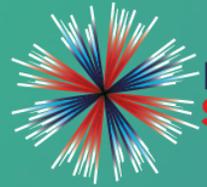


**HDRUK**  
Health Data Research UK

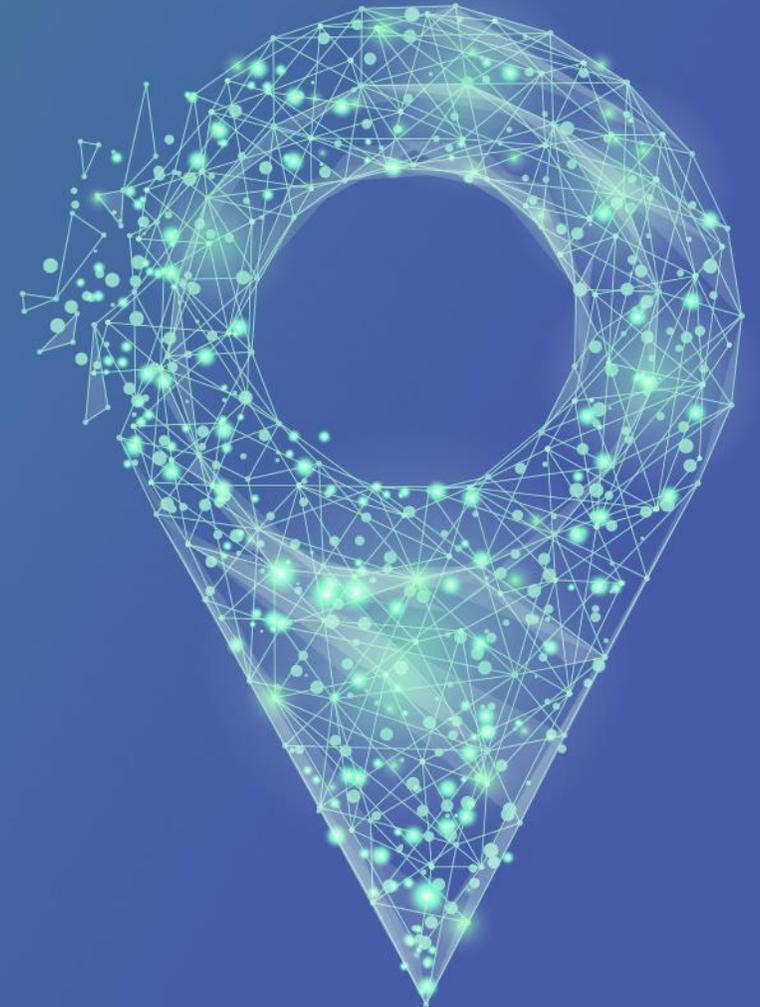


**INDUSTRIAL  
STRATEGY**

UK Research  
and Innovation

# Introducing the UK's robust health data research infrastructure

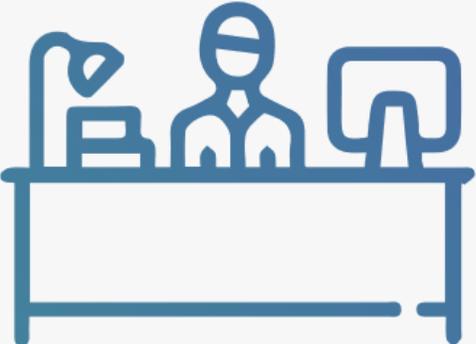
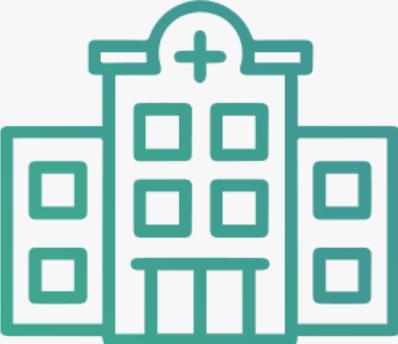
5 December 2019





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

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



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!

