Breast Cancer Network Australia
Submission on the exposure draft of the Private Health Insurance (Reforms) Amendment Rules 2018

August 2018

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 comment on the exposure draft of the Private Health Insurance (Reforms) Amendment Rules 2018 (the Rules).

We commend the Rules for their clarity in describing Clinical Categories as well as the Hospital Treatment Product Tiers. Taken together, these two documents provide a comprehensive picture of which procedures and conditions are covered by each level of cover. It is our belief that this clarity will help people make an informed choice about the level of coverage that is right for them.

As the peak national body representing Australians affected by breast cancer, we are particularly pleased to learn that surgery to the other breast to correct asymmetry due to breast cancer treatment, and surgery to associated lymph nodes, is included in the scope of cover around what is deemed medically necessary. We are encouraged that the scope of cover explicitly notes that: 'these forms of treatment are considered medically necessary, rather than cosmetic.' This will be welcome news to the many Australian women who may require ongoing procedures following treatment for breast cancer.

These documents address some of the questions we raised in our submission to the Senate Standing Committee on Community Affairs Legislation Committee inquiry into the Private Health Insurance Legislation Amendment Bill 2018 and related bills (please see attached). While we welcome the documents you have provided – and the clarity they bring – it would have been helpful to have been provided with these documents concurrently with the Bill and related Bills to allow our submission to be more streamlined and focused on the issues upon which we were seeking further clarification.

293 Camberwell Road Camberwell VIC 3124
1800 500 258 (03) 9805 2500 beacon@bcna.org.au **www.bcna.org.au** ABN 16 087 937 531

We note the additional documents provided do not address our concerns relating to the continued omission of outpatient radiotherapy in the private health insurance cover tiers. Costs of radiotherapy can significantly contribute to the high out-of-pocket costs for people who are treated in the private system (see p.6 of our submission, attached). We also note that the additional documents do not clarify the inclusion – or exclusion – of exercise physiologists from the list of natural therapies to be removed from the definition of private health insurance general treatment (see p.7 of our submission, attached).

As per our submission, we recommend the Government undertakes further consultation in a number of important areas covered in the Bills, including the impact of the option to increase the amount of excess and the inclusion of benefits for transport, travel and accommodation. We wish to take this opportunity to reiterate the following recommendations made in our submission:

- That any legislative changes to provide an option to increase the amount of excess people can add to their insurance policy is considered carefully given the already high out-of-pocket costs that people must meet in the weeks and months following a breast cancer diagnosis
- That the removal of waiting periods on policy upgrades is removed for cancer treatment, as proposed for urgent psychiatric cover
- That a special category for radiation oncology treatment is developed ensuring radiotherapy – including out-patient delivered services – is included in private health insurance policies
- That careful consideration and extensive consultation is conducted to ensure that the inclusion of benefits for travel and accommodation for hospital treatment does not unintentionally disadvantage rural and regional cancer patients, particularly those who need to travel long distanced for radiotherapy
- That exercise physiology continues to be supported in the private system through rebates for this important evidence based treatment.

Thank you once again for the opportunity to comment. We welcome any opportunity to consult with you further on the impact of this legislation on Australians affected by breast cancer.

Danielle Spence
Director of Advocacy, Policy and Programs

Attachment 1

Breast Cancer Network Australia Submission to The Senate Standing Committee on Community Affairs Legislation Committee inquiry into the Private Health Insurance Legislation Amendment Bill 2018 and related bills

July 2018

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 Private Health Insurance Legislation Amendment Bill 2018 and related Bills.

Our submission reflects BCNA's key area of expertise and interest – women with breast cancer. We note that around 148 men are diagnosed with breast cancer in Australia every year. As the vast majority of Australians diagnosed with breast cancer are women, this submission refers to women with breast cancer.

Over the years BCNA has heard from our membership that being treated for breast cancer in the private health care system, even with private health insurance, can result in substantial out-of-pocket costs. Research published by BCNA in 2017, based on a survey of almost 2,000 Australians diagnosed with breast cancer, demonstrates that women who hold private health insurance actually have significantly higher out-of-pocket expenses than women who do not have private health insurance. At a time when private health insurance premiums are increasing at a greater rate than the Consumer Price Index (CPI), many people are questioning the value of their private health insurance policies, particularly when these policies do not cover the cost of all of the treatments they may need should they be diagnosed with a serious illness such as cancer.

