



Health Data Research UK (HDR UK) & HDR UK Midlands

Kevin Dunn BA (Hons) MBA

Senior Programme Manager

University of Birmingham & University Hospitals Birmingham NHS Foundation Trust

<https://www.hdrmidlands.org.uk/>



Kevin Dunn – The career journey to date...

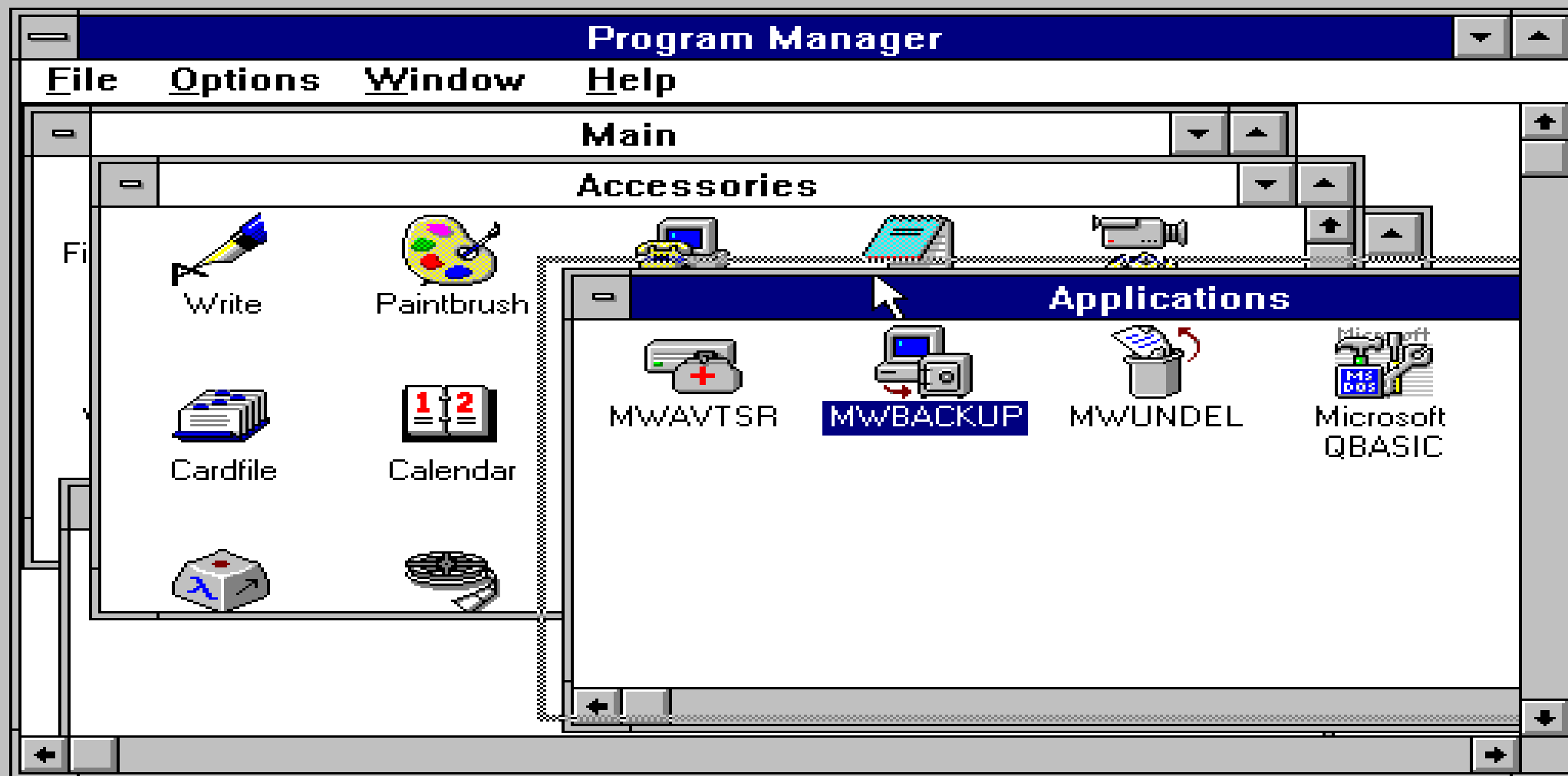


- YTS – Clerical Trainee - The Royal Wolverhampton Hospitals NHS Trust – **GP MDB / PMS – (PAS)**
 - Renal Unit Clerk – The Royal Wolverhampton Hospitals NHS Trust – **Clinical Data Input**
 - Research Data Manager – Black Country Cancer Research Network - **Database Development**
 - Cancer Information Officer – The Royal Wolverhampton Hospitals NHS Trust – **Cancer Waits, CMDs, National Audits, Coding, transfer data, data sharing (video conferencing)**
 - Research Coordinator – The Royal Wolverhampton Hospitals NHS Trust – **Link data, screen + track**
 - NHS R&D Manager – The Royal Orthopaedic Hospital NHS Foundation Trust - **National Ca. MDT, Ops**
 - Head of Operations - West Midlands Academic Health Science Network - **Regional Partnerships and Events**
 - HDR UK Programme Manager (Midlands) – University of Birmingham – **Network Development, SharePoint Collaborate**
- 

How it all started...

- 17th August 1998
- YTS [NVQ II Business Administration]
- Working in Clinical Support Unit
- £35 week







HDRUK

Health Data Research UK



NIHR | National Institute for
Health and Care Research



Partnerships at Scale

Our initial investment supports six 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)

The HDR UK Midlands Team



Simon Ball



Anthony Brookes



George Gkoutos



Kevin Dunn



Phil Quinlan



Theo Arvanitis



Keith Abrams



UNIVERSITY OF
BIRMINGHAM



UNIVERSITY OF
LEICESTER



The University of
Nottingham

THE UNIVERSITY OF
WARWICK



University Hospitals
Birmingham
NHS Foundation Trust



OXFORD



SCOTLAND



CAMBRIDGE



WALES & NI



LONDON



MIDLANDS

“Breathing the Same Air”

HDR UK Directors & National Strategic Priorities

- National and regional responsibility
- Senior Scientific Leadership Committee

Simon Ball
Midlands



John Danesh
Cambridge



Harry Hemingway
London



Martin Landray
Oxford



Ronan Lyons
Wales/NI



Cathie Sudlow
Scotland



Beter Care

Understanding
Cause of
disease

Human
Phenome

Clinical Trials

Public Health

Applied
Analytics

Health Data Research Hubs



Page

BREATHE – The Health Data Research Hub for Respiratory Health

BREATHE will enable high quality research and cutting-edge innovation to improve the lives of people living with respiratory conditions, such as asthma and chronic obstructive pulmonary disease...



Page

DATA-CAN – The Health Data Research Hub for Cancer

DATA-CAN aims to transform how cancer clinical data across the UK can be used to improve patient care.



Page

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

This Hub will work with data from the NHS in London and Manchester, with appropriate controls and consent, to support research to find new ways to diagnose and treat disease and make care for...



Page

G.I. Know – The Health Data Research Hub for Inflammatory Bowel Disease

The Centre will use data to address the urgent need to better understand why patients with Crohn's Disease and Ulcerative Colitis respond differently to treatments in order to improve people's...



Page

INSIGHT – The Health Data Research Hub for Eye Health

INSIGHT is focused on eye disease and its application to wider health, including diabetes and dementia. It will use anonymised large-scale data and advanced analytics, including artificial...



Page

NHS DigiTrial – The Health Data Research Hub for Clinical Trials

The Hub will focus on the development of a foundation service to improve the assessment of clinical trial feasibility - supporting improved planning and delivery of clinical trials in the UK



Page

PIONEER – The Health Data Research Hub for Acute Care

By integrating information about how acutely unwell people access and use health services – such as from community health, the ambulance service and hospitals, PIONEER will allow innovative...

HDR UK Better Care Partnership

Oxford

London

Cambridge

Scotland

Wales & NI

Northern

South West



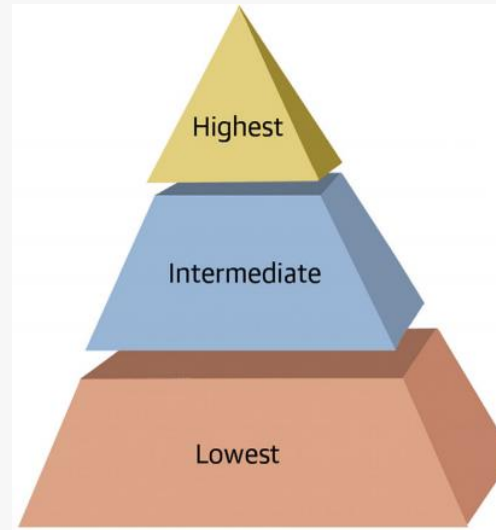
Midlands



Hypertrophic cardiomyopathy (HCM)

