

Consumer Advisory Committee Terms of Reference: Summary of consultation comments and PHARMAC response

ToR REF	SUBMISSION COMMENT	PHARMAC RESPONSE	ACTION
2.2	The CAC suggested that the ToR should include a specific reference to PHARMAC's Maori Responsiveness Strategy and Pacific Strategy (which is in development).	We agree that the ToR should reflect CAC's role in providing advice on the implementation of strategies and policies. We consider it appropriate that this activity is described in broad terms. There are a range of strategies, other than the Maori Responsiveness Strategy and Pacific Strategy, which may change over time and on which PHARMAC may wish to seek CAC advice.	The following description of one of the CAC's activities has been modified as follows: 'how PHARMAC's implementation of <i>funding decisions, and policies and strategies</i> , including information and education related to those <i>funding decisions, policies and strategies</i> is best communicated to consumers;'
	The CAC suggested adding the following statement to the aims and purpose section: <i>'To ensure that the voice of consumers is effectively represented in PHARMAC decision making in order to achieve optimal health outcomes.'</i>	We have received feedback that suggests there is not universal understanding of the intent of this statement. Some stakeholders consider the statement suggests that CAC can represent all consumer voices. While this meaning does not reflect CAC's intention, we consider it preferable to reduce the risk of ambiguity and to clarify the primary role of the CAC as ensuring PHARMAC seeks and considers the views of consumers and considers the interests of consumers generally.	No change
	The CAC noted the ToR did not provide for the CAC to raise with PHARMAC issues that it may want to provide a consumer view on or engage in.	We agree that the CAC needs to be able to raise with the Board issues it wants to provide advice on or engage in. This new statement gives the CAC the opportunity to raise issues with PHARMAC which it considers warrant input from a consumer perspective, including those being undertaken by other agencies and maintains the ability of PHARMAC to request additional activities of the CAC.	The following description of one of the CAC's activities has been modified as follows: 'other activities required by PHARMAC, or <i>proposed by the CAC and agreed to by PHARMAC</i> '.

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	<p>The CAC noted that the ToR do not allow CAC to provide advice on work being undertaken by other agencies.</p>	<p>We consider that the provision for CAC to propose activities it wants to engage in as noted above provides for this.</p> <p>As the CAC is an advisory Committee to PHARMAC, the Committee's advice will largely be on PHARMAC's own work.</p>	<p>No change.</p>
	<p>One submitter noted disappointment that the CAC would not be involved in funding decisions.</p>	<p>Responses to earlier consultation documents did not indicate that consumer involvement in the prioritisation and funding process would greatly increase consumer confidence in PHARMAC decision-making. Though some submitters noted they would like consumer, or CAC, involvement in funding decisions, others noted that:</p> <ul style="list-style-type: none"> • the CAC would be unable to represent the views of all consumers and it would not be possible for the CAC to consolidate consumers' views into one opinion without the risk of misrepresenting the views of some consumers; • it would be unrealistic to expect consumers to put their own interests aside; • there is a risk of consumer capture by manufacturers; • confidentiality issues would be a barrier; • '<i>human considerations</i>' could undermine scientific decisions and '<i>emotions cloud the issues</i>'; and • the complexity of the science and economic factors to be considered require specialist knowledge and skills. 	<p>No change</p>

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		<p>Some consumer groups noted a preference for representing their own views through the submission process and/or direct contact with PHARMAC.</p> <p>We note that consumers and consumer groups will continue to be consulted on funding decisions issues and continue to be able to submit their views directly to PHARMAC. One of the CAC's proposed roles is to continue to advise on how PHARMAC can improve this consultation process.</p>	
3.1.1	<p>One submitter noted that the following statement in the draft ToR about the Board's consideration of CAC's advice was unnecessarily negative</p> <p><i>The CAC is an advisory committee established by PHARMAC to provide advice to PHARMAC from a consumer or patient point of view. The CAC may advise PHARMAC on matters described in these Terms of Reference, however PHARMAC is not bound to accept CAC's advice or follow its recommendations.</i></p> <p>The submitter recommended a more positive statement be included:</p>	<p>PHARMAC agrees that the description of the Board's process for considering the CAC's advice could be phrased more positively.</p>	<p>The statement has been amended as follows:</p> <p><i>'The CAC is an advisory committee established by PHARMAC to provide advice to PHARMAC from a consumer or patient point of view. The CAC may advise PHARMAC on matters described in these Terms of Reference. PHARMAC will consider the recommendations of the CAC along with other advice and information, before deciding whether to follow the CAC's recommendations.'</i></p>

