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Listen to Me Study: Making and using a digital survey to collect Patient Reported Experience Measures (PREMs) with and for people with intellectual disability

Dr Beth Catlett, Maya Tokutake: Australian Institute of Health Innovation
On behalf of Listen to Me Project team

24th September 2025

Acknowledgement of Country

THE ARTWORK CIRCLES OF THE NIGHT SKY IS CREATED BY PROFESSOR LIZ CAMERON, DHARUG WOMAN AND MACQUARIE UNIVERSITY ALUMNUS

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We respect the Traditional Custodians of the land where Macquarie University is where most of this work took place

•The Wallumattagal people of the Dharug Nation

•They have cared for this land for a very long time

•We respect the Traditional Custodians of the lands where we are today

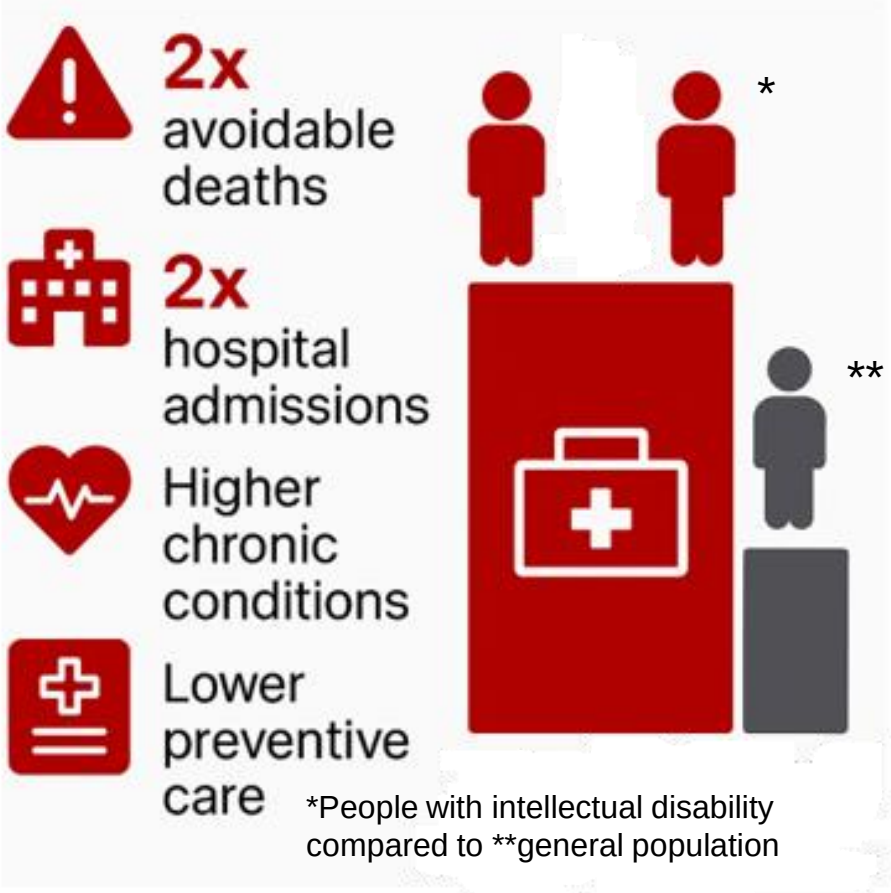
•We also warmly acknowledge any Aboriginal and Torres Strait Islander people joining this meeting in person and online

•We pay our respect to Elders past, present and emerging

What Will We Talk About

- Why healthcare feedback is important - PREMs
- What is “Listen to Me”?
- How we did inclusive research
- How we made the ePREM together
- A video showing the ePREM in use
- What’s next for the project

Introduction



Contents lists available at ScienceDirect

Seizure: European Journal of Epilepsy

journal homepage: www.elsevier.com/locate/seizure

Mortality rate, risk factors, and causes of death in people with epilepsy and intellectual disability

Peiwen Liao [a], Claire M Vajdic [b,d], Simone Reppermund [*,a,c], Rachael C Cvejic [a], Preeyaporn Srasuebkul [a], Julian N Trollor [a,b]

Open access Cohort profile

BMJ Open

Health and wellbeing of people with intellectual disability in New South Wales, Australia: a data linkage cohort

Simone Reppermund,[1,2] Theresa Heintze,[1] Preeyaporn Srasuebkul,[1] Rebecca Reeve,[3] Kimberlie Dean,[4,5] Melinda Smith,[5] Eric Emerson,[6] Phillip Snoyman,[7] Eileen Baldry,[8] Leanne Dowse,[3] Tracey Szanto,[9] Grant Sara [10,11] Tony Florio,[1] Anina Johnson,[12] Melissa Clements,[13] Kathryn McKenzie,[14] Julian Trollor [1,2]

