

## **Readme too: Thinking of using this dataset? Read the team's approach to Open Data that involves people with learning disabilities<sup>1</sup>**

**Nikita Hayden, [Bojana Daw Srdanovic](#) and Dan Goodley**

### **Abstract**

This contextual paper sits critically, conceptually, pragmatically and problematically with the idea, ethics and practice of Open Data. Contemporary research, science and innovation sectors engage with the remit of Open Research: making available, open and public the research data and outputs that are produced through research projects. Open Data is one element of Open Research and Open Science which promotes the sharing, repurposing and redistribution of research data through online repositories that can then be used by others including other researchers, policy-makers and non-government organisations. With reference to a research project (*Humanising Healthcare*) and an interdisciplinary field of inquiry (*critical disability studies*) we subject Open Data to critical scrutiny. First, we introduce Open Data as one element of the Open Science movement, engage with a perspective (critical disability studies) and consider wider questions of social justice. Second, we describe the data that has emerged from the Humanising Healthcare project to ground the paper. Third, we critically expand on our decision making around the curation of Open Data from this project. We conclude the paper with an appeal: the humanisation of Open Data.

***This paper will also be drawn upon for a forthcoming paper led by Nikita Hayden; working title 'Humanising Open Data' For more information about this follow up publication email [d.goodley@sheffield.ac.uk](mailto:d.goodley@sheffield.ac.uk)***

---

<sup>1</sup> The term learning disabilities is the one used in the UK with other labels being used in different countries ranging from development disabilities, intellectual disabilities and cognitive impairments. I will refrain from offering a mainstream administrative definition of learning disabilities—which would normally refer to issues of competence, intelligence and maladaptive functioning—in response to the wider aims of this paper to centralise people so-labelled in broader and more affirmative discussions of humanity.

## **Section 1: Introduction**

The impulse to share research data has been emboldened by the Open Science movement. According to the British Psychological Society (2020: 1) a key ambition of this movement is ‘to make science more reliable and to increase trust in research through openness and transparency. Sharing research data – ‘open data’ – so that it can be freely used, repurposed and redistributed is integral to open research’. Some have made an impassioned case for Open Research (Dienlin, et al, 2021) while others have dismissed the Open Science Movements as a form of data/platform colonial-capitalism: enacting new forms of extraction, co-optation, and erasure that reproduce disciplinary whiteness (Dutta, et al, 2021).

Some of the underlying assumptions of Open Science rub up against our own epistemological, ontological and methodological positionalities. As qualitative researchers, concepts such as reliability and trust in data do not resonate (Pownhall, 2025). We are, to be honest, often more interested in specificity and authenticity. The very idea that the data we produce can contribute to a wider project of replicability is one that we struggle to get behind. Moreover, as we delve deeper into the assumptions and practices of Open Data we find that these are in friction with many of the ambitions and aspirations of our research and its potential impact and reach across a host of potential consumers. Pownall (2025) makes the point that qualitative researchers often have a different view of their participants - and their ‘data’ - than quantitative researchers. This is particularly the case with co-produced research projects where the very idea of data sharing sits in direct opposition to non-extractive collaborative research.

As members of the *Humanising Healthcare*<sup>2</sup> research team, our alliances are less with the Open Science and Open Research movements and more *with* people with learning disabilities and capturing *their* stories and perspectives as they relate to notions of humanising and compassionate healthcare. Moreover, the idea that the deeply personal and sensitive stories of people with learning disabilities are ‘repurposed and redistributed’ as data raises alarm bells. The social histories of people with learning disabilities are marked by historical epochs where this societal group has been subjected to forms of over-monitoring and surveillance. To render, yet again, their data as open for repurposing and reuse by researchers feels like another form of abuse and dehumanisation. All of us hold on to an idea that we might maintain our personal data in ways that are heightened by societal concerns around privacy, choice and autonomy. And we are mindful of the dangers associated with Big Data and Open Data. Questions of data ownership are complicated further for people with learning disabilities who continue to occupy disempowered positions in society. We are also minded of the words of Prosser et al (2023: 1648) who write that for qualitative researchers such as us; ‘the arguments around the democratization of knowledge are more complex, particularly when we consider who the imagined users of our shared data are and how data might be used (or misused). Indeed, ‘the idea of sharing data with anyone other than participants is anathema to their professional values and is seen as compromising the future of such research’ (Prosser et al, 2023: 1648).

Our commitment to working in collaboration with our participants - particularly researchers with learning disabilities - in order to ensure that *their* experiences and aspirations are put out in the world for *their* benefit - means that we cannot simplistically align with the ambitions of Open Science and Open Research. Instead, following Fox et al (2021), we want to centre ***questions of social justice*** specifically: How might we

---

<sup>2</sup> **Humanising Healthcare, Economic and Social Research Council**  
[Humanising the Healthcare of People with Learning Disabilities and/or Autism funded by the Economic and Social Research Council \(ES/W003406/1\)](#)

approach data sharing and archiving in a way that puts the aspirations and experiences of people with learning disabilities front and centre?

