Minutes of the PHARMAC Consumer Advisory Committee meeting

Thursday 14 and Friday 15 November 2002

The meeting was held over two days at the offices of Bell Gully, Level 22 IBM House, Featherston St, Wellington, beginning at 10am on Thursday 14 November.

Present

Sandra Coney	Chair
Vicki Burnett	CAC member
Sharron Cole	CAC member
Matiu Dickson	CAC member
Anna Dillon	CAC member (from 9.30am, Friday 15 November)
Deirdre Nehua	CAC member
Dennis Paget	CAC member (absent 1.30pm-4.30pm, Thursday 14 November)
Kuresa Tiumalu-Faleseuga	CAC member

Apologies

Paul Stanley	CAC member

In attendance

Simon England	PHARMAC Communications Advisor (minutes)

Peter Moodie, Rachel Wilson, Jeanine van Kradenburg and Tracey Barron (PHARMAC staff) attended for relevant items.

1. Record of previous CAC meeting

Members noted the record of the orientation meeting held on 28 August 2002. Members requested this document record who was present and the movers and seconders of motions.

2. Chairperson's report

The chair reported verbally on a meeting with PHARMAC Chief Executive Wayne McNee. A written chairperson's report will be provided to the next CAC meeting.

3. Matters arising

3.1. A draft conflicts of interest register was circulated. Members requested clarification of what constituted a conflict of interest. The secretary provided copies of a State Services Commission document defining conflicts of interest. Members were informed that the PHARMAC policy

was that when identified, an interest should be declared as a protection for the member.

3.2. Members noted the Board's response to the recommendations made at the CAC meeting of 28 August 2002. It was still not clear whether CAC members would have access to the minutes of Board meetings. It was noted that a number of decisions had been made by the Board since the last CAC meeting that members had not been aware of, and had not had an opportunity to comment on. This was limiting on how effective CAC could be and placed members in an uncomfortable position within their community. It was felt that discussion on PHARMAC's consultation process might provide some clarity during the meeting.

4. CAC meeting procedures

4.1. Minutes of meetings should record those present, movers and seconders of motions and main points of discussion. Minutes should record whether decisions were made unanimously.

4.2. Members agreed that decisions and recommendations would be reached by consensus. However, where a consensus was not reached, then different points of view would be recorded.

4.3. Members noted the need to keep some documents or discussions confidential. However, if a document was marked confidential and its status changed, this should be notified to members and noted in the minutes. The reason for confidentiality should also be indicated. The meeting agenda should also indicate which items were subject to confidentiality.

4.4. Members noted that the confidentiality undertaking as drafted conflicted with paragraph 13.1 of the CAC Terms of Reference. This paragraph would need to be amended to reflect the signed undertakings.

4.5. The committee noted that it would be difficult to carry out external consultation with a blanket confidentiality clause. However, members accepted the need for some materials to remain confidential. How much this impacted on, or impeded the workings of the committee would need to be monitored.

4.6. Members agreed to sign the redrafted confidentiality agreements.

4.7. Members expressed a desire to take a proactive advisory role with PHARMAC, rather than reacting to complaints.

4.8. At the request of Maori members, it was agreed that Maori members would `caucus' before full CAC meetings, but that in general, the start of full meetings would be at 10 am.

4.9. Members agreed that meetings should open with a mihi or karakia, and close with a karakia. A meeting style should be adopted that made all members feel comfortable and able to contribute fully.

4.10. Where appropriate, the committee could meet via teleconference to discuss issues. Email discussions were also an option.

5. Vision for the Consumer Advisory Committee

5.1. Members spent some time discussing a vision for the committee.

5.2. Key reasons identified for being on the committee included

- Ensuring the recommendations of the Maori Responsiveness Strategy are implemented
- Advocating for consumers
- Ensuring PHARMAC's role, in terms of the New Zealand Public Health and Disability Act 2000, is adhered to
- Ensuring good information goes out to patients
- Ensuring the consumer's voice is heard
- Maximising health outcomes for New Zealanders and
- Assessing the social impact of decisions.

5.3. Members agreed to a vision statement:

"To ensure that the voice of consumers is effectively represented in PHARMAC decision making in order to achieve optimal health outcomes."

6. Briefing on PHARMAC's drug assessment and prioritisation process

6.1. PHARMAC medical director Dr Peter Moodie briefed the committee and answered questions on PHARMAC's assessment process and consultation. The proceedings of the Pharmacology and Therapeutics Advisory Committee (PTAC) were becoming more publicly available and PTAC was likely to receive submissions before considering new applications. This provided an opportunity for the CAC to have input.

6.2. Members expressed concern at who was currently consulted, and around short time frames for consultation, which disadvantaged some groups.

