

# Section 11

## Discussion

## Introduction

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

This PEEK study in hormone receptor-positive breast cancer includes 52 people diagnosed with hormone receptor-positive breast cancer throughout Australia.

## Background

The estimated incidence of breast cancer in Australia was over 19,000 cases, and it was the most diagnosed cancer in women, and the most diagnosed cancer overall<sup>1</sup>. 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<sup>1</sup>. Approximately 55% of women aged 50 to 74 participated in breast cancer screening in the 2015 to 2016 period<sup>1</sup>.

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%<sup>1</sup>.

Hormone-receptor positive breast cancers are sensitive to estrogen or progesterone, approximately 70% of breast cancers are hormone-receptor positive<sup>2</sup>. Adjuvant treatment with tamoxifen is recommended, followed by an additional five years for pre or perimenopausal women, and an additional five years with tamoxifen or an aromatase inhibitor for postmenopausal women<sup>2</sup>.

Hormone therapy increases overall survival, decreases risk recurrence, and decreases risk of contralateral breast cancer<sup>2,3</sup>. However, risks from hormone treatment include menopausal symptoms, additional risks from tamoxifen included endometrial cancer, deep vein thrombosis or pulmonary embolism, and

uterine cancer, additional risks from aromatase inhibitors include heart disease, and osteoporosis<sup>2,4</sup>.

## Demographics

The demographic data we collect in the PEEK study helps us to understand how our PEEK participants compares to people in Australia, and with people that have breast cancer.

In this PEEK study, the proportions of participants that lived in areas with higher socioeconomic status, that had non-school qualifications (certificate, diploma or degree), and the proportion in paid employment were all similar to that of Australia. There were more that lived in major cities, and with compared to the Australian population<sup>5-7</sup>. There were no participants from the Northern Territory, or Canberra, and there were a lower proportion of participants from Victoria, while a greater proportion from Queensland compared to the proportion that live in each state<sup>8</sup>.

**Table 12.1: Demographics**

Demographic	Australia %	Hormone receptor-positive breast cancer PEEK %
Live in major cities	71	79
Non-school qualification	65	67
Higher socioeconomic status (7 to 10 deciles)	40	65
Employment (aged 15 to 64)	74	72
New South Wales	32	35
Victoria	26	17
Queensland	20	27
South Australia	7	6
Western Australia	10	12
Tasmania	2	0
Northern Territory	1	0
Australian Capital Territory	2	4

## Health status

In PEEK studies we collect information about other health conditions that participants manage, as well as health-related quality of life (with the SF36 questionnaire). The purpose of this is to have an idea of the general health of the participants in the study. We can also compare this data with the Australian population, and with other studies with breast cancer participants.

## Other health conditions

The National Health Survey was conducted in 2017 to 2018, it is an Australia wide survey conducted by the Australian Bureau of statistics. Almost half of the Australian population have one chronic condition<sup>9</sup>. 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%)<sup>9</sup>. The Australian Bureau of statistics reports that 10% of Australians have depression or feelings of depression and 13.1% have an anxiety-related condition<sup>9</sup>.

In this PEEK study, participants had higher levels of anxiety (60% compared to 13%), depression (37% compared to 10%) compared to the Australian population.

### Baseline health

The Short Form Health Survey 36 (SF36) measures baseline health, or the general health of an individual<sup>10</sup>. 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<sup>10</sup>.

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<sup>11</sup>. The hormone-receptor positive breast cancer PEEK participants on average had considerably lower scores for all SF36 domains with the exception of emotional well-being, role functioning physical, and role functioning emotional.

### Risks and Symptoms

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

In the PEEK study, information about symptoms and quality of life from symptoms before diagnosis are collected in the online questionnaire, and in the interview, participants talk about the symptoms that actually lead them to get a diagnosis. Taken together, we can get an insight into the number and type of symptoms participants get, the symptoms that impact quality of life, and the symptoms that prompt medical attention.

The most common symptom of breast cancer among women is breast lump with other symptoms commonly reported including nipple abnormalities, breast pain and breast skin abnormalities<sup>12</sup>. Other less common symptoms are a change in the appearance of nipples, nipple discharge, breast contour abnormalities, breast ulceration and infection or inflammation of breast<sup>12</sup>.

Half of the participants noted that they had a breast lump which led them to seeking medical attention, and subsequently diagnosed. Almost 27% had no symptoms and were diagnosed following screening. In addition, approximately 13% noted a family history or a history of non-cancerous breast conditions that made them more vigilant about breast cancer screening. Where participants had symptoms, most sought medical attention soon after noticing symptoms.

Breast cancer can also lead to psychological distress, lymphoedema, fatigue, estrogen deprivation, insomnia and cognitive impairments<sup>13,14</sup>. In addition, people with breast cancer have reported ongoing mental health issues including depression and anxiety<sup>15</sup>.

Similarly, in this PEEK study, almost half of the participants had current symptoms, most commonly fatigue, pain, weight and muscle changes, cognitive problems, anxiety and depression. In addition, over half reported sleep problems. Participants rated their quality of life from these symptoms in the distressing to a little distressing range.

