HDRUK
Health Data Research UK

Public and Participant Involvement in Population Research UK (PRUK): A scoping review of different approaches and recommendations

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Table of Contents

Executive Summary

The aim of this scoping review was to develop a set of recommendations for Population Research UK (PRUK) on their approach to participant and public involvement and engagement (PPIE). Information from 18 relevant reports were found and analysed by searching research databases, the grey literature and through stakeholder input. The following recommendations are based on the identified themes related to PPIE in data linkage using longitudinal population studies (LPS): Transparency, Public benefit, Acceptability, Two-way dialogue, Opportunities and mechanisms for decision making, and Education. Building trust was identified as an overarching goal underlying the PPIE activities.

1. Prioritise transparency throughout the entire life cycle of data use

Transparency of the full life-cycle of data sharing and linkage was seen as essential to building and maintaining trust in those practices. Transparency can be achieved by maximising publicly accessible information on data governance, access and use, and including PPIE representatives on all panels that govern these processes.

2. Recognise the evolving definition of public benefit

Use of data was seen as acceptable if it provided benefit to the public. With differing views between various public groups, researchers, stakeholders and PRUK, the definition should be continually broadly agreed upon and piloted or tested against potential harms during the development phase and for any future research or data linkage projects it over sees. This should be the standard to which all PRUK research is done.

3. Engage to understand perceptions of third parties and industry partners

PRUK should further engage with both the general public and LPS members to better understand perceptions on third parties and industry partners accessing LPS data and how the challenge of negative perceptions could be addressed. Individual LPS may be able to facilitate these relationships to improve public and participant trust in PRUK.

4. Involve the public at all stages of PRUK’s work

Promoting two-way dialogue at every stage of the data journey will enable the public to be involved in governance, shaping research priorities and improving the quality of research projects. In addition to providing opportunities for involvement and decision making, PRUK should build in mechanisms for change in response to PPIE activities and feedback.

5. Support individual longitudinal and population studies in their PPIE activities

PRUK should support LPS in their PPIE activities, for example by providing training, resources, evaluation tools, and by providing PPIE standards in order to advance the field of population research and build public trust.

6. Consider a national education strategy or campaign

National education and awareness campaigns can allow PRUK to be positioned as a national leader in population research, aiming to inspire and support the public, individual researchers, data organisation and longitudinal population studies. Campaigns should be co-designed with the public to ensure accessibility and to more effectively engage with diverse and historically neglected groups.

Introduction

Population Research UK (PRUK) is a new research initiative that aims to bring data from the UK's rich collection of longitudinal and cohort studies together, making them more discoverable and accessible to researchers and to promote data linkage. A key part of the development is to determine the role of patient and public involvement and engagement (PPIE) in PRUK.

PPIE is most commonly used to refer to Patient and public involvement and engagement. In the context of longitudinal population studies and this review, it is used to represent participant and public involvement and engagement. The relevance of 'patient' is not always relevant in the context of LPS, and it is important to recognise that the views of study participants may be different to those of general public.

PPIE is a central component to health research comprising a range of activities: *involvement* typically occurs when members of the public take a role in the activities of a research project or data organisation (for example providing feedback on public facing information materials, or sitting on decision making committees) whereas *engagement* often refers to activities where information about the research is disseminated to members of the public (National Institute for Health Research 2019). A collaborative definition of public engagement is proposed by The National Co-ordinating Centre for public engagement: "…a two-way process, involving interaction and listening, with the goal of generating mutual benefit" (National Co-ordinating Centre for Public Engagement 2021).

One of the challenges for PRUK to develop their PPIE strategy is that the types of PPIE traditionally reported on for individual longitudinal and population studies (LPS) focus on recruitment and retention, which may not be relevant to meta-activities. PRUK must ensure it widens the scope of population studies rather than replicating or taking over what the individual LPS are doing. Meta-activities refer to activities which are not directly involved in research projects, and are one-step removed from the research participants. The reason we draw this distinction is to be able to draw a narrower focus on literature relevant to Population Research UK (PRUK) which will be facilitating and conducting research utilising the wealth of longitudinal and population study data but not directly liaising with participants.

There has already been a significant volume of research on the best approaches to PPIE in longitudinal studies and regarding data linkage practices. The aim of this report was to gain an understanding of previous approaches to PPIE activities with LPS and data linkage and to better understand what best practice approach Population Research UK (PRUK) should take for public and participant involvement. There were four key questions:

1. What is the role of a meta-activity such as PRUK?
2. How can it operate in a way that builds public trust?
3. If, and how it should involve the public in its decision making?
4. How to support a wider understanding of the longitudinal studies?

The findings from this report will be used to generate a set of recommendations for PRUK to consider during its development and to guide further PPIE scoping activities.

Methods

Our approach followed the scoping review methodology of Arksey and O'Malley (2005), which outlines the steps to identify relevant information, analyse the data and consult with stakeholders.

