

# Population Research UK prospectus: potential purpose, activity and approach

## Contents

Overview .....	1
Vision and purpose .....	2
Proposed activities for Population Research UK .....	3
Principles for delivering Population Research UK.....	7
A model to deliver Population Research UK.....	8
The anticipated benefits from creating Population Research UK.....	11
Next steps .....	12
Appendix 1: Population Research UK scoping programme .....	13
Appendix 2: Initiatives that support discovery or access to multiple UK LPS data.....	15
Appendix 3: Jointly agreed Population Research UK data principles .....	18

## Overview

The UK supports an unparalleled collection of Longitudinal Population Studies (LPS) – studies that follow the same individuals over time such as longitudinal panel and cohort studies – that provide a wealth of long-term information from their participants, describing both them and the society and environment in which they live. The LPS are supported by a rich set of resources that enhance delivery of findable, accessible, interoperable and reusable (FAIR) LPS data and aid scientific reproducibility<sup>1</sup>. To maximise the scientific potential of these data and resources now and for the future, three key funders, the Economic and Social Research Council (ESRC), the Medical Research Council (MRC) and Wellcome, have come together to respond to the needs of the LPS community, building on commonality in strategic reviews of longitudinal studies by each of these funders.<sup>2</sup>

In November 2020, the three funders commissioned Health Data Research UK (HDR UK) to undertake a scoping programme in conjunction with the LPS community and wider stakeholders to provide an understanding of how to further maximise data use and benefit across the full biomedical to socio-economic spectrum of UK LPS. Fundamental to the scoping programme was exploring the opportunities to leverage and learn from current LPS and existing data resources to enhance, broaden or align their activities, alongside capitalising on cutting-edge approaches in data capture, data storage and processing technologies and analytics.

This prospectus outlines possible activities and a structure for a new initiative, Population Research UK (PRUK), as the result of the scoping programme. A summary of the consultation findings is provided in Appendix 1 with supporting Annexes that document interim outputs from the scoping programme.

---

<sup>1</sup> [A guiding set of principles](#) scientific data management and stewardship which support research reproducibility.

<sup>2</sup> [MRC Maximising the value of UK population cohorts](#) (2014); [ESRC Longitudinal Studies Strategic Review](#) (2017); [Wellcome Longitudinal Population Studies Strategy](#) (2017)

## Vision and purpose

The vision for Population Research UK (PRUK) is to maximise the use, innovation and benefit from the UK's rich collection of longitudinal population studies (LPS) across social and economic, and biomedical science. This is expected to enable a greater understanding of biological, behavioural, social, economic and environmental determinants, and the complex interplay between them, that influence health and societal wellbeing and can guide intervention and policy development.

PRUK would achieve this by bringing together and developing the infrastructure, processes and people that enable LPS data to be efficiently enhanced, accessed and used for research across the social science and biomedical spectrum. PRUK would promote collaboration, alignment and interoperability across studies and disciplinary domains that use LPS, whilst enabling further innovation.

## Study and data scope

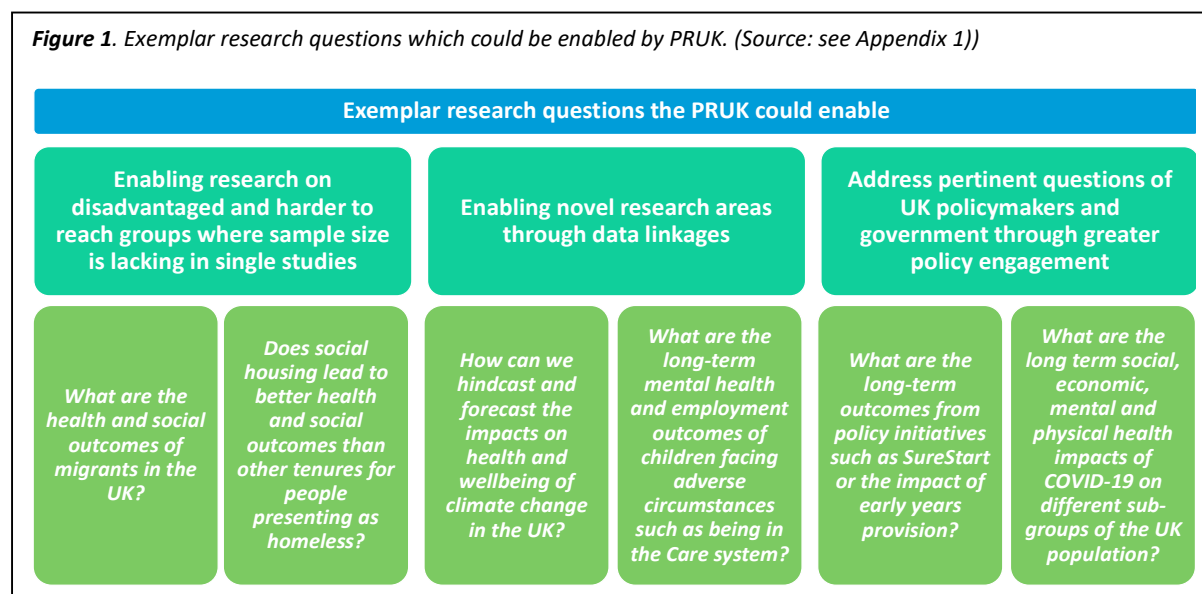
The scope of PRUK should be inclusive to significant UK LPS, encompassing cohorts, panel studies and associated biobanks, and be non-preferential about the funder(s) of a study. Whilst the focus is on raising the use and profile of UK studies, PRUK should develop practices that ensure LPS infrastructures are interoperable with international LPS data sharing initiatives and standards.

