

Study Protocol

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

Acronym: UK LLC Citizen Panel

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List of Abbreviations

UK LLC	UK Longitudinal Linkage Collaboration
TRE	Trusted Research Environment
UKRI	UK Research and Innovation
ESRC	Economic and Social Research Council
MRC	Medical Research Council
LPS	Longitudinal Population Study

PROJECT SUMMARY

1. Start date and anticipated duration:

15 May 2024 – 31 December 2025

2. Overview and context:

UK Longitudinal Linkage Collaboration (UK LLC) has received a research grant from ESRC and MRC to fund the piloting of a novel 'Citizen Panel' project. The concept of a 'Citizen Panel' is developed by the organisation Understanding Patient Data ([Understanding Patient Data](#)) as a learning data governance model for data access in Longitudinal Population Studies (LPS). The model aims to shift the involvement of the public in data access from a one-way direction to a feedback cycle. This is exemplified in Figure 1 below.

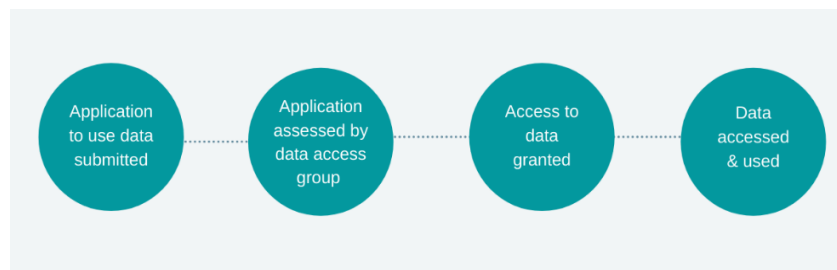


Fig. 1 Visual outline of how data access decisions are currently made (Understanding Patient Data)

The new learning model involves two key ideas: (1) The outcomes from access to data are reported back to the decision-making group (2) A Citizen Panel reviews previous data access decisions and their outcomes. It provides feedback to the decision-making group, to inform their future decisions.

This new model is visually represented in Figure 2 below.



Fig. 2. Visual of a new learning data governance model (Understanding Patient Data)

The UK LLC Citizen Panel is a public assessment of the UK LLC access process that aims to create a new way of involving the public in decisions around the acceptance and suitability of longitudinal data use and linkage and assessing the scope of such research for public good.

The UK LLC Citizen Panel pilot will establish a dialogue between the data community and wider public that ensures good governance and enhances mutual learning.

3. Aims:

The aims of the UK LLC Citizen Panel are:

- (1) to embed public feedback and perceptions into UK LLC's data access process design and decision-making;
- (2) to bring insights to other data providers and academic organisations, aiming to foster trust in data sharing for impactful research for public good;
- (3) to publish outputs from the Citizen Panel that will inform best practice for data access for critical initiatives such as new UKRI LPS, specialised research resources and whole population datasets which integrate data from a wide range of publics including those seldom heard or who have sceptical opinions.

4. Objectives:

The UK LLC Citizen Panel has the following objectives:

- (1) to involve the public in decisions around the acceptance and suitability of data use,
- (2) to assess the scope and benefit of research questions used in applications for data held in the UK LLC Trusted Research Environment,
- (3) to create a learning feedback loop which enables decision-making about data access to linked data resources to remain informed, responsive to change and inclusive of diverse views.

The UK LLC Citizen Panel is intended to enhance and complement the existing ways in which public involvement is conducted. This 'learning model' will embed a diverse public voice in UK LLC's planning and decision-making, enabling UK LLC to remain responsive to new opportunities and changes in context.

The UK LLC Citizen Panel aim to answer these **types of questions**:

- Did UK LLC ask the appropriate questions of the LPS 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 our future thinking on potential risks and benefits from proposals to use data?
- What questions are not being asked by the community that should be?

5. Methodology: this will include the following phases:

5.1 Design Phase:

The UK LLC Citizen Panel will have a two-stage co-design process explained below.