## Where this all started...

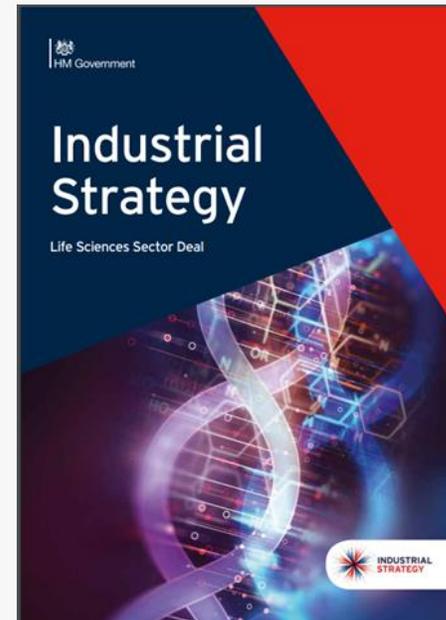
Funded as part of the Industrial Strategy Challenge Fund (ISCF) *Data to Early Diagnosis and Precision Medicine Challenge*

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

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

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

Four-year programme launched in September 2018





## 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



**HDRUK**  
Health Data Research UK



**INDUSTRIAL  
STRATEGY**

UK Research  
and Innovation

## 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**

## Building a UK-wide capability, where we are today

- The overarching programme - Building a UK-wide capability that will enable the safe and responsible use of health-related data at scale for research and innovation
- 18 members of the UK Health Data Research Alliance
- 7 Health Data Research Hubs
- Innovation Gateway – the metadata catalogue and Minimum Viable Product
- 7 members of the User Group – the Sandbox
- Our roadmap and how we are going to be working together

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



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



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



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



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



**Scale:** High quality data with UK-wide coverage



**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**

## 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

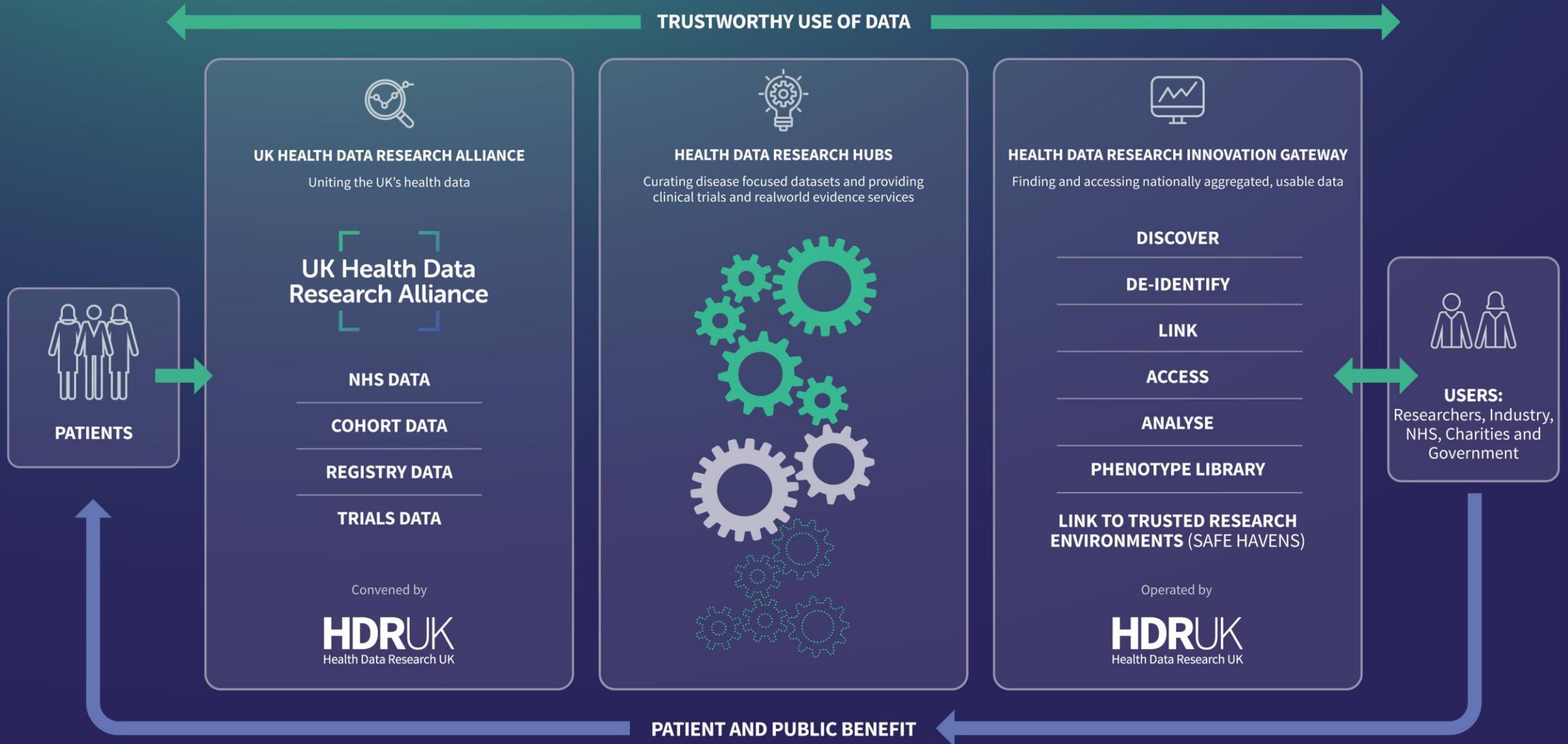
To better develop, test and deploy new products, devices, tools and AI technologies in health and care earlier



