


A call to action for more disability-inclusive health policy and systems research

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ABSTRACT

To date, the exclusion of people with disability participating in research has limited the evidence base informing health system strengthening policy and practice more generally, and addressing disability-related inequalities in access to health services and better health outcomes more particularly. Given that more than 1 billion people, or 16% of the world's population, have a disability, we may fail to respond to the needs of a large proportion of the population unless we are purposeful with inclusion. Our research in this area indicates that online qualitative methods can be effective in engaging under-represented groups and are essential to ensure their input into health policy and systems research. This has important implications for researchers whose responsibility it is to make all health research disability inclusive, for ethical and methodological reasons, so they do not perpetuate the under-representation of people with disability in health policy and systems research. Our paper puts forward several recommendations to facilitate more people with disability participating in health policy and systems research. By critically reflecting on a health system strengthening research project, in which we purposefully aimed to support the participation of people with disability, we identify lessons learnt and issues to consider when planning and conducting accessible research. We also propose a set of actions for moving the agenda forward.

INTRODUCTION

Increasingly, researchers are responding to the call of 'nothing about us without us'¹ by including people with disability in research undertaken about them and their lives, not just as participants, but as researchers and coproducers of research ideas.^{2–5} This shift to inclusive research^{4 6 7}—where people with disability are engaged in all stages of the research process, from identifying the research question to dissemination of findings—has resulted in an emergence of accessible and creative methods.^{3 4 8 9} However, a range of systemic and structural barriers in the health policy and systems research process

SUMMARY BOX

- ⇒ The exclusion of people with disability participating in health policy and systems research has limited the evidence base needed to address disability-related inequalities in access to health services and better health outcomes.
- ⇒ Recommendations and possible approaches to facilitate people with disability participating in online focus groups and to identify lessons learnt.
- ⇒ A suite of proposed actions to move forward a disability-inclusive research agenda for health policy and systems research.
- ⇒ It is our responsibility to make all health policy and systems research disability inclusive so as to grow the knowledge base, while also addressing ethical and methodological imperatives.
- ⇒ The lessons learnt have important implications for researchers whose responsibility it is to make all research disability inclusive.

continues to exclude people with disability, their perspectives and life experiences.^{10–17}

These barriers include: unconscious ableism by researchers and clinicians^{17–20}; so few researchers with disability are employed in research teams^{20 21}; physically inaccessible premises and medical equipment; and research designs that include study documents, interventions and/or measures that are difficult for people with disability to access.²² Even if a study location is ostensibly accessible, if participants cannot physically reach the premises without great cost to or effort from themselves, this effectively reduces their potential participation.⁵ Furthermore, people with disability may be excluded from research through overly rigid inclusion and exclusion criteria that are poorly justified.^{11 13 16 23 24} For example, Plosky *et al*¹⁵ examined the inclusion and exclusion criteria used for screening potential participants in clinical trials, between 2015 and 2021, focusing on the eligibility of people with disability. They found that people with

disability were explicitly permitted to make use of some form of supports to facilitate autonomous study participation in only 18% of the protocols reviewed.¹⁵

Promoting the human rights and equality of people with disability is a core objective of the 2006 United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in all its aspects, including research.^{25 26} More recently, the UNCRPD has expedited a crucial and core debate with regard to research ethics and principles in the field of disability research.^{14 26} For example, the WHO in its recently released *Global Report on Health Equity for Persons with Disabilities*²⁶ has, as a key recommendation, that all member states develop a national policy and systems research agenda on disability to address the health inequities experienced by people with disability.

Over 1 billion people, or 16% of the global population, experience disability,²⁶ suggesting that most research effectively fails to incorporate the views of more than 1 in 6 people.^{10 27–29} Thus, researchers need to heed the maxim that ‘who counts depends on who is counted’.^{27 30 31} Like others,³² we argue that apart from research explicitly focusing on disability, accessibility is rarely, if ever, deemed a consideration.

