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Via email: consult@pharmac.govt.nz

BCAC feedback to PHARMAC on proposed changes to advisory committees

The Breast Cancer Aotearoa Coalition (BCAC) is pleased to see PHARMAC seeking input on how its advisory committees operate, with the aims of bringing consumer perspectives to the committees, enhancing diversity and strengthening health equity knowledge within the committees.

Consumer Advisory Committee

The purpose of Pharmac's Consumer Advisory Committee (CAC) as defined in the revised Terms of Reference is to "provide input from a consumer or patient point of view, specifically to provide advice and to work with PHARMAC to enable the views and perspectives of consumers to be integrated into PHARMAC's work".

1. Since the formation of BCAC in 2004, we have not observed CAC adding any value or meaningful advice for breast cancer or any other patients. CAC does not communicate with affected stakeholders, i.e. individual patients or patient groups representing users of medicines or medical devices, but appears to act as a lay group with no apparent influence on Pharmac's operations or assessments. The absence of any connection to the consumers and patients affected by decisions means that the group is unable to provide any meaningful advice or input. Neither does CAC appear to have had any other input into Pharmac's operations, assessments or decision processes. If the members of CAC are to have any meaningful input then its ability to provide advice needs to be strengthened and the opportunities for this clearly defined.
2. The proposed Terms of Reference define consumers as any person who uses *or may use* a health and disability service or their whānau, support persons, groups representing people with a condition or with a community perspective or world view. This broad definition could potentially see membership of CAC extended to anyone regardless of any lived experience, knowledge or expertise on significant diseases or affected people. The committee would have a greater ability to represent patients if it consisted of people who are actually patients or their representatives, with a knowledge of a disease and the ability to represent others affected. The definition of consumer should be refined to better reflect the role of providing advice that is genuinely from the perspective of affected patients rather than a generalised "consumer".
3. In order to provide meaningful advice and input into Pharmac's work, CAC members should be required to have appropriate knowledge or expertise from a patient perspective.

Members of CAC should be drawn from individuals who have been nominated by groups representing patients. Additionally, the committee should be required to consult those needing a particular medicine or medical advice under consideration, both through recognised patient groups and individual patients. At the end of this submission we provide examples of groups that could provide credible patient representation.

4. CAC members should be trained to undertake their role of patient consultation and representation effectively.
5. BCAC believes Pharmac's committees, including the Specialist Subcommittees (Specialist Advisory Committees) and PTAC, should each have a representative from CAC as a member. These consumer members should additionally contact affected patient groups to seek a representative to attend appropriate parts of these meetings to provide direct and genuine advice from the patient perspective. The CAC member's role would be to support such representatives by informing them of the opportunity to present advice and evidence on patient experience and the format required for such input. They should accompany the representative to the relevant meeting and act as a "buddy" and supporter during the meeting. It should be clear that the CAC member is there to genuinely represent patients and facilitate the provision of patient information.
6. CAC should proactively advise Pharmac on how it should develop better consumer interaction to influence policies, strategies and behaviour that will ensure a consumer-centric approach to provision of medicines and devices in the future. This should be an ongoing and meaningful role for CAC.
7. Clear Key Performance Indicators should be defined for CAC and performance against these reported on regularly. A record of consultation and representation of affected patient groups should be shared publicly.

Strengthening Clinical Advisory Committees

1. The changes proposed in membership are welcome but do not go far enough. In particular, BCAC supports the inclusion of a consumer representative on both PTAC and its Specialist Advisory Committees. We would like to see PTAC and its Specialist Advisory Committees having a core membership, which includes a permanent consumer representative. In addition, experts in the disease area (such as clinicians who have been involved in clinical trials) and consumers in the disease area under discussion are brought in to provide their knowledge, experience and insight when particular treatments are under consideration. This could easily be done via video-link for particular items under discussion. Such expertise could be sought beyond New Zealand if necessary. BCAC believes a more flexible approach to garnering expertise would greatly contribute to the quality of PTAC recommendations, as it would help bring all the "Factors for Consideration" to light in discussions.

