

# Appendix Two - Update on PHARMAC's transparency work programme: Increasing public trust, confidence and understanding of PHARMAC

## Purpose

This paper provides the Health Select Committee with an update on the progress of PHARMAC's work programme to improve public trust, confidence and understanding of PHARMAC through increased transparency and improved engagement with consumers.

## Executive Summary

- Increasing transparency and improving public trust, confidence and understanding of PHARMAC is an organisational priority. PHARMAC wants to better incorporate New Zealanders' views in our decisions and communicate our assessment and decision-making processes clearly and simply. We are working hard to improve how we engage with New Zealand consumers and to better include them in our assessment and decision-making processes.
- We have embarked on a wide-ranging programme of work. This includes activities that encompass both:
  - process improvements; and
  - an improved communication and engagement approach.

## Background

As part of our 2018 Consumer Voices engagement, we received feedback that New Zealand consumers are concerned about the transparency of PHARMAC's assessment and decision-making processes. We heard that it can be difficult to understand how PHARMAC makes its decisions, what stage in PHARMAC's assessment and decision-making process a funding application is at, and if, or when, we will fund a medicine. Some of these concerns have been highlighted further this year in recent public petitions and Health Select Committee hearings.

PHARMAC's work plan was presented to the Health Select Committee in March 2019 which included an action plan to respond to this feedback.

The Minister of Health through the 2019/20 Letter of Expectations, asked PHARMAC to *"prioritise its planned internal work on improving the transparency of its processes; and development of its communication with the public and other stakeholders."*

Increasing transparency and improving public perception and understanding of PHARMAC is an organisational priority, and our most recent accountability documents reflect this. One of the new measures in the 2019/20 PHARMAC Statement of Performance Expectations (the SPE) is directly related to this work programme under Output 2.1:

*"Improvements to the transparency of PHARMAC's processes, including how PHARMAC receives and communicates information about medicine funding applications."*

Specific SPE targets for this measure in the 2019/20 year relate to activities discussed in this paper.

## Work underway

We consider that PHARMAC is transparent with the information that we share (in terms of openness, accountability and honesty), particularly relating to the decisions we make and within the constraints that we face. We publicly consult on all our funding decisions.

The perception that PHARMAC lacks transparency is driven to a large extent by PHARMAC not sharing where on the priority list a pharmaceutical has been ranked, and not being able to indicate a timeframe for when a pharmaceutical may be funded. As these factors relate to PHARMAC's negotiating position and commercial strategies, we are unable for commercial reasons to provide this level of detail to people, and therefore are unlikely to meet a threshold for 'transparency' that people would like to see.

Having said this, we acknowledge that there are areas where we can make improvements, and we are actively pursuing these. These include improvements to the way we involve patients and consumers in our decision-making, and improvements to the timeliness, clarity, and public understanding of the work that we do.

PHARMAC now has a dedicated workplan to capture this continuous improvement work. The workplan incorporates activity that is external facing and contributes to increasing public trust and confidence in PHARMAC.

Key activities we are undertaking as part of this work plan are:

### 1. Process improvements

- Implement PHARMConnect – an easy-to-use on-line tool that suppliers, clinicians and consumers can use to more easily make funding applications and track their progress.
- Funding Application Close-out Project - making decisions on funding applications that are on PHARMAC's "waiting list" but are not currently under active consideration and are unlikely to be funded under current circumstances.
- Faster publication of reports and recommendations from our expert clinical advisors.
- Proactive publishing of OIA responses, Board minutes and other information.
- Continuous improvement in how we prepare for and implement brand changes.
- Earlier assessment of new medicine applications for cancer (in parallel with Medsafe assessment).

### 2. Improved communication and engagement with consumers

- Reviewing the communication style we use in our interactions with the public, to ensure consumers are able to understand our processes and decisions, as well as creating a more people-focused, empathetic organisational voice.
- Exploring how to increase consumer input into our assessment and decision-making processes.
- Reviewing the role and function of PHARMAC's Consumer Advisory Committee.

Each of these activities is discussed in more detail below.

Note that we are in the process of developing a new strategic framework for PHARMAC that will inform our Statement of Intent for 2020/21 – 2024/25. Our continuous improvement activities will be extremely relevant to this new strategic framework and will be aligned with it.

## 1. Process Improvements

### ***PHARMConnect***

Since early 2018 we have been working on improvements to the way PHARMAC receives and communicates information about new medicine funding applications.

PHARMConnect is an online pharmaceutical funding application management system that will provide improved transparency of all funding applications and enable status timeline tracking for internal and external users.

We understand that information on funding applications and our process can be confusing and difficult to navigate. In developing the Application Tracker part of PHARMConnect we have taken the opportunity to address some of the concerns we have heard. The new Application Tracker:

- provides up to date information on funding applications. A “progress bar” is displayed for each application providing a simple, visual explanation of where an application is in the assessment process and what happens next.
- provides information in a user-friendly way, with an improved search function. An example of this user-friendly approach is providing links directly to medicine specific information from our clinical advisors.
- is publicly available on the PHARMAC website, with no requirement to register before accessing the information.

