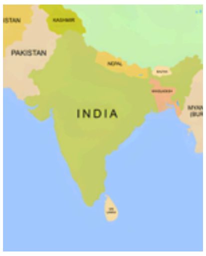
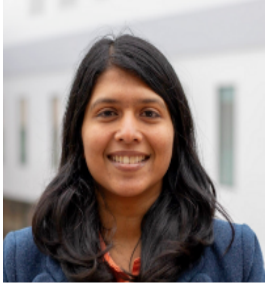
Information sheet



We are a research team from in Sheffield, England and in India. Our names are:



Ankita,

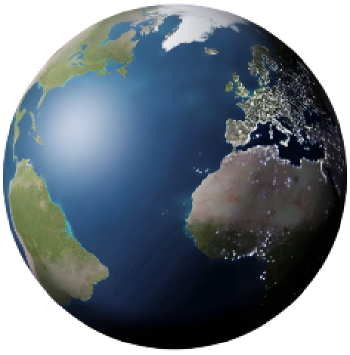
Shweta,

Smitha,

Sruti

Syamala.

We are working together on a project called Disability Matters.

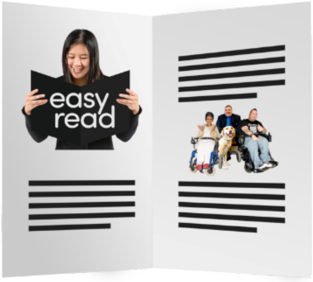


This is happening across the world in, Canada, India, Singapore and the UK.

We want to change health research for the better, so that disability is at the centre of research.

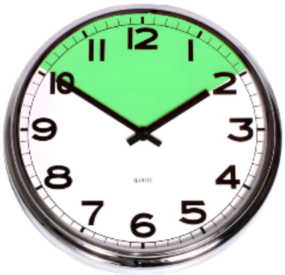
We would like to ask you to take part in our project, which is looking at what people with disabilities think is most important for their health.

Before you decide if you want to take part, we need to explain why the project is needed and how you could be involved in it.

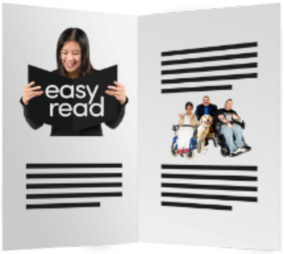


Please take time to read this information carefully and talk about it.

Ask us if there is anything that is not clear or if you would like more information.

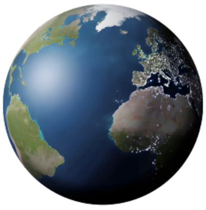


Take time to decide if you want to take part.



Thank you for taking the time to read this Participant Information Sheet.

What is the project about?




This is part of the international Disability Matters project.

In this project, we want to look at how people with disabilities understand their health, care, and wellbeing.

This means finding the most important things to do with people’s health needs and making sure that everyone gets good healthcare.

With this project, we try our best to put people with disabilities at the centre of research.

People with disabilities are the ones who know best about their own lives.

We want to support people with disabilities from different backgrounds to take part.

Would you like to take part?

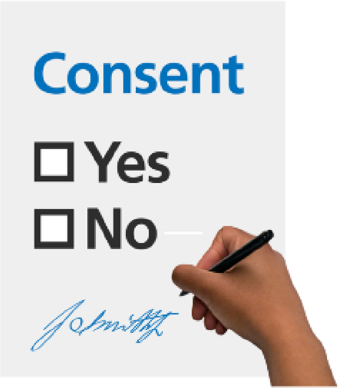
We would like to ask you to be part of our project if:

- you are a person with a disability
- you are neurodivergent (this means you might be autistic or have another condition like ADHD or dyslexia)
- you are a person with an illness that doesn't go away.

We would like to ask you to be part of our work.

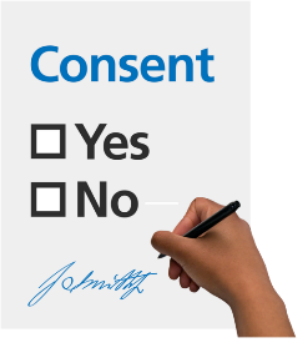
We would welcome people from backgrounds that are not often asked to do work like this, including women from Dalit, Adivasi and religious minorities.

