






# BMJ Open Codesigning patient experience measures for and with children and young people with intellectual disability: a study protocol

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## ABSTRACT

**Introduction** Children and young people with intellectual disability represent one of the most vulnerable groups in healthcare, yet they remain under-represented in projects to design, develop and/or improve healthcare service delivery. Increasingly, healthcare services are using various codesign and coproduction methodologies to engage children and young people in service delivery improvements.

**Methods and analysis** This study employs an inclusive approach to the study design and execution, including two co-researchers who are young people with intellectual disability on the project team. We will follow an adapted experience-based co-design methodology to enable children and young people with intellectual disability to participate fully in the co-design of a prototype tool for eliciting patient experience data from children and young people with intellectual disability in hospital.

**Ethics and dissemination** This study was granted ethical approval on 1 February 2021 by the Sydney Children's Hospitals Network Human Research Ethics Committee, reference number 2020/ETH02898. Dissemination plan includes publications, doctoral thesis chapter, educational videos. A summary of findings will be shared with all participants and presented at the organisation quality and safety committee.

## INTRODUCTION

Approximately 4.5% of Australian children who are under 15 years of age have intellectual disability.<sup>1</sup> Children and young people with intellectual disability have high healthcare needs and utilisation,<sup>2-4</sup> poorer experiences of care quality when in hospital and are at higher risk of adverse events from healthcare than their peers.<sup>5-7</sup> Yet these children and young people are rarely consulted or involved in service improvements. Exclusion of children and young people with intellectual disability from service design activities further contributes to the health inequities experienced by this marginalised group.<sup>8</sup>

## Strengths and limitations of this study

- Adapted experience-based co-design methodology can enable meaningful involvement of children and young people with intellectual disability to voice their experiences of healthcare.
- Providing the appropriate supports for children and young people with intellectual disability to participate in research and service improvement projects may be met by including co-researchers with intellectual disability on the project team.
- This study provides a framework for other health services to adapt, appropriate to context, to include children and young people with intellectual disability in service design and improvement activities in their context.
- The prototype tool that is developed from this study will undergo future feasibility testing in the clinical space before wider application is possible.

In a previous review, we found that healthcare worker assumptions and reliance on parents to provide care contributed to deficiencies in the quality and safety experience for inpatient children with intellectual disability.<sup>6</sup> Members of our project team recently conducted a cross-sectional study of 1367 admissions for 1018 randomly selected patients admitted to the Sydney Children's Hospitals Network (SCHN) in Sydney, Australia, between 1 January and 31 December 2017 for more than 23 hours (SCHN HREC no.: 2019/ETH00367).<sup>9</sup> We found almost 14% of admissions were for a child or young person with intellectual disability or developmental delay. Furthermore, these children had a longer median length of stay, cost of admission and were over-represented in the reported clinical incident data.

Despite this, children and young people with intellectual disability are not reliably



identified when admitted to hospital nor are their experiences of hospital routinely sought.<sup>10</sup> Exclusion from service design and improvement activities also limits health services' capacity to improve quality and safety and enhance the patient experience for this group of children and young people. Parents are routinely called on to contribute experiences of care on behalf of children with disability, however the perspectives of what is important with regard to their healthcare experience can differ between a parent and their child with disability,<sup>11</sup> though increasingly researchers are developing and sharing methods to obtain children's experiences of care.<sup>12 13</sup> This is an important expansion of the evidence base as there are observations and events that are only experienced from the child's perspective; however, it is the perspective of the child with intellectual disability that is wanting in health services research literature.

