



# Writing and Dissemination

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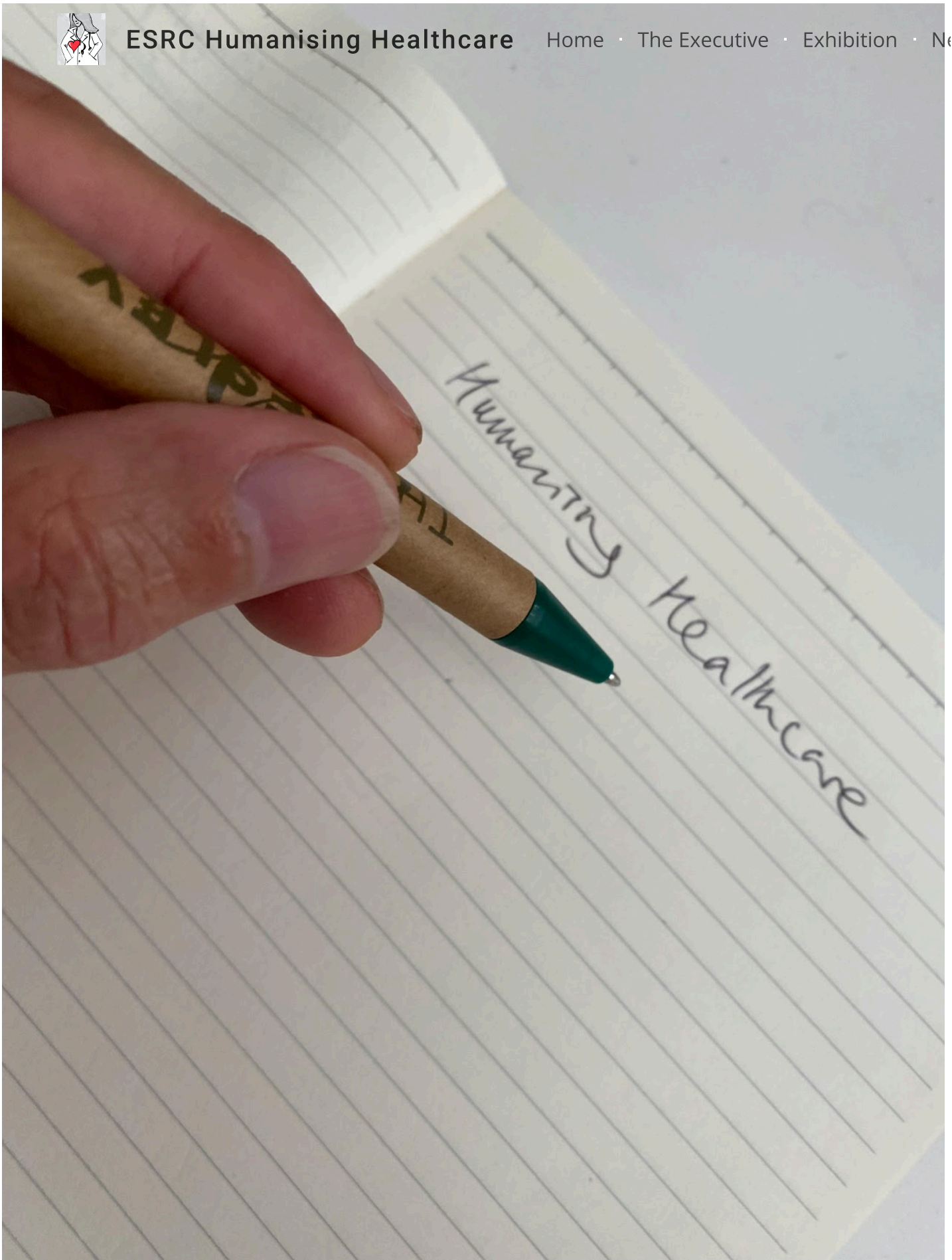


Image of a hand with a pen writing 'Humanising Healthcare' on a lined note book





# Our commitment to different audiences and different styles of dissemination

As a team of researchers from advocacy-based organisations, universities and clinical settings, we are committed to disseminating our findings to:

- people with learning disabilities, self-advocacy groups and their supporters and families;
- healthcare practitioners, service providers and policy makers;
- social science, humanities and clinical researchers

We use different formats including online presentations, Easy Read publications, illustrations, podcasts and journal articles.



