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ORIGINAL ARTICLE

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Co-producing ethics guidelines together with people with learning disabilities

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Abstract

Background: We are a research team of clinical, academic and advocacy-based researchers with and without learning disabilities, working on the *Humanising Healthcare* (for people with learning disabilities) project. The project is dedicated to finding and sharing healthcare practices that enhance the lives of people with learning disabilities. As part of our ethics applications to access National Health Service study sites for fieldwork, we worked together to write guiding principles for co-producing research ethics with researchers with learning disabilities. In this paper, we introduce these Participatory Ethics Good Practice Guidelines and reflect on our collaboration.

Methods: We reflect on developing the Participatory Ethics Good Practice Guidelines. These guidelines were developed during online co-production meetings with our full research team, including advocacy-based organisation researchers, clinical researchers and university researchers. We considered consent, understanding research, and understanding research methods during the development of these Guidelines.

Findings: We present ten guidelines for co-producing research with people with learning disabilities.

Conclusions: Our findings may be helpful to researchers with learning disabilities, university and clinical researchers, funders, and those who work in research governance (e.g., ethics committees and university research departments).

KEYWORDS

co-production, ethics, inclusive research, intellectual disability, learning disability

Accessible Summary

- An Easy Read version of this accessible summary can be found in Appendix A.
- It is important to do disability research together with researchers with learning disabilities.
- Co-production is where researchers with and without learning disabilities work as partners. Co-produced learning disability research should be led by people with learning disabilities.
- An important part of doing research is thinking together about research ethics. Research ethics is about doing fair research that does not harm people with learning disabilities.
- We are a research team of people with and without learning disabilities. We worked together to develop 10 ideas for co-producing research.
- We called these 10 ideas 'Participatory Ethics Good Practice Guidelines'. This paper includes an Easy Read version of these 10 ideas (Appendix B).
- Researchers with learning disabilities on our study team are not just experts in being a person with a learning disability but also experienced researchers; a point all researchers should keep in mind.

1 | INTRODUCTION

The *Humanising Healthcare*[1] project is an ongoing Economic and Social Research Council-funded project that aims to examine humanising healthcare in practice for people with learning disabilities[2] who are accessing NHS services.[3] We are carrying out fieldwork in a neurology unit in South Wales and a learning disability service in Cornwall, England. The fieldwork includes a health ethnography following at least 12 people with learning disabilities over 12+ months. We will conduct narrative interviews and use creative methods with these 12 participants with learning disabilities as well as key individuals involved in their lives and care. We are also exploring different ideas about care, what it means to be human, and what it means to be treated like a human being.

Humanising Healthcare is co-produced by researchers from universities, clinical and advocacy-based organisations, including researchers with learning disabilities. Researchers from advocacy-based organisations include self-advocacy groups and a community cooperative with many experienced researchers with learning disabilities who have personal experience and extensive research and campaigning experience and expertise. Our ambition—as a project team—is to recognise the ways in which health services fail people with learning disabilities and identify examples of healthcare that are compassionate, caring and empowering. Our view is that researchers from clinical, university and advocacy-based organisations must work together to identify such healthcare. Whilst collaborating on the ethics application for the *Humanising Healthcare* project, we also co-produced the Participatory Ethics Good Practice Guidelines which we present in this paper.

Conducting learning disability health research *with* people with learning disabilities is fundamental to producing high-quality and meaningful research. Yet, according to a recent study by Bishop et al. (2023), much health research continues to exclude people with learning disabilities. A significant issue for the researchers working on this project concerns the question of how to conduct ethical research that balances safeguarding, inclusivity, and accessibility, whilst avoiding paternalism. Working together with researchers with learning disabilities can help address this issue.

1.1 | Co-production and inclusive research

We are dedicated to co-production but recognise that this is 'a messy and unclear concept' (Durose et al., 2022, p. 4). In the context of health research where our project is situated, 'ambiguity in co-production also comes from its unclear relationship with patient and public involvement/and engagement (PPI/E)' (Smith et al., 2022). PPI/E is a requirement in health care and health research in England (Williams et al., 2020). Though often used interchangeably, PPI/E and co-production should not be conflated. While 'state-sponsored PPI/E' can be seen to instrumentalise public involvement for 'technocratic' ends, 'grassroots co-production' is more 'radical' and 'democratically-focussed' (Williams et al., 2020, p. 227), foregrounding the conditions of a 'shared power dynamic' (Smith et al., 2022, p. 34). Furthermore, as Filipe and colleagues argue, co-production is

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[1] Our project website documents the progress of our work—https://sites.google.com/sheffield.ac.uk/esrchumanisinghealthcare/home

[2] Also known as an intellectual disability in other national contexts.

[3] The UK's National Health Service.

