CENTRE FOR COMMUNITY-DRIVEN RESEARCH

Personal Experience, Expectations and Knowledge (PEEK)

People diagnosed with:

Triple negative breast cancer

Volume 4 (2021), Issue 3

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Number of participants	50

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Summary of results

Executive summary

There were 50 participants with triple negative 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 35 and 54. About half of the participants had completed some university, and most were employed either full time or part time. Almost half of the participants were carers to family members or spouses.

About half of this group had ongoing breast cancer symptoms, commonly had thinking and memory problems, weight and muscle changes, and pain, which all contributed to their 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 experienced breast lumps which lead to their diagnosis. Most participants sought medical attention after noticing symptoms and were diagnosed after their general practitioner sent them for imaging studies. Very few participants were diagnosed through breast cancer screening.

On average, this group had three diagnostic tests for breast cancer, they were diagnosed by a general practitioner in a general practice. The cost of diagnosis was not 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, but 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 study cohort that had little knowledge of triple negative breast cancer before they were diagnosed. This patient population described prognosis in terms of no evidence of disease or in remission, or in terms of statistics, particularly reaching five years.

This is a patient population that had discussions about multiple treatment options, with most being told what to do with little discussion.

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

Within this patient population, most participants had changed decision making over time this was because they had become more informed and assertive.

When asked about their personal goals of treatment or care participants most commonly described wanting to treat the disease and get better.

This is a group who felt they were mostly treated with respect throughout their experience. They were cared for by a medical oncologist, and it usually took less than an 30 minutes to travel to medical appointments.

Three-quarters of this cohort had private health insurance, and equal numbers were treated as either private or public patients. They were equally treated in the private and public hospital systems. This is a group that did not have trouble paying for healthcare appointments, prescriptions. They had some trouble paying for basic essentials such as food, housing and power. Their monthly expenses due to breast cancer were slightly significant.

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

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

More than third had conversations about clinical trials, and they 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 those which can be self-managed and do not interfere with daily life.

This is a study cohort that described severe side effects as those that impact everyday life and the ability to conduct activities of daily living.

This is a patient population that would adhere to treatment according to the advice of their doctor, or as long as prescribed. This is a study cohort that needed to see a reduction in physical signs and symptoms to feel that treatment is working as well. If treatments worked, it would allow them to 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 disease management, treatment options and hereditary considerations from health care professionals, and searched for interpreting test results, and complementary therapies 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, their treating clinician or social media.

This is a study cohort that found information about other people's experience, what to expect from the disease, and information specific to their type of breast cancer as being most helpful.

Participants commonly found information form sources that are no credible unhelpful.

This is a group that preferred online information, or talking to someone. This is a study cohort that generally felt most receptive to information from the beginning, at diagnosis, or during treatment.

Most participants described receiving an overall positive experience with health professional communication (some with a few exceptions) which was holistic, two way and comprehensive. For those that had a negative experience it was mostly communication limited or not forthcoming.

The participants in this study experienced very good quality of care, and 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 most found support through charities, and about a third had no support.

This is a patient population that experienced a negative impact on quality of life largely due to emotional strain on family, and changes to relationships.

Life was a little distressing for this group, due to having breast cancer.

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 remaining social, lifestyle changes and hobbies, and consulted mental health professionals.

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 or after treatments, and when having sensitive discussion about their breast cancer. To manage vulnerability, they relied on support from their medical team.

This cohort most commonly felt there was a mix of positive and negative impacts on their relationships, with some relationships strengthened.

Participants felt they were a burden on their family, due to the extra household duties and responsibilities they had to take on.

Most 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 less side effects and be more effective.

This is a study cohort that would like more information about available services, treatments, and mental and emotional health support.

Participants in this study would like future communication to be more transparent and forthcoming. Many participants were happy with their communication with healthcare professionals.

Participants would like future care and support to include more access to support services..

This patient population was grateful for the timely access to treatment and they were grateful for healthcare staff.

It was important for this cohort to control fatigue, pain, and heart problems. 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 care and support.

This is a patient population that wished they had known more about the pros and cons of treatment, what to expect from their condition especially the disease trajectory and disease biology and about the support services available to them.

The aspect of care or treatment that participants in this study would most like to change is to have changed or stopped the kind of treatment they had, however, many wouldn’t change any aspect of their treatment or care.

Section 1

Introduction and methods

Section 1 Introduction and methodology

Triple negative breast cancers are defined by the lack of progesterone and oestrogen receptors, and HER2 proteins. Triple negative breast cancers are an aggressive form of breast cancer that typically affects younger women, has a poor prognosis, and lack of targeted therapies.

In 2019, there were 19,371 new cases of breast cancer reported in Australia[5]. Approximately 12 to 17% of all breast cancers are triple negative, that is an estimated 3000 new cases of triple negative breast cancer in Australia 2019.

A PubMed search was conducted in 2021 to identify studies reporting patient experience, patient reported outcomes, and quality of life studies in the triple negative breast cancer community. Studies conducted more than 10 years ago were excluded, and studies that included multiple types of breast cancers that did not report triple negative breast cancers separately (as a subgroup) were excluded. There were 12 studies identified of between six and 902 participants. There was only one study identified that interviewed participants or used qualitative methods, this study was focused on African Americans diagnosed with triple negative breast cancer.

This PEEK study appears to be among the largest cohorts of women diagnosed with triple negative breast cancer that includes a structured interview and it also covers the most domains.

Section 2

Demographics

Section 2 Demographics

There were 50 people with that took part in this study with triple negative breast cancer. Participants were aged from 25 to 74 years of age, most were aged between 45 to 54 years (n = 22 ,44.00%).

Participants were most commonly from New South Wales (n = 14, 28.00%), Queensland (n = 14, 28.00%), and Victoria (n = 11, 22.00%). Most participants were from major cities (n = 34, 68.00%), and they lived in all levels of advantage, defined by Socio-economic Indexes for Areas (SEIFA) (www.abs.gov.au) with 30 participants (60.00%) from an area with a high SEIFA score of 7 to 10 (more advantage), and 20 participants (40.00%) from an area of mid to low SEIFA scores of 1 to 6 (less advantaged).

There were 26 participants that had completed university to at least an associate degree (54.00%). There were 27 participants who were employed either full time (54.00%), or part time (n =14, 28.00%).

Almost half of the participants were carers to family members or spouses (n = 26, 54.00%), most commonly carers to children (n = 25, 50%).

Breast cancer stage

There were 50 people with triple negative breast cancer who took part in this study. There were six participants (12.00%) with Stage I, 17 participants (34.00%) with, Stage II, 24 participants (6.00%) with Stage III, and three participants (6.00%) with Stage IV.

Other health conditions

The majority of participants had at least one other condition that they had to manage (n = 44, 88.00%), the maximum number reported was eight other conditions, with a median of three other conditions (IQR = 4.00). The most commonly reported health condition was anxiety either self or doctor diagnosed (n = 27, 54.00%), followed by sleep problems or insomnia (n = 22, 44.00%), chronic pain (n =13, 26.00%), and depression (Self or doctor diagnosed) (n = 19, 38.00%).

Baseline health

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

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

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

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

Section 3

Symptoms and diagnosis

Section 3: Symptoms and diagnosis

Symptoms leading to diagnosis

In the structured interview, participants were asked to describe the symptoms that actually *led* to their diagnosis. The most common symptom leading to diagnosis was having a lump or lumps in breasts (n=39, 78.00%), this was followed by having no symptoms (n=5, 10.00%). Other symptoms (n=6, 12.00%) leading to breast cancer included pain and symptoms from metastases.

Symptoms leading to diagnosis: Seeking medical attention

Participants described when they sought medical attention after noticing symptoms. There were 31 participants (62.00%) that described having symptoms and seeking medical attention relatively soon. There were six participants (12.00%) that described not having any symptoms before diagnosis, and six participants (12.00%) described having symptoms and not seeking medical attention initially.

Diagnostic pathway

Participants were most commonly diagnosed by their general practitioner due to concerns about symptoms (following imaging studies) (n=29, 58.00%). Other participants were referred directly to a specialist from their general practitioner which led to their diagnosis (n=11, 22.00%), and diagnosed through a population screening program (n=5, 10.00%)

Time from symptoms to diagnosis

Participants were asked to give the approximate date of when they first noticed symptoms of triple negative breast cancer and the approximate date of diagnosis with triple negative breast cancer. Duration was calculated for 18 participants (23 participants had no symptoms before diagnosis), there were six participants (14.63%) that were diagnosed less than a month after noticing symptoms, four participants (9.76%) diagnosed between 3 and 10 months after noticing symptoms, and eight participants (19.51%) that were diagnosed more than 12 months after noticing symptoms (Table 3.7, Figure 3.4).

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=27,57.45%). There were two participants (4.26%) diagnosed between 1 and 2 weeks, 12 participants (25.53%) diagnosed between 2 and 3 weeks, and three participants (6.38%) diagnosed between 3 and 4 weeks (Table 3.8, Figure 3.5).

Diagnostic tests

Participants were asked in the questionnaire which diagnostic tests they had for their diagnosis with triple negative breast cancer. Participants reported between 1 and 6 diagnostic tests (median = 3.00, IQR = 0.00) (Table 3.9, Figure 3.6). The most common tests were breast ultrasound (n = 42, 84.00%), core biopsy (n = 41, 82.00%), mammogram (n = 39, 78.00%), and fine needle aspiration (n = 34, 34.00%) (Table 3.10, Figure 3.7).

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 general practitioner (n = 28, 59.57%), and there were 13 participants (27.66%) given the diagnosis by a breast surgeon.

Understanding of disease at diagnosis

Participants were asked in the structured interview how much they knew about their condition at diagnosis. The most common theme was that participants had no knowledge of their condition at diagnosis (n=22, 44.00%), followed by having had a good knowledge (n=15, 30.00%). There were 10 participants(20.00%) who had a limited knowledge about their condition at diagnosis.

The most common reasons for a good knowledge were being informed by a healthcare professional at the time of diagnosis (n=4, 8.00%), having a professional background (n=4, 8.00%), and researching the condition during the diagnostic process (n=4, 8.00%). The most common reason for having limited knowledge was because of general public awareness

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 11 participants (23.40%) who had enough support, nine participants (19.15%) that had some support but it wasn't enough, and 27 participants (57.45%) that 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 21 participants (44.68%) who had enough information, 20 participants (42.55%) that had some information but it wasn't enough, and six participants (12.76%) that 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 13 participants (27.66%) who had no out of pocket expenses, and nine participants (19.15%) who did not know or could not recall. There were 10 participants (21.28%) that spent Less than $500, 11 participants (23.40%) that spent between $500 to $1000, and four participants (8.51%) that spent more than $1000 (Table 3.21, Figure 3.15).

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

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 = 13, 27.66%). There were 7 participants (14.89%) who brought up the topic with their doctor, and 27 participants (57.45%) whose doctor brought up the topic with them.

The majority of participants (n=32 68.09%) recalled having biomarker tests, and there were 14 participants (29.79%) that did not recall having biomarker tests but would like to have them (Table 3.24, Figure 3.18).

This question from the online questionnaire addresses the participants knowledge and understanding of having had biomarker tests. Despite all participants knowing that they had triple negative breast cancer, there were 70% that could relate this to biomarker status. The majority of participants knew the status for at least one biomarker (n = 42, 84.00%). Most commonly, participants knew their TNBC status (n = 35, 70.00%), followed by BRCA status (n = 19, 38.00%).

Current symptoms

More than half of the participants had symptoms to deal with at the time of completing the questionnaire (n = 21, 44.68%). Participants had between 5 to 12 symptoms (median = 8.00, IQR = 3.00) (Table 3.26, Figure 3.20).

The most common current symptoms, and those where more than 35% of the participants experienced the symptom were; anxiety (n = 21, 44.68%), fatigue (n=21, 44.68%), thinking and memory problems (n = 20, 42.55%), depression (n = 19, 40.43%) weight and muscle changes (n = 18, 38.30%), and pain (n = 18, 38.30%).

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”. The median quality of life was between 2.5 and 4.5, for all of the symptoms listed in the questionnaire, this is in the “Life was distressing to a little distressing” to “Life was average to good” range.

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=26, 54.00%), this was followed by prognosis described in relation to statistics such as five year survival rates (n=18, 36.00%). There were 14 participants (28.00%) who described prognosis in relation to probable recurrence/cycle of recurrence, 11 participants (22.00%) who described prognosis in relation to monitoring their condition without treatment until there is an exacerbation or progression, and seven participants (14.00%) who described prognosis in relation to it being positive that the condition will be cured in the future with treatment.

Section 4

Decision-making

Section 4 summary

Discussions about treatment

Participants were asked to recall what treatment options they were presented with and how they felt about such options. The most common description was being presented with multiple options/approaches, and this was described by 38 participants (76.00%). This was followed by being presented with one option/approach (n=8, 16.00%).

Discussions about treatment (Participation in discussions)

In relation to participant in discussions about treatments, there were 28 participants (56.00%) who described feeling that they were told what to do with little or no discussion, and 29 participants (38.00%) who described that they participated in decision making or had informed discussions.

Considerations when making decisions

Participants were asked in the structured interview what they considered when making decisions about treatment. The most reported theme was taking the advice of their clinician, and this was described by 18 participants (36.00%). This was followed by taking side effects into account when making decisions about treatments (n = 11, 22.00%). There were seven participants (14.00%) who described taking efficacy into account, and the same number who described taking the survival benefit into account (n=7, 14.00%), and taking statistics/outcome of treatment into account (n=7, 14.00%). Other participants described taking cost into account (n=6, 12.00%), and taking quality of life into account when making decisions about treatment (n=6, 12.00%).

Decision-making over time

Participants were asked if the way they made decisions had changed over time. There were 27 participants (54.00%) that felt the way they made decisions about treatment had changed over time, and 18 participants (36.00%) that described decision making not changing.

Where participants had changed the way they make decisions, this was primarily in relation to becoming more informed or assertive (n=13, 26.00%), becoming more proactive (n=6, 12.00%), and becoming more cautious and considered over time (n=5, 10.00%).

Personal goals of treatment or care

Participants were asked what their own personal goals of treatment or care were. The most common response was to treat the disease and get better (n=14, 28.00%), and this was followed by getting through medical treatment (n=12, 24.00%). Other themes included wanting to live independently, (n=7, 14.00%), wanting to see mental/neurological improvements (n=6, 12.00%), returning to work (n=5, 10.00%), physical improvements (n=5, 10%), and managing side effects (n=5, 10.00%).

Section 5

Treatment

Section 5: Experience of treatment

Main provider of treatment

The most common providers of treatment and care were medical oncologists (n = 23, 52.27 %), followed by general practitioners (n = 9, 20.45%).

There were 16 participants (37.21%) that travelled for less than 15 minutes, 15 participants (34.88%) that travelled between 15 and 30 minutes, eight participants (18.60%) that travelled between 30 and 60 minutes, three participants (6.98%) that travelled between 60 and 90 minutes, and one participant (2.33%) that travelled more than 90 minutes

Access to healthcare professionals

All participants had access to a medical oncologist (n = 44, 100%), and almost all had a specialist surgeon (n = 42, 95.45%) and a general practitioner (n = 41, 93.18%). There were 38 participants (86.36%) that had an oncology/chemotherapy nurse and 37 participants (84.09%) that had a breast care nurse.

Almost half of the participants had a pharmacist to care for their condition (n = 18, 40.91%). There were 21 participants (47.73%) treated by a physiotherapist and, 11 participants (25.00%) treated by a dietitian/nutritionist.

Respect shown

There were 34 participants (77.27%) that indicated that they had been treated with respect throughout their experience, and nine participants (20.45%) who were treated with respect with the exception of one or two occasions. .

Health care system

The majority of participants had private health insurance (n = 33, 75.00%). The majority of participants were asked if they wanted to be treated as a public or private patient (n = 28, 63.64%), and, they were asked if they had private health insurance (n = 39, 88.64%).

Throughout their treatment, there were 20 participants (45.45%) who were treated as a private patient, 20 participants (45.45%) were mostly treated as a public patient, and there were four participants (9.09%) who were equally treated as a private and public patient.

Affordability of healthcare

The majority of participants never or rarely had to delay or cancel appointments due to affordability (n = 39, 88.64%).

Almost all of the participants never or rarely were unable to fill prescriptions (n = 40, 90.91%).

There were 34 participants (79.28%) that never or rarely had trouble paying for essentials, such as such as food, housing and power, and six participants (13.64%) that sometimes found it difficult, and four participants (9.09%) often or very often found it difficult to pay for basic essentials.

There were four participants (9.09%) that paid for additional carers due to their condition.

Cost of condition

Participants spent between \$50 and \$10,000 per month, most commonly between \$101 or less (n = 10, 22.73%), and \$101 to \$250 (n =10, 22.73%).

The amount spent was an extremely significant or moderately significant burden for 11 participants (25.00%), somewhat significant for nine participants (20.45%), and slightly or not at all significant for 24 participants (54.55%).

Changes to employment status

Work status for 12 participants (27.27%) had not changed since diagnosis, or were retired or did not have a job. There were four participants (9.09%) had to quit their job, 10 participants (22.73%) reduced the number of hours they worked, and four participants (9.09%) that accessed their superannuation early. There were 16 participants (36.36%) that took leave from work without pay, and 12 participants (27.27%) who took leave from work with pay.

There were 11 participants (25.00%), 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 = 22, 50.00%). There were four participants (9.09%) whose partners reduced the numbers of hours they worked, and no partners quit their job. The partners of five participants (11.36%) took leave without pay, and there were eight partners (18.18%) who took leave with pay.

Reduced income due to condition

Participants reported a reduced income from 500 to 10,000 per month, most commonly \$1501 to 2500 (n = 6, 13.64%).

For eight of these participants (42.11%), the burden of this reduced income was slightly or not at all significant, for five participants (26.32%) the burden was somewhat significant, and for 6 participants (31.58%) the burden was extremely or moderately significant.

Summary of surgery

There were 35 participants (79.55%) that had surgery for breast cancer (excluding biopsies). There were 15 participants (34.09%) that had one operation, 10 participants (22.73%) that had two operations, three participants (6.82%) that had three operations, and seven participants (15.91%) that had four or more operations.

There were 35 participants (79.55%) that had surgery for breast cancer (excluding biopsies). The most common types of surgeries were mastectomies (n=19, 43.18%), and lumpectomies (n=19, 43.18%). There were 13 participants (29.55%) had breast reconstruction, and seven participants (2.27%) had surgery to remove ovaries

Summary of drug treatments

There were 40 participants (90.91%) that had used drug treatments to treat their breast cancer. The most common treatment regimen was doxorubicin, cyclophosphamide, and paclitaxel (n=17, 38.64%), followed by single agent paclitaxel (n=11, 25.00%), Capecitabine (n=10, 22.73%), Doxorubicin and cyclophosphamide (n=8, 18.18%), Carboplatin paclitaxel (n=6, 13.64%), and Doxorubicin (n=5, 11.35%)

Summary of radiotherapy

There were 25 participants (56.82%) that had radiotherapy to the primary cancer site, and three participants (6.82%) that had radiotherapy to the secondary cancer site .

Allied health

Most participants used at least one type of allied health service (n = 34, 77.27%), and on average used 2 services (median = 2.00, IQR = 1.00).

The most common allied health service used was psychology services (n = 21, 47.73%), followed by physiotherapy (n = 20, 45.45%), and Dietician (n = 10, 22.73%). There were six participants (13.64%) who saw an occupational therapist, five participants (11.36%) who saw a podiatrist, and four participants (9.09%) who saw a social worker.

Lifestyle changes

Most participants used at made at least one lifestyle change (n = 38, 86.36%), and on average made 2 changes (median = 2.00, IQR = 2.00).

The most common lifestyle change used was exercise (n = 28, 63.64%), followed by diet changes (n = 23, 52.27%), and reducing or stopping alcohol if applicable (n = 24, 54.55%).

Complementary therapies

Most participants used at made at least one complementary therapy (n = 29, 65.91%), and on average used one therapy (median = 1.00, IQR = 2.00).

The most common complementary therapy used was mindfulness or relaxation techniques (n = 20, 45.45 %), followed by massage therapy (n = 17, 38.64%), and taking supplements (n = 16, 36.36%) (Table 5.21, Figure 5.24).

Clinical trials

There was a total of 16 participants (36.36%) that had discussions about clinical trials, six participants (13.64%) had brought up the topic with their doctor, and the doctor of 10 participants (22.77%) brought up the topic. The majority of participants had not spoken to anyone about clinical trials (n = 28, 63.64%).

There were four participants (9.09%) who had taken part in a clinical trial, 32 participants (72.73%) who would like to take part in a clinical trial if there was a suitable one, and eight participants, who have not participated in a clinical trial and do not want to (18.18%).

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 28 participants (56.00%) was the internet (including health charities). There were 18 participants (36.00%) that described Facebook and/or social media and 17 participants (34.00%) that described their treating clinician. Other types of information accessed included other patient's experience (n=16, 32.00%), books, pamphlets and newsletters (n=11, 22.00%), and nursing staff (n=10, 20.00%).

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 19 participants (38.00%) was other information from people's experiences (Peer-to-peer). There were 14 participants (28.00%) that described hearing what to expect (e.g. from disease, side effects, treatment) , and 13 participants (26.00%) that described condition-specific (including sub-types), as being useful. Other types of information described as being helpful included condition-specific information (including information about sub-types or stage) (n=13, 26.00%), talking to healthcare staff (n=9, 18.00%), treatment options (n=9, 18.00%), and information from charities (n=5, 10.00%).

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 13 participants (26.00%) that responded that no information was not helpful. The most common type of information found to be unhelpful by 17 participants (34.00%) were sources that are not credible (not evidence-based). There were 11 participants (22.00%) that described information from healthcare staff or hospital, and six participants (12.00%) that described lack of new information, as not helpful.

Information preferences

Participants were asked whether they had a preference for information online, talking to someone, in written (booklet) form or through a phone App. Overall, the most common preference was online information (n=15, 30.00%) followed by talking to someone (n=12, 24.00%), talking to someone plus online information (n=11, 22.00%), and written information (n=11, 22.00%).

The main reasons for a preference for online information was accessibility (n=11, 22%), having control or personal research (n=7, 14%), convenience (n=6, 12%), and access to a lot of information (n=6, 12%). The main reason for talking to someone as a preference was it was valuable and knowledgeable (n=8, 16%), followed by having time for interaction and to ask questions (n=7, 14%). The main reason for written information as a preference was accessibility (n=7, 14%).

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=12, 24.00%), this was followed by participants describing being open to information during treatment (n=11, 22.00%), after the shock of diagnosis (n=8, 16.00%), and before starting treatment (n=8, 16.00%). There were five participants (10.00%) that were receptive to information a week after diagnosis, and the same number receptive three weeks after diagnosis (n=5, 10.00%).

Health 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=26, 52.00%). There were 10 participants (20.00%) that described overall positive, with the exception of one or two occasions, and 8 participants (16.00%) that described a mix of positive and negative. There were four participants (8.00%) who described having an overall negative experience of health professional communication.

Participants that had positive communication, described the reason for this was because communication was holistic (two way, supportive and comprehensive conversations) (n=20, 40.00%), and helpful (n=5, 10.00%). The main reason for negative communication was communication that was not forthcoming, or generally lacking (n=11, 22.00%). This was followed by communication that was dismissive (one way conversations) (n=5, 10.00%), and that had limited understanding of the condition (n=4, 8.00%).

Partners in health

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

The overall scores for the cohort were in the highest quintile for the **Partners in health: knowledge** (mean = 25.98, SD = 3.51), **Partners in health: recognition and management of symptoms** (median = 20.00, IQR = 2.50), **Partners in health: adherence to treatment** (median = 15.00, IQR = 2.00), scales, indicating very good scores for managing their health.

The overall scores for the cohort were in the second highest quintile for the **Partners in health: coping** (mean = 16.18, SD = 4.26), **Partners in health: total score** (mean = 76.23, SD = 8.93), scales, indicating good scores for managing their health.

Ability to take medicines 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 = 23, 52.27%), and 18 participants (40.91%) responded that they took medicines as prescribed most of the time. There were 3 participants (6.82%) that sometimes took medicines 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=41, 93.18%), Hereditary considerations (n=30, 68.18%), Disease management (n=26, 59.09%) and, Physical activity (n=20, 45.45%) were most frequently given to participants by healthcare professionals, and, information about Complementary therapies (n=6, 13.64%), Interpret test results (n=6, 13.64%) and, Clinical trials (n=6, 13.64%) 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 Interpret test results (n=28, 63.64%), Complementary therapies (n=23, 52.27%), Disease Cause (n=21, 47.73%) Disease management (n=21, 47.73%) and, Treatment options (n=21, 47.73%) were most frequently given to participants by healthcare professionals, and, information about Dietary (n=17, 38.64%), Psychological/ social support (n=13, 29.55%) and, Clinical trials (n=12, 27.27%) 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 = 27, 61.36%) and Dietary (n = 20, 45.45%).

The topics that participants did not search for independently after not receiving information from healthcare professionals were Treatment options (n = 22, 50.00%) and Hereditary considerations (n = 18, 40.91%).

The topics that participants were given most information from both healthcare professionals and searching independently for were Sum of Complementary therapies (n = 20, 45.45%) and Treatment options (n = 19, 43.18%).

The topics that participants searched for independently after not receiving information from healthcare professionals were Disease management (n = 24, 54.55%) and Sum of Complementary therapies (n = 15, 34.09%) (Table 6.35, Figure 6.48).

Information accessed

Across all participants, information from non-profit, charity or patient organisations were most accessed followed by information from the government. Information from pharmaceutical companies and from medical journals were least accessed.

My Health Record

My Health Record is an online summary of key health information, an initiative of the Australian Government. There were 19 participants (43.18%) had accessed My Health Record, 21(47.73%) had not. Of those that had accessed My Health Record, there were 9 participants (47.37%) who found it to be poor or very poor, four participants (21.05%) who found it acceptable, and two participants (10.53%) who found it to be good or very good.

Section 7

Care and support

Section 7: Experience of care and support

Care coordination

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

The overall scores for the cohort were in the highest quintile for the Care coordination: Quality of care global measure (median = 9.00, IQR = 1.00), scales, indicating very good scores for quality of care.

The overall scores for the cohort were in the second highest quintile for the Care coordination: Communication (mean = 44.64, SD = 7.85), Care coordination: Navigation (mean = 26.55, SD = 3.87), Care coordination: Total score (mean = 71.18, SD = 10.28), Care coordination: Care coordination global measure (median = 8, IQR = 2.25), scales, indicating good scores for care coordination, navigation, and communication.

There we no significant differences between sub-groups within the Care Coordination measure.

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 received support through charities (n=19, 38%). This was followed by receiving support from a hospital or clinical setting (n=11, 22%). There were 15 participants (30.00%) that described not receiving any support. There were five participants (10.00%) who described getting peer support, and the same number described getting support through a psychologist or counselling service (n=5, 10.00%).

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 26 participants (52.00%) who described a negative impact on quality of life. There were seven participants (14.00%) who reported a mix of positive and negative impact on quality of life, and six participants (12.00%) who reported an overall positive impact on quality of life, and five participants. There were five participants (10.00%) who described no impact on quality of life, and three participants (6.00%) who described minimal 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 (n=25, 50.00%), the impact of symptoms/side effects (n=15, 30.00%), and the reduced capacity for physical activity (n=8, 16.00%).

Impact on mental health

In the structured interview, participants were asked if there had been an impact on their mental health. There were 45 participants (90.00%) who gave a description suggesting that overall there was some impact on their mental health and three participants (6.00%) who gave a description suggesting that overall there was no impact on mental health.

Regular activities to maintain mental health

In the structured interview, participants were asked what they needed to do to maintain their emotional and mental health. The most common ways that participants reported managing their mental and emotional health was maintaining social, lifestyle changes, and hobbies (n=18, 36.00%), consulting a mental health professional (n=17, 34.00%), and physical exercise (n=15, 30.00%). There were eight participants (16.00%) who described the importance of accepting their condition and having a positive outlook, and the same number who described the importance of family and friends (n=8, 16.00%). Other ways to maintain mental health included self-care (n=6, 12.00%), and mindfulness or meditation (n=5, 10.00%).

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 way that participants reported managing their health was by being physically active (n=26, 52.00%), followed by the importance of self-care (n=19, 38.00%). There 13 participants (26.00%) who described the importance of understanding their limitations, 12 participants (24.00%) who described maintaining a healthy diet and 11 participants (22.00%) who described the importance of treatment compliance. Other ways of maintaining health included keeping up with daily activities (n=7, 14.00%), and socialising with family and friends (n=5, 10.00%). There were five participants (10.00%) who described no regular activities to maintain their health.

Experience of vulnerability

In the structured interview, participants were asked if there had been times that they felt vulnerable. There were 43 participants (86.00%) who gave a description suggesting that overall they had experiences of feeling vulnerable, and four participants (8.00%) who gave a description suggesting that overall they did not have feelings of being vulnerable.

In relation to when participants felt most vulnerable, the most common theme was feeling vulnerable during or after treatments (n=20, 40.00%), followed by feeling vulnerable when having negative thoughts (n=15, 30.00%). There were 14 participants (28.00%) who described feeling vulnerable when having sensitive discussions for example at diagnosis and treatment decisions, and nine participants (18.00%) described feeling vulnerable when feeling sick.

Methods to manage vulnerability

In the structured interview, participants described ways that they managed feelings of vulnerability. Participants described support from their medical team to manage the feeling of vulnerability (n=9, 18.00%), and using self-help methods such as resilience, acceptance, and staying positive to manage the feeling of vulnerability (n=7, 14.00%). Other methods included adapting, for example being proactive. Assertive and understanding boundaries (n=6, 12.00%), and getting support from family and friends (n=5, 10.00%).

Impact on relationships

In the structured interview, participants were asked whether their condition had affected their personal relationships. Overall, there were 19 participants (38.00%) who described a mix of positive and negative impacts on relationships. Other participants reported a negative impact on relationships (n=11, 22.00%), no impact on relationships (n=8, 16.00%), and a positive impact on relationships (n=7, 14.00%).

The most common theme in relation to having an impact on relationships was a mixed impact on relationships, some strengthened, others disappeared (n=14, 28.00%). There were eight participants (16.00%) who described relationships suffering, because of people not knowing what to say or do and withdrawing from relationships, and the same number who described no impact on relationships with no specific reason (n=8, 16.00%). Other reasons included relationships with family being strengthened (n=7, 14.00%), and relationships suffering, due to emotional strain (n=6, 12.00%).

Impact on relationships

In the structured interview, participants were asked whether their condition had affected their personal relationships. Overall, there were 19 participants (38.00%) who described a mix of positive and negative impacts on relationships. Other participants reported a negative impact on relationships (n=11, 22.00%), no impact on relationships (n=8, 16.00%), and a positive impact on relationships (n=7, 14.00%).

The most common theme in relation to having an impact on relationships was a mixed impact on relationships, some strengthened, others disappeared (n=14, 28.00%). There were eight participants (16.00%) who described relationships suffering, because of people not knowing what to say or do and withdrawing from relationships, and the same number who described no impact on relationships with no specific reason (n=8, 16.00%). Other reasons included relationships with family being strengthened (n=7, 14.00%), and relationships suffering, due to emotional strain (n=6, 12.00%).

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 30 participants (60.00%) who felt there was an additional burden, and 18 participants (36.00%) who reported no additional burden.

Participants who described that they were no additional burden, mostly did this without giving any examples or explanations (n=13, 26.00%), followed by not being a burden because they manage their condition independently (n=5, 10.00%). For people that felt they were a burden on their family, most commonly did not give any specific reasons for this (n=12, 24.00%). The main reasons for burden on families were the extra household duties and responsibilities that their family must take on (n=10, 20.00%), and the mental/emotional strain placed on their family (n=6, 12.00%).

Cost considerations

In the structured interview, participants were asked about any significant costs associated with having their condition. There were 36 participants (72.00%) that described some cost burden and 11 participants (22.00%) who described no cost burden.

Where participants described a cost burden associated with their condition, it was most commonly in relation to the cost of treatments, including repeat scripts (n=25, 50.00%). Other cost burdens were in relation to diagnostic tests and scans (n=15, 30.00%), taking time off work (n=9, 18.00%), and the cost of private care (n=7, 14.00%). There were six participants (12.00%) who described the cost of specialist appointments, and the same number who described the cost of allied healthcare (n=6, 12.00%), and the cost of parking and travel to attend appointments, including accommodation (n=6, 12.00%). There were six participants (12.00%) that described no cost burden and that nearly everything was paid for through the health system or private coverage.

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. The average score was in the Life was a little distressing range (median = 3.00, IQR = 3.00) (Table 8.29, Figure 8.15).

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 a mean total score of 35.89 (SD = 7.50), which corresponds to moderate levels of anxiety (Table 8.29)

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 themes reported were for future treatments to have fewer or less intense side effects (n= 12, 24.00%), followed by more effective future treatments (n = 11, 22%), and treatments that less cost (n = 11, 22.00%).There were eight participants (16.00%) who described wanting more research and more treatment advances, seven participants (14%) that described wanting more holistic treatments, and seven participants (14%) who described wanting a change in administration of the treatment. There were five participants (10%) that described wanting future treatment to be the same as it is now, and the same number who described wanting preventative measures (n=5, 10.00%).

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. There were eight participants (16%) who described that future information will provide more details about where to find available services and this was the most common theme. There were seven participants (14.00%) who described the expectation that future information will provide more details about treatments, and the same number described the expectation that future information will provide more details about mental health and emotional support (n = 7, 14.00%).

Other expectations included, how to manage personal and intimate problems (n = 6, 12.00%), general information about the condition (n = 6, 12.00%), symptom and side effect control (n = 5, 10.00%), and that information will be mores accessible and easy to find (n = 5, 10.00%). There were seven participants (14.00%) that had no recommendations and were satisfied with the information 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 themes were that participants had no recommendations and they had experienced good communication (n = 13, 26.00%), and that future communication should be more transparent and forthcoming (n = 13, 26.00%). There were 10 participants (20.00%) who described that future communication should be more accurate and detailed, 10 participants (20.00%) who described future communication should include listening to the patient, nine participants (18.00%) who described future communication should be more empathetic, and five participants (10.00%) who described future communication should include a care plan with follow-up.

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. There were 24 participants (48.00%) who described that future care and support should include access to support services and this was the most common theme. Other participants described that future care and support should include access to specialist clinics or services (n= 10, 20.00%), access to mental health and emotional support (n = 7, 14.00%), and access to peer support (n = 6, 12%). There were five participants (10.00%) as they were satisfied with the care and support available.

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 reported were that participants were grateful for timely access to treatment (n = 17, 34.00%), followed by grateful for healthcare staff (n = 16, 32.00%). There were 12 participants (24.00%) that described being grateful for low cost or free medical treatments , 10 participants (20.00%) that described being grateful for the entire health system, and 9 participants (18.00%) that described being grateful for low cost/free medical care.

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. The most important aspects reported were fatigue pain, Heart problems and, memory loss and cognitive function. The least important were fertility, body image and sexual difficulties.

Values in making decisions

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

Values for decision makers

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

Time taking medication to improve quality of life

Participants were asked in the online questionnaire, how many months or years would you consider taking a treatment, provided it gave you a good quality of life, even if it didn't offer a cure. The majority of participants (n = 28, 63.64%) 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 were asked in the online questionnaire, in what form did they think medicine was most effective in. Participants they were equally effective (n = 15, 34.09%), followed by IV form (n = 16, 36.36%).

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?". There were 22 participants (44.00%) with the message to improve access to support and care (including treatment) and this was the most common theme. Other participants had the message: to understand the financial implications (n = 16, 32.00%), to have a tailored care plan (n = 11, 22.00%), to invest in research (n = 7, 14.00%), and to invest in specialist health professionals, especially nurses (n = 7, 14.00%). There were five participants who were satisfied and thought that things should stay the same, and the same number who had the message that treatments need to be holistic (n= 5, 10.00%).

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. There were 11 participants (22.00%) that described that they wish they had known more about the pros and cons of treatment options, and this was the most common theme. Other participants wished they had known what to expect from their condition, particularly disease trajectory and understanding of disease biology (n = 10, 20.00%), participants wished they had known more about what support was available to them (n = 10, 20.00%), and participants wished they had known more about side effects of treatments (n = 9, 18.00%). There were 10 participants (20.00%) who did not describe anything that they wish they had known earlier without giving a reason.

Aspect of care or treatment they would change

The most common themes reported were that participants would not change any aspect of their care or treatment/satisfied with care and treatment received (n = 12, 24.00%), followed by participants would not change any aspect of their care or treatment without giving a reason (n = 9, 18.00%). There were seven participants (14.00%) that described that they would change or stop the kind of treatment they received.

Section 1

Introduction and methods

Section 1 Introduction and methodology

Triple negative breast cancers are defined by the lack of progesterone and oestrogen receptors, and HER2 proteins. Triple negative breast cancers are an aggressive form of breast cancer that typically affects younger women, has a poor prognosis, and lack of targeted therapies.

In 2019, there were 19,371 new cases of breast cancer reported in Australia[5]. Approximately 12 to 17% of all breast cancers are triple negative, that is an estimated 3000 new cases of triple negative breast cancer in Australia 2019.

A PubMed search was conducted in 2021 to identify studies reporting patient experience, patient reported outcomes, and quality of life studies in the triple negative breast cancer community. Studies conducted more than 10 years ago were excluded, and studies that included multiple types of breast cancers that did not report triple negative breast cancers separately (as a subgroup) were excluded. There were 12 studies identified of between six and 902 participants. There was only one study identified that interviewed participants or used qualitative methods, this study was focused on African Americans diagnosed with triple negative breast cancer.

This PEEK study appears to be among the largest cohorts of women diagnosed with triple negative breast cancer that includes a structured interview and it also covers the most domains.

Introduction

Triple negative breast cancers are defined by the lack of progesterone and oestrogen receptors, and HER2 proteins[1,2]. Triple negative breast cancers are an aggressive form of breast cancer that typically affects younger women, has a poor prognosis, and lack of targeted therapies[3,4].

In 2019, there were 19,371 new cases of breast cancer reported in Australia[5]. Approximately 12 to 17% of all breast cancers are triple negative[3], that is an estimated 3000 new cases of triple negative breast cancer in Australia 2019.

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 triple negative 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.

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 in 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 in 2021.

Online questionnaire (quantitative)

The online questionnaire consisted of the 36-Item Short Form Health Survey (SF36) (RAND Health)[6], a modified Cancer Care Coordination Questionnaire for Patients (CCCQ)[7], the Short Fear of Progression Questionnaire (FOP12)[8], and the Partners in Health version 2 (PIH)[9]. 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, physical function, year of diagnosis, age, location of residence, education status and socio-economic status. Scales and subscales were calculated according to reported instructions[6-9].

The location of participants was evaluated by postcode using the Australian Statistical Geography Maps (ASGS) Remoteness areas accessed from the Australian Bureau of Statistics[10].

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[11].

For comparisons by age, 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.

Position of this study

A PubMed search was conducted in 2021 to identify studies reporting patient experience, patient reported outcomes, and quality of life studies in the triple negative breast cancer community. Studies conducted more than 10 years ago were excluded, and studies that included multiple types of breast cancers that did not report triple negative breast cancers separately (as a subgroup) were excluded.

There were 12 studies identified of between six and 902 participants. There was only one study identified that interviewed participants or used qualitative methods, this study was focused on African Americans diagnosed with triple negative breast cancer[12].

There were 11 studies that collected patient experience/patient reported data by questionnaire. The two largest studies of 902 and 190 participants with triple negative breast cancer respectively, were multi-national drug clinical trials[13,14]. There were three other clinical trials identified that collected patient reported outcomes, two were conducted in USA, and had between 37 and 38 triple negative breast cancer participants[15,16], one trial conducted in Spain with 73 participants[17].

There was one study conducted in China focused on patient activation with 121 participants[18], and one study conducted in the USA focused on health-related quality of life of 83 participants[19]. There were two studies conducted in North America that focused on clinical trial participation that included between 15 and 74 participants[20,21]. One study was focused on lifestyle changes, conducted in the USA with 23 participants[22], and one USA study of 13 participants focused on coping[23].

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
Adams et al, 2020[13]	International	902	Questionnaire	Clinical trial	x							
Rugo et al, 2019[14]	International	190	Questionnaire	Clinical trial	x							
Shen et al, 2020[18]	China	121	Questionnaire	Patient activation	x				x	x		
Vadaparampil et al, 2017[19]	USA	83	Questionnaire	HRQOL	x						x	
Jacobs et al, 2017[20]	Canada	74	Questionnaire	Clinical trial participation				x				
Manso et al, 2015[17]	Spain	73	Questionnaire	Clinical trial	x							
Filho et al, 2021[16]	USA	38	Questionnaire	Clinical trial	x							
Anders et al, 2014	USA	37	Questionnaire	Clinical trial	x							
Swisher et al, 2015[22]	USA	23	Questionnaire	Lifestyle changes	x							
Kuderer et al, 2017[21]	USA	15	Questionnaire	Clinical trial participation		x	x				x	
Watkins et al, 2017[23]	USA	13	Questionnaire	Coping							x	
Bollinger et al, 2018 [12]	USA	6	Interview	Biopsychosocial challenges				x	x	x	x	

Abbreviations and terminology

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

There were 50 people with that took part in this study with triple negative breast cancer. Participants were aged from 25 to 74 years of age, most were aged between 45 to 54 years (n = 22 ,44.00%).

Participants were most commonly from New South Wales (n = 14, 28.00%), Queensland (n = 14, 28.00%), and Victoria (n = 11, 22.00%). Most participants were from major cities (n = 34, 68.00%), and they lived in all levels of advantage, defined by Socio-economic Indexes for Areas (SEIFA) (www.abs.gov.au) with 30 participants (60.00%) from an area with a high SEIFA score of 7 to 10 (more advantage), and 20 participants (40.00%) from an area of mid to low SEIFA scores of 1 to 6 (less advantaged).

There were 26 participants that had completed university to at least an associate degree (54.00%). There were 27 participants who were employed either full time (54.00%), or part time (n =14, 28.00%).

Almost half of the participants were carers to family members or spouses (n = 26, 54.00%), most commonly carers to children (n = 25, 50%).

Breast cancer stage

There were 50 people with triple negative breast cancer who took part in this study. There were six participants (12.00%) with Stage I, 17 participants (34.00%) with, Stage II, 24 participants (6.00%) with Stage III, and three participants (6.00%) with Stage IV.

Other health conditions

The majority of participants had at least one other condition that they had to manage (n = 44, 88.00%), the maximum number reported was eight other conditions, with a median of three other conditions (IQR = 4.00). The most commonly reported health condition was anxiety either self or doctor diagnosed (n = 27, 54.00%), followed by sleep problems or insomnia (n = 22, 44.00%), chronic pain (n =13, 26.00%), and depression (Self or doctor diagnosed) (n = 19, 38.00%).

Baseline health

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

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

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

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

Demographics

There were 50 people with triple negative breast cancer that took part in this study. Participants were aged from 25 to 74 years of age, most were aged between 45 to 54 years (n = 22 ,44.00%).

Participants were most commonly from New South Wales (n = 14, 28.00%), Queensland (n = 14, 28.00%), and Victoria (n = 11, 22.00%). Most participants were from major cities (n = 34, 68.00%), and they lived in all levels of advantage, defined by Socio-economic Indexes for Areas (SEIFA) (www.abs.gov.au) with 30 participants (60%) from an area with a high SEIFA score of 7 to 10 (more advantage), and 20 participants (40.00%) from an area of mid to low SEIFA scores of 1 to 6 (less advantaged).

There were 26 participants that had completed university to at least an associate degree (54.00%). There were 27 participants who were employed either full time (54.00%), or part time (n = 14, 28.00%).

Almost half of the participants were carers to family members or spouses (n = 26, 54.00%), most commonly carers to children (n = 25, 50.00%). The demographics of participants are listed in Table 2.1.

Table 2.1: Demographics

Demographic	Definition	Number (n=50)	Percent
Age	25 – 34	4	8.00
	35 – 44	15	30.00
	45 – 54	22	44.00
	55 – 74	9	18.00
Location	Major Cities of Australia	34	68.00
	Inner Regional Australia	13	26.00
	Outer Regional Australia	2	4.00
	Remote Australia	1	2.00
State	New South Wales	14	28.00
	Queensland	14	28.00
	Victoria	11	22.00
	Western Australia	9	18.00
	South Australia	1	2.00
	Tasmania	1	2.00
	Australian Capital Territory	0	0.00
	Northern Territory	0	0.00
Socio-Economic Indexes for Areas (SEIFA)	1	2	4.00
	2	6	12.00
	3	3	6.00
	4	2	4.00
	5	5	10.00
	6	2	4.00
	7	6	12.00
	8	4	8.00
	9	9	18.00
	10	11	22.00
Race/ethnicity	Caucasian/White	47	94.00
	Other	3	6.00
Education	Less than high school degree	0	0.00
	High school degree or equivalent	12	24.00
	Some college but no degree	11	22.00
	Trade	1	2.00
	Associate degree	4	8.00
	Bachelor degree	14	28.00
	Graduate degree	8	16.00
Employment	Currently receiving Centrelink support	2	4.00
	Disabled, not able to work	1	2.00
	Employed, working full time	27	54.00
	Employed, working part time	14	28.00
	Full/part time carer	2	4.00
	Full/part time study	1	2.00
	Not employed, looking for work	2	4.00
	Retired	2	4.00
	Currently on sick/maternity leave	5	10.00
Carer status	I am not a carer	24	48.00
	Children	25	50.00
	Other	2	4.00

Participants

There were 50 people with triple negative breast cancer who took part in this study. There were 6 participants (12.00%) with Stage I, 17 participants (34.00%) with, Stage II, 24 participants (48.00%) with Stage III and three participants (6.00%) with Stage IV (Table 2.2, Figure 2.1).

Table 2.2: Participants

Participants and diagnosis	Number (n=50)	Percent
Stage I	6	12.00
Stage II	17	34.00
Stage III	24	48.00
Stage IV	3	6.00

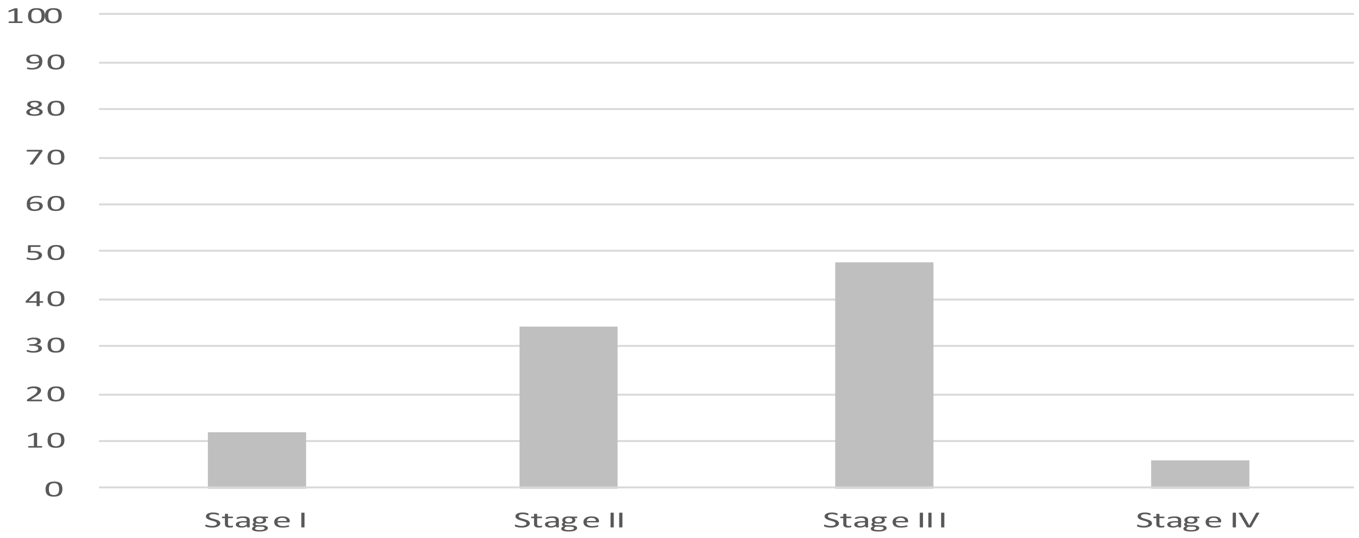


Figure 2.1: Participants

Other health conditions

Participants were asked about health conditions, other than triple negative 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 = 44, 88.00%), the maximum number reported was eight other conditions, with a median of three other conditions (IQR = 4.00) (Table 2.3, Figure 2.2). The most commonly reported health condition was anxiety either self or doctor diagnosed (n = 27, 54.00%), followed by sleep problems or insomnia (n = 22, 44.00%), chronic pain (n =13, 26%), and depression either self or doctor diagnosed (n = 19, 38%) (Table 2.4, Figure 2.3).

Table 2.3: Number of other health conditions

Number of other conditions	Number (n=50)	Percent
No other conditions	6	12.00
1 to 2	18	36.00
3 to 4	8	16.00
5 to 6	14	28.00
7 to 8	4	8.00

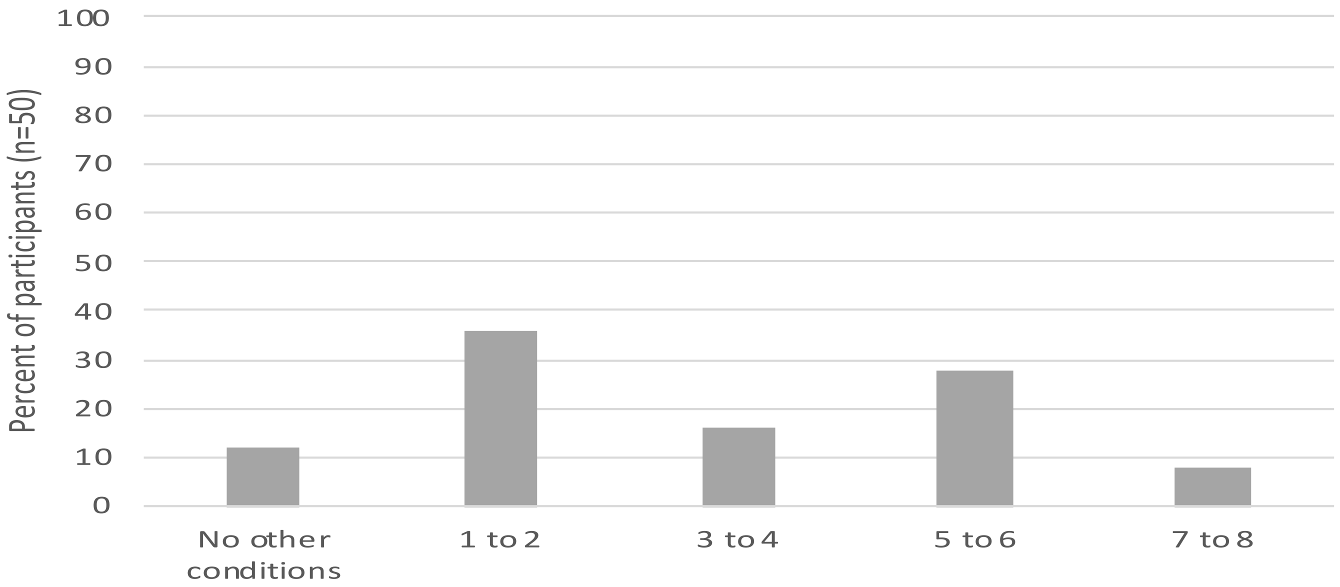


Figure 2.2: Number of other health conditions

Table 2.4: Other health conditions

Other conditions	Number (n=50)	Percent
Anxiety (Self or doctor diagnosed)	27	54.00
Anxiety (that you diagnosed) yourself	25	50.00
Anxiety (that a doctor diagnosed)	11	22.00
Sleep problems or insomnia	22	44.00
Chronic pain	13	26.00
Depression (Self or doctor diagnosed)	19	38.00
Depression (that you diagnosed yourself)?	14	28.00
Depression (that a doctor diagnosed)	10	20.00
Arthritis	9	18.00
High cholesterol	7	14.00
Hypertension	4	8.00
Atrial fibrillation or arrhythmias	4	8.00
Diabetes	3	6.00
Cancer (other than breast cancer)	2	4.00
COPD (Chronic obstructive pulmonary disease)	1	2.00
Have you had a stroke?	1	2.00
Chronic heart failure	0	0.00
Angina	0	0.00
Other	28	56.00

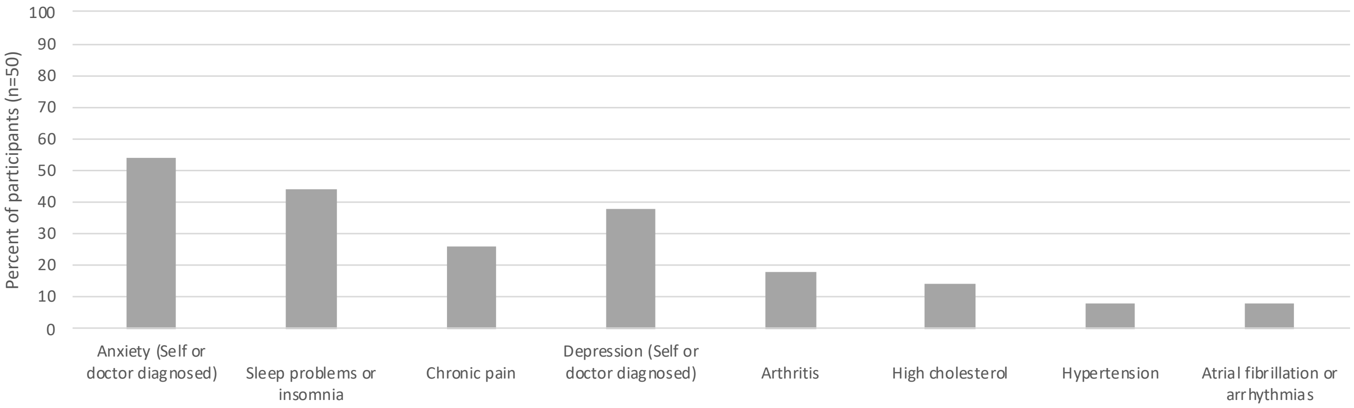


Figure 2.3: Other health conditions (% of all participants)

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 23 participants (46.00%) with *Early breast cancer* (Stage I or Stage II) and, 27 participants (54.00%) with *Advanced breast cancer* (Stage III or Stage IV).

Physical function was evaluated by the SF36 Role functioning/physical, this measures how physical health interferes with work or other activities. Participants that had an SF36 Role functioning/physical score of 40 or less were included in the *Poor physical function* subgroup (n=19, 43.18 %), and participants that scored more than 40 were included in the *Good physical function* subgroup (n=25, 56.82%).

Comparisons were made by the **year of diagnosis**, there were 26 participants that were *Diagnosed before 2020* (52.00%), and 24 participants *Diagnosed in 2020 or 2021* (48.00%).

Comparisons were made by **education** status, between those with *Trade or high school* qualifications, (n = 24, 48.00%), and those with a *University* qualification (n = 26, 52.00%).

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 =16, 32.00%) were compared to those living in a major city, *Metropolitan* (n = 34, 68.00%).

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 to 6, *Mid to low status* (n = 20, 40.00%) compared to those with a higher SEIFA score of 7 to 10, *Higher status* (n = 30, 60.00%).

Participants were grouped according to **age**, with comparisons made between participants *Aged 25 to 44* (n = 19, 38.00%), participants *Aged 45 to 54* (n = 22, 44.00%), and participants *Aged 55 to 74* (n = 9, 18.00%).

Table 2.5: Subgroups

Subgroup	Definition	Number (n=50)	Percent
Breast cancer stage	Early breast cancer	23	46.00
	Advanced breast cancer	27	54.00
Physical function (n=44)	Poor physical function	19	43.18
	Good physical function	25	56.82
Year of diagnosis	Diagnosed before 2020	26	52.00
	Diagnosed in 2020 or 2021	24	48.00
Education	Trade or high school	24	48.00
	University	26	52.00
Location	Regional or remote	16	32.00
	Metropolitan	34	68.00
Economic status	Mid to low status	20	40.00
	Higher status	30	60.00
Age	Aged 25 to 44	19	38.00
	Aged 45 to 54	22	44.00
	Aged 55 to 74	9	18.00

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 the **SF36 Role functioning/emotional** (median = 100, IQR = 33.33), scales, indicating very good health-related quality of life scores.

The overall scores for the cohort were in the second highest quintile for the **SF36 Physical functioning** (median = 77.50, IQR = 36.25), **SF36 Role functioning/physical** (median = 75.00, IQR = 81.25**),** **SF36 Emotional well-being** (median = 74.00, IQR = 21.00), **SF36 Social functioning** (median = 75.00, IQR = 40.63), **SF36 Pain** (median = 67.50, IQR = 37.50), scales, indicating good health-related quality of life scores.

The overall scores for the cohort were in the middle of the scale for the **SF36 Energy/Fatigue** (mean = 41.93, SD = 19.39**), SF36 General health** (mean = 51.93, SD = 18.02), SF36 Health change (median = 50.00, IQR = 50.00), scales, indicating moderate health-related quality of life scores.

Comparisons of SF36 have been made based on **breast cancer stage** (Tables 2.7 to 2.8, Figures 2.4 to 2.12), **physical function** (Tables 2.9 to 2.10, Figures 2.13 to 2.20), **year of diagnosis** (Tables 2.11 to 2.12, Figures 2.21 to 2.29), **education** (Tables 2.13 to 2.14, Figures 2.30 to 2.38), **location** (Tables 2.15 to 2.16, Figures 2.39 to 2.47), **socioeconomic status** (Tables 2.17 to 2.18, Figures 2.48 to 2.56), and **age** (Tables 2.19 to 2.20, Figures 2.57 to 2.65).

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 slightly 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 rarely 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 moderately 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 a little pain.

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

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

Table 2.6: SF36 summary statistics

SF36 scale (n=44)	Mean	SD	Median	IQR	Possible range	Quintile
Physical functioning	71.36	23.36	77.50	36.25	0 to 100	4
Role functioning/physical	55.11	41.96	75.00	81.25	0 to 100	4
Role functioning/emotional	77.27	34.31	100.00	33.33	0 to 100	5
Energy/Fatigue*	41.93	19.39	45.00	26.25	0 to 100	3
Emotional well-being	70.91	14.13	74.00	21.00	0 to 100	4
Social functioning	69.60	26.61	75.00	40.63	0 to 100	4
Pain	63.92	26.23	67.50	37.50	0 to 100	4
General health*	51.93	18.02	55.00	35.00	0 to 100	3
Health change	51.14	34.92	50.00	50.00	0 to 100	3

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

SF36 by breast cancer stage

Comparisons were made by **breast cancer stage**, there were 23 participants (46.00%) with *Early breast cancer* (Stage I or Stage II) and, 27 participants (54.00%) with *Advanced breast cancer* (Stage II or Stage IV).

A two-sample t-test was used when assumptions for normality and variance were met (Table 2.7), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 2.8).

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

Table 2.7: SF36 by breast cancer stage summary statistics and T-test

SF36 scale	Group	Number (n=44)	Percent	Mean	SD	T	dF	p-value
Energy/Fatigue	Early breast cancer	20	45.45	40.75	21.11	-0.37	42	0.7166
	Advanced breast cancer	24	54.55	42.92	18.23			
Emotional well-being	Early breast cancer	20	45.45	70.60	15.26	-0.13	42	0.8965
	Advanced breast cancer	24	54.55	71.17	13.45			
Pain	Early breast cancer	20	45.45	64.25	27.21	0.08	42	0.9404
	Advanced breast cancer	24	54.55	63.65	25.98			
General health	Early breast cancer	20	45.45	52.75	18.32	0.27	42	0.7870
	Advanced breast cancer	24	54.55	51.25	18.13			

Table 2.8: SF36 by breast cancer stage summary statistics and Wilcoxon test

SF36 scale	Group	Number (n=44)	Percent	Median	IQR	W	p-value
Physical functioning	Early breast cancer	20	45.45	80.00	41.25	247.00	0.8774
	Advanced breast cancer	24	54.55	75.00	32.50		
Role functioning/physical	Early breast cancer	20	45.45	75.00	100.00	251.00	0.7971
	Advanced breast cancer	24	54.55	62.50	75.00		
Role functioning/emotional	Early breast cancer	20	45.45	100.00	33.33	275.00	0.3435
	Advanced breast cancer	24	54.55	100.00	66.67		
Social functioning	Early breast cancer	20	45.45	81.25	53.13	271.50	0.4584
	Advanced breast cancer	24	54.55	75.00	37.50		
Health change	Early breast cancer	20	45.45	62.5	50.00	240.00	1.0000
	Advanced breast cancer	24	54.55	50.00	56.25		

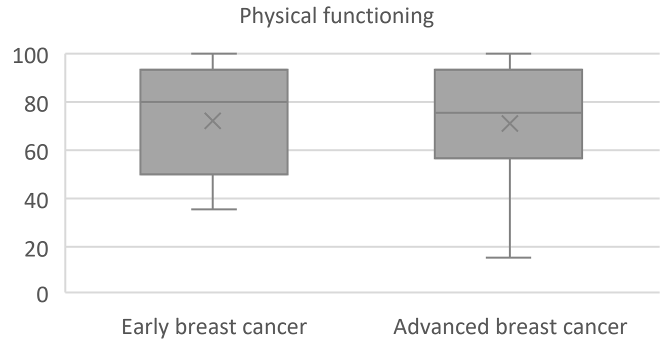


Figure 2.4: Boxplot of SF36 Physical functioning by v breast cancer stage breast cancer stage

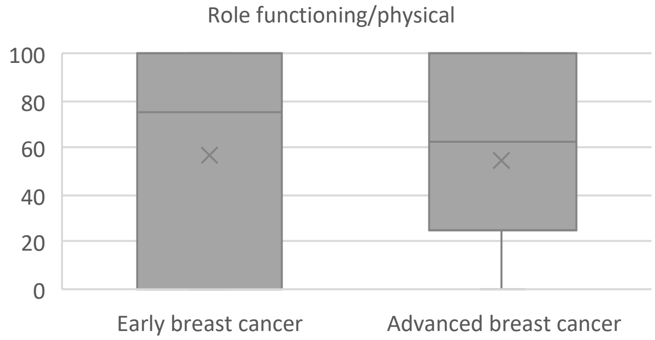


Figure 2.5: Boxplot of SF36 Role functioning/physical by breast cancer stage

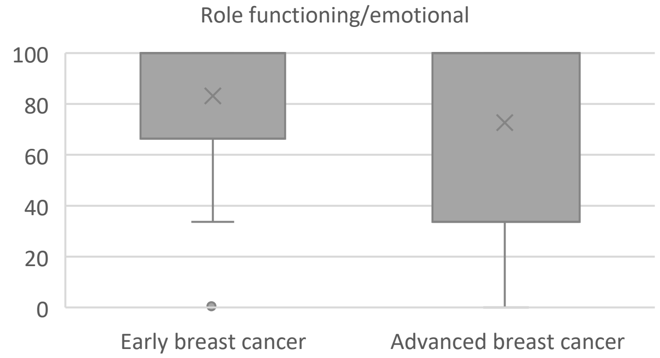


Figure 2.6: Boxplot of SF36 Role functioning/emotional by breast cancer stage

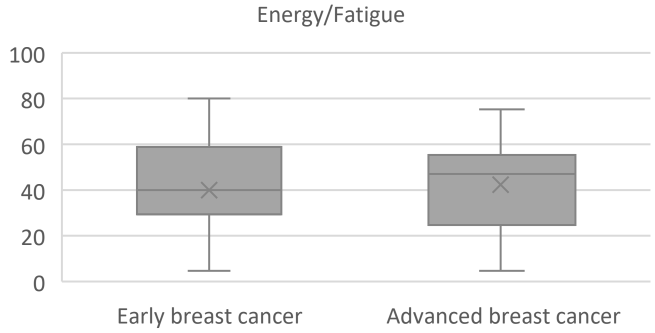


Figure 2.7: Boxplot of SF36 Energy/fatigue by breast cancer stage

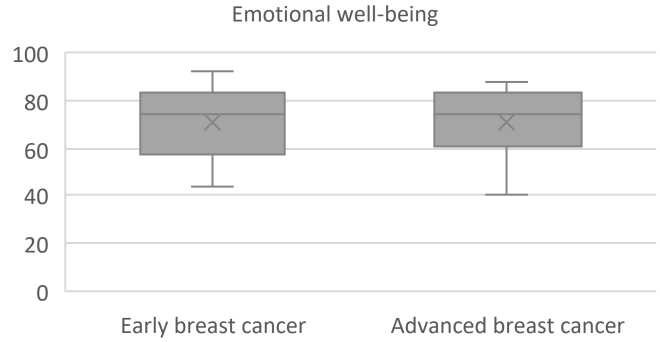


Figure 2.8: Boxplot of SF36 Emotional well-being by breast cancer stage

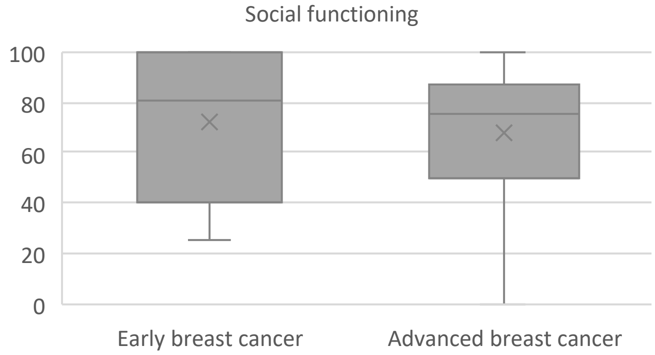


Figure 2.9: Boxplot of SF36 Social functioning by breast cancer stage

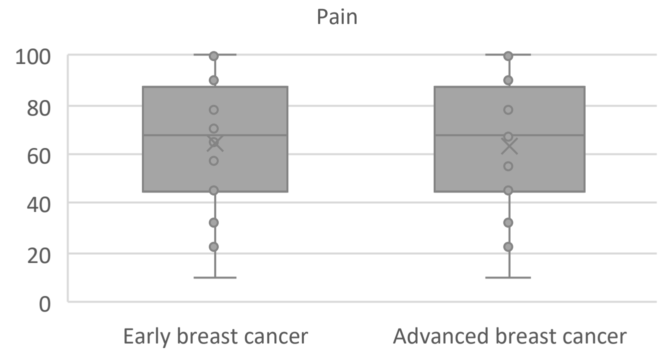


Figure 2.10: Boxplot of SF36 Pain by a breast cancer stage

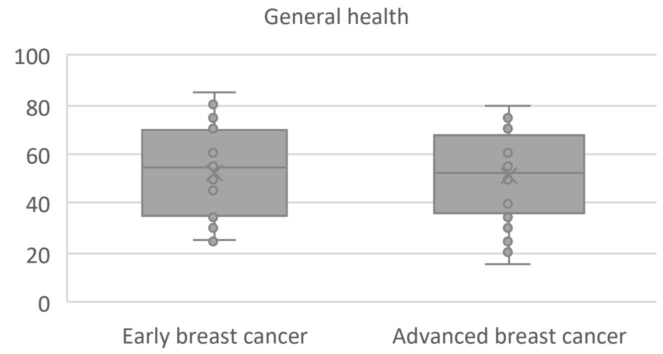


Figure 2.11: Boxplot of SF36 General health by breast cancer stage

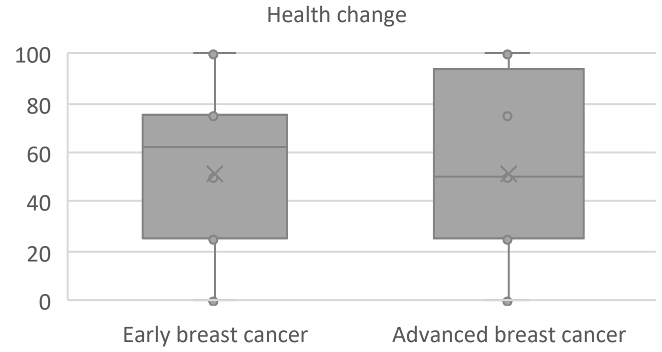


Figure 2.12: Boxplot of SF36 Health change by breast cancer stage

SF36 by physical function

Physical function was evaluated by the SF36 Role functioning/physical, this measures how physical health interferes with work or other activities. Participants that had an SF36 Role functioning/physical score of 40 or less were included in the *Poor physical function* subgroup (n=19, 43.18 %), and participants that scored more than 40 were included in the G*ood physical function* subgroup (n=25, 56.82%).

A two-sample t-test was used when assumptions for normality and variance were met (Table 2.9), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 2.10).

A two sample t-test indicated that the mean score for the **SF36 Energy/Fatigue** scale [t(42) = -4.19 , p = 0.0001] was significantly lower for participants in the *Poor physical function* subgroup (Mean = 30.00, SD = 18.93) compared to participants in the *Good physical function* subgroup (Mean = 51, SD = 14.36).

A two sample t-test indicated that the mean score for the **SF36 Pain** scale [t(42) = -4.14 , p = 0.0002] was significantly lower for participants in the *Poor physical function* subgroup (Mean = 47.89, SD = 27.05) compared to participants in the *Good physical function* subgroup (Mean = 76.1, SD = 18.07).

A two sample t-test indicated that the mean score for the **SF36 General health** scale [t(42) = -4.22 , p = 0.0001] was significantly lower for participants in the *Poor physical function* subgroup (Mean = 40.79, SD = 14.84) compared to participants in the *Good physical function* subgroup (Mean = 60.40, SD = 15.61).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the **SF36 Physical functioning** scale [W = 104.5 , p = 0.0016*] was significantly lower for participants in the *Poor physical function* subgroup (Median = 55.00, IQR = 35.00) compared to participants in the *Good physical function* subgroup (Median = 85.00, IQR = 20.00).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the **SF36 Social functioning** scale [W = 56.00 , p <0.0001*] was significantly lower for participants in the *Poor physical function* subgroup (Median = 50.00, IQR = 37.50) compared to participants in the *Good physical function* subgroup (Median = 87.5, IQR = 25.00).

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

SF36 Energy/fatigue scale measures the proportion of energy or fatigue experienced. On average, participants in the *Good physical function* subgroup scored higher than participants in the *Poor physical function s*ubgroup. This indicates that participants in the *Good physical function* subgroup were sometimes fatigued, and participants in the *Poor physical function* subgroup were often fatigued.

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

SF36 Pain scale measures how much pain, and how pain interferes with work and other activities. On average, participants in the *Good physical function* subgroup scored higher than participants in the *Poor physical function* subgroup. This indicates that participants in the *Good physical function* subgroup had mild pain, and participants in the *Poor physical function* subgroup had moderate pain.

SF36 General health scale measures perception of health. On average, participants in the *Good physical function* subgroup scored higher than participants in the *Poor physical function subgroup*. This indicates that participants in the *Good physical function* subgroup had good health, and participants in the *Poor physical function* subgroup had average health.

Table 2.9: SF36 by physical function summary statistics and T-test

SF36 scale	Group	Number (n=44)	Percent	Mean	SD	T	dF	p-value
Energy/Fatigue	Poor physical function	19	43.18	30.00	18.93	-4.19	42.00	0.0001*
	Good physical function	25	56.82	51.00	14.36			
Pain	Poor physical function	19	43.18	47.89	27.05	-4.14	42.00	0.0002*
	Good physical function	25	56.82	76.10	18.07			
General health	Poor physical function	19	43.18	40.79	14.84	-4.22	42.00	0.0001*
	Good physical function	25	56.82	60.40	15.61			

*Statistically significant at p<0.05

Table 2.10: SF36 by physical function summary statistics and Wilcoxon test

SF36 scale	Group	Number (n=44)	Percent	Median	IQR	W	p-value
Physical functioning	Poor physical function	19	43.18	55.00	35.00	104.50	0.0016*
	Good physical function	25	56.82	85.00	20.00		
Role functioning/emotional	Poor physical function	19	43.18	100.00	66.67	179.50	0.1125
	Good physical function	25	56.82	100.00	33.33		
Emotional well-being	Poor physical function	19	43.18	72.00	24.00	166.00	0.0909
	Good physical function	25	56.82	80.00	20.00		
Social functioning	Poor physical function	19	43.18	50.00	37.50	56.00	<0.0001*
	Good physical function	25	56.82	87.50	25.00		
Health change	Poor physical function	19	43.18	25.00	75.00	166.00	0.0856
	Good physical function	25	56.82	50.00	75.00		

*Statistically significant at p<0.05

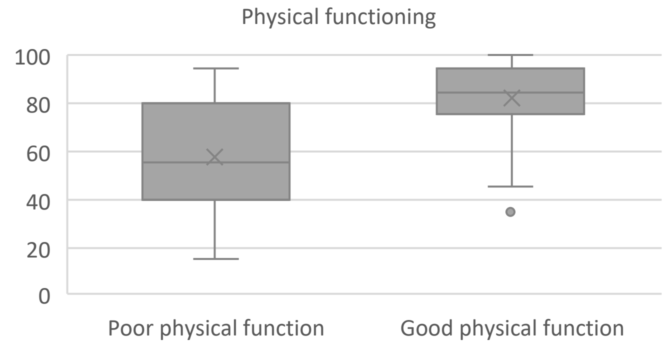


Figure 2.13: Boxplot of SF36 Physical functioning by physical function

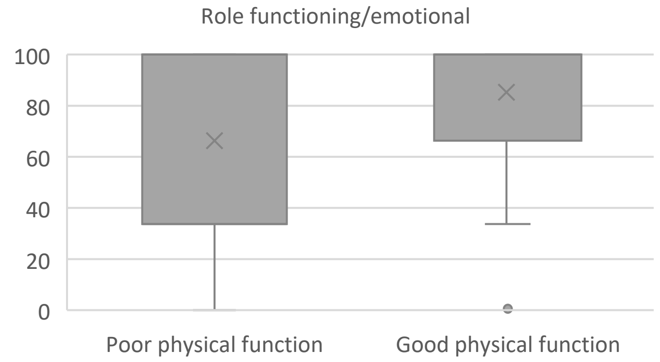


Figure 2.14: Boxplot of SF36 Role functioning/emotional by physical function

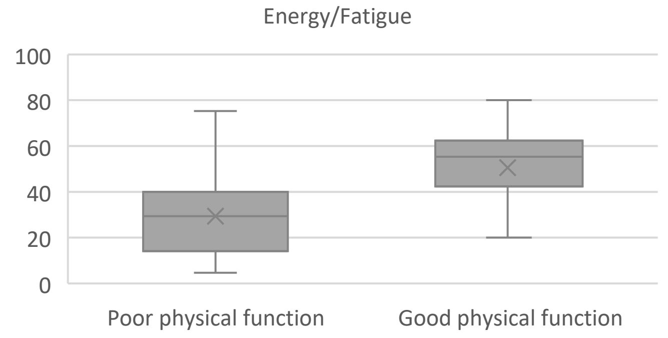


Figure 2.15: Boxplot of SF36 Energy/fatigue by physical function

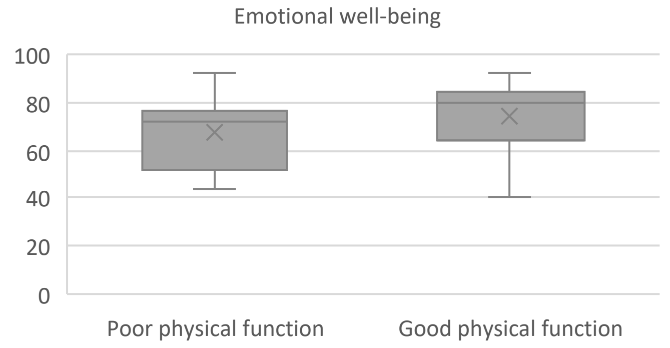


Figure 2.16: Boxplot of SF36 Emotional well-being by physical function

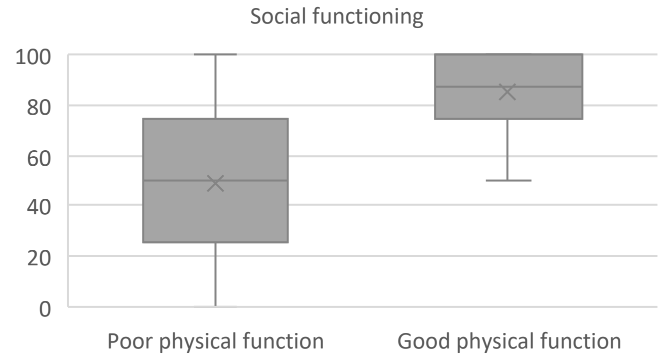


Figure 2.17: Boxplot of SF36 Social functioning by physical function

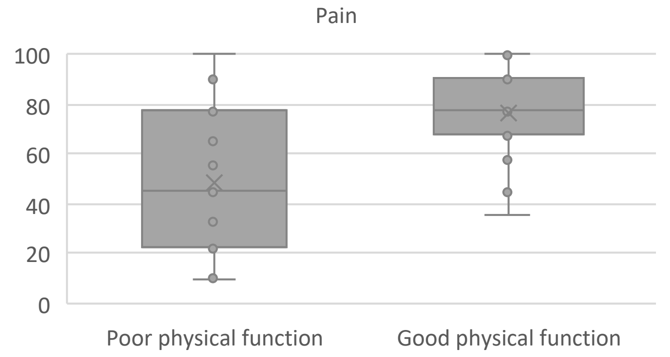


Figure 2.18: Boxplot of SF36 Pain by a physical function

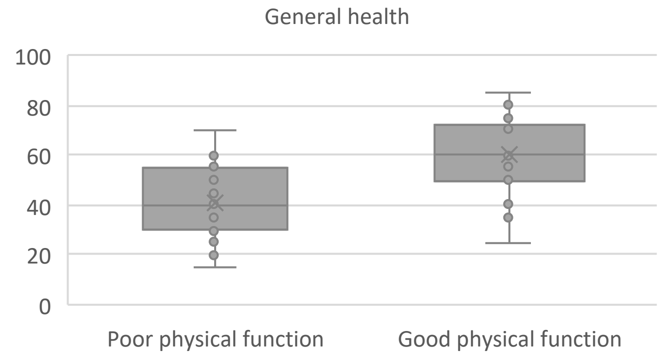


Figure 2.19: Boxplot of SF36 General health by physical function

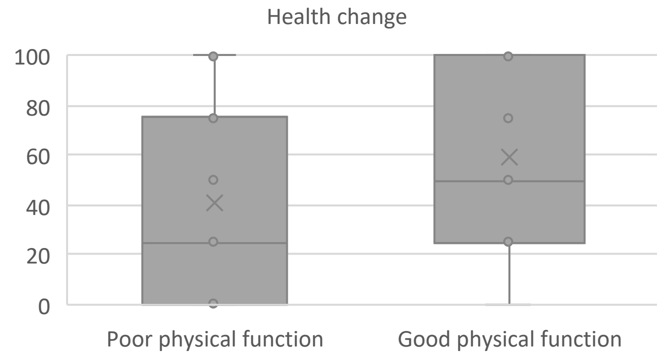


Figure 2.20: Boxplot of SF36 Health change by physical function

SF36 by year of diagnosis

Comparisons were made by the **year of diagnosis**, there were 26 participants that were *Diagnosed before 2020* (52.00%), and 24 participants *Diagnosed in 2020 or 2021* (48.00%).

A two-sample t-test was used when assumptions for normality and variance were met (Table 2.11), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 2.12).

A two sample t-test indicated that the mean score for the **SF36 General health** scale [t(42) = 2.43 , p = 0.0195] was significantly higher for participants in the *Diagnosed before 2020* subgroup (Mean = 58.18, SD = 17.01) compared to participants in the *Diagnosed in 2020 or 2021* subgroup (Mean = 45.68, SD = 17.13).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the **SF36 Physical functioning** scale [W = 352.00, p = 0.0097] was significantly higher for participants in the *Diagnosed before 2020* subgroup (Median = 90.00, IQR = 15.00) compared to participants in the *Diagnosed in 2020 or 2021* subgroup (Median = 70, IQR = 20.00).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the **SF36 Role functioning/physical** scale [W = 333.50 , p = 0.0265] was significantly higher for participants in the *Diagnosed before 2020* subgroup (Median = 87.50, IQR = 68.75) compared to participants in the *Diagnosed in 2020 or 2021* subgroup (Median = 25.00, IQR = 75.00).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the **SF36 Pain** scale [W = 336.00 , p = 0.0274] was significantly higher for participants in the *Diagnosed before 2020* subgroup (Median = 77.50, IQR = 46.88) compared to participants in the *Diagnosed in 2020 or 2021* subgroup (Median = 57.50, IQR = 30.00).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the SF36 Health change scale [W = 369.5, p = 0.0023*] was significantly higher for participants in the Diagnosed before 2020 subgroup (Median = 75, IQR = 43.75) compared to participants in the Diagnosed in 2020 or 2021 subgroup (Median = 25, IQR = 68.75.

SF36 Physical functioning scale measures health limitations in physical activities such as walking, bending, climbing stairs, exercise, and housework. On average, participants in the *Diagnosed before 2020* subgroup scored higher than participants in the *Diagnosed in 2020 or 2021* subgroup. This indicates that physical activities were not limited for participants in the *Diagnosed before 2020* subgroup, and were slightly limited for participants in the *Diagnosed in 2020 or 2021* subgroup.

SF36 Role functioning/physical scale measures how physical health interferes with work or other activities. On average, participants in the *Diagnosed before 2020* subgroup scored higher than participants in the *Diagnosed in 2020 or 2021* subgroup. This indicates that physical health never interfered with work or other activities for participants in the *Diagnosed before 2020* subgroup, and often interfered for participants in the *Diagnosed in 2020 or 2021* subgroup.

SF36 Pain scale measures how much pain, and how pain interferes with work and other activities. On average, participants in the *Diagnosed before 2020* subgroup scored higher than participants in the *Diagnosed in 2020 or 2021* subgroup. This indicates that participants in the *Diagnosed before 2020* subgroup had mild pain, and participants in the *Diagnosed in 2020 or 2021* subgroup had moderate pain.

SF36 General health scale measures perception of health. On average, participants in the *Diagnosed before 2020* subgroup had a higher score for general health compared to *Diagnosed in 2020 or 2021*, however, both groups had moderate health.

SF36 Health change scale measures health compared to a year ago. On average, participants in the *Diagnosed before 2020* subgroup scored higher than participants in the *Diagnosed in 2020 or 2021* subgroup. This indicates that participants in the *Diagnosed before 2020* subgroup reported that their health was a better than a year ago, and participants in the *Diagnosed in 2020 or 2021* subgroup reported somewhat worse health.

Table 2.11: SF36 by year of diagnosis summary statistics and T-test

SF36 scale	Group	Number (n=44)	Percent	Mean	SD	T	dF	p-value
Energy/Fatigue	Diagnosed before 2020	22	50.00	44.09	20.68	0.73	42	0.4665
	Diagnosed in 2020 or 2021	22	50.00	39.77	18.22			
Emotional well-being	Diagnosed before 2020	22	50.00	70.73	15.58	-0.08	42	0.9332
	Diagnosed in 2020 or 2021	22	50.00	71.09	12.88			
General health	Diagnosed before 2020	22	50.00	58.18	17.01	2.43	42	0.0195*
	Diagnosed in 2020 or 2021	22	50.00	45.68	17.13			

*Statistically significant at p<0.05

Table 2.12: SF36 by year of diagnosis summary statistics and Wilcoxon test

SF36 scale	Group	Number (n=44)	Percent	Median	IQR	W	p-value
Physical functioning	Diagnosed before 2020	22	50.00	90.00	15.00	352.00	0.0097*
	Diagnosed in 2020 or 2021	22	50.00	70.00	20.00		
Role functioning/physical	Diagnosed before 2020	22	50.00	87.50	68.75	333.50	0.0265*
	Diagnosed in 2020 or 2021	22	50.00	25.00	75.00		
Role functioning/emotional	Diagnosed before 2020	22	50.00	100.00	58.33	246.00	0.9238
	Diagnosed in 2020 or 2021	22	50.00	100.00	33.33		
Social functioning	Diagnosed before 2020	22	50.00	75.00	37.50	281.00	0.3592
	Diagnosed in 2020 or 2021	22	50.00	75.00	46.88		
Pain	Diagnosed before 2020	22	50.00	77.50	46.88	336.00	0.0274*
	Diagnosed in 2020 or 2021	22	50.00	57.50	30.00		
Health change	Diagnosed before 2020	22	50.00	75.00	43.75	369.50	0.0023*
	Diagnosed in 2020 or 2021	22	50.00	25.00	68.75		

*Statistically significant at p<0.05

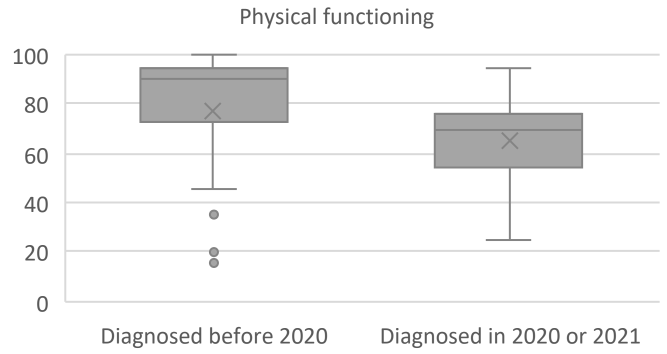


Figure 2.21: Boxplot of SF36 Physical functioning by year of diagnosis

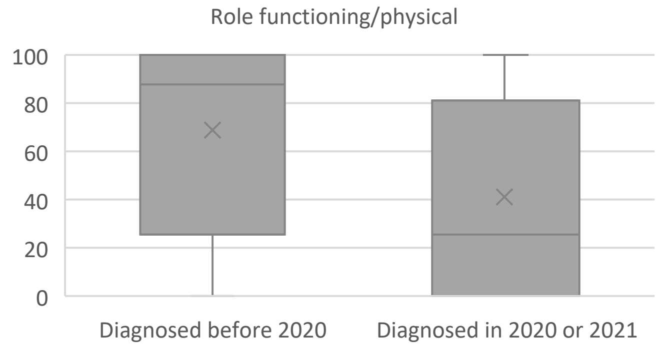


Figure 2.22: Boxplot of SF36 Role functioning/physical by year of diagnosis

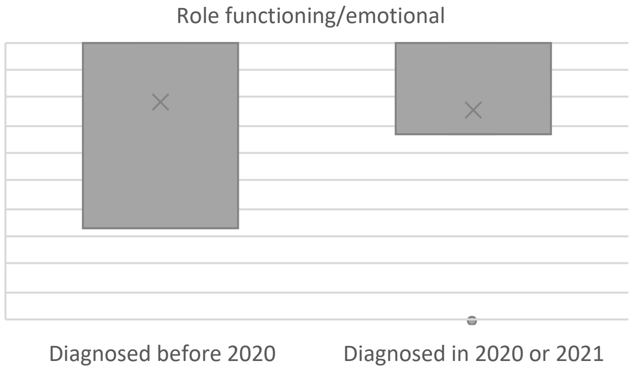


Figure 2.23: Boxplot of SF36 Role functioning/emotional by year of diagnosis

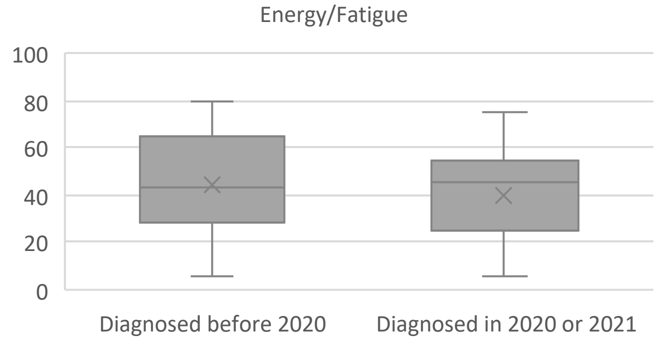


Figure 2.24: Boxplot of SF36 Energy/fatigue by year of diagnosis

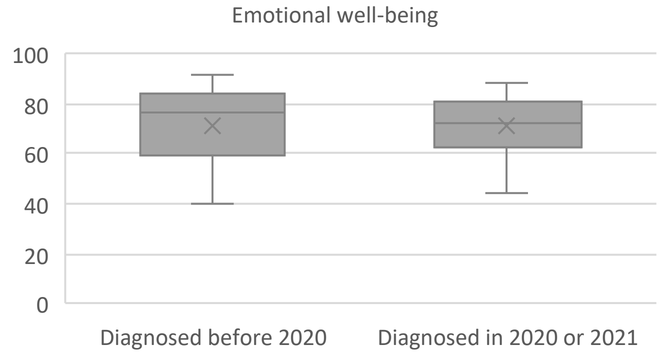


Figure 2.25: Boxplot of SF36 Emotional well-being by year of diagnosis

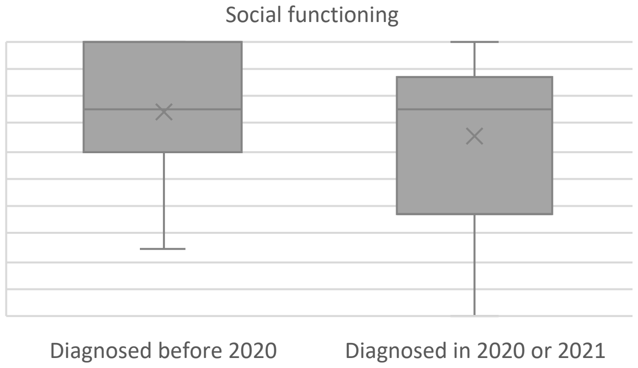


Figure 2.26: Boxplot of SF36 Social functioning by year of diagnosis

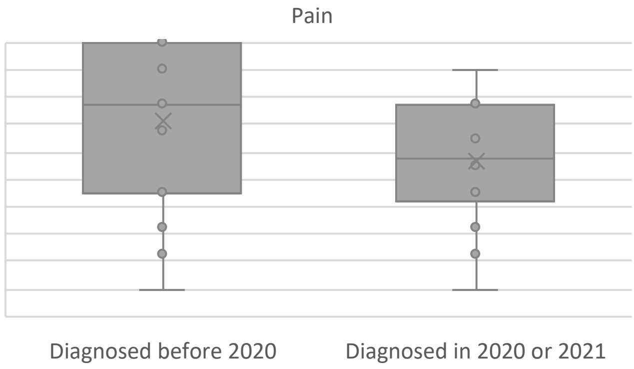


Figure 2.27: Boxplot of SF36 Pain by a year of diagnosis

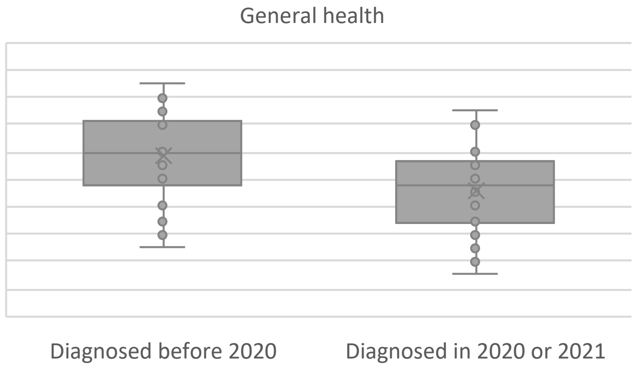


Figure 2.28: Boxplot of SF36 General health by year of diagnosis

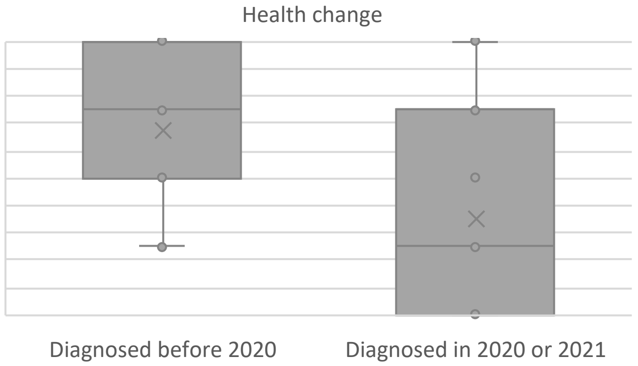


Figure 2.29: Boxplot of SF36 Health change by year of diagnosis

SF36 by education

Comparisons were made by **education** status, between those with *Trade or high school* qualifications, (n = 24, 48.00%), and those with a *University* qualification (n = 26, 52.00%).

A two-sample t-test was used when assumptions for normality and variance were met (Table 2.13), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 2.14).

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

Table 2.13: SF36 by education summary statistics and T-test

SF36 scale	Group	Number (n=44)	Percent	Mean	SD	T	dF	p-value
Energy/Fatigue	Trade or high school	21	47.73	43.33	16.98	0.45	42	0.6522
	University	23	52.27	40.65	21.65			
General health	Trade or high school	21	47.73	50.71	17.34	-0.42	42	0.6736
	University	23	52.27	53.04	18.93			

Table 2.14: SF36 by education summary statistics and Wilcoxon test

SF36 scale	Group	Number (n=44)	Percent	Median	IQR	W	p-value
Physical functioning	Trade or high school	21	47.73	75.00	30.00	231.50	0.8222
	University	23	52.27	80.00	45.00		
Role functioning/physical	Trade or high school	21	47.73	75.00	75.00	263.50	0.5997
	University	23	52.27	50.00	100.00		
Role functioning/emotional	Trade or high school	21	47.73	100.00	66.67	177.50	0.0822
	University	23	52.27	100.00	16.67		
Emotional well-being	Trade or high school	21	47.73	72.00	24.00	181.00	0.1565
	University	23	52.27	76.00	12.00		
Social functioning	Trade or high school	21	47.73	75.00	37.50	246.50	0.9146
	University	23	52.27	75.00	50.00		
Pain	Trade or high school	21	47.73	57.50	32.50	191.50	0.2425
	University	23	52.27	70.00	40.00		
Health change	Trade or high school	21	47.73	50.00	50.00	233.00	0.8477
	University	23	52.27	50.00	62.50		

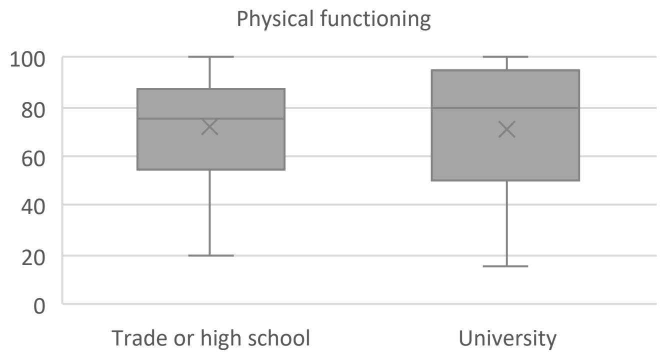


Figure 2.30: Boxplot of SF36 Physical functioning by education

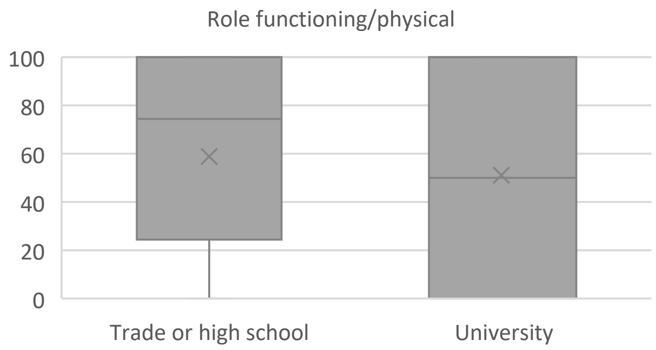


Figure 2.31: Boxplot of SF36 Role functioning/physical by education

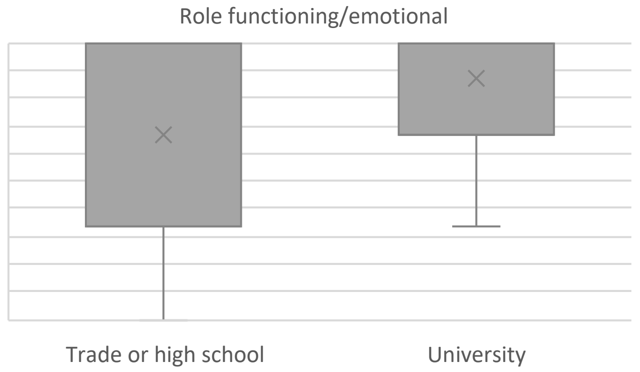


Figure 2.32: Boxplot of SF36 Role functioning/emotional by education

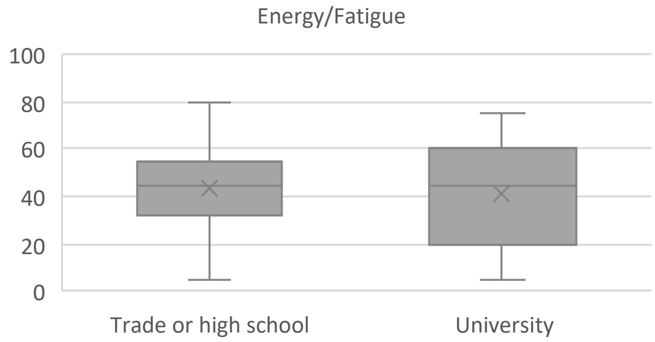


Figure 2.33: Boxplot of SF36 Energy/fatigue by education

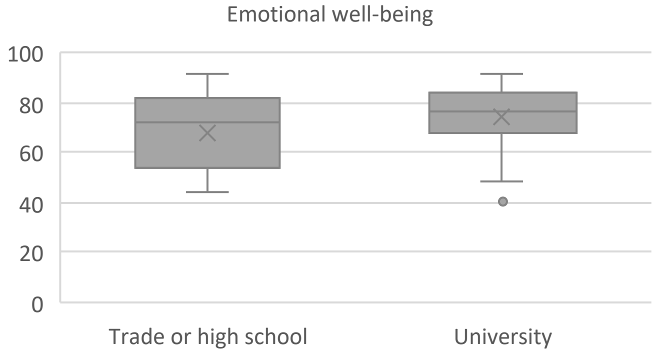


Figure 2.34: Boxplot of SF36 Emotional well-being by education

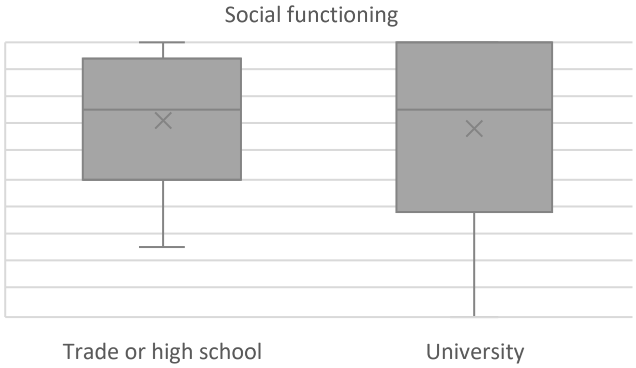


Figure 2.35: Boxplot of SF36 Social functioning by education

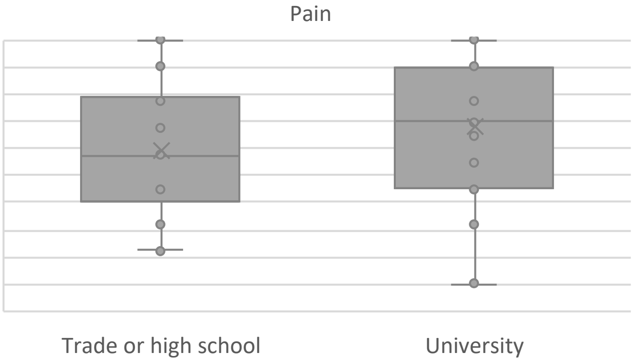


Figure 2.36: Boxplot of SF36 Pain by a education

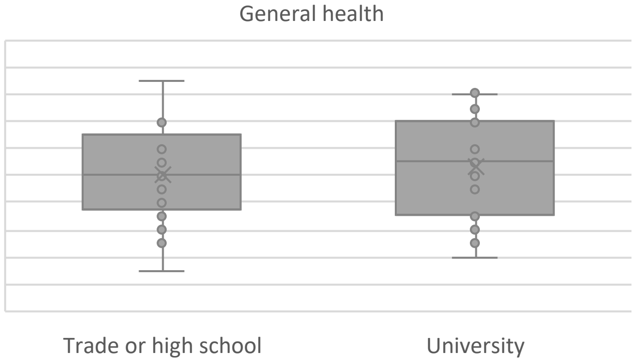


Figure 2.37: Boxplot of SF36 General health by education

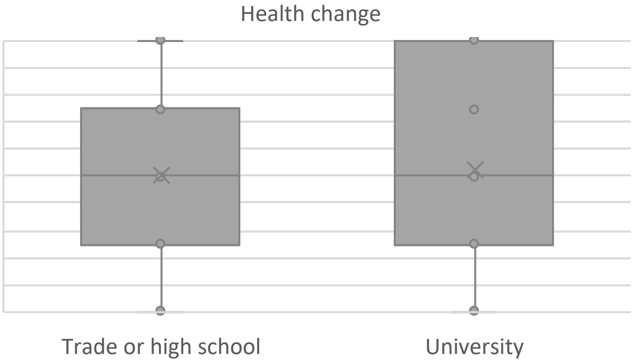


Figure 2.38: Boxplot of SF36 Health change by education

SF36 by location

The **location** of participants was evaluated by postcode using the Australian Statistical Geography Maps (ASGS) Remoteness areas accessed from the Australian Bureau of Statistics. Those living in regional/rural areas*, Regional or remote* (n =16, 32.00%) were compared to those living in a major city, *Metropolitan* (n = 34, 68.00%).

A two-sample t-test was used when assumptions for normality and variance were met (Table 2.15), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 2.16).

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

Table 2.15: SF36 by location summary statistics and T-test

SF36 scale	Group	Number (n=44)	Percent	Mean	SD	T	dF	p-value
Energy/Fatigue	Regional or remote	14	31.82	45.00	18.50	0.71	42	0.4798
	Metropolitan	30	68.18	40.50	19.93			
Pain	Regional or remote	14	31.82	69.64	21.21	0.99	42	0.3287
	Metropolitan	30	68.18	61.25	28.21			
General health	Regional or remote	14	31.82	54.29	15.17	0.59	42	0.5601
	Metropolitan	30	68.18	50.83	19.35			

Table 2.16: SF36 by location summary statistics and Wilcoxon test

SF36 scale	Group	Number (n=44)	Percent	Median	IQR	W	p-value
Physical functioning	Regional or remote	14	31.82	77.50	26.25	238.50	0.4775
	Metropolitan	30	68.18	77.50	38.75		
Role functioning/physical	Regional or remote	14	31.82	50.00	68.75	175.50	0.3735
	Metropolitan	30	68.18	75.00	75.00		
Role functioning/emotional	Regional or remote	14	31.82	83.33	66.67	163.00	0.1723
	Metropolitan	30	68.18	100.00	33.33		
Emotional well-being	Regional or remote	14	31.82	72.00	11.00	239.50	0.4627
	Metropolitan	30	68.18	76.00	30.00		
Social functioning	Regional or remote	14	31.82	75.00	25.00	202.00	0.8479
	Metropolitan	30	68.18	75.00	50.00		
Health change	Regional or remote	14	31.82	37.50	50.00	186.00	0.5451
	Metropolitan	30	68.18	50.00	50.00		

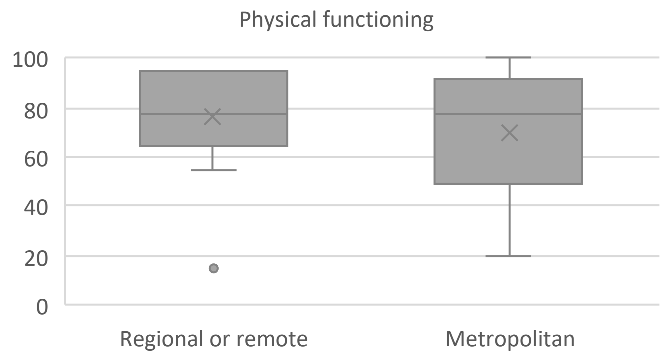


Figure 2.39: Boxplot of SF36 Physical functioning by location

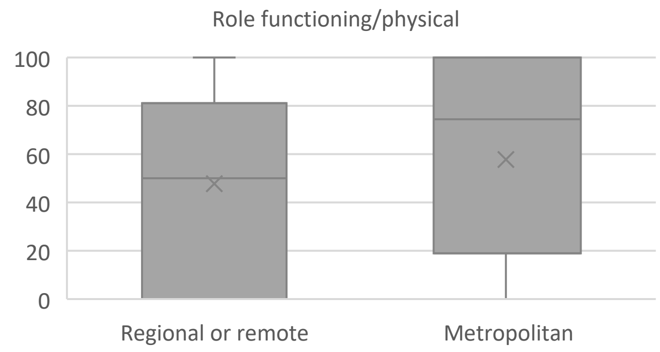


Figure 2.40: Boxplot of SF36 Role functioning/physical by location

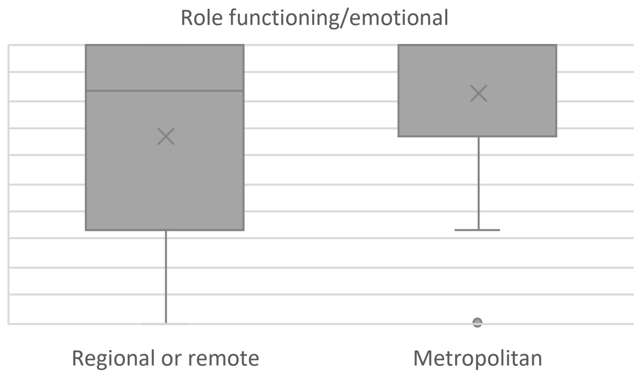


Figure 2.41: Boxplot of SF36 Role functioning/emotional by location

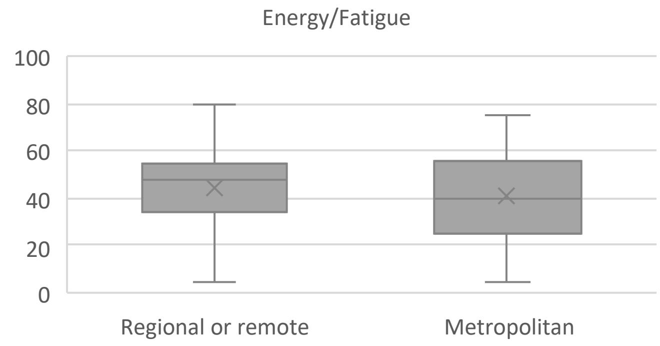


Figure 2.42: Boxplot of SF36 Energy/fatigue by location

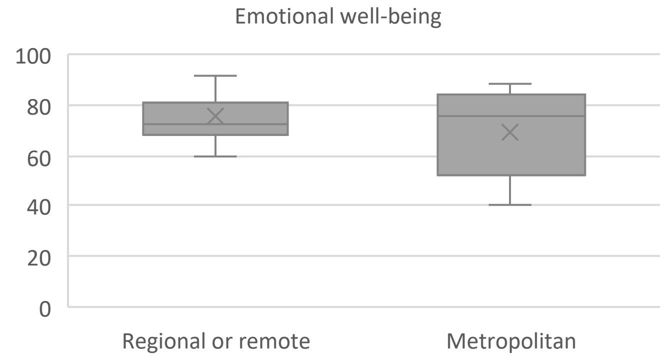


Figure 2.43: Boxplot of SF36 Emotional well-being by location

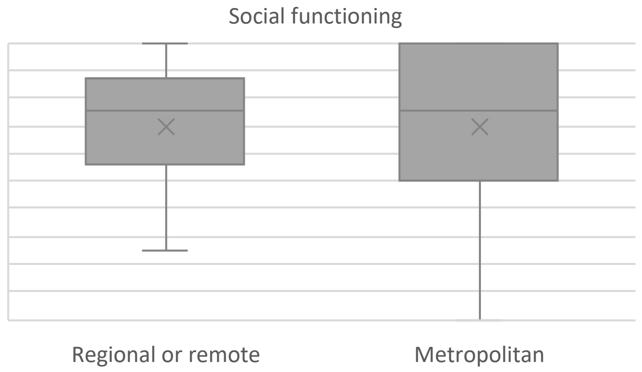


Figure 2.44: Boxplot of SF36 Social functioning by location

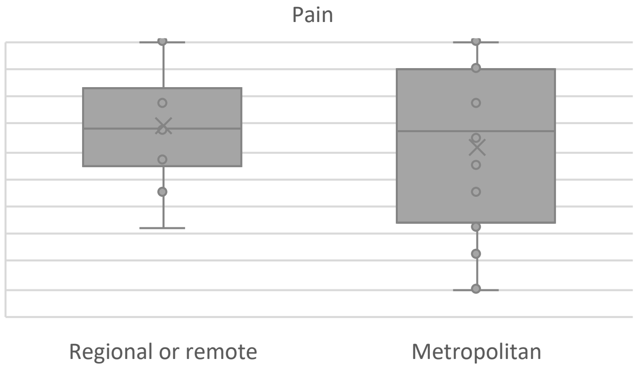


Figure 2.45: Boxplot of SF36 Pain by a location

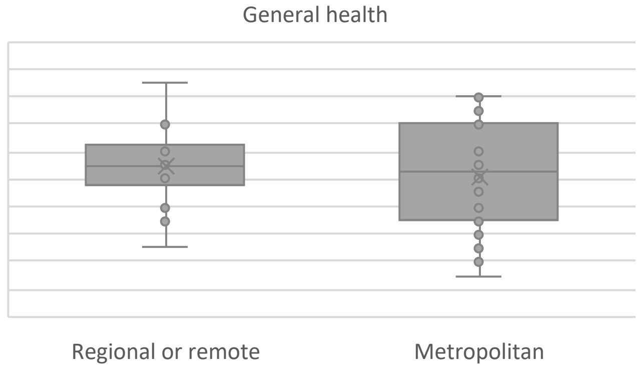


Figure 2.46: Boxplot of SF36 General health by location

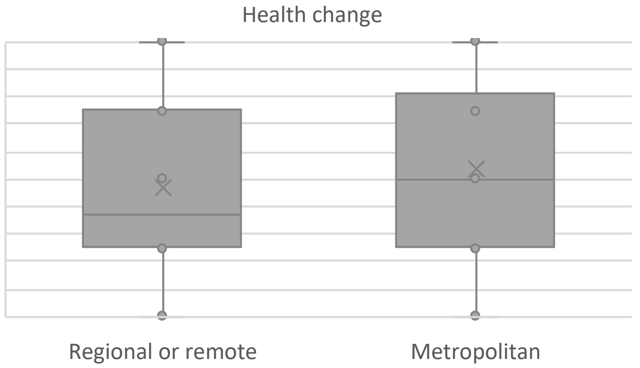


Figure 2.47: Boxplot of SF36 Health change by location

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 to 6, *Mid to low status* (n = 20, 40.00%) compared to those with a higher SEIFA score of 7 to 10, *Higher status* (n = 30, 60.00%).

A two-sample t-test was used when assumptions for normality and variance were met (Table 2.17), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 2.18).

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

Table 2.17: SF36 by socioeconomic status summary statistics and T-test

SF36 scale	Group	Number (n=44)	Percent	Mean	SD	T	dF	p-value
Energy/Fatigue	Mid to low status	17	38.64	40.59	18.28	-0.36	42	0.7199
	Higher status	27	61.36	42.78	20.35			
General health	Mid to low status	17	38.64	53.82	18.75	0.55	42	0.5865
	Higher status	27	61.36	50.74	17.80			

Table 2.18: SF36 by socioeconomic status summary statistics and Wilcoxon test

SF36 scale	Group	Number (n=44)	Percent	Median	IQR	W	p-value
Physical functioning	Mid to low status	17	38.64	75.00	35.00	210.50	0.6535
	Higher status	27	61.36	80.00	42.50		
Role functioning/physical	Mid to low status	17	38.64	50.00	75.00	220.50	0.8315
	Higher status	27	61.36	75.00	100.00		
Role functioning/emotional	Mid to low status	17	38.64	100.00	66.67	195.50	0.3469
	Higher status	27	61.36	100.00	33.33		
Emotional well-being	Mid to low status	17	38.64	72.00	24.00	236.00	0.8844
	Higher status	27	61.36	76.00	18.00		
Social functioning	Mid to low status	17	38.64	75.00	25.00	220.50	0.8353
	Higher status	27	61.36	75.00	50.00		
Pain	Mid to low status	17	38.64	67.50	35.00	225.00	0.9228
	Higher status	27	61.36	67.50	40.00		
Health change	Mid to low status	17	38.64	50.00	50.00	231.00	0.9804
	Higher status	27	61.36	50.00	50.00		

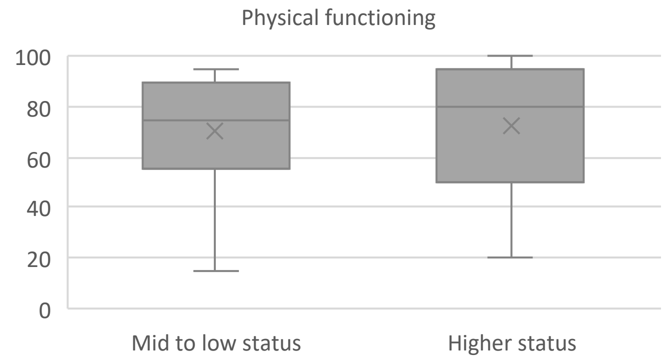


Figure 2.48: Boxplot of SF36 Physical functioning by socioeconomic status

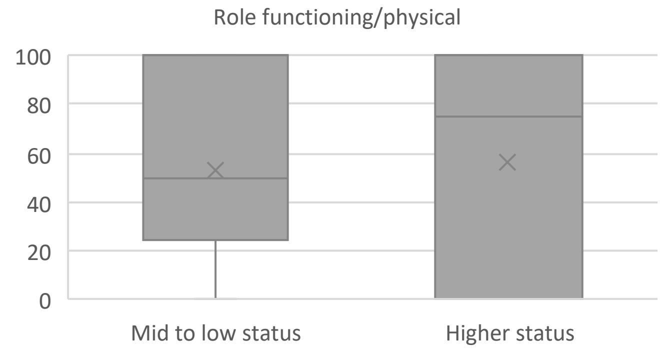


Figure 2.49: Boxplot of SF36 Role functioning/physical by socioeconomic status

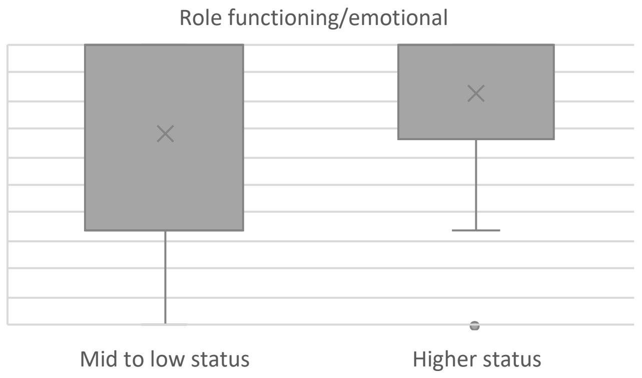


Figure 2.50: Boxplot of SF36 Role functioning/emotional by socioeconomic status

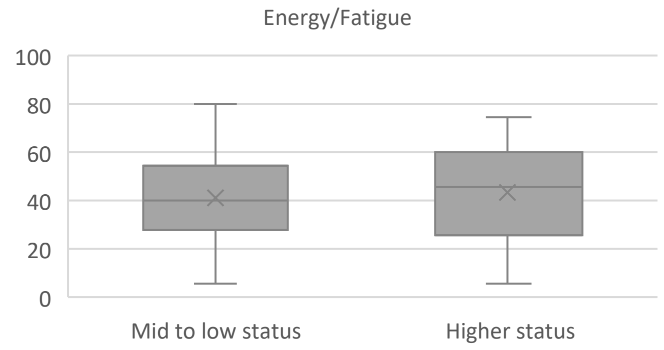


Figure 2.51: Boxplot of SF36 Energy/fatigue by socioeconomic status

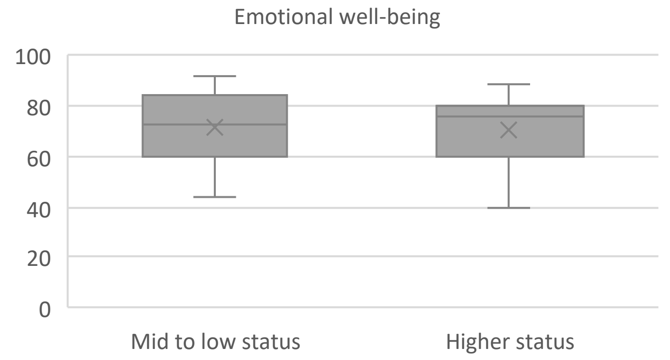


Figure 2.52: Boxplot of SF36 Emotional well-being by socioeconomic status

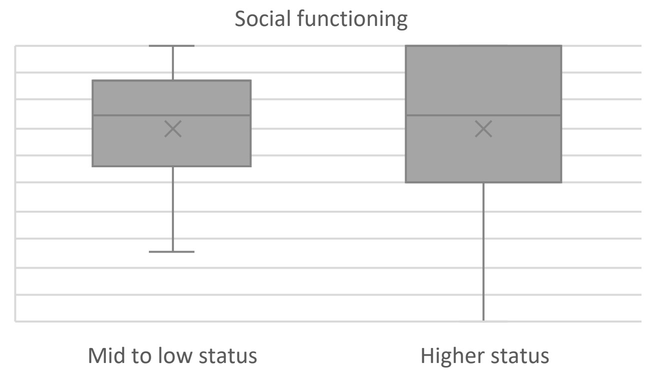


Figure 2.53: Boxplot of SF36 Social functioning by socioeconomic status

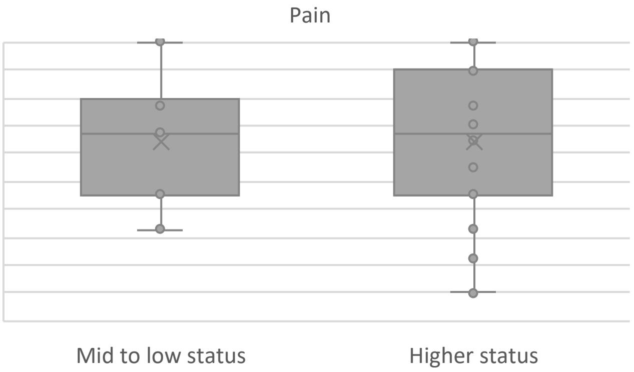


Figure 2.54: Boxplot of SF36 Pain by a socioeconomic status

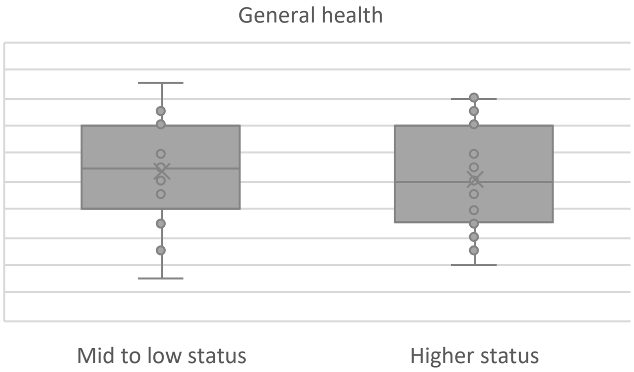


Figure 2.55: Boxplot of SF36 General health by socioeconomic status

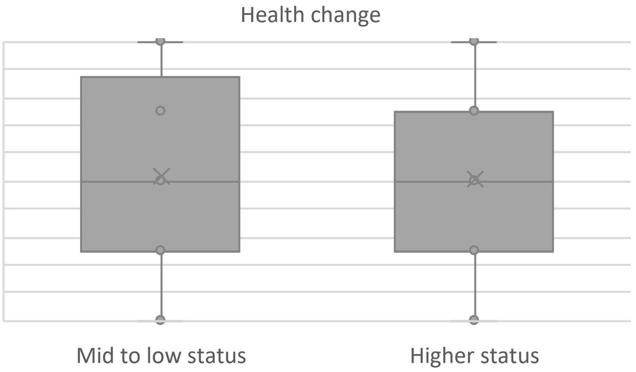


Figure 2.56: Boxplot of SF36 Health change by socioeconomic status

SF36 by age

Participants were grouped according to **age**, with comparisons made between participants *Aged 25 to 44* (n = 19, 38.00%), participants *Aged 45 to 54* (n = 22, 44.00%), and participants *Aged 55 to 74* (n = 9, 18.00%).

A one-way ANOVA test was used when the assumptions for response variable residuals were normally distributed, and variances of populations were equal (Table 2.19). When the assumptions for normality of residuals was not met, a Kruskal-Wallis test was used (Table 2.20).