However, while we recognise the ethical and scientific imperative to include people with disability at all stages of research, which we did in this research, our focus in this paper is specifically on offering practical advice to researchers on how to ensure they broaden the diversity of online focus groups. To this end, we critically reflect on a health policy and systems research project in which we purposefully worked to create an inclusive research environment for people with disability to participate in online focus groups. We describe the research setting and inclusive approaches employed, and identify lessons learnt and issues to consider when planning and conducting accessible research. Finally, we present some considerations for future directions, in particular, for all researchers to ensure that their research—not just disability-focused research—is inclusive.

The points presented here were clarified and refined through a collaborative writing process, multiple review cycles and discussions between coauthors (see authors’ information).

SETTING AND OVERVIEW OF ONLINE FOCUS GROUPS

Social distancing regulations introduced during COVID-19 have led to more researchers using online qualitative data collection methods, such as online focus groups.^{33–39} This is because they offer an accessible alternative to face-to-face data collection, are cost-effective and more easily able to reach socially isolated and/or dispersed populations.^{35 39–44} As a result, there is an emerging body of literature on the benefits of online methodologies to support the accessibility of research for people with disabilities,^{9 37 44–47} which we trust will continue to grow.⁴⁶

In 2021, the Australian Department of Health commissioned researchers from The University of Sydney to develop a set of self-report disability questions suitable for a potential voluntary patient registration (VPR) enrolment form being considered for Australian general practices.^{31 48 49} The purpose of the VPR scheme is to strength the continuity of care relationship between individuals and their regular general practice.³¹ As the questions were designed to identify people with disability, it was imperative to ensure their input into the type of questions asked, in the focus groups employed in this study, the processes to be used for asking them and the analysis and potential uses of the information gathered.³¹ Others with an interest in VPR were also included in specific focus groups, for example, national representative bodies for general practitioners, health consumers and general practice nurses.

As this work occurred during the COVID-19 pandemic, the planned mixture of face-to-face and online focus groups could not proceed due to the imposition of public health restrictions and lockdowns. Instead, between August and October 2021, we ran 16 online focus groups with input from 65 individuals across 26 organisations throughout Australia.^{31 48}

Methods and findings from this work are described elsewhere.^{31 48} In brief, each 1-hour online focus group was cofacilitated by two members of the research team, and always included at least one team member with disability. Participants were given the option for an individual interview rather than a focus group if they preferred, and Easy Read versions of all consultation materials were provided. Importantly, people with disability were employed on the research team and were instrumental in guiding the development of the focus group materials and methods and participant recruitment strategy, cofacilitating the focus groups, providing input into the analysis and interpretation of focus group data, and the dissemination strategies.⁴⁸ Table 1 highlights several of the inclusive features at different stages of the online focus group process and the specific accessibility features we employed.

INSIGHTS AND LESSONS LEARNED FROM OUR APPROACH

Working with organisations of people with disability must be well resourced

Throughout the project, we worked with Disabled People’s Organisations (DPO) and Disability Representative Organisations (DRO)¹ to promote the participation of people with disability in focus groups. For example, we contracted a DPO and DRO to bring together groups of people with intellectual disability to explain the research purpose and process, to obtain consent, to support the facilitation process and to assist participants with any follow-up queries. Having resources available to cover

¹Disabled People’s Organisation is an organisation that is controlled by people with disability. A Disability Representative Organisation is an organisation that represents the interests of and advocates for people with disability.