## Research priorities

PRUK would not directly fund health or social science research or data collection but provide an enhanced research infrastructure that enables ambitious research to be conducted with greater efficiency or to draw on a wider range of UK LPS data assets. The PRUK-driven developments would need to be prioritised with the research community, so they align to the scientific use needs. The research benefits arising of PRUK are envisioned to be threefold:

1. enabling data use across a wider range of population characteristics, age and diversity, by removing barriers to the use of multiple LPS resources
2. broadening insights from LPS data through data linkage to routine and other data
3. increasing policy relevance and impact through engagement of policymaker stakeholders.

Figure 1 outlines examples of contemporary research questions that were perceived in the scoping programme as challenging, and offered as examples for where a future investment, like PRUK, may add most value.



## Proposed activities for Population Research UK

For PRUK to achieve the vision outlined above, the following recommendations for its activities are made to the funders. Throughout, the ambition is for PRUK to work with other data infrastructures, experts and strategies to develop greater alignment and commonality.

### Recommendation 1: Enable wider discovery of LPS data

To maximise research, LPS data should be findable and described in a commonly recognised format.

PRUK should work with existing infrastructures, activities and expertise to:

- Work across the LPS community to develop and implement solutions to deliver the fundamental policy of findability across all LPS data. This should include common approaches to metadata spanning different types of data, based on widely recognised standards.
- Provide transparency on discovery by making clear where LPS are catalogued, and by extension, highlighting which are not yet compliant with these requirements.
- Bring together providers of LPS catalogues and discovery tools to develop and test federated search capability, meaning that any dataset listed on one of the major platforms can be searched for once across them.
- Develop and promote wide adoption of approaches that increase the findability, and by extension replicability, of all research outputs associated with LPS data use, such as syntax (used for common data management tasks), analytical research code and data citation.

#### Scoping programme findings: Discovery

There already exist multiple platforms that can support discovery of LPS data (summarised in Appendix 2); some support discovery of specific data types or support topic-specific research. In addition, many LPS house catalogues and data dictionaries on study websites. A theme of the scoping consultation is this landscape was complex and resource intensive for both studies to maintain their metadata and data and for users to search and understand datasets held across multiple platforms.

The need for a significant investment in new discovery infrastructure was not well supported through the consultation. Respondents highlighted the need to work with the existing platforms, promote their visibility, and ensuring that LPS have the resources to structure metadata in standardised formats and contribute data to these discovery platforms.

### Recommendation 2: Streamline access to LPS data

PRUK should aim to increase the number of users receiving timely access to LPS data, and to support development of data access processes that are broadly predictable across datasets.

PRUK should work with existing infrastructures, activities and expertise to:

- Develop, curate and share resources that support management of data sharing processes, for instance, data access request application forms, approval criteria, data sharing agreements, ethics, data governance compliance, researcher accreditation, data access registers, and support the broader use of these across studies and data infrastructures that enable data access (see Appendix 2).
- Describe and implement a long-term strategy for a coordinated data infrastructure that supports both secure remote access and/or distribution of LPS data. This strategy would

recognise the need for a phased approach of working towards deeper levels of federation between current infrastructure that provide access to different types of LPS data.

- Develop a data use register across LPS, including who is provided access and the purpose and duration of access.
- Work with stakeholders (funders, study leads) to develop a strategy by which access (and discovery) of data is made available when a study is closed or not in receipt of active funding.
- Over the longer term, work with funders to address costing models for data access and develop sustainable solutions to support data sharing.

#### **Scoping programme findings: study data access**

An online survey was used during the scoping programme to collect users' experiences of accessing LPS data<sup>3</sup>.

- Approximately one-third of survey respondents reported typically planning for data access permissions to take 6 months or more.
- 40% of survey respondents reported delays or abandonment of an analysis in the last 5 years.

Consultation responses consistently highlighted heterogeneity in approaches to access as a barrier to wider use of LPS data. Challenges with access are compounded when making requests for data from multiple studies.

Moving towards access processes that ease the burden on both study teams and users and reduce delays was seen as important and laudable, although challenging to implement especially for established studies governed by long-standing assurances to participants and local requirements. It was seen by respondents as essential that where access is already seen to be efficient, for instance, the access to some LPS datasets via download under licence via the UK Data Service, that no additional barriers should be created.

### **Recommendation 3: Facilitate linkage between LPS data and other types of data**

Linked data can provide new avenues of scientific enquiry, but challenges have existed in their creation and access.

