



Fieldwork, data and Key findings





What did we plan to do?

Home The Executive Exhibition Ne

(1) To qualitatively investigate the cultures, conventions, systems, relationships and practices of a neurology service and A learning disability service through co-production, ethnography and narrative interviews.

(2) To identify the ways in which two distinct services and their practitioners deliver humanising healthcare for people with learning disabilities (including people with learning disabilities who are also autistic people).



Got Informed Consent from the patient and the GP



Who were the key people involved in our research?



ESRC Humanising Healthcare Home The Executive Exhibition Ne

People with learning disabilities who were accessing two NHS sites. We observed their meetings, consultations and appointments with healthcare professionals and we also carried out interviews with them.

Healthcare professionals - as we were observing the different appointments and consultations that people with learning disabilities were having with these professionals.

Significant others (including parents, siblings, trusted friends and trusted professionals) of the people with learning disabilities that we observed and interviewed. We wanted to talk to these trusted folk to get their understanding of the healthcare experienced by those close to them.

[Accessible intro \(2\).pdf](#)

What did we actually do?

After receiving Health Research Authority (HRA) ethical approval (a process that took over 9 months) we spent the next 18 months recruiting 14 people with learning disabilities who were accessing two NHS sites. 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. This confirmed 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.

41 ethnographic encounters with 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

10 interviews were undertaken with people with learning disabilities accessing the two NHS services.

23 interviews were carried out with the 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.

An accessible introduction to the research is provided in the leaflet to the left of this box of text.





Ethics balance right





How did we do this research in an ethical way?

ESRC Humanising Healthcare Home The Executive Exhibition Ne

We worked with **The Executive Team** to make sure that any potential participant was given the right amount of information to make an informed decision about whether or not to participate in our research.

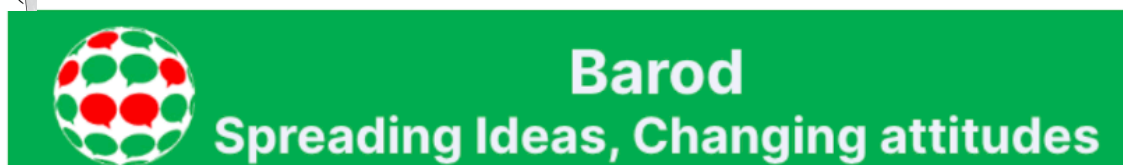
We worked carefully to write our research participants' information sheets (to explain the research) and consent forms (for people to sign up to if they agreed to be part of our research).



 <p>Understand</p>	<p>I have read and understood the Information Sheet dated 16/01/2024 or the project has been fully explained to me.</p>
	<p>I agree to take part in the project.</p>
	<p>I understand that taking part means allowing the researcher to watch my NHS service meetings.</p>

What information sheets and consent forms did we share with participants?

You can access all the the information sheets and consent forms that were shared with participants by clicking on the link to the left.



Barod logo



Speakup Logo



Sheffield Voices logo



Sunderland People First logo



Did we do any other fieldwork?

We did. In addition to the fieldwork we also asked self-advocates to interview other self-advocates. There were two elements to this. First, Speakup Self-advocacy group interviewed 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. Second, a number of individual self-advocates interviewed one 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.



Who checked up on how we did our research?

The Executive is made up of university, clinical and advocacy-group based researchers. We met at regular stage during the time of the fieldwork - through **14 online and face-to-face Online Workshops** - to review the progress of the fieldwork. You can find out more about The Executive [here](#)



What did we do with the data from the fieldwork?

So, the following data was collected and saved on our university X drive:

- Recordings of interviews
- Transcriptions of interviews
- Contact and personal details of participants and their pseudonyms
- Fieldwork diaries and notes made by the researchers during their observations.

The X Drive is a secure platform where we can save information which includes people's personal information. Only the university researchers can access this information.



How are you sharing the data?

Of course we share the data across the university team. In addition, we are also committed to sharing data from this project with other researchers and other people who might be interested in humanising healthcare.

