

UK Health Data Research Alliance Board – actions and meeting notes

Wednesday 20th October 10.00-12.00

Immediate actions for Alliance members:

All Alliance members are requested to:

- Submit final comments on the White Paper on Principles and best practice for trusted research environments (Paper C) by 8 November 2021.
- Submit final comments on the White Paper on Recommendations for data use register standards (Paper D) by 8 November 2021.
- Contact the Data Improvement team Alison.Elderfield@hdruk.ac.uk to prepare data for loading and continue to improve the quality of metadata in the Innovation Gateway.
- Contact Varsha.Khodiya@hdruk.ac.uk to discuss data access options for your datasets in the gateway.
- The Gateway Data Use Register will launch in November. We invite all Alliance members to provide a list of approved projects for use of datasets listed in the Gateway, following the Data Use Standard template provided. For more information on how to complete the spreadsheet, please contact Nada.Karrar@hdruk.ac.uk.

Actions for HDR UK secretariat:

- Circulate dates and Zoom invites to next Alliance Board meetings.
- Circulate registration details for Frontiers meeting on 15 November.
- Distribute survey on QQR and next steps for the Alliance.

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 convening expertise and drive best practice.
- Action points from last meeting were reviewed and an update was given on:
 - New Board members joining the Alliance.
 - The launch of the UKRI DARE programme (Hans-Erik Aronson).
 - Developments from the Health Data Research Hubs and progress of newly developed Hubs, the APDP Pain Research Data Hub [Alleviate](#) and Hub for Mental Health Informatics Research Development [DATAMIND](#) (Kay Snowley and James Pickett).
 - Patient, public and practitioner involvement and the establishment of an Alliance PPIE Leads quarterly meeting.

Updates from members

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

- Michael Chapman provided an update on behalf of NHS Digital.
 - Demand on data services continues to be very high showing a 30% increase in activity compared to a year ago. The increase in number of datasets available resulted in increase of possible data linkages, but also some complexities.
 - Currently recruiting for several roles to increase capacity and respond to demand.
 - From 1 October, the National Disease Registration Service was transferred to NHS Digital. Access route is still through Office for Data Release and operated and maintained by the UK Health Security Agency.
 - Work is ongoing to create the collection General Practice Data for Planning and Research (GPDR) but this will be made available only when certain conditions are met, including patient choice around how their data is included in this collection.
- Michael Quinn updated on behalf of Health and Social Care Northern Ireland.
 - This has been a difficult year for Northern Ireland but a new strategic group chaired by Chief Scientific Advisor Ian Young has now been established.
 - Collaboration with Data & Connectivity and HDR UK is continuing successfully, with additional involvement in the [CO-CONNECT](#) project.
 - Collaboration between the Honest broker Service and the UK Secure eResearch Platform (UKSeRP) is currently providing a mechanism to facilitate Northern Ireland health related research by enabling remote and safe access to data.
 - Work is ongoing on access to GP data which will improve towards the end of the year.
- David Crossman provided an update on behalf of Public Health Scotland and Scottish government:
 - Research Data Scotland (RDS) launched in September and now offers a route by which researchers can access admin and health data across sector (with eDRIS team and Public Health Scotland being part of RDS). This structure will enable coordination and linkage of data. There is potential for alignment and opportunity for collaboration with HDR UK to streamline data access.
 - David Crossman reiterated his support to the UK Health data Alliance and highlighted the important function in a 4-nation approach. It will be helpful to identify the areas of work that need to be brought together and would benefit from joint approaches.
- Chris Orton and Alex Newberry provided an update on the work of SAIL Databank and on behalf of Welsh Government:
 - Work under the Data & Connectivity NCS banner is continuing at pace, while supporting the latest funded projects coming through. Much work is ongoing with Innovation Gateway to enable API integration and manage access requests in a seamless manner.
 - Also looking at feasibility studies like those part of CO-CONNECT.
 - Across the safe haven, and including via the BREATHE Hub, SAIL Databank have listed 140 datasets on the Gateway. Quality and metadata updates is increasing progressively.
 - SAIL continues to provide services across the UK and internationally.
 - From a Welsh governance perspective, work is ongoing with wider digital health colleagues about communicating research use and making sure data driven research is not restricted by policy.

Gateway update

- Update on Gateway development and new features released was provided by Paola Quattroni (Alliance Delivery Manager). Gateway report for data custodians (Paper B) was circulated to provide an update on the level of engagement and progress of Alliance members in metadata onboarding and improvements, data access requests and cohort discovery.
- A [press release](#) on the launch of a Data Utility Wizard to improve data discovery has been published.

Trusted Research Environments

David Seymour (Alliance Executive Director) chaired this session highlighting the value of building and sharing good practice across Alliance members.

