2	3.85	0	0.00	0	0.00	2	7.69	1	9.09	1	2.44	1	5.56	1	2.94

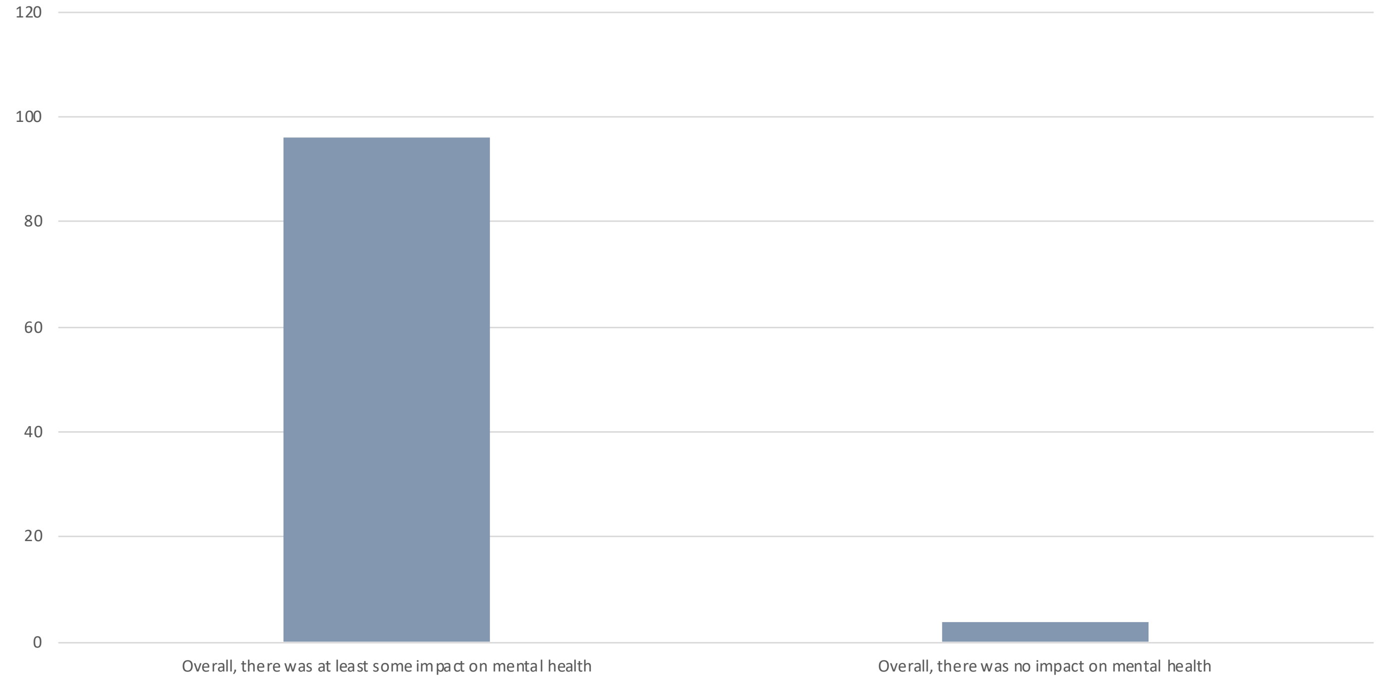


Figure 8.3: Impact on mental health

Table 8.6: Regular activities to maintain mental health

Regular activities to maintain mental health	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participant describes using mindfulness and/or meditation	25	48.08	9	47.37	10	47.62	6	50.00	13	44.83	12	52.17	9	47.37	16	48.48
Participant describes the importance of physical exercise	19	36.54	6	31.58	7	33.33	6	50.00	11	37.93	8	34.78	10	52.63	9	27.27
Participant describes consulting a mental health professional	16	30.77	4	21.05	8	38.10	4	33.33	8	27.59	8	34.78	4	21.05	12	36.36
Participant describes using coping strategies such as remaining social, lifestyle changes and hobbies	13	25.00	6	31.58	5	23.81	2	16.67	7	24.14	6	26.09	6	31.58	7	21.21
Participant describes the importance of family and friends in maintaining their mental health	13	25.00	5	26.32	4	19.05	4	33.33	5	17.24	8	34.78	7	36.84	6	18.18
Participant describes no activities to maintain mental health	5	9.62	3	15.79	2	9.52	0	0.00	3	10.34	2	8.70	3	15.79	2	6.06

Regular activities to maintain mental health	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participant describes using mindfulness and/or meditation	25	48.08	4	40.00	8	50.00	13	50.00	6	54.55	19	46.34	11	61.11	14	41.18
Participant describes the importance of physical exercise	19	36.54	4	40.00	6	37.50	9	34.62	4	36.36	15	36.59	8	44.44	11	32.35
Participant describes consulting a mental health professional	16	30.77	4	40.00	5	31.25	7	26.92	5	45.45	11	26.83	7	38.89	9	26.47
Participant describes using coping strategies such as remaining social, lifestyle changes and hobbies	13	25.00	1	10.00	6	37.50	6	23.08	3	27.27	10	24.39	2	11.11	11	32.35
Participant describes the importance of family and friends in maintaining their mental health	13	25.00	2	20.00	4	25.00	7	26.92	4	36.36	9	21.95	3	16.67	10	29.41
Participant describes no activities to maintain mental health	5	9.62	2	20.00	1	6.25	2	7.69	1	9.09	4	9.76	3	16.67	2	5.88

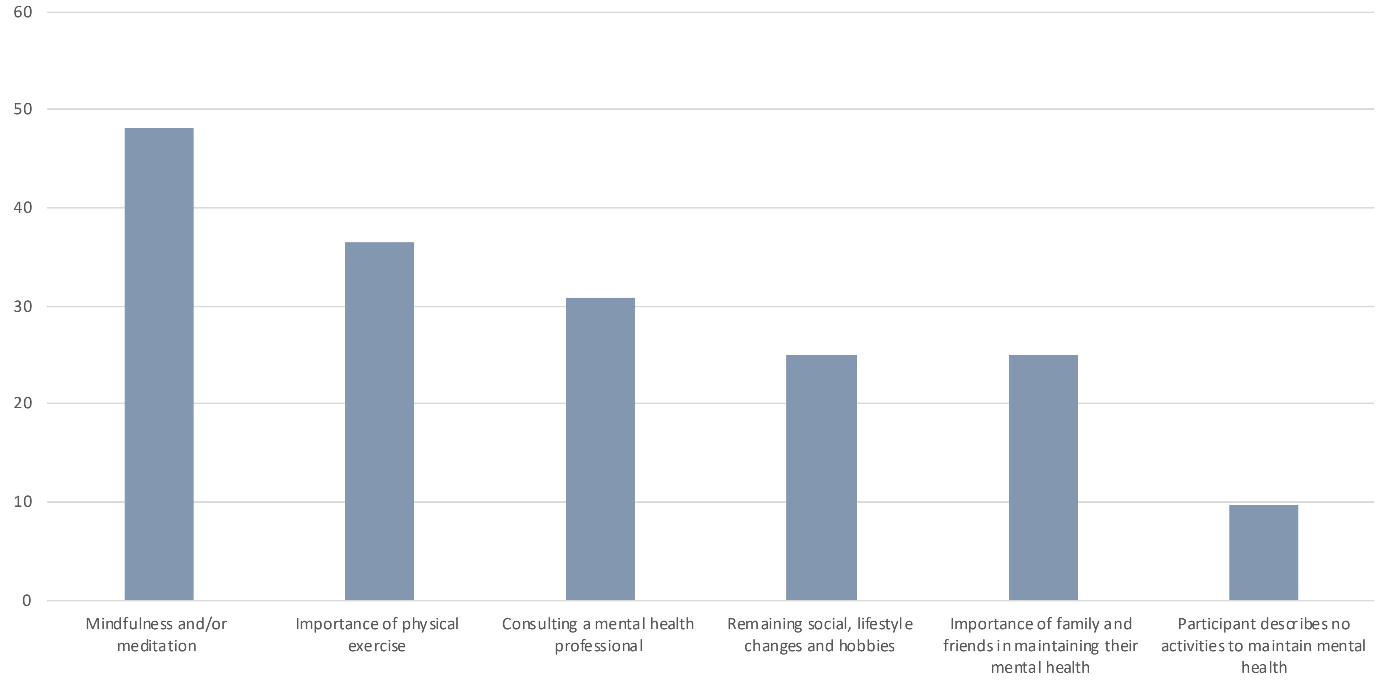


Figure 8.4: Regular activities to maintain mental health

Table 8.7: Regular activities to maintain mental health – subgroup variations

Regular activities to maintain mental health	Reported less frequently	Reported more frequently
Participant describes using mindfulness and/or meditation	-	Mid to low status
Participant describes the importance of physical exercise	-	Stage III and IV Trade or high school
Participant describes consulting a mental health professional	-	Regional or remote
Participant describes using coping strategies such as remaining social, lifestyle changes and hobbies	Diagnosed in 2016 or before Mid to low status	Diagnosed in 2017 to 2019
Participant describes the importance of family and friends in maintaining their mental health	-	Trade or high school Regional or remote
Participant describes no activities to maintain mental health	-	Diagnosed in 2016 or before

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 by being physically active (n=25, 48.08%), and the importance of self-care (n=24, 46.15%). There were 16 participants (30.77%) that described understanding their limitations, ten participants (19.23%) that described the importance of complying with treatment, and eight participants (15.38%) that described maintaining a healthy diet. There were eight participants (15.38%) that described no activities to maintain health.

Participant describes being physically active

I think it's exercise is the most important thing to me. It's keeping the bloating down. I'm not having a glass of wine in the evening anymore. I have to take magnesium to help me sleep a little bit, but I've cleaned out. I used to take turmeric for my joint. You can't take that now with tamoxifen. I really spent some time looking at my personal habits. I've never been a big meat eater. I eat a lot of vegetables, but I've really spent time looking at what's in my kitchen cabinet and my diet. Participant 007_2021AUHRP

I think you got to keep as active as you possibly can. Even if that physical activity doesn't help you physically, I think it helps you mentally. You think you're doing something to help you. Participant 010_2021AUHRP

Well, activity is it sounds weird, but for fatigue and aches, actually, you've got to keep moving. Movements, exercise, connecting with others that might understand, and talking, not being afraid to actually just say, "This is good. This is not so good. This is shit. This is happening." It's always there. Participant 043_2021AUHRP

Participant describes the importance of self care e.g. more rest, support for housework etc.

So when I was getting treatment, but mostly I sort of just didn't plan anything for the first week after I lived with my parents for that, that week other than that there wasn't the other two weeks after that I sort of got back to normal life and could go back to living by myself and look after myself and those sorts of things. As the treatments progressed, I did feel it would take me a lot longer to do things than it normally would s0, you know, like housework and I'd have to have a bit of a break or something like that. Participant 020_2021AUHRP

Also, taking time to relax. The more I went through treatment and while I was taking the tablets, I couldn't really do much of-- I do cross-stitch like tapestry, and I couldn't do it. I couldn't hold it. I couldn't focus on the pattern, or I just couldn't enjoy it. The last couple of months since I've been off the tablets, I've really, really enjoyed being able to sit down for a few hours at a time and just keep going. It's great. Participant 025_2021AUHRP

I guess sometimes the physical effects, I'm still, "Have I got neuropathy, I can't open jars and stuff?" I used to do a lot for my kids and now it's like, "No, kids, you've got to help out more." Those physical steps. Then there's the mental side of things as well. I'm very much more grateful so I've got a gratitude book. I am much more mindful, mindful practices, being grateful, trusting yourself, and just believing that this is the life that's been chosen for you in some ways. Participant 021_2021AUHRP

Participant describes the importance of understanding their limitations

Really, I've just got to keep up the exercises, and accept the limitations instead of thinking I can get back to where I was. Participant 022_2021AUHRP

I've got to pace myself in terms of if I do overdo it in terms of cleaning and housework and that sort of thing I can flare up my lymphoedema a little bit. I do need to pace myself, but I can do everything that I need to be able to do. It just sometimes takes a few workarounds. I used to spend money on powder-free gloves, so I don't ruin my compression gloves, that sort of thing. I've got to pace myself. Participant 023_2021AUHRP

Yes, okay. I certainly have slowed my day down in terms of I don't live my life at a fast pace. I've made sure that I am-- I have definitely slowed the pace of my days down and I don't rush. I give myself every day plenty of time and I don't push myself to try and accomplish too much in a day. In terms of even mentally planning things, I have to give myself plenty of time to just mentally plan what I'm doing. I try and exercise every day, get some form of physical exercise. My spiritual activity, I pray and meditate every day, first thing in the morning, to help me. Participant 047_2021AUHRP

Participant describes the importance of complying with treatment

Yes. Well, one is, I have the lymphatic drainage once every month or six weeks. If don't have that, I get really, really sore. That's something that I can do. That's an expense too but, yes, that's it. Then the other things are just like using the support staff, using the lubricant, using the cortisone cream for my eyes. All of that daily. Participant 004_2021AUHRP

For the most part, it really hasn't changed much. Life is pretty normal. I have tamoxifen at bedtime. I spoke to the medical oncologist about it because I realized I was getting a lot more cramps and she said it probably is related. I take magnesium now, which has helped with that. I've had restless legs my whole life and it's helped with that too. Participant 011_2021AUHRP

Making sure that you're doing everything possible to reduce the chances of it coming back. You're taking medication, getting your exercise, you're also going to really work on having a positive mindset. When those thoughts come into your mind, you've got to have people that you can talk to and things that you can do that can reduce that stress and reduce that. Just be able to talk through this with people and get that rational response. There's definitely a need to be able to talk to people and do things that are going to reduce that stress. Participant 037_2021AUHRP

Participant describes maintaining a healthy diet

Just eat properly and try and exercise a little bit. I'm just getting back into-- I can walk a bit further in that now, because I'm not feeling like I was. Participant 015_2021AUHRP

Oh, okay. Just got to do my checks and just make sure to look for lumps and things like that and massage my arm for lymphedema, and that's about it. Just eat well and exercise well. Participant 029_2021AUHRP

Okay. Daily walking. I do meditation quite regularly. I try to eat as healthy as possible. Catching up with friends and seeing my mum who is doing really well. She's a bit of an inspiration. Catching up with our children. It's just the daily checking in with the closest friends and family, and walking, meditation is a big thing for me, and doing my lymphedema exercises. There's certain things that I do have to do daily. Participant 049_2021AUHRP

Nothing really like this just my life now. Okay. Yeah. Like, I don't have to have any, like, I'm not having routine follow up anymore. Like, as I was, you know, seeing the oncologist once a year, but then I hit my 10 years, and she was like, No, we're good now. Participant 033_2021AUHRP

I really wasn't affected enough for anything to change. Like I went to work every day. Nothing changed. I'm just very lucky. It was fade to zero. Participant 001_2021AUHRP

Oh, no. No. Not really. No, I don't. Participant 040_2021AUHRP

Participant describes no activities to maintain health

Table 8.8: Regular activities to maintain health

Regular activities to maintain health	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participant describes being physically active	25	48.08	9	47.37	9	42.86	7	58.33	13	44.83	12	52.17	9	47.37	16	48.48
Participant describes the importance of self care e.g. more rest, support for housework etc.	24	46.15	6	31.58	11	52.38	7	58.33	13	44.83	11	47.83	8	42.11	16	48.48
Participant describes the importance of understanding their limitations	16	30.77	7	36.84	7	33.33	2	16.67	7	24.14	9	39.13	8	42.11	8	24.24
Participant describes the importance of complying with treatment	10	19.23	3	15.79	5	23.81	2	16.67	5	17.24	5	21.74	4	21.05	6	18.18
Participant describes maintaining a healthy diet	8	15.38	3	15.79	5	23.81	0	0.00	4	13.79	4	17.39	5	26.32	3	9.09
Participant describes no activities to maintain health	8	15.38	3	15.79	4	19.05	1	8.33	6	20.69	2	8.70	3	15.79	5	15.15

Regular activities to maintain health	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participant describes being physically active	25	48.08	6	60.00	6	37.50	13	50.00	7	63.64	18	43.90	9	50.00	16	47.06
Participant describes the importance of self care e.g. more rest, support for housework etc.	24	46.15	4	40.00	4	25.00	16	61.54	8	72.73	16	39.02	10	55.56	14	41.18
Participant describes the importance of understanding their limitations	16	30.77	3	30.00	3	18.75	10	38.46	6	54.55	10	24.39	10	55.56	6	17.65
Participant describes the importance of complying with treatment	10	19.23	2	20.00	6	37.50	2	7.69	2	18.18	8	19.51	6	33.33	4	11.76
Participant describes maintaining a healthy diet	8	15.38	3	30.00	2	12.50	3	11.54	3	27.27	5	12.20	3	16.67	5	14.71
Participant describes no activities to maintain health	8	15.38	3	30.00	2	12.50	3	11.54	2	18.18	6	14.63	2	11.11	6	17.65

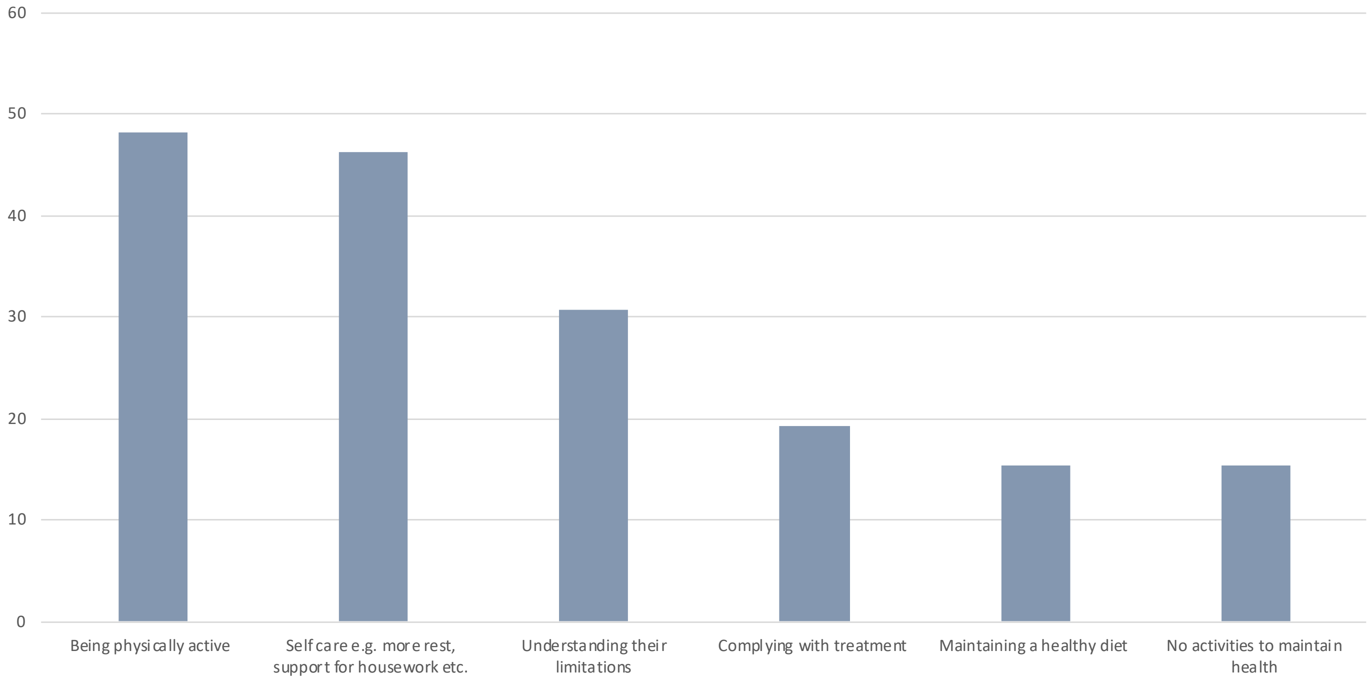


Figure 8.5: Regular activities to maintain health

Table 8.9: Regular activities to maintain health – subgroup variations

Regular activities to maintain health	Reported less frequently	Reported more frequently
Participant describes being physically active	Diagnosed in 2017 to 2019	Stage III and IV Diagnosed in 2016 or before Regional or remote
Participant describes the importance of self care e.g. more rest, support for housework etc.	Stage 0 and I Diagnosed in 2017 to 2019	Stage III and IV Diagnosed in 2020 or 2021 Regional or remote
Participant describes the importance of understanding their limitations	Stage III and IV Diagnosed in 2017 to 2019 Higher status	Trade or high school Regional or remote Mid to low status
Participant describes the importance of complying with treatment	Diagnosed in 2020 or 2021	Diagnosed in 2017 to 2019 Mid to low status
Participant describes maintaining a healthy diet	Stage III and IV	Trade or high school Diagnosed in 2016 or before Regional or remote
Participant describes no activities to maintain health		Diagnosed in 2016 or before

Experience of vulnerability

In the structured interview, participants were asked if there had been times that they felt vulnerable. There were 47 participants (90.38%) who gave a description suggesting that overall they had experiences of feeling vulnerable, and five participants (9.62%) 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 themes were feeling vulnerable during or after treatments (n=19, 36.54%), and feeling vulnerable during the diagnostic procedure (n=19, 36.54%). There were 11 participants (21.15%) that described feeling vulnerable because of interactions with their medical team, and eight participants (15.38%) described feeling vulnerable during the surgical procedure.

Participant describes feeling vulnerable during/after treatment

I think I felt pretty vulnerable that first day at the chemo unit. Just that day. Participant 044_2021AUHRP

Oh, yes. When they were doing the radiation planning stage when you're lying there with your arms above your head and your breasts are exposed and they're taking photographs of your breasts on camera photos, and then the oncologist came in and he drew a circle around the area that was to be radiated, and then the poor girls had to then attach some wire to that. Participant 012_2021AUHRP

Physically vulnerable. I was been on six simulations, That's the most scary part. I'm usually pretty good with needles and they give me those. So it's like that just like that created a lot of anxiety for me. Actually, and I think that for me, was the worst thing from the chemo, I think, cannulated. Mentally, I felt vulnerable because I was just tired. I couldn't do the thing that I just do and I think I felt bad for my children, but I tried to keep it as normal as possible. Participant 040_2021AUHRP

Participant describes feeling vulnerable during the diagnostic procedure

That i felt vulnerable I didn't, oh, the only time I felt vulnerable with during the biopsy. The biopsy was, you know, you have four people holding you down in that many people in the room and then they clap at the end of it, they think that must be right, whatever they were trying to do that that unnerved me, the clapping. Participant 001_2021AUHRP

Probably from the diagnosis until I went to the specialist because the GP didn't know anything about it, really. He didn't explain it like the specialist did, which was a lot better. Participant 006_2021AUHRP

The worst time was not so much the initial diagnosis. So that was bad enough. It was getting that metastatic diagnosis. So I think waiting is always hard waiting for results. Everyone says that I know, almost once you've got the bad news, even though it's terrible, you kind of your mind goes into planning. Okay, so this is what I need to do. Whereas when you're waiting for the bad news, which might not be bad news, you don't go ahead with that planning, because it may not be needed. So I think that periods between testing and results is really, really difficult. And then for me, it was it was being told that I was going to die in the near future. With with the two sort of most vulnerable periods. Participant 034_2021AUHRP

Participant describes feeling vulnerable because of interactions with their medical team

Yes actually. After I would get a certain type of chemo and nurses would have to come over to my house and *give me an injection. It was pretty in and out but one particular nurse, who I managed to get a couple of times, didn't follow procedure, like hand sanitizing, wearing gloves, or wiping my skin down before. I was really immune-compromised and I just felt like I was someone she had to tick off on her list for the day. That's when I felt very vulnerable there because I felt like I wasn't being heard. Participant 008_2021AUHRP*

Yes. With the medical oncologist that I had. She was almost menacing. When I actually suggested that I didn't want to take medication, she went, "I knew it, I should have just given you chemotherapy." I walked out, I burst into tears. I went, "Oh my God, so mean." Then being on the drugs, of course, your hormones are suppressed, you'll gain weight. You don't have a choice. I'm a size 12. I'm not a big, huge girl. She'd make comments and say, "Oh, you're getting fat." I'd be like, "Oh my God, you're so not helpful." Participant 038_2021AUHRP

In LOCATION, yes. I really felt like I wasn't worth the effort. It really was and I think I said quite bluntly, "If you can't be compassionate during this process for someone who's got a disease that they may not make it through, don't be here." But generally speaking, most of the people that you come across, there are a few for who it's just a job. But generally speaking in the cancer side of things, in the oncology side of things, they're pretty empathetic and they are very supportive, which makes the difficult shit storm much easier to deal with. Participant 018_2021AUHRP

Participant describes feeling vulnerable during the surgical procedure

Emotionally you're just a mess after your surgery. The week I got told when I got told I had breast cancer that was probably the worst time of my life. You're just in denial, you're just "No, it couldn't be no. Oh, no. I must have dreamt it." Participant 010_2021AUHRP

Going to theatre. That sitting in a bed waiting to go to the theatre, just wanting to run and knowing that you can't. Participant 011_2021AUHRP

Probably just after surgery, I was probably feeling the most vulnerable then. That's probably because it was so painful because of the nerve damage. I know not everybody has that. Not everybody has that nerve damage in their arm, a lot of people don't have it at all. I was probably vulnerable for several weeks because the pain was a constant pain, and I don't know that there was anything really that I could have done. Probably just after surgery, I was probably feeling the most vulnerable then. That's probably because it was so painful because of the nerve damage. Participant 017_2021AUHRP

Participant describes not feeling vulnerable

No, I don't think so. Yes, no, I'm going to say no about that one. Participant 005_2021AUHRP
Not really. Again, I'm a pretty healthy person, really seeing the world, we'll leave it at that. I've been able to do all this on my own with just minimal support from friends. I have felt safe and in a good space. I looked for a top hospital here in Sydney. I had a top surgeon who actually teaches at LOCATION University. I always felt I was in very, very good hands and I trusted the medical system. Participant 007_2021AUHRP

No, not really. Participant 015_2021AUHRP

Table 8.10: Experience of vulnerability (details)

Experience of vulnerability (details)	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participant describes feeling vulnerable during/after treatment	19	36.54	6	31.58	10	47.62	3	25.00	12	41.38	7	30.43	6	31.58	13	39.39
Participant describes feeling vulnerable during the diagnostic procedure	19	36.54	6	31.58	7	33.33	6	50.00	10	34.48	9	39.13	9	47.37	10	30.30
Participant describes feeling vulnerable because of interactions with their medical team	11	21.15	4	21.05	5	23.81	2	16.67	6	20.69	5	21.74	4	21.05	7	21.21
Participant describes feeling vulnerable during the surgical procedure	8	15.38	2	10.53	2	9.52	4	33.33	5	17.24	3	13.04	3	15.79	5	15.15
Participant describes not feeling vulnerable	5	9.62	3	15.79	2	9.52	0	0.00	3	10.34	2	8.70	1	5.26	4	12.12

Experience of vulnerability (details)	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participant describes feeling vulnerable during/after treatment	19	36.54	3	30.00	6	37.50	10	38.46	3	27.27	16	39.02	8	44.44	11	32.35
Participant describes feeling vulnerable during the diagnostic procedure	19	36.54	6	60.00	4	25.00	9	34.62	5	45.45	14	34.15	7	38.89	12	35.29
Participant describes feeling vulnerable because of interactions with their medical team	11	21.15	1	10.00	5	31.25	5	19.23	2	18.18	9	21.95	4	22.22	7	20.59
Participant describes feeling vulnerable during the surgical procedure	8	15.38	2	20.00	5	31.25	1	3.85	1	9.09	7	17.07	4	22.22	4	11.76
Participant describes not feeling vulnerable	5	9.62	0	0.00	2	12.50	3	11.54	0	0.00	5	12.20	0	0.00	5	14.71

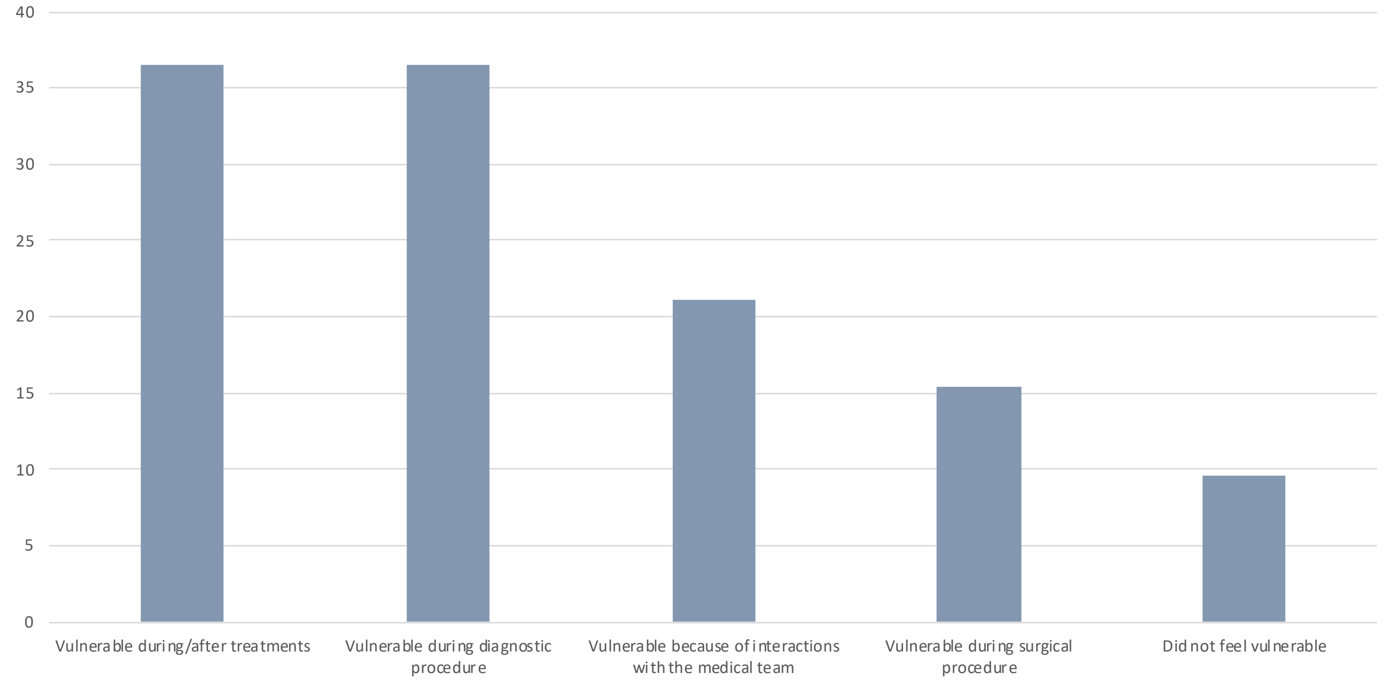


Figure 8.6: Experience of vulnerability

Table 8.11: Experience of vulnerability – subgroup variations

Experience of vulnerability (details)	Reported less frequently	Reported more frequently
Participant describes feeling vulnerable during/after treatment	Stage III and IV	Stage II
Participant describes feeling vulnerable during the diagnostic procedure	Diagnosed in 2017 to 2019	Stage III and IV Trade or high school Diagnosed in 2016 or before
Participant describes feeling vulnerable because of interactions with their medical team	Diagnosed in 2016 or before	Diagnosed in 2017 to 2019
Participant describes feeling vulnerable during the surgical procedure	Diagnosed in 2020 or 2021	Stage III and IV Diagnosed in 2017 to 2019

Methods to manage vulnerability

In the structured interview, participants described ways that they managed feelings of vulnerability. Participants described self-help, such as resilience, acceptance and staying positive to manage the feeling of vulnerability (n=16, 30.77%). Others described support from their nurse or treatment team (n=10, 19.23%), and support from their family and friends (n=8, 15.38%) to manage their vulnerability. There were five participants (9.62%), that were unsure of how to manage their vulnerability.

