

Realising patient and NHS benefits from health and care data – From policy to practice

Wednesday 22 January 2020

Academy of Medical Sciences, 41 Portland Place, London



Network: 41PortlandPlace-Guest
WifiCode: HelloFellow1

Welcome and introduction

Professor Sir John Tooke FMedSci, Chair of Collaboration for the Advancement of Sustainable Medical Innovation (CASMI)



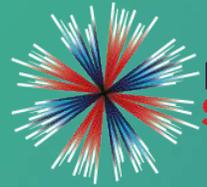
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Health Data Research Hubs: commercial challenges

Professor Andrew Morris CBE FRSE FMedSci, Director of Health Data Research UK



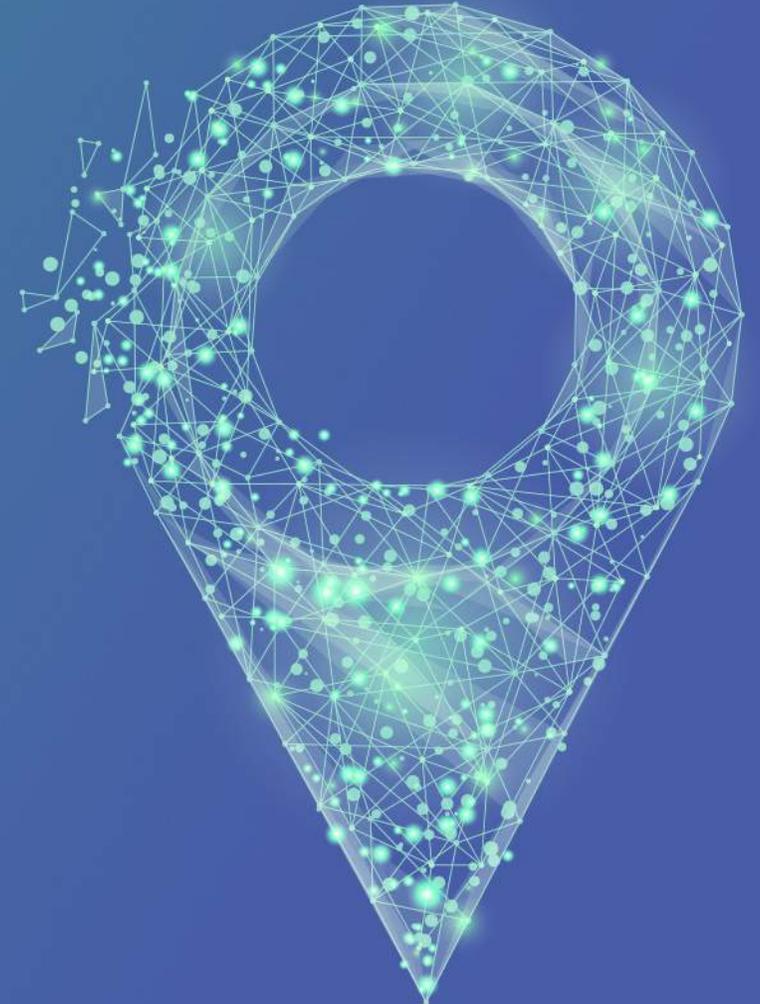
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Health Data Research Hubs: commercial challenges

