

SUMMARY OF FEEDBACK: CONSUMER VOICE IN PHARMAC'S WORK

INTRODUCTION

PURPOSE OF THE CONSULTATION

In May-June 2018 PHARMAC initiated consultation on how consumer voices are incorporated into PHARMAC's work. Specifically, we were wanting to:

- Find out how consumers feel about the way that we seek consumers' views and incorporate their voices in the work that we do.
- Understand whether consumers think what we're currently doing to incorporate consumers' voices is adequate, and if not, how we can improve.
- Gather feedback and ideas about the role of the Consumer Advisory Committee (CAC) to help inform any changes to how the Committee operates.

PROCESS FOR SEEKING FEEDBACK

PHARMAC released a [consultation document](#) in May 2018, and invited feedback through a number of avenues:

- written feedback to be submitted to PHARMAC by email or post;
- attendance at a 'community conversation' event at five locations around New Zealand;
- a session with consumer advocacy groups in Wellington; and
- an online survey released via PHARMAC's website and advertised through social media channels.

The table below summarises responses received. Appendix One provides a more detailed breakdown of respondents.

Feedback mechanism		Attendance/ submissions received
Community conversations	Nelson	3
	Christchurch	15
	Wellington	5
	Auckland	33
	Whangarei	5
	Consumer advocacy group session	11 (groups represented)
Written submissions		8
Online survey		326
Skype meetings		2

STRUCTURE OF THE SUMMARY OF FEEDBACK

This report is structured into the three broad topics that were focused on as part of this consultation. Within each of the topic, feedback has been collated into themes.

The topic areas are as follows:

- Pharmaceutical funding decisions.
- Brand changes.
- Consumer Advisory Committee.

These reflect the main topics covered by the 12 questions in PHARMAC's consultation document. They were also the topics covered at the community conversation events.

The online survey asked respondents four questions:

1. In what ways have you, as a consumer, engaged with PHARMAC before?
2. Do you feel that your views were listened to?
3. Other comments
4. Are there parts of PHARMAC's work where you think there could be improved consumer input?

Feedback to the online survey was particularly wide-ranging and, in many instances, reflected the issues that were hot topics for submitter at the time. All the feedback has been incorporated into the report structure as shown in the table below. The question number correlates with the questions in the consultation document.

Report structure	Consultation feedback
Pharmaceutical funding applications	Q1 Input to the application process
	Q2 The nature of that input
	Q3 How PHARMAC should seek this input
	Q4 How (Q1-3) would improve PHARMAC's work
	Q6 Consumer voice in other areas
	Q7 How (Q6) would improve PHARMAC's work
	Online survey responses
	Community conversation feedback
Brand changes	Q5 Consumer voice when brands change
	Q6 Consumer voice in other areas
	Q7 How (Q6) would improve PHARMAC's work
	Online survey responses
	Community conversation feedback
Consumer Advisory Committee	Q8 Membership of the CAC
	Q9 Skills etc of the CAC members
	Q10 The role of the CAC
	Q11 Consumer views not represented
	Q12 Examples of consumer voice
	Online survey responses
	Community conversation feedback

TERMINOLOGY

PHARMAC has defined the term 'consumer' as 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). We acknowledge the feedback received indicated some submitters have a preference for 'patient.'

The summary of feedback differentiates between feedback received in person through community conversations and meetings ("attendees") and feedback received in writing through the survey or via written submission ("submitters").

PART 1: CONSUMER INPUT INTO PHARMACEUTICAL FUNDING DECISIONS

Clarity of PHARMAC's process

A key theme across the feedback received through written submissions and from attendees at the consumer conversation events was the lack of clarity in PHARMAC's current processes about how consumers can input and provide feedback into pharmaceutical funding decisions.

Submitters who had experience making a pharmaceutical application, or being involved in this process, often found it was unclear what would happen next. Attendees at consumer conversations spoke of similar experiences, where there was a long period of silence after an application had been received by PHARMAC.

Several submitters and attendees at a number of the community conversations also thought the opportunity to provide feedback to PHARMAC on consultations was too late in the process. A number of submitters felt that by the time of consultation, PHARMAC had already received clinical advice and the decision had largely been made. The opportunity for earlier input was suggested by a large number of submitters and attendees at forums who were experienced in their dealings with PHARMAC.

Visibility of consumer input

Consumers largely felt that there was lack of visibility of where consumer input had been taken into account in PHARMAC's processes for pharmaceutical funding applications. At community conversations events, attendees were taken through the process where consumers can input and many were surprised at the number of avenues for input. However, attendees and some written submitters noted that it is unclear how consumer input is actually used in the ultimate decision-making by PHARMAC.

Relatedly, a number of submitters and some attendees reinforced the importance of feedback loops to acknowledge input had been received and, where feasible, explain why a decision had been made. Submitters particularly emphasised the need for information to be presented back to consumers in lay language. A couple of submitters used the publication of clinical committee minutes as an example of information that was too technical for most people to understand.

