A global call to action for disability inclusion in health research: Webinar transcript

Webinar details

- Date: 8th June 2026
- Time: 15:00 to 16:30 BST
- Format: Online via Zoom

Webinar speakers

- Dr Anna Anderson, University of Leeds, UK
- Professor Bonnielin Swenor, Johns Hopkins Disability Health Research Center, USA
- Jasjot Maggo, University of Otago, New Zealand
- Dr Amy M Russell, University of Leeds, UK
- Dr Victoria Shepherd, Cardiff University, UK
- Katherine Deane, University of East Anglia, UK

Slide 1: Logistics

Anna Anderson: We're recording now. So, hi everyone, I'm Anna Anderson, I'm a Research Fellow at the University of Leeds in the UK.

I'll be introducing our webinar further in a moment, but before we get underway, I just wanted to explain some logistics and the steps we're taking to make our webinar as accessible as possible.

Our British Sign Language interpreters are spotlighted so they should be displayed on your screen.

We've got real-time captions, which you can access by clicking the 'CC' button at the bottom of your screen or via the live captions link that Libby is sharing in the chat if she hasn't already.

We've already shared our slides on the webpage of the Disability Inclusion in Research Collaboration, or DIRECT as it's known for short. And as I've mentioned, the webinar is being recorded, and we'll be posting the recording and transcript on the DIRECT webpage after the webinar.

As presenters, we'll describe any visually important elements on the slides, and we'll also provide visual descriptions of ourselves as part of our introductions. So, I'm a white woman in my thirties with curly brown hair and glasses and I've got a blurred background today as I'm joining from my flat.

I also wanted to mention that we've had quite a few discussions about what style of slides to use as we know that people's accessibility needs for slides vary. So, the approach we've used to try to balance different needs is to mainly use a pale coloured background and dark text, which is often helpful for neurodivergent people, and we've intentionally used black text to maximise the contrast to support people with low vision.

We've also got an example later in the presentation of a different template with white text on a black background to showcase an alternative approach that can be particularly helpful for some people with low vision.

For questions, please use the Vevox platform, which you can access via vevox.app. You can go directly to our webinar questions using the QR on this slide or via the link in the chat, or you can type in our webinar ID which is 179-519-560.

And when you get to the Vevox platform, there's a home page and a question page, so just need to make sure you're on question page to add a question.

And I just wanted to highlight that one of the key reasons we're not using the chat in this webinar is because if people use screen readers for accessibility, then the screen readers will read out the text in the chat, so it can be quite distracting if there's lots of text being read out whilst people are trying to listen to the presenters.

And finally, just to say, if you're experiencing any technical difficulties, please email PPIBRC@leeds.ac.uk, and that email address is in the chat as well.

Slide 2: A global call to action for disability inclusion in health research

Anna Anderson: So, thanks so much again for joining this webinar presenting a global call to action for disability inclusion in health research.

The webinar is being jointly hosted by DIRECT and two centres funded by the NIHR, which stands for the National Institute for Health and Care Research and that's the research arm of the NHS in the UK.

So, those two centres are the NIHR Biomedical Research Centre Leeds and the NIHR HealthTech Research Centre in Accelerated Surgical Care.

And on this slide, as well as the DIRECT and NIHR logos and today's date, we've also got a little 20-year symbol as it's the NIHR's 20th anniversary this year.

Slide 3: Agenda

Anna Anderson: For our agenda, this webinar is structured around a global call action published by our DIRECT team. I'll firstly give a brief introduction, and then we're going to focus on three main areas we identified that present challenges to disability inclusion in health research.

The first of these is monitoring disability inclusion, and to discuss that we're focusing on using data to advance disability-inclusive health research.

We're then going to discuss the research cycle, including providing practical examples related to working with people with learning disabilities and research with people with impaired capacity to consent.

Then the final main area we're going to discuss is the research and advisory workforce, including providing a practical example of Lab Access Guidelines.

We'll then finish by summarising our take-home messages and have an opportunity for questions.

I also just wanted to highlight that due to the timing of this webinar, a lot of our presenters' examples are from the UK and USA, but we are aiming to organise a separate webinar if possible that provides examples in other contexts, including the Global South.

Slide 4: Introduction

Anna Anderson: So, as I've mentioned, I'm going to give an introduction to our webinar. I'm Anna Anderson and I'm a Research Fellow at the University of Leeds in the UK and lead the DIRECT collaboration.

Slide 5: Some questions

Anna Anderson: So, to start off with, I've included some questions on this slide to encourage you to think about your own experiences related to disability inclusion in health research.

So firstly, how would you define disability?

Secondly, thinking about studies you're familiar with – what disability data have been collected? For example, has any information about disability been collected as part of the demographic data collection?

And again, thinking about studies you're familiar with, what steps have helped or hindered inclusion of disabled people?

And then lastly, what proportion of the research workforce do you think declare they are disabled or have a disability?

Slide 6: Who do we mean by 'disabled people'?

Anna Anderson: So, a key point to consider when we're talking about disability is 'Who do we by mean 'disabled people?' This is a tricky question because there are lots of different ways of defining disabled people.

These include legal definitions. For example, the UK Equality Act 2010 considers someone to be disabled if they have a physical or mental impairment that has a substantial impact on their ability to carry out normal daily activities and lasts or is expected to last at least 12 months.

Another option is to consider conceptual approaches. For example, the social model views disability as a form of social injustice experienced by people with impairments, so this is suggesting that disability is created by barriers in society.

And the social model was developed by disabled activists to counter the individual or medical model view that disability is a problem within an individual that needs to be prevented, treated or rehabilitated.

So, I've included a couple of infographics on the slide to illustrate these models. One represents the social model and shows barriers outside the person, which could be things like inaccessible buildings, negative attitudes, and lack of sign language interpreters etc. The other represents the individual model and shows the problem is considered to be within the individual.

So, what we're not going to do in this webinar is say that there's one right way to define disabled people that should always be used, as different approaches can be helpful in different circumstances.

But I did just want to highlight that the social model can be particularly helpful when thinking about disability inclusion in research as it draws attention to the need to identify and address socially created barriers to inclusion.

Slide 7: Language choices

Anna Anderson: So, I also wanted to mention disability language choices, as this is again something where the best approach depends on the specific situation, as people's language preferences vary.

I've been using 'disabled people' as that aligns with the social model. And the phrase 'disabled people' can include a broad range of groups such as people with long-term physical or mental health conditions, people with learning disabilities, neurodivergent people, Deaf people etc.

And it's important to recognise that people who might meet a specific definition of disability might not identify as disabled. For example, someone who's Deaf and uses sign language might consider that being Deaf is their cultural identity or even their ethnicity and not want to be referred to as disabled.

