



Co-researching patient experiences of healthcare amongst children and young people with intellectual disability



Laurel Mimmo^{1,2}, Susan Woolfenden^{1,2}, Joanne Travaglia³, Iva Strnadová⁴, Maya Tokutake and Karen Phillips⁵, Matthew and Debbie van Hoek⁵, Éidín Ni She⁶, Bronwyn Newman⁷, Reema Harrison⁷

¹Sydney Children's Hospitals Network; ²School of Women's and Children's Health, University of New South Wales; ³Centre for Health Services Management, University of Technology Sydney, Sydney; ⁴School of Education, University of New South Wales; ⁵Co-researcher and parent; ⁶School of Population Health, University of New South Wales; ⁷Australian Institute of Health Innovation, Macquarie University

This work is supported by a University of New South Wales Disability Innovation Institute seed funding grant 2020, and the Maridulu Budyari Gumat SPHERE translational research fellowship scheme, 2019-2022, awarded to LM

Background

- ❖ Views of inpatient children/young people and/or parents are sought through **routine patient and carer surveys**.
- ❖ Experiences of **children/young people with intellectual disability are often excluded due to survey design**, exacerbating health inequities (Emerson & Spencer, 2015).

Method

- ❖ Inclusive approaches aim to **minimise hierarchy**; members of the population have control and input at any and/or all phases of the research (Nind, 2014).
- ❖ One such approach is **training co-researchers** (Nind, Chapman, Seale, & Tilley, 2015; Strnadová et al., 2014).

Results

Six co-researcher training workshops

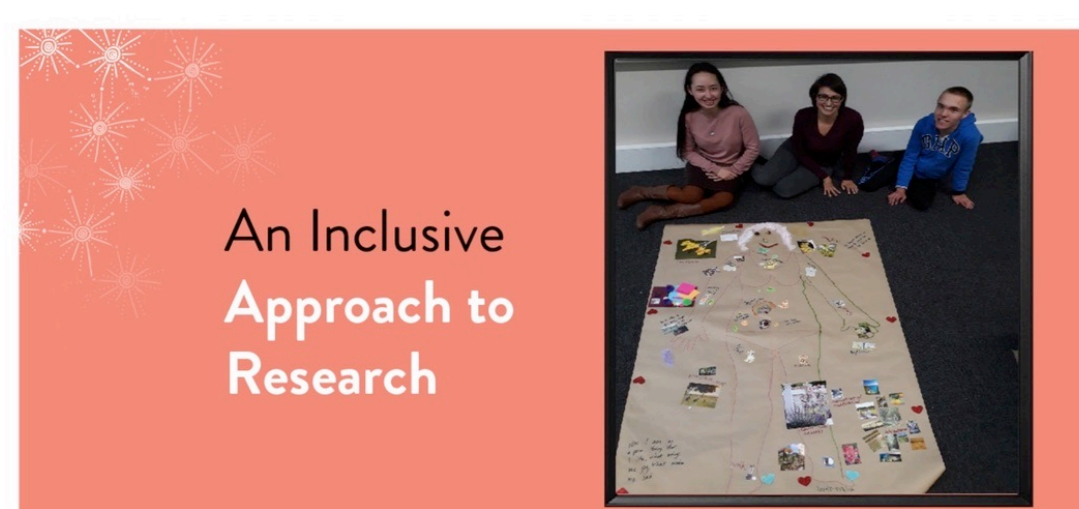
July 2020

October 2020



Since October 2020...

Co-researcher training with young people with intellectual disability – An inclusive approach to research



Risk Management Plan - Working with co-researchers
Version 10th May 2021

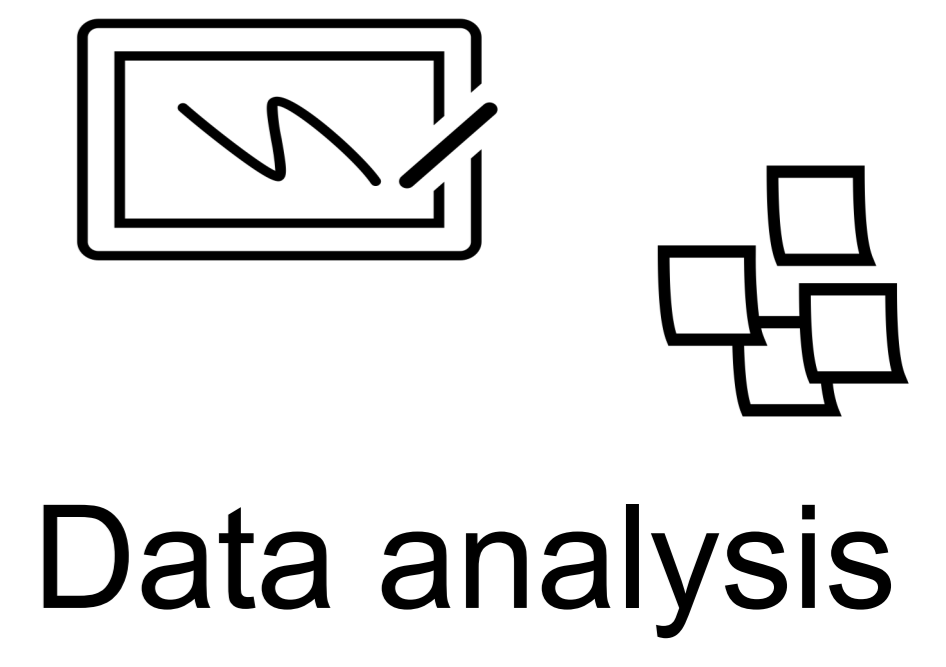
Situation or task	Why might this be a problem or cause harm?	What sort of problem or harm might happen?	What can we do to try to avoid or get rid of this harm?	Is there anything else we need to think about?



BMJ Open

Co-designing patient experience measures for and with children and young people with Intellectual disability: A study protocol

Journal	BMJ Open
Manuscript ID	20210111
Article Type	Protocol
Date Submitted by the Author	1/11/2021
Complete List of Authors	Mimmo, Laurel; Sydney Children's Hospitals Network; Woolfenden, Susan; Travaglia, Joanne; Strnadová, Iva; Phillips, Reema; Tokutake, Maya; Van Hoek, Matthew; Ni She, Eidin; Newman, Bronwyn; Harrison, Reema
Keywords	Quality in health care; HEALTH SERVICES ADMINISTRATION & MANAGEMENT; PEDAGOGICS; QUALITATIVE RESEARCH



Conclusion

- ❖ Inclusive research approaches give young people with intellectual disability opportunity to partake in research activities in an **accessible and supported manner** and address associated inequities with research participation.
- ❖ Understanding unique needs for **time and space to learn, reflect and adapt** as well as consideration of evolving needs in future research work, will form part of the workshop evaluations, currently in progress.