### Theoretical framework

Including children and young people with intellectual disability in research or service improvement activities can be challenging due to perceived communication and cognitive impairments and ethical concerns.<sup>14</sup> However, these concerns can be overcome by making reasonable adjustments such as using easy read information and consent forms, using an inclusive approach and adapting existing methodologies to enable children and young people to participate in research and service delivery improvements.<sup>15 16</sup> Furthermore, by providing the appropriate supports to children and young people with intellectual disability to participate and have a voice, we can shift the perception of these children and young people as vulnerable victims of poor quality care.<sup>17</sup>

In this study we will use experience-based co-design (EBCD) methodology. A 2014 review of the use of EBCD healthcare staff reported a shift in their perceptions and attitudes around working with patients and how they listened to the patient voice.<sup>18</sup> For patients, EBCD improved their understanding of the service and feelings of empowerment when working with staff.<sup>18</sup> In a recently published co-design study with young people with intellectual disability, the young people involved in the co-design process were found to have had genuine participation and demonstrated creative choice in the process.<sup>19</sup> Participants in the co-design reported a sense of satisfaction and value as their ideas were listened to and came to fruition, as well as reporting feelings of learning, ownership and making new friends.<sup>19</sup>

To further support meaningful involvement of children and young people with intellectual disability, we will apply adapted EBCD methodology, with an inclusive research approach, to co-design a prototype tool to elicit patient experience data from children and young people with intellectual disability. Inclusive research encompasses a spectrum of approaches ranging from work akin to community development to major projects.<sup>20</sup> Diverse ways of involving co-researchers with intellectual disability have been discussed in the literature, such as training

co-researchers,<sup>21 22</sup> co-designing research methods<sup>23</sup> or participatory data analysis.<sup>24 25</sup>

### Objectives and research questions

The study objectives are:

1. To co-produce video vignettes of experiences of hospital.
  - Drawing on previously collected video interview data to co-produce video vignettes of participatory research for:
    - a. current and future co-design workshops;
    - b. consumer education; and
    - c. health professional video-reflexivity exercises.
2. To co-design and co-develop a prototype tool for eliciting patient experience data from children and young people with intellectual disability for use in the clinical setting.
  - We will work with an external digital design team to synthesise the findings from the co-design workshops to guide the development of a prototype tool.
3. To identify opportunities within the healthcare organisation to pilot the tool in an inpatient setting.

In this way, our EBCD study will seek to answer the following questions:

1. What are the key touch points improving the hospital experiences for children and young people with intellectual disability in hospital?
2. What are effective ways for supporting children and young people with intellectual disability to express their experience of hospital?
3. Are there existing digital platforms or tools for inputting patient experience data that can be used and/or adapted for children and young people with intellectual disability?

## METHODS AND ANALYSIS

### Patient and public involvement

For this research project, we will take an inclusive approach, including co-researchers with intellectual disability as part of the research team, and employing an adapted EBCD methodology<sup>26</sup> to ensure children and young people with intellectual disability can fully participate in the co-design process. This inclusive approach allows for capacity building on an individual level (co-researchers learning research skills, teamwork, further developing their communication skills and for academic researchers further developing their skills in engaging people with intellectual disability as equal partners in producing research). Two co-researchers with intellectual disability are members of the research team. The co-researchers have previously undertaken co-researcher training with the research study team. Furthermore, the co-researchers will be paid for their work as part of the research team.

### Methodology

EBCD methodology is an increasingly popular way for healthcare services to bring together service users/

consumers and healthcare staff to identify service delivery failings and design and implement solutions.<sup>26</sup> EBCD can involve up to eight stages to collect patient experience data, obtain feedback, identify touch points for intervention, develop improvement ideas and strategies, testing and refinement and reporting and evaluation.<sup>26</sup> However, EBCD can be time consuming and resource intensive; using accelerated and/or adapted approaches facilitate inclusion of patient groups and staff by minimising time and cost impacts, further supporting participation.<sup>26</sup>

Adapted EBCD is recommended when working with vulnerable groups such as children.<sup>26</sup> This method has been successfully applied with children and young people to co-design mental health services and eHealth interventions.<sup>27 28</sup> Adapted EBCD methodology allows the researcher/facilitator to make adaptations that take account of the needs of participants while retaining the core aspects of the methodology, namely use of patient interviews and patient–staff interactions to identify areas for improvement and intervention.<sup>26</sup>

The primary means our study takes in adapting EBCD is by taking a two-phase approach. The first phase uses video vignettes which will be developed based on analysed inpatient interviews and arts based methods (ie, body mapping and photovoice) with children and young people participants with intellectual disability. The second phase focuses on joint patient–staff workshops to review and reflect on the thoughts and ideas presented in the vignettes. Working together with the research team, the patient and staff participants will inform the design and development of a prototype tool that will enable a child with intellectual disability to express their experiences of hospital care.