PRUK should work with existing infrastructures, activities and expertise to:

- Facilitate and manage linkages between LPS and high-value routine health, administrative, environmental and other datasets, in partnership with a consortium of LPS and the organisations that collect and provide routine data<sup>4</sup>. Appropriate engagement and involvement of the public/ study participants should be included throughout to inform trustworthy processes.
- Address the training needs that arise for the field by making linked data assets more widely availability of for analysis, in partnership with other initiatives active in this area.
- Ensure all linked dataset assets are discoverable and accessible, in line with Recommendations 1 and 2, and support activities to make linked datasets research ready.

---

<sup>3</sup> See Annex 1 for more information, n=138, n=110

<sup>4</sup> In many instances this will be a government department, or arms-length body that processes data on their behalf.

- Support sharing of learning and practice from study-led linkage programmes to novel data types, via collaboration with relevant initiatives and supporting consortia and dissemination of practice in line with recommendation 4.

#### **Scoping programme findings: data linkage**

Findings from the scoping programme identified high demand for advocating and facilitating data linkage – 78% of survey respondents considered this a high priority activity<sup>5</sup>. There are a wide and diverse range of linkages sought by users and study leads across health, financial, educational, environmental, and geospatial data, in addition to data generated from wearable devices and multi-omic technologies to enhance the potential of data for new analyses.

The scoping programme identified the need for greater support for routine data linkages being developed and maintained centrally in partnership with LPS, as is being developed by the UK Longitudinal Linkage Collaboration for Covid-19 research. Two themes from the consultation were the need to continue support for innovative linkage programmes at a study level, and the need for investment in development of skills, capacity and methodology for linked data analyses.

#### **Recommendation 4: Act on behalf of the LPS community and catalyse new cross-community activities.**

Bringing together the LPS community expands opportunities to coordinate activity between studies, as well as interacting with stakeholders across the wider research, funding, innovation and policy landscape.

PRUK should work with existing infrastructures, activities, and expertise to:

- Provide resources for strategic working between UK LPS to develop and test solutions to common challenges, and to work jointly on improving the interoperability and quality of their data across all types of LPS data (examples given in the box below).
- Create shared-interest forums for LPS to engage as a collective with industry, and government policy makers.
- Provide the LPS research community with a conduit for a collective voice in the broader national research and innovation landscape, including funders, to articulate the requirements of this research community to achieve sustainable and trusted data sharing and use.
- Input to and influence the evolving public conversation on trusted data use, privacy, consent and linkage at a sector level, providing a conduit for LPS to feed through their experiences from engaging with their participants at a study level.
- Develop communications and sector-level engagement with the public to increase the understanding and impact of longitudinal and population research (alongside other organisations acting in this area).

#### **Scoping programme findings: acting on behalf and with the LPS community**

Examples of strategic working between LPS highlighted through the scoping programme:

- Standardisation in collection and linkage of new types of data such wearable data, social media, consumer data and 'omics data

<sup>5 5</sup> See Annex 1 for more information, n=122

- Develop common approaches to biosample collection, storage, handling and analysis.
- Prospective harmonisation between groups of studies, e.g., standardised question sets.
- Approaches to increasing participant engagement/reducing participant attrition amongst different groups.
- Negotiating with industry for services (e.g., analytics) or providing access to data and samples.
- Contribute to the planning of future LPS by providing descriptive and contextual information across a large sample of UK LPS in terms of over and underrepresented groups and data collection.
- Share good practice and learning.

Consultees saw that these activities might be carried out as a central function, facilitated by PRUK on behalf of the community, or could be community led through consortia and working groups resourced across studies. A mix of both models could be delivered in practice, depending on activity objectives.

The scoping programme identified areas of ongoing activity in some of these areas; for example, the study convening, or policy engagement activities facilitated by CLOSER, and the engagement of government data custodians by Administrative Data Research UK (ADR UK) and HDR UK, as well as the strong stakeholder networks that some individual studies have built up and maintained. PRUK should seek to leverage and build on existing networks as opposed to replicating them.

### **Recommendation 5: Build capacity and skills in data management and practices**

The ambitions to increase use and improve quality of data are dependent on the development and retention of expertise, knowledge and staff across LPS.

PRUK should work with existing infrastructures, activities, and expertise to:

- Work with wider initiatives to develop standard measures for recognising contributions, outputs and impact for data curation, management, linkage and data science ways of working.
- Curate and maintain a library of appropriate research tools, with required guidance and training, for LPS data users to contribute to data documentation and open science practices.
- Set out and deliver a strategy for skills development for those with roles in the delivery of LPS, such as data and linkage managers.
- Contribute, as part of the broader ecosystem, in the wider development of analytical skills and methods for utilising LPS.

### **Scoping programme findings: Build capacity and skills in data management and practices**

A relative lack of incentives was identified for aligning to FAIR data practices, and that across the field there was a need to support the development, retention and growth of staff who manage and deliver LPS. Consultees highlighted the work of CLOSER, as an example of good practice in supporting data managers and data linkages, but in general there is a sparsity of formal training and career development opportunities for data managers and science support teams.

