**Get Involved in Research**

**Come help improve understanding of disability or disability-related questions in UK surveys**

**What is the study about?**

Disability is a complex term that varies by context and data. Definitions of disability are not perfect but are often linked to conceptual models. A conceptual model is a term or a group of terms that can be used together to help us try to understand the concept of disability.

Recently, efforts have attempted to use similar disability questions across UK surveys however, data collection on disability is still inconsistent between surveys. Disability survey questions are often difficult to identify, due to spreading across different websites. Searching for these questions takes time, requires research experience, and often excludes the 14 million UK disabled people and their advocacy groups.

It is key that information on disability and its measurement in surveys is presented clearly so that everyone can understand it, especially disabled people.

**Our study aims to:**

(a) help researchers, policy makers and the public to understand the complicated concept of disability in survey data, and

(b) boost the use of disability/disability-related questions in research and the insights they offer to different conceptual models of disability.

**Who are we looking for?**

We are looking for twelve members of the public who can contribute to this study, particularly adults who are in North-East, North-Central, and East London, and Mid and South Essex geographical regions and currently identify as disabled.

We welcome individuals with a variety of disabilities from a wide range of backgrounds (e.g., cultures, ages, experiences) to offer their perspectives. Interested members of the public will be invited to form a group to share their views and contribute to the following key parts of the study:

* Introduction to the study – understand the study’s key concepts and conceptual models of disability.
* Group discussion – discuss in a group how to use the findings from the disability or disability-related questions in practice.
* ‘Mapping’ – work together to match disability survey questions with the disability models.
* Post-activity discussion – discuss what things should come out of the study’s findings, such as how to use them, what the takeaway messages are, and how to share this information with a broad audience.
* Reflective discussion – share your experience and learnings from participating in this study to help design future studies and research in this area.

**What does participation involve?**

The group will have four sessions with the study team between April and September 2023. The sessions may be moved a little bit depending on the study progress and participants’ availabilities. The format of the sessions will be online (via Zoom), or in a one-to-one setting should this be the participant’s preferred option.

Reasonable adjustments and accommodations (e.g., materials format, special software, comfort breaks) will be discussed with the participants prior to the first session and can be reviewed ahead of each follow-up session. The provisional schedule is outlined below:

|  |  |  |  |
| --- | --- | --- | --- |
| Session 1 (April 2023) | Session 2 (May/June 2023) | Session 3(July/August 2023) | Session 4(September 2023) |
| Duration: 2 hours | Duration: 2 hours | Duration: 1.5 hours | Duration: 1 hour |
| Introduction to the study | Group discussion and ‘mapping’ | Post-activity discussion | Reflective discussion |

Any answer will be treated as confidential, and participants’ names will not be connected to any of the questions. Participants’ names will not be shared with any other individuals or organisations outside of the study team.

To thank participants for taking part, we will compensate them at £25/hour, according to National Institute of Health and Care Research standards. We will also provide £5/session for internet fees.

**How is the study being done?**

This study is funded by the [NIHR Applied Research Collaboration North Thames](https://www.arc-nt.nihr.ac.uk/) and led by a team from University College London.

**Who to contact if I want to take part?**

If you are interested in helping us with the study, please contact Eirini or William who will be happy to talk through everything and answer any questions you may have.

We want you to feel comfortable and able to fully participate so please let us know about any individual needs that you might have. Please be assured that a conversation with William or Eirini will not commit you to being involved if you decide it is not right for you!

**William Lammons**

Patient, Public Involvement and Engagement (PPIE) Lead

NIHR ARC North Thames, University College London

Email: william.lammons@ucl.ac.uk

**Dr Eirini-Christina Saloniki**

Senior Research Fellow in Health Economics

NIHR ARC North Thames, University College London

Email: e.saloniki@ucl.ac.uk Tel: 02031 083665