Identifying relevant information

Search strategy

Relevant literature was obtained through three methods: 1) primary literature search of research databased and subject specific journals; 2) grey literature search and 3) recommendations and suggestions by stakeholders. A combination of keywords and subject headings were used to search Medline and Web of Science on the 8th of April 2021 (Box 1). We searched three subject specific journals (Research for All Journal, Research Involvement and Engagement, and International Journal of Population Data Science) to identify any additional papers.

Box 1. Example search strategy (Web of Science)

PPIE or "patient involvement" or "public involvement" or "public engagement" or "patient engagement"

AND

data linkage or longitudinal or cohort or "population study

The grey literature search involved searching list of specific websites identified by the stakeholders. These were: CLOSER, Health Data Research UK (HDRUK), Administrative Data Research UK (ADRUK), Dementia Platforms UK (DPUK), Health Data Service, Clinical Practice Research Datalink (CPRD), Office for National Statistics (ONS), Secure Research Service, UK Data Service, HMRC DataLab, The Secure Anonymised Information Linkage (SAIL) DataBank, The electronic Data Research and Innovation Service (eDRIS). Further articles and reports were found by running a Google advanced search with the same search terms in Box 1 and screening the first 200 results. Finally, the reference lists of all included reports were searched to find any further relevant reports and papers.

Screening

The inclusion criteria for articles and reports were public or participant involvement as the main topic of the report, refers to work undertaken in the UK, and contains information relevant to best-practice for public and participant involvement. We excluded reports which describe public and participant involvement for a specific study or for specific health services, direct evaluation of PPIE activities and those focused on consent and privacy. Appendix 1 outlines how we identified and selected articles for inclusion in the analysis. After de-duplication, we screened 745 records for inclusion, of which 30 were assessed in-depth for eligibility. A total of 18 articles and reports were included in the qualitative narrative synthesis (Table 1.).

Analysing the data

A semi-structured data extraction form was created to collect data on descriptive information of the sources in addition to the principles and best practice for PPIE. Once the data were extracted, a qualitative narrative synthesis of the findings was conducted independently by two reviewers. Common themes were then discussion and identified and a list of recommendations was developed in relation to research questions (Clarke and Braun 2014).

Consultation with stakeholders

Consultation with stakeholders occurred throughout the project. The initial invitation to tender was co-produced with lay members and the research question and scope of the review was agreed upon with James Pickett, the hub development manager at HDRUK. Two public members of the project participated in identifying additional sources of evidence, and interpreting and appraising the evidence. Feedback on preliminary findings were sought from a wider range of stakeholders including public engagement and involvement officers at HDRUK and key partners of PRUK.

Table 1. Summary of articles and reports included in the review

Author	Institution/Organisation	Title	Type
Aitken et al. (2016)	University of Edinburgh and the Scottish Health Informatics Programme	Moving from trust to trustworthiness: Experiences of public engagement in the Scottish Health Informatics Programme	Journal article
Aitken et al. (2019)	University of Edinburgh	Consensus statement on public involvement and engagement with data-intensive health research	Journal article
Atkinson et al. (2017)	Dementias Platform UK	Ethical, legal and social issues in dementia research	Report
Beange et al. (2020)	University of Edinburgh	Using a knowledge exchange event to assess study participants' attitudes to research in a rapidly evolving research context	Journal article
Elias (2021)	University of Warwick and Economic and Social Research Council	Promoting public engagement with longitudinal research	Report
Genomics England (2015)	Genomics England	Earning Trust: Public Engagement and Patient Involvement Strategy	Strategy
Health Data Research UK (2020)	Health Data Research UK	Communications, Engagement and Involvement Strategy 2020/2023	Strategy
Health Data Research UK (2021)	Health Data Research UK	Pioneering data research centres enable cutting-edge research and innovation and improving lives	Report
Hopkins Van Mil (2021)	National Data Guardian, Understanding Patient Data, Sciencewise, and UK Research and Innovation	Putting Good into Practice: A public dialogue on making public benefit assessments when using health and care data	Report
Jones et al. (2020)	Swansea University and SAIL Databank	Public involvement & engagement in the work of a data safe haven: a case study of the SAIL Databank (Including Jones, K. (2020). SAIL Databank: Public Involvement and Engagement Policy)	Journal article and Policy
Kispeter (2019)	Warwick Institute for Employment Research, University of Warwick	Public support for accessing and linking data about people from various sources: Literature review	Report
Mitchell et al. (2021)	PHG foundation	The ethical and legal framework for a Genomics England and Sano Genetics participant engagement platform	Report
Reed et al. (2018)	Newcastle University	A common standard for the evaluation of public engagement with research	Journal article
Scott (2018)	Involve, Carnegie UK Trust and Understanding Patient Data,	Data for Public Benefit: Balancing the risks and benefits of data sharing	Report
Understanding Patient Data (2018)	Understanding Patient Data	Public attitudes to patient data use: A summary of existing research	Slide deck
Understanding Patient Data (2020)	Understanding Patient Data	Public attitudes to the use of patient data Sept 2019-Sept 2020	Slide deck
Waind (2020)	Administrative Data Research UK	Trust, Security and Public Interest: Striking the Balance; A review of previous literature on public attitudes towards the sharing and linking of administrative data for research	Report
Wilson et al. (2015)	University of Hertfordshire	ReseArch with Patient and Public invOlvement: a RealisT evaluation – the RAPPORT study	Journal article

Results

In this section, the findings of the literature review are presented for each of the four research questions outlined previously. Six key issues emerged that are necessary to appropriately guide the goals and practices of meta-activity PPIE (outlined in Figure 1): 1) transparency 2) public benefit 3) acceptability of researchers and data organisations, 4) opportunities for decision making, 5) mechanisms for decision making, and 6) education. A key theme running through each of these is building trust which underpins all PPIE activities. Each is described in greater depth in the following sections, with accompanying specific recommendations for PRUK.

