HDRUK
Health Data Research UK

INDUSTRIAL STRATEGY | UK Research and Innovation

Uniting the UK's health data to make discoveries that improve people's lives

An introduction to Health Data Research UK

4 December 2019

Option

HDRUK
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Our mission is to unite the UK's health data to enable discoveries that improve people's lives

Bringing benefits to all

For researchers
Faster, more accurate and less expensive research and development

For clinicians and patients
Identification of new medicines, treatments and technologies

For businesses large and small
To better develop, test and deploy new products, devices, tools and AI technologies in health and care earlier

For society
Creating jobs, generating investment, improving health services

A national Institute for health data science

Launched in April 2018, we work in partnership with the NHS, industry, academia and patients, and by providing safe and secure access to rich health data, we aim to help better understand diseases and discover new ways to prevent, treat and cure them.

We are funded by UK Research and Innovation, the Medical Research Council, the British Heart Foundation, the National Institute for Health Research, the Economic and Social Research Council, the Engineering and Physical Sciences Research Council, Health and Care Research Wales, Health and Social Care Research and Development Division (Public Health Agency, Northern Ireland), Chief Scientist Office of the Scottish Government Health and
Social Care Directorates, and the Wellcome Trust.

About Health Data Research UK

Operating Model

- One single national institute
- Federated across the UK
- Ten funders
- Strong Board
- Separate legal entity, tiered structure
- Wellcome Trust base
- Not a data controller
- Partnerships with academia, industry, NHS, charities

We’re working in partnership with patients, the NHS, universities, business & charities to create a world-leading and robust health data infrastructure

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We’re gearing up the UK for quality health care, research and innovation

We’re enabling data science and innovation as a catalyst for change

But with big data comes with big responsibilities!

Part of the industrial strategy

Industrial Strategy for Life Sciences (November 2017) Hubs for health data research (*digital innovation hubs*)

Funded as part of the Industrial Strategy Challenge Fund (ISCF) *Data to Early Diagnosis and Precision Medicine Challenge*

Health Data Research UK asked to lead delivery of this programme on behalf of UK Research and Innovation in September 2018

Ensure that the enormous potential value of the UK's health data assets can be realised

Four-year programme launched in September 2018

We've been listening and designing a model that's fit for the future of health data research

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We've engaged with over

2,700

people

We've spoken to over

350 organisations

in the UK and globally across NHS, industry and academia

35

Events

32

Interviews with Businesses

With thanks to

abpi Bringing medicines to life

Pistoia Alliance

CATAPULT Medicines Discovery

Office for Life Sciences

NHS National Institute for Health Research

NIHR | Research Design Service North East and North Cumbria

What we heard

The UK has **good health data resources**, but these can be **difficult to identify and access**

Data research and innovation takes place outside of the UK because of the **difficulty in working with UK data**

Members of the public support research using health data, where this is **transparent and leads to benefits to the NHS**

We need to be **clear and concise** on the benefits, risks and how these will be managed

We need **to involve patients and the public** throughout the process

We are delivering what patients expect and what industry, NHS and academic data users want

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Data: Longitudinal, event-based, multi-modal, curated datasets on disease sub-groups

Access: Single, easy-to-use route to data

Scale: High quality data with UK-wide coverage

Speed: Fast response times and streamlined contracting, governance and approvals

Expertise: Access to domain specialists, AI and applied analytics, phenotyping

Multiple purposes: Real world data, ability to rapidly identify trial cohorts

All underpinned by building people's confidence and trust in how data is used

Creating a clear strategy for engaging patients and public

Kush Kanodia

Rachel Plachcinski

Margaret Rogers

Ben Johnson

Sara Brooke

Claire Cooper

Angela Coulter

Colin Wilkinson

Our Public Advisory Board is one part of our strategy for involving patients and the public
Ensuring that our work is driven by delivering benefits to patients and the public

