



A Guide to the Health Data Research Hubs





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Health Data Research Hubs: An overview

The Health Data Research Hubs (Hubs) provide a rich toolkit of healthcare datasets, infrastructure and capabilities that enable users to identify, access, understand and use data to improve people's lives.

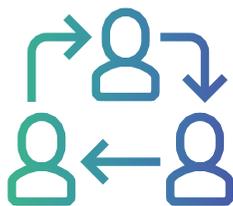
Working in partnership with HDR UK, each Hub is the product of strong collaboration between the NHS, academia, industry and the public and forms an integral part of the vibrant UK research data ecosystem.

Each of the nine Hubs provides safe and ethical access to data concerning a particular area of focus, and the tools to analyse it.

The Hubs were set up following a competitive awards process managed by HDR UK, with initial financing from the UK government's Industrial Strategy Challenge Fund. They have since benefitted from further funding from a range of public and third sector sponsors. These include the Medical Research Council and Versus Arthritis.

9
HUBS

provide access to data concerning a particular area of focus



each Hub is the product of strong collaboration between the NHS, academia, industry and the public



enable users to identify, access, understand and use data to improve people's lives



What is a Hub?

The Health Data Research Hubs are collaborations of leading universities, NHS Foundation Trusts and other non-academic partners that use their tools knowledge and expertise to facilitate the use of health data for beneficial research purposes. Each Hub is a centre of excellence supporting researchers to maximise the insights and innovations developed using this data.



Why are there nine different Hubs?

Each Hub holds topic-specific knowledge, expertise and data in particular disease areas or types of health data. There are currently nine Hubs that provide coverage across multiple disease areas and data sources.





“

As a patient, I am pleased that PIONEER is helping researchers to improve healthcare. On a personal level, I also feel hugely reassured about the safety of my data, and that people like me help guide which projects PIONEER supports.

Mr M Ahmed
Member of the Public

“

It's incredibly important that we understand more about treatment, diagnosis and prevention and data is absolutely key to that. All of the treatments and diagnostics that we have for bowel cancer patients have been refined and improved over generations by using data. I would urge any charities that are interested in making those improvements to see if there is a way for them to work with DATA-CAN.

Dr Lisa Wilde

Director of Research and External Affairs, Bowel Cancer UK

Watch Lisa's video – [DATA-CAN – working with charity partners](#)



The Hub Network



Domain expertise: Pain



Domain expertise: Inflammatory Bowel Disease



Domain expertise: Eye health



Domain expertise: Acute Care



Domain expertise: Mental Health



Domain expertise: Linked real world data



Domain expertise: Respiratory



Domain expertise: Cancer



Domain expertise: Clinical Trials



How do Hubs work together?

HDR UK coordinates the Hubs into a network, allowing them to align practices and share knowledge effectively.

All Hubs are part of the UK Health Data Research Alliance, a broader group of leading healthcare and research organisations that develops ethical standards and solutions for complex data sharing challenges.

The Hubs collaborate with each other to address users' bespoke data needs. However, each Hub has established its own governance and access mechanisms around the data which it holds.



What do the Hubs offer?

200+
rich datasets

Streamlined, ethical access to data

- Hubs provide a predictable governance mechanism and secure environment for research analysis
- The median time to data access after submitting an application is 26 days*

Research ready, high-quality data

- The Hubs curate, improve and link datasets so they are ready to use
- They have made over 200 rich datasets available for research

Expertise and support

- Hubs provide an end-to-end 'concierge' data service to support users in finding, understanding, accessing and analysing data.
- They have delivered over 500 separate research projects with academia and industry

30,000
public interactions

Partnerships with patients and the public

- Joint decision-making and development of practices with the public and patients
- Hubs have formed strong partnerships with charities and other patient organisations to ensure they act fairly and openly, in the best interests of patients.

National best practice

- Hubs are part of the HDR UK community, benefiting from advances the institute is making in data sharing practices at scale
- There are nine Hubs currently in the Hub network

26
days to access

500+
research projects

9
Hubs

*figure obtained through quarterly reporting from 7 Hubs



Demonstrating trustworthy use of patient data

Core to the ethos of all Hubs is authentic and meaningful partnership with patients and the public – whether that’s with individuals or groups and networks. To build public confidence and demonstrate a trustworthy approach, Hubs must listen to, understand and respond to public views and opinions around data use and work with patients and the public to ensure their processes align and met public expectations.

Hubs achieve this by working with their patient and public groups in both advisory and decision-making roles to ensure their voice runs throughout the Hub’s strategy and operational decisions including judgments of who and for what purpose access to data is given.

Many Hubs have formed strong partnerships with charities and other patient organisations to ensure they act fairly and openly, in the best interests of patients.

