

Minutes of the PHARMAC Consumer Advisory Committee (CAC) meeting

Wednesday 6 March 2019

The meeting was held on Level 9, 40 Mercer St, Wellington from 9.30 am.

Present

David Lui
Stephanie Clare
Adrienne von Tunzelmann
Neil Woodhams
Te Ropu Poa
Tuiloma Lina Samu
Key Frost
CAC member
CAC member
CAC member
CAC member
CAC member
CAC member

Apologies

Francesca Holloway CAC member Lisa Lawrence CAC member

In attendance

Katie Sherriff (Acting CAC Secretary), Sarah Fitt, Chief Executive, Alison Hill, Director Engagement and Implementation, Rebecca Elliott, Policy Manager, Emma Holloway, Policy Analyst, Michael Johnson, Director of Strategic Initiatives, Katie Appleby, PHARMConnect Project Advisor, Catherine Kingsbury, PHARMConnect Project Coordinator, Rachel Watt, Senior Policy Analyst, Janet Mackay, Manager Implementation Programmes, Megan Nagel, Implementation Lead (for relevant items)

1. Record of previous meeting

Minutes of the 10 October 2018 meeting were accepted as a true and accurate record.

Clare/von Tunzelmann

2. Chair's report

The Chair noted the signing of a Memorandum of Agreement (MoA) between the Pacific Pharmacists Association (PPA) and PHARMAC in November 2018. The Chair commented that the launch of the PPA marks a momentous occasion for Pacific communities. The Chair will attend the official launch of the PPA in Auckland on 22 March 2019.

The Chair also noted that Te Pātaka Whaioranga (the storehouse of wellbeing) – an expression of PHARMAC's identity - was launched internally on 5 February 2019. It was noted that Te Pātaka Whaioranga is being gradually implemented into the organisation. The Chair encouraged the organisation to put this extension of PHARMAC's identity into practice. Members also noted their support of Te Pātaka Whaioranga and commented on the importance of lifting the organisation's cultural awareness and use of Te Reo Māori.

Matters arising and grapevine

Members commented on the following themes expressed from members' communities and networks:

There is a consultation underway for the relaunch of the Positive Ageing Strategy, with a draft version likely to be released by April 2019.

Members commented on PHARMAC's reputation, especially in the Southland region. It was noted that due to recent media coverage calling for PHARMAC to fund a number of medicines, there is a lot of misinformation about PHARMAC's role. Members encouraged PHARMAC to develop effective communication strategies to tell PHARMAC's story and reach regional populations.

3. Update on PHARMConnect – Application Tracker

PHARMAC staff presented PHARMAC's new online application tracker which will be developed as part of the PHARMConnect project. The aim of the project is to develop a tool that will help to manage medicine funding applications. PHARMConnect will be launched in August 2019.

PHARMConnect aims to make the funding application process easier for both people who make funding applications and the PHARMAC staff who assess and process them.

PHARMConnect will have several different functions. Externally, PHARMConnect will enable people to submit funding applications online and will provide clearer and more transparent information on the progress of a funding application. For PHARMAC staff, PHARMConnect will help better manage funding applications by automating the current funding application assessment process.

Members noted that transparency is a big issue for PHARMAC and that the development of PHARMConnect was timely for the organisation.

Members commented on the need for plain English and a focus on the user's journey and needs, specifically commenting on information the user is looking for, rather than information that is relevant to PHARMAC's internal processes. Members noted that the project team could learn from existing services to support the design thinking, such as online shopping. It was commented that, when designing the application tracker, the project team be mindful of user preferences. It was commented, that wherever possible, a 'human relationship' should be supported, acknowledging that users may be emotional, so ease of use and clarity is very important.

Members suggested that it would be beneficial to be upfront with users that the system may not be perfect for them when it is initially launched, but PHARMAC can encourage input into ways of improving the system. Members also requested that this system be tested with people before it is implemented.

