

**Minutes of the
Consumer and Patient Working Group Meeting
Thursday 4 December 2025**

The meeting was held online from 2pm to 4pm.

Present:

Chris Higgins (Acting Chair)
Tim Edmonds
Francesca Holloway
Trent Lash
Gerard Rushton
Tracy Tierney

Reset programme team

Jannel Fisher (Reset Programme Manager), Sarona Iosefa (Reset Programme Engagement Lead), Sam McCarthy (Reset Programme Project Manager), Becky Littlewood (Reset Programme Coordinator)

Pharmac staff

Caroline De Luca (Manager, Expert Advisory), Melissa Copland (Clinical Lead - Medicines Management, Expert Advisory), Jayne Watkins (Principal Advisor - Pharmaceutical Funding)

Apologies:

Malcolm Mulholland (Chair)
Rachel Smalley (Deputy Chair)
Deon York
Libby Burgess

1. Karakia and welcome

Opening by the Chair

2. Minutes of previous meeting

Minutes of the previous meeting minutes were approved.

- Moved by: Francesca
- Seconded by: Gerard

3. Action items

Approved.

4. Interest register

No new declarations or changes were made.

5. Embedding lived experience

Members began the discussion by clarifying how lived experience is currently included. They noted an overlap between previous consultation discussions and today's focus. Pharmac clarified that this discussion centres on strengthening the consumer voice within the expert advice stage, while acknowledging that some consultation actions – such as organisational frameworks and future consultation principles – remain relevant.

Members highlighted that patient-led applications are challenging and require significant input from Pharmac. They queried the success rate of these applications. Pharmac noted patient-led applications often help to identify unmet health needs.

It was clarified that a consumer member was appointed to PTAC in July 2022. This role is currently held by the CAC Chair, who participates as a consumer rather than in their CAC Chair capacity. Pharmac also has two consumer members providing a non-clinical lens on expert advisory committees. Members observed mixed feedback on the citizen approach. Pharmac acknowledged some challenges due to the generalised nature of consumer member role.

Members emphasised the gap between clinicians' understanding of conditions and patients' lived experience, noting that wellbeing aspects are often overlooked. One member suggested using the term "lived expertise" rather than "lived experience", as experience is only one component of expertise.

Members noted progress over the past year; however, current efforts remain insufficient. Consumers continue to experience uncertainty about how their input will influence outcomes, limited engagement opportunities that often occur too late in the process, and emotional and practical barriers that make participation difficult.

Members engaged in a constructive discussion on opportunities to strengthen the embedding of lived experience, guided by pre-meeting questions. While some question summaries were considered relatively high level, they were viewed as helpful in maintaining momentum and enabling a focused, forward-looking conversation.

Members highlighted that having consumer representatives on Pharmac's advisory committees builds trust and accountability. They discussed balancing continuity of consumer presence with disease-specific representation and suggested leveraging advocacy groups to source patient voices. It was proposed that citizen members could provide neutrality, provided their scope is clearly defined. Their role could include ensuring that first-hand patient perspectives are not overlooked.

Members discussed practical ways for Pharmac to demonstrate how lived experience informs assessments and decisions. Suggestions included publishing clear "what we heard and what we decided" summaries and transparent guidance on how lived experience is used. The group acknowledged the tension between additional documentation for transparency and maintaining timely decisions, with one member noting that transparency is more important than timeliness in this area.

Members emphasised the need for clear, practical guidance to support consumers, including confidentiality assurances, plain language explanations, and flexible submission options. Members agreed that keeping people engaged now, while working on longer-term improvements, is essential.

Agreed action:

- *Pharmac will provide data on the proportion of consumer-led applications that are successful and report back to the group.*
- *Pharmac will return with proposed actions based on members' suggestions and questionnaire results while also ensuring best use of resources.*

6. General business

OFI update

Overall feedback on Pharmac's proposal to remove some medicines from the OFI was largely unsupportive, with concerns that the OFI proposal is out of step with the Reset Programme. Pharmac is reviewing alternative options and preparing a Board paper. The proposal will go to the Board for a decision. Pharmac confirmed that a public update will be issued before the holiday break and published on its website.

Quarter three 90-day actions

Members discussed proposed quarter 3 actions, which are based on priorities previously raised by members and Pharmac's planned work with a significant impact on patients.

Proposed actions:

- Exceptional circumstances framework, including NPPA
- Timeframes and reporting for the medicine funding application process
- Trialling new approaches to clear the current application backlog
- Planning for the four-year improvement programme.

Members cautioned that the pace of 90-day plans risks insufficient time for completing actions and stressed the need to avoid overpromising. Pharmac confirmed detailed planning is in place to ensure deliverability and accountability.

A February working group meeting will explore what future consumer involvement should look like beyond June 2026 to support the four-year improvement programme, forming part of a broader consumer framework. The agreed approach will need endorsement by the working group.

Quarter three 90-day actions endorsed:

- Moved by: Tracy
- Seconded by: Gerard
- No objections

Close of meeting at 4.00pm.

Next meeting is 2.00pm – 4.00pm on Thursday 18 December to progress action items.