

## **Breast Cancer Network Australia Submission to the Productivity Commission: Reforms to Human Services Inquiry Draft Report**

**July 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) thanks the Productivity Commission for the opportunity to comment on the draft report, *Introducing Competition and Informed User Choice into Human Services*, released in June 2017 as part of the Reforms to Human Services Inquiry.

Breast cancer is the most common cancer affecting Australian women. In 2017, it is estimated that 17,586 women and 144 men will be diagnosed with breast cancer.<sup>1</sup>

### **BCNA's submission focuses on the following areas identified for reform in the report:**

- end-of-life care services
- public hospitals and promoting user choice
- services in remote Indigenous communities.

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<sup>1</sup> Cancer Australia (2017). Breast cancer statistics. Retrieved July 12, 2017, from <https://canceraustralia.gov.au/affected-cancer/cancer-types/breast-cancer/breast-cancer-statistics>

# Submission

## End-of-life care services

### Draft recommendation 4.1

BCNA strongly supports draft recommendation 4.1.

Dying well, and the option to die at home, are very important considerations for those with a terminal illness and the people around them.

Surveys consistently show that between 60 and 70 per cent of Australians would prefer to die at home and that hospitals and nursing homes are their least preferred places to die.<sup>2</sup> Yet over the past 100 years home deaths have declined and hospital and nursing home deaths have increased.<sup>3</sup> Today only about 14 per cent of people die at home.<sup>4</sup>

While the mortality rate from breast cancer is falling, breast cancer is the second most common cause of death from cancer in women after lung cancer.<sup>5</sup> Approximately 3,040 women and 25 men died from metastatic (secondary, advanced, stage 4) breast cancer in 2015. It has been estimated that around 9,000 Australians are living with metastatic breast cancer at any one time.<sup>6</sup> There is no cure, although people can live with the disease for many years.

Over the years we have heard from our members about barriers to choice in their end-of-life-care, In particular we hear that the option to die at home is often not available due to a lack of appropriate services in their local area.

While this affects people in all parts of Australia, it is especially true for those living in rural and regional areas where there may be fewer local supports for people dying in their own home. This forces people into local community-based palliative care services or, where those are also lacking, to palliative care services or hospitals in major centres. A consequence of this is families having to travel sometimes significant distances to support a loved one and patients relying on services that are far from their support networks and the familiarity of home.

BCNA believes additional funding is required nationally for palliative care services to ensure people can access the services they need at the time they need them, including appropriate support services to enable those who wish to die at home to do so.

More information on the supports offered by community-based end-of-life care is also needed for carers and family members of people nearing the end of their lives. Many people are surprised to learn that palliative care services offer a family-centred model of care. This

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<sup>2</sup> Swerissen, H and Duckett, S., 2014, *Dying Well*. Grattan Institute ISBN: 978-1-925015-61-4

<sup>3</sup> *ibid*

<sup>4</sup> *ibid*

<sup>5</sup> Australian Institute of Health and Welfare & Australasian Association of Cancer Registries, *Cancer in Australia: an overview 2014*

<sup>6</sup> Clements, M.S., Roder, D, Yu, Z.Q., O'Connell, D., L. (2012). *Estimating prevalence of distant metastatic breast cancer: a means of filling a data gap* Cancer Causes Control, 23, 1625-1634.

means that family members and carers can receive practical and emotional support, as well as physical support such as home help. Many people find that support for family members is as valuable as the direct support they receive themselves.

We note that support for families and carers is not universally funded and can incur an out-of-pocket cost. We support the provision of additional funding to ensure that family members and carers can access support services affordably and equitably.

*I always thought of it (palliative care) as something for me, but hadn't thought it was there to support my family. – Kate*

### **Draft recommendation 4.3**

We support the recommendation for the Australian Government to require and enable advance care planning conversations within the primary care setting for Australians over the age of 75. However, we would urge the Productivity Commission to consider introducing a similar, nationally consistent approach for people diagnosed with a terminal illness. While the median age of a breast cancer diagnosis is 60, breast cancer is not just an older woman's disease. In 2014, it is predicted that 1,830 (12 per cent of all women diagnosed) will be aged under 45.<sup>7</sup> Focusing on those aged 75 and over would preclude an important cohort of people who would benefit from timely discussions and information on advance care planning within the primary care setting.

