

**Minutes of the PHARMAC Consumer Advisory Committee (CAC) meeting
Thursday 27 June 2013**

The meeting was held at PHARMAC, 9th floor, 40 Mercer St, Wellington from 9 am.

Present:

Kate Russell	Chair
Anna Mitchell	CAC member
Maurice Gianotti	CAC member
Moana Papa	CAC member
Jennie Michel	CAC member
Barbara Greer	CAC member
Katerina Pihera	CAC member

Apologies:

Anne Fitisemanu	Deputy Chair
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In attendance:

Simon England (CAC Secretary), Jude Ulrich, Siobhan O'Donovan, Rachel Melrose, Rachel Mackay, Steffan Crausaz, Janet Mackay, Meena Vallabh, Marama Parore

1. Record of previous meeting (7 March)

Minutes of the 7 March 2013 meeting were accepted as a true and accurate record.

2. Chair's report

PHARMAC Board discussions have been fairly standard with few specific comments being asked for from the consumer perspective. The Consumer Forum schedule looks good and I believe most of us will be taking part in at least one meeting.

I have provided advice to management regarding some wording around the Soliris Consultation to ensure that there is no appearance of predetermination.

I wish to formally record the committee's thanks to Moana Papa for her service to the CAC. Moana's experience and knowledge have been very valuable to the committee and to Pharmac. We wish her well in her future career.

3. Matters arising

Members discussed ways to raise the committee's profile or the capacity of members. Members considered it would be useful for skills training to be provided to enable members to build CAC's profile; facilitate discussions; assess priorities etc.

Additional time (an hour was suggested) could be added to future meetings specifically devoted to skills development.

Action point: Members to look at what training options are available and make suggestions via email to CAC.

Options on fold-out wallet cards were presented. Positive feedback was provided on the PHARMAC-developed card being issued as part of the Hospital Medicines List implementation. Members considered that, in addition to wallet cards, fridge magnets could be included as a discussion option.

4. Correspondence

Members discussed examples of correspondence provided to the committee for review. Members sought clarification from staff as to whether PHARMAC gave greater credence to volume of submissions or weight of arguments. Members also sought information on whether template letters are given the same weighting as people writing off their own bat. Consumer groups sometimes issue submission templates for members to fill out – it would be disappointing if such an approach was seen to be ineffective.

All consultation submissions are provided to the decision-maker (PHARMAC Board or Chief Executive), so the volume of responses and weight of arguments is apparent to the decision-maker. For the purposes of analysing submissions, templates are easy to categorise as the same point comes through, so the analysis treats them as noting the same points. The same depth of analysis needs to be given to each point, whether raised in one letter or 100.

PHARMAC considers every point to be valid, and is looking for views from a range of groups including clinicians, consumers, pharmaceutical industry etc. PHARMAC regards both strength of arguments and volume as important. PHARMAC encourages people to put forward their views.

Members commented that in some of the email messages provided for review, more could be done to demonstrate empathy for the writer.

5. Decision criteria consultation

The first consultation forums had been held the previous day. Future forums have variable levels of registration and CAC's assistance and view is sought on how to encourage attendance at the forums.

Members who had attended the first two forums provided feedback to the committee. Points made included:

- Forums need a strong facilitator to ensure people with strongly-held views are heard while also giving others the opportunity to provide their view
- Venues may not be ideal (one was changed at last minute due to double-booking); maybe ask local people for venue suggestions in future
- Not many Māori or Pacific people at Auckland central event
- Timing important – perhaps consider holding evening event(s)
- Registrations at some events are low – but people may just turn up.

Issues of fairness and equity appeared likely to be main themes of the forums. These emerged unprompted at the Auckland events, indicating they are foremost in the minds of people attending. Members discussed how best to stimulate discussion on the topic using an analogy most people could identify with. A shopping cart analogy was proposed – this was good for visual learners and relates well to everyone. Would assist with the discussion on 'what is best', or defining what 'best' means.

Members recommended that visual imagery be used at all forums. The current presentation preamble for the forums is a little short on PHARMAC background. Members considered more time needs to be taken painting the big picture.

CAC members were introduced at the Forums but their role wasn't clarified. Members came to forums wearing several 'hats' so it would be useful to clarify the role of CAC members at forums.

Staff were asked to confirm which forums CAC members were required at.