#### Key point

- Rates of anxiety and depression in the PEEK study were higher compared to the Australian population

### Screening and diagnosis

Early screening can help in reducing breast cancer related mortality and deaths<sup>16</sup>. Mammography is one such procedure which is commonly used and helps in evaluating local stage of disease and response to treatment<sup>16,17</sup>. Ultrasonography can be used as an additional tool for diagnosis of breast cancer<sup>16,18</sup>. 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<sup>16,18</sup>. Breast self-examination is a cheap and easy procedure which woman can conduct at home<sup>16,19,20</sup> and helps woman to learn about basic structure of breast and detect atypical structures in mammary gland<sup>16,21</sup>.

In this PEEK study, more than 60% of the participants found had symptoms of breast cancer and sought medical attention from their general practitioner, the remaining were diagnosed with breast cancer following breast cancer screening. Participants on average had three diagnostic tests, and the most common diagnostic tests were mammogram, breast ultra sound, an core biopsy.

#### Key point

- Half of the participants were diagnosed as a result of finding a lump after-breast self-examination

### Biomarkers or genetic markers

Biomarkers can be used for diagnosis, to monitor a condition, to predict response to therapy, or to predict disease course.

In Australia, immunohistochemical assays to determine oestrogen receptor (ER) and progesterone receptor (PR) status are routinely performed on invasive breast carcinomas and are often performed on ductal carcinoma in situ<sup>22</sup>. The receptor status provides prognosis information and prediction of response to endocrine therapy<sup>23-25</sup>. 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<sup>26</sup>.

In this PEEK study, about a third of participants did not have any discussions about biomarkers, and about half of the participants were not aware that they had any biomarker tests, however, all the participants were aware of their ER status. This suggests that participants were not given enough information, or that communication was lacking about tests and the significance of the biomarker status.

### Support at diagnosis

Other breast cancer studies have reported that people with early breast cancer were not prepared for their diagnosis despite early warnings from screening clinic or GP<sup>27</sup>. In a meta-analysis of qualitative breast cancer studies, common themes at diagnosis included shock, being overwhelmed, emotional upset, and disbelief, surprised they were diagnosed with cancer despite maintaining a healthy life style such as good diet, having regular mammograms, not smoking or drinking and not experiencing high level of stress<sup>28</sup>.

In this PEEK study, over 70% had either no support, or not enough support at diagnosis, and a little over 40% had no information or not enough information at diagnosis.

### Understanding and knowledge

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

Knowledge about chronic disease before diagnosis varies between individuals. Some will gain information from family and friends with the condition, though it can result in misconceptions and misunderstandings<sup>29,30</sup>. Some people will seek out information about a possible diagnosis, or explore the reasons for symptoms, before receiving a final diagnosis<sup>31,32</sup> 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<sup>33</sup>. For some people, the first time they have heard of their chronic condition is when they are diagnosed<sup>32</sup>. 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<sup>32</sup>.

In this PEEK study, most participants had at least some knowledge of breast cancer at diagnosis, often because of their professional background or because they researched breast cancer during the diagnostic process. Some participants noted a lack of knowledge about the different types of breast cancer, and the age group that breast cancer can occur. The majority of participants (60%) thought that they had enough information at diagnosis.

A qualitative study of older women with breast cancer reported that unless the women had worked as medical professionals themselves or knew other women with breast cancer, they were largely unfamiliar with breast cancer and its treatment before diagnosis<sup>34</sup>. In this PEEK study, one of the most common reasons for having some understanding of breast cancer was from having a professional background, and also having had a friend or family member with breast cancer.

In another early breast cancer study, people with breast cancer felt unable to cope with the situation and the large amount of information they were given, and felt unable to ask questions<sup>27</sup>. In this PEEK study,

timing of information was important, with many feeling unable to digest information at the time of diagnosis.

#### Key points

- Emotional support and information needs are not being met at the time of diagnosis
- Information and discussion about biomarkers, including what they are, and relevance in treatment and prognosis is lacking, despite participants being well informed about biomarker status

### Decision making

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

The decision-making process in healthcare is an important component in care of chronic or serious illness<sup>35</sup>. 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<sup>36,37</sup>, 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<sup>38</sup>.

The majority of participants in this PEEK study were presented with multiple treatments or approaches to manage their breast cancer. More than half of the participants felt they did not take part in the decision making process, sometimes there was a discussion about treatments, but some participants described being told what to do without discussion.

People with breast cancer discussed importance of information exchange with their doctor to encourage communication about values and to give the patient greater ownership of treatment decisions<sup>39</sup>. Another study reported that some worked collaboratively and were able to decide their treatment based on own preferences, others felt they had no choice, or were so confused by information presented that they did what the doctor told them to<sup>40</sup>.

Treatment decision making in oncology requires a balance between efficacy and toxicity in order to maintain quality of life. Women with breast cancer have an identifiable role to play in taking part in

decision making, however there is often an imbalance between health providers and patients in shared decision-making process and it has been reported not all women wish to be actively involved in shared decision making<sup>41</sup>. In this PEEK study, about 15% of participants took the advice of their doctor as the only consideration when making decisions about their treatment.

People with breast cancer have reported that did not have any choices for neoadjuvant systemic therapy, the decisions were made during or shortly after first consultation, most felt they made the final decision to have treatment but did not feel actively involved in the process<sup>42</sup>. In Another study, most women agreed with doctors recommendations but did not see this as decision making. Over 80% felt they had some part in decision making, with similar rates in metropolitan and rural locations<sup>43</sup>. In this PEEK study, less than half of the participants described actively taking part in the decision making process, with about 15% being told what to do without discussion.

