Minutes of the PHARMAC Consumer Advisory Committee (CAC) meeting
Thursday 24 October 2013

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

Present:

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

Apologies:

Barbara Greer	CAC member

In attendance:

Simon England (CAC Secretary), Jude Urlich, Steffan Crausaz (Chief Executive), Fiona Rutherford, Raylene Bateman, Janet Mackay, Meena Vallabh, Karen Jacobs-Grant, Rachel Melrose, Rebecca Keat (PHARMAC Staff); Stephanie Fletcher (IT Health Board), Sarah Hoyle (IT Health Board)

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1. **Record of previous meeting (27 June)**

Minutes of the 27 June 2013 meeting were accepted as a true and accurate record.

2. **Chair's report**

The Consumer Forums around NZ were well-attended although it seems that there is always a difficulty of keeping people's minds above their own personal issues when conducting such a forum.

In a few cases there was a significant lobby from the PNH group and diabetes were also represented in many areas and voiced their dissatisfaction at the recent changes to the blood glucose meters. There remains a reasonable level of discomfort on the accuracy of the meters and this is something the committee needs to be aware of.

There is a lot happening in the rare diseases space with many groups now combining to lobby and create media attention. We may at some stage be asked to hear from this lobby at one of our meetings.

The Board was receptive to the suggestion from our last meeting that we might wish to upskill in some areas over time by inviting experts in governance etc into our meetings for short learning opportunities. They are happy to support this.

I wish to formally record our condolences to Shane on the loss of his parents. Our thoughts continue to be with his family at this sad time.

Members acknowledged the Board's recognition of the Committee's request to upskill members. Staff will seek information on available opportunities and circulate to members.

Action Point: Māori health team to present to CAC on He Rongoa Pai or activities interacting with consumers/community.

3. Matters arising

Members commented favourably on the flyer developed for the decision criteria consultation featuring Barbara Greer and circulated via the Māori Women's Welfare League conference. Members suggested such a flyer could be personalised and useful for raising the profile of the CAC in communities. Depending on content, it could even be translated into other languages. Members requested PHARMAC develop such a flyer for each CAC member.

Members considered it would be useful to invite Grey Power to talk with the committee at its next meeting.

Minutes from the June meeting included a list of factors members considered relevant to people using or not using medicines (adherence). Members considered this was a useful list and could be used more widely, to promote discussion and debate. The committee requested PHARMAC turn this content into a short discussion document that members could use within communities (action point). Members considered this was a good example of the sort of advice the committee gives.

Anne Fitisemanu also requested information on adherence for PACIFICA Womens AGM in Wellington February 2014.

4. Correspondence

Members considered PHARMAC's responses to written enquiries continued to be to a high standard. Discussion raised by correspondence provided to the committee included:

- How does PHARMAC deal with things people want considered as `formal complaints'? PHARMAC doesn't usually differentiate correspondence on that basis, it treats all correspondence the same way. Members considered it would be desirable to acknowledge the writer's desire to have the comment treated as a complaint, and respond as appropriate. This would close the feedback loop.

- Does the tendering process take into account any hidden costs, for example changes from plastic to glass ampoules which may have a higher risk of breakage and may lead to consumers encountering hidden costs? PHARMAC looks at a range of factors in its tendering process, including size, colour, flavour, differences between products. Direct costs to patients are taken into account in our decision-making process.

- Continued correspondence around differences in blood glucose meter readings. Pharmaco (the supplier) has been up front; perhaps this is something PHARMAC should have prepared advance information about. The meters change has put a focus on diabetes management in the community – including people's understanding about meter accuracy.

5. IT Health Board consumer engagement

Stephanie Fletcher (chair of national IT Health Board consumer panel) and Sarah Hoyle, IT Health Board, presented to the committee about the Board's consumer engagement work.

The purpose of the consumer panel is to provide a consumer perspective within the IT Health Board, including consumer representation on the clinical group. The panel is looking to put together a co-ordinated communications plan for engagement with the consumer sector.

