

Minutes of the PHARMAC Consumer Advisory Committee (CAC) meeting Thursday 12 July 2012

The meeting was held at PHARMAC, 9th floor, 40 Mercer St, Wellington from 9.30 am.

Present:

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

Apologies:

Shane Bradbrook	CAC member
Katerina Pihera	CAC member

In attendance:

Bryce Wigodsky	PHARMAC (CAC Secretariat)
Jude Urlich	PHARMAC (Management Team representative)
Rachel Hargreaves	PHARMAC (Senior Policy Analyst)

Steffan Crausaz, Marama Parore, Lisa Williams, Jackie Evans, Janet Mackay, Simon England, Kaye Wilson, Sean Dougherty (PHARMAC staff) attended for relevant items.

1. Minutes of February 2012 meeting

The Chair reviewed the 15 February 2012 minutes. The Committee confirmed the minutes as true and accurate.

2. Chair's Report

Since the last meeting I have attended all Board meetings but have been very much in the observer role and have not been asked, in recent times to comment on any aspects of Pharmac's work in the meetings themselves.

An email was circulated to committee members in May asking for comment on the OPP document and putting in my own thoughts as a starting point. I only received a couple of replies to this and so proceeded to create our response according to the thoughts I had already articulated.

Congratulations to Anne, Anna and Jennie on their re-appointment to the committee. It is good to see consistency on the committee at this time.

Our congratulations to Steffan on his permanent appointment as CEO of Pharmac. I sent him a card on behalf of our committee, wishing him well. Steffan has a complicated period to navigate as Pharmac comes to terms with the implications in terms of resourcing, of taking

more responsibility in hospital medications and devices. I am sure we all look forward to working with him going forward.

I have been particularly gratified to observe over recent Board meetings, the careful and considered way that Pharmac has taken account of the overwhelming amount of consumer feedback received on mooted changes to diabetes products. It is always heartening to witness an organization such as Pharmac, genuinely taking note of the strong feelings that exist and giving respect to the views expressed and slowing processes down to allow for appropriate continued consultation.

A round of emails was noted expressing the disappointment of some committee members that we were not warned of impending increases to prescription charges. My thanks to Jude for responding so fully to this concern to assure members that Pharmac was not ever in a position to share this information and that where information of this type CAN be shared – it is. It is worth noting that there is some commercially or legislatively sensitive information that simply cannot be shared with this group prior to public release.

The Chair verbally added to her report noting that, at times, Committee recommendations have been made to the Board where the recommendation was raised by a single member and not endorsed by the Committee. The Chair stated that when points are raised the Committee can choose to either decline or accept the point as a recommendation to the Board, or it can choose to submit the point noting it was raised by a single member.

3. Matters arising

3A. Interests register

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

Members discussed what process to follow to determine whether to declare their interests. Members clarified with PHARMAC staff that the identification of interests that may be a conflict is up to each individual member to determine, and that members are not obliged to declare an interest that they do not consider would raise a conflict in connection with their membership of the Committee. Further, members are able to declare previously un-declared interests at any time, including at the time a topic is raised for discussion.

3B. Action points

The Committee reviewed and agreed upon the action points.

The Committee moved Items Carried Forward 1 to Standing Items.

Noting Items Carried Forward 12, the Committee agreed that its Annual Plan and PHARMAC's Statement of Intent (SOI) are linked documents and that it is a given that the CAC Annual Plan aligns with PHARMAC's SOI. The Chair undertook to contact an absent member to confirm the original intent of this action point.

The Committee noted some disappointment at the lack of Board members present at the post-PHARMAC Forum meet and greet, reiterating its desire for greater engagement with the Board.

The Committee discussed ways to increase its engagement with other consumer groups. Members discussed possible contacts with groups such as Aotearoa Consumer Coalition, the Health Quality

and Safety Commission, the Health and Disability Commission, Accident Compensation Corporation and a mental health advisory group. Members undertook to contact relevant groups with shared networks to establish relationships.

3C. Correspondence

The Committee noted the PHARMAC Correspondence Report.

Members noted verbal comments they received expressing appreciation for the consultation process used in PHARMAC's recent consultation on proposed changes to the funding arrangements for some diabetes management products.

The Committee commented on the improved tone and provision of information in PHARMAC's responses to consumers. Members noted PHARMAC no longer comes across as risk-averse or defensive, putting "all the facts on the table."

Regarding one of the correspondence examples provided to the CAC for review, members felt the fundamental question was not being answered by PHARMAC. Some patients had written to PHARMAC expressing difficulties swallowing the newly funded brand of paracetamol tablets. Members queried what PHARMAC can do to influence pharmaceutical manufacturers to alter their products where consumers are having difficulties.

