

**Population Research UK – Green paper  
consultation public perspectives workshop**

**September 2021**



## Overview

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Population Research UK (PRUK) is a new initiative which will seek to increase the insights, innovations and research efficiency of the UK's wealth of social and biomedical longitudinal population studies (LPS) by bringing studies and data together. PRUK aims to address high-impact research questions that single studies cannot address alone. Health Data Research UK (HDR UK) has been commissioned by the MRC, ESRC and the Wellcome Trust to scope this new initiative. After an initial consultation phase, a Green Paper was developed and published in July 2021.<sup>1</sup> This outlined the key recommendations for how PRUK could be developed and identified further questions for consultation. A scoping review on best practices and recommendations for engagement and involvement with the public and study participants was published in July 2021.<sup>2</sup>

To address gaps from the scoping review and ensure that the public perspectives are well understood, a workshop was held in August 2021 with 16 public participants to discuss the proposals and recommendations for PRUK (see Appendix 1 for the agenda). 13/16 participants were recruited through HDR UK Voices – a network of individuals signed up to receive opportunities to contribute to involvement and engagement opportunities. 2/16 were recruited from People in Research website, a National Institute of Health Research for Public and Participant Engagement and Involvement opportunities. Characteristics of the attendees were not collected. During the workshop four attendees volunteered that they were participants in a longitudinal population study or cohort.

A public perspectives survey which had 37 respondents over a 4-week period (see Appendix 2 for the summary and link to responses) was also run in parallel.

The general public perception was very positive about PRUK's potential, acknowledging the huge benefit that could come from this initiative. Discussions centred largely around public benefit, transparency, governing access to data, data linkage and how to engage diverse public groups. This report summarises the public workshop perspective of the four key recommendations for PRUK activities that were discussed in the workshops:

- Streamline data access processes and mechanisms (R2);
- Facilitate linkage between LPS data and health, administrative and further types of data (R3);
- Sustain public trust and transparency in LPS data sharing (R5);
- Maximise the connectedness of LPS with the research, innovation and policymaking ecosystem (R6).

These four recommendations were chosen for discussion based on alignment with topics identified in the scoping review as needing further insight and through previous PPIE work which identified these topics as having higher potential for damage to public trust. Adding to the findings from the scoping review, the public perspectives workshop and survey identified four key implications that will inform the final PRUK recommendations. These were:

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<sup>1</sup> <https://www.hdr.uk/population-research-uk/>

<sup>2</sup> [https://www.hdr.uk/wp-content/uploads/2021/07/Annex-2-PRUK-PPIE-Scoping-Review\\_final.pdf](https://www.hdr.uk/wp-content/uploads/2021/07/Annex-2-PRUK-PPIE-Scoping-Review_final.pdf)

- i. Create a national register of PPIE representatives, or utilise an existing one, to facilitate public contribution and perspective in all PRUK activities. This can improve the relationship between the public and PRUK, encourage meaningful contribution from diverse public groups and may be a more efficient approach compared to recruiting PPIE representatives only when needed (Topic 1).
- ii. Support the development of transparency on the data linkage process to educate and safeguard against existing public concerns; this includes recording and communicating any PRUK-facilitated data linkage to the public (e.g. via website) (Topic 2).
- iii. Early engagement with diverse public groups (e.g. schools, all ages, diverse groups) to educate about the benefit of LPS and PRUK (Topic 3).
- iv. Conduct further consultation to understand how concerns about commercial companies can be addressed. There is substantial scepticism on government and industry partners and no potential benefit was acknowledged. If PRUK moves forward without addressing this issue, this could impact the perception and public trust in PRUK (Topic 4).

## Narrative of discussions

### Topic 1: Streamline data access processes and mechanisms (R2)

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Workshop participants recognised the advantages of PRUK's involvement in streamlining data access as it could reduce time and effort for all parties. Individuals queried many aspects about data access, suggesting that there is a gap in public knowledge on how researchers currently access data. Queries included: anonymisation, which LPS exist, if approval must be given in order to access the data, how researchers can demonstrate their legitimacy before gaining access and how PRUK fits with other meta-data activities (e.g. HDRUK Gateway). Participants expressed a view that the public should be involved in the data access and approval process. This could take a number of different roles: ensuring data access is legitimate, sharing lived experience, upholding standards around transparency to eliminate any public suspicion and involving people from a range of backgrounds.

