

## UK Health Data Research Alliance Executive Committee

**Date:** Thursday 12 June 2025

### Meeting attendees

#### *Executive Committee members*

Richard Ballerand (use MY data), Roger Halliday (RDS), Alex Newberry (Welsh Government), David Seymour (Chair; HDR UK), Jan Speechley (HDR UK PAB), Inesa Thomsen (DHSC)

#### *Alliance Secretariat*

Claire Argent (HDR UK), Stephen Burrows (HDR UK), Simon Jobson (HDR UK)

#### *Guests*

Macey Murray (UCL)

#### *Apologies*

Michael Chapman (NHSE), Andrew Morris (HDR UK), Nicola Perrin (AMRC), Janet Valentine (ABPI), Ian Young (HSC NI)

The Chair welcomed attendees, noted apologies, and introduced the agenda.

### Actions log

Several long-standing items were closed as they have been integrated into business-as-usual activities or the ongoing implementation phase following the Alliance Strategic Review:

- Closed actions – A026, A038, A042, and A048 have been incorporated into the Alliance delivery plan.
- Ethnicity coding work (A037) – Leicester Diversity in Data project team working towards delivering training to address the recommendations of the recent Nature Medicine ethnicity coding standards publication.
- Communications and engagement (A050, A052) – Website analytics and a Gateway spotlight blog remain in development; progress has continued despite recent staff leave.

### Alliance quarterly progress report

- Membership – Two new members (University of Exeter and Bradford Teaching Hospitals NHS FT) bring the total number of Alliance members to 119, although a forthcoming administrative review will likely reduce this figure as members who represent some programmatic investments are removed after closure of programmes or merger into other organisations.
- Engagement – The Alliance Community Bulletin list is being rebuilt following changes to subscription requirements. From a previous distribution list of ~300, approximately 100 re-subscriptions have been recorded to date, and regular monthly distribution is being resumed.
- Ongoing activity – The Quarterly Report included updates on working groups, convened communities, and standardisation work.

### Alliance Council agenda

The Council meeting (08 July 2025) will focus on the Health Data Research Service (HDRS):

- HDRS item – A joint presentation by DHSC, NHS England, and Wellcome Trust, followed by breakout discussions.

- Objectives – Provide members with an early opportunity to engage with HDRS development and provide member input into the emerging design.
- Discussion structure – Proposals include a panel presentation, Executive Committee reflections, mixed breakout groups, and structured feedback.

Additional items:

- ICO anonymisation guidance and Data Access and Use Bill
- Green Paper on access to routinely collected healthcare systems data for clinical trials
- Review and ratification of updated Alliance Principles for Participation

### The role and future direction of the Alliance

Attendees engaged in a strategic discussion on the Alliance’s evolving role considering:

- The Alliance Strategic Review
- The announcement of HDRS
- Planning for 2025/26 and beyond

Key discussion points:

- Ongoing need and value – Members reaffirmed that the Alliance remains a critical, UK-wide forum for collaboration, particularly as health data governance and service delivery evolve rapidly.
- Independence and influence – The Alliance is well placed to help shape the development of the HDRS, particularly ensuring it reflects the priorities and standards valued by researchers, patients, and devolved nations.
- UK-wide inclusivity – Members from devolved nations (Wales, Scotland) stressed the importance of avoiding an “England-centric” system. The Alliance must reinforce its role as a forum for balanced, Four Nations input.
- 2025/26 Priorities:
  - Enhance mechanisms for member engagement and influence
  - Clarify and communicate the Alliance’s strategic purpose
  - Reinforce the Alliance’s role as a standards-setter and trusted system-level partner

This discussion will inform an update to the Alliance delivery plan later in 2025.

ID	Action	Owner	Due Date
AEC-25/26-001	Circulate to members Alliance and relevant HDR UK Infrastructure & Services Objectives and Key Results (OKRs).	SJ	12 Jul 2025

### Review of Alliance Principles for Participation

Key updates:

- New Principle 11 – commits Alliance members to the responsible, transparent, and proactive use of artificial intelligence (AI) in research and the development of AI-enabled health technologies.
- Updated references – includes latest guidance and frameworks (e.g. augmenting the Five Safes with broader safeGUARDS language).

- Overview revision – reflects the development of HDRS and clarifies the ongoing relevance of the Principles to the evolving UK health data research environment.

Discussion points:

- Governance and accountability – Questions were raised on how compliance is measured. Suggestions included:
  - An annual reaffirmation of commitment by members
  - The introduction of self-assessment or audit mechanisms
 There was interest in embedding the principles within a practical framework for tracking and reinforcing member adherence.
- Value and credibility – There was strong support for making the principles more than symbolic. The Committee discussed how the Alliance could help members demonstrate compliance in a way that builds public trust.
- Resource signposting – Members suggested a link (at Principle 11) to the Scottish AI Playbook.

The committee agreed to forward the revised Principles to the July Alliance Council for ratification and to design a reaffirmation process for existing members.

ID	Action	Owner	Due Date
AEC-25/26-002	Refine Alliance Principles for Participation document.	SJ	27 Jun 2025
AEC-25/26-003	Develop a strategy to reinforce compliance and engagement with Alliance principles.	SJ	02 Sep 2025

### Clinical Trials Stakeholder Prioritisation Forum – Green Paper

Guest speaker Macey Murray (UCL) presented a draft Green Paper, a product of the Clinical Trials Stakeholder Prioritisation Forum, representing trialists, data custodians, regulators, patients, and funders.

Core issues identified:

- Disjointed approval processes across data custodians and regulators
- Significant delays impacting trial design and data analysis
- Inconsistent standards in assessing trial consent documentation
- Lack of coordination across the four UK nations
- Minimal patient and public involvement in high-level decisions on data use

Recommendations:

- Centralised approval pathway – a single access point to streamline applications and eliminate redundancy; with the HDRS identified as a potential vehicle for delivery
- National consent framework – a shared, flexible standard for evaluating adequacy of trial consent, to be co-produced with patients and public representatives
- Precedent-based review routes – standardised review paths for well-understood datasets to reduce administrative load on researchers and data custodians

Discussion Highlights:

- Support for consideration at Alliance Council.

- Complexity acknowledged – Members cautioned against underplaying the legal and operational barriers, including legacy systems and institutional power dynamics.
- Public engagement – Strong encouragement to produce an easy-read or public-facing summary to ensure accessibility and build confidence.
- Practical next steps – Suggested alignment with HDRS teams, clearer framing of governance roles, and direct engagement with funders and regulators.
- Implementation caution – Recommendations are high-level and must be grounded in real-world trial operations, with recognition of legal and organisational variation across the UK.

The Green Paper will be refined in advance of the July Alliance Council, incorporating this feedback and targeting a Zenodo publication and wider dissemination plan.

ID	Action	Owner	Due Date
AEC-25/26-004	Finalise and circulate Clinical Trials Green Paper for Alliance Council consideration.	MM	27 Jun 2025

#### AOB and close

- Format and distribution for meeting notes were reviewed.
- The next meeting of the UK Health Data Research Alliance Executive Committee will take place on 10 September 2025.

#### Summary of Actions

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AEC-25/26-002	Refine Alliance Principles for Participation document.	SJ	27 Jun 2025
AEC-25/26-003	Develop a strategy to reinforce compliance and engagement with Alliance principles.	SJ	02 Sep 2025
AEC-25/26-004	Finalise and circulate Clinical Trials Green Paper for Alliance Council consideration.	MM	27 Jun 2025