'less about delivering predictable impacts and outputs and more about developing new communities, interactions, practices, and different modes of knowledge and value production' (Filipe et al., 2017, p. 5). Co-production conducted with people with learning disabilities falls under the umbrella of inclusive research, which draws on participatory and emancipatory research traditions (Walmsley & Johnson, 2003, p. 62) and involves people with learning disabilities as 'more than just research subjects or respondents' (Walmsley, 2001, p. 188). While the core principles of inclusive research were outlined over two decades ago (Walmsley, 2001), inclusive research is noted as lacking conceptual clarity (Bigby et al., 2014). Indeed, researchers highlight that 'figuring out how to operationalise these principles is essential to fostering and maintaining inclusive research collaborations' (Schwartz et al., 2020, p. 237). As a research team, we hope to build on a solid body of research that has demonstrated that co-production makes for better research in the lives of people with learning disabilities (e.g., Aspis, 2002; Frankena et al., 2019; Northway et al., 2014; Walmsley & Johnson, 2003).

Discussions about inclusive research have tended to focus on promoting supportive and accessible frameworks and research cultures that include and utilise the research skills of people with learning disabilities. As this inclusive approach to research has become more routinised in university-based research projects, researchers with learning disabilities and their allies have made the case for their own research capacities—working both within and outside of the Academy (e.g., Carlisle People First Research Group, 2002; Chapman & McNulty, 2004). The prominent researcher and activist Simone Aspis has long argued for academic researchers to consider how they can truly engage with the expertise of researchers with learning disabilities (Aspis, 2002). In a recent piece, Aspis expressed grave concerns about the current state of disability research; specifically, the tendency of academic researchers to dominate proceedings and still talk of rather than with people with learning disabilities (Aspis, 2022).

1.2 | The research team

The *Humanising Healthcare* research team consists of clinical researchers, academic researchers and researchers from advocacy-based organisations. With the exception of the research associates who were recruited later, the research team collaborated on the project from the start. In writing this paper, the team has collaborated from inception through to reviewing and revising the paper, drawing on a number of online meetings and workshops. Many of the researchers from advocacy-based organisations who are named authors on this paper are researchers with learning disabilities with numerous years of experience in carrying out research, with and without university partners, (e.g., Armstrong et al., 2019; Butler et al., n.d.; Lewis et al., 2020). While we acknowledge categories such as 'experts-by-experience', our collaboration foregrounds researchers with learning disabilities as research professionals in their own right.

During the process of writing this paper, different research team members played different roles. Having met for four online workshops facilitated by the study chief investigator and the two clinical researchers to develop these ethical guidelines (see Appendix B), researchers from the advocacy-based organisations made the principal intellectual contribution to this paper. NKH and BDS drafted the full manuscript, which was then reviewed and enhanced by the other authors.

1.3 | Our approach to co-production

While some co-produced research involves researchers with learning disabilities in empirical inquiry, our approach emphasises the advocacy-based researchers as leaders and supervisors of the *Humanising Healthcare* project. Thus, the researchers with learning disabilities will not conduct every study task. Their role reflects the conventional chief investigator's role, where they may have a minimal direct role in data collection, but supervise other researchers to do so. Similarly, the researchers from advocacy-based organisations were directly involved in the recruitment of the research associates.

Executive meetings and co-production workshops are the mainstay of our collaborative practice—held both online and face-to-face. We use accessible methods, Easy Read format, and art-based methods (e.g., forum theatre), to collaboratively write ethics applications, set research aims, design research methods and analyse data. The advocacy-based organisations are hereby the research leaders to whom academic and clinical researchers remain accountable. The main sections of the funding application, which was eventually submitted to and funded by the Economic and Social Research Council, were written by researchers with and without learning disabilities. The guidelines outlined in this paper were similarly co-produced at the early stages of the project along with the study ethics application. The advocacy-based organisations were paid daily consultancy rates funded internally via the University of Sheffield. Researchers with learning disabilities also peer-mentor the two full-time employed research associates who will be responsible for the collection and analysis of data (ethnographic and interview methods at two NHS sites). Thus, in the *Humanising Healthcare* project, researchers with learning disabilities are not only experts by experience when it comes to ethics and methodology but are also researchers and theorists in their own right. By this, we mean that people with learning disabilities help explain phenomena, even as their marginalisation from higher education may mean that, in doing so, they do not draw on the language of existing social theories. For example, in our recent theory workshop, we analysed videos that one of the self-advocacy organisations had produced with the aim of representing 'good' and 'bad' healthcare. The research associates gathered the views of the researchers with learning disabilities and used them to inform the project's theoretical framework. Rather than teaching existing theories to self-advocacy-based researchers, the workshops are conceptually generative, positioning the researchers with learning disabilities on the project as analysts, theorists, research leaders and supervisors. At the time of writing, we are currently midway through a series of face-to-face workshops exploring together the meaning and application of theory. We are using various media and methods including forum theatre and poetry.[4]

1.4 | Ethics

Research must minimise harm and mitigate risk (Iphofen & Tolich, 2018). Ethical research involves considerations around gaining and maintaining informed consent from participants. While there are important questions around the capacity to consent for some people with learning disabilities, it is important that people with learning disabilities are not unnecessarily excluded from research (Hamilton et al., 2017). For people with learning disabilities with the capacity to consent, researchers need to design their study materials and communicate in an accessible way (Crook et al., 2016). Bunning et al. (2022) argue that providing accessible participant-facing documentation to adults with 'capacity-affecting conditions' and 'communication difficulties' requires a more nuanced approach that considers 'supported conversation and the management of fluctuating capacity' (2022, p. 9). Ethics applications, which have to be approved by university ethics committees,[5] are an opportunity for researchers to think through the ethics of the research project. In research that includes disabled researchers, ethics encompass not only participants' but also researchers' access needs.