Confidence to take part in decision-making is increased by knowledge, being prepared with relevant questions for their consultation, and summaries of previous consultations and results<sup>44,45</sup>.

People with breast cancer consider the experiences of others with breast cancer, comorbidities, logistic and convenience, survival, recurrence and access to clinical trial or new treatment, when making treatment decisions<sup>34,39,43,46-49</sup>.

In this PEEK study, taking side effects into account was the most common consideration when making decisions. Other considerations were taking the advice of their doctor, efficacy, and survival benefit. Some considered quality of life, the impact on their family, their ability to work, and how the treatment is given.

People with breast cancer noted that their lived experience of illness and treatment had made them more self-confident and assertive<sup>39</sup>. In this PEEK study, about half of the participants had changed the way they made decision-making about treatments over time, because they had become more informed and assertive over time, and considered quality of life and the impact of side effects. For those that did not change their decision making over time, this is because they were always informed or assertive, or always took the advice of their doctor.

### Goals of treatment and decision-making

People with breast cancer have stated goals such as being around for their children or family, being around for important events, and to have peace of mind<sup>46-48,50</sup>.

The most common goal of treatment was to be cancer free, and avoid recurrence. However, minimising side effects, improving quality of life, improving mental and emotional health were also common treatment goals. People with breast cancer reported that supportive resources from family and friend and medical advice from clinicians helped with treatment goals<sup>39</sup>.

### Access to health professionals

People with breast cancer have described a preference for oncology based follow up, driven by the need for reassurance that the cancer has not returned, but also want their GP involved<sup>51</sup>. In this PEEK study, the main treatment provider for half of the participants was their oncologist, other main providers of treatment were surgeons and general practitioners.

People with breast cancer living in regional areas have barriers to treatment, including low socioeconomic status, limited health services, distances to health services, and a lack of support for women that need to travel<sup>52</sup>. There were 12% of participants in this PEEK study that had to travel for more than an hour to get to their main provider of treatment, and 21% of participants lived in regional or remote areas.

### Affordability of healthcare

*Obviously, those systems to be there in place to support the family, financially, especially, but making it more simple. I found, obviously, not being able to get support, financially, from all authority but several income places like that really frustrating and I feel like that thing that I didn't have to deal with and I shouldn't have had to deal with. I think I'm not the first person with a chronic illness or an illness that can't go to work for a period of time that intends on going back to work. I think having support better there, in losing a person's entire income it shouldn't just be on the other person to pick up the slack. I think that's really crap and I think that's really put a lot of pressure on us that didn't need to be there. I'm just grateful for everything else because of the government and in saying that Medicare has been amazing. We were so grateful to have Medicare to support me through my treatments because, obviously, without that, it could have been a lot more difficult. Having that support to gain that financial support would have been really good because I had to use it for my leave or my sick leave and I was just glad*

*I had that there. Then for Centrelink to not come to the party once that run out, I was like, "Why? Why are you not helping me?" That was frustrating but otherwise, it worked. Participant 042\_2021AUHRP*

Almost half of the Australian population have private health insurance with hospital cover<sup>53</sup>. 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%<sup>53</sup>. The majority of participants in this PEEK study had private health insurance (80%), 57% were mostly treated as a private patient, 25% as a public patient, and 18% a mix of both. Almost half of the participants were mostly treated in private hospitals, approximately 22% were treated mostly in the public system, and 29% were treated in both systems.

Financial difficulties have been reported for people with breast cancer, including difficulties for themselves and their families, interruptions to work and career progression<sup>28</sup>. People with low socioeconomic status have reported difficulties affording transportation, and housing<sup>54,55</sup>. Participants in this PEEK study rarely delayed or missed paying for healthcare appointments due to cost, and rarely did not fill prescriptions due to cost, and while they generally did not have trouble paying for basic essentials, this was more of a problem than paying for medical appointments and prescriptions.

Almost all the participants in this PEEK study described at least some cost burden as a result of their diagnosis with breast cancer. The cost burdens mostly related to the cost of treatments, the cost of specialists, scans and diagnostic tests, and the costs of parking and travel associated with their treatments.

Women with breast cancer have reported changing work tasks or changing jobs to manage in the workforce<sup>56,57</sup>. As a result of cognitive side effects, people with breast cancer have made work changes such as reduced hours, changing roles, and working extra hours to complete tasks<sup>58</sup>. Almost half of the participants in this PEEK study described a cost burden from loss of income, not only from having to take time off themselves, but also from family members needing to take time off. In another study, almost 80% of spouses reported absences from work due to their partners breast cancer, and had a mean salary loss of \$1820 Canadian<sup>59</sup>.

*I was at work the day I went for my mammogram and then I couldn't go back because I was having treatment. Then I really couldn't give my work a date when I would go back. As a result of it all, I ended up taking now redundancy. I struggled with that because I absolutely loved my work. I wasn't ready to give up but in hindsight now, I'm over that now. I don't know what you've seen in terms of costs in there. Out of pocket was almost treatment at the time of the radiation. The radiation I think was \$22,000 and I think I got back about \$10 so I was out of pocket \$12,000. What annoyed me and this is just a little bit of a gripe I guess, I've worked all my life. I've paid my Medicare, I've paid private health. Then there's people beside me there who were getting it for free, having exactly the same treatment as me so that was a little bit like—I know that they probably deserve. Everyone deserves the right to get the treatment but they were there at the private hospital having it for free where I was paying the \$22,000. I've worked hard all my life to get savings to do all that. This isn't nearly true at all but that sum was a little bit, well, I think if it was good enough for them to have it for nothing, it probably was good enough for me to have it for nothing. Participant 004\_2021AUHRP*

#### Key points

- With a large proportion of private healthcare usage and cost burden, there is a need for transparency around treatment costs
- Loss of income places a financial burden on people with breast cancer and their families.