Participant describes self-help (resilience, acceptance, staying positive) to manage the feeling of vulnerability

I just had to try and be positive and focus on the positive things in my life. Participant 016_2021AUHRP

I think there's two things. There's the physical aspect, and then there's the mental aspect as well. You can concentrate on the physical and once the treatment has finished, and a lot of people have said that, then you've really got to figure yourself out mentally, what is it that you've been through. It's funny that at the end, it's virtually, "Well, what do we do now?" It's like, "Well, go and live your life." That is just, "Oh." It may go, "What the heck?" Participant 021_2021AUHRP

Acknowledge it and allow myself to grieve at times. I'm a very, very strong person. I did do amazing. No one even knew. People used to say to me, "Oh my God, you looked radiant. You would never have known you've got breast cancer. We didn't know you were having treatment." To allow myself to be vulnerable and to acknowledge that. It was really important to acknowledge it, but then pick myself up and continue to move forward. Participant 027_2021AUHRP

Participant describes support from nurse or treatment team to manage the feeling of vulnerability

I don't know this was at BreastScreen, New South Wales. I don't know because I'll be honest, everything worked like clockwork, everybody. And I don't think *they could have done it any different. But because mine was only three millimeters to begin with, to try and find it through CT scans and X rays, and then I had to be very still. If they had explained that, to me, like of this is a difficult procedure. This is how you've got to be so still for 20 minutes. If they went on about it, I would have been even more nervous, I think in a way, by not saying anything. much other than we need to do this. It was probably the best thing. And they even had one nurse crouching with her face next to mine. This holding my hands, so I don't think they could have done better. Yeah, just the nature of the fact that it was so small, that it was going to be difficult to pinpoint it and to grab it. Participant 001_2021AUHRP*

The oncologist said that to me too, she said, "Don't feel like you-- Other people might think, 'Oh, no, you look fine. You're okay. You look great. You look very healthy and well and all that sort of thing,' but don't underestimate health. Allow yourself, give- be kind to yourself, give yourself time. Don't feel like you have to run them out next week." Participant 009_2021AUHRP

I think speaking regularly, speaking to that breast cancer nurse at HOSPITAL, so she's can be a bit of calm in my storm at times when it gets too bad. Yes, she's been pretty good, she can be a bit of calm, and she's offered me a few suggestions, some of which I've managed to incorporate to into doing stuff. Participant 030_2021AUHRP

Participant describes support from family and friends to manage the feeling of vulnerability

Yes, I had a partner, so I was very fortunate. My husband's partner. He's an incredible man. But he was he had my back. My daughter had my back. I have a very strong community. So everyone had my back. So I couldn't ask for anything more. If anyone else is just up to me to I had to look forward and not backwards, couldn't change anything. I just have to to fix me. That was my one job. Everyone else was ready to catch me if I failed. You know, I have a couple of moments before I lost it. for all of you because you just kind of it's a bit more disbelief. But why? it was just lucky to do well, and then you start to worry about what else is lurking here. Participant 002_2021AUHRP

Yes. Just be kind to yourself. Don't force. Then my hubby, he'd go, "Darling, you had the surgery three weeks ago, like are you serious? What do you think you should be doing?" You need somebody like that to go, "Hang on, just check what you've been through. Hang on, just rewind a little bit. Three weeks ago you just come out of surgery and now you think you should be able to do this?" Participant 009_2021AUHRP

Well, I think my Savior was one of my best friends from high school. So she, her, she was living with her mom and dad at the time, she was studying at uni, moved back from LOCATION. And so having she was 20 minutes out of town, but just simply having one of my best friends there was really kind of what saved me. Participant 013_2021AUHRP

Participant describes being unsure of how to manage the feeling of vulnerability

No. Just felt teary for three of four days and overwhelmed and that was it. I never said I think it was just being brave for everyone around, just a bit tired. I don't know, maybe I'm a slow learner, it could take longer for me. Participant 014_2021AUHRP

I don't think I could do anything and I really didn't. I just ended up almost giving up and just going with it. Participant 036_2021AUHRP

I'm not sure there's a lot they can do. You're in so much shock after you get diagnosed that you don't take a lot in, it takes a little while for it to sink in. I think if they were able to give you information on, "Here's some websites you can go to, don't use Dr. Google, here are some documented websites that you can go to-- The questions. Here are some people you can call who might be able to answer the questions that you've got." I think the most vulnerable part is not knowing what's happening until you get your treatment plan. For me, I was lucky that I didn't have to wait a week to get my treatment plan. Other women have to wait up to four or five weeks. Participant 037_2021AUHRP

Table 8.12: Methods to manage vulnerability

Methods to manage vulnerability	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participant describes self help (resilience, acceptance, staying positive) to manage the feeling of vulnerability	16	30.77	3	15.79	6	28.57	7	58.33	6	20.69	10	43.48	7	36.84	9	27.27
Participant describes support from nurse or treatment team to manage the feeling of vulnerability	10	19.23	3	15.79	4	19.05	3	25.00	7	24.14	3	13.04	4	21.05	6	18.18
Participant describes support from family and friends to manage the feeling of vulnerability	8	15.38	2	10.53	5	23.81	1	8.33	3	10.34	5	21.74	4	21.05	4	12.12
Participant describes being unsure of how to manage the feeling of vulnerability	5	9.62	5	26.32	0	0.00	0	0.00	2	6.90	3	13.04	2	10.53	3	9.09

Methods to manage vulnerability	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participant describes self help (resilience, acceptance, staying positive) to manage the feeling of vulnerability	16	30.77	2	20.00	4	25.00	10	38.46	6	54.55	10	24.39	5	27.78	11	32.35
Participant describes support from nurse or treatment team to manage the feeling of vulnerability	10	19.23	2	20.00	4	25.00	4	15.38	0	0.00	10	24.39	3	16.67	7	20.59
Participant describes support from family and friends to manage the feeling of vulnerability	8	15.38	1	10.00	3	18.75	4	15.38	2	18.18	6	14.63	2	11.11	6	17.65
Participant describes being unsure of how to manage the feeling of vulnerability	5	9.62	2	20.00	1	6.25	2	7.69	0	0.00	5	12.20	2	11.11	3	8.82

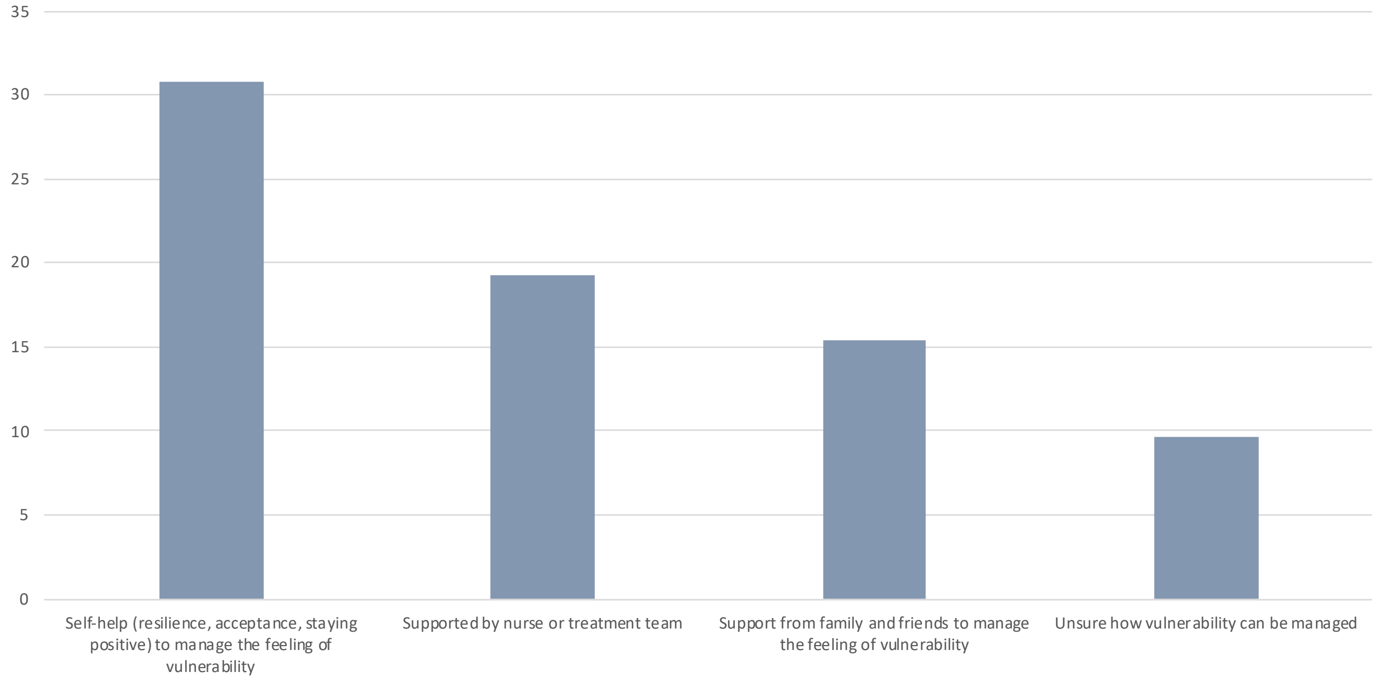


Figure 8.7: Methods to manage vulnerability

Table 8.13: Methods to manage vulnerability– subgroup variations

Methods to manage vulnerability	Reported less frequently	Reported more frequently
Participant describes self help (resilience, acceptance, staying positive) to manage the feeling of vulnerability	Stage 0 and I Aged 25 to 54 Diagnosed in 2016 or before	Stage III and IV Aged 55 to 74 Regional or remote
Participant describes support from nurse or treatment team to manage the feeling of vulnerability	Regional or remote	
Participant describes being unsure of how to manage the feeling of vulnerability		Stage 0 and I Diagnosed in 2016 or before

Impact on relationships

In the structured interview, participants were asked whether their condition had affected their personal relationships. Overall, there were 13 participants (25.00%) that described no impact on relationships, and the same number that described a mix of positive and negative impacts on relationships. Other participants reported a positive impact on relationships (n=12, 23.08%), and a negative impact on relationships (n=9, 17.31%).

The most common themes in relation to having a positive impact on relationships were because of people being well-meaning and supportive (n=11, 21.15%), and from family relationships being strengthened (n=10, 19.23%). The most common theme in relation to having a negative impact on relationships were because of people not knowing what to say or do and withdrawing from relationships (n=16, 30.77%).

Participant describes a positive impact on relationships from people being well-meaning and supportive

I've haven't had those kinds of experiences from close friends or close family so for me, all my friend interactions have been positive only again, meaning well, not not negative, but just did it but you know, but not all bad. Participant 013_2021AUHRP

I don't think that much. A lot of my friends are very supportive and my family too. I don't think it's made a huge difference one way or another, if that makes sense. Participant 036_2021AUHRP

They were quite supportive of it, it's probably like brought us a little bit closer. Most of my friends anyway. I've got really good friends and family network anyway. It probably brought us a little bit closer. Yes, I could see, they really had to rely on my kids and stuff and I was going to chemo from school and stuff like that. They still come around and they're happy to do that. We're very lucky. Participant 040_2021AUHRP

Participant describes relationships with family being strengthened

With friends? Most definitely, with family, no. No, it's actually strengthened the family relationships. More for them towards me rather than the other way. Obviously, I have two children, so they suddenly realised, oh, mummy's not immortal and she's human and but friends, mention any way, shape or form the word cancer and I would say 99 percent of my friends I haven't heard from since my diagnosis. Participant 003_2021AUHRP

I've lost friends. I have strained relationships with family because of the way they've treated me during treatment, but then it's strengthened my relationship with my husband to like a real depth. I found out who true friends are. Participant 043_2021AUHRP

Yes. Not so much family I think, in a positive way perhaps, we were a relatively close family anyway and it probably brought us a bit closer. I've definitely had an impact on friendships as well in a not-so-great way, my older or as I said, previously best friend I rarely speak to. Another friend who stood up really well during my breast cancer treatment suddenly dropped off the radar about two years after and I've never been able to work out what why. I think just generally. Participant 023_2021AUHRP

Participant describes relationships suffering, that is people not knowing what to say or do and withdrawing from relationships

Yes. I've lost friends. I have people that I thought were my best friends who no longer talk and it's purely and simply because they can't deal. It's not me personally. It's they can't deal with the fear of losing someone so they withdraw. One of my best friends is bipolar and she said to me, "People can see your illness. They can't see mine." Then she stopped talking to me. I can't change that but yes it definitely impacts people. Participant 018_2021AUHRP

One of my close girlfriends. She never came and visited me. Immediately, she lived a few hours away but she was down here a lot seeing her mother. She rang me but she never came and visit with me. Another friend of mine, him and his wife moved away up to LOCATION. I didn't really hear from him. I rang him and I had a cold, I called and I said, "I didn't have a common cold." I said, "I had breast cancer." I said, "You could have picked up the phone." I no longer contact him. We're friends on Facebook but I don't bother with him. I suppose that sort of thing. Participant 027_2021AUHRP

I lost friends. People couldn't really cope with the diagnosis. And I also was probably in such in those friendship groups. Although, you know, those friendships that I lost, I was probably before this all happened. I was the friends that helped them rather than the other way around. And then when I became the friend that needed help people do disappear. You know, you see the true side of which part of your family is supportive and which isn't. Yeah, so just it really opens your eyes to different types of people. But then on the flip side, as well, then I've made friends. Since that, you know, I can't imagine, you know, that. They're amazing. So you win some you lose some I guess. Participant 033_2021AUHRP

Participant describes a positive impact on relationships (general, no specifics articulated)

Probably for the positive Yes. Yeah. Okay. Participant 020_2021AUHRP

I think I've got really good relationships around me so I think we've been okay. Participant 042_2021AUHRP

Table 8.14: Impact on relationships

Impact on relationships	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participant gives a description suggesting that overall, there no impact on relationships	13	25.00	4	21.05	6	28.57	3	25.00	9	31.03	4	17.39	3	15.79	10	30.30
Participant gives a description suggesting that overall, there was a mix of a positive and a negative impact	13	25.00	4	21.05	6	28.57	3	25.00	6	20.69	7	30.43	6	31.58	7	21.21
Participant gives a description suggesting that overall, there was a positive impact on relationships	12	23.08	7	36.84	4	19.05	1	8.33	7	24.14	5	21.74	3	15.79	9	27.27
Participant gives a description suggesting that overall, there was a negative impact on relationships	9	17.31	3	15.79	2	9.52	4	33.33	4	13.79	5	21.74	4	21.05	5	15.15
Participant gives a description suggesting that overall there is an impact on quality of life, but does not describe the impact	3	5.77	1	5.26	2	9.52	0	0.00	1	3.45	2	8.70	3	15.79	0	0.00
Participant gives a description suggesting that overall, there was an impact on relationships that was neither positive nor negative	2	3.85	0	0.00	1	4.76	1	8.33	2	6.90	0	0.00	0	0.00	2	6.06

Impact on relationships	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participant gives a description suggesting that overall, there no impact on relationships	13	25.00	1	10.00	6	37.50	6	23.08	2	18.18	11	26.83	4	22.22	9	26.47
Participant gives a description suggesting that overall, there was a mix of a positive and a negative impact	13	25.00	2	20.00	3	18.75	8	30.77	3	27.27	10	24.39	3	16.67	10	29.41
Participant gives a description suggesting that overall, there was a positive impact on relationships	12	23.08	4	40.00	3	18.75	5	19.23	3	27.27	9	21.95	6	33.33	6	17.65
Participant gives a description suggesting that overall, there was a negative impact on relationships	9	17.31	1	10.00	2	12.50	6	23.08	0	0.00	9	21.95	2	11.11	7	20.59
Participant gives a description suggesting that overall there is an impact on quality of life, but does not describe the impact	3	5.77	2	20.00	0	0.00	1	3.85	3	27.27	0	0.00	3	16.67	0	0.00
Participant gives a description suggesting that overall, there was an impact on relationships that was neither positive nor negative	2	3.85	0	0.00	2	12.50	0	0.00	0	0.00	2	4.88	0	0.00	2	5.88

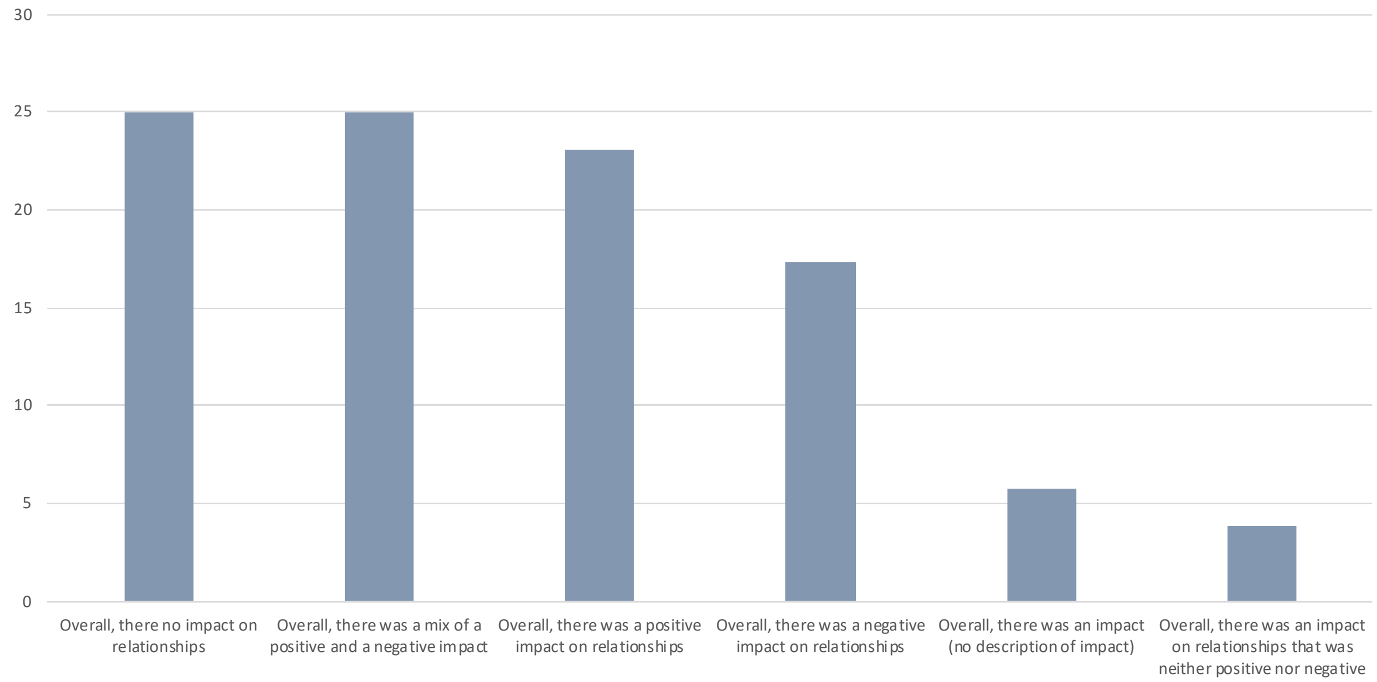


Figure 8.8: Impact on relationships

Table 8.15: Impact on relationships – subgroup variations

Impact on relationships	Reported less frequently	Reported more frequently
Participant gives a description suggesting that overall, there no impact on relationships	Diagnosed in 2016 or before	Diagnosed in 2017 to 2019
Participant gives a description suggesting that overall, there was a positive impact on relationships	Stage III and IV	Stage 0 and I Diagnosed in 2016 or before Mid to low status
Participant gives a description suggesting that overall, there was a negative impact on relationships	Regional or remote	Stage III and IV
Participant gives a description suggesting that overall there is an impact on quality of life, but does not describe the impact	-	Trade or high school Diagnosed in 2016 or before Regional or remote Mid to low status

Table 8.16: Impact on relationships (Reason for impact)

Reasons for impact on relationships	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participant describes relationships suffering, that is people not knowing what to say or do and withdrawing from relationships	16	30.77	6	31.58	6	28.57	4	33.33	8	27.59	8	34.78	7	36.84	9	27.27
Participant describes relationship with family changing: dynamics of relationships change due to anxiety, exacerbations and/or physical limitations of condition	4	7.69	2	10.53	1	4.76	1	8.33	0	0.00	4	17.39	3	15.79	1	3.03
Participant describes a negative impact on relationships (general, no specifics articulated)	3	5.77	0	0.00	1	4.76	2	16.67	2	6.90	1	4.35	1	5.26	2	6.06
Participant describes a positive impact on relationships from people being well-meaning and supportive	11	21.15	6	31.58	2	9.52	3	25.00	6	20.69	5	21.74	4	21.05	7	21.21
Participant describes relationships with family being strengthened	10	19.23	6	31.58	3	14.29	1	8.33	6	20.69	4	17.39	1	5.26	9	27.27
Participant describes a positive impact on relationships (general, no specifics articulated)	8	15.38	1	5.26	6	28.57	1	8.33	3	10.34	5	21.74	3	15.79	5	15.15

Reasons for impact on relationships	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participant describes relationships suffering, that is people not knowing what to say or do and withdrawing from relationships	16	30.77	3	30.00	3	18.75	10	38.46	3	27.27	13	31.71	3	16.67	13	38.24
Participant describes relationship with family changing: dynamics of relationships change due to anxiety, exacerbations and/or physical limitations of condition	4	7.69	0	0.00	0	0.00	4	15.38	1	9.09	3	7.32	0	0.00	4	11.76
Participant describes a negative impact on relationships (general, no specifics articulated)	3	5.77	0	0.00	2	12.50	1	3.85	0	0.00	3	7.32	2	11.11	1	2.94
Participant describes a positive impact on relationships from people being well-meaning and supportive	11	21.15	2	20.00	3	18.75	6	23.08	3	27.27	8	19.51	6	33.33	5	14.71
Participant describes relationships with family being strengthened	10	19.23	2	20.00	2	12.50	6	23.08	2	18.18	8	19.51	4	22.22	6	17.65
Participant describes a positive impact on relationships (general, no specifics articulated)	8	15.38	2	20.00	3	18.75	3	11.54	3	27.27	5	12.20	3	16.67	5	14.71

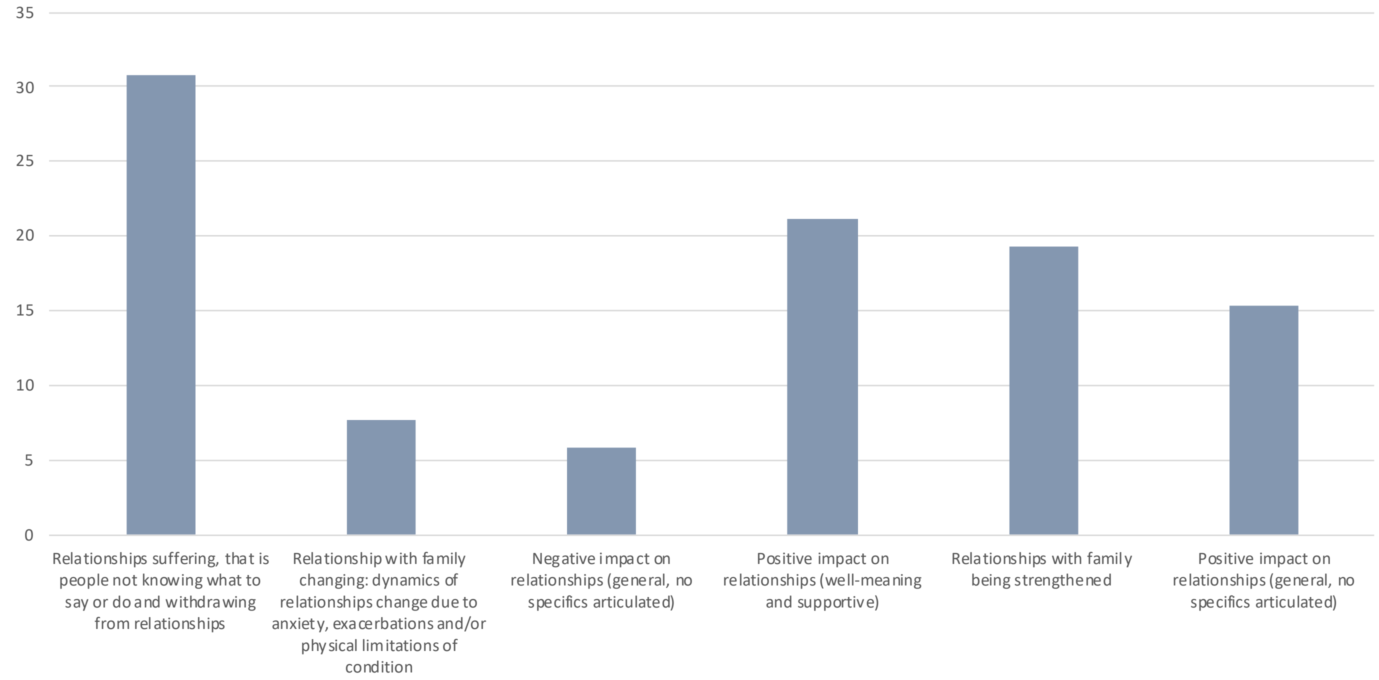


Figure 8.9: Impact on relationships

Table 8.17: Impact on relationships: Reason for impact – subgroup variations

Reasons for impact on relationships	Reported less frequently	Reported more frequently
Participant describes relationships suffering, that is people not knowing what to say or do and withdrawing from relationships	Diagnosed in 2017 to 2019 Mid to low status	-
Participant describes a positive impact on relationships from people being well-meaning and supportive	Stage II	Stage 0 and I Mid to low status
Participant describes relationships with family being strengthened	Stage III and IV Trade or high school	Stage 0 and I
Participant describes a positive impact on relationships (general, no specifics articulated)	Stage 0 and I	Stage II Regional or remote

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 26 participants (50.00%) that felt there was an additional burden, and 26 participants (50.00%) that reported no additional burden.

The main reason that participant described their condition not being a burden in general was that they and remained independent and did not need any help (n=10, 19.23%). For participants that felt they were a burden on their family, the main reason was the extra household duties and responsibilities that their family must take on (n=14, 26.92%). There were six participants (9.62%) that described that the burden on their family was only temporary or during treatment .

Participant describes their condition not being a burden in general (No specific examples)

No, I don't think I do need any extra care or assistance from them. I guess the only thing in terms of a burden is it has implications for my sisters, in terms of they need to do more frequent screening. I don't think that's necessarily overly onerous, though. I guess, in some ways, knowing that there's a risk there might actually be helpful if it gets diagnosed earlier. I think a mammogram every year is probably acceptable. I've done worse for them, I'm sure. Participant 005_2021AUHRP

No, because mine was only stage 1A with a grade 2 lump. I'm back to normal again, for want of a better word, except the pain. Participant 012_2021AUHRP

No. No. I think I've fixed that problem, [chuckles]. Participant 028_2021AUHRP

Participant describes extra household duties and responsibilities that their family must take on

One of my boys is now my-- He takes care of all my financial stuff because my brain is in stupid mode and I forget basic-- I have a memory-- A short-term memory problem which is shocking. That's not me but it is my new reality. I've severely been impacted cognitively from the chemo so he took over power of attorney pre-chemo and he keeps a check on everything. I run everything by him now because that way I can't make a mistake because some of those mistakes could be costly and I haven't got the money to do that anymore. He takes care of my insurances and registrations. He just tells me, "You need to put this much in the bank every week and I'll take care of them all for you." Because I would forget. I've done so and I'm aware that that's a problem so I have the support but then I feel guilty because he's got to make sure that mom's got her shit together. Participant 018_2021AUHRP

No, I think that I'm probably more likely now to ask my husband to carry the washing out the washing line for a meal or two things. But he's a man that's always wanted to do those things. But in the past, I've always felt able to do them. But no, I was trying to ask him to to give me a hand. Participant 019_2021AUHRP

Participant describes their condition not being a burden in general, as they remained independent or did not need help

No, I didn't have to do anything extra. I've been very independent. Participant 016_2021AUHRP

No, I don't know whether it was because I was stubborn, or whether it's just I was lucky, but I actually didn't need any help from family to be able to maintain my treatment. When I was going through chemo, I could still do my housework. I could still do my cooking, or I could still take the kids to school and stuff like that. Granted that cooking wasn't necessarily a good one when I'd had to have the chemotherapy, that was not fun. Having to cook a bit more then, but other than that, yes, he got off pretty lucky. Participant 025_2021AUHRP

No, because I always told them I was doing so well. I never showed anyone. I didn't want to do that to anyone, so I made sure that I made sure everyone would think that I was doing very well all the time. Participant 029_2021AUHRP

Participant describes their condition being a temporary burden, or a burden during treatment only

Not at this stage. During the time early on when I was having the radiation when I was tired and that sort of thing, they were all quite supportive my immediate family. Participant 010_2021AUHRP

No. Cancer treatment, yes. It was it was a big burden, but not anymore now. Participant 037_2021AUHRP

Not at the moment, no. Certainly during that initial few months of chemo and radiation and the recovery from surgery very much so, but that's all over and done with. Participant 039_2021AUHRP

Participant describes their condition being a burden in general (No specific examples)

A little bit, but we've also been out of work, we've been able to get through it and we're coming to the end of it now. We've been okay. Participant 042_2021AUHRP

I helped my husband through cancer a few years back. I guess, I know what he's feeling, and I know that I never felt like he was a burden during that time. I guess that sort of helped me in a way. Participant 052_2021AUHRP

Table 8.18: Burden on family

Burden on family	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participant gives a description suggesting that overall, there was not a burden on their family	26	50.00	11	57.89	10	47.62	5	41.67	19	65.52	7	30.43	10	52.63	16	48.48
Participant gives a description suggesting that overall, there was a burden on their family	26	50.00	8	42.11	11	52.38	7	58.33	10	34.48	16	69.57	9	47.37	17	51.52

Burden on family	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participant gives a description suggesting that overall, there was not a burden on their family	26	50.00	5	50.00	9	56.25	12	46.15	4	36.36	22	53.66	9	50.00	17	50.00
Participant gives a description suggesting that overall, there was a burden on their family	26	50.00	5	50.00	7	43.75	14	53.85	7	63.64	19	46.34	9	50.00	17	50.00

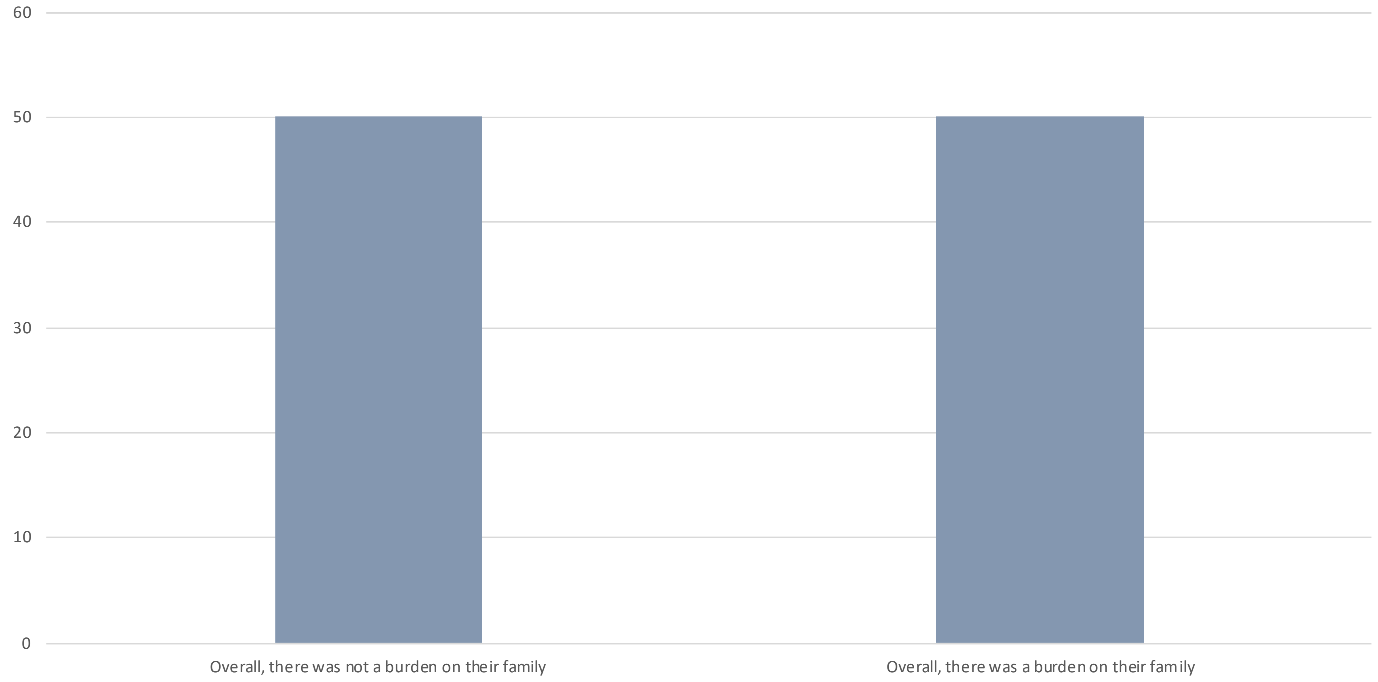


Figure 8.10: Burden on family

Table 8.19: Burden on family – subgroup variations

Burden on family	Reported less frequently	Reported more frequently
Participant gives a description suggesting that overall, there was not a burden on their family	Aged 55 to 74 Regional or remote	Aged 25 to 54
Participant gives a description suggesting that overall, there was a burden on their family	Aged 25 to 54	Aged 55 to 74 Regional or remote

Table 8.20: Burden on family (description)

Burden on family (description)	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participant describes their condition not being a burden in general (No specific examples)	15	28.85	9	47.37	4	19.05	2	16.67	11	37.93	4	17.39	6	31.58	9	27.27
Participant describes extra household duties and responsibilities that their family must take on	14	26.92	5	26.32	6	28.57	3	25.00	5	17.24	9	39.13	7	36.84	7	21.21
Participant describes their condition not being a burden in general, as they remained independent or did not need help	10	19.23	2	10.53	5	23.81	3	25.00	6	20.69	4	17.39	3	15.79	7	21.21
Participant describes their condition being a temporary burden, or a burden during treatment only	6	11.54	2	10.53	1	4.76	3	25.00	2	6.90	4	17.39	3	15.79	3	9.09
Participant describes their condition being a burden in general (No specific examples)	5	9.62	0	0.00	3	14.29	2	16.67	2	6.90	3	13.04	0	0.00	5	15.15

Burden on family (description)	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participant describes their condition not being a burden in general (No specific examples)	15	28.85	3	30.00	6	37.50	6	23.08	2	18.18	13	31.71	3	16.67	12	35.29
Participant describes extra household duties and responsibilities that their family must take on	14	26.92	2	20.00	1	6.25	11	42.31	5	45.45	9	21.95	2	11.11	12	35.29
Participant describes their condition not being a burden in general, as they remained independent or did not need help	10	19.23	2	20.00	2	12.50	6	23.08	2	18.18	8	19.51	5	27.78	5	14.71
Participant describes their condition being a temporary burden, or a burden during treatment only	6	11.54	1	10.00	3	18.75	2	7.69	0	0.00	6	14.63	2	11.11	4	11.76
Participant describes their condition being a burden in general (No specific examples)	5	9.62	0	0.00	3	18.75	2	7.69	1	9.09	4	9.76	3	16.67	2	5.88

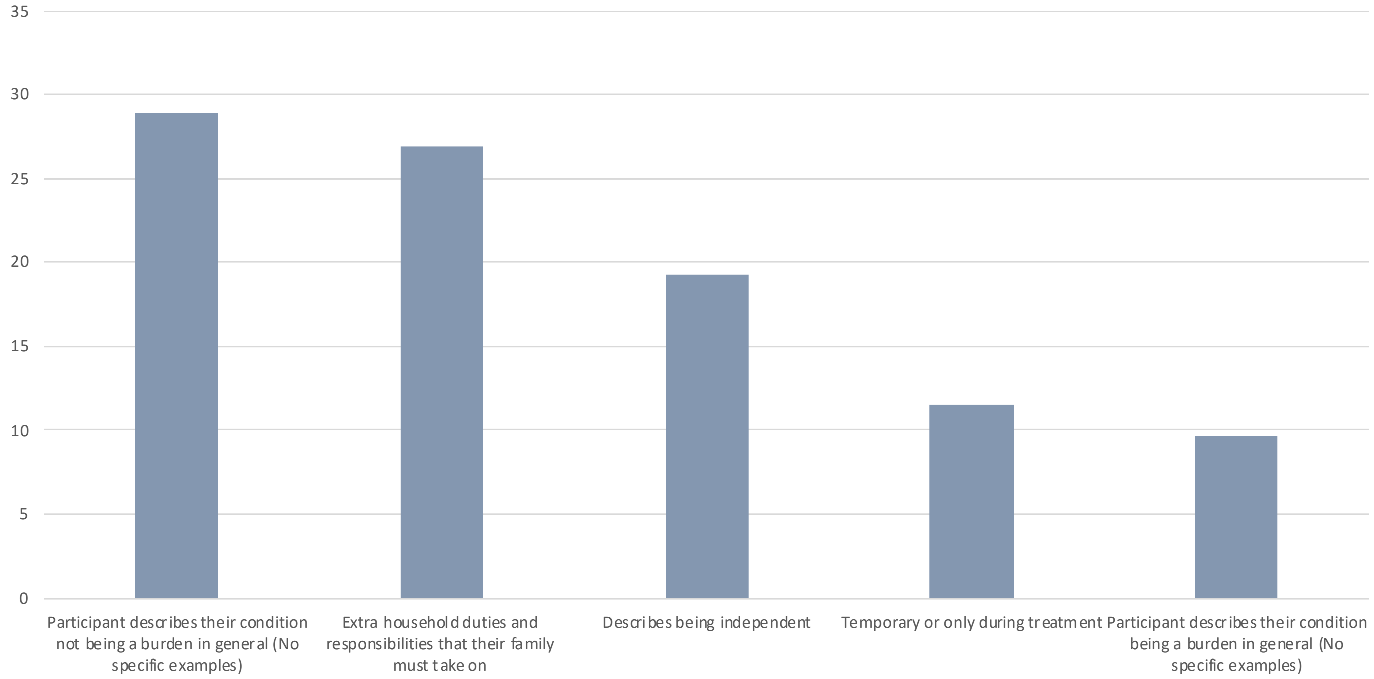


Figure 8.11: Burden on family (description)

Table 8.21: 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)	Stage III and IV Aged 55 to 74 Regional or remote Mid to low status	Stage 0 and I
Participant describes extra household duties and responsibilities that their family must take on	Diagnosed in 2017 to 2019 Mid to low status	Aged 55 to 74 Diagnosed in 2020 or 2021 Regional or remote
Participant describes their condition being a temporary burden, or a burden during treatment only	Regional or remote	Stage III and IV

Cost considerations

In the structured interview, participants were asked about any significant costs associated with having their condition. There were 48 participants (92.31%) that described some cost burden and four participants (7.69%) that 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=43, 82.69%). Other cost burdens were in relation to taking time off work (n=24, 46.15%), the cost of specialist appointments (n=20, 38.46%), the cost of diagnostic tests and scans (n=20, 38.46%), family members needing to take time off work (n=7, 13.46%), and the cost of parking and travel to attend appointments, including accommodation (n=5, 9.62%). There were seven participants (13.46%) that described no cost burden and that nearly everything was paid for through the health system or private coverage.