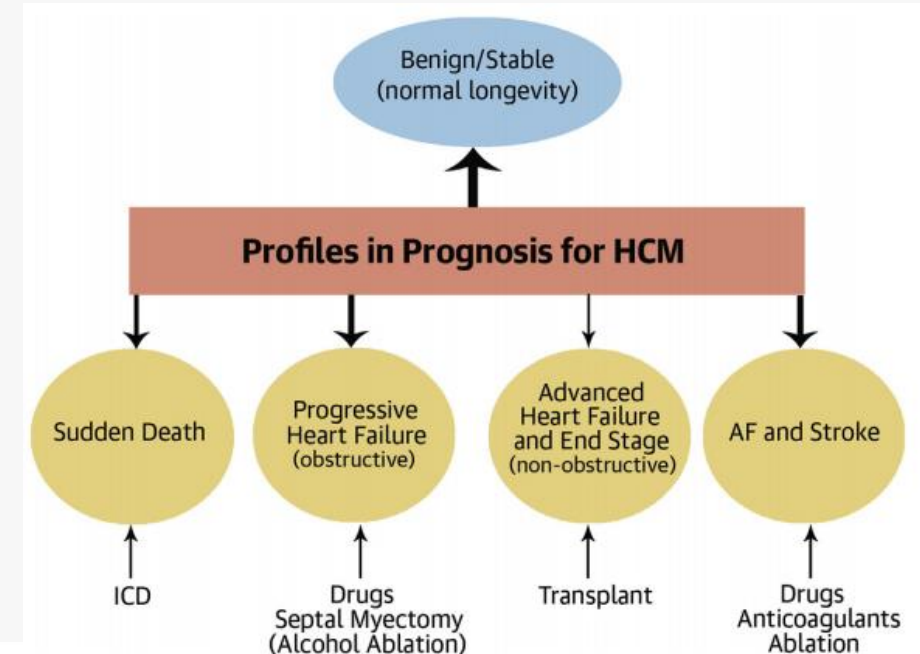


Unexplained thickening of the heart
Inherited cardiac condition
Affects 1 in 500
Risk of:
Sudden death
Heart Failure and AF



Risk stratification algorithm

- ICD10 codes
- Lab and Imaging Data
- Medication
- Procedures
- Outcome





Second 5 years - QQ2

Our mission

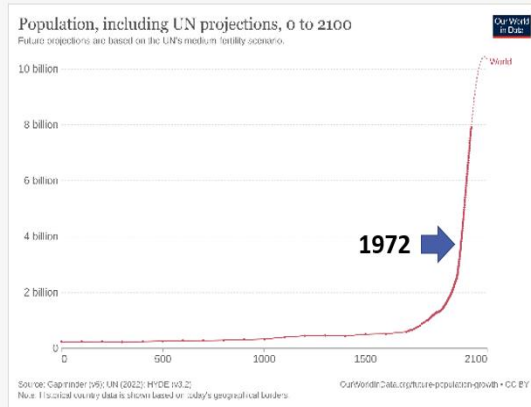
HDR UK's mission is to unite the UK's health data to enable discoveries that improve people's lives

Our 20-year vision is for large scale data and advanced analytics to benefit every patient interaction, clinical trial, biomedical discovery and enhance public health.

Core funders



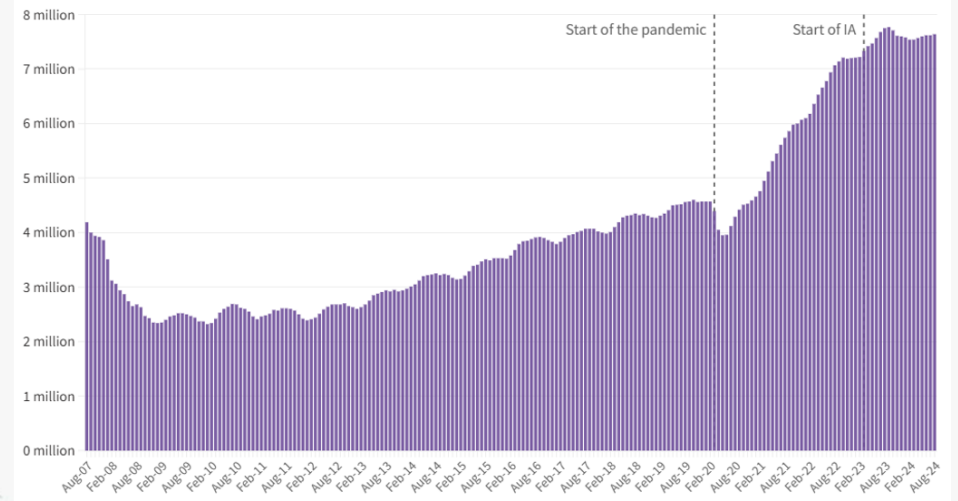
The pace of change Global population – now exceeds 8 billion



See it in real time – <https://www.worldometers.info/world-population/>

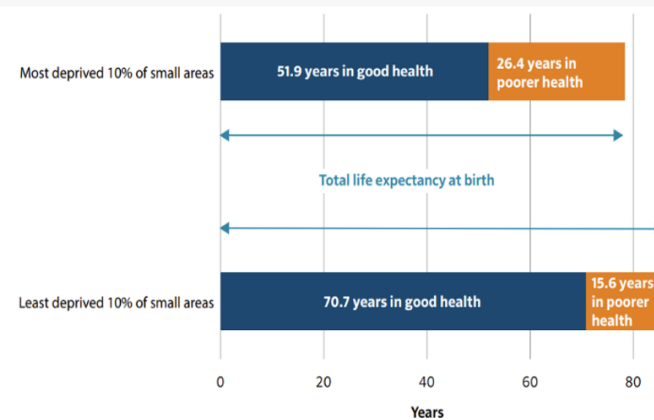
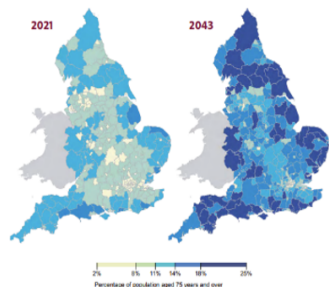
The care context – waiting lists

Total NHS waiting list for consultant-led elective care
August 2007 to August 2024



Pace of change – inequalities

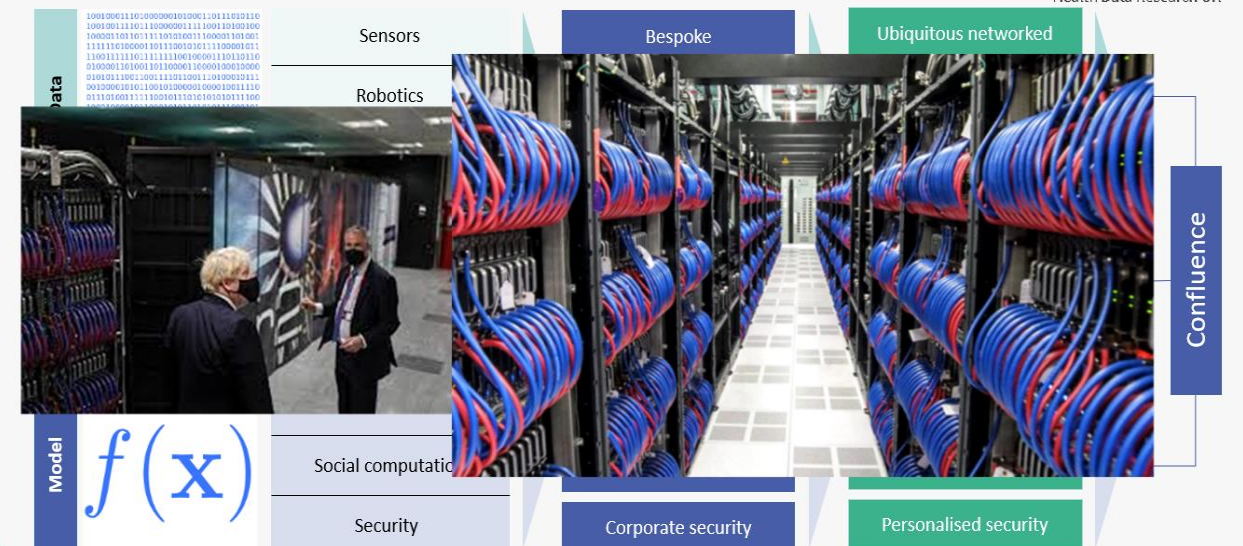
Chief Medical Officer's Annual Report 2023 Health in an Ageing Society Executive summary and recommendations



Source data: Office for National Statistics (ONS), Health state life expectancies by national deprivation deciles, England: 2018 to 2020*

New technologies are accelerating at pace

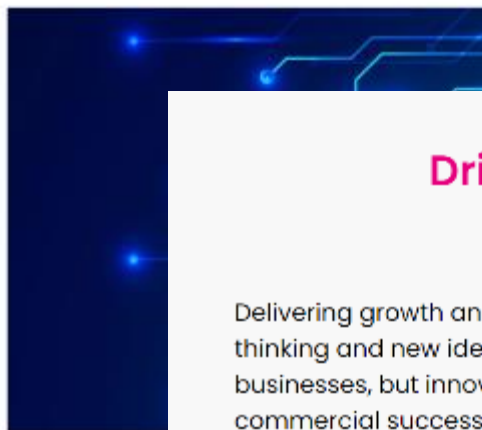
Option



Policy paper

Chair's Summary of the 2024 £100 million investor Institute announced

Published



7 March 2024

The Chancellor has
Turing Institute, the
Artificial Intelligence

Dri

Delivering growth and
thinking and new ideas
businesses, but innova
commercial success
make Britain the best

We will ensure our in
of the **Artificial Intellig**
to new datacentres. I
bring together existin
data-driven public se
safeguards and ensu

Labour's five missions to rebuild

1) Kickstart economic growth

to secure the highest sustained growth in the G7 – jobs and productivity growth in every part of the country, for everyone, not just a few, better off.

2) Make Britain a clean energy superpower

to cut bills, create jobs and deliver security with clean carbon electricity by 2030, accelerating to net zero

3) Take back our streets

by halving serious violent crime and raising confidence in police and criminal justice system to its highest level

4) Break down barriers to opportunity

by reforming our childcare and education systems: there is no class ceiling on the ambitions of young Britain.

