

# UK Health Data Research Alliance Board

Wednesday 20<sup>th</sup> January 10:00-12:00

## Immediate actions for Alliance members:

- Express your interest to attend the first **Special Interest Group meeting on Data Diversity on 8 February** (13.00-15.00) by emailing [Paola.Quattroni@hdruk.ac.uk](mailto:Paola.Quattroni@hdruk.ac.uk)
- 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
- Please let [Paola.Quattroni@hdruk.ac.uk](mailto:Paola.Quattroni@hdruk.ac.uk) if there are any changes to contact details for those included in the current mailing list.

## Actions for HDR UK secretariat:

- Confirm Alliance members' contact details
- Provide regular update on SAGE reporting, Data & Connectivity Programme of work, vaccination data availability
- Approach all Alliance members to explore opportunities for adoption of the Five Safe data access form and associated workflow for datasets in the Gateway
- Circulate link to 'Data access processes – public involvement, trust and transparency' survey and invite to special interest group meeting on Data Diversity.

## 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
  - Patient, public and practitioner involvement

### Updates from members

As part of the general updates, representatives from the devolved nations provided a summary of recent work.

- Jackie Gray and Heather Pinches provided an update on behalf of NHS Digital.
  - Work is progressing to create linked NHSD-ONS data assets and make them available for the research community.
  - A Data Alliance Partnership has been convened by NHS-X with the aim to improve collection of data from NHS organisations; improve access and sharing of information; provide better access to data that can be made available in an anonymous fashion.

- Work with ICO in progress on developing a new Article 40 code of conduct for healthcare and provide guidance building on available resources. The Code of Conduct is being progressed through the Health and Care IG Panel.
- Work on getting vaccination data into NHSD is progressing.
- Indra Joshi, NHSX highlighted that access to the [National COVID-19 Chest Imaging Database \(NCCID\)](#) has now been extended to hospitals and universities across the country who are using the images to track patterns and markers of illness. In subsequent discussion, the [Buyers Guide to AI in Health and Care](#) was also highlighted as an available resource.
- Alex Newberry provided an update on behalf of Public Health Wales.
  - Work on legacy contracts for accessing data beyond the pandemic
  - Consultation in Wales about replacing NHS Informatics to improve data processing
  - Work with the Department of Health on a new research strategy, where the data element is strong.
  - Onboarding of vaccination data from the Welsh Immunisation Service.
- David Crossman and Phil Couser provided an update on behalf of Public Health Scotland and Scottish government.
  - Focus on COVID research and importance of bringing data together to make decisions on management of pandemic.
  - Research Data Scotland has been created and service will be provided by Public Health Scotland and eDRIS.
  - Programme of the Scottish government in the last year has seen Artificial Intelligence as a major deliverable.
  - Consideration on linking work on AI and whether HDR UK could have a role in developing an AI stream.
  - In relation to data for secondary use and with high volumes of data flowing to the government for analyses, consideration should be given how the public is involved and how to maintain public trust.

### Black Internship programme

Tammy Palmer provided an update on the Black Internship programme. Twenty-one organisations are taking part on the programme with approximately 3405 internships being offered. Interviews to identify suitable interns are already taking place and successful applicants will be notified of outcomes the first week of February.

### Vaccine research

Janet Valentine (CPRD) provided an overview of vaccine data flows.

- Pharmacovigilance Vaccination data are flowing to MHRA supported by CPRD.
- Partnership with NHSD (as processor) on making three datasets available: vaccination dataset, adverse reaction datasets and SUS raw data (already in NHSD).
- CPRD will have around 25% population coverage linked data.
- Data are expected to be available for the research community by end of March.



- When answering research questions around vaccination, it is important to connect groups and avoid duplication of efforts.

David Seymour (HDR UK) provided an update on recent involvement of Data & Connectivity National Core Study in accelerating vaccine data availability for research.

- Data & Connectivity National Core Study is supporting the UK Vaccines Science Coordination group chaired by Professor Wendy Barclay. The group has identified a set of research questions aimed at addressing topics around effectiveness of vaccines, effect of vaccines on virus transmission, immunity and how dosing schedules affects efficacy of vaccines. To support answers to these research questions a sophisticated data infrastructure is needed.
- Working on definition of minimum dataset at point of care to be recorded.
- ONS is receiving data feeds directly by NHS England. Both NHSD and ONS are working towards a joint controllership to enable access to this data for research.
- Major efforts to accelerate vaccination data flows are ongoing in all devolved nations.