It's also important to recognise that people can face barriers to getting a formal diagnosis of a particular condition, so some people may identify as disabled but not have a formal diagnosis.

So, in practice, the choice of language should always be determined by the people with lived experience being engaged. And to reflect that there's no one right or wrong term to use, different presenters in this webinar are going to be using different terms.

Slide 8: Current context

Anna Anderson: So, just to give some background to the current context of disability inclusion in health research, a report from the World Health Organization in 2022 suggested that around 1 in 6 people worldwide experience disability. This makes disabled people the largest marginalised and underserved group in many nations.

Disabled people have valuable insights and skills to bring to health research, both as research participants and as members of the research and advisory workforce. But despite this, disabled people are often unjustly excluded from all these roles.

This exclusion occurs due to a complex range of factors, including explicit exclusion, for example due to overly strict eligibility criteria, implicit exclusion due to factors such as ambiguous eligibility criteria and lack of accessibility in research studies and workplaces, and then wider barriers, such as mistrust in research.

And I've put these three groups of factors in inter-linked boxes on the slide just to show that these factors are all inter-related and they can compound each other.

Slide 9: Why is action needed?

Anna Anderson: So, why action is needed? And I've included a quote on this slide from our call-to-action publication, which highlights the risk of making healthcare changes that are based on research that hasn't adequately included disabled people.

So, this quote states: ‘[…] evidence-based changes in healthcare may not be safe, effective, acceptable or accessible for disabled people, and so risk increasing health inequities’, and this is particularly significant because we know that disabled people already experience stark health inequities.

And there are lots of reasons why we need to improve disability inclusion in health research. These include moral and ethical reasons. For example, the Declaration of Helsinki, which outlines key ethical principles for medical research, states that groups with increased vulnerability should be given specifically considered support and protections so that they are fairly included in research.

There are also legal and human rights reasons, including related to the United Nations Convention on the Rights of Persons with Disabilities, which is an international human right treaty.

It’s also really important to include disabled people from a scientific perspective, as if we want research to apply to people in the real world, we need recruit representative samples.

Additionally, including disabled people in research is important from a health equity perspective, and actually many of changes that benefit disabled people, such as improved accessibility, ultimately benefit everyone.

There’s also economic justification, given improving people’s health has economic benefits and, if the research workforce doesn’t include disabled people, it’s missing out on the valuable skills and experiences that a substantial proportion of the population could bring.

And in some countries, research funders are prioritising research inclusion, so making sure studies are inclusive is actually a requirement to obtain funding.

Slide 10: Global call to action

Anna Anderson: So, just moving onto our global call to action. To encourage efforts to advance disability inclusion in health research, we recently published a global call to action as a Comment in Nature Medicine. And this calls for multi-level actions to improve disability inclusion in health research.

It was developed by what we've called our Disability Inclusion in Research Collaboration or DIRECT as I've mentioned, and we're a global and interdisciplinary team who have a wide range of lived and professional experiences of disability. So, in our call to action, we drew on both published literature and our own experiences.

And our approach was ground in the social model, which I've already mentioned, and also the human rights model, which can be considered as complementary to the social model.

And the human rights model is a little bit different to descriptive models like the social model, as it focuses on how to advance disability inclusion through law and policy, particularly linked to the United Nations Convention on the Rights of Persons with Disabilities, so it can be considered as a model of disability policy.

Slide 11: Key challenge areas

Anna Anderson: So, in our call to action, we highlighted three key challenge areas to disability inclusion in health research. These are monitoring disability inclusion, the research cycle, and the research and advisory workforce. We viewed these as mutually reinforcing so we included them in a Venn diagram as shown on this slide.

Our diagram also shows that challenges in these areas can lead to negative outcomes, in terms of limited relevance, quality and real-world applicability of research, and this can lead to a negative impact, which is the compounding of health inequities.

And we feel these challenge areas are globally applicable, but some are accentuated in the Global South due to factors such as resource constraints and attitudinal barriers.

So, we're going to go through each of these challenge areas in turn. And key challenges related to our first area of monitoring disability inclusion include that there are varying legal and conceptual definitions of disability, and also that there is limited and inconsistent reporting of disability data both in research studies and teams.

So, because I've already outlined some of the challenges with defining disability, the next section of our webinar is going to focus particularly on disability data. And I'm delighted to be handing over to Professor Bonnielin Swenor who is an internationally leading expert in this area.

Slide 12: Introduction: references

Anna Anderson: Just before I hand over to Bonnie, I included a slide here with the references that I've used, and this includes a direct link to our global call to action, so everyone should be able to access from the PDF version of the slides. So, I'll now hand over to Bonnie.

Slide 13: Using Data to Advance Disability-Inclusive Research

Bonnielin Swenor: Thank you so much Anna. This is Bonnie. My visual description is that I am a middle-aged white woman with long blond hair wearing a dark jacket and top and I've a blurred background.

I am the Endowed Professor of Disability Health and Justice at Johns Hopkins University as well as the Founder and Director of the Disability Health Research Center at Johns Hopkins.

Slide 14: Data is power: Who counts depends on who is counted

Bonnielin Swenor: So, as Anna indicated, I am going to talk a little bit about data as it is so essential to drive change.

Data is power. Data are powerful tools to let us know where we are, where we want to be, and to support accountability.

But when we are talking about disability data, the problem is that we are often not counted.

Slide 15: Limited data on disabled academics and researchers

Bonnielin Swenor: We are often not included, so we talk about to be counted, you have to be counted, to count you have to be counted, sorry, my slide moved forward.

And so, the problems with the limited collection of data comes from a multitude of factors. Today I'm going got talk specifically about the limitations of disability data on the inclusion of people with disabilities as researchers and academics themselves.

One of the drivers of these limitations of data is that our academic literature really is limited in the area of disability inclusion as decision makers and as researchers ourselves.

There are very few studies that focus on that topic, although that's starting to change. Oops, can you go back, I apologise.

Disabled people are underrepresented across research fields, we know this those of us who have disabilities working in these fields, but it is hard to ask for change when we don't have the data to make the case.

Additionally, as Anna indicated, there are profound challenges to how we measure disability. Oftentimes the measures that we do use are insufficient, inadequate and they lead to under-estimates.

So, for example, at an international level, the Washington Group Disability Questions would not be appropriate for determining the number of disabled researchers or disabled academics. There's progress on this area, but we still have far to go. Next slide.

Slide 16: Limited representation in academia and research

Bonnielin Swenor: So, as an example of the limited data we have on the representation of people with disabilities in academia and research, I am showing this table.

And this table provides some estimates of the percentage of disabled people in the academic and research workforce. In the US, we have data showing that only about 9% of our academic workforce report having a disability. In the UK it's quite similar, 8%. In Canada, 7%. And some work from Australia has shown that 0% of senior academic leaders have a disability.

