

Submission to the Senate Standing Committee on Finance and Public Administration Inquiry into the Government's administration of the Pharmaceutical Benefits Scheme

Breast
Cancer
Network
Australia



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About Breast Cancer Network Australia

Breast Cancer Network Australia (BCNA) 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 57,000 individual members and more than 294 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.

GIVING A VOICE TO AUSTRALIANS AFFECTED BY BREAST CANCER

Submission

Breast Cancer Network Australia welcomes the opportunity to provide a submission to the Senate Standing Committee on Finance and Public Administration Inquiry into the Government's administration of the Pharmaceutical Benefits Scheme (PBS) and commends The Senate for establishing this inquiry.

We have limited our comments to four key aspects of the Inquiry Terms of Reference as outlined below.

Our submission reflects BCNA's key area of expertise and interest – women with breast cancer.

The deferral of listing medicines on the PBS that have been recommended by the Pharmaceutical Benefits Advisory Committee

BCNA is very concerned about the decision taken by the Australian Government in February 2011 to change the process for the listing of medicines on the PBS to require Federal Cabinet approval of all new listings. We believe this decision unduly politicises the listing process, undermines the work of the Pharmaceutical Benefits Advisory Committee (PBAC) and is not in the best interests of Australian health consumers.

As the independent expert authority established by government to assess applications for medicines to be included on the PBS, the PBAC is in the best position to determine which medicines should be included on the PBS, and which should not. We note that in reaching its decisions, the PBAC is required to consider the efficacy and cost-effectiveness of new medicines, and whether the proposed medicine meets a need not already met by other PBS-listed medicines.

It is our view that governments should accept the recommendations of the PBAC. We believe the previous approvals process, which provided for Federal Cabinet approval of medicines over a threshold of \$10 million per annum, was an appropriate process that worked in the interests of government and health consumers.

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BCNA believes Federal Cabinet's decision in February to defer approval of eight new PBAC-recommended medicines for inclusion on the PBS was not in the interests of the Australian public and set a dangerous precedent. We are concerned about the implications of this decision for the listing of medicines into the future.

Any consequences for patients of such deferrals

As the peak consumer organisation for women with breast cancer, BCNA believes women with breast cancer should have access to the latest, most effective treatments and that individual women should be able to access the medicines that best suit their individual needs.

Decisions by Cabinet to defer the listing of medicines on the PBS can severely restrict peoples' access to important drugs. We cite by way of example the bowel cancer drug Erbitux, which can cost patients up to \$30,000 per year without a subsidy. Erbitux was one of the medicines deferred by Federal Cabinet in February. It is a medicine that can extend the lives of people with late stage bowel cancer, but its prohibitive cost puts it out of the reach of many who need it. While we acknowledge that the Minister for Health and Ageing announced in June that Erbitux will now be listed, the listing does not take effect until 1 September 2011, leaving many patients unable to access it until that time.

BCNA is concerned that a similar situation may arise for women with breast cancer. If Cabinet continues to defer approval of new medicines on the PBS, it may decide to defer a breast cancer drug, leaving women with breast cancer disadvantaged. Such a decision may result in women having to pay privately for medicines. For those who cannot afford to pay, it may mean not receiving the best possible treatment available for them.

We strongly support women being able to access, through the PBS, the medicines that their health professionals recommend as the best treatments for them.

Many women have raised with us the considerable financial implications of breast cancer. In addition to the cost of medicines, these can include:

- out-of-pocket expenses for surgery, radiotherapy, tests and other procedures
- travel expenses, especially for rural women
- loss of income
- increased child care and home help costs.

'The emotional and financial stress of a breast cancer diagnosis is enormous. Even with full private medical insurance the additional costs coupled with lack of income was very difficult. Women need to be assured of the best possible treatment irrespective of their financial position. The additional stress of funding appropriate treatment is not conducive to recovery.' – Lorraine, BCNA member

We are also aware that sometimes medical oncologists decide not to offer women medicines that are not listed on the PBS, even though they may be the best treatment for them, because they do not think women can afford them. As a result, women may not be given all their treatment options, denying them the chance to make a fully informed decision about the best treatment for them.

It is important that breast cancer medications are subsidised by government so that all women can have access to them, not just those women who can afford to do so. BCNA Member Suzanne reflected this view in her comments to us on this submission:

'As one who forked out nearly \$10,000 for Taxotere for early breast cancer treatment in 2008 after it was recommended to me by an oncologist as one of the drugs of choice, with less impact on the heart and improved survival outcomes compared to Adriamycin, I have personal experience of the implications of what drugs are available to women on the PBS.

At the time it was not available on the PBS to women with early breast cancer, so two other oncologists I consulted didn't even offer it to me, thus limiting my treatment options. Fortunately Taxotere is now on the PBS, but it was an extra stress and financial outlay when I was no longer working.

