

UK Health Data Research Alliance Board – actions and meeting notes

Wednesday 26th January 10.00-12.00

Immediate actions for Alliance members:

All Alliance members are requested to:

- Provide contact details for people within organisations to engage on building Gateway data use registers.
- Possible Alliance working group or event on using consented and non-consented data for research. If you are interested to join the conversation email ukalliance@hdruk.ac.uk.
- If interested, participate in the Clinical Trials Stakeholder Prioritisation Forum, email ukalliance@hdruk.ac.uk.

Actions for HDR UK secretariat:

- Circulate dates and Zoom invites to next Alliance Board meetings.
- Share a Data & Connectivity update to SAGE.
- Arrange data use register demo and training sessions for Alliance members.

Meeting notes:

Welcome, Action points from last meeting and update

Andrew Morris, Director of HDR UK, welcomed everyone to the first Alliance Board meeting of 2022. Andrew started by reflecting on where we are with the pandemic and suggested that there is an opportunity for legacy and apply learnings from COVID to other disease areas, so to demonstrate the benefits of the convergence of care and research. Action points from last meeting were reviewed and an update was given on:

- New Board members joining the Alliance.
- The publication of [Building Trusted Research Environments - Principles and Best Practices; Towards TRE ecosystems](#) paper.
- The publication of [Improving transparency in the use of health data for research: Recommendations for a data use register standard](#) paper.

Updates from members

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

- Carole Morris provided an update on behalf of Public Health Scotland (PHS).

- Ongoing COVID projects are progressing, working in partnership with the University of Edinburgh in developing the outbreak data analysis platform.
- Continuing to work closely with the EAVE II project which is a collaboration between the University of Edinburgh, PHS and other academic colleagues.
- PHS is a key service delivery partner within Research Data Scotland.
- Work ongoing around releasing and accessing GP data within Scotland.
- Michael Chapman provided an update on behalf of NHS Digital. Main highlights included:
 - Publication of the [Laura Wade-Gery review](#) outlining importance of ensuring that research and life science communities continue to receive priority attention.
 - The announcement of the merger of NHS Digital and NHSX as well as Health Education England with NHS England.
 - Current data access processes are still under review and work with NHSX to develop NHS Digital's TRE is ongoing.
 - Work on metadata is continuing towards automated federation.
- Chris Orton provided an update on the work of SAIL Databank and on behalf of Welsh Government
 - Establishing the ADR Wales (Administrative Data Research Wales) grant recently awarded.
 - Supporting DEA accreditation of the data linkage ecosystem for research across the UK
 - Moving forward with establishing and being the constituent TRE for the DATAMIND Hub.
 - Planning service improvements and trailing a federated analysis pipeline.
 - Completed ICODA pilot – currently writing up findings.
 - Integrating SAIL and Gateway Data Access System and making changes to allow federation between the two to make the governance process more streamlined.
 - Provisioning initial feeds to the Gateway data use register.
- Declan Bradley provided an update on behalf of Health and Social Care Northern Ireland.
 - Currently 27 live projects including 2 NSC projects are hosted in SeRP. The platform is fully operational. Many COVID-19 datasets currently available.
 - Until recently all researchers using data were based in Northern Ireland. The Gateway has attracted first researchers from outside Northern Ireland to study these datasets which is a great step forward.
 - A new metadata developer is in post and 11 datasets are listed on the Gateway with platinum metadata.
 - The Gateway Five Safes form has been adopted and to be fully implemented over the coming months.
 - Established a group called the Northern Ireland Trusted Research Environment (NITRE) with Strategic Programme Board.
 - Using Data and Connectivity funding have established pilot Northern Ireland Public Data Panel.

Update on HDR UK Quinquennial review

- David Seymour provided a summary of the plans for the next quinquennium, including the future of the Alliance and the network of HDR UK Research Hubs – The Alliance has a key role in driving adoption of standards, creating a recognised community of experts to drive change and communicate the impact to ensure public trust.
- Ethics, information governance, trust and transparency will be a major focus.

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



Transforming data for trials

Matt Sydes (Professor of clinical trials and methodology at the MRC Clinical Trials Unit at UCL) and Marion Mafham (Kidney specialist and clinical trialist at University of Oxford) provided an overview of future plans to convene a Clinical Trials Stakeholder Prioritisation Forum. Both HDR UK and the Alliance are well placed to facilitate development of this forum.

Route to engagement in Trusted Research Environments

Joint work with NHSX

- Tim Hubbard (HDR UK) and Chris Russell (NHSX) provided an update on joint work between NHSX and HDR UK.
 - Following publication of the TRE paper published in December 2021, NHSX and HDR UK are now working together to take the work forward.
 - Conversations will continue through a TRE Design Group with focus on policy, technical specifications and accreditation.
 - First outputs from this group are expected around April 2022.
 - The Alliance will still offer a route to participate in these discussions. To be involved please email ukalliance@hdruk.ac.uk.
 - To be kept up to date Alliance members can join the [Slack channel](#).

Data & Connectivity: TRE federation

Lara Edwards (HDR UK) provided an update on work to date with national TRE partners (NHS Digital, Public Health Scotland and EPCC, SAIL Databank of Wales, Northern Ireland, ONS).

