**Grant Number:** ES/W003406/1

**Sponsor:** University of Sheffield

**Project title:** :[Humanising the Healthcare Experiences of People with Learning Disabilities and/or Autism: Qualitative data from interviews and ethnographic data and research materials; Materials from Co-production Workshops; data from interviews between researchers with learning disabilities; Emerging Co-produced key findings; Details of Online Exhibition showcasing the humanising work of organisations run by and for people with learning disabilities; a new approach to co-producing Humanising Open Data.](https://reshare.ukdataservice.ac.uk/cgi/users/home?screen=EPrint::View&eprintid=857910)

| Folder / file name | File description (Short description of content, sample size, format, any linking between different types of data, i.e. survey and interviews/focus groups) |
| --- | --- |
| readme files | |
| readme Goodley Humanising Healthcare 2025 | **This document which gives an overview of the folders and files deposited on reshare** |
| read me too: Thinking of using this dataset? Read the team’s approach to Open Data that involves people with learning disabilities | **A compulsory read for anyone who wants to use our Data Set. This document provides the essential contextual background for anyone thinking of using our data set. This document should be read before accessing any of the data.**  We follow the advice of Prosser et al ‘data is deposited with a clear audit trail, reflexivity statement and overarching narrative that encourages the user to read and understand the data in terms of a time and place’ (Prosser et al, 2023).  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.  **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) |
| Phase 0: Overarching project documents Phase 0 and Phase 4: Emerging findings | |
| FOLDER: phase 0 and phase 4-20250822T102215Z-1-001.zip | Folder containing all the files detailed below |
| FILE: Phase 0 the original case for support research proposal | The original case for support that was agreed to be funded by the ESRC as word document |
| FILE: Phase 0 and Phase 4 A fieldwork and key findings page of the website | Links to a page of the project website on key findings and accessible overview of the fieldwork as a pdf |
| FILE: Phase 0 An accessible version of the research proposal | An accessible version of the original research proposal as a pdf |
| FILE: Phase 0 An introduction to the website | A link to introduction on the project website as a pdf |
| FILE: Phase 0 Podcast series | A link to the podcast series with people with learning disabilities exploring humanising healthcare as a pdf |
| FILE: Phase 0 and Phase 4 writing and dissemination page of the project website | A link to all publications and outputs of the project website |
| FILE: Phase 0 and Phase 4 Humanising Healthcare Seminars, symposia and keynotes presentations 2022 - 2025 | A full list of presentations, seminars, workshops and keynotes given by the team |
| Phase 1 Qualitative fieldwork on people with learning disabilities experiences of healthcare services | |
| FOLDER: Phase 1 Codes from the ‘Healthcare Worker Practical Approaches’ category -20250822T093724Z-1-001.zip | Folder with coded excerpts from interviews with patients with learning disabilities, their close others and professionals involved in their healthcare. Organised into 15 Word documents detailed below: |
| Above and Beyond 22AUG2025 v.1.0.docx | Code with interview transcripts |
| Being Included in the Conversation 22AUG2025 v.1.0.docx | Code with interview transcripts |
| Connecting with the Patient 22AUG2025 v.1.0.docx | Code with interview transcripts |
| Constancy 22AUG2025 v.1.0.docx | Code with interview transcripts |
| Creativity 22AUG2025 v.1.0.docx | Code with interview transcripts |
| Direct Advice for Clinicians 22AUG2025 v.1.0.docx | Code with interview transcripts |
| Healthcare Worker Knowledge, Expertise, Training, Experience 22AUG2025 v.1.0.docx | Code with interview transcripts |
| Healthcare Worker Practical Approaches 22AUG2025 v.1.0.docx | Code with interview transcripts |
| Hospital Passports 22AUG2025 v.1.0.docx | Code with interview transcripts |
| Knowing the Patient 22AUG2025 v.1.0.docx | Code with interview transcripts |
| Professional & Follows Protocols inc. failure to 22AUG2025 v.1.0.docx | Code with interview transcripts |
| Reasonable Adjustments 22AUG2025 v.1.0.docx | Code with interview transcripts |
| Team Work and Collaboration 22AUG2025 v.1.0.docx | Code with interview transcripts |
| Time 22AUG2025 v.1.0.docx | Code with interview transcripts |
| Waiting 22AUG2025 v.1.0.docx | Code with interview transcripts |
| FOLDER: Phase 1 All information sheets and consent forms-20250822T093915Z-1-001.zip | Phase 1: All information sheets and consent forms (files detailed below) |
| Phase 1 - Ethnography healthcare professionals | |
| FILE: Phase 1 - Universal Healthcare Professional Ethnography Participant Information Sheet – v1.2 16JAN2024 – Redacted archive version | Information sheet shared with healthcare professionals about our ethnographic research |