It was suggested that PRUK should seek to build a sustainable and long-term relationship with public representatives. One way to do this could be the creation of a national electronic database of PPIE representatives, where public members can outline their interests, experience and desired involvement and contributions. This approach, in contrast to PPIE involvement where organisations rush to have 1 or 2 representatives to fulfil a requirement, was considered more collaborative and could build better trust between PRUK and the public. Participants highlighted that advertising on the PRUK website and other networks would limit the breadth of participants to those who are already involved in PPIE roles. To reach a more inclusive segment of society, local health boards and local authorities could help advertise roles and PRUK could collaborate with local community organisations to provide short-term internships. It was proposed these might be fixed-term full or part-time positions that would allow public representatives to have a larger, more substantial role in contrast to participating in one-off workshops. There was some discussion around whether public

representatives should be remunerated or not, with a general consensus that the public deserve to be paid for their contributions.

## **Topic 2: Facilitate linkage between LPS data and health, administrative and further types of data**

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There was a positive and enthusiastic response about the potential of data linkage. However, there were some immediate concerns that reflected three key findings from the scoping review: the desire to understand data linkage governance and consent, the fundamental need for all PRUK research/linkage to be for public benefit and transparency in what data is being linked.

First, participants were concerned about the dangers of re-identification of participants, and possible misuse or exploitation of data. To avoid these risks, participants suggested that PRUK must develop a robust governance and consent model for data access and linkage. There was curiosity about the ethics and logistics of linking, including what standard operating procedures and data safety measures would look like and whether other big data organisations were already doing what PRUK has proposed. For example, it was questioned how PRUK could merge two or more datasets with different consent models and if data linkage could take place within Trusted Research Environments (TREs) instead of researchers being provided with physical copies of the data. Participants suggested that cohort members from LPS should be involved in open consultation with PRUK to develop these procedures and ensure understanding of what consent means in data linkage. This could help participants retain a sense of control of their data. There was a brief discussion around whether consent for data sharing should be one-time acquisition and how ill-health or age-related cognitive decline may impact consent.

Next, several participants reinforced that any data linkage must be done for the benefit of the public. Failure to do so could create public mistrust in PRUK, and individual participants may wish to withdraw their consent for PRUK to share their data. One tangible suggestion to improve trust was for PRUK to effectively communicate the governance regulation and the processes involved in data linkage. This transparent approach could be beneficial in pre-empting any concerns that the public may have about linkage and could create more opportunities for the public to get involved. Several participants spoke about the need for this communication to be delivered in a common language that people understand. It was recommended that individuals with a wide range of backgrounds be sought to create accessible materials and terminology.

## **Topic 3: Sustain public trust and transparency in LPS data sharing (R4)**

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Consistent with the findings of the scoping review and observations on access and linkage above, transparency of data governance and ensuring the public benefit of any research were recognised as the most crucial aspects in building and sustaining public trust in PRUK. Three pathways were identified that could help build and sustain this trust: accountability, avoiding misinformation and reaching diverse public audiences. First, PRUK must ensure accountability by continual evaluation to ensure their work adheres to the original vision and aim. There must be a willingness of PRUK to

constantly adapt and evolve so that the public benefit is at the forefront. Involving public representatives and publicising results from evaluations will help build and sustain trust.

Next, the potential of misinformation and the resulting repercussions were discussed. Misinformation can stem from ambiguity and thus PRUK should aim to educate the public about its aims, governance processes and research from its inception. PRUK can learn from the stark difference in public perception between the NHS (high trust) and the government (high scepticism and mistrust), with some participants suggesting that PRUK has the advantage of being seen more similarly to the NHS than the government. It is important that PRUK publicises themselves as an organisation who cares about the people and make it very clear its main aim is to support research that will help the public. On the other hand, participants cautioned that PRUK could immediately, and possibly permanently, lose public trust if there is any misuse of data (e.g. the Cambridge Analytical scandal was given as an example).

Finally, there were valuable discussions across both breakout groups about how PRUK can reach diverse and marginalised groups. Participants largely agreed that public involvement and engagement can be seen as a 'secret club', where only select individuals can share and contribute their perspectives. To reduce this stigma, prioritise transparency and reach more diverse groups, PRUK must carefully evaluate how information is disseminated. One suggestion was that material can reflect the same key information, but should be altered to reflect the target population (e.g. social media for younger adults, non-digital mediums for older adults). There were several suggestions that early engagement in primary school environments could be a sustainable way to fulfil the long-term strategic goal of PRUK reaching all parts of society. As an upstream approach, in-school activities in early years could embed the benefits of population research and PRUK for each new generation. Another way to target young people was to provide short-term internships or opportunities for those aged 16-17, who are old enough to have some responsibility, and may be able to meaningfully contribute to PRUK.

