

# What is a Health Data Research Hub?

Hub Playbook Module 1

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**Updated By:** Alasdair Rankin

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## Purpose

This module is written for a wide audience as an entry point to understanding Health Data Research Hubs. For individuals and organisations that are considering making a case to establish a new Hub, this module is intended to help you understand whether Hubs are the right way to deliver on your priorities, and what to do next. If you have been asked to participate in or support the development of a Hub, as a host institution, partner or payer, this module will help you understand what a Hub needs to deliver, and signpost you to more information about the role that you might play.

## Summary

Health Data Research Hubs are part of Health Data Research UK's wider mission to unite health data assets across the UK to make health data research and innovation happen at scale. Hubs provide a service to a wide user community, working to improve both data quality and access to data in a thematic area of high unmet need, grounded in the principles of open science. They work within a framework of communities, resources, support and expertise provide by HDR UK, which includes patients and data custodians as part of the UK Health Data Research Alliance, and comprehensive data access provision through the Health Data Research Innovation Gateway. HDR UK facilitates a development process for new Hubs, both for potential Hub providers and funders. Prospective Hubs need to be able to commit to our principles for participation and other entry requirements. Hubs provide a research service, but are not a mechanism for funding individual research programmes or consortia.

## Learning objectives

When you've read this module you will:

- Be able to explain what a Health Data Research Hub is
- Understand the relevance of Hubs to you or your organisation
- Be able to explain the role Health Data Research UK plays in developing new Hubs
- Know what you need to do next if you want to be involved in developing a new Hub

# 1. Health Data Research Hubs are a central part of HDR UK’s mission

## 1.1 HDR UK is the UK’s national institute for health data science

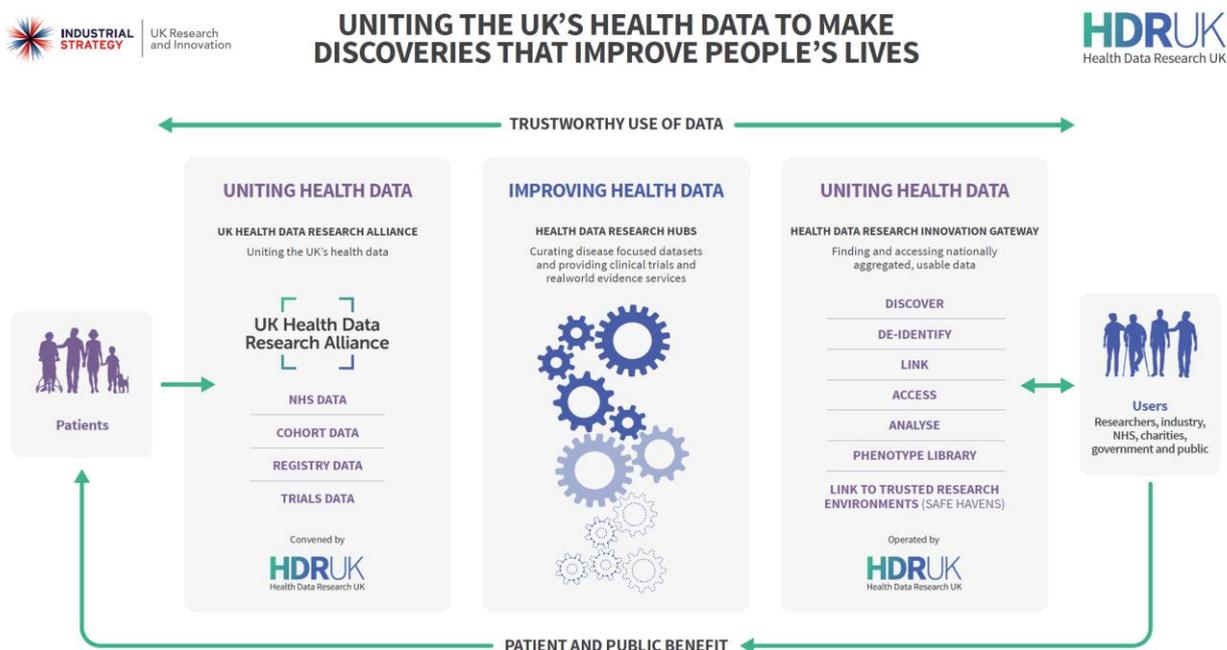
HDR UK is uniting health data assets across the UK to make health data research and innovation happen at scale. Our vision is that every health and care interaction and research endeavour will be enhanced by access to large scale data and advanced analytics. To achieve that vision we work in a number of ways to improve the quality and accessibility of health data, and develop the tools and capabilities needed to generate replicable insights. Health Data Research UK does not control any health data. We work with organisations that hold and manage datasets and we support connections between these datasets to support access for research and innovation.