Data from other parts of the world like Japan, South Africa, India, Latin America, we have very little to no data, and so it's hard to make change. Next slide.

Slide 17: Using data to drive change: An example from the U.S.

Bonnielin Swenor: I am going to give an example today about how data can be used to drive change on disability inclusion and research using an example from the United States. Next slide.

Slide 18: <3% of the U.S. STEM workforce report having a disability

Bonnielin Swenor: So, in the United States, we have data showing that less than 3% of the US STEM or Science, Technology, Engineering and Mathematics workforce report having a disability.

Importantly this is the only group of people that have shown no improvement in representation in the United States in these careers over the past decade.

We actually have had data showing the lack of representation or inclusion of disabled people in STEM for 10 years. And since there has not been change, that's also indicating that we are not doing much to change that. Next slide.

Slide 19: <2% of research U.S. investigators report having a disability

Bonnielin Swenor: On this side I am showing additional data from the US, indicating that less than 2% of National Institutes of Health grantees and National Science Foundation grantees report having a disability.

These are two federal agencies that, I should say until recently, provided significant amounts of funding to US researchers and researchers around the world.

This low percentage or low representation of people with disabilities receiving funding and grants from these influential federal agencies really highlights a gap. Next slide.

Slide 20: Disabled scientists earn less

Bonnielin Swenor: Additionally, we have data in the US showing that disabled scientists earn less. Disabled people working in STEM careers

earn over $10,000, US dollars, per year less than their colleagues without disabilities.

And, if you're working in academia, that pay gap is even bigger. People with disabilities, particularly disabilities that began before the age of 25, earn less the $14,000 per year less than their counterparts without disabilities. Next slide.

Slide 21: Qualitative Data: Barriers to research careers

Bonnielin Swenor: So, at my centre, we have done some research to investigate some of the barriers to being a disabled researcher. And we have conducted both qualitative and quantitative data, and on the slide, I'm showing results from some of our qualitative work.

One of the statements from that work that tends to always stick with me is someone who said: "I have never had a mentor with a disability".

This study included disabled researchers from across United States.

Other statements included: "Sometimes I think there's a perception that researchers and academics with disabilities, especially those that disclose their disabilities, are only 'advocates'…"

Others in our study stated: "The pandemic gave me the accommodations the institution wouldn't…"

"It's ridiculous that I'm regularly the only disabled person in a room, group, etc. focused on the study of people with disabilities."

And lastly, "The whole problem with academia is it presumes that you're able to put in a 60-hour week."

These quotes are intending to illustrate some of the barriers to including people with disabilities in academic research. And when we are keeping people with disabilities out, it's hard to advance the way we are measuring, and the way we are including disabled people in the work that we do. Next slide.

Slide 22: NIH designates people with disabilities as a health disparity population

Bonnielin Swenor: But in the US there has been some change, some positive change in the past five years.

The National Institutes of Health designated people with disabilities as a population that faces health disparities in 2023. This was a remarkable change that helped open the door for funding around disability health research and to support the inclusion of people with disabilities in research.

This change, this designation, was the result of having data to show the gaps, the gaps in the percentage of people with disabilities in our workforce, and in our research studies.

On this side I am showing snapshots of headlines around that designation, from the National Institutes of Health itself and from an article in the Washington Post, a US newspaper, as well as the cover of the NIH strategic plan for disability health research that recently came out. And in that plan, the first priority is to advance measurements so that we can have better data on the inclusion of people with disabilities within our workforce and in our research. Next slide.

Slide 23: Global progress

Bonnielin Swenor: Additionally, I want to close by highlighting some other areas of progress. Importantly, the World Health Organization has launched a Disability Health Equity Initiative, and data is a core and central part of that.

Anna has described our efforts in DIRECT. I also want to highlight the Docs with Disabilities Initiative, which is focusing on collecting data to highlight the gaps of disability inclusion in our healthcare workforce.

And the Disability Health Equity Research Network which is also focused on advancing how we measure and include people with disabilities in health research. And on this side, I'm showing logos for each of these organisations. I think that is the end of my sides and I'll turn it back to Anna I believe.

Slide 24: Research cycle

Anna Anderson: Great, thanks so much Bonnie. So, we are now going to hand over to Jasjot Maggo from the University of Otago in New Zealand. Thanks so much Jasjot.

Jasjot Maggo: Thank you so much, thank you all. I am Jasjot Maggo from University of Otago, New Zealand. For my visual description, I am an Indian woman, I am wearing dark top, I wear glasses, and I have got black hair, and I have got headphones on the top.

I will be talking about, giving you all overview of research cycle and inclusion of people with disabilities in research cycle. Please next slide. Thank you.

Slide 25: Stages of the Research Cycle

Jasjot Maggo: So, first we will start with what is research cycle. A simple definition is it consists of a series of stages or steps used to develop new knowledge.

And I've provided on the right-hand side a cycle showing the different steps. So, we start with an idea, so any research cycle will start with conception of an idea, which researchers or academics as Bonnie mentioned earlier, will develop, will have an idea, and they will start developing that idea and come to almost what we call as a research proposal stage, that I want to test this idea.

And once that idea is developed, we then approach funders. We will try to gain funding to change that idea from, change it from an idea to a reality.

And as Bonnie mentioned a few minutes ago, that we are saying that, you know, the academics and the leadership roles are less, less than 3% of US, of in US, less than 3% of population is in STEM, so we can see there is already a lack of academic leaders who are developing these ideas.

And as there is a lack of people with disability in these leadership roles, it trickles down to design. If people with lived experience are not included in development of the idea, the study designs end up being inflexible, they're not inclusive.

And that can be simple example of clinical trials, that if I wanted to do a study, I will say if nobody disability has been included, the design will not show that.

This goes onto the next stage of data collection, where data collection when we say, it’s tools that we gather, collect data from. It could be questionnaires. It could be something like doing your blood tests or measuring your weight. So, those data collection tools are not inclusive. A lot of the questionnaires, they are ableist, they use language more for what we call ableist society than including people with disabilities.

This pattern then continues in the analysis, which always ends up being mathematical or using statistics, which is not meaningful for people with disability.

Further we see in the sharing, so the last stage of research cycle is sharing and using this information to make a change. A lot of time, the language that is used is scientific not inclusive. It ends up being published in manuscripts or published articles, which are not available, easily available for the community.

So, the different stages of research cycle we come across different barriers of inclusion of people with disability. If you look at the next slide, please.

Slide 26: Key Challenge

Jasjot Maggo: So, during the global call of action, one of the key challenges we noticed was that people with disabilities are often seen as research subjects rather than active partners in the research process.