| FILE: Phase 1 - Universal Healthcare Professionals Ethnography Consent Form – v1.2 16JAN2024 Redacted archive version | Consent form for participant-clinicians to agree to take part in ethnography/observation in NHS settings |
| Phase 1 - ethnography and narrative interviews - people with learning disabilities | |
| FILE: Phase 1 - Universal Easy Read Ethnography and Observations Information Sheet for participants with learning disabilities– V1.2 16JAN2024 Redacted archive version | Easy read information sheet explaining our ethnography and narrative interviews to people with learning disabilities |
| FILE: Phase 1 - Universal Easy Read Consent form for participants with learning disabilities – V1.2 16JAN2024 Redacted archive version | Easy read consent form |
| Phase 1 - Universal Easy Read Narrative Interviews and Storytelling Information Sheet for participants with learning disabilities– V1.2 16JAN2024 Redacted archive version | Easy read version of the narrative interview stage |
| Phase 1 - Universal Easy Read General Patient Information Sheet for participants with Learning Disabilities – V1.2 16JAN2024 Redacted archive version | Easy read version of general information sheet explaining the research in its entirety |
| Phase 1 - Universal Full Text Information Sheet for participants with learning disabilities – V1.2 16JAN2024 Redacted archive version | Full version information sheet explaining our ethnography and narrative interviews to people with learning disabilities |
| Phase 1 - Universal Full version Consent form for participants with learning disabilities – V1.2 16JAN2024 Redacted archive version | Full version consent form |
| Phase 1 - Universal Letter, information sheet and Declaration form for personal consultees – V1.2 16JAN2024 – Redacted archive version | information sheet and declaration for personal consultees in the case of recruiting people with learning disabilities who do not have the full capacity to consent. |
| Phase 1 - interviews with significant others of people with learning disabilities | |
| Phase 1 - Universal Easy Read Consent form for carers\_friends\_family and other significant others – V1.2 16JAN2024 – Redacted archive version | Easy read consent form |
| Phase 1 - Universal Easy Read Parent, carer, friend and other significant others Ethnography Participant Information Sheet – V1.2 16JAN2024 Redacted archive version | Easy read explaining involvement in our ethnographic study of their NHS consultations, meetings and appointments |
| Phase 1 - Universal Easy Read Parent, carer, friend and other significant others Narrative Interviews and Storytelling Information Sheet – V1.2 16JAN2024 Redacted archive version | Easy read version explaining the interviews elements of the research |
| Phase 1 - Universal Parent, carer, friend and other significant others Ethnography Consent Form – V1.2 16JAN2024 Redacted archive version | Consent form full version for ethnography |
| Phase 1 - Universal Parent, carer, friend and other significant others Ethnography Participant Information Sheet – V1.2 16JAN2024 Redacted archive version | Full version information sheet about ethnography |
| Phase 1 - Universal Parent, carer, friend and other significant others Narrative Interview Participant Information Sheet – V1.2 16JAN2024 Redacted archive version | Full version information sheet about narrative interviews |
| Phase 1 - Universal Parent, carer, friend and other significant others Narrative Interview Consent Form – V1.2 16JAN2024 Redacted archive version | Full version consent form for narrative interviews |
| Phase 2: The Executive Meetings | |
| All files below for Phase 2 saved as ‘Phase 2-20250822T093228Z-1-001.zip’ | |
| Phase 2 Co-production workshop agenda template | from the Executive Team Meetings so that other researchers might adopt a co-production approach to research |
| Phase 2 Accessible information sheet | An easy read information sheet shared with The Executive team |
| Phase 2 Dictionary | A dictionary of key research terms written to demystify research |
| Phase 2 Accessible consent form | An easy read consent form completed by members of the Executive Team |
| Phase 2 Coproducing Open Data Agenda coproduction workshop May 2025 | A copy of the agenda as a pdf from the Coproduction workshop we held with our Executive which introduced the ideas of Open Research and Open Data and garnered members’ opinions on what data should be shared and for what reasons |
| Phase 3: Self-advocates interviewing self-advocates | |
| Phase 3 and 5 Online Exhibition (1).pdf | A pdf print off of the Online Exhibition - this is a live space regularly updated; visit <https://sites.google.com/sheffield.ac.uk/esrchumanisinghealthcare/exhibition> |
| Phase 5: Online Exhibition | |
| Phase 3 and 5 Online Exhibition (1).pdf | A pdf print off of the Online Exhibition - this is a live space regularly updated; visit <https://sites.google.com/sheffield.ac.uk/esrchumanisinghealthcare/exhibition> |