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

Table 2.19: SF36 by age summary statistics and one-way ANOVA

SF36 scale	Group	Number (n=44)	Percent	Mean	SD	Source of difference	Sum of squares	dF	Mean Square	f	p-value
Energy/fatigue	Aged 25 to 44	16	36.36	39.06	21.77	Between groups	287.00	2	143.60	0.37	0.6920
	Aged 45 to 54	19	43.18	44.74	18.89	Within groups	15874.00	41	387.20		
	Aged 55 to 74	9	20.45	41.11	17.10	Total	16161.00	43			
Emotional well-being	Aged 25 to 44	16	36.36	71.25	12.33	Between groups	135.00	2	67.63	0.33	0.7220
	Aged 45 to 54	19	43.18	72.21	14.20	Within groups	8452.00	41	206.16		
	Aged 55 to 74	9	20.45	67.56	17.83	Total	8587.00	43			
General health	Aged 25 to 44	16	36.36	48.75	18.21	Between groups	390.00	2	194.90	0.59	0.5600
	Aged 45 to 54	19	43.18	55.26	19.04	Within groups	13571.00	41	331.00		
	Aged 55 to 74	9	20.45	50.56	16.09	Total	13961.00	43			

Table 2.20: SF36 by age summary statistics and Kruskal-Wallis test

SF36 scale	Group	Number (n=44)	Percent	Median	IQR	C^2	dF	p-value
Physical functioning	Aged 25 to 44	16	36.36	72.50	27.50	1.86	2	0.3948
	Aged 45 to 54	19	43.18	80.00	37.50			
	Aged 55 to 74	9	20.45	85.00	20.00			
Role functioning physical	Aged 25 to 44	16	36.36	50.00	100.00	0.47	2	0.7887
	Aged 45 to 54	19	43.18	75.00	87.50			
	Aged 55 to 74	9	20.45	75.00	75.00			
Role functioning emotional	Aged 25 to 44	16	36.36	83.33	66.67	1.94	2	0.3793
	Aged 45 to 54	19	43.18	100.00	33.33			
	Aged 55 to 74	9	20.45	100.00	0.00			
Social functioning	Aged 25 to 44	16	36.36	75.00	37.50	1.09	2	0.5798
	Aged 45 to 54	19	43.18	75.00	43.75			
	Aged 55 to 74	9	20.45	75.00	50.00			
Pain	Aged 25 to 44	16	36.36	66.25	28.13	0.72	2	0.6967
	Aged 45 to 54	19	43.18	67.50	40.00			
	Aged 55 to 74	9	20.45	77.50	45.00			
Health change	Aged 25 to 44	16	36.36	25.00	81.25	1.57	2	0.4559
	Aged 45 to 54	19	43.18	50.00	50.00			
	Aged 55 to 74	9	20.45	50.00	25.00			

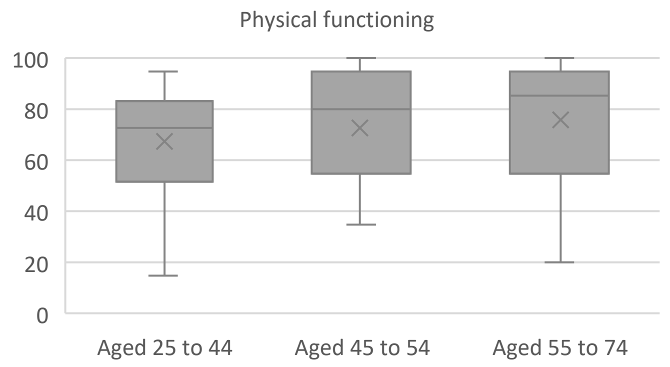


Figure 2.57: Boxplot of SF36 Physical functioning by age

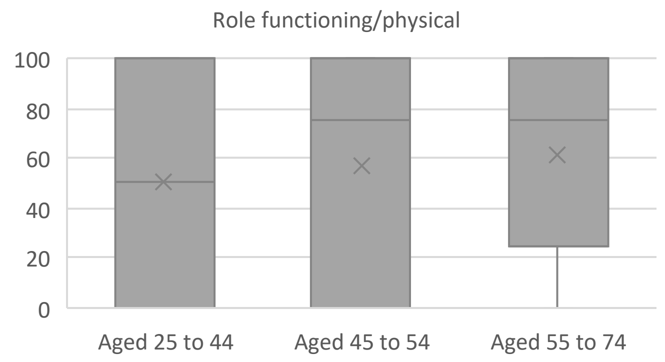


Figure 2.58: Boxplot of SF36 Role functioning/physical by age

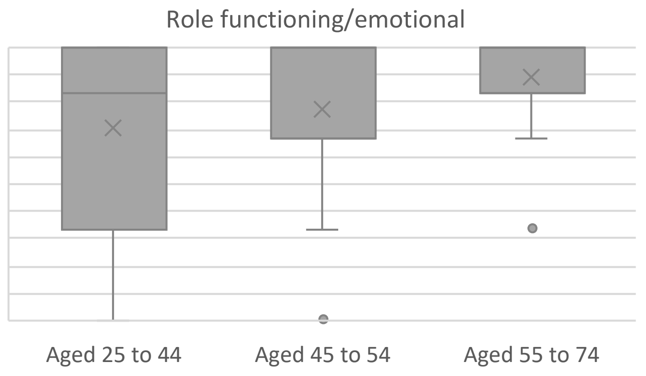


Figure 2.59: Boxplot of SF36 Role functioning/emotional by age

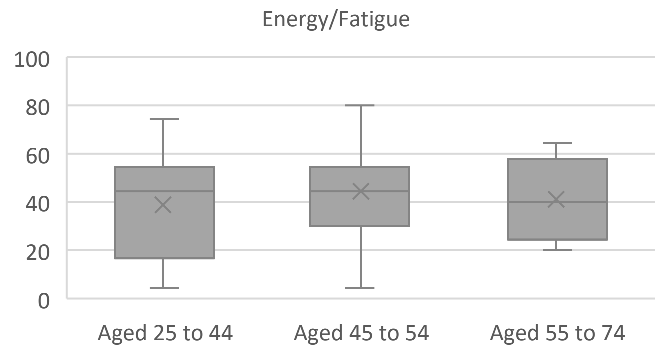


Figure 2.60: Boxplot of SF36 Energy/fatigue by age

Figure 2.61: Boxplot of SF36 Emotional well-being by age

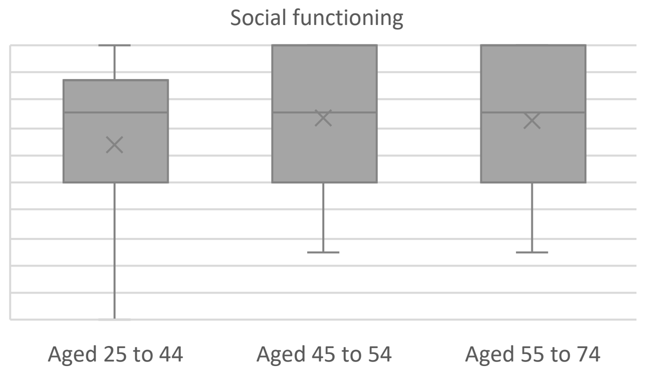


Figure 2.62: Boxplot of SF36 Social functioning by age

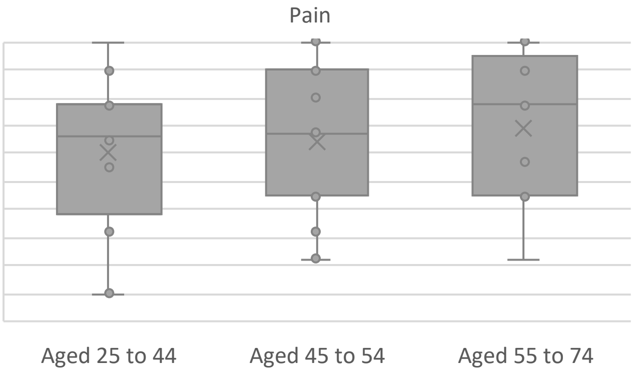


Figure 2.63: Boxplot of SF36 Pain by a age

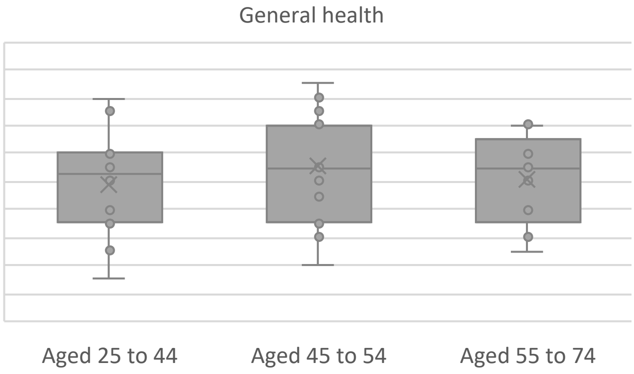


Figure 2.64: Boxplot of SF36 General health by age

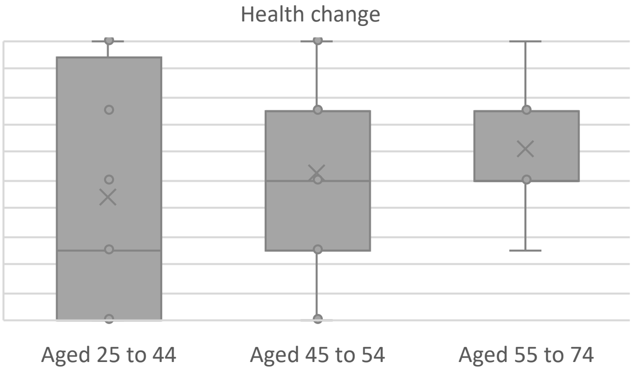


Figure 2.65: Boxplot of SF36 Health change by age

Section 3

Symptoms and diagnosis

Section 3: Symptoms and diagnosis

Symptoms leading to diagnosis

In the structured interview, participants were asked to describe the symptoms that actually *led* to their diagnosis. The most common symptom leading to diagnosis was having a lump or lumps in breasts (n=39, 78.00%), this was followed by having no symptoms (n=5, 10.00%). Other symptoms (n=6, 12.00%) leading to breast cancer included pain and symptoms from metastases.

Symptoms leading to diagnosis: Seeking medical attention

Participants described when they sought medical attention after noticing symptoms. There were 31 participants (62.00%) that described having symptoms and seeking medical attention relatively soon. There were six participants (12.00%) that described not having any symptoms before diagnosis, and six participants (12.00%) described having symptoms and not seeking medical attention initially.

Diagnostic pathway

Participants were most commonly diagnosed by their general practitioner due to concerns about symptoms (following imaging studies) (n=29, 58.00%). Other participants were referred directly to a specialist from their general practitioner which led to their diagnosis (n=11, 22.00%), and diagnosed through a population screening program (n=5, 10.00%)

Time from symptoms to diagnosis

Participants were asked to give the approximate date of when they first noticed symptoms of triple negative breast cancer and the approximate date of diagnosis with triple negative breast cancer. Duration was calculated for 18 participants (23 participants had no symptoms before diagnosis), there were six participants (14.63%) that were diagnosed less than a month after noticing symptoms, four participants (9.76%) diagnosed between 3 and 10 months after noticing symptoms, and eight participants (19.51%) that were diagnosed more than 12 months after noticing symptoms (Table 3.7, Figure 3.4).

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=27,57.45%). There were two participants (4.26%) diagnosed between 1 and 2 weeks, 12 participants (25.53%) diagnosed between 2 and 3 weeks, and three participants (6.38%) diagnosed between 3 and 4 weeks (Table 3.8, Figure 3.5).

Diagnostic tests

Participants were asked in the questionnaire which diagnostic tests they had for their diagnosis with triple negative breast cancer. Participants reported between 1 and 6 diagnostic tests (median = 3.00, IQR = 0.00) (Table 3.9, Figure 3.6). The most common tests were breast ultrasound (n = 42, 84.00%), core biopsy (n = 41, 82.00%), mammogram (n = 39, 78.00%), and fine needle aspiration (n = 34, 34.00%) (Table 3.10, Figure 3.7).

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 general practitioner (n = 28, 59.57%), and there were 13 participants (27.66%) given the diagnosis by a breast surgeon.

Understanding of disease at diagnosis

Participants were asked in the structured interview how much they knew about their condition at diagnosis. The most common theme was that participants had no knowledge of their condition at diagnosis (n=22, 44.00%), followed by having had a good knowledge (n=15, 30.00%). There were 10 participants(20.00%) who had a limited knowledge about their condition at diagnosis.

The most common reasons for a good knowledge were being informed by a healthcare professional at the time of diagnosis (n=4, 8.00%), having a professional background (n=4, 8.00%), and researching the condition during the diagnostic process (n=4, 8.00%). The most common reason for having limited knowledge was because of general public awareness

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 11 participants (23.40%) who had enough support, nine participants (19.15%) that had some support but it wasn't enough, and 27 participants (57.45%) that 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 21 participants (44.68%) who had enough information, 20 participants (42.55%) that had some information but it wasn't enough, and six participants (12.76%) that 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 13 participants (27.66%) who had no out of pocket expenses, and nine participants (19.15%) who did not know or could not recall. There were 10 participants (21.28%) that spent Less than $500, 11 participants (23.40%) that spent between $500 to $1000, and four participants (8.51%) that spent more than $1000 (Table 3.21, Figure 3.15).

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

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 = 13, 27.66%). There were 7 participants (14.89%) who brought up the topic with their doctor, and 27 participants (57.45%) whose doctor brought up the topic with them.

The majority of participants (n=32 68.09%) recalled having biomarker tests, and there were 14 participants (29.79%) that did not recall having biomarker tests but would like to have them (Table 3.24, Figure 3.18).

This question from the online questionnaire addresses the participants knowledge and understanding of having had biomarker tests. Despite all participants knowing that they had triple negative breast cancer, there were 70% that could relate this to biomarker status. The majority of participants knew the status for at least one biomarker (n = 42, 84.00%). Most commonly, participants knew their TNBC status (n = 35, 70.00%), followed by BRCA status (n = 19, 38.00%).

Current symptoms

More than half of the participants had symptoms to deal with at the time of completing the questionnaire (n = 21, 44.68%). Participants had between 5 to 12 symptoms (median = 8.00, IQR = 3.00) (Table 3.26, Figure 3.20).

The most common current symptoms, and those where more than 35% of the participants experienced the symptom were; anxiety (n = 21, 44.68%), fatigue (n=21, 44.68%), thinking and memory problems (n = 20, 42.55%), depression (n = 19, 40.43%) weight and muscle changes (n = 18, 38.30%), and pain (n = 18, 38.30%).

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”. The median quality of life was between 2.5 and 4.5, for all of the symptoms listed in the questionnaire, this is in the “Life was distressing to a little distressing” to “Life was average to good” range.

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=26, 54.00%), this was followed by prognosis described in relation to statistics such as five year survival rates (n=18, 36.00%). There were 14 participants (28.00%) who described prognosis in relation to probable recurrence/cycle of recurrence, 11 participants (22.00%) who described prognosis in relation to monitoring their condition without treatment until there is an exacerbation or progression, and seven participants (14.00%) who described prognosis in relation to it being positive that the condition will be cured in the future with treatment.

Symptoms leading to diagnosis

In the structured interview, participants were asked to describe the symptoms that actually *led* to their diagnosis. The most common symptom leading to diagnosis was having a lump or lumps in breasts (n=39, 78.00%), this was followed by having no symptoms (n=5, 10.00%). Other symptoms (n=6, 12.00%) leading to breast cancer included pain and symptoms from metastases.

Participant describes finding a breast lump, which led to their diagnosis

Okay. Well, I first noticed a lump on my breast in the shower one day, and I felt like it was like the size of a marble. I hadn't noticed it before, so I wasn't overly concerned about it, but I thought it was worth getting it checked. Just to be on the safe side, I thought it was probably just [unintelligible 00:02:13] or something. I went to my doctor and from there, I went ahead and mammogram and then ultrasound. Participant_020

No. I don't really recall any signs or symptoms. I know one of my friends told me that it was getting harder to wake me up, so maybe I was a bit more tired than usual. Actually, I found the lump on my breast. I was in pain. My breast was sore, and I felt a lump there. Then when I looked at myself in the mirror, I don't know whether I was imagining or not, I swear I saw bruising, so I thought I'd injured myself at the time. That's pretty much what happened with me. Participant_028

Okay. It was actually on a Wednesday. I was getting ready for work. I noticed a large lump under my left arm, and I just thought that's a bit unusual. I went to work and mentioned it to a few people. What I actually did was I thought I'll ring up and make an appointment for the doctor on Friday. If the lump is still there on Friday, I'll go to the doctor. If it's not there, I'll cancel it. It was there on Friday, so I went to the doctor. Participant_046

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

PARTICIPANT: I didn't have any symptoms. I went for a regular mammogram and it was picked up in the mammogram.
INTERVIEWER: Okay, all right. Just a routine mammogram?
PARTICIPANT: Yes.
INTERVIEWER: From this, who then ordered the first tests, if you remember that, and what was the tests that were ordered? Yes, the initial tests that were ordered, and maybe you can remember who.
PARTICIPANT: Are we talking about just this particular mammogram or how far back do I go?
INTERVIEWER: After you had the mammogram.
PARTICIPANT: Oh, after I had the mammogram. I had that done in a BreastScreen LOCATION facility. It was then I got a phone call about two weeks later from BreastScreen LOCATION, I think, requesting that I go into the HOSPITAL, there's a Family History Clinic on the ground floor of the HOSPITAL. They requested that I go there for further investigations because they'd seen an anomaly come up on the mammogram. I did that towards the end of February. Then I had a barrage of tests done there. I had an ultrasound. Is it breast examination? Participant_014

I have a history of breast cysts, so I used to be monitored yearly for any changes in my breast. That got changed to two-yearly, literally two years prior to my diagnosis. I was diagnosed from mammograms. I'm a country patient. I live in LOCATION. I was sent to LOCATION to have a mammogram. Prior to the mammogram, on the day, I was given an ultrasound, and I knew myself from the ultrasound what we were looking at, even though no one said anything. By the time I got home, I was already in panic mode without having a diagnosis from anyone. I just knew myself what was going on. I'd done my own research to find a surgeon who I wanted to see, which was NAME at HOSPITAL. When my doctor phoned me the following day after my mammogram and ultrasound, he said, "How you going?" I said, "I know." He goes, "Right. What do you want to do?" I said, "This is who I want to see. Send me to LOCATION." That's how it went. Participant_034

Table 3.1: Symptoms leading to diagnosis

Symptoms leading to diagnosis	All participants n=50	%	Early breast cancer n=23	%	Advanced breast cancer n=27	%	Poor physical function n=19	%	Good physical function n=25	%	Diagnosed before 2020 n=26	%	Diagnosed in 2020 or 2021 n=24	%	Trade or high school n=24	%	University n=26	%
Participant describes finding a breast lump, which led to their diagnosis	39	78.00	21	91.30	18	66.67	14	73.68	21	84.00	19	73.08	20	83.33	17	70.83	22	84.62
Participant describes having no symptoms or not noticing any symptoms before diagnosis	5	10.00	1	4.35	4	14.81	2	10.53	2	8.00	3	11.54	2	8.33	3	12.50	2	7.69
Other	6	12.00	1	4.35	5	18.52	3	15.79	2	8.00	2	7.69	4	16.67	4	16.67	2	7.69

Symptoms leading to diagnosis	All participants n=50	%	Regional or remote n=16	%	Metropolitan n=34	%	Mid to low status n=20	%	Higher status n=30	%	Aged 25 to 44 n=19	%	Aged 45 to 54 n=22	%	Aged 55 to 74 n=9	%
Participant describes finding a breast lump, which led to their diagnosis	39	78.00	15	93.75	24	70.59	16	80.00	23	76.67	13	68.42	20	90.91	6	66.67
Participant describes having no symptoms or not noticing any symptoms before diagnosis	5	10.00	1	6.25	4	11.76	2	10.00	3	10.00	2	10.53	2	9.09	1	11.11
Other	6	12.00	0	0.00	6	17.65	2	10.00	4	13.33	4	21.05	0	0.00	2	22.22

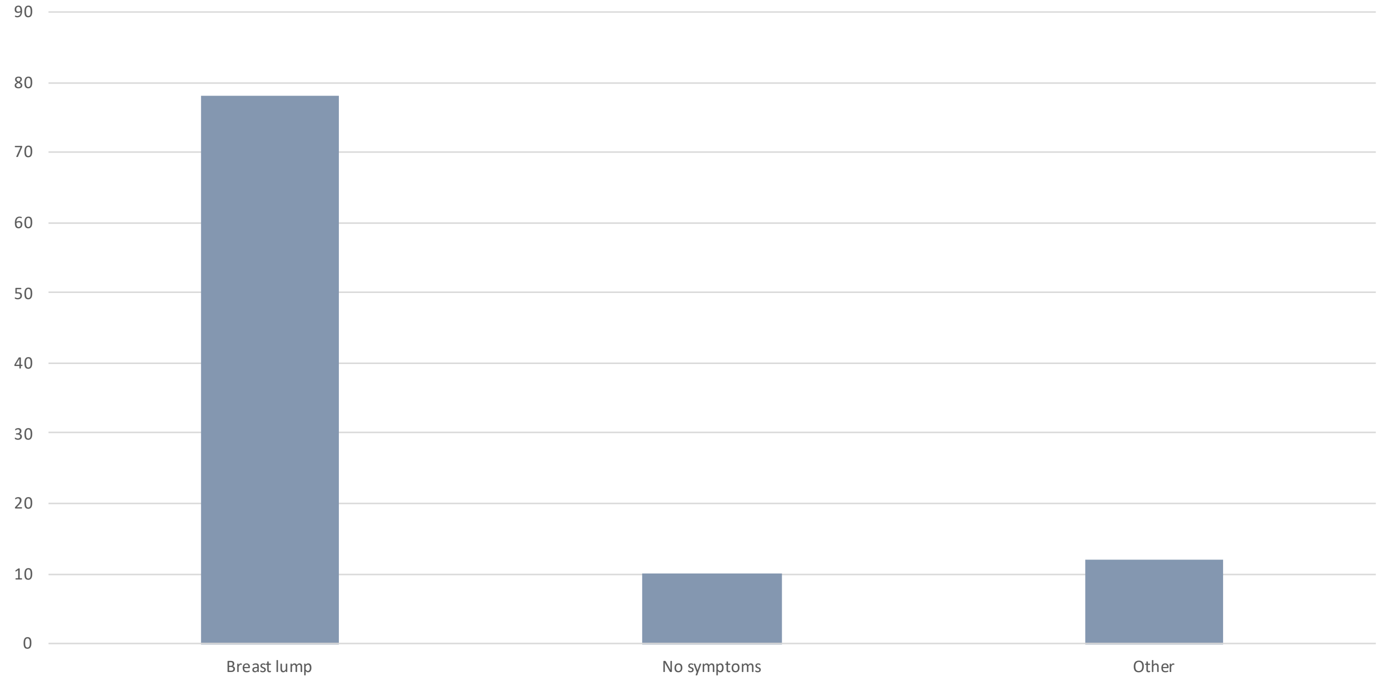


Figure 3.1: Symptoms leading to diagnosis

Table 3.2: Symptoms leading to diagnosis – subgroup variations

Theme	Reported less frequently	Reported more frequently
Participant describes finding a breast lump, which led to their diagnosis	Advanced breast cancer Aged 55 to 74	Early breast cancer Regional or remote Aged 45 to 54

Symptoms leading to diagnosis: Seeking medical attention

Participants described when they sought medical attention after noticing symptoms. There were 31 participants (62.00%) that described having symptoms and seeking medical attention relatively soon. There were six participants (12.00%) that described not having any symptoms before diagnosis, and six participants (12.00%) described having symptoms and not seeking medical attention initially.

Participant describes having symptoms and seeking medical attention relatively soon

Okay, well, I wasn't under any surveillance because there's no history of cancer in my family. When I went to the doctor when I first noticed the lump, she sent me off to get a mammogram and an ultrasound done. Based on the ultrasound images, she then sent me to get a fine needle biopsy done. That was what showed us that it was a cancerous mass. Participant_027

Okay. Well, I first noticed a lump on my breast in the shower one day, and I felt like it was like the size of a marble. I hadn't noticed it before, so I wasn't overly concerned about it, but I thought it was worth getting it checked. Just to be on the safe side, I thought it was probably just [unintelligible] or something. I went to my doctor and from there, I went ahead and mammogram and then ultrasound. Participant_020

I had nothing before diagnosis. There was nothing worse than seeing a doctor regularly or anything like that. So I found the lump riding to see my GP. And because it was hurting, because I did it so not my doctor was you know, she's I remember him saying, you don't usually hit me. And she said it's probably just hit with it so much. But yes, she booked me in for an ultrasound. Outstanding mammogram or I think no, I think to start with, it was just an ultrasound. And I went to the radiology place and I had the ultrasound. And before I left, that had to mean that deadpan, I don't tell you anything, but before I left the like, OK, we need you to come back for biopsy. So I had set up to that, to that to wait and the biopsy and then I had the biopsy. And then this is the part that 12 or nine years later do shits me the most. I went to I think the doctor said call-back will come back in X amount and I days, something like that. So I went back and my doctor, she wasn't even like my regular doctor, but the doctor that had the biopsy, you know, all of that stuff was she was away. And I said, that's fine. I'll just say whoever so went in to see my doctor or the doctor of the day, how can I help you? And I said, oh, I'm here for some test results, you know? So she looked up and she was a young doctor and she could just see her face just basically in the head. I could see what she had to tell me, that the test results were positive, that, yes, I had cancer. And she was like, I'm so sorry. This should have been red flagged. We should have called you in. She had me walking into her office to tell me I had cancer, yet she had no idea what she was about to tell me. So I was quite floored myself because I went to the appointment by myself and my husband was on nightshift. He was asleep and I just found out I had cancer and I didn't know. Participant_003

Participant describes having no symptoms or not noticing any symptoms before diagnosis, diagnosis was through routine screening

Yes. I did a mammogram and they called me back and said that they wanted to do a follow-up screening. They didn't say anything at the time. I had to go and do a further ultrasound and biopsy. Then they said to me that they would call me in a week's time with the results. They called me two days later and asked me to come in and I suspected then that it wasn't good. I met the breast surgeon or the surgeon that I go to the BreastScreen. He went through my diagnosis with me in LOCATION at the center there and told me the results of the biopsy and the further ultrasound. Participant_029

Participant describes having symptoms and not seeking medical attention initially

PARTICIPANT: Yes, so I was pregnant. It was in about May last year, 2020. I noticed a lump that had started, but I put that down to hormonal prepping for birth and breastfeeding and all that stuff, I didn't really think much of it. Then, it gradually grew bigger and bigger. Once I birthed my baby and when she was about four months old, I actually went and got it checked out.
INTERVIEWER: PARTICIPANT, can you describe how you came to be diagnosed? Now, for this, you can talk about any tests that were ordered and who ordered them for you if you can remember that. This might also include any ongoing management or surveillance that you might have been under before you were diagnosed.
PARTICIPANT: I went to my GP and had a referral for an ultrasound. Then, from that ultrasound, my GP referred me to a specialist, which was of my choosing because background-wise, I've got family history. I'd already been linked in with HOSPITAL previously and all the family history. My mother and my grandmother all went through HOSPITAL, so I requested for the referral to go to HOSPITAL. Then I had a sited biopsy and from that is when they did the diagnosis. Participant_030

PARTICIPANT: The first time I noticed was a lump, which I get lots of lipomas anyway so at first I thought, "I wonder if that's just the lipoma." It was right at the late February, early March last year and everybody was starting to get nervous and worried about COVID. I thought, "I'll just let that flow over and then I'll go to the doctor," [chuckles] thinking it's going to be a short-term thing.
INTERVIEWER: Yes. [chuckles] Unfortunately, not.
PARTICIPANT: Yes. When it got May and looked like things were not going to settle down and the lump was getting bigger, I thought, "I've got to do something." I had a telehealth appointment with my doctor and she said, "Get a check straightaway." Then I got scans and things.
INTERVIEWER: That leads me into my next question about how you came to be diagnosed. What tests did you have, PARTICIPANT? Who ordered those for you?
PARTICIPANT: It was my GP who ordered them. I had a mammogram and ultrasound. They called the doctor when I did the ultrasound and the doctor said they wanted a biopsy. My GP doesn't work every day. They ended up getting a referral from another GP for surgery because I wanted the biopsy the next day and I didn't want to wait. I knew already at that point that things weren't looking good. Then the biopsy confirmed it Participant_011

Thinking now before I was diagnosed, I was getting pins and needles down my arm and in my hand, on my right which is the same breast. I don't know whether it's linked or not, but I do remember that now. I do remember up in my lymph nodes, I do also remember feeling that they were enlarged and I did see my GP about it but she just said-- I think she did feel my breasts at that stage and she said, "Oh no, that's just whatever." She didn't even think about the cancer sort of thing. I also do think before I was diagnosed, probably a couple of months beforehand, I did have a tender breast but I didn't really think too much of it. I thought one of my kids had knocked me in my breasts and I didn't think too much of it. Participant_017

Table 3.3: Seeking medical attention

Seeking medical attention	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=23	%	n=27	%	n=19	%	n=25	%	n=26	%	n=24	%	n=24	%	n=26	%
Participant describes having symptoms and seeking medical attention relatively soon	31	62.00	11	47.83	20	74.07	13	68.42	15	60.00	16	61.54	15	62.50	14	58.33	17	65.38
Participant describes having no symptoms or not noticing any symptoms before diagnosis, diagnosis was through routine screening	6	12.00	4	17.39	2	7.41	2	10.53	3	12.00	3	11.54	3	12.50	3	12.50	3	11.54
Participant describes having symptoms and not seeking medical attention initially	6	12.00	4	17.39	2	7.41	2	10.53	4	16.00	2	7.69	4	16.67	2	8.33	4	15.38
Participant describes having symptoms and not seeking medical attention initially, but recognising the importance of those symptoms in hindsight	4	8.00	3	13.04	1	3.70	1	5.26	1	4.00	2	7.69	2	8.33	3	12.50	1	3.85
Other	3	6.00	1	4.35	2	7.41	1	5.26	2	8.00	1	3.85	2	8.33	2	8.33	1	3.85

Seeking medical attention	All participants		Regional or remote		Metropolitan		Mid to low status		Higher status		Aged 25 to 44		Aged 45 to 54		Aged 55 to 74	
	n=50	%	n=16	%	n=34	%	n=20	%	n=30	%	n=19	%	n=22	%	n=9	%
Participant describes having symptoms and seeking medical attention relatively soon	31	62.00	10	62.50	21	61.76	11	55.00	20	66.67	0	0.00	13	59.09	4	44.44
Participant describes having no symptoms or not noticing any symptoms before diagnosis, diagnosis was through routine screening	6	12.00	2	12.50	4	11.76	5	25.00	1	3.33	14	73.68	3	13.64	3	33.33
Participant describes having symptoms and not seeking medical attention initially	6	12.00	3	18.75	3	8.82	1	5.00	5	16.67	2	10.53	4	18.18	0	0.00
Participant describes having symptoms and not seeking medical attention initially, but recognising the importance of those symptoms in hindsight	4	8.00	1	6.25	3	8.82	1	5.00	3	10.00	1	5.26	1	4.55	2	22.22
Other	3	6.00	0	0.00	3	8.82	2	10.00	1	3.33	2	10.53	1	4.55	0	0.00

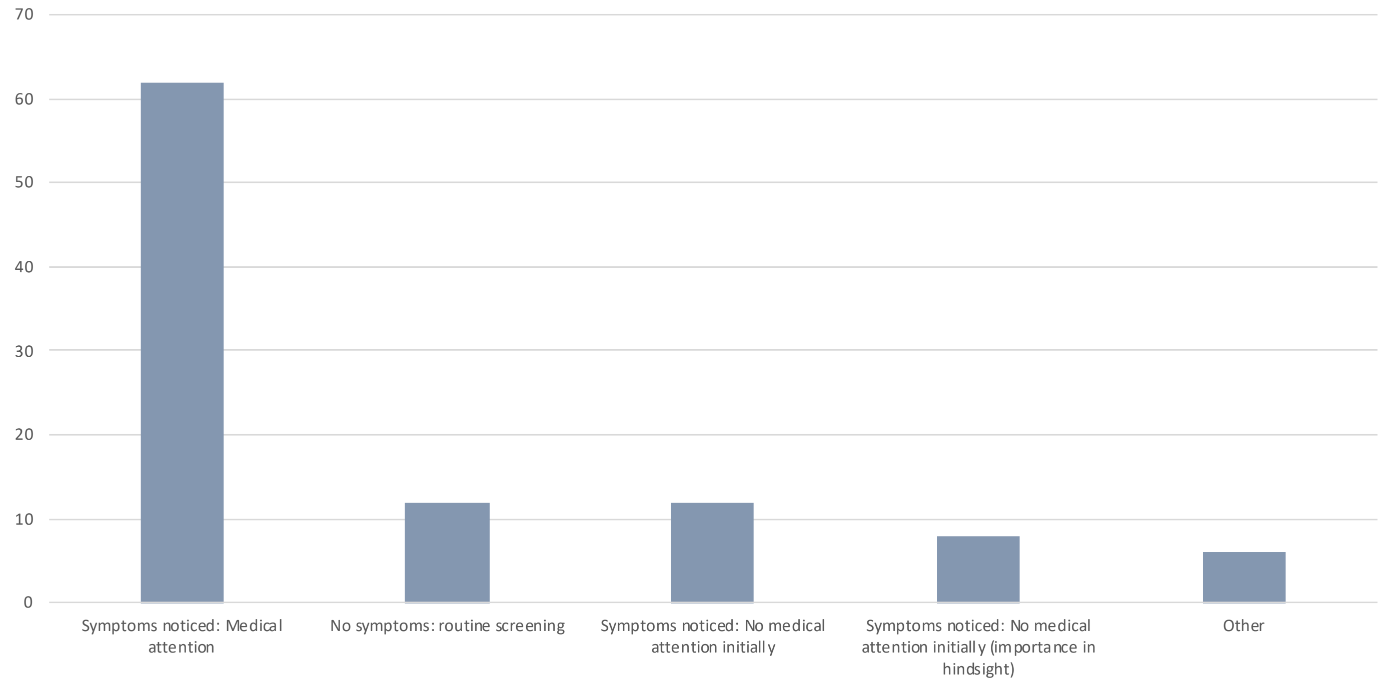


Figure 3.2: Seeking medical attention

Table 3.4: Seeking medical attention – subgroup variations

Theme	Reported less frequently	Reported more frequently
Participant describes having symptoms and seeking medical attention relatively soon	Early breast cancer Aged 25 to 44 Aged 55 to 74	Advanced breast cancer
Participant describes having no symptoms or not noticing any symptoms before diagnosis, diagnosis was through routine screening	-	Mid to low status Aged 25 to 44 Aged 55 to 74
Participant describes having symptoms and not seeking medical attention initially	Aged 55 to 74	-

Diagnostic pathway

Participants were most commonly diagnosed by their general practitioner due to concerns about symptoms (following imaging studies) (n=29, 58.00%). Other participants were referred directly to a specialist from their general practitioner which led to their diagnosis (n=11, 22.00%), and diagnosed through a population screening program (n=5, 10.00%)

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

OK, so I had no family history, no symptoms, so I wasn't any kind of surveillance. I went to the doctor and he ordered mammograms and said, look, I had already anticipated was going to be needed. So I actually ran up and made an appointment with a local clinic thinking, I'll be on my way to find out and have a look inside. So he ordered that and an ultrasound and I think he ordered to do a core biopsy to activate that. And so that was all through the GP. And then I went back to the GP diagnosis. Participant_002

When I went to the doctor, he felt the lump. He was concerned. He sent me off for a mammogram and then ultrasound on my breast, and also sent me to get blood tests. I had the mammogram and the ultrasound that afternoon. When I was having that done, I was very lucky I had the head of the place there doing my ultrasound. I said to him, "It's cancer that's gone to my lymph nodes, hasn't it?" Because my dad had cancer before, and I knew about the lymph nodes side of things. He said, "Yes, it has." He said, "You're going to have to have a biopsy. The doctor will order that for you," but he said, "If you want me to, I can do that now for you." I said, "Yes, go ahead. Do it now," so I had the biopsy done then and there. I had the blood tests done the next day. Then I had an appointment with the doctor on the Wednesday to get all the results. That's when he informed me that I had breast cancer. It was all very quick. Participant_046

OK, now I just after feeling the lump, I got up the courage three days later to go see my GP and he had a feel for it and they said, Oh, I'm going to send you for an ultrasound and biopsy for biopsy. I think it was. And I like, oh, OK. So what are you thinking? And he said, well, I need to check that it's not breast cancer. But he said that I had a feeling I knew it was. I remember feeling, you know, that he knows something here. And so a few days later, I got into the whole biopsy and the ultrasound and I knew from then I had trouble doing the biopsy, very painful. And then when I went back to the GP, he said to me, I just have to confirm you've got cancer in your breast. And I'm very sorry if you are, but I have breast cancer. And he said, yes, you have. And oh. Oh, hang on. I was expecting him to say that. And then he just basically said, well, now, but I refer you to a surgeon to have a lumpectomy and to see how we go from there. And then it all started. Participant_049

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

I was very, very healthy at the time, hardly went to the doctor. I found the lump. I made an appointment within a day or two to see-- I knew that it was not supposed to be there, so I went and saw my GP. He straight away felt it and was quite concerned. Sent me straight away for a mammogram, got in the next day for a mammogram and an ultrasound. The results came back, I think, the next day. I had to go there. There is definitely something there. They made me an appointment with a surgeon and I saw the surgeon within two days, basically. From that point on the surgeon sort of looked at it, felt it, realized that he thought it would be something. Sent me for a biopsy, I think. Some sort of scan, I can't exactly remember what it was but I do know I went for a biopsy. While having the biopsy, they basically told me that it was cancer. They didn't come out and say, "You have cancer" but they spoke about, "It looks like cancer" so you know, I've got five sisters, so I went back to the surgeon, he confirmed that, yes, it was. Put me in touch with an oncologist. Because of the triple-negative, they decided that I would do chemo first. Participant_035

I had my first mammogram in 2014, I think, because a friend of mine had breast cancer. I was only 46 at the time, I guess. A friend of mine had had breast cancer, so she said, "Oh, we should all--" The rest of us all went and had mammograms, and then I didn't have another one until 2019, I guess it was. Then, I found the lump myself just a few days before Christmas, and I went to see my GP. I called and got in to see her immediately that afternoon. She did a manual examination and sent me straight to CLINIC in LOCATION for a scan. Then the scan came back and she let me know that there was something that she felt needed some attention, so she organized a meeting to DOCTOR. Participant_041

Yes. I did a mammogram and they called me back and said that they wanted to do a follow-up screening. They didn't say anything at the time. I had to go and do a further ultrasound and biopsy. Then they said to me that they would call me in a week's time with the results. They called me two days later and asked me to come in and I suspected then that it wasn't good. I met the breast surgeon or the surgeon that I go to the BreastScreen. He went through my diagnosis with me in LOCATION at the center there and told me the results of the biopsy and the further ultrasound. Participant_029

Participant describes being diagnosed through a population screening program

I have a history of breast cysts, so I used to be monitored yearly for any changes in my breast. That got changed to two-yearly, literally two years prior to my diagnosis. I was diagnosed from mammograms. I'm a country patient. I live in LOCATION. I was sent to LOCATION to have a mammogram. Prior to the mammogram, on the day, I was given an ultrasound, and I knew myself from the ultrasound what we were looking at, even though no one said anything. By the time I got home, I was already in panic mode without having a diagnosis from anyone. I just knew myself what was going on. I'd done my own research to find a surgeon who I wanted to see, which was DOCTOR at HOSPITAL. When my doctor phoned me the following day after my mammogram and ultrasound, he said, "How you going?" I said, "I know." He goes, "Right. What do you want to do?" I said, "This is who I want to see. Send me to LOCATION." That's how it went. Participant_034

Table 3.5: Diagnostic pathway

Diagnostic pathway	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=23	%	n=27	%	n=19	%	n=25	%	n=26	%	n=24	%	n=24	%	n=26	%
Participant describes being diagnosed by their general practitioner due to concerns about symptoms (following imaging studies)	29	58.00	14	60.87	15	55.56	11	57.89	15	60.00	16	61.54	13	54.17	13	54.17	16	61.54
Participant describes being referred directly to a specialist from their general practitioner which led to their diagnosis	11	22.00	2	8.70	9	33.33	4	21.05	6	24.00	4	15.38	7	29.17	7	29.17	4	15.38
Participant describes being diagnosed through a population screening program	5	10.00	4	17.39	1	3.70	2	10.53	2	8.00	3	11.54	2	8.33	2	8.33	3	11.54
Other	5	10.00	3	13.04	2	7.41	2	10.53	2	8.00	1	3.85	4	16.67	2	8.33	3	11.54

Diagnostic pathway	All participants		Regional or remote		Metropolitan		Mid to low status		Higher status		Aged 25 to 44		Aged 45 to 54		Aged 55 to 74	
	n=50	%	n=16	%	n=34	%	n=20	%	n=30	%	n=19	%	n=22	%	n=9	%
Participant describes being diagnosed by their general practitioner due to concerns about symptoms (following imaging studies)	29	58.00	11	68.75	18	52.94	8	40.00	21	70.00	11	57.89	14	63.64	4	44.44
Participant describes being referred directly to a specialist from their general practitioner which led to their diagnosis	11	22.00	3	18.75	8	23.53	5	25.00	6	20.00	5	26.32	3	13.64	3	33.33
Participant describes being diagnosed through a population screening program	5	10.00	2	12.50	3	8.82	5	25.00	0	0.00	0	0.00	3	13.64	2	22.22
Other	5	10.00	0	0.00	5	14.71	2	10.00	3	10.00	3	15.79	2	9.09	0	0.00

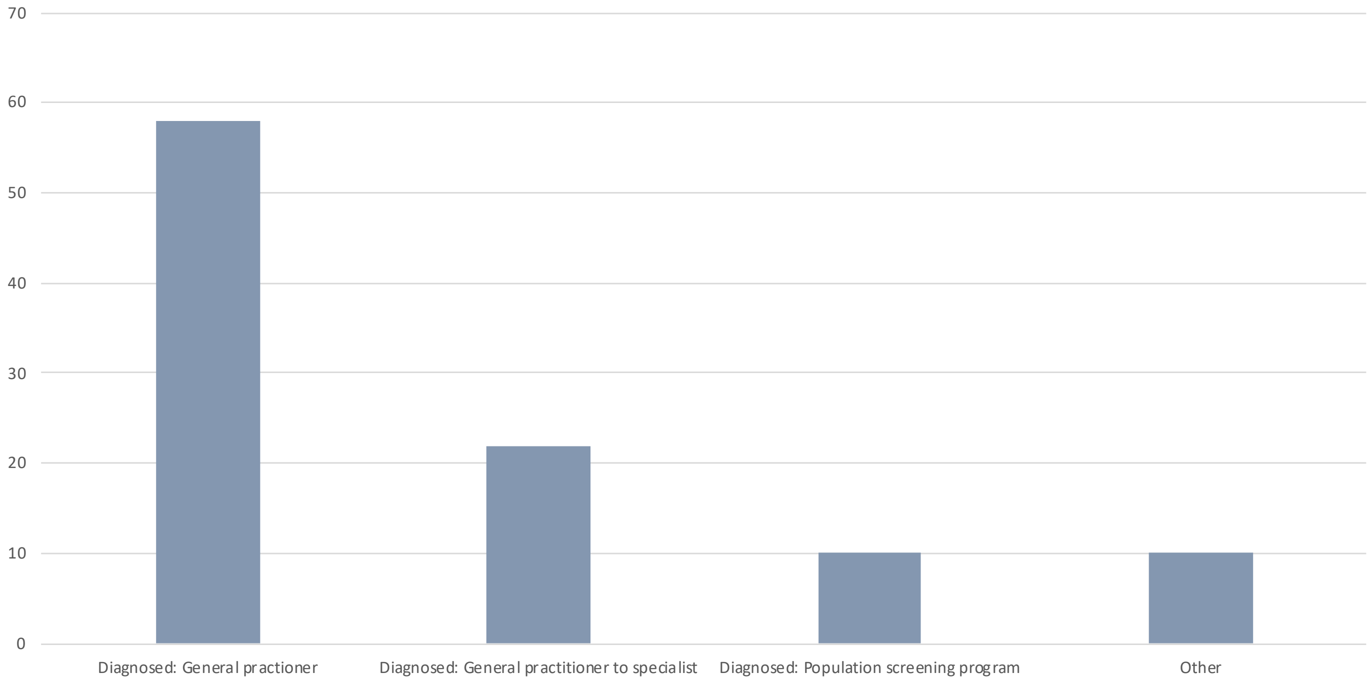


Figure 3.3: Diagnostic pathway

Table 3.6: Diagnostic pathway – subgroup variations

Theme	Reported less frequently	Reported more frequently
Participant describes being diagnosed by their general practitioner due to concerns about symptoms (following imaging studies)	Mid to low status Aged 55 to 74	Regional or remote Higher status
Participant describes being referred directly to a specialist from their general practitioner which led to their diagnosis	Early breast cancer	Advanced breast cancer Aged 55 to 74
Participant describes being diagnosed through a population screening program	-	Mid to low status Aged 55 to 74

Timing of diagnosis

Time from symptoms to diagnosis

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

Duration was calculated for 18 participants (23 participants had no symptoms before diagnosis), there were six participants (14.63%) that were diagnosed less than a month after noticing symptoms, four participants (9.76%) diagnosed between 3 and 10 months after noticing symptoms, and eight participants (19.51%) that were diagnosed more than 12 months after noticing symptoms (Table 3.7, Figure 3.4).

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=27,57.45%). There were two participants (4.26%) diagnosed between 1 and 2 weeks, 12 participants (25.53%) diagnosed between 2 and 3 weeks, and three participants (6.38%) diagnosed between 3 and 4 weeks (Table 3.8, Figure 3.5).

Table 3.7: Time from symptoms to diagnosis

Time from symptoms to diagnosis	Number (n=41)	Percent
Less than a month	6	14.63
Between 3 and 10 months	4	9.76
More than 12 months	8	19.51
No symptoms	23	56.10
Incomplete data	6	14.63

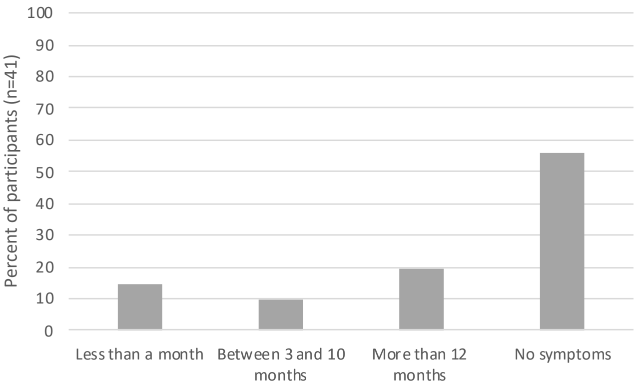


Figure 3.4: Time from symptoms to diagnosis

Table 3.8: Time from diagnostic test to diagnosis

Time from diagnostic tests to diagnosis	Number (n=47)	Percent
Less than 1 week	27	57.45
Between 3 and 4 weeks	2	4.26
Between 1 and 2 weeks	12	25.53
Between 2 and 3 weeks	3	6.38
4 weeks or more	1	2.13
Not specified	2	4.26

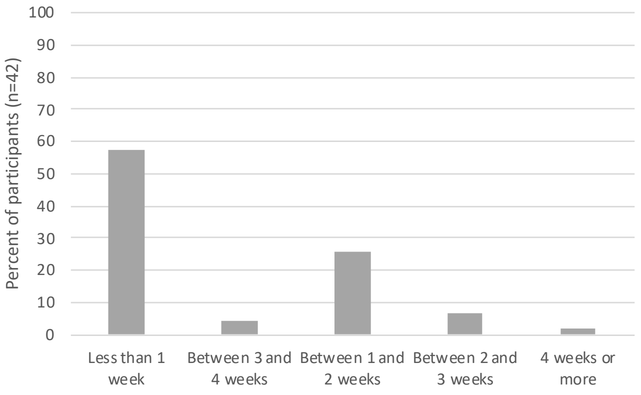


Figure 3.5: Time from diagnostic test to diagnosis

Diagnostic tests

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

Participants reported between 1 and 6 diagnostic tests (median = 3.00, IQR = 0.00) (Table 3.9, Figure 3.6). The most common tests were breast ultrasound (n = 42, 84.00%), core biopsy (n = 41, 82.00%), mammogram (n = 39, 78.00%), and fine needle aspiration (n = 34, 34.00%) (Table 3.10, Figure 3.7).

Table 3.9: Number of diagnostic tests

Number of diagnostic tests per participant	Number (n=50)	Percent
1 to 2	11	22.00
3 to 4	38	76.00
5 to 6	1	2.00

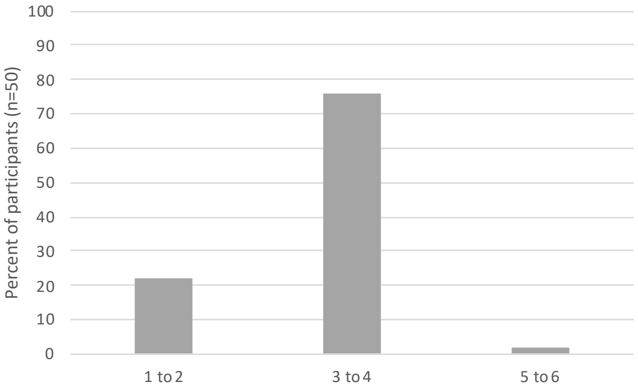


Figure 3.6: Number of diagnostic tests

Table 3.10: Diagnostic tests

Diagnostic tests	Number (n=50)	Percent
Breast ultrasound	42	84.00
Core biopsy (A wider needle is used to remove a piece of tissue)	41	82.00
Mammogram	39	78.00
Fine needle aspiration (A thin needle is used to take tissue from the breast lump)	17	34.00
Surgical biopsy	2	4.00
Vacuum assisted biopsy	2	4.00
Other	6	12.00

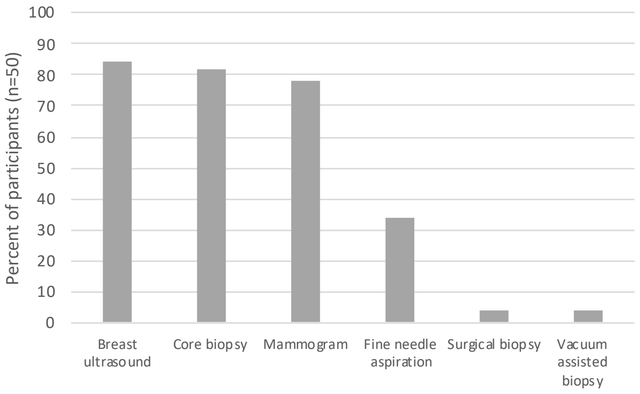


Figure 3.7: Diagnostic tests

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 general practitioner (n = 28, 59.57%), and there were 13 participants (27.66%) given the diagnosis by a breast surgeon, and two participants (4.26%) were diagnosed by a general surgeon (Table 3.11, Figure 3.8).

Participants were most commonly given their diagnosis in the general practice (n = 24, 51.06%), this was followed by the Specialist clinic (n = 14, 29.79%), and by phone or telehealth appointment (n = 7, 14.90%) (Table 3.10, Figure 3.9).

Table 3.11: Diagnosis provider

Health professional gave diagnosis	Number (n=47)	Percent
General practitioner (GP)	28	59.57
Breast surgeon	13	27.66
General Surgeon	2	4.26
Specialist - other or not speciified	5	10.64

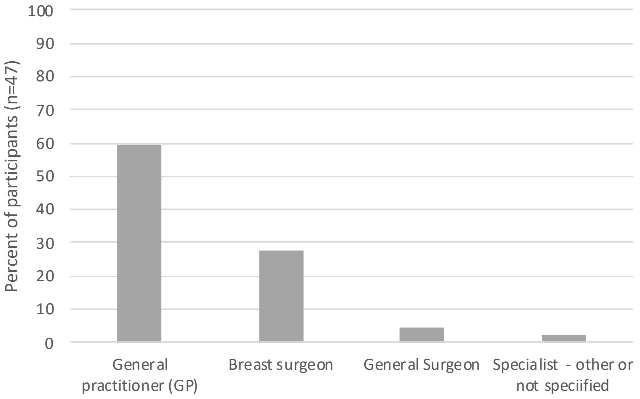


Figure 3.8: Diagnosis provider

Table 3.12: Diagnosis location

Location of diagnosis	Number (n=50)	Percent
General practice (GP)	24	51.06
Specialist clinic	14	29.79
Phone/telehealth	7	14.89
Other	2	4.26

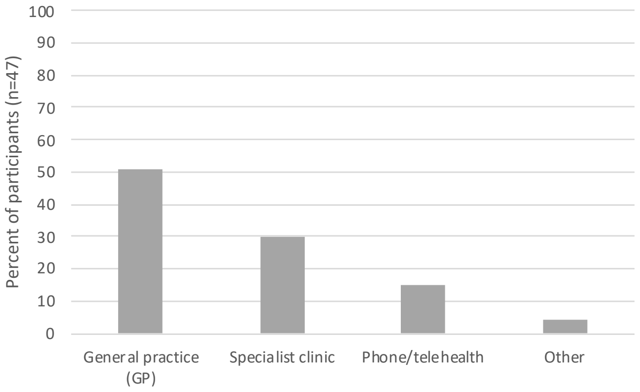


Figure 3.9: Diagnosis location

Breast cancer spread

Participants were asked in the online questionnaire if their breast cancer had spread. There were 24 participants (51.06%) with breast cancer that had not spread. The most common site of spread was to lymph nodes under arms (n=18, 38.30%) (Table 3.13, Figure 3.10).

Table 3.13: Breast cancer spread

Cancer spread	Number (n=47)	Percent
Lymph nodes under your arm	18	38.30
Lymph nodes lymph nodes inside your breast	4	8.51
Other lymph nodes	2	4.26
Distant sites	5	10.64
Cancer has not spread	24	51.06

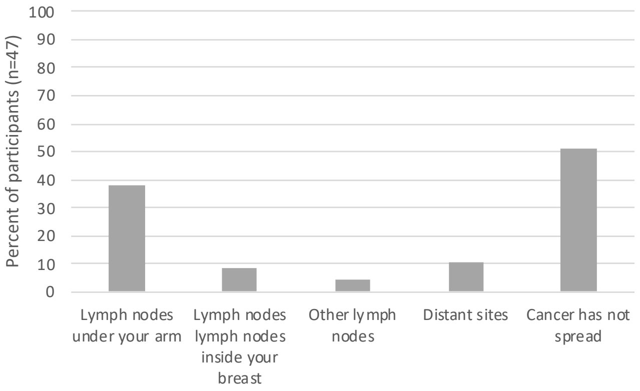


Figure 3.10: Breast cancer spread

Year of diagnosis

In the online questionnaire, participants noted the approximate date of diagnosis, the year of diagnosis is presented in Table 3.14, Figure 3.11.

Participants were diagnosed between 2004 to 2021. There were 26 participants (53.06%) that were diagnosed in the last two years.

Table 3.14: Year of diagnosis

Year of diagnosis	Number (n=50)	Percent
Before 2015	5	10.64
2015 to 2019	19	38.78
2020 to 2021	26	53.06

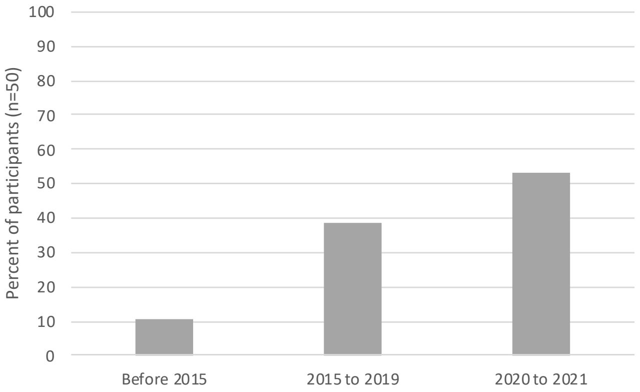


Figure 3.11: Year of diagnosis

Understanding of disease at diagnosis

Participants were asked in the structured interview how much they knew about their condition at diagnosis. The most common theme was that participants had no knowledge of their condition at diagnosis (n=22, 44.00%), followed by having had a good knowledge (n=15, 30.00%). There were 10 participants(20.00%) who had a limited knowledge about their condition at diagnosis.

The most common reasons for a good knowledge were being informed by a healthcare professional at the time of diagnosis (n=4, 8.00%), having a professional background (n=4, 8.00%), and researching the condition during the diagnostic process (n=4, 8.00%). The most common reason for having limited knowledge was because of general public awareness.

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

A lot. Due to our family history, I knew a lot. Obviously, there's all sorts of different types of breast cancer. Not everybody is the same and of course, mine was not hormone-based but I've had two sisters hormone- based, one sister who was triple-negative and my mum was triple-negative. Yes. Participant_022

I knew enough about the fact that it was a very aggressive cancer. I had just lost a friend 18 months earlier to the same cancer. She had orphaned three kids. We had been quite involved in-- I didn't know a lot about the treatment side of things, apart from she's had chemo. Then we all thought she was fine. Within a few weeks or months, she was told that-- she had a pain basically, which was in her shoulder. Then she thought it was just from the chemotherapy. Then going to the doctor afterwards said it had gone to her liver and it was a referred pain. She was given three months and died two and a half weeks later. I knew that being triple-negative was-- In my head, I sort of felt it was a death sentence. I knew that it was one of the worst cancers to get. Participant_036

I knew a bit, but I guess I knew a bit because I'm in nursing. [chuckles] Also, my nan also had breast cancer. I was quite young at the time, so I don't know. I guess it's through studying nursing that I knew a little bit to be able to arm myself to research for myself to try and get best care, I guess. Participant_034

Participant describes knowing very little about the condition at diagnosis

Not a huge amount, although I had a friend go through it four years before. I hadn't been closely involved with her through her treatment. She moved in with her mom during that time so I didn't see her quite as much. I went with her to chemo once so I'd seen what chemo involved. I didn't really know anywhere near as much as I do now. [chuckles] Participant_011

PARTICIPANT: I wasn't diagnosed until after surgery, when they found out it was triple-negative.
INTERVIEWER: When they told you what your diagnosis was and that it was triple-negative, did you know much about breast cancer, in general, at that time?
PARTICIPANT: I only knew about hormone breast cancer. I just knew that ladies would be on Tamoxifen. I'd had a few friends over the years that had been on Tamoxifen, but I had no idea that there was all the different subgroups and subtypes. Participant_040

Nothing. I thought breast cancer- I didn't know that there were different types of breast cancer. That was the first thing that I, had no idea. I thought breast cancer was breast cancer. I thought breast cancer, everybody lives, and it's really easy to cure. Because it's so common. I didn't know that obviously, there's Triple-negative, but it's high rate of people that don't survive., I learned so much, I knew nothing. Participant_019

Participant describes knowing nothing about the condition at diagnosis

I didn't know a lot because I haven't had anyone close to me have breast cancer before, so I really didn't know much at all. I knew the basic things of cancer equals possible operation, chemo, radiotherapy. I knew that sort of thing, but just what everyone assumes about cancer really. The fact that it was triple-negative breast cancer, I'd never heard of that before. When I looked into that, it completely freaked me out because everything you read about triple-negative is negative. Very negative indeed. [laughs] Participant_004

Not a lot and I guess the best example of how little I knew about it was, I went to see the surgeon. She said okay, well NAME do surgery, first of all, just to remove it. I said, that's fine not a problem. I have a trip overseas booked in three weeks, will I be better by then? She was like, no. Yes, it really was something that didn't sink in for quite some time, but it was a long hard process to go through. Participant_020

Nothing, zero. Absolutely zero. We were in the middle of COVID here in LOCATION. There were no resources. There was no emotional health. I felt very isolated, really lonely. Someone who has no family history, I wasn't offered a help from a nurse or anyone who's been through it, you know any volunteers. What to expect from the chemo. What other questions that I needed to ask? In fact, I had to fight to get my- Participant_042

Table 3.15: Understanding of disease at diagnosis

Understanding of disease at diagnosis	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=23	%	n=27	%	n=19	%	n=25	%	n=26	%	n=24	%	n=24	%	n=26	%
Participant describes knowing a good amount about the condition at diagnosis e.g. understood diagnosis and aspects of treatment	15	30.00	7	30.43	8	29.63	4	21.05	9	36.00	9	34.62	6	25.00	5	20.83	10	38.46
Participant describes knowing about the condition as they were given information by a healthcare professional during the diagnostic process	4	8.00	1	4.35	3	11.11	2	10.53	2	8.00	1	3.85	3	12.50	1	4.17	3	11.54
Participant describes knowing about the condition as they have a medical, research or relevant professional background	4	8.00	2	8.70	2	7.41	1	5.26	2	8.00	3	11.54	1	4.17	0	0.00	4	15.38
Participant describes knowing about the condition at diagnosis as they has began researching the condition before or throughout the diagnostic process	4	8.00	2	8.70	2	7.41	1	5.26	2	8.00	3	11.54	1	4.17	2	8.33	2	7.69
Participant describes knowing very little about the condition at diagnosis	10	20.00	**7**	**30.43**	3	11.11	4	21.05	4	16.00	6	23.08	4	16.67	5	20.83	5	19.23
Participant describes knowing very little about the condition at diagnosis through general public awareness	7	14.00	5	21.74	2	7.41	3	15.79	3	12.00	4	15.38	3	12.50	3	12.50	4	15.38
Participant describes knowing nothing about the condition at diagnosis	22	44.00	8	34.78	14	51.85	10	52.63	10	40.00	**8**	**30.77**	**14**	**58.33**	12	50.00	10	38.46

Understanding of disease at diagnosis	All participants		Regional or remote		Metropolitan		Mid to low status		Higher status		Aged 25 to 44		Aged 45 to 54		Aged 55 to 74	
	n=50	%	n=16	%	n=34	%	n=20	%	n=30	%	n=19	%	n=22	%	n=9	%
Participant describes knowing a good amount about the condition at diagnosis e.g. understood diagnosis and aspects of treatment	15	30.00	**7**	**43.75**	8	23.53	8	40.00	7	23.33	**3**	**15.79**	**9**	**40.91**	3	33.33
Participant describes knowing about the condition as they were given information by a healthcare professional during the diagnostic process	4	8.00	1	6.25	3	8.82	2	10.00	2	6.67	1	5.26	3	13.64	0	0.00
Participant describes knowing about the condition as they have a medical, research or relevant professional background	4	8.00	**3**	**18.75**	1	2.94	3	15.00	1	3.33	1	5.26	1	4.55	**2**	**22.22**
Participant describes knowing about the condition at diagnosis as they has began researching the condition before or throughout the diagnostic process	4	8.00	2	12.50	2	5.88	2	10.00	2	6.67	1	5.26	1	4.55	**2**	**22.22**
Participant describes knowing very little about the condition at diagnosis	10	20.00	2	12.50	8	23.53	2	10.00	8	26.67	5	26.32	**2**	**9.09**	**3**	**33.33**
Participant describes knowing very little about the condition at diagnosis through general public awareness	7	14.00	1	6.25	6	17.65	1	5.00	6	20.00	4	21.05	**0**	**0.00**	**3**	**33.33**
Participant describes knowing nothing about the condition at diagnosis	22	44.00	7	43.75	15	44.12	8	40.00	14	46.67	9	47.37	10	45.45	**3**	**33.33**

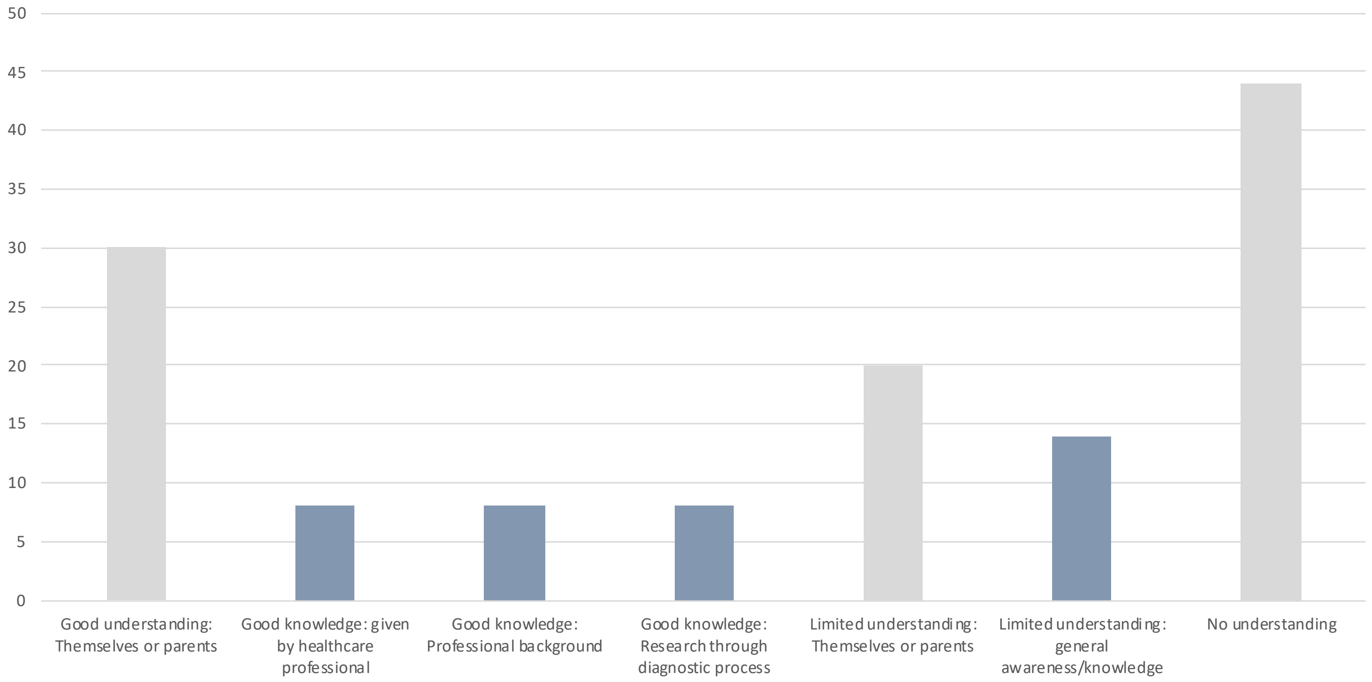


Figure 3.12: Understanding of disease at diagnosis

Table 3.16: Understanding of disease at diagnosis – subgroup variations

Theme	Reported less frequently	Reported more frequently
Participant describes knowing a good amount about the condition at diagnosis e.g. understood diagnosis and aspects of treatment	Aged 25 to 44	Regional or remote Aged 45 to 54
Participant describes knowing very little about the condition at diagnosis	Aged 45 to 54	Early breast cancer Aged 55 to 74
Participant describes knowing nothing about the condition at diagnosis	Diagnosed before 2020 Aged 55 to 74	Diagnosed in 2020 or 2021

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 11 participants (23.40%) who had enough support, nine participants (19.15%) that had some support but it wasn't enough, and 27 participants (57.45%) that had no support (Table 3.78, Figure 3.13).

Subgroup variations of more than 10% are listed in Table 3.16

Table 3.17: Emotional support at diagnosis

Emotional support at diagnosis	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=20	%	n=24	%	n=19	%	n=25	%	n=22	%	n=22	%	n=21	%	n=23	%
Enough support	11	25.00	8	40.00	3	12.50	5	26.32	6	24.00	6	27.27	5	22.73	3	14.29	8	34.78
Some support but it wasn't enough	9	20.45	1	5.00	8	33.33	3	15.79	3	12.00	5	22.73	4	18.18	6	28.57	3	13.04
No support	27	61.36	12	60.00	15	62.50	11	57.89	16	64.00	13	59.09	14	63.64	14	66.67	13	56.52

Emotional support at diagnosis	All participants		Regional or remote		Metropolitan		Mid to low status		Higher status		Aged 25 to 44		Aged 45 to 54		Aged 55 to 74	
	n=50	%	n=14	%	n=30	%	n=17	%	n=27	%	n=16	%	n=19	%	n=9	%
Enough support	11	25.00	5	35.71	6	20.00	4	23.53	7	25.93	6	37.50	4	21.05	1	11.11
Some support but it wasn't enough	9	20.45	4	28.57	5	16.67	4	23.53	5	18.52	3	18.75	5	26.32	1	11.11
No support	27	61.36	7	50.00	20	66.67	11	64.71	16	59.26	7	43.75	13	68.42	7	77.78

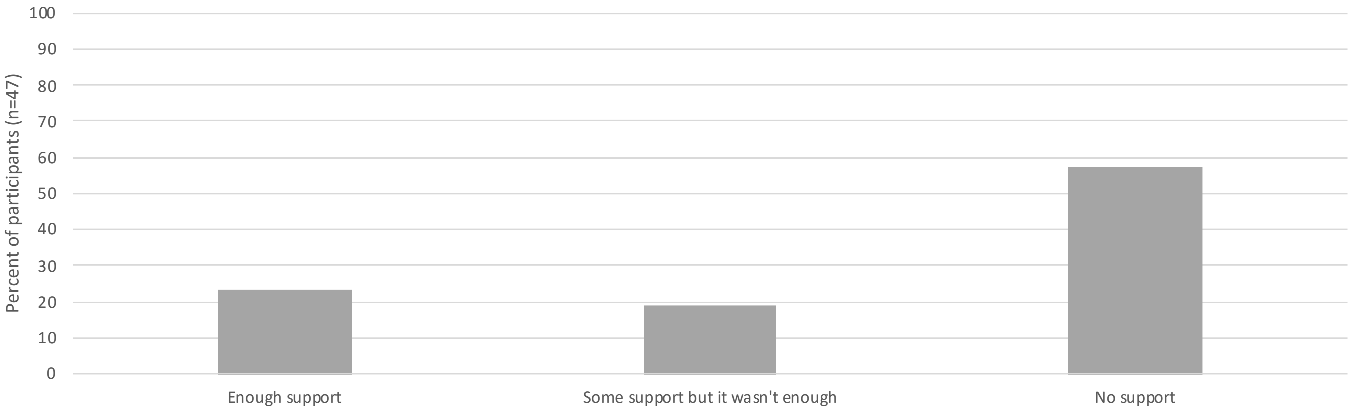


Figure 3.13: Emotional support at diagnosis

Table 3.18: Emotional support at diagnosis – subgroup variations

Emotional support at diagnosis	Less Frequently	More frequently
Enough support	Advanced breast cancer Trade or high school Aged 55 to 74	Early breast cancer Regional or remote Aged 25 to 44
Some support but it wasn't enough	Early breast cancer	Advanced breast cancer
No support	Regional or remote Aged 25 to 44	Aged 55 to 74

Information at diagnosis

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

There were 21 participants (44.68%) who had enough information, 20 participants (42.55%) that had some information but it wasn't enough, and six participants (12.76%) that had no information (Table 3.19, Figure 3.14).

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

Table 3.19: Information at diagnosis

Information at diagnosis	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=20	%	n=24	%	n=19	%	n=25	%	n=22	%	n=22	%	n=21	%	n=23	%
Enough information	21	47.73	11	55.00	10	41.67	**7**	**36.84**	13	52.00	11	50.00	10	45.45	8	38.10	13	56.52
Some information but it wasn't enough	20	45.45	**7**	**35.00**	13	54.17	9	47.37	9	36.00	10	45.45	10	45.45	**12**	**57.14**	**8**	**34.78**
No information	6	13.64	3	15.00	3	12.50	3	15.79	3	12.00	3	13.64	3	13.64	3	14.29	3	13.04

Information at diagnosis	All participants		Regional or remote		Metropolitan		Mid to low status		Higher status		Aged 25 to 44		Aged 45 to 54		Aged 55 to 74	
	n=50	%	n=14	%	n=30	%	n=17	%	n=27	%	n=16	%	n=19	%	n=9	%
Enough information	21	47.73	6	42.86	15	50.00	8	47.06	13	48.15	8	50.00	9	47.37	4	44.44
Some information but it wasn't enough	20	45.45	**8**	**57.14**	12	40.00	**10**	**58.82**	10	37.04	7	43.75	10	52.63	**3**	**33.33**
No information	6	13.64	2	14.29	4	13.33	1	5.88	5	18.52	1	6.25	3	15.79	2	22.22

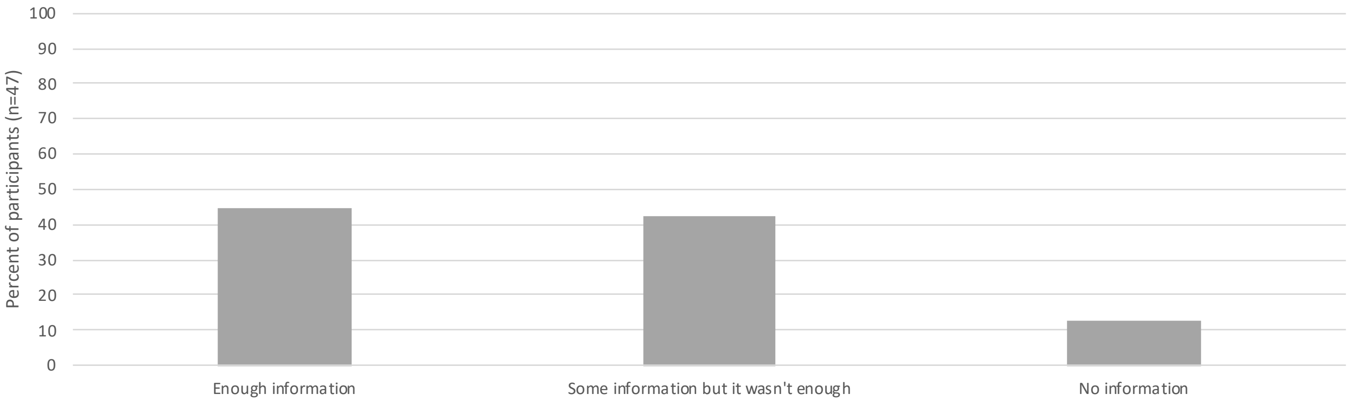


Figure 3.14: Information at diagnosis

Table 3.20: Information at diagnosis – subgroup variations

Information at diagnosis	Less Frequently	More frequently
Enough information	Poor physical function	-
Some information but it wasn't enough	Early breast cancer University Aged 55 to 74	Trade or high school Regional or remote Mid to low status

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 13 participants (27.66%) who had no out of pocket expenses, and nine participants (19.15%) who did not know or could not recall. There were 10 participants (21.28%) that spent Less than $500, 11 participants (23.40%) that spent between $500 to $1000, and four participants (8.51%) that spent more than $1000 (Table 3.21, Figure 3.15).

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 20 participants (58.82%) the cost was slightly or not at all significant. For seven participants (20.59%) the out-of-pocket expenses were somewhat significant, and for seven participants (20.59%), the burden of out-of-pocket expenses were moderately or extremely significant (Table 3.22, Figure 3.16).

Table 3.21: Out of pocket expenses at diagnosis

Out of pocket expenses for diagnostic tests	Number (n=47)	Percent
$0	13	27.66
Less than $500	10	21.28
$500 to $1000	11	23.40
More than $1000	4	8.51
Not sure	9	19.15

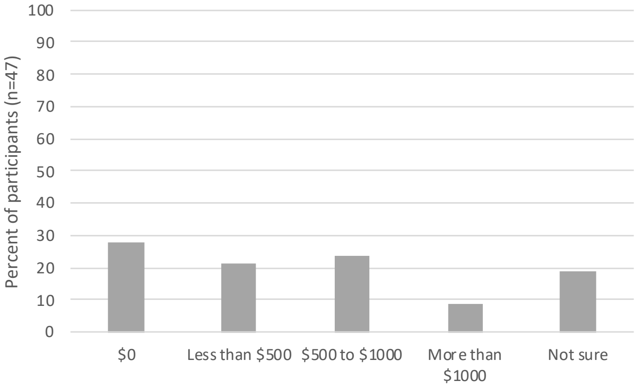


Figure 3.15: Out of pocket expenses at diagnosis

Table 3.22: Burden of diagnostic costs

Burden of diagnostic costs	Number (n=34)	Percent
Not at all significant	8	23.53
Slightly significant	12	35.29
Somewhat significant	7	20.59
Moderately significant	5	14.71
Extremely significant	2	5.88

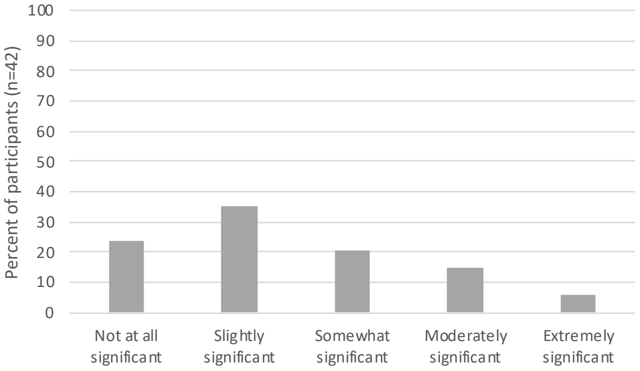


Figure 3.16: Burden of diagnostic costs

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 = 13, 27.66%). There were 7 participants (14.89%) who brought up the topic with their doctor, and 27 participants (57.45%) whose doctor brought up the topic with them (Table 3.23, Figure 3.17).

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

The majority of participants (n=32 68.09%) recalled having biomarker tests, and there were 14 participants (29.79%) that did not recall having biomarker tests but would like to have them (Table 3.24, Figure 3.18).

Table 3.23: Discussions about biomarkers

Discussions about biomarkers	Number (n=47)	Percent
Participant brought up the topic with doctor for discussion	7	14.89
Doctor brought up the topic with participant for discussion	27	57.45
Participant had no discussion about this type of test	13	27.66

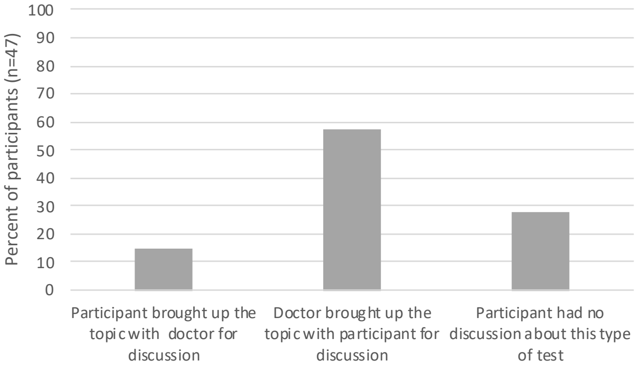


Figure 3.17: Discussions about biomarkers

Table 3.24: Experience of genetic tests and biomarkers

Experience of genetic tests and biomarkers	Number (n=47)	Percent
Participant had this test and did not have to pay out of pocket for it	28	59.57
Participant had this test athrough a clinical trial	0	0.00
Participant had this type of test and paid for it	4	8.51
Participant did not have this test and is not interested in it	1	2.13
Participant did not have this test but would like to	14	29.79

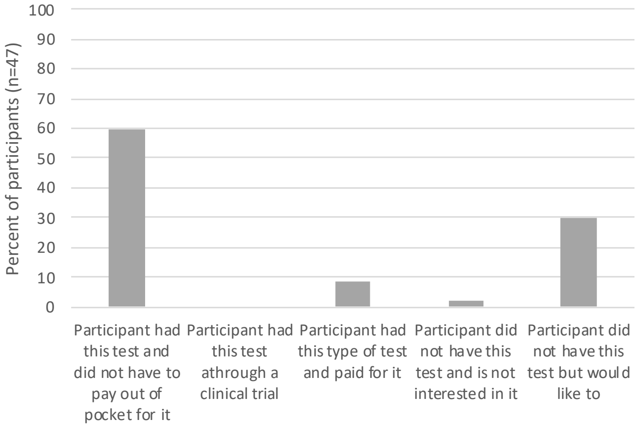


Figure 3.18: Experience of genetic tests and biomarkers

Biomarker status

This question from the online questionnaire addresses the participants knowledge and understanding of having had biomarker tests. Despite all participants knowing that they had triple negative breast cancer, there were 70% that could relate this to biomarker status. The majority of participants knew the status for at least one biomarker (n = 42, 84.00%). Most commonly, participants knew their TNBC status (n = 35, 70.00%), followed by BRCA status (n = 19, 38.00%) (Table 3.25, Figure 3.19).

While all participants knew that they had triple negative breast cancer, this question addresses their know

Table 3.25: Biomarker status

Biomarkers	Number (n=50)	Percent
TNBC	35	70.00
BRCA	19	38.00
ER	2	4.00
HER2	2	4.00
PR	2	4.00
Other	3	6.00
Not sure/Not tested	8	16.00

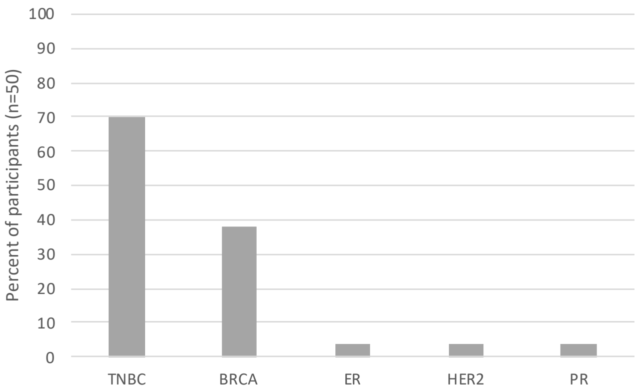


Figure 3.19: Biomarker status

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.

More than half of the participants had symptoms to deal with at the time of completing the questionnaire (n = 21, 44.68%). Participants had between 5 to 12 symptoms (median = 8.00, IQR = 3.00) (Table 3.26, Figure 3.20).

Type of current symptoms

The most common current symptoms, and those where more than 35% of the participants experienced the symptom were; anxiety (n = 21, 44.68%), fatigue (n = 21, 44.68%), thinking and memory problems (n = 20, 42.55%), depression (n = 19, 40.43%) weight and muscle changes (n = 18, 38.30%), and pain (n = 18, 38.30%) (Table 3.27, 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” (Table 3.27, Figure 3.22).

The median quality of life was between 2.5 and 4.5, for all of the symptoms listed in the questionnaire, this is in the “Life was distressing to a little distressing” to “Life was average to good” range.

Table 3.26: Number of current symptoms

Number of symptoms per participant	Number (n=47)	Percent
0	26	55.32
5 to 6	3	6.38
7 to 8	8	17.02
9 to 10	6	12.77
11 to 12	4	8.51

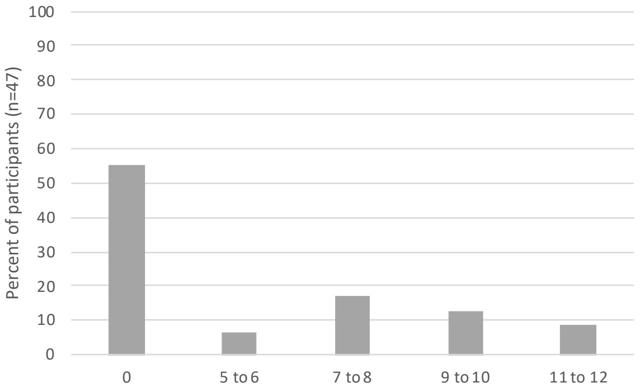


Figure 3.20: Number of current symptoms

Table 3.27: Type of current symptoms

Symptom	Number (n=50)	Percent	Quality of life	
			Mean	SD
No symptoms	26	52.00	NA	NA
Anxiety/anxious mood	21	44.68	3	3
Fatigue	21	44.68	3	2
Thinking and memory problems	20	42.55	3	2.25
Depression/depressed mood	19	40.43	4	2
Weight and muscle changes	18	38.30	3	1
Pain	18	38.30	3	2.5
Sleep problems	17	36.17	3	2
Sexual function/ability to have inimate relationships	14	29.79	2.5	2
Bone problems	14	29.79	4.5	2
Bladder problems	6	12.77	4.5	1.75
Other	13	27.66	-	-

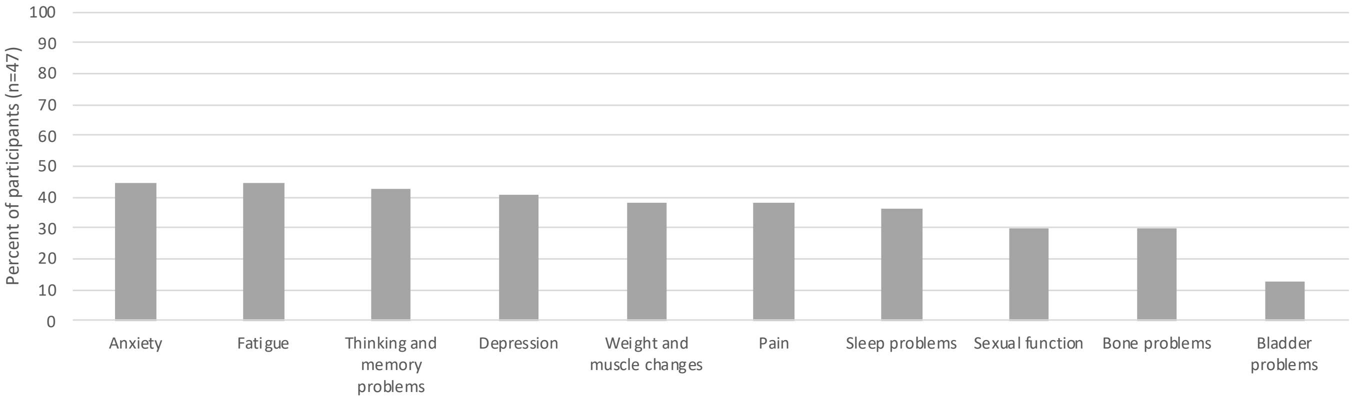


Figure 3.21: Type of current symptoms

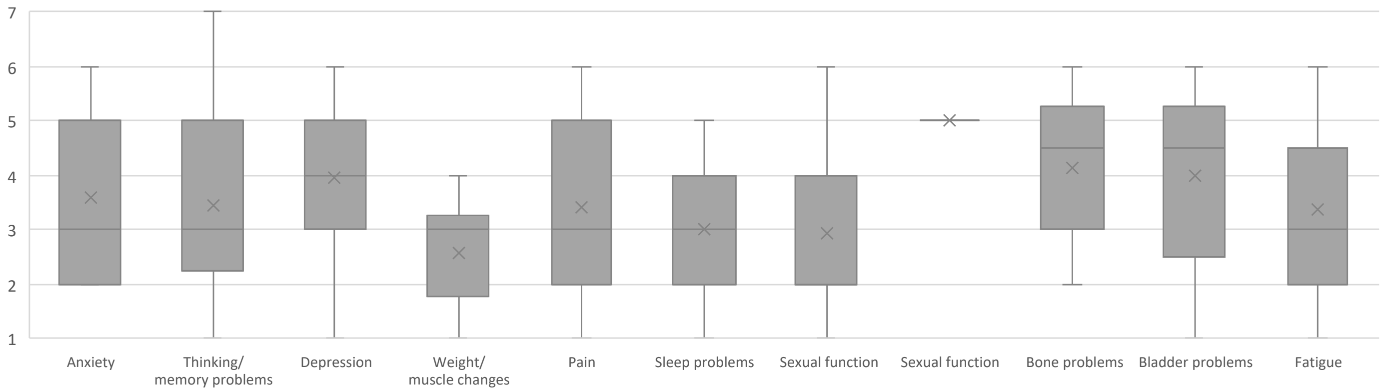


Figure 3.22: Quality of life from current symptoms

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=26, 54.00%), this was followed by prognosis described in relation to statistics such as five year survival rates (n=18, 36.00%). There were 14 participants (28.00%) who described prognosis in relation to probable recurrence/cycle of recurrence, 11 participants (22.00%) who described prognosis in relation to monitoring their condition without treatment until there is an exacerbation or progression, and seven participants (14.00%) who described prognosis in relation to it being positive that the condition will be cured in the future with treatment.

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

I'm NED at the moment and we're just doing the chemotherapy and the radiation to mop up, is my understanding, and make sure there's no very small particles in there that could be growing to reoccur. Participant_007

I finished radiation on Friday. I had a complete response, so I did chemo then surgery, then radiation. I had a complete response to chemo. Both of my tumors- I've had three tumors were all dead. My prognosis is good, but they don't give statistics. Participant_019

I hate the word remission. Apparently, they don't use it anymore. But to me, I don't have cancer. In my eyes, I was told because I had triple negative breast cancer. You know, I said I remember them saying if if it's going to come back, it'll come back in the first five years after that. If I get breast cancer again, it'll be a completely it's not like my breast cancer would have metastasised or come back to haunt me. Said if I get it again, it's literally bad luck to have nothing to do with my first case that. Yeah. So in terms of my career, I think I'm in the clear and if I get it again, it's like lightning. Participant_003

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

Yes. I've got no evidence of the disease, and they're not expecting that it's to return, because next year, I think I'm at five years, and I had a very good response to everything. My lump was also quite small and caught very early. Participant_005

Well, when you look at statistics, mine's triple-negative, obviously that's the worst-case breast cancer you can get. My outlook was technically, if I can get beyond the 5 years, I've got a good chance of surviving 10 and then further if I had have had all my treatment, that's the big if. I did not have all my treatment because I reacted to the chemo. Because of that, they stopped the chemo. Obviously, I know my outlook is a lot less. I have seen my oncologist, my last oncology appointment, my oncologist did say "Oh, you know, you're coming up to three years, that's really awesome." I said, "I didn't think I'd make it to three years." He said, "I didn't think you would either." I've made it past 3 years and I'm happy with that and I'm hoping to last another 10, 15 years but obviously, I know the risks and I know the chances of it becoming metastatic is a lot higher than normal. Participant_022

Well, since then I have been diagnosed with the PALB2 gene, once, I got that diagnosis, the specialist told me that it was more likely that the cancer would return because I had the gene. I had a double mastectomy and reconstruction. Later on, the risk for the PALB2 gene of ovarian cancer increased. Last year I had a hysterectomy and my ovaries removed. Now I've got less risk than the general population of getting breast cancer again because of both procedures. Participant_037

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

Well, currently, I've been told I have a good prognosis. My cancer is really aggressive, so there's still a high chance that it can come back in the next three years. I'm being closely monitored but other than that, I've been told it's still on the positive side because I got a good response to chemo. Participant_016

Because I've had chemotherapy already and that reduced my tumor but it didn't get rid of it, so I had a double mastectomy and there's still tumor tissue, cancer in my lymph nodes and and in my breast but they've obviously removed it all so I've got clear margins. I'm now doing 5 weeks of radiotherapy and 6 months of oral chemo. I don't know what my chances are. It can still come back. Participant_017

Yes. At the moment, I've had really good reactions to all of my treatments. I have apparently, like a 15% chance of it coming back. I'm now officially two years since my diagnosis. I've got another three years to go before I'm technically, go back to the same percentage of getting cancer, go back to the same percentage as someone else in the general population of having cancer. Participant_025

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

I'm still waiting for the buy the clearance, but it can come back any time. So, OK, so I still have to keep doing so. I have to do yearly surveillance and then after five years I'll drop to still daily surveillance that I might be a breath team. I'll be your normal surveillance. Participant_006

Yes, well I finished all treatment. I've had my six-month checkup and everything was all clear. Now I'm at the stage where I'm getting checked every six months to make sure it continues to be all clear. Participant_020

Yes. I've had pathological complete results, so no evidence of disease anymore. All being clear. I've had a double mastectomy and do a reconstruction at the same time. At the moment, it's just three monthly checkups with oncologists and my breast surgeon. I have had lots of nerve issues from having that done. I've got an ongoing treatment for that. Participant_036

Participant describes prognosis in relation to it being positive: Condition will be cured in the future with treatment

Yep. So in four years into my five year survival period, I'm triple negative. So once I've had my treatment, 15 percent chance of recurrence in the initial phase, three years. So my prognosis now is yes. Participant_002

As far as I'm aware, good. The tumor was tiny. I had a lumpectomy and a sentinel node biopsy. They got all of the tumor, and they only needed to take out three lymph nodes, and it hadn't gone anywhere which is good. As far as I'm aware, my outlook is good apart from all of the surgeries I'm going to have to go moving forward. [laughs] Participant_014

Yes. I'm currently undergoing an oral chemo now just to clean up if there's any residual. I will undergo monitoring for the next few years really and because of the type that I have, which is triple-negative, the chances of reoccurrence is extremely high, so I need to have that monitoring. Then, as the years go on, the chances decrease of it recurring. Participant_030

Table 3.28: Understanding of prognosis

Understanding of prognosis	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=23	%	n=27	%	n=19	%	n=25	%	n=26	%	n=24	%	n=24	%	n=26	%
Participant describes prognosis in relation to no evidence of disease or that they are in remission	26	52.00	**15**	**65.22**	**11**	**40.74**	10	52.63	12	48.00	13	50.00	13	54.17	13	54.17	13	50.00
Participant describes prognosis in relation to statistics such as five year survival rates	18	36.00	9	39.13	9	33.33	**3**	**15.79**	**12**	**48.00**	**13**	**50.00**	**5**	**20.83**	11	45.83	7	26.92
Participant describes prognosis in relation to probable recurrence/cycle of recurrence	14	28.00	6	26.09	8	29.63	**3**	**15.79**	8	32.00	7	26.92	7	29.17	9	37.50	5	19.23
Participant describes prognosis in relation to monitoring their condition without treatment until there is an exacerbation or progression	11	22.00	4	17.39	7	25.93	**2**	**10.53**	7	28.00	6	23.08	5	20.83	6	25.00	5	19.23
Participant describes prognosis in relation to it being positive: Condition will be cured in the future with treatment	7	14.00	4	17.39	3	11.11	4	21.05	3	12.00	**1**	**3.85**	**6**	**25.00**	2	8.33	5	19.23

Understanding of prognosis	All participants		Regional or remote		Metropolitan		Mid to low status		Higher status		Aged 25 to 44		Aged 45 to 54		Aged 55 to 74	
	n=50	%	n=16	%	n=34	%	n=20	%	n=30	%	n=19	%	n=22	%	n=9	%
Participant describes prognosis in relation to no evidence of disease or that they are in remission	26	52.00	9	56.25	17	50.00	10	50.00	16	53.33	**12**	**63.16**	**9**	**40.91**	5	55.56
Participant describes prognosis in relation to statistics such as five year survival rates	18	36.00	**8**	**50.00**	10	29.41	9	45.00	9	30.00	6	31.58	10	45.45	**2**	**22.22**
Participant describes prognosis in relation to probable recurrence/cycle of recurrence	14	28.00	6	37.50	8	23.53	7	35.00	7	23.33	**8**	**42.11**	5	22.73	**1**	**11.11**
Participant describes prognosis in relation to monitoring their condition without treatment until there is an exacerbation or progression	11	22.00	3	18.75	8	23.53	3	15.00	8	26.67	4	21.05	5	22.73	2	22.22
Participant describes prognosis in relation to it being positive: Condition will be cured in the future with treatment	7	14.00	3	18.75	4	11.76	2	10.00	5	16.67	3	15.79	4	18.18	**0**	**0.00**

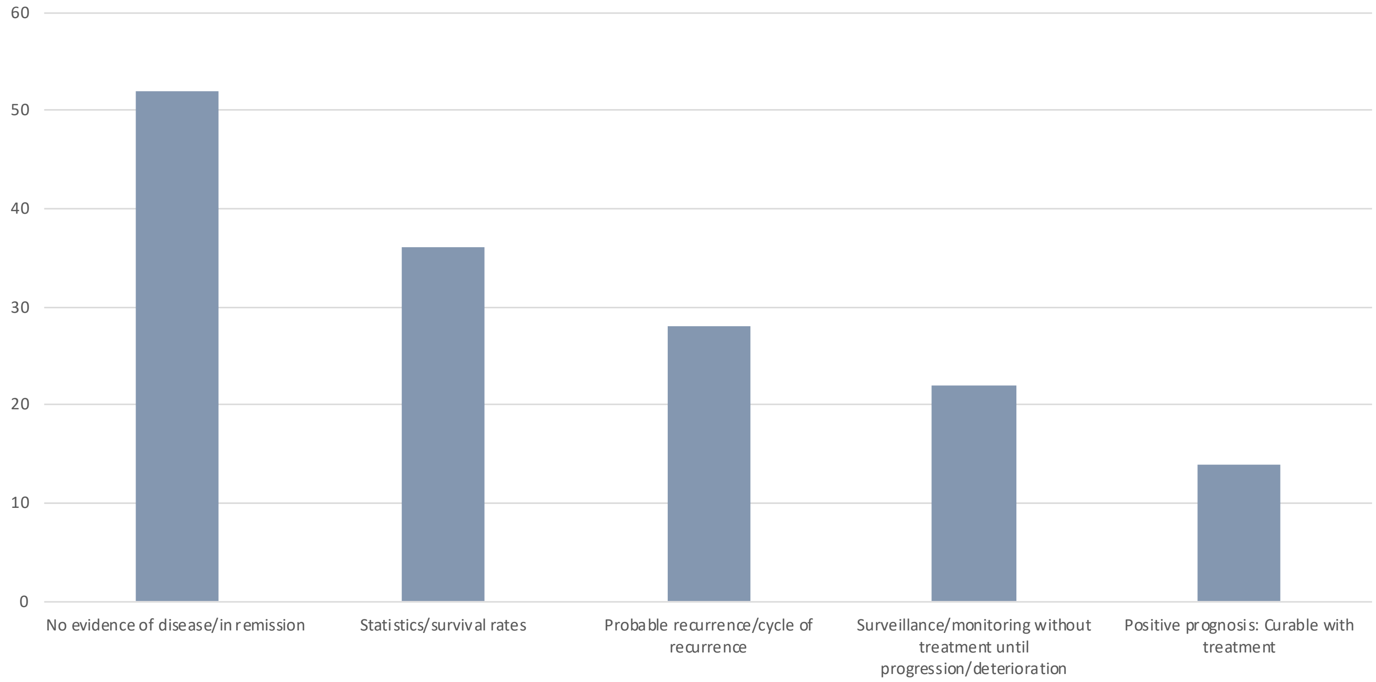


Figure 3.23: Understanding of prognosis

Table 3.29: Understanding of prognosis – subgroup variations

Theme	Reported less frequently	Reported more frequently
Participant describes prognosis in relation to no evidence of disease or that they are in remission	Advanced breast cancer Aged 45 to 54	Early breast cancer Aged 25 to 44
Participant describes prognosis in relation to statistics such as five year survival rates	Poor physical function Diagnosed in 2020 or 2021 Aged 55 to 74	Good physical function Diagnosed before 2020 Regional or remote
Participant describes prognosis in relation to probable recurrence/cycle of recurrence	Poor physical function Aged 55 to 74	Aged 25 to 44
Participant describes prognosis in relation to monitoring their condition without treatment until there is an exacerbation or progression	Poor physical function	-
Participant describes prognosis in relation to it being positive: Condition will be cured in the future with treatment	Diagnosed before 2020 Aged 55 to 74	Diagnosed in 2020 or 2021

Section 4

Decision-making

Section 4 summary

Discussions about treatment

Participants were asked to recall what treatment options they were presented with and how they felt about such options. The most common description was being presented with multiple options/approaches, and this was described by 38 participants (76.00%). This was followed by being presented with one option/approach (n=8, 16.00%).

Discussions about treatment (Participation in discussions)

In relation to participant in discussions about treatments, there were 28 participants (56.00%) who described feeling that they were told what to do with little or no discussion, and 29 participants (38.00%) who described that they participated in decision making or had informed discussions.

Considerations when making decisions

Participants were asked in the structured interview what they considered when making decisions about treatment. The most reported theme was taking the advice of their clinician, and this was described by 18 participants (36.00%). This was followed by taking side effects into account when making decisions about treatments (n = 11, 22.00%). There were seven participants (14.00%) who described taking efficacy into account, and the same number who described taking the survival benefit into account (n=7, 14.00%), and taking statistics/outcome of treatment into account (n=7, 14.00%). Other participants described taking cost into account (n=6, 12.00%), and taking quality of life into account when making decisions about treatment (n=6, 12.00%).

Decision-making over time

Participants were asked if the way they made decisions had changed over time. There were 27 participants (54.00%) that felt the way they made decisions about treatment had changed over time, and 18 participants (36.00%) that described decision making not changing.

Where participants had changed the way they make decisions, this was primarily in relation to becoming more informed or assertive (n=13, 26.00%), becoming more proactive (n=6, 12.00%), and becoming more cautious and considered over time (n=5, 10.00%).

Personal goals of treatment or care

Participants were asked what their own personal goals of treatment or care were. The most common response was to treat the disease and get better (n=14, 28.00%), and this was followed by getting through medical treatment (n=12, 24.00%). Other themes included wanting to live independently, (n=7, 14.00%), wanting to see mental/neurological improvements (n=6, 12.00%), returning to work (n=5, 10.00%), physical improvements (n=5, 10%), and managing side effects (n=5, 10.00%).

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 options/approaches, and this was described by 38 participants (76.00%). This was followed by being presented with one option/approach (n=8, 16.00%).

Participant describes being presented with multiple options/approaches

My first appointment with the surgeon, he was the first specialist I saw. I suppose he explained triple-negative breast cancer, that it's not related to hormones and all that, and said I had two options. I could either have a lumpectomy and radiotherapy afterwards or I could have a mastectomy and the outcome, he said, for either was very similar. Then he went further, and he described it as a weed in a garden and a mastectomy is ripping up the whole garden bed to get rid of one weed. He explained it that way. Participant_002

So when I went to the surgeon, she went through all the statistics of the different surgical options about whether you have a lumpectomy versus a mastectomy versus a double mastectomy. She talked about because of how aggressive mine was and to do with it being triple negative, that the better option was to do neoadjuvant chemotherapy. And so I was going to be doing IV chemo first. So she explained that generally. And then I went to the oncologist the next week and he went into it further and they talked about the different chemo options, what most women were doing, but versus what they wanted to trial with me as a bit extra to throw the kitchen sink at it because it was so aggressive and it was growing so quickly. So he went through all that there and certainly told you about my prognosis and my statistics and treatment options and which would give me the best outcome. And then it wasn't until halfway through the chemo that I met back up with the surgeon and made the final decision about it because they told me all that back then and to appointments. Participant_010

When I first saw the surgeon and he booked me in pretty much straight away for surgery, and there wasn't really a discussion around other options it was a case of, "You will need surgery, you will need chemo, and you will need radiation for this type of cancer and this is what we do." I was booked in for surgery, and then while doing a little bit of investigating I found a triple-negative trial that was taking place at our local hospital. I followed that up to see if I'd be a participant for the trial. I met with the trial's team and the oncologist because I wanted to see if that was my only option. The trial was for neoadjuvant chemo and immunotherapy. Sadly, I wasn't eligible because the cancer was too far advanced for what they needed. However, those discussions led me to choose to do the chemo first before surgery, but I hadn't known that was an option at the beginning. It was just, "This is what we'll do. It will be surgery, chemo, radiation." Participant_033

Participant describes being presented with one option/approach

Well, I didn't really have an option. It was either treatment or no treatment. That was that discussion. Wasn't really a discussion. It was, this is what we're going to do. If you don't do this, then you've got probably 18 months. That was my discussion. Participant_012

The only one conversation I had was removal. They had to remove both breasts. That's all. They didn't suggest anything else, not a thing. Participant_032

Basically that I had to start chemo as soon as possible. I didn't really have a choice because my cancer was very aggressive and it was very large. It had already travelled to the lymph nodes. They just basically said the smaller they can get it, the safer it would be to have surgery. They really didn't give me an option, in the sense that it was too big and it was growing too fast. They believed that that was the safest and best option for me. Participant_046

Table 4.1: Discussions about treatment

Discussions about treatment	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=23	%	n=27	%	n=19	%	n=25	%	n=26	%	n=24	%	n=24	%	n=26	%
Participant describes being presented with multiple options/approaches	38	76.00	18	78.26	20	74.07	14	73.68	19	76.00	**17**	**65.38**	**21**	**87.50**	**15**	**62.50**	**23**	**88.46**
Participant describes being presented with one options/approach	8	16.00	4	17.39	4	14.81	4	21.05	3	12.00	5	19.23	3	12.50	6	25.00	2	7.69
Participant describes no treatment discussions	1	2.00	0	0.00	1	3.70	0	0.00	1	4.00	1	3.85	0	0.00	1	4.17	0	0.00
Other	2	4.00	1	4.35	1	3.70	1	5.26	1	4.00	1	3.85	1	4.17	1	4.17	1	3.85

Discussions about treatment	All participants		Regional or remote		Metropolitan		Mid to low status		Higher status		Aged 25 to 44		Aged 45 to 54		Aged 55 to 74	
	n=50	%	n=16	%	n=34	%	n=20	%	n=30	%	n=19	%	n=22	%	n=9	%
Participant describes being presented with multiple options/approaches	38	76.00	12	75.00	26	76.47	12	60.00	26	86.67	14	73.68	17	77.27	7	77.78
Participant describes being presented with one options/approach	8	16.00	4	25.00	4	11.76	5	25.00	3	10.00	2	10.53	4	18.18	2	22.22
Participant describes no treatment discussions	1	2.00	0	0.00	2	5.88	1	5.00	1	3.33	1	5.26	1	4.55	0	0.00
Other	2	4.00	0	0.00	1	2.94	1	5.00	0	0.00	1	5.26	0	0.00	0	0.00

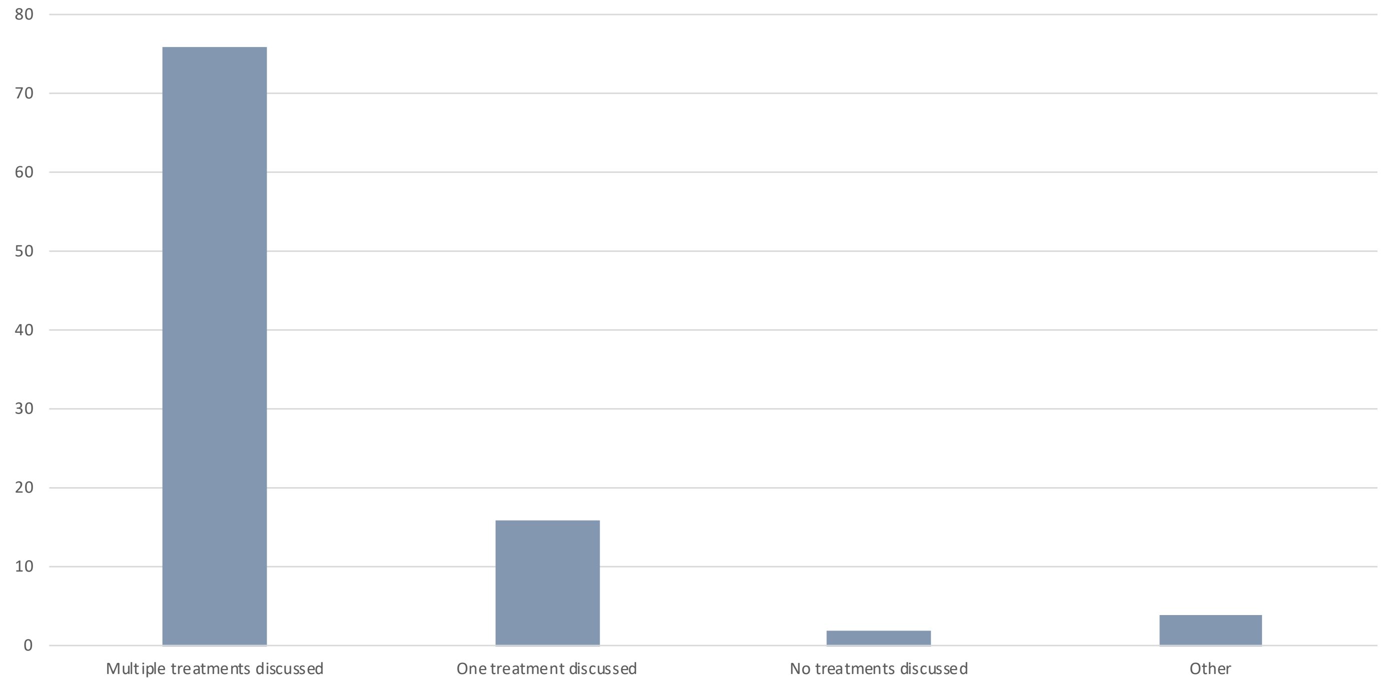


Figure 4.1: Discussions about treatment

Table 4.2: Discussions about treatment – subgroup variations

Theme	Reported less frequently	Reported more frequently
Participant Participant describes being presented with multiple options/approaches multiple treatments discussed	Diagnosed before 2020 Trade or high school Mid to low status	Diagnosed in 2020 or 2021 University Higher status

Discussions about treatment (Participation in discussions)

In relation to participant in discussions about treatments, there were 28 participants (56.00%) who described feeling that they were told what to do with little or no discussion, and 29 participants (38.00%) who described that they participated in decision making or had informed discussions.

Participant describes feeling that they were told what to do/ little or no discussion

Well, that was actually pretty crap, really, because I went back to the GP to get the results after the biopsy. But I knew because as soon as I felt the lump, you know, I knew what it was. And then when I was having the cold biopsy, just the manner of the guy who was doing it, he sort of quite sympathetic. And I just know this is not good. I know I just knew I had this real gut feeling. That's why I rang the because really horrible after the biopsy. So then I went back to the GP and he pretty much just said, yes, it is breast cancer and you need to make an appointment with the surgeon because you don't have to get it removed and they'll be able to tell you all the options. So here's the form you need to send this off and try and make an appointment. And it's probably going to take a little while because I do it as soon as you can. That was pretty much it. There really wasn't any discussion. Participant_001

Pretty short, really, because it was triple negative. That basically said and because I was only 37 at the time, as I said, you're young, we want to pump you full of whatever we can to give you the best chance of life, you know, a good life expectancy. But they also, like they said, we will hit you with the chemo and radiotherapy. But that's actually all you can have, the triple negative because it's not a hormonal cancer and that kind of thing. My choices were actually limited. It was that or nothing yet. So it wasn't we didn't need to have a lot of conversation about. Participant_003

Well, I didn't really have an option. It was either treatment or no treatment. That was that discussion. Wasn't really a discussion. It was, this is what we're going to do. If you don't do this, then you've got probably 18 months. That was my discussion. Participant_012

Participant describes feeling that they participated in decision-making/Had informed discussion

I think that discussion probably took place with the breast surgeon. She was talking either lumpectomy or mastectomy, and she just gave me the rundown on both. I said, "Well, why would I have a mastectomy?" There wasn't any really good reason to, so I just went with the lumpectomy. After the surgery, and after the results came back of what type of cancer it was, that led into what I would do next. There was never any discussion about having chemo first. It was always the surgery first and then chemo may or may not happen because of the type of cancer it was and my age. They just went and said, "Yes, you're definitely having chemo and you're actually having radiation as well." That pretty much all took place with the breast surgeon, and then after that, I went over and started with oncology at the hospital. Participant_005

So I had discussions about my options and I was definitely having surgery. It was suggested I have radiation, but then we discussed, because with the BRAC one, gene, that suggested you have came back because of an underlying bail condition. I opted not to have that with a lot of discussion with my doctor. Participant_006

The very first conversation would have been with my breast surgeon. After that initial consult where all the investigations were ordered and a rough outline was given of what I could expect in the way of treatment. Once I got all of those tests done and the results went back to that breast surgeon, I then went and saw him again, and my treatment plan was then discussed in detail. Because of the type of breast cancer that I had and the size of the lump, it was explained to me that the best course of action was to begin with chemotherapy to reduce the size of the lump. Then from there to have the surgery and following surgery, to go on with radiotherapy. I knew from that second consult what my plan was going to be. Once I then was referred to the medical oncologist I was given an option then of going through treatment with what he explained to me was the routine course of action. I was also given the option of participating in a clinical trial. Once I had that explained to me, I was then given more detail about the clinical trial and I elected to participate in that clinical trial. Participant_013

Table 4.3: Discussions about treatment (Participation in discussions)

Discussions about treatment (Participation in discussions)	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=23	%	n=27	%	n=19	%	n=25	%	n=26	%	n=24	%	n=24	%	n=26	%
Participant describes feeling that they were told what to do/ little or no discussion	28	56.00	9	39.13	19	70.37	10	52.63	15	60.00	11	42.31	17	70.83	15	62.50	13	50.00
Participant describes feeling that they participated in decision-making/Had informed discussion	19	38.00	13	56.52	6	22.22	8	42.11	8	32.00	12	46.15	7	29.17	7	29.17	12	46.15
Other	3	6.00	1	4.35	2	7.41	1	5.26	2	8.00	1	3.85	2	8.33	2	8.33	1	3.85

Discussions about treatment (Participation in discussions)	All participants		Regional or remote		Metropolitan		Mid to low status		Higher status		Aged 25 to 44		Aged 45 to 54		Aged 55 to 74	
	n=50	%	n=16	%	n=34	%	n=20	%	n=30	%	n=19	%	n=22	%	n=9	%
Participant describes feeling that they were told what to do/ little or no discussion			9	56.25	19	55.88	8	40.00	20	66.67	9	47.37	14	63.64	5	55.56
Participant describes feeling that they participated in decision-making/Had informed discussion			12	75.00	0	0.00	2	10.00	1	3.33	8	42.11	7	31.82	4	44.44
Other			0	0.00	3	8.82	2	10.00	1	3.33	2	10.53	1	4.55	0	0.00

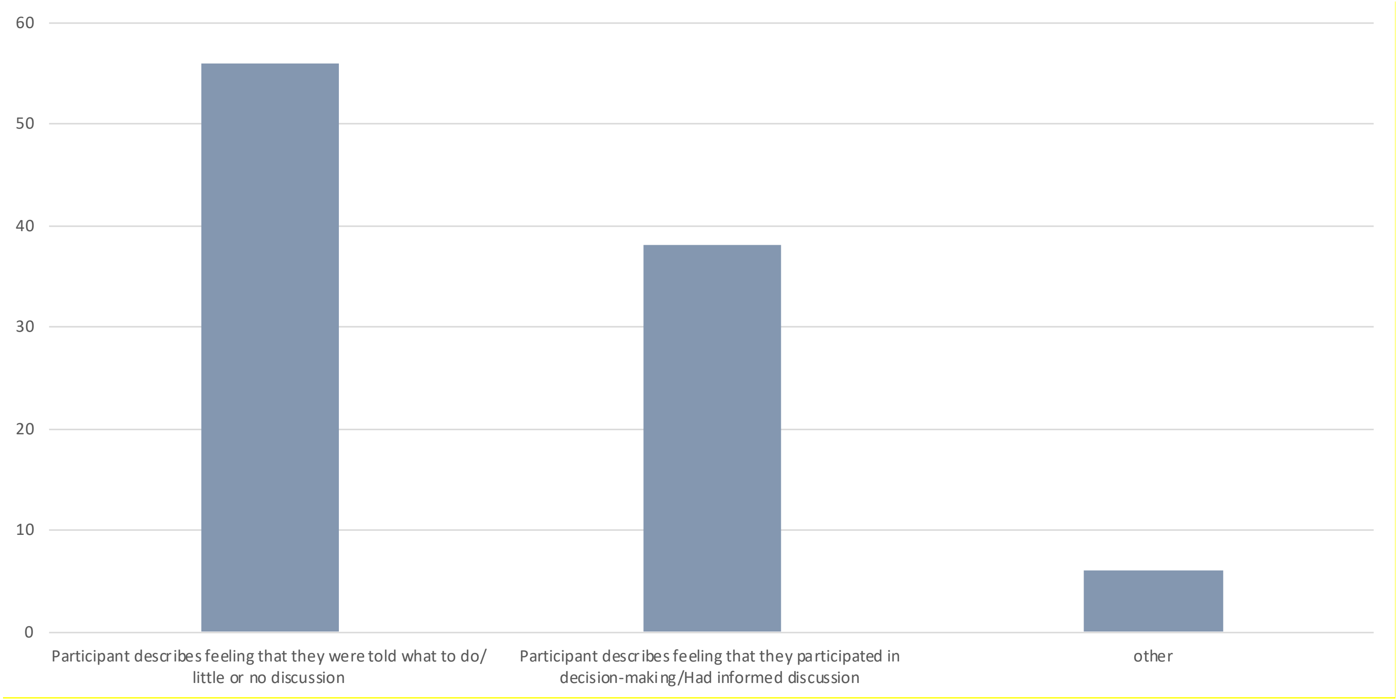


Figure 4.2: Discussions about treatment (Participation in discussions)

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

Theme	Reported less frequently	Reported more frequently
Participant describes feeling that they were told what to do/ little or no discussion	Early breast cancer Diagnosed before 2020 Mid to low status	Advanced breast cancer Diagnosed in 2020 or 2021 Higher status
Participant describes feeling that they participated in decision-making/Had informed discussion	Advanced breast cancer Metropolitan Mid to low status Higher status	Early breast cancer Regional or remote

Considerations when making decisions

Participants were asked in the structured interview what they considered when making decisions about treatment. The most reported theme was taking the advice of their clinician, and this was described by 18 participants (36.00%). This was followed by taking side effects into account when making decisions about treatments (n = 11, 22.00%). There were seven participants (14.00%) who described taking efficacy into account, and the same number who described taking the survival benefit into account (n=7, 14.00%), and taking statistics/outcome of treatment into account (n=7, 14.00%). Other participants described taking cost into account (n=6, 12.00%), and taking quality of life into account when making decisions about treatment (n=6, 12.00%).

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

The biggest thing I take into consideration is obviously the specialist's advice. The other thing was my age, I personally wanted to go as aggressive as possible with this because I'm young and I wanted to give myself the best chance of surviving this and prevent a reoccurrence, so I think those things. Obviously, also the distance from my house to the hospital. For me, the biggest thing was I had a baby, so I just wanted to have enough provisions, that someone can look after him. Participant_016

To be honest, I didn't know enough information to really make the decisions. I kind of just trusted them and listened to what they said. I was not a very good person. I didn't ask many questions. I kind of just went along with it. Participant_019

I probably was a little stunned at the time. Like I said, my mum has been five years with cancer. I think I just trusted what they were saying to me. I felt like I needed to trust the options they were giving me. I was only ever really given one option and that was to do the chemo first. I don't feel like I really had any options there. I think it was, "This is triple-negative. This is the best course." I think if I'd jumped up and down and said I want to know the other stuff maybe they would have given it to me, but I was quite happy to take under consideration what they were suggesting. Participant_035

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

I guess how it's going to impact my health further. How I'm going to be feeling. I've got to think about my family as well. I've got young children. Can I care for them? Can I go to work? How am I going to earn money? How am I going to support my family? I'm a single parent, and how long it's going to be for, and what the side effects are? Participant_017

As far as the cancer, I was never given any options. If I had, I guess the side effects and how they were going to impact my life, would have been my main concern. Participant_027

The success rate, the side effects, has it been used before for these cases, and, the convenience of it, I guess, like how much it's going to affect my day to day life? Participant_044

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

I guess efficacy and symptoms and long term side effects and quality of life? Just going through the treatment, I guess it would be a balance, as I say. Participant_001

My biggest consideration is the effectiveness of that treatment. I put that way above any side effects or any long-term effects. If it's effective, then I'm going to want to try it. That's my biggest decision-maker. It's regardless of how terrible I might feel, if it has a good outcome or it's potentially got a good outcome, that would sway me very easily into trying that treatment. That's been my main motivator, I guess. Is what gives me the best chance of getting through this and beating it. The other things are factors, but nothing would sway me away from trying something if it's documented and known to be effective or more likely to be effective. Participant_033

I like to look at some of the research, about the effect, the effectiveness of the treatment, side effects, the cost is an issue with some of the cancer treatments. I will take on board advice from my oncologist, but I'll also check it with getting an alternative opinion or another, not alternative, but another opinion from my naturopathic oncologist. At this stage, my treatment hasn't changed, so I haven't had to re-research things again. I'm still on the same treatment. Yes, side effects, and if there's anything that can help alleviate any of the side effects. Participant_050

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

The biggest thing I take into consideration is obviously the specialist's advice. The other thing was my age, I personally wanted to go as aggressive as possible with this because I'm young and I wanted to give myself the best chance of surviving this and prevent a reoccurrence, so I think those things. Obviously, also the distance from my house to the hospital. For me, the biggest thing was I had a baby, so I just wanted to have enough provisions, that someone can look after him. Participant_016

I guess the first priority is staying alive and making sure that I'm not just saying no to something because I don't want to do it, when I know that really, it's the only option, I've got to do it. The first priority is always being alive and planning on being alive for not just three years, but 70 more years kind of thing. Obviously not 70, but like another 30 plus years. Participant_025

Basically, what the results are. Basically, what the chances are of survival. What's the chances with that form of treatment, and what were the side effects involved. Participant_046

Participant describes taking statistics/outcome of treatment into account when making decisions about treatment (Total)

Well, it was my decision to do neoadjuvant chemo and the reason I chose that or pushed for that was because even though I had the cancer in me, in my body, if it hadn't been cut out, because I had triple-negative, statistically, 3% of women who have triple-negative, chemo doesn't work on that particular type of cancer. Without the tumor, we didn't have a marker to go against. I wouldn't have known whether the chemo was working. Just for me, I wasn't going to go through that horrendous part of the treatment without knowing for certain that it was working. Participant_009

Professional opinion, statistics to a point and I don't know, really. Other than that I probably google. [chuckles] Participant_012

I didn't consider anything. I considered that my oncologist was making all the right decisions for me. It wasn't till the end that I realized I should have taken more charge of my body, and ask more questions, and ask the success statistics. I didn't do any of that. That's what I would do now. If I was to go back in time or I *have to start any treatment again, I'd be asking what are all my alternatives? Why do I have to just have that one? I'd want more options this time, because I was in shock, I just did what they told me to do. Participant_046*

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

Time frame, cost, although I was lucky it was all pretty much covered. Although, my surgery, I did myself. Side effects, pretty much. Participant_021

Children, finances, physical mobility, probably emotional as well, and that's about it. Participant_024

Cost sometimes comes into it a little bit. I've definitely learned that I just ask now, do I have to pay for this? Can you bulk bill me? Because nobody tells you that getting cancer is actually expensive so that's definitely something, yes. Participant_043

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

I guess efficacy and symptoms and long term side effects and quality of life? Just going through the treatment, I guess it would be a balance, as I say. Participant_001

My well-being, my mental health, how it will affect my mental health. How it will affect my life and what the outcome will be. Participant_018

As far as the cancer, I was never given any options. If I had, I guess the side effects and how they were going to impact my life, would have been my main concern. Participant_027

Table 4.5 Considerations when making decisions

Considerations when making decisions	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=23	%	n=27	%	n=19	%	n=25	%	n=26	%	n=24	%	n=24	%	n=26	%
Participant describes taking the advice of their clinician into account when making decisions about treatment (Total)	18	36.00	9	39.13	9	33.33	6	31.58	8	32.00	8	30.77	10	41.67	8	33.33	10	38.46
Participant describes taking the advice of their clinician into account as the only thing that they consider when making decisions about treatment	15	30.00	7	30.43	8	29.63	6	31.58	7	28.00	6	23.08	9	37.50	7	29.17	8	30.77
Participant describes taking the advice of their clinician into account as part of multiple aspects that they consider when making decisions about treatment	3	6.00	2	8.70	1	3.70	0	0.00	1	4.00	2	7.69	1	4.17	1	4.17	2	7.69
Participant describes taking side effects into account when making decisions about treatment (Total)	11	22.00	4	17.39	7	25.93	6	31.58	5	20.00	6	23.08	5	20.83	5	20.83	6	23.08
Participant describes taking side effects into account as the only thing that they consider when making decisions about treatment	2	4.00	0	0.00	2	7.41	1	5.26	1	4.00	0	0.00	2	8.33	2	8.33	0	0.00
Participant describes taking side effects into account as part of multiple aspects that they consider when making decisions about treatment	9	18.00	4	17.39	5	18.52	5	26.32	4	16.00	6	23.08	3	12.50	3	12.50	6	23.08
Participant describes taking efficacy into account when making decisions about treatment (Total)	7	14.00	3	13.04	4	14.81	3	15.79	3	12.00	4	15.38	3	12.50	1	4.17	6	23.08
Participant describes taking efficacy into account as the only thing that they consider when making decisions about treatment	1	2.00	0	0.00	1	3.70	0	0.00	0	0.00	0	0.00	1	4.17	1	4.17	0	0.00
Participant describes taking efficacy into account as part of multiple aspects that they consider when making decisions about treatment	6	12.00	3	13.04	3	11.11	3	15.79	3	12.00	4	15.38	2	8.33	**0**	**0.00**	**6**	**23.08**
Participant describes taking the survival benefit into account when making decisions about treatment (Total)	7	14.00	5	21.74	2	7.41	2	10.53	4	16.00	4	15.38	3	12.50	1	4.17	6	23.08
Participant describes taking the survival benefit into account as the only thing that they consider when making decisions about treatment	3	6.00	2	8.70	1	3.70	1	5.26	2	8.00	2	7.69	1	4.17	1	4.17	2	7.69
Participant describes taking the survival benefit into account as part of multiple aspects that they consider when making decisions about treatment	4	8.00	3	13.04	1	3.70	1	5.26	2	8.00	2	7.69	2	8.33	0	0.00	4	15.38
Participant describes taking statistics/outcome of treatment into account when making decisions about treatment (Total)	7	14.00	4	17.39	3	11.11	3	15.79	2	8.00	2	7.69	5	20.83	4	16.67	3	11.54
Participant describes taking statistics/outcome of treatment into account as the only thing that they consider when making decisions about treatment	3	6.00	1	4.35	2	7.41	2	10.53	0	0.00	0	0.00	3	12.50	2	8.33	1	3.85
Participant describes taking statistics/outcome of treatment into account as part of multiple aspects that they consider when making decisions about treatment	4	8.00	3	13.04	1	3.70	1	5.26	2	8.00	2	7.69	2	8.33	2	8.33	2	7.69
Participant describes taking cost into account when making decisions about treatment (Total)	6	12.00	2	8.70	4	14.81	3	15.79	3	12.00	**6**	**23.08**	**0**	**0.00**	3	12.50	3	11.54
Participant describes taking cost into account as the only thing that they consider when making decisions about treatment	1	2.00	0	0.00	1	3.70	0	0.00	1	4.00	1	3.85	0	0.00	0	0.00	1	3.85
Participant describes taking cost into account as part of multiple aspects that they consider when making decisions about treatment	5	10.00	2	8.70	3	11.11	3	15.79	2	8.00	5	19.23	0	0.00	3	12.50	2	7.69
Participant describes taking quality of life into account when making decisions about treatment (Total)	6	12.00	2	8.70	4	14.81	1	5.26	5	20.00	5	19.23	1	4.17	3	12.50	3	11.54
Participant describes taking quality of life into account as the only thing that they consider when making decisions about treatment	1	2.00	0	0.00	1	3.70	1	5.26	0	0.00	1	3.85	0	0.00	0	0.00	1	3.85
Participant describes taking quality of life into account as part of multiple aspects that they consider when making decisions about treatment	5	10.00	2	8.70	3	11.11	0	0.00	5	20.00	4	15.38	1	4.17	3	12.50	2	7.69

Considerations when making decisions	All participants		Regional or remote		Metropolitan		Mid to low status		Higher status		Aged 25 to 44		Aged 45 to 54		Aged 55 to 74	
	n=50	%	n=16	%	n=34	%	n=20	%	n=30	%	n=19	%	n=22	%	n=9	%
Participant describes taking the advice of their clinician into account when making decisions about treatment (Total)	18	36.00	4	25.00	14	41.18	5	25.00	13	43.33	4	21.05	10	45.45	4	44.44
Participant describes taking the advice of their clinician into account as the only thing that they consider when making decisions about treatment	15	30.00	2	12.50	13	38.24	4	20.00	11	36.67	3	15.79	9	40.91	3	33.33
Participant describes taking the advice of their clinician into account as part of multiple aspects that they consider when making decisions about treatment	3	6.00	2	12.50	1	2.94	1	5.00	2	6.67	1	5.26	1	4.55	1	11.11
Participant describes taking side effects into account when making decisions about treatment (Total)	11	22.00	3	18.75	8	23.53	4	20.00	7	23.33	4	21.05	4	18.18	3	33.33
Participant describes taking side effects into account as the only thing that they consider when making decisions about treatment	2	4.00	0	0.00	2	5.88	0	0.00	2	6.67	0	0.00	1	4.55	1	11.11
Participant describes taking side effects into account as part of multiple aspects that they consider when making decisions about treatment	9	18.00	3	18.75	6	17.65	4	20.00	5	16.67	4	21.05	3	13.64	2	22.22
Participant describes taking efficacy into account when making decisions about treatment (Total)	7	14.00	3	18.75	4	11.76	4	20.00	3	10.00	3	15.79	2	9.09	2	22.22
Participant describes taking efficacy into account as the only thing that they consider when making decisions about treatment	1	2.00	0	0.00	1	2.94	1	5.00	0	0.00	1	5.26	0	0.00	0	0.00
Participant describes taking efficacy into account as part of multiple aspects that they consider when making decisions about treatment	6	12.00	3	18.75	3	8.82	3	15.00	3	10.00	2	10.53	2	9.09	2	22.22
Participant describes taking the survival benefit into account when making decisions about treatment (Total)	7	14.00	2	12.50	5	14.71	3	15.00	4	13.33	3	15.79	3	13.64	1	11.11
Participant describes taking the survival benefit into account as the only thing that they consider when making decisions about treatment	3	6.00	1	6.25	2	5.88	0	0.00	3	10.00	1	5.26	2	9.09	0	0.00
Participant describes taking the survival benefit into account as part of multiple aspects that they consider when making decisions about treatment	4	8.00	1	6.25	3	8.82	3	15.00	1	3.33	2	10.53	1	4.55	1	11.11
Participant describes taking statistics/outcome of treatment into account when making decisions about treatment (Total)	7	14.00	5	31.25	2	5.88	6	30.00	1	3.33	1	5.26	5	22.73	1	11.11
Participant describes taking statistics/outcome of treatment into account as the only thing that they consider when making decisions about treatment	3	6.00	2	12.50	1	2.94	3	15.00	0	0.00	0	0.00	3	13.64	0	0.00
Participant describes taking statistics/outcome of treatment into account as part of multiple aspects that they consider when making decisions about treatment	4	8.00	3	18.75	1	2.94	3	15.00	1	3.33	1	5.26	2	9.09	1	11.11
Participant describes taking cost into account when making decisions about treatment (Total)	6	12.00	4	25.00	2	5.88	2	10.00	4	13.33	3	15.79	1	4.55	2	22.22
Participant describes taking cost into account as the only thing that they consider when making decisions about treatment	1	2.00	1	6.25	0	0.00	0	0.00	1	3.33	1	5.26	0	0.00	0	0.00
Participant describes taking cost into account as part of multiple aspects that they consider when making decisions about treatment	5	10.00	3	18.75	2	5.88	2	10.00	3	10.00	2	10.53	1	4.55	2	22.22
Participant describes taking quality of life into account when making decisions about treatment (Total)	6	12.00	3	18.75	3	8.82	3	15.00	3	10.00	3	15.79	3	13.64	0	0.00
Participant describes taking quality of life into account as the only thing that they consider when making decisions about treatment	1	2.00	1	6.25	0	0.00	1	5.00	0	0.00	1	5.26	0	0.00	0	0.00
Participant describes taking quality of life into account as part of multiple aspects that they consider when making decisions about treatment	5	10.00	2	12.50	3	8.82	2	10.00	3	10.00	2	10.53	3	13.64	0	0.00

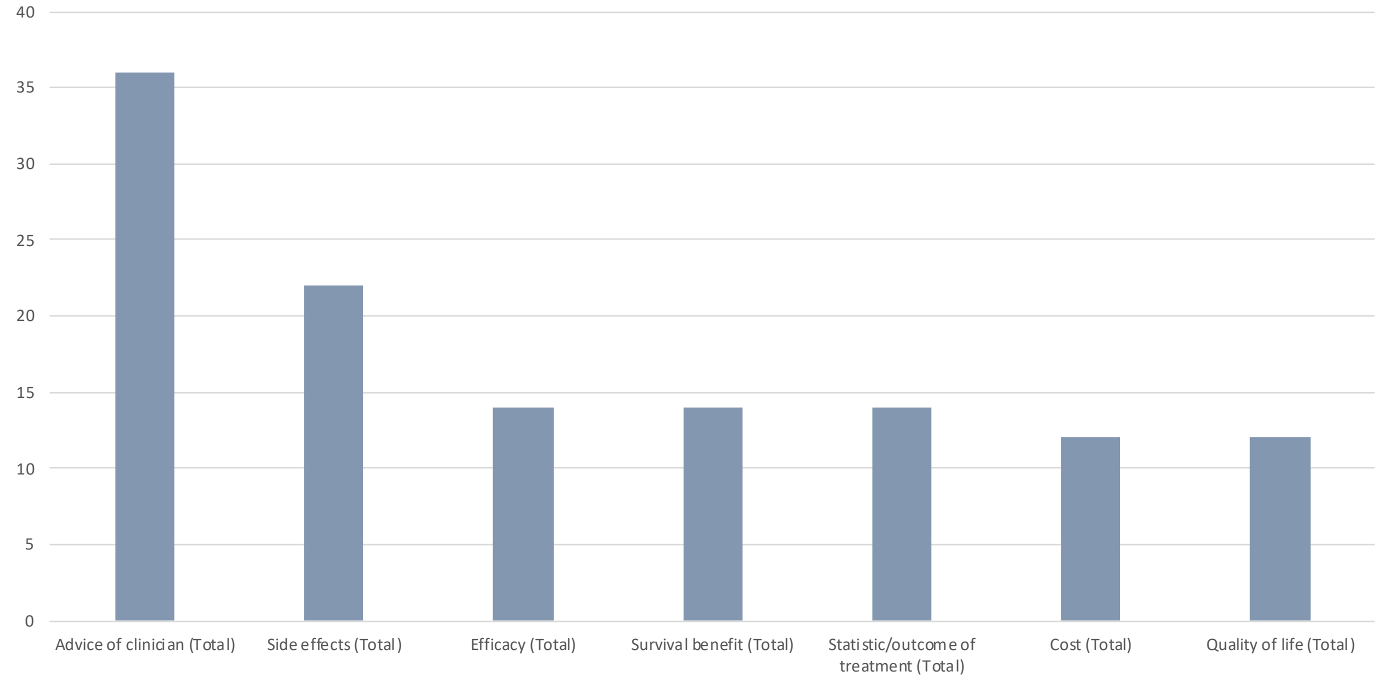


Figure 4.3 Considerations when making decisions

Table 4.6: Considerations when making decisions – subgroup variations

Theme	Reported less frequently	Reported more frequently
Participant describes taking the advice of their clinician into account when making decisions about treatment (Total)	Regional or remote Mid to low status Aged 25 to 44	-
Participant describes taking side effects into account when making decisions about treatment (Total)	-	Aged 55 to 74
Participant describes taking statistics/outcome of treatment into account when making decisions about treatment (Total)	Higher status	Regional or remote Mid to low status
Participant describes taking cost into account when making decisions about treatment (Total)	Diagnosed in 2020 or 2021	Diagnosed before 2020 Regional or remote Aged 55 to 74
Participant describes taking quality of life into account when making decisions about treatment (Total)	Aged 55 to 74	-

Decision-making over time

Participants were asked if the way they made decisions had changed over time. There were 27 participants (54.00%) that felt the way they made decisions about treatment had changed over time, and 18 participants (36.00%) that described decision making not changing.

