



**Letter of Intent to join  
UK Health Data Research Alliance  
[Insert Date]**

The *UK Health Data Research Alliance* is a member-led collaboration of organisations committed to improving human health by maximising the potential of multiple forms of data at scale.

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This nonbinding Letter of Intent serves to confirm the intent of  
[Insert Name of Organisation] to be a partner in the **UK Health Data Research Alliance**.

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## Background

Whilst the UK has some of the richest health care and research data assets world-wide, only a fraction of all our NHS and research data can be truly considered FAIR (Findable, Accessible, Interoperable and Re-usable). These data have the potential to transform care and outcomes as well as deliver economic benefit, but the UK risks losing its competitive advantage and ability to attract significant inward investment, underpinning better treatments, innovation and more efficient health and social care.

Some progress has been made since 2018 when a group of UK leaders met under the convenorship of Sir Mark Walport to discuss the current challenges and opportunities in health data research and how data science (across all its sub-disciplines) might be harnessed to improve medicine, health and care. Inspired by the examples of the Global Alliance for Genomics and Health, the World Wide Web Consortium and the Human Genome Project, the participants recognised the need to bring together the right organisations and digital health leaders with the expertise, trusted governance, public involvement and endorsement and gravitas to work in partnership to address the challenges and realise the opportunities.

The *UK Health Data Research Alliance* (the Alliance) was launched in February 2019, convened by HDR UK and made up of the main national data custodians. It formed part of the Digital Innovation Hub programme, which itself was part of the Innovate UK Industrial Strategy Challenge Fund (ISCF) Data to Early Diagnosis and Precision Medicine challenge.

Several waves of partner organisations joined between 2019 and 2023 and as at February 2023 membership had increased to more than 70 diverse organisations. The importance of the Alliance has been recognised by the core funders of HDR UK and it forms an integral part of HDR UK's funded plans for the period 2023-2028 to ensure continuity from the ISCF funding.

The overarching goal of the Alliance remains to accelerate progress in biomedicine, health and care by encouraging widespread, trustworthy use of structured and unstructured clinical, administrative, imaging, genomic and other molecular data.

During the first phase of the Alliance, membership was focused on data custodians. From 2023, membership has been opened up to representation across the whole ecosystem.

## Founding Principles

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

- (i) **Respect** for the data sharing and privacy preferences of participants;
- (ii) **Transparency** of governance and operations;
- (iii) **Accountability** to best practices in technology, ethics, and public outreach;
- (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** to ensure swift action to benefit those suffering with disease; and
- (viii) **Independence** through structures and governance.

The Alliance is also guided by a set of “Principles for Participation”, developed as part of the Digital Innovation Hub programme that have been updated for the next phase of the Alliance’s development.

Alliance members commit to:

- **Adhere to the Alliance Principles of Participation and use a proportionate approach to the governance of data access based on the five “safes”<sup>1</sup>.**
- **Demonstrate active and ongoing engagement with patients and the public** in the design, development and governance of their activities involving health data to provide assurance that these activities are in the public interest.
- **Encourage the availability and use** of structured and unstructured health and care data, including clinical, administrative, imaging, genomic and other molecular data, for research and innovation that serves public interest purposes in line with guidance issued by the National Data Guardian<sup>2</sup>.
- **Promote the protection of privacy and data security** in line with the OECD Recommendation of the Council on Health Data Governance<sup>3</sup> through the adoption of best practices in privacy enhancing technologies, including providing access to sensitive data through Secure Data Environments (also referred to as Trusted Research Environments) accredited by a recognised authority in line with Digital Economy Act, DHSC Secure Data Environment Policy and Charter for Safe Havens in Scotland<sup>4</sup>.
- **Contribute to a joined-up and UK-wide offer** for researchers in all sectors by collaborating with existing, relevant health research infrastructure.

**Data custodians and data controllers will also commit to:**

- **Make data Findable, Accessible, Interoperable and Reusable** by adopting the FAIR Guiding principles for scientific data management and stewardship<sup>5</sup>.
- **Maximise the benefits of data for research and innovation through non-preferential access** to data for uses that serve the public interest, by ensuring that data remains available to, and accessible by, any organisation (concurrently or otherwise) provided the five "safes" criteria are met and the organisation meets the access requirements of the data custodian.
- **Establish mutually beneficial ways of working in partnership** including contractual arrangements and Intellectual Property agreements in line with commercial principles set out in the Life Sciences Sector Deal 2<sup>6</sup>.
- **Work collaboratively to increase harmonisation and reduce the complexity** of data access arrangements to improve the efficiency of using data for trustworthy and ethical research and innovation purposes. This includes making the terms of access clear, such as expected timescales and costs, and being transparent about the type and quality of data available. **Protect patient privacy** by providing access to sensitive data through Secure Data Environments (also referred to as Trusted Research Environments) accredited by a recognised authority and through the adoption of best

