

UK Health Data Research Alliance Council

Actions and meeting notes

Wednesday 22nd May 2024 (10:00 – 12:00)

Immediate actions for Alliance members:

- Explore how the insights gained from the Research Data Scotland (RDS) ‘spotlight session’ can be used and disseminated to other regions in the UK.
- Investigate opportunities to enhance skills transfer across the academic sector and the NHS, potentially through collaboration with NHS England.
- Review ‘[Enhancing diversity and quality in health data](#)’ paper by 19th June 2024 and send comments to the Alliance secretariat via ukalliance@hdruk.ac.uk.

Actions for the Alliance secretariat:

- Share slides from the Council meeting with attendees.
- Invite Chris Whitty to contribute a Foreword for the paper on ‘Enhancing quality and diversity in health data’.
- Develop an action plan based on the ‘Enhancing quality and diversity in health data’ paper recommendations and engage with funders.
- Develop a strategy for increasing adoption of transparency standards across the Alliance, including an action plan following the Transparency Showcase event.
- Aid the Professional Records Standards Body (PRSB) in promoting the adoption of standards within the systems used by stakeholders.

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:

- [National Institute for Health and Care Excellence \(NICE\)](#)
- [Data Research Access and Governance Network \(DRAGoN\)](#)
- [UK Health Security Agency \(UKHSA\)](#)

Alliance draft paper on ‘[Enhancing diversity and quality in health data](#)’

Kamlesh Khunti, CBE, Professor at University of Leicester, Director of Centre for Ethnic Health Research, co-Chair Alliance Special Interest Group (SIG) on ethnicity coding standards, provided an update on

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recommendations from the Ethnicity Coding SIG. The ethnicity coding SIG held three online working sessions with up to 70 participants and a face-to-face meeting in May 2023 in Leicester with 60 participants. The paper, which is the results these working sessions, focuses not only on collecting ethnicity data but also on broader health determinants like socioeconomic status and individual characteristics and highlights the need for standardisation of processes. The paper makes five key recommendations and proposes the need for action around improvements in data collection and harmonisation, acknowledging the current challenges. The paper has been submitted to the Alliance Council for approval and endorsement and will be published on behalf of the working group. Prof. Khunti also proposed the addition of a Foreword by Chris Whitty to increase impact of the recommendations.

Insights from Alliance Executive Committee & next steps

Paola Quattroni, HDR UK Head of Alliance Strategy and Engagement provided insights from the recent Alliance Executive Committee meeting.

- A [progress report](#) was shared outlining the alliance's activities over the last six months, focusing on convening the community, activities, and adoption of standards.
- The three main goals are building communities, shaping standards, and driving adoption of best practices.
- The Alliance Executive Committee meeting highlighted the need to focus on specific standards and actions for adoption.
- One suggested focus is on transparency of data use and access, with over 50% of Alliance members currently having data use registers or websites to highlight data usage.
- Improving transparency in data use is identified as a top priority for the year.
- Past work on data use registers will inform the implementation plan to increase adoption of transparency standards.
- More details on activities, including data standards, technologies, capacity, and information governance, are available in the shared progress report.

Horizon Scanning: updates from across the UK

Andrew welcomed representatives from across the Wales, England, and Scotland to provide updates from their organisations. Representatives from Northern Ireland sent apologies for the meeting.

Roger Halliday & Tom Barlow (Research Data Scotland) - spotlight session

Roger Halliday, Chief Executive, Research Data Scotland (RDS), [presented slides and provided an update on their efforts to enhance data accessibility and collaboration in Scotland](#).

- RDS's mission, in summary, is to facilitate access to existing data in Scotland to enable timely and cost-effective analysis, using advanced data science and geospatial approaches.
- RDS, established as a charity by the Scottish Government and partnered with several Scottish universities, focuses on case-sensitive data, encompassing various sectors including health and

social care. Their objectives include reducing complexity and speeding up data access, widening the range of available datasets, aligning current approaches, and ensuring sustainable operations with public engagement and secure data handling at the core.

- The development of a federated network of safe havens or trusted research environments (TREs) to connect data across the UK was emphasised. Roger mentioned ongoing projects like the Teleport program, which links data between the Scottish TRE and the SAIL Databank and the partnership with Public Health Scotland to expand its data offerings and improve governance models and data access efficiency.
- RDS is committed to aligning with the Alliance's objectives and invites collaboration and engagement from other partners.