Participant describes a cost burden in relation to the cost of treatments (including repeat scripts)

I was at work the day I went for my mammogram and then I couldn't go back because I was having treatment. Then I really couldn't give my work a date when I would go back. As a result of it all, I ended up taking now redundancy. I struggled with that because I absolutely loved my work. I wasn't ready to give up but in hindsight now, I'm over that now. I don't know what you've seen in terms of costs in there. Out of pocket was almost treatment at the time of the radiation. The radiation I think was $22,000 and I think I got back about $10 so I was out of pocket $12,000. What annoyed me and this is just a little bit of a gripe I guess, I've worked all my life. I've paid my Medicare, I've paid private health. Then there's people beside me there who were getting it for free, having exactly the same treatment as me so that was a little bit like-- I know that they probably deserve. Everyone deserves the right to get the treatment but they were there at the private hospital having it for free where I was paying the $22,000. I've worked hard all my life to get savings to do all that. This isn't nearly true at all but that sum was a little bit, well, I think if it was good enough for them to have it for nothing, it probably was good enough for me to have it for nothing. Participant 004_2021AUHRP

My husband gave up his job to help me through when I wasn't coping. The prosthetics are quite expensive. I know that you get money back, but unfortunately with the Medicare system, you have to find the $800 first before you get reimbursed, so that system definitely needs to be looked at because a lot of people don't have that kind of disposable income. I paid for physios myself. Complementary treatments aren't covered, so if you want to have anything like [unintelligible] therapy or lymphatic drainage outside of the hospital system, that'll cost you money and it's not cheap. I think in the last five years, I've probably spent close to $10,000 out of pocket for treatment. Participant 018_2021AUHRP

I think that it's not cheap to get cancer, that's for sure. I was overwhelmed by the information that I had sent to me via the email from my breast surgeon after I saw him. So I received some of the possible figures of how much his fees would be, anaesthetic fees, the hospital, all of those things. And so they came hard and fast. And so I think coping with the unexpected diagnosis, coupled with having all of the cost, I was overwhelmed by it. You know, I was concerned by it. And I mean, I was reassured by my husband, who said, look, you know, we have to do this and don't think about it. But I'm the money manager in the house, so I was concerned. Having said that, I didn't, regardless of how much it was going to cost, I wasn't going to go through the public system because I wouldn't have had any form of control about my choices in the public system. Participant 019_2021AUHRP

Participant describes a cost burden in relation to needing to take time off work

Other than having no money coming in for a year for me. Otherwise, we probably would have-- I did use a charity as well that helped pay bills.

INTERVIEWER: Are you happy to name that charity?

PARTICIPANT: Yes, Be Uplifted Incorporated. They were amazing. They paid bills, this is the local Brisbane one. They support women going through breast cancer and Mummy's Wish, they got me a cleaner for a few months after my surgery, or six weeks or something. There were things like that that were amazing. Participant 024_2021AUHRP

Because of the type of work I do in the hospital, it's demanding, I didn't go back to it. I had time off. It was the first time in my life that I actually went, "Right. You're going to stop and you're going to take care of yourself-

INTERVIEWER: Excellent.

PARTICIPANT: -at any cost." That's exactly what I did. I surrendered to the process. That has left me with a debt. Participant 027_2021AUHRP

Look, a phenomenal amount, as such. Unfortunately, I did lose my job over my diagnosis. All along though, my employer told me that yes, my job would be there when I returned, but it turned out that no, it wasn't. Unfortunately, in a small community and the stress of it all, it just wasn't worth pursuing that, and good on that lady that has been successful, obviously. That was huge. Probably the other thing is we were able to speak to my oncologist and talk to him about the cost, and he was happy to do a loan scheme, and we just had to pay that off over the years. Then the finding new employment and, of course, not being physically able to stand five days a week, or manage employment five days a week, manage to find employment as such. That was a lot. That was huge. Participant 031_2021AUHRP

Participant describes a cost burden in relation to the cost specialist appointments

Oh, huge impact, yes. Financially I'm out-of-pocket, I would say thousands of dollars out-of-pocket and it's continuing because I've got to, but luckily I'm in a good health fund but I still got to pay the gap, so yes, financially it's taken a toll at work. I can't with my shoulder the way it is and for how tight I am, I've had to reduce my workdays, I work full time but I've used up all my sick leave and I'm taking holidays. I'm using all my annual leave now just to go to work four days a week rather than five but rather than pay, so yes it's impacted my work and impacted me financially. It will continue to impact me financially because you've got to pay the gap every time you see a specialist and you've got to pay $40 something every month for the medication. Participant 035_2021AUHRP

I've had to pay for the respiratory physician. I've had to pay for scans and X-rays related to the respiratory physician. I guess the other cost in a sense is that I haven't been able to work. My income has been reduced. I'm on income protection. I do have that, but it has meant that my wage has decreased. Participant 047_2021AUHRP

The costs like the mammogram and the ultrasound, I vaguely remember they were something like $400 and something, and I think you got $250 back or something. I had the PET scan which I think might have been bulk billed. My surgeon, he was all bulk billed, so there was no cost there. The medical oncologist, I chose to pay up-front, so I could get it sorted out very quickly. I paid the extra money for him, for private. I can't remember what it was, $400 and something, and I might have got $150 back or something, off the top of my head. Biopsy, I think it was out of pocket, maybe $50 or $60 with those. Participant 017_2021AUHRP

Participant describes a cost burden in relation to diagnostic tests and scans

I had costs from the original ultrasound scan, from the biopsy, and I had an MRI done. I had costs from that. I have private health insurance, so I had a gap for the first hospital stay. Probably all up, I'm going to guess around $1,500 to $2,000. Participant 011_2021AUHRP

The costs like the mammogram and the ultrasound, I vaguely remember they were something like $400 and something, and I think you got $250 back or something. I had the PET scan which I think might have been bulk billed. My surgeon, he was all bulk billed, so there was no cost there. The medical oncologist, I chose to pay up-front, so I could get it sorted out very quickly. I paid the extra money for him, for private. I can't remember what it was, $400 and something, and I might have got $150 back or something, off the top of my head. Biopsy, I think it was out of pocket, maybe $50 or $60 with those. Participant 017_2021AUHRP

I chose to go private with my surgery, so I had to pay for the hospital. I had to pay for the surgeon. I had to pay for the anesthetist. I had to pay for the assistance surgeon. There'd been substantial costs there. Not a lot in terms of medication. When I had to go back and-- I had to go back and have more mammograms, ultrasounds and core biopsies. I had to pay for that. I've had to pay for the one physiotherapy, the one that I found the physiotherapist. I've had to pay for her. Participant 047_2021AUHRP

I tell you what, I'm very, very lucky just as a professional. I ended up taking, from the point of diagnosis, I took five days off of work for the surgery and for some time to heal, and luckily I was very supported by my employer, so that was good. From a cost standpoint, my total out-of-pocket including doctor appointments, including the biopsies, et cetera, was about $8,000. I learned a lot about the healthcare system and that Medicare, they can pay for everything, and that private doesn't pay for everything. Participant 007_2021AUHRP

I'm going to be $615 out of pocket because that's not the normal follow-through. You should be happy with the mammogram and an ultrasound when lobular breast cancer doesn't always show until it's too late. I've opted to have and pay and I went privately through a private hospital as well. You're continually getting $100, $200, $300 bills. I had to pay for my radiation because well, and it's not even exactly because it's where you went through because my girlfriend went through the same hospital for her radiation and she wasn't charged. I was $750 out of pocket for that. Which in retrospect isn't a lot of money because it's the total cost of its $14,000. In retrospect it's not a lot of money but how do they decide who pays and who doesn't. Participant 010_2021AUHRP

Participant describes a cost burden in relation to a family member needing to take time off work

My husband runs his own business. So, you know, any days off, he had to take because he had to take me to treatment or had to be at home for the kids or whatever. We just didn't earn an income because he couldn't work. So yeah. But we also, you know, I was only off work for six months. So we didn't actually qualify for any, you know, external assistance from the government or anything, because I wasn't, you know, in theory that week, you know, what I consider my good week post treatment, I probably could have worked in there. But, you know, no cancer patient wants to work in a hospital when they're undergoing treatment. Yeah, you know what I do? Yeah. So, you know, I was fortunate that I could make that decision. But, and then now with this, the hysterectomy, I'm out of pocket. Probably about $3,000 for this year. That's just the gap between what the AMA says should be paid and what Medicare actually pays. Participant 033_2021AUHRP

My husband works part-time. We'd just make sure things fitted in that if I needed him, he'd be around. One of my children, the one that lives overseas, a contract finished, so he came back to Australia while I had chemo and was here. That was very good. He had, I guess, a three-month break from work that he wouldn't have had otherwise. That was a significant cost to him. That's probably it. I wasn't working. I had been made redundant at my request and rather than getting a new job, I just stopped working. Participant 039_2021AUHRP

Participant describes no cost burden and that nearly everything was paid for through the health system

No cost, I'm on a disability pension. Because it is... Well, the first one was cancer related, I did have to wait nearly two years to get the second mastectomy because of the triage system, because they're saying you don't technically have cancer now, but not taking into account the high reoccurrence rate and the high rate of metastases. So, yes, again, it -- that's been very frustrating. Participant 003_2021AUHRP

Well, I had literally just started a new job a week-and-a-half into my diagnosis. I was on probation. That was a loophole for them because they obviously needed to fill the position. I'm currently not working. It's been a very, very costly thing for us as a family. In terms of the treatment itself, I've been very fortunate. I've had that all covered by Medicare, so I'm very, very lucky, but it's been very hard on us. Very, very hard on us to manage without me earning money. Participant 008_2021AUHRP

Luckily, it was all done through the public health system, so I had no costs involved with the operation, no costs involved with radiation. I haven't had any cost. It's all paid. Participant 026_2021AUHRP

Participant describes a cost burden in relation to the cost of parking and travel to attend appointments (including accommodation)

I'm a bit useless on the subject because my husband tends to fill the load of that. I know that he feels the bills are piling up. There's a lot of expenses, a lot of appointments, a lot of extra things like parking, juggling health insurance, or all that sort of jazz. There's a lot of administrative stuff. It's not just simply the treatment, but all the appointments and the dental appointments and the complementary and, what is it, the Allied stuff, it all adds up. He's actually taken less days at work, but some of that has been part of COVID and having to reduce hours. Because of my ability or health issues, I've obviously had to lessen my hours as well, but he's definitely the breadwinner. I know we're on a good wicket, but I think that does play on his mind. I couldn't tell you the figures because I literally don't know. Participant 051_2021AUHRP

Just the travel back and forwards from LOCATION to LOCATION, the cost of the studio, the cost of food. I wasn't aware of the costs. That was hideous. Participant 031_2021AUHRP

There was the parking fees mainly. I've had to buy different bras because I used to wear them with wires. I bought support sleep bras to sleep in at night, and because we're retired, we didn't have to take time off work, so it didn't impede anything like that, but I feel really strongly that Medicaid do not refund anything if you have a core biopsy done in a private place, it's almost $500. They're always saying, they're advertising about your breast cancer and be alert and all that, and yet the government want to slug nearly $500 to have that test. I'm sorry, that just needs to be looked at. Participant 012_2021AUHRP

Table 8.22: Cost considerations

Cost considerations	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participant gives a description suggesting that overall, there was at least some cost burden	48	92.31	18	94.74	19	90.48	11	91.67	27	93.10	21	91.30	18	94.74	30	90.91
Participant gives a description suggesting that overall, there was no cost burden	4	7.69	1	5.26	2	9.52	1	8.33	2	6.90	2	8.70	1	5.26	3	9.09

Cost considerations	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participant gives a description suggesting that overall, there was at least some cost burden	48	92.31	9	90.00	15	93.75	24	92.31	11	100.00	37	90.24	16	88.89	32	94.12
Participant gives a description suggesting that overall, there was no cost burden	4	7.69	1	10.00	1	6.25	2	7.69	0	0.00	4	9.76	2	11.11	2	5.88

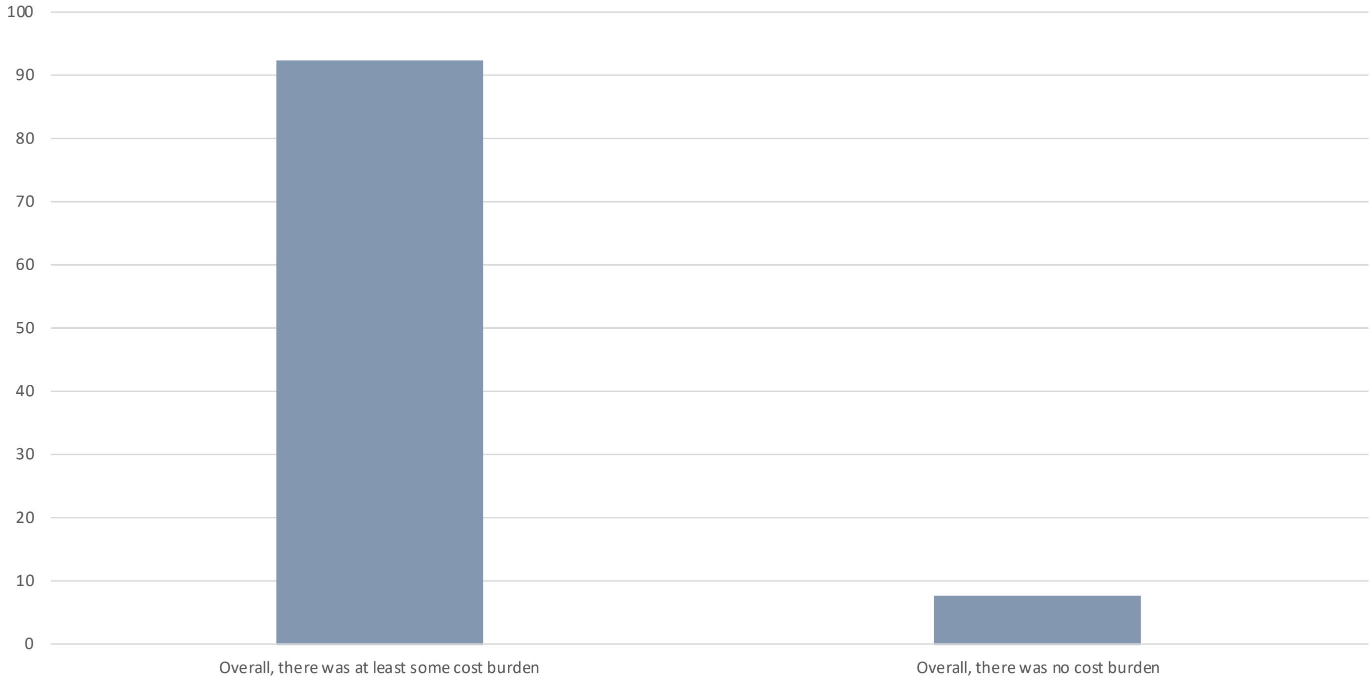


Figure 8.12: Cost considerations

Table 8.23: Cost considerations (Reasons for cost)

Cost considerations (Reasons for cost)	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participant describes a cost burden in relation to the cost of treatments (including repeat scripts)	43	82.69	17	89.47	16	76.19	10	83.33	25	86.21	18	78.26	17	89.47	26	78.79
Participant describes a cost burden in relation to needing to take time off work	24	46.15	9	47.37	10	47.62	5	41.67	12	41.38	12	52.17	10	52.63	14	42.42
Participant describes a cost burden in relation to the cost specialist appointments	20	38.46	8	42.11	8	38.10	4	33.33	9	31.03	11	47.83	10	52.63	10	30.30
Participant describes a cost burden in relation to diagnostic tests and scans	20	38.46	10	52.63	5	23.81	5	41.67	9	31.03	11	47.83	6	31.58	14	42.42
Participant describes a cost burden in relation to a family member needing to take time off work	7	13.46	4	21.05	2	9.52	1	8.33	1	3.45	6	26.09	4	21.05	3	9.09
Participant describes no cost burden and that nearly everything was paid for through the health system	7	13.46	1	5.26	4	19.05	2	16.67	4	13.79	3	13.04	1	5.26	6	18.18
Participant describes a cost burden in relation to the cost of parking and travel to attend appointments (including accommodation)	5	9.62	2	10.53	3	14.29	0	0.00	1	3.45	4	17.39	2	10.53	3	9.09

Cost considerations (Reasons for cost)	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participant describes a cost burden in relation to the cost of treatments (including repeat scripts)	43	82.69	9	90.00	13	81.25	21	80.77	10	90.91	33	80.49	16	88.89	27	79.41
Participant describes a cost burden in relation to needing to take time off work	24	46.15	4	40.00	7	43.75	13	50.00	8	72.73	16	39.02	10	55.56	14	41.18
Participant describes a cost burden in relation to the cost specialist appointments	20	38.46	7	70.00	4	25.00	9	34.62	6	54.55	14	34.15	8	44.44	12	35.29
Participant describes a cost burden in relation to diagnostic tests and scans	20	38.46	3	30.00	8	50.00	9	34.62	5	45.45	15	36.59	9	50.00	11	32.35
Participant describes a cost burden in relation to a family member needing to take time off work	7	13.46	0	0.00	2	12.50	5	19.23	2	18.18	5	12.20	2	11.11	5	14.71
Participant describes no cost burden and that nearly everything was paid for through the health system	7	13.46	1	10.00	2	12.50	4	15.38	0	0.00	7	17.07	1	5.56	6	17.65
Participant describes a cost burden in relation to the cost of parking and travel to attend appointments (including accommodation)	5	9.62	1	10.00	2	12.50	2	7.69	2	18.18	3	7.32	1	5.56	4	11.76

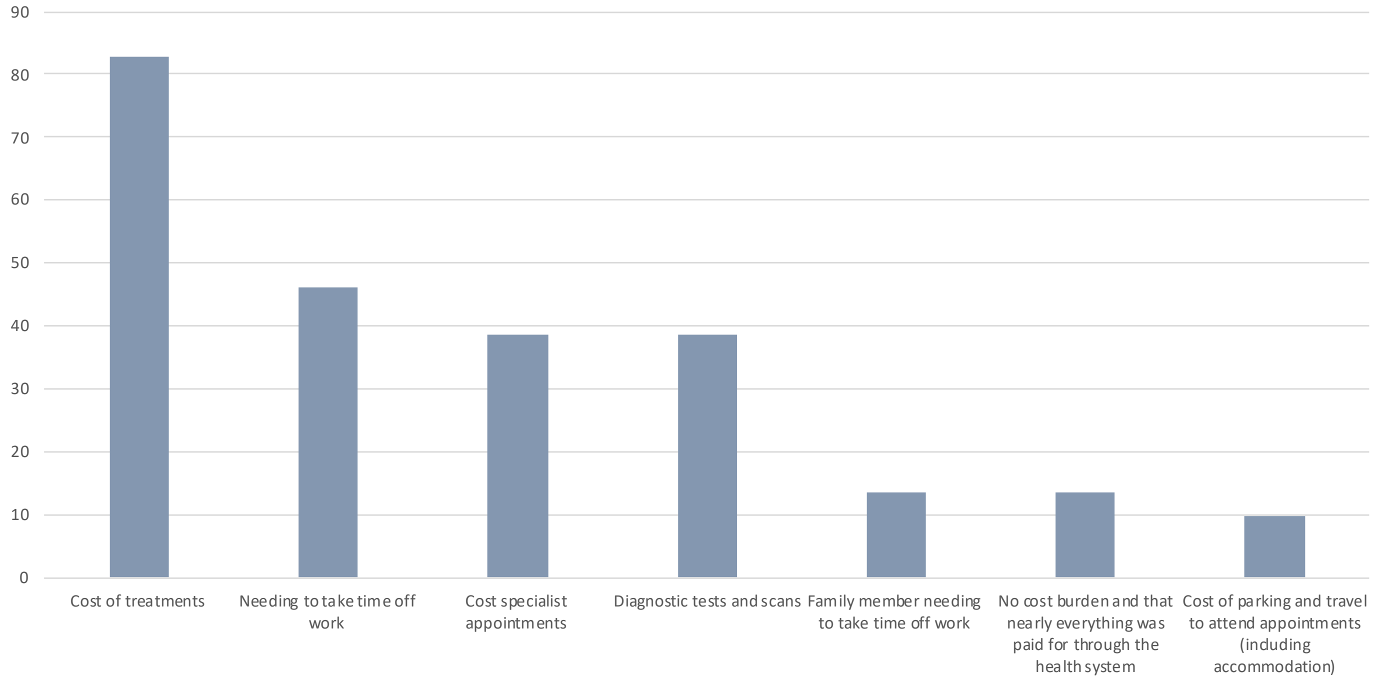


Figure 8.13: Cost considerations (Reasons for cost)

Table 8.24: Cost considerations (Reasons for cost)– subgroup variations

Cost considerations (Reasons for cost)	Reported less frequently	Reported more frequently
Participant describes a cost burden in relation to needing to take time off work	-	Regional or remote
Participant describes a cost burden in relation to the cost specialist appointments	Diagnosed in 2017 to 2019	Trade or high school Diagnosed in 2016 or before Regional or remote
Participant describes a cost burden in relation to diagnostic tests and scans	Stage II	Stage 0 and I Diagnosed in 2017 to 2019 Mid to low status
Participant describes a cost burden in relation to a family member needing to take time off work	Aged 25 to 54 Diagnosed in 2016 or before	Aged 55 to 74
Participant describes no cost burden and that nearly everything was paid for through the health system	Regional or remote	-

Overall impact of condition on quality of life

In the online questionnaire, participants were asked to rate the overall impact their condition on quality of life. 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.

The average score was in the life was average range (median = 4.00, IQR = 2.00) (Table 8.25, Figure 8.14).

Table 8.25: Overall impact of condition on quality of life

Impact of condition on quality of life	Number (n=51)	Percent
1 Life is/was very distressing	3	5.88
2 Life is/was distressing	8	15.69
3 Life is/was a little distressing	13	25.49
4 Life is/was average	10	19.61
5 Life is/was good	12	23.53
6 Life is/was very good	4	7.84
7 Life is/was great	1	1.96

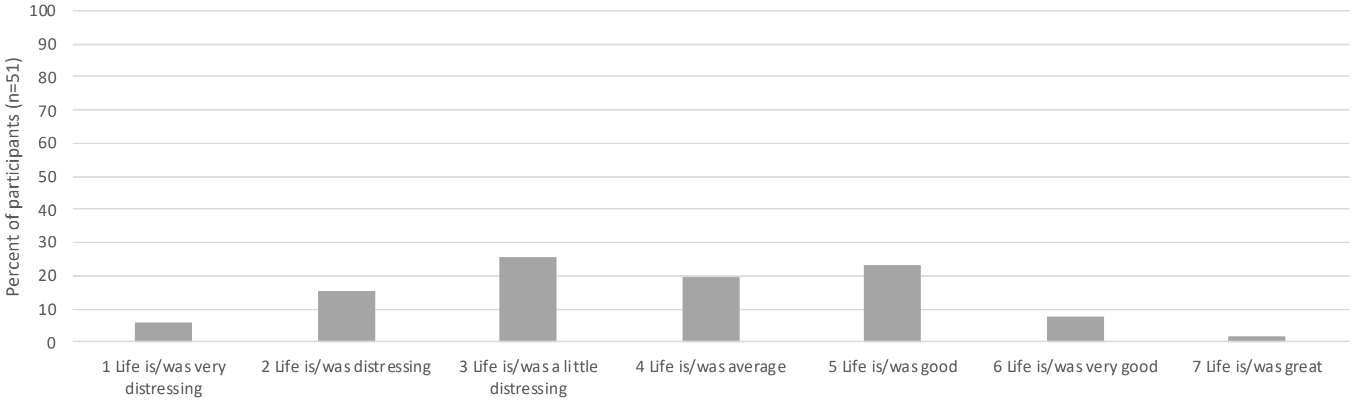


Figure 8.14: Overall impact of condition on quality of life

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. Overall the entire cohort had an average score for **Fear of progression: Total score** (mean = 33.86, SD = 8.23) which corresponds to moderate levels of anxiety (Table 8.26).

Comparisons of Care co-ordination have been made based on **stage** (Table 8.27, Figure 8.15), **age** (Table 8.28, Figure 8.16), **education** (Table 8.29, Figure 8.17), **year of diagnosis** (Table 8.30, Figure 8.18), **location** (Table 8.31, Figure 8.19), and **socioeconomic status** (Table 8.32, Figure 8.20).

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 8.26: Fear of progression summary statistics

Fear of progression (n=51)	Mean	SD	Median	IQR	Possible range	Quintile
Total score*	33.86	8.23	34.00	9.50	12 to 60	3

*Normal distribution use mean and SD as measure of central tendency

Fear of progression by stage

Comparisons were made by breast cancer **stage**, there were 18 participants (35.29%) with *Stage 0 and I* breast cancer, 21 participants (41.18%) *with Stage II*, and 12 participants (23.53%) with *Stage III and IV.*

The assumptions for response variable residuals were normally distributed and variances of populations were equal, a one-way ANOVA test was used. No significant differences between groups was observed (Table 6.27).

No significant differences were observed between participants by **stage** for the Fear of progression total score.

Table 8.27: Fear of progression total score by stage summary statistics and one-way ANOVA

Fear of progression	Group	Number (n=51)	Percent	Mean	SD	Source of difference	Sum of squares	dF	Mean Square	f	p-value
Total score	Stage 0 and I	18	35.29	32.44	7.37	Between groups	229.10	2	114.56	1.743	0.1860
	Stage II	21	41.18	32.90	8.01	Within groups	3154.90	48	65.73		
	Stage III and IV	12	23.53	37.67	9.29	Total	3384.00	50			

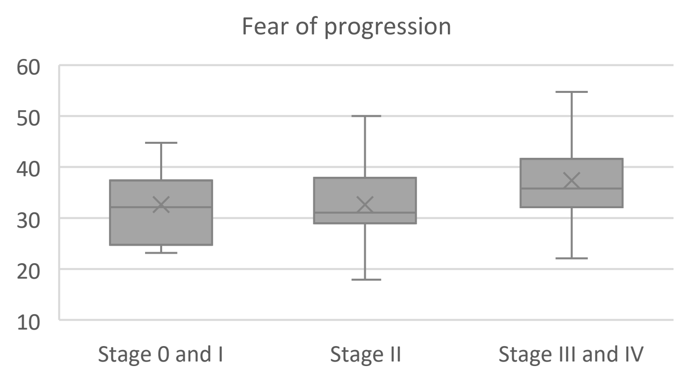


Figure 8.15: Boxplot of Fear of progression total score by stage

Fear of progression by age

Participants were grouped according to **age,** with comparisons made between participants *Aged 25 to* 54 (n=29, 56.86%) and participants *Aged 55 to 74* (n=22, 43.14%).

Assumptions for normality and variance were met, a two-sample t-test was used (Table 6.28).

No significant differences were observed between participants by **age** for the Fear of progression total score.

Table 8.28: Fear of progression total score by age summary statistics and T-Test

Fear of progression	Group	Number (n=51)	Percent	Mean	SD	T	dF	p-value
Total score	Aged 25 to 54	29	56.86	34.31	8.67	0.44	49	0.6601
	Aged 55 to 74	22	43.14	33.27	7.76			

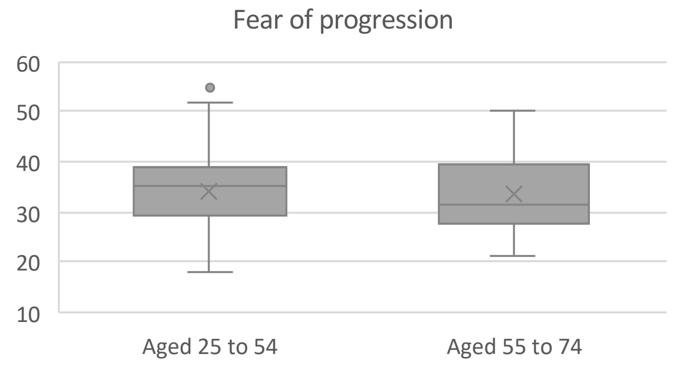


Figure 8.16: Boxplot of Fear of progression total score by age

Fear of progression by education

Comparisons were made by **education** status, between those with trade or high school qualifications, *Trade or high school* (n=19, 37.25%), and those with a university qualification, *University* (n= 32, 62.75%).

Assumptions for normality and variance were met, a two-sample t-test was used (Table 6.29).

No significant differences were observed between participants by **education** for the Fear of progression total score.

Table 8.29: Fear of progression total score by education summary statistics and T-test

Fear of progression	Group	Number (n=51)	Percent	Mean	SD	T	dF	p-value
Total score	Trade or high school	19	37.25	33.21	8.65	-0.43	49	0.6671
	University	32	62.75	34.25	8.08			

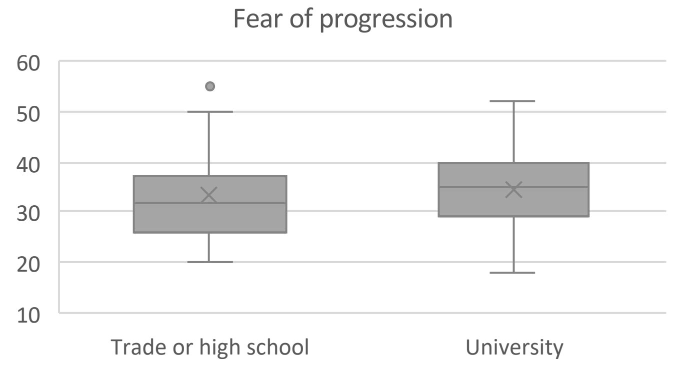


Figure 8.17: Boxplot of Fear of progression total score by education

Fear of progression by year of breast cancer diagnosis

Participants were grouped according to the **year of breast cancer diagnosis**, with 9 participants (17.65%) *Diagnosed in 2016 or before,* 16 participants (31.37%) *Diagnosed in 2017 to 2019*, and 26 participants (50.98%) *Diagnosed in 2020 or 2021.*

The assumptions for response variable residuals were normally distributed and variances of populations were equal, a one-way ANOVA test was used. No significant differences between groups was observed (Table 6.30).

No significant differences were observed between participants by **year of breast cancer diagnosis** for the Fear of progression total score.

Table 8.30: Fear of progression total score by year of breast cancer diagnosis summary statistics and one-way ANOVA

Fear of progression	Group	Number (n=51)	Percent	Mean	SD	Source of difference	Sum of squares	dF	Mean Square	f	p-value
Total score	Diagnosed in 2016 or before	9	17.65	32.22	6.24	Between groups	31.00	2	15.35	0.22	0.8040
	Diagnosed in 2017 to 2019	16	31.37	34.44	10.61	Within groups	3353.00	48	69.86		
	Diagnosed in 2020 or 2021	26	50.98	34.08	7.36	Total	3384.00	50			

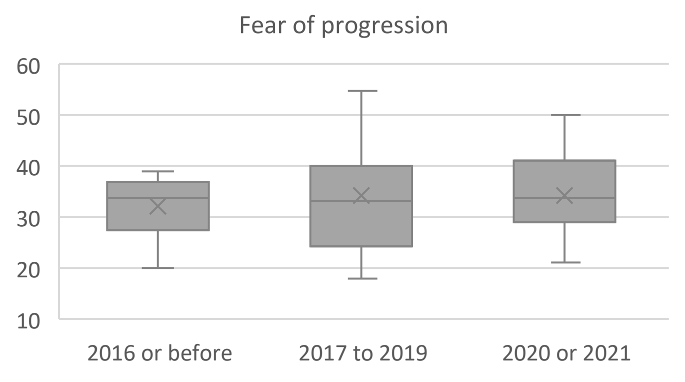


Figure 8.18: Boxplot of Fear of progression total score by year of breast cancer diagnosis

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/rural areas, *Regional or remote* (n=10, 19.61%) were compared to those living in a major city, *Metropolitan* (n=41, 80.39%).

