



16th February 2015

Committee Secretary
Senate Standing Committees on Community Affairs
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Parliament House
Canberra ACT 2600

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Availability of New, Innovative and Specialist Cancer Drugs in Australia

A guiding principle for our organisation is to

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- *Effect improvements in and access to new cancer treatments, care and support by contributing to national cancer policy and program development, management and evaluation*

Accordingly we make our submission in support of people with cancer.

On average there are 125 deaths every day from cancer, accounting for about 3 in every 10 deaths in Australia.¹ 46,000 deaths annually – an horrific number!

The members of CanSpeak, many of whom have survived or are now living with their disease are now contributing to a society that supports access to a universal healthcare system. Access to new cancer treatments has enabled them to remain an active and vibrant person, and reduced the burden of their disease on their family and the community.

We are strong advocates for a robust Pharmaceutical Benefits Scheme (PBS) and the role of the Pharmaceutical Benefits Advisory Committee (PBAC), but these organisations were formulated almost 60 years ago. Cancer consumers have influenced policy and changed the way consumers have engaged with the PBAC – a positive move which has provided consumers with the opportunity to have their voice heard. But we believe that for our members, more could be and needs to be done.

Australians are risk – takers, we are prepared to have a go! None more so than cancer patients who consent to participate in clinical trials to improve the outcomes of their cancers. Australia can be justifiably proud of its international reputation in conducting clinical trials in this country. We have some of the best clinical researchers in the world. The Government (through Cancer Australia) continues to provide seed funding to cancer

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clinical trials groups to undertake this important work. Our regulatory system is robust, but the current system is seen by many consumers to be cumbersome, lengthy and constrained by economic imperatives that to the cancer consumer are not representative of the international picture.

We constantly hear both state and federal politicians and their respective governments say 'we are part of the international community, and need to think globally, engage with other countries and international organisations, and seek best practice where appropriate and avoid duplication'. This statement resonates with the cancer community and to be all encompassing, must include our health system.

CanSpeak is aware of another Government Inquiry – Review of Medicines and Medical Devices Regulation - conducted by three eminent Health professions, Emeritus Professor Lloyd Sansom AO, Mr. Will Delaat AM, and Professor John Horvath AO. Although this is a Government Inquiry and we are responding to your separate Senate Inquiry, there will no doubt be synergies and perhaps both important investigations need to be reviewed concurrently. Cancer consumers welcome these important inquiries but not at the expenses of clouding the real issue – timely and appropriate access to new medicines.

For cancer patients an optimal endpoint is cure, or failing that, access to cost effective treatments, where quality of life must be the major imperative. For many cancer patients and their disease there is no other option; treatment must be immediate - we cannot afford to wait!

National consumers speaking on behalf of people affected by cancer

CanSpeak continues to promote the issues of people affected by cancer at a local and national level by working collaboratively with health service organisations, government, non-government and charitable organisations for better outcomes and improved health services.

CanSpeak is a national network of consumers and consumer organisations representing the views and perspectives of a broad range of people and the community affected by cancer.

Yours sincerely

John Stubbs
CEO

1 Australian Institute of Health and Welfare 2014. Cancer in Australia: an overview 2014. Cancer series No 90. Cat. no. CAN 88. Canberra: AIHW