

PHARMAC has withheld some material from this Minute in accordance with section 6a of the Official Information Act 1982

Minutes of the PHARMAC Consumer Advisory Committee (CAC) meeting

Friday 3 October 2008

The meeting was held at PHARMAC, 9th floor, Cigna House, 40 Mercer St, Wellington from 9.00am.

Present:

Sandra Coney	Chair
Matiu Dickson	CAC member
Dennis Paget	CAC member
Sharron Cole	CAC member
Vicki Burnett	CAC member
Te Aniwa Tutara	CAC member
Heather Thomson	CAC member

Apologies

Paul Stanley	CAC member
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In attendance:

Fiona Rutherford	PHARMAC (CAC Secretary)
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Adam McRae, Matthew Brougham, Sean Dougherty (PHARMAC Staff) attended for relevant items.

1. Minutes of July 2008 meeting

Subject to the changes agreed, the minutes of the July 2008 meeting were accepted as a true and accurate record.

Coney/Dickson (**carried**)

2. Action points

The Committee requested an update from PHARMAC on the outcome of discussions with Medsafe on monitoring the impact of widening the prescribing of isotretinoin, if the change occurs.

Coney/Dickson (**carried**)

3. Correspondence

The Committee agreed not to provide a reply to a further form letter it had received from U'Learn'n'Care, as it had responded to previous similar communication from the company.

The Committee noted the reply PHARMAC had provided to correspondence from the Western Australia Centre for Cancer and Palliative Care, and that PHARMAC would respond to subsequent requests for information from the Centre.

The Committee noted that PHARMAC had responded to an email that a consumer sent to the Committee about a specific medication, and agreed to provide a separate response.

4. Chair's report

The Chair reported that since the July meeting, PHARMAC had asked Committee members for their comments on:

- draft versions of the PHARMAC information sheets;
- the updated Herceptin resource; and
- the child asthma action plan and prevention leaflet.

In addition the Chair reported that:

- the Voluntary Checklist for Consumer Groups Considering Health Industry Sponsorship had been issued for consultation and was available on the PHARMAC website;
- Committee members had attended PHARMAC Board meetings in observer capacity; and
- further progress had been made with the establishment of the Aotearoa Consumer Collaboration.

Coney/Paget (**carried**)

5. Conflicts of interests

The Committee reviewed and updated the Conflicts of Interest register.

No conflicts relating specifically to items on the October meeting agenda were declared.

6. Matters arising

The Committee discussed the PHARMAC Forum planned for March 2009 and recommended to the Board that the:

- Committee be engaged in the planning process leading up to the PHARMAC Forum
- Committee may consider it appropriate to be on the agenda and this should be considered
- aim and purpose of the Forum is communicated to participants well in advance of the Forum.

Tutara/Coney (**carried**)

The Committee discussed the recruitment process for a Pacific Committee member, and recommended to the Board that the panel interviewing applicants should include:

- the CAC Chairperson (or Deputy Chairperson); and
- a senior Pacific Island representative.

Coney/Burnett (**carried**)

7. Consumer Advisory Committee Terms of Reference review

PHARMAC staff provided a verbal update on progress with the CAC Terms of Reference work and upcoming opportunities for Committee involvement.

The Committee commented that it is concerned it may not have sufficient opportunity to provide substantive feedback prior to consultation commencing in December, and is willing to hold a teleconference between now and the December meeting.

The Committee recommended to the Board that the Committee be provided with a brief plan, by the end of October 2008, which outlines the process that is to be used to review the CAC Terms of Reference.

Tutara/Coney (**carried**)

8. Update on Maori caucus

The Maori Caucus members of CAC updated the other Committee members on a recent Caucus meeting. The Caucus members advised that it will be:

- using the Te Whaioranga Māori Responsiveness Strategy Action Plan as guide for the Caucus's work;
- focussing on increasing connection with the Māori community;
- overseeing a number of Access and Optimal Use projects, including One Heart Many Lives.

