Minutes of the PHARMAC Consumer Advisory Committee (CAC) meeting

Thursday 15 October 2015

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

Present

Shane Bradbook	Chair
David Lui	Deputy Chair
Stephanie Clare	CAC member
Key Frost	CAC member
Katerina Pihera	CAC member
Neil Woodhams	CAC member
Adrienne von Tunzelmann	CAC member

Apologies

Barbara Greer	CAC member
Lina Samu	CAC member

In attendance

Simon England (CAC Secretary), Jude Urlich, Lauren Grierson, Hayden Holmes, Jenny Langton, Rebecca Elliott, Steffan Crausaz, Chloe Dimock, Sarah Fitt, Lisa Williams, Chris Peck (PHARMAC staff) attended for relevant items.

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1. Record of previous meeting

Minutes of the 19 June 2015 meeting were accepted as a true and accurate record.

2. Chair's report

The Chair presented an oral report to the meeting. The Chair had attended Board meetings including as part of the handover from the previous Chair, and in his new role. Part of this handover and transition management will also include attendance by the Deputy Chair at future meetings.

The PHARMAC Board had a very high workload that was handled efficiently. While there were limited opportunities to seek consumer input, it was encouraging that where the Board saw the opportunity to seek consumer input on the material before them, they did so. That was evidenced by two items on the agenda for the current CAC meeting.

3. Action points

Members were reminded to update the interests register if required.

Note action points and move to achieved.

Members noted the action point related to common messaging for CAC members, and requested the introduction to CAC presentation to be re-sent (actioned).

Members discussed the appropriateness of having early input to technical papers and when was the optimal time to do this. While there may be items that are too early or too complex for a broad audience, this could be tested through discussion with the committee and/or the community. Members see that there are opportunities to have input to important policy work, to help develop resources that are accessible to consumers. In these cases it is good to involve the Committee early.

Members noted examples of correspondence provided. Some responses mentioned the Named Patient Pharmaceutical Assessment policy as a potential funding avenue. Members considered care needed to be taken when outlining this as a potential pathway, as it may not lead to a positive outcome and may raise false hopes.

Members considered it would be desirable to have a presentation from the NPPA policy team at a future meeting.

Overall, members felt comfortable with the quality, content and tone of the correspondence provided.

4. Review of the PFPA

The Prescription for Pharmacoeconomic Analysis (PFPA) is the document that guides PHARMAC's economic analysis methodology. It was developed in the 1990s,updated in the mid-2000s and again this year to ensure it reflected PHARMAC's wider role and new decision-making framework. PHARMAC is now looking at making a more comprehensive update to make sure it is in line with international best practice, and intends to run a broad engagement process around it.

Staff are starting with discussions with health economists to get a view on what we're reviewing, with a view to beginning public consultation next year.

The PFPA is an important document. It affects the things that we take into account in our analysis, and also the priority of funding applications. However, it's a long and technical document that may be difficult for people to engage with. Staff are interested to hear views on the types of people who might be interested, and the best format for consultation – whether this is all at once, or staggered with chunks of the document consulted on separately.

Staff were interested in knowing who we should engage with, and when was the best time to do it. Will people be interested or see the technical/methodological nature of it as a barrier?

Members considered that, depending on the group or stakeholder involved, both approaches could be appropriate. A staggered approach would be good to unpack the technical nature of the document and let people approach it in bite-sized chunks. An all-at-once approach would enable people to see issues in context and the overall picture. Having questions within a discussion or consultation paper could also be useful to guide people's thinking and responses.

Whatever approach is taken, members considered it would be highly useful to provide an engaging introductory document – similar to or even an updated version of the current *CUA Explained* book –

to help people understand the nature of the content. A snappier title would also be a useful addition. Many people still think that all PHARMAC takes into consideration is the cost-benefit analysis. It would help to make sure it wasn't presented as the decision-making framework itself, but as an input into decision-making.

The project was an opportunity to present the Mission Impossible exercise to a wider audience. It was challenging, meaningful and fun and confronts people with the hard choices PHARMAC has to make.

Members considered the U3A ('University' of the Third Age) might be a good avenue to glean feedback from.

Groups with interests in mental health and different ethnicities would be good to include in consultation.

5. Pacific Responsiveness Strategy

PHARMAC has done some initial thinking from the input it's had so far, and was now at the stage of engaging with the community.

Members commended the inclusive nature of the work so far and indicated a desire for this to continue. CAC members can provide names for the Pacific leaders' focus group proposed by PHARMAC. Other areas with Pacific populations such as Hawke's Bay, Northland, Hamilton and central North Island, also South Island could also be included. It would be a good approach to seek out voices that are sometimes missed out.

The draft strategy could be launched at a public announcement, which could provide a media focus for the likes of Tagata Pasifika or Spasifik magazine.

Members discussed the effectiveness of the DHBs' regional Pacific plans, which seemed quite variable. PHARMAC had had good engagement with Capital & Coast. Members considered that in DHBs where Pacific peoples were fewer in number – such as in the South Island – that a regional approach could be taken. This had been effective for other health policy work affecting Pacific peoples.