And what we would like to achieve is change of the narrative from research on people with disabilities to research with people with disabilities.

So, the work that DIRECT is doing, as well as Bonnie highlighted some of the other key groups, they are trying to change this relative let's move on from research on people to research with people.

But before we can do that, we need to look at some of the barriers in the next side will show some of the barriers that we have.

Slide 27: Barriers to Inclusion

Jasjot Maggo: These are the ones that are repeated in a lot of publications, and you know, even in our general conversations. So, one of the top ones that we see is attitudinal and societal barrier. There is, there is a misconception about a disabled person's capability to lead or, you know, the workplace description or the social isolation. So, there is a societal barrier to inclusion of people with disabilities.

Then there are physical or infrastructure barriers. I've also shown a picture that basically highlights, highlights that, that a person in a wheelchair is looking up to stairs and this we do see a lot of times in our research visits, where will have research visits or a test needs to be done and it's on first or second floor, there is no ramp available, the lift is

not working. So, it physically stops people from, with disability to participate in this study.

But physical infrastructure is one, there is, there is a lot of communication barriers as well. I work in clinical trials and at times our consent forms are 30 to 40 pages long. They are word-dense, legal documents and there is no accommodation available, there is no alternate format available, making just entry into the trial difficult. And, I think in our webinar we further discuss about consenting issues.

Then there are, you know, looking at institutional, there are lack of inclusive policies and strategies available.

And then some of them are research specific, like rigid protocol. So just giving an example from clinical trials, a lot of, and Anna mentioned that there will be implicit exclusion or explicit exclusion of people with disability.

Some of our eligibility criteria specify if you have got a disability you're excluded or if you've got a systemic disease you are excluded, without looking at if this person can be included in the study with, you know, without any kind of harm being done, for being part of the study. But we don't want to make those changes.

A lot of our study designs, they are inflexible, and the strict deadline of this needs to be done and what Bonnie also mentioned, that, you know sometimes with what the participant, what the people were saying, that you are expected to work 60 hours or this needs to be done. So, those things result in a barrier to inclusion.

Now, highlighting all these barriers, I think in a way we do need to know our barriers because that's one way that we are going to mitigate them or eliminate them. And in our call to action, we have come up with some of the guiding principles which are shown in the next slide.

Slide 28: Guiding principles

Jasjot Maggo: Yes, thank you. So, some of these guiding principles, and I just want to mention over there, these are just some, and there is much more out there that we can be doing so we are just highlighting a few of those. And the speakers after me will give you more tips and tricks, you know, those tips and practical advice on how to utilise these.

So, looking at our guiding principles, first and foremost is building a respectful relationship with people with disability, with our participants, with our community partners. Nothing can progress without having that mutual respect with each other.

And then involving people, disabled people at all the stages. So, it's basically that changing the narrative that we are not, just you know including them as participants, but they can be the leaders, they can be the ones who are doing the whole study at different stages.

A lot of time, we tend to use the weakness-based approach where, oh I do not have, you know, I cannot accommodate a person, I do not have the availability of an interpreter, so we are not going to include people with disabilities. So, let's look at the strengths, let's change that narrative again, let's look at strengths-based approach.

The common one that we do, the other one is address power imbalance. I work in clinical field, and there is that imbalance between a clinician and a patient or participant. It is participants' health, it is patients' health, so let's bring that balance together where only clinician is not holding all the power.

And then offering a range of involvement roles. And we have, you know, repeatedly heard that persons with disabilities tend to join an advisory group or join a consultancy group. We need to offer them much more than that, we need to offer them leading roles, or if not leading roles, there could be a number of options available. Let's not just go with you are an advocate, and let's not box them in one role.

And I think we cannot stress that enough, we need to maximise our accessibility, I think that should be a bare minimum, that we are

providing accessible information, accessible platform to all our participants and all our collaborators.

You know, working with them, same, you know, same, we cannot offer the same role to every person, everyone has different skill sets and ways of working. So, let's work with the person so that, you know, collaboration can work properly.

And then make sure everyone benefits. I think this is the biggest one that comes to me as researcher, is we take, we take a lot of information. We never give back. So, let's work together so that it is mutually benefit, that we are not just taking the knowledge, we are acknowledging efforts of everyone.

And let's, let's be transparent, our weaknesses, our strengths, our limitations, let's put it all out there and work towards it.

Slide 29: Impact of Meaningful Involvement

Jasjot Maggo: And then what we're trying to achieve. If we apply these guiding principles and much more, what we are trying to achieve is meaningful involvement that we want to move from a tokenistic involvement to a meaningful involvement and bring those changes, drive those changes into our research cycle.

I've given a few examples, such as design and data collection. If we involve people with lived experience, our methods of data collection will be inclusive of diverse needs, and that, this will help us, you know, address the historical mistrust between researchers and people with disability.

As well as looking into if, in analysis is, we can look at, you know, they can become more flexible, they can become more person-centred and be more meaningful to disabled people.

And finally, if you're looking at the last process of sharing and using, then the findings are interpreted at multiple levels, the language that is

utilised is inclusive and the dissemination strategies are also accessible so that our community partners, our disabled partners can have access to this information and provide us feedback.

So, these are a few of the things that, you know, the global, the global call had tried, had discussed and this is all from me but the speakers coming after me will be now talking specifically on these and some of the topics. So, I hand it back to Anna. Thank you so much.

Anna Anderson: Great, thank you Jasjot. Great overview. So, what we're going to do now is a have a couple of really practical examples to highlight how to put some of the points that Jasjot has mentioned into practice.

Slide 30: Working with people with learning disabilities

Anna Anderson: So, our first presentation is going to be from Dr Amy M Russell, who's an Associate Professor in Health Inequalities at the University of Leeds in the UK, and she's going to be talking about working with people with learning disabilities.

Unfortunately, Amy has not ended up being able to join just at the moment so what we're going to do is share a recording, so I'll just be a moment switching over to sharing that recording. So hopefully that recording is now visible okay. Please wave if it's not those of you who are able to view that.

So, just to say Amy is a white woman with brown hair and glasses, and she's got a lovely piece of artwork as her background today that Amy tends to use. It's of Runswick Bay by Mark Senior in 1924 and it's part of the University of Leeds Art Collection. So, I'll hand over to Amy.

Amy M Russell: Thanks for joining us today. My name's Amy Russell. I'm based at the University of Leeds in the UK. And my talk today is some practical tools that support researchers and self-advocates to work together. So, it's entitled 'Working with People with Learning Disabilities'.

And you might note that I'm using the phrase ‘people with learning disabilities’ and this is because that's the preferred term that the people I work with like to use.

Slide 31: Routine Exclusion

Amy M Russell: So, I'm going to begin by talking about the routine exclusion that's historically happened to people with learning disabilities. And in 2013, Fieldman's team found that 90% of research studies out of a sample in the UK had excluded people with learning disabilities.

