

Minutes of the PHARMAC Consumer Advisory Committee (CAC) meeting

Friday 14 July 2017

The meeting was held on Level 9, 40 Mercer St, Wellington from 10 am.

Present

David Lui	Chair
Stephanie Clare	CAC member
Key Frost	CAC member
Lisa Lawrence	CAC member
Te Ropu Poa	CAC member (teleconference)
Tuiloma Lina Samu	CAC member
Neil Woodhams	CAC member
Adrienne von Tunzelmann	CAC member (teleconference)

Apologies

Francesca Holloway	CAC member
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In attendance

Simon England (CAC Secretary), Kerri Osborne, (PHARMAC staff), Janet Mackay, Sarah Fitt, Ātene Andrews, Bronwyn Locke, Vanessa Young, Karen Jacobs-Grant (teleconference), attended for relevant items.

1. Record of previous meeting

Minutes of the 7 April 2017 meeting were accepted as a true and accurate record.

Samu/Woodhams

2. Chair's report

David has attended return Fonos with Pacific Community – four had been held with more to come. Attendance had been variable although engagement and quality of conversations had been high and very positive. Some good media coverage has resulted and this was ongoing.

Members asked to be sent PHARMAC's weekly key messages to be kept updated on current issues.

A positive outcome had already resulted from the Pacific responsiveness engagement. Pacific pharmacists are now connected and sharing information, creating national body – a result of the PHARMAC strategy. PHARMAC had helped facilitate the connection through its Pacific responsiveness work.

A notable development was the establishment of DHB consumer councils at various DHBs. There was the possibility these might establish a link and potentially an interlinkage with CAC. Discussion at the Counties Manukau DHB consumer council had included discussion about PHARMAC funding of HIV medicines, and funding of blister packs.

3. Session with the Chief Executive

Director of Operations Sarah Fitt presented an update on behalf of the Chief Executive.

PHARMAC Strategy

Members were updated on the development and publication of the new PHARMAC strategy, which is contained in the 2017/18 PHARMAC Statement of Intent. The Strategy outlines PHARMAC's vision, mission, and bold goals which the Committee had been involved in helping develop.

PHARMAC was now aligning its internal work to be able to deliver on the bold goals, which are:

1. Eliminate inequities in access to medicines
2. Generate \$1 billion in savings for reinvestment in the sector
3. Create systems to enable best investment choices to be made across all our activity. System-oriented goal.

As well as internal changes, the bold goals will require PHARMAC to work closely with agencies across the health system.

PHARMAC was creating a new director position to oversee the goals. There would also be a new management role to oversee the access inequalities bold goal.

Part of developing the PHARMAC Strategy had been to be clear how it links with the NZ Health Strategy. PHARMAC recognises it's not an island.

PHARMAC Board discussion about the bold goals continues. The Board is committed to the goals, while mindful that they are significant targets that will be challenging to make headway in.

CAC members were supportive of the bold nature of the strategy, and willing to help PHARMAC work towards the goals. Members considered PHARMAC is on a good trajectory. This reflected PHARMAC's development as an organisation, maturing into a 'young adult' that was grown up, looking to make a difference and perhaps lead others. Members considered there will likely be some systemic barriers that arise, but welcomed PHARMAC's determination to make progress.

While welcoming PHARMAC's commitment, members commented that not all parts of the sector are as ambitious. There were also issues outside the immediate health portfolio (social welfare, housing) which impacted health status. For its part, PHARMAC has become involved in social investment discussions led by Treasury – these looked at the intersection between health/social issues.

2017/18 budget announcement

In a pre-Budget announcement, the Minister of Health had announced an increase in the Combined Pharmaceutical Budget of \$60 million over four years. In response, PHARMAC had been able to quickly progress a suite of funding proposals, most of which became funded from 1 July 2017. Some key decisions:

- Widening of access to HIV medications (removal of CD-4 threshold)
- Listing of bendamustine for chronic lymphocytic leukaemia and indolent non-Hodgkin's lymphoma

- Listing of sildenafil injections (in hospital) for pulmonary arterial hypertension in children
- Listing of melatonin for children with neuro-developmental disorders
- Widening of access to new medicines for hepatitis C
- Widening access to chickenpox vaccine (decision made last year).

