UK Health Data Research Alliance Board – actions and meeting notes

Tuesday 12th April 2022 (10.00-12.00)

Immediate actions for Alliance members:

All Alliance members are asked to:

- Help us define the future structure and governance for the Alliance and ways of working. We are looking for volunteers who could help us draft some options for consideration in advance of the July Board meeting. If interested, please email ukalliance@hdruk.ac.uk.
- Please nominate leads from your organisation who could take part in the discussion around skills gaps, training and recruitment/retention. Contact rosie.wakeham@hdruk.ac.uk.
- Contribute to discussions around the use of synthetic data. If you wish to take part in this workshop, please email alison.elderfield@hdruk.ac.uk.
- Join us at the Digital Innovation Hubs Event: "Building the legacy" on 28th June, in Birmingham. For more information and to register click here.

Actions for HDR UK secretariat:

- Circulate dates and Zoom invites to next Alliance Board meetings.

Meeting notes:

Welcome, Action points from last meeting and update

Andrew Morris, Director of HDR UK, opened the meeting highlighting the role of the Alliance in serving the community and encouraged members to suggest ways the Alliance can support members in terms of standardisation and expertise to drive trustworthy use of health data.

Three new members joined the Alliance recently: Northern Care Alliance NHS Foundation Trust, The Royal Marsden NHS Foundation Trust and National Pathology Imaging Co-operative (NPIC). All 5 centres of excellence in medical imaging and digital pathology are now Alliance members.

Andrew and colleagues recently attended the House of Commons select committee to discuss the right to privacy in the use of health data – there is a lot of interest on this at Government level about how we can harness data not only to sustain health services but also to drive research and innovation.

The Goldacre Review was recently published, with 185 recommendations across 30 theme areas. The Alliance is majoring on many of the recommendations.

Action points from last meeting were reviewed and an update was given on:

- New Alliance members asked to engage with Gateway services. Metadata listing on the Gateway and Data Use Registers are a priority for all members.
- A new working group on using consented and non-consented data for research is now being set up. Discussions were led my Meredith Leston who will chair this group and produce a one pager to circulate in advance of the first meeting. More information to follow.

Updates from members

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

Dani Breitinger Blatt provided an update on behalf of NHS Digital.

- Main activities are focussed on the merger of NHS England and Improvement directorates.
- The recommendations in the Ben Goldacre review are very clear and are in line with work ongoing at NHS Digital.
- Work to improve data access request services is continuing.

Carole Morris and Alastair Rennie provided an update on behalf of Public Health Scotland (PHS) and Research Data Scotland (RDS).

- The priority for the National Safe Haven is to increase computing capabilities as well as work on security and governance. This will help to support some of the research projects that are coming through the National Core Studies among others.
- Working on developing a research strategy. PHS continues to deliver research projects, working alongside CO-CONNECT and making data available through the Gateway.
- PHS and RDS are working closely together to ensure public sector organisations and regional safe havens make data available for research purposes in a streamlined manner. Workstreams include: information governance, guidance for researchers, model data and synthetic data, data and metadata catalogue. This work in in alignment with Alliance and Gateway activities.

Alex Newberry provided an update on behalf of Welsh Government.

- Focusing on what the Welsh service offer looks like as part of the find, recruit and follow up service.
- Provided some resource to the SAIL Databank to look at developing intelligence driven feasibility for placing trials in Wales more effectively. As part of that work, scoping what a data for research programme within our digital health and care Wales heath board would look like.
- Working with wider Health and Care policy team on a new information governance framework for sharing and use of data within Wales. This includes looking at the potential for some new secondary legislation specifically around the use and sharing of data in Wales.

Declan Bradley provided an update on behalf of Health and Social Care Northern Ireland.

- Embarking on a series of system changes – moved a lot of our systems from manual to more cloud based.
- Work continuing as part of the NCS Data & Connectivity programme.

Chris Russell provided an update on behalf of NHS England

- Work is progressing to ensure the TRE continues to become more functional.
- Work is continuing with HDR UK to draft policy around Secure Data Environments. A first draft of the policy will be produced during the summer. If you have not had an opportunity to contribute, please get in touch (chris.russell@nhsx.nhs.uk).

Updates were also provided across HDR UK major programme teams including Data & Connectivity, BHF Data Science Centre and Black Internship programme. Relevant information is provided in paper A.

HDR UK Quinquennial review: Alliance development

David Seymour (Interim Chief of Staff & Alliance Executive Director) presented an update on transition of the Alliance in the next quinquennium. It was agreed that a small sub-group of Alliance members would help draft a proposal for a new Alliance structure and governance to be discussed at the next Board meeting. If interested in participating in the discussion, please email ukalliance@hdruk.ac.uk. Presentation slides are available to view here.

Capacity Building

Addressing the skills gaps

An update was provided by Rosie Wakeham (Head of Training).
It was agreed that a 'task and finish' group would be set up to explore skills gaps in data science as well as current challenges and/or success stories around recruitment and retention within health organisations. Please nominate leads from your organisation who could take part in the discussion. Contact rosie.wakeham@hdruk.ac.uk
Presentation slides are available to view here.

Ecosystem technology

Trusted Research Environments

An update was provided by Tim Hubbard (TRE workstream Lead).

- HDR UK are working closely with the NHS Transformation Directorate on this workstream to provide policies for the NHS to implement TRE's across the board.
- About 10 workshops were held to explore different aspects of principles.
- HDR UK co-hosted a joint webinar with NHS Transformation Directorate on 21st April, titled "Data Access & Discovery - A Forest Through the TREs". Outputs from this event will be shared here.
- Theme for remaining workshops: reproduceable pipelines and openness. This will feed into the NHS policy documents.