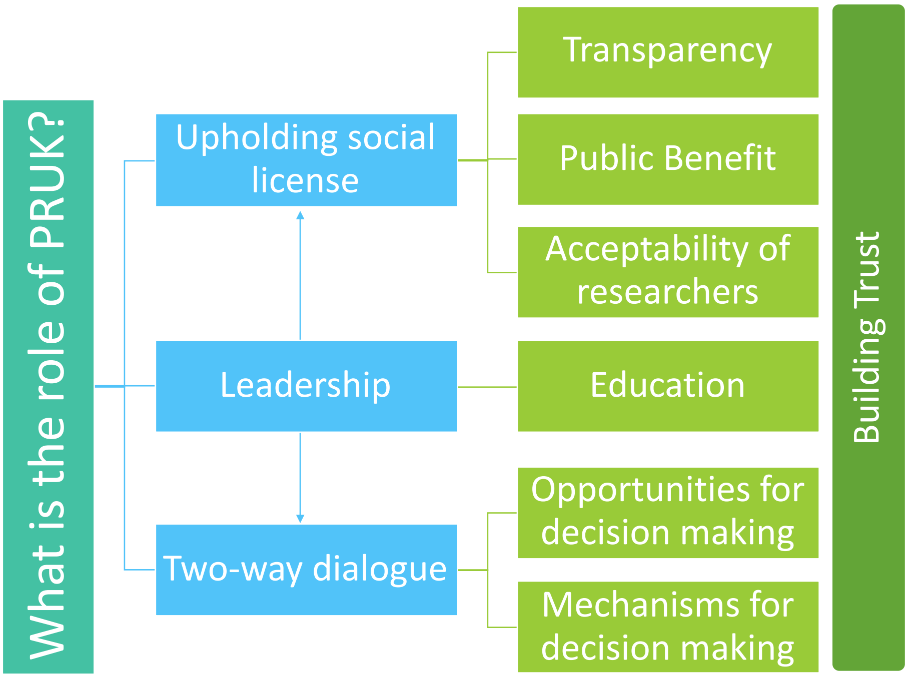


Figure 1. Themes identified in the literature about PPIE activities related to LPS and data linkage

1. What is the role of a meta-activity such as PRUK?

Together, the six themes outline a clear role for a meta-activity such as PRUK in sustaining public support toward population data sharing and linkage, and maximising the quality and impact these activities can have. These activities can be broadly grouped into the three categories below.

Upholding the social license

Reviews summarising the last decade of public attitudes toward data linkage and sharing have described the existence of 'a social license' needed to legitimise the use and linkage of personal information for research (Elias 2021, Jones et al. 2020, Waind 2020). A social licence emphasises the responsibility of any organisation to meet the "expectations of society regarding the conduct and activities that go beyond the requirements of formal regulation" (Carter et al. 2015). This includes demonstrating *transparency*, ensuring data use brings *public benefit* and ensuring the *acceptability of the researcher or data organisation* partner; question 2 (page 8) explores each of these areas in further detail. As public attitudes towards data continue to change, PRUK may need to constantly generate new data on the current social licence and ensure that this is reflected in current and future practices (Aitken et al. 2019). To sustain its practices, PRUK must lead on upholding the social license for them.

Two-way dialogue

There has been a clear shift away from the one-way transfer of information to the public toward a two-way dialogue; deepening understanding of what the public wants regarding research that uses their data and ensuring that they are central to decision making around it (Elias 2021, Waind 2020, Wilson et al. 2015). Encouraging debate with the public to identify the meta-activity's research priorities can maximise public benefit of the work and therefore the sustainability of meta-activity practices (Aitken et al. 2019, Genomics England 2015). One fundamental aspect needed to deepen conversations is to seek engagement and involvement with new and more diverse groups, focusing on specific communities relevant to the research (Aitken et al. 2019, Waind 2020). See question 3 (page 8) for detailed findings on how PRUK can involve the public in its decision making.

Leadership

PRUK has the opportunity to position itself as a national leader in best practice for population research PPIE. Rather than replicating the PPIE activities of individual studies, PRUK should seek to support, challenge and address gaps in the reach of current PPIE activities. PPIE activities led by individual LPS have focused on their study members, who have understanding of population research through their direct involvement in their study. This leaves a large gap in public understanding of longitudinal research, including its aims, users, data governance regulation, and potential for public benefit (Atkinson et al. 2017, Elias 2021, Genomics England 2015, Kispeter 2019, Scott 2018, Waind 2020). PRUK can lead on national activities aimed to educate the public about longitudinal research, which will contribute to public trust and acceptability of the meta-activity. There was little evidence on how PRUK can support individual LPS. This would require further discussion with studies to determine if and how they could benefit from PRUK-provided training and tools aimed to inspire and facilitate PPIE activities. Support could also include setting clear standards by which individual studies should include public representatives in their decision making and engage the public to share study results. See question 4 (page 10) for detailed findings on how PRUK can support a wider understanding of the longitudinal studies.