Medical devices

PHARMAC had considerable momentum in devices now, with an increase in internal capacity and contracting. The level of savings continued to increase incrementally.

Recent activity had included a series of DHB Forums which had been well attended (including by some members of CAC). It was noticeable that the tone of questions had changed compared to forums in past years, and that people in DHBs now accepted PHARMAC's role in devices and were more concerned about the timing of when various pieces of work would occur.

4. Māori health areas of focus

The Māori health areas of focus had been developed with community input from 2002, and were used by PHARMAC in its decision-making under the Factors for Consideration, and by Whānau Ora partners to inform projects for funding. The areas of focus included obesity, mental health, diabetes & renal disease, cardiovascular disease including smoking cessation, arthritis and gout, respiratory illness and rheumatic fever.

The Māori health areas of focus were now to be reviewed because of the new status they have because of the Factors for Consideration decision model, ensuring Māori health needs are included when prioritisation for medicines is implemented, and the need to align with the bold goals.

PHARMAC was seeking CAC's view on the best way to engage the community in this work.

Members made the following points for consideration around seeking input to refreshing the Māori health areas of focus:

- Consultation should focus on fairness and distribution of resources, and be about reducing all barriers for whānau to have access to medicines.
- Consultation should adhere to the principles of Te Tiriti O Waitangi.
- The goal of consultation should be clear, and key stakeholders should be identified for engagement.
- Discussion should be based on equity and the current poor Māori health status.
- Iwi buy in would be useful.
- Discussion around a partnership model with Maori, primary care providers, PHOs.
- Support for a locality-based approach/local iwi driven
- Need to collect relevant data that can assist us in making good decisions
- Poverty is an issue, and poverty issues eg access to quality housing, family violence can impact on people's adherence to medicines and general health outcomes. Whānau Ora Collectives can help connect that up by linking to social services etc.
- Whānau Ora collectives are already well organised and in a wellbeing mindset. But some other organisations, for example DHB governance groups may be useful to connect with.
- Stand-alone hui may not be effective, people want to know who is PHARMAC. Sharing an event may be the way to go.
- Social media including Facebook is a good engagement tool. Most young people are on social media.

- Because of shrinkage in Māori providers, many Māori are not covered by a Māori health provider. Look also to mainstream organisations that cater for Māori.
- Important for PHARMAC to influence the system (Bold Goal 3). CAC can encourage PHARMAC to be strong in kaupapa Māori mahi. Then it would be better placed to pursue Bold Goal 1.
- Use networks of current and former members of CAC and Te Rōpū Āwhina Māori. Work smart and make those community links work. There were also opportunities in exploring cross-regional alliances, and in other networks such as networks of older people.

Members considered PHARMAC was on the right track in engaging with Whānau Ora Collectives, and tapping into their networks. Members expressed confidence that if PHARMAC sets out its programme and objectives then the key stakeholders will emerge. Some mainstream providers also had specific projects for Māori and these should also be tapped into. Members noted PHARMAC was already engaging urban Māori organisation such as Te Whānau o Waipareira Trust. PHARMAC should also investigate participation in events such as Te Matatini and Polyfest – go where the people are. This could be combined with a service, such as wellness checks.

Different regions and localities have different circumstances. Priorities in one area may not match priorities in another. The only way to explore this was to take time, build long-term relationships based on trust, and go out to the community. PHARMAC has done this well in the past.

A key foundation for engagement work was ensuring PHARMAC staff had appropriate cultural competency.

Members indicated they are keen to support PHARMAC's work in their localities.

The Committee noted that PHARMAC was engaging early with CAC as it sets about refreshing the Māori health areas of focus. The Committee supported and encouraged the work, and considered the work PHARMAC is undertaking in Māori and Pacific health, and around its Bold Goals, is the right thing to do.

5. Engaging consumers with hepatitis C treatment

New generation hepatitis C treatments have been funded by PHARMAC since July 2016. While there had initially been encouraging uptake, current uptake seems to be plateauing. We want to better understand why and think one of the reasons could be lack of consumer awareness. Staff were keen to understand the committee's perspective.

Members considered access to diagnostic tools could be one issue in this first year of funding. For example, in Nelson the only fibro scanner had been one that was on loan from Canterbury DHB. So a scanner was financed through fundraising. Some time delays in access to treatments may have occurred due to system delays and lack of engagement at the primary care level. Members considered it could be worthwhile to consider supporting general practice to identify patients.

