Minutes of the PHARMAC Consumer Advisory Committee (CAC) meeting

Friday 4 July 2008

The meeting was held at PHARMAC, 14th floor, Cigna House, 40 Mercer St, Wellington from 9.00am.

Present:

Chair Sandra Coney CAC member Matiu Dickson CAC member Dennis Paget **Sharron Cole** CAC member **CAC** member Vicki Burnett Te Aniwa Tutara CAC member CAC member Kuresa Tiumalu-Faleseuga **CAC** member Paul Stanley

Apologies

Heather Thomson

CAC member

In attendance:

Fiona Rutherford

PHARMAC (CAC Secretary)

Peter Moodie, Mike Bignall, Adam McRae, Marama Parore, Matthew Brougham, Sharon Ponniah, Moana Tane, Lisa Williams and Rico Schoeler (PHARMAC Staff) attended for relevant items.

1. Minutes of March 2008 meeting

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

Dickson/Coney (carried)

2. Action points

The Committee asked that PHARMAC staff continue to advise the Committee of Access and Optimal Use events that members can attend. The Committee commented that their involvement in such activities assists them to be able to advise their networks of PHARMAC's AOU activities.

The Committee expressed its disappointment with the Board's response to the Committee's recommendations regarding the priority of the Pacific strategy, and expressed frustration that this again demonstrated that Pacific Health was not yet a significant issue for PHARMAC. The Committee did note that there was a Pacific focus within the One Heart Many Lives and other programmes but these activities could not be considered as a de facto substitute for a proper Pacific Health strategy. The Committee strongly recommended that the development



of a Pacific Strategy be included in PHARMAC's formal planning and be included in the Statement of Intent for the 2009/10.

Coney/Dickson (carried)

3. Correspondence

The Committee commented positively on PHARMAC's responses to consumers who had written or emailed with questions and comments. The Committee noted that the replies reflect a greater appreciation of individuals' concerns and circumstances and suggested that PHARMAC ensure all correspondence consistently reflects this.

The Committee suggested that a similar improvement in tone for PHARMAC's communications with health practitioners would be desirable.

4. Chair's report

The Chair's report noted a number of CAC activities since the March meeting, including:

- a CAC representative attending PHARMAC Board meetings
- a submission on the PTAC Appointment protocol and PTAC Guidelines review
- comments on the PHARMAC Statement of Intent
- comments on the style and tone of the Herceptin consultation letter
- comments on a brand change leaflet.

The report also updated CAC members on the strengthening consumer voice initiative and the CAC Chair's presentation to the IPAC conference.

The report was received by the Committee.

Coney/Paget (carried)

5. Conflicts of interests

The Committee discussed the updated process for identifying interests and assessing conflicts of interests and completed updated conflict of interest declaration forms.

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

The Committee requested that PHARMAC provide each member with a copy of the Report into Conflicts of interest and other matters at the Hawke's Bay District Health Board.

6. Matters arising

The Committee commented positively on the new meeting paper format.

The Committee requested that those meeting papers that PHARMAC considered to be 'commercial in confidence' be labelled as such so that Committee members are aware of the material that they can and cannot discuss with their networks.



The Chair requested that all correspondence addressed specifically to the Chair be scanned and forwarded to them so that they can determine whether they want to respond on behalf of the Committee, in addition to any response from PHARMAC.

The Chair advised the Committee of the invitation from Saunders Unsworth to attend the Wyeth-sponsored high cost medicines forum. The Committee noted that the Chair received the invitation too late to organise for a CAC member to attend.

7. Access and Optimal Use Update

The Committee noted the Maori Health edition of BPAC's Best Practice publication.

PHARMAC staff advised the Committee of PHARMAC's Maori pharmacy scholarship to support Maori in pharmacy training. The Committee provided suggestions for the information distribution list for this initiative.

PHARMAC staff also advised the Committee of the release of PHARMAC's *Te Whaioranga*: *Maori Responsiveness Strategy Action Plan*. The Committee resolved to:

note the release of *Te Whaioranga*; **congratulate** PHARMAC on the production of *Te Whaioranga*; and **note** its support for actualising the role of the Maori Caucus as described in *Te Whaioranga*.

Tutara/Dickson (carried)

The Committee noted the AOU's Pacific-related activities, including the intention to contract for Pacific input into AOU campaigns such as One Heart Many Lives and Space to Breathe.

The Committee noted PHARMAC's survey on the implementation of medication brand changes. The Committee asked that the survey results and feedback obtained in focus groups be provided at the Committee's next meeting.

One Committee member provided feedback that the PHARMAC letter on the change from branded omeprazole to a generic alternative had reassured some doctors who had previously had concerns about the brand change. The PHARMAC letter was reportedly well laid-out.

The Committee discussed its desire for the Maori Caucus to become a key component of PHARMAC's work. The Committee asked to be advised of the forward-plan for the Maori Caucus.

PHARMAC staff advised the Committee on progress of the implementation of the One Heart Many Lives campaign. The Committee suggested PHARMAC proactively ensure that the mental health community are aware of the campaign and encourage attendance of mental health consumers and staff at the next Lakes region meeting.

The Committee identified three Committee members to attend the 23 July 2008 workshop on how to nationalise One Heart Many Lives.

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8. Funding and Procurement Update

The Committee discussed a number of funding decisions including the omeprazole brand change and change in formulation of thyroxine.

Thyroxine

Specifically, in relation to the thyroxine formulation change, PHARMAC staff advised the Committee that some patients and consumers were commenting on increased side-effects. The Committee noted that a formulation change differs to a brand change and in this case occurred because of a change in the factory location from which the manufacturer sources product for New Zealand. The Committee further noted that Medsafe has approved the changed formulation and that Medsafe and the Centre for Adverse Reactions Monitoring will continue to monitor patient and consumer responses.