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3.3.1	The CAC noted section 3.3.1 on consumer engagement seemed inappropriate in the 'remuneration and expenses' section of the draft ToR.	We agree that this section should be shifted.	<p>We have added a new section (3.3) on 'relationships with consumers' section.</p> <p>There is also an additional statement about the importance of CAC members engaging with consumers, as follows:</p> <p><i>'While noting that it is not intended the CAC represent all consumer views or act as a conduit for consumer opinion, it is important that members are able to engage with consumers to help them understand consumer/patient perspectives.'</i></p>
4.1	One consumer submitter mentioned that the CAC members needed to be aware of the place of medicines and the funding of medicines in the broader context of other treatments and the costs associated with non-medicine based treatments.	We agree that it is important that CAC membership reflect an understanding of the broader context in which medicines sit.	<p>An additional criterion has been added to the list of skills and experience required by CAC Members as follows:</p> <p><i>'... who can demonstrate an understanding of issues associated with the use of medicines within a wider health context.'</i></p>
4.1.5		We realised that more flexibility with CAC members Term duration was desirable to manage member turn-over.	<p>The statement about CAC member terms now states:</p> <p><i>'The term for CAC members will be up to three (3) years.'</i></p>
4.1.3	One consumer group suggested a PHARMAC Board member involved in the interview panel process.	The PHARMAC Board is responsible for the governance and strategic direction of PHARMAC and delegates operational matters to PHARMAC staff. Appointment of Committee members is an operational activity and is therefore appropriately undertaken by PHARMAC staff. However, the statement 'and others as appropriate' gives the Board the opportunity to be involved should it choose to do so.	No change

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4.1.5	The CAC disagreed with limiting appointments to two three-year terms and suggested longer terms could be enabled through the inclusion of a mutual agreement provision.	<p>Submitters in earlier rounds of consultation indicated a desire for CAC members to have limited terms of office and several submitters who responded to the draft ToR noted they were pleased with the limitation on the length of tenure.</p> <p>If a circumstance were to arise in the future where an extended tenure was necessary, this could be achieved under section 11 of the ToR which states that the ToR can be revised by the PHARMAC Board.</p>	No change
4.1.6		We realised after releasing the draft ToR for consultation that the ToR needed to describe the process for the appointment of the Deputy Chair as well as the Chair.	<p>We have amended the appointment provision as follows:</p> <p><i>'The Board will appoint the Chairperson and the Deputy Chairperson of the CAC, after consultation with the CAC.'</i></p>
4.1.6	The CAC recommended altering the wording of clause 4.1.6 to reflect that the CAC would nominate its Chairperson to the Board, and to be confirmed by the Board.	As the CAC is an advisory Committee to the Board, we consider it appropriate that the Board appoint the Chair and Deputy Chair. The ToR specify that the Board's appointment of these roles will occur 'after consultation with the CAC' – providing an opportunity for the CAC to express its preferences to the Board	No change
7.4		We realised we need to specify our commitment in relation to the costs associated with the activities described in the new section 3.3 Relationship with Consumers.	<p>We have included the following statement about costs:</p> <p><i>'PHARMAC will meet agreed expenses for engagement activities that PHARMAC has approved under section 3.3.'</i></p>

