Minutes of the PHARMAC Consumer Advisory Committee (CAC) meeting Thursday 7 March 2013

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

Present:

Kate Russell Chair

Anne Fitisemanu Deputy 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

In attendance:

Simon England PHARMAC (CAC Secretariat)

Jude Urlich PHARMAC (Management Team representative)

Steffan Crausaz, Fiona Rutherford, Scott Connew, Rachel Melrose, Siobhan O'Donovan, Alexander Rodgers (PHARMAC staff), Dr Sisira Jayathissa (PTAC chair); and Linda Gilbert and Christine Walsh (Health Quality and Safety Commission) attended for relevant items. Lynda Williams and Jo Fitzpatrick (Auckland Women's Health Council) joined the meeting via videoconference.

1. Hospital medical devices

PHARMAC Staff re-capped what was discussed at CAC's previous meeting and noted that hospital medical devices is now a standing item on CAC agenda. An update was provided on current activities:

- Clinical consultation is underway
- PHARMAC working closely with Health Benefits Ltd (HBL)
- Recruitment and project management to build PHARMAC's capacity.

Work is also underway to identify some national procurement projects. PHARMAC expects to inform the sector of specific procurement initiatives over the next few months.

Because of the size of the devices work, more than 20 individual projects have been scoped in order to keep workload manageable. A key question for CAC is where is consumer input most important? Some aspects of the work will require greater consumer input than others.

It was noted that the definition of what a device is will be important, and will help shape the nature of CAC's advice on how to obtain consumer input. Specificity will be important (different advice may be valid for different types of devices).

PHARMAC staff noted that a definition of medical devices is contained in legislation, but it is broad. It provides a starting point and a framework for what PHARMAC will consider to be a medical device. However, this definition may be further refined.

A question was raised about when consultation would occur with consumers? When will consumers have an opportunity to input to what is on the list or which product they end up using/having used on them. It was noted that safety and having informed discussions about devices are key concerns amongst many consumer groups. It was also noted that contributing advice about some specific types of devices might be of more interest to consumers than some others types of devices.

There was discussion on characteristics of devices that are different to those of medicines, such as on training for consumers and clinicians. There was also discussion on whether a devices-focused CAC sub-committee would be necessary. It was agreed that an additional committee would not be necessary, but members agreed that PHARMAC's expansion into devices would raise new issues, and new stakeholder groups, for CAC to engage with.

PHARMAC is currently going through a process of asking how to get clinician input. This is part of the work involved in defining a process around devices.

The extent of choice will depend on the type of device involved. In some areas there will be a less restrictive approach but in other areas the list might be quite prescriptive. One of the areas consumers could have input is in how exceptions to the list are managed – an exceptions scheme for devices along the lines of that used for pharmaceuticals (NPPA).

Members considered there may be an opportunity for discussion or focus groups across DHBs – these could be useful to give PHARMAC feedback on devices questions. These could be similar to regional forums, which CAC could be involved with or lead. These would be an opportunity for PHARMAC to connect with the community around devices work and to engage with relevant stakeholder groups. Some key stakeholder groups were identified.

2. Briefing on work of the Health Quality and Safety Commission

The committee received a presentation from Linda Gilbert and Chris Walsh of the Health Quality and Safety Commission on the work of HQSC. These are the current members of the HQSC consumer engagement team. The HQSC Board has endorsed a four year programme looking at a framework around three workstreams:

- Health literacy
- Consumer participation
- Increasing consumer and clinician capacity.

The first step for HQSC was to 'get our own house in order'. This involved teaching staff how to engage with consumers; establishing a consumer register; establishing a policy for engaging with consumers; asking consumers to contribute their stories of experiences with the health system. Resources have been brought together with a staff intranet. Longer-term, the intention is to share resources with DHBs and the community.

A gap that has been identified is a lack of consumer representation at Board level throughout the health system. The HQSC is promoting consumer participation at all levels, including seeking a consumer representative on the HQSC Board.

A health literacy programme is currently running in community pharmacy. Two test sites are to be set up in south Auckland and New Plymouth. Evaluation programmes will follow.

The committee discussed how to get the 'right' sort of consumer representation. The HQSC is approached to use their networks but also accepts that from time to time there will be disagreement over their approach, and they are adaptable to suit.

The CAC considered there were many synergies between the work of CAC, and what the HQSC is working to achieve.

3. Chief Executive discussion

The CE updated the committee on PHARMAC's current areas of focus:

- Getting value from current activity
- Integrating vaccines
- Hospital list of medicines
- Getting value from hospital medical devices.

PHARMAC's staff numbers are expanding. Late last year was 70, now 85. Within a year numbers are anticipated to be 127.