We welcome disabled women in particular who are never given opportunities like this.

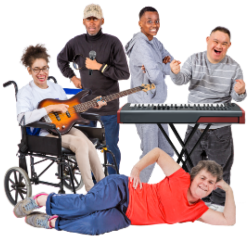


Do you have to take part?

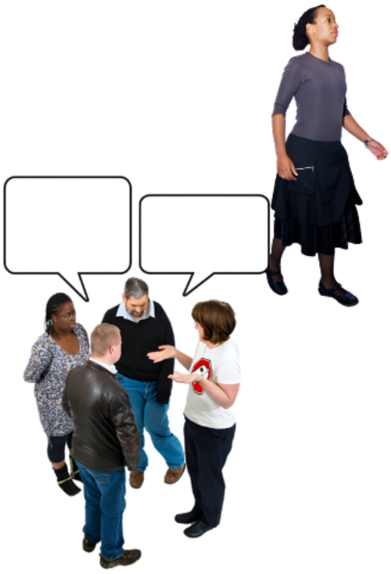
It is up to you to decide if you want to take part, you don't have to.



If you decide to take part, we will tell you how you can give your consent.



You can still change your mind and can leave at any time without having to say why,



But, because these activities happen in groups, we may not be able to take out everything you say.

What would taking part mean?

We are running workshops that will include lots of ways that will help people with disabilities think about the important things about their health.


Welcome

If you choose to take part, you will be asked to take part in:

Workshops

These workshops will ask you to share your hopes and dreams for a healthy future, for yourself and your community.

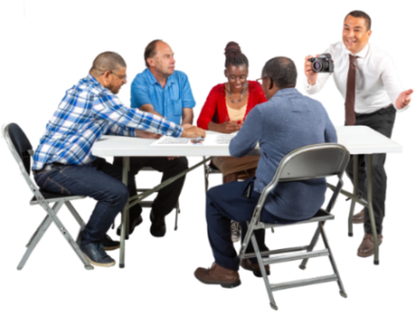
Community Story Circles

In these sessions, you will be able to tell us stories about your health experiences and what you think about them.

You can tell us your stories by speaking, drawing, writing, photos or any other way that you would like.

Mapping Workshops

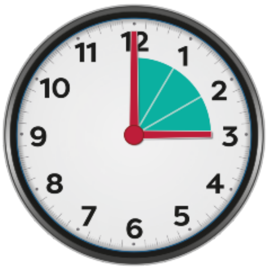
These sessions will look at how people with disabilities experience rules that affect them in life.



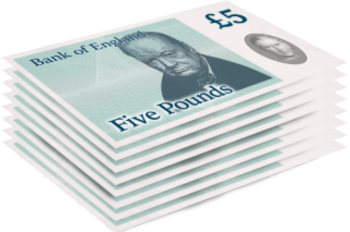
You'll help map what works, what doesn't, and what's missing—using different activities to think about this.

We will also meet and present our mapping work to people who write the rules. The rules are often called policies.

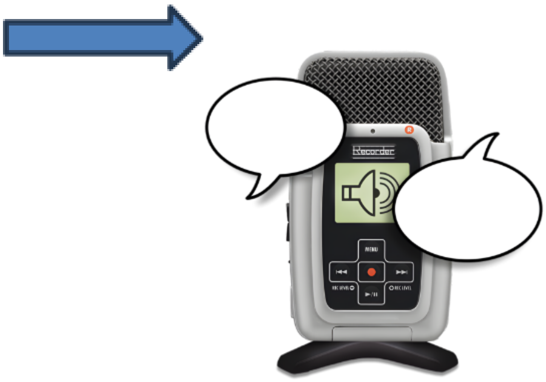
Workshops will be held in-person, depending on where you are and what support needs you have.



The sessions will last between 2–3 hours each.



You will be offered a small payment to thank you for taking part and to help cover your travel expenses.



Will I be recorded, and how will this be used?

If you decide to take part, workshops may be voice-recorded (if you are okay with this) to help us think about what has been said in the workshop.