Where participants had changed the way they make decisions, this was primarily in relation to becoming more informed or assertive (n=13, 26.00%), becoming more proactive (n=6, 12.00%), and becoming more cautious and considered over time (n=5, 10.00%).

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

I've learned to go with my gut instinct and to be my own advocate. If I don't get the answer I want, I'll now keep asking. Whereas before, I would have been like, "Oh, okay. Well, you're the doctor, you know best." Participant _027

PARTICIPANT: I think I evolved as I went along. At first, I couldn't. You're in such deep shock with that diagnosis. I don't care what anybody says, I was so shocked. There's no history of breast cancer or anything in my family, I was not expecting that. In the end, I would take along my list of questions, write down my list of questions, and I would sit there. [chuckles] Like, "I'm going to list the questions I really want them answered." Every time I went somewhere, I had a list of questions so that I could get answers to stuff.
INTERVIEWER: Did it help to write them down?
PARTICIPANT: Yes.
Participant _029

PARTICIPANT: No, I definitely have changed.
INTERVIEWER: Yes? In what way has it changed?
PARTICIPANT: I just look at the big picture and the end result now, not just the immediate-- Initially, I used to just make a decision on, "Okay, what's the right thing to do right now?" Moving forward now, I ask a lot more questions about why did they say this? Why are they suggesting this for me? Even just my surgery, I was like, "Why am I only having a lumpectomy? Why aren't I having a breast removal? Then she talked to me through that and I was like, "Okay, I'll just have a lumpectomy then." I didn't ask a question. I just went with what she was saying. Participant _045

Participant describes decision-making changing over time as they are more proactive

I think maybe I do more of my own research, maybe rather than I didn't know it was hard. When you're in that situation and it's also you, you just go with what you're told. Yeah, but maybe being a bit more experienced, I think I would try and be a bit quicker in doing my own research and finding out alternative. Participant _001

I think yes, the way I make decisions is probably a little bit more considered than it was before. Prior to diagnosis, I'd be more inclined to be slower with decision-making. Whereas now, with my health, if I find something wrong I'm like ah, I better get on to that just in case. I'm a bit more proactive, I guess is what I'm saying. For example, in the past, I've known I've had high cholesterol, but I hadn't really done much about it. Since diagnosis, I'm like oh, well now I better take these things a bit more seriously. I went through a series of tests to check my cholesterol, and a few different ways of living, and how it was impacted. Now a take a statin to keep that cholesterol under control, because I don't want it to be an issue later on. I know things can happen if you leave things. I'm probably just a bit more proactive. For example, again, I'm having a bone density scan this afternoon which I'm now having every two years because I'm in menopause and blah, blah, blah. I'm just more proactive. Participant _005

It has changed, in the sense, I realized that I thought that the approach I was presented with initially, I felt it was a very tunnel-view, like just, "This is what your treatment should be," kind of thing. Whereas, over the course, I realized I have to be in charge of things a lot more. I think I was quite trusting, and I'm not saying I should doubt the health professionals, but I definitely feel like I have a right to ask questions and it's okay to have a more active role in my treatment rather than passive. Participant _016

Participant describes decision-making changing over time as they are more cautious and considered

No, now I think that I'm more considerate of how my decisions will affect me in my day-to-day life and life going forward. I take time to think about things now, whereas I didn't then. Participant_004

Definitely changed, definitely. I think about the impact of any decision are going to have on my health, whereas before maybe I'd make a decision and not really worry about it, or I'd just go ahead and do it and not even think about the consequences. I do stop and think about it more now. Participant _020

Probably now it's slightly changed in that it was all so quick back then. I probably put a bit more thought to it but I don't think it would change any decision I've made either Participant_021

Participant describes no change in decision-making over time

For me, we pretty much approached the decisions in the same way, but that's because prior to breast cancer, as I mentioned, we had already gone through infertility treatment. For me, breast cancer wasn't the end of my world, I'd already had the bad news. My world had already fallen apart, pretty much, so by the time I got told I had cancer, it was more of a reaction, "Of course it is, why wouldn't it be?" Every decision we've ever made for any medical purpose has always been made with us acknowledging that this is the decision we're making now, based off the information we currently have. We might in 10 months' time, know more information that may have changed the decision we would have made, but right now, this is the reason we're making this decision and that's what we accept. From a medical perspective, it hasn't changed the way that we make decisions. Participant _025

I think for me, I do make decisions in the same way. I rely on the the specialists to be advising me on the best course of action and that I trust my oncologist. Participant _049

I think the same way. I'm a very, fact and research-driven person about anything health-related. Participant _050

Table 4.7: Decision-making over time

Decision-making over time	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=23	%	n=27	%	n=19	%	n=25	%	n=26	%	n=24	%	n=24	%	n=26	%
Participant describes decision-making changing over time	27	54.00	**16**	**69.57**	**11**	**40.74**	12	63.16	11	44.00	12	46.15	15	62.50	13	54.17	14	53.85
Participant describes decision-making changing over time as they are more informed and/or more assertive	13	26.00	5	21.74	8	29.63	5	26.32	5	20.00	5	19.23	8	33.33	6	25.00	7	26.92
Participant describes decision-making changing over time as they are more proactive	6	12.00	5	21.74	1	3.70	3	15.79	2	8.00	2	7.69	4	16.67	1	4.17	5	19.23
Participant describes decision-making changing over time as they are more cautious and considered	5	10.00	**5**	**21.74**	0	0.00	2	10.53	3	12.00	3	11.54	2	8.33	4	16.67	1	3.85
Participant describes no change in decision-making over time	18	36.00	**5**	**21.74**	**13**	**48.15**	5	26.32	11	44.00	10	38.46	8	33.33	8	33.33	10	38.46
Participant describes no change in decision-making over time and there is no particular reason noted	7	14.00	2	8.70	5	18.52	3	15.79	4	16.00	4	15.38	3	12.50	5	20.83	2	7.69
Participant describes no change in decision-making over time as they have always been proactive	4	8.00	2	8.70	2	7.41	1	5.26	2	8.00	1	3.85	3	12.50	0	0.00	4	15.38
Other	6	12.00	3	13.04	3	11.11	3	15.79	3	12.00	2	7.69	4	16.67	4	16.67	2	7.69

Decision-making over time	All participants		Regional or remote		Metropolitan		Mid to low status		Higher status		Aged 25 to 44		Aged 45 to 54		Aged 55 to 74	
	n=50	%	n=16	%	n=34	%	n=20	%	n=30	%	n=19	%	n=22	%	n=9	%
Participant describes decision-making changing over time	27	54.00	**11**	**68.75**	16	47.06	11	55.00	16	53.33	12	63.16	12	54.55	**3**	**33.33**
Participant describes decision-making changing over time as they are more informed and/or more assertive	13	26.00	**6**	**37.50**	7	20.59	6	30.00	7	23.33	5	26.32	7	31.82	**1**	**11.11**
Participant describes decision-making changing over time as they are more proactive	6	12.00	2	12.50	4	11.76	2	10.00	4	13.33	2	10.53	4	18.18	**0**	**0.00**
Participant describes decision-making changing over time as they are more cautious and considered	5	10.00	1	6.25	4	11.76	2	10.00	3	10.00	2	10.53	2	9.09	1	11.11
Participant describes no change in decision-making over time	18	36.00	5	31.25	13	38.24	6	30.00	12	40.00	5	26.32	8	36.36	**5**	**55.56**
Participant describes no change in decision-making over time and there is no particular reason noted	7	14.00	3	18.75	4	11.76	2	10.00	5	16.67	3	15.79	2	9.09	2	22.22
Participant describes no change in decision-making over time as they have always been proactive	4	8.00	2	12.50	2	5.88	2	10.00	2	6.67	0	0.00	3	13.64	1	11.11
Other	6	12.00	**0**	**0.00**	6	17.65	3	15.00	3	10.00	2	10.53	3	13.64	1	11.11

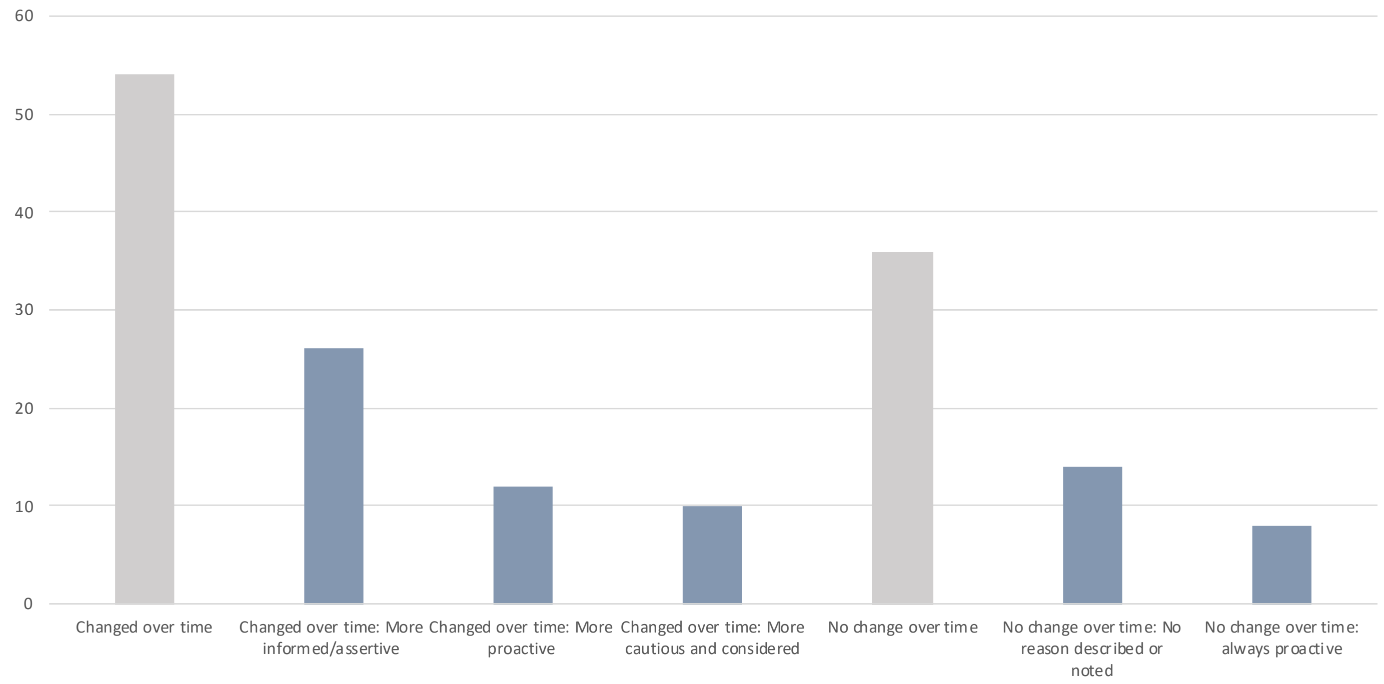


Figure 4.4: Decision-making over time

Table 4.8: Decision-making over time – subgroup variations

Theme	Reported less frequently	Reported more frequently
Participant describes decision-making changing over time	Advanced breast cancer Aged 55 to 74	Early breast cancer Regional or remote
Participant describes no change in decision-making over time	Early breast cancer	Advanced breast cancer Aged 55 to 74

Personal goals of treatment or care

Participants were asked what their own personal goals of treatment or care were. The most common response was to treat the disease and get better (n=14, 28.00%), and this was followed by getting through medical treatment (n=12, 24.00%). Other themes included wanting to live independently, (n=7, 14.00%), wanting to see mental/neurological improvements (n=6, 12.00%), returning to work (n=5, 10.00%), physical improvements (n=5, 10%), and managing side effects (n=5, 10.00%).

Goals of treatment

Participant describes wanting to treat the disease/get better

To be honest, at those first appointments, it was all just about how do we get rid of the cancer? I think all the other stuff kind of just seemed part and parcel that you would have side effects and it would affect your life negatively. But I think my main goals would just how the hell do we get rid of it and the rest will deal with as it comes, if that makes sense. Participant_010

Yes, so my goals were basically just to get the best, praying that the chemo gives me the best outcome. Afterwards, now my goals are from now on just to get back on my feet and basically keep my fitness up. I've modified my diet as well, just to minimize any processed foods and to eliminate anything possibly that could have led to it. Participant_016

Pretty much the goal was to get rid of the cancer, and get through this part of my life, and get back to normal life. Pretty much the goal was to get rid of the cancer, and get through this part of my life, and get back to normal life. Participant_025

Participant describes wanting to follow/get through treatment

I think mine were-- I was happy to have whatever was necessary just to get it over and done with. My goals, obviously, it would have been nice to avoid chemo and all those sorts of things, but yes, the goal was really just to get it all done so I could get on with living. I wasn't going to go out and seek alternative therapies or anything like that. I just went through the process, and I think the triple-negative, it funnels you down a

very narrow set of options, from what I could gather. My goal was just to do things efficiently, quickly, and just have it over and done with I suppose. Participant_005

I probably in the initial stages, I think in my mind that I was just really concentrating on treatment and getting through the treatment. I didn't really have a detailed conversation about how that might impact on me once treatment was finished. At the time that I was diagnosed, I was working full time in a fairly-- I had a nurse management position so it was a reasonably stressful job, but I elected, I was lucky enough that I had plenty of leave, so I elected to take leave from work and I actually didn't work for the whole time that I was receiving treatment. I discussed about return to work partway through my treatment and it was indicated to me that once I'd finished chemotherapy and radiation therapy, once I started feeling better then there should be no reason why I couldn't return to work, which I did initially. I returned to work after I completed radiation therapy, but I returned to work full time and I found after six weeks I wasn't coping, so I took more leave. I think I took about three months' leave, and when I returned, I was given the option by my immediate manager to return to work part-time, which I did for six months. I still found that I wasn't coping with the fatigue. I was fortunate enough to be in a position financially that I didn't need to work, so I made the decision to actually retire early. Participant_013

My goals are really just to get through the treatment cycles and then go on to live a full life. That's my ultimate goal. Obviously, managing the side effects and the treatment things has been okay, I'm getting through that quite well. My goal at the moment is just to get through each step as I come to it. For chemo, I just focused on getting through chemo and now that's finished. Now, I'm focusing on the surgery and what comes next and things like the lymphedema and what might happen. Then when I've done that, I'm sure I'll focus on the radiation, but it's just been I like to do it in stages. Participant_033

Participant describes wanting to live independently

My goal in treatment really is just to try and continue on with life as normal with as minimal side effects as possible. I think when you're first diagnosed, it's all very overwhelming and you really don't know at that stage whether you've got a year, whether you've got six months or whether you've got 10 years you don't know. I think to have a normal life as possible which is have as little and minimal side effects as possible was my ultimate gain. Participant_018

My goals are really just to get through the treatment cycles and then go on to live a full life. That's my ultimate goal. Obviously, managing the side effects and the treatment things has been okay, I'm getting through that quite well. My goal at the moment is just to get through each step as I come to it. For chemo, I just focused on getting through chemo and now that's finished. Now, I'm focusing on the surgery and what comes next and things like the lymphedema and what might happen. Then when I've done that, I'm sure I'll focus on the radiation, but it's just been I like to do it in stages. Participant_033

I'm not having active treatment anymore because I'm out the other side, I'm having reconstruction and surgeries and stuff like that. My thing is just to try and get back to normal really, I want to feel normal again. Participant_043

Participant described wanting to see mental/emotional health improvements in their condition

I feel I'd like to know more-- and I have been doing stuff by myself but, I think it would be nicer if the establishment told you more about what you can do to minimize your chances of getting a recurrence or metastasis. Also, the whole mental health aspect as well. I feel when you finish treatment, that's not really addressed at all. The fear of recurrence and that sort of thing, I don't feel that there was any support for mental health throughout the whole thing, really, honestly. I had to take it upon myself to go to my GP and ask for a mental health care-plan. Going forward, I'd like to basically know more about what I can do to keep myself healthy and to keep my mental health healthy too. Participant_004

I'm doing a UQ, a trial about exercise helping out with chemotherapy and I'm finding that extremely helpful. That's one of my goals, small goals, like being out of balance and ride on the bike. Physically, I have those goals. Mentally, I've tried to just to be negative if I want to be negative and positive if I want to be positive, and not be too hard on myself. Participant_007

Well, I don't know. I had to actually stop my Taxol treatment early because I got neuropathy and they were worried that if they kept treating me that it'd become permanent. I had to stop that early. Going through chemo has been really, really hard for me. I've had a lot of very bad side effects. I've been very sick. I'm glad I finished chemo. The only thing that I've really done, I haven't even done it yet. I would like to participate in this return to wellness exercise program, et cetera that they're running at LOCATION Health. It's a Paula program. I'm basically waiting to see how I feel. I would like to do that and just like to do more exercise and obviously talk to a psychologist, because this is really bad for mental health as well. I haven't really, really made any plans yet. I just want to get through all this. Participant_028

Participant describes wanting to return to work

I think after radiation, I'm having trouble with my right side. So my goal would be to be able to garden without being in bed and doing my job, my job. I do a lot of reporting and cutting, but I find that if I do a lot of that, then it's all set off just to leave like pain free and be able to do things. Participant_006

All of the above. I've got a lot more physical limitations now and mental as in fatigue and stuff like that. I had quite a senior executive role that I can't do anymore because I've got such bad fatigue and cognitive issues and then body pain as well. I'd love to be able to have some help in terms of that. Participant_008

I don't really know to tell you the truth. I've been through my chemotherapy and I decided to stop work because I had insurance so I didn't work during that period, but I'm just looking at going back to work now and I still got insurance. I'm only going to do that part-time because I know I'm still going to be fatigued and tired and my immune system will be down due to oral chemo. But, physio-wise, while I'm in Perth, I'm seeing a physio when I finish radiation, just to make sure that I've still got movement and make sure I don't have lymphedema. Other than that, I don't-- I've got my appointments with my oncologist and my surgeon, they will be scheduled but that's about it. Participant_017

Participants describe wanting to see physical improvements in their condition

I'm doing a UQ, a trial about exercise helping out with chemotherapy and I'm finding that extremely helpful. That's one of my goals, small goals, like being out of balance and ride on the bike. Physically, I have those goals. Mentally, I've tried to just to be negative if I want to be negative and positive if I want to be positive, and not be too hard on myself. Participant_007

All of the above. I've got a lot more physical limitations now and mental as in fatigue and stuff like that. I had quite a senior executive role that I can't do anymore because I've got such bad fatigue and cognitive issues and then body pain as well. I'd love to be able to have some help in terms of that. Participant_008

Participant describes wanting to manage the side effects

Look, it's a hard one. I'm extremely fortunate with side effects from the treatments I've had have been minimal and not ongoing as such. Once that treatment's finished, the side effects stopped, I've been really lucky in that sense. I just probably want-- and I will probably do is once the treatments even finished is, I just want more education for people on how to handle the side effects as opposed to just being told what to do and not actually have that support there. Participant_030

I was told I would have chemotherapy, there'd be no question of that. I was just terrified of vomiting, to be honest. I didn't really care about losing my hair or anything like that, it was more just being sick. Participant_040

Table 4.9: Personal goals of treatment or care

Personal goals of treatment or care	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=23	%	n=27	%	n=19	%	n=25	%	n=26	%	n=24	%	n=24	%	n=26	%
Participant describes wanting to treat the disease/get better	14	28.00	7	30.43	7	25.93	5	26.32	7	28.00	9	34.62	5	20.83	5	20.83	9	34.62
Participant describes wanting to follow/get through treatment	12	24.00	7	30.43	5	18.52	5	26.32	6	24.00	8	30.77	4	16.67	5	20.83	7	26.92
Participant describes wanting to live independently	7	14.00	3	13.04	4	14.81	2	10.53	4	16.00	4	15.38	3	12.50	1	4.17	6	23.08
Participant describes wanting to see mental/emotional health improvements	6	12.00	3	13.04	3	11.11	2	10.53	3	12.00	2	7.69	4	16.67	4	16.67	2	7.69
Participant describes wanting to returning to work	5	10.00	5	21.74	0	0.00	3	15.79	1	4.00	3	11.54	2	8.33	1	4.17	4	15.38
Participants describe wanting to see physical improvements in their condition	5	10.00	3	13.04	2	7.41	3	15.79	0	0.00	1	3.85	4	16.67	2	8.33	3	11.54
Participant describes wanting to manage the side effects	5	10.00	0	0.00	5	18.52	1	5.26	3	12.00	1	3.85	4	16.67	4	16.67	1	3.85

Personal goals of treatment or care	All participants		Regional or remote		Metropolitan		Mid to low status		Higher status		Aged 25 to 44		Aged 45 to 54		Aged 55 to 74	
	n=50	%	n=16	%	n=34	%	n=20	%	n=30	%	n=19	%	n=22	%	n=9	%
Participant describes wanting to treat the disease/get better	14	28.00	4	25.00	10	29.41	5	25.00	9	30.00	**9**	**47.37**	**3**	**13.64**	2	22.22
Participant describes wanting to follow/get through treatment	12	24.00	5	31.25	7	20.59	6	30.00	6	20.00	**2**	**10.53**	**8**	**36.36**	2	22.22
Participant describes wanting to live independently	7	14.00	**4**	**25.00**	3	8.82	2	10.00	5	16.67	**6**	**31.58**	1	4.55	**0**	**0.00**
Participant describes wanting to see mental/emotional health improvements	6	12.00	2	12.50	4	11.76	2	10.00	4	13.33	2	10.53	3	13.64	1	11.11
Participant describes wanting to returning to work	5	10.00	2	12.50	3	8.82	2	10.00	3	10.00	3	15.79	0	0.00	**2**	**22.22**
Participants describe wanting to see physical improvements in their condition	5	10.00	0	0.00	5	14.71	1	5.00	4	13.33	**4**	**21.05**	1	4.55	0	0.00
Participant describes wanting to manage the side effects	5	10.00	2	12.50	3	8.82	2	10.00	3	10.00	1	5.26	2	9.09	**2**	**22.22**

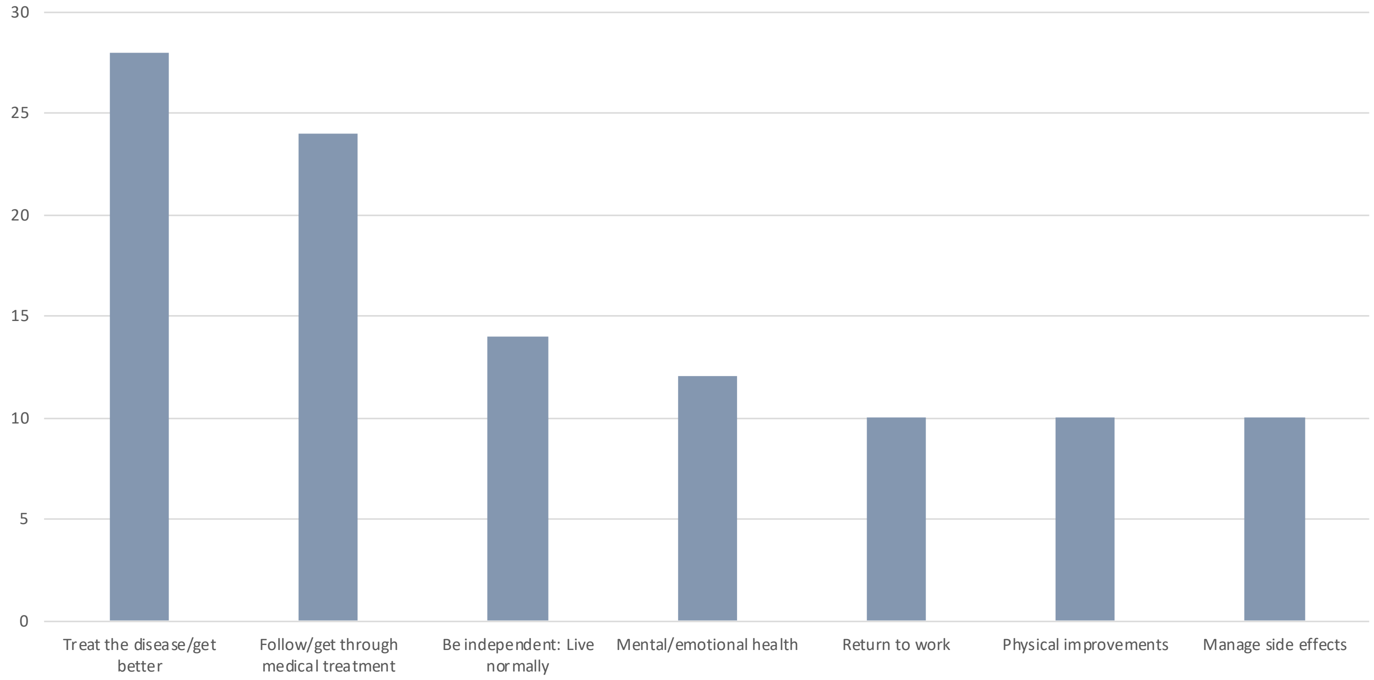


Figure 4.5: Personal goals of treatment or care

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

Theme	Reported less frequently	Reported more frequently
Participant describes wanting to treat the disease/get better	Aged 45 to 54	Aged 25 to 44
Participant describes wanting to follow/get through treatment	Aged 25 to 44	Aged 45 to 54
Participant describes wanting to live independently	Aged 55 to 74	Regional or remote Aged 25 to 44
Participant describes wanting to returning to work	-	Early breast cancer Aged 55 to 74
Participants describe wanting to see physical improvements in their condition	-	Aged 25 to 44
Participant describes wanting to manage the side effects	-	Aged 55 to 74

Section 5

Treatment

Section 5: Experience of treatment

Main provider of treatment

The most common providers of treatment and care were medical oncologists (n = 23, 52.27 %), followed by general practitioners (n = 9, 20.45%).

There were 16 participants (37.21%) that travelled for less than 15 minutes, 15 participants (34.88%) that travelled between 15 and 30 minutes, eight participants (18.60%) that travelled between 30 and 60 minutes, three participants (6.98%) that travelled between 60 and 90 minutes, and one participant (2.33%) that travelled more than 90 minutes

Access to healthcare professionals

All participants had access to a medical oncologist (n = 44, 100%), and almost all had a specialist surgeon (n = 42, 95.45%) and a general practitioner (n = 41, 93.18%). There were 38 participants (86.36%) that had an oncology/chemotherapy nurse and 37 participants (84.09%) that had a breast care nurse.

Almost half of the participants had a pharmacist to care for their condition (n = 18, 40.91%). There were 21 participants (47.73%) treated by a physiotherapist and, 11 participants (25.00%) treated by a dietitian/nutritionist.

Respect shown

There were 34 participants (77.27%) that indicated that they had been treated with respect throughout their experience, and nine participants (20.45%) who were treated with respect with the exception of one or two occasions. .

Health care system

The majority of participants had private health insurance (n = 33, 75.00%). The majority of participants were asked if they wanted to be treated as a public or private patient (n = 28, 63.64%), and, they were asked if they had private health insurance (n = 39, 88.64%).

Throughout their treatment, there were 20 participants (45.45%) who were treated as a private patient, 20 participants (45.45%) were mostly treated as a public patient, and there were four participants (9.09%) who were equally treated as a private and public patient.

Affordability of healthcare

The majority of participants never or rarely had to delay or cancel appointments due to affordability (n = 39, 88.64%).

Almost all of the participants never or rarely were unable to fill prescriptions (n = 40, 90.91%).

There were 34 participants (79.28%) that never or rarely had trouble paying for essentials, such as such as food, housing and power, and six participants (13.64%) that sometimes found it difficult, and four participants (9.09%) often or very often found it difficult to pay for basic essentials.

There were four participants (9.09%) that paid for additional carers due to their condition.

Cost of condition

Participants spent between $50 and $10,000 per month, most commonly between $101 or less (n = 10, 22.73%), and $101 to $250 (n =10, 22.73%).

The amount spent was an extremely significant or moderately significant burden for 11 participants (25.00%), somewhat significant for nine participants (20.45%), and slightly or not at all significant for 24 participants (54.55%).

Changes to employment status

Work status for 12 participants (27.27%) had not changed since diagnosis, or were retired or did not have a job. There were four participants (9.09%) had to quit their job, 10 participants (22.73%) reduced the number of hours they worked, and four participants (9.09%) that accessed their superannuation early. There were 16 participants (36.36%) that took leave from work without pay, and 12 participants (27.27%) who took leave from work with pay.

There were 11 participants (25.00%), 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 = 22, 50.00%). There were four participants (9.09%) whose partners reduced the numbers of hours they worked, and no partners quit their job.   The partners of five participants (11.36%) took leave without pay, and there were eight partners (18.18%) who took leave with pay.

Reduced income due to condition

Participants reported a reduced income from 500 to 10,000 per month, most commonly $1501 to 2500 (n = 6, 13.64%).

For eight of these participants (42.11%), the burden of this reduced income was slightly or not at all significant, for five participants (26.32%) the burden was somewhat significant, and for 6 participants (31.58%) the burden was extremely or moderately significant.

Summary of surgery

There were 35 participants (79.55%) that had surgery for breast cancer (excluding biopsies). There were 15 participants (34.09%) that had one operation, 10 participants (22.73%) that had two operations, three participants (6.82%) that had three operations, and seven participants (15.91%) that had four or more operations.

There were 35 participants (79.55%) that had surgery for breast cancer (excluding biopsies). The most common types of surgeries were mastectomies (n=19, 43.18%), and lumpectomies (n=19, 43.18%). There were 13 participants (29.55%) had breast reconstruction, and seven participants (2.27%) had surgery to remove ovaries

Summary of drug treatments

There were 40 participants (90.91%) that had used drug treatments to treat their breast cancer. The most common treatment regimen was doxorubicin, cyclophosphamide, and paclitaxel (n=17, 38.64%), followed by single agent paclitaxel (n=11, 25.00%), Capecitabine (n=10, 22.73%), Doxorubicin and cyclophosphamide (n=8, 18.18%), Carboplatin paclitaxel (n=6, 13.64%), and Doxorubicin (n=5, 11.35%)

Summary of radiotherapy

There were 25 participants (56.82%) that had radiotherapy to the primary cancer site, and three participants (6.82%) that had radiotherapy to the secondary cancer site .

Allied health

Most participants used at least one type of allied health service (n = 34, 77.27%), and on average used 2 services (median = 2.00, IQR = 1.00).

The most common allied health service used was psychology services (n = 21, 47.73%), followed by physiotherapy (n = 20, 45.45%), and Dietician (n = 10, 22.73%). There were six participants (13.64%) who saw an occupational therapist, five participants (11.36%) who saw a podiatrist, and four participants (9.09%) who saw a social worker.

Lifestyle changes

Most participants used at made at least one lifestyle change (n = 38, 86.36%), and on average made 2 changes (median = 2.00, IQR = 2.00).

The most common lifestyle change used was exercise (n = 28, 63.64%), followed by diet changes (n = 23, 52.27%), and reducing or stopping alcohol if applicable (n = 24, 54.55%).

Complementary therapies

Most participants used at made at least one complementary therapy (n = 29, 65.91%), and on average used one therapy (median = 1.00, IQR = 2.00).

The most common complementary therapy used was mindfulness or relaxation techniques (n = 20, 45.45 %), followed by massage therapy (n = 17, 38.64%), and taking supplements (n = 16, 36.36%) (Table 5.21, Figure 5.24).

Clinical trials

There was a total of 16 participants (36.36%) that had discussions about clinical trials, six participants (13.64%) had brought up the topic with their doctor, and the doctor of 10 participants (22.77%) brought up the topic. The majority of participants had not spoken to anyone about clinical trials (n = 28, 63.64%).

There were four participants (9.09%) who had taken part in a clinical trial, 32 participants (72.73%) who would like to take part in a clinical trial if there was a suitable one, and eight participants, who have not participated in a clinical trial and do not want to (18.18%).

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 providers of treatment and care were medical oncologists (n = 23, 52.27 %), followed by general practitioners (n = 9, 20.45%) (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 16 participants (37.21%) that travelled for less than 15 minutes, 15 participants (34.88%) that travelled between 15 and 30 minutes, eight participants (18.60%) that travelled between 30 and 60 minutes, three participants (6.98%) that travelled between 60 and 90 minutes, and one participant (2.33%) 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=44)	Percent
General practitioner (GP)	9	20.45
Medical oncologist	23	52.27
Multidisciplinary team	3	6.82
Specialist surgeon	9	20.45

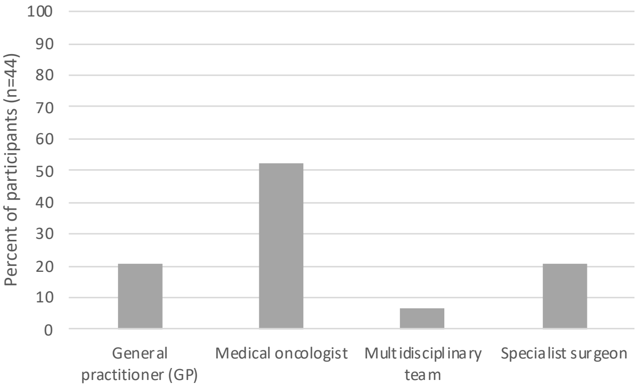


Figure 5.1: Main provider of treatment

Table 5.2: Time to travel to main provider of treatment

Time to travel to main provider of treatment	Number (n=43)	Percent
Less than 15 minutes	16	37.21
Between 15 and 30 minutes	15	34.88
Between 30 and 60 minutes	8	18.60
Between 60 and 90 minutes	3	6.98
More than 90 minutes	1	2.33

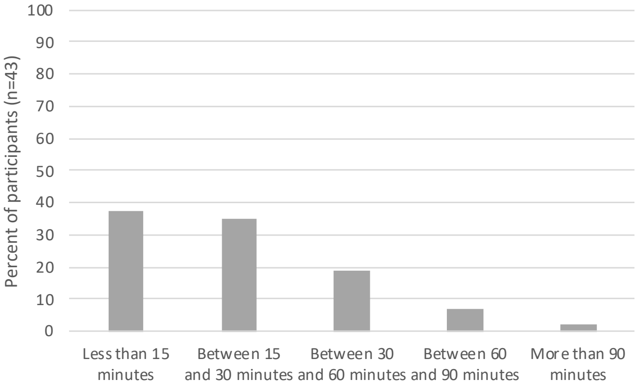


Figure 5.2: Time to travel to main provider of treatment

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.

All participants had access to a medical oncologist (n = 44, 100%), and almost all had a specialist surgeon (n = 42, 95.45%) and a general practitioner (n = 41, 93.18%). There were 38 participants (86.36%) that had a oncology/chemotherapy nurse and 37 participants (84.09%) that had a breast care nurse.

Almost half of the participants had a pharmacist to care for their condition (n = 18, 40.91%). There were 21 participants (47.73%) treated by a physiotherapist and, 11 participants (25.00%) treated by a dietitian/nutritionist (Table 5.3, Figure 5.3).

Table 5.3: Access to healthcare professionals

Healthcare professional	Number (n=44)	Percent
Medical oncologist	44	100.00
Radiation oncologist	31	70.45
Specialist surgeon	42	95.45
Palliative care specialist	2	4.55
Breast cancer care coordination discharge planner or key worker	14	31.82
Oncology/chemotherapy nurse	38	86.36
Breast care nurse	37	84.09
Lymphoedema practitioner	16	36.36
Speech therapist	0	0.00
Genetic counsellor	22	50.00
General practitioner	41	93.18
Physiotherapist	21	47.73
Weight loss specialist	0	0.00
Dietitian/nutritionist	11	25.00
Occupational therapist	4	9.09
Exercise physiologist	14	31.82
Pharmacist	18	40.91
Counsellor	9	20.45
Psychologist	20	45.45
Chiropractor	6	13.64
Osteopath	6	13.64
Social worker	2	4.55

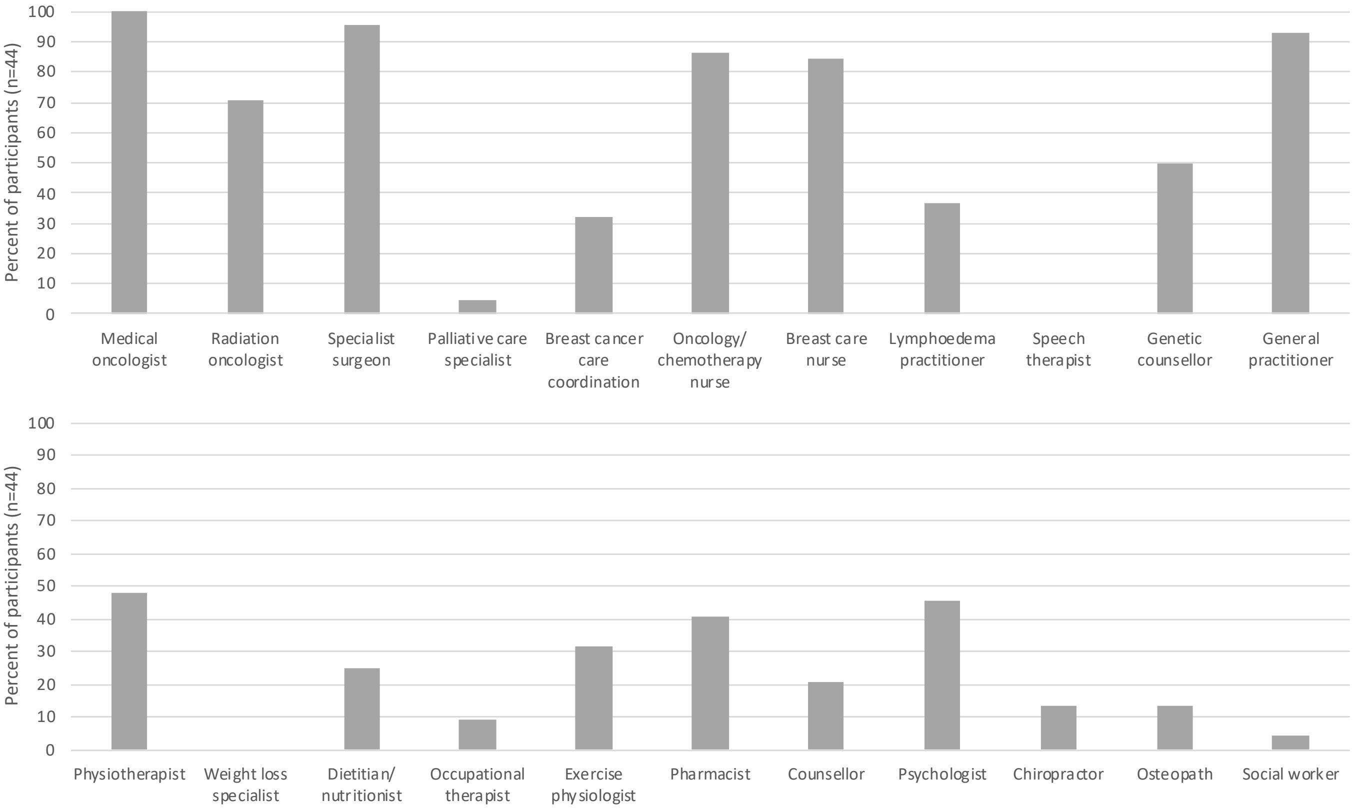


Figure 5.3: Access to healthcare professionals

Respect shown

Participants were asked to think about how respectfully they were treated throughout their experience, this question was asked in the online questionnaire.

There were 34 participants (77.27%) that indicated that they had been treated with respect throughout their experience, and nine participants (20.45%) who were treated with respect with the exception of one or two occasions (Table 5.4, Figure 5.4).

Table 5.4: Respect shown

Respect shown	Number (n=44)	Percent
Respect shown	34	77.27
Respect shown, with the exception of one or two occasions	9	20.45
Respect not shown	1	2.27

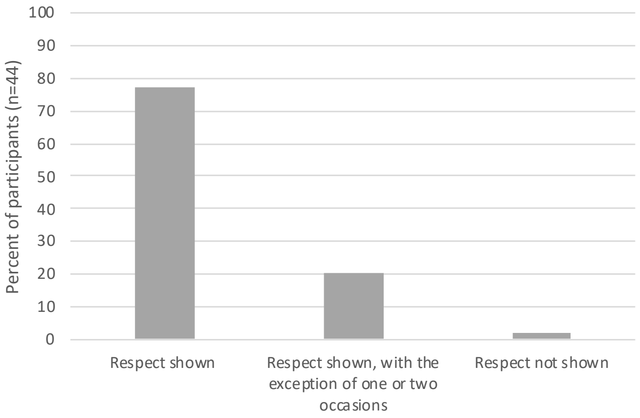


Figure 5.4: Respect shown

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 5.5, Figures 5.5 and 5.6).

The majority of participants had private health insurance (n = 33, 75.00%). The majority of participants were asked if they wanted to be treated as a public or private patient (n = 28, 63.64%), and, they were asked if they had private health insurance (n = 39, 88.64%).

Throughout their treatment, there were 20 participants (45.45%) who were treated as a private patient, 20 participants (45.45%) were mostly treated as a public patient, and there were four participants (9.09%) who were equally treated as a private and public patient.

Table 5.5: Health care system

Health care services	Response	Number (n=44)	Percent
Private health insurance	No	11.00	25.00
	Yes	33.00	75.00
Asked whether you want to be treated as a public or private patient	No	16.00	36.36
	Yes	28.00	63.64
Asked whether you had private health insurance	No	5.00	11.36
	Yes	39.00	88.64
Throughout your treatment in hospital, have you most been treated as a public or a private patient	Equally as a public and private patient	4.00	9.09
	Private patient	20.00	45.45
	Public patient	20.00	45.45
Which hospital system have you primarily been treated in	Both public and private	4.00	9.09
	Private	20.00	45.45
	Public	20.00	45.45

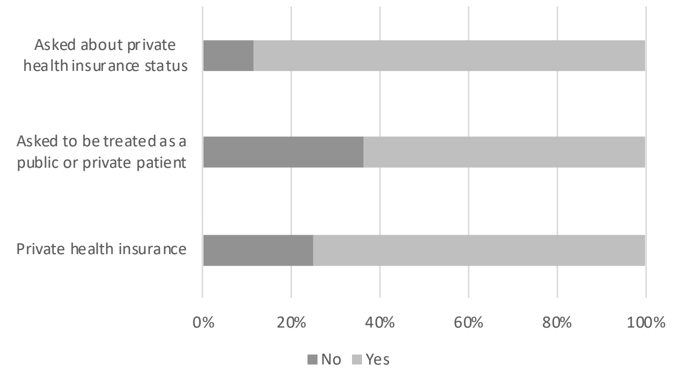


Figure 5.5: Health insurance

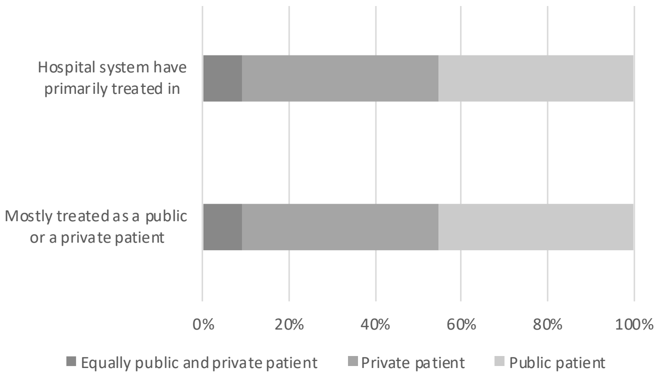


Figure 5.6: Hospital system

Affordability of healthcare

Participants were asked a series of questions about affordability of healthcare in the online questionnaire (Table 5.6, Figure 5.7).

The first question was about having to delay or cancer healthcare appointments because they were unable to afford them. The majority of participants never or rarely had to delay or cancel appointments due to affordability (n = 39, 88.64%).

The next question was about the ability to fill prescriptions. Almost all of the participants never or rarely were unable to fill prescriptions (n = 40, 90.91%).

The third question was about the affordability of basic essentials such as such as food, housing and power. There were 34 participants (79.28%) that never or rarely had trouble paying for essentials, and six participants (13.64%) that sometimes found it difficult, and four participants (9.09%) often or very often found it difficult to pay for basic essentials.

The final question was about paying for additional carers for themselves or for their family, there were four participants (9.09%) that paid for additional carers due to their condition.

Table 5.6: Affordability of healthcare

Affordability of healthcare	Response	Number (n=44)	Percent
Delay or cancel healthcare appointments due to affordability	Never	37.00	84.09
	Rarely	2.00	4.55
	Sometimes	2.00	4.55
	Often	1.00	2.27
	Very often	2.00	4.55
Did not fill prescriptions due to cost	Never	37.00	84.09
	Rarely	3.00	6.82
	Sometimes	4.00	9.09
	Often		0.00
	Very often		0.00
Difficult to pay for basic essentials	Never	28.00	63.64
	Rarely	6.00	13.64
	Sometimes	6.00	13.64
	Often	2.00	4.55
	Very often	2.00	4.55
Pay for additional carers for self or family	Yes	4.00	9.09
	No	40.00	90.91

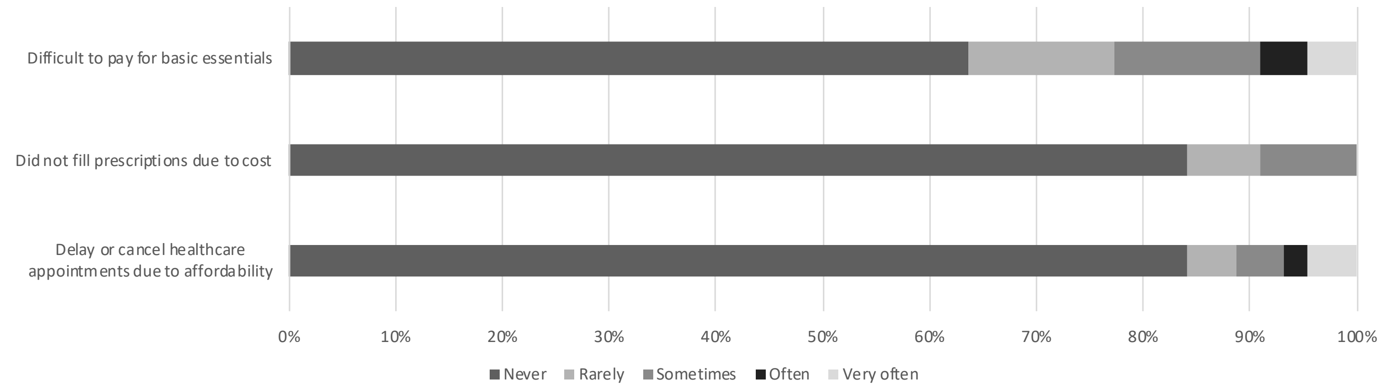


Figure 5.7: Affordability of healthcare

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 5.7, Figure 5.8).

Participants spent between $50 and $10,000 per month, most commonly between $101 or less (n = 10, 22.73%), and $101 to $250 (n =10, 22.73%).

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 5.8, Figure 5.9).

The amount spent was an extremely significant or moderately significant burden for 11 participants (25.00%), somewhat significant for nine participants (20.45%), and slightly or not at all significant for 24 participants (54.55%).

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

Estimated monthly out of pocket expenses	Number (n=44)	Percent
$0	4	9.09
$100 or less	10	22.73
$101 to $250	10	22.73
$251 to $500	7	15.91
$501 to $1000	5	11.36
$1001 or more	4	9.09
Not sure of amount	4	9.09

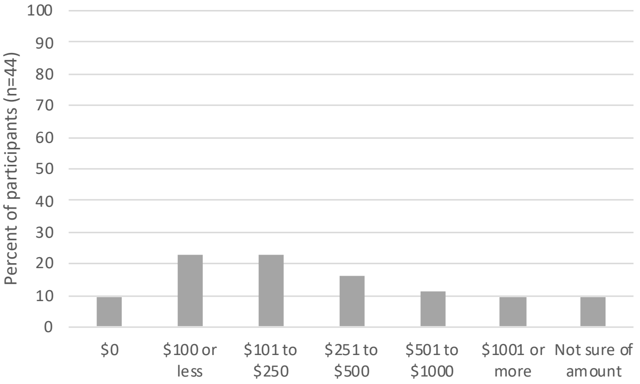


Figure 5.8: Estimated monthly out of pocket expenses due to condition

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

Burden of out of pocket expenses	Number (n=44)	Percent
Extremely significant	5	11.36
Moderately significant	6	13.64
Somewhat significant	9	20.45
Slightly significant	15	34.09
Not at all significant	9	20.45

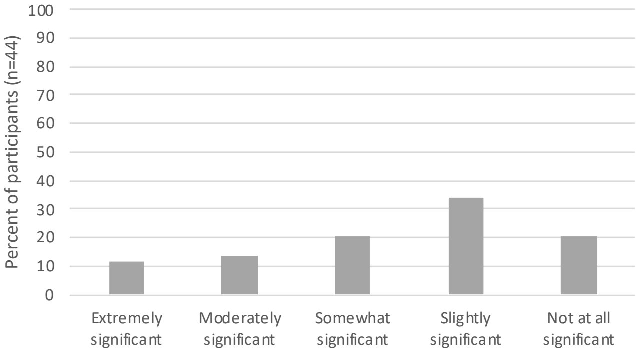


Figure 5.9: Burden of out-of-pocket expenses due to condition

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 5.9, Figure 5.10).

Work status for 12 participants (27.27%) had not changed since diagnosis, or were retired or did not have a job. There were four participants (9.09%) had to quit their job, 10 participants (22.73%) reduced the number of hours they worked, and four participants (9.09%) that accessed their superannuation early. There were 16 participants (36.36%) that took leave from work without pay, and 12 participants (27.27%) 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 5.10, Figure 5.11).

There were 11 participants (25.00%), 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 = 22, 50.00%). There were four participants (9.09%) whose partners reduced the numbers of hours they worked, and no partners quit their job. The partners of five participants (11.36%) took leave without pay, and there were eight partners (18.18%) who took leave with pay.

Table 5.9: Changes to employment status

Changes in employment status due to condition	Number (n=44)	Percent
Work status has not changed	11	25.00
Retired or did not have a job	1	2.27
Had to quit job	4	9.09
Reduced number of hours worked	10	22.73
Leave from work without pay	16	36.36
Leave from work with pay	12	27.27
Accessed Superannuation early due to condition	4	9.09

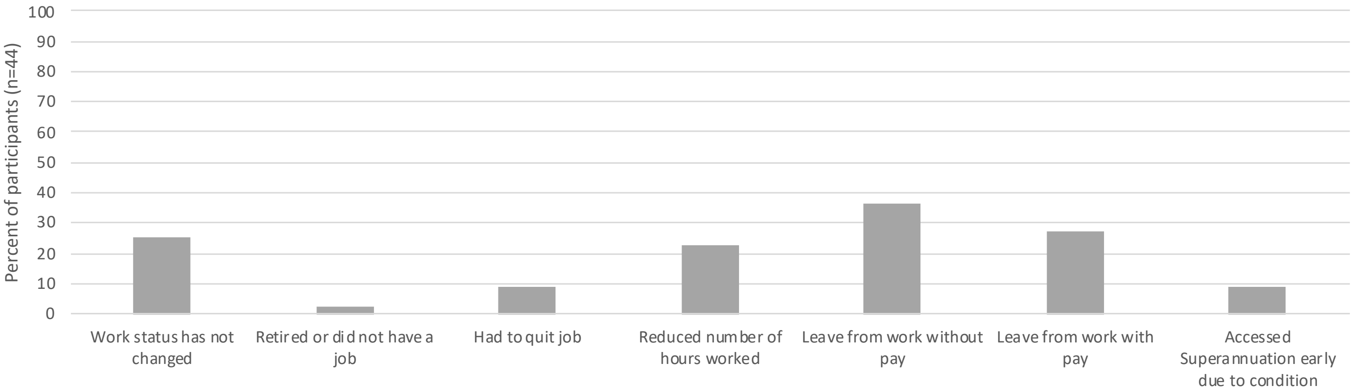


Figure 5.10: Changes to employment status

Table 5.10: Changes to care/partner employment status

Changes to care/partner employment status	Number (n=44)	Percent
Does not have a partner/main carer	11	25.00
Work status has not changed	22	50.00
Retired or did not have a job	0	0.00
Had to quit job	0	0.00
Reduced number of hours worked	4	9.09
Leave from work without pay	5	11.36
Leave from work with pay	8	18.18

Figure 5.11: Changes to care/partner employment status

Reduced income due to condition

Almost of the participants (n = 19, 43.18%) 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 5.11, Figure 5.12).

Participants reported a reduced income from 500 to 10,000 per month, most commonly $1501 to 2500 (n = 6, 13.64%).

Burden of reduced income

Participants were then asked if this reduced family or household income was a burden.

For eight of these participants (42.11%), the burden of this reduced income was slightly or not at all significant, for five participants (26.32%) the burden was somewhat significant, and for 6 participants (31.58%) the burden was extremely or moderately significant (Table 5.12, Figure 5.13).

Table 5.11: Estimated monthly loss of income

Estimated monthly loss of income	Number (n=44)	Percent
$0	25	56.82
$500 to 1500	5	11.36
$1501 to 2500	6	13.64
$2501 to 5000	3	6.82
More than $5000	3	6.82
Not sure/not specified	2	4.55

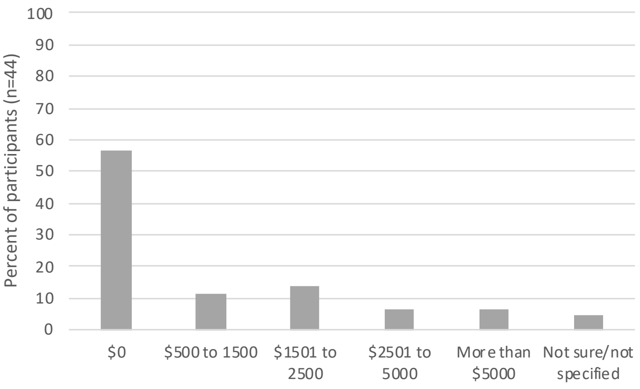


Figure 5.12: Estimated monthly loss of income

Table 5.12: Burden of reduced income

Burden of reduced income	Number (n=44)	Percent
Extremely significant	4	21.05
Moderately significant	2	10.53
Somewhat significant	5	26.32
Slightly significant	5	26.32
Not at all significant	3	15.79

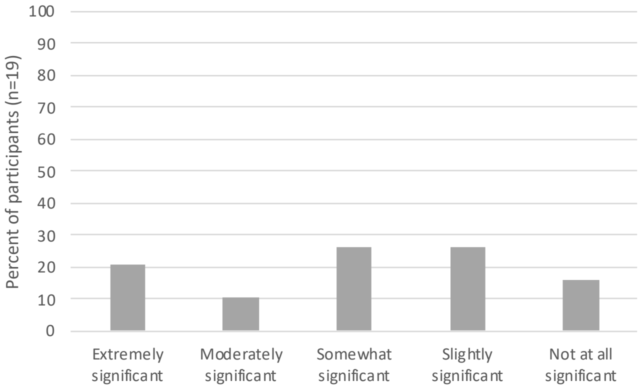


Figure 5.13: Burden of reduced income

Summary of surgery

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

There were 35 participants (79.55%) that had surgery for breast cancer (excluding biopsies). There were 15 participants (34.09%) that had one operation, 10 participants (22.73%) that had two operations, three participants (6.82%) that had three operations, and seven participants (15.91%) 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=44)	Percent
0	9	20.45
1	15	34.09
2	10	22.73
3	3	6.82
4 or more	7	15.91

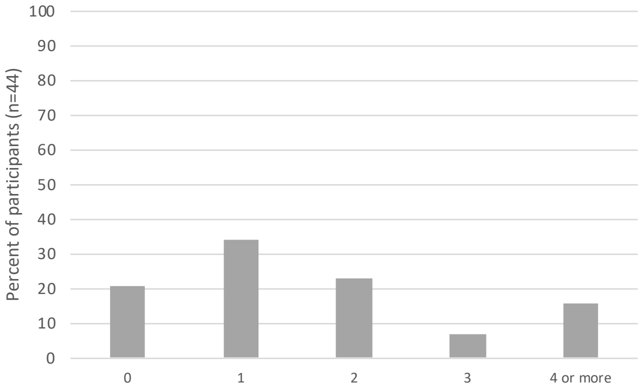


Figure 5.14: Number of surgeries

Surgical treatments

Participants completed a series of questions about surgery, including type of surgery, quality of life, effectiveness of surgery, and side effects. Details about year of surgery, side effects, quality of life and effectiveness are given in Table 5.14.

There were 35 participants (79.55%) that had surgery for breast cancer (excluding biopsies). The most common types of surgeries were mastectomies (n=19, 43.18%), and lumpectomies (n=19, 43.18%). There were 13 participants (29.55%) had breast reconstruction, and seven participants (2.27%) 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". Values are calculated where there was adequate data available. Median quality of life from surgery ranged from 2.00 to 4.00, in the life was a distressing to life was average range. The lowest quality of life was reported from mastectomy (median = 2.00, IQR =1.00), and the highest quality of life from removal of ovaries (median = 4.00, IQR = 2.00) (Figure 5.16).

Effectiveness of treatment was rated on a five-point scale where one is ineffective, and five is very effective. The median effectiveness of all surgery was between 4.00 and 5.00, in the effective to very effective range (Figure 5.17).

Table 5.14: Details of surgeries

Surgery		Lumpectomy		Re-excision following lumpectomy		Mastectomy		Breast reconstruction		Surgery to remove ovaries		Surgery to relieve symptoms	
		n=19	**%**	**n=2**	**%**	**n=19**	**%**	**n=13**	**%**	**n=7**	**%**	**n=1**	**%**
Number		19	43.18	2	4.55	19	43.18	13	29.55	7	15.91	1	2.27
Year of surgery	2020 to 2021	9	47.37	0	0.00	9	47.37	6	46.15	2	28.57	0	0.00
	2017 to 2019	6	31.58	1	50.00	8	42.11	6	46.15	3	42.86	1	100.00
	2016 or before	4	21.05	1	50.00	2	10.53	1	7.69	2	28.57	0	0.00
Side effects	No side effects	8	42.11	1	50.00	1	5.26	1	7.69	1	14.29	0	0.00
	A high temperature	1	5.26	0	0.00	0	0.00	1	7.69		0.00	0	0.00
	Feeling generally unwell	3	15.79	1	50.00	4	21.05	2	15.38	2	28.57	0	0.00
	Feeling hot and cold	0	0.00	0	0.00	1	5.26	2	15.38		0.00	0	0.00
	Feeling sick	1	5.26	0	0.00	1	5.26	2	15.38	1	14.29	0	0.00
	Pain	0	0.00	1	50.00	17	89.47	11	84.62	3	42.86	1	100.00
	Shivering	10	52.63	0	0.00	1	5.26	2	15.38		0.00	0	0.00
	Swelling/redness around wound	3	15.79	0	0.00	5	26.32	6	46.15		0.00	0	0.00
	Other	1	5.26	0	0.00	4	21.05	2	15.38	1	14.29	0	0.00
		Median	**IQR**	**Median**	**IQR**	**Median**	**IQR**	**Median**	**IQR**	**Median**	**IQR**	**Median**	**IQR**
Quality of life		3	1.00	-	-	2	1.00	3	2.00	4	2.00	-	-
Effectiveness		5	1.00	-	-	5	1.00	4	1.00	5	1	-	-

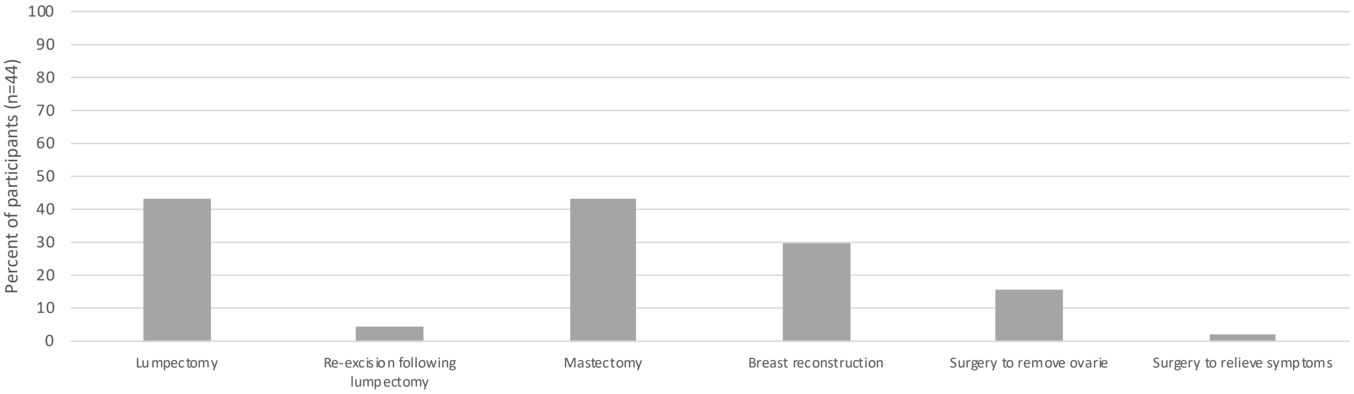


Table 5.15: Type of surgery

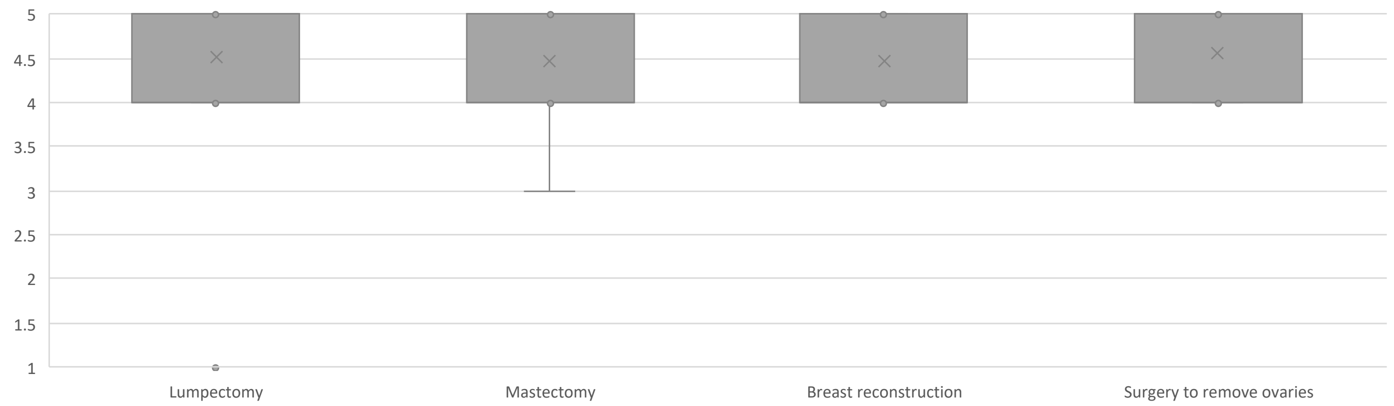


Figure 5.16: Quality of life from surgery

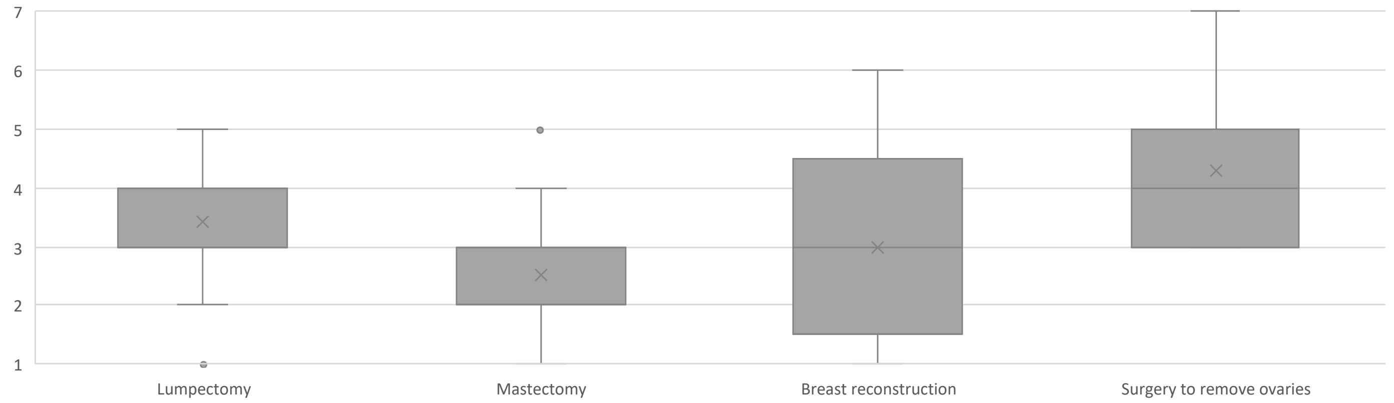


Figure 5.17: Effectiveness of surgery

Summary of drug treatments

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

A review was then conducted to compare the results of the online questionnaire and the structured interview responses to a question asked about the treatments that participants had experienced. Where treatments were mentioned in the structured interview but not marked by participants in the online questionnaire, these were added manually, but do not include a quality of life and effectiveness rating.

Where participants were unsure of names of treatments, these were also cross validated with interview transcripts. Where it was clear that an error had been made in the online questionnaire, these were removed. In this study, there were two occasions where the participant had entered a treatment in error that was later removed.

There were 40 participants (90.91%) that had used drug treatments to treat their breast cancer. The most common treatment regimen was doxorubicin, cyclophosphamide, and paclitaxel (n=17, 38.64%), followed by single agent paclitaxel (n=11, 25.00%), Capecitabine (n=10, 22.73%), Doxorubicin and cyclophosphamide (n=8, 18.18%), Carboplatin paclitaxel (n=6, 13.64%), and Doxorubicin (n=5, 11.35%) (Table 5.15,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”. Values are calculated where there was adequate data available. Median quality of life from treatments ranged from 2.00 to 3.00, in the life was distressing to life was a little distressing range (Table 5.16, Figure 5.19).

Effectiveness of treatment was rated on a five-point scale where one is ineffective, and five is very effective. Median effectiveness from treatments ranged from 2.00 to 5.00, in the somewhat to very effective range. (Table 5.16, Figure 5.10)

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

On average, quality of life from paclitaxel was in the 'life was a little distressing' range (median = 3.00, IQR = 2.00), and was found to be very effective (median = 5.00, IQR = 4.00).

On average, quality of life from Capecitabine was in the 'life was a little distressing' range (median = 3.00, IQR = 1.00), and was found to be effective (median = 4.00, IQR = 0.00).

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

On average, quality of life from Carboplatin paclitaxel was in the 'life was a distressing' range (median = 2.00, IQR = 1.50), and was found to be effective (median = 4.00, IQR = 0.75).

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

Table 5.15: Summary of drug treatments

Drug treatments	Number (n=44)	Percent
Doxorubicin, cyclophosphamide, and paclitaxel	17	38.64
Paclitaxel	11	25.00
Capecitabine	10	22.73
Doxorubicin and cyclophosphamide	8	18.18
Carboplatin paclitaxel	6	13.64
Doxorubicin	5	11.36
Carboplatin	3	6.82
Docetaxel	3	6.82
Docetaxel and cyclophosphamide	3	6.82
Fluorouracil, epirubicin, and cyclophosphamide	3	6.82
Cyclophosphamide and methotrexate	2	4.55
Denosumab	1	2.27
Zoledronic acid	1	2.27

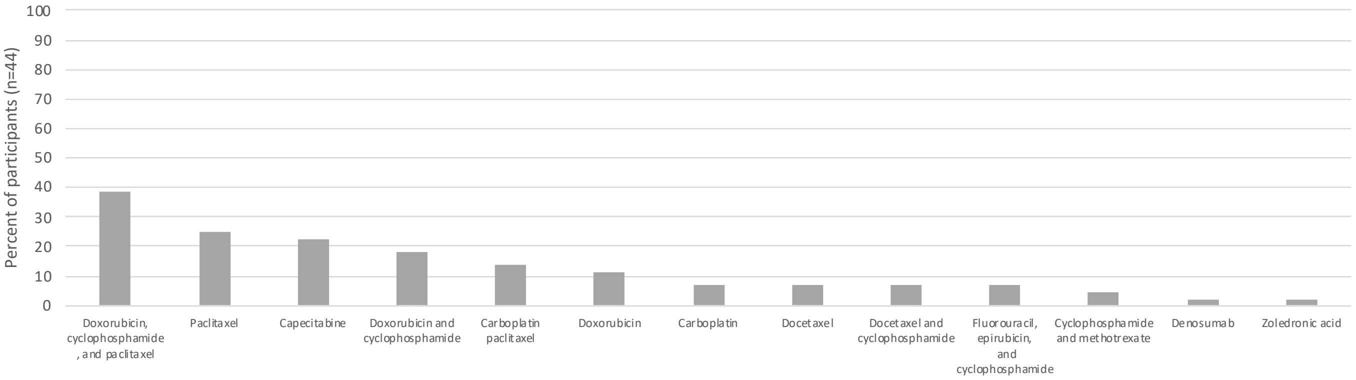


Figure 5.18: Type of drug treatments

Table 5.16: Summary of drug treatments taken by more than five participants

Drug treatments		Doxorubicin and cyclophosphamide, and paclitaxel		Capecitabine		Paclitaxel		Doxorubicin and cyclophosphamide		Carboplatin paclitaxel		Doxorubicin	
		n=17	%	n=10	%	n=11	%	n=8	%	n=6	%	n=5	%
Number		17	38.64	10	22.73	11	25.00	8	18.18	6	13.64	5	11.36
Year of treatment	2020 to 2021	8	47.06	6	60.00	6	54.55	4	50.00	2	33.33	2	40.00
	2017 to 2019	7	41.18	3	30.00	4	36.36	4	50.00	4	66.67	3	60.00
	2016 or before	2	11.76	1	10.00	1	9.09	0	0.00	0	0.00	0	0.00
Status	Finished treatment as planned	13	76.47	6	60.00	8	72.73	8	100.00	6	100.00	5	100.00
	Finished due to side effects or ineffectiveness	3	17.65	1	10.00	1	9.09	0	0.00	0	0.00	0	0.00
	Currently taking	1	5.88	3	30.00	1	9.09	0	0.00	0	0.00	0	0.00
Side effects	No side effects	4	23.53	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
	Appetite loss	0	0.00	3	30.00	0	0.00	0	0.00	0	0.00	0	0.00
	Bone pain	13	76.47	0	0.00	0	0.00	0	0.00	2	33.33	0	0.00
	Chemo brain	15	88.24	0	0.00	0	0.00	7	87.50	4	66.67	0	0.00
	Diarrhoea	7	41.18	5	50.00	6	54.55	3	37.50	1	16.67	0	0.00
	Flu-like symptoms	1	5.88	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
	Hair loss	17	100.00	0	0.00	9	81.82	8	100.00	4	66.67	5	100.00
	Hand-foot syndrome	0	0.00	9	90.00	0	0.00	0	0.00	0	0.00	0	0.00
	Heart problems	0	0.00	1	10.00	0	0.00	0	0.00	0	0.00	2	40.00
	High blood bilirubin levels	0	0.00	1	10.00	0	0.00	0	0.00	0	0.00	0	0.00
	Infection risk (neutropenia)	14	82.35	1	10.00	1	9.09	4	50.00	4	66.67	3	60.00
	Injection-site reaction or pain	2	11.76	0	0.00	0	0.00	1	12.50	0	0.00	1	20.00
	Joint and muscle pain / stiffness	1	5.88	0	0.00	0	0.00	0	0.00	4	66.67	0	0.00
	Low platelets	5	29.41	0	0.00	1	9.09	1	12.50	2	33.33	3	60.00
	Low red blood cells (anaemia)	4	23.53	0	0.00	2	18.18	0	0.00	2	33.33	2	40.00
	Menopausal symptoms	13	76.47	1	10.00	7	63.64	6	75.00	0	0.00	0	0.00
	Mouth pain and soreness	8	47.06	2	20.00	3	27.27	5	62.50	3	50.00	2	40.00
	Nail changes	12	70.59	0	0.00	7	63.64	2	25.00	4	66.67	3	60.00
	Nausea and or vomiting	8	47.06	2	20.00	5	45.45	6	75.00	2	33.33	1	20.00
	Nerve damage	11	64.71	0	0.00	6	54.55	0	0.00	5	83.33	0	0.00
	Redness and itching along vein	2	11.76	0	0.00	0	0.00	2	25.00	0	0.00	1	20.00
	Skin colour changes	0	0.00	0	0.00	0	0.00	2	25.00	0	0.00	1	20.00
	Skin rash	2	11.76	0	0.00	2	18.18	0	0.00	0	0.00	0	0.00
	Radiation recall	1	5.88	0	0.00	0	0.00	0	0.00	0	0.00	1	20.00
	Photosensitivity	5	29.41	4	40.00	0	0.00	0	0.00	0	0.00	1	20.00
	Stomach pain	0	0.00	2	20.00	0	0.00	0	0.00	0	0.00	0	0.00
	Taste and smell changes	13	76.47	3	30.00	7	63.64	3	37.50	5	83.33	3	60.00
	Tiredness and lack of energy	17	100.00	10	100.00	9	81.82	8	100.00	5	83.33	4	80.00
	Urine turning orange or red	15	88.24	0	0.00	0	0.00	7	87.50	0	0.00	4	80.00
	Other	0	0.00	3	30.00	3	27.27	1	12.50	1	16.67	0	0.00
		Median	**IQR**	**Median**	**IQR**	**Median**	**IQR**	**Median**	**IQR**	**Median**	**IQR**	**Median**	**IQR**
Quality of life		2.00	4.00	3.00	1.00	3.00	2.00	2.00	1.00	2.00	1.50	2.00	1.00
Effectiveness		2.00	1.00	4.00	0.00	5.00	4.00	5.00	1.00	4.00	0.75	5.00	1.00

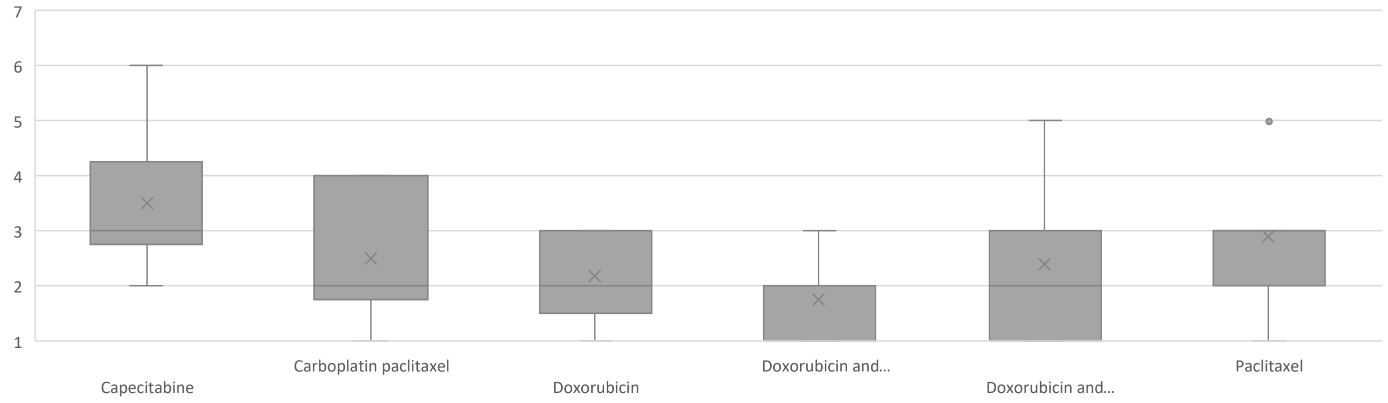


Figure 5. 19: Quality of life from drug treatments

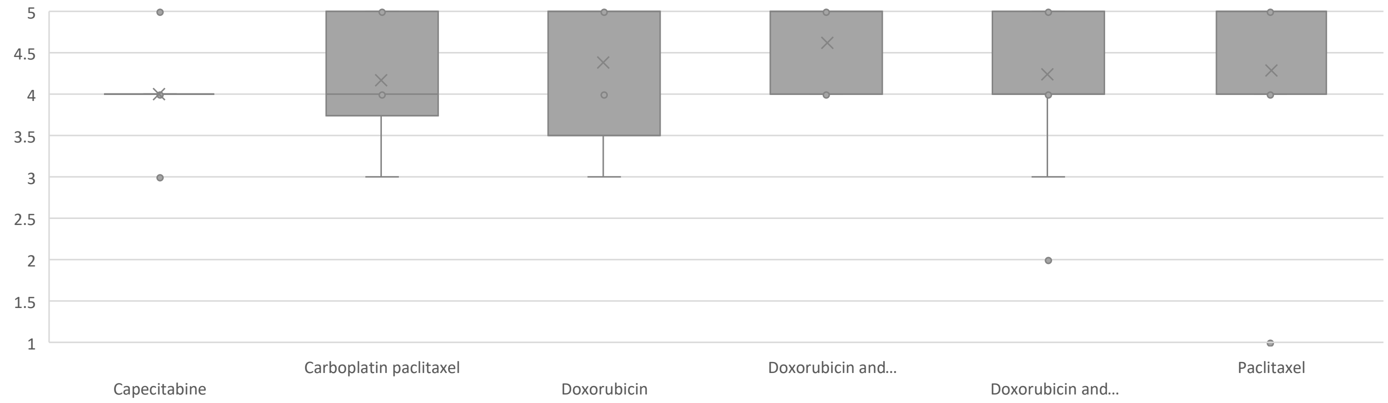


Figure 5.20: Effectiveness of drug treatments

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, more details about side effects are given in Table 5.17.

There were 25 participants (56.82%) that had radiotherapy to the primary cancer site, and three participants (6.82%) that had radiotherapy to the secondary cancer site .

Quality of life was rated on a Likert scale from one to seven, where one is “Life was very distressing” and seven is “Life was great”. Median quality of life from radiotherapy for the primary cancer site was 4.00, in the life was a average range .

Effectiveness of treatment was rated on a five point scale where one is ineffective, and five is very effective. Median effectiveness from radiotherapy for primary cancer site was 4.50 in the effective to very effective range.

Table 5.17: Radiotherapy quality of life and effectiveness

Radiotherapy		Primary site		Secondary site	
		n=25	%	n=3	%
Number		25	56.82	3	6.82
Year of treatment	2020 to 2021	12	27.27	1	33.33
	2017 to 2019	9	20.45	1	33.33
	2016 or before	4	9.09	1	33.33
Treatment status	Treatment completed	22	88.00	0	0.00
	Treatment ongoing	1	4.00	0	0.00
	No response	2	8.00	0	0.00
Side effects	No side effects	2	8.00	0	0.00
	Discomfort when swallowing	3	12.00	0	0.00
	Fatigue	18	72.00	3	100.00
	Loss of appetite and weight loss	2	8.00	1	33.33
	Nausea and vomiting	2	8.00	1	33.33
	Sexual issues	2	8.00	0	0.00
	Skin problems (red, irritated, swollen, blistered, sunburned, tanned)	19	76.00	3	100.00
	Sore mouth	2	8.00	0	0.00
	Stiff joints and muscles	5	20.00	1	33.33
	Swollen limbs	0	0.00	1	33.33
		Median	**IQR**	**Median**	**IQR**
Quality of life		4	2	-	-
Effectiveness		4.5	1	-	-

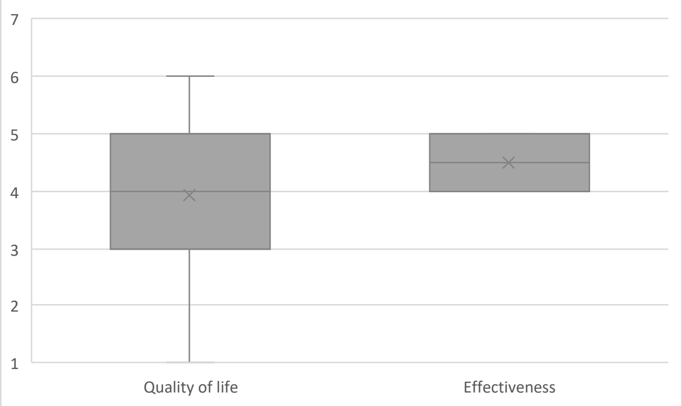


Figure 5.21: Quality of life and effectiveness

Allied health

Participants were asked about allied health services they used, the quality of life from these therapies, and how effective they found them (Table 5.18, Figures 5.22 to 5.24).

Most participants used at least one type of allied health service (n = 34, 77.27%), and on average used 2 services (median = 2.00, IQR = 1.00).

The most common allied health service used was psychology services (n = 21, 47.73%), followed by physiotherapy (n = 20, 45.45%), and Dietician (n = 10, 22.73%). There were six participants (13.64%) who saw an occupational therapist, five participants (11.36%) who saw a podiatrist, and four participants (9.09%) who saw a social worker.

On average, quality of life from psychology services 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 = 2.00).

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 = 1.25).

On average, quality of life from dietary services was in the 'life was distressing to a little distressing' range (median = 3.50, IQR = 2.00), and was found to be moderately effective to effective (median = 3.00, IQR = 2.25).

Table 5.18: Allied health

Allied health	Number (n=44)	Percent	Median quality of life	IQR	Median effectiveness	IQR
Psychologist	21	47.73	3.00	2.00	4.00	2.00
Physiotherapist	20	45.45	4.00	2.00	4.00	1.25
Dietician	10	22.73	3.50	2.00	3.00	2.25
Occupational therapist	6	13.64	4.00	1.50	3.50	1.00
Podiatrist	5	11.36	4.00	1.00	4.00	1.00
Social worker	4	9.09	-	-	-	-

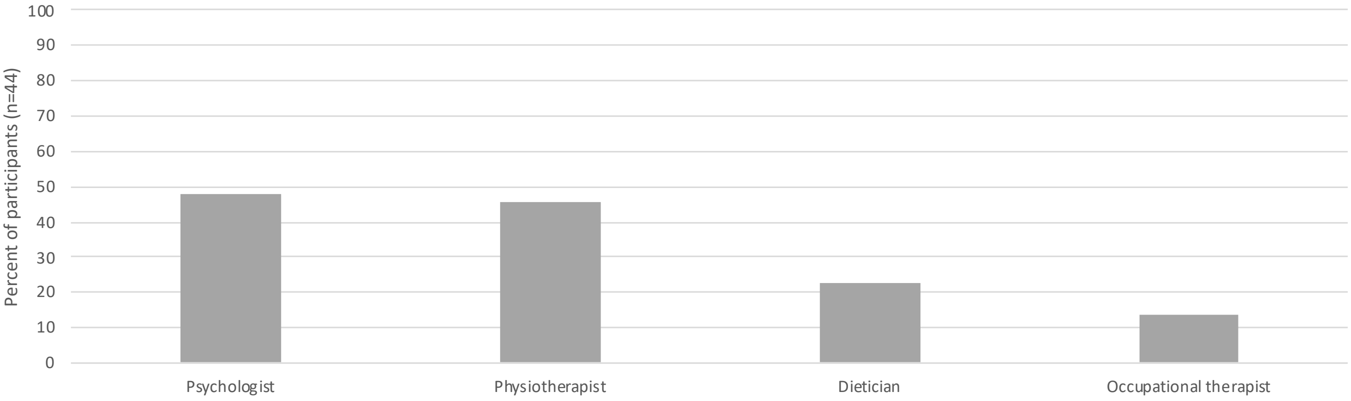


Figure 5.22: Allied health

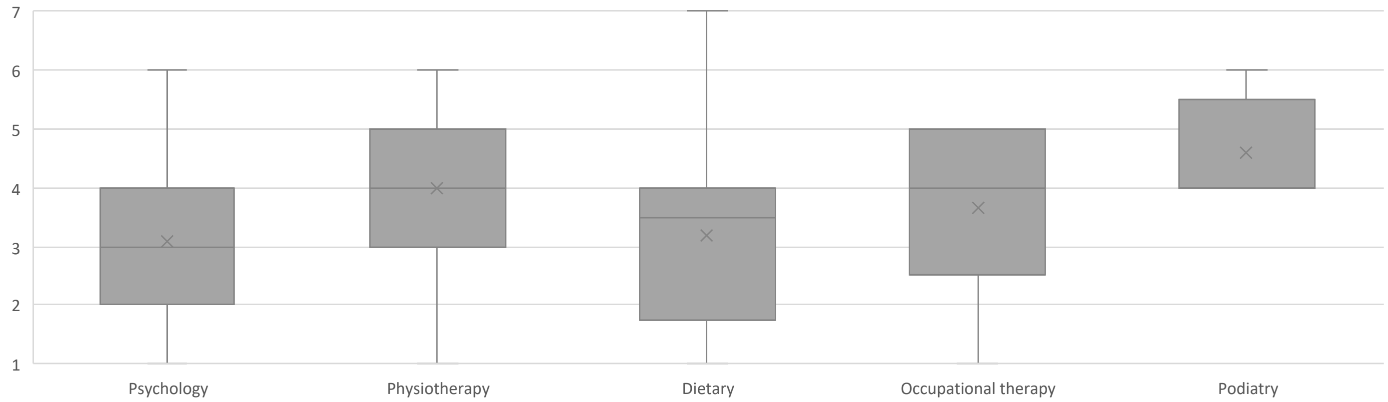


Figure 5.23: Quality of life from allied health

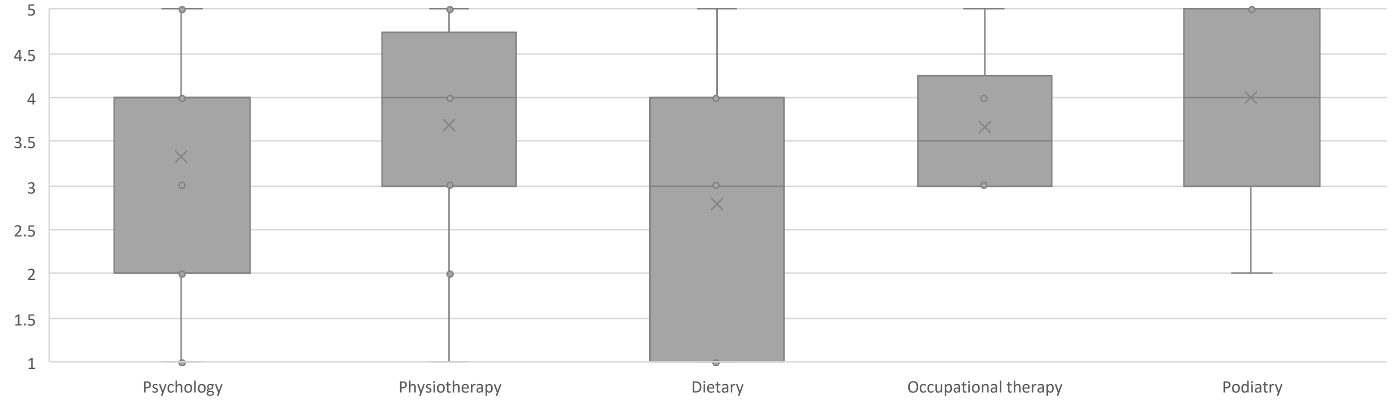


Figure 5.24: Effectiveness of allied health

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, Figures 5.25 to 5.27).

Most participants used at made at least one lifestyle change (n = 38, 86.36%), and on average made 2 changes (median = 2.00, IQR = 2.00).

The most common lifestyle change used was exercise (n = 28, 63.64%), followed by diet changes (n = 23, 52.27%), and reducing or stopping alcohol if applicable (n = 24, 54.55%) (Table 5.21, Figure 5.24).

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 = 4.00, IQR = 1.00).

On average, quality of life from exercise was in the 'life was average' range (median = 4.00, IQR = 1.50), and was found to be effective (median = 3.00, IQR = 1.00).

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

Table 5.19: Lifestyle changes

Lifestyle changes	Number (n=44)	Percent	Median quality of life	IQR	Median effectiveness	IQR
Exercise	28	63.64	4.00	2.00	4.00	1.00
Diet changes	23	52.27	4.00	1.50	3.00	1.00
Reduce alcohol (n=30)	24	54.55	4.00	4.00	5.00	4.00
Quit smoking (n=6)	2	4.55				

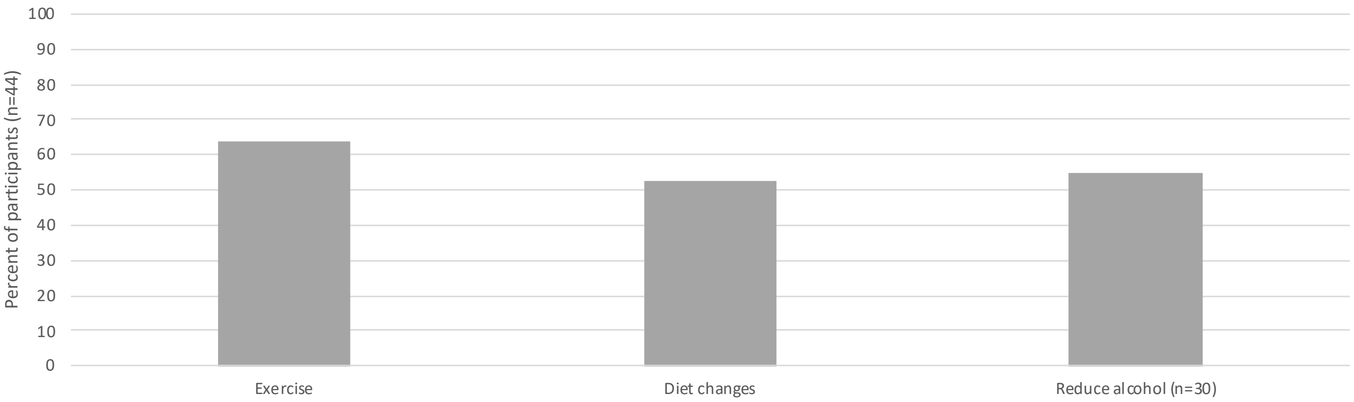


Figure 5.25: Lifestyle changes

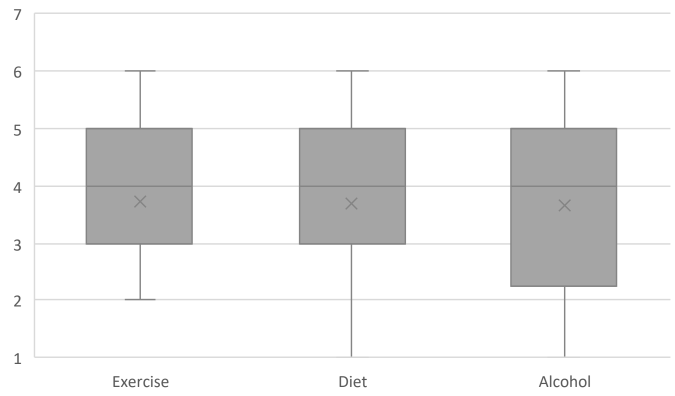


Figure 5.26: Quality of life from lifestyle changes

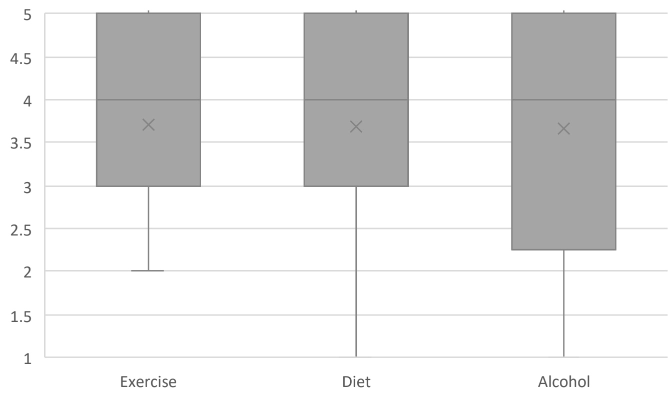


Figure 5.27: Effectiveness from lifestyle changes

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, Figures 5.28 to 5.30).

Most participants used at made at least one complementary therapy (n = 29, 65.91%), and on average used one therapy (median = 1.00, IQR = 2.00).

The most common complementary therapy used was mindfulness or relaxation techniques (n = 20, 45.45 %), followed by massage therapy (n = 17, 38.64%), and taking supplements (n = 16, 36.36%) (Table 5.21, Figure 5.24).

On average, quality of life from mindfulness or relaxation 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 massage therapy was in the 'life was average' range (median = 4.00, IQR = 1.00), and was found to be effective (median = 4.00, IQR = 2.00).

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 = 1.25).

Table 5.20: Complementary therapies

Complementary therapies	Number (n=44)	Percent	Median quality of life	IQR	Median effectiveness	IQR
Mindfulness or relaxation	20	45.45	3.00	2.00	4.00	1.00
Massage therapy	17	38.64	4.00	1.00	4.00	2.00
Supplements	16	36.36	4.00	2.00	3.00	1.25
Acupuncture	6	13.64	4.50	1.75	3.50	1.00
Naturopathy	5	11.36	4.00	5.00	1.00	2.00
Homeopathy	2	4.55	3.50	1.50	4.00	1.00

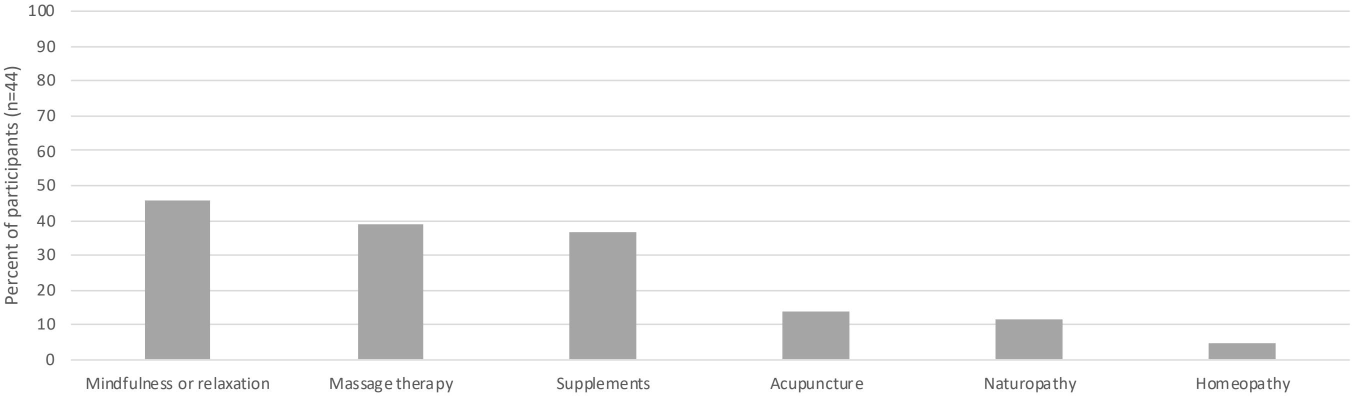


Figure 5.28: Complementary therapies

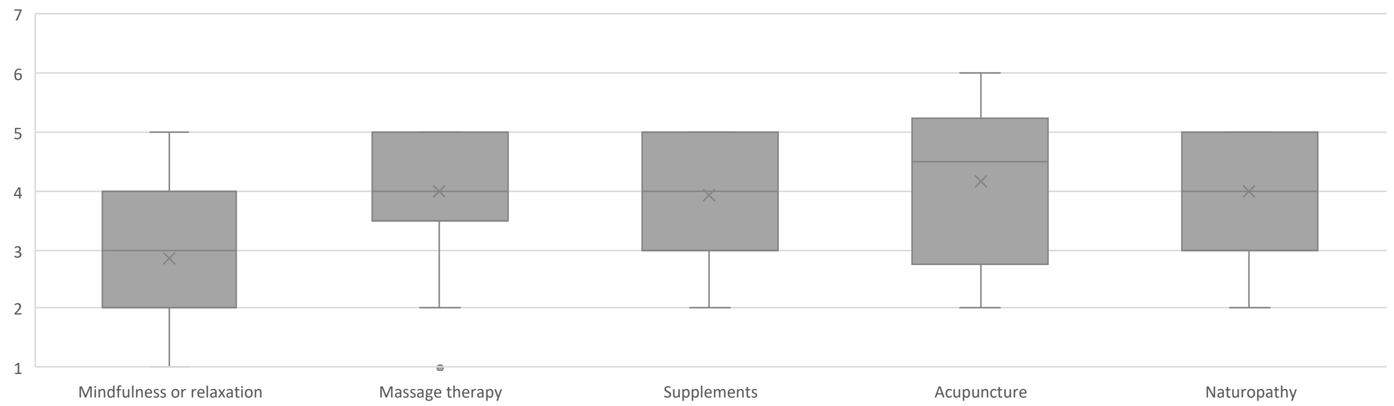


Figure 5.29: Quality of life from complementary therapies

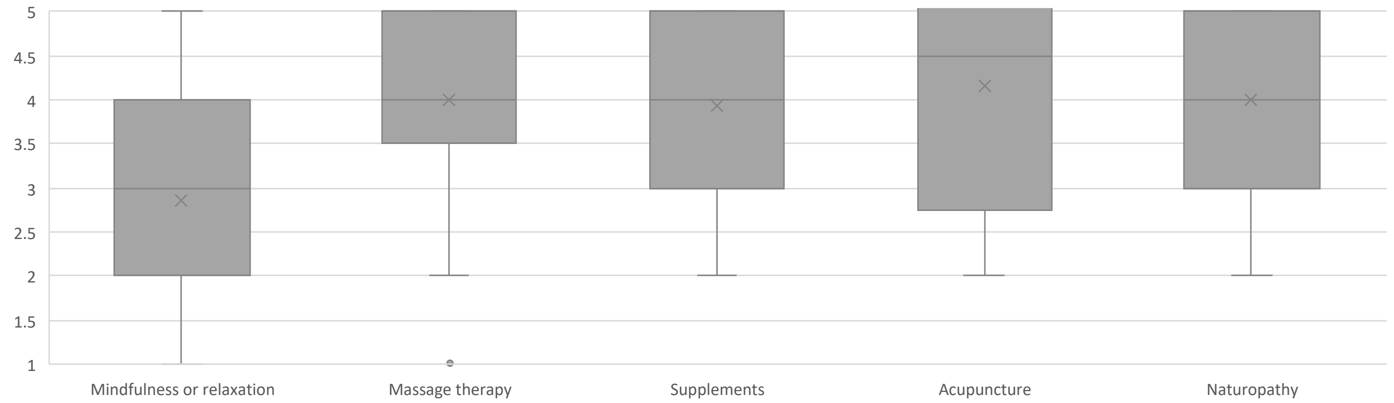


Figure 5.30: Effectiveness of complementary therapies

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 5.31).

There was a total of 16 participants (36.36%) that had discussions about clinical trials, six participants (13.64%) had brought up the topic with their doctor, and the doctor of 10 participants (22.77%) brought up the topic. The majority of participants had not spoken to anyone about clinical trials (n = 28, 63.64%).

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 5.32).

There were four participants (9.09%) who had taken part in a clinical trial, 32 participants (72.73%) who would like to take part in a clinical trial if there was a suitable one, and eight participants, who have not participated in a clinical trial and do not want to (18.18%).

Table 5.21: Clinical trial discussions

Clinical trial discussions	Number (n=44)	Percent
Participant brought up the topic of clinical trials doctor for discussion	6	13.64
Doctor brought up the topic of clinical trials for discussion	10	22.73
Participant has ever spoken to me about clinical trials	28	63.64

Table 5.22: Clinical trial participation

Clinical trial participation	Number (n=44)	Percent
Has not participated in a clinical trial and does not want to	8	18.18
Has not participated in a clinical trial but would like to if there is one	32	72.73
Has participated in a clinical trial	4	9.09

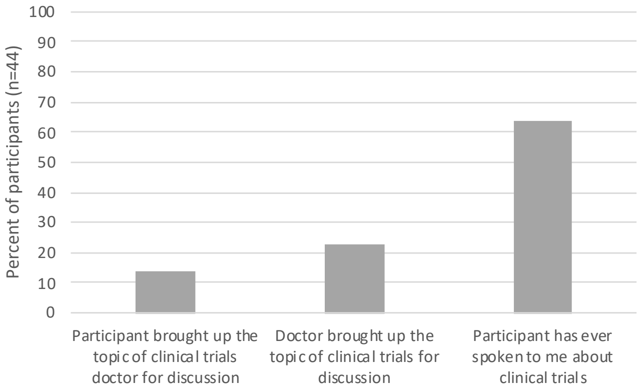


Figure 5.31: Clinical trial discussions

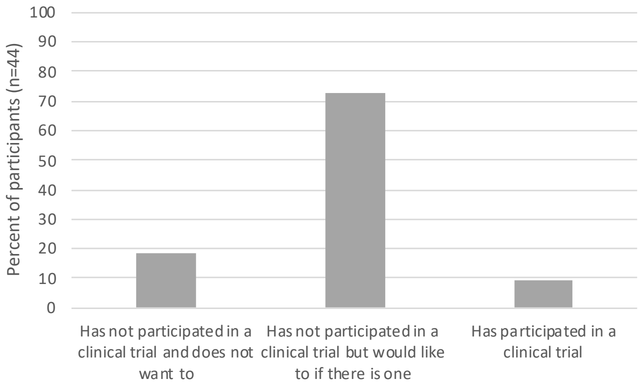


Figure 5.32: Clinical trial participation

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 those that are self managed or do not interfere with life (n=38, 76.00%), and others described mild side effects by using an example (n=21, 42.00%), or described them as side effects that could be managed with medications or treatment (n=5, 10.00%).

Where participants used an example to describe a mild side effect, this was most commonly nausea (n=10, 20.00%), followed by a feeling of discomfort (n=7, 10.00%).

Participant describes mild side effects as those that can be self-managed and do not interfere with daily life

Mild side effects…this is a good question. Mild side effects is an effect that you're aware of, that is impacting you, but it doesn't interfere with your day. You can still function, you can still get jobs done, you can still interact with people, but there's a background of discomfort. Participant_005

Oh, I guess it's hard because I got through it all. So it was all doable. And I guess you learn strategies that makes it more manageable. So they seem more mild. I guess things like the reflux, the nausea, the what else? Like losing your hair, I guess, in theory is a mild side effect. But if that had massive emotional and mental effects from it, I guess so. It's hard to try and categorise them separately. But I guess in theory that fits into both of the categories. Yeah, the fingernail changes. Yeah, I think they're more the mild ones, whereas the more severe ones, once again, I could say hair loss, but that was more to do with the emotional side of it. The fatigue was really hard and I had to manage that, especially being half naked. I was precancer that was really mentally challenging as well. And I had to really manage that. And then the peripheral neuropathy and the pain, that was another side effect. Participant_010

I would say mild side effects is something that I could deal with at home, something that could be managed with over-the-counter drugs and which didn't affect my quality of life Participant_016

Participant describes mild side effects giving the specific example of nausea

Some mild side effect is something that would not really affect your everyday living or life. You would still be able to have something for it like mild nausea, mild bone pain. You might be able to take a tablet and it would come better. For me, that's mild side effects. Participant_018

I guess mild side effects-- seems like the nausea where you feel bad, but it's not stopping you from going on with your day. You can work through it. It doesn't impede you. Participant_020

Oh, well, just maybe a bit of nausea. Yes, a little aches and pains. I'm pretty tough. Pain, it takes a bit to get me down, but yes, things off-color and headaches and the usual things. They weren't enormous compared to from what I've heard other people have, it was not enormous. Participant_032

Participant describes mild side effects giving the specific example of feeling of discomfort

I suppose to me, mild side effects would be feeling slightly off-color, maybe to do radiation just nothing that impeded my going on with daily life. I think mild side effects would be. Participant_004

Mild side effects to me would be still being able to go about your daily business, but just at a slower pace, and maybe you're feeling a bit uncomfortable. Participant_037

My minor discomfort or. Yeah, like the city I consider very mild. OK, yeah, I didn't really have any. It's not like I can say, oh yeah, I had ulcers in my mouth and that was really horrible. Participant_003

Participant describes mild side effects as those that can be managed with medications/treatment

I would say mild side effects is something that I could deal with at home, something that could be managed with over-the-counter drugs and which didn't affect my quality of life. Participant_016

Reactions to your body that can be treated or dealt with, with medicines or alternative treatments that can not impact your life. Participant_036

I think all of the side effects I had were mild, other than the bone pain that came with Taxol, that was awful. Mild was just anything that didn't really mess up with my day. I could still do things. There was never a day I didn't get out of bed, showered, dressed, and go about my day, ever. If that's the case, I think they were all mild. There was nothing that I couldn't cope with or needed to take to my bed. There was certain events I would have to cancel. I didn't feel like going out in the evenings and things like that. The symptoms were mild. There was nothing that required hospital treatment. There was nothing that required GP treatment. It was all manageable at home with over-the-counter medications and a few cuddles. Participant_033

Table 5.23: Description of mild side effects

Description of mild side effects	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=23	%	n=27	%	n=19	%	n=25	%	n=26	%	n=24	%	n=24	%	n=26	%
Participant describes mild side effects as those that can be self-managed and do not interfere with daily life	38	76.00	18	78.26	20	74.07	12	63.16	20	80.00	20	76.92	18	75.00	16	66.67	22	84.62
Participant provides a specific side effect as an example to describe mild side effects	21	42.00	11	47.83	10	37.04	7	36.84	11	44.00	11	42.31	10	41.67	12	50.00	9	34.62
Participant describes mild side effects as those that can be managed with medications/treatment	5	10.00	2	8.70	3	11.11	2	10.53	2	8.00	1	3.85	4	16.67	1	4.17	4	15.38

Description of mild side effects	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=23	%	n=27	%	n=19	%	n=25	%	n=26	%	n=24	%	n=24	%	n=26	%
Participant describes mild side effects as those that can be self-managed and do not interfere with daily life	38	76.00	18	78.26	20	74.07	12	63.16	20	80.00	20	76.92	18	75.00	16	66.67	22	84.62
Participant provides a specific side effect as an example to describe mild side effects	21	42.00	11	47.83	10	37.04	7	36.84	11	44.00	11	42.31	10	41.67	12	50.00	9	34.62
Participant describes mild side effects as those that can be managed with medications/treatment	5	10.00	2	8.70	3	11.11	2	10.53	2	8.00	1	3.85	4	16.67	1	4.17	4	15.38

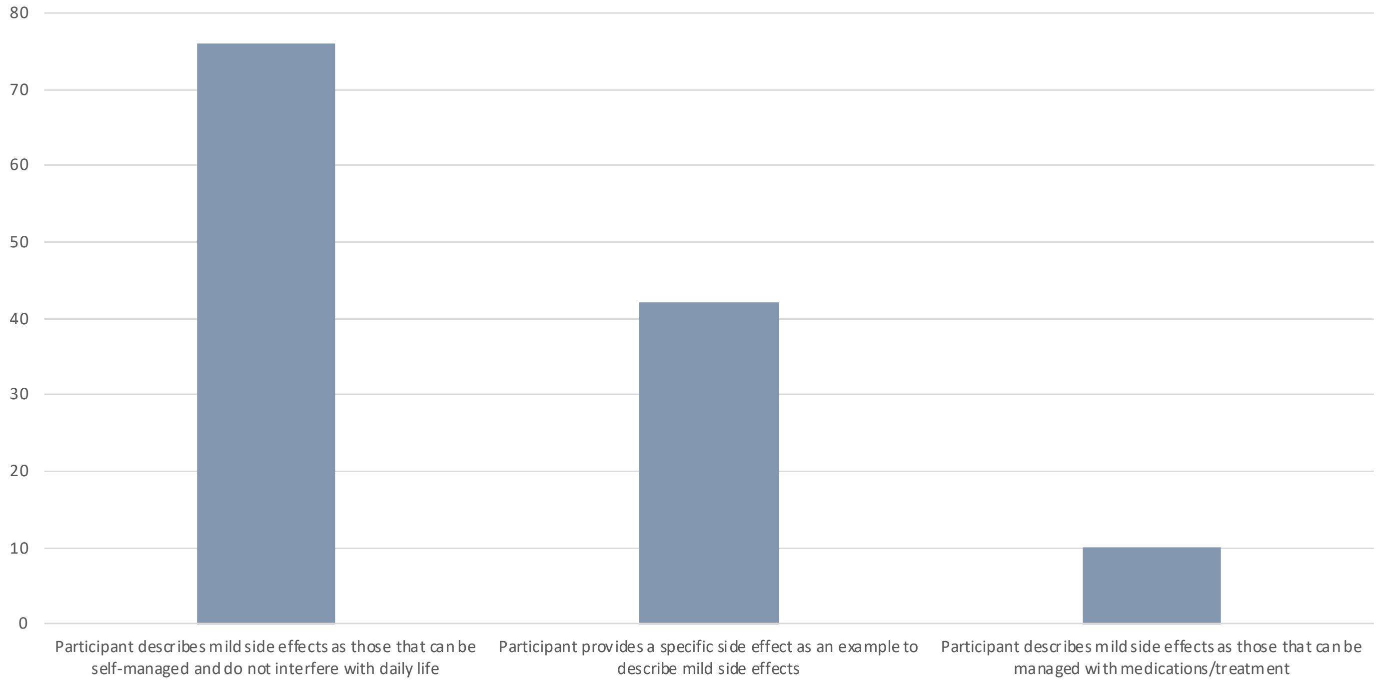


Figure 5.33: Description of mild side effects - percent of all participants

Table 5.24: Description of mild side effects - subgroup variations

Theme	Reported less frequently	Reported more frequently
Participant describes mild side effects as those that can be self-managed and do not interfere with daily life	Poor physical function Aged 45 to 54	Aged 25 to 44 Aged 55 to 74
Participant provides a specific side effect as an example to describe mild side effects	Aged 25 to 44 Aged 55 to 74	Aged 45 to 54

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

Description of mild side effects (Specific side effects)	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=23	%	n=27	%	n=19	%	n=25	%	n=26	%	n=24	%	n=24	%	n=26	%
Participant describes mild side effects giving the specific example of nausea	10	20.00	4	17.39	6	22.22	5	26.32	5	20.00	5	19.23	5	20.83	8	33.33	2	7.69
Participant describes mild side effects giving the specific example of feeling of discomfort	7	14.00	5	21.74	2	7.41	1	5.26	4	16.00	4	15.38	3	12.50	3	12.50	4	15.38

Description of mild side effects (Specific side effects)	All participants		Regional or remote		Metropolitan		Mid to low status		Higher status		Aged 25 to 44		Aged 45 to 54		Aged 55 to 74	
	n=50	%	n=16	%	n=34	%	n=20	%	n=30	%	n=19	%	n=22	%	n=9	%
Participant describes mild side effects giving the specific example of nausea	10	20.00	4	17.39	8	23.53	5	25.00	5	16.67	2	10.53	6	27.27	2	22.22
Participant describes mild side effects giving the specific example of feeling of discomfort	7	14.00	5	21.74	4	11.76	2	10.00	5	16.67	2	10.53	4	18.18	1	11.11

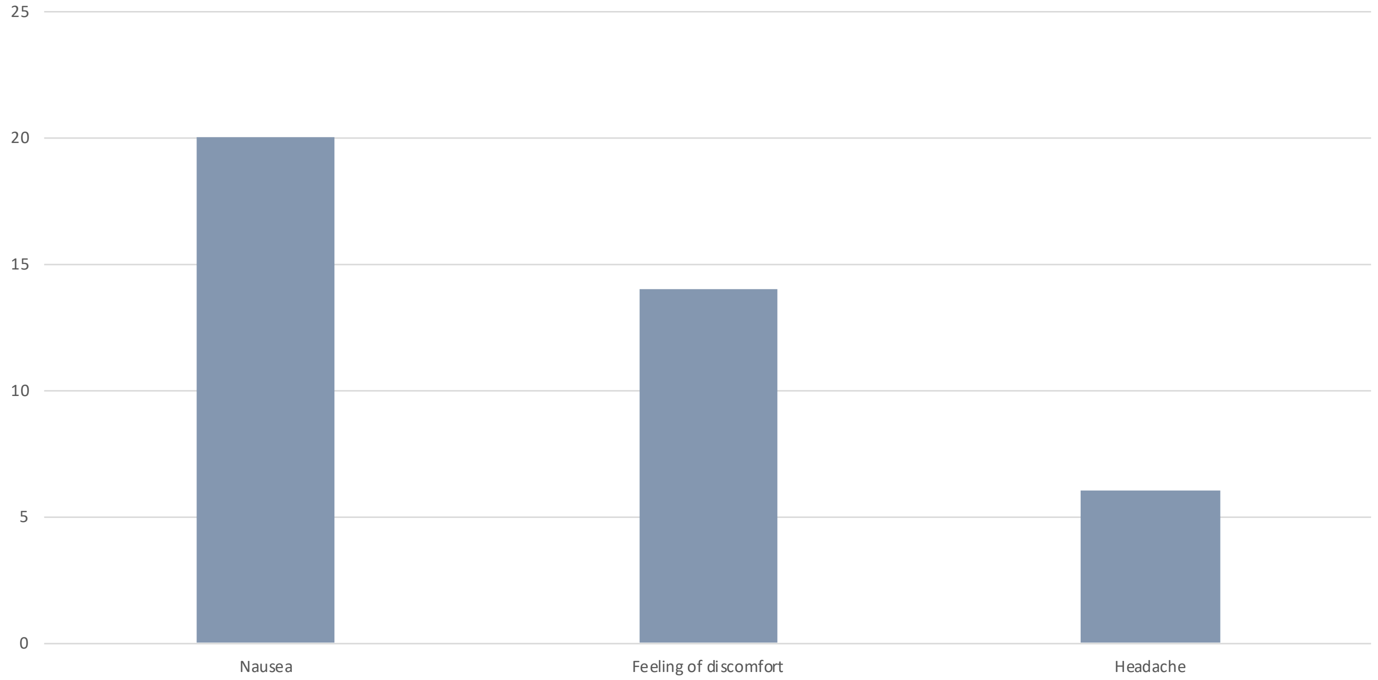


Figure 5.34: Description of mild side effects (Specific side effects) - percent of all participants

Table 5.26: Description of mild side effects (Specific side effects) – subgroup variations

Theme	Reported less frequently	Reported more frequently
Participant describes mild side effects giving the specific example of nausea	University	Trade or high school

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 side effects that impact everyday life, or ability to conduct daily living (n=34, 68.00%). Other descriptions of ‘severe side effects’ included using an example to describe severe side effects (n=28, 56.00%), and side effects that are life threatening, or require hospitalisation (n=7, 14.00%).

Of those who described a specific side effect, the most commonly described side effects were extreme or chronic pain (n=14, 28.00%), emotional or mental struggle (n=9, 18.00%), neuropathy (n=7, 14.00%), fatigue (n=6, 12.00%), and nausea and vomiting (n=5, 10.00%).

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

Severe would be not able to behave like your usual self. Irritable and tired and exhausted and not able to get the jobs done that you would need to get done.

