Summary of results

Executive summary

There were 52 participants with hormone receptor positive breast cancer in the study from across Australia. The majority of participants lived in major cities, they lived in all levels of economic advantage. Most of the of participants identified as Caucasian/white, aged mostly between 45 and 64. More than half of the participants had completed some university, and most were employed either full time or part time. Half of the participants were carers to family members or spouses.

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

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

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

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

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

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

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

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

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

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

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

Over 80% of this cohort had private health insurance, they were mostly private patients in the private health system. This is a group that did not have trouble paying for healthcare appointments, prescriptions, and paying for basic essentials. Their monthly expenses due to breast cancer were somewhat of a burden.

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

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

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

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

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

This is a patient population which described an amount of time they were willing to adhere to a treatment before giving up, or would continue treatments on the advice of their doctor. This is a study cohort that needed to see symptom reduction to feel that treatment is working. If treatment was working, it would mean that they could do everyday activities and return to a normal life.

Participants in this study had very good knowledge about their condition, were good at coping with their condition, were very good at recognizing and managing symptoms, and were very good at adhering to treatment.

Participants were given information about treatment options, disease management, and physical activity from health care professionals, and searched for treatment options, interpreting test results, and disease management most often. This is a group who accessed information from non-profit, charity or patient organisations most often.

This is a patient population that access information primarily through the internet, and health charities.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Participants' message to decision-makers was to improve access to support and care.

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

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

Section 1

Introduction and methods

Section 1 Introduction and methodology

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

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

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

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

This PEEK study includes 52 people diagnosed with hormone-receptor positive breast cancer throughout Australia, including a qualitative structured interview and quantitative questionnaire. This study in hormone-receptor positive breast cancer is therefore the largest mixed method study reported in an Australian population. In addition, PEEK is a comprehensive study covering all aspects of disease experience from symptoms, diagnosis, treatment, healthcare communication, information provision, care and support, quality of life, and future treatment and care expectations.

Section 2

Demographics

Section 2 Demographics

Breast cancer stage

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

Demographics

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

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

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

Other health conditions

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

Baseline health

SF36 Physical functioning scale measures health limitations in physical activities such as walking, bending, climbing stairs, exercise, and housework. On average, physical activities were slightly limited for participants in this study.

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

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

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

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

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

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

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

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

Section 3

Symptoms and diagnosis

Section 3: Symptoms and diagnosis

Symptoms leading to diagnosis

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

Symptoms leading to diagnosis: Seeking medical attention

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

Symptoms leading to diagnosis: Description of diagnostic pathway

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

Time from symptoms to diagnosis

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

Time from diagnostic test to receiving a diagnosis

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

Diagnostic tests

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

Diagnosis provider and location

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

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

Breast cancer diagnosis

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

Breast cancer stage

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

Understanding of disease at diagnosis

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

Emotional support at diagnosis

Participants were asked in the online questionnaire how much emotional support they or their family received between diagnostic testing and diagnosis. There were 15 participants (28.85%) who had enough support, 11 participants (21.15%) that had some support but it wasn't enough, and 26 participants (50.00%) had no support.

Information at diagnosis

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

Costs at diagnosis

Participants noted in the online questionnaire the amount of out-of-pocket expenses they had at diagnosis, for example doctors' fees, and diagnostic tests. There were 19 participants (36.54%) who had no out of pocket expenses, and 12 participants (23.08%) who did not know or could not recall. There were eight participants (15.38%) that spent Less than $500,, and 13 participants (25.00%) that spent more than $1000.

Burden of diagnostic costs

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

Genetic tests and biomarkers

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

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

Biomarker status

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

Current symptoms

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

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

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

Understanding of prognosis

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

Section 4

Decision-making

Section 4 summary

Discussions about treatment

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

Discussions about treatment (Participation in discussions)

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

Considerations when making decisions

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

Decision-making over time

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

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

Personal goals of treatment or care

Participants were asked what their own personal goals of treatment or care were. The most common response was wanting to be cancer free or avoid recurrence (n=23, 44.23%), and this was followed by wanting to minimise or control side effects (n=20, 38.46%). Other themes included wanting quality of life or return to normality (n=9, 17.31%), and wanting to see improvements in mental or emotional health (n=5, 9.62%).