Our question emerges from a project (that we will describe below) and in conversation with an interdisciplinary field of inquiry: critical disability studies (e.g. Meekosha and Shuttleworth, 2009; Shildrick, 2009; 2012). This community of scholars, researchers and activists positions disability as the driving subject of inquiry: contemplating the ways in which normative, everyday and institutionalized forms of knowledge and convention are troubled by the excessive possibilities of disability. When we contemplate Open Data and Open Research we foreground the lives, histories and aspirations of disabled people. We know from foundational disabled scholars such as Oliver (1990) that research and researchers have intervened in the lives of disabled people in dangerous, pernicious and medicalising ways. Disability is too often considered to be an individual flaw, deficit and problem requiring a solution. And disciplines such as psychology, education and psychiatry have been emboldened by these deficit perspectives; set up as the solutions to the problem of disability. Critical disability studies approaches disability research in a very different way. Rather than being a passive object of research, disabled people are repositioned as active participants and researchers of disability. Disability research is oftentimes an exploration of social justice and injustice (Terzi, 2005). And for research to become more socially just then this requires centralising disabled people in the conceptualisation, planning, decision-making, doings and applications of research. Any engagement with Open Research and Open Data is also an engagement with the key concerns of critical disability studies (Goodley, Lawthom and Liddiard, 2021). While these concerns are multiple and multifaceted, one of these sits with us throughout the paper: ***how can Open Data be used in ways that contribute to the emancipation and activism of people with learning disabilities?***

'Humanising the Healthcare Experiences of People with Learning Disabilities and/or Autism' - *Humanising Healthcare* for short - is a project that brings together researchers with learning disabilities, clinical researchers and social scientists to investigate and identify forms of compassionate and affirmative healthcare that are experienced by

people with learning disabilities. Our dataset includes accessible project proposals, information sheets and consent forms; qualitative data including coded interview transcripts and participant observations fieldnotes of patients with learning disabilities; coded interviews between self-advocates with learning disabilities and entries to an online exhibition which showcases the innovative advocacy, consultancy, training, advice and innovation produced by our non-academic advocacy-based organisation partners (who are researchers in their own right): Barod, Speakup Self-advocacy, Sheffield Voices and Sunderland People First. Our team has worked together to prepare this data set and we insist that anyone using or accessing our dataset should read this document - ***Thinking of using this dataset?*** - which works as a background document setting out how we critically, conceptually and pragmatically engage with the idea and practice of Open Data. This document explains some of our decision making process - in collaboration with researchers with learning disabilities - about the data we agreed to make open and the data we chose to keep back. We approach Open Data with a conviction: ***that any user of our data must keep in mind the importance of co-researching the lives of people with learning disabilities in collaboration with these people so-labelled.*** Moreover, our dataset will also include access to Gold Open Access publications, working papers and a series of [Disability Dialogues papers](#) that provide theoretical, methodological and analytical reflections on doing disability research with rather than on disabled people. Sharing these outputs means that we can, to some extent, control the narrative to the emerging data from our project. Whatever data or outputs are shared with the wider world - perhaps an imagined potential community of data users - we want to make a point: ***that open data has to become part of a wider project of humanising the lives of people with learning disabilities.***

## **Section 2: The Humanising Healthcare project**

Scandals, inquiries and reports into Winterbourne View, Whorlton Hall, Mendip House, Slade House and Yew Trees Hospital have revealed the tragic consequences of dehumanising care for adults with learning disabilities and/or autism. Previous research has evidenced a number of stubborn problems within healthcare; including ignorance, indifference and diagnostic overshadowing on the part of professionals (where

underlying health conditions such as constipation or epilepsy are missed and symptoms incorrectly attributed to learning disability/autism). Uptake of annual health checks, screening and follow up appointments are low and there is evidence of inappropriate prescriptions of psychotropic drugs. Despite previous attempts to promote empowering, person-centred and holistic care practices, many people with learning disabilities and/or autism are dehumanised by healthcare.

Humanising Healthcare posits a new approach; the development of the concept of 'Humanising Healthcare', where we identify principles and practices of empathy, dignity, compassion, kindness and recognition. Our research team sought to investigate the cultures, conventions, systems, relationships and practices of a neurology service and a learning disability service. Our thinking was that this focus on specific services would allow us to identify the ways in which these two distinct services and their practitioners deliver humanising healthcare. The project started in August 2022 and run for three years. Throughout the time of the project we have provided regular updates on our work through our [project website](#). Our research fieldwork has five key phases to it.

The **1st phase, qualitative research fieldwork**, has focused on two NHS healthcare services - a neurology service and a learning disability service - two social science researchers (Dr Nikita Hayden and Dr Bojana Daw Srdanovic) have carried out the following qualitative fieldwork:

We recruited 8 (neurology service) and 6 (Learning disability service) people with learning disabilities. One participant with learning disabilities (neurology) passed away during the time of our project, while another person so-labelled and their family decided to withdraw from the study (neurology): thus confirming that our ongoing informed consent and withdrawal processes were responsive. One participant with learning disabilities (learning disability service) did not engage with the study after recruitment.

51 ethnographic encounters with 12 people with learning disabilities were carried out - across the two NHS sites - encompassing face-to-face and online

observations of consultants' appointments, cancelled appointments, multidisciplinary team meetings, clinical meetings, checkups and open clinical days.

