



## POSITION STATEMENT

### *Access to high cost cancer drugs*

#### ISSUE:

People affected by cancer need to be assured that their ability to access new cancer drugs is supported by rigorous evidence and time efficient approval processes. Due to changes in the type and cost of new cancer drugs, dialogue between all relevant stakeholders and the wider community is pressing.

#### BACKGROUND

Cancer is now the greatest cause of death of Australians (ABS) and around 1220,000 new diagnoses were made in 2012 (World Cancer Report). It is estimated that 50 new cancer drugs will be submitted to the Pharmaceutical Benefits Advisory Committee (PBAC) by 2015. A recent report (Access to Cancer Medicines in Australia, Deloitte Access Economics, 2013) estimates the time between listing and approval is around 14 months, with some drugs having to go through the process a number of times. Time to access is further lengthened when delays are caused due to difficult price negotiations and high prices requested by drug companies.

The case has been made that due to the nature of the current and future generation of cancer drugs, which are more targeted, require different technology and smaller patient groups, that our present requirements for evidence and processes need to be looked at in a new light.

#### PRESENT POSITION:

Our present situation leaves many cancer patients unable to get the drugs recommended by their medical oncologist without paying full price – and this can be up to \$100,000 per year. Or they may never be offered them due to the cost. Patient Access programs offered by some pharmaceutical companies to assist consumers until PBS listing also often require high patient co-payments. In effect, this results in a two-tier system – those who can pay benefit from new therapies, and those who can't, do not. Waiting for approval and PBS listing may mean that the opportunity to extend life, and/or its quality, is lost.

We highly value the rigour and consistency provided by the current funding processes including the Pharmaceuticals Benefits Advisory Committee (PBAC). However, the involvement of consumers in the PBAC decision-making processes is currently limited. Better information should be obtained about societal preferences for cancer treatments including preferences of the growing number of cancer survivors and those with advanced cancer. *There needs to be a wider public debate about the priority funding medicine policy issues, including which decision criteria should be used to fund new cancer medicines and at what price.*

We acknowledge that research efforts for new cancer medicines need to be paid for and encouraged. However, the despair of cancer patients and their hope of new treatments should not be a pretext for pharmaceutical companies to ask for prices that cannot be afforded by most of the world population including those living in the wealthiest countries.

## RECOMMENDATIONS:

- That broad stakeholder dialogue be held to consider optimum processes for the approval and subsidy of cancer drugs, a dialogue which includes leading cancer consumer organisations
- That the approvals process between TGA and PBAC be reviewed, for timeliness, perhaps considering access to cancer drugs as special category, due to the nature of the disease
- That affordability and costs to patients be considered in light of the ethics involved and the public purse
- That post-marketing studies of new cancer medicines be undertaken to assess their actual usage, benefit and associated health outcomes.
- That drug companies review their pricing policies for their new medicines to allow better access to cancer patients.
- That a review of overseas approvals and subsidies for cancer drugs be conducted, over say the last five years, to inform the discussion.
- That other options like the UK Cancer Drug Fund, possibly as a short term measure, be examined

February 2014

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Cancer Voices Australia is the independent, 100% volunteer voice of people affected by cancer, working to improve the cancer experience for Australians, their families and friends. We are active in the areas around diagnosis, information, treatment, research, support, care, survivorship and policy.

To achieve this we work with decision-makers, ensuring the patient perspective is heard.

Cancer Voices has led the cancer consumer movement in Australia since 2000. The CVA network works together on national issues identified as important by their members, with consumers working to help others affected by cancer.

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