

**Minutes of the PHARMAC Consumer Advisory Committee (CAC) meeting
Friday 8 July 2011**

The meeting was held at PHARMAC, 9th floor, Simpl House, 40 Mercer St, Wellington from 9.40 am.

Present:

Kate Russell	Chair
Anne Fitisemanu	Deputy Chair
Barbara Greer	CAC member
Anna Mitchell	CAC member
Maurice Gianotti	CAC member
Shane Bradbrook	CAC member
Katerina Pihera	CAC member

Apologies:

Jennie Michel, Moana Papa (CAC members)

In attendance:

Bryce Wigodsky	PHARMAC (CAC Secretariat)
Jude Urlich	PHARMAC (Management Team representative)
Jessica Dougherty	PHARMAC (Corporate Support)

Matthew Brougham, Peter Moodie, Dilky Rasiah, Paul Alexander, Scott Metcalfe, Sue Anne Yee, Janet Mackay, Davina Carpenter, Simon England, Julie Watson, Marama Parore (PHARMAC staff), and Tim Jones and Ian Edwards (Webstruxure) attended for relevant items.

1. Minutes of March 2011 meeting

The Chair reviewed the 10 March 2011 minutes. The Committee confirmed the minutes as true and accurate.

Russell/Greer (carried)

A committee member enquired about the Committee developing a resource kit for use in the community. It was suggested this would be simple and primarily a visual tool for consumers.

The Committee briefly discussed recent media attention relating to PHARMAC and the Trans-Pacific Partnership free trade negotiations. Members discussed whether it would be appropriate to engage with consumers to voice support for PHARMAC. It was asked if this was a possible topic for the CAC at PHARMAC's Forum or Consumer Forums. PHARMAC staff advised that the Ministry of Foreign Affairs and Trade was leading the Government's response and that PHARMAC's public role was limited to providing information on PHARMAC's role and functions. .

2. Chair and Deputy Chairs' Reports

Chairperson's report

Due to a gap in my availability due to surgery, Anne Fitisemanu attended the March and April meetings in my stead and will be reporting her impressions of those meetings.

The May/June meetings of the Board included ongoing and interesting presentations regarding the Exceptional Circumstances review. This has been a huge piece of work for Pharmac Staff and I note with satisfaction that the two main reservations voiced by the committee (along with many other submitters) resulted in a change in wording so that clinical circumstances must no longer be 'unique', but now only 'unusual' to allow greater flexibility. Also it is now noted that if a medication is subsequently accepted for consideration under the schedule, whilst this process is underway (which, as we all know, can take some time) applications under the new NPPA will still be accepted.

The consultation process around the EC review was a particular triumph, I feel, for Pharmac and its staff. The changes that were made may invariably lead to greater cost, but because they LISTENED to the feedback with an open mind, they were willing to modify the new system in order to recognise and address these very real concerns. I congratulated the staff at the June meeting on the process they followed.

I am sorry to hear that Matthew Brougham is leaving Pharmac. I feel he has been a highly effective and approachable CEO and that he has encouraged CAC to 'be all it can be' during his time. I am sure the CAC all join me in wishing him well for his future in Canada.

It is pleasing to see that Pharmac is pursuing the idea of 'mini-for a' to lead up to the main Pharmac Forum early in the New Year. I know Pharmac feel that CAC have a strong role to play here, in facilitating the meeting and making sure we encourage groups to attend closer to home where attending the main forum is not possible. These forums will be a great place for us to start in terms of connecting with and gaining the views of, the community groups that have an interest in Pharmac's work. From these for a, I believe we will get a clearer idea of how, how often and for what purpose CAC may begin to have more regular direct consumer engagement in the future.

This will also present us with an opportunity to begin to look at how Pharmac might more effectively engage with the ethnic 'outliers' such as Asian/ Somali etc populations.

I have signaled that I am unavailable for the August meeting of the Pharmac Board due to sinus surgery on the 28th meaning I will not be able to fly for a week or so (note: this comment was amended upon reading as the Chair is now available).

