

# UK Health Data Research Alliance Board – actions and meeting notes

Wednesday 14<sup>th</sup> July 2021 14.00-16.00

## Immediate actions for Alliance members:

All Alliance members are requested to:

- Comment on the [Data use registers standards green paper](#) by completing [this survey](#). The survey will remain open until 20 August 2021.
- Contact the Data Improvement team [Alison.Elderfield@hdruk.ac.uk](mailto:Alison.Elderfield@hdruk.ac.uk) to prepare data for loading and continue to improve the quality of metadata in the Innovation Gateway.
- Inform [Sarah.Fullegar@hdruk.ac.uk](mailto:Sarah.Fullegar@hdruk.ac.uk) of any changes to contact details for those included in the current mailing list.
- Contact [Paola.Quattroni@hdruk.ac.uk](mailto:Paola.Quattroni@hdruk.ac.uk) to discuss data access options for your datasets in the gateway.
- Contact [Susheel.Varma@hdruk.ac.uk](mailto:Susheel.Varma@hdruk.ac.uk) to learn more about what the Cohort Discovery Tool would add to discovery and understanding of your datasets.

## Actions for HDR UK secretariat:

- Circulate dates and invites to next Alliance Board meetings as well as PPIE Leads workstream and diversity in data meetings.
- Circulate information about Health Data Research Hubs development and requirements.

## Meeting notes:

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

- Andrew Morris welcomed everyone to the meeting and stressed the importance of the Alliance in increasing transparency of data use and availability of diverse and complete data for research and innovation. The work of the Alliance sets the foundation work that will have relevance and applicability internationally.
- Action points from last meeting were reviewed and an update was given on:
  - New Board members joining the Alliance.
  - Developments on the Gateway and the formation of the Infrastructure Advisory Group to shape the Gateway (Paola Quattroni and Tim Hubbard).
  - Developments from the Health Data Research Hubs and launch of new Hubs, the APDP Pain Research Data Hub [Alleviate](#) and Hub for Mental Health Informatics Research Development [DATAMIND](#).
  - 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.

- David Ford provided an update on the work of SAIL Databank in Wales:
  - SAIL continues to provide services across the UK and internationally.
  - Work with ICODA is ongoing to accelerate international COVID-19 research.
  - Involvement in the National Core Studies Longitudinal Linkage Consortium work - bringing what will be a couple of dozen of the UK's best cohorts studies all together onto one data platform.
- Scott Heald and David Crossman provided an update on behalf of Public Health Scotland and Scottish government:
  - Research Data Scotland launched in September and now offers a route by which researchers can access admin and health data across sector. The eDRIS team and Public Health Scotland are part of Research Data Scotland.
  - A new research hub and a Covid related research repository also launched recently.
  - David Crossman reiterated his support to the UK Health data Alliance and highlighted the important function in a 4-nation approach.
- Paul Gilliatt provided an update on behalf of NHS Digital.
  - Demand on data services continues to be very high for both Covid and non-Covid research, with pressure especially on teams working in data access and production.
  - The DigiTrial service demonstrated the success of the Hub programme and was highly commended in category of team of the year at recent HDR UK awards and the RECOVERY trial was joint winner of the Impact of the year.
  - The CVD COVID UK consortium was recognised as Team of the Year.
  - Most of the NHS Digital metadata listed in the Gateway are platinum standard.
  - Work is ongoing to create a new data collection General Practice Data for Planning and Research (GPDPR).

**Post meeting note:** A [new letter published by Jo Churchill on 19 July](#) specified that while work is continuing on the infrastructure and communication for the project, the initially set out data of 1 September for the collection launch has been removed. Data will only be uploaded when certain conditions are met, including a functional NHSD Trusted Research Environment. Data will be accessed and used by the research community only via the NHSD TRE.

## Gateway update

- An update on Gateway development and new releases was provided by Paola Quattroni (Alliance Delivery Manager). A Gateway report for data custodians (Paper B) was circulated for the first time to provide an update on the level of engagement and progress of Alliance members in metadata onboarding, improvements, data access requests and cohort discovery. A report will be produced in advance of each Alliance Board meeting to demonstrate progress.



- Tim Hubbard (Genomics England) updated on the Infrastructure Advisory Board who met 3 times so far and is providing advice on Gateway functionalities and general direction of travel. Federated identity management is one of the next pieces of work being undertaken.

### Data use and transparency

David Seymour introduced the session and highlighted work across the sector on improving transparency of how health data is used for research.