Humanising Healthcare Seminars, symposia and keynotes presentations 2022 - 2025

## Seminars, symposia and keynotes presentations 2022 - 2025

The Humanising Healthcare team have presented findings from the project to a number of inter/national and multi/disciplinary audiences. You can find a link to the powerpoint slides for many of these presentations on our [News Page](#). and we have provided an up to date list to the left. If you require any further information about these presentations please email [d.goodley@sheffield.ac.uk](mailto:d.goodley@sheffield.ac.uk)

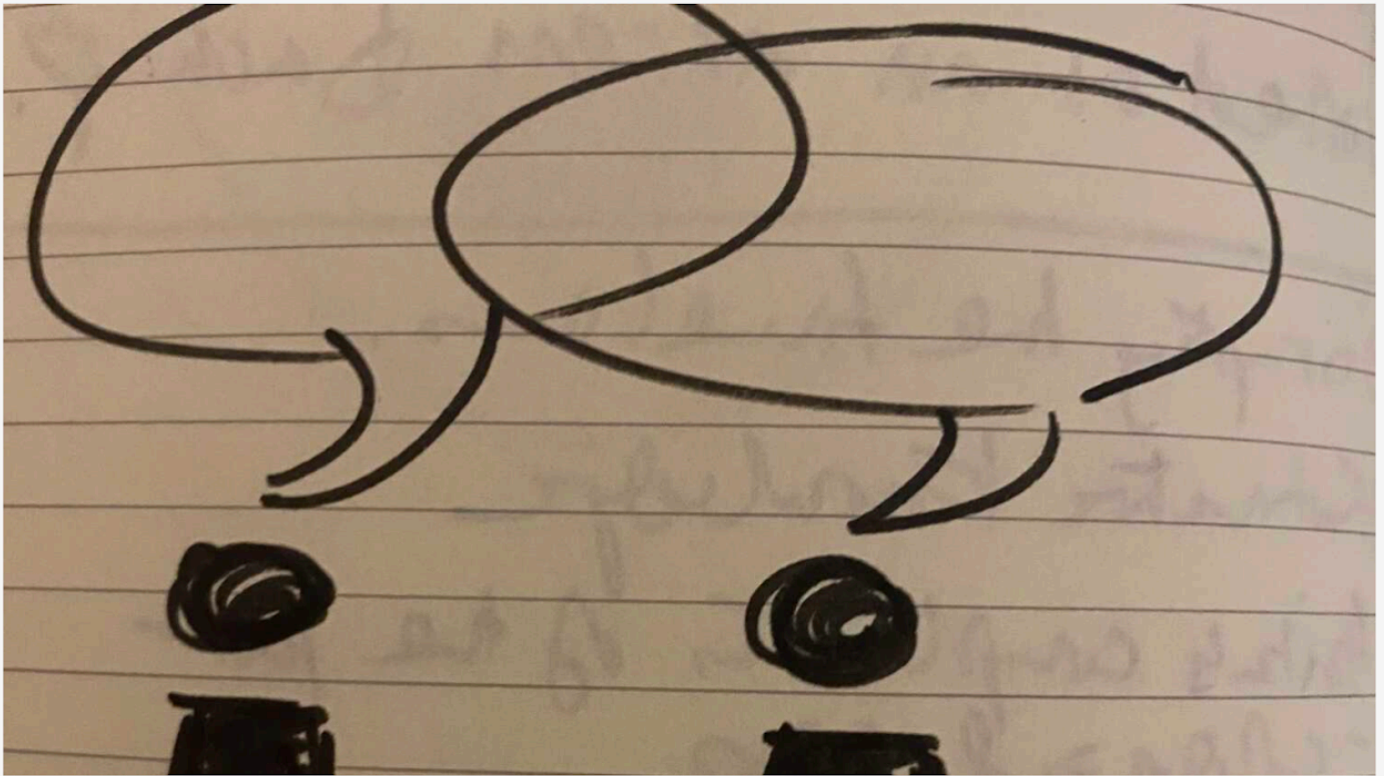


# Disability Dialogues



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A joint venture of iHuman, University of Sheffield; Centre for Disability Studies, University of Leeds; Disability Innovation Institute, UNSW and NIE/NTU Singapore



two simple cartoon characters with overlapping speech bubbles

## Team contributions to *Disability Dialogues*

**Disability Dialogues:** a series of short provocative pieces about disability studies and research and a joint venture of iHuman, University of Sheffield; Centre for Disability Studies, University of Leeds; Disability Innovation Institute, UNSW and NIE/NTU Singapore. Some of our team have written pieces for Disability Dialogues as part of a wider commitment to ensuring the politics of self-advocacy and people with learning disabilities are a key part of critical disability studies scholarship