Following adapted EBCD methodology, we plan to use video vignettes, developed from qualitative interviews using arts based methods conducted with children and young people with intellectual disability in our previous study (SCHN HREC ref no.: 2019/ETH13465), for use in co-design workshops. In the qualitative interviews using arts based participatory methods, we aim to determine what is good quality care from the perspective of inpatient children and young people with intellectual disability.

Further adaptations to EBCD will include: preparing video vignettes before the workshops commence, providing brief summaries to allow participants to think about their feedback pre session, using workshops to conduct patient feedback sessions and patient–staff experience sharing sessions on the same day and conducting workshops in school holidays. Preparing video vignettes and pre-workshop summaries are adaptations that support accelerated EBCD.<sup>18</sup>

#### Co-researchers

The co-researchers on the project team have participated in co-researcher training with LM, IS and RH funded through the UNSW Disability Innovation Institute 2020 Research Seed funding scheme. The idea to train co-researchers with intellectual disability was initially suggested

by IS, who has extensive expertise in working and training co-researchers with intellectual disability.<sup>22 29–32</sup> One of our project team members is the parent of a young person with intellectual disability who was keen to be involved. Through this connection, we identified a second potential co-researcher and the training was undertaken from July to December 2020.

Each co-researcher will have a nominated support person with them during the EBCD workshops. This support person may be a parent/unpaid family member or a paid support worker. The co-researchers will be paid for their time and any unpaid support person will be given a voucher for costs associated with travel. The co-researchers will also assist in the development of easy read materials for service users who attend the workshops.

#### Participants

Participants will be children and young people aged 4–18 years with intellectual disability (self or parent/guardian reported), who are enrolled in school and who were participants in the first phase qualitative video interviews, along with their nominated parent/guardian. These participants will be invited to participate in the EBCD workshops. Key clinical staff and health managers from the healthcare organisation will also be invited to participate in the workshops. We are using a purposeful sampling approach, as may be necessary for EBCD,<sup>33</sup> to enable the same children and young people participants from the first phase and the appropriate clinical staff, to be included in the workshops. The study lead, co-researchers, with their nominated support person and one to two members of the research team will facilitate the workshops. Due the age group of the children and young people participants, we anticipate that school holidays may be a preferred time for workshops.

#### Recruitment and consent

Children/young people with intellectual disability and parent/guardian participants will be invited to participate in workshops. These will take place either onsite at the paediatric organisation or using an online videoconference platform such as Zoom, Skype or Microsoft Teams or a hybrid of onsite/online formats, whichever is preferred by each participant and is compliant with current public health orders regarding public gatherings. A participant information and consent form (PICF) and verbal explanation of EBCD and workshop process will be given by study lead (LM). Written consent will be obtained prior to the workshops commencing and confirmed at the start of each workshop; for child participants, this would be from both the child and their parent/guardian. In the event that a parent/guardian consents to the workshop but their child does not, we will not coerce the child to attend and seek another participant group.

Participation in workshops would be voluntary and consent can be withdrawn at any stage while the EBCD workshops are being run and in the 4 weeks following the final workshop.

