

ELECTION ISSUES FOR AUSTRALIANS AFFECTED BY CANCER – 2015 Survey



The coming federal election gives us a great opportunity to make sure our political leaders know the issues which are important to Australians with cancer and their families.

Cancer Voices is conducting a survey to identify the major *generic* issues for people affected by cancer.

The results will inform political parties in the lead up to the election, and will advise national and state cancer agencies and community organisations about what we think they should focus on.

This survey is about generic cancer issues only – the issues that are common to all of us dealing with cancer and which underpin our advocacy roles.

We have sent this list to the 30 groups within the Australian Cancer Consumer Network and we also want CVN member views. **We invite you to complete this survey and return it to us by 30 September.** Please mail or scan / email to Cancer Voices NSW.

We will collate the results and plan to publish them in the December Newsletter. As Cancer Voices and ACCN, we will be sharing them with our political leaders and other organisations.

Thank you in advance for taking the time to complete the survey and we look forward to sharing the results. This is a perfect opportunity to get our message across with a much louder voice.

*Please rate each of the following issues according to how important they are to you.
The scale is 1 = Very Important; 2 = Somewhat Important; 3 = Not Important*

1. Access to treatment:

<i>Thinking about the following issues, how important are these to you?</i>	1	2	3
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.			
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.			
Treatment and care plans: We need patient-held care plans to improve understanding, decision-making, efficiency and outcomes.			
Equity in access to palliative care services: Cancer patients should be able to reach adequate palliative care services, at home, in hospitals, in nursing homes and in hospices.			
Cancer drug fund: We need to examine a specialised fund to enable equitable access to approved drugs while drug subsidy applications are in progress.			
Access to drugs for less common cancers: Improve access to off-label drugs for less common and rare cancers, where clinical trials may never happen, yet there is evidence of benefit.			
MBS Rebate for diagnostic and testing tools: Medicare rebates should be given to those cancer diagnostic and drug suitability tools which are currently in use.			
MBS rebate for genetic testing: Genetic testing to determine predisposition to cancers should be covered by Medicare to maximise the community's ability to prevent cancers.			
Greater access to clinical trials: We need more trials available and more funding for trials here in Australia.			
Information about clinical trials: The website www.australiancancertrials.gov.au should have all cancer trials on it. Funding of trials should be conditional on registration with ANZCTR.			
Precision medicine trials: Fund a precision medicine initiative, similar to US and Canada, to conduct clinical trials according to molecular profile rather than tumour type.			

2. Standards and Treatments:

<i>Thinking about the following issues, how important are these to you?</i>	1	2	3
Accreditation of cancer centres: Cancer treatment centres, public and private clinics should be required to be accredited for safety and quality standards of clinical cancer care.			
Coordination of Cancer Care Guidelines: Delineate best practice and close the gaps in the coordination of cancer care continuum.			
Consistency of treatment across different centres: Cancer care and outcomes differs across the country. Australians need the same best practice standard of care irrespective of where they are treated.			

A national Cancer Survivorship Framework: Needed to address what to expect and how to navigate the cancer journey from diagnosis onwards.			
Directories of Cancer Specialist Services: Develop directory websites for each state and territory – to allow patients to find the best multidisciplinary care within their reach.			
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.			
Central Guidelines resource: Cancer patients and their medical advisers need central access to authoritative best practice and up to date clinical guidelines in one easily accessible place so they can make sure they are getting the best treatment available and know what to expect.			
Transparency re out of pocket expenses: Patients should always be provided with written information about costs of all cancer treatment upfront, whether not covered or partially covered by health insurance.			
Informed consent: Patients should be provided with sufficient, written information about treatment and costs in order to make best decisions and to provide informed consent.			

3. Generic issues:

<i>Thinking about the following issues, how important are these to you?</i>	1	2	3
Legalise the production and use of medicinal cannabis for the terminally ill and for patients with chronic pain and other conditions which respond well.			
Voluntary euthanasia/ dying with dignity. We want to see a political discussion which reflects the views and needs of Australians.			
Human gene patents: Removal of the ability to grant patents over human genetic material			
Lymphoedema: Patients should be able to claim all necessary garments and treatment under Medicare and more practitioners are badly needed to treat and prevent lymphoedema.			
Travel assistance for rural patients: We need more supportive patient travel assistance schemes, including assistance to participate in clinical trials.			
Travel insurance: cancer patients need clear options and fair coverage. At the moment they cannot get coverage from insurance companies or it is prohibitively expensive and/or limited.			
Consumer priorities and involvement in cancer research: Cancer research should more reflect the priorities of cancer consumers. Funding should be conditional on consumer involvement and consumers should be more involvement in the direction and funding decisions.			
Nothing about us without us: We seek formal adoption of the principle of informed consumer participation. It should be a feature of all decision-making regarding treatment, care and support, at both collective and individual levels.			

4. Please circle the top five issues overall which, in your view, we should prioritise.

5. What do you think should be done about them?

6. Have you any other issues that should be included in this list – please note them below.