

UK Health Data Research Alliance Board – Actions and Meeting Notes

Friday 14th October 2022 (09:00 – 11:00)

Immediate actions for Alliance members:

- For metadata onboarding and use of any additional Innovation Gateway functionality such as data access, data use registers, cohort discovery and federated metadata automation please email servicedelivery@hdruk.ac.uk.
- Alliance members that wish to link with Roger on the synthetic data approaches work can contact him via Roger.Halliday@researchdata.scot.
- The 7th and LAST open call for European data partners is now OPEN and will run until 11th November (17:00 CET). EHDEN has partnered with Health Data Research UK for this call. If you wish to apply follow this [link](#).
- If you require advice or guidance from HDR UK in relation to your EHDEN Data Partner Call application, email the Alliance via ukalliance@hdruk.ac.uk.
- Alliance members that wish to be involved in the Talent and Training Advisory Group can email Sarah Cadman via Sarah.Cadman@hdruk.ac.uk.
- Alliance members are invited to provide feedback on the Alliance governance and ways of working proposal via this survey.

Actions for HDR UK secretariat:

- Circulate slides presented at the meeting.
- Circulate Alliance governance and ways of working consultation survey for further input from Alliance Board members.
- Share information regarding the cancer research data frontiers meeting with the Alliance Board members, as it is available.
- Alliance to contact an OSCHR representative to engage with, prior to their meeting in January 2023.
- The 'Improving Access to Linked Data for Research' workshop, convened by the Alliance and chaired by Meredith Leston took place on 19th October 2022. Outcomes from this workshop to be shared on the Alliance website.

Meeting notes:

Welcome, introductions and opening remarks

Andrew Morris, Director of HDR UK, opened the meeting by welcoming the attendees and providing an overview of the agenda. Andrew briefly highlighted key points within the Convenor's paper and opened the call to questions from attendees. Andrew thanked the Board members for their support and involvement



with the Black Internship Programme. 41 Alliance members have taken part to support 81 Internships across the UK and announced plans to extend the programme next year.

David Seymour, Director of Infrastructure and Services, highlighted the announcement of [NIHR Biomedical Research Centres](#) and the importance of working with them in the future. The BRCs have concentrated institutes with high-resolution data from research cohorts and acute trusts in England and would be key stakeholders for the Alliance to engage with.

Action points from the last meeting & Gateway report

Action points from the last meeting were briefly highlighted and reviewed by Paola Quattroni, Head of Alliance Engagement and Strategy, HDR UK. There are several new functionalities within the Innovation Gateway. Federated metadata functionality, co-discovery tool and data use registers. If any Alliance members require support with these functionalities, they are invited to contact the new HDR UK Service Delivery Team for support (servicedelivery@hdruk.ac.uk).

The Alliance team are also scoping the possibility of a frontiers meeting on Cancer research data, to be co-chaired by Geoff Hall (HDR UK / University of Leeds) and Melissa Lewis-Brown (Cancer Research UK). More information will be shared with Alliance members in due course.

Horizon Scanning: updates from across the UK

Hardeep Jhutti, Deputy Director, Strategy and Development at the Centre for Improving Data Collaboration, from NHS England Transformation Directorate

provided an update on the overall NHS policy and strategy on Secure Data Environments (SDEs).

- The [SDE Policy guidance](#) has been published by NHS England. For more information, or to get involved, please email SDE.policy@dhsc.gov.uk.
- Next steps include publishing a technical guidance as well as an outline of the accreditation process for SDEs.
- The Data for R&D programme, 200-million-pound investment into infrastructure and services over the next 3 years is being led by Dr Claire Bloomfield. As part of this work, NHS England have issued an expression of interest process for sub-national SDE development. The deadline for submissions was 21/10/2022.
- NHS England have published a [strategy](#) to embed genomics in research nationally.
- Working with colleagues at HDR UK to support the [PEDRI initiative](#), recently launched in partnership with Administrative Data Research UK (ADR UK), Office for National Statistics, Research Data Scotland and DARE UK
- A joint workplan between NHS England and HDR UK to allow better collaboration and streamlined work has been announced: <https://www.hdruk.ac.uk/news/joint-statement-from-health-data-research-uk-and-nhs-england/>



Michael Chapman provided an update from NHS Digital.

- NHS England and NHS Digital merger into NHD Transformational Directorate is moving ahead at pace. A central data and analytics function is being designed.
- National SDE for NHS Digital which builds on BHF Data Science Centre model is now in private beta.
- NHS DigiTrials recruitment service is now showing value. The Galleri trial has seen the fastest randomised controlled trial recruitment in England at scale, with 140,000 participants recruited in 10 months. This is done in collaboration with Our Future Health and DigiTrials.
- Working on a cancer research focus group. There is an opportunity to link up Alliance cancer working group.

