



27 April 2018

Dr Harmer
Chair
Private Health Ministerial Advisory Committee

Dear Dr Harmer

RE: Changes to private health policy conditions – Clinical definitions consultation process

Breast Cancer Network Australia (BCNA) is the peak national consumer organisation for Australians personally 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 130,000 individual members and 300 member groups across Australia.

Cancer Council is Australia's largest non-government cancer organisation, involved in all cancer types and all areas of cancer control, from prevention through to patient support, research, health education and the production of clinical practice guidelines.

We are writing to collaboratively express our concerns around changes to private health insurance policies proposed by the Private Health Ministerial Advisory Committee which we believe will severely impact Australian women diagnosed with, or at risk of, breast cancer. Whilst we applaud any changes that increase transparency around the level of cover consumers have within their hospital insurance policies, we are deeply concerned that the proposed new standard clinical definitions related to breast cancer will restrict women's access to treatment in the private system.

BCNA and Cancer Council Australia were first alerted to this issue on 23 April 2018 through discussions with BreastSurgANZ. It is of great surprise to us that as peak organisations representing Australians with cancer, neither BCNA nor Cancer Council have been included in the consultation process. This is of particular concern considering other stakeholders have raised queries around the absence of a cancer category in the proposed definitions. A closing date of April 27 does not provide our organisations with enough time to provide a comprehensive response. We are therefore seeking an extension to the public consultation process to allow us time to consider our position.

Meantime, we alert you to a number of high level issues that we believe will gravely disadvantage people with breast cancer under the proposed changes. These include

ambiguity around definitions related to what is deemed 'medically necessary' breast surgery. Too often we hear the stories of women with breast cancer whose private health funds fail to cover surgery related to their illness, deeming associated surgery such as nipple reconstruction or prophylactic mastectomy to be cosmetic. Just this week we were dismayed to hear from a young BCNA member in Queensland who faces \$38,000 out of pocket for risk reducing surgery related to her BRCA gene mutation due to her private health insurer deeming her reconstructive surgery to be cosmetic. This woman was advised she faced a two year wait in the public health system, so felt forced to withdraw funds from her superannuation to pay for the procedure so she can have it more urgently. There have been a number of women on the maternal side of her family who have died of breast cancer and she is currently caring for her mother who is struggling with the side effects of breast cancer treatment. It is incomprehensible that this woman and others like her face such astronomical costs for what is potentially lifesaving surgery.

We are also concerned by proposed changes that categorise cancer treatment according to the biological system that may mean that women with breast cancer can only choose to have treatment in the private health system if they have silver or gold status private health cover. It appears a strange anomaly that, unlike much other oncology treatment which will be covered by bronze and above health cover, breast surgery would not be covered for those with bronze membership. This will lead to further fragmentation in care, particularly for those women who have neoadjuvant treatment in the private system and then find they are unable to have their surgery in the same institution.

Based on evidence of inequity and opportunity for reform, in BCNA's and Cancer Council's view one of the most pressing issues that the Private Health Ministerial Advisory Committee should address is open financial disclosure around out of pocket costs associated with treatment in the private system and the establishment of greater rigour around monitoring of such disclosure. BCNA's 2017 *Financial Impact of Breast Cancer* report found that those with private health insurance had significantly greater out of pocket costs than those without and that many people were unaware of the costs they would incur until after their treatment was completed. There was commonly no advice provided around other options such as seeking a second opinion or public health referral. This research is mirrored by the 2018 research conducted by Consumer Health Forum (CHF) which found that out of pocket expenses related to private health are of huge concern to Australians. Around 19 per cent of the 1,200 people who participated in the CHF research were women with breast cancer.

The consumer and not-for-profit voice is essential in the public consultation process to ensure that Australians with breast and other cancers are not disadvantaged by any changes to private health policy conditions. Both Breast Cancer Network Australia and Cancer Council Australia would value any time to discuss our concerns with you either individually or collectively.

In addition we are seeking an extension for time for the public submission process for a further two weeks to ensure that we can provide a comprehensive response to the concerns raised above.

For further information, please contact:

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Paul Grogan, Director Public Policy and Knowledge Management, Cancer Council Australia
– 02 8063 4155 or paul.grogan@cancer.org.au

Yours sincerely

A handwritten signature in black ink, appearing to be 'S Aranda', written in a cursive style.

Professor Sanchia Aranda
Chief Executive Officer

A handwritten signature in black ink, appearing to be 'K Pilatti', written in a cursive style with a long horizontal stroke extending to the right.

Kirsten Pilatti
Chief Executive Officer