The Committee discussed general involvement of Māori people in the organisation, and the importance of PHARMAC and its stakeholders recognising that the Māori world view is valid.

9. Discussion with Chief Executive

The Committee discussed the recruitment process for the Māori PTAC member, and provided suggestions for identifying potential candidates for this role.

The Committee also discussed the options for consumer engagement in decision-making. The Committee considered that the draw-backs of citizens' juries are that the jury members are not necessarily selected for their experience in consumer representation for their group; their individual views may be atypical; they are unlikely to be accountable to a broader constituency; and they are usually not present at the end of the process to advocate for implementation of the decisions.

The Committee considered that the purpose for seeking information should determine the characteristics of the consumers from whom views are being sought. For example, it may be beneficial in some circumstances to seek the views of consumers who have recently used a service, in to obtain their perceptions of the service.

In other circumstances it may be more beneficial to seek input from people who are involved in consumer representation and can report back, and be representative to, their constituencies. The Committee considered that by virtue of being grounded in their communities and widely-networked, these people will have a greater understanding of the breadth of issues that consumers experience. It was also suggested that such people can be used to develop questions that can then be asked of service users.

The Committee suggested that organisations should move away from complying with legal obligations to sectors of the community and instead consider what is 'fair and proper' to do.

The Committee commented on the importance of the information that is put in front of people for their consideration, given the distortion in views that can occur as a result of information selection bias.

With respect to determining the success of consumer engagement the Committee commented that process – particularly the level and breadth of engagement – is more important than the outcome.

One member commented that there had been fears about increasing consumer engagement in the mental health sector that have not been borne out by the experience. Instead, in the member's view, the systems and decisions have improved.

With respect to funding decisions that Committee stressed the importance of listening to people, being open to considering what they have to say, and being clear about the decisions that are made. While people may not be happy with the decisions made they should understand and be satisfied with the process.

The Committee also considered that a measure of success for PHARMAC's consumer engagement activities in that people have a general understanding and acceptance of the difficult choices that PHARMAC has to make.

10. Access and Optimal Use Update

Medication brand changes

The committee noted the results of the medication brand change survey. They considered that the focus groups in relation to consumers were insufficient to provide meaningful feedback and expressed disappointment that a survey of consumers was not undertaken.

The committee recommended that a full survey of consumers is conducted to gain a better understanding of consumer perspectives in relation to medication brand changes.

The committee noted the recommendations made as a result of the medication brand changes work. The committee supported those recommendations for areas of further work.

The committee requested additional information from PHARMAC on how it monitors the impacts of medication brand changes on consumers. The committee requested that PHARMAC share the sources of information monitored and that a full report back on the omeprazole (Losec) brand change be provided to the committee, including how many patients ceased treatment and how many are paying to receive treatment instead of changing their medication.

The Committee recommended that a report be drafted that examines the consumer experience of brand switches and the mechanisms PHARMAC uses to identify, monitor and mitigate adverse impacts on consumers.

Coney/Thomson (**carried**)

Space to Breathe

The committee noted progress on the childhood asthma programme and did not have questions or concerns in relation to the implementation of the programme.

Antipsychotics in the elderly

The committee noted progress on the antipsychotics and dementia programme. They noted that additional work was required in relation to the patient information leaflet for the review and agreed that this would be conducted via e-mail after the meeting.

One Heart Many Lives

The committee noted an update on One Heart Many Lives and PHARMAC's consideration of how best project management for the programme can be organised.

The committee discussed options for how to improve the reach of the programme nationally. The committee was keen to see the programme expanded to reach as many areas as possible and supported using partnership models to achieve this. The committee also suggested that PHARMAC staff investigate how screening models (such as the HIV screening in pregnancy) had been rolled out nationwide.

The committee considered the One Heart Many Lives currently paid insufficient attention to the role of diabetes and its relationship to cardiovascular health, and to the impact of heart disease on women.

The Committee sought specific information from PHARMAC staff about how they intend to include specific mental health involvement in OHML in the Lakes region. Staff advised that implementation activities in the Lakes area had not progressed since the last CAC meeting.