2. How can PRUK operate in a way that builds public trust?

Existing reviews have articulated the conditions necessary for the public to trust and support data linkage and sharing by meta-activities. Broadly, the public have asked for transparency of research and governance processes, acceptability of the organisation using the data, and for assurance that data use is for public benefit (Kispeter 2019, Scott 2018, Waind 2020). The sections below detail findings on these three conditions and meta-activity PPIE practices designed to sustain them.

Transparency

Existing meta-activities proposed that PPIE activities make visible the full life-cycle of data sharing and linkage (Aitken et al. 2016, Aitken et al. 2019, Atkinson et al. 2017, Elias 2021, Hopkins Van Mil 2021, Jones et al. 2020). This strategy is based on the need for greater transparency about data governance, reasons for use and identification of users, which are the main conditions for public trust of data linkage practices (Aitken et al. 2019, Atkinson et al. 2017, Elias 2021, Kispeter 2019, Scott 2018, Waind 2020). Providing more information to individuals can directly increase public trust; this was shown both between groups and within the same individuals over a single session or workshop (Atkinson et al. 2017, Elias 2021).

An example of a minimum level of PPIE is transparent guidance on data protection practices and standards require for all data applicants; this may be publicly visible through websites or disseminated through LPS to participants (Aitken et al. 2019). Several meta-activities publish requests for data access online (including those refused) and encourage and respond to public requests for information in a timely manner (Genomics England 2015, Health Data Research UK 2021). ADR UK additionally suggested more interactive public seminars and festivals built around data sharing and linkage (Waind 2020). Some meta-activities increased transparency by using PPIE input to create information materials designed to be most understandable and accessible to a variety of audiences (Aitken et al. 2019, Elias 2021, Hopkins Van Mil 2021).

Beyond a one-way information transfer, several meta-activities collaborated with members of the public to shape their data protection processes (Aitken et al. 2016, Jones et al. 2020). Genomics England (2015) state "The 100,000 Genomes Project is built on their data so we think that participants should be the people most closely involved in assuring that the data is being properly protected." However, the best practice for PPIE in transparency was through facilitation of public decision making. For example, data access criteria used by HDRUK were agreed upon with PPIE representatives (Health Data Research UK 2021), while the Access Review Committee for Genomic England (Genomics England 2015) involves PPIE representatives in all data access applications. Further discussion on PPIE involvement in PRUK decision making is addressed on page 8.

Public benefit

Demonstrating the public benefit of any data use is paramount; public and study participants were far more comfortable with data being used outside of its original purpose if the reason for research had clear public benefit (Hopkins Van Mil 2021, Kispeter 2019, Waind 2020). The clearer and more tangible the value to the public, the greater the acceptance of meta-activity practices (Waind 2020). Notably, there is no consensus on the definition of public benefit, which can differ substantially between the public and the researchers. Furthermore, as the definition of public benefit may change over time and with specific research projects, there should be continual discussion between PPIE representatives and the meta-activity.

Engagement with specific subgroups can improve understanding for meta-activities of issues important to those directly affected by the research (Waind 2020). Workshops with PPIE experts (Aitken et al. 2019) spoke to the importance of varying recruitment practices to reach diverse and unheard perspectives, and of continually rotating the membership of lay panels to allow new voices to be heard (Wilson et al. 2015). It was perceived as helpful, especially for smaller research groups, for the meta-activity to identify appropriate PPIE representatives for such conversations (Aitken et al. 2019, Wilson et al. 2015). These conversations ranged from simply asking the public if they agreed with the value of pre-defined research questions to more collaborative attempts to stimulate open debate on what constitutes 'research in the public interest' (Aitken et al. 2019, Beange et al. 2020, Wilson et al. 2015).

There is a strong public desire for meta-activities to better communicate the anticipated public benefit of all research linkage projects (ESRC) and to follow up with the findings and notable impact (Atkinson et al. 2017, Hopkins Van Mil 2021). The general public and members of lay meta-activity panels reported that they often hear about potential research benefits, but there is a gap in dissemination of the outcomes and impact of each project (Aitken et al. 2019, Wilson et al. 2015). Lay members report feeling 'disengaged and disenchanted' (Wilson et al. 2015) by the lack of follow up on work they have contributed to. Appropriately disseminating this knowledge and sharing research stories of how the effective use of data has delivered benefit is essential for winning and sustaining public support for data linkage research (Elias 2021, Understanding Patient Data 2018, Understanding Patient Data 2020). This is discussed further on page 10 on how PRUK can support a wider understanding of the longitudinal studies.