Chris Russell, Head of Delivery, Data for R&D, NHS England

Chris Russell from NHS England provided updates on the NHS England Secure Data Environment (SDE) and the broader NHS research network.

- The NHS Research SDE network programme is progressing, aiming for public beta assessments to soon onboard more users and streamline the application process.
- Collaborations with the British Heart Foundation (BHF) Data Science Centre and the Department of Health have yielded productive tools and services for SDE users.
- The network includes 11 regional SDEs, focusing on federation and integrated governance. Efforts are ongoing to implement the Observational Medical Outcome Partnership (OMOP) common data model for research within the UK, Europe, and the USA.
- Public and patient involvement (PPI) is a priority, with national engagement informed by successful regional initiatives.
- Funding is secured across the SDE network until the end of the financial year, supporting recruitment and research activities.
- Collaboration with the Medical Research Council (MRC) and the National Institute for Health and Care Research (NIHR) aims to enhance research infrastructure and leverage existing investments to scale data science across the UK.

Chris Orton, Programme Manager, SAIL Databank

- There is an upcoming workshop in June, in collaboration with RDS, aimed at exploring collaborative opportunities across various data-led initiatives. This partnership will particularly focus on the technical crossover of platforms managed by RDS, SAIL Databank, and SERP, especially in light of the ongoing development of federated analytics and operational complementarity.
- Chris also highlighted the support being provided to some regional SDEs in England concerning TRE operating models, covering areas like data management, governance, and sustainability.
- Swansea University have a new SAIL TRE Hub, a technical innovation and partnership offering. The flagship example is the BHF cohorts platform, partnered with SAIL.



- The hub allows organisations to partner with SAIL for a TRE platform, leveraging flexible technologies provided by the Secure e-Research Platform (SeRP) and accessing data from Wales and other sources like the Office for National Statistics (ONS).
- The hub offers a branded virtual desktop environment, the ability to load, link, and share new datasets, and utilises SAIL's operational model.
- SAIL Consumer Panel, a lay panel, consulted on a project and programme basis for advice and updates on SAIL's work.
- Welsh representatives will discuss current work plans and gather feedback from the panel.
- The first linkage and sharing of Welsh data to the UK Longitudinal Linkage Collaboration (UKLLC) is imminent, moving beyond solely COVID-19 use cases. This initiative has been long in the making and will become a regular practice.
- There is ongoing work with the Association of British Pharmaceutical Industries (ABPI) to develop programmatic options for pharmaceutical access to Welsh data for research studies, aiming to enhance accessibility.
- SAIL are collaborating with the Welsh Government and Digital Health and Care Wales to improve data granularity and availability for clinical trial development, supporting pre, mid, and post-trial data linkages in health records and trial recruitment setups.

Panel Session: Importance of data standards for research productivity and healthcare improvements (Chaired by David Seymour, Director of Infrastructure & Services, HDR UK)

Rebecca Hughes and Sarah Jackson (Professional Record Standards Body) presented [slides on PRSB and their mission](#)

PRSB, a not-for-profit community interest company established over a decade ago, has published around 25 standards in various healthcare sectors. Their future priorities include research, audit, and particularly data quality, which is central to their mission. Currently in work, is a diabetes record standard to ensure consistent data recording for direct care and secondary uses, crucial due to rising number of diabetes cases. This standard aids in data sharing between clinicians and patients and is mandated through the Data Alliance Partnership Board. PRSB are also enhancing encounter record activity in general practice to adapt to changes in care delivery and new workforce roles, aiming to improve data quality for better resource allocation and workforce planning.

Hannah Whittaker (Imperial College London) and Chris Orton (SAIL Databank) [presented slides on the curation of standardised respiratory cohorts](#)

Standardised methodologies have enabled the creation of reproducible cohorts across the UK, using harmonised data from CPRD in England, SAIL in Wales, and DataLoch in Scotland, with plans to include Northern Ireland's Honest Broker Service. These harmonised cohorts cover asthma, Chronic obstructive pulmonary disease (COPD), and Interstitial lung disease (ILD), with detailed methodologies published

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online. Research has described the burden of respiratory diseases from 2004 to 2023, amplified by social inequalities. Ongoing studies focus on the link between socioeconomic deprivation and asthma outcomes, aiming to inform policy and reduce care inequalities. Future efforts include validating clinical trial recruitment, developing criteria for care variations, and collaborating with Northern Ireland to complete a UK-wide data set for a standardised research ecosystem.