Yes, lots of resting, and avoiding life. [chuckles] Participant_005

It's your new world so the side effects where you have to actually make changes to your life because you can't live your life as you used to before. Participant_008

Side effects that stop me from being able to participate in daily activities. For example, the couple of times that I got admitted to hospital where I just, for example, the episode of colitis that I had started off with bouts of diarrhea that were sending me to the toilet 14, 15 times a day where I was so ill, I couldn't lift my head off the pillow and ended up in hospital. I could have-- I was pretty well totally out of it. Participant_013

I would describe severe as, like you said, side effects that affected me, affected my ability to carry on daily activities, like brushing my teeth, going to the toilet, carrying on life as normal. Ones which gave me extremely severe fatigue. It was hard to even get out of the bed. Also, ones which had a more longer-term side effect. Participant_016

Participant describes severe side effects giving the specific example of extreme/chronic pain

A severe side effect would be something that would affect your life greatly, whether it's through pain or whatever. Pain where you would not be able to perform your day-to-day life, and taking medication for it would not help at all. Participant_018

The severe side effects were crippling. They messed with your mind in the sense that every part of your body ached from your toes to the top of your head and it was a [inaudible] pain. It was an internal pain and it was unbearable and as I said to several people, it's something I wouldn't wish on my worst enemy was to have to go through that kind of pain. Participant_027

Well, the pins and needles that it must still get bad cramps in my veins as well because of the pain pangs. And you and your breast. Yeah, from the surgery and stitches in the bone, which makes it hard to move around sometimes. So, yeah, and there's probably a few other ones, but also the thining of the skin from the chemotherapy I think can but also in the ear, in the bladder and the common area. Yet you became pretty quick Participant_031

Severe side effects to me would be uncontrolled nausea, uncontrolled pain, and immobility. Participant_037

Participant describes severe side effects giving the specific example of emotional/mental struggle

Oh, I guess it's hard because I got through it all. So it was all doable. And I guess you learn strategies that makes it more manageable. So they seem more mild. I guess things like the reflux, the nausea, the what else? Like losing your hair, I guess, in theory is a mild side effect. But if that had massive emotional and mental effects from it, I guess so. It's hard to try and categorise them separately. But I guess in theory that fits into both of the categories. Yeah, the fingernail changes. Yeah, I think they're more the mild ones, whereas the more severe ones, once again, I could say hair loss, but that was more to do with the emotional side of it. The fatigue was really hot and I had to manage that, especially being half naked. I was precancer that was really mentally challenging as well. And I had to really manage that. And then the peripheral neuropathy and the pain, that was another side effect. Participant_010

Severe side effects weren't pretty at all for me. Obviously, I had some very strong reactions. They were very hard for me to cope with mentally because I felt that I was putting a strain on my family. Having the cancer diagnosis is a hard enough thing to cope with when you have young children and a partner. Not that my kids were that young, but they were young enough for me to be concerned because you still want to do things. Having no energy, and having the reactions that I did like with the pneumonia, and the herniated disks, and the nerve damage, it was quite debilitating for me. As a mother, you feel like a failure because you can't do the things that you wanted to do, or need to do to provide for your family. Participant_022

There are two words in English, it was debilitating and another was, it sucks life out of you, you have no joy…You can't do anything, you're sad, yes, dark, sad, you can't do anything. Participant_042

Participant describes severe side effects as those that are life threatening or require hospitalisation

I would say about sort of let's call an ambulance. You need to get extra medical assistance. And yeah, well, I guess that's really super severe. But then severe is also when are just in constant pain. Extreme discomfort. Yes. Participant_001

I think severe side effects, as you said, would be side effects that I couldn't cope with on my own and would need to get help with either extra medication or be admitted to the hospital, to me that would be severe that I would have to ask for help. Participant_004

Severe to me, is when I need other help. When I can't cope with it at home or I need some medical input. For me, that would be more severe. If I can cope with it at home, it's not. Severe would be when I have to go and get some outside help to deal with something. Participant_033

Participant describes severe side effects giving the specific example of neuropathy

Like I just had the fecal impaction, that was pretty stressful. I was freaking out on a Sunday. I managed to calm myself down though. That was really bad. [unintelligible]. Oh, my God. I haven't been able to-- you can't eat. It's just, yes, they were horrible and they're so painful. There's hardly anything you could do for them, so yes, that's really bad. The neuropathy as well. My fingers and my fingertips and my toes are numb. I was feeling like my right hand is being quite painful as well with the neuropathy. I've tried to handle it to the best my ability, but it still-- I mean you drop things, you can't open things, it's hard to walk. It's actually quite stressful. Participant_028

When I say life, your activities that you did prior to your diagnosis. With my neuropathy, I can't walk around for extended periods of time without my feet becoming so painful. I used to run and walk with friends all the time. I can't do any of that. Participant_029

The diarrhoea was definitely the worst. Never knowing where you when you would have to go to the toilet, having to keep, you know, change of clothes in my office at work, having to take change of clothes in my car, having to make sure that you're at a you go out to dinner, you know where the toilets are located. That was for the diarrhoea. But the neuropathy was really hard to cope with when you got no feelings in your fingers and toes, you couldn't I couldn't pick anything up off the table. You know, you couldn't hold a pen, things like that. That sounds quite severe. Participant_049

Participant describes severe side effects giving the specific example of fatigue

Severe would be not able to behave like your usual self. Irritable and tired and exhausted and not able to get the jobs done that you would need to get done. Yes, lots of resting, and avoiding life. [chuckles] Participant_005

Yes, I still have some. I still have the chronic pain and the fatigue that slides me right down and for someone with four children and a full-time job, I can't function. I can't do what I'm supposed to do. That's what I would call a severe side effect. Participant_012

I would describe severe as, like you said, side effects that affected me, affected my ability to carry on daily activities, like brushing my teeth, going to the toilet, carrying on life as normal. Ones which gave me extremely severe fatigue. It was hard to even get out of the bed. Also, ones which had a more longer-term side effect. Participant_016

Participant describes severe side effects giving the specific example of nausea/vomiting

Exactly what I had on AC, where I was nauseous and felt like I needed to vomit and I couldn't. I had a high temperature. I found it difficult to get out of bed. The mouth sores made it very difficult to eat, so it was very uncomfortable and painful. It hurt to speak. Sorry, I've blocked it out a bit, I think. The reflux was horrendous. Couldn't brush my teeth. It was difficult. You just feel it all the time, so uncomfortable. That's that. Participant_007

Severe side effects to me would be uncontrolled nausea, uncontrolled pain, and immobility. Participant_037

I think that would be like vomiting all the time and I didn't have any of that. I think I thought that that's what was going to happen when they said, "You might get sick and you might have really bad diarrhea." I thought it was going to be coming from both ends and you'd be green like they are on TV, whereas I didn't have that. Sorry. [laughs] Participant_045

Table 5.27: Description of severe side effects

Description of severe side effects	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=23	%	n=27	%	n=19	%	n=25	%	n=26	%	n=24	%	n=24	%	n=26	%
Participant describes severe side effects as those that impact everyday life/ability to conduct activities of daily living	34	68.00	17	73.91	17	62.96	13	68.42	17	68.00	**15**	**57.69**	**19**	**79.17**	14	58.33	20	76.92
Participant provides a specific side effect as an example to describe severe side effects	28	56.00	**16**	**69.57**	**12**	**44.44**	**13**	**68.42**	12	48.00	12	46.15	**16**	**66.67**	14	58.33	14	53.85
Participant describes severe side effects as those that are life threatening or require hospitalisation	7	14.00	5	21.74	2	7.41	3	15.79	3	12.00	3	11.54	4	16.67	2	8.33	5	19.23

Description of severe side effects	All participants		Regional or remote		Metropolitan		Mid to low status		Higher status		Aged 25 to 44		Aged 45 to 54		Aged 55 to 74	
	n=50	%	n=16	%	n=34	%	n=20	%	n=30	%	n=19	%	n=22	%	n=9	%
Participant describes severe side effects as those that impact everyday life/ability to conduct activities of daily living	34	68.00	**13**	**81.25**	21	61.76	12	60.00	22	73.33	14	73.68	14	63.64	6	66.67
Participant provides a specific side effect as an example to describe severe side effects	28	56.00	9	56.25	19	55.88	12	60.00	16	53.33	10	52.63	14	63.64	**4**	**44.44**
Participant describes severe side effects as those that are life threatening or require hospitalisation	7	14.00	**4**	**25.00**	3	8.82	4	20.00	3	10.00	**0**	**0.00**	5	22.73	2	22.22

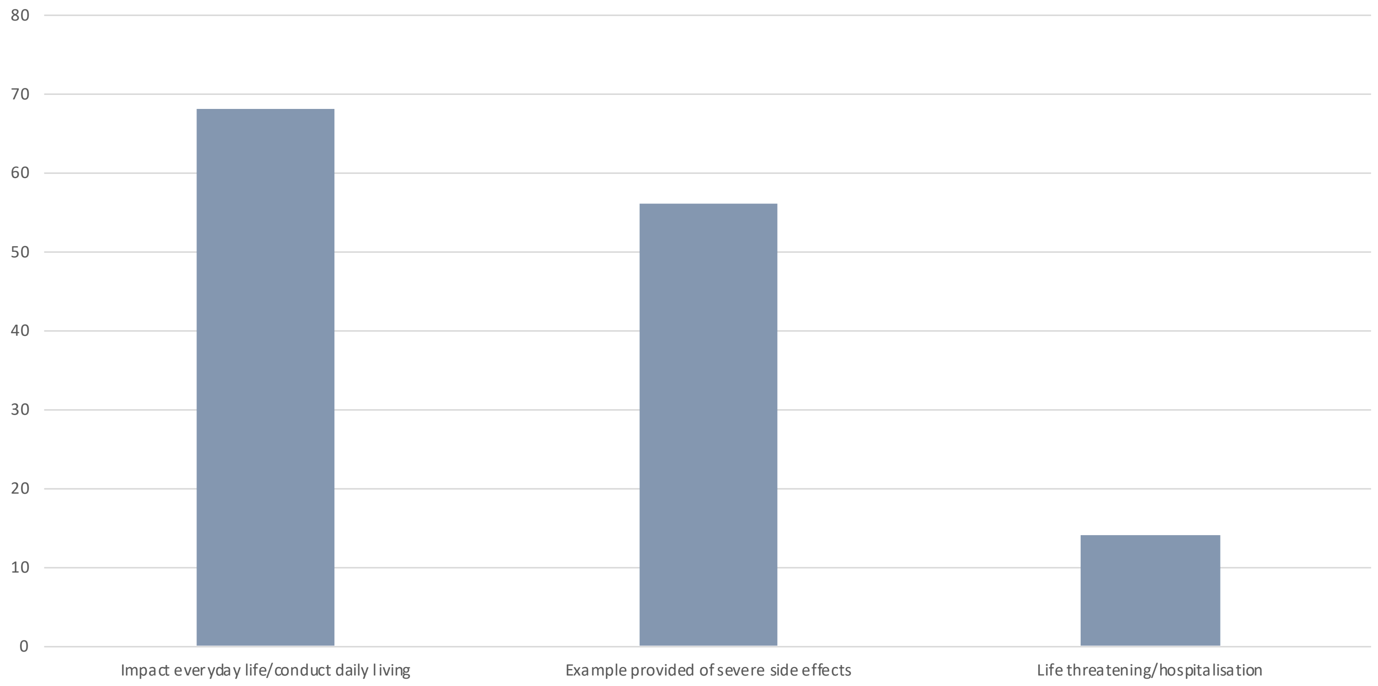


Figure 5.35: Description of severe side effects - percent of all participants

Table 5.28: Description of severe side effects – subgroup variations

Theme	Reported less frequently	Reported more frequently
Participant describes severe side effects as those that impact everyday life/ability to conduct activities of daily living	Diagnosed before 2020	Diagnosed in 2020 or 2021 Regional or remote
Participant provides a specific side effect as an example to describe severe side effects	Advanced breast cancer Aged 55 to 74	Early breast cancer Poor physical function Diagnosed in 2020 or 2021
Participant describes severe side effects as those that are life threatening or require hospitalisation	Aged 25 to 44	Regional or remote

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

Description of severe side effects (Specific example)	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=23	%	n=27	%	n=19	%	n=25	%	n=26	%	n=24	%	n=24	%	n=26	%
Participant describes severe side effects giving the specific example of extreme/chronic pain	14	28.00	6	26.09	8	29.63	6	31.58	6	24.00	6	23.08	8	33.33	9	37.50	5	19.23
Participant describes severe side effects giving the specific example of emotional/mental struggle	9	18.00	3	13.04	6	22.22	3	15.79	6	24.00	5	19.23	4	16.67	2	8.33	7	26.92
Participant describes severe side effects giving the specific example of neuropathy	7	14.00	3	13.04	4	14.81	4	21.05	3	12.00	3	11.54	4	16.67	5	20.83	2	7.69
Participant describes severe side effects giving the specific example of fatigue	6	12.00	6	26.09	0	0.00	2	10.53	2	8.00	4	15.38	2	8.33	4	16.67	2	7.69
Participant describes severe side effects giving the specific example of nausea/vomiting	5	10.00	1	4.35	4	14.81	2	10.53	2	8.00	3	11.54	2	8.33	2	8.33	3	11.54

Description of severe side effects (Specific example)	All participants		Regional or remote		Metropolitan		Mid to low status		Higher status		Aged 25 to 44		Aged 45 to 54		Aged 55 to 74	
	n=50	%	n=16	%	n=34	%	n=20	%	n=30	%	n=19	%	n=22	%	n=9	%
Participant describes severe side effects giving the specific example of extreme/chronic pain	14	28.00	4	25.00	10	29.41	4	20.00	10	33.33	5	26.32	7	31.82	2	22.22
Participant describes severe side effects giving the specific example of emotional/mental struggle	9	18.00	1	6.25	8	23.53	5	25.00	4	13.33	4	21.05	4	18.18	1	11.11
Participant describes severe side effects giving the specific example of neuropathy	7	14.00	0	0.00	7	20.59	1	5.00	6	20.00	0	0.00	4	18.18	3	33.33
Participant describes severe side effects giving the specific example of fatigue	6	12.00	3	18.75	3	8.82	4	20.00	2	6.67	3	15.79	3	13.64	0	0.00
Participant describes severe side effects giving the specific example of nausea/vomiting	5	10.00	0	0.00	5	14.71	1	5.00	4	13.33	1	5.26	4	18.18	0	0.00

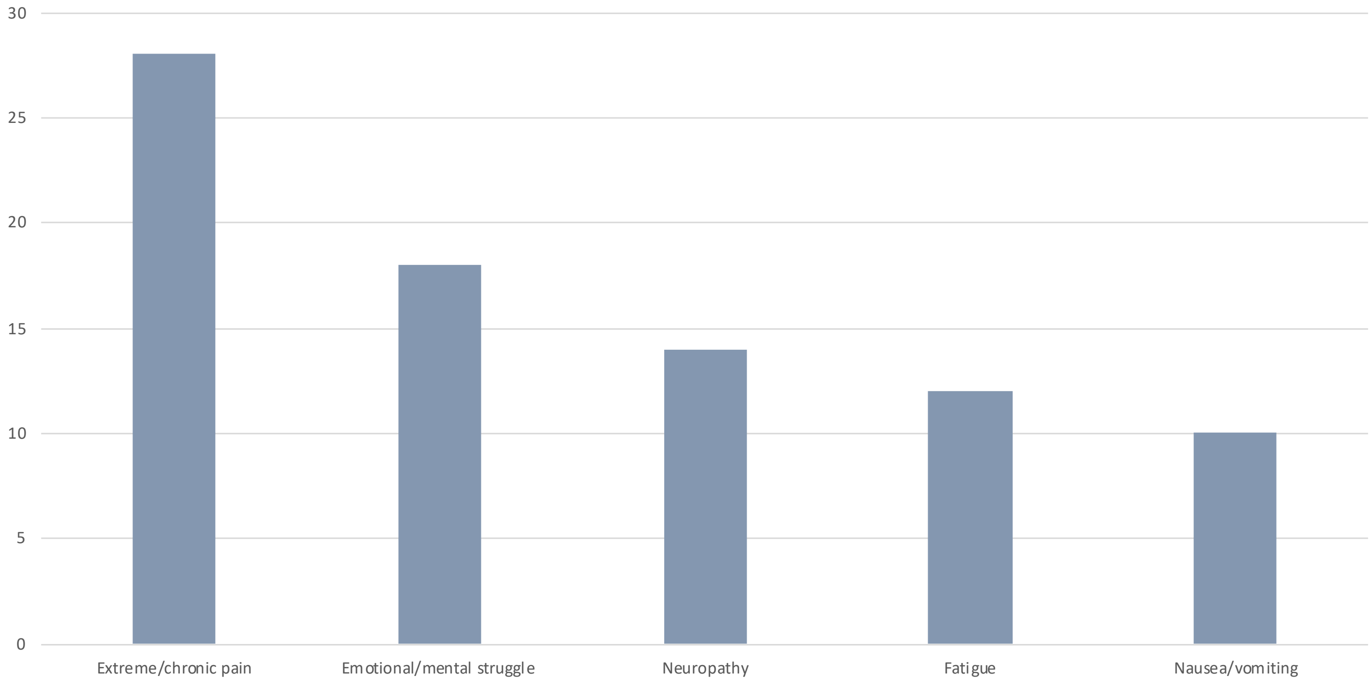


Figure 5.36: Description of severe side effects (Specific example) - percent of all participants

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

Theme	Reported less frequently	Reported more frequently
Participant describes severe side effects giving the specific example of emotional/mental struggle	Regional or remote	-
Participant describes severe side effects giving the specific example of neuropathy	Regional or remote Aged 25 to 44	Aged 55 to 74
Participant describes severe side effects giving the specific example of fatigue	Advanced breast cancer Aged 55 to 74	Early breast cancer

Adherence to treatment

Participants were asked in the structured interview what influences their decision to continue with a treatment regime. The most common theme described were taking the advice of specialist, or taking it as prescribed (n=27, 54.00%). This was followed by participants describing not giving up on any treatment (n=16, 32.00%), taking treatments for a specific amount of time (n=13, 26.00%), seeing test results with no evidence of disease or reduction of disease (n=8, 16.00%), and as long as side effects tolerable (n=7, 14.00%).

Where participants stated a specific amount of time to adhere to a treatment, the most common amount of time was one week.

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

If I don't think it's working, I don't know. I would keep going with it because I wouldn't, I wouldn't assume that I knew if it was working or not. OK, so I think I would stick with it, although I did refuse some medication they would of after my surgery. So I was being offered drugs for pain relief, but I researched side effects and so I just didn't want to take it. So I refused drugs. But pain relief, I wouldn't. I would. I trusted my oncologist. Participant_001

Would depend on the medication and what they what the medical advice was about, how long it takes to work. For example, if I said it takes three months to work on what if it wasn't working the way it was, like if you were hoping that it came to spread after three months and that's not what we need. Participant_002

If it's something that I can order in bulk, I normally order bulk, so I can try it. I've got a very close relationship with my GP. Anything that I've tried, I've discussed with him about, how long I should take it and to give that a try. It's usually at least three or four months that I've done something for. Participant_008

Participant describes not giving up on any treatment

My treatment, I was never going to quit it. I was never going to say after round three of chemo, this is too much or I don't think it's working. And I was not I wouldn't never would never have considered stopping. Participant_003

I'm not going to give up on it because I have a 10-year-old daughter, so we were just going to persevere. Participant_007

I've been lucky that everything that I've been given has not really been an issue, so I haven't had to give up on it as such. I've known there's an end date or whatever with chemo, in particular. Everything else, I haven't really gone, "I can't do this anymore Participant_021

Participant describes adhering to treatment for a specific amount of time

Would depend on the medication and what they what the medical advice was about, how long it takes to work. For example, if I said it takes three months to work on what if it wasn't working the way it was, like if you were hoping that it came to spread after three months and that's not what we need. Participant_002

Oh. I try really hard not to give up on it. Because mine was triple-negative, I haven't had to do any of the hormone replacement side of things, like long term, so I'm not currently on any medications for cancer. I think it would really need to be some severe side effects, but I would have those discussions with my specialist and see what other medications they can prescribe to help with those side effects so that you can continue doing it. I think at the end of the day, the decisions all need to be based off of if they give me the best chance of living. Participant_025

Probably a few weeks, depending on what it is like. You've got to look at what you take and why you're taking it and how long your fixes to take it anymore. But, you know, when you should see an improvement or whether you should say that it's making some sort of benefit. So you've got to go through all of that size before you can, that this isn't for me. Participant_044

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

I don't really given up on anything, I don't think, except for maybe the Taxol, the Paclitaxel, because I was getting neuropathy so they had to stop that. I still take Endone occasionally if I'm in a lot of pain. Participant_028

I feel like I manage pain better than nausea. So whenever I'm given pain medication and I take antiemetic with it, but if it still makes me sick, I want the animatics off in my sleep. And I don't like that feeling and I don't like the feeling of sleeping tablets and I don't sleep well. But I think that that's just that's my choice. I don't like I feel like I'm hung over the next day if I take some medication Participant_038

Table 5.31: Adherence to treatment

Adherence to treatment	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=23	%	n=27	%	n=19	%	n=25	%	n=26	%	n=24	%	n=24	%	n=26	%
Participant describes adhering to treatment as per the advice of their specialist/as long as prescribed	27	54.00	12	52.17	15	55.56	10	52.63	15	60.00	15	57.69	12	50.00	10	41.67	17	65.38
Participant describes not giving up on any treatment	16	32.00	8	34.78	8	29.63	7	36.84	8	32.00	8	30.77	8	33.33	8	33.33	8	30.77
Participant describes adhering to treatment for a specific amount of time	13	26.00	7	30.43	6	22.22	7	36.84	5	20.00	7	26.92	6	25.00	7	29.17	6	23.08
Participant describes needing to see test results/no evidence or reduction of disease in order to adhere to treatment	8	16.00	2	8.70	6	22.22	2	10.53	4	16.00	4	15.38	4	16.67	1	4.17	7	26.92
Participant describes adhering to treatment as long as side effects are tolerable	7	14.00	3	13.04	4	14.81	3	15.79	3	12.00	5	19.23	2	8.33	3	12.50	4	15.38

Adherence to treatment	All participants		Regional or remote		Metropolitan		Mid to low status		Higher status		Aged 25 to 44		Aged 45 to 54		Aged 55 to 74	
	n=50	%	n=16	%	n=34	%	n=20	%	n=30	%	n=19	%	n=22	%	n=9	%
Participant describes adhering to treatment as per the advice of their specialist/as long as prescribed	27	54.00	8	50.00	19	55.88	9	45.00	18	60.00	11	57.89	9	40.91	7	77.78
Participant describes not giving up on any treatment	16	32.00	5	31.25	11	32.35	4	20.00	12	40.00	7	36.84	3	13.64	6	66.67
Participant describes adhering to treatment for a specific amount of time	13	26.00	4	25.00	9	26.47	6	30.00	7	23.33	5	26.32	7	31.82	1	11.11
Participant describes needing to see test results/no evidence or reduction of disease in order to adhere to treatment	8	16.00	4	25.00	4	11.76	4	20.00	4	13.33	2	10.53	6	27.27	0	0.00
Participant describes adhering to treatment as long as side effects are tolerable	7	14.00	2	12.50	5	14.71	4	20.00	3	10.00	3	15.79	2	9.09	2	22.22

Figure 5.37: Adherence to treatment - percent of all participants

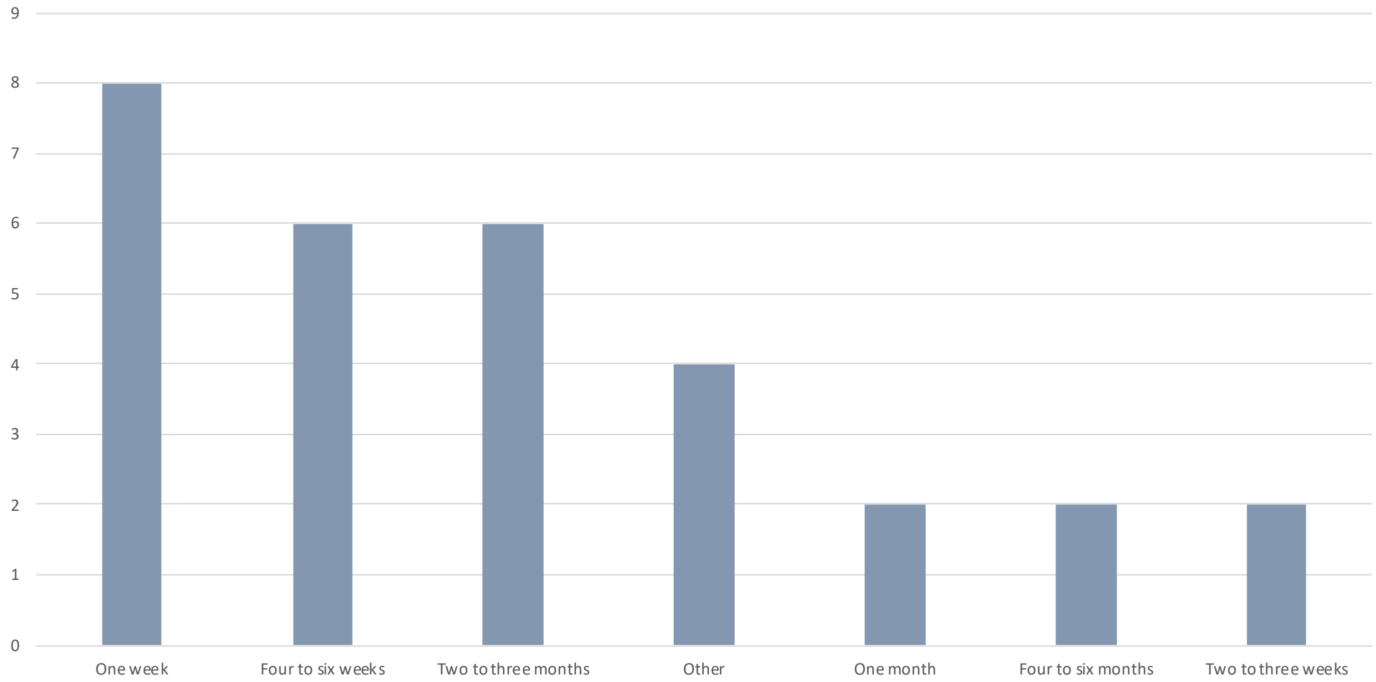


Figure 5.38: Adherence to treatment (Time to adhere to treatment)

Table 5.32: Adherence to treatment – subgroup variations

Theme	Reported less frequently	Reported more frequently
Participant describes adhering to treatment as per the advice of their specialist/as long as prescribed	Trade or high school Aged 45 to 54	University Aged 55 to 74
Participant describes not giving up on any treatment	Mid to low status Aged 45 to 54	Aged 55 to 74
Participant describes adhering to treatment for a specific amount of time	Aged 55 to 74	Poor physical function
Participant describes needing to see test results/no evidence or reduction of disease in order to adhere to treatment	Trade or high school Aged 55 to 74	University Aged 45 to 54

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 21 participants (42%) who described the reduction or disappearance of physical signs and symptoms. There were 17 participants (34%) who described seeing positive results of tests, or scans showing disease reduction, eight participants (16%) who described seeing evidence of stable disease, or no disease progression, and six participants (12.00%) who described needing to return to day-to-day functionality.

Where participants described seeing reduction in specific signs and symptoms, this was most commonly a reduction in pain levels (n=10, 20.00%), and a reduction in nausea (n=7, 14.00%).

Participants reported needing to see physical signs and symptoms disappear/reduced

I generally just observe over time my symptoms and how I'm feeling. Then if I don't feel like it's changing, then I probably speak to my GP and even speak to my psychologist or what have you. They've helped me realize sometimes that it's actually not working. There's some things I've taken that I hadn't really realized that, of course, they're not working, but they aren't. Participant_008

Yes, so reduction in pain, visually reduction in, for example, the tumor when they did ultrasounds, reduction in size of it. Also, a palpable time is when I couldn't feel the lump anymore physically myself, or if my doctor said, "Good job, we can't feel the lumps anymore." Those things, so clinical markers, physically feeling better, absence of pain and inflammation. Participant_016

It's hard. For me, I need facts to know that it's working. I need scans, I need reports, that thing, whereas you just don't know. That's probably the hardest thing about this whole thing, is you just don't know that it's worked unless there's been a physical change. Participant_030

Symptoms, so either less nausea or less rashes or less visible and physical symptoms Participant_036

Participants reported needing to see positive results of tests/or scan showing disease reduction

PARTICIPANT: Surgery is you go in and you have it and you're out. Decision on which surgery has it be cool. INTERVIEWER: When you take any medication, what is it that you're looking for that helps you indicate if it's working or not? Is it reduction in why you're taking it? What treatment are you looking for? Changes in your blood results or imaging?
PARTICIPANT: Yes. I guess from that point of view, your [unintelligible] changes in your blood results, the [unintelligible] was making sure you had the white blood cells to make sure I had enough ready to go to the next one. See, I didn't take much treatment. I took the supplements, and anti-nausea, those tablets I took them then that they had to stop the nausea. I just took them as much as I could. The constipation, the tablets that you took for that, you were trying to make sure that your bowels were operating. That was having a physical effect on you. The only other medication I took was the reflux medication, and that was to relieve the pain. There was a physical response to that as well. Participant_047

I'd look at the scan results, or I'd look at the blood test results and any other ways that they were for measuring its effectiveness. Participant_050

Yes, so reduction in pain, visually reduction in, for example, the tumor when they did ultrasounds, reduction in size of it. Also, a palpable time is when I couldn't feel the lump anymore physically myself, or if my doctor said, "Good job, we can't feel the lumps anymore." Those things, so clinical markers, physically feeling better, absence of pain and inflammation. Participant_016

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

I guess evidence of disease progression, that would be my primary thing, I wouldn't just judge if it was working or not buy side effects or symptoms. Participant_001

Well, I have no visibility of whether somethings working because they got all the lump out and I just had to have faith that it's doing something to make sure that there's no more cancer growing. Participant_007

Well, it's one for me. I never knew throughout the journey whether it was working or not, what they could test, anything to say it's working, the cancer's shrunk or anything like that, because I had a lumpectomy and then it was just let's just kill your body, fill it with poison to get any stragglers. I knew after my lumpectomy and sentinel node was removed that it hadn't spread to any other nodes. So that was a good thing. Participant_003

Participants reported needing to experience a return to day-to-day functionality

That would've been amazing. I would have been able to, I think, eat better, and just generally, I don't know, be part of my family better if you know what I mean. Take part in family life. Participant_004

It would. Being able to take that medication helped my quality of life. It allowed me to get out of the house and socialise with friends. It allowed me to go for walks on the beach on really good days. It meant that I could exercise to the point of going for a run or going for a swim during treatment. I had my 30th birthday, so it meant that I was able to still go out to dinner with friends and enjoy those kinds of things. It also meant that I wasn't sleeping all day, every day, and I was able to do activities to distract myself or to find joy in my every day during treatment. Participant_010

It means I can live normally. It means I can get in my car and drive, I can go to work and do my job properly. It means I can exercise to a similar level to what I was doing before. It means I can live my life how I did before I got cancer. Participant_020

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		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=23	%	n=27	%	n=19	%	n=25	%	n=26	%	n=24	%	n=24	%	n=26	%
Participants reported needing to see physical signs and symptoms disappear/reduced	21	42.00	10	43.48	11	40.74	9	47.37	**7**	**28.00**	9	34.62	12	50.00	9	37.50	12	46.15
Participants reported needing to see positive results of tests/or scan showing disease reduction	17	34.00	8	34.78	9	33.33	8	42.11	7	28.00	8	30.77	9	37.50	**5**	**20.83**	**12**	**46.15**
Participants reported needing to experience evidence of stable disease/no disease progression	8	16.00	4	17.39	4	14.81	4	21.05	3	12.00	5	19.23	3	12.50	2	8.33	6	23.08
Participants reported needing to experience a return to day-to-day functionality	6	12.00	3	13.04	3	11.11	2	10.53	4	16.00	2	7.69	4	16.67	**6**	**25.00**	**0**	**0.00**

What needs to change to feel like treatment is working	All participants		Regional or remote		Metropolitan		Mid to low status		Higher status		Aged 25 to 44		Aged 45 to 54		Aged 55 to 74	
	n=50	%	n=16	%	n=34	%	n=20	%	n=30	%	n=19	%	n=22	%	n=9	%
Participants reported needing to see physical signs and symptoms disappear/reduced	21	42.00	**10**	**62.50**	11	32.35	8	40.00	13	43.33	**10**	**52.63**	10	45.45	**1**	**11.11**
Participants reported needing to see positive results of tests/or scan showing disease reduction	17	34.00	5	31.25	12	35.29	**4**	**20.00**	13	43.33	8	42.11	**5**	**22.73**	**4**	**44.44**
Participants reported needing to experience evidence of stable disease/no disease progression	8	16.00	4	25.00	4	11.76	4	20.00	4	13.33	**1**	**5.26**	5	22.73	2	22.22
Participants reported needing to experience a return to day-to-day functionality	6	12.00	1	6.25	5	14.71	1	5.00	5	16.67	2	10.53	1	4.55	**3**	**33.33**

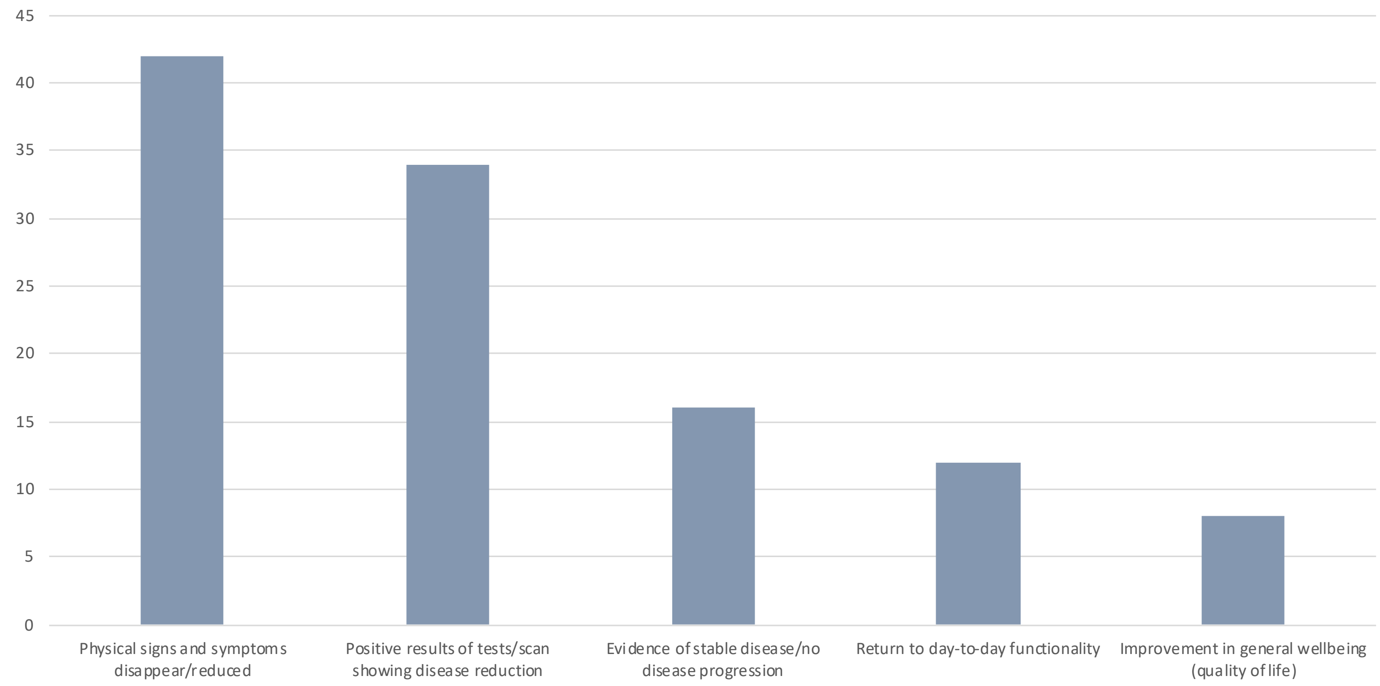


Figure 5.39: What needs to change to feel like treatment is working - percent of all participants

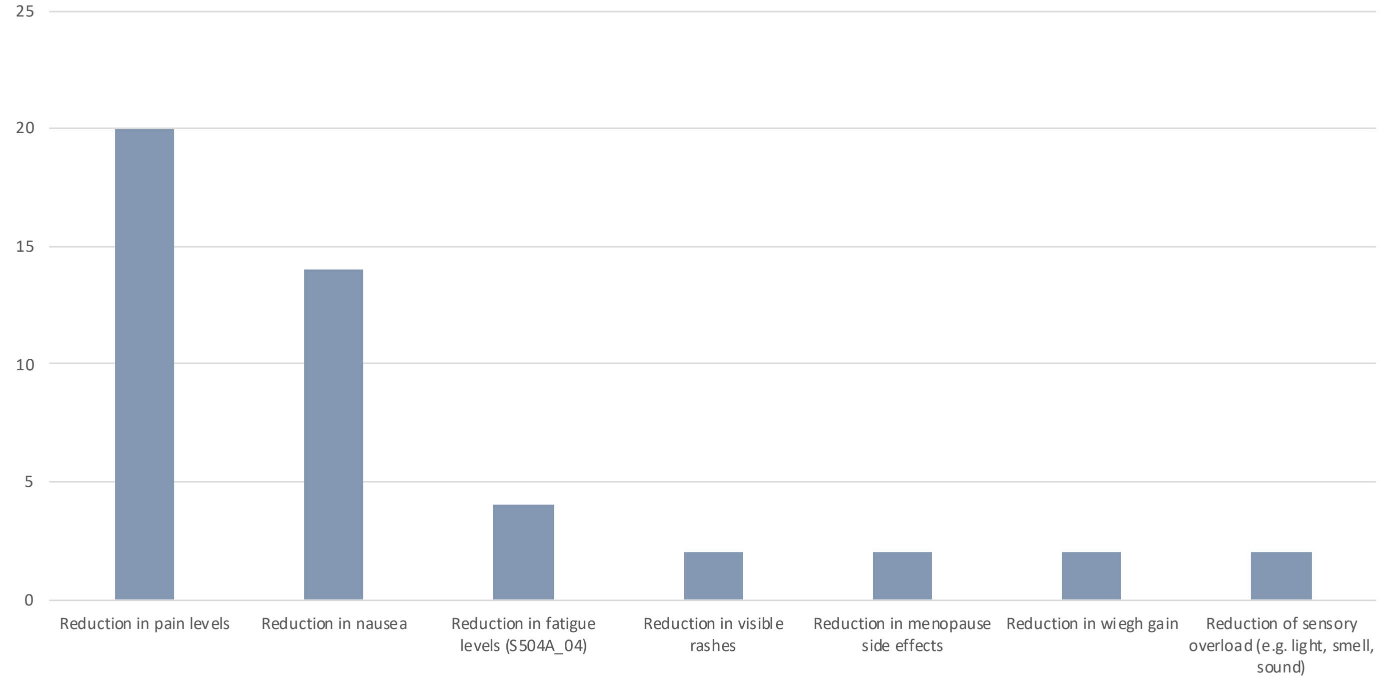


Figure 5.40: What needs to change to feel like treatment is working (specific symptoms) - percent of all participants

Table 5.34: What needs to change to feel like treatment is working – subgroup variations

Theme	Reported less frequently	Reported more frequently
Participants reported needing to see physical signs and symptoms disappear/reduced	Good physical function Aged 55 to 74	Regional or remote Aged 25 to 44
Participants reported needing to see positive results of tests/or scan showing disease reduction	Trade or high school Mid to low status Aged 45 to 54	University Aged 55 to 74
Participants reported needing to experience evidence of stable disease/no disease progression	Aged 25 to 44	-
Participants reported needing to experience a return to day-to-day functionality	University	Trade or high school Aged 55 to 74

What it would mean if treatment worked

Participants were asked what it would mean for them in their everyday life if treatment worked. The most common response from 35 participants (70.00%) was that it would allow them to do everyday activities, or return to normal life. Other responses included being able to engage more with social activities and family life (n=14, 28.00%), a reduction in symptoms and side effects (n=11, 22.00%), the ability to return to work (n=7, 14.00%), and allowing them to do domestic tasks (n=6, 12.00%).

Participant describes treatment allowing them to do everyday activities/ return to normal life

That would've been amazing. I would have been able to, I think, eat better, and just generally, I don't know, be part of my family better if you know what I mean. Take part in family life. Participant_004

It would. Being able to take that medication helped my quality of life. It allowed me to get out of the house and socialise with friends. It allowed me to go for walks on the beach on really good days. It meant that I could exercise to the point of going for a run or going for a swim during treatment. I had my 30th birthday, so it meant that I was able to still go out to dinner with friends and enjoy those kinds of things. It also meant that I wasn't sleeping all day, every day, and I was able to do activities to distract myself or to find joy in my every day during treatment. Participant_010

It means I can live normally. It means I can get in my car and drive, I can go to work and do my job properly. It means I can exercise to a similar level to what I was doing before. It means I can live my life how I did before I got cancer. Participant_020

Allowing them to engage more with social activities and family life

It would. Being able to take that medication helped my quality of life. It allowed me to get out of the house and socialise with friends. It allowed me to go for walks on the beach on really good days. It meant that I could exercise to the point of going for a run or going for a swim during treatment. I had my 30th birthday, so it meant that I was able to still go out to dinner with friends and enjoy those kinds of things. It also meant that I wasn't sleeping all day, every day, and I was able to do activities to distract myself or to find joy in my every day during treatment. Participant_010

Yes, obviously, if I was out of pain and not nauseous, I could eat and drink as normal, which would help my recovery, I believe. Also, just being able to spend time with my child, because that was my priority, because he needed me last year more than now. Basically, even be able to just eat, drink, have a shower myself without relying on anyone. Yes, just daily house chores. Participant_016

I would have been able to [unintelligible] get up and actually do things and continue on with life, and have less impact on myself and my family's life. Participant_018

It would mean I would be able to participate more in daily activities. My youngest daughter, I think she was seven, and I was trying to brush her hair, and get her ready for school, and I was vomiting. If I've been able to control my nausea, that would've been easier. Participant_037

Participant describes treatment leading to a reduction in symptoms/side effects

I took tablets for the nausea, and that meant that I could go out. Go to the shops and function. What else did I take? I didn't take much else. I might have taken Panadol to reduce some of the joint pain, and Nurofen. That one just allowed me to relax and not be in pain. That's about it. Participant_017

That would be if I could take something for that AC, in particular. If you can minimize just the overall effects of that, that would be amazing because that really made you feel like you had cancer. You knew that it was doing something to your body. The paclitaxel not so much. Like I said, I'd have it on the Friday and I'd be a bit high on the weekend but I went to work like nothing happened on the Monday. It was a big difference between the two, to me, so if there's something that makes you feel-- Because I always said I wasn't sick. There was nothing other than that pain. I'm not sick, don't make me feel like I'm sick. I was a bit horrible. Don't ask me how I am because I'm not sick. That was probably the difference where like going through AC, you do definitely feel sorry for yourself because you're like, "Now I feel sick." [chuckles] "Now I feel like crap," whereas if paclitaxel was an absolute walk in the park compared to it. Participant_021

Oh, if you take nausea, for example, the fact that you can actually concentrate, and you're not worried that you're going to vomit somewhere. It's quite just distressing in terms of just that feeling that you just think you're going to vomit, and you just need to keep walking. You can't sit still, you can't concentrate, but when you try to stop yourself from vomiting. On the [unintelligible] I have no idea but it's good anyway, whatever he told me I took it. Participant_047

Participant describes treatment allowing them to return to work

It'd be very different. My life would be very different because it's changed everything this fatigue. I'd be able to work again. I'd be able to participate more in social events. I still exercise, but I can't do it to the same extent I used to. Then family life would be a lot easier as well. Participant_008

Yes, correct. It means that you could function and do the tasks that you need to do in the household or work or whatever. Participant_036

If I could take pain medication, that would allow me to be on to stand for long periods of time, then I would be able to go back to work. So it would change a lot and it would allow me to be able to be more physically active with my kids, which is very. Important to me, but not being able to do that. Participant_038

Participant describes treatment allowing them to do domestic tasks

Drive my daughter to school. Make meals. I wasn't really able to get up to do any of that while I was on AC. Participant_007

Everything's harder to cope with when you're exhausted. Stress at work gets harder to deal with. Everything gets harder to deal with when you don't have energy. For example, I've just had a week off work. I'm off this week so it's the first time in ages that I've been able to do some of the deep cleaning in my house that's been neglected. I can't deal with that when I'm working five days and only got the weekend to recover kind of thing. That's the sort of thing that makes a difference. I can just get more life admin done. Participant_011

At the moment, I can barely look after my four-year-old. I'm actually going to have him tonight by myself to see if I can handle that. I can't bend from the hips, so bending over to try to change him or dress him or--I cannot pick him up. He used to go to sleep in my bed and I'd carry him into his, I can't do that. I can’t up and down off the floor to play with him when he wants. It's really affecting what I can do with him. I'm not able to do a lot of housework. I've had to move my microwave that was an under bench one up on top of the bench so I can actually bend over and use it and get things out. There's a lot that's affected at the moment. Participant_048

Table 5.35: What it would mean if treatment worked

What it would mean if treatment worked	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=23	%	n=27	%	n=19	%	n=25	%	n=26	%	n=24	%	n=24	%	n=26	%
Participant describes treatment allowing them to do everyday activities/ return to normal life	35	70.00	17	73.91	18	66.67	14	73.68	17	68.00	17	65.38	18	75.00	18	75.00	17	65.38
Participant described treatment allowing them to engage more with social activities and family life	14	28.00	8	34.78	6	22.22	3	15.79	7	28.00	7	26.92	7	29.17	6	25.00	8	30.77
Participant describes treatment leading to a reduction in symptoms/side effects	11	22.00	5	21.74	6	22.22	5	26.32	4	16.00	6	23.08	5	20.83	3	12.50	8	30.77
Participant describes treatment allowing them to return to work	7	14.00	3	13.04	4	14.81	3	15.79	2	8.00	3	11.54	4	16.67	3	12.50	4	15.38
Participant describes treatment allowing them to do domestic tasks	6	12.00	3	13.04	3	11.11	3	15.79	3	12.00	2	7.69	4	16.67	1	4.17	5	19.23

What it would mean if treatment worked	All participants		Regional or remote		Metropolitan		Mid to low status		Higher status		Aged 25 to 44		Aged 45 to 54		Aged 55 to 74	
	n=50	%	n=16	%	n=34	%	n=20	%	n=30	%	n=19	%	n=22	%	n=9	%
Participant describes treatment allowing them to do everyday activities/ return to normal life	35	70.00	12	75.00	23	67.65	14	70.00	21	70.00	8	42.11	18	81.82	9	100.00
Participant described treatment allowing them to engage more with social activities and family life	14	28.00	6	37.50	8	23.53	3	15.00	11	36.67	9	47.37	3	13.64	2	22.22
Participant describes treatment leading to a reduction in symptoms/side effects	11	22.00	5	31.25	6	17.65	5	25.00	6	20.00	5	26.32	5	22.73	1	11.11
Participant describes treatment allowing them to return to work	7	14.00	1	6.25	6	17.65	3	15.00	4	13.33	3	15.79	4	18.18	0	0.00
Participant describes treatment allowing them to do domestic tasks	6	12.00	3	18.75	3	8.82	1	5.00	5	16.67	4	21.05	2	9.09	0	0.00

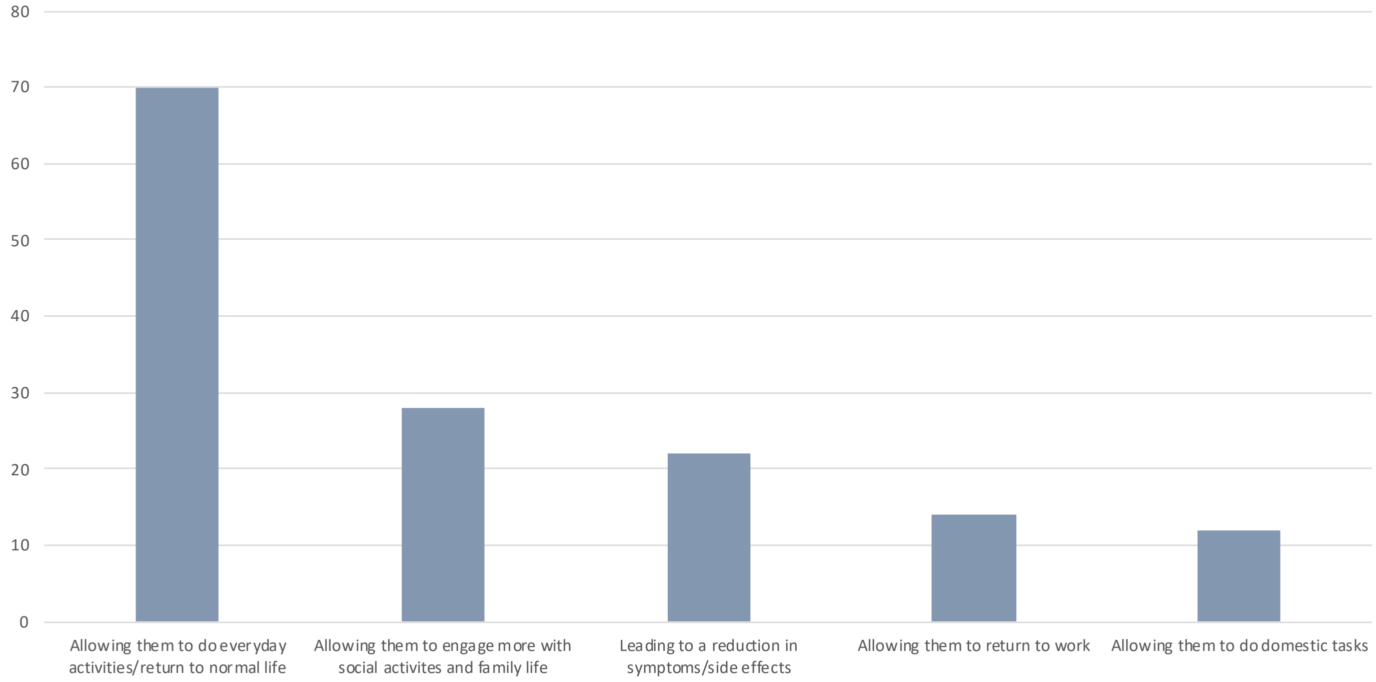


Figure 5.41: What it would mean if treatment worked - percent of all participants

Table 5.36: What it would mean if treatment worked – subgroup variations

Theme	Reported less frequently	Reported more frequently
Participant describes treatment allowing them to do everyday activities/ return to normal life	Aged 25 to 44	Aged 45 to 54 Aged 55 to 74
Participant described treatment allowing them to engage more with social activites and family life	Poor physical function Mid to low status Aged 45 to 54	Aged 25 to 44
Participant describes treatment leading to a reduction in symptoms/side effects	Aged 55 to 74	-
Participant describes treatment allowing them to return to work	Aged 55 to 74	-
Participant describes treatment allowing them to do domestic tasks	Aged 55 to 74	-

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 28 participants (56.00%) was the internet (including health charities). There were 18 participants (36.00%) that described Facebook and/or social media and 17 participants (34.00%) that described their treating clinician. Other types of information accessed included other patient's experience (n=16, 32.00%), books, pamphlets and newsletters (n=11, 22.00%), and nursing staff (n=10, 20.00%).

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 19 participants (38.00%) was other information from people’s experiences (Peer-to-peer). There were 14 participants (28.00%) that described hearing what to expect (e.g. from disease, side effects, treatment) , and 13 participants (26.00%) that described condition-specific (including sub-types), as being useful. Other types of information described as being helpful included condition-specific information (including information about sub-types or stage) (n=13, 26.00%), talking to healthcare staff (n=9, 18.00%), treatment options (n=9, 18.00%), and information from charities (n=5, 10.00%).

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 13 participants (26.00%) that responded that no information was not helpful. The most common type of information found to be unhelpful by 17 participants (34.00%) were sources that are not credible (not evidence-based). There were 11 participants (22.00%) that described information from healthcare staff or hospital, and six participants (12.00%) that described lack of new information, as not helpful.

Information preferences

Participants were asked whether they had a preference for information online, talking to someone, in written (booklet) form or through a phone App. Overall, the most common preference was online information (n=15, 30.00%) followed by talking to someone (n=12, 24.00%), talking to someone plus online information (n=11, 22.00%), and written information (n=11, 22.00%).

The main reasons for a preference for online information was accessibility (n=11, 22%), having control or personal research (n=7, 14%), convenience (n=6, 12%), and access to a lot of information (n=6, 12%). The main reason for talking to someone as a preference was it was valuable and knowledgeable (n=8, 16%), followed by having time for interaction and to ask questions (n=7, 14%). The main reason for written information as a preference was accessibility (n=7, 14%).

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=12, 24.00%), this was followed by participants describing being open to information during treatment (n=11, 22.00%), after the shock of diagnosis (n=8, 16.00%), and before starting treatment (n=8, 16.00%). There were five participants (10.00%) that were receptive to information a week after diagnosis, and the same number receptive three weeks after diagnosis (n=5, 10.00%).

Health 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=26, 52.00%). There were 10 participants (20.00%) that described overall positive, with the exception of one or two occasions, and 8 participants (16.00%) that described a mix of positive and negative. There were four participants (8.00%) who described having an overall negative experience of health professional communication.

Participants that had positive communication, described the reason for this was because communication was holistic (two way, supportive and comprehensive conversations) (n=20, 40.00%), and helpful (n=5, 10.00%). The main reason for negative communication was communication that was not forthcoming, or generally lacking (n=11, 22.00%). This was followed by communication that was dismissive (one way conversations) (n=5, 10.00%), and that had limited understanding of the condition (n=4, 8.00%).

Partners in health

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

The overall scores for the cohort were in the highest quintile for the **Partners in health: knowledge** (mean = 25.98, SD = 3.51), **Partners in health: recognition and management of symptoms** (median = 20.00, IQR = 2.50), **Partners in health: adherence to treatment** (median = 15.00, IQR = 2.00), scales, indicating very good scores for managing their health.

The overall scores for the cohort were in the second highest quintile for the **Partners in health: coping** (mean = 16.18, SD = 4.26), **Partners in health: total score** (mean = 76.23, SD = 8.93), scales, indicating good scores for managing their health.

Ability to take medicines 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 = 23, 52.27%), and 18 participants (40.91%) responded that they took medicines as prescribed most of the time. There were 3 participants (6.82%) that sometimes took medicines 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=41, 93.18%), Hereditary considerations (n=30, 68.18%), Disease management (n=26, 59.09%) and, Physical activity (n=20, 45.45%) were most frequently given to participants by healthcare professionals, and, information about Complementary therapies (n=6, 13.64%), Interpret test results (n=6, 13.64%) and, Clinical trials (n=6, 13.64%) 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 Interpret test results (n=28, 63.64%), Complementary therapies (n=23, 52.27%), Disease Cause (n=21, 47.73%) Disease management (n=21, 47.73%) and, Treatment options (n=21, 47.73%) were most frequently given to participants by healthcare professionals, and, information about Dietary (n=17, 38.64%), Psychological/ social support (n=13, 29.55%) and, Clinical trials (n=12, 27.27%) 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 = 27, 61.36%) and Dietary (n = 20, 45.45%).

The topics that participants did not search for independently after not receiving information from healthcare professionals were Treatment options (n = 22, 50.00%) and Hereditary considerations (n = 18, 40.91%).

The topics that participants were given most information from both healthcare professionals and searching independently for were Sum of Complementary therapies (n = 20, 45.45%) and Treatment options (n = 19, 43.18%).

The topics that participants searched for independently after not receiving information from healthcare professionals were Disease management (n = 24, 54.55%) and Sum of Complementary therapies (n = 15, 34.09%) (Table 6.35, Figure 6.48).

Information accessed

Across all participants, information from non-profit, charity or patient organisations were most accessed followed by information from the government. Information from pharmaceutical companies and from medical journals were least accessed.

My Health Record

My Health Record is an online summary of key health information, an initiative of the Australian Government. There were 19 participants (43.18%) had accessed My Health Record, 21(47.73%) had not. Of those that had accessed My Health Record, there were 9 participants (47.37%) who found it to be poor or very poor, four participants (21.05%) who found it acceptable, and two participants (10.53%) who found it to be good or very good.

Access to information

In the structured interview, participants were asked what information they had been able to access since they were diagnosed. The most common type of information accessed by 28 participants (56.00%) was the internet (including health charities). There were 18 participants (36.00%) that described Facebook and/or social media and 17 participants (34.00%) that described their treating clinician. Other types of information accessed included other patient's experience (n=16, 32.00%), books, pamphlets and newsletters (n=11, 22.00%), and nursing staff (n=10, 20.00%).

Where participants described a specific health charity, they most commonly referred to the Breast Cancer Network Australia (n = 20, 40.00%), followed by the Cancer Council (n = 9, 18.00%). There were 7 participants (14.00%) that described the National Breast Cancer Foundation, 2 participants (4.00%) that described the Pink Hope Organisation, and 2 participants (4.00%) that described Mummy's Wish.

Participant describes accessing information through the internet in general

The breast cancer network. I think it's the breast cancer network. I listened to quite as much as their podcasts and looked at their website and found that really good and informative. I also mentioned that I joined a couple of Facebook groups. I learned things through the Facebook groups as well. Just by the by things really. Those were probably my main two sources of information. Participant_004

I'm been really looking online. I've got a Facebook group for my cancer type, triple-negative Australia and New Zealand. They are really, really good. They say, "Everyone says don't Google or whatever, but their information is always accurate." Some of the groups can be wild accusations, but this is pretty normal. I've read a fair few books. I look at functional and integrated medicine doctors, especially in America, who are treating cancer, and listen to a lot of doctors, breast care oncologists' podcasts, and integrated medicine doctors podcast. That's probably the main ones. Participant_008

Most of it is on the internet, and I've learnt to be very wary of what I read about on the internet to make sure that it's coming from a reliable source, like the Cancer Council will tell you, or the National Breast Cancer Foundation. Something that's valid, and also if I'm looking on the internet, looking at the date because if you read something that's a research paper from 2012, that's probably completely irrelevant to now. Participant_020

Mainly off the internet, like going on to the Cancer Australia. Is that what it's called? Cancer Australia website, National Breast Cancer Foundation website. On Facebook, I found that a group of women in Australia and New Zealand who have the same type of cancer that I had. A triple-negative and that was actually quite a good source of support. If you had questions like, ''Oh, this happened to me, or this happened to anyone else. Should I go and see my doctor?'' That was more moral support, but mostly on the internet from reliable sources. Participant_027

Participant describes accessing information primarily through Facebook and/or social media

The breast cancer network. I think it's the breast cancer network. I listened to quite as much as their podcasts and looked at their website and found that really good and informative. I also mentioned that I joined a couple of Facebook groups. I learned things through the Facebook groups as well. Just by the by things really. Those were probably my main two sources of information. Participant_004

I'm been really looking online. I've got a Facebook group for my cancer type, triple-negative Australia and New Zealand. They are really, really good. They say, "Everyone says don't Google or whatever, but their information is always accurate." Some of the groups can be wild accusations, but this is pretty normal. I've read a fair few books. I look at functional and integrated medicine doctors, especially in America, who are treating cancer, and listen to a lot of doctors, breast care oncologists' podcasts, and integrated medicine doctors podcast. That's probably the main ones. Participant_008

Oh, sorry, I forgot to mention, I did get information from Facebook as well. I know this is not ideal but there was a triple-negative-- there's a breast cancer book specific to my cancer. I know all the information on it isn't 100%, but sharing my experience, reading other people's experiences and having a little friendship group where people understand what we are going through, that was helpful. Participant_016

Participant describes primarily accessing information through treating clinician

Okay, I think the best resource for me was BCNA website. They were very clear in explaining the different types of breast cancers and understanding my report and everything else, so that was an excellent resource. Cancer Council was another good resource, and obviously, my oncologist and all the advice they had. Plus, being from a medical background, and my husband's from medical background too, we did know radiologists directly. One of my uncle's a radiologist, so he was quite good as well in guiding us through the process and pre-empting, telling me what to expect. The hospital I received radiotherapy, they had excellent nurses and support network. Participant_016

From my doctors. I haven't really used the Internet to look stuff up because I just don't want to get misinformation. I've tried to be careful about that, or I've got friends that are nurses, so sometimes I've asked them to clarify something for me, or if I'm not sure about something, I have my breast care nurse. She was really good when I was having treatment at explaining stuff. Participant_043

Oh, tons of it. [scoffs] My oncologist gave me some really good information from, I think it was Queensland or New South Wales. Anyway, with just good information about the drugs. I've just done heaps and heaps of Googling through PubMed and other sorts of-- not doctor Googling. I'm looking at reputable journal articles. I'm a member of a number of forums through Breast Cancer Australia, and also a couple of closed Facebook groups for people on the particular drugs and with the same sort of diagnosis that I have. I read a lot. I'm on alert for drug trials, and I read details. I do quite a bit of reading and research all the time. Participant_050

Participant describes primarily accessing information through other patient's experience

I have [unintelligible 00:55:31] different forums, so internet, breast cancer Australia and so forth to just get information about my type of cancer. I've joined some different forums on Facebook, which have-- it's like different groups, so then there's a support network there. If any there's questions you have, you can ask, "Has anybody else experienced this?" That's how I've gained a lot of my questions and [inaudible] I've learnt a lot too because-- Participant_015

Okay, I just sought out everything. I think I've had access to My Journey through Breast Care-- what's it? National Association which had then information groups, little blogs, and webinars, and things that you could access. I found through Breast Cancer Care WA, they have had classes and courses like Look Good, Feel Good. Also, stress management, all sorts of, yes, lots. Lots on menopause. I've sought out a menopause specialist since finishing treatment. What else? Facebook triple-negative groups, go to my same cancer treatment and also, young peoples under-45's local support groups. They send the information. Yes, I probably surf the net and I try to find as much as I can that way talking to other people that have been through it. Participant_036

I've been on the Cancer Council Foundation website, the Breast Cancer WA website. They're probably the main two, and then obviously you've got your other things like Facebook. You've got your own little groups in there that you join with other people going through the same thing. Participant_017

Participant describes receiving information from books, pamphlets and newsletters

The booklets from the hospital, and the Breast Care Network or whatever that is, BCNA. The Breast Cancer Association whatever. I also joined some Facebook groups. Okay. Participant_007

I've relied heavily on the Breast Cancer Network Associations information pages. My specialist, my breast surgeon on the first day that I saw him, gave me a book, called, Getting To Know Early Breast Cancer or You've Been Diagnosed With Early Breast Cancer. I actually really heavily relied on that book as my Bible. It actually travelled with me for the first three weeks of my diagnosis and I read things on the train and I treated that as the encyclopaedia of things. I really avoided going on and googling stuff or finding people's opinions that have been through my type of cancer. I had two friends, two family members not biological family members, but external family members who had gone through cancer, who I actually had them as a great support to kind of talk to about things but I never got them to tell me all the bad stuff or the…They never gave me the bad stories and it was only as things happen that I would call them and be like, "Oh, I had this happen," and they're like, "Yes, we had that too, it's completely normal." I didn't use a lot of the forums and I didn't use a lot of the Facebook pages until I was quite well far into my journey. It was probably almost done through chemotherapy before I even kind of joined any

Facebook pages for support or any of the forums to support because I relied on making sure that I was getting the information from accurate breast cancer websites rather than some person who set up a breast cancer website. This book, which I think has now become My Journey tool with Breast Cancer Network Association, that really, for me was my-- if this is what it says in here, then this is what it says. Participant_025

You go to the hospital and you get a lot of pamphlets and they give you a lot of information from there. Of course, you tend to get on the internet, but sometimes I think that can be a little harmful to your psyche. I joined a couple of Facebook support groups, but I found, probably three months into it, I left because it can be very depressing. They were suggesting things that I think you have to find those things out for yourself anyway. The doctor would give you a whole heap of stuff and I found them probably the best rather than looking at the Internet. Participant_035

Participant describes receiving information through nursing staff

Probably the most information that I had thought out is just in relation to the types of breast cancer that I had, and outcomes, survival rates, and what the current therapies are for that type of cancer, where there's been any advancement in treatment. I tend to try and keep up to date with that. I either do that through BCNA, so the Breast Care Network Australia. Through our support group, we're all members of that network, so you do get regular updates on what's happening We can link into podcasts and virtual conferences. We also have access to our Breast Care Nurse, thermograph Breast Care Nurse. She does attend our support meetings, if she's available, and keeps us abreast of any updates in relation to breast cancer treatments. That's probably the main thing. Obviously, there's things that pop up on the internet as well, but I tend to go to recognized sites if I have any queries, so mostly the BCNA. Also the breast care trials website as well. Participant_013

From my doctors. I haven't really used the Internet to look stuff up because I just don't want to get misinformation. I've tried to be careful about that, or I've got friends that are nurses, so sometimes I've asked them to clarify something for me, or if I'm not sure about something, I have my breast care nurse. She was really good when I was having treatment at explaining stuff. Participant_043

OK, so I've had a bit of good stuff. Everyone Googles. I've had a try after joining a support group with breast cancer care WA, I learnt a lot through that with through the counsellor giving us information and also a breast nurse who was constantly updating me with anything that was on. And then my oncologist, he would give me information Participant_049

Participant describes accessing information from a specific chealth charity: Breast Cancer Network Australia

I came to look at information through BCNA and I think it's hugely valuable and I've read a lot of research to what comes up through. Like, obviously Facebook knows I've had breast cancer research information about it so that I get it from there and, you know, through the media. And then I'll go and read this study through my oncologist. I do some volunteer stuff that integrated suddenly integrated cancer services and we felt we could treat those kind of body. Participant_002

The breast cancer network. I think it's the breast cancer network. I listened to quite as much as their podcasts and looked at their website and found that really good and informative. I also mentioned that I joined a couple of Facebook groups. I learned things through the Facebook groups as well. Just by the by things really. Those were probably my main two sources of information. Participant_004

Participant describes accessing information from a specific chealth charity: Cancer Council

Lots of stuff from the hospital. There was a whole pack that I brought home that had pretty much everything that I could wonder about. I also telephoned the Cancer Council website just with some questions before I started chemo to ask about how long the side effects take to occur and all that. The man at the Cancer Council was very informative about many different things. He also told me about a particular grant that they give you through the Cancer Council that you can apply for to have. It's just a one-off thing, of a bill paid. It's worth $300 or $350 or something like that, that you can apply for and then they give it to you, and that just helps out with the bill or it helps out with some legitimate cost. That I would never have known had he not just thrown it into the conversation. Where else have I sought? Definitely online. Not so much looking for, again, anything questionable, but on websites like the Cancer Council and other things that are specific to triple-negative breast cancer, because it seems to be a little bit more harder to come *by. The doctors, I just ask questions if I'm ever needing to know anything. They were full of information. Afterwards, I joined a triple-negative breast cancer Facebook page, but I was past everything by then. I wasn't really getting information from them, it was more of a support thing. It was more depressing, really than anything else so I don't look at it too often. Where else have I gotten information from? That would be about it. The breast care nurse, she was a very, very huge source of information, and the cancer nurses-- What are they called? Chemo nurses as well were a wealth of information. That's about it, I think. Just everyone. Everyone who I came into contact with. Participant_005*

The very first thing I did was looked up what all the pathology meant. [chuckling]. The pathology report had all these words I'd never heard before. Just to understand exactly what the diagnosis meant. On my first day into the chemo, they gave me the Cancer Council pack with all the relevant booklets in it for me. That was also quite useful. Then I did a lot of reading up about the different surgeries and different options in terms of reconstruction. I also did look up the different chemo drugs that I was being given. What else? That's probably the main things, I guess. Participant_011

Okay, I think the best resource for me was BCNA website. They were very clear in explaining the different types of breast cancers and understanding my report and everything else, so that was an excellent resource. Cancer Council was another good resource, and obviously, my oncologist and all the advice they had. Plus, being from a medical background, and my husband's from medical background too, we did know radiologists directly. One of my uncle's a radiologist, so he was quite good as well in guiding us through the process and pre-empting, telling me what to expect. The hospital I received radiotherapy, they had excellent nurses and support network. Participant_016

Table 6.1: Access to information.

Access to information	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=23	%	n=27	%	n=19	%	n=25	%	n=26	%	n=24	%	n=24	%	n=26	%
Participant describes accessing information through the internet in general	28	56.00	**16**	**69.57**	**12**	**44.44**	11	57.89	12	48.00	14	53.85	14	58.33	13	54.17	15	57.69
Participant describes accessing information primarily through Facebook and/or social media	18	36.00	8	34.78	10	37.04	8	42.11	8	32.00	7	26.92	11	45.83	**6**	**25.00**	**12**	**46.15**
Participant describes primarily accessing information through treating clinician	17	34.00	6	26.09	11	40.74	**3**	**15.79**	11	44.00	10	38.46	7	29.17	9	37.50	8	30.77
Participant describes primarily accessing information through other patient's experience	16	32.00	6	26.09	10	37.04	**8**	**42.11**	**5**	**20.00**	8	30.77	8	33.33	8	33.33	8	30.77
Participant describes receiving information from books, pamphlets and newsletters	11	22.00	5	21.74	6	22.22	3	15.79	7	28.00	6	23.08	5	20.83	6	25.00	5	19.23
Participant describes receiving information through nursing staff	10	20.00	5	21.74	5	18.52	5	26.32	3	12.00	7	26.92	3	12.50	3	12.50	7	26.92

Access to information	All participants		Regional or remote		Metropolitan		Mid to low status		Higher status		Aged 25 to 44		Aged 45 to 54		Aged 55 to 74	
	n=50	%	n=16	%	n=34	%	n=20	%	n=30	%	n=19	%	n=22	%	n=9	%
Participant describes accessing information through the internet in general	28	56.00	9	56.25	19	55.88	11	55.00	17	56.67	12	63.16	**10**	**45.45**	**6**	**66.67**
Participant describes accessing information primarily through Facebook and/or social media	18	36.00	5	31.25	13	38.24	**3**	**15.00**	**15**	**50.00**	**12**	**63.16**	**3**	**13.64**	3	33.33
Participant describes primarily accessing information through treating clinician	17	34.00	7	43.75	10	29.41	8	40.00	9	30.00	6	31.58	8	36.36	3	33.33
Participant describes primarily accessing information through other patient's experience	16	32.00	6	37.50	10	29.41	8	40.00	8	26.67	**8**	**42.11**	6	27.27	2	22.22
Participant describes receiving information from books, pamphlets and newsletters	11	22.00	2	12.50	9	26.47	3	15.00	8	26.67	3	15.79	5	22.73	**3**	**33.33**
Participant describes receiving information through nursing staff	10	20.00	**5**	**31.25**	5	14.71	6	30.00	4	13.33	5	26.32	3	13.64	2	22.22

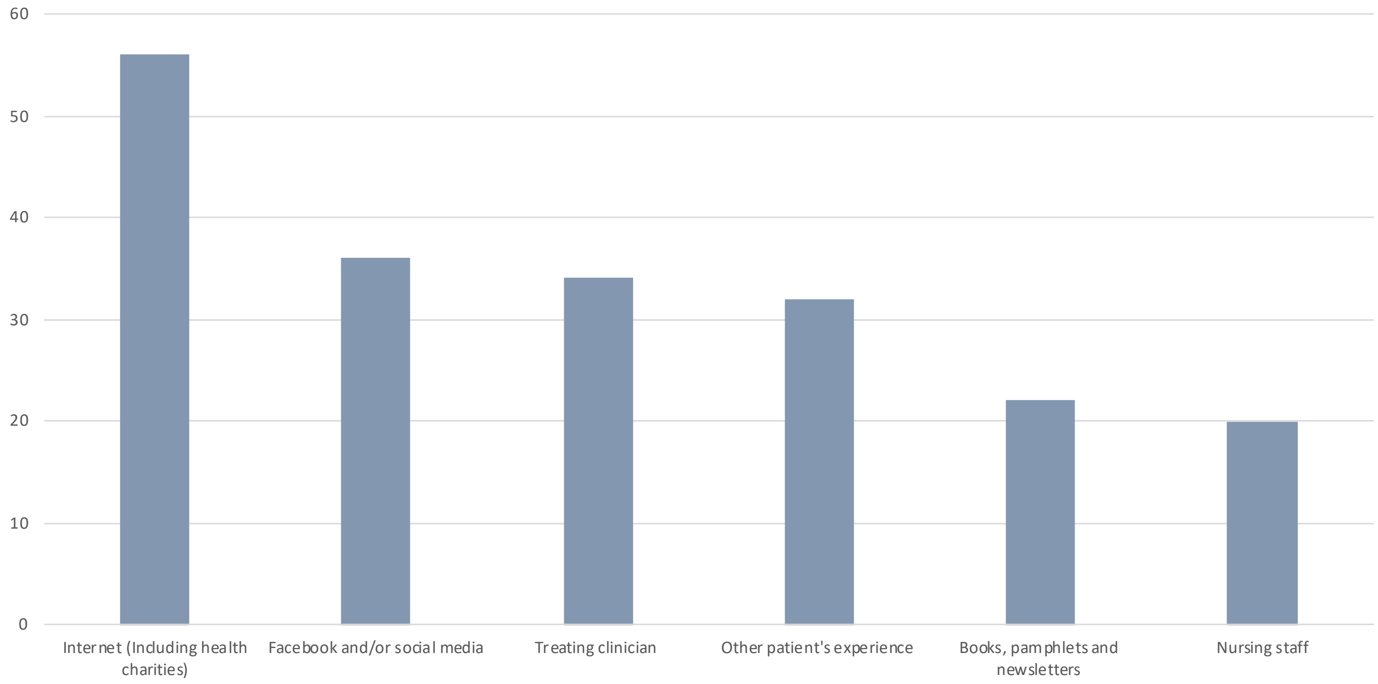


Figure 6.1: Access to information

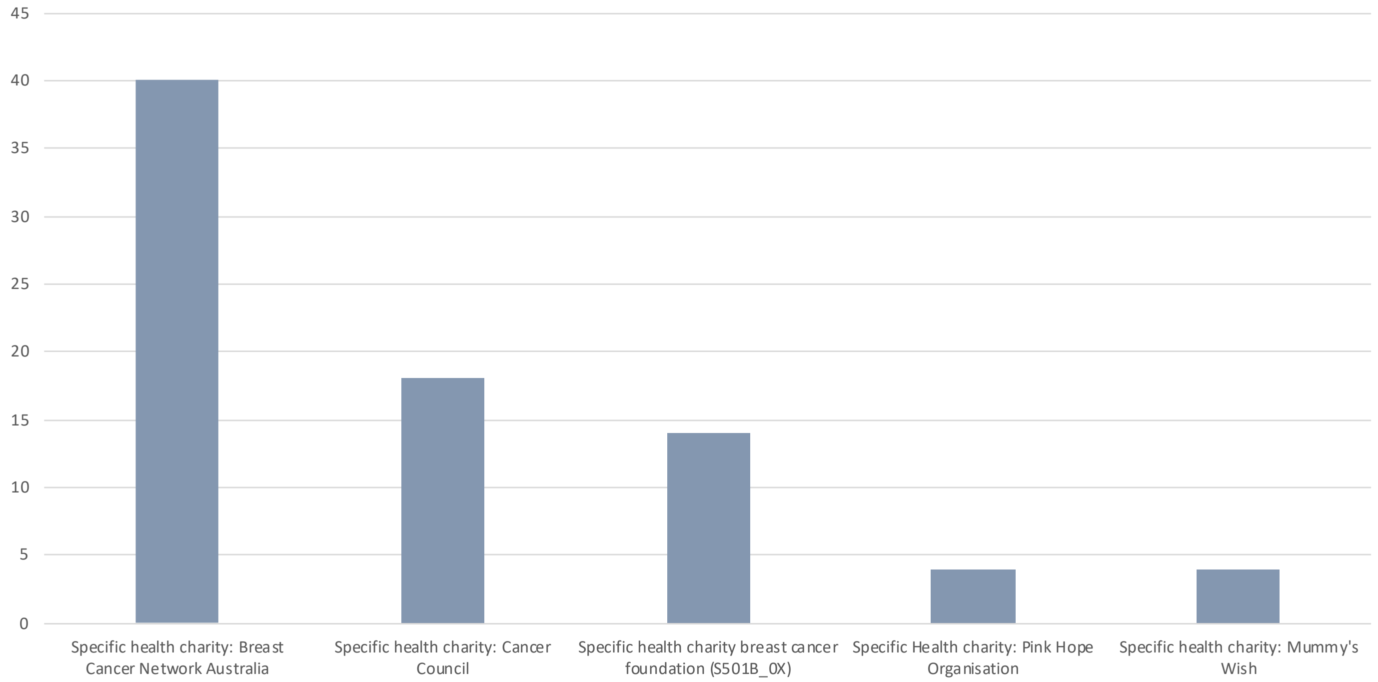


Table 6.2: Access to information – subgroup variations

Theme	Reported less frequently	Reported more frequently
Participant describes accessing information through the internet in general	Advanced breast cancer Aged 45 to 54	Early breast cancer Aged 55 to 74
Participant describes accessing information primarily through Facebook and/or social media	Trade or high school Mid to low status Aged 45 to 54	University Higher status Aged 25 to 44
Participant describes primarily accessing information through treating clinician	Poor physical function	-
Participant describes primarily accessing information through other patient's experience	Good physical function	Poor physical function Aged 25 to 44
Participant describes receiving information from books, pamphlets and newsletters	-	Aged 55 to 74
Participant describes receiving information through nursing staff	-	Regional or remote

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 19 participants (38.00%) was other information from people's experiences (Peer-to-peer). There were 14 participants (28.00%) that described hearing what to expect (e.g. from disease, side effects, treatment) , and 13 participants (26.00%) that described condition-specific (including sub-types), as being useful. Other types of information described as being helpful included condition-specific information (including information about sub-types or stage) (n=13, 26.00%), talking to healthcare staff (n=9, 18.00%), treatment options (n=9, 18.00%), and information from charities (n=5, 10.00%).

Participant describes other people's experiences as helpful (Peer-to-peer)

The most helpful was the sort of direct support from women who are also going through it. So the connexions I made with other women who were able to say, this is how I coped with this, this is what I find. This is this is what it looks like to have a mastectomy. And even that was one lovely woman who said, do you want to feel like you should see and feel the reconstruction was like. So that was the most useful was real people sharing their experiences. That was the information I needed. The actual reality, rather than just a paragraph on, you know, triple negative means this and that. Whatever it was, the real experiences themselves. Participant_001

Actually, the most helpful information that I've had is from previous cancer patients. Participant_009

I think it's the experience of all the other women, what they've been through at the time of that particular [UNINTELLIGABLE] , having a chemotherapy without going through radiation. It's hearing true stories of what other women have have gone through. And for you to know what to expect or not expect to understand that not everyone has the same side effects over time, even if so, knowing in advance information. Participant_049

Participant describes information about what to expect as helpful (Disease progression)

I think probably listening to the Breast Cancer Network podcast was really helpful because they addressed all sorts of different aspects of having breast cancer in those podcasts. I found those really useful. Participant_004

The most helpful, I would say, would have been at the start when I've got all the information of what type of cancer it was and what happens and stages and so forth and what to expect. Apart from that the other most helpful information I've been given is from the chemo nurses, and obviously of side effects and what to expect, and their help was just tremendous. Participant_018

I guess the most helpful has been finding out about the outcomes and the recurrence rate versus the survival rate. I guess that kind of thing about what the future potentially had in front of me. Participant_027

Participant describes information specific to their condition (and sub-types) as helpful

I guess all of it has been helpful, depending on where I was in the particular journey. Yes, I would have to say, if I think, definitely that phone call with the Cancer Council. That was infinitely incredible. The discussions that I would have with the breast care nurse, definitely. My lymphatic massage therapist was a huge source because she's an oncology massage therapist, and she just was delving right into it. She was huge in my learning curve, and the chemo nurses, I would say, as Participant_005

I think the most helpful is knowing that it's okay and it's really normal and that the type of cancer I had is treatable. At the beginning, as I said, realistically, none of my specialists told me too much about triple-negative and the really negative connotations it has, but the really scary side effects or the scary prognosis that you can find on a lot of pages now when you start to do your research. It was nice to get information that was really necessarily necessary but wasn't too much information. For example, everyone talks about the stage of breast cancer they have. I remember asking my surgeon two appointments in what stage mine was. We knew it was grade three, which was really aggressive, but he said to me the stages-- He implied that the staging is really old school terminology, and they talk either early breast cancer or metastatic *breast cancer. I've never done the, "Oh, I'm a stage 2B grade 4, whatever type of breast cancer." I just have always been early breast cancer. Having done my own research, I'm fortunate to know I was stage 1. I was pretty early stage. I think for me the benefit of getting information that was absolutely necessary, but not too much and not too scary, I suppose, the really positive information. Participant_025*

Probably the pamphlets and the sheets that they printed off from your chemo place, from your oncologist, from your breast cancer. Anything like that is the best thing. They give you a book, which I probably didn't read until two or three weeks, four weeks into my treatment because I just couldn't process what was going on. Going back, I found a lot of that was helpful as well. The information that they give you when at the time of your diagnosis mightn't help you right at the start because you're still trying to understand what's going on. Being able to go back and look at it, I think, is a good thing as well. Participant_035

Being specific to my type of cancer because a lot of the time it's to do with hormonal cancer. Most people just presume that if you've got breast cancer, it's a hormonal type, having people understand there's different types of finding specific information for me has been helpful. Participant_036

Participant describes talking to healthcare staff as helpful

I guess all of it has been helpful, depending on where I was in the particular journey. Yes, I would have to say, if I think, definitely that phone call with the Cancer Council. That was infinitely incredible. The discussions that I would have with the breast care nurse, definitely. My lymphatic massage therapist was a huge source because she's an oncology massage therapist, and she just was delving right into it. She was huge in my learning curve, and the chemo nurses, I would say, as Participant_005

Probably from my breast care nurse. If she doesn't know it, she'll find it. The BCNA is sort of helpful. There's been a couple of times where I've looked in there and I'm like, "Hmm, can't find anything," but not to do with what I wanted to find out about. My breast care nurse and also the support group. There's a brave young women's breast cancer, they've got a support group on Facebook, which is full of other breast cancer ladies. If you pose a question on there, sometimes you get some information place to go and find it anyway. Participant_012

The most helpful? I can't think of any one thing. Most helpful? Just being about to talk to somebody, as I said just to confirm if…because with the triple-negative, you have this underlying fear of it returning, so any little ache and pain, is, "Is that cancer coming back?" Which I did ask the doctor yesterday. I said, "Is there anything I should really look out for, or worry about?" He said, "Well, the first thing you don't do, is you don't worry. " [chuckles] Which is really nice and positive. Participant_029

Participant describes information about treatment options as helpful

When I went and saw the oncologist the first time, they gave me wads of paper with the different types of chemo that I'm going to be having. I had an education session in the chemo- What do you call it?- chemo ward? I don't know, with a nurse and she gave me so many brochures and it was good but it was really information overload. Whilst it's all good, I found my most effective method of research has been on that website. Participant_014

I guess at the outset, the research showing the effectiveness of the treatments that I'm on was encouraging, and more recently, I probably find some of the forums where people discuss side effects and things that occur when they're on the [unintelligible] treatments to me and also the same psychological issues that we deal with. I find that helpful, seeing that other people go through the same sorts of things and looking at how other people have dealt with some side effects. It's given me some ideas to pursue and follow and often reject, but [laughs] sometimes you could go on with [unintelligible] Participant_050

I got provided a booklet at very beginning on breast cancer. I can't remember what it's called, but it basically walks you through each step-by-step, which is offered from [unintelligible] from the National Breast Cancer Council. That was my best resource. Participant_024

Participant describes health charities information as helpful

I think probably listening to the Breast Cancer Network podcast was really helpful because they addressed all sorts of different aspects of having breast cancer in those podcasts. I found those really useful. Participant_004

Probably the most helpful would be the BCNA virtual conferences. There was a recent one on Living Your Best Life After Breast Cancer, and I found that quite useful. It supported what I'm currently doing. Also our breast support group, as well. We all keep trying to keep ourselves pretty well up to date with what's actually happening in the breast cancer treatment world, and keeping one another informed as well. Trying to stay away from myths, and rumors, and gossip in relation to breast cancer. Participant_013

Good question, trying to think. I think when I was first diagnosed, before I started any of my treatments, I went in for an appointment at the cancer care center I went to. They gave me a whole lot of literature brochures from the Cancer Council about some of the side effects, and how I would feel, and then how people around me could help. I think it was beneficial that you could read about it and go, "Oh okay, this may happen." Then, [unintelligible] be like "Oh gosh, that doesn't feel right,". Participant_020

Table 6.3: Information that was helpful

Information that was helpful	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=23	%	n=27	%	n=19	%	n=25	%	n=26	%	n=24	%	n=24	%	n=26	%
Participant describes other people's experiences as helpful (Peer-to-peer)	19	38.00	9	39.13	10	37.04	**11**	**57.89**	**5**	**20.00**	9	34.62	10	41.67	8	33.33	11	42.31
Participant describes information about what to expect as helpful (Disease progression)	14	28.00	7	30.43	7	25.93	5	26.32	9	36.00	8	30.77	6	25.00	7	29.17	7	26.92
Participant describes information specific to their condition (and sub-types) as helpful	13	26.00	5	21.74	8	29.63	4	21.05	7	28.00	7	26.92	6	25.00	5	20.83	8	30.77
Participant describes talking to healthcare staff as helpful	9	18.00	6	26.09	3	11.11	4	21.05	4	16.00	**2**	**7.69**	**7**	**29.17**	5	20.83	4	15.38
Participant describes information about treatment options as helpful	9	18.00	5	21.74	4	14.81	4	21.05	4	16.00	5	19.23	4	16.67	3	12.50	6	23.08
Participant describes health charities information as helpful	5	10.00	3	13.04	2	7.41	2	10.53	3	12.00	3	11.54	2	8.33	4	16.67	1	3.85

Information that was helpful	All participants		Regional or remote		Metropolitan		Mid to low status		Higher status		Aged 25 to 44		Aged 45 to 54		Aged 55 to 74	
	n=50	%	n=16	%	n=34	%	n=20	%	n=30	%	n=19	%	n=22	%	n=9	%
Participant describes other people's experiences as helpful (Peer-to-peer)	19	38.00	**9**	**56.25**	10	29.41	7	35.00	12	40.00	9	47.37	7	31.82	3	33.33
Participant describes information about what to expect as helpful (Disease progression)	14	28.00	4	25.00	10	29.41	**3**	**15.00**	11	36.67	5	26.32	6	27.27	3	33.33
Participant describes information specific to their condition (and sub-types) as helpful	13	26.00	**7**	**43.75**	6	17.65	**3**	**15.00**	10	33.33	**7**	**36.84**	4	18.18	2	22.22
Participant describes talking to healthcare staff as helpful	9	18.00	3	18.75	6	17.65	3	15.00	6	20.00	3	15.79	4	18.18	2	22.22
Participant describes information about treatment options as helpful	9	18.00	3	18.75	6	17.65	3	15.00	6	20.00	2	10.53	5	22.73	2	22.22
Participant describes health charities information as helpful	5	10.00	2	12.50	3	8.82	2	10.00	3	10.00	0	0.00	2	9.09	**3**	**33.33**

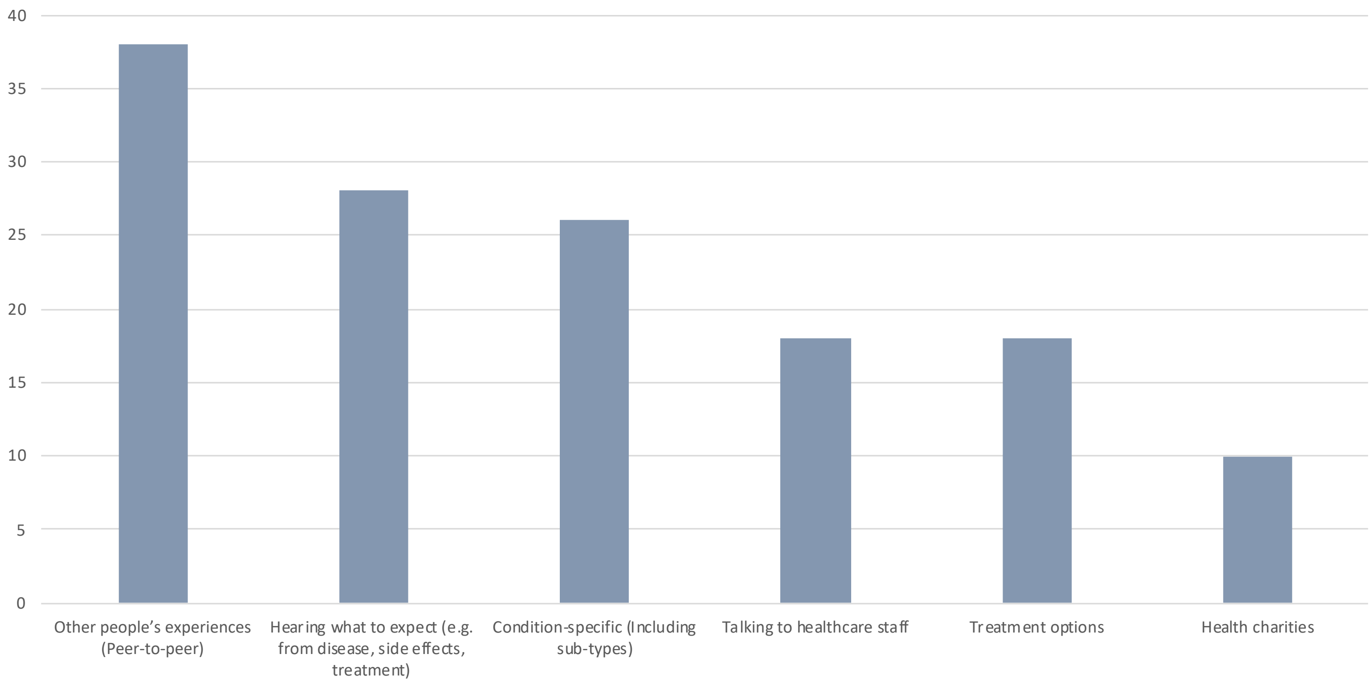


Figure 6.3: Information that was helpful

Table 6.4: Information that was helpful – subgroup variations

Theme	Reported less frequently	Reported more frequently
Participant describes other people's experiences as helpful (Peer-to-peer)	Good physical function	Poor physical function Regional or remote
Participant describes information about what to expect as helpful (Disease progression)	Mid to low status	
Participant describes information specific to their condition (and sub-types) as helpful	Mid to low status	Regional or remote Aged 25 to 44
Participant describes talking to healthcare staff as helpful	Diagnosed before 2020	Diagnosed in 2020 or 2021
Participant describes health charities information as helpful	-	Aged 55 to 74

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 13 participants (26.00%) that responded that no information was not helpful. The most common type of information found to be unhelpful by 17 participants (34.00%) were sources that are not credible (not evidence-based). There were 11 participants (22.00%) that described information from healthcare staff or hospital, and six participants (12.00%) that described lack of new information, as not helpful.

Participant describes information from sources that are not credible as not helpful (Not evidence-based)

In general. I think googling is not helpful. Using Google to look up breast cancer and generally in triple-negative breast cancer, that was very unhelpful. Participant_004

No, I think the only things that were upsetting or unhelpful were non cancer patients just giving stupid advice or other cancer patients giving you advice when they've got different cancers or different types of breast cancer and their mentality around that type of cancer compared to mine, I guess. Participant_010

Well, once again, just probably gossip that's either come third hand through different conversations that you've had or also it might be social media things like Facebook. Often, things will pop up on there that are not very helpful, I tend to stay clear of stuff like that. Probably, having that medical background or health background that does help avoid a lot of that because you're aware of whether things are actual information or whether it's just garbage Participant_013

Only the things that I found by myself on Google, they weren't helpful. I joined a Facebook group and left within 10 minutes, that wasn't helpful at all. Those sorts of blogs and stories, they haven't been helpful at all for me. Maybe they are for other people, but for me, that wasn't helpful at all. Just typing in triple-negative breast cancer into Google is probably the most unhelpful thing that you can do. I found that out the hard way. Participant_033

Participant describes no information being not helpful

I wouldn't say nothing, it's not helpful for me, it's more that it's unnecessary, more than unhelpful. Participant_003

Like my oncologist? Oh, I didn't say that, sorry. No, not really. I found that 95% of the people I've dealt with have been great, and were definitely there to listen, and to help. Participant_020

No, I don't think there's anything. I think the more information you have, the better you are Participant_049

Participant describes the healthcare staff/hospital as being not helpful

I think yes, one thing that wasn't helpful. I was seeing the breast surgeon, and she was basically about to hand me over to an oncologist. She said, "You can see this doctor, and you'll see him pretty soon, but if you see him through the hospital, then you'll be waiting forever." I diligently went and made an appointment with him privately, to then find out that what she told me wasn't the case. That I could have just gone and seen him through the public hospital, and I wouldn't be waiting because I do have private health, but my private health doesn't cover cancer. I thought, "Well, that's what the government's for," but because of her saying that, I was like, "Oh my God, I can't be waiting for weeks. I need to get onto this quickly, quickly, quickly." I was getting ready to spend hundreds and hundreds and hundreds of dollars to go privately because I really wanted to get started on it when that wasn't the case. That was probably the biggest stress and unhelpful thing that could have happened. It all got sorted out, and I think I didn't mean for her to get in trouble, but ultimately that did, I'm pretty sure, get back to the people that need to address that sort of *stuff. I think her understanding was corrected, and maybe she was working off old information where there was a massive wait at the hospital or something, but yes, that was pretty diabolical at the time. Participant_005*

The public hospital system. It's not been all that, I don't want to seem like I'm not thankful because I really am, but it's not been all bad. It's the really the actual people that, the doctors and the nurses and the my breast care nurse and everybody. They're great, I just think it's the system thing. If there were different processes is in play, that yes, it probably would give the patient a bit more of a-- To me, it's about me being aware of what's happening, and I feel like I just was not kept in the loop. It was not patients focused. It was just very medically driven. You have for each section, surgeon, and then the medical oncologist, they come together, and then pathology. They all come together and have those discussions about me, but what about me? I'm not a part of that journey at all, I'm just pretty much told, "Well, this is what you need to do." Why do I need to do that? I don't feel like some of the responses I got from the oncologists, either, were informed responses. I think they were just, "This is just how we do it." It's almost like they just follow a specific protocol, process, that they don't look outside. It's kind of black and white and they don't look at the gray, and look at what other options could be available. Whether, again, that that's just a public system of, "This is what we do," or whether it's just how it works in that hospital I was in, I don't. It really was not a great experience in that sense. Participant_015

Not really. Probably it's my experience with my breast cancer nurse. More the fact that I, for the first month, thought breast cancer nurses were unicorns that they apparently existed but I never saw one. The treatment hospital that I had had three breast cancer nurses, but they're based around the treatment you're having. There's a breast cancer nurse for surgical, there's a breast cancer nurse for medical, and a breast cancer nurse for radiation oncology. They're not I guess, what a lot of people think of breast cancer nurses. They weren't my best buddy. They weren't there for me to sit with me and talk me through everything. I had my first surgery and still had never met the surgical breast care nurse. I had, as I mentioned, the medical oncologist, breast care nurses. I have a great relationship with her, but she wasn't sitting in on my appointments and hold my hand and guide me through the process, which is what it seems like a lot of McGrath nurses do, for example. She was the one who gave me my Zoladex injections, but for me, I think that and I know a lot of people at the hospital I went to, they all have the same reaction is that there's a breast care nurse but there's not a breast care nurse. Participant_025

If the hospital would have said to me at the time, "We can do the double mastectomy and the reconstruction," I would have gone with that. I don't know, in hindsight, whether that would have been the-- In hindsight, that wouldn't have been the right decision, but at the time, I thought that was pretty unhelpful, that whole scenario of, go and see the breast surgeon, then you've got to go and see a plastic surgeon. I found that whole experience the worst. Participant_029

Participant describes a lack of new information as not helpful

I guess looking back, that that pink book, because it was I don't know, I guess maybe things are different now, but because it was posted out and it took a few weeks or whatever for me to be on the mailing list and for it to be shipped out by the time it arrived, I'd already gone through. I guess maybe I was into my treatment and I just looked to even want to look at it. And so that was such a waste that I think I'd donate to someone else. So that was to like so that was particularly useful. What other information was useful? I don't know, because I didn't actually get a lot of information and the lack of information wasn't useful. So when I first went to my GP and he gave me that initial diagnosis, the lack of information was really not useful, not being told about this parallel private health system that was really not useful because that could have set me back weeks and not knowing that it was triple negative and so fast growing, that could have made a difference if I had sought out the information and had a friend to do that for me. Participant_001

Not really. Probably it's my experience with my breast cancer nurse. More the fact that I, for the first month, thought breast cancer nurses were unicorns that they apparently existed but I never saw one. The treatment hospital that I had had three breast cancer nurses, but they're based around the treatment you're having. There's a breast cancer nurse for surgical, there's a breast cancer nurse for medical, and a breast cancer nurse for radiation oncology. They're not I guess, what a lot of people think of breast cancer nurses. They weren't my best buddy. They weren't there for me to sit with me and talk me through everything. I had my first surgery and still had never met the surgical breast care nurse. I had, as I mentioned, the medical

oncologist, breast care nurses. I have a great relationship with her, but she wasn't sitting in on my appointments and hold my hand and guide me through the process, which is what it seems like a lot of McGrath nurses do, for example. She was the one who gave me my Zoladex injections, but for me, I think that and I know a lot of people at the hospital I went to, they all have the same reaction is that there's a breast care nurse but there's not a breast care nurse. Participant_025

If the hospital would have said to me at the time, "We can do the double mastectomy and the reconstruction," I would have gone with that. I don't know, in hindsight, whether that would have been the—in hindsight, that wouldn't have been the right decision, but at the time, I thought that was pretty unhelpful, that whole scenario of, go and see the breast surgeon, then you've got to go and see a plastic surgeon. I found that whole experience the worst...With breast cancer, nobody will tell you, "Have a lumpectomy," or, "Have a mastectomy," and then you have an oncologist tell me, "Oh, why wouldn't you just have a mastectomy?" Then you have somebody having a lumpectomy. Everybody just has an opinion one way or the other, really, you're torn about what you want to do about that. There's no clear guideline about which way to go. I found that the most distressing time for me. It wasn' t until I went and saw DOCTOR the second time and he said, "I don't think you need put yourself through that unless you have an underlying condition." It just seemed to be the right thing. He said the right thing at the right time, to me, anyway. Participant_029

Table 6.5: Information that was not helpful

Information that was not helpful	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=23	%	n=27	%	n=19	%	n=25	%	n=26	%	n=24	%	n=24	%	n=26	%
Participant describes information from sources that are not credible as not helpful (Not evidence-based)	17	34.00	9	39.13	8	29.63	4	21.05	10	40.00	8	30.77	9	37.50	7	29.17	10	38.4
Participant describes no information being not helpful	13	26.00	5	21.74	8	29.63	5	26.32	5	20.00	6	23.08	7	29.17	9	37.50	4	15.3
Participant describes the healthcare staff/hospital as being not helpful	11	22.00	5	21.74	6	22.22	5	26.32	6	24.00	6	23.08	5	20.83	3	12.50	8	30.7
Participant describes a lack of new information as not helpful	6	12.00	3	13.04	3	11.11	3	15.79	3	12.00	4	15.38	2	8.33	2	8.33	4	15.3

Information that was not helpful	All participants		Regional or remote		Metropolitan		Mid to low status		Higher status		Aged 25 to 44		Aged 45 to 54		Aged 55 to 7	
	n=50	%	n=16	%	n=34	%	n=20	%	n=30	%	n=19	%	n=22	%	n=9	%
Participant describes information from sources that are not credible as not helpful (Not evidence-based)	17	34.00	7	43.75	10	29.41	7	35.00	10	33.33	6	31.58	7	31.82	4	44.4
Participant describes no information being not helpful	13	26.00	5	31.25	8	23.53	6	30.00	7	23.33	3	15.79	7	31.82	3	33.3
Participant describes the healthcare staff/hospital as being not helpful	11	22.00	1	6.25	10	29.41	2	10.00	9	30.00	6	31.58	4	18.18	1	11.1
Participant describes a lack of new information as not helpful	6	12.00	2	12.50	4	11.76	3	15.00	3	10.00	3	15.79	2	9.09	1	11.1

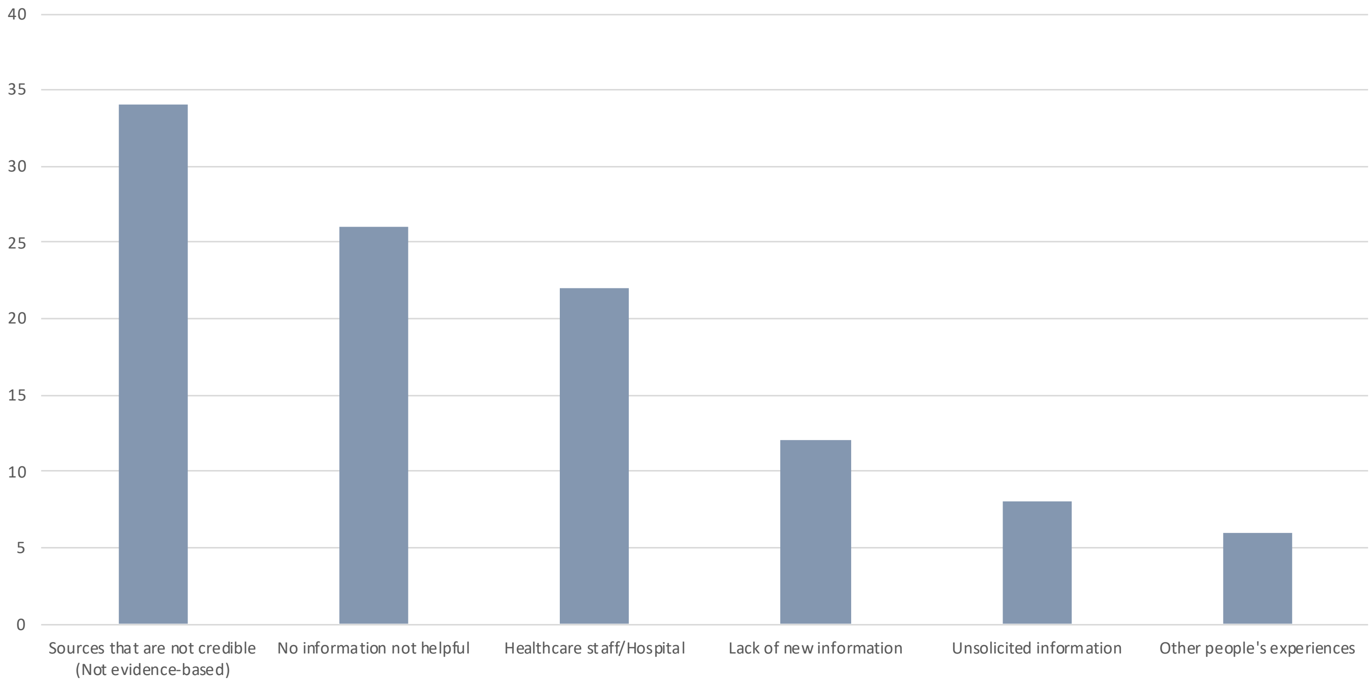


Figure 6.4: Information that was not helpful

Table 6.6: Information that was not helpful – subgroup variations

Theme	Reported less frequently	Reported more frequently
Participant describes information from sources that are not credible as not helpful (Not evidence-based)	Poor physical function	Aged 55 to 74
Participant describes no information being not helpful	University Aged 25 to 44	Trade or high school
Participant describes the healthcare staff/hospital as being not helpful	Regional or remote Mid to low status Aged 55 to 74	

Information preferences

Participants were asked whether they had a preference for information online, talking to someone, in written (booklet) form or through a phone App. Overall, the most common preference was online information (n=15, 30.00%) followed by talking to someone (n=12, 24.00%), talking to someone plus online information (n=11, 22.00%), and written information (n=11, 22.00%).

The main reasons for a preference for online information was accessibility (n=11, 22%), having control or personal research (n=7, 14%), convenience (n=6, 12%), and access to a lot of information (n=6, 12%). The main reason for talking to someone as a preference was it was valuable and knowledgeable (n=8, 16%), followed by having time for interaction and to ask questions (n=7, 14%). The main reason for written information as a preference was accessibility (n=7, 14%).

Participant describes online information as main preference

Generally, online, because I'm a researcher. I like to get on and have a look and read and find information myself. Participant_018

Probably online because you can access it any time and you're not filing a bookshelf full of books and pamphlets that you will probably never look at again, and definitely you've got an in-person thing too. Participant_030

Online information probably, because I can read it and then reread it and I can print it out. I can give it to my partner to read and then we can discuss things and I can bounce ideas with him. Phone conversations, I think you don't retain all the detail from a phone conversation. I know you I don't. Participant_050

Participant describes talking to someone as main preference

I'd prefer talking to someone, a professional, because then all the information they have is accurate. The next preference is online because, again, I know where to look, I know which journals to look at and things like that, so I believe I do have a good process of filtering this information myself, for myself. Participant_016

I would prefer to talk face-to-face, if I can. Otherwise, booklets when you've got time to actually comprehend things. I also do like the resources of emails, works I contact or somebody that you can contact.
INTERVIEWER: What's your reason for preferring a face-to-face conversations?
PARTICIPANT: I think that face-to-face is easier to talk about it, instead of like with an email. You can certainly talk about it as well, but face-to-face, you have got that personal contact, so you feel like there's somebody on the other end that's listening. Participant_024

PARTICIPANT: Probably talking to someone. One-on-one seems to be a lot easier these days.
INTERVIEWER: Are there other reasons why you prefer one-on-one?
PARTICIPANT: Not really, no. I think when you're actually sitting with somebody that you absorb more probably. Participant_032

I think talking to someone is the best because you've got the interaction, that personal side of things, you can ask questions then and there, that sort of thing, yes. Participant_046

Participant describes talking to someone plus online information as main preference

Probably I would probably start with a reliable online source with it. You know, my dad said he had jumped onto this website. This is what I recommend. Have a rate of that. I would do that and then either speak to a GP or briskness. If I'd been had questions that online, didn't you know that I didn't comprehend the information, not then speak to someone so it could be explained one on one. Participant_003

I like to do my research online. I don't tend to use apps very often unless I have to. I kind of forget about them. Then I like to go and talk to someone about it or talk on the phone, whatever it is. Participant_008

I'm probably online because it's small world wide, and you can get a wide range of outcomes, a wide range of knowledge. And I do like to talk to people as well just because, you know, you can get some really interesting information from different people. So it's open to communication and knowledge. So if anybody has any information that they know that I can learn from that out and Participant_044

Participant describes written information as main preference

I think booklets because sometimes when you get overwhelmed, you forget things and you could always like booklets and pamphlets. You can go back to and go, oh, okay, that's what it said. Whereas if you told something, you forget about it and you want to clarify something, you can go back to the booklet. Participant_006

I like written or online information. Talking to people is lovely, but I don't always-- I think when you're in a new diagnosis state, I know that I don't always remember what they've said or I remember incorrectly. I've found written information the most useful for me that I can go back to and look again, whether that be printed and handed out in booklet form, I don't mind, but online is great too. It's just knowing where to go and what to read, and not going rogue. Participant_033

I think the booklet. Online is easy, but I think you can get a lot of misinformation online. You've got to be very careful where you look in. I think there's a couple of good places that we were encouraged to join from the hospitals that have been quite good. I think a book that you can, every now and again, go back and have a look is also something that is quite good. Probably, I find book-type stuff rather than online because, like I said, online, you're just not too sure where it's coming from. Participant_035

Table 6.7: Information preferences

Information preferences	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=23	%	n=27	%	n=19	%	n=25	%	n=26	%	n=24	%	n=24	%	n=26	%
Participant describes online information as main preference	15	30.00	6	26.09	9	33.33	6	31.58	7	28.00	6	23.08	9	37.50	9	37.50	6	23.08
Participant describes talking to someone as main preference	12	24.00	3	13.04	9	33.33	4	21.05	6	24.00	6	23.08	6	25.00	4	16.67	8	30.77
Participant describes talking to someone plus online information as main preference	11	22.00	7	30.43	4	14.81	6	31.58	5	20.00	6	23.08	5	20.83	5	20.83	6	23.08
Participant describes written information as main preference	11	22.00	5	21.74	6	22.22	3	15.79	8	32.00	6	23.08	5	20.83	4	16.67	7	26.92

Information preferences	All participants		Regional or remote		Metropolitan		Mid to low status		Higher status		Aged 25 to 44		Aged 45 to 54		Aged 55 to 74	
	n=50	%	n=16	%	n=34	%	n=20	%	n=30	%	n=19	%	n=22	%	n=9	%
Participant describes online information as main preference	15	30.00	6	37.50	9	26.47	6	30.00	9	30.00	4	21.05	10	45.45	1	11.11
Participant describes talking to someone as main preference	12	24.00	4	25.00	8	23.53	4	20.00	8	26.67	6	31.58	4	18.18	2	22.22
Participant describes talking to someone plus online information as main preference	11	22.00	4	25.00	7	20.59	3	15.00	8	26.67	3	15.79	4	18.18	4	44.44
Participant describes written information as main preference	11	22.00	4	25.00	7	20.59	6	30.00	5	16.67	3	15.79	5	22.73	3	33.33

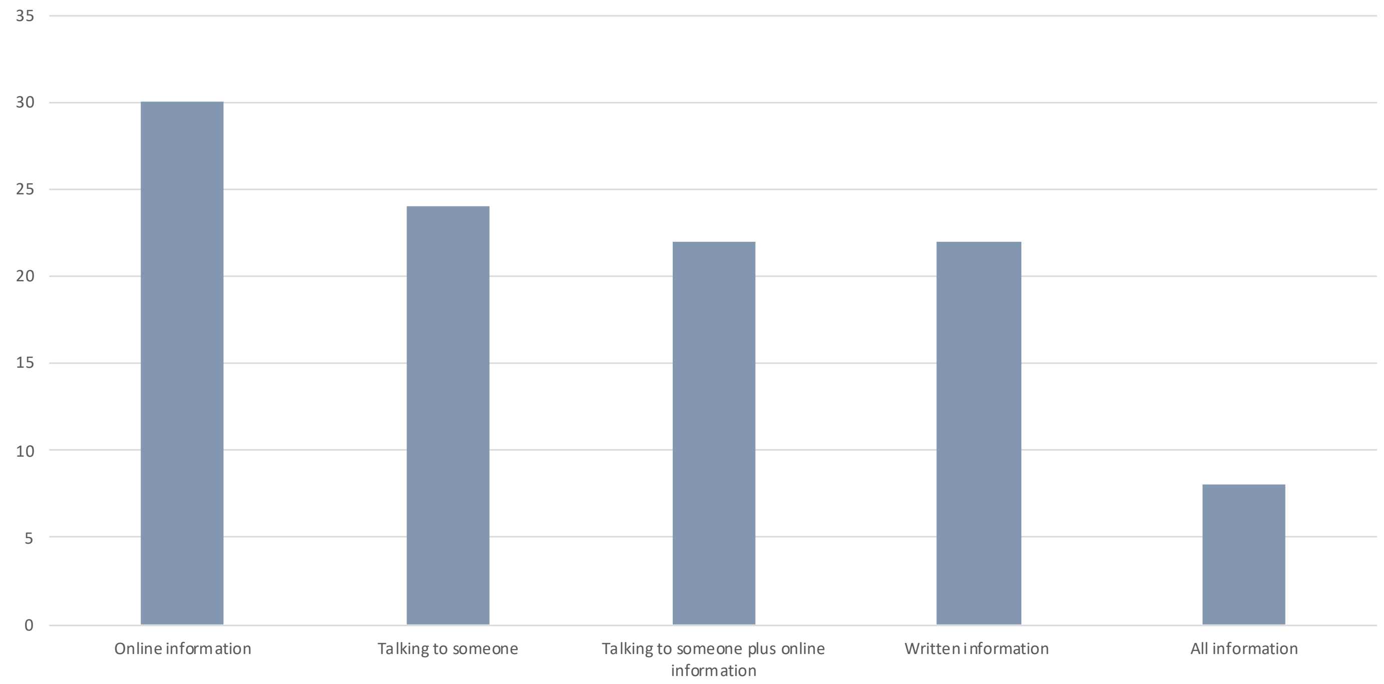


Figure 6.5: Information preferences

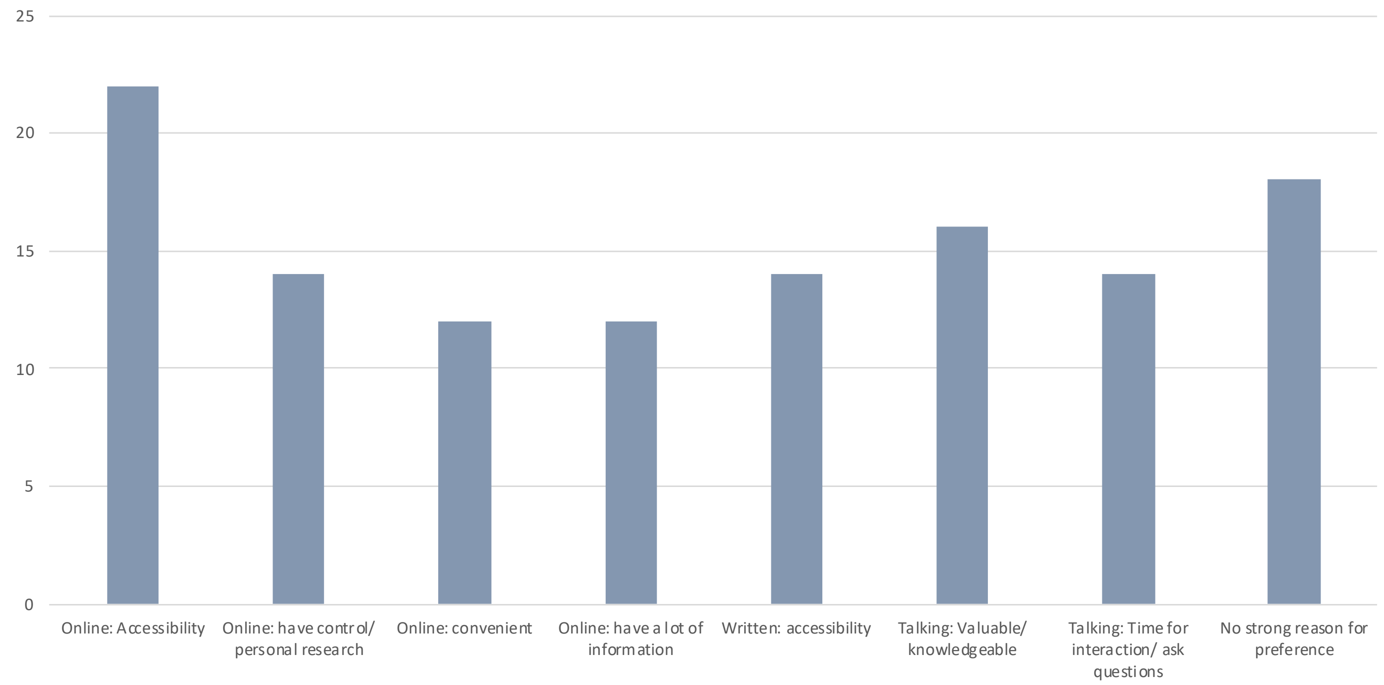


Figure 6.6: Reasons for information preferences by format

Table 6.8: Information preferences – subgroup variations

Theme	Reported less frequently	Reported more frequently
Participant describes online information as main preference	Aged 55 to 74	Aged 45 to 54
Participant describes talking to someone as main preference	Early breast cancer	-
Participant describes talking to someone plus online information as main preference	-	Aged 55 to 74
Participant describes written information as main preference	-	Aged 55 to 74

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=12, 24.00%), this was followed by participants describing being open to information during treatment (n=11, 22.00%), after the shock of diagnosis (n=8, 16.00%), and before starting treatment (n=8, 16.00%). There were five participants (10.00%) that were receptive to information a week after diagnosis, and the same number receptive three weeks after diagnosis (n=5, 10.00%).

Participant describes being receptive from the beginning (diagnosis)

Well, I wanted every scrap of information from that. Right now I'm different to average, but I know it something that point of diagnosis is it's too much to take all the data within clinicians, which, like I said, I want to know what is available right to someone in my situation. So I was asking for more detail and being provided. It helps. I say that point of diagnosis being absolutely overloaded could be. Participant_002

I was very hungry for information straightaway. It was probably a little bit overwhelming because it was so much to learn at that stage. Everything was new. Even the friend of mine who had had cancer had a totally different type of breast cancer to me. The treatments that they used for her were different to mine and all that sort of thing. Really everything was new even though I had some idea of some of what she'd been through. It was a little bit overwhelming, but it was necessary for me. I really needed to find that info at the beginning. It was probably easier to absorb info a little bit further into the process when I was familiar with what was happening and how chemo worked and all that kind of thing because it wasn't so much to take in all at once. Participant_011

This is a good question. I think at the very beginning, all this is quite good up to a point, and then you freak out [chuckles] and stop taking it in. During treatment was really hard because concentration was not my friend. I was ill anyway, probably about a year to two years down them check post-diagnosis and at the very beginning. That was probably two key moments that I went research-mad about and I wanted to find out stuff. That's when I got the information that I wanted. During treatment, it's hard because your concentration span and your ability to retain information is quite difficult because you're struggling with other things and dealing with other things. Participant_012

Participant describes being receptive to information during treatment

Definitely not at the start, definitely not probably even partway through treatment. Probably not until I was in the latter part of my treatment, because up until then you're so busy surviving each day that any information you get doesn't really necessarily sink in. I used to take a notepad and pen with me to any of my appointments. If I had questions I thought of, I'd write them down, because I knew I wouldn't remember them. I'd write down any important things that they'd say, the doctor or the specialist would say. Participant_020

Probably after my surgery, once that sort of complete whirlwind in the first two weeks of testing, diagnosis, and surgery. Then I was at home and I had a month off work, so I had time in my own time to process and to ask or to find the information I was looking for. When I was asking it, it was a breather in-between everything else. Participant_021

Probably I didn't start fully taking the information until after I started chemo. I think, right up to the moment that the surgeon was drawing on for surgery, I was in that, "This isn't really happening mindset. Maybe at the point of surgery, and then again at the point of where chemo started because I guess until then, I didn't really know what was going to happen. They can tell you, "Okay, you you're going to get an IVA." Until you're actually in there and having the nurse explain, "This is what we're going to do. This is how long it's going to take. This is why we're doing it.'" That's where it all becomes real. Participant_027

Participant describes being receptive to information after the shock of diagnosis

Definitely. I mean, maybe I should have been given something printed. I had that very. Diagnosis at the GP that then once I got home and sort of recovered from the shock of it, then I could have read that then because that kind of wasn't as scary as when I had the results of after the lumpectomy, when I was told what kind of cancer it was. And then I was going to have to have the mastectomy and the chemo because that was really shocking that at that point. I was I would not have been receptive, because I know when the surgeon said mastectomies, I remember hearing it, but it sounded sort of all echoey and weird, so I was not receptive. Then at that, that's when I was told the type of cancer. But probably shortly after that, I was really wanting to get into the research and find out all about the chemo. Participant_001

Funnily enough, I think probably when I was most receptive probably would have been when I was almost finished treatment. I think that initial diagnosis, you're very shell shocked. I think probably the initial reaction is to go and search for all of the information you possibly can. I do remember my Breast Care Nurse saying to me, "Please do not go online and Google, triple-negative breast cancer because you won't like what you see. It's made to sound a lot worse than it actually is." Of course, the first thing I did was Google it, and as soon as I started reading, I just shut it down. I closed the article and didn't go back again. What I found most useful was my journey kit that I was given. I know that are all online now, but when I was diagnosed, it was in hard form copy. I tended to use that, and the diaries that was given just to map my treatment, but also just to refer back to if I needed to. I was also given some information by the oncology nurses at the HOSPITAL. That probably answered some of my questions as well, or if it didn't, it gave me the resources of where I could access that information. Initially, I was just too consumed with my actual treatment that was happening at the time. I think going through chemotherapy every week, all I was concentrating on was getting through the chemotherapy, dealing with the side effects, making sure that I was keeping myself in the best health that I could. For example, trying to keep my diet up and my energy levels, and just really concentrating on being well, more than anything. Asking the questions that I needed to at the time. I think I was just treading water through that first six months. Really, it was until I was probably through the worst of that chemotherapy that I started looking more at what was actually happening to me? What my diagnosis was? What the implications of that were? What were the survival rates? What was the best treatment? Both questions came later Participant_013

I think, to begin with, you've got no ability to take information in, there's so many-- You're scared shitless and you don't know what to do. As soon as you have a plan, I think you can start to take information in. Once I went and got a plan from the medical oncologist. I knew what NAME had said, "Get the surgery, but there's going to be chemotherapy and radiation." I needed a plan. Until I had that plan, I just couldn't-- there's no point reading anything, you don't know what you're going to get. It's just too confusing. Once I got Gavin's plan and then I understood a little bit more about it-- everyone else was reading pathology results and I'm like, "I don't know what all that means. I don't know how to deal with that." For me, sometimes it was too much and so I just, I don't know, I just stepped away from it. When it was, I have to say halfway through, so when I talked to the genetic specialist, she was great. She gave me more-- when we were talking to her, I could prep up questions. That was really good because it made me think you had to focus on certain elements. Then when I came away from that, I did more research. That was halfway through the chemotherapy. I was in a better position to listen and not be so scared. Participant_047

Participant describes being receptive to information before starting treatment

Definitely not at the start. Probably once I had my first visit with the oncologist, I think I was okay with all the information that I'd been given once I'd gotten the okay from the surgeon and he jumped up and down for joy to tell me that he got it all and that he was very, very happy. Then because I saw the surgeon and the oncologist on the same day, I guess once I'd gotten that information then I was able to go, "Okay, I can now move forward. It hasn't gone anywhere. It's all okay, so now we can start this fire and get this bugger." Participant_014

Before I started treatment. Participant_028

Probably before the operation. Yes, before she operated, I saw her a few times and she explained things quite well and my new oncologist is very good. Participant_032

Participant describes being receptive to information with a week after diagnosis

I think probably a week or two after the initial shock of being diagnosed would have been the best time to receive good information. Helpful information. I think that would have helped me in my decision-making. All through, honestly, all through the whole thing at different points in time, it would have been. It's useful to have information all through. Participant_004

Probably a wait after diagnosis because you sort of had to come to terms with it and then, yes, maybe a week after. Participant_006

Probably a week after my diagnosis. Participant_016

Participant describes being receptive to information two to three weeks after diagnosis

Three weeks after my diagnosis. For the first three weeks, I was going along and doing everything, but I literally was still reeling from the shock. Participant_045

Probably, early on. A couple of weeks into my diagnosis because I did a lot of research in how to manage the side effects and what have you? I proactively did that because my mom had had lung cancer, so I'd seen her side effects. I was trying to work out how to trick them all and not get them. I think probably, just before each stage because then I was dealing with the information about chemo. Then once that was finished or coming to a close, then I'd start to look at the information about surgery. Once that was finished, I start to look at that healing. [laughter]. I think it's most relevant when it's coming up next. Participant_008

I think in a couple of weeks after the diagnosis, when I'd accepted it and understood a little bit more, that was a good time to give information, but right at the beginning, I feel like there probably wasn't enough information given at the diagnosis time. Hence, why I Googled on my own because I had a lot of questions and they weren't necessarily answered and I didn't understand anything. I think at that point, more targeted information would have been really good, whether I'd read it there and then I don't know, but to have been given it and had it at hand so that when I was ready, I had something that was useful and helpful to look at. Rather than when I was ready, taking to Google because I didn't know stuff and thought that's what I needed to find out. The diagnosis day, I don't think enough information was given at all. It was really a case of, "This is what we're going to do. We're going to get you into surgery. You're booked in two weeks' time da da and this is what's happening." I hadn't even understood the different grades of cancer or stages or what triple-negative cancer was. I didn't know anything. It was really a lack of information at diagnosis I found. That would have been helpful. Whether I'd read it or not, I don't know, but it would have been good to have. Participant_033

Table 6.9: Timing of information

Timing of information	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=23	%	n=27	%	n=19	%	n=25	%	n=26	%	n=24	%	n=24	%	n=26	%
Participant describes being receptive from the beginning (diagnosis)	12	24.00	7	30.43	5	18.52	3	15.79	8	32.00	6	23.08	6	25.00	6	25.00	6	23.08
Participant describes being receptive to information during treatment	11	22.00	5	21.74	6	22.22	4	21.05	5	20.00	6	23.08	5	20.83	5	20.83	6	23.08
Participant describes being receptive to information after the shock of diagnosis	8	16.00	5	21.74	3	11.11	3	15.79	5	20.00	5	19.23	3	12.50	2	8.33	6	23.08
Participant describes being receptive to information before starting treatment	8	16.00	1	4.35	7	25.93	3	15.79	5	20.00	5	19.23	3	12.50	4	16.67	4	15.38
Participant describes being receptive to information with a week after diagnosis	5	10.00	5	21.74	0	0.00	1	5.26	3	12.00	2	7.69	3	12.50	2	8.33	3	11.54
Participant describes being receptive to information three weeks after diagnosis	5	10.00	1	4.35	4	14.81	5	26.32	0	0.00	2	7.69	3	12.50	1	4.17	4	15.38

Timing of information	All participants		Regional or remote		Metropolitan		Mid to low status		Higher status		Aged 25 to 44		Aged 45 to 54		Aged 55 to 74	
	n=50	%	n=16	%	n=34	%	n=20	%	n=30	%	n=19	%	n=22	%	n=9	%
Participant describes being receptive from the beginning (diagnosis)	12	24.00	4	25.00	8	23.53	4	20.00	8	26.67	2	10.53	8	36.36	2	22.22
Participant describes being receptive to information during treatment	11	22.00	3	18.75	8	23.53	5	25.00	6	20.00	9	47.37	2	9.09	0	0.00
Participant describes being receptive to information after the shock of diagnosis	8	16.00	1	6.25	7	20.59	3	15.00	5	16.67	1	5.26	4	18.18	3	33.33
Participant describes being receptive to information before starting treatment	8	16.00	2	12.50	6	17.65	2	10.00	6	20.00	1	5.26	4	18.18	3	33.33
Participant describes being receptive to information with a week after diagnosis	5	10.00	1	6.25	4	11.76	1	5.00	4	13.33	2	10.53	1	4.55	2	22.22
Participant describes being receptive to information three weeks after diagnosis	5	10.00	2	12.50	3	8.82	3	15.00	2	6.67	3	15.79	2	9.09	0	0.00

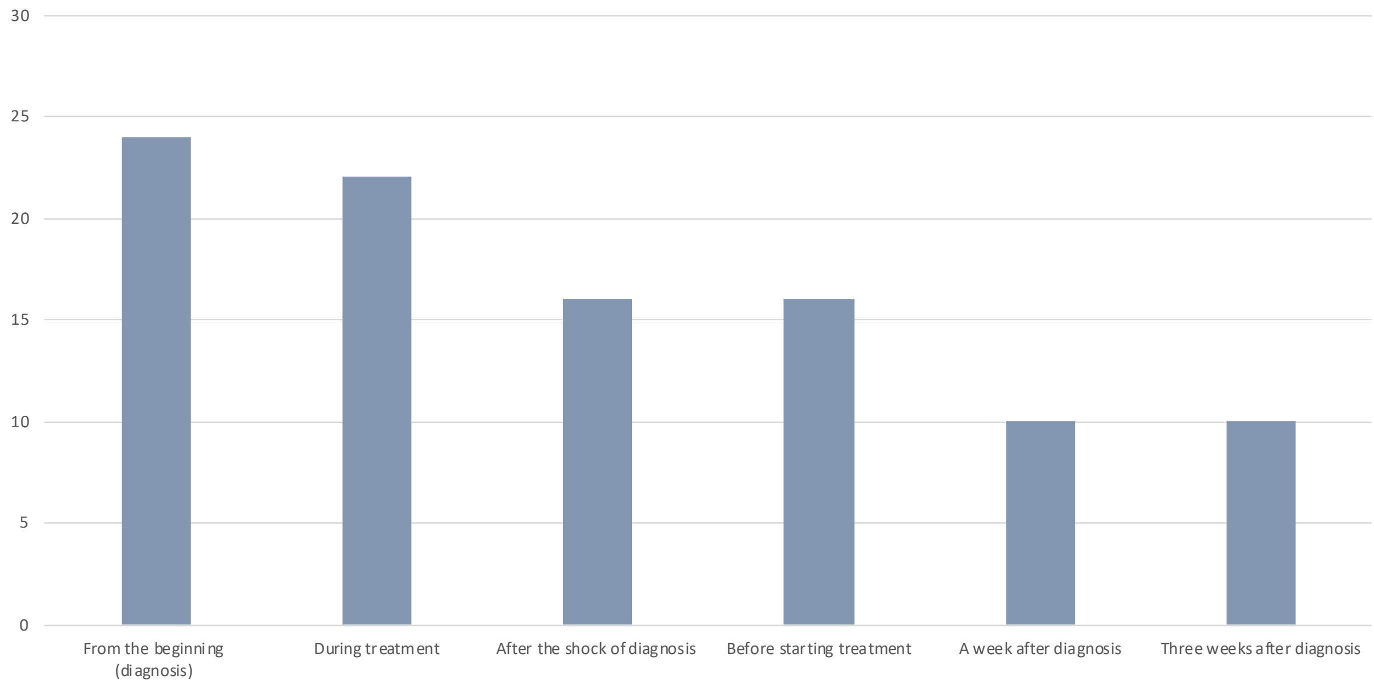


Figure 6.7: Timing of information

Table 6.10: Timing of information – subgroup variations

Theme	Reported less frequently	Reported more frequently
Participant describes being receptive from the beginning (diagnosis)	Aged 25 to 44	Aged 45 to 54
Participant describes being receptive to information during treatment	Aged 45 to 54 Aged 55 to 74	Aged 25 to 44
Participant describes being receptive to information after the shock of diagnosis	Aged 25 to 44	Aged 55 to 74
Participant describes being receptive to information before starting treatment	Early breast cancer Aged 25 to 44	Aged 55 to 74
Participant describes being receptive to information with a week after diagnosis	-	Early breast cancer Aged 55 to 74
Participant describes being receptive to information three weeks after diagnosis	-	Poor physical function

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=26, 52.00%). There were 10 participants (20.00%) that described overall positive, with the exception of one or two occasions, and 8 participants (16.00%) that described a mix of positive and negative. There were four participants (8.00%) who described having an overall negative experience of health professional communication.

