

CASE STUDY



Helping people with intellectual disability talk about their healthcare

In 2018, a group of people with intellectual disability, doctors, and researchers started working together at Macquarie University. They wanted to make healthcare better for people with intellectual disability. They also wanted to make sure that people with intellectual disability can talk about how they feel about their healthcare.

One way to do this is through something called PREMs. That stands for **Patient Reported Experience Measures**

What are PREMs?

PREMs are surveys that ask patients how they felt when they received health care. The surveys ask questions like:

- Did you feel safe?
- Did the doctors and nurses listen to you?

What was the problem?

In 2022, Professor Reema Harrison and her team looked at the PREMs that are used in healthcare. They found some big problems:

- The surveys had too many questions
- The words used in the survey were hard to understand
- The surveys did not have helpful things like pictures.

These problems meant that the surveys were hard for people with intellectual disability to complete. If people with intellectual disability cannot complete the surveys, their feelings cannot be shared with people who can make healthcare better.

What happened next?

In 2024, Macquarie University started a new project called [Listen to Me](#). People with intellectual disability worked with researchers to make the PREMs better. Together, they made a new survey. This survey is easier for people with intellectual disability because:

- It only has 8 questions
- It uses simple language
- It has pictures that make the questions easier to understand.

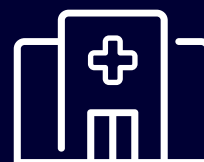
A person with intellectual disability might have trouble with:

- Understanding things
- Talking and communicating
- Remembering things
- Solving problems.



With the right support, people with intellectual disability can participate in lots of activities, including research.



Healthcare helps people stay healthy or get better when they are sick. It might include:



- Going to the doctor
- Going to the hospital
- Taking medicine.





Here is one of the questions from the new survey:

 Did the people who work at the hospital tell you things in a way that you understand? 

 Yes 

 Sometimes 

 No 

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.

Here are some photos of the team working together:

