**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: Letter, Participant information Sheet and Declaration Form for Personal Consultee**



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**Introduction**

We feel your relative/friend is unable to decide for himself/herself whether to participate in this research.

To help decide if he/she should join the study, we’d like to ask your opinion whether or not they would want to be involved. We’d ask you to consider what you know of their wishes and feelings, and to consider their interests. Please let us know of any advance decisions they may have made about participating in research. These should take precedence.

If you decide your relative/friend would have no objection to taking part we will ask you to read and sign the consultee declaration on the last page of this information leaflet. We’ll then give you a copy to keep. We will keep you fully informed during the study so you can let us know if you have any concerns or you think your relative/friend should be withdrawn.

If you decide that your friend/relative would not wish to take part it will not affect the standard of care they receive in any way.

If you are unsure about taking the role of consultee you may seek independent advice.

We will understand if you do not want to take on this responsibility.

The following information is the same as would have been provided to your relative/friend.

**1. Research project title**

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

**2. Invitation**

Your friend/relative is 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**. We have also written an **Easy Read Patient Information Sheet** and we can send you a **Short Film Version of the Information** (with captions) if you would prefer.

**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.

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: a neurology service and a learning disability service. 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 up to 24 people with learning disabilities and/or

autism through days of observational research of a neurology service and a learning disability service, as well as 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 has your friend/relative been chosen?**

They have been chosen because they are a patient who uses one of two NHS services that we are focusing on in our study: [Information redacted]. We want to recruit a minimum of 12 patients in total: six from each service. We would like your friend/relative to be one of these participants.

**5. Does your friend/relative have to take part?**

No, it is completely up to them and you whether you take part or not. Their participation is entirely voluntary.

You will be asked to sign a declaration form to say that you are happy for your friend/relative to take part in our project. However, you can still change your mind and stop taking part (also known as ‘withdrawing’). Your friend/relative can withdraw at any time, and you do not even have to give a reason.

The care that your friend/relative receives from the service will stay the same whether you decide to take part or not

**6. What will happen to your relative/friend if they take part? What do they have to do?**

They will be involved in our study in three ways.   
  
First, a researcher from our research team will ask to accompany your

friend/relative to ten of the meetings, appointments and other contact times that they have with the NHS Service, their teams and their professionals. These could include face-to-face and online meetings and appointments. This researcher will sit in and **observe** these meetings. They will take research notes. Your friend/relative is not expected to do anything differently other than to agree to the researcher being present when you access the NHS service. We plan for the researcher 10 days of time with you; ***observing*** consultations, appointments and meetings that you have with professionals across clinical contexts. This will take place between January 2023 and December 2024. We plan to observe:

* meetings between your friend/relative and a healthcare professional (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 observations will include un/structured, face-to-face/online encounters within the two services.

Second, also between January 2023 and December 2024, the researcher will also arrange to carry out a semi-structured **narrative interview** with your friend/relative.This means that we have some **questions** that we would like to ask you and we would like to collect your **stories of healthcare.** These interviews will last no more than two hours.

**TOPIC GUIDES**

These questions might include:

* Can you tell me about yourself? I’d like to hear about where you’re from, who you live with, about leisure (what you do in your spare time), education and work for examples.
* Who are your friends and family? How do you help one another?
* How do you stay well and healthy? Do you take exercise? Do you take any prescribed drugs?
* Can you tell me some stories about NHS services you have received? What is the best and worst story?
* Can you tell me a story about a bad, a good and an ideal NHS service?
* Have you been let down by a service? Have you been treated really well by a service?
* How long have you been accessing the NHS service? What type is it?
* Why do you use this service? Has anyone explained to you what this service offers?
* What kinds of healthcare do you get from the NHS service? - where are these services in relation to where you live? Are they online?
* Can you tell me if you tried to access services and could not – what happened?
* When services are working well, how can you tell?
* What does it mean to be ‘treated well’ by professionals?
* Can you tell me a story about the best doctor, nurse or social worker you have met? What made them ‘the best’?
* We are exploring the word humanising: what does this word mean to you? What does it mean to be treated like a human being?
* Why is it important for healthcare professionals and services to treat people like humans?
* What advice do you have for healthcare professionals to make their work more ‘humanising’?
* Are there any questions you think we have missed?

We will not ask you all of these questions: but they might help our conversation. We think of these questions more like prompts – some we will ask, some we won’t. We expect the interview to last for at most two hours, but we can also think of carrying out a number of shorter interviews.

We know that some people might not be able to speak freely so we will also seek to use different methods like **drawings, the arts or photographs** to make the interview more accessible, but we will think about these ideas together. We could for example:

* Draw your friend/relative’s lifeplan – from birth until today – and think of good times in your life.
* Create a cartoon called ‘My great day in the NHS service’.
* Look at some leaflets or websites together to see how they see people like me, and if they are accessible.
* Share some stories from other patients that have been collected by other researchers.
* Look at some of your photographs and think about how doctors, nurses, social workers and other professionals have helped to create happy memories.
* We could walk around the NHS Service together, take some photos and collect some memories.
* We could create a collage of ‘My health and my body’.

Before the interview we will agree on a time that is convenient for your friend/relative, a suitable venue so that they can talk freely (home, private room in library, neutral space) and mode (face-to-face or online). You will decide what works best for your friend/relative. We would like to audiorecord our meetings/interviews.

We will also plan to interview three people who are important to your friend/relative – a member of their family, a friend, or a professional that they trust. We will discuss these options with your friend/relative to get their preference.

Third, we would like to **share our findings** with you. A researcher from our research team will arrange a time to share these findings with you. We give details of these findings in section 11 of this information sheet.

If after reading this information sheet you are happy for your friend/relative to participate then we will ask you to complete the **Declaration form** below.

If you think that your friend/relative would like to take part, we will take you through our **Easy Read Ethnography and Observations Participant Information Sheet** document. You can then decide if you are prepared for us to come along to your friend/relative’s meetings and observe.

If you think that your friend/relative would like to take part, we will also take you through our **Easy Read Narrative Interviews and Storytelling Participant Information Sheet.** You can then decide if you are prepared for us to interview your friend/relative.

**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, sometimes reflecting on the healthcare services we receive can be upsetting. This might be the case with interviews. Let us remind you that:

* Your friend/relative does not have to answer every question in the interview.
* Your friend/relative does not have to have the researcher observe every interaction they have with a professional.
* Your friend/relative has the right to say no to questions if they do not wish to answer them.
* Your friend/relative has the right to leave the research at any time.

If your friend/relative feels like they need it, support after the interview can be provided. For example, this might be in the form of a counselling session or telephone conversation with a trained counsellor – but only if they feel that this is right for them.  
  
Some patients and their families worry that being involved in this study might change the care they receive and make it worse. We do not expect this to happen. If anything, we think that telling one’s story might be a positive experience. Nevertheless, we will continuously talk to you about any concerns and you can stop taking part in the research at any time.

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

As a thank you for taking part in the research, we will offer you friend/relative a £50 gift voucher in total. Whilst taking part in this study may not benefit your friend/relative directly it is a chance for their stories about healthcare to be told. Their stories will contribute to an important research project that aims to improve the healthcare of patients who use the NHS service and other services.

**9. Will my friend’s/relative’s taking part in this project be kept confidential? Will they remain anonymous?**

Your friend/relative’s taking part in the project will be kept strictly confidential and you remain anonymous. They and you **will** **not be identified** in any reports or publications when we write up the findings of the research. We will use pseudonyms (e.g. a fake name).

We aim to keep what your friend/relative told us as confidential: their interview data will only be shared with the research team (who are identified at the end of this document). However, if they told us something that worries us, whereby they or others are in danger or at serious risk, then we might have to share it with someone else, such as a professional. We will let you know if we plan to do this.

**10. What is the legal basis for processing my and my friend’s/relative's 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/findings 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 information - (e.g., your name, and email address) will be stored securely on the University of Sheffield’s secure X drive. University’s Google 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). on the University’s Google 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, in the diary 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. What happens if the research project stops earlier than expected?**

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

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

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

If you feel that your complaint has not been dealt with appropriately, you can contact the Head of Department at the School of Education at the University of Sheffield, [Information redacted], who will escalate the complaint through the appropriate channels:

[Information redacted]

[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.

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 also 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.

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

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

**15. Contact for further information**

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

[Information redacted]

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

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



**17. 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]

**18. Who do I contact if I have a complaint?**

| [Information redacted] | [Information redacted] |
| --- | --- |

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

**IRAS ID: 317389**

**Centre Number: [to add] Study Number: [to add]**

**Participant Identification Number for this study: XXX**

**CONSULTEE DECLARATION FORM**

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

**Name of Researcher:** Professor Dan Goodley

**Please initial box**

I [name of consultee] have been consulted about [name of potential participant]’s participation in this research project. I have had the opportunity to ask questions about the study and understand what is involved.

In my opinion he/she would have no objection to taking part in the above study.

I understand that I can request he/she is withdrawn from the study at any time, without giving any reason and without his/her care or legal rights being affected.

I understand that relevant sections of his/her care record and data collected during the study may be looked at by responsible individuals from [name of sponsor and/or host organisation] or from regulatory authorities, where it is relevant to their taking part in this research.

I agree to their GP or other care professional being informed of their participation in the study.

(If appropriate) I understand that the information collected about him/her will be used to support other research in the future, and may be shared anonymously with other researchers.

Name of Consultee Date Signature

Relationship to participant:

Person undertaking consultation (if different from researcher):

Name Date Signature

Researcher Date Signature

When completed: 1 (original) to be kept in care record, 1 for consultee; 1 for researcher site file