Deputy Chairperson's report

It was indeed an honor and a learning curve for me to attend the March / April meetings of the Board. After a warm welcome and within the first hour I was quickly aware of the Boards commitment to CAC and how we can bring consumers' perspectives to particular discussions. In March, items discussed that called for CAC comment included:

- The new SOI – The board was keen to ask CAC thoughts about the SOI in terms of its appeal to, consumers. I reminded the Board that consumers come in a multitude of cultures and demographics and that SOIs are often large written and wordy documents. I suggested the Board consider what aspect of the SOI and of PHARMAC's business is most important for consumers to know and understand. Then based on this they consider varying means of presenting this information to their audience. This includes the use of other communications medium, as well as the use of languages, visuals and other forms of illustration and social networks.*

The April meeting included a few items of business that allowed comment from CAC. I have noted the items along with brief notes of my comment as CAC representative.

- *Confirmation of newly elected CAC Chair and Deputy Chair – I thanked the Board for their vote of confidence.*
- *Approval of the Māori Responsiveness Plan – On behalf of CAC I congratulated the efforts of PHARMAC, [the Manager, Access and Optimal Use and Māori Health Manager] and her team on the impact the plan, and its strategic programmes have had on the Māori community. I also used the opportunity to challenge the Board to support the continued development of the Pacific Responsiveness Plan. Adding to this I reminded the Board that there are other key minority communities for whom health disparities also feature. The Board's discussion included the consideration of developing a Inequalities Strategy , that may reach out to communities beyond that of Māori and Pacific.*
- *Exceptional Circumstances Review – A major piece of work in progress, with pleasing results and improvements.*
- *PHARMAC Forum – The current model, despite being cost effective, does not accommodate well for community participation. In response to CAC's proposal to strengthen engagement with consumers and communities the board approved CAC's plan to develop an engagement strategy that would assist with adding value to the next PHARMAC Forum*

Finally I noted that the Board receives in its papers some great articles that could be of interest and good reading to CAC. A request will be made relevant of interest articles available to CAC members.

Further discussion

The Committee discussed opportunities for members to build stronger relationships with PHARMAC Board and PTAC members. Suggestions included organising a dinner function for all Board and Committee members to attend.

The Committee also discussed the potential value of having a different CAC member observe PHARMAC Board meetings alongside the CAC Chair each month. The Committee felt this could be included as part of new CAC member orientations, helps to inform CAC members how the Committee can advise the Board and would contribute to the idea of a PHARMAC whānau and kaupapa in providing face to face interaction. The Chair agreed to raise this with the Board Chairman.

3. Matters arising

3A. Interests register

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

3B. Action points

The Committee reviewed and agreed upon the action points.

In discussing the Action Points, the Committee noted Standing Item 3: "CAC to pursue opportunities to raise the Committee's profile." Members received new CAC business cards and feel this will assist with helping to raise the Committee's profile.

The Committee noted it needs to be more proactive in relation to Standing Item 3 and discussed reaching out to consumers via PHARMAC's consumer database. The Chair agreed to write a letter to consumer stakeholders on behalf of the CAC, advising of who the CAC is and that they are available to attend consumer group conferences and meetings, etc. The Committee agreed it wants to hear

from consumer groups and be made aware of conferences and events it can attend. The Chair will also note the upcoming PHARMAC Consumer Forums in this letter.

3C. Correspondence

The Committee noted the PHARMAC Correspondence Report. The Committee suggested setting up an automatic email response acknowledging receipt of emailed enquiries and providing a timeframe in which to expect a reply. One member suggested another useful option is that PHARMAC staff telephone correspondents to reply to their enquiry.

The Committee advised that PHARMAC be sure to address all issues raised in consumers' letters, including personal issues for which there is no policy framework to reply with. In such cases, the Committee suggested that more sympathy was expressed and that PHARMAC outline how "usable" and applicable the policy or changes may be to the consumer.

The Committee noted consumer correspondence sent directly to the Committee.

4. Grapevine

The Committee briefly discussed the purpose of beginning a register of the consumer interests ("Grapevine") that members are made aware of from their interactions with consumers. Initial topics added to the Grapevine include concerns around patient information provided (or not) with medicine blister packs, High Use Health Cards and co-payment information, and educating consumers and consumer groups on the optimal way to respond to consultations.

