PHARMAC
Pharmaceutical Management Agency

Minutes of the PHARMAC Consumer Advisory Committee (CAC) meeting
Thursday 10 July 2014

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

Present:

Kate Russell	Chair
Anne Fitisemanu	Deputy Chair
Shane Bradbook	CAC member
Key Frost	CAC member
Maurice Gianotti	CAC member
Barbara Greer	CAC member
David Lui	CAC member
Anna Mitchell	CAC member
Lina Samu	CAC member

Apologies:

Katerina Pihera	CAC member

In attendance:

Simon England (CAC Secretary); Jude Urlich, Janet Mackay, Joy Gribben, Kerri Osborne, Caroline De Luca (PHARMAC Staff); Jo Millar, Terry King (Grey Power).

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1. Record of previous meeting (15 April 2014)

Minutes of the 15 April meeting were accepted as a true and accurate record.

Russell/Fitisemanu

2. Chair's report

This meeting marks several changes to the makeup of our committee. We farewell old friends and welcome new friends to our group. Firstly I would like to acknowledge the work of outgoing members, Anna Mitchell and Anne Fitisemanu, who both have been outstanding representatives and advocates for the consumer voice at the PHARMAC table. Anna has provided an important disability perspective to our deliberations whilst Anne has been a shining example of the connectivity that exists in the Pasifika network. I also wish to thank Anne for being such a valuable Deputy Chair for me over these past six years. We all wish you well and hope we will continue to see your faces at PHARMAC community forums and other opportunities.

We also welcome today our new members Key and Lina who, along with David, will freshen our ideas, add important new perspectives and help us to continue to provide good counsel to the Board.

The Board was pleased with the progress on the Ask 3 resource and we will be looking at ways we can coalesce with the HQSC to synergise our own work in this space with theirs.

The main PHARMAC issue that pertains to consumers over this period has been the development of the RFP for the Rare Disorders Fund. It will be interesting to note the reactions to the development of the fund from the rare disorders network over the coming weeks and whether the solution that PHARMAC is trialling will provide a permanent solution to the issue of high cost meds.

With the rolling over of July, this marks the beginning of my own final year on CAC. I started with Sandra Coney in the Chair which seems a very long time ago now. I have found this work both stimulating and an important growth experience for me in terms of my understanding of the health perspectives of multiple communities. I am sure that the new members of our group will enjoy this work as much as we all have and will find it provides perspectives to your work that can be broadly used in your practice in the community.

Again, I wish Anne and Anna all the best and a heartfelt thanks for all you have brought to this table.

Kate Russell
Chair

3. Action points

Members noted that they appreciate opportunities to attend community events with the support of PHARMAC. Members suggested a calendar is put together that could map out future opportunities for members to interact with other consumer groups/communities. Potentially this could be developed together with a display or information stand about PHARMAC. The Pacific Medical Association conference was suggested as a possible option.

Members were asked to provide suggested dates and events for inclusion in a calendar.

4. Correspondence

Members commented positively on the content and tone of PHARMAC responses, which acknowledged the writer's concerns and then answered questions. Members also commented favourably on the response time, which averaged 9.6 days for the three-month period. PHARMAC staff commented that the aim is to keep improving and to have response times down to a week.

Picking up one point in a letter, members asked if it's reasonable to expect people to try all funded options before a NPPA application can be considered. People may not want to for fear of side effects. The approach doesn't feel patient-centred. Staff explained that the NPPA policy requires options to be `reasonably' tried, this recognises there are times when it's not reasonable for people to try all funded options. It's up to the applying clinician to explain the patient's situation and why they think patients meet the prerequisites.

Members also noted that some terminology in letters could be seen as jargon by some communities, such as `funded' vs `subsidised'. A glossary could be developed for the community, and perhaps made available on the PHARMAC website.

5. Consumer question card

A draft of the consumer question card was provided to the April meeting. Following initial advice from the committee, PHARMAC staff held discussions with the Health Quality and Safety Commission

(HQSC), which is developing similar resources as part of a wider health literacy project. This is scheduled for release during Patient Safety Week in November 2014.