Stage 1: UK LLC Project team will identify and invite a Steering Group to help co-design the Citizen Panel Pilot. This will consist of 6 people, 3 from (a) UK LLC's Public Involvement Programme, and 3

from (b) study participants from UK LLC partner studies will be selected based on submitting an expression of interest by email and having a short interview online with the UK LLC Citizen Panel team. The Citizen Panel team will aim to maximize diversity and inclusion of underrepresented groups when selecting the LPS participants as Citizen Panel members.

Stage 2: the Citizen Panel members (max 20), will be made of the 6 members of the Steering Group as explained above and 14 to be recruited equally from two sources, 7 from (a) UK LLC partner LPS study participants, as explained above, and the other 7 from (2) minoritized groups via third sector organisations (not exclusively).

They will have an induction and be provided with training to get to know and understand the work of UK LLC.

This two-stage co-design process will contribute to developing **methodological innovations** in the way the UK LLC Citizen Panel is planned, formed, piloted, executed, evaluated and how it will inform the next cycle / round, by co-producing new knowledge with various publics.

5.2 Recruitment:

For recruiting our Citizen Panel our audience is the population groups within (a) our partner LPS and (b) people from seldom heard communities which are known to be under-represented or prone to attrition in LPS. We aim to recruit a core group of 15-20 Citizen Panel members from these two groups, who will meet regularly to co-design the format and working of the panel. We will invite existing study participants from UK LLC's 20 partner LPS to apply to be a member of the Citizen Panel. And we will also invite participants from seldom heard groups such as those from ethnic minorities, to apply to be a member of the Citizen Panel. We will engage with third sector organisations that support minoritized communities to inform the development of our approaches, and as routes to advertising and advocating the role of a Citizen Panel member. We aim to ensure diversity and inclusion including across age groups, gender, un/employment, and education.

We will advertise the role via materials such as posters and leaflets on social media and via emails sent out to UK LLC partner LPS and third sector community organisations. Interested candidates will be invited to submit a short expression of interest form, in which they explain why they are applying and mention if they had any previous experience as public contributors. They can send this form to an email address provided on the poster. The project team will receive the forms and pre-select candidates who are suitable. These will be invited to an informal interview with two members from the project team and maximum 20 of them will be selected to be members of the Citizen Panel in the first cycle. As mentioned earlier, this will be an iterative process and the membership of the Citizen Panel will be reviewed and updated regularly.

5.3 Inclusion/exclusion criteria:

The inclusion criteria for the Citizen Panel members are: 50% participants from the existing UK LLC partner LPS and 50% public representatives, with a focus on under-represented and seldom heard groups and minority communities.

Children and young people under 18y old will be excluded from recruitment. Those who cannot provide informed consent will also not be recruited.

5.4 Data management and data protection for research participants

This project will collect two types of data:

1. Quantitative: demographic data about the Citizen Panel members, including age group, gender, education, occupation status, home address and email address and ethnicity.
2. Qualitative: the views and feedback of the Citizen Panel members about the UK LLC data access process, collected during online and in person meetings facilitated by the Citizen Panel Research Lead, Dr Lidis Garbovan. The Citizen Panel will have a maximum of 20 members.

The participants in this project recruited as Citizen Panel members will have their personal data protected and kept confidential. The personal data will be collected via online forms and will include name, postal address, email address, age group, gender, education, employment status, ethnicity, and bank details, the latter for the purpose of financial recognition.

Only minimal data will be collected to fulfil the research purposes detailed in the Protocol.

The personal data will be stored on a password protected Excel spreadsheet only accessible to a small number of UK LLC at UoE research staff. All data collected by the project will be stored on the UK LLC secure folder in UoE Sharepoint with access to the folder limited to the Edinburgh UK LLC Team and UoE IT. The data will not be shared with any third parties or any other groups within UoE. Personal data will be retained according to UoE retention policy and backed up regularly through UoE standard Datastore policies.

The personal data of the Citizen Panel members will mainly be used to ensure that we recruit a diverse group of public to maximise inclusion of diverse and underrepresented groups and to ensure that their voices are heard.

Individuals will be provided with a Personal Information Sheet and a Consent form - they will have an informed choice to take part in the research.