Science – Activating world-class health data science

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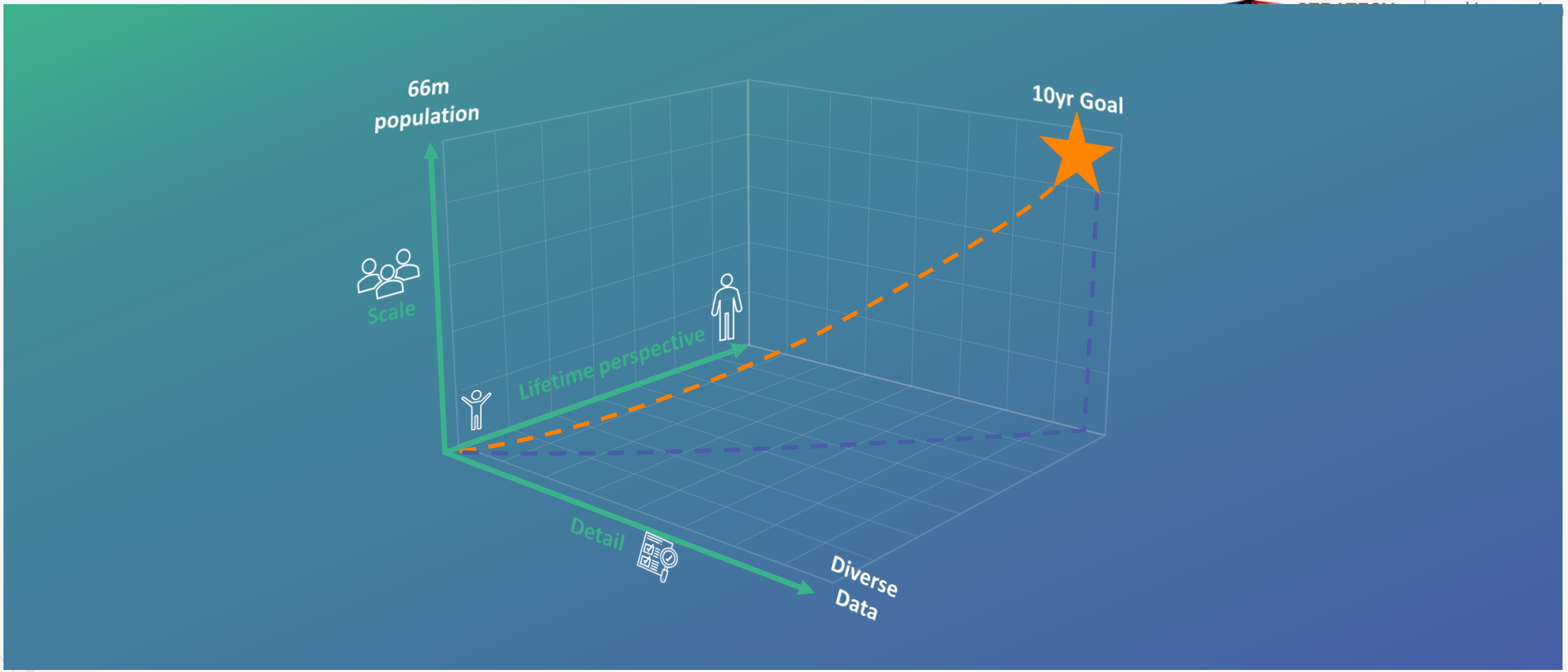
Ambition:
We will develop advanced health data science tools and technologies to analyse complex and diverse health data and seize its power to solve health challenges

Priorities:

- Human Phenome Project
- Applied Analytics
- Understanding the Causes of Disease
- Better, Faster and More Efficient Clinical Trials
- Improving Public Health
- Better Care