Attendees at consumer conversations also discussed PHARMAC's decision-making framework, the Factors for Consideration. Several attendees noted that explicit input from consumers would be valuable in assessing several of the Factors. For example, understanding health need of the person, and the impact on family, whanau and wider society.

Consumer advocacy groups discussed whether 'weightings' should be applied for consumer-related factors. A couple of submitters also proposed the need to weight "consumer preferences" as part of PHARMAC's decision-making framework. The view was that this would make what is important to consumers more visible.

Whilst most submitters and attendees at community conversations provided feedback about their experiences with process for new pharmaceutical funding applications, a small number of submitters specifically commented on PHARMAC's Named Patient Pharmaceutical Assessment Process (NPPA). The shared view of the small number of submitters was that consumers have limited ability to input into NPPA applications because of the reliance on health professionals to make the application. Submitters said it was unclear whether their condition or situation was adequately reflected in the application, and wanted to be more a part of this process.

Current tools for consumers

PHARMAC has a range of tools and mechanisms to provide consumers with information on pharmaceutical funding applications. Feedback was received from consumers on the following:

Website

The ease of access and navigability of the PHARMAC website was a core criticism of many respondents, with many noting this was a barrier to better understanding PHARMAC's work. Submitters also noted that content was too technical and was difficult to find the information that was most important to consumers.

Application form

A significant number of attendees at consumer conversations were not aware that consumers could make funding applications. Most submitters who were aware, or had experience making an application, considered that the form was inaccessible for consumers. One consumer noted that although a consumer can technically make an application, the information and data required is not available to the average consumer. This view was shared by attendees at a couple of consumer conversation events.

One submitter praised the inclusion of impacts on family, whanau and wider society.

Application tracker

A number of attendees at community conversations didn't know the application tracker existed. Several other attendees and submitters who were familiar with the application tracker thought the tool was useful but could be improved to make it more consumer-friendly. Suggestions for this included providing more plain-language information on where the pharmaceutical is in PHARMAC's process, summarising clinical advice, and signalling what happens next.

Connecting with all consumers

Another key theme that came through the feedback on pharmaceutical funding applications was the need for PHARMAC to connect with all consumers. This feedback was in relation to both the consumers who PHARMAC is (or is not) reaching, and the type of feedback that we seek from consumers:

Identifying the 'voiceless' consumers

A number of attendees at the consumer conversation events talked about the need to ensure PHARMAC's messaging (including information on how to input into PHARMAC's pharmaceutical funding decisions) reached minority groups, smaller communities, and consumers without a consumer advocacy group to represent them. A number of attendees signalled the lack of diversity at the community conversation events was indicative of the voices that were likely missing in PHARMAC's engagement processes.

Several submitters also commented on the need to ensure a wider range of voices are captured. One submitter noted that whilst PHARMAC is good at engaging with established consumer groups, this may come at the expense of representation of all voices on a particular issue.

The role of consumer groups was also raised by a number of submitters and those who attended the consumer conversation events. Though consumer advocacy groups represented their consumers, relying solely on these groups risked PHARMAC only hearing from 'those at the top of the group.' Relatedly a couple of submitters noted that not everyone is represented by a consumer advocacy group.

Listening to peoples lived experiences

The importance of giving consumers an opportunity to share their experiences of living with/ surviving/ caring for someone with a condition consistently came through submitter feedback and from attendees at consumer events. Many submitters felt that real-world experience should supplement clinical advice and should be an integral part of PHARMAC's decision-making process.

In contradiction to these views a couple of submitters felt that PHARMAC must focus on scientific evidence and that, if more consumer voice is incorporated into the process than at present, it risks 'the loudest voices being heard rather than the most sensible.'

Opportunities for improvement

A number of opportunities were raised for PHARMAC to improve consumer input into pharmaceutical funding decisions. The points below are suggestions put forward by several people who attended community conversations and/or provided written submissions:

- Consumer input into PHARMAC's understanding of health need as part of the Factors for Consideration and at any earlier point in the process.
- Provision of more and plain English information on applications that have been considered and/or are currently in the process. This includes summaries of evidence (and evidence gaps), timeframes, and clinical committee advice.
- A way to keep consumers informed of updates to applications that consumers are interested in, for example via a notification.
- Redesign of PHARMAC website and application form.

- Greater use of intermediary organisations to disseminate information.
- Consumers represented on PTAC and/or other subcommittees.
- More relationship building with smaller community groups and consumer groups where relationships are not currently as strong.
- More, and more visible, information informing consumers of their rights to input into PHARMAC's processes.

PART 2: CONSUMER INPUT INTO PHARMACEUTICAL BRAND CHANGES

Feedback captured in this section reflects the key themes across all feedback received.

Earlier engagement and visibility of consumer input

A central theme relating to consumer input into pharmaceutical brand changes was the need for PHARMAC to undertake engagement before a decision is made.

Written feedback emphasised the need for targeted engagement before brand change decisions with affected consumers. It was noted that this would help to validate individuals' experiences. Attendees at a few community conversations also discussed the need for this earlier engagement to happen through health professionals such as GPs and Pharmacists. Some attendees noted that change was difficult for certain groups, such as elderly, and earlier engagement would not necessarily change this.