Participants will be provided with information about how their personal data will be anonymised as part of this research and they will have the choice to have their quotes used in research outputs if they agree to this. The quotes will not use their names, or other identifiable personal data. Any reference to participants in public facing documents will be anonymised.

Citizen Panel members will have the choice to be co-authors of publications and research outputs if they wish to do so. In this case their names would be used in publications as co-authors.

5.5 Citizen Panel operation:

Literature on PPIE research includes the role a Steering Committee or Group, usually made of 3-6 members from the public, at times people with lived-experience on a specific topic required in the project. The Steering Group's role is to advise the research team on the planned project PPIE activities and collaboration, to provide direction, advice and guidance for the project, to consult over the objectives, timelines, risks and deliverables (Kaisler and Missbach, 2020).

In this specific UK LLC Citizen Panel project, the Steering Group will set the parameters of the full Citizen Panel review. Also, the Steering Group members will provide guidance and advice to the

activities and tasks co-designed for the Core Citizen Panel and will co-create trainings for the Core Citizen Panel, they will also attend regular meetings on average once a month.

The Core UK LLC Citizen Panel team will then co-develop ways to enhance involvement of public members and seeking answers about whether the questions being asked by applicants wishing to access data held in UK LLC's TRE are appropriate, including whether they address underserved communities/groups/are representative of the population, and are engaging effectively with them as part of the research process.

As the process is cyclical and iterative, we will be learning and not retaining a static view of public perceptions and engagements. The UK LLC Citizen Panel will have regular meetings to answer the questions mentioned above in online and in-person sessions. As a minimum we anticipate 20 members to meet quarterly for two hours.

Payments: Citizen Panel members will receive payments for their time and guided by the NIHR standards of payment (2023). When they meet quarterly for two hours, they will be paid a minimum of £25 per hour, and £15 per pre-meeting activity e.g. feedback on webpages or completion of survey (NIHR, 2023).

Potential risks: There are no anticipated risks or burdens for the Citizen Panel members. They will be volunteers, providing informed consent and can withdraw at any time. The panel will be facilitated by the Panel lead (researcher 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.

There are no anticipated or potential risks for the researchers involved in this study.

Potential benefits: The Citizen Panel members will potentially benefit from being part of this project by being involved in decisions around the acceptance and suitability of data use, including their own data when they are LPS participants. They will also provide unique views and perspectives as members of seldom heard groups and communities, since the Citizen Panel will involve a diverse public. The Citizen Panel members will also make a unique contribution to this project by helping provide confidence in public perceptions of UK LLC and the research community's inclusivity of research into underserved communities/groups. The Citizen Panel provides a new model for the review of the data access process and revision that could be adopted by other data providers in future, including national, regional and specialist areas.

6 Evaluation:

The evaluation will include capturing the public voice in design decisions, knowledge exchange emerging from interactions with stakeholders, key objectives (ie. diversity of membership) and the outcomes and iterative development of the model. Final evaluation methods will be agreed with the Panel itself as a part of the co-production work. The evaluation will focus on process and outcomes. The consent form and Participant Information Sheet will make clear the co-produced nature of the evaluation and that the data will be used for research purposes, including academic and other publications.

Findings will be published in relevant journals and key learning distributed to stakeholders across the TRE ecosystem. The evaluation outputs will make a strong contribution to evolution of programmes to understand public views and build engagement and trust.

Publication and dissemination of outputs:

The project will be made publicly visible by publishing and updating a lay summary on the website and social media sites of UK LLC. The UK LLC Citizen Panel project team will report and disseminate the results of the study in peer-reviewed academic articles, internal reports, at conferences and external events and on the UK LLC website.

The Citizen Panel members will be co-designing the project and will do member-checking exercises for qualitative analyses, as well as sharing final results summaries.

7 References

1. Understanding Patient Data, [Learning data governance: a new approach to decisions about data | Understanding patient data](#)
2. NIHR (2023), [Payment guidance for researchers and professionals | NIHR](#)
3. Kaisler, R.E., Missbach, B. Co-creating a patient and public involvement and engagement 'how to' guide for researchers. *Res Involv Engagem* 6, 32 (2020). <https://doi.org/10.1186/s40900-020-00208-3>