Given the importance of conducting ethical research and the value offered by co-production, we developed guidelines to support our own approach to co-production and ethics. We present here these 10 guidelines as the Participatory Ethics Good Practice Guidelines. To improve the accessibility of this manuscript, we have provided Easy Read versions of the Participatory Ethics Good Practice Guidelines and of the accessible summary of this paper (see Appendices A and B). In what follows, we first provide context to the Participatory Ethics Good Practice Guidelines. This includes (1) an overview of the co-production process used to develop these guidelines; (2) an overview of the *Humanising Healthcare* project, which the study team used as a case study in exploring ethics and developing guidelines; and (3) we summarise and explain each of the 10 Ethics Good Practice Guidelines (Appendix B).

2 | DEVELOPING THE PARTICIPATORY ETHICS GOOD PRACTICE GUIDELINES

The Ethics Good Practice Guidelines were developed by a group of researchers working on the following project: Promoting Participatory Research in Ethics Applications with Marginalised Communities (Participatory Ethics project). The group included 12 researchers with learning disabilities and four researchers without learning disabilities. The researchers with learning disabilities came from four organisations: the self-advocacy groups Sheffield Voices, Sunderland People First, and Speakup Self-advocacy Rotherham, and the Welsh community co-operative, Barod. These four organisations and their members have been involved in many research projects before. The researchers without learning disabilities came from the University of Sheffield, which received funds from Research England to support participatory research.[6] This stage of the work took place over four co-production workshops between January and June 2022. These four co-production workshops helped produce the research protocol and NHS ethics application for the Humanising Healthcare project.

2.1 | The co-production workshops

The co-production workshops took place on Zoom and lasted 2 h each, with a 15 min break in the middle. The research group used accessible materials, including Easy Read images, produced with Photosymbols©. Each workshop focussed on a specific topic:

(1) introducing each other and the NHS ethics process,
(2) training for NHS ethics applications,
(3) developing the research protocol,
(4) submitting the ethics application.

A series of activities were prepared with the explicit aim of eliciting discussion between team members with and without learning disabilities which sought to:

(1) demystify the ethics process,
(2) share literacy and understanding of the NHS process,
(3) consider the ways in which researchers and participants with learning disabilities are included/excluded by the process and,
(4) coauthor the Participatory Ethics Good Practice Guidelines.

In the first workshop, the researchers introduced themselves to one another. The group spent time together reading the accessible participant information sheet that explained the aims and ambitions of the *Accessible Ethics* project.[7] The group then discussed the information sheet, focussing on the questions it raised, and finding solutions to these questions. The researchers then read and completed the consent form for the *Accessible Ethics* project.

In the second workshop, the research team explored the meaning of the word consent and focussed on understanding research. All researchers consented to taking part in the project.

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[4] See our project exhibition webpage——https://sites.google.com/sheffield.ac.uk/esrchumanisinghealthcare/exhibition

[5] Research that takes place in the NHS, as ours does, requires additional ethical approval from the Health Research Authority.

[6] The University of Sheffield is committed to supporting participatory research across a host of disciplines and our project contributed to the development of the Participatory Research Network that formed in 2023—https://www.sheffield.ac.uk/research/participatory-research

[7] Please see https://sites.google.com/sheffield.ac.uk/esrchumanisinghealthcare/co-producing-ethics for copies of the accessible information sheet and consent form used in the Accessible Ethics project.

The team then moved on to work on understanding the terms 'research' and 'research methods' by focussing on the *Humanising Healthcare* project as an example. To make this more accessible, the Chief Investigator (DG), using Easy Read slides, spent time carefully explaining and describing the NHS sites to the rest of the research team.

In the third workshop, the research team discussed in detail the research methods they were hoping to use in the *Humanising Healthcare* project. These research methods were thus chosen following extensive discussions across the team of clinical, university and advocacy-based researchers. The research team then started to produce the information sheets and consent forms for the *Humanising Healthcare* project. These documents were compiled outside of the workshops. The team shared ideas via email, held impromptu online meetings and conversations and eventually wrote what we agreed to be the most coherent, understandable and clear information sheets for the participants of the *Humanising Healthcare* research project.

Following the meetings, DG (one of the university researchers) drafted an Easy Read version of the 10 guidelines. These were then sent to two of the collaborating advocacy-based organisations, Barod and Sheffield Voices, so that researchers with learning disabilities could review and critique the Easy Read version of the guidelines. University-based researchers then redrafted them further. In May 2023, following a *Humanising Healthcare* executive meeting, these guidelines were revisited and revised again by researchers with learning disabilities. We present these guidelines here.

