



**Letter of Intent to join
UK Health Data Research Alliance
March 2020**

The *UK Health Data Research Alliance* is an **independent alliance of data providers, custodians and curators** dedicated to improving human health by maximising the potential of multiple forms of data at scale.

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

Background

The UK has some of the richest health care and research data assets world-wide. Some assets – such as the Clinical Practice Research Datalink, Genomics England and UK Biobank are well organised – but only a fraction of all our NHS and research data is accessible. Users are increasingly impatient to see successful extraction of value from this data and 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.

We propose that this can only be done with the right expertise, trusted governance, and the development of interoperability (i.e. able to work across organisations and systems with no additional effort) through a UK-wide health research alliance. The Alliance will offer intermediary data solutions to NHS, public & private sector and academic institutions to help them to optimise trustworthy data sharing, and the provision of value-added services for them and their clients, with a transparent set of rules for ethics, business and engagement.

In 2018 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 that this can only be done through partnership working, and the need to bring together the right organisations and digital health leaders with the expertise, trusted governance, public involvement and endorsement and gravitas to deliver. The *UK Health Data Research Alliance* was launched in February 2019, convened by HDR UK and made up of the main national data custodians. A second wave of partner organisations joined in July 2019. Organisations are encouraged to sign this letter of intent and engage in alliance activities. Formal announcement of new members will take place approximately every 3 months.

What it means to be a member

The overarching goal of the *UK Health Data Research Alliance* is to accelerate progress in in biomedicine, health and care by encouraging widespread access to structured and unstructured clinical, administrative, imaging, genomic and other molecular data.

In order to achieve this goal, the *UK Alliance* organisations will work collectively to:

1. Bring together the research, clinical, and disease advocacy communities and the private sector to support and promote the responsible sharing 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 to help shape developments to create a responsible and ethical infrastructure for health data research and innovation in the UK.

Founding Principles

The UK Health Data Research Alliance is an open and inclusive organisation. 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.

Alliance members are also expected to role model the principles for participation in the DIH Programme that were [updated in January 2020](#) and commit to:

- **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, while promoting the protection of privacy and data security in line with the OECD Recommendation of the Council on Health Data Governance¹
- **Make data Findable, Accessible, Interoperable and Reusable** by adopting the FAIR Guiding principles for scientific data management and stewardship²
- **Adhere to the Foundation Principles and Core Elements for Responsible Data Sharing** set out in the Global Alliance for Genomics and Health Framework for Responsible Sharing of Genomic and Health Related Data³ and **use a proportionate approach to the governance of data access based on the five "safes"**⁴
- **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 principles set out in the Life Sciences Sector Deal 2 (and as updated by NHSX led Centre of Expertise)
- **Work collaboratively to increase harmonisation and reduce the complexity** of data sharing arrangements to improve the efficiency of accessing 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.
- **Contribute to a joined-up and UK-wide offer** for researchers in all sectors by collaborating with existing, relevant health research infrastructure.

Members will work together to ensure that the *UK Health Data Research Alliance*:

- Serves the **public good**
- Supports the needs of a **broad community of patients, clinicians, researchers** and innovators,
- Functions to the **highest ethical standard**
- Is well-**governed and is resourced and funded for the first three years** of operations
- Achieves its **goals** in the first three years and is positioned for **ongoing success**

Composition & Governance

1. The *UK Health Data Research Alliance* is an **independent alliance of health data providers, custodians and curators** dedicated 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 organizations, life science and information technology companies to fulfil its vision.
2. The *UK Health Data Research Alliance* is established by **Partner Organisations**, each of which brings world-leading experience in domains relevant to the mission, along with an outstanding record of **servicing the public good**.
3. The *UK Health Data Research Alliance* is an unincorporated **not-for-profit association**. To provide long-term stability and support, the *Alliance* will initially be administered and hosted by agreement by Health Data Research UK. Funded as part of the Digital Innovation Hubs (DIH) programme.
4. The *UK Health Data Research Alliance* has established an **Alliance Board**, initially composed of senior leaders from the Partner Organisations. The board will provide oversight and direction of the *UK Health Data Research Alliance* as it seeks to maximise benefit and will organise subgroups as needed to address issues as they arise. Ultimately the Board is accountable to the membership of the alliance. It will ensure that it aligns with, and does not duplicate, efforts currently overseen by the OSCHR Health Informatics Sub-Group, National Information Board and other relevant current or future forums.
5. 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 *UK Health Data Research 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.

Members 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 public facing website and include at least the minimum dataset defined by the Alliance Board. It should be updated at least quarterly.
- Providing equivalent data in csv or equivalent format to Alliance Secretariat for consolidated reporting and analysis.
- Supporting development and use of a common database of unique identifiers for research and innovation organisations and users (to be linked to Innovation Gateway) to enable tracking of research and innovation activity across the Alliance.

Members are expected to **encourage the availability and use of data** for research and innovation through the Innovation Gateway. As the functionality comes online, 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 Innovation Gateway.

- Demonstrate substantial progress to making datasets discoverable within 12 months of joining Alliance.
- Agree to process data access requests via the online Access Management module of the Innovation Gateway to waiting time standards agreed by Alliance board (within 6 months of joining Alliance). NB. This can be in addition to existing channels.

Benefits of the Alliance

Members will benefit, from being part of the *UK Health Data Research Alliance* by:

- **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
- being part of a **single, powerful voice**, required to address common barriers to the scale-up and adoption of health data research innovations
- **retaining freedom** to develop new, proprietary products and services, with a focus on collaboration at the interfaces

Patients and the public will benefit by:

- the **rapid translation** of innovate health data driven interventions, developed with UK data to address UK health needs
- **minimising regional inequalities** though 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 organization 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 _____