DMCN Developmental Medicine & Child Neurology

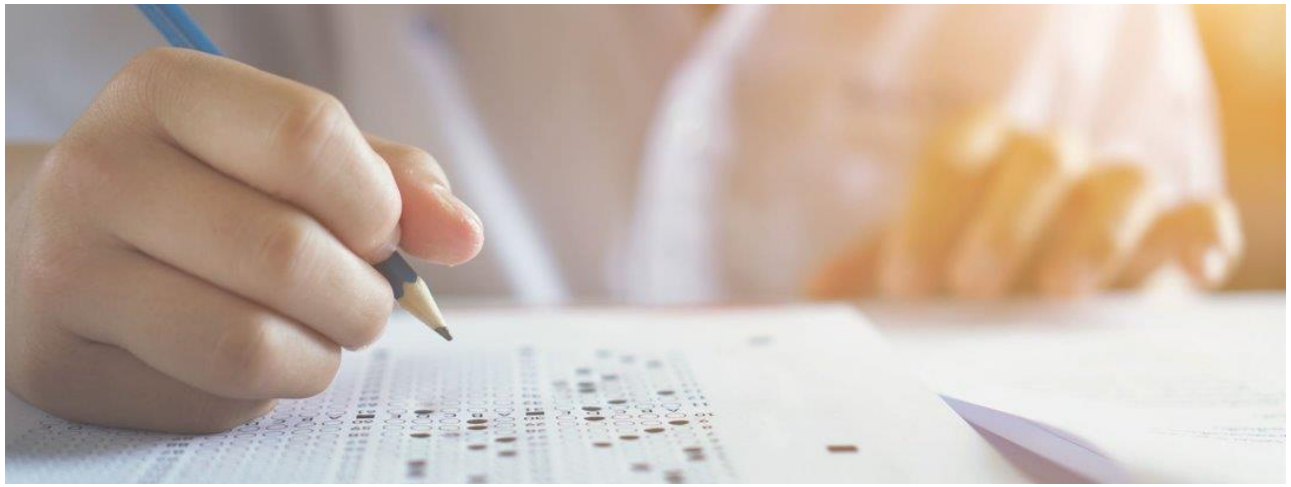
Original Article | Open Access

Inequities in quality and safety outcomes for hospitalized children with intellectual disability

Laurel Mimmo, Reema Harrison, Joanne Travaglia, Nan Hu, Susan Woolfenden

Introduction

What are Patient Reported Experience Measures surveys (PREMs)?



PREMs are questions about your health care experience.

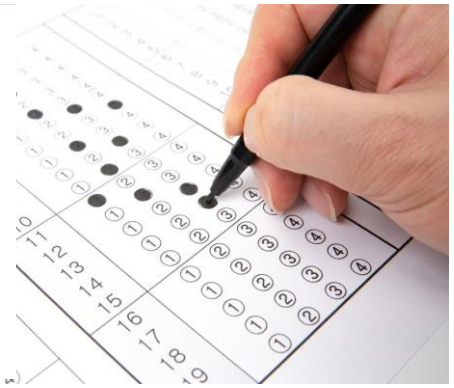
They ask what it was like for you when you got care.

PREMs ask things like:

Did the staff listen to you?
Was it easy to get an appointment?
Were things explained clearly?

Introduction

Why are PREMs surveys sometimes difficult to complete?



- They only have words. No pictures or audio
- The writing is small and hard to read
- They have complicated instructions or confusing questions
- You must finish the whole survey in one go
- They often have too many questions (50 to 80 questions)

ScienceDirect

Contents lists available at sciencedirect.com

Journal homepage: www.elsevier.com/locate/jval

Systematic Literature Review

Measuring Healthcare Experiences Among People With Intellectual Disability: A Rapid Evidence Synthesis of Tools And Methods

Reema Harrison, PhD, Corey Adams, RN, Bronwyn Newman, PhD, Laurel Mimmo, PhD, Rebecca Mitchell, PhD, Elizabeth Manias, PhD, Megan Alston, RN, Anne-Marie Hadley, PhD

Introduction

How can we make PREMs surveys inclusive?

Co-design and Co-production

People with intellectual disability or supporters

- Co-design: People help make the survey
- Co-production: People are involved from start to finish

Ways to give feedback

- **Visual:** Emoji's, Yes or No, Stars
- **Audio:** Listen to the questions
- **Verbal or plain language**
- **Phones, computers**

What Is listentome

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Why does Listen to Me matter?

- People with intellectual disability often miss out on the care they need.
- We need to hear their views on care so we can improve it together.

Why is this a challenge?

- PREMs Questions are hard for some people with intellectual disability.
- If they can’t answer, hospital leaders don’t hear their views.