#### Treatment

The aim of surgery is excision of tumour with adequate margins or greater than 1mm. If local excision of not achievable or the tumour is large, multifocal or at the choice of the patient, a mastectomy is performed<sup>60</sup>. Neo-adjuvant therapies are used to reduce tumour size and breast conservation<sup>61</sup>. Pathological staging of the axilla is dependent on clinical presentation, clinically negative sentinel lymph node biopsy is usually conducted at the time of surgery<sup>61</sup>. Axillary lymph node dissection is used for clinically positive or if the sentinel lymph node is positive in clinically negative patients<sup>61</sup>.

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<sup>62</sup>. 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)<sup>62</sup>. For locally advanced breast cancer, treatment is mastectomy followed by radiation.

Adjuvant treatment is determined by pathological outcomes, the biology of the tumour including histological grade, hormone receptor status and the amplification status of the HER2 gene in addition to lymph node status<sup>61</sup>. Five year Tamoxifen treatment is standard for pre-menopausal treatment of oestrogen receptor positive causes<sup>60</sup>, and aromatase inhibitors for post-menopausal women<sup>63</sup>, women who become post-menopausal benefit from changing to aromatase inhibitors<sup>3</sup>. There is benefit in continuing hormonal therapies to ten years, those who remain pre-menopausal continue with tamoxifen<sup>3</sup> and post-menopausal the aromatase inhibitor letrozole<sup>64</sup>. The use of bisphosphonates reduces the risk of distant recurrence in post-menopausal women<sup>65</sup>. For HER2 positive, the monoclonal antibody trastuzumab<sup>65</sup> is used. Combination chemotherapy for early breast cancer only gives a small improvement on survival because the curative rate of surgery and hormone therapy in this group is high<sup>66</sup>.

Chemotherapy is used in hormone receptor negative disease, HER2 positive, and rapidly progressive disease<sup>61</sup>. For early and locally advanced breast cancer with positive lymph nodes, docetaxel chemotherapy is recommended<sup>62</sup>. On progression of advanced breast cancer, a sequence of single agent and combinations are used including single agent docetaxel, single agent vinorelbine, single agent capecitabine and combination gemcitabine and paclitaxel<sup>67</sup>.

The aim of treatment in advanced breast cancer is disease control, symptom palliation and improvement in survival<sup>61</sup>. Hormonal treatment is used in oestrogen receptor positive women, the type is dependent on menopausal status<sup>61</sup>. Following resistance to hormone treatment, the hormone therapy exemestane is used with an enzyme inhibitor everolimus<sup>68</sup>. 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<sup>67</sup>.

In this PEEK study, there were 46 participants (88.46%) that had surgery (most commonly a lumpectomy), 48 participants (92.31%) that had drug treatments (most commonly Tamoxifen), and 42 participants (80.77%) that had radiotherapy. Almost half of the participants in this PEEK study were at least sometimes were concerned about what will happen when a successful treatment is finished.

## Allied health

Allied health is important to manage the physical, emotional, practical and financial consequences of breast cancer. side effects of breast cancer.

More than 75% of participants in this PEEK study had used at least one type of allied health to manage their breast cancer. The most common type was physiotherapy, with about 60% having used this type of support. Approximately a third had seen a psychologist. In other breast cancer studies, people with breast cancer have reported that they had a lack of psychological support, physiotherapy, and counselling<sup>69,70</sup>.

## Lifestyle changes

Diet and exercise needs of people with cancer change throughout the course of their treatment and survivorship<sup>71</sup>, and lifestyle changes may be made by individuals to improve treatment outcomes, improve quality of life and reduce recurrence risk factors<sup>72</sup>. 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<sup>73</sup>.

People with breast cancer have reported weight gain, this is from treatment side effects, and psychological issues related to readiness to change and self-regulation<sup>74</sup>. Habitual physical activity has been reported to help with making positive diet changes<sup>74</sup>. Other benefits of lifestyle changes are demonstrated in a yoga intervention, where participants described improved physical, mental and social functioning, in addition, they benefited from being able to share breast cancer experience within yoga group<sup>75</sup>.

In this PEEK study, 87% of participants described making at least one lifestyle change, this was most commonly exercise and diet. In addition, physical exercise was cited as a way to manage both their mental and general health.

## Complementary therapies

The advancements in the treatment of breast cancer and improvements in survival come with ongoing side effects which need to be managed, and one area of practice that has the potential to alleviate symptoms and side effects is complementary therapies<sup>13</sup>. People with breast cancer have expressed a belief that

complementary therapies plays role in delivering personalised and holistic treatment<sup>76</sup>.