The panel has a Terms of Reference, and contains 15 members with a mix of ages, ethnicities, socio-economic status etc. Recruitment is by asking member organisations to nominate people. The panel co-opts or invites expressions of interest from members to be part of other IT Health Board panels or working groups.

There's a consumer on each of the Board's working groups; on the tele-health forum (about providing health information services to people in hard to reach or isolated rural areas); the health information governance expert advisory group; and the national information clinical leadership group.

Currently the major piece of work is a paper called Protecting Personal Health Information, Consumer Expectations. This is about how the panel thinks minimum standards/requirements should be developed for protecting personal health information. It sets out things like establishing an audit trail of everyone who has accessed my information; when or by whom information can be withheld (right for others not to be able to see certain information); role-based access (eg administrators not accessing, only clinicians). The paper seeks a national privacy statement for everyone working with health information. It seeks greater transparency so people can see who has accessed medical records.

Consultation will occur. CAC members considered that such a paper needed to be distributed widely to consumer groups.

The IT Health Board consumer is aware of intersection of this work with other agencies, such as Human Rights Commission and Office of the Privacy Commissioner.

Another piece of work related to researchers' access to personal health information. Such information is meant to be anonymised, however it was not clear what assurances there are.

CAC members advised that, when considering which consumer groups to engage in relation to health information, that the computer hacker community might be able to provide useful insights. Many people assume systems are safe, however this is not always the case.

CAC members considered this was an important piece of work for consumers to be involved in, and asked to be kept informed of, and involved in, the process as it develops.

CAC also considered it would be helpful to have an understanding of the Health IT Board's projects and vision for the sector.

6. Hospital Medical Devices

PHARMAC's work on medical devices had previously sought feedback on how to get clinical engagement in the process. Now, as part of its work towards management of hospital medical devices, PHARMAC was asking more general questions to get information from the sector around what considerations need to be taken into account when developing the policies and processes to apply the PHARMAC model to this area. Consumer involvement in this process is welcomed.

At the same time as seeking input to development of its overall approach to management of hospital medical devices from 2015, PHARMAC has identified some specific areas of procurement – wound care, sutures and orthopaedic implants – where activity will begin immediately.

Management is likely to occur from 2015, when data and financial management systems are in place. Interim procurement is happening in the current financial year, aiming to get some price reductions for DHBs through national contracting. This work is welcomed by DHBs but shouldn't affect clinicians in the first instance. Full budget management will occur some time later.

PHARMAC is keeping groups informed about what is happening, talking to groups of clinicians, professional colleges and societies, such as orthopaedic surgeons.

Members sought information about whether PHARMAC's activity would likely curtail the availability or choice of products, or hamper the introduction of new technology/new products. For the interim procurement activity, it is not envisaged that this will be the case. These issues are being considered as part of the work to develop the processes for management. Members considered it desirable to preserve flexibility.

Members considered that different levels of knowledge or input were needed for different devices. For example, the type of scalpel a surgeon chooses to use is probably not of concern to consumers. However, take-home items or items implanted in the body would be.

Before consumers are engaged, PHARMAC needs to be clear about what the consumer can think about or have input to. Not all device processes would require consumer engagement, but members felt some kind of consumer focus group could be consulted early in the process to get an idea of the sort of engagement that might be necessary.

Using focus groups early in the process would enable very well-informed advice to be obtained, including whether it would be necessary or desirable to seek broader consumer input. For example, people who have had orthopaedic joint replacements (knee or hip), pressure ulcer dressings or pacemakers would have a lot of knowledge about how these things affected them. Such a focus group would feed into the creation of a consultation document, rather than the other way round.

The choice of language would be important. Consumers don't tend to think of `devices', but specific types of product (hip replacement, pacemaker etc). More specific information may be required.

PHARMAC is progressing its development work and once management is in place, it will be slowly considering items on a category by category basis – the framework will include looking at things like consumer impact. For the interim procurement work, PHARMAC is getting feedback on what clinicians think is important for the categories chosen for activity this year, including what they think is relevant to consumers. PHARMAC intends to set up mechanisms to look at which categories will require consumer input, which might be something as simple as a checklist that will flag whether this is something consumer input needs to be sought on.

