

UK Health Data Research Alliance Council Actions and meeting notes

Wednesday 17th January 2024 (14:00 – 16:00)

Immediate actions for Alliance members:

- This year there are over 1600 applicants for the 2024 HDR UK Black Internship Programme cohort. We would like to extend the invitation to become a host organisation to all Alliance members. More information can be found on the [HDR UK website](#). If you would like to express an interest in becoming a host organisation or have any questions, please get in touch via blackinternprog@hdruk.ac.uk.
- Contact UKAlliance@hdruk.ac.uk if you would like to provide input on the Alliance white paper on emerging recommendations for ethnicity data collection or if you would like to be involved in the project.
- Research Data Scotland will be in touch with Alliance members to collaborate on a project to update the charter of data safe havens in Scotland.

Actions for the Alliance secretariat:

- Share slides from the Council meeting with attendees.
- Share information regarding the Black Internship Programme including the commitments required from host organisations.
- Consider a driver project to demonstrate the importance of adopting good ethnicity coding standards.

Meeting notes:

Welcome, introductions and opening remarks

Andrew Morris, Director of HDR UK and Chair of the Alliance, welcomed the attendees and introduced the latest [new members to the Alliance](#), including:

- [techUK](#)
- [Association of British HealthTech Industries \(ABHI\)](#)
- [Centre for Longitudinal Studies](#)
- [Action Against Age-related macular degeneration \(AAAMD\)](#)
- [Administrative Data Research UK \(ADR UK\)](#)
- [MRC Regulatory Support Centre](#)
- [Professional Record Standards Body](#)
- The [Data Research Access and Governance Network \(DRAGoN\)](#), University of the West of England Bristol

Update from the Alliance secretariat

David Seymour, Director of Infrastructure & Services and Paola Quattroni, Head of Alliance Strategy & Engagement, HDR UK, presented [slides to update on the Alliance progress and the 2024 work plan](#).

- Andrew opened up to comments and questions from attendees.
- Andrew commented on the efforts across the Alliance and HDR UK to better collaborate with the UK four nations. There is an opportunity to coordinate and leverage existing work across three main areas: technology and data; trust and transparency and capacity building.
- Participants commented that whilst driving infrastructure capabilities, Alliance members should also be increasing the uses of data at scale, using the infrastructure. These are parallel processes, not linear. It would be helpful to see case studies of good practice in this area.
- The work on the adoption of the Observational Medical Outcome Partnership (OMOP) common data model was highlighted as an opportunity to drive use cases demonstrating the use of infrastructure. However, challenges to encourage researchers to engage and adopt standards were also mentioned.
- On trust and transparency, it was suggested that the Alliance could better highlight the successes of good trust and transparency programmes. We need to be transparent about the value of using health data, showcasing positive stories as well acknowledging what should be improved.
- The [UK Trusted Research Environment \(TRE\) community](#) was highlighted as an initiative that the Alliance could work closely with. This group is a forum currently bringing together various communities and tackling widespread issues across data ecosystems. The tools and programmes need to be useable across ecosystems and internationally. Partnerships with Data Analytics Research Environment UK (DARE UK) European Health Data Evidence Network (EHDEN) are important examples of this.

Alliance Draft White Paper on “Recommendations towards an ethnicity data collection framework”

Sara Khalid, Associate Professor, University of Oxford, presented [slides on a first draft of the Alliance Special Interest Group: Diversity in Data and the Ethnicity coding standards white paper](#) recently developed. The paper includes a series of recommendations for improving the recording of ethnicity data.

- Participants suggested that it would be helpful to share these recommendations with Electronic Patient Records providers.
- It is also important to communicate the standards to a range of stakeholders, including funders.
- Work on dissemination and communication is ongoing, and this will include engagement with funders and medical charities.
- A participant queried how the group considers mixed ethnicity and self-reporting. Sara Khalid reassured that these considerations have been carefully thought out and the recommendations will be tackling this.

Horizon Scanning: updates from across the UK



Andrew welcomed representatives from across the four UK nations to provide updates from their organisations. He also highlighted the efforts of TRE leaders across the UK and the important contribution of this infrastructure in delivering important research.

Michael Chapman, Director of Research and Clinical Trials, NHS England

- Claire Bloomfield has left NHS England and Michael recognised her contributions.
- Rebecca Cosgriff has been appointed Deputy Director of Data for R&D programme.
- There was a 3-day residential conference in Birmingham at the end of 2023, bringing together people from the sub-national Secure Data Environment network.
- NHS England are part of the COALESCE study and highlighted [Cathie Sudlow's interview on the Today programme \(beginning at 1:49:05\)](#). More information is available on the [HDR UK website](#).
- NHS England are now collaborating with OpenSAFELY. They are working closely on training and education to improve access to and use of OpenSAFELY and the NHS England Secure Data Environment (SDE).
- There is now a focus on standardisation, interoperability, and growth of SDEs.
- NHS DigiTrials is still being supported by Data for R&D. Many high-profile studies are delivered successfully due to NHS DigiTrials.