Andrew Morris

22 January 2019

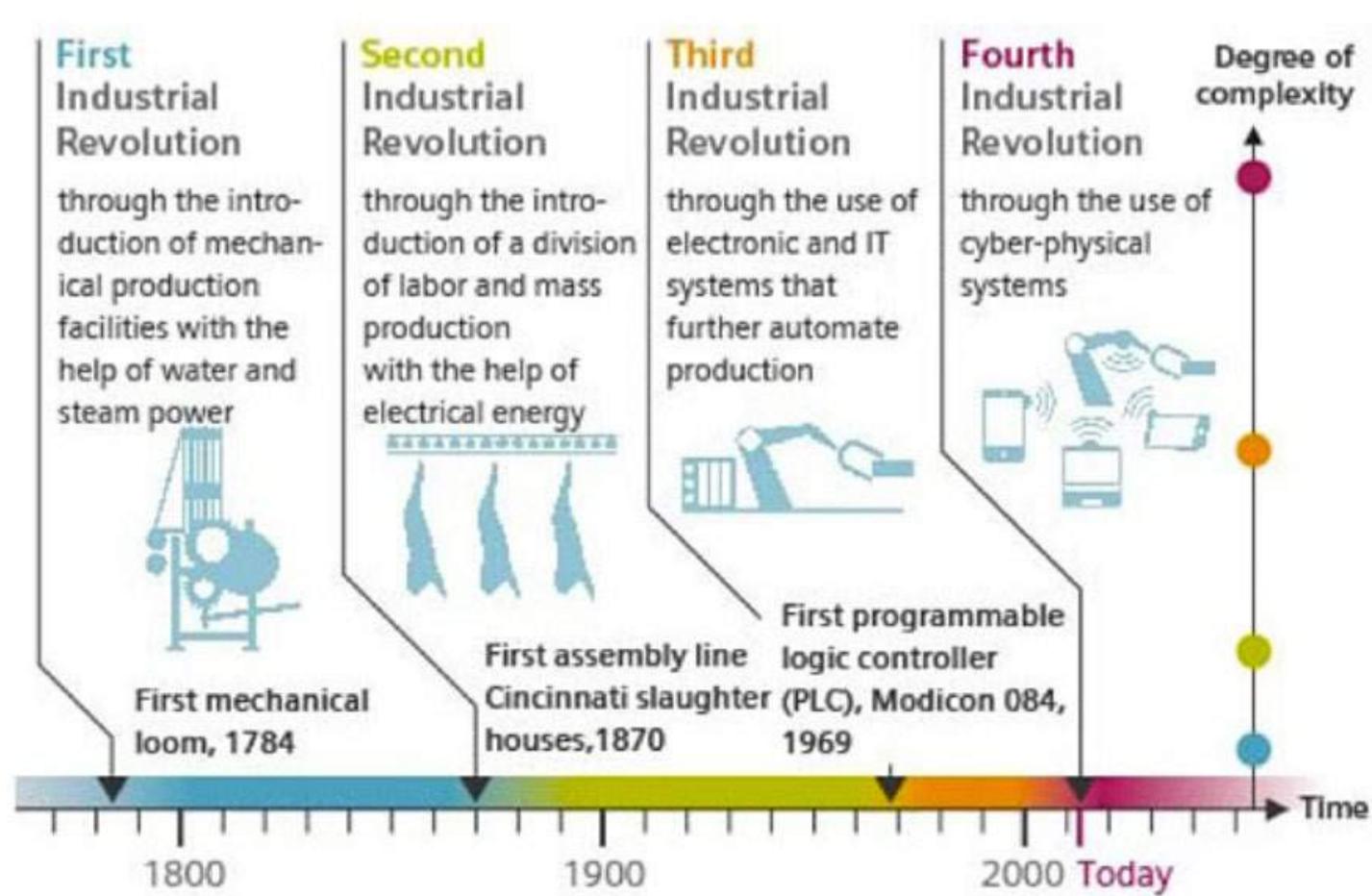


The Next 15 minutes

- Gearing an entire country for quality health care, research and innovation through data science
- The Digital Innovation Hub Programme
- With big data goes big responsibilities
 - Earning Trust
 - Challenges when partners from the public and private sector collaborate to use health data



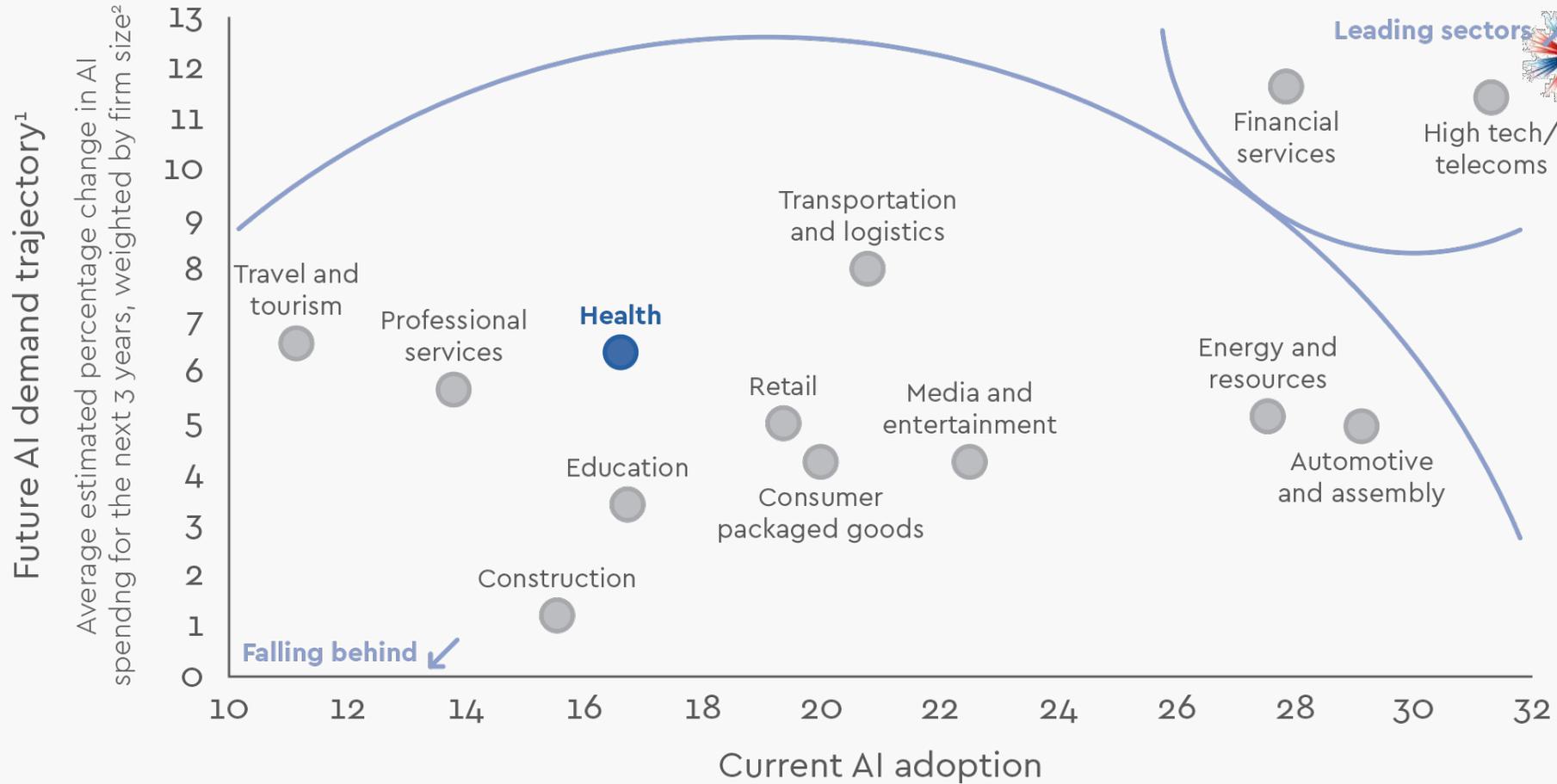
The 4th Industrial Revolution



WORLD ECONOMIC FORUM

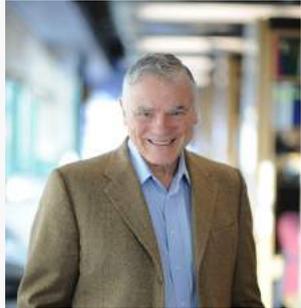


Sectors leading in Data Science and AI adoption today



SOURCE: McKinsey Global Institute, AI adoption and use survey.
 1 Based on the midpoint of the range selected by the survey respondent
 2 Results are weighted by company size.

