

UK Health Data Research Alliance Council

Actions and meeting notes

Thursday 13th July 2023 (13:00 – 15:00)

Immediate actions for Alliance members:

- Contact Roger Halliday to know more about work happening around single point of access, single approval and commercialisation.
- Contact UKAlliance@hdruk.ac.uk if you would like to be involved in PEDRI and Alliance activities on Public and Patient Involvement and Engagement (PPIE).
- Provide input into the draft transparency standard ([Paper D](#)) via emailing Yemi.macaulay@hdruk.ac.uk.
- Members interested in attending workshops on the adoption of the data access transparency standards, please email Yemi.macaulay@hdruk.ac.uk.

Actions for HDR UK secretariat:

- Circulate slides presented at the meeting to all attendees.
- Produce and circulate a 1-page brief regarding the OMOP Common Data Model project, articulating the value of data transformation and highlighting impact.

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.

Paola Quattroni, Head of Alliance Strategy and Engagement, HDR UK welcomed [ten new members to the Alliance](#), including:

- [Association of Medical Research Charities](#)
- [BioIndustry Association \(BIA\)](#)
- [Association of the British Pharmaceutical Industry \(ABPI\)](#)
- [Dementia Platform UK \(DPUK\)](#)
- [IBD Registry Ltd](#)
- [Optimum Patient Care](#)
- [Lancashire & South Cumbria NHS Foundation Trust](#)
- [Norfolk and Norwich University Hospitals NHS Foundation Trust](#)
- [Newcastle upon Tyne Hospitals NHS Foundation Trust](#)



- [Royal Free London NHS Foundation Trust](#)

These new members included the first non-data custodians and the first industry trade associations to join the Alliance.

Action points from the last meeting update on governance and workstreams

Paola Quattroni updated on previous action points from the last Alliance Council meeting and Alliance workstreams, thanking relevant contributors.

- Adoption of data use register standard is still progressing. Any questions about this can be directed to Nara Karrar via ukalliance@hdruk.ac.uk.
- The Diversity in Data – Ethnicity Coding working group had their final working session, in-person and are working towards a number of recommendations for best practice around data collection and ethnicity coding. More can be read about this on the [Alliance website](#).
- The Alliance launched a special interest group for OMOP common data model, chaired by Geoff Hall (University of Leeds) and Dani Prieto-Alhambra (University of Oxford). This work focuses on interoperability. The meeting outputs will be published on the Alliance website. Currently, they are available [here](#).

Horizon Scanning: updates from across the UK

Andrew welcomed representatives from across the four UK nations to provide updates from their organisations.

Chris Orton, Programme Manager, provided an update for SAIL Databank, Swansea University, and an update on behalf of Alex Newberry from Welsh Government.

- A minimum viable product launched recently for a feasibility tool, to aid conversations with sponsors about potential participant pools and rough geographical location – this has been developed in partnership between Health and Care Research Wales and the SAIL Databank team.
- In addition to (and separate from the feasibility tool), Welsh Government has asked Digital Health and Care Wales to develop and implement 'Digitrials Wales' – this work is to provide digital methods to aid identification and approach of individuals to recruit to specific trials. This work is still in the development stage and has received great support from the NHS England Digitrials team, who they expect to work in partnership with on the Digitrials offering in the coming months.
- Work is currently ongoing between Swansea University and Welsh Government to ensure a refreshed funding model for SAIL Databank moving forward. The aim is to become the core national research data infrastructure for Wales.
- SAIL Databank is directly involved with two of the DARE UK federation projects and working closely with two others.



Joe Watts, Head of Data Access Policy provided an update from NHS England on the recent data access policy consultation and Data for R&D programme.

- In May 2023, the Data for R&D project had their budget officially signed-off. Delivery has now officially begun.
- NHS England developed and published a Secure Data Environment data access policy update in May. This was open to a 4-week consultation.
- They had 62 responses and many Alliance organisations contributed to this. NHS England are now working through the responses and plan to incorporate comments and redraft later in 2023.
- An SDE accreditation scheme is being set-up and discussions with the UK Statistics Authority are ongoing. The data saves life strategy included updates on how existing frameworks for non-health data will be used to move forward with this.
- Further considerations of scope will be made in the future.

