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A novel protocol for a “Citizen Panel” for diverse Public and Participant Involvement in the review and development of the process to access data in the UK Longitudinal Linkage Collaboration Trusted Research Environment

Lidis Garbovan^{1,2*}, Betty O. Idemudia^{1,2}, Robin Flaig^{1,2}, Kirsteen Campbell^{1,2}, Katharine Evans^{3,4}, Andy Boyd^{3,4,5}, Sarah Cunningham-Burley^{1,2}, and Emma L. Turner^{1,2}

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¹ UK Longitudinal Linkage Collaboration, The University of Edinburgh, Edinburgh, UK

² Usher Institute, The University of Edinburgh, Edinburgh, UK

³ UK Longitudinal Linkage Collaboration, University of Bristol, Bristol, UK

⁴ Population Health Sciences, Bristol Medical School, University of Bristol, UK

⁵ Health Data Research UK, London, UK

Abstract

Background

Researchers can apply to UK Longitudinal Linkage Collaboration (UK LLC) to access Longitudinal Population Study (LPS) data linked to health, non-health administrative and geo-environmental data. This paper describes the protocol for the “UK LLC Citizen Panel”: a new method of incorporating a diverse public in decisions about the acceptability and suitability of the UK LLC data access process. The UK LLC Citizen Panel aims to embed public feedback and perceptions into UK LLC’s data access process design and decision-making.

Methods

The UK LLC Citizen Panel will be created through a two-stage co-design process. Stage 1: UK LLC will identify and invite a public Steering Group to co-design the work of the Citizen Panel. The Steering Group will include public contributors from UK LLC’s Public Involvement Programme and participant representatives from partner LPS. Stage 2: the UK LLC Citizen Panel will comprise participants of partner LPS and seldom-heard groups, primarily recruited via third sector organisations. The Panel will review the data access process during several online and in-person meetings. Findings will be analysed using thematic analysis and disseminated to UK LLC partner organisations, third sector organisations working with minority communities and young people under-represented in longitudinal studies, and networks of the Universities of Edinburgh and Bristol.

Discussion

The UK LLC Citizen Panel is a novel methodological approach that aims to consider a diverse public view of the use of a Trusted Research Environment to provide access to LPS data linked to health, non-health administrative and geo-environmental data. This diversity complements the existing public involvement in decision-making in all UK LLC data access and enables populations that are rarely heard in such decision-making to participate in and review the UK LLC data access process.

Keywords

longitudinal population studies; UK Longitudinal Linkage Collaboration; citizen panel; linked data; seldom-heard communities; trusted research environment; patient and public involvement

*Corresponding Author:

Email Address: Lgarbova@ed.ac.uk (Lidis Garbovan)



Introduction

A major driver of the transition of population data science [1] to occurring within Trusted Research Environments (TRE) is the concern regarding ‘Social Licence’ which suggests that factors such as demonstrable public good are essential for socially acceptable data use [2]. Yet, whilst public dialogue has helped identify the criteria to define what is ‘in the public good’ [3], we currently lack the methodologies necessary to bring a diverse perspective as to whether we are achieving this. The ‘Citizen Panel’ concept may be a mechanism to integrate a diverse public voice into decision-making as a form of public audit of such data access decision-making.

The concept of a ‘Citizen Panel’ is developed by the organisation Understanding Patient Data as a learning data governance model for data access in Longitudinal Population Studies (LPS) that shift the involvement of the public in data access from a one-way direction to a feedback cycle [4]. To date, this model has not been deployed in the context of data access to public data as recommended by Understanding Patient Data and therefore it is not known whether the model will work as intended or how a panel would be constituted and operate in practice.

LPS employ continuous or repeated measures to follow particular individuals over prolonged periods of time—often decades or lifetimes. They are usually observational in nature and include collections of quantitative and/or qualitative data on any combination of exposures and outcomes [5].