6.3. Members were concerned that the Committee had not had an opportunity to meet with PHARMAC Board member Helmut Modlik. The committee agreed there was need for Maori members of CAC to meet with Helmut Modlik. This could be arranged for the next meeting of CAC.

7. Discussion on where CAC fits into PHARMAC structure

7.1. Members agreed that for CAC to have an effective role, it should be involved at an early stage of drug funding applications being assessed, initially at the PTAC level.

7.2. The committee could have a role in stepping in where consumer voices were expressed and not taken on board. This could involve going through new applications and provide advice. However, this may be difficult to achieve.

7.3. The committee had a role to play in being vigilant to ensure the decision criteria were adhered to. It was not the committee's role to do things, but to ensure things were done.

7.4. Members felt it was appropriate for the committee to be kept informed of where drugs were in the assessment process and in ensuring that interested parties were informed and had an opportunity to comment.

7.5. The committee had a role in looking at what issues were raised in consultation and supporting them where appropriate.

7.6. In seeking an input, members were wary of being overwhelmed by too much information.

7.7. Members felt that it was important the committee have an input at an early stage of funding proposals. The committee should also be involved in strategic planning.

7.8. Members requested that the committee be provided with a brief summary of which drugs were being considered at each PTAC meeting.

Recommendations:

That CAC members be provided with information on how the PHARMAC decision criteria are used and assessed – i.e. how these criteria are used and reported on.

That CAC members be provided with a summary of submissions from consultation on drug funding proposals.

That a process be established to enable the committee to track where drug funding applications are at.

8. Prioritisation exercise from Orientation Day

8.1. PHARMAC's Manager, Demand Side Rachel Wilson presented three scenarios on proposed Demand Side projects involving asthma medicines, statins and hormone replacement therapy. The committee divided into two groups to consider proposals on asthma medicines and statins.

8.2. Group 1 considered an information campaign on asthma medicines to counter a direct-to-consumer advertising campaign, with a budget of

$200,000. The group advocated a campaign aimed at clinicians supported by newspaper advertising.

8.3. Group 2 examined a campaign on cardiovascular risk management and the use of statins drugs for reducing cholesterol, with a budget of $1.5 million. The group identified existing health consumer networks as a way of disseminating their message, a holistic approach involving lifestyle modification as the primary way of reducing cardiovascular risk and linking with existing programmes such as Push Play and the Quit smoking cessation project.

9. Information on asthma medicine -- CONFIDENTIAL

9.1. Rachel Wilson and PHARMAC Demand Side Manager Jeanine van Kradenburg briefed the committee on a proposed campaign on recommended doses of asthma medicines. The aim of the campaign is to get people to use asthma medicines correctly.

9.2. The committee provided a number of comments on the proposed campaign, including:

- A campaign using community educators rather than advertising or posters would be more effective for Pacific people. This could link with campaigns in churches.
- The lack of a central contact point in Auckland, where a third of the population lives, was of concern.
- Translating English text to other languages is not necessarily the best way of developing resources in other languages. Each group needs to be consulted about the sort of questions they want answered and the information they need.
- A number of documents had already been produced in the health sector providing guidance for developing resources, in particular for Maori and Pacific Island people.
- Use of clinical language could discourage some people. Ideally the information resources should be developed in full consultation with the groups for whom they were intended, including pretesting with potential users. Taking the time to get the information right is important.
- Written materials are most effective when they are an aid to a discussion with a health care provider or educator, particularly for Maori and Pacific Island people. Resources should be provided to enable this.
- Culturally specific resource material should be developed
- Using Maori to deliver the message to Maori is more effective

- Looking at the human side first, rather than the clinical or fiscal side, produced a more effective campaign

9.3. Members felt the committee could have a role in developing a framework or guidelines around information campaigns. This could include developing resources that could be personalised for different communities.

Recommendation

That PHARMAC develop a health promotion/health education framework and guidelines for future programmes aimed at consumers.

10. Hormone Replacement Therapy

10.1. Peter Moodie answered questions on PHARMAC's response to new research on hormone replacement therapy.

10.2. The two issues being examined were the safety of HRT, and the relationship to treatments for osteoporosis.

10.3. PHARMAC had a number of tools at its disposal to ensure medicines were targeted, these included

- Specialist endorsement
- Endorsement
- Special Authority

10.4. The committee agreed a useful step might be to have warning labels placed on prescriptions for HRT.

Recommendation:

That warning labels be placed on prescriptions for HRT

10.5. This recommendation could be taken to the next meeting of the hormones sub-committee of PTAC

11. Discussion on PHARMAC's consultation process

11.1. Peter Moodie saw no reason why CAC should not see new funding applications before they were considered by PTAC. This assessment process was becoming more open and more submissions were being made prior to applications being considered by PTAC.