### For society

Creating jobs, generating investment, improving health services

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



# 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

<p><b>National bodies:</b> Genomics England, Health and Social Care Northern Ireland, NHS Digital, NHS England, NHS Scotland, NHS Wales, NHSX, Public Health England</p>	<p><b>NHS trusts:</b> Barts Health, University Hospitals Birmingham, Nottingham University Hospitals</p>
<p><b>Members</b></p>	
<p><b>Charities:</b> The Brain Tumour Charity, Cystic Fibrosis Trust,</p>	<p><b>Research Cohorts:</b> Clinical Practice Research Datalink, Healthcare Quality Improvement Partnership (HQIP), NIHR Bioresource, Royal College of General Practitioners Research and Surveillance Centre, UK Biobank</p>



UK HEALTH DATA RESEARCH ALLIANCE  
Uniting the UK's health data

UK Health Data Research Alliance

NHS DATA

COHORT DATA

REGISTRY DATA

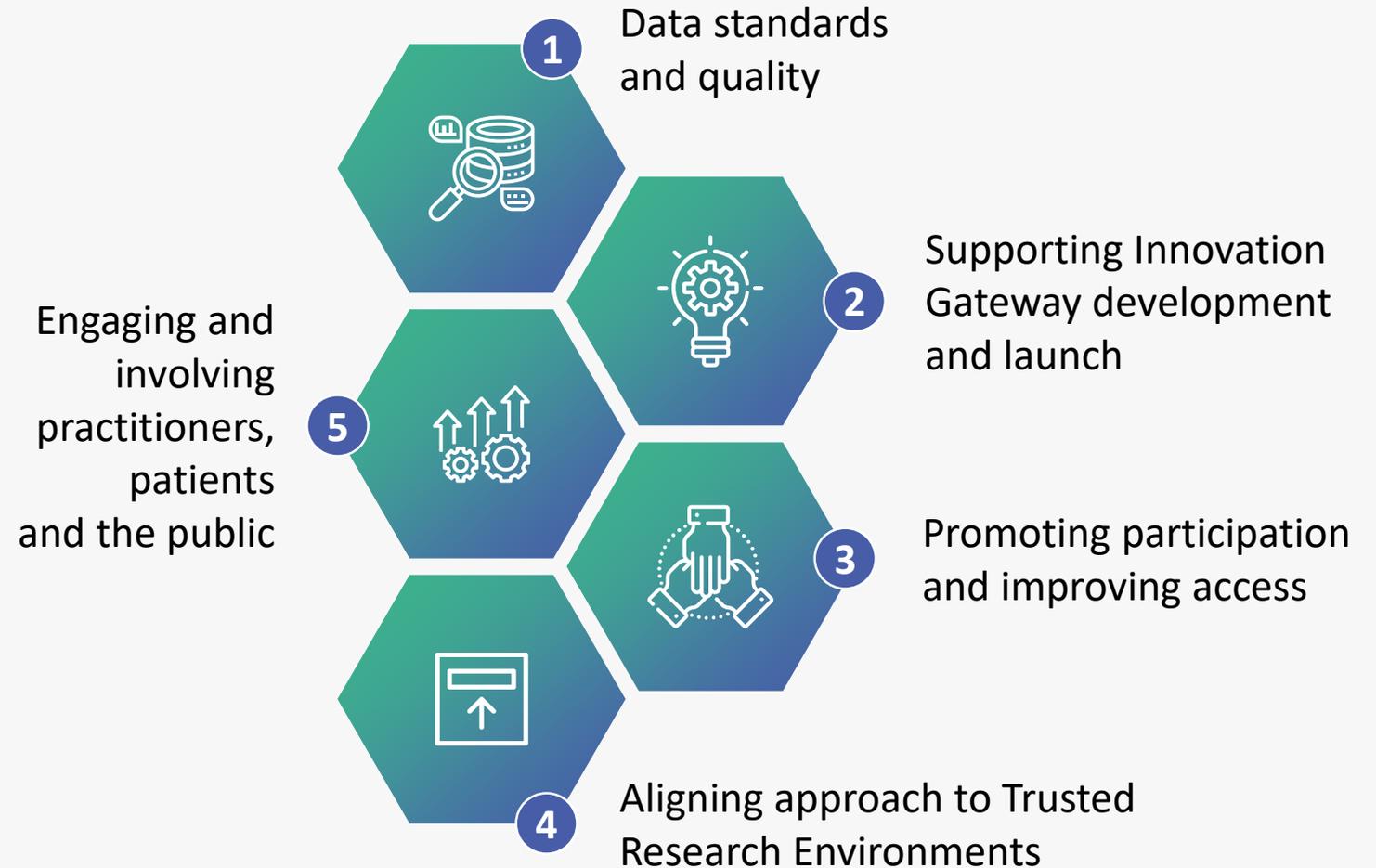
TRIALS DATA

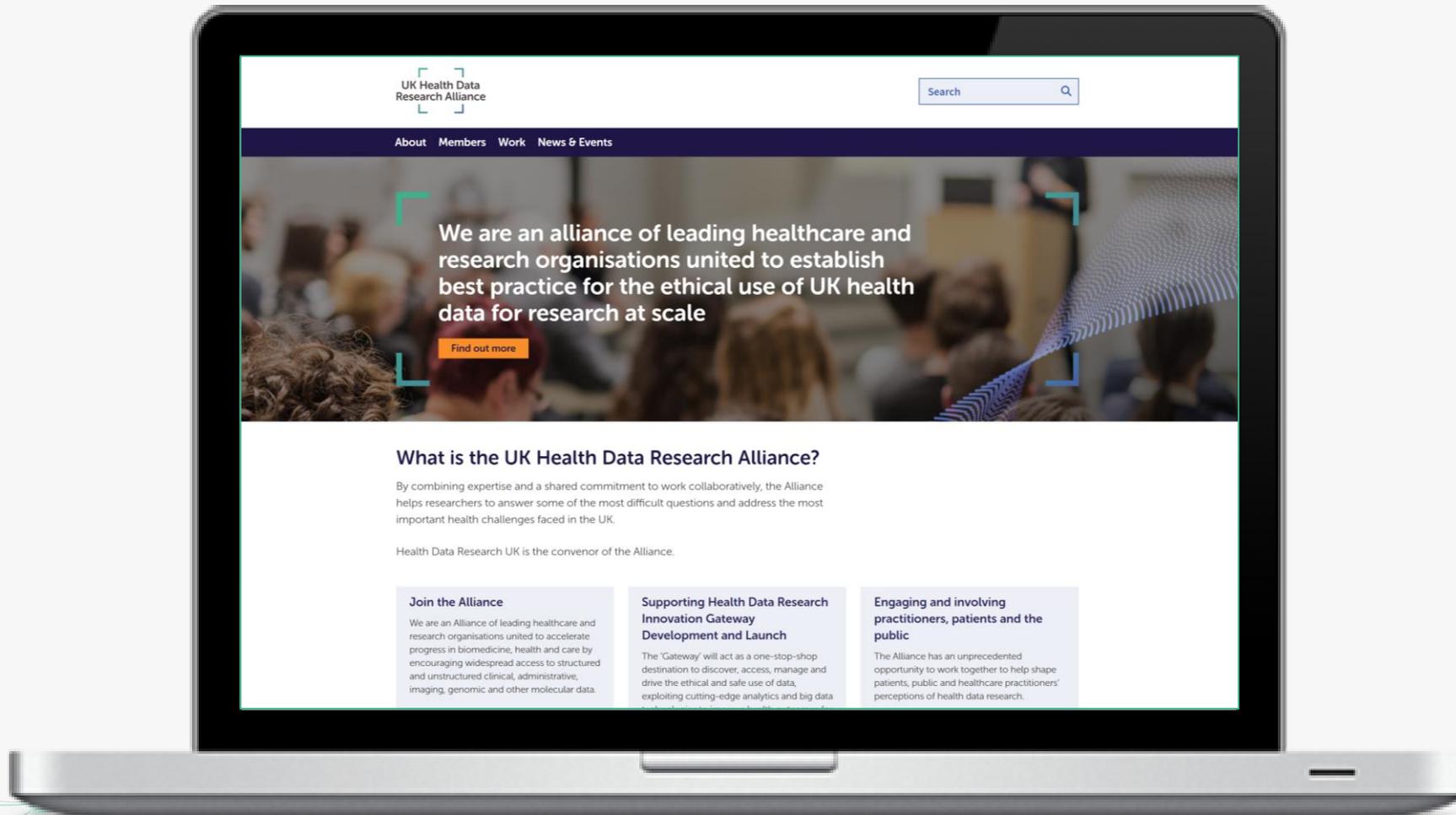
Convened by





## UK Health Data Research Alliance workstreams





# 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



