













Lymphoma Australia















The Hon. Malcolm Turnbull, MP Prime Minister of Australia Parliament House Canberra ACT 2600

Dear Prime Minister,

## Re: Your policies in regard to Australians affected by cancer

Australians affected by cancer wish to draw your attention to one of their most pressing needs – the need (and demand) for subsidised access to cancer medicine (new and new uses of existing) in a way that is timely, equitable and sustainable for all Australians. Our organisations represent **over 500,000 Australians** living with cancer and these patients, your constituents, are in desperate need of an improved and more transparent system.

In recent days we have seen statements by various members of the Government indicating that you intend to allow a faster and more flexible approach to the funding of life saving and life extending cancer medicines. Whilst we very much welcome these announcements we are anxious to understand the details of your proposed reforms.

Cancer now kills more Australians than any other disease (ABS) and is Australia's greatest disease burden (AIHW). Many more Australians are living longer with cancer due to early intervention, better information and improved treatment. But we could do much better for those who have to live with and be treated for this insidious disease, especially in the area of timely, equitable and sustainable access to the drugs we need.

Due to the nature of cancer, patients can't wait the years our present approval process takes. Nor can they afford to pay the full cost. This situation was clearly highlighted by the ABC's Australian Story program on 9 May, and often impacts those with a rare cancer, or a rare sub-type of a common cancer, more adversely than usual.

Last year the Senate Community Affairs Committee published their report on the *Inquiry into the availability of new, innovative and specialist cancer medicines*. The committee findings acknowledged that for many cancer patients delays in access to new and innovative cancer medicines come at a huge personal loss that can be measured in both loss of quality of life years and loss of life. Recommendations made by the committee that the Australian Government initiate a comprehensive review of the system for registration and subsidisation of medicines were unanimously supported by all Inquiry parties and by consumers.

We advised the Minister for Health of our particular interest in the following aspects of those recommendations, and now seek your endorsement of them:

- o Increased consumer involvement in all aspects of PBAC decision making, and in any review of the registration and subsidisation processes (Rec 1).
- o Improved flexibility in regulations around the access and analysis of data, particularly combined MBS and PBS data (Rec 2).
- Establishment of a National Register of Cancer Medicines to ensure we can make assessment of the value of all medicines (Rec 3).

Further, a recent survey of the 30 organisations within the Australian Cancer Consumer Network identified their top priority issue as:

Getting better and quicker access to cancer treatments: Timing of approvals for new cancer drugs and their subsidies is slow and lacks transparency. The consumer voice is not sufficiently heard in processes.

We, the undersigned cancer consumer organisations, look forward to your reply, preferably by 10 June. We will publish it on our websites and social media so our members and the community can understand your specific policies surrounding this important matter.

Yours Sincerely

cancer voices australia

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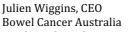
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