Minutes of the PHARMAC Consumer Advisory Committee (CAC) meeting

Wednesday 12 June 2019

The meeting was held on Level 9, 40 Mercer St, Wellington from 9 am.

Present

David Lui	Chair
Lisa Lawrence	CAC member
Adrienne von Tunzelmann	CAC member
Key Frost	CAC member

Apologies

Te Ropu Poa	CAC member
Stephanie Clare	CAC member
Tuiloma Lina Samu	CAC member
Francesca Holloway	CAC member

In attendance

Simon England (CAC Secretary), Sarah Fitt, Chief Executive, Alison Hill, Director Engagement and Implementation, Jannel Fisher, Communications and Engagement Manager, Katie Appleby, Davina Carpenter, Adam McRae, Janet Mackay (for relevant items)

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1. Record of previous meeting

Minutes of the 6 March 2019 meeting were accepted as a true and accurate record.

Poa/Clare (via email)

2. Chair's report

Only four members attended this meeting, which was not enough for a quorum under the Terms of Reference. Accordingly, as permitted by the Terms of Reference, the Chair directed that for the purposes of this meeting, a quorum would be four people.

The Committee asked that the contributions of Neil Woodhams and Stephanie Clare be noted. Neil had resigned and Stephanie had completed her second term, and as a result was no longer on the Committee.

The Chair considered that, now that two people have left the committee, it's important to progress the search for new members. Ideally, these new members would be present at the next meeting in September.

The Chair commented that the Board continues to be interested in the work of the Committee, including the recent discussion on PHARMAC's reputation. He also noted that the PHARMConnect system and the new communications strategy will support PHARMAC's connection to the community.

Members noted there were no update papers for this meeting. With the lengthy gap between meetings, members feel a loss of continuity if not kept up to date with ongoing PHARMAC work like access equity, Te Whaioranga and the Pacific Responsiveness Strategy.

Members asked that, for future meetings, update papers be presented on topics like the Te Whaioranga strategy, PHARMAC's work in access equity, and the Pacific Responsiveness Strategy, even if there was nothing substantive to report.

Matters arising and grapevine

There is interest in putting the 'missing million prescriptions for Māori' story out in the public arena, (ie the Variations in Access to Medicines research).

GPNZ is doing some work in the consumer space, using Sapere, and focus groups. They are putting lots of resources into it. Osteoporosis NZ have been involved.

3. Communications strategy

Jannel Fisher, Manager Communications and Engagement, presented the Communications Strategy. This is a three-year plan that has been endorsed by senior management and the Board.

It identifies six strategic priority areas, in three phases:

- Phase one: Stocktake and audit, what's working well and not working well.
- Phase two: Use learnings from phase 1 to develop strategies.
- Phase three: Implementation of strategies.

The first step is to understand what the public actually thinks. Jannel suggested that we may be underestimating the public's level of understanding about PHARMAC. Views would be sought from the general public including consumers.

Members indicated a willingness to help implement the strategy, as advisers.

A review of the Style Guide was seen as essential, including a guide to using inclusive language (we, us etc), to put a human face on PHARMAC.

Members asked that the Style Guide for staff also be available to 'friends' of PHARMAC, like members of advisory committees who may like to speak up in support of PHARMAC.

Members recommended PHARMAC use visual media such as videos and infographics. They noted that many Māori and Pacific people are visual communicators.

Members asked that communications be a regular part of the CAC agenda.

4. Session with the Chief Executive

Sarah Fitt, Chief Executive joined the meeting. PHARMAC's current focus is on transparency work, and the PHARMConnect project is key. This will provide the capacity to let people add their own experiences of living with conditions to active funding applications.

PHARMAC also has an ongoing programme of declining funding applications that are not currently being actively assessed. These include applications that have been overtaken by other funded medicines, or where there is no New Zealand supplier. Currently we are consulting on a proposal to decline eight proposals. PHARMAC has received some good feedback about this approach.

In line with the new Communications Strategy we are generally being more proactive. We are working on publishing the records of clinical advisory committees more quickly, and we're also now proactively publishing Official Information Act responses.

