

# **Review of Submissions on Draft Terms of Reference for the PHARMAC Consumer Advisory Committee**

**For PHARMAC**

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## Contents

1 Background .....	3
2. Methods .....	3
2.1 Consultation process .....	3
2.2 Submissions received .....	3
2.3 Coding and analysis of submissions .....	4
2.3.1 Submission questions and analysis .....	4

# 1 Background

PHARMAC is dedicated to undertaking sound consumer participation and has been working to improve consumer engagement in its activities for some time in accordance with the Government's *Medicines New Zealand Strategy*. Part of this work has been the review of the Consumer Advisory Committee's (CAC) Terms of Reference.

PHARMAC sought comments on the Consumer Advisory Committee Terms of Reference (ToR) in August 2009, and in November 2009 invited 380 organisations to provide feedback on *Consumer Participation Discussion Document: Seeking Your Views*.

In total, twenty-three submissions were received on the CAC Terms of Reference and sixteen on the consumer participation document. These submissions were analysed and used to guide a revision of the CAC ToR. Stakeholder feedback was sought on the revised ToR and the rationale for the main changes to the ToR in March 2010.

This report summarises the submissions received.

## 2. Methods

### 2.1 Consultation process

Stakeholders who had responded to the previous consultations were sent a copy of the draft ToR and a document explaining the rationale for the changes made to the ToR, and invited to provide further feedback. The draft ToR, the rationale document and invitation to provide a submission were also posted on the PHARMAC website and an email advising of the consultation and including a link to the website was sent to 225 (excluding the CAC) people.

The documents were distributed on 5 March 2010 and stakeholders were given until 1<sup>st</sup> April 2010 to provide submissions.

### 2.2 Submissions received

Five submissions were received, two from special interest consumer groups, one each from a DHB and a professional organisation and one from the CAC. No submissions were received from individual consumers, individual professionals, medical service providers, Pacific or Māori health organisations, education providers, individual academics, political organisations / parties, or health research organisations.

The submissions received are set out in the table below. The coding categories are the same as those used in the analysis of submissions on PHARMAC's *Consumer Advisory Committee Terms of Reference: Seeking your views* and *Consumer Participation Discussion Document: Seeking Your Views*. The coding is explained below.

**Table 1: List of Submissions**

Group		Number of Submissions
<b>A</b>	Individual consumers	-
<b>B</b>	Individual professionals e.g., doctor	-
<b>C</b>	Special interest consumer groups	2 submissions (C1, C2)
<b>D</b>	District Health Boards	1 submission (D3)
<b>E</b>	General advocacy associations	-
<b>F</b>	Health advocacy associations	-
<b>G</b>	Medical service provider	-
<b>H</b>	Specialist service providers	-
<b>I</b>	Professional organisations	1 submission (I4)
<b>J</b>	Industry	-
<b>K</b>	Iwi	-
<b>L</b>	Pacific health organisations	-
<b>M</b>	Education providers	-
<b>N</b>	Individual academics	-
<b>O</b>	Political organisations / parties	-
<b>P</b>	Health research organisation	-
-	The Consumer Advisory Committee	1 submission
<b>Total</b>		<b>5 submissions</b>

### **2.3 Coding and analysis of submissions**

All five submissions were reviewed and considered. Groups of organisations were ordered from A – P (see Table 1 above) and submissions were numbered from 1-4. Submissions were given a code, e.g. C1, indicating they were a special interest consumer group. The codes protect the submitters' identities while giving their comments a context.

The submission received from the Consumer Advisory Committee was not given a number and is referred to as 'the CAC'. PHARMAC thought allowing the CAC to make a submission was a transparent way of the CAC conveying its views.

This following section outlines the points raised in the submissions.

#### **2.3.1 Submission questions and analysis**

Submissions were analysed under the five questions listed in the consultation document.

Two submissions noted overall support for the Draft ToR. (C1, D3)

The other three submitters were also supportive and made specific comments on particular clauses in the proposed draft ToR.

**Question 1:**

*Do you have any comments on the rationale for CAC's role and activities as described in the draft ToR?*

Three submitters (C1, C4, D4) agreed the CAC should provide generic advice to PHARMAC with the two consumer submitters commenting on the need for individual consumers and consumer groups to continue having direct access to PHARMAC.