5) Build an NHS fit for the future

that is there when people need it; with fewer lives lost to the biggest killers; in a fairer Britain, where everyone lives longer.

FINANCIAL TIMES

UK COMPANIES TECH MARKETS CLIMATE OPINION LEX WORK & CAREERS LIFE & ARTS HTSI

UK politics + Add to myFT

AI bill and votes at 16 among measures missing from King's Speech

Dedicated bill on tech regulation had been expected by the industry



Science secretary Peter Kyle is hopeful an AI measure could yet be finalised and included later in the first session of parliament. © Tejas Sandhu/PA

Anna Gross, George Parker and Lucy Fisher JULY 17 2024

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Uniting the UK's Health Data: A Huge Opportunity for Society



Prof Cathie Sudlow

A review of the UK health data landscape commissioned by the Chief Medical Officer for England, the UK National Statistician and NHS England's National Director for Transformation

November 2024

#SudlowReview

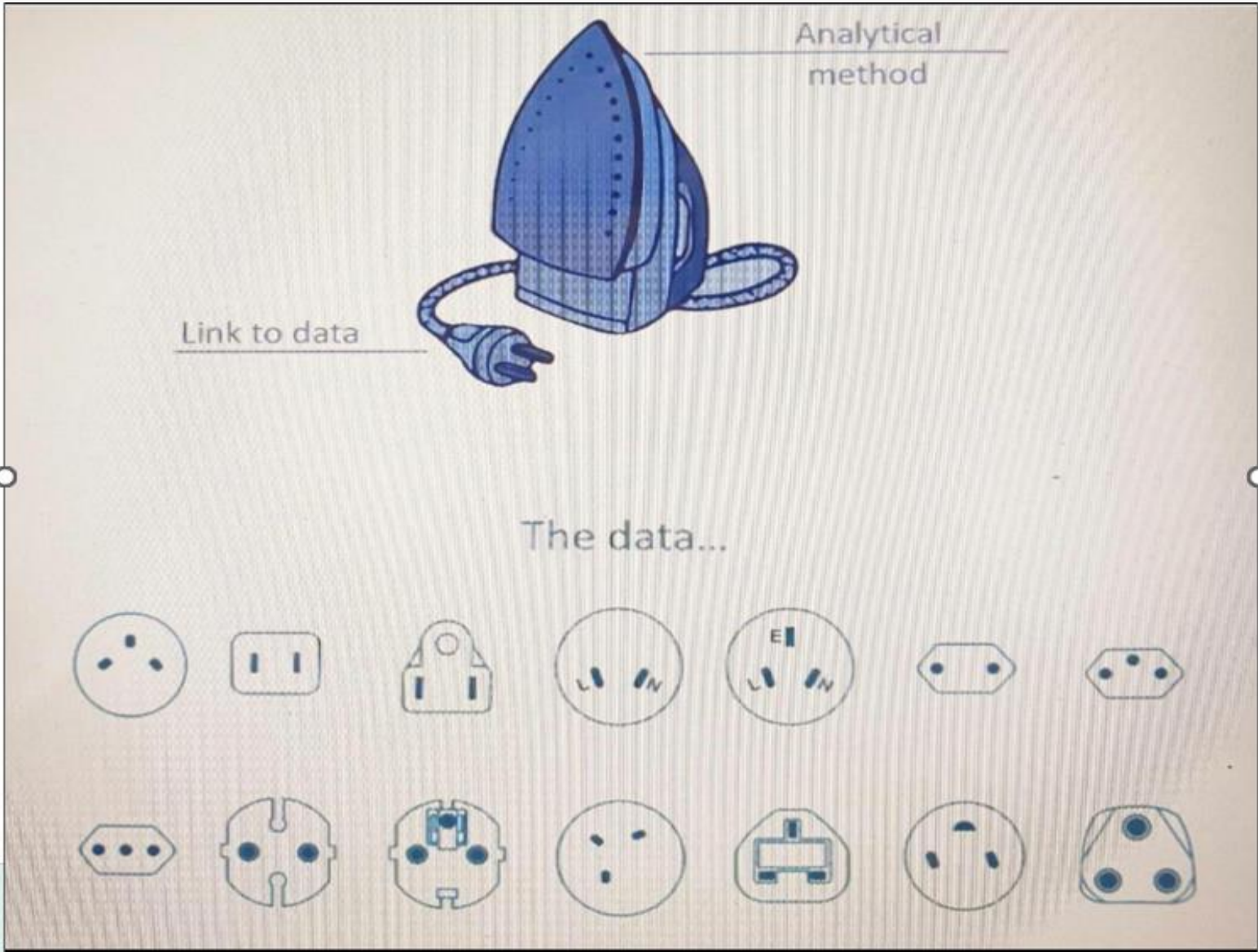
Key points

- Health data is used safely every day to improve people's health and lives
- People overwhelmingly support use of their health data to benefit themselves and others
- The UK has abundant sources of health data, from the NHS and beyond
- Transformational insights come from linking different sources of data together
- But there are many obstacles and delays to access, link and analyse health data
- These barriers arise from the UK's complex and inefficient data systems
- They prevent or delay crucial analysis and research about health conditions affecting millions of people across the UK
- We need to recognise the UK's health data as **critical national infrastructure**.

Recommendations

- 1) Coordinated strategy for England's health data as a **critical national infrastructure**
- 2) Establish a **national health data service** for England with senior accountable leadership
 - Single national health data access system
 - Streamlined and standardised data governance and access
 - A national system for general practice data for the full range of beneficial uses
 - Improve and accelerate access to other major national and regional NHS data assets
 - Transform access to data from other sectors linked to healthcare data at national scale
- 3) Co-ordinated engagement with patients, public, health professionals, policy makers and politicians
- 4) UK-wide approach for data access processes and proportionate data governance
- 5) UK-wide system for standards and accreditation of secure data environments holding health data

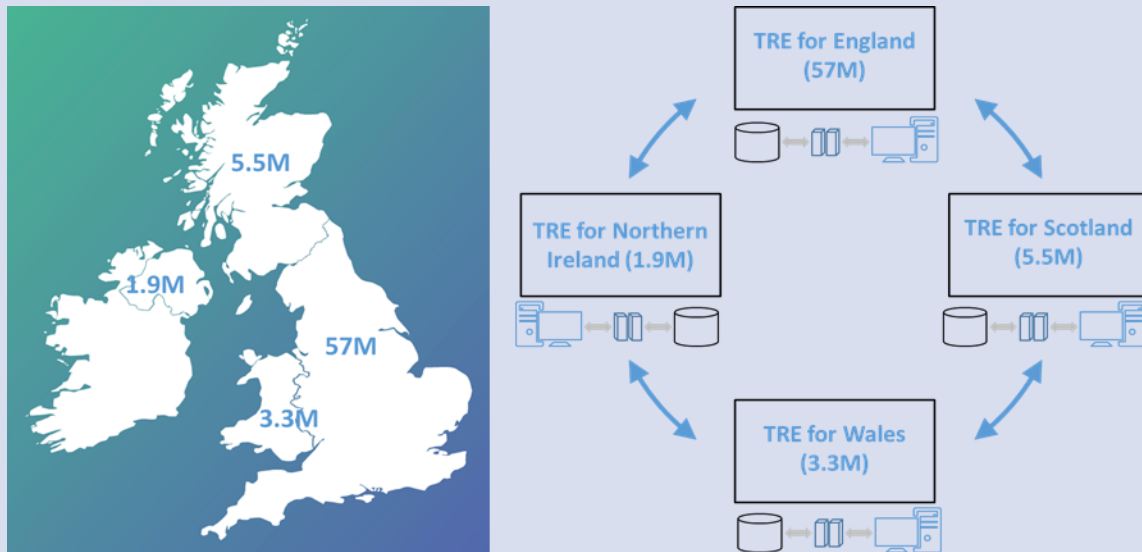
But in health - there is a lot to do to “sort the data”



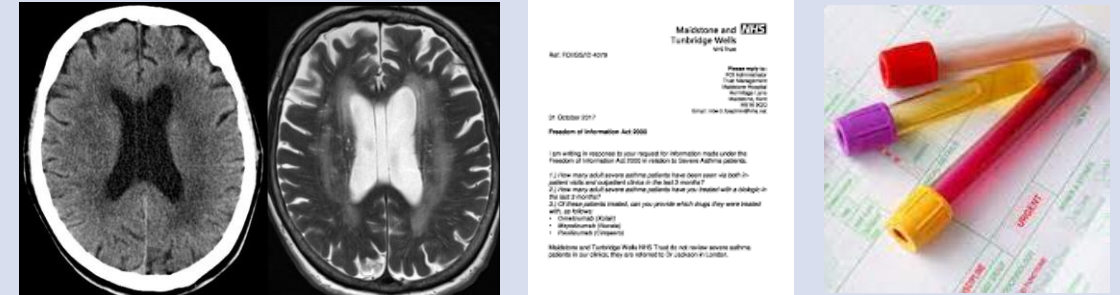
1. Accelerate Trustworthy Data Use

Through a national data strategy

NHS: NATIONALLY COLLATED, POPULATION-WIDE DATA



NHS: REGIONAL DATA



NON-NHS: HEALTH-RELEVANT ADMINISTRATIVE DATA

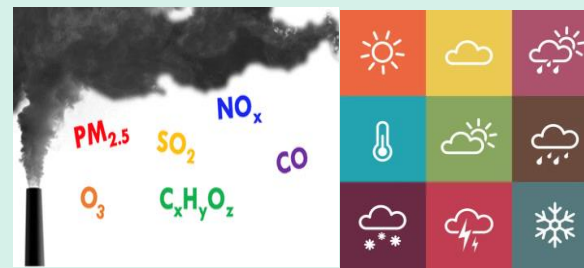
Census, education, disability, income...