UK Longitudinal Linkage Collaboration (UK LLC) - the national TRE for data linkage in longitudinal research - has been funded by UK Research and Innovation (UKRI), the Economic and Social Research Council (ESRC) and Medical Research Council (MRC) to pilot the first operational Citizen Panel.

The social licence for population data science

The concept of social licence suggests that publics expect that organisations that are holding and using the public’s data will go beyond the requirements of formal regulation, and adhere to voluntary codes of trustworthy behaviour and transparency. According to social licence theory, only when the public are satisfied that the motivations of the organisation are trustworthy, will they confer a “social license” to operate [6]. This is particularly pertinent within longitudinal research, given the requirement for building a trust relationship between participants and their study which needs to extend over very long time periods – often lifetimes – and which can survive dramatic changes in technologies, scientific opportunities and changes in social expectations [7].

One element in creating and maintaining the reciprocity that underpins social licence is transparency about, for example, the policies and procedures for handling personal information as well as the outcomes of research projects [8]. Within longitudinal research, factors such as these have been seen to influence participants’ views regarding linkage of study data to routine records [9], the committees which make decisions regarding data use [9] and has led to some studies – such as the Avon Longitudinal Study of Parents and Children [10] to develop participant facing frameworks consisting of study “commitments to you”. These

commitments and principles include safeguards relating to data use processes and reassure participants that all data use is in the public good [11].

Recent research [12] suggests that data teams and researchers should move towards a shared or reflexive data governance model, which focuses on mutual learning, communication and deliberation, in which all stakeholders share power and are consulted. While public views on data sharing, including public concerns, are now well established, there is limited research on how to transform public expectations into a testable social licence to operate. Furthermore, achieving a social licence is not a one-off event – it requires continuous reflection and maintenance [6]. For instance, recent research measured and modelled the critical elements of social licence by conducting a longitudinal study in an Australian mining region. The results showed that building trust with local communities was crucial for mining companies to obtain and maintain a social licence to operate [13].

Public involvement and social licence

Public Involvement and Engagement (PIE) is a crucial method for creating and maintaining the required social acceptance for data-intensive health research [14]. The public, with their varied viewpoints and valuable insights, should have a significant influence on the development of research infrastructures, procedures and applications. Additionally, the public may offer a broader social viewpoint [15]. The best results from public participation are probably obtained when dialogic and deliberative communication styles are used. As a result, continuous attempts to increase transparency should concentrate on “informational transparency,” “participatory transparency” and “accountability transparency” [27].

This paper will provide a background about UK LLC and the Citizen Panel concept and will then, within the methodology, describe our iterative co-development protocol. This represents the protocol as conceived by the UK LLC team and approved by the EMREC - Edinburgh Medical School Research Ethics Committee at the University of Edinburgh (REC Reference: 24-EMREC-034). We provide initial conclusions drawn primarily from the motivations for instigating the Citizen Panel within UK LLC and reflect on potential impact for the longitudinal research community and wider TRE and population data science communities.

Background information – about UK LLC and Citizen Panels

UK Longitudinal Linkage Collaboration (UK LLC)

UK LLC is the national TRE for data linkage in longitudinal research, supporting its unparalleled collection of Longitudinal Population Studies (LPS). Initially set up as a COVID-19 research resource, UK LLC is now a generic database for any research in the public good [16]. The UK LLC TRE is a regulated, highly secure computing environment that allows authorised researchers remote access to de-identified data about LPS participants. This includes self-reported data collected by the LPS, and where permissions allow, these data

are linked to participants' health and non-health administrative routine records, and environment and neighbourhood data.

UK LLC provides a secure analytics environment, a trusted third-party linkage processor and a comprehensive governance framework to minimise risks to participant confidentiality. UK LLC is ISO 27001 certified and accredited by the UK Statistics Authority as a processor under the Digital Economy Act (2017). UK LLC's Public Involvement Programme integrates LPS participants and the wider public views into the operation of UK LLC.

