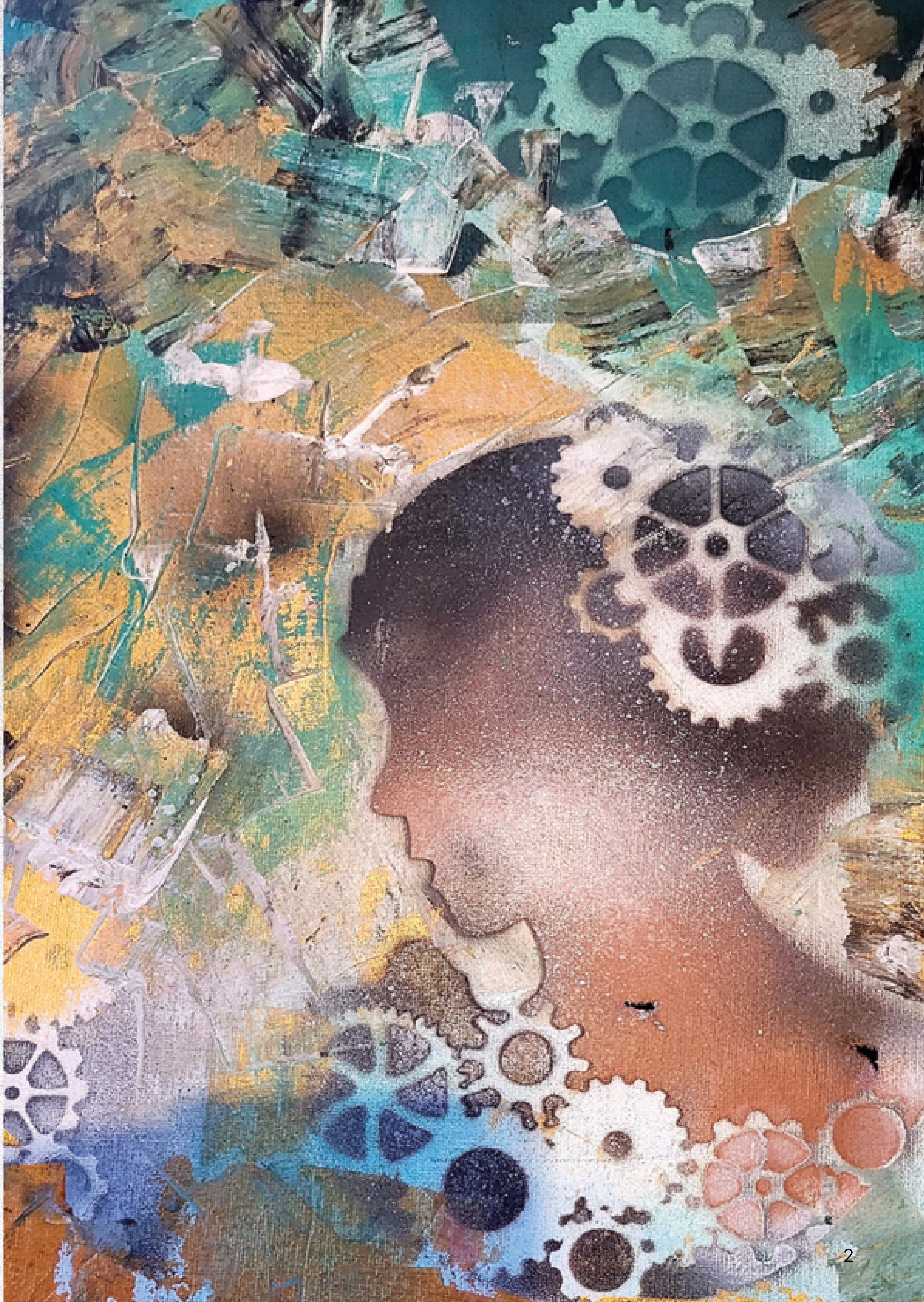
Understanding disability research: How our questions shape our answers