13 semi-structured interviews were undertaken with nine people with learning disabilities accessing the two NHS services. Although we did employ inclusive interview methods, a further four interviews were completed with additional patient-participants with learning disabilities, but the methods were not sufficiently inclusive for the interviews to contribute data for this study.

28 semi-structured interviews with significant others of the people with learning disabilities (including parents, siblings, trusted friends and trusted professionals). One of our significant others passed away during the time of the study.

We have planned follow up meetings with all people with learning disabilities and their families in Summer 2025; where we will share key findings of the research to honour their contributions and accounts.

Running in parallel with this fieldwork, we have worked with researchers with learning disabilities to help us lead, manage and direct the research project. The **2nd phase** relates to work of **The Executive Team**; which prioritises the expertise and input of those members with learning disabilities who are paid to work with us through the consultancy fees of their organisations; Speakup Self-advocacy Rotherham; Sheffield Voices; Sunderland People First and Barod. These members of The Executive are researchers in their own right - holding the social science and clinical researchers to account - and are involved in all stages of the project from writing the successful research grant; submission of ethics; assessment of methods and fieldwork plans; analysis of emerging data and collaborative writing of different outputs and dissemination. The Executive has met online and face-to-face 15 times over the course of the two year project. Researchers with learning disabilities are not just involved in the process of doing research; they are a central part of The Executive that is responsible

for the curation of Open Data. We know that research on the lives of people with learning disabilities is often undertaken by researchers without learning disabilities. In contrast, we work in collaboration with researchers with learning disabilities towards a model of research and a research reality that they support.

In addition to the work of The Executive, a further element of empirical work has been carried out which foregrounds researchers with learning disabilities as the generators of their own knowledge about humanising healthcare. This **Phase 3 self-advocates interviewing self-advocates** had two elements to it. The first invited Speak Up to group interview Sheffield Voices; Sunderland People First interviewed Speak Up; Sheffield Voices interviewed Barod; Barod interviewed Sunderland People First. This sharing of peer generated knowledge has been invaluable and has fuelled our analysis. Four interviews were completed. The second element to this phase involved a number of one-to-one self-advocates interviewing another about their experiences of the NHS; with an emphasis on sharing stories about when healthcare appears to be positive and affirmative. 12 interviews were completed.

As a team of researchers from advocacy-based organisations, universities and clinical settings, we are committed to disseminating through **Phase 4: Emergent 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; and which we publicise via [the project website](#). Indeed, in our Researchfish.com submission (itself an example of Open Research), we write that our early findings at this stage of the research include:

- A review of the literature where we identified that, 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. This evidence demands that we identify, share and inculcate forms of humanising healthcare.

- Researchers with learning disabilities can and should be involved with all stages of research from conception, to grant submission, to ethics, the design of methods and methodology, analysis of data and the dissemination of findings.
- People with learning disabilities' engagement with self-advocacy groups provides essential support and peer advocacy during the post-pandemic period of society; a time where their human value, worth and human rights have been seriously undermined.
- The healthcare of people with learning disabilities cannot be divorced from a broader understanding of society's continued dehumanisation and devaluation of people so-labelled which risks rendering them fragile, anxious and separated from their local communities.
- People with learning disabilities and their involvement with self-advocacy creates new kinds of empathic relationships, forms of support, access to knowledge and communities that not only sustain their lives and aspirations but also create new kinds of knowledge about humanising healthcare.
- While it is important to understand healthcare practices, services and professional interventions, self-advocacy groups have the potential to also raise the health and well-being of people with learning disabilities.
- Examples of humanising healthcare on the part of clinical practitioners - from consultants, nurses to professional services - are associated with compassion, empathy affirmation and care that assume patients with learning disabilities are human beings first.

- We need to be consistently mindful of the dangers of the ideology of diagnostic overshadowing: where the assumed learning disability of a person over-shadows a more thorough understanding of the health and well-being as a human being.
- Researching humanising healthcare raises important questions about epistemology (how we understand people with learning disabilities); methodology (how we research with and for people with learning disabilities) and ontology (how we conceptualise the very nature of humanisation and healthcare).
- Empathic, compassionate and humanising healthcare can only be understood in the context of contemporary cultural logics which continue to construe people with learning disabilities as less than human.
- A 'Reclaiming the Human in Healthcare Manifesto' is required to convey the key tenets of compassionate healthcare for people with learning disabilities: one that we write in collaboration with people with learning disabilities.