**Publications**: **with embedded links (below)  
Also please visit** [**writing and dissemination**](https://sites.google.com/sheffield.ac.uk/esrchumanisinghealthcare/writing-and-dissemination) **page of website**

[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](https://orda.shef.ac.uk/articles/media/Open_Research_Conversation_Participants_as_Co-investigators_Opening_up_Research_with_Co-production_12th_October_2022_/21334857/1?file=37863834).  
  
[Barod, Sheffield Voices, Speakup Self-advocacy, Sunderland People First and iHuman Sheffield (2022b). Participatory Ethics - Good Practice Guidelines. Sheffield: University of Sheffield.](https://docs.google.com/presentation/d/1e42du31JWbx9o6uiG3MxSek8yUkr__0Ec9rDyxYBYWo/present?slide=id.p1)  
  
[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.](https://onlinelibrary.wiley.com/doi/10.1111/jir.13097)

[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://onlinelibrary.wiley.com/doi/10.1111/bld.12590) <https://doi.org/10.1111/bld.12590>

[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/intljofdissocjus.1.1.0027.](https://www.scienceopen.com/hosted-document?doi=10.13169/intljofdissocjus.1.1.0027)

[Goodley, D. Lawthom, R and Runswick-Cole, K (2022) ‘Affect, dis/ability and the pandemic’, *Sociology of health and llness* [Preprint]. doi:10.1111/1467-9566.13483.](https://onlinelibrary.wiley.com/doi/full/10.1111/1467-9566.13483)  
  
[Goodley, D. (2023a). Disability and the Medical Posthumanities. *Interconnections: Journal of Posthumanism / Interconnexions: revue de Posthumanisme.*](https://journals.library.brocku.ca/index.php/posthumanismstudies/index)  
  
[Goodley, D. (2023b). Being human as praxis: for people with learning disabilities. *Subjectivity* 30, 167–184 (2023).](https://link.springer.com/article/10.1057/s41286-023-00159-6)

[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.](https://sjdr.se/articles/10.16993/sjdr.1240)

[Humanising healthcare team (2025). Project Dictionary. Sheffield: University of Sheffield.](https://drive.google.com/file/d/10EGENNj57g53F9LpeX0I8PwCZrnhDDr8/view)  
  
[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.*](https://www.tandfonline.com/doi/full/10.1080/14780887.2024.2348128)  
  
[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](https://onlinelibrary.wiley.com/doi/10.1111/1467-9566.70047)