Roger Halliday, Chief Executive Officer for Research Data Scotland

- Research Data Scotland are launching a new researcher access service in early 2024.
- There are a range of improvements being developed including:
 - Fast-track approvals process for low risk projects
 - Changes to the broader data access approval systems
 - Official links to work on shaping policy for industry access to data. A draft policy had just been completed.
 - Within Scotland Data Safe Haven, they are able to test a number of approaches
 - There is a re-established PPIE network within Scotland
 - A genomics strategy is being developed by Scottish Government that is due for publication later this summer.

Scott Heald, Director of Data for Digital Innovation, Public Health Scotland

- Scotland's national Data Safe Haven platform is being updated to provide sufficient infrastructure for large datasets, such as medical imaging.
- There are agreements in place from the national picture archiving communications system. This means they will have access to medical imaging for research. This system has been successfully tested and will be readily used for research in Scotland.
- Work is continuing on streamlining processes around access to primary care data. The goal is one streamlined route to allow researchers permission.

Ian Young, Assistant Director Health and Social Care Northern Ireland, HSCNI, R&D Division

- HSCNI are in the process of implementing their new data strategy. This includes the introduction of a new data institute and Trusted Research Environment. This shouldn't change functionality but should provide a sustained long-term pathway to funding.
- HSCNI are rolling out 'encompass', a new electronic healthcare record that aims to hold all health and social care records in one system. Legacy data will not be included but will still be held in a TRE.
- Irish government are yet to pass secondary use of data legislation which is causing some delays to progress at HSCNI. Further progress requires restoration of Northern Ireland government.

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Transparency Standards Sign-Off

Yemi Macaulay presented slides to update on the [Transparency in Data Access work](#) that has been developed by HDR UK, the Pan-UK Data Governance Steering Group and the Alliance.

The attendees provided some feedback on the standards presented. Council members noted that some of the standards may be difficult to implement for organisations such as large NHS Trusts, where resources available might be limited.

A working group to support the implementation of the data access transparency standards will be established to explore standard implementation further. Those that wish to get involved should email her via yemi.macaulay@hdruk.ac.uk.

Panel presentations: Participation and Public involvement in data-driven research.

This session was chaired by Cassie Smith, Head of Legal, Trust and Ethics at HDR UK.

Emma Maker, Head of Digital Engagement, NIHR Clinical Research Network presented [slides on NIHR Be Part of Research](#).

Liz Perraudin, Clinical Policy Manager, AMRC gave a verbal presentation on the role of medical charities in ensuring inclusive research.

Medical charities often have very strong community networks and are excellent leaders in PPIE, in particular with marginalised or underrepresented communities.

Trustworthiness and transparency are fundamental values of medical research charities. AMRC and the NIHR are in early conversations on how to further link patient registries with research opportunities.

Liz highlighted recommendation 14 of the O'Shaughnessy review (An ongoing public campaign should be conducted to promote research and to generate evidence on the most effective communication methods, in partnership with medical and research charities). This recommendation could involve some risk to public trust if industry partners are included within this campaign. Any joint campaign with industry will need to be very carefully risk assessed.

Patient enabled research is a key goal of medical research charities and they hold a very unique perspective as they fund high-quality research and also represent patients for which the research is ultimately being designed. Many medical research charities will hesitate to support a government or NHS communications campaign without being highly critical. This is to ensure patients are always represented and their trust and confidence are not compromised.

Ben Thomas, Project Manager, HDR UK, PEDRI presented [slides on Public Engagement in Data Research Initiative \(PEDRI\)](#).

Doreen Tembo outlined PPIE next steps for HDR UK and PEDRI. The plans are to work upon what has already been done and work towards sharing best standards practice, working with PEDRI members and the wider community. PEDRI will be expanding membership and considering how to scale up.