Members were asked for their views on how best to proceed, in light of the current investment by HQSC.

Members agreed they are keen to see the concept develop and be made available to consumers. However, given HQSC's project being in progress and comprehensive, it made sense to look to work alongside and contribute to the HQSC programme, rather than try to develop a resource in parallel. Members expressed a desire to continue following HQSC's progress and be part of the future process. Members requested PHARMAC staff inform HQSC of the CAC's view and desire to be involved, and ask HQSC to involve CAC in the development of the programme.

6. Chief executive discussion

Members received an outline of, and the rationale behind, changes to PHARMAC's internal structure. These changes are to enable PHARMAC to manage its expanded role. Changes are still bedding in, and part of that process will involve looking at how PHARMAC best uses CAC's advice.

Having a central agency involved in hospital contracting/procurement had led to some issues that PHARMAC was managing with DHBs. PHARMAC is also working on long-term budget planning for management of hospital medicines. Meanwhile PHARMAC continues to be under pressure to deliver savings and keep up performance in managing the Combined Pharmaceutical Budget, which heightens the challenging environment further.

Data and IT issues are central for success in the hospital space, underscoring the importance of PHARMAC's stated strategy for future success, `e-influence'.

This and other strategies are spelled out in PHARMAC's Statement of Intent (SOI), which is now published for 2014/15. The SOI outlines PHARMAC's strategic priorities and objectives for the coming three years, with an annual workplan outlined in the Statement of Performance Expectations (SPE). Key points for the coming year include:

- PHARMAC's work in bedding in organisational change.
- Medical devices work, which is underway and expanding. So far savings are modest, but encouraging. PHARMAC is looking at working with the DHBs to understand if there's any reluctance or barriers to uptake of national contracts. Staff noted it is difficult to compel DHBs without a system to enforce compliance. PHARMAC is looking at a pilot audit with three DHBs to see if they are compliant with the Hospital Medicines List.
- Stakeholder engagement work. This includes being a great Treaty partner and looking at what that means. PHARMAC intends running a survey on stakeholder perceptions/engagement to get a baseline.
- Monitoring medicines use by ethnicity, including a new measure around the He Rongoa Pai He Oranga Whānau programme.

PHARMAC will also be focused on meeting the Government's and Minister's expectations – this is also outlined in the SOI.

Members were invited to read the SOI and SPE and provide any questions they had to PHARMAC.

7. Communications and community engagement

PHARMAC staff sought the committee's views on PHARMAC's communications and how these could be more effective. This was useful for building a communications strategy.

PHARMAC's changing work will change the way PHARMAC tells its story – how it informs people about what it does or how people understand PHARMAC's work. An issue was how does PHARMAC communicate effectively through change?

New work in hospitals had brought PHARMAC in contact with a more complex mix of stakeholders, including groups not previously encountered such as clinical engineers. At the same time, PHARMAC had relationships with stakeholders in the community that were good, but with room for improvement.

Members outlined the various community networks they were part of or had access to:

School health	Pacific Island advisory/cultural	DHB – mental health
Mental Health Alliance across 5 DHBs	Health and Disability Pacific	Injury prevention
Disability Community	Arthritis NZ	Iwi – Board and leaders
Public health – Māori and mainstream	Dementia	Drug and alcohol
Mental health board	DHBs	Whānau ora
Mother/family	Tobacco control	Diverse NZ
Citizens Advice Bureau	Hospice	Health Consumer network – advisory
Dentists/Midwives/GPs	Health consumer 1st hand	AUT
Community worker	Pacific NGO	Health Clinic management
Pacific Board health – open forum	Church congregation and community	Auckland health
YWCA	Well Women	Pasifika links – Niuean, Cook Island
Māori Women's Welfare League	Māori health providers	Grey Power
Health and disability providers	Diabetes	Haemophilia
Rare conditions including cystic fibrosis	Suicide prevention	Mental health of Pacific islanders in both Auckland region and nationally
Nga mana o Mangere	Literacy Aotearoa	Massey University – academic health research
Pacifica national exec		

Members were asked to share their thoughts on PHARMAC's reputation and how it is perceived in the community.

