

# Submission form for consultation on paediatric cancer treatments in New Zealand

In addition to standard background information, we have provided focus questions to help shape your feedback. You don't need to respond to all the questions – only the ones you want to. The final question is open for you to add anything that hasn't been covered by the earlier questions.

## Background information

### Your name

(optional)

### The name of the group or organisation you represent

(if relevant)

### Are you one or more of the following?

(Tick as many boxes as appropriate )

- Someone who has been treated for cancer as a child
- Family or whānau of someone who has been treated for cancer as a child
- A professional working with children who have cancer
- A paediatric cancer researcher
- Other

### How old are you?

- 14 years or younger
- 15 to 30 years
- 31 to 50 years
- 51 years or older

### Which of these ethnic groups do you strongly identify with?

(Tick as many boxes as appropriate )

- Māori
- Pacific peoples
- Asian
- Middle Eastern / Latin American / African
- European and other

## Contacting you

### If you choose, you can provide an email address

If you've provided an email address, we will be in touch to confirm we have received your submission and tell you when a summary of submissions has been published online.

#### Let us know if you we can contact you:

- to seek further clarification about something in your submission
- about information on further steps to be taken following this stage of the review
- about general news and updates from Pharmac

## Your feedback may be shared

We will only use your information to inform our review of rule 8.1. Feedback we receive is, however, subject to the Official Information Act 1982 (OIA). Please be aware that we may need to share your feedback, including your identity, in response to an OIA request.

If you want any part of your feedback treated as confidential, you need to tell us which information and why. For example, would you like us to withhold your identity or a particular part of your submission because it is personal, confidential, commercially sensitive, or proprietary? If your request meets the Official Information Act criteria we won't be required to disclose it.

[Pharmac's privacy statement](#)

### Is there anything in your submission you would like us to consider withholding and why?

## **How well do we understand child cancer and the system of care?**

**Is our understanding of the overall health outcomes being achieved for people with paediatric cancers correct?**

If not, please provide any further information or context

**In what other clinical contexts is participation in clinical trials the 'standard of care'?**

**To what extent is access to paediatric cancer clinical trials dependent on access to medicines through rule 8 1b?**

**How sensitive is this system of care to changes to rule 8 1b?**

## **How effective is rule 8.1 in terms of achieving the best health outcomes?**

**To what extent are good health outcomes for children with cancer in New Zealand dependent on making paediatric cancer treatments available through rule 8 1b?**

**Is timely access to paediatric cancer treatments more important than timely access to other medicines or for other populations? If so, why?**

## **Does the current policy support efficient and sustainable use of available resources?**

**Is our understanding of how rule 8 1 operates in practice correct? What else should we know?**

**How much increase in the use of rule 8 1b do you think will happen as a result of the growing range of new paediatric cancer treatments?**

**Do you see the costs of paediatric cancer treatments accessed through rule 8 1b increasing significantly in the foreseeable future?**

**How could we assess what value paediatric cancer treatments provide against other medicines that could be funded with the same money?**

## **Does the current policy support equity?**

**What should Pharmac take into account when considering equity issues with respect to rule 8 1b of the Pharmaceutical Schedule?**

**Do you consider rule 8 1b to be inequitable from the perspective of other children or those with rare disorders? Why?**

**To what extent do the current policy settings, including rule 8 1b, contribute to the health outcomes achieved for tamariki Māori and Pacific children with cancer?**

**Do you consider rule 8 1b to be inequitable from the perspective of adolescent and young adults with cancer? Why?**

**How might we address equity and fairness concerns related to paediatric cancer medicines through rule 8 1b and access to medicines for other groups?**

## Other information or thoughts?

Is there anything else we need to know to inform the review? If so, please add your information or thoughts here