Section 5

Treatment

Section 5: Experience of treatment

Main provider of treatment

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

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

Access to healthcare professionals

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

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

Health care system

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

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

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

Affordability of healthcare

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

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

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

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

Cost of condition

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

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

Changes to employment status

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

Changes to carer/partner employment status

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

Reduced income due to condition

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

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

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

Treatments overview

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

Surgical treatments

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

Drug treatments

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

Radiotherapy

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

Allied health

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

Lifestyle changes

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

Complementary therapies

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

Clinical trials

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

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

Description of mild side effects

In the structured interview, participants were asked how they would describe the term 'mild side effects'. The most common description of 'mild side effects' was
to describe them with specific examples (n=27, 51.92%). There were 25 participants (48.08%) that described mild side effects as those that do not interfere with daily life, and 19 participants (36.54%) that described mild side effects as those that can be self-managed.

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

Description of severe side effects

In the structured interview, participants were asked how they would describe the term 'severe side effects'. The most common description of 'severe side effects' was a specific side effect as an example (n=30, 57.69%). Other descriptions of 'severe side effects' included those that impact everyday life/ability to conduct activities of daily living (n=26, 50.00%), those that require medical intervention (n=5, 9.62%).

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

Adherence to treatment

Participants were asked in the structured interview what influences their decision to continue with a treatment regime. The most common themes described were adhering to treatment for a specific amount of time (n=20, 38.46%), and as per the advice of their specialist/as long as prescribed (n=19, 36.54%). Other participants described adhering to treatment as long as side effects are tolerable (n=15, 28.85%), and not giving up on any treatment (n=15, 28.85%).

What needs to change to feel like treatment is working

Participants were asked to describe what needs to change to feel like treatment is effective. The most common response from 24 participants (46.15%) was needing to see an improvement in specific symptoms, and this was followed by 19 participants (36.54%) that reported needing to experience an improvement in side effects in general, and needing evidence of stable disease or no disease progression (n= 12, 23.08%). There were 12 participants (23.08%) that described needing to have a balance between benefits and potential side effects, and 11 participants (21.15%), that reported that it was difficult to know if the treatment was working and that they needed evidence.

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

What it would mean if treatment worked

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

Section 6

Information and communication

Section 6: Information and communication

Access to information

In the structured interview, participants were asked what information they had been able to access since they were diagnosed. The most common type of information accessed by 40 participants (76.92%) was the internet in general. There were 29 participants (55.77%) that described accessing from a specific health charity, 24 participants (46.15%) accessed information primarily through other patient's experience. Other types of information accessed included books, pamphlets and newsletters (n=21, 40.38%), from Facebook or social media (n=17, 32.69%), nursing staff (n=17, 32.69%), and their treating clinician (n=14, 36.992%), and through journals and research articles (n=13, 25.00%).

Information that was helpful

In the structured interview, participants were asked to describe what information they had found to be *most* helpful. The most common type of information found to be helpful by 20 participants (38.46%) was information about what to expect (e.g. from disease, side effects, treatment). There were 17 participants (32.69%) that described talking to their doctor or specialist as being helpful, and 11 participants (21.15%) that described other people's experiences as being helpful. Other types of information described as being helpful included information from health charities (n=10, 19.23%), and and information that is specific to their condition and sub-types (n=5, 9.62%).

Information that was not helpful

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

Information preferences

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

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

Timing of information

Participants in the structured interview were asked to reflect on their experience and to describe when they felt they were most receptive to receiving information. The most common time that participants described being receptive to receiving information was from the beginning when diagnosed (n=20, 38.46%), this was followed by participants describing being receptive to information after the shock of diagnosis (n=13, 25.00%), continuously throughout their experience (n=9, 17.31), and after treatment (n=7, 13.46%).

Healthcare professional communication

Participants were asked to describe the communication that they had had with health professionals throughout their experience. The most common theme was that participants described having an overall positive experience (n=32, 61.54%). There were 16 participants (30.77%) that described an overall positive experience, with the exception of one or two occasions, and four participants (7.69%) that had an overall negative experience.