Right: Right to reply, by artist Shahina Jaffer

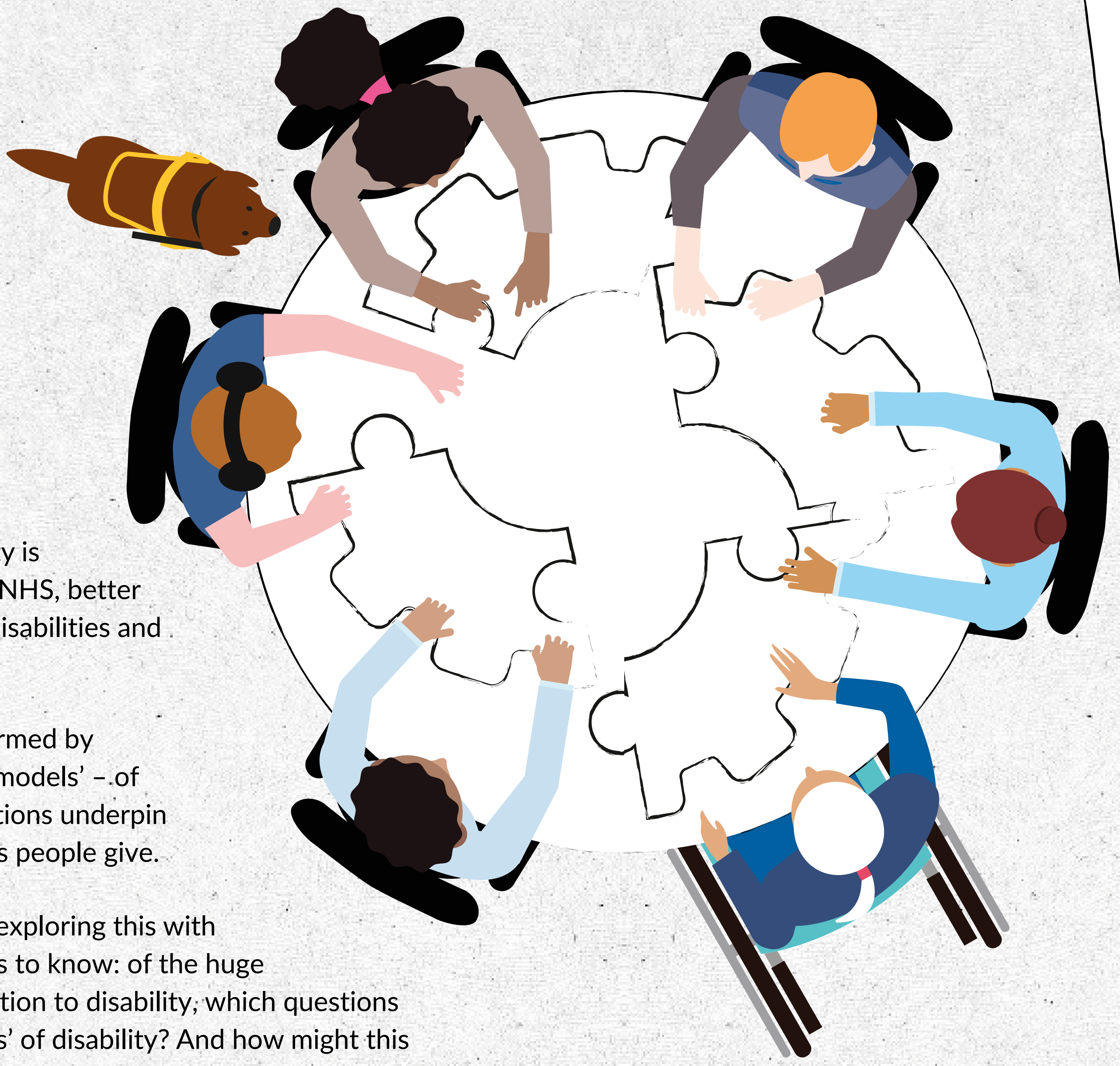


How do questions shape our answers and decisions about disability?

