# CASE STUDY

# Working alongside people with intellectual disability to improve health outcomes

**Listen to Me project, Macquarie University**

## The reseach and its impact

In 2018, a team of lived experience researchers, clinicians, and academics at the Australian Institute of Health Innovation at Macquarie University started collaborating to design research to improve healthcare quality for people with intellectual disability and help them to share their experiences. One way that patients can provide feedback on their experiences is through patient reported experience measures (PREMs).

PREMs use feedback from patients to improve healthcare services. They are usually conducted as surveys. PREMs assess things like whether a patient felt safe, listened to, and cared for. They also help to identify harm and distress caused by healthcare.

In 2022, Professor Reema Harrison and her team reviewed PREMs that are currently used in healthcare, and found a major gap:

- No PREMs had been designed for or with people with intellectual disability.
- Existing PREMs were not suitable for use by people with intellectual disability because:
  - the surveys had too many questions (as many as 80)
  - the language was too complex
  - the surveys did not have features that make them easier to use, like large checkboxes and images.

In 2024, Macquarie University received a grant supported by funding from the Australian Government Department of Health, Disability and Ageing under the Medical Research Future Fund (MRFF) and launched the Listen to Me project. People with intellectual disability are leaders within the Listen to Me team and work alongside clinicians and academics. A major piece of work undertaken by the Listen to Me team was developing a new PREM survey designed for people with intellectual disability for use in Australian hospitals. This survey:

- has a small number of targeted questions (8)
- was co-designed and tested by people with intellectual disability, their families, and carers
- is available digitally and can be completed using accessible audio and visual features.

By including people with intellectual disability in developing the PREMs, the researchers made sure the survey is able to be understood and completed by people with intellectual disability. This means that people with intellectual disability can more easily share their healthcare experiences and ultimately benefit from subsequent improvements to healthcare.

> *"Professor Harrison pioneers innovative approaches to support consumer contributions such as including people with intellectual disability as chief investigators on grants where concepts have been co-initiated, and workshops with specific support mechanisms for people with disability to attend and contribute."*

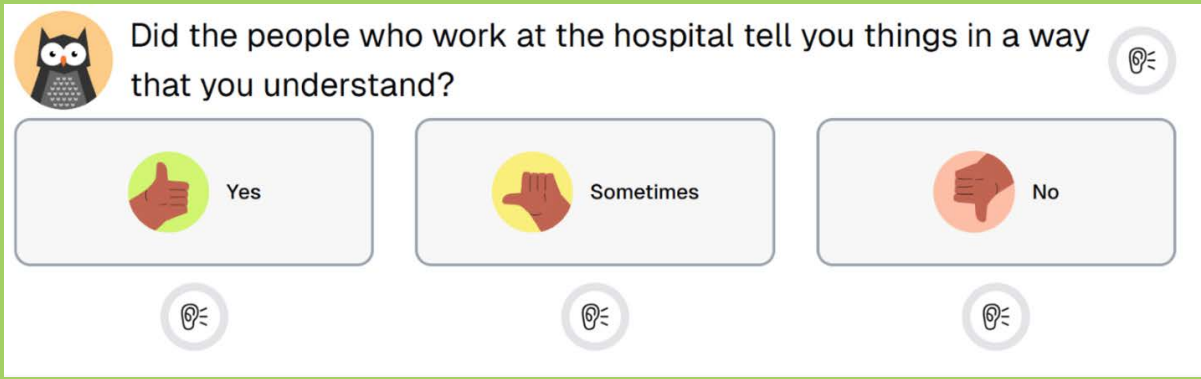
Professor Sakkie Pretorius, Deputy Vice-Chancellor (Research), Macquarie University

NHMRC

## What is intellectual disability?

Intellectual disability is defined by limitations to a person's intellectual functioning and adaptive behaviours. It can cause difficulties with communication, memory, understanding, and problem-solving. Support and adjustments can help people living with intellectual disability to actively participate in society, including in health and medical research.

## Sample PREM question




The new PREM survey helps people with intellectual disability tell people how they feel about their healthcare. In the future, the new PREM survey might be used in lots of hospitals. This will help more people to get the care and support they need.

Coproduction group members