3 | PARTICIPATORY ETHICS GOOD PRACTICE GUIDELINES

Appendix B shows an Easy Read version of the 10 guidelines in the Participatory Ethics Good Practice Guidelines that we developed. Below we expand on these guidelines. In doing so we, once again, use the *Humanising Healthcare* project as an example.

3.1 | Guideline 1

We *pay our research partners for their time*. Paying research partners for their time is an important part of ethical research. By paying research partners we recognise the contributions of all researchers involved in the project. In our view, not paying research partners for their time suggests that their skills and knowledge are not as valuable as those of academic researchers who get paid for their work. Any time spent by members of the organisations in the workshops is covered by the daily consultancy rate already budgeted for and paid for through the project. We know that paying researchers with learning disabilities can be difficult—not least if this impacts on people's benefits (NIHR, 2022). Therefore, we have found paying organisations to be a more streamlined way of remunerating researchers with learning disabilities. We thus remunerate participants for their involvement in the *Humanising Healthcare* project by paying organisations' daily consultancy rates. We have learnt from this that paying people with learning disabilities for their contributions is important, regardless of whether they make their contributions as researchers, advisors or participants.

3.2 | Guideline 2

We *always start a research meeting with some friendly introductions*. Our *Humanising Healthcare* workshops bring together around 20 people from groups that are based in different parts of the country. Because we meet roughly once each month and it is easy to forget names, we find it important to begin each meeting with introductions. This makes everyone feel more comfortable and sets the tone for collaboration. The introductions are a time when people might highlight what is going on for them. This can be playful and fun, but it can sometimes also touch on difficult subjects. Having the space to share what is going on means that we, as a team, can be more sensitive to each other's needs, highlighting our shared ambition to create caring spaces. Research meetings can be intimidating and hierarchical, and attention to each other contributes to group bonds, creativity, and a sense of safety. Sharing opinions, ideas and criticism can feel risky to many of us, regardless of whether we have learning disabilities or not.

3.3 | Guideline 3

In addition to Easy Read, we always *use plain English* to write documents such as meeting agendas, meeting slides, minutes and outputs. We often use Photosymbols® to source the supporting images for our Easy Read documents. Appendices A–D are examples of Easy Read documents. Images should be selected thoughtfully so that they enhance readers' understanding of the words used. Words used should be as clear as possible. Colleagues with learning disabilities feedback on draft Easy Read documents, which helps ensure that our Easy Read is as clear as possible. Based on such feedback, the workshop chairs (usually the research associates and two researchers with learning disabilities) stop sharing slides during group discussions. This can make it easier for people to lip-read and follow the conversation. Researchers with learning disabilities tell us they generally prefer we:

- use a consistent format, with the images on the left, and Plain English text on the right;
- keep documents brief, with a maximum of 10–15 pages or slides;
- use a pale, nonwhite background colour;
- get feedback on what font to use. Our default font on the project was previously Arial, as it has a reputation for being accessible. However, our colleagues with learning disabilities did not like commonly used fonts such as Arial, Calibri or Times New Roman. Although there was not a consensus on one specific font, Century Gothic was preferred by the group.

3.4 | Guideline 4

We *always start a research meeting with a reminder of what the research is*. This reminder is very important for the *Humanising Healthcare* project. The research team members with learning disabilities often work on many research projects at once. For this reason, we start each co-production meeting with a reminder about what our research project is all about; including the study aims, why the research is important and the research objectives. If there are lots of research objectives, then we focus on the ones that are most important for that particular co-production meeting.

3.5 | Guideline 5

Our fifth guideline is that *we remind people that they can leave research projects if they no longer want to be involved*. We have provided example slides that we have used to help us talk about the right to leave research (Appendix C). It is well known that research participants need to understand that they can withdraw from research projects. It is also important that researchers with learning disabilities are reminded that they can stop working on, or take a break from, the project. Sometimes we discuss difficult things in our co-production meetings, such as high-profile cases where people with learning disabilities have been abused and neglected. It can be very hard to talk about such events, especially for those on our team who have learning disabilities themselves and have loved ones who have learning disabilities. Researchers with and without learning disabilities may need to stop working on the project, or come out of meetings, for lots of different reasons, such as caring responsibilities, or changes in their personal lives, illness, or simply that the project was not what they thought it would be. For this reason, we remind researchers with learning disabilities that they are free to leave or enter the research meetings whenever they want. Researchers without learning disabilities are also free to leave a project. However, due to the nature of their employment contracts, these researchers have to follow more formal processes. We must acknowledge that how we convey that researchers can leave the project, and what this means in practice, will be different for researchers with and without learning disabilities. Researchers without learning disabilities tend to be employed by universities, which afford certain protections and responsibilities. For example, the research associates on the *Humanising Healthcare* project would need to provide a notice period or go on formal sick leave to leave the project. For the researchers with learning disabilities on the project, their contracts are not specific to one particular research project or another, theoretically making it easier to dip in and out of research projects without structural consequences. In practice, however, there is a need to remind our colleagues with learning disabilities that they are able to come and go on the project, or leave entirely, for whatever reason. This need arises due to the oppression that people with learning disabilities continue to face. For example, the choices of people with learning disabilities are routinely constrained as many experience discrimination, control, intimidation and coercion. People who experience these controlling and abusive forces over a lifetime may end up being more compliant than people who do not have such experiences. We must be constantly aware of these differences in life experiences between our team members who have learning disabilities and those who do not, and seek to disrupt and redress these power imbalances.