Jenny Lane (Barts Health NHS Foundation Trust) presented [slides on OMOP common data model: Beyond Research](#)

OMOP and OHDSI were introduced for federated network analysis using observational data, standardised into a common data model for interoperability, covering 6 million patients. This system ensures data security while enabling collaborative analysis, offering benefits like reproducible analytical pipelines and efficient data utilisation. Highlighted use cases in East London include a data console service for quality improvement, collaborative studies for regulatory purposes with MHRA, and device safety surveillance. The transformative potential of OMOP data, especially in orthopaedics, and collaborations with partners like Lancashire Teaching Hospitals Trust, CPRD, and SAIL were emphasised throughout the presentation.

Sophie Williams (Barts Health/QMUL) presented [slides on the use of SNOMED CT at Barts Health](#)

SNOMED is an international clinical terminology widely used in electronic health records (EHRs), aiding data analytics by mapping to ICD-10 and OPCS-4. It is mandated for emergency care data and supports point-of-care coding in the Oracle Millennium EHR system. During the COVID-19 pandemic, SNOMED-coded datasets identified rare vaccine complications, with studies replicated across five SDEs. Natural language processing (NLP) extracted SNOMED concepts from free text, improving data quality. A trial identified diabetic foot conditions in hospitalised patients, helping podiatrists prioritise care. NHS England's terminology server facilitates saving and sharing value sets. The potential of SNOMED data in data analytics and quality improvements were highlighted, particularly when used with machine learning.

Following the presentation there was a discussion amongst the attendees:

- All presenters were thanked for their contributions and attendees highlighted the importance of the practical application of data science and the effective reuse of existing tools and methodologies. There was a particular emphasis on the significance of the work being delivered at Bart's Health in bridging theoretical concepts with practical implementation.
- Attendees discussed and acknowledged the collaboration between Imperial College London and SAIL Databank and the focus on the harmonisation of activities.
- There was discussion around the challenges and progress of implementing data standards, particularly from the perspective of suppliers. Attendees highlighted the importance of establishing strong relationships with suppliers and the gradual improvement in the conformance process.
- Discussions moved on to the critical need for generating high-quality data at the point of care. Attendees discussed the challenges associated with multiple data flows across various levels of healthcare systems and stressed the importance of streamlining data collection and coding processes to facilitate harmonisation efforts.



- Patient representatives within the group passionately advocated for the use of patient data for research and secondary purposes, drawing from personal experiences to underscore its life-saving potential. This resonated with other attendees, highlighting the profound impact of patient data on clinical decision-making and outcomes.
- There was a proposal to shift the narrative surrounding data usage, particularly in demonstrating immediate benefits for direct care. Attendees emphasised the need to bridge the gap between data usage for research and its practical applications in clinical settings, suggesting creative strategies for conveying the value of secondary data usage to clinicians.

Andrew concluded the meeting by thanking participants and summarising key action points, captured above.



