**Humanising the Healthcare of people with learning disabilities (including autistic people who also have learning disabilities)**

[**https://esrchumanisinghealthcare.wordpress.com**](https://esrchumanisinghealthcare.wordpress.com)

**Title: Parent, carer, friend or other significant other  
Ethnography   
participant information sheet**



**1. Research project title**

‘Humanising Healthcare of people with learning disabilities (including those who also have autism)’ - or ‘Humanising Healthcare’ for short.

**2. Invitation**

You are being invited to participate in a research project called **Humanising Healthcare.** Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Feel free to ask us if there is anything that you do not understand, or if you would like more information. Thank you for taking the time to read this **Participant Information Sheet**.

**3. What is the project’s purpose?**

A number of people with learning disabilities (and those who also have autism) have complained that the NHS services they receive are not good enough. Some have said that the NHS has failed them. Inquiries and reports into the treatment of disabled people at Winterbourne View, Whorlton Hall, Mendip House, Slade House and Yew Trees Hospital have had tragic consequences. People with learning disabilities and/or autism have not been given the same treatment, respect and rights as other human beings - this is dehumanising care. Previous research has found a number of problems within healthcare which have not gone away. This includes 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 or to their ‘behaviour’). Uptake of annual health checks, screening and follow up appointments are low and there is evidence of inappropriate prescriptions of psychotropic drugs. Despite many attempts to promote empowering, person-centred and holistic care practices, many people with learning disabilities and/or autism are not getting the healthcare they deserve

We believe that a new approach is needed; especially now after the Covid-19 pandemic. We want to find those moments and occasions when NHS services treat patients with empathy, dignity, compassion, kindness and recognition. We call this good practice **'Humanising Healthcare’**. Simply, this means putting people with learning disabilities and/or autism at the heart of health care services and recognising them as fully human, just like everyone else. We will investigate how healthcare works in two NHS services: [Information redacted]. This will allow us to identify the ways in which these two distinct services and their practitioners deliver healthcare.

Our team of researchers includes people with learning disabilities and/or autism, medical clinicians and social scientists who worked together over 18 months to develop this project together. There are a number of phases to our research.

* First, we will write a literature review that captures the key priorities and determinants of health for people with learning disabilities and/autism.
* Second, we will identify ideas and concepts to understand humanising healthcare by reading medical humanities, disability studies, posthumanities and disability activism literature and discuss the merits of these ideas during co-production workshops.
* Third, we will carry out an investigation of the healthcare experiences of 30 people with learning disabilities and/or autism through days of observational research of a neurology service and a learning disability service and narrative interviews with professionals, patients and family members.
* Fourth, we will analyse the observations and interviews, informed by co-production workshops and our theoretical resources.
* Fifth, we will identify healthcare practices - including referrals, assessments, diagnoses, clinical judgements, investigations, treatments, service management, commissioning, medical training and continued professional development - that are under-pinned by the principles of empathy, compassion, dignity, kindness and recognition. We will share these through a website, manifesto, healthcare toolkit, practitioner training materials, journal articles, conference presentations and co-production research resources, supported by an experts-by-experience advisory board and clinical and practitioner expert group.
* Finally, we will increase public awareness of the healthcare realities and aspirations of people with learning disabilities and/or autism through festivals, a digital exhibition, a social media campaign and podcast series.

The research will run for 3 years, beginning in September 2022 and ending in August 2025.

**4. Why have I been chosen?**

Because you are a family member, a parent, a carer or a friend who accompanies during healthcare appointments a patient who is taking part in this study We will be focusing on the healthcare experiences of a minimum of 12 patients who use the two services (six patients per service): [Information redacted].

**5. Do I have to take part?**

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep (and be asked to sign a consent form) and you can still withdraw at any time without any negative consequences. You do not have to give a reason. If you wish to withdraw from the research, please contact Dan Goodley to withdraw your participation [Information redacted].

