Minutes of the PHARMAC Consumer Advisory Committee (CAC) meeting
Tuesday, 7 September 2010

The meeting was held at PHARMAC, 9th floor, Cigna House, 40 Mercer St, Wellington from 9.10 am.

Present:

Kate Russell	Acting Chair
Anne Fitisemanu	Acting Deputy Chair
Jennie Michel	CAC member
Barbara Greer	CAC member
Moana Papa	CAC member
Anna Mitchell	CAC member

Apologies:

Maurice Gianotti	CAC member
Shane Bradbrook	CAC member
Katerina Pihera	CAC member

In attendance:

Bryce Wigodsky	PHARMAC (CAC Secretariat)
Jude Urlich	PHARMAC (Management Team representative)

Matthew Brougham, Steffan Crausaz, Rico Schoeler, Fiona Rutherford, Susan Haniel (PHARMAC Staff) and Carl Burgess (PTAC Chair) attended for relevant items.

The Acting Chair welcomed the three new Committee members in attendance and introductions were made.

1. Minutes of June 2010 meeting

The Acting Chair reviewed the 18 June 2010 minutes and briefly discussed that meeting's items. The Committee confirmed the minutes as true and accurate.

Russell (carried)

One member sought to ensure that the Committee would review PHARMAC's existing consumer documents on a rolling basis, in addition to reviewing new and upcoming items.

2. Acting Chair's Report

The Acting Chair gave a verbal report to the Committee regarding recent Committee matters.

The Acting Chair updated the Committee on the August PHARMAC Board meeting. She stated she signaled to the Board the Committee's desire to develop a workplan and engage directly with various consumer groups, such as presenting at the next PHARMAC Forum about the CAC.

The Acting Chair also emphasised the CAC should have a strong position within PHARMAC to better reflect consumer input. For example, this could be done by providing more tangible outputs and giving a clear reflection of CAC ideas and comment to the public to create differentiation between the Committee and PHARMAC.

The Committee was asked by the Researched Medicines Industry of New Zealand (RMI) to provide feedback on the RMI's draft revised Code of Conduct. The Acting Chair felt there was not much for the Committee to comment on, received no comments from other CAC members and decided there was no need to provide feedback at this point. The Committee expressed appreciation at being included in the RMI's list of stakeholders for this consultation.

3. Matters arising

3A. Conflicts of Interest

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

3B. Action points

The Committee agreed upon the action points.

Committee members discussed creating a "CAC Bucket" consisting of PHARMAC and CAC resources to distribute to the community as opportunities arose. Members deemed this would be especially valuable for consumers without regular Internet access.

3C. PHARMAC correspondence report

Due to time constraints, the Committee did not provide comments on PHARMAC's correspondence report or the examples provided of PHARMAC's correspondence with consumers.

4. Session with Chief Executive: PHARMAC's new functions

The PHARMAC Chief Executive (CE) welcomed new Committee members and provided a brief discussion of PHARMAC's functions and the role of the CAC. He discussed the primary outcomes of the CAC's recent Terms of Reference review as clarifying the Committee's role, reflecting consumer views but not necessarily "representing" all consumers, and ensuring PHARMAC interacts with consumer groups.

The CE briefly discussed PHARMAC's current Exceptional Circumstances review. He noted the approach PHARMAC is taking is unusual for PHARMAC in that it is a two-phase consultation process beginning with an open-view public discussion before consulting on a specific proposal.

The CE discussed PHARMAC's new movement into hospital pharmaceuticals purchasing. He commented this new role is an extension of PHARMAC's current work in community pharmaceuticals and will help ensure national consistency and equity in hospital provided pharmaceutical treatments. The CE noted the project to take over hospital pharmaceutical purchasing is in the very early phases of a multi-year project where PHARMAC is working with senior-level DHB officials. PHARMAC will engage with the CAC and consumers once it gathers further information about the existing process and how PHARMAC can manage this new role.

One Committee member asked if there would be a ring-fenced pharmaceutical budget for hospital pharmaceuticals. The CE replied there likely would be as there is significant variation in the purchasing strategies of hospitals and that PHARMAC has no immediate intention to transfer pharmaceutical funds between the Community Pharmaceutical Budget and hospital pharmaceutical purchasing.