11.2. Members agreed it would be useful if they received an automatic email notification of new applications, what they were for, approximate patient numbers and when the application was to be considered by PTAC.

Recommendation:

That the feasibility of a subscription-based automatic email notification system for new funding applications be investigated, and set up on the PHARMAC website if possible.

11.3. Members felt a table setting out new applications, their use and estimate of patient numbers would enable input to be provided to the PTAC assessment process.

11.4. The committee reiterated its desire to be proactive and take part at an early stage of the assessment process. Having input at the PTAC level would enable this. Further input could then be given at the consultation phase and some advice could be given to the PHARMAC Board. This was a way in which CAC could ensure the voice of the consumer was heard, rather than trying to be the voice of the consumer.

12. Links between CAC and the wider community

12.1. Members agreed to provide details to enable them to be contacted by interest groups wanting to bring issues to PHARMAC. Members with existing networks could provide them with information on the CAC and PHARMAC's processes.

12.2. Members felt it was important to make clear that CAC has been established to play a part in the PHARMAC process, rather than to respond to individual complaints.

12.3. Issues raised could be forwarded to the CAC Secretary for consideration by PHARMAC or CAC at its next meeting.

12.4. Members felt it was appropriate PHARMAC had a complaints register to keep track of issues being raised by people outside PHARMAC.

12.5. Existing networks such as those used by District Health Boards or the Ministry of Pacific Island Affairs could be used to distribute information about CAC.

12.6. The committee requested it have an opportunity to comment on the new PHARMAC website before it goes live.

12.7. Pacific representative requested a fono in Auckland to introduce and explain PHARMAC to Pacific people in the area.

13. Glivec

13.1. The committee discussed the process that led to the funding of Glivec. It was reported that cancer patient groups felt this decision set a precedent for funding very expensive drugs for small groups of patients.

13.2. The committee considered it might have a role in providing input into PHARMAC's strategic planning process, in making PHARMAC aware of

concerns and ensuring there is a strategy around funding of pharmaceutical cancer treatments.

13.3. Questions were also raised around the funding of treatments for Alzheimer's Disease. The CAC Secretary was asked to provide information to the committee. Treatments for Alzheimer's could be included as an agenda item for the next CAC meeting.

14. Take Control of Your Cholesterol Campaign

14.1. PHARMAC Demand Side Manager Tracey Barron briefed the committee on progress around the campaign to promote lifestyle changes as a way of reducing overall cardiovascular risk.

14.2. The committee felt there were a number of programmes already in place that could be tapped into. It was important to have culturally specific programmes to make the campaign effective.

14.3. The use of `role models' was effective for some groups, but not all.

14.4. The committee considered that a guideline for patient information based on the Ottawa Charter or guidelines produced by the Ministry of Health or others, might be useful.

15. General

15.1. After further discussion, members made three further recommendations

Recommendations

That PHARMAC's Demand Side budget be increased to enable increased spending on consumer information needs and projects to enhance the responsible use of medicines.

That any projects to provide information to consumers should include specific funding for Maori and Pacific components in line with the PHARMAC Maori Responsiveness Strategy.

CAC welcomed the Maori Responsiveness Strategy and recommended that funding be allocated for the development of a Pacific Responsiveness Strategy

The meeting closed at 2.30pm, Friday 15 November.

Chairperson Date

Recommendations from the Consumer Advisory Committee meeting

14-15 November 2002

The Consumer Advisory Committee (CAC) recommended that:

1. CAC members be provided with information on how the PHARMAC decision criteria are used and assessed – i.e. how these criteria are used and reported on.

2. CAC members be provided with a summary of submissions from consultations on drug funding proposals.

3. A process be established to enable the committee to track where drug funding applications are at.

4. Warning labels be placed on prescriptions for HRT and that this recommendation be taken to the Hormones sub-committee of PTAC.

5. That the Board inform CAC of its overall strategic direction in the cancer control area.

6. The feasibility of a subscription-based automatic email notification system for new funding applications be investigated and set up on the PHARMAC website if possible.

7. PHARMAC's Demand Side budget be increased to enable increased spending on consumer information needs and projects to enhance the responsible use of medicines.PHARMAC develop a health promotion/health education framework and guidelines for future programmes aimed at consumers.

8. Any projects to provide information to consumers should include specific funding for Maori and Pacific components in line with the PHARMAC Maori Responsiveness Strategy.

9. CAC welcomed the Maori Responsiveness Strategy and recommended that funding be allocated for the development of a Pacific Responsiveness Strategy.

10. CAC would like to meet with new Maori members of the PHARMAC Board and PTAC.