Researchers without learning disabilities have ethical responsibilities towards researchers with learning disabilities. These responsibilities are articulated not only through ethics applications but also as caring practices. We must not ignore the reciprocal and multi-directional nature of these ethical and caring practices. Throughout the *Humanising Healthcare* project, we see examples of researchers with and without learning disabilities being thoughtful, caring and practising ethical principles towards one another. A concern for those of us who must take time away from a project or leave a project altogether is whether we can still expect to be treated with kindness and respect in the future. As a research team, we must find ways to meaningfully convey that we are kind and respectful to one another regardless of individuals' outputs. This is important for both researchers with and without learning disabilities. Conveying this praxis is important for colleagues to genuinely feel able to leave a project without social consequences. The right to leave a research project is so important because having a genuine choice allows us to feel more confident that all the researchers on the team genuinely consent to be there.

3.6 | Guideline 6

We *spend time explaining consent*. Researchers with learning disabilities have highlighted during the ethics co-production workshops that researchers need to take time to carefully explain the research and gain informed consent. While participant information sheets aim to share relevant information, such information is complex and often uses jargon. Anonymisation, data management, and withdrawal are terms that usually form the bedrock of participant information sheets. These practices are very academic and therefore not necessarily accessible to people outside of the university. Although we aim to simplify the language, participants may still have questions. Taking the time to address these questions is crucial as it is the only way to ensure that consent is informed. Researchers with learning disabilities have highlighted that information is often best given through examples. As a result, our *Humanising Healthcare* information sheet explicitly lists the different forms a narrative interview may take. We highlight that participants can use different methods to tell their healthcare stories. We talk through the study information with the participants, checking for understanding and adapting our explanations to suit individual participants.

We gained ethical approval for the co-production workshops both to develop the Participatory Ethics Good Practice Guidelines and the NHS ethics application for the *Humanising Healthcare* project. This process included obtaining informed consent from our colleagues with learning disabilities to take part in these co-production workshops. We acknowledge an important tension and contradiction in our approach to consent and participatory research here. We are a team of researchers with and without learning disabilities. We believe that our colleagues with learning disabilities are expert researchers and we want to reduce power imbalances in our work together. And yet, we have sought ethical approval and taken informed consent only from our team members with learning disabilities. This can be seen as paternalistic, transforming our colleagues from researchers to participants. As a research team, this contradiction feels particularly pressing and we continue grappling with it as we work on the *Humanising Healthcare* project. We want to research together and write together, to value and respect each other, and yet both ethical and publishing conventions create barriers to this. Team members without learning disabilities having to obtain formal consent from researchers with learning disabilities reinforces hierarchies and power imbalances. After all, we never ask research colleagues without learning disabilities to give their consent before they contribute or write into various outputs. Yet, we cannot deny that power imbalances do exist between people with and without learning disabilities, and ethical processes require researchers without learning disabilities to take responsibility for redressing such imbalances. We must find ways of researching together safely, equally, meaningfully, and respectfully.

3.7 | Guideline 7

We *always recap on previous meetings*. These recaps allow the research associates to remind the rest of the team about the last meetings' highlights and provide updates on any agreed actions. Such recaps help to keep the meetings focused and progressive. Again, in the weeks and months between our co-production meetings, colleagues with learning disabilities work on multiple research projects. Being clear about what we have already agreed and talked about together, and where we are at with any actions that arose from prior meetings, helps us to make the most of our time together and respects how busy everyone is in our co-production meetings. These recaps also support those who have had to miss prior meetings to catch up with the project.

3.8 | Guideline 8

We *explain the research context*. To understand ethics, we need to understand the research context. Many people with learning disabilities and other marginalised people are used to being the objects of research. Understandably, they might be very wary of participating in research. Ethical research is clear about the contexts it seeks to research. Ethical research recognises that when researchers enter a social context, they change it. We are conducting learning disability research in the context of a society that has neglected, abused, controlled, and over-studied people with learning disabilities while dismissing their contributions. The *Humanising Healthcare* project was developed in response to the dehumanising treatment of people with learning disabilities in health and social care contexts in the UK.[8] We talk about this wider research context because it highlights the project's motivations and its importance. Often, it is colleagues with learning disabilities who initiate conversations about recent media coverage of the mistreatment of people with learning disabilities. It is important that we talk about this context clearly and carefully because people with and without learning disabilities are likely to find these cases of abuse and neglect upsetting. To mitigate such upset, we take our time to check how the group is feeling, we check in with colleagues who show signs of distress outside of the meeting and we consider practical things that we can do to try and help raise awareness of the situation.

We also explain the research context of our study design. For example, we have included Easy Read slides from the *Humanising Healthcare* project providing context about our research sites (see Appendix D). We included:

- where our two NHS sites are on a map,
- what those services do to help people with learning disabilities,
- who in the research team leads those sites,
- who will be doing the fieldwork at each site,
- what fieldwork could look like at those sites (e.g., the research methods).

