



Population Research UK – questions and answers

We will periodically publish answers to common questions that arise during the design and dialogue programme. The questions answered here were submitted during and since the PRUK development launch webinar on 16 December 2020.

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The aims and purpose of PRUK	
Will this make it easier and quicker to re-purpose data from multiple cohorts better to address urgent research questions?	<p>Yes. The aims of PRUK will be to make more longitudinal population studies datasets discoverable and accessible across biomedical and social science studies, to promote the use of common standards that facilitates cross-study and other multiple longitudinal dataset analyses, and to support linkage across multiple data types.</p> <p>Through this, PRUK will enable research across multiple studies and support researchers in addressing urgent, as well as longer-term important research questions.</p>

<p>Is part of the idea to create harmonized data like the g2aging project (that created harmonized data with the ELSA/HRS/SHARE sisters studies)? That would be amazing also for teaching.</p>	<p>The aims of PRUK will be broader than g2aging in bringing together as many of the UK longitudinal studies as feasible and focused on supporting the reuse of data for a wide range of purposes. Whilst, the aims of PRUK will not be to retrospectively harmonise many LPS (like g2aging), it is hoped that PRUK will enable new research initiatives that use and enhance groups of studies where there is high scientific opportunity.</p>
<p>Existing research infrastructures</p>	
<p>UK Data Archive already curates -- very well -- many (especially ESRC) longitudinal data. Wouldn't it be better to simply expand this to MRC etc. rather than adding another layer of complication?</p>	<p>ESRC and MRC are currently the major funders of UK Data Archive, Dementias Platform UK and CLOSER; initiatives that deliver impactful research infrastructures to support the use of longitudinal population studies in research. The funders recognise that more could be done to facilitate the use of LPS across biomedical, social and economic sciences, and none of these initiatives have the funding or remit to join up all UK longitudinal population studies. The design and dialogue phase of PRUK was initiated to understand the options of how PRUK could work alongside current initiatives and add value to the research data infrastructure.</p> <p>Representatives from UKDS, CLOSER and DPUK are members of the PRUK Partnership Group that are working to make recommendations to the funders on the functions and structure of PRUK. Through the design and dialogue programme, the mission of PRUK will be refined to be distinctive with clear public benefit.</p>
<p>Can the UK Data Archive be used as an example of good practice? It has been curating social science & health data and facilitating use for 30 years. Very cost effective to model PRUK on this.</p>	
<p>How is this platform different from UK Data Service (https://www.ukdataservice.ac.uk/) or Dementia Platforms UK (https://portal.dementiasplatform.uk/)? Or will it be inclusive of the data available there?</p>	
<p>CLOSER's mission is to maximise the use, value and impact of LPS - how is PRUK's mission different to this?</p>	
<p>The Census Longitudinal Studies haven't been mentioned — are these out of scope?</p>	
<p>Working with other funders and stakeholders</p>	

Can existing cohorts not funded by the 3 funders be included?	<p>All longitudinal population studies that bring scientific value, regardless of their funding source, will be welcome to engage with PRUK. Through the design and dialogue programme we will engage with other research funders and explore the opportunities for involvement in PRUK.</p> <p>PRUK will engage with other research funders; both that may directly fund longitudinal population studies or that fund research or resources that might analyse or enhance the use of data.</p>
How will PRUK work with other funders in population research (other than PRUK's core funders)?	
How would PRUK work with other funders and charity during the consultation process and further in the future?	
Will there be an opportunity to learn from Wellcome and Arts and Humanities Research Council funded work to improve discoverability and linkability of highly sensitive historical data?	
Is there a possibility of involving the other research councils if the work is to truly cover all influences on health and wellbeing? Also current cohorts are challenged when representation of those most disadvantaged in society are in focus - large population studies at scale do not necessarily reach these folk.	
It will be good if the PRUK programme governance could link to SCOPHR as there are many of the same folk involved and there are clear recommendations for research direction from this group that PRUK might consider whether it can tackle across existing and future studies.	<p>During the design and dialogue phase, HDR UK, on behalf of the three funders, will consult with a wide range of stakeholders, and the importance of these stakeholders is recognised.</p>
Please consider working with NHS Digital to facilitate data flow and sharing..... they are key to promote health linking data and their systems are challenging.	
Data lineage and bias	
I'm extremely concerned that we risk under-appreciating the importance of data lineage here. Every dataset has it's own complex sampling and selection history that has to be carefully considered and accounted for in order to conduct robust research. Those problems are magnified - and the solutions become ever more difficult - once you're linking different samples and studies together. Without a huge	<p>These are important issues and HDR UK will explore how PRUK could contribute to method development through the design and dialogue programme. Linkage of studies is one potential aspect of PRUK; it is hoped PRUK will also stimulate more cross-study comparison studies and replication of findings in different studies.</p>

