

# UK Health Data Research Alliance Board

Thursday 23<sup>rd</sup> July 14:00-16:00

## Immediate actions for Alliance members:

- Provide contact names and details of their Data Access Leads and PPIE representatives.
- Nominate representatives to attend a Data Access Deep Dive on 14 August 10:00-12:00 and participate in the 'Early Adopters' programme, with the aim of trialling the data access request module in October 2020.
- Complete survey on [Data standards and usage](#) to inform work on Data Utility.
- Continue work with HDR UK Metadata Onboarding team to prepare data for loading and continue to improve the quality of metadata in the Innovation Gateway.
- Save the date for the next UK Health Data Research Alliance Symposium on 1 December 2020.
- Contact Julia Levy [Julia.Levy@hdruk.ac.uk](mailto:Julia.Levy@hdruk.ac.uk) if you'd like more information on joining the International COVID-19 Alliance.

## Immediate actions for Alliance secretariat:

- Publish the green paper on Trusted Research Environment on the UK Health Data Research Alliance website.
- Send metadata improvement updates to individual Alliance member organisations.
- Circulate the One London Local Health Care Record Exemplar (LHCRE) report on 'Public deliberation in the use of health data', exploring views that came out of the One London Citizen's Summit held in February and March 2020.

## Meeting notes:

### Welcome, Action points from last meeting and Update

- Andrew Morris (Chair) welcomed everyone to the meeting and set out the agenda.
- Action points from last meeting were reviewed and an update was given on:
  - New Board members joining the Alliance
  - Developments from the Health Data Research Hubs
  - Alliance delivery sub-groups
  - Launch of the International COVID-19 Alliance and Workbench.
- Peter Williams (NHSx) provided an update on the COPI Notices issued as part of the response to the pandemic and confirmed that an extension has been granted until 31<sup>st</sup> March 2021.  
<https://www.hra.nhs.uk/about-us/news-updates/extension-covid-19-copi-notice/>

## COVID-19 National Core Studies – Data & Connectivity



- Data & Connectivity is one of the themes of work commissioned by Sir Patrick Vallance to consider what national core studies are required to enhance understanding of SARS-COV-2 virus and the UK's pandemic at the national level. The purpose is to identify those studies that are essential to support research for HMG policy developments and operational decision making.
- HDR UK and The Office for National Statistics have been tasked to define the infrastructure, data and services needed to create a trustworthy health and cross-sectoral data capability that can support the next phase of pandemic preparedness.
- Board welcomed this work and acknowledged the need of addressing the fragmentation of work leveraging cross-sectoral opportunities. It was noted that often conflicting insights might lead to uncertainties among the public, so it will be important to deliver consistent messages for the public.

#### **Diversity and Inclusion statement and immediate actions**

- The Board endorsed the statement with minor edits and acknowledged the importance of seeking diversity and representativeness in data samples. Statement will be published on the UK Health Data Research website.
- It was agreed that improving quality of ethnicity coding and use data to help increase the representativeness of research studies will be the initial focus of this work that will be initiated by the Data Officers Group.
- Understanding differences in ethnicity coding across the devolved nations is an important first step.

#### **Principles for data in the Gateway**

- It was agreed that these principles are required to guide inclusion of private sector and international datasets as part of the gateway.
- It was also generally agreed that we should extend the scope of the proposed review of new datasets to cover all datasets including those from publicly funded UK custodians.
- The principles are expected to be operational from September 2020.

#### **Trusted Research Environment green paper**

- Board approved the updates to the green paper resulting from stakeholder engagement over the last few months and online consultation ran between 30 April and 26 May. This will be published on Alliance website and distributed to stakeholders.
- Board noted that during the implementation phase it will be crucial to involve all relevant stakeholders and potential users to inform direction of travel, including industry as well as clinical colleagues.
- Consideration should also be given to addressing researcher productivity, i.e. balancing computing/analytical capability while ensuring safe use of health data.
- Many Alliance members expressed interest in being involved in the next steps and are keen to collaborate.



### **Innovation Gateway**

- Recent updates on the phase 2 development of the Innovation Gateway were presented and demonstrated.
- Development of the data access module also presented and Alliance members invited to nominate representatives to attend a Data Access Deep Dive on 14 August 10:00-12:00 and participate in the 'Early Adopters' programme, with the aim of having Alliance members trialling the data access request module in October 2020.

### **Next Alliance Board meeting**

- The next Alliance Board meeting will take place on 14 October 10:00-12:00 via teleconference (Zoom details to be provided). Please save the date, a calendar invite will follow.



## Appendix

### Attendees via Zoom

Name	Organisation
Alex Newberry	Welsh Government
Peter Bradly	Public Health England
Anne Powell	National Consortium of Intelligent Medical Imaging
Chris Orton	SAIL Databank
David Porteous	Generation Scotland
Daren Lunn	CPRD
Else Krajenbrink	RCGP
Emily Jefferson	Health Informatics Centre, University of Dundee
Janet Valentine	CPRD
John Bradley	NIHR Bioresources
Kate Blake	Guy's and St Thomas Hospital Foundation Trust
Kate Northstone	ALSPAC
Mark Howells	Nottinghamshire Healthcare NHS Foundation Trust
Neena Modi	NDAU Imperial College
Neil Sebire	Great Ormond Street Hospital NHS Foundation Trust
Nicola Armstrong	HSCNI
Peter Bradley	PHE
Peter William	NHSx
Phil Quinlan	UKCRC Tissue Directory and Coordination Centre
Stephen Lock	NIHR Clinical Research Network
Tim Hubbard	Genomics Enlgand
Tom Denwood	NHS Digital
Yvonne Silove	HQIP
Andrew Morris	HDR UK
Adam Milward	MetadataWorks
Ben Gordon	HDR UK
Caroline Cake	HDR UK
David Seymour	HDR UK
Gerry Reilly	HDR UK
Melissa Lewis-Brown	HDR UK
Paola Quattroni	HDR UK
Peggy Barthes-Streit	HDR UK
Sinduja Manohar	HDR UK
Susheel Varma	HDR UK
Trish Falegan	HDR UK