Some Hubs also can help companies and academics work with public members as a wider service. This is through **Patient and Public Involvement** (activities or research carried out ‘with’ or ‘by’ members of the public or patients, rather than ‘to’, ‘about’ or ‘for’ them) as well as **Engagement**, ensuring that information and outcomes from research or activities are disseminated to patients and the public.

How Hubs embed patients and the public in their operations

- Patients and the public as full members of operational and strategic management groups
- Membership of data trust, and data access boards that advise on data use
- Citizen juries to develop positions on contemporary and emerging topics
- Mobilised the public behind #datasaveslives campaigns
- Supporting the development of communications through reviews of public facing materials and messaging

How PPIE networks in the Hubs are working with data users

- Helping design public and patient involvement and engagement strategies
- Reviewing processes for public understanding and acceptability
- Organising and facilitating workshops
- Joining and participating in project steering groups



15

charity partners of Hubs



30,000

total number of engagements* the Hubs have undertaken with the public

*patients and members of the public participating in events and consultation (in person and remote)



Who do Hubs work with?



Academia



The NHS



Industry and innovative life sciences companies



Charities and patient organisations



Regulators



International researchers



Digital health, Medtech and AI companies

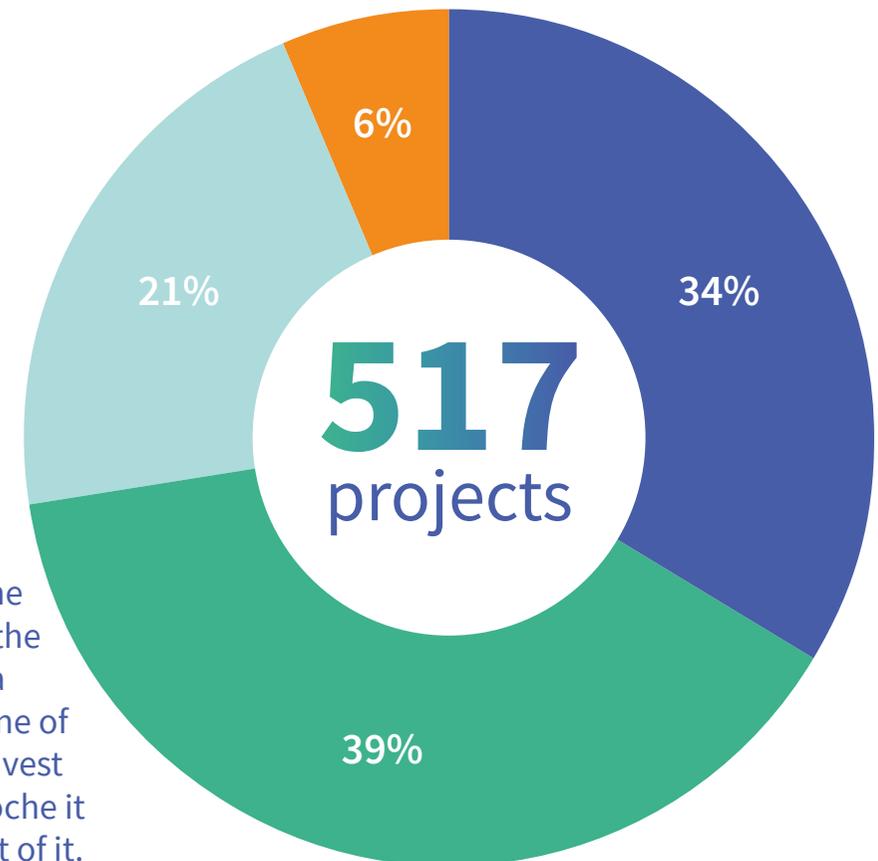
Research projects by sector (August 2019 – Feb 2022)

● Projects – Academia	201
● Projects – Industry	175
● Projects – NHS	108
● Projects – International	33

“

Partnerships like INSIGHT are crucially important in shaping the transformation of healthcare in the digital age together. INSIGHT is a great example of the UK being one of the best places in the world to invest in global life sciences, and for Roche it makes complete sense to be part of it.

ROCHE spokesperson, commenting on their commitment as an industry partner to support the establishment of INSIGHT in 2019





What services do the Hubs provide?

Each Hub has developed a distinctive service offer based on its understanding of its users. Hubs can support the following types of activity, often tailored to the user's needs:

Academic study development service

- Application support services
- Research collaborations



Analysis and evaluation service

- Retrospective clinical or population health analyses & evaluations
- Real time data services



Clinical trial design and support services

- Trial feasibility and design support
- Patient recruitment services
- Trial outcomes and remote monitoring services



Client responsive consultancy

- Joint ventures including development or implementation of new digital or data products



Commercial data services

- Analysis in support of regulatory submissions or due diligence activities



Data as a service

- Access to standard and bespoke datasets
- Provision of trusted research environments



Expertise-based consultancy

- Education & training
- Access to clinical expertise



Public and patient involvement

- Study design and reviews
- Public acceptability studies





How you can work with the Hubs

+ 1. Understand more about each Hub's offer

Learn more about each Hub in this brochure, online and via the **Innovation Gateway**. The Hubs also often run events to explain their data, and service offer.