<p>increase in knowledge of collider-selection bias - and a corresponding increase in skills capacity and capability - then I think we actually risk making the quality of UK non-experimental research even worse.</p>	
<p>How will concurrent investment in epidemiological theory and methodological improvements be leveraged? A focus on interoperability (an analytical driven approach rather than a population health theory approach) will not remove significant limitations of individual cohorts (e.g. especially selection bias)</p>	
<p>The strength of the UK's national birth cohorts have been their size and representativeness. What work will PRUK do to address that challenges in recruiting participants in birth cohorts (ideally pre-conception) in light of the challenges experienced by Life Study.</p>	
<p>Training and support for ECR and students</p>	
<p>One thing that is needed is making it easier for students & ECR to understand the relevance of longitudinal data from their work</p>	<p>Training and capacity building are recognised as crucial issues for the wider longitudinal population community, and delivering training and capacity building is part of the remit of many activities and studies. This is an area where PRUK, once established, is envisaged to work alongside studies and infrastrucutres, to ensure there is a coherent and comprehensive offer for researchers and study managers.</p>
<p>Nothing much has been said yet about training and capacity building - for 'research ready scientists' and study and data managers. We need this to be developed. What are the ideas for training and capacity building?</p>	
<p>Sustainability, data access and funding models</p>	
<p>This is probably a question that can't be answered right now but my main question is about cost - some cohorts charge a data access fee will PRUK be charging for data access on behalf of the cohorts or will everything be free but an initial access fee? Also the main barrier is applying for data cohorts it currently takes too long and delays research.</p>	<p>Part of the design and dialogue programme will be to work with study leads to understand how studies can engage with PRUK. This will include discussion of the resources involved in fully participating in initiatives such as PRUK.</p> <p>ESRC, MRC and Wellcome meet regularly to discuss policies and processes related to the longitudinal population studies, and are</p>

	committed to discussing areas of policy that are required for PRUK to function effectively.
Enhancing data collection	
Can existing data be extended/enhanced by using new forms of technology to collect better data than old style questionnaires?	The aims of PRUK are not to fund primary data collection, but to facilitate the wider use of LPS across biomedical, social and economic sciences. Through the design and dialogue phase the aim is to understand fully how the community see LPS being utilised more effectively and efficiently.
Will there be any measures to check if individual participants took part in more than one study included on the database, so that they are not over-represented within the data?	These are important method considerations for PRUK and building in these functionalities to support cross-study comparisons will be needed.
Routine and administrative data linkage	
A federated approach to curation but easily discoverable and linkable data across the 4 countries is more likely to be achievable - there are important gaps in the infrastructure in all countries but complementary approaches likely to be required to maintain engagement	Strategic reviews of ESRC and MRC have highlighted the scientific opportunity that may come from greater scientific linkage between LPS, and health and administrative data. This has been identified as an area where PRUK might function with and on behalf of many studies to address the common challenges. In addition, PRUK will work closely with Administrative Data Research (ADR) UK in enhancing linkages of LPS to routine datasets.
How do you propose approaching linked administrative data across the UK when each national compiles its data differently?	
Are there any plans to include local level data within the remit, such as data held by local authorities?	
How does this link, if at, to routine health, social and education data? A longer-term plan, or intended to be kept entirely separate...?	
Public and participant involvement	