3D. Grapevine

The Committee discussed outstanding Grapevine issues.

One member noted he has been invited to speak at a local gathering to report-back on the outcomes of PHARMAC's Regional Forum held in his area. He stated this is evidence to PHARMAC of a genuine interest in its engagement with consumers.

4. Report of activities

Two members verbally reported on their attendance at the Health and Disability Sector NGO – Ministry of Health Forum. The members reported that the event was beneficial for networking with NGO groups, many of whom expressed interest in learning more about the Committee. The members were able to share some information and resources about the CAC with these groups. Both members commented that the venue chosen for the event was unsuitable.

One member provided a written report on her attendance at the Arthritis New Zealand national conference in May:

On the 10th May I attended the Arthritis NZ Conference public day on behalf of the Consumer Advisory Committee. I took some resource material which was displayed alongside the ANZ pamphlets & flyers. Quite a bit of it was taken by those attending the conference & the remainder was retained for future use by ANZ. I noticed that ANZ themselves already had a pile of "Out With Gout" booklets which was good to see.

There were many interesting speakers but the following points are particularly relevant in relation to Pharmac:

- *Arthritis NZ & Pharmac are working together on the "Out With Gout" initiative. A workshop entitled "Gout in Auckland Maori & Pacific Island Communities" was held at the conference & ANZ have held recent gout seminars in Hamilton & Blenheim & one is planned for Whangarei later in the month. More will follow.*

- *In partnership with ANZ, drug company Pfizer has produced a report on chronic pain which was presented at the conference. A poll of over 1,600 adults showed that many people with chronic pain feel their condition is misunderstood even sometimes by healthcare professionals & is not controlled as well as it should be. Interestingly 30% of those with chronic pain are purchasing pain medications in addition to those prescribed for them. Sandra Kirby, CEO of Arthritis NZ said that there is “an urgent need for a national pain strategy to provide further education, resources & information to both patients & healthcare professionals about lifestyle & treatment options for those living with chronic pain”. My own thought is that chronic pain management could be considered by Pharmac as a worthwhile future public health initiative to encourage optimal use of medicines.*
- *At the conference a room was set aside for trade displays & among others there were several drug company stands including one for Pfizer. They were actively promoting the NSAID (non-steroidal anti-inflammatory drug) Celebrex. At present this pain killer is not subsidised but I understand that there will be another attempt at some stage to lobby Pharmac to do so.*
- *A keynote address was given by rheumatologist Lisa Stamp who spoke on the latest research in rheumatology & two points which may be of particular interest to Pharmac were discussed. The first was the continuing availability of newer biologic drugs which may be more effective in halting the progression of various arthritic disorders. Unfortunately they are also very expensive so it is accepted that a wider range of this type of medicine is unlikely to be subsidised. Secondly, new research has indicated that smoking greatly increases the risk of getting rheumatoid arthritis & worsens the condition of those who already have it. Another reason to continue with the programmes which encourage people to quit!*
- *Finally, while I was at the conference the news came through that prescription fees were going to be increased from \$3 to \$5 per item. The people I spoke to generally realised that this was a pre-budget announcement from the government & not a decision that Pharmac had made. Although we were pleased that the extra money raised would be ploughed back into the healthcare sector most would have liked at least some of it to go towards funding new medicines.*

A member tabled the conference programme for a recent Pacific conference that was sponsored in part by PHARMAC. The member thanked PHARMAC for its support, saw this support as a sign of following through with PHARMAC's Pacific Responsiveness Strategy and encouraged PHARMAC to be involved in the next conference in 2014.

5. Agenda and minutes process

The CAC Secretariat briefly discussed with the Committee the timeline and process for setting Committee agendas and drafting/reviewing/finalizing Committee minutes.

The Committee agreed that members will communicate via the Chair if significant changes are needed to draft minutes during the review process. The Committee also agreed that members are able to consider issues and have discussions or make suggestions in between CAC meetings, and to carefully consider the Committee's recommendations put to the Board during the review process.

6. Session with Chief Executive

The Chief Executive began his session with a discussion of PHARMAC's key organisational "strategies for future success" – improved clinical leadership, enhancing e-influence, core strength and value from extended functions. The Chief Executive briefly outlined some activities PHARMAC is undertaking to achieve these strategies.