3.9 | Guideline 9

We *spend time together understanding and co-producing research methods*. We agreed on the *Humanising Healthcare* project that we will use narrative interviews, creative methods, and ethnographic methods. When we talked about narrative (or storytelling) interviews, colleagues with learning disabilities talked about their experiences of being interviewed for jobs and shared that it was easier when the questions were shared before the interview. We have, therefore, included our interview questions in the participant information sheets.

The research team also told us about being an interviewer for research. We agreed that we may have to keep our participants on track. To help with this issue, we could use an Easy Read interview schedule so that participants have a reminder about what question we are talking about. Our creative methods may also help to keep participants on track, for example, we could use participants' photos as prompts for their interview (i.e., photo elicitation interviews). We considered that there might be silence in the interview and agreed that while we might need to ask clarifying questions, we should avoid the urge to fill the silence. We talked about how the stories that get shared with us might not be in the order of the events. One colleague highlighted that participants can worry that they have not told their

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[8] There are various care home scandals involving the abuse and neglect of people with learning disabilities, for example, at Winterbourne View (Department of Health, 2012).

story well and that we will need to reassure participants by telling them that we appreciate their stories. We noted that narrative interviews are very open interviews, and so it is expected that participants will take detours and tangents. One colleague pointed out that we should keep in regular contact with participants because they might otherwise forget about the research and their agreement to take part in it. We considered how it might help to prepare short and clear summaries to remind participants of the research when we call them.

We also talked together about our experiences of being interviewed for research as participants. Colleagues with learning disabilities shared examples of researchers failing to hear and respect their stories. We also shared examples of research studies that were unclear about what information they were gathering and how it would be used. As researchers, we must be clear about what we are collecting or measuring and be clear about the rights of the participants to view their own data.

We also noted that participants becoming upset during interviews does not necessarily mean that they do not want to share their stories. After all, some experiences are so difficult that they might be impossible to talk about without us getting upset. We agreed that in such instances we would need to check with participants if they are happy to continue telling their stories. We acknowledge that it may be controversial to continue an interview when a participant is getting upset. However, letting someone finish telling their story and listening to them when they are upset is a form of care and kindness. What happens once the participant has finished telling their story, however, does require consideration. The researcher must ask themselves: Is the participant safe? Do I need to share with the participant support resources? Do I need to initiate the study safeguarding protocol? Do I need support? Do I need to discuss this interview with my colleagues and supervisors? Is the participant happy for me to still include their interview in the study? Does the participant want to remove the part of the interview where they got upset? Overall, these discussions on the *Humanising Healthcare* project highlighted the need to ask questions about what humanising *research* looks like, as well as humanising healthcare.

3.10 | Guideline 10

We *make sure information sheets and consent forms are co-produced in accessible ways*. As Guideline 3 highlights, we produce our written documents in Easy Read. Producing documents in collaboration takes this a step further because it harnesses the knowledge and expertise of researchers with learning disabilities. Co-producing documents are also important because access needs are not always foreseeable. For example, even though white backgrounds are generally taken as standard for Easy Read, one colleague with learning struggled with the glare of a white page background. This led us to adopt the practice of using a muted colour for backgrounds. We have found that co-production is also best understood as a process. Thinking about access can take some time as we begin to appreciate the many ways in which a text can be inaccessible. It remains crucial for researchers to be flexible and willing to adjust materials to meet access needs as they present themselves. The fact that access needs cannot always be known in advance can feel intimidating, especially if we are producing accessible materials for participants we have not met yet. Ethical restrictions can make it difficult to make changes to study documents in a timely and responsive way once a project has commenced. We urge researchers to not be disheartened by this. Using Easy Read is a very good place to start and so is getting advice from people with learning disabilities.

4 | CONCLUSIONS

Our research builds on the innovative work of researchers with learning disabilities. A unique contribution of this paper relates to the inclusion of researchers with learning disabilities in the development of an ethics application to research healthcare settings. We know that these ethics processes are complex, cumbersome and difficult—but these challenges should not be used as an excuse to exclude researchers with learning disabilities. In this paper, we have introduced the Participatory Ethics Good Practice Guidelines. These have been co-produced by the *Humanising Healthcare* project team. This research team includes researchers who have learning disabilities. We hope that these guidelines will be used by;

- people with learning disabilities who work as researchers and also those who become involved in research as participants,
- university and clinical health researchers,
- students across medicine, social sciences, and the humanities,
- funders of research,
- ethics committees in universities and the NHS.