In 2023, 10 years later, Bishop et al.'s team went back, and they had a look at studies in the National Institute of Health Research portfolio in the UK and found that 78% of studies were still excluding people with learning disabilities.

So, when they interviewed the PIs or the lead researchers about what was causing this, they found that people were facing struggles with recruitment, not knowing how to recruit that population, not understanding how to communicate about recruitment.

They had inherited inclusion and exclusion criteria that left people out and not really questioned it. They didn't know how to conduct capacity assessments, and they felt they lacked the skills to do that.

They thought that maybe ethical review wouldn't allow the inclusion of people with learning disabilities in research.

They felt they had insufficient funding to make reasonable adjustments and hadn't asked for it in advance, so now had what they had.

And they felt that the team lacked communication skills to communicate with people with learning disabilities.

So, bearing those challenges in mind, we'll move on to the tools and I'll show how we can challenge some of those and correct it with better investment in our research project design.

Slide 32: Nothing About Us, Without Us 1

Amy M Russell: So, in Nothing About Us Without Us, which was a co-produced, co-led project with people with learning disabilities, we created a series of tools.

So, the first one I want to share is an icebreaker, which you might not think is that important. But actually, as a team, we invested time in building trust, building our relationships.

And that was really important. We hadn't all worked together before. We started by doing these kind of mood, rate your mood on a squirrel scale things, and people could say what number they were, squirrel or llama or whatever else we used. But as time went by, we got to know each other and we started using our own images of holidays and pets to show our mood or to vote.

And it was a way of bonding as a team. And we should have built more in actually. And any team that I now design, I build in a lot more face-to-face relationship building activities because of how important that is.

Slide 33: Nothing About Us, Without Us 2

Amy M Russell: The Matrix of Support is a fantastic tool, and it illustrates the steps that we used to make sure that all of the team members who have a learning disability meaningfully contributed to the team meetings. So, this is the last slide that gives a summary of it, but the whole thing's available online.

Basically, Gary and I were running the project. Gary has a PA called Anna. So, the three of us would meet. We would go through, plan the project, make an agenda for the next team meeting, check an overview of the strategy, that sort of thing. Then I would go away and make a visual slide show, which would be shown through the meeting, but it would also stand as our agenda.

I'd then send it to Anna, who'd make it accessible, and she would add in images and simplify the wording potentially or adapt the wording to phrases she knew would make more sense.

Gary would then take that adapted slideshow to Jodie and Vicky, the self-advocates with learning disabilities, and they would talk through it. They would adapt it, explain any elements they didn't understand, and they would prepare their responses for the big team meeting, so that they didn't have to think on their feet. They had time to consider their options and discuss them.

We would then share the adapted slideshow with the big team and have our discussion. And they would say what they wanted to say, that they had prepared or thought through. And then after the team meeting, they would have a debrief with somebody. So actually, we should have two more people on that slide. It's not just five; it's seven people that were involved in the matrix.

So, if you're costing a project, think about that. Think about how many people need to be involved for meaningful inclusion and how much time that process would take each cycle of team meetings. But if you want to do inclusion right, it's necessary.

Slide 34: Nothing About Us, Without Us 3

Amy M Russell: We also created a lot of accessible information. When we wanted to discuss a document or a report, we would make it into Easy Read. If we wanted to publish something, we made sure it was also available in Easy Read. And that way, we signalled who we were interested in reading our findings.

So, this is the easy read that you can see on the screen of a report that we wrote for a journal about how to make a clinical trial more inclusive for people with a learning disability.

Slide 35: Nothing About Us, Without Us 4

Amy M Russell: We created lots of videos. We knew that even Easy Read isn't accessible to some people. People prefer different formats for different things. And so, we made videos for our top tips and to explain our project. And our videos always had captions.

That meant that we weren't relying on people to be able to consume one type of information. Multiple formats is always more accessible.

Slide 36: Nothing About Us, Without Us 5

Amy M Russell: We also used visual branding. We tried to make sure that everybody working in the project understood what the project was doing and where it was going.

And we visually branded the tasks and the mini work packages to help people understand. So, the Blue Whale group were working on a particular task and everything they did was headed in blue with a little whale to help us remember and recall what we were working on.

Slide 37: Nothing About Us, Without Us 6

Amy M Russell: We also used creative methods a lot. We did it especially when we met in person to evaluate our project.

Creative methods are great in that they don't rely on verbal skills. They support self-expression of maybe difficult concepts. Maybe people don't want to talk about something that they're not happy with the project but they could draw a picture about it or signal that they might want to talk about that.

So, you can see the image here is of the team holding up their campaign posters that they designed at one of our evaluation meetings.

Slide 38: Yes? An Audio story about research consent

Amy M Russell: And then finally, two other tools that I want to talk about. One is an audio story that I co-created with Made by Mortals and a team at Bloom in Manchester.

And after observations of ethics committees, interviewing researchers, we co-produced a script about a man called Bart Bloom who wants to take part in research but is struggling to because it's not being explained to him properly.

He doesn't understand what is being asked of him to give consent and he doesn't have the right support to help him understand the process.

And so, we're hoping that that story can be shared with others, ethics committees, third sector organisations, to provoke discussions about this tension between autonomy and protection and the importance of the right kind of support to make choices in research.

Slide 39: Creative Inclusion

Amy M Russell: Finally, Creative Inclusion, another fantastic set of tools and resources, was made with Melissa Kirby in Purple Patch Arts and the Purple Research Group. And we co-produced a series of fun activities that researchers can use to introduce research concepts.

And we cover research, consent, withdrawal and anonymity. There are some more on the way. And they're really great if you're going out to a new group and you want to make sure everybody has a shared understanding of what you're talking about.

Because let's be honest, research happens outside the lives of a lot of people and they don't see it, they don't understand it. And so, we need to make sure we all understand what we're talking about before we start research.

Slide 40: Working with people with learning disabilities: references

Amy M Russell: And finally, those are the references. Thank you very much for listening today.

Anna Anderson: Great, so hopefully everyone enjoyed Amy's presentation, and you can have a look at those practical tools online. I'm just going to go back to our slide show.

Slide 41: Research with people with impaired capacity to consent

Anna Anderson: And I'm going to hand over to Dr Victoria Shepherd from Cardiff University who's going to be talking about research with people with impaired capacity to consent. Thanks so much Vicky.

Victoria Shepherd: Lovely, thank you very much Anna. So, I'm Vicky Shepherd, I'm a Principal Research Fellow from Cardiff University.

And for my visual description, I'm a white middle-aged woman with shoulder length ginger hair and today I have a black top and a blurred background.

