UK Health Data Research Alliance Board – Actions and Meeting Notes

Thursday 26th January 2023 (13:00 – 15:00)

Immediate actions for Alliance members:

- The first Alliance bulletin has now been circulated to all members. If any Alliance members have news that they would like to be shared via this bulletin, please email ukalliance@hdruk.ac.uk.
- If any Alliance members would like to express interest in becoming a host organisation for the Black Internship Programme, please email blackinternprog@hdruk.ac.uk.
- If you are interested in joining the discussion on industry access to health data please contact Roger Halliday (Research Data Scotland) via roger.halliday@researchdata.scot to help develop a potential UK-wide approach.
- If you or anyone in your organisation would like to attend any of the training courses presented by Sarah Cadman, please express your interest by emailing learn@hdruk.ac.uk.
- If you would like to help develop the Terms of Reference for the new Alliance Council and Alliance Executive Committee please email ukalliance@hdruk.ac.uk.

Actions for HDR UK secretariat:

- Circulate slides presented at the meeting.
- Consolidate consultation feedback on the Alliance Governance and Next Steps Proposal and establish the Alliance Executive Committee, accordingly.
- Circulate training opportunities presented by Sarah Cadman during the Capacity Building update.

Meeting notes:

Welcome, introductions and opening remarks

Andrew Morris, Alliance Chair and Director of HDR UK, welcomed the attendees and highlighted key points within the Convenor's paper.

Andrew welcomed two new members to the Alliance, including **Grampian Data Safe Haven (University of Aberdeen)** and **Moorfields Eye Hospital NHS Foundation Trust** (announcement to follow). He also welcomed Pete Stokes from the Bennett Institute of Data Science, who is leading their work on OpenSAFELY and invited Emily Jefferson, Chief Technology Officer, HDR UK to introduce herself to the Alliance Board members in her new position.

Andrew noted that the Black Internship Programme (BIP) has accelerated the careers of many interns and has received much national and international interest. The 2023 cohort has had 661 applicants. Hosting an intern as part of the BIP is simple and hugely beneficial to the community. Currently, there are ~40 Alliance member hosts, with expressions of interest to host still open to whoever wishes to do so.

Action points from the last meeting & Gateway report

Action points from the last meeting were briefly highlighted by Paola Quattroni, Head of Alliance Engagement and Strategy, HDR UK.

- The 'Improving Access to Linked Data' working group to date have held two working group sessions and will hold a third session In February/March 2023.
- The 'Diversity in Data' working group have now held 3 working sessions on Ethnicity Coding standards and will be writing a recommendations paper on best practice for the collection of ethnicity data.

Horizon Scanning: updates from across the UK

Margaret Charleroy, Head of Strategy, from NHS England Transformation Directorate, provided an update on the overall NHS policy and strategy on Secure Data Environments. Michael Chapman provided updates on the NHS Digital merger with NHS England.

- Through the Data for Research and Development Programme, NHS England have announced £13.5 million of funding to support the development of the interoperable network of NHS-owned sub-national data environments. They have selected 11 bids which represent a sub-national coverage of the whole of England. The aim is to bring together integrated care boards, local universities and industry partners to build on existing relationships and research partnerships. Community of practices to ensure further success in this space will be developed. A blog has been published which gives more information on this initiative.
- As the programme develops, NHS England are working on SDE Accreditation. Further updates will be provided in due course.
- NHS Digital / NHS England merger was approved after a debate within the House of Lords. NHS England will continue delivering programmes as planned and improving engagement with partners and collaborators in the future. During this period of transition, there is an expectation that some contacts will change, as well as timelines for delivery. Legal merger of NHS Digital / NHS England will transfer all NHS Digital powers to NHS England. This includes all data sharing agreements and contracts, NHS Digital staff and the Data Services Function.
- In the short term, there will be some disruption but ultimately, the merger will largely improve processes and opportunities.

Chris Orton provided an update from SAIL Databank:

- SAIL Databank are working on integrating several new data sources. This includes work with ONS to incorporate census 2021 data and the Ministry of Justice to incorporate prison and justice datasets.
- There is work being done to ensure legacy datasets and work led by the hubs will continue in the next quinquennium.
- Recent work showcasing a partnered approach between BHF Data Science Centre and SAIL Databank as part of the CVD-COVID-UK consortium has just been published in the BMC Medical Informatics and Decision Making Journal.

- Finalising asset version 3 within Swansea University. This is a system that allows a suite of software to document relevant research project resources and catalogues, which can federate directly across to the Innovation Gateway.

Alex Newberry provided an update from Public Health Wales.