PHARMConnect<sup>1</sup> went live in August 2019 and we will continue to refine its functionality over the coming months.

### ***The Funding Application Close-out Project***

The Funding Application Close-out Project aims to identify which of the currently open funding applications could be formally declined or otherwise closed as an application. This work will make it much clearer to everyone, including consumers, whether a medicine is being actively considered for funding, and will reduce the number of open applications PHARMAC is managing.

Traditionally, PHARMAC has rarely declined funding applications. Rather, we have kept applications open (albeit inactive) so that if new information such as clinical evidence or commercial considerations becomes available, we are able to reactivate it without requiring a full new submission.

Because of this, PHARMAC now has several hundred open applications that are inactive and unlikely to ultimately be progressed for funding in the absence of changed circumstances. There is a range of reasons for the inactivity. They may have been recommended for decline by our clinical advisory committees, there may be no supplier for the medicine in New Zealand, or the application may have been superseded by PHARMAC funding another medicine that offers better health outcomes for patients in the same clinical group.

We have heard from our stakeholders and consumers that people want certainty and timeliness in our assessment and decision-making processes, even if this means declining a funding application.

We have taken a proactive approach to informing the public about what the Funding Application Close-out Project is doing and inviting their input. In line with PHARMAC’s approach to all decisions on medicines, and our long-term commitment to transparency, we invite further

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<sup>1</sup> <https://www.pharmac.govt.nz/medicines/how-medicines-are-funded/new-funding-applications/>

information or comment before we take a decision on whether or not to close applications. We do this through a consultation document – as we do with other decisions.

In May 2019 we consulted the public on a proposal to decline 14 inactive funding applications. In July 2019 we made public the first decisions resulting from this work. We will consult on further applications proposed for decline throughout 2019/20.

### ***Faster publication of expert clinical advice reports***

Applicants and others who are interested in funding applications have sometimes been frustrated by the time it has taken for expert clinical advice reports about the applications (previously referred to as minutes) from our clinical expert committees to be published.

The information considered by PHARMAC's Pharmaceutical Therapeutics Assessment Committee (PTAC) and subcommittees is often extremely complex and includes detailed clinical data and research. Because of the technical subject matter and the number of committee members who need to review meeting records to ensure the accuracy of the notes, it often takes some time to finalise them for publication.

We have set a target of 12 weeks (84 days) to complete and publish the reports of PTAC meetings and 14 (98 days) weeks for records of subcommittee meetings. We have prioritised this work as an organisation and have appointed two additional staff to focus on assessing funding applications and producing the records from the meetings.

We have already begun making significant improvements to the time taken to publish clinical advice records (minutes). Improvements to these times is now included as a target in the 2019/20 Statement of Performance Expectations.

### ***Proactively publishing more information***

PHARMAC receives many Official Information Act (OIA) and general requests from the public for a range of information and data. As part of our move to make our work more accessible we have been publishing our OIA responses on our website.

We are also looking at the types of information that are sought most frequently under the OIA. Where possible, we are proactively making this information more publicly available – to reduce the need for people to request this information through the OIA process.

We have also begun to publish PHARMAC Board minutes. Beginning from the March 2019 Board meeting, we now provide a record of each Board meeting on the PHARMAC website as soon as practicable after the meeting<sup>2</sup>.

### ***Medicine brand changes***

PHARMAC regularly implements medicine brand changes. For every medicine brand change decision PHARMAC makes, we consider the impact on patients and the sector and what we need to do to support the change. While there are some activities that we consider for all brand changes<sup>3</sup>, we also look at whether additional support is needed for specific changes. Ongoing improvements to our management of brand changes over the past few years, have included:

- Developing a separate exceptional circumstances application process (outside of the Named Patient Pharmaceutical Application (NPPA) process) that considers applications for the alternative brand allowance. An alternative brand allowance enables individuals to stay on their funded brand of pharmaceutical if a brand change would be clinically challenging for that patient. This approach has been used for venlafaxine and most recently the

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<sup>2</sup> <https://www.pharmac.govt.nz/about/accountability-documents/information/pharmac-board-minutes/>

<sup>3</sup> This includes activities such as a Brand Switch Fee (for first time a brand change occurs) for pharmacists to acknowledge extra time to counsel patients with a brand change, information on PHARMAC's website, production of leaflets to be used by healthcare professionals when supporting patients, and other supporting activities as required.

lamotrigine brand changes, and we have ensured that clinicians and patients are informed about it.