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

Partners in health

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

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

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

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

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

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

Information given by health professionals

information they were given by healthcare professionals. Information about treatment options (n=46, 88.46%), physical activity (n=26, 50.00%), disease management (n=25, 48.08%) and, hereditary considerations (n=22, 42.31%) were most frequently given to participants by healthcare professionals, and, information about how to interpret test results (n=10, 19.23%), complementary therapies (n=9, 17.31%) and, clinical trials (n=7, 13.46%) were given least often.

Information searched independently

Participants were then asked after receiving information from healthcare professionals, what information did they need to search for independently. The topics participants most often searched for were treatment options (n=29, 55.77%), how to interpret test results (n=27, 51.92%), disease management (n=25, 48.08%), and disease cause (n=24, 46.15%) were most searched for by participants, and information about psychological and social support (n=12, 23.08%) and, clinical trials (n=10, 19.23%) were searched for least often.

Information gaps

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

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

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

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

Most accessed information

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

My Health Record

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

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

Section 7

Care and support

Section 7: Experience of care and support

Care coordination

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

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

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

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

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

Experience of care and support

In the structured interview, participants were asked what care and support they had received since their diagnosis. This question aims to investigate what services patients consider to be support and care services. The most common theme was that participant did not receive any help (n=18, 34.62%). This was followed by receiving support through the hospital and clinical setting (n=14, 26.92%), through charities (n=11, 21.15%) and face-to-face peer support (n=8, 15.38%). There were six participants that described not needing any help (11.54%).

Section 8

Quality of life

Section 8: Quality of life

Impact on quality of life

In the structured interview, participants were asked whether they felt that their condition had affected their quality of life. Overall, there were 27 participants (51.92%) that described a negative impact on quality of life, 11 participants (21.15%) that described a minimal impact on quality of life, and six participants (11.54%) that described an overall positive impact on quality of life. There were four participants (7.69%) that reported no impact on quality of life, and the same number that reported a mix of positive and negative impact.

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

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

Impact on mental health

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

In the structured interview, participants were asked what they needed to do to maintain their emotional and mental health. The most common ways that participants reported managing their mental and emotional health was using mindfulness or meditation (n=25, 48.08%), physical exercise (n=19, 36.54%), and consulting a mental health professional (n=16, 30.77%). Other ways to maintain mental health were remaining social and enjoying hobbies (n=13, 25.00%), and the importance of family and friends (n=13, 25.00%). There were five participants (9.62%) that described no activities to maintain mental health.

Regular activities to maintain health

In the structured interview, participants were asked what were some of the things they needed to do everyday to maintain their health? The most common ways that participants reported managing their health were by being physically active (n=25, 48.08%), and the importance of self-care (n=24, 46.15%). There were 16 participants (30.77%) that described understanding their limitations, ten participants (19.23%) that described the importance of complying with treatment, and eight participants (15.38%) that described maintaining a healthy diet. There were eight participants (15.38%) that described no activities to maintain health.

Experience of vulnerability

In the structured interview, participants were asked if there had been times that they felt vulnerable. There were 47 participants (90.38%) who gave a description suggesting that overall they had experiences of feeling vulnerable, and five participants (9.62%) who gave a description suggesting that overall they did not have feelings of being vulnerable.

In relation to when participants felt most vulnerable, the most common themes were feeling vulnerable during or after treatments (n=19, 36.54%), and feeling vulnerable during the diagnostic procedure (n=19, 36.54%). There were 11 participants (21.15%) that described feeling vulnerable because of interactions with their medical team, and eight participants (15.38%) described feeling vulnerable during the surgical procedure.

Methods to manage vulnerability

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

Impact on relationships

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

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

Burden on family

In the structured interview, participants were asked whether they felt that their condition placed additional burden on their family. Overall, there were 26 participants (50.00%) that felt there was an additional burden, and 26 participants (50.00%) that reported no additional burden.

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

Cost considerations

In the structured interview, participants were asked about any significant costs associated with having their condition. There were 48 participants (92.31%) that described some cost burden and four participants (7.69%) that described no cost burden.

Where participants described a cost burden associated with their condition, it was most commonly in relation to the cost of treatments, including repeat scripts (n=43, 82.69%). Other cost burdens were in relation to taking time off work (n=24, 46.15%), the cost of specialist appointments (n=20, 38.46%), the cost of diagnostic tests and scans (n=20, 38.46%), family members needing to take time off work (n=7, 13.46%), and the cost of parking and travel to attend appointments, including accommodation (n=5, 9.62%). There were seven participants (13.46%) that described no cost burden and that nearly everything was paid for through the health system or private coverage.