The ultimate objective of UK LLC is to support research in the public good [3]. Suggests that public good means minimising harm, providing clear and accessible public-facing communications about the use of data and practicing safeguarding principles to ensure secure access to data. Therefore, involving the public in the review of the data access process through the UK LLC Citizen Panel initiative appears to be a step in the right direction towards accomplishing this objective.

The UK LLC Citizen Panel is funded by UKRI, ESRC and MRC. It is building on an existing UK LLC Public Involvement Programme spanning public contributor involvement in (i) strategic advisory board; (ii) a network tackling emerging issues and shaping future developments of UK LLC; (iii) advising on the clarity and content of information materials and (iv) an advisory committee forming part of the data application review process (Supplementary Appendix 5 – UK LLC Public Involvement - Overview). As distinct from these, the UK LLC Citizen Panel will be designed to improve and supplement existing public involvement methods with the goal of enhancing trust in data science and the TRE ecosystem

To present, while it is common to incorporate the public/participants in data access and governance processes for LPS, such as the TwinsUK Voluntary Advisory Panel (VAP) [17] or ALSPAC Law and Ethics Committee (ALEC) [18, 28], the UK LLC Citizen Panel recruited across both LPS and minoritised groups, and explicitly set up as an external review of existing processes is novel, innovative and uncommon.

Citizen Panels

When it comes to gathering public opinions, a Citizen Panel is typically understood to be a stable and representative sample of a specific demographic [19]. Although PIE has been extensively promoted and implemented over the past decade, there are concerns that its involvement is restricted to a specific group of individuals, and does not reflect the diversity of the community [20].

In the wider literature, Citizen Panels are groups of purposively selected members of the public, usually mixed in terms of age, gender and socio-economic group, who meet several times and consider presentations by experts about particular issues, and who then question and challenge those experts. They debate and deliberate within the group and then formulate their own priorities and recommendations for policy-making. They are not required to reach a specific decision (unlike Citizens' Juries) but rather are seen as a method for identifying broader issues of public concern, especially in areas of uncertainty about science or policy [21].

By articulating the perspectives of diverse social groups, Citizen Panels may foster a symbolic sense of being represented among people who identify with those groups. Although participation on Citizen Panels is limited by the constraints of the selection process, those who do participate can shape the representations of the public interest produced by the panel [22]. Additionally, Citizen Panels may improve the capacities of participants to represent both their own experiential perspectives and their conceptions of the public interest during the meetings of the panel [22].

Methods and co-design

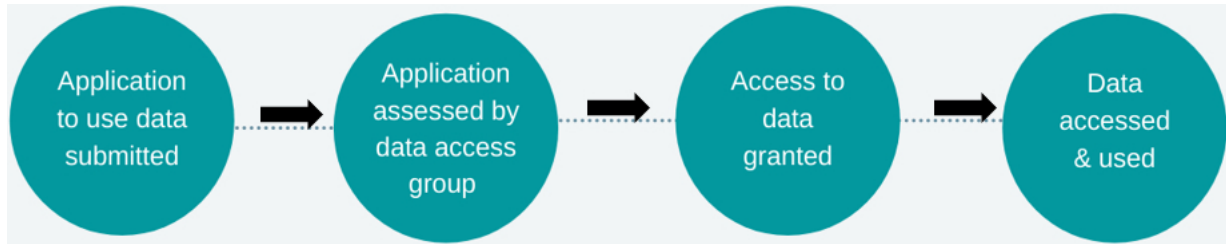
The Citizen Panel at UK LLC

The concept of a 'Citizen Panel' is developed by the organisation Understanding Patient Data as a learning data governance model for data access in LPS. The aim is to shift the involvement of the public in data access from a one-way direction to a feedback cycle, as exemplified in Figures 1 and 2 below.