Researching people's experiences of disability is important. It can help public bodies, like the NHS, better understand the needs of people living with disabilities and help them shape services accordingly.

Yet research survey questions are often informed by pre-existing understanding – or 'theoretical models' – of disability. It is not always clear what assumptions underpin the questions, nor if this impacts the answers people give.

At NIHR ARC North Thames, we have been exploring this with people living with disability. We were curious to know: of the huge number of survey questions that exist in relation to disability, which questions can be linked to different 'conceptual models' of disability? And how might this influence the ways in which people with disabilities answer these questions?



The four artworks featured throughout are by artist Shahina Jaffer, a mixed-media artist, and graduate of St. Martin's School of Art, who has made an indelible mark on the global art scene. Shahina's work explores how perception and observation shapes our understanding of reality, and her artistic journey is characterised by a profound commitment to diversity and inclusivity. Her work embodies her belief in the power of art to forge connections and make a meaningful impact, which has led her to various community art collaborations, including with BlindAid and Women's International League for Peace and Freedom. The pieces chosen here all demonstrate richness, texture, complexity and interconnectedness, all themes of this research. Of our work together, Shahina says: "This project is particularly meaningful to me because of my close relationship with my aunt, who grew up with polio. Witnessing her challenges and the resilience with which she overcame difficult situations has profoundly deepened my understanding of disability".

By ‘conceptual model’, we mean the different ways we view and understand disability.

Can you match the definitions with the models?

The medical model

The social model

The biopsychosocial model

A person’s disability is a dynamic interaction between her or his health conditions, environmental factors, and personal factors.

A person’s disability is determined by their society’s failure or success in accommodating people’s different abilities.

A person’s disability is determined by their individual physical and mental impairments.

(National Disability Arts Collection and Archive. The Social Model of Disability | NDACA. 2020. https://www.youtube.com/watch?v=kmAfpmGO7DU; Social Care Institute for Excellence (SCIE). Co-production: The social model of disability. 2021. https://www.youtube.com/watch?v=iGPkS_Lm-a0; Scope. Social model of disability. 2021. https://www.scope.org.uk/aboutus/ social-model-of-disability/)

Bringing lived experience into disability research

As part of this work, we worked with members of the public who have lived experience of disability in a series of workshops. We explored the medical, social, and biopsychosocial models of disability and how they might shape the question wording and answers.

Karl Leowe was one of these participants, and below he shares his reflections on his involvement in the work.

Thanks for talking with us, Karl. First it would be great to hear: Why were you drawn to participate in this project about Understanding Disability?

The project was one that really resonated with me and my passion at that time.

Becoming disabled through a motor accident as a young person brought a lot of changes in my life. It is something I was not prepared for and it changed my outlook on life. Projects like this – and all the other things that I have channelled myself into – serve as a purpose for the second life that I have today.

There's this resilience that I have now to talk about disability, especially for young people. I can help them understand that it is not the end of their life – that who they are still makes sense, and there is also a whole lot more they can do with themselves, you know?

The Understanding Disability project was one of those avenues for me to come up and talk about my experience. I could use my experience to shape the project so that it could be helpful and impact people.

It sounds like you contributed a lot. Did anything stay with you about the experience?

From my experience, disability was something that I viewed as exclusively mine. I did not think about how it relates to my social environment: the people around me, interactions with support systems, all of that.

Also, the representation in the group was diverse. So, I really liked seeing people bringing new perspectives to the group.