5. Session with Chief Executive

The PHARMAC Chief Executive (CE) began by discussing his pending departure from PHARMAC and the process for finding a replacement. He expressed his belief that PHARMAC is in a good position for the future.

The CE discussed the recent media attention regarding PHARMAC and the Trans-Pacific Partnership free trade negotiations. He noted that the media and other public commentary had been broadly supportive of PHARMAC.

In response to a member's question about the potential impact of the TPP negotiations, the CE commented that the Government would be weighing-up the total benefits and costs of any trade agreement, whether it had implications for PHARMAC or not, and would act in the best interests of New Zealand.

The Committee asked whether consumers could or should advocate for PHARMAC's involvement in TPP negotiations because of their desire to keep PHARMAC. The CE replied that this was not PHARMAC's role, nor the role of its advisers. The Committee noted consumers can always write to their Ministers, Members of Parliament and media expressing their support for PHARMAC.

The CE briefly discussed the PHARMAC Board's approval of proposed changes to the Exceptional Circumstances schemes (to be called Named Patient Pharmaceutical Assessment, NPPA). The CE noted the success of the changes will be determined by implementation and time, especially regarding the amount of permissiveness and flexibility when assessing and approving individual applications. He noted one of the aims of the changes was to address patients in a patient group of

more than ten individuals who were “falling through the gaps” of the current system. He stated the CAC will continue to be consulted throughout implementation.

The Committee complimented PHARMAC on its open and responsive consultation process regarding changes to its Exceptional Circumstances schemes.

The Committee wished the CE well on his future endeavours.

6. Informing health need

PHARMAC staff and Committee members discussed measuring health need in medicines funding.

7. Patient resources for dabigatran implementation

PHARMAC staff presented the Committee with existing patient resources regarding the medicine dabigatran as developed by other parties. Staff asked whether these resources were adequate or if more could be done to better communicate information about dabigatran to patients.

The Committee felt the existing resources were satisfactory, simple and easy to understand and did not recommend that PHARMAC develop its own consumer resources on this subject.

8. Consumer focus groups for PHARMAC website review

PHARMAC staff and external contractors from Webstruxure introduced PHARMAC’s current review of its web services, including the goals of the review and the process to date. Presenters noted the aim is to make PHARMAC’s websites more useful and usable. Presenters explained they are seeking to gain input from health consumers to help achieve the review’s aims.

The Committee suggested that any initial survey of website users consist of only a few, simple questions. The Committee supported the plan to run focus groups to determine the website needs of users. The Committee suggested that if focus groups are used, user demographics should be kept separate, i.e. clinicians and consumers should not be in the same focus group due to their different needs. The CAC also suggested that a “sub-committee” format could be used as a focus group, consisting of CAC members and other consumers.

The Committee suggested that ideal focus points would be to create a website that is easy to use, easy for users to find what they are looking for and would have an option to provide feedback to PHARMAC. On this latter point, a member suggested developing a short pop-up survey when users exit the site to determine what type of user they are (i.e. consumer, clinician, etc) and if they found what they were looking for. Other members suggested adding questions to identify other user demographics such as ethnicity.

The Committee suggested that PHARMAC ask several representative consumer groups to nominate people to be part of the focus groups. Members offered to utilise their professional networks as well.

The CAC suggested PHARMAC clarifies that the scope of the project also includes the content as well as the design of the website. The CAC also enquired about the possibility of making the online Pharmaceutical Schedule more user friendly.

The Committee suggested a revised website could better integrate information regarding other health sector topics, such as co-payments and High Health User Cards.

The Committee supported the idea of having discussions on this subject at the PHARMAC Forum and Consumer Forums.

Members suggested aiming to learn the needs of people who do not currently use the website, i.e. what would help them to start using it?

Committee members advised that PHARMAC could find out from consumers at the Consumer Forums what information consumers need and want from the website. The Committee suggested that the PHARMAC Consumer Forums be used to validate focus group findings or to test assumptions or concepts.

A member suggested creating a strong connection between the PHARMAC website and Google searches as many users begin their search for information on Google rather than the PHARMAC website.

