

Minutes of the PHARMAC Consumer Advisory Committee (CAC) meeting

Friday 11 June 2021

The meeting was held on Level 9, 40 Mercer St, Wellington from 9.00 am.

Present:

Lisa Lawrence Chair
Adrienne von Tunzelmann Deputy Chair
Hazel Heal
Robyn Manuel
Leslie Robinson
Mary Schnackenberg
Tui Taurua
Sione Vaka
Vivien Verheijen
Janfrie Wakim

PHARMAC staff in attendance:

Alison Hill (Director of Engagement and Implementation), Janet Mackay (Manager, Implementation), Trish Elise (Minute taker)

For relevant items: Sarah Fitt (Chief Executive), Trevor Simpson (Chief Advisor, Māori), Michael Johnson (Director of Strategic Initiatives), Logan Heyes (Senior Therapeutic Group Manager), Gina Armstrong (Funding Application Advisor), Angela Cathro (Kaiwhakahaere Te Whaioranga)

1. Welcome and whanaungatanga

The meeting was opened with a karakia, followed by a mihi whakatau to welcome Robyn Manuel (first meeting at PHARMAC premises). Attendees introduced themselves.

Members only time was held. PHARMAC staff re-joined the meeting at 9.15 am.

2. Chair update / Board meeting report back

The Chair provided an update of the May Board meeting. Key items of interest to the committee included the guest speaker being Diana Sarfati, CEO of the Cancer Control Agency, and an update on the PHARMAC Review. The interim report for the PHARMAC Review is due at the end of August, with the final report due at the end of December. The Chair asked members to be mindful of the work the Review was generating for staff.

Action: Diane Sarfati's slides to be circulated to the members if available.

3. Action items / notes from previous meeting / interest register

Action items

The Action list was reviewed.

It was agreed that action item 2020-11-06-03 relating to nocebo/placebo effects information could be addressed through sharing of Professor Keith Petrie's presentation and published journal articles.

Notes from previous meeting

Noted that the last CAC meeting was a meeting with the PHARMAC Review Committee and no notes were taken.

Interest register

The interest register was noted and no new interests were declared.

4. Asthma and COPD medicine competitive procurement

Committee members' early advice was sought on a potential competitive procurement process PHARMAC staff are considering for budesonide with eformoterol dry powder inhalers. This is used to help manage respiratory conditions. This could result in a change of brands. A Request for Proposals (RFP) is planned to be released later this year. The committee were provided with samples of the two currently funded budesonide with eformoterol dry powder inhalers.

The Committee noted that there was increasing use of budesonide with eformoterol dry powder inhalers throughout the country given the recent changes to the Adult and Adolescent Asthma Guidelines.

The views of members were sought on what activities PHARMAC staff should consider to support consumers and messaging in the planning and release of the RFP, evaluation, and decision-making stages and in implementing any change (should there be a change in funded brand).

The Committee suggested that:

- Consideration should be given to sustainability in the RFP process, including seeking
 information from suppliers about whether the inhaler device is recyclable, costs of
 manufacture, environmental impacts and sustainable disposal of inhalers.
- Instructions for the use of each inhaler need to be in accessible formats to meet the needs of the end users (eg. visually impaired, users who speak different languages).
- End users should be provided with information on appropriate disposal of inhalers.
- Consideration should be given to the potential for consumer concern associated with a change in inhaler. A brand change may be particularly impactful for people that have been on a specific inhaler for a long time.

Given the recent update to the Adult and Adolescent Asthma guidelines and the promotion of anti-inflammatory reliever therapy, it was noted a competitive process for budesonide with eformoterol may cause some confusion or concern for people using other currently funded inhalers, such as salbutamol.

Members suggested the following should be considered when communicating publicly about the competitive process, consultation, and decision:

- be proactive and early in any communication before making any decisions;
- engage with Māori and Pacific in the design of any communication, and the inclusion of known personalities/community role models could help with any messaging;
- primary care and community nurses and pharmacists would likely be the main avenues to inform patients. Māori navigators are also a key communication channel for Māori communities;
- when consulting, there needs to be public confidence that a decision has not been made and there is an opportunity to genuinely share feedback;
- consider communication via churches for Pacific communities. Discussion with church communities early in the process could mean easier implementation of any change (should there be a change);
- additional implementation support could be considered for tangata whaiora in the community should there be a brand change

5. Te Rautaki o Te Whaioranga

As an induction for committee members, PHARMAC's Chief Advisor Māori, Director Engagement and Implementation and Kaiwhakahaere Te Whaioranga presented on Te Rautaki o Te Whaioranga, PHARMAC's Māori responsiveness strategy.

The presentation outlined:

- ways we have been working to increase Māori advice at all levels of the organisation.
 This includes the establishment of a Māori advisory rōpū to provide strategic expert
 advice to the PHARMAC Board and senior leaders (expressions of interest will be
 released later in June);
- there is an ambitious, whole of organisation approach, to embedding Te Tiriti which will take time to work through;
- Māori staff in the organisation, including new roles established under Te Whaioranga.
 PHARMAC is committed to having Māori staff in a variety of roles, not just Māori specific roles and are actively recruiting to achieve this.