# **Bojana Daw Srdanovic (2025). Allyship in Healthcare for People With Learning Disabilities as a Praxis of Respect, Attention and Collaborative Action. Sociology of Health and Illness**

## **Gold Open Access**

There is a dearth of literature focusing on how allyship in health may be enacted in relation to people with learning disabilities (LD). This is concerning, because people with LD are vulnerable to health inequalities and forms of medical dehumanisation including do-not-resuscitate orders, diagnostic overshadowing and overprescription of psychotropic drugs. Deploying critical disability studies as a lens through which to understand disability, this paper reviews models of disability allyship developed in healthcare, research and theatre. In doing so it advocates transformative allyship as a model that can both animate action in support of people with learning disabilities and accommodate the involvement of others, including clinicians, carers and relatives, without compromising the all-important commitment to supporting disability cultures. The paper presents and analyses ethnographic data gained through observations of eleven healthcare appointments between seven clinicians and five patients with LD, undertaken as part of the ESRC-funded study Humanising Healthcare. It documents the potential of transformative allyship in healthcare to transform harmful disablist practices through emphasising respect, attention and collaborative action while also noting that broader structural conditions and diagnostic technologies limit the extent to which clinicians can enact transformative allyship.



Dictionary – Humanising Healthcare-2.pdf

## **Impact output**

### **Humanising healthcare team (2025): Project Dictionary**

University and clinical researchers have worked with Barod, Sheffield Voices, Speakup Self-advocacy, Sunderland People First to produce a Plain English dictionary of keywords that are commonly used on our research project. The document to the left is in pdf format and is also available in word - please contact [d.goodley@sheffield.ac.uk](mailto:d.goodley@sheffield.ac.uk) if you prefer a word version.





