



Population Research UK Partnership Group minutes and actions

Date: Friday 26 February 2021; 13:00 – 15:00

Attendees

Chair: Hetan Shah, The British Academy

Attendees: Frank Windmeijer, University of Oxford; Andy Boyd, University of Bristol; Mike Daly, Department of Work and Pensions; Emma Gordon ADR UK, ESRC; Rebecca Hardy, UCL; John Gallacher, University of Oxford; Cathie Sudlow, University of Edinburgh; Matthew Woollard, UK Data Service; Lucy Dixon, public member; Maisie McKensie, public member.

Ben Gordon, HDR UK; James Pickett, HDR UK; Bridget Taylor, ESRC; Laura Morrell ESRC; Catherine Moody, MRC; Bruna Galobardes, Wellcome

1. PRUK development programme update

HDR UK provided an overview of current progress in the PRUK development programme:

- HDR UK staff and a contracted consultant have started 1-2-1 and small group interviews to understand current challenges in longitudinal population studies (LPS) and opportunities for PRUK. Approximately 35/60 scheduled interviews had been completed as of 26/2.
- A public survey would go live the following week and remain open until 9 April. A link to the live survey is now added to the minutes [Population Research UK design and dialogue survey \(surveymonkey.co.uk\)](https://surveymonkey.co.uk)
- Since the previous PG meeting, HDR UK has worked with the Partnership Group (PG) public members to discuss a public and participant approach for informing PRUK. The public members of the PG discussed it was essential to focus on the benefits that would arise for different groups from PRUK but especially the public. HDR UK also presented and discussed PRUK with the HDR UK Public Advisory Board on 16/2/21 and received helpful feedback.
- In March and April, HDR UK will complete stakeholder interviews and online survey data collection. Outputs of these engagement activities will be synthesised and presented as options and recommendations at the next PG meeting (21 April) and Programme Board (PB) (5 May). Following these meetings, HDR UK will refine recommendations and options for PRUK and publish consultation 'Green paper' for a further round of stakeholder input. The Green paper consultation is anticipated to open from early June and be open for consultation for approximately six weeks.
- The development programme plan and stakeholder interview documents will be updated to reflect the consultation paper stage and will be circulated to the PG.

Action: HDR UK to share updated project plan and engagement activity with PG.

2. The scope of LPS studies for inclusion in PRUK

PG discussed that the criteria for studies engaged with PRUK. It was noted:

- PRUK should not prioritise inclusion of studies by their number of participants or have a defined lower limit. An LPS could offer potential scientific value to users through its duration of follow-up, sampling framework, or the uniqueness in the demographic covered. PRUK would need to engage with each LPS to understand current barriers and level of resources required to support studies in data management, consents and IG that would enable wider use of data, enable data linkage and participation with PRUK. If funding/resources were to be made available to LPS to engage with PRUK then this would need to be provided in a fair and transparent way.
- Variability in data management, curation and current participant consent would also determine the readiness of LPS to engage with LPS.
- Disease-based cohorts or registries would be lower priority for PRUK, at least at the start.

PG recommended that the aspirations of PRUK could be captured by aiming to support 'inclusive research' – e.g. establish a portfolio of PRUK LPS that sought inclusive coverage of different demographics and groups in the UK population.

3. PRUK Functionality

The PG discussed a problem statement created by ESRC, MRC and Wellcome describing the challenges that it was intended PRUK would help overcome.

Data Discovery - *Currently, there is no comprehensive directory of LPS across the socioeconomic-health scientific spectrum that includes a description of the data available for each study. Therefore, researchers do not always know whether relevant LPS exist and then whether those studies have the data they need for their research plans, so the contribution of these resources to science is under-realised and some research questions are not pursued.*

Data Access – *There is a variance in how readily accessible LPS data resources are to researchers (e.g. via UKDS, DPUK, directly from studies). This includes difference in the time and processes for getting access to data, and the standards and expectations of both studies and data requestors.*

Combining LPS data - *For some research questions, combining data from multiple LPS is an important approach but currently difficult to achieve for several reasons.*

Data linkage - *There is a growing demand for data from a wide range of LPS to be linked to a broad range of routine administrative, health and novel data types in order better to address important research questions.*

Collaboration across LPS studies and research communities - *Research questions and real-world problems demand an understanding across the socioeconomic and biomedical sectors. More opportunities are needed for both those responsible for running LPS and researchers using LPS data to share issues and develop solutions that can be implemented to maximise the value of LPS and to realise this value in using the data in research.*

The PG endorsed the challenges set out by the funders and provided recommendations for further exploration in the development programme. Additional points were noted:

- Differences in data management, storage and access practices and culture between ESRC, MRC and Wellcome funded studies.
- Achieving the right balance between legacy activities (e.g. improving data retrospectively) with prospective activities that support new studies and data collection.

- The role of PRUK in providing an overview across the breath of all UK LPS to consider coverage and inclusiveness of population coverage. This could support researchers and funders in making strategic decisions understanding gaps and needs of new studies and study enrichments.
- It was suggested that PRUK could facilitate (and potentially seed-fund) methodology research into recruitment, retention of participants or feasibility activity for new studies.
- PG highlighted training at both entry and complex level analysis for which there is high demand and is required to support the ambition of increasing the amount and quality of LPS research.
- It was noted there was high need for user support to be development alongside platforms and capabilities PRUK developed or support, which could vary from simple to technical. (e.g. to support users with discovery tools, interpreting metadata). PRUK would require knowledgeable support staff to assist users.

No specific actions were noted. The points and recommendations raised by the PG would be presented to the PB and inform the ongoing PRUK development programme.

4. PRUK design considerations

HDR UK presented four recommendations arising from the development programme for the design of PRUK.

PRUK should facilitate and incentivise the use of trusted research environments

The PG strongly endorsed that PRUK should adopt and promote the use of Trusted Research Environments for accessing data (TREs). It was discussed that it should not be the ambition of PRUK to hold all LPS data in a single TRE, but to work across several environments that provided access to different types of data. This could include investment in expanding capabilities of current research environments. It was discussed PRUK would require a TRE for enabling data linkage (if the ambition were to conduct linkage on behalf of LPS).

PRUK should facilitate streamlining of data access

This was considered as priority functionality of PRUK; PG discussed several mechanisms for how it could be facilitated.

- PRUK might develop technical solutions that support LPS teams with managing data access process.
- PRUK should outline a generic data access mechanism which can be used across LPSs
- PRUK may support a centralised data access committee.

These options would be developed further.

Implementation of metadata standards across LPS

It was discussed that the priority of PRUK should be to define the purpose of a metadata standard (for example, for enabling linkage, for enabling LPS discovery) and to implement across a portfolio of LPS.

Involvement of LPS in commissioning and delivery of PRUK

PG discussed that it was important that studies were incentivised to participate in PRUK. There would need to be additional resources available to studies for activities that were part of PRUK. Studies should benefit from participating in PRUK in non-financial ways, e.g. access to expertise, novel linkages.

In designing any subsequent funding call for the delivery and leadership of PRUK, PG recommended that individual LPS were not required to be part of any consortium bid. A second-stage mechanism for studies onboarding individual studies should be implemented.

Action: HDR UK to update PRUK recommendations ahead of PRUK PB (3/3/21) and circulate to PG.

Action: A follow-up discussion has been organised for 22/3 on TREs.

5. Close

HDR UK thanked PG for their input and outlined that the PG recommendations would be discussed with the PRUK funder PB on 3/3/21. HS thanked all for their contributions

The next PG meeting is scheduled for Wednesday 21 April.