Please note that by choosing to participate in this research, this will not create a legally binding agreement, nor is it intended to create an employment relationship between you and the University of Sheffield.

**6. What will happen to me if I take part? What do I have to do?**

We will designate a full time researcher from our research team to focus on the NHS service used by your family member/friend/relative. The researcher will sit in and **observe** these meetings. They will take field notes. If **you are also present** during any of these meetings we need to ask if you are prepared for our researcher to be present and observing these professional meetings, appointments and consultations. You are not expected to do anything differently other than to agree to the researcher being present. We plan for the researcher to carry out 10 days of observations with each patient between January 2023 and December 2024. We plan to observe:

* meetings between patients and professionals (e.g. doctors, nurses, support workers);
* referrals, waiting rooms, assessments, diagnoses, clinical judgements, investigations and treatments.
* the ways services are managed and commissioned.
* the training and continued professional development of healthcare practitioners.

As we observe these different aspects of healthcare we will ask: in what ways do these professional and patient interactions demonstrate humanising principles of empathy, compassion, dignity, kindness and recognition. Our aim is to identify good practice and share this good practice.

Our observations will include face-to-face and online encounters within the two services. If you agree to being involved, we will share with you our **Easy Read Ethnography and Observations Participant Information Sheet**. We have prepared this document for patients with learning disabilities but we think it is an accessible way of explaining the observational elements of our research. We have co-produced this with researchers who have learning disabilities.

If after reading these information sheets you are happy to participate then we will ask you to complete a **Consent Form**. We would also like toshare our findingswith you. A researcher from our research team will arrange a time to share these findings with you. We are committed to sharing our findings in a number of ways which we detail below.

**7. What are the possible disadvantages and risks of taking part?**

We don’t foresee any serious disadvantages or risks in participating in our project. However, some patients and their families worry that being involved in this study might negatively impact on your family member’s care experiences. We do not expect this to happen. If anything, we think that finding good practice will be a positive experience. Nevertheless, we will continuously monitor your concerns through a model of ongoing informed consent and will exclude those who express concerns that involvement is impacting negatively on their healthcare.

**8. What are the possible benefits of taking part?**

As a thank you for taking part in the research , we will offer you a £25 gift voucher in total.

Allowing the researcher to observe the ways professionals support your family member will allow us to share good practice with others.

**9. Will my taking part in this project be kept confidential? Will I remain anonymous?**

All the information that we collect about you during the course of the research will be kept strictly confidential and will only be accessible to members of the research team. You will not be able to be identified in any reports or publications unless you have given your explicit consent for this. If you agree to us sharing the information you provide with other researchers (e.g. by making it available in The University of Sheffield’s data archive (ORDA) then your personal details will not be included

However, if you told us something that led us to believe that you or someone else is at risk of harm we would be obliged to report this to The University of Sheffield Safeguarding Lead.

**10. What is the legal basis for processing my personal data?**

According to data protection legislation, we are required to inform you that the legal basis we are applying in order to process your personal data is that ‘processing is necessary for the performance of a task carried out in the public interest’ (Article 6(1)(e)). Further information can be found in the University’s Privacy Notice <https://www.sheffield.ac.uk/govern/data-protection/privacy/general>*.*

*The University of Sheffield and The University of Plymouth will act as the Joint Data Controllers for this study. This means that these Universities are responsible for looking after your information and using it properly.*

**11. What will happen to the data collected, and the results of the research project?**

Your data will be held on secure and encrypted online drives approved by the University of Sheffield’s information security team. Your personally identifiable data(e.g., your name, email address) will be stored securely on the University of Sheffield’s secure X drive. . Only the Chief Investigator (Dan Goodley), Co-investigator [Information redacted] and the study Research Associates will have access to your personal data. We will ask you if we can keep your name and email address or phone number for two years so we can contact you about future research.