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<sup>1</sup> <https://www2.uwe.ac.uk/faculties/BBS/Documents/1601.pdf>

<sup>2</sup> <https://www.gov.uk/government/publications/what-do-we-mean-by-public-benefit-evaluating-public-benefit-when-health-and-adult-social-care-data-is-used-for-purposes-beyond-individual-care>

<sup>3</sup> <https://www.oecd.org/health/health-systems/health-data-governance.htm>

<sup>4</sup> <https://www.gov.uk/government/publications/data-saves-lives-reshaping-health-and-social-care-with-data/data-saves-lives-reshaping-health-and-social-care-with-data>

<sup>5</sup> <https://www.nature.com/articles/sdata201618>

<sup>6</sup> <https://www.gov.uk/government/publications/life-sciences-sector-deal/life-sciences-sector-deal-2-2018>

practices in privacy enhancing technologies, in line with the Data Safe Life strategy<sup>7</sup> and policy on Secure Data Environments for health and social care data<sup>8</sup> and the Goldacre recommendations<sup>9</sup>. 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**.

## 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 versatile information platform that is open and accessible, and provides common standards, formats and tools to stakeholders in the health data research community.
3. Publish a series of Green and White 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.

### (i) Composition & Governance

1. The Alliance is a member-led collaboration of organisations committed to improving human health by maximising the potential of multiple forms of health data to accelerate progress in biomedicine, health and care. It engages with research institutions, disease advocacy organisations, life science and information technology companies to fulfil its vision.
2. The Alliance is established by **Partner 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 as part of the ISCF Digital Innovation Hubs (DIH) programme for the first 4 years, it currently 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 (renamed from the initially set up Alliance Board) is the body bringing together representation from all Alliance member organisations and informing strategy and workstream delivery through the Alliance Executive Committee. Subgroups, special interest groups and workstreams are developed as needed to address issues as they arise. Ultimately the Alliance Council ensures that it aligns with, and does not duplicate, efforts across the ecosystem.

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<sup>7</sup> <https://www.gov.uk/government/publications/data-saves-lives-reshaping-health-and-social-care-with-data/data-saves-lives-reshaping-health-and-social-care-with-data>

<sup>8</sup> <https://www.gov.uk/government/publications/secure-data-environment-policy-guidelines>

<sup>9</sup> <https://www.goldacrerereview.org/>

6. An **International Council of Reference (ICR)** advises the Alliance Board in relation to ethics and information governance, as part of the development of the DIH programme. The ICR provides an international perspective and acts as a reference towards meeting best practice standards.

## Expectations of members

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

- 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.
- 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 Innovation Gateway as a common data discovery portal. Alliance members are expected to:
  - 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 the metadata catalogue and discoverable through the Gateway.
  - Demonstrate substantial progress in making datasets discoverable within 12 months of joining Alliance.

Member organisations that are also data custodians or controllers will **demonstrate the principle of transparency** by:

- Publishing a register of active projects accessing the data under their custodianship and new data access requests received. The register should be available on a public-facing website and include at least the minimum dataset defined by the Alliance Board<sup>10</sup>. It should be updated at least quarterly.

Members are expected to adopt a proportionate approach to governance and:

- Commit to harmonisation of data access requests based on the Five Safes framework and transparency of waiting times standards agreed by Alliance Council (within 6 months of joining Alliance).

## 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 scale-up and the development and adoption 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);

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<sup>10</sup> <https://zenodo.org/record/5902743#.Y88bWnbP02w>

- benefit for **networking**, introductions and information sharing via events and Alliance secretariat;
- have access to services provided through the **Innovation Gateway** to make datasets FAIR:
  - Findability (data assets, tool and services) to generate interest from new research communities
  - Accessibility through use of an online **Data Access Request management system** (based on the Five Safe framework) to deliver a more efficient process harmonised with other custodians
  - Interoperability through Gateway APIs (in development)
  - Reusability through **data use registers**/links to outputs
- have an 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.

**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 Partner Organisation in *The UK Health Data Research Alliance* and to work collaboratively with the other Partner 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 Partner Organisations and does not establish a joint venture, partnership, association or other entity.

Name \_\_\_\_\_

Position \_\_\_\_\_

Organisation \_\_\_\_\_