



Letter of Intent to join

UK Health Data Research Alliance

[Aligned to [Principles for Participation, July 2025](#)]

The UK Health Data Research Alliance is a member-led collaboration of leading healthcare and research organisations united to establish best practice for the ethical use of UK health-relevant data for research at scale.

This non-binding Letter of Intent confirms the intent of [Insert Name of Organisation] to become a member of the UK Health Data Research Alliance and to operate in accordance with the [Alliance Principles for Participation \(July 2025\)](#) and associated standards, including the [Data Access Transparency Standards](#), the [Data Use Register Standard](#), and the [Data Access Agreement Template](#).

Background

The UK's longitudinal, linkable health datasets are internationally significant, and the scientific community has the skills to use them for public benefit. Yet without transparent, ethical and secure routes to use data, that advantage erodes. The risk to the UK's competitive edge stems from: (i) historically fragmented access pathways and variable transparency about who is using data and why; (ii) uneven adoption of Secure Data Environments (SDEs) and inconsistent, sometimes slow approvals and contracting; and (iii) incomplete implementation of FAIR and interoperable metadata standards that make data findable and reusable at scale. Meanwhile, peers are moving fast: the European Health Data Space (EHDS) Regulation entered into force in March 2025 to standardise secondary use across the EU; Finland's Findata operates a national "one-stop" data-permit authority; and France's Health Data Hub provides a secure platform model where approved users analyse data remotely rather than exporting it. Together these raise expectations on speed, predictability and trust.

Since 2018, UK policy has converged on SDEs as the default for sensitive NHS data access, with strong emphasis on Five Safes governance, robust output checking and public-facing transparency of data use. The Goldacre Review (2022) called for TRE/SDE-first access and open, reproducible analytical pipelines; the DHSC SDE policy guidelines (2022) and the government's "data access as default" commitment (2023) have made that direction explicit; and NHS England's SDE network (2024) is operationalising a consistent service. The Alliance Principles for Participation (July 2025) reflect these shifts – committing members to publish Data Use Registers, adopt Data Access Transparency Standards and the Alliance Data Access Agreement (DAA) Template, and take a responsible, inclusive approach to AI.

The UK Health Data Research Alliance, launched in 2019, was created to address these systemic issues through common standards and a joined-up UK offer. The Alliance's current focus – set out in the 2025 Principles – includes reducing unnecessary complexity and harmonising data-access and governance models, promoting FAIR and interoperable data, supporting SDE-based access, ensuring non-preferential access that serves the public interest, and transparent reporting of data use and outcomes via minimum-standard Data Use Registers.

To realise the UK's potential, Alliance members commit to turning principles into practice: publish what is being accessed and why; use accredited SDEs; adopt common templates and standards to shorten access times without lowering safeguards; enable reproducible, open methods; involve patients and the public in meaningful ways; and articulate public benefit clearly.

The Alliance's overarching goal is to accelerate improvements in biomedicine, health and care by enabling the widespread, trustworthy use of health and care data through FAIR, interoperable standards, Secure Data Environments, and transparent, reproducible practice.

Guiding Principles

The Alliance is an open and inclusive collaboration. Members are expected to subscribe to the following principles:

- (i) **Respect** for participants and communities, including data sharing and privacy preferences.
- (ii) **Transparency** of governance and operations.
- (iii) **Accountability** through best practice in governance, technology, security and public involvement.
- (iv) **Inclusivity** by partnering and building trust among stakeholders.
- (v) **Collaboration** to share data and information to advance human health.
- (vi) **Innovation** in order to develop an ecosystem that accelerates progress.
- (vii) **Agility** through harmonised processes and templates.
- (viii) **Independence** through appropriate governance and non-preferential access that serves public interest.

Members will work together to ensure that the Alliance:

- Serves the **public good**.
- Supports the needs of a **broad community of patients, clinicians, healthcare professionals, researchers** and innovators.
- Functions to the **highest ethical standard**.
- Is well-governed, achieves its **goals** and is positioned for **ongoing success**.

Composition & Governance

1. The Alliance is a **member-led collaboration**. It engages with health and social care organisations, research institutions, patient advocacy groups, life science and information technology companies and trade bodies to fulfil its vision.
2. The Alliance is established by **Member Organisations**, each of which brings experience in domains relevant to the mission, along with an outstanding record of **servicing the public good**.
3. The Alliance is an unincorporated **not-for-profit association** administered and hosted by agreement by Health Data Research UK. Initially funded by Innovate UK, from April 2023 it receives funds through HDR UK core funding.
4. The Alliance has established a representative **Alliance Executive Committee** to provide oversight and direction of the Alliance as it seeks to maximise public benefit from the use of health data.
5. **The Alliance Council** has representation from all Alliance member organisations. It informs strategy and workstream delivery through the Alliance Executive Committee and ensures that the Alliance aligns with, and does not duplicate, efforts across the ecosystem.