An additional consideration for the Productivity Commission is the importance of early consultations and discussions around palliative care for people with a life-limiting illness. Many people with metastatic breast cancer are not aware that palliative care is something that can support them soon after their diagnosis, assist in the management of pain and other aspects of their treatment and the disease, and enable them to plan ahead for end-of-life care. Preliminary data from our 2017 Members Survey suggests that more than a third of respondents with metastatic breast cancer did not feel they were informed about what palliative care offers across the spectrum of supportive care to end-of-life care.

*I'm comforted and relieved that palliative care is looking out for me to help me manage pain and symptoms. I see them as an extension of my medical team at home. They have brought up issues in relation to developing a health plan and end of life plan for me and my family. It was done in a very compassionate way and has seeded the thought of organising the next phase in my journey to reduce the trauma for my family and myself. - Karen*

BCNA has worked with Palliative Care Australia (PCA) to develop an online tool to help improve people's understanding of palliative care and the benefits of early connection to palliative care services. Our research has shown that when people understand what palliative care services can actually provide, they are much more comfortable with the idea of using these services and having discussions around important end of life issues including advance care planning.

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<sup>7</sup> Australian Institute of Health and Welfare, Cancer Australia *Breast Cancer in Australia: an overview*, October 2012

We believe that people with a life-limiting illness who can benefit from early and as-needed access to palliative care should be able to do so. We are aware however that some services are overstretched and not able to accommodate the needs of people not at end-of-life. Additional funding is required to enable palliative care services to better meet the needs of all those living with a terminal illness. This, together with a nationally consistent approach to palliative care, will increase consumer choice in palliative and end-of-life care.

#### **Draft recommendation 4.5**

We support the proposed development of an end-of-life care data strategy to monitor how well these services are meeting the needs of people at the end of life. We also emphasise the value of inclusion of qualitative consumer experience data into measures of performance of individual services.

The collection of linked data on primary and secondary diagnoses of people in end-of-life care would also assist in collection on a national basis of data on the incidence of metastatic breast cancer and the number of people currently living with the disease in Australia, at least within the palliative care setting. The prevalence and incidence of metastatic breast cancer, as well as survival data, is currently unknown because this data is not usually collected. The only reliable data currently is state and territory reported data on metastatic breast cancer deaths.

We acknowledge Cancer Australia's Stage, Treatment and Recurrence (STaR) project, which is aimed at collecting/collating and reporting data relating to cancer stage, treatments and recurrence of five major cancer types (breast, prostate, colorectal, lung and melanoma) at the national level. This project requires data input from each state and territory cancer registry, however little or no additional resourcing has been provided to registries to assist with this project. Any project to collect linked data on end-of-life care will require funding to resource it.

Information on the number of people with metastatic disease in end-of-life care— while not a complete picture of prevalence and need – would go some way in informing the way in which resources can be properly allocated and managed to meet the needs of people with metastatic cancer.

### **Services in remote Indigenous communities**

#### **Draft recommendations 8.4 and 8.5**

We support the focus of draft recommendations 8.4 and 8.5 and emphasise the importance of culturally appropriate service provision as a key part of this.

Between 1998 and 2012, the cancer mortality rate for non-Indigenous Australians fell by 10%. During this same period, the cancer mortality rate for Aboriginal and Torres Strait Islanders increased by 16%.<sup>8</sup> These results are as confronting as they are disturbing.

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<sup>8</sup> Cancer Australia, *National Aboriginal and Torres Strait Islander Cancer Framework 2015*.

Australia's record of cancer survival is one of the best in the world, yet Aboriginal and Torres Strait Islander people continue to experience disparities in cancer outcomes. Cancer is the second most common cause of death for Indigenous Australians (20%), after cardiovascular disease.<sup>9</sup>

A priority for BCNA is to ensure that hospitals and BreastScreen services provide not only effective screening and care, but culturally appropriate services for Aboriginal and Torres Strait Islander communities in order to increase their engagement and improve their survivorship outcomes. It is also important that these services are responsive to community needs. If Aboriginal and Torres Strait Islander women from remote communities do not feel culturally safe when they travel long distances to attend treatment, they are less likely to return or to spread positive word of mouth to others in their community.

End-of-life care is also an important consideration for Aboriginal and Torres Strait Islander women with metastatic breast cancer. Consideration should be given to the needs of women who live on country or in communities to ensure they are able to receive appropriate end-of-life care should they choose to stay at home at the end of their lives.