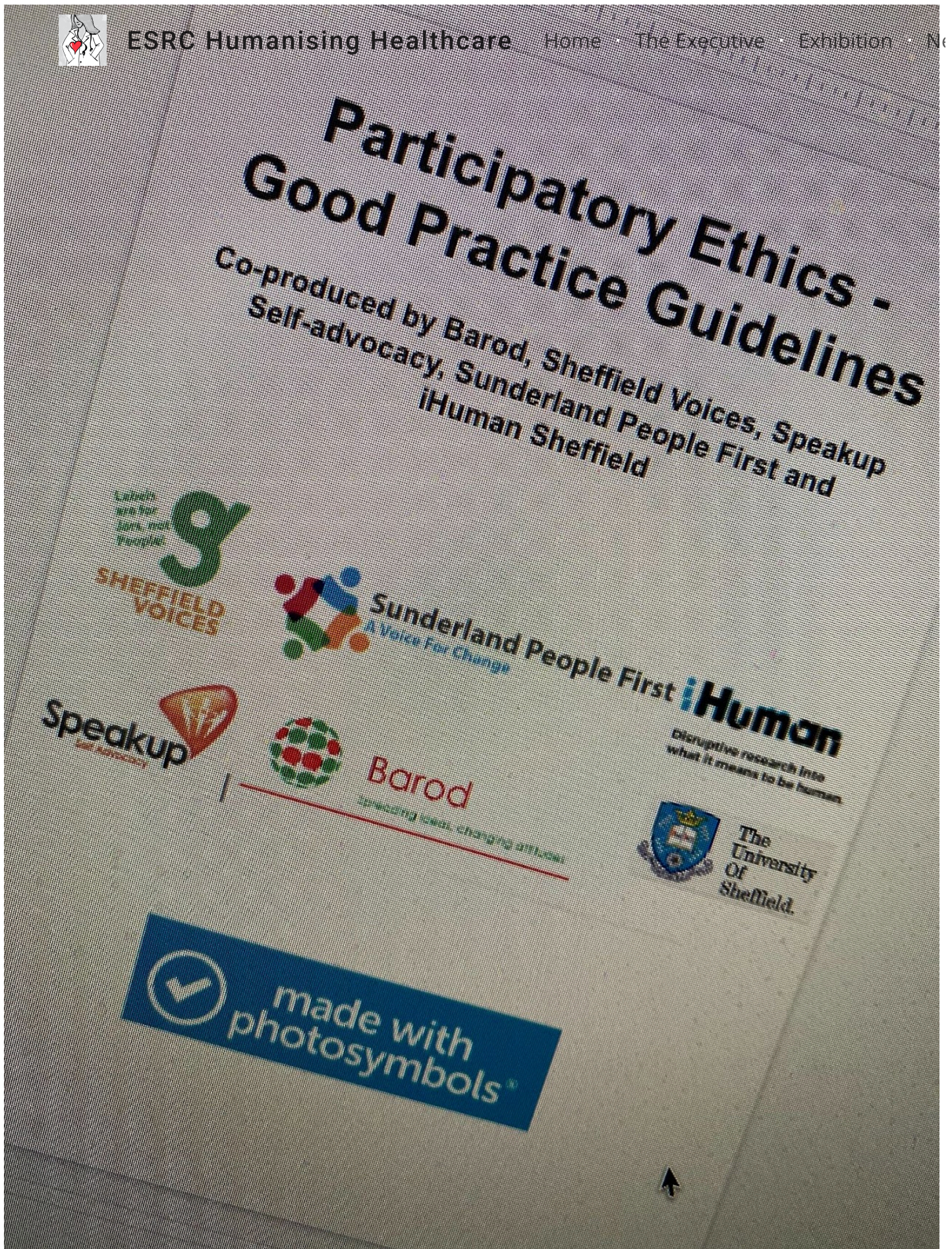


Photo of the cover of the Good Practice Guidelines Document





[Impact](#)
[Barriers](#)
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[Speakup Self-advocacy](#)
[Sunderland People First](#)
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**ESRC Humanising Healthcare**  
**Sheffield (2022). Participatory Ethics - Good Practice Guidelines. Sheffield: University of Sheffield.**  
[Available here](#)

This document details 10 guidelines for researchers to make their ethics applications more accessible to researchers with learning disabilities.