Members asked whether PHARMAC was clear about its objectives and how success would be measured. The objective of the project would be to provide a framework so that we can work to improve the health of Pacific peoples, to help ensure they obtained best health outcomes from pharmaceutical treatment. Staff acknowledged measuring success will be important, and such measures will come from activities within the strategy. Part of the process will be to ask the community what it thinks is important, rather than take a PHARMAC-centric approach.

Members considered the project was an opportunity for PHARMAC to be seen as a leader in developing Pacific peoples' strategies in health. This could be something highlighted to Associate Health Minister Sam Lotu-Iiga. The Deputy Chair had a scheduled meeting with the Minister in the near future and offered to outline to him what PHARMAC has underway.

6. Health disparities work

Populations facing health disparity is included in the Factors for Consideration as something PHARMAC will take into account with its decision-making. PHARMAC was continuing to do some thinking around defining the Factor, so that people understand what PHARMAC means by populations facing a health disparity.

Members were largely comfortable with the explanation and definition of populations facing health disparity:

> *"Health disparities are avoidable, unnecessary and unjust differences in the health of groups of people"*

Past work in some DHBs had shown that considerable savings could be made by identifying disparities and taking steps to put in place approaches to resolve those differences. Making people healthier could, for example, reduce acute hospital admissions and lead to cost savings.

Members considered that the issue is equity, not equality, and that the public conversation should be about equity, rather than disparity. Pacific peoples were not specified in the Factors, but visibility of populations is important. An answer was that, rather than reduce the visibility of Pacific peoples, to elevate the visibility of other groups facing disparity.

Action: Invite HQSC to present the Atlas of Healthcare Variation (HQSC) to a future meeting of CAC.

7. Update from the chief executive

TPPA

The Chief Executive outlined the outcome of the TPPA round in Atlanta. Some of the aspects related to PHARMAC, although their implementation would take place after New Zealand and other countries had ratified the TPPA, perhaps in another couple of years.

Debate around TPP seems to have helped people better understand the role and value of PHARMAC. It has been a mature discussion where people recognise they won't always agree with decisions but support the model.

Timing intersects with the rise in very high pharmaceutical pricing. Pricing is the big issue internationally and impacting on access. Discussion internationally with funders is about affordability, for both new and old drugs. A high level of awareness around PHARMAC and its role and value helps us in that debate.

Rare disorders

PHARMAC had made its first decision to fund a medicine emerging from the rare disorders medicines RFP. This was for icatibant, which treats the genetic condition hereditary angioedema.

More discussions were underway and PHARMAC was optimistic of further agreements being reached.

Diabetes meters report

PHARMAC has published the second of two reports looking into the blood glucose meters for diabetes brand change from 2012. This report looked at whether there were any clinical impacts arising from the change. PHARMAC was also thinking about what the report's finding mean, for diabetes and for other changes.

Medical devices

PHARMAC's work was now moving into the next phase of hospital medical devices – a move toward market share procurement which will encourage greater competition and price reductions. This should give PHARMAC a better idea of whether the approach we take to pharmaceuticals can be applied to devices. PHARMAC has received a very positive response from suppliers.

8. Promoting PHARMAC performance indicators

PHARMAC was considering advertising the outcomes from its work over the financial year in major newspapers; members were with a draft example of what could be used. Members were largely supportive of the concept. Improvements were suggested such as:

- Including footnotes to explain jargon (or eliminating jargon)
- be clear about what is being said – actual numbers vs percentage increase
- Imagery may not be appropriate – eg male doctor/female nurse
- Language around savings could talk about reinvestment – savings are a critical part of what PHARMAC does and illustrate the value of PHARMAC.

Size-wise members considered the ad could be 1/3 of a broadsheet page and could also run in specialist publications such as Spasifik magazine.

Members were encouraged to provide further feedback via email.

9. Labelling preferences

PHARMAC has developed labelling guidelines to highlight some of the aspects of labelling that the Tender Medical Subcommittee finds useful. During the tender process quite a few products arrive in front of the committee without labelling that is good enough. The Subcommittee believes it can be improved.

For example, in some labels the visibility of the generic name is poor, font size is too small, and the dosage and strength are not clear. Greater visibility of the generic name is also beneficial for helping patients understand what their medicine is. Improved labelling could potentially lower the risk of medication errors for consumers as well. Patient familiarity with generic name may reduce possible risk associated with consuming different medication brands with the same chemical substance.

Primarily the work would be of benefit to health professionals, as many tendered medicines are re-packaged by pharmacists for dispensing to patients. But sometimes the manufacturer labels are provided to patients as well.

PHARMAC's work does not displace the regulatory rules. Medicines need to be approved by Medsafe, which determines whether the labelling meets standards outlined in the current regulatory

legislation. The PHARMAC labelling preferences are a guide to international best practice as advised by PHARMAC's clinical advisors.

Members considered that there is definitely a place for the consumer voice in labelling standards. Members noted a lot of variability in the information provided to patients about their medicine. Although PHARMAC may not have a direct influence over what reaches the patient, PHARMAC could instigate a conversation with the body which sets labelling standards for pharmacy labels.