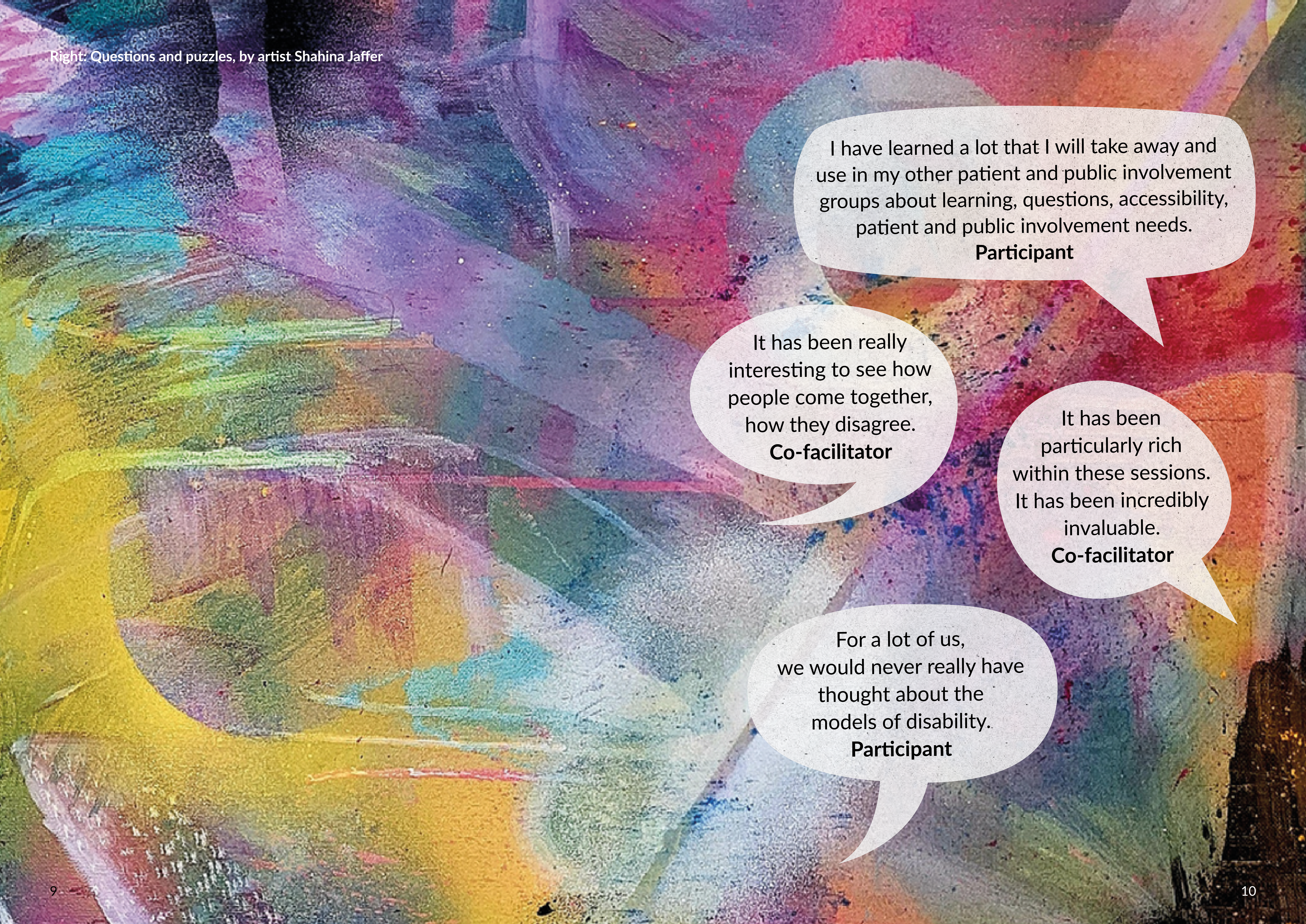
That gave me a lot of insight about how different people from different cultures might perceive disability. Some may conceptualise disability from a medical perspective where it is just seen as a physical impairment. Some people may see it from a social model, where it is more about your environment and experiences.

Given what you have contributed and got out of the project, what impact do you hope it will have?

I think the impact that we hope that this project will have is to help shape understanding of disability more broadly.

Also, we want there to be a repository of all questions about disability, stored with information about those questions and how they have been informed.

That way, you will be able to help people ask the right questions when you are interacting with disabled people. Because if you are asking the right questions, then you are getting the right answers.