If you are interested in attending future TRE workshops, please email Tim Hubbard: tim.hubbard@hdruk.ac.uk.

DARE UK

An update was provided by Hans-Erik Aronson (National Digital Research Infrastructure Director). Presentation slides are available to view here.

Usable data

Diversity in Data: Ethnicity coding working group

Update provided by Paola Quattroni (Head of Alliance Strategy & Engagement (Interim)).

- The Alliance has been working with Ashley Akbari (Swansea University) and Kamlesh Khunti (University of Leicester) to convene the custodian and research community and address concerns around use of ethnicity data. The second session of this series focused on terminology, definitions and standard harmonisation. More information on this page.
- If you are interested in participating in this group going forward, please email ukalliance@hdruk.ac.uk.

Implementation of metadata specification v3

An update was provided by Alison Elderfield (Data Strategy Manager).

We have been working with Anaeko and DCS to update our metadata specification. This is primarily to make data discovery simpler, quicker and easier for custodians and researchers to use. We are introducing new structures and standards so that researchers can have access to persistent and high-quality metadata. The recommendations for this metadata spec went to our Data officer Groups and we have since began to create the actual metadata specification. We expect the specification to be completed by end of May and will hope to begin the implementation in June, which will use a phase approached.

Trust & Transparency

Transparency in data use: implementation phase

Update provided by Nada Karrar (Project Manager - Data Access and Use)

Presentation slides are available to view here.

ICO consultation on draft guidance for the research provisions within the UK GDPR and the DPA 2018

Edel McNamara (Data Protection and Information Governance Lead (Global)) provided an update on main recommendations from HDR UK. A response to the consultation has now been submitted.

Presentation slides are available to view here.

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Plans for a UK-wide Public campaign on data

Sinduja Manohar (Senior Manager - Public Engagement and Involvement) provided an update on a new joint initiative in collaboration with ADR UK and ONS called "Public Engagement in Data Research initiative". This is a sector wide partnership focussing on four key objectives:

- Subscribing to best practice in public involvement
- Sharing and creating resources that will enable the sector to embed principles for best practice
- Communications and the media
- UK-wide public campaign on data

There are currently 12 organisations involved in this initiative however this continues to grow.

Presentation slides are available to view here.

Next Alliance Board meetings
The next Alliance Board meeting will take place via Zoom on **20 July 2022 15.00-17.00**. An invite has been circulated.
We also have the following dates held for the end of 2022, early 2023: 12 October 2022 13:00-15:00 and 26 January 2023 13:00-15:00. Invites to follow.

Appendix

Attendees via Zoom

Name	Organisation
Sophie Williams	Barts Health NHS Trust
John Bradley	Cambridge University Hospitals NHS Foundation Trust
Darren Lunn	CPRD
Kathy Harrison	DataLoch
Eleanor Hall	Gut Reaction
Kate Blake	Guy's and St Thomas' NHS Foundation Trust
Andrew Morris	HDR UK
Claire Argent	HDR UK
David Seymour	HDR UK
Edel McNamara	HDR UK
Fergus McDonald	HDR UK
Hans-Erik Aronson	HDR UK
Lara Edwards	HDR UK
Nada Karrar	HDR UK
Paola Quattroni	HDR UK
Rosie Wakeham	HDR UK
Sinduja Manohar	HDR UK
Susheel Varma	HDR UK
Tim Hubbard	HDR UK
Lynn Morrice	HDR UK / BHF DSC
Alex Newberry	Health and Care Research Wales / Welsh Government
Jenni Harrison	Health Informatics Centre, University of Dundee
Yvonne Silove	HQIP
Declan Bradley	HSCNI
Nicola Armstrong	HSCNI
Elliot Bridges	Human Fertilisation and Embryology Authority

John Zurowski	iCAIRD
David Harrison	ICNARC / iCAIRD
Ben Glampson	Imperial College Healthcare NHS Trust
Alastair Denniston	Insight
Jorge Cardoso	LMIAIC
Lucy O'Neill	LMIAIC
Claire MacDonald	Manchester University NHS Foundation Trust
Katherine Boylan	Manchester University NHS Foundation Trust
Dani Blatt	NHS Digital
Chris Russell	NHS X
James Ritchie	Northern Care Alliance NHS Foundation Trust
Andrew Roddam	Our Future Health
Meredith Leston	Oxford-RCGP RSC network - University of Oxford
Sneha Anand	Oxford-RCGP RSC network - University of Oxford
Carole Morris	Public Health Scotland
Jo Martin	Queen Mary University of London
Retha Steenkamp	Renal Registry
Zoe Plummer	Renal Registry
Alastair Rennie	Research Data Scotland
Martin Browne	Research Data Scotland
Helen Quinn	Royal Devon & Exeter NHS Foundation Trust
David Crossman	Scottish Government
David Jenkinson	The Brain Tumour Charity
Lisa Scerri	The Royal Marsden NHS Foundation Trust
Richard Lee	The Royal Marsden NHS Foundation Trust
Sam Organ	UK Health Security Agency
Tim Robbins	University Hospitals Coventry and Warwickshire
Deborah Griggs	University Hospitals Coventry and Warwickshire / PathLAKE
Giovanni Bucci	University Hospitals Coventry and Warwickshire / PathLAKE