Table 1 Design, recruitment and preparation, implementation, and follow-up of online focus groups

Stages	Inclusive features of the online focus groups
Design	<ul style="list-style-type: none"> ▶ Employment of people with disability on research team. ▶ Ethical consent sought from The University of Sydney Human Research Ethics Committee. ▶ Advice on accessibility features sought, fully costed and budgeted, for example, Live captioning and the use of Auslan interpreters. ▶ Focus group question guide and accessibility approaches developed by research team, which included people with disability. ▶ Facilitators of focus groups participated in a series of ‘test runs’ of online focus groups to refine roles and processes, and to test accessibility features. ▶ Engaged and funded the Victorian Advocacy League for Individuals with Disability and the Council for Intellectual Disability to develop Easy Read versions of materials to support online focus groups for people with intellectual disability.
Recruitment and preparation	<ul style="list-style-type: none"> ▶ Participants were recruited through approach emails sent to key contacts in Disabled People’s Organisations, Disability Representative Organisations, healthcare consumer organisations and Primary Health Networks.* ▶ The approach email described the purpose of the research and invited up to four representatives from each organisation to participate in a focus group. ▶ Participants were offered an individual interview with flexible times rather than a focus group if they preferred. ▶ On confirmation of availability, participants were emailed a fact sheet about the voluntary patient registration scheme; a participant information sheet; a list of discussion questions for the focus group; and a link to complete the consent process using the online platform RedCap or the option of an oral consent process. ▶ On registration, all participants were asked if they had any accessibility requirements and, if so, to advise us. ▶ Instructions on how to use Zoom were sent to participants ahead of time and participants offered support to test run and troubleshoot. ▶ The technical support person was available to participants 15 min before the online focus group meeting and for its duration.
Implementation	<ul style="list-style-type: none"> ▶ Online focus groups were generally scheduled for 1 hour and cofacilitated by two members of the research team, one of whom had lived experience of disability. ▶ Live captioning was used for online focus groups, and other accessibility features, such as Auslan, were available as required. ▶ Participants were invited to use the ‘chat’ function in Zoom to write their immediate thoughts or to contribute as they saw fit. ▶ The discussion questions were placed in the ‘chat’ function by technical support person to aid access to these as required. ▶ PowerPoint slides used for the online focus groups had a large sans serif font (Arial 24 pt), black text on white background, minimal words and ample white space between dot points to avoid overcrowded text. ▶ The slides were read out by a cofacilitator to ensure accessibility for all participants. For the groups involving participants with intellectual disability, an Easy Read version of the slides was used with images to accompany the text. ▶ All focus groups were recorded with participants’ consent. ▶ Cofacilitators met before each focus group to decide on roles, and afterwards to debrief about what worked and what could be changed for future focus groups.
Follow-up	<ul style="list-style-type: none"> ▶ Participants were offered AUD\$50 vouchers if they were participating in their own time, not as part of their paid employment. ▶ Everyone received a ‘participant feedback report’ outlining the results of the research, with an Easy Read version provided to participants with intellectual disability.

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these costs—as well as those associated with the live captioning, producing the Easy Read project materials and the vouchers offered to participants to acknowledge their time and expertise—was essential to ensuring that as many people with disability as possible could participate in the project.

Careful preparation and planning aided accessibility

At all project phases, we discussed and reflected on accessibility issues. Having researchers with experience working in disability research, as well as researchers on the team with disability and lived experience of disability, helped to ensure an accessible and inclusive model. Live captioning provides an excellent example of our approach. As automatic captioning available through Zoom was not sufficiently accurate to be useful

for participants, we decided to opt for external live captioning. A link for this service was emailed to participants ahead of time and put in the ‘chat’ function in Zoom at the start of the focus group. The link opened a separate window containing the live captioned text, which participants could keep open in addition to the Zoom window where the focus group was occurring. Within hours of finishing each focus group, we received an accurate transcript that also assisted our research team in analysing the focus group findings. The ‘chat function’ in Zoom was used to enhance accessibility, offering participants the option to provide written input. We informed participants that, while we would not be able to respond to the chat during the meeting, we would include this input in the analysis.

Time invested in focus group ‘test runs’ improved team rapport and running of groups

As the research team had not worked together before and had varying experience in facilitating focus groups, we held a series of planning meetings with role-playing as facilitators and participants. Four focus group ‘test runs’, with various combinations of cofacilitators, enabled us to establish rapport and to become comfortable with each other’s styles of working, cofacilitation timing and turn-taking. These ‘test runs’ also provided the opportunity to consider the time needed for a range of specific accommodations, such as reading out loud on-screen materials, delivering questions and responses more slowly and how best to give clarification when required. During these ‘test runs’, we developed and refined a ‘run sheet’ that outlined the steps in facilitating each focus group.