Vaccines is an ongoing issue, and we are going to Health Select Committee next week (June19) to update them on the meningococcal W outbreak in Northland.

Members commented that the current media focus on cancer is misleading because it gives the impression access to medicines is the only hope for patients. Sarah said that PHARMAC is only part of the cancer treatment continuum. Other interventions, like early detection, screening and access to surgery are far more important; medicines make up only about 8-10 percent of cancer control.

PHARMAC had held a Facebook ask-me-anything session the day before the meeting, on the Lamotrigine brand change. This was the first time PHARMAC had done this, and it was another way to be more approachable, in line with the new Communications Strategy.

In response to a question, the Chief Executive said PHARMAC is still committed to its Bold Goals, and looking at ways to deliver on them. PHARMAC is small and cannot effect change on its own, so needs to influence others. The paper *Achieving Medicine Access Equity in Aotearoa New Zealand Towards a Theory of Change*, was a good example of PHARMAC's work to influence the sector. PHARMAC is also seeking opportunities such as small-scale equity pilots with partners in the sector, like the Health, Quality and Safety Commission.

It was noted that, while the public debate was centred on the medicines that aren't funded, we know that currently funded medicines aren't being accessed or used equitably.

5. PHARMConnect update

Davina Carpenter and Katie Appleby joined the meeting to present an update on PHARMConnect following on from the March meeting. The purpose was to give an update on progress and seek the Committee`s feedback on the draft consumer application forms. They noted that the system is still under construction, and that they would appreciate the Committee`s assistance and feedback on the test system.

The Committee commented on the importance of accessibility of the application forms.

The team noted that:

- PHARMConnect will be accessed from the main PHARMAC website, like the existing Application Tracker, and attention is being given to the appearance of the public interface.

- The general public is unlikely to have some of the information PHARMAC requires to make decisions, such as price and clinical trial evidence. For these reasons the questions and mandatory information fields on the consumer application forms will be different to that required from suppliers. For example, the consumer interface will ask about a patient's experience of living with the disease.

- Consumers will have the ability to create a new funding application, or add information to an existing funding application.

- The test site currently uses the same branding as the main PHARMAC website. As branding of the PHARMAC website changes, so will the branding of PHARMConnect /Application Tracker.

- The first iteration of the system may not be perfect, so launch communications will indicate that PHARMAC will be open to feedback about potential changes and improvements. Our intention is to be up-front about timeframes for making changes, to show our responsiveness.

- At present the test site shows a simple linear process, even though the process is often not like that. This was in the interests of keeping it simple and clear.

A demonstration of the proposed new Application Tracker was given.

Committee members commented that, at first glance, some of the terms on the test site could be misinterpreted. For example, the clinical advice step could be interpreted by patients that they needed to go to their doctors to seek clinical advice on their situation. The PHARMConnect team noted this and requested that any areas where the Committee consider there is potential misinterpretation or room for improvement, particularly in the language used, be reported back in the feedback to the team.

The Committee would be sent a link to the test site and invited to provide feedback on the development consumer application forms, by the end of the month, when the test system will be shut down.

6. Management of brand changes

Janet McKay, Manager Implementation and Adam McRae, Senior Implementation Lead, presented on generic medicines and PHARMAC's management of brand changes, using the current brand change of lamotrigine as an example. There was often media attention focussed on specific brand changes.

The presentation outlined the product life cycle of a medicine and what a generic medicine is. Originator companies put a lot of energy into developing, and defending, their patents and the brand of medicine. Patents could also be applied to certain colours, or packaging of products.

Generic medicines allow PHARMAC to get better value for funded medicines. Generics manufacturers must show bioequivalence, which is assessed by Medsafe.

Members asked about the power of the placebo/nocebo effect: if health professionals themselves believed it, what influence were they having on their patients? Janet said the University of Auckland Department of Psychological Medicine have been researching the nocebo effect, and PHARMAC has been partnering with them on research that is of particular interest, to support PHARMAC's approach to managing brand changes in the future.