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

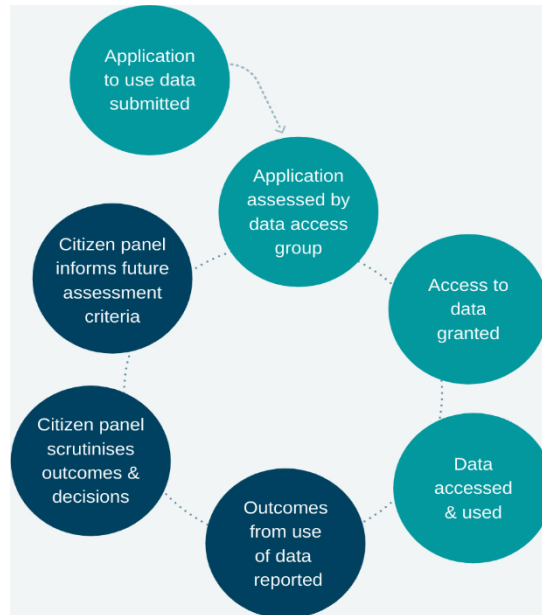
The UK LLC Citizen Panel is an open evaluation of the UK LLC data access process that attempts, first, to establish a new method of incorporating the public in decisions regarding the acceptability and usefulness of longitudinal population data usage and linkage. Secondly, the Panel will seek to incorporate diverse public opinions and feedback into data access decision-making processes. In addition to contributing to UK LLC, the Citizen Panel project will provide insights to other TREs, data producers and academic institutions, thus increasing trust in data science and the TRE ecosystem. Publicly available results will contribute to important projects, novel UKRI cohort studies, clinical trials and whole population datasets that incorporate information from a diverse range of the public, including individuals who are more difficult to reach or who hold uncertain views. This novel methodological approach confers credibility on public views of the TRE, involves a more diverse public and gives ethical standing to decision-making in populations that are seldom-heard. There is a risk that any PIE process or finding can introduce barriers to research (e.g., introducing new steps to application processes or restrictive policy requirements); after all most governance is effectively balancing the different, and potentially incompatible, expectations of different stakeholders. There is therefore a risk that findings from the Citizen Panel could add complexity or barriers to the UK LLC access process. UK LLC will manage this risk by factoring in panel recommendations and balancing them against wider stakeholder needs: whilst all recommendations will be treated seriously, it is likely that not all will be adopted. The UK LLC Citizen Panel, as a Public Governance Group, has the ability to influence decisions on the applications to access data and the process by which this is assessed. The Citizen Panel has an advisory role and this is made clear

Figure 1: Visual outline of how data access decisions are currently made (adapted from Understanding Patient Data)



Source: <https://understandingpatientdata.org.uk/learning-data-governance-new-approach-decisions-about-data>.

Figure 2: Visual of a new learning data governance model (adapted from Understanding Patient Data)



Source: <https://understandingpatientdata.org.uk/learning-data-governance-new-approach-decisions-about-data>.

to all participants. The UK LLC commit to the transparent reporting of recommendations and considerations relating to whether these are, or are not, adopted. UK LLC will be guided in deliberations by its wider PIE structures.

Citizen Panel objectives

The UK LLC Citizen Panel has the following objectives:

- (1) to involve diverse publics 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 TRE.
- (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 aims to answer questions such as: 'Did UK LLC ask the appropriate questions of the applicants?'; 'Are the questions inclusive of seldom-heard communities?'; '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 research community that should be?'

Consent, data management and data protection for UK LLC Citizen Panel members

Individuals will be provided with a Participant Information Sheet (Appendix 1) and a Participant Consent form (Appendix 2), i.e. they will have an informed choice to take part in the research project. The Panel members will be provided with information about how their personal data will be anonymised as part of this research and they will choose if their unattributed and de-identified quotes can be used in research outputs. Any reference to participants in public-facing documents will be anonymised. The 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, but not linked to specific quotes or contributions.

