

A discussion document on THE CONSUMER VOICE in PHARMAC's work

FOREWORD

The work that PHARMAC does and the decisions we make directly affect New Zealanders. We work hard to ensure that New Zealanders get the best health outcomes from medicines and medical devices, from the funding we receive from the government.

We can't achieve this alone. To make the best choices we need to ensure our decisions are well-informed. Understanding the views of consumers is part of this. By seeking and considering these viewpoints, we hope to instil consumer trust and confidence in our decisions.

PHARMAC has a history of seeking consumer input into our work. Consumers have recently provided us feedback that has helped shape the way we work - from a new framework for making decisions (the Factors for Consideration), to our refreshed Pacific Responsiveness Strategy. We are currently asking Māori communities what areas of health are most important to them to help inform the decisions we make.

Since 2002, we have also had a statutory Consumer Advisory Committee (CAC) which provides advice to PHARMAC on a broad range of our activities.

PHARMAC is committed to continually improving the way we do things. This includes how we seek and use the consumer's voice in our work. We are keen to know if the way we do this now is working, and if not, what opportunities there are for PHARMAC to enhance your voice in our work.

PHARMAC will be gathering feedback about this in various ways – via this discussion document, a short online survey, and a meeting with consumer advocacy groups. We are also visiting five locations around New Zealand during May and June 2018 holding 'community conversations'. Our website has more information about the different ways you can provide your feedback.

I hope that you take this opportunity to help PHARMAC make improvements to the way that we engage with consumers, and incorporate your voice in our work. I look forward to receiving your feedback.

"He waka eke noa" A vehicle upon which everyone may embark

Sarah fitt

Sarah Fitt Chief Executive

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PART 1: WHY ARE WE ASKING FOR YOUR THOUGHTS?

Introduction to PHARMAC

PHARMAC is the government agency responsible for making decisions about which medicines and medical devices are funded by the government. We make funding decisions within a fixed budget that is decided by the government. Our mission is to ensure that we get the best health outcomes from that budget.

We do this by taking into account a wide range of issues (using the <u>Factors for Consideration</u>), getting expert clinical advice, promoting competition and negotiating with pharmaceutical companies to get the best prices we can on medicines and medical devices. We do this for new medicines and medical devices, and also for the products we already fund. Running competitive processes like tenders allows us to make savings which we can reinvest in new medicines and medical devices, for more people.

PHARMAC also helps ensure that funded medicines and medical devices are used well – that they are not overused, underused or misused. We work with others in the health sector to help ensure medicines reach the people they are intended for, and are used well.

PHARMAC has a growing role in hospital medical devices where we negotiate national contracts for items DHB hospitals already use and buy. As with medicines, in due course the consumer voice will be sought when we are making funding decisions on medical devices.

Who is a consumer?

When PHARMAC talks about a consumer, we mean any person who receives (or may receive) a funded medicine or medical device. This may also include the person's family or whānau, or support groups representing people with a condition(s).

Why is the consumer voice important to us?

Effective decision making happens when the decisionmaker has all the available information and has considered all the likely impacts of their decisions — this enables robust and well-informed choices. This includes seeking and incorporating the views of people affected by PHARMAC's funding decisions, including family and whānau.

What are we seeking from you?

- We want to find out how consumers feel about the way that we seek and incorporate the consumer voice in the work that we do.
- We want to understand whether you think what we're currently doing to incorporate the consumer voice is adequate, and if not, how we can improve.
- This year, PHARMAC will be updating our Consumer Advisory Committee (CAC) Terms of Reference. Your feedback and ideas on the role of the CAC will help inform any changes to how the Committee operates.

Scope

PHARMAC encourages all feedback about incorporating the consumer voice into our work. In considering feedback, we will be mindful of what is practical to change.

For example, the PHARMAC Board is legally responsible for making decisions and cannot delegate this responsibility outside of the organisation. To fulfil our objective of getting the best health outcomes within the funding provided, we also must protect confidential and commercially sensitive information. This restricts our ability to share some information.

We will also need to consider the resource impacts and trade-offs of any change in our processes.

How to provide feedback

Throughout this document we have asked some questions we would appreciate your thoughts on. Please do not limit yourselves to these questions we welcome any feedback you may have about the consumer voice in PHARMAC's work. The complete list of the questions can also be found in Appendix 1.