Assumptions for normality and variance were met, a two-sample t-test was used (Table 6.31).

No significant differences were observed between participants by **location** for the Fear of progression total score.

Table 8.31: Fear of progression total score by location summary statistics and T-test

Fear of progression	Group	Number (n=51)	Percent	Mean	SD	T	dF	p-value
Total score	Regional or remote	10	19.61	33.09	7.67	-0.35	49	0.7291
	Metropolitan	41	80.39	34.08	8.45			

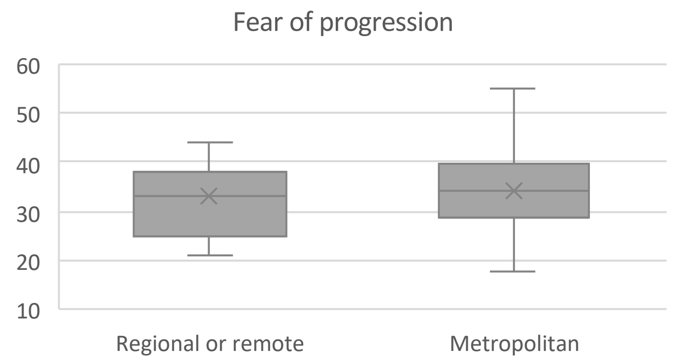


Figure 8.19: Boxplot of Fear of progression total score by location

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, *Mid to low status* (n=17, 33.33%) compared to those with a higher SEIFA score of 7-10, *Higher status* (n=34, 66.67%).

Assumptions for normality and variance were met, a two-sample t-test was used (Table 6.32).

No significant differences were observed between participants by **socioeconomic status**, for the Fear of progression total score.

Table 8.32: Fear of progression total score by socioeconomic status summary statistics and T-test

Fear of progression	Group	Number (n=51)	Percent	Mean	SD	T	dF	p-value
Total score	Mid to low status	17	33.33	31.06	8.35	-1.76	49	0.0852
	Higher status	34	66.67	35.26	7.92			

Figure 8.20: Boxplot of Fear of progression total score by socioeconomic status

Anxiety about treatment

Anxiety about treatment with no side effects

Participants were asked if a treatment is working well (limited side effects, no progression of disease), did they worry about what will happen if treatment is stopped.

The majority of participants were never or seldom worried about this (n = 42, 82.35%), there were 6 participants (11.76%) that were sometimes worried about this, and 3 participants (5.88%) were often or very often worried about this (Table 8.33, Figure 8.21).

Table 8.33: Anxiety about treatment with no side effects

Anxious if not experiencing any side effects think it doesn't work	Number (n=51)	Percent
Never	28	54.90
Seldom	14	27.45
Sometimes	6	11.76
Often	3	5.88
Very often	0	0.00

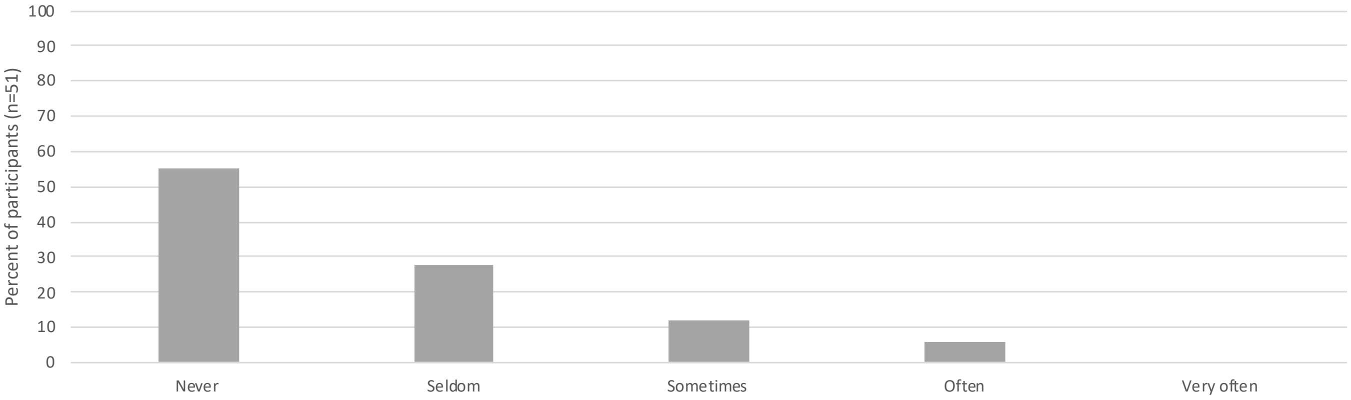


Figure 8.21: Anxiety about treatment with no side effects

Concern about what will happen if successful treatment is stopped

Participants reported how concerned they were about treatments working if they did not experience any side effects.

The majority of participants were never or seldom worried about this (n = 27, 52.94%), there were 15 participants (29.41%) that were sometimes worried about this, and 9 participants (17.65%) were often or very often worried about this (Table 8.34, Figure 8.22).

Table 8.34: Concern about what will happen if successful treatment is stopped

If a treatment and it is working well (limited side effects, no progression of disease), worry what will happen if treatment stopped	Number (n=51)	Percent
Never	10	19.61
Seldom	17	33.33
Sometimes	15	29.41
Often	2	3.92
Very often	7	13.73

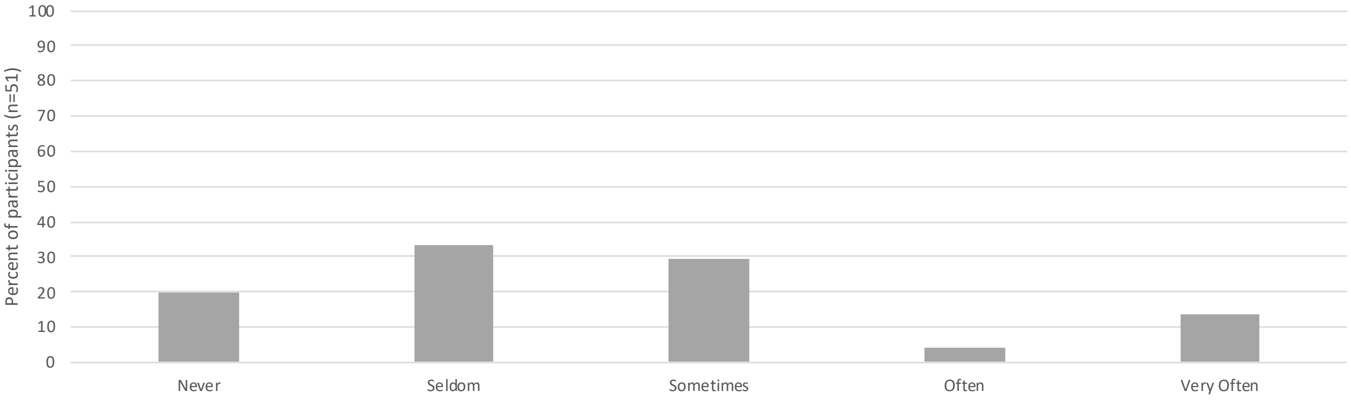


Figure 8.22: Concern about what will happen if successful treatment is stopped

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 that future treatments would have fewer or less intense side effects (n=27, 51.92%), would have less cost burden (n=17, 32.69%), would be more effective (n=14, 26.92%), and more accessible, (n=8, 15.38%). Other participants would like future treatments to be accompanied with more information about treatment and treatment pathways (n=8, 15.38%), and more open and informed discussions (options, side effects etc) (n=8, 16.00%).

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 the expectation that future information will have detailed information about symptom and side effect control) (n=16, 30.77%), and this was followed by more information about services (n=13, 25.00%). Other participants described wanting future information to be more accessible (n=11, 21.15%), to provide details about holistic treatments (n=6, 11.54%), specific to type and stage (n=6, 11.54%), and to age or life stage (n=5, 9.62%). There were six participants (11.54%) that recommended information include personalised records of diagnosis and treatments, and 11 participants (22.00%) that had no recommendations and were satisfied with the information currently available.

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 had no recommendations and they had experienced good communication (n=29, 55.77%). Other themes about expectations of future communication included that communication will be more transparent and forthcoming (n=16, 30.77%), and that communication will be more empathetic (n=11, 21.15%).

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 future care and support support will include more access to appropriate, real-world support services (n=34, 65.38%). Other expectations include long term condition management (n=7, 13.46%), mental health and emotional support (n=6, 11.54%), being able to connect with other patients through peer support (support groups, online forums) (n=6, 11.54%). There were 11 participants (21.15%) with no recommendation as they were satisfied with the care and support received.

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 themes were that participants were grateful for the healthcare staff (n=17, 32.77%), and the entire health system (Includes having access to good healthcare and having options) (n=16, 30.77%). Other participants were grateful for access to private healthcare/private insurance (n=15, 28.85%), timely access to treatment (n=13, 25.00%), low cost treatment and medical care through the government (n=12, 23.08%), and timely access to diagnostics (n=6, 11.54%).

Symptoms and aspects of quality of life

The most important aspects reported were memory loss and cognitive function, fatigue, pain problems with movement and strength, and effects on bones and joints. The least important was fertility.

Values for decision makers

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”.

Values in making decisions

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 “The ability to include my family in making treatment decisions” and “The financial costs to me and my family”.

Time taking medication to improve quality of life

Almost half of participants (n = 25, 49.02%) would use a treatment for more than ten years for a good quality of life even if it didn’t offer a cure.

Most effective form of medicine

Participants most commonly responded that they thought that IV and pill were equally effective (n = 21, 41.18%), followed by not being sure.

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 messages were to improve access to support and care (n=26, 50.00%), and to that treatments need to be more affordable (n=13, 26.00%). Other messages included the need to invest in research (n=9, 17.31%), the need for timely access to treatments (n=9, 17.31%), to understand the financial implications (and provide financial support) (n=8, 15.38%), the need to be compassionate and empathetic (n=6, 11.54%), the need for holistic treatments (n=6, 11.54%), invest in screening and early detection (n=6, 11.54%), better treatment access in rural and remote communities (n=6, 11.54%), and support for side effects and symptoms including long term follow up and support (n=6, 11.54%).

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 that future treatments would have fewer or less intense side effects (n=27, 51.92%), would have less cost burden (n=17, 32.69%), would be more effective (n=14, 26.92%), and more accessible, (n=8, 15.38%). Other participants would like future treatments to be accompanied with more information about treatment and treatment pathways (n=8, 15.38%), and more open and informed discussions (options, side effects etc) (n=8, 16.00%).

Participant describes the expectation that future treatments will have fewer or less intense side effects

I guess, the holy grail would be the hormone blocker that didn't cause menopause in the rest of the body. The true breast specific hormone blocker would be fantastic because it would just reduce the side effects and not leave you with that decision to make between maintaining your future health and given your cancer. Participant 005_2021AUHRP

They probably do need to look at the medication that they want you on for the next five years and how to make that much better for women. I feel sorry for some of the younger women though they got to be pushed into early menopause and all of that stuff at least I don't have to do that. Really been there done that sort of thing. Participant 030_2021AUHRP

I don't think anyone should have to pay in Australia for health care of that nature. Because I think it puts a value on people's lives, that is unrealistic because you know you can't do that assess that someone's life is more valuable than someone else's or someone else's can afford it more than someone else. I think it should all be free or you know covered like with Medicare. As far as treatment something other than chemo would be fantastic that doesn't mush your brain and puts you in a perpetual state of old ladyness. No offense to old ladies but I would have liked to go up there naturally and then um you know if there are side effects you know what work harder on getting treatments for it not to say well you know suck it up because like like like I have realized recently that we are living longer which means they're living longer with the side effects. I you know, you need to have a good quality of life not just enough just to live because you might last five years or whatever. I'm gonna live a long life hopefully. Participant 045_2021AUHRP

Participant describes the expectation that future treatments will have lower treatment costs or expand Medicare cover

There would be some women out there that had the benefit from a treatment that just clearly can't afford it, so that would be helpful. In terms of their special stuff, they know their stuff, and I wouldn't want to change anything with them. Let me explain that a little bit better. If they say that I need Tamera or whatever medication I need, then I need that, otherwise, this cancer is going to come back, so I have a choice. I either take the medication, and I've got a life, or I don't take the medication because I can't stand the side effects, and then, well, I take my chances. Every individual has to make that decision themselves, but I'll put up with the side effects to give myself the best possible chance of surviving. Participant 004_2021AUHRP

Oh, definitely. I think the side effects and the impact on the day-to-day loss, because you often have your treatment away, you don't actually know what impact that's going to have on your day-to-day life until you return to work or you return home and you start care of resuming your role as a wife or a mom. That's probably a big thing. The cost, yes, definitely. Participant 031_2021AUHRP

For new treatments? I think we need to be quicker in getting things funded on the PBS, the new treatments, or new protocols. For instance, an MRI isn't standard scanning for my type of cancer, although in the States, I know they've got a different approach to funding and stuff like that but it isn't. Let's get a bit quicker around the funding that's available. With regards to reconstruction, like really looking at some of the second phase stuff that happens around reconstruction. I think for DX, which is seen as the gold standard in reconstruction, really starting to open that up as being more available to people, particularly on public because there's such a long waiting list for it. Participant 043_2021AUHRP

Participant describes the expectation that future treatment will be more effective

I am disappointed at my tissue loss in my breast because of the hook, or I would I really wish there was a more sophisticated clinical way to get to that tumour without removing as much tissue as I experience. And from my interpretation of things that when you have dense breasts and you got fatty tissue, that the risk of losing is a very real risk. And, you know, it occurs to me twice and I know that when the hook was replaced in situ and they were quite in situ and things like that, and I did nothing at all to kind of move them or that I wish I wish that there was a better technique of seeing them removing the tumour. Participant 019_2021AUHRP

I mean, ultimately, it'd be nice to have a cure for at the very least a treatment that what didn't have the side effects, I guess. It is what it is. And yeah. Participant 020_2021AUHRP

Now I consider that not only the fact that I have fought breast cancer, but now it's all these other things that are going to go along with it. I think that that needs to improve in more understanding and more, I don't know, surely there is something that they can do to that is going to target better or I don't know. You try to get through one thing, but now you have just jeopardized a whole lot of other body systems. Participant 048_2021AUHRP

Participant describes the expectation that future treatments will more accessible (Timely, equitable, location)

I think the accessibility to treatments is really important, that cost shouldn't be a barrier. With any area, I think there's ongoing work towards improving outcomes and reducing side effects. That's always a good thing. That's what we strive for.
Participant 011_2021AUHRP

I just think that because of the distances in Australia they could do a lot more with setting up clinics outside of the main hospitals. Main public hospitals. The public hospital system here needs to do a little bit more I think because if you live a long way away you've got to come in and drive in and you've got to drive distances and in my view, I just think the geographic side of where these hospitals are based and they're too far apart. Participant 032_2021AUHRP

Could I have none of that stuff, no cost, no side effects? That'd be awesome. It's interesting that where it's been administered does impact. I feel like an absolute winger to say that the trial just being in LOCATION went on both in LOCATION, that was-- I wouldn't say problematic, but it was more impactful than the ones at my closer hospital, which is only within 10, 15 minutes, as different to half an hour, 45 minutes drive. Having to wait six weeks for a specialist appointment rather than get in in a timely fashion, when you know things are hanging in the balance, that's really a relief when that stuff comes through. Obviously, it'd be nice if things were reasonably priced, but I think just having availability is the first and most important thing. Sure, I don't want side effects, but damn I want availability of stuff if it's going to make a difference. Participant 051_2021AUHRP

Participant describes the expectation that future treatments will come with more information about treatment and treatment pathways

The cost of the core biopsy, I think, needs to be looked at. I think people need to be given more information at the time when they're told if they've got breast cancer. I know it's probably a shock to a lot of people, but I think I knew what I was getting into anyway. I think I knew it was already cancer. Yes, I just think people need to-- because it's the nurse's job, they just do it automatically. I don't think-- because I had an experience with the radiation, one of the nurses there, and I didn't think she was at all had any empathy. She was quite cold. I think they need to realize that they know it, but they've got to pass that information on. They can't just slide over it if you already know. Do you know what I'm trying to say? Participant 012_2021AUHRP

Probably, I had to find some of the services myself, things like Breast Cancer Care and Solaris. Once you've been diagnosed and going, maybe looking at things to help you maybe for those community process to be introduced to the patient early on maybe through a breast cancer nurse or something like that, or if there's a website or something that would give you all this information of where you can access more services. Participant 049_2021AUHRP

> *I don't know if this fits in here, but I would like there to be more communication. I didn't have an experience of having, I didn't feel I had a team of people who were looking after me in relation to my treatment, so I would like a more coordinated, in the sense of a, team. I think it's important that people are offering treatments that there's some coordination between them. The other thing is that for me, I'm sorry if I'm not, it's just difficult to sometimes to think of what I've got to say. I'd like them to be clearer about dealing with the side effects. It wasn't really clear to me who was going to manage because I didn't think ask, I just assumed that, say, the radiation therapist would manage the side effects related to that. That wasn't my experience at all. In terms of managing side effects, knowing who was going to manage that, who do I go to, to manage that?*
> *Participant 047_2021AUHRP*

Table 9.1: Expectations of future treatment

Expectations of future treatment	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participant describes the expectation that future treatments will have fewer or less intense side effects	27	51.92	9	47.37	13	61.90	**5**	**41.67**	17	58.62	10	43.48	**7**	**36.84**	20	60.61
Participant describes the expectation that future treatments will have lower treatment costs or expand Medicare cover	17	32.69	6	31.58	6	28.57	5	41.67	11	37.93	6	26.09	8	42.11	9	27.27
Participant describes the expectation that future treatment will be more effective	14	26.92	6	31.58	5	23.81	3	25.00	5	17.24	**9**	**39.13**	5	26.32	9	27.27
Participant describes the expectation that future treatments will more accessible (Timely, equitable, location)	8	15.38	3	15.79	2	9.52	3	25.00	3	10.34	5	21.74	3	15.79	5	15.15
Participant describes the expectation that future treatments will come with more information about treatment and treatment pathways	8	15.38	3	15.79	3	14.29	2	16.67	4	13.79	4	17.39	4	21.05	4	12.12

Expectations of future treatment	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participant describes the expectation that future treatments will have fewer or less intense side effects	27	51.92	5	50.00	8	50.00	14	53.85	6	54.55	21	51.22	11	61.11	16	47.06
Participant describes the expectation that future treatments will have lower treatment costs or expand Medicare cover	17	32.69	**5**	**50.00**	6	37.50	6	23.08	3	27.27	14	34.15	5	27.78	12	35.29
Participant describes the expectation that future treatment will be more effective	14	26.92	**4**	**40.00**	4	25.00	6	23.08	2	18.18	12	29.27	6	33.33	8	23.53
Participant describes the expectation that future treatments will more accessible (Timely, equitable, location)	8	15.38	2	20.00	3	18.75	3	11.54	2	18.18	6	14.63	3	16.67	5	14.71
Participant describes the expectation that future treatments will come with more information about treatment and treatment pathways	8	15.38	2	20.00	4	25.00	2	7.69	2	18.18	6	14.63	3	16.67	5	14.71

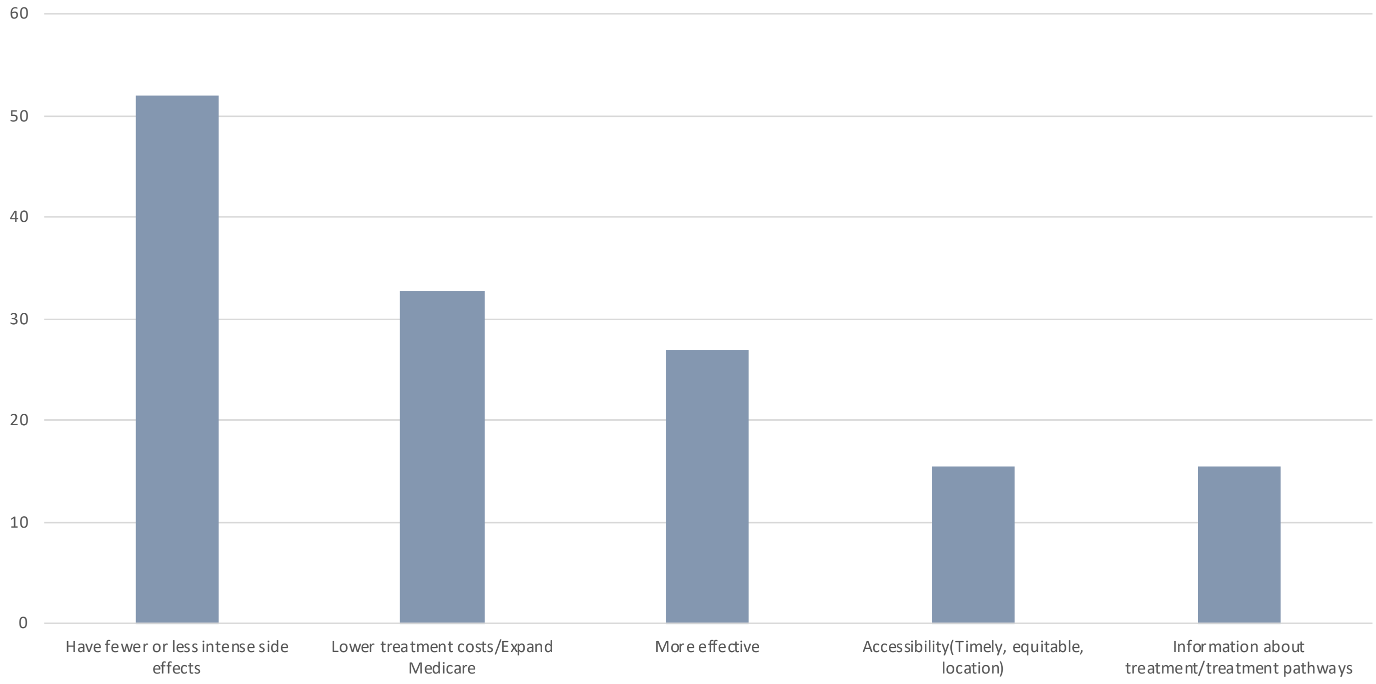


Figure 9.1: Expectations of future treatment

Table 9.2: Expectations of future treatment – subgroup variations

Expectations of future treatment	Reported less frequently	Reported more frequently
Participant describes the expectation that future treatments will have fewer or less intense side effects	Stage III and IV Trade or high school	-
Participant describes the expectation that future treatments will have lower treatment costs or expand Medicare cover	-	Diagnosed in 2016 or before
Participant describes the expectation that future treatment will be more effective	-	Aged 55 to 74 Diagnosed in 2016 or before

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 the expectation that future information will have detailed information about symptom and side effect control) (n=16, 30.77%), and this was followed by more information about services (n=13, 25.00%). Other participants described wanting future information to be more accessible (n=11, 21.15%), to provide details about holistic treatments (n=6, 11.54%), specific to type and stage (n=6, 11.54%), and to age or life stage (n=5, 9.62%). There were six participants (11.54%) that recommended information include personalised records of diagnosis and treatments, and 11 participants (22.00%) that had no recommendations and were satisfied with the information currently available.

Participant describes the expectation that future information will provide more details about symptom and side effect control

Probably more of menopause, because I went straight into that. I wish someone would've warned me what menopause was like. Participant 006_2021AUHRP

I think probably the issue with the nerve. The nerve pain that you actually get, but not everybody gets. That's something I had no idea about. Even with all my 40 years nursing experience, I had never heard anybody say anything about the nerve pain, and maybe that's because mostly it doesn't happen until you actually leave hospital. It wasn't actually until I'd got home and been home for a day or two that it started. That may be because of the local anesthetics and all that that are put in when you have the surgery maybe, and you don't feel it. That's probably something that people should be told about and given ways to deal with it, rather than-- It was a week later before I actually-- When I went and saw the breast care nurse a week later, and she told me what had to be done to relieve it, which was basically massaging it, which was excruciating. Participant 017_2021AUHRP

Maybe a little bit more explanation about the radiation. When they were doing the planning and everything, they said, "Look, if you can, we'd like you to hold your breath for 30 seconds." I couldn't do it and because each time-- I had to do it six or seven times, but they said, "That's fine." At the end of it, it was one of the reasons you've got radiation pneumonitis is probably because you weren't holding your breath. Maybe if that had been spelled out a little bit more, I'd asked some more questions and worked a way around minimizing that risk.
Participant 039_2021AUHRP

Participant describes the expectation that future information will provide more details about where to find available services

Well, I did a project of my own me absence of other things. So in actually, just before I was diagnosed, the second time, I just did my own grassroots project where I got money from local cancer care and groups, too. And I put together a booklet, which are called the Breast Cancer Resource Guide for the LOCATION or something I helped the LOCATION breast groups do they already had this similar thing, and then I updated theirs while I was going through all my cancer as a way of saying thank you for the help. They did. Put together a booklet for, you know, services in the LOCATION. But not just about people going through breast cancer, but also support and services available to their partners, their children, friends, and pulled all sorts of information from places like the BCNA think about lymphedema, like the holistic view of going through treatments that were literally you know, books that you could pop in your handbag and go okay, I've heard about that things about you know, if you go through you know, you're not well enough in how do I get to the hospital for my treatment? Well, you know, what is that might be not community transport, but things like yeah, they Cancer Council have a transport service and things like that would be great to have more, you know, perhaps in each local health district around the state that it really does is something that has to be updated and can get out of date quickly Participant 013_2021AUHRP

I don't think there's anything that wasn't covered that I saw. I mean, everyone's going to be different, but in my situation, everything was pretty well covered. I suppose as technology goes on, maybe it could be done digitally as an app with different, obviously different states would require different contact information. You could make it relevant to the state or even to the hospitals that it's through, which would give you all the numbers that you'd need in an emergency and things like that. I know when I was going through chemo, I had like a card from the hospital and had my name and my hospital number on *it, and it had the numbers on there, and it was a card that if you got a fever, you just showed this card at the hospital, and you were admitted pretty quickly, and what I did was I took a photo of it with my phone and had it as my lock screen. Participant 025_2021AUHRP*

I think that's support. The direct link of this is what you need to fill out. This is how you're going to get that financial support and someone directly there to help you and take out all that time. I spent I don't even know how long on hold, waiting for letters, waiting for support, getting turned around from person to person. Like a ridiculous RSM. I spent a good 20 hours on the phone for them trying to get the support to then fill out all the documents and be told no because we've done something wrong, and then to resubmit it. Then by the time we resubmit it, we had to get the accountant involved, just that sort of thing. That really needs to change. Participant 042_2021AUHRP

Life after cancer, I think. We are in a country that is top for success in treatment for breast cancer. Via that, you have more women who have fabulously that kind of surviving through it. It can feel like you've fallen off a cliff once you finish treatment because you've had such amazing care, this nest of support that's been around you. What happens after? Actually, on Instagram, it's one of the real-- Even on the Facebook groups, it's one of the real questions, and real--People are not sure how to navigate it, what to do after post-treatment. I think there's an amazing amount of support and care around in treatment. I think we need to be looking at post-treatment, because what we want is more women to be surviving this. If that is the case, then the post-treatment breast cancer community is just going to grow and get bigger. What are we going to do to be able to support that, whether that's through allied health or through getting some of these networks in place so that people just don't feel abandoned? Because that's what you hear. A lot of the abandonment feeds into the mental health issues that surround it.
Participant 043_2021AUHRP

Participant describes the expectation that future information will be more accessible/easy to find

Well, I honestly think you can source any amount of information you like through Dr. Google however, is it really accurate? Being able to access breast care psychiatrists or psychologists or whatever they call them and that most of that's free of charge. I think that's important to have and that's accessible so that's fine. I don't know. Participant 010_2021AUHRP

As I said, I've had to find lots of other-- I think, after finding like a face group work, which is basically women, that was probably-- It shows how much topics that aren't covered through what these women are discussing? Participant 021_2021AUHRP

I think the exercise business is really important, and I think things have changed since I was diagnosed. I've noticed other groups have set up. Whether or not that's in the information you get when you first get it. Definitely, things like, I can't get over that no arm exercises were mentioned. The ones I picked out, I would have thought they'd have something diagrammatically, just as I found them, to be-- The help was unbelievable on them, and yet, I can't believe there's not a standard booklet for it. Participant 022_2021AUHRP

Participant has no recommendations/is satisfied with the information currently available

Not really. Obviously, when you're in the radiation, they've got every single pamphlet about every type of cancer on the wall. I think I had the information that I needed. Participant 007_2021AUHRP

PARTICIPANT: No, not really, because I did that workshop and that went from nutrition to exercise to all sorts of different topics. I was going when- was postponed at one time because of COVID but it was twice a week. That covered the exercise program then you'd have the talk afterwards.
INTERVIEWER: Sounded really valuable
PARTICIPANT: Yes. Participant 015_2021AUHRP

Participant describes the expectation that future information will provide more details about holistic treatments

Yeah, yeah. So I think as I sort of alluded to with the medical oncologist, just the availability of potentially complementary alternative, integrative kind of options, just to let people know that they're out there, because they are people that won't go and look, and they just throw all their trust in the doctor and that oncologist, and maybe I think, you know, to be honest, having brother and sister in law, who were, you know, nice interests, and whatever, as well, I think the medical profession is extremely arrogant. And I'm not saying they're not caring, but I think it's the way they taught. They, you know, they kind of, you know, turn their nose up at anything that's, you know, like, the chiropractor or, you know, they, it's not traditional medicine, they seem to sort of discount. And I think that's a, that's a really dangerous concept. Participant 034_2021AUHRP

I don't know. I just think of food, nutrition. Then again, they did provide me with making an appointment with a nutritionist, so that was me not taking advantage of it. Participant 040_2021AUHRP

I think for me personally, I'd like to see the medical profession, maybe be a little bit more open to alternative options and not so cut and dried about no, don't go there. Participant 047_2021AUHRP

Participant describes the expectation that future information will be specific to type/stage

Yes, I think the one thing that would be useful would be to start to really see breast cancer as multiple diseases, which of course it is, and to try and really separate out what we're talking about because sometimes that's the hard bit to split-- even in the big clinical trials, it can be really hard to work out even what were the age of the participants?
Participant 005_2021AUHRP

One of my son's friend's mothers had a relapse after 10 years or more, and very aggressive disease. She's been through the wringer. We're talking to them. She's doing well now, which is good. Talking to them, and also talking to them about [unintelligible 00:50:39]. One of the things I said to them was, "You can tell people. If you say to people mum's got breast cancer, some people may react like I'm dying. I'm not dying." and they trust us and believe us. Yes. The information and stuff for them, I thought, could have been a bit better. Participant 011_2021AUHRP

Participant describes the expectation that future information will include personalised records of diagnosis and treatments

Probably not because luckily my husband was able to be there as the support person at the time and just sort of, i don't know, you just don't hear everything anyway. So the bits that I didn't hear he seemed to hear. But don't think I could have taken in much more information at the time but think then, the support person can't go in any where with you for the COVID so that's hard this additional thing that you don't have anyone to confirm it with. Most of my problems are COVID related. Participant 014_2021AUHRP

Participant describes the expectation that future information will be more targeted to a specific age group

Okay. This is actually one's that I do have an interest in, in not so much perhaps what the information is, but the way that we as consumers comprehend especially those initial appointments. The hospital where I now work does have a policy around recording appointments. I actually think that there should be a lot more of it, it will both protect the clinician and provide the consumer, patient, whatever you want to call everyone with-- They can go home and listen back and go, oh, I didn't actually pick up on that during the appointment. It's actually something that lots of people on the BCNA forum talk about that suppose I heard about it. I actually think that to protect themselves hospitals probably need, to look at recording all outpatient appointments and providing the client, the patient with a copy of it. I think that in terms of that way, they've got proof of what information was provided, not just for what's written, but what can be actually heard. As I said, the patient can listen back and go on. "I missed that, I've got to ask about that the next time I'm there, so the way of that side of communications, in terms of the way things are delivered, I'm very happy with verbal communication, being given links to websites, but paper-based still needs to be provided for people that don't have access to the internet, your elderly population. Participant 023_2021AUHRP

Yes, I think-- I think-- There seems to be a bit of a connection with menopausal women and getting older, and as I said in my group I've got younger women but from around about 45. A lot of the women I know are 45 or older. Whether there's a connection with menopause but I would like to see women here being encouraged to see an endocrinologist or whatever about hormones. From where that plays a part in it. Participant 032_2021AUHRP

I definitely think we need more information for young women with breast cancer. Like. And, you know, and making it more accessible. And I guess that, you know, like, I haven't, you know, asked my oncologist, that question, you know, about, you know, whereas she might have more information about that now, but because I'm so far down the track, the conversation we had, but, you know, being able to, you know, ask about how is how are all the medications going to affect me what happens when I come off them, you know, that access to other women who had similar age? You know, I know that there. There are definitely Young Women support groups out there now. But there they weren't when I was first diagnosed, there was like one that was up in LOCATION. And that was it. And I was like, Well, I can't get to that, because it's really far away. And so now, like, you know, you know, needing support doesn't necessarily go away. But now I'm like, 12 years down the track, and at a completely different stage, to those people that are accessing the support groups are sort of, like I still can't accept them, because it's not the same. You know, and so that's, I think, especially, that's why I looked at, looked at the online support through Facebook page and stuff and got annoyed with people because writing dumb stuff, so I was tapping out of that. Participant 033_2021AUHRP

