



How patient experience can optimise the quality and safety of healthcare delivery for inpatient children and young people with intellectual disability

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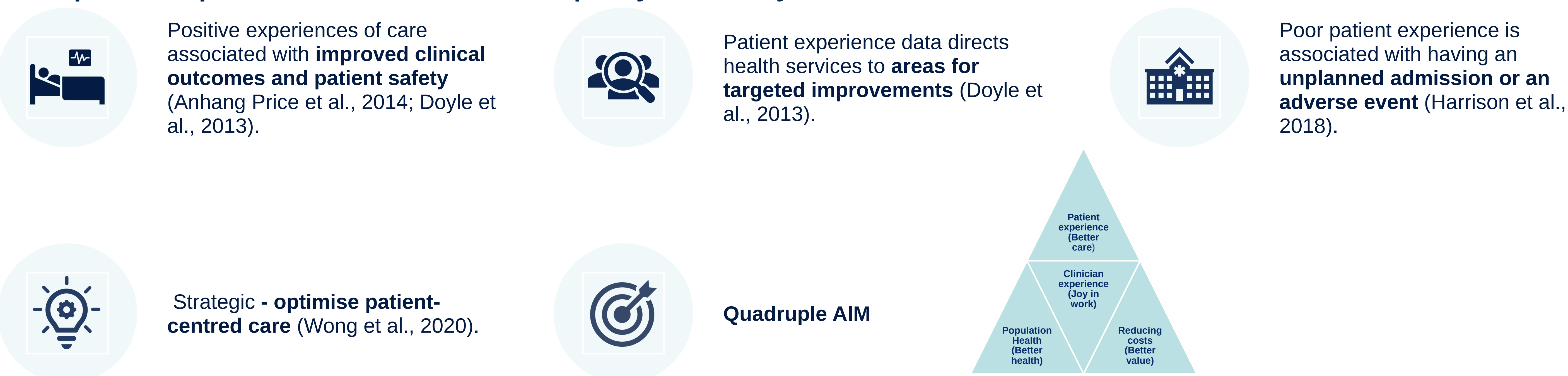
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Background

Patient experience data can inform enhancements to quality and safety, particularly those that are intended to be patient centred. However, this data is not routinely collected for people with intellectual disability. Inpatient children with intellectual disability are frequent users of healthcare, have longer median length of stay and have heightened risks of harm from healthcare delivery. However, this data only tells part of the story.