PERSONAL MONITORING DATA



ENVIRONMENTAL DATA



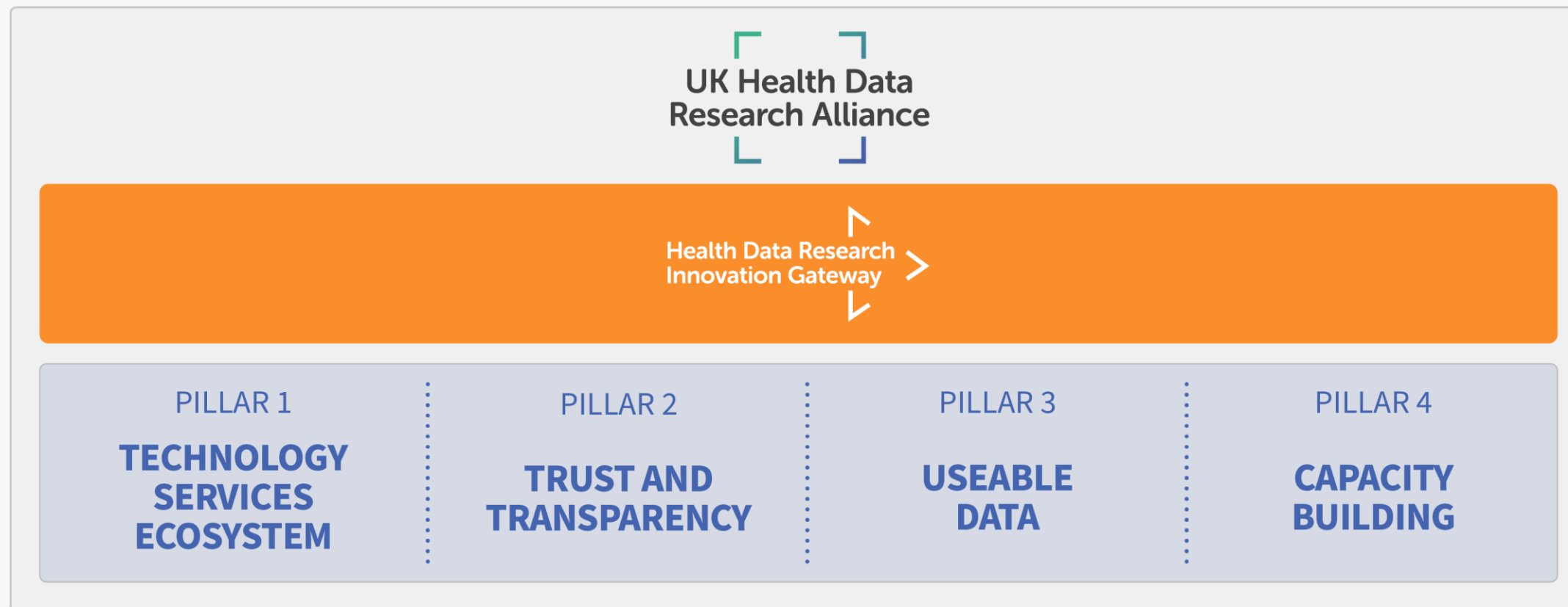
RESEARCH-GENERATED DATA

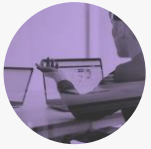
Longitudinal cohorts & clinical trials, e.g.



1. Accelerate Trustworthy Data Use

...and by assembling advanced infrastructure and services



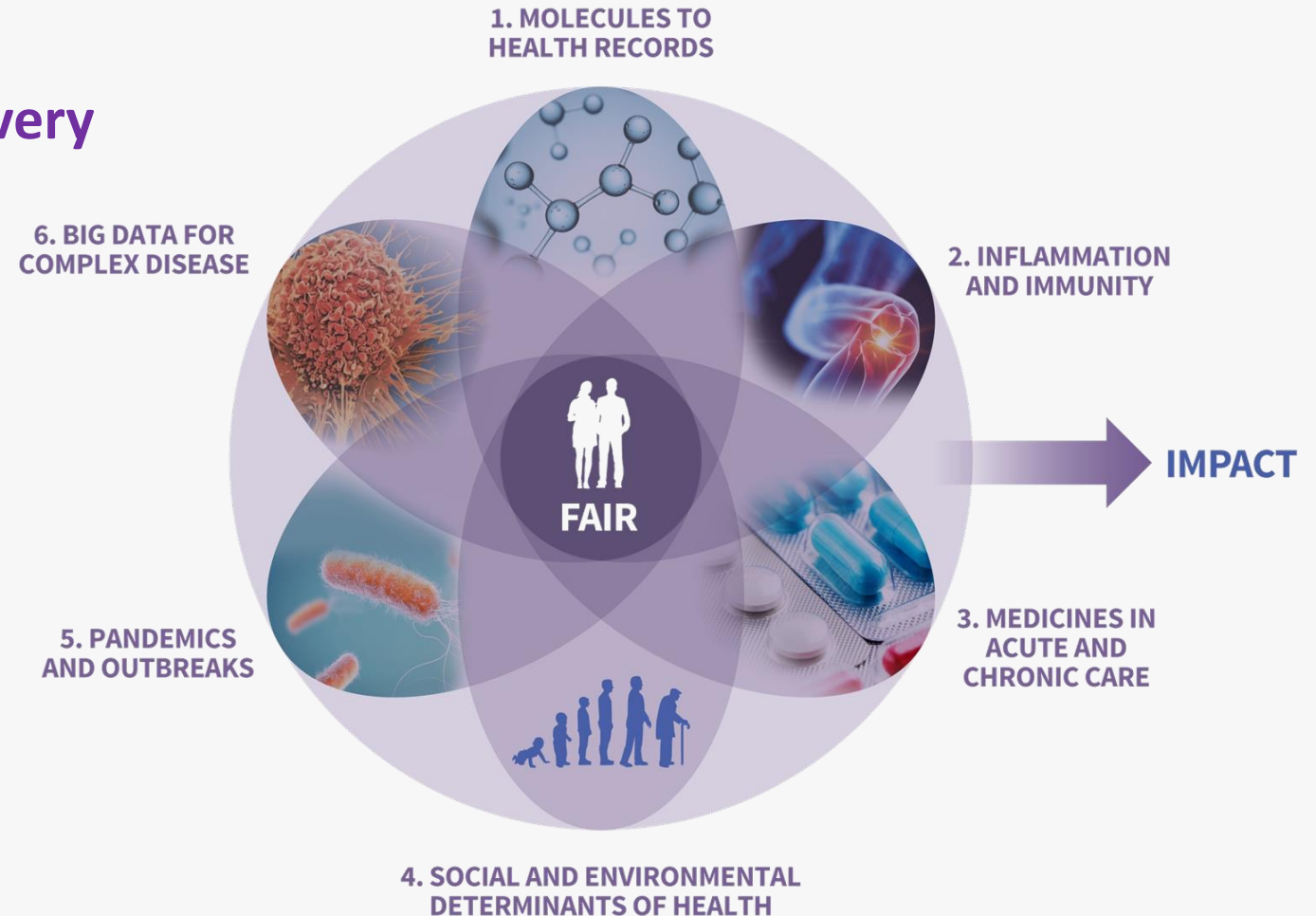


2. Empower Researchers

Valuing people with diverse perspectives committed to **open and team science** to **advance scientific discovery** and deliver **patient and public benefit**.

