

**Minutes of the PHARMAC Consumer Advisory Committee (CAC)
meeting**

Monday 24 November 2003

The meeting was held in the Tait Room, 14th floor, Cigna House, 40 Mercer St, Wellington from 9.30am.

Present:

Matiu Dickson	Acting Chair
Vicki Burnett	CAC member
Sharron Cole	CAC member
Anna Dillon	CAC member

Apologies:

Sandra Coney	CAC chair
Dennis Paget	CAC member
Paul Stanley	CAC member
Kuresa Tiimalu-Faleseuga	CAC member

The chair moved that the apologies be accepted

Dickson/Burnett carried

In attendance

Simon England	PHARMAC (minutes)
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Stuart Bruce, Dr Peter Moodie, Tracey Barron, Cristine Della Barca, Steffan Crausaz (PHARMAC Staff), attended for relevant items.

The acting chair noted that paragraph 9.2 of the CAC Terms of Reference specified a quorum of five members, although in exceptional circumstances this may be four members. The acting chair considered that, as a member had only notified of non-attendance through illness on the morning of the meeting, that circumstances were exceptional and the meeting should proceed.

1. Record of previous CAC meeting

The minutes of the 21 August 2003 meeting of the Consumer Advisory Committee (CAC) were accepted as a true and accurate record.

Burnett/Dickson carried

2. Chairperson's report

No chairperson's report had been prepared. This could be tabled at a future meeting.

The acting chair reported verbally on his attendance at the PHARMAC Board meeting in October 2003, to present the committee's recommendations from its August 2003 meeting.

3. Conflicts of Interest

No conflicts of interest were declared.

4. Demand Side Update

Members were updated on the cardiovascular risk management campaign, One Heart Many Lives. A decision has yet to be made on whether to roll the campaign out nationally or target further pilots at regional areas of high need.

Another area of potential Demand Side activity was in diabetes test strips, where there was anecdotal evidence of overuse. This was an area where the committee's input could be sought.

Members expressed a desire to be kept informed on Demand Side activities and to have further information on upcoming campaigns.

5. Supply Side update

Felodipine, a calcium channel blocker drug used to treat raised blood pressure and angina, had been the major supply side issue in the last month. PHARMAC had decided to re-list the 5mg and 10mg strengths of the generic Felo ER after Medsafe decided it was safe and effective. AstraZeneca then announced it was withdrawing its product.

AstraZeneca had now agreed to supply the 2.5mg strength of felodipine after reaching an agreement with PHARMAC. This meant the 2.5mg strength was now more expensive than the 5mg strength, so PHARMAC would be monitoring its use.

Members asked for information on new investments. These included the antidepressant venlafaxine and a new drug to treat children with arthritis, etanercept. Consultation letters would be issued on new funding proposals.

Other supply side changes included a subsidy reduction for mesalazine, and a new supplier for morphine sulphate tablets.

6. Update on Maori Responsiveness Strategy

Marama Parore-Katene had accepted the position of Maori Health Manager at PHARMAC. She commenced employment on 1 December 2003. Marama had extensive experience working in Maori health through the Health Funding Authority, and more recently through a privately-owned company Kahui Tautoko. PHARMAC was delighted to have a person of her calibre appointed to the role.

PHARMAC has provided a report to the Associate Minister of Health, Tariana Turia, on progress against the Maori Responsiveness Strategy, and is seeking a meeting with

the Minister. The report had been provided to CAC members. The committee would be updated on when that meeting would occur.

The PHARMAC Board had requested quarterly updates of progress against the strategy, and agreed to provide these to CAC.

7. All at once dispensing

The partial return to all-at-once dispensing was implemented from 1 October 2003. Implementation had gone reasonably smoothly, although some instances of pharmacists charging where they were not allowed had been identified. The use of close control was being monitored to see how it was being used, and whether it was being overused.

An issue had been identified around allowing monthly dispensing for residential care facilities, such as nursing homes and IHC homes. Issues were being worked through with HealthPAC.

A review of all-at-once dispensing would take place within a year. Some medicines that had been removed from the original all-at-once list may be put back on once supply issues were addressed. Updated general practitioner software would be ready in early 2004.

8. Terms of Reference review

A teleconference had been held with the CAC chair to discuss the review of the CAC Terms of Reference. Overall the Terms of Reference had worked well and enabled the committee to function effectively.

Alterations were proposed to the Terms of Reference regarding confidentiality, and the role of the chairperson.

Members noted that:

- Amended confidentiality provisions as proposed would align this paragraph with confidentiality undertakings signed by members. Members welcomed this change as it provided clarity on what documents were to be regarded as confidential.
- The Terms of Reference allow the committee to participate in consultation, and do not specifically exclude the committee from consultation exercises. The committee had participated in consultation, for example with all-at-once dispensing. PHARMAC Staff agreed to provide further advice to CAC on the Terms of Reference relating to the committee being consulted.
- The redrafted paragraph 11.3 gave further scope for the chair, or a representative, to attend meetings of the PHARMAC Board. Members felt the chair, or a representative, should be able to attend Board meetings as an observer for items other than CAC-related papers. The committee noted that under the redrafted paragraph attendance at Board meetings would continue to be at the invitation of the PHARMAC Board chair.

9. High Cost medicines

PHARMAC is examining issues around an increasing number of highly specialised drugs being developed, often for small numbers of patients at very high cost, which are not cost-effective. These are medicines that would most likely not be funded under PHARMAC's current decision criteria.

PHARMAC was examining contracting health ethicists and/or health economists to obtain expert opinions. This could involve overseas experts or working with other health authorities overseas, although PHARMAC was concerned not to enter into an unnecessarily protracted process.

Members expressed support for the direction of the proposal and considered that a review might include an examination of incorporating indirect costs and inter-sectoral co-ordination (e.g. Work and Income NZ) for funding high cost medicines.