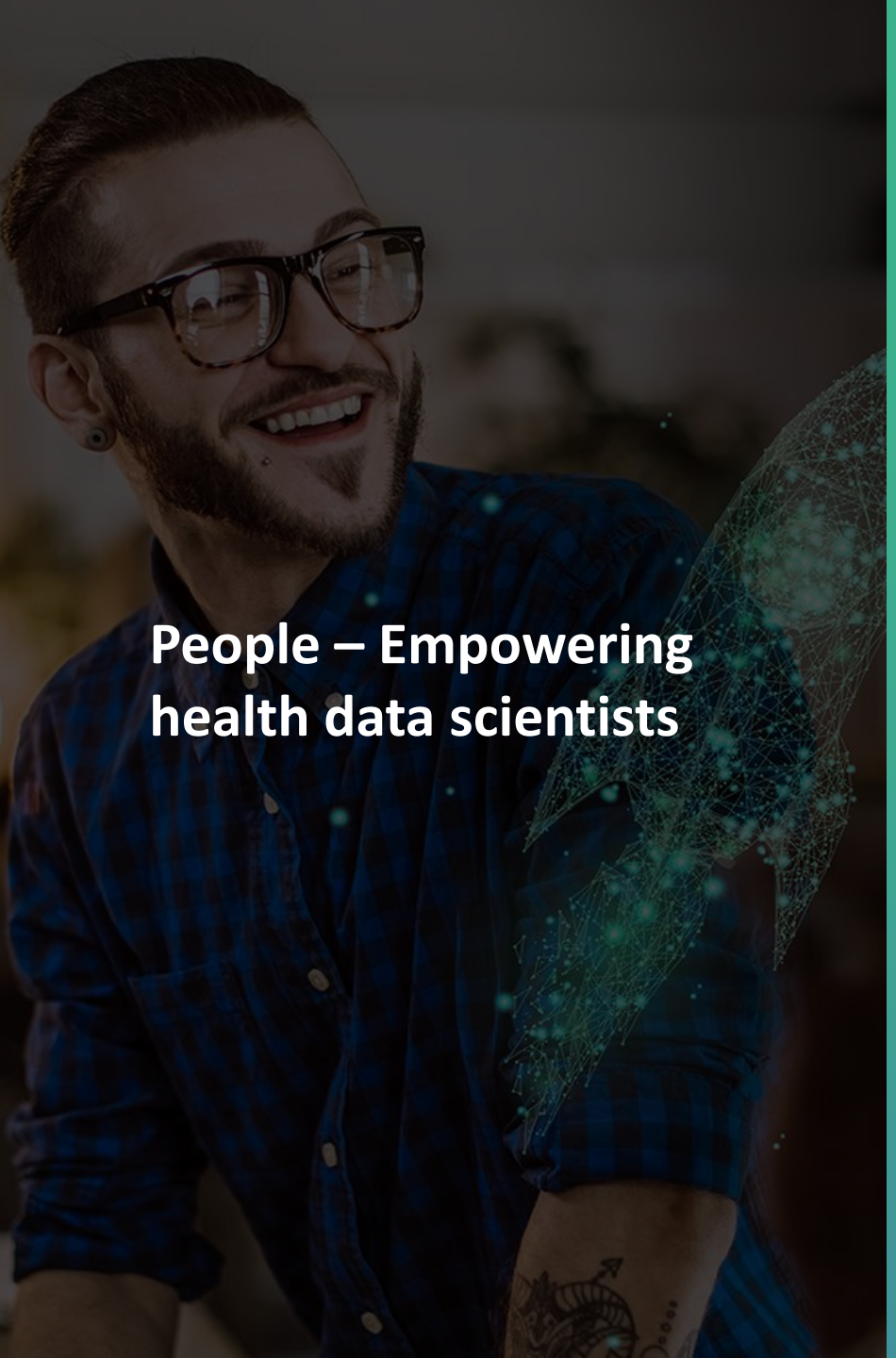
Our 10-year ambition for scale



An outstanding partnership

Our initial investment supports six research sites. Each has world-class expertise; a track record in using health data to derive new knowledge, scientific discovery and insight; and works in close partnership with NHS bodies, industry and the public to translate research findings into benefits for patients and populations.

1. Wales and Northern Ireland (Swansea and Queen's University Belfast)
2. Midlands (Birmingham, Leicester, Nottingham, Warwick)
3. Scotland (Glasgow, Edinburgh, Dundee, Aberdeen, Strathclyde, St Andrews)
4. London (Imperial, Kings, London School of Hygiene and Tropical Medicine, Queen Mary, UCL)
5. Oxford
6. Cambridge (EBI, Sanger, Cambridge University)



People – Empowering health data scientists

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Ambition:
We will create 10,000+ health data scientists spanning all career stages, from school-leaver to senior research manager and international opinion leaders

Priorities:

- School leavers
- Postgraduate
- Post doctoral
- Supporting career pathways

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UNITING THE UK'S HEALTH DATA TO MAKE DISCOVERIES THAT IMPROVE PEOPLE'S LIVES

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TRUSTWORTHY USE OF DATA

PATIENTS

UK HEALTH DATA RESEARCH ALLIANCE

Uniting the UK's health data

UK Health Data Research Alliance

- NHS DATA
- COHORT DATA
- REGISTRY DATA
- TRIALS DATA

Convened by HDRUK Health Data Research UK

HEALTH DATA RESEARCH HUBS

Curating disease focused datasets and providing clinical trials and realworld evidence services

HEALTH DATA RESEARCH INNOVATION GATEWAY

Finding and accessing nationally aggregated, usable data

- DISCOVER
- DE-IDENTIFY
- LINK
- ACCESS
- ANALYSE
- PHENOTYPE LIBRARY
- LINK TO TRUSTED RESEARCH ENVIRONMENTS (SAFE HAVENS)

Operated by HDRUK Health Data Research UK

USERS:
Researchers, Industry, NHS, Charities and Government

PATIENT AND PUBLIC BENEFIT

UK Health Data Research Alliance

An alliance of leading healthcare and research organisations united to establish best practice for the ethical use of UK health data for research at scale.