In this PEEK study, 77% of participants used at least one type of complementary therapy, most commonly taking supplements, or using mindfulness or relaxation techniques. Mindfulness and relaxation techniques were described as ways that helped participants deal with the impact of breast cancer on their mental health and to deal with their vulnerability. Similar to a study of complementary therapy use in Canada, menopausal women with breast cancer, nearly 70% used complementary therapies including mindfulness, and taking supplements<sup>77</sup>.

### Key point

- Complementary therapies and lifestyle changes were used by over 75% to help manage their breast cancer

## Clinical Trials

Clinical trials are essential for development of new treatments. The benefits to participants include access to new treatments, an active role in healthcare, and closer monitoring of health condition. The risks to participants include new treatment may not be as effective, and side effects.

A search of the Australian New Zealand Clinical Trials Registry was conducted on 4 October 2021. The search included any study that was specific to hormone-receptor positive (ER and/or PR positive) breast cancer participants, was conducted in Australia, and was open to recruitment in the last five years. A total of 37 studies were identified that had a target recruitment of between 8 and 5101 participants (median=221), there were 27 studies that were international, and 10 studies that were conducted exclusively with in Australia. There were 32 studies that were for drug treatments, two radiotherapy treatment, one lifestyle intervention, and one pathology/multidisciplinary team study.

There were 29 studies conducted in Victoria, 27 in New South Wales, 16 in Western Australia, 15 in Queensland, 13 in South Australia, four in Canberra, two in Tasmania, and one in the Northern Territory. There were no studies identified that were open to recruitment in Tasmania or the Northern Territory.



In this PEEK study, 33% of participants had discussions about clinical trials with their doctors. Very few participants had taken part in a clinical trial, though more than 76% had either taken part or were willing to take part in a clinical trial if there was one suitable.



**Figure 12.1: Distribution of clinical trials for Hormone-receptor positive breast cancer in Australia 2016-2021**

#### Patient treatment preferences (side effects)

*We're given information sheets with each new drug that we're taking or going to take, but they skim through some of the side effects that maybe if they have information sheets about the actual side effect itself and what that could look like for you. For example, things like peripheral neuropathy. It's not just hands and feet, there's so many different things that it affects, and I wasn't aware of that until-- I didn't get that information from my medical team, it was more from the McGrath nurse, breast cancer nurse. She was able to give me a huge-- or she printed off a lot of information and sent it to me about what affected. When I read that information sheet, I went, "Oh my gosh, this is what I'm going through." I was able to take that to my medical team and say, "This is what I'm--" I couldn't put it into the right words that this is what I'm going through. Then, there was other treatments that was offered to me because of that. I think it's more information on each specific side effect.*  
**Participant 049\_2021AUHRP**

Clinical guidelines that are aligned to patient preferences are more likely to be used and lead to higher rates of patient compliance<sup>78-80</sup>. 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<sup>78,81</sup>.

To help inform patient preferences in the hormone receptor-positive breast cancer community, participants in this PEEK study discussed side effects, treatment administration, adherence to treatment. Mild side effects were often described by using a specific example, such as fatigue, aches and pains, and hair-loss. They were also described as side effects that did not interfere with life or could be self-managed. Similarly, severe side effects were often described using an example, as those that interfered with every day life, or those that required medial intervention. Aches and pains were used to describe both mild and severe side effects, in addition, examples of severe side effects were nausea and those that impacted mental of emotional health, and those that impacted sleep. For people with breast cancer, understanding types and severity of side effects along with the potential impact on daily life and how to manage side effects may be important for treatment decision making.

In this PEEK study, the most important symptoms to control for quality of life reported in the quantitative section were fatigue, pain, cognitive function, bone problems, heart problems, and anxiety and depression. In contrast, another study report people with breast cancer ranked sleeping difficulties as the the most troublesome symptom, followed by concerns about family or partner, and loss of hair. Vomiting and nausea was also reported as troublesome symptom<sup>82</sup>.

Cognitive side effects included memory problems, recalling how to do previously known tasks, verbal functions, executive functions, processing speeds and inability to stay focused<sup>58,83</sup>. This had economic impact including changes to work, or having to quit jobs, psychosocial impacts such as reduced confidence in trying new things or going out, reluctance to socialise, frustration of partners, and a decreased tolerance to stress and criticism, and some had minimal impacts. <sup>83</sup>. In this PEEK study, cognitive function was ranked as one of the most important symptoms to control to improve quality of life.

Hormonal side effects such as pain, fatigue, poor sleep, lack of concentration and low motivation, hot flushes, anxiety, depression and poor self-esteem impacted personal and social life<sup>15</sup>. In this PEEK study, the impact of side effects, in particular menopause, was a common theme contributing to poor quality of life, or having an impact on relationships due to intimacy problems.

The impact of side effects in this PEEK study was a reoccurring theme throughout the structured interviews. It was the most common theme for considerations when making treatment decisions, to know that treatment is working (see a reduction in side effects), recommending more information about side effects from treatment in future and hoping that future treatments will have fewer or less intense side effects. It was also a common theme in relation to treatments goals (reducing side effects), adhering to treatment (as long as side effects were tolerable), and impact on quality of life.

#### Key point

- Information about side effects of treatment could include the types of side effects, the impact on day-to-day life, the severity, and how to manage them.

### Self-management

Self-management of chronic disease encompasses the tasks that an individual must do to live with their condition. Self-management is supported by education, support, and healthcare interventions. It includes regular review of problems and progress, setting goals, and providing support for problem solving<sup>84</sup>. Components of self-management include information, activation and collaboration<sup>84</sup>.

