

HDRUK
Health Data Research UK



**INDUSTRIAL
STRATEGY**

UK Research
and Innovation



Health Data Research Hubs

Hub Milestone 1 – Report Summary

March 2020

The Digital Innovation Hub programme, launched in 2018, has three major strands

The ISCF Digital Innovation Hub (DIH) Programme, led by Health Data Research UK (HDR UK) on behalf of UK Research and Innovation, is a £37.5m investment to create a UK-wide capability to enable the safe and responsible use of health-related data at scale for research and innovation. This is being achieved through embedding a robust governance framework across the three elements of the DIH Programme:

- The UK Health Data Research Alliance
- The Health Data Research Innovation Gateway
- Health Data Research Hubs

Seven hubs were announced on 12 September 2019 and went live on 1 October 2019; In just 3 months, the Hubs achieved their first major milestone.



GUT REACTION – The Health Data Research Hub for Inflammatory Bowel Disease



DATA-CAN – The Health Data Research Hub for Cancer



DISCOVER-NOW – The Health Data Research Hub for Real World Evidence



INSIGHT – The Health Data Research Hub for Eye Health



PIONEER – The Health Data Research Hub for Acute Care






BREATHE – The Health Data Research Hub for Respiratory Health



NHS DigiTrials – The Health Data Research Hub for Clinical Trials

Highlights – the variety of activities across the Hubs are already making a difference for patients and for the wider life sciences sector


<p>100% of the 7 hubs met milestone 1</p> 	<p>Involving >100 organisations from NHS, academia, industry and charities involved</p> 	<p>Hubs have been featured at many high-profile events including:</p> <ul style="list-style-type: none"> World Cancer Summit, Cancer52 and EFPIA Oncology Data Summit ABPI event with 85 attendees from 20 pharma companies UseMyData (Leeds) and Medicines Discovery Catapult (Macclesfield) Biopharma Ambition Dublin event with over 400 delegates from the Biopharma Industry
<p>in 22 locations across England, NI, Scotland & Wales</p> 		



"I can see that if researchers had been able to access and use my health data, I might have been offered more effective treatments, quicker."


Rosanna Fennessy, patient representative for Gut Reaction

6 disease areas prioritised



Cancer	Diabetes	Respiratory health
Inflammatory bowel disease	Eye health	Acute care

>4 high profile global partnerships



Discover-NOW	AstraZeneca	Gut Reaction Health Data Research Hub	Microsoft
INSIGHT Health Data Research Hub	Roche	DIGITRIALS Health Data Research Hub for Clinical Trials	NOVARTIS

Quality of datasets

★★★★☆

Level 4: Full technical submission

Demonstrated technical maturity and capability to submit quality metadata

- DATA-CAN
- DiscoverNOW
- INSIGHT
- Gut Reaction
- BREATHE

Hubs are supporting projects across industry, academia and the NHS including:

39 New projects across all hubs



Hubs are currently supporting

6 UK SMEs as users through specific projects



4 publications were released in the first few months, and

3 more are currently under review



Examples of projects include:

- Developing a tool to automate prescription of treatment for paracetamol overdose
- Creating a digital app for breast cancer management
- Epidemiological study for childhood asthma
- Health technology assessment
- Reviewing how high street ophthalmic imaging can inform diagnosis of dementia

Data – Hubs have made 47 datasets discoverable on the Innovation Gateway, with metadata available for a range of dataset types

The datasets discoverable across the hubs cover a range of modalities, including: Genome Wide Association Studies, linked clinical and genomics, Electronic Health Records, community, primary care, research cohorts, imaging, longitudinal real-world studies. Examples include:



A specifically developed and manually validated dataset of acute care contacts (including physiological, biochemical, outcome and hospital activity data) along with genomics



National hospital episode datasets to enable an England-wide clinical trial feasibility service



Linked, longitudinal dataset, covering a population of 2.4m people, bringing together data from community services, mental health, primary and secondary care

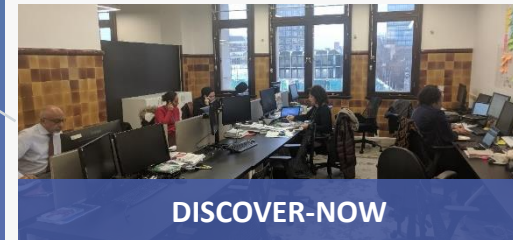
Milestone 1 required Hubs to deliver rapidly against their plans



Milestone 1 requirements were ambitious. Between 1 October and 31 December 2019, Hubs were required to:

1. Sign up to the DIH Programme [Principles for Participation](#) – including the FAIR data principles (Findable, Accessible, Interoperable and Reusable).
2. Make the metadata about their datasets available and discoverable through the [Health Data Research Innovation Gateway](#) – providing a description of the number of datasets, and their scale and quality.
3. Demonstrate that their physical environment was operational.
4. Set out their plans to engage with and involve patients and the public on access to, use of and security of patient data.