The Chief Executive clarified for the Committee PHARMAC's role in the recent Government decision to change the patient co-payment for subsidised medicines from \$3 to \$5. The Chief Executive stated that, due to sensitivity reasons, PHARMAC first became involved in discussions of this subject late in the process, but had no decision-making role. He stated PHARMAC is part of the implementation group.

The Chief Executive briefly discussed recent changes arising from the recently agreed Community Pharmacy Services Agreement (CPSA). He also discussed recent changes in relation to dispensing frequency that form part of the CPSA.

A member enquired about issues she is aware of where patients are discharged from hospital without picking up their medicines and without proper support. It was agreed to raise this question during discussion item 13.

The Committee noted its appreciation, and the helpfulness, of having the Chief Executive brief the Committee on PHARMAC issues.

7. PHARMAC Forum debrief

Members discussed the PHARMAC Forum, held in February 2012. Members agreed the Forum carried on the spirit of health sector stakeholders working together. Members felt there was a good atmosphere at the Forum, with good challenges given by speakers and attending delegates.

Some members noted their observation from Forum discussions around PHARMAC's new role in procuring medical devices, that the main concern from stakeholders was around resourcing to carry out the task, not necessarily that PHARMAC is not the appropriate agency to do this work.

One member noted that Ken Whyte, a Forum speaker, led a good session and provided good challenges for delegates to consider.

Members appreciated the different perspectives presented by both speakers and delegates.

Members suggested PHARMAC hold its Forum every year and does not cap attendance at a pre-specified number of attendees. It was also suggested that the Forum be held over more than one day and/or have fewer sessions, allowing for more in-depth discussions.

Members discussed that the CAC co-hosted breakout session on consumers and pharmacy was very interactive. Members also noted that the NPPA breakout session at the Forum was more presentation and less discussion. Members also stated that the Māori health session was largely presentation and perhaps to the wrong audience ("preaching to the choir"). Members stated that such sessions on Māori health should be to the entire Forum rather than primarily Māori stakeholders.

8. Māori Health update: He Rongoa Pai He Oranga Whanau, e-Panui

PHARMAC staff briefed the Committee on activities in the Māori health space. Staff discussed the development of Te Whaioranga currently in progress and the e-Panui newsletter.

Staff also discussed PHARMAC's He Rongoa Pai, He Oranga Whānau workshops, stating the programme is looking to tap into the Pacific health workforce and the primary care workforce. Staff also noted that more workshops will be held in the South Island soon.

9. PHARMAC's OPP review

PHARMAC staff briefed the Committee on PHARMAC's current review of its Operating Policies and Procedures (OPP), including the process to date and next steps. The Committee was informed that PHARMAC received 23 submissions to the first phase of consultation.

PHARMAC staff and the Committee discussed the optimal process for engaging with stakeholders early in a review or proposal process where the content of the consultation is high-level or pre-proposal. The Committee suggested PHARMAC should develop an idea of where it intends to go on a particular proposal before consulting. The Committee noted that engaging with consumers too early, prior to a more substantial proposal being developed, risks confusing consumers and having too wide of a scope for meaningful feedback.

The Committee suggested PHARMAC could undertake more targeted engagement with appropriate stakeholders early in such processes, and then proceed to wider engagement when a more substantial proposal is developed. One member noted PHARMAC could undertake targeted group trials or focus groups, including by ethnicity, to enable better engagement.

One member noted that the level of engagement can depend on the nature of the topic being consulted upon. If the topic is a fundamental baseline issue for PHARMAC, early and frequent engagement is necessary, whereas if the topic is a minor tweaking, more thorough engagement may not be necessary.

The Committee noted, from its submission to the OPP review, that PHARMAC should maintain consistent engagement with stakeholders in all it does.

The Committee recommended PHARMAC utilise existing mechanisms, such as the CAC, to improve engagement. Members mentioned this could be particularly useful for targeted or focus group engagement, where PHARMAC could provide members with a profile of what it is seeking and members could put the group together. It was noted this would be similar to the process used for PHARMAC's Regional Forums in 2011.

10. Biosimilars: what are they?

PHARMAC staff presented to the Committee on biosimilar medicines, the "generic" versions of biological pharmaceuticals. Staff outlined what biologics and biosimilars are, how they are produced, PHARMAC's interest in this matter, and challenges to PHARMAC in this space. PHARMAC staff noted that they may seek further input from CAC on engagement with consumers on specific biosimilar topics in the future.

11. Proposed implementation plan for diabetes changes

PHARMAC staff met with the Committee to discuss PHARMAC's proposed implementation plan for changes to funding arrangements for some diabetes management products. Staff stressed that no decision is final yet and staff are waiting for further information about the proposed products. Staff emphasised the need for members to not discuss this subject with anyone outside this meeting until an announcement has been made.