Participant describes health professional communication as overall positive

Outstanding. My surgeon says he looks after me and if I have any overall questions, I'm to contact him in terms of overall care. He's been very clear that he'll be seeing me after all the treatment's over to make sure we're keeping a good eye on it not coming back. When I was all stressed about diagnosis, I didn't ever have to pick up the phone to make an appointment or anything. All the scans everything, the oncology, everything was booked for me by [unintelligible]. Participant_007

The communication with all the healthcare professionals I've experienced with breast cancer has been phenomenal. I have such a great relationship with all of my medical professionals. I can ask them any question at any point in time and they will always answer me. I never have felt like because I wasn't having an appointment with them that I couldn't ask the question. For me, I've had no issues with communication. My surgeon came in on a day off after he played tennis on a weekend to make sure that he'd heard that I'd had all of this nerve pain. He wanted to come and check I was okay. I've had really great communication with them. Participant_025

It's been good. Regular check-ups, regular catch-ups, all that sort of thing, so I can ask any questions that I need to ask. I always write down things if I think of them before I go, so I can ask questions. Participant_046

I think it's been good. I've got a very open doctor who's happy to work with me and not just tell me what he thinks should happen and respect that I'm going to be talking to other people and is happy to sit and talk to me about any questions I have or we negotiate when I'll have restaging scans and how I'll manage appointment times around going on holidays and he's great from that point of view. Participant_050

Participant describes health professional communication as overall positive, with the exception of one or two occasions

Overall, they've been fine and nice and everything and pretty helpful, but very much looking at everything just from their medical point of view. It didn't ever feel very holistic. It was fine. They were good, they explained things well, but it was all very medical. Participant_004

I would say pretty good. I know, I'm probably sounding like I haven't had an amazing, but I would say that on a whole-- If I looked at all of my healthcare professionals, there'd be a couple where I'd go, "Uh, that needed to be different." As a whole, I just feel like if the system could be more patient-focused, then it would be 100% better. Overall, I still think that individually, it was okay. Participant_015

Look, every time I've seen a doctor or a nurse they've been fabulous. I could not complain about any of the health professionals that I saw apart from the plastic surgeon. I thought his bedside manner could have done with some improvement. They're all fabulous, but there was this underlying thing of that they're just so overworked that you feel for them. Participant_029

I would class it as good. Because I'm obviously going to a big hospital, sometimes you're not getting back the information that you need in a timely manner I guess, or what I consider a timely manner. I did butt heads with my surgeon. Don't get me wrong, she's a brilliant surgeon, but we did butt heads on a few occasions in regards to my treatment because I felt like I was being forced down a path without being given options. Participant_034

Participant describes health professional communication as a mix of positive and negative

Not bad, not great kind of average, you know, like even now, like I'm going to see my doctor next week and I'm still like I still every year have to go. OK, so are you sending me a referral or do I wait for a phone call from the hospital to make an appointment like I never know from year to year exactly what's going to happen. Like even last year's mammogram, for example, was light because my doctor didn't get off to the hospital and I'm ringing the hospital saying I'm due for one and a lot, but we don't have the referral. So little bit lacking that sense. And, you know, my initial actual diagnosis appointment was the worst experience I've ever had in my life. But between then, you know, between you know, I have like a year like when I used to see my oncologist, I'd go see I went in October 2015, he would give me the piece of paper to go to the hospital 12 months later, and I would just pin it on my pin up at home. And it would be so some aspects of it were really reliable then, because you using different care providers that don't all have the same level of service. Participant_003

It's been good and bad. I honestly expected a bit more care and personal-- a little bit more care factor. I have switched oncologists. I would have preferred a little bit more empathy and care overall, but then my radiation oncologist and my surgeon were fantastic, so I did appreciate their care. I think it just depends on who your treating doctor is. Participant_016

It's hard to differentiate because it's been a year, a year-long journey. I would say I had two different practices that I was part of. The first one, it was really false hope, not giving me enough information. It was only telling me, "You're fine. Keep going. You're fine." Brushing it off, like not making appointments in person or through certain phone calls. Just really, really poor. Second time, unfortunately, I'm in a situation where I have to be taken quite seriously. My doctors have been very thorough and my oncologist saved my life because pretty much, I had days to live before they were going to affect my brain. Participant_042

Participant describes health professional communication as overall negative

The communication has been I might get a recall for an appointment or I have a question. I have to try and chase up and find someone to answer it. But really, there's been it's definitely not been holistic at all or anything about emotional wellbeing at all. It's been very functional. Participant_001

PARTICIPANT: Pretty poor.
INTERVIEWER: Do you have any examples that come to mind that you would like to share?
PARTICIPANT: My main problem with my oncologist who [chuckles] she made assumptions about my treatment rather than checking my file before she put me on different medications. She doesn't return phone calls, she doesn't return emails. Her lack of follow-up is very frustrating. The turning point for me was when she put me on medication and when I did my annual research and contacted her and said, "Should I really be on this?" She was like, "Well, this is why I put you on it." I'm like, "That's not why I was taking that." She said, "Oh, yes. I forgot." It was like I lost all confidence at that time. Participant_027

The thing is no one, actually, has come back to me and said, "All the guidelines have changed, maybe you should go and get genetically tested." None of my breast care providers did that. It was only that I had a, what do you call them, my gastroenterologist. I have ulcerative colitis and it's in remission, so every three years, I have a colonoscopy. Then one of my colonoscopies he found these flat hollowed. He said that I should look into getting genetically tested for breast cancer because there can be a link between bile cancer and breast cancer. He told me to go and get genetically tested. Then, when I got my results, I happened to seen him again and I'd been to the breast clinic and explained to them and I'd say, "We'll just monitor the condition." My gastroenterologist said, "No, no, no, you need to go and get a different opinion and see this breast specialist because she specializes in genetic conditions as well." I went and saw her. Whenever the guidelines changed for being able to be genetically tested, I think I should have been notified back then. Participant_037

Table 6.11: Healthcare professional communication.

Healthcare professional communication	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=23	%	n=27	%	n=19	%	n=25	%	n=26	%	n=24	%	n=24	%	n=26	%
Participant describes health professional communication as overall positive	26	52.00	11	47.83	15	55.56	11	57.89	15	60.00	14	53.85	12	50.00	**9**	**37.50**	**17**	**65.3**
Participant describes health professional communication as overall positive, with the exception of one or two occasions	10	20.00	6	26.09	4	14.81	4	21.05	5	20.00	3	11.54	7	29.17	7	29.17	3	11.5
Participant describes health professional communication as a mix of positive and negative	8	16.00	4	17.39	4	14.81	3	15.79	2	8.00	4	15.38	4	16.67	4	16.67	4	15.3
Participant describes health professional communication as overall negative	4	8.00	2	8.70	2	7.41	0	0.00	2	8.00	3	11.54	1	4.17	2	8.33	2	7.69

Healthcare professional communication	All participants		Regional or remote		Metropolitan		Mid to low status		Higher status		Aged 25 to 44		Aged 45 to 54		Aged 55 to 7	
	n=50	%	n=16	%	n=34	%	n=20	%	n=30	%	n=19	%	n=22	%	n=9	%
Participant describes health professional communication as overall positive	26	52.00	8	50.00	18	52.94	9	45.00	17	56.67	8	42.11	**14**	**63.64**	4	44.4
Participant describes health professional communication as overall positive, with the exception of one or two occasions	10	20.00	**5**	**31.25**	5	14.71	4	20.00	6	20.00	2	10.53	3	13.64	**5**	**55.5**
Participant describes health professional communication as a mix of positive and negative	8	16.00	3	18.75	5	14.71	4	20.00	4	13.33	**5**	**26.32**	3	13.64	**0**	**0.00**
Participant describes health professional communication as overall negative	4	8.00	0	0.00	4	11.76	1	5.00	3	10.00	2	10.53	2	9.09	0	0.00

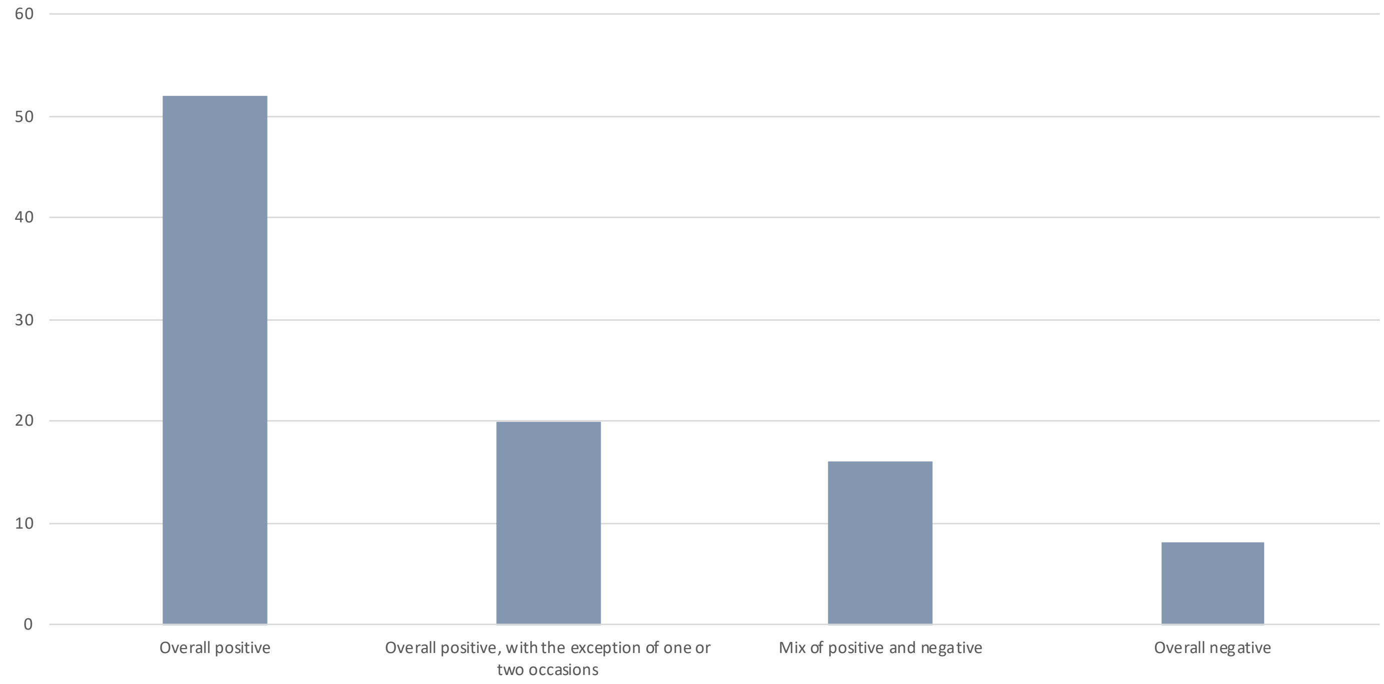


Figure 6.8: Healthcare professional communication

Table 6.12: Healthcare professional communication – subgroup variations

Theme	Reported less frequently	Reported more frequently
Participant describes health professional communication as overall positive	Trade or high school	University Aged 45 to 54
Participant describes health professional communication as overall positive, with the exception of one or two occasions	-	Regional or remote Aged 55 to 74
Participant describes health professional communication as a mix of positive and negative	Aged 55 to 74	Aged 25 to 44

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 communication was holistic (two way, supportive and comprehensive conversations) (n=20, 40.00%), and helpful (n=5, 10.00%).

The main reason for negative communication was communication that was not forthcoming, or generally lacking (n=11, 22.00%). This was followed by communication that was dismissive (one way conversations) (n=5, 10.00%), and that had limited understanding of the condition (n=4, 8.00%).

Participant describes health professional communication as holistic (Two way, supportive and comprehensive conversations)

Excellent, excellent. Everyone's on the same page. No one's contradicting each other and all that sort of stuff. Everyone's clear, optimistic, and good. Participant_005

The communication with all the healthcare professionals I've experienced with breast cancer has been phenomenal. I have such a great relationship with all of my medical professionals. I can ask them any question at any point in time and they will always answer me. I never have felt like because I wasn't having an appointment with them that I couldn't ask the question. For me, I've had no issues with communication. My surgeon came in on a day off after he played tennis on a weekend to make sure that he'd heard that I'd had all of this nerve pain. He wanted to come and check I was okay. I've had really great communication with them. Participant_025

It's been good. Regular checkups, regular catch-ups, all that sort of thing, so I can ask any questions that I need to ask. I always write down things if I think of them before I go, so I can ask questions. Participant_046

Participant describes health professional communication as helpful

I think I can't fault them. They have been very attentive, and they got me in very, very quickly. Within a week, I was basically about to receive chemo and all that kind of stuff. I've never found any of my doctors-- There were a couple that are a little bit abrupt. That's just doctors. If you ask the right questions, they've always been very helpful. I think the oncologist was probably the most helpful out of all of them. I've not really had a problem. The health care nurse was good when I saw her, but I just didn't see her enough. There has been time after it where I wouldn't have minded talking to someone, but I just didn't really know we could go to get that. Participant_035

I've been very lucky that I have a beautiful oncologist and he answers all my questions and to my parents questions, takes my concerns into consideration and will do follow up scans of anything. But we're unsure of my surgeon is the same, although she doesn't do sarcasm as much as I do and so much more serious conversation with her. But once again, she answers all my questions, gives me all the information, and I guess both of them have learnt the way I think and that I, I personally feel more control and power having lots of information, especially being a nurse as well. Whereas I've got friends that ignorance is bliss and they don't want to know the statistics or the ins and outs. I feel more in control knowing that stuff. So they'll give me a lot more of that information than they might. Just a general cancer patient and my McGraw nurses and the twenty four hour line were always able to pick up my phone calls and answer any questions I had or come with me if I had any concerns. We also have a it's called the Kinkier Wellness Programme, and so it offered weekly torchy and weekly art classes. That was something that I accessed. And so I was able to meet other cancer patients. And I think even that level of communication is really important because no one in your life understands what you're going through. So it connects it with other people that you can vent to when they're not going to say stupid, positive hallmark saying back to try and make you feel better or they'll just understand what you're saying. And I think even that communication within the community was really helpful. Participant_010

Overall, they've been fine and nice and everything and pretty helpful, but very much looking at everything just from their medical point of view. It didn't ever feel very holistic. It was fine. They were good, they explained things well, but it was all very medical. Participant_004

Participant describes healthcare communication as limited (not forthcoming/lacking)

Pretty okay. I think I've had one or two doctors where I thought, okay. For the next ones come on…I think it was because I was getting conflicting information. One person was telling me one thing, another person was telling me something else. I was like, "Well, Hmm. I don't know what's going on here. I'll just wait," and it was incorrect information in the end. Participant_012

Great. If I ask a question, they will answer. The nurses and breast care nurses have been great, but they're not forthcoming with bad news, so to speak. They will only be forthcoming with good news. They don't like to talk about what the bad things could happen. They rather just focus on the good, which has been great, which you need, but then sometimes you need to face reality as well. Participant_018

PARTICIPANT: Vague.
INTERVIEWER: Okay. [laughs] Not much information from your perspective.
PARTICIPANT: It almost feels like nobody knows anything, but I obviously know that they do. They just don't tell you anything. Participant_019

Participant describes health professional communication as being dismissive (One way conversation)

A bit mixed because sometimes they're a bit like-- Even my oncologist with the side effects sometimes she's like, "Well, maybe it's just menopause." I'm like, "No, I'm fairly sure that all of this isn't just menopause. It's early menopause." I found that her admitting that it's the drugs that she gave me that were causing these symptoms that sometimes wasn't always there. She sometimes was trying to say it was just normal women going through menopause, that kind of stuff. I actually got a strong personality obviously and so I said, "No, I know that this drug causes this, and this drug causes this." She goes, "Oh, yes. Okay. Yes." Getting believed about why and what sometimes is a bit difficult. No one told me about menopause and what happened. either because [chuckles] I was only 42, 43. I hadn't really worked out the *symptoms of menopause and what that can do to you as well. I was a bit surprised that I wasn't warned about that. Participant_008*

It's hard to differentiate because it's been a year, a year-long journey. I would say I had two different practices that I was part of. The first one, it was really false hope, not giving me enough information. It was only telling me, "You're fine. Keep going. You're fine." Brushing it off, like not making appointments in person or through certain phone calls. Just really, really poor. Second time, unfortunately, I'm in a situation where I have to be taken quite seriously. My doctors have been very thorough and my oncologist saved my life because pretty much, I had days to live before they were going to affect my brain. Participant_042

Table 6.13: Healthcare professional communication (Rationale for response)

Healthcare professional communication (Rationale for response)	**All participants**		**Early breast cancer**		**Advanced breast cancer**		**Poor physical function**		**Good physical function**		**Diagnosed before 2020**		**Diagnosed in 2020 or 2021**		**Trade or high school**		**University**	
	n=50	**%**	**n=23**	**%**	**n=27**	**%**	**n=19**	**%**	**n=25**	**%**	**n=26**	**%**	**n=24**	**%**	**n=24**	**%**	**n=26**	**%**
Participant describes health professional communication as holistic (Two way, supportive and comprehensive conversations)	20	40.00	9	39.13	11	40.74	7	36.84	**13**	**52.00**	10	38.46	10	41.67	**6**	**25.00**	**14**	**53.85**
Participant describes health professional communication as helpful	5	10.00	3	13.04	2	7.41	1	5.26	4	16.00	3	11.54	2	8.33	3	12.50	2	7.69
Participant describes healthcare communication as limited (not forthcoming/lacking)	11	22.00	5	21.74	6	22.22	**2**	**10.53**	4	16.00	5	19.23	6	25.00	7	29.17	4	15.38
Participant describes health professional communication as being dismissive (One way conversation)	5	10.00	3	13.04	2	7.41	2	10.53	2	8.00	3	11.54	2	8.33	1	4.17	4	15.38
Participant describes no specific reason for healthcare communication	13	26.00	6	26.09	7	25.93	**8**	**42.11**	5	20.00	6	23.08	7	29.17	7	29.17	6	23.08

Healthcare professional communication (Rationale for response)	**All participants**		**Regional or remote**		**Metropolitan**		**Mid to low status**		**Higher status**		**Aged 25 to 44**		**Aged 45 to 54**		**Aged 55 to 74**	
	n=50	**%**	**n=16**	**%**	**n=34**	**%**	**n=20**	**%**	**n=30**	**%**	**n=19**	**%**	**n=22**	**%**	**n=9**	**%**
Participant describes health professional communication as holistic (Two way, supportive and comprehensive conversations)	20	40.00	7	43.75	13	38.24	7	35.00	13	43.33	7	36.84	9	40.91	4	44.44
Participant describes health professional communication as helpful	5	10.00	1	6.25	4	11.76	2	10.00	3	10.00	1	5.26	0	0.00	**4**	**44.44**
Participant describes healthcare communication as limited (not forthcoming/lacking)	11	22.00	5	31.25	6	17.65	5	25.00	6	20.00	4	21.05	4	18.18	**3**	**33.33**
Participant describes health professional communication as being dismissive (One way conversation)	5	10.00	0	0.00	5	14.71	1	5.00	4	13.33	**4**	**21.05**	1	4.55	0	0.00
Participant describes no specific reason for healthcare communication	13	26.00	5	31.25	8	23.53	5	25.00	8	26.67	**3**	**15.79**	**8**	**36.36**	2	22.22

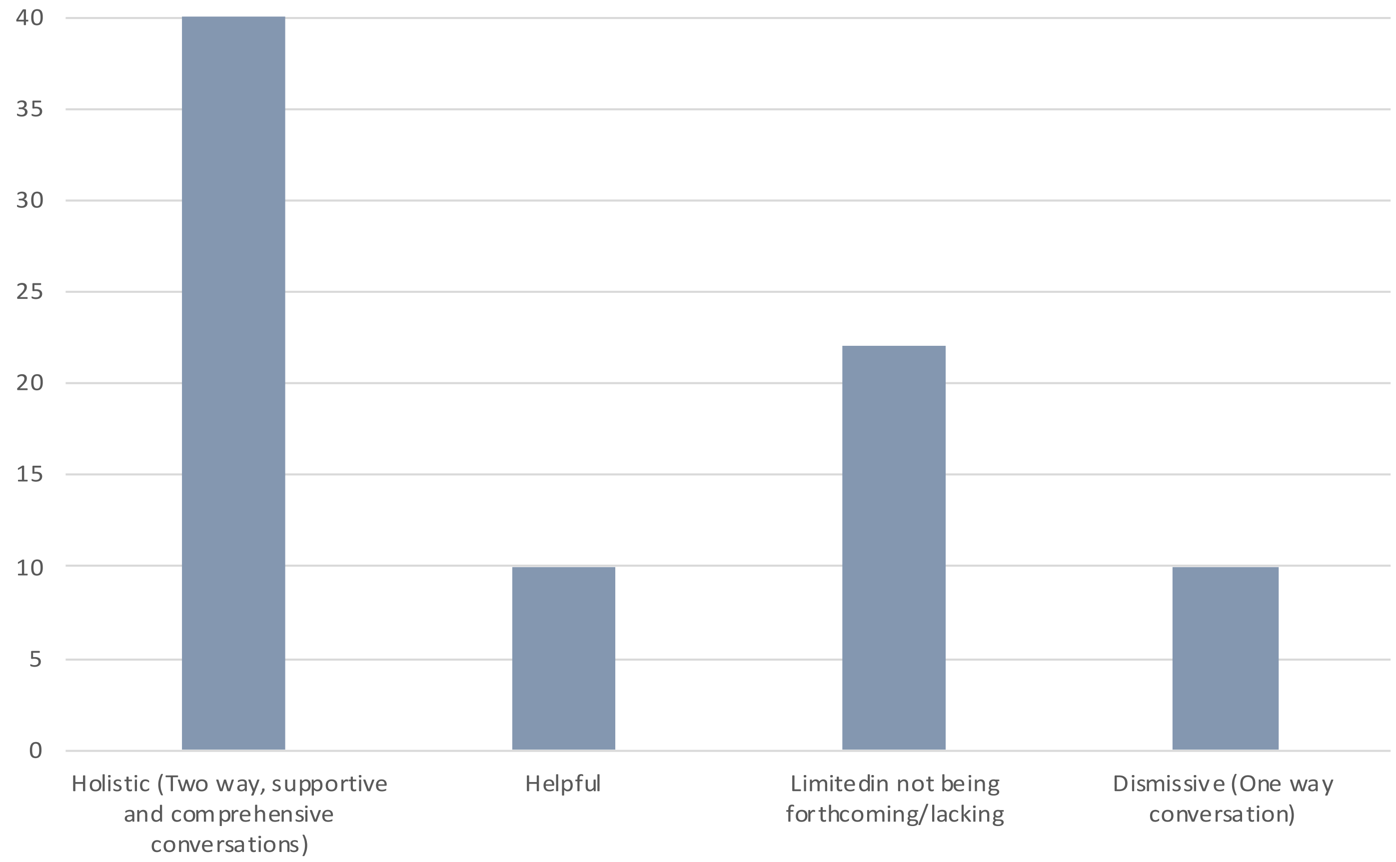


Figure 6.9: Healthcare professional communication (Rationale for response)

Table 6.14: Healthcare professional communication (Rationale for response) – subgroup variations

Theme	Reported less frequently	Reported more frequently
Participant describes health professional communication as holistic (Two way, supportive and comprehensive conversations)	Trade or high school	Good physical function University
Participant describes health professional communication as helpful	-	Aged 55 to 74
Participant describes healthcare communication as limited (not forthcoming/lacking)	Poor physical function	Aged 55 to 74
Participant describes health professional communication as being dismissive (One way conversation)	-	Aged 25 to 44
Participant describes no specific reason for healthcare communication	Aged 25 to 44	Poor physical function Aged 45 to 54

Partners in health

The Partners in Health questionnaire (PIH) measures an individual’s knowledge and confidence for managing their own health. The Partners in Health comprises a global score, 4 scales; knowledge, coping, recognition and treatment of symptoms, adherence to treatment and total score. A higher score denotes a better understanding and knowledge of disease. Summary statistics for the entire cohort are displayed alongside the possible range of each scale in Table 6.15.

The overall scores for the cohort were in the highest quintile for the **Partners in health: knowledge** (mean = 25.98, SD = 3.51), **Partners in health: recognition and management of symptoms** (median = 20.00, IQR = 2.50), **Partners in health: adherence to treatment** (median = 15.00, IQR = 2.00), scales, indicating very good scores for managing their health.

The overall scores for the cohort were in the second highest quintile for the **Partners in health: coping** (mean = 16.18, SD = 4.26), **Partners in health: total score** (mean = 76.23, SD = 8.93), scales, indicating good scores for managing their health.

Comparisons of Partners in health have been made based on **breast cancer stage** (Tables 6.16 to 6.17, Figures 6.10 to 6.14), **physical function** (Tables 6.18 to 6.19, Figures 6.15 to 6.19), **year of diagnosis** (Tables 6.20 to 6.21, Figures 6.20 to 6.24), **education,** (Tables 6.22 to 6.23, Figures 6.25 to 6.29), **location** (Tables 6.24 to 6.25, Figures 6.30 to 6.34), **socioeconomic status** (Tables 6.26 to 6.27, Figures 6.35 to 6.39), and **age** (Tables 6.28 to 6.29, Figures 6.40 to 6.44).

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

Table 6.15: Partners in health summary statistics

Partners in health scale (n=44)	Mean	SD	Median	IQR	Possible range	Quintile
Knowledge*	25.98	3.51	26.50	5.00	0 to 32	5
Coping*	16.18	4.26	16.00	8.00	0 to 24	4
Recognition and management of symptoms	19.61	2.66	20.00	2.50	0 to 24	5
Adherence to treatment	14.45	1.65	15.00	2.00	0 to 16	5
Total score*	76.23	8.93	76.00	12.50	0 to 96	4

*Normal distribution use mean and SD as measure of central tendency

Partners in health by breast cancer stage

Comparisons were made by **breast cancer stage**, there were 23 participants (46.00%) with *Early breast cancer* (Stage I or Stage II) and, 27 participants (54.00%) with *Advanced breast cancer* (Stage II or Stage IV).

A two-sample t-test was used when assumptions for normality and variance were met (Table 6.16), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 6.17).

No significant differences were observed between participants by **breast cancer stage** for any of the Partners in health scales.

Table 6.16: Partners in health by breast cancer stage summary statistics and T-test

Partners in health scale	Group	Number (n=44)	Percent	Mean	SD	T	dF	p-value
Knowledge	Early breast cancer	20	45.45	26.20	3.32	0.38	42	0.7059
	Advanced breast cancer	24	54.55	25.79	3.73			
Coping	Early breast cancer	20	45.45	15.20	4.67	-1.41	42	0.1655
	Advanced breast cancer	24	54.55	17.00	3.79			
Recognition and management of symptoms	Early breast cancer	20	45.45	19.15	2.92	-1.06	42	0.2968
	Advanced breast cancer	24	54.55	20.00	2.41			
Total score	Early breast cancer	20	45.45	75.05	9.23	-0.80	42	0.4309
	Advanced breast cancer	24	54.55	77.21	8.74			

Table 6.17: Partners in health by breast cancer stage summary statistics and Wilcoxon test

Partners in health scale	Group	Number (n=44)	Percent	Median	IQR	W	p-value
Adherence to treatment	Early breast cancer	20	45.45	15.00	2.25	265.50	0.5419
	Advanced breast cancer	24	54.55	14.50	2.00		

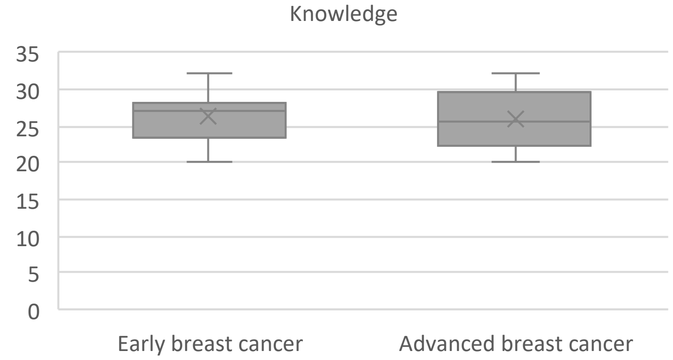


Figure 6.10: Boxplot of Partners in health: knowledge by breast cancer stage

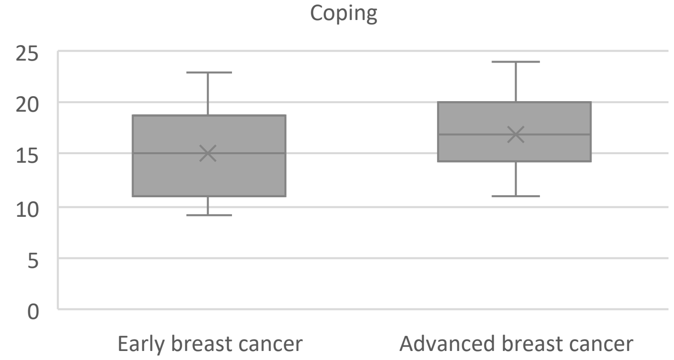


Figure 6.11: Boxplot of Partners in health: coping by breast cancer stage

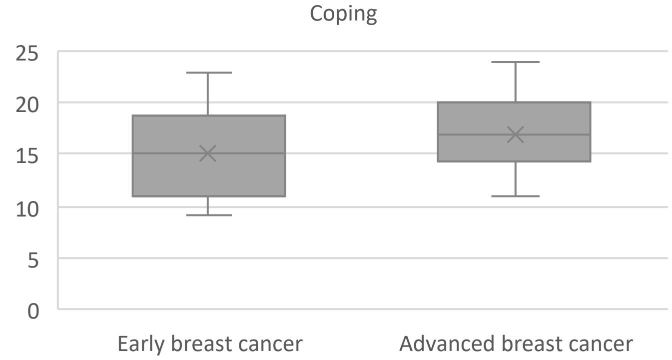


Figure 6.12: Boxplot of Partners in health: recognition and management of symptoms by breast cancer stage

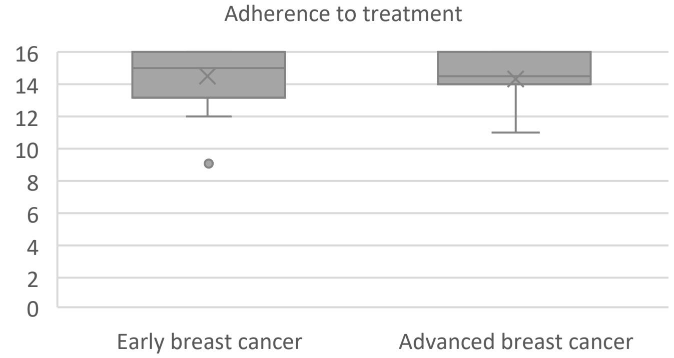


Figure 6.13: Boxplot of Partners in health: adherence to treatment by breast cancer stage

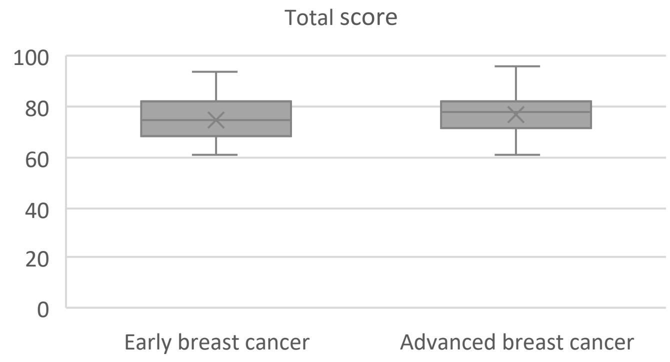


Figure 6.14: Boxplot of Partners in health Total score by breast cancer stage

Partners in health by Physical function

Physical function was evaluated by the SF36 Role functioning/physical, this measures how physical health interferes with work or other activities. Participants that had an SF36 Role functioning/physical score of 40 or less were included in the *Poor physical function* subgroup (n=19, 43.18 %), and participants that scored more than 40 were included in the G*ood physical function* subgroup (n=25, 56.82%).

A two-sample t-test was used when assumptions for normality and variance were met (Table 6.18), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 6.19).

No significant differences were observed between participants by **physical function** for any of the Partners in health scales.

Table 6.18: Partners in health by physical function summary statistics and T-test

Partners in health scale	Group	Number (n=44)	Percent	Mean	SD	T	dF	p-value
Knowledge	Poor physical function	19	43.18	26.26	3.51	0.47	42.00	0.6435
	Good physical function	25	56.82	25.76	3.57			
Coping	Poor physical function	19	43.18	15.21	4.64	-1.33	42.00	0.1907
	Good physical function	25	56.82	16.92	3.88			
Recognition and management of symptoms	Poor physical function	19	43.18	19.05	3.01	-1.23	42.00	0.2269
	Good physical function	25	56.82	20.04	2.34			
Total score	Poor physical function	19	43.18	75.21	9.54	-0.65	42.00	0.5165
	Good physical function	25	56.82	77.00	8.55			

Table 6.19: Partners in health by physical function summary statistics and Wilcoxon test

Partners in health scale	Group	Number (n=44)	Percent	Median	IQR	W	p-value
Adherence to treatment	Poor physical function	19	43.18	15.00	2.00	270.00	0.4325
	Good physical function	25	56.82	14.00	2.00		

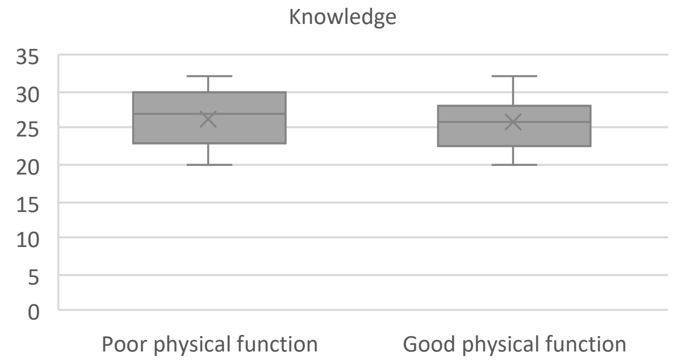


Figure 6.15: Boxplot of Partners in health: knowledge by Pphysical function

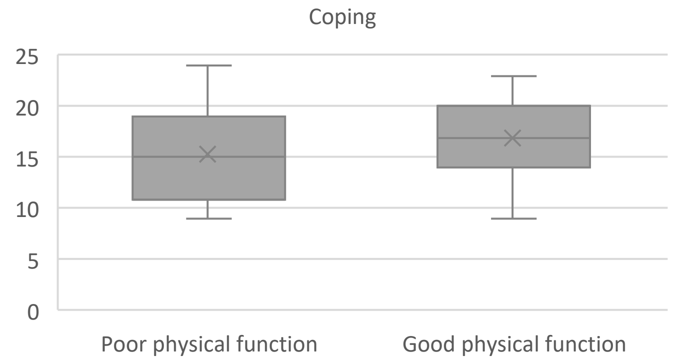


Figure 6.16: Boxplot of Partners in health: coping by physical function

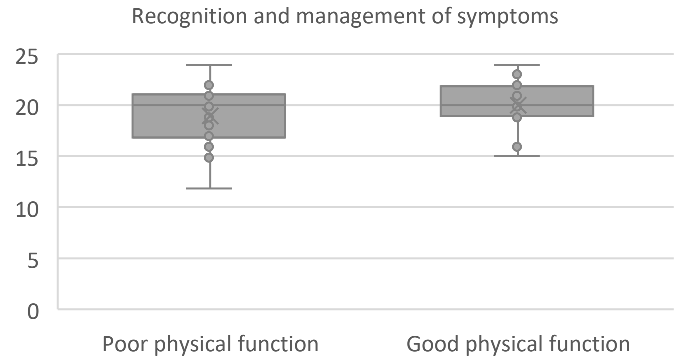


Figure 6.17: Boxplot of Partners in health: recognition and management of symptoms by physical function

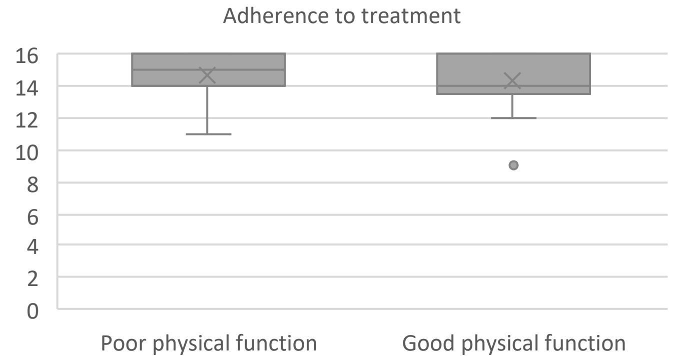


Figure 6.18: Boxplot of Partners in health: adherence to treatment by physical function

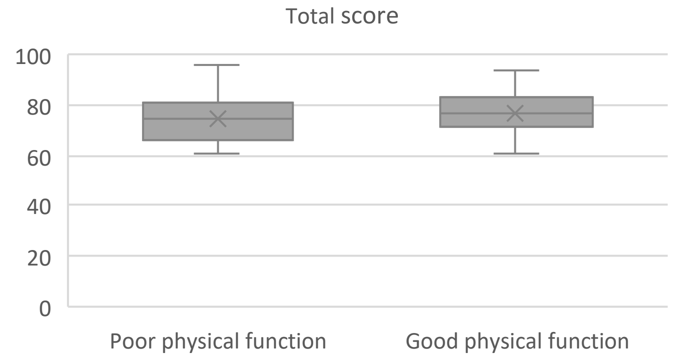


Figure 6.19: Boxplot of Partners in health Total score by physical function

Partners in health by year of diagnosis

Comparisons were made by the **year of diagnosis**, there were 26 participants that were *Diagnosed before 2020* (52.00%), and 24 participants *Diagnosed in 2020 or 2021* (48.00%).

A two-sample t-test was used when assumptions for normality and variance were met (Table 6.20), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 6.21).

No significant differences were observed between participants by **year of diagnosis** for any of the Partners in health scales.

Table 6.20: Partners in health by year of diagnosis summary statistics and T-test

Partners in health scale	Group	Number (n=44)	Percent	Mean	SD	T	dF	p-value
Coping	Diagnosed before 2020	22	50.00	16.64	3.71	0.70	42	0.4856
	Diagnosed in 2020 or 2021	22	50.00	15.73	4.79			
Recognition and management of symptoms	Diagnosed before 2020	22	50.00	19.86	2.25	0.62	42	0.5394
	Diagnosed in 2020 or 2021	22	50.00	19.36	3.05			
Total score	Diagnosed before 2020	22	50.00	77.09	8.56	0.64	42	0.5273
	Diagnosed in 2020 or 2021	22	50.00	75.36	9.40			

Table 6.21: Partners in health by year of diagnosis summary statistics and Wilcoxon test

Partners in health scale	Group	Number (n=44)	Percent	Median	IQR	W	p-value
Knowledge	Diagnosed before 2020	22	50.00	27.50	6.50	276.50	0.4226
	Diagnosed in 2020 or 2021	22	50.00	25.50	4.50		
Adherence to treatment	Diagnosed before 2020	22	50.00	15.00	2.00	235.00	0.8745
	Diagnosed in 2020 or 2021	22	50.00	15.00	2.00		

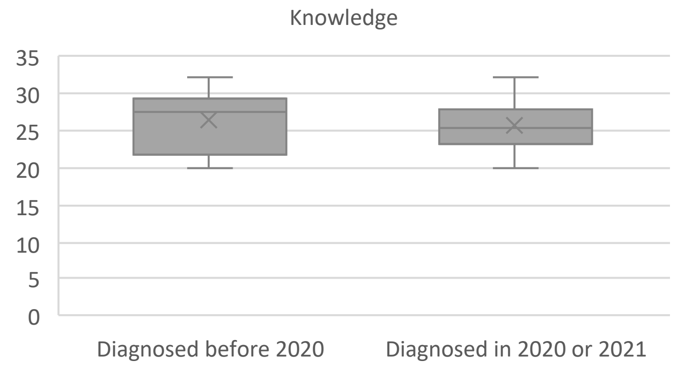


Figure 6.20: Boxplot of Partners in health: knowledge by year of diagnosis

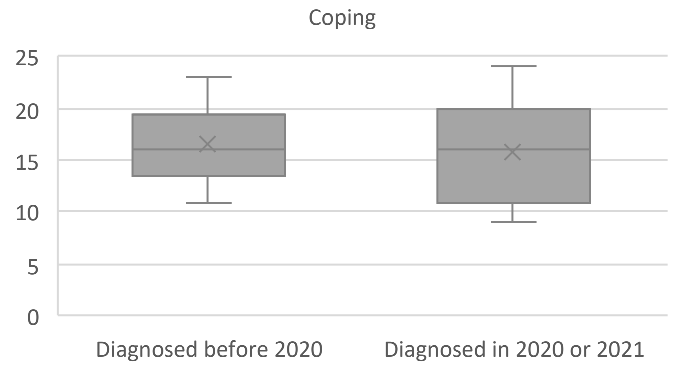


Figure 6.21: Boxplot of Partners in health: coping by year of diagnosis

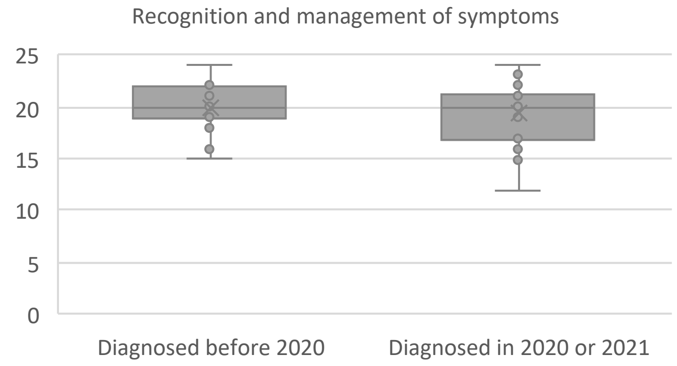


Figure 6.22: Boxplot of Partners in health: recognition and management of symptoms by year of diagnosis

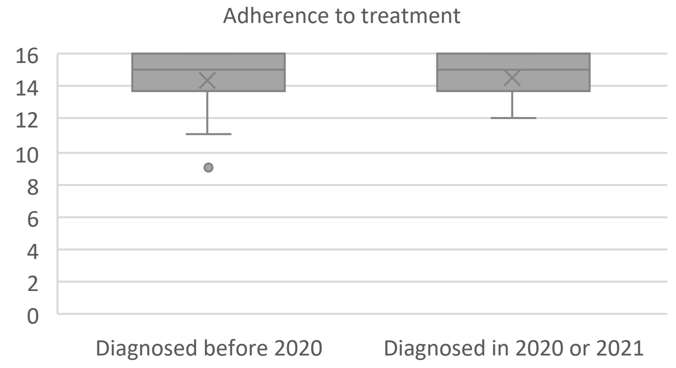


Figure 6.23: Boxplot of Partners in health: adherence to treatment by year of diagnosis

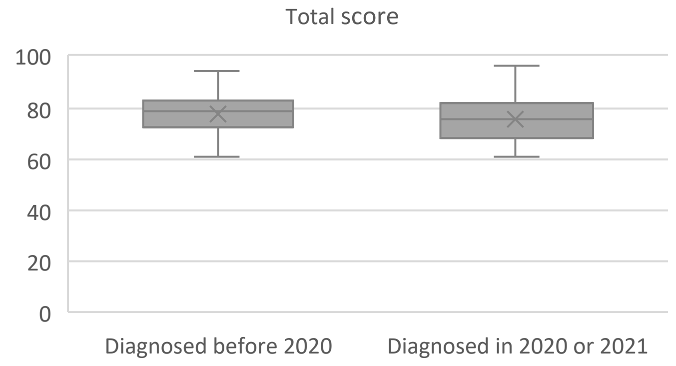


Figure 6.24: Boxplot of Partners in health Total score by year of diagnosis

Partners in health by education

Comparisons were made by **education** status, between those with *Trade or high school* qualifications, (n = 24, 48.00%), and those with a *University* qualification (n = 26, 52.00%).

A two-sample t-test was used when assumptions for normality and variance were met (Table 6.22), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 6.23).

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

Table 6.22: Partners in health by education summary statistics and T-test

Partners in health scale	Group	Number (n=44)	Percent	Mean	SD	T	dF	p-value
Knowledge	Trade or high school	21	47.73	25.62	3.63	-0.64	42	0.5246
	University	23	52.27	26.30	3.46			
Coping	Trade or high school	21	47.73	16.05	4.08	-0.20	42	0.8445
	University	23	52.27	16.30	4.51			
Total score	Trade or high school	21	47.73	75.43	8.17	-0.56	42	0.5767
	University	23	52.27	76.96	9.69			

Table 6.23: Partners in health by education summary statistics and Wilcoxon test

Partners in health scale	Group	Number (n=44)	Percent	Median	IQR	W	p-value
Recognition and management of symptoms	Trade or high school	21	47.73	20.00	2.00	220.00	0.6182
	University	23	52.27	21.00	5.00		
Adherence to treatment	Trade or high school	21	47.73	14.00	3.00	200.50	0.3246
	University	23	52.27	15.00	2.00		

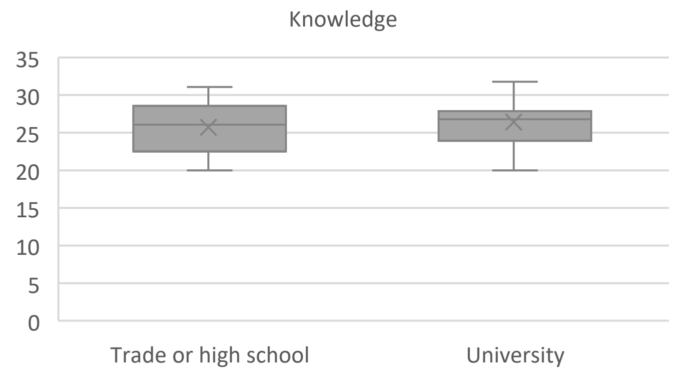


Figure 6.25: Boxplot of Partners in health: knowledge by education

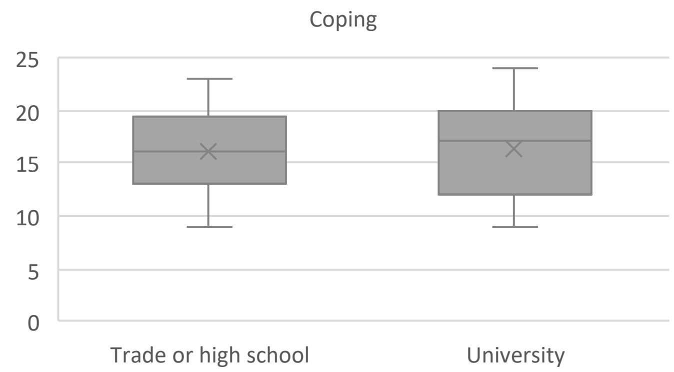


Figure 6.26: Boxplot of Partners in health: coping by education

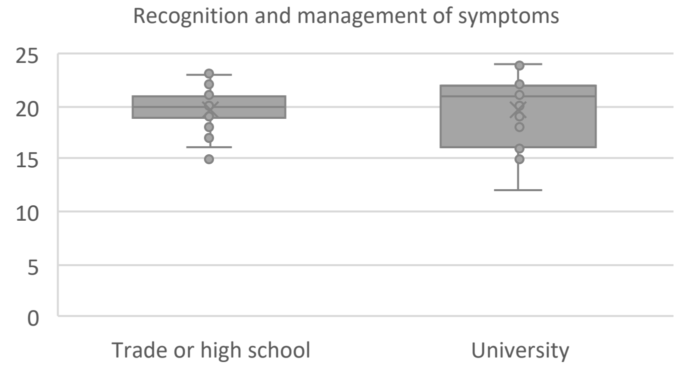


Figure 6.27: Boxplot of Partners in health: recognition and management of symptoms by education

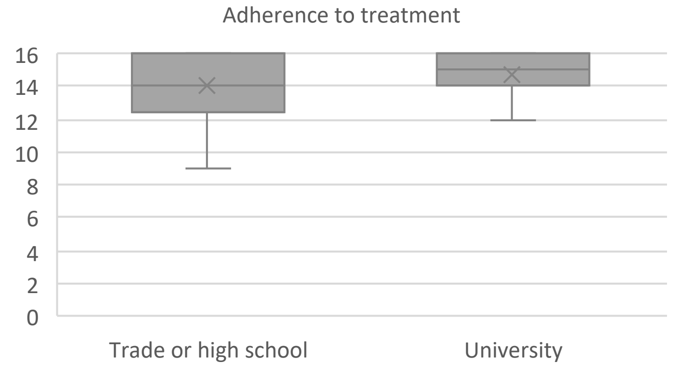


Figure 6.28: Boxplot of Partners in health: adherence to treatment by education

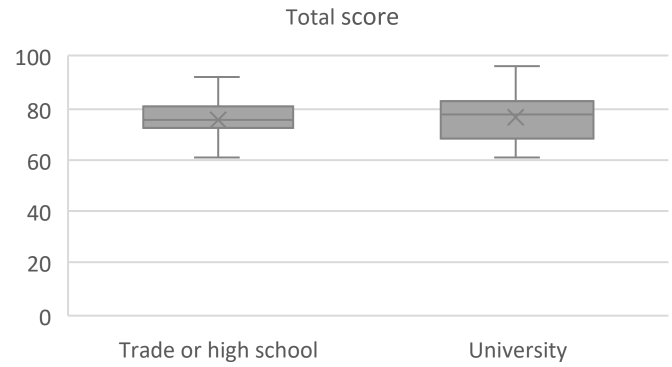


Figure 6.29: Boxplot of Partners in health Total score by education

Partners in health by location

The **location** of participants was evaluated by postcode using the Australian Statistical Geography Maps (ASGS) Remoteness areas accessed from the Australian Bureau of Statistics. Those living in regional/rural areas, *Regional or remote* (n =16, 32.00%) were compared to those living in a major city, *Metropolitan* (n = 34, 68.00%).

A two-sample t-test was used when assumptions for normality and variance were met (Table 6.24), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 6.25).

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

Table 6.24: Partners in health by location summary statistics and T-test

Partners in health scale	Group	Number (n=44)	Percent	Mean	SD	T	dF	p-value
Knowledge	Regional or remote	14	31.82	27.14	3.44	1.53	42	0.1345
	Metropolitan	30	68.18	25.43	3.47			
Coping	Regional or remote	14	31.82	17.57	4.33	1.50	42	0.1413
	Metropolitan	30	68.18	15.53	4.14			

Table 6.25: Partners in health by location summary statistics and Wilcoxon test

Partners in health scale	Group	Number (n=44)	Percent	Median	IQR	W	p-value
Recognition and management of symptoms	Regional or remote	14	31.82	20.00	1.75	259.00	0.2170
	Metropolitan	30	68.18	20.00	4.75		
Adherence to treatment	Regional or remote	14	31.82	15.00	2.00	233.00	0.5573
	Metropolitan	30	68.18	15.00	3.00		
Total score	Regional or remote	14	31.82	79.00	6.75	284.50	0.0619
	Metropolitan	30	68.18	73.00	15.25		

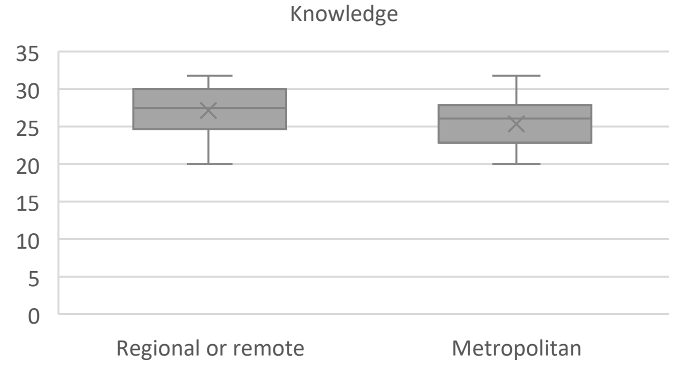


Figure 6.30: Boxplot of Partners in health: knowledge by location

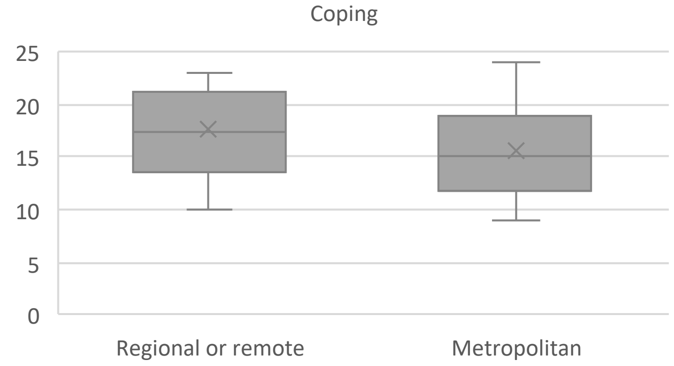


Figure 6.31: Boxplot of Partners in health: coping by location

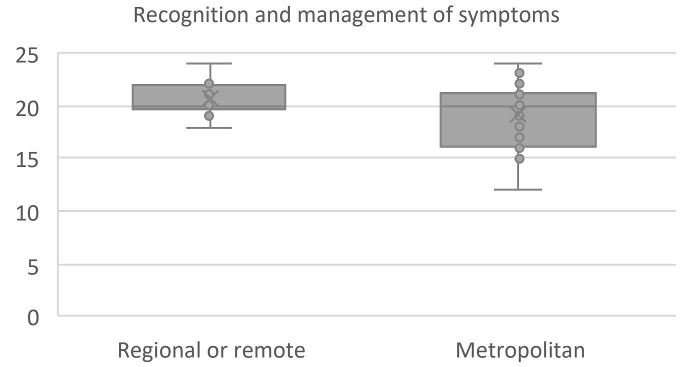


Figure 6.32: Boxplot of Partners in health: recognition and management of symptoms by location

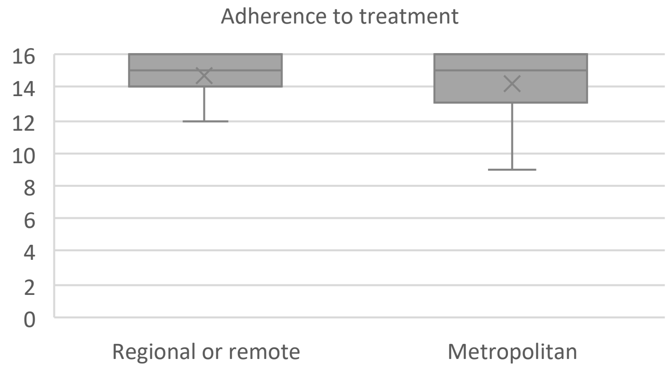


Figure 6.33: Boxplot of Partners in health: adherence to treatment by location

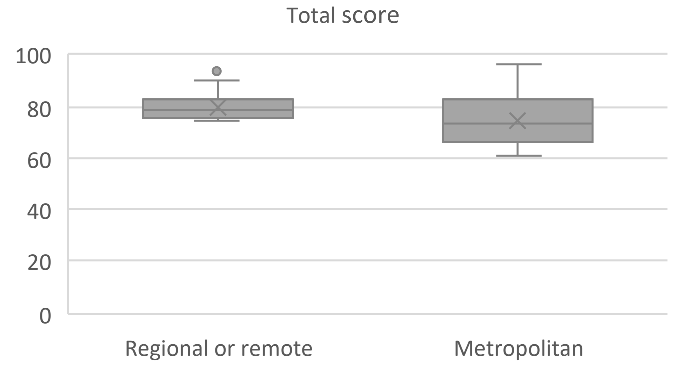


Figure 6.34: Boxplot of Partners in health Total score by location

Partners in health by socioeconomic status

Comparisons were made by **socioeconomic status**, using the Socio-economic Indexes for Areas (SEIFA) (www.abs.gov.au), SEIFA scores range from 1 to 10, a higher score denotes a higher level of advantage. Participants with a mid to low SEIFA score of 1-6, *Mid to low status* (n = 20, 40.00%) compared to those with a higher SEIFA score of 7-10, *Higher status* (n = 30, 60.00%).

A two-sample t-test was used when assumptions for normality and variance were met (Table 6.26), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 6.27).

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

Table 6.26: Partners in health by socioeconomic status summary statistics and T-test

Partners in health scale	Group	Number (n=44)	Percent	Mean	SD	T	dF	p-value
Knowledge	Mid to low status	17	38.64	26.35	3.16	0.56	42	0.5797
	Higher status	27	61.36	25.74	3.76			
Coping	Mid to low status	17	38.64	16.71	4.63	0.64	42	0.5237
	Higher status	27	61.36	15.85	4.06			
Total score	Mid to low status	17	38.64	77.65	7.42	0.83	42	0.4088
	Higher status	27	61.36	75.33	9.79			

Table 6.27: Partners in health by socioeconomic status summary statistics and Wilcoxon test

Partners in health scale	Group	Number (n=44)	Percent	Median	IQR	W	p-value
Recognition and management of symptoms	Mid to low status	17	38.64	21.00	1.00	268.50	0.3485
	Higher status	27	61.36	20.00	4.00		
Adherence to treatment	Mid to low status	17	38.64	15.00	2.00	257.00	0.5005
	Higher status	27	61.36	14.00	2.50		

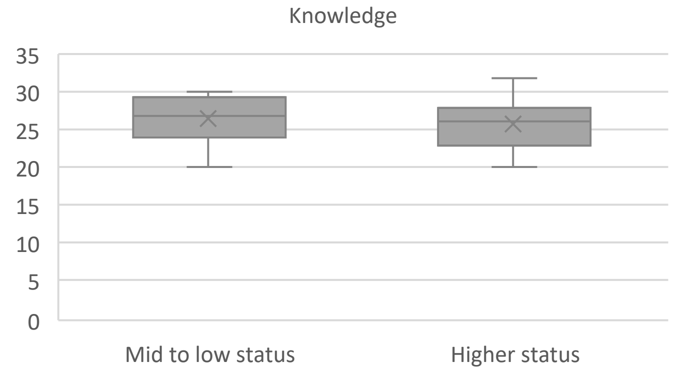


Figure 6.35: Boxplot of Partners in health: knowledge by socioeconomic status

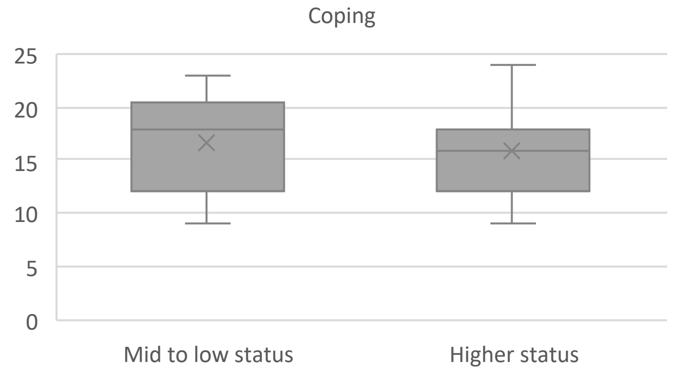


Figure 6.36: Boxplot of Partners in health: coping by socioeconomic status

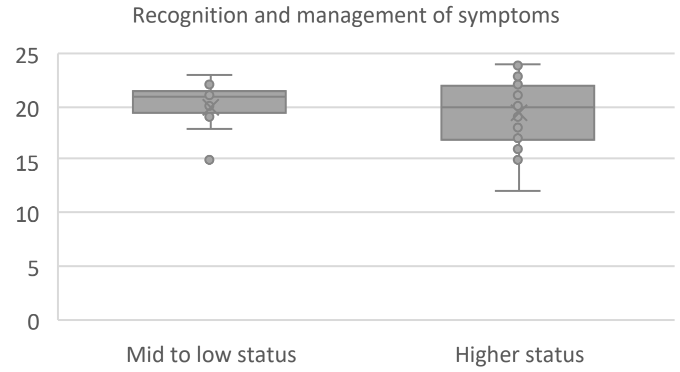


Figure 6.37: Boxplot of Partners in health: recognition and management of symptoms by socioeconomic status

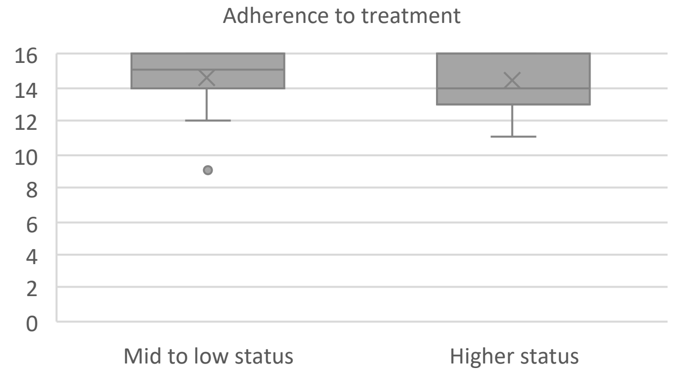


Figure 6.38: Boxplot of Partners in health: adherence to treatment by socioeconomic status

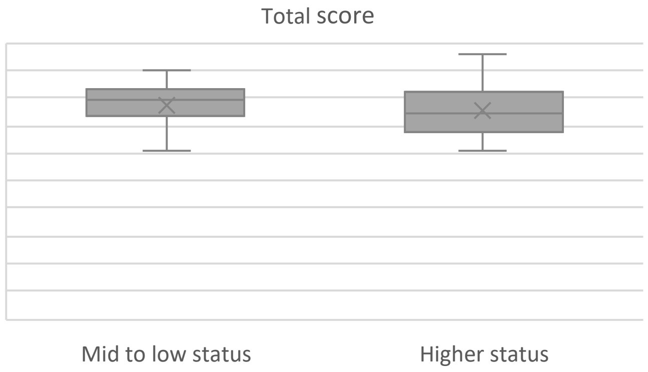


Figure 6.39: Boxplot of Partners in health Total score by socioeconomic status

Partners in health by age

Participants were grouped according to **age**, with comparisons made between participants *Aged 25 to 44* (n = 19, 38.00%), participants *Aged 45 to 54* (n = 22, 44.00%), and participants *Aged 55 to 74* (n = 9, 18.00%).

A one-way ANOVA test was used when the assumptions for response variable residuals were normally distributed and variances of populations were equal (Table 6.28). When the assumptions for normality of residuals was not met, a Kruskal-Wallis test was used (Table 6.29).

No significant differences were observed between participants by **age** for any of the Partners in health scales.

Table 6.28: Partners in health by age summary statistics and one-way ANOVA test

Partners in health scale	Group	Number (n=44)	Percent	Mean	SD	Source of difference	Sum of squares	dF	Mean Square	f	p-value
Coping	Aged 25 to 44	16	36.36	15.81	3.62	Between groups	10.30	2	5.14	0.27	0.7620
	Aged 45 to 54	19	43.18	16.05	5.12	Within groups	770.30	41	18.79		
	Aged 55 to 74	9	20.45	17.11	3.59	Total	780.60	43			
Recognition and management of symptoms	Aged 25 to 44	16	36.36	19.88	2.19	Between groups	3.02	2	1.51	0.21	0.8150
	Aged 45 to 54	19	43.18	19.32	3.18	Within groups	301.41	41	7.35		
	Aged 55 to 74	9	20.45	19.78	2.44	Total	304.43	43			
Total score	Aged 25 to 44	16	36.36	76.31	7.10	Between groups	44.00	2	22.09	0.27	0.7660
	Aged 45 to 54	19	43.18	75.32	9.89	Within groups	3382.00	41	82.48		
	Aged 55 to 74	9	20.45	78.00	10.39	Total	3426.00	43			

Table 6.29: Partners in health by age summary statistics and Kruskal-Wallis test

Partners in health scale	Group	Number (n=44)	Percent	Median	IQR	C^2	dF	p-value
Knowledge	Aged 25 to 44	16	36.36	26.50	4.25	0.94	2	0.6264
	Aged 45 to 54	19	43.18	26.00	5.50			
	Aged 55 to 74	9	20.45	28.00	7.00			
Adherence to treatment	Aged 25 to 44	16	36.36	15.00	2.00	0.97	2	0.6143
	Aged 45 to 54	19	43.18	15.00	2.00			
	Aged 55 to 74	9	20.45	14.00	3.00			

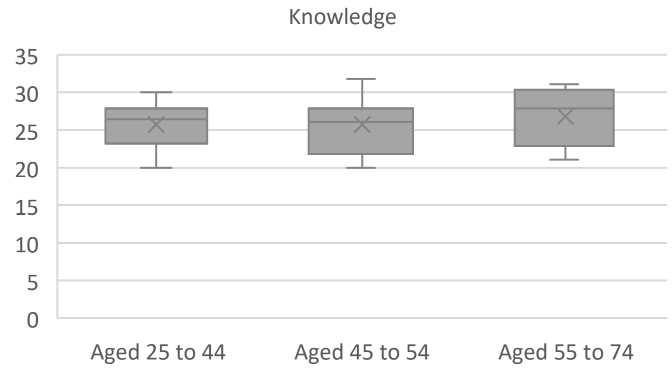


Figure 6.40: Boxplot of Partners in health: knowledge by age

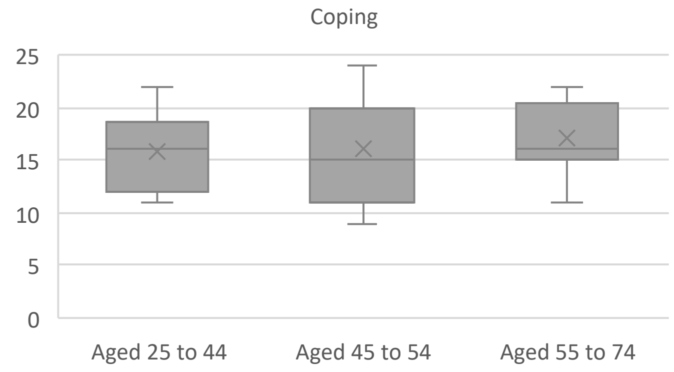


Figure 6.41: Boxplot of Partners in health: coping by age

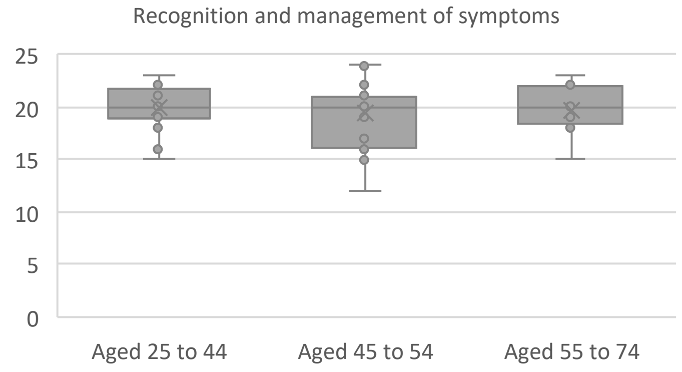


Figure 6.42: Boxplot of Partners in health: recognition and management of symptoms by age

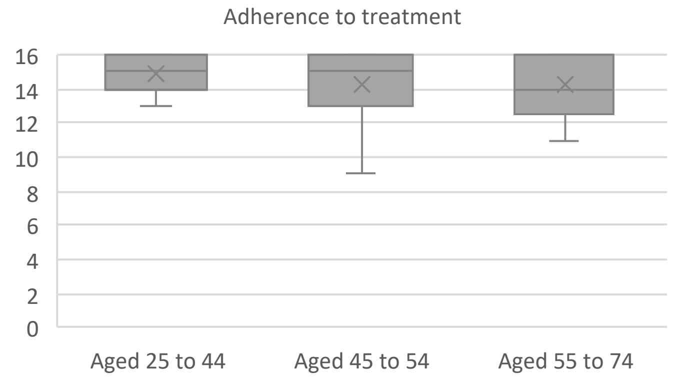


Figure 6.43: Boxplot of Partners in health: adherence to treatment by age

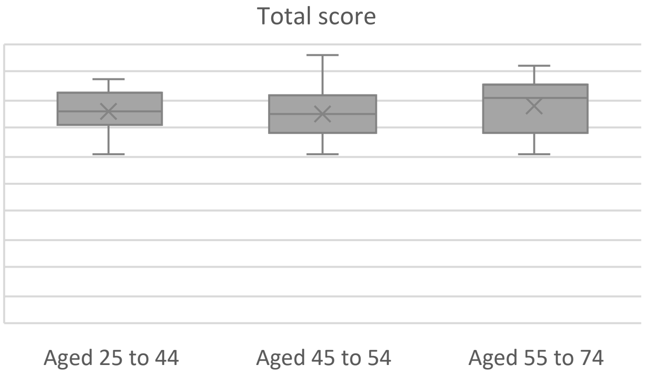


Figure 6.44: Boxplot of Partners in health Total score by age

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 = 23, 52.27%), and 18 participants (40.91%) responded that they took medicines as prescribed most of the time. There were 3 participants (6.82%) that sometimes took medicines as prescribed (Table 6.30, Figure 6.45).

Table 6.30: Ability to take medicine as prescribed

Ability to take medicine and stick to prescription	n=44	Percent
All of the time	23	52.27
Most of the time	18	40.91
Sometimes	3	6.82
Rarely	0	0

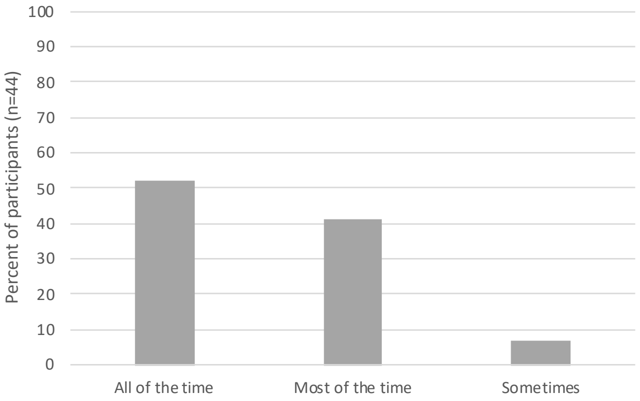


Figure 6.45: Ability to take medicine as prescribed

Information given by health professionals

Participants were asked about what type of information they were given by healthcare professionals, information about Treatment options (n=41, 93.18%), Hereditary considerations (n=30, 68.18%), Disease management (n=26, 59.09%) and, Physical activity (n=20, 45.45%) were most frequently given to participants by healthcare professionals, and, information about Complementary therapies (n=6, 13.64%), Interpret test results (n=6, 13.64%) and, Clinical trials (n=6, 13.64%) were given least often (Table 6.31, Figure 6.46).

Subgroup variations of more than 10% are listed in Table 6.32.

Table 6.31: Information given by health professionals

Information given by health professionals	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=44	%	n=20	%	n=24	%	n=19	%	n=25	%	n=22	%	n=22	%	n=21	%	n=23	%
Disease Cause	11	25.00	6	30.00	5	20.83	4	21.05	7	28.00	7	31.82	4	18.18	7	33.33	4	17.39
Treatment options	41	93.18	18	90.00	23	95.83	17	89.47	24	96.00	21	95.45	20	90.91	19	90.48	22	95.65
Disease management	26	59.09	9	45.00	17	70.83	10	52.63	16	64.00	16	72.73	10	45.45	11	52.38	15	65.22
Complementary therapies	6	13.64	2	10.00	4	16.67	3	15.79	3	12.00	4	18.18	2	9.09	2	9.52	4	17.39
Interpret test results	6	13.64	3	15.00	3	12.50	4	21.05	2	8.00	4	18.18	2	9.09	1	4.76	5	21.74
Clinical trials	6	13.64	3	15.00	3	12.50	5	26.32	1	4.00	4	18.18	2	9.09	2	9.52	4	17.39
Dietary	11	25.00	3	15.00	8	33.33	6	31.58	5	20.00	6	27.27	5	22.73	5	23.81	6	26.09
Physical activity	20	45.45	6	30.00	14	58.33	10	52.63	10	40.00	10	45.45	10	45.45	10	47.62	10	43.48
Psychological/ social support	20	45.45	9	45.00	11	45.83	11	57.89	9	36.00	11	50.00	9	40.91	10	47.62	10	43.48
Hereditary considerations	30	68.18	14	70.00	16	66.67	12	63.16	18	72.00	15	68.18	15	68.18	16	76.19	14	60.87

Information given by health professionals	All participants		Regional or remote		Metropolitan		Mid to low status		Higher status		Aged 25 to 44		Aged 45 to 54		Aged 55 to 74	
	n=44	%	n=14	%	n=30	%	n=17	%	n=27	%	n=16	%	n=19	%	n=9	%
Disease Cause	11	25.00	4	28.57	7	23.33	7	41.18	4	14.81	4	25.00	6	31.58	1	11.11
Treatment options	41	93.18	13	92.86	28	93.33	16	94.12	25	92.59	15	93.75	17	89.47	9	100.00
Disease management	26	59.09	6	42.86	20	66.67	11	64.71	15	55.56	9	56.25	11	57.89	6	66.67
Complementary therapies	6	13.64	3	21.43	3	10.00	2	11.76	4	14.81	2	12.50	3	15.79	1	11.11
Interpret test results	6	13.64	3	21.43	3	10.00	3	17.65	3	11.11	1	6.25	4	21.05	1	11.11
Clinical trials	6	13.64	4	28.57	2	6.67	5	29.41	1	3.70	4	25.00	1	5.26	1	11.11
Dietary	11	25.00	4	28.57	7	23.33	2	11.76	9	33.33	3	18.75	5	26.32	3	33.33
Physical activity	20	45.45	7	50.00	13	43.33	8	47.06	12	44.44	8	50.00	9	47.37	3	33.33
Psychological/ social support	20	45.45	6	42.86	14	46.67	7	41.18	13	48.15	9	56.25	8	42.11	3	33.33
Hereditary considerations	30	68.18	9	64.29	21	70.00	11	64.71	19	70.37	12	75.00	15	78.95	3	33.33

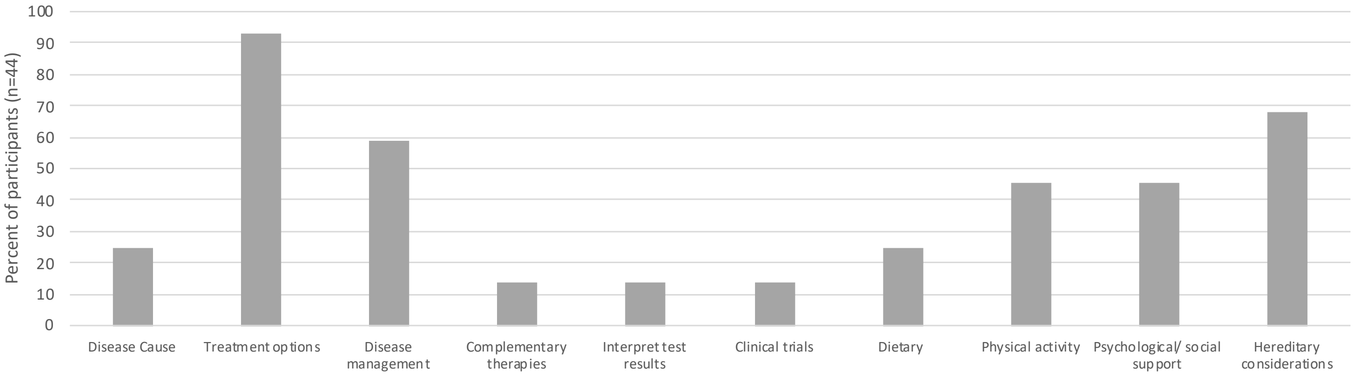


Figure 6.46: Information given by health professionals

Table 6.32: Information given by health professionals – subgroup variations

Information given by health professionals	Less Frequently	More frequently
Disease Cause	Higher status Aged 55 to 74	Mid to low status
Disease management	Early breast cancer Diagnosed in 2020 or 2021 Regional or remote	Advanced breast cancer Diagnosed before 2020
Clinical trials		Poor physical function Regional or remote Mid to low status Aged 25 to 44
Dietary	Mid to low status	
Physical activity	Early breast cancer Aged 55 to 74	Advanced breast cancer
Psychological/ social support	Aged 55 to 74	Poor physical function Aged 25 to 44
Hereditary considerations	Aged 55 to 74	Aged 45 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 Interpret test results (n=28, 63.64%), Complementary therapies (n=23, 52.27%), Disease Cause (n=21, 47.73%) Disease management (n=21, 47.73%) and, Treatment options (n=21, 47.73%) were most frequently given to participants by healthcare professionals, and, information about Dietary (n=17, 38.64%), Psychological/ social support (n=13, 29.55%) and, Clinical trials (n=12, 27.27%) were searched for least often (Table 6.33, Figure 6.47).

Subgroup variations of more than 10% are listed in Table 6.34.

Table 6.33: Information searched for independently

Information searched independently	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=44	%	n=20	%	n=24	%	n=19	%	n=25	%	n=22	%	n=22	%	n=21	%	n=23	%
Disease Cause	21	47.73	11	55.00	10	41.67	10	52.63	11	44.00	11	50.00	10	45.45	12	57.14	9	39.13
Treatment options	21	47.73	9	45.00	12	50.00	8	42.11	13	52.00	9	40.91	12	54.55	12	57.14	9	39.13
Disease management	21	47.73	6	30.00	15	62.50	10	52.63	11	44.00	8	36.36	13	59.09	13	61.90	8	34.78
Complementary therapies	23	52.27	10	50.00	13	54.17	11	57.89	12	48.00	13	59.09	10	45.45	12	57.14	11	47.83
Interpret test results	28	63.64	12	60.00	16	66.67	11	57.89	17	68.00	14	63.64	14	63.64	13	61.90	15	65.22
Clinical trials	12	27.27	3	15.00	9	37.50	4	21.05	8	32.00	6	27.27	6	27.27	7	33.33	5	21.74
Dietary	17	38.64	12	60.00	5	20.83	9	47.37	8	32.00	10	45.45	7	31.82	6	28.57	11	47.83
Physical activity	19	43.18	10	50.00	9	37.50	8	42.11	11	44.00	11	50.00	8	36.36	6	28.57	13	56.52
Psychological/ social support	13	29.55	7	35.00	6	25.00	8	42.11	5	20.00	7	31.82	6	27.27	5	23.81	8	34.78
Hereditary considerations	18	40.91	8	40.00	10	41.67	6	31.58	12	48.00	8	36.36	10	45.45	8	38.10	10	43.48

Information searched independently	All participants		Regional or remote		Metropolitan		Mid to low status		Higher status		Aged 25 to 44		Aged 45 to 54		Aged 55 to 74	
	n=44	%	n=14	%	n=30	%	n=17	%	n=27	%	n=16	%	n=19	%	n=9	%
Disease Cause	21	47.73	9	64.29	12	40.00	9	52.94	12	44.44	11	68.75	6	31.58	4	44.44
Treatment options	21	47.73	7	50.00	14	46.67	10	58.82	11	40.74	4	25.00	12	63.16	5	55.56
Disease management	21	47.73	7	50.00	14	46.67	11	64.71	10	37.04	5	31.25	10	52.63	6	66.67
Complementary therapies	23	52.27	7	50.00	16	53.33	11	64.71	12	44.44	10	62.50	10	52.63	3	33.33
Interpret test results	28	63.64	11	78.57	17	56.67	12	70.59	16	59.26	10	62.50	15	78.95	3	33.33
Clinical trials	12	27.27	6	42.86	6	20.00	6	35.29	6	22.22	5	31.25	6	31.58	1	11.11
Dietary	17	38.64	8	57.14	9	30.00	9	52.94	8	29.63	6	37.50	8	42.11	3	33.33
Physical activity	19	43.18	8	57.14	11	36.67	8	47.06	11	40.74	7	43.75	9	47.37	3	33.33
Psychological/ social support	13	29.55	3	21.43	10	33.33	5	29.41	8	29.63	7	43.75	3	15.79	3	33.33
Hereditary considerations	18	40.91	7	50.00	11	36.67	8	47.06	10	37.04	5	31.25	9	47.37	4	44.44

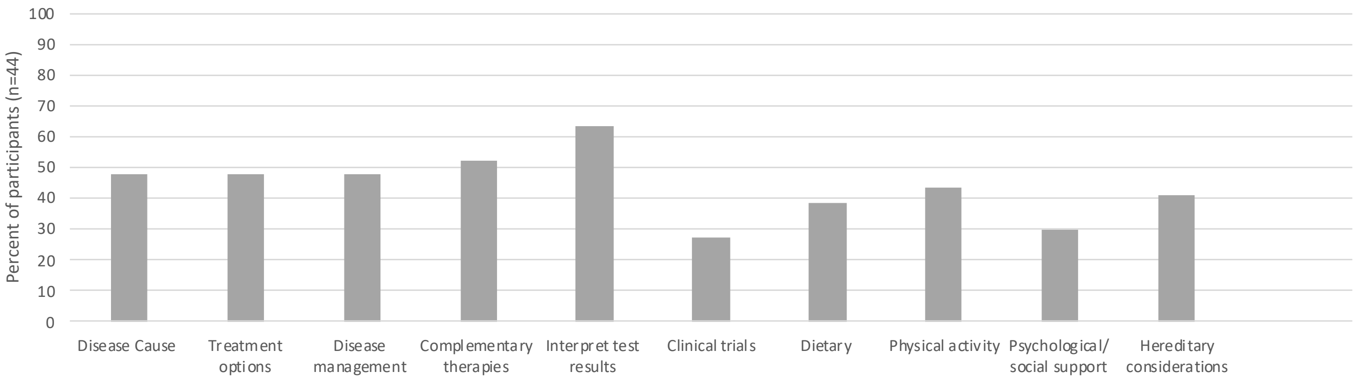


Figure 6.47: Information searched for independently

Table 6.34: Information searched for independently – subgroup variations

Information given by health professionals	Less Frequently	More frequently
Disease Cause	Aged 45 to 54	Regional or remote Aged 25 to 44
Treatment options	Aged 25 to 44	Mid to low status Aged 45 to 54
Disease management	Early breast cancer Diagnosed before 2020 University Higher status Aged 25 to 44	Advanced breast cancer Diagnosed in 2020 or 2021 Trade or high school Mid to low status Aged 55 to 74
Complementary therapies	Aged 55 to 74	Mid to low status Aged 25 to 44
Interpret test results	Aged 55 to 74	Regional or remote Aged 45 to 54
Clinical trials	Early breast cancer Aged 55 to 74	Advanced breast cancer Regional or remote
Dietary	Advanced breast cancer Trade or high school	Early breast cancer Regional or remote Mid to low status
Physical activity	Trade or high school	University Regional or remote
Psychological/ social support	Aged 45 to 54	Poor physical function Aged 25 to 44

Information gaps

The largest gaps in information, where information was neither given to patients nor searched for independently were Clinical trials (n = 27, 61.36%) and Dietary (n = 20, 45.45%).

The topics that participants did not search for independently after not receiving information from healthcare professionals were Treatment options (n = 22, 50.00%) and Hereditary considerations (n = 18, 40.91%).

The topics that participants were given most information from both healthcare professionals and searching independently for were Sum of Complementary therapies (n = 20, 45.45%) and Treatment options (n = 19, 43.18%).

The topics that participants searched for independently after not receiving information from healthcare professionals were Disease management (n = 24, 54.55%) and Sum of Complementary therapies (n = 15, 34.09%) (Table 6.35, Figure 6.48).

Table 6.35: 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=44	%	n=44	%	n=44	%	n=44	%
Disease cause	18	40.91	5	11.36	6	13.64	15	34.09
Treatment options	1	2.27	22	50.00	19	43.18	2	4.55
Disease management	10	22.73	13	29.55	13	29.55	8	18.18
Complementary therapies	18	40.91	3	6.82	20	45.45	3	6.82
How to interpret test results	14	31.82	2	4.55	4	9.09	24	54.55
Clinical trials	27	61.36	5	11.36	1	2.27	11	25.00
Dietary information	20	45.45	7	15.91	4	9.09	13	29.55
Physical activity	11	25.00	14	31.82	6	13.64	13	29.55
Psychological/social support	17	38.64	14	31.82	6	13.64	7	15.91
Hereditary considerations	8	18.18	18	40.91	12	27.27	6	13.64

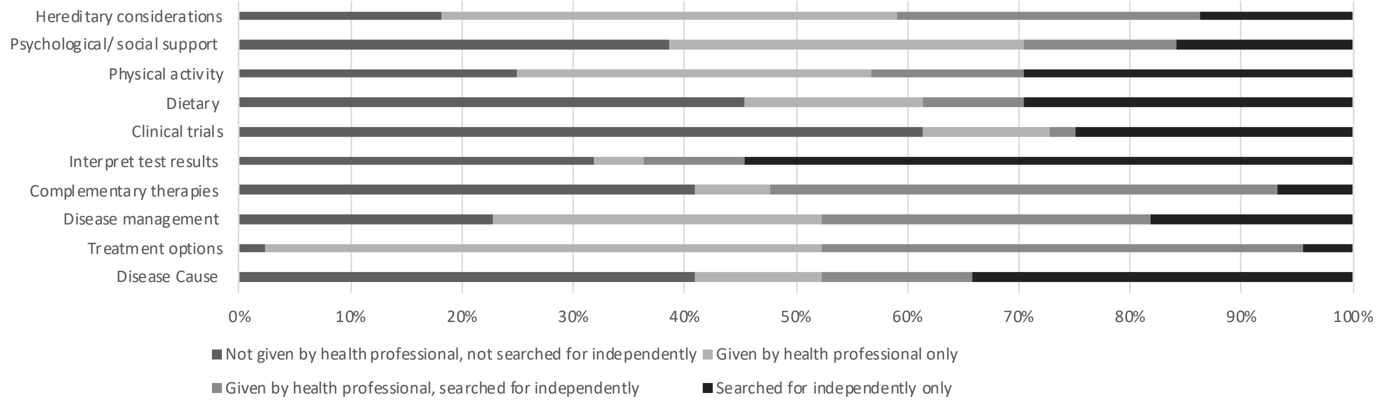


Figure 6.48: Information gaps

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 6.36 and Figure 6.49. With a weighted ranking, the higher the score, the more accessed the source of information.

Across all participants, information from non-profit, charity or patient organisations were most accessed followed by information from the government. Information from pharmaceutical companies and from medical journals were least accessed.

Table 6.36: Most accessed information

Information source	Weighted average (n=44)
Non-profit organisations, charity or patient organisations	4.36
Government	3.25
Pharmaceutical companies	1.95
Hospital or clinic I am being treated in	3.11
Medical journals	2.32

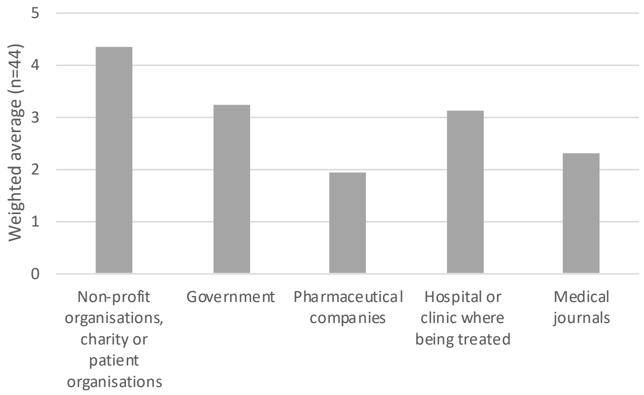


Figure 6.49: Most accessed information

My Health Record

My Health Record is an online summary of key health information, an initiative of the Australian Government. There were 19 participants (43.18%) had accessed My Health Record, 21(47.73%) had not (Table 6.37. Figure 6.50).

Of those that had accessed My Health Record, there were 9 participants (47.37%) who found it to be poor or very poor, four participants (21.05%) who found it acceptable, and two participants (10.53%) who found it to be good or very good (Table 6.38, Figure 6.51).

Table 6.37: Accessed My Health Record

Accessed “My health record”	Number (n=44)	Percent
Yes	19	43.18
No	21	47.73
Not sure	2	4.55
Doesn't know what ‘My Health Record’ is	2	4.55

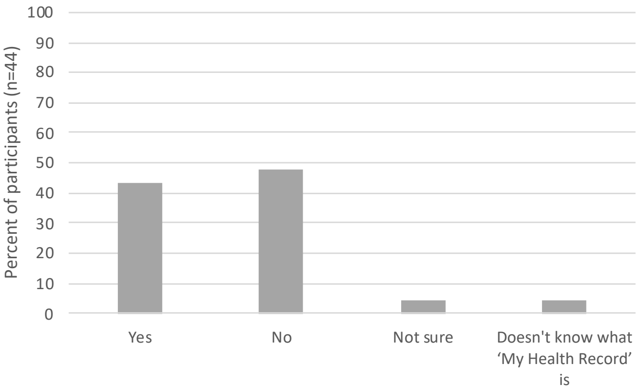


Figure 6.50: Accessed My Health Record

Table 6.38: How useful was My Health Record

How useful was “My health record”	Number (n=19)	Percent
Very poor	4	21.05
Poor	4	26.32
Acceptable	5	21.05
Good	4	10.53
Very good	2	0.00

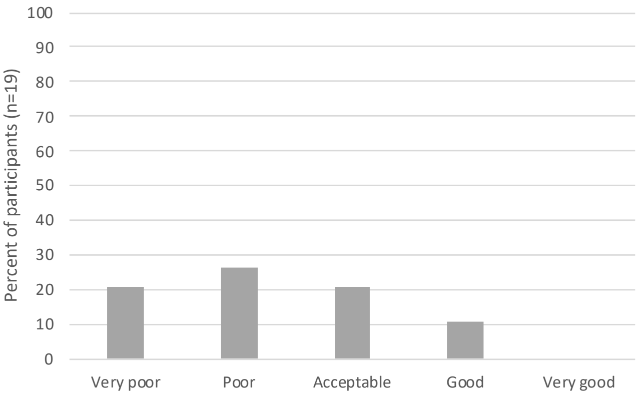


Figure 6.51: How useful was My Health Record

Section 7

Care and support

Section 7: Experience of care and support

Care coordination

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

The overall scores for the cohort were in the highest quintile for the Care coordination: Quality of care global measure (median = 9.00, IQR = 1.00), scales, indicating very good scores for quality of care.

The overall scores for the cohort were in the second highest quintile for the Care coordination: Communication (mean = 44.64, SD = 7.85), Care coordination: Navigation (mean = 26.55, SD = 3.87), Care coordination: Total score (mean = 71.18, SD = 10.28), Care coordination: Care coordination global measure (median = 8, IQR = 2.25), scales, indicating good scores for care coordination, navigation, and communication.

There we no significant differences between sub-groups within the Care Coordination measure.

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 received support through charities (n=19, 38%). This was followed by receiving support from a hospital or clinical setting (n=11, 22%). There were 15 participants (30.00%) that described not receiving any support. There were five participants (10.00%) who described getting peer support, and the same number described getting support through a psychologist or counselling service (n=5, 10.00%).

Care coordination

A Care Coordination questionnaire was completed by participants within the online questionnaire. The Care Coordination questionnaire comprises a total score, two scales (communication and navigation), and a single question for each relating to care-coordination and care received. A higher score denotes better care outcome. Summary statistics for the entire cohort are displayed alongside the possible range of each scale in Table 7.1.

The overall scores for the cohort were in the highest quintile for the **Care coordination: Quality of care global measure** (median = 9.00, IQR = 1.00), scales, indicating very good scores for quality of care.

The overall scores for the cohort were in the second highest quintile for the **Care coordination: Communication** (mean = 44.64, SD = 7.85), **Care coordination: Navigation** (mean = 26.55, SD = 3.87), **Care coordination: Total score** (mean = 71.18, SD = 10.28), **Care coordination: Care coordination global measure** (median = 8, IQR = 2.25), scales, indicating good scores for care coordination, navigation, and communication.

Comparisons of Care co-ordination have been made based **breast cancer stage** (Tables 7.2 to 7.3, Figures 7.1 to 7.5), **physical function** (Tables 7.4 to 7.5, Figures 7.6 to 7.10), e**motional function** (Tables 7.6 to 7.7, Figures 7.11 to 7.15), **education** (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), **socioeconomic status** (Tables 7.12 to 7.13, Figures 7.26 to 7.30), and **age** (Tables 7.14 to 7.15, Figures 7.31 to 7.35).

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 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=44)	Mean	SD	Median	IQR	Possible range	Quintile
Communication*	44.64	7.85	45.00	10.25	13 to 65	4
Navigation*	26.55	3.87	27.00	5.00	7 to 35	4
Total score*	71.18	10.28	72.00	12.50	20 to 100	4
Care coordination global measure	7.66	1.72	8.00	2.25	1 to 10	4
Quality of care global measure	8.45	1.21	9.00	1.00	1 to 10	5

*Normal distribution use mean and SD as measure of central tendency

Care coordination by breast cancer stage

Comparisons were made by **breast cancer stage**, there were 23 participants (46.00%) with *Early breast cancer* (Stage I or Stage II) and, 27 participants (54.00%) with *Advanced breast cancer* (Stage II or Stage IV).

A two-sample t-test was used when assumptions for normality and variance were met (Table 7.2), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 7.3).

No significant differences were observed between participants by **breast cancer stage** for any of the Care coordination scales.

Table 7.2: Care coordination breast cancer stage summary statistics and T-test

Care coordination scale	Group	Number (n=44)	Percent	Median	IQR	W	p-value
Care coordination global measure	Early breast cancer	20	45.45	8.00	2.25	248.00	0.8570
	Advanced breast cancer	24	54.55	8.00	2.25		
Quality of care global measure	Early breast cancer	20	45.45	8.00	1.00	220.00	0.6345
	Advanced breast cancer	24	54.55	9.00	1.25		

Table 7.3: Care coordination breast cancer stage summary statistics and Wilcoxon rank sum tests

Care coordination scale	Group	Number (n=44)	Percent	Median	IQR	W	p-value
Care coordination global measure	Early breast cancer	20	45.45	8.00	2.25	248.00	0.8570
	Advanced breast cancer	24	54.55	8.00	2.25		
Quality of care global measure	Early breast cancer	20	45.45	8.00	1.00	220.00	0.6345
	Advanced breast cancer	24	54.55	9.00	1.25		

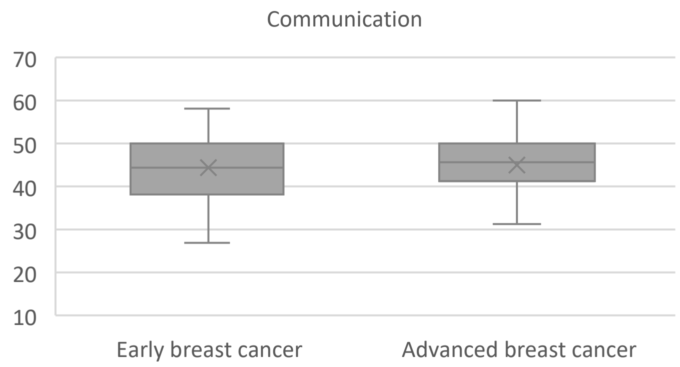


Figure 7.1: Boxplot of Care coordination: Communication by breast cancer stage

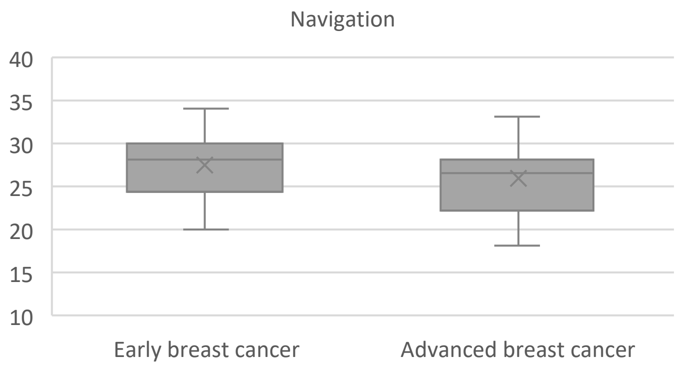


Figure 7.2: Boxplot of Care coordination: Navigation by breast cancer stage

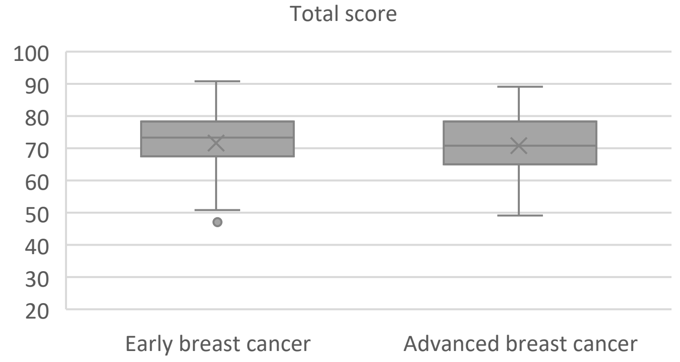


Figure 7.3: Boxplot of Care coordination: Total score by breast cancer stage

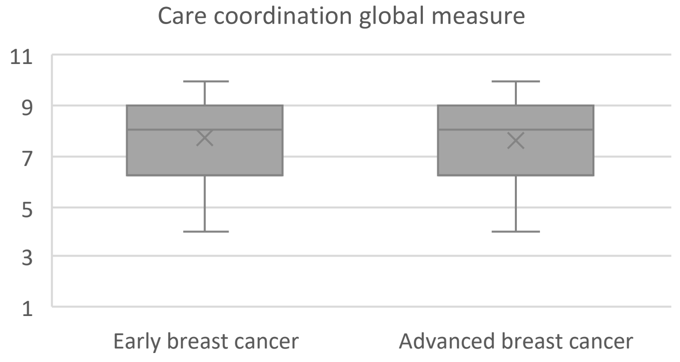


Figure 7.4: Boxplot of Care coordination: Care coordination global measure by breast cancer stage

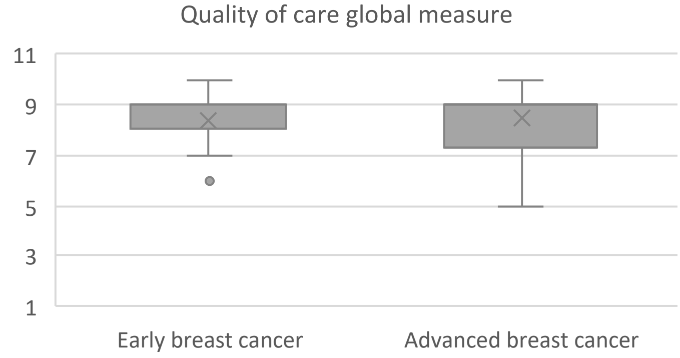


Figure 7.5: Boxplot of Care coordination: Quality of care global measure by breast cancer stage

Care coordination by physical function

Physical function was evaluated by the SF36 Role functioning/physical, this measures how physical health interferes with work or other activities. Participants that had an SF36 Role functioning/physical score of 40 or less were included in the *Poor physical function* subgroup (n=19, 43.18 %), and participants that scored more than 40 were included in the G*ood physical function* subgroup (n=25, 56.82%).

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(42) = -2.37 , p = 0.0224] was significantly lower for participants in the *Poor physical function* subgroup (Mean = 41.58, SD = 8.03) compared to participants in the *Good physical function* subgroup (Mean = 46.96, SD = 7.00).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the **Care coordination: Quality of care global measure** scale [W = 149.5 , p = 0.0320] was significantly lower for participants in the *Poor physical function* subgroup (Median = 8.00, IQR = 2.00) compared to participants in the *Good physical function* subgroup (Median = 9.00, IQR = 2.00).

The **Care coordination: communication** scale measures communication with healthcare professionals, measuring knowledge about all aspects of care including treatment, services available for their condition, emotional aspects, practical considerations, and financial entitlements. On average, participants in the *Good physical function* subgroup scored higher than participants in the *Poor physical function* subgroup. This indicates that healthcare communication was good for participants in the *Good physical function* subgroup, and average for participants in the *Poor physical function* subgroup.

The **Care coordination: Quality of care global measure** scale measures the participants overall rating of the quality of their care. On average, participants in the *Good physical function* subgroup scored higher than participants in the *Poor physical function* subgroup. This indicates that, quality of care was very good for participants in the *Good physical function* subgroup, and good for participants in the *Poor physical function* subgroup.

Table 7.4: Care coordination physical function summary statistics and T-test

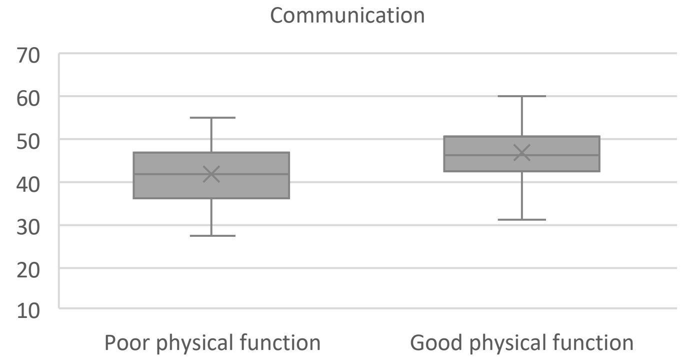
Care coordination scale	Group	Number (n=44)	Percent	Mean	SD	T	dF	p-value
Communication	Poor physical function	19	43.18	41.58	8.03	-2.37	42.00	0.0224*
	Good physical function	25	56.82	46.96	7.00			
Navigation	Poor physical function	19	43.18	26.47	3.27	-0.11	42.00	0.9161
	Good physical function	25	56.82	26.60	4.34			
Total score	Poor physical function	19	43.18	68.05	9.65	-1.81	42.00	0.0783
	Good physical function	25	56.82	73.56	10.30			

*Statistically significant at p<0.05

Table 7.5: Care coordination physical function summary statistics and Wilcoxon rank sum tests

Care coordination scale	Group	Number (n=44)	Percent	Median	IQR	W	p-value
Care coordination global measure	Poor physical function	19	43.18	7.00	2.00	161.00	0.0664
	Good physical function	25	56.82	9.00	1.00		
Quality of care global measure	Poor physical function	19	43.18	8.00	2.00	149.50	0.0320*
	Good physical function	25	56.82	9.00	2.00		

*Statistically significant at p<0.05



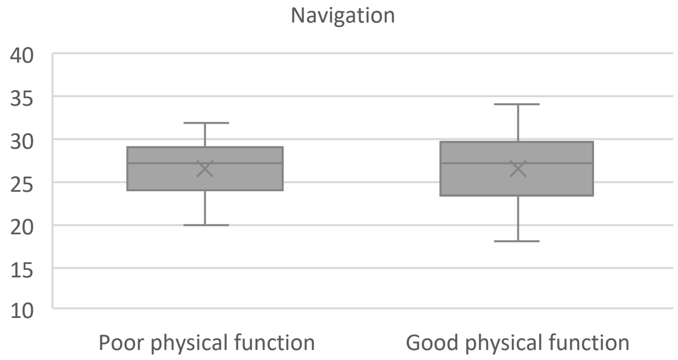
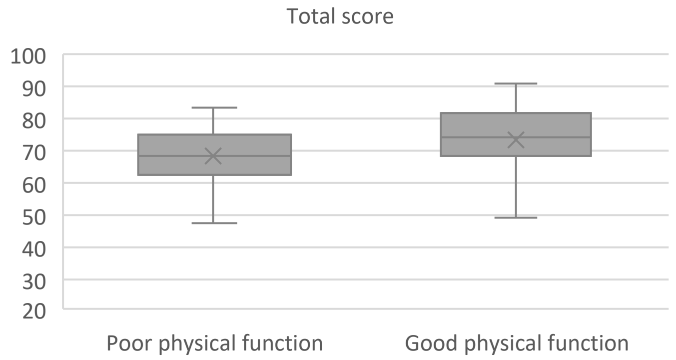


Figure 7.6: Boxplot of Care coordination: Communication by physical function

Figure 7.7: Boxplot of Care coordination: Navigation by physical function



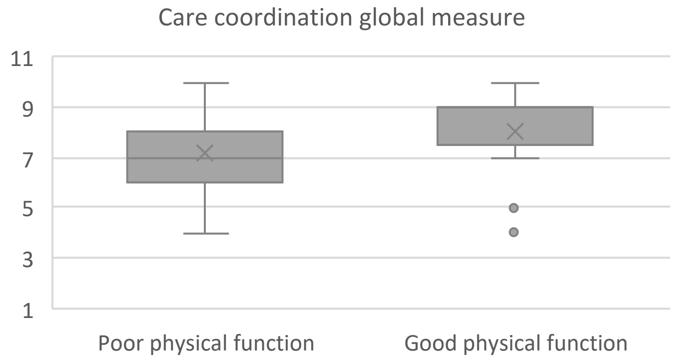


Figure 7.8: Boxplot of Care coordination: Total score by physical function

Figure 7.9: Boxplot of Care coordination: Care coordination global measure by physical function

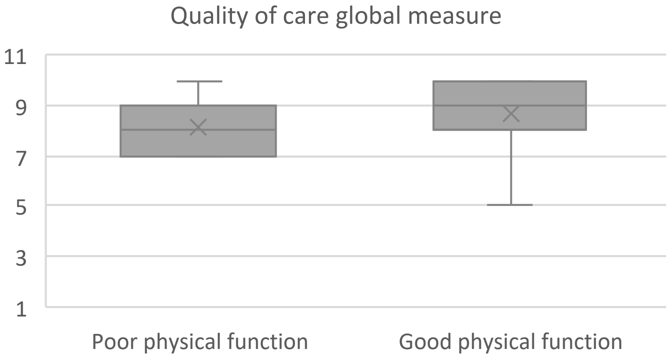


Figure 7.10: Boxplot of Care coordination: Quality of care global measure by physical function

Care coordination by year of diagnosis

Comparisons were made by the **year of diagnosis**, there were 26 participants that were *Diagnosed before 2020* (52.00%), and 24 participants *Diagnosed in 2020 or 2021* (48.00%).

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 **year of diagnosis** for any of the Care coordination scales.

Table 7.6: Care coordination year of diagnosis summary statistics and T-test

Care coordination scale	Group	Number (n=44)	Percent	Mean	SD	T	dF	p-value
Navigation	Diagnosed before 2020	22	50.00	16.64	3.71	0.70	42	0.4856
	Diagnosed in 2020 or 2021	22	50.00	15.73	4.79			
Total score	Diagnosed before 2020	22	50.00	19.86	2.25	0.62	42	0.5394
	Diagnosed in 2020 or 2021	22	50.00	19.36	3.05			
Quality of care global measure	Diagnosed before 2020	22	50.00	77.09	8.56	0.64	42	0.5273
	Diagnosed in 2020 or 2021	22	50.00	75.36	9.40			

*Statistically significant at p<0.05

Table 7.7: Care coordination year of diagnosis summary statistics and Wilcoxon rank sum tests

Care coordination scale	Group	Number (n=44)	Percent	Median	IQR	W	p-value
Communication	Diagnosed before 2020	22	50.00	27.50	6.50	276.50	0.4226
	Diagnosed in 2020 or 2021	22	50.00	25.50	4.50		
Care coordination global measure	Diagnosed before 2020	22	50.00	15.00	2.00	235.00	0.8745
	Diagnosed in 2020 or 2021	22	50.00	15.00	2.00		

*Statistically significant at p<0.05

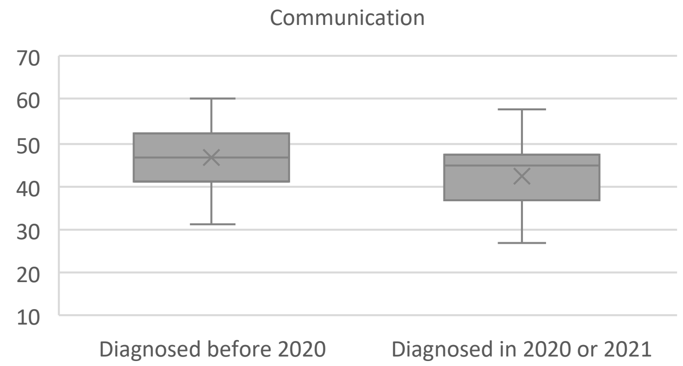


Figure 7.11: Boxplot of Care coordination: Communication by year of diagnosis

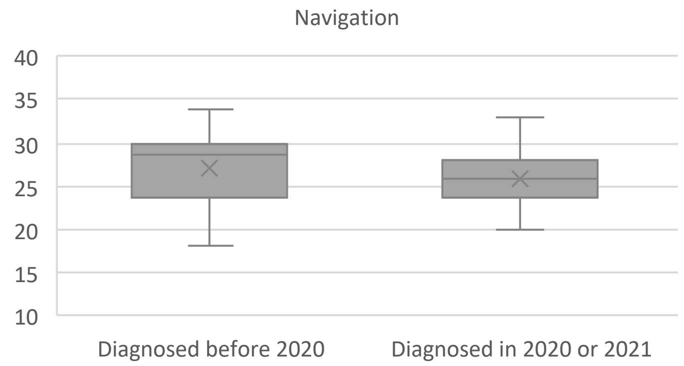


Figure 7.12: Boxplot of Care coordination: Navigation by year of diagnosis

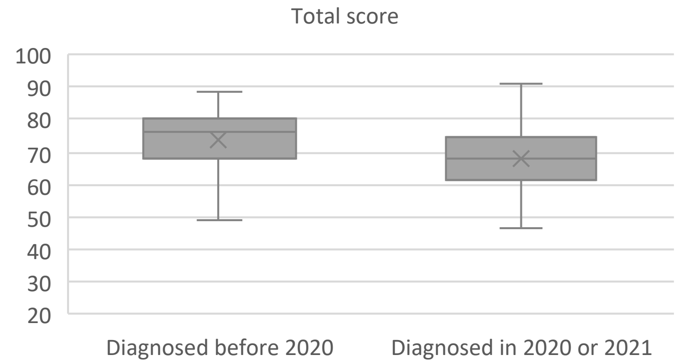


Figure 7.13: Boxplot of Care coordination: Total score by year of diagnosis

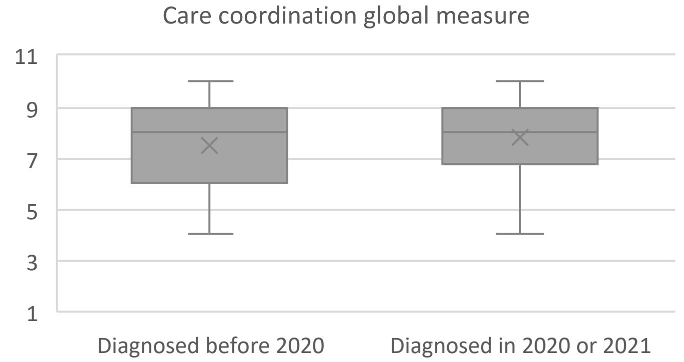


Figure 7.14: Boxplot of Care coordination: Care coordination global measure by year of diagnosis

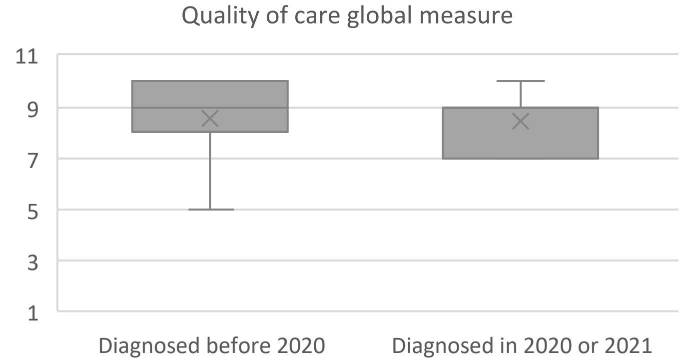


Figure 7.15: Boxplot of Care coordination: Quality of care global measure by year of diagnosis

Care coordination by education

Comparisons were made by **education** status, between those with *Trade or high school* qualifications, (n = 24, 48.00%), and those with a *University* qualification (n = 26, 52.00%).

A two-sample t-test was used when assumptions for normality and variance were met (Table 7.8), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 7.9).

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

Table 7.8: Care coordination education summary statistics and T-test

Care coordination scale	Group	Number (n=44)	Percent	Mean	SD	T	dF	p-value
Communication	Trade or high school	21	47.73	42.86	8.13	-1.46	42	0.1529
	University	23	52.27	46.26	7.38			
Navigation	Trade or high school	21	47.73	26.10	4.28	-0.73	42	0.4677
	University	23	52.27	26.96	3.51			
Total score	Trade or high school	21	47.73	68.95	10.74	-1.39	42	0.1722
	University	23	52.27	73.22	9.63			

Table 7.9: Care coordination education summary statistics and Wilcoxon rank sum tests

Care coordination scale	Group	Number (n=44)	Percent	Median	IQR	W	p-value
Care coordination global measure	Trade or high school	21	47.73	8.00	2.00	227.00	0.7374
	University	23	52.27	8.00	3.00		
Quality of care global measure	Trade or high school	21	47.73	8.00	2.00	183.50	0.1622
	University	23	52.27	9.00	1.50		

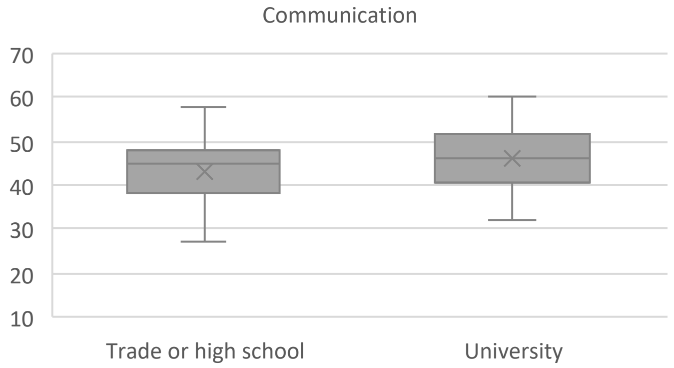


Figure 7.16: Boxplot of Care coordination: Communication by education

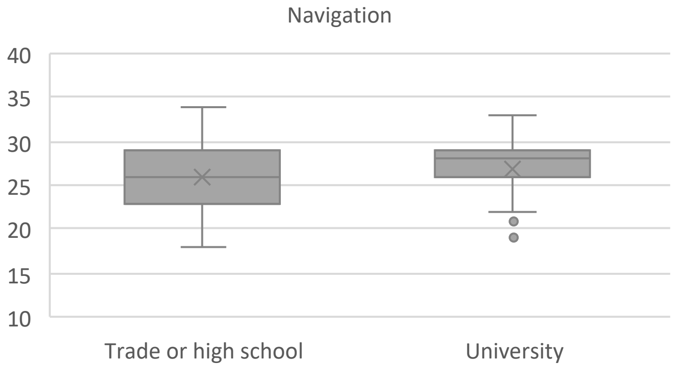


Figure 7.17: Boxplot of Care coordination: Navigation by education

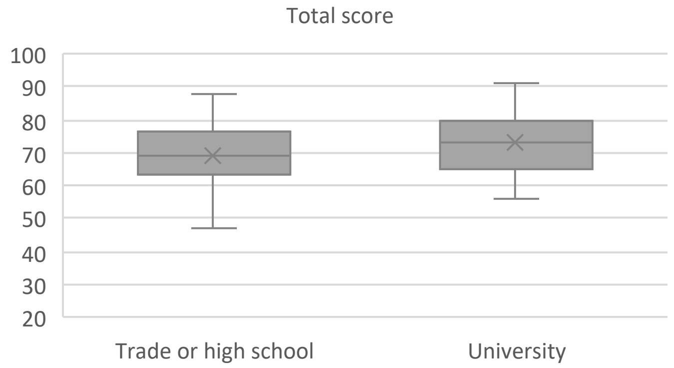


Figure 7.18: Boxplot of Care coordination: Total score by education

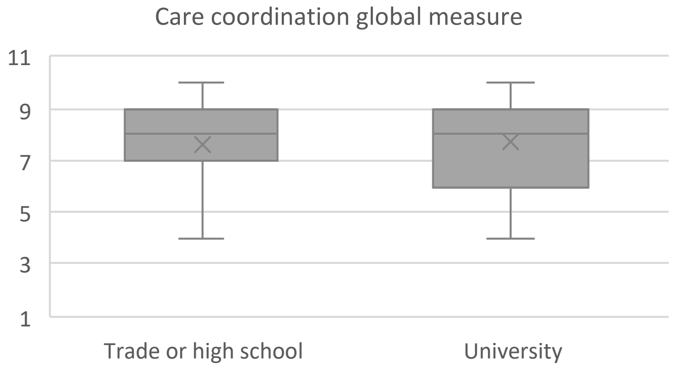


Figure 7.19: Boxplot of Care coordination: Care coordination global measure by education

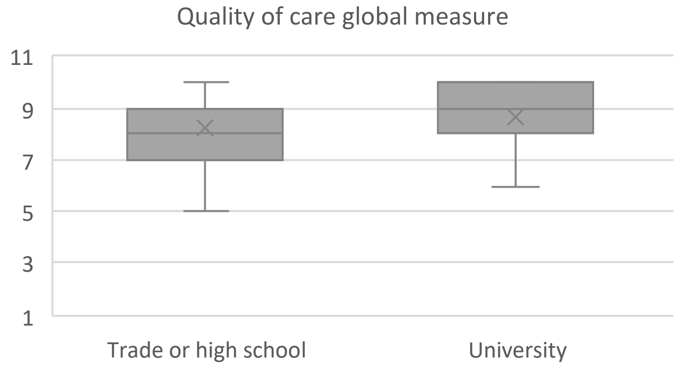


Figure 7.20: Boxplot of Care coordination: Quality of care global measure by education

Care coordination by location

The **location** of participants was evaluated by postcode using the Australian Statistical Geography Maps (ASGS) Remoteness areas accessed from the Australian Bureau of Statistics. Those living in regional/rural areas, *Regional or remote* (n =16, 32.00%) were compared to those living in a major city, *Metropolitan* (n = 34, 68.00%).