+ 2. Contact the Hub

Each Hub has a Partnership or Commercial Development lead on hand to discuss your needs and help develop a proposal.



+ 3. Scope a project

You and the Hub team spend time understanding your challenges, how the data held by the Hub could be used and to co-design a project.



+ 4. Costs and contracts

The Hub will cost its involvement in the work transparently, based on the complexity and scale of the project. If you agree, the project can move to contracting, using tried and tested terms and conditions.



+ 5. Access and approval

The Hub will support you in obtaining permissions for your project. Each Hub maintains an independent data access request process, which will efficiently review each request.



+ 6. Project delivery

The project gets underway in a safe and secure way and with the agreed support from the Hub's experts. These experts will have a deep knowledge of the data with which you will be working.





What data do Hubs have?

The Hubs provide access to a variety of data types:

- Extensive real-world NHS data, including health records, test results and high-quality imaging
- Patient registries and clinical cohorts
- Research studies and clinical trial data
- Research cohorts

Hubs improve the usefulness of data by:

- Improving annotation and standard formats
- Providing quality assurance
- Linking datasets
- Phenotyping
- Converting to common data models (e.g. OMOP)
- Creating synthetic data for algorithm development

Do Hubs charge for accessing data?

Generally, yes. Hubs work on a model of sustainability where they are maintained through their use and through this model the Hubs also return value to the NHS and the wider public.

The Hubs have developed flexible costing models, including academic collaborations in grant submissions, depending on the nature and scale of the activities proposed.



Example datasets:

PIONEER: Deeply phenotyped clinical data from unplanned hospital admissions

Multiple linked data assets across all unplanned admissions to hospital in West Midlands covering a diverse population of 5.9 million. It provides granular care pathway data and information on demography, multi-morbidities, investigations, treatments and outcomes.

INSIGHT: The imaging and ocular phenotype bioresource

A longitudinal eye imaging dataset comprising routinely collected patient data from 2001 to the present from Moorfields Eye Hospital. This dataset has more than 13 million high quality images, making it one of the largest retinal image collections in the world.

DATA-CAN: Real time cancer network

Near real-time aggregated cancer activity data from eight major sites across the UK, for the purpose of understanding the effect of the pandemic on cancer diagnostic and treatment pathways.

Discover-NOW: North West London integrated care record

A linked dataset combining multiple primary, secondary and social care data sources for a population of over 2.6 million people. This rich data enables comprehensive capture of clinical pathways and population health analysis.

GUT REACTION: Inflammatory Bowel Disease (IBD) data resource

A consented collection of data from around 36,000 participants with Inflammatory Bowel Disease, which include health and lifestyle questionnaires, linked health records, genetics, and biosamples.

BREATHE: Respiratory data

Key clinical research studies, patient registries, population cohorts and real-world data sets from across the UK, and lower-and-middle income countries accessible for respiratory research.



200+ datasets
on the
Gateway



Benefits of the Hubs

How could working with a Hub benefit you



Hubs are hosted within world-class institutions and led by some of the UK's leading experts in clinical and data science.

Hubs have expert knowledge on the data they work with and can provide an end-to-end service for the efficient design and delivery of research.

Hubs have transparent approaches to costing the involvement of their work in research activities.

The Hubs provide real-world population data, enabling researchers to analyse inequalities and diversity in patient groups.

Hubs have some of the largest and **MOST** well-curated datasets in specific disease areas known to exist nationally.

Hubs provide assurance that health data is being stored, accessed and analyzed fairly, safely and in line with relevant legislation.

Hubs provide a predictable and reliable service and access times for users.

Hubs build public trust by placing engagement and involvement with both patients and the wider public at their heart.



Hubs provide data that is:





The Hubs: Testimony

Hubs benefit all sectors of the life sciences industry, and ultimately the public

“

INDUSTRY

The Hubs' role as a facilitator between the NHS, academia and industry partners to provide a level playing field and a safe environment to experiment is critical to the success of innovative and transformational work.

Ross Stone

Global programme director, Healthcare, AstraZeneca

“

INNOVATIVE SMEs

The facilitation of data-sharing agreements, establishment of a trusted research environment and relationships with key UK academic groups was significantly quicker and smoother via BREATHE Hub than it would have been if we had to negotiate separately with every institution involved.

Steve Gardner

Chief Executive, PrecisionLife

“

ACADEMIA

As a researcher I gained valuable insights into the application of data to answer clinically important research questions. My collaboration with the Discover-NOW team on real-world studies using the dataset, has been an intellectually stimulating and fruitful experience led by a very professional team with expertise in navigating the complexity of high-volume data studies.