One area where PHARMAC was looking to change was in how it implemented decisions – introducing an element of customer service. There is a need to have a look at current processes to ask if PHARMAC is doing impact assessments at the right time. This is about being fit for purpose for future work, if this is going to be a new way of working. Change would be more about how we do things, rather than what we do. Such changes aligned with expectations outlined in the Minister's Letter of Expectations.

Implementation of the diabetes meters decision was progressing. To date 54,000 patients had changed. Fifteen meters had been returned to the supplier as faulty, however when tested they were found to be within tolerance. Changeover is going well. PHARMAC would be supporting the change with further communication delivered through PHO networks.

Once the initial change management period is over there will need to be an evaluation at two levels – any learnings on how to implement decisions, and secondly whether there has been any impact on diabetes care.

The Hospital list of medicines (will be known as Section H) is expected to be up and running in July. Implementation of this will be 'soft' as it will be likely things that are used or needed have been missed. In this first phase there will be some tolerance and leeway as hospitals adjust to having a national list of medicines. Next phase will be 'making it real' to DHBs. Longer-term the challenge is to provide a data set that sits within hospital e-prescribing systems, replacing the current paper-based system. Considerable differences in the way hospital purchasing and dispensing is managed across DHBs will mean implementation will differ from one DHB to another, and there will be different impacts.

The committee discussed the interface between primary and secondary care. This is something the Health IT Board is working on. The committee is interested in having a briefing on the work the Health IT Board is doing around this.

4. Consumers and Medical Devices (videoconference with Lynda Williams and Jo Fitzpatrick, Auckland Women's Health Council)

Auckland Women's Health Council (AWHC) has an interest in medical devices, and has been concerned for some time with the issue of lack of oversight of devices. Concerns were over safety and efficacy, regulatory issues around devices, particularly related to gynaecological mesh and metal on metal joints. It now wishes to see how PHARMAC's process might work and how CAC will work to fulfil its stated objective to have more contact with other consumer organisations.

The chair commented that CAC's main mandate is to advise PHARMAC on how to engage with consumers. CAC's engagement with consumer groups will be for the purpose of better advising PHARMAC. CAC does not want to be a gatekeeper between PHARMAC and consumer groups.

Lynda Williams commented that she has had difficulty in the past contacting people within PHARMAC. She related a recent experience. This opened up a wider issue about PHARMAC's responsiveness and availability of contact information for individuals on certain issues. Lynda Williams asked that general interest and health groups such as AWHC and Women's Health Action be included in any hospital devices database PHARMAC is creating.

Lynda Williams would like to see PHARMAC advertise the possibility of people being able to join particular interest groups, and to also increase the profile of the CAC.

An issue was raised about the Operating Policies and Procedures review, and whether any stakeholder engagement changes would come out of that review? Was the role of CAC or its Terms of Reference part of the OPP review? The chair commented that the committee would have an expectation of involvement but more in an overview role. The Terms of Reference were recently thoroughly reviewed and published in April 2010. It was too early to say if there would be a further review of CAC's role but a high priority will be on consumer involvement in any future Terms of Reference review.

5. Introduction to PTAC from Sisira Jayathissa

The chair of the Pharmacology and Therapeutics Advisory Committee (PTAC) joined CAC for an introductory discussion. Dr Jayathissa outlined his background in coming to New Zealand from Sri Lanka via Australia, and is now a senior clinician at Hutt DHB. Chairing PTAC is one of many public health bodies that Dr Jayathissa provides his services to. He has chaired PTAC since 2012, having been appointed to the committee in 2004.

Dr Jayathissa commented that the strength of PTAC is that all members are practicing doctors and pharmacists. They see and relate to patients/consumers on a day to day basis and bring this experience to their deliberations on medicine funding. The committee has a wide representation of members, including generalists, clinical pharmacologists, pharmacists, emergency medicine specialists, psychiatrists, skin and cancer specialists. It is a very dedicated group with a high workload; 30-40 hours reading per month plus membership of subcommittees.

There has been interaction between PTAC and CAC in the past. The previous chair of CAC had attended a PTAC meeting as an observer. Both the chair of PTAC and the chair of CAC routinely attend PHARMAC Board meetings.

In PTAC's discussions there is a very strong sense of members taking account of patient impact. This is something that could be better communicated to the community.

An example is benzbromarone for gout. PTAC saw a benefit for patients even though the medicine is not registered. PTAC gave its funding a high priority, PHARMAC has now found a supplier. There is still a regulatory issue but the Board has now made a funding decision.

A question was raised around biologic medicines. Dr Jayathissa commented that these are seen as revolutionary but they are not a magic bullet or a cure. There can be high expectations of them being funded which is natural in a developed country, however in New Zealand this is not always possible when thinking about value for money. In Hutt Valley their introduction has allowed the hospital to

reduce the number of inpatient beds for rheumatology. Issues such as access to biologics are challenges for PTAC and difficult issues to grapple with.