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 location summary statistics and T-test

Care coordination scale	Group	Number (n=44)	Percent	Mean	SD	T	dF	p-value
Communication	Regional or remote	14	31.82	43.07	7.11	-0.90	42	0.3724
	Metropolitan	30	68.18	45.37	8.18			
Navigation	Regional or remote	14	31.82	25.57	4.80	-1.14	42	0.2592
	Metropolitan	30	68.18	27.00	3.35			

*Statistically significant at p<0.05

Table 7.11: Care coordination location summary statistics and Wilcoxon rank sum tests

Care coordination scale	Group	Number (n=44)	Percent	Median	IQR	W	p-value
Total score	Regional or remote	14	31.82	69.00	10.25	175.50	0.3908
	Metropolitan	30	68.18	73.00	12.25		
Care coordination global measure	Regional or remote	14	31.82	7.50	2.75	159.50	0.1990
	Metropolitan	30	68.18	8.00	2.00		
Quality of care global measure	Regional or remote	14	31.82	9.00	1.00	225.00	0.7055
	Metropolitan	30	68.18	8.50	1.75		

*Statistically significant at p<0.05

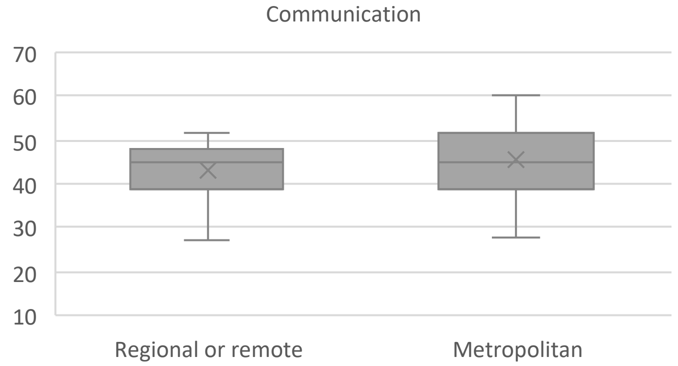


Figure 7.21: Boxplot of Care coordination: Communication by location

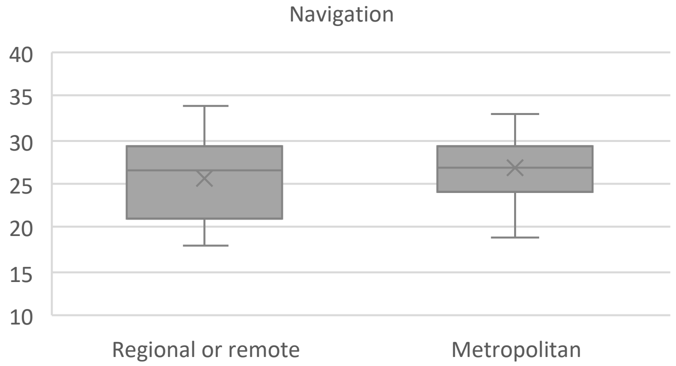


Figure 7.22: Boxplot of Care coordination: Navigation by location

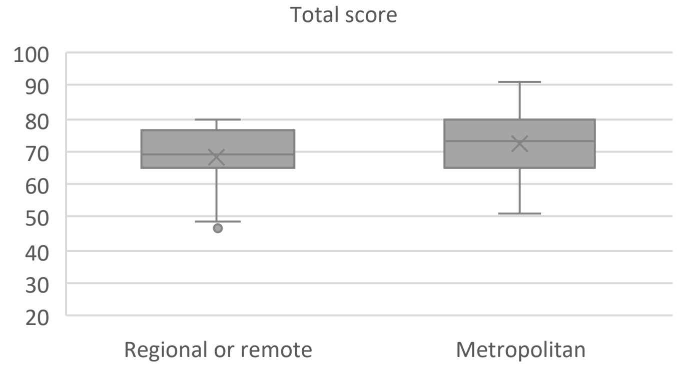


Figure 7.23: Boxplot of Care coordination: Total score by location

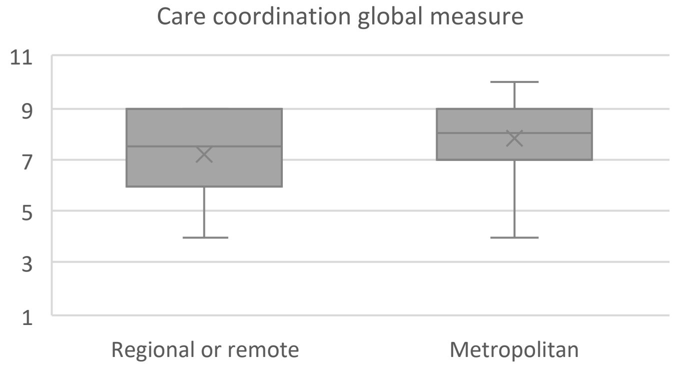


Figure 7.24: Boxplot of Care coordination: Care coordination global measure by location

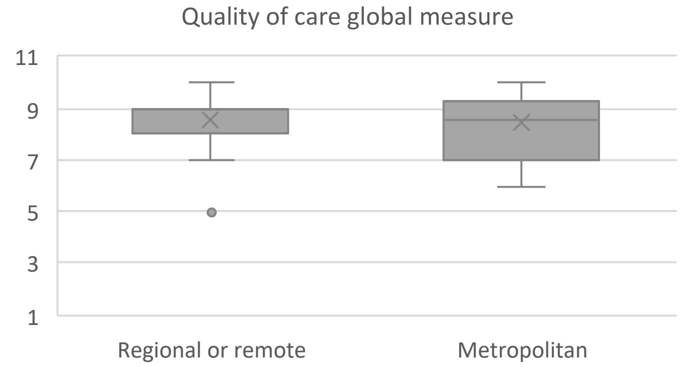


Figure 7.25: Boxplot of Care coordination: Quality of care global measure by location

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 = 20, 40.00%) compared to those with a higher SEIFA score of 7-10, *Higher status* (n = 30, 60.00%).

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 socioeconomic status summary statistics and T-test

Care coordination scale	Group	Number (n=44)	Percent	Mean	SD	T	dF	p-value
Communication	Mid to low status	17	38.64	43.88	7.77	-0.50	42	0.6188
	Higher status	27	61.36	45.11	8.01			
Navigation	Mid to low status	17	38.64	25.59	4.24	-1.31	42	0.1967
	Higher status	27	61.36	27.15	3.57			
Total score	Mid to low status	17	38.64	69.47	10.57	-0.87	42	0.3875
	Higher status	27	61.36	72.26	10.15			

Table 7.13: Care coordination socioeconomic status summary statistics and Wilcoxon rank sum tests

Care coordination scale	Group	Number (n=44)	Percent	Median	IQR	W	p-value
Care coordination global measure	Mid to low status	17	38.64	8.00	1.00	180.50	0.2334
	Higher status	27	61.36	8.00	2.50		
Quality of care global measure	Mid to low status	17	38.64	8.00	1.00	181.00	0.2314
	Higher status	27	61.36	9.00	2.00		

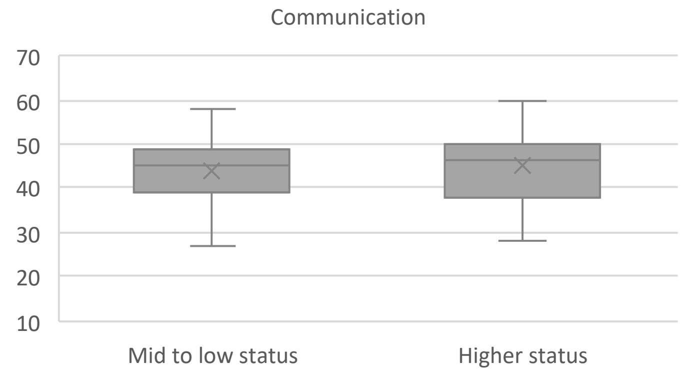


Figure 7.26: Boxplot of Care coordination: Communication by socioeconomic status

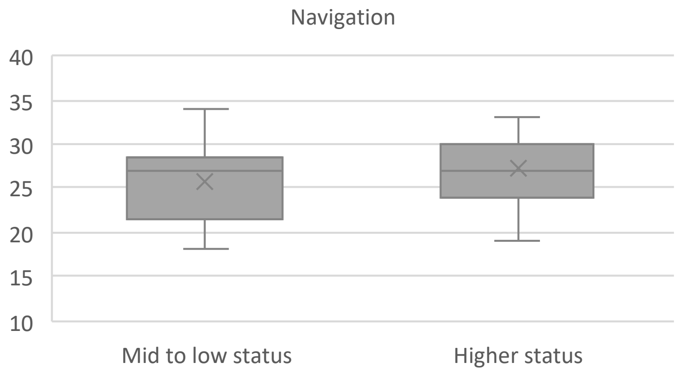


Figure 7.27: Boxplot of Care coordination: Navigation by socioeconomic status

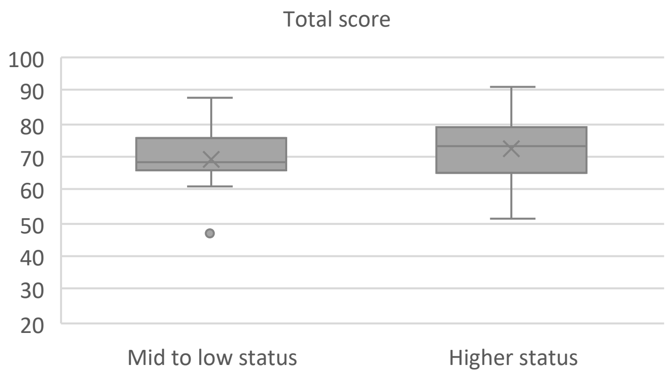


Figure 7.28: Boxplot of Care coordination: Total score by socioeconomic status

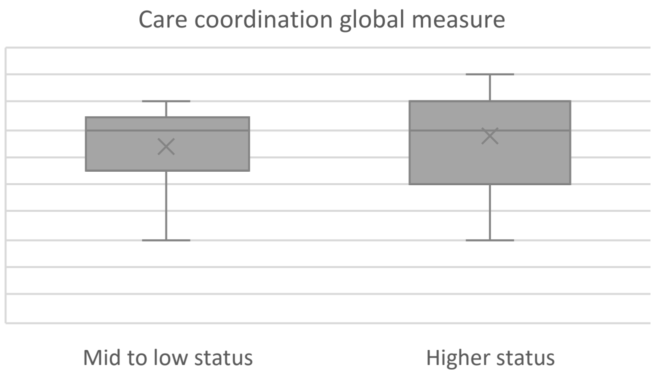


Figure 7.29: Boxplot of Care coordination: Care coordination global measure by socioeconomic status

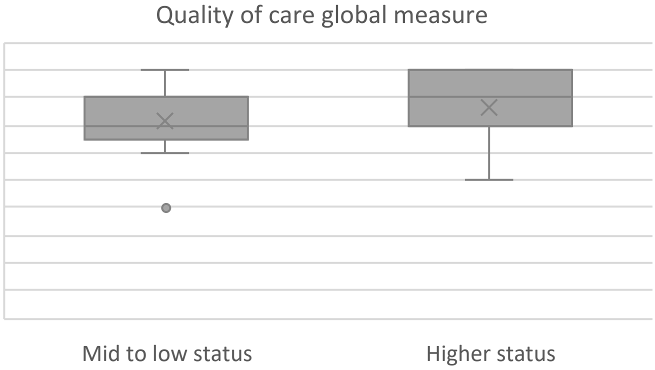


Figure 7.30: Boxplot of Care coordination: Quality of care global measure by socioeconomic status

Care coordination by age

Participants were grouped according to **age**, with comparisons made between participants *Aged 25 to 44* (n = 19, 38.00%), participants *Aged 45 to 54* (n = 22, 44.00%), and participants *Aged 55 to 74* (n = 9, 18.00%).

A one-way ANOVA test was used when the assumptions for response variable residuals were normally distributed and variances of populations were equal (Table 7.14). When the assumptions for normality of residuals was not met, a Kruskal-Wallis test was used (Table 7.15).

No significant differences were observed between participants by **age** for any of the Care coordination scales.

Table 7.14: Care coordination age summary statistics and one-way ANOVA

Care coordination scale	Group	Number (n=44)	Percent	Mean	SD	Source of difference	Sum of squares	dF	Mean Square	f	p-value
Communication	Aged 25 to 44	16	36.36	45.75	7.00	Between groups	133.50	2	66.76	1.09	0.3460
	Aged 45 to 54	19	43.18	42.68	8.81	Within groups	2514.70	41	61.33		
	Aged 55 to 74	9	20.45	46.78	6.91	Total	2648.20	43			
Navigation	Aged 25 to 44	16	36.36	26.13	2.63	Between groups	40.90	2	20.47	1.39	0.2610
	Aged 45 to 54	19	43.18	26.00	4.91	Within groups	604.00	41	14.73		
	Aged 55 to 74	9	20.45	28.44	2.88	Total	644.90	43			
Total score	Aged 25 to 44	16	36.36	71.88	8.57	Between groups	273.00	2	136.60	1.31	0.2810
	Aged 45 to 54	19	43.18	68.68	11.94	Within groups	4275.00	41	104.30		
	Aged 55 to 74	9	20.45	75.22	8.73	Total	4548.00	43			
Quality of care global measure	Aged 25 to 44	16	36.36	8.56	0.96	Between groups	2.26	2	1.13	0.76	0.4730
	Aged 45 to 54	19	43.18	8.21	1.47	Within groups	60.65	41	1.48		
	Aged 55 to 74	9	20.45	8.78	0.97	Total	62.91	43			

Table 7.15: Care coordination age summary statistics and Kruskal-Wallis test

Care coordination scale	Group	Number (n=44)	Percent	Median	IQR	C^2	dF	p-value
Care coordination global measure	Aged 25 to 44	16	36.36	8.00	2.00	1.62	2	0.4459
	Aged 45 to 54	19	43.18	8.00	3.00			
	Aged 55 to 74	9	20.45	8.00	1.00			

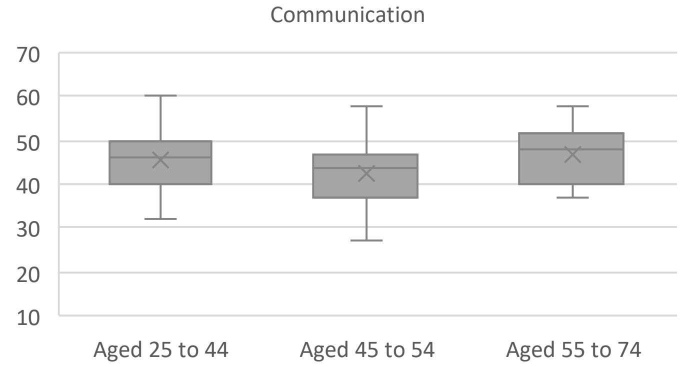


Figure 7.31: Boxplot of Care coordination: Communication by age

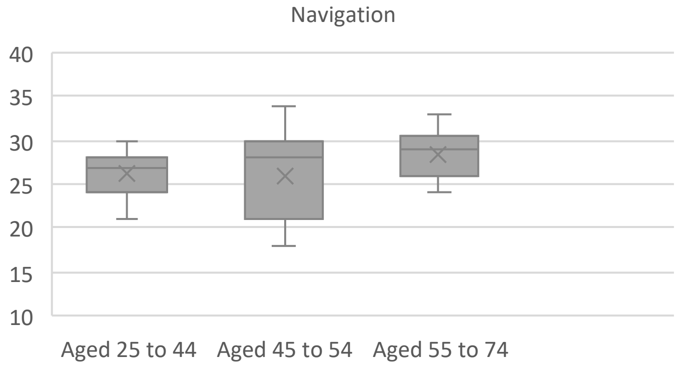


Figure 7.32: Boxplot of Care coordination: Navigation by age

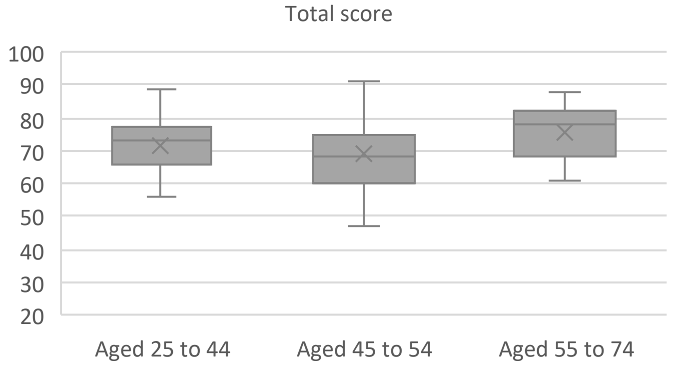


Figure 7.33: Boxplot of Care coordination: Total score by age

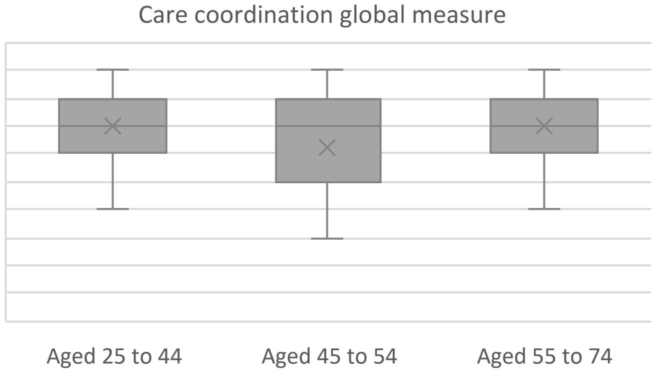


Figure 7.34: Boxplot of Care coordination: Care coordination global measure by age

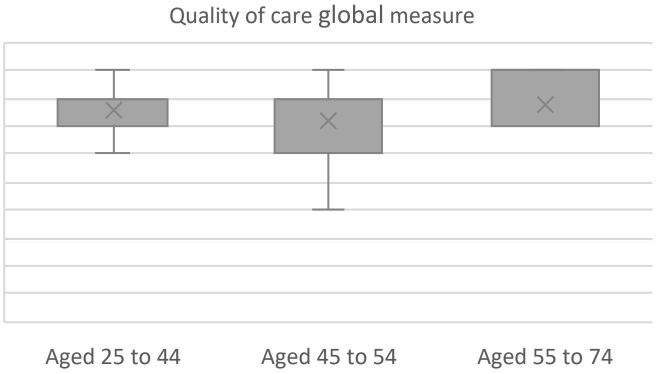


Figure 7.35: Boxplot of Care coordination: Quality of care global measure by age

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 received support through charities (n=19, 38%). This was followed by receiving support from a hospital or clinical setting (n=11, 22%). There were 15 participants (30.00%) that described not receiving any support. There were five participants (10.00%) who described care through accessing peer support, and the same number described getting support through a psychologist or counselling service (n=5, 10.00%).

Participant describes receiving support through charities

I received some support from, again, that organization called Mummy's Wish. Through them, I came to know I can have access to something called in-home care for my child. There was a point when my family, they were feeling the burden of having to take time off, especially my mum. She'd exhausted along, obviously. Then I came to know of the service. I was able to organize a caretaker to come and look after my son and at least maintain the environment for him as positively as possible while I could go and get my treatment and rest up. That was through Centrelink. We got ACCS, which is complete subsidy, so we didn't have to pay for it either. That really, really helped me because I was relieved someone looked after my son. The service continued right up until I reintegrated with the workforce. Participant_016

PARTICIPANT: I did one of those Look Good Feel Better workshops online. I had the Cancer Council booklets, and I did look up some of their info online and that sort of thing in the Breast Cancer Network. My GP was fantastic. She would give me a call every few months just to see how I was. That was really amazing. I saw my breast care nurse pretty much every week when I was at chemo, so I had easy access to her as I needed it which was great. That's probably really the main things that I would have accessed.
INTERVIEWER: Did you find the Look Good Feel Better program helpful?
PARTICIPANT: I did the make up one. I don't generally wear makeup. I'm not sure that I was the right kind of person for that particular thing. Friends just said to me, "Oh, this thing you can do. Why don't you enrol?" I didn't get that much out of it, but that's because I don't wear makeup normally, anyway. I didn't end up doing the one for..They do another one for wigs and stuff, because I ended up just not wearing anything. I just went bald because it was too hot. In the end, I realized that that probably wouldn't be for me either, so I didn't bother to do the second one…The friend who recommended it to me was really concerned about losing her hair, and she did the ice caps and the whole thing. For her, that was probably a really useful thing, but for me, it was just not. That's not me. Participant_011

Not really. The social worker referred me to a charity, a local charity in Brisbane called Be Uplifted who were amazing. They came over and gave me a food hamper, a basket full of goodies and a couple of blankets. One was crocheted, one was a quilt. They're able to bring in a cleaner for me to help with my floors. They're getting someone to help me my yard…The social worker also referred me to another charity. Oh, what is it called? Look Good, Feel Better, I think they're called. I did a skin and makeup tutorial and got the most amazing thing of makeup from them. Other than that, I really haven't had much assistance or support Participant_014

Participant describes not receiving any support

No I didn't get any. Participant_006

I haven't, that's my choice. I think there are those support services out there, but I haven't really needed that. Participant_019

No. I haven't had any. Participant_035

Participant describes receiving support through a community service program

Oh, really? I mean, the only, you know, my friends like the six times that I had my chemo. Yeah. I had a friend who made sure that dinner was cooked for my family, that not because I'm was too tired to do it, but other people think I think I recall there being you know I think they were saying, don't you get told don't hesitate to ask to help me write down. Many times I hope. But the other people I'm sure I know there is community life and the home and community care programme that I has that is usually aimed at older people and sick people say, know when you're having cancer, it's only short term, but something like that where you have someone coming into your bathroom, all those services would be good. And if I could have got that first six or seven dollars an hour, I probably would have taken it up knowing that it was just for the short term while I went through my chemo. Participant_003

Yes. There's a local one in LOCATION called Reacher. They're a community group that's been put together. I think they've been there for a couple of years, charity group. They have offered me counselling. I've had two sessions with a counsellor through them. They have offered to assist with gardening with my home in LOCATION because I'm in LOCATION. I'm not there to look after it. They've offered that. They've also offered memberships…They've offered me that and I'm just going to actually just go through that now. Then you've got Breast Care LOCATION who assisted me with counselling services. Participant_017

Yes, I have. I suppose you call it community service, a breast care nurse has probably put me in touch with a few. I have reached out to what's called Mummy's Wish which has got some support components in there as well. What else is there? There's not much community-wise in that sense that isn't through our local cancer centre. There's a support network group that they've finally been able to get going again after all the COVID stuff. That's one we just started so that's something I'll actively participate in. Other than that, a lot of it's just online. Participant_030

Participant describes receiving support from a hospital or clinical setting

I think the main support would be the the breast care nurse, even during treatment, very busy person. In our regional town, it's a point five position. She's run off her feet, but she made regular contact, just to see how I was going. Like I said, she still maintains that contact through our support group. Other than that, I guess, no. That was the main impetus for the group of women that set up our support group. That was the main reason that we did come together and set that support group up and have maintained that because we felt that there wasn't that support out there in the community. While we initially set it up for women that were going through that breast cancer diagnosis, we've opened that up to other women that are going through a cancer diagnosis to come along as well. I've found that the most beneficial. We've also, most of us are like, one to two years, down the track of finishing treatment. We've gone on to set up our own charity, to fundraise, to support people within our community financially that are struggling with treatment. I think, in that regard, we found our own support. Participant_013

I had the hospital group, which was good, the Cancer Council, the peer support group, our breast reconstruction group. It's just support from professionals, isn't it? Participant_040

I got a food voucher from a private hospital on the LOCATION, which was nice because I told them I was struggling with money. LOCATION is a partially funded service, the Cancer Wellness Center that I go to. I only pay very small amount of out-of-pockets. They even have drivers to pick you up and all that kind of stuff. I find that very supportive. That's probably about it. That's all I can think of right now. That's another thing when they're raising money for women with breast cancer, I'm like, "Where's this money going?" [laughs] Participant_008

Participant describes receiving support through peer support (Face-to-face)

I think the main support would be the, the breast care nurse, even during treatment, very busy person. In our regional town, it's a point five position. She's run off her feet, but she made regular contact, just to see how I was going. Like I said, she still maintains that contact through our support group. Other than that, I guess, no. That was the main impetus for the group of women that set up our support group. That was the main reason that we did come together and set that support group up and have maintained that because we felt that there wasn't that support out there in the community. While we initially set it up for women that were going through that breast cancer diagnosis, we've opened that up to other women that are going through a cancer diagnosis to come along as well. I've found that the most beneficial. We've also, most of us are like, one to two years, down the track of finishing treatment. We've gone on to set up our own charity, to fundraise, to support people within our community financially that are struggling with treatment. I think, in that regard, we found our own support. Participant_013

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Participant describes receiving support through a psychologist or counselling service

I had two telephone counselling sessions with a psychologist who's specialized in breast cancer. After I was diagnosed with the gene, I had an in-person counselling session through the breast cancer organization, I can't remember which one. I had one in-person session. The biggest help, at the time, was the first cancer nurse. I could ring her. I met with her a few times, and I could call her any time. She totally understood what I was going through. Participant_037

The support I've had from Cancer Council, once I had contacted them, they gave me some financial support at the beginning of the breast to me so she could be in contact with me at any time, or I could contact her at any time to talk through things. Also, I supplied a counsellor where we had monthly meetings and she would facilitate it. And then I'd seen her on a personal basis over the years. I then joined another support group, which was a group of ladies where we did activities together once every quarter sort of thing, and then we started doing monthly catch up and now we're doing catch up to talk to various professional. We had a person coming to talk to us about exercise therapy. Participant_049

Table 7.16: Experience of care and support

Experience of care and support	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=23	%	n=27	%	n=19	%	n=25	%	n=26	%	n=24	%	n=24	%	n=26	%
Participant describes receiving support through charities	19	38.00	10	43.48	9	33.33	7	36.84	10	40.00	11	42.31	8	33.33	8	33.33	11	42.31
Participant describes not receiving any support	15	30.00	6	26.09	9	33.33	4	21.05	9	36.00	4	15.38	11	45.83	8	33.33	7	26.92
Participant describes receiving support through a community service program	12	24.00	9	39.13	3	11.11	5	26.32	7	28.00	6	23.08	6	25.00	4	16.67	8	30.77
Participant describes receiving support from a hospital or clinical setting	11	22.00	6	26.09	5	18.52	5	26.32	5	20.00	9	34.62	2	8.33	4	16.67	7	26.92
Participant describes receiving support through peer support (Face-to-face)	5	10.00	2	8.70	3	11.11	1	5.26	4	16.00	3	11.54	2	8.33	2	8.33	3	11.54
Participant describes receiving support through a psychologist or counselling service	5	10.00	2	8.70	3	11.11	3	15.79	1	4.00	4	15.38	1	4.17	3	12.50	2	7.69

Experience of care and support	All participants		Regional or remote		Metropolitan		Mid to low status		Higher status		Aged 25 to 44		Aged 45 to 54		Aged 55 to 74	
	n=50	%	n=16	%	n=34	%	n=20	%	n=30	%	n=19	%	n=22	%	n=9	%
Participant describes receiving support through charities	19	38.00	6	37.50	13	38.24	6	30.00	13	43.33	8	42.11	7	31.82	4	44.44
Participant describes not receiving any support	15	30.00	6	37.50	9	26.47	6	30.00	9	30.00	4	21.05	7	31.82	4	44.44
Participant describes receiving support through a community service program	12	24.00	5	31.25	7	20.59	2	10.00	10	33.33	6	31.58	5	22.73	1	11.11
Participant describes receiving support from a hospital or clinical setting	11	22.00	3	18.75	8	23.53	3	15.00	8	26.67	4	21.05	5	22.73	2	22.22
Participant describes receiving support through peer support (Face-to-face)	5	10.00	2	12.50	3	8.82	2	10.00	3	10.00	2	10.53	1	4.55	2	22.22
Participant describes receiving support through a psychologist or counselling service	5	10.00	1	6.25	4	11.76	0	0.00	5	16.67	1	5.26	2	9.09	2	22.22

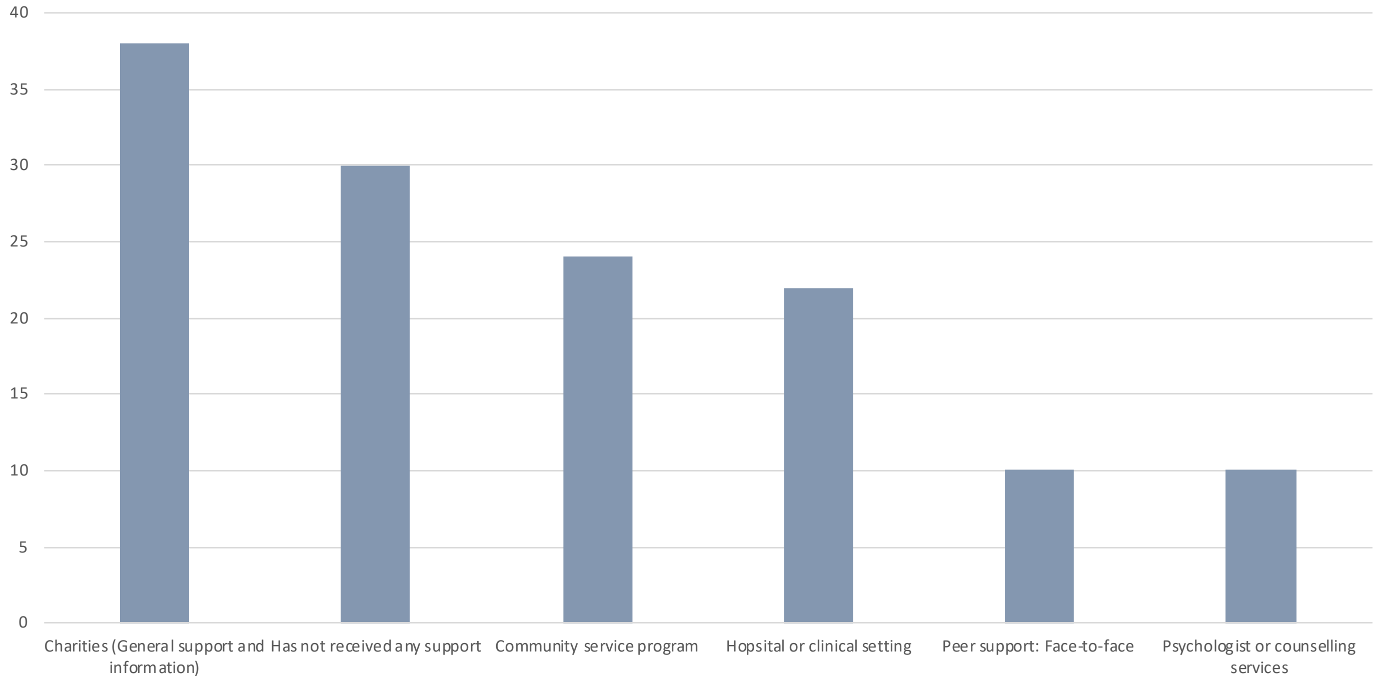

Figure 7.36: Experience of care and support – percent of all participants

Table 7.18: Experience of care and support – subgroup variations

Theme	Reported less frequently	Reported more frequently
Participant describes not receiving any support	Diagnosed before 2020	Diagnosed in 2020 or 2021 Aged 55 to 74
Participant describes receiving support through a community service program	Advanced breast cancer Mid to low status Aged 55 to 74	Early breast cancer
Participant describes receiving support from a hospital or clinical setting	Diagnosed in 2020 or 2021	Diagnosed before 2020

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 26 participants (52.00%) who described a negative impact on quality of life. There were seven participants (14.00%) who reported a mix of positive and negative impact on quality of life, and six participants (12.00%) who reported an overall positive impact on quality of life, and five participants. There were five participants (10.00%) who described no impact on quality of life, and three participants (6.00%) who described minimal 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 (n=25, 50.00%), the impact of symptoms/side effects (n=15, 30.00%), and the reduced capacity for physical activity (n=8, 16.00%).

Impact on mental health

In the structured interview, participants were asked if there had been an impact on their mental health. There were 45 participants (90.00%) who gave a description suggesting that overall there was some impact on their mental health and three participants (6.00%) who gave a description suggesting that overall there was no impact on mental health.

Regular activities to maintain mental health

In the structured interview, participants were asked what they needed to do to maintain their emotional and mental health. The most common ways that participants reported managing their mental and emotional health was maintaining social, lifestyle changes, and hobbies (n=18, 36.00%), consulting a mental health professional (n=17, 34.00%), and physical exercise (n=15, 30.00%). There were eight participants (16.00%) who described the importance of accepting their condition and having a positive outlook, and the same number who described the importance of family and friends (n=8, 16.00%). Other ways to maintain mental health included self-care (n=6, 12.00%), and mindfulness or meditation (n=5, 10.00%).

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 way that participants reported managing their health was by being physically active (n=26, 52.00%), followed by the importance of self-care (n=19, 38.00%). There 13 participants (26.00%) who described the importance of understanding their limitations, 12 participants (24.00%) who described maintaining a healthy diet and 11 participants (22.00%) who described the importance of treatment compliance. Other ways of maintaining health included keeping up with daily activities (n=7, 14.00%), and socialising with family and friends (n=5, 10.00%). There were five participants (10.00%) who described no regular activities to maintain their health.

Experience of vulnerability

In the structured interview, participants were asked if there had been times that they felt vulnerable. There were 43 participants (86.00%) who gave a description suggesting that overall they had experiences of feeling vulnerable, and four participants (8.00%) who gave a description suggesting that overall they did not have feelings of being vulnerable.

In relation to when participants felt most vulnerable, the most common theme was feeling vulnerable during or after treatments (n=20, 40.00%), followed by feeling vulnerable when having negative thoughts (n=15, 30.00%). There were 14 participants (28.00%) who described feeling vulnerable when having sensitive discussions for example at diagnosis and treatment decisions, and nine participants (18.00%) described feeling vulnerable when feeling sick.

Methods to manage vulnerability

In the structured interview, participants described ways that they managed feelings of vulnerability. Participants described support from their medical team to manage the feeling of vulnerability (n=9, 18.00%), and using self-help methods such as resilience, acceptance, and staying positive to manage the feeling of vulnerability (n=7, 14.00%). Other methods included adapting, for example being proactive. Assertive and understanding boundaries (n=6, 12.00%), and getting support from family and friends (n=5, 10.00%).

Impact on relationships

In the structured interview, participants were asked whether their condition had affected their personal relationships. Overall, there were 19 participants (38.00%) who described a mix of positive and negative impacts on relationships. Other participants reported a negative impact on relationships (n=11, 22.00%), no impact on relationships (n=8, 16.00%), and a positive impact on relationships (n=7, 14.00%).

The most common theme in relation to having an impact on relationships was a mixed impact on relationships, some strengthened, others disappeared (n=14, 28.00%). There were eight participants (16.00%) who described relationships suffering, because of people not knowing what to say or do and withdrawing from relationships, and the same number who described no impact on relationships with no specific reason (n=8, 16.00%). Other reasons included relationships with family being strengthened (n=7, 14.00%), and relationships suffering, due to emotional strain (n=6, 12.00%).

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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 30 participants (60.00%) who felt there was an additional burden, and 18 participants (36.00%) who reported no additional burden.

Participants who described that they were no additional burden, mostly did this without giving any examples or explanations (n=13, 26.00%), followed by not being a burden because they manage their condition independently (n=5, 10.00%). For people that felt they were a burden on their family, most commonly did not give any specific reasons for this (n=12, 24.00%). The main reasons for burden on families were the extra household duties and responsibilities that their family must take on (n=10, 20.00%), and the mental/emotional strain placed on their family (n=6, 12.00%).

Cost considerations

In the structured interview, participants were asked about any significant costs associated with having their condition. There were 36 participants (72.00%) that described some cost burden and 11 participants (22.00%) who described no cost burden.

Where participants described a cost burden associated with their condition, it was most commonly in relation to the cost of treatments, including repeat scripts (n=25, 50.00%). Other cost burdens were in relation to diagnostic tests and scans (n=15, 30.00%), taking time off work (n=9, 18.00%), and the cost of private care (n=7, 14.00%). There were six participants (12.00%) who described the cost of specialist appointments, and the same number who described the cost of allied healthcare (n=6, 12.00%), and the cost of parking and travel to attend appointments, including accommodation (n=6, 12.00%). There were six participants (12.00%) that described no cost burden and that nearly everything was paid for through the health system or private coverage.

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. The average score was in the Life was a little distressing range (median = 3.00, IQR = 3.00) (Table 8.29, Figure 8.15).

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 a mean total score of 35.89 (SD = 7.50), which corresponds to moderate levels of anxiety (Table 8.29)

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 26 participants (52.00%) who described a negative impact on quality of life. There were seven participants (14.00%) who reported a mix of positive and negative impact on quality of life, and six participants (12.00%) who reported an overall positive impact on quality of life, and five participants. There were five participants (10.00%) who described no impact on quality of life, and three participants (6.00%) who described minimal 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 (n=25, 50.00%), the impact of symptoms/side effects (n=15, 30.00%), and the reduced capacity for physical activity (n=8, 16.00%).

The most common theme in relation to a positive impact on quality of life was giving perspective on what is important in life (n=5, 18.00%).

Participant describes an overall negative impact on quality of life

Yes, definitely. It's totally different. It's getting better. It's no nowhere near what it was before breast cancer. I've changed my career to a less stressful local-based workplace. I'm not as active as I used to be because every time I get tired. I have to fight just fatigue and then I get a lot of chronic pain. I've had that many surgeries in the last five years. Silly. Every time you have surgery it's like six or eight weeks. Participant_012

Yes. It affected my physical quality of life, because of the symptoms and the significance around just what I've experienced through having done chemo. You're told this in the beginning, but you don't get it until it happens. Yes, so it's one of those things you've got to wait up. Participant_015

Participant describes a mix of positive and negative impact on quality of life

It's affected my quality of life because obviously I only have one breast and I've had side effects, but I think it's strengthened my relationship with my husband most definitely. My kids well, they're teenagers. I've got two older kids that aren't living at home that I get on very well with. My son who's in the car now obviously he likes to keep to himself so it doesn't really say much about whether or not it's affected him at all. My youngest daughter, she was a lot younger when I was diagnosed so I think that she seems to be fine as well. I think that those relationships, like the familial relationships are all fine. My husband's, a different way strengthened our relationship. I don't know why, it just made it better, just stronger. Stronger. Not better, stronger. Participant_022

To me, sort of a yes and a no. I mean, obviously yes, in that it's added a degree of at different times heightened and at other times just low level anxiety to my general life, which I didn't have before my family. I think they did have felt that to some degree, too. So in that respect, if I just find that aspect of quality of life. Yes. But on the other hand, I guess having had this, it's made me, as I probably said earlier, more conscious of how time is precious. And I know it sounds cliche, but it's just what the reality and trying to not, as I say, don't sweat the small stuff. Another cliche, but again, it is true and. So, yes, it has had an impact, but I wouldn't say bad with the negative, there's been some positive swings, swings around, you know, the other way. Participant_023

During treatment, it definitely was difficult because I had the daughter going to the HSC and another daughter first year law school and my son moved from LOCATION to LOCATION. That was a disaster for me personally, but I understood they had to get on with their life. Then, once I started feeling better, we started doing more as an adult family and I think it improved my quality of life. I've gotten a lot fitter, I've lost weight, I make the most of life now. Participant_040

Participant describes an overall positive impact on quality of life

Yes, it has, but I'd have to say it has improved my quality of life, and it's improved everything. I take better care of myself now, I'm way less stressed. I go out of my way to not be a stressed-out person because I believe that that is probably what caused the cancer in the first place. I have a better perspective on everything and now that I've been through that rather than just taking life for granted, I suppose. Participant_005

No, it hasn't. I think the quality and relationship with my family has probably only strengthened as a result of that. I think getting a diagnosis like cancer does impact on those around you, either for the better or worse. With my family, we were very close. Prior to the diagnosis, this only made us a lot closer. Like I said, my family were really supportive as a result of it. I felt very loved and nurtured right the way through treatment and still do. Yes, it has impacted on the quality of my life a little, in regards to the fact, like I say I probably gave up work earlier than what I had originally planned. I probably would have worked a bit longer before I retired, but I was lucky enough to be in a situation where I was able to retire early. Financially, I don't have any issues in that regard. I do have some ongoing health issues and that has impacted a little bit on my day-to-day life. Yes, in that regard, yes. It has impacted although, once again, I look at it like, "Okay, yes, I might have a few long term effects from my chemo, but I'm still here and I'm still able to do most of the things that I want to do." Yes, I'm grateful for that. Participant_013

I think it's probably improved my quality of life and my family life, as in my children. I'm sorry, I didn't have any family support really at the time. I faced that with my husband at the time. Yes, I think now it's just more about living for me and my children. Participant_024

Participant describes no impact on quality of life

Not really. It's just myself and my son. No, but my son's quite-- I don't know whether he's-- I took him with me to get my diagnosis and I said to him in the car before we went in, "What are you going to do if they come back and say I've got cancer and he was like, should be all right." Participant_014

I'm determined that it's not going to affect my quality of life. That's why I went to the physio and stuff like that. At the moment, yes, I'm certainly not as active as I was, but I have a very loving partner who never made me feel that I was a burden or being sick was a problem so I was very lucky there. I never felt like that. Participant_029

Participant describes an overall minimal impact on quality of life

During treatment, yes, afterwards, no.
Participant_009

Not necessarily. I wouldn't say that it's changed me and are now all like live the moment every day. It definitely makes you think about life a bit more, but yes, I don't think it's really changed our quality of life. We're still pretty much doing what we were doing pre-cancer. I have to remind myself most days that, "Hey, you actually had cancer." It's not something that I dwell on. It's not something that I focus on every day. Yes, I don't think it's really drastically changed that quality of life, I suppose. Participant_025

Probably in the beginning. Now we're starting to get on top of things. We have a bit of social life. It's not too bad at the moment. Participant_032

Participant describes negative impact on quality of life as a result of emotional strain on family/change in relationship dynamics

Yes, yes. Yes. How much detail do you want to have? Because at the time it was there were all sorts of aspects for my children. There was the stress and the worry for my eldest child, who was sort of taking on more of the caring for my role. And then my younger daughter, she he even now she'll wake up and she'll have a nightmare about losing me. So, yeah, there was that sort of stress and anxiety on my children. There was the pressure on my husband to try and look after all the family and hold on to his job and keep up with that to do work after hours. And the worry, the stress for him about losing me and doing all the appointments, all these random appointments that you couldn't change. And he would just have to try and make it work fit into it. So, yes, at the time, the quality of life, it really affected it. And that's had the ongoing effect. It's just had all these knock on effects with our family life. Participant_001

Yes, it has. My quality of life has decreased for a little bit. I have had to slow down professionally. I was doing really well before my diagnosis and I've had to give up on a lot of things and start again. That's been the hardest for me, starting from dot one in my *profession and having to give up-- I wanted to specialize and I was accepted into it, but I have to turn it all down. Cancer has changed my perspective and I just don't know what's going to happen, so I don't think I'll ever go and specialize again. It's also stopped my husband's progress in a way because we want to be close to our family and medical services. If he ever gets offered promotions or better jobs in some state, we can't just move as freely now as we used to. Participant_016*

Yes, it very much has affected my quality of life. I only have my daughter. It hasn't really affected her too much. She's had to help me out a few times, but I would imagine it's stressful for her because her mum has got cancer. I've tried very hard to not let her know everything that's going on. She's had to make meals for me and all that sort of stuff to put in the freezer, "Just come over and keep me company," or whatever, just to try and keep me sane. Like I said, I've tried not to involve her too much. Participant_028

Participant describes negative impact on quality of life as a result of symptoms/side effects

PARTICIPANT: Mine, yes, but not the family.
INTERVIEWER: How has it affected your quality of life?
PARTICIPANT: That I think when I continue to do things like poorly because I'm in pain and then I get cranky and short with people around me, Participant_006

Yes, definitely. It's totally different. It's getting better. It's no nowhere near what it was before breast cancer. I've changed my career to a less stressful local-based workplace. I'm not as active as I used to be because every time I get tired. I have to fight just fatigue and then I get a lot of chronic pain. I've had that many surgeries in the last five years. Silly. [crosstalk] Every time you have surgery it's like six or eight weeks. Participant_012

Look, yes, it has, but COVID has a lot to do with that as well. I think if COVID wasn't here and there were no travel restrictions, and there were no restrictions at all, then it would have affected my life a lot more. I haven't really been able to do much because I haven't been well, so you know chemo isn't great. I haven't felt like wanting to do much on weekends and stuff. With COVID here I haven't really been able to travel or go anywhere far anyway. Yes, it has affected my life, but so has COVID. Participant_018

Participant describes negative impact on quality of life as a result of reduced capacity for physical activity

Don't really know. I would say probably for a while last year, while I was actually going through treatment things were-- we couldn't live our normal life. I couldn't be out and about and couldn't do things. I was relying a lot more on my son in particular because he lived here, but also my daughter from time to time, to do the things that I couldn't do. Keeping up with housework and cooking and all those sorts of things. Yes. It impacted on them. After surgery, I needed a lot more help, so my daughter moved in for a couple of weeks and things like that. It affected them in that way, but that was during and after the treatment and surgeries and things like that. Now I don't think so. I think now we're pretty much back to-- It's not affecting our quality of life now. Participant_011

Yes, definitely. It's totally different. It's getting better. It's no nowhere near what it was before breast cancer. I've changed my career to a less stressful local-based workplace. I'm not as active as I used to be because every time I get tired. I have to fight just fatigue and then I get a lot of chronic pain. I've had that many surgeries in the last five years. Silly. [crosstalk] Every time you have surgery it's like six or eight weeks. Participant_012

Yes. It affected my physical quality of life, because of the symptoms and the significance around just what I've experienced through having done chemo. You're told this in the beginning, but you don't get it until it happens. Yes, so it's one of those things you've got to wait up. Participant_015

Participant describes positive impact on quality of life as the diagnosis helps you realise what is important (giving perspective)

Yes, it has, but I'd have to say it has improved my quality of life, and it's improved everything. I take better care of myself now, I'm way less stressed. I go out of my way to not be a stressed-out person because I believe that that is probably what caused the cancer in the first place. I have a better perspective on everything and now that I've been through that rather than just taking life for granted, I suppose. Participant_005

To me, sort of a yes and a no. I mean, obviously yes, in that it's added a degree of at different times heightened and at other times just low level anxiety to my general life, which I didn't have before my family. I think they did have felt that to some degree, too. So in that respect, if I just find that aspect of quality of life. Yes. But on the other hand, I guess having had this, it's made me, as I probably said earlier, more conscious of how time is precious. And I know it sounds cliche, but it's just what the reality and trying to not, as I say, don't sweat the small stuff. Another cliche, but again, it is true and. So, yes, it has had an impact, but I wouldn't say bad with the negative, there's been some positive swings, swings around, you know, the other way. Participant_023

It's probably changed my point of view on loss in general, in that now I'm like, I've been given a second chance so to speak. Just living your best life and making the most out of every situation. There's people out there that are worse off than me, just because I've had breast cancer, it doesn't make me a sad sack of potatoes for the rest of my life. I've had it, I survived it and I just got to move on now. I'll just continue to be this forward, positive person that I am. Participant_045

Table 8.1: Impact on quality of life

Impact on quality of life	All participants n=50	%	Early breast cancer n=23	%	Advanced breast cancer n=27	%	Poor physical function n=19	%	Good physical function n=25	%	Diagnosed before 2020 n=26	%	Diagnosed in 2020 or 2021 n=24	%	Trade or high school n=24	%	University n=26	%
Participant describes an overall negative impact on quality of life	26	52.00	13	56.52	13	48.15	10	52.63	11	44.00	11	42.31	15	62.50	12	50.00	14	53.85
Participant describes a mix of positive and negaitve impact on quality of life	7	14.00	3	13.04	4	14.81	2	10.53	5	20.00	6	23.08	1	4.17	2	8.33	5	19.23
Participant describes an overall positive impact on quality of life	6	12.00	2	8.70	4	14.81	3	15.79	3	12.00	3	11.54	3	12.50	3	12.50	3	11.54
Participant describes no impact on quality of life	5	10.00	2	8.70	3	11.11	1	5.26	4	16.00	2	7.69	3	12.50	3	12.50	2	7.69
Participant describes an overall minimal impact on quality of life	3	6.00	2	8.70	1	3.70	2	10.53	1	4.00	2	7.69	1	4.17	2	8.33	1	3.85
Other	2	4.00	0	0.00	2	7.41	1	5.26	1	4.00	0	0.00	2	8.33	2	8.33	0	0.00

Impact on quality of life	All participants n=50	%	Early breast cancer n=23	%	Advanced breast cancer n=27	%	Poor physical function n=19	%	Good physical function n=25	%	Diagnosed before 2020 n=26	%	Diagnosed in 2020 or 2021 n=24	%	Trade or high school n=24	%	University n=26	%
Participant describes an overall negative impact on quality of life	26	52.00	13	56.52	13	48.15	10	52.63	11	44.00	11	42.31	15	62.50	12	50.00	14	53.85
Participant describes a mix of positive and negaitve impact on quality of life	7	14.00	3	13.04	4	14.81	2	10.53	5	20.00	6	23.08	1	4.17	2	8.33	5	19.23
Participant describes an overall positive impact on quality of life	6	12.00	2	8.70	4	14.81	3	15.79	3	12.00	3	11.54	3	12.50	3	12.50	3	11.54
Participant describes no impact on quality of life	5	10.00	2	8.70	3	11.11	1	5.26	4	16.00	2	7.69	3	12.50	3	12.50	2	7.69
Participant describes an overall minimal impact on quality of life	3	6.00	2	8.70	1	3.70	2	10.53	1	4.00	2	7.69	1	4.17	2	8.33	1	3.85
Other	2	4.00	0	0.00	2	7.41	1	5.26	1	4.00	0	0.00	2	8.33	2	8.33	0	0.00

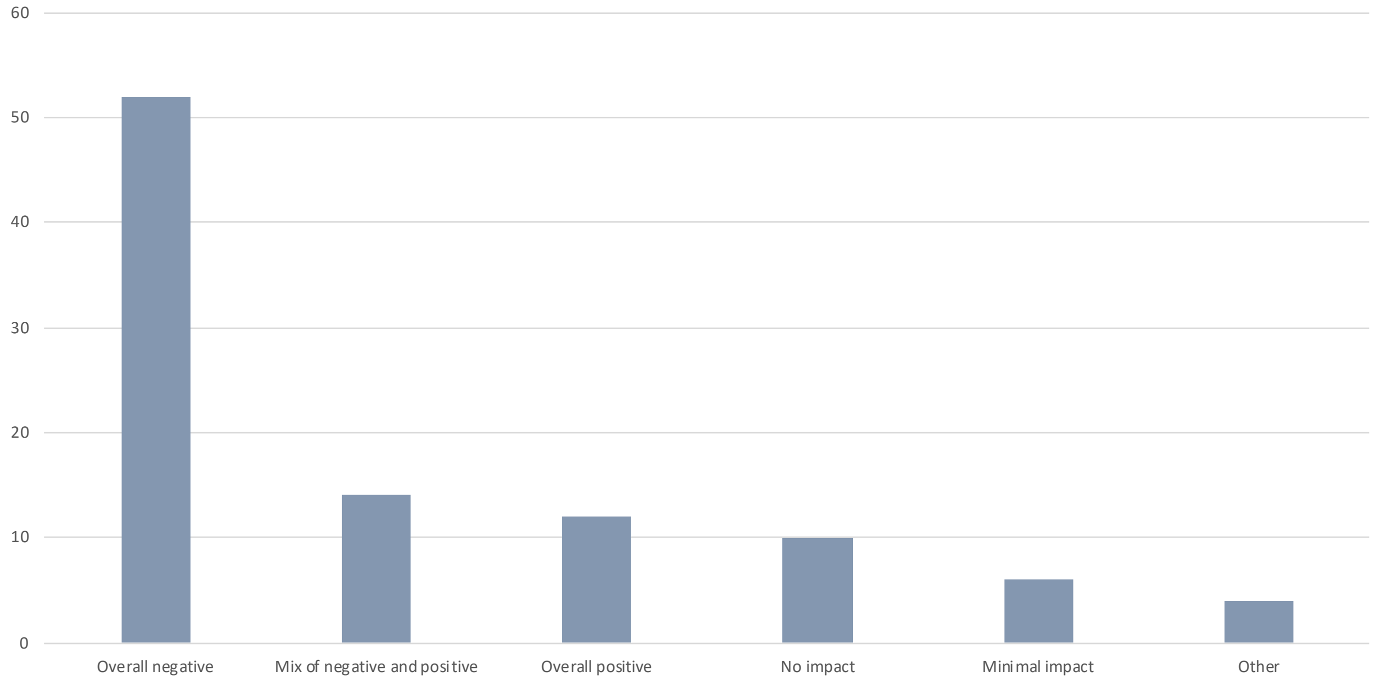

Figure 8.1: Impact on quality of life

Table 8.2: Impact quality of life – subgroup variations

Theme	Reported less frequently	Reported more frequently
Participant describes an overall negative impact on quality of life	Mid to low status Aged 55 to 74	Diagnosed in 2020 or 2021 Higher status
Participant describes no impact on quality of life	-	Aged 55 to 74

Table 8.3: Impact on quality of life (Reasons)

Impact on quality of life (Reasons)	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=23	%	n=27	%	n=19	%	n=25	%	n=26	%	n=24	%	n=24	%	n=26	%
Participant describes negative impact on quality of life as a result of emotional strain on family/change in relationship dynamics	25	50.00	11	47.83	14	51.85	10	52.63	10	40.00	11	42.31	14	58.33	11	45.83	14	53.85
Participant describes negative impact on quality of life as a result of symptoms/side effects	15	30.00	10	43.48	5	18.52	6	31.58	8	32.00	9	34.62	6	25.00	6	25.00	9	34.62
Participant describes negative impact on quality of life as a result of reduced capacity for physical activity	8	16.00	6	26.09	2	7.41	3	15.79	3	12.00	3	11.54	5	20.83	4	16.67	4	15.38
Participant describes positive impact on quality of life as the diagnosis helps you realise what is important (giving perspective)	5	10.00	3	13.04	2	7.41	1	5.26	4	16.00	4	15.38	1	4.17	1	4.17	4	15.38
Participant describes no impact on quality of life (general comment)	5	10.00	2	8.70	3	11.11	1	5.26	4	16.00	2	7.69	3	12.50	3	12.50	2	7.69

Impact on quality of life (Reasons)	All participants		Regional or remote		Metropolitan		Mid to low status		Higher status		Aged 25 to 44		Aged 45 to 54		Aged 55 to 74	
	n=50	%	n=16	%	n=34	%	n=20	%	n=30	%	n=19	%	n=22	%	n=9	%
Participant describes negative impact on quality of life as a result of emotional strain on family/change in relationship dynamics	25	50.00	6	37.50	19	55.88	7	35.00	18	60.00	11	57.89	9	40.91	5	55.56
Participant describes negative impact on quality of life as a result of symptoms/side effects	15	30.00	6	37.50	9	26.47	6	30.00	9	30.00	5	26.32	8	36.36	2	22.22
Participant describes negative impact on quality of life as a result of reduced capacity for physical activity	8	16.00	2	12.50	6	17.65	3	15.00	5	16.67	2	10.53	6	27.27	0	0.00
Participant describes positive impact on quality of life as the diagnosis helps you realise what is important (giving perspective)	5	10.00	1	6.25	4	11.76	2	10.00	3	10.00	2	10.53	2	9.09	1	11.11
Participant describes no impact on quality of life (general comment)	5	10.00	1	6.25	4	11.76	2	10.00	3	10.00	1	5.26	2	9.09	2	22.22

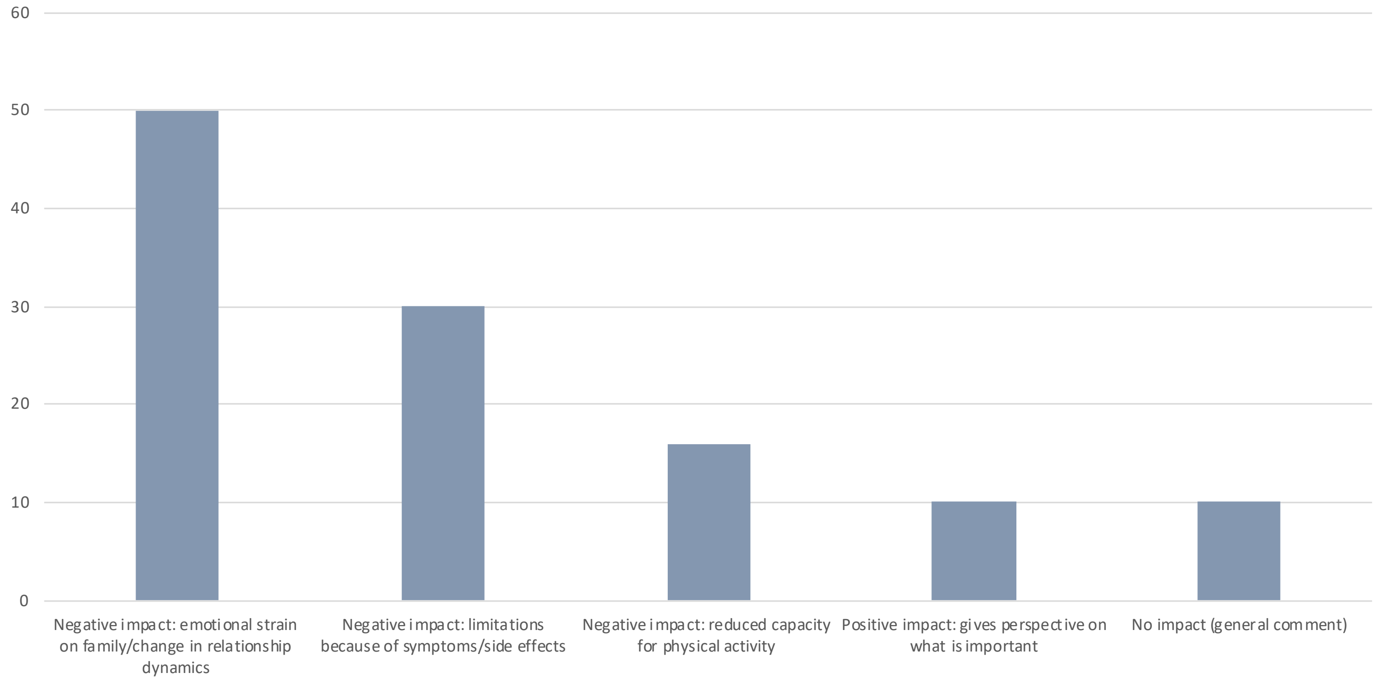

Figure 8.2: Impact on quality of life (Reasons)

Table 8.4: Impact on quality of life (Reasons)– subgroup variations

Theme	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	Regional or remote Mid to low status	-
Participant describes negative impact on quality of life as a result of symptoms/side effects	Advanced breast cancer	Early breast cancer
Participant describes negative impact on quality of life as a result of reduced capacity for physical activity	Aged 55 to 74	Early breast cancer Aged 45 to 54
Participant describes no impact on quality of life (general comment)	-	Aged 55 to 74

Impact on mental health

In the structured interview, participants were asked if there had been an impact on their mental health. There were 45 participants (90.00%) who gave a description suggesting that overall there was some impact on their mental health and three participants (6.00%) who gave a description suggesting that overall there was no impact on mental health.

Participant gives a description suggesting that overall, there was at least some impact on mental health

It does because especially as a female, you lose all your hair and it's debilitating or it was me. Some women say, "Well, I shaved my head before it started falling out myself. Fantastic and I had control." And I conceded off and said I cried the whole time I was sitting my head shaved and couldn't look in a mirror. When I had no hair. How did I look after it? I probably didn't, to be quite honest. I was just at this stage, I was just getting through each day as it came without looking too far ahead because I couldn't cope with it. Participant_027

I think the other day I thought I might actually look up someone to talk to about it, because I didn't really think about it throughout the process because I just wanted to get on with it and keep working so that I could just be focused. Now, you're at the end, it's like, "I actually survived something pretty amazing." It does get a bit overwhelming every now and then. Yes, I get like, "Oh, no." I just start crying like, "Whoa, that was good you know. Well done that you did that." but it might be beneficial for me to go talk to someone about it. That's probably where I'm at right now. Participant_045

Yes, it does affect, obviously. It does affect that side of things. I find I'm a lot more emotional now, just overall. I try to have time out for me all the time, like most days, have a little bit of time to do that. I love walking on the beach or something like that. Being around water helps me. The local cancer support groups, they do pamper days on the coast, so we go to those. They have massage and do different things like that just to treat you, so I try to do them when I can. Participant_046

Table 8.5: Impact on mental health

Impact on mental health	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=23	%	n=27	%	n=19	%	n=25	%	n=26	%	n=24	%	n=24	%	n=26	%
Participant gives a description suggesting that overall, there was at least some impact on mental health	45	90.00	22	95.65	23	85.19	17	89.47	22	88.00	24	92.31	21	87.50	20	83.33	25	96.15
Participant gives a description suggesting that overall, there was no impact on mental health	3	6.00	1	4.35	2	7.41	0	0.00	3	12.00	1	3.85	2	8.33	3	12.50	0	0.00
Other	2	4.00	0	0.00	2	7.41	1	5.26	1	4.00	0	0.00	2	8.33	2	8.33	0	0.00

Impact on mental health	All participants		Regional or remote		Metropolitan		Mid to low status		Higher status		Aged 25 to 44		Aged 45 to 54		Aged 55 to 74	
	n=50	%	n=16	%	n=34	%	n=20	%	n=30	%	n=19	%	n=22	%	n=9	%
Participant gives a description suggesting that overall, there was at least some impact on mental health	45	90.00	14	87.50	31	91.18	18	90.00	27	90.00	17	89.47	20	90.91	8	88.89
Participant gives a description suggesting that overall, there was no impact on mental health	3	6.00	2	12.50	1	2.94	1	5.00	2	6.67	1	5.26	1	4.55	1	11.11
Other	2	4.00	0	0.00	2	5.88	2	10.00	0	0.00	2	10.53	0	0.00	0	0.00

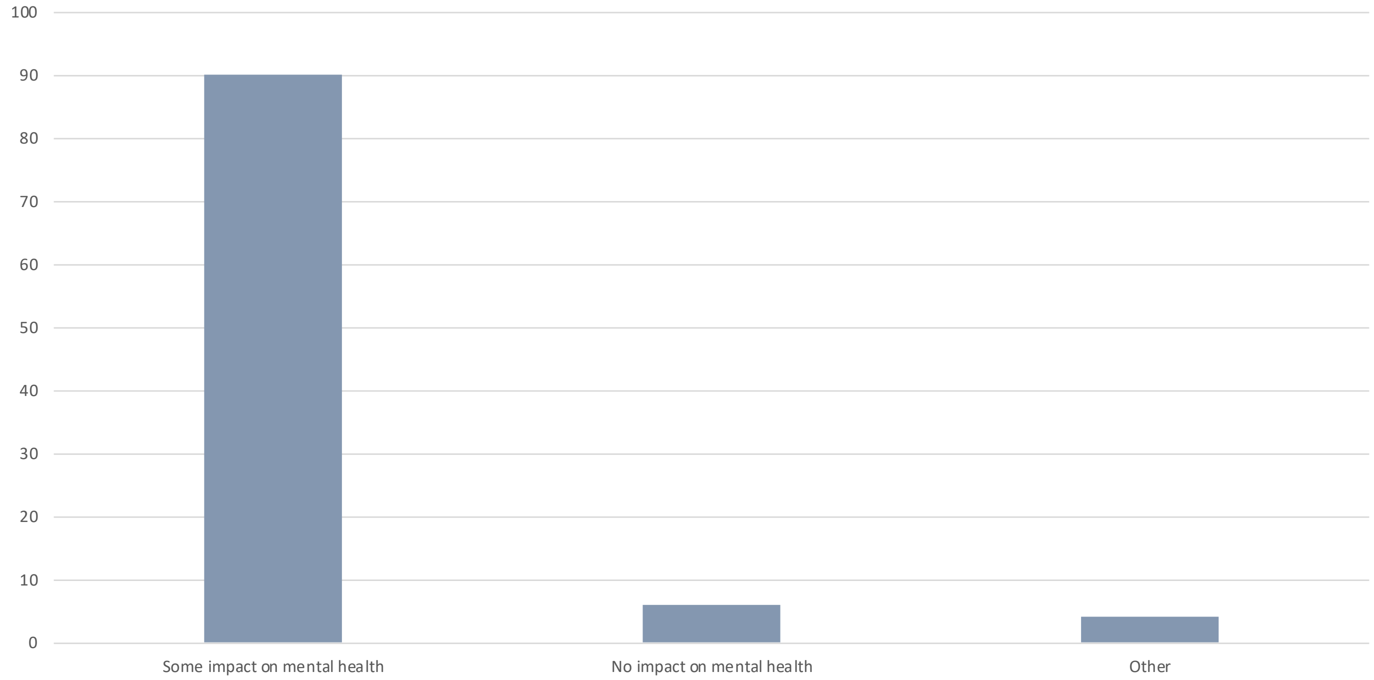

Figure 8.3: Impact on mental health

Regular activities to maintain mental health

In the structured interview, participants were asked what they needed to do to maintain their emotional and mental health. The most common ways that participants reported managing their mental and emotional health was maintaining social, lifestyle changes, and hobbies (n=18, 36.00%), consulting a mental health professional (n=17, 34.00%), and physical exercise (n=15, 30.00%). There were eight participants (16.00%) who described the importance of accepting their condition and having a positive outlook, and the same number who described the importance of family and friends (n=8, 16.00%). Other ways to maintain mental health included self-care (n=6, 12.00%), and mindfulness or meditation (n=5, 10.00%).

Participant describes using coping strategies such as remaining social, lifestyle changes and hobbies

It probably does so. And my one go to with gardening. But that's a hard question to answer when you've been in Lockdown's and stuff like that. So because your quality of life is like crappy anyway, because you can't go anywhere and do anything. Gardening has been my so I do that in shorter bursts now than when I used to do it, like I used to be in there all day, but now I only do it like for an hour here and now with it. And we haven't been able to go out with friends that I normally go out with friends and you know, Participant_006

It definitely affects my mental and emotional health. The things that I do, I guess I have those self care strategies. So whether it's having a day in bed or a day of eating chocolate and takeaway food, whether it's booking in with a friend and going out to dinner and cocktails, or whether it's going for a massage or a run or a swim, whether it's just being out in the environment and absorbing some of the sun, whether it's going for a facial, I have access the counsellor who's a friend when need be, sometimes just, I guess, to check in and see how I'm going to talk about some things will come up with some strategies to implement, making sure that I sleep very well and that majority of time I am getting a balanced diet and exercise and looking after myself. I'm better at cancelling things. So whereas once upon a time I would be very much about what anyone in my life needed. Now I'm better about putting myself first and not seeing that is selfish, but just also looking after me. So I guess that's an important strategy, is thinking about what my body needs and giving it in that moment and not feeling guilty about that. Participant_010

Again, 100%. Yes. I'm trying, I'm working on it [crosstalk] doing the exercise. Staying social, I'm trying to stay as social as possible. Participant_019

Participant describes consulting a mental health professional

It does. I think fear of recurrence is way there and it was a big thing for me when suddenly all the treatment stopped and you're just left. Off you go, you're finished now. Even though you know you're going to get checkups every six months or whatever, it's quite hard to cope with. What do I do now? I'm so scared of definitely a recurrence or metastasis. Yes, mental health-wise, I think it had quite a big effect and I did eventually manage to see a psychologist and talk through things and find ways to manage my fears so that they didn't take over my life. Participant_004

Yes, it does. For sure. The things that I've done is seek the support of the psychologist through Breast Cancer WA, and also the breast care nurse calls me about every month and that is very good. They're the main areas of support for my mental health care. Participant_017

Yes, breast cancer has probably, really ruined my mental health, before then I was very happy, easygoing person. Now, I'm constantly worried about the future. Yes, I see a psychologist for that. Participant_018

Seeing a psychologist at the moment. During treatment, no, I didn't. Didn't have the time or that wellness to deal with it at the time. My treatment started so quickly there wasn't time to get in really beforehand, but now I am, yes. Participant_036

Participant describes the importance of physical exercise

Yes, it does affect your emotional and mental health. I work out, I go to the gym. I do personal training once a week. If I don't go to the gym, I walk. I try and do that and it actually helps with my fatigue as well as my mental health. That's a massive change in my life. Done that. I've changed my career. I was working in law now I'm in an office looking after electricians which is super less stressful than where I was. That's what I've done Participant_012

Obviously, yes, as I've mentioned a few times. So I try to keep exercising both for mental and emotional, mental and physical health. I tended to journal, haven't done so as much, but I do occasionally bring myself back there to reflect on where my head is at or not at all. I try to remember some of the techniques that the counsellors shared with me about managing worry and if I at any time am concerned that I am sliding some way, I'll try to do some things that will help me, whether it's go buy myself a bunch of flowers or listen to some music or take a walk or do I'll do something or go to my favourite movies. I'll do something that will try to soothe a bit if I'm feeling a little bit down or something. Participant_023

Yes, I'm back at work so I have the social aspect. I'm back at my gym three times a week. The physical activity is helping but it's also the social interaction, which helps the mental side because I've got so many friends there who are like, "You're looking so well. You're back at the gym already." and so that kind of thing has really helped me get through it. Participant_027

Participant describes the importance of accepting condition/positive outlook

I'm very aware of that all the emotions of what's going on. I make sure that I deal with them as they come. For me, that means sometimes I'm not happy, I'm sad, and that's okay. I try to focus a lot on why I'm lucky. That's how I deal with it mentally. Participant_007

100%. The stress and the anxiety, I mean, I still get it. I'm trying to be positive and I try to just keep focused on everything's going to be okay, but I mean, you just don't know with triple-negative breast cancer. Unfortunately, it's one of those things where it can go. It could go either way, but I just tried to have a positive spin on it too and not think about that negative side but it still creeps in every day. I'm still trying to push it to the back. I'll have times where I break down because, for me, it's like, "I might not get to see my daughter grow up," I just see things pop into my head frequently and it's all things that I'd have to be talking to my psychologist about. I don't think I would have coped if I didn't have somebody to talk to about. Participant_015

I'm a ridiculously positive person. I've managed to maintain that probably 90% of the time. There are those moments where you do have those awful thoughts that you really don't want to be having. I do allow myself a little more [unintelligible] I think sometimes I'll just allow myself an hour of wallowing and then I step out of it. This is enough because all this *wallowing isn't going to change anything. We really, as a family and as a person, want to focus on the positives and good outcomes. I find that when I let myself slide, that's really difficult. We try as best as possible to drag out of that and then focus on, "Okay this is the hand we're dealt with, what are we going to do about it? Let's be positive. What next?" There's been probably a little change in mood at times, but not desperately. Participant_033*

Participant describes the importance of family and friends in maintaining their mental health

I think I touched on the mental side of it where there's always that thought of, "What if it's going to come back?" and, "What are these aches?" I don't think that that's ever going to change. I still like to do the things I used to do before which is like watching telly and all of that kind of stuff. I don't know. I try to be more positive but at times it can be a little bit harder. My husband and I, we have date nights now. We go away camping or caravanning a lot more now than what we used to. I think that we've been trying to see a little bit more and do a little bit more than what we used to do in the past. Participant_022

Absolutely. When I was first diagnosed, it was terrifying. I have a long health history of not being very well with some pretty serious illnesses. In between that period of time from diagnosis to initial diagnosis to having a PET scan, I was terrified about what was my prognosis. Getting your head around having cancer is just an extraordinary thing to try to do. I couldn't even say the word out loud for a couple of weeks. It was so overwhelming, and just that thing where you wake up in the morning for that brief second, you forget what's really going on, and then it just hits you like a ton of bricks. I just be going about my day and it'd be like getting this reality slap every once in a while where it's just I'd go and I would just remember what was going on. It was like my whole body would just flood with this fear. I go for walks every day on the beach, I do a lot of meditation, guided meditations. I've got my psychologist. I do go for walks with friends most days when we're allowed to. I do try to talk to my partner once, if not twice a day. I just make sure that I'm keeping up those human connections, trying to have some enjoyable time, but also practicing well-being techniques that really helped me, and massage really helps a lot, too. Participant_041

Apart from seeing a psychologist and talking to my daughter endlessly, no I don't. I guess I do think it's affected me in some ways. I haven't got the patience I once did. Yes, talking to people helps. Participant_032

Participant describes the importance of self care in maintaining their mental health

Yes, I think it does because I've been diagnosed with PTSD and I've got anxiety. That's why I speak to the psychologists and stuff as well. That's my thing that I'm booking in and going to that all the time. I do a lot of meditation. I'm just giving myself the time to rest, which I probably wouldn't have done ever before. Just really focusing on making sure that I don't have much stress, and that I'm eating well, that I'm exercising, I'm getting massages, all that self-care stuff. Participant_008

It definitely affects my mental and emotional health. The things that I do, I guess I have those self care strategies. So whether it's having a day in bed or a day of eating chocolate and takeaway food, whether it's booking in with a friend and going out to dinner and cocktails, or whether it's going for a massage or a run or a swim, whether it's just being out in the environment and absorbing some of the sun, whether it's going for a facial, I have access the counsellor who's a friend when need be, sometimes just, I guess, to check in and see how I'm going to talk about some things will come up with some strategies to implement, making sure that I sleep very well and that majority of time I am getting a balanced diet and exercise and looking after myself. I'm better at cancelling things. So whereas once upon a time I would be very much about what anyone in my life needed. Now I'm better about putting myself first and not seeing that is selfish, but just also looking after me. So I guess that's an important strategy, is thinking about what my body needs and giving it in that moment and not feeling guilty about that. Participant_010

Obviously, yes, as I've mentioned a few times. So I try to keep exercising both for mental and emotional, mental and physical health. I tended to journal, haven't done so as much, but I do occasionally bring myself back there to reflect on where my head is at or not at all. I try to remember some of the techniques that the counsellors shared with me about managing worry and if I at any time am concerned that I am sliding some way, I'll try to do some things that will *help me, whether it's go buy myself a bunch of flowers or listen to some music or take a walk or do I'll do something or go to my favourite movies. I'll do something that will try to soothe a bit if I'm feeling a little bit down or something. Participant_023*

Participant describes using mindfulness and/or meditation

Yes, it has. I think it's quite changed. My personality. I used to be confident and I've become more introverted, more anxious, and I haven't gone back to work because I just get panicky at the thought. It it's like I can't deal with stress anymore. I took a long time to get past every morning waking up wondering what's going to happen today, what bad things is going to happen, just that panic and fear every time I'd wake up in the morning. So that's definitely been ongoing. And I think I'm a bit fatalistic as well as to just thinking now I'm probably going to die soon anyway. And just really not I don't I can't picture myself too far ahead in the future, but I do try and meditate and keep myself calm. I try, but I just think I just it's like I've changed my personality. Participant_001

I do personal development courses at different times and just general ones, not specifically related to cancer. I try to spend time doing meditation. I find that helps calm my mind. Participant_037

Absolutely. When I was first diagnosed, it was terrifying. I have a long health history of not being very well with some pretty serious illnesses. In between that period of time from diagnosis to initial diagnosis to having a PET scan, I was terrified about what was my prognosis. Getting your head around having cancer is just an extraordinary thing to try to do. I couldn't even say the word out loud for a couple of weeks. It was so overwhelming, and just that thing where you wake up in the morning for that brief second, you forget what's really going on, and then it just hits you like a ton of bricks. I just be going about my day and it'd be like getting this reality slap every once in a while where it's just I'd go and I would just remember what was going on. It was like my whole body would just flood with this fear. I go for walks every day on the beach, I do a lot of meditation, guided meditations. I've got my psychologist. I do go for walks with friends most days when we're allowed to. I do try to talk to my partner once, if not twice a day. I just make sure that I'm keeping up those human connections, trying to have some enjoyable time, but also practicing well-being techniques that really helped me, and massage really helps a lot, too. Participant_041

Table 8.6: Regular activities to maintain mental health

Regular activities to maintain mental health	**All participants**		**Early breast cancer**		**Advanced breast cancer**		**Poor physical function**		**Good physical function**		**Diagnosed before 2020**		**Diagnosed in 2020 or 2021**		**Trade or high school**		**University**	
	n=50	**%**	**n=23**	**%**	**n=27**	**%**	**n=19**	**%**	**n=25**	**%**	**n=26**	**%**	**n=24**	**%**	**n=24**	**%**	**n=26**	**%**
Participant describes using coping strategies such as remaining social, lifestyle changes and hobbies	18	36.00	10	43.48	8	29.63	**3**	**15.79**	11	44.00	10	38.46	8	33.33	**6**	**25.00**	**12**	**46.15**
Participant describes consulting a mental health professional	17	34.00	9	39.13	8	29.63	8	42.11	9	36.00	9	34.62	8	33.33	6	25.00	11	42.31
Participant describes the importance of physical exercise	15	30.00	**10**	**43.48**	**5**	**18.52**	5	26.32	6	24.00	10	38.46	5	20.83	5	20.83	10	38.46
Participant describes the importance of accepting condition/positive outlook	8	16.00	**6**	**26.09**	2	7.41	4	21.05	4	16.00	4	15.38	4	16.67	**1**	**4.17**	**7**	**26.92**
Participant describes the importance of family and friends in maintaining their mental health	8	16.00	2	8.70	6	22.22	2	10.53	6	24.00	5	19.23	3	12.50	5	20.83	3	11.54
Participant describes the importance of self care in maintaining their mental health	6	12.00	4	17.39	2	7.41	3	15.79	3	12.00	4	15.38	2	8.33	1	4.17	5	19.23
Participant describes using mindfulness and/or meditation	5	10.00	3	13.04	2	7.41	2	10.53	2	8.00	4	15.38	1	4.17	1	4.17	4	15.38

Regular activities to maintain mental health	**All participants**		**Regional or remote**		**Metropolitan**		**Mid to low status**		**Higher status**		**Aged 25 to 44**		**Aged 45 to 54**		**Aged 55 to 74**	
	n=50	**%**	**n=16**	**%**	**n=34**	**%**	**n=20**	**%**	**n=30**	**%**	**n=19**	**%**	**n=22**	**%**	**n=9**	**%**
Participant describes using coping strategies such as remaining social, lifestyle changes and hobbies	18	36.00	5	31.25	13	38.24	**10**	**50.00**	8	26.67	**4**	**21.05**	**12**	**54.55**	**2**	**22.22**
Participant describes consulting a mental health professional	17	34.00	4	25.00	13	38.24	**2**	**10.00**	**15**	**50.00**	**10**	**52.63**	**4**	**18.18**	3	33.33
Participant describes the importance of physical exercise	15	30.00	4	25.00	11	32.35	6	30.00	9	30.00	**8**	**42.11**	5	22.73	2	22.22
Participant describes the importance of accepting condition/positive outlook	8	16.00	4	25.00	4	11.76	3	15.00	5	16.67	**1**	**5.26**	**6**	**27.27**	1	11.11
Participant describes the importance of family and friends in maintaining their mental health	8	16.00	2	12.50	6	17.65	3	15.00	5	16.67	2	10.53	4	18.18	2	22.22
Participant describes the importance of self care in maintaining their mental health	6	12.00	1	6.25	5	14.71	2	10.00	4	13.33	3	15.79	3	13.64	**0**	**0.00**
Participant describes using mindfulness and/or meditation	5	10.00	0	0.00	5	14.71	0	0.00	5	16.67	2	10.53	3	13.64	0	0.00

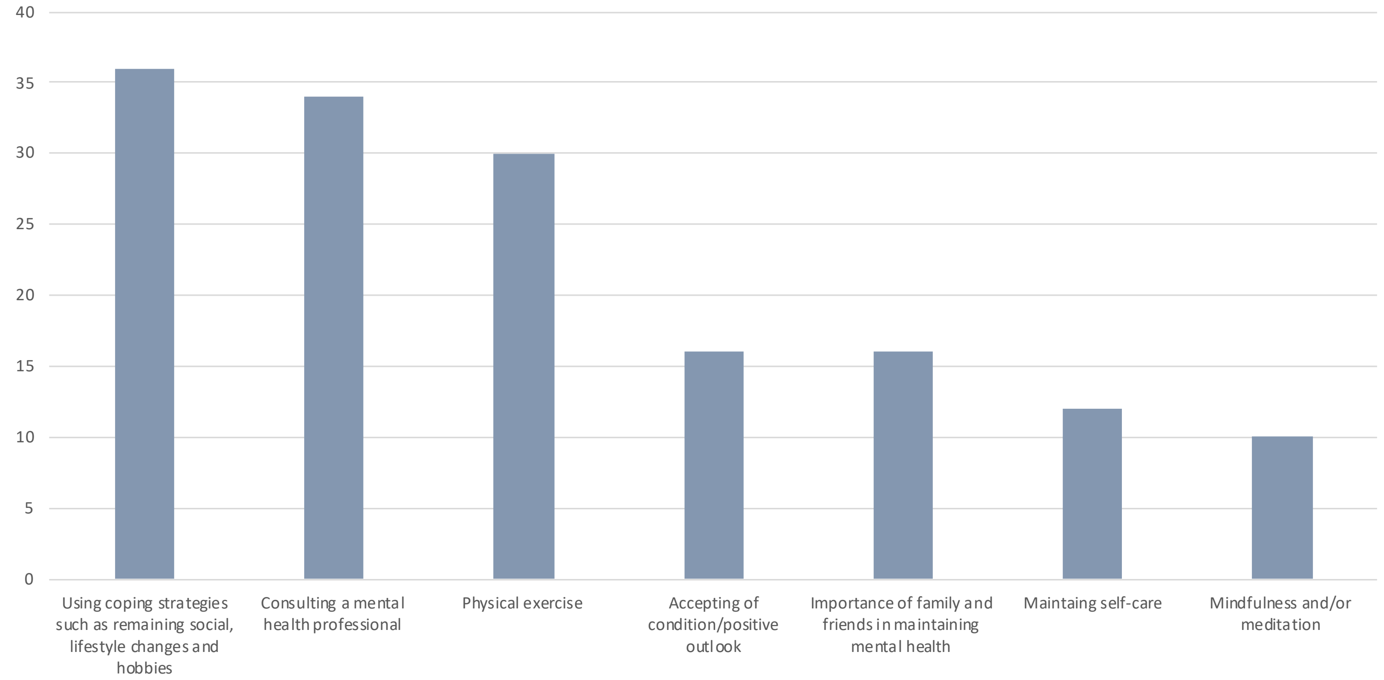

Figure 8.4: Regular activities to maintain mental health

Table 8.7: Regular activities to maintain mental health – subgroup variations

Theme	Reported less frequently	Reported more frequently
Participant describes using coping strategies such as remaining social, lifestyle changes and hobbies	Poor physical function Trade or high school Aged 25 to 44 Aged 55 to 74	University Mid to low status Aged 45 to 54
Participant describes consulting a mental health professional	Mid to low status Aged 45 to 54	Higher status Aged 25 to 44
Participant describes the importance of physical exercise	Advanced breast cancer	Early breast cancer Aged 25 to 44
Participant describes the importance of accepting condition/positive outlook	Trade or high school Aged 25 to 44	Early breast cancer University Aged 45 to 54
Participant describes the importance of self care in maintaining their mental health	Aged 55 to 74	-

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 way that participants reported managing their health was by being physically active (n=26, 52.00%), followed by the importance of self-care (n=19, 38.00%). There 13 participants (26.00%) who described the importance of understanding their limitations, 12 participants (24.00%) who described maintaining a healthy diet and 11 participants (22.00%) who described the importance of treatment compliance. Other ways of maintaining health included keeping up with daily activities (n=7, 14.00%), and socialising with family and friends (n=5, 10.00%). There were five participants (10.00%) who described no regular activities to maintain their health.

Participant describes being physically active

Well, I think you have now you have osteoporosis or osteopenia. So I have to do strength training in building. The menopause is expected to be the biggest ongoing thing of my life. And, you know, things like being hot flushes impact because those kind of things are ongoing, things that I manage. Participant_002

Once, again, the exercise that I do, like I say, I exercise daily, so that exercise class, I attend twice a week. In between times, I either walk or run daily. We have a dog, so I take the dog out most days. I either alternate with a walk or run, it just depends on what else I've done that day. As I said, at the moment, I am fairly focused on my diet, because as I said, the chemotherapy has had some residual side effects on my intestine. I'm currently having to monitor my diet. I've found that I have become intolerant to lactose gluten. I'm currently seeing and probably I forgot to

mention this, but I am currently seeing a nutritionist, a guy in LOCATION. I sought him out as a result of my gut issues, just to see whether that may help. I am seeing him and taking some medications, just to see whether that might help. I've had a couple of consults in the last couple of months with him. Participant_013

I just keep active. I need to keep my mind active. I need to keep my body active. I found throughout treatment if I kept my life as normal as possible and try to keep my routine, I got through things better. Even with my radiotherapy, I know people said they had terrible fatigue. I didn't notice that fatigue because I kept my day normal. I did my radiotherapy as the last thing I did during the day, got home, went from my daily walk, made dinner, had dinner, had my rest, and then go to sleep. I found that doing that all throughout treatment helped me because I wasn't being fatigued at the time of the day when I shouldn't be, sort of being fatigued when I should be. Participant_034

Participant describes the importance of self care e.g. more rest, support for housework etc.

Sleep is really important, rests, not overbooking myself, only doing things that I want to, not feeling pressured into, overcommit to things, to just being strategic in not doing too much every day, but making sure I do something nice every day yet and counselling if I need to. Participant_010

Yes. I know the last week I've been having a nap for two hours a day during the middle of the day. I'm looking at going back to work shortly. I used to work full time, but I'm going to go back 10 to 15 hours a week to start with, just to try and build up using my brain again and also going back into an office environment. The other thing I've been doing is going to group counseling with other women with breast cancer. That's helped as well, talking to other people. Participant_017

I find I still get fatigued. That has a bit of a bearing in that. I say I either have to exercise or clean on the weekend. I can't do both. I just have to listen to my body. I really pay attention that my feet can feel it coming in. It's not worth. I quit my old job because it was too stressful. I was like that's, I'm not healing me sick again. I'm not going to get sick, and I'm not working [unintelligible] going to be the cause of it. I sort of lucky to pick another job up in between and- well, afterwards. My employer was really, really good through treatments, as well. I can't fault that side of it. It was just my role as such, and it was just an eye-opener to go, "Well, hang on a minute." I don't need to be doing this and making myself do again. That's part of it. Yes, it's more fatigue these days. Everything else I'm pretty-- Oh, obviously, I've had surgery again, so no heavy lifting and running in that for a little bit longer again. Other than that, I'm pretty stoked in to begin. Participant_021

Participant describes the importance of understanding their limitations

Sleep is really important, rests, not overbooking myself, only doing things that I want to, not feeling pressured into, overcommit to things, to just being strategic in not doing too much every day, but making sure I do something nice every day yet and counselling if I need to. Participant_010

Yes. I know the last week I've been having a nap for two hours a day during the middle of the day. I'm looking at going back to work shortly. I used to work full time, but I'm going to go back 10 to 15 hours a week to start with, just to try and build up using my brain again and also going back into an office environment. The other thing I've been doing is going to group counseling with other women with breast cancer. That's helped as well, talking to other people. Participant_017

Lie down, set a bit more boundaries. Participant_019

I have to minimise my stress. I have to minimise outside stresses and demands on my time if I get overwhelmed. Yeah, it's the state of panic and also just even my energy levels, because they have not returned as much as I've tried, really upping my fitness and diet and everything. I just haven't got the energy. And I felt like I think, you know, all the chemo and all the menopause and everything, everything is just harder. And I just can't do as much as I'd like. I get tired too easily. And my brain, I'm still not as switched on as I was. I forget stuff. Participant_001

Participant describes maintaining a healthy diet

Well, there's nothing that I have to do medical-wise, but I eat a healthy diet, I exercise every day. I walk every day. I do yoga every day. I contact friends regularly. I don't know. That's basically what I do, but no one's ever said, do these things. They just come together. Participant_004

Once a month, I have to do a self-examination to just tick that box and to make sure that I'm not getting a recurrence. I do that. I try to walk maybe four times a week, just to, I guess, keep the lymphatics working. I eat in a certain way so I keep my weight down, but again, just with general health, and not letting weight be a factor for cancer coming back and things like that. How does it not affect me? That's basically it. I take fish oil and-- Yes, pretty much fish oil for inflammation and things like that. Again, I think that inflammation is a factor for stagnation and cancers returning, so those are the things just to keep-- My body has been as best as I can in lieu of doing proper exercise. Participant_005

The most regular thing is healthy eating. That's one thing. I do have to eat, and staying hydrated because I do get headaches more frequently since radiation and things. Staying hydrated, exercising regularly. Those two and healthy eating, exercise, and healthy lifestyle. I think that's the main thing. Participant_016

Participant describes the importance of complying with treatment

Exercise, I have to exercise every day. I have to move. I have to take my medication. Participant_020

Well, I need to I need to wear a lymphedema compression gloves every day. Well, most days to manage some mild lymphedema exercises, to manage the stiffness in my shoulders, which is being chronic now, and try to get strength and mobility back to me. Think again. I just try to building some exercise at least half an hour's some exercise every day. If I can almost stay still working on the sleep. I'm terribly light sleeper. So but I'm trying to keep working on that because I finally learnt how important that is supposed to be. Yeah, I think I think that that's OK. Participant_023

I need to take multiple tablets [chuckles] for dealing with the pain and things like that and other associated issues. I go to a physio and hydrotherapy to try and just get some movement back and things like that, exercises. I see a support group of ladies which just gives me the reassurance of having someone else there to talk to and feed off if you need help or anything like that. Participant_036

Participant describes the importance of keeping up with daily activities

For me to function and to do most of the things I need to do, I need my life to be as close to what it was as possible. That's really important to me. I want to be able to go out and do things, and that's really important. I don't want to cancel things or not be able to do stuff because that affects my ability. I don't want to fall in that pattern of I've got cancer, I'm having chemo, I can't do this, this and this. For me, it's a mental battle, I think, to make sure that I don't allow myself to fall into that pattern of getting out of things or using it to not do things. I find that helpful for me. Obviously, I probably rest more than I did. I didn't use to stop very much. Now I probably do rest more and I allow myself to do that. That's a change, I guess, just going, "Actually, I need a break. I need to just put my feet up for an hour or do something, have a rest." That's different from how I used to be. Where you just power through all day long because that's what the days are for. Really, I don't think there's-- I think I answered your question. Participant_033

I just keep active. I need to keep my mind active. I need to keep my body active. I found throughout treatment if I kept my life as normal as possible and try to keep my routine, I got through things better. Even with my radiotherapy, I know people said they had terrible fatigue. I didn't notice that fatigue because I kept my day normal. I did my radiotherapy as the last thing I did during the day, got home, went from my daily walk, made dinner, had dinner, had my rest, and then go to sleep. I found that doing that all throughout treatment helped me because I wasn't being fatigued at the time of the day when I shouldn't be, sort of being fatigued when I should be. Participant_034

I walk every day. Even during the peak of chemo where I was like out of breath, I still made myself walk. I've got this thing about getting fresh air every single day, but my thing was, is just getting up and getting dressed and having a routine that I have to do it every day. I can't go, "I'm feeling crappy and I'm just going to stay in bed." I pushed myself to not do that because you're not going to achieve anything. I just kept pushing myself every day to get out of bed and get up, get a routine. Dropping my son off was really important to me, at school. Participant_045

Participant describes socialising with friends and/or family

Well, there's nothing that I have to do medical-wise, but I eat a healthy diet, I exercise every day. I walk every day. I do yoga every day. I contact friends regularly. I don't know. That's basically what I do, but no one's ever said, do these things. They just come together. Participant_004

I guess for me right now, what I need to do is just-- Then this is the process I'm trying to get happening at the moment, trying to get back into doing some regular exercise, changing how I eat, getting back into healthier habits. Part of it is also just keeping connections with friends. A lot of it for me at the moment is just getting my body healthy again, just rebuilding my immunity and things like that. Participant_011

I need to take multiple tablets [chuckles] for dealing with the pain and things like that and other associated issues. I go to a physio and hydrotherapy to try and just get some movement back and things like that, exercises. I see a support group of ladies which just gives me the reassurance of having someone else there to talk to and feed off if you need help or anything like that. Participant_036

Participant describes no activities to maintain health

There's nothing that I need to do on a regular basis to control the side effects of my condition. I was fortunate that I didn't have any-- I haven't had any neuropathy for many of the chemos because I did-- I have pus and on my hands and fingers. I have a little bit on two of my toes, but you don't even notice it. I don't think there's anything that I do differently to manage. There's no real side effects that I have. Participant_025

Just not overthink it. Participant_009

Table 8.8: Regular activities to maintain health

Regular activities to maintain health	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=23	%	n=27	%	n=19	%	n=25	%	n=26	%	n=24	%	n=24	%	n=26	%
Participant describes being physically active	26	52.00	12	52.17	14	51.85	9	47.37	13	52.00	12	46.15	14	58.33	12	50.00	14	53.85
Participant describes the importance of self care e.g. more rest, support for housework etc.	19	38.00	11	47.83	8	29.63	9	47.37	9	36.00	11	42.31	8	33.33	**5**	**20.83**	**14**	**53.85**
Participant describes the importance of understanding their limitations	13	26.00	8	34.78	5	18.52	5	26.32	6	24.00	8	30.77	5	20.83	5	20.83	8	30.77
Participant describes maintaining a healthy diet	12	24.00	6	26.09	6	22.22	**2**	**10.53**	**9**	**36.00**	6	23.08	6	25.00	5	20.83	7	26.92
Participant describes the importance of complying with treatment	11	22.00	5	21.74	6	22.22	5	26.32	5	20.00	4	15.38	7	29.17	6	25.00	5	19.23
Participant describes the importance of keeping up with daily activities	7	14.00	3	13.04	4	14.81	**5**	**26.32**	1	4.00	2	7.69	5	20.83	3	12.50	4	15.38
Participant describes socialising with friends and/or family	5	10.00	2	8.70	3	11.11	2	10.53	3	12.00	1	3.85	4	16.67	3	12.50	2	7.69
Participant describes no activities to maintain health	5	10.00	2	8.70	3	11.11	2	10.53	2	8.00	3	11.54	2	8.33	3	12.50	2	7.69

Regular activities to maintain health	All participants		Regional or remote		Metropolitan		Mid to low status		Higher status		Aged 25 to 44		Aged 45 to 54		Aged 55 to 74	
	n=50	%	n=16	%	n=34	%	n=20	%	n=30	%	n=19	%	n=22	%	n=9	%
Participant describes being physically active	26	52.00	8	50.00	18	52.94	9	45.00	17	56.67	**7**	**36.84**	13	59.09	**6**	**66.67**
Participant describes the importance of self care e.g. more rest, support for housework etc.	19	38.00	7	43.75	12	35.29	8	40.00	11	36.67	9	47.37	7	31.82	3	33.33
Participant describes the importance of understanding their limitations	13	26.00	4	25.00	9	26.47	4	20.00	9	30.00	**8**	**42.11**	**1**	**4.55**	**4**	**44.44**
Participant describes maintaining a healthy diet	12	24.00	3	18.75	9	26.47	**2**	**10.00**	10	33.33	**2**	**10.53**	4	18.18	**6**	**66.67**
Participant describes the importance of complying with treatment	11	22.00	2	12.50	9	26.47	3	15.00	8	26.67	**2**	**10.53**	6	27.27	**3**	**33.33**
Participant describes the importance of keeping up with daily activities	7	14.00	3	18.75	4	11.76	**5**	**25.00**	2	6.67	1	5.26	5	22.73	1	11.11
Participant describes socialising with friends and/or family	5	10.00	1	6.25	4	11.76	1	5.00	4	13.33	1	5.26	3	13.64	1	11.11
Participant describes no activities to maintain health	5	10.00	1	6.25	4	11.76	2	10.00	3	10.00	2	10.53	3	13.64	0	0.00

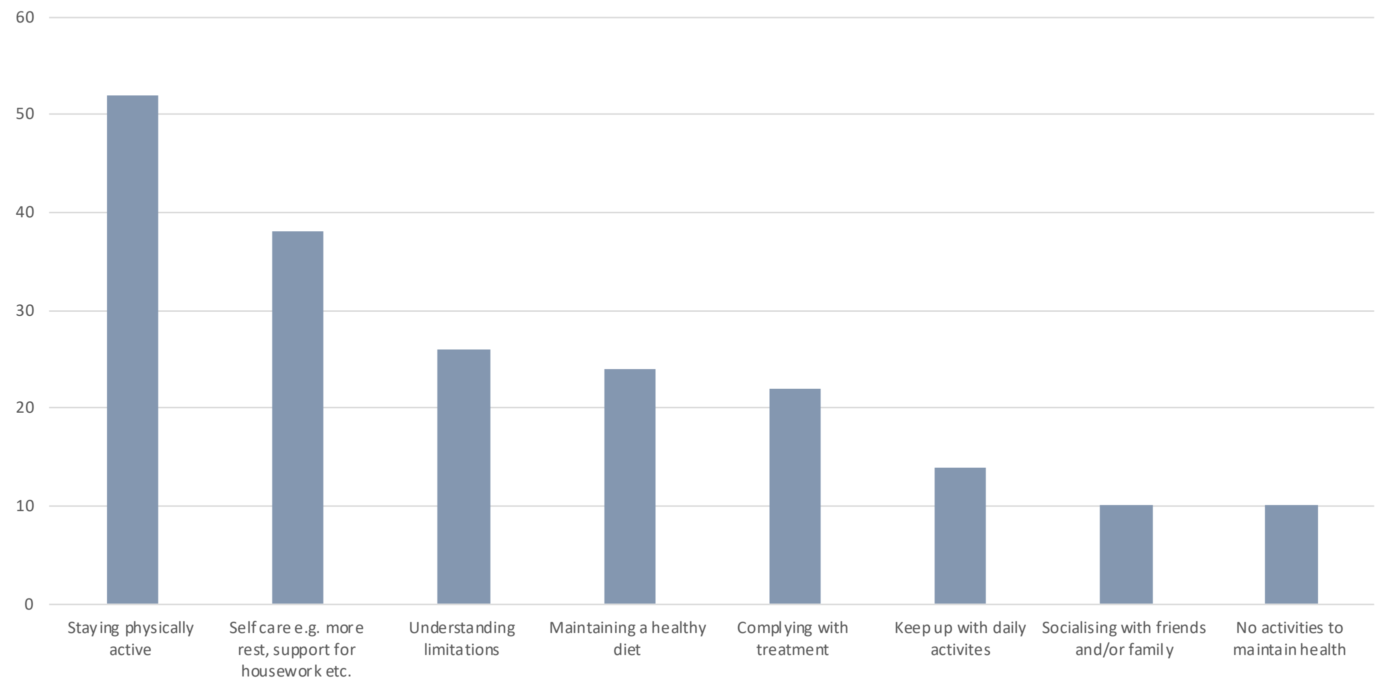

Figure 8.5: Regular activities to maintain health

Table 8.9: Regular activities to maintain health – subgroup variations

Theme	Reported less frequently	Reported more frequently
Participant describes being physically active	Aged 25 to 44	Aged 55 to 74
Participant describes the importance of self care e.g. more rest, support for housework etc.	Trade or high school	University
Participant describes the importance of understanding their limitations	Aged 45 to 54	Aged 25 to 44 Aged 55 to 74
Participant describes maintaining a healthy diet	Poor physical function Mid to low status Aged 25 to 44	Good physical function Aged 55 to 74
Participant describes the importance of complying with treatment	Aged 25 to 44	Aged 55 to 74
Participant describes the importance of keeping up with daily activities	-	Poor physical function Mid to low status

Experience of vulnerability

In the structured interview, participants were asked if there had been times that they felt vulnerable. There were 43 participants (86.00%) who gave a description suggesting that overall they had experiences of feeling vulnerable, and four participants (8.00%) who gave a description suggesting that overall they did not have feelings of being vulnerable.

In relation to when participants felt most vulnerable, the most common theme was feeling vulnerable during or after treatments (n=20, 40.00%), followed by feeling vulnerable when having negative thoughts (n=15, 30.00%). There were 14 participants (28.00%) who described feeling vulnerable when having sensitive discussions for example at diagnosis and treatment decisions, and nine participants (18.00%) described feeling vulnerable when feeling sick.

Participant gives a description suggesting that overall, they had experiences of feeling vulnerable

The whole way through. Participant_009

In some ways, having chemo or having cancer during COVID made me feel very vulnerable because obviously, I had no immune system. At the same time, the whole world, everybody around me was more hygiene conscious. Most people were in some kind of working from home. I didn't feel like I was missing out on quite so much because everybody else was also either in lockdown or events were canceled, things weren't happening that would have been. I felt vulnerable in the sense that I live with my son and he was still out in the world working. When there was risks around close to our area, I would get a bit nervous of him coming in bringing anything in. I guess

in some ways, everybody around was more conscious of it and being more careful of it so that helped as well. That's probably the most vulnerable was just not having an immune system and having a pandemic around me. Participant_011

Yes, yes. The main the main times have been when I've been in hospital and I've been on my own after surgery in pain. And some of the some of the things that have happened in hospital have been great. But being put into a shared ward with people having sort of minor operations and then having grandchildren coming to visit. And I'm completely wrecked after having my reconstruction, my hysterectomy and everything and being really unwell and yeah. Trying to say these people are really noisy. Can I have a different room and not having anyone to advocate for me that that was tough and have the attitude to stop sort of joking when they're doing my carpetbag back thing making. So those embarrassing comments made me feel bad. Yeah. Just being just feeling really, really vulnerable in hospital. Participant_001

Participant describes feeling vulnerable during/after treatment

Yeah, I guess really the point of diagnosis, I'm going to say right through treatment, but then again, probably maybe the two in points where around diagnosis and treatment and then into treatment because the triple negative they did or anything to go on it. So it's like, well, the parachute, we don't home, but it's time for you to jump off the cliff. So it's a diagnosis made of training. And in that situation that you've mentioned, where you felt vulnerable. Participant_002

I guess during the AC because I felt so weak and frail. Participant_007

There were a couple of times during of the chemotherapy that I guess I wondered how it was all about you just going to take this one day at a time. But that concept of one day at a time for a really long time on those really bad days, especially when I was coming down off the IV steroids, you just start to wonder if you are able to cope or handle all that there is during after surgery. Some of those those times when you look in the mirror and you've had both your breasts removed and you've got no hair, they were emotionally tough times that were hard to process. Those thoughts of anyone ever want to see me naked again or will find me sexy or love me or those kinds of things, the emotional moments rather than the physical ones with sometimes really hard the days where I was when I'd finished oral chemo. But still that first month there was a lot of just sleeping in bed. And I just was watching everyone in my life get on with their life and getting married and having kids. And there I was thirty and I'm too tired to get out of bed. So I think they were certainly tough times. Participant_010

Um. I'm just trying to think I mean, obviously, I was scared and nervous at different times going into the big surgery for the first time and never having had surgery like that ever before going under and all of that, probably, probably the most vulnerable I felt so far would have actually been at the beginning of last year, to be honest, when I had to go and get my two year check-up. I actually could very well with the waiting and the uncertainty. And I was seeing a counsellor again at the time try and get through that. I was very anxious and worried. So to be to be honest, to feeling that vulnerable, like feeling like a baby falling apart, that would have been, in my mind, the most out of control. I sort of felt, I think being introspective treatment, it's sort of for me a couple of people who said they feel similarly for me. And I was like, I'm missing, you know, I mean, checking in and then throwing everything at it. We've got a plan. And because my condition. So there's no medication I can take afterwards. And so some people might feel a little bit of the peace of mind that popping a delivery, however often you do that might be the ongoing treatment for me. There's nothing other than my own attempt to try to live a good life and as well a life as I can help in that exercise and whatnot. So I think that's why I really struggled this year, wasn't as bad, had some good techniques. I was taught to manage it. Yes, that probably would have been my most vulnerable I saw. Participant_023

Participant describes feeling vulnerable when having negative thoughts (uncertainty, loneliness, worries)

Yes. Pretty much from the start at times. Probably right at the start when I didn't know what the hell was going on and I was trying to get my head around everything. Probably in the day to stock is middle of the chemo when I was trying everything in one Participant_012

Yes, it would be right at the start, right at the first diagnosis. I was very overwhelmed by everything. Obviously, all the COVID rules and everything in the hospital when I was getting on my test done, just for *an example, I was walking into the hospital and they wouldn't let my husband in with me. I was getting the test done to see if it has advanced anywhere in my body, and I had a bit of a breakdown in the hospital because they are stopping people coming to support people, which is not great. The early diagnosis, you have no idea what's going on, everything is happening. You've got all these appointments. It was a very, very much a crazy time in my life. Participant_018*

I suppose a little bit, because you feels like it's all happening to you and you don't really have any control. I suppose there's a bit of vulnerability there and that you'll just need to put your life in the hands of these people who are telling you what to do, but you've only just met them, or guiding you as what to do. There is some vulnerability there. Also with the lack of knowledge and lack of understanding, that makes you quite vulnerable because I didn't have enough information to make decisions. I was floundering about, I guess, just trying to guess at what I should do next. That vulnerability, but I think as soon as I have knowledge and you can make some informed choices and informed decisions, that goes away. I feel in a much better place now to not challenge particularly, but at least to ask questions and to ask questions of my oncologist and the surgeon and say, "Is this the right thing? Do I need to do this? How about that?" and happy to have those conversations. Whereas to start with it felt very much, you just sit there and they tell you what it is that you need to do, and that does make me feel quite vulnerable. Participant_033

Participant describes feeling vulnerable when having sensitive discussion (treatment, diagnosis)

Yeah, I think after I had the biopsy and I didn't know what it was, I found those days between the Friday and that Tuesday when I got my diagnosis. That was pretty scary. And even after the diagnosis, I think all of that time up until I had the surgery and they removed the tissue and told me that there was no cancer cells. And, you know, I think that you're vulnerable right up until then. It's a very scary time. Yes. Yes. Participant_038

Vulnerable? Yes. It was the same breast surgeon that was telling me that I needed to go off to do it all privately. When I went to get my results from her after the surgery, we went into the room and she looked at my wound, checked it, and-- The tape had come off too early and she was saying, "Oh, they shouldn't have done that, you shouldn't have--" "That tape needed to stay on there, it needs to be healing, it needed to be safe" The last time she was-- there was no sort of bedside manner happening. She was giving my results, telling me that I'm triple negative, telling me all this sort of stuff, telling me that I'll be having chemo, but barely even sat down behind her desk to be informing me of all this. It was all just rush, rush, rush, rush rush, "This is what you're doing, this is where you need to go, this is who you need to see." My mum was with me and we both just came away from it going, "Wow, that was really yuk," and didn't really even know what was going on afterward. That was in that same conversation that she was saying, "You can go to the hospital, but you'll be waiting for weeks so you should go and see him privately, blah, blah, blah." I felt very unsettled from that. Participant_005

Yes, it would be right at the start, right at the first diagnosis. I was very overwhelmed by everything. Obviously, all the COVID rules and everything in the hospital when I was getting on my test done, just for an example, I was walking into the hospital and they wouldn't let my husband in with me. I was getting the test done to see if it has advanced anywhere in my body, and I had a bit of a breakdown in the hospital because they are stopping people coming to support people, which is not great. The early diagnosis, you have no idea what's going on, everything is happening. You've got all these appointments. It was a very, very much a crazy time in my life. Participant_018

Constantly. Definitely sitting there, and making decisions, and then being in a hospital room by yourself every week knowing that you've got to go back for more treatment. That whole time-- I men I never was a, "Why me?" Like you really do have to just get on with it, but there are definitely times when you're like, "Oh, I've still got this long to go," or, "What does this week hold," sort of thing. Actually, the worst was probably- obviously, I'm being diagnosed. I actually I was about to come home from hospital after my mastectomy and the geneticists had rung me to say he hadn't had my results yet. I said, "Okay, it was a Friday." I've had a really good day, I'd actually had a hospital pass and went out for lunch and came back in. At literally at five o'clock on the dot, he actually rang again to say, "No, I don't usually do this over the phone, but I thought you'd like to know." I went from these massive high and got told that I was BRCA positive. I look at it now and it means nothing because I've already been diagnosed, but it was such *a good day where I felt good and then it was another result, sort of thing. Participant_021*

Participant describes feeling vulnerable when feeling sick/unwell

Yes. When I had the really high fevers and nobody understood what it was, because it's frustrating, even for the doctors. My oncology nurse implied it could be psychological. That was a really frustrating time for me because I was physically unwell. I was having shivers and uncontrolled fevers and I was being told it's all in my head. That time I felt really disappointed and depressed which didn't help me at all. Participant_016

Yes, when I was going through chemo. I was not in a good space because I was so sick. As I said, I had to go and see the psychologist. Yes, I was in a particularly vulnerable space going through chemo. Participant_029

Yes, I must admit there was one time. It was the last week of radiation or the second last-- I was in the second last week of radiation treatment, and the nurse was really rude to me. It was the first time in the whole process, someone had ever just not been sensitive. She started to tell me off about taking Panadol and not managing my pain appropriately and I don't know this. It was the only time, and I had 10 months of going in and out of hospitals and that sort of stuff, it was this one single time I can say I didn't like it. Yes, this was the only time I can think of. Participant_047

Table 8.10: Experience of vulnerability

Experience of vulnerability	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=23	%	n=27	%	n=19	%	n=25	%	n=26	%	n=24	%	n=24	%	n=26	%
Participant gives a description suggesting that overall, they had experiences of feeling vulnerable	43	86.00	20	86.96	23	85.19	15	78.95	23	92.00	21	80.77	22	91.67	19	79.17	24	92.31
Participant gives a description suggesting that overall, they did not have feelings of being vulnerable	4	8.00	2	8.70	2	7.41	3	15.79	1	4.00	2	7.69	2	8.33	2	8.33	2	7.69
Other	2	4.00	0	0.00	2	7.41	1	5.26	1	4.00	0	0.00	2	8.33	2	8.33	0	0.00

Experience of vulnerability	All participants		Regional or remote		Metropolitan		Mid to low status		Higher status		Aged 25 to 44		Aged 45 to 54		Aged 55 to 74	
	n=50	%	n=16	%	n=34	%	n=20	%	n=30	%	n=19	%	n=22	%	n=9	%
Participant gives a description suggesting that overall, they had experiences of feeling vulnerable	43	86.00	**12**	**75.00**	31	91.18	**14**	**70.00**	**29**	**96.67**	15	78.95	19	86.36	**9**	**100.00**
Participant gives a description suggesting that overall, they did not have feelings of being vulnerable	4	8.00	**3**	**18.75**	1	2.94	3	15.00	1	3.33	2	10.53	2	9.09	0	0.00
Other	2	4.00	0	0.00	2	5.88	2	10.00	0	0.00	2	10.53	0	0.00	0	0.00

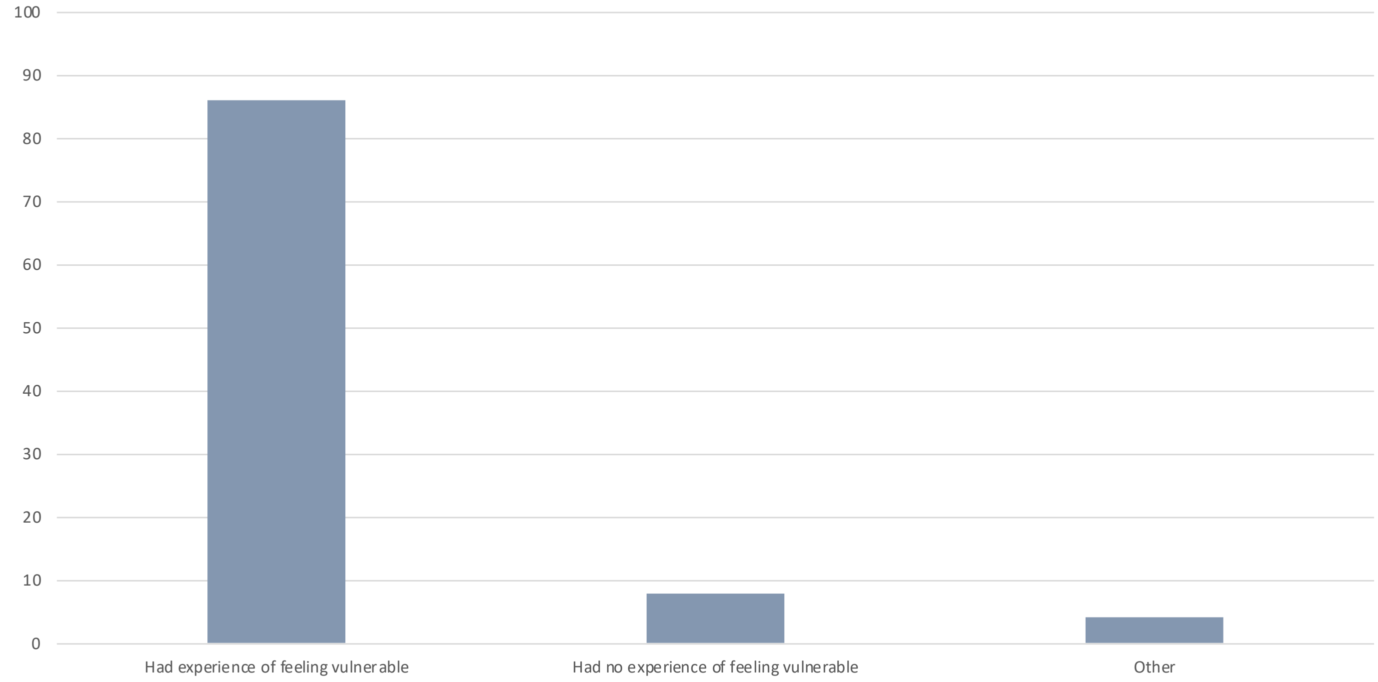

Figure 8.6: Experience of vulnerability

Table 8.11: Experience of vulnerability – subgroup variations

Theme	Reported less frequently	Reported more frequently
Participant gives a description suggesting that overall, they had experiences of feeling vulnerable	Regional or remote Mid to low status	Higher status Aged 55 to 74
Participant gives a description suggesting that overall, they did not have feelings of being vulnerable	-	Regional or remote

Table 8.12: Experience of vulnerability (details)

Methods to manage vulnerability	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=23	%	n=27	%	n=19	%	n=25	%	n=26	%	n=24	%	n=24	%	n=26	%
Participant describes feeling vulnerable during/after treatment	20	40.00	7	30.43	13	48.15	3	15.79	14	56.00	11	42.31	9	37.50	8	33.33	12	46.15
Participant describes feeling vulnerable when having negative thoughts (uncertainty, loneliness, worries	15	30.00	9	39.13	6	22.22	3	15.79	11	44.00	10	38.46	5	20.83	8	33.33	7	26.92
Participant describes feeling vulnerable when having sensitive discussion (treatment, diagnosis)	14	28.00	10	43.48	4	14.81	7	36.84	5	20.00	6	23.08	8	33.33	5	20.83	9	34.62
Participant describes feeling vulnerable when feeling sick/unwell	9	18.00	3	13.04	6	22.22	2	10.53	5	20.00	4	15.38	5	20.83	4	16.67	5	19.23

Methods to manage vulnerability	All participants		Regional or remote		Metropolitan		Mid to low status		Higher status		Aged 25 to 44		Aged 45 to 54		Aged 55 to 74	
	n=50	%	n=16	%	n=34	%	n=20	%	n=30	%	n=19	%	n=22	%	n=9	%
Participant describes feeling vulnerable during/after treatment	20	40.00	5	31.25	15	44.12	5	25.00	15	50.00	8	42.11	8	36.36	4	44.44
Participant describes feeling vulnerable when having negative thoughts (uncertainty, loneliness, worries	15	30.00	3	18.75	12	35.29	5	25.00	10	33.33	4	21.05	7	31.82	4	44.44
Participant describes feeling vulnerable when having sensitive discussion (treatment, diagnosis)	14	28.00	5	31.25	9	26.47	6	30.00	8	26.67	6	31.58	6	27.27	2	22.22
Participant describes feeling vulnerable when feeling sick/unwell	9	18.00	1	6.25	8	23.53	1	5.00	8	26.67	2	10.53	5	22.73	2	22.22

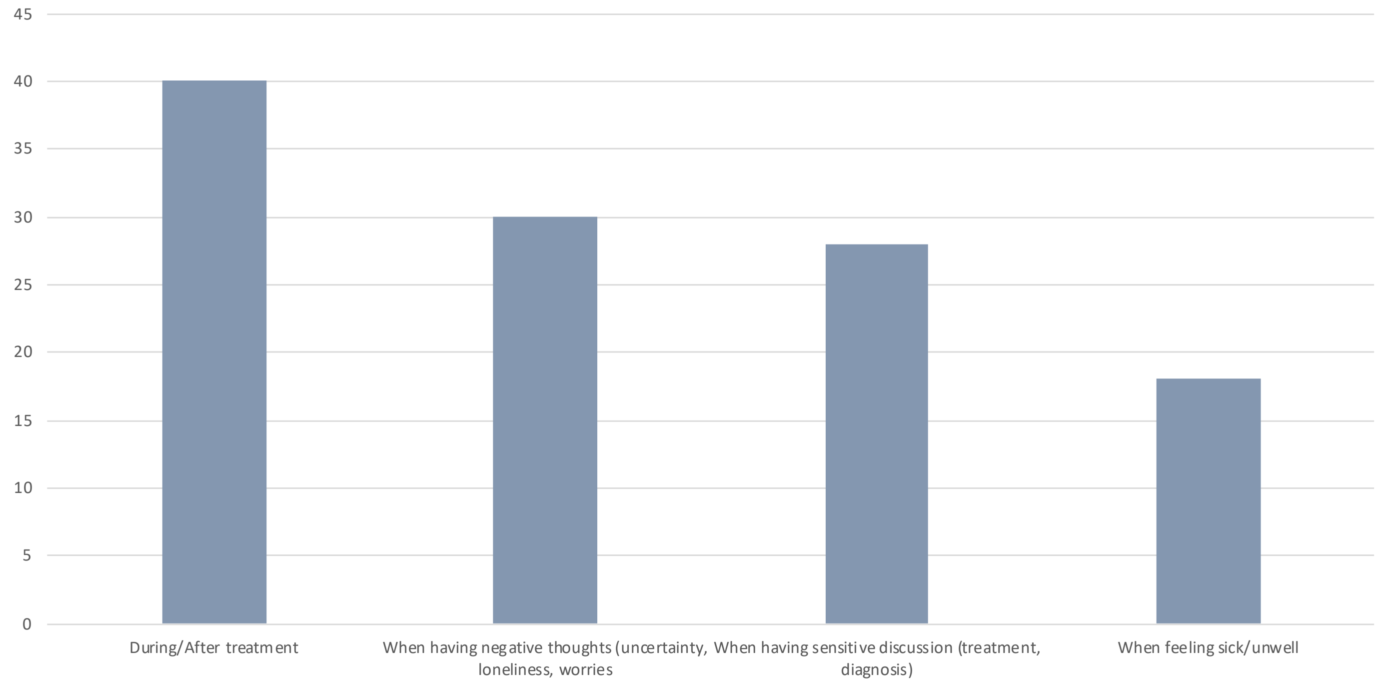

Figure 8.7: Experience of vulnerability (details)

Table 8.13: Experience of vulnerability (details) – subgroup variations

Theme	Reported less frequently	Reported more frequently
Participant describes feeling vulnerable during/after treatments	Stage IV	Stage I
Participant describes feeling vulnerable when having sensitive discussion (diagnosis, treatment decision)	Aged 55 to 74	Aged 25 to 44
Participant describes feeling vulnerable when feeling sick/unwell	Good emotional function Aged 25 to 44	Aged 45 to 54

Methods to manage vulnerability

In the structured interview, participants described ways that they managed feelings of vulnerability. Participants described support from their medical team to manage the feeling of vulnerability (n=9, 18.00%), and using self-help methods such as resilience, acceptance, and staying positive to manage the feeling of vulnerability (n=7, 14.00%). Other methods included adapting, for example being proactive. Assertive and understanding boundaries (n=6, 12.00%), and getting support from family and friends (n=5, 10.00%).

Participant describes support from medical team to manage the feeling of vulnerability

Oh, yes. A bit of both, really. It did feel totally out of my control. I did seek help via the oncology unit and that's when I got access to all the other information. I got access to information. I got support via the physio. I could understand what was happening a little bit more through the breast care nurse and the oncologist explained to me what was going on. Participant_012

Actually, the health care professionals, I think fix that because they were really amazing, and they also always brought me a warm blanket, which helps. Participant_019

I was because the nurses could see how nervous I was and they did take the time to explain the whole process to me, and then to explain how I might feel the next day and what I could do to alleviate that. The nurses in the day Ward area we're fabulous. Participant_027

Participant describes self help (resilience, acceptance, staying positive) to manage the feeling of vulnerability.