Slide 42: Research and impaired capacity to consent

Victoria Shepherd: And as Anna mentioned today, I'm going to talk a little bit about research involving people who may not be able to provide their own consent to participate in research.

This might affect more people than you might imagine. So, well over 2 million people in the UK alone have significantly impaired decision-making. And that might be due to illnesses, such as dementia or an acute event, such as something like an acquired brain injury or a stroke or perhaps associated with a long-term disability.

And people who have impaired decision-making should of course be provided with the appropriate support to enable them to make a decision about participating in a study if they wish, wherever that is possible.

But we know for some people they may lack capacity to consent event when provided with support, and in those situations, other arrangements may be needed in order for them to participate in the study.

And that could include involving an alternative person to help make a decision about whether they talk part and, in the UK, we would call that a consultee or a legal representative.

But research with people who have impaired decision-making, particularly if they are found to lack capacity to provide their own consent, can raise a number of ethical, legal and practical challenges and that leads to this group often being excluded from research.

Slide 43: Cognitive impairment as an exclusion

Victoria Shepherd: And to give an example, a recent review looking at disability-related exclusion in a sample of over 2,700 trials found that there were explicit exclusion criteria relating to disability in about 35% of them, with ‘cognitive impairment’ being present in almost half those exclusions, so they were the second highest group who were excluded.

And you can see on the slide an example of a study with a long title and in this study example they had a blanket exclusion of anyone with a known history of cognitive impairment. But they didn’t provide a justification as to why this group were excluded or describe what support they had in place in order to support people to provide their own consent.

Slide 44: Challenges across the research cycle

Victoria Shepherd: And we know from some of the work that we've done that this exclusion of these populations is due to challenges across the research cycle.

And you can see in the diagram on the screen, which shows a circle with overlapping phases that that includes kind of methodological issues, such as knowing how to design more inclusive research.

It includes concerns from researchers about how to navigate the complex ethical and legal frameworks that govern research involving these populations.

About, challenges about being able to communicate study information in accessible ways when seeking consent, and to assess capacity to consent when required as we've already heard from Amy.

And also, then the process for involving alternative decision-makers where required and revisiting consent as required throughout a study. Of course, it's not a one-off event.

Slide 45: Researchers' views about barriers

Victoria Shepherd: And you can also see in the quotes here which came from talking to researchers about the experiences and why they found it so challenging that they described the complexity of the ethical and legal frameworks like an insurmountable black box of horrendousness that they dare not go near, feeling that if they get something wrong they'll be doing something illegal and the ethics police will come for them.

They described how there's inadequate support and resources for them. They described stabbing in the dark looking for information, this kind of potluck Googling, wondering where they could find accurate information to use.

They also described the need for better support and guidance, which they thought would give people, researchers and others, more confidence when setting up a study of this kind.

And this together led to the development of a number of practical tools for researchers to help improve inclusion and I'll just highlight a few in the coming slides.

Slide 46: Ensuring consent is accessible by design

Victoria Shepherd: So, because consent acts as the kind of gatekeeper to research, the priority is to ensure that people are provided with accessible information and adjustments to support them to be able to make consent decisions wherever possible, as we've heard from the previous speakers.

But, as I say, researchers report that they lack the knowledge about how to design more inclusive consent processes.

So, we developed the OPTIMISE recommendations, which highlight seven domains across which accessibility can be improved. And that's shown in the diagram on the slide as these kinds of overlapping jigsaw pieces.

And the recommendations have links to examples and resources about how to do this. The key message overall being that even the small, achievable adaptations can meaningfully improve accessibility

Slide 47: Identifying and addressing barriers

Victoria Shepherd: And of course, to ensure that the whole study is designed to be inclusive, as we've already heard, the INCLUDE Impaired Capacity to Consent Framework can help researchers to identify some of the ethical and practical issues that may arise in their study at the earliest opportunity, and so that can help to minimise barriers to inclusion.

The framework includes four key questions for researchers to consider, such as ‘How might the study design, things like eligibility criteria, consent processes, data collection methods, make it harder for some groups to take part?’

And there are worksheets that then researchers can work through to help address some of these questions such as identifying the resources that may be needed to be built into a funding application.

Slide 48: Practical tips to improve inclusion

Victoria Shepherd: And then lastly from me, just to summarise some of the key practical tips to take away today.

And that’s to provide accessible information about your study in a range of formats. You can see on the screen there the image of a page that’s in Easy Read format. And that’s one example of a more accessible format.

But also, to ensure there is a focus on inclusive design right throughout the study. You should carefully consider and justify any eligibility criteria and particularly where that might exclude people with disabilities.

I also encourage you to review the legal and ethical requirements to help anticipate and address any ethical issues that may arise. We heard from Amy about concerns about ethics committees and how they may view studies, so anticipating some of those questions and challenges will help.

Importantly, to ensure that you build in sufficient time, support, including of course accessible public involvement, and resources to allow you to be more inclusive in your work.

And you can find all of these tools I’ve mentioned and other resources on our study website, which can be found at www.capacityconsentresearch.com, or you can use the QR code shown on the screen.

Slide 49: Consent example: references

Victoria Shepherd: Thanks very much, I'll hand back to you Anna.

Anna Anderson: Great, thanks so much Vicky.

Slide 50: Research and advisory workforce

Anna Anderson: So, our last main section of the presentation is going to be on the research and advisory workforce, and it's presented by Associate Professor Katherine Deane from the University of East Anglia.

I know Katherine has had a few challenges being here today. Katherine, are you able to unmute okay? Just wait and see, Libby, are you able to make sure that Katherine has all the, any required permissions?

Elizabeth Atkinson: Yes, Katherine, I believe I've just updated, I think your login has changed. Can you just check you can unmute now?

Katherine Deane: Hello, hello, I hope you can…now?

Anna Anderson: That's great, thank you Katherine, we can hear you.

Katherine Deane: Right, apologies for the technical glitches, I won't be joining you with my camera on because I'm joining you from Bradford Interchange and I'm on my mobile because Internet here is very unstable here.

I am, however, a white woman with short brown hair, and if you met me in person I would be in a wheelchair and I would have blue tinted glasses on.

And currently, a brace on my wrist because I managed to run myself over with my own wheelchair this morning, hence the slightly disorganised joining of this, I apologise. Next slide please.

Slide 51: The Ideal Academic (Kate Sang, EDICa, 2017, 2025)

Katherine Deane: So, as we have been mentioning all the way through, there are unreasonable and unfeasible expectations of what an ideal academic is.

And this fabulous slide by Kate Sang, really highlights the complete plethora of completely unattainable standards that are expected of a standard academic, working within research or just teaching et cetera.

And it is really important that we remember that this is unachievable for absolutely everyone. But it is particularly unachievable for those who are disabled. Next slide please.