Similar issues may arise around brand changes, particularly where this may impact on a person's quality of life.

Members suggested PHARMAC develop resources that would be available to patients/consumers, for example in hospital service delivery, clinics and key reception areas. These could outline PHARMAC's role in hospital medical devices, the possibility that products might change, and information on how to contact PHARMAC. The committee thought this should be presented as positive information for consumers, to keep them informed, establishing a reason for people to engage with PHARMAC.

Members expressed a desire to make a submission to PHARMAC on the current consultation.

7. Medication adherence

PHARMAC has identified two preferred suppliers for pilot programmes. CAC's input was sought as to what can be included in the contract rather than general advice on adherence, which was provided at the committee's last meeting.

Members considered the type of people being sought would determine the best method for enrolment, including the use of large poster ads for a broad population. Specific disease states would require greater targeting. GPs and other health professionals should be part of both pilots – they need to know what their patients are doing and can also refer people into the programme.

The CAC considered technology is only likely to be part of the answer. Smartphone apps may be effective but may not be useful for everyone. Members considered it desirable to have multiple channels for contacting people. Some people might want phone calls. PHARMAC staff noted the specific focus of these pilots was on the use of technology, rather than a broader assessment of the full range of interventions

Middlemore Hospital has an established programme to capture information on Pacific patients (mainly cardiac), this may be something that can be tapped into.

PHARMAC staff outlined that the Type 2 diabetes programme is seeking to recruit 600 people, with probable enrolment through pharmacies in the Waikato DHB area. Recruitment for a second pilot, looking at multiple medication use, would be through GPs. The programmes will run for a year.

The Committee supported a pilot programme that recruited across a mix of demographics. The Committee expressed concern about the recruitment process and questioned whether any ethical approval might be required. In particular they asked about the rights of a consumer taking part in a study or project and how PHARMAC would obtain informed consent as laid out in Rights 6 and 7 of the Code of Consumers' Rights which is part of the Health and Disability Commissioner's Act 1994 and its amendments. PHARMAC staff assured the Committee that it would ensure the pilots complied with any obligations of this nature.

The adherence service would be free to patients – medicines would continue to be same cost to patients. PHARMAC will be looking to gather information on reasons for non-adherence as part of the pilot programmes, as well as determine what, if any, effect the services have specifically on medication adherence.

Future pilots may be run targeting different approaches.

8. Chief Executive discussion

The Chief Executive updated the committee on notable milestones.

PHARMAC is keen to find out the non-clinical and clinical impacts of the diabetes meters brand change. The change has put a focus on diabetes management so any impacts may be beneficial, but that won't be known until data becomes available next year.

People's reactions to the change are understandable. Responses have been a mixture of negative and positive. 110,000 people have changed, so implementation is effectively over.

Investments in new medicines are more or less complete for the year. Ticagrelor has been a significant transaction.

Currently PHARMAC is looking at the budget bid for next year (2013/14), analysing the profile of pharmaceutical volume and price.

Members asked whether consideration could be given to taking over-the-counter products off the Schedule. These are important products for some people, and taking them off the Schedule could raise the cost for consumers. Also, most of those products are low cost, so it wouldn't release much funding.

Community forums
The chief executive thanked members for the community Forum initiative and for taking part. This was a successful venture and CAC's participation was welcomed by staff and Board.

Members commented that levels of emotion at some Forums was high. PHARMAC staff were commended for how they handled this.

PHARMAC accepts the views expressed were genuine and valuable. The community input was appreciated.

Members noted that feedback from participants was more positive than negative. Comments in the feedback survey recognised benefits and expressed appreciation of PHARMAC coming into the community. Members considered a similar programme could be looked at for the next round of consultation, perhaps including evening sessions to make them more accessible.

Members considered attendees might find the results of the feedback survey useful.

Medical devices
This work is ramping up but PHARMAC's focus remains very much on hospital medicines. Hospital medicines work has led to a lot of new investments and transactions.