One recommended rewording clause 3.1.1 more positively to say 'PHARMAC will consider the recommendations of the CAC alongside other advice'. (C2)

The CAC suggested:

- Including the following vision for the Committee that the original members had developed when the Committee was established, to the description of CAC's role and activities:  
*'To ensure that the voice of consumers is effectively represented in PHARMAC decision making in order to achieve optimal health outcomes' to the aims and purpose section.'*
- the CAC's input into activities being undertaken by external agencies should be specified in the list of activities
- in addition to the phrase *'other activities as required by PHARMAC'*, the list of activities should also include *'other activities as the Committee should propose from time to time to the PHARMAC Board.'*

**Question 2:**

*a. Do you consider the activities described in the draft Terms of Reference would increase consumer confidence in, and the transparency of, CAC and its activities?*

*b. If not, why not?*

*c. What, if any, other suggestions do you have that would increase consumer confidence in CAC?*

The professional organisation suggested consumer confidence in PHARMAC would be increased by consumer representation which could give a lay member view of the topics under discussion. The submitter noted other health professional regulatory bodies and disciplinary tribunals use lay members in this way. (I4)

One consumer submitter commented on the cost of observers attending CAC meetings and requested the meeting agenda be posted two weeks prior to the meeting to assist consumers to decide if it was appropriate for them to attend. (C2)

The same submitter commented on the length of time it can take for Minutes of CAC meetings to be posted and noted it was difficult to assess the actions/input/activities from the Minutes. (C2)

This submitter was positive about CAC members engaging with consumers through representation at conferences, but noted cost may result in this not being a priority for PHARMAC. (C2)

**Question 3:**

*Do you have any comment about the proposed appointment process, membership criteria and term limits?*

**Selection criteria**

Three submitters (C1, C2, I4) were positive about the added criterion of an appreciation of the issues associated with medicine use. One submitter recommended the statement be reworded to *'demonstrate an understanding of the issues surrounding the use of medicines within the wider health context'*.

**Term of office and appointment process**

Both consumer submitters and the professional organisation supported the change to the length of CAC membership (C1, C2, I4), with one submitter also supporting the inclusions of training and review of the CAC's performance. (C1)

The CAC disagreed with limiting appointments to two three-year terms and suggested longer terms could be enabled through the inclusion of the following provision:

*'The length of both the first and second terms may be varied by mutual agreement.'*

The CAC suggested this would enable variation of appointment timeframes by mutual agreement with the PHARMAC Board.

The CAC recommended altering the wording of clause 4.1.6 to reflect that the CAC would nominate its chairperson to the Board to be confirmed by the Board.

One consumer group suggested a PHARMAC Board member be involved in the interview panel process. (C2)

**Responsibilities of board members**

One submitter recommended an additional responsibility to section 9.1 to reflect the connection of CAC members to the community, e.g. *'Engagement with consumers and consumer groups outside of the CAC meeting'*. (C2)

The CAC suggested the Terms of Reference include reference to PHARMAC's Maori Responsiveness Strategy and Pacific Strategy and describe the role of the Maori members of the Committee in PHARMAC's Maori Caucus.

The CAC suggested 7.4 and 7.5 regarding the CAC's engagement with consumers 'out and about' be moved to section 5 (Training and Support of the CAC Members) or to a new separate section.

**Meetings**

The CAC expressed disappointment over the PHARMAC Board's decision to not increase the number of CAC meetings to six per year, noting that two meetings a year does not reflect current practice.

The CAC noted the risks and impracticalities of holding remote media meetings on a regular basis and requested the circumstances when such meetings should be held be specified.

**Observers at CAC meetings**

CAC requested a distinction be made between observers and people invited to speak to, or participate in, CAC meetings.

**Question 4:**

*Do you have any comment on CAC having a role in advising on the process of funding decisions but not being involved in the decision making on specific funding decisions? Bear in mind that consumers can provide input directly into the funding decision making process by making a funding application and/or contacting PHARMAC directly about an active funding application or through consultation.*

One submitter expressed disappointment that the CAC would not participate in subsidy assessment decisions, noting access to appropriate medicines and formulations suitable for different patient groups would be appropriate for CAC involvement. The submitter said '*... there is a widely held belief that financial rather than patient considerations over-dominate Pharmac funding considerations.*' (I4)

The two consumer submitters agreed the CAC should not be involved with direct funding decisions. (C1, C2)

**Question 5:**

*Do you have any further comments on the draft ToR for CAC?*

No additional issues were raised in the submissions.