6. Record of the previous meeting held 24 October 2012

The minutes from the 24 October 2012 meeting were accepted as a true and accurate record.

Russell/Fitisemanu

A chair's written report was not provided as no issues of substance have arisen. A CAC representative was unable to attend the February meeting of the PHARMAC Board.

7. Matters arising

A desire was expressed to see action on the carried forward item on a wallet card for consumers. The committee resolved to write to HQSC to see whether a joint approach is a good way forward. This could be to ask if there is an opportunity for collaboration or to give them the opportunity to input to CAC's resource bucket on matters of patient safety.

Correspondence

The Committee noted correspondence to the Committee and the replies. Members noted most correspondence directed to CAC is usually referred to PHARMAC to answer as they ask questions of specific medicines and medicine decisions. Members provided positive feedback on the tone of PHARMAC correspondence. Members noted the comments of Lynda Williams from earlier in the meeting about difficulty in contacting PHARMAC. However, members noted that in general PHARMAC responds well to enquiries it receives.

8. OPP Review: Decision criteria review

Staff briefed the committee on progress on the Operating Policies and Procedures review. PHARMAC proposed that the first substantive part of the review would be a review of the decision criteria. An academic article has been commissioned from an Australian academic about the various frameworks for thinking about allocating health resources.

PHARMAC is currently thinking about ways in which consumers and stakeholders can be engaged, including roadshows.

Members agreed that the two-step approach is good. Suggestions included framing discussion in a format that makes it attractive for people to engage – emphasising no decisions are yet made and PHARMAC is open to options. Members felt it likely arguments over community values would be put forward. Decision criterion nine could be one for revision – members felt as currently worded it gives the impression that it allows PHARMAC to do whatever it wants. The general consensus of the meeting was that criteria nine could be removed altogether

The `Mission Impossible' exercise appealed as a good idea but ought to be presented in a more visually attractive way. Members felt the exercise was best conducted in a workshop as an icebreaker and a challenge, rather than as a written document sent out in packs. Members considered the objective of the exercise is to get people to think about what sits behind the choices they make – what values do they bring to the table. Options included:

- Recording the exercise with an expert commentator to talk through it (hosted online or videoed as a web cast)
- Creating an interactive online tool

• Using the exercise in public meetings.

Members considered PHARMAC ought to consider a 'roadshow' type approach to consultation on the decision criteria. This could be combined with discussions on hospital medical devices. CAC members could attend or host regional meetings as they had during the 2011 regional forums. Members felt these would be well received, although some work would be required to have the consumer sector attend in useful numbers.

Members felt that, whatever approach PHARMAC ultimately chose, it was important to offer opportunities for individuals and groups to meet with PHARMAC to express their views.

9. Grapevine

Auckland members agreed to meet with Lynda Williams to follow up the discussion at today's meeting. Jennie Michel would approach Lynda Williams and lead the response.

Members sought updates to the online CAC profiles. These would be circulated for review and the update posted to the PHARMAC website.

Issues Register

Members agreed to seek advice from HQSC on the blister packs issue highlighted in the issues register. Currently there are no standards and members felt this was a project HQSC might pick up.

10. Prioritisation

Staff outlined PHARMAC's approach to prioritising pharmaceuticals for investment. The process includes advice from PTAC, economic analysis, and using the decision criteria to rank investment opportunities. Members felt the presentation clearly illustrated the way PHARMAC incorporates PTAC's advice into its decisions, and was a useful follow-on from the information presented by the PTAC chair earlier in the meeting.

Staff outlined to the committee that even though PHARMAC puts considerable resource into prioritising decisions, some may appear to have 'jumped the queue' following commercial agreements reached with pharmaceutical suppliers. Typically this occurred within the context of multi-product agreements, when a lower-priority product is offered at a discount along with other medicines within a supplier's portfolio. Alternatively, some medicines with high PTAC priority can appear to not be progressed, as is the case where there is no known supplier.

11. Members report back: Local consumer advisory groups

Members reported on interactions with DHB consumer groups in Counties Manukau. These are groups along the lines of CAC but which also include clinicians. Membership of the groups is voluntary.

In Canterbury Pegasus health and Partnership Health Canterbury are amalgamating and setting up a community board. Anna Mitchell has applied to join.

Jennie Michel has been asked to be consumer rep on Waitemata DHB.

Barbara Greer reported on a positive engagement provided through PHARMAC's He Rongoa Pai He Oranga Whānau programme being presented in Hokitika. This was very well attended and well received by local people.

Members considered that updates on Te Whaioranga and the Pacific Responsiveness Strategy could be presented by staff to the next meeting of CAC.

Noting papers

Noted:

Access and Optimal Use update Te Whaioranga update Summary of new investments PHARMAC's new website