

Participant Information Sheet

Project title:

Conducting and evaluating a Citizen Panel for Public Involvement in the access review of UK Longitudinal Linkage Collaboration (UK LLC Citizen Panel)

Invitation:

You are invited to take part in the **UK LLC Citizen Panel project** as a Citizen Panel member. This is a project funded by the Medical Research Council (MRC) and the Economic and Social Research Council (grant details: ESRC ES/X000567/1). The UK LLC Citizen Panel aims to embed public feedback into decision-making about access to data in the UK Longitudinal Linkage Collaboration (UK LLC) Trusted Research Environment (TRE). The UK LLC Citizen Panel members will be involved in reviewing the UK LLC data access process including whether it supports public good research. The project will start in May 2024 and will end in December 2025.

Project team:

The study is led by the project team at UK LLC, comprised of Robin Flaig, Principal Investigator, the Co-Investigators Kirsteen Campbell from UK LLC and Sarah Cunningham-Burley, Professor of Medical and Family Sociology, Dean Molecular, Genetic and Population Health Sciences, Dr Lidis Garbovan who is the Lead Citizen Panel Research Fellow and Julia Moon as the Communication Lead.

The project received Ethical approval from the University of Edinburgh Ethics Committee on 27th May 2024.

What will happen in this project:

You will be a member of a group of 15-20 people from diverse backgrounds who will make up the UK LLC Citizen Panel. All members will be invited to take part in regular meetings, online and in-person to discuss and review the data access process in UK LLC. Prior to the first review meeting you will attend training sessions to learn about the UK LLC and how it works. The agenda of the meetings and the review methods will be co-agreed with the Citizen Panel members.

Some of the possible questions you may discuss as part of the Citizen Panel are exemplified below: 'Did UK LLC ask the appropriate questions of the data applicants?'; 'Are questions inclusive of underserved communities/groups in their framing?'; 'What (or who) is missing from the decision-making process?'; 'How should the outcomes of previous projects inform future thinking on potential risks and benefits from proposals to use data?'; 'What questions are not being asked by the community that should be?'

The meetings may be recorded to aid with note taking. The recordings will be kept safe on a password-protected encrypted file, on the University's secure encrypted cloud storage services (SharePoint). Only the UK LLC Citizen Panel project team will have access to the data and it will not be shared with any third or external party. The data will be preserved on the SharePoint of the University of Edinburgh for a minimum of 3 years, after the end of the project, according to the

University of Edinburgh Data Protection Policy. The information shared will be kept confidential and personal information will be anonymised so none of your personal data will be made public.

You can volunteer to be named co-author to research outputs such as articles, blogs, opinion pieces or reports where appropriate.

You will be involved in co-designing the different stages of this project, such as examining when public involvement in a research application is required, sharing the results with the wider public and evaluating the work of the Citizen Panel itself for future learning.

Time commitments and payment:

As a participant in this project, you will receive payment for your time and activities as a member of the UK LLC Citizen Panel. The meetings will be structured based on the availability and decisions of all UK LLC Citizen Panel members and they may take place quarterly for two hours. Each member will be paid a minimum of £25 per hour, additional amount for pre-meeting activity as well as £15 per activity e.g. feedback on webpages or completion of survey. For in-person sessions there will be reimbursements offered for travel and accommodation. Payment is optional and be paid either via BACS or e-voucher. We aim to have minimum three online sessions and one or two in-person sessions for the UK LLC Citizen Panel. The format and precise timing of these meetings will be agreed together with all the UK LLC panel members.

Benefits and risks:

There are no known potential risks affecting any participants to this project who will be members of the UK LLC Citizen Panel. All the participants are volunteers, providing informed consent and can withdraw at any time by contacting the UK LLC Citizen Panel team in written format, e.g. by email, and expressing their wish to withdraw from the project. The panel will be facilitated by the Panel Lead, researcher Dr Lidis Garbovan, supported by Professor Sarah Cunningham-Burley. The subject matter of the discussions is unlikely to be sensitive. The facilitator will ensure all discussion is respectful and ensure there are multiple ways for participants to engage.

As a UK LLC Citizen Panel member, you will potentially benefit from being part of this research project by being involved in decisions around the acceptance and suitability of data use, including your own data if you are a participant in a Longitudinal Population Study that is partnering with UK LLC. You will also provide unique views and perspectives to the Citizen Panel if you are a member of seldom heard groups and communities, since the Citizen Panel will involve a diverse section of the public. As a Citizen Panel member, you will be helping to provide confidence in the access to and research carried out using on longitudinal population data.

Next steps:

Based on the information provided in this form, you have the right to decide if you would like to take part in this project. If you consent to take part in this study, please read the **Consent Form** attached, tick the boxes for each consent statement and add your name and signature on the Consent form to agree to take part in the UK LLC Citizen Panel project.

Further Contact details

For any further questions about the study, please contact Dr Lidis Garbovan at the email address: Lgarbova@ed.ac.uk.

Thank you for taking time to read this participant information sheet.

On behalf of UK LLC project team,

UK Longitudinal Linkage Collaboration

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