

UK Health Data Research Alliance Board

Tuesday 27th April 14.00-16.00

Immediate actions for Alliance members:

- Please contact the Data Onboarding and Improvement team Alison.Elderfield@hdruk.ac.uk to prepare data for loading and continue to improve the quality of metadata in the Innovation Gateway.
- Please let Sarah.Fullegar@hdruk.ac.uk know if there are any changes to contact details for those included in the current mailing list.
- Please contact Paola.Quattroni@hdruk.ac.uk to discuss data access options for your datasets in the gateway.
- Sign up for the HDR UK Scientific Conference: Data Insights in a Pandemic on 23 June 2021 <https://www.eventbrite.co.uk/e/hdr-uk-scientific-conference-data-insights-in-a-pandemic-tickets-147112546587> and/or COVID-19 National Core Studies Symposium on 24 June <https://www.eventbrite.co.uk/e/covid-19-national-core-studies-symposium-tickets-148035152125>

Actions for HDR UK secretariat:

- Inform Alliance Board when public consultation on Data Use Registers standards green paper is open.
- 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 a survey to map current PPIE activities across the Alliance.
- Circulate a survey about next Alliance Symposium to provide an opportunity for all Alliance members to shape the event.
- Circulate information about Special Interest Group on Diversity in Data and next meeting dates.

Meeting notes:

Welcome, Action points from last meeting and Update

- Andrew Morris welcomed everyone to the meeting and thanked Sarah Wilkinson who recently announced she was stepping down from NHS Digital and Peter Bradley who leaves Public Health England in June for their leadership in the health data research space and their resolute contribution to the Alliance from its formation.
- 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
 - Publication of HDR UK input on the Goldacre review

- <https://www.hdruc.ac.uk/news/goldacre-review-of-use-of-health-and-care-data-for-research-and-analysis/>
- <https://www.hdruc.ac.uk/news/response-to-the-goldacre-review-trusted-research-environments-and-data-management/>
- Black internship programme
- 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.

- Michael Chapman provided an update on behalf of NHS Digital.
 - The linked NHSD-ONS data asset has been established and is now available for the research community. This is an important step for linking other health and non-health data assets in the future.
 - Work is ongoing with NHS England to make vaccination data available for research.
 - NHS Digital trials work is continuing at pace in collaboration with industry.
 - Good developments around Trusted Research Environments (TREs) thanks to collaborative work with BHF Data Science Centre and DATA-CAN.
 - NHS Digital has currently more than 500 active data sharing agreements in place.
 - A review of NHS Digital data access and assurance processes is currently taking place.
- Ian Young provided an update on behalf of Health and Social Care Northern Ireland.
 - Work continues to address consequences of legislative gap in place in terms of using non-anonymised data for research purposes.
 - Work is ongoing with SAIL to set up Northern Ireland TRE to make data available and accessible remotely across the UK.
- David Crossman and Phil Couser provided an update on behalf of Public Health Scotland and Scottish government.
 - Work on establishing Research Data Scotland is progressing well and work on federation is starting.
 - Scottish AI strategy was launched in March and discussions are taking place on how to incorporate AI and machine learning in future plans.

Andrew Morris highlighted HDR UK's partnership with ADR UK and ONS, stressing the importance of research based on both health and non-health data and the necessity to share learnings across sectors.

Public benefit assessment when using health and care data – report on public dialogue

Jenny Westaway (Office of the National Data Guardian) presented findings from a public dialogue on benefit assessment when using health and care data (recently [published](#)). The report aimed to address anxiety around use of data and the need to meet public benefit criteria when using data for research. The



public dialogue is directly informing development of a guidance that can be used by data custodians to ensure they incorporate the public benefit criteria effectively into their processes.

Main report highlights include:

- Transparency cannot be separated from public benefit
- To demonstrate public benefit, transparency is required throughout the whole data life cycle
- Public benefit is undermined if authentic public engagement is not integrated into data assessment
- Equitable distribution of benefits of data use in health and social care
- Identifiable and sensitive data should be treated with utmost care
- Safeguards and provisions in place to protect society from data manipulation
- Public benefit must outweigh profit
- Being ambitious for health and care data use

Alliance Board members are asked to contact Jenny Westway if they are interested to input on the guidance before public consultation launches in mid-May.

