

UK Health Data Research Alliance Council actions and meeting notes

Tuesday, 08 July 2025 (13:00–15:00)

Actions for Alliance members:

- Submit feedback on Clinical Trials Green Paper by mid-July.
- Provide input to HDR UK's ICO anonymisation response.
- Help shape HDRS priorities by sharing relevant use cases and operational feedback.

Actions for the Alliance secretariat:

- Publish updated Principles for Participation.
- Coordinate Green Paper publication.
- Support integration of Alliance inputs into HDRS planning.

Meeting notes:

Welcome, introductions and highlights from Convenor's update

David Seymour, Director of Data Partnerships, HDR UK, opened the meeting, welcoming attendees and noting the busy and strategically important agenda. Key points included:

- [NHS 10-Year Health Plan](#) released during the summer, alongside the [EU Commission's Life Sciences Strategy](#) and the [DSIT 'A Year in Metascience' report](#).
- Welcomed Bradford Teaching Hospitals NHS Trust as the newest Alliance member.
- Encouraged attendees to connect via the chat and follow up with one another.
- [Health Data Research Gateway](#) continues to evolve to support data discovery and access.
- The work of HERON UK (the HEalth Research OMOP Network for the UK) was featured at OHDSI Europe 2025.
- Black Internship Programme 2025 is underway with 115 interns.
- Updates from DARE UK:
 - New [funding round for community groups](#).
 - Invitation to participate in the [Infrastructure Landscape Review](#).
- Notable programme activity around brain health and cardiovascular disease.

Alliance Principles for Participation

Simon Jobson, Alliance Delivery Manager, introduced a light-touch update to the [Alliance Principles for Participation](#).

- The primary change is a new Principle 11 addressing AI in research, promoting a proactive, responsible, and transparent approach.
- Additional minor clarifications were made to ensure the Principles remain current and relevant.
- With no objections raised, the updated principles were adopted and will be published.

Information Commissioner's Office (ICO) guidance on anonymisation/Data (Use and Access) Act

Cassie Smith, Head of Legal, Trust & Ethics, HDR UK, provided a comprehensive [update on legal and governance changes](#):

- Data (Use and Access) Act 2025
 - Now passed into UK law, with phased implementation.
 - Key changes include:
 - Clarified definition of scientific research (includes commercial use).
 - Broad consent formally recognised.
 - Revised test for international data transfers: from "equivalent" to "not materially lower" protections.
- ICO Anonymisation Guidance
 - Significant clarification that individual-level data can be anonymous if reidentification risk is negligible.
 - Introduced a model for assessing anonymity using factors like environment, context, technical measures.
 - Some inconsistencies in the guidance were noted (e.g. contradictory statements about linkage).
 - Raised concerns about:
 - Practical burden of reassessing identifiability for each new data recipient.
 - Rigid interpretation of joint controllership, especially in research contexts.
 - Next Steps:
 - [ICO consultation on international transfers](#) open until 7 August 2025.
 - HDR UK preparing a collective response and seeking input from Alliance members.
 - Development of research-specific case studies with ICO is ongoing.

Use of healthcare data in clinical trials

Macey Murray (UCL), co-chair of the Clinical Trials Stakeholder Prioritisation Forum (with Fiona Lugg-Widger [Cardiff University]), presented a draft [Green Paper \(Paper D\)](#) that outlines barriers and proposes solutions to streamline use of health system data in clinical trials.

- Identified Barriers:
 - Fragmented, inconsistent approval systems.
 - Variability in consent assessment.
 - Limited processing capacity of data custodians.
 - Retroactive application of new data standards.
 - Lack of trial participant voice in governance.