Alex Newberry provided an update from Public Health Wales.

- The Welsh government have set up a data for research working group to advise on how to reach their goals in Public Health Wales. This work focuses on two key areas.
- How to continue building on the excellence of SAIL Databank, a national Trusted Research Environment. Progressing this work as well as the emergence of an NHS Wales national data resource that compliments and enhances how they deliver through SAIL.
- Using data to support clinical trial delivery by agreeing on a model of resources for an NHS Wales recruitment support service, similar to DigiTrials and procuring a partner to support PPIE activities.

Chris Orton sent his apologies and provided a written update from SAIL Databank:

- Signed agreements with the Ministry of Justice for crown and magistrates court data to be linked to SAIL and Cafcass for England.
- Family courts data has now arrived into SAIL and is being linked through the BOLD (Better Outcomes through Linked Data) initiative at the Ministry of Justice.
- Currently working with Our Future Health to collaborate and plan the linkage of consented participants and interoperation with their TRE setup and data sharing.
- Much of the Administrative Data Research (ADR) Wales team are now working towards governance applications on creating a pan-research theme programme of work to set up data analysis and cohorts for climate change, wellbeing, and social justice.
- Working to finalise the federation of SAIL metadata catalogue with the HDR UK Innovation Gateway through National Core Studies (NCS) Data & Connectivity (D&C), as well as completing Data Access Request (DAR) integration with SAIL Information Governance Review Panel (IGRP).

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

- Declan thanked the HDR UK team for their efforts to respond to the HSC Northern Ireland Data Strategy consultation.
- Frances Burns has been appointed to the Department of Health and Social Care to support the Northern Ireland Confidentiality Advisory Group (CAG) equivalent processes.
- Northern Ireland national TRE is currently in a transition stage. There are measures in place to ensure there will be no gaps in service during this transition.



- Early-stage applications to enter Primary Care GP data into the TRE for the first time.
- HSC Northern Ireland are in talks to engage with the HDR UK Black Internship Programme in 2023, for the first time.

Anna Dominicczak and Tom Barlow provided an update from Scottish Government

- It was suggested to link the Alliance with OSCHR. OSCHR are meeting face-to-face in January. This is an opportunity for a member of the Alliance to meet and engage with them.
- Update on a programme of work on unlocking the value of using public sector data in the private sector, to the public.

Roger Halliday provided an update for Research Data Scotland

- Research Data Scotland was set-up 1 year ago. Roger extended a thank you to SAIL Databank and ONS for their support.
- Research Data Scotland are working on synthetic data approaches and are keen to link with other colleagues across the UK that are working on this. The work involved evaluating different approaches and how they can be operationalised.
- Any Alliance members that wish to link with Roger on the synthetic data approaches work can contact him on roger.halliday@researchdata.scot.

Proposed Alliance governance and way of working

David Seymour chaired a working session to gather feedback from Alliance members on the Alliance governance and ways of working proposal. A consultation has been taking place over the last few months to gather feedback from Alliance members and partners, via individual meetings, workshops, and a survey. The survey is still open to responses. Alliance members can contribute via this [link](#).

Paola Quattroni, Head of Alliance Strategy and Engagement, presented her slides on the Alliance model review and update.

David Seymour invited the Board members to provide feedback and comments on the above proposals. Geoff Hall queried whether for-profit organisations can become full members of the Alliance. Paola clarified that we would like to link with and engage better with for-profit organisations but feedback received indicated that full Alliance membership might not be appropriate.

Phil Quinlan suggested that for-profit organisations that want to share data sets with researchers would have different needs from for-profit organisations that wish to access other data sets. Hardeep Jhutti explained that systematically engaging with industry may be a better use of resources than targeting individual organisations. There is more work to do on how to operationalise a potential industry engagement strategy, but there was general agreement that the Alliance should engage more with for profit organisations.

Neil Walker highlighted the value of quarterly Alliance board meetings in terms of information sharing and networking. Mark Howells expressed concern that losing this would disadvantage many members and this

may be at risk if the board moved to a smaller representative model. It was suggested that if that were to happen, the existing meetings should still go ahead as a forum for information sharing. Michael Chapman mirrored these concerns. The Board agreed that we could move to a small and representative Alliance Board but regular meetings to bring together all Alliance members should also continue.

Meredith Leston suggested regular Alliance newsletters to keep Alliance members informed, engaged and involved with Alliance workstreams and the wider health data ecosystem.

Updates and actions from Alliance sub-groups

Technology Services Ecosystems

Tim Hubbard, Associate Director of HDR UK London Research Site, added to Hardeep Jhutti's update on SDE policy guidance.