- There are two main data for research workstreams at Public Health Wales. One being focused on trusted research environments. The second is focused on how to digitally enable and support clinical research recruitment and delivery.
- Public Health Wales are about to launch a feasibility tool for research delivery staff to use with sponsors when bringing trials to Wales. It will allow them to enquire with the SAIL databank to better inform feasibility conversations.
- Digital Health and Care Wales have developed a more formal structure and are looking at internal resources on how best to support research delivery in Wales as well as exploring external resources they may be able to use.
- Wales are working towards a Welsh version of DigiTrials. Currently, they are developing the governance and architecture.
- A public dialogue piece of work has started to broadly look at how health and care data is used in Wales, with specific research aspects focussing on the use of data to identify appropriate patients for trials. Alex is keen to link in with PEDRI to share resources and improve this work.

Declan Bradley provided an update for Health and Social Care Northern Ireland.

- Health and Social Care Northern Ireland are preparing for their HDR UK regional community meeting in the coming months.
- Funding for Honours Brokers Service staff has been confirmed for another year. This will be a bridging period for their trusted research environment until further integration can be developed.
- Northern Ireland are moving forward to establish a Confidentiality Advisory Group, to align with the rest of the UK.
- One big development affecting the whole ecosystem is the advent of a new electronic health record system, which will be rolled out over the next year.

Roger Halliday provided an update for Research Data Scotland, followed by Carole Morris from Public Health Scotland.

- Currently simplifying end-to-end service for researchers and aligning across services in Scotland, including data governance, storage, and flows.
- A synthetic data UK-wide group has been established.
- Industry access for public sector data approaches in Scotland is being explored. Industry is feeding back that a common model across the UK would be very helpful.
- Public Health Scotland have a new Chief Executive (Paul Johnston), starting in Spring 2023.
- Work is developing in primary care to assist General Practitioners in providing access to public health data for research purposes.
- Work with Administrative Data Research UK (ADR) is continuing to bring more data into the Data Safe Haven.

Data Access Transparency

Angela Coulter, Chair of the HDR UK Public Advisory Board, presented her slides on Data Governance – Public Information and Involvement. Angela acknowledged the June 2021 publication of a number of recommendations from PAB around improving transparency of data access processes and the Alliance response welcoming these recommendations. One year following publication of these recommendations, PAB conducted an analysis of Alliance member websites and data access documentation and concluded that there was no measurable evidence to suggest public trust and engagement had been improved. This resulted in a call for action to help improve public trust and engagement in an impactful and measurable way. The issue will be brought to one of the next Pan-UK steering group meetings for consideration.

Angela also announced that she will be stepping down as Chair of the HDR UK Public Advisory Board. Members of the Board thanked her for her time as chair and recognised the tremendous work she and the advisory board have achieved in her time as Chair.

Presentation slides are available to view here

Secure Data Environment accreditation

Andy Boyd, Director, UK Longitudinal Linkage Collaboration opened a discussion on establishing an accreditation mechanism for SDEs.

- There are several existing accreditations that still remain vital to ensure vigour and independent oversight, and there is also an opportunity for further alignment and streamlining.
- The digital economy act system along with the SDE accreditation effectively could cover the complexity and diversity of health data across the UK. There is an opportunity to explore best ways to formalise accreditation and align with existing best practice.
- Emily Jefferson explained that in Scotland, the ISO27001 incorporated existing criteria to avoid duplication. This could be considered when formalising SDE accreditation in England.
- Carole Morris emphasised the need to clearly explain what exactly will be accredited, to avoid any confusion.
- SDE accreditation alignment as well as increasing transparency and clarity around data access processes are top priorities for the Pan-UK Data Governance Steering Group.
- More details on this work will be circulate to Alliance members in due course.

Updates and actions from Alliance sub-groups

Technology Services Ecosystems

Emily Jefferson, Chief Technology Officer, HDR UK provided an update on Technology Ecosystems.

- HDR UK are looking to work with people in the community to help them develop their technologies and increase their scale.
- HDRUK are looking for feedback from the wider community on how to develop the Innovation Gateway and how to help it serve the community further.
- On Monday 6th February 2023 the team hosted an event to launch the HDR UK Technology Services Ecosystems workstream.

Trust and Transparency

Andy Boyd, Director, UK Longitudinal Linkage Collaboration provided an update on Trusts & Transparency and the Pan-UK Data Governance Steering Group

- A Legal Toolkit is being developed for data-sharing contracts to improve standardisation.
- The data access 'tube map' is still in development.
- Further work to improve PPIE, as explained in Paper C.

Usable Data

Geoff Hall, Chief Clinical Data Officer, HDR UK provided an update on Useable Data.