#### **Topic 4: Maximise the connectedness of LPS with the wider research, innovation and policymaking ecosystem (R6)**

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The possibility of linking LPS data to government or third-party operations was met with a high level of concern, with no positive discourse. Consistent with differing public perceptions of the NHS and the government above, participants were reluctant for data from LPS to be connected with the government. The reaction to the potential of government and third-party involvement highlighted a sense of mistrust of the motives of those groups, removal of control from the public, and a lack of data science standards. This contrasted the clear trust that participants have in scientists, doctors and academics. Many expressed concerns with commercial organisations, such as pharmaceutical companies, private health providers and health insurance companies, who could misuse or interpret LPS data in a way that could be used against the public (e.g. deny health insurance, raise commercial prices, etc.). Sharing data without investigating the ethical standards of partner organisations and their intended use for the data was suggested as bad practice. When connecting LPS data with other organisations, PRUK should consider the same issues discussed above: for public benefit, clear governance processes in place and transparency. Specifically, participants wanted assurance of where their data would be used, clarity on the integrity of the data and clear boundaries in its use.

It was recognised that PRUK could build on recent initiatives related to public data (e.g. GDPR, NHS Digital, Covid-19 related research) that have raised public awareness on how data is used and shared across platforms.

## Implications for PRUK recommendations

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Many of the concerns and recommendations discussed in the workshop and raised in the survey were previously summarised in the scoping review and incorporated in the Green Paper. These include transparency throughout the entire life cycle of data use, ensuring public benefit, involving public and participant representatives in all stages of PRUK's work and educating and empowering the public about LPS. There were several additional recommendations and insight from the workshops that should be further considered for the final PRUK recommendations. These include:

- i. Create a national register of PPIE representatives, or utilise an existing one, to facilitate public contribution and perspective in all PRUK activities. This can improve the relationship between the public and PRUK, encourage meaningful contribution from diverse public groups and may be a more efficient approach compared to recruiting PPIE representatives only when needed (Topic 1).
- ii. Support the development of transparency on the data linkage process to educate and safeguard against existing public concerns; this includes recording and communicating any PRUK-facilitated data linkage to the public (e.g. via website) (Topic 2).
- iii. Early engagement with diverse public groups (e.g. schools, all ages, diverse groups) to educate about the benefit of LPS and PRUK (Topic 3).
- iv. Conduct further consultation to understand how concerns about commercial companies can be addressed. There is substantial scepticism on government and industry partners and no potential benefit was acknowledged. If PRUK moves forward without addressing this issue, this could impact the perception and public trust in PRUK (Topic 4).

## Appendix 1. Agenda – public perspectives workshop

Time	Item	Lead	Paper
1.30pm	<p><b>Introduction to PRUK and</b> Presentation on the background of Population Research UK (PRUK), and the aims and objectives of this research initiative</p> <p>Time to ask any clarifying questions and share immediate thoughts.</p>	Alice Dowden (Public Engagement and Involvement Officer, HDR UK) and James Pickett (Hubs Development Manager, HDR UK)	
1.45pm	<p><b>Green Paper discussion</b> Move into breakout rooms to discuss recommendations for PRUK in detail. Attendees will be presented the information and are encouraged to refer to their glossary as needed.</p> <p>Discussing overarching questions on:</p> <ul style="list-style-type: none"> <li>• What are their concerns about PRUK?</li> <li>• What do the public need to have confidence in the activities of PRUK?</li> <li>• What do the attendees see as the public benefit of PRUK?</li> </ul>	Alice Dowden (Public Engagement and Involvement Officer, HDR UK) and Sinduja Manohar (Public Engagement and Involvement Manager)	<ul style="list-style-type: none"> <li>• PRUK information slides</li> <li>• PRUK glossary</li> </ul>
2.50pm	<p><b>Group discussion on key conversations</b></p> <p>Facilitators to share highlights from between the breakout groups Attendees are welcome to share any other additional thoughts or comments</p>	Alice Dowden (Public Engagement and Involvement Officer, HDR UK) and Sinduja Manohar (Public Engagement and Involvement Manager)	
3.00pm	<b>Next steps and close of meeting</b>		

## Appendix 2. Summary of PRUK public perspectives survey and links to responses

Of the 37 survey respondents, over 10% indicated that they had been part of a cohort or longitudinal study, and nearly 50% indicated that they had participated in research, for example a clinical trial. PRUK public perspectives survey. The completion rate was 62% - 31/37 completed parts of the survey. Summary graphs and proportions for the multiple choice questions on prior PPIE involvement and the level of support and concern for each of the four topics can be found at: <https://www.hdruk.ac.uk/wp-content/uploads/2021/09/Population-Research-UK-Understanding-Public-Perspectives-survey-graphs-and-full-responses.xlsx>.