What it means to be a member

In pursuit of the overarching Alliance goal, members will work collectively to:

1. Bring together the research, clinical, and disease advocacy communities and the private sector to support and promote the responsible and trustworthy use of health data for research and innovation.
2. Collaborate to create a federated UK-wide offer that is open and accessible, providing common standards, formats and tools to stakeholders in the health data research community.
3. Publish guidance/position papers on key work areas for consultation and engage with workstreams and activities to help shape developments to create a responsible and ethical infrastructure for health data research and innovation in the UK.
4. Share best practice and contribute to development and facilitate adoption of gold standards for data management and use, technologies and tools to enable ethical use of data for research and innovation at scale.

Principles for Participation

The Alliance’s activities are guided by a set of “Principles for Participation” that draw on national and international best practice frameworks, policy and recommendations. The Principles are intended for all organisations involved in the Alliance (whether as a user of data, a provider of Secure Data Environments, a Health Data Research Hub, or a data custodian). They will guide working practices which will vary depending on the nature of the member organisation. They are summarised below and set out in full in the accompanying document¹:

- Demonstrate active and ongoing engagement with patients and the public.
- Encourage the availability and use of data for research and innovation that serves public interest purposes.
- Promote the protection of privacy and data security through the adoption of best practices in privacy enhancing technologies.
- Make data and code Findable, Accessible, Interoperable and Reusable (FAIR).
- Use a proportionate approach to the governance of data access based on the five “safes” framework (safe people, projects, data, settings, and outputs).
- Maximise the benefits of data for research and innovation through non-preferential access to data for uses that serve the public interest.
- Establish mutually beneficial ways of working in partnership including contractual arrangements and Intellectual Property agreements.
- Work collaboratively to increase harmonisation and reduce the complexity of data sharing arrangements and data governance models.
- Contribute to a joined-up and UK-wide offer for researchers in all sectors.
- Demonstrate transparency and clarity in the processes and criteria for accessing data.
- Take a proactive, responsible and transparent approach to the use of artificial intelligence.

Contribution of members

Members will **contribute substantially** to the capabilities and capacity of the Alliance in one or more of the following ways:

- Attend and contribute to Alliance Council meetings.
- Contribute **expertise**, driving the evolution of an interoperable research and innovation infrastructure.
- Shape the **regulatory environment, including consent and accountability requirements** to enable the responsible sharing of data within the community.
- Contribute to **development and adoption of standards** for data, data access and transparency of data use.
- Adopt a **proportionate approach to governance** and commit to harmonisation of data access processes based on the Five Safes framework and transparency of processing times as agreed by Alliance Council.

Expectations of data custodians

Member organisations that are also data custodians or controllers will:

- **Make data they hold available for research and innovation** and demonstrate efforts to make this data FAIR. Members are expected to use the Health Data Research Gateway as a common data discovery portal. Alliance members are expected to:

¹ https://ukhealthdata.org/wp-content/uploads/2025/07/Alliance_Principles_for_Participation_Jul2025.pdf

- Agree a timescale and approach to providing the necessary metadata to ensure that all relevant datasets under the custodianship of the member organisation are included in a searchable metadata catalogue and discoverable through the Gateway.
- Demonstrate substantial progress in making datasets discoverable within 12 months of joining the Alliance.
- **Demonstrate transparency** by publishing a Data Use Register on a public website that meets the [Alliance Recommendations for a Data Use Register Standard](#), and update it at least quarterly (preferably near-real time from the access workflow).
- Adopt the [Data Access Transparency Standards](#) (clear access criteria/processes) and use the [Alliance DAA Template](#) where SDE access is provided.

Benefits of the Alliance

Members will benefit from being part of the Alliance by:

- Being part of a **recognised community of experts** and be a single, powerful voice, required to address common barriers to the development, adoption and scale-up of health data research innovations.
- **Actively shaping** the design and delivery of a coherent, UK-wide federated health data research landscape, ensuring that the applications, tools and services they provide can be rapidly scaled, attracting additional partnerships and investment.
- **Retaining freedom** to develop new, proprietary products and services, with a focus on collaboration at the interfaces.
- Benefit from all the **open tools, services and expertise** of the Alliance (including common protocols, data use registers, metadata services and data standards).
- Having access to services provided through the **Health Data Research Gateway** to make datasets FAIR.
- Having opportunity to meet funding requirements by **fostering collaboration and partnership**, embedding transparency and patient and public involvement; **enabling FAIR data**; and contributing to a trustworthy and efficient infrastructure for health data research.
- **Networking**, introductions and information sharing via events and Alliance secretariat.

Patients and the public will benefit by:

- The **rapid translation** of innovative health data driven interventions, developed with UK data to address UK health needs.
- **Minimising regional inequalities** through easier access to new health data tools and technologies, no matter where in the UK you live.
- **Better understanding** of the lifestyle and environmental factors that contribute to health and disease, through an increase in research and innovation on large and multidimensional datasets.

By signing this Letter of Intent, the below-referenced organisation acknowledges its intent to participate as a Member Organisation in the UK Health Data Research Alliance and to work collaboratively with the other Member Organisations. This Letter of Intent is not intended to and does not create any legally binding financial or other obligation on the part of the signatory organisation or between the signatory organisation and the *UK Health Data Research Alliance*, or any of the other Member Organisations and does not establish a joint venture, partnership, association or other entity.

Name _____

Position _____

Organisation _____

Date signed _____