The consultation also highlighted quantitative analytical training needs of users of longitudinal studies, especially if increasing availability of linked datasets and novel forms of data were priorities for PRUK. There are already multiple initiatives supporting longitudinal data training needs<sup>6</sup> and therefore for PRUK to provide activities which were specific and add value over the current activities, or act in a broader coalition of training provision, was seen as important.

<sup>6</sup> [A review of quantitative analytical training needs for users of longitudinal studies - CLOSER \(2019\)](#)

# Principles for delivering Population Research UK

The scoping programme identified important principles to guide the development of PRUK:

- ***Collaborate with, build on and learn from current LPS activities and data resources.*** There are multiple existing initiatives that currently support discovery, access and use of LPS, although few are resourced to cover the full breadth of UK LPS across the social science and biomedical spectrum (identified throughout this prospectus and Appendix 2). The approach of PRUK should be to support expansion and alignment, not duplication, of the existing work and infrastructures, combined with progressive new activities, resources and initiatives where needed.
- ***Embrace the individuality of different studies rather than seek to implement a one-size-fits-all approach.*** Each LPS and the funders that support them have different starting points in terms of their resources and approach to making data FAIR for research, and each has a particular role. Newer studies may have more flexibility in their adoption of processes and ways of working, over long-standing LPS with established governance and consent mechanisms. In many cases, PRUK should support a spectrum of approaches, rather than striving for a single model. However, to advance progress, there is a requirement for an initiative that is ambitious enough to tackle the challenge of incorporating the full breadth of significant UK based LPS, breaking down any unhelpful silos and facilitating further and easier cross-domain, interdisciplinary working.
- ***Consistently take a sector-wide and sustainable approach to activities.*** All LPS have at least one established mechanism for making data discoverable and supporting data access requests and use by external users<sup>7</sup>. Further data curation and sharing mechanisms place additional resource demands on studies. PRUK should ensure that resources flow down to studies for auxiliary activities, as well as working with LPS and funders to create replicable and sustainable mechanisms of funding for LPS to engage across the data sharing infrastructure.
- ***Be enabled through parallel activities by the funders of LPS.*** The funders, who jointly commissioned this scoping activity, have committed to working together in areas such as data policy to encourage and reasonably support best practice in data discovery, access and use/reuse. Working towards their shared ambition, the ESRC, MRC and Wellcome have committed to a joint set of common data principles that would underpin PRUK future data policy (see Appendix 3). The funders would also need to maintain their broader strategies of support for LPS with continued investment into the underlying studies for their delivery and collection of data, and funding for research, methods development, and capacity building programmes.
- ***Remain agile to future changes and needs in the data landscape.*** PRUK is being scoped during a time of rapid increases in the ability to process huge quantities of data, and a dynamic digital and data environment. In addition, the research response to Covid-19 pandemic has brought new capabilities and initiatives into the LPS field as well as changes in the public interest in epidemiology and research more widely, and evolving attitudes to data sharing. PRUK should be developed so that can be responsive to future needs and developments in the UK data infrastructure.

---

<sup>7</sup> In the case of ESRC funded studies they are resourced to make data available via UK Data Service at no cost to the user. Other studies have established routes of access directly by request to the study via an established process, often with a cost-recovery charge applied to the resources required in the request.



## A model to deliver Population Research UK

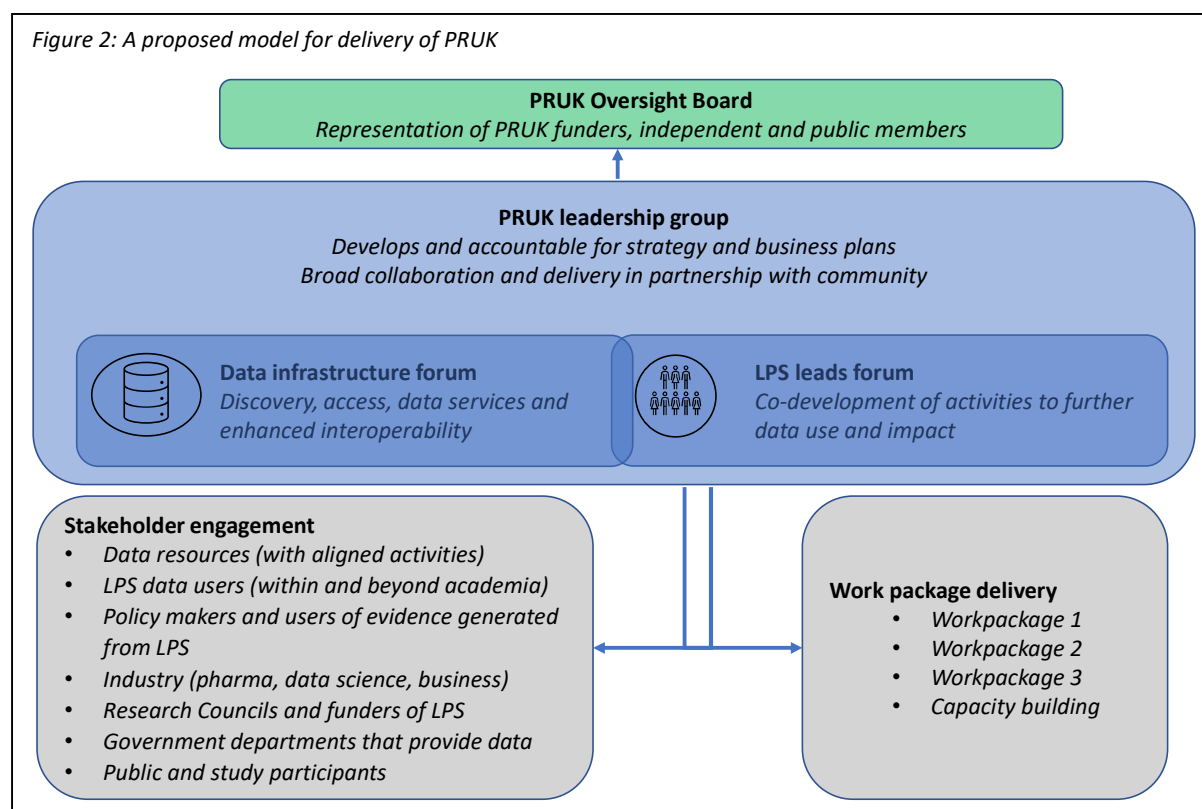
PRUK could take the following structure (set out in Figure 2.)