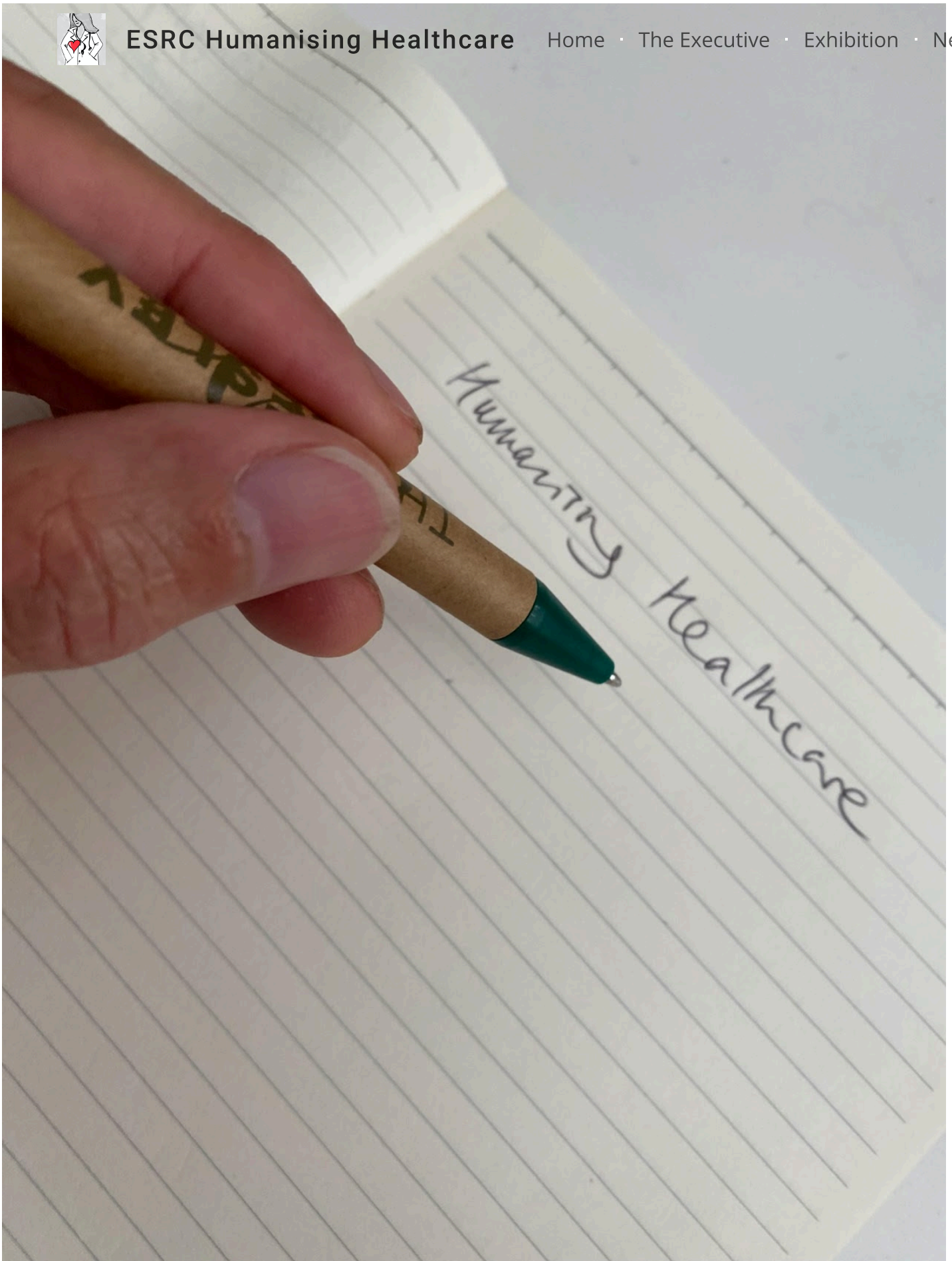
Our participants consent to have their words and actions anonymisely quoted in our analysis but we need to think carefully about when 'data generation based on painstaking ethnographic and field research that are nuanced and situated, immersed in communities, cannot easily become "accessible data." In aligning with the logic of OS [Open Science], these data become devoid of contextual meanings and in turn, become sites of erasure that benefit neoliberal agendas'. ([Dutta et al, 2021: 807-808](#))

Any decision about the data that we share is influenced by our commitment to working in collaboration with our participants - particularly researchers with learning disabilities - in order to ensure that *their* experiences, *their* data and *their* aspirations are put out in the world for *their* benefit. Following [Fox et al \(2021\)](#), we want to centre **questions of social justice** specifically: ***How might we approach data sharing and archiving in a way that puts the aspirations and experiences of people with learning disabilities front and centre?***



What data have we agreed to share?

We have worked with The Executive to agree on the data that we can share in the UK Data Archive - which we explain in the document that you can access to the left



What are the key findings emerging from the data

While we have already produced a number of outputs based on our analysis we continue to work on the data.

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.



The ESRC Humanising 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.