Lamotrigine can be used for epilepsy and mood stabilisation. When PHARMAC was considering this brand change we sought more clinical advice than usual. We have produced information for consumers on the brand change (available on our website), and brand switch fees were being paid to pharmacists to acknowledge their role in providing reassurance and support to consumers. We have set up a mechanism to enable patients to remain on their existing brand, and also a process where patients do not need to pay for an additional visit to their GP if they require a follow-up appointment because of the brand change.

Members asked about whether support information had been provided to health help lines, and practice nurses, as these tended to be first points of contact for patients?

Staff acknowledged this point, and said they would look into it.

7. Update on PHARMAC work programmes

Consumer voices

Alison Hill, Director Engagement and Implementation, provided an update on work underway to explore options for engaging consumers earlier in PHARMAC's decision-making.

She said that we have formed a working group of PHARMAC staff to consider how we can best seek input from consumers on funding applications, and determine which stages in the assessment process consumer input will be most relevant to our decision-making.

The options being considered to inform PHARMAC's analysis of health need, and to provide contextual advice to PTAC and our sub-committees include:

- Establishing a web portal for online submissions that would invite consumers to provide their stories about living with a condition.
- Patient meetings. A small selection of consumers would be invited to share their lived experiences with a condition.
- Using community champions to engage with consumer groups in communities. This option would enable more engagement with grassroots organisations.
- Creating a consumer library to provide a New Zealand perspective on living with various conditions.
- Holding consumer consortiums, where we would invite a number of key consumers to discuss living with a particular condition at regular meetings throughout the year.

Alison said 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 PBAC (the Pharmaceutical Benefits Advisory Committee) considers consumer feedback.

The Australian model operates differently to New Zealand in that:

- PBAC includes consumer feedback in their decision process by holding patient hearings. Patients are asked about their experience with a particular drug, daily routine and what factors would make their lives better.

- PBAC has a dedicated consumer evidence and engagement unit to resource this work. The unit chooses relevant consumers for hearings by assessing online submissions made on their consumer web-portal (open to everyone) and from consumer groups they actively meet with throughout the year.

- There are criteria for the types of consumers they engage with, ie they must have an established patient network and be able to provide comment and evidence for PBAC to review.

- PBAC usually engages more with grassroots associations than with foundations as associations tend to be more connected with communities and those who PBAC may have a disconnect with.

- There is no formal weighting on this evidence.

We are considering what elements of the Australian model could be applied to a New Zealand context.

We will come back to your next meeting to discuss this work in more detail, and seek your feedback on the options.

Members commented that there were dangers in looking at Australian models, because they sometimes failed to incorporate the indigenous voice. Members suggested also looking at what other New Zealand Government agencies were doing, as that would show what works well in the NZ context. Members cautioned that consumers may not perceive the system used as working for them, so don't forget to check in with consumers.

Members advised that a lot can be learned by looking at things that aren't working well.

Members would think about what other models there were in the NZ public sector and feed these through.

Review of the Consumer Advisory Committee

Alison also outlined how establishing how and when we can be more effective in incorporating the consumer voice in our processes will inform the upcoming review of the Consumer Advisory Committee (CAC).

The purpose is to:

- review the role and function of the CAC

- identify options for changes that will enable the CAC to better represent consumers and to provide the most effective advice to PHARMAC

We are in the process of engaging a suitably experienced external contractor to undertake this review. This will help to ensure the advice is impartial. We expect to have someone starting the work in July.

We will be asking the reviewer to go back to first principles. The CAC was set up to provide PHARMAC with input from a patient or health consumer perspective. We will expect the review to answer the following questions:

- What is the CAC's current process for engaging on topics that PHARMAC is interesting in receiving advice on? What does the CAC do to engage the community and seek consumers views and input?

- What format could input and advice from the CAC take in the future?

- How can the CAC support PHARMAC to engage with the right mix of consumers?

- Where are some gaps in PHARMAC's information about consumers that CAC can help to fill?

The process will include initial discussions with you to develop options, and then seek the Committee's feedback on the result of the review.

Meeting closed 1 pm.