

DECK Research Study Living Experience Group: Co-Produced Terms of Reference

What is the 'Understanding Diverse Cultural Backgrounds and Ethnicity for Adult Social Care (DECK)' study about?

The purpose of this study is to better understand the influence of diverse cultural backgrounds and ethnicity as barriers to access and uptake of local authority commissioned adult social care services, in the London Boroughs of Newham and Redbridge.

It is a scoping study, that uses realist action research methods.

The study website is: <https://www.arc-nt.nihr.ac.uk/research/projects/understanding-diverse-cultural-backgrounds-and-ethnicity-for-adult-social-care-deck/>

What is NIHR Applied Research Collaboration North Thames, and what is their role in this study?

The [National Institute of Health and Care Research \(NIHR\)](#) funds, enables and delivers world-leading health and social care research that improves people's health, care and wellbeing and promotes economic growth. [NIHR Applied Research Collaborations \(ARCs\)](#) are regional collaborations between organisations that undertake applied health and care research. [NIHR ARC North Thames](#) is one of 15 ARCs, supporting applied health and care research that responds to the needs of local populations and health and care systems – and it has **funded** this research study.

What is the purpose of the Living Experience group?

The purpose of the Living Experience Group for the [DECK Research Study](#), is to enable individuals with experience of adult social care to provide insights and contribute to this action research study to better understand the influence of diverse cultural backgrounds and ethnicity as barriers to access and uptake of local authority commissioned adult social care services, in the London Boroughs of Newham and Redbridge.

The Living Experience Group will have up to six members to help to plan and shape the [DECK Research Study](#), from a wide range of backgrounds with a variety of experiences of adult social care services provided in the London

Boroughs of Redbridge & Newham. The decisions made by the Living Experience Group will be owned by the group rather than an individual.

Ground Rules

- Turn up on time
- Respect everybody
- No foul language
- Cameras on when possible
- Try not to speak all at once
- Embody shared values, dignity, respect for each other
- No intended racist comments
- Meetings should be a safe space, where members feel like they can be transparent, open, and know that no-one intends to cause offence
- Let everyone take the time to express themselves
- If you cannot attend (part of) a meeting – let Sarah know in advance
- No question is silly as we are all trying to learn
- Tackling disagreements promptly outside of the meeting
- Agree to respectfully disagree
- If something distressing / upsetting comes up – there is always an opportunity to talk to someone / we can signpost outside of the meeting
- You can always approach any of us (Sarah / Fiona / Aurora) before / during / after meetings

Responsibilities

- Attend all five online meetings (1.5 hours in length)
- Read documents in advance and raise issues for clarification prior to meetings
- Review the Terms of Reference for the Living Experience Group, and sign up and work to these
- Maintain confidentiality where appropriate

Training and support

There will be opportunities to discuss and identify any needs for training and ongoing support. Living Experience Group Members will also be offered support with all the practical issues of group membership such as:

- Help with claiming expenses
- Explanation or a glossary of technical terms when necessary
- Documents circulated in advance of group meetings to allow sufficient time to read them

Length of membership

Membership of the group is voluntary, and members may withdraw from the role at any time; the study lead will be available to discuss any issues and look at ways of supporting continued involvement where possible if a member needs to withdraw. Membership of the group will be for 12 months in the first instance.

Time commitment

The group will meet online on the following dates and times (we will notify Sarah in advance if we cannot make meetings / part of meetings):

1. Friday 20th October 2023 (2-3.30pm)
2. Thursday 23rd November 2023 (11-12.30pm)
3. Thursday 8th February 2024 (2-3.30pm)
4. Thursday 23rd May 2024 (11-12.30pm)
5. Summer/Autumn 2024 - group members to decide date + time

Payment

Group members will be offered a £75 payment (plus an additional £5 to cover the cost of your internet connection) to your UK bank account for every full meeting attended (partial attendance will be remunerated at different rates) – this includes some e-mails, pre-reading and/or small tasks you might have to do to prepare for the meetings. Retail vouchers can be offered, if preferred.

Declaration of interests

All Living Experience Group members are required to declare if they have any interests that might conflict with the work of the Group. A conflict of interest is a situation where a person would consider that a decision taken by an individual has been or could have been influenced by an interest they currently hold, or may hold in the future. A conflict of interest does not stop you from being a member of the Group. However, it does mean that you cannot take part in any discussions or decisions made on an issue where you have a conflict of interest.

Confidentiality

Group members must not communicate any confidential information that they learn through being a member of the Living Experience Group.

However, there may be occasions when members are specifically asked to share information within their own communities or seek the opinions and views of others.