**Table 1** Plan for workshops

	Workshop one	Workshop two	Workshop three	Workshop four
Pre workshop	Circulate easy read summary of findings from hospital experience study—interviews with children and young people with intellectual disability, their parent/guardian and focus groups with staff—to all participants	Circulate easy read summary of workshop one to all participants	Circulate easy read summary of workshop two to all participants	(Optional—dependent on progress and outcomes in workshop three) Circulate easy read summary of workshop three to all participants
9:30–10:00	Registration	Registration	Registration Online or in person	Registration Online or in person
10:00–12:00	Children and young people and parent/guardian <ul style="list-style-type: none"> <li>▶ Getting to know each other over coffee/tea</li> <li>▶ Introduction to EBCD and purpose of workshops</li> <li>▶ Study lead and co-researchers present findings from ‘What is a good experience of hospital’ study</li> <li>▶ Questions or concerns?</li> <li>▶ Think about the activities for talking about what it was like being in hospital</li> <li>▶ Brainstorming session:               <ul style="list-style-type: none"> <li>– What activities worked well and why?</li> <li>– What questions worked well and why?</li> </ul> </li> </ul>	Children and young people and parent/guardian <ul style="list-style-type: none"> <li>▶ Hello and catch up over coffee/tea</li> <li>▶ Review outcome and decisions from workshop one</li> <li>▶ Questions or concerns?</li> <li>▶ Action decisions</li> </ul>	Children and young people and parent/guardian <ul style="list-style-type: none"> <li>▶ Hello and catch up over coffee/tea</li> <li>▶ Review outcome and decisions from workshop two</li> <li>▶ Questions or concerns?</li> <li>▶ Prototype ideas</li> <li>▶ Next steps</li> </ul>	Children and young people and parent/guardian <ul style="list-style-type: none"> <li>▶ Hello and catch up over coffee/tea</li> <li>▶ Final prototype testing</li> <li>▶ Questions or concerns?</li> <li>▶ Optional as online or in person follow-up with study lead.</li> </ul>
12:00–13:00	Lunch			
13:00–15:00	Children and young people and parent/guardian+clinical staff <ul style="list-style-type: none"> <li>▶ Get to know each other</li> <li>▶ Revisit the findings from ‘What is a good experience of hospital’ study</li> <li>▶ Watch video vignettes</li> <li>▶ Review discussion from the morning workshop</li> <li>▶ Brainstorming session:               <ul style="list-style-type: none"> <li>– Touch points</li> <li>– Questions we think are good to be asking about patient experience</li> <li>– Methods to include children with intellectual disability</li> </ul> </li> </ul>	Children and young people and parent/guardian+clinical staff <ul style="list-style-type: none"> <li>▶ Meet our digital designer (online)</li> <li>▶ Discuss what we want from the tool/prototype</li> <li>▶ Questions to include</li> <li>▶ Physical requirements of a tool</li> </ul>	Children and young people and parent/guardian+clinical staff <ul style="list-style-type: none"> <li>▶ Working with our digital designer.</li> <li>▶ Prototype development.</li> </ul>	Children and young people and parent/guardian+clinical staff <ul style="list-style-type: none"> <li>▶ Final prototype testing</li> <li>▶ Questions or concerns?</li> <li>▶ Optional as online or in person follow-up with study lead</li> <li>▶ Next steps</li> <li>▶ Easy read summary of outcomes circulated to all participants in the weeks after workshops</li> </ul>

EBCD, experience-based co-design.

### Plan for workshops

Four to seven children and young people with mild-to-moderate intellectual disability and their nominated parent/guardian and key organisation staff will be invited to participate in the workshops, with two to four members of the research team, including at least one co-researcher. The digital design person will attend via videoconference as necessary. We anticipate four workshops of no longer than 4 hours will be required, split into two sessions,

morning and afternoon, of 2 hours each, see [table 1](#). The morning sessions will be for the children and young people participant groups only to allow time to consider the aims of the workshop, discuss any concerns and familiarise themselves with the team and other participants. Organisation staff will only be required to attend the afternoon sessions of each workshop.

The workshops will be primarily design focused with the final workshop focused on prototype testing, refinement

and design of the prototype trial study in the clinical space. The workshops will also involve reviewing the patient experience tools currently used in the Australian healthcare system and how these tools are used to produce data that inform improvements to care delivery. In this way, we will have broad parameters to be followed so the prototype tool is fit for purpose. Given we are working in a paediatric context, it is likely the tool will incorporate audiovisual processes and child-friendly design.