### Topic 1: Streamline data access processes and mechanisms (R2)

When asked whether they could see the benefit to the public in PRUK streamlining access to datasets for research, just under three quarters of survey respondents said they strongly agreed with the statement. Only one respondent indicated that they somewhat disagreed. When asked to indicate whether they are concerned about streamlining access to datasets for research, 25% of respondents said that they somewhat agreed with this statement, while just under 60% said that they neither agreed nor disagreed or that they somewhat disagreed, showing that there is some public cautiousness around streamlining access.

The follow up question of ‘what might help you and the wider public have confidence in PRUK streamlining and improving access to datasets for research’, survey respondents said that there needs to be accessible and clear educational resources available which explains how the data will be used, the safeguards in place and what is meant by streamlining data access. The need to improve public awareness on the benefits of research in general was also highlighted, and that all activities around data access and improving access should be transparent and easily accessible to the public. Finally, respondents also suggested that PRUK helps to reduce duplication of work, and therefore any linkage should be clearly recorded and communicated to the public and the research community.

### Topic 2: Facilitate linkage between LPS data and health, administrative and further types of data (R3)

Respondents were asked whether they could see the benefit to the public in PRUK helping to facilitate linkage of LPS data and other types of data, including health and administrative data for research, with just over 90% of respondents indicating they either somewhat or strongly agreed with the statement. 33% of respondents said they had concerns about linkage between different types of datasets for researchers compared to nearly 60% who did not.

The follow up question of ‘what might help you have confidence in PRUK facilitating linkage of LPS data with other types for research’ focused on the importance of tracking all data sharing rigorously and ensuring that researchers and organisations are held accountable for the safe and legal use of

data. They also highlighted that the public may be concerned about linkage enabling individuals to be identified, so PRUK should make sure that this is not possible, and that this is clearly communicated to the public. Respondents also raised concerns about data standardisation and stated that work needs to be done to ensure that different datasets are compatible for linkage. A strong theme in this area was the importance of a clear communications strategy around why PRUK is carrying out its activities.

### **Topic 3: Sustain public trust and transparency in LPS data sharing (R5)**

Respondents were asked whether they could see the benefit to the public in PRUK playing a leading role in building and sustaining public trust and transparency in LPS data sharing and hearing how the public want to be involved. Over 90% of respondents strongly or somewhat agreed with this statement, and when asked whether they were concerned with PRUK playing this role over 55% somewhat or strongly disagreed. Just over 20% indicated that they somewhat or strongly agreed that they concerned about PRUK playing this role.

When exploring what might help the public have confidence in PRUK playing this role in building and sustaining public trust and transparency in LPS data access, many people stated that PRUK needs to ensure proper governance of data use and clearly articulate its goals and strategy for achieving them to the public. It was also stated that PRUK should show that they understand the lack of public trust in data sharing due to previous scandals such as the GDPR dataset by listening to concerns and engaging with diverse groups and communities to help build trust. Providing information on who can access data and why, and ensuring that there are plain English summaries and public facing information will be vital if PRUK wants to position itself as a trusted voice in LPS data research. One suggestion for supporting this goal was to develop a patient data ambassador role at PRUK, where members of the public are involved from day one with the project.

### **Topic 4: Maximise the connectedness of LPS with the wider research, innovation and policymaking ecosystem (R6)**

Respondents were asked whether they can see benefit to the public in PRUK working to maximise the connectedness of LPS with the wider research, innovation and policymaking ecosystem, with over 85% stating that they somewhat or strongly agreed with this statement. When asked whether they were concerned about PRUK working to maximise connectedness of LPS with wider research, just over 30% agreed with this statement, while over 50% disagreed, indicating that there is a difference of opinion on PRUK playing this role.

We asked respondents what PRUK could do to help them have confidence in PRUK playing this role, and a clear theme that came through was the importance of explaining who they are working with, how and why. It was also raised that PRUK should be transparent about how industry partners might benefit from working with PRUK i.e., whether they or we would benefit financially. There is a strong mistrust in commercial organisations being involved, as the public are concerned about misuse of

data and any conflict of interest as a result of working with companies. Some survey respondents always raised that this type of activity will require large capacity and resources within PRUK, so stressed that this should be properly considered and funded. Finally, it was clear from the survey that the public feel that patients and the public should be front and centre in this area to ensure that these relationships are explained to and considered by public representatives, and that PRUK should regularly communicate about these relationships and that they are for public benefit above all else.

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