Collaboration and co-production of research with communities have been deemed important for research equity and impact [23]. Moreover, co-produced research with the public or communities allows collaborators/co-authors to contribute to the research agenda and decision-making

processes [24]. Contribution of non-academic partners, and how this should be recognised, is often missing from authorship guidelines and there are suggested ways of how to do co-authorship with community or public members involved in the research process, depending on the context. In this paper, we acknowledge the importance of co-produced authorship with the Citizen Panel members as one way in which we can improve how we do community participation and help mitigate institutional and socio-economic hierarchies and we aim to follow a set of proposed guidelines for academic authorship in collaborative health research [24].

The Panel members will have their personal data collected to administer the study and to help ensure that we recruit a diverse group of public contributors. Personal information includes names and contact details and demographic data (age group, gender, ethnicity, education level, occupation status). These data will be protected and kept confidential and separately from any research data. Qualitative data on the views and feedback of the Panel members about the UK LLC data access process will be de-identified and stored separately from the contact and demographic data.

The personal information will be stored on a password protected Excel spreadsheet only accessible to a small number of University of Edinburgh-based UK LLC staff. All qualitative data collected during the project will be stored on a University of Edinburgh secure research server with access to the folder limited to University of Edinburgh UK LLC staff and IT services staff. The data will not be shared with any third parties. Personal data will be retained according to the University retention policy and backed up regularly through standard Datastore policies.

Potential risks: There are no anticipated or potential risks for the Panel members involved in this project. They will be volunteers, providing informed consent and can withdraw at any time. The Panel will be facilitated by the Panel lead, supported by experienced academic Co-Investigators. 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. The risk of pre-existing bias of participants from LPS, as members who are already involved in data collection and might have an inherently optimistic view of the research and could thus limit critical or diverse perspectives, is very low. When deciding to include 50% LPS members in the UK LLC Citizen Panel membership, the Panel co-leads anticipated the benefits of their membership in terms of (1) knowledge and experience of taking part in LPS research, (2) equal membership on the Panel, with no privileged status and no anticipated influencing power over the other Panel Members and (3) as representatives of direct stakeholders whose data are being used. However, this is a risk that is monitored as part of UK LLC business risk management.

Potential benefits: The 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 where they are LPS participants. They will also provide unique views and perspectives as members of seldom-heard groups and communities and will therefore help increase confidence in public perceptions of UK LLC and the wider research community's approach to inclusive research.

The UK LLC 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.

Citizen Panel co-design

The UK LLC Citizen Panel will have a two-stage co-design process (Figure 3). This 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 round, by co-producing new knowledge with various publics.

Steering Group

The small amount of current literature on Patient and Public Involvement and Engagement (PPIE) research includes the role a Steering Committee or Group, usually made of 3-6 members from the public, usually including 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 [25].

The six Steering Group members will be recruited from three UK LLC partner LPS (three members) and from the current UK LLC Public Involvement Programme (three members). The UK LLC Citizen Panel team will develop materials to recruit Steering Group members and circulate them to the three partner LPS. Interested applicants will submit an expression of interest by email and will have a short interview with the UK LLC Citizen Panel team. They will then be selected based on agreed selection criteria and invited to join the Steering Group.

The UK LLC Citizen Panel Steering Group will set the parameters of the full Panel review. The Steering Group will co-design the recruitment, induction and operation of the Panel, and provide guidance and advice on the activities and tasks for the Citizen Panel. They will attend regular meetings, on average once a month.

Recruitment of the Citizen Panel

For recruiting the Citizen Panel, target population groups are: (1) UK LLC partner LPS participants and; (2) people from seldom-heard communities that are known to be under-represented or prone to attrition in LPS. This small number of people (max 14 people) is not intended to represent all LPS participants and/or all underserved groups. However, their participation in the Citizen Panel is aimed at responding to identified patterns in LPS attrition and lack of representation in LPS of participants from certain groups, such as ethnic minorities, those with particular health or social conditions and those from a migrant and asylum seeker background who may not have stable accommodation [7]. Our objective for this strategy is to build confidence that the UK LLC access process is reviewed by a broad range of public stakeholders with diverse backgrounds, to inform its development and to build broad trust in the safeguards used within the longitudinal research community.