Staff specified that they were seeking from the Committee ideas on engaging, specifically with Māori and Pacific stakeholders, or to identify any stakeholder groups that may have been missed out from the proposed implementation plan. The Committee suggested PHARMAC take advantage of all mechanisms possible for reaching stakeholders, including through Primary Health Organisations, churches, etc.

One member suggested contacting Māori non-governmental organisations and the Māori Women's Welfare League. Members noted that face-to-face meetings are important for engaging with Māori and Pacific peoples.

To reach Pacific peoples, one member suggested PHARMAC work through local churches, Pacific community groups, Pacific health professional organisations, DHB Pacific General Managers and radio media to implement any changes. Members also suggested PHARMAC recruit "champions" to front implementation for certain target groups. Members noted that the "messenger is more important than the message."

One member noted PHARMAC could utilise Pacific events leading up to the annual Pasifika festival. It was suggested that diabetes management could be a theme of such an event and PHARMAC could take advantage of this to inform about any changes to funded diabetes management products.

One member noted PHARMAC needs to consider how to engage with New Zealand citizens who live abroad, such as in Samoa or Tonga, but return to New Zealand for health care as they are eligible for it.

Members also noted PHARMAC should provide information in a number of relevant languages, including at face-to-face meetings, to better communicate with Māori and Pacific peoples.

Members also suggested PHARMAC "reach into" residential care to implement any decision. Staff agreed, but noted this was difficult given the living and medicines dispensing arrangements in this setting.

One member suggested PHARMAC contact key registered nurses and caregivers through DHBs, as these professionals can often act as the front-line health worker for patients with diabetes.

Members suggested PHARMAC do an implementation road show alongside key people from the relevant communities and in conjunction with other key messages, such as diabetes management as a whole rather than insulin test meters and strips specifically.

Members raised the possibility of connecting with Age Concern's national network of volunteer "visitors" to connect with patients. However, one member cautioned that while these personnel may be great for connecting with patients, they are volunteers and not necessarily health professionals. This member noted that utilising these personnel for this could be outside their scope. Members noted it may still be useful if these personnel are informed about any decision and how a patient could access the appropriate service.

The Chair complimented staff on the careful and considerate process used, including with the PHARMAC Board, for discussing the proposed changes and proposed implementation plan.

12. Demonstration of online Pharmaceutical Schedule

PHARMAC staff provided the Committee with a demonstration of PHARMAC's online Pharmaceutical Schedule. Staff showed members the different ways to access the Schedule and different download versions. Staff provided examples of searching for different medicines in the online Schedule and noted the YouTube video clip demonstrating this.

The Committee suggested developing a multi-language online Schedule. Members also suggested PHARMAC continue improving the online Schedule as it takes over more responsibility for managing hospital pharmaceuticals.

13. Hospital pharmaceuticals consultation

PHARMAC staff updated the Committee on progress relating to PHARMAC's increased role in managing hospital pharmaceuticals funding. Staff noted PHARMAC has just begun a consultation seeking feedback on the policies and rules for a defined list of publicly funded hospital medicines.

One Committee member queried PHARMAC's proposal to allow for some local flexibility in prescribing restrictions, asking who the local DHB would need to justify its decisions to. The member wondered whether this part of the proposal was counter-intuitive to the aim of improving national consistency. Staff replied that different DHB hospitals across the country all have different specialties on staff and different decision-making frameworks, which is very different from the community setting. Staff commented that most DHB hospitals already have some version of a committee reviewing funded medicines use and ensuring prescribing is appropriate.

Members noted that PHARMAC's proposal to require DHB funding approval even where the medicine is to be provided free of charge by a company/organisation could have potentially large implications for patients. One member commented that PHARMAC will need a significant amount of clear communication to patients and prescribers to convey the purpose of this proposal if implemented.

Members followed up on a question raised during agenda item 6, asking how PHARMAC might address the issue of patients being discharged from a hospital without picking up their medicines and without proper support once they return home. Staff commented that PHARMAC understands that patients should be provided with 10 days' worth of medicines upon discharge. Members suggested PHARMAC take a role in emphasising to hospitals and patients the importance of ensuring prescribed medicines are picked up upon discharge from the hospital.

PHARMAC staff commented that the core issue in relation to this matter is the flow of care of patients from hospital to community and ensuring information is shared between carers and prescribers in the hospital and community settings. Members queried whether PHARMAC could take a role in re-starting the initiative previously begun to establish electronic referrals and discharge records. One member suggested the use of "discharge pharmacies" that are charged with filling this role for DHB hospitals.