The Committee noted that PHARMAC should decide two to four key messages it wants to inform users about. These should be kept very simple and background information should be kept at a minimum

Members suggested the homepage could begin with simple “bubble” gateways for each user group to click on to link them to the relevant information for that user group. Members noted users need a gateway to the information they want that does not include other, irrelevant information.

The Committee discussed that the key question for determining user needs is “what do you want from PHARMAC” and then “what services would you like delivered via the web?”

The Committee suggested PHARMAC utilise events that already target user groups to gain feedback, such as the Student Forum, Seminar Series and Access and Optimal Use Campaigns. This could include asking questions such as those noted above.

9. PHARMAC Forum

PHARMAC staff discussed the plan for the PHARMAC Consumer Forums that will provide greater input into the primary PHARMAC Forum. Staff noted the Consumer Forums are designed to gain greater participation from the consumer and community level in the PHARMAC Forum. Staff sought the CAC’s advice and assistance in setting up Consumer Forums in members’ home areas.

Committee members stated they could advise PHARMAC on the kaupapa of the location where each Consumer Forum is held.

Possible topics for Consumer Forum discussions currently include: PHARMAC’s Māori Responsiveness Strategy, PHARMAC’s Pacific Responsiveness Strategy, the Exceptional Circumstances review and background information on PHARMAC. The Committee suggested PHARMAC prepare a suite of presentations and discussions and that the audience could decide what to discuss on the day of the Consumer Forum.

The Committee discussed whether the Consumer Forums should focus on a single topic relevant to the area it is being held in or if there should be more than one topic of discussion. The Committee noted this may be dependant on the location or target audience of each Consumer Forum.

Committee members stated they could identify discussion topics relevant to their communities, but that they would need to understand what audience PHARMAC is targeting.

The Committee suggested PHARMAC plans for an introductory presentation at each Consumer Forum to help the audience understand the purpose and better engage on the issues.

The Committee suggested PHARMAC have longer Consumer Forums than the planned two-hour sessions.

Members offered help with providing RSVPs and other support for the Consumer Forums. Committee members offered to utilise their professional networks to help promote and gain attendance at the Consumer Forums. The Committee suggested PHARMAC develop promotional material that members can disseminate in their communities.

One member discussed taking a strategic and targeted approach to contacting people, such as providing information to those who are more involved and more likely to be interested.

One member stated it would be good to be able to target and reach consumers who are not part of established or formal consumer groups or networks and who are not part of CAC members' networks.

The Committee noted the Consumer Forums offer members and PHARMAC a chance to build better dialog with consumers.

Members also suggested they could provide information and resources to local groups and at other community meetings instead of limiting discussion to the Consumer Forums. Members noted this would further widen the spread of feedback to PHARMAC.

PHARMAC staff stated PHARMAC needs to know when CAC members are available and recommendations for local venues so staff can make appropriate arrangements. The Committee stated it should be provided with a timeframe of when key objectives need to be met and that it should be provided with information on the key questions and topics.

10. CAC Annual Plan

The Chair noted that many actions for the development of the CAC's Annual Plan have arisen out of discussions from earlier in the day. The Chair stated she will draft a plan for the Committee's and the PHARMAC Board's review.

AOU verbal update and other matters

PHARMAC staff gave a brief verbal update on Access and Optimal Use team's activities. Staff noted the team's activities were aligned with helping to develop assessment of the health need Decision Criteria and the recent funding approval for dabigatran.

The Committee recommends to the PHARMAC Board that, in selecting a new Chief Executive, it give consideration to Māori participation in the selection process to ensure ongoing efforts from PHARMAC with respect to Māori health.

Bradbrook/Greer carried

The Committee noted, in an attachment to *Matters Arising: Correspondence*, the 2010 Summary of Submissions to PHARMAC's review of consumer participation. The Committee noted the low number of responses to this consultation (16) and stated this was indicative of the need for PHARMAC to better target its consultations and broaden its scope to include verbal consultations.

The Committee agreed its next meeting be held 17 November 2011.

Noting papers

Noted:

PHARMAC Vision, Missions and Values update (One member raised the issue of an apparent lack of Treaty of Waitangi or cultural references in the Vision, Missions and Values, particularly given PHARMAC is a Crown Entity. Other members agreed this could be added to the document.)

Access and Optimal Use update

Summary of new investments