Information is a key component of health self-management<sup>85,86</sup>. 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<sup>85,86</sup>.

### Information

*The Breast Care Network has been really helpful. They've got a really helpful website that gives a lot of information. I've also joined a couple of Facebook pages of women who have also been suffering from breast cancer and being able to share the knowledge that they've gained, and also talking to my breast care nurse. I haven't seen her for a while, but when I was going through treatment, talking to my breast care nurse as well was quite helpful. The Australian government's cancer sites as well have a lot of good information. I get my information from what I consider reputable sources. I'd rather get them from people who know what they're talking about rather than the hearsay. Participant 037\_2021AUHRP*

In this PEEK study, about 13% of participants were satisfied the type and amount of information they received for breast cancer, and just over half of the participants were satisfied with the amount of information that they received at diagnosis. An exploratory qualitative study observed that the cancer patients have a desire to receive more information in relation to their specific condition, in a more detailed manner<sup>87</sup>.

Participants in this PEEK study accessed information from combinations of the internet, pamphlets, phone apps, and from talking to their doctor. In other studies, people with breast cancer reported getting information from a range of sources including family and friends, healthcare professionals, the internet, written resources, cancer support organisations and others with breast cancer<sup>34,88-92</sup>. In this PEEK study, participants most accessed information from health charities, the government or the hospital where they were treated. Similarly, the most accessed materials were government websites, scientific publications and printed patient materials<sup>93</sup>.

Participants in this PEEK study described some of the advantages of each type of information were highlighted by participants, for example, the internet is accessible and allows them to digest information at their own pace. Talking to their doctor is beneficial as it allows them to ask questions, and they know that their doctor is only giving them relevant information. Having a booklet is useful as they can annotate it.

In other studies, people with breast cancer described that the benefit of speaking to someone was the ability to ask questions, get clarifications, and feeling supported. In other studies, people with breast cancer reported liking complex information presented visually, and they liked to discuss information materials with their doctor, with the ability to take information home, while they valued the multiple sources of information available on the internet and social media, found the information could be both positive and negative<sup>89-91</sup>. In addition, the internet was described as a good place to get information and support, good for rural, concerns about limited information for advanced breast cancer, and that everyone with breast cancer is different<sup>88</sup>.

The types of information most frequently given to participants by healthcare professionals were about, treatment options, physical activity, and disease management, the topics least frequently given were how to interpret test results, complementary therapies, and clinical trials. The types of information

most frequently search for were treatment options, how to interpret test results, disease management and disease cause, and the least searched for topics were psychological/ social support and, clinical trials. This is similar to other breast cancer studies where people with breast cancer wanted information about side effects of treatments, managing symptoms, and peer support<sup>38,70,77,88</sup>.

The types of information that participants in this PEEK study found useful tended to be information that helped them understand what to expect. This could be information about the disease course or side effects from treatments, about their particular type of breast cancer, and also what other people with breast cancer have experienced. They also describe helpful information in terms of where the information came from, for example their doctor or a health charity. In other studies, people with breast cancer valued concise and credible information<sup>77</sup>, and a mixture of positive and negative value placed on other people's experiences<sup>90,91</sup>.

Participants in this PEEK study described what they expect for information in the future. Information about symptoms and side effect control was the most common theme. Information about services and holistic treatments were also common themes. Participants also wanted details about their own health records related to breast cancer, for example their diagnosis and treatments, and also information that was specific to their breast cancer stage or type, and also relevant to their age group.

### Activation (skills and knowledge)

*Definitely. I think right at the start, I didn't know much about all that side of things. I was in a shock a lot of the time but then, my partner was excellent. He's really good at asking questions. I think you just learn that you've got to write all the questions down. Anything that would come up before you do that appointment next. I just do it every time I go. Okay, I've got my question today just with the oncologist. I just go through. I say we are going through all the questions make her go through them with me, which has been really good. It helps me to clear my head a bit because sometimes you don't understand why they want you to do certain things. Participant 048\_2021AUHRP*

Patient activation is the skills, knowledge, and confidence that a person has to manage their health and care; and is a key component to health self-management. Components of patient activation are

support for treatment adherence and attendance at medical appointments, action plans to respond to signs and symptoms, monitoring and recording physiological measures to share with healthcare professionals, and psychological strategies such as problem solving and goal setting.

Patient activation is measured in the PEEK study using the Partners in Health questionnaire<sup>94</sup>. Participants in this PEEK study had very good knowledge about their condition, were good at coping with their condition, were very good at recognizing and managing symptoms, and were very good at adhering to treatment.

In another breast cancer study, people with breast cancer reported that in follow up post-treatment, they did not know how to manage ongoing concerns relating to their self-image due to scarring, lymphoedema, fatigue and the side effects of medication<sup>15</sup>. In this PEEK study, wanting information about side effects of treatment was a common theme throughout the semi-structured interviews.