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

- Work driven by the National Core Study programme and the of [Data & Connectivity Study](#) is continuing at pace.
- Twelve project teams have been funded through a rapid funding call to answer priority questions driven by use of priority datasets made available through the [Innovation Gateway](#). All project teams are expected to submit their first data access request through the Gateway by January 31<sup>st</sup>.
- The Board acknowledged the need of addressing the fragmentation of work leveraging cross-sectoral opportunities. We have an opportunity to unify strands across core studies and propagate the conversation to non-core studies.
- 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 latest COVID-19 Round-up can be accessed [here](#).
- The latest SAGE report (26 Jan 2021) can be found [here](#).

### Innovation Gateway

- Peggy Barthes-Streit presented recent updates on development of the [Innovation Gateway](#) and data access work.
- The first version of the Five Safe data access application form is now available for NHS Digital, SAIL, Databank, Public Health Scotland, Health and Social Care Northern Ireland, Office for National Statistics, and INSIGHT. This is currently being used by the data custodians to provide access to COVID-19 related datasets as part of the National Core Study programme as well as to INSIGHT datasets.
- The HDR UK team will be approaching all Alliance members to explore options to replace their current enquiry form with the new Five Safe data access request form.



### **Data Access Registers**

David Seymour and Sinduja Manohar introduced a project aimed at improving transparency on how health data is used for research and innovation across the UK. A paper outlining 'data access volumes and estimates' was circulated before the meeting.

Alliance members are now requested to:

1. Provide feedback on the estimates outlined in the paper.
2. Contribute to the list of public data access registers where their organisation is not listed.
3. Continue to support the onboarding of metadata for any datasets made available for research by their organisation.
4. Support the continued development of the gateway as a common data access request portal by adopting the Five Safes form and associated workflow.
5. Engage in the work being undertaken on Data Access Registers to increase the number and accessibility of them and improve how the information is presented to a lay audience, including the role of the Gateway in improving transparency of data access

The Board welcomed this work and agreed that improving transparency on how health data is accessed and used is important for the public, researchers and funders.

The Board proposed to focus on

- Best practice and standard way of communicating how data is used
- Linking outputs to application and tracking
- Identifying a minimum set of information available

The Board cautioned that maintenance of registers, responsibilities and resources are aspects to consider when planning this work.

### **Next Alliance Board meetings**

The next Alliance Board meetings will take place via Zoom on:

- 20 April 14.00-16.00
- 14 July 14.00-16.00
- 20 Oct 10.00-12.00

Please save the dates, a calendar invite will follow.



## Appendix

### Attendees via Zoom

Name	Organisation
David Jenkison	Brain Tumour Charity
Chris Orton	SAIL Databank
Brendan O'Brien	NHS National Services Scotland
Matt Cooper	Data-CAN
Mark Beggs	NCIMI
Andy Roddam	Our Future Health
David Crossman	Scottish Government
Janet Valentine	CPRD
Colin Smith	UK Brain Bank Network
Mark Howells	Nottinghamshire Healthcare NHS Foundation Trust
Nicola Armstrong	HSCNI
Phil Quinlan	Tissue Directory Coordination Centre
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
Suzie Gallier	PIONEER
Julia Hippisley-Cox	QResearch
Stephen Lock	NIHR Clinical Research Network
Tim Skelton	University Hospitals Leicester NHS Foundation Trust
Eleanor Hall	Gut Reaction
Mark Howells	Nottinghamshire Healthcare NHS Foundation Trust
Alex Newberry	Wales Government
Yvonne Silove	HQIP
Heather Pinches	NHS Digital
Steven Casson	Public Health England
Shekha Modhw	UHB
Alastair Denniston	INSIGHT
Jon Smart	Swansea University
Shaun Cochrane	Guy's and St Thomas Hospital
Phillip Courser	Public Health Scotland
Nic Timpson	ALSPAC
David Porteous	Generation Scotland
Jackie Gray	NHS Digital
Mark Weeks	Gut Reaction

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Alastair Denniston	Insight
Mark Caulfield	Genomics England
Joel Backman	HDR UK
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
Ben Gordon	HDR UK
Sinduja Manohar	HDR UK
David Seymour	HDR UK
Paola Quattroni	HDR UK
Tammy Palmer	HDR UK
Clara Fennessy	HDR UK
Richard Edwards	PA Consulting