Acceptability of researchers and data organisations

The acceptability of researchers and data organisations emerged as an important, yet complex issue. Public and LPS members are largely trusting of universities and NHS using the data, as there is a widespread belief that they are motivated by public benefit (Aitken et al. 2016, Atkinson et al. 2017, Elias 2021, Kispeter 2019). There is greater suspicion of any third-party organisation sharing the data, with minimal public acceptability for industry partners (Atkinson et al. 2017, Beange et al. 2020, Kispeter 2019). Given that meta-activities are viewed by the public as unfamiliar third-party organisations, this is a considerable obstacle that PRUK must overcome.

There were inconsistent reports of how LPS members felt about their data being shared through a meta-activity. For example, some believed that they had not given consent for secondary use of their data (Atkinson et al. 2017), while others did not believe future data use should be restricted to its original purpose if it could bring public benefit (Hopkins Van Mil 2021). Although individual LPS will engage with their members on this issue, PRUK could partner with LPS to improve members' understand of the potential uses of their data and encourage further acceptance and enthusiasm for PRUK (Mitchell et al. 2021). One mechanism to improve acceptability of meta-activity practices is to create a review process whereby members of the public can ensure that meta-activity-based research reflects understanding of the conditions under which the public are comfortable with data use (Jones et al. 2020, Mitchell et al. 2021).

Recommendations

1) **PRUK should prioritise transparency throughout the entire life cycle of data use**; this should include publicly available information and PPIE representatives on all panels that govern data access, security and use.
2) **PRUK should recognise the evolving definition of public benefit during the development phase and for any future research or data linkage projects it over sees**. With differing views between various public groups, researchers, stakeholders and PRUK, the definition must be continually, broadly agreed upon and piloted or tested against potential harms. This should be the standard to which all PRUK research is done.
3) **PRUK should further engage with both the general public and LPS members to better understand perceptions on third parties and industry partners and how these challenges can be overcome**. Individual LPS may help facilitate these relationship to improve public and participant trust in PRUK.

3. How should PRUK involve the public in its decision making?

Two-way dialogue

Reports strongly emphasise the necessity for PPIE to move away from a one-way transfer of information towards a non-hierarchical and dynamic two-way conversation. A common model of PPIE considers a spectrum of participation which demonstrates the different ways in which public participation can inform, consult, involve, collaborate and empower the public (International Association for Public Participation 2018). This spectrum of participation can be a useful way to define the specific type of PPIE activity taking place. Although it has been previously argued that collaborative approaches should always be preferred, there is increasing acknowledgement that the choice of PPIE activity taken should first and foremost be aligned with the context and purpose (Reed et al. 2018). Across all reports included, interactive PPIE was identified as best practice, given the potential of PPIE as a "model of partnership synergy… where the sum of the whole (PPI and researcher working together) is greater than the sum of its parts" (Wilson et al. 2015). Involving the public in its decision making will further allow PRUK to build trust by ensuring the principles of transparency, public benefit and acceptability of the researcher/data organisation identified above.

Opportunities for decision making

As reported in earlier sections, existing meta-activities aspire for public decision-making to be sought out early and used continually throughout the cycle of the data linkage activities (Aitken et al. 2019). In addition to wider public feedback guiding decision making, lay members should be considered as colleagues central to decision-making rather than as an adjunct to the process (Wilson et al. 2015). Three main areas emerged in which decision making should involve the public: to establish governance and approve data access, to guide research priorities to maximise public benefit, and finally, to support researchers and data organisations in shaping their research questions and projects. For the latter, PPIE can improve the quality of the research by gathering public input on the proposed research questions and design, which often identified issues overlooked by researchers (Waind 2020, Wilson et al. 2015). This may include workshops or roundtable discussions with relevant communities, an ongoing feedback panel available for each research priority, and an outreach model in which a lay member act as a bridge between the data organisations and their broader community (Wilson et al. 2015).

To ensure transparency, build trust and improve the quality of research, PRUK should involve PPIE representatives on all panels. Examples of PPIE in panels for other meta-activities map well onto the three main areas in which decision making should involve the public: a *Participant, Public, Consumer Panel*, which ensures the data is used in the best interest of the participants (Aitken et al. 2019, Genomics England 2015, Jones et al. 2020, Mitchell et al. 2021); a *Data Access, Data Management or Access Review Committee,* to provide assurance on data access requests (Atkinson et al. 2017, Genomics England 2015, Hopkins Van Mil 2021); a *Co-Development Panel*, to aid in shaping research questions and translating research (Health Data Research UK 2021).

Mechanisms to support public decision making

For a true collaboration between the public and the researcher or organisation, there must be formal mechanisms that ensure 1) the public is heard, 2) PPIE meaningfully contributes at all stages of PRUK-based activities and 3) processes, including PPIE involvement, are continually evaluated and improved (Atkinson et al. 2017, Jones et al. 2020, Wilson et al. 2015). There is value in equipping PPIE representative with knowledge and skills to ensure they are confident to engage in discussion with researchers on their purpose, designs and potential harms (Aitken et al. 2019). Dialogue between researchers or organisations and PPIE representatives must allow appropriate space and time for genuine conversations to ensure that individuals are "…encouraged to ask questions and...provided with digestible information and adequate consideration time" (Jones et al. 2020). Consenus in these conversations is not necessarily the goal, as healthy discussion can be beneficial for both sides (Aitken et al. 2019). Given past concerns of non-accessible PPIE, it is important to involve PPIE representatives in the design and production of PPIE activities themselves to ensure activities reach a broad audience (Health Data Research UK 2020).