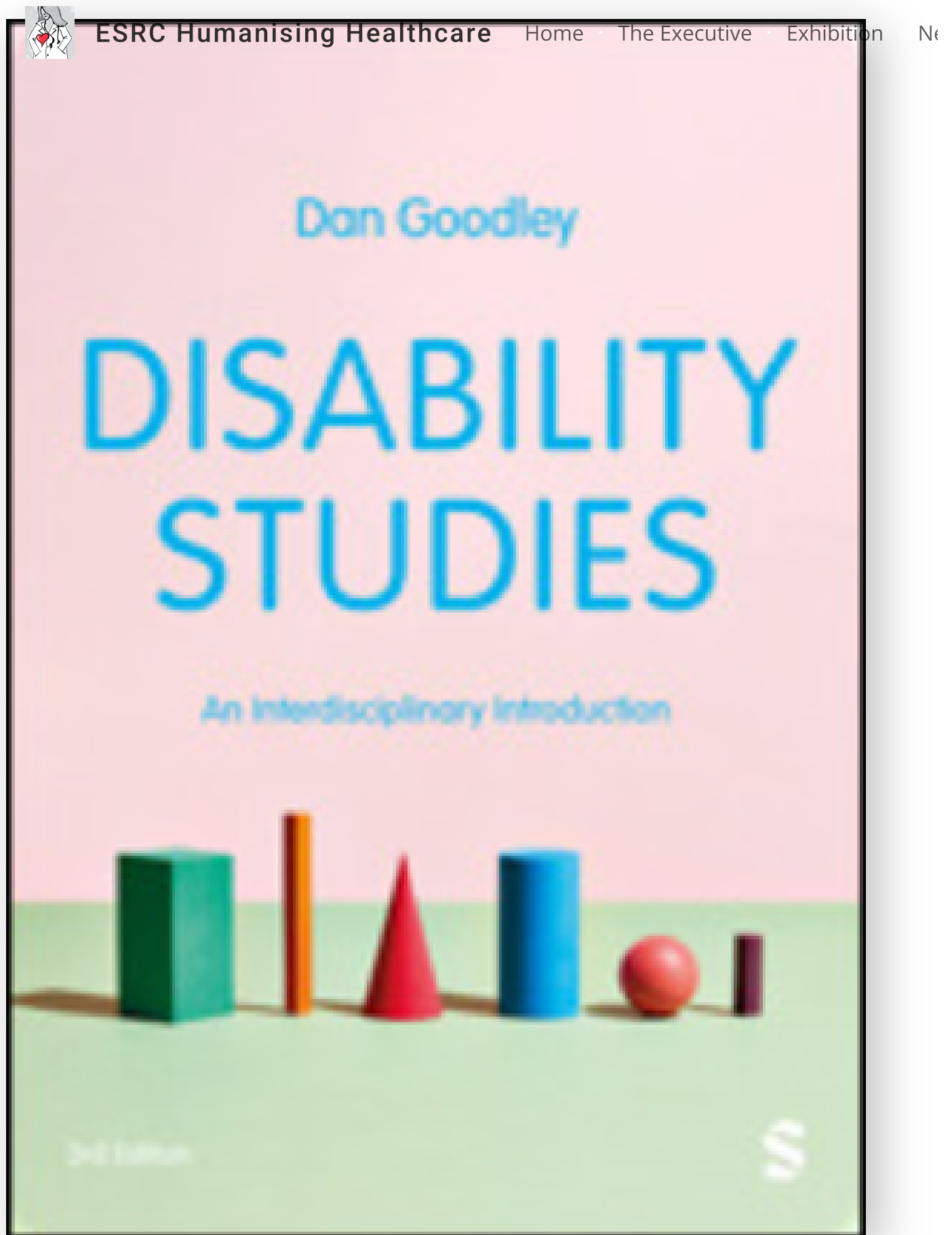


A logo for the journal Scandinavian Journal of Disability Research

## Academic output

**Goodley, D., Liddiard, K. and Lawthom, R. (2025) 'The Depathologising University',**  
***Scandinavian journal of disability research : SJDR*, 27(1), p. 120. doi: 10.16993/sjdr.1240.**  
[Gold Open Access](#)

It has been argued that the university needs depathologising, a radical rethink and reorientation of the university's relationship with disability. This paper offers an original affirmative proposition: that the university is already depathologising. Inspired by disabled people's activism and scholarship, we explore the ways in which academics, researchers and research professional colleagues are depathologising the disablist and ableist university. We reflect on our practices as principal investigators and research leaders of three funded research projects using novel composite conversations (a unique methodological form of experimental writing) and explore (i) pushing back at university bureaucracy towards co-production; (ii) critically appropriating the performative university and (iii) enabling access as colleagues. Depathologisation invites us to pause, to meditate and to significantly reimagine the university. And those of us who work in the university are the university, and we all have work to do.



The book cover for Dan Goodley's Disability Studies third edition text







# Academic outputs

**Goodley, D. (2024). Disability Studies: An interdisciplinary introduction. London: Sage.**

This third edition of a disability studies textbook makes direct reference to the humanising healthcare project in order to unpack questions of ethics, methods, analysis and participation with a specific focus on the importance of emancipatory disability research.



A picture of the opening slide for the Open Research Conversations presented by Barod, Sheffield Voices, Speakup Self-advocacy, Sunderland People First and iHuman Sheffield

## **Impact output**

**Barod, Sheffield Voices, Speakup Self-advocacy, Sunderland People First and iHuman Sheffield (2022). Participatory Ethics - Good Practice Guidelines.**

Presentation given by Vicky Farnsworth (Speakup self-advocacy) as part of the Open Research Conversation on Co-production, University of Sheffield, 12 October 2022. A recording of this presentation is now available to view in the University of Sheffield repository, ORDA





ORIGINAL ARTICLE | Open Access |

# Affect, dis/ability and the pandemic

Dan Goodley , Rebecca Lawthom, Kirsty Liddiard, Katherine Runswick-Cole

First published: 02 June 2022 | <https://doi.org/10.1111/1467-9566.13483>

SECTIONS

PDF

Cover of a journal article: Goodley, D. Lawthom, R and Runswick-Cole, K (2022) 'Affect, dis/ability and the pandemic', Sociology of health & illness [Preprint]. doi:10.1111/1467-9566.13483.

OPEN ACCESS

# **Goodley, D. Lawthom, R and Runswick-Cole, K (2022) 'Affect, dis/ability and the pandemic', *Sociology of health & illness* [Preprint]. doi:10.1111/1467-9566.13483.**

## **OPEN ACCESS**

### **Abstract**

The pandemic has heightened anxieties, impacted mental health and threatened to create an overwhelming sense of existential dread. We recognise the material ways in which disabled people have been differentially impacted by Covid-19 and make a case for understanding the affective dimensions of the pandemic. We develop a theoretical approach - cutting across medical sociology and critical disability studies - that understands affect as a social, cultural, relational and psychopolitical phenomenon. We introduce a public engagement project that took place in March and April of 2020 that garnered blogspots from around the world to capture the pandemic's impact on the lives of disabled people. Our data analysis reveals three key affective themes: fragility, anxiety and affirmation. To understand the emotional impacts of Covid-19 upon the lives of disabled people we embed critical analyses of affect in the dual processes of disablism and ableism: the dis/ability complex. We conclude by considering how we might conceive of a post-pandemic recovery that places the health and well-being of disabled people at the centre of proceedings.





