Minutes of the PHARMAC Consumer Advisory Committee (CAC) meeting

Friday 3 July 2009

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

Present:

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

Apologies

Anne Fitisemanu CAC member Paul Stanley CAC member

In attendance:

Fiona Rutherford PHARMAC (CAC Secretary)

Matthew Brougham, Steffan Crausaz, Marama Parore, Janet MacKay, Cherie Jacobson, Adam McRae, Peter Moodie (PHARMAC Staff) attended for relevant items.

1. Minutes of March 2009 meeting

The minutes of the March 2009 meeting were accepted as a true and accurate record with changes.

Coney/Thomson (carried)

2. Chair's Report

The Chair:

Reported that the Committee's Voluntary Checklist for Health Consumer
 Organisations Considering Health Industry Sponsorship had been finalised and sent
 out quite widely. The Committee had received a congratulatory letter from the
 Medical Council of New Zealand regarding the Voluntary Checklist.

- Reported that the Chair had attended most of the 2009 PHARMAC Board meetings and that this had proved useful in terms of being able to discuss recommendations from the Committee; provide a consumer perspective on agenda items; and identify items being discussed by the Board which would benefit from the Committee's input.
- Reported on the recruitment process currently underway for new CAC members and the Chair's involvement in the process.
- Noted the Chair's apologies for the short time frame members were given for commenting on the Committee's submission on the Committee's Terms of Reference review. However, the Chair also noted that most members responded and there was general comfort with the submission.
- Noted that Dennis Paget and Anne Fitisemanu attended a workshop with PHARMAC to discuss PHARMAC's consumer engagement work.
- Noted that Committee members provided comments on the draft generic medicines survey and the *Tips for Giving Medicine to Kids* resource.
- Advised that the Chair participated in an interview with Jo Manning from Auckland University School of Law, as part of an academic research project regarding analysis of the Herceptin decision.

Thomson/Cole (carried)

3. Conflicts of Interest

The Committee reviewed and updated the Conflicts of Interest register.

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

4. Action points

The Committee agreed upon the action points

Dickson/Burnett (carried)

5. Correspondence

The Committee noted the PHARMAC correspondence report.

The Committee noted PHARMAC's responses to correspondence have been much improved in recent years. With regards to the correspondence addressing the issue of Lemnis Fatty Cream, the Committee noted that PHARMAC could have better informed consumers of the change, despite PHARMAC not being responsible for the discontinuation of supply. The Committee requested a reply drafted be drafted in response.

The Committee noted that there was currently a consultation underway regarding the Proposal to fund healthE Fatty Cream. The Committee asked that PHARMAC ensure the

consultation and any further information regarding this product went to consumer groups identified by the Committee.

The Committee noted the Medical Council's response to the *Voluntary Checklist for Health Consumer Organisations Considering Health Industry Sponsorship*.

6. Matters arising

Matiu Dickson reported that he and other members of the Māori Caucus attended the launch of the Te Whaioranga website on July 1st and that he attended the PHARMAC organisational development session focussing on Matariki at Takapuwahia Marae. He noted that both events were very successful.

The Committee discussed the number of Māori members on the Committee now that Paul Stanley's term has ended and sought clarity about ToR requirements for the number of Māori members.

7. Pacific Strategy

The Committee noted that they were pleased that the Board had authorised the development of the Pacific Strategy.

Points of discussion included that:

- the term 'Pacific Peoples' does not recognise the specific differences between communities that fall under the broader category of 'Pacific Peoples' such as the Samoan community and the Tongan community;
- the success of the Māori Strategy grew from the appointment of a Māori person to PHARMAC for this purpose. The Committee noted that its previous recommendation regarding the appointment of a Pacific person to implement the Strategy, is a standing recommendation;
- PHARMAC needs to make sure that it has all Pacific organisations on their database for consultation and that the database is up-to-date and used when consulting on relevant issues;
- the Ministry of Health has a lot of information on communicating with Pacific Island groups/communities that may be useful for PHARMAC staff to consult; and
- that once completed it would be beneficial to send this Pacific Strategy to all DHBs for their information

The Committee resolved to thank the Board for the development of the Pacific Strategy and commented that it looks forward to the further development and implementation of the Strategy.

Coney/ Thomson (Carried)

8. Discussion with the Access to Medicines Coalition

John Forman, Florence Leota and Sarah Perry of the Access to Medicines Coalition (ATM) attended the meeting to discuss their views of PHARMAC, the Committee and medicines issues with the Committee. Discussion included the role of the Committee and consumer engagement, and ATM's membership and activities.