- A multidisciplinary leadership team with overall responsibility for delivery PRUK activity, with academic and delivery expertise
- A data infrastructure forum that brings together existing LPS data infrastructures through which LPS data discovery, access and linkage would be progressed
- An inclusive forum for LPS study-leads/representatives to drive forward strategic work and implementation of shared practices.

The PRUK leadership team would need to ensure:

- Appropriate division of responsibilities across work packages to address the recommendations
- Public involvement was active throughout PRUK decision-making
- Comprehensive approach to engagement with stakeholder groups that are critical to the vision of PRUK.

The funders of PRUK should establish an independent Oversight Board, which would support the funders in providing direction to the initiative and its delivery.



**PRUK leadership team.** The leadership team should have the capabilities to motivate and inspire across a diverse set of stakeholders and LPS community, as well as the operational decisiveness to prioritise and deliver on its activities. The PRUK core leadership group should have in-depth understanding of



and credibility with the disciplines represented by its funders, and both academic and non-academic stakeholder groups. The leadership team would be required to be institutionally and disciplinarily agnostic, meaning it would be likely led by a collaboration across universities. The leadership team should work to deliver improvements and impacts that are system-wide and be broader than a group of individuals representing the interests of studies and infrastructures with which they are involved.

The leadership group should remain of a size to be functional, up to 5-6 individuals, which would prohibit it being inclusive of all infrastructure and studies that PRUK should engage with. The leadership group could contain the following roles, some of which may be occupied by the same person:

- **Director** – an overall lead accountable for delivery of PRUK’s aims
- **Deputy Director** – the second most senior individual in the initiative, likely from a different domain to the Director to support wider engagement
- **Operations Lead** – responsible for designing and implementing the scalable processes underpinning PRUK
- **Workstream leads** – this could include: a data and linkages lead responsible for ensuring data standards are applied in a pragmatic and proportionate way to facilitate linkage and interoperability, a governance lead responsible for developing streamlined and harmonised approaches to data access, and a capacity building lead.

The leadership group would need to define a way of working with the data infrastructure and LPS leads forums that represents the close interdependency of these groups to deliver the proposed objectives of PRUK. The leadership group should be supported by a small team of professional staff to support delivery to include project management, and engagement with the infrastructures and LPS leads forums and wider stakeholders.

***Data infrastructures forum:*** Discovery and access (recommendation 1 and 2) of LPS data and data services such as curation or linkage (recommendation 3) would be supported through a coordinated forum of LPS data platforms and infrastructures. Components of this forum would bring specialism in the types of data and services that they provide whilst working towards alignment in their operation. Additional resources, where required, would support the enhancement of the data platforms towards alignment in their practices and federated approaches. The component initiatives could be identified through the selection process for PRUK.

***LPS leads forum:*** The requirements of LPS to contribute to and benefit from PRUK should be transparent. PRUK should develop clear ways to enable wide engagement of LPS leads in its planned activities, ideally with co-development of initiatives. The forum would support and identify the activities that are centrally driven, and those delivered between consortia of studies, the latter supported by availability of PRUK resources for multi-study strategic working (recommendation 4).

### **Embedding the public in PRUK decision making**

The scoping programme has involved representation of the public throughout, both in reviewing what activities PRUK should undertake, and how the study participants and public could be involved in its operations (see Appendix 1). This underscored the opportunity for PRUK to support transparency by maximising publicly accessible information on data governance, access and use, and include public and participant representatives on panels that govern these processes.