Several reports highlight that evaluation of PPIE is essential to ensuring that its goals can be met (Aitken et al. 2019, Reed et al. 2018, Wilson et al. 2015). Despite this, there is a clear gap with no evidence of evaluation of meta-activity-based PPIE activities. Some progress has been made in attempts to standardise evaluation (Reed et al. 2018), noting that the quality of PPIE can be enhanced by investing in evaluation training and capacity building. Dissemination of evaluation results are rare within individual studies, which prohibits any demonstrable improvements in public involvement or engagement activities. A meta-activity such as PRUK may have an important role as a leader in population to create an evaluation data repository to facilitate PPIE by individual longitudinal studies and enable lessons to be shared and acted on (Reed et al. 2018). While training of PPIE representatives is highlighted above, training of researchers about the benefits of PPIE may be needed to increase activities at a study-level. This may improve openness to both the moral significance and the methodological value of public contributors rather than PPIE being seen as ‘a problem to be overcome’ (Aitken et al. 2019, Atkinson et al. 2017, Wilson et al. 2015).

Recommendations

1) **The public should be adequately represented at all stages of PRUK’s initial development, concurrent management and ongoing coordination.** At a minimum, three panels are recommended:
    i. *Public or Participant Panel* to ensure that all PRUK activities and research are in the best interest of the public;
    ii. *PPIE representative(s) on a Data Access Committees* to provide transparency and assurance on all projects that access study data;
    iii. *PPIE representative(s) on a Research and Knowledge Translation Panel* in defining research at early stages and making it publicly accessible in the final stages.
2) **PRUK should support (e.g. training, resources, evaluation tools) individual studies in their PPIE activities, yet also set and create PPIE standards for which individual LPS must meet in order to advance the field of population research and build public trust.**

4. How can PRUK support a wider understanding of the longitudinal studies?

Education

The findings identified above regarding trust, transparency and the social license of data linkage and sharing underscore the need to communicate the public value of longitudinal studies, which will facilitate PRUK’s vision of population research linkage and data sharing. There is poor public understanding of longitudinal studies, their research practices and governance, and their potential for policy (Atkinson et al. 2017, Elias 2021, Genomics England 2015). Several reviews summarised that individuals find it hard to envisage non-laboratory based research; further, there as greater scepticism of the research value of social data that is viewed as ‘common sense’ knowledge (Aitken et al. 2016, Elias 2021, Kispeter 2019).

These findings emphasise the need to strengthen the social license for the linking and sharing of longitudinal studies. As described earlier, increasing knowledge can directly increase support of data linkage practices (Aitken et al. 2016, Atkinson et al. 2017, Kispeter 2019). There is a clear public desire for longitudinal research ‘success stories’ to better understand how such data can bring about public benefit (Kispeter 2019, Scott 2018). PRUK can play a role in educating the UK population through broader information campaigns, awareness raising activities, and education programmes (Elias 2021, Waind 2020). One example of a promising activity was the social media #datasaveslives campaign aimed to promote the positive use of data in health research on social media. The campaign was led by the Farr Institute for Health Informatics Research, a publicly funded UK-wide research collaboration between academic institutions and health partners, and demonstrated the feasibility and opportunity of using social media to communicate the use of data for public benefit (Hassan et al. 2021).

While there is online information on population research, there are crucial gaps in both the accessibility and the mode of dissemination. The literature highlighted the need for and the benefit of broader engagement events such as public seminars, non-scientific festivals, and knowledge exchange symposiums to communicate the potential public benefit that population research and data linkage can bring (Waind 2020). For example, the Wellcome Trust has funded several collaborative and interactive exhibits on longitudinal research at the Greenman Music Festival in Wales. These exhibits have had substantial impact on educating a non-traditional audience about UK LPS and how factors at all stages of life can impact health outcomes (Smith 2018). Non-traditional public engagement activities may help reach a larger and more diverse audience.

Activities that empower the public such as workshops, advocacy training, participatory appraisal or interactive exhibits may be more impactful than one-way education campaigns (Aitken et al. 2019). There is a need for accessible and inclusive resources with clear messaging styles and a wide selection of communication channels such as posters, visuals, animations, and documentaries (Aitken et al. 2019, Elias 2021, Hopkins Van Mil 2021, Understanding Patient Data 2018, Understanding Patient Data 2020). A wider range of public engagement events can allow non-traditional groups to be targeted (Hopkins Van Mil 2021, Kispeter 2019). Further, PRUK has the potential to reach minority groups that do not typically participate in LPS (Atkinson et al. 2017).