Established in February 2019

18 current members, more expected to join the coming months

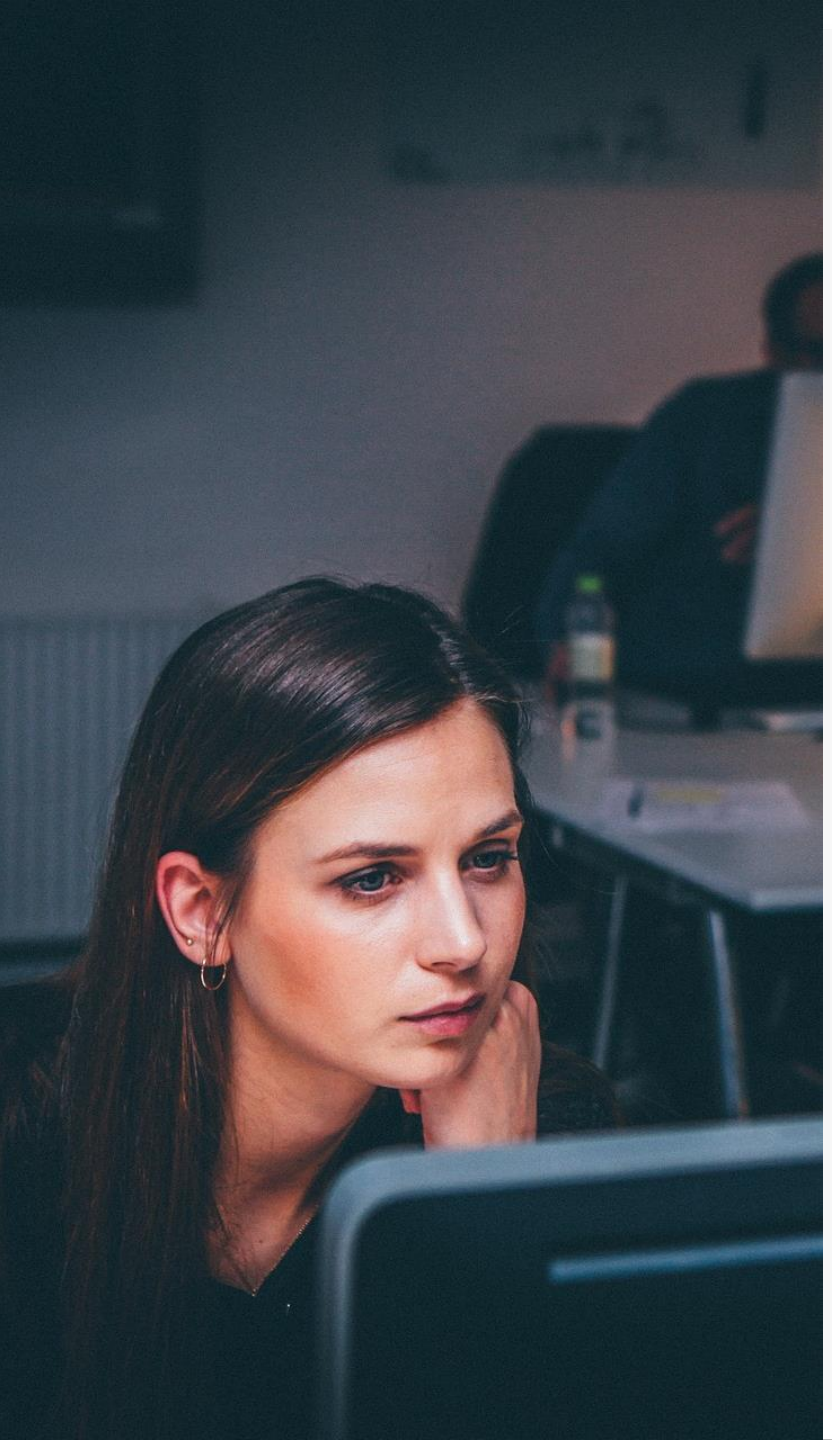
Members

National bodies: Genomics England, Health and Social Care Northern Ireland, NHS Digital, NHS England, NHS Scotland, NHS Wales, NHSX, Public Health England