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Image of the abstract





Academic output



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Goodman, D. (2023). Disability and the Medical Posthumanities. *Interconnections: Journal of Posthumanism / Interconnexions: revue de Posthumanisme*.

## Abstract

This paper makes a case for being in but not of the medical posthumanities; cognisant of our contemporary times that continue to render some human beings as valued and others as expendable. I provide a brief reading of medical posthumanities before turning to a field (critical disability studies), an event (the deployment of [Do Not Attempt Cardiopulmonary Resuscitation notices](#) to disabled people during the Covid-19 pandemic in the UK) and a response (reflected in the activism of People First; the international movement of people with learning disabilities). I contemplate some tensions that emerge when the field, event and response rub up against the medical posthumanities; working the humanist register, more-than-human possibilities and human troubles. I conclude with the argument that unless the medical humanities engage with disability then they are in danger of 'ability-washing' their research and scholarship



WILEY  Online Library





**Bottomley, M. et al. (2024) 'Co-producing ethics guidelines together with people with learning disabilities'. British Journal of Learning disabilities.**

## Abstract

### Background

We are a research team of clinical, academic and advocacy-based researchers with and without learning disabilities, working on the *Humanising Healthcare* (for people with learning disabilities) project. The project is dedicated to finding and sharing healthcare practices that enhance the lives of people with learning disabilities. As part of our ethics applications to access National Health Service study sites for fieldwork, we worked together to write guiding principles for co-producing research ethics with researchers with learning disabilities. In this paper, we introduce these Participatory Ethics Good Practice Guidelines and reflect on our collaboration.

### Methods

We reflect on developing the Participatory Ethics Good Practice Guidelines. These guidelines were developed during online co-production meetings with our full research team, including advocacy-based organisation researchers, clinical researchers and university researchers. We considered consent, understanding research, and understanding research methods during the development of these Guidelines.

### Findings

We present ten guidelines for co-producing research with people with learning disabilities.

### Conclusions

Our findings may be helpful to researchers with learning disabilities, university and clinical researchers, funders, and those who work in research governance (e.g., ethics committees and university research departments).

### Accessible Summary

- An Easy Read version of this accessible summary can be found in Appendix A.
- It is important to do disability research together with researchers with learning disabilities.
- Co-production is where researchers with and without learning disabilities work as partners. Co-produced learning disability research should be led by people with learning disabilities.
- An important part of doing research is thinking together about research ethics. Research ethics is about doing fair research that does not harm people with learning disabilities.
- We are a research team of people with and without learning disabilities. We worked together to develop 10 ideas for co-producing research.
- We called these 10 ideas 'Participatory Ethics Good Practice Guidelines'. This paper includes an Easy Read version of these 10 ideas (Appendix B).
- Researchers with learning disabilities on our study team are not just experts in being a person with a learning disability but also experienced researchers; a point all researchers should keep in mind.





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# LEARNING DISABILITIES & HEALTH INEQUALITIES

Men with learning disabilities die on average 22 years younger than men in the general population<sup>1</sup>



Women with learning disabilities die on average 26 years younger than women in the general population<sup>1</sup>



AVOIDABLE DEATHS –  
LEARNING DISABILITY<sup>2</sup>



AVOIDABLE DEATHS –  
GENERAL POPULATION<sup>2</sup>

Avoidable deaths are those that could have been avoided through healthcare or public health intervention



33.6%

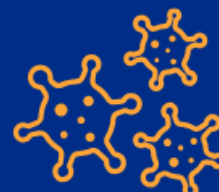
Of people with a learning disability have a psychiatric condition<sup>3</sup>



Almost half of people with learning disabilities have at least one other health condition<sup>4</sup>