Experience of anxiety related to disease progression

The **Fear of Progression** questionnaire measures the level of anxiety people experience in relation to their conditions. On average fear of progression score for participants in this study indicated moderate levels of anxiety.

Section 9

Expectations and messages to decision-makers

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

Expectations of future treatment

Participants were asked in the structured interview what their expectations of future treatments are. The most common theme was that future treatments that future treatments would have fewer or less intense side effects (n=27, 51.92%), would have less cost burden (n=17, 32.69%), would be more effective (n=14, 26.92%), and more accessible, (n=8, 15.38%). Other participants would like future treatments to be accompanied with more information about treatment and treatment pathways (n=8, 15.38%), and more open and informed discussions (options, side effects etc) (n=8, 16.00%).

Expectations of future information

Participants were asked in the structured interview if there was anything that they would like to see changed in the way information is presented or topics that they felt needed more information. The most common theme was the expectation that future information will have detailed information about symptom and side effect control) (n=16, 30.77%), and this was followed by more information about services (n=13, 25.00%). Other participants described wanting future information to be more accessible (n=11, 21.15%), to provide details about holistic treatments (n=6, 11.54%), specific to type and stage (n=6, 11.54%), and to age or life stage (n=5, 9.62%). There were six participants (11.54%) that recommended information include personalised records of diagnosis and treatments, and 11 participants (22.00%) that had no recommendations and were satisfied with the information currently available.

Expectations of future healthcare professional communication

Participants were asked in the structured interview what they would like to see in relation to the way that healthcare professionals communicate with patients. The most common theme was that participants had no recommendations and they had experienced good communication (n=29, 55.77%). Other themes about expectations of future communication included that communication will be more transparent and forthcoming (n=16, 30.77%), and that communication will be more empathetic (n=11, 21.15%).

Expectations of future care and support

Participants were asked in the structured interview whether there was any additional care and support that they thought would be useful in the future, including support from local charities. The most common theme was that future care and support support will include more access to appropriate, real-world support services (n=34, 65.38%). Other expectations include long term condition management (n=7, 13.46%), mental health and emotional support (n=6, 11.54%), being able to connect with other patients through peer support (support groups, online forums) (n=6, 11.54%). There were 11 participants (21.15%) with no recommendation as they were satisfied with the care and support received.

What participants are grateful for in the health system

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

Symptoms and aspects of quality of life

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

Values for decision makers

The most important values were “Quality of life for patients”, and “All patients being able to access all available treatments and services”. The least important was “Economic value to government and tax payers”.

Values in making decisions

The most important aspects were “How safe the medication is and weighing up the risks and benefits”, and “The severity of the side effects”. The least important were “The ability to include my family in making treatment decisions” and “The financial costs to me and my family”.

Time taking medication to improve quality of life

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

Most effective form of medicine

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

Messages to decision-makers

Participants were asked, “If you were standing in front of the health minister, what would your message be in relation to your condition?” The most common messages were to improve access to support and care (n=26, 50.00%), and to that treatments need to be more affordable (n=13, 26.00%). Other messages included the need to invest in research (n=9, 17.31%), the need for timely access to treatments (n=9, 17.31%), to understand the financial implications (and provide financial support) (n=8, 15.38%), the need to be compassionate and empathetic (n=6, 11.54%), the need for holistic treatments (n=6, 11.54%), invest in screening and early detection (n=6, 11.54%), better treatment access in rural and remote communities (n=6, 11.54%), and support for side effects and symptoms including long term follow up and support (n=6, 11.54%).

Section 10

Advice to others in the future: The benefit of hindsight

Section 10: Advice to others in the future

Anything participants wish they had known earlier

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

Aspect of care or treatment they would change

In the structured interview, participants were asked if there was any aspect of their care or treatment they would change. The most common themes were that they would not change any aspect of treatment or care without giving a reason (n=13, 25.00%), and that they would not change any aspect because they were satisfied with their care or treatment (n=9, 17.31%). Other themes include changing or stopping treatment sooner (n=4, 7.69%), and having a better understanding of their condition (n=4, 7.69%).