Another member asked who was responsible for communicating to patients about hospital pharmaceutical schedules and budgets. The CE answered that there are some organisations dealing with this subject, including PHARMAC's Access and Optimal Use team. However, for PHARMAC, work in this space is still in its early phases.

5. How PHARMAC makes funding decisions

PHARMAC's Manager, Funding and Procurement spoke with the Committee about how PHARMAC makes funding decisions. He discussed some of the differences in pharmaceutical purchasing between New Zealand and most other countries. He noted that PHARMAC's processes encourage competition and achieves lower pharmaceutical prices.

6. Role of PTAC and Subcommittees

Carl Burgess, Chair of the Pharmacology and Therapeutics Advisory Committee (PTAC), discussed the role of PTAC as an advisory committee to PHARMAC.

7. Brainstorm on role of the CAC: Annual Plan and community discussion points

The Committee engaged in a brief discussion of this item, but agreed to defer full discussion until its December meeting when all Committee members were in attendance.

The Acting Chair posed five questions she wished Committee members to consider prior to discussion of this item at the Committee's December meeting:

1) What does our Committee want to achieve?
2) Do we want to be proactive as well as reactive? And does our mandate from PHARMAC allow for this?
3) Do we want to develop an active programme of CAC engagement with consumer groups? How would this work? Will PHARMAC support it?
4) How do we increase confidence in our ability to portray and encourage the consumer viewpoint?
5) What are the parts of PHARMAC's work where we can add the most value?

Committee members expressed a desire to develop a framework outlining outcomes, goals, etc to measure CAC success.

Members discussed the idea of utilising CAC members as spokespeople for various issues of concern for consumers. The Committee believed this will add value, identify gaps, help the public understand PHARMAC and help PHARMAC understand the public.

8. Introduction to Analysis and Assessment

PHARMAC's Manager, Analysis and Assessment presented to the Committee on PHARMAC's analysis and assessment activities. Topics included the use of forecasting, achieving value for

money, impacts on the pharmaceutical budget, determining the next best spend, the funding process, and different methods of analysis.

9. Exceptional Circumstances Review

PHARMAC staff presented PHARMAC's current Exceptional Circumstances (EC) review to the Committee. Staff discussed the background of PHARMAC's requirement to provide pharmaceutical funding consideration in exceptional circumstances, the arrangements of the three current EC schemes (Community, Cancer and Hospital) and the process of the review.

Committee members stated that a definition of what is an exceptional circumstance is not defined in the legislation requiring this part of PHARMAC's work because of New Zealand's system of case law. Thus, it seems definitions of an exceptional circumstance have arisen and fluctuated over time as EC decisions are made.

The Committee expressed nervousness about trying to define something that covers a number of different circumstances. Members stated an underlying issue may be that the conventional treatments are not working.

One member noted that many patients will be represented in the EC review process by specific interest groups related to the patient's circumstances, even if those patients are not aware of it.

Members suggested it is worthwhile for PHARMAC to examine the origins of the EC policy and the legislation to help determine what an exceptional circumstance is. One member cautioned PHARMAC not to lose or brush aside previous work or decisions regarding the EC policy when developing a definition for EC.

Members suggested PHARMAC employ flexibility regarding the EC criteria of there being less than ten patients nationally in a particular clinical situation. Members also expressed concern over other patient categories, such as those whose disease is common but who fail on common treatments. The Committee agreed there is a grey area between what is EC and EC that will lead to a future Pharmaceutical Schedule listing.

Members discussed how the nature of exceptional circumstances means PHARMAC cannot adequately predict how much will be spent on EC in the future. Members commented that the budget must remain notional for this reason.

Members discussed the role of patients in the EC policy. The Committee agreed that the concerns of patients who do not receive EC funding but feel they should needs to be addressed. Members also discussed the importance of making patients and consumers aware of what is happening in the EC and wider health systems. Members wondered whether it was possible to provide a resource to inform patients about the EC process, including what to ask about, what to expect and the responsibilities of clinicians.