Proposals for PRUK could be required to demonstrate plans for including members of the public in decision-making and governance in how it operates and ensure that research outcomes from its work

are linked to participant and public benefits. Individual LPS should remain to primary route of engagement with their study participants, and it would be unhelpful for PRUK for duplicate this.

### **Stakeholder engagement**

The ambitions for PRUK require extensive collaboration and engagement with multiple groups, organisations and types of stakeholders across the research ecosystem (see figure 2). PRUK could develop and maintain beneficial engagement with each of these groups, cognisant of the stakeholder relationships that are maintained at an individual study level. PRUK could support the community at a national or sectoral level, learning from studies and groups that operate effectively across national organisations or departments. To support this, mechanisms could be developed that enable PRUK to rapidly survey, as well as develop in-depth knowledge over time of, the needs and views of the LPS community, to authentically provide a collective voice on behalf of a community.

## The anticipated benefits from creating Population Research UK

It is proposed PRUK should deliver the following benefits, across different stakeholder groups. These could inform the success criteria for PRUK over time.

For users of LPS data:

- Increase visibility and discoverability of UK LPS data
- Reduce time and unpredictability in data access processes leading to faster findings and fewer abandoned analyses
- Make it easier to bring together multiple data sources for comparative, combined and replicative analyses
- Significantly increase the efficiency and volume of LPS data linked to routine records available for research.

For LPS and the LPS infrastructure which supports current data use:

- Increase the profile and visibility of LPS data assets, supporting a wider pool of potential users
- Development of community standards and consensus approaches to delivery of FAIR data principles across LPS
- Formation of new collaborations from across the spectrum of the LPS research community and opportunities for addressing shared challenges and opportunities in the field
- Broadened use of sustainable and scalable infrastructure for data storage, access and distribution
- Increase capacity and expertise in LPS data management
- Prime the UK population research infrastructure to be more readily responsive to emerging research and policy needs.

For the public:

- Provide value for money from LPS investment and research through increasing the use and reuse of data collected
- Speed up the validation and replication of findings across datasets, and their dissemination through to policy and practice
- Enable research that may be applicable to more and wider populations.
- Create greater public awareness and understanding of the impacts and public benefits arising from LPS research.

## Next steps

This prospectus sets out a proposal, based on the findings of the scoping phase, to increase the use and research potential of LPS data and, ultimately, the scientific and policy impact that arises from these rich resources for their funders to consider.

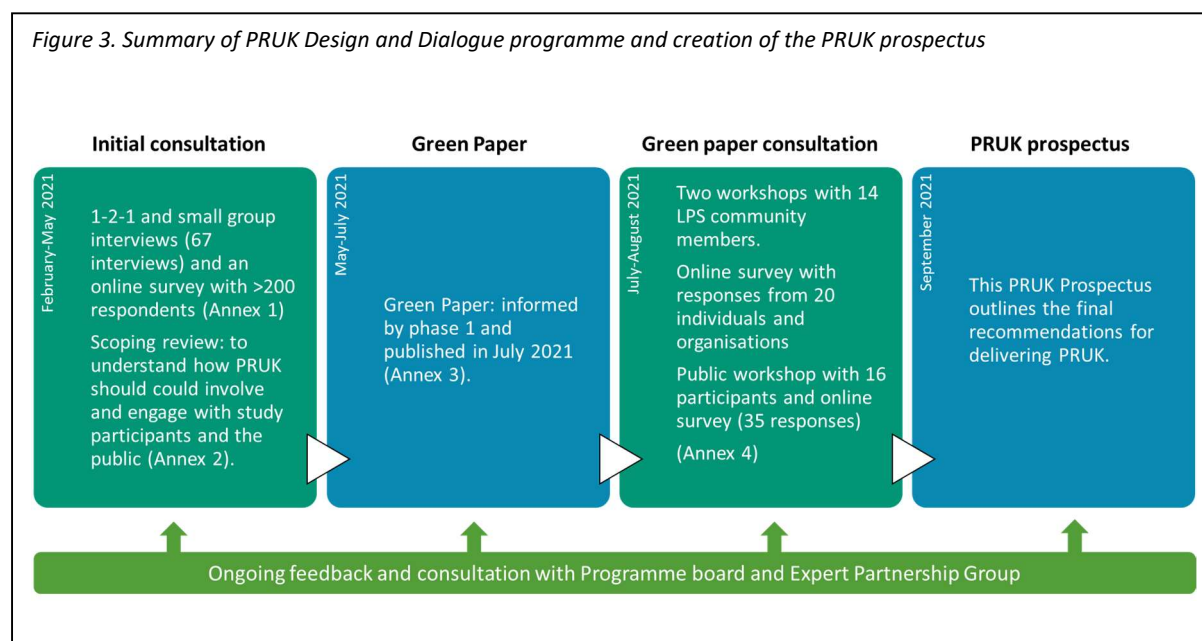
The next steps are for funders to decide on a suitable commissioning model based on the recommendations, and whether any further preparatory work needs to be undertaken to ensure the data infrastructure landscape is in the best position for any future investments to be a success and add value. Following this, identification of a multidisciplinary and diverse leadership team might follow, with the capabilities to motivate and coordinate across a diverse set of stakeholders and LPS community and the operational decisiveness to deliver long-standing benefit envisioned.