What Is listentome

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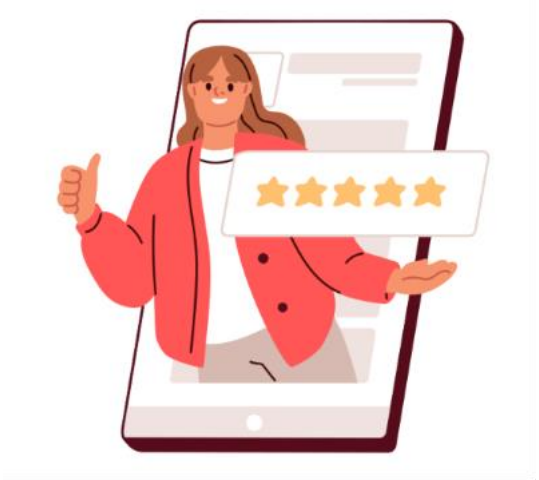

About the Listen to Me Project

Research team at Macquarie University, including people with lived experience of intellectual disability

Goal: Create a new, easy-to-use survey

Project name: **Listen to Me**

•Timeline: **3 years**

•Funded by: **MRFF national grant**

•Purpose: Help people with disability share what they think about their care in hospitals and clinics

Project Overview

Our Goal

Make health care better for people with intellectual disability.

How we will do this

Work together with people who have lived experience.
Help people learn research skills.

What is new

Make new PREMs (questions about health care experience).
Use online tools made with Action Lab (Monash University)

Who will use this

Up to 20 hospitals across Australia.

Why this matters

The information will help make health care safer and better in NSW and Victoria.

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Inclusive Research

How do we work together inclusively?