Members drew parallels between the labelling preferences work and that of Prof Alan Merry, an anaesthetist, Chair of the Health Quality and Safety Commission and head of the Auckland University Medical School. Prof Merry introduced colour coding to reduce the risk of medication errors in hospitals. PHARMAC's work had a similar focus – reducing medication errors – but was broader.

Members raised a number of related issues including:

- Sometimes patient information leaflets are provided, and sometimes not. There was little consistency in this.
- Terminology was not always helpful to consumers – eg use of the term 'cytotoxic'.
- Ex-pharmacy labelling often had very little information on them, such as expiry dates
- Lack of information about medicine disposal, or clarity of instructions.

Staff noted these and other issues fell outside the scope of the labelling preferences work, but PHARMAC had good links into Medsafe, Health Quality and Safety Commission and the Pharmacy Council, and could provide members' feedback to those bodies as well. Members agreed it would be useful to have a representative from the Pharmacy Council to speak to CAC about ex-pharmacy packaging.

10. Member report back

Katerina Pihera-Ridge provided her verbal report on attendance at the He Manawa Whenua Conference, which PHARMAC had supported. The conference was a great overview of indigenous issues including health, and well worth attending.

PHARMAC has also signed a Mermorandum of Agreement with Te Arawa Whānau Ora collective – the latest in PHARMAC's implementation of its Te Whaioranga strategy. This was seen as a very positive development because it's making information available to people at grass roots. How the implementation of the MoA is rolled out is up to the collective.

Stephanie Clare reported on engagement with the Ministry of Health over the proposed Pharmacy Action Plan. Although the document was largely completed ahead of the meeting, the engagement was still useful with contributions taken on board.

The proposed Pharmacy Action Plan has since been released publicly for further comment and feedback.

11. Pharmaceutical funding – current issues

Diabetes meters

PHARMAC is in the middle of the procurement process for blood glucose testing meters. It's an open process, with multiple opportunities for assessment and input. First came information gathering on

the proposed process, then a request for information from suppliers. Some initial assessment is being done on responses to the RFI, and those meters that 'pre-qualify' from that process can then participate in a Request for Proposals. PHARMAC remains open-minded about the funding approach we ultimately take.

A difference this time round is that the process includes usability testing. In the current stage, that involves laboratories conducting accuracy tests, and suitability being assessed by health professionals. Consumer testing will occur in the next phase (post-RFP). This will need to be reasonably broad, and current thinking is to include representations of elderly, people with sight problems, type 1 and 2 diabetes, parents of children with diabetes (including adolescents), Māori and Pacific peoples.

Members considered that, regardless of the process followed, people may react negatively to change, so expect it.

Members considered it would be good to state the status the consumer input has. This could avoid the perception that consumers are having the final say. Consumer testing is an input to the process – not the ultimate choice.

Medicines for rare disorders

The rare disorders work began with input from the community and policy work in 2013, followed by a discussion paper and ultimately a Request for Proposals to suppliers in August 2014. PHARMAC has now approved funding for the first medicine from this process - icatibant for hereditary angioedema. The treatment avoids people needing to go to hospital, giving them more freedom and flexibility in their lives. The decision is likely to impact about 25 people, and has been well received by the HAE community.

PHARMAC continues to negotiate with other suppliers and is optimistic of further agreements being reached for other medicines. One of the issues has been that, because many suppliers are new to New Zealand, the regulatory and supply chain environment and PHARMAC contracting, it is taking some time to reach agreements.

Once the process is complete, PHARMAC will evaluate it to see what the outcomes have been.

Personalised medicine

Staff provided a discussion paper to CAC members on personalised medicine, a theme that was common in discussions over new medicines. PHARMAC's view is that the concept of targeting or personalising treatment is not a new phenomenon – but what is new is the availability of new biomarkers or tests to identify which patients will likely benefit from a pharmaceutical.

An associated issue is that there are often companion tests for new medicines, which have an additional cost. PHARMAC can take the cost of these tests into account in its assessments, but at present PHARMAC does not fund diagnostic or testing services. Part of the discussion is whether PHARMAC takes on the cost of tests, although no decision has been made at this time.

Members considered there were some difference between targeting and personalising, although from a PHARMAC point of view they are both tools to enable best health outcomes to be achieved from pharmaceutical treatment.

12. Primary care distribution

PHARMAC's work looking at funding systems is currently looking at mechanisms for improving the way medicines are accessed by health practitioners, to provide to their patients. A discussion paper has been issued to canvass views on how best to proceed.

A related issue was the administration cost for medicines. For medicines delivered at a medical practice (infusions for example), there was often a service cost that's not funded and has to be picked up by the patient. The cost of those patient-funded services is not nationally-consistent.

Members were generally supportive of the work, seeing it as potentially improving the efficiency of the pharmaceutical supply chain and making it easier for some patients to access medicines. One member also noted that any savings generated by improvements in the distribution model could be reinvested into the delivery of services for disadvantaged populations.

Members considered there was untapped value in community nurses. For example, in some cases Plunket nurses can administer vaccines. This could be a good option for some people. Members noted there still seem to be barriers to people getting treatment and services close to home.