The Promise of Data Science in Medicine



- Predictive
- Pre-emptive
- Personalised
- Participatory

Customise diagnosis and treatment

Better than curative – earlier diagnosis

Determine risk profiles, predict outcomes

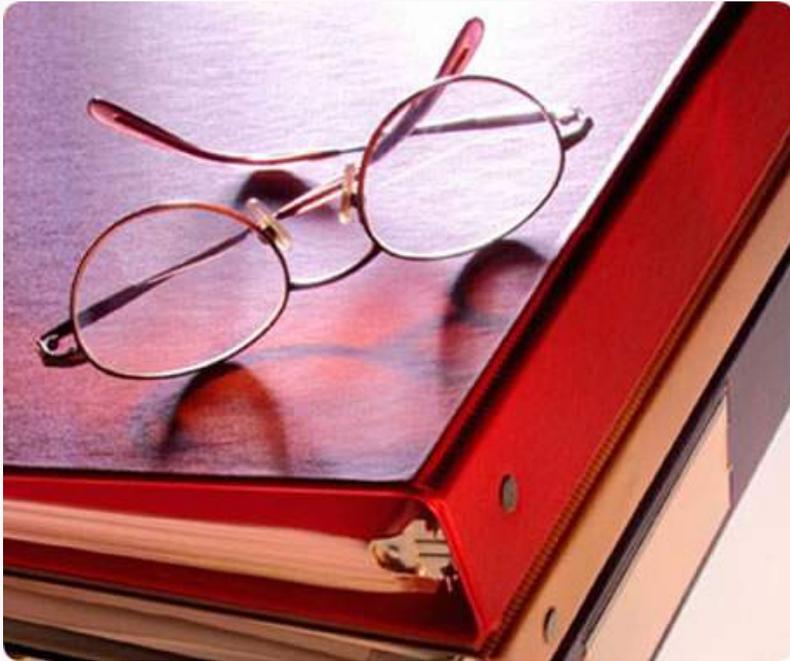
Involve patients

Made Possible by

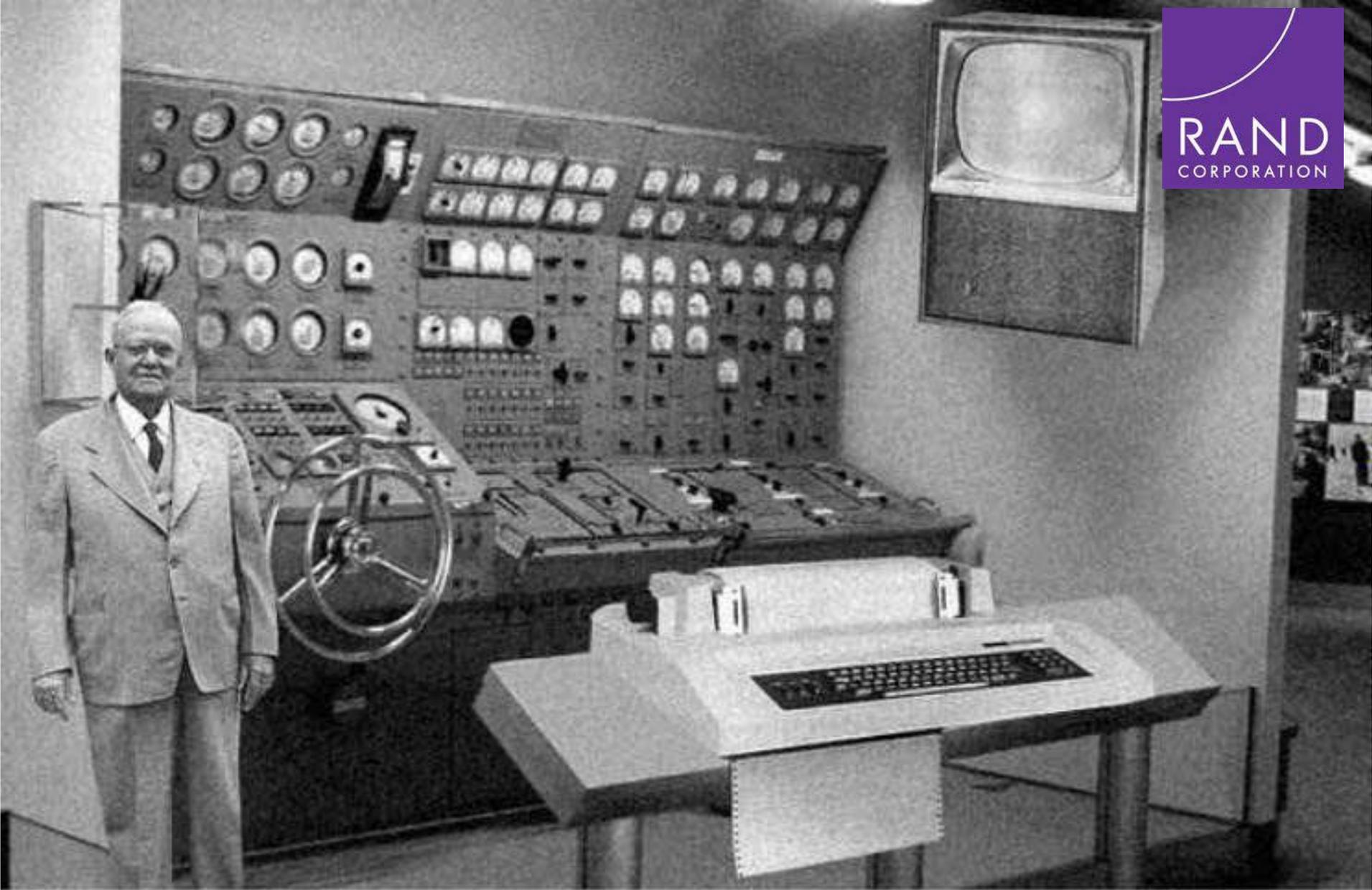
- Genomics
- Phenotyping
- Informatics
- Analytics
- New social contract

Case Studies of a Learning Health System

“Collect once use often”



- Prevention of disease
- Earlier diagnosis
- Safer and more effective treatments
- More effective integrated pathways
- New Diagnostics
- A greater understanding of how to use NHS funding most effectively
- Driving clinical research
- Precision Medicine



DRUK
Data Research UK

UK Research
and Innovation

Scientists from the RAND Corporation have created this model to illustrate how a "home computer" could look like in the year 2004. However the needed technology will not be economically feasible for the average home. Also the scientists readily admit that the computer will require not yet invented technology to actually work, but 50 years from now scientific progress is expected to solve these problems. With teletype interface and the Fortran language, the computer will be easy to use.



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

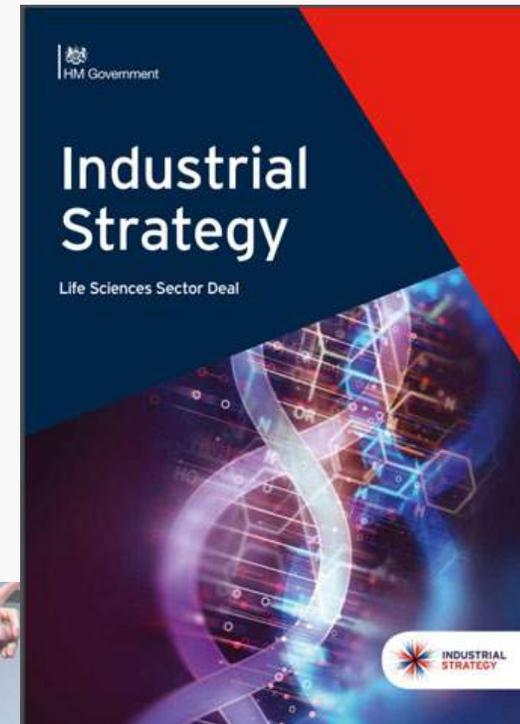
A Robust UK Health Data Research Infrastructure

Where this all started...

