

# PHARMAC CONSUMER VOICE CONSULTATION – NZORD RESPONSE

NZORD congratulates PHARMAC on recognising the need for review of the current Consumer Advisory Committee (CAC) and commitment to reformulating the CAC to enable real structural change.

## **1. Are there parts in this process where consumer input could be incorporated or changed?**

The patient voice should be included from the start of the process to ensure equity for all people requiring Pharmaceutical treatment in New Zealand. NZORD would envision this occurring at key points throughout the current process, including membership of the CAC.

## **2. What should the nature of that input be (e.g. inform, consult, involve, collaborate, empower)?**

A joint partnership between PHARMAC and patient groups will ensure a fairer outcome for patients in New Zealand. Broad consumer representation and collaboration will improve transparency and raise trust (of consumers) in PHARMAC's statutory objectives detailed in the 'Factors for consideration'. This equitable and fair system makes for greater engagement and more effective decisions.

There should be patient input into all funding decisions, with an agreed weighting such as 5%. There must be a clear requirement to report back to stakeholders to ensure a fair and transparent process.

## **3. How do you suggest PHARMAC should seek this input?**

There needs to be specific seats of membership for patient groups on the new CAC, for example, three permanent seats. NZORD suggests that the representative for each seat have a fixed term as part of the Committee, and be voted in by the patient groups they represent.

These representatives could be required to connect with stakeholders and report back to patient groups regularly through written reports and annual meetings. This way patient groups will be able to have clear input into PHARMAC's processes, particularly around funding. This transparency is vital to ensure all needs are considered.

## **4. How do you think it would help improve the quality of PHARMAC's decisions?**

NZORD believes that ensuring the patient voice is part of the process will make a difference to the health and wellbeing of patients with rare disorders, who are currently institutionally discriminated against through the purchasing process.

New Zealand lags far behind other countries in funding medicines for rare disorders.

## **5. How could the consumer voice be better incorporated when we change the brand of a medicine?**

Patient group membership of the Committee will ensure these views are represented. In addition, any changes that will affect a specific community could be discussed and shared for issues prior to progressing to a definitive change. There may be practical challenges with a new brand that have detrimental health consequences that may alter PHARMAC's choice of preferred provider, for example ostomy products.

## **6. Does the consumer voice need to be enhanced in any areas of the above areas of work? If so, how?**

Although patient factors such as health benefits and need appear to be part of the factors for consideration as part of the decision-making process, they don't seem to be given as much weighting as cost considerations.

These health benefits need to have an equitable weight along with input from health economists.

## **7. How would it help improve the quality of PHARMAC's work?**

PHARMAC's role is to make decisions on which medicines and medical devices are funded in order to get the best health outcomes from within the available funding.

Patients with rare disorders are discriminated against by being considered as part of the "general pool" of funding applications and have poorer health outcomes compared to the general population as a result. PHARMAC would be enabled to deliver more equitable and thus quality health outcomes to rare disease patients by considering their input into funding decisions.

## **8. What should membership on the CAC look like?**

Patient groups should have specific seats of membership on the Committee to ensure representation at all stages of decision making, including broad funding decisions.

## **9. What skills, experience or characteristics you think members of the CAC should have?**

These patient group representatives will be voted in by patients and will need to be able to represent their views clearly, as well as report back the Committee's findings.

Skills include:

- Good communication skills
- Ability to understand technical documents
- Understanding of PHARMAC and government processes
- Understanding of patient issues and specific needs

**10. What role do you think the CAC can have in supporting PHARMAC to ensure it is receiving and considering consumer's views and perspectives?**

The Committee has an important role in communicating the health needs of patients for consideration by PHARMAC. At its most functional the CAC needs to be a two-way conduit on information from the community to PHARMAC with high public and sector visibility.

**11. Are there consumer voices that are not represented?**

The views of rare disorder patient groups are currently not represented in the decision-making process.

**12. Are there examples that you are aware of, where the consumer voice is well represented?**

Mental health providers gain consumer engagement throughout their organisational structure to ensure their voice is not only represented, but also heard and acted upon. Many of these organisations have interview panel representation, board positions, workshop brainstorming etc. This allows for a positive and beneficial respected consumer view and input.

SUBMITTED BY NEW ZEALAND ORGANISATION FOR RARE DISORDERS

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