Driver Programmes

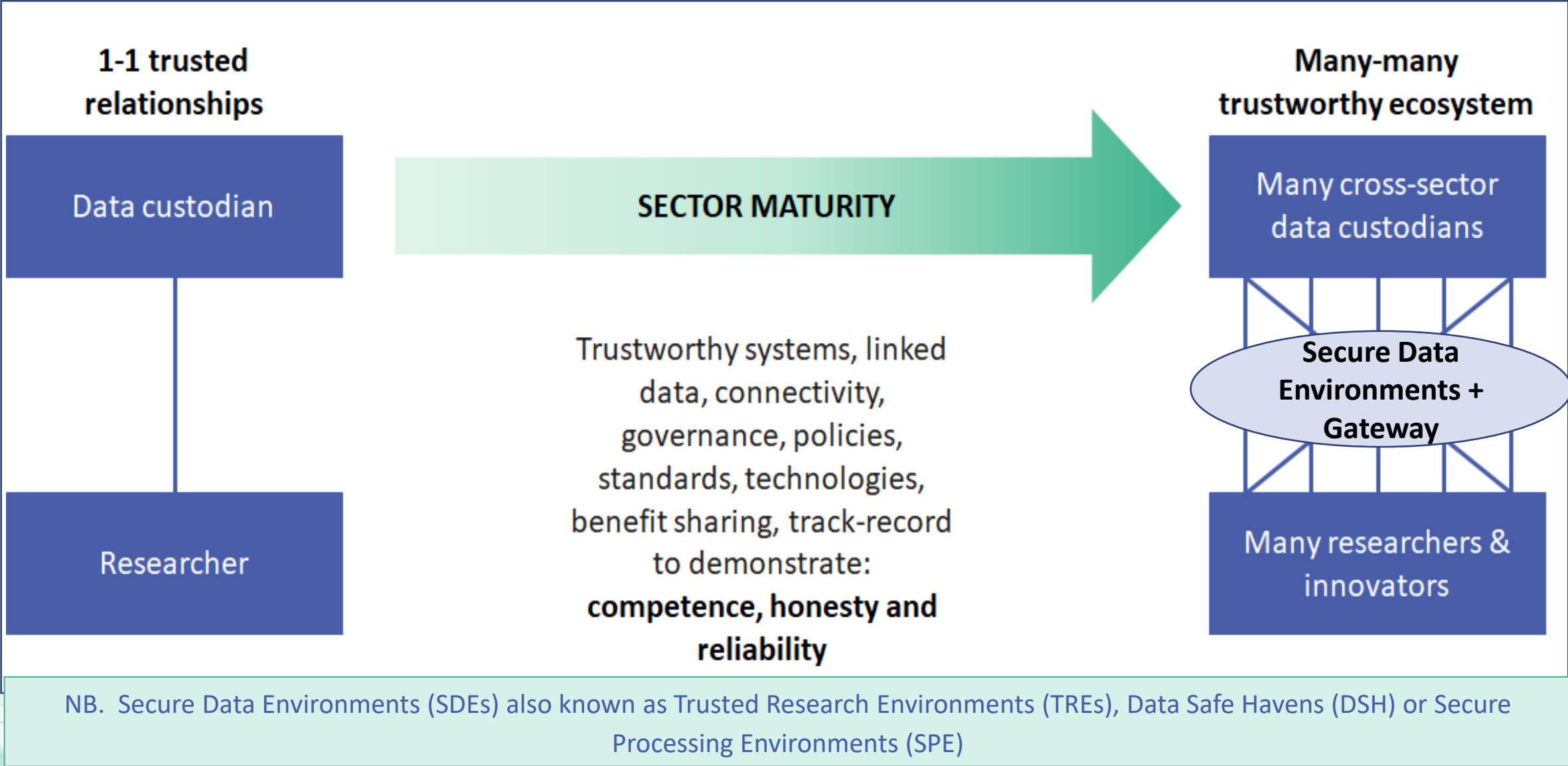
- Driving the design and delivery of a world-leading health data infrastructure
- Generate UK-wide 'research-ready' data foundations for wider re-use
- Deliver health & care impact



The challenge! Working in partnership across the UK and globally



Realising the potential of UK's multimodal longitudinal health records across 67m people requires a trustworthy data and research ecosystem





National Scale Data for R&D

A single programme delivering access to 55 million population scale, whilst nurturing regional innovation.

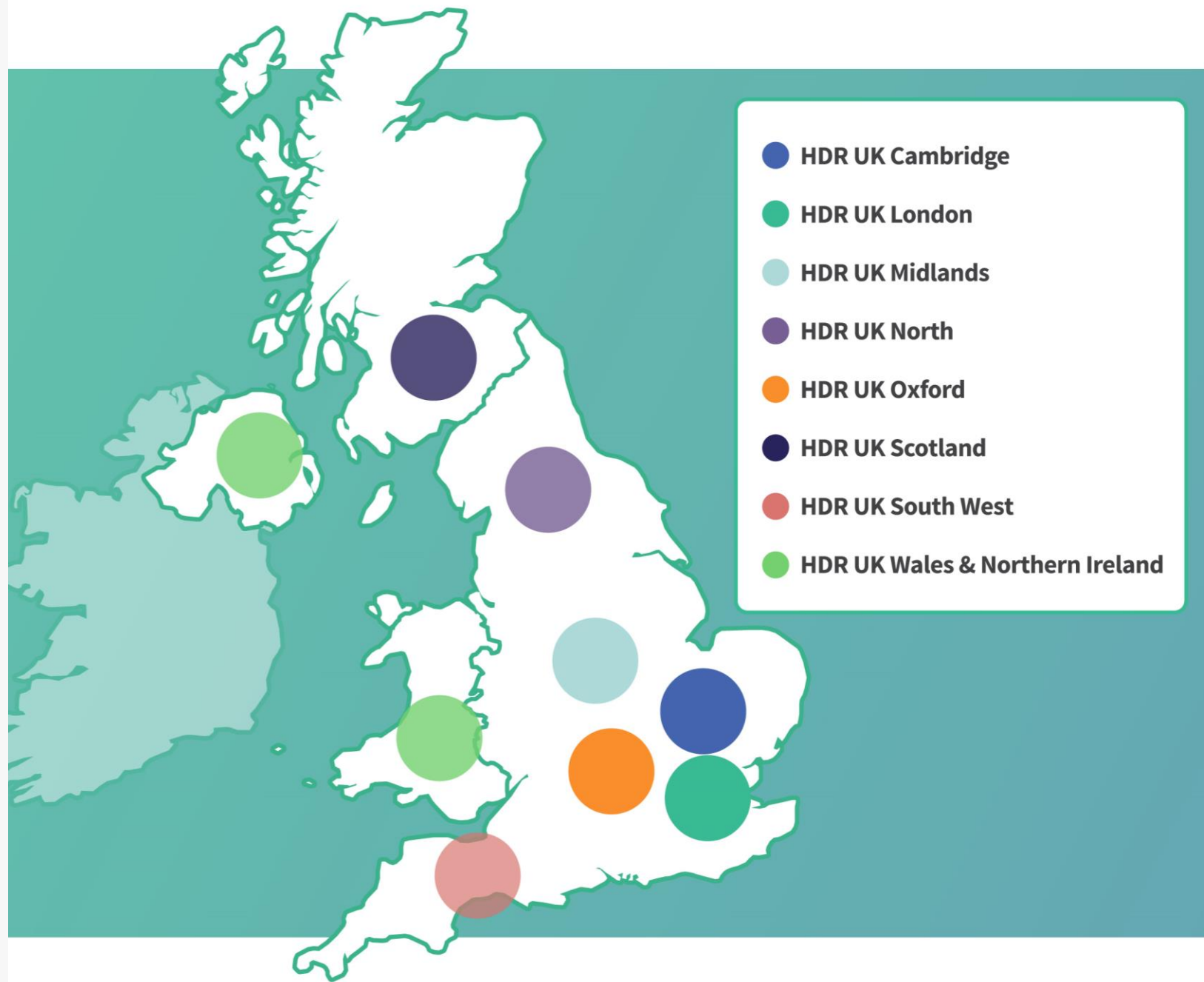
- Full coverage of rich multimodal data across imaging, pathology, genomics and structured data sets
- NHS and academic partnerships for delivery spanning >200 staff
- 40 industry projects already underway



Nine UK Regional Networks

HDR UK regional funding has been transformational in creating the partnerships necessary for health data research. These networks will be maintained and further developed to:

- Enhance regional partnership with HDR UK
- Speed up adoption of health data science innovation into practice
- Act as a focus of investment leverage



The Midlands



Population ~11 Million, Ethnically Diverse (>20% non-White British)

Mix of industrial towns/cities and rural countryside

21 Higher Education Institutions (HEIs)

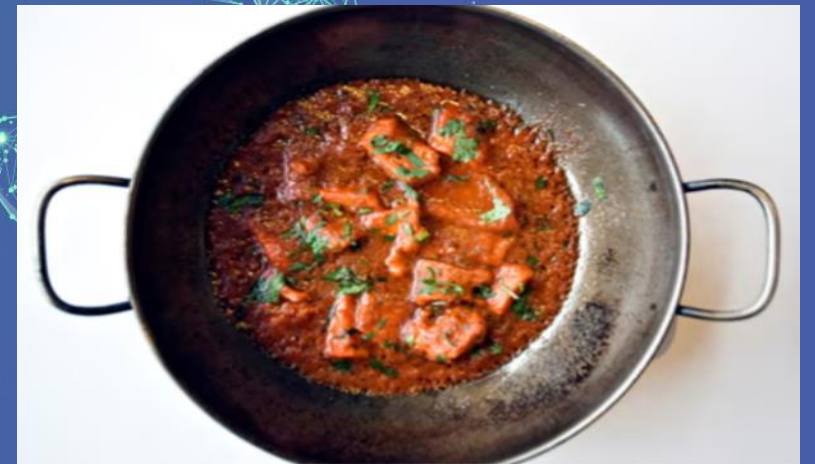
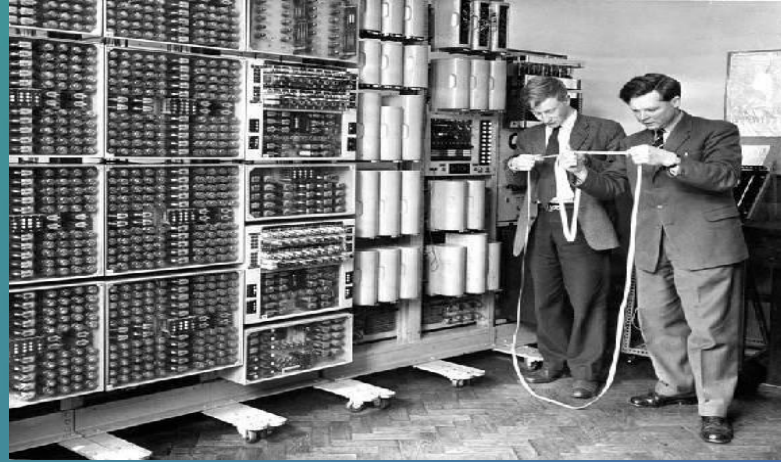
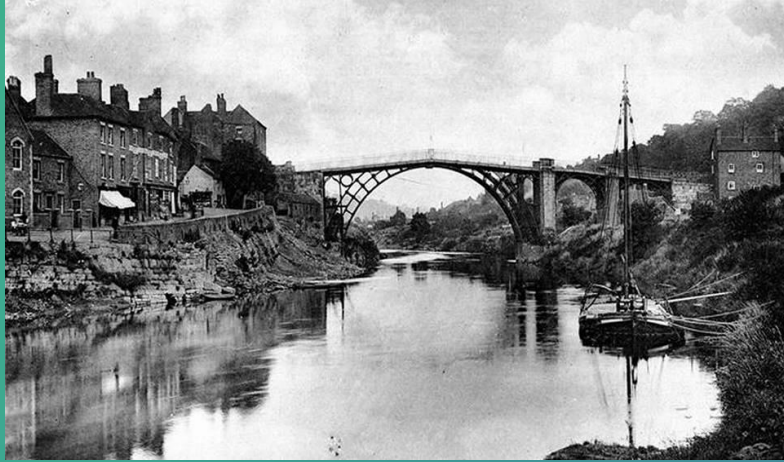
11 integrated care systems and 42 Trusts (5 Major Trauma Centres)