Table 9.3: Expectations of future information

Expectations of future information	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participant describes the expectation that future information will provide more details about symptom and side effect control	16	30.77	**8**	**42.11**	6	28.57	**2**	**16.67**	**5**	**17.24**	**11**	**47.83**	**8**	**42.11**	8	24.24
Participant describes the expectation that future information will provide more details about where to find available services	13	25.00	5	26.32	6	28.57	2	16.67	7	24.14	6	26.09	4	21.05	9	27.27
Participant describes the expectation that future information will be more accessible/easy to find	11	21.15	3	15.79	5	23.81	3	25.00	4	13.79	7	30.43	**6**	**31.58**	5	15.15
Participant has no recommendations/is satisfied with the information currently available	7	13.46	2	10.53	4	19.05	1	8.33	4	13.79	3	13.04	3	15.79	4	12.12
Participant describes the expectation that future information will provide more details about holistic treatments	6	11.54	4	21.05	1	4.76	1	8.33	3	10.34	3	13.04	2	10.53	4	12.12
Participant describes the expectation that future information will be specific to type/stage	6	11.54	2	10.53	2	9.52	2	16.67	4	13.79	2	8.70	1	5.26	5	15.15
Participant describes the expectation that future information will include personalised records of diagnosis and treatments	6	11.54	1	5.26	3	14.29	2	16.67	5	17.24	1	4.35	2	10.53	4	12.12
Participant describes the expectation that future information will be more targeted to a specific age group	5	9.62	**4**	**21.05**	1	4.76	0	0.00	2	6.90	3	13.04	3	15.79	2	6.06

Expectations of future information	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participant describes the expectation that future information will provide more details about symptom and side effect control	16	30.77	3	30.00	5	31.25	8	30.77	**5**	**45.45**	11	26.83	**9**	**50.00**	**7**	**20.59**
Participant describes the expectation that future information will provide more details about where to find available services	13	25.00	2	20.00	5	31.25	6	23.08	3	27.27	10	24.39	4	22.22	9	26.47
Participant describes the expectation that future information will be more accessible/easy to find	11	21.15	3	30.00	2	12.50	6	23.08	**5**	**45.45**	6	14.63	**2**	**11.11**	9	26.47
Participant has no recommendations/is satisfied with the information currently available	7	13.46	1	10.00	2	12.50	4	15.38	**0**	**0.00**	7	17.07	1	5.56	6	17.65
Participant describes the expectation that future information will provide more details about holistic treatments	6	11.54	**3**	**30.00**	1	6.25	2	7.69	**4**	**36.36**	2	4.88	**4**	**22.22**	2	5.88
Participant describes the expectation that future information will be specific to type/stage	6	11.54	1	10.00	3	18.75	2	7.69	1	9.09	5	12.20	2	11.11	4	11.76
Participant describes the expectation that future information will include personalised records of diagnosis and treatments	6	11.54	**0**	**0.00**	1	6.25	5	19.23	1	9.09	5	12.20	1	5.56	5	14.71
Participant describes the expectation that future information will be more targeted to a specific age group	5	9.62	1	10.00	1	6.25	3	11.54	**3**	**27.27**	2	4.88	2	11.11	3	8.82

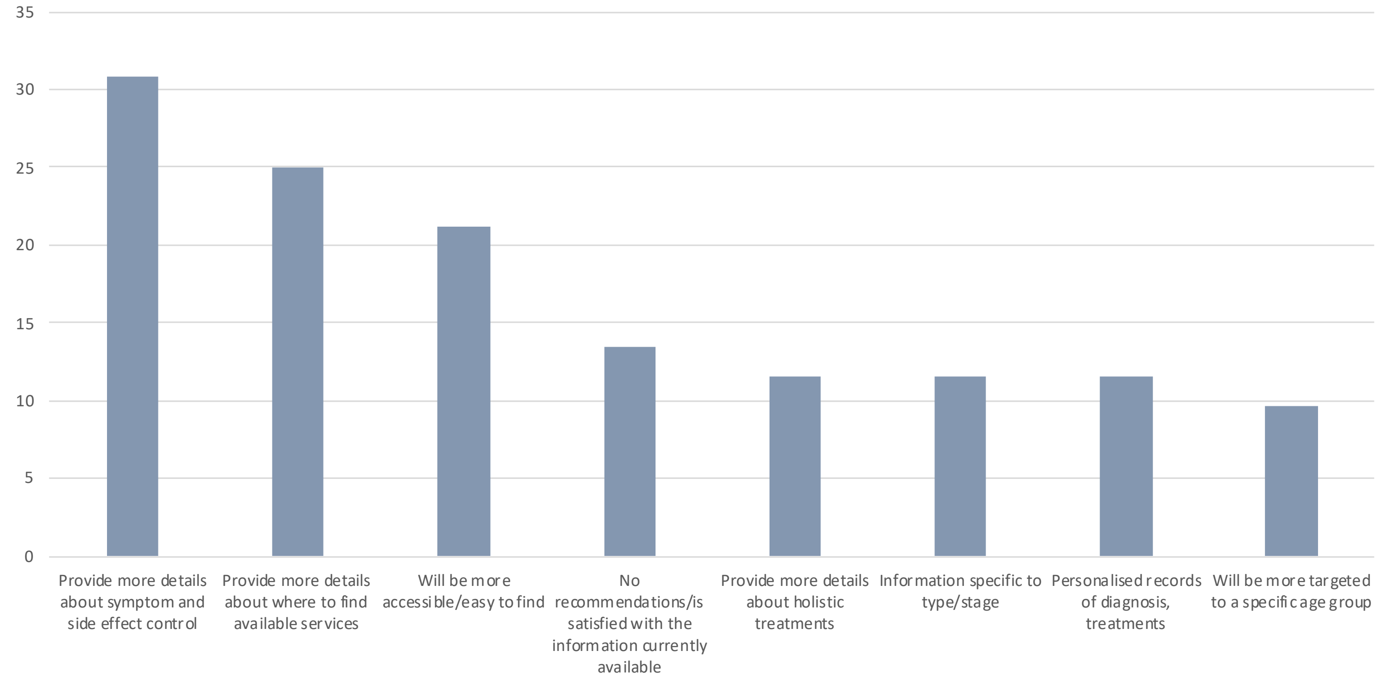


Figure 9.2: Expectations of future information

Table 9.4: Expectations of future information – subgroup variations

Expectations of future information	Reported less frequently	Reported more frequently
Participant describes the expectation that future information will provide more details about symptom and side effect control	Stage III and IV Aged 25 to 54 Higher status	Stage 0 and I Aged 55 to 74 Trade or high school Regional or remote Mid to low status
Participant describes the expectation that future information will be more accessible/easy to find	Mid to low status	Trade or high school Regional or remote
Participant has no recommendations/is satisfied with the information currently available	Regional or remote	-
Participant describes the expectation that future information will provide more details about holistic treatments		Diagnosed in 2016 or before Regional or remote Mid to low status
Participant describes the expectation that future information will include personalised records of diagnosis and treatments	Diagnosed in 2016 or before	-
Participant describes the expectation that future information will be more targeted to a specific age group	-	Stage 0 and I 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 had no recommendations and they had experienced good communication (n=29, 55.77%). Other themes about expectations of future communication included that communication will be more transparent and forthcoming (n=16, 30.77%), and that communication will be more empathetic (n=11, 21.15%).

Participant has no recommendations/experienced good communication

No, I think mine has been very good. They've been very clear in what they say, I can't fault any of them, really. I've just been very, very lucky with the surgeon and the oncologist that I've got and I have a good rapport with my GP. Participant 004_2021AUHRP

No, I don't think so. I had a very good experience with all of my health professionals. I think they all worked really hard to meet me where I was at, rather than where the average kind of thing. If you asked for more information they gave it. It's very hard to always immediately picture that's exactly the right amount of information because nobody wants to know as well which is hard. Some people want to know almost nothing. Just tell me what to do, and other people want to know everything, but I think they all do very well to try and match me. Participant 005_2021AUHRP

No. I think they're pretty understanding. I felt well cared for and compassionate to what we're going through, I think. I think in general the people I came in contact with were like that. Even from having the PET scans and the MRIs and things like that before I had the surgery, everyone was very compassionate and understanding. Participant 009_2021AUHRP

Participant describes the expectation that future communication will be more transparent and information more forthcoming

Yes, as I said, once again, I think they need to be more open and more honest about the whole process. Look, I understand that everything's a learning curve even for these guys, but they've been doing it long enough now to know what the realities are and I think that transparency and honesty has to be the key. It just has to be because without it, it makes it difficult for us to process what we're going through because a lot of what we go through is not being validated. It really isn't being validated. It's being brushed aside as, "You're in a small minority," when the reality is no, I'm not. Participant 018_2021AUHRP

I can't fault the women really. Look, the other two were so appalling, I can't find words to describe them. It's this business of answering a question, and not feeling threatened by the questions they've asked and accepting the fact there wouldn't be a person alive today who wouldn't look things up on the internet, and to accept that and not see it as a threat. They need the training way back in medical school and be mentored when they're doing their residency and so on. Participant 022_2021AUHRP

I think they need to learn that people going through cancer generally, it's their first time so they don't really know what's going on. Don't assume people know what's going on and don't assume that we're all alike because everybody's got their own stuff going on. As I said, I come from a healthcare background so a lot of people that don't, would be terrified. Really, even at this stage, I don't know what my prognosis is. I hope that I'm cancer-free but I don't know. Who knows? If I get to five years, well, that's terrific but we don't really know. It always sits in the back of your head. Participant 038_2021AUHRP

Participant describes the expectation that future communication will be more empathetic

Yes! Empathy goes a wonderfully long way. I mean, can you imagine being told you have cancer and then having a piece of paper thrusted you saying go and do your own research? That's not good. Being told that on a Check-Up after a mastectomy. Well, it's not like it was cancer, because I had read somewhere that over 60% of these things are benign and you have 30% that are borderline and then you have 10% like me that are malignant. Participant 003_2021AUHRP

I think the only really negative experience was when the receptionist called me. It was literally a one-minute conversation of your tumours are not benign, you need to see a surgeon. In my mind, benign means non-cancer but not non-cancerous, and this call came at six o'clock on a Thursday night. Again, it was a receptionist. I could not marry that up in my mind. Now, I had an appointment with my GP the next morning at 11:00. When I got her on the phone, it seemed very disconnected because she was like, "Hello, how can I help you today?" I'm like, "Well, I got a call last night and I wanted to get my results." She had to break it to me over the phone, "You have cancer." That was the only negative experience I really had. I could not believe that somebody would call me and then in a one-minute conversation tell me I have cancer. Participant 007_2021AUHRP

She was absolutely couldn't believe it. If that's what's happening with somebody who has a lot of contact with breast cancer patients, we've got a lot of work to do. Similarly with the fellow who said to me, "As long as your MRI doesn't come up with like a Christmas tree, then you'll go and have them done any other." That's like no, that is not acceptable.
Participant 043_2021AUHRP

Table 9.5: Expectations of future healthcare professional communication

Expectations of future healthcare professional communication	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participant has no recommendations/experienced good communication	29	55.77	11	57.89	12	57.14	6	50.00	18	62.07	11	47.83	10	52.63	19	57.58
Participant describes the expectation that future communication will be more transparent and information more forthcoming	16	30.77	**10**	**52.63**	**4**	**19.05**	**2**	**16.67**	9	31.03	7	30.43	7	36.84	9	27.27
Participant describes the expectation that future communication will be more empathetic	11	21.15	3	15.79	5	23.81	3	25.00	5	17.24	6	26.09	**1**	**5.26**	10	30.30

Expectations of future healthcare professional communication	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participant has no recommendations/experienced good communication	29	55.77	5	50.00	8	50.00	16	61.54	6	54.55	23	56.10	**8**	**44.44**	21	61.76
Participant describes the expectation that future communication will be more transparent and information more forthcoming	16	30.77	4	40.00	**3**	**18.75**	9	34.62	**5**	**45.45**	11	26.83	**8**	**44.44**	8	23.53
Participant describes the expectation that future communication will be more empathetic	11	21.15	**1**	**10.00**	4	25.00	6	23.08	**1**	**9.09**	10	24.39	3	16.67	8	23.53

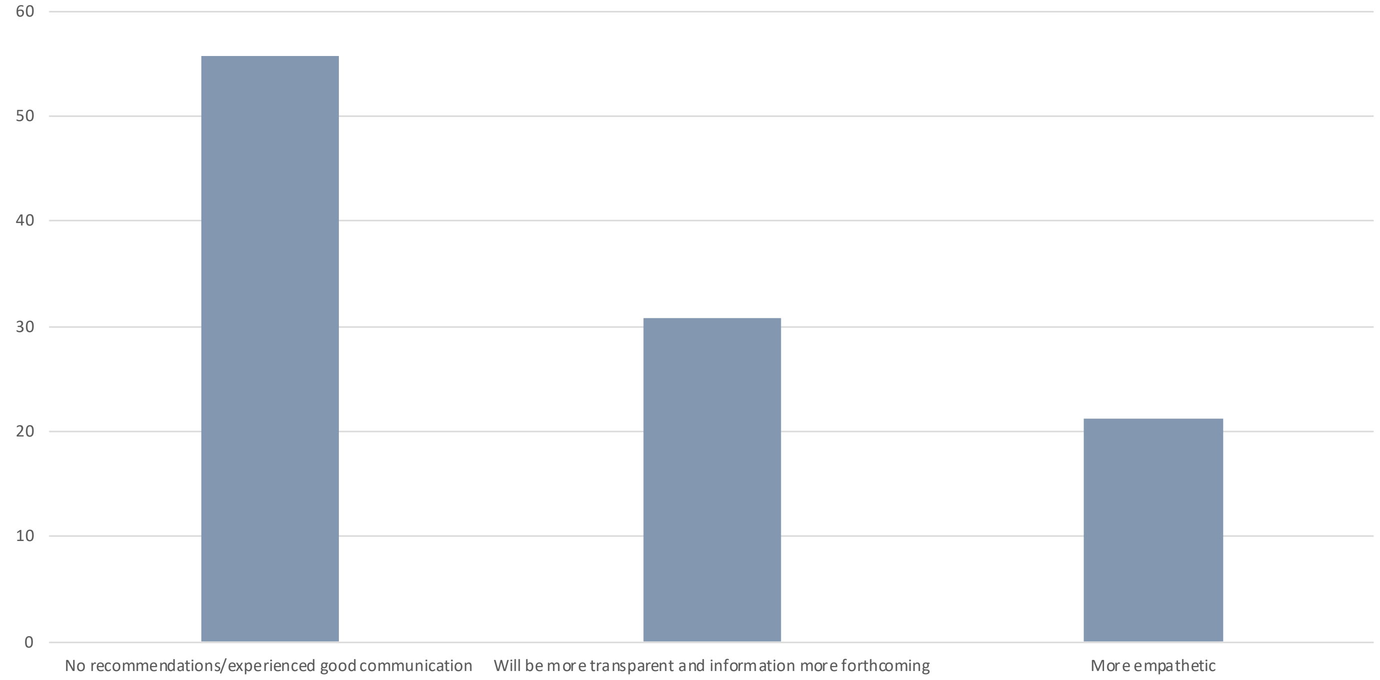


Figure 9.3: Expectations of future healthcare professional communication

Table 9.6: Expectations of future healthcare professional communication – subgroup variations

Expectations of future healthcare professional communication	Reported less frequently	Reported more frequently
Participant has no recommendations/experienced good communication	Mid to low status	-
Participant describes the expectation that future communication will be more transparent and information more forthcoming	Stage II Stage III and IV Diagnosed in 2017 to 2019	Stage 0 and I Regional or remote Mid to low status
Participant describes the expectation that future communication will be more empathetic	Trade or high school Diagnosed in 2016 or before Regional or remote	-

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 future care and support support will include more access to appropriate, real-world support services (n=34, 65.38%). Other expectations include long term condition management (n=7, 13.46%), mental health and emotional support (n=6, 11.54%), being able to connect with other patients through peer support (support groups, online forums) (n=6, 11.54%). There were 11 participants (21.15%) with no recommendation as they were satisfied with the care and support received.

Participant describes the expectation that future care and support will include more access to support services

No, I don't think so. I think I got everything that was relevant and that was helpful. I think, then, if you start getting a heap of stuff thrown at you, you don't know where you're going. A lot of people need home help and all that because, mentally, they can't cope with

the diagnosis. I suppose if you're strong, then people won't offer you that because they know that you don't need that. Participant 026_2021AUHRP

I think it'd be really helpful to somebody just to talk to you more about diet and exercise. I think especially the exercise stuff just to give you some information, I have certain exercises the can help you with the side effects, I think, or what you can actually do. Or how to modify what exercise you're doing. I think stuff like that could be really important. Participant 052_2021AUHRP

I will take myself out of the equation here because again, I think I was very lucky. I would say that individuals undergoing chemotherapy, I think we really should be focusing on helping them. I think if I had to undergo chemotherapy and I live here alone, I have friends nearby but you don't want to be a burden to your friends. I think I would have struggled had I had to have chemotherapy living here on my own and that even includes getting to the hospital. I cannot tolerate nausea at all. I know there are programs about driving people to take care of and I think you would probably understand. You don't want to be a burden on your friends. I would love to see more programs to really support people who are doing it much worse. Participant 007_2021AUHRP

Participant has no recommendations/is satisfied with care received

I can't think of anything off the top of my head, to be honest, because there may be help and support out there but I didn't reach out for it, so I don't know what's out there and I don't know what's missing as far as that's concerned. Participant 035_2021AUHRP

Yes, I think the model that is used by the martyr the early breast cancer program. Whenever I've mentioned it to anybody, whether they live in Australia or they live in the UK, they have been blown away by what is singularly one of the best things I've ever did. It quells the panic that I had. It quells the overwhelm of information because I have this one point. I've done it via Zoom as a mentor with them. It works via Zoom. I think that should be looked at as a model and should be replicated as a model. Then the other thing is there needs to be something that may be similar or such is really looking at this post-treatment. It's not just relying on Facebook groups because there's a lot of misinformation that comes from people that mean to what is coming from a good place, but it's not helping. Participant 043_2021AUHRP

Nothing I can think of. I've had access to everything I need. Participant 044_2021AUHRP

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)

I'm not big on the charities in as much as I. I think that when this funding I want to see if it's funded like for the breast cancers, I think that all women, regardless of public or private, should have access to regular communication with the breast cancer and that they should be they should be well funded. I think that yeah. Participant 019_2021AUHRP

Just probably more calls just to check up on people. Some kind of liaison service so people just know that someone's thinking of them just, "Oh, how did your treatment go today? How are you feeling today?" It doesn't have to be a lot, but just someone touching base every now and then. Participant 038_2021AUHRP

Yes. As I said, the financial assistance is very tough on people. I wouldn't even know where to start with all of that, but everything was always there apart from-- Everything was always at your fingertips, I think, in the sense of, if you needed help with something, you could still speak to someone. The oncologists are really, really good where if you were struggling with something, they would pass you on to someone. Like I said, I was quite happy.
Participant 008_2021AUHRP

Participant describes the expectation that future care and support will include more long-term condition management (care planning)

I think in lots of ways, breast cancer does better than a lot of other cancers but probably if there's anything resulting around metastatic breast cancer and an increase in awareness and knowledge and communication to the public at large that for a lot of people with breast cancer they're getting to five years isn't the end of it all that it doesn't actually ever end. Participant 023_2021AUHRP

But it seems to me post treatment support because just because you're not you're not checking into the hospital definitely not requires you to contact the social support websites. Participant 002_2021AUHRP

Yeah, look definitely in the area of lymphedema across the whole states, what the country like it's so under resourced, so not known about, you know, there's no support groups, generally, the LOCATON, one fold that it started and it folded because it couldn't continue, because it's all based on volunteer and goodwill, is that, in terms of what's available for through the public system is almost non existent. But me, the intensive treatments only available through the private healthcare system unless you pay for it yourself. So that's the very under known under resourced part of the breast cancer aspect, even though people can have it as primary lymphedema as well. So even though it's there outside of someone from cancer, it's still there's not enough resources in that avenue. And it's chronic, you know, it's ongoing, so. And in terms of that, as well, there's virtually no garment making in Australia as well. So the stress of waiting for garments to come from overseas can be weeks, you know, and then if they get it wrong, you got to send it back. And you could be waiting months. And so trying to get that kind of manufacturing in Australia is really difficult. Participant 013_2021AUHRP

Participant describes the expectation that future care and support will include mental health/emotional support

*Probably more access to the mental health side of things. Yeah.
Participant 033_2021AUHRP*

*My husband was saying, for him, it was more like there was no one that he could really talk to. You're focused on me, but the breast cancer surgeon, he always asked him, "How are you coping with it all?" He did check up on him, but I think maybe it would've been nice in the chemo, if, I don't know, they did have a partner's group or something, where they could, I don't know, join in for a cup of coffee and a chat.
Participant 040_2021AUHRP*

*I think that the program that I had at my hospital that helps with distance and management, I think that is a fantastic thing they've done. I just don't think it's funded enough and there's not enough hours there. I think that, potentially, would be something that's perfect that even the best [unintelligible] can get involved on. You have a hotline that you can ring up and use, whether it be your symptoms and stuff, because you can have physical symptoms, but then you can also have things that you're struggling with. It could be mentally troubling you.
Participant 048_2021AUHRP*

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)

Perhaps maybe- and they probably use something out there already, but I get a lot of comfort, I guess, from reading other people's stories and listening to other people's stories. Maybe they've been through the next phase that you're just going through or maybe to have that more accessible. It doesn't have to be maybe in person, but just shared stories. As I said, they probably use more things out there that I haven't tapped into. I think it makes you put your mind at rest that when you have children, you go to another group or whatever and other mothers are feeling like you're feeling, and you walk away and think, "Just maybe it feels like that. She's just like that too. That's how I felt." Something like that. Unless you go searching for it, the information is not sent to you. Participant 009_2021AUHRP

The only things that I would have liked, and it's only COVID that's probably stopped it, was to be able to go physically to a support group. Just to actually be face to face with people going through what you're going through. It's not the same talking to strangers online. As I said, most of the breast care support groups are American orientated. The BCNA one in Australia, every time I go into it, nothing much is happening. There's no new conversations. Just to be able to go and physically meet and have a good old heart-to-heart with someone that's going through what you're going through. Participant 010_2021AUHRP

Just someone who's maybe been through it to talk to you. Participant 016_2021AUHRP

Table 9.7: Expectations of future care and support

Expectations of future care and support	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participant describes the expectation that future care and support will include more access to support services	34	65.38	13	68.42	16	76.19	5	41.67	17	58.62	17	73.91	11	57.89	23	69.70
Participant has no recommendations/is satisfied with care received	11	21.15	6	31.58	2	9.52	3	25.00	7	24.14	4	17.39	5	26.32	6	18.18
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)	9	17.31	2	10.53	4	19.05	3	25.00	5	17.24	4	17.39	7	36.84	2	6.06
Participant describes the expectation that future care and support will include more long-term condition management (care planning)	7	13.46	2	10.53	2	9.52	3	25.00	4	13.79	3	13.04	0	0.00	7	21.21
Participant describes the expectation that future care and support will include mental health/emotional support	6	11.54	3	15.79	2	9.52	1	8.33	2	6.90	4	17.39	4	21.05	2	6.06
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)	6	11.54	1	5.26	2	9.52	3	25.00	5	17.24	1	4.35	1	5.26	5	15.15

Expectations of future care and support	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participant describes the expectation that future care and support will include more access to support services	34	65.38	8	80.00	11	68.75	15	57.69	7	63.64	27	65.85	13	72.22	21	61.76
Participant has no recommendations/is satisfied with care received	11	21.15	1	10.00	2	12.50	8	30.77	2	18.18	9	21.95	4	22.22	7	20.59
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)	9	17.31	2	20.00	4	25.00	3	11.54	3	27.27	6	14.63	4	22.22	5	14.71
Participant describes the expectation that future care and support will include more long-term condition management (care planning)	7	13.46	1	10.00	1	6.25	5	19.23	1	9.09	6	14.63	2	11.11	5	14.71
Participant describes the expectation that future care and support will include mental health/emotional support	6	11.54	1	10.00	3	18.75	2	7.69	2	18.18	4	9.76	4	22.22	2	5.88
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)	6	11.54	0	0.00	5	31.25	1	3.85	0	0.00	6	14.63	2	11.11	4	11.76

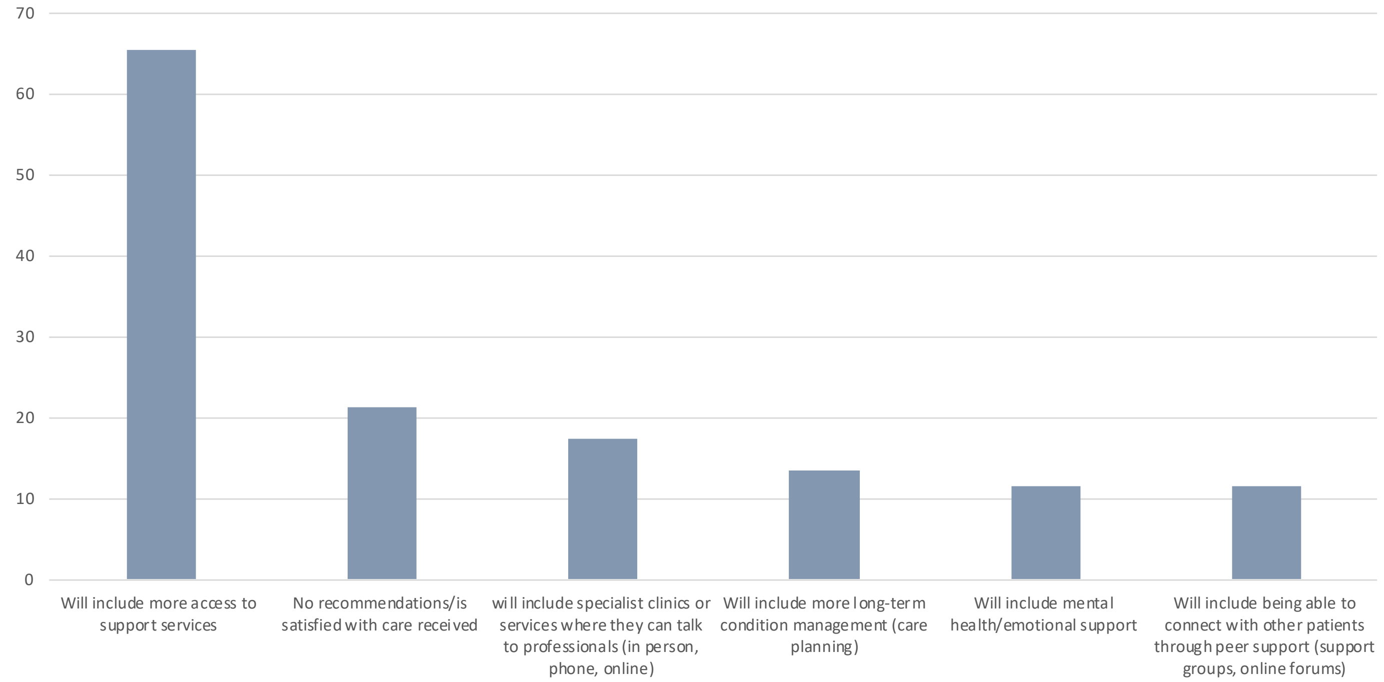


Figure 9.4: Expectations of future care and support

Table 9.8: Expectations of future care and support – subgroup variations

Expectations of future care and support	Reported less frequently	Reported more frequently
Participant describes the expectation that future care and support will include more access to support services	Stage III and IV	Stage II Diagnosed in 2016 or before
Participant has no recommendations/is satisfied with care received	Stage II Diagnosed in 2016 or before	Stage 0 and I
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)	University	Trade or high school
Participant describes the expectation that future care and support will include more long-term condition management (care planning)	Trade or high school	Stage III and IV
Participant describes the expectation that future care and support will include mental health/emotional support	-	Mid to low status
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)	Diagnosed in 2016 or before Regional or remote	Stage III and IV Diagnosed in 2017 to 2019

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 themes were that participants were grateful for the healthcare staff (n=17, 32.77%), and the entire health system (Includes having access to good healthcare and having options) (n=16, 30.77%). Other participants were grateful for access to private healthcare/private insurance (n=15, 28.85%), timely access to treatment (n=13, 25.00%), low cost treatment and medical care through the government (n=12, 23.08%), and timely access to diagnostics (n=6, 11.54%).

Participant is grateful for healthcare staff

The people, particularly the experts, with the specialists. The good treatment that I've had, that I've had access to. The patience that they had with me in terms of-- I think it's not easy being a doctor because a doctor-patient for other doctors because you know stuff. My GP is brilliant in that regard at giving me information at the right level. Treating me like a patient who has some knowledge. I've just been really grateful for the people whose care I've been under. Participant 011_2021AUHRP

Um you know, I saw some of the best specialists, you know, being particularly being in regional Australia, I saw some of the best specialists, you know, outside of a major city. And I was quite lucky in that regard. But, you know, in the same token, living in Australia, they have access to the internet and things like that to be able to go and do my own research. That sort of side things as well. Participant 020_2021AUHRP

But again, I will come back to radiotherapy and the radiation therapist and how caring and holistic in their care they were. They did what they needed to do to get it all right, to make sure that everything was right for you but they also did everything they could to make me as comfortable as they could. Participant 023_2021AUHRP

Participant is grateful for the entire health system

The fact that we're in Australia, that we have a world class system. Despite what people say, we still have a world class system. And we do have a lot of campaigns. And we do have a correct screening program if people take advantage of it. And that Breast screen New South Wales, everything that they do, every appointment, every everything worked like clockwork, I didn't have to chase anybody for anything. And, and so I'm grateful that I'm grateful that I'm educated. And that I can actually do my own research. And then I can also look at alternate therapies. Participant 001_2021AUHRP

All of it really because I went through the system, and the system is amazing for what it covers for no cost. I was very lucky I didn't have to wait for services. I didn't have to pay out of pocket, except for the radiation, but even that could be easily done. I think we are just so lucky to have the health system that we do have. It's a pity that we can't have access to more, so that we can get more patients through because I know the whole system does struggle, but I was lucky. Participant 025_2021AUHRP

All of it. Absolutely all of it. From my GP, getting an appointment for me the next day at the hospital with the surgeon that I need to see to have all this done. All of it, I'm grateful for all of it. I had no idea that our public system was as good as this, but it is a really good system. When you really need it, it does the job. Participant 044_2021AUHRP

Participant is grateful for access to private healthcare/private insurance

I'm grateful for all the treatment really because it was done so fast, but I did have private health insurance. I went through the services privately and I was just delayed for the surgery, for the breast surgery; the reconstruction. If we didn't have private health insurance, we would have to wait a long time to get that. That's the thing that I always thought, that we discussed with my husband and he was like, "Yes, we'll go so that we are able to just pay the things that-- the out-of-pocket expenses." There's other families that don't have that. They have to travel. I saw this little kid, he was only just probably seven or less going through radiation. The dad was on the phone going, "Oh, can I just have it? I've paid this and all these things?" You could see that there's a financial stress in that situation there, that they already have enough going on. They shouldn't be stressing about finances. Participant 040_2021AUHRP

I had private health care. All my treatment has been through private. This is all in relation to that. Thank God it wasn't an American private health care model. The two-tier that we have, I was really fortunate and it worked for me, I guess that. Thank goodness. It was the two-tier private model. We have not the ridiculous American model. Participant 043_2021AUHRP

I think that the fact that I've got private health cover and I didn't have to wait long. The waiting is the worst part, just hanging around and waiting for this test and that test and the other test. I think that could actually probably be worked on. When you actually go to LOCATION REGIONAL, and they actually know that you've got cancer, but they're not allowed to tell you because they do know. They're not there to tell you, "You've got to hang around and wait for another week to be told by the breast surgeon." Did I not get that the waiting is the worst part? The not knowing and having weeks of no sleep because you're imagining all sorts of things. We need to have our minds put at rest by knowing this ASAP. Participant 010_2021AUHRP

Participant is grateful for timely access to treatment

Well, just the timing with everything. I didn't really have to wait to have that operation. I was straight in a week later to have that and then everything lined up after that. Participant 015_2021AUHRP

I will be forever grateful that even though it was during COVID, that because I was classed as a Category 1 urgent, that this happened. I was a public patient, I wasn't a private patient, and it was all done and over in some weeks, as if I was the one and only patient. Participant 026_2021AUHRP

I think having access to all of it has been a blessing and the speed of which I've been able to access has been terrific. I can't fault it. Participant 051_2021AUHRP

Participant is grateful for low cost/free medical care through the government

I'm very happy we have a wonderful surgeon. He works out of the hospital and bulk bills for everything, so you're not out-of-pocket at a private surgery. We're incredibly lucky that way. Very, very lucky that the public system does the radiation, so you're not out-of-pocket that way either. I think we're incredibly lucky in Australia not to have to fork out lots of money. Participant 017_2021AUHRP

PARTICIPANT: Well, the fact that I haven't had to pay for anything has been incredible. I've always said that. I always think that our health system if you're sick, it's there, it's available. There's no reason for people not to go and have mammograms. Well, recently there was because they weren't doing them but generally, you know what I mean?
INTERVIEWER: Yes.
PARTICIPANT: There's always ways if don't have any money there's still ways around it to get stuff done. Participant 038_2021AUHRP

Pretty much grateful for everything because we are lucky where we are. Despite having to wait for things, once you are diagnosed, it is pretty much taken, everything sort of flows, and it is quick to access. The cost is, like I said, I haven't had to pay for anything of my medical treatment at all. Participant 049_2021AUHRP

Participant is grateful for timely access to diagnostics

I think I'm really very grateful to be second ultrasound person that you know, she was told to look at 10 o'clock, and she decided to look at the whole breast. That's where it got picked up. Very grateful for that technician saying I don't do a half job. That was good. Yeah. I guess I'm grateful, it all happened very quickly. Participant 014_2021AUHRP

Yes. I was grateful that I got it diagnosed early. The van came to LOCATION because otherwise, I probably would have put it off. I had to wait. When I was diagnosed, I was contacted by one of the breast care nurses before I could see the specialist. I got in to the specialist within a few days and in the surgery like a week later. Participant 006_2021AUHRP

I think I'm really very grateful to be second ultrasound person that you know, she was told to look at 10 o'clock, and she decided to look at the whole breast. That's where it got picked up. Very grateful for that technician saying I don't do a half job. That was good. Yeah. I guess I'm grateful, it all happened very quickly. Participant 014_2021AUHRP

