

THE AUSTRALIAN CANCER CONSUMER NETWORK



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Hon. Catherine King MP
Shadow Minister for Health and Medicare
PO Box 6022
House of Representatives
Parliament House
CANBERRA ACT 2600
By email: catherine.king.MP@aph.gov.au ; Andrew.Garrett@aph.gov.au

Dear Shadow Minister

Re: EQUITY OF ACCESS FOR CANCER PATIENTS

This submission is made on behalf of the 30 organisations comprising the Australian Cancer Consumers Network (ACCN). (see <https://www.cancervoicesaustralia.org/WhosWho>- page 5 for membership).

The ACCN brings cancer consumer groups together to share information, experiences and issues.

Cancer continues to carry Australia's largest disease burden, and despite Australia having an enviable health system, there are great inequities in access to treatments depending on a patient's disease type, their place of residence and their socio-economic standing. Two consensus Senate Inquiries in the last five years have helped to raise the profile of the changing understanding of the nature of cancer, as well as innovative technologies and medicines either already here or in development. This changing understanding and treatment of cancer has presented notable challenges to our pathways for registration and reimbursement of technologies and medicines.

We acknowledge that work is currently being undertaken to date to introduce systems changes, particularly in streamlining TGA processes to provide Australians with faster access to new medicines and medical devices. The new TGA-PBAC parallel process has also helped to speed up the availability of new medicines via the PBS. There is still much to be done in this space however. We understand that you are aware of the challenges with the system and we would like to work with you to help find solutions.

The report from the Senate Inquiry into Funding for Research into Cancers with Low Survival Rates identified many areas of high unmet need. There is a large crossover between high unmet need and rare and less common (RLC) cancers, and despite RLC cancers accounting for only 38 per cent of cancer diagnoses, they make up 52 per cent of cancer deaths. There are several factors that lead to these poorer outcomes, including historically lower research funding and low patient numbers affecting trials, together with registration and reimbursement issues. One of the ways to address these poorer outcomes is through identifying opportunities for new research, technology and treatment to be equitably accessible across disease types.

Genomic technology to uncover the drivers of cancer, personalised medicine and immunotherapies are all increasingly in clinician's toolkits to improve patient care and outcomes. There are many cases however, where technologies and treatments do not have MSAC or PBAC approval, despite evidence of patient benefit. Patients at one of the most stressful times of their lives can then be left without access. This can be due to the patient's inability to pay the retail price or trials being unavailable locally. All these new developments are exciting and it is essential that our regulatory systems are fit-for-purpose to harness them thereby giving timely and equitable access to patients who so need them.

As noted previously, the ACCN is highly appreciative of the significant reform already underway at the TGA to expedite access to new treatments. In addition to these, the ACCN is seeking clarification on further reforms underway or planned by your office. In particular, the ACCN is interested in reform areas relating to the TGA, the PBAC and MSAC that aim to streamline and increase flexibility for technologies, tests, co-dependent technologies and medicines.

Some of the issues which are by no means exhaustive include:

- The link between expedited and more flexible registration (TGA) and expedited and more flexible reimbursement (PBAC)
- Expedited assessments for co-dependent technologies
- Provisional access to medicines in those instances where there is clinical benefit but further evidence still needs to be collected

Many of the ACCN member organisations have eminent cancer specialists as members and we know that many of these specialists would, along with consumers, be willing to assist in designing processes that would benefit both the people diagnosed and the government bodies that administer this aspect of Australia's world class health system.

Australia's systems must be fit-for-purpose to ensure cancer patients across the board are able to improve their outcomes. Patients should not be disadvantaged because of their disease type, and we look forward to working with you further to improve equity in our health system and harness the exciting technologies on our doorstep.

We would be pleased to receive your response to this submission by 30 April 2019. We will provide your response to our membership and also publish it on our website and social media.

Yours faithfully,

A handwritten signature in black ink that reads "Dan Kent." The signature is written in a cursive style with a large initial 'D'.

Dan Kent for ACCN

3 April 2019

Cancer Voices Australia (CVA) convenes the Australian Cancer Consumer Network (ACCN), bringing approximately 30 cancer consumer groups together to share information and issues
<http://www.cancervoicesaustralia.org/accn/>