3 NIHR BRCs, 3 NIHR CRFs, 2 NIHR ARCs, 2 NIHR CRNs, 2 Health Innovation Networks (AHSNs)



Midlands Region

HDRUK
Health Data Research UK



HDR UK Midlands Regional Community

Our Mission

Improve health through uniting the health care, social care and data science communities across the Midlands region

Our Network

1

Maintain and expand the HDR UK Midlands Regional Network reaching out to all parts of our region

Our People

2

Upskilling and improving the knowledge and capabilities of our workforce by learning from each other

Our Opportunities

3

Maximising opportunities for our region through the HDR UK Midlands Regional Community Platform

Expanding our network



Expanding our network



HDR UK Midlands Regional Community Platform



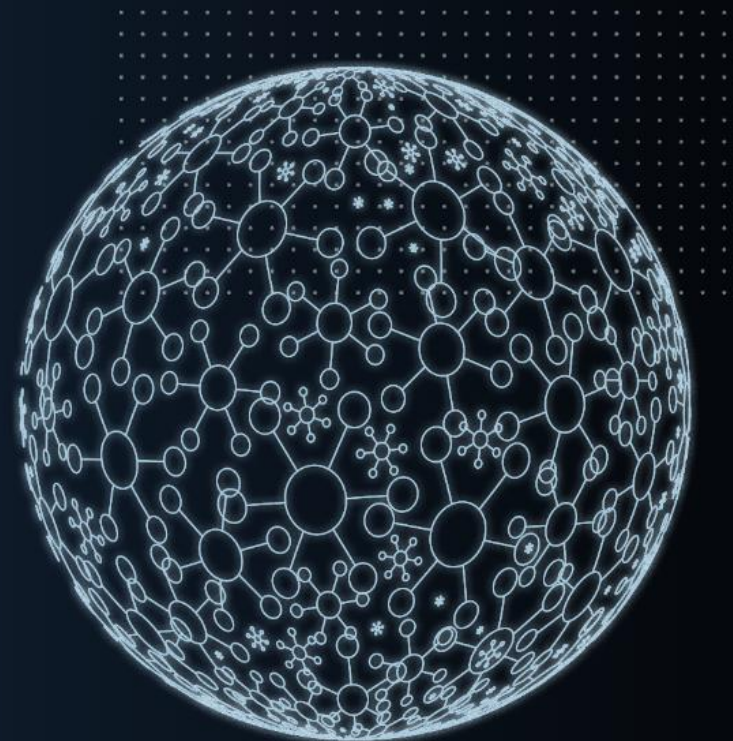
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Health Data Research UK

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Improving health through uniting the
healthcare and data science
communities across the Midlands

Our network is not exclusive and is therefore open to
anyone who has an interest in health data science. This
includes our patients and the public

Join our community



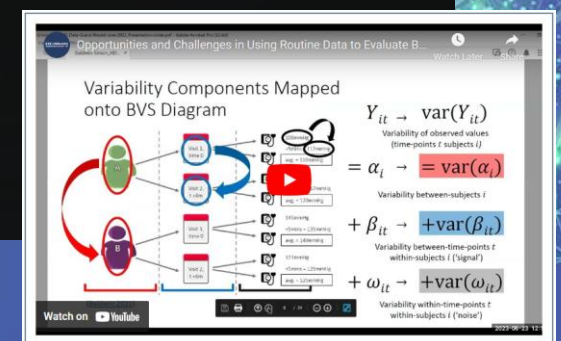
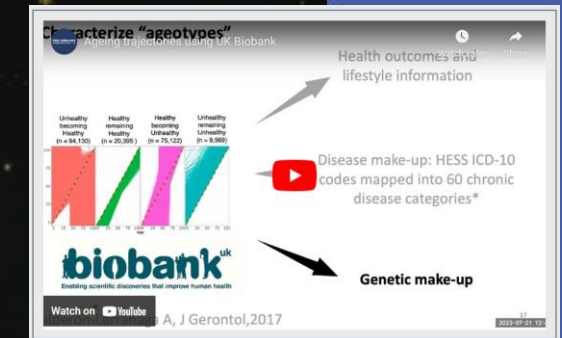
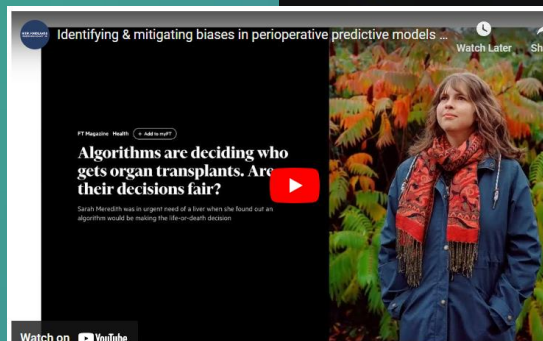
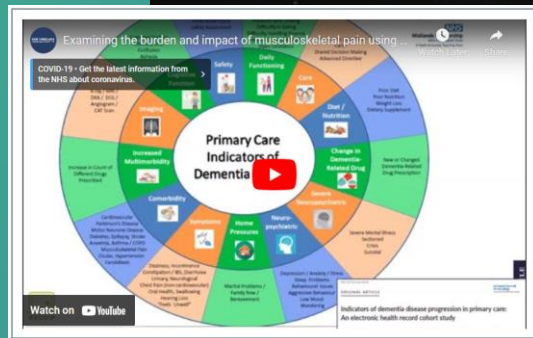
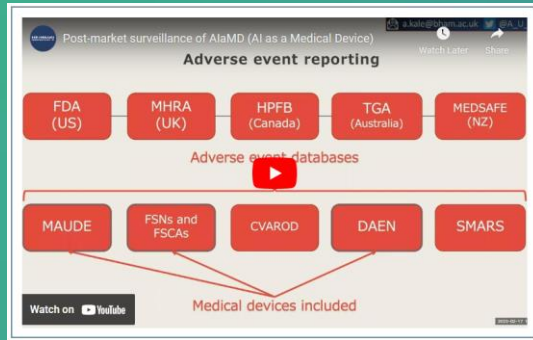
Monthly Data Grand Round (Data Science Meetings)

HDR UK Midlands Data Grand Round

The place for learning

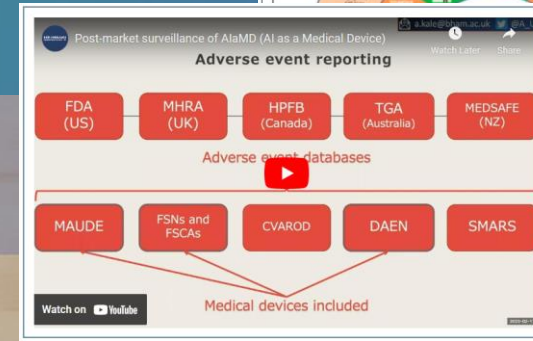
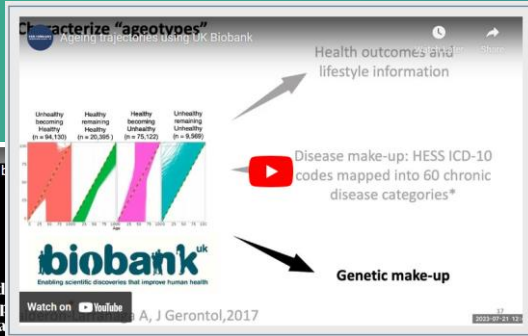
Our Monthly Data Science Meeting

Join our community



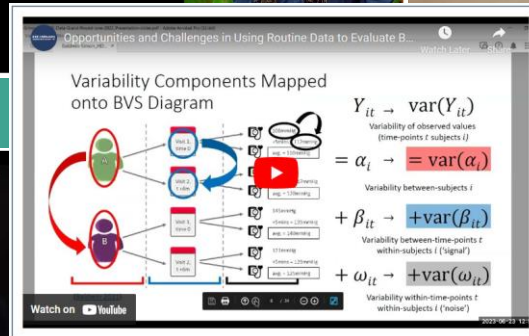
Quarterly Insight Sharing Webinars

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Health Data Research UK



Health Inequalities and Diversity in Health Data Science

18 Oct 2023



HDRUKMIDLANDS
Health Data Research UK

Home About Us Community Projects Events Opportunities HDR UK News

Using Artificial Intelligence (AI) Responsibly

8th Oct 2024

Making a difference: Using Data to Improve Care

29 Feb 2024

Making a difference: Using Data to Improve Care
29 Feb 2024

29 February 2024 / 1 - 4pm / Online (Via Zoom)



Page

Medicines in Acute and Chronic Care

We aim to understand and transform the use of medicines for patients of all ages, especially those with complex care needs caused by multiple long-term conditions.



