

UK Health Data Research Alliance Council

Actions and meeting notes

Wednesday 14th August 2024 (10:00 – 12:00)

Decisions:

- The Alliance Council agreed with the proposal to update the Principles for Participation, including a 10th Principle specifically dedicated to upholding transparency.
- The next Alliance Council will include a deep-dive session on the Sudlow review and how to deliver a UK-wide impact from the insights of the final report.

Immediate actions for Alliance members:

- There is an opportunity to collaborate and be involved in the testing of the new and enhanced Gateway. Interested members should reach out to [Stephen Lavenberg](#).
- Members are encouraged to consider [applying for funding](#) as a data partner to join the pilot, Real World Evidence Network. The call closes on Friday 30th of August.
- Commercial organisations interested in submitting a project proposal for a driver study in the NHS Research SDE Network should submit a '[Concierge proposal](#)'.
- Alex Bailey to circulate the MRC draft data access guidance with Council for feedback.
- Members are invited to attend the [closing ceremony](#) of the [Black Internship Programme](#) on Thursday 29th August, from 12:00 to 18:00, at the Wellcome Trust. This will be followed by Paola's leaving drinks at 31 Marchmont Street, London WC1N 1AP.

Actions for the Alliance secretariat:

- Share slides from the Council meeting with attendees.
- Publish updated [Principles for Participation](#).
- Update Alliance members on publication of the Transparency Standard co-development paper.
- Share proposals on different membership types with Council when finalised.

Meeting notes:

Welcome, introductions and opening remarks

David Seymour, Director of Data Partnerships at HDR UK, welcomed the attendees and introduced the latest [new members to the Alliance](#), which brings the total Alliance membership to 107. The Four new members are:

- [National PET Imaging Platform \(NPIP\)](#)
- [NIHR Yorkshire and Humber-Patient Safety Research Collaboration \(PSRC\)](#)
- [Mother & Infant Research Electronic Data Analysis \(MIREDA\)](#)
- [Nuffield Department of Orthopaedics, Rheumatology and Musculoskeletal Sciences \(NDORMS\)](#)

Sudlow review updates and reflections on government changes

Jonathan Wood, Director of Communications and External Affairs at HDR UK presented outline recommendations from the draft Sudlow review.

Background:

- Cathie Sudlow (in her previous role as Chief Scientist at HDR UK) was commissioned by Chris Whitty (Chief Medical Officer), Ian Diamond (National Statistician), and Tim Ferris (former Director of Transformation at NHS England, currently covered by Vin Diwakar) to carry out a review of the UK's health data landscape.
- The review required mapping the landscape of linkable health datasets across the nation and outlining the barriers to sharing data for public benefit to identify solutions that overcome these challenges.

Priorities:

- Common themes that emerged following broad consultations were grouped according to data and system priorities

Need for cultural change:

- Data organisations are too focused on how to protect data and minimise security risks, rather than maximising the benefit for patients while preserving privacy and security.

Draft recommendations:

- The final recommendations will not be shared until the full report is published but may cover the following five areas: Strategy for critical national infrastructure, National Health Data Research Service with high-level leadership, Coordinated and continued engagement with patients and the public, UK-wide strategy for data access processes and proportionate data governance, and a UK-wide system for standards and accreditation of SDEs.

Launch event:

- There is likely to be a hybrid launch event held in London in October to promote the publication of the final report.

Feedback from membership to consider UK-wide perspective and data standards:

- The need for a UK-wide outlook when implementing the recommendations was emphasised. If not, other key initiatives such as clinical trials will be difficult to deliver.
- It was queried whether there are any recommendations about using national and international data standards, to help reinforce the message to healthcare organisations that using accepted and published standards is essential for efficient data use and interoperability.
- There was also interest in how the recommendations will be taken forward by organisations and initiatives across Europe, as the European Health Data Space regulation is coming into place.

ACTION: The next Alliance Council will include a deep-dive session on the Sudlow review and how to deliver a UK-wide impact from the insights of the final report.