We welcome many of the measures proposed in the Bills provided for comment, in particular the changes to improve transparency and the strengthening of powers of the Private Health

Insurance Ombudsman to provide patients with an option for investigation and redress in disputes with their health insurer (Schedule 3).

We also note the Minister's announcement earlier this week confirming that cancer will be its own category and that all types of cancer will be covered in Bronze level policies. We are very encouraged that this also includes breast reconstruction surgery.

Nonetheless, there are still some specific areas of concern in the Bills for people living with and beyond breast cancer.

BCNA's submission focuses on the following areas of concern:

- 'Bill shock' from policies with larger excesses in the broader context of high out-of-pocket costs for breast cancer (Schedule 1)
- The need for clarification:
    - that the entire package of breast cancer treatment has been included in bronze bands including sentinel node biopsy and breast reconstruction surgery
    - around MBS rules relating to breast reconstruction surgery to reduce current confusion around which of the medical procedures required to restore the look and shape of the breast following a diagnosis of breast cancer are classified as reconstructive and which are currently deemed 'cosmetic'. The cosmetic classification means some women are missing out on claiming the costs of required procedures. This includes nipple reconstruction, symmetry surgery and risk reducing surgery for those who carry a hereditary or familial risk of breast cancer (Reform 4)
    - on arrangements for people who have already had breast cancer (or other serious illnesses) who may seek to upgrade their band of insurance under the new classification, and how their prior diagnosis will be treated in the definitions of pre-existing conditions.
- Consequences of including benefits for travel and accommodation for hospital treatment as part of private health insurance cover (Schedule 5 part 1)
- Removal of private health insurance rebates for exercise physiology (Reform 11)

BCNA makes the following recommendations as part of our submission:

1) that any legislative changes to provide an option to increase the amount of excess people can add to their insurance policy is considered carefully given the already high out-of-pocket costs that people must meet in the weeks and months following a breast cancer diagnosis.
2) that MSB rules relating to breast reconstruction surgery are reviewed to establish which procedures are currently covered by private health insurance and which procedures are not able to be covered. This is important for transparency for both patients and private health insurance providers – both of whom report that currently there is confusion around this issue.
3) that the removal of waiting periods on policy upgrades is removed for cancer treatment, as proposed for urgent psychiatric cover.

4) that a special category for radiation oncology treatment is developed ensuring radiotherapy - including out-patient delivered services - is included in private health insurance policies.
5) that careful consideration and extensive consultation is conducted to ensure that the inclusion of benefits for travel and accommodation for hospital treatment does not unintentionally disadvantage rural and regional cancer patients, particularly those who need to travel long distances for radiotherapy.
6) that exercise physiology continues to be supported in the private system through rebates for this important evidence based treatment.

BCNA Submission

Private health insurance and the financial impact of breast cancer

Australia has the fourth highest rate of breast cancer in the world[1] and breast cancer is the most common cancer in Australian women.[2] It is estimated that this year (2018) 18,087 women and 148 men will be diagnosed with breast cancer.[3]

Women diagnosed with early breast cancer can face up to twelve months of active treatment including surgery, chemotherapy, targeted therapy and/or radiotherapy. The majority of women, up to 80 per cent, may then be treated with daily oral endocrine treatments (e.g. Tamoxifen) for a further five to 10 years. Out-of-pocket costs for treatment and care can be compounded if women need to reduce their paid work hours or stop all paid work for a time.

Women diagnosed with metastatic (incurable) breast cancer face additional challenges as their treatment will continue for the rest of their lives. The uncertainties around their disease progression means they may have great difficulty with financial planning and budgeting, and with maintaining an income stream.

In 2016, BCNA commissioned Deloitte Access Economics to conduct research into the financial impact of breast cancer. This research included an extensive financial survey completed by almost 2,000 BCNA members. This research showed that there is a large disparity in the out-of-pocket costs women face following a breast cancer diagnosis. While some women (12 per cent) reported no out-of-pocket costs, one quarter (25 per cent) of all women who completed our survey reported out-of-pocket costs of more than $17,200.