While we are content to share our recommendations, we also recognise the importance of ongoing review and adjustment of the guidelines based on feedback and evolving best practices in the field of inclusive research. The learning disability research field has generally understood the value of including the views of people with learning disabilities for several decades. On the *Humanising Healthcare* project, however, we understand the contributions of people with learning disabilities as more than simply being 'experts-by-experience'. Team members with learning disabilities are professional researchers who each have significant research expertise, knowledge, and experience. It is imperative that we recognise and value the multiple forms of expertise brought into research projects by researchers with learning disabilities. Furthermore, we seek to bring this expertise to health research as a field where the perspectives of people with learning disabilities continue to be notably underrepresented (Bishop et al., 2023; Frankena et al., 2019). Finally, our hope is that through pollinating the nascent field of inclusive research in health with research approaches that foreground people with learning disabilities as researchers and research leaders (rather than experts by experience), we will contribute to inclusive health research that retains a democratic focus which serves the emancipation of people with learning disabilities. This, we argue, matters as health inequalities cannot be decoupled from the pervasive dehumanisation of people with learning disabilities.

We have argued that researchers with and without learning disabilities working together have the potential to enhance health research and significantly improve its real-world applicability. Given the significant health inequalities faced by people with learning disabilities, the potential of these enhancements should not be underestimated. Promoting humanising principles in healthcare has the potential to disrupt the health inequalities faced by people with learning disabilities.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

No data are available for further study.

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APPENDIX A: EASY READ ACCESSIBLE SUMMARY

Easy Read Accessible Summary

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We are a research team of people with and without learning disabilities.

It is important to ask people with learning disabilities about their good healthcare experiences.

	We know that people with learning disabilities have had bad healthcare experiences.
	We want to find together an example of good healthcare.
	Co-production is where researchers with and without learning disabilities work as partners.

(Continues)

We think that co-produced learning disability research should be led by people with learning disabilities.

Many researchers agree that co-production makes learning disability research better.

For example, co-production helps to make research more accessible to participants with learning disabilities.

Co-production helps to make sure that learning disability research deals with issues that are important to people with learning disabilities.

Co-production makes research more inclusive. It teaches researchers without learning disabilities how to make research accessible to researchers with learning disabilities.

An important part of doing research is thinking about doing ethical research.

Research ethics is about doing fair research that does not harm people with learning disabilities.

(Continues)

Our team of researchers with and without learning disabilities worked together to develop 10 ideas for co-producing research.

4 Notes from the last meeting
Talk about important things from the last meeting.

5 Valuing People Now

6 Planning for the South West
Making plans and working with other groups.

7 News about Social Services
from two ADASS meetings.

8 Any other business
to talk about.

9 Date for the next meeting
and finish.

We called these 10 ideas Participatory Ethics Good Practice Guidelines. This paper includes an Easy Read version of these 10 ideas.

We know that the researchers with learning disabilities on our study team are not just experts in being a person with a learning disability, but they are also expert researchers.

We think other researchers without learning disabilities should also understand that their colleagues with learning disabilities are expert researchers.

APPENDIX B: PARTICIPATORY ETHICS GOOD PRACTICE GUIDELINES— EASY READ

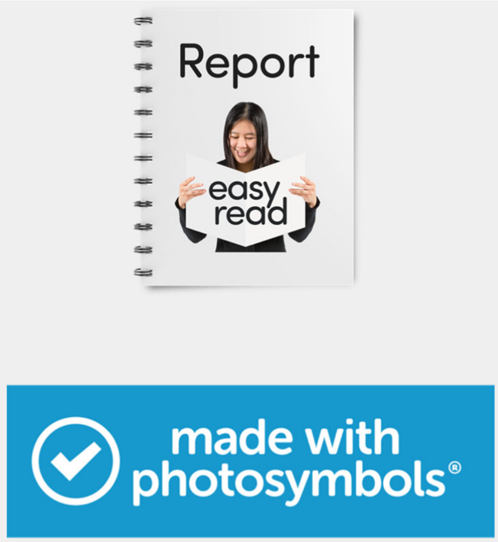
All images from Photosymbols ©

Participatory Ethics Good Practice Guidelines

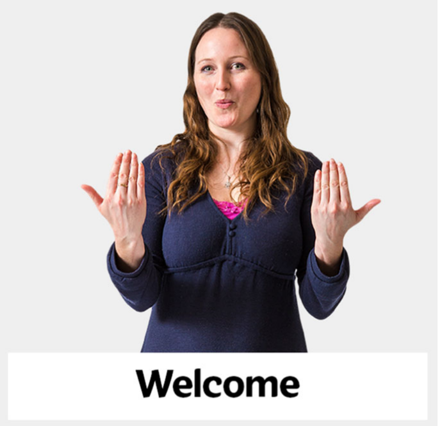
Guideline 1
Pay our research partners for their time.

Guideline 2
Always start a research meeting with some friendly introductions.

(Continues)

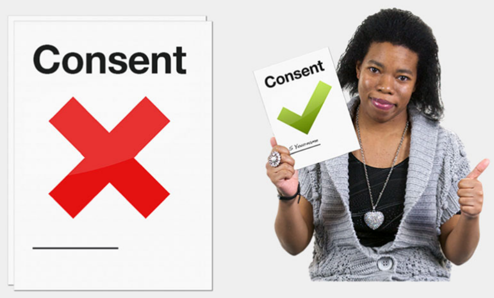


Guideline 3
Always use Plain English and supporting images.
We use Photosymbols.



