

Minutes of the Consumer and Patient Working Group Meeting Thursday 15 January 2026

The meeting was held online from 2pm to 3.45pm.

Present:

Malcolm Mulholland (Chair)
Rachel Smalley (Deputy Chair)
Libby Burgess
Tim Edmonds
Chris Higgins
Francesca Holloway
Trent Lash
Gerard Rushton
Tracy Tierney
Deon York

Reset programme team:

Jannel Fisher (Reset Programme Manager), Becky Littlewood (Reset Programme Coordinator)

Pharmac staff attendees:

Susan Melvin (Senior Policy Advisor), Rose Simpson (Policy Manager), Lauren Romanos (Senior Exceptions Advisor), Chris Gilman (Senior Exceptions Advisor)

1. Karakia and welcome

Opening by the Chair

2. Minutes of previous meeting

Minutes of the previous meeting minutes were approved.

- Moved by: Trent
- Seconded by: Chris

3. Action items

Action items were noted. The group discussed Pharmac's four-year improvement programme and noted the need for further consideration of scope clarity.

4. Interest register

No new declarations or changes were made.

5. Exceptional Circumstances Framework

Members welcomed the review of the Exceptional Circumstances Framework, noting it was long-requested by consumer advocates.

Feedback provided ahead of the meeting was discussed, including general questions about the framework. Members sought clarification on several aspects of the current process, including application outcomes, funding, patient need, and specialist input. Concerns were raised about inequities, particularly for people living rurally.

The discussion highlighted areas where greater clarity and consistency are needed in the documents. The scope of the review was confirmed as broad, including the principles.

There was general support for the proposed engagement approach, with suggestions to include a wide range of stakeholders such as Rare Disorders support groups, suppliers, rural clinicians, and people who have had both positive and negative experiences with the process. Members stressed the importance of clearly articulating Pharmac's intent and approach within the consultation.

Agreed actions:

- The discussion document will be updated to reflect member feedback and suggestions.
- Written responses will be provided to address pre-meeting questions from members on the Exceptional Circumstances Framework.
- Members will email details of long-term conditions organisations or other stakeholders to be added to the consultation list to the Reset Programme inbox.

6. General business

Members discussed the upcoming face-to-face meeting on 29 January. The meeting will include facilitated workshops, with pre-reading circulated in advance. The morning will focus on building shared understanding of Pharmac processes and the fundamentals of the advice and assessment model. The afternoon will involve a workshop to support the design of the four-year improvement programme.

The application backlog pilot, along with prioritisation and decision-making topics, will be progressed separately in future sessions.

Agreed actions:

- Reset Programme Team to circulate the updated agenda finalised by the Chair and Deputy Chair.
- Reset Programme Team to provide members with the terms of reference for the clinical advisory groups, including PTAC.
- Reset Programme Team to send members a consolidated list of meeting dates and required actions.
- Application backlog pilot topic and prioritisation and decision-making topic to be added to future meeting agendas.

Close of meeting at 3.45pm.

Next meeting is an all day workshop from 9.00am – 4.00pm on Thursday 29 January