

Launching the development of Population Research UK

16 December 2020



Agenda

Welcome and vision for Population Research UK

Andrew Morris, Director, Health Data Research UK

Chelsea Cinquegrani, Senior Policy Manager Data & Infrastructure,
Economic and Social Research Council

Catherine Moody, Head of Population Health, Medical Research Council

Mary de Silva, Head of Population Health, Wellcome

An overview of Population Research UK phase 1 development programme

Ben Gordon, Executive Director of Hubs and Data Improvement, HDR UK

James Pickett, Hub Development Manager, HDR UK

Questions and answers



Population Research UK

The mission of Population Research UK (PRUK) is to maximise the use and impact of the UK's Longitudinal Population Study portfolio.

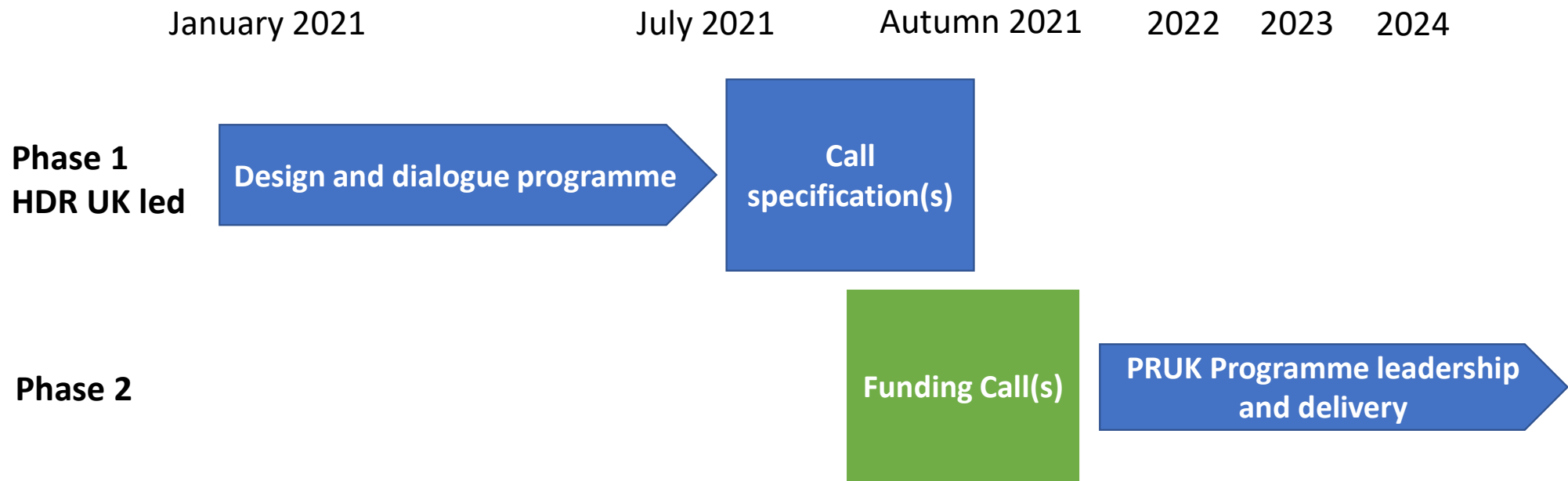
The UK has previously funded over 50 studies, covering some 70+ years of data collection. Many have very rich data and represent a significant public investment over time.

Building on these investments and data infrastructures there is opportunity through PRUK to further integrate individual studies and coordinate the community.

The phase 1 design and dialogue programme will shape the form and function of PRUK, in preparation for subsequent funding call for PRUK leadership and delivery partners.



Population Research UK – timeline overview



Population Research UK

Studies in scope

PRUK is expected to focus on **consented longitudinal population studies (LPS)**

- Studies include panel studies, and cohorts and linked biobanks
- **Across the spectrum** of biomedical and social science studies

Selection of studies driven by:

- User demand
- Where there are efficiencies and advantages of bringing studies together
- Where it offers new functionality to the community



Population Research UK

The proposed long-term successes of PRUK:

- Researchers will be **more easily able to find and access** different multidisciplinary LPS datasets across biomedical and social science studies
- **Enhanced interoperability** based on detailed study metadata using common standards, with linkage across multiple data types.
- **Comprehensive data linkage.** PRUK will make linkages more efficiently than each individual study could alone
- Provide a long-term solution to **scalable LPS trusted research environments**
- A highly coordinated, cohesive and efficient research community across the social and health science sectors.



The public benefit

Greater research impact

Through combining multiple types of data from across the biomedical and social sciences, PRUK can enable high-impact research questions that can not be addressed by single studies alone.

This has been seen in the response to the COVID-19 pandemic and can extend to inform policy and interventions for other grand challenges facing society.

Greater research efficiency

Addressing challenges together, PRUK can act *on behalf of* a community of LPS to deliver benefits and efficiencies to individual studies.