- Claire Bloomfield provided an update on behalf of NHSX on policy, strategy and planned investments over the next 3 years.
 - NHSX is [supporting NHS alignment](#) around TREs and how data is used for R&D and the focus is on supporting the Life Science Vision. They have been working also on the Goldacre review and data strategy, both of which are due to be published this coming month.
 - The TRE policy work for NHSX is led by Lisa Murphy around supporting alignment around TREs and policy implications. There is a design working group aimed at convening people from across the system and there is an interest in connecting with colleagues across the UK and working transparently and collaboratively.
 - This year's portfolio is small in scope. Work with NHSD is important as the GDPR will come into the portfolio. The TRE will need to meet the commitments of GDPR.
 - Piloting work on imaging data, pathology and AI and how that factor into TREs.
 - Launched call for ICSs regional Trusted research Environments, up to 500k per region. This is to support ICSs thinking about the uses of data for research and define arrangements, including exploring federation.
 - A larger commitment is expected pending outcome of spending review, to expand and invest in a national TRE and explore imaging medical platforms and other platforms like GEL, Bioresources and Our Future Health.
 - NHSX focus is NHS data and maintaining public trust, while driving capability and capacity in the NHS itself.
 - This work will provide an opportunity to define how TREs operate across the UK and beyond. Close collaboration between NHSX and HDR UK will be key; HDR UK can have a role on scaling up to England and beyond England, and expand to international. The link to DARE UK will also be important.
- Tim Hubbard (Genomics England) presented recent developments on principles and best practice for Trusted Research Environments. A draft White Paper (Paper C) was circulated to Board members and will be published on behalf of the Alliance in the coming weeks (comments can still be submitted by **8 November**).
 - This White Paper is an evolution of a Green Paper published a year ago that went through public consultation. Each of the sections of the different safes are narratives with a list of



principles and best practices. There is increased focus on transparency and public involvement.

- Purpose is help define and align capabilities that are required to provision TREs in any cloud environment. Capability definitions are around how TREs manage users (SAFE People), projects (SAFE Projects), (SAFE Data), the security/governance perimeter (SAFE Settings) and how TREs release outputs (SAFE Outputs).
- Opportunity beyond UK and including admin data. European Health Data Space programme includes plan for federation across Europe.

Board members recognised the importance of working collaboratively across all Nations. The next steps will include publishing the White Paper and identify what best practice processes exist, identity gaps, policies, standards, modular software and exemplar use cases. Four nation approach and consideration of non-health data and link to DARE UK will be key.

Data Use Register standards White Paper

Paola Quattroni provided an update on the public consultation and feedback received on the Green Paper on Data use registers standards. Feedback was incorporated in a revised version of the paper which the Board agreed to publish by the end of November. It was suggested that the importance of recognising the digital divide and of reaching out to all communities could be more prominent in the paper. Comments can still be submitted by Alliance members by **8 November**.

A Gateway data use register will launch in November, with the aim to increase transparency of how datasets listed in the Gateway are used. All Alliance members are invited to provide information relevant to approved projects using Gateway datasets. A template for Alliance members to use is going to be circulated soon.

Data Standards White Paper

Ben Gordon provided an update on the status of the White Paper on Data standards that went out for public consultation in the past months. The White Paper recommends particular data standards, as guided by user need, to encourage increased interoperability across the UK.

The Board approved publication of this paper.

Quinquennial review and next steps for the Alliance

Caroline Cake presented an overview of the quinquennial review being undertaken by HDR UK. HDR UK has decided to include the work of the Alliance in its QQ2 funding bid and commit to use QQ1 core funds to bridge the gap between ISCF funding ending in August 2022 and the start of QQ2 in April 2023. Alliance members are invited to contribute to the shaping of both the proposed demonstrator programmes and the infrastructure services outlined in the review. A survey will be distributed to hear perspectives from all Alliance members.

AOB

Gerry Reilly proposed the formation of a Special Interest Group on Imaging data and invited interested Alliance members to participate. If interested, please contact gerry.reilly@hdruk.ac.uk.

Next Alliance Board meetings

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



The next Alliance Board meeting will take place via Zoom on **26 January 10.00-12.00**. An invite will be circulated soon.



Appendix

Attendees via Zoom

Name	Organisation
John Zurowski	iCAIRD
David Jenkinson	Brain Tumour Charity
Carole Morris	Public Health Scotland
Mark Avery	Gut Reaction Hub
David Crossman	Scottish Government
Darren Lunn	CPRD
Claire Bloomfield	NHSX
Ewan Harrison	COG-UK
Kathy Harrison	Dataloch
Jenni Harrison	ALLEVIATE
Hilary Fanning	University Hospitals Birmingham NHS Foundation Trust
Seb Ourselin	LMIAIC
Michael Quinn	HSCNI
Manjit Benning	INSIGHT Hub
Robert Stewart	DATAMIND
Nathalie Kingston	NIHR BioResource
Alex Newberry	Welsh government
David Snead	PATHLAKE
Kerrie Woods	Oxford University Hospital
Rakesh Uppal	Barts Health NHS Trust
Suzy Gallier	PIONEER
Stephen Lock	NIHR Clinical Research Network
Erik Mayer	Imperial College Healthcare NHS Trust
Yvonne Silove	HQIP
Michael Chapman	NHS Digital
Lisa Murphy	NHSX
Alistair Weir	Guy's and St Thomas Hospital
Will Victor	RCGP
Erik Mayer	Imperial College Healthcare NHS Trust
Hans-Erik Aronson	DARE UK
Tim Hubbard	Genomics England
Amanda White	HDR UK

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Lynn Morrice	HDR UK
Alice Dowden	HDR UK
Caroline Cake	HDR UK
Varsha Khodiyar	HDR UK
Charles Gibbons	HDR UK
Andrew Morris	HDR UK
Kay Snowley	HDR UK
James Pickett	HDR UK
Lindsay Cockcroft	HDR UK
David Seymour	HDR UK
Gerry Reilly	HDR UK
Ben Gordon	HDR UK
Jasmine Kelson-Otoo	HDR UK
David Seymour	HDR UK
Paola Quattroni	HDR UK
Susheel Varma	HDR UK