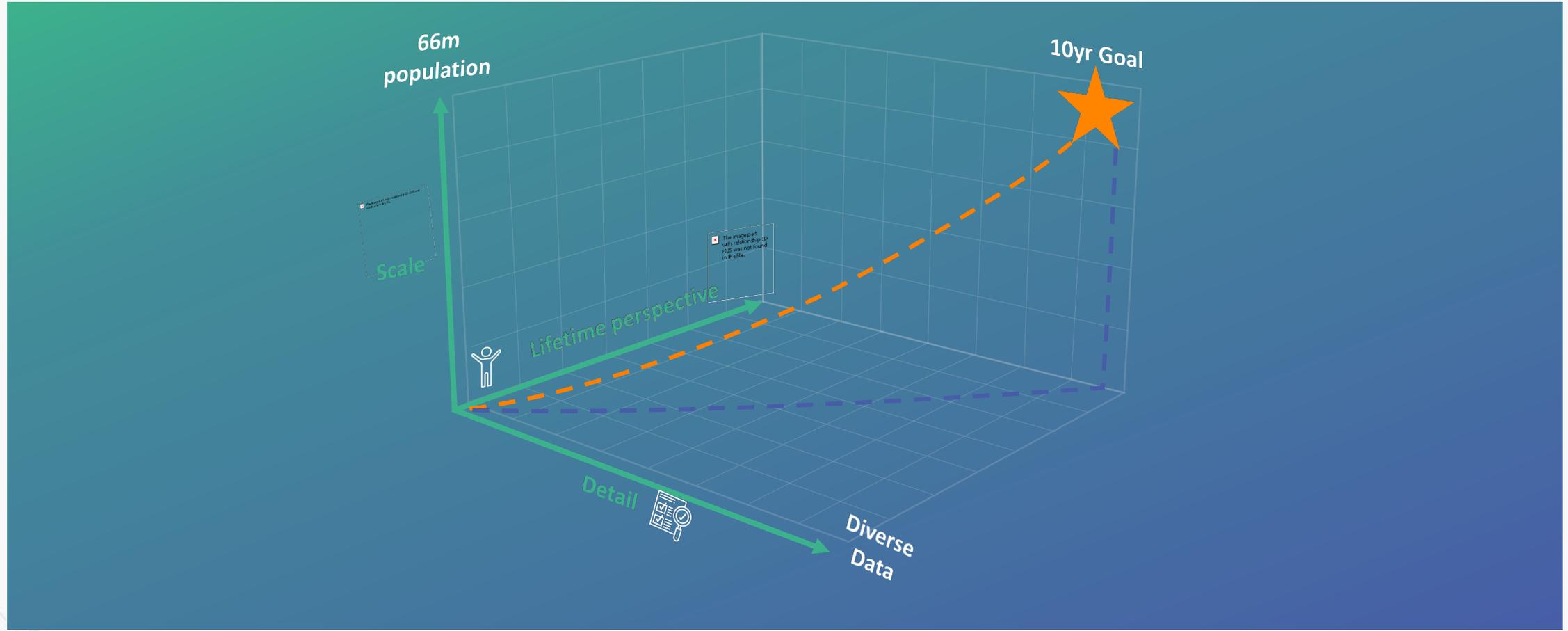
HDRUK
Health Data Research UK



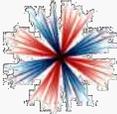
- Industrial Strategy for Life Sciences (November 2017) Hubs for health data research (*digital innovation hubs*)
- Funded as part of the Industrial Strategy Challenge Fund (ISCF) *Data to Early Diagnosis and Precision Medicine* Challenge
- Health Data Research UK asked to lead delivery of this programme on behalf of UKRI in September 2018
- Ensure that the enormous potential value of the UK's health data assets can be realised
- Four-year programme



A 10-year ambition for scale



Since September 2018, we've been listening and designing a model that's fit for the future of health data research



INDUSTRIAL STRATEGY

UK Research and Innovation

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

Five Big Issues

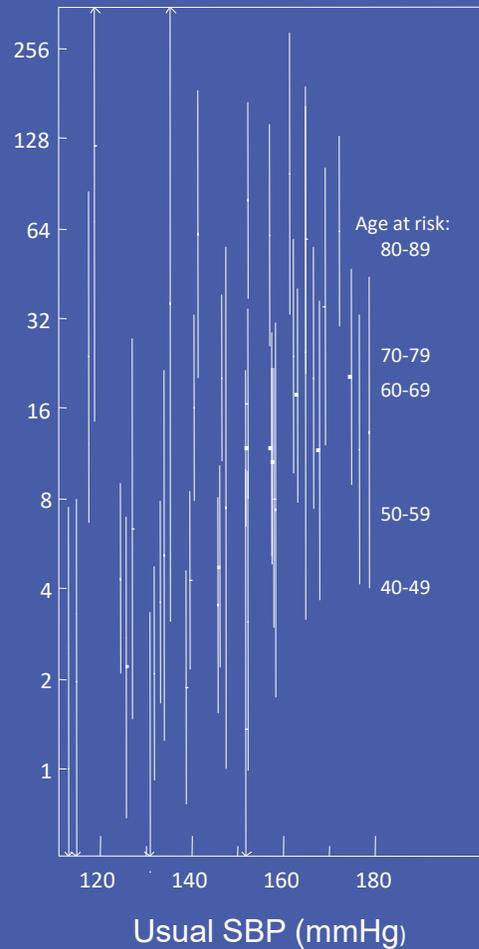


SCALE!