… looking at that diagnosis information, more information was it makes you feel like you had some control and probably at the end of treatment it was and, you know, logical techniques, I guess, cognitive behavioural sort of strategies to keep things in perspective and face the facts. Participant_002

I think I got maybe more used to them. And when I was in those situations, I just allowed myself the space to feel those feelings because they were valid to try and not get overwhelmed by them, but to acknowledge them and to give my body what they needed. So those days when I was tired, rather than getting upset about just allowing myself to sleep or ordering takeaway if I couldn't be bothered to cook some days was certainly a lot easier than others. But I think I learnt self care strategies to just give my body what it needed in those moments and also being able to be real with my support network or to people that to my other cancer friends and to be able to talk to them about it and how they would understand, you know, just being able to talk about it helped a lot. Participant_010

I think everything was out of my hands, but I just had to do what I had to do, and keeping a positive attitude as much as I could helped me through it. It was like, okay, this has happened. We're going to deal with it and get on with life. You just had to push it away and do that. Participant_046

Participant describes adapting (e.g, more proactive, assertive, put boundaries) to manage the feeling of vulnerability)

No, I stood there and said, "Well, I'm not going on." I said, "I'm not going in without my husband." What happened was I went got a manager and the manager let him in. They were fine. They were like, "Yes, of course, you can come in," so it was just the person at the door. Now looking back and I think I stand my ground a lot more than what I would have beforehand because I know what they're doing it for but I don't always think it's right. Participant_018

Oh, no, I stood up. I said something. The surgeon who was coming in to put it in, walked in with gloves on, rubber gloves, and I said to him, "Oh, can you change your gloves?" because what have you been doing? It was full COVID situation at that stage as well. Everyone that came into the room came in with no gloves and then put gloves on, but he walked in, opened the door with his hand, and then he was supposed to be cutting open my breasts and putting something in. He's like, "Well, I haven't touched anything." and I said, "I don't know that." I made him change his gloves. That's why I reckon I got such a badly bruised breast because he was very aggressive when he put it in. I did put in a report about him because I wasn't happy. That was the only time. I've had the best, best experiences. I can't fault any practitioner or staff member or receptionist, everyone has been amazing. Participant_045

Aside from trying to schedule the appointments as close as I to each other? There's always a couple of days in between and just, I guess making sure that I tell my family that I'm anxious and I'm stressed and basically leave me alone until I get the results. I don't know. I haven't mentioned, I should have mentioned earlier when you were talking about complimentary things. I've been doing a lot of yoga, and I find that incredibly helpful. At those times when I'm feeling really anxious, the yoga is particularly good. It helps settle, helps me settle, and refocus. Participant_050

Participant describes support from family and friends to manage the feeling of vulnerability

I think I got maybe more used to them. And when I was in those situations, I just allowed myself the space to feel those feelings because they were valid to try and not get overwhelmed by them, but to acknowledge them and to give my body what they needed. So those days when I was tired, rather than getting upset about just allowing myself to sleep or ordering takeaway if I couldn't be bothered to cook some days was certainly a lot easier than others. But I think I learnt self care strategies to just give my body what it needed in those moments and also being able to be real with my support network or to people that to my other cancer friends and to be able to talk to them about it and how they would understand, you know, just being able to talk about it helped a lot. Participant_010

I don't know if there is specifically anything that could be done, because I think it's all just a fear of the unknown. I guess the only thing you can do is have a good support system around you. Not just the medical support system, but like family, friends, work colleagues. Having people who can go to appointments with you, or who can make your meal when you don't feel like cooking. I don't think there's anything you can do that really prepares you for it. Participant_020

I did try to address certain things. Basically, with those finances because I didn't work for 18 months, so I was lucky that I could work from home with my job. Obviously, it wasn't every day so you only get paid for the hours that you do. I did have friends and neighbors at the time, not so much family. I really only had my resources that were in my current area, I guess. Participant_024

Table 8.14: Methods to manage vulnerability

Experience of vulnerability (details)	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=23	%	n=27	%	n=19	%	n=25	%	n=26	%	n=24	%	n=24	%	n=26	%
Participant describes support from medical team to manage the feeling of vulnerability	9	18.00	4	17.39	5	18.52	3	15.79	3	12.00	4	15.38	5	20.83	5	20.83	4	15.38
Participant describes self help (resilience, acceptance, staying positive) to manage the feeling of vulnerability)	7	14.00	3	13.04	4	14.81	2	10.53	5	20.00	4	15.38	3	12.50	1	4.17	6	23.08
Participant describes adapting (e.g, more proactive, assertive, put boundaries) to manage the feeling of vulnerability)	6	12.00	3	13.04	3	11.11	2	10.53	4	16.00	3	11.54	3	12.50	3	12.50	3	11.54
Participant describes support from family and friends to manage the feeling of vulnerability	5	10.00	3	13.04	2	7.41	2	10.53	3	12.00	4	15.38	1	4.17	2	8.33	3	11.54

Experience of vulnerability (details)	All participants		Regional or remote		Metropolitan		Mid to low status		Higher status		Aged 25 to 44		Aged 45 to 54		Aged 55 to 74	
	n=50	%	n=16	%	n=34	%	n=20	%	n=30	%	n=19	%	n=22	%	n=9	%
Participant describes support from medical team to manage the feeling of vulnerability	9	18.00	**1**	**6.25**	8	23.53	2	10.00	7	23.33	4	21.05	4	18.18	1	11.11
Participant describes self help (resilience, acceptance, staying positive) to manage the feeling of vulnerability)	7	14.00	3	18.75	4	11.76	2	10.00	5	16.67	4	21.05	2	9.09	1	11.11
Participant describes adapting (e.g, more proactive, assertive, put boundaries) to manage the feeling of vulnerability)	6	12.00	3	18.75	3	8.82	2	10.00	4	13.33	2	10.53	3	13.64	1	11.11
Participant describes support from family and friends to manage the feeling of vulnerability	5	10.00	3	18.75	2	5.88	3	15.00	2	6.67	2	10.53	2	9.09	1	11.11

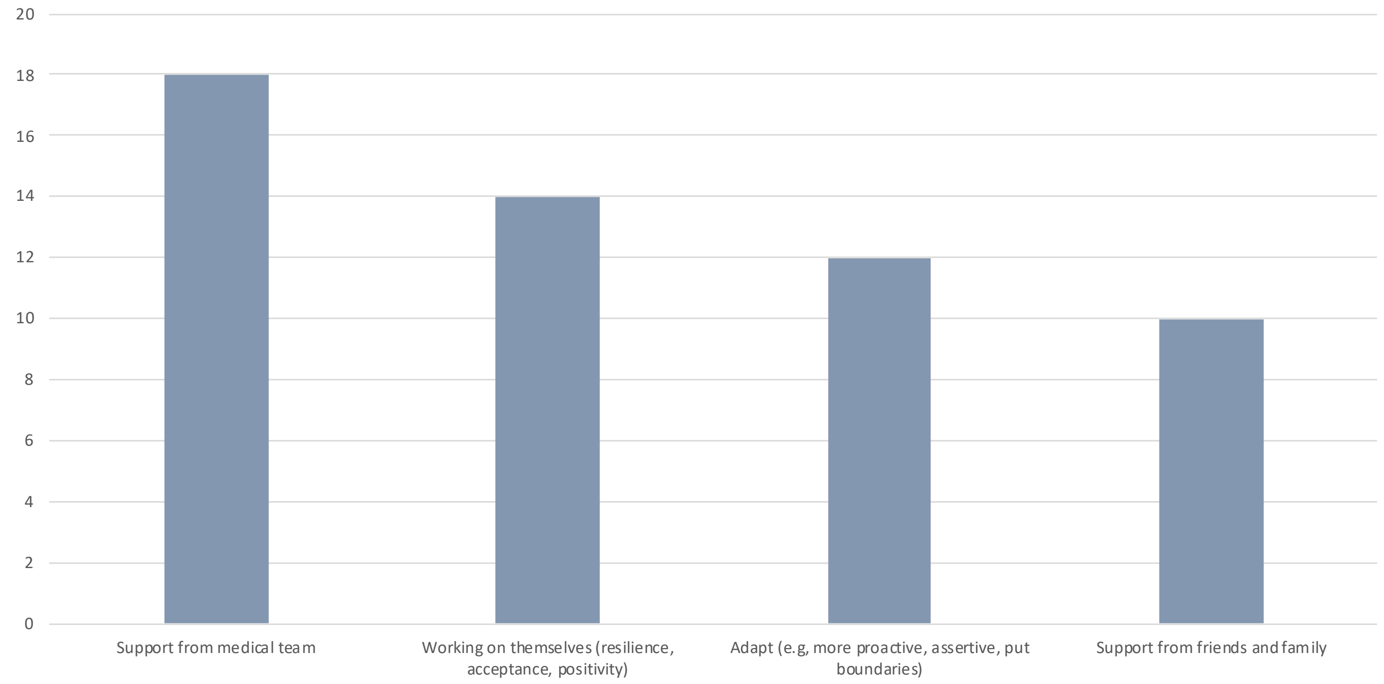

Figure 8.8: Methods to manage vulnerability

Table 8.15: Methods to manage vulnerability– subgroup variations

Theme	Reported less frequently	Reported more frequently
Participant describes support from medical team to manage the feeling of vulnerability	Regional or remote	-

Impact on relationships

In the structured interview, participants were asked whether their condition had affected their personal relationships. Overall, there were 19 participants (38.00%) who described a mix of positive and negative impacts on relationships. Other participants reported a negative impact on relationships (n=11, 22.00%), no impact on relationships (n=8, 16.00%), and a positive impact on relationships (n=7, 14.00%).

The most common theme in relation to having an impact on relationships was a mixed impact on relationships, some strengthened, others disappeared (n=14, 28.00%). There were eight participants (16.00%) who described relationships suffering, because of people not knowing what to say or do and withdrawing from relationships, and the same number who described no impact on relationships with no specific reason (n=8, 16.00%). Other reasons included relationships with family being strengthened (n=7, 14.00%), and relationships suffering, due to emotional strain (n=6, 12.00%).

Participant gives a description suggesting that overall, there was a mix of positive and negative impact

Some friends yes. We're no longer friends because they decided to make it all about them and share my story on social media, and talk about how it was affecting them. Yes, I've definitely moved on from some friendships, but my family, it's brought us closer. My mum, especially, weirdly, at first she was like, "Oh, you'll be alright; you'll get through this." and I think she realized how serious it was. She's just been really good and doing checks every day, whereas she never used to do any of that. My dad and I both got diagnosed cancer on the same day. Unfortunately, he was at the end of his journey. He passed in March this year. Participant_045

I think it's improved them, if anything, honestly, most of them. Some people just disappeared off the radar a bit, friends and some family actually. Some relationships, have improved, others have just not progressed at all. They're not there anymore. Participant_004

Yes. Nothing's going to be the same because I'm not the same. I actually think, my immediate family, my husband, and my daughter, I think we're closer than ever because we're more grateful for each other. Some friends are a bit-- Everyone's scared of you when you have cancer, and that's all right. I don't really want people in my space with it anyway, so I just want my husband and a handful of very, very close people. I'm a very private person and it's not something I want everyone to know about. Participant_007

Participant gives a description suggesting that overall, there was a negative impact on relationships

Yes, I think it has, some of them dropped off. Some of the friends dropped off. I don't understand. Family, my parents are more like treating me with kid gloves because they're like, "Are you okay? Are you okay? Are you okay?" It's annoying. There's some people they don't fully understand what I'm still going through because they just think if your hair grows back, you're fine again. Participant_008

Well, yeah, it's affected it with my husband for sure, because it's sort of like, you know, intimate stuff, because basically I don't want anyone to touch me anymore. Everyone can just go away. I do not want anyone coming near me because I've had so many people poking and prodding me. I would just back off everyone. So, yeah, I guess that does affect. With my husband, but yeah, even just generally with friends and family, I'm more I keep everyone up on stage. Participant_001

Yes, I guess in the aspect that I'm an adult, but I certainly had to lean on my parents a lot more, so I had to rely on them for that and for my kids. I guess the my friends around me and how they needed to support me, I required them to emotionally and mentally support me more than I normally would outside of cancer treatment. I guess there's that aspect of how much you tell someone like a new partner and being vulnerable with them about what I've been through and my scars. That certainly affects relationships. But also I think the people in my life who just want me to be happy and to move on with my life, I want to say positive, warm and fuzzy things to try and make me feel better. And I think sometimes they can be hurtful without meaning to because they're minimising what I'm going through or just not listening to me when I need them to listen. So I think and it affects the friendships that I have and what I say to who because of it. Participant_010

Participant gives a description suggesting that overall, there no impact on relationships

No, I wouldn't say so. No. Participant_015

No, not at all. Participant_035

Participant gives a description suggesting that overall, there was a positive impact on relationships

No, as I said, I think it's just strengthened the relationships that I have with family and friends. We're probably discussing things more openly and honestly, since having that diagnosis. I don't hold anything back, and I don't think my family does anymore. We've realize, that life is precious, and you just don't know how long you've got, and how well you're going to be. Yes, I think it's just strengthen those relationships. Same with my friends, we're all similar age group. We're, you know, we're getting on in in years. I think, my experience has just made me appreciate those relationships a lot more and vice versa. Participant_013

Yeah, I think I think that it has more. In a positive way, I feel like I've got everyone just surrounded me when I was diagnosed and you like that, I guess I've got stronger relationships with, you know, a few of my friends because of it. Participant_038

Yes. Not in a bad way though. There's people who've turned up and really been there for me that were unexpected. People that I didn't even necessarily know that well who turned up with meals for me every few days. I've got a colleague, for example, who had breast cancer years ago before I met her who has also just really been there for me. I think it's strengthened a few friendships in a lot of ways. Other than my children, the rest of my family don't live in LOCATION, and my mum, my sister are all in WA. I think it was harder on them because they weren't here, and it was in the middle of COVID, and they couldn't get here. Participant_011

Participant described a mixed impact on relationships, some strengthened, others disappeared

It's starting to sound a bit awful but you know who your real friends are, you know who your family members are. The people that weren't there at the time, I think we just don't talk to them anymore. Participant_024

So much, yes. I've become a lot close to my husband, which is great for family. Just emotional support and the physical and beautiful. [unintelligible] that part so much. I have become more close to my mother- in-law as well, because we have to rely on them with the kids. By the same token, some relationships have ceased to exist because some of my girlfriends can't have me being sick because I scare them. Participant_042

Yes. It's actually improved my personal relationship with my husband and my in-laws a lot. I've just grown to respect them a lot and appreciate them. It definitely solidified that. On the same token, with friends, I have identified people who were there for me and those who weren't. I've realized I'm a very emotional person, but it's made me learn to see people for what they are. Overall, it's been good, I would say. It hasn't affected anything negatively. Participant_016

Participant describes relationships suffering, that is people not knowing what to say or do and withdrawing from relationships

Yes, I think it has, some of them dropped off. Some of the friends dropped off. I don't understand. Family, my parents are more like treating me with kid gloves because they're like, "Are you okay? Are you okay? Are you okay?" It's annoying. There's some people they don't fully understand what I'm still going through because they just think if your hair grows back, you're fine again. Participant_008

You find out who your real friends are. I had some friends I didn't hear from the whole entire time and then I had friends that I hadn't seen in years, really set out to try and help me out. It was an interesting experience, you find out who's really going to be there for you in a moment of crisis. Participant_027

With friends certainly, yes. I have lost a lot of friends when I was first diagnosed. Through no fault of my own, I've had people send me emails saying, "We can't handle being around you while you're sick, so you won't be seeing us while you're going through this." Another woman downstairs in our foyer, told me when I lost my hair that it offended her seeing me bald. That I wouldn't be seeing her. I felt like, yes, I have lost a few friends because of it …

Participant describes no impact on relationships, without specifying reason

Not my parents, actually. Obviously not no one to help, you know. Yeah. It's not like my husband needed someone to come in and look after the kids because I couldn't manage it. It was never anything like that. Participant_003

No, I wouldn't say so. No. Participant_015

Participant describes relationships with family being strengthened

It has affected some friendships but on the whole, I think it has strengthened a lot of my relationships more than anything. Participant_022

Yeah, I think I think that it has more. In a positive way, I feel like I've got everyone just surrounded me when I was diagnosed and you like that, I guess I've got stronger relationships with, you know, a few of my friends because of it. Participant_038

I guess, yes, I've said earlier that it makes you focus on the things that are important. I think focusing on the relationships that are important and looking at whether when you have restrictions to your energy, the things that you do do have to be important and good things. There's no place to deal with toxic sorts of relationships. I had realized that, yes there were a couple that weren't serving me any good in the mix, so they're no longer in the mix. Participant_050

Participant describes relationships suffering, due to emotional strain

Yes, I think it has, some of them dropped off. Some of the friends dropped off. I don't understand. Family, my parents are more like treating me with kid gloves because they're like, "Are you okay? Are you okay? Are you okay?" It's annoying. There's some people they don't fully understand what I'm still going through because they just think if your hair grows back, you're fine again. Participant_008

Yes. What I've noticed is it's always the first thing that they want to talk about. I know that's in a kind and thoughtful way, but sometimes it has affected it because now I feel like I'm just a walking cancer patient. People, that's the first thing they say, "How're you going? How's treatment?" and that's lovely, but really I'd like to just be me. Yes, it's affected it because I'm not me first. It's just you've got no hair, you've got *no eyelashes, you've got no eyebrows. It's quite obvious. That's every time, if I bumped into someone at the supermarket it's "Oh my gosh, how are you? I heard, it's awful." and actually, I'm just me. Yes, it's affected relationships in that way because that's what people see first and you can't move past that. I think they can't move past that. Even family to some extent, you see that too. It's "How are you going? How are you?" Let's just have a laugh and a joke. I don't want to be a patient all the time. Yes, it has been effective. Participant_033*

Yes, I guess in the aspect that I'm an adult, but I certainly had to lean on my parents a lot more, so I had to rely on them for that and for my kids. I guess the my friends around me and how they needed to support me, I required them to emotionally and mentally support me more than I normally would outside of cancer treatment. I guess there's that aspect of how much you tell someone like a new partner and being vulnerable with them about what I've been through and my scars. That certainly affects relationships. But also I think the people in my life who just want me to be happy and to move on with my life, I want to say positive, warm and fuzzy things to try and make me feel better. And I think sometimes they can be hurtful without meaning to because they're minimising what I'm going through or just not listening to me when I need them to listen. So I think and it affects the friendships that I have and what I say to who because of it. Participant_010

Table 8.16: Impact on relationships

Impact on relationships	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=23	%	n=27	%	n=19	%	n=25	%	n=26	%	n=24	%	n=24	%	n=26	%
Participant gives a description suggesting that overall, there was a mix of positive and negative impact	19	38.00	9	39.13	10	37.04	7	36.84	9	36.00	7	26.92	12	50.00	11	45.83	8	30.77
Participant gives a description suggesting that overall, there was a negative impact on relationships	11	22.00	4	17.39	7	25.93	5	26.32	6	24.00	7	26.92	4	16.67	3	12.50	8	30.77
Participant gives a description suggesting that overall, there no impact on relationships	8	16.00	4	17.39	4	14.81	3	15.79	4	16.00	6	23.08	2	8.33	6	25.00	2	7.69
Participant gives a description suggesting that overall, there was a positive impact on relationships	7	14.00	4	17.39	3	11.11	2	10.53	4	16.00	4	15.38	3	12.50	2	8.33	5	19.23
Participant gives a description suggesting that overall, there was neither a positive or negative impact on relationships	3	6.00	2	8.70	1	3.70	1	5.26	1	4.00	1	3.85	2	8.33	0	0.00	3	11.54
Other	2	4.00	0	0.00	2	7.41	1	5.26	1	4.00	0	0.00	2	8.33	2	8.33	0	0.00

Impact on relationships	All participants		Regional or remote		Metropolitan		Mid to low status		Higher status		Aged 25 to 44		Aged 45 to 54		Aged 55 to 74	
	n=50	%	n=16	%	n=34	%	n=20	%	n=30	%	n=19	%	n=22	%	n=9	%
Participant gives a description suggesting that overall, there was a mix of positive and negative impact	19	38.00	9	56.25	10	29.41	7	35.00	12	40.00	6	31.58	10	45.45	3	33.33
Participant gives a description suggesting that overall, there was a negative impact on relationships	11	22.00	1	6.25	10	29.41	4	20.00	7	23.33	4	21.05	6	27.27	1	11.11
Participant gives a description suggesting that overall, there no impact on relationships	8	16.00	3	18.75	5	14.71	5	25.00	3	10.00	3	15.79	3	13.64	2	22.22
Participant gives a description suggesting that overall, there was a positive impact on relationships	7	14.00	3	18.75	4	11.76	3	15.00	4	13.33	2	10.53	3	13.64	2	22.22
Participant gives a description suggesting that overall, there was neither a positive or negative impact on relationships	3	6.00	0	0.00	3	8.82	0	0.00	3	10.00	3	15.79	0	0.00	0	0.00
Other	2	4.00	0	0.00	2	5.88	2	10.00	0	0.00	2	10.53	0	0.00	0	0.00

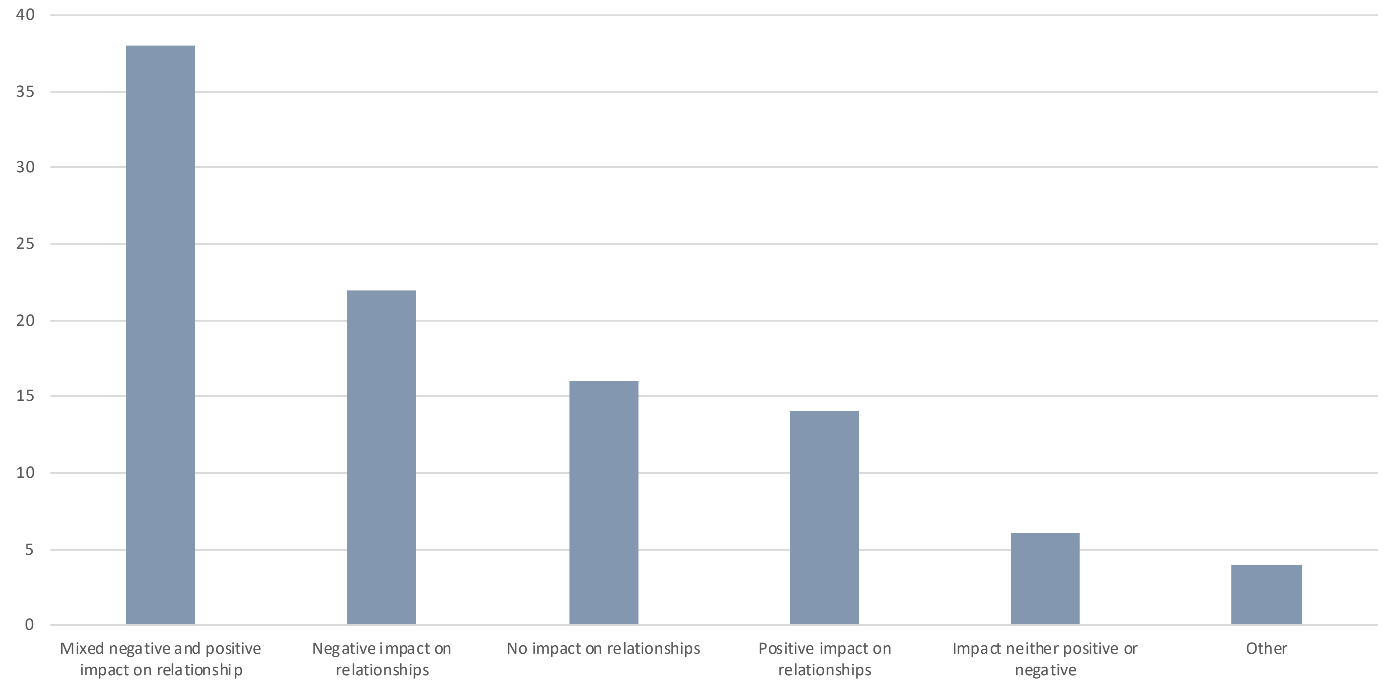

Figure 8.9: Impact on relationships

Table 8.17: Impact on relationships – subgroup variations

Theme	Reported less frequently	Reported more frequently
Participant describes a mixed impact on relationships, some strengthened, others disappeared	Diagnosed before 2020	Diagnosed in 2020 or 2021
Participant describes relationships suffering, that is people not knowing what to say or do and withdrawing from relationships	Early breast cancer Regional or remote	Poor physical function
Participant describes relationships with family being strengthened	-	Aged 55 to 74
Participant describes relationships suffering, due to emotional strain	Trade or high school Aged 55 to 74	University

Table 8.18: Impact on relationships (Reason for impact)

Impact on relationships (Reason for impact)	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=23	%	n=27	%	n=19	%	n=25	%	n=26	%	n=24	%	n=24	%	n=26	%
Participant describes a mixed impact on relationships, some strengthened, others disappeared	14	28.00	8	34.78	6	22.22	6	31.58	6	24.00	4	15.38	10	41.67	9	37.50	5	19.23
Participant describes relationships suffering, that is people not knowing what to say or do and withdrawing from relationships	8	16.00	1	4.35	7	25.93	5	26.32	3	12.00	5	19.23	3	12.50	4	16.67	4	15.38
Participant describes no impact on relationships, without specifying reason	8	16.00	4	17.39	4	14.81	3	15.79	4	16.00	6	23.08	2	8.33	6	25.00	2	7.69
Participant describes relationships with family being strengthened	7	14.00	3	13.04	4	14.81	2	10.53	4	16.00	5	19.23	2	8.33	3	12.50	4	15.38
Participant describes relationships suffering, due to emotional strain	6	12.00	5	21.74	1	3.70	2	10.53	4	16.00	5	19.23	1	4.17	0	0.00	6	23.08

Impact on relationships (Reason for impact)	All participants		Regional or remote		Metropolitan		Mid to low status		Higher status		Aged 25 to 44		Aged 45 to 54		Aged 55 to 74	
	n=50	%	n=16	%	n=34	%	n=20	%	n=30	%	n=19	%	n=22	%	n=9	%
Participant described a mixed impact on relationships, some strengthened, others disappeared	14	28.00	5	31.25	9	26.47	6	30.00	8	26.67	4	21.05	8	36.36	2	22.22
Participant describes relationships suffering, that is people not knowing what to say or do and withdrawing from relationships	8	16.00	0	0.00	8	23.53	2	10.00	6	20.00	3	15.79	3	13.64	2	22.22
Participant describes no impact on relationships, without specifying reason	8	16.00	3	18.75	5	14.71	5	25.00	3	10.00	3	15.79	3	13.64	2	22.22
Participant describes relationships with family being strengthened	7	14.00	2	12.50	5	14.71	3	15.00	4	13.33	1	5.26	3	13.64	3	33.33
Participant describes relationships suffering, due to emotional strain	6	12.00	2	12.50	4	11.76	2	10.00	4	13.33	2	10.53	4	18.18	0	0.00

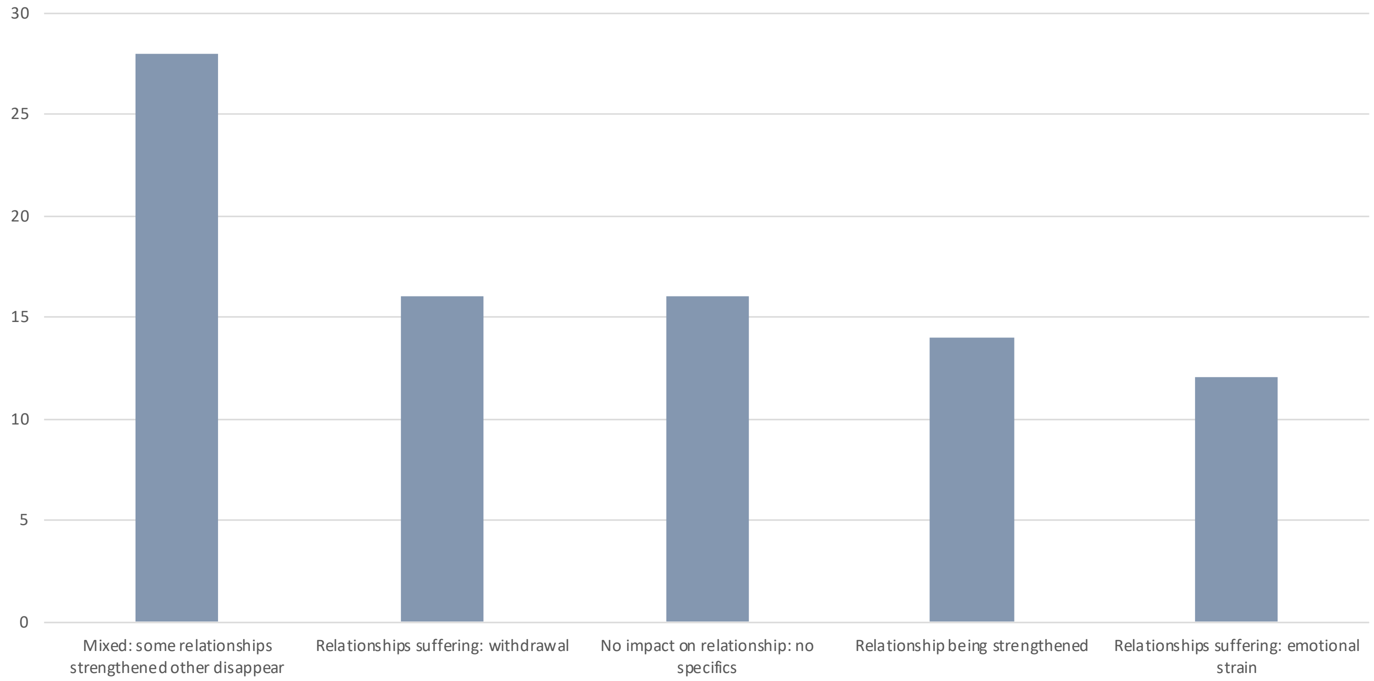

Figure 8.10: Impact on relationships

Table 8.19: Impact on relationships: Reason for impact – subgroup variations

Theme	Reported less frequently	Reported more frequently
Participant described a mixed impact on relationships, some strengthened, others disappeared	Diagnosed before 2020	Diagnosed in 2020 or 2021
Participant describes relationships suffering, that is people not knowing what to say or do and withdrawing from relationships	Early breast cancer Regional or remote	Poor physical function
Participant describes relationships with family being strengthened	-	Aged 55 to 74
Participant describes relationships suffering, due to emotional strain	Trade or high school Aged 55 to 74	University

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 30 participants (60.00%) who felt there was an additional burden, and 18 participants (36.00%) who reported no additional burden.

Participants who described that they were no additional burden, mostly did this without giving any examples or explanations (n=13, 26.00%), followed by not being a burden because they manage their condition independently (n=5, 10.00%). For people that felt they were a burden on their family, most commonly did not give any specific reasons for this (n=12, 24.00%). The main reasons for burden on families were the extra household duties and responsibilities that their family must take on (n=10, 20.00%), and the mental/emotional strain placed on their family (n=6, 12.00%).

Participant gives a description suggesting that overall, there was a burden on their family

Well, yeah, yeah. For my husband, yeah. He's had to pick up so much more because I don't have the energy and because for a long time things like just even putting the quilt cover on the bed, putting it, you know, stuff like that was hard and hanging, washing up because I couldn't do the reaching and all the arms stretching and stuff. So he's just more heavy stuff that he's been doing all that. And just because I just get tired or because I'm now more I'm just more anxious. And so definitely it's affected him so much because I'm not I'm not myself. Participant_001

It was during treatment, I don't think it is now. If they've got concerns, I feel reassured that they will discuss them with me. They have in the past, so I don't have any issues that they wouldn't discuss it with me during treatment, yes, I felt like, definitely it did place a burden on them because my girls they participated in a bit of a roster with my husband. They took turns in, you know, taking me to and from LOCATION for my treatment. That meant they were giving up time from work with it and time from their families, but I was never made to feel like I was a burden. I think that was just in my own mind, I felt that's just an extra workload for them. Participant_013

Yes. I think that-- I don't know. You sort of feel like you're a burden or you get made to feel like you're a burden because there's so many treatments or appointments to get to and whatever else it's like, "Oh, there's your cancer getting in the way again?" It's like, "Yes, well, I didn't ask for it." Participant_034

At the time when I was going through treatment, yes, I felt really guilty about that, but now the only guilt I feel now is that I'm not working so I'm not bringing any income in. Participant_046

Participant gives a description suggesting that overall, there was not a burden on their family

Only because I-- it's difficult to get out. I'm very headstrong to a certain extent. I don't like to put people out. I don't go looking for people to come to chemo with me. Then I have the two treatments that I've had. I've had two friends come with me. They both offer it and then I'm like, "Are you sure you're okay to do this?" They're like, "No, yes, yes. It's fine." Which is good, but then I do feel that I'm a bit of a burden to a certain extent as well. Participant_014

No, I never felt like I was a burden on anybody, and I don't really need any ongoing care at the moment, so definitely, no. Participant_025

No, I don't think it's a burden. I think the burden is that they've got the gene. My mother also has the gene, but she's never had cancer. I have to keep reminding myself of that. Participant_037

Participant describes their condition being a burden in general (No specific examples)

Yes, absolutely. Participant_009

Oh God, yes. You don't really want to admit this but probably. Participant_012

Yes. I sometimes feel that I'm a burden although I don't try to be, and I do as much as I can. Nobody complained, it's just the way I feel. Participant_032

Participant describes extra household duties and responsibilities that their family must take on

Well, yeah, yeah. For my husband, yeah. He's had to pick up so much more because I don't have the energy and because for a long time things like just even putting the quilt cover on the bed, putting it, you know, stuff like that was hard and hanging, washing up because I couldn't do the reaching and all the arms stretching and stuff. So he's just more heavy stuff that he's been doing all that. And just because I just get tired or because I'm now more I'm just more anxious. And so definitely it's affected him so much because I'm not I'm not myself. Participant_001

Well, the kids have to do a few more extra chores and I figure they probably don't like that but they don't complain, so that's something. Participant_022

Oh, absolutely. My kids are just like-- It's quite funny. Because your kids somehow-- Like my kids at the time, they're 21 and 24 now, two years ago is 19, 22, there had to take on parenting, looking after things and driving me around, and that happened for a while afterwards. Memory-wise, you're not that good so they'd have to correct you, they'd go, "Mum, that's not right. You missed this," or, "we've forgotten that." They'd go, "Mum, mum, you can't do that," it's funny, they're definitely taken on a parent-- when they're older, they should take on a parenting role. I guess, other people in the family that you thought would be closer to help you do things, just didn't do any respite for the kids or for my husband. It's a quite funny thing that you look back on. Participant_047

Participant describes the mental/emotional strain placed on their family

I see it as a burden and they wouldn't. They were obviously extremely happy to just be able to support me in every way possible. But I feel like I was a burden and negatively affected their life. And they obviously had to look after this 30 year old daughter who. Like most of you, I had moved out of home and was living independently, I was certainly a lot more dependent on them during that year and emotionally and mentally since then. So I feel like that was a burden. Participant_010

That was more early, during active treatment, but yes, I think it is. I think everybody would be less mentally stressed for the next few years to come. Participant_016

It was when I was going through my treatment, I felt like I was a burden. But they seem to think that they would happy. But I didn't want my kids to emotionally deal with them. I'm sick. And all that sort of stuff to me was the bit that the thought of us, which Participant_044

Participant describes their condition not being a burden in general (No specific examples)

I don't think so. Not now, no. Participant_004

No. Especially not now. Participant_021

Participant describes their condition being a burden as they have managed their condition independently

No, because I actually was alone for the whole thing. I was in a city on my own. I just didn't go through it with anyone. Yes, it wasn't. [chuckles] Participant_008

It hasn't been yet. I've been really happy about that because I've managed to maintain all of the things I was doing before, but I was initially really worried about that, that I don't want to be cared for. I don't want people having to do my housework and my cooking and thankfully, that hasn't happened. That was a huge concern. I think it would be again. I don't know how post-surgery, what happens. I assume I may need a little bit more help after that. I don't want that. Yes, I don't want that to burden them. Again, because I just don't want to be a patient. I want to be the matriarch of the family getting on and doing what I do. I don't like that. Participant_033

PARTICIPANT: No, because nobody's had to provide any for me. [chuckles]
INTERVIEWER: Yes, you're living by yourself. You've mentioned.
PARTICIPANT: Yes. Participant_041

Table 8.20: Burden on family

Burden on family	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=23	%	n=27	%	n=19	%	n=25	%	n=26	%	n=24	%	n=24	%	n=26	%
Participant gives a description suggesting that overall, there was a burden on their family	30	60.00	14	60.87	16	59.26	10	52.63	15	60.00	14	53.85	16	66.67	11	45.83	19	73.08
Participant gives a description suggesting that overall, there was not a burden on their family	18	36.00	9	39.13	9	33.33	8	42.11	9	36.00	10	38.46	8	33.33	11	45.83	7	26.92
Participant gives a description suggesting that overall, there was not a burden on their family now but they anticipate this will change in the future	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
Other	2	4.00	0	0.00	2	7.41	1	5.26	1	4.00	0	0.00	2	8.33	2	8.33	0	0.00

Burden on family	All participants		Regional or remote		Metropolitan		Mid to low status		Higher status		Aged 25 to 44		Aged 45 to 54		Aged 55 to 74	
	n=50	%	n=16	%	n=34	%	n=20	%	n=30	%	n=19	%	n=22	%	n=9	%
Participant gives a description suggesting that overall, there was a burden on their family	30	60.00	11	68.75	19	55.88	10	50.00	20	66.67	13	68.42	11	50.00	6	66.67
Participant gives a description suggesting that overall, there was not a burden on their family	18	36.00	5	31.25	13	38.24	8	40.00	10	33.33	4	21.05	11	50.00	3	33.33
Participant gives a description suggesting that overall, there was not a burden on their family now but they anticipate this will change in the future	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
Other	2	4.00	0	0.00	2	5.88	2	10.00	0	0.00	2	10.53	0	0.00	0	0.00

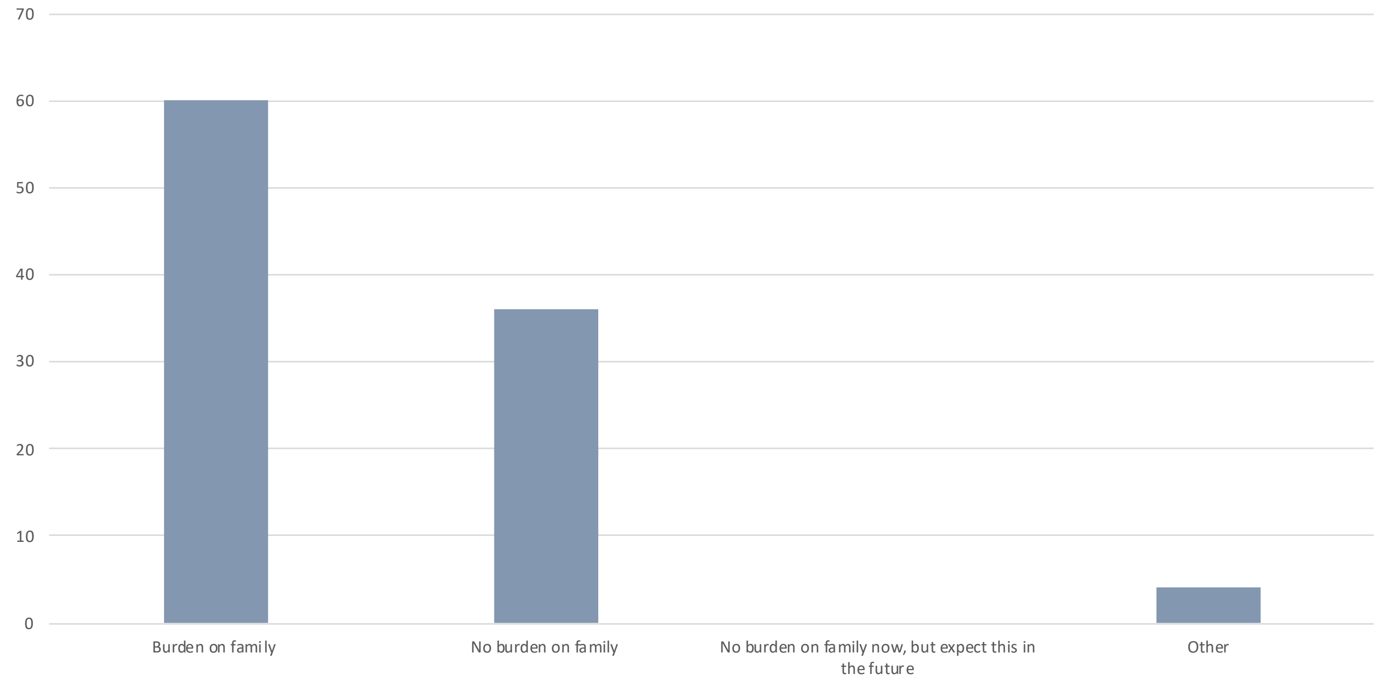

Figure 8.11: Burden on family

Table 8.21: Burden on family – subgroup variations

Theme	Reported less frequently	Reported more frequently
Participant gives a description suggesting that overall, there was a burden on their family	Trade or high school	University
Participant gives a description suggesting that overall, there was not a burden on their family	Aged 25 to 44	Aged 45 to 54

Table 8.22: Burden on family (description)

Burden on family (description)	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=23	%	n=27	%	n=19	%	n=25	%	n=26	%	n=24	%	n=24	%	n=26	%
Participant describes their condition being a burden in general (No specific examples)	12	24.00	5	21.74	7	25.93	8	42.11	2	8.00	5	19.23	7	29.17	5	20.83	7	26.92
Participant describes extra household duties and responsibilities that their family must take on	10	20.00	7	30.43	3	11.11	1	5.26	8	32.00	5	19.23	5	20.83	4	16.67	6	23.08
Participant describes the mental/emotional strain placed on their family	6	12.00	3	13.04	3	11.11	0	0.00	5	20.00	4	15.38	2	8.33	2	8.33	4	15.38
Participant describes their condition not being a burden in general (No specific examples)	13	26.00	7	30.43	6	22.22	4	21.05	8	32.00	8	30.77	5	20.83	10	41.67	3	11.54
Participant describes their condition being a burden as they have managed their condition independently	5	10.00	2	8.70	3	11.11	4	21.05	1	4.00	2	7.69	3	12.50	1	4.17	4	15.38

Burden on family (description)	All participants		Regional or remote		Metropolitan		Mid to low status		Higher status		Aged 25 to 44		Aged 45 to 54		Aged 55 to 74	
	n=50	%	n=16	%	n=34	%	n=20	%	n=30	%	n=19	%	n=22	%	n=9	%
Participant describes their condition being a burden in general (No specific examples)	12	24.00	5	31.25	7	20.59	3	15.00	9	30.00	6	31.58	3	13.64	3	33.33
Participant describes extra household duties and responsibilities that their family must take on	10	20.00	2	12.50	8	23.53	3	15.00	7	23.33	5	26.32	4	18.18	1	11.11
Participant describes the mental/emotional strain placed on their family	6	12.00	1	6.25	5	14.71	2	10.00	4	13.33	2	10.53	3	13.64	1	11.11
Participant describes their condition not being a burden in general (No specific examples)	13	26.00	3	18.75	10	29.41	5	25.00	8	26.67	3	15.79	7	31.82	3	33.33
Participant describes their condition being a burden as they have managed their condition independently	5	10.00	2	12.50	3	8.82	3	15.00	2	6.67	1	5.26	4	18.18	0	0.00

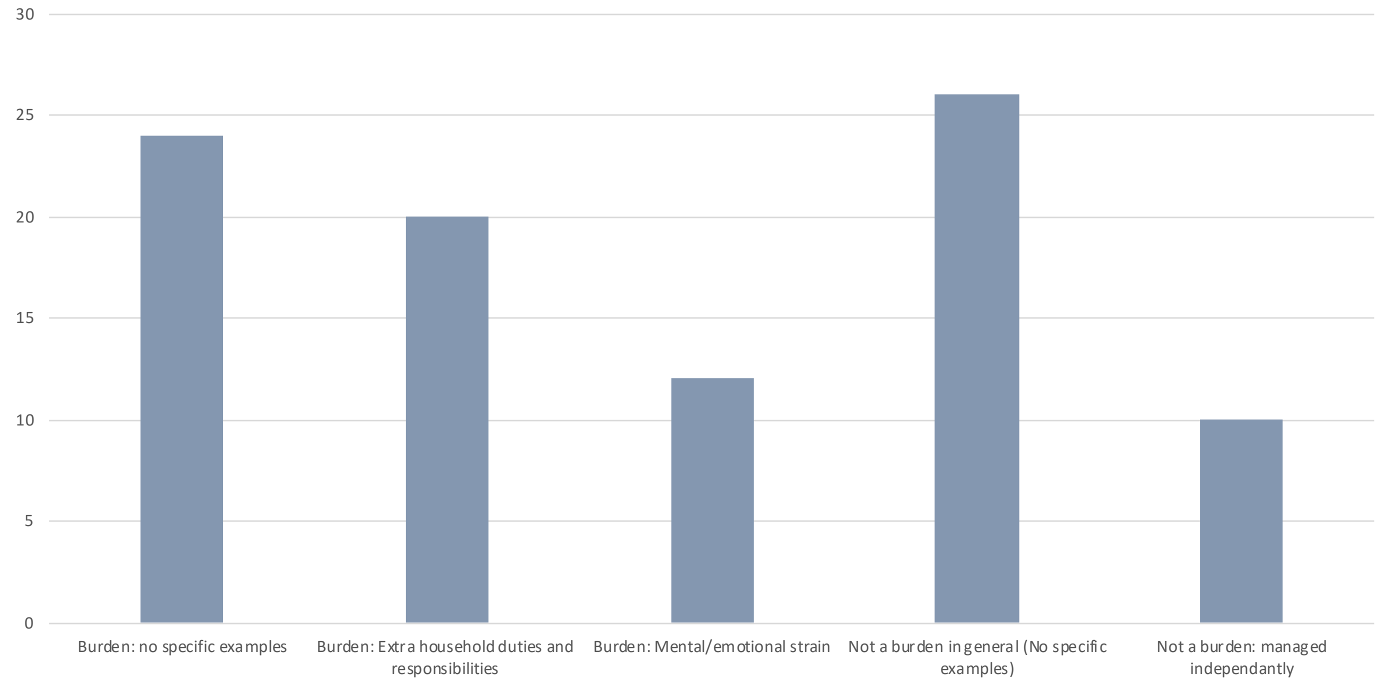

Figure 8.12: Burden on family (description)

Table 8.23: Burden on family (description)– subgroup variations

Theme	Reported less frequently	Reported more frequently
Participant describes their condition being a burden in general (No specific examples)	Good physical function Aged 45 to 54	Poor physical function
Participant describes extra household duties and responsibilities that their family must take on	Poor physical function	Early breast cancer Good physical function
Participant describes the mental/emotional strain placed on their family	Poor physical function	-
Participant describes their condition not being a burden in general (No specific examples)	University Aged 25 to 44	Trade or high school
Participant describes their condition being a burden as they have managed tehir condition independently	-	Poor physical function

Cost considerations

In the structured interview, participants were asked about any significant costs associated with having their condition. There were 36 participants (72.00%) that described some cost burden and 11 participants (22.00%) who described no cost burden.

Where participants described a cost burden associated with their condition, it was most commonly in relation to the cost of treatments, including repeat scripts (n=25, 50.00%). Other cost burdens were in relation to diagnostic tests and scans (n=15, 30.00%), taking time off work (n=9, 18.00%), and the cost of private care (n=7, 14.00%). There were six participants (12.00%) who described the cost of specialist appointments, and the same number who described the cost of allied healthcare (n=6, 12.00%), and the cost of parking and travel to attend appointments, including accommodation (n=6, 12.00%). There were six participants (12.00%) that described no cost burden and that nearly everything was paid for through the health system or private coverage.

Participant gives a description suggesting that overall, there was at least some cost burden

It's been extremely expensive. We've reached our Medicare safety net. I don't know how you could have no savings and get cancer. We've ended up having to get someone to come in and help us a few hours a week just with things around the house. Everything just costs a lot of money. It's like all the drugs you have to have. It's very expensive. Participant_007

It's been very expensive because I think the treatment costs me about $10,000. Then I haven't been working since the last August, but I did get a redundancy payout. It has cost me a lot of money in terms of lost income. It cost me a lot of time because I was trying to get the disability pension and that I'm not disabled enough apparently. That's probably it. I used to keep a running tab of how much money I was spending on the doctors and stuff, but I'm trying to not spend it or think about it now. Participant_008

Oh gosh, I've had heaps of costs. I couldn't work. I had kids at home in daycare, the preschool age. Daycare fees. I did get a bit of help with daycare fees once we filled out the 1,400 forms that we had to fill out. My husband had taken extended time off work and to help. All my lymphatic drainage and massage, I had to pay privately. That's about it, really. When you can't work, you really don't have a lot of money. You have to find out what you can get via the government or through charity support and what's available through on Medicare. Participant_012

Participant gives a description suggesting that overall, there was no cost burden

PARTICIPANT: So it was, I think, the parking and just a couple of weeks off work. But I got covered by so a long service leave so it didn't really affect me greatly.
INTERVIEWER: And with any scans or medications, did you have to bear the cost of any of that?
PARTICIPANT: No, all resolved through public hospital Participant_006

No. There's been no issues with costs because it's been minimal. Participant_030

I have been so fortunate. We have been with the same private health insurance for the last seven or eight years, so our level of cover is golden or platinum. Because we've been members for them for so long. Me and my husband are just very lazy people and we forgot to switch the cover [inaudible] so all of my chemo and radiation and surgery were covered. Participant_042

Participant describes a cost burden in relation to the cost of treatments (including repeat scripts)

Well, for me, the biggest cost was the surgery. That nearly killed me on its own but other than that, I've really haven't had through the process of the actual treatment, I haven't had any out of profit. The only things that I've paid for would be when I went to see the physio or a massage. Participant_027

It's a huge financial burden. Particularly, we own our own business, so time off work, luckily for me wasn't an issue, but for others, it is. The medical bills aside. Yes. I'd say we probably spent close to $30,000. My surgery alone was $20,000, $21,000. and then ongoing pharmacy deals and medical -the follow-up physio bills and things that. Yes. It's significant. I don't know how you would deal with it if you weren't as financially secure. You'd have to go into the public system I guess. I feel as though being a private patient, I didn't expect there to be so many additional costs. Participant_036

Participant describes a cost burden in relation to diagnostic tests and scans

I know initially all your scans that you have done out of hospital, when you're not actually in hospital, there is out of pocket expenses that I've had. I do have private health, but there's out of pocket expenses and it can be a few hundred dollars. With my chemo medication, every week when I would go to the pharmacist, I was probably out of pocket about $60 a week. Not being able to drive so I was out of pocket taxi fares going to hospital to receive my treatments. Then when you get to surgery, I had to make a choice. You've got the choice of going your public and your private. I ended up choosing to go public. It didn't have out of pocket expenses, even though I've had private health cover, because I pay a fortune for private health cover, but I'm just more out of pocket again when it's covered publicly, so I chose to go public. The really significant one for me is, so I've had a double mastectomy. I haven't had a reconstruction yet, because I need to do radiotherapy first. For reconstruction, I'm looking at if I want to do it privately and I want to do it fast. I'm looking at being something like $30,000 out of pocket. Participant_017

Okay, so the biggest cost for me was the fine needle biopsy, which was just before Christmas, which was like a 500 but I got 400 of that back, obviously, or maybe 150 of it back with Medicare. Then the cost of treatment at the start when I first started chemotherapy, because of all the medication I needed, which was the 8 needle afterwards, which was $30 a go. Then all the steroids and the anti-nausea, so my medication bill every fortnight was anywhere up to $100. Participant_018

The costs have been a huge shock. Actually, I had no idea how much cost would be involved in a breast cancer diagnosis. It's been quite an eye-opener. It hasn't affected us too much financially. Luckily we're in a position that we can cope with that. I worry for people who can't, and it also makes me quite angry that we are so massively out of pocket. Things like all the testing, the PET scans, the mammograms, and they want to do them repeatedly, and then another scan and then there's this, and then there's that, and it's costing hundreds of dollars each time with minimal back from Medicare. Those costs are huge. My biggest annoyance with costs, I suppose, was not being asked at the beginning if I wanted to be a public or private patient, that was never mentioned, it was just assumed. Have you got a private health card? Yes, I do. Here you go. That means now that I've had to pay gap fees for the surgeon, and gap fees for the hospital, and additional fees that the person sitting next to me, who's in the public system isn't having to pay and is getting the same treatment. I find that that was a shock. The costs have been huge, obviously, I've given up work now for a short time just while I go through surgery. I don't know, I might work part-time after that. The loss of income has been obviously a challenge, and the costs continue to mount up. Each week there's something else. Participant_033

Yes, diagnosis, that cost us a lot of money. That was a real shock. When I went and had an ultrasound and a biopsy, I was not expecting to be told that it'll be $500. Me and my husband just about had a heart attack. [chuckles] We've had lots of costs on it. It's cost us money, we've had to travel. My husband had to take time off work. My medication, different medications that I've had to take. I'm trying to think what else, and just different tests. Even doctors, you get rebates back on some of them and some of them you don't. Every time I go see my oncologist, that costs money. Every time I see my surgeon, it costs money. Participant_043

Participant describes a cost burden in relation to needing to take time off work

It's been very expensive because I think the treatment costs me about $10,000. Then I haven't been working since the last August, but I did get a redundancy payout. It has cost me a lot of money in terms of lost income. It cost me a lot of time because I was trying to get the disability pension and that I'm not disabled enough apparently. That's probably it. I used to keep a running tab of how much money I was spending on the doctors and stuff, but I'm trying to not spend it or think about it now. Participant_008

Yes, basically, time off work was one. Accessing income support was terrible. Bills, a few, like we've the scans and things that you've still got to go through, so the mammograms and all that you have to pay for afterwards, the ultrasounds. Pretty much all the regular testing. Medication, I didn't have any, so I was lucky there. Paying out for bills and things like that was probably my biggest one. Participant_024

Well, for the surgery, I was very lucky. I spoke to the specialist, and they did it all out-of-pocket on Gov Private Health fund, and there was going to be a large out-of-pocket, but I got that all covered. Scans are very expensive. All your PET scans and all that stuff, that's costly there. Radiation is a ridiculous cost, but I spoke to someone in my cancer support group here and they told me that I should be able to get it all bulk-billed and not have to pay, so I ended up not having to pay. That was going to be something like $10,000. That was hard. I got that. Well, I'm still on long-term sick leave since surgery, and I haven't felt that I'm ready to go back to work yet. I did try to go back a couple of months ago and I lasted a day and I had to come home and lie down. I couldn't even stand in the shower. I was physically and mentally exhausted. I have been off work for nearly 12 months. I had holidays and long service and everything like that, which took me until February, but I haven't been paid anything since then because I've got some money in the bank put away. I'm not entitled to any Centrelink payments or anything like that. Financially, yes, it's been really tough. There's no form of income. Yes, mentally, it's pretty tough on the family as well as yourself. [crosstalk] It has been [unintelligible] financially and mentally. Participant_046

Participant describes a cost burden in relation to the cost of private care

I had my surgery because I mean, no health funds so I had my surgery privately. That actually, that costs us $10,000 to trade out. That was literally a credit card job at the time. I got a couple of thousand back between Medicare and my health fund. That sort of helped. Then we had IVF costs in on that, which obviously we had no idea was coming sort of things. That was another 5,000 I think, at the time. I had all this spreadsheet, how much I got back and what day. We did on those two things, which was very out of pocket. Something we never obviously thought was coming. My treatment as such [unintelligible] None of my tests I've had to pay for. It was the surgery and then IVF. Again, I've just paid for surgery again, which I could had publicly but I had the [unintelligible] and it was definitely worth it. I would not change anything about that. The hospital was amazing. Participant_021

While we were out on the farm, we were farming, we got a housekeeper in because we were busy on the farm and I had a child to look after. We paid for a housekeeper, a live-in housekeeper. Then, there was out-of- pocket costs because I went private for surgery and for chemotherapy therapy. Radiotherapy, there was no out-of- pocket because I went public. Then, there was the ongoing costs of the surveillance, like every time I had a mammogram and ultrasound. That was always out-of-pocket. Participant_037

I went privately and say, you know, there was a lot of gaps in everything, particularly the surgery. But yeah, so and I'm still not back at work yet. So that's obviously financially hard on us. And then, you know, it's quite frustrating because when if you go through the public system, you get all the physios, it's for free. And I asked if I could join that group and I said no, because you're a private patient. But just because I pay private health covid doesn't mean I'm rich and I can't afford all the other treatments, you know? So, yeah, that's been a bit frustrating. That's how I do it, because I want to get back to work and I have to get back to work, but I've just got to pay for it. You know that part. I have covered some of that. Participant_038

Participant describes a cost burden in relation to the cost specialist appointments

It's been very expensive because I think the treatment costs me about $10,000. Then I haven't been working since the last August, but I did get a redundancy payout. It has cost me a lot of money in terms of lost income. It cost me a lot of time because I was trying to get the disability pension and that I'm not disabled enough apparently. That's probably it. I used to keep a running tab of how much money I was spending on the doctors and stuff, but I'm trying to not spend it or think about it now. Participant_008

That's probably been one of the very challenging parts as well. My surgery is going to be $6,000 out of pocket. The specialists, the scans, every biopsy, and I had to go to emergency three times during chemo. One time when I called my oncologist, he was away and the one standing in for him suggested I went to a private hospital. I didn't realize what financial implication that had until the bills came. Even though I have private health insurance, I still had $800 out of pocket for the pathology tests. It's cost thousands and thousands of thousands out of pocket, and I'm a single mother. I wasn't able to take time off. I've continued working almost full-time through this whole thing, and that's been horrendous. Thank God I'm working from home because a lot of days I work on the sofa, [chuckles] and I was fortunate that I had six weeks of leave that I'd saved up for holidays with my parents in Canada because otherwise, I wouldn't have had enough leave to get me through it. The financial side of it is terrible. Participant_041

Yes, diagnosis, that cost us a lot of money. That was a real shock. When I went and had an ultrasound and a biopsy, I was not expecting to be told that it'll be $500. Me and my husband just about had a heart attack. [chuckles] We've had lots of costs on it. It's cost us money, we've had to travel. My husband had to take time off work. My medication, different medications that I've had to take. I'm trying to think what else, and just different tests. Even doctors, you get rebates back on some of them and some of them you don't. Every time I go see my oncologist, that costs money. Every time I see my surgeon, it costs money. Participant_043

Participant describes a cost burden in relation to the cost of allied healthcare

Well, for me, the biggest cost was the surgery. That nearly killed me on its own but other than that, I've really haven't had through the process of the actual treatment, I haven't had any out of profit. The only things that I've paid for would be when I went to see the physio or a massage. Participant_027

It's a huge financial burden. Particularly, we own our own business, so time off work, luckily for me wasn't an issue, but for others, it is. The medical bills aside. Yes. I'd say we probably spent close to $30,000. My surgery alone was $20,000, $21,000. and then ongoing pharmacy deals and medical - the follow-up physio bills and things that. Yes. It's significant. I don't know how you would deal with it if you weren't as financially secure. You'd have to go into the public system I guess. I feel as though being a private patient, I didn't expect there to be so many additional costs. Participant_036

I went privately and say, you know, there was a lot of gaps in everything, particularly the surgery. But yeah, so and I'm still not back at work yet. So that's obviously financially hard on us. And then, you know, it's quite frustrating because when if you go through the public system, you get all the physios, it's for free. And I asked if I could join that group and I said no, because you're a private patient. But just because I pay private health covid doesn't mean I'm rich and I can't afford all the other treatments, you know? So, yeah, that's been a bit frustrating. That's how I do it, because I want to get back to work and I have to get back to work, but I've just got to pay for it. You know that part. I have covered some of that. Participant_038

Participant describes a cost burden in relation to the cost of parking and travel to attend appointments (including accommodation)

Yes, I was off work for six months. The costs, we had initially, where we lived to where my initial treatment was is a fair distance because we used to live that side, and then we moved but I wanted to continue my treatment. The cost of traveling to and from treatment was quite excessive. Then there was parking and tolls, and me being off work didn't help much at all. My husband took up a second job to help us through. I did have some annual leave and sick leave saved up. I had actually quite a lot but it wasn't enough. I was still two months short. My work did help out a little bit after I broke down and they gave me my annual leave in advance, but only a month or the four weeks, and that was weeded out over two months. so I sort of got half pay and I did a little bit of work from home when I could. Still, obviously, there was a lot of added cost like if I was at the hospital then my husband would get takeout or even cost of parking and coming up to see me. Extra fuel costs. It did all add up obviously COVID hasn't helped that either because my husband lost his job in COVID. We're back on track now but the initial cost of diagnosis it can-- Unless you are financially stable and have some form of insurance, it can get very, very hard especially having to be off of work for so long. Like I say, with my family history I couldn't get any insurance so that was pretty tough. Participant_022

Yes, diagnosis, that cost us a lot of money. That was a real shock. When I went and had an ultrasound and a biopsy, I was not expecting to be told that it'll be $500. Me and my husband just about had a heart attack. [chuckles] We've had lots of costs on it. It's cost us money, we've had to travel. My husband had to take time off work. My medication, different medications that I've had to take. I'm trying to think what else, and just different tests. Even doctors, you get rebates back on some of them and some of them you don't. Every time I go see my oncologist, that costs money. Every time I see my surgeon, it costs money. Participant_043

I think we could go on forever about this. When I first got diagnosed, I was actually quite shocked at the amount of money outlined for you. You're paying six, seven, eight hundred dollars and only getting two or three back for Medicare. The parking that while you're at the hospital, it could range from five dollars. Twenty five dollars. The pharmacy costs for even just down to having to have Panadol all the time. And, you know, you don't have to have grastro stop antinausea. It was just constant. I just felt like I was out money all the time trying to think of other things. I mean, just petrol for your car to get to appointments, you know, just everything like that. It just it was and it was skyrocketing all the time.. Participant_049

Participant describes no cost burden and that nearly everything was paid for through the health system

PARTICIPANT: So it was, I think, the parking and just a couple of weeks off work. But I got covered by so a long service leave so it didn't really affect me greatly.
INTERVIEWER: And with any scans or medications, did you have to bear the cost of any of that
PARTICIPANT: No, all resolved through public hospital. Participant_006

I haven't had to pay for anything so far. Participant_014

Table 8.24: Cost considerations

Cost considerations	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=23	%	n=27	%	n=19	%	n=25	%	n=26	%	n=24	%	n=24	%	n=26	%
Participant gives a description suggesting that overall, there was at least some cost burden	36	72.00	17	73.91	19	70.37	15	78.95	16	64.00	18	69.23	18	75.00	16	66.67	20	76.92
Participant gives a description suggesting that overall, there was no cost burden	11	22.00	6	26.09	5	18.52	3	15.79	7	28.00	5	19.23	6	25.00	6	25.00	5	19.23
Other	2	4.00	0	0.00	2	7.41	1	5.26	1	4.00	0	0.00	2	8.33	2	8.33	0	0.00

Cost considerations	All participants		Regional or remote		Metropolitan		Mid to low status		Higher status		Aged 25 to 44		Aged 45 to 54		Aged 55 to 74	
	n=50	%	n=16	%	n=34	%	n=20	%	n=30	%	n=19	%	n=22	%	n=9	%
Participant gives a description suggesting that overall, there was at least some cost burden	36	72.00	12	75.00	24	70.59	15	75.00	21	70.00	14	73.68	18	81.82	4	44.44
Participant gives a description suggesting that overall, there was no cost burden	11	22.00	4	25.00	7	20.59	3	15.00	8	26.67	3	15.79	3	13.64	5	55.56
Other	2	4.00	0	0.00	2	5.88	2	10.00	0	0.00	2	10.53	0	0.00	0	0.00

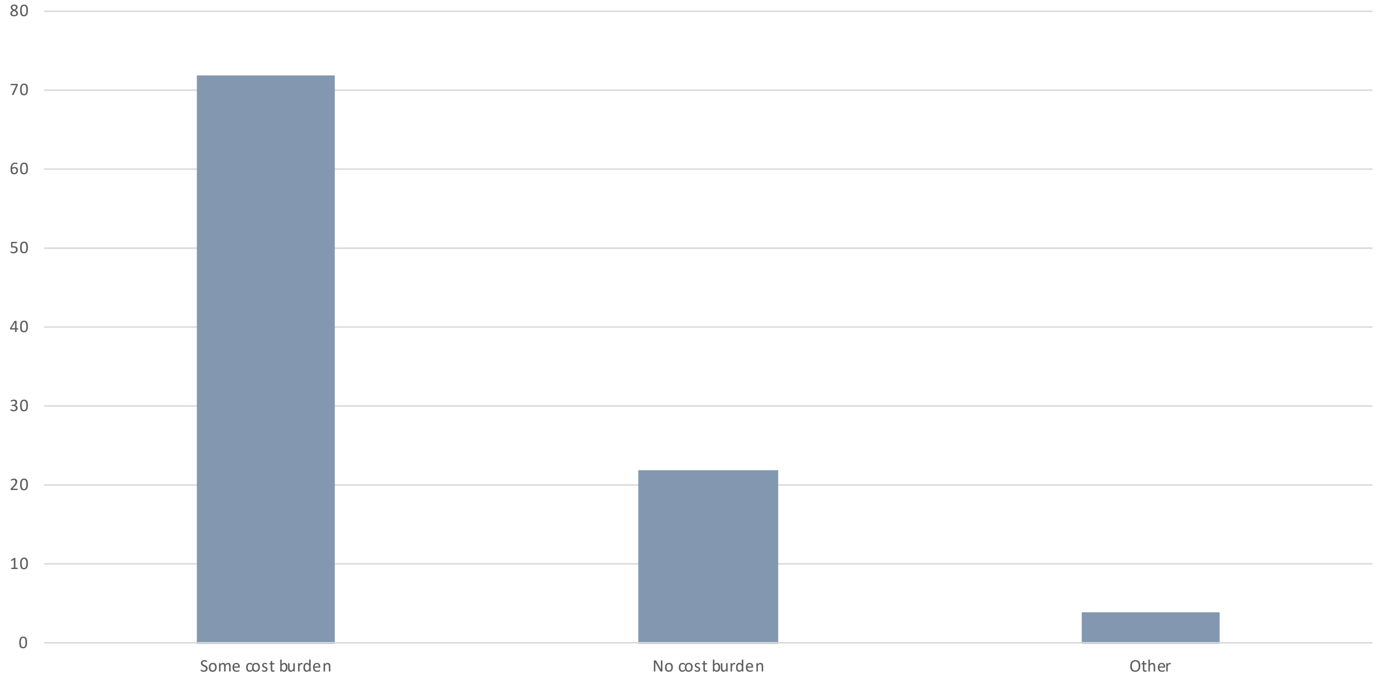

Figure 8.13: Cost considerations

Table 8.25: Cost considerations – subgroup variations

Theme	Reported less frequently	Reported more frequently
Participant gives a description suggesting that overall, there was at least some cost burden	Aged 55 to 74	-
Participant gives a description suggesting that overall, there was no cost burden	-	Aged 55 to 74

Table 8.26: Cost considerations (Reasons for cost)

Cost considerations (Reasons for cost)	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=23	%	n=27	%	n=19	%	n=25	%	n=26	%	n=24	%	n=24	%	n=26	%
Participant describes a cost burden in relation to the cost of treatments (including repeat scripts)	25	50.00	13	56.52	12	44.44	12	63.16	10	40.00	12	46.15	13	54.17	12	50.00	13	50.00
Participant describes a cost burden in relation to diagnostic tests and scans	15	30.00	5	21.74	10	37.04	4	21.05	9	36.00	7	26.92	8	33.33	5	20.83	10	38.46
Participant describes a cost burden in relation to needing to take time off work	9	18.00	4	17.39	5	18.52	1	5.26	6	24.00	6	23.08	3	12.50	4	16.67	5	19.23
Participant describes a cost burden in relation to the cost of private care	7	14.00	2	8.70	5	18.52	3	15.79	2	8.00	3	11.54	4	16.67	5	20.83	2	7.69
Participant describes a cost burden in relation to the cost specialist appointments	6	12.00	3	13.04	3	11.11	4	21.05	2	8.00	4	15.38	2	8.33	1	4.17	5	19.23
Participant describes a cost burden in relation to the cost of allied healthcare	6	12.00	2	8.70	4	14.81	2	10.53	2	8.00	3	11.54	3	12.50	4	16.67	2	7.69
Participant describes a cost burden in relation to the cost of parking and travel to attend appointments (including accommodation)	6	12.00	4	17.39	2	7.41	3	15.79	3	12.00	5	19.23	1	4.17	3	12.50	3	11.54
Participant describes no cost burden and that nearly everything was paid for through the health system	6	12.00	5	21.74	1	3.70	1	5.26	4	16.00	4	15.38	2	8.33	2	8.33	4	15.38

Cost considerations (Reasons for cost)	All participants		Regional or remote		Metropolitan		Mid to low status		Higher status		Aged 25 to 44		Aged 45 to 54		Aged 55 to 74	
	n=50	%	n=16	%	n=34	%	n=20	%	n=30	%	n=19	%	n=22	%	n=9	%
Participant describes a cost burden in relation to the cost of treatments (including repeat scripts)	25	50.00	7	43.75	18	52.94	9	45.00	16	53.33	11	57.89	11	50.00	3	33.33
Participant describes a cost burden in relation to diagnostic tests and scans	15	30.00	6	37.50	9	26.47	6	30.00	9	30.00	6	31.58	8	36.36	1	11.11
Participant describes a cost burden in relation to needing to take time off work	9	18.00	3	18.75	6	17.65	5	25.00	4	13.33	3	15.79	6	27.27	0	0.00
Participant describes a cost burden in relation to the cost of private care	7	14.00	3	18.75	4	11.76	3	15.00	4	13.33	3	15.79	2	9.09	2	22.22
Participant describes a cost burden in relation to the cost specialist appointments	6	12.00	2	12.50	4	11.76	2	10.00	4	13.33	4	21.05	2	9.09	0	0.00
Participant describes a cost burden in relation to the cost of allied healthcare	6	12.00	1	6.25	5	14.71	4	20.00	2	6.67	4	21.05	2	9.09	0	0.00
Participant describes a cost burden in relation to the cost of parking and travel to attend appointments (including accommodation)	6	12.00	3	18.75	3	8.82	3	15.00	3	10.00	1	5.26	3	13.64	2	22.22
Participant describes no cost burden and that nearly everything was paid for through the health system	6	12.00	3	18.75	3	8.82	3	15.00	3	10.00	1	5.26	3	13.64	2	22.22

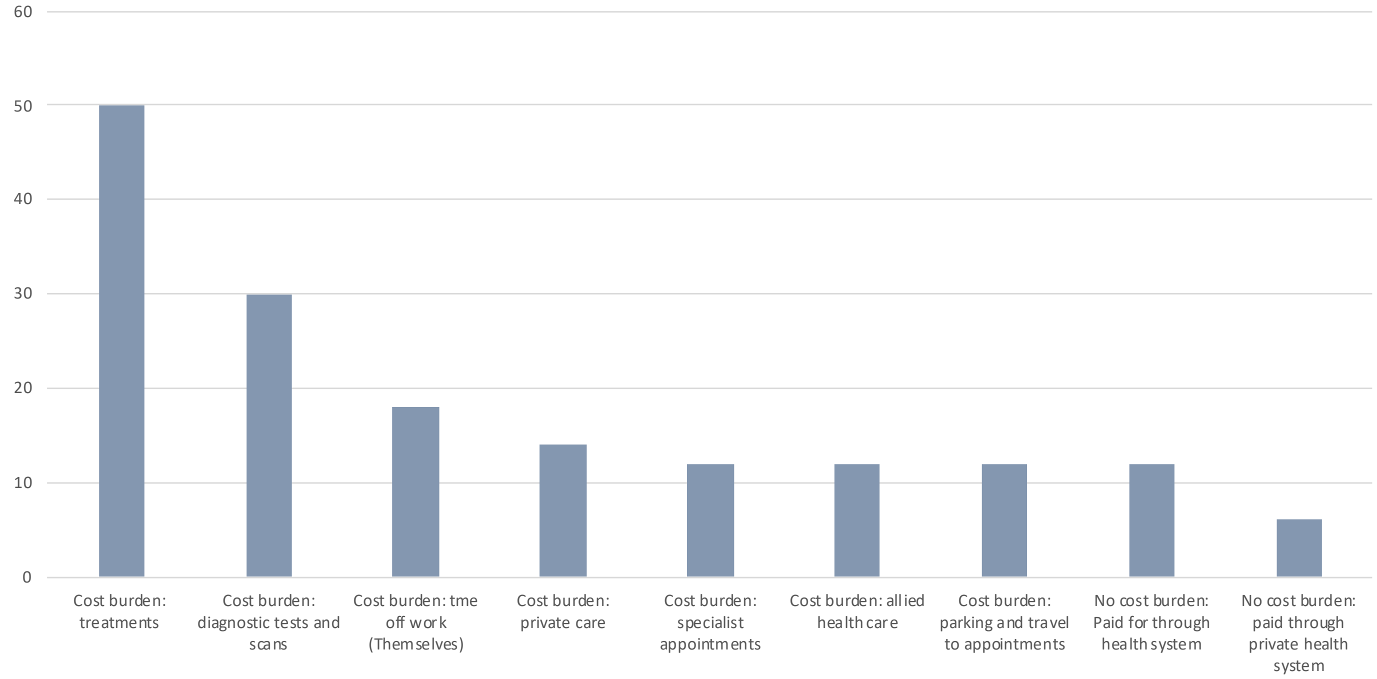

Figure 8.14: Cost considerations (Reasons for cost)

Table 8.27: Cost considerations (Reasons for cost)– subgroup variations

Theme	Reported less frequently	Reported more frequently
Participant describes a cost burden in relation to the cost of treatments (including repeat scripts)	Aged 55 to 74	Poor physical function
Participant describes a cost burden in relation to diagnostic tests and scans	Aged 55 to 74	-
Participant describes a cost burden in relation to needing to take time off work	Poor physical function Aged 55 to 74	-
Participant describes a cost burden in relation to the cost specialist appointments	Aged 55 to 74	-
Participant describes a cost burden in relation to the cost of allied healthcare	Aged 55 to 74	-
Participant describes a cost burden in relation to the cost of parking and travel to attend appointments (including accommodation)	-	Aged 55 to 74
Participant describes no cost burden and that nearly everything was paid for through the health system	-	Aged 55 to 74

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.

Table 8.28: Overall impact of condition on quality of life

Impact of condition on quality of life	Number (n=44)	Percent
1 Life is/was very distressing	6	13.64
2 Life is/was distressing	9	20.45
3 Life is/was a little distressing	9	20.45
4 Life is/was average	4	9.09
5 Life is/was good	10	22.73
6 Life is/was very good	5	11.36
7 Life is/was great	1	2.27

The average score was in the Life was a little distressing range (median = 3.00, IQR = 3.00) (Table 8.29, Figure 8.15).

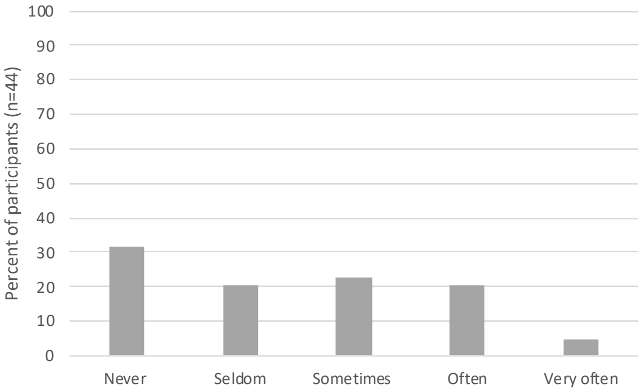

Figure 8.15: Overall impact of condition on quality of life

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 a mean total score of 35.89 (SD = 7.50), which corresponds to moderate levels of anxiety (Table 8.29)

Comparisons of Care co-ordination have been made based on **breast cancer stage** (Table 8.30, Figure 8.16), **physical function** (Table 8.31, Figure 8.17), **year of diagnosis** (Table 8.32, Figure 8.18), **education** (Table 8.33, Figure 8.19), **location** (Table 8.34, Figure 8.20), **socioeconomic status** (Table 8.35, Figure 8.21), and **age** (Table 8.36, Figure 8.22).

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 8.29: Fear of progression summary statistics

Fear of progression (n=50)	Mean	SD	Median	IQR	Possible range	Quintile
Total score*	35.89	7.50	36.00	9.25	12 to 60	3

*Normal distribution use mean and SD as measure of central tendency

Fear of progression by breast cancer stage

Comparisons were made by **breast cancer stage**, there were 23 participants (46.00%) with *Early breast cancer* (Stage I or Stage II) and, 27 participants (54.00%) with *Advanced breast cancer* (Stage II or Stage IV).

Assumptions for normality and variance for a two-sample t-test were not met, a Wilcoxon rank sum test with continuity correction was used (Table 8.30).

No significant differences were observed between participants by **breast cancer stage** for any of the Fear of progression scales.

Table 8.30: Fear of progression total score by breast cancer stage summary statistics and Wilcoxon rank sum tests

Fear of progression	Group	Number (n=44)	Percent	Median	IQR	W	p-value
Total score	Early breast cancer	20	45.45	37.00	12.00	267.50	0.5238
	Advanced breast cancer	24	54.55	36.00	7.25		

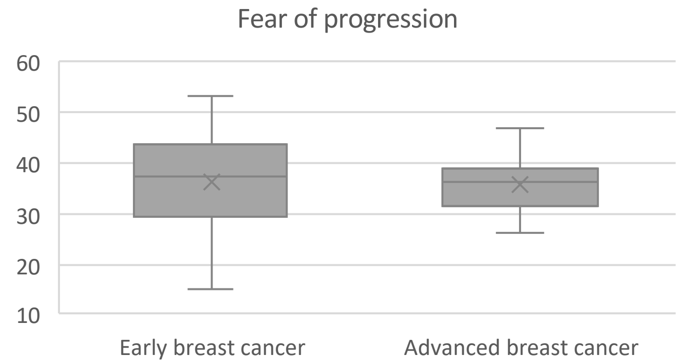

Figure 8.16: Boxplot of Fear of progression total score by breast cancer stage

Fear of progression by physical function

Physical function was evaluated by the SF36 Role functioning/physical, this measures how physical health interferes with work or other activities. Participants that had an SF36 Role functioning/physical score of 40 or less were included in the *Poor physical function* subgroup (n=19, 43.18 %), and participants that scored more than 40 were included in the G*ood physical function* subgroup (n=25, 56.82%).

Assumptions for normality and variance for a two-sample t-test were not met, a Wilcoxon rank sum test with continuity correction was used (Table 8.31).

No significant differences were observed between participants by p**hysical function** for any of the Fear of progression scales.

Table 8.31: Fear of progression total score by physical function summary statistics and Wilcoxon rank sum tests

Fear of progression	Group	Number (n=44)	Percent	Median	IQR	W	p-value
Total score	Poor physical function	19	43.18	38.00	12.00	294.00	0.1838
	Good physical function	25	56.82	36.00	7.00		

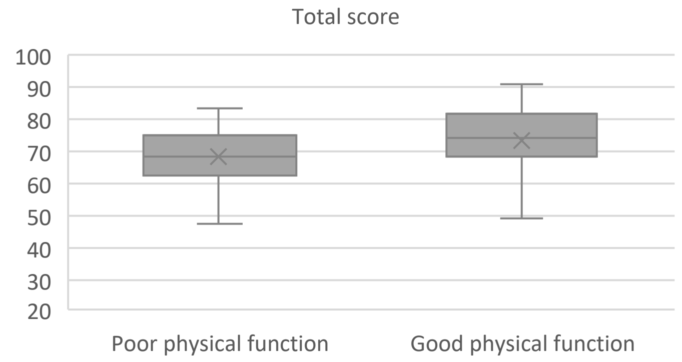

Figure 8.17: Boxplot of Fear of progression total score by physical function

Fear of progression by year of diagnosis

Comparisons were made by the **year of diagnosis**, there were 26 participants that were *Diagnosed before 2020* (52.00%), and 24 participants *Diagnosed in 2020 or 2021* (48.00%).

Assumptions for normality and variance were met, a two-sample t-test was used (Table 8.32).

No significant differences were observed between participants by **year of diagnosis** for any of the Fear of progression scales.

Table 8.32: Fear of progression total score by year of diagnosis summary statistics and T-test

Fear of progression	Group	Number (n=44)	Percent	Mean	SD	T	dF	p-value
Total score	Diagnosed before 2020	22	50.00	35.05	8.50	-0.74	42	0.4635
	Diagnosed in 2020 or 2021	22	50.00	36.73	6.43			

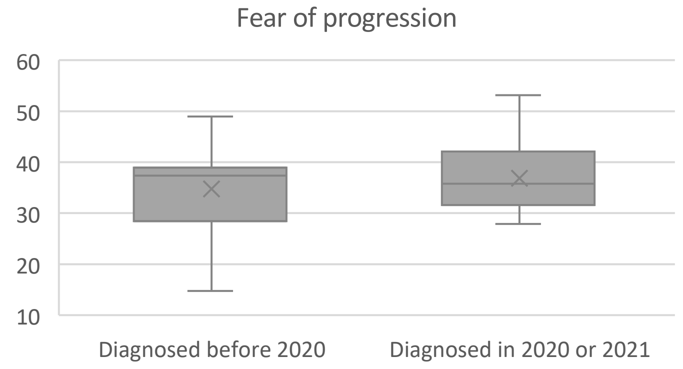

Figure 8.18: Boxplot of Fear of progression total score by year of diagnosis

Fear of progression by education

Comparisons were made by **education** status, between those with *Trade or high school* qualifications, (n = 24, 48.00%), and those with a *University* qualification (n = 26, 52.00%).

Assumptions for normality and variance were met, a two-sample t-test was used (Table 8.33).

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

Table 8.33: Fear of progression total score by education summary statistics and T-test

Fear of progression	Group	Number (n=44)	Percent	Mean	SD	T	dF	p-value
Total score	Trade or high school	21	47.73	36.29	8.36	0.33	42	0.7400
	University	23	52.27	35.52	6.79			

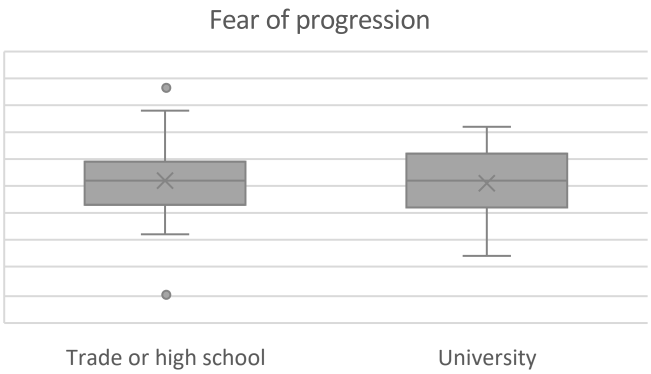

Figure 8.19: Boxplot of Fear of progression total score by education

Fear of progression by location

The **location** of participants was evaluated by postcode using the Australian Statistical Geography Maps (ASGS) Remoteness areas accessed from the Australian Bureau of Statistics. Those living in regional/rural areas, *Regional or remote* (n =16, 32.00%) were compared to those living in a major city, *Metropolitan* (n = 34, 68.00%).

Assumptions for normality and variance were met, a two-sample t-test was used (Table 8.34).

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

Table 8.34: Fear of progression total score by location summary statistics and T-test

Fear of progression	Group	Number (n=44)	Percent	Mean	SD	T	dF	p-value
Total score	Regional or remote	14	31.82	35.64	9.01	-0.15	42	0.8851
	Metropolitan	30	68.18	36.00	6.85			

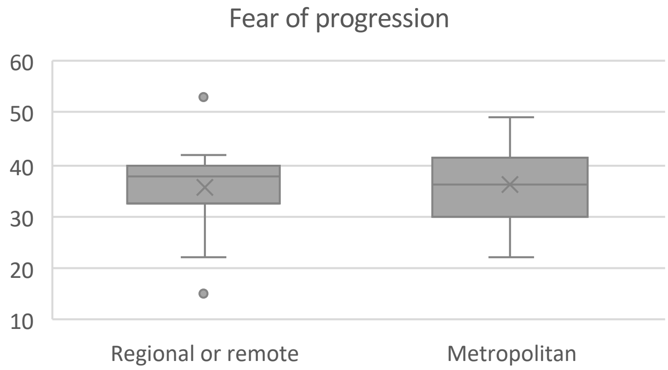

Figure 8.20: Boxplot of Fear of progression total score by location

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 = 20, 40.00%) compared to those with a higher SEIFA score of 7-10, *Higher status* (n = 30, 60.00%).

Assumptions for normality and variance for a two-sample t-test were not met, a Wilcoxon rank sum test with continuity correction was used (Table 8.35).

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

Table 8.35: Fear of progression total score by socioeconomic status summary statistics and Wilcoxon rank sum tests

Fear of progression	Group	Number (n=44)	Percent	Median	IQR	W	p-value
Total score	Mid to low status	17	9.62	37.00	Mid to low status	219.50	0.8186
	Higher status	27	5.98	36.00	Higher status		

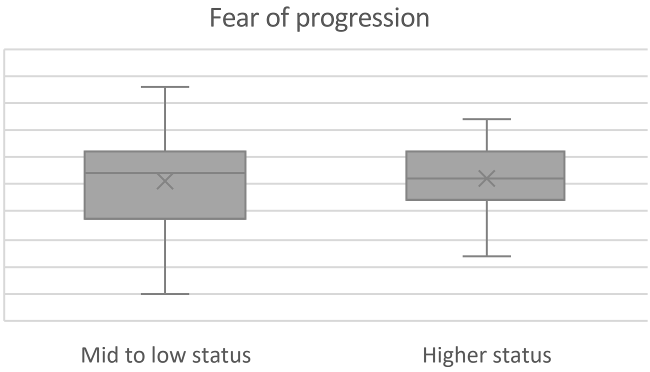

Figure 8.21: Boxplot of Fear of progression total score by socioeconomic status

Fear of progression by age

Participants were grouped according to **age**, with comparisons made between participants *Aged 25 to 44* (n = 19, 38.00%), participants *Aged 45 to 54* (n = 22, 44.00%), and participants *Aged 55 to 74* (n = 9, 18.00%).

A one-way ANOVA test was used when the assumptions for response variable residuals were normally distributed and variances of populations were equal (Table 8.36).

No significant differences were observed between participants by **age** for any of the Fear of progression scales.

Table 8.36: Fear of progression total score by age summary statistics and one-way ANOVA

Fear of progression	Group	Number (n=44)	Percent	Mean	SD	Source of difference	Sum of squares	dF	Mean Square	f	p-value
Total score	Aged 25 to 44	16	36.36	36.88	6.55	Between groups	24.60	2	12.29	0.21	0.8110
	Aged 45 to 54	19	43.18	35.32	8.51	Within groups	2393.90	41	58.39		
	Aged 55 to 74	9	20.45	35.33	7.47	Total	2418.50	43			

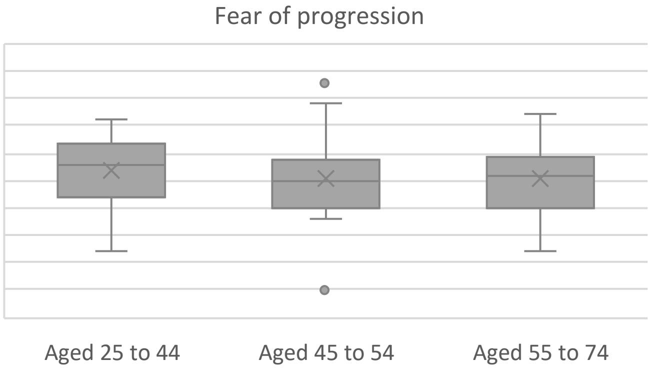

Figure 8.22: Boxplot of Fear of progression total score by age

Anxiety about treatment

Anxiety about treatment with no side effects

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 = 23, 52.27%), there were 10 participants (22.73%) that were sometimes worried about this, and 11 participants (25.00%) were often or very often worried about this (Table 8.37, Figure 8.23).

Concern about what will happen if successful treatment is stopped

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 = 32, 72.77%), there were 7 participants (15.91%) that were sometimes worried about this, and 5 participants (11.36%) were often or very often worried about this (Table 8.38, Figure 8.24).

Table 8.37: Anxiety about treatment with no side effects

If a treatment and it is working well (limited side effects, no progression of disease), worry what will happen if treatment stopped	Number (n=44)	Percent
Never	14	31.82
Seldom	9	20.45
Sometimes	10	22.73
Often	9	20.45
Very often	2	4.55

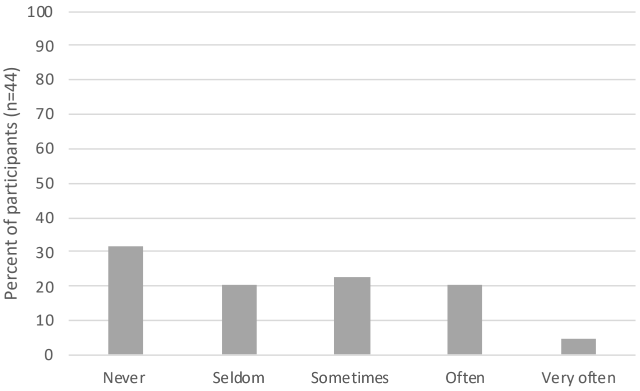

Figure 8.23: Anxiety about treatment with no side effects

Table 8.38: Concern about what will happen if successful treatment is stopped

Anxious if not experiencing any side effects think it doesn't work	Number (n=44)	Percent
Never	21	47.73
Seldom	11	25.00
Sometimes	7	15.91
Often	5	11.36
Very often	0	0.00

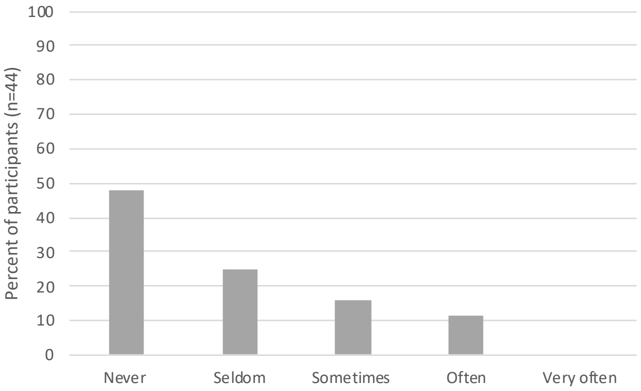

Figure 8.24: Concern about what will happen if successful treatment is stopped

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 themes reported were for future treatments to have fewer or less intense side effects (n= 12, 24.00%), followed by more effective future treatments (n = 11, 22%), and treatments that less cost (n = 11, 22.00%).There were eight participants (16.00%) who described wanting more research and more treatment advances, seven participants (14%) that described wanting more holistic treatments, and seven participants (14%) who described wanting a change in administration of the treatment. There were five participants (10%) that described wanting future treatment to be the same as it is now, and the same number who described wanting preventative measures (n=5, 10.00%).

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. There were eight participants (16%) who described that future information will provide more details about where to find available services and this was the most common theme. There were seven participants (14.00%) who described the expectation that future information will provide more details about treatments, and the same number described the expectation that future information will provide more details about mental health and emotional support (n = 7, 14.00%).

Other expectations included, how to manage personal and intimate problems (n = 6, 12.00%), general information about the condition (n = 6, 12.00%), symptom and side effect control (n = 5, 10.00%), and that information will be mores accessible and easy to find (n = 5, 10.00%). There were seven participants (14.00%) that had no recommendations and were satisfied with the information 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 themes were that participants had no recommendations and they had experienced good communication (n = 13, 26.00%), and that future communication should be more transparent and forthcoming (n = 13, 26.00%). There were 10 participants (20.00%) who described that future communication should be more accurate and detailed, 10 participants (20.00%) who described future communication should include listening to the patient, nine participants (18.00%) who described future communication should be more empathetic, and five participants (10.00%) who described future communication should include a care plan with follow-up.

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. There were 24 participants (48.00%) who described that future care and support should include access to support services and this was the most common theme. Other participants described that future care and support should include access to specialist clinics or services (n= 10, 20.00%), access to mental health and emotional support (n = 7, 14.00%), and access to peer support (n = 6, 12%). There were five participants (10.00%) as they were satisfied with the care and support available.

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 reported were that participants were grateful for timely access to treatment (n = 17, 34.00%), followed by grateful for healthcare staff (n = 16, 32.00%). There were 12 participants (24.00%) that described being grateful for low cost or free medical treatments , 10 participants (20.00%) that described being grateful for the entire health system, and 9 participants (18.00%) that described being grateful for low cost/free medical care.

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. The most important aspects reported were fatigue pain, Heart problems and, memory loss and cognitive function. The least important were fertility, body image and sexual difficulties.

Values in making decisions

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

Values for decision makers

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

Time taking medication to improve quality of life

Participants were asked in the online questionnaire, how many months or years would you consider taking a treatment, provided it gave you a good quality of life, even if it didn’t offer a cure. The majority of participants (n = 28, 63.64%) 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 were asked in the online questionnaire, in what form did they think medicine was most effective in. Participants they were equally effective (n = 15, 34.09%), followed by IV form (n = 16, 36.36%).

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?”. There were 22 participants (44.00%) with the message to improve access to support and care (including treatment) and this was the most common theme. Other participants had the message: to understand the financial implications (n = 16, 32.00%), to have a tailored care plan (n = 11, 22.00%), to invest in research (n = 7, 14.00%), and to invest in specialist health professionals, especially nurses (n = 7, 14.00%). There were five participants who were satisfied and thought that things should stay the same, and the same number who had the message that treatments need to be holistic (n= 5, 10.00%).

Expectations of future treatment

Participants were asked in the structured interview what their expectations of future treatments are. The most common themes reported were for future treatments to have fewer or less intense side effects (n= 12, 24.00%), followed by more effective future treatments (n = 11, 22%), and treatments that less cost (n = 11, 22.00%).There were eight participants (16.00%) who described wanting more research and more treatment advances, seven participants (14%) that described wanting more holistic treatments, and seven participants (14%) who described wanting a change in administration of the treatment. There were five participants (10%) that described wanting future treatment to be the same as it is now, and the same number who described wanting preventative measures (n=5, 10.00%).

Participant describes the expectation that future treatments will have fewer or less intense side effects

I'd love to see people's treatments being individualized because otherwise, you're just battering people with side effects and they could not work. That's probably the biggest one. Treatment at home or something would be great. I found that my oncology team didn't talk much about the side effects and how they might be ongoing. They really, really played them down. I think it's because people experience different things, but also they're just so focused on killing whatever it is.

I don't feel like I was properly prepared for the side effects afterwards. They give you a sheet with them. They go, "You might get tired." When I said, I didn't take much time off work, my oncologist said, "Oh, people who don't take much time off work generally get tired later." She just said it like that not like, "Yes, you'll feel like you've been hit by a truck for like two years." [chuckles] There's not enough even information about side effects. They don't focus that much on side effects. Participant_008

PARTICIPANT: Oh, probably more support for the side effects. I just said it, I totally underestimated it and was too positive in the beginning, I think, and not realistic enough. Then when I got stuck into it and had all the side effects, it was all scrambling around trying to get the support that I needed.
INTERVIEWER: Okay. Your hope's really for future treatment so that side effects are dealt with better.
PARTICIPANT: Definitely. People are more prepared. No one really prepared me for the side effects. I was given a…not until I asked. I had to ask or speak and call my breast care nurse and said, "Oh, by the way, this is happening," and then she told me about it which was great. In the beginning, the oncology team gave me all the handouts for all the different drugs and the information that's about side effects and whatever but there's not many side effects. Does anyone read those straight away? I don't know. I didn't until I knew that there was something not right then I said "I better look at that this." [chuckles] Maybe a little bit more information right at the beginning. It was there but I had to ask for it. Participant_012

Participant describes the expectation that future treatment will be more effective

OK. Oh, gosh. Well, triple negative is the area that has the least advances in treatment outcomes, poor prognosis. So I guess I would like to see, you know, having ongoing research and trials into triple negative, looking at immunotherapy in particular, you know, combining chemo and that kind of stuff. The treatment that is more effective was basically just I mean, ultimately we can have all the supportive care and all the rest that we like. But a research institute for negative people still going to die to me would be, you know, research or curative to at least, you know, significantly extend a lot of things. Participant_002

That's one thing I would really like to see. I would also really like to see that every person who is diagnosed has a genome test at the beginning, to test their actual tumour, to explore whether or not they are going to benefit from the chemo that they're actually given. To be told, "These are the four chemo that you have to do, and these are the only ones that really potentially will work with your tumour." At the beginning, that's just the blanket. It's what everybody with triple negative breast cancer is really told. These are the blanket chemo, but it's not factored in that, "Well, Taxol might not work for this person the way it works for this person." Side effects will be significantly minimized, in my mind, if that testing's done right at the beginning, to actually help, again, complement your treatment plan. How oncologists should be expected to make a decision when they don't have all the information about a person's body, I don't think it's fair on an oncologist to be quite frank, but also for the patient to have to then go through unnecessary side effects when there are tests there that can be done to help. Those are the two things for me. Participant_015

I'd just like to see new treatments that are more successful with less side effects, more targeted, I guess. More targeted treatments, rather than your whole body getting sick. Participant_037

Participant describes the expectation that future treatment will have less cost burden

Obviously because I was triple-negative, I'd like to see a proper targeted treatment for triple-negative, so that it's not just a case of, "Well, let's just throw everything at it and hope for the best." Definitely, for me, that's a really big thing is finding the reason for triple-negative and why triple-negative happens when it's not a genetic mutation, and having a proper targeted treatment for it. Obviously, having access to the current drugs that we have, that may not necessarily have been created for breast cancer, but now they're finding work on particularly triple-negative, having them added to the PBS and not paying a ridiculous amount out of pocket, and making it within people's financial reach would be really important. Participant_025

I personally think that you shouldn't have to pay for anything. I don't know why some stuff is charged for, and some stuff isn't. I wish the government just funded it. That was something that we found really difficult. We just didn't know if we went if we were going to get a bill for something or not. I wish chemo didn't make them sick, but I don't really think there's anything anybody can tell about that. Participant_043

Cost is a big one. There was a clinical trial that I could've had the immunotherapy for free, but the doctor said it was too risky to wait. It boggles my mind to think about the poor people that couldn't afford to have it and therefore the positive effects that I won't be having for them just because they weren't in a good financial position or have somebody either that could fund it for them or to gather the funding to cover it. I know it can't be offered everywhere, but I've got a friend, she has to travel well over an hour to get treatment for a different kind of cancer from where she lives. Participant_048

Participant describes the expectation that future treatment will informed by more research/advances in treatments

I think my biggest push would be for research into stage four breast cancer. At this point, we don't have anything to cure stage for breast cancer, just life prolonging. And so being that if my cancer was to come back, it would be a different recurrence, it would be stage four. And at some point I would die for me. I see big and I've also lost a lot of friends in the breast cancer community since being diagnosed myself. For me personally, I would like to see the biggest push for stage for research. Participant_010

Chemo's such a horrific thing to do to your body, so if there were treatments that you could avoid that, that would be amazing. Obviously, researchers are working on that all the time. I don't know. I like the way that chemo was done for me because just being in a room where other people are, where you see familiar faces and all that kind of thing. I think that really was helpful for me, just being in the room where everybody is dealing with something similar. Participant_011

For regional Australia. I would like to see more possibilities, yes. More different treatments if more choices given even for trial things and stuff. Participant_031

Participant describes the expectation that there will be more holistic approach to treatment in the future

I would really like to see oncology work alongside naturopaths so that you can get a combination of what are some good vitamins, minerals, all of those. What are some good things that we can be adding to our body to help prop us up when we're actually then having chemo, I say, destroy your body? That's what it does. An oncologist isn't necessarily going to know the things that a naturopath does, and they both could complement one another. I don't know if that answers. Does that? Participant_015

Look, I thought the chemo nurses were amazing the way they walk you through everything. I can't say anything wrong about any of that. I think what I feel is that people tell you you have to do things to get through it, like exercise, eat healthy, all those sort of things, but they tell you and they don't give you a guide or a plan, or somewhere to go to achieve that. I think you battle through all the chemo and the surgery knowing that you've go to get through that to get rid of the cancer. You just accept that, but it's hard to accept the consequences of everything without a plan. I'm just somebody that likes to plan anyway, so the weight gain and that sort of stuff…Nobody tells you, "Look, expect to gain weight between 5 and 7 kilos." Nobody tells you that, but they all know that you will. Nobody tells you, "At the end of it, this is how we're going to get rid of that 5 or 7 kilos so that you can get

back to being a healthy weight so the cancer won't return." We've got rid of the cancer once and everybody is telling you you've got to be a healthy body weight so that the cancer won't return, but they don't give you the tools to achieve that success.
INTERVIEWER: Okay, so a bit more structure around what to expect and how to approach it, and what you need to do.
PARTICIPANT: Yes. I actually went and saw…and I forgot about this, but now that I'm thinking about it. I went and saw a nutritionist when I was going because I was so concerned about the weight gain. She helps cancer patients with their diets. She gave me some really good tips on-- and this did help because she said, "Do this to try and help with the steroids," and it did. It slowed it down. I went from 1 kilo to 100 grams and stuff like that by eating what she recommended. I think you need a nutritionist at the hospital that sits cancer patients down and tells them-- because everything else is just, "Don't eat this," or, "Don't eat that," but nobody gives you a structure on what to eat or not what. Nobody tells you. Participant_029

It's probably not so much what they are having because there's so many different ways of doing things with breast cancer. I was treated before surgery whereas there's a lot more that probably get surgery and then treatment. In terms of the drugs, my knowledge of them is only what I've been told and then given on paper. I can't see there being a way around what the side effects are or what it's doing to your body. I'd like to see the ability to have more natural therapies in conjunction with the hard toxic drugs….It's really hard to access that. I know that there's naturopaths that have an oncology science behind it that compliments the chemotherapy. Whereas where we are, the oncologists, they're not against the natural therapy side of things. The pharmacists that give you the drugs are. The oncologist, I said to him that I take natural supplements and everything like that. He said, "Look, I want you not to take any while we're doing chemotherapy because it's just counterproductive. Once you've finished your chemo, absolutely get on it, prep for surgery, do all that sort of stuff." There is a bit of an okay about it, but I just wish there was a holistic way of doing it. I didn't have that choice if that makes sense. This probably takes you back to what answer do you want to those questions. There was no choice in the treatment side of things because within getting diagnosed within two weeks I was on chemotherapy. To then try and find someone to do oncology and natural therapies in conjunction, which I know they are out there, I wouldn't have time. Participant_030

Participant describes the expectation that there will be changes in the way treatments are given

New treatments. Personally, for me, I struggle with things being injected into me. I think, if I could do something orally, I guess that would be preferred. I realize it's not as an efficient means of getting it into you, but I did struggle with having stuff injected. I don't know, everything did just seem very incredible that we're still doing this stuff. Even though we're such an advanced society, it all just does seem very barbaric to be injecting all these liquids and it's all just disgusting. Something, it's more oral and that still just lets you get on with your day, but at the end of the day, we can only…I don't know where modern medicine is. I don't really follow the changes and things, but I know that there's good things coming. I don't know where they're at with things, I don't really think about that sort of stuff. I can't really answer it very well. Participant_005

And I'd like to see my side effects, obviously, from chemo, but I think it would be nice to have it has the chemo administered at home. But you've still got to see the doctor anyway, say, you know, and I think that a lot of the time you could be that video game or something like that, you could be with the doctor. So I think that that would be helpful so that you don't have to leave the house and especially in the uncertainty when you're immunocompromised. It's really scary to go into a hospital because you don't know, you know, who everybody is or where they've been. Participant_038

Oh, gosh, if there could be a treatment that has no side effects, that would be a miracle. Obviously, if you weren't having cell, you're having IV That would be great because I have come out of treatment at times looking like the walking wounded where they've tried three or four times to hit a vein. Yes, avoiding that would be great. It's really anything that can lessen side effects, and then is more easily administered would be wonderful. Participant_027

I think it would be good if we were given the option to be tested prior to starting a treatment. I didn't know about that test until after I finished my treatment. It would've been good to have that initially. I would have paid for it had I known, but I didn't even know about it. Participant_045

Participant describes the expectation that future treatment will be the same as it is now

But, you know, like the radiation, it's amazing. Like they put music on and stuff for you. So it's really calming and they're pretty amazing. I don't know if I could improve it much more. The hospital was amazing, like when, when I had my surgery. So I don't know if there's a lot that you could improve Participant_006

Right. As I say, I was delighted with the public hospital system. The treatment-- well, I'm still here, so it has obviously worked and they knew what they were doing. I had no issues with costs. They were absolutely marvelous. They used to ring me, just to check on me and everything that the private system didn't do, you were just a number to them. Participant_032

No, you know what? I think I feel that everything was done for a reason, so I don't feel like-- I can't sit there and go that, that needs to change off the top of my head. I'm trying to think, and I can't think of anything like that. I was one of the unfortunate ones with the COVID that I had to do all my chemo on my own. I got to the hospital and the nurses were lovely, but they're also run of their feet a little bit. You would have to sit there by yourself and either read or watch TV. I found that probably at first, a little bit hard because you normally have people with you while you're going through chemo, but I didn't find it as hard as some. I saw a couple of old ladies that were really struggling with that, but that was not their fault, that was not the hospital's fault. That was because it was COVID. I felt like I got quite good care. Participant_035

Participant describes the expectation that future treatment includes preventative measures

That I would really like is to see the preventative measure for gene mutations. So I would like to see something that my daughters could take that will protect them if they have the mutation as well. So that would be the number one thing that I would want for from future treatments is something that will protect my daughters. Participant_001

Well, I've heard a little bit about some things going on in relation to immunotherapy and stuff like that. I guess I hope that No. One, there are less invasive treatments that essentially put poison in your body like chemo. That would be good if also immunotherapies or whatever. The therapy is a cold where apparently the cancer grows because obviously your immune system doesn't realise it's a bad thing that cells. So whatever. I think that's what immunotherapy is. If I understand the basics, just yeah, it is ways of then having that help to also prevent any reduce significantly any likelihood of recurrence to the people. That would be lovely. And I guess I hope that the treatments would get to the point that it is something that hopefully most people don't end up having to lose their life over in the long run. But certainly that's the big, big wish. . And you know, particularly because I think metastasis tastes tend to tends to be the the problem over a long time, a longer term, and hopefully that can somehow be managed, treated. I don't know, pie in the sky hoping now that. Yes, that's kind of the you you sort of ask me a question that led me down there, but yeah. Like ones that seem to be. Yeah, I think, I think I heard you immunotherapy was one that was being looked at, but I don't think it's as widespread for cancer at the moment. Participant_023

Table 9.1: Expectations of future treatment

Expectations of future treatment	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=23	%	n=27	%	n=19	%	n=25	%	n=26	%	n=24	%	n=24	%	n=26	%
Participant describes the expectation that future treatments will have fewer or less intense side effects	12	24.00	5	21.74	7	25.93	5	26.32	4	16.00	8	30.77	4	16.67	6	25.00	6	23.08
Participant describes the expectation that future treatment will be more effective	11	22.00	7	30.43	4	14.81	4	21.05	4	16.00	7	26.92	4	16.67	**1**	**4.17**	**10**	**38.46**
Participant describes the expectation that future treatment will have less cost burden	11	22.00	**1**	**4.35**	**10**	**37.04**	6	31.58	5	20.00	7	26.92	4	16.67	3	12.50	8	30.77
Participant describes the expectation that future treatment will informed by more research/advances in treatments	8	16.00	4	17.39	4	14.81	2	10.53	6	24.00	5	19.23	3	12.50	2	8.33	6	23.08
Participant describes the expectation that there will be more holistic approach to treatment in the future	7	14.00	5	21.74	2	7.41	2	10.53	5	20.00	2	7.69	5	20.83	4	16.67	3	11.54
Participant describes the expectation that there will be changes in the way treatments are given	7	14.00	3	13.04	4	14.81	2	10.53	4	16.00	3	11.54	4	16.67	5	20.83	2	7.69
Participant describes the expectation that future treatment will be the same as it is now	5	10.00	3	13.04	2	7.41	2	10.53	3	12.00	3	11.54	2	8.33	**5**	**20.83**	0	0.00
Participant describes the expectation that future treatment include preventative measures	5	10.00	3	13.04	2	7.41	0	0.00	4	16.00	3	11.54	2	8.33	0	0.00	5	19.23

Expectations of future treatment	All participants		Regional or remote		Metropolitan		Mid to low status		Higher status		Aged 25 to 44		Aged 45 to 54		Aged 55 to 74	
	n=50	%	n=16	%	n=34	%	n=20	%	n=30	%	n=19	%	n=22	%	n=9	%
Participant describes the expectation that future treatments will have fewer or less intense side effects	12	24.00	4	25.00	8	23.53	7	35.00	5	16.67	4	21.05	6	27.27	2	22.22
Participant describes the expectation that future treatment will be more effective	11	22.00	3	18.75	8	23.53	3	15.00	8	26.67	5	26.32	5	22.73	1	11.11
Participant describes the expectation that future treatment will have less cost burden	11	22.00	4	25.00	7	20.59	2	10.00	9	30.00	5	26.32	4	18.18	2	22.22
Participant describes the expectation that future treatment will informed by more research/advances in treatments	8	16.00	3	18.75	5	14.71	3	15.00	5	16.67	2	10.53	5	22.73	1	11.11
Participant describes the expectation that there will be more holistic approach to treatment in the future	7	14.00	2	12.50	5	14.71	1	5.00	6	20.00	2	10.53	3	13.64	2	22.22
Participant describes the expectation that there will be changes in the way treatments are given	7	14.00	1	6.25	6	17.65	4	20.00	3	10.00	4	21.05	2	9.09	1	11.11
Participant describes the expectation that future treatment will be the same as it is now	5	10.00	1	6.25	4	11.76	2	10.00	3	10.00	0	0.00	2	9.09	3	33.33
Participant describes the expectation that future treatment include preventative measures	5	10.00	0	0.00	5	14.71	1	5.00	4	13.33	1	5.26	4	18.18	0	0.00

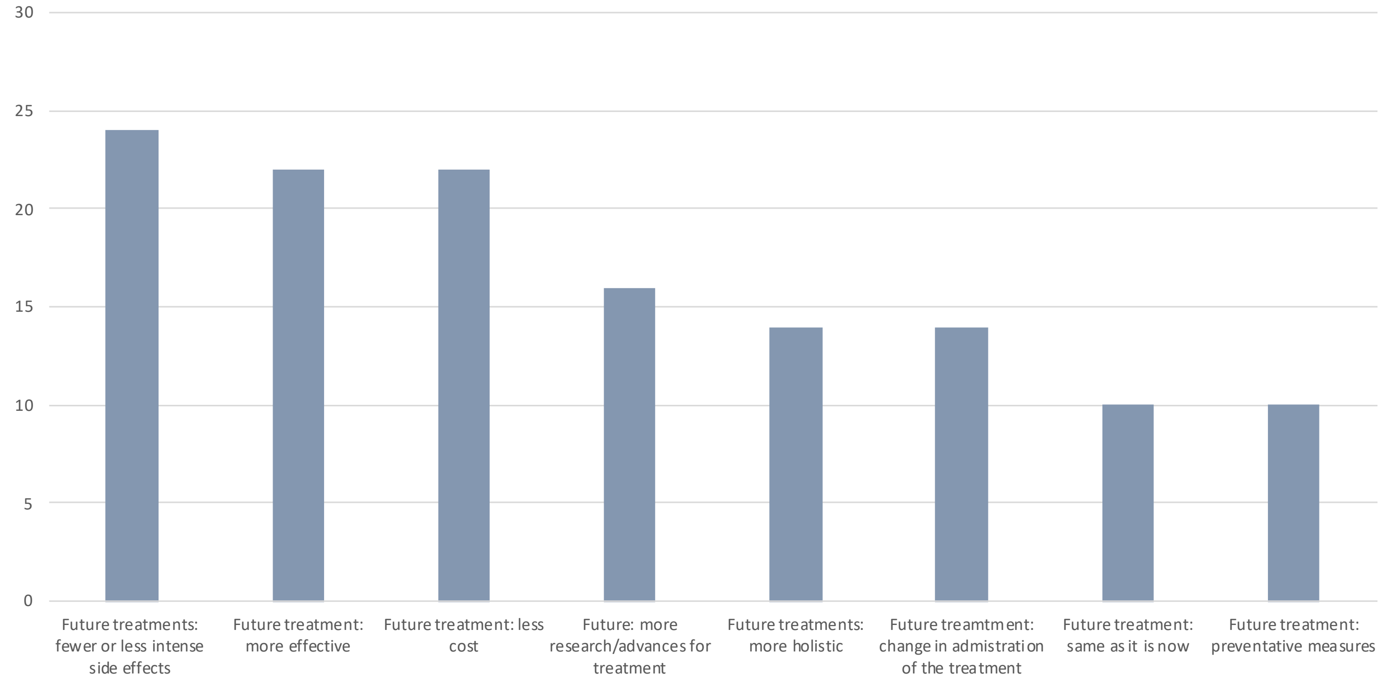

Figure 9.1: Expectations of future treatment

Table 9.2: Expectations of future treatment – subgroup variations

Theme	Reported less frequently	Reported more frequently
Participant describes the expectation that future treatments will have fewer or less intense side effects	-	Mid to low status
Participant describes the expectation that future treatment will be more effective	Trade or high school Aged 55 to 74	University
Participant describes the expectation that future treatment will have less cost burden	Early breast cancer Mid to low status	Advanced breast cancer
Participant describes the expectation that future treatment will be the same as it is now	-	Trade or high school Aged 55 to 74

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. There were eight participants (16%) who described that future information will provide more details about where to find available services and this was the most common theme. There were seven participants (14.00%) who described the expectation that future information will provide more details about treatments, and the same number described the expectation that future information will provide more details about mental health and emotional support (n = 7, 14.00%).

Other expectations included, how to manage personal and intimate problems (n = 6, 12.00%), general information about the condition (n = 6, 12.00%), symptom and side effect control (n = 5, 10.00%), and that information will be mores accessible and easy to find (n = 5, 10.00%). There were seven participants (14.00%) that had no recommendations and were satisfied with the information available.

Participant describes the expectation that future information will provide more details about where to find available services

I think what would have been good was like when you have a baby and then they say, oh, her are mother's in your area, would you like to start a mothers group? And you have that sort of peer support where you can meet people in your area and you can just help each other and so you don't feel alone. So maybe having that option that you could opt into that if you want to just said, do you want to talk to people in your area or somehow just link you up, even if it was just to send each other a text, just know that there be other people around you also going through the tough time rather than feeling you're the only person I know. So I guess I was relatively younger because I was 42. So, yes, to link up with sort of your demographic of people would be good. Participant_001

Yes. Even if it was, I don't know, a little pack that you've got towards, I don't know, at some stage in your treatment going, "Hey, these are some of the services that are going to be available to you" whether it's through the health system, whether it's through local community groups." A little information pack, I guess, would be good. Participant_020

I don't know whether it was because I walked into my first appointment with my specialists and I walked into my first appointment with my medical oncologist, and I talked to them about my infertility that we'd been through that it was just assumed, but I felt like at no point did anyone kind of talk to me too much about the infertility side of what chemotherapy can do things to fertility. It was never really talked to me about fertility preservation options because I think it was just assumed I already had a specialist, so I had all of that under control, and I could deal with that myself. I was 37 at the time, and so I think there was that-- I felt like I was too old to be the young patient but too young to be the old patient. I said, given this, I didn't fit in the mode, I suppose, of certain people. I definitely think more inflammation around fertility and the side effects of that would be really good. I also think more information, it was really helpful to see people who've been out of cancer and who were 15 years, 20 years down the track from having their cancer diagnosis. Having information provided to you in the first appointment about…Do you know what? This is really hard One of my biggest pet peeves is that everyone talks about how amazing the National Breast Cancer Foundation is and how amazing the Breast Cancer Network Australia is. I still have actually no idea what they do to help with cancer patients. Having a bit more information about the services that they offer and what they can do for you, I think would be really useful. If you go into their website, I can find 10 different ways of how I can donate money to them but I can't find what they…They say they support breast cancer patients, but what do they actually do to support breast cancer patients. I think it's really important too to have a local area, information pack. You're having a…You live in LOCATION because there's all of these amazing charities that exist, that you don't know about until someone tells you about them. There's a thing called the OTIS foundation that provides holiday accommodation to breast cancer patients. I think there's a company called Pink Things which is in the LOCATION, there's all of these things. I found and felt that if I had children, there would be way more support information given to me in the first instance. Because I didn't have children, and I had a husband who worked from home, I didn't really get a lot of information about support resources that were available, which is probably why I didn't access any of them because I didn't know they existed. The other thing that would have been really useful to me was actually knowing about…like getting some information on where to go to get a wig, or where to go to get nice scarves. Again, there's all these amazing organizations like Bravery, sews the scarves and real French headbands for some hair things, and all of these things that exist for cancer patients that you really almost need to be in the cancer world and have a secret connection to someone who goes, "Oh, by the way, this exists." When you're first diagnosed with that you don't know about that. Six months down the track, I now know where to go to find a wig, I now know where to go to do this and it's really hard to get those level of-- not the everyday 17 support but then where do I go for a headband? Or where do I go for a headscarf? That level of information would be really good. As I said, I think if it was like a local by region by region thing that was even just a website that had links to all these companies, it would be really good. Interviewer: Yes, that would be fantastic. A lot of these little charities who don't have a big platform people don't know about it and I think a lot of people find out about these little charities through Facebook pages or by word of mouth or things like that. I think if there was some online service to know what you can access in your area…I know it's a huge, big thing to do, and there's probably no money for it and that's probably what prevented a lot of people from doing it because they cost money but it's like, for instance, the cancer council's website, and they have that on their website or just something that you can be told, "This is what you do. This is who you go to," it would be great. Participant_025

Participant describes the expectation that future information will provide more details about treatments

I think information on rehab after a lumpectomy, or a mastectomy, or the lymph nodes removed could be improved. Participant_007

Oh, maybe with choices with treatment. I really wasn't offered any different options and there was no discussion given when they put me on a treatment plan. It was just this is what we're doing. The only other option is not to do it and then that's your choice. There wasn't really that much and I've sort of learned since then that there are other options and there are other paths I could have gone down potentially. Maybe that. I think that's pretty big. Participant_012

It's funny because each time, if you rang me last week there'd probably be other things I've noticed. This week, I've been trying to find information on the optimum time to have surgery after chemo because I'm now at the stage of worrying about tumors returning or growing, or cancer cells growing while I'm waiting for surgery and what's the recommended time, and what's the optimal time. I haven't been able to find that information. I had conflicting information from my oncologist and the surgeon, that didn't help. The oncologist said two to three weeks, the surgeon's saying eight weeks is fine. I'm sitting in the middle thinking, "Well, I don't like this. I want to know." That's what I want this week, but last week it would have been another thing, a different question. I've not been able to find an answer that says, "This is gold standard recommended treatment protocol." I haven't been able to find that. I just have to hope for the best and I don't like that. I like information. Participant_033

Participant describes the expectation that future information will provide more details about mental health and emotional support

Probably, what I've just said. More to do with what else I could do to help myself-- to support me through the treatment alternative therapy-wise or allied health-wise Participant_004.

