



CENTRE FOR COMMUNITY-DRIVEN RESEARCH

personal experience, expectations & knowledge

# DECISION-MAKER BRIEF

## 2023

### Hormone positive breast cancer

## **Brief for decision-makers considering treatments and services for people diagnosed with hormone positive breast cancer**

**Purpose:** When making decisions about the type of treatment and services people diagnosed with hormone positive breast cancer can access, decision-makers need to understand the context in which their decisions are being made, what characterises the patient population, and ensure assumptions are not being made on behalf of this patient population.

This brief provides this context and information about the experience and expectations of people diagnosed with hormone positive breast cancer, based on the knowledge of 52 women across Australia as experts with lived experience.

### **Key points**

- This is a population that are most often in paid employment and are carers to family members including children
- Rates of anxiety and depression in the PEEK study were higher compared to the Australian population
- 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
- 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
- Breast cancer had an overall negative impact on quality of life, mental and emotional health
- Emotional support and information needs are not being met at the time of diagnosis
- Cost burden was noted by this patient population including the need to quit work or reduce hours
- Avoiding recurrence is a common treatment goal for this patient population

**Introduction:** Patient Experience, Expectations and Knowledge (PEEK) is a research program developed by the Centre for Community-Driven Research (CCDR). PEEK studies give us a clear picture of what it is like to be a patient at a given point in time. PEEK studies give us a way forward to support patients and their families with treatments, information and care. There are very few studies that report the personal experience, expectations, and knowledge of people with hormone positive breast cancer. The data presented from the PEEK study in hormone positive breast cancer represents the most comprehensive study covering all aspects of disease experience and represents the largest cohort of structured interviews conducted with this patient population reported in a focused, single study. [Access at [www.cc-dr.org](http://www.cc-dr.org)]

**Background:** Hormone-receptor positive breast cancers are sensitive to estrogen or progesterone, approximately 70% of breast cancers are hormone-receptor positive<sup>1</sup>. Adjuvant treatment with tamoxifen is recommended, followed by an addition five years for pre or perimenopausal women, and an additional five years with tamoxifen or an aromatase inhibitor for postmenopausal women<sup>1</sup>.

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

The overall scores for the cohort were in the highest quintile for SF36 Role functioning/emotional. The overall scores for the cohort were in the second highest quintile for SF36 Physical functioning, SF36 Emotional well-being, SF36 Social functioning, and SF36 General health. The overall scores for the cohort were in the middle of the scale for SF36 Role functioning/physical, SF36 Energy/Fatigue, and SF36 Pain.

**Support at diagnosis:** The majority of participants in this PEEK study (71.15%) did not feel that they had enough support at the time of diagnosis. In terms of information given at diagnosis, 55.77% were given at least some information but almost half felt they did not have enough information, especially those that lived in regional areas.

**Biomarkers or genetic markers:** All participants in this study knew that they had hormone positive breast cancer, however, about 30% did not relate this to biomarker status and did not have discussions about biomarkers with their doctor.

**Understanding and knowledge:** 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%). The most common reason for having good knowledge of the condition at diagnosis was having a medical, research or relevant professional background.

**Affordability of healthcare:** Most participants in this PEEK study were able to access currently available and subsidised treatments, and healthcare appointments.

Women with breast cancer have reported changing work tasks or changing jobs to manage in the workforce <sup>2,3</sup>. In this PEEK study, 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.

**Goals of treatment:** To help inform patient preferences in the community, participants in this PEEK study were asked about their treatment goals. 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%). It is important to note that half of the participants in this PEEK study had family or children under their care.

**Anxiety associated with condition:** In this PEEK study, anxiety associated with breast cancer was measured by the fear of progression questionnaire<sup>8</sup>. On average, participants had moderate levels of anxiety with relation to their condition.

**Quality of life:** Participants in this PEEK study commonly reported that hormone positive breast cancer had an overall negative impact on their quality of life. This was largely due to emotional and mental strain on their partners, children, and themselves. The symptoms that most impact quality of life of this group are pain, fatigue, and cognitive problems.

## Decision-making

Participants were asked to rank what is important for decision-makers to consider when they make decisions that impact treatment and care. This patient population urges decision-makers to consider as a priority quality of life for patients, and that all patients are able to access all available treatments and services. For patients, the most important considerations for them were “How safe the medication is and weighing up the risks and benefits”, and “The severity of the side effects”.

## 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%).

*I would just implore them to think about it as if it was their loved one going through the treatment, what would they want for their loved one? Would they want easy access, do they want financially, are they able to afford it or they have to go through the public system, and if they go through the public system, do they have to wait? Is that wait going to impact on the prognosis? Pretty much just-- Imagine that it was you going through it, what would you want? Participant 025\_2021AUHRP*

## References

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2. Kalfa S, Koelmeyer L, Taksa L, et al. Work experiences of Australian cancer survivors with lymphoedema: A qualitative study. *Health Soc Care Community* 2019; 27(4): 848-55.
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