Update from Alliance Executive Committee

Paola Quattroni, Head of Alliance Strategy and Engagement provided an update from the recent Alliance Executive Committee meeting.

- A summary of the key insights from the quarterly [progress report](#) was shared, outlining the Alliance's activities over the last three months, which included updates on membership growth, communities convened, standards in development, activities to support adoption, and a spotlight on the recent Transparency Showcase.
- The Trust and Transparency team is about to submit a paper on the co-development of the [Transparency Standards](#) between members of the public, members of the Alliance, and the role of the Pan-UK Data Governance Steering Group.
- There was also a discussion on the value of introducing different membership categories into the Alliance, where it was agreed that segmenting the membership into different categories may be helpful. The secretariat will work on developing proposals on different membership types and the possible impact on the Letter of Intent and Principles for Participation.

ACTION: Update Alliance members on publication of transparency standard co-development paper.

ACTION: Share proposals on different membership types with Council when finalised.

Proposal to the update the Alliance Principles for Participation

- Nada Karrar, Alliance Delivery Manager shared a proposal from the Alliance Executive Committee to update the [Principles for Participation](#). The update includes the addition of a 10th Principle specifically dedicated to upholding transparency.
- There were no objections from the Council regarding the publication of the updated Principles for Participation.

DECISION: The Alliance Council agreed with the proposal to update the Principles for Participation, including a 10th Principle specifically dedicated to upholding transparency.

Horizon Scanning: updates from across the UK

David welcomed representatives from across the Scotland, Northern Ireland, Wales and England to provide updates.

Roger Halliday, Chief Executive, Research Data Scotland (RDS) and Anna Dominiczak, Scotland's Chief Scientist for Health:

- Progress has been made on the Cohort Discovery pilot, which is a partnership with HDR Gateway, Public Health Scotland and the University of Dundee. The service is expected to be launched before the end of the year.
- The new Researcher Access Service is operational, with projects already flowing through. The service aims to scale up to around 40 datasets by the end of this year, while also expanding the scope of the types of projects it supports.
- A new project with the Office for National Statistics (ONS) has begun, called Connect Four, which aims to test a shared service for data access between Scotland and the ONS, with the

potential to expand this model to the Four Nations of the UK. This could also serve as a useful model for the health side.

- The importance of working closely with industry on commercial clinical trials across the UK over the next few years was highlighted. Currently, the focus is on sharing large, anonymised datasets. However, there is also a need for high-quality consented and well-followed-up data from large phase three commercial clinical trials, with industry access. While this is very much a Four Nations activity, there is still considerable work to be done.
- It was noted that the appointment of Matthew Sydes to an NHS England Data Enabled Trials role will help ensure a UK-wide perspective is maintained. There is also ongoing work through the Dementia Trials Accelerator to support this effort.
- The Alliance [Clinical Trials Stakeholder Prioritisation Forum](#) was highlighted for its strong focus on the governance and operational challenges around access to this type of data.

Ian Young, Chief Scientific Advisor to the Department of Health, Northern Ireland:

- A programme is underway to develop a cohort discovery tool, and a Project Lead has been appointed to work with the Honest Broker Service in the Northern Ireland Trusted Research Environment (TRE).
- The transition process onto a new single electronic health and social care record (the Encompass system) continues. This currently covers two of the five Acute Trusts and will extend to the remaining three within the next 12 months.
- The impact of the [Windsor Framework](#) is being monitored, particularly given Northern Ireland's unique position of operating under a range of European legislation. For areas under UK legislation, ongoing work with the MHRA and the Health Research Authority is underway.
- Significant European data legislation, as well as new European AI legislation, is coming into effect, which can be difficult to navigate. Any barriers this may cause for others in the UK wishing to work in Northern Ireland should be flagged directly with Ian.

Rebecca Cosgriff, Deputy Director: Data for R&D, NHS England

NHS England Data Access Request Service (DARS) backlog:

- The backlog of applications has been reduced to 153 as of the beginning of August, which is the lowest number since monitoring began in 2021.