Project members - Consumer Leadership Group

Lived Experience Researchers

Matthew Van Hoek

Maya Tokutake

Dalal Dawood Baumgartner

Deborah Van Hoek

Karen Philips

Kim Bowen

Pandora Patterson

Professor Elizabeth Manias

Inclusive project governance

- We have a **Consumer Leadership Group (CLG)**

8 people

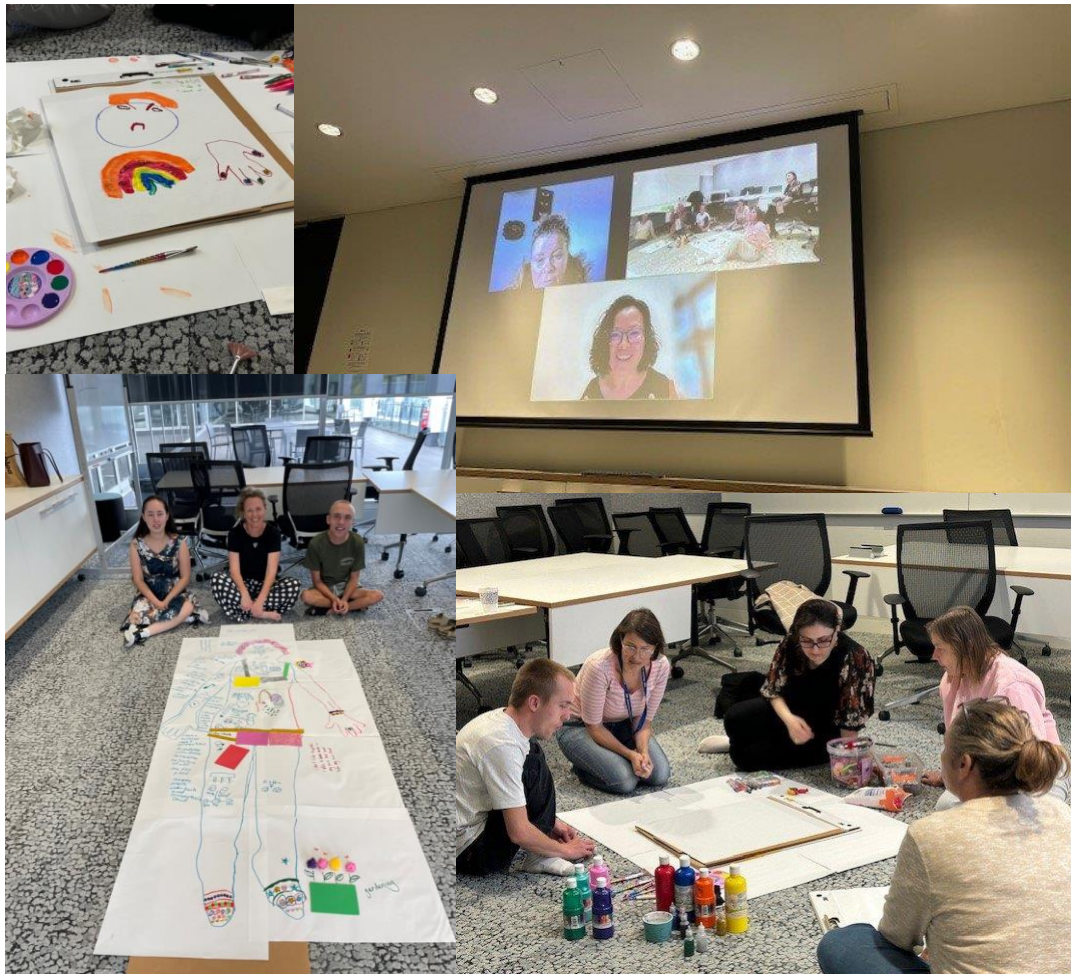
- We have a **Project Team**

30 people

- We have a **Steering Group**

10 people

Inclusive Research



How we work together

Making the ePREM

We worked together with the CLG.
We had **inclusive workshops**.
We worked **online and in person** (hybrid).

Refining the ePREM

We tested it with the CLG.
We used an **accessible online survey** (called **eDelphi**) two times.

How we made the ePREM together

1. Decide what is important to ask about

2. Talk about how to ask the questions

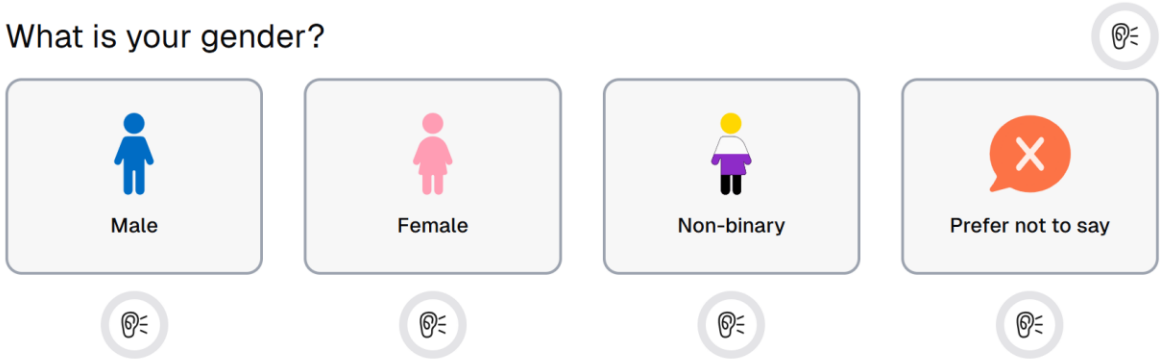
3. Try out different ideas for making the PREM

4. Finish the PREM

5. Try out the PREM with other people

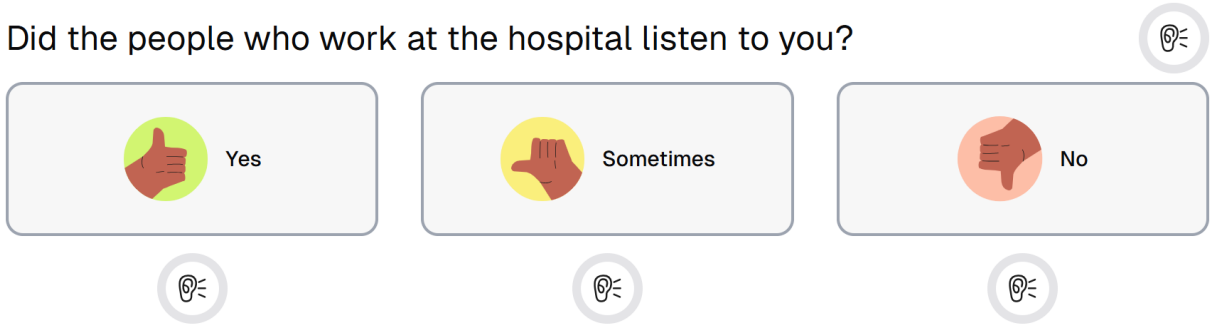
How we made the ePREM together

Example questions from Listen to Me ePREM



6 questions ask about you

- This survey does not ask for your name and address. It is anonymous.



9 questions ask about your hospital or clinic experience

What we have learnt so far

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We used inclusive and flexible ways to do our research

This means we worked with people who have different needs and preferences.

We had some challenges

It was hard to find times to meet in person.

People like to communicate and learn in different ways.

We had to change how we did the research

We needed to make meetings work for people joining online and in person.

Some tasks were hard for people to join if they were not art or activity-based.

What we learnt

Good relationships and clear communication helped us solve problems

Being part of a big, well-supported project helped us do more

Listen to Me – what's next?

What's next for the project?

- Use the survey in **hospitals and clinics**
- Collect feedback to **make health care better**
- Design **easy interface for staff and patients to use**
- Check that the ePREM works well (**validation**)
- Try the ePREM in **different places** in the future

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MRFF grant: 2026313