**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

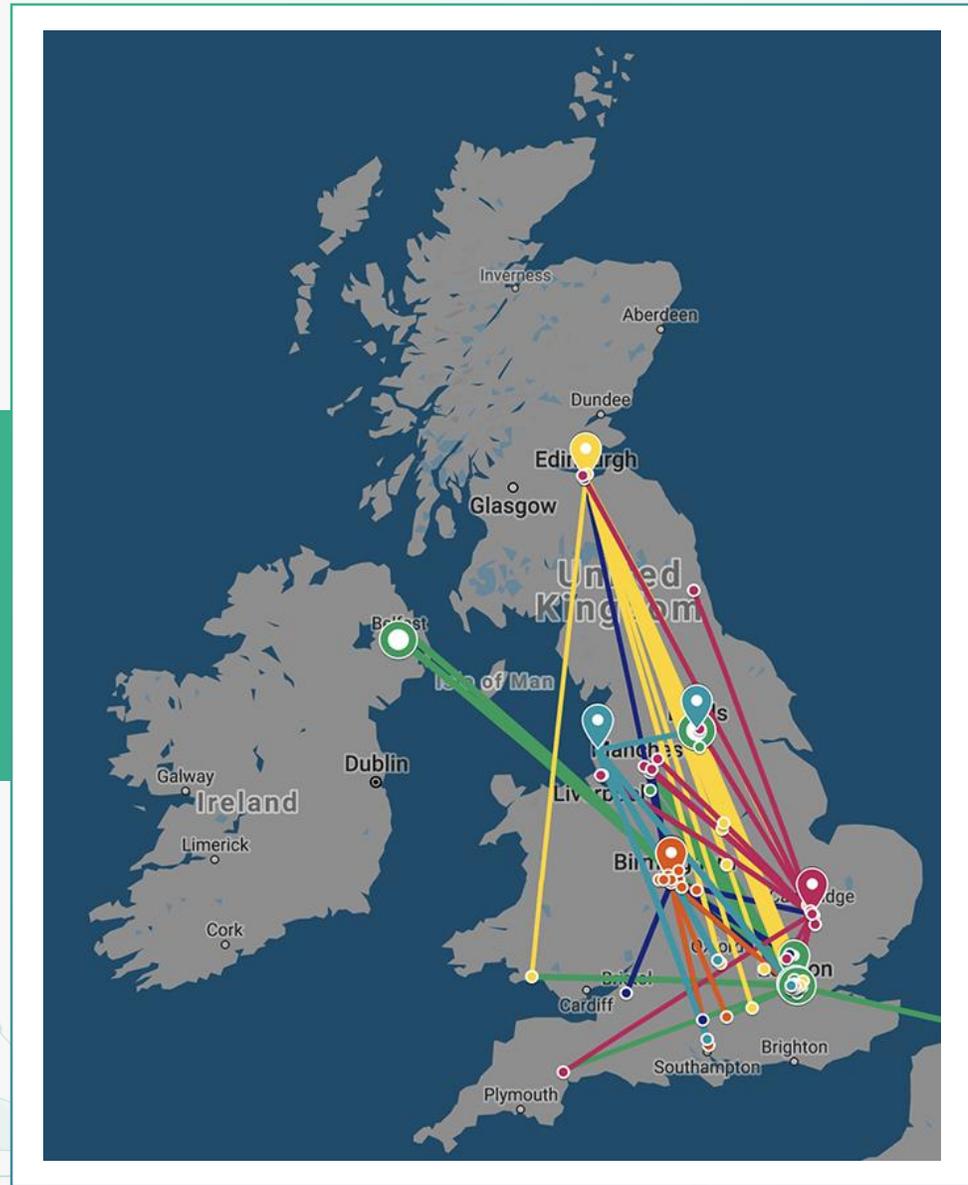
**NHS DigiTrial**

Health Data Research Hub for Clinical Trials

**PIONEER**

Health Data Research Hub for Acute Care





# Partnerships spanning across the UK

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# Health Data Research Innovation Gateway

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



  
**HEALTH DATA RESEARCH INNOVATION GATEWAY**  
Finding and accessing nationally aggregated, usable data

**DISCOVER**

**DE-IDENTIFY**

**LINK**

**ACCESS**

**ANALYSE**

**PHENOTYPE LIBRARY**

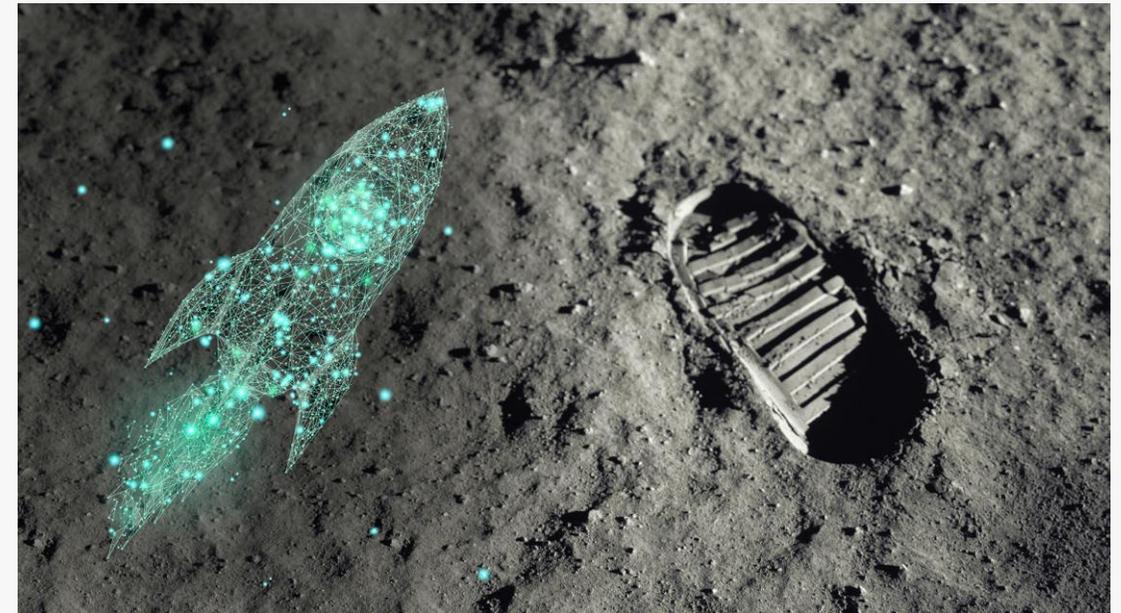
**LINK TO TRUSTED RESEARCH ENVIRONMENTS (SAFE HAVENS)**

Operated by

  
Health Data Research UK

## Health Data Research User Group – the Sandbox

- Use cases for products, services, innovations or knowledge that require access to large scale data to improve the health of patients and the population
- Supports the design of the infrastructure, and benefits from the overall programme
- Integrates and uses the full spectrum of the infrastructure, including the Alliance, Innovation Gateway and the newly selected Hubs