The data collected in the form of an anonymised observational record written by the Research Associate will be stored on the University of Sheffield’s secure Google Drive, and processed using NVivo (collaborative software to support the management of qualitative data). These observation records will be stored separately from your personally identifiable data (which will be saved on the University of Sheffield’s X drive). . All data will be anonymised and pseudonymised - this means that we will not use your actual name in, for example, observation records, our diaries or publications and presentations about the study, but will ask you to choose a pseudonym, or alternative name. The University of Sheffield will destroy your anonymised observation data 48 months after the project is complete.

Although the University of Sheffield will not retain your study data after 48 months of the project completion date, we will seek your consent to deposit your anonymised transcript/data to a research repository, held indefinitely. Due to the nature of this research it is very likely that other researchers may find the data collected to be useful in answering future research questions. We will ask for your explicit consent for your data (e.g., anonymised observations) to be shared in this way via the University of Sheffield’s Data Repository (ORDA) and the UK Data Service. Over the three years of the project we will share our findings about Humanising Healthcare, for example via:

* *Journal articles* aimed at researchers and healthcare professionals.
* A *Humanising Healthcare Website* to house news, blogs, policy briefings and empathic, compassionate and caring ethnographic case studies and narratives (drawn from the fieldwork) - <https://esrchumanisinghealthcare.wordpress.com/>
* A *Humanising Healthcare Toolkit* focused on improving professional practice and service provision.
* A *Reclaiming the Human in Healthcare Manifesto* setting out a declaration of humanising healthcare.
* *Practitioner Training Materials -*  written for the two healthcare professionals.
* *Teaching materials* for medical students.
* A *Co-production Research Resources* website to share good practice about working with expert-by-experience.
* *Festival Events* in Cardiff, Sheffield and Plymouth to target the wider public.
* A *Digital Exhibition* sharing artistic outputs from co-production workshops and crowd-sourced arts from people with learning disabilities and/or autism.
* A *Social Media Campaign* will raise public discourse in relation to #humanisinghealthcare.
* A *Podcast* *Series* *‘The Art of Medicine: Love of Humanity’* will share anonymised ethnographic case studies and narratives of compassionate humanising healthcare and include interviews with influential self-advocates, families/carers and professionals (external to the project.

**12. Who is the data controller?**

The University of Sheffield will act as the Data Controller for this study. This means that the University is responsible for looking after your information and using it properly.

**13. What happens if the research project stops earlier than expected?**

Although unlikely, if for any reason the research project stops earlier than expected, you will be offered a full and clear explanation as to why.

**14. What if something goes wrong?**

If you feel something has gone wrong or would like to raise an issue/complaint about our research or our researchers, you are advised to make contact with the Chief Investigator Professor Dan Goodley. You can find their contact details at the end of this document.

If you feel that your complaint has not been dealt with appropriately, you can contact the [Information redacted]

If your complaint relates to how your personal data has been handled, information about how to raise a complaint can be found in the University’s Privacy Notice: <https://www.sheffield.ac.uk/govern/data-protection/privacy/general>.

[Information redacted] is the project’s **Designated Safeguarding Officer** - you can contact her if you are worried about the impact of the research on the well-being or safety of patients, families or professionals. [Information redacted] will also contact the NHS Safeguarding Team if she thinks that there is reason to complain about this research and its impact on your healthcare.

**15. Who has ethically reviewed the project?**

This project has been ethically reviewed and approved by the NHS Health Research Authority.

**16. Who is funding the research?**

The Economic and Social Science Research Council (ESRC) funds Humanising Healthcare (ES/W003406/1).



**17. Contact for further information**

If you have any questions about the study, please contact either:

[Information redacted]

**18. Who is organising this research?**

Our research team includes **University and Clinical researchers**:

[Information redacted]

Our team also includes **advocacy based researchers.** Researchers with learning disabilities (including those with autism) have helped us co-create this project. They will continue to act as research partners throughout the lifetime of the project. We will pay these organisations to make sure we address the rights and aspirations of the patients of NHS services.These partners will not participate in the research but will help lead, design and manage the project.

[Information redacted]

**Thank you for taking the time to read about the project ☺**