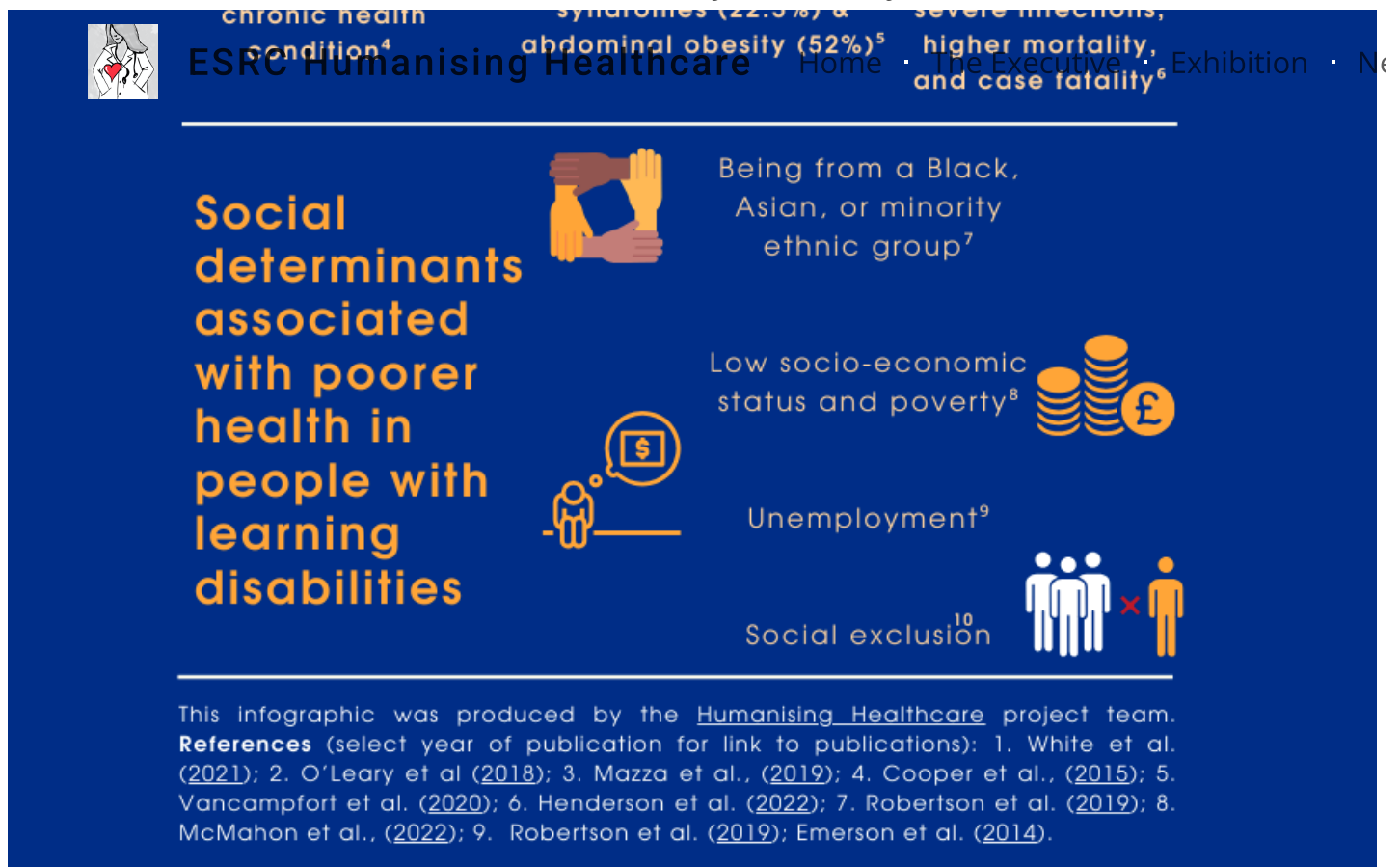


People with learning disabilities have high rates of risk factors associated with cardiovascular problems, e.g., metabolic syndromes (22.5%) &



People with learning disabilities had more COVID-19 infections, more severe infections





## Public engagement output

We have produced an infographic about the health inequalities facing people with learning disabilities.

### **This is why humanising healthcare is so important!**

Compared to the general population, people with learning disabilities die on average younger, are more likely to die from avoidable deaths, and are at a higher risk of a range of mental and physical health conditions.

Check out our infographic summarising some of these health inequalities.

**References** (select year of publication for link to publications): 1. White et al. (2021); 2. O'Leary et al (2018); 3. Mazza et al., (2019); 4. Cooper et al., (2015); 5. Vancampfort et al. (2020); 6. Henderson et al. (2022); 7. Robertson et al. (2019); 8. McMahon et al., (2022); 9. Robertson et al. (2019); 10. Emerson et al. (2014).







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# Qualitative Research in Psychology

Volume 17, 2020

Included in this print edition:

Number 4, October–December

David Giles  
Brendan Gough  
Antonia Lyons

 Routledge  
Taylor & Francis Group





# Academic Output

Srdanovic B, D., Hayden N, Goodley D, Lawthom R & Runswick-Cole K (2024) **Failing ethnographies as post-qualitative possibilities: reflections from critical posthumanities and critical disability studies**. *Qualitative Research in Psychology*.