NHS trusts: Barts Health, University Hospitals Birmingham, Nottingham University Hospitals

Charities: The Brain Tumour Charity, Cystic Fibrosis Trust,

Research Cohorts: Clinical Practice Research Datalink, Healthcare Quality Improvement Partnership (HQIP), NIHR Bioresource, Royal College of General Practitioners Research and Surveillance Centre, UK Biobank



UK Health Data Research Alliance workstreams

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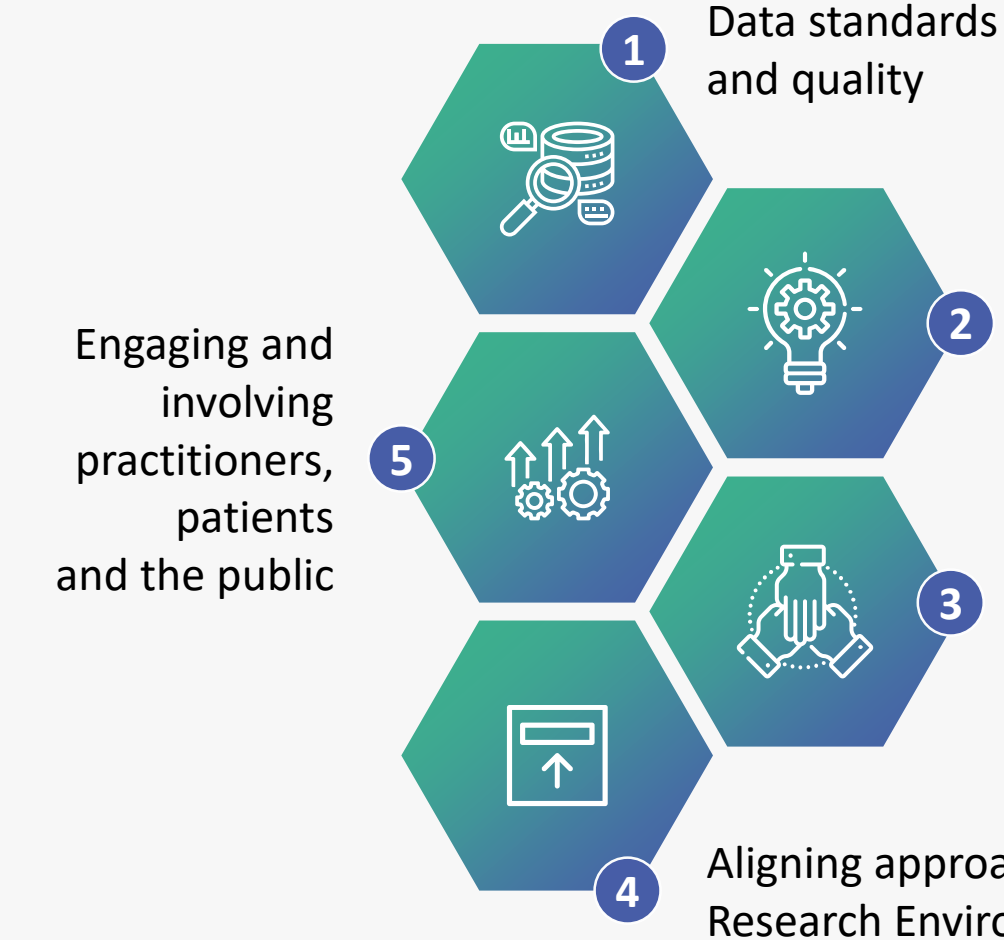
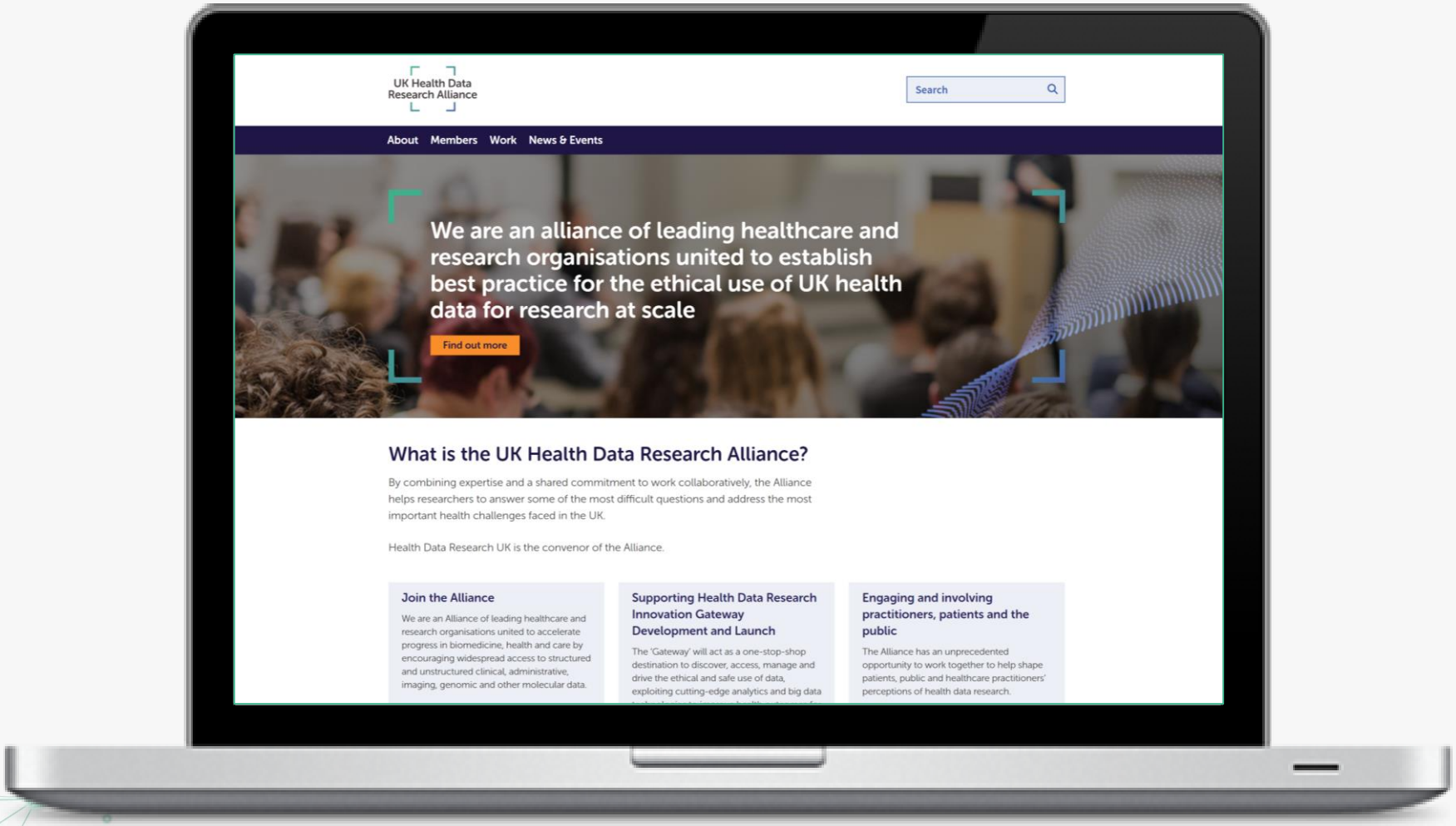


1. Data standards and quality
2. Supporting Innovation Gateway development and launch
3. Promoting participation and improving access
4. Aligning approach to Trusted Research Environments
5. Engaging and involving practitioners, patients and the public

Alliance – Ukhealthdata.org



Health Data Research Hubs

The Hubs will focus on curated, disease focused datasets, clinical trials, and real-world evidence. They will involve patients and the public in shaping the research activities and will improve secure and responsible access to data

- Competition launched in May 2019
- Over 160 organisations in 21 consortia applied
- Independent Expert Panel, chaired by Lord Darzi
- 7 Hubs selected