Dr Naila Arebi

Consultant Gastroenterologist,
St Mark's National Bowel Hospital
Honorary Senior Lecturer, Imperial College London

“

PUBLIC

Through the work of DATA-CAN – getting data to the people that need it, such as cancer researchers – we are able to get better diagnostics. And we know that the sooner cancers are diagnosed, the better patient outcomes tend to be.

Yvonne Adebola

Global programme director, Healthcare, AstraZeneca

“

CHARITIES AND PATIENT ORGANISATIONS

Our collaboration with HDR UK is enhancing a lot of the work that we are doing in many different ways. We're developing skill sets within our teams, which have been supported by the work that HDR UK does.

Dr Sarah Clarke

Interim Director of Data and Quality Improvement,
Cystic Fibrosis Trust





Future direction of the Hub Network

The Hubs have developed rapidly since their creation in 2019. They have defined their data and service offer, created efficient, safe and transparent data sharing mechanisms and have become known and trusted by their users.

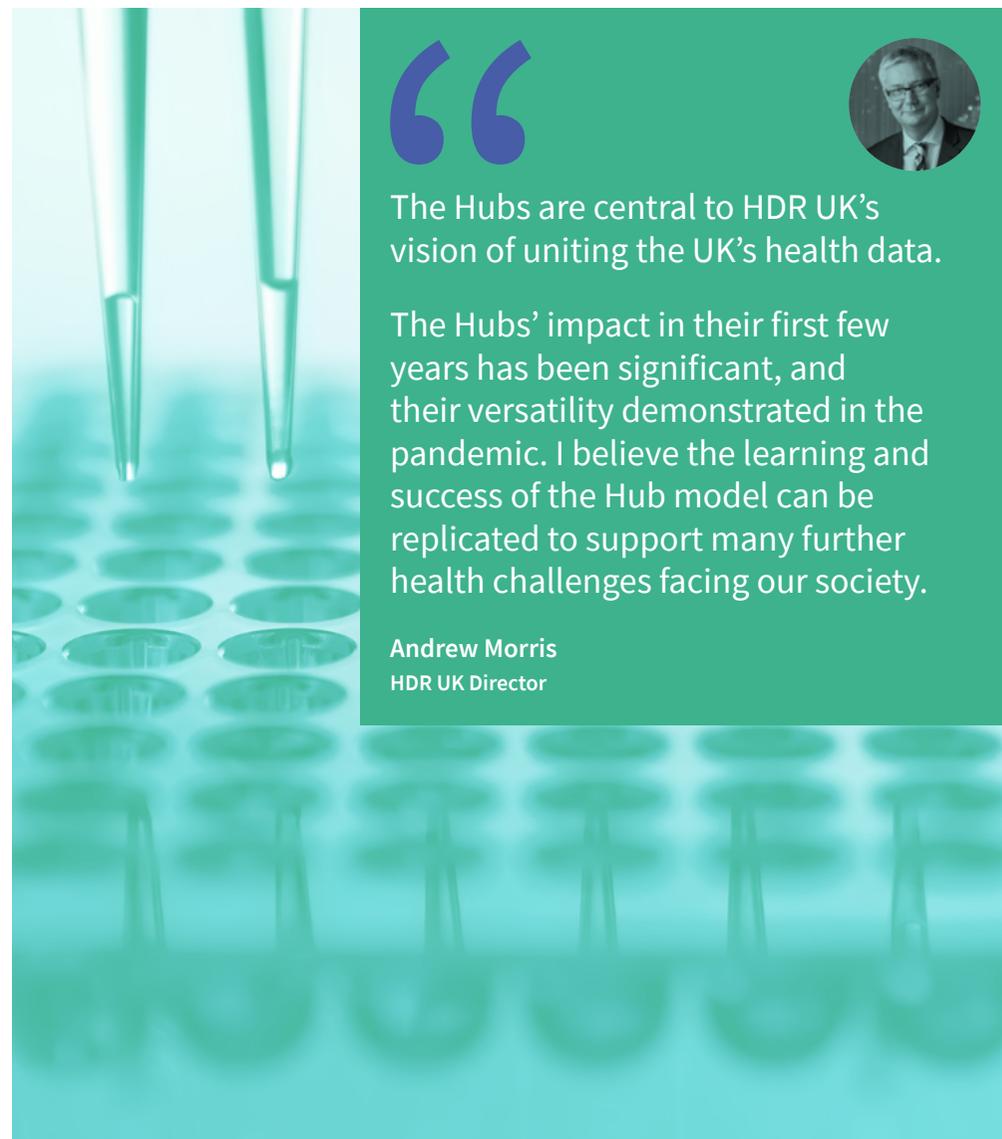
Looking to the future, HDR UK and the Hub Network will work in partnership to offer world-leading, innovative data services to a wide range of organisations, both nationally and internationally, to deliver benefits to researchers and patients. Our goal is for the Hubs to become a long-term and sustainable part of the UK research data landscape.

