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Senate Standing Committees on Community Affairs  
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7 July 2015

Dear Committee Secretary

**Medical Research Future Fund Bill 2015 and Medical Research Future Fund (Consequential Amendments) Bill 2015**

Thank you for the opportunity to comment on these bills.

We are supportive, in principle, of the Government's plan to fund and to increase expenditure on medical research in Australia. Every day we are reminded of the need for more and better research and trials here. We need a mechanism to ensure long term sustainable research capability, and ensure support for young Australian researchers' innovation and expertise. However, we feel very strongly that funding for this should not come from those most in need and least able to pay. The community cares passionately about universal access to quality healthcare irrespective of income.

It is also vital that the patient/consumer voice be heard in allocating money to medical research. It is our money and our health.

We note particularly the Minister's comments when introducing the bill that:

The government will establish an advisory board to provide strategic advice to the government on medical research priorities and expenditure of the disbursements from the fund. This advice will inform how the new medical research funding is allocated in each budget cycle.

Also that the bill provides:

The Advisory Board consists of up to eight members, including the CEO of the NHMRC. The board members, with the exception of the CEO of the NHMRC are appointed by the Health Minister for a period of up to five years.

Members of the Advisory Board must satisfy the Health Minister that, collectively, they possess an appropriate balance of experience or knowledge in the following fields: medical research; policy relating to health systems; management of health services; medical innovation; financing and investment; and commercialisation of research and innovation.

We were pleased to see this detail on the Advisory Board and its role in the Government's amendments to the original bill but remain very concerned a key element has been overlooked. The bill must also stipulate that the advisory board have at least two consumer members. Given the significance of research and burden of cancer on the Australian community, one of those consumer members should represent Australians affected by cancer.

There is a lot of evidence that better decisions are made when consumers are involved and the obvious benefit is community involvement in allocating community and donor funds. Most large research funders in Australia have recognised this and include consumers in their panels of people who allocate research eg the various Cancer Councils, Cancer Institute NSW, National Breast Cancer Foundation etc. It is also accepted that two, rather than one, consumer voices should be the standard, best practice approach. We were disappointed such an approach was dropped by the Government with the new appointments to the Pharmaceutical Benefits Scheme Committee.

We strongly request that the bill be amended to include two consumer representatives on the Advisory Board, including one representing Australians with cancer due to the size of its burden in terms of people affected and costs.

While we are concerned about duplication of existing processes, we would not favour the existing NHMRC process being used to allocate these funds because of our concerns regarding the way the NHMRC operates currently. It has comparatively little consumer engagement and involvement, for example, and processes are cumbersome.

Any system to allocate funding must certainly be efficient, effective and accountable to community priorities. We recommend that Cancer Australia's example be followed, with input from consumers trained for review and priority setting processes and where meaningful consumer engagement is an essential element in the criteria for funding.

Cancer Voices Australia would be pleased to meet or discuss these issues at any time. Please just email us at [info@cancervoicesaustralia.org.au](mailto:info@cancervoicesaustralia.org.au).

Cancer Voices Australia is the independent, 100% volunteer voice of people affected by cancer, working to improve the cancer experience for Australians, their families and friends. We are active in the areas around diagnosis, information, treatment, research, support, care, survivorship and policy. To achieve this we work with decision-makers, ensuring the patient perspective is heard.

Cancer Voices has led the cancer consumer movement in Australia since 2000. Its networks, such as the Australian Cancer Consumer Network of 30 groups, work together on national issues identified as important, with consumers working to help others affected by cancer.

Thank you again for the opportunity to comment on the bills.

Yours sincerely



Sally Crossing AM

Julie Marker

Bridget Whelan