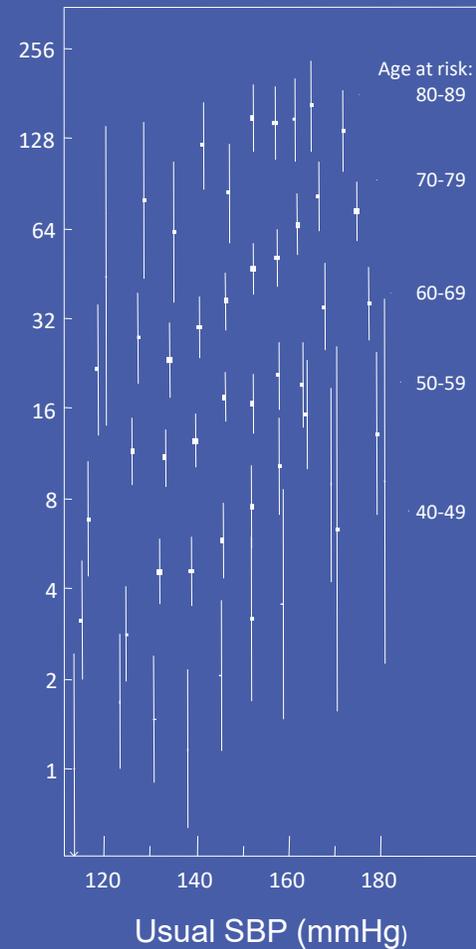
Prospective studies need to be LARGE

Heart disease mortality vs systolic blood pressure

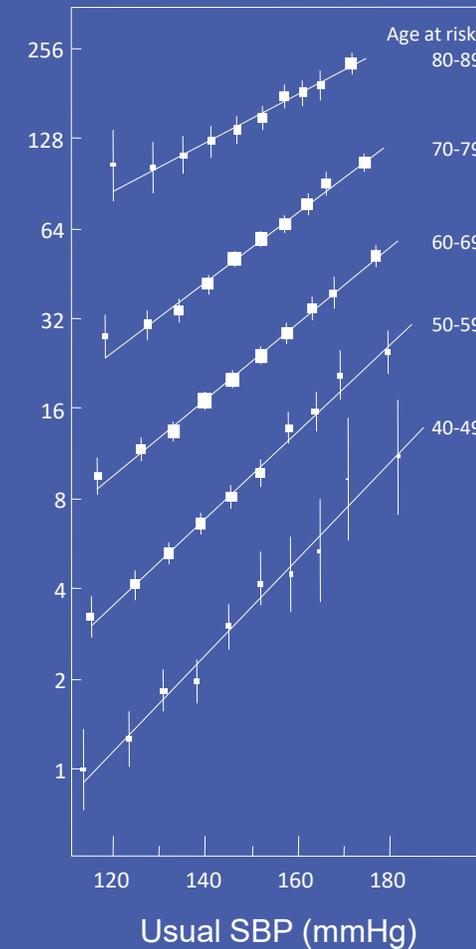
5000 people



50,000 people

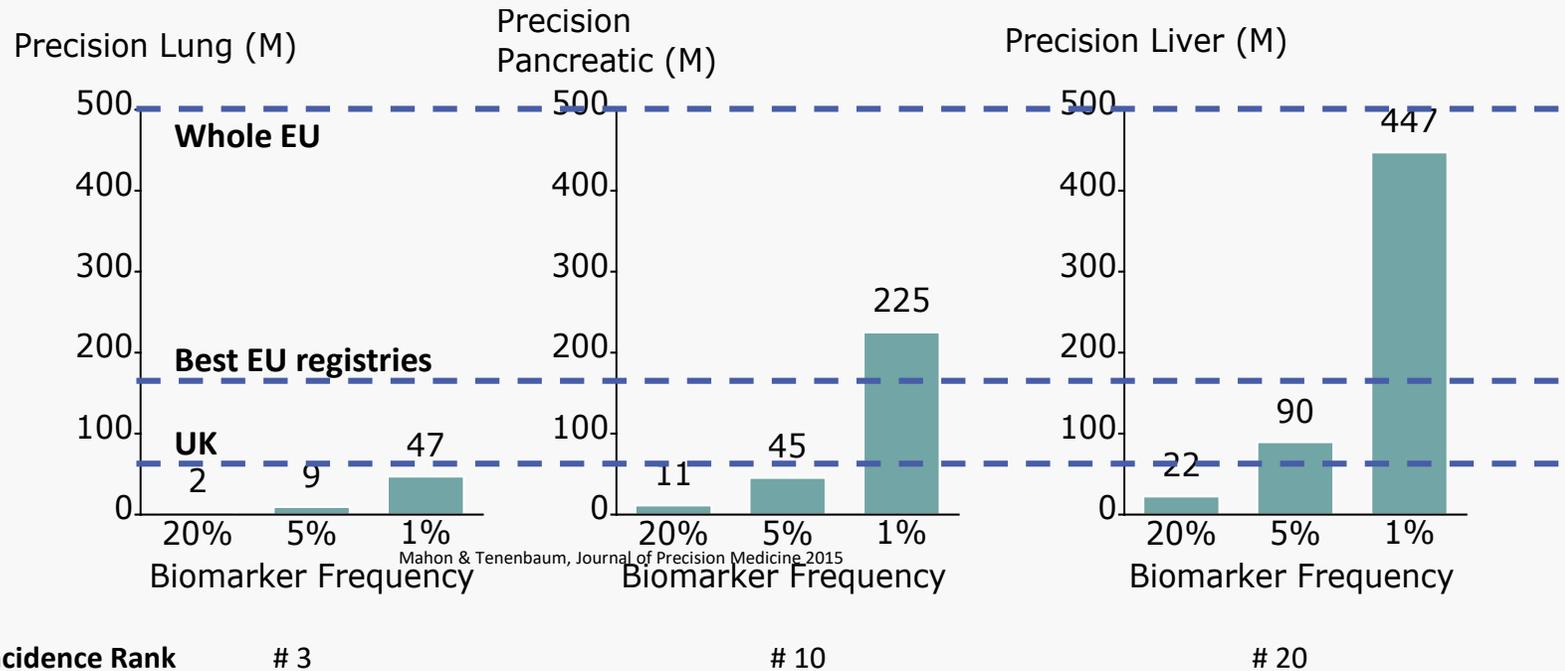


500,000 people



Enormous scale required to establish clinical utility in Cancer

Thought experiment: How many millions of people does it take to get 250 a year sick with a specific cancer and biomarker of various frequencies?



Courtesy of Piers Mahon

The Deeply Human Core Of Roche's \$2.1 Billion Tech Acquisition -- And Why It Made It



David Shaywitz Contributor ⓘ
Pharma & Healthcare



Amy Abernethy, MD, PhD, Chief Medical Officer, Chief Scientific Officer, and Senior Vice President, Flatiron Health

“what Flatiron did was not be scared off by doing the hard stuff – everyone else says ‘That is someone else’s problem to solve.’”