Resource: Find out more about [what we do](#)

## 1.2 Hubs provide a service that improves the quality and increases the use of health data

The purpose of the Health Data Research Hubs is to bring together data that can inform and improve health -- from “routine” NHS systems (e.g. NHS clinics, laboratories, diagnostics, primary care), relevant registry or cohort data, to wider types of data generated outside the healthcare system, and to curate these to provide new high value data resources for research and innovation. In doing so they must both improve the quality of health data, and increase its availability for research.

Figure 1. The Layers of the Health Data Programme



Hubs are focused on supporting research, rather than undertaking it directly, so must demonstrate an understanding of, and a focus on, the needs of users of data from a range of sectors. This will allow them to focus their data improvement and services on the areas of greatest need and value.

To achieve their purpose, Hubs work closely with patients and data custodians as part of the UK Health Data Research Alliance, to bring different sources of health data together. And they work with the Health Data Research Innovation Gateway to make that data accessible to data users.

## 1.3 Individual Hubs are part of a growing national network

The first seven Hubs, initially known as “Digital Innovation Hubs”, were created in October 2019 with funding from the UK Government’s Industrial Strategy Challenge Fund. Their remits cover cancer, eye health, inflammatory bowel disease, respiratory conditions, acute care, clinical trials and real world data. An eighth Hub, the BHF Data Science Centre, was created shortly after with funding from the British Heart Foundation, and two new MRC funded Hubs for Mental Health and Pain were created in 2021. Through this programme HDR UK have built a wealth of expertise and resources that can support the development of additional hubs. This knowledge can help hubs establish efficiently and rapidly to provide data as a service.

**Resource:** [the current Health Data Research Hubs](#)

The potential of Health Data Research Hubs is enormous, and while it is important to avoid duplicating the resources that have already been created, there are many opportunities for further investment. The creation of the first Hubs has stimulated many more conversations, both about creating new Hubs, and about how existing health data resources that serve a similar function can benefit from the framework HDR UK is developing. For any prospective Hubs, the starting point for that conversation is a clear understanding of the requirements Hubs need to meet, and of where the remit of Hubs ends.

## 1.4 Health Data Research Hubs are not a research funding stream

It is really important to understand from the outset that Hubs do not provide funding to conduct research. A Hub is a service that provides high quality data for research, grounded in the principles of open science. Hubs cannot include costs for a research programme, nor are they a vehicle for offsetting the costs of a single research programme or consortium. If you need to secure funding to conduct research with data curated by a Hub, you will need to consider the other funding streams provided by many of our partners.

# 2. Requirements for entry to the Hub development process

As you begin to build a development plan for your Hub, HDR UK will work with you to help you meet some key requirements of the development process. You will also need to be able to commit to some principles for participation in the Hub programme.

## 2.1 Key requirements for prospective Hubs

Prospective Hubs that want to enter the Hub development process need to be aware of our eligibility requirements, and the overarching conditions you will need to meet, both to achieve and retain Hub status.

You can find out how we ask you to demonstrate that you can meet our requirements in the following playbook module, which links to more detailed information in relevant sections of the playbook.

### Module: Developing a business case: the Hub development process

Figure 2. Eligibility requirements

Contribution to HDR UK mission	<ul style="list-style-type: none"> <li>Evidence how you will contribute to the HDR UK mission to unite health data to enable discoveries that improve people's lives</li> </ul>
Cross-sector partnership	<ul style="list-style-type: none"> <li>Represent a partnership across multiple sectors, led by a public sector organisation or a charity</li> </ul>
Contributing data	<ul style="list-style-type: none"> <li>Contribute data to support the operation of the Hub that demonstrably provides patient or public benefit and addresses an unmet research need</li> </ul>

Figure 3. Conditions of operation

Adopting Principles, Values and Policies	<ul style="list-style-type: none"> <li>Adopt Principles of Participation</li> <li>Subscribe to HDR UK values and policies, including EDI and attribution policies</li> </ul>
Branding, Communications and Publication	<ul style="list-style-type: none"> <li>Align with HDR UK branding, communications and publications guidelines</li> </ul>
Contracting	<ul style="list-style-type: none"> <li>Adopt standard contract requirements</li> </ul>
Budgeting, Income and Costs	<ul style="list-style-type: none"> <li>Identify funding to support delivery, including contribution to HDR UK central costs for the Gateway, Alliance and Hub coordination</li> </ul>
Service provision to user community	<ul style="list-style-type: none"> <li>Be externally facing, providing services for a recognised user group, at a national and/or international scale, based on user needs</li> </ul>
Delivery plans and key milestones	<ul style="list-style-type: none"> <li>Meet agreed milestones for set-up (3 months), initial (18 months) and steady state delivery as a condition of continuing operation</li> </ul>
Health Data Alliance	<ul style="list-style-type: none"> <li>Join the UK Health Data Alliance and contribute to each Hub cross-cutting workstream, developing and adopting best practice</li> </ul>
Innovation Gateway	<ul style="list-style-type: none"> <li>Actively participate in the Gateway: identify datasets to be made discoverable, provide the metadata and integrate access management</li> </ul>

## 2.2 Principles for participation

HDR UK established eight [principles for participation](#)<sup>1</sup> when the first Health Data Research Hubs were identified, with funding from the UK Government's Industrial Strategy Challenge Fund, through the Digital Innovation Hub Programme competition in 2019. These principles focus on how Hubs will work to curate health data and also apply to participants in the UK Health Data Research Alliance and the Health Data Research Innovation Gateway.