6. Hospital Medicines List

The Hospital Medicines List (HML) was coming into effect 1 July 2013. This was the culmination of four years' work. The list aims to achieve national consistency of access to hospital medicines for patients. It has been a challenge to work with all 20 DHBs, many of whom have different systems, levels of understanding and engagement in the process.

PHARMAC has agreed to have a roughly six-month transition period, during which there will be some flexibility over which medicines can be prescribed in hospitals. PHARMAC is aware the rules may not be 100% correct. We have already made a change to one of the rules in response to feedback. DHBs are being advised to continue current practice and then seek clarification/changes from PHARMAC. Patient safety comes first.

Meetings have been held in every DHB – met more than 700 clinical staff. Five regional representatives have been appointed – these are hospital pharmacists whose job is to be the 'eyes and ears' on the ground, providing feedback to PHARMAC on implementation. The five representatives are PTAC advisory committee members so are familiar with PHARMAC's processes.

Communication is continuing with both weekly and fortnightly newsletters (different audiences). A resource pack has been sent out which is proving popular.

Members asked what consumers would notice. Consumers shouldn't notice a difference, except the national consistency. Also, with the HML it should be easier to transition from hospitals back into the community.

PHARMAC sought feedback on whether engagement with the consumer sector would be helpful at this time. CAC members responded that on this occasion, the clinician was the 'consumer' and that PHARMAC had addressed their needs well.

CAC members welcomed PHARMAC's approach of giving clinicians the discretion to put patient care first and then think about fixing the rules. Members noted this was different to approaches used when other health changes were made by other agencies. CAC considered this put patient care ahead of bureaucracy, which was welcomed.

7. Chief Executive discussion

The Chief Executive updated the committee on notable milestones. PHARMAC turns 20 on 1 July, which is also the implementation date for the Hospital Medicines List. The current meeting would also be the last CAC meeting for Moana Papa as a member and he thanked her for her contribution.

Community forums

PHARMAC had taken the committee's advice on board and thought about the best structure for the forums. PHARMAC wants people to feel their time is well spent and getting value from it, and are

having their voice heard. PHARMAC staff don't want to be seen to be moderating or shutting down conversation. Some media coverage has occurred which has helped to raise the profile.

Members suggested sharing the agenda with members so this could be distributed to the community.

Social media such as Facebook was potentially a further way CAC could get the message out the community and 'feel the pulse'. PHARMAC was taking advice on how to engage with Māori during the review of decision criteria.

Diabetes meters

Nearly 100,000 people changed to the new meters. People are continuing to compare the new with the old and this was leading to concern over differential readings. PHARMAC was concerned this was leading to changes in how people treated themselves.

Members considered pharmacy was a critical point of contact. A flyer for pharmacists to distribute to patients could be helpful. Messages needed to be delivered by an authoritative voice. This could be community pharmacy, diabetes nurses, or Healthline. Members suggested providing payment to pharmacy to encourage them to monitor and work with patients.

PHARMAC had received correspondence from many people but was concerned about people struggling to change but not contacting PHARMAC. Potentially whānau ora providers could be a channel.

Medical devices

This is ramping up but the focus remains very much on hospital medicines. Hospital medicines work has led to a lot of new investments and transactions as funding rules are tidied up.

Members reiterated comments made supporting the approach to hospital medicines. This will have good effects on PHARMAC's reputation.

New investments

A major investment had just been announced – ticagrelor for heart disease. In terms of expenditure, this is likely to be the most significant funding decision for PHARMAC in the 2013/14 financial year.

8. Medication adherence

PHARMAC has been seeking proposals from suppliers of technology products designed to aid with patients' medicine adherence. The process had just closed, and PHARMAC will be considering whether to choose one or more suppliers. CAC's view was sought on what they would like to see from an adherence programme.

The committee considered that while there was general understanding of what led to non-adherence, it was an area where more research could be done to delve into the variations in people's circumstances that led to them being non-compliant. This could be work undertaken by a researcher or PhD student.

Possible reasons people were non-adherent included:

- Side effects
- Taking medicine takes too long
- Too many other things to take
- Not understanding the benefits – low health literacy
- Lack of information from health professionals about why people need to take medicine

Non-adherence could be unintentional or intentional. Reminders (eg text reminders) could be useful for unintentional non-adherence, but some people may have made a choice not to take medicines. The reasons for this non-adherence need to be better understood.