We would be grateful to receive feedback by 5pm Friday 6 July 2018. You can provide your feedback and responses to questions in this document in one of the following ways:

Email: enquiry@pharmac.govt.nz

Post: Consumer Voice Discussion Document PHARMAC PO Box 10254 Wellington 6143

PHARMAC will also be gathering feedback about the consumer voice in three other ways. We will be visiting five locations around New Zealand during May and June 2018 holding 'community conversations', we will be talking with consumer advocacy groups, and we will also have a short online survey with some key questions from this document. The PHARMAC website has more information about the different ways you can provide feedback. Should you wish to discuss these matters further with PHARMAC and are unable to attend a forum, please let us know and we will do our best to make appropriate arrangements.

A summary of the feedback we receive will be put on our website. We will also let people know the changes that will be made as a result.

Copies of responses may be requested under the Official Information Act

The responses we receive to this discussion document could be requested by someone under the Official Information Act 1982 (OIA). Anyone providing feedback should be aware that their response and their identity may need to be disclosed in response to an OIA request.

If there is any part of your response or that you would like withheld under the OIA, please let us know in your response, and identify the relevant parts that you would like withheld and we will consider that along with our obligations under the OIA.

PART 2: HOW DO WE CURRENTLY INVOLVE CONSUMERS?

We've talked about how important consumer input is to us – so how do we currently seek and incorporate this in our work?

Most of PHARMAC's interaction with consumers relates to the decisions we make about medicines and medical devices. This includes funding decisions for new medicines or medical devices, and brand changes for products that are already funded.

Factors for Consideration

In some of the descriptions of our work described below, we refer to the Factors for Consideration (the Factors), which PHARMAC uses when making decisions about whether to fund a medicine or medical device.

The Factors were developed in consultation with communities around New Zealand during 2013-2014, and reflect what people told us were important things for us to take into account when making decisions. This includes things like how unwell a person is, health disparities in groups of people, and the broader impact of a condition on family, whānau and wider society. Not every factor is relevant to every decision we make.

2A: DECISIONS ABOUT MEDICINES AND MEDICAL DEVICES

How PHARMAC considers an application for funding

The diagram below is a general guide to how PHARMAC assesses and makes decisions on funding a medicine or medical device. Assessments could be for a new medicine or medical device, or for providing a broader range of people access to a funded medicine or medical device.

The images of people in the diagram below indicate where PHARMAC currently engages with the consumer. Further detail about the process for considering an application for funding can be found on our website.

CURRENT PROCESS FOR CONSIDERING AS APPLICATION FOR FUNDING

Prepare application (supplier, consumer, clinician)

Anyone, including consumers, can make applications to PHARMAC for us to consider funding a medicine or medical device.



APPLICATION TRACKER UPDATED

Information about applications that we have received and are working on are available on our website.



2&3 Consider evidence (PHARMAC and clinical advisors) using factors for consideration

consideration Assess relative value (PHARMAC) using factors for consideration prioritisation At these stages, we use the Factors for Consideration - our decision-making framework. The Factors were developed in consultation with consumers and represent what people told us were important to take



Negotiate (PHARMAC and supplier)

Consult and decide using factors for consideration

into account when making decisions.

If an agreement is reached, PHARMAC may consult on funding the medicine or medical device. People's feedback is taken into account before a decision is made.



6 Implement

5

QUESTIONS

- 1. Are there parts in this process where consumer input could be incorporated or changed?
- 2. What should the nature of that input be (e.g. inform, consult, involve, collaborate, empower)?
- 3. How do you suggest PHARMAC should seek this input?
- 4. How do you think it would help improve the quality of PHARMAC's decisions?

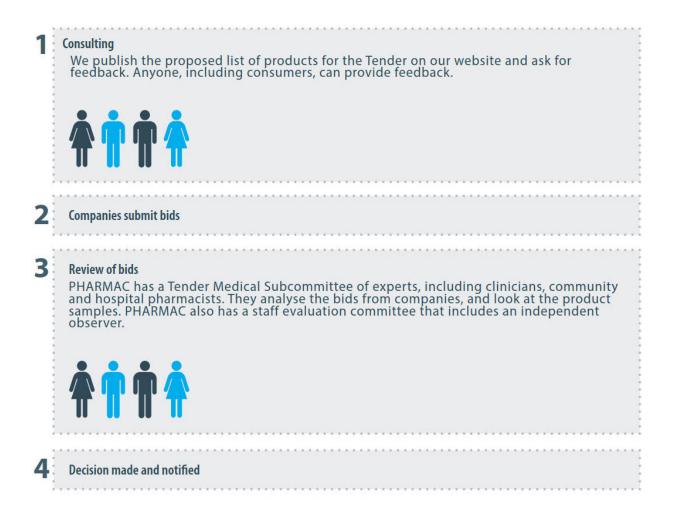
Changes to the brand of a medicine or medical device (Tender process)

Sometimes there will be a change in the brand name of a medicine that people take. There can be a few reasons for this, but the most common is that PHARMAC has negotiated a better price for medicine but it is supplied by a different company. Because the medicine is already funded and available to people, the majority of the consumer input was received at the time the medicine was first funded.