Members reiterated comments made supporting the approach to hospital medicines. This will have good effects on PHARMAC's reputation.

Changing PHARMAC
PHARMAC is undergoing an internal structural change to better position it for future growth. The new structure has been decided and the aim is to have it in place from 1 December. The concept is to build a new senior leadership team, with an operational management team below it. This should not impact on how PHARMAC interacts with CAC.

PHARMAC is already seeing the impact of expanded roles on its work across the board. For example, since the establishment of hospital medicines, the flow of correspondence has doubled.

9. Te Whaioranga 2-year action plan

Members expressed their concern for PHARMAC's kaumatua Bill Kaua, who is recuperating from illness, and wished him a speedy recovery.

Members' views were sought on priorities for PHARMAC to deliver, from the draft 2-year Te Whaioranga action plan.

Members noted that while a Māori responsiveness action plan had been developed, this was not the case for the Pacific responsiveness plan. This could require additional resourcing but would

contribute to improving the health of the Pacific communities, which are similar to that of Māori. Members requested a response as to whether PHARMAC has plans to turn the plan into action.

Members noted the potential impact of PHARMAC's changed structure on the Māori health team, and expressed a desire for Māori responsiveness to continue to have a high priority in the new structure. The strategy has been signed off by the Board. Ultimately the action plan will be agreed by the Management Team, then implementation will begin. Regular reports are made to the Board on progress.

Points made by members on the draft plan:

- Cultural competency programmes for staff – at the least these should include new staff, and can then be expanded to include existing staff.
- Offer a programme to CAC – this could potentially be the He Rongoa Pai online course, or the Seminar Series.
- For health literacy, make sure language and presentation resources are appropriate for the audience. These can be adapted for Māori, Pacific, Asian audiences.
- Members discussed a proposed scholarship for Māori science students. Some expressed the view that this did not link directly to PHARMAC's business (or if there was a link, it wasn't clearly articulated). Others supported the idea of a scholarship, stating Māori or Pacific health professionals often bring a community with them and can make a real difference to health outcomes in community. Alternatively, PHARMAC could recognise or acknowledge an existing programme, for example one run by iwi encouraging uptake of science in schools.
- The approach of focussing on iwi and hapu was supported. People from outside the mainstream `health sector' could often bring in a broader or different community perspective.

10. Decision criteria consultation – next steps

The Decision Criteria is the first substantive part of the Operating Policies and Procedures (OPP) to be reviewed. The current medical devices consultation also fits within the OPP review.

Staff reflected on the community Forums. Feedback was generally positive, and staff also got a lot out of the discussions. Submissions are now being reviewed with the intention of publishing a summary before the end of the year. A further consultation with a proposed new set of criteria is likely to occur in the New Year.

PHARMAC was also mindful of a lack of Māori and Pacific engagement in the Forums and consultation process. CAC's view was sought on how this could be improved.

Members noted some Forums were dominated by people wanting to discuss issues outside the scope of the Forum agenda. Members considered it should be made clear what the specific purpose of the Forum is. Issues raised that were outside the published agenda could be acknowledged, then `parked'. The purpose of the meeting should be clear. Strong facilitation would then ensure discussion remained focussed. Members noted that PHARMAC facilitated the Forums, and recommended having a neutral facilitator, as this may enable a stronger hand to be applied to keeping discussions `on track'.

Different formats could be looked at – longer events, or evening sessions. For Pacific peoples, a good idea would be to work through churches. Pacific health providers could help organise sessions.

Developing a flyer for CAC members (as recommended earlier), could help persuade Māori to attend. Potentially CAC members could serve as a local contact to develop networks.

Members considered the location of venues is important. An approach might be to think about the type of audience being sought, then look for a venue within a community representative of that audience. Also think about the best communications channels to reach those communities. These can differ for Pacific, Chinese, Korean and other diverse communities.

11. General Business

Members noted upcoming events touching on medicine and/or consumer issues, including an Arthritis NZ public day, and Medicines New Zealand workshop on lobbying being held 14 November.

Noting papers

Noted:

Diabetes meters update