

28 May 2025

Meeting summary

The Neurodegenerative, Palliative Care and Rare Diseases (NPR) Advisory Group met online on 28 May 2025.

The Chair, Ms Olivia Nassaris, CEO Parkinson's Australia, welcomed everyone to the meeting.

Focus of the meeting

The meeting covered:

- A summary of consultation on the Impairment Mapping Guide.
- An update from Scheme Eligibility Branch.
- An update on funding periods for old framework plans.

Summary on the Impairment Mapping Guide

The NDIA Participant Outcomes, Evidence and Evaluation Branch shared a summary from external consultation on the Impairment Mapping guide.

Members suggested to include reference in the Notice of Impairment letters, outlining that the NDIA is aware that participants' conditions may change over time.

Update from Scheme Eligibility Branch

The NDIA Scheme Eligibility Branch shared an update on timeframes to understand blockages to access, the early intervention pathway and evidence for access requests.

The priority access decision pathway was discussed.

Members discussed when applying for access, people may not be aware of the specific language to use or how to be explicit in asking for a priority access decision and suggested that further support and guidance on how to access this pathway would be beneficial.

Further member feedback included the importance of workforce training for NDIA delegates on early intervention. Early intervention can slow down progression of conditions and reduce symptoms, which is cost saving in the long term.

Update on funding periods for old framework planning

The NDIA Scheme Policy Branch shared information with members about how budgets will be arranged between flexible and non-flexible funding, under old framework planning.

Members queried the appropriateness of shorter funding periods for people with neurodegenerative conditions, those who require palliative care and people with rare diseases. Members also discussed impacts on participant choice and control, and reduced flexibility to manage the projected, but unpredictable progression of conditions.

Members would like further information about the training for delegates in the decision making for funding periods and in communicating the change to participants and it was agreed that this would be discussed at a future meeting.

NPRAG next meeting

The next meeting of the Neurodegenerative Palliative Care and Rare Diseases Advisory Group is on 5 August 2025.

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