

UK Health Data Research Alliance Executive Committee

Date: Wednesday 10 December 2025

Meeting attendees

Executive Committee members

Simon Ball (Chair; HDR UK), Richard Ballerand (useMYdata), Roger Halliday (RDS), Andrew Morris (HDR UK), Alex Newberry (Welsh Government), Jan Speechley (HDR UK PAB), Janet Valentine (ABPI)

Alliance Secretariat

Simon Jobson (HDR UK), Kay Snowley (HDR UK), Sarah Ward (HDR UK)

Guests

Nicola Armstrong (HSC NI)

Apologies

Michael Chapman (NHS England), Nicola Perrin (AMRC), Ian Young (HSC NI)

(1) Welcome and introductions

- Round-table introductions and confirmation of attendees/apologies.
- Chair welcomed Dr Nicola Armstrong attending as alternate for Prof Ian Young.

(2) Actions log (Paper A) & Quarterly progress report (Paper B)

- Closed actions: A052, AEC-25/26-003, AEC-25/26-006, AEC-25/26-009, AEC-25/26-010 (per Actions Log, Paper A).
- Committee discussion reinforced the need for reporting to evidence member value and utility (products/services adopted in practice), not only process metrics (e.g., engagement counts).
- Council attendance challenges were discussed in the context of the evolving HDRS landscape, including the volume of concurrent consultation activity, emerging consultation fatigue, and perceptions of fragmentation or duplication across the system.

(3) Alliance refresh

- Chair set out emerging thinking for an Alliance ‘refresh’, with a stronger emphasis on being member-led and a shift towards adoption and implementation of trustworthy health data practice (beyond producing guidance).
- Key elements of the proposed direction included:
 - 12-month operating plan to clarify outputs, success measures and how the Alliance will interface with HDRS and Four Nations activity.
 - Member-led, time-bounded interest groups with tightly defined scope, explicit deliverables and a clear route to adoption/implementation, whilst avoiding duplication with existing initiatives.
 - A more overt service orientation (including a “service catalogue”/knowledge-management approach, i.e. *Health Data Connect*) to make practical assets – templates, standards, tools and boilerplate – easy to find, re-use and embed.
 - Regional leverage and segmented engagement, recognising differing needs across constituencies (e.g., data custodians, delivery programmes, umbrella bodies, industry), and supporting appropriate routes to implementation in different UK contexts.

- Committee emphasised the importance of:
 - Prioritisation and deliverability: focusing on members’ “knotty” implementation challenges, selecting a small number of high-value topics, and ensuring outputs are usable in practice (not just advisory).
 - Clear pathways to adoption: specifying who needs to use the outputs, what will change, and how uptake will be supported (including avoiding parallel forums and duplication).
 - PPIE as a core design feature: ensuring clear, practical arrangements for public involvement in both priority-setting and delivery, with outputs framed in accessible language and aligned to expectations of transparency and trust.

ID	Action	Owner	Due Date
AEC-25/26-012	Refine the draft 12-month operating plan, informed by ongoing one-to-one discussions with Executive Committee members.	SJ	10 Mar 2026
AEC-25/26-013	Propose a structured approach to identifying and prioritising member-led interest groups (criteria, deliverables, resourcing, non-duplication).	SJ	10 Mar 2026

(4) Feedback from Alliance Council (4 December 2025)

- Low attendance at the 4 December Council was attributed (at least in part) to the later meeting time and a process-focused agenda.
- Committee steer was to strengthen Council value by:
 - Building agendas around “must-know” system developments; and
 - Increasing member showcase content and practical, adoption-focused “service” outputs (e.g., templates, standards, implementation support).

ID	Action	Owner	Due Date
AEC-25/26-014	Review Alliance Council engagement and propose changes to agenda structure/format to improve relevance and attendance.	SJ	10 Mar 2026

(5) Four Nations updates

Wales (Alex Newberry)

- Updates covered ongoing engagement on principles for UK delivery of HDRS, and establishment of a Wales Data for Research Task Force to build consensus on infrastructure and policy positions (including COPI changes, commercial access and opt-out considerations).
- Additional points included GP engagement and wider public engagement activity supported through current funding, alongside work aligned to cross-nation collaboration and readiness.

Scotland (Roger Halliday)

- Updates included progress on an industry access framework, plans to widen data sources (including GP and imaging), and work towards a single route of entry and more federated governance.
- Three-nations activity (Scotland/Wales/Northern Ireland) on readiness to federate across nations and development of a roadmap was referenced.

Northern Ireland (Nicola Armstrong)

- Continued engagement aligned to the cross-nation HDRS-related work was noted.

(6) Updated Alliance documents

Data Use Register White Paper (Paper C)

- PPIE wording refinements proposed: replace “lay summary” with “plain language summary”; replace “understandable” with “accessible”.
- Additional comments were to be incorporated, with a view to seeking electronic approval following revision.

Letter of Intent (Paper D)

- Paper agreed.

ID	Action	Owner	Due Date
AEC-25/26-015	Update the Data Use Register White Paper (incorporating agreed language changes and received comments) and circulate for electronic approval.	SJ	31 Jan 2026

(7) AOB and close

- Chair closed the meeting with thanks and reiterated the intent to continue one-to-one conversations to refine the Alliance approach and operating plan.

Summary of Actions

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AEC-25/26-013	Propose a structured approach to identifying and prioritising member-led interest groups (criteria, deliverables, resourcing, non-duplication).	SJ	10 Mar 2026
AEC-25/26-014	Review Alliance Council engagement and propose changes to agenda structure/format to improve relevance and attendance.	SJ	10 Mar 2025
AEC-25/26-015	Update the Data Use Register White Paper (incorporating agreed language changes and received comments) and circulate for electronic approval.	SJ	31 Jan 2025