



HDRUK
Health Data Research UK



04. Population Research UK Partnership Group minutes and actions

Date: Tuesday 15 December 2020

Time: 10:00 -12:00

Chair: Hetan Shah, The British Academy

Attendees:

Andy Boyd, University of Bristol

Cathie Sudlow, University of Edinburgh, BHF Data Science Centre

Emma Gordon, ESRC, Administrative Data Research UK

Frank Windmeijer, University of Oxford

John Gallacher, University of Oxford, Dementias Platform UK

Lucy Dixon, Public Member

Maisie McKenzie, Public Member

Matthew Woollard, University of Essex, UK Data Archive

Mike Daly, Department of Work and Pensions

Rebecca Hardy, UCL, CLOSER

Bridget Turner, ESRC (observer)

Catherine Moody, MRC (observer)

Gavin Malloch, MRC (observer)

Mary de Silva (observer)

Laura Morrell (observer)

Ben Gordon, HDR UK (secretariat)

James Pickett, HDR UK (secretariat)

Minutes and actions

- The Partnership Group members introduced themselves to each other.
- The Partnership Group members described the different research infrastructures and initiatives to which they were associated.
- The Partnership Group discussed the terms of reference and the relationship of the Partnership Group to the Programme Board. The terms of reference of both groups are included in Annex 1.
- The commitment to the Partnership Group being transparent in its activity through making minutes of its meetings and key papers available was discussed and endorsed by the membership.
- There was discussion about the best way for interested stakeholders to engage and it was agreed that the stakeholder community be encouraged to contact the HDR UK team centrally via the

details on the HDR UK website in the first instance rather than Partnership Group members individually.

- HDR UK and the research funders presented a slide set providing an overview of the ambitions of PRUK and its proposed activities as well as the planned design and dialogue programme. The updated slide set 'Launching the Development of Population Research UK' is available on the [HDR UK Population Research UK webpage](#).
- Partnership Group welcomed and endorsed the ambition of the ESRC, MRC and Wellcome to fund jointly a longitudinal population studies resource.
- It was clarified that the aim of PRUK was to be an enabling initiative and resource for longitudinal population research. PRUK was not to be a research project.
- HDR UK explained that the structure of PRUK had yet to be decided. It was to be informed by the design and dialogue phase. PRUK may be a single entity or could function as a more distributed structure.
- It was clarified that PRUK was a continuation of previous discussions facilitated by ESRC, MRC and Wellcome to create 'Population Research Resource' (PRR).
- The Partnership Group provided helpful feedback on the slide set. HDR UK agreed to update the slides in response to these points ahead of tomorrow's webinar. These changes are reflected in the publicly available copy of the slide set.
- The Partnership Group also provided recommendations of areas for further development for PRUK through the design and dialogue phase. These covered:
 - Additional clarity on the scope of PRUK – in particular coverage beyond Longitudinal Population Studies – so as to focus on something ambitious but achievable
 - The public value of the proposition. In other words, a 'mission' focus where benefit and research questions enabled by PRUK are described
 - Defining success criteria for PRUK and gap analysis on what is not currently in place
 - The positioning of PRUK to other initiatives with functionality, services or data relevant to the proposed operating space of PRUK
 - Options on the structures of PRUK and the incentives to encourage studies to join
 - The importance of involving other funders outside of those currently represented
 - Joining up with any existing public engagement initiatives and ensuring it was clear what is already decided and what is being consulted on
- HDR UK thanked the Partnership Group for their input and agreed to take the recommendations as actions for further development.
- The next Partnership Group meeting would be scheduled for early February.
- The Chair thanked the group for their participation and closed the meeting.

Annex 1 - Population Research UK Partnership Group

Terms of Reference

About PRUK

The vision of PRUK is to create a new research infrastructure that maximises the insights, innovations and research efficiency of the UK's world leading social and biomedical data assets. PRUK will enable new insights and improved outcomes for the UK population by enabling a greater understanding of the complex interplay between biological, social, economic and environmental determinants of health, social and economic outcomes.