### Adherence

*I just cracked on through tamoxifen. I'm not at that point yet. Even if I stop my medication-- A lot of women talk about stopping tamoxifen or Aromasin because of the impact it's having on them being in menopause, but the fact is even if I stop taking those drugs now, I've had my gynae surgery. I have those side effects. I'm not at that stage. I think it's also difficult to try and differentiate. Is that side effect because I'm in menopause, is it because of the Aromasin, or is it because I'm getting older, or is it just because of the cancer or of all the treatment? Is it all of those things? It's really difficult to actually isolate what's what. Participant 043\_2021AUHRP*

Adjuvant endocrine therapy effectively prevents recurrence and progression of estrogen-receptor positive breast cancer, however, studies reveal substantial non-adherence<sup>95</sup>. The majority of the participants in this PEEK study had taken or are taking hormone blockers long term. On average, quality of life while on these treatment was in the life was a little distressing to average range, and was thought to be effective to very effective. Participants in this PEEK study described adhering to treatment in terms of a specific amount of time, on advice of their doctor, never giving up on a treatment, and the ability to cope with side effects.

In other studies, people with breast cancer have described reasons or ways that adherence to endocrine therapy is improved. These include, having sufficient information, understanding efficacy, fear of negative consequences of non-adherence such as recurrence, the ability to cope with side effects, ease of access to medication and setting up reminder systems, personal determination, regular follow up with treatment team, and affordability of treatment<sup>95-97</sup>. Reasons for non-compliance include forgetfulness, not believing in that the treatment is effective or needed, side effects and costs<sup>96,97</sup>.

Having a belief that a treatment is working may encourage adherence to endocrine therapy<sup>96</sup>, in this PEEK study participants described how they could tell if a treatment was working. This was often seeing the reduction of a specific symptoms, such as aches and pain, or hot flashes. Some described needing to see a reduction in side effects in general, while others needed to balance the benefits of a treatment with the potential side effects. Others described the need to see evidence of no disease or no disease progression, or that it was difficult to know if a treatment was working without having test results.

#### Key point

- Physical activity was used to maintain both physical and mental health

#### Communication and collaboration

*My surgeon has always been really open to discussions and answering questions and to a great degree, she has been a go-to and my medical oncologist is also fabulous, in a different way. He is very good at using statistics for and against things to help with decision-making and doesn't push a decision overly in one direction. He'll gently encourage but he's not a you-must-do-this person, it's, "I suggest this because the research shows." My GP, hit and miss. Participant 023\_2021AUHRP*

Collaboration is an important part of health self-management, the components of collaboration include healthcare communication, details for available information, psychosocial and financial support<sup>85,86</sup>. Communication between healthcare professionals and patients can impact the treatment adherence, self-management, health outcomes, and patient satisfaction<sup>98-101</sup>.

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<sup>102</sup>.

Building a relationship with patient, families and support networks is fundamental to establishing good communication<sup>102</sup>. 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<sup>102</sup>. 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<sup>102</sup>. 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<sup>102</sup>. 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<sup>103</sup>. The participants in this study experienced very good quality of care, and very good coordination of care. They had a good ability to navigate the healthcare system, and experienced good communication from healthcare professionals.

Participants in this PEEK study described generally described communication with their healthcare team as positive. When communication was described in a positive way, this was mainly because the communication was holistic, two-way, and comprehensive. Similarly, in other studies people with breast cancer described their understanding of breast cancer was improved when delivered in a two-way exchange<sup>104,105</sup>.

While the communication was seen as positive, participants in this PEEK study described limitations such as their understanding of the communication, and the lack of time in appointments, in additions, participants would like to see communication that is more transparent and more forthcoming, as well as being more empathetic. Likewise, in other studies, people with breast cancer reported that communication was limited by lack of time, conflicting information, not understanding medical terms, and noting that while clinicians are medical experts but they must earn trust through being professional<sup>39,40</sup>

## Care and support

**PARTICIPANT:** *In terms of other relationships, I would say that other relationships have been positive in the sense that I've had like 30 something people sign up to an app to offer assistance, if I need it. I've had--*

**INTERVIEWER:** *Can you give the name of the app?*

**PARTICIPANT:** *It's called Gather My Crew. It's a platform where people can sign up, and then you post tasks like appointments and other things you need help with, and they can volunteer for those tasks. That way you don't have to go around asking every single person. That's been a real positive thing. I didn't know that I would have 30 people voluntarily sign up just to offer assistance with. Participant 044\_2021AUHRP*

When asked about the care and support they received, about a third of participants in this PEEK study responded that they did not receive any care or support. Support limitations have been reported elsewhere due to family and friends not meeting support needs, timing, personal difficulty in asking for help<sup>88</sup>. Other participants in this PEEK study described getting care and support from their hospital or clinical setting, from charities, and from support groups. About 10% described that they did not need any help. This is similar to other studies that have reported that people with breast cancer felt supported during their treatment, especially with the information, emotional support and feeling safer in hospital, trust important<sup>28,57,106</sup>. In terms of future care and support, participants in this PEEK study would like more access to support services, in particular access to specialist clinics where that can talk to healthcare professionals, long term condition management, and mental and emotional support.

Almost all of the participants in this PEEK study described having feelings of vulnerability since their diagnosis with breast cancer. The most common times that participants in this study felt vulnerable was during the time around diagnosis, and during and after they had treatment. Some described feeling vulnerable because of interactions they had with their medical team.