14. Te Roopu Awhina Māori report-back

Te Roopu Āwhina Māori - July 2012 CAC Meeting Report

Te Roopu Āwhina Māori, a group made up of PHARMAC Māori advisory members and Māori staff provides a forum where issues impacting on Māori health and wellbeing can be discussed. The Roopu plays a significant role in ensuring that PHARMAC is fully briefed on how its funding decisions will affect tāngata whenua

WHAKATAUKI – Proverb

*Nā tō rourou, nā taku rourou ka ora ai te iwi
With your food basket and my food basket the people will thrive*

This proverb refers to co-operation and the combination of resources to get ahead

1. RECORDING MEETING DECISIONS AND DISCUSSIONS

At our last CAC meeting, I raised concerns regarding the omission of our discussions regarding the Treaty of Waitangi at the previous CAC meeting. I sent a letter to Steffan stating my concerns as I believed that by writing and formally stating my concerns that the issue would be addressed as previous attempts to correct minutes had not happened (see the attached letter to the CEO). In the June 2012 Te Roopu Awhina meeting, I asked Steffan for feedback on the situation – he did not get my letter therefore he could not respond

Recommendation

As per my letter to the CEO – I wish to formally request of PHARMAC staff information regarding the process to re-introducing the Treaty of Waitangi principles into PHARMAC's Strategic documents

2. TE WHAIORANGA 2013-2018

Te Roopu Āwhina Māori have met twice since our last CAC meeting. Some important work and progress has taken place building upon the existing Maori Responsiveness Strategy. Two strategy areas in Te Whaioranga that are particularly exciting and noteworthy is i. Championing evidence-based Maori Medicines Management and ii. Leading Indigenous Pharmaceutical Management

3. INGOA MAORI PHARMAC

Te Roopu Āwhina Māori have discussed the Maori name that best reflects the role and purpose of PHARMAC

*Option 1 is based on the word "Pataka" meaning storehouse
Option 2 is based around Rongoā, traditional Maori medicine*

A recommendation will be communicated to PHARMAC staff and stakeholders before the end of the year advising of the chosen name

MATARIKI ANNUAL CELEBRATION DAY

Last month, I was invited to the PHARMAC Matariki Annual Celebration Day. PHARMAC staff and whanau spent the day gaining insight and increasing knowledge on Maori culture,

language and values. We toured Te Papa Tongarewa learning about medicinal properties of plants, and enjoyed a traditional Maori meal with food shown to us during our tour.

In the afternoon we visited the Wellington Observatory learning about Matariki - the Maori name for the group of stars also known as the Pleiades star cluster or The Seven Sisters; and what is referred to as the traditional Maori New Year.

The Maori new year is marked by the rise of Matariki and the sighting of the next new moon = The pre-dawn rise of Matariki can be seen in the last few days of May every year and the new year is marked at the sighting of the next new moon which occurs during June.

Matariki has two meanings, both referring to a tiny constellation of stars; Mata Riki (Tiny Eyes) and Mata Ariki (Eyes of God).

TE WHAIORANGA E-PANUI

The latest e-panui was sent to all CAC members last month

MAURI ORA!

Moana Papa, CAC member

PHARMAC staff and the Committee discussed the process for including the Treaty of Waitangi in PHARMAC's strategic documents (OPP, Statement of Intent, Framework for Success). Staff noted that the Treaty is already included and routinely considered when developing/updating strategic documents. One member queried whether the role of the Treaty within PHARMAC could be highlighted and further emphasised in such documents. Further discussion with PHARMAC staff was suggested as the way forward to better understand the context and framework of these documents, as well as the individual members' concerns.

15. Resource review: NPPA "front-line" leaflet

This item was discussed prior to the lunch break.

The Committee provided feedback on a draft resource for consumers about PHARMAC's Named Patient Pharmaceutical Assessment (NPPA) scheme. One member provided comments on a copy of the resource and provided it to staff for review/actioning.

Members suggested translating the resource into multiple languages.

Members queried who, under NPPA, has the right to make the decision whether a NPPA application is made – the patient or the clinician – as only clinicians can submit an application. Understanding that only prescribers can submit a NPPA application, members suggested PHARMAC could re-word the resource to signify that patients can contact PHARMAC to enquire about options if their doctor does not want to apply for NPPA funding but the patient wishes an application to be made.

Noting papers

Noted:

- Access and Optimal Use update
- Summary of new investments
- PHARMAC consumer website project update