The results of this research show that women with private health insurance typically pay more than twice as much for their breast cancer treatment and care than women without private health insurance. One quarter of privately insured women reported out-of-pocket costs greater than $21,000. These costs are not lifetime costs: rather, the costs borne in the first few years immediately after a breast cancer diagnosis. These figures also do not reflect reduced or foregone wages and superannuation.

[1] Australian Institute of Health and Welfare, *Breast Cancer in Australia: an overview*, October 2012
[2] Australian Institute of Health and Welfare & Australasian Association of Cancer Registries, *Cancer in Australia: an overview 2017*
[3] Australian Institute of Health & Welfare 2017, Cancer in Australia 2017. Cancer series no 101. Cat no. CAN 100. Canberra: AIHW.

Given that nearly three quarters of respondents to the survey had private health insurance at the time of their breast cancer diagnosis, and that industry data provided in the explanatory memorandum to these Bills indicates that 60 per cent of chemotherapy treatments are conducted in the private system[4], this financial burden impacts a significant proportion of women affected by breast cancer.

'Bill shock' from policies with larger excesses in the broader contexts of high out-of-pocket costs for breast cancer (Schedule 1)

In light of the high out-of-pocket costs outlined above, we have concerns about the proposals in Schedule 1 to increase maximum excess levels. We appreciate that this measure is intended to lower private health insurance premiums – a source of budgetary strain for many households. Despite the benefits of this, the impact of increasing excesses – meaning that people need to pay more when they become unwell and need to use their health insurance – will most likely result in higher upfront out-of-pocket cost for people in the immediate aftermath of a breast cancer diagnosis.

As outlined above, our research shows that the period immediately after a breast cancer diagnosis is a time of significant financial pressure, particularly if a woman has had to pay out-of-pocket costs for diagnostic tests such as MRI scans. We recommend that any legislative changes to provide an option to increase the amount of excess people can add to their insurance policy is considered carefully given the already high out-of-pocket costs that people must meet in the weeks and months following a breast cancer diagnosis.

Standardising MBS categorisations of breast reconstruction surgery as 'reconstructive' rather than 'cosmetic' (Reform 4)

A significant driver of high out-of-pocket costs for women diagnosed with breast cancer is breast reconstruction surgery. While breast reconstruction surgery after breast cancer surgery is available in the public health system, many women face lengthy wait times, especially women in rural and remote areas. In parts of Far North Queensland, women have reported wait times of upwards of five years for breast reconstruction surgery in the public health system. As such, many women find that breast reconstruction surgery through the private health system is the best option for them; however, this can result in high out-of-pocket costs. Our survey showed that breast surgery – including reconstructive surgery – was the most expensive aspect of a woman's breast cancer experience.

There can be much ambiguity around definitions related to what is deemed 'medically necessary' breast surgery. Too often we hear that private health funds fail to cover all surgery related to a woman's breast cancer, deeming associated surgery such as nipple reconstruction or prophylactic risk reducing mastectomy to be cosmetic in some instances. This is also the case for symmetry surgery to the non-affected breast. It is insulting for a woman who faces losing a breast through mastectomy to be advised that surgical

4 The Parliament of the Commonwealth of Australia, House of Representatives (2018) *Private health insurance legislation amendment bill 2018, a new tax system (Medicare levy surcharge – fringe benefits) amendment (excess levels for private health insurance policies) bill 2018, Medicare levy amendment (excess levels for private health insurance polices) bill 2018 – Explanatory Memorandum.*

procedures to restore the look and feel of her breasts are deemed cosmetic by some providers and by the MBS.

Breast reconstruction following a diagnosis of cancer is not a cosmetic procedure. For many women, it is a significant part of moving on with life after breast cancer. The rate of breast reconstruction surgery in Australia is considerably lower than other comparable countries and not having a breast reconstruction can be associated with significantly worse mental health outcomes.[5]

We welcome the announcement earlier this week from Health Minister the Hon. Greg Hunt that breast reconstruction surgery will be covered in Bronze level policies; however we remain concerned about the details of how reconstruction and associated surgeries, such as symmetry surgery and risk reducing surgery for people who carry a hereditary family risk, will be classified in the four tiered system. We also seek clarification about whether sentinel node surgery, used to determine whether cancer has spread to nearby lymph nodes, will be included in the bronze category.