11. Identifying topics for future Access and Optimal Use Campaigns

The committee noted the process and constraints in relation to the implementation of new or proposed campaigns.

The committee considered that in the first instance the focus for the Access and Optimal Use team should be on optimising the current campaigns such as One Heart Many Lives and Space to Breathe. They considered that significant attention should be devoted to bedding down these programmes, and expanding their focus. In relation to One Heart Many Lives this could include;

- examining issues in relation to diabetes;

- looking at extending reach into Pacific communities; and
- national coverage of the campaign.

The committee's recommendations for additional work in the Access and Optimal Use area follow.

Mental Health

The committee noted that there were significant adverse effects in relation to the use of the atypical antipsychotic olanzapine. It was noted that this medication often resulted in significant and rapid weight gain. As a result mental health consumers are often experience medical complications from obesity related conditions such as diabetes. The committee considered that a programme to look at the appropriateness of this medication and lifestyle interventions to reduce risk of medical complications would be worth while. The committee considered that it was important to deal with such side effects proactively. It was noted that there was some concern among psychiatrists that this medication was potentially being over used.

The committee noted that many psychotropic medications (such as antipsychotics) resulted in sexual dysfunction. The committee considered that the combination of a mental illness with sexual dysfunction caused significant harm. The committee recommended that a campaign to raise awareness of the impacts on sexual function in relation to mental health medications would be of merit.

Medication use:

The committee considered that there was limited understanding of the role of generic medications in the wider community. It was noted that this was one of a broader set of issues associated with medication management. The committee recommended that a campaign similar to that run by the National Prescribing service in Australia would be useful.

The Committee suggested that such a campaign could include information on improving knowledge of medications, the questions to ask prescribers and pharmacists about medication, practical information about medication and promoting understanding of generic medications. The committee considered that this campaign should be approached in collaboration with interested non-government organisations such as Grey Power and Age Concern as there should be a focus on older people with multiple medication use.

PHARMAC staff noted that many of the aims were similar to the objectives of He Rongoa Pai He Oranga Whanau programme and that potentially this programme could be expanded for a wider audience. The committee recommended that the focus could be educational programmes with consumers and consumers' families.

Pacific Peoples:

The committee recommended that Access and Optimal Use consider furthering a Pacific Strategy and programmes that focus on Pacific people. PHARMAC staff noted that the Board decided on the priority of the development of a Pacific Strategy, however, individual Access and Optimal Use campaigns would consider a focus on Pacific communities where this was relevant. PHARMAC staff noted that both One Heart Many Lives and the Space to Breathe Campaign had a strong Pacific component which would continue to be developed.

PHARMAC staff undertook to provide feedback to the committee as and when progression is made on these recommendations.

12. [Section withheld in accordance with section 6a of the Official Information Act 1982]

13. Consultation on the CAC voluntary checklist for consumer groups

PHARMAC staff provided an update on progress with consultation on the Voluntary checklist. The Committee agreed to consider all consultation responses at its December meeting.

14. Funding and Procurement Update

PHARMAC discussed thyroxine, including the effect that the reformulation of a medicine can have on the body. The Committee commented on the risk of presenting information about adverse reactions as being “all in the mind”.

The Committee discussed the role of CARM in monitoring drug changes, and noted that the ability to identify the reasons for an adverse reaction is dependent to some extent on the quality of the information provided by the prescriber. The Committee discussed whether CARM should proactively contact patients for permission to obtain more information from a prescriber when the report is incomplete.

The Committee considered that PHARMAC should be monitoring the effects of its funding decisions and suggested that PHARMAC and CARM need to work together to ensure that an effective system is in place. PHARMAC staff agreed to provide information on the adverse reactions monitoring arrangements in its report on the impact of medication brand changes on consumers.

The Committee discussed concerns about direct-to-consumer advertising of imiquimod but recognised that this is outside of PHARMAC’s legislative responsibility.