A number of submitters also commented that there is no visibility of consumer input when it comes to making brand-change decisions. These submitters asked whether there was opportunity to give feedback on potential brand changes, and thought consultation on brand changes should be more visible and longer.

Attendees at a consumer forum and one submitter noted that it is unclear when products re-enter PHARMAC's tender process, whether PHARMAC has considered feedback received from consumers in the past. Submitters felt this needed to be made clearer.

Supporting consumer understanding

A key point of discussion at a number of the community conversations was the need for more support to help consumers understand why brand changes happen. This was supported in several written submissions. Consumers thought knowledge was key in relation to brand changes, and that a clear rationale for why the change is being made and reassurance about what consumers can expect (eg. potential for side-effects) was important.

A couple of submitters specifically discussed generics and the need for PHARMAC to better explain changes between generic medications.

Feedback mechanisms

A strong theme particularly from attendees at some community conversations, but also through several written submissions, was the need for better mechanisms for user feedback after a brand change.

Submitters discussed the need for more avenues for feedback that are clearer and tailored to meet the needs of particular groups. Submitters also questioned whether health professionals, including GPs and pharmacists, needed a bigger role in reporting adverse events relating to brand changes. A couple of submitters suggested thresholds at which

point PHARMAC needed to initiate a more comprehensive response to reports of adverse events.

Attendees at community conversations also reinforced the need for PHARMAC to be more responsive in monitoring consumer impacts after implementation of a brand change. Attendees also discussed the need for more support for consumers where it was known that a brand change may be difficult.

Opportunities for improvement

A number of opportunities were raised for PHARMAC to improve consumer input into brand change decisions. The points below are suggestions put forward by several people who attended community conversations and/or provided written submissions:

- Dissemination of proactive and targeted information to affected consumers before a brand change has been made.
- An alert system to inform consumers that a brand change is being considered, or is coming up.
- Using more communication channels to inform consumers of upcoming brand changes; including social media, GPs and pharmacists, existing forums and events, through consumer groups, and face to face opportunities to talk to PHARMAC.

PART 3: CONSUMER ADVISORY COMMITTEE

Feedback captured in this section reflects the key themes across all feedback received. Very little feedback was received from most of the community conversations, with the exception being the session facilitated with consumer advocacy groups.

Representation

Submitters generally felt that CAC wasn't representative enough of consumers. Consumer groups in particular felt the current membership did not reflect all consumer voices. Consumers made a number of suggestions for improved representation across demographics, health conditions, and consumer advocacy groups.

A couple of submitters noted the challenge of incorporating the range of consumer perspectives within a single group, and felt the CAC should be a conduit between PHARMAC and consumers and consumer groups not represented, and that this was not currently the case.

Role and function

A number of submitters suggested a more formalised structure be established to enable consumer representation to be a part of clinical recommendations and other critical parts of PHARMAC's business. A couple of submitters additionally reflected on the opportunity to use co-design principles to consider how consumers could be involved throughout PHARMAC's processes.

Several submitters, and attendees at some community conversations, reflected on their role as a consumer (and/or as part of a consumer advocacy group) and that the current role of CAC has limited value for them. Attendees at the community conversations noted that CAC does not engage widely with consumer advocacy groups.

A couple of submitters noted that the brief of CAC is very wide, and one suggested that this may impact on CAC's ability to influence change.

Looking to other examples of good practice

A number of submitters mentioned other models of good practice in relation to consumer input that PHARMAC could look to. Within government, submitters mentioned HQSC and ACC which have both changed their committee structures and methods of seeking consumer input. Other examples were provided of more localised models including the cervical screening guidelines on consultation, within the mental health sector, and 'Caring Counts.'

Other submitters also suggested international models including NICE in the UK, PBAC in Australia, and also models of engagement including the International Association for Public Participations (IAP2 model).

Appendix One: People and groups who provided input to the consultation

Community Conversations (attendance)

Nelson (3)
Christchurch (15)
Wellington (5)
Whangarei (5)
Auckland (33)

Other meetings

Consumer Advocacy Group meeting in Wellington

Asthma and Respiratory Foundation New Zealand
Crohn's and Colitis New Zealand
Cystic Fibrosis New Zealand
Diabetes New Zealand
Federation of New Zealand Ostomy Societies Inc
Grey Power New Zealand Federation Inc
Haemophilia Foundation of New Zealand Inc
Lung Foundation New Zealand
New Zealand Organisation for Rare Disorders
New Zealand Pompe Network
Prader-Willi Syndrome Association

Skype meetings

Thyroid Association of New Zealand
Unicorn Foundation

Written submissions

Auckland Women's Health Council
Breast Cancer Aotearoa Coalition
Cystic Fibrosis New Zealand
Heather Williams
New Zealand Aids Foundation
John Forman, Rare Disease Advocate
New Zealand Organisation for Rare Disorders
Shaun McNeil, Mental Health Consumer Consultant and Suicide Prevention Activist

Note that some individuals and groups may have both attended a meeting and made a written submission.