Finally, our project has curated **Phase 5: An online Exhibition**. [This space](#) is a live online celebration of the advocacy, consultancy, training, advice and innovation produced by Barod, Speakup Self-advocacy, Sheffield Voices and Sunderland People First that seeks to promote the humanisation of people with learning disabilities. This work engages with healthcare services and the NHS but also the broader social context which includes social care, education and community living. Our job as researchers here is to act as ***Open Data and Open Research conduits: to share the research and innovation excellence of the work of our research partners.***

### **Section 3: Curating Open Data**

Clearly, Humanising Healthcare has produced a lot of data. Questions need to be raised and addressed in relation to what goes public, what does not and for what reasons. At the same time, we also want to sit with the problematic notion of 'data' that is often implicitly conceptualised in Open Research: as reusable material and information that

risks reducing the human qualities of research encounters and the very real lives that are depicted via qualitative methods. Data as a concept has a dehumanising feel to it. When we approach questions of Open Data we need to bring the human back into our discussions and deliberations. This is why we prefer to term ***curating open data***: ***where we select, organize, look after, present and give context to the data that we share.***

Much of the **Phase 1: qualitative research fieldwork** data we have gathered is deeply sensitive, taken from a small often marginalised group of patients with learning disabilities who are drawn from two NHS sites named in the application and named in this paper. While we have clear ideas ourselves as the main researchers on the viability and ethics of making this data open and accessible to others we sought advice from our Open Access team at the University of Sheffield. They informed us:

*Sensitive data would not normally be shared openly, and the UK Data Service provides options for controlled access to sensitive data (you can find details [here](#)). It would be a good idea to contact the UK Data Service ReShare team, who can advise on appropriate options for sharing and ways of ensuring that data is anonymised as fully as possible. You can find contact details for the ReShare team [here](#).*

*There may be some material that can be made openly available, e.g. analysed data; blank consent forms; interview questions; methodological details. These could be shared openly via the UK Data Service or ORDA, which as an institutional repository is permissible for deposit of ESRC research data. If ESRC-funded research data is deposited in ORDA, the details should be provided to the UK Data Service.*

Clearly, we have a number of options, which we will come back to below. One consideration to pull out from our thread of communication with our Open Access university team relates to data that is not only sensitive but also readily identifiable and attributable to some of the participants that we spent time interviewing and observing in

their healthcare encounters. Anonymising this data would not only render much of it meaningless to the dispassionate outsider user (decontextualised, anonymise and fictionalised): it would also feel dehumanising to make public some deeply personal and private encounters and experiences. ***Any data that we share from our fieldwork has to be given an analytical context: so that the potential user knows why and how the data was gathered and for what means.***

Our other data also raises interesting ethical and pragmatic questions. **Phase 2: The Executive Team** meetings provided, in many ways, an innovative template for working collaboratively and in participatory ways with our different researchers. Our clinical and university researchers came to serve and service the online Executive Meetings; focused on the remit of foregrounding our partner organisations which included self-advocacy and workers co-operative groups. It is neither ethical nor responsible to share the details of these meetings. What is more potentially useful to other researchers is for us to share our materials that helped us to implement a process of participatory research which foregrounds researchers with learning disabilities as research leaders, theoretical provocateurs, methodology consultants, co-analysts and experts-by-experience. Data sharing in this way contributes in some small way to the burgeoning literature on co-produced and participatory research with people with learning disabilities (Walmsley and Johnson, 2003; Nind, 2016; Williams et al, 2020; Schwartz et al, 2020; Bottomley et al, 2024).

**Phase 3 self-advocates interviewing self-advocates** was an opportunity to share their own examples of how they as organisations are themselves trying to improve the healthcare experiences of people with learning disabilities (element 1) while also capturing individual stories of the NHS from peer interviews (element 2). While in the first element, the different organisations shared practices, work and interventions that are already public knowledge, critical reflections were often more personal. In the second element, very personal and sensitive stories were written which are simply not appropriate for sharing.

**Phase 4 emergent findings** are thematically pulled from all of our data sources. We

are mindful of the potential impact of a finding on the wider perceptions of our partner organisations. In short, were we to propose a finding as a recommendation that was controversial in nature then we would think carefully as a team about our association with that recommendation; pulling in the involvement of our Executive.

Finally, our **Phase 5 An online Exhibition** celebrates the advocacy, consultancy, training, advice and innovation produced by Barod, Speakup Self-advocacy, Sheffield Voices and Sunderland People First that seeks to promote the humanisation of people with learning disabilities. It is tempting to view this data as ethically unproblematic: in the sense that this is work produced by people with learning disabilities for a wider audience (primarily for people with learning disabilities, their families, service providers, other self-advocacy groups and healthcare practitioners). Nevertheless, we need to recognise that all Open Data lands in a social, cultural and political context. We write this at a time when disabled people are feeling the material impacts of changes to disability benefits (Ryan, 2025). Many of the materials showcased in the Exhibition offer provocative viewpoints on the place of people with learning disabilities in British Society; authored at a time before huge changes to the welfare system which now render disabled people with at the very least a sense of deep precarity.

Following Prosser et al (2023) we are wary of offering any prescriptive response to Open Data. Instead, each and every example of data needs to be considered carefully. We can choose to **reject** making our data open access on the basis of:

- **Epistemology:** as social constructionists we would argue that our 'data' is a specific, subjective and constructive: interview accounts, stories shared and ethnographic materials gather reflect and create narratives of a given time and place that has no connection whatsoever with the pseudo-positivist notions of rigour and replicability (Prosser et al, 2023).
- **Accountability,** for example, when conducting research involving illegal, sensitive, or stigmatized topics, maintaining the anonymity of participants is likely to be a key ethical responsibility for researchers in order to protect participants from physical, emotional, and reputational harm (Prosser et al, 2023).