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8.1		We realised we needed to add a requirement associated with sign-off of the CAC minutes to assist with rapid posting of these on the PHARMAC website.	In addition to the CAC Chair's responsibility of signing off on the CAC's minutes, we included the requirement that this occur prior to the minutes being provided to the Board. This now reads: 'signing off the final version of the Minute of each meeting of the CAC in a timely manner following each meeting and <i>prior to these being provided to the Board;</i> '
9.1	The CAC suggested the ToR should describe the role that the Maori members of the Committee have in other PHARMAC meetings.	We don't consider it appropriate that the CAC ToR define the participation criteria of other groups. While Maori CAC members have the opportunity to also be members of other PHARMAC groups, there may be instances in which this is not possible (e.g. if members commitments do not allow for such participation) We consider it preferable to retain flexibility for the Maori CAC members.	No change
9.1	One submitter recommended an additional responsibility be added 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'.	We consider we have adequately described this responsibility in the new section 3.3.	See new section 3.3

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10.1	<p>The CAC expressed concern the draft ToR did not reflect its request for the number of meetings per year to be increased to six meetings and noted that it did not represent the current practice of meeting four times a year.</p>	<p>In the context of constrained resources, especially in the public sector, we consider it appropriate that the number of CAC meetings per year is driven by the existence of suitable material for the CAC's consideration rather than a requirement to meet.</p> <p>Video- or tele-conference meetings remain an alternative for single agenda items as additions to the regular face-to-face meetings.</p> <p>We will give careful consideration to the impact of any reduction in the number of CAC meetings as we need to continue to ensure the CAC fulfils its legislative role of providing advice to PHARMAC.</p>	No change
10.2.1	<p>The CAC noted remote media conferences were an unsatisfactory way of communicating, especially for Maori who prefer face to face discussion. However, the CAC also noted remote media meetings were an appropriate method for dealing with some urgent issues.</p>	<p>Remote media meetings are not intended to replace regular face-to-face meetings. We agree that the ToR should explain more clearly the situations in which remote media conferences may be appropriate.</p>	<p>We changed the wording of the section on remote media conferences to clarify how we see these occurring in practice:</p> <p><i>In some circumstances, (e.g. when there is a single agenda item that needs urgent discussion or when a member cannot attend a full meeting but may be able to take part in the discussion on particular agenda item(s)), it may be appropriate for the CAC to hold a meeting by contemporaneously linking together by remote media conferencing (such as teleconference or videoconference).</i></p>

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10.3.1	<p>One of the consumer submitters noted there would be costs both in the time and resources involved in attending CAC meetings as an observer. This submitter suggested consumer groups would need to see the agenda of meetings in advance to see if any agenda items were of particular concern to them. This would help consumers decide when, and if, it was worth the considerable resource involved to attend the meetings. The submitter suggested two weeks in advance of the meeting was an appropriate timeframe.</p>	<p>We agree that consumer groups will need to be able to identify whether any items on the CAC agenda are of interest to them.</p> <p>We also thought we should clarify our view that observers would normally be expected to meet their own costs.</p>	<p>We have included the following provision in the Terms of Reference to enable consumer observers to identify items of interest:</p> <p><i>'Meeting dates for the year will be published on the PHARMAC website at the beginning of each calendar year and the agenda for each meeting will be posted on the website two weeks prior to the meeting to assist observers to decide whether or not any agenda items are relevant for them.'</i></p> <p>The following statement in relation to costs has also been added:</p> <p><i>'Observers would normally be expected to meet the costs of their attendance.'</i></p>
10.3.5	<p>The CAC noted that from time to time individuals/groups are invited to either present to, or participate in the discussion at meetings. The Committee asked that the ToR clarify the difference between observers and invitees.</p>	<p>We agree that the ToR should be clearer about the distinction.</p>	<p>This new statement covers the distinction between those who attend meetings as observers and those invited to participate:</p> <p><i>'The CAC Chair may also invite representatives from consumer or other groups to present to the CAC and/or to participate in the Committee's discussion on a particular issue if the CAC is interested in that group's view on that issue.'</i></p>
13.1		<p>We considered we needed to more clearly communicate what the implementation of the new Terms of Reference would mean for current Committee members.</p>	<p>We have amended the transitional provisions as follows:</p> <p><i>'Each member of the CAC in office at the commencement of this Terms of Reference may continue in office for the remainder of his or her current term of appointment.'</i></p>