Members considered some factors leading to non-adherence may be:

- Cost - people weighed up which medicines are the important ones to 'buy' and take
- Inconsistent or conflicting advice from doctors and pharmacists – For example take with water or take with food; after, before or with food. This was not well understood by patients and worried them.
- Blister packs can be daunting. If people have multiple medicines and experience a side effect they can end up stopping everything, because they can't isolate what the problem is.
- People decide not to take medicine because they don't feel unwell.
- With older people, some are socially isolated and lose track of time of day. There's a caring caller service that rings and reminds people.
- Time pressure and/or stress at the doctor or pharmacy means people can't think of the right questions to ask, or understand explanations. Some doctors are focussed on keeping to tight consultation timeframes.
- Research that Māori have shortest time with doctors. Members considered it's the doctor's responsibility to ask people if they understand. Important to have another person in the room as a support.
- Young people moving from home to flatting can affect their medication adherence as the person who usually reminds them (mum) isn't always around.
- People fumbling and dropping medicines, then having to take a replacement. More of a wastage problem but related to non-adherence.
- People holding onto old medicines, which may have different regimens (eg a once a day vs twice a day formulation), can cause confusion.
- People who are diligent can forget and over-medicate.

Members considered factors that can assist with adherence include, or could include:

- Patients having pre-prepared questions to ask the doctor. If the doctor writes the reply this can help consistency of messages from the pharmacist.
- Having pharmacists as part of the prescribing discussion. This happens in some practices but not others.
- A strong relationship with the doctor, with high levels of trust.
- A resource for patients, produced from prescribing software, that outlines what medicines a patient is taking. This can be a reminder to people (put up on fridge or similar), plus also act

as a prompt to health professionals if people decide not to take a medicine. Could also be a prompt for people living alone who are visited by caregivers etc.

Members considered it would be useful for PHARMAC to conduct focus groups to tease these issues out.

9. Evaluation of implementation of funding decisions

PHARMAC is looking to evaluate the implementation of the change for blood glucose testing meters. The review would look at the way in which the change was implemented.

This would be a useful exercise as PHARMAC is moving into more medical device contracting where change could occur. Staff are seeking some general guidance. What sort of themes should be explored, what information could be gathered from users of diabetes products that will be useful for future change decisions? How should people be interviewed in a helpful way as we don't want to focus solely on diabetes change, and elicit information that will be useful across a range of device change implementations.

Members considered it would be useful to talk to a group to find out what is driving concerns. Grants to groups were useful but needed to be available for longer.

Good quality information might come from secondary sources – pharmacists, diabetes nurses etc. These sources would have an understanding of what the barriers are.

Members advised PHARMAC, when gathering information from the community, to avoid telephone calls at dinner time, and ask 'positive' questions.

It would be useful to interview groups who haven't been affected yet by any PHARMAC change, to get their feedback.

10. Te Whaioranga action plan

Members had been provided with a final draft of the Te Whaioranga 10-year Māori health strategy, developed by PHARMAC. This strategy has now been approved by the PHARMAC Board.

Work is now underway with all teams within PHARMAC to put the strategy into action. The Māori health team is realigning to enable it to implement the strategy. There is strong support within PHARMAC for work on the strategy's implementation to proceed.

An initial 2-year action plan is being developed, and CAC's input is sought for that process. This would hopefully result in some activities and measures that give effect to the strategy.

Members considered it was important to ensure the organisation – management and staff – were aware of what the strategy is about. Members noted there were already posters around PHARMAC highlighting the strategy. Aspects of the strategy could be adopted into PHARMAC's vision statements.

Tino Rangatiratanga is important. Part of the work should involve talking to iwi and the community about PHARMAC and its role. The community needed to be aware that PHARMAC was the Crown. That way the relationship is clear.

Members considered they needed more time to discuss and think about what to include in a two-year action plan and how it could be implemented. Te Roopu Awhina Māori was an important group to include in the discussion too.

This should be an item included on the agenda for the next CAC meeting.

11. General Business

Members sought clarification on their role in the PHARMAC community forums. Members would be introduced as part of a PHARMAC advisory committee, however they would be attending as members of the community to give their input to the process. Tangata whenua members wishing to welcome PHARMAC should do so prior to any introductions. PHARMAC was arranging all logistics for the forums, including room bookings, catering and publicity/advertising.

Noting papers

Noted:

PHARMAC website update