HDR UK are leading, on behalf of ESRC, MRC and Wellcome Trust, a design and dialogue programme to set out the functions and form of PRUK. A PRUK network, with open membership, is being established to ensure input from all interested stakeholders. The Partnership Group will be composed of invited representatives from the PRUK network to advise on the engagement processes, provide a collective perspective from LPS communities, and make recommendations on the aims, function and mission of PRUK to the Programme Board (annex 1) throughout the project duration.

The output of the design and dialogue phase of PRUK is expected to be a Call specification(s) for the leadership and delivery of PRUK (subject to funding being secured).

Partnership group remit

Partnership Group members will have recognised expertise in one or more areas that are relevant to the objectives of PRUK, representing the breadth of disciplines within the PRUK vision.

The Partnership Group act in an advisory capacity only and make recommendations to the Programme Board, which is composed of senior representatives of ESRC, MRC and Wellcome Trust (annex 1). The Partnership Group will have no decision-making authority, but are:

- To be 'critical friends' to the development of the PRUK operating model and overall proposition.
- To monitor engagement of stakeholder groups with PRUK design and dialogue phase, including current LPS leaders, LPS infrastructures, and the public and LPS participants.
- To support alignment of PRUK with other key initiatives and infrastructure that support and enable LPS.
- To advise on public and patient involvement (PPI) needs and approaches in the PRUK design and dialogue phase.
- To promote and amplify communications about PRUK through partnership group members' networks and contacts.

Mode of Working

- Meetings will be scheduled every two months until the completion of the design and dialogue phase or as otherwise agreed by the Programme Board.
- An independent Chair will be appointed by the Programme Board. The Chair will have an open invitation to attend Programme Board meetings.
- Secretariat will be provided by HDR UK
- Representatives of the funding organisations (ESRC, MRC and Wellcome Trust) are invited to attend as observers.
- Minutes of the meetings will be public documents and expected to be put in the public domain.
- Members of the partnership group will be eligible to apply to any subsequent funding made available for phase 2 of PRUK.

Membership

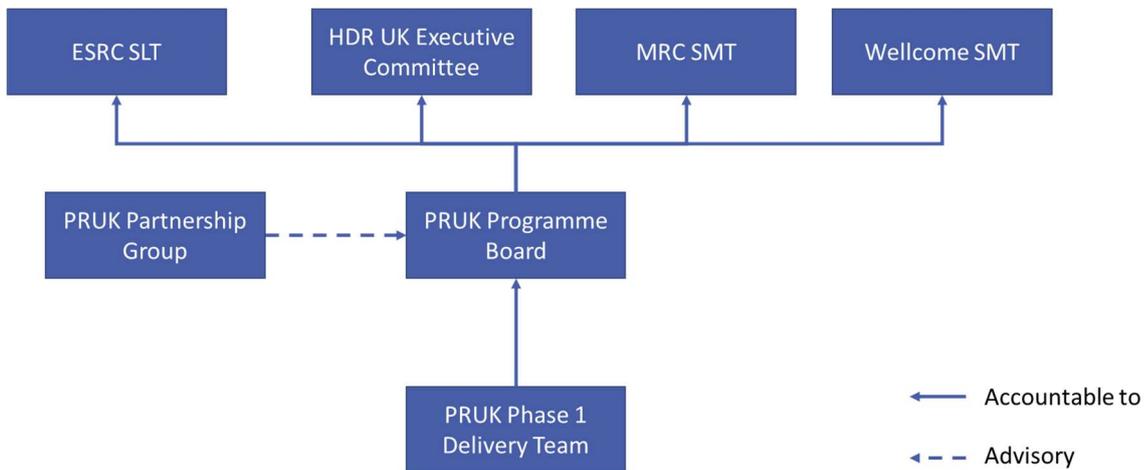
- Partnership Group membership will be by invitation of the Programme Board based on their expertise and ensuring balanced geographic and institutional coverage.