- Work to date focussed on implementation of the Five Safe Data Access Request form and federation of metadata catalogues.
- In collaboration with Phil Quinlan and the CO-CONNECT project led by the University of Nottingham. Data partners within CO-CONNECT are using the Gateway cohort discovery tool allowing researchers to search across datasets to identify cohorts of people from multiple datasets.
- Working closely with ONS & UK Statistic Authority to develop a proof of concept, accredited researcher API – this will interface with the data access request process in the Gateway.

DARE programme update

Susheel Varma and Hans-Erik Aronson provided an update on the DARE programme, aiming to design and implement a national secure and interoperable digital research infrastructure and associated services. This is a collaborative effort and there is an opportunity to build on expertise built so far. Input from Alliance members will be important. More information about the programme can be found [here](#).



Supporting adoption of data use register standards

Nada Karrar provided an update on publication of the [White Paper on data use register standard](#) and implementation of this standard through the Innovation Gateway data use register. More information on can be found [here](#).

All data custodian organisations within the Alliance will be contacted to start work on building content for their data use registers in the Gateway. Custodians will be encouraged to upload legacy data uses for datasets listed in the Gateway, adopt the Five Safe Data Access Request form to enable data use register automation and update their data use registers on a regular basis.

To learn more about this work please contact Nada.Karrar@hdruk.ac.uk.

Influencing Policy

Cassie Smith provided an update on the recent HDR UK responses to the 'Call for Evidence: The right to privacy' and the 'UK data reform proposals'.

Members are invited to email Cassie.Smith@hdruk.ac.uk to provide feedback or share their responses.

David Seymour explored whether there was interest from members in producing collective responses to this type of consultation. It was highlighted that reaching consensus on a specific position might be difficult.

Next Alliance Board meetings

The next Alliance Board meeting will take place via Zoom on **12 April 10.00-12.00**. An invite will be circulated soon.



Appendix

Attendees via Zoom

Name	Organisation
Jenni Harrison	Alleviate Hub & Health Informatics Centre, University of Dundee
Rob French	Cardiff University
Darren Lunn	CPRD
Ann John	DATAMIND Hub
Rob Stewart	DATAMIND Hub & King's College London
Tim Hubbard	HDR UK
Kate Blake	Guy's and St Thomas' NHS Foundation Trust
Andrew Morris	HDR UK
Ben Gordon	HDR UK
Cassie Smith	HDR UK
Charles Gibbons	HDR UK
Chris Milner	HDR UK
Claire Argent	HDR UK
David Seymour	HDR UK
Edel McNamara	HDR UK
Fergus McDonald	HDR UK
Gerry Reilly	HDR UK
Hans-Erik Aronson	HDR UK
James Pickett	HDR UK
Kay Snowley	HDR UK
Lara Edwards	HDR UK
Nada Karrar	HDR UK
Paola Quattroni	HDR UK
Sinduja Manohar	HDR UK
Susheel Varma	HDR UK
Varsha Khodiyar	HDR UK



Lynn Morrice	HDR UK & BHF DSC
Declan Bradley	HSCNI
Nicola Armstrong	HSCNI
Elliot Bridges	Human Fertilisation and Embryology Authority
John Zurowski	iCAIRD
David Harrison	ICNARC
Vibhuti Laroia	ICNARC
Erik Mayer	Imperial College Healthcare NHS Trust
Mark Weeks	Imperial College Healthcare NHS Trust
Neena Modi	Imperial College London & Neonatal Data Analysis Unit (NDAU)
Alastair Denniston	INSIGHT Hub
Sebastien Ourselin	London Medical Imaging & Artificial Intelligence Centre
Vishnu Chandrabalan	Lancashire Teaching Hospitals NHS Foundation Trust (LHTR)
Anthony Wilson	Manchester University NHS Foundation Trust
Katherine Boylan	Manchester University NHS Foundation Trust
Geoff Hall	DATA-CAN Hub
Michael Chapman	NHS Digital
Chris Russell	NHSX
Nathalie Kingston	NIHR Bioresource
Neil Walker	NIHR Bioresource
Samantha Liscio	NIHR Clinical Research Network
Jennifer Boston	Nottingham University Hospitals NHS Foundation Trust
Michael Cook	Our Future Health
Clare Bankhead	ORCHID
Tanya Smith	Oxford Health NHS Foundation Trust
Deborah Griggs	PathLAKE
Carole Morris	Public Health Scotland
Ian Young	Health and Social Care Northern Ireland
Will Victor	Royal College of GP Practices
Retha Steenkamp (UKKA)	The Renal Association

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Alastair Rennie	Research Data Scotland
Martin Browne	Research Data Scotland
Helen Quinn	Royal Devon and Exeter NHS Foundation Trust
Chris Orton	SAIL Databank & BREATHE HUB
The Brain Tumour Charity	The Brain Tumour Charity
David Jenkinson	The Brain Tumour Charity
David Porteous	The University of Edinburgh
Kathy Harrison	The University of Edinburgh
Matt Sydes	University College London MRC Clinical Trial Unit
Charlie Davies	DATA-CAN Hub
Mahesh Pancholi	UK Biobank
Janet Valentine	UKRI
Paul Faulkner	University Hospitals Bristol and Weston NHS Foundation Trust
Giovanni Bucci	University Hospitals Coventry and Warwickshire
Robert Klimek	University Hospitals Coventry and Warwickshire
Elizabeth Sapey	PIONEER Hub
Ewan Harrison	COG-UK
Philip Quinlan	University of Nottingham
Marion Mafham	University of Oxford
Meredith Leston	Royal College of GP Practices