Positive

- Recognition that PHARMAC has forced down the prices of medicines through competitive tendering
- Attitudes towards PHARMAC have tempered, even with those groups still not getting what they want. Less adversarial behaviour from consumer groups.

- Real consultation has occurred from PHARMAC – leads to respect
- Forums have made a big difference – led to greater awareness and understanding
- PHARMAC has shown a willingness to take criticism on the chin and help people understand.
- Media activity has heightened awareness
- Increased awareness that even though co-payment went up to $5, people are paying a lot more in other countries
- Committee minutes are available online – this leads to greater transparency.
- Seen as making medicines affordable to the public, and making funding available for elsewhere. People coming from Pacific can't believe how little people pay here.
- Perception that cheaper is not as good, this is an issue for brand switches. Information is power. People will take what they trust. PHARMAC can help with that. People are brand loyal, but this can be broken down by a trusted person such as a prescriber.

Neutral

- People don't tend to think too much about PHARMAC until it affects them. Most people are indifferent. Not really thought about until people see it on the front page.
- PHARMAC seen as just about medicines.
- Mental health and diabetes consumers very aware of PHARMAC. Mental health consumers very aware about when something changes.

Negative

- When PHARMAC says no – particularly for NPPA and rare disorders. PHARMAC is at the frontline of saying no – people blaming them know it's about budgeting and that companies base pricing on what they can get in other countries. PHARMAC ends up wearing the criticism.
- People find it hard to get into their head that PHARMAC works within a budget – could be better explained by PHARMAC.
- Some decisions seen as `inhumane' – it's not widely known that PHARMAC is very aware of human issues.
- People see drugs in other countries being available and think it's unfair it's not available here
- Media portrayal often negative
- PHARMAC is seen as powerful, but also seen as inaccessible, unaccountable, untouchable. Media doesn't help on that front.
- Media emphasises heartbreaking stories, don't usually present the wider context
- PHARMAC could make better use of imagery rather than words – humanise its decisions and communications.
- Brand switches could sometimes be a negative.
- PHARMAC did well in delivering programmes such as One Heart Many Lives. Changing to a different delivery method could be a negative. There are future plans for OHML.
- People are sensitive to price, whether caused by PHARMAC or not.
- PHARMAC is `on the wing', it wears criticism even though it may not be their doing. People blame PHARMAC rather than take responsibility
- Literacy and translations – not enough done.
- People think consultation means positive action will result – or that PHARMAC will do what people tell it to do.
- Lack of understanding about what PHARMAC doesn't do. Medsafe is invisible. Explaining PHARMAC's role and how it works with or connects with other agencies.
- How long it takes to make decisions.
- Forums can be captured by special interest groups. Can lead to conversation going off on a tangent.

Issues and actions that might make a difference

- Arthritis NZ co-operation with PHARMAC over Out With Gout programme – has been positive
- Compliance – including wastage/sharing. People can't afford to pay – so they save a little and then sometimes share with family/neighbours/whānau. Was there a way of influencing pharmacy? "What happens when the medicine gets in your cupboard?"
- PHARMAC needs to attach itself to positive programmes or messages, such as OHML.
- Proactively counter negative comments and stereotypes. Visually be in mainstream media.
- Develop Mission Impossible into a web tool; or present it at conferences, or be part of a trade stand.
- Relate messages to things people do every day – shopping lists etc. Easier for communities to understand.
- Make more videos. Make a video of the decision-maker explaining decisions. Could be powerful and help humanise PHARMAC. Telling people's stories can be powerful. Narrowcasting is an option.
- Get on Shortland St.
- Seek speaking slots at NGO conferences.
- Use existing technology – website and social media. Makes PHARMAC messages more accessible to younger audiences.