Secure Data Environment (SDE) Network:

- OpenSAFELY has started new COVID-19 research in the [TPP environment](#), and work is continuing to extend that legal basis to allow wider research and to restart research within the EMIS environment.
- The NHSE SDE team has recently met with cancer charities on the Cancer Data Collaborative to support the use of NHS data for research in that area, including making data available through the [National Disease Registration Service \(NDRS\)](#).
- Some of the 11 regional SDEs are turning around data requests in as little as one month. While two more of the regional SDEs have added metadata to [the HDR Gateway](#), which has been formally adopted across the whole network as the common front door.
- A fully operational minimum viable product should be ready by March 2025. Currently, there are nine SDEs with a live service across the network.

Driver Projects & Industry collaborations:

- The Prostate Progress driver project was recently launched. This is a multi-SDE driver project to establish a virtual registry and support research in prostate cancer. It is a collaboration with Prostate Cancer Research and IQVIA and serves as a great example of how registries in the future might function in this new context of SDEs.
- An interim concierge service is available, managed by the Data for R&D Programme team, to review and assess project proposals from industry.

ACTION: Commercial organisations interested in submitting a project proposal for a driver study in the NHS Research SDE Network should submit a 'Concierge proposal' to data.healthresearch@nhs.net

NHS DigiTrials:

- This service has now invited over 20 million citizens to participate in research, particularly supporting [Our Future Health](#) to reach its recruitment milestones.
- They are currently undergoing an evaluation of their self-service feasibility tool. Feedback is welcome from anyone who has engaged with the tool, which is essentially a cohort discovery tool.
- Matthew Sydes, Head of Data-Driven Clinical Trials and Cohorts will be working with DigiTrials and the SDEs on the clinical trials use case across the entire Data for R&D portfolio. He is also keen on leveraging the Clinical Trials Prioritisation Forum of the Alliance to ensure alignment and maintain cross-border working as well.

Patient and Public Involvement and Engagement (PPIE):

- Large scale public deliberations are underway, complementing the local work undertaken by the regional SDEs, which has effectively involved over 5,000 members of the public, indirectly shaping our work.

Risk of [British Medical Association \(BMA\) recommendations for GP collective action:](#)

- It was noted that the recent recommendations from the BMA for GPs to withdraw permission for data-sharing agreements that exclusively use data for secondary purposes as part of its 'collective action' present a risk to SDEs and wider use of primary care data for research.
- This has formally been escalated as a risk within the Data for R&D programme. Currently, NHSE is awaiting more clarity on the likelihood of uptake of this recommendation and potential implications.

Sinead Brophy, Professor of Data Science in Public Health HDR UK Wales, Swansea University:

- With both Chris Orton (Swansea University) and Alex Newberry (Welsh Government) on annual leave, Sinead provided a brief update to highlight a webinar programme to showcase examples of how health and administrative data have been combined across the four nations and the impact this has made. Further details to follow.

Panel Session: Implementing the FAIR Guiding Principles for Data and Code

Alex Bailey, Programme Manager, Medical Research Council's Regulatory Support Centre [presented an overview of the MRC Data Sharing Policy:](#)

Main revisions:

- The [MRC data sharing policy](#) has been revised to reflect international standards, other UKRI/MRC policies and the MRC's strategic delivery plan.
- The MRC has simplified and broadened its data sharing policy, removing specific details and placing them in separate guidance documents.
- The updated policy is more explicit in its expectations from researchers, requiring research teams to follow clear data sharing terms and conditions as part of their funding.
- The definition of data has been expanded to include digital assets like code and software.
- There is increased focus on involving the public and recognising everyone involved in data sharing.

Monitoring compliance:

- MRC is exploring methods for monitoring compliance, including potential outsourcing of audits, random sampling, and the use of automated tools like ORCID to track data sharing activities.
- It was noted that there is potential to improve this by using the HDR Gateway Data Use Register to track data use and link it to research outputs, which could attract more support from funders. Although there is ample guidance on software and code, there is still a need for training, possibly in collaboration with HDR UK.

