

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

An introduction for Use My Data – All Talk and No Access?

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May 2019

@HDR_UK
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A national Institute for health data science



Launched in April 2018, our UK team of experts work together to use cutting-edge data science approaches to all types of health data to address the most pressing health research challenges facing the public.

We are funded by the 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 Wellcome.

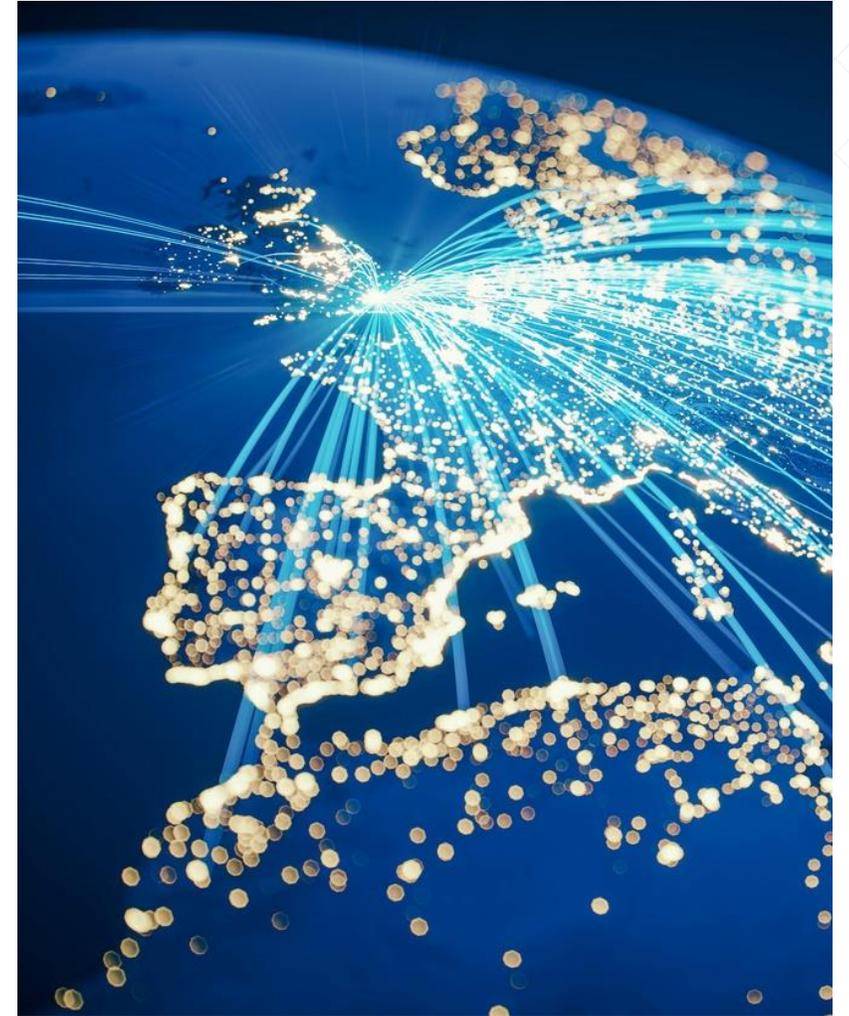


Our mission is to unite the UK's health data to make discoveries that improve people's lives



Our vision

Our vision is for large scale data and advanced analytics to benefit every patient interaction, clinical trial, biomedical discovery and enhance public health.



What this means for me and my family?