How patient experience data contributes to quality and safety

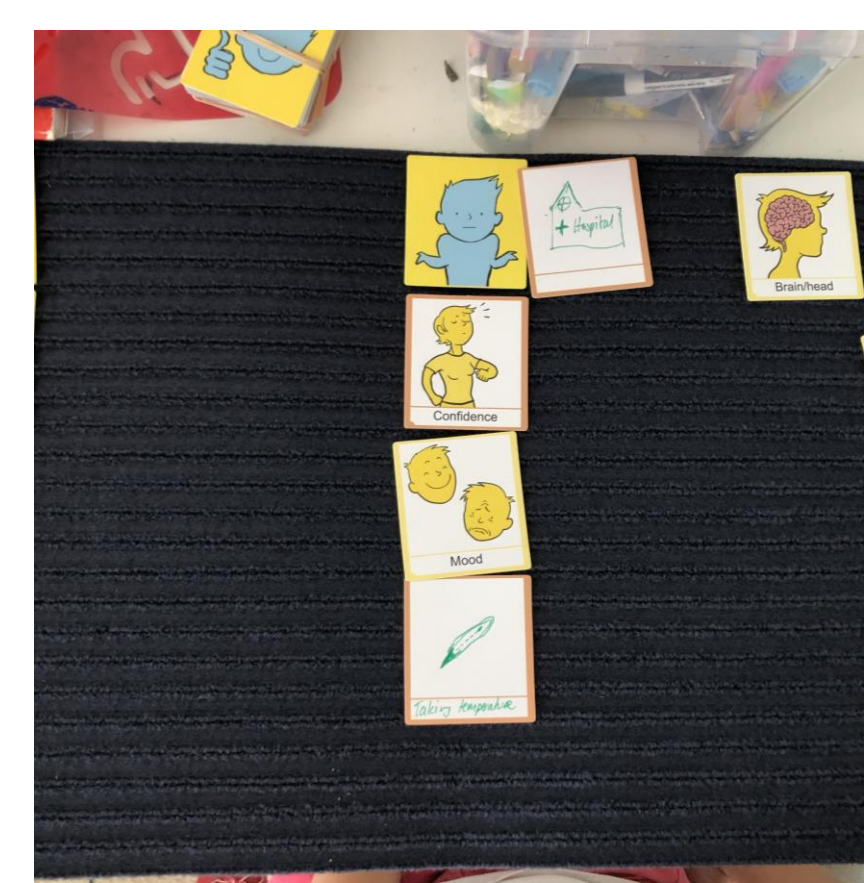


Methods and Results

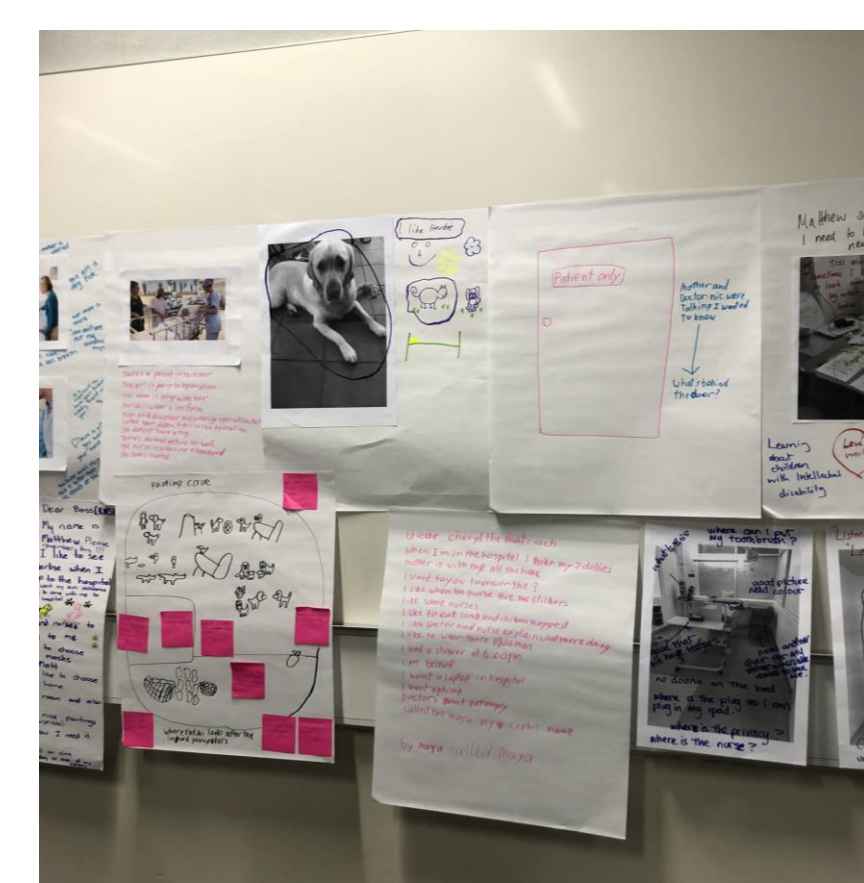
Cognitive biases, such as diagnostic anchoring and overshadowing, where health professionals see the presenting signs and symptoms as related to the intellectual disability, rather than an indication of an acute illness, compromising the quality and safety of care delivery.

Inclusive research is a broad term used to describe approaches to research activities that move 'towards democratization of the research process' (Nind, 2014, p1). Such approaches aim to minimise hierarchy between the researcher and the population or group under study, so members of the population have control and input at any and/or all phases of the research (Nind, 2014).