Incentives/Penalties:

- Incentives for good data sharing practices are being considered, with discussions around awarding prizes or giving more favourable consideration to future funding applications. However, the MRC is also contemplating stricter measures for non-compliance, such as negative scoring for future funding applications or even withholding funding, although these actions are not yet set in stone.
- There was a question of why UK funders have not adopted stricter data sharing policies, similar to the European Commission, despite progress in this area.

Exemptions & SDEs:

- Finally, the MRC is working on additional guidance around data sharing, including how to manage exemptions, and is considering ways to provide training and support to research organisations.
- The policy also encourages the use of SDEs (TREs) as an effective means of complying with data sharing requirements. Although the questions around linking consented and unconsented data are complex, beginning the conversation will help clarify the direction and reduce confusion.

Data accessibility statement/data management plans:

- Data access guidance will be shared very soon and will outline different scenarios and requirements from research teams.
- There is ongoing discussion within UKRI about the inconsistencies in data management plans across different councils, including why some councils require them and others do not, and the varying levels of detail expected.

ACTION: Circulate MRC draft data access guidance with council for feedback.

Clara Fennessy, Senior Technical Programme Manager, HDRUK [presented an introduction to the Health Data Research Gateway](#) and how it is supporting findability of data and its uses:

Background and key functionality:

- The Gateway, launched in 2020, is designed to simplify the discovery and access to health data resources, addressing the challenge of finding high-quality healthcare data for research. It does not store patient data but provides metadata (currently for over 860 datasets), offering standardised descriptions that help researchers quickly determine the usefulness of a dataset for their projects. The Gateway also supports direct communication with data custodians and streamlines the process from data discovery to access.

New Gateway enhancements:

- In response to user feedback, significant enhancements are being made to the Gateway, including improved search capabilities using tools like Elastic Search, which enhances the relevance and reliability of search results. The Gateway will also automate the integration of data resources, allowing for more up-to-date and comprehensive metadata with no additional effort, and will visualise relationships between datasets to assist researchers throughout their journey.

Launch and opportunity for collaboration:

- The vision for the enhanced Gateway, set to launch in September, is to be the primary platform for discovering, exploring, and accessing health data, with an emphasis on community co-creation and the reuse of existing solutions. As the health data landscape evolves, the Gateway will continue to adapt, ensuring it meets the emerging needs of its users. The technology team behind these developments invites further collaboration and testing from the community to refine and improve the platform.

ACTION: Contact [Clara Fennessy](#) or [Stephen Lavenberg](#) to be involved in testing of the HDR Gateway.

Rob Stewart, Co-Director, DATAMIND Health Data Research Hub [presented insights](#) from FAIR curated mental health data and use of natural language processing (NLP) tools:

FAIR principles:

- We are still in the early stages of achieving fully interoperable and reusable data, with many challenges ahead. The FAIR principles are part of the broader open science framework. DATAMIND, the mental health data research hub, has been extended for another five years and will focus on FAIR principles in its operations. This includes enhancing a catalogue of mental health measures and curating interoperable mental health data.

Catalogue of mental health measures:

- The [catalogue](#), which predates DATAMIND and the Gateway, helps researchers find longitudinal mental health data and links to relevant studies. It will continue to operate independently but will ensure compatibility with the Gateway to streamline data discovery.

NLP & CRIS System:

- A significant initiative involves natural language processing (NLP) to analyse unstructured text in mental health records. The [CRIS \(Clinical Record Interactive Search\) system](#) at the South London and Maudsley NHS Trust, operational since 2008, has been crucial in processing and linking health records. This system uses NLP to extract detailed information from text,

enabling research into mental health conditions and treatment outcomes. The goal is to create a service marketplace for NLP within the NHS, improving accessibility and allowing other trusts to benefit from similar services.