I know we live in the real world where cost/benefit is always the bottom line for politicians, but when a drug has been assessed thoroughly by the PBAC and is recommended by one's treatment team as the drug of choice for an optimal outcome, it's withholding from those most in need of it should not be decided on the basis of political gain in a process with no transparency.

Nor should oncologists be placed in the situation where they know there is a better drug available but they will not offer it because they believe the patient may not be able to afford it.'

The criteria and advice used to determine medicines to be deferred

BCNA questions the criteria and advice used by Federal Cabinet in making its decisions about which medicines should be listed on the PBS and which should be deferred. Given that Cabinet appears not to be following the advice of its own expert authority, the PBAC, we would like to know where it is obtaining its advice and on what criteria it is basing its decisions regarding new listings.

We are worried that decisions about listing of drugs may be made on the basis of their cost to the Australian Budget, rather than their health benefits to people who are in need of them.

The financial impact on the Commonwealth Budget of deferring the listing of medicines

We understand that the Government is looking to reduce costs across all areas of government. We do not, however, believe that restricting access to medicines that can make a real difference to peoples' lives, including quality of life, is an appropriate Budget measure.

We are not convinced that deferring the listing of new medicines will save the government significant funding in the long term. In assessing applications for PBS listings, the PBAC considers cost-effectiveness of the proposed medicine. By not listing these medications and so denying people access to them through the PBS, doctors may feel forced to prescribe other medicines that may be inferior, off-label or, in some cases, more expensive but already subsidised through the PBS. In the long-term, this could lead to increased costs for government. The poorer health outcomes that result from people not being able to access the best treatments for their condition may also lead to increased health costs, through more visits to health professionals, more requirements for medications and more hospitalisations.

Conclusion

It is BCNA's strong view that the new process for listing medicines on the PBS, whereby Federal Cabinet approval is required for all new listings, is not in the interests of Australian health consumers. We are deeply concerned that medications that can provide people with substantial health benefits are not being listed on the PBS and that, as a result, some Australians are not receiving the best possible treatment for their medical condition.

We do not believe the Federal Cabinet is in the best position to make decisions about which medicines should be listed on the PBS and which should not.

We believe the Australian Government should revert to the previous listing process, and that it should accept the recommendations of its own independent expert authority, the PBAC.

The transparency in the PBAC's processes, with meeting agendas available on the website six weeks prior to meeting dates, opportunities for consumers to make submissions on the listing of particular medicines, and the online publishing of the PBAC Public Summary documents providing advice on meeting outcomes, has been a key benefit of our drug approval system over recent years. This approach to increased transparency is something of which BCNA has been very supportive, and we believe it is a highly effective component of the decision making process. We also believe this is consistent with broader policy environment moves to increased transparency with other key government functions, such as the Therapeutic Goods Administration. We are concerned that having Federal Cabinet make the decisions on all new listings reduces transparency, with no consumer input to this process and no information publicly available on the criteria Cabinet uses to reach its decisions.

While we appreciate that the Government is endeavouring to bring the budget back to surplus, and that this is a difficult process with many claims being made on it from many different sectors of the Australian community, we do not believe that deferring from the PBS medicines that are recommended by the PBAC is the best way to do this. It has too great an impact on the health of Australians.

BCNA is one of 60 consumer health organisations to have joined with Consumers Health Forum of Australia to voice the concerns of Australian health consumers about this issue. While no breast cancer drugs have yet been affected by the new listing process, we know that our 57,000 members would be outraged if a medicine that could make a substantial difference to women's lives, and was recommended for inclusion on the PBS by the PBAC, was deferred by Cabinet.

We know, for example, that the 2006 PBS listing of the expensive but potentially life-saving breast cancer drug Herceptin has made a huge difference to the lives of many women with early breast cancer, and their families.

Having been listed, Herceptin is now 'standard treatment' for women with a particular type of breast cancer (HER2-positive). Previously only those women who could afford to pay the high cost could access it.

'I was on it (Herceptin) before it was on the PBS and had to pay the full cost of treatment and was out of pocket about \$40,000. The drug company paid for the last few sessions of Herceptin which was a big help, and my parents, in-laws and grandmother also gave me some money to help pay for several rounds of Herceptin.' – BCNA Member

Women continue to tell us how grateful they are that this expensive drug is now available to them through the PBS. These comments were made in response to a survey BCNA distributed to members in 2010.

'I paid for the first 2 doses and am very happy that Herceptin is now on the PBS for women who can't afford it.' – BCNA Member

'I am so glad that it (Herceptin) was placed on the PBS just before I was diagnosed and therefore I was not up for thousands of dollars to have the treatment.' – BCNA Member

We wonder if Cabinet would accept a PBS listing of Herceptin in the current circumstances.

Thank you for the opportunity to contribute to the Committee's Inquiry. For further information on our submission, please contact Kathy Wells, Senior Policy Officer, on (03) 9805 2562 or at kwells@bcna.org.au.

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