- A green paper proposing recommendations for [Data Use Registers](#) to increase transparency has been published and is now open for consultation.
- The crucial role of trusted research environments to ensure safe and trustworthy access and use of data for research has been mentioned by the [House of Commons](#) several times in the past few weeks.
- Both importance of using health data to deliver public benefit and how we can use the UK infrastructure to drive and reinforce standards and recommendation of best practice are to be addressed.
- Vicky Chico (National Data Guardian) highlighted work on the [Putting Good into Practice](#) guidance and collaboration with HDR UK on embedding some of the public benefit work into the Gateway. A final guidance following consultations will be published later this year.
- Gerry Reilly (Technologist in Residence, HDR UK) introduced a [new programme of work to deliver secure flexible interoperable infrastructure](#). A design and dialogue phase has commenced and will continue throughout 2022.

Debbie Keatley, member of the HDR UK Public Advisory Board, outlined main points from a [recommendation paper developed by the Public Advisory Board](#) suggesting how public and patient understanding of and involvement in data governance procedures could be improved to maintain public trust.

The Board welcomed these recommendations and agreed to the publication of a supportive response to the recommendations that has now been published on the [Alliance website](#).

### Diversity and Inclusion

This session covered two main projects: the Black Internship programme and Diversity-in-data.

- Tammy Palmer (HDR UK) provided a brief update on the internship programme currently ongoing. Internships in all organisations involved will end on August 6<sup>th</sup>.
- Three interns: [Shukrat O. Salisu-Olatunji](#), [Abigail Medhin](#) and [Sean Muchenje](#) from the programme provided an overview of their personal experience.
- Karim Mahmoud (HDR UK Data Science intern) provided a summary of his internship experience and showcased an initial analysis of diversity-related variables for metadata listed by Alliance members in the Innovation Gateway. The analysis showed technical metadata are incomplete, with a low percentage of datasets including diversity-related variables and highlighted need for improvement.



## Next Alliance Board meetings

The next Alliance Board meeting will take place via Zoom on 20 Oct 10.00-12.00. Please contact [Sarah.Fullegar@hdruk.ac.uk](mailto:Sarah.Fullegar@hdruk.ac.uk) if you have not received an invite. Invites to 2022 Board meetings will be circulated soon.

## Appendix

### Attendees via Zoom

Name	Organisation
Kathy Rowan	ICNARC
David Jenkinson	Brain Tumour Charity
Vicky Chico	Office of National Data Guardian
Mark Avery	Gut Reaction Hub
David Crossman	Scottish Government
Aziz Sheikh	BREATHE Hub
Kinga Varnai	Oxford University Hospital
Janet Valentine	CPRD
Ewan Harrison	COG-UK
Shukrat Salisu-Olatunji	Black internship programme
Abbi G-Medhin	Black internship programme
Sean Muchenje	Black internship programme
Dorothea Nitsch	The Renal Association
Maria Koufali	Nottingham University Hospitals NHS Trust
Debbie Keatley	HDR UK Public Advisory Board
Kerrie Woods	Oxford University Hospital
Ricardo Ribas	NDAU Imperial College
Becky Moss	NDAU Imperial College
Debbie Keatley	HDR UK Public Advisory Board
Suzy Gallier	PIONEER
Julia Hippisley-Cox	QResearch
Stephen Lock	NIHR Clinical Research Network
Erik Mayer	Imperial College Healthcare NHS Trust
Jessica Catone	DATA-CAN
Yvonne Silove	HQIP
Paul Gilliatt	NHS Digital
Andy Roddam	Our Future Health
Alastair Denniston	INSIGHT
Alistair Weir	Guy's and St Thomas Hospital

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Scott Heald	Public Health Scotland
Reshma Raycoba	Health and Care Research Wales
David Porteous	Generation Scotland
Georgina Pike	RCGP
Erik Mayer	Imperial College Healthcare NHS Trust
Tim Hubbard	Genomics England
Alice Dowden	HDR UK
Melissa Lewis-Brown	HDR UK
Damon Chow	HDR UK
Andrew Morris	HDR UK
Kay Snowley	HDR UK
James Pickett	HDR UK
Sarah Fullegar	HDR UK
David Seymour	HDR UK
Gerry Reilly	HDR UK
Ben Gordon	HDR UK
Sinduja Manohar	HDR UK
David Seymour	HDR UK
Paola Quattroni	HDR UK
Tammy Palmer	HDR UK
Karim Mahmoud	HDR UK
Susheel Varma	HDR UK
Joel Beckman	HDR UK
Nada Karrar	HDR UK