Updates and actions from Alliance sub-groups

Dona Reddiar, Doctoral and Internship Programme Manager, HDR UK presented slides on the [Black Internship Programme](#).

Emily Jefferson, Chief Technology Officer, HDR UK presented slides on [Technology Services Ecosystems](#)

Monica Jones, Chief Data Officer, University of Leeds / Associate Director, HDR UK provided a verbal update on the HDR UK workstream on Useable Data. This workstream is concentrating on data improvement, providing thought leadership and convening thinking across the Alliance to enable research, streamlining routes for ingesting metadata, perfecting the use of data profiling, and establishing good working relationships with standards-developing organisations. A slide deck summarising priorities for this workstream can be accessed [here](#).



Appendix

Attendees

Name	Organisation
Alison Elderfield	HDR UK
Amonida Zadissa	UK Dementia Research Institute
Anastasia Ushakova	Lancashire & South Cumbria NHS Foundation Trust
Andrew Morris	HDR UK
Andrew Pennington	Lancashire & South Cumbria NHS Foundation Trust
Andrew Percy	University Hospitals Birmingham NHS Foundation Trust
Andy Boyd	UK LLC
Andy Wong	MRC Unit for Lifelong Health and Ageing
Ashley Akbari	Swansea University / SAIL Databank
Ben Thomas	HDR UK / PEDRI
Cassie Smith	HDR UK
Chris Orton	Swansea University / SAIL Databank
Claire Argent	HDR UK
David Harrison	iCAIRD
Dona Reddiar	HDR UK
Doreen Tembo (HDRUK)	HDR UK
Elliot Bridges	Human Fertilisation and Embryology Authority
Emily Jefferson	HDR UK
Emma Maker	NIHR Clinical Research Network
Emma Squires	Swansea University
Erik Mayer	Imperial College London
Fergus McDonald	DARE UK
Gail Roadknight	Oxford University Hospitals NHS Foundation Trust
Guy Smallman	Guy Smallman
Imogen Shillito	NIHR Clinical Research Network
James Peach	UK BioIndustry Association
Janet Valentine	Association of the British Pharmaceutical Industry
Jo Knight	Lancashire & South Cumbria NHS Foundation Trust
Joe Watts	NHS England
Jon Smart	Swansea University / SAIL Databank
Katie Wilde	University of Aberdeen
Kinga Varnai	Oxford University Hospitals NHS Foundation Trust
Lara Edwards	HDR UK
Laura Cocking	NIHR BioResource
Lesley McShane	Newcastle upon Tyne Hospitals NHS Foundation Trust

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Lisa Scerri	Royal Marsden NHS Trust
Liz Perraudin	AMRC
Lucy Lennon	University College London
Lynn Morrice	British Heart Foundation Data Science Centre
Manjit Benning	Moorfields Eye Hospital NHS Foundation Trust
Melissa Lewis-Brown	Cancer Research UK
Michael Chapman	NHS England
Monica Jones	University of Leeds
Nick Kennedy	Royal Devon University Healthcare NHS Foundation Trust
Olivier Roth	BIA
Paola Quattroni	HDR UK
Pete Stokes	Bennett Institute for Applied Data Science
Ian Young	Queen's University Belfast / HSCNI
Rachel Brophy	HDR UK
Richard Lee	Royal Marsden
Robert Stewart	King's College London
Roger Halliday	Research Data Scotland
Samina Begum	Use MY Data
Sarah Cadman	HDR UK
Scott Heald	Public Health Scotland
Sneha Anand	Oxford-RCGP RSC network - University of Oxford
Sophie Harriman	Optimum Patient Care
Stephen Burrows	HDR UK
Susan Hodgson	CPRD
Tim Hubbard	HDR UK / Genomics England
Uwaye Ideh	HDR UK
Yemi Macaulay	HDR UK
Yvonne Silove	Healthcare Quality Improvement Partnership
Zoe Plummer	UK Renal Registry