## Appendix 1: Population Research UK scoping programme

The Economic and Social Research Council (ESRC), the Medical Research Council (MRC) and Wellcome, commissioned Health Data Research UK (HDR UK) to undertake a scoping programme in conjunction with the LPS community and wider stakeholders to provide an understanding of:

- where more action was needed to maximise LPS data use
- how the funders might commission a new initiative called Population Research UK (PRUK)

The online of the scoping programme is outlined in Figure 3. The programme of work was guided by an expert Partnership Group drawn from membership of the LPS community and the public and overseen by a Programme Board with senior representation from the three funders<sup>8</sup>.



### Initial consultation

An initial consultation on the needs and opportunities in the field and potential activities for PRUK was conducted from February – April 2021. This consisted of 67 interviews with invited individuals who had roles in the use or delivery of LPS within and outside academia, across disciplines and career points, to explore current experiences, and opportunities and challenges for LPS. This was supported with an online survey to which over 200 responses were received. A separate scoping review was commissioned to establish best practice and recommendations for engagement and involvement with the public and study participants (see Annex 1 and Annex 2 for summaries of these outputs)

### Green Paper

The findings from the initial consultation were synthesised into a PRUK Green Paper, which was published in July 2021 (Annex 3). The Green Paper set out a proposed vision and recommendations for PRUK and invited feedback and comments from stakeholders to develop and refine the proposition for PRUK.

### Green paper consultation

Consultation on the Green Paper (between July – August 2021) took the format of two workshops with 14 leaders in the LPS community, and an online consultation to which 20 individuals and

<sup>8</sup> [PRUK Partnership Group and Programme Board terms of Reference](#)

organisations responded. In addition, a public facing workshop was held with 16 public participants and an online public survey was launched with 35 responses to understand their perspective on PRUK's proposed activities (see below for details of these outputs).

### PRUK prospectus

The Green Paper recommendations have been updated based on the feedback received and the revisions are published in this document as a prospectus. Here is set out the vision for how PRUK could work to maximise LPS data use, including the opportunities this presents for social, economic, and medical research, alongside the recommendations for PRUK's activities.

The scoping programme generated the following summary outputs which have informed the PRUK prospectus, which are published as Annexes to the prospectus.

### Initial consultation outputs

**Annex 1:** PRUK Design and Dialogue first consultation summary. *A synthesis from 67 interview and online survey conducted February – April 2021.*

**Annex 2:** Public and Participant Involvement in Population Research UK (PRUK): A scoping review of different approaches and recommendations. *A literature review and synthesis conducted by Kohlrabi Consulting on behalf of HDR UK.*

**Annex 3:** Population Research UK Green Paper. *An interim set of recommendations and proposals for PRUK, published in July 2021, which was the basis of further consultation.*

**Annex 4:** PRUK Green paper consultation response summary. Summarises the responses collected from three consultation exercises.

- a) *A summary of two workshops held in July 2021 with invited representatives from LPS leads.*
- b) *Written responses received to an online survey supporting the Green Paper*
- c) *A summary of a workshop on online consultation with members of the public.*

## Appendix 2: Initiatives that support discovery or access to multiple UK LPS data

The criteria for including these initiatives were that they support discovery and/or access to multiple UK LPS and were cited throughout the consultation by the community as part of the current LPS data resources ecosystem. The functionality and scope of each is briefly described.

*Is initiative specific to LPS?* Whether the initiative is specific to supporting discovery and/or access of LPS or forms part of a broader scope of the initiative.

*Searchable variable-level discovery:* If the initiative supports discovery of LPS data, does it provide functionality to run variable-level queries across metadata held.

*Support data access request processes:* Once a dataset is identified, how are any requirements to access the data supported by the initiative.

*Provide access to data:* Once any access requirements have been met, does the initiative provide the user access to the dataset (either by download or remote access).

This does not document the individual discovery and access mechanisms utilised by each study. Discovery via individual study websites varies from data dictionaries being available on request, metadata being available for download, through to searchable metadata catalogues. For data access, all ESRC funded studies are available via the UK Data Service as a condition of funding. Non-ESRC studies make data available for reuse through a variety of mechanisms, either controlled release of approved data to the researcher, or via remote access for sensitive data.