- Recommendations:
 - Centralised data access approval system (aligned with HDRS).
 - National framework for assessing consent adequacy.
 - Precedent-based review pathways for common datasets.
- Discussion Highlights:
 - Strong support for the proposals.
 - David Snelson (use MY data) raised concerns about follow-through: “How do we ensure it doesn’t sit on a shelf?”
 - Michael Chapman referenced alignment with work on GP data for consented cohorts, noting the challenge of retrospective consent.
 - Andrew Morris suggested a clinical trials driver project to model real-world implementation and test adoption pathways.
 - Alan Harbinson stressed early and meaningful Four Nations engagement to ensure legal validity of consent frameworks across jurisdictions.
- Next Steps:
 - Final feedback to be submitted within two weeks.
 - Publication of the Green Paper to proceed.
 - The Alliance Secretariat will coordinate the definition of implementation pathways.

Health Data Research Service (HDRS)

The session introduced the Health Data Research Service (HDRS), a major UK Government initiative announced in April 2025. HDRS aims to establish a single, trusted, and streamlined point of access to health data across the UK for approved research. The session covered the policy rationale, technical framework, and strategic vision behind HDRS, and emphasised collaboration across government, NHS bodies, and research funders. [Slides presented included an overview of the proposed federated service model and priority capabilities.](#)

Presenters:

- Jen Boon (Deputy Director, Data Operations and Partnerships, Chief Data Officer’s Directorate, DHSC)
- Michael Chapman (Director of Data Access & Partnerships, NHS England)
- Beth Thompson (Executive Director, Policy & Partnerships, Wellcome Trust)

Jennifer Boon – Policy & Programme Overview

- HDRS is a flagship UK Government initiative announced in April 2025 and central to the NHS 10-Year Plan.
- Designed to deliver a single point of access to health data, supporting research across NHS, academic, and industry partners.
- Will function as an independent organisation, not housed within DHSC or NHS England.
- Will embed public trust, transparency, and national stakeholder alignment from the start.

Michael Chapman – Technical and Operational Design

- Described the proposed wireframe model:
 - Core HDRS entity coordinating access.

- Federated data infrastructure: no centralisation of data.
- Services to include researcher support, brokerage, contracting, and approvals.
- Emphasis on continued investment in:
 - SDEs across England.
 - GP data mechanisms for consented cohorts.
 - OpenSAFELY expansion.
- Recognised challenges in balancing short-term service improvements with long-term transformation.

Beth Thompson – Strategic Vision and Public Mandate

- Wellcome Trust is co-funding HDRS alongside HM Government.
- HDRS seen as a key enabler for the UK to lead in health research and AI.
- Called for:
 - Equitable access for diverse researchers.
 - Embedding public voice in HDRS governance.
 - Close coordination with the Alliance to shape priorities and track delivery.

Following the main presentations, perspectives were invited from each of the UK's devolved nations. Representatives from Northern Ireland, Scotland, and Wales provided reflections on how HDRS could align with existing regional infrastructure, policy priorities, and engagement approaches.

Alan Harbinson (Principal Statistician and Head of the Honest Broker Service, Health & Social Care Northern Ireland)

- Stressed importance of early engagement with devolved nations.
- Flagged risk of applying England-centric models across UK.
- Urged clarity on controller-processor relationships and jurisdictional consent validity.

Roger Halliday (Chief Executive Officer, Research Data Scotland)

- Welcomed HDRS vision, emphasising need for alignment with Scotland's Safe Haven Charter.
- Highlighted expansion of Researcher Access Service and the importance of benefit sharing frameworks.

Alex Newberry, Head of Research and Development, Welsh Government

- Sought integration with SAIL Databank and alignment with ongoing Life Sciences Sector Deal work.
- Public engagement via HRA collaboration on implied consent in care-as-research contexts is ongoing.
- HDRS provides great opportunity and excited for this to operate across the UK but the model for how this achieved will be critical to maximising what the Devolved Nations have to offer.

Breakout room discussions

Attendees split into breakout groups to respond to four key questions on HDRS:

1. How do we ensure HDRS gains credibility rapidly and maintains public trust?
 - Embed public and patient voices in governance structures from inception.