We recommend that the MSB rules relating to breast reconstruction surgery are reviewed to establish which procedures are currently covered by private health insurance and which procedures are not able to be covered. This is important for transparency for both patients and private health insurance providers – both of whom report that there is currently confusion around this issue.

Removing waiting periods for cancer treatment (Reform 2)

BCNA seeks clarification around what arrangements will be made for people who have already had breast cancer who may seek to upgrade their band of insurance under the new classification scheme, and how their prior diagnosis will be treated in definitions of pre-existing conditions. We are concerned that women who have previously had breast cancer may be precluded from accessing breast reconstruction surgery (or associated procedures) when they purchase or upgrade their health insurance.

We commend the Government for supporting better access to mental health by removing the two month wait period for upgrading psychiatric cover on a once-off basis. This measure is encouraging as it acknowledges that acute episodes of ill health are unlikely to be planned, and that treatment is often needed on an urgent basis. It is our view that the proposed model for acute mental health care services could be adopted for cancer treatment. This would acknowledge that no one plans to get cancer, and treatment for cancer is usually too urgent to serve out a waiting period. A person who has recently joined a health fund, or who has only previously held Basic cover, should be able to access the cancer treatment they need immediately, without having to serve a wait period.

We recommend that waiting periods on policy upgrades are removed for cancer treatment, as proposed for urgent psychiatric cover.

[5] Flitcroft et al, 2016. *Documenting patterns of breast reconstruction in Australia: the national picture.* The Breast, iss. 30. http://www. hebreastonline.com/article/S0960-9776(16)30156-4/fulltext. Accessed 14 July 2017.

Development of a radiotherapy category for private health insurance (Reform 1 and Reform 4)

Radiotherapy is a treatment often used for breast cancer; however, because it is performed as an outpatient procedure, it is not covered by private health insurance policies. This means that patients who choose – or in some cases are strongly encouraged by their treating team – to have their radiotherapy in the private health system can face thousands of dollars in out-of-pocket costs. BCNA's *Financial Impact of Breast Cancer* survey found that out-of-pocket costs for radiotherapy treatment were second only to out-of-pocket costs for surgery. The average out-of-pocket cost for radiotherapy was $2,465, however women reported out-of-pocket costs ranging up to $9,750 for radiotherapy treatment.

Often there is an assumption by health professionals that because a patient has had part of their treatment in the private health system, they will want to have their radiotherapy treatment in the private health system also. However, patients may not be aware that this may mean high out-of-pocket costs.

Even though I said to my surgeon that I'd go public with the radiation, when she referred me to the radiation oncologist they assumed I was a private patient. – Susan

Developing a specialised category for radiation oncology that could be incorporated into cancer cover would offer a better value proposition for privately insured patients with cancer. We recommend that a special category for radiation oncology treatment is developed, ensuring that all radiotherapy - including out-patient delivered services - is included in private health insurance policies.

Consequences of including benefits for travel and accommodation for hospital treatment as part of private health insurance cover (Schedule 5 part 1 and reform 5)

The inadequacy of existing state and territory Patient Assisted Travel Schemes ('PATS') was a consistent issue around Australia, which emerged during our consultations for our *State of the Nation* report. While we are encouraged to see that the Bills contain reforms to address this inadequacy by allowing private health insurance policies to provide travel and accommodation benefits, we have concerns about the unintended consequences of the proposal. These unintended consequences may include state and territory governments reducing the rebates they offer under their various PATS schemes on the basis that private health insurers are providing coverage. This would leave uninsured rural and regional people at a significant disadvantage and potentially mean that private patients are being forced to pay for a service previously covered by state/territory governments.

We are also concerned about what sort of treatment would be classified as 'hospital treatment' in the proposed coverage offered by private health insurers meaning that travel for outpatient treatments such as radiotherapy may not be covered. Radiotherapy for breast cancer is typically performed daily over a period of three to six weeks, with patients traveling to and from hospital between treatments or staying closer to treatment. The costs of travel and/or accommodation for rural and regional people who need radiotherapy can add up quickly. Currently, depending on the state or territory, a patient may receive a PATS subsidy for their travel and accommodation for radiotherapy. If, under the proposed reforms, private

health insurers were *not* classifying radiotherapy as 'hospital treatment' for the purposes of their travel and accommodation provisions, this could mean that privately insured rural and regional patients would be at a significant disadvantage.