4. CAC Terms of Reference update

Members were provided an update on the work to refresh the CAC Terms of Reference. PHARMAC will engage an external party to conduct a review of CAC and provide options for consideration about the future role of the Committee.

Members commented on the existing Terms of Reference, noting that they put boundaries around the Committee and stop members from engaging with people PHARMAC is not currently reaching.

Members were also provided an update on PHARMAC's response to the 2018 Consumer Voices Review. Feedback to this review highlighted the underlying disconnect between PHARMAC and consumers and, in response, PHARMAC has identified key areas within its funding application process where people can potentially have more input into PHARMAC's decision- making, going forward. This work includes learnings from both indigenous and international models of care. After further exploratory work has been completed over the coming months, PHARMAC will look to implement this change into its funding process at the end of the year.

5. Equity Outcomes Framework and update on access equity programme of work

Members were presented a paper on the Equity Outcomes Framework, a proposed cross-sector framework to assess medicines access equity.

Members were also presented a think piece shortly to be published by PHARMAC, *Achieving medicine access equity in Aotearoa New Zealand: towards a theory of change.* Through this, PHARMAC aims to generate action and opportunities for collaboration across the health system.

Members noted that this paper highlighted the level and underlying drivers of inequity in relation to medicines.

6. Session with the Chief Executive

The Chief Executive commented on PHARMAC's decision to fund Maviret, a potential cure for hepatitis C, from 1 February 2019. Over 500 people have accessed this treatment in one month - the highest rate of uptake of hepatitis C treatments to date.

The Chief Executive noted that there may be up to 20,000 people who have hepatitis C but have not been diagnosed. PHARMAC is supporting a Ministry of Health campaign to encourage people to get tested for hepatitis C. The Chief Executive encouraged members to share the campaign with their networks.

The Chief Executive commented on PHARMAC's appearances at the Health Select Committee (HSC) in December 2018 and February 2019, and PHARMAC's response to questions from the Māori Select Committee. The Chief Executive noted that these were good opportunities to explain PHARMAC's work and provide an update on the 2018 Consumer Voices Review.

The Chief Executive noted that PHARMAC has a programme of work underway to respond to issues raised by members of the HSC, including transparency and timeliness.

There was discussion of recent confusion in Northland regarding the meningococcal W outbreak response, that had resulted in negative perceptions about PHARMAC in the Northland community as the assumed agency responsible for the vaccination programme. This was due to the two different vaccines and dosing requirements, eligibility criteria for access to funded meningococcal vaccines, and misinformation about potential stock shortages. It was also noted that communication was not tailored for local whānau.

Members were assured that PHARMAC had responded to the outbreak as quickly as possible, securing sufficient stock for the outbreak response and other potential outbreaks. PHARMAC would engage with the Ministry of Health to improve communications with whānau in any future outbreak scenarios.

7. Medical devices consultation

Members were updated on PHARMAC's work to manage fairer access to hospital medical devices. PHARMAC is currently consulting on the approach for applying the PHARMAC model to medical devices within DHB hospitals. This is an extensive consultation that will run for four months, ending in June 2019.

Members noted that there is an opportunity to consider sustainability and ethical procurement practices and apply an access equity lens to this work.

Members noted that while this consultation would not directly affect consumers accessing DHB services, as PHARMAC's work progresses in this area there will be more opportunities to engage directly with consumers about what the changes would mean.

8. Update on the Review of the Health and Disability System and update on the Therapeutic Products Bill consultation

Members were updated on PHARMAC's response to the Review of the Health and Disability System.

It was noted that despite PHARMAC being excluded from the review, there are opportunities to improve the transparency and timeliness of PHARMAC's decision making, and leverage PHARMAC's role as an influencer in the health system. The PHARMAC Board would be considering PHARMAC's initial response to the review at its March 2019 meeting.

Members were also updated on the Therapeutic Products Bill consultation that the Ministry of Health is leading. Key areas that impact PHARMAC have been identified and include, increased regulation of medical devices, mechanisms to access unapproved (unregistered) products, equity and direct to consumer advertising.