

# **Breast Cancer Network Australia**

## **Submission to The Senate Standing Committees on Community Affairs inquiry into the availability and accessibility of diagnostic imaging equipment around Australia**

**October 2017**

### **About Breast Cancer Network Australia**

Established in 1998, Breast Cancer Network Australia (BCNA) is the peak national consumer organisation for Australians personally affected by breast cancer. We support, inform, represent and connect people whose lives have been affected by breast cancer. We work to ensure that Australians diagnosed with breast cancer receive the very best support, information, treatment and care appropriate to their individual needs.

BCNA represents more than 120,000 individual members and 300 member groups across Australia.

Breast Cancer Network Australia (BCNA) welcomes the opportunity to provide a submission to the Senate Standing Committee on Community Affairs *inquiry into the availability and accessibility of diagnostic imaging equipment around Australia*.

Australia has the fourth highest rate of breast cancer in the world<sup>1</sup> and breast cancer is the most common cancer in Australian women.<sup>2</sup> It is estimated that this year (2017) 17,586 women and 144 men will be diagnosed with breast cancer.<sup>3</sup>

Our submission reflects BCNA's key area of expertise and interest – women with breast cancer. As the vast majority of Australians diagnosed with breast cancer are women, this submission refers to women with breast cancer.

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<sup>1</sup> Australian Institute of Health and Welfare, *Breast Cancer in Australia: an overview*, October 2012

<sup>2</sup> Australian Institute of Health and Welfare & Australasian Association of Cancer Registries, *Cancer in Australia: an overview 2014*

<sup>3</sup> Australian Institute of Health & Welfare 2017, *Cancer in Australia 2017*. Cancer series no 101. Cat no. CAN 100. Canberra: AIHW.

**BCNA's submission focuses on the following Terms of Reference item:**

Out-of-pocket costs for services that are not subsidised by the Commonwealth and the impact of these on patients.

**Summary**

Australians diagnosed with breast cancer encounter many different diagnostic imaging services, some of which are not covered by Medicare. These include:

- Breast MRI for pre-surgical work up and a number of other indications
- PET scans for women diagnosed with, or suspected to have, metastatic breast cancer
- DXA (Dual Energy X-Ray Absorptiometry) bone mineral density scans for women taking aromatase inhibitors.

While these imaging services are not covered by Medicare, they help clinicians and women diagnosed with breast cancer to make informed decisions about their treatment and can help to improve outcomes.

Medicare rebates for these imaging services will:

- reduce the out-of-pocket costs faced by women and their families and alleviate some of the financial burdens of breast cancer treatment
- improve access to these imaging services, which can help clinicians and women diagnosed with breast cancer make treatment decisions, improve their health outcomes and reduce hospital readmissions.

## BCNA Submission

### Out-of-pocket costs for services that are not subsidised by the Commonwealth and the impact of these on patients.

*These tests are a huge cost. A long time after cancer, the financial burden continues. – BCNA survey respondent*

Australians diagnosed with breast cancer encounter many different diagnostic imaging services – mammography, diagnostic ultrasound, ultrasound-guided biopsy or fine needle aspiration, MRI and localising procedures. Making the best possible treatment decisions is important for women newly diagnosed with breast cancer. To help make decisions, doctors will sometimes suggest imaging tests that are not covered by Medicare. These include:

- Breast MRI for pre-surgical work up and other indications
- PET scans for women affected by metastatic breast cancer
- DXA (Dual Energy X-Ray Absorptiometry) bone mineral density scans for women taking aromatase inhibitors

For many years BCNA has heard from its members about out-of-pocket costs they incur for these tests. They tell us these costs are a source of stress and can result in financial strain for them and their families. Over the years BCNA has written to the Medical Services Advisory Committee in support of Medicare rebates for these imaging services.

Late last year, BCNA also endorsed the *Statement of Principles: Breast Cancer Imaging in Australia*, as part of a coalition of peak organisations with expertise in the diagnosis, treatment and follow-up care of people with breast cancer. The statement recommended a number of areas of action, including the need to rebate breast MRI.

Without a Medicare rebate these services can have high out-of-pocket costs, and significant variation in costs depending on the clinic attended..

