Minutes of the PHARMAC Consumer Advisory Committee (CAC) meeting Friday 18 June 2010

The meeting was held at PHARMAC, 9th floor, Cigna House, 40 Mercer St, Wellington from 9.30am.

Present:

| Sandra Coney Matiu Dickson Anne Fitisemanu Vicki Burnett Maurice Gianotti Jennie Michel Kate Russell Te Aniwa Tutara | CAC Chair CAC Deputy Chair CAC member CAC member CAC member CAC member CAC member CAC member |
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| Apologies: | |
| Heather Thomson | CAC member |
| In attendance: | |
| Bryce Wigodsky Jude Urlich | PHARMAC (CAC Secretariat) PHARMAC Management Team representative |

Matthew Brougham, Simon England, Andrew Davies, Geoff Lawn (PHARMAC Staff) attended for relevant items.

1. Minutes of March 2010 meeting

The Committee confirmed the minutes of the 19 March 2010 meeting subject to the amendments italicized:

• the *constitution of the* Consumer Collaboration charter will *hopefully* be finalised shortly and 20 or more consumer groups will be required for incorporation of the Collaboration.

Dickson/Coney (carried)

2. Chair's Report

The Chair outlined the outcomes from submissions made by the CAC on the CAC Terms of Reference and recommendations made by the CAC members on the changeover to take on new Committee members. She reported that the Board had accepted some changes to payment regarding outside events, where CAC members attend in their CAC role, but had accepted the staff recommendations around the number of meetings (minimum two, not the 4-6 sought by CAC), and staff advice not to include the role of Maori CAC members in the Maori Caucus as this was an informal group.

The Chair was informed after the meeting that it had been decided to manage the changeover by inviting herself and the Deputy-Chair to attend the September meeting, where it was proposed to hold an orientation of new members, as well as hold a meeting. The Chair said that she did not think it helpful to act as an observer at the meeting once the new chair had taken over and the CAC was attending to business. The new Chair should be allowed to get on with the job.

The Chair also discussed her role at Board meetings, and her concern that with the CAC meetings in June and September being taken up with matters to do with departing and arriving committee members, there was a loss of time to actually do the job of the Committee. In the past six or more months, the CAC had been very caught up in the TOR Review and the consumer participation project, and it needed to refocus on its role.

She recommended that the incoming CAC establishes how it wants to work, develop a plan for the year, and make recommendations about how to enable engagement with the community (for example, identifying opportunities for doing so).

She also reported on the process of interviewing candidates for new positions on the CAC and the high calibre of people applying.

There was discussion among committee members of the effectiveness of the CAC and improvements that could be made.

It was resolved to ask retiring members to make recommendations to the incoming committee. Gianotti/Burnett (carried)

It was resolved that the CAC will commence at its next meeting to determine an annual set of objectives and planned milestones for the 2010/11 year.

Tutara/Fitsemanu (carried)

It was recommended that the new CAC have a two-day meeting in September: day 1 to be a group orientation and Day 2 for the meeting proper.

Tutara/Fitsemanu (carried)

3. Matters arising

3A. Conflicts of Interest

No interests relating specifically to items on the June meeting agenda were declared.

3B. Action points

The Committee agreed upon the action points.

4. PHARMAC correspondence report

The Committee provided feedback on anonymous examples of PHARMAC's correspondence with consumers. The Committee suggested some minor wording alterations to the provided correspondence. Members recommended including the PHARMAC 0800 telephone number somewhere in responses for consumers to call should they have further questions.

5. Session with Chief Executive: Upcoming financial year

The Chief Executive provided the CAC with an update on the health of PHARMAC Board Chairman Richard Waddel. The Committee resolved to note:

The CAC expresses its appreciation and good working relationship as to the support given by Richard Waddel, Chair of the Board of PHARMAC, to the CAC over the previous eight years and expresses its best wishes for his speedy recovery.

Coney/Dickson (carried)

The Chief Executive discussed the Ministerial Review Group report as it relates to PHARMAC and noted some potential significant changes for PHARMAC's role as a result of the report. The Committee inquired what the potential changes may mean for the CAC and the Chief Executive responded that while some changes were possible, none had been planned to date – further thought would be given to this during the project planning stage.

The Chief Executive noted the final report of the High Cost, Highly Specialised Medicines Panel and its general support of, and recommended changes for, PHARMAC. The Committee expressed a desire to be involved earlier in system improvement development work (particularly those directly affecting patients) – for example, Exceptional Circumstances schemes – and not simply consulted after the options are developed.

The Committee expressed its thanks to the Chief Executive for his support of the Committee and his regular sessions discussing items with the Committee.

6. Recommendation of interim Chair and Deputy Chair

The Committee discussed a paper outlining the process for selecting an interim chairperson and interim deputy chairperson for nomination to the PHARMAC Board upon the departure of the current Chair and Deputy Chair. The Committee discussed issues such as the timing of the selection process and who is best placed to make the nominations. Departing CAC members expressed a preference to refrain from the discussion and selection of nominees for the interim CAC chair and deputy chair.

The Committee suggested the title of the interim positions be called "acting chair" and "acting deputy chair" to highlight the fact these positions are for a short time period before selection of the ongoing CAC chair and deputy chair.

Re-appointed CAC members expressed the desire to have a two-day September CAC meeting, at which it may be possible to select an ongoing CAC chair and deputy chair.