Learning from, and working with, existing research infrastructure

Illustrative examples



the National Core Studies,
individual LPS, and others....



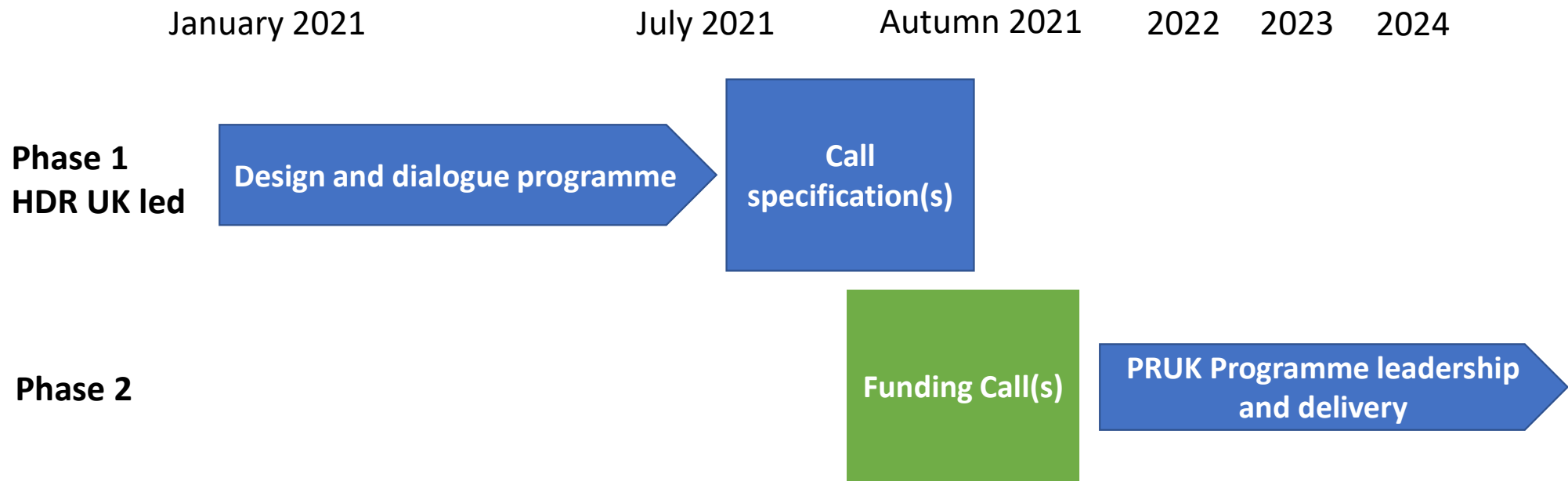
Population Research UK

PRUK is not a research project. PRUK is an infrastructure and resource to enable research using longitudinal population studies.

The full details of PRUK's structure are yet to be developed and will be informed by the design and dialogue programme.



Population Research UK – timeline overview



Phase 1 PRUK Design and dialogue programme

6 month programme to develop and refine the model of PRUK:

What questions the phase 1 will programme ask:

What priorities should PRUK take on?

What capabilities and functions should PRUK develop?

What form and model should PRUK take on?

How PRUK will synergise and work with other existing infrastructure?



Phase 1 PRUK Design and dialogue programme

6 month programme to develop and refine the model of PRUK:

Who will the phase 1 PRUK programme engage?

Data owners and studies

Existing and potential data users

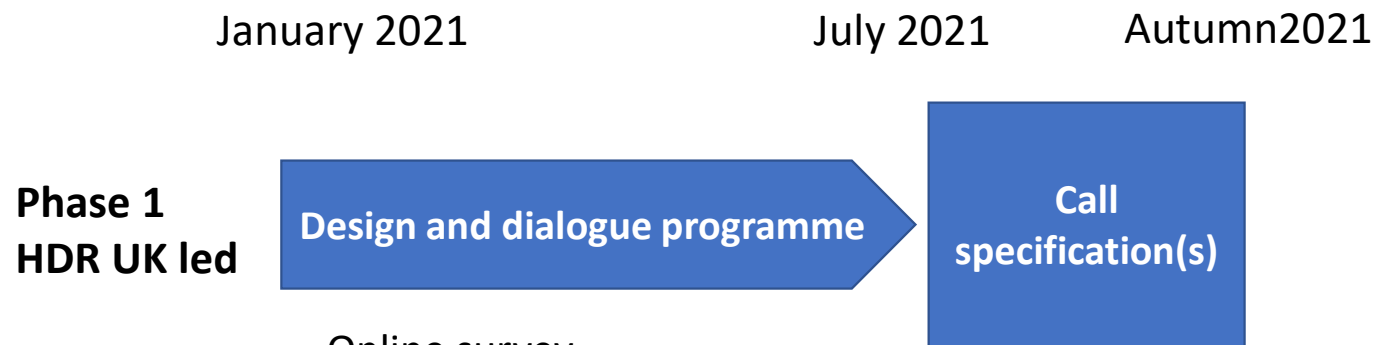
The public and study participants

Academia
Industry
Public policy
Third sector



Phase 1 PRUK Design and dialogue programme

How will stakeholders be involved?