- ***Our commitment to contesting helicopter research:*** we are wary of researchers extracted from secondary research without making efforts to give back to the very communities from which the original research originated (Prosser et al, 2023).
- ***Adopting an oppositional tactic to contest hegemonic Open Science;*** to ensure that, for example, disabled lives and perspectives or not simply again problematically co-opted into Big Data as objectives of study.

We can choose to **accept** making some of our data open access:

- ***When we redact*** aspects of the data that are sensitive and potentially identifiable.
- ***When we do so with a deep commitment to anonymisation and fictionalisation:*** because qualitative data emerges from a specific time and place, in collaboration with a small and at times easily identifiable group of people, it makes sense for us to be cautious and careful in our representation of qualitative material. Our data therefore might benefit from practices that sit on the borders of anonymisation/fictionalisation: changing of names, places and protected characteristics.
- ***When we put a timeframe on the availability of data by putting data under embargo;*** carefully edited data that are made available after a given period of time.
- ***When our data are given an adequate context:*** data is deposited with a clear audit trail, reflexivity statement and over-arching narrative that encourages the user to read and understand the data in terms of a time and place (Prosser et al, 2023). Fox et al (2021: 767) note that this approach starts with providing context and ends with 'Open workflow' where researchers should 'be transparent at every stage from idea generation to execution, sharing their notes, plans, and progress'. Giving context and being open are of course not the same. Giving context might actually proactively engage with disguising and protecting those involved in the research. We are mindful of Dienlin et al's (2021: 14) words who

argue that ‘qualitative researchers who are committed to sharing of their data research might include considering sharing research designs, interview and interrogation protocols, anonymized data and coded data files, and coding strategies used to analyze these data’. They argue that these strategies ‘allow other scholars to better understand their interpretive lenses, to better assess the quality of the findings, and to use or adapt these materials in their own research’ (Ibid).

- ***When we have added break points in the data*** - which prevent others who might use the data from making links across the data about one specific participant.
- ***When we have adequately safeguarded researchers*** by redacting stories or personal details that the researchers shared with participants that they do not wish to be shared nor archived
- ***When our data and research outputs are co-produced with our collaborators with learning disabilities*** - and this latter conviction is key to the dataset that we share.

What we decide in terms of accepting or rejecting data we need to do so in ***collaboration with our self-advocacy and workers cooperative partners***. From the very start of our research we have worked collaboratively with our research partners with learning disabilities - through regular meetings of The Executive - to pitch for a collaborative and participatory approach to research. We therefore implemented a **Co-production Workshop on Open Data** which brought together university researchers and researchers with learning disabilities from our partner organisations. We considered a number of questions including:

- What kinds of data do you think other self-advocacy and workers co-operative groups would be interested in?
- What kinds of data do you think the providers of healthcare should engage with?
- What kinds of data are we comfortable with sharing?
- What methods do we need to put in place to ensure anonymity while also promoting examples of humanising healthcare?

- What advice, recommendations and critical learning have already been produced by our self-advocacy partners that should be shared with others?

In addressing these questions we have sought to co-produce an approach to Open Research and Open Data; which has been picked up on by our Open Research team at the University of Sheffield as an example of good practice; where we were invited to present to an online staff seminar series (Barod et al, 2022a). Some key considerations in relation to Open Data were raised by our research collaborators with learning disabilities, these included:

- Sharing data is important because it might be used by other self-advocacy groups and researchers with learning disabilities.
- Any data that is shared must be done so ethically: maintaining confidentiality and anonymity.
- Coding the data we share is a good idea: because it gives shape to the data which might guide other researchers who use that data: to find their own examples of humanising healthcare.

### **What data should we share and why**

Open Science has been critiqued for its location in and centralisation of global northern research contexts. Dutta et al (2021) make the point that open knowledge has been a historical reality for many researchers, activists and communities based in the Global South. We could make similar observations about disability communities. Disabled people's organisations (DPOs) have historically been committed to sharing their data, research and policy aspirations and political mandates with other DPOs. For example, the self-advocacy movement - a political movement peopled and led by people with learning disabilities - has been built upon the distribution of knowledge across the movement. But what kind of data and knowledge is being shared? Our answer lies in ***the sharing of resources that seek to improve the lives of people with learning disabilities rather than data which objectifies, pathologises or measures people so-labelled.*** Useful data reproduced through the self-advocacy movement is often



downgraded or belittled through its categorisation as 'grey literature'. And yet its **utility to serve the politics of self-advocacy** means that it is not driven by objective measures nor operational definitions of good research. Instead, self-advocates 'produce valuable knowledge from the margins operate under different sets of ontological and epistemological assumptions that allow for discreet, messy, nonlinear, and sometimes, intangible sets of data to be generated and analyzed to engender new theories for and about disenfranchised and oppressed communities' (Dutta et al, 2021:807-808).

The data we share with others 'look and feel far removed from the neat, tangible, ordered, and copious data generated by scholars in the North that are aligned with the colonizing logic of reproducibility' (Dutta et al, 2021: 808). This is data with a purpose: to contribute to academic debate, public discourse and professional practice that is engaging with compassionate and humanising forms of healthcare. Ironically, some of our best data are not data produced directly from our research project: they are data, analyses, recommendations, provocations and suggestions that have emerged from the work of our self-advocacy and workers cooperative non-academic research partners. Citing their work is very important because it contests pre-existing 'white-washed colonial notions of rigor and prestige influence' (Dutta et al, 2021: 808) - and to which we would add **ability-washed** notions of what counts as good high quality data.