2. DATA QUALITY!

HDRUK
Health Data Research UK



- **2.1 M patient records – 210 Oncology Practices**
- Flatiron has created a meticulously assembled oncology dataset that pulls information from the electronic health records and organizes it in a fashion **that approaches the quality of clinical research**
- This enables investigators (and regulators) to ask questions of the data that might normally require a dedicated, stand-alone study to resolve.
- Flatiron’s key insight wasn’t so much recognizing the foundational need for a robust, clinical research-grade dataset, but rather, realizing that creating this **required meticulous, artisanal data curation – largely done by hand, Mechanical Turk style.**

Data maturity and standardisation Pharmacogenetics of Metformin



HDRUK
Health Data Research UK

**INDUSTRIAL
STRATEGY**

**UK Research
and Innovation**

- take one 2 twice a day for 1
- 1 6: take onetab 3 times daily 1
- 2 7: take one twice a day for 2 1
- 3 8: take one at 8 am and 1 at 1
- 4 9: three daily as directed 1
- 5 10: two daily in addition to c 1
- 6 11: 1 tablet eve meal 1
- 7 12: 1 tablet five times dai 1
- 8 13: take one twics a daily 1
- 9 14: take one twice a daily 1
- 10 15: 2 caplets twice a day 1
- 1 16: take one 2 times/day with m 1
- 1 17: 2 tablet 3 times daily cpus 4 1
- 1 18: 1 tablet daily for 1 week then 1 tablet bd 1
- 1 19: one 3 times daily 1
- 1 20: one 5 times daily 1
- 16: 2 bd 116
- 17: 1 tablet bd 114
- 18: 1 tablet in the morning 103
- 19: take one 2 times/day 99
- 20: 1 tablet 3 times daily 95



**5720 variations
for Metformin
alone!**



Data

China's success at AI has relied on good data

But cheap labour has also played an important part

Technology Quarterly

Jan 2nd 2020 edition

- MBH
- One of China's largest data factories
- 300,000 data labellers
- Each labeller works a six-hour shift each day, tagging a stream of faces, medical imagery and cityscapes

3. Digital Maturity of Health Systems and Data

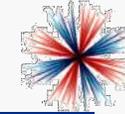
- Level 8 - Personalized Medicine & Prescriptive Analytics
- Level 7 - Clinical Risk Intervention & Predictive Analytics
- Level 6 - Population Health Management and Suggestive Analytics
- Level 5 - Waste & Care Variability Reduction
- Level 4 - Automated External Reporting
- Level 3 - Automated Internal Reporting
- Level 2 - Standardized Vocabulary & Patient Registries
- Level 1 - Enterprise Data Warehouse
- Level 0 - Fragmented Point Solutions

HIMMS 2013

Strategic Development – NHSX

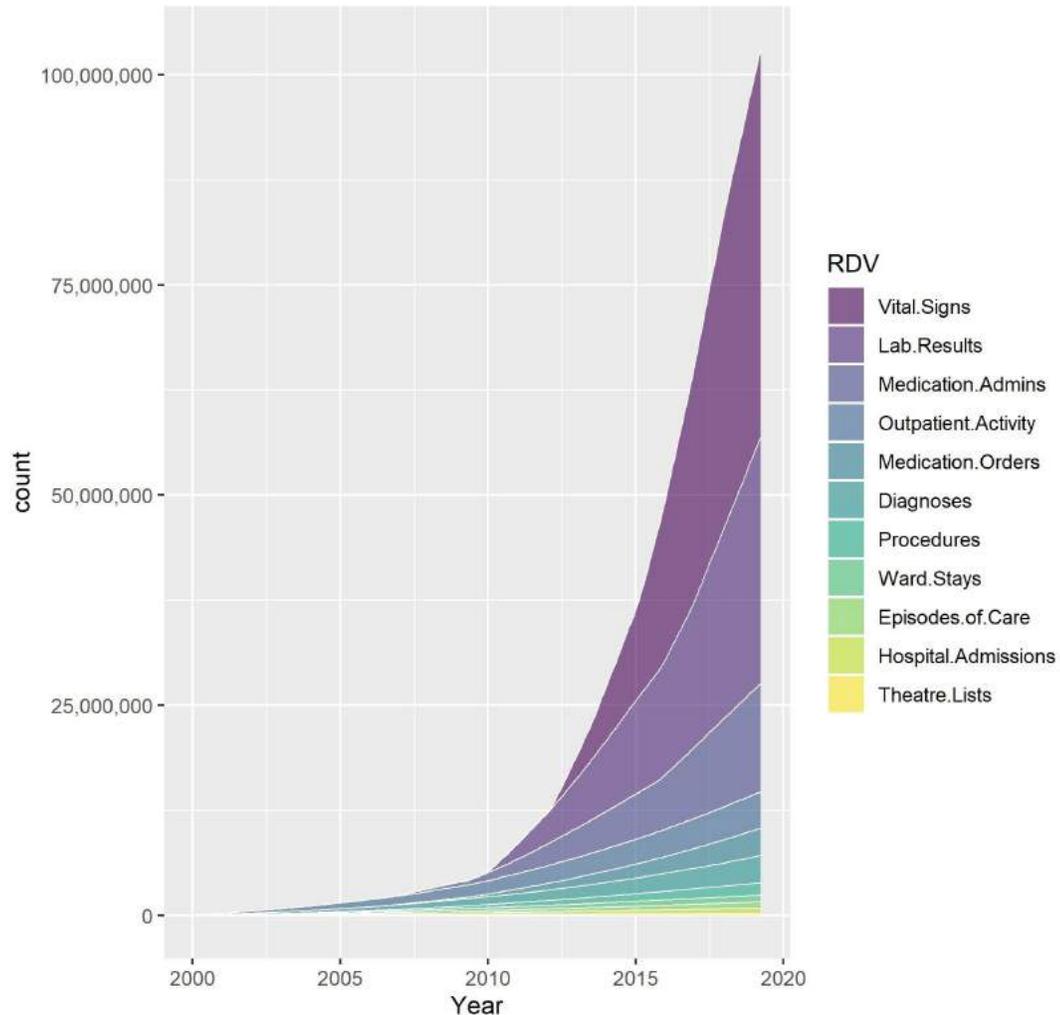
- Co-ordination and consistency
- Setting standards
- Driving implementation
- Radical innovation
- Common technologies and services
- Governance
- Centre of Expertise

- Led by Matthew Gould



We Can Do it!

