

Co-designing PREMS with and for people with intellectual disability

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INTRODUCTION

Patient Reported Experience Measures (PREMs) are routinely used by healthcare services to establish, monitor and improve service delivery in Australia and internationally. However, PREMs often exclude children, young people and adults with intellectual disability despite this group having inequitable quality and safety outcomes and experiences when accessing healthcare than the broader population. In conducting a Rapid Evidence Appraisal we discovered that, although there are numerous methods and approaches to support patient experience measurement with people with intellectual disability, there is a dearth of suitable system-wide measures in use (Harrison et al, 2024). Hence, our research is seeking to collaboratively design PREMs prototype with and for people with intellectual disability, that will be piloted across paediatric and adult healthcare service settings.

METHODS

Citizen science method of co-creation, underpinned by an implementation science framework.

Workshops with lived experience researchers, digital designers, clinician and academic researchers to co-develop PREMs and prototype instrument.



RESULTS

A Consumer Leadership Group was formed to develop the project name and partake in the workshops. The project logo was devised by one of the lived experience researchers.



RESULTS

Four workshops with lived experience researchers, digital designers, healthcare staff and researchers have been held.

We have developed a number of PREMs suitable for people with intellectual disability for testing.



Process of co-producing the PREM and prototype for testing is almost complete.

The prototype will be piloted at approximately 20 Australian Hospitals in 2025 including hospitalised children, young people and adults with intellectual disability.

CONCLUSION

Collection of patient experience data from people with intellectual disability across the life span is vital in light of poorer healthcare quality and safety outcomes and experiences unfairly incurred by this population.

This co-produced PREMs seeks to increase equity and improve health outcomes for children, young people and adults with intellectual disability accessing hospital care.

Co-production with lived experience researchers requires sustained commitment to inclusive principles for success.

WORKSHOP PROCESS



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