1. **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.
2. **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 Governance](#)<sup>2</sup>.
3. Make data Findable, Accessible, Interoperable and Reusable by adopting the [FAIR Guiding principles for scientific data management and stewardship](#)<sup>3</sup>.
4. 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 Data](#)<sup>4</sup> and use a **proportionate approach to the governance** of data access based on the [five "safes"](#)<sup>5</sup>.
5. **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.
6. **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<sup>6</sup>
7. **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.
8. Contribute to a **joined-up and UK-wide** offer for researchers in all sectors by collaborating with existing, relevant health research infrastructure.

## 2.3 How HDR UK supports Health Data Research Hubs

### 2.3.1 Supporting you through the Hub development process

The role that HDR UK plays is very different from that of a research funder. We are both the custodian of Hub standards and practices, and the provider of a number of core resources. HDR UK does not itself provide the costs of Health Data Research Hubs and, importantly, the cost of the core services we provide needs to be included in each Hub's budget.

For aspiring Hubs, we help facilitate the development of your Hub, guiding you through a process of developing a delivery plan that fits the requirements of funders and your circumstances. We also work with

research funders to develop funding calls where they have a strategic need to invest in a Hub, and we can help aspiring Hubs work through their options for securing funding from a variety of sources.

You can read more about the development process in the following playbook module.

**Module: [Developing a business case: the Hub development process](#)**

## 2.3.2 Resources and support for approved Hubs

Once a Hub is approved, the Hub team will actively support the Hub's development. HDR UK will also provide access to a range of in-house expertise, including technical, research development, data access and standards, communications and patient public involvement and engagement. And as part of our community you will have access to the convening power of HDR UK to shape national health data policy.

We provide approved Hubs with the following core resources:

### Innovation Gateway

- A data access module, which accelerates access to data by streamlining management of your data access processes.
- A data utility module, with tools and a framework to curate and improve data against standards to increase utility for a wider audience
- Inclusion of findable datasets in the Innovation Gateway - with over 5000 searches a month of researchers looking for data
- A specific "research collection" for your Hub to use as a vehicle for wider dissemination and promotion of all hub activities. This may replace or complement the need for a separate website.

### HDR UK Alliance

- Access to a wide and growing network of engaged data custodians working on the knotty problems of the UK health data sphere, such as data standards, information governance and interoperability

### Health Data Research Hub Network

- Access to a growing shared practice network of other Hubs that are engaged in similar activities to you, via cross cutting workstreams (such as data curation, business development, sustainability models, patient public involvement and engagement (PPIE), communications and dissemination).

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## 3. Resources

The following resources have been referenced in this module. This list excluded references to other modules in the Hub playbook.

**Resource: [Find out more about what we do](#)**

**Resource: [the current Health Data Research Hubs](#)**

**Resource: Health Data Research Hubs [Principles of Participation](#)**

<sup>1</sup> Digital Innovation Hub Programme Prospectus: Principles for Participation (Jan 2020).

<https://www.hdruk.ac.uk/about-us/our-strategy/policies/digital-innovation-hub-programme-prospectus-principles-for-participation/>

<sup>2</sup> **OECD, *Recommendation of the Council on Health Data Governance***, OECD/LEGAL/0433

<http://www.oecd.org/health/health-systems/Recommendation-of-OECD-Council-on-Health-Data-Governance-Booklet.pdf>

<sup>3</sup> Wilkinson, M. D. *et al.* **The FAIR Guiding Principles for scientific data management and stewardship.** *Sci. Data*3:160018 doi: [10.1038/sdata.2016.18](https://doi.org/10.1038/sdata.2016.18) (2016)

<sup>4</sup> **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 Data.

<https://www.ga4gh.org/genomic-data-toolkit/regulatory-ethics-toolkit/framework-for-responsible-sharing-of-genomic-and-health-related-data/#fp>

<sup>5</sup> **The Five Safes.** Desai, Tanvi; Ritchie, Felix; Welpton, Richard (2016). "[Five Safes: designing data access for research](#)". Bristol Business School Working Papers in Economics

<sup>6</sup> **Creating the right framework to realise benefits for patients and the NHS where data underpins innovation** – Guiding principles<sup>6</sup> set out in the Life Sciences Sector Deal 2;

<https://www.gov.uk/government/publications/creating-the-right-framework-to-realise-the-benefits-of-health-data/creating-the-right-framework-to-realise-the-benefits-for-patients-and-the-nhs-where-data-underpins-innovation>