The inclusion of consumer representatives as permanent members of PTAC and its Specialist Advisory Committees, augmented by our proposal to draft in suitable advisors for particular topics, will improve the provision of patient perspective in the advice process. This will not necessarily improve decision-making as this takes place in Pharmac, not its committees. This is an element of the process outside of the scope of this consultation but worthy of examination. It is not clear if changes proposed will improve health equity as defined by

Pharmac. Increasing diversity on committees is desirable and should not be at the expense of getting the best expert advice on a particular issue.

We are concerned that both PTAC and Specialist Advisory Committees should be able to include those working in the private sector as well as the public sector. The best experts should be sought, irrespective of their place of employment.

2. A consumer representative should be nominated by patient organisations and could additionally be a member of CAC, if that group's membership consists of people with appropriate background, knowledge and skills. The person can be inducted into the role by the Chair of PTAC. Some training may need to be provided. This person would have the role of representing the patient view and also supporting the patient representative before and during meetings (see suggestions on CAC above).
3. Pharmac should consider employing a consumer advocate on staff, additional to CAC, who could facilitate liaison with patient groups, CAC and the PTAC and Specialist Advisory Committee Consumer representatives.
4. BCAC would like to see PTAC and its Specialist Advisory Committees provide much more advice to Pharmac – beyond the current system of providing advice on applications for funding. They should be providing Pharmac with advance knowledge across particular disease areas, so they can plan for future developments, rather than just react to submissions. This should be coordinated with budget setting processes, so that the current situation whereby multiple treatments designated as priorities by the clinical community cannot be funded due to limited budget – essentially because of poor forward planning. We would see PTAC and the Specialist Advisory Committees enabling Pharmac to become more proactive in addressing health outcomes needs of all New Zealanders, particularly in the era of specialised medicines becoming available.
5. Another important issue that has not been mentioned in the consultation is the timeliness of committee meetings and procedures for circulating minutes (or Records of Advice). The time taken to publish minutes is far too long. They should be circulated within weeks – not months after the meeting. This applies to both PTAC and Specialist Advisory Committees meetings.
6. Meetings also need to be organised in a timely manner. PTAC meets four times yearly, but Specialist Advisory Committees meetings do not take place regularly, if at all in some cases. There should be regular meetings and the committees' role should be widened to proactively review current and future developments in a therapeutic area at least once a year. Currently, they only meet when there are enough agenda items to justify a meeting. This causes significant delays in obtaining appropriate advice and recommendations. In this age of virtual meetings, there could be meetings held without the need to wait for a full agenda. BCAC suggest that the current delays undermine the confidence of consumers in the decision-making process and Pharmac.

Patient groups that could offer representatives for PHARMAC committees and considerations

The following list is by no means exhaustive, but provides examples of groups that could offer members who could genuinely represent patients on PHARMAC committees and in its consideration processes and meetings. We suggest PHARMAC seek representatives from such groups to ensure patient perspective is genuinely represented in all processes.

Allergy NZ, Arthritis NZ, Asthma NZ, Amyloidosis Patients Association NZ, Brain Tumour Support NZ, Breast Cancer Aotearoa Coalition and its many member groups, CLL Advocates NZ, Cure Ovarian Cancer, Cystic Fibrosis NZ, Diabetes NZ, FACS NZ, Gut Cancer Foundation, Head and Neck NZ, Heart Foundation, Leukaemia and Blood Foundation, Lung Foundation, Lysosomal Diseases NZ, Melanoma NZ, MND NZ, Multiple Sclerosis NZ, Muscular Dystrophy NZ, Myeloma NZ, NZ AIDS Foundation, NZ Pompe Network, Ovarian Cancer Awareness NZ, Parkinsons NZ, Prostate Cancer Foundation NZ, Rare Disorders NZ, SMA NZ, Tahu Hikuroa Foundation, Talk Peach, Unicorn Foundation NZ.