| Member | Organisation | Role / affiliations |
|--------------------|-------------------------|---|
| Hetan Shah (Chair) | The British Academy | Chief Executive. Deputy Chair, Ada Lovelace Institute, Visiting Professor, King's College |
| Andy Boyd | University of Bristol | Data linkage manager ALSPAC National Core Studies Longitudinal Linkage Consortium co-lead |
| Cathie Sudlow | University of Edinburgh | Professor of Neurology & Clinical Epidemiology Director, BHF Data Science Centre for cardiovascular health |
| Frank Windmeijer | University of Oxford | Professor of Econometrics |
| Emma Gordon | ESRC | Director, Administrative Data Research UK |
| John Gallacher | University of Oxford | Professor of Cognitive Health Director of Dementias Platform UK |
| Lucy Dixon | Public Member | |
| Matthew Woollard | UK Data Service | Director of UK Data Archive and the UK Data Service |
| Maisie McKenzie | Public Member | |

| | | |
|---------------|---------------------------------|---|
| Mike Daly | Department of Work and Pensions | Central Analysis & Science Strategy Unit |
| Rebecca Hardy | UCL | Professor of Epidemiology and Medical Statistics, UCL Social Research Institute Director of CLOSER |

There are up to two spaces reserved on the Partnership Group for additional expertise as needed.

Annex 1 – PRUK governance overview



Population Research UK Programme Board (phase 1)

Terms of Reference

Remit

The Programme Board is a decision-making group that oversees delivery of the PRUK design and dialogue (phase 1) programme. Its composition was selected to be a senior representative of each funder (ESRC, MRC and Wellcome), empowered to make decisions on behalf of their respective organisation.

- To oversee governance structures of PRUK, including the effective operation of the Partnership Group
- To oversee the delivery of PRUK by HDR UK
- To consider and approve recommendations related to the aims, activities and operational model of PRUK and the related process for the award of funding.
- To monitor engagement of stakeholder groups with PRUK phase 1 development, including the Partnership Group, current LPS leaders, LPS infrastructures, LPS data users, and the public and LPS participants.
- To advise and support on alignment of PRUK with established and future activities within the funders' portfolios.
- To approve the final deliverables of phase 1, expected to be a draft commissioning document outlining the expectations, leadership and technical requirements of PRUK.

To oversee that risks within the project are being appropriately controlled

Membership

| Member | Organisation | Deputy | Role |
|---------------|--------------|---------------------|----------------------------|
| Alison Park | ESRC | TBC | Decision making Member |
| Rob Buckle | MRC | Catherine Moody | Decision making Member |
| Mary de Silva | Wellcome | Bruna Galobardes | Decision making Member |
| Ben Gordon | HDR UK | Melissa Lewis-Brown | Non decision-making Member |

| | | | |
|---------------|---------------------|--|---|
| James Pickett | HDR UK | | Non-decision-making Member |
| Hetan Shah | The British Academy | | Non-decision-making Member Partnership Group Chair |

The Partnership Group Chair will have an open invitation to attend meetings.

Other members of the funding organisations may attend as observers.

Mode of Working

- Decisions should be made unanimously between the three decision-making members (ESRC, MRC and Wellcome).
- Meeting's will be scheduled every two months until the completion of project until summer 2021 or otherwise agreed.
- Chair will rotate between ESRC (Dec, May), MRC (Jan), Wellcome (March).
- Secretariat will be provided by HDR UK
- Minutes of meetings will be public documents and expected to be shared



Population Research UK Partnership Group - agenda

Date: Tuesday 15 December 2020

Time: 10:00 -12:00

Chair: Hetan Shah, The British Academy

| Timing | Item | Lead, Papers |
|---------------|--|--|
| 10:00 – 10:30 | Welcome and Introductions | Hetan Shah, none <i>Each panel member to introduce themselves.</i> <i>For those that lead an LPS infrastructure please introduce the aims of the initiative.</i> |
| 10:30 – 11:00 | The role and terms of reference for the Partnership Group <i>Discussion and Partnership Group ways of working</i> | James Pickett, Ben Gordon HDR UK Partnership Group terms of reference Programme Board terms of reference |
| 11:00 – 11:30 | An overview of PRUK and the design and dialogue programme | James Pickett, Ben Gordon HDR UK Slides will be presented, PRUK project plan PRUK Communications and PPIE plan |
| 11:30 – 11:50 | Discussion <i>Defining the important questions for the design and dialogue programme to address</i> <i>Open feedback and discussion</i> | All |
| 11:50 | AOB – Next steps and actions | All |