



Eleanor Harvey

Profile:

Dr Eleanor Harvey is a researcher in Complex Systems in the School of Design and Creative Arts at Loughborough University.

She applied her Human Factors expertise to transport (rail, marine, and aviation) and the construction sector before joining the DECODE team in November 2023.

DECODE is an NIHR-funded research project which aims to improve the health of people with a learning disability (sometimes known as an intellectual disability), 9 in 10 of whom have at least 2 long-term health conditions.

Dr Harvey's role in the project is to co-design with health and social care professionals, carers, and people with a learning disability how best to put DECODE's research into practice.

Transcript:

[00:00:00] I'm Dr. Eleanor Harvey. I'm a Human Factors and Complex Systems Researcher. It's also known sometimes as User Centred Design. And I work at Loughborough University on a project called the DECODE project.

(Voiceover) Can you share why you think it is important for your research to have diverse inputs?

[00:00:14] Okay, so I think the obvious reason is that lots of these groups are underserved by research and if we don't reach out to these groups then we're never going to address the health inequalities that they face.

[00:00:23] I also think it's been really important for me as a researcher to think about how I'm going to communicate my research to a really diverse audience on lots of different platforms. So we work with people with learning disabilities so I have to think about how I'm going to turn my research into an academic paper but also how I'm going to turn it into perhaps easy read.

[00:00:40] Or plain English summary or an animation. And that's really pushed me out of my comfort zone into kind of communicating in lots of different ways. And another thing it's really done is push me to think about my accountability and my role as a researcher, because some of the people that we speak to, they've never really been asked what they think of these things and nobody's ever listened to them and they share things which are really personal and they are vulnerable.

[00:01:03] And so I have to, I have that responsibility of them making sure that I do something with that research. So it's been a really positive thing for me working with diverse groups as well.

(Voiceover) How have you used diverse participants or co-design in your research?

[00:01:20] Okay, so PPI underpins everything that we do. So PPI stands for Public and Patient Involvement and this is a group, it's like an advisory board of people with lived experience of the conditions that we are researching. So they've been there from the very beginning. Some of them were co-applicants on the proposal. They've helped to shape the proposal and think about what this research is going to look like, what they want to know, really, because that's the most important thing that this is serving them and that this is research for them.

[00:01:44] Then later on once we built this kind of, we recruited a community of PPI Members or partners who to work with us and we take things to them like rating scales to make sure that makes sense to them or how are we going to word the questions that sort of thing. How the activities that we're going to run with them are going to be fun and understandable that we're going to get the right data from them.

[00:02:05] So it's got to work both ways, I suppose and what's feasible in the timeframe. So all those sorts of things. Everything goes through PPI before we take it to our participants. And they help us to co-design the research. And another thing that they do is to work with us on the outputs. So how we're going to communicate the research.

(Voiceover) Can you share something you have learnt in terms of best practice when working alongside a diverse range of contributors?

[00:02:36] So the best thing that I've learnt is that you absolutely cannot underestimate the value of doing everything with PPI. So that's our volunteers with lived experience of the conditions that we're researching. It's really good for the research because it helps shape it and make it meaningful to the people that you're working with but it's also really good for me. So it keeps me really grounded. I love meeting with our PPI team it's actually the highlight of my week It really keeps me grounded. And it It's really humbling sometimes, I think, the things that people share with you and the fact that you've got an opportunity to make a difference to them.

[00:03:11] And it's also been really good for our PPI partners that we've been working with. So some of them have developed skills that, that meant they've gone on to get other positions like voluntary work or even paid employment. They've made really great friendships. And some of the carers, they say it's so energising to be able to make a difference.

[00:03:30] It's really therapeutic to have someone to listen to you and just an outlook for these kind of frustrations. And to know that someone is there doing this research to improve things is really yeah great for them.

(Voiceover) What advice would you recommend to early career researchers to create inclusive settings when co-creating or conducting research?

[00:03:48] So there's loads that you need to do in terms of accommodating people practically, emotionally, socially. I think the most important thing for us has been to allow enough time. We are always rushing. And I think when you have people there that have never been asked to do that, their opinion on things and nobody's ever listened to what they want to say.

[00:04:06] It doesn't matter if they go off on tangents and things, just being there to listen to them and listen to what they have to say. It's more important than staying on your protocol. And okay. Back to my script. Now these are the questions that I want to find out about. Yeah, so allowing enough time, especially when we are working with people with learning disabilities, so it can take more time for them to process information and to communicate.

[00:04:27] But giving them that time is really meaningful and it just. The quality of the data is so much better if you do give people that time. The other thing that I think is really important is to ask people what they need. So everyone's completely different and I think you, you have to ask people what adjustments they need. Don't make any assumptions.
(Voiceover) Can you share any common mistakes that researchers should avoid?

[00:04:53] I think it can be easy to underestimate the amount of time that doing inclusive research takes. I've done some interviews with clinicians. And it's very easy. It's just me. I go out with my dictaphone and my questions. It takes an hour. For doing the same interviews with people with learning disabilities, we had to completely rethink the way that we were going to conduct the interviews. So we gave them some like little houses and we drew out the map of the journeys that they would take, the different people that were involved in their care so that they could physicalise and visualise what was going on.

[00:05: 26] And keep that all in front of them while we were doing the interviews. So then to recruit people before we even mentioned the research, some of our our PPI leads, they went out to community centres with craft activities just to befriend people before they even approached the idea of taking part in research and then they did some research-

[00:05:46] -gently explained what the research was about and gave them an opportunity to go away and talk to someone that they trusted about it before there was any pressure to take part. Then before they took part in a mental capacity assessment before they could consent. And then we had to book them taxis so they could come to or do it in their home, so that meant traveling for us, or they, we booked them a taxi so they could come over to us.

[00:06:11] And then and then the interview itself was much longer. So altogether, that's perhaps four or five, even six times as much work. But it's essential because that's the data that we want.

(Voiceover) Is there anything else researchers should be mindful of when working with diverse audiences?

[00:06:25] I think you definitely need to be mindful of the language that you use. And I don't just mean in terms of being politically correct or that sort of thing. But I remember the first time I went to meet our PPI group and I said, hi, I'm Ellie. I'm one of the scientists. Okay. And there was this kind of intake of breath and they looked a little bit scared. And I think the word scientist was a really loaded, intimidating word.

[00:06:46] And one of them said, Oh, are you going to be doing experiments on us? And that was the kind of connotation that word had. They associated it with that I was some kind of scary psychoanalyst. So I think the only way you can get over that is to work with the people that have lived experience with these conditions, so you understand your audience and how they're going to interpret these language.

[00:07:04] At the time, our speech and language therapist Amy, she just said, Oh, Ellie's one of the researchers. And then they all breathed a sigh of relief and everything was fine. So I think another thing to be mindful of is how attached people can become when they're taking part in research. We've been working with some of these participants for two and a half years.

[00:07:23] Some of them have been back to take part in different studies for five or six times. They've made friends with the researchers, with the other participants, and now as the project's coming to an end, we need to really think about what's going to happen afterwards, because saying goodbye is going to be really emotional.

[00:07:38] It's been such an enjoyable, fulfilling experience for them, so we've put together an aftercare pack. For them it includes some details of other projects that they could get involved in. It includes how to write up their skills into a CV, so they could go on to get other opportunities. And it includes who to speak to if they're feeling upset because this is, yeah, a really sad time. I'm going to miss them a lot.