<p>It will be very interesting to see what participants and the public say about trust, especially as data is aggregated across sources. Participants build a trust with a longitudinal study and benefit from study level engagement and communications. They also like to be contributing to the wider population health space. PRUK needs to build and add to trust and engagement.</p>	<p>PRUK will engage with public and study participants as part of the design and dialogue phase, supported by the Partnership Group that includes two public members.</p>
<p>Study coverage</p>	
<p>How would this translate to large scale resources like UKBiobank and new prospective cohort studies like Our Future Health?</p>	<p>UK Biobank and Our Future Health are part of the scope of PRUK.</p>
<p>Are there plans to expand PRUK to longitudinal population studies hosted overseas?</p>	<p>The initial focus will be on UK-based data and their requirements. This may be a future consideration, as well as working with international LPS consortium activities.</p>
<p>The phase 1 PRUK Design and dialogue programme</p>	
<p>How does this differ from the previous PRR initiative which already completed a similar phase 1 of community/stakeholder engagement?</p>	<p>This is a continuation of the Population Research Resource (PRR) exercise, which informed the scope of the design and dialogue phase.</p>
<p>Are you confident that six months is enough to produce the kinds of specifications that European Open Science Cloud (EOSC) still hasn't got off the ground after two years?</p>	<p>Whilst the design and dialogue phase of work is 6 months long, PRUK has been under discussion and development since ESRC, MRC and Wellcome published their respective strategies for longitudinal population research and studies. The 6-month design and dialogue phase aims to deliver recommendations to the funders and inform funder business cases to support creating PRUK. The timelines to the launch of PRUK extend beyond this 6-month phase, and we therefore believe this timescale to be sufficient for this phase of the programme.</p>
<p>Can you say a bit more about the design and implementation of the design and dialogue phase? e.g. Will this be done by internal HDR staff with expertise in qualitative methods/public dialogue methods? Will it be outsourced to independent research agency? How many</p>	<p>HDR UK are committed to delivering the design and dialogue programme across social and biomedical sciences on behalf of the funders. The design and dialogue programme will be conducted by internal HDR UK staff and external consultants. HDR UK have previously led similar stakeholder engagement exercises in the creation of the Industrial</p>

stakeholder interviews/workshops are you envisaging? It is a big community with many different stakeholders!	Strategy Challenge Fund (ISCF) Digital Innovation Hubs programme and will draw on learning and expertise from within this programme.
Great initiative but challenging and difficult one. What practical steps will be taken to ensure that the initiative has trust and confidence of the LPS and wider community? Commitment to transparency and today webinar a welcome first step!	The design and dialogue phase will be carried out in an open and transparent way to try to address these important points, including publication partnership group and programme Board discussions that are used to inform the recommendations to the funders.
How will public group harness advocacy and expertise of groups that are interested and articulate important research and methodological questions but are often missing and a source of biases	These will be available via the PRUK page of the HDR UK website Population Research UK - HDR UK
The role of HDR UK	
When the funding call(s) is made- will HDRUK be submitting a funding bid to this/will they be implementing this new infrastructure?	HDR UK are leading the Design and Dialogue phase 1 programme on behalf of ESRC, MRC and Wellcome. HDR UK will not lead a bid to any subsequent funding calls, which will be run independently by the funders.
How might PRUK interact with the Health Data Research Hubs supported by HDR UK?	It has not been decided how PRUK might work with the Health Data Research hubs. The Health Data Research Hubs curate and make available health data built around disease areas and domain expertise. The data hubs collaborate and share best practice in a number of areas, including PPIE, improving data, commercial models and others. They also make data discoverable and support access to it using a web platform called the Innovation Gateway, and draw on shared resources.
Next steps and materials	
Please can you share the slides?	These are available online here: Microsoft PowerPoint - 151220 Launching the development of PRUK FINAL (hdruk.ac.uk)

	The website will be updated with updates arising from the design and dialogue programme.
What is the process to find a leadership team for PRUK?	The ESRC, MRC and Wellcome expect to run an open call. The form of this has yet to be decided on.
When do the funders expect to launch the leadership competition?	Currently, the call is expected to be launched later in 2021, and these timelines are to be confirmed.
When is Phase 2 of PRUK expected to begin?	