Cofacilitators shared the leading of the groups and, prior to each focus group, had a short meeting to work out ‘who would do what’ on the run sheet. This meant that no single facilitator dominated on the day and that there was some built-in flexibility for all. Both the test runs and having two facilitators for each group enabled other facilitators to step in with minimal interruption if technical issues arose or one facilitator was unavailable at short notice.

Use of an online platform with which people were familiar

We selected the Zoom platform because we had access to The University of Sydney’s institutional account with no meeting time limits and additional security features not available in the public version. More importantly, Zoom had been widely used both for business and social interaction during the pandemic, which meant that many of our participants were already familiar with it. Nevertheless, we offered everyone the opportunity to practise using Zoom prior to the focus group, as well as dialling in 15 min beforehand, in case of initial issues (eg, volume control, muting, turning video on and off), but no one requested this additional support.

Having a technical support person to assist facilitators and participants before and during online focus groups

In addition to offering a ‘drop-in style’ support for technical issues prior to the focus groups, the technical support person also created and sent the Zoom link to participants, and organised the schedule for all focus groups. During the session, they also controlled screen sharing, placed discussion questions in the chat function for easy reference, checked live captioning and recorded all meetings. Participants who required additional technical support could access this in a breakout room but, again, this option was not taken up. These features allowed the cofacilitators to concentrate more effectively on facilitation and interacting with participants.

Smaller numbers of participants in each group encouraged discussion

We limited the number of participants to a maximum of eight plus an additional four from the facilitation team—two cofacilitators, one technical support person and one

live captioner—to ensure that all could be seen together on one screen (as opposed to scrolling across screens). The technical support person and live captioner turned their videos off to reduce excess visual stimulation and to optimise interactions between participants and cofacilitators.

Online interactions more limited

When reflecting on how the online approach affected the ability of cofacilitators to connect and establish rapport, we identified several drawbacks, including the difficulty we had in reading the body and facial cues of participants. Interactions between group participants is a hallmark of focus groups but we observed only limited interaction between participants, although they did build on the comments offered by others and expand on their ideas. Despite a reduction both in visual cues for facilitators and in interaction between participants, the overall quality of the data was rich and nuanced.

Despite our efforts, we recognise that our online focus groups may have been inaccessible to some. People with disability are not homogenous in terms of opinions and perspectives,⁵⁰ and this, coupled with the variety of impairments and disabling environments, means that more effort must be given to ensuring a wider range of researchers and participants with disability are involved from the start. Furthermore, we were not able to validate the extent to which access to our research was improved by the approach we developed. However, we are currently commissioned to devise and implement measures to assess the accessibility of our research for people with disability.⁵¹

Box 1 Six guiding principles for inclusive research⁷

1. Power sharing—Acknowledge and manage any power differentials between individuals and groups: for example, ensure shared responsibility and ownership of the research process and recognition of the specific skills each person brings to the research.
2. Accessibility—Actively address barriers that may potentially prevent or discourage involvement from people with disability in the research process: for example, ensure accessibility of physical environments and all information relevant to the research project.
3. Flexibility—Identify how best to work together to achieve common goals in the context of each specific project: for example, understand the team’s particular needs and implications for the coproduction strategies to be put in place.
4. Diversity—Facilitate everyone’s differing perspectives and value and celebrate their skill sets: for example, encourage individuals to become involved in aspects of the research that best suit their interests, skills and expertise.
5. Reciprocity—Ensure that everybody benefits from coproducing the research: for example, through financial recompense, learning from each other, building new relationships and skill sets and working towards social good.
6. Transparency—Openly communicate about the context, goals, scope and process, each person’s role, and potential outcomes of the research: for example, ensure that everyone has a shared understanding of the parameters of the research project.