Recommendations

1) **PRUK should consider a national education strategy or campaign to clearly communicate to the public what population research is, how it benefits the public and provide sufficient information to address concerns about data linkage, security or access**. Such a campaign can allow PRUK to be positioned as a national leader in population research aiming to inspire and support the public, individual researchers, data organisation and longitudinal population studies. Campaigns should be co-designed with the public to ensure accessibility to all and to more effectively engage with diverse and historically neglected groups.

Conclusion

This scoping review collates a range of literature on the role of public and participant involvement engagement and highlights a range of recommendations for PRUK to consider. In doing so, it aims to answer four key questions involving the approaches that PRUK should take for public and participant involvement: the role of PRUK as a meta-activity, building public trust, involving the public in its decision making and supporting a wider understanding of longitudinal research. Five key themes emerged to answer these questions: transparency, public benefit, two-way dialogue, acceptability of the researcher or data organisation and education. Each theme is central to building public trust in population research, in PRUK and in present and future uses of LPS data.

Six key recommendations were provided, with additional recommendations throughout the report. However, there were several gaps that would benefit from further investigation. Evidence from meta-activities focused primarily on public involvement (e.g. PPIE representatives, panel members) rather than public engagement activities. If PRUK wishes to emerge as the UK leader on population research, they should liaise with PPIE representatives to better understand how public engagement events at a national level can be delivered in an accessible and widespread way. Additionally, there is strong reluctance for industry partners to access personal data for research purposes. PRUK should engage with the public to better understand under what conditions this is can be considered acceptable and how public acceptance and trust in such partners can be improved. Finally, PRUK should work with individual LPS to better understand how they can support them with PPIE activities and determine standards of PPIE involvement for any LPS involved in PRUK. The findings and recommendations in this report will be used to guide the development of future PPIE at PRUK, including the creation of topic guides for focus groups and other scoping activities.

References

Aitken, M., S. Cunningham-Burley and C. Pagliari (2016). "Moving from trust to trustworthiness: Experiences of public engagement in the Scottish Health Informatics Programme." Science & Public Policy **43**(5): 713-723.

Aitken, M., K. H. Jones, M. Kaarakainen, F. Lugg-Widger, K. McGrail, A. McKenzie, R. Moran, M. J. Murtagh, M. Oswald and A. Paprica (2019). "Consensus statement on public involvement and engagement with data-intensive health research." International Journal of Population Data Science **4**(1).

Arksey, H. and L. O'Malley (2005). "Scoping studies: towards a methodological framework." International journal of social research methodology **8**(1): 19-32.

Atkinson, S., S. Badger, R. Milne and C. Brayne (2017). Ethical, legal and social issues in dementia research, Dementias Platform UK.

Beange, I., E. J. Kirkham, S. Fletcher-Watson, M. H. Iveson, S. M. Lawrie, G. D. Batty, J. P. Boardman, I. J. Deary, C. Black, D. J. Porteous and A. M. McIntosh (2020). "Using a knowledge exchange event to assess study participants' attitudes to research in a rapidly evolving research context." Wellcome Open Research **5**: 24.

Carter, P., G. T. Laurie and M. Dixon-Woods (2015). "The social licence for research: why care. data ran into trouble." Journal of medical ethics **41**(5): 404-409.

Clarke, V. and V. Braun (2014). Thematic analysis. Encyclopedia of critical psychology, Springer**:** 1947-1952.

Elias, P. (2021). Promoting public engagement with longitudinal research: A report to the Economic and Social Research Council, Warwick Institute for Employment Research.

Genomics England (2015). Earning Trust: Public Engagement and Patient Involvement Strategy, Genomics England.

Hassan, L., G. Nenadic and M. P. Tully (2021). "A Social Media Campaign (# datasaveslives) to Promote the Benefits of Using Health Data for Research Purposes: Mixed Methods Analysis." Journal of Medical Internet Research **23**(2): e16348.

Health Data Research UK (2020). Communications, Engagement and Involvement Strategy 2020/2023.

Health Data Research UK (2021). Pioneering data research centres enable cutting-edge research and innovation and improving lives

Hopkins Van Mil (2021). Putting Good into Practice: A public dialogue on making public benefit assessments when using health and care data, National Data Guardian, Understanding Patient Data, Sciencewise, and UK Research and Innovation.

International Association for Public Participation (2018). Spectrum of Public Participation. Canada.

Jones, K. H., S. Heys, R. Thompson, L. Cross and D. Ford (2020). "Public involvement & engagement in the work of a data safe haven: a case study of the SAIL Databank (Including Jones, K. (2020). SAIL Databank: Public Involvement and Engagement Policy)." International Journal of Population Data Science **5**(3).

Kispeter, E. (2019). Public support for accessing and linking data about people from various sources: Literature review, Warwick Institute for Employment Research, University of Warwick.

Mitchell, C., T. Brigden and A. Hall (2021). The ethical and legal framework for a Genomics England and Sano Genetics participant engagement platform, PHG foundation.

National Co-ordinating Centre for Public Engagement. (2021). "What is public engagement?" Retrieved 30th April 2021, from https://www.publicengagement.ac.uk/about-engagement/what-public-engagement.

National Institute for Health Research (2019). Going the extra mile: Improving the nation's health and wellbeing through public involvement in research.