Discussion covered:

- whether PHARMAC was connecting with the, to be formed, Māori Health Authority, as part of the Health and Disability system changes. It was noted that PHARMAC was working with the Ministry of Health and maintaining contact with the Māori Health Directorate in terms of the formation of the Māori Health Authority
- how there is a huge workload ahead for PHARMAC staff, and for Māori staff, in embedding Te Tiriti across the organisation;
- whether there was a plan for developing young Māori leaders. It was noted that the
 updated PHARMAC values sent positive signals as a good place for Māori to work and
 there was the opportunity to build on that.

Action: The website to be updated to reflect the importance of the Chief Advisor Māori and Te Whaioranga within the organisational structure.

6. PHARMAC update

The Chief Executive gave an update on current PHARMAC projects or issues, including:

- The independent PHARMAC Review. The PHARMAC Review Committee continues to meet with various stakeholders, and staff are currently busy providing responses to the Committee. To date briefings have been provided on over 50 different topics.
- Government's announcement on changes to New Zealand's health system. We will be
 working to understand the impact these changes will have on PHARMAC, including
 identifying opportunities. A paper was provided to the Board in May meeting, and this will
 be shared with the Committee.
- Coroner's report on deaths of people taking lamotrigine. No clear link was made between
 the brand change and the seizures that led to deaths. The Coroner and the Health and
 Disability Commissioner have made some observations. These centred around the need
 for clarification on the roles and responsibilities of communicating brand changes to
 consumers. The Ministry of Health will be leading this work. We will share with the
 Committee the paper that is being presented to the Board in June on PHARMAC's
 response to the observations.

Members took the opportunity to ask the Chief Executive about some operational matters, including:

- what work is being taken to increase the number of Māori staff at PHARMAC, and increase Māori 'buy-in' of PHARMAC;
- importance of linking closely with other government agencies, including HQSC;
- the value of the committee's advice for the implementation of future brand changes;
- the relationship between Medsafe and PHARMAC.

7. Advice coming into PHARMAC

The Committee was provided with an overview of the ways and types of advice that PHARMAC receives to support its work. It was noted that the committee had received a similar overview at its November meeting. However, November was the first time the committee had met and the induction had occurred as part of the CAC and PTAC Terms of Reference review discussion.

There are three broad operational areas where PHARMAC seeks advice and feedback:

- New medicine funding applications;
- Medicines that are already funded; and
- Supporting PHARMAC's cross-organisational work.

Members were provided with an overview, and opportunity to discuss, the stages of assessing new medicine funding applications and how advice (both internal and external) feeds into this. This includes the stages of receipt of a funding application, review and assessment, prioritisation, negotiation, consultation, decision and implementation.

It was noted that the <u>Application Tracker</u> on the PHARMAC website shows the stage a funding application is at.

It was noted that prioritisation and negotiation is carried out by PHARMAC staff, who also come with significant experience and advice, including health economics, clinical, Māori, equity, and implementation expertise.

Members asked whether there was an impact of bias in the assessment of applications. It was recommended that staff training should be undertaken on bias. It was noted that a review of bias within PHARMAC is to be undertaken as part of delivering on Te Rautaki o Te Whaioranga.

8. Advisory committees' terms of reference review

The Committee was provided with a summary of the feedback received to the consultation on the CAC and PTAC Terms of Reference review. Members were asked for their feedback and ideas on how PHARMAC can best give effect to, and support, having a consumer representative on PTAC.

Members noted that for consumer representation on PTAC to be successful, PTAC members would have to be open to a consumer representative/s being in meetings and participating.

Members were supportive of, in the first instance, having two members of the CAC (or previous alumni) attend an upcoming PTAC meeting in an observer capacity. It was noted that this could help:

- identify any support and training that may be required for consumer representatives, and
- identify key areas where consumer representatives would be able to best add value to PTAC meetings.

Members noted that given the technical nature of PTAC, any consumer representatives would need to bring mana.

It was agreed that CAC members would discuss at their next meeting who the CAC observers could be.

Action: At their July meeting, CAC members to identify potential observers to attend the PTAC meeting in August, and questions/feedback the observers could consider.

9. Stakeholder engagement survey – results and engagement plans

Members were provided with a summary of the results of PHARMAC's stakeholder engagement survey. PHARMAC's advisory network has been identified as an important stakeholder group for PHARMAC.

Members were asked for their thoughts on how PHARMAC and the committee could have a more collaborative, strategic and transparent relationship. Members acknowledged the good work on this by PHARMAC staff to date, but noted there was the opportunity for further improvements.

Members suggested:

• the committee could be informed of consultations and decisions before they are released publicly (potentially at least 24-hours in advance if possible), especially if there would be the potential for media coverage.

- collaborative engagement should be based on the values of manaakitanga and whanaungatanga these are part of respectful relations.
- transparency around the appointment of members to the Māori Advisory Rōpū.

It was noted that PHARMAC is currently doing some work looking at different relationship management models across government organisations. There would be the opportunity to share this with the CAC when the work is completed.

Action: Members to provide further suggestions or feedback on how the CAC and PHARMAC could have improved engagement to the CAC email inbox.

10. Poroporoaki and Closing

PHARMAC staff gathered to acknowledge, thank and farewell Adrienne von Tunzelmann. Adrienne has been a member of the committee since 2015, and was previously a PHARMAC Board member from 2003 - 2010. She was thanked for her contribution to the committee, and to PHARMAC.

The meeting closed at 3.15 pm.