Right: Questions and puzzles, by artist Shahina Jaffer

I have learned a lot that I will take away and use in my other patient and public involvement groups about learning, questions, accessibility, patient and public involvement needs.
Participant

It has been really interesting to see how people come together, how they disagree.
Co-facilitator

It has been particularly rich within these sessions. It has been incredibly invaluable.
Co-facilitator

For a lot of us, we would never really have thought about the models of disability.
Participant

Asking questions about asking questions: Why highlighting assumptions in disability data matters

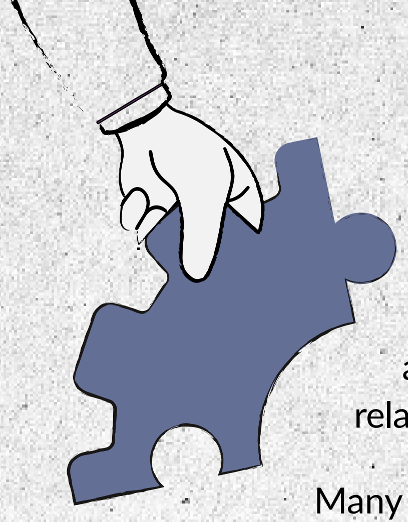
Dr Eirini-Christina Saloniki,
Senior Health Economist,
at NIHR ARC North Thames

These were the questions we wanted to explore in this work.

Disability is a complex and often misunderstood concept.

What can researchers like me do to ensure more people understand the concept of disability?

And how can more people with lived experiences of disability be involved in this process?



As a senior economist with a long-standing interest in disability research, I am always curious about new research that becomes available and whether it includes unique aspects of disability.

Yet I often find there is a strong disconnect between theories about disability and the data about disability, and how the two relate. This is what fuelled my exploration through this work.

Many commonly-used disability-related questions exist, frequently included in surveys, and collectively used to respond to topical research questions set by governments and organisations.

These questions are often developed and analysed with a particular concept or 'theoretical model' of disability in mind.

While the models are ultimately used to define disability, individuals are rarely informed about the different models nor their association with specific survey questions.

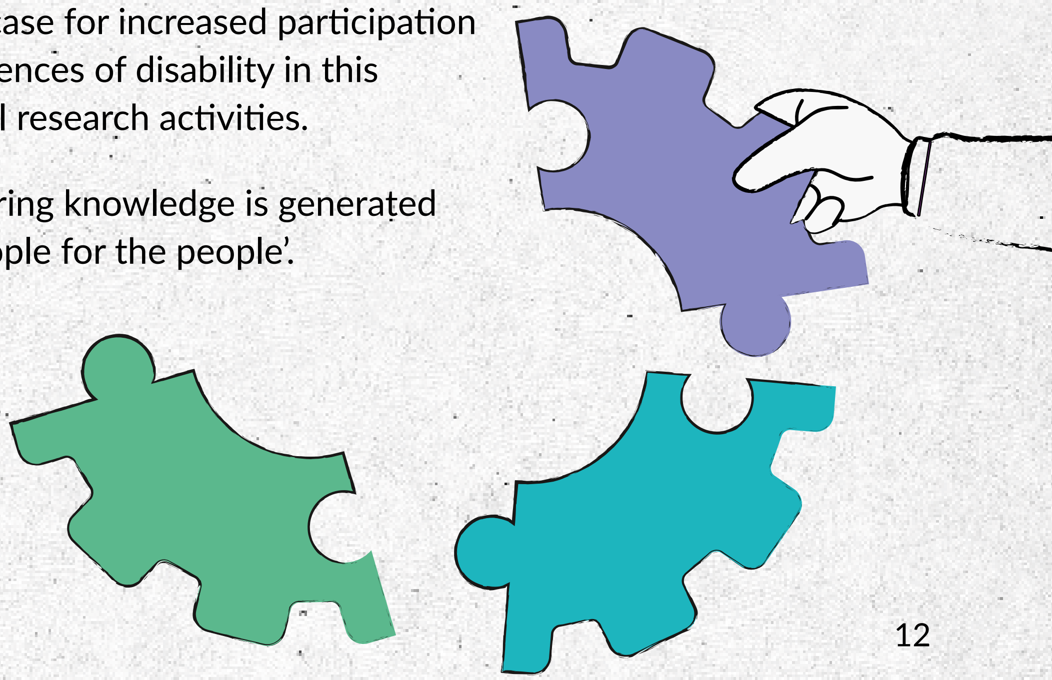
It is a bit like a puzzle: what happens if we have all the pieces, but these are not connected to each other? The puzzle is incomplete, and we cannot see the full picture.