HDRUK MIDLANDS

Health Data Research UK



EAST MIDLANDS SDE FOR R&D



NIHR | Birmingham Biomedical Research Centre

NIHR | Leicester Biomedical Research Centre

NIHR | Nottingham Biomedical Research Centre



HDR UK Midland Annual Conference

HDRUK
Health Data Research UK

Annual Conference 2024



Midlands CCIO Network

64 Members from 52 NHS
Organisations

NHS Trusts and ICBs involved
and engaged

Presentations from various
CCIOs, AI Incubator, Imaging
Networks, SDEs, Regional
Analysts,



64 Senior Clinicians from 52 NHS Organisations

Metrics (Key performance indicators – KPIs)

Community members
registered

570

Number of
organisations involved

65

Stakeholders
signed up

402

No of Events Held

34

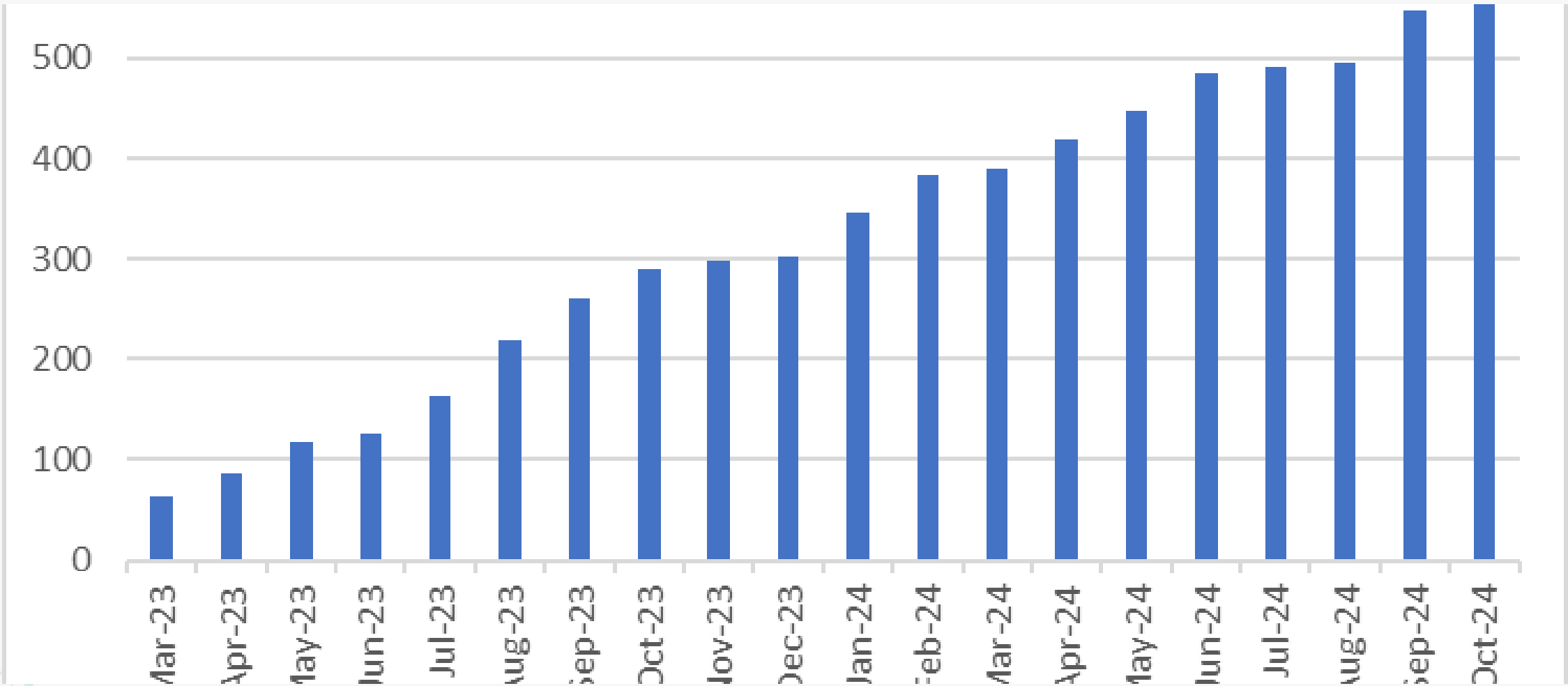
No of People Trained

1539

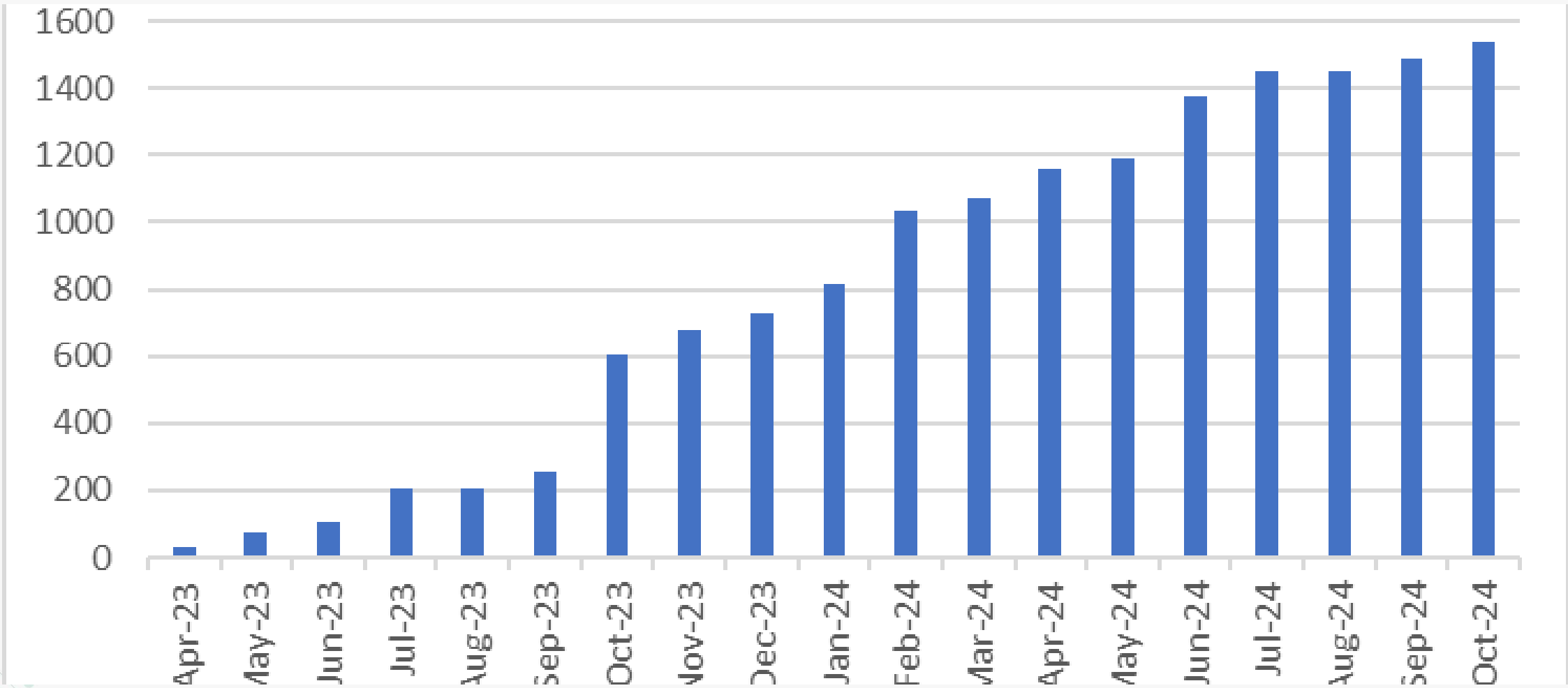
YouTube videos

72

New members joining HDR UK Midlands Regional Network (Cumulative totals)



Number of people accessing learning events (Cumulative totals)



How it's going?