Whilst each Hub developed individually, in future we will explore the synergies between Hubs and ways for users to access the collective expertise and data assets held across the network.

Expanding the Hub Network

The areas of focus covered by the current Hubs were selected via an open funding competition across a range of disease areas. We intend to expand the data and scientific expertise of the network by growing the remit of current Hubs and adding new Hubs, collaborations and expertise to the network where there is need.

We have developed a [Playbook of materials](#) for anyone interested in setting up a new Hub





Introducing the Health Data Research Hubs

Alleviate

Health Data Research Hub for the Advanced Pain Discovery Platform (APDP)

Created in 2021, Alleviate is transforming UK pain datasets by providing expert data engineering to enhance analysis by researchers and innovators in the fields of pain treatment and management.

Purpose

Chronic pain is a major unmet global public health challenge. To help address this we need a better understanding of the mechanisms of pain and to improve the range of available treatments.

Until now, there has been no UK-wide approach to co-ordinating and managing relevant pain-related data. This has hindered national efforts to link data from various research cohorts with data collected at the point of care.

Alleviate forms part of the Advanced Pain Discovery Platform (APDP), an innovative £multimillion initiative designed to address the problem of chronic pain and improve the lives of those living with pain conditions.

Hub services and expertise

Alleviate will tackle the long-term research challenges in understanding the complexity and unpredictability of pain by:

- Providing a key resource for national and international pain communities
- Making high quality, chronic pain-focused datasets available to researchers
- Innovating integrated approaches that allow discovery of data across many data custodians
- Linking pain datasets to routine health and social care records, (e.g. prescribing and hospital admission), and research on other relevant conditions, such as those related to mental health.



Linking pain datasets to routine health and social care record



Providing a key resource



Professor Emily Jefferson

Director, HDR Alleviate Pain Data Hub
Chair, Health Data Science, and Director,
Health Informatics Centre, University of Dundee



Why Alleviate?

- **Alleviate** provides data, infrastructure, and research services to support pain research at scale.
- This will allow an individually targeted approach to management that takes account of the significant variation and unpredictability faced by people living with chronic pain.

Find out more:

[Visit the Alleviate website](#)

[View Alleviate's accessible datasets on the Gateway](#)



BREATHE

BREATHE enables the use of respiratory health data in cutting-edge research to address conditions such as asthma and chronic obstructive pulmonary disease (COPD).

Purpose

BREATHE brings together respiratory data from multiple sources, and combines them with the expertise needed to deliver meaningful impact.

Through an extensive network of connections and resources, BREATHE is committed to driving the use of health data in research to deliver improvements in respiratory health. BREATHE protects the interest of patients at all stages by working in partnership with them and the wider public to promote the reasonable use of health data.

1 in 5

people across the UK has a long-term respiratory condition



Hub services and expertise

The Hub's offerings fall under three key areas:

- **Sourcing and Accessing Data:** Streamlined access to high quality data that is Findable, Accessible, Interoperable and Reusable (FAIR)
- **Data Linkage:** Combining data from different sources to create new enhanced datasets for deeper research insights
- **Data Analysis:** Our expertise includes a particular focus on genomics (led by Professors Martin Tobin and Ian Hall) and epidemiology (led by Professors Aziz Sheikh and Jenni Quint), as applied to chronic respiratory diseases. This is underpinned by an internationally recognised data science team (led by Professor David Ford).



Professor Aziz Sheikh

Director, BREATHE

Director, Usher Institute and Dean of Data, University of Edinburgh



Why BREATHE?

- The Hub offers unique access to, and understanding of, respiratory data sets alongside global subject matter experts
- It has invested in cleaning, curating and linking multiple data sets to offer a rich research journey, making full use of its deep subject matter expertise
- The **BREATHE** Industry Forum brings together representatives from multinational companies, SMEs and university spin-outs, to ensure the Hub's services are constantly developing to meet their needs.

Find out more:

[Visit the BREATHE website](#)

[View BREATHE's accessible datasets on the HDR Gateway](#)

Keep up with the latest news from BREATHE:

[@BREATHEdata](#)

[LinkedIn](#)



DATA-CAN

Health Data Research Hub for Cancer

DATA-CAN is a UK-wide partnership designed to unlock the power of health data to improve cancer services and patient outcomes.

Purpose

DATA-CAN works in partnership with universities, charities, industry, and NHS organisations to make high quality health data more accessible for cancer researchers, clinicians, and other health professionals.

The aim is to make it easier to conduct research into new treatments, identify opportunities for earlier diagnosis, give patients faster access to clinical trials and create new investment in UK healthcare.

Our data services are guided by a respect for patient involvement and a commitment to empowering cancer research across the UK.



24 PROJECTS

with industry, NHS, academia
and international organisations.