Table 9.9: What participants are grateful for in the health system

What participants are grateful for in the health system	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participant is grateful for healthcare staff	17	32.69	6	31.58	8	38.10	3	25.00	10	34.48	7	30.43	5	26.32	12	36.36
Participant is grateful for the entire health system	16	30.77	7	36.84	6	28.57	3	25.00	8	27.59	8	34.78	3	15.79	13	39.39
Participant is grateful for access to private healthcare/private insurance	15	28.85	6	31.58	3	14.29	6	50.00	6	20.69	9	39.13	6	31.58	9	27.27
Participant is grateful for timely access to treatment	13	25.00	6	31.58	5	23.81	2	16.67	8	27.59	5	21.74	4	21.05	9	27.27
Participant is grateful for low cost/free medical care through the government	12	23.08	4	21.05	5	23.81	3	25.00	6	20.69	6	26.09	7	36.84	5	15.15
Participant is grateful for timely access to diagnostics	6	11.54	2	10.53	3	14.29	1	8.33	5	17.24	1	4.35	3	15.79	3	9.09

What participants are grateful for in the health system	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participant is grateful for healthcare staff	17	32.69	3	30.00	3	18.75	11	42.31	3	27.27	14	34.15	7	38.89	10	29.41
Participant is grateful for the entire health system	16	30.77	1	10.00	4	25.00	11	42.31	4	36.36	12	29.27	5	27.78	11	32.35
Participant is grateful for access to private healthcare/private insurance	15	28.85	4	40.00	5	31.25	6	23.08	4	36.36	11	26.83	6	33.33	9	26.47
Participant is grateful for timely access to treatment	13	25.00	1	10.00	3	18.75	9	34.62	3	27.27	10	24.39	6	33.33	7	20.59
Participant is grateful for low cost/free medical care through the government	12	23.08	1	10.00	2	12.50	9	34.62	3	27.27	9	21.95	5	27.78	7	20.59
Participant is grateful for timely access to diagnostics	6	11.54	0	0.00	4	25.00	2	7.69	0	0.00	6	14.63	1	5.56	5	14.71

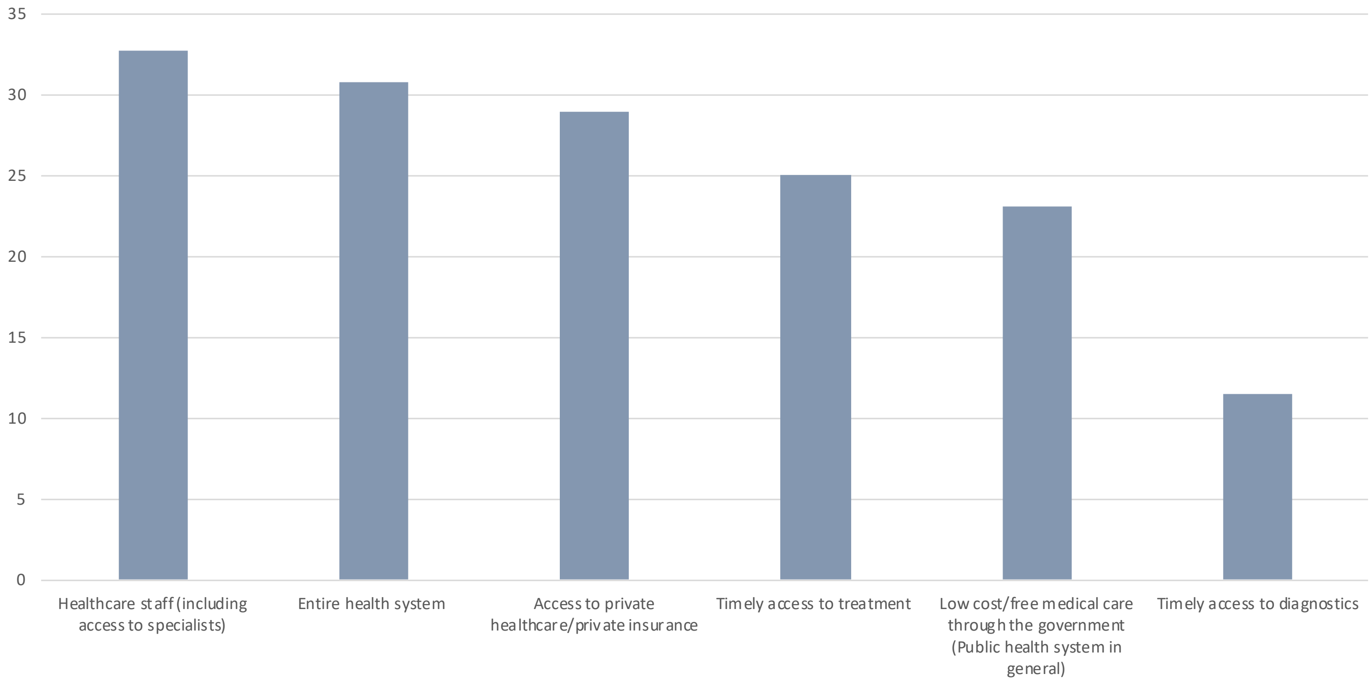


Figure 9.5: What participants are grateful for in the health system

Table 9.10: What participants are grateful for in the health system – subgroup variations

What participants are grateful for in the health system	Reported less frequently	Reported more frequently
Participant is grateful for healthcare staff	Diagnosed in 2017 to 2019	-
Participant is grateful for the entire health system	Trade or high school Diagnosed in 2016 or before	Diagnosed in 2020 or 2021
Participant is grateful for access to private healthcare/private insurance	Stage II	Stage III and IV Aged 55 to 74 Diagnosed in 2016 or before
Participant is grateful for timely access to treatment	Diagnosed in 2016 or before	-
Participant is grateful for low cost/free medical care through the government	Diagnosed in 2016 or before Diagnosed in 2017 to 2019	Trade or high school Diagnosed in 2020 or 2021
Participant is grateful for timely access to diagnostics	Diagnosed in 2016 or before Regional or remote	Diagnosed in 2017 to 2019

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 memory loss and cognitive function, fatigue, pain problems with movement and strength, and effects on bones and joints. The least important was fertility.

Table 9.11: Symptoms and aspects of quality of life

Symptom	Weighted average (n=51)
Fatigue Pain	8.12
Lymphoedema	5.43
Fertility	1.78
Menopause and menopausal symptoms	5.37
Anxiety and depression	6.67
Body image	4.41
Sexual difficulties	4.61
Problems with movement and strength	7.33
Heart problems	6.84
Memory loss and cognitive function	8.08
Effects on bones and joints	7.35

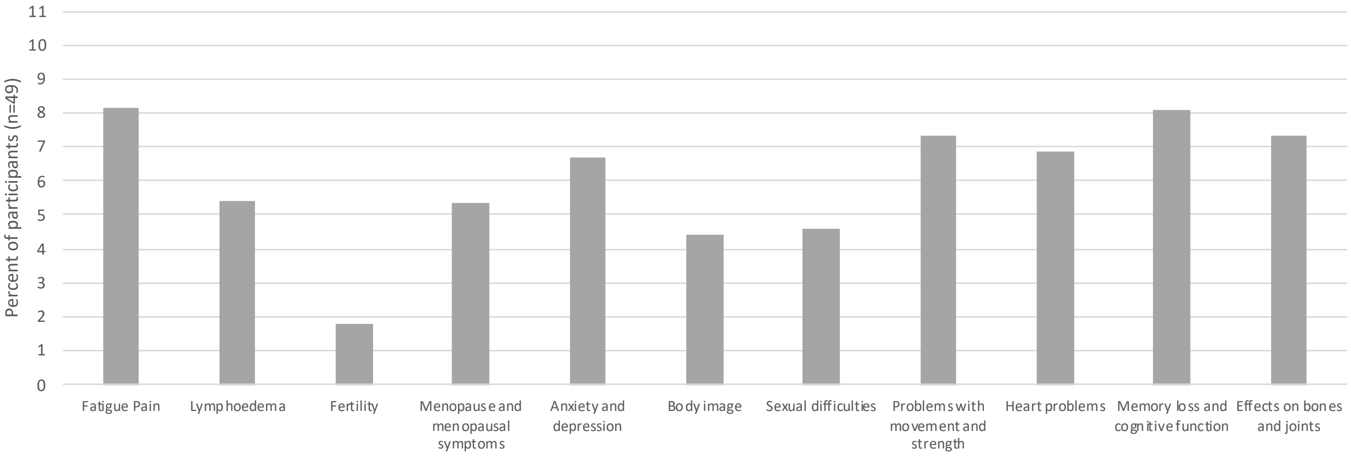


Figure 9.6: Symptoms and aspects of quality of life

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 9.7. 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 9.12: Values for decision makers

Values for decision makers	Weighted average (n=51)
Economic value to government and tax payers	1.22
Economic value to patients and their families	2.55
Quality of life for patients	4.12
Compassion	3.00
All patients being able to access all available treatments and services	4.12

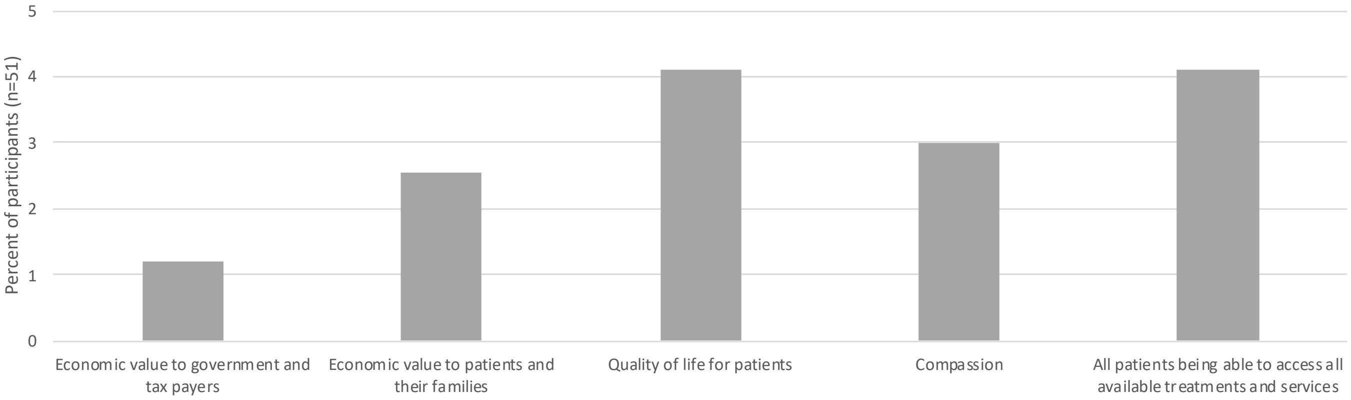


Figure 9.7: Values for decision makers

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 9.8. 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 "The ability to include my family in making treatment decisions" and "The financial costs to me and my family".

Table 9.13: Values in making decisions

Values when making decisions	Weighted average (n=51)
How safe the medication is and weighing up the risks and benefits	6.51
The severity of the side effects	5.76
Time impact of the treatment on my quality of life	5.16
How the treatment is administered	3.51
How personalised the treatment is for me	5.35
The ability to include my family in making treatment decisions	2.80
Ability to follow and stick to a treatment regime	3.94
The financial costs to me and my family	2.96

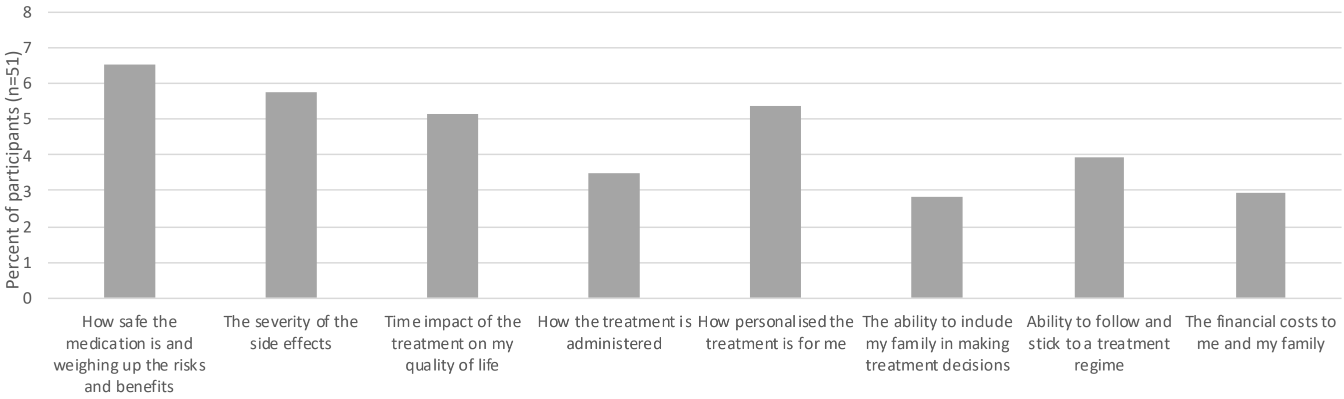


Figure 9.8: Values in making decisions

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.

Almost half of participants (n = 25, 49.02%) would use a treatment for more than ten years for a good quality of life even if it didn't offer a cure (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=51)	Percent
1 to 5 years	24	47.06
5 to 10 years	2	3.92
More than 10 years	25	49.02

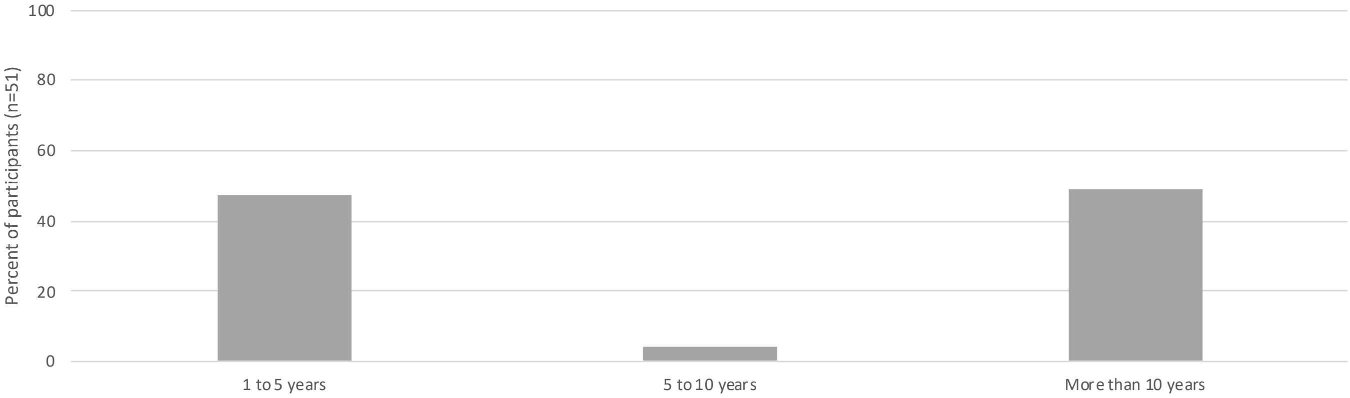


Figure 9.9: Time taking treatment to improve quality of life

Most effective form of medicine

Participants were asked in the online questionnaire, in what form did they think medicine was most effective in.

Participants most commonly responded that they thought that IV and pill were equally effective (n = 21, 41.18%), followed by not being sure (n = 19, 37.25%) (Table 9.15, Figure 9.10).

Table 9.15: Most effective form of medicine

Most effective form of medicine	Number (n=51)	Percent
IV form (through a drip in hospital)	5	9.80
In a pill form that can be taken at home	6	11.76
Equally effective	21	41.18
Not sure	19	37.25

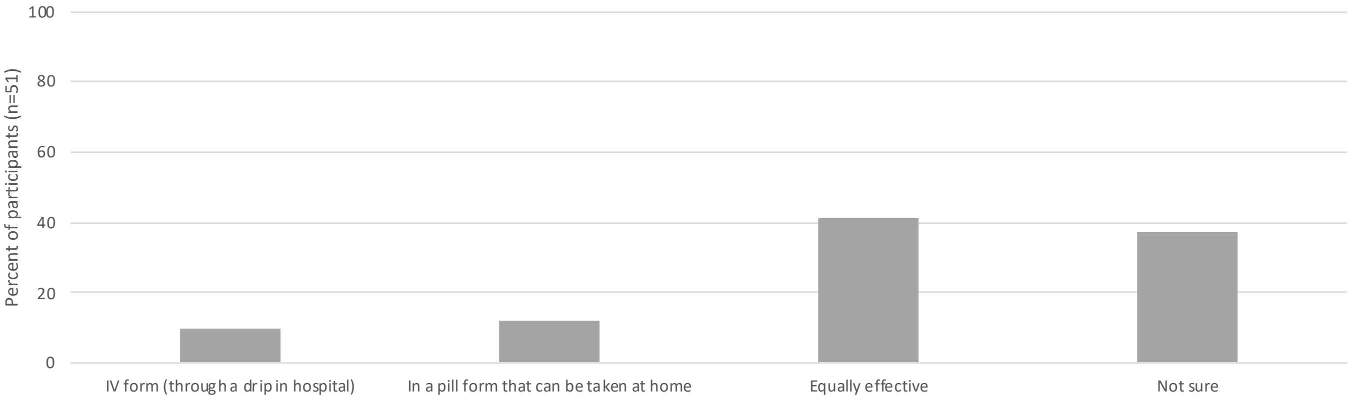


Figure 9.10: Most effective form of medicine

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 messages were to improve access to support and care (n=26, 50.00%), and to that treatments need to be more affordable (n=13, 26.00%). Other messages included the need to invest in research (n=9, 17.31%), the need for timely access to treatments (n=9, 17.31%), to understand the financial implications (and provide financial support) (n=8, 15.38%), the need to be compassionate and empathetic (n=6, 11.54%), the need for holistic treatments (n=6, 11.54%), invest in screening and early detection (n=6, 11.54%), better treatment access in rural and remote communities (n=6, 11.54%), and support for side effects and symptoms including long term follow up and support (n=6, 11.54%).

Participant's message is to improve access to support and care

I would just implore them to think about it as if it was their loved one going through the treatment, what would they want for their loved one? Would they want easy access, do they want financially, are they able to afford it or they have to go through the public system, and if they go through the public system, do they have to wait? Is that wait going to impact on the prognosis? Pretty much just-- Imagine that it was you going through it, what would you want? Participant 025_2021AUHRP

I would say to the health minister, "Make it all free. Make it free. Take away that financial burden for people whilst they're going through breast cancer treatment, and provide additional support that's consistent for everybody." Some people get access to McGrath nurses, some people get access to breast care nurses, other people get access to no support whatsoever. I think make it free and make sure that there is that consistent support for everybody. Participant 037_2021AUHRP

Probably I think people think once you've had treatment and you've had the chemo when your so called cancer free and that's it. I think psychologically afterwards I think women would be good if there was follow up and some sort of psychological or mental health check or Yeah, I think it all happens while you're having treatment and the breast care nurse comes out and all that and then once you're done, that's it, you don't hear from anyone. Except for this study. It's like your treatment's done, but you're better now you're good, off you go. You're on your own, and I still don't have a boob. Participant 041_2021AUHRP

Participant's message is that treatments need to be affordable

I would say that people with breast cancer, there is good access within the system to be had but it is not available to everybody and I'm incredibly privileged in that I'm medical, I have really great health literacy, I don't have problems signing people up to make appointments. Even saying, "No, I need this to happen this week." I'm very privileged in the sense that I don't have to contemplate whether I can afford $500 for an MRI or not. Coming from a place of privilege, where I live in a metropolitan regional place, with access to all those services, and with the skill set to be able to access them, or health services, fantastic. I think it probably isn't that way for everybody.
Participant 005_2021AUHRP

I probably hope that there's no discrimination of age and in regards to the support services, your home health and whether or not you've received care in public or private. It shouldn't matter but when you're dealing with breast cancer, or any cancer for that matter, and it should be all funded through PBS. That's why we pay our taxes. Participant 031_2021AUHRP

Oh, gosh. I don't know. [laughs] It is free if you go through the public system. Maybe pull the private health insurance companies more into line, because they're just getting out of control with their costs. I can't think of anything other than that really. Participant 012_2021AUHRP

Participant's message is to invest in research (including to find new treatments)

Breast cancer... I mean, we get great care with breast cancer. I do think that some of the testing should not be out of pocket. They throw millions and billions of dollars at testing that, they would get a lot more if I could understand why we get them, which means genetic testing. I mean, I still may need to find six hundred dollars to get my genetic testing if I don't qualify for the free testing through the NAME HOSPITAL. But I need to know because I have a *daughter who is at the perfect age for getting what I've got. She's thirty one. I have grandchildren. So genetic testing is needed and it maybe through some of the research dollars, not all of them, but just a few of them to maybe look at some of the rarer forms of cancer because everyone's so busy throwing the research dollars and all the research and clinical trials at normal breast cancer. The rest of us are left standing there with no research and no clinical trials. Participant 003_2021AUHRP*

Fund more Stage 4. One in three women potentially will move on to be metastatic. I think it's underfunded. Actually, could I change that? Get more support for stage 4, but particularly research around the recurrence of stage 4. The fact that we don't actually know is outrageous. The fact that they don't actually track and have any statistics about stage 4. More funding and research around stage 4. Participant 043_2021AUHRP

Please keep funding a variety of research into breast cancer. A variety of research. Participant 047_2021AUHRP

Participant's message is that there needs to be more timely access to treatments

I would say to him that through the public health system in the bigger cities and I'm talking from experience because I am supporting a woman who I've never met, but I was put in touch with her through a friend, 71 year old lady. She's got bilateral breast cancer at this stage in both breasts from the time of mammogram and diagnosis and then the period that she had to wait to have a biopsy and then to see a surgeon at LOCATION and then to wait another month or more. Of course, she had surgery. I just think that that that just exacerbates the emotional trauma of the whole experience. So I think that I would say, look, you know, we need more money funding into our hospital waiting lists because it's not you know, it's just not it's it's everything. Participant 019_2021AUHRP

I would just implore them to think about it as if it was their loved one going through the treatment, what would they want for their loved one? Would they want easy access, do they want financially, are they able to afford it or they have to go through the public system, and if they go through the public system, do they have to wait? Is that wait going to impact on the prognosis? Pretty much just-- Imagine that it was you going through it, what would you want?
Participant 025_2021AUHRP

I think if you're in the public system-- it depends because, I can't talk about doing it through the public system, but for me if people want to get on with it. The sooner they get on with it, the for them. That gives you peace of mind. Keeping people on long waiting lists, it's not mentally healthy for them. I do think too that, psychologists for some people need to be in the mix. Especially if they don't know anybody that's ever been touched by cancer. Participant 032_2021AUHRP

Participant's message is to understand the financial implications (and provide financial support)

The cost costs are terrible. The local public hospital doesn't have testing equipment or an oncology department at all. I guess the public system couldn't provide my healthcare needs and therefore I had to go private as a public patient so it cost a lot. And that's probably it. Participant 014_2021AUHRP

I would say to the health minister, "Make it all free. Make it free. Take away that financial burden for people whilst they're going through breast cancer treatment, and provide additional support that's consistent for everybody." Some people get access to McGrath nurses, some people get access to breast care nurses, other people get access to no support whatsoever. I think make it free and make sure that there is that consistent support for everybody. Participant 037_2021AUHRP

Gee, that's a hard one because I think, for younger women that is possibly really important. I just can't say-- you've caught me-- you realize that not everything can be free. I just think of women with children. There's things like Can Assist where you can get some money. I really don't know how to answer your question there because it's very different for people with children, et cetera, and younger women. Participant 022_2021AUHRP

Participant's message is to be compassionate and empathetic

Being in a big unit of patients whereas I was in a nice small unit, it's just not so daunting. I see people and they would find it daunting because I'd actually done a shift just before my diagnosis in this day unit. I was overwhelmed even as a nurse I was like, "Oh my God, this is huge." Let alone being a patient who's chucked in like sardines. There's no privacy. If they're having a bad day, they can't escape everyone, sort of thing. Does that make sense? Participant 024_2021AUHRP

Again, I'm blowing the trumpet of the stage for people that we need more funding and more concentration of research and fast tracking. I was the novo so that was my first diagnosis and if there's confusion even with early stages. A lot of early stages aren't aware that 30% of them are likely to have recurrent if not progression to Stage 4. I think a lot of people including the health minister would do well to put more into that box of researching and funding. Even though it might be outdated if a two to three year lifespan post diagnosis is what some people have to look at, that's not a lot of time. To say that much a lot of that two to three years may not be in comfort or in emotional well-being, a lot of that might be in immobilized, bedridden, or whatever or just going between appointments rather than actually having a life. I think that's an important thing to throw in there because it's not all sunny days and picnics. Participant 051_2021AUHRP

I think they need to have a look at the whole system and maybe there isn't something to change, but I think from diagnosis to a five-year plan, it needs to be far more transparent and probably a little bit kinder to most of us. The research side of things, if the government spent possibly a little bit more money on the research side, some of the treatments that we have to go through, you wouldn't have to go through. Participant 018_2021AUHRP

Participant's message is that treatments need to be holistic

They need to increase funding for health. I think you need to listen to your nurses. And they tell you that they're actually because that's why mental health isn't well looked after as because nurses and doctors as well, but I'm going to get on the bandwagon of nurses. You know, we can't, you can't give the emotional support. Because you're so busy chasing your tail doing the physical support. He's so busy, like just taking care of patients physically, that you can't, you don't have the time to factor in their emotional. But yeah, it's important that they require like in a clinical setting. You know, we need to we need to be thinking about, you know, okay, if we can't provide this support in a clinical setting, because there's not physically enough nurses to do the job, then we need to step up another way. So either get better patient staff ratio, and provide that full centered holistic nursing care or provide better mental health care that's accessible, so like, either way you can have to spend some money so choose which way you are going to spend it. Participant 033_2021AUHRP

I think my advice would be to look at everything holistically. Don't just look at it as a physical condition because it is such a knock-on effect to all the other aspects of human life. Participant 038_2021AUHRP

It's such a huge thing now, such a big population of people have breast cancer so I think that all hospitals-- I think they are starting to have it now should have specialty areas for that demographic of people. I think that has access through a lot of different services to help people mentally, physically get through this and rehabilitate because it is something that you'll--especially after a double mastectomy or anything. If I had my legs chopped off, I'd be sent to rehab to get a new, and they'll have services available to help me walk again and to do all the things and they'll probably address my mental health and all that stuff more than when you get your breasts cut off. I think that's not recognized. I think that that there needs to be some form of rehabilitation after that to help people get through because breast cancer diagnosis isn't something that you can just then get well from, I think it's something that you live with for the rest of your life, and you're mentally going to be always worried that it's going to come back again. I think there needs to be more fully into improving the quality of life and helping people get through this situation. Participant 048_2021AUHRP

Participant's message is to invest in screening/early detection

Well, again, I can only speak from the private system. I have heard from other people who've been through public, it's quite a different experience that given the-- It seems as though breast cancer is, unfortunately, becoming a little bit more common, or a bit more diagnosed in our society, just to make sure that the number of clinics increase, the number of breast care nurses increase, females who choose to have their mammogram to be checked regularly. Participant 004_2021AUHRP

There's many different types of breast cancer for starters. They need to realize that not all breast cancers can be treated the same way, can be found the same way. We need to be more open to offering more available screenings and not at excessive costs like me having to pay $615 because of my breast cancers, the type of breast cancer, there's often found too late because it doesn't show on a mammogram or an ultrasound. Those things that helped to find it earlier, should be made available, and at least at a reasonable cost, if not for free. Participant 010_2021AUHRP

Well, I think they need to screen people earlier with mammogram. What is it now from 50, 50 years old or something? Participant 015_2021AUHRP

Participant's message is that there needs to be better access to care and treatment in rural and remote locations

I would like to see it be a system that supports everybody a little bit more, in particular, people who live a bit further away from all these things. The solution is never going to be have a oncologist in every town, you can't do it, but we need to have better access to get people in and out of the metropolitan areas when they need it. I would also probably have a whinge about the lack of genomic testing being covered by Medicare and MRIs while I was at it, because why not? Participant 005_2021AUHRP

Yes, maybe more to regional areas and more to help people mentally when they're going through it. Participant 016_2021AUHRP

As far as being in a rural area, having to travel two and a half hours and stay in LOCATION for radiation, I suppose all those things. That's what you do, you're living in a rural area, you haven't got much choice, they can't have a radiation machine in every rural town. There's probably not much that can be done about that, but maybe it would be nice to have better accommodation up where the radiation is. [unintelligible 00:54:54] but from all reports, the accommodation at the hospital isn't fantastic. It's like shared kitchen and that sort of thing, that'd be nice, [chuckles] but I can't see it happening. It's going to be a perfect world. Participant 017_2021AUHRP

Participant's message is that there needs to be support for side effects and symptoms, including long term follow up and support

I think that there is another problem, if you'd call it a problem, is that so many people are surviving now, so what are you meant to do with the survivors? There's a lot of money spent in treatment but there needs to be what happens after breast cancer treatment? None of that's really discussed. You'd gone through the machine and that's it sort of thing. More in the post-treatment care. I can't comment too much because I didn't have those complications that some people have gone through. Could have been a lot worse. Participant 021_2021AUHRP

I'm afraid, I think possibly because I see a gap, I would be going lymphoedema, lymphoedema, lymphoedema. There are huge gaps in funding, recognition, treatment for lymphoedema. Participant 023_2021AUHRP

I think that's not recognized. I think that that there needs to be some form of rehabilitation after that to help people get through because breast cancer diagnosis isn't something that you can just then get well from, I think it's something that you live with for the rest of your life, and you're mentally going to be always worried that it's going to come back again. I think there needs to be more fully into improving the quality of life and helping people get through this situation. Participant 048_2021AUHRP

Table 9.16 Messages to decision-makers

Message to decision-makers	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participant's message is to improve access to support and care	26	50.00	8	42.11	11	52.38	7	58.33	12	41.38	**14**	**60.87**	10	52.63	16	48.48
Participant's message is that treatments need to be affordable	13	25.00	**8**	**42.11**	5	23.81	**0**	**0.00**	5	17.24	8	34.78	4	21.05	9	27.27
Participant's message is to invest in research (including to find new treatments)	9	17.31	4	21.05	3	14.29	2	16.67	**1**	**3.45**	**8**	**34.78**	3	15.79	6	18.18
Participant's message is that there needs to be more timely access to treatments	9	17.31	2	10.53	4	19.05	3	25.00	3	10.34	6	26.09	3	15.79	6	18.18
Participant's message is to understand the financial implications (and provide financial support)	8	15.38	3	15.79	2	9.52	3	25.00	7	24.14	**1**	**4.35**	**0**	**0.00**	8	24.24
Participant's message is to be compassionate and empathetic	6	11.54	2	10.53	2	9.52	2	16.67	3	10.34	3	13.04	2	10.53	4	12.12
Participant's message is that treatments need to be holistic	6	11.54	4	21.05	2	9.52	**0**	**0.00**	3	10.34	3	13.04	4	21.05	2	6.06
Participant's message is to invest in screening/early detection	6	11.54	2	10.53	2	9.52	2	16.67	5	17.24	1	4.35	2	10.53	4	12.12
Participant's message is that there needs to be better access to care and treatment in rural and remote locations	6	11.54	3	15.79	1	4.76	2	16.67	5	17.24	1	4.35	2	10.53	4	12.12
Participant's message is that there needs to be support for side effects and symptoms, including long term follow up and support	6	11.54	2	10.53	3	14.29	1	8.33	2	6.90	4	17.39	3	15.79	3	9.09

Message to decision-makers	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participant's message is to improve access to support and care	26	50.00	3	30.00	7	43.75	16	61.54	6	54.55	20	48.78	9	50.00	17	50.00
Participant's message is that treatments need to be affordable	13	25.00	5	50.00	4	25.00	4	15.38	4	36.36	9	21.95	6	33.33	7	20.59
Participant's message is to invest in research (including to find new treatments)	9	17.31	2	20.00	2	12.50	5	19.23	4	36.36	5	12.20	4	22.22	5	14.71
Participant's message is that there needs to be more timely access to treatments	9	17.31	0	0.00	1	6.25	8	30.77	5	45.45	4	9.76	3	16.67	6	17.65
Participant's message is to understand the financial implications (and provide financial support)	8	15.38	3	30.00	2	12.50	3	11.54	0	0.00	8	19.51	2	11.11	6	17.65
Participant's message is to be compassionate and empathetic	6	11.54	1	10.00	0	0.00	5	19.23	2	18.18	4	9.76	1	5.56	5	14.71
Participant's message is that treatments need to be holistic	6	11.54	2	20.00	1	6.25	3	11.54	3	27.27	3	7.32	3	16.67	3	8.82
Participant's message is to invest in screening/early detection	6	11.54	1	10.00	4	25.00	1	3.85	0	0.00	6	14.63	0	0.00	6	17.65
Participant's message is that there needs to be better access to care and treatment in rural and remote locations	6	11.54	0	0.00	2	12.50	4	15.38	0	0.00	6	14.63	1	5.56	5	14.71
Participant's message is that there needs to be support for side effects and symptoms, including long term follow up and support	6	11.54	1	10.00	2	12.50	3	11.54	1	9.09	5	12.20	2	11.11	4	11.76

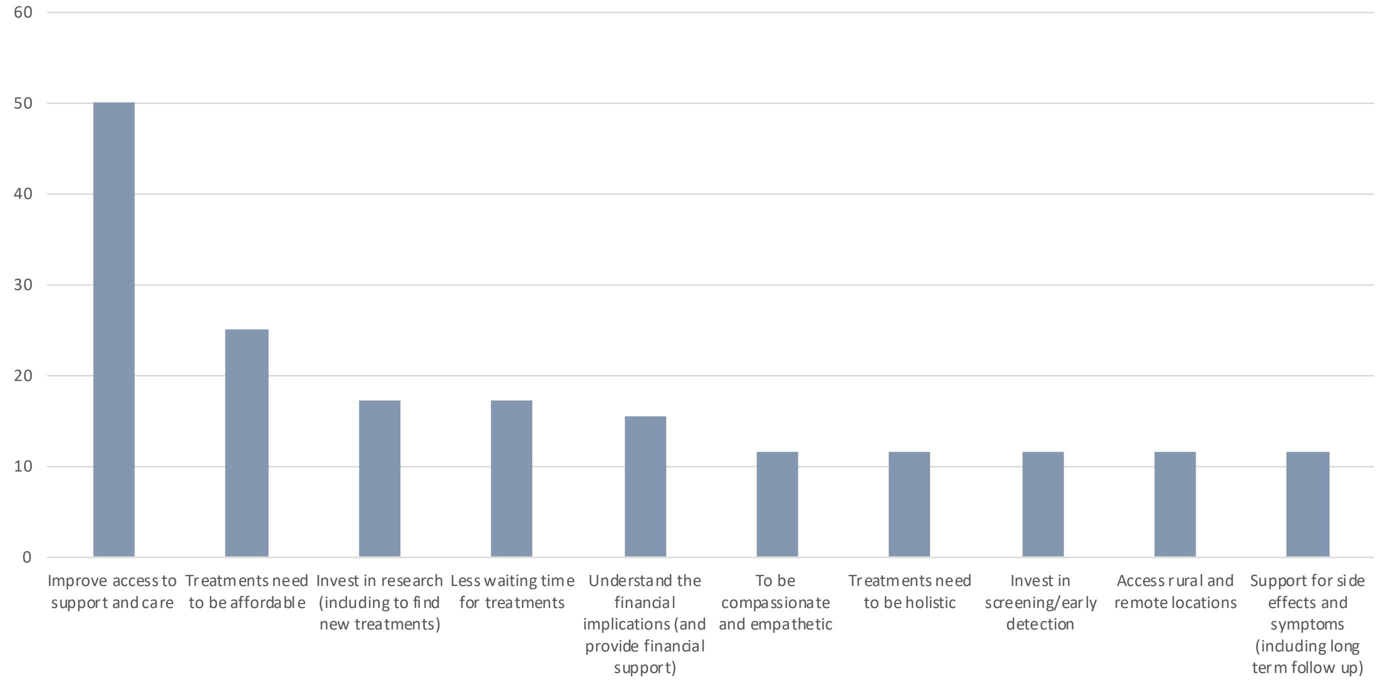


Figure 9.11: Messages to decision-makers

Table 9.17: Messages to decision-makers – subgroup variations

Message to decision-makers	Reported less frequently	Reported more frequently
Participant's message is to improve access to support and care	Diagnosed in 2016 or before	Aged 55 to 74 Diagnosed in 2020 or 2021
Participant's message is that treatments need to be affordable	Stage III and IV	Stage 0 and I Diagnosed in 2016 or before Regional or remote
Participant's message is to invest in research (including to find new treatments)	Aged 25 to 54	Aged 55 to 74 Regional or remote
Participant's message is that there needs to be more timely access to treatments	Diagnosed in 2016 or before Diagnosed in 2017 to 2019	Diagnosed in 2020 or 2021 Regional or remote
Participant's message is to understand the financial implications (and provide financial support)	Aged 55 to 74 Trade or high school Regional or remote	Diagnosed in 2016 or before
Participant's message is to be compassionate and empathetic	Diagnosed in 2017 to 2019	-
Participant's message is that treatments need to be holistic	Stage III and IV	Regional or remote
Participant's message is to invest in screening/early detection	Regional or remote Mid to low status	Diagnosed in 2017 to 2019
Participant's message is that there needs to be better access to care and treatment in rural and remote locations	Diagnosed in 2016 or before Regional or remote	-

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 response was that participants wished they had known what to expect from their condition, particularly symptoms and side effects of treatment (n=22, 42.31%). Other themes included participants wished they had known to be more assertive in relation to understanding treatment options and discussions about treatment (n=10, 19.23%), and they wished that they had sought medical attention or attended screening sooner (n=5, 9.62%). There were eight participants that did not describe anything that they wished they had known (n=10, 19.23%).