Understanding health data access

Yvonne Silove (Healthcare Quality Improvement Partnership) highlighted the outputs from an initiative that started in spring 2020 to produce entry level resources explaining key concept for using health data for applicants needed to submit data access requests.

The information included in written resources and the series of videos explore some of the key legal requirements for data sharing in England and Wales. The aim is for these resources to be used other across systems and not only by researchers wanting to access HQIP data.

The project benefitted from input from other partners and organisations including NHS Digital and other Alliance custodians.

HDR UK and HQIP are now planning to explore future work to produce additional resources for researchers, in particular how data access via a Trusted Research Environment can help researchers access linked data more quickly.

Videos can be accessed [here](#).

Data Use Registers

David Seymour (Alliance Executive Director) and Nada Karrar (Project Manager) provided an update on the work on Data Use Registers (defined as a public record of data an organisation has shared with other organisations for the purpose of research, innovation and service evaluation). The aim was to seek feedback on an initial draft of recommendations for a minimum standard for Data Use Registers that could be adopted by data custodians within the Alliance and beyond.

Alliance members are asked to:

1. Provide feedback on the draft recommendations by 14 May.
2. A green paper will be made available for public consultation in May. Alliance members and organisations interested in this work will have the opportunity to input on the proposed recommendations.



Following public consultation, a new iteration of the green paper will be presented at next Alliance Board meeting for final approval.

Data standards

- Ben Gordon provided an update on the development of a green paper on Data standards which opened for consultation on 5 May.
- Organisations are invited to provide input on the paper.

Cohort Discovery Tool

Susheel Varma presented a new Cohort Discovery tool <https://www.healthdatagateway.org/pages/cohort-discovery-search-tool> to allow researchers to perform fine-grained search in the Gateway across multiple datasets that match their specific research-project defined cohort definition. Alliance members are invited to explore the tool and consider enabling use of the tool for any relevant dataset. For more information about Cohort Discovery, contact Susheel.Varma@hdruk.ac.uk.

Next Alliance Board meetings

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

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

Please contact Sarah Fullegar if you have not received an invite.



Appendix

Attendees via Zoom

Name	Organisation
Jenny Westaway	Office of the National Data Guardian (Guest speaker)
David Jenkinson	Brain Tumour Charity
Brendan O'Brien	NHS National Services Scotland
Andrew Roddam	Our Future Health
David Crossman	Scottish Government
Tom Fowler	Genomics England
Ana Stipancic	RCGP
Rachael Williams	CPRD
David Harrison	ICNARC
Paul Mouncey	ICNARC
Maria Koufali	Nottingham University Hospitals NHS Trust
Ian Young	HSCNI
Phil Quinlan	Tissue Directory Coordination Centre
Sneha Anad	University of Oxford, RCGP Research and Surveillance Centre
Neena Modi	NDAU Imperial College
Eleanor Berg	NHS England/Improvement
Suzy Gallier	PIONEER
Julia Hippisley-Cox	QResearch
Stephen Lock	NIHR Clinical Research Network
Erik Mayer	Imperial College Healthcare NHS Trust
Jessica Catone	DATA-CAN
Neil Walker	NIHR BioResource & Gut Reaction
Colin Smith	MRC Brain Bank Network
Nathalie Kington	NIHR BioResource
Mark Howells	Nottinghamshire Healthcare NHS Foundation Trust
Yvonne Silove	HQIP
Fran Woodard	NHS Digital
Steven Casson	Public Health England
Alastair Denniston	INSIGHT
Rebecca Cosgriff	Cystic Fibrosis Trust
Phillip Couser	Public Health Scotland
Nic Timpson	ALSPAC
Kate Northstone	ALSPAC
David Porteous	Generation Scotland

UK Health Data Research Alliance Gibbs Building, 215 Euston Road, London NW1 2BE
 enquiries@hdruk.ac.uk | @HDR_UK | ukhealthdata.org



Michael Chapman	NHS Digital
Mark Caulfield	Genomics England
Tim Hubbard	Genomics England
Retha Steenkamp	UK Renal Registry
Andrew Morris	HDR UK
Kay Snowley	HDR UK
Caroline Cake	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
Charles Gibbons	HDR UK
Susheel Varma	HDR UK
Joel Beckman	HDR UK
Nada Karrar	HDR UK