It is also important to note that as this work was carried out in Australia it may not be relevant to other global settings. In low-resource settings, there are many barriers such as geographical isolation, community attitudes towards people with disability and access to technology.³⁵² That said, each setting is unique and contextual barriers require full consideration to devise the most inclusive methods possible which may or may not involve online environments including social media. Nevertheless, the quality of our data provided direct input into the development of the proposed policy regarding a set of disability questions to be used for VPR in general practice.

These strategies for a more inclusive research process, which were developed collaboratively by our team, while comprehensive, are by no means exhaustive. As researchers we are continually looking to evolve our practice and are committed to ensuring that people with disability are included as coresearchers. For unless we are purposeful in ensuring inclusion in all stages of the research process, we will continue to perpetuate the now out-dated perspective of people with disability only as research subjects with the resultant gaps in knowledge this will create.⁵³

MOVING FORWARD A DISABILITY-INCLUSIVE RESEARCH AGENDA FOR HEALTH POLICY AND SYSTEMS RESEARCH

Including people with disability in all stages of research is not the only component needed to advance disability-inclusive health policy and systems research. In Australia, a good starting point would be some national guidelines for conducting ethical research with people with disability along the lines of those developed by the National Health and Medical Research Council for working with Aboriginal and Torres Strait Islander people.⁵⁴ The Disability Innovation Institute⁷ and the National Disability Research Partnership⁵³ have, however, produced guiding principles for inclusive research practice, and these could form the basis of future national guidelines. The key principles articulated by the Disability Innovation Institute (Strnadová et al, pg. 8)⁷ are summarised in [box 1](#), accompanied by some practical actions to implement these principles.

A second step is to undertake more research on the power dynamics and representation within health policy and systems research which, by its nature, is interdisciplinary and requires bringing together a diverse range of stakeholders to tackle complex issue, and with forms of power that may not always be visible or easily challenged.⁵⁵ For this reason, principles—for example those outlined in [box 1](#)—need to be embedded in the research design and constantly monitored and reflected on as drivers in addressing power imbalances.^{56–58} Principles can act both as a compass requiring researchers to continually take stock of their actions, and as indicators for monitoring and evaluating outcomes during and post implementation.⁵⁶

Thirdly, we must address the attitudinal barriers of researchers and health staff that affect access to health policy and systems research for people with disability. To this end, training on disability inclusion in the education of researchers and of all healthcare workers is urgently required.^{17 18 26} Furthermore, we advocate for more purposeful employment of people with disability as researchers in academic organisations at all levels, not just in disability research centres, but rather across the board.

Finally, we must align our approaches and look for potential synergies, especially at the global and national levels.⁵⁵ Despite the attention that disability health inequity has received in the WHO *Global Report on Health Equity for Persons with Disabilities*, and its specific call for the development of health policy and systems research agenda to address disability health inequities,²⁶ there was no mention of disability health inequities in the flagship report *Systems for Health: Everyone has a Role*⁵⁵ released by the Alliance for Health Policy and Systems Research (an international partnership hosted by WHO) in November 2022. We call on the Alliance to focus its efforts on disability health and for this to be a thematic area of work for them (<https://ahpsr.who.int/what-we-do/thematic-areas-of-focus>).

CONCLUSION

Globally, the health of people with disability has received little attention in health policy and systems research, yet people with disability experience significant disadvantages that contribute to their poorer health. Researchers have a responsibility to ensure that their methods and findings are accessible to all, so they do not perpetuate the under-representation of people with disability in health policy and systems research. Without having disability-inclusive health policy and system research as we propose, health systems are much less likely to ask for, hear or consider the needs or perspectives of people with disabilities, or to be held accountable for ensuring better health outcomes. Our reflections add to the growing body of evidence indicating that online qualitative methods can be effective in engaging under-represented groups and are essential to ensuring their input into health policy and systems research.

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