PHARMAC most often does this work through the annual Invitation to Tender, where we ask for bids from companies. Further detail about each stage can be found on our website.

We are not currently using this process in our early stages of work in hospital medical devices.

ANNUAL TENDER PROCESS



QUESTIONS

5. How could the consumer voice be better incorporated when we change the brand of a medicine?

2B: OTHER AREAS OF PHARMAC'S WORK

As well as making funding decisions, PHARMAC also seeks the consumer voice across several other areas of our work.

Ongoing engagement with consumer advocacy groups

PHARMAC staff often meet and talk with consumer advocacy groups. This can range from regular meetings, to PHARMAC staff contacting groups to discuss access to medicines and medical devices, a particular funding proposal, a decision that's been made, or to seek their advice on how to best engage with the people they represent.

PHARMAC forums

PHARMAC regularly holds forums in communities around New Zealand to talk with people about the work we do. This is an important opportunity for us to get feedback from people on how we are doing and to talk about any concerns they may have.

Responsible use activity

One of PHARMAC's functions is to improve how the medicines we fund, are used. This includes looking at medicines that are overused, underused or misused. This is an important way to improve people's health. We work closely with health professionals and partner organisations to promote optimal use of medicines to health professionals and consumers.

Operating Policies and Procedures

Our <u>Operating Policies and Procedures</u> (OPPs) guide how we undertake our work. When we propose any substantial changes to our OPPs, we seek input from all interested people via a consultation on our website.

Consumer Advisory Committee

PHARMAC has a Consumer Advisory Committee (CAC) that provides advice to us on a range of our work from the consumer perspective. The CAC is described in more detail below.

QUESTIONS

- 6. Does the consumer voice need to be enhanced in any areas of the above areas of work? If so, how?
- 7. How would it help improve the quality of PHARMAC's work?

PART 3: CONSUMER ADVISORY COMMITTEE

Our Consumer Advisory Committee (CAC) was established via legislation in 2002. The CAC provides advice to PHARMAC on how we can better seek the views of, and be responsive to, consumers.

The scope, structure and activities of the CAC are guided by its Terms of Reference. The Terms of Reference for our CAC are currently being reviewed. The feedback we receive from this discussion document will help to inform any changes to the Terms of Reference. The current Terms of Reference can be found on our website, here.

The CAC's role

The CAC provide advice to PHARMAC from a consumer point of view across a range of PHARMAC's work; including policy, campaigns supporting optimal use of medicines, and medicines funding issues. The CAC's functions do not include providing input on our evaluation or prioritisation of medicines or medical devices for funding.

Membership of the CAC

The current members of the CAC cover a broad range of backgrounds, experience and interests in the health and social service sectors. It is not intended that the CAC members represent all consumer views but a primary function of the committee is to advise PHARMAC on how best to access the diversity of consumer views and consider these when carrying out its role. Information about the current CAC members can be found on our website. The CAC Terms of Reference also note that the committee should consist of up to nine members and include:

- at least two Māori representatives;
- at least one Pacific people's representative;
- people from different cultures;
- people from different age groups and genders; and
- people from different locations (urban and rural).



- 8. What should membership on the CAC look like?
- 9. What skills, experience or characteristics do you think members of the CAC should have?
- 10. What role do you think the CAC can have in supporting PHARMAC to ensure it is receiving and considering consumer's views and perspectives?
- 11. Are there consumer voices that are not represented?
- 12. Are there examples that you are aware of, where the consumer voice is well represented?

APPENDIX 1: LIST OF ALL QUESTIONS

- 1. Are there parts in this process where consumer input could be incorporated or changed?
- 2. What should the nature of that input be (e.g. inform, consult, involve, collaborate, empower)?
- 3. How do you suggest PHARMAC should seek this input?
- 4. How do you think it would help improve the quality of PHARMAC's decisions?
- 5. How could the consumer voice be better incorporated when we change the brand of a medicine?
- 6. Does the consumer voice need to be enhanced in any areas of the above areas of work? If so, how?

- 7. How would it help improve the quality of PHARMAC's work?
- 8. What should membership on the CAC look like?
- 9. What skills, experience or characteristics you think members of the CAC should have?
- 10. What role do you think the CAC can have in supporting PHARMAC to ensure it is receiving and considering consumer's views and perspectives?
- 11. Are there consumer voices that are not represented?
- 12. Are there examples that you are aware of, where the consumer voice is well represented?



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