Hubs operate across the UK, with multiple physical locations that allow academia, NHS and industry to “breathe the same air”



Patient and Public Involvement and Engagement has been central to Hub development from the beginning

- All Hubs have involved patients and the public in the development of their bids from the start
- Hubs have patients and members of the public involved in decision-making at all levels, and several hubs have multiple patient or lay representatives on their boards
- This has involved varied media, including leaflets, social media, videos, workshops,
- Hubs are working with charity partners to expand their reach, including to hard-to-reach groups

Highlights in this area include:

Deliberative engagement in London, supported by IpsosMORI and The King's Fund. Bringing together 100 citizens reflective of London population over two full weekends in a Citizens' Summit to discuss and deliberate Londoners' expectations in relation to the use of their health and care data.

Engagement with 100s of patients and the public in direct, physical interactions to communicate the intentions and listen to needs

Setting up a data trust board with the Open Data Institute and AAAMD



"All research is based on data and I want my data to be used to give the most benefit to others and to myself."

Margaret Grayson, patient representative for DATA-CAN

In addition to delivering against the milestones, Hubs have contributed to national thinking in cross-cutting priority areas

As well as the required focus on PPIE, Hubs are involved in cross-cutting workstreams:

Data Standards and Curation

- Hubs are sharing their initial approach to data quality, and will be supporting the work to develop a shared data utility framework in the first half of 2020. This approach will be informed by the specific use cases encountered by the Hubs, and will lead to insight on the different approaches to improving the data

Participation & Sustainability

- Strong progress has been made in the co-creation of a commercial framework for the Hubs who continue to work on sustainable business models which will enable them to continuously improve the range and quality of data available to researchers for fair and ethical use. This was reviewed at the joint event on 22 January hosted by the Academy of Medical Sciences and the Centre for Advancement of Sustainable Medical Innovation. [Read the report here.](#)
- The Innovation Gateway will become the vehicle for providing transparent information about Hub business models.



What new research or potential use of the data has been made possible following completion of Milestone 1?

BREATHE

BREATHE's datasets will accelerate studies in respiratory health conditions, both in terms of broader access of data by facilitating relationships between data controllers and interested parties, and curated definitions of phenotypes with data dictionaries, meta-data, genome-wide association results and individual level data, provided through SAIL databank. The BREATHE datasets are supporting epidemiological research and health services research as well as genomic studies.

NHS DIGITRIALS

NHS DigiTrials is enabling researchers to better understand the data that NHS Digital holds and signpost them to data access processes. Positioning this alongside the data held by other data controllers enables researchers to look across the breadth of data available and identify where to go for the data that will best answer their research queries. The feasibility tool being developed by NHS DigiTrials will be able to query across a range of NHS Digital datasets, allowing researchers to understand the structure and content of the underpinning data to help them to construct their feasibility queries.

INSIGHT

The Hub achieved the first cataloguing of metadata for the entire ophthalmic imaging datasets of two major NHS Trusts, including the UK's leading eye hospital, representing the largest ophthalmic imaging database in the world. In addition to providing an index that facilitates opportunities to improve eye health using the data, this catalogue provides important insights in its own right, such as the rate at which the demand on ophthalmic imaging is increasing, the relative contribution of different imaging platforms, and the demographic profile of the patients undergoing imaging.

GUT REACTION

Gut Reaction's datasets relate to the **IBD Bioresource**. The primary purpose of these datasets is to use data to facilitate participant recall to experimental medicine studies. Interest is already increasing, with the BioResource Steering Committee approving four inflammatory bowel disease - related recall studies in December, including one industry-led study. Interest in this data is expected to rise further with the Hub's enhanced data holding and visibility of metadata via the Gateway. The Hub is already developing collaborations with NHS Trusts and industry.

What new research or potential use of the data has been made possible following completion of Milestone 1?

DATA-CAN

Via the Oncology Data Network DATA-CAN have agreements in place with Leeds Teaching Hospitals NHS Trust and now a second large NHS Teaching Hospital.