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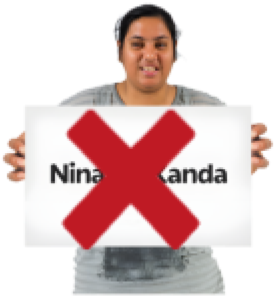
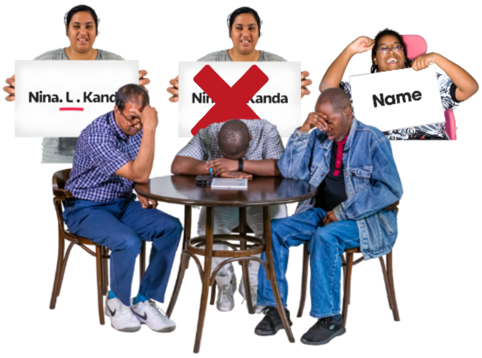
Only the research team will have these recordings, and they will be kept safe.

Recordings will be removed once we have written what people said and taken out their names.

What you said will be written in reports and articles.



We will take out any information from things you have said that gives away who you are unless you want to be named as a co-author.



You can decide if you want to be named or not named, or given a different name, in any we make.

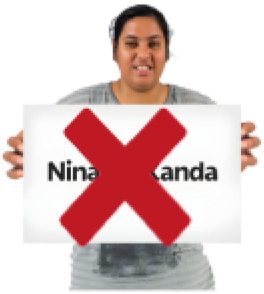
What are the risks of taking part?

Sometimes, talking about bad things can make you feel bad, and experiences you share might be very personal.

We understand this and will give breaks and support during each session.

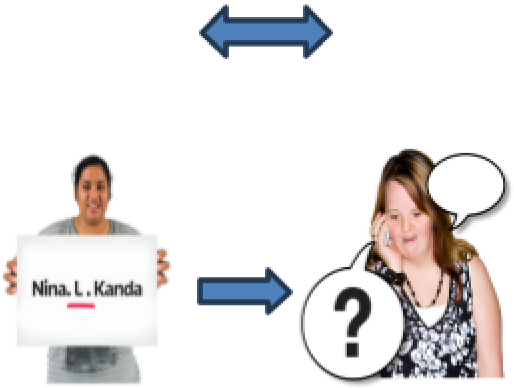
You can stop for a few minutes, or you can leave at any time.

Ground rules about respect and care will be agreed at the start of each workshop.



Will my taking part in this project be kept confidential?

Yes, all personal information will be kept safe and private



Anything that tell people who you are will be stored separately and not linked to what you told us.

If we share what you have said in reports or articles, we will use another name - unless you tell us you want to use your own name.

Your personal information will only be used if we need to get in touch with you about the project; they will not be shared with anyone else.

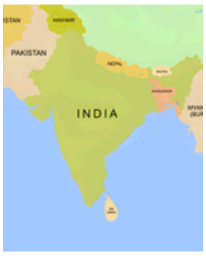
What will happen to the results/findings of the research project?

The research team will study the information collected during the research and use it for articles, reports and presentations.

Who is organising and funding the research?

University of Sheffield

University of Sheffield

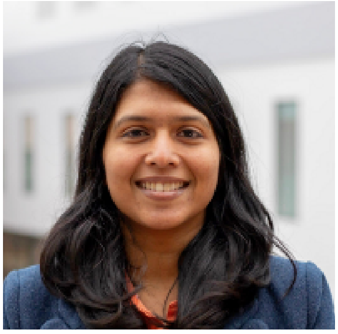


The University of Sheffield is doing this, in partnership with AADI and Swabhiman in India. It has been funded by the Wellcome Trust in the UK.

Who has ethically reviewed the project?

This study has been reviewed to find out how fair and okay it is, by the University of Sheffield Research Ethics Committee.

Contact for further information



For any other information about the project, please speak to the researcher

Ankita Mishra. You can contact her by email at ankita.mishra@sheffield.ac.uk

You can also contact Daniel Goodley, who is the Principal Investigator at the University of Sheffield. His email address is d.goodley@sheffield.ac.uk

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