Slide 52: If you build it they will come….

Katherine Deane: So, if you go into this with a different mindset, if you say: “If you build it, they will come.” At University of East Anglia we have now got a pretty accessible campus et cetera and that’s increased our number of undergraduates coming in and declaring a disability to 40%, which is much higher than the sector average of around 20%.

So, if you do expect, welcome and value diversity, and ensure that people, whether that’s staff, students or research participants, have the needed time, space and flexibility to be able to engage and work with you, then you will get increased numbers of participants.

You have to prioritise taking action. Unfortunately, the research field at the moment is very dominated by research around the level of impact of exclusion.

And whilst that is important, it’s even more important that we take action and we assess how to change this situation effectively. We need to make sure there’s feedback from the disabled community to make sure this works, but that also that we are researching and sharing this and

making sure that we can defend the reasonable accommodations that we are requiring.

Because unfortunately, you can expect pushback, you can expect resistance in this area. Next slide please.

Slide 53: Accessible systems of employment

Katherine Deane: So, we need to start by designing accessible systems of employment. When you are doing your recruitment process, do you explicitly state how accessible the place somebody is going to work in is? Do you provide the questions in advance? Do you highlight access to staff well-being facilities et cetera?

Do you make sure that, where possible, the working practices are flexible and hybrid? Do you provide basic information, a welcome pack of access around information, not just about your facility but all of the infrastructure necessary to reach you and stay there? So, hotels, taxis, restaurants, it's all important and it's needed every time. So, if you can provide that in advance that's fabulous.

Obviously, some of this costs extra, and so how do you make sure that you are very visible about how that will be funded, who is responsible for asking for it?

And make sure that your reasonable accommodations are put in place with speed, because the legal framework, the legal precedent within the UK states that reasonable accommodations should be put in place within a month of the employee starting their work.

Now, I know most of us do not manage to achieve that standard. I certainly have failed to do that with a researcher in my team. And at the end of the six-month project, we had still not got in place all the accommodations she should have needed. So, it's very frustrating, but it is also really challenging.

Really important that people can get access to relevant post support. Unions, charities, mental well-being, admin support, training, all of this is absolutely critical.

No one institution has all the answers. So, don't expect yourself to have it. Reach out and asked for additional help, but require accountability, reward actions and make sure that things are actually taking place and that you can track that they are doing so. Next slide please.

Slide 54: Patient involvement as a tool for inclusion

Katherine Deane: Patient involvement can be an amazing tool for inclusion. If you go out and explicitly welcome underserved communities and expect disabled participants, then this diversity of viewpoints can be immensely valuable and really make your research design far more practicable, far more achievable, far more welcoming.

Your use of language, your provision of assistance, technology, funds, all of that is absolutely critical. Next slide please.

Slide 55: Training to ensure inclusion

Katherine Deane: And we've got to make sure that we are providing the training so that everybody involved in this research has the relevant skills to make sure this can happen.

So, for staff and advisers, you really want to focus on the behaviour change needed for accessibility, not just the legal compliance, not just knowing the nine protected characteristics of the UK's Equality Act.

No, that's not enough. We want you to be able to know how you get things changed, how you identify and rebut biases, so getting things changed using the Capability, Opportunity and Motivation model of behaviour change, the COM-B model, and Lund University's values work, which really identifies how biases are embedded within systems and then how you can pushback both on an individual and systemic way.

So, you know, really got to make sure that that training is relevant for audiences. I cannot tell you how many people tell me “Oh EDI training is boring. It doesn’t help me. It’s not useful.”

And I sit there and I go yeah, I’ve sat through some of that myself too, I don’t blame you for going “I don’t know why we have to do this.” But if it’s done well, it can be absolutely brilliant.

And examples of training things that you might want to be thinking about is how do you design research so that it is inclusive? How do you support people who may not have ever been on a committee to contribute effectively to that committee?

How do you support the other members of the committee if there’s somebody who has a communication deficit, to really listen and to really facilitate that communication?

How do you ensure that everybody involved has appropriate cultural competency, can respond to poor behaviours with bystander interventions?

And how do you support everybody with reciprocal mentoring, which is really fabulous because you go in, whether you are the more senior person or the more junior person, you both go and explicitly going “I want to learn from this, I want to see how I can make change in the future, I want to see if there are lessons that can be learned from talking to somebody I wouldn’t otherwise normally talk to.” Next slide please.

Slide 56: How is the research accessible for you?

Katherine Deane: So, we have heard, again, multiple pleas for multiple formats for information, making sure that the venues are accessible.

And I highlight there, having tea and biscuits, refreshments are never optional, they should always be provided, no matter what you are doing. It makes a massive amount of difference to people’s resilience and

ability to focus on what's going on, whether that's a meeting or a research assessment or whatever. Next slide please.

Slide 57: Inclusive dissemination

Katherine Deane: And we have created a few checklists around accessible meetings and accessible research. It's highlights, not comprehensive, but it gets you the key things.

And, again, it highlights that we are needing those documents in multiple formats, videos, websites that are WCAG compliant, and conferences, in particular, are increasingly becoming more and more inclusive and accessible, which is brilliant. But this gives you a checklist of things you can be considering to do. Next slide please.

Slide 58: Lab access guidelines

Katherine Deane: So, going into more specific areas, I have also done some work around laboratory accessibility. Next slide please.

Slide 59: Getting the basics wrong

Katherine Deane: And unfortunately, currently, laboratories have historically been regarded as 'Disabled people can't come in here. You will be a health and safety risk.'

And as a result, they have been almost the last place to be made accessible. But actually, we are not getting it wrong just for people with disabilities. We are getting it wrong for absolutely everybody.

We did a very quick survey a few years back and identified that over half of the labs we surveyed didn't even have a seat in them.

90% of them didn't have height adjustable benches and equipment. A third of them didn't have an accessible toilet in the same building as them.

And unfortunately, 80% of people who needed one, didn't have a personal emergency evacuation plan, a PEEP. So, you can see that poor access is leading to poor safety, unlawful practices, and it does lead to poor recruitment and retention. So, we created a whole suite of access guidelines. Next slide please.

Slide 60: Access Guidelines: https://bit.ly/4od2J84

Katherine Deane: And this covers the entire ecosystem of working. Whilst these were designed laboratory access, 90% of them are actually relevant to any other working environment that you might be in

The cover the structures, the equipment, the protocols you might be using, the dissemination and this includes conferences and webpages and working practices, which is all the human relations staff, all the HR stuff to keep working practices good and relevant. Next slide please.

Slide 61: Nice – but do they work?

Katherine Deane: So, we created those in collaboration with quite a lot of people and with using a lot of evidence informed guidelines that are already out there. Just brought them all together in a usable format.

