

Dear Parliamentarians Supporting Cancer Causes

Priority issues for Australians affected by cancer

It is with great pleasure that we provide you with the results of a survey which the Australian Cancer Consumer Network (ACCN) undertook late last year. The ACCN links nearly 30 cancer consumer organisations of various kinds. Its aim is to facilitate the sharing of information about national level issues for people affected by cancer with a view to offering a clearer, louder consumer voice - if and when necessary. It was launched by Parliamentarians Supporting Cancer Causes, and is presently facilitated by Cancer Voices Australia.

We surveyed the ACCN's member groups to establish the most important issues facing cancer consumers in Australia. We understand that this is an Australian "first"; we don't believe that there has been such a collection of shared issues for people affected by cancer in our country before.

The issues considered the most important are:

- *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.*
Every respondent ranked this as either Very Important or Important.
- *Greater access to clinical trials with more trials available and more funding for trials here in Australia.*
92% respondents ranked this as either Very Important or Important
- *Cancer Nurse/ Care coordinators/Patient Navigators: Cancer centres need to be able to fund the appropriate number and cancer-type positions to underpin this role.*
96% respondents ranked this as either Very Important or Important
- *Access to drugs for less common cancers and improvements to access to off-label drugs for less common and rare cancers, where clinical trials may never happen, yet there is evidence of benefit.*
92% respondents ranked this as either Very Important or Important.
- *More information about treatment outcomes: Treatment outcomes vary greatly across different centres. We need a national registry so that treatment and outcomes can be tracked and reviewed across treatment centres, information which should be publicly available for informed choices.*
88% respondents ranked this as either Very Important or Important.

We stress that this survey was carried out by *an independent, volunteer cancer consumer organisation*. Our only interest is reflecting the views of others like ourselves.

We trust that you will find these consumer priorities useful in the development of robust policy which reflects the needs and views of the now very large constituency of the survivors of Australia's now number one disease – cancer.

We would greatly appreciate your response outlining what you, or your Party, propose to do to advance these issues. We intend to share your response with the ACCN network and our members to better inform them of your position on these most important issues to cancer consumers in the lead up to the 2016 federal election. If the ACCN or its members can assist in any way, please do not hesitate to contact us.

Yours sincerely



Sally Crossing AM
Convenor, Cancer Voices Australia

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