Similarly, if we do not know the theoretical models of disability and which of these are linked to survey questions, then our responses to disability-related questions may be misinformed.

Making this linkage visible for everyone is crucial for raising awareness and improving understanding of the term disability more widely.

It further strengthens the case for increased participation of people with lived experiences of disability in this process, including technical research activities.

In the end, it is about ensuring knowledge is generated and transferred 'by the people for the people'.



What we found through our research

Right: Directions and decisions, by artist Shahina Jaffer

Involving people with lived experience of disability in disability research

William Lammons, Lead Investigator, Public and Patient Involvement and Engagement Lead at NIHR ARC North Thames

For people with disabilities, disability is a key part of daily life that touches almost every aspect of living.

So, it is difficult and unwise to research a person's disability in isolation from a person as a whole. And of course, that is why it is also very important to involve people with disabilities in research in an active way, not only as survey respondents. Our research has done so, and I think illustrates how powerful this can be.

We summarised conceptual models of disability, then communicated and discussed these in supportive and open environments with public contributors with living experience of disability.

More importantly, involving people with lived experience in using concepts like these helps create broader understandings of disability based on the insights of people most intimately connected to and affected by it.

Have a go: Below are some questions about disability. Which of the conceptual models do you think underpins these questions?

Does your condition or illness/do any of your conditions or illnesses reduce your ability to carry-out day-to-day activities?

Do you consider yourself disabled?

The medical model

The social model

Our findings cut across differing experiences of, at times, multiple disabilities to examine and improve understanding of the disability concept itself. They advocate for co-produced or collaborative research on disability with those who have and continue to experience disability.

To do this successfully and inclusively, we must use flexibility to balance supporting disabled members of the public's access needs with the pursuits of the research.

Read the full write-up of our patient and public involvement research in our article 'Using public involvement to refine the concept and understanding and move towards a multidimensional concept of disability' and link to https://onlinelibrary.wiley.com/doi/10.1111/hex.14072

Mapping the questions: What participants thought

As a key part of this research, public participants with living experience of disability gathered to learn about and discuss the different conceptual models of disability and explore how these models might influence survey questions.