- Communicate transparently and frequently about purpose, safeguards, and benefits.
 - Work visibly with underserved communities to demonstrate relevance and accountability.
 - Leverage existing trust anchors (e.g. NHS, SAIL) to establish legitimacy.
 - Note was made of the [use MY data position statement on HDRS](#), highlighting the importance of early public involvement, clarity of purpose, and demonstrable public benefit.
2. What system levers does HDRS need to be successful?
- National policy mandates for data access harmonisation.
 - Interoperability standards endorsed by regulators and custodians.
 - Aligned incentives across stakeholders (researchers, custodians, regulators).
 - Clear legal frameworks for controller/processor relationships.
3. What features of the entire user journey need to be provided by HDRS, and which should be prioritised?
- Onboarding: researcher credentialing, training, and access rights.
 - Application process: seamless, standardised, and transparent.
 - Data discovery and metadata: rich, up-to-date, and searchable.
 - Priorities include user onboarding and contract support as immediate needs.
4. What should HDRS prioritise in its first year of operation?
- Deliver a demonstrator use case (e.g. clinical trials data access).
 - Provide a visible, usable minimum viable product (MVP).
 - Build credibility through user support services.
 - Coordinate across Four Nations to ensure interoperability and inclusivity.

Other themes included: importance of clarity on the HDRS operating model, early wins that demonstrate value to both researchers and the public, and the need to avoid complexity that impedes adoption.

These reflections will be used to inform the next stages of HDRS co-design, ensuring that development is grounded in lived experience, national diversity, and operational reality.

AOB and Closing Remarks

David Seymour, Director of Data Partnerships, Health Data Research UK, provided closing remarks and reflections on the meeting.

- Final call for feedback on:
 - The Clinical Trials Green Paper.
 - ICO anonymisation consultation.
 - Engagement in HDRS stakeholder discussions.
- The next Alliance Council meeting will take place on 8 October 2025.
- David Seymour closed the meeting by thanking members for their contributions and reaffirming the Alliance's role in shaping national health data strategy.