Chris Orton, Programme Manager, SAIL Databank

- SAIL Databank will provide data for [COALESCE study](#).
- SAIL Databank working very closely with BHF Data Science Centre on the set-up of their cohort TRE.
- DARE UK driver project [TELEPORT project report](#) is now available, as well as the [TRE-FX project report](#).

Alex Newberry, Head of Research Involvement, Governance & Informatics, Welsh Government

- The independent review of Welsh Government funded research groups recognised SAIL Databank as an excellent investment. The funding for 2025 needs to be confirmed.
- There is an agreement that investment into SAIL Databank should be broader than just health and social care. It will likely expand to a broader public services databank.
- In the planning stages of a deliberative public dialogue event to identify the public expectations of the use of patient data for identification and approach for studies. The event is due to take place in April 2024 and a report will be available in July 2024.

Tom Barlow, Senior Research Manager, Scottish Government

- Research Data Scotland (RDS) is a partnership of Scottish Government, Public Health Scotland, National Records Scotland, and several academic institutes. It is set up to improve the use of public data for research and public good.
- RDS are launching the first version of its researcher access service. A digital service to provide researchers with data, focusing on 9 health data sets.
 - In-patient

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- Out-patient
 - Maternity
 - Mental health
 - Cancer
 - Prescribing
 - A&E
 - Births
 - Death
-
- There is a small fund that researchers can apply for to use the service and provide research. The link can be found. More information can be found on the [RDS website](#).
 - RDS are focusing on speeding up trustworthy access to data for research. They are developing new Information Governance arrangements, using a functional anonymisation approach. Moving from safe projects to safe programmes and portfolios. This should speed up decision-making and lower the burden on researchers when accessing and using data.
 - Scottish Government data board have recently agreed to facilitate a project to update the charter of data safe havens in Scotland. IT and IG policy was developed 9 years ago and is in need of reviewing and updating. RDS will lead this work and wish to do so in collaboration with other nations across the UK and with other Alliance members, to avoid duplication.
 - Anna Dominiczak added that the offer from RDS to clinicians is a greatly impressive and a huge step forward.
 - Emma Gordon highlighted that ADR UK would provide funding to RDS through funding given to Scottish Government, to open up access to data for researchers.

Ian Young, Director of Research and Development, Health and Social Care Northern Ireland

- Northern Ireland's (NI) TRE is part of the [UK TRE community](#) and encourages ongoing collaboration.
- NI are rolling out a new EPR system called [encompass](#), bringing together health and social care data together in a single patient record. There will be significant opportunities to support research with this new EPR.
- NI's data and digital strategy includes a proposal to establish a data institute to oversee governance arrangements and the use of data for health and social care purposes and secondary purposes. The implementation will be dependent on funding and government.

Panel Session: 5 Safes Framework: Safe People and Accreditation (Chaired by Cassie Smith, Head of Legal, Trust and Ethics, HDR UK)

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Becky Purvis, Director of Policy, Health Research Authority (HRA) presented [slides on Earning public trust in research and recent results from the HRA public attitudes survey](#).

- Emphasis was placed on the importance of 'earning trust' in relation to the Transparency standards being developed by the Pan-UK Data Governance Steering Group.
- It was highlighted that there is a significant difference between the public and patient perspectives, with patients generally having higher acceptance and trust in the use of data for research. Support from UseMyData was offered to help HRA communicate the importance of data use in research, to the public.
- There was a query as to what the existing bottom-up pathways are to ensure research that is commissioned is responsive to public priorities. It was clarified that HRA has little influence on what research is funded but rather they can influence how research is delivered.
- There was further discussion around patient and public trust in researchers and research teams being difficult to gain, as those teams do not control or hold the data.

Kerrie Woods, Director, Thames Valley and Surrey NHS Secure Data Environment presented [slides on NHS Research SDE Network plans for researcher accreditation](#).

- Attendees discussed caution around the term 'researcher passport' and recommended adding the word 'data' to alleviate confusion, as the term may be used elsewhere.
- It was raised that CPRD's accreditation of researchers should be closely collaborated with to prevent duplication and complement the work presented by Kerrie.
- Attendees suggested that organisations or institutions should be validated before individuals, potentially allowing the institution to 'vouch' for the individuals when they then seek accreditation.