Accumulated data in the GOSH DRE Data Lake



- Cumulative curated mapped, FHIR aligned data available in GOSH DRE sept 2019.
- Legacy digital systems were implemented with known good enough quality data from 2000
- Prescribing etc being more recent.
- 100M data items

4. It's a complex

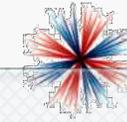
Establishing processes

Dutch Complexity!

Health-RI consolidates the activities of multiple Dutch ESFRI and e-infrastructure nodes by their landing into the Health-RI platform



HDRUK
Health Data Research UK



INDUSTRIAL STRATEGY

UK Research and Innovation



National Institute for Health Research

UK Research and Innovation



Health Research Authority NATIONAL INFORMATION BOARD

Private UK



EMBL-E

Interoperability: to work across systems with no additional effort

5. - The biggest of all – Transparency and Earning Trust



DJIA 29348.10 0.17% ▲

Nasdaq 9388.94 0.34% ▲

U.S. 10 Yr 0/32 Yield 1.823% ▼

Crude Oil 58.66 0.20% ▲

Euro 1.1098 0.02%

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Hospitals Give Tech Giants Access to Detailed Medical Records

Deals with Microsoft, IBM and Google reveal the power medical providers have in deciding how patients' sensitive health data is shared

SHARE



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**

Design of the DIH Programme

Inspired by global collaborations

HDRUK
Health Data Research UK



- No single organisation possesses all the information required to address every health and well-being issue facing society.
- Timely access to data across organisations requires:
 - Expertise
 - Trusted governance
 - Interoperability

Inspired by...



Global Alliance
for Genomics & Health
Collaborate. Innovate. Accelerate.



W3C[®]



“As a neutral global cooperative, SWIFT is defined by its community of users around the world”.

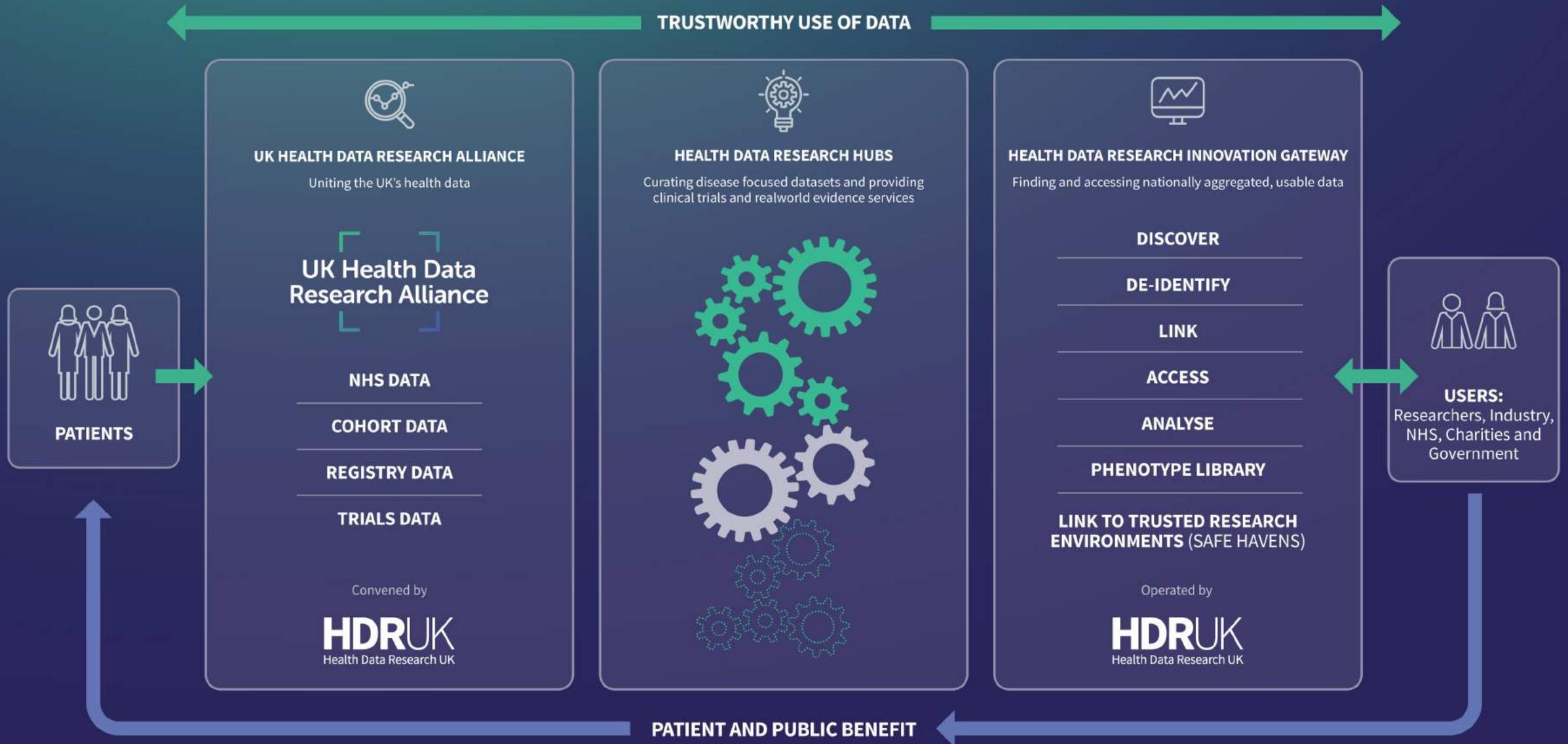


The DIH Programme will deliver what industry, NHS and academic users want

- **Public trust:** a way to ‘close the loop’ and return insights to the NHS, patients and the public
- **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 full 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



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





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

27 current members, more expected to join the coming months

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



www.healthdatagateway.org

HDRUK
Health Data Research UK



Health Data Research
Innovation Gateway

Explore & Discover our 414 health datasets from across the UK.

Search and explore information about these datasets. If you have an OpenAthens account, you can log in to enquire about access to these datasets for research and innovation.