DATA-CAN
The Health Data Research Hub for Cancer

Hub services and expertise

- In partnership with NHS Digital, DATA-CAN is providing approved researchers from trusted organisations with timely and secure access to de-identified cancer data through the NHS Trusted Research Environment.
- DATA-CAN is working with several large NHS cancer centres across the UK to curate patient-level data at source within the electronic health records (EHR) to generate Real World Evidence.
- One of the Hub's founding partners, IQVIA, is working with DATA-CAN and NHS trusts to deliver the Cancer Data Network (CDN). Members of the network can harness data and technology to improve the quality of their care and outcomes patients.
- Our patient engagement expertise can be deployed as a commissioned service to external organisations as part of relevant research projects.



Dr Charlie Davie

Director of DATA-CAN,
Consultant Neurologist, Royal Free
London NHS Foundation Trust



Why DATA-CAN?

- Hosted by UCLPartners, DATA-CAN is a unique, and growing, partnership of NHS organisations, patients, charities, academia and industry working across all four nations of the United Kingdom.
- The Hub is led by an experienced and energetic management team that includes clinicians, academics, data scientists, patients and the life sciences sector.
- The Hub has a unique reputation for the way in which it works with patients, the public and health professionals to make sure that data is used transparently and responsibly and that the benefits are returned to the NHS and the wider UK community.

Find out more:

[Visit the DATA-CAN website](#)

[View DATA-CAN's accessible datasets on the HDR Gateway Gateway](#)

Keep up with the latest news from DATA-CAN:

 [@data_can_hub](#)

 [LinkedIn](#)



DATAMIND

Health Data Research Hub for Mental Health

DATAMIND is making the best use of the UK's rich mental health data by enabling coordinated research with the aim of improving people's lives across the UK.

Purpose

Mental health conditions are the biggest cause of ill health, with poor mental health affecting almost everyone at some point in their lives. People with mental illness are less likely to take part or remain in the usual types of research studies about physical or mental health. Worse still, many are actively excluded from this work. This means that much of what is known about mental illness is not based on data from the people who are worst affected.

The UK has some of the best mental health data in the world to help in the prevention of mental ill health, alongside maintenance and improvement of people's mental health. DATAMIND aims to overcome these challenges, co-ordinate research and enable innovators to make the best use of this mental health data. The Hub acts as the key nexus for UK data science applied in mental health research.

Hub services and expertise

DATAMIND is improving the discoverability of relevant cohort data with the **Catalogue of Mental Health Measures**

It works with people who have personal experiences with mental illness to understand who they trust to use their data, and to develop ways people can work together on mental health.



Why DATAMIND?

- Experience in combining diverse sources across health and non-health data to create novel insights to mental health
- Ensures that the patients and the public are heavily involved with it's work.



Professor Ann John

Co-Director of DATAMIND
Professor of Public Health and
Psychiatry at Swansea University



Professor Rob Stewart

Co-Director of DATAMIND
Professor of Psychiatric Epidemiology
and Clinical Informatics at King's
College London

Find out more:

[Visit the DATAMIND website](#)

[View DATAMIND's accessible datasets on the HDR Gateway](#)

[@DatamindUK](#)



Discover-NOW

Health Data Research Hub for Real World Evidence (NHS data)

Discover-NOW employs real-world data responsibly to support research into treating and preventing disease and improving patient care.

Purpose

Discover-NOW brings together those on the cutting edge of data and population health to accelerate the development of new treatments, devices and apps to more effectively manage, and even prevent health conditions through ground-breaking research.

It does this in part by providing safe and secure access to one of Europe's largest de-identified linked health datasets.

The Hub is a collaboration between NHS organisations, globally recognised academic, technology, industry, and charity partners as well as patients and the public. It is led by Imperial College Health Partners, a group of NHS providers, clinical commissioning groups, and leading universities across North West London.

2.6m

The Discover-NOW dataset has coded primary care, secondary, acute, mental health, community health and social care records for over 2.6 million patients who live and are registered with a GP in North West London.

Discover-NOW
Health Data Research Hub for Real World Evidence

Hub services and expertise

The Discover-NOW dataset has coded primary care, secondary, acute, mental health, community health and social care records for over 2.6 million patients who live and are registered with a GP in North West London. The Hub can offer:

- Leading regulation-ready and GDPR-compliant tools, technologies, and expertise to support real-world evidence health research and improvements
- Real-world evidence studies providing evidence of clinical and commercial impact in real-life settings for patients
- Retrospective real-world data studies to make improvements to existing products or map out clinical pathways to improve commercial and clinical effectiveness
- Clinical trials and prospective research that identify patients, alongside new patterns and associations of disease and guidance on how to treat these effectively
- Development of new devices, health apps and algorithms that can be tested or validated in real-time through secure access to a de-personalised data asset



Dr Axel Heitmueller

Managing Director of Discover-NOW



Why Discover-NOW?