Levetiracetam

PHARMAC staff advised the Committee of PHARMAC's decision to fund levetiracetam under a special access scheme. The Committee noted that applications will be considered by a panel of clinicians.

Herceptin

The Committee noted that PHARMAC was provided with further information about 12 months Herceptin treatment in late April, and that this is being considered by PHARMAC's Cancer Treatments Sub-Committee and Pharmacology and Therapeutics Advisory Committee. The Consumer Advisory Committee requested the publicly available elements of this information.

9. PHARMAC's engagement with consumer groups

The Committee considered a proposed approach to PHARMAC improving its engagement with consumer groups. The proposal included PHARMAC holding one-on-one meetings with a range of consumer groups to determine their preferences and changes that PHARMAC could make to better meet these.

The Committee considered that PHARMAC needs to be aware of the differences between groups that are governed by the people who are constituents of the group, and other organisations that may provide services to consumers or represent the interests of a group of consumers but do not have the mandate of consumers. The Committee considered that PHARMAC should seek to improve its engagement with all these groups but should be aware of the distinctions between them.

The Committee suggested that rather than holding one-on-one meetings, PHARMAC should consider holding meetings in regional localities and inviting consumer groups in the area to attend. The purpose of these would be to inform people of PHARMAC's role and functions and gain information from a range of consumer groups about their engagement preferences with PHARMAC. The Committee suggested regional meetings could be promoted through regional and community newspapers, and through the consumer organisation lists held by DHBs in the area. The Committee also suggested that PHARMAC seek distribution lists from the Ministry of Consumer Affairs and the New Zealand Guidelines Group (which holds the contact details of the Consumer Summit attendees).

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The Committee suggested that separate approach would be required for Maori and Pacific groups. The links between the consumer group engagement work and *Te Whaioranaga* were noted by the Committee. The Committee advised that PHARMAC use established Maori networks, and work through community meetings, churches and/or service providers to engage with Pacific communities. The Committee also advised PHARMAC to talk to other government departments about approaches that work for Pacific communities.

The Committee suggested that PHARMAC staff advise those groups that PHARMAC has established relationships, with that PHARMAC is seeking to identify the preferences of a broader range of consumer groups before identifying the measures PHARMAC will take to improve engagement. Such groups should have the opportunity to attend regional meetings.

The Committee suggested providing an invitation to the regional meetings setting out the programme, and a separate fact sheet explaining what PHARMAC does and why people may be interested in attending.

10. Isotretinoin - widening prescribing rights

PHARMAC advised the Committee that it is considering widening the prescribing rights for isotretinoin, a treatment for severe acne that is currently restricted to specialist-only (dermatologist) prescription.

To reduce the safety and clinical risks (particularly around pregnancy and suicidal ideation) of widening prescribing rights, a decision-support tool has been developed to assist GPs with the appropriate prescribing of the medicine.

The Committee viewed the decision-support software and discussed whether the checks and balances on prescribing were sufficient to ensure that prescribing is appropriate and that patients are protected.

Specifically, the Committee asked PHARMAC to consider whether there is any way to monitor prescribing to ensure that general practitioners are prescribing appropriately. The Committee asked whether it would be possible include the medicine on the Intensive Medicines Monitoring Programme. The Committee requested that PHARMAC report-back on these issues.

The Committee discussed limiting prescribing to patients in lower-decile groups, given that expanded prescribing was aimed in part to reduce inequalities, but decided against recommending this approach.

11. Review of CAC Terms of Reference

The Committee provided comment on PHARMAC's proposed approach to initiating the CAC Terms of Reference review. PHARMAC staff had suggested sending a letter to as broad a range of consumer groups as possible, seeking their views on the key questions that the review needs to address, as well as any other matters the consumer groups wanted to raise.

The Committee expressed concern about this 'blank-sheet' approach and considered it would be more useful to provide information about the functioning of the Committee under

the current Terms of Reference. Such information would include the Committee's vision statement.

The Committee considered that the 5-year review of its activity would also provide a useful input into this work as it would explain what the Committee has achieved under the current Terms of Reference.

The Committee suggested sending out the current Terms of Reference along with a template that people can complete to reflect their views of desirable changes to the Terms of Reference.

The Committee asked PHARMAC to provide a timeline of intended steps for the review and to identify opportunities for CAC involvement.

12. Consumer Advisory Committee information sheet

PHARMAC staff sought the Committee's comments on a draft information sheet on the role of the Consumer Advisory Committee. The Committee noted that their previous draft leaflet was not implemented by PHARMAC and questioned whether this proposed sheet should be written from the PHARMAC or Committee perspective. The Committee asked PHARMAC staff to consider this and provide a response to the Committee.

The Committee suggested a number of changes to the format and content of the information sheet, which supported the Committee having a more active role with consumers.

The Committee noted that it would have the opportunity to comment on the other information sheets before these are finalised and that these are likely to be distributed to CAC members via email.

13. Farewell to Kuresa Tiumalu-Faleseuga

The Committee and PHARMAC staff thanked Kuresa Tiumalu-Faleseuga for his contribution to the committee over the last 5 years. Kuresa's input to all CAC discussions, but particularly his Pacific perspectives were highly valued.

The Committee expressed regret that the achievement of the Pacific Health issues that Kuresa has raised over the years had not yet occurred but noted that this would remain part of the CAC vision for PHARMAC.

Kuresa reflected on his time on the Committee, thanked the Committee members for their support, and encouraged the continued prioritisation of Pacific health issues.

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Signed

Date

3/10/2008