Participants will be compensated for time taken to attend workshops; for each child and young person participant group, \$AUS75 per workshop and catering for all workshop participants will be provided.

### Workshop activities

The workshops will be interactive, incorporating ice breaker activities, brainstorming and reflective exercises using video vignettes of the children and young people expressing their thoughts on a good experience of hospital. Only project team members who are either organisation employees or hold contingency worker status will have direct contact with the workshop participants. In the Australian context, an adult who has access to or works with children and young people is required to undergo a series of police and criminal checks; in addition, the organisation where this study will be undertaken requires any adult working within the organisation to hold contingency worker status and undergo further identification checks.

### Data analysis

Data analysis will be collaborative and iterative, focussing on the workshop process and content produced. In EBCD methodology, patients and staff review patient stories and work together to identify key touch points for intervention.<sup>26</sup> The workshop facilitator and research team, including the co-researchers, would encourage brainstorming with the workshop participants to generate design ideas for further development at subsequent workshops. Qualitative content analysis of the workshop process,<sup>34</sup> including transcripts, notes and materials produced, will be employed by the research team after each workshop. We will apply an inductive content analysis over three phases: preparation, where the researchers are immersed in the data to for sense making; organising, where the researchers will code, categorise and group the data to develop key categories and then resulting, where the key categories are described.<sup>34</sup> These categories will inform the content of the next workshop and the content and format of the tool. The workshop process and content analysis by the research team including co-researchers would also be used when working with the designer to develop a prototype tool.

## ETHICS AND DISSEMINATION

### Ethical approval

This study was granted ethical approval on 1 February 2021 by the SCHN Human Research Ethics Committee, reference number 2020/ETH02898.

## Ethical considerations

### Age and healthcare needs

As other researchers have identified, children and young people can tire easily when participating in qualitative research,<sup>35</sup> particularly when unwell. In addition, consideration should be given to providing appropriate additional supports to facilitate meaningful participation and inclusion of children and young people with intellectual disability.<sup>17 36</sup> To manage this, we will use a variety of strategies including:

1. Pre-workshop meeting, via videoconference or in person, to prepare each child/young person and their parent/guardian. During this meeting we will obtain informed, written consent, discuss and agree to the location for the workshops and provide any support or communication needs for the child/young person, or their parent/guardian, for the workshops.
2. Pre-workshop meetings will not be scheduled for longer than 30 min unless the child/young person requests.
3. Participants will be offered the option to have the meeting conducted over two to three sessions of up to 15 min each.
4. Follow-up meetings will be offered if the child/young person wishes to stop early, would like to think about participating and/or would like the researcher to provide more information.

Home visits for the pre-workshop meetings may be required if preferred by child/young person and parent/guardian participants. In this situation, compliance to any public health orders and the organisation home visit policy will be followed.<sup>37</sup>

### Potential for discomfort and distress

Contingency plans include identifying relevant and known professional supports for the child and parent participants to contact should the meetings or workshops cause distress. This will be discussed with the child/young person and parent/guardian participants and an agreed contact identified during the pre-workshop meeting.

Where a reportable clinical incident is identified through or during the EBCD process, an incident report will be lodged in the organisation's incident investigation and management system as per the NSW Health Clinical Incident Policy.<sup>38</sup>

### Organisation staff involvement

Each workshop will include key clinical staff and health managers from the healthcare organisation. Participation in the workshops will be voluntary and subject to the support of the staff member's direct line manager and department head or director. Organisation staff will only be required to attend the afternoon workshop session and will be given a one page summary of the plan for the session 2 days before each workshop. An information sheet explaining the study and purpose of the EBCD workshops would be provided and written consent obtained at the pre-workshop meeting. Multidisciplinary groups would



be encouraged, including junior and senior medical and nursing staff and allied health staff from a variety of disciplines. As this healthcare organisation incorporates two tertiary children's hospitals, staff will be able to attend the workshops at their primary site, either in person or online, depending on the location for the workshop. Where there are current public health orders regarding public gatherings, the workshops will be conducted using an online videoconference platform such as Zoom, Skype or Microsoft Teams.