We recommend that careful consideration and extensive consultation is conducted to ensure that the inclusion of benefits for travel and accommodation for hospital treatment does not unintentionally disadvantage rural and regional cancer patients, particularly those who need to travel long distances for radiotherapy.

Removal of private health insurance rebates for exercise physiology (Reform 11)

Research is increasingly showing strong links between exercise and reducing the risk of a breast cancer diagnosis or recurrence, and between exercise and improvements in quality of life for people with breast cancer. A recent report by the Australian Institute of Health and Welfare (AIHW) estimated that 22 per cent of the breast cancer disease burden in females was due to overweight and obesity, and that insufficient physical activity was linked to several diseases, including breast cancer, and is responsible for between 10 and 20 per cent of disease burden for these diseases.[6]

This growing body of research strongly indicates that exercise – for weight management and for its own benefits – is a vital part of breast cancer management. For many women, working out how to get back into exercise after breast cancer treatment is a challenge, particularly if they have had extensive surgery, difficult treatment side effects or have never exercised before. Exercise physiologists play a significant role in helping women who have had breast cancer exercise in a way that suits their changed bodies.

Currently, a limited number of sessions (five) per year with an allied health care professional is available under a GP allied health care plan. These visits can be used for appointments with a registered exercise physiologist. Rebates for exercise physiology may also be offered by private health insurers to help women access this important service.

It is with great concern that we read on page 22 of the explanatory memorandum that exercise physiology would be the second largest sub group of providers affected by the removal of some natural therapies from private health insurance cover. Exercise physiology is not a natural therapy. It is an evidence based treatment strongly supported by medical experts both within Australia and internationally. We refer to the recent Clinical Oncology Society of Australia (COSA) position statement recommending that best practice cancer care includes a referral to an accredited exercise physiologist or physiotherapist with experience in cancer care[7].

While we note that exercise physiology was not included in the list of natural therapies to be removed from general treatment products provided on page 22, we assume that the mention of exercise physiologists as impacted providers means that exercise physiology is one of the so-called 'natural' therapies being removed. We would welcome clarification of this point and for a correction to be made if exercise physiology has been included in error. In order to

[6] Australian Institute of Health and Welfare, 2018. *Australia's Health 2018*.

[7] Clinical Oncology Society of Australia. COSA Position Statement on Exercise in Cancer Care. April 2018.

assist people with cancer to reduce their risk of new and subsequent cancers it essential that exercise physiology continue to be supported in the private system through rebates for allied health.

Conclusion

BCNA has made six recommendations as outlined on page two of our submission. These are:

1. that any legislative changes to provide an option to increase the amount of excess people can add to their insurance policy is considered carefully given the already high out-of-pocket costs that need to be met in the weeks and months following a breast cancer diagnosis.
2. that MSB rules relating to breast reconstruction surgery are reviewed to establish which procedures are currently covered by private health insurance and which procedures are not able to be covered. This is important for transparency for both patients and private health insurance providers – both of whom report that currently there is confusion around this issue.
3. that the removal of waiting periods on policy upgrades is removed for cancer treatment, as proposed for urgent psychiatric cover.
4. that a special category for radiation oncology treatment is developed ensuring radiotherapy - including out-patient delivered services - is included in private health insurance policies.
5. that careful consideration and extensive consultation is conducted to ensure that the inclusion of benefits for travel and accommodation for hospital treatment does not unintentionally disadvantage rural and regional cancer patients, particularly those who need to travel long distances for radiotherapy.
6. that exercise physiology continue to be supported in the private system through rebates for this important evidence-based treatment.

BCNA welcomes the work that has already been done around increasing transparency of private health insurance cover and strengthening of powers of the Private Health Insurance Ombudsman. It is our hope that the new changes proposed under the Private Health Insurance Legislation Amendment Bill 2018 and related bills may help reduce the financial burden faced by people who have been diagnosed with breast cancer. For further information, please contact Dr Ellie Kirk on (03) 9805 2506 or ekirk@bcna.org.au.

Danielle Spence
Director of Advocacy, Policy and Programs