Earlier diagnosis and better treatment of diseases such as cancers



Better understanding of causes and treatments for children with rare diseases



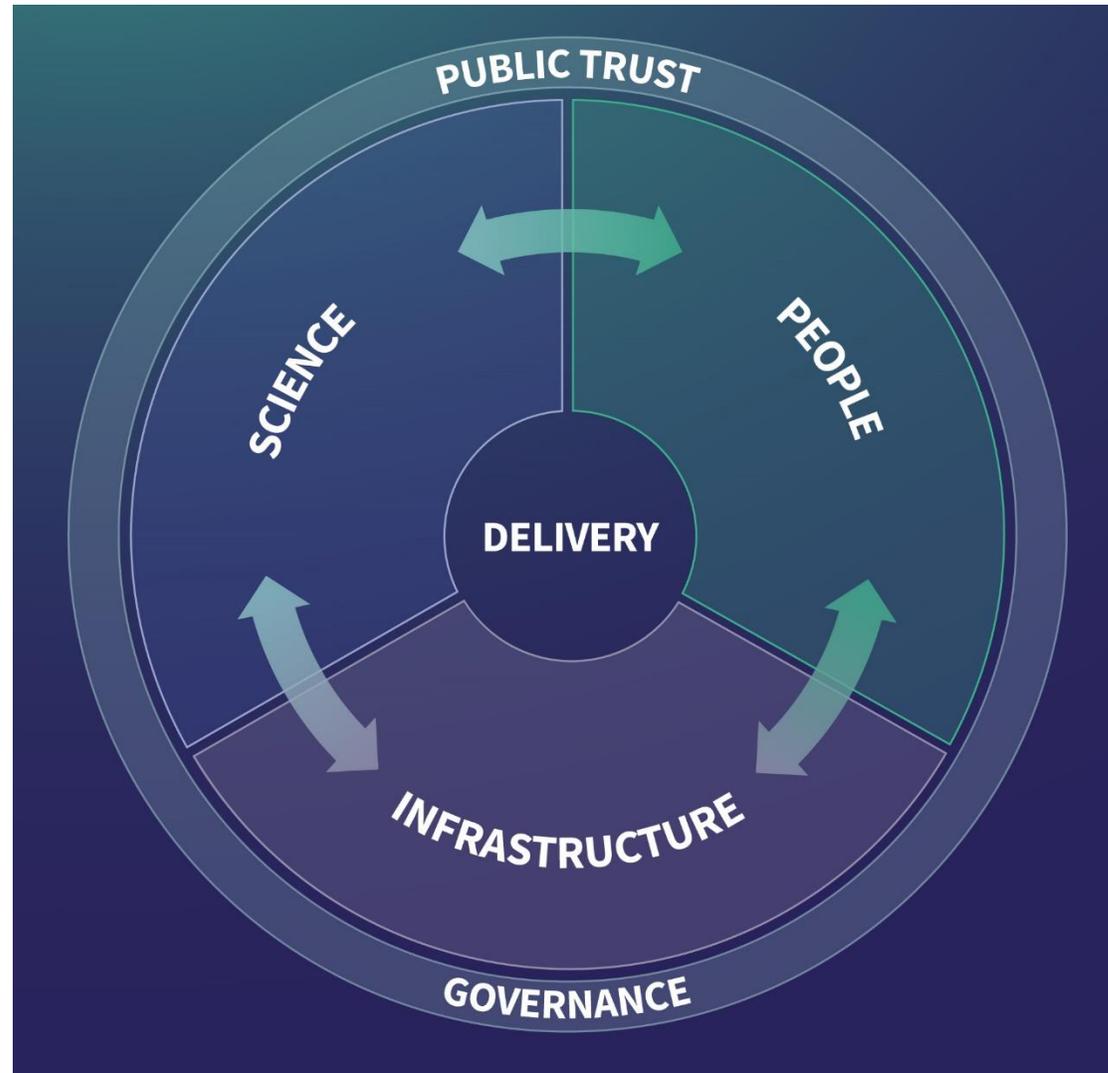
Finding previously unknown connections between different diseases via molecular data



Creating more effective and more targeted drugs

An opportunity to make a difference by donating our health data

We will deliver our mission through a united strategy

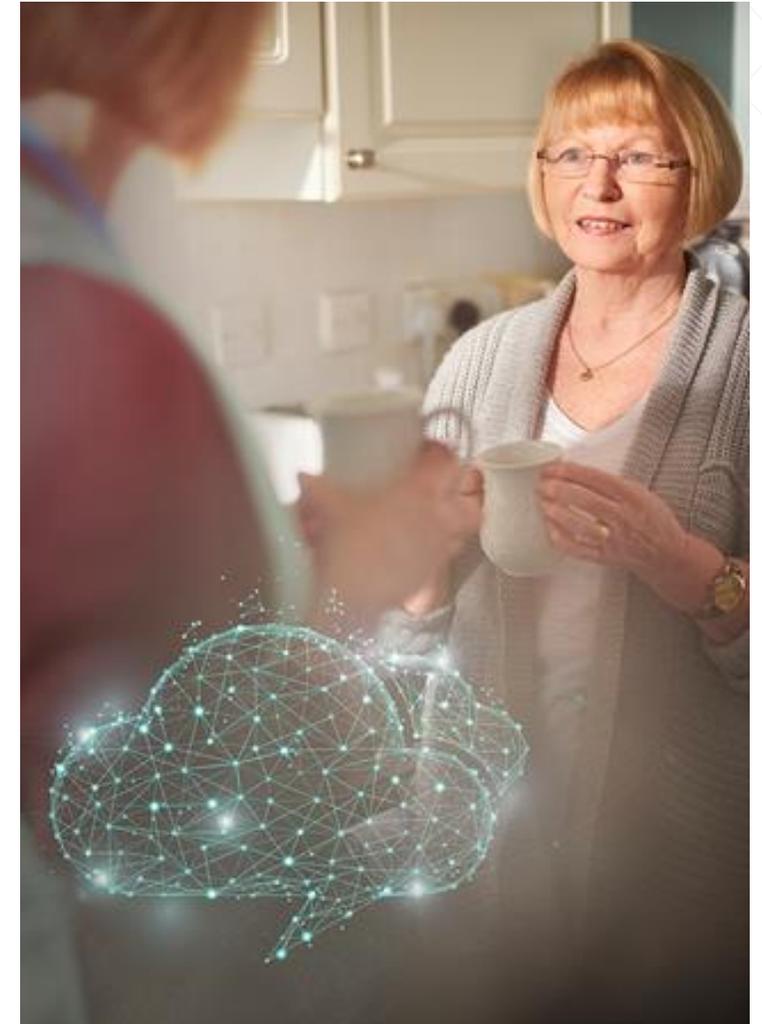


Public Engagement and Involvement

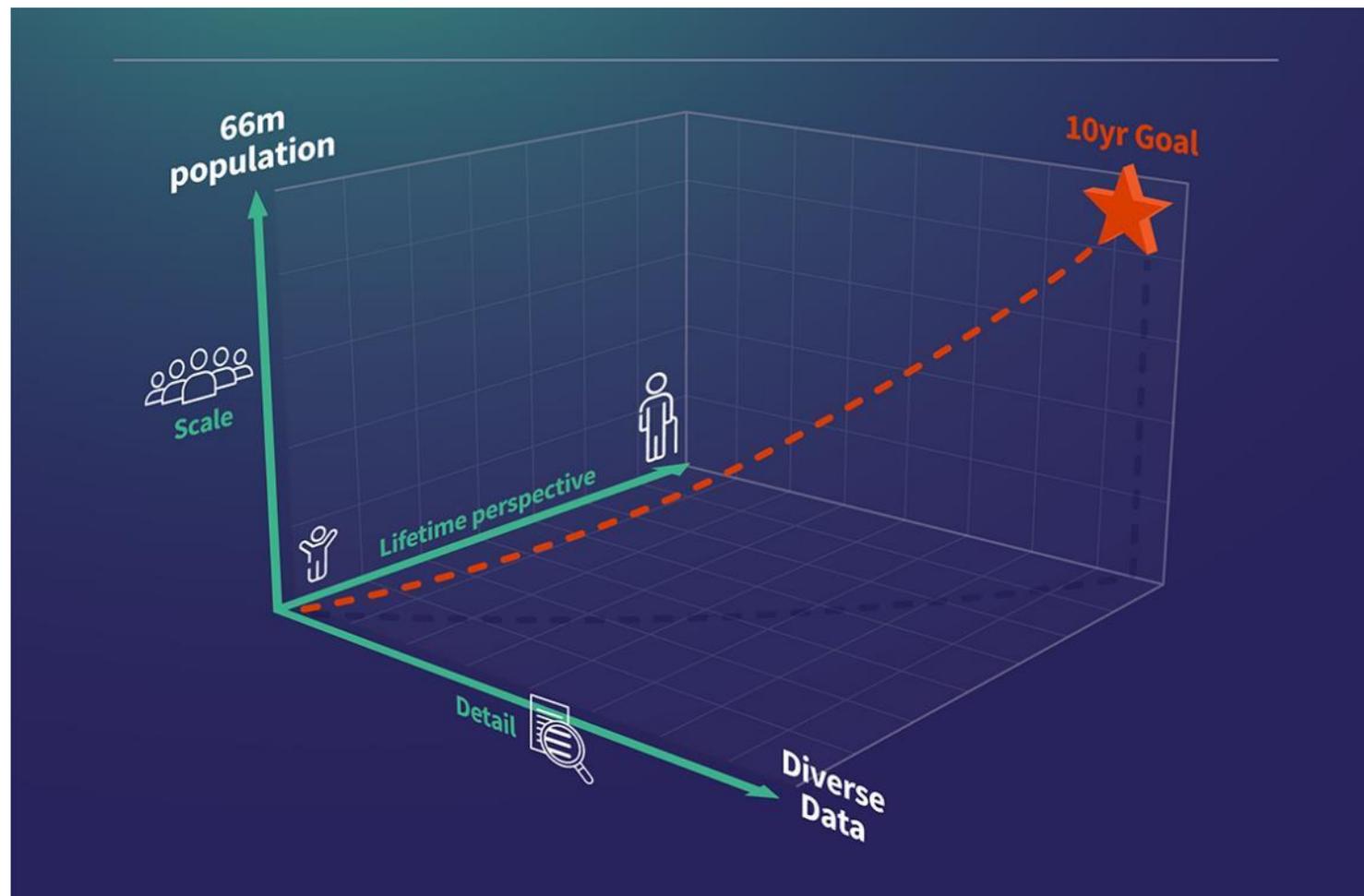
Ambition: We will encourage more effective health data science by involving users at all stages of the innovation process

Priorities:

- Patients and the public will inform our direction, policy, decisions, planning and delivery
- We will be transparent, open and accountable on how and why data are gathered, stored, secured, safeguarded, accessed, used and shared
- We will be innovative in our approach and use mechanisms and stories that help earn public trust



Science – Our 10-year ambition for scale

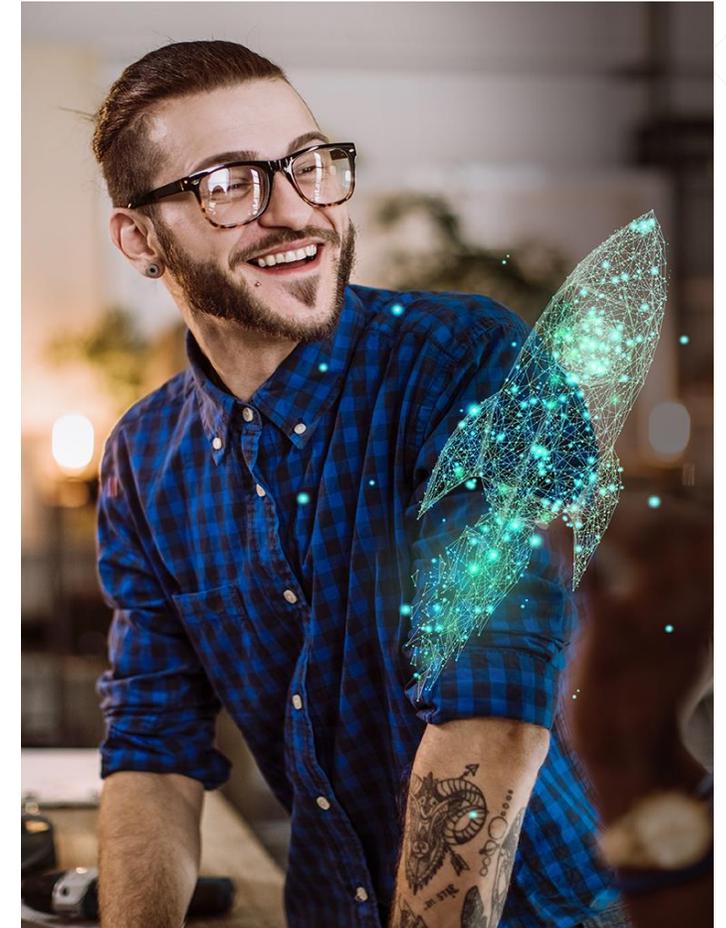


People – empowering health data scientists

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:

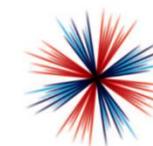
- School leavers – apprenticeships and undergraduate medical curricula
- Postgraduate – masters degree schemes and doctoral training programme
- Post doctoral – the NIHR/HDR UK Incubator in Health Data Science, career-break returner fellowships, co-funding with research councils and summer schools
- Supporting career pathways – career pathways for data science specialists, transition to and from industry, opportunities for continuing professional development



Infrastructure – Digital Innovation Hub Programme

Health Data Research UK is leading the delivery of the DIH Programme on behalf of UK Research and Innovation

- Part of the Industrial Strategy Challenge Fund (ISCF) Data to Early Diagnosis and Precision Medicine Challenge.
- Four-year programme launched in September 2018
- Designed to address the current fragmented structure and inconsistent approach to health data research in the UK
- Ensure that the enormous potential value of the UK's health data assets can be realised.



**INDUSTRIAL
STRATEGY**

UK Research
and Innovation



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

← **TRUSTWORTHY USE OF DATA** →



PATIENTS



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

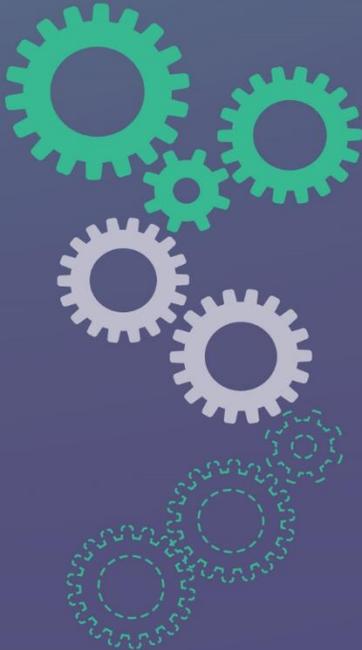
NHS DATA
Current members include:

COHORT, TRIALS AND REGISTRY DATA
Current members include:

Convened by



DIGITAL INNOVATION 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



USERS:
Researchers, Industry, NHS, Charities and Government

← **PATIENT AND PUBLIC BENEFIT** →

Today we are launching a competition for up to 5 hubs

- £22million competition for up to five Digital Innovation Hubs
- Make datasets accessible
- Curate new datasets for research and innovation
- Benefits to NHS for the greater public good
- Partnerships NHS, academia, industry and other partners
- 2 hub themes:
 - Disease focused
 - Clinical Trials and Real World Evidence (RWE)



Hubs will contribute to a secure, joined-up and UK-wide offer for industry and researchers



Local Health and Care Records



National Data Guardian



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

NHS DATA
Current members include:

- NHS England
- NHS SCOTLAND
- HSC Health and Social Care
- Public Health England
- GIG CYMRU NHS WALES
- NHS Digital

COHORT, TRIALS AND REGISTRY DATA
Current members include:

- CPRD
- Genomics england
- RCGP Royal College of General Practitioners Research & Surveillance Centre

Convened by

- HDRUK Health Data Research UK

Sprint Exemplar Projects

Sprint Exemplar Innovation Programme
MyEyeSite
MyEyeSite: a feasibility study and prototype for a patient-owned repository of rare-disease clinical and genetic data using inherited retinal disease as a paradigm

Digital Pathology, Imaging and AI centres of excellence

Hubs will deliver benefits to patients, industry and academic researchers

- Faster, more accurate and less expensive research and development
- Identification of new therapeutic targets or application of drugs
- Industry, large and small, to better develop, test and deploy new products, devices, tools and AI technologies in health and care earlier



A focus on patient and public benefit

* use MY data

Case Study - Patient Advocate Stories

Ann Muir
Patient Advocate, use MY data

My name is Ann Muir and I'm a laryngectomy patient.

Our cancer is the Cinderella of cancers in terms of funding and research. So it is vital that our data is used.

It may not help me, but may help others prevent their cancers in the future. That is why donating your data is so important. It could save future generations suffering some of the diseases in today's world.

I acknowledge that things don't always go right, but by sharing data, it is the only way to make progress in saving lives.

Joining use MY data has helped me understand better the importance of my data. Research and all data should be shared.



* use MY data

Case Study - Patient Advocate Stories

Hilary Stobart
Patient Advocate, use MY data

I was successfully treated for breast cancer in 2009. I knew the type of treatment that I had depended so much on the data of patients who went before me.

By 2009 it was known that I didn't need chemotherapy for my type of breast cancer; fifteen years earlier I would have been given it anyway.

I am so grateful for other people's data and so I am so pleased to know that my own data is stored in cancer registries to help others.



Find out more



For further information:

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Email: enquiries@hdruk.ac.uk

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