9. Consumer Engagement Workshop

PHARMAC's consumer engagement activities

PHARMAC staff sought the Committee's views on options for improving its relationships with consumer groups.

The Committee provided feedback on a range of specific suggestions that PHARMAC staff raised for potential improvements to PHARMAC's consumer activities.

The Committee questioned whether consumers would read a quarterly consumer-specific newsletter (one of the PHARMAC suggestions) and commented that instead, PHARMAC could develop occasional discussion papers. Members have suggested circulating similar pieces of work previously, and commented that people may be more responsive to this type of communication than to a newsletter.

Review of the Committee's Terms of Reference

PHARMAC staff provided the Committee with a summary of the submissions on the information collection phase of the Terms of Reference review. There was a view that while some submissions received criticised the Committee as it currently operates, few made concrete suggestions about activities that the Committee wasn't doing, or what should be changed.

It was noted that there is a general lack of information and misunderstanding about what the Committee actually does and it seemed from the submissions that it was more about smaller improvements than a fundamental change. The sentence 'at the request of the Board' creates the perception that the Committee is constricted in what it can consider whereas, in practice, the Committee has initiated a number of actions in its own right, and does not simply respond to requests from the Board.

10. Seeking CAC's feedback on a consumer focused generic medicine campaign

PHARMAC staff described the results of PHARMAC's survey on generic changes and explained that focus groups were also planned as these are more appropriate for Māori and Pacific peoples. Focus groups also provide the ability to explore in greater depth issues such as opportunity cost.

The Committee suggested questions that could be asked in focus groups, including:

 Did people stop taking medication if provided with the generics instead of the brandname medicine? Where do people source information from – are they confident to ask those sources of information?

The Committee considered it useful to find out the views of those consumers who don't trust health professionals. The suggestion was also made that the focus groups should be used to identify what would help people overcome their concerns about generic changes.

11. Funding and procurement update

Isotretinoin

The Committee was updated on isotretinoin. PHARMAC staff advised that data-matching would be undertaken to monitor the impact of broadening access to isotretinoin through removing the prescribing restriction however at this point in time there was very limited data.

Funding decisions

PHARMAC staff advised of a number of recent funding decisions including:

- Adalimumab (Humira), a TNF-alpha, now funded for "last-line" treatment of ankylosing spondylitis, Crohn's disease, chronic severe plaque psoriasis and psoriatic arthritis;
- Entecavir (Baraclude) funded for the treatment of Hepatitis B infection;
- Dasatinib (Sprycel) funded for the treatment of Chronic Myeloid Leukaemia; and
- Dipyridamole (Pytazen) now funded without special authority restrictions allowing it to be used for patients following a stroke and in patients who are intolerant or allergic to aspirin.

Other matters

The Committee noted that another brand of thyroxine (Synthroid) had been made available. The Committee discussed correspondence it had received on Lemnis Fatty Cream and PHARMAC staff advised that an alternative brand (healthE Fatty Cream) had been funded.

12. Pharmaceutical subsidy and distribution mechanisms review

PHARMAC noted that it is beginning to review a number of aspects of how patients have access to medicines, including:

- whether entitlement to subsidy should be linked to prescribing rights;
- how the current dispensing restrictions could be amended to improve access to medicines and create efficiencies;

PHARMAC noted that the review will be commencing subject to further consideration by the

There was full discussion about the impact of such changes if they were made and the Committee advised that PHARMAC needs to consider the impact on consumers of this work.

13. Access and Optimal Use Update

The Committee was advised of PHARMAC's application to the Ministry of Health for funding from the Māori provider development scheme for the Māori Use for Medicines work.

The BPAC report to GPs

The Committee expressed support for the 'Best Practice' publications from BPAC on topical issues, which they considered to be short, sharp, quick to read, and well presented.

Update on anti-psychotics and dementia

PHARMAC staff advised that they did not get the uptake of the anti-psychotics review process that was expected. As a result PHARMAC has gone back to the drawing board – and is considering incentivising uptake to get the sample size up to level required to analyse the data.

14. Farewell to Sharron and Paul

This was the last meeting for Sharron Cole and Paul Stanley (Paul absent).

Matthew Brougham noted Sharon's contribution to the Committee – her particular interest in women's health and ethics and her significant input since the establishment of the Committee.

The Committee identified Sharron's level-headedness, consistency and wisdom as strong attributes that the Committee would miss.

Sharron noted that she felt it was always important that the decisions made by PHARMAC were backed up by transparent and fair evidence and that, perceptions aside, PHARMAC does this well.

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Date			