That's a difficult one because like you say, initially, when you're given the diagnosis, there's so much information that's available, but you just don't take it in initially. It is quite difficult, but I think probably the absolute minimum that I think is having that information about what your treatment is going to entail. Whether it's, for example, "You have to have chemotherapy," or, "You need to have chemotherapy, what those drugs are, what they do, what the possible side effects are." What I found the most lacking out of all the information I was given was about the long-term effects of the treatment. The thoughts of things that are impacting on my health now, I wasn't aware of until I actually am experiencing it. That information would have been useful to prepare yourself for it. The other thing, I think, is the psychological support. I know, some of the other women in my group who didn't have treatment in the private system. They were actually set up with consults with a clinical psychologist, and they found that very helpful. I think all patients that have that diagnosis should have that option. Some people might need it and might not need an ongoing. I certainly don't think I suffered as a result of that, but I think I believe I would have liked to have maybe had that option. Now, I might have only had one consult and might have been given a lot of useful information. I know that there's other women in my group that still have ongoing psychological issues, and they've either had access to that resource, or they've had to seek it out themselves. I know that I did go to a BCNA conference, and one of the presenters there a clinicals cycle psychologists who was excellent has, I think, now been taken on as an ongoing resource for BCNA for conferences. She was very useful, some of her tips were fantastic, very down to earth person and guide very useful information. I think that resource should be mandatory. Participant_013

If I ruled the world and I could have it how I wanted, I guess maybe to have someone like a counselor that you would speak to before you start your treatment just to see where your head's at and make sure the information you're hearing is accurate information. I guess, to have that reassurance at the start that you're on the right plan or whatever. Maybe something like that when you walk in and you know nothing, you have someone to talk you through the process in a non-clinical way. Participant_027

Participant has no recommendations/is satisfied with the information currently available

No, I think it was really good. And I guess once again, being a nurse, I had a greater understanding of the different resources that I could access. And I think we're all different in how much information we want to receive and where we want to receive it from. So I think it's more just continuing to have that broad range of whether it's online videos or pamphlets or, you know, telehealth, those kinds of things. I think *we're all different and we want those different levels and levels of information. So I think that's done well at this point. Participant_010*

No. I've always like I said the oncologist and the hospital staff and the breast care nurse has always printed out information to give to me and pointing me in the right direction. I mean the information I received is what [unintelligible] myself so I can-- I would say it's great information. Participant_018

I remember the first thing is giving me information and stuff, so I think it was pretty much readily available and in an easier to read format. Participant_037

Participant describes the expectation that future information will provide more details about how to manage personal and intimate problems

PARTICIPANT: Probably more about holding of-- What do you call it? I guess, yes, relationships, I guess could be one, but more information on that. Well, guess what, sex life went out the window, so more information on that…Yes. The CAT scans obviously provides a little bit of information about that, but there'll probably be more like who you can go to, who you can be referred to to help with that thing. Same with a bit of- I mean, it might be available now- but counseling and that sort of thing for your own general health and well-being. Participant_024

Yes, I think, again, through the networks themselves. One of the hospitals in LOCATION, this is quite a good one, they actually had sexual health information as well, but that wasn't available at the hospital I was at. I think, especially for young couples, information around healthy sexual relationship during and after chemo and things, that would be one thing. Just in general, having better access, having kind oncology nurses, not being treated just as a number, that would be another thing. More on diet would be great. I don't think there's enough information on what you should eat. and stuff on diet. Participant_016

Well, I feel like menopause wasn't really covered…Sexual changes to your body from menopause. My friends weren't even talking about it because they were all too young. It was thanks to that cancer group that I got told a little bit about it. I had to manage that kind of stuff. I still have had to go to about five different doctors to talk about it. The information on how to get treatment and stuff like that, it's so mixed. I don't find that it's very standardized. That's probably the biggest one. Then side effects, how to deal with that. There's no holistic kind of putting you back together treatment plan afterwards. Participant_008

Participant describes the expectation that future information will provide more general information about the condition

I had to look up a lot of the terminology in terms of what the diagnosis meant. The Cancer Council booklets and all those sorts of things don't really go into the details of what the different diagnoses mean. I guess they probably do that intentionally because I know a lot of doctors prefer to sit with you and go through it rather than you read it yourself. For a person like me, that's the stuff-- I had to Google it and then try and understand it from medical texts which are not always that easy to read. Whereas just having a simple layman's term glossary of what some of that stuff means would be-- I think for someone like me it would be really good just to be able to understand what the difference-- because there's still some things that were on my pathology reports that I've never really been able to find what exactly they mean. Just having more information about that. A lot of the other information was pretty easily available in the booklets and things that were there. When I saw the oncologist before each of the two different types of chemo, they would give me a whole booklet of, "This is what you're about to have. This is all the possible side effects," and all that stuff. They gave us quite a lot of info about everything in that sense as well. Participant_011

I think like I said at the beginning there, I really think that there needs to be-- Your initial point of contact should be with someone that talks to you about your diagnosis, like talk to you about, "Okay, well, you've got breast cancer. This is what breast cancer is. This is what you can expect there or the different types." Then have somebody who actually goes through, "And this is your story. You have triple-negative, or you have estrogen positive. The different types to be able to process it because like I said, I didn't process any of it. I felt like I just had my oncologist talk at me, and I didn't take anything in. I just went with, "Right. Well, okay. You're telling me what I need to do, let's do it." That, I think, needs to happen. Participant_015

Yes. When I was first diagnosed, there probably wasn't a lot on triple-negative and outside of being told don't Google I wasn't given much insight, so I did Google, so I could find my own insight. I think that there needs to be more printed information given to a *patient so that they know exactly what they're dealing with and exactly what it is. Participant_034*

Participant describes the expectation that future information will provide more details about symptom and side effect control

I think the I would like more information on what happens after the chemotherapy as far as side effects and what people are left with afterwards. And I'd like to see more follow up from the teams around that to make sure that you are doing OK. Sorry. Have I answer the question that I. Yeah. Participant_038

Menopause 100%. Never pain, nerve damage, chemo side effects afterwards Participant_036

My oncologist just gave me a piece of paper with all the symptoms that I would experience. That could have been a bit prettier, if what I mean, like a little bit less or sear, but he was giving me the most up-to-date information. Participant_040

Participant describes the expectation that future information will be more accessible/easy to find

I think COVID made it extremely difficult for a lot of this because the face-to-faces just aren't there. The information that is given to you is either a booklet or a piece of paper. I'd like to be able to see more in-person stuff. Time is so important to this, whereas when you're in an appointment and there's 500 people waiting to see the same specialist that day, it's all time-poor. That's probably more time, I suppose. Participant_030

It's very hard to get things online I find and that's not blaming anyone else. Maybe I'm just incompetent when it comes to computers.
INTERVIEWER: You found it difficult looking for things online?
PARTICIPANT: I did.
INTERVIEWER: Okay.
PARTICIPANT: Yes. My husband's a computer whiz so he does everything for me. Participant_032

I do think that those drug information sheets should be rewritten. Realistically they're for the doctors, not the patients, but if they are going to be using them for the patients then they need to be different, or they need to develop something else that is more for the patients. Participant_048

Table 9.3: Expectations of future information

Expectations of future information	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=23	%	n=27	%	n=19	%	n=25	%	n=26	%	n=24	%	n=24	%	n=26	%
Participant describes the expectation that future information will provide more details about where to find available services	8	16.00	5	21.74	3	11.11	4	21.05	3	12.00	3	11.54	5	20.83	3	12.50	5	19.23
Participant describes the expectation that future information will provide more details about treatments	7	14.00	**6**	**26.09**	**1**	**3.70**	**6**	**31.58**	**0**	**0.00**	3	11.54	4	16.67	2	8.33	5	19.23
Participant describes the expectation that future information will provide more details about mental health and emotional support	7	14.00	3	13.04	4	14.81	1	5.26	5	20.00	5	19.23	2	8.33	4	16.67	3	11.54
Participant has no recommendations/is satisfied with the information currently available	7	14.00	3	13.04	4	14.81	1	5.26	5	20.00	3	11.54	4	16.67	4	16.67	3	11.54
Participant describes the expectation that future information will provide more details about how to manage personal and intimate problems	6	12.00	4	17.39	2	7.41	2	10.53	2	8.00	4	15.38	2	8.33	2	8.33	4	15.38
Participant describes the expectation that future information will provide more general information about the condition	6	12.00	2	8.70	4	14.81	2	10.53	3	12.00	1	3.85	5	20.83	1	4.17	5	19.23
Participant describes the expectation that future information will provide more details about symptom and side effect control	5	10.00	2	8.70	3	11.11	2	10.53	2	8.00	3	11.54	2	8.33	2	8.33	3	11.54
Participant describes the expectation that future information will be more accessible/easy to find	5	10.00	0	0.00	5	18.52	**4**	**21.05**	1	4.00	3	11.54	2	8.33	4	16.67	1	3.85

Expectations of future information	**All participants**		**Regional or remote**		**Metropolitan**		**Mid to low status**		**Higher status**		**Aged 25 to 44**		**Aged 45 to 54**		**Aged 55 to 74**	
	n=50	**%**	**n=16**	**%**	**n=34**	**%**	**n=20**	**%**	**n=30**	**%**	**n=19**	**%**	**n=22**	**%**	**n=9**	**%**
Participant describes the expectation that future information will provide more details about where to find available services	8	16.00	3	18.75	5	14.71	1	5.00	7	23.33	3	15.79	4	18.18	1	11.11
Participant describes the expectation that future information will provide more details about treatments	7	14.00	5	31.25	2	5.88	4	20.00	3	10.00	3	15.79	3	13.64	1	11.11
Participant describes the expectation that future information will provide more details about mental health and emotional support	7	14.00	3	18.75	4	11.76	4	20.00	3	10.00	2	10.53	2	9.09	3	33.33
Participant has no recommendations/is satisfied with the information currently available	7	14.00	1	6.25	6	17.65	3	15.00	4	13.33	2	10.53	3	13.64	2	22.22
Participant describes the expectation that future information will provide more details about how to manage personal and intimate problems	6	12.00	2	12.50	4	11.76	2	10.00	4	13.33	5	26.32	1	4.55	0	0.00
Participant describes the expectation that future information will provide more general information about the condition	6	12.00	2	12.50	4	11.76	2	10.00	4	13.33	1	5.26	5	22.73	0	0.00
Participant describes the expectation that future information will provide more details about symptom and side effect control	5	10.00	1	6.25	4	11.76	1	5.00	4	13.33	3	15.79	1	4.55	1	11.11
Participant describes the expectation that future information will be more accessible/easy to find	5	10.00	2	12.50	3	8.82	2	10.00	3	10.00	2	10.53	1	4.55	2	22.22

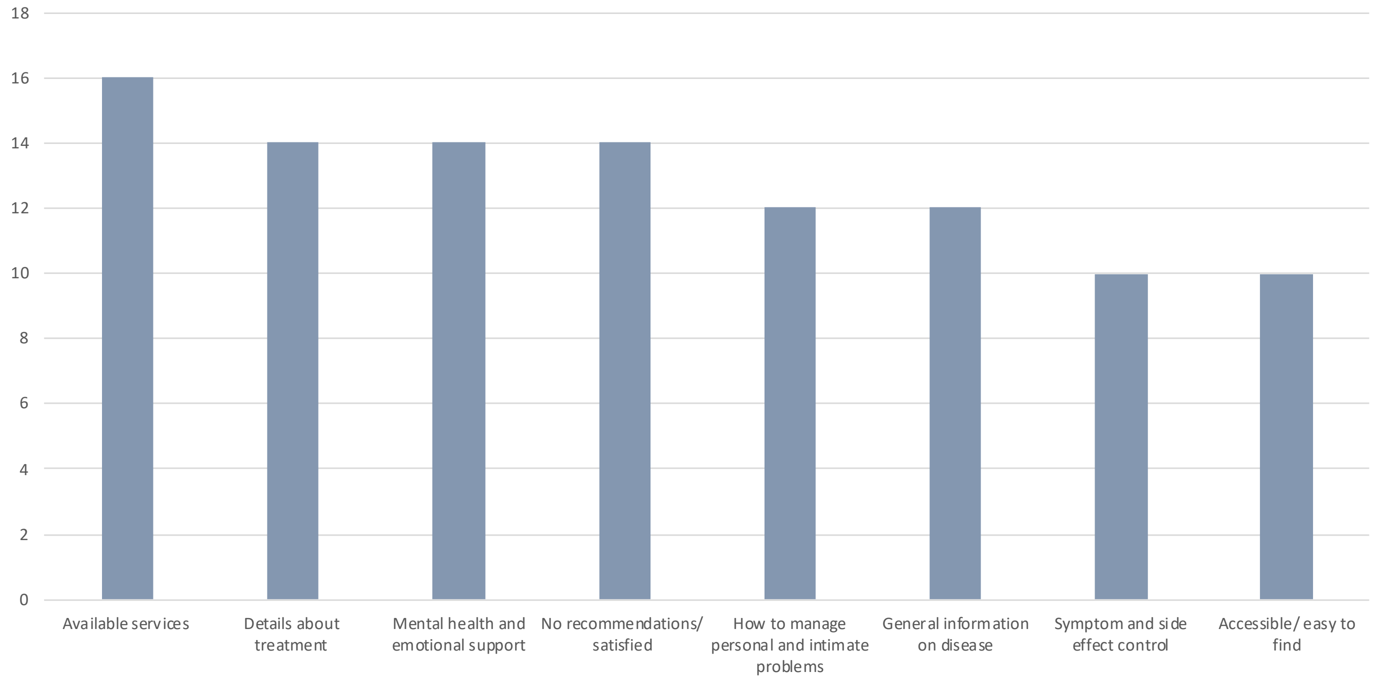

Figure 9.2: Expectations of future information

Table 9.4: Expectations of future information – subgroup variations

Theme	**Reported less frequently**	**Reported more frequently**
Participant describes the expectation that future information will provide more details about where to find available services	Mid to low status	-
Participant describes the expectation that future information will provide more details about treatments	Advanced breast cancer Good physical function	Early breast cancer Poor physical function Regional or remote
Participant describes the expectation that future information will provide more details about mental health and emotional support	-	Aged 55 to 74
Participant describes the expectation that future information will provide more details about how to manage personal and intimate problems	Aged 55 to 74	Aged 25 to 44
Participant describes the expectation that future information will provide more general information about the condition	Aged 55 to 74	Aged 45 to 54
Participant describes the expectation that future information will be more accessible/easy to find	-	Poor physical function Aged 55 to 74

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 themes were that participants had no recommendations and they had experienced good communication (n = 13, 26.00%), and that future communication should be more transparent and forthcoming (n = 13, 26.00%). There were 10 participants (20.00%) who described that future communication should be more accurate and detailed, 10 participants (20.00%) who described future communication should include listening to the patient, nine participants (18.00%) who described future communication should be more empathetic, and five participants (10.00%) who described future communication should include a care plan with follow-up.

Participant has no recommendations/experienced good communication

Honestly, I can't complain. It'd be nice if you turned up for a 1:30 PM appointment and you didn't go in at two o'clock, but I'm not going to hold that against anyone. If that's my only complaint, that's not a complaint. That's thinking up something there. I can't fault these cancer nurses. There is no one that's terrible. Participant_007

No. In my case it's been quite good. If I've needed anything extra, I've been able to go to my oncologist and he contacts me straight away, more or less straight away, so not really. It's been good, great. Participant_017

No. I had a very good medical professional who looked after me. I don't have any issues there. Participant_024

Participant describes the expectation that future communication will be more transparent and information more forthcoming

Yes. I actually had a conversation with someone at the hospital one day about this. I guess it's hard for the medical teams to deal with because they're dealing with it all day every day, but sometimes you just feel like a number. For example, at one stage I was doing my radiation, into treatment, and said, "We need you to go and have CT scan." Okay it's as good as you said. No one ever explained to me why I needed to have CT scan. I think that to explain, have someone explain to you why this has happened or what is happening iit's really the only thing that I can think of. Participant_020

They've actually been really good. There's massive gaps I think, in the communication in general, but I don't know if that's in relation to that question. I might answer that and you'll tell me it's not what you're looking for, is not the right time to say that. What I've noticed with the whole journey is how much coordination and organizing you have to do yourself as a cancer patient. There's an expectation that you'll know what to do and where to go and who to talk to and how to do that. Things like contacting surgeons yourself, finding a surgeon, making an arrangement to go there, trying to get scans organized, you have to do all that yourself. Following up things that haven't been done, contacting the oncology rooms because they haven't got back to you about something where you don't know when the next appointment date is. There seems to be an awful lot of things that you need to do yourself to coordinate your own treatment, that I didn't think would be that way. I thought it would be more scheduled, "This is what happened, this is your journey, you need to see this person, this person, and this person." but I felt like that information wasn't given, that wasn't communicated and it's been trying to find out for myself, "Who do I see? Who do I need to see? Where do I go next? Where do I go for scans? Where do I go?" Then you need a heart ultrasound, well, you need to get that done before your chemo next Monday. Where do I go to get that done? Then you find everywhere is booked. You're trying to look at traveling two hours away to try and get an appointment for a scan that you've just been told that you need in the next four days without any information on where to go. That sort of stuff is just not communicated, and that's being really challenging. Participant_033

You have to read the patient. Some of us want to know all the truth, doesn't matter how grim it is, whereas others should be protected from the truth and the partner should be should be made aware. Sorry, I'm such a such a chatterbox. If it wasn't for the PET scan, I would have never known that I had the disease in my bones. Now I know it so now I'm just checking in all the time, so I have extra anxiety. Read your patient, provide all the resources, provide various places where you can go to without judgment. Without judging, yes. Participant_042

Participant describes the expectation that future communication will be more accurate and detailed (including more scientific)

My only miscommunication has only ever been about my annual follow ups, which is sort of easy enough, but is that something they're somehow to, you know, even if it's just to let us three months before your mammograms, do you decide this is what's going to. And that's still current for me, you know, nine, eight, nine years down the track that I, too, would like my doctor three months to put something in your calendar or the reception calendar to say that he needs an email regarding her upcoming mammogram to explain to me still because. Has to hang on. What's going on with them? That's literally my only. And that's always like I said once I stop seeing my oncologist because he gave me that bit of paper every year for three or five years, however long it was. Participant_003

Just being just for them to be upfront and honest? I think they all are. But you're just saying I have to give some more small details of what what we can expect. I mean, when you get diagnosed, you get told you're going on a trip. Yes. I'll tell you about we're going to give you this chemotherapy and it's going to give you the product. But it would be nice to have more information about those side effects. It might not be there, but maybe they could put you on to someone who could help you solve things. So it's just some little information about that. And not just even no one really wants the prognosis, but at the same time, you don't want a prognosis. So having having them been able to to help you with that and to help you cope with it and and knowing what is what, you know, that's what I'm trying to say. But, you know, like I've got a prognosis and and I literally took that and my prognosis know, I had to use to live. Well, I literally took that as I had to use to live for years past that used by date. So it's a little bit hard to sort of grasp, well, how come I'm doing that now? But a little more information on, say, you know, this can happen. This this drug can give you another six, six months of life or whatever, some little bit more information that way. Participant_049

Participant describes the expectation that future communication will include listening to the patient, as they know their body best

Yes, it's definitely not an inclusive process for the patient, I don't feel. I feel like it's very medical-based. It's very much the medical professionals come together and they talk about the patient, and then you go back to the patient to talk through. It might be, in my case, I feel like I didn't get a choice around things, although they'd probably say differently. That's not necessarily even the medical professionals' fault because there's not a lot of treatment options for triple- negative. I feel like, for the patient to be included in that, for me, my thought process is that I don't have a lot of trust in my medical professionals now, because I just feel like I'm either not being told the whole story, or I'm only being told certain things. When in actual practice, if they just included me in that process right from the outset and given me reasons as to why decisions were made and why things weren't, instead of just telling me, "Well, this is what's happened and this is what we've got to do," I probably would have processed that differently and had a different outlook on just the process in general if that makes sense. Participant_015

I don't think so, because I've actually had-- I think I, fortunately, had a really incredible and supportive experience going through my breast cancer with all of my medical professionals and their communication. I don't think there's really anything that I felt I've missed out on that they could improve on. Sorry, I'd say that. I think for me, the biggest thing that made my communication with my specialists really good was that I didn't go in and go, "Oh, I read this on a forum and this is what you need to be doing," and I never questioned by specialists. Also, I, from the very beginning, because I knew my surgeon had one treatment plan option and my oncologist had a different view, I knew that they were all talking and they were talking to each other about me. I never felt like one person didn't know something about me that the other did. I think as long as people know that they're being supported and that their specialists are communicating with each other and the decisions are being made as a whole not just by one person. I think that would be really important for other people. I had that experience. Participant_025

Whenever I've spoken to anyone, they say they only tell you this much because if they told you everything, perhaps wouldn't go through with it or wouldn't go down the path that they suggest is the best way I feel as though that's a very blanketed statement for some people. Myself, I would have dealt better if I knew upfront what I was dealing with. I think it needs to be more individualized to the person. I feel as though that needs to be a discussion with your breast care nurse or your oncologist of how much information you really want to know, do you want to know, like from *here to the end of the process, or do you want to know just what you're dealing with now? I think that would be better dealt with, and explanation of cost would be another one, as what you're in for, for the whole journey, that would be the two things. Participant_036*

Participant describes the expectation that future communication will be more empathetic

Oh, it would just be good if maybe it was a bit more rounded and that the emotional well-being was factored in and the families as well, because we were lucky. We were we don't have any family here, but we relied on our friends and the support of friends. But there wasn't any of the emotional support. It was purely this is the treatment. There you go by that was there, that there was there was not even a contact point of if you're having a tough time or your husband or your children. Yeah, I don't know, maybe it's changed. I probably have the hope so. Participant_001

I don't know. I think that I've had fairly good communication with most of my health professionals. As I said, the only one which I've butted heads with has been my surgeon, NAME. I don't know if it's just her as a person. I think it is. She's quite abrupt. The last thing you want is someone who's abrupt dealing with you when you got breast cancer and you tried to make heads and tails of what's going on in your life and being told, this is what you're doing, whether you like it or not, doesn't really sit well with some people. It's like, "How about you give us some options? How about you [unintelligible] yourself a little bit because you're not advocating for me?". Participant_034

Yes, and I actually said this to them one day. I think they'd need to remember that the people they're treating are people and that while for the person administering the treatment, it might be the one they stabbed that day. The person receiving the treatment it might be the first time they've ever done this, so you just need to explain what's being done and why it's being done. Participant_027

Participant describes the expectation that future communication will include developing a care plan with follow-up

My only miscommunication has only ever been about my annual follow ups, which is sort of easy enough, but is that something they're somehow to, you know, even if it's just to let us three months before your mammograms, do you decide this is what's going to. And that's still current for me, you know, nine, eight, nine years down the track that I, too, would like my doctor three months to put something in your calendar or the reception calendar to say that he needs an email regarding her upcoming mammogram to explain to me still because. Has to hang on. What's going on with them? That's literally my only. And that's always like I said once I stop seeing my oncologist because he gave me that bit of paper every year for three or five years, however long it was. Participant_003.

Yes. I definitely want to see one app that has everything in it. For example, Peter Mac have their own, all your results go in it, your blood tests, your follow-ups, notes from the appointments, everything like that. Whereas in my hometown, my radiation is run by a company called Icon. That's got a separate app. The oncology side of things in Melbourne is done separately. I'd love to see one access point for all of that because everything's so online. Like I said, I file the pieces of paper on everything that they do but I don't want to have a folder for it. I just want one locale for everything. Participant_030

Table 9.5: Expectations of future healthcare professional communication

Expectations of future healthcare professional communication	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=23	%	n=27	%	n=19	%	n=25	%	n=26	%	n=24	%	n=24	%	n=26	%
Participant has no recommendations/experienced good communication	13	26.00	7	30.43	6	22.22	5	26.32	8	32.00	4	15.38	9	37.50	5	20.83	8	30.77
Participant describes the expectation that future communication will be more transparent and information more forthcoming	13	26.00	6	26.09	7	25.93	6	31.58	4	16.00	8	30.77	5	20.83	7	29.17	6	23.08
Participant describes the expectation that future communication will be more accurate and detailed (including more scientific)	10	20.00	8	34.78	2	7.41	2	10.53	5	20.00	6	23.08	4	16.67	7	29.17	3	11.54
Participant describes the expectation that future communication will include listening to the patient, as they know their body best	10	20.00	3	13.04	7	25.93	4	21.05	3	12.00	5	19.23	5	20.83	4	16.67	6	23.08
Participant describes the expectation that future communication will be more empathetic	9	18.00	6	26.09	3	11.11	3	15.79	4	16.00	6	23.08	3	12.50	4	16.67	5	19.23
Participant describes the expectation that future communication will include developing a care plan with follow-up	5	10.00	3	13.04	2	7.41	0	0.00	5	20.00	3	11.54	2	8.33	3	12.50	2	7.69

Expectations of future healthcare professional communication	All participants		Regional or remote		Metropolitan		Mid to low status		Higher status		Aged 25 to 44		Aged 45 to 54		Aged 55 to 74	
	n=50	%	n=16	%	n=34	%	n=20	%	n=30	%	n=19	%	n=22	%	n=9	%
Participant has no recommendations/experienced good communication	13	26.00	5	31.25	8	23.53	6	30.00	7	23.33	4	21.05	7	31.82	2	22.22
Participant describes the expectation that future communication will be more transparent and information more forthcoming	13	26.00	3	18.75	10	29.41	6	30.00	7	23.33	5	26.32	5	22.73	3	33.33
Participant describes the expectation that future communication will be more accurate and detailed (including more scientific)	10	20.00	2	12.50	8	23.53	3	15.00	7	23.33	3	15.79	3	13.64	4	44.44
Participant describes the expectation that future communication will include listening to the patient, as they know their body best	10	20.00	4	25.00	6	17.65	5	25.00	5	16.67	4	21.05	5	22.73	1	11.11
Participant describes the expectation that future communication will be more empathetic	9	18.00	4	25.00	5	14.71	4	20.00	5	16.67	3	15.79	4	18.18	2	22.22
Participant describes the expectation that future communication will include developing a care plan with follow-up	5	10.00	2	12.50	3	8.82	1	5.00	4	13.33	2	10.53	2	9.09	1	11.11

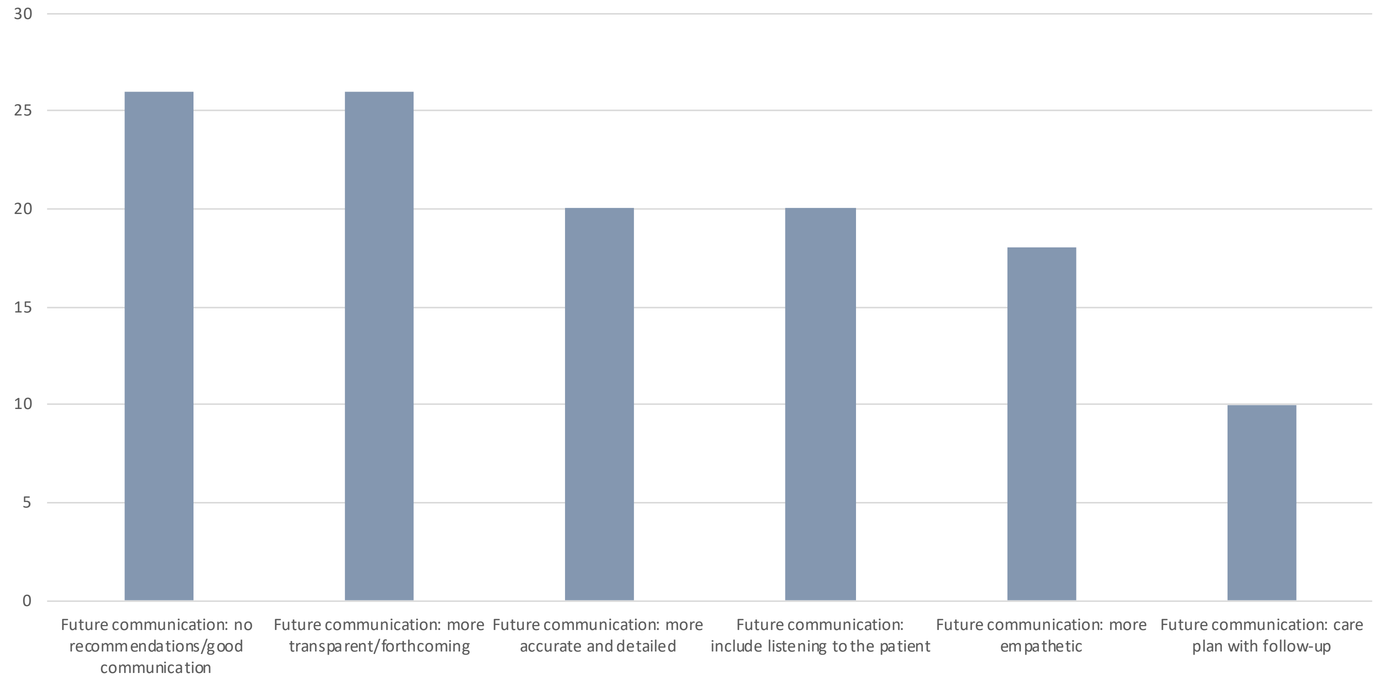

Figure 9.3: Expectations of future healthcare professional communication

Table 9.6: Expectations of future healthcare professional communication – subgroup variations

Theme	Reported less frequently	Reported more frequently
Participant has no recommendations/experienced good communication	Diagnosed before 2020	Diagnosed in 2020 or 2021
Participant describes the expectation that future communication will be more accurate and detailed (including more scientific)	Advanced breast cancer	Early breast cancer Aged 55 to 74

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. There were 24 participants (48.00%) who described that future care and support should include access to support services and this was the most common theme. Other participants described that future care and support should include access to specialist clinics or services (n= 10, 20.00%), access to mental health and emotional support (n = 7, 14.00%), and access to peer support (n = 6, 12%). There were five participants (10.00%) as they were satisfied with the care and support available.

Participant describes the expectation that future care and support will include more access to support services

I think that everything along the way is adequate. I think we need to focus on people that have finished treatment, and rehabilitation, physically, and mentally after treatment Participant_007

I don't know. I'd probably get support with doing my housework and all that sort of stuff. I think if there are people like myself who I'm very independent, and God, I hate asking for help. I think if they could maybe have more-- I don't know, maybe sit down and talk to people about their situation more. I could have probably done with, maybe, some help around the house, that sort of stuff. I know, like I said, I got the transport, which is awesome. Participant_028

Maybe in-home support, especially if someone could-- I'm on my own…so I am having to fend for myself with everything and I haven't really had anyone come to me and say, is there anything you might need help with at home? I've had to go looking for it and asking…Yes, just some practical support to help. Participant_014

I would have loved, absolutely loved the day I was diagnosed to be given the name of someone to go and speak to about the practical stuff. As in what that journey is going to be like, the sorts of people you're going to need to come into contact with, what their roles are, what they do, where you find them, how you contact them. That real step-by-step guide, and I feel like that was the crucial thing that was missing. For me, I think the diagnosis was just walking out of the doctor's office, not having a clue where to go or who to talk to or what to do, or where I needed to go, and if they say, "Oh, you need this, you need an oncologist, you need to do this, you need these scans." but no guidance as to where to go. I feel like the key thing for me would be a person that you are put in contact with whether it's a breast care nurse, or whether it's another role completely. Someone that you speak to immediately on diagnosis, that we'll be able to answer all of the questions you have about the practical stuff and the treatment. Things around who's involved in the care and what your team is going to look like, and what those people do because when you're new to the journey you have no idea, you have absolutely no clue who these people are and what their roles- Participant_033

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 would have loved, absolutely loved the day I was diagnosed to be given the name of someone to go and speak to about the practical stuff. As in what that journey is going to be like, the sorts of people you're going to need to come into contact with, what their roles are, what they do, where you find them, how you contact them. That real step-by-step guide, and I feel like that was the crucial thing that was missing. For me, I think the diagnosis was just walking out of the doctor's office, not having a clue where to go or who to talk to or what to do, or where I needed to go, and if they say, "Oh, you need this, you need an oncologist, you need to do this, you need these scans." but no guidance as to where to go. I feel like the key thing for me would be a person that you are put in contact with whether it's a breast care nurse, or whether it's another role completely. Someone that you speak to immediately on diagnosis, that we'll be able to answer all of the questions you have about the practical stuff and the treatment. Things around who's involved in the care and what your team is going to look like, and what those people do because when you're new to the journey you have no idea, you have absolutely no clue who these people are and what their roles-. Participant_033

I would love there to be a one-stop-shop so that you go and somebody is there for your physio, your chiropractic, all the breast care, questions that you have. Yes, just a whole umbrella where it's so hard to-- like lymphedema, side effects from chemo, or whatever. Just someone that would deal with all of it. You don't have to run around to so many different professionals and you're constantly-- it's hard to get into appointments as well. Somewhere that just dealt with everything.. Yes. Like a hub for everything. Like you could have your own oncologist in different paths, but this is where you went for everything else. Participant_036

Participant describes the expectation that future care and support will include mental health/emotional support

I'll probably think I have three kids, so maybe something more for them, which we were pointed into canteen's directions which my kids accessed the counselling services for a little bit there. Just something more to help them, take them on [inaudible] At the start, it was a little bit overwhelming for them, and with [unintelligible] charity coming out to take them out for the day or something-- I'm not sure just to help them deal with them.. Participant_018

I think the most important thing is just support and the counselling. For people, specifically breast cancer, having no services there and making sure, like Breast care WA has been awesome for me. If I wasn't here in Perth, I don't know what would have…If I was remote in LOCATION I don't know whether I would have had the same level of support. Participant_017

Psychologists. Cancer psychologists. Participant_042

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)

I got a lot out of the Facebook groups. Being able to reach out to survivors, even those ones that have reached stage four or whatever, being able to talk to them and get stuff from their experience. Participant_009

I would like to see support groups or people with similar types of cancer that you have say that you're able to meet other people and talk about your experience with them, because I feel like they understand more like that to me is more beneficial than seeing a psychologist and. So can you repeat the question? Yes, there was something else I had in my head. Participant_038

I believe that the cancer support group, that's just an organization of people going through cancer, that has been very helpful for me. What they're trying to do with the group is to get to people when they're diagnosed because they supply a lot of information that we don't know. You don't know about options about breast surgeons. My GP, who recommended a breast surgeon, he said if his wife had it, he wouldn't send her anywhere else, so I took that as my recommendation, but you've got to make all those decisions and you don't know. Us, as a group together, a list of the surgeons in the area and all that sort of thing and costings and everything like that, but when you're first diagnosed, you're not part of that group because you don't know. It's something that those support groups of people that have gone through it, I think help you more than anything, and getting the information to them. They're putting brochures in the hospitals and things like that to help people. That's the big thing is when you're first diagnosed, you've got so much going on and you don't know. They're saying, "Okay, you got to go and see an oncologist. Who would you like to see?" It's like you never look at-- No one doesn't know who an oncologist in the area is if you haven't had to deal with anything like that. It's that information in that crucial time when you're first diagnosed that needs to get to people because you don't know. It's even like, I would have been out-of-pocket $10,000 for my radiation if I hadn't have gone to the morning tea that the cancer group had and mentioned it to one of the ladies there, and she told me how to get out of paying it. Things like that. It's that crucial time, right at the beginning when you're up in the air, not knowing where you're coming or going, and you're in such a shock and you've got to make all those decisions. Participant_046

Participant has no recommendations/is satisfied with care received

Not that I could think of. Participant_006

And I think I've been very lucky with the breast nurses and counsellors that I've had, the access I've had to different activities at different hospitals where I support women and men with cancer. It's just getting that information out. But I think I've been very lucky with that sort of thing. Participant_049

I really can't think of anything. I'm sorry. Participant_020

Table 9.7: Expectations of future care and support

Expectations of future care and support	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=23	%	n=27	%	n=19	%	n=25	%	n=26	%	n=24	%	n=24	%	n=26	%
Participant describes the expectation that future care and support will include more access to support services	24	48.00	9	39.13	15	55.56	**7**	**36.84**	12	48.00	**9**	**34.62**	**15**	**62.50**	**9**	**37.50**	15	57.69
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)	10	20.00	**1**	**4.35**	**9**	**33.33**	5	26.32	5	20.00	5	19.23	5	20.83	6	25.00	4	15.38
Participant describes the expectation that future care and support will include mental health/emotional support	7	14.00	4	17.39	3	11.11	4	21.05	3	12.00	2	7.69	5	20.83	3	12.50	4	15.38
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	12.00	4	17.39	2	7.41	2	10.53	3	12.00	3	11.54	3	12.50	3	12.50	3	11.54
Participant has no recommendations/is satisfied with care received	5	10.00	3	13.04	2	7.41	3	15.79	2	8.00	4	15.38	1	4.17	4	16.67	1	3.85

Expectations of future care and support	All participants		Regional or remote		Metropolitan		Mid to low status		Higher status		Aged 25 to 44		Aged 45 to 54		Aged 55 to 74	
	n=50	%	n=16	%	n=34	%	n=20	%	n=30	%	n=19	%	n=22	%	n=9	%
Participant describes the expectation that future care and support will include more access to support services	24	48.00	**5**	**31.25**	19	55.88	**7**	**35.00**	17	56.67	**7**	**36.84**	12	54.55	5	55.56
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)	10	20.00	4	25.00	6	17.65	4	20.00	6	20.00	5	26.32	3	13.64	2	22.22
Participant describes the expectation that future care and support will include mental health/emotional support	7	14.00	3	18.75	4	11.76	1	5.00	6	20.00	3	15.79	4	18.18	**0**	**0.00**
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	12.00	3	18.75	3	8.82	**5**	**25.00**	1	3.33	3	15.79	3	13.64	**0**	**0.00**
Participant has no recommendations/is satisfied with care received	5	10.00	0	0.00	5	14.71	1	5.00	4	13.33	1	5.26	1	4.55	**3**	**33.33**

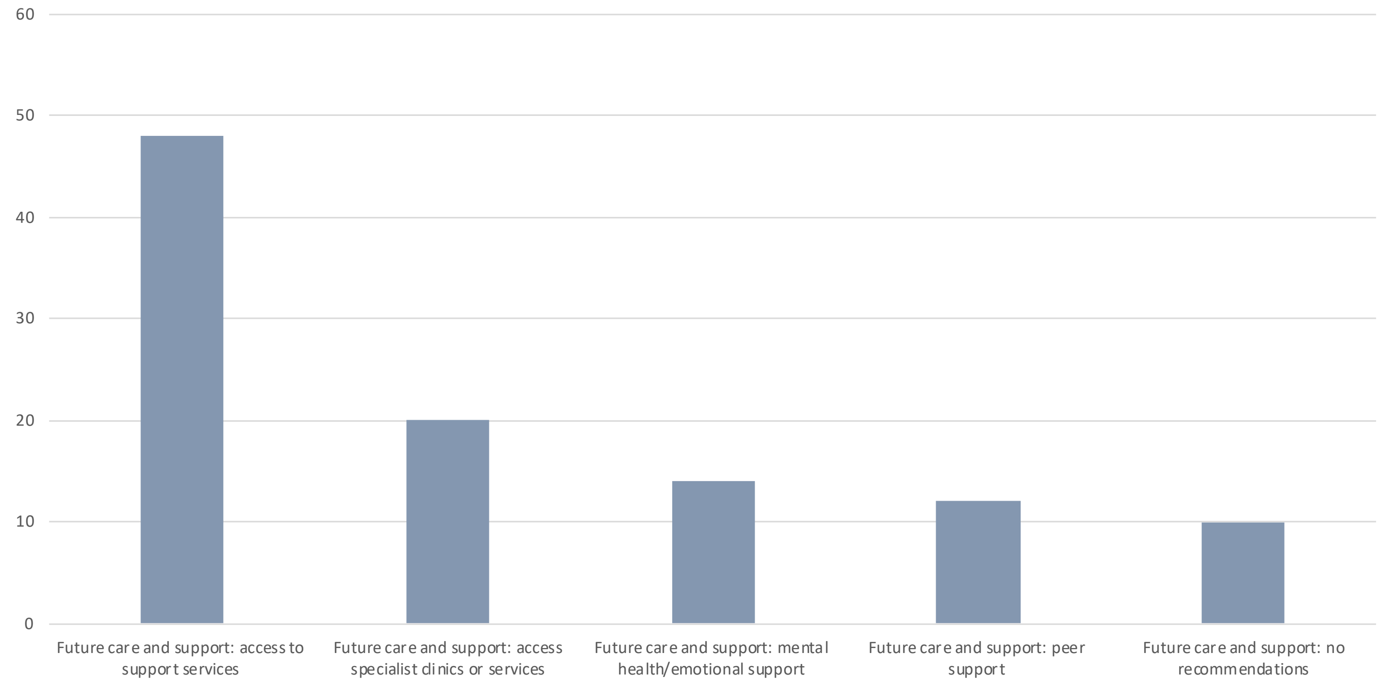

Figure 9.4: Expectations of future care and support

Table 9.8: Expectations of future care and support – subgroup variations

Theme	Reported less frequently	Reported more frequently
Participant describes the expectation that future care and support will include more access to appropriate, real-world support services	Stage IV Aged 55 to 74 Higher status	Stage III Aged 45 to 54 Regional or remote
Participant describes the expectation that future care and support will include financial help	-	Stage I
Participant describes the expectation that future care and support will include mental health/emotional support	-	Regional or remote
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)	-	Stage II Aged 45 to 54
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)	-	Stage III Aged 25 to 44

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 reported were that participants were grateful for timely access to treatment (n = 17, 34.00%), followed by grateful for healthcare staff (n = 16, 32.00%). There were 12 participants (24.00%) that described being grateful for low cost or free medical treatments , 10 participants (20.00%) that described being grateful for the entire health system, and 9 participants (18.00%) that described being grateful for low cost/free medical care.

Participant is grateful for timely access to treatment

Yes, all of it has been really good. The speed from diagnosis to getting treatment was really quick. It didn't feel it at the time, but I think it was only five weeks from diagnosis to starting chemo. It was quite a quick turnaround. I was able to get appointments with the people I needed to see. The oncologist has been amazing, the breast care nurse has been amazing, the treatment team of the hospital are fantastic. It's all been excellent. There's been no issues at all with the treatment that I've been given. No. Participant_033

Yes. That would be someone's [unintelligible] I was referred straight on to the hospital, and within even though it was over Christmas and New Year period, it was within two weeks of being referred there. All my tests were done, and I was seeing people and it was all happening. I am very grateful and all of my treatment has gone through the public health system and has been free so far. Participant_018

Everything. Everything. I've got relatives in England and I know sometimes they have to wait weeks until they can access stuff. Everything happened within a week. The chemo facilities were lovely. The radiation people were marvellous. Like I said, I was lucky to have the Mepitel for nothing. Even the chemo, the oral chemo was easy to get and all that kind of stuff. The lumpectomy was very, very smooth, and they make sure everything is good. I think everything in Australia is very, very good, and we're very lucky. Participant_035

Participant is grateful for healthcare staff

Well, having just back to the hospital experiences I had, yes, I am very grateful. My surgeons and my oncologist were just amazing. I. So even though I'm actually terrified of my oncologist and she's maybe doesn't have the greatest bedside manner and so she could be a little bit makes you feel like you stupid sometimes because she's just operating on a different level and she see so many people. But she is fantastic. And her husband, who is a breast surgeon and my plastic surgeon who was at that stage, he was right at the forefront of different techniques for reconstruction. So I was so grateful that I had them also that I had the private health because that just opened up everything. And I'm sure that saved my life as well, being able to get into that private system. Participant_001

Yes, I guess my particular team has just been outstanding. Participant_041

The fantastic doctors. We've got some of the best breast care nurses in the world, and very lucky to have gotten into here and had an exceptional result. I feel as though the team of nurses and everything are all very caring and very loving. The staff, they do amazing things. Participant_036

Participant is grateful for low cost/free medical treatments through the government

Oh, absolutely. Definitely. Like you said, we do have a really good system even financially. Not having to worry about the stresses of paying for treatments. I've seen some horror things through the forums, especially in America, where you've got to rely on insurance to come through to then get certain treatments, and this is life- saving treatments. Absolutely, I think the financial side, the medicare side of things, we are so fortunate, so fortunate here because here you don't have to worry. You can just do the treatment. The ability, the availability of tests and scans, and things like that. Participant_015

Well, when I was going through chemo and radiation and it was completely free, I was so grateful that the level of care was there. I must say, even though those doctors-- when I'm saying the doctors, anything that I've said is not against the doctors or the nurses that I dealt with because they've all been amazing, the level of care, caring people, but they're busy and that's not their fault. I would never say that it's their fault because they've all been very caring and concerned, and lovely people. No, I felt grateful that I lived in Australia [chuckles] and had that level of hospital care. Participant_029

The fact that I can receive Palbociclib, the CDK4/6 inhibitor on the PBS for $40 a month is absolutely life-changing because I would be much, much sicker without it. I strongly believe it's responsible for my metastasis disappearing. I know that it's not available in many countries, not accessible and hugely expensive in others. Participant_050

Participant is grateful for the entire health system

I think honestly looking at the whole thing, grateful that the system is there, and just can go into action almost straight away to help you. Very grateful for the whole system really and that it appears to work and different specialists can work together to get you through it medically. Participant_004

I am eternally grateful I live in Australia and we have the health care system we have. The fact that I could go through the treatment I had to go through and not the out-of-pocket other than the surgery, I will be eternally grateful for. My ex-husband who is American and he has often said to me, "If we were living in America, we couldn't afford to be treated." Yes. I feel that we're truly blessed to have the healthcare system we have in this country. Participant_027

Medicare, definitely. I used to bring home the injections at no cost, and they had $1,000 something written on the box. I'd be like, "Whoa. I wouldn't be able to have this treatment at all if it wasn't for Medicare." Hugely, hugely grateful for Medicare. Just really grateful to be in Australia because our healthcare system is pretty good. I grew up in OVERSEAS. If this had happened to me there, I could have had a very, very different outcome because the cost and everything would have been exorbitant. The health system there would have been at that time overrun with COVID, so it could've been a very scary time to be in hospital. I guess if I had to pick one thing, Medicare, for sure. Participant_011

Participant is grateful for low cost/free medical care through the government

So I'm so grateful, so lucky if I'm really lucky to be able to access all those minimal costs through Medicare. Actually pay my taxes every year until I have my money. So having a public health system that provides at least some level of equity, I'm very grateful for that. I'm very grateful for the quality of care I got in a regional area. I think it has been every bit as good as Melbourne. And in fact, I would say things better than the public system because I've had consistent clinicians. I'm grateful for all of it being able to get psychological care. The White House. Participant_002

I'm grateful for all of it. I mean, I know that that needle that got poked in my stomach after each chemo was apparently like a 2000 dollar needle. Like if we had to pay for those things, that would just crush people. Yet, you know, had something in my body that could have killed me. But because of our system, I'm still here. And it didn't it's not even like we had to take out a small loan to, you know, like it didn't even cost us five grand or ten grand or twenty grand. It cost us nothing. You know, when people get their taxes done and complain about the Medicare levy, don't. Yes, it is an amazing thing. Participant_003

I'm just very thankful of that our town rallied for a cancer center down here, so I didn't have to travel to get my treatment. The only thing I went through is surgery, so chemo and radiation was all done in my hometown, which is 10 minutes away. I'm probably thankful for the fact that it costs minimal. That we're not having to pay and remortgage houses for the treatment. [laughs] That's probably the biggest thing I've had with it. Participant_030

Table 9.9: What participants are grateful for in the health system

What participants are grateful for in the health system	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=23	%	n=27	%	n=19	%	n=25	%	n=26	%	n=24	%	n=24	%	n=26	%
Participant is grateful for timely access to treatment	17	34.00	8	34.78	9	33.33	7	36.84	9	36.00	10	38.46	7	29.17	5	20.83	12	46.15
Participant is grateful for healthcare staff	16	32.00	8	34.78	8	29.63	9	47.37	5	20.00	8	30.77	8	33.33	8	33.33	8	30.77
Participant is grateful for low cost/free medical treatments through the government	12	24.00	7	30.43	5	18.52	2	10.53	8	32.00	6	23.08	6	25.00	5	20.83	7	26.92
Participant is grateful for the entire health system	10	20.00	5	21.74	5	18.52	2	10.53	7	28.00	2	7.69	8	33.33	4	16.67	6	23.08
Participant is grateful for low cost/free medical care through the government	9	18.00	6	26.09	3	11.11	2	10.53	7	28.00	6	23.08	3	12.50	3	12.50	6	23.08

What participants are grateful for in the health system	All participants		Regional or remote		Metropolitan		Mid to low status		Higher status		Aged 25 to 44		Aged 45 to 54		Aged 55 to 74	
	n=50	%	n=16	%	n=34	%	n=20	%	n=30	%	n=19	%	n=22	%	n=9	%
Participant is grateful for timely access to treatment	17	34.00	9	56.25	8	23.53	5	25.00	12	40.00	8	42.11	6	27.27	3	33.33
Participant is grateful for healthcare staff	16	32.00	6	37.50	10	29.41	7	35.00	9	30.00	4	21.05	8	36.36	4	44.44
Participant is grateful for low cost/free medical treatments through the government	12	24.00	4	25.00	8	23.53	4	20.00	8	26.67	5	26.32	5	22.73	2	22.22
Participant is grateful for the entire health system	10	20.00	2	12.50	8	23.53	4	20.00	6	20.00	3	15.79	5	22.73	2	22.22
Participant is grateful for low cost/free medical care through the government	9	18.00	3	18.75	6	17.65	2	10.00	7	23.33	3	15.79	5	22.73	1	11.11

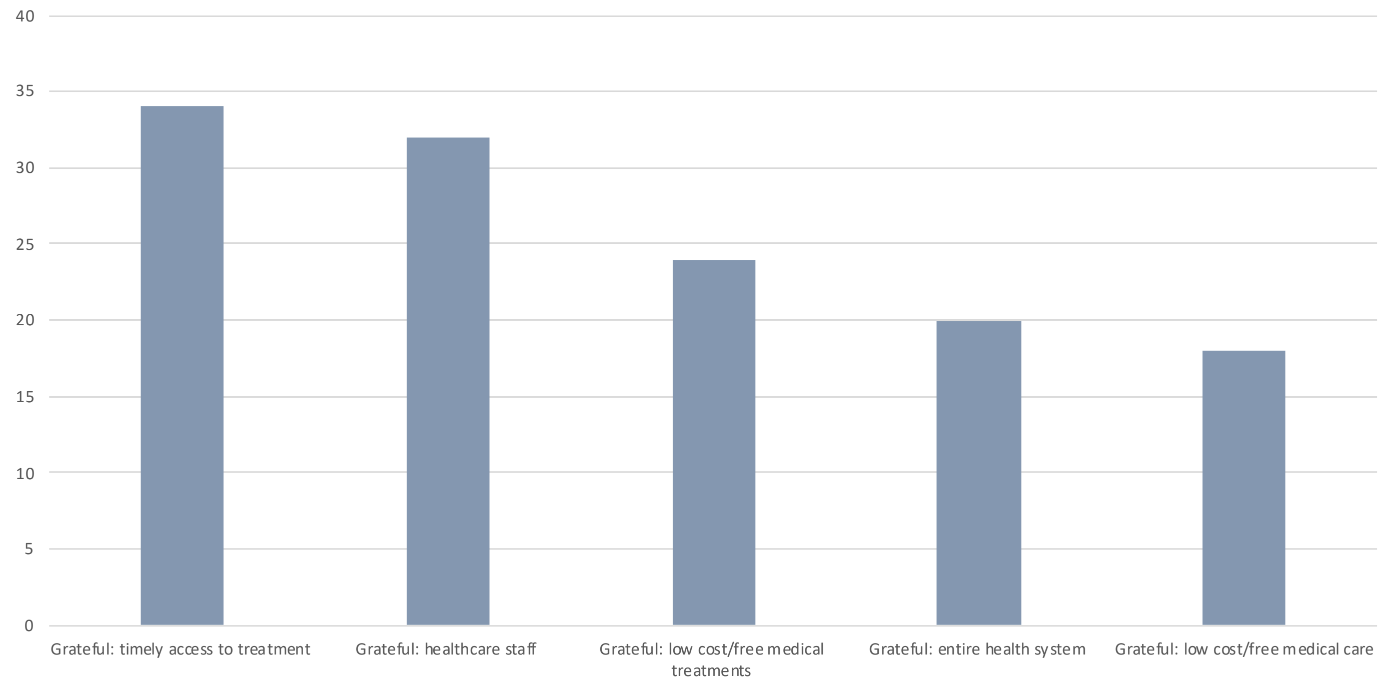

Figure 9.5: What participants are grateful for in the health system

Table 9.10: What participants are grateful for in the health system – subgroup variations

Theme	Reported less frequently	Reported more frequently
Participant is grateful for timely access to treatment	Trade or high school Metropolitan	University Regional or remote
Participant is grateful for healthcare staff	Good physical function Aged 25 to 44	Poor physical function Aged 55 to 74
Participant is grateful for low cost/free medical treatments through the government	Poor physical function	-
Participant is grateful for the entire health system	Diagnosed before 2020	Diagnosed in 2020 or 2021

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 fatigue pain, Heart problems and, memory loss and cognitive function. The least important were fertility, body image and sexual difficulties.

Table 9.11: Symptoms and aspects of quality of life

Symptom	Weighted average (n=44)
Fatigue Pain	10.35
Lymphoedema	5.30
Fertility	1.65
Menopause and menopausal symptoms	4.17
Anxiety and depression	6.78
Body image	3.87
Sexual difficulties	3.91
Problems with movement and strength	7.09
Heart problems	7.78
Memory loss and cognitive function ("chemo brain")	7.61
Effects on bones and joints	7.48

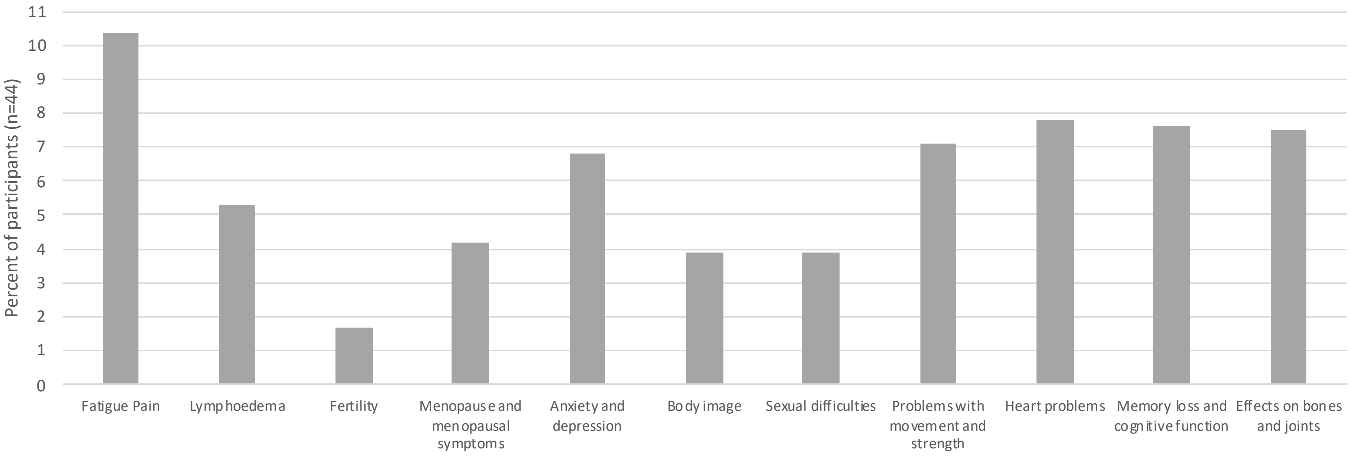

Figure 9.6: Symptoms and aspects of quality of life

Values in making decisions

Participants were asked to rank what is important for them overall when they make decisions about treatment and care, where 1 is the most important and 8 is the least important. A weighted average is presented in Figure 9.7. With a weighted ranking, the higher the score, the greater value it is to participants.

The most important aspects were "How safe the medication is and weighing up the risks and benefits", and "How personalised the treatment is for me". The least important were "Ability to follow and stick to a treatment regime" and "The financial costs to me and my family".

Table 9.12: Values in making decisions

Values when making decisions	Weighted average (n=44)
How safe the medication is and weighing up the risks and benefits	6.25
The severity of the side effects	5.55
Time impact of the treatment on my quality of life	4.84
How the treatment is administered	3.25
How personalised the treatment is for me	5.61
The ability to include my family in making treatment decisions	3.82
Ability to follow and stick to a treatment regime	3.11
The financial costs to me and my family	3.57

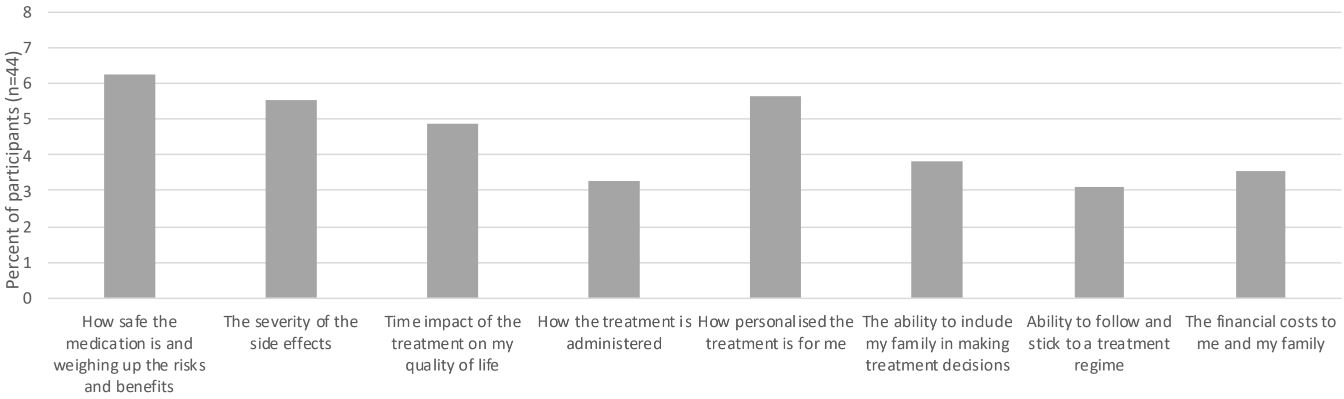

Figure 9.7: Values in making decisions

Values for decision makers

Participants were asked to rank what is important for decision-makers to consider when they make decisions that impact treatment and care, where 1 is the most important and 5 is the least important. A weighted average is presented in Figure 9.8. With a weighted ranking, the higher the score, the greater value it is to participants.

The most important values were "Quality of life for patients", and "All patients being able to access all available treatments and services". The least important was "Economic value to government and tax payers".

Table 9.13: Values for decision makers

Values for decision makers	Weighted average (n=44)
Economic value to government and tax payers	1.27
Economic value to patients and their families	2.68
Quality of life for patients	3.80
Compassion	3.16
All patients being able to access all available treatments and services	4.09

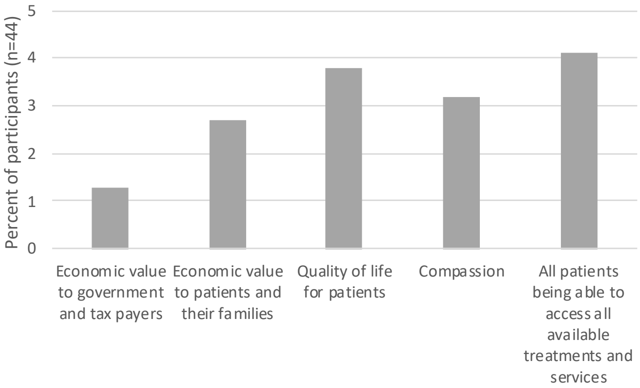

Figure 9.8: Values for decision makers

Time taking medication to improve quality of life

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

The majority of participants (n = 28, 63.64%) 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=44)	Percent
Less than 1 year	1	2.27
1 to 5 years	10	22.73
5 to 10 years	5	11.36
More than 10 years	28	63.64

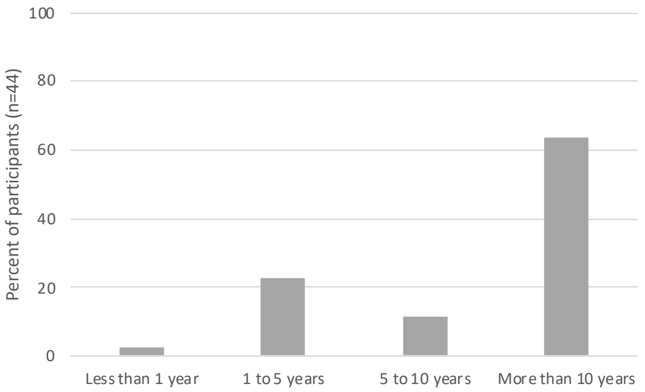

Figure 9.9: Time taking treatment to improve quality of life

Most effective form of medicine

Participants were asked in the online questionnaire, in what form did they think medicine was most effective in.

Participants they were equally effective (n = 15, 34.09%), followed by IV form (n = 16, 36.36%) (Table 9.15, Figure 9.10).

Table 9.15: Most effective form of medicine

Treatment most effective in what form	Number (n=44)	Percent
IV form (through a drip in hospital)	15	34.09
In a pill form that can be taken at home	0	0.00
Equally effective	16	36.36
Not sure	13	29.55

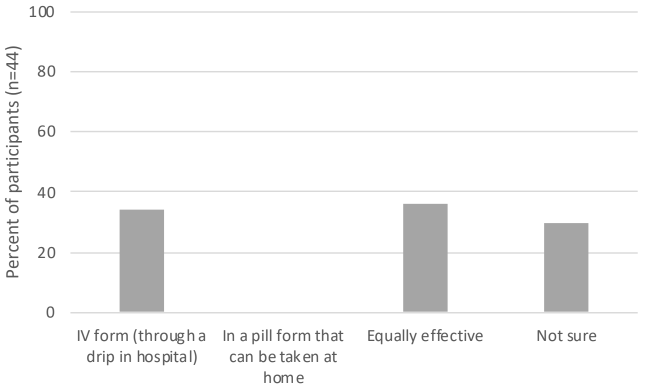

Figure 9.10: Most effective form of medicine

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?”. There were 22 participants (44.00%) with the message to improve access to support and care (including treatment) and this was the most common theme. Other participants had the message: to understand the financial implications (n = 16, 32.00%), to have a tailored care plan (n = 11, 22.00%), to invest in research (n = 7, 14.00%), and to invest in specialist health professionals, especially nurses (n = 7, 14.00%). There were five participants who were satisfied and thought that things should stay the same, and the same number who had the message that treatments need to be holistic (n= 5, 10.00%).

Participant's message is to improve access to support and care (including treatment)

I know that there's lots of treatments that could help some people with breast cancer that they don't have access to…some people with more advanced breast cancer than I had don't have access to and possibly other types of cancer have access to. I just think that something needs to be done about speeding up access to possibly helpful drugs for people because I know that some of them are horrifically expensive. Participant_004

Oh God, I don't know. I'd have to think about this one. It would probably have to be with more access to the support from the side effects of it all. For instance, with my physio and lymphatic massage, a lot of it I've had to spend out of my own pocket and organize myself and source for myself where that could have been dealt with as part of my treatment plan from the get-go knowing what I know they know. They knew more than I did at that stage and a lot of the issues could have been dealt with initially, so I'd probably say that. I'd probably say that there needs to be more funding for them to-- Not just the treatment but the side effects of the treatment. Participant_012

That's a difficult one, but I would say I think that people like the breast care nurse, those liaison nurses need to be supported more fully. I specifically think in our region, that FTE could be increased. I think the more that you're able to access treatment resources for cancer in regional areas, obviously, makes less impact on that person emotionally, financially when they're receiving treatment. The more money that's put into getting those treatments locally, the better. I understand that sometimes that's not always possible. The health budget is not a finite budget, but however, for those people, setting up some local treatment centres, I think from a standpoint of people not having to travel great distances to receive their treatments, must be more financially and emotionally beneficial. Also looking at those trial drugs that you see lots of different information about putting medications onto the PBS that people can access that may improve quality of life. While we argue over that, it should just be a given. Participant_013

Participant's message is to understand the financial implications (and provide financial support)

I would say that, "It's great, and thank you." I think we just need to be looking at some of the costs associated with the ongoing monitoring and maintenance because while I can afford it and there's lots of people who would struggle with that yearly maintenance. Sometimes when I found random weirdness in my boobs, I’ve had to go and have appointments that again have cost hundreds of dollars that I wasn't really factoring in. Just having some sort of system to manage that. Obviously, everything just cost money and money and money. It'd be nice if that sort of thing could be bulk billed or further reduced than just the standard fee for some other person who comes in and does it that doesn't even have a long-standing condition. Participant_005

Look, I think it's to make sure everyone's informed and know they have choices and not feel alone, but make sure they know of all the options, not just what that specific oncologist normally deals with or that specific surgeon. I think the cost. I read a lot of forums, and people were paying for a lot of other scans and stuff, even in Australia. I find, like I said, other than my surgery and IVF, which really threw us, I didn't pay another cent. That was one big thing because it's one less worry, one really big less worry, especially if you're not able to work. I think finance is a big-- Not everyone's in a position to go private or things like that. That's one thing that will keep you awake at night. It's my life, but I can't afford to save it. Participant_021

I think the radiation, it's a big thing for treatment, the costings and all that sort of thing. Even though I go Private Health, the out-of-pocket is ridiculous. If you pay into a health fund, you shouldn't have to pay any out-of- pocket for anything, I believe. With the *radiation, I would have had to travel an hour there and an hour back each day, if I wanted to go somewhere where I had bulk-billed radiation. Anyone in this area, it's an hour travel there and back, and you'd have to get someone to take you because you don't feel like driving afterwards. It's something that's a bit tough if you can't get to the public radiation places. They should be able to provide some assistance through the others, but like I said, you can, and you don't know those things unless you have people that will tell you those things beforehand. Participant_046*

Participant's message is that tailored care plans are needed

I think for me, my message would be that it's not a one size fits all treatment for everybody. Your treatment plan has to be unique and individualized to you specifically. The only way to do that and to make informed decisions about that is to have access to the test. The resources that are available in the world, and Australia should be catching up with-- Doing these things more regularly not just relying on the way it's always happened, if that makes sense, just jumping straight into chemo. Having the test available so that informed decisions can be made about treatment plans and also access to treatment too, and ensuring the availability of that and that it doesn't cost a fortune to access that if it's going to save your life. One patient may have access to a specific type of chemotherapy that for, I don't know, bowel cancer, but if you got breast cancer it's going to cost you $10,000. Having a little bit more appreciation to the fact that everybody's case is different, so that's why I think the genomic testing would help right in the beginning. It could save money along the way, too. Because you're not having to then go down a path of engaging in different chemos that aren't going to work, and so forth. Also on the health system, I mean, I've had access to hospital system numerous times because of my side effects from neuropathy and possible infection, and things like that that really, I might not have that if we've gone down a different path and had other things available so yes [unintelligible] where I'd go. Participant_015

This is a discussion on my Facebook page that not all cancer is the same. Even though my cancer was triple-negative, all cancers mutate differently and some respond to chemo and some don't. A lot of people go through chemotherapy to find out that after six months of chemo, that it actually hasn't responded greatly to their cancer at all. It would be to have better access, to get out cancer genetically tested for different mutations. Participant_018

I know that there's lots of treatments that could help some people with breast cancer that they don't have access to-- some people with more advanced breast cancer than I had don't have access to and possibly other types of cancer have access to. I just think that something needs to be done about speeding up access to possibly helpful drugs for people because I know that some of them are horrifically expensive. Participant_004

Participant's message is to invest in research (including to find new treatments)

They just need to have a lot more trials available and they need to get a lot more of the immunotherapies and that sort of thing are expensive. It's proven to work, but we can't access it. That's just ridiculous. It doesn't affect you the way chemotherapy does. Participant_009

First thing I'd tell him is that all of the nurses need a pay raise, huge, huge pay raise, for what they do, for what they go through, for the care they give. I guess I'd just want to make sure that we were putting as much time and effort and money as possible into researching new ways of treating breast cancer, any cancer, different medications that could potentially be used, different types of treatment. Participant_020

I haven't really thought of something like that. I know that there's a lot of courses out there that are pushing more money, obviously is one and that's generally to support. If we could have a couple of extra breast care nurses in our hometown, I think the things that I've got concerns about would be answered. It's getting more bodies in there to then create that access. Yes, and just generally pour more money to research, get it done. The amount of money going into cancer research and stuff like that and to not have, we can get a COVID vaccine for crying out loud. [crosstalk] We can't get something to cancer why? But, anyway. Participant_030

Participant's message is to invest in specialised health professionals, especially nurses.

Breast care nurses. We need more breast care nurses, 24 hours, 7 days a week. We need that resource. I was going through treatment and one of the nurses was telling me that they had their hours cut at the hospital. I just thought, "How can they cut their hours? It's just crazy." I go to Gold Coast Uni and there was hundreds of cancer patients through there at the time. I think they did a bit of a petition too. I was telling somebody in one of the Facebook groups, and I think they all petitioned to see if we can get more hours for the breast care nurses. They're so underrated and their assistance is amazing. Participant_029

First thing I'd tell him is that all of the nurses need a pay raise, huge, huge pay raise, for what they do, for what they go through, for the care they give. I guess I'd just want to make sure that we were putting as much time and effort and money as possible into researching new ways of treating breast cancer, any cancer, different medications that could potentially be used, different types of treatment. Participant_020

I think, look, me personally, would have liked to have had a little bit more emotional support. Someone who talked to me about your feelings and what you're going through. Not at the time when you're going through it. I feel like I finished my lumpectomy and I haven't heard from that breast care nurse then. I was still going through radiation. I was still going through chemo and I was very, very lucky that I have sisters and I have older daughters that I can talk to about it because I feel if you didn't have that, there were times where you want to bash your head because you're just not feeling 100%. Like I said, at times I've-- The friend that I know who had breast cancer a year before me and said, if you found someone you can talk to. She said you've got to ring this number and that number. Otherwise, you've got to pay for it. I think that needs to be a little bit more clear for patients. The help that you can get faster, to be more clear. I feel like I finished and apart from when I see my oncologist who is very, very great, who does-- He's very caring and stuff. It would be nice to have someone just check up on you every now and again and say, "How you doing?" I feel like the breast care nurse was supposed to do that, but because of everything with COVID, she never really got to get a rapport going with all the patients. I think we need care after-- We need a little bit of aftercare to make sure that we're doing okay after it because I think a lot of your friends tend to think, "Oh, you've finished treatment. You're back normal." They don't realize that you're still fatigued and your bones are still hurting and you're still not sleeping at night. I think they just think, "Oh, the treatment's over and you're back to normal." type of thing. Participant_035

Participant's message is that the health system they are satisfied with their care, that it should stay the same

You know what? Just to put a spanner on it on you, I actually think that breast cancer is really one of the more well-funded-- it gets a lot of attention already. My mum had uterine cancer and a fairly rare kind. They don't even have a protocol. They use the ovarian cancer protocol. It's those rare cancers that worry me more because I think breast cancer gets a lot of attention, and big names put a lot of fundraising and support into it. I felt fortunate because -- It's so much more treatable now than it used to be. So many women are surviving it really well. For me, the concern is more those other cancers that are getting forgotten. Participant_011

Oh, goodness. Just don't change it. Participant_014

I'm eternally grateful for the treatment that's available to me to get a chance at beating this. I know that in other countries I may not be so fortunate. I believe that the treatments I'm getting are the gold standard treatments for triple-negative breast cancer. I believe that the dose-dense chemo, everything that's available that I'm able to access pretty much immediately, 10 minutes down the road from my house, is phenomenal, and I'm very, very grateful. That's what I'd be telling him. It's fantastic the treatment that is available and I have no issues with that whatsoever. Just knowing that it's all available on our doorstep is pretty cool. Participant_033

Participant's message is that treatments need to be holistic

Well, I think for breast cancer, I think we're actually really lucky, I think, because there's a lot of focus on breast cancer. I think that some of the other types are neglected. But I would say more funding for the holistic emotional support because your mental state is so crucial to your recovery. And so I don't think it can be neglected and just go to the purely functional, cut it out, whack the drugs and off you go. So there's so much more to a person. So I think the doctors and nurses that they're just all doing their best. So much more funding round. Participant_001

They also need to make treatment more affordable, that sort of thing. That has to change. Just because you don't have a lot of money and, say, can't afford to pay hundreds of thousands of dollars for treatment, doesn't mean you should be punished for it. We should all be able to access the treatment, especially if we can see that it's working. Basically more, unfortunately, more money needs to be spent on curing cancer or cancer treatments. I don't know if that's ever going to happen. I don't know how much they're going to be able to perfect it, but I can see that it is starting to happen. They also need to do something with regards to the impact that it has on a person's mental health as well. It's still a lot that needs to be done. Participant_038

I would definitely say that people should have equal access to everything. I said before about having surgery paid publicly, so it shouldn't matter. It should all be the same for everybody regardless of whether you're through a private health fund or you have none at all. I feel as though you're actually worse off being through the private system yet our whole tax system says that you need to be part of a private health fund over 30 so it feels very contradictory to me. It'd be one thing I'll definitely say you need to look at. I also think I would be telling him that there needs to be more care given in terms of, I guess if you said holistic. There needs to be more access to physios and psychologists and things like that as part of a government rollout. Participant_036.

Table 9.16 Messages to decision-makers

Message to decision-makers	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=23	%	n=27	%	n=19	%	n=25	%	n=26	%	n=24	%	n=24	%	n=26	%
Participant's message is to improve access to support and care	22	44.00	11	47.83	11	40.74	7	36.84	10	40.00	11	42.31	11	45.83	**8**	**33.33**	14	53.85
Participant's message is to understand the financial implications (and provide financial support)	16	32.00	8	34.78	8	29.63	6	31.58	7	28.00	10	38.46	6	25.00	7	29.17	9	34.62
Participant's message is that tailored care plans are needed	11	22.00	5	21.74	6	22.22	7	**36.84**	3	12.00	4	15.38	7	29.17	7	29.17	4	15.38
Participant's message is to invest in research (including to find new treatments)	7	14.00	4	17.39	3	11.11	2	10.53	4	16.00	3	11.54	4	16.67	4	16.67	3	11.54
Participant's message is to invest in specialist health professionals, especially nurses	7	14.00	3	13.04	4	14.81	2	10.53	4	16.00	2	7.69	5	20.83	5	20.83	2	7.69
Participant's message is that the health system they are satisfied with their care, that it should stay the same	5	10.00	4	17.39	1	3.70	2	10.53	3	12.00	2	7.69	3	12.50	2	8.33	3	11.54
Participant's message is that treatments need to be holistic	5	10.00	2	8.70	3	11.11	2	10.53	2	8.00	2	7.69	3	12.50	3	12.50	2	7.69

Message to decision-makers	All participants		Regional or remote		Metropolitan		Mid to low status		Higher status		Aged 25 to 44		Aged 45 to 54		Aged 55 to 74	
	n=50	%	n=16	%	n=34	%	n=20	%	n=30	%	n=19	%	n=22	%	n=9	%
Participant's message is to improve access to support and care	22	44.00	**9**	**56.25**	13	38.24	7	35.00	15	50.00	9	47.37	8	36.36	**5**	**55.56**
Participant's message is to understand the financial implications (and provide financial support)	16	32.00	5	31.25	11	32.35	**9**	**45.00**	7	23.33	7	36.84	8	36.36	**1**	**11.11**
Participant's message is that tailored care plans are needed	11	22.00	5	31.25	6	17.65	5	25.00	6	20.00	4	21.05	5	22.73	2	22.22
Participant's message is to invest in research (including to find new treatments)	7	14.00	3	18.75	4	11.76	3	15.00	4	13.33	4	21.05	3	13.64	**0**	**0.00**
Participant's message is to invest in specialist health professionals, especially nurses	7	14.00	2	12.50	5	14.71	2	10.00	5	16.67	3	15.79	1	4.55	**3**	**33.33**
Participant's message is that the health system they are satisfied with their care, that it should stay the same	5	10.00	2	12.50	3	8.82	4	20.00	1	3.33	0	0.00	4	18.18	1	11.11
Participant's message is that treatments need to be holistic	5	10.00	1	6.25	4	11.76	1	5.00	4	13.33	1	5.26	3	13.64	1	11.11

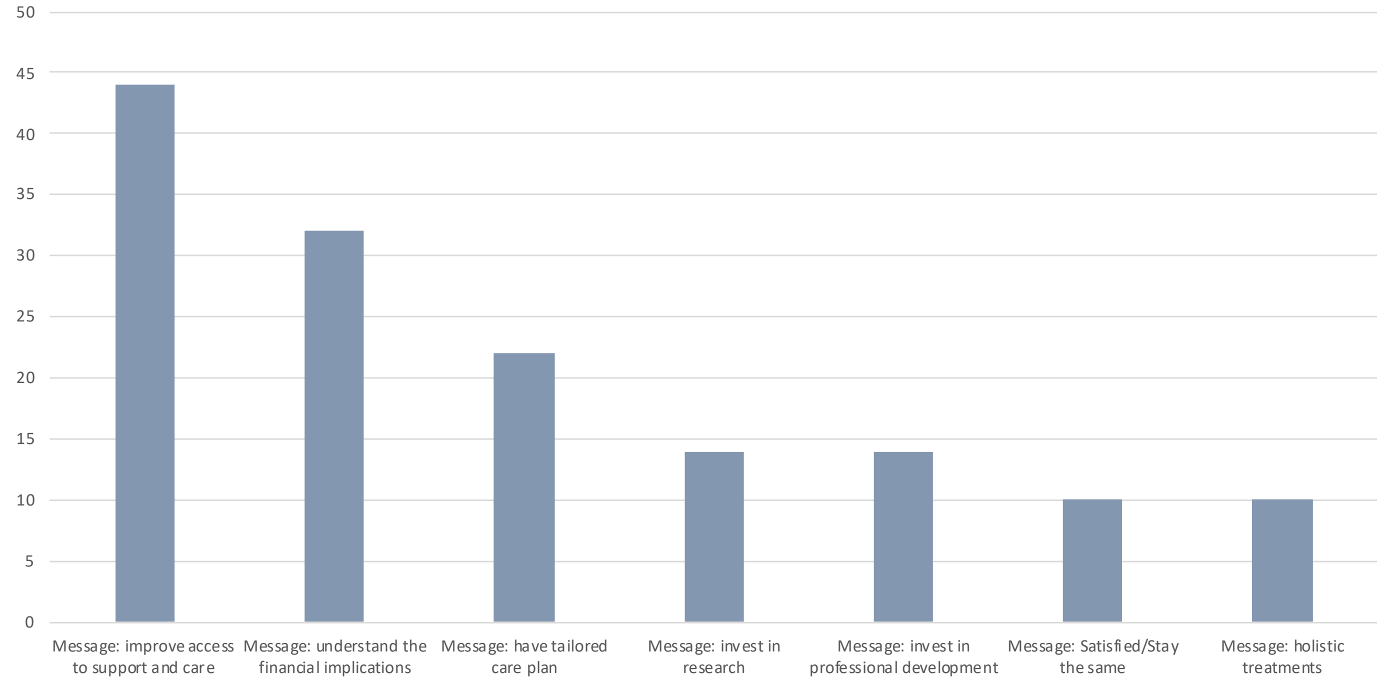

Figure 9.11: Messages to decision-makers

Table 9.17: Messages to decision-makers – subgroup variations

Theme	Reported less frequently	Reported more frequently
Participant's message is to improve access to support and care	Trade or high school	Regional or remote Aged 55 to 74
Participant's message is to understand the financial implications (and provide financial support)	Aged 55 to 74	Mid to low status
Participant's message is that tailored care plans are needed	-	Poor physical function
Participant's message is to invest in research (including to find new treatments)	Aged 55 to 74	-
Participant's message is to invest in professional development so that clinicians understand the condition	-	Aged 55 to 74

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. There were 11 participants (22.00%) that described that they wish they had known more about the pros and cons of treatment options, and this was the most common theme. Other participants wished they had known what to expect from their condition, particularly disease trajectory and understanding of disease biology (n = 10, 20.00%), participants wished they had known more about what support was available to them (n = 10, 20.00%), and participants wished they had known more about side effects of treatments (n = 9, 18.00%). There were 10 participants (20.00%) who did not describe anything that they wish they had known earlier without giving a reason.

Aspect of care or treatment they would change

The most common themes reported were that participants would not change any aspect of their care or treatment/satisfied with care and treatment received (n = 12, 24.00%), followed by participants would not change any aspect of their care or treatment without giving a reason (n = 9, 18.00%). There were seven participants (14.00%) that described that they would change or stop the kind of treatment they received.

Anything participants wish they had known earlier

In the structured interview, participants were asked if there was anything they wish they had known earlier. There were 11 participants (22.00%) that described that they wish they had known more about the pros and cons of treatment options, and this was the most common theme. Other participants wished they had known what to expect from their condition, particularly disease trajectory and understanding of disease biology (n = 10, 20.00%), participants wished they had known more about what support was available to them (n = 10, 20.00%), and participants wished they had known more about side effects of treatments (n = 9, 18.00%). There were 10 participants (20.00%) who did not describe anything that they wish they had known earlier without giving a reason.

Participant wishes they had known more about the pros and cons of treatment options

I guess the main thing for me would have been to know more about the long-term side effects and that if you need to stop treatment, it's okay to stop treatment. I think more knowledge and discussion about if you're having bad side effects, what your options are, and again what the pros and cons of stopping or continuing would make. For me, yes that would be the biggest one. Participant_020

Not really actually. I think I know most of the things, it's just a few questions and answers, but I don't get a straight answer for that anyway. I wish there was more information on the differences between mastectomy, lumpectomy, and then to choose which. I was put in that situation on making my own decision, what I wanted, and it's a huge decision. I just wish there was a bit more guidance in relation to that. Participant_016

Oh my God, there would be lots of things, but basically, a lot of the things that I have already touched on. I think what happens is so much, that obviously the doctors and staff don't know how it actually feels to be with all the treatment and stuff. I think it would have been nice when they are telling you your treatments things, maybe actually have someone there who's been through it, so you can sit with them, and they can actually tell you what to expect. Participant_019

Participant does not describe anything they wish they had known earlier (no reason given)

No, it's nothing. Participant_003

Not that I could think of. Participant_006

No. Participant_007

Participant wishes they had known what to expect from their condition, particularly disease trajectory and understanding of disease biology

I wish I could've seen that I'd come out of it okay but that's impossible. I think maybe talking to people who had-- and I got a certain amount of that through the Facebook group, but talking to people who - someone who's been through the same thing would probably have been useful actually or having access to somebody, not necessarily talking. Participant_004

Yes, just how hard it was going to be. I have stressed what was going to be, not a walk in the park. Participant_028

They don't talk about scans and things at the end. I wish I'd known at diagnosis that they don't scan you at the end of your treatment and things. There's no closure from that point of view. There's no, "I'm getting a PET scan or other scan to make sure it hasn't got anywhere in my body." That seems to be something common that a lot of my friends are all talking about. There's no end-of-treatment scan to say it's all gone. That plays on your mind. I'd like to see that talked about and told that that's the way it's going to be. Also, as I said, the ongoing medical menopause, that side of things afterwards, or how it affects your relationship. I had no idea that at the end of this you wouldn't be-- I knew you'd be not yourself, but I didn't realize that this is still another however many months before you feel well again. All those sort of fud things. Nobody talks about sex either. Nobody tells you that you're not going to have sex the whole time because if you're so sick and then you've got menopause. That's not going to happen either, you need to talk-- I feel as though your partners need to be told that. Your partner is a big part of your life, and that's a big part of most young people's cancer journey. That is just not even discussed, it's a big taboo subject. Participant_036

Participant wishes they had known more about what support was available to them

I wish I could've seen that I'd come out of it okay but that's impossible. I think maybe talking to people who had…and I got a certain amount of that through the Facebook group, but talking to people who - someone who's been through the same thing would probably have been useful actually or having access to somebody, not necessarily talking.
INTERVIEWER: How long did it take for you to access the Facebook groups after your diagnosis? Did it take a little while?
PARTICIPANT: I think it took at least a couple of weeks. I don't think, I even really realized there were Facebook groups and I'm not sure how I even came across them. Participant_004

Definitely the nutrition to start with, the side effects of the chemo, and the neuropathy. If I could have found out there was a way to mitigate that a little bit more. Participant_029

I don't think so. Probably just said access to other services. The broader may be some lists of people that you might consider contacting, and then the track, once you get your head around what's going on for you. In terms of social supports, and physical support at home. Yes. Participant_050

Participant wishes they had known more about side effects of treatments

Yes, the effects of radiation. Participant_012

I guess the main thing for me would have been to know more about the long-term side effects and that if you need to stop treatment, it's okay to stop treatment. I think more knowledge and discussion about if you're having bad side effects, what your options are, and again what the pros and cons of stopping or continuing would make. For me, yes that would be the biggest one. Participant_020

Yes. Probably wish I had of have known more about the gastrointestinal effect and how that can-- That really does alter your life when you're running to and from a room for months on end. That is the biggest pain in the ass. Knowing more about those sort of things. This is really what you have to look out for. If you're going out for a walk, make sure you got a toilet nearby. Those sort of things. Participant_034

Table 10.1: Anything participants wish they had known earlier

Anything participants wish they had known earlier	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=23	%	n=27	%	n=19	%	n=25	%	n=26	%	n=24	%	n=24	%	n=26	%
Participant wishes they had known more about the pros and cons of treatment options	11	22.00	5	21.74	6	22.22	4	21.05	3	12.00	**2**	**7.69**	**9**	**37.50**	6	25.00	5	19.23
Participant does not describe anything they wish they had known earlier (no reason given)	10	20.00	6	26.09	4	14.81	4	21.05	6	24.00	4	15.38	6	25.00	4	16.67	6	23.08
Participant wishes they had known what to expect from their condition, particularly disease trajectory and understanding of disease biology	10	20.00	4	17.39	6	22.22	4	21.05	6	24.00	5	19.23	5	20.83	4	16.67	6	23.08
Participant wishes they had known more about what support was available to them	10	20.00	4	17.39	6	22.22	4	21.05	4	16.00	3	11.54	7	29.17	3	12.50	7	26.92
Participant wishes they had known more about side effects of treatments	9	18.00	5	21.74	4	14.81	4	21.05	3	12.00	4	15.38	5	20.83	4	16.67	5	19.23
Participant wishes they had know the early signs and symptoms of the condition	7	14.00	2	8.70	5	18.52	4	21.05	2	8.00	2	7.69	5	20.83	5	20.83	2	7.69
Participant does not describe anything they wish they'd known earlier as they are learning progressively/continuously	6	12.00	3	13.04	3	11.11	1	5.26	5	20.00	5	19.23	1	4.17	2	8.33	4	15.38

Anything participants wish they had known earlier	All participants		Regional or remote		Metropolitan		Mid to low status		Higher status		Aged 25 to 44		Aged 45 to 54		Aged 55 to 74	
	n=50	%	n=16	%	n=34	%	n=20	%	n=30	%	n=19	%	n=22	%	n=9	%
Participant wishes they had known more about the pros and cons of treatment options	11	22.00	**1**	**6.25**	10	29.41	**2**	**10.00**	9	30.00	6	31.58	3	13.64	**6**	**66.67**
Participant does not describe anything they wish they had known earlier (no reason given)	10	20.00	3	18.75	7	20.59	**7**	**35.00**	3	10.00	**1**	**5.26**	**8**	**36.36**	1	11.11
Participant wishes they had known what to expect from their condition, particularly disease trajectory and understanding of disease biology	10	20.00	**0**	**0.00**	10	29.41	**1**	**5.00**	9	30.00	4	21.05	3	13.64	**4**	**44.44**
Participant wishes they had known more about what support was available to them	10	20.00	4	25.00	6	17.65	3	15.00	7	23.33	4	21.05	3	13.64	**4**	**44.44**
Participant wishes they had known more about side effects of treatments	9	18.00	3	18.75	6	17.65	4	20.00	5	16.67	3	15.79	4	18.18	**3**	**33.33**
Participant wishes they had know the early signs and symptoms of the condition	7	14.00	3	18.75	4	11.76	3	15.00	4	13.33	3	15.79	4	18.18	**3**	**33.33**
Participant does not describe anything they wish they'd known earlier as they are learning progressively/continuously	6	12.00	2	12.50	4	11.76	1	5.00	5	16.67	4	21.05	1	4.55	**4**	**44.44**

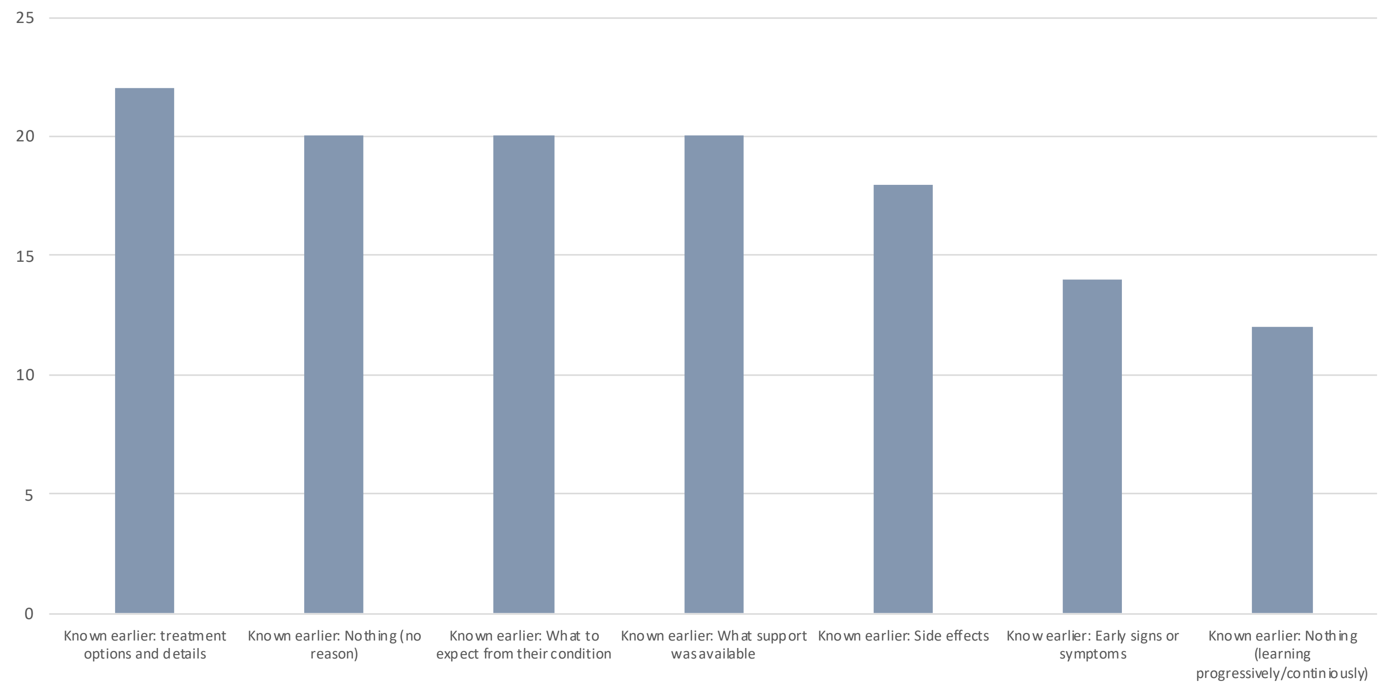

Figure 10.1: Anything participants wish they had known earlier

Table 10.2: Anything participants wish they had known earlier – subgroup variations

Theme	Reported less frequently	Reported more frequently
Participant wishes they had known more about the pros and cons of treatment options	Regional or remote Mid to low status	Aged 55 to 74
Participant wishes they had known what to expect from their condition, particularly disease trajectory and understanding of disease biology		Aged 55 to 74
Participant wishes they had known more about what support was available to them		Aged 55 to 74
Participant wishes they had known more about side effects of treatments		Aged 55 to 74

Aspect of care or treatment they would change

The most common themes reported were that participants would not change any aspect of their care or treatment/satisfied with care and treatment received (n = 12, 24.00%), followed by participants would not change any aspect of their care or treatment without giving a reason (n = 9, 18.00%). There were seven participants (14.00%) that described that they would change or stop the kind of treatment they received.

Participant would not change any aspect of their care or treatment/satisfied with care and treatment received

No. Tiny little things here and there but no, I was quite happy with how everything went. No, I would keep it all definitely. Participant_005

No, because I'm sitting here cancer free and so I. Any changes that I'd made? Might have changed my outcome now, so I can't live with regret. So what if I think. Participant_010

I don't think so. Like I say, I've been fairly good at taking out what I needed in relation to the exercise, and diet, and looking after myself, if there were issues with my care, asking questions and getting the answers that I needed. Yes, I don't think I would have changed anything. I was fortunate that I was able to access the professionals that I needed to in a timely manner. Treatment started fairly quickly and progressed as I thought. I didn't think of the fact that treatment was going to go over such a significant period of time. Other than, like I said, being aware of the long-term effects of treatment, I don't think there's anything else that I would have changed. Participant_013

I would change-- no. I don't believe so, I have the utmost respect for everybody that has been part of my treatment, and I'm forever grateful, the doctors and nurses that have helped me, so no. Participant_029

Participant would not change any aspect of their care or treatment (no reason given)

No, I don't think so. Participant_021

No, not really. Participant_047

No, I don't think so. Participant_049

Participant would change or stop the kind of treatment they received

I think if at the time I wasn't so rushed, I understand a lot of ladies now have chemo before surgery and if that has worked, where that's good psychologically is that you know the chemo has started destroying the tumor and it's shrinking or pitted. In my case, it would've made it smaller, so possibly I wouldn't have had to have some of the muscle in the ribs taken out, which is a little bit painful and possibly, it wouldn't have been such a big lump. Even now, and I say to a lot of people, if I had to have my time again, I would have had the double DIEP reconstruction, to take the anxiety out of having still have mammograms or ultrasounds on the other breast. I would always would have done that. I haven't mentioned that I've had a hysterectomy before and I've also had a new neurectomy from anxiety of being worried about my ovary, that I still had left after a hysterectomy 10 years before.
INTERVIEWER: Okay. You went ahead with that preventatively?
PARTICIPANT: Yes, I did. With the DIEP you can't feel your stomach. When I'd had an ovarian cyst 10 years before, which was a little bit large, I did get flight backache from it and I was worried. Even though the doctors told me it wouldn't happen, I just didn't want to have this ovary sitting in there and never knowing anything about what's going on there. Of course, that's the one cancer that they've got no symptoms. Participant_040

I didn't want to do radiation, and I still don't…I'm not a 100% sure if I did the right thing in having it because obviously, that forced me to have a full surgery rather than have a breast implant put in which is major surgery where he's putting a breast implant and it's not as big a deal. Participant_043

If I'd known I had the gene, I would've had a double mastectomy, instead of a lumpectomy. Other than that, no. Participant_037

Table 10.3: Aspect of care or treatment they would change

Aspect of care or treatment they would change	All participants		Early breast cancer		Advanced breast cancer		Poor physical function		Good physical function		Diagnosed before 2020		Diagnosed in 2020 or 2021		Trade or high school		University	
	n=50	%	n=23	%	n=27	%	n=19	%	n=25	%	n=26	%	n=24	%	n=24	%	n=26	%
Participant would not change any aspect of their care or treatment/satisfied with care and treatment received	12	24.00	**9**	**39.13**	**3**	**11.11**	4	21.05	7	28.00	6	23.08	6	25.00	**3**	**12.50**	**9**	**34.62**
Participant would not change any aspect of their care or treatment (no reason given)	9	18.00	3	13.04	6	22.22	5	26.32	4	16.00	6	23.08	3	12.50	5	20.83	4	15.38
Participant would change or stop the kind of treatment they received	7	14.00	2	8.70	5	18.52	2	10.53	3	12.00	5	19.23	2	8.33	4	16.67	3	11.54
Participant would have liked more time and personalised attention with specialists	4	8.00	2	8.70	2	7.41	2	10.53	2	8.00	2	7.69	2	8.33	1	4.17	3	11.54
Participant would have liked more information/discussion from healthcare staff	4	8.00	1	4.35	3	11.11	3	15.79	0	0.00	1	3.85	3	12.50	2	8.33	2	7.69

Aspect of care or treatment they would change	All participants		Regional or remote		Metropolitan		Mid to low status		Higher status		Aged 25 to 44		Aged 45 to 54		Aged 55 to 74	
	n=50	%	n=16	%	n=34	%	n=20	%	n=30	%	n=19	%	n=22	%	n=9	%
Participant would not change any aspect of their care or treatment/satisfied with care and treatment received	12	24.00	5	31.25	7	20.59	6	30.00	6	20.00	4	21.05	5	22.73	**4**	**44.44**
Participant would not change any aspect of their care or treatment (no reason given)	9	18.00	**6**	**37.50**	3	8.82	5	25.00	4	13.33	3	15.79	4	18.18	**3**	**33.33**
Participant would change or stop the kind of treatment they received	7	14.00	3	18.75	4	11.76	2	10.00	5	16.67	1	5.26	5	22.73	1	11.11
Participant would have liked more time and personalised attention with specialists	4	8.00	0	0.00	4	11.76	0	0.00	4	13.33	2	10.53	1	4.55	**2**	**22.22**
Participant would have liked more information/discussion from healthcare staff	4	8.00	0	0.00	4	11.76	1	5.00	3	10.00	3	15.79	1	4.55	**3**	**33.33**

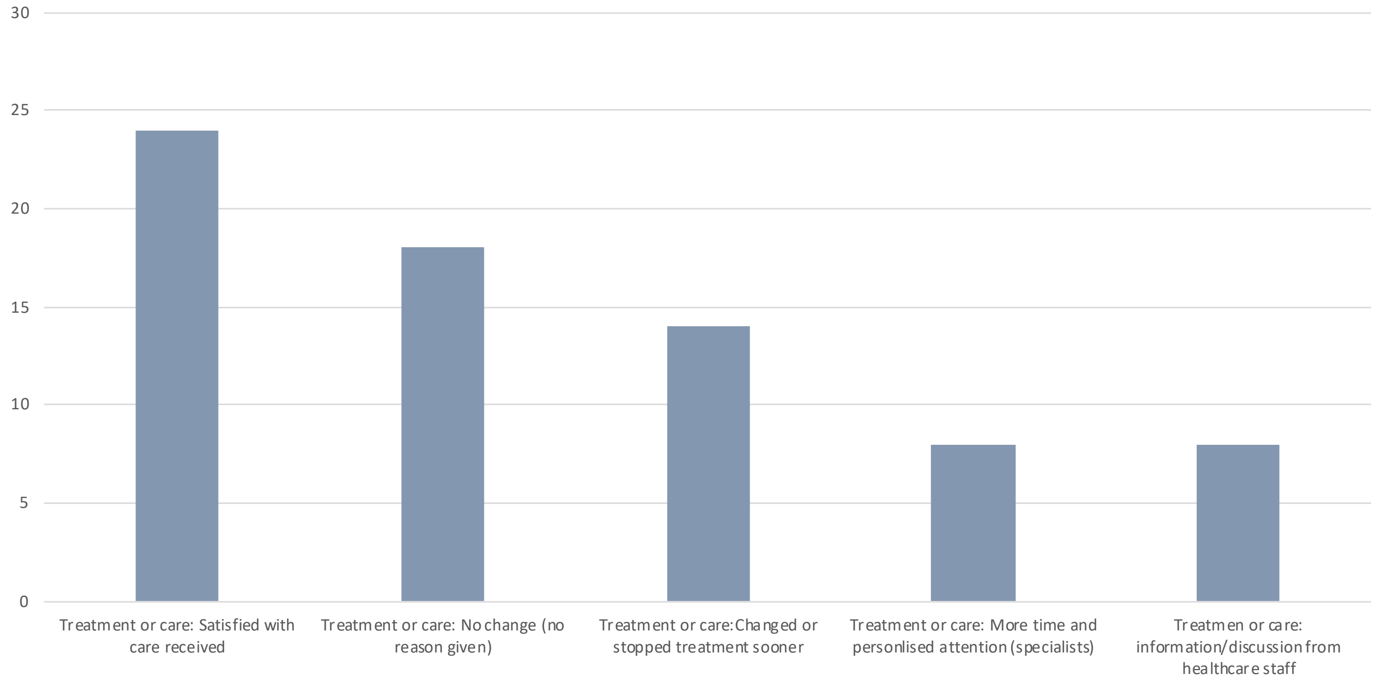

Figure 10.2: Aspect of care or treatment they would change

Table 10.4: Anything participants wish they had known earlier – subgroup variations

Theme	Reported less frequently	Reported more frequently
Participant would not change any aspect of their care or treatment/satisfied with care and treatment received	Advanced breast cancer Trade or high school	Early breast cancer University Aged 55 to 74
Participant would not change any aspect of their care or treatment (no reason given)		Regional or remote Aged 55 to 74

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.

There are very few studies that report the personal experience, expectations, and knowledge of people with triple negative breast cancer. A search of PubMed identified 12 studies conducted in the last 10 years that were focused on triple negative breast cancers. There was a single study that conducted interviews, this was focused on young African-American women with triple negative breast cancer[1]. Five studies reported quality of life as an outcome of clinical trials[2-6]. Two studies focused on clinical trial participation[7,8], one study each on patient activation, health related quality of life [9], lifestyle changes[10], and coping[11].

This PEEK study in triple negative breast cancer includes 50 people diagnosed with triple negative breast cancer throughout Australia. About half were advanced breast cancer, and about half were diagnosed in the last two years. It 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 in a under-reported patient population.

Background

Triple negative breast cancers are defined by the lack of progesterone and oestrogen receptors, and HER2 proteins[12,13]. Triple negative breast cancers are an aggressive form of breast cancer that typically affects younger women, has a poor prognosis, and lack of targeted therapies[14,15].

In 2019, there were 19,371 new cases of breast cancer reported in Australia[16]. Approximately 12 to 17% of all breast cancers are triple negative[14], that is an estimated 3000 new cases of triple negative breast cancer in Australia 2019.

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 proportion of participants that lived in major cities was all similar to that of Australia. There were more that lived in areas with a higher socioeconomic status, higher rates of paid employment, and lower rates of non-school qualifications (certificate, diploma or degree), compared to the Australian population[17-19]. In addition to being in paid employment, half of the participants in this PEEK study were carers to children. There were no participants from the Northern Territory, or Canberra, and there were a higher proportion of participants from Queensland and Western Australia, compared to the proportion that live in each state[20].

Table 12.1: Demographics

Demographic	Australia %	Lupus PEEK %
Live in major cities	71	60
Non-school qualification	65	52
Higher socioeconomic status (7 to 10 deciles)	40	34
Employment (aged 15 to 64)	74	56
New South Wales	32	26
Victoria	26	22
Queensland	20	20
South Australia	7	12
Western Australia	10	12
Tasmania	2	2
Northern Territory	1	0
Australian Capital Territory	2	6

Health status

In PEEK studies we collect information about other health conditions that participants manage, as well as health-related quality of life (with the SF36 questionnaire). The purpose of this is to have an idea of the general health of the participants in the study. We can also compare this data with the Australian population, and with other studies with 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[21]. 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%)[21]. The Australian Bureau of statistics reports that 10% of Australians have depression or feelings of depression and 13.1% have an anxiety-related condition[21].

In this PEEK study, participants had higher levels of anxiety (54% compared to 13%), depression (38% compared to 10%), and similar levels of arthritis (18% compared to 15%), and diabetes (6% compared to 5%) compared to the Australian population.

Baseline health

The Short Form Health Survey 36 (SF36) measures baseline health, or the general health of an individual[22]. 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[22].

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[23]. The triple negative positive breast cancer PEEK participants on average had considerably lower scores for all SF36 domains with the exception of emotional well-being, and role functioning/emotional.

Compared to a PEEK study of 100 participants with breast cancer that was conducted in 2018[24], participants in this Triple negative breast cancer study scored higher in the role functioning/physical, emotional well-being, and pain domains, and worse in the general health domain. The higher scores could in part be due to the younger participant population in the triple negative breast cancer study, and the lower general health due to half of the recent diagnosis for participants in the triple negative study. Another quality of life study comparing 85 African American people with triple negative breast cancer with 245 non- triple negative breast cancer reported worse quality of life in the triple negative groups, in particular with relation to health related anxiety and depression, emotional well-being and functional well-being[9].

In this PEEK study, participants that had poor physical function had lower scores (worse health related quality of live) in the energy/fatigue, social functioning, pain and general health domains, and those that had been diagnosed in the past two years had lower scores for the physical function, pain, and general health domains. A study of 121 participants with triple negative breast cancer in china reported that quality of life was positively associated with income, self-efficacy, and social support, and negatively associated with cancer stage[25], in contrast this PEEK study found no differences in health related quality of life by socio-economic status, or breast cancer stage.

Key points

- This is a population that are in paid employment and are carers to children
- Health related quality of life lower for most domains compared to Australian population

Risks and Symptoms

Early screening can help in reducing breast cancer related mortality and deaths.[26] Mammography is one such procedure which is commonly used and helps in evaluating local stage of disease and response to treatment[26,27]. Ultrasonography can be used as an additional tool for diagnosis of breast cancer [26,28]. 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 [26,28]. Breast self-examination is a cheap and easy procedure which woman can conduct at home [26,29,30] and helps woman to learn about basic structure of breast and detect atypical structures in mammary gland[26,31].

In this PEEK study the most common diagnostic pathway described was self-detecting a lump or other breast abnormality, seeking attention from a general practitioner and being referred to mammogram, ultrasound and biopsy. Very few participants were diagnosed as a result of population screening, as most of the participants are under the recommended age of breast screening in Australia.

Participants in this PEEK study did not feel that they had enough support at the time of diagnosis, in particular older participants. In terms of information given at diagnosis, most were given at least some information but almost half felt they did not have enough information, especially those with trade or high school education, and those that lived in regional areas or lower socioeconomic status areas.

Key points

- Most were diagnosed as a result of finding a lump after self-breast examination
- Emotional support and information needs are not being met at the time of diagnosis

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[32]. The receptor status provides prognosis information and prediction of response to endocrine therapy[33-35]. 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[36].

All participants in this study knew that they had triple negative breast cancer, however, about 30% did not relate this to biomarker status and did not have discussions about biomarkers with their doctor, and wanted to have this sort of testing. Additional information about the implications of breast cancer markers may be important at the time of diagnosis and to help with decision-making.

My breast surgeon explained to me that it wasn't responsive to hormones, and it didn't come back with a HER2. He was the one who explained a little bit more about what triple-negative was, but at no point did I actually grasp how scary triple-negative is. I remember our fertility specialist telling us, because it wasn't hormonally driven, he was happy for us to do another round of IVF with fertility preservation. My husband and I thought we'd got the good breast cancer. Not that there's any good or bad breast cancer, but we were like, "Cool, we get to still do something. We're lucky that we got this version and hadn't got a hormonally driven version. It wasn't until pretty much I'd finished chemotherapy that I actually fully understood what triple-negative meant, and the statistics around triple-negatives, the statistics around survival rate. I remember my surgeon saying to me at the beginning that we needed to make some decisions within the first four weeks because they'd like to do something within the first week, but it was never because it's triple-negative. As far as we were concerned, we've got some good breast cancer and that was what it was. Partcicpant_025

Understanding and knowledge

Knowledge about chronic disease before diagnosis varies between individuals. Some will gain information from family and friends with the condition, though it can result in misconceptions and misunderstandings[37,38]. Some people will seek out information about a possible diagnosis, or explore the reasons for symptoms, before receiving a final diagnosis[39,40] 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[41]. For some people, the first time they have heard of their chronic condition is when they are diagnosed[42]. 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[42].

Most participants in this PEEK study were aware of breast cancer, however, did not know much about triple negative breast cancer. Those that had a good understanding of triple negative breast at diagnosis had a level of understanding due to the explanations given by healthcare professionals, or because of research they had sone themselves during the diagnostic process, or because they had a professional background.

Nothing. I thought breast cancer- I didn't know that there were different types of breast cancer. That was the first thing that I, had no idea. I thought breast cancer was breast cancer. I thought breast cancer, everybody lives, and it's really easy to cure. Because it's so common. I didn't know that obviously, there's Triple-negative, but it's high rate of people that don't survive., I learned so much, I knew nothing. Participant_019

Key point

- There was a lack of awareness of different types of breast cancer, in particular, a lack of knowledge about triple negative breast cancer at the time of diagnosis.

Decision making

The decision-making process in healthcare is an important component in care of chronic or serious illness[43]. 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[44,45], 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[46].

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[47,48]. Most participants were presented with different treatment options (surgery, chemotherapy, and radiotherapy), but when it came to decision making and taking part in treatment decision making, few participated. This could be due to the lack of targeted therapies for this patient group, and the aggressive nature of the disease.

Participants in this PEEK study considered multiple factors when it came to decision making. The most important were taking the advice of their doctor, side effects, efficacy, cost, and quality of life.

Decision making over time had changed for participants, as they become more informed, assertive, and proactive. This may indicate this information needs change over time – with more information needed as treatments progress, especially information about side effects, cost, efficacy, and quality of life.

It has changed, in the sense, I realized that I thought that the approach I was presented with initially, I felt it was a very tunnel-view, like just, "This is what your treatment should be," kind of thing. Whereas, over the course, I realized I have to be in charge of things a lot more. I think I was quite trusting, and I'm not saying I should doubt the health professionals, but I definitely feel like I have a right to ask questions and it's okay to have a more active role in my treatment rather than passive. Participant _016

Key point

- Participants became more assertive and proactive in decision making over time – information should reflect important factors for decision making: side effects, efficacy, cost, and quality of life

Treatment and healthcare provision

In this PEEK study, to get an insight healthcare access, information about access to healthcare professionals, health insurance, health system, and financial consequences from having breast cancer are collected.

Access to health professionals

The main provider of treatment for participants in this PEEK study were medical oncologists. The time to travel to the main provider for treatment was less than 30 minutes for most of the participants in this study. Every participant had access to a medical oncologist, and most had access to a breast cancer surgeon. Over 80% had access to oncology nurses, and access to breast care nurses.

Affordability of healthcare

Almost half of the Australian population have private health insurance with hospital cover[49]. 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%[49]. In this PEEK study, a higher proportion had private health insurance compared to the Australian population. Equal numbers of participants in this PEEK study were treated in the public and private hospital systems.

Most participants in this PEEK study had no problem paying for treatments, and healthcare appointments. However, there was more difficulty paying for essentials such as housing, food and power. Most participants spent under $250 a month in out of pocket expenses, and about half had experienced a reduced household income due to their diagnosis.

Women with breast cancer have reported changing work tasks or changing jobs to manage in the workforce [50,51]. In this PEEK study, approximately a third had either had to quit their job or reduce the number of hours worked, and family members took leave from work to support them. 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[52]. In addition to changes in employment, cost burdens in this PEEK study were also from the cost of treatments, diagnostic tests and scans, and travel and accommodation costs from medical appointments.

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[53]. Neo-adjuvant therapies are used to reduce tumour size and breast conservation[54]. Pathological staging of the axilla is dependent on clinical presentation, clinically negative sentinel lymph node biopsy is usually conducted at the time of surgery[54]. Axillary lymph node dissection is used for clinically positive or if the sentinel lymph node is positive in clinically negative patients[54].

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[55]. 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)[55]. For locally advanced breast cancer, treatment is mastectomy followed by radiation.

The aim of treatment in advanced breast cancer is disease control, symptom palliation and improvement in survival[54]. 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[56].

The majority of participants (80%) had at least one surgery for breast cancer, most commonly a lumpectomy or mastectomy. Over 90% had chemotherapy, the most common regimens were doxorubicin, cyclophosphamide, and paclitaxel, single agent paclitaxel (n=11, 25.00%), and capecitabine. More than half of the participants had radiotherapy, mostly to the primary cancer site.

About half of the participants in this PEEK had current symptoms to deal with; mostly anxiety, fatigue, depression, weight and muscle, sleep, sexual function, and bone problems, of these reported quality of life was lowest from weight changes. Pain and fatigue were ranked as the most important symptoms to control.

Allied health

Allied health is important to manage the physical, emotional, practical and financial consequences of breast cancer. Most participants (77%) used at least one type of allied health service, and on average used two services. The most common types of allied health were psychology and physiotherapy In other breast cancer studies, people with breast cancer have reported that they had a lack of psychological support, physiotherapy, and counselling[57,58]

Lifestyle changes

Diet and exercise needs of people with cancer change throughout the course of their treatment and survivorship[59], and lifestyle changes may be made by individuals to improve treatment outcomes, improve quality of life and reduce recurrence risk factors[60]. 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[61]. In this PEEK study, 86% made at least one lifestyle change following their diagnosis with breast cancer, most commonly diet and exercise changes. A study that included 23 people with triple negative breast cancer lifestyle intervention reported loss in body fat and improved quality of life following exercise and dietary counselling[10].

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[62]. People with breast cancer have expressed a belief that complementary therapies plays role in delivering personalised and holistic treatment[63]. Over 65% of participants in this PEEK study used at least one type of complementary therapy, most commonly mindfulness, massage therapy, and supplements. Similarly, a study of complementary therapy use in Canada, menopausal women with breast cancer, nearly 70% used complementary therapies including mindfulness, and supplements [64]

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 11 August 2021. The search included any study that specifically included triple negative positive breast cancer participants, was conducted in Australia, and was open to recruitment in the last five years. A total of 57 studies were identified that had a target recruitment of between 5 and 2300 participants (median n=178), there were 43 studies that were international, and 14 studies that were conducted exclusively with in Australia. There were 56 studies that were for drug treatments, and one education study. There were 18 studies that were specifically for triple negative breast cancer, and the remaining 39 studies included triple negative breast cancer among other breast cancer or cancer types.

There were 41 studies conducted in Victoria, 40 in New South Wales, 22 in Western Australia, 19 in Queensland, 12 in South Australia, and four in Canberra. There were no studies identified that were open to recruitment in Tasmania or the Northern Territory.

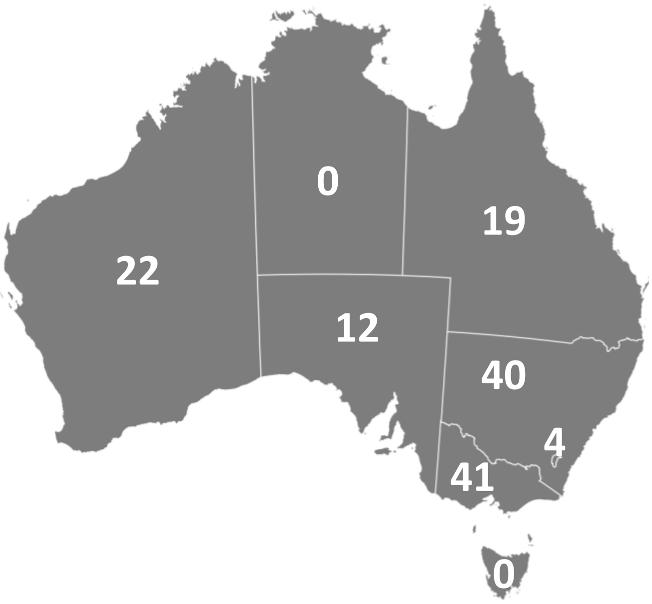

Figure 12.1: Distribution of clinical trials for triple negative breast cancer in Australia 2016-2021

In this PEEK study, 36% of participants had discussions about clinical trials with their doctors. Very few participants had taken part in a clinical trial, though more than 80% had either taken part or were willing to take part in a clinical trial if there was one suitable. One in five participants were not willing to take part in a clinical trial. Another study indicated that 60% of people with triple negative breast cancer would be willing to take part in a clinical trial evaluating different adjuvant treatments[7]. Another study of 15 participants with triple negative breast cancer indicated that people are motivated to take part in clinical trials to benefit both others and themselves[8].

Patient treatment preferences

Clinical guidelines that are aligned to patient preferences are more likely to be used and lead to higher rates of patient compliance[65-67]. 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[65,68].

To help inform patient preferences in the triple negative breast cancer community, participants in this PEEK study discussed side effects, treatment administration, adherence to treatment. Mild side effects were described as side effects that are self managed or do not interfere with life. Some participants used examples to describe mild side effects, such as nausea, feeling of discomfort, or headaches. In a similar way, participants describe severe side effects, broadly as those that impact every day life, or using the examples of pain, emotional/mental struggle, neuropathy, fatigue, and nausea and vomiting. It is interesting to note that participants described, nausea and pain as both mild and severe side effects. Discussing both a list of side effects and the potential impact on daily life may be important for treatment decision making.

In the structured interviews, participants were asked about their treatment goals, what needs to happen to make them feel like the treatment is working, and what it would mean to them if treatments worked. A common theme for these questions was a return to day-to day functionality, and similar themes allowing participation in social and family life, return to work, ability to do domestic tasks, and live with independence.

Physical signs and symptoms was another reoccurring theme for treatment, seeing change in physical signs and symptoms was a signal that treatment is working, and treatment goals included managing side effects, physical improvements in their condition, and improvements in mental and emotional health.

> ***Okay, so for example, with nausea, I would generally only take antiemetics if it was impacting on my diet, the ability of me being able to have a reasonable diet, and also, being able to allow me just to get up and do things. There were a couple of times, I guess, when the nausea was, I wouldn't say it was severe, but it was incapacitating, where you just really didn't feel like getting up and doing too much. Yes, taking antiemetics did relieve that, and allowed me to obviously continue to eat a reasonable diet, and be able to get up and do things. Same with pain, I don't think-- I had very minimal pain through any of my treatments, I really didn't-- I wasn't required--I didn't have to take any analgesia to improve my quality of life. Participant_013***

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[69]. Components of self-management include information, activation and collaboration[69].

Information is a key component of health self-management[70,71]. 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[70,71].

I was very confused actually at the start. The GP told me that I had what mum had. It turns out that was not the case. Hers was DCIS, whereas mine was invasive. I also didn't understand the meaning of triple negative. I actually took that to be a positive because I thought if hormones can't feed the cancer, then it can't grow, but I didn't understand that you can also target the hormones to treat the cancer and I didn't have that option. It took me a bit to understand that because I really thought it was a better diagnosis, but it was actually worse because it was more unknown. Participant 048

Participants in this PEEK study accessed information from a variety of sources including the internet, social media, healthcare providers, and pamphlets or books. They appreciated information from other people with triple negative breast cancer, information specific to triple negative breast cancer, and treatment options. They valued information from healthcare professionals and health charities. Information that is not helpful included information from non-credible sources, and also, a lack of new information was also unhelpful.

A preference for information found on the internet was because it is accessible, allows control and personal research, and because it is convenient. A preference for speaking to a healthcare professional was because of their knowledge, and the ability to ask questions,

Participants in this PEEK study were most often given information about treatment options, hereditary information, disease management and physical activity and least amount of information was given about complementary therapies, interpreting test results, and clinical trials. Of the topics given least by healthcare professionals, complementary therapies and how to interpret test results were the most often searched for topics.

Activation (skills and knowledge)

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[72]. On average, participants in this PEEK study had very good scores for knowledge, recognition and management of symptoms, adherence to treatment, and good scores for coping with breast cancer.

Communication and collaboration

Collaboration is an important part of health self-management, the components of collaboration include healthcare communication, details for available information, psychosocial and financial support [70,71] Communication between healthcare professionals and patients can impact the treatment adherence, self-management, health outcomes, and patient satisfaction[73-76].

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[77].

Building a relationship with patient, families and support networks is fundamental to establishing good communication[77]. 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[77]. 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[77]. 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[77]. 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[78]. On average, the participants in this PEEK study had good communication and navigation of the healthcare system, and rated their quality of care as very good and care coordination as good.

In general, participants in this PEEK study had experienced good communication with healthcare professionals, and they felt they had been treated respectfully. Positive communication was was holistic and helpful, while negative communication was described as limited, not forthcoming, and dismissive. Similarly, another study reported that patient understanding of their condition and ability to seek care when needed was improved when information was delivered in a two-way exchange. [79,80]

I would say that on overall it's been very reasonable. Or however, I think the best information that I was given would have been from the McGrath Breast Care nurse that we have locally. She was excellent. She was very good at explaining, "Okay, about your type of breast cancer, what to expect in regards to treatment, what not to worry about. Don't, don't go looking for information that you don't need to know yet." She was very good at outlining all of that stuff and giving the information that I needed. The manner in which she approached it was very reassuring and settling. I found her the most useful. My breast surgeon was very good. He explained things in detail, and once again, easy to relate to, easy to communicate with. Probably the least helpful would have been my medical oncologist. He's very reserved, and I really had to drag information out of him. I think that, like I said, if I wasn't a health professional, I maybe wouldn't have got told a lot of things, informed a lot of things that I asked questions about. I don't know. I found that while the oncology nurses were great, they were just so busy that often I didn't have time to just stop and chat with you. Participant_013

Key points

- Returning to day-to-day functionality is a common treatment goal.
- Participants actively searched for information about interpreting test results and complementary therapies.

Anxiety associated with condition

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[81].

In this PEEK study, anxiety associated with breast cancer was measured by the fear of progression questionnaire[82]. On average, participants had moderate levels of anxiety with relation to disease progression.

Quality of life

Symptoms from breast cancer and treatments, especially fatigue, nausea, cognitive problems, and physical limitations from loss of muscle strength and limitations on arm movement, impacted their day to day activities[51,83,84]. In particular, it made household tasks, hobbies, work difficult, and had an impact on their ability to maintain their role in the family[51,83,84]. On average, participants in this PEEK study rated their overall quality of life in the life is a little distressing range. Participants in this PEEK study commonly reported that breast cancer had an overall negative impact on their quality of life. This was because of the emotional strain on family, and symptoms and side effects. However, some reported a positive impact, and that was mostly due to changing perspectives on what is important in life.

Participants in this PEEK study commonly reported that breast cancer had an overall negative impact on their quality of life. This was because of the emotional strain on family, and symptoms and side effects. However, some reported a positive impact, and that was mostly due to changing perspectives on what is important in life. Another study that included six interviews with young African-American women with triple negative breast cancer that identified longer and more aggressive treatments with higher burden of care, and feeling out of place with peers had an impact on their quality of life[1].

Yes, yes. Yes. How much detail do you want to have? Because at the time it was there were all sorts of aspects for my children. There was the stress and the worry for my eldest child, who was sort of taking on more of the caring for my role. And then my younger daughter, she he even now she'll wake up and she'll have a nightmare about losing me. So, yeah, there was that sort of stress and anxiety on my children. There was the pressure on my husband to try and look after all the family and hold on to his job and keep up with that to do work after hours. And the worry, the stress for him about losing me and doing all the appointments, all these random appointments that you couldn't change. And he would just have to try and make it work fit into it. So, yes, at the time, the quality of life, it really affected it. And that's had the ongoing effect. It's just had all these knock on effects with our family life. Participant_001

Self-management and self-care can support patients with breast cancer to manage their own care and improve quality of life[85]. Physical activity is considered as a universally accepted self-management technique and it has been demonstrated to have a positive effect on QoL[85]. Physical activity has been observed to improve symptoms related to breast cancer such as fatigue[86,87], psychological problems and physical functioning[87,88] and overall improvements on QOL.[85]

Participants in this PEEK study reported ways they coped with the mental and emotional impact that breast cancer had. The most common ways to cope were remaining social, making lifestyle changes and hobbies , consulting a mental health professional , accepting condition and having a positive outlook, recognising the importance of family and friends, and physical exercise . Some of these coping mechanisms were used to maintain health, such as being physically active socialising with friends and/or family . In addition, health was maintained by diet, complying with treatment, and self care.

It definitely affects my mental and emotional health. The things that I do, I guess I have those self care strategies. So whether it's having a day in bed or a day of eating chocolate and takeaway food, whether it's booking in with a friend and going out to dinner and cocktails, or whether it's going for a massage or a run or a swim, whether it's just being out in the environment and absorbing some of the sun, whether it's going for a facial, I have access the counsellor who's a friend when need be, sometimes just, I guess, to check in and see how I'm going to talk about some things will come up with some strategies to implement, making sure that I sleep very well and that majority of time I am getting a balanced diet and exercise and looking after myself. I'm better at cancelling things. So whereas once upon a time I would be very much about what anyone in my life needed. Now I'm better about putting myself first and not seeing that is selfish, but just also looking after me. So I guess that's an important strategy, is thinking about what my body needs and giving it in that moment and not feeling guilty about that. Participant_010

Key points

- Physical activity was used to maintain both physical and mental health

Characterisation

There were 50 participants with triple negative 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 35 and 54. About half of the participants had completed some university, and most were employed either full time or part time. Almost half of the participants were carers to family members or spouses.

About half of this group had ongoing breast cancer symptoms, commonly had thinking and memory problems, weight and muscle changes, and pain, which all contributed to their 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 experienced breast lumps which lead to their diagnosis. Most participants sought medical attention after noticing symptoms and were diagnosed after their general practitioner sent them for imaging studies. Very few participants were diagnosed through breast cancer screening.

On average, this group had three diagnostic tests for breast cancer, they were diagnosed by a general practitioner in a general practice. The cost of diagnosis was not 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, but 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 study cohort that had little knowledge of triple negative breast cancer before they were diagnosed. This patient population described prognosis in terms of no evidence of disease or in remission, or in terms of statistics, particularly reaching five years.

This is a patient population that had discussions about multiple treatment options, with most being told what to do with little discussion.

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

Within this patient population, most participants had changed decision making over time this was because they had become more informed and assertive.

When asked about their personal goals of treatment or care participants most commonly described wanting to treat the disease and get better.

This is a group who felt they were mostly treated with respect throughout their experience. They were cared for by a medical oncologist, and it usually took less than an 30 minutes to travel to medical appointments.

Three-quarters of this cohort had private health insurance, and equal numbers were treated as either private or public patients. They were equally treated in the private and public hospital systems. This is a group that did not have trouble paying for healthcare appointments, prescriptions. They had some trouble paying for basic essentials such as food, housing and power. Their monthly expenses due to breast cancer were slightly significant.

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

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

More than third had conversations about clinical trials, and they 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 those which can be self-managed and do not interfere with daily life.

This is a study cohort that described severe side effects as those that impact everyday life and the ability to conduct activities of daily living.

This is a patient population that would adhere to treatment according to the advice of their doctor, or as long as prescribed. This is a study cohort that needed to see a reduction in physical signs and symptoms to feel that treatment is working as well. If treatments worked, it would allow them to 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 disease management, treatment options and hereditary considerations from health care professionals, and searched for interpreting test results, and complementary therapies 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, their treating clinician or social media.

This is a study cohort that found information about other people's experience, what to expect from the disease, and information specific to their type of breast cancer as being most helpful.

Participants commonly found information form sources that are no credible unhelpful.

This is a group that preferred online information, or talking to someone. This is a study cohort that generally felt most receptive to information from the beginning, at diagnosis, or during treatment.

Most participants described receiving an overall positive experience with health professional communication (some with a few exceptions) which was holistic, two way and comprehensive. For those that had a negative experience it was mostly communication limited or not forthcoming.

The participants in this study experienced very good quality of care, and 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 most found support through charities, and about a third had no support.

This is a patient population that experienced a negative impact on quality of life largely due to emotional strain on family, and changes to relationships.

Life was a little distressing for this group, due to having breast cancer.

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 remaining social, lifestyle changes and hobbies, and consulted mental health professionals.

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 or after treatments, and when having sensitive discussion about their breast cancer. To manage vulnerability, they relied on support from their medical team.

This cohort most commonly felt there was a mix of positive and negative impacts on their relationships, with some relationships strengthened.

Participants felt they were a burden on their family, due to the extra household duties and responsibilities they had to take on.

Most 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 less side effects and be more effective.

This is a study cohort that would like more information about available services, treatments, and mental and emotional health support.

Participants in this study would like future communication to be more transparent and forthcoming. Many participants were happy with their communication with healthcare professionals.

Participants would like future care and support to include more access to support services..

This patient population was grateful for the timely access to treatment and they were grateful for healthcare staff.

It was important for this cohort to control fatigue, pain, and heart problems. 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 care and support.

This is a patient population that wished they had known more about the pros and cons of treatment, what to expect from their condition especially the disease trajectory and disease biology and about the support services available to them.

The aspect of care or treatment that participants in this study would most like to change is to have changed or stopped the kind of treatment they had, however, many wouldn't change any aspect of their treatment or care.

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Section 12

Next steps

Next steps

At the end of each PEEK study, CCDR identifies key areas that, if improved, would significantly increase the quality of life and/or the ability for individuals to better manage their own health.

In relation to this community, these three areas are:

1. Information: Many participants were unaware of the different types of breast cancer. Sometimes information given was misinterpreted as good news e.g. 'Your cancer is not fed by hormones' was interpreted as good, and not understood that this resulted in different treatment options and a different prognosis. Likewise, all participants knew that they are triple negative, but not aware that these are biomarkers or in-depth understanding of the implications of biomarkers. To this end, it is recommended that at diagnosis, triple negative breast cancer-specific information be discussed (not just provided in writing) and this could be done for example by a nurse educator via telehealth.

2. Cost: This is a group that have an aggressive cancer and are often motivated to opt for private surgery to get it done quickly. Out of pocket expenses from private treatment costs are often unexpectedly high and over time are very costly. Initiatives to educate women on the cost of treatment and likely trajectory of ongoing care would help them to plan ahead, anticipate costs and be able to make more informed decisions.

3. Support: As this is a type of cancer that typically affects younger women, we have seen through the study the impact on ability to work and also, impact on families, particularly those who have young children. Initiatives to support women and families to live with as little interruption to their everyday lives would likely increase quality of life, particularly during treatment. Given the demographic, this may also include additional support to women that are pregnant when diagnosed.

2021 PEEK study in Triple negative 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 Triple negative breast cancer 2021 Metrics

Measure	Detail	Mean	Median
Baseline health (SF36)	Physical functioning	71.36	77.50
	Role functioning/physical	55.11	75.00
	Role functioning/emotional	77.27	100.00
	Energy/fatigue	41.93*	45.00
	Emotional well-being	70.91	74.00
	Social functioning	69.60	75.00
	Pain	63.92	67.50
	General health	51.93*	55.00
	Health change	51.14	50.00
Knowledge of condition and treatments (Partners in Health)	Knowledge	25.98*	26.50
	Coping	16.18*	16.00
	Recognition and management of symptoms	19.61	20.00
	Adherence to treatment	14.45	15.00
	Total score	76.23*	76.00
Care coordination scale	Communication	44.64*	45.00
	Navigation	26.55*	27.00
	Total score	71.18*	72.00
	Care coordination global measure	7.66	8.00
	Quality of care global measure	8.45	9.00
Fear of progression	Total Score	35.89*	36.00
		Percent	
Accessed My Health Record	-	43.18	-
Participants that had discussions about biomarkers/genetic tests	-	72.34	-