Figure 3: Citizen Panel co-development process diagram



The role of a Citizen Panel member will be advertised via materials such as e-leaflets on social media, posters to be distributed to community meeting places, 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 via email, in which they explain why they are applying and mention if they have any previous experience as public contributors. The project team will receive the forms and pre-select candidates who are suitable, based on selection criteria. These will be invited to an informal interview with two members from the project team and a maximum of 14 will be selected to join the six members of the Steering Group and become members of the Citizen Panel. As mentioned earlier, this will be an iterative process and the membership of the Citizen Panel will be reviewed and updated regularly.

Payments: The Panel Members will receive payments for their time guided by the NIHR standards of payment.

When they meet monthly 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 [26].

The Citizen Panel operation

The UK LLC Citizen Panel will meet on average once per month or more often if required, for a duration of approximately two hours, during online meetings sessions and at least one in-person session.

The UK LLC Citizen Panel will co-design the sessions and seek answers about whether the questions asked by UK LLC applicants wishing to access data held in UK LLC's TRE are appropriate, including for example, whether they address underserved communities, engaging effectively with them as part of the research process.

The findings, such as notes on the meetings and surveys will be synthesized and analysed using thematic analysis.

Findings will be reported in different co-produced outputs, such as blogposts, academic articles, reports and visual and artistic outputs.

As the process is designed to be cyclical and iterative, the UK LLC Citizen Panel team will be learning and not retaining a static view of public perceptions and engagements. The Terms of Reference for the Steering Group (Appendix 3), the Participant Consent Form and Participant Information Sheet will make clear the co-produced nature of the operation and that the data will be used for research purposes, including academic and other publications.

Evaluating the UK LLC Citizen Panel

The evaluation of the UK LLC Citizen Panel will include capturing the publics' perspectives in design decisions, knowledge exchange emerging from interactions with stakeholders, key objectives (i.e. diversity of membership) and the outcomes and iterative development of the model. The methods for evaluation will potentially include short surveys and individual interviews with Citizen Panel members to gather their insights and reflections of the process.

Final evaluation methods will be agreed with the Panel itself as a part of the co-production work. The evaluation will focus both on process and outcomes.

The intended aim and impact of the evaluation activity is to assess how the UK LLC Citizen Panel would have enhanced and complemented 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.

Publications and dissemination of outputs

Findings will be published in relevant academic journals and key learning distributed to stakeholders across the TRE ecosystem, including the UK's national data science institutions (Health Data Research (HDR) UK and ADR UK), data owner organisations such as NHS England, the Office for National Statistics, Public Health Scotland, regulators (e.g. Health Research Authority and UK Statistics Authority) and organisations representing the public voice (National Data Guardian (NSG), UPD) and across the TRE community. The evaluation outputs will make a strong contribution to the evolution of programmes to understand public views and to build engagement and trust.

The findings will be disseminated to UK LLC partner organisations including our partner LPS, CLOSER (www.closer.ac.uk), Population Research UK (www.pruk.ac.uk), Administrative Data Research UK (www.adruk.org), UK government data owners (e.g., NHS and Office for National Statistics), Health Data Research UK (www.hdruk.ac.uk), Public Engagement in Data Research Initiative (<https://www.pedri.org.uk/>), and UK Research and Innovation, third sector organisations working with minority communities and young people under-represented in longitudinal studies, networks of the Universities of Edinburgh and Bristol, young people and public engagement communities and Research Data Scotland.

The project will be made publicly visible by publishing and updating a lay summary on the UK LLC website and social

channels. The UK LLC Citizen Panel project team will report and disseminate the results of the research in peer-reviewed academic articles, internal reports, at conferences and external events and on the UK LLC website.