One member stated PHARMAC should have a "consumer pathway" in its work to understand the role of consumers. This pathway could help determine how far removed from the process consumers are at any point, where consumers should be in the process, when consumers can engage with PHARMAC or impact the system, etc. She stated this should be shared with consumers to inform and educate them so they do not have to rely solely on doctors.

Members also discussed the possibility of providing a form for consumers to complete to describe their experiences while taking a medicine. These forms could be returned to reception at the patient's doctor's office to inform the doctor of their experiences, and so not requiring a follow up appointment or the resulting fee.

One member expressed concern about the consumer at the point of entry into the process or when thought is being given to applying for EC funding when they are ill, frightened or overwhelmed. The member agreed on the benefits of a resource for patients outlining the EC process and the options available if EC funding were denied. The member believed this would provide patients and their loved ones some control over a stressful situation. The member stated the resource should also provide contact details for an independent advocate, cultural support or interpreter to assist them and their family.

Members stated it is important to allow consumers to engage in the EC process, not just clinicians. One member believed many patients may not even know they are in the EC process as currently it is a clinician-oriented system. One member believed greater patient knowledge of the EC process would take some blame off of doctors for declined EC funding, which is possibly a reason for some doctor's hesitancy to apply for EC funding.

Members discussed the option of having a "navigator" for patients. One member explained that some Pacific patients have a navigator to enable good communication and understand between patients and doctors and nurses. Navigators can help bridge language and cultural gaps, for example.

One member discussed how clinicians are focused on not raising the expectations of their patients, and so any definition and operational changes to the EC policy should not damage the doctor-patient relationship.

One member stated she believed there would be positive consequences for patients and decision turn-around times if PHARMAC were to manage in-hospital exceptional circumstances.

10. Pacific Responsiveness Strategy

In coordination with PHARMAC staff, the Committee's Pacific representative led discussion on a draft of PHARMAC's Pacific Responsiveness Strategy (PRS). The member expressed a desire to see similar outcomes from the PRS as those provided by PHARMAC's Māori Responsiveness Strategy.

The member noted the PRS is currently a three year plan being driven by PHARMAC, and suggested that over time it could be picked up and run by community providers. This plan is similar to PHARMAC's One Heart Many Lives programme.

The member recommended including a "Community" section in the PRS to provide key goals that can be measured to improve the use and understanding of pharmaceuticals amongst Pacific peoples and an understanding of Pacific health needs within PHARMAC.

The member noted that when identifying key stakeholders in Pacific health, it is important to understand the role of churches. She suggested including engagement and training of church committees to enable them to deliver PHARMAC's Pacific health activities and resources into the community.

Members wondered how much of PHARMAC's AOU (Access and Optimal Use) work and activities can be made Pacific-specific. This could be achieved by engaging with the key players in the sector that the PRS aims to promote.

Members suggested beginning implementation of the PRS with Pacific populations in Auckland and Wellington, and branching out to other population centres elsewhere. The Pacific representative also noted the CAC could become more involved in implementation of the PRS to establish and build relationships. She suggested the CAC have a presence at Pacific health forums and conferences, which could be included in a Committee annual calendar.

The member wondered if it were possible to create an informal Pacific caucus within PHARMAC.

The member provided names of a number of Pacific health providers, key players and events that PHARMAC could engage with and become involved in to develop its understanding of Pacific health issues.

The member commented that the PHARMAC Forum is too high a level to obtain good representative populations of Pacific and Māori people. She suggested PHARMAC develop a lead-in to the Forum, such as hui and fono, to discuss specific matters. Representatives from these meetings could then represent their group's issues at the Forum. The member also suggested the possibility of a group "hosting" PHARMAC or the CAC, making it less intimidating than the formal PHARMAC Forums.

Members commented that PHARMAC could stay connected with Pacific communities by having key players organise meetings between PHARMAC and a particular community at certain times of the year, with certain sub-groups of populations, etc.

Noting papers

Noted:

Access and Optimal Use update
Funding and Procurement update.