High impact papers where DATA-CAN is cited include Lawler et al *Lancet Oncol* 2019
Moonshot of Groundshot:
Addressing Europe's cancer challenge through a patient focussed data enabled lens

DISCOVER-NOW

The Hub is currently supporting over 30 projects through the longitudinal, linked dataset. These feature a range of projects from *academic retrospective studies* including investigating psychological factors predicting clinical outcomes following bariatric surgery, to *retrospective studies* including the journey of patients with chronic cough for a global pharmaceutical company through *to evaluations* including looking into 'Community Well Living' primary care mental health services. T

PIONEER

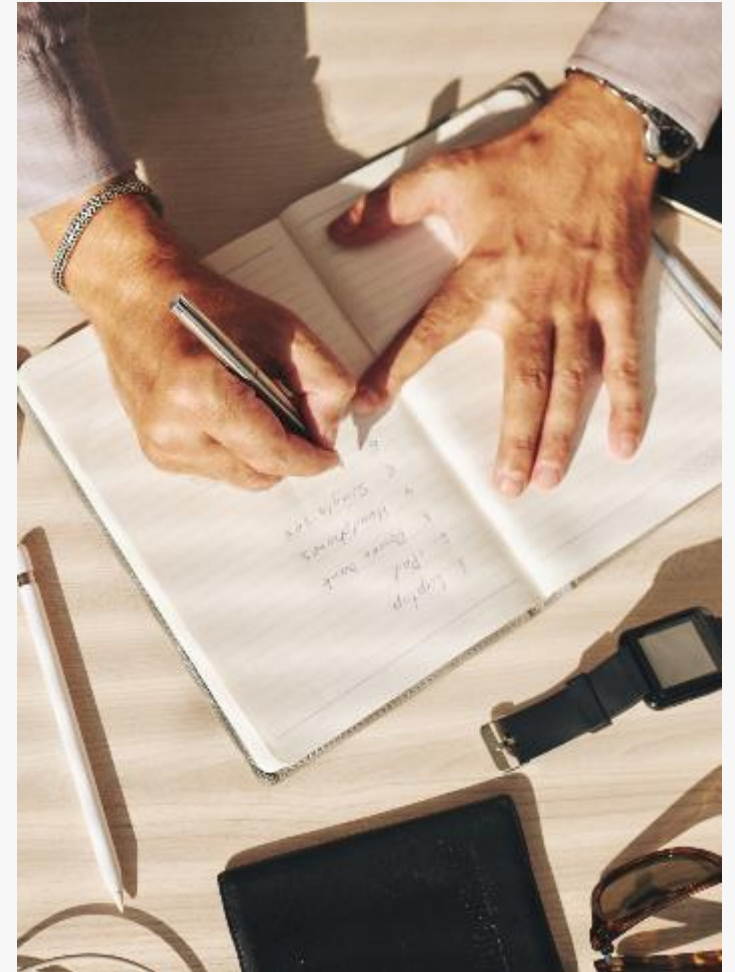
The main dataset delivered in Milestone 1 by PIONEER describes the acute care use of 2018 patients who have contributed to the **100,000 Genomes Project**. This includes the number of Emergency department presentations, acuity scores (a measure of unwellness), biochemical and haematology results, physiological measurements, co-morbidities, length of stay and outcome.

Principles for Participation align behaviors and intent

As part of Milestone 1, all Hubs were required to sign up to the [Principles for Participation](#)

Summarised principles:

- 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, while promoting the protection of **privacy and data security**.
- Make data Findable, Accessible, Interoperable and Reusable (**FAIR**)
- Adhere to the GA4GH Foundation Principles and Core Elements for Responsible Data Sharing and use a proportionate approach to the governance of data access based on the five “**safes**” (Safe projects; Safe people; Safe settings; Safe data; Safe outputs)
- Maximise the benefits of data for research and innovation through **non-preferential access** to data
- Establish **mutually beneficial** ways of working in partnership in line with principles set out in the Life Sciences Sector Deal .
- Work collaboratively to increase **harmonisation, transparency** and reduce the complexity of data sharing arrangements
- Contribute to a **joined-up and UK-wide** health data offer for researchers in all sectors



Hubs will be required to achieve Milestone 2 in March 2021, which will focus on improving the data and support the use and application

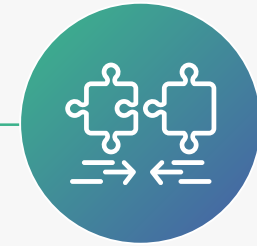
MILESTONE 2, DELIVERED BY 31 MARCH 2021, REQUIRES HUBS TO:



Show that the quality of the datasets has been improved (curated) and that the curated data is discoverable through the Gateway.



Provide publishable enhanced service case studies (e.g. from industry, academia and NHS) that demonstrate impact (and expected impact) and value to researchers and innovators from a range of sectors, and to patients and populations.



Provide evidence that the Hub is continuing to engage and involve patients and the public in a meaningful manner.

Thank you

Find out more:

Health Data Research UK
Web: hdruk.ac.uk

UK Health Data Research Alliance
Web: ukhealthdata.org

Social: [@HDR_UK](https://twitter.com/HDR_UK)

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