Appendix

Attendees

Name	Organisation
Alex Knight	Health Data Research UK (HDR UK)
Alexandra Lawrence	techUK
Alison Stone	use MY data
Amarpreet Judge	Health Data Research UK (HDR UK)
Amonida Zadissa	European Bioinformatics Institute
Amy Berrington	The Institute of Cancer Research (ICR)
Andrew Davies	Association of British HealthTech Industries (ABHI)
Andrew Morris	Health Data Research UK (HDR UK)
Andrew Wong	MRC Unit for Lifelong Health and Ageing
Aziz Sheikh	BREATH
Ben Crosby	Health Data Research UK (HDR UK)
Caleb Meath	The Association of the British Pharmaceutical Industry (ABPI)
Chris Carrigan	use MY data
Chris Gush	Healthcare Quality Improvement Partnership (HQIP)
Chris Orton	SAIL Databank
Chris Russell	NHS England
Claire Argent	Health Data Research UK (HDR UK)
Claire Harrison	Medicines and Healthcare products Regulatory Agency
Claire MacDonald	Manchester University NHS Foundation Trust
Clara Fennessy	Health Data Research UK (HDR UK)
David Harrison	Intensive Care National Audit and Research Centre (ICNARC)
David Seymour	Health Data Research UK (HDR UK)
David Snelson	use MY data
Desislava Staykovska	Healthcare Quality Improvement Partnership (HQIP)
Doreen Tembo	Health Data Research UK (HDR UK)
Edel McNamara	Health Data Research UK (HDR UK)
Eleanor Yelland	National Institute for Health and Care Excellence (NICE)
Elizabeth Lloyd-Owen	use MY data
Elliot Bridges	Human Fertilisation & Embryology Authority
Emily Jefferson	Health Data Research UK (HDR UK)
Emma Lagerstedt	Understanding Patient Data
Emma Lawrence	UK BioIndustry Association
Estelle Spence	NHS England
Felix Ritchie	Data Research Access and Governance Network (DRAGoN), University of the West of England Bristol

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Finola Higgins	King's College London
Garry Coleman	NHS England
Geoff Hall	University of Leeds / Health Data Research UK (HDR UK)
Graham Prestwich	National Pathology Imaging Co-operative
Guy Smallman	University Hospitals Coventry and Warwickshire NHS Trust
Hannah Whittaker	Imperial College London
Helena Ahlfors	NIHR BioResource
Hilary Fanning	University Hospitals Birmingham NHS Foundation Trust
James Peach	UK BioIndustry Association
James Squires	The Association of the British Pharmaceutical Industry (ABPI)
Jennifer Lane	Queen Mary University of London
Jo Knight	Lancaster University
Joe Packham	UK Health Security Agency (UKHSA)
Jonathan Smart	Swansea University
Kamlesh Khunti	University of Leicester
Karina O'Neill	Royal College of General Practitioners (RCGP) / Research and Surveillance Centre (RSC)
Katherine O'Sullivan	University of Aberdeen
Kathy Harrison	The University of Edinburgh
Katie Wilde	University of Aberdeen
Lara Edwards	Health Data Research UK (HDR UK)
Lisa Scerri	The Royal Marsden NHS Foundation Trust
Liz Perraudin	Association of Medical Research Charities (AMRC)
Magali Ruffier	Eastern Academic Health Science Network (AHSN)
Matt Thompson	UK Health Security Agency (UKHSA)
Mark Caulfield	Queen Mary University
Michael Smith	Manchester University NHS Foundation Trust
Monica Jones	University of Leeds / HDR UK
Montserrat García-Closas	The Institute of Cancer Research (ICR)
Paola Quattroni	Health Data Research UK (HDR UK)
Ping Yu	Health Data Research UK (HDR UK)
Rachael Brannan	UK Health Security Agency (UKHSA)
Rachel Brophy	Health Data Research UK (HDR UK)
Rachel Turner	The Royal Marsden NHS Foundation Trust
Rebecca Hughes	The Professional Record Standards Body (PRSB)
Richard Ballerand	Public Representative
Richard Lee	The Royal Marsden NHS Foundation Trust
Roger Halliday	Research Data Scotland
Sanjay Hegde	The Institute of Cancer Research (ICR)
Sarah Jackson	The Professional Record Standards Body (PRSB)

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Shaun Rowark	National Institute for Health and Care Excellence (NICE)
Simon Ball	University Hospitals Birmingham NHS Foundation Trust
Simon Newman	The Brain Tumour Charity
Simone Croft	The University of Sheffield
Sophie Williams	Barts Health / Queen Mary University London
Stephen Burrows	Health Data Research UK (HDR UK)
Steven Riley	UK Health Security Agency (UKHSA)
Susan Hodgson	Clinical Practice Research Datalink (CPRD)
Tim Hubbard	ELIXIR
Toby Nonnenmacher	Imperial College London
Tom Barlow	The University of Sheffield
Uwaye Ideh	Health Data Research UK (HDR UK)
Yvonne Silove	Oxford Health
Zoe Plummer	Health Data Research UK (HDR UK)