Attendees

Name	Organisation
Alan Harbinson	Health & Social Care Northern Ireland
Alex Bailey	UK Research & Innovation (UKRI)
Alex Knight	Health Data Research UK (HDR UK)
Alex Newberry	Welsh Government
Alexander Wright	Leeds Teaching Hospitals NHS Trust
Alexis Webb	Health Data Research UK (HDR UK)
Amarpreet Judge	Health Data Research UK (HDR UK)
Amilta Stephen Boyd	Department of Health & Social Care (DHSC)
Amy Tilbrook	Health Data Research UK (HDR UK)
Andrew Morris	Health Data Research UK (HDR UK)
Andrew Wong	University College London
Anna Steere	Understanding Patient Data
Anne Wozencraft	Health Data Research UK (HDR UK)
Anthony Wilson	Manchester University NHS FT
Ashley Akbari	SAIL Databank
Augusto Rendon	Genomics England
Becca Dikuyi	UK Health Security Agency (UKHSA)
Ben Crosby	Health Data Research UK (HDR UK)
Beth Thompson	Wellcome Trust
Bethany Gilbert	Health Data Research UK (HDR UK)
Carolyn McNamara	Institute of Cancer Research
Cassie Smith	Health Data Research UK (HDR UK)
Charles Gutteridge	Barts Health NHS Trust
Chris Gush	Healthcare Quality Improvement Partnership
Chris Orton	Swansea University
Chrissie Walker	University of Exeter
Christopher Yau	Health Data Research UK (HDR UK)
Clara Miglio	Macmillan Cancer Support
Cosette Davey	The Brain Tumour Charity
Daljeet Bansal	Leeds Teaching Hospitals NHS Trust
Damilola Awe	Health Data Research UK (HDR UK)
Damon Chow	Health Data Research UK (HDR UK)
Dan Hawcutt	Alder Hey Children's NHS Foundation Trust
Daniel Prieto Alhambra	University of Oxford, Nuffield Department of Orthopaedics, Rheumatology and Musculoskeletal Sciences (NDORMS)
Dave Robertson	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
Dona Reddiar	Health Data Research UK (HDR UK)
Doreen Tembo	Health Data Research UK (HDR UK)
Edel McNamara	Health Data Research UK (HDR UK)
Eleanor Hall	Health Innovation East
Ella Nania	Department of Health & Social Care (DHSC)
Elliot Bridges	Human Fertilisation and Embryology Authority (HFEA)
Emily Jefferson	Health Data Research UK (HDR UK)
Emma Gordon	ESRC UKRI
Emma Lawrence	BioIndustry Association
Erik Mayer	Imperial College London
Estelle Spence	NHS England
Fiona Lugg-Widger	Cardiff University
Graham Prestwich	Yorkshire and Humber Academic Health Science Network (YHAHSN)
Helena Ahlfors	NIHR BioResource
Iain Finlinson	NHS England
Inesa Thomsen	Department of Health & Social Care (DHSC)
Izzy Hampson	Department of Health & Social Care (DHSC)
James Peach	Human Centric Drug Discovery
James Squires	ABPI
Jaroslav Dymiter	University of Aberdeen
Jennifer Boon	Department of Health & Social Care (DHSC)
Jo Knight	Lancaster University
John Danesh	University of Cambridge
Jonathan Smart	Swansea University
Jonathan Wood	Health Data Research UK (HDR UK)
Kate O'Sullivan	University of Sheffield
Kathy Harrison	University of Edinburgh
Kay Snowley	Health Data Research UK (HDR UK)
Kevin Dunn	University of Birmingham
Kirsty O'Mailey	Imperial College Health Partners
Louise J Jones	PharosAI
Macey Murray	University College London
Manjit Benning	Moorfields Eye Hospital NHS Foundation Trust
Marti Catala Sabate	University of Oxford, Nuffield Department of Orthopaedics, Rheumatology and Musculoskeletal Sciences (NDORMS)
Melissa Lewis-Brown	Cancer Research UK
Michael Chapman	NHS England
Michael Cook	Our Future Health
Michael Smith	Manchester University NHS FT

Mark Caulfield	Barts Health NHS Trust
Nicola Armstrong	Health & Social Care Northern Ireland
Pamela Linksted	University of Edinburgh
Pela Derizioti	Genomics England
Peter Harrison	Health Data Research UK (HDR UK)
Rachael Brannan	UK Health Security Agency (UKHSA)
Rachel Brophy	Health Data Research UK (HDR UK)
Rachel Woodcock	Professional Records Standards Body (PRSB)
Reecha Sofat	Health Data Research UK (HDR UK)
Richard Ballerand	use MY data
Richard Walls	University of Dundee
Robin Flaig	University of Edinburgh
Roger Halliday	Research Data Scotland
Rushil Ranchod	Smart Data Research UK
Ruth Gilbert	University College London
Sarah Cadman	Health Data Research UK (HDR UK)
Sarah Ward	Health Data Research UK (HDR UK)
Shaun Rowark	National Institute for Health and Care Excellence (NICE)
Simon Ball	Health Data Research UK (HDR UK)
Simon Jobson	Health Data Research UK (HDR UK)
Sinead Brophy	Swansea University
Steffen Petersen	Health Data Research UK (HDR UK)
Susan Hodgson	Medicines and Healthcare products Regulatory Agency (MHRA)
Suzanne Mason	Barnsley Hospital NHS Foundation Trust
Tanya Smith	Oxford Health NHS Foundation Trust
Tim Chico	University of Sheffield
Tim Hubbard	ELIXIR
Tom Barlow	Scottish Government
Tracy Austin	Oxford University Hospitals
Uwaye Ideh	Health Data Research UK (HDR UK)
Vicky Maskell	NHS England
Zoe Plummer	UK Renal Registry