

# UK Health Data Research Alliance Board

Wednesday 14<sup>th</sup> October 10:00-12:00

## Immediate actions for Alliance members:

- Provide contact names and details of Alliance member PPIE representatives.
- 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.
- [Register](#) to attend the next UK Health Data Research Alliance Symposium on 1 December 2020.
- Promote the [Open Call for Lightning Talks](#) at the Alliance Symposium to your networks.

## Immediate actions for Alliance secretariat:

- Set up a Special Interest Group on data diversity to start work on improving ethnicity coding. If interested in joining the group, please contact [Paola.Quattroni@hdruk.ac.uk](mailto:Paola.Quattroni@hdruk.ac.uk)
- Circulate details about first [International COVID-19 Alliance Forum](#).

## 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
- As part of the Convenor's Update, Caroline Cake provided the Health Data Research narrative to highlight main achievements resulting from the work of HDR UK and partners (slides will be circulated).

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

- An important theme of this Board meeting was the COVID-19 pandemic and the work to tackle the second wave of the pandemic.
- David Seymour provided an overview of the National Core Studies programme and the [Data & Connectivity Study](#).
- HDR UK and the Office for National Statistics have now received confirmation from Treasury on the first phase of the Data & Connectivity programme through to 31 Mar 2021 and commenced the first 'sprint' on Monday 5 Oct. Data & Connectivity will be a very major activity for HDR UK over the next 6 months.

- The Board welcomed this work and acknowledged the need of addressing the fragmentation of work leveraging cross-sectoral opportunities.
- It was noted that studies not currently part of the National programme are still of great importance and it will be interesting to see how these will fit within the National Core Studies work.
- The Board also noted that it would be helpful to clarify if there will be a process for members to get involved in this work.

### **Data diversity and ethnicity coding improvements**

- Following the previous Board meeting, it was agreed that improving quality of ethnicity coding and using data to help increase the representativeness of research studies will be the initial focus of this work to be initiated by the Data Officers Group. This also strengthens HDR UK's data diversity commitment set out in our Diversity and Inclusion policy.
- We are now seeking volunteers to create a Special Interest Group to define the initial set of activities and complement the work of the Data Officers Group. Several Alliance members expressed interest in joining this group.
- This work will also be complementary to recording ethnicity data elements within the metadata of datasets listed in the gateway (technical metadata element/data profiling).
- Alastair Denniston mentioned the concept of Data Poverty and the work of PIONEER and Insight Hubs, also highlighted in [this blog](#) and [this paper](#). Ensuring inclusiveness and representativeness of data is important to ensure reliability of insights.
- Liz Sapey shared a design series of infographics that are currently used to describe visually the attributes of datasets. This is a helpful tool to describe the importance of data ethnicity in hospitals providing an instant taste of what data holds. It was suggested it could also be used to describe datasets in the gateway).
- Stephen Lock highlighted the NIHR strategy around Underserved community. NIHR CRN analysis showed that there is an inverse correlation between the areas of high prevalence of disease (or high levels of deprivation) and areas of high levels of recruitment to research. We're actively looking to improve this by (for example) changing the way we allocate sites in multi-centre studies or fund studies that actively seek to address this. [This paper](#) showcases an example of how NIHR CRN were used to address health inequality.
- Stephen Lock stressed the importance of inclusiveness in clinical trial enrolment and supporting everyone's participation. The NIHR CRN is involved in the [INCLUDE project](#), aiming to examine how under-represented groups can better included in clinical research and published a guidance around this.
- Neena Modi highlighted the importance of including pregnant women out in vaccine trials, currently an under-represented group.

### **Black internship programme**

- Caroline Cake presented the new HDR UK Black Internship Scheme for health data scientists to work with Alliance members and other partner organisations.
- To date, 27 organisations have agreed to take part in the programme.



### Data Utility

- Data utility work provides a means of articulating the usefulness of datasets.
- This is intended to support user activity through the Gateway and includes development of a Data Utility Evaluation Framework and using open source tools for data profiling.
- An update on data improvement work undertaken by Hubs was provided by Andy Rees (DigiTrials) and Chris Orton (BREATHE). Learnings can be applied across the UK Alliance.

### Innovation Gateway

- Recent updates on the phase 2 development of the [Innovation Gateway](#) and updates on data access work were presented.
- The first version of the Five Safe data access application form will be available for some custodians within the next couple of months.

### Next Alliance Board meeting

- The next Alliance Board meeting will take place on **20 January, 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
Claire Bloomfield	National Consortium of Intelligent Medical Centre (NCIMI)
Alistair Weir	Guy's and St Thomas Hospital Foundation Trust
Chris Orton	SAIL Databank
David Porteous	Generation Scotland
Ian Young	Health & Social Care Northern Ireland
Mark Beggs	NCIMI
Andy Roddam	Accelerating Detection of Disease Project
Geoff Huggins	NHS Scotland
Janet Valentine	CPRD
John Bradley	NIHR BioResource
Kate Blake	Guy's and St Thomas Hospital Foundation Trust
David Crossman	Scottish Government
Mark Howells	Nottinghamshire Healthcare NHS Foundation Trust
Rebecca Cosgriff	Cystic Fibrosis Trust
David Ford	SAIL DataBank
Hilary Fanning	University Hospitals Birmingham NHS Foundation Trust
Sneha Anad	University of Oxford, RCGP Research and Surveillance Centre
Neena Modi	NDAU Imperial College
Indra Joshi	NHSX
Peter Bradley	Public Health England
Katie Kissick	BREATHE
Matt Cooper	Data-CAN
Stephen Lock	NIHR Clinical Research Network
Fran Woodard	NHS Digital
Tom Denwood	NHS Digital
Yvonne Silove	HQIP
Alastair Denniston	INSIGHT
Liz Sapey	PIONEER
Cathie Sudlow	HDR UK
Andrew Morris	HDR UK
Kay Snowley	HDR UK
Caroline Cake	HDR UK
David Seymour	HDR UK
Gerry Reilly	HDR UK
Peggy Barthes-Streit	HDR UK

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