- Tim recently attended the Global Alliance for Genomics and Health (GA4GH) 10th Plenary meeting. The GA4GH has over 60 active countries and was developed from the genome-sharing community, with a starting point of sharing data. There has been a slight change of attitude towards providing data access rather than sharing.
- There are various global activities that are influencing and being influenced by the SDE policy guidance.
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Trust and Transparency

Cassie Smith, Head of Legal, HDR UK presented an update on the Pan-UK Data Governance Steering Group, followed by Sinduja Manohar, Public and Patient Involvement and Engagement Senior Manager.

- The Pan-UK Steering group have established three Action Forces, to deliver on three workstreams.
 - TRE Legal Toolkit – To provide a clearly standardised template for data access, data sharing agreements and DPIAs.
 - Mapping data access processes – To design a single map of all ethics and governance approvals needed to link data.
 - Five Safes Form – To promote increased adoption of the 5-safes framework data access application form, understand the challenges in adoption and create training to support the use of the Form including “step-by-step guidance”.
- Sinduja Manohar continued presenting on the Alliance PPIE Workstream and mentioned the launch of the PEDRI initiative: <https://www.pedri.org.uk/>.
- The PPIE team will also be running a pilot campaign over the next three months to engage new young families, a population identified as not being engaged in health data.

Usable Data

Geoff Hall, Chief Clinical Data Officer, HDR UK provided an update on the HDRUK-EHDEN Data Partner Call. For more information and to apply please visit <https://www.ehden.eu/open-calls/10-2022-7th-and-last-call/>.



Capacity Building

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

- HDR UK will be forming a new Talent and Training Advisory Group and would like Alliance members to join.
- The advisory group will have three main purposes. To focus on the most urgent skills gaps within the health data research landscape, to minimise duplication and to use analytics and evaluation to continuously improve the training offer.
- The advisory group will be made up of representatives from industry, medical charities, academia, and the NHS. There will be good representation from users, employers, and subject matter experts.
- The advisory group will meet 3 times a week and already have a list of committed members.
- The Black Internship Programme which closed for this year in September 2022, will continue in 2023, with more interns and more employers. A webinar for prospective host organisations will take place on 27 October. For more information visit <https://www.hdruk.ac.uk/events/hdr-uk-black-internship-programme-2023-becoming-a-host-organisation/>.

Next Alliance Board meetings

The next Alliance Board meeting will take place via Zoom on 26th January 2023 13:00 – 15:00. An invite will be circulated shortly.

Appendix

Attendees

Name	Organisation
Alex Newberry	Health and Care Research Wales
Alison Elderfield	HDR UK
Andy Boyd	UK Longitudinal Linkage Collaboration (UK LLC)
Anna Dominiczak	Scottish Government
Anthony Wilson	Manchester University NHS Foundation Trust
Cassie Smith	HDR UK

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Chris Orton	SAIL Databank
Clare Normand	The Brain Tumour Charity
David Harrison	iCAIRD
David Jenkinson	The Brain Tumour Charity
David Seymour	HDR UK
Declan Bradley	Health and Social Care Northern Ireland
Edel McNamara	HDR UK
Elliot Bridges	Human Fertilisation and Embryology Authority
Erik Mayer	Imperial College London
Geoff Hall	HDR UK / University of Leeds
Hardeep Jhutti	NHS England Transformation Directorate
James Pickett	HDR UK
John Zurowski	iCAIRD
John Schofield	Manchester University NHS Foundation Trust
Jon Smart	Swansea University
Kathy Harrison	DataLoch
Kazuyo Machiyama	London School of Hygiene & Tropical Medicine
Lara Edwards	HDR UK
Lindsay Cockcroft	HDR UK
Lisa Scerri	The Royal Marsden NHS Foundation Trust
Liz Merrifield	Cardiff University
Lynn Morrice	HDR UK
Mark Howells	Nottinghamshire Healthcare NHS Foundation Trust
Meredith Leston	Oxford-RCGP RSC network - University of Oxford
Michael Chapman	NHS Digital
Michael Cook	University of Manchester / Our Future Health
Natalie Garratt	Northern Care Alliance NHS Foundation Trust
Nathalie Kingston	NIHR Bioresource
Nay Aung	Queen Mary University of London
Neil Walker	NIHR BioResource

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Nicola Armstrong	Health and Social Care Northern Ireland
Paola Quattroni	HDR UK
Philip Quinlan	University of Nottingham
Reza Razavi	King's College London
Richard Lee	The Royal Marsden NHS Foundation Trust
Rob French	Cardiff University
Roger Halliday	Scottish Government
Simon Bolton	NHS Digital
Sinduja Manohar	HDR UK
Stephen Burrows	HDR UK
Sven Bunn	Barts Health NHS Trust
Tim Hubbard	HDR UK
Tim Robbins	University Hospitals Coventry and Warwickshire
Tom Barlow	Scottish Government
Yasser Mushtaq	Manchester University NHS Foundation Trust
Yemi Macaulay	HDR UK
Zoe Plummer	UK Renal Registry