- Discover-NOW has a team of experts, including specialised data scientists and analysts, to support any requests and get the answers needed, providing justification for further investigation
- It supports the healthcare industry and academia to identify and recruit to studies. The Hub's Health Research Register comprises thousands of patients who have consented to be contacted about taking part in research studies relevant to them

Find out more:

[Visit the Discover-NOW website](#)

[View Discover-NOW's accessible datasets on the HDR Gateway](#)

[Keep up with the latest news from Discover-NOW:](#)

 [@DiscoverNOWhub](#)

 DiscoverNow@imperialcollegehealthpartners.com



Gut Reaction

Health Data Research Hub for Inflammatory Bowel Disease (IBD)

Gut Reaction is a unique, secure data resource designed to facilitate academic and industry research in inflammatory bowel disease (IBD). Working with the IBD community, Gut Reaction aims to improve treatment options and patient outcomes through safe, transparent and responsible use of health data.

Purpose

Gut Reaction aims to build on the high-quality health data in the National Institute for Health and Care Research (NIHR) IBD BioResource by securely linking it with consented real-world data from participating NHS hospitals, NHS Digital, the UK IBD Registry and the Wellcome Sanger Institute. This will allow approved researchers controlled access to previously unavailable datasets, promoting clinical innovations with the potential to benefit the IBD community and wider NHS.

56
PROJECTS

across industry and academia

Hub services and expertise

- Gut Reaction has created the world's largest single repository of data from people with IBD, containing information from more than 34,000 IBD patients who have consented to participate in the NIHR BioResource.
- Researchers can search available datasets through the HDR UK Innovation Gateway and, via Gut Reaction's partner organisation AIMES, access and analyse de-identified data in a secure virtual research environment upon study approval.
- Through Gut Reaction and the NIHR BioResource, it will also be possible to invite people with IBD to take part in clinical studies and trials that might be suitable for them.



Professor John Bradley CBE

Director, Gut Reaction
Chief Investigator, NIHR BioResource
Consultant Physician & Director of Research, Cambridge University Hospitals

+ Why Gut Reaction?

- Provides researchers secure controlled access to a wide variety of high quality, consented IBD datasets from patients participating in the NIHR IBD BioResource
- Allows approved researchers a unique opportunity to study rich clinical data with the aim of improving the management of IBD
- Offers support for the whole research journey, from initial cohort analysis to brokerage of analytical services as required.

Find out more:

[Visit the Gut Reaction website](#)

[View Gut Reaction's accessible datasets on the HDR Gateway](#)

Keep up with the latest news from Gut Reaction:

[@GutreactionHub](#)

[LinkedIn](#)

INSIGHT

INSIGHT is an NHS-led partnership focused on eye health and associated conditions. It uses anonymised large-scale data and advanced analytics, including artificial intelligence, to develop new insights in disease detection, diagnosis, treatments, and personalised healthcare.

Purpose

The Hub makes anonymised eye data available for research to benefit patients, the NHS, and the wider UK public. INSIGHT aims to transform the way eye diseases are diagnosed, treated, and managed in the UK and beyond. It is also measuring the impact of the COVID-19 pandemic on eye services and helps the NHS plan care delivery. Over the next few years, it will continue to develop capabilities to reach beyond eye health through the science of 'Oculomics', and lead to breakthroughs in a range of conditions such as diabetes, cardiovascular disease, and dementia.

22m

Home to the world's largest ophthalmic imaging bioresource, with some 22 million images and growing.

Hub services and expertise

The Hub curates imaging and clinical data from patient records across two leading NHS Foundation Trusts, Moorfields Eye Hospital and University Hospitals Birmingham. The technology the Hub has developed ensures this data is continually refreshed. INSIGHT has:

- Created the world's largest ophthalmic imaging bioresource, with some 22 million images and growing.
- An efficient cloud-based data pipeline that can generate anonymised eye data and make this available for research intended to benefit patients.
- The ability through Oculomics to detect systemic diseases using high resolution imaging and therefore impact diagnostics and treatments for large and diverse populations.



Professor Alastair Denniston

Co-Director of INSIGHT
Consultant Ophthalmologist, University Hospitals Birmingham NHS Foundation Trust and Honorary Professor, University of Birmingham



Professor Pearse Keane

Co-Director of INSIGHT
Professor of Artificial Medical Intelligence at University College London and Honorary Consultant Ophthalmologist at Moorfields Eye Hospital NHS Foundation Trust



Why INSIGHT?