- Work is being developed to increase the use of the OMOP Common Data Model to help facilitate collaborative research.
- 5 additional data partners have been funded by EHDEN to incorporate the OMOP Common Data Model:
  - National Joint Registry
  - Discover Now
  - BHF Data Science Centre
  - Lancashire Teaching Hospitals NHS Trust
  - Genomics England
- There are now 23 EHDEN data partners in the UK.
- There were a number of applications that were eligible for funding. However, there were no additional funds at this time. Further funding is being considered.

Capacity Building

Sarah Cadman, Programme Director for Talent and Training, HDR UK, provided an update on Capacity Building:

- The deadline for host organisations to express an interest in hosting an intern for the Black Internship Programme has officially passed but Alliance members can email blackinternprog@hdruk.ac.uk to express interest.
- 92 interns have been placed across 47 host organisations for the Black Internship Programme.
- Over half of inters so far are woman, over half are from non-Russell group universities and over half are first-generation university students.
- There are a number of workshops being delivered by the training team. There are a number of free places for Alliance members. Further details can be found in Sarah's slides below.
- If you would like to attend any of the mentioned training courses, please express your interest by emailing learn@hdruk.ac.uk.

Presentation slides are available to view here.

Alliance governance and ways of working

David Seymour, Director of Infrastructure Services, and Paola Quattroni, Head of Alliance Strategy and Engagement, highlighted the results of a consultation run over the past few months to update the Alliance governance and ways of working as we move into the next five years of the Alliance. A proposal, outlining plans for developing an Alliance Council (currently Alliance Board) and a smaller and representative Alliance Executive Committee was presented.

This proposal is detailed in Paper D and are summarised in the slides below. There was a consensus from the board members that this proposal was acceptable.

Of note, the Alliance will be funded through HDR UK core funds from April 2023, allowing the Secretariat team to continue convening the Alliance to improve access to data for patient benefit.

Over the next three months, the team will focus on developing Terms of Reference for the Alliance Council and Alliance Executive Committee and update relevant documentation (Letter of Intent and Alliance Principles for Participation).

Presentation slides are available to view here

Appendix

Attendees

Name	Organisation
Alex Newberry	Health and Care Research Wales
Alison Elderfield	HDR UK
Andrew Morris	HDR UK
Andy Boyd	UK Longitudinal Linkage Collaboration (UKLLC)
Angela Coulter	HDR UK Patient Advisory Board (PAD)
Cassie Smith	HDR UK
Chris Orton	SAIL Databank
Claire Argent	HDR UK
Claire MacDonald	Manchester University NHS Foundation Trust
Dale Kirkwood	Lancashire Teaching Hospitals NHS Trust (LTHTR)
Danielle Fisher	RCGP
Darren Lunn	CPRD
Deborah Griggs	PathLake / University Hospitals Coventry & Warwickshire
Declan Bradley	Health and Social Care Northern Ireland
Edel McNamara	HDR UK
Elliot Bridges	Human Fertilisation and Embryology Authority
Emily Jefferson	HDR UK
Ester Bellavia	HDR UK
Fergus McDonald	HDR UK
Geoff Hall	HDR UK / University of Leeds
Katherine O'Sullivan	University of Aberdeen / NHS Grampian	Grampian Data Safe Haven
Kathy Harrison	DataLoch
Kay Snowley	HDR UK
Lara Edwards	HDR UK
Lisa Scerri	The Royal Marsden NHS Foundation Trust
Manjit Benning	Moorfields Eye Hospital NHS Foundation Trust / INSIGHT (Hub)
Margaret Charleroy	NHS England
Mark Howells	Nottinghamshire Healthcare NHS Foundation Trust
Melissa Lewis-Brown	Cancer Research UK (CRUK)
Michael Chapman	NHS Digital
Michael Cook	Our Future Health
Nada Karrar	HDR UK
Nay Aung	Queen Mary University of London

Neena Modi	Imperial College London
Nicola Armstrong	Health and Social Care Northern Ireland
Paola Quattroni	HDR UK
Pete Stokes	Bennett Institute for Data Science
Rachel Brophy	HDR UK
Richard Lee	The Royal Marsden NHS Foundation Trust
Rob French	Cardiff University
Robert Stewart	King's College London / DATAMIND
Sarah Cadman	HDR UK
Sion Parry	University Hospitals Coventry and Warwickshire NHS Trust
Stephen Burrows	HDR UK
Tim Hubbard	HDR UK
Tim Robbins	University Hospitals Coventry and Warwickshire
Tom Barlow	Scottish Government
Vishnu Chandrabalan	Lancashire Teaching Hospitals NHS Trust (LTHTR)
Yemi Macaulay	HDR UK
Yvonne Silove	Healthcare Quality Improvement Partnership (HQIP)
Zoe Plummer	UK Renal Registry