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The voice of people affected by cancer

The Secretariat

The Government's Administration of the Pharmaceutical Benefits Scheme (PBS)

Cancer Voices NSW notes the Terms of Reference of this Inquiry and wishes to provide a short submission which addresses most of them.

Cancer Voices NSW provides the peak, independent voice of people affected by cancer, working to improve the cancer experience of the 40,000 people who are diagnosed each year in NSW. Established in 2000, we are active in the areas of diagnosis, information, treatment, research, support and care. To achieve this we work in partnership with providers of these services, ensuring the patient perspective is heard.

The February 2011 decision by Government to defer listing of medicines recommended by the Pharmaceutical Benefits Advisory Committee (PBAC) onto the Pharmaceutical Benefits Scheme (PBS) has alarmed Cancer Voices NSW and many other Australian health consumer organisations.

People with cancer rely on affordable drugs to stay alive, to delay progression of their disease, and/or to maintain their quality of life. Cancer Voices NSW respects and supports the existing robustly developed PBAC process for deciding which medicines should be subsidised by the public purse. We believe that this system offers the best opportunity for evidence based expert consideration of possible new listings. We especially welcome the relatively new opportunity for health consumer organisations to provide information about the need and impact of the proposed drug on individual's lives. The PBAC process has been well managed, and at a reasonable cost to the community which uses and appreciates it. It is internationally recognised as a leader in effective and proper process.

To politicise decision-making instead of relying on agreed and transparent process is a retrograde step. It will also offer opportunity for pharmaceutical companies to exert extra pressure on the Government, which previously was contained.

Other arguments which address the specific Terms of Reference have been well covered by submissions from organisations of which we are a member – specifically the Consumers Health Forum of Australia and the Chronic Illness Alliance – and we refer the Inquiry to these.

Thankyou for this opportunity to express our concern. We look forward to hearing of the Senate Committee's recommendations to Government.

Yours sincerely