Discussion

The Citizen Panel at UK LLC is a novel methodological approach that aims to confer credibility on public views of UK LLC, involve a diverse section of the public, and give ethical standing to decision-making in populations that are rarely accessible.

The Panel members will be co-designing the project, as well as sharing final results summaries. The Panel members will be invited to contribute to writing and co-producing outputs, such as blog posts, academic articles and reports and their co-authorship will be acknowledged in these publications.

This work is important for UK LLC because (1) it will inform mechanisms to develop a dynamic social licence for UK LLC's data use through regular and ongoing consultations; (2) it will provide insight into the UK LLC data use decision-making process, to help evolve this; (3) it will provide confidence in the 'delegated decision-making' for stakeholders such as the NHS; and (4) it will provide insights for UK LLC governance on shifting public perceptions around data use, acceptability of different types of data being used for research and by whom e.g. sensitive data, allowing the learning to steer future strategy.

More broadly, the UK LLC Citizen Panel will provide insight for global TREs as to whether the Citizen Panel model is an effective framework for including a wide public voice in the critical evaluation of TRE operations. The findings it generates will contribute to thinking regarding social licence and the acceptable use of data for public good research.

Conclusion

The UK LLC Citizen Panel aims to create a dialogue between the data community and the wider public that is embedded in governance and enhances mutual learning. In future the UK LLC team will consider applications for further funding to continue the Citizen Panel at UK LLC or in collaboration with other organisations that may be interested in applying this concept. From a sustainability perspective, a future project might consider scaling up the Citizen Panel concept in size, for instance designing a panel with >100 members, and geography, e.g. Citizen Panel groups running in each of the four UK nations, or elsewhere globally, to engage closely with the wider TRE ecosystem, data community and those shaping governance frameworks.

Ethics statement

The Citizen Panel project received ethical approval from the Edinburgh Medical School Research Ethics Committee at the University of Edinburgh (REC Reference: 24-EMREC-034) on 28th May 2024 and the overarching UK LLC infrastructure has ethical approval from the Health Research Authority

(HRA) Research Ethics Committee (Haydock Committee; ref: 20/NW/0446).

Funding statement

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Conflict of interests statement

The authors have no conflicts of interest to declare. All co-authors agree with the contents of the manuscript, certify that the submission is original work and is not under review at any other publication.

Data availability statement

Data are available within the submitted article and supplementary files.

Authors' contribution

LG led the manuscript writing and review process, wrote the Ethical application submitted to the Ethics Committee at the University of Edinburgh which includes the Protocol (Appendix 4).

BI contributed to the literature review and drafting the manuscript.

RF co-designed the UK LLC Citizen Panel pilot concept, contributed to the funding application, and reviewed the manuscript.

KC is the operational lead for the UK LLC Public Involvement Programme, co-designed the UK LLC Citizen Panel pilot concept, contributed to the funding application, and reviewed the manuscript.

AB co-designed the UK LLC Citizen Panel pilot concept, led the funding application, and reviewed the manuscript.

KE contributed to co-writing the Data Protection Impact Assessment (DPIA), which formed part of the Ethical application submitted to the Ethics Committee and reviewed the manuscript.

S C-B co-designed the UK LLC Citizen Panel pilot concept, contributed to the funding application, and reviewed the manuscript.

ET contributed to the funding application, and reviewed the manuscript.

Supplementary appendices

Supplementary Appendix 1 – Participant Information Sheet UK LLC Citizen Panel

Supplementary Appendix 2 – Participant Consent Form UK LLC Citizen Panel

Supplementary Appendix 3 – Terms of Reference for the Steering Group UK LLC Citizen Panel

Supplementary Appendix 4 – Protocol document UK LLC Citizen Panel

Supplementary Appendix 5 – UK LLC Public Involvement - Overview

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