Reed, M. S., S. Duncan, P. Manners, D. Pound, L. Armitage, L. Frewer, C. Thorley and B. Frost (2018). "A common standard for the evaluation of public engagement with research." Research for All **2**(1): 143-162.

Scott, K. (2018). Data for Public Benefit: Balancing the risks and benefits of data sharing, Involve, Carnegie UK Trust and Understanding Patient Data, .

Smith, K. (2018). Einstein's Garden Society Award: Individual Project Reports 2017: Tangle, Einstein's Garden

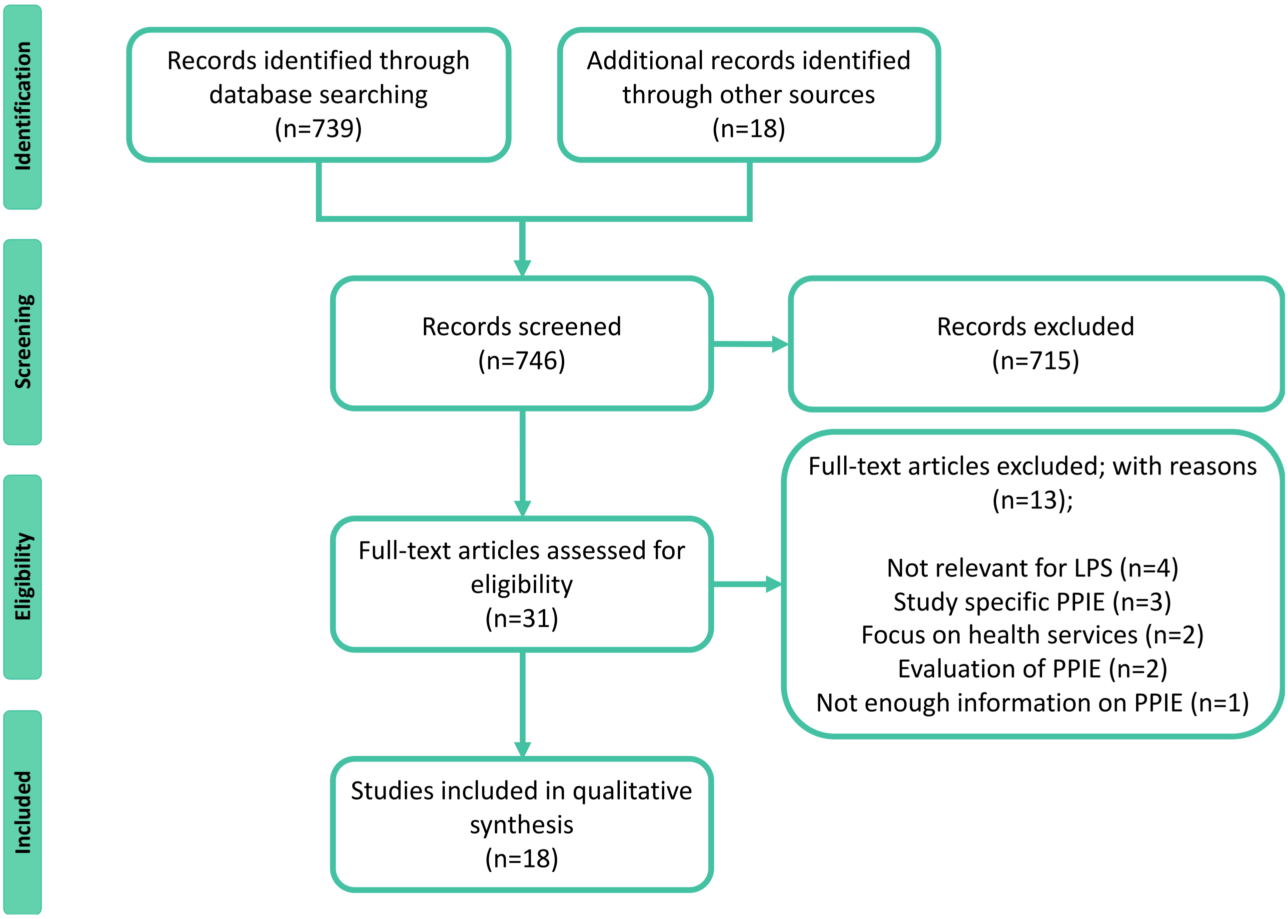
Understanding Patient Data (2018). Public attitudes to patient data use: A summary of existing research.

Understanding Patient Data (2020). Public attitudes to the use of patient data Sept 2019-Sept 2020.

Waind, E. (2020). Trust, Security and Public Interest: Striking the Balance; A review of previous literature on public attitudes towards the sharing and linking of administrative data for research, Administrative Data Research UK

Wilson, P., E. Mathie, J. Keenan, E. McNeilly, C. Goodman, A. Howe, F. Poland, S. Staniszewska, S. Kendall, D. Munday, M. Cowe and S. Peckham (2015). "ReseArch with Patient and Public invOlvement: a RealisT evaluation – the RAPPORT study." Health Services and Delivery Research **3**(38).

Appendix



Flow diagram of the literature search and article selection process