Initiative	Description / scope	Is initiative specific to LPS?	Searchable variable-level discovery	Support data access request processes	Provide access to LPS data
<a href="#">Centre for Longitudinal Studies</a>	Management of four established cohorts, and two new studies, led at UCL	yes	Via CLOSER Discovery	yes – and via UKDS	Via UKDS
<a href="#">CLOSER Discovery</a>	Curation and discovery of dataset and variable level metadata to DDI3 international standard (Data Documentation Initiative)) and made findable through CLOSER Discovery platform. CLOSER also supports harmonisation of data, linkage, training and convening the LPS community	yes	yes – provides detailed search and overview of each variable	signposts to UKDS	no
<a href="#">European Genome-Phenome Archive</a>	Discovery for genomic and biomolecular data	no	no	signpost to the Data Access Committee of each study	yes – access via download after access requirements met
<a href="#">HDR UK Innovation Gateway</a>	Discovery of health data	no	no	Users can submit a data access request to	no



				the data custodian	
<a href="#">Office for National Statistics Secure Research Service (ONS SRS, supported by ADRUK (link))</a>	Provides secure access to government data to accredited researchers for approved research projects	no	no	yes – access request made to ONS	yes – remote access for accredited and approved researchers in SRS
<a href="#">Maelstrom Research (Canada)</a>	Dataset and variable level metadata to DDI2 international standard	yes	yes – allows variable search across studies	Signposts to LPS/ UKDS access processes	no
<a href="#">MRC Cohort Directory</a>	Dataset level description of significant UK cohorts (not maintained)	yes	no	Signposts to LPS	no
UK Data Archive/ <a href="#">UK Data Service (UKDS)</a>	UK Data Archive holds UK social science data, including all LPS funded by ESRC. UK Data Service supports discovery, access and use of data held.	no	yes via <a href="#">Question bank</a>	yes – may require registration or application for controlled data	yes – Via download or Controlled data through <a href="#">SecureLab</a>
<a href="#">The UKCRC Tissue Directory and Coordination Centre</a>	Discovery of biosamples	no	yes – a pilot service is <a href="#">ATLAS</a>	Signposts to LPS for access	no
<a href="#">UKSeRP (Secure eResearch Platform)</a>	Provides a customisable data sharing and analysis platform, which is utilised by some UK LPS and initiatives (clients)	no	Requires access approval	Signposts to LPS	Provides an ISO 27001 accredited research environment for controlled remote access

Topic specific initiatives that support discovery and/ or access to multiple UK LPS data

Platform	Description / scope	Specific for LPS?	Searchable variable-level discovery	Support data access request processes	Provide access to data
<a href="#">Birthcohorts.net</a>	Global catalogue of cohorts and variables commenced at or preceding birth	yes	no	via UKDS	no
<a href="#">Census &amp; Administrative data Longitudinal Studies Hub (CALLS-HUB)</a>	Variable discovery of 3-national census studies (ONS Longitudinal Study, Northern Ireland Longitudinal Study and Scottish Longitudinal Study)	yes	yes	Via the support units based in <a href="#">England</a> , <a href="#">Scotland</a> or <a href="#">Northern Ireland</a>	Via ONS Secure Research Service

<a href="#">Catalogue of Mental Health Measures</a>	Discovery of mental health and wellbeing measures in British cohort and longitudinal studies	yes	yes	Can facilitate access request to LPS	no
<a href="#">Dementias Platform UK</a>	Discovery and facilitated access to clinical and LPS data for neurodegenerative research	yes	yes	yes	yes – via UKSeRP
<a href="#">Gateway to Global Ageing</a>	Provides discovery of harmonised datasets and variables related to ageing research	yes	yes	no – signposts to studies	no
<a href="#">International HundredK+ Cohorts Consortium (IHCC)</a>	Global discovery of large cohorts with >100k participants via the <a href="#">Cohort Atlas</a>	yes	no	no -signposts to LPS	no
<a href="#">UK Longitudinal Linkage Collaboration</a>	Discovery and facilitated access to LPS linked to routine data for Covid-19 research	yes	yes	yes	yes – via UKSeRP

### Appendix 3: Jointly agreed Population Research UK data principles

The UKRI Common principles on research data<sup>9</sup> have been agreed to be adopted across PRUK funders:

1. Publicly funded research data are a public good and produced in the public interest. They should be made openly available with as few restrictions as possible in a timely and responsible manner.
2. Any organisational and project-specific data management policies and plans you develop should align with wider best practice and standards. For example, data that has acknowledged long-term value should be preserved to remain accessible and usable for future research.
3. You should record and make metadata available and discoverable to other researchers in a way that helps them to understand the research and re-use potential of the data. Published results should always include information about how to access the supporting data.
4. To comply with all legal, ethical, disciplinary and commercial requirements on the release of research data, you must ensure that the policies and practices of your research organisation consider these constraints at all stages of the research process.
5. To ensure you get appropriate recognition, you may be entitled to a limited period of privileged use of the data you have collected and analysed to publish the results of your research. The length of time depends on research discipline and the research council running the funding opportunity.
6. To recognise the intellectual contributions of researchers who generate, preserve and share key research datasets, for any research data you use you should acknowledge the source and follow the terms and conditions under which you accessed the data.
7. We believe it is appropriate to use public funds to support the management and sharing of publicly-funded research data. To maximise the research benefit, your mechanisms for these activities should be both efficient and cost-effective. As such, all costs associated with research data management are eligible under UKRI funding. Certain conditions apply, for example, expenditure must be incurred before the end date of the grant.

---

<sup>9</sup> [Making your research data open – UKRI](#)