Our approach to data archiving followed the guidance provided by the UK Data Service:

We have assessed the offer in accordance with our Data Collections Development Policy and we have concluded your collection is best suited for our self-deposit repository ReShare.

In order to create a record, you need to log in to ReShare <https://reshare.ukdataservice.ac.uk/> and "Create a new data collection".

Please complete the catalogue metadata in as much detail as possible and please upload any documentation and data that can be shared following the guidance below:

- group your data files in zip bundles (max 4gb) according to their content or file format, to make upload and download easier, e.g. a zip bundle for transcripts, a zip bundle for the documentation (for large collections, keep a folder structure for the files in your zip bundle)
- give files meaningful names that reflect the file contents; these should not contain spaces and/or special characters
- check that files contain no disclosive information (beware of hidden tracked changes in text or table files and remove names and disclosive info from 'file properties'); to anonymise data consider techniques such as:
  - removing direct identifiers e.g. respondents' names, addresses (physical, email and IP), institution name, telephone numbers etc.; respondents' names can be replaced by pseudonyms
  - aggregating variables, restricting the upper or lower ranges of continuous variables, reducing the precision of variables or textual information by replacing potentially disclosive free-text responses with more general text
- create a [ReadMe file](#) for your data collection, which should contain:
  - for each filename a short description of what it includes
  - any relationships between the data files
- prepare essential documentation to upload with your data:
  - your ReadMe file (see above)
  - blank copies of consent form(s) and information sheet used
  - clear variable descriptions and code labels in each data file
  - questionnaire(s) or data dictionary for surveys
  - topic list(s) for interviews
  - methods description o data list of interviews
  - PDF of website materials

We also have a [short video](#) detailing depositing via ReShare.

For any questions or queries please don't hesitate to contact us at [reshare@ukdataservice.ac.uk](mailto:reshare@ukdataservice.ac.uk)

And we drew upon this guidance - alongside the advice of our Executive - to make our decisions around which data was kept back and which was shared.

## Table 1: Our Data Archiving decisions

### What will we keep back or share and why?

We have decided to share the following data with the proviso that this document - ***Phase 0 Thinking of using this dataset? Read the team's approach to Open Data that involves people with learning disabilities*** - is included as the key *Setting the Context* document. Anyone accessing this data is asked to read this document so that they are provided with a wider understanding of the Humanising Healthcare project.

---

### Phase 0: Overarching documents underpinning the research and Phase 4 Emerging Findings

#### Keep back

We keep back findings that we feel might compromise the co-authors or participants. This relates mainly to works in progress that remain within the team.

#### Share

**This document - *Thinking of using this dataset?*** which offers a critical reading of Open Research in the context of disability research

**The Research Proposal** so that other researchers might consider deploying modes of co-production and qualitative research to identify examples of good, compassionate and humanising healthcare.

**An accessible version of the research protocol** in Easy Read - Plain English supported by Photosymbols ©

**An introduction to our research on the Project Website**

## **A Fieldwork and Key findings page of the Project website**

**A document listing all the seminars, workshops, conference papers, presentations and keynotes presented by the research team**

**Details of our Podcast series** with people with learning disabilities and about how they have humanised healthcare.

Share **research outputs** that reflect critically, reflexively, theoretically and analytically on the qualitative research fieldwork data:

Goodley et al (2022) a 'setting the context' paper 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.

Goodley (2023a) 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.

Goodley (2023b) posits a theoretical case for conceptualising the *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.

Bishop et al (2023) explores the exclusion of people with learning disabilities in healthcare research and makes a staunch case for their inclusion.

Daw Srdanovic et al (2024) - with reference to the Humanising Healthcare project 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.

Daw Srdanovic (2025) 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.

**Reclaiming the Human in Healthcare Manifesto** a document that will be shared on our project website by December 2025

[The Online Exhibition](#) which documents key findings, guidance and recommendations related to Humanising Healthcare produced by and/or in collaboration with Barod, Sheffield Voices, Sunderland People First, Sheffield Voices.

---

## **Phase 1: Qualitative research fieldwork**

### **Keep back**

The archiving of redacted and anonymised interview transcriptions because of concerns about personal and identifiable data. This data emerges from a small sample of people with learning disabilities, their significant others and associated healthcare professionals across two NHS sites (which are named in project proposal and the project website):

- The archiving of ethnographic field notes which have been redacted to anonymise and maintain anonymity would render the data meaningless.
- The sharing of interview transcripts would be precarious because the data reveals specific health conditions and experiences that would make participants readily identifiable.