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 themes were that they would not change any aspect of treatment or care without giving a reason (n=13, 25.00%), and that they would not change any aspect because they were satisfied with their care or treatment (n=9, 17.31%). Other themes include changing or stopping treatment sooner (n=4, 7.69%), and having a better understanding of their condition (n=4, 7.69%).

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 response was that participants wished they had known what to expect from their condition, particularly symptoms and side effects of treatment (n=22, 42.31%). Other themes included participants wished they had known to be more assertive in relation to understanding treatment options and discussions about treatment (n=10, 19.23%), and they wished that they had sought medical attention or attended screening sooner (n=5, 9.62%). There were eight participants that did not describe anything that they wished they had known (n=10, 19.23%).

Participant wishes they had known what to expect from their condition (e.g. symptoms, side effects of medication)

I guess the thing that dawned on me the slowest of all is how long the journey is. When you're first diagnosed, it's sort of this is the problem that I've got to work out how to tackle it, and then you're like, "Well, okay, you can deal with it and I'll be back to normal in a month," it's like no. Three months? No. Six months? No. Actually, it's 15 years. It will be 15 years from diagnosis when I finally stop treatment. I think the thing that I probably know now that I think it would've been-- I don't know it would've been good to know then, but perhaps the thing that I was really thinking at first was that this is a chronic slow treatment process. It's going to go on a long time. Participant 005_2021AUHRP

Oh no, no, just radiation treatment. The stuff that I found out afterwards that I thought would be temporary that are going to be permanent was nice to know at the start, I wouldn't change my mind. It just would have been nice to know. Participant 014_2021AUHRP

Ooh [laughs]. I don't really. I wish I'd known more about lymphedema and how it would affect me. I don't think things can prepare you though. No matter how much information they give you, nothing can prepare you really for what it is until you go through it sort of thing. [crosstalk] else. Participant 024_2021AUHRP

Just the mental health stuff again, you know, that how vulnerable like how that vulnerability doesn't really go away. I wish somebody had said to me like, this is going to change your brain, your brain works differently now. Just just how it is. So everyone talks about chemo fog, and they talked about, you know, mood swings and bits and pieces. They talked about all that kind of stuff, but they didn't talk about, you know, how that, you know, intrinsically really like it's almost like a PTSD really, isn't it? You know, that acknowledgement that that's actually normal. You know, like, you know, physically, like I knew it was normal, from a professional headspace. Right, you know, you've worked with enough people that have had, like life altering diagnosis as and then you know, working in maternity, you know, life changing thing that changes your brain a bit as well, but just never put two and two together. Yeah. Yeah, yes, it affects me for this period of time, but then I have treatment, and then I'll be fine. Or actually, you know, just you are a different person after I feel. Participant 033_2021AUHRP

Participant wishes they had known to be more assertive in relation to understanding treatment options and discussions about treatment

As I say, about the-- when they tell you you're going to have the sentinel node biopsy, I think that needs explaining more. If there's cancer cells, we're going to have to take more lymph nodes. I just felt that that wasn't explained clearly to me. Participant 012_2021AUHRP

Yeah, it probably will probably, well, if I had known all of it, I would have been a lot less stressful. Yeah, and being and being more comfortable in the early days of the decisions that I make. And I guess in terms of the first surgery and the second surgeries, and it's all hindsight, because I didn't get it a second time, I would have gone back and done things differently. The first diagnosis round, like it would have just had to double mastectomy straight away and just gone up. But that because I was younger, and I was like oh no. And then you know, my surgeon sort of well, meaning that he didn't talk me out of it. We didn't really talk about it. It was an option, but he didn't push it because he said of my scenario and he was genuine about that. And, you know, he was he was well known for being breast conserving. And I'm like yeah, that's good. When about I just, I just look back now and go You can't mess around with that stuff. Participant 013_2021AUHRP

How the system works. This is pretty tricky. I think it would have been nice if they'd maybe been a bit of a flow diagram of, "This is how it could go" and this is, as I said, would be, "and if you need help or if you need from the side effects from anything else, this is who you contact". Participant 047_2021AUHRP

Participant does not describe anything they wish they had known earlier (no reason given)

No, no, look, it's one of those things that happens in life. Something…I actually never ever thought it would ever happen to me but it did, so you just have to deal with it. You don't know how strong you are until you're faced with it. I never thought I could deal with it, but you have to. I don't really feel when somebody tells you you've got breast cancer. I really don't know any softer way, there's no soft landing for it. I just got to deal with it. I myself, I like to research. I know another friend of mine who was diagnosed similar, she didn't want to know anything about it, accept it. I think everyone's different, so everyone's journey gotta be their own journey. Participant 004_2021AUHRP

No, well, because as I said to you the first time, if I didn't have treatment well, goodness knows what will happen. Yeah, I can't think of anything you kind of do at the time you think, god I wish I knew that [Unintelligible] I don't know how to answer that one. 045_2021AUHRP

Participant wishes they had sought medical attention sooner, or had population screening sooner

I spent a lot of time blaming myself. I wish, in some ways, that some people I could almost feel judgment in their eyes. I blame myself that I should have gone earlier about the lumps that I had and I wish that that the health professionals just, in some ways, say, "It's not your fault" and repeat that, "It's not your fault." Again, "It's not your fault."
I was in the false belief that I was a very-- Was, still am, a very healthy person. As I said before, a bit sheltered. "I eat well and I exercise. I am not one of those people. I'm very unlikely. It's for people that are overweight or don't exercise, eat badly." It's given me a new outlook. I've come off my high horse. Participant 021_2021AUHRP

Yes, I wish I'd gone straight away when I got my referral, rather than wait till-- I put it off and put it off and put it off and I'm sure it was growing bigger and bigger and bigger. I wish I'd gone earlier and caught it earlier. I wish I didn't miss my one set up for the year that because it may have been a lot smaller yes, anyway that's one thing I regret. Participant 035_2021AUHRP

Well, I think, I probably would've wished-- The first thing I knew about the whole mammogram was getting this letter when-- When you turn 50, you get a whole stack of letters about please go to these things. You can go to a mammogram at 40, which I would've done. That would have been scheduled if that picked up whatever I had when it was a lumpectomy and then I would have avoided all of it. Participant 036_2021AUHRP

Table 10.1: Anything participants wish they had known earlier

Anything participants wish they had known earlier	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participant wishes they had known what to expect from their condition (e.g. symptoms, side effects of medication)	22	42.31	7	36.84	10	47.62	5	41.67	12	41.38	10	43.48	8	42.11	14	42.42
Participant does not describe anything they wish they had known earlier (no reason given)	10	19.23	5	26.32	3	14.29	2	16.67	6	20.69	4	17.39	4	21.05	6	18.18
Participant wishes they had known to be more assertive in relation to understanding treatment options and discussions about treatment	10	19.23	2	10.53	6	28.57	2	16.67	5	17.24	5	21.74	3	15.79	7	21.21
Participant wishes they had sought medical attention sooner, or had population screening sooner	5	9.62	1	5.26	1	4.76	**3**	**25.00**	4	13.79	1	4.35	2	10.53	3	9.09

Anything participants wish they had known earlier	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participant wishes they had known what to expect from their condition (e.g. symptoms, side effects of medication)	22	42.31	5	50.00	**5**	**31.25**	12	46.15	5	45.45	17	41.46	6	33.33	16	47.06
Participant does not describe anything they wish they had known earlier (no reason given)	10	19.23	2	20.00	2	12.50	6	23.08	2	18.18	8	19.51	3	16.67	7	20.59
Participant wishes they had known to be more assertive in relation to understanding treatment options and discussions about treatment	10	19.23	**3**	**30.00**	4	25.00	3	11.54	2	18.18	8	19.51	3	16.67	7	20.59
Participant wishes they had sought medical attention sooner, or had population screening sooner	5	9.62	**2**	**20.00**	2	12.50	1	3.85	0	0.00	5	12.20	2	11.11	3	8.82

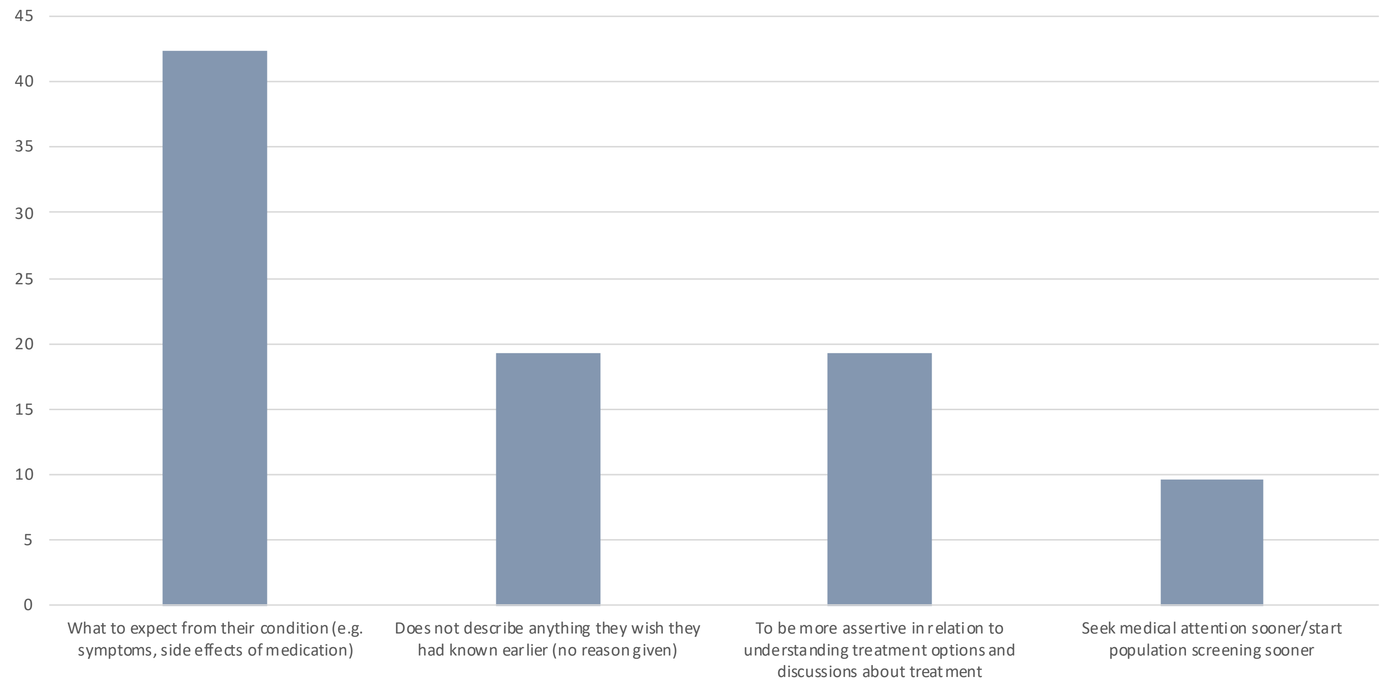


Figure 10.1: Anything participants wish they had known earlier

Table 10.2: Anything participants wish they had known earlier – subgroup variations

Anything participants 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)	Diagnosed in 2017 to 2019	-
Participant wishes they had known to be more assertive in relation to understanding treatment options and discussions about treatment	-	Diagnosed in 2016 or before
Participant wishes they had sought medical attention sooner, or had population screening sooner	-	Stage III and IV Diagnosed in 2016 or before

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 themes were that they would not change any aspect of treatment or care without giving a reason (n=13, 25.00%), and that they would not change any aspect because they were satisfied with their care or treatment (n=9, 17.31%). Other themes include changing or stopping treatment sooner (n=4, 7.69%), and having a better understanding of their condition (n=4, 7.69%).

Participant would not change any aspect of their care or treatment (no reason given)

No, because they've got to do what they've got to do really. You can't change anything. Participant 012_2021AUHRP

No, I don't think so. The system is what the system is. I can't change what they offer because that's what they offer. In a perfect world, there would be something better than the chemo train but there's not, is there? Participant 018_2021AUHRP

Not any of the important things, no. Participant 039_2021AUHRP

Participant would not change any aspect of their care or treatment/satisfied with care and treatment received

No, I don't think so. It was acted on quickly, from when I got diagnosed on the Friday, I went to the specialist on the Monday, he gave me all the information and had a plan, "I need you to go off and do X, Y, and Z, then come back and see me." It was very quick and less time to worry about it. I felt like it happened quickly. Participant 009_2021AUHRP

No, I don't think so. I think I got through pretty unscathed, and I'm happy with how everything went. Participant 020_2021AUHRP

No, I don’t think so. I think for a public system where everything that I’m receiving is funded by Medicare, it would be great if I didn’t have to wait as long when I turn up to an appointment. Honestly, I wouldn’t really change anything about the actual treatment. I understand that I’m being treated in a really good hospital with really good healthcare professionals, and I trust that it’s the right thing. I believe it’s the right thing for me and it’s working. No, there isn’t anything to change. It would be lovely if doctors ran on time but that’s not a cancer thing. That’s a doctor thing. Participant 044_2021AUHRP

Participant would have liked to have had a better understanding of their condition

So it’s the fact that we don’t know, we don’t get polled. It’s very much being a mushroom. It’s being kept in the dark and fed manure. They don’t bring us out into the world, we get told nothing, so we don’t know anything unless we go looking for and not everybody does that. I’m very interested in the medical side of things. A lot of women: out of sight, out of mind. I don’t want to know about it. And then it’s too late and, you know, it’s gotten to stage four metastases and that type of thing. That’s my issue. To me, this is all very frustrating. Participant 003_2021AUHRP

No, I don't think so. I'm lucky that I've [unintelligible 01:04:16] early-stage cancer, although, when you get into these groups, you talk about people with early-stage cancer and two years later, they're in stage four. I'd like to know more about why that happens. You get told you've got early stage, and you'll probably live till you're 100. I guess there's such a thing as information overload as well. Maybe you can only take in what you can take in, and maybe sometimes you're better off not to know too much. I don't know. There's many different angles you could look at. I'm one of those people that want to be proactive, I think, and know as much as I can to stop the bloody thing from coming back. Participant 010_2021AUHRP

Probably it's the way sometimes they speak as I think I mentioned earlier and sometimes you're not quite a person that can be a bit frustrating angering to get angry but I did find I really had to push to get all the information I wanted. So they kept trying I think to protect me from overwhelming me but when I'm asking for it, yeah. I because I'm ready it's because it's what I want I think again, that's not treating everyone the same. Participant 045_2021AUHRP

Table 10.3: Aspect of care or treatment they would change

Aspect of care or treatment they would change	All participants		Stages 0 and I		Stage II		Stages III and IV		Aged 25 to 54		Aged 55 to 74		Trade or high school		University	
	n=52	%	n=19	%	n=21	%	n=12	%	n=29	%	n=23	%	n=19	%	n=33	%
Participant would not change any aspect of their care or treatment (no reason given)	15	28.85	6	31.58	6	28.57	3	25.00	8	27.59	7	30.43	8	42.11	7	21.21
Participant would not change any aspect of their care or treatment/satisfied with care and treatment received	10	19.23	4	21.05	2	9.52	4	33.33	5	17.24	5	21.74	3	15.79	7	21.21
Participant would have liked to have had a better understanding of their condition	6	11.54	4	21.05	1	4.76	1	8.33	1	3.45	5	21.74	1	5.26	5	15.15

Aspect of care or treatment they would change	All participants		Diagnosed in 2016 or before		Diagnosed in 2017 to 2019		Diagnosed in 2020 or 2021		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=52	%	n=10	%	n=16	%	n=26	%	n=11	%	n=41	%	n=18	%	n=34	%
Participant would not change any aspect of their care or treatment (no reason given)	15	28.85	4	40.00	5	31.25	6	23.08	3	27.27	12	29.27	6	33.33	9	26.47
Participant would not change any aspect of their care or treatment/satisfied with care and treatment received	10	19.23	0	0.00	4	25.00	6	23.08	1	9.09	9	21.95	4	22.22	6	17.65
Participant would have liked to have had a better understanding of their condition	6	11.54	3	30.00	1	6.25	2	7.69	2	18.18	4	9.76	3	16.67	3	8.82

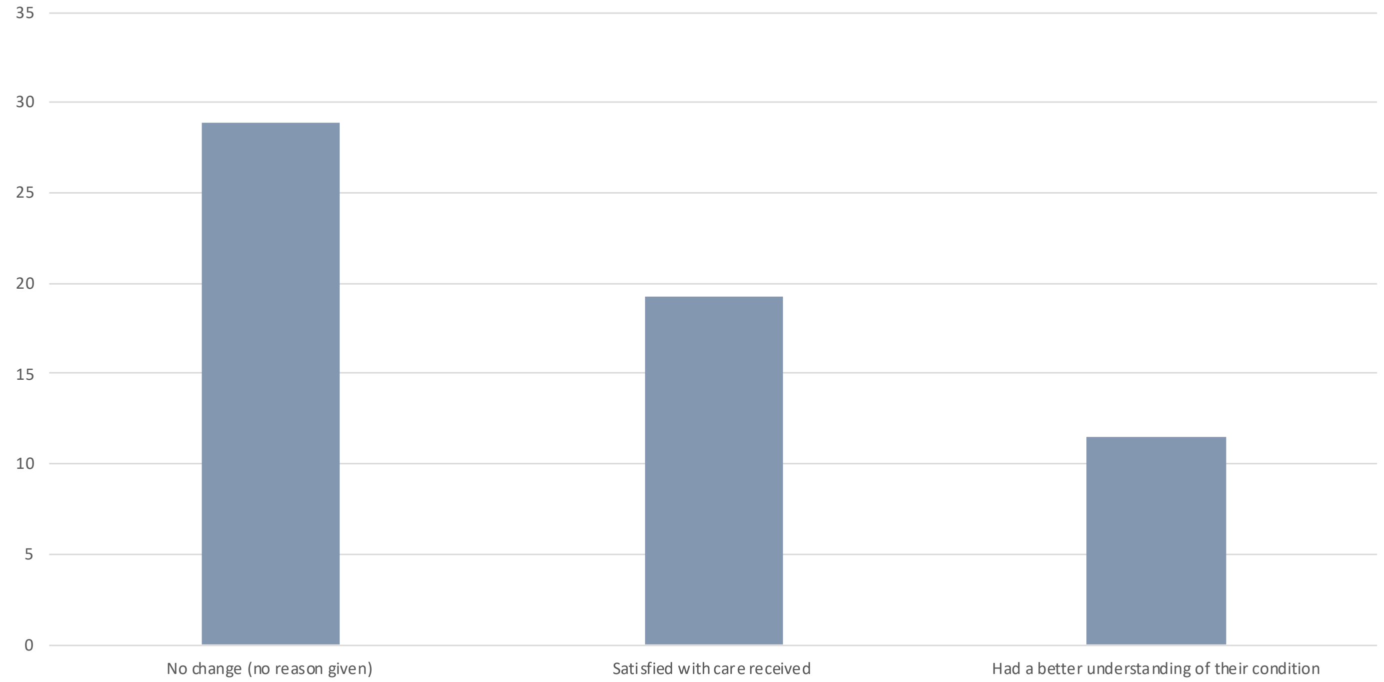


Figure 10.2: Aspect of care or treatment they would change

Table 10.4: Anything participants wish they had known earlier – subgroup variations

Aspect of care or treatment they would change	Reported less frequently	Reported more frequently
Participant would not change any aspect of their care or treatment (no reason given)	-	Trade or high school Diagnosed in 2016 or before
Participant would not change any aspect of their care or treatment/satisfied with care and treatment received	Diagnosed in 2016 or before Regional or remote	Stage III and IV
Participant would have liked to have had a better understanding of their condition	-	Aged 55 to 74 Diagnosed in 2016 or before

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 hormone receptor-positive breast cancer includes 52 people diagnosed with hormone receptor-positive breast cancer throughout Australia.

Background

The estimated incidence of breast cancer in Australia was over 19,000 cases, and it was the most diagnosed cancer in women, and the most diagnosed cancer overall[1]. There were over 3000 deaths from breast cancer in 2019, and this was the second most common cause of death from cancer for women, and the fourth most common overall. Over three quarters of breast cancers are diagnosed at stage I or stage II[1]. Approximately 55% of women aged 50 to 74 participated in breast cancer screening in the 2015 to 2016 period[1].

The five-year survival from breast cancer (2011 to 2015) was 90.8%, survival when diagnosed at stage I is almost 100%, however, when diagnosed at stage IV, the survival is 32%[1].

Hormone-receptor positive breast cancers are sensitive to estrogen or progesterone, approximately 70% of breast cancers are hormone-receptor positive[2]. Adjuvant treatment with tamoxifen is recommended, followed by an addition five years for pre or peri-menopausal women, and an additional five years with tamoxifen or an aromatase inhibitor for post-menopausal women[2].

Hormone therapy increases overall survival, decreases risk recurrence, and decreases risk of contralateral breast cancer[2,3]. However, risks from hormone treatment include menopausal symptoms, additional risks from tamoxifen included endometrial cancer, deep vein thrombosis or pulmonary embolism, and uterine cancer, additional risks from aromatase inhibitors include heart disease, and osteoporosis[2,4].

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 breast cancer.

In this PEEK study, the proportions of participants that lived in areas with higher socioeconomic status, that had non-school qualifications (certificate, diploma or degree), and the proportion in paid employment were all similar to that of Australia. There were more that lived in major cities, and with compared to the Australian population[5-7] . There were no participants from the Northern Territory, or Canberra, and there were a lower proportion of participants from Victoria, while a greater proportion from Queensland compared to the proportion that live in each state[8].

Table 12.1: Demographics

Demographic	Australia %	Hormone receptor-positive breast cancer PEEK %
Live in major cities	71	79
Non-school qualification	65	67
Higher socioeconomic status (7 to 10 deciles)	40	65
Employment (aged 15 to 64)	74	72
New South Wales	32	35
Victoria	26	17
Queensland	20	27
South Australia	7	6
Western Australia	10	12
Tasmania	2	0
Northern Territory	1	0
Australian Capital Territory	2	4

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 breast cancer participants.

Other health conditions

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 (60% compared to 13%), depression (37% compared to 10%) compared to the Australian population.

Baseline health

The Short Form Health Survey 36 (SF36) measures baseline health, or the general health of an individual[10]. 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[10].

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 breast cancer community in this PEEK study compares with the Australian population[11]. The hormone-receptor positive breast cancer PEEK participants on average had considerably lower scores for all SF36 domains with the exception of emotional well-being, role functioning physical, and role functioning emotional.

Risks and Symptoms

Yes, so then. So it was pretty scary, because the lump was quite big. So I went straight into a GP, a medical practice the next morning and saw a GP just got their first thing for when they opened for a GP. And he then was it gave me a referral to the hospital to get some scans done. Participant 013_2021AUHRP

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.

The most common symptom of breast cancer among women is breast lump with other symptoms commonly reported including nipple abnormalities, breast pain and breast skin abnormalities[12]. Other less common symptoms are a change in the appearance of nipples, nipple discharge, breast contour abnormalities, breast ulceration and infection or inflammation of breast[12].

Half of the participants noted that they had a breast lump which led them to seeking medical attention, and subsequently diagnosed. Almost 27% had no symptoms and were diagnosed following screening. In addition, approximately 13% noted a family history or a history of non-cancerous breast conditions that made them more vigilant about breast cancer screening. Where participants had symptoms, most sought medical attention soon after noticing symptoms.

Breast cancer can also lead to psychological distress, lymphoedema, fatigue, estrogen deprivation, insomnia and cognitive impairments[13,14]. In addition, people with breast cancer have reported ongoing mental health issues including depression and anxiety[15].

Similarly, in this PEEK study, almost half of the participants had current symptoms, most commonly fatigue, pain, weight and muscle changes, cognitive problems, anxiety and depression. In addition, over half reported sleep problems. Participants rated their quality of life from these symptoms in the distressing to a little distressing range.

Key point

- Rates of anxiety and depression in the PEEK study were higher compared to the Australian population

Screening and diagnosis

Early screening can help in reducing breast cancer related mortality and deaths[16]. Mammography is one such procedure which is commonly used and helps in evaluating local stage of disease and response to treatment[16,17]. Ultrasonography can be used as an additional tool for diagnosis of breast cancer[16,18]. Magnetic resonance imaging (MRI) is another non-invasive procedure used for diagnosis of breast cancer to provide highly accurate imaging of the lesion; the disadvantage of MRI is that is an expensive and invasive procedure[16,18]. Breast self-examination is a cheap and easy procedure which woman can conduct at home[16,19,20] and helps woman to learn about basic structure of breast and detect atypical structures in mammary gland[16,21].

In this PEEK study, more than 60% of the participants found had symptoms of breast cancer and sought medical attention from their general practitioner, the remaining were diagnosed with breast cancer following breast cancer screening. Participants on average had three diagnostic tests, and the most common diagnostic tests were mammogram, breast ultra sound, an core biopsy.

Key point

- Half of the participants were diagnosed as a result of finding a lump after-breast self-examination

Biomarkers or genetic markers

Biomarkers can be used for diagnosis, to monitor a condition, to predict response to therapy, or to predict disease course.

In Australia, immunohistochemical assays to determine oestrogen receptor (ER) and progesterone receptor (PR) status are routinely performed on invasive breast carcinomas and are often performed on ductal carcinoma in situ[22]. The receptor status provides prognosis information and prediction of response to endocrine therapy[23-25]. HER2 (human epidermal growth factor receptor 2) status is recommended for early invasive cancers and for metastatic or recurrent disease, it is a prognostic factor and also predicts response to biological therapies[26].

In this PEEK study, about a third of participants did not have any discussions about biomarkers, and about half of the participants were not aware that they had any biomarker tests, however, all the participants were aware of their ER status. This suggests that participants were not given enough information, or that communication was lacking about tests and the significance of the biomarker status.

Support at diagnosis

Other breast cancer studies have reported that people with early breast cancer were not prepared for their diagnosis despite early warnings from screening clinic or GP[27]. In a meta-analysis of qualitative breast cancer studies, common themes at diagnosis included shock, being overwhelmed, emotional upset, and disbelief, surprised they were diagnosed with cancer despite maintaining a healthy life style such as good diet, having regular mammograms, not smoking or drinking and not experiencing high level of stress[28].

In this PEEK study, over 70% had either no support, or not enough support at diagnosis, and a little over 40% had no information or not enough information at diagnosis.

Understanding and knowledge

Not much, really, when I think about it. I didn't know that there were so many different varieties of breast cancer. I had no idea. Participant 032_2021AUHRP

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[29,30]. Some people will seek out information about a possible diagnosis, or explore the reasons for symptoms, before receiving a final diagnosis[31,32] 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[33]. For some people, the first time they have heard of their chronic condition is when they are diagnosed[32]. 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[32].

In this PEEK study, most participants had at least some knowledge of breast cancer at diagnosis, often because of their professional background or because they researched breast cancer during the diagnostic process. Some participants noted a lack of knowledge about the different types of breast cancer, and the age group that breast cancer can occur. The majority of participants (60%) thought that they had enough information at diagnosis.

A qualitative study of older women with breast cancer reported that unless the women had worked as medical professionals themselves or knew other women with breast cancer, they were largely unfamiliar with breast cancer and its treatment before diagnosis [34]. In this PEEK study, one of the most common reasons for having some understanding of breast cancer was from having a professional background, and also having had a friend or family member with breast cancer.

In another early breast cancer study, people with breast cancer felt unable to cope with the situation and the large amount of information they were given, and felt unable to ask questions[27]. In this PEEK study, timing of information was important, with many feeling unable to digest information at the time of diagnosis.

Key points
- Emotional support and information needs are not being met at the time of diagnosis
- Information and discussion about biomarkers, including what they are, and relevance in treatment and prognosis is lacking, despite participants being well informed about biomarker status

Decision making

So, like side effects and then the short term effects as well as the long term effects there whether it whether the doctor thought it was necessary or not and why. What else? How it was sort of going to affect my lifestyle at the time. And the kind of support I could get to go through that. Treatment I suppose. Participant 020_2021AUHRP

The decision-making process in healthcare is an important component in care of chronic or serious illness[35]. 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[36,37], 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[38].

The majority of participants in this PEEK study were presented with multiple treatments or approaches to manage their breast cancer More than half of the participants felt they did not take part in the decision making process, sometimes there was a discussion about treatments, but some participants described being told what to do without discussion.

People with breast cancer discussed importance of information exchange with their doctor to encourage communication about values and to give the patient greater ownership of treatment decisions[39]. Another study reported that some worked collaboratively and were able to decide their treatment based on own preferences, others felt they had no choice, or were so confused by information presented that they did what the doctor told them to[40].

Treatment decision making in oncology requires a balance between efficacy and toxicity in order to maintain quality of life. Women with breast cancer have an identifiable role to play in taking part in decision making, however there is often an imbalance between health providers and patients in shared decision-making process and it has been reported not all women wish to be actively involved in shared decision making[41]. In this PEEK study, about 15% of participants took the advice of their doctor as the only consideration when making decisions about their treatment.

People with breast cancer have reported that did not have any choices for neoadjuvant systemic therapy, the decisions were made during or shortly after first consultation, most felt they made the final decision to have treatment but did not feel actively involved in the process[42]. In Another study, most women agreed with doctors recommendations but did not see this as decision making. Over 80% felt they had some part in decision making, with similar rates in metropolitan and rural locations[43]. In this PEEK study, less than half of the participants described actively taking part in the decision making process, with about 15% being told what to do without discussion.

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**[44,45].**

People with breast cancer consider the experiences of others with breast cancer, comorbidities, logistic and convenience, survival, recurrence and access to clinical trial or new treatment, when making treatment decisions[34,39,43,46-49].

In this PEEK study, taking side effects into account was the most common consideration when making decisions. Other considerations were taking the advice of their doctor, efficacy, and survival benefit. Some considered quality of life, the impact on their family, their ability to work, and how the treatment is given.

People with breast cancer noted that their lived experience of illness and treatment had made them more self-confident and assertive[39]. In this PEEK study, about half of the participants had changed the way they made decision-making about treatments over time, because they had become more informed and assertive over time, and considered quality of life and the impact of side effects. For those that did not change their decision making over time, this is because they were always informed or assertive, or always took the advice of their doctor.

Goals of treatment and decision-making

People with breast cancer have stated goals such as being around for their children or family, being around for important events, and to have peace of mind[46-48,50].

The most common goal of treatment was to be cancer free, and avoid recurrence. However, minimising side effects, improving quality of life, improving mental and emotional health were also common treatment goals. People with breast cancer reported that supportive resources from family and friend and medical advice from clinicians helped with treatment goals[39].

Access to health professionals

People with breast cancer have described a preference for oncology based follow up, driven by the need for reassurance that the cancer has not returned, but also want their GP involved [51]. In this PEEK study, the main treatment provider for half of the participants was their oncologist, other main providers of treatment were surgeons and general practitioners.

