



*Together we're stronger*  
Tangata tū pakari tonu

25 March 2023

Pharmac

Wellington

[Consult@pharmac.govt.nz](mailto:Consult@pharmac.govt.nz)

### **Re Funding paediatric cancer treatments**

The Breast Cancer Aotearoa Coalition is a patient-based organisation that supports, informs and represents New Zealanders diagnosed with breast cancer, from an evidence base. Our membership includes over 30 breast cancer groups as well as individuals across Aotearoa.

We appreciate the opportunity to respond to Pharmac's consultation on potential changes to Rule 8.1b of the Pharmaceutical Schedule that governs the way in which treatments for paediatric cancers are funded.

We are alarmed by the proposal to review Rule 8.1b that currently allows Te Whatu Ora hospitals to provide any pharmaceutical for use within a paediatric service for the treatment of cancer.

The current model allows best practice care for tamariki who have cancer. It also enables our clinicians and their young patients to participate in clinical trials, which in themselves lead to more knowledge and identification of effective treatments.

The current funding model has not resulted in significant ethnic, socioeconomic or locational inequities for children with cancer and, given the rarity of paediatric cancers, has not had significant budgetary impact. We expect that inequities would grow if access to new medicines was restricted.

Importantly, we note that the five-year survival rate for children with cancer has improved from 28% in 1961-1970 to 86% in 2010 – 2019, with the 10-year survival rate being 85%. These are improvements to be very proud of. There is no doubt that ease of access to unfunded medicines has contributed greatly to the improvement in the length and quality of the lives of the tamariki of Aotearoa and has reduced the burden on their whānau and communities. Children treated successfully for cancer will become our productive citizens of the future. Rule 8.1b ensuring the availability of a full suite of modern medicines has enabled Aotearoa to reach a standard of



treatment and survival comparable to those of other similar countries including Australia, the UK, Canada, Germany and the USA.

This high standard of care should be commended and certainly retained. We believe that this is the standard that Pharmac should aspire to for adult cancers, where our survival rates fall below those of other similar countries, particularly in the cases of Māori and Pasifika.

That there is consideration of a proposal to remove access to these medicines for children with cancer is troubling. The review of Rule 8.1b appears to be a response to those caring for children with other diseases who do not have access to best practice treatments. Pharmac's response should not have been a proposal to remove the good access that children with cancer benefit from, but instead a proposal to provide a better standard of care for children with other diseases in need of unfunded treatments. The current proposal could be interpreted as an attempt to ensure equity at the lowest common denominator, with poor medicines access and poor outcomes for children with various diseases. Such an approach is neither fair nor just and is in fact unprincipled and abhorrent.

In short, we believe that a principled approach to the review of Rule 8.1b would be to acknowledge and celebrate the success of the rule and to retain it, in order to ensure continued world-class treatment, clinical trial participation and survival of tamariki with cancer, along with extension of the rule to cover other paediatric diseases.

We would also like to see a similar aspirational approach from Pharmac in securing sufficient budget to extend the approach to adult cancers, including breast cancer.

Yours faithfully



Elisabeth PJ Burgess

Chair

Breast Cancer Aotearoa Coalition