10. Alzheimer's Medicines

Members considered a paper prepared by PHARMAC Staff in response to a letter from Alzheimer's New Zealand.

PHARMAC had been examining issues around funding Alzheimer's medicines for a number of years. This had included funding applications for three medicines for the treatment of Alzheimer's, clinical advice from PTAC and sub-committees, economic analysis and examining running a pilot programme to allow subsidised access to the drugs for a small number of patients.

Issues identified included:

- Medicines were most effective in the early stages of Alzheimer's Disease, but diagnosis was not always made early.
- Once treatment with medicines began, people were reluctant to cease treatment, even when benefits were not evident.
- It was difficult to ascertain whether any change in patient health was due to the medicines or the natural variation of the disease's progression.

A pilot programme was considered to be difficult to administer, and might create ethical issues.

The committee agreed that ethical issues were a real barrier to any pilot programme. There were instances of people involved in clinical trials demanding to continue treatment even when evidence showed there was no longer any benefit, or that harm was being caused.

CAC members considered that PHARMAC had made considerable effort to progress funding for Alzheimer's Medicines. PHARMAC was faced with a difficult decision but had a clear process to follow and had been faithful to the process.

Members requested that PHARMAC write to Alzheimer's New Zealand informing them of the committee's view and providing a copy of the briefing paper.

11. Summary of correspondence to PHARMAC

Members had asked that PHARMAC provide information to the committee summarising issues raised with PHARMAC by clinicians and consumers.

Members considered the proposal of PHARMAC staff to provide monthly summaries of correspondence received to the committee to be an acceptable solution.

12. Discussion on CAC's progress

Members considered that the committee's earlier uncertainty over its direction and role had largely dissipated. The committee had been learning about its role and about PHARMAC, and was cautious of being overwhelmed by information.

The committee considered PHARMAC to be receptive to its recommendations and requests for information. PHARMAC appeared to have a culture of being prepared to accept new ideas and try new things. PHARMAC Staff and the PHARMAC Board had been supportive of the committee and its direction, and had shown a willingness to interact with the committee, for example the PHARMAC Chief Executive and Board chairman taking the time to attend CAC meetings in person.

Members considered attendance at meetings was an issue and could be improved. However, the committee had made progress and could see its input being responded to in a number of areas, including:

- Advice on hormone replacement therapy
- Recommendations in relation to all-at-once dispensing
- Advice and correspondence on medicines being used off-label.

The committee considered that it had been effective and had had the opportunity to have input into a number of areas. PHARMAC had been receptive to this input.

Members requested PHARMAC provide the committee with consumer information that was in development. This could be done via PDFs, as well as at meetings.

Members considered that the CAC's membership should continue to reflect New Zealand society, including if possible a Maori representative from Auckland, and members from rural New Zealand and the South Island.

13. General Business

Members were informed that Deirdre Nehua had indicated that, with regret, she was resigning from the committee.

Action points/recommendations

Carried over:

Item	Actioned
1. A protocol to be developed so that when PHARMAC was issuing a media release that mentioned CAC, that members should first be notified.	Ongoing
2. CAC to be provided with a report at a future date (for example six months), on the cancer drugs assessment process, on feedback received from patients and clinicians.	Carried over
3. CAC Secretary to write to members outlining what steps had been taken with Venlafaxine (for depression), Epilim (as a psychotropic medication), the removal of Special Authority on Olanzapine (short and long acting – when available), Cipramil dispersable 20mg tablet, Rosiglitazone for diabetes control.	Achieved October 2003
4. CAC stated its support for a request to the PHARMAC Board for Maori members of PHARMAC staff and advisory committees to meet.	Carried over
5. CAC to have at least two further meetings during 2003. One of these meetings could discuss the committee's progress and provide a report to the PHARMAC Board, and seek feedback.	Achieved November 2003
6. CAC to be provided with a paper on how PHARMAC could provide the committee with information on issues raised by the public or clinicians.	Achieved November 2003
7. A copy of the EC panel reports to the PHARMAC Board to be provided to CAC.	Ongoing
8. PHARMAC to write to the Health and Disability Commissioner raising the CAC's concerns about the issue of informed consent around the use of unregistered medicines, or medicines being used for unregistered indications.	Achieved September 2003
9. CAC members to be provided with copies of a report outlining progress against the Maori Responsiveness Strategy, being prepared for Associate Health Minister Tariana Turia.	Achieved October 2003
10. Framework for Consumer Information to include: <ul style="list-style-type: none"> • using focus groups of the target audience to determine what information people want to know; • using a wider range of people to comment on draft content (community, NGO groups), • including other material such as sources, references, authorship, publication date, contacts for other relevant agencies or groups; • using design criteria to keep material simple, and relevant to targeted groups. 	Achieved September 2003
11. Members to be provided with information on a register of women who continue using epilepsy medicines during pregnancy.	Carried over

From 24 November meeting:

Item	Action
1. Members to have ongoing information on Demand Side campaigns	Ongoing
2. CAC to be provided with quarterly updates on progress against the Maori Responsiveness Strategy	Ongoing
3. Review of High Cost Medicines examine incorporating indirect costs and inter-sectoral co-operation.	
4. PHARMAC to write to Alzheimer's New Zealand providing CAC's view of Alzheimer's Medicines and a copy of the briefing paper.	
5. PHARMAC Staff to provide CAC members with monthly summaries of correspondence received by PHARMAC from clinicians and consumers.	Ongoing
6. CAC members to view consumer information being prepared by PHARMAC while it is in development.	Ongoing
7. PHARMAC Staff to provide further advice to CAC on the Terms of Reference relating to the committee being consulted.	

Signed



Date

9. 1. 04.