In both cases we believe 'data generation based on painstaking ethnographic and field research that are nuanced and situated, immersed in communities, cannot easily become "accessible data". In aligning with the logic of OS, these data become devoid of contextual meanings and in turn, become sites of erasure that benefit neoliberal agendas'. (Dutta et al, 2021: 807-808)

**Share:**

Copies of all our **Information Sheets and Easy Read Consent Forms shared with our participants**

**Phase 1 Codes from the 'Healthcare Worker Practical Approaches' category -** which pulls out 15 codes from the interviews - organised into 15 word documents named as follows: Direct advice for clinicians; HCW Practical approaches; Above and Beyond; Being included in conversation; Connecting with the patient; Creativity; HCW knowledge, expertise, training, experience; Hospital passports; Knowing the patient; Professional & follows protocols inc. failure to; Reasonable adjustments; Team work and collaboration; Time; Constancy; Waiting.

We archive this data based on the following points of justification:

(1) Because our data reflects a small number of patients with learning disabilities accessing two services which are named on our publicly available project materials (e.g. website and outputs), depositing the anonymised raw data would render it meaningless because of the sheer amount of redaction required to maintain anonymity; The data we have on participants and their close others is so in-depth, that providing full transcriptions would make them identifiable.

(2) Archiving coded extracts gives context to the data which can then be used by other researchers interested in engaging with the humanising healthcare experiences of people with learning disabilities;

(3) This approach has been agreed and co-produced with our research partners, researchers with learning disabilities who argue that interview extracts which have already passed the coding stage are more useful to them - as researchers - than full transcripts.

(4) The resulting coded extracts reflect an ethical, theoretical, analytical and political commitment to analysing interview transcripts utilising an affirmative approach to researching learning disability as outlined in the original proposal.

(5) The coded data that are shared permit other researchers - especially researchers with learning disabilities - to access some of the key findings in relation to humanising healthcare in practice.

(6) To ensure anonymity in line with our application of care ethics to research, only a selection of coded data are shared. The remaining data—deemed too revealing of the participants' identities— have not been shared, but will be used for future publications by the research team, who have made an interpersonal commitment to affirmative research with all research participants, and have contextual knowledge and understanding stemming from a careful approach to field work.

---

## **Phase 2: The Executive Meetings**

### **Keep back**

Minutes of Executive Team Meetings for reasons of anonymity.

### **Share**

**Easy read templates for meetings** from the Executive Team Meetings so that other researchers might adopt a co-production approach to research.



**Easy Read information sheet** and **consent form** that were from the Executive Team Meetings so that other researchers might adopt a co-production approach to research.

**A Dictionary** of key research teams written in an Easy Read and Plain English manner to demystify research for researchers with learning disabilities

**Share outputs** that critically reflect on a co-produced approach to leading, managing, delivery and auditing a research project on humanising healthcare (full links available in the reference list):

Barod et al (2022a) and (2002b) an online seminar recording and written guidance document (deploying Easy Read) that outlines advice and recommendations for researchers to co-produce ethics applications with researchers with learning disabilities.

Goodley et al (2025) makes a case for collaborative research with disabled researchers contributing to a wider politics of depathologising the university.

---

### **Phase 3: Self-advocates interviewing self-advocates**

**Element 1: Self-advocates group interviewing self-advocates about their organisations' work to promote humanising healthcare**

#### **Keep back**

The archiving of redacted group interview transcripts in line with the decision of self-advocates not to make this data available.

#### **Share**

[The Exhibition webpage](#) which captures some of the research and innovation work of Barod, Sheffield Voices, Speakup Self-advocacy, Sunderland People First that is

already in the public domain and is indicative of some of the work referred to by self-advocates in their interviews.

## **Element 2: Self-advocates 1-to-1 interviewing another self-advocate**

### **Keep back**

The archiving of even redacted interview transcripts in line with the decision of self-advocates not to make this data available.

### **Share**

Individual self-advocates stories that they are prepared to share in public on the project website's Exhibition page. For example:

[Sunderland People First's work on Cancer Awareness](#)

[Alison Owen and Vicky Farnsworth's presentation on humane and inhumane Appointments](#)

[Barod's Humanising Healthcare two scenes](#)

---

## **Phase 5: An online Exhibition**

### **Share**

[Examples of the innovative work of Barod, Speakup self-advocacy, Sunderland People First and Sheffield Voices that promotes the humanisation of people with learning disabilities across health, education, social care and community contexts.](#)

## **References (with URL links for Humanising Healthcare outputs)**

[Barod, Sheffield Voices, Speakup Self-advocacy, Sunderland People First and iHuman Sheffield \(2022a\). 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.](#)

[Barod, Sheffield Voices, Speakup Self-advocacy, Sunderland People First and iHuman Sheffield \(2022b\). Participatory Ethics - Good Practice Guidelines. Sheffield: University of Sheffield.](#)

[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.](#)

[Bottomley, M., Bradley, J., Clark, L., Collis, B., Daw Srdanovic, B., Farnsworth, V., Ferguson, A. V., Goodley, D., Fox, A., Hayden N. K., Lawthom, C., Lawthom, R., Magwood, C., McLean, R., Middleton, I., Owen, A., Prothero, M., Rice, S., Richards, S., Runswick-Cole, K., Scargill, K., Shankar, R., & Wood, T. A. \(2024\), 'Co-production with people with learning disabilities: Writing ethics guidelines together', \*British Journal of Learning Disabilities\* <https://doi.org/10.1111/bld.12590>](#)

|

British Psychological Society (BPS). (2020). *The truth about open data: As open as possible, as closed as necessary*. BPS, 1 -3 <https://www.bps.org.uk/news-and-policy/truth-about-open-data>