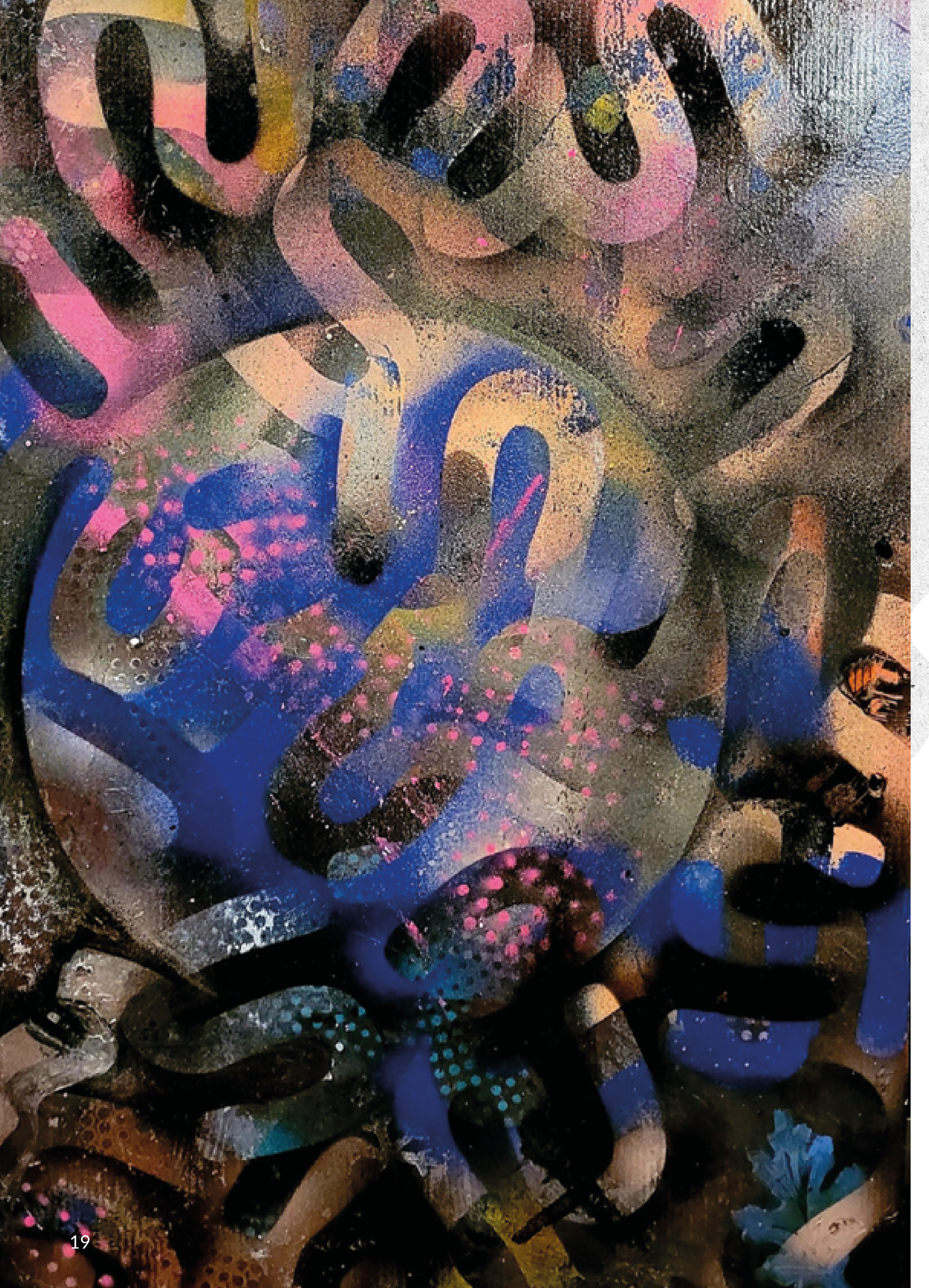
For participants, it was not always clear which disability-related survey questions linked to which theoretical models of disability. The questions were presented in groups, but participants felt a need to separate the questions out and map them to models individually.

Furthermore, to "assign" a survey question to a specific model, they needed to make sense out of things for themselves. This meant reflecting on their own experiences and relating the questions to themselves.

The participants found the biopsychosocial model relatable and more akin to how they thought about their own disabilities and lived experiences. Importantly, the biopsychosocial model is a highly theoretical research concept. The fact that participants preferred this model shows that complex research terms can offer helpful tools for those with relevant living experiences to reflect on their own identity and think about their experiences, even if they are not a researcher.

Our research reveals two important findings.

- First, people with living experiences of disability understand disability as a complex, multifaceted phenomenon. Understanding and measuring it properly through surveys is equally complex and difficult. It is important for greater clarity and transparency around how survey questions are formulated and analysed.
- Second, public collaborators did not have research or technical backgrounds, but they were able to understand what theoretical models of disability are, and how to analyse them in relation to survey questions. This shows that greater active involvement of people with lived experience of disability in disability research is possible and fruitful.



What next?

If this research has inspired you, here is what we think needs to happen next

- Expand this research to explore disability research in countries beyond the UK.
- Create a database that hosts all disability-related questions and insights on their link with specific theoretical models of disability.
- Enable greater patient and public involvement in disability-related research.

Left: Word on loop, by artist Shahina Jaffer