People with breast cancer living in regional areas have barriers to treatment, including low socioecomonic status, limited health services, distances to health services, and a lack of support for women that need to travel[52]. There were 12% of participants in this PEEK study that had to travel for more than an hour to get to their main provider of treatment, and 21% of participants lived in regional or remote areas.

Affordability of healthcare

Obviously, those systems to be there in place to support the family, financially, especially, but making it more simple. I found, obviously, not being able to get support, financially, from all authority but several income places like that really frustrating and I feel like that thing that I didn't have to deal with and I shouldn't have had to deal with. I think I'm not the first person with a chronic illness or an illness that can't go to work for a period of time that intends on going back to work. I think having support better there, in losing a person's entire income it shouldn't just be on the other person to pick up the slack. I think that's really crap and I think that's really put a lot of pressure on us that didn't need to be there. I'm just grateful for everything else because of the government and in saying that Medicare has been amazing. We were so grateful to have Medicare to support me through my treatments because, obviously, without that, it could have been a lot more difficult. Having that support to gain that financial support would have been really good because I had to use it for my leave or my sick leave and I was just glad I had that there. Then for Centrelink to not come to the party once that run out, I was like, "Why? Why are you not helping me?" That was frustrating but otherwise, it worked. Participant 042_2021AUHRP

Almost half of the Australian population have private health insurance with hospital cover[53]. 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%[53]. The majority of participants in this PEEK study had private health insurance (80%), 57% were mostly treated as a private patient, 25% as a public patient, and 18% a mix of both. Almost half of the participants were mostly treated in private hospitals, approximately 22% were treated mostly in the public system, and 29% were treated in both systems.

Financial difficulties have been reported for people with breast cancer, including difficulties for themselves and their families, interruptions to work and career progression[28]. People with low socioeconomic status have reported difficulties affording transportation, and housing[54,55]. Participants in this PEEK study rarely delayed or missed paying for healthcare appointments due to cost, and rarely did not fill prescriptions due to cost, and while they generally did not have trouble paying for basic essentials, this was more of a problem than paying for medical appointments and prescriptions.

Almost all the participants in this PEEK study described at least some cost burden as a result of their diagnosis with breast cancer. The cost burdens mostly related to the cost of treatments, the cost of specialists, scans and diagnostic tests, and the costs of parking and travel associated with their treatments.

Women with breast cancer have reported changing work tasks or changing jobs to manage in the workforce[56,57]. As a result of cognitive side effects, people with breast cancer have made work changes such as reduced hours, changing roles, and working extra hours to complete tasks[58]. Almost half of the participants in this PEEK study described a cost burden from loss of income, not only from having to take time off themselves, but also from family members needing to take time off. In another study, almost 80% of spouses reported absences from work due to their partners breast cancer, and had a mean salary loss of $1820 Canadian[59].

I was at work the day I went for my mammogram and then I couldn't go back because I was having treatment. Then I really couldn't give my work a date when I would go back. As a result of it all, I ended up taking now redundancy. I struggled with that because I absolutely loved my work. I wasn't ready to give up but in hindsight now, I'm over that now. I don't know what you've seen in terms of costs in there. Out of pocket was almost treatment at the time of the radiation. The radiation I think was $22,000 and I think I got back about $10 so I was out of pocket $12,000. What annoyed me and this is just a little bit of a gripe I guess, I've worked all my life. I've paid my Medicare, I've paid private health. Then there's people beside me there who were getting it for free, having exactly the same treatment as me so that was a little bit like—I know that they probably deserve. Everyone deserves the right to get the treatment but they were there at the private hospital having it for free where I was paying the $22,000. I've worked hard all my life to get savings to do all that. This isn't nearly true at all but that sum was a little bit, well, I think if it was good enough for them to have it for nothing, it probably was good enough for me to have it for nothing. Participant 004_2021AUHRP

Key points

- With a large proportion of private healthcare usage and cost burden, there is a need for transparency around treatment costs
- Loss of income places a financial burden on people with breast cancer and their families.

Treatment

The aim of surgery is excision of tumour with adequate margins or greater than 1mm. If local excision of not achievable or the tumour is large, multifocal or at the choice of the patient, a mastectomy is performed[60]. Neo-adjuvant therapies are used to reduce tumour size and breast conservation[61]. Pathological staging of the axilla is dependent on clinical presentation, clinically negative sentinel lymph node biopsy is usually conducted at the time of surgery[61]. Axillary lymph node dissection is used for clinically positive or if the sentinel lymph node is positive in clinically negative patients[61].

For early breast cancer, following local excision with clear margins, it is standard for five weeks treatment with whole breast radiotherapy, this may also be offered to women with DCIS[62]. Following mastectomy, radiotherapy may be given to the chest wall for those with high risk of recurrence (four or more involved lymph nodes, involved margins), or at intermediate risk of recurrence (one to three involved lymph nodes, grade 3 disease, oestrogen receptor negative and aged under 40)[62]. For locally advanced breast cancer, treatment is mastectomy followed by radiation.

Adjuvant treatment is determined by pathological outcomes, the biology of the tumour including histological grade, hormone receptor status and the amplification status of the HER2 gene in addition to lymph node status[61]. Five year Tamoxifen treatment is standard for pre-menopausal treatment of oestrogen receptor positive causes[60], and aromatase inhibitors for post-menopausal women[63], women who become post-menopausal benefit from changing to aromatase inhibitors[3]. There is benefit in continuing hormonal therapies to ten years, those who remain pre-menopausal continue with tamoxifen[3] and post-menopausal the aromatase inhibitor letrozole[64]. The use of bisphosphonates reduces the risk of distant recurrence in post-menopausal women[65]. For HER2 positive, the monoclonal antibody tzastuzumab[65] is used. Combination chemotherapy for early breast cancer only gives a small improvement on survival because the curative rate of surgery and hormone therapy in this group is high[66].

Chemotherapy is used in hormone receptor negative disease, HER2 positive, and rapidly progressive disease[61]. For early and locally advance breast cancer with positive lymph nodes, docetaxel chemotherapy is recommended[62]. On progression of advanced breast cancer, a sequence of single agent and combinations are used including single agent docetaxel, single agent vinorelbine, single agent capecitabine and combination gemcitabine and paclitaxel[67].

The aim of treatment in advanced breast cancer is disease control, symptom palliation and improvement in survival[61]. Hormonal treatment is used in oestrogen receptor positive women, the type is dependent on menopausal status[61]. Following resistance to hormone treatment, the hormone therapy exemestane is used with an enzyme inhibitor everolimus[68]. Radiation is used in advanced breast cancer in patients with bone metastases and pain, and in patients with brain metastases whole brain radiotherapy with or without resection[67].

In this PEEK study, there were 46 participants (88.46%) that had surgery (most commonly a lumpectomy), 48 participants (92.31%) that had drug treatments (most commonly Tamoxifen), and 42 participants (80.77%) that had radiotherapy. Almost half of the participants in this PEEK study were at least sometimes were concerned about what will happen when a successful treatment is finished.

Allied health

Allied health is important to manage the physical, emotional, practical and financial consequences of breast cancer. side effects of breast cancer.

More than 75% of participants in this PEEK study had used at least one type of allied health to manage their breast cancer. The most common type was physiotherapy, with about 60% having used this type of support. Approximately a third had seen a psychologist. In other breast cancer studies, people with breast cancer have reported that they had a lack of psychological support, physiotherapy, and counselling[69,70].

Lifestyle changes

Diet and exercise needs of people with cancer change throughout the course of their treatment and survivorship[71]**,** and lifestyle changes may be made by individuals to improve treatment outcomes, improve quality of life and reduce recurrence risk factors[72]**.** People with breast cancer have described the need for education about physical activity during chemotherapy, especially impact of side effects, and described the importance of personalised programs and support from peers, friends and family[73].

People with breast cancer have reported weight gain, this is from treatment side effects, and psychological issues related to readiness to change and self-regulation[74]. Habitual physical activity has been reported to help with making positive diet changes[74]. Other benefits of lifestyle changes are demonstrated in a yoga intervention, where participants described improved physical, mental and social functioning, in addition, they benefited from being able to share breast cancer experience within yoga group[75].

In this PEEK study, 87% of participants described making at least one lifestyle change, this was most commonly exercise and diet. In addition, physical exercise was cited as a way to manage both their mental and general health.

Complementary therapies

The advancements in the treatment of breast cancer and improvements in survival come with ongoing side effects which need to be managed, and one area of practice that has the potential to alleviate symptoms and side effects is complementary therapies[13]. People with breast cancer have expressed a belief that complementary therapies plays role in delivering personalised and holistic treatment[76].

In this PEEK study, 77% of participants used at least one type of complementary therapy, most commonly taking supplements, or using mindfulness or relaxation techniques. Mindfulness and relaxation techniques were described as ways that helped participants deal with the impact of breast cancer on their mental health and to deal with their vulnerability. Similar to a study of complementary therapy use in Canada, menopausal women with breast cancer, nearly 70% used complementary therapies including mindfulness, and taking supplements[77].

Key point

- Complementary therapies and lifestyle changes were used by over 75% to help manage their breast cancer

Clinical Trials

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 4 October 2021. The search included any study that was specific to hormone-receptor positive (ER and/or PR positive) breast cancer participants, was conducted in Australia, and was open to recruitment in the last five years. A total of 37 studies were identified that had a target recruitment of between 8 and 5101 participants (median=221), there were 27 studies that were international, and 10 studies that were conducted exclusively with in Australia. There were 32 studies that were for drug treatments, two radiotherapy treatment, one lifestyle intervention, and one pathology/multidisciplinary team study.

There were 29 studies conducted in Victoria, 27 in New South Wales, 16 in Western Australia, 15 in Queensland, 13 in South Australia, four in Canberra, two in Tasmania, and one in the Northern Territory. There were no studies identified that were open to recruitment in Tasmania or the Northern Territory.

In this PEEK study, 33% of participants had discussions about clinical trials with their doctors. Very few participants had taken part in a clinical trial, though more than 76% had either taken part or were willing to take part in a clinical trial if there was one suitable.

Figure 12.1: Distribution of clinical trials for Hormone-receptor positive breast cancer in Australia 2016-2021

Patient treatment preferences (side effects)

We're given information sheets with each new drug that we're taking or going to take, but they skim through some of the side effects that maybe if they have information sheets about the actual side effect itself and what that could look like for you. For example, things like peripheral neuropathy. It's not just hands and feet, there's so many different things that it affects, and I wasn't aware of that until-- I didn't get that information from my medical team, it was more from the McGrath nurse, breast cancer nurse. She was able to give me a huge-- or she printed off a lot of information and sent it to me about what affected. When I read that information sheet, I went, "Oh my gosh, this is what I'm going through." I was able to take that to my medical team and say, "This is what I'm--" I couldn't put it into the right words that this is what I'm going through. Then, there was other treatments that was offered to me because of that. I think it's more information on each specific side effect. Participant 049_2021AUHRP

Clinical guidelines that are aligned to patient preferences are more likely to be used and lead to higher rates of patient compliance[78-80]. 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[78,81].

To help inform patient preferences in the hormone receptor-positive breast cancer community, participants in this PEEK study discussed side effects, treatment administration, adherence to treatment. Mild side effects were often described by using a specific example, such as fatigue, aches and pains, and hair-loss. They were also described as side effects that did not interfere with life or could be self-managed. Similarly, severe side effects were often described using an example, as those that interfered with every day life, or those that required medial intervention. Aches and pains were used to describe both mild and severe side effects, in addition, examples of severe side effects were nausea and those that impacted mental of emotional health, and those that impacted sleep. For people with breast cancer, understanding types and severity of side effects along with the potential impact on daily life and how to manage side effects may be important for treatment decision making.

In this PEEK study, the most important symptoms to control for quality of life reported in the quantitative section were fatigue, pain, cognitive function, bone problems, heart problems, and anxiety and depression. In contrast, another study report people with breast cancer ranked sleeping difficulties as the the most troublesome symptom, followed by concerns about family or partner, and loss of hair. Vomiting and nausea was also reported as troublesome symptom[82].

Cognitive side effects included memory problems, recalling how to do previously known tasks, verbal functions, executive functions, processing speeds and inability to stay focused[58,83].. This had economic impact including changes to work, or having to quit jobs, psychosocial impacts such as reduced confidence in trying new things or going out, reluctance to socialise, frustration of partners, and a decreased tolerance to stress and criticism, and some had minimal impacts. [83]. In this PEEK study, cognitive function was ranked as one of the most important symptoms to control to improve quality of life.

Hormonal side effects such as pain, fatigue, poor sleep, lack of concentration and low motivation, hot flushes, anxiety, depression and poor self-esteem impacted personal and social life[15]. In this PEEK study, the impact of side effects, in particular menopause, was a common theme contributing to poor quality of life, or having an impact on relationships due to intimacy problems.

The impact of side effects in this PEEK study was a reoccurring theme throughout the structured interviews. It was the most common theme for considerations when making treatment decisions, to know that treatment is working (see a reduction in side effects), recommending more information about side effects from treatment in future and hoping that future treatments will have fewer or less intense side effects. It was also a common theme in relation to treatments goals (reducing side effects), adhering to treatment (as long as side effects were tolerable), and impact on quality of life.

Key point

- Information about side effects of treatment could include the types of side effects, the impact on day-to-day life, the severity, and how to manage them.

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[84]. Components of self-management include information, activation and collaboration[84].

Information is a key component of health self-management[85,86]. 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[85,86].

Information

The Breast Care Network has been really helpful. They've got a really helpful website that gives a lot of information. I've also joined a couple of Facebook pages of women who have also been suffering from breast cancer and being able to share the knowledge that they've gained, and also talking to my breast care nurse. I haven't seen her for a while, but when I was going through treatment, talking to my breast care nurse as well was quite helpful. The Australian government's cancer sites as well have a lot of good information. I get my information from what I consider reputable sources. I'd rather get them from people who know what they're talking about rather than the hearsay. Participant 037_2021AUHRP

In this PEEK study, abut 13% of participants were satisfied the type and amount of information they received for breast cancer, and just over half of the participants were satisfied with the amount of information that they received at diagnosis. An exploratory qualitative study observed that the cancer patients have a desire to receive more information in relation to their specific condition, in a more detailed manner[87].

Participants in this PEEK study accessed information from combinations of the internet, pamphlets, phone apps, and from talking to their doctor. In other studies, people with breast cancer reported getting information from a range of sources including family and friends, healthcare professionals, the internet, written resources, cancer support organisations and others with breast cancer[34,88-92]. In this PEEK study, participants most accessed information from health charities, the government or the hospital where they were treated. Similarly, the most accessed materials were government websites, scientific publications and printed patient materials[93].

Participants in this PEEK study described some of the advantages of each type of information were highlighted by participants, for example, the internet in accessible and allows them to digest information at their own pace. Talking to their doctor is beneficial as it allows them to ask questions, and they know that their doctor is only giving them relevant information. Having a booklet is useful as they can annotate it.

In other studies, people with breast cancer described that the benefit of speaking to someone was the ability to ask questions, get clarifications, and feeling supported. In other studies, people with breast cancer reported liking complex information presented visually, and they liked to discuss information materials with their doctor, with the ability to take information home, while they valued the multiple sources of information available on the internet and social media, found the information could be both positive and negative[89-91]. In addition, the internet was described as a good place to get information and support, good for rural, concerns about limited information for advanced breast cancer, and that everyone with breast cancer is different[88].

The types of information most frequently given to participants by healthcare professionals were about, treatment options, physical activity, and disease management, the topics least frequently given were how to interpret test results, complementary therapies, and clinical trials. The types of information most frequently search for were treatment options, how to interpret test results, disease management and disease cause, and the least searched for topics were psychological/ social support and, clinical trials. This is similar to other breast cancer studies where people with breast cancer wanted information about side effects of treatments, managing symptoms, and peer support[38,70,77,88].

The types of information that participants in this PEEK study found useful tended to be information that helped them understand what to expect. This could be information about the disease course or side effects from treatments, about their particular type of breast cancer, and also what other people with breast cancer have experienced. They also describe helpful information in terms of where the information came from, for example their doctor or a health charity. In other studies, people with breast cancer valued concise and credible information[77], and a mixture of positive and negative value placed on other people's experiences[90,91].

Participants in this PEEK study described what they expect for information in the future. Information about symptoms and side effect control was the most common theme. Information about services and holistic treatments were also common themes. Participants also wanted details about their own health records related to breast cancer, for example their diagnosis and treatments, and also information that was specific to their breast cancer stage or type, and also relevant to their age group.

Activation (skills and knowledge)

Definitely. I think right at the start, I didn't know much about all that side of things. I was in a shock a lot of the time but then, my partner was excellent. He's really good at asking questions. I think you just learn that you've got to write all the questions down. Anything that would come up before you do that appointment next. I just do it every time I go. Okay, I've got my question today just with the oncologist. I just go through. I say we are going through all the questions make her go through them with me, which has been really good. It helps me to clear my head a bit because sometimes you don't understand why they want you to do certain things. Participant 048_2021AUHRP

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[94]. Participants in this PEEK 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.

In another breast cancer study, people with breast cancer reported that in follow up post-treatment, they did not know how to manage ongoing concerns relating to their self-image due to scarring, lymphoedema, fatigue and the side effects of medication[15]. In this PEEK study, wanting information about side effects of treatment was a common theme throughout the semi-structured interviews.

Adherence

I just cracked on through tamoxifen. I'm not at that point yet. Even if I stop my medication-- A lot of women talk about stopping tamoxifen or Aromasin because of the impact it's having on them being in menopause, but the fact is even if I stop taking those drugs now, I've had my gynae surgery. I have those side effects. I'm not at that stage. I think it's also difficult to try and differentiate. Is that side effect because I'm in menopause, is it because of the Aromasin, or is it because I'm getting older, or is it just because of the cancer or of all the treatment? Is it all of those things? It's really difficult to actually isolate what's what. Participant 043_2021AUHRP

Adjuvant endocrine therapy effectively prevents recurrence and progression of estrogen-receptor positive breast cancer, however, studies reveal substantial non-adherence[95]. The majority of the participants in this PEEK study had taken or are taking hormone blockers long term. On average, quality of life while on these treatment was in the life was a little distressing to average range, and was thought to be effective to very effective. Participants in this PEEK study described adhering to treatment in terms of a specific amount of time, on advice of their doctor, never giving up on a treatment, and the ability to cope with side effects.

In other studies, people with breast cancer have described reasons or ways that adherence to endocrine therapy is improved. These include, having sufficient information, understanding efficacy, fear of negative consequences of non-adherence such as recurrence, the ability to cope with side effects, ease of access to medication and setting up reminder systems, personal determination, regular follow up with treatment team, and affordability of treatment[95-97]. Reasons for non-compliance include forgetfulness, not believing in that the treatment is effective or needed, side effects and costs[96,97].

Having a belief that a treatment is working may encourage adherence to endocrine therapy[96], in this PEEK study participants described how they could tell if a treatment was working. This was often seeing the reduction of a specific symptoms, such as aches and pain, or hot flashes. Some described needing to see a reduction in side effects in general, while others needed to balance the benefits of a treatment with the potential side effects. Others described the need to see evidence of no disease or no disease progression, or that it was difficult to know if a treatment was working without having test results.

Key point

- Physical activity was used to maintain both physical and mental health

Communication and collaboration

My surgeon has always been really open to discussions and answering questions and to a great degree, she has been a go-to and my medical oncologist is also fabulous, in a different way. He is very good at using statistics for and against things to help with decision-making and doesn't push a decision overly in one direction. He'll gently encourage but he's not a you-must-do-this person, it's, "I suggest this because the research shows." My GP, hit and miss. Participant 023_2021AUHRP

Collaboration is an important part of health self-management, the components of collaboration include healthcare communication, details for available information, psychosocial and financial support [85,86] Communication between healthcare professionals and patients can impact the treatment adherence, self-management, health outcomes, and patient satisfaction[98-101].

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[102].

Building a relationship with patient, families and support networks is fundamental to establishing good communication[102]. 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[102]. 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[102]. 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[102]. 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[103]. The participants in this study experienced very good quality of care, and very good coordination of care. They had a good ability to navigate the healthcare system, and experienced good communication from healthcare professionals.

Participants in this PEEK study described generally described communication with their healthcare team as positive. When communication was described in a positive way, this was mainly because the communication was holistic, two-way, and comprehensive. Similarly, in other studies people with breast cancer described their understanding of breast cancer was improved when delivered in a two-way exchange[104,105.].

While the communication was seen as positive, participants in this PEEK study described limitations such as their understanding of the communication, and the lack of time in appointments, in additions, participants would like to see communication that is more transparent and more forthcoming, as well as being more empathetic. Likewise, in other studies, people with breast cancer reported that communication was limited by lack of time, conflicting information, not understanding medical terms, and noting that while clinicians are medical experts but they must earn trust through being professional[39,40]

Care and support

PARTICIPANT: In terms of other relationships, I would say that other relationships have been positive in the sense that I've had like 30 something people sign up to an app to offer assistance, if I need it. I've had--

INTERVIEWER: Can you give the name of the app?

PARTICIPANT: It's called Gather My Crew. It's a platform where people can sign up, and then you post tasks like appointments and other things you need help with, and they can volunteer for those tasks. That way you don't have to go around asking every single person. That's been a real positive thing. I didn't know that I would have 30 people voluntarily sign up just to offer assistance with. Participant 044_2021AUHRP

When asked about the care and support they received, about a third of participants in this PEEK study responded that they did not receive any care or support. Support limitations have been reported elsewhere due to family and friends not meeting support needs, timing, personal difficulty in asking for help [88]. Other participants in this PEEK study described getting care and support from their hospital or clinical setting, from charities, and from support groups. About 10% described that they did not need any help. This is similar to other studies that have reported that people with breast cancer felt supported during their treatment, especially with the information, emotional support and feeling safer in hospital, trust important [28,57,106]. In terms of future care and support, participants in this PEEK study would like more access to support services, in particular access to specialist clinics where that can talk to healthcare professionals, long term condition management, and mental and emotional support.

Almost all of the participants in this PEEK study described having feelings of vulnerability since their diagnosis with breast cancer. The most common times that participants in this study felt vulnerable was during the time around diagnosis, and during and after they had treatment. Some described feeling vulnerable because of interactions they had with their medical team.

There are number of interventions to help patients suffering from psychological distress including cognitive and behavioural cancer stress management interventions (improves depressive symptoms, anxiety, self-efficacy, fatigue, social functioning, perceived social support, and benefit finding) supportive-expressive therapy (improves in depressive symptoms, hopelessness and helplessness, trauma symptoms) and meaning-centred psychotherapy (improves quality of life, depressive symptoms, and hopelessness)[107-110]. Participants in this PEEK study described self-help methods such as resilience, acceptance and remaining positive as a way to manage their vulnerability. They also described the support of nurses or their treatment team, and family and friends to manage their vulnerability.

Key point

- Good communication with healthcare care professionals was two-way, holistic, and comprehensive

Anxiety associated with condition

I suppose there's still that element of vulnerability. Even though I've moved on, sometimes I go, "You've had cancer and cancer is a terminal illness. Whether I'm cancer free or not, it's irrelevant. At the end of the day, I have had a cancer diagnosis." That's the way I look at that. I don't dwell on it. I don't feel sorry for myself. I don't wallow. I don't whinge and whine but I've had cancer. Participant 027_2021AUHRP

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[111]. Nearly all participants in this PEEK study described that their diagnosis with breast cancer had an impact on their mental health. In addition, approximately 60% of participants in this PEEK study reported anxiety, and 37% reported depression.

In this PEEK study, anxiety associated with breast cancer was measured by the fear of progression questionnaire[112]. There was a moderate fear of progression. This was consistent for all subgroups.

Quality of life

Then also, actually, one of the places that I was working, I'm not working now. She actually said to all staff, which was lovely. You need to ask PARTICIANT how she's going? Because if you ignore it, because I found at the beginning, I knew everyone knew. But they also, were just going on as business as usual. And how are you going? Oh, good. And I just felt really, really lonely. Because I thought it almost I knew they did care. And they just didn't know what to say. Because they didn't want to see me crying or something. But then when COLLEAGUE said something to them, I noticed the difference, because I walked in and everyone was going, how are you going? How are you feeling? And it was actually really, really sweet. And she said it. You know, it's really hard for that person and explained that I will feel really lonely. And like no one cares if, if no one asked me and so everyone did. It was as simple as that, which was really lovely. Participant 034_2021AUHRP

Over half of the participants in this PEEK study described that their diagnosis with breast cancer had a negative impact on quality of life, about 20% described a minimal impact, there were less than 20% that described at least some positive impact on quality of life. The reasons for a negative impact were mostly due to emotional strain on either partners or children, and also on the participant with breast cancer. Other reasons for a negative impact were due to side effects, such as the reduced capacity for physical activity, fatigue, menopausal symptoms, and the impact of menopause on intimacy. For those that described a positive impact on quality of life, this was mostly due to their diagnosis giving them perspective and realising what is important in life. In other studies, people with breast cancer have reported the negative impacts of side effects on their quality of life, in particular as it interferes with day-to-day activities, domestic tasks, work, hobbies and maintain their role in the family[28,34,57].

A quarter of participants in this PEEK study described no impact on relationships following their diagnosis with breast cancer. The remaining 75% described an impact, some completely negative, some completely positive, and others a mix of both. Overall, similar numbers described positive impacts and negative impacts. Negative impacts on relationships was primarily due to other people withdrawing from the relationship, not knowing what to do or say. Positive impacts on relationships were a result of other people being well-meaning and supportive, and relationships with family being strengthened. Similarly, other breast cancer studies have reported that relationships are impacted by the changes to relationship dynamics, new demands on relationships, and changing roles in the family[113,114], in addition, the impact of prioritising their own health was sometimes at the expense of relationships[113,114].

Nearly all participants in this PEEK study described that their diagnosis with breast cancer had an impact on their mental health. The most common way to maintain mental health in this cohort was to use mindfulness or meditation. In terms of other ways participants used self-help techniques, other ways of maintaining mental health were to exercise, remaining social, keeping up with hobbies, and they described the importance of family and friends. Approximately a third consulted a mental health professional. In terms of regular activities to maintain health, almost half described the importance of being physically active. It is interesting to note that exercise was also an important way to maintain mental health. Other ways to maintain health included self-care, for example getting more rest or support for domestic tasks, also understanding their limitations, and maintaining a healthy diet. Almost 20% described the importance of complying with treatment. This is similar to other studies, were people with breast cancer reported seeking professional help, exercising, making changes to diet, taking part in social events, and taking a rest when needed[28,57,75,115,116]. In addition, people with breast cancer described the other ways to maintain mental and physical health by educating themselves, volunteering to help others, physiotherapy, and adapting work schedules[28,57].

Key point

- Breast cancer had an overall negative impact on quality of life, mental and emotional health.

Characterisation

There were 52 participants with hormone receptor positive breast 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, aged mostly between 45 and 64. More than half of the participants had completed some university, and most were employed either full time or part time. Half of the participants were carers to family members or spouses.

Physical health and emotional problems interfered with work and other activities for participants in this study.

Approximately half had symptoms before diagnosis, and approximately half have ongoing symptoms from breast cancer or breast cancer treatments. Before diagnosis, they most commonly had breast lumps, and fatigue. The most common current symptoms were sleep problems, weight and muscle changes, thinking and memory problems, anxiety, fatigue and pain that all contributed to poor quality of life.

This is a group that had health conditions other than breast cancer to deal with, most often anxiety, sleep problems, and depression.

This is a patient population that did not experience symptoms and were diagnosed by having breast cancer screening. Of those that did have symptoms, on finding a breast lump, they sought medical attention and were diagnosed by their GP following referral to imaging studies.

This group had some knowledge of their condition before diagnosis, mostly because of their professional background or because they researched it during the diagnostic period. They understood their prognosis in terms of there being no evidence of cancer.

This is a cohort that were mostly diagnosed with breast cancer without experiencing symptoms. On average, this group had three diagnostic tests for breast cancer, they were diagnosed by a specialist doctor. The cost of diagnosis was somewhat of a burden to them and their families. They were mostly diagnosed with invasive breast cancer, and stage II or III. This is a group that did not have enough emotional support at the time of diagnosis, they did have enough information. This is a cohort that had conversations about biomarker/genomic/gene testing, and had knowledge of their biomarker status.

This is a group that were presented with multiple options and approached to managing their condition, and took part in making decisions about their treatment.

This is a study cohort that took side effects into account the of many considerations when making decisions about treatment.

Within this patient population, near equal numbers of participants had changed decision making over time and hadn't changed over time, in both cases, this was linked to being informed and assertive.

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

They were cared for by a medical oncologist, and it usually took less than an hour to travel to medical appointments.

Over 80% of this cohort had private health insurance, they were mostly private patients in the private health 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 breast cancer were somewhat of a burden.

Participants in this study had to quit, reduce hours, or take leave from work. Carers and family did not have to change their employment status. The loss of family income was a burden.

Participants had surgery, drug treatments, and radiotherapy for breast cancer. They on average used one allied health service, one complementary therapy and made two lifestyle changes.

A third of this cohort had conversations about clinical trials. The majority of participants would take part in a clinical trial if there was a suitable one for them.

This is a patient population that described mild side effects as symptoms such as fatigue, pain and hair loss, they also described them as those which can be self-managed and do not interfere with daily life.

This is a study cohort that described severe side effects as symptoms such as pain, nausea, impact mental and emotional health or sleep. They also described severe side effects as those that impact everyday life and the ability to conduct activities of daily living.

This is a patient population which described an amount of time they were willing to adhere to a treatment before giving up, or would continue treatments on the advice of their doctor. This is a study cohort that needed to see symptom reduction to feel that treatment is working. If treatment was working, it would mean that they could do everyday activities and return to a 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 physical activity from health care professionals, and searched for treatment options, interpreting test results, 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, and health charities.

This is a study cohort that found information about what to expect from the disease, side effects and treatments as being most helpful.

Participants commonly found no information unhelpful, and information from other people's experience as unhelpful.

This is a group that preferred to get their information from a combination of resources, most commonly talking to someone plus online information. This is a study cohort that generally felt most receptive to information from the beginning, at diagnosis.

Most participants described receiving an overall positive experience with health professional communication (some with a few exceptions) which was holistic, two way and comprehensive. Despite having good communication, it was limited by time, and their understanding.

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

This is a patient population that felt that they did not receive any care and support, for those that did, it was from their hospital or treatment clinic.

This is a patient population that experienced a negative impact on quality of life largely due to emotional and mental strain on their partners, children, and themselves.

Life was a average for this group, due to having breast cancer. The symptoms that most impact quality of life of this group are pain, fatigue, and cognitive problems.

This is a study cohort that experienced at least some impact on their mental health and to maintain their mental health they used coping strategies such as mindfulness and meditation, and physical exercise.

Within this patient population, participants described being physically active, and the importance of self-care, in order to maintain their general health.

Participants in this study had felt vulnerable especially during the diagnostic process, and during or after treatments. To manage vulnerability, they relied on their own resilience, acceptance, and being positive.

This cohort most commonly felt there was a mix of positive and negative impacts on their relationships, with some relationships strengthened, and others described family and friends withdrawing from relationships because they don't know what to say or do .

Half of the Participants in this study felt they were a burden on their family, due to the extra responsibilities that had to take on, and the other half of participants were not a burden as they didn't need any help and remained independent.

Almost all participants felt there was some cost burden which was from the costs of treatments, tests and scans, and also from having to take time off work.

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

Participants would like future treatments to have fewer or less intense side effects.

This is a study cohort that would like more information about symptoms and side effect management and control.

Participants in this study would were mostly happy with their communication with healthcare providers, but suggested that future communication could be more transparent, forthcoming, and empathetic.

Participants would like future treatments to include more access to support services.

This patient population was grateful for the healthcare staff, and the entire health system, both public and private.

It was important for this cohort to control memory loss and cognitive function, fatigue, and pain. 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 improve access to support and care.

This is a patient population that wished they had known what to expect from their condition especially the disease trajectory and disease biology. They also wished they had been more proactive in asking for information.

This is a patient group that were satisfied with the care received and would not change it, though they wish they had a better understanding of their condition.

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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:

SUPPORT: As this was a cohort that felt it was important for treatment to be able to control memory loss and cognitive function, fatigue, and pai additional long-term, holistic support would be beneficial. This should include physical, emotional, mental, and medical support particularly for those on long term treatments to support adherence.

COSTS: Transparent information about the costs of treatment is important to this patient population. Cost includes knowing the trajectory of the condition so that they can plan their life and work accordingly and know what costs to expect, especially with private health insurance. This transparent information may help improve quality of life as it was noted that this is a patient population that experienced a negative impact on quality of life largely due to emotional and mental strain on their partners, children, and themselves.

INFORMATION: This is a study cohort that found information about what to expect from the disease, side effects and treatments as being most helpful. They also wished they had known what to expect from their condition especially the disease trajectory and disease biology. To this end, more detailed information about treatment side effects that describes the types of side effects, the impact on day-to-day life, the severity, and how to manage them would benefit this patient population.

2021 PEEK study in Hormone receptor-positive breast cancer

Data collected in this PEEK study also provides a basis on which future interventions and public health initiatives can be based. Some of the 2021 metrics that the sector can work together to improve upon are provided in Table 12.1

Table 12.1 Hormone receptor-positive breast cancer 2021 Metrics

Measure	Detail	Mean	Median
Baseline health (SF36)	Physical functioning	76.83	75.00
	Role functioning/physical	48.56	50.00
	Role functioning/emotional	67.31	83.33
	Energy/fatigue	43.56*	45.00
	Emotional well-being	70.15	72.00
	Social functioning	67.55	75.00
	Pain	60.10	57.50
	General health	60.48*	60.00
	Health change	46.63	50.00
Knowledge of condition and treatments (Partners in Health)	Knowledge	28.00	29.00
	Coping	17.22	18.00
	Recognition and management of symptoms	20.71	21.00
	Adherence to treatment	14.94	15.00
	Total score	80.86*	82.00
Care coordination scale	Communication	45.75*	46.00
	Navigation	26.86*	27.00
	Total score	72.61*	75.00
	Care coordination global measure	8.12	9.00
	Quality of care global measure	8.80	9.00
Fear of progression	Total Score	33.86*	34.00
		Percent	
Accessed My Health Record	-	23.53	-
Participants that had discussions about biomarkers/genetic tests	-	69.23	-