- Engaging consumers in the decision process. For the most recent change of blood glucose meters, for example, PHARMAC supported Diabetes New Zealand to undertake user testing with their members, to get their views about the support that would be required if there was a change in brand. We will consider using this approach for other similar changes.
- Providing for people to have extra time or an extra visit to their prescriber to help them manage the change. For the lamotrigine brand change PHARMAC has put in place a process to reimburse the co-payment portion of the cost of an extra visit for patients who need additional support. We also give careful thought to the length of the transition period for individual brand changes in the light of the specific consumer groups.
- Trialling new opportunities for consumers to engage with PHARMAC in 'real-time'. Through the recent 'ask me anything' Facebook live event, consumers were able to ask us questions about any PHARMAC issue, including the lamotrigine brand change decision.

We continue to evaluate how well we are implementing brand changes and to apply what we learn to future brand change activity.

### ***Parallel assessment of new medicine applications***

PHARMAC is proposing to assess funding applications for new cancer medicines in parallel with Medsafe's assessment process. Currently, PHARMAC does not usually accept funding applications for new medicines unless they have already been assessed and approved by Medsafe. A key exception to this practice is for medicines for rare disorders, under the new policy settings that were agreed in 2018.

This aims to shorten the time it takes for a new cancer medicine to reach PHARMAC's priority list of options for potential funding. This change was referenced in the recent Cancer Action Plan.

We consider that this change is ready to implement from 1 January 2020. If successful, we will consider rolling out this approach for all new medicine funding applications.

## **2. Communications and Consumer Engagement**

### ***PHARMAC's revised organisational voice***

PHARMAC is reviewing the organisational voice we use in our interactions with the public and shifting to a more people-focused and empathetic voice. This includes a strong focus on clear, accessible language.

To guide this work, PHARMAC has developed a new Communications and Engagement Strategy. The strategy outlines how we intend to improve our understanding and response to the public's perceptions of PHARMAC, and our intended change in tone to better meet the needs of people who are interested in and affected by our work.

There are six strategic focus areas outlined in the Strategy, of which four relate directly to our work to improve public perception and understanding of PHARMAC. These are:

1. Our organisational voice is consistent and empathetic,
2. Communications reach the right people,
3. Stakeholder engagement is authentic and purposeful, and
4. We are transparent and trustworthy.

## *Website improvements*

As an example of work related to the Communications and Engagement Strategy, we are improving some of the key content on the PHARMAC website. We have recently updated sections about what PHARMAC does and our place in the health system and the section on rare disorders medicines<sup>4</sup>. These sections have been re-written in plain English to ensure they could be more easily understood by anyone who wanted to find out more about PHARMAC.

There is still significant work to do to improve the functionality and content of our website and to make it more user friendly. We are reviewing the website analytics to understand how people currently use it and we are looking into what information we are frequently asked for by media and through OIA requests and general enquiries. Once we understand what people want and how the website fits with other digital channels such as social media, we will develop digital channels strategy that will include changes to improve the website.

## **Consumer input into PHARMAC processes and decisions**

At the end of 2018 we published a Consumer Voices action plan on our website that maps how we are responding to what people have told us. One of the actions that is particularly pertinent to the wider transparency work programme is: *Exploring options for earlier consultation with consumers when a new funding application is received.*

Currently consumers' input into PHARMAC's process once an application is received is ad-hoc and often limited until we undertake consultation nearer to the end of the funding application process. With the introduction of PHARMConnect this will change, and consumers will be able to provide supplementary information on an open application.

PHARMAC is also exploring other options for consumers to have earlier input when an application is received. These include how consumers could inform PHARMAC's analysis of health need, and provide contextual advice to the PTAC and our sub-committees. Options we are exploring focus on providing opportunities for consumers to tell us about what it's like to live with a condition. This could be through online tools, consumer meetings or community champions.

We are weighing up the potential effectiveness of each of these options, the practicalities of implementing them within our existing framework, and what resource will be required. These options are not mutually exclusive.

We have also engaged with our Australian counterparts to learn more about how the Pharmaceutical Benefits Advisory Committee (PBAC) considers consumer feedback. The Australian model operates differently to New Zealand, but we are considering what elements of the Australian model could be applied to a New Zealand context.

## **Reviewing the role and function of PHARMAC's Consumer Advisory Committee**

PHARMAC is required to have a Consumer Advisory Committee to "provide input from a consumer or patient point of view" under the New Zealand Public Health and Disability Act (2000). Input from consumers has suggested that the Committee as it currently operates may not provide the best possible input from a consumer perspective.

We are now reviewing the role and function of the Committee, particularly looking at whether the Committee's process or structure can be improved. This review includes considering international and New Zealand models of consumer advisory groups and statutory committees. We intend to complete this review by the end of 2019.

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<sup>4</sup> <https://www.pharmac.govt.nz/about/your-guide-to-pharmac/>

## Summary

We have embarked on a wide-ranging programme of work encompassing both process improvements and an improved communication and engagement approach and are already seeing significant progress and improvements. The workplan will be updated regularly.

The work as a whole is ongoing, and we will be measuring our progress and reporting to the Minister of Health on a regular basis.

Yours sincerely



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Chief Executive