Groups or individuals that could be influential

- Send info/key messages to NGOs or community groups to include in their magazines. Or approach them to ask for regular space in newsletters. Provide PHARMAC `fact boxes'. Feed out content. Helps with cut-through as seen to be owned by the group.
- Health and disability NGO council
- Inpharmation
- Pasifika medical association is very important and influential, also Pacific nurses. Church-based programmes – four in Auckland cover hundreds of PI churches.
- Health Promotion Agency. Sends out regular updates to sector. Also MPIA
- Iwi leaders' forum could be useful although PHARMAC needs to develop a relationship that is authentic, long and sustainable.
- Educate health students – medical and pharmacy schools, nursing schools.

8. Update on implementation activity

PHARMAC is putting additional resources into supporting medicine brand changes, and there was currently a lot of activity going on. These include tacrolimus for transplants, changes to growth hormone, and upcoming changes to antipsychotics. PHARMAC is experimenting with different approaches to implementation, realising one size doesn't fit all. This includes using different languages, visual tools, videos etc.

PHARMAC is also looking at evaluating the implementation work – asking stakeholders whether what we did works and what could have been done better. This recognises different communities have different needs.

Rheumatic fever programme

The implementation team is working closely with the Ministry of Health's Rheumatic Fever Prevention Programme, and its evaluation programme. The programme is identifying that many people have co-morbidities and these are also being treated, such as skin infections.

Medication adherence is a major issue. Ways are being investigated as to how to improve adherence, such as a texting service and various incentives for patients, such as a free texting top-up for those accepting the texting service.

The use of bicillin injection, as an alternative to oral medicines, is also being explored as a way to enhance compliance. Bicillin is a once-only injection that delivers a full dose of antibiotics, which is then released slowly in the body. It would be used for those patients with recurring infection.

PHARMAC staff sought the CAC's view on using bicillin injection. It's painful, which could lead to patient refusal, but liquid pain relief can help, as could distraction techniques.

Members considered that if the injection would be an effective way of delivering a full treatment course, then it should be used. Members felt consumers often considered trade-offs when opting for treatments – this was no different.

An incentive such as a $10 grocery voucher would also be well received – particularly in Pasifika communities – although incentives may not be needed. Members commented that Pasifika parents were likely to accept the injection, as they would see that it will help the child. This was often the experience in mental health treatments and in the Pacific islands.

Members considered that the complexity of taking oral medicines could be a major barrier, and the injection avoids that complexity. There was short-term pain, but it was manageable. Providers could adjust their delivery style to provide a one-off programme. This had been done in other areas of healthcare.

PHARMAC staff advised that if large-scale use occurred this would have to be planned, as there was only one supplier in the world and there was a significant production lead-time.

PHARMAC was also looking at other ways it could support the rheumatic fever programme, such as by putting the Ministry's videos on its website.

9. Presentation by Grey Power

Jo Millar, chair of the Grey Power health portfolio, and Terry King, NZ president of Grey Power, briefed the committee on Grey Power's work and role in health.

Grey Power has 67,000 members in 70 associations nationwide. Organisationally it is broken down into seven zones, each with its own director, and each zone has a representative who sits on the Grey Power Board. All executive positions are voluntary.

Jo Millar's role is to chair a health committee of the Board. The committee is made up of members from throughout the country. Through the committee Grey Power has twice a year advocacy meetings with Government, ministers, the Ministry of Health and other sector bodies. Grey Power also seeks meetings with organisations, including PHARMAC, on an issue by issue basis.

Grey Power is branching out, its philosophy is no longer just about old people. As an example, Grey Power now has an electricity supply company, Grey Power Electricity, which has been opened up to anyone. However, Grey Power does remain focussed on people aged 50 and over.

In relation to PHARMAC, Jo Millar commented that the biggest recent issue has been over diabetes meters. She considered that learnings from the change can be used to change the way things are done in the future.