Structural data vs text data:

- In mental health care, text data remains crucial because structured fields often don't capture the depth of patient experiences. Patients and clinicians prefer detailed, narrative descriptions over tick-box forms, which can oversimplify complex conditions. Although structured data is easier to analyse and download, it can be biased and lacks context, making it less reliable. Text, however, offers a direct source that can be revisited for clarity and validation.
- For example, text can reveal detailed personal circumstances and insights, such as mentions of loneliness, which are critical for mental health research but not typically captured in structured fields. This ability to uncover nuanced information makes text a valuable resource for understanding and addressing mental health issues more effectively.

Future:

- Looking ahead, efforts will focus on improving the findability, accessibility, and reusability of data through better integration with the Gateway and ongoing research collaboration. The aim is to enhance data discovery and usability while fostering a robust network of data and technology resources for mental health research.

Thank you and farewell to Paola Quattroni:

- This was Paola Quattroni last Alliance Council meeting. Appreciation and thanks were expressed for the phenomenal contribution she has made to the Alliance over the past four and a half years. Paola has been instrumental in the growth and development of the Alliance, and the team will work hard to build on the legacy she leaves behind.

Appendix

Attendees

Name	Name of Organisation
Alex Bailey	Medical Research Charities-UKRI
Alex Eavis	Dovetail Lab
Alex Knight	Health Data Research UK
Alison Elderfield	Health Data Research UK
Amonida Zadissa	University College London
Andrew Davies	Association of the British Pharmaceutical Industry
Andrew Wong	University College London
Ann John	University of Swansea
Anna Dominiczak	The Scottish Government
Ashley Akbari	Swansea University
Aziz Sheikh	University of Oxford
Becca Dikuyi	United Kingdom Health Security Agency
Ben Crosby	Health Data Research UK
Carolina Arevalo	United Kingdom Health Security Agency
Caroline Shriver	Macmillan Cancer Support
Cassie Smith	Health Data Research UK
Charles Gutteridge	Barts Health NHS Foundation Trust
Chris Price	Optimum Patient care
Clara Fennessy	Health Data Research UK
Cristian Lungu	United Kingdom Health Security Agency
David Harrison	Intensive Care National Audit and Research Centre
David Seymour	Health Data Research UK
Doreen Tembo	Health Data Research UK
Eleanor Hall	Health Innovation East
Elizabeth Sapey	University of Birmingham
Emily Jefferson	Health Data Research UK
Emma Gordon	Economic and Social Research Council-UK Research and Innovation
Graham Prestwich	National Pathology Imaging Co-operative
Helena Ahlfors	National Institute for Health and Care Research (NIHR)- Cambridge Biomedical Research Centre
Ian Young	Department of Health Northern Ireland
James Squires	The Association of the British Pharmaceutical Industry
Jo Knight	University of Lancaster
Jonathan Wood	Health Data Research UK

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Lara Edwards	Health Data Research UK
Lisa Scerri	The Royal Marsden NHS Foundation Trust
Liz Perraudin	Association of Medical Research Charities
Lynn Morrice	Health Data Research UK
MacDonald Claire	Manchester University NHS foundation Trust
Mark Caulfield	Queen Mary University London
Matt Thompson	United Kingdom Health Security Agency
Monica Jones	University of Leeds
Nada Karrar	Health Data Research UK
Nicola Armstrong	Health and Social Care-Southeastern Health and Social Care Trust- Northern Ireland
Nicola Hamilton	Understanding Patient Data
Paola Quattroni	Health Data Research UK
Peter Harrison	Health Data Research UK
Rachael Brannan	United Kingdom Health Security Agency
Rebecca Cosgriff	NHS England Transformation Directorate
Robert Stewart	Kings College London
Roger Halliday	Research Data Scotland
Samina Begum	Use My Data
Sarah Cadman	Health Data Research UK
Sarah Jackson	The Professional Record Standard Body
Simon Ball	University Hospitals Birmingham NHS foundation Trust
Sinead Brophy	University of Swansea
Smith Michael	Manchester University NHS foundation Trust
Sophie Harriman	Optimum Patient Care
Uwaye Ideh	Health Data Research UK
Viola Pastorino	techUK
Wendy Harrison	National Health services-England
Wilde Katie	University of Aberdeen
Yvonne Silove	Healthcare Quality Improvement Partnership

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