## **Patient choice in public hospitals**

### **Draft recommendations 9.1 and 9.2**

We support the proposal for the Australian Government to amend the *Health Insurance Regulations 1975* to make it clear that patients can choose which public clinic or private specialist they go to when given a referral. We also support the development of best-practice guidelines on how GPs can best support patient choice at the point of referral.

In order for people to exercise choice and make an informed decision about the public hospital services that will be best for them from referral point onwards, more transparency, including published/written information, is required on:

- The range of public hospitals and specialists a patient can choose from
- Any out of pocket costs that may arise, including information on the costs of procedures and treatments and the costs of seeing a specialist privately compared to options for attending a public outpatient clinic for follow-up care
- The right of patients to get a second opinion if they are unhappy with the costs of treatment quoted to them.

### **Draft recommendation 9.3**

We support the recommendation for public outpatient clinics to accept any patient with a referral letter for a condition the clinic covers, regardless of where the patient lives. The closest hospital or specialist is not always the most appropriate.

An additional consideration for the Productivity Commission is including elective (planned) admissions to public hospitals as part of these proposed reforms to enable better patient choice and access.

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<sup>9</sup> Australian Institute of Health and Welfare, Cancer Australia *Breast Cancer in Australia: an overview*, October 2012

One significant issue for our members is timely access to elective surgery for women with breast cancer who may be waiting for delayed breast reconstruction surgery in the public hospital system. In October 2010, BCNA surveyed members about waiting times for breast reconstruction surgery and found that some women were waiting around two years for their surgery in a public hospital. This year, we have been working with women from Far North Queensland who have been advised that the waiting time for breast reconstruction in Cairns is seven years. As part of national health reform, the Australian Government is working to improve hospital standards by introducing new emergency department and elective surgery targets, and a National Access Guarantee.

Most delayed breast reconstruction surgery is classified as Urgency Category 3. The new target for Category 3 surgery is: *95 per cent of Urgency Category 3 patients waiting for surgery are seen within the clinically recommended time (365 days) by 31 December 2015.* In consulting with women around Australia, we have still encountered significant disparities in the waiting times for breast reconstruction surgery between hospitals and PHNs. We are concerned about how the Government will promote the new elective surgery targets and National Access Guarantee to ensure that members of the public are aware of their rights under these new standards.

#### **Draft recommendation 9.4**

BCNA strongly supports the proposal for eligible patients to be able to access patient travel assistance schemes regardless of which provider they choose to attend. We have long-standing concerns about the effectiveness of PATS in supporting those who need assistance to get to treatment centres.

Our main concerns are that the schemes fail to provide adequate assistance to women who:

- choose to re-locate to major cities to attend daily radiotherapy for five to six weeks (even if the return journey can be physically completed within one day)
- choose to re-locate to a major centre other than the one closest to them for radiotherapy treatment (often because they have family members in that centre who can support them during their treatment)
- are accompanied by support persons (for reasons other than 'medical')
- are travelling with dependent children
- choose to travel to specialist centres best suited to treating their breast cancer and meeting their needs, irrespective of state or territory borders
- travel for treatment provided by a multidisciplinary team of specialists of their choice
- receive specialist allied health assessments and treatments.

In addition, BCNA has found that women's experiences of PATS are less than ideal:

- the process for referral is unnecessarily complex, adding an additional layer of burden to their treatment experience
- there is insufficient information about the schemes
- the amount of paperwork is often daunting
- there can be significant delays in reimbursement.

BCNA is disappointed that despite these ongoing issues, there is a lack of real progress in improving PATS across the country. What is needed is a nationally consistent PATS system that cuts through the inconsistencies, red tape and inequities between states and territories.

The Australian Government must work with the state and territory governments and hold them to account to ensure an improved and national consistent PATS system.

## **Conclusion**

BCNA supports the proposed draft recommendations discussed in this submission. We recommend the Productivity Commission additionally consider:

- A nationally consistent approach to palliative care, including better resourcing to enable early, as-needed access to palliative care services for people with a terminal illness, not just at the end of life
- More support within community palliative care services for carers and family members of people nearing the end of their lives
- Facilitation of an advance care planning scheme within the primary care setting for people diagnosed with a terminal illness
- Inclusion of elective (planned) admissions to public hospitals as part of proposed reforms to enable better patient choice and access
- The Australian Government must hold state and territory governments to account to ensure an improved and nationally consistent PATS system.

We look forward to learning the outcomes of the submission process in due course and working in partnership to achieve the goals of the Human Services Reform Inquiry.

For further information, please contact Kathy Wells, Head of Policy, Research and Advocacy

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