But we recognise that they are all very well and nice, we think they work but can we prove it? We actually had the huge advantage that we did have two buildings, New Science, which is a brand-new building and Productivity East, which was a refurbished set of engineering workshops, which actually had been designed with my structural guidelines being taken account of.

So, we went, and we talked to people that had been using these facilities for five or six years and said "Okay does it work? Is it useful?"

And they said “Yeah, actually the design is safe, durable, effective.” Most importantly, there was a huge wash-over effect, it works well for everybody. It’s a comfortable, inclusive workplace for absolutely everybody.

And if they did have any criticisms of our guidelines, they were generally of the “Yes but do more.” So, we have height adjustable benches in the labs at the front and the back of the labs, and they were saying “Why don’t we just have them on every single row of the benches?” Next slide please.

Slide 62: Access Assessments

Katherine Deane: So, the next point along the sort of trajectory is to then, you’ve got the guidelines, let’s see can you assess your environment and check that it meets the guidelines, that is actually accessible.

And so, we did a very quick project called DALE, which derived the assessment from the guidelines, plus we had 17 partners on this project, and we did a quick external call for advice and information on this to create a whole suite of access assessments for structures and equipment.

These were tested across four universities, multiple lab types and we are working on creating a shareable electronic version of this assessment that anybody can use. We promise we are trying to get it out for the summer.

It’s very pragmatic assessment of disability access. We hope it is accessible by everyone to a fairly consistent standard. And it provides you with information that you can put on your website so you can tell people how accessible your facilities are.

But it also allows you to create a long list of things that you need to improve in the future. Whether you have the money for it today or not is not relevant.

Having a list of where you know you have got barriers, where you know you have got problems is incredibly important because in my experience serendipity is a wonderful thing and suddenly money can appear and people can be interested in wanting to improve specific aspects of accessibility and you now have a list and can say “Oh yes, actually we could really spend the money here.” Next slide please.

Slide 63: Assessment as an intervention

Katherine Deane: We did find that just doing the assessment was an intervention in and of itself. It really raised the awareness of it. It really increased the priority of in people’s minds and challenged the thinking about disability access.

It really highlighted small deficits in current practice. So, none of our universities were asking people who had a broken leg and were on crutches “Do you have an evacuation plan?” And they all went “Ah, no we don’t actually ask that normally.” And realised that they did.

But it also highlighted that there was really a need to make sure that you talk to people around accessibility for things like maintenance, equipment purchases, particularly discussing with the manufacturers, who are interested in this area but ignorant.

And again, refurbishments and newbuilds answered and creating those lists of quick wins and longer-term considerations to sort out these barriers.

Slide 64: Accessibility as a system

Katherine Deane: So, accessibility as a system. It really is important to remember that this is a complex interconnected system. Small things can lead to large impacts both positive and negative.

But there is very limited training at the moment, and it's not uncommon that staff are actually paying out of pocket, which is unacceptable in my view.

We do risk burn out with our advocates, who feel very unsupported. And one of the things we really did find, and this was in all four universities, was that information would be fed into the university in the form of evacuation plans, reasonable accommodations, even safety concerns, but nothing came back out.

So, you didn't know that just down the corridor, one of your colleagues had already sorted out how to manage wheelchair access, or how to adapt a certain piece of equipment if the buttons are too hard to press. So, a lot of reinventing the wheels going on.

So, we still need to recognise that there is a challenge in assessing the less tangible aspects of disability access, attitudes and behaviours, and we recognise that these are as important as the structural ones, so we intend to work on that in the future. Next slide please.

Slide 65: Accessible environment driving culture change

Katherine Deane: And the thing that I would like to highlight is the wash over effect, washes over into culture.

We got this quote from one of my colleagues and it says having these accessible facilities emboldens people. It's inclusive practice in action. Students are happier to talk about their additional needs, and cohorts are more supportive of each other in terms people who might not look like them. Next slide please.

Slide 66: k.deane@uea.ac.uk

Katherine Deane: And here is a list of all the references to all of the checklists, guidelines and hopefully the assessments coming soon, plus a few references, thank you very much.

Anna Anderson: Great thanks ever so much Katherine.

Slide 67: Take-home messages

Anna Anderson: So, we'll just go to our take-home messages to finish off.

Slide 68: Key points

Anna Anderson: So, in terms of our key points. The first is that disabled people are an under-served group in health research and are often unjustly excluded both from research studies and from the research and advisory workforce.

We all have a part to play in improving inclusion, and even small steps like providing information in a more accessible format can make a big difference.

And I've just included one more quote on this slide from our call to action, that states 'By taking responsibility and working in partnership with disabled people, we can all play our part in advancing disability inclusion to help achieve high-quality, impactful and equitable research.'

Slide 69: Key actions

Anna Anderson: So just to highlight some key actions. Firstly, we can all advocate for disability inclusion, and the social and human rights models are valuable tools that can help with that.

As I mentioned at the start, it's really important to use people's preferred language when engaging with disabled people.

Then as Bonnie discussed, collecting and reporting disability data is essential to monitor disability inclusion, and that applies both to research studies and the research and advisory workforce.

As Jasjot, Amy and Vicky explained, key steps for improving disability inclusion include meaningfully involving disabled people across the entire research cycle and maximising accessibility and inclusion in all activities.

Then, as Katherine's highlighted, it's also really important to promote inclusion in workplaces and teams.

And finally, we all have a responsibility for building our own knowledge and skills in disability inclusion and as you've heard today, there are an increasing number of resources to support that.

So, this slide includes a photo of someone in an online meeting saying thank you in British Sign Language.

Slide 70: Thank you!

Anna Anderson: So, I just want to finish by saying thank you for joining the webinar and a big thank to all the people and organisations who've supported the webinar, with a special thanks to everyone who contributed to our call-to-action, everyone who's presented today and helped with the organisation, and to our BSL interpreters and captioners.

And just to formally recognise the groups and organisations who've supported this webinar, we've got our declaration on this slide which states 'This webinar is supported by the Disability Inclusion in Research Collaboration (DIRECT), the National Institute for Health and Care Research (NIHR) Biomedical Research Centre Leeds and the NIHR HealthTech Research Centre in Accelerated Surgical Care. The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.'

Slide 71: Questions

Anna Anderson: So, we're now just going to end the slide show and have a time for questions.

And just to confirm, for questions, please use the Vevox platform, which you can access via vevox.app. And you can go to that directly using the QR code on this slide or via the link in the chat, or you can go to vevox.app and type in our webinar ID which is 179-519-560.

And when you get to the Vevox platform, there’s a home page and a question page, so just need to make sure you’re on question page to add a question.

So, I’m just going to stop our recording now and then I’ll stop the slide share.