Members considered that there continued to be some stigma associated with hepatitis C, so this could cause embarrassment for some patients. Some awareness raising or normalisation might be worth investigating.

Equally, many people could have hepatitis C without symptoms and so awareness raising of behaviours 'at risk' of developing hepatitis C could be useful.

Members considered the prison population was a key group. Members suggested working with Corrections to have a hepatitis C test included on routine blood testing forms so screening occurs.

Members considered there was a need to balance universal screening for hepatitis C with the Choosing Wisely campaign, which seeks to reduce unnecessary diagnostics while still identifying people who might be ill. Screening low risk people may conflict with the aims of Choosing Wisely.

Members suggested using channels such as social media or Health TV to raise awareness. Members considered that utilising what we know from direct to consumer advertising (DTCA) could be worthwhile.

Members discussed whether consumers would respond to a direct approach from their GP. This was already done for things like cardiovascular checkups. Members considered it might be worth investigating a dedicated clinic/provider for 'anonymity', but needing to balance that with continuity of care.

Members also noted that for some population groups, there might not be the same potential stigma associated with hepatitis C and it would be important to test any messages and approaches first.

6. Engaging consumers using social media

PHARMAC has been using Twitter for two years. Social media was seen as a key way to raise awareness about PHARMAC as a brand and our place in the system. PHARMAC was working to demystify its work through increased use of visual media, video and animation. However, engagement numbers on Twitter were low and PHARMAC was now looking to expand into Facebook. Members' views were sought as to how this could best be managed.

Members considered that it was not a matter of should we, it's how do we do it. Conversations about PHARMAC were already occurring on social media - creating its own channel gives PHARMAC more opportunity to participate and control discussion.

Facebook was now seen as an important business tool that promoted transparency and conversations. Members considered it was important to have strategies to manage people's passions, without ignoring their opinion.

One option was to have more than one page – such as a PHARMAC for Health Professionals page, and a PHARMAC for consumers page. This might help with managing conversations.

Members considered PHARMAC had taken a well-managed approach in first starting with Twitter, then seeking to expand as its experience and confidence grew. Concerns about responses can be managed through close monitoring. PHARMAC should be transparent about the rules of engagement. You're within your rights to take posts down but be clear as to why, for example if posts were abusive. People could be followed up and conversations taken offline.

PHARMAC would need to be alert to people trying to take its brand.

Website and social media platforms have to be integrated. Link to website, also inter-link Facebook with Twitter to create an online and social media 'triangle'.

PHARMAC should also be thinking about what its next step might be - Reddit, Instagram, Snapchat – for reaching different groups of consumers.

7. Diabetes meters

PHARMAC is looking at funding of blood glucose and ketones testing meters and strips, used by people with diabetes. Two points were made at the outset of the discussion to CAC members:

- The process is very different from last time in 2011-12. We listened to feedback. We have spent quite some time engaging with stakeholders - medical, consumer groups, individual consumers and clinicians.
- PHARMAC is preparing for the consultation phase and is not in the decision making phase as yet.

Members' views were sought on how best to obtain feedback from consumers in consultation. Suggestions included:

- Take advantage of networks created through Pacific Responsiveness Strategy work. Diabetes is a big issue for Pacific communities. Pacific health providers were important, also mainstream PHOs like Procure, East Tamaki Health can help with links.
- Seek to obtain regional views, not just Wellington/Auckland
- Consider whether 5 weeks is enough to do 'genuine' consumer engagement, depending on the level of change that may be proposed.
- Consider using face to face opportunities for feedback – not just written. Pacific and Māori groups are orators and prefer opportunities for oral feedback.
- Consider disabilities and carers? Sometimes it's people using these devices on behalf of others.

If training is required for meters PHARMAC would work with suppliers to ensure this is provided.

8. A brief history of CAC

Members were provided with a presentation on the origins, early development, membership and work of the Consumer Advisory Committee since its establishment in 2002.

Members considered it important to honour those who had gone before them on the Committee, and recommended that the history of CAC should be included in the 25th anniversary of PHARMAC work, which will come to fruition in 2018.

Members also noted the voluntary checklist for consumer organisations considering health industry sponsorship, and asked for a copy of the final document to be distributed to CAC members.

Meeting closed 3.30 pm.