

Breast Cancer Network Australia Submission to the Cancer (Reporting) Regulations 2012 Regulatory Impact Statement



11 January 2012

About Breast Cancer Network Australia

Breast Cancer Network Australia is the peak national organisation for Australians personally affected by breast cancer. We empower, inform, represent and link together people whose lives have been affected by breast cancer.

BCNA represents more than 64,000 individual members and 315 Member Groups from across Australia.

BCNA works to ensure that women diagnosed with breast cancer and their families receive the very best information, treatment, care and support possible – no matter who they are or where they live. BCNA is represented by the pink lady silhouette. The pink lady depicts the organisation's focus – women diagnosed with breast cancer.

Submission

Breast Cancer Network Australia (BCNA) welcomes the opportunity to comment on the Cancer (Reporting) Regulations 2012 Regulatory Impact Statement.

As the peak national organisation for Australians affected by breast cancer, we support the collection of cancer incidence statistics, which can provide important information to governments, health providers and cancer organisations to assist in the prevention, control and treatment of cancer.

Regulatory Option 2

BCNA supports the changes proposed in the preferred option, Regulatory Option 2, particularly:

- the extension of the reporting schedule to include private radiotherapy centres and day oncology centres
- the amendment to the Staging data item to comply with existing international standards, specifically the use of the Tumour, Node and Metastases (TNM) site specific staging system as the preferred reporting method
- the collection of additional information about individual cancer patients.

We believe these changes will result in more complete and accurate data about new cancer diagnoses in Victoria.

We also support Regulatory Option 3, which would provide more quality data for cancer research.

A network of support for Australians affected by breast cancer

Patron: Her Excellency
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Incidence of secondary cancer

BCNA urges the Department of Health to consider and implement measures to capture data on the incidence of all secondary (metastatic) cancer diagnoses, in particular secondary breast cancer.

While data is collected on the number of Victorian women diagnosed with early (primary) breast cancer and the number who die as a result of breast cancer, no specific data is collected on the number of Victorian women whose cancer progresses to secondary disease.

We acknowledge that the clarification of the TNM staging system as the preferred model will help in the collection of data on metastases, and are encouraged by the ability of the Victorian Cancer Registry to stage 96% of all eligible breast cancer incident cases diagnosed in 2006 and 2007 by using this system.¹ It appears, however, that the current reporting arrangements primarily capture this information at the time of the initial diagnosis of cancer, and that the reporting of any subsequent metastases may be less reliable. We are concerned that data about women who are not treated by a Prescriber Referrer may be missed, and that some Prescribed Referrers may not routinely report cases of secondary disease.

For example, not all women who develop metastases will require hospitalisation. They may also not require further pathology testing. These particular cases are therefore not reported by hospitals or pathologists. We note, as a further complication, that the completeness of hospital reporting was identified as a 'problem' in the *Breast cancer staging and treatment: Data linkage report 2010*.²

Further, while the inclusion of private radiotherapy centres and day oncology treatment centres as Prescribed Referrers should assist in capturing more diagnoses of metastatic disease, data may be missed on women who have endocrine therapy prescribed by a private medical oncologist, as these women may not attend a day oncology centre or radiotherapy centre.

There may also be aged care residents with secondary breast cancer whose data will not be captured as their care may not be overseen by any of the Prescribed Referrers.

BCNA believes it is important that a reporting system that ensures all cases of secondary breast cancer are routinely reported is implemented.

Women with secondary breast cancer have specialised health care needs, which can at times be complex and resource intensive. As treatments and care improve, many women with secondary disease are now living for many years, with their condition treated as a chronic illness.

¹ National Breast and Ovarian Cancer Centre: Breast cancer staging and treatment: Data linkage report 2010

² *ibid*

The collection of data providing statistics on the number of Victorian women living with secondary breast would greatly assist the Victorian Department of Health and health providers in the planning and provision of treatments and allied health services for this group of women. These include:

- Appropriate early referral to palliative care, including specialised pain management
- Psycho-oncology services for women, their partners and other family members
- Information for general practitioners who integrate primary care with complex specialised cancer treatments and multidisciplinary care.

Thank you for the opportunity to contribute to this review of the cancer reporting regulations. For further information on our submission please contact Kathy Wells, Senior Policy Officer, on (03) 9805 2562 or at kwells@bcna.org.au.

Yours sincerely

A handwritten signature in black ink, consisting of a large, stylized loop followed by a vertical line and a long horizontal stroke extending to the right.

Michelle Marven
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