Felix Ritchie, Director, Data Research Access and Governance Network presented [slides on Research passports and evaluating 'safe' researchers](#)

- Participants highlighted the principles-based approach that Felix presented and the work of the Pan-UK Data Governance Steering Group. Assuring alignment and centralisation will help to prevent diversion and duplication.
- It was echoed that the work presented is very much about the individual researcher. However, it is also important to consider organisation or institution verification/validation to really cement the trustworthy use of data. It would be helpful to consider how other sectors review and accredit individuals and organisations, for example, the financial sector.
- There was further discussion on the need to anticipate and overcome technical and operational issues, to ensure successful delivery and adoption.

Appendix

Attendees

Name	Organisation
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Aida Sanchez	Centre for Longitudinal Studies
Alex Bailey	UKRI
Alex Knight	HDR UK
Alex Newberry	Welsh Government
Alison Elderfield	HDR UK
Ameet Bakhai	Royal Free London
Amonida Zadissa	UK Dementia Research Institute
Amrita Ahluwalia	Queen Mary University of London
Amy Berrington	The Institute of Cancer Research
Andrew Davies	Association of British HealthTech Industries
Andrew Wong	UCL
Andrew Morris	HDR UK
Andy Boyd	UK LLC / HDR UK
Anna Dominiczak	Scottish Government
Anthony Wilson	HRA
Becky Purvis	HRA
Ben Crosby	HDR UK
Ben Goldacre	OpenSAFELY
Benjamin Cairns	University of Oxford
Carole Morris	Public Health Scotland
Cassie Smith	HDR UK
Chris Orton	SAIL Databank / Swansea University
Claire Argent	HDR UK
Colin Brown	NHS Education for Scotland
Damon Chow	HDR UK
Dave Chuter	UseMyData
David Harrison	ICNARC
David Seymour	HDR UK
Dona Reddiar	HDR UK
Doreen Tembo	HDR UK
Emma Gordon	UKRI ESRC
Erik Mayer	Imperial College London
Estelle Spence	NHS England
Felix Ritchie	Data Research Access and Governance Network (DRAGoN), University of the West of England Bristol
Fergus McDonald	HDR UK / DARE UK
Geoff Hall	University of Leeds
Ian Young	Health and Social Care
Jack Hardinges	Foresight / AAAMD
James Peach	UK BioIndustry Association

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Janet Valentine	ABPI
Joanna Zapisek	AAAMD
Karina O'Neill	RCGP
Katherine O'Sullivan	Grampian Data Safe Haven
Kay Snowley	HDR UK
Kerrie Woods	Oxford University Hospitals NHS Trust
Lara Edwards	HDR UK
Laura Cocking	NIHR Bioresource
Lisa Scerri	The Royal Marsden
Liz Perraudin	AMRC
Loki Sinclair	HDR UK
Lorraine Foley	The Professional Record Standards Body
Louis MacGregor	The Brain Tumour Charity
Lucy Lennon	UCL
Luke Readman	NHS England
Lynn Morrice	HDR UK / BHF DSC
Manjit Benning	INSIGHT
Mark Avery	Cambridge University Hospitals NHS Foundation Trust
Melissa Lewis-Brown	HDR UK
Meredith Leston	RCGP
Michael Chapman	NHS England
Monica Jones	University of Leeds / HDR UK
Montserrat Garcia	The Institute of Cancer Research
Nada Karrar	HDR UK
Nick Kennedy	Royal Devon University Healthcare NHS Foundation Trust
Nicola Hamilton	Understanding Patient Data
Nicola Armstrong	HSC NI, R&D Division
Olivier Roth	UK BioIndustry Association
Pamela Linksted	NHS Scotland
Paola Quattroni	HDR UK
Pete Stokes	OpenSAFELY
Philip Quinlan	NIHR Nottingham Biomedical Research Centre
Ping Yu	HDR UK
Rachel Tesfaye	HDR UK
Rachel Turner	Royal Marsden
Richard Lee	Royal Marsden
Ruth Milne	HDR UK
Sam Patel	NHS Education for Scotland
Sara Khalid	Nuffield Department of Orthopaedics, Rheumatology and Musculoskeletal Sciences

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Sarah Cadman	HDR UK
Sarah Jackson	PRSB
Sophie Harriman	Optimum Patient Care
Stephen Burrows	HDR UK
Susan Hodgson	CPRD
Suzanne Mason	The University of Sheffield
Tanya Smith	Oxford Health
Tim Hubbard	HDR UK
Tom Barlow	Scottish Government
Uwaye Ideh	HDR UK
Wen Hwa Lee	AAAMD
Yemi Macaulay	HDR UK
Yvonne Silove	HQIP
Zoe Plummer	Renal Association