Returning CAC members nominated the following to the PHARMAC Board for appointment:

• Kate Russell as acting chair

• Anne Fitisemanu as acting deputy chair

Fitisemanu/Gianotti (carried)

Russell/Gianotti (carried)

The full Committee noted that, with departing members abstaining from this discussion, a quorum was lacking. The Chair moved to confirm the decision in accordance with section 10.1.3 of the Committee's Terms of Reference.

7. Forum actions

Coney/Dickson (carried)

The Committee discussed a paper from PHARMAC staff updating the Committee on PHARMAC's progress on the action plan developed in response to the 2009 PHARMAC Forum.

The Committee reiterated the importance of PHARMAC engaging consumer stakeholders, particularly by increasing involvement among Māori and Pacific peoples. The Committee suggested PHARMAC hold the Forum in different locations in New Zealand to engage with a wider sector of the population. Members also suggested that wider engagement could be achieved by focusing on specific health issues at future forums and PHARMAC and the CAC maximizing their presence at various consumer events.

Committee members noted the importance of Committee members engaging their consumer networks to assist in generating involvement in the Forum.

8. Previewing the Application Tracker

PHARMAC staff demonstrated for the Committee a test version of the pharmaceutical Application Tracker currently being developed by PHARMAC for future public use. The Committee discussed the usefulness of the Application Tracker and suggested improvements to enhance the consumer's experience of using the tool. These include:

- clearly stating what medicines are currently funded along with what medicines have applied for funding but are not yet funded;
- linking the application tracker to the Pharmaceutical Schedule;
- creating the ability to search by pharmaceutical company;
- clearly displaying the PHARMAC 0800 telephone number and other contact details;
- using more user-friendly terms;
- displaying dates for when assessments of applications are due;
- being sure to continue updating the status of pharmaceuticals that take longer to evaluate to demonstrate they are still under consideration;
- providing information on how individuals and consumer groups can apply for funding of a pharmaceutical; and
- linking to Medsafe data sheets.

Overall, the Committee was pleased with the Application Tracker as it thought it would enhance transparency and the ability of consumers to access PHARMAC's application processes.

The Committee noted for a future CAC meeting it should undertake a stocktake of PHARMAC's consumer engagement resources to review and further improve informing consumers how they can become involved in PHARMAC activities.

9. Consumer Participation Review results

The Committee discussed an update paper from PHARMAC staff on the results of PHARMAC's consultation on its consumer participation activities.

The Committee commended PHARMAC for taking up the challenge of improving its consumer engagement activities and encouraged PHARMAC to continue developing in this area. This consultation was noted by the Committee as being one step for PHARMAC in engaging with consumers and urged PHARMAC to continue developing a strong framework for its interaction with consumers.

The Committee suggested that PHARMAC may have incorrectly assumed that the lack of submissions to this consultation meant a lack of interest from consumers. Members expressed concern that the consultation document may have been too long, too time-consuming, too complex and required too much pre-existing knowledge of PHARMAC; thus resulting in the small number of submissions PHARMAC received (16). Members felt the small number of submissions means the sample size is statistically insignificant and this would inherently lead to skewed results, upon which no true conclusions could be made.

The Committee suggested that PHARMAC place its consumer engagement focus on two-way engagement with consumer stakeholders rather than one-way information sharing, even if only by small actions given financial and resource constraints.

The Committee provided feedback on useful means of obtaining consumer viewpoints for future consultations of this nature, including using various consultation methodologies, creating simpler documents and conducting the consultation during a better time of the year rather than just prior to the holiday season.

The Committee noted that most respondents to the consultation continued to show an explicit desire to maintain direct contact with PHARMAC staff and the CAC. Members noted that this reinforces their view that PHARMAC staff and CAC members should attend relevant community meetings and events to engage with consumers. CAC members also reported being contacted prior to the survey by non-governmental organisations (NGO) and, following discussion with the CAC member, no submission was deemed necessary by the NGO because of the CAC's own submission.

10. Handover to new members and recruitment update

PHARMAC staff updated the Committee on the current progress of recruitment for new CAC members. The CAC Chair and Deputy Chair noted the high calibre and varied mix of applicants.

The Committee discussed the topic of transitioning new CAC members and organising an orientation session for those, and returning, members. The Committee proposed a two-day session at its September meeting (the first CAC meeting with new members) and a number of topics and actions were discussed that could be included in the induction session. These include:

- discussing the CAC vision statement;
- learning about PHARMAC's structure and people;
- how the CAC fits within PHARMAC;
- learning how PHARMAC makes funding decisions;
- the CAC's involvement in consumer conferences and events;
- developing a CAC annual workplan;
- discussing the PHARMAC Forum;

- discussing a calendar of PHARMAC sponsored-events and other involvement; and
- undertaking a stocktake of how consumers can be involved in the PHARMAC process.

The Committee noted a desire for PHARMAC to continue to provide information about its operations and activities in future meeting.

11. Updates

The Committee noted the Access and Optimal Use update.

Final notes

This meeting is the final CAC meeting for Sandra Coney, Matiu Dickson, Vicki Burnett, Te Aniwa Tutara and Heather Thomson. These members' terms expire on 31 July 2010. Sandra, Matiu and Vicki have each served on the CAC since its establishment in 2002. Te Aniwa and Heather have each served for six years.

Committee members noted their appreciation and thanks for other Committee members, both returning and departing, and for PHARMAC staff. The Committee thanked PHARMAC staff for the quality of the reports presented to the CAC and the access to individual PHARMAC staff on various subjects. The Committee particularly noted its appreciation of PHARMAC's efforts to take up projects to improve Māori health and encouraged PHARMAC to maintain kaupapa Maori in its meeting format.