Tobias Dienlin, Niklas Johannes, Nicholas David Bowman, Philipp K Masur, Sven Engesser, Anna Sophie Kümpel, Josephine Lukito, Lindsey M Bier, Renwen Zhang, Benjamin K Johnson, Richard Huskey, Frank M Schneider, Johannes Breuer, Douglas A Parry, Ivar Vermeulen, Jacob T Fisher, Jaime Banks, René Weber, David A Ellis, Tim Smits, James D Ivory, Sabine Trepte, Bree McEwan, Eike Mark Rinke, German

Neubaum, Stephan Winter, Christopher J Carpenter, Nicole Krämer, Sonja Utz, Julian Unkel, Xiaohui Wang, Brittany I Davidson, Nuri Kim, Andrea Stevenson Won, Emese Domahidi, Neil A Lewis, Claes de Vreese (2021). An Agenda for Open Science in Communication, *Journal of Communication*, Volume 71, Issue 1, February 2021, Pages 1–26, <https://doi.org/10.1093/joc/jqz052>

Fox, J., Pearce, K. E., Massanari, A. L., Riles, J. M., Szulc, Ł., Ranjit, Y. S., Trevisan, F., Soriano, C. R. R., Vitak, J., Arora, P., Ahn, S. J., Alper, M., Gambino, A., Gonzalez, C., Lynch, T., Williamson, L. D., & Gonzales, A. L. (2021). Open Science, Closed Doors? Countering Marginalization through an Agenda for Ethical, Inclusive Research in Communication. *Journal of Communication*, 71(5), 764-784.  
<https://doi.org/10.1093/joc/jqab029>

[Goodley, D., Lawthom, R. and Liddiard, K. \(2021\) Key Concerns for Critical Disability Studies. \*International Journal of Disability and Social Justice\*. 2021. Vol. 1\(1\):27-49. DOI: 10.13169/intljofdissojus.1.1.0027.](#)

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

[Goodley, D. \(2023a\). Disability and the Medical Posthumanities. \*Interconnections: Journal of Posthumanism / Interconnexions: revue de Posthumanisme\*.](#)

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

[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.](#)

[Humanising healthcare team \(2025\). Project Dictionary. Sheffield: University of Sheffield.](#)

Nind, M. (2016), "Towards a second generation of inclusive research", in T. Buchner, O. Koenig and S. Schuppener (eds.), *Inklusive Forschung. Gemeinsam mit Menschen mit Lernschwierigkeiten forschen*, 186 - 198, Bad Heilbrunn: Klinkhardt.

Schwartz, A. E., Kramer, J. M., Cohn, E. S. and McDonald, K. E. (2020), "'That Felt Like Real Engagement': Fostering and Maintaining Inclusive Research Collaborations With Individuals With Intellectual Disability", *Qualitative Health Research* 30 (2): 236–249.

Walmsley, J. and Johnson, K. (2003), *Inclusive Research with People with Learning Disabilities: Past, Present and Futures*, London; New York: Jessica Kingsley Publishers.

Meekosha, H. and Shuttleworth, R. 2009. What's So 'Critical' about Critical Disability Studies? *Australian Journal of Human Rights*. 15(1), pp.47–75.

Oliver, M. 1990. *The Politics of Disablement*. London: The Macmillan Press.

Pownall, M. Bridging qualitative methods and open research. *Nat Rev Psychol* (2025). <https://doi.org/10.1038/s44159-025-00477-3>

Prosser AMB, Hamshaw RJT, Meyer J, Bagnall R, Blackwood L, Huysamen M, Jordan A, Vasileiou K, Walter Z. (2023). When open data closes the door: A critical examination of the past, present and the potential future for open data guidelines in journals. *British Journal of Social Psychology*, 62(4), 1635-1653. doi: 10.1111/bjso.12576. Epub 2022 Sep 8. PMID: 36076340; PMCID: PMC10946880.

Ryan, F. (2025). Reeves faces anger from her local party over plans to cut disability benefits. The Guardian, 17th May, <https://www.theguardian.com/politics/2025/may/17/rachel-reeves-labour-leeds-disability-benefits>

Shildrick, M. 2009. *Dangerous Discourses of Disability, Subjectivity and Sexuality*. London: Palgrave Macmillan.

Shildrick, M. 2012. Critical Disability Studies: Rethinking the Conventions for the Age of Postmodernity. In: Watson, N., Roulstone, A. and Thomas C. eds. *Routledge Handbook of Disability Studies*. London: Routledge, pp.30–41.

[Daw Srdanovic B, 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\*.](#)

[Daw Srdanovic. B. \(2025\). 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](#)

Terzi, L. 2005. A Capability Perspective on Impairment, Disability and Special Needs. *Theory and Research in Education*. 3(2), pp.197–223.

Williams, O., Robert, G., Martin, G. P., Hanna, E. and O'Hara, J. (2020), 'Is Co-production Just Really Good PPI? Making Sense of Patient and Public Involvement and Co-production Networks', in M. Bevir and J. Waring (eds.), *Decentring Health and Care Networks*, 213-237, Basingstoke: Palgrave