Introducing the UK's Health Data Research Hubs

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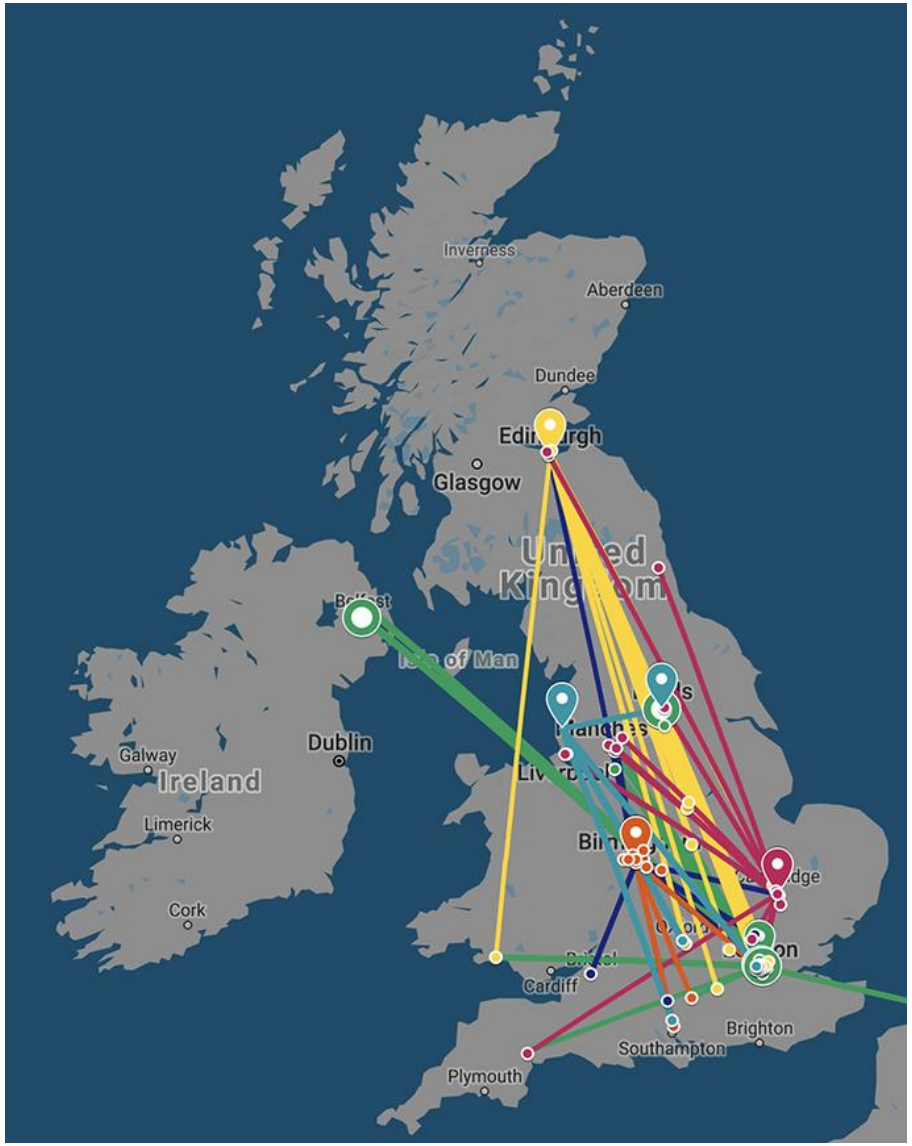
BREATHE	Health Data Research Hub for Respiratory Health
DATA-CAN	Health Data Research Hub for Cancer
Discover-NOW	Health Data Research Hub for Real World Evidence
Gut Reaction	Health Data Research Hub for Inflammatory Bowel Disease
INSIGHT	Health Data Research Hub for Eye Health
NHS DigiTrial	Health Data Research Hub for Clinical Trials
PIONEER	Health Data Research Hub for Acute Care



Partnerships spanning across the UK

Health Data Research Innovation Gateway

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The Gateway is a common access point to UK health research data for accredited researchers and innovators

Developed in 2 phases:

Phase 1 (Minimum Viable Product) – Sep 2019 to Jan 2020

- Portal (Discovery and Access) – developed by IBM
- Metadata catalogue – delivered by NHS Digital and University of Oxford

Phase 2 – Mar 2020 to Aug 2022

- Technology Partnership

Thank you & Any Questions

Find out more:

Health Data Research UK
Web: hdruk.ac.uk

UK Health Data Research Alliance
Web: ukhealthdata.org

Social: @HDR_UK
Email: enquiries@hdruk.ac.uk