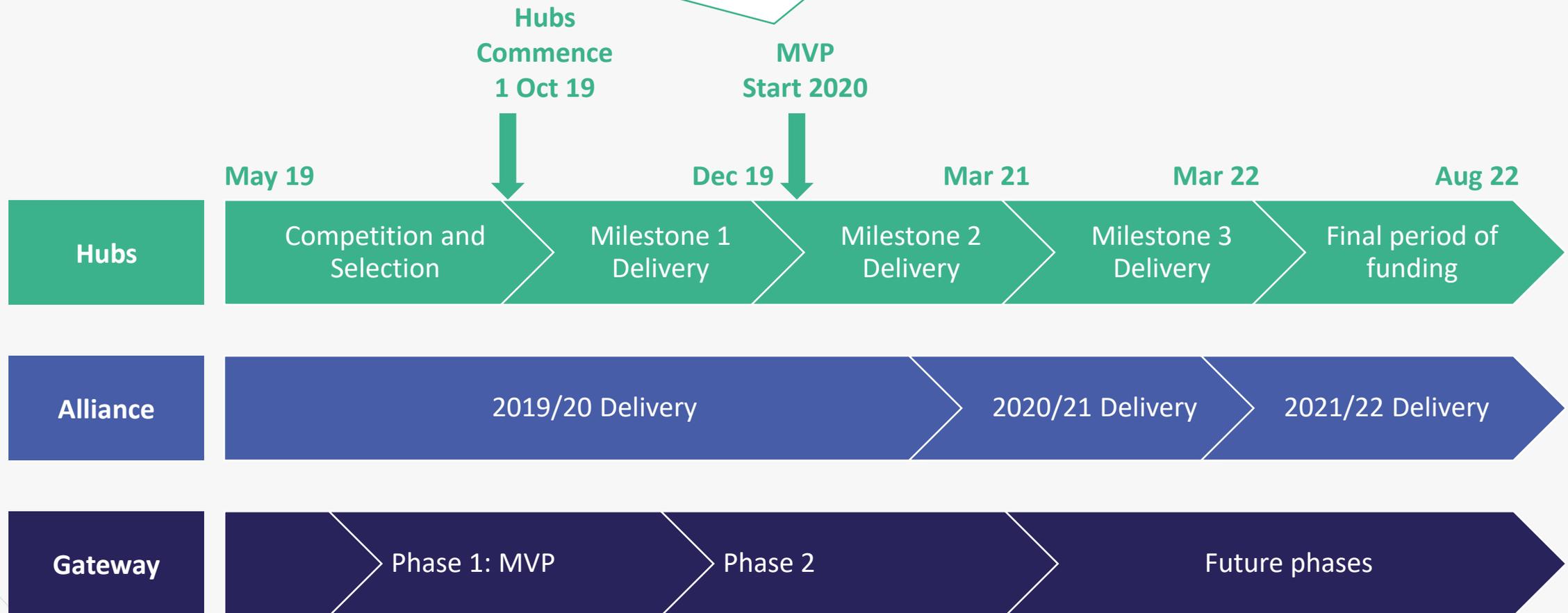


## Health Data Research User Group – the Sandbox

Project Title	Organisation
The Early Detection of Neurodegenerative diseases	Alzheimer's Research UK
HealthSpan™ and Healthy Lifespan® Index metric validation using anonymised linked, longitudinal data	Outcomes Based Healthcare
The Emergency Care Data Research Resource	University of Leicester
MendelScan: Rare disease EHR scanning platform for healthcare providers	Mendelian
Antidepressant response and usage profiles	University of Edinburgh
Long term health outcomes in the UK NCRI RAPID trial in early stage Hodgkin lymphoma: RAPID-digital	The Christie NHS Foundation Trust, Manchester, UK
MyDiabetesMyWay and MyDiabetesClinical	MyWay Digital Health

# Programme Roadmap

3 strategic areas: PPIE, Curation and Sustainability



## What this means for data access

In the first instance (MVP)

- Common portal to discover >300 datasets (metadata), including to existing linked datasets
- Access rights transparent to users and public
- Simple access request functionality to the custodians of the datasets

Over time, improvements including:

- Increased numbers of datasets, from more custodians, across health, care, social and environmental
- More linked datasets, with transparent and improved data quality
- Tools and approaches to improve data access (eg synthetic data, decision support tools for access management, enhanced Trusted Research Environments, training materials )
- Transparent use and access performance information

**Each of these improvements in data access developed in partnership with members of the public, practitioners, patients, custodians and data users**

## Thank you

### Find out more:

Health Data Research UK

Web: [hdruk.ac.uk](https://hdruk.ac.uk)

UK Health Data Research Alliance

Web: [ukhealthdata.org](https://ukhealthdata.org)

Social: @HDR\_UK

Email: [enquiries@hdruk.ac.uk](mailto:enquiries@hdruk.ac.uk)