- **INSIGHT** is built on an exceptional partnership from leaders in health, technology, therapeutics and data.
- The Hub has created the world's largest ophthalmic bioresource for discovery, innovation, and improved care
- It puts patients and public at the heart of all it does, applying the highest standards of ethics, transparency and safety in data and services

Find out more:

[Visit the INSIGHT website](#)

[View INSIGHT's accessible datasets on the HDR Gateway](#)

Keep up with the latest news from INSIGHT:

[@INSIGHTeyehub](#)

NHS DigiTrials

Health Data Research Hub for Clinical Trials

NHS DigiTrials helps researchers to reduce the time, effort and cost of developing new drugs, treatments and services. It does this by offering data services and infrastructure to support clinical trials that bring benefits to patients, the public and the NHS.

As part of this work, the Hub helps NHS patients across England participate in clinical trials of new treatments. The results generated will go on to influence the day-to-day care of millions of future NHS patients with a wide range of conditions.

Purpose

NHS DigiTrials' vision is to create and provide a service that provides clear benefits at the right time and in the right way for its users. The Hub aims to:

- Enable more opportunities for participation in research
- Reduce the cost and complexity of developing new treatments
- Reduce drug costs to the NHS
- Improve the quality of evidence on the effectiveness and safety of new treatments for patients and their doctors.

Hub services and expertise

- **Trial feasibility:** The Hub discovers whether there are enough potential patients to take part in a trial, it identifies patients who could be interested, and it locates the most practical geographical areas or research centres for a trial.
- **Trial delivery and outcomes:** It follows the participants taking part in a clinical trial by linking with relevant NHS data. This can help patients by reducing the number of follow-up visits and reduce burden on the medical staff caring for them, as data is often collected as part of treatment.
- **Follow-up and retention:** It enables longer term follow-up to help assess the clinical safety and effectiveness of treatments during and after the trial. It also ensures patients are not lost from the trial because they have moved or lost touch.



Michael Champman

Director, Research & Clinical Trials



Dani Breitingger-Blatt

Associate Director, Research & Clinical Trials



Why NHS DigiTrials?

- The Hub is embedded within the NHS offering a deep understanding of the data and the governance required to access NHS health data for research.
- NHS DigiTrials understands the needs of both industry-led and academic-led clinical trials.

Find out more:

[Visit the NHS DigiTrials website](#)

[View NHS DigiTrials' accessible datasets on the HDR Gateway](#)

PIONEER

Health Data Research Hub for Acute Care

PIONEER is a secure research database and analytical environment containing data from healthcare organisations that provide unplanned and emergency care.

Purpose

PIONEER collects and curates data covering every aspect of the provision of unplanned medical care across a diverse population of 5.9million across West Midlands. This covers from out of hours primary care, admissions data, ambulance assessment, emergency medicine, surgery and intensive care.

The data for which our Hub is the data custodian comes from across the health economy, including primary, secondary, social care, and ambulance data.

PIONEER is committed to improving the healthcare pathways through supported access to health data and specialist consultancy services of exceptional quality with public support, trust and oversight.



Professor Liz Sapey

Director of PIONEER

Professor in Acute and Respiratory Medicine at University of Birmingham

Acute Medicine and Respiratory Consultant at University Hospitals Birmingham NHS Foundation Trust



Hub services and expertise

PIONEER provides the following capabilities:

- Mapping of how, where, when and why patients access acute care, with significant data granularity to identify areas for innovation.
- It can provide both test and separate validation data sets;
- It can develop, test and modify algorithms;
- Access to synthetic data;
- Assistance with regulatory processes,
- Unrivalled access to service users, healthcare professionals and purchasers to facilitate the innovation pipeline.

PIONEER is able to support projects which range from complex machine learning on medical images for multinational businesses to small pilots using structured data with SMEs, and everything in between.

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PROJECTS

across industry, SME, academia, NHS and international bodies



Why PIONEER?

- The Hub adapts in an agile way to meet customer need. With two dedicated teams to support data access requests, it provides timely responses to enquiries. It can also build up a detailed data request working with the customer to ensure data use processes meet the needs of partners.
- The Hub is able to highlight significant improvements to the data, informed by users' needs and increasing data uses across multiple sectors including academia, SMEs and the NHS.
- Birmingham has one of the largest clinical trials bases in Europe, with excellent clinical research facilities and access to an ethnically diverse, non-transient, regional population of over five million, the perfect landscape for delivering clinical trials and research.

Find out more:

[Visit the PIONEER website](#)

[View PIONEER's accessible datasets on the HDR Gateway](#)

Keep up with the latest news from PIONEER:

[@Pioneer_hub](#)

[Youtube](#)

[LinkedIn](#)





Invest in innovation

Our Hubs harness the power of healthcare data to accelerate medical innovation to improve lives.

Each Hub focuses on an area where research is needed most, collating all relevant data from across the UK. This means users can access data safely, ethically, and in a standardised way. The Hubs are a great example of our partnerships with data custodians and processors creating a community for impact.

Invest in the Hubs to invest in the future of research and health data innovation.

Why don't you join us on our journey?

Contact us on hubs@hdruk.ac.uk