There are number of interventions to help patients suffering from psychological distress including cognitive and behavioural cancer stress management interventions (improves depressive symptoms, anxiety, self-efficacy, fatigue, social functioning, perceived social support, and benefit finding) supportive-expressive therapy (improves in depressive symptoms,

hopelessness and helplessness, trauma symptoms) and meaning-centred psychotherapy (improves quality of life, depressive symptoms, and hopelessness)<sup>107-110</sup>. Participants in this PEEK study described self-help methods such as resilience, acceptance and remaining positive as a way to manage their vulnerability. They also described the support of nurses or their treatment team, and family and friends to manage their vulnerability.

### Key point

- Good communication with healthcare care professionals was two-way, holistic, and comprehensive

### Anxiety associated with condition

*I suppose there's still that element of vulnerability. Even though I've moved on, sometimes I go, "You've had cancer and cancer is a terminal illness. Whether I'm cancer free or not, it's irrelevant. At the end of the day, I have had a cancer diagnosis." That's the way I look at that. I don't dwell on it. I don't feel sorry for myself. I don't wallow. I don't whinge and whine but I've had cancer. Participant 027\_2021AUHRP*

The rates of depression and anxiety are higher in people with chronic conditions compared to the general population. In a meta-analysis of 20 qualitative studies, it was reported that people with chronic conditions experienced anxiety or depression as either as independent of their chronic condition or as a result of, or inter-related with the chronic disease, usually however, anxiety and depression develops as a consequence of being diagnosed with a chronic disease<sup>111</sup>. Nearly all participants in this PEEK study described that their diagnosis with breast cancer had an impact on their mental health. In addition, approximately 60% of participants in this PEEK study reported anxiety, and 37% reported depression.

In this PEEK study, anxiety associated with breast cancer was measured by the fear of progression questionnaire<sup>112</sup>. There was a moderate fear of progression. This was consistent for all subgroups.

## Quality of life

*Then also, actually, one of the places that I was working, I'm not working now. She actually said to all staff, which was lovely. You need to ask PARTICIANT how she's going? Because if you ignore it, because I found at the beginning, I knew everyone knew. But they also, were just going on as business as usual. And how are you going? Oh, good. And I just felt really, really lonely. Because I thought it almost I knew they did care. And they just didn't know what to say. Because they didn't want to see me crying or something. But then when COLLEAGUE said something to them, I noticed the difference, because I walked in and everyone was going, how are you going? How are you feeling? And it was actually really, really sweet. And she said it. You know, it's really hard for that person and explained that I will feel really lonely. And like no one cares if, if no one asked me and so everyone did. It was as simple as that, which was really lovely. Participant 034\_2021AUHRP*

Over half of the participants in this PEEK study described that their diagnosis with breast cancer had a negative impact on quality of life, about 20% described a minimal impact, there were less than 20% that described at least some positive impact on quality of life. The reasons for a negative impact were mostly due to emotional strain on either partners or children, and also on the participant with breast cancer. Other reasons for a negative impact were due to side effects, such as the reduced capacity for physical activity, fatigue, menopausal symptoms, and the impact of menopause on intimacy. For those that described a positive impact on quality of life, this was mostly due to their diagnosis giving them perspective and realising what is important in life. In other studies, people with breast cancer have reported the negative impacts of side effects on their quality of life, in particular as it interferes with day-to-day activities, domestic tasks, work, hobbies and maintain their role in the family<sup>28,34,57</sup>.

A quarter of participants in this PEEK study described no impact on relationships following their diagnosis with breast cancer. The remaining 75% described an impact, some completely negative, some completely positive, and others a mix of both. Overall, similar numbers described positive impacts and negative impacts. Negative impacts on relationships was primarily due to other people withdrawing from the relationship, not knowing what to do or say. Positive impacts on relationships were a result of other people being well-meaning and supportive, and relationships

with family being strengthened. Similarly, other breast cancer studies have reported that relationships are impacted by the changes to relationship dynamics, new demands on relationships, and changing roles in the family<sup>113,114</sup>, in addition, the impact of prioritising their own health was sometimes at the expense of relationships<sup>113,114</sup>.

Nearly all participants in this PEEK study described that their diagnosis with breast cancer had an impact on their mental health. The most common way to maintain mental health in this cohort was to use mindfulness or meditation. In terms of other ways participants used self-help techniques, other ways of maintaining mental health were to exercise, remaining social, keeping up with hobbies, and they described the importance of family and friends. Approximately a third consulted a mental health professional. In terms of regular activities to maintain health, almost half described the importance of being physically active. It is interesting to note that exercise was also an important way to maintain mental health. Other ways to maintain health included self-care, for example getting more rest or support for domestic tasks, also understanding their limitations, and maintaining a healthy diet. Almost 20% described the importance of complying with treatment. This is similar to other studies, were people with breast cancer reported seeking professional help, exercising, making changes to diet, taking part in social events, and taking a rest when needed<sup>28,57,75,115,116</sup>. In addition, people with breast cancer described the other ways to maintain mental and physical health by educating themselves, volunteering to help others, physiotherapy, and adapting work schedules<sup>28,57</sup>.

### Key point

- Breast cancer had an overall negative impact on quality of life, mental and emotional health.

## Characterisation

There were 52 participants with hormone receptor positive breast cancer in the study from across Australia. The majority of participants lived in major cities, they lived in all levels of economic advantage. Most of the 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 have been mostly happy with their communication with healthcare providers, but suggested that future communication could be more transparent, forthcoming, and empathetic.

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

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

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

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

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

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

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