*It is a shame that you don't get a Medicare rebate for an MRI. My surgeon recommends having an MRI but it is very expensive. It seems unfair that this valuable test is only available to women who can afford it. - BCNA Review & Survey Group participant*

In late 2016, BCNA contracted Deloitte Access Economics to undertake research to explore the financial impact of breast cancer. Nearly 2,000 women who have been diagnosed with breast cancer in the last five years completed a comprehensive survey of the out-of-pocket costs associated with their breast cancer treatment and care. The outcomes of this survey are available in BCNA's report *The Financial Impact of Breast Cancer*, available on BCNA's website [bcna.org.au](http://bcna.org.au).

The key findings in relation to breast imaging are:

- Breast MRI can cost hundreds of dollars (\$450 - \$1,500) with no Medicare or private health rebate. Over half of the women who paid for a breast MRI paid at least \$753 for this service.
- A PET scan typically costs \$370.

A previous study undertaken by BCNA in 2012 found that women having a DXA bone mineral density scan as part of their breast cancer care incurred an out-of-pocket cost of \$100 or more each year for the five to ten years of their treatment with an aromatase inhibitor.

*“Bone mineral density tests result in an out of pocket expense for me of approximately \$150 per year.” – BCNA survey respondent*

When these tests are repeated over time, the costs accumulate. This can be a particular concern for women with metastatic breast cancer, who may require many ongoing tests over months or years.

While these imaging services are not covered by Medicare, they may help clinicians and women diagnosed with breast cancer make treatment decisions and improve outcomes. Many people reflect on the importance of these tests in helping them make good treatment decisions with their doctor.

*I had a PET scan which clearly showed metastasis in my shoulder. My oncologist was then able to recommend the most suitable treatment for me. This has given me real peace of mind. – BCNA member with metastatic breast cancer*

However, the high costs of these tests add to the financial burden of breast cancer. BCNA's *Financial Impact of Breast Cancer* survey found that around two thirds of women – 67 per cent – paid for their breast cancer medical expenses with household savings. Many used their 'nest egg' – money that was being saved for something particular such as a house deposit, retirement, travel or other significant goal – to support themselves and their families during treatment. Using this money to fund cancer treatment changes people's plans. Years of careful saving are lost.

*We reached flat broke and that's when my parents financially supported us. I just felt bad having to constantly ask my gorgeous parents for financial help. I thought 'All their hard-earned savings are going on our electricity bill'. The medical tests, surgeries and reconstructions were very expensive and there, again, my parents covered the outgoings on those things. – BCNA survey respondent*

For those who did not have sufficient savings to help them through this period, borrowing money, often from family, was an alternative source of income. Eleven per cent of survey respondents said they borrowed or were given money by family, friends or community fundraising. Borrowing from family and friends can add to the emotional burden, and it contributes to ongoing financial burden if or when these loans need to be repaid.

Travel costs for women in rural and regional areas can also contribute to the out-of-pocket costs of accessing imaging services. In October 2016, BCNA undertook a survey of its members about their experiences with imaging scans and tests related to breast cancer. In total, 113 women completed the survey. The survey found that while most respondents were able to access imaging services close to their home, for the 11 per cent of respondents who needed to travel more than one hour each way to access imaging services, additional transport costs were typically between \$41 and \$60 but, for some, up to \$100.

BCNA are also concerned that some women may not be able to access an imaging test recommended by their doctor because of high out-of-pocket costs. Unaffordability of diagnostic imaging can impact on treatment decisions and health outcomes. For example, for women recommended to have MRI for pre-surgical work-up, not being able to afford this test can mean the risk of needing to return to hospital for repeated surgeries. This adds to the costs for both the woman and the health system.

*“I won't be having any more bone mineral density tests as I can't afford the high cost.” – BCNA survey respondent*

## Conclusion

BCNA believes that subsidising breast MRI, PET scans and DXA bone mineral density scans for women with breast cancer who need these services would not only reduce the financial burden associated with out-of-pocket costs of treatment, but ensure equitable access, improve health outcomes and lessen some of the emotional impact of breast cancer.

It is our hope that these services are reconsidered by the Medical Services Advisory Committee for government subsidy.

For further information, please contact Kathy Wells on 03 9805 2562 or [kwells@bcna.org.au](mailto:kwells@bcna.org.au).



Christine Nolan  
Chief Executive Officer



Kathy Wells  
General Manager, Policy