Guideline 4
Always start a research meeting with a reminder of what the research is.

Guideline 5
We remind people that they can leave research projects if they no longer want to be involved.



Guideline 6
Spend time explaining consent.

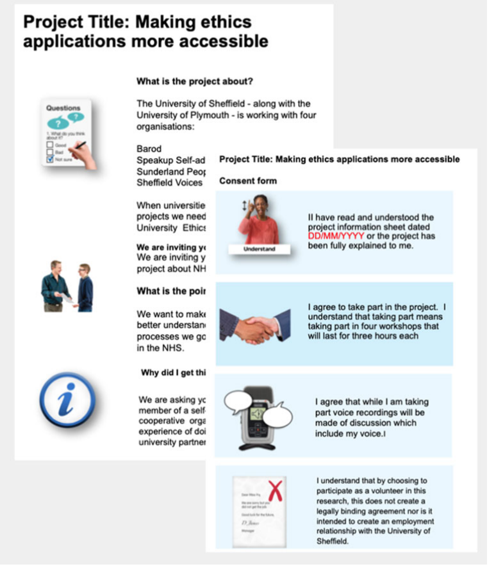
	**Guideline 7** Always recap on previous meetings.
	**Guideline 8** Explain the research context.
	**Guideline 9** Spend time together understanding and co-producing research methods.
	**Guideline 10** Make sure Information Sheets and Consent Forms are co-produced in accessible ways.

APPENDIX C: EXAMPLE SLIDES EXPLAINING THE RIGHT TO LEAVE RESEARCH

The Right to Leave Research

Guideline 5:
We remind people that they can leave research projects if they no longer want to be involved.
We used these slides to explain …

The University of Sheffield has approved our application to do this research on ethics.



Project Title: Making ethics applications more accessible

What is the project about?

The University of Sheffield - along with the University of Plymouth - is working with four organisations:

Barod
Speakup Self-ad
Sunderland Peo
Sheffield Voices

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university partne

Project Title: Making ethics applications more accessible

Consent form

Il have read and understood the project information sheet dated DD/MM/YYYY or the project has been fully explained to me.

I agree to take part in the project. I understand that taking part means taking part in four workshops that will last for three hours each

I agree that while I am taking part voice recordings will be made of discussion which include my voice.I

I understand that by choosing to participate as a volunteer in this research, this does not create a legally binding agreement nor is it intended to create an employment relationship with the University of Sheffield.

Dan Goodley has sent you a copy of the Participant Information Sheet and the Consent form.

We will ask you before and after the meeting if you are still willing to be involved?

If yes please click the 'thumb' reaction in Zoom. If no, you are free to leave.

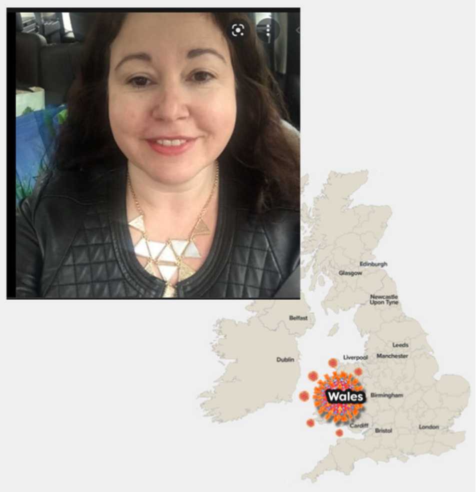
You can ask any questions you need before deciding.

You are free to leave or enter the research meetings whenever you want.

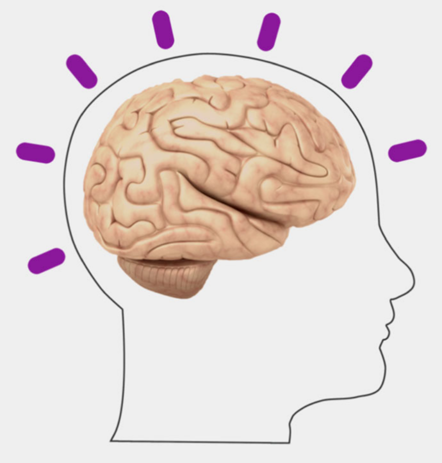
APPENDIX D: EXAMPLE SLIDES DESCRIBING THE STUDY SITES FOR THE *HUMANISING HEALTHCARE* PROJECT

The *Humanising Healthcare* study sites

We have talked about our plan to research two healthcare services. One of our sites is in South Wales. The other site is in Cornwall.



Our site in South Wales is a **Neurology** Service. It is led by Dr Charlotte Lawthom. Charlotte is a **neurologist**.



Neurologists help with epilepsy and other conditions that affect the brain and spinal cord.

Nikita Hayden is the research associate based at our South Wales site.

Our site in Cornwall is a Learning Disability Service. It is led by Dr Rohit Shankar. Rohit is a **psychiatrist**.

Psychiatrists are medical doctors who work with people who need help with their mental health.

(Continues)

Rohit's service aims to offer care to people in their homes and communities.

Bojana Daw Srdanovic is the research associate based at our Cornwall site.