Recent moves from qualitative to post-qualitative inquiry can be traced back to various developments and methodological quandaries. Posthuman philosophy and methodology is one origin story of the move to post-qualitative inquiry. This broad approach contests the humanist impulse at the heart of qualitative inquiry and demands imaginative forms of post-qualitative inquiry, theory and research that engage with the more-than-human realities and nuances of everyday life. What might it mean to hold post-qualitative sympathies and tackle a foundational methodology of qualitative inquiry (ethnography) from a quintessentially posthuman position (disability)? With reference to an ongoing ESRC funded project—Humanising Healthcare—we provide two writings about the possibilities and challenges of failing ethnography. Through reference to critical posthumanities and critical disability studies theory, we attend to broken, patchwork, kintsugi and crip ethnographies that, we argue, allow us to sit in the liminal space between qualitative/post-qualitative research and human/posthuman theory.





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# Subjectivity

[Overview](#)[About](#)

**Editor:** Lisa Blackman; Valerie Walkerdine  
**ISSN:** 1755-6341 (print)  
**ISSN:** 1755-635X (electronic)  
**Journal no.:** 41286

A photo of the Subjectivity Journal homepage





**Goodley, D. Being human as praxis: for people with learning disabilities. *Subjectivity* 30, 167–184 (2023).**

**Gold Open Access**

### **Abstract**

The paper posits that *being human as praxis*—in relation to the lives of People with Learning Disabilities—offers a significant and original insight into critical and social theory across the social sciences and humanities. Drawing on postcolonial and critical disability theory I suggest that being human as praxis of People with Learning Disabilities is sophisticated and generative but is always enacted in a deeply disablist and ableist world. I explore being human as praxis in (i) a culture of disposability; (ii) the midst of absolute otherness and (iii) the confines of a neoliberal-ableist society. For each theme I start with a provocation, follow up with an exploration and end with a celebration (with the latter referencing the activism of people with learning disabilities). I conclude with some thoughts on simultaneously *decolonising* and *depathologising* knowledge production, the importance of recognition and writing *for* rather than *with* People with Learning Disabilities.



# JIDR

**Journal of Intellectual Disability Research**

The Foremost International Journal on Intellectual Disability

**volume 68  
part six  
June 2024**



**International Association for  
the Scientific Study of Intellectual  
and Developmental Disabilities**

**Published on behalf of MENCAP and in association  
with IASSIDD by John Wiley & Sons Ltd**

**The support of the Challenging Behaviour &  
Mental Health Special Interest Research  
Group of IASSIDD is gratefully acknowledged.**

Bishop R, Laugharne R, Shaw N, Russell AM, Goodley D, Banerjee S, Clack E & Shankar R (2023) **The inclusion of adults with intellectual disabilities in health research - challenges, barriers & opportunities: a mixed-method study among stakeholders in England**. Journal of Intellectual Disability Research.

## Background

To understand system barriers to research participation for people with intellectual disabilities.

## Methods

A mixed methods approach examined the inclusivity of people with intellectual disabilities in a random sample of National Institute for Health and Care Research (NIHR) studies conducted in 2019-2020. An online questionnaire (stage one) was sent to the selected studies lead investigators. An expert by experience panel of 25 people with intellectual disabilities (stage 2), discussed the stage one feedback. Descriptive statistics for quantitative data and thematic analysis for qualitative data was conducted.

## Results

Of 180 studies reviewed, 131 studies (78%) excluded people with intellectual disabilities. Of these, 45 (34.3%) study researchers provided feedback. Seven (20%) of the 34 studies which included people with intellectual disabilities gave feedback. Of all respondents over half felt their study had some relevance to people with intellectual disabilities. A minority (7.6%) stated their study had no relevance. For a quarter of respondents (23.5%), resource issues were a challenge. Qualitative analysis of both stages produced four overarching themes of Research Design & Delivery, Informed Consent, Resource allocation and Knowledge & Skills.

## Conclusion

Health research continues to exclude people with intellectual disabilities. Researchers and experts by experience identified non-accessible research design, lack of confidence with capacity and consent processes, limited resources such as time and a need for training as barriers. Ethics committees appear reluctant to include people with cognitive deficits to "protect" them. People with intellectual disabilities want to be included in research, not only as participants but also through coproduction.