Another issue of concern to Grey Power members is medicine brand changes. People sometimes have reactions to changes, and then are faced with a large doctor's bill to have another prescription written. Grey Power members also felt this leads to wastage, as three-months of medicine can be dispensed at once. Jo Millar said a solution might be to have a trial prescription written, which could then be extended if patients adapt to the changed medicine, or the patient have a dose adjustment at reduced cost.

CAC members asked if Grey Power was aware of CARM. PHARMAC staff would provide contact information.

In addition to Government sector agencies, Grey Power also raises issues like additional charging to the Pharmacy Guild. Its key driver is to keep people healthy, which will cut the health bill down overall.

One of Grey Power's main political policies is a desire to have two free doctor visits per year for the elderly. Grey Power is supportive of children getting free visits, but would like to see it extended to elderly.

Grey Power also questioned the policy for three month prescribing, as it saw this as contributing to wastage.

CAC members commented that people could take unused medicines to their pharmacy.

PHARMAC staff commented that the rules in the Pharmaceutical Schedule allow prescribers to write scripts for shorter durations. If patients are enrolled in the Long Term Conditions system (part of the community pharmacy services agreement) they should be getting a higher level of support. Pharmacists are paid for that.

Staff considered there could be some useful articles to provide to Grey Power, about brand changes, medicine disposal, or seeking out the best deal for pharmacy services. CAC members also noted the HQSC patient literacy programme that encourages patients to ask their pharmacists/prescribers.

10. Biosimilars

CAC members were briefed on biologic medicines – those made from or of living things – and their biosimilar copies which compete with the innovator biologic product.

As more biosimilars are becoming available, PHARMAC is increasing its communications and being proactive to raise awareness about biosimilars and the regulatory process around them. The underlying message is that biosimilars are just as safe and effective as the medicines they are competing against.

Members considered that, given the complexity of the issue, it made sense to interact with specialist clinicians in the first instance. These are the people who interact with patients. If specialists are on board first, this will help engagement with consumers.

Once in the consumer space, this should be mixed up to capture a range of responses. There should be a diverse group interacted with, picking up different ethnicities, ages etc.

Members considered that PHARMAC's explanation of the technology and processes is good but probably needs further simplification for a consumer audience. A key message could be confidence

in the safety process, and the fact that biosimilars could potentially save money and help widen access.

Members considered information could be supported by Question/Answers on the PHARMAC website. This could answer potential questions around safety, health risk etc.

Members considered that, when considering the audience, PHARMAC needs to bear in mind that a disease affects more than just the afflicted person. Family members and carers are also affected – this needs to be thought about in supporting the message.

It was also possible that genetic modification would be raised – it has been a consumer issue. Religious and cultural issues may also need to be teased out. An example is imagery around cows, which are sacred in some cultures. PHARMAC should use safer imagery, such as flowers. CAC members could help advise PHARMAC on such issues.

11. Annual Review

Staff outlined plans for development of the 2014 Annual Review. This would likely explore themes around PHARMAC's expanded role and emphasise the human element of PHARMAC's decisions. PHARMAC was also investigating the format of the Annual Review, opening up the graphs and charts to make them more interactive.

Members considered that emphasising the human impact was a good place to be coming from – showing that PHARMAC was about trying to help more people, and not being `all about the money'.

Members considered it would be useful to link in Te Whaioranga to underline PHARMAC's commitment as a Treaty partner.

It would be useful to outline how many people's lives PHARMAC touches. Members advised PHARMAC to look at the impact in terms of impact on people, to demonstrate the difference PHARMAC makes. There may be little stories that highlight the human element.

Another way to introduce a human element is to outline who PHARMAC's people are – through the Board, senior staff, clinicians on advisory committees and CAC.

Another good story that would help humanise PHARMAC would be talking about the challenge of change. The audience of the Annual Review is likely to be receptive to that kind of theme and message.

Another positive message was PHARMAC connecting across DHBs through its work in hospitals.

Once prepared, members considered the Annual Review could be distributed through NGOs by sending them a link to PHARMAC's website and inviting them to share with their membership. CAC members could also assist by sending links out through their networks.

Noting papers

Noted:

Rare disorders fund – update on progress