Support from the site-based directors of nursing, allied health and clinical governance and medical administration and relevant department heads would be sought for recruitment of organisation staff, including identification of relevant staff and time to attend workshops. Workshop times have been determined to minimise conflicts for staff with clinical duties. This approach is intended to ensure voluntary participation by staff while taking into consideration available times for those with a clinical workload to attend.

Details for the site-based employee assistance programme team will be provided for staff participants to contact should the workshops cause distress.

Where a reportable clinical incident is identified through or during the workshops, an incident report will be lodged in the organisation incident investigation and management system as per the NSW Health Clinical Incident Policy.<sup>38</sup>

### Informed consent

In obtaining informed consent, we will adhere to the organisation's human research consent procedure.<sup>39</sup> All participants will be asked to sign a relevant PICF to participate in the EBCD workshops and given a copy of each signed PICF.

Informed consent will be obtained from each child/young person and parent/guardian participants for the involvement of the child/young person in the EBCD workshops. Where only audio consent is obtained from one or more participants, the workshop facilitator (LM) will ensure only consented participants are in any video recordings. After each workshop, LM will also review all videos taken; if any footage of a non-consenting

participant is found, it will be deleted and only audio recording will be retained.

### Child/young person and parent/guardian participants

Written consent from the participants will be obtained at the pre-workshop meeting and reconfirmed before each workshop commences. In the event that a parent/guardian consents to attend the workshop but their child does not, we will seek another participant group. However, we will still include their video vignettes developed from the previous qualitative study in the EBCD workshops.

Child/young person and parent/guardian participants will be provided with an easy read information sheet regarding the EBCD workshops along with a verbal explanation at the time of recruitment, at the pre-workshop meeting when obtaining written consent and again before commencing the workshops. The information sheets will be used as an aid and not the sole method for communicating details of the study and obtaining informed consent. Additional time will be allowed for communicating details of the study and obtaining consent in a way that is best suited to participants. Co-researchers with lived experience of intellectual disability will be involved in adapting the information sheet for child/young person participants. Professional interpreters will be used as required and the information sheet will be translated into the preferred language of participants.

If any child participant turns 18 during the course of the study, they will be approached to be reconsented.

### Organisation staff participants

Informed consent will be obtained from staff who are identified to be involved in EBCD workshops. An information sheet regarding the study and purpose of the workshops will be provided at the time of recruitment and at the pre-workshop meeting when obtaining written consent. Participants will be asked to confirm consent before the workshops commence.

### Proposed timeline

We anticipate that this study would be conducted over 8 months, as per [table 2](#).

**Table 2** Proposed timeline for study

		Recruitment and pre-workshop meetings	Codesign workshops	Prototype development	Follow-up workshop for prototype testing
2022	February	█			
	March	█			
	April	█	█	█	
	May		█	█	
	June			█	
	July		█		
	August				█
	September		█		█

## Dissemination

Dissemination plan includes publications, doctoral thesis chapter, educational videos. A summary of findings will be shared with all participants and presented at the organisation quality and safety committee.

## Primary outcome measures

1. Prototype of a tool to obtain patient experience data from children and young people with intellectual disability.
2. Established relationship with group of children and young people with intellectual disability to participate in future co-design.
3. Building capacity of children and young people with intellectual disability to participate in both research and service improvement activities.

## Secondary outcome measure

- ▶ Video vignettes from interview data for use as an educational resource for organisation clinical staff and for future co-design workshops.

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**Contributors** LM, RH, SW and JT conceived the study. All authors contributed to the design of the study. LM drafted the manuscript and SW, JT, IS, MT, KP, MvH, DvH and RH contributed to the critical review of the study design and manuscript drafts and have given approval for this version to be submitted for publication.

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**Competing interests** None declared.

**Patient and public involvement** Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

**Patient consent for publication** Not applicable.

**Provenance and peer review** Not commissioned; externally peer reviewed.

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