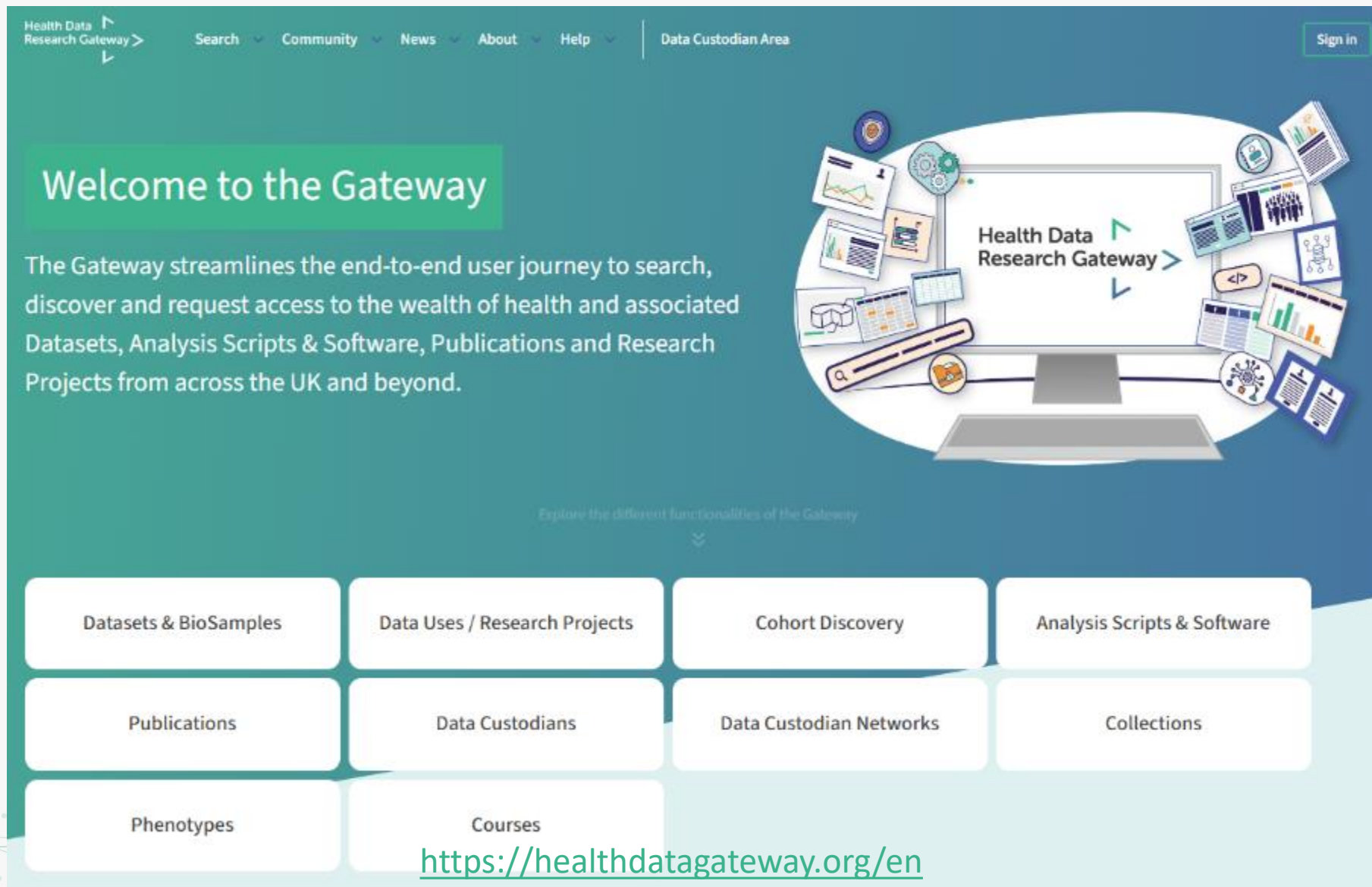


Upcoming activities

- Webinar with Strategy Unit (NHS) – How data may not always be helpful
- Webinar with Keele University – Prof. Kelvin Jordan - Digital Society Institute Keele
- Annual Conference – Prof. Eiman Kanjo – Tech conference with Industry (agenda item 7)
- Patient and Public Involvement and Engagement (PPIE)
 - Developing a new network for patients and the public



Health data Gateway supporting data discovery and much more



The screenshot shows the homepage of the Health Data Research Gateway. At the top, there is a navigation bar with the logo 'Health Data Research Gateway' on the left, a menu with 'Search', 'Community', 'News', 'About', and 'Help' in the center, and a 'Data Custodian Area' link on the right. A 'Sign in' button is located in the top right corner. The main content area features a large green box with the text 'Welcome to the Gateway' and a paragraph explaining that the Gateway streamlines the end-to-end user journey to search, discover, and request access to health data, analysis scripts, software, publications, and research projects. To the right of this text is an illustration of a computer monitor displaying the Gateway logo, surrounded by various icons representing data, research, and technology. Below the main text, there is a section titled 'Explore the different functionalities of the Gateway' with a downward arrow. This section contains a grid of ten white buttons with rounded corners, each representing a different functionality: 'Datasets & BioSamples', 'Data Uses / Research Projects', 'Cohort Discovery', 'Analysis Scripts & Software', 'Publications', 'Data Custodians', 'Data Custodian Networks', 'Collections', 'Phenotypes', and 'Courses'. At the bottom of the page, the URL <https://healthdatagateway.org/en> is displayed in green text.

Health Data Research Gateway >

Search Community News About Help Data Custodian Area

Sign in

Welcome to the Gateway

The Gateway streamlines the end-to-end user journey to search, discover and request access to the wealth of health and associated Datasets, Analysis Scripts & Software, Publications and Research Projects from across the UK and beyond.

Explore the different functionalities of the Gateway

Datasets & BioSamples

Data Uses / Research Projects

Cohort Discovery

Analysis Scripts & Software

Publications

Data Custodians

Data Custodian Networks

Collections

Phenotypes

Courses

<https://healthdatagateway.org/en>

Building Capacity in Health Data Science

100%



Developing the next generation

- Flagship PhD programme delivered in collaboration with seven leading UK universities, shaping the next generation of health data science leaders.
- Six new MSc programmes in Health Data Science across the UK, enrolling 400+ students.
- Partnering with medical research charities to award 16 Masters Scholarships focused on specific disease areas
- National fellowship programme supporting 40 multi-disciplinary researchers across the UK.



Increasing diversity of the workforce

- Widening access through initiatives like the award-winning Black Internship Programme, with 316 internships completed across sectors
- Support for apprenticeship programmes including level 7 in health data.



Supporting early careers

- Alumni network with 500+ health data scientists from multiple career stages and sectors benefiting from careers advice, networking and knowledge sharing.
- Mentor scheme pilot modelled on the Academy of Medical Sciences approach
- Annual Early Career Researcher Conference



Continuing professional development via the HDR UK Futures learning hub

- 14,000+ learners subscribed to our on-demand and live courses to keep pace with the latest cutting edge skills and innovations
- 200+ modules across 15 CPD accredited learning pathways, with an average user rating of 4.6/5.
- Leveraging expertise from the HDR UK community and beyond.
- Signposting to educational and training programmes from trusted partners.



Governance

Oversight by a committee of 40+ multidisciplinary educationalists from HDR UK's research programmes and regional networks.

FUTURES

Our new and improved HDR UK Futures is here

The same high-quality data science content in an easy-to-use platform

Sign up for free today

hdruklearn.org

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Health Data Research UK

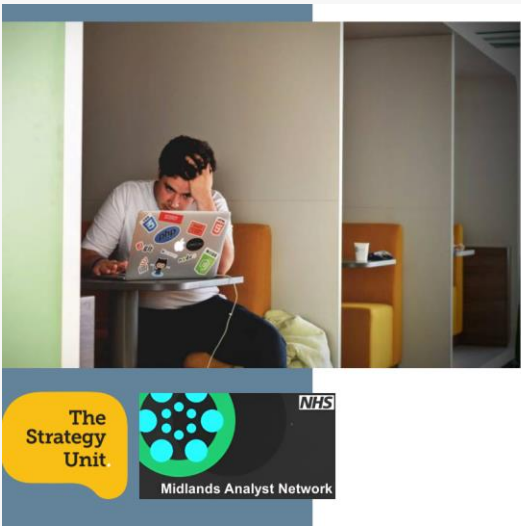


HDR UK Black Internship Programme in Health Data Science

- National **8 week internship programme** for aspiring Black Health Data Scientists
- **Why Participate?**
 - **Impactful Engagement:** Contribute to a more inclusive health data research community by actively supporting the professional development of Black data scientists
 - **Mutual Benefit:** Interns bring diverse perspectives and fresh ideas that can enhance your work and drive innovation.
 - **Demonstrated Leadership:** Show leadership in the sector by being part of a flagship diversity and inclusion initiative.



Practical ways to get involved



HDR UK Midlands Insight Sharing Webinar

Failure Parade: why and how we learn more when things don't go as planned

Delivered in partnership with the Strategy Unit (NHS) & Midlands Analyst Network

Tuesday 28th January 2025, 1 – 4pm – Online (Via TEAMS)

Webinar highlights include :

- Embracing Failure: Learn why sharing failures is as valuable as celebrating success.
- From Mistakes to Mastery: Discover how failure drives improvement and prevents future missteps.
- Reframing the Narrative: See how individual failures lead to collective success.
- Sharing to Inspire: Celebrate those brave enough to share their lessons from failure.
- Actionable Takeaways: Practical tips to turn failures into opportunities for growth.

[Find out more](#)



Join us for the next Data Grand Round:

Using Healthcare Data to Address Inequalities and Transform Services

Andi Orlowski, Health Economist and Director of the Health Economics

Wednesday 18th December 2024 @ 12.30pm

[Find out more](#)



Zoë Turner

Senior Data Scientist
The Strategy Unit (NHS
ML)
Community



Professor Tricia McKeever

Professor of Epidemiology
and Medical Statistics
University of Nottingham
Community



Mr Colin Monckton

Director of Performance
and Information
Nottingham University
Hospitals NHS Trust
Community



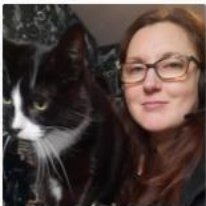
Rachel Caswell

Senior Healthcare Analyst
Midlands Analyst Network
Lead Strategy Unit
Community



Kelly Dixon

Senior Data Analyst –
Cancer Services
NHS Lincolnshire



Miss Jo Thompson

Principal Analyst
NHS Arden & Greater East



Mr Glen Howard

Programme Manager
Health Analytics and



Mr Andrew Barraclough

Head of Quality, Safety
and Improvement Analysis

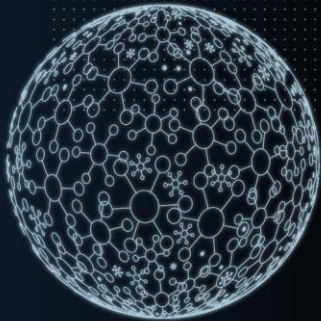
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