Online survey

1-2-1 or small group interviews

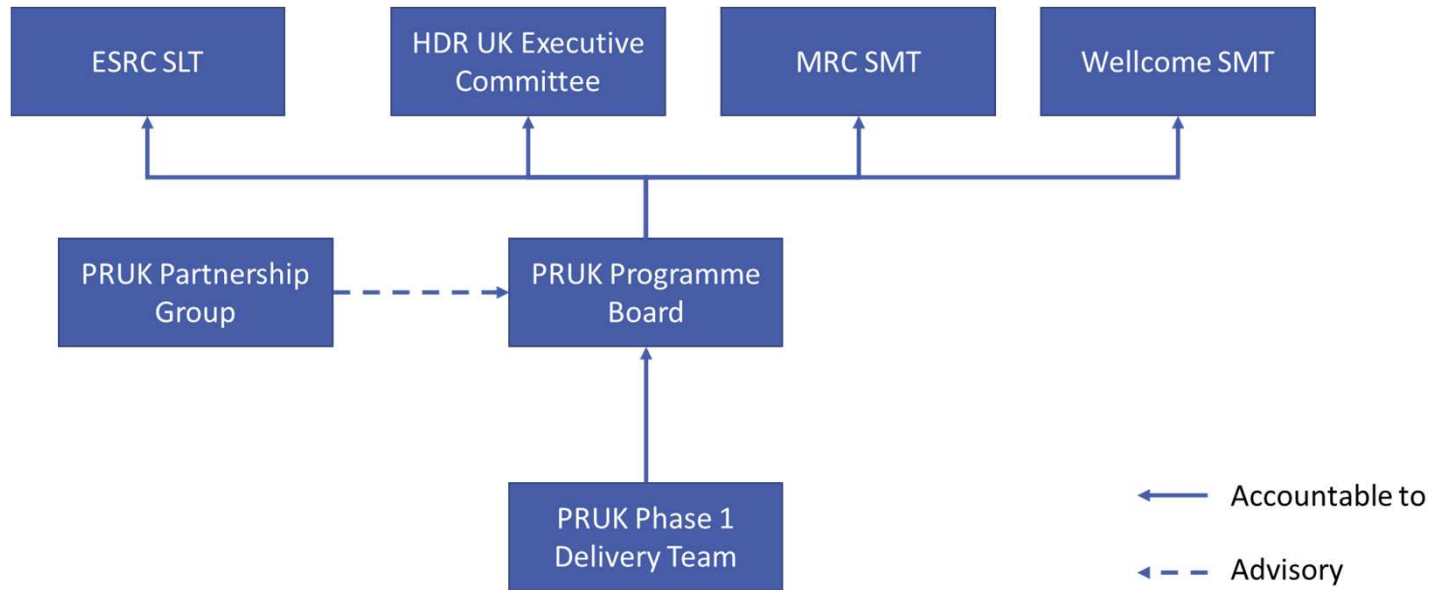
Design workshops

Patient and Public Involvement and Engagement

Consultation responses



Phase 1 PRUK Design and dialogue programme - governance



<https://www.hdruc.ac.uk/population-research-uk>



Phase 1 PRUK Partnership Group

Representation, invited by the funders, to be across the disciplines and initiatives PRUK will operate and work with.

- Advise on the engagement processes
- Provide a collective perspective from LPS communities
- Make recommendations on the aims, function and mission of PRUK

Public minutes of Partnership Group meetings

To engage with the programme, and find out how to ask questions, please visit:

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

Member	Organisation
Hetan Shah (Chair)	The British Academy
Frank Windmeijer	University of Oxford
Andy Boyd	University of Bristol
Mike Daly	Department of Work and Pensions
Emma Gordon	ESRC, Director of Administrative Data Research UK
Rebecca Hardy	UCL, Director of CLOSER
John Gallacher	University of Oxford, Dementias Platform UK
Cathie Sudlow	University of Edinburgh, BHF Data Science Centre
Matthew Woollard	University of Essex, UK Data Archive
Lucy Dixon	Public member
Maisie McKenzie	Public member



Public and study participants

- Co-create PRUK to be acceptable to the public in a way that builds trust
- Learn from the exceptional engagement LPS have with their participants
- Partnership Group membership
- To advise and develop appropriate ways to involve public and study participants in PRUK.



The PRUK network

The phase 1 programmes needs your engagement and help inform the design of PRUK.

- Regularly updated information and key outputs of HDR UK website
- Regularly publish frequently asked questions
- Minutes, meetings and progress outputs



Sign up at:

<https://www.hdruk.ac.uk/population-research-uk>



Questions and discussion

<https://www.hdruk.ac.uk/population-research-uk>



HDRUK
Health Data Research UK