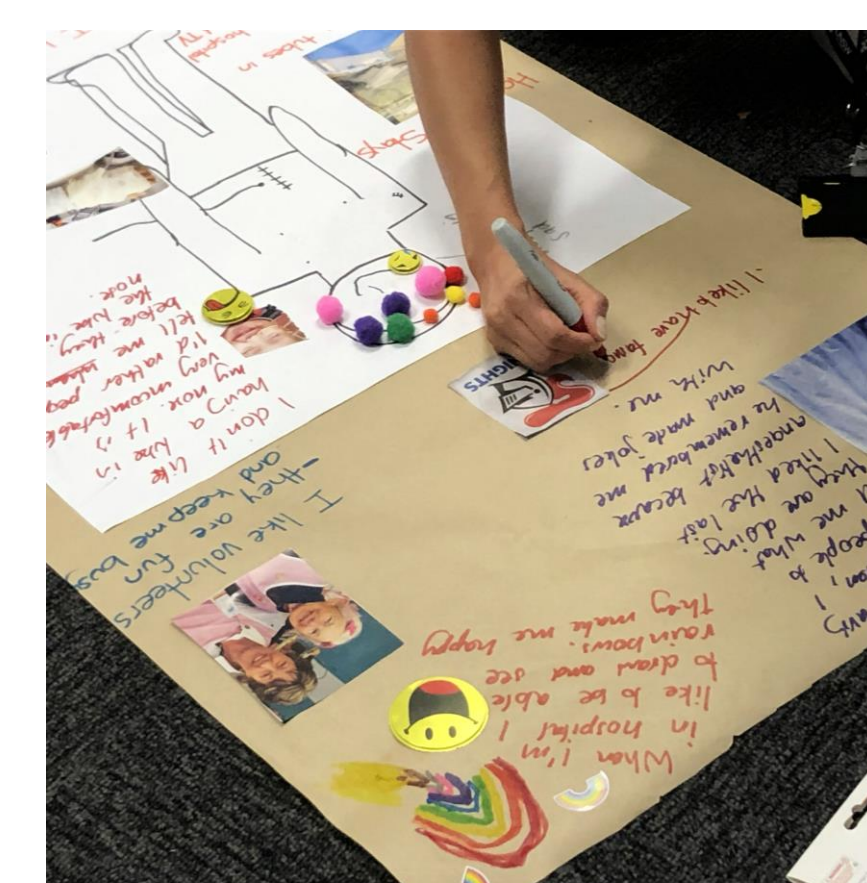
Examples of inclusive research methods



Talking Mats™



Photovoice



Body Mapping

Conclusions

Understanding how healthcare is experienced by patients is intertwined with their quality and safety outcomes.

Using strengths-based, inclusive approaches, when working with children and young people with intellectual disability can facilitate engagement with and for children and young people with intellectual disability, and enhance quality and safety.

Recommendations for practice

See the child as a person
What is the child/person trying to communicate?

Use play and rapport
Speak to the child, say hello and ask their name, ask how they want to communicate with you.

Deliver information in a way the person understands
Work with the parent
Check understanding

Empower through choice, partnerships and shared decision-making
Be honest and open: 'This is what will happen, this is how it will feel;

Ask 'what can I do to make sure you feel safe and in control?'

References

- Anhang Price, R., Elliott, M. N., Zaslavsky, A. M., Hays, R. D., Lehrman, W. G., Rybowski, L., Edgman-Levitan, S., & Cleary, P. D. (2014). Examining the role of patient experience surveys in measuring health care quality. *Medical Care Research and Review*, 71(5), 522-554.
- Doyle, C., Lennox, L., & Bell, D. (2013). A systematic review of evidence on the links between patient experience and clinical safety and effectiveness. *BMJ open*, 3(1), e001570.
- Harrison, R., Walton, M., Kelly, P., Manias, E., Jorm, C., Smith-Merry, J., Iedema, R., Luxford, K., & Dyda, A. (2018). Hospitalization from the patient perspective: a data linkage study of adults in Australia. *International journal for quality in health care*, 30(5), 358-365. <https://doi.org/10.1093/intqhc/mzy024>
- Nind, M. (2014). *What is inclusive research?* (1st ed.). Bloomsbury Academic.
- Wong, E., Mavondo, F., & Fisher, J. (2020). Patient feedback to improve quality of patient-centred care in public hospitals: a systematic review of the evidence. *BMC health services research*, 20(1), 1-17.