[Continue as a guest](#)

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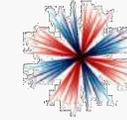
Health Data Research Hubs

- The Hubs are curating 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**
- **£22M plus ~ £22M leverage**
- **1st October start**



Introducing the UK's Health Data Research Hubs



HEALTH DATA RESEARCH HUBS

Curating disease focused datasets and
providing clinical trials and real
world evidence services



- **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
- **G.I. Now** 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

Health Data Research Hubs Announcement

HDRUK
Health Data Research UK



• 12 September, BMA House

Industry Partners



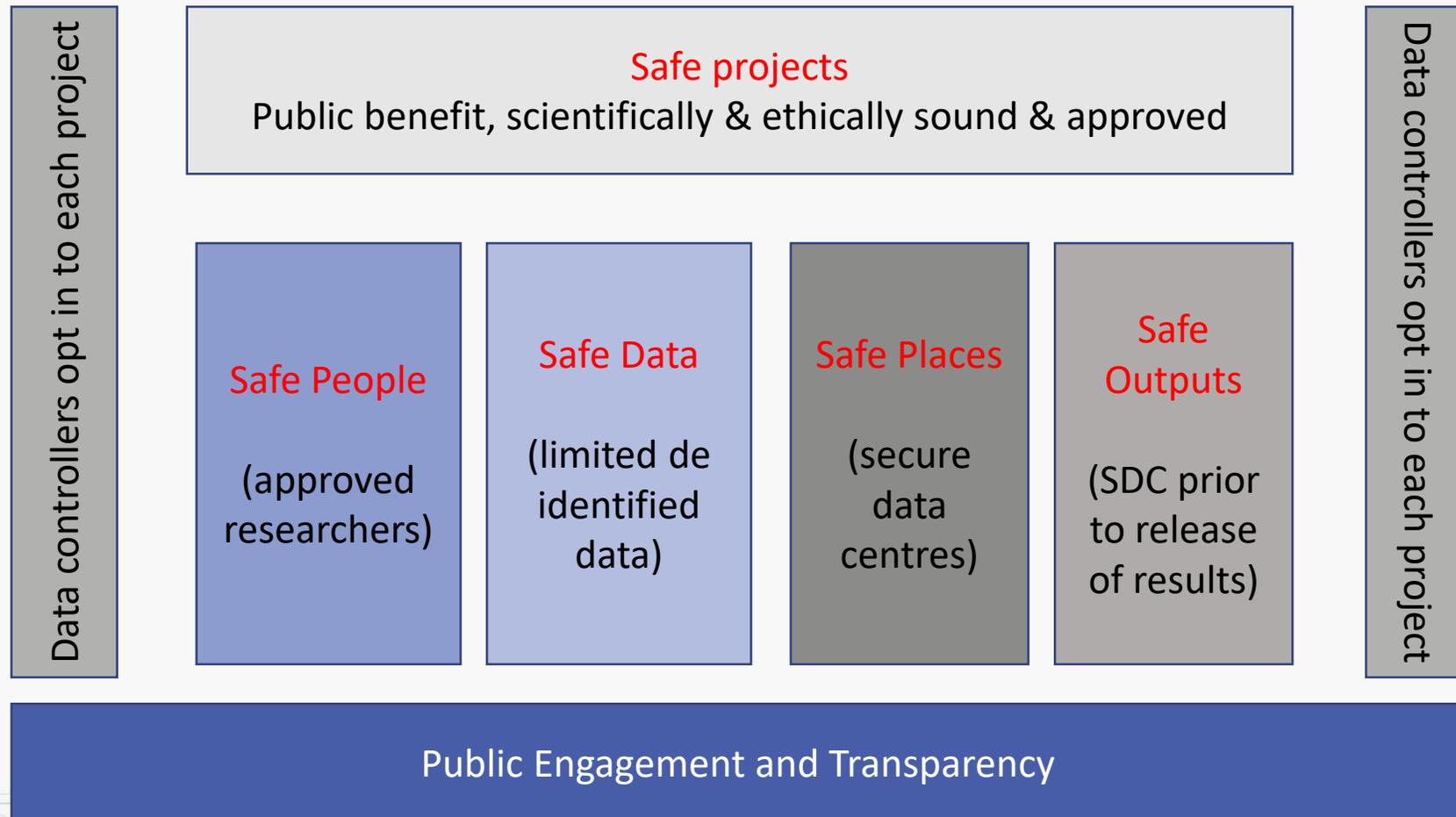
- AIMES
- AMAZON
- Astra Zeneca
- BreatheOx
- Dr Foster
- GE Healthcare Finnamore Partners
- Google Health UK
- IBM
- Insignia Medical Systems
- IQVIA
- Janssen
- Medicines Company
- Medopad
- Microsoft,
- NewSignature
- Novartis
- Optimum Patient Care
- Privitar
- Respiri Ltd
- StormID
- Tiny Medical Apps

Companies are (i) supporting the development of disease-specific data assets, (ii) providing tools and strategies for data curation, patient engagement and involvement; (iii) enabling real-time anonymised data access for research to improve cancer care; (iv) Cloud-based environments for storage and analysis

No company has preferential access to the data (principles of participation)

Developing a DIH Framework

Earning Trust: the “5 safes”





It's an International Challenge



Asian Bioethics Review (2019) 11:315–326
<https://doi.org/10.1007/s41649-019-00100-7>

ORIGINAL PAPER

Big Data and Public-Private Partnerships in Healthcare and Research

The Application of an Ethics Framework for Big Data in Health and Research

Angela Ballantyne¹ • Cameron Stewart²

Received: 1 August 2019 / Revised: 29 August 2019 / Accepted: 30 August 2019 /
Published online: 30 September 2019
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Asian Bioethics Review (2019) 11:227–254
<https://doi.org/10.1007/s41649-019-00099-x>

ORIGINAL PAPER

An Ethics Framework for Big Data in Health and Research

Vicki Xafis¹ • G. Owen Schaefer¹ • Markus K. Labude¹ •
Iain Brassington² • Angela Ballantyne³ • Hannah Yeefen Lim⁴ •
Wendy Lipworth⁵ • Tamra Lysaght¹ • Cameron Stewart⁶ • Shirley Sun⁷ •
Graeme T. Laurie⁸ • E Shyong Tai^{9,10}

Received: 2 August 2019 / Revised: 28 August 2019 / Accepted: 29 August 2019 /
Published online: 1 October 2019
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Transparency

- **A potential barrier to transparency in relation to PPPs is the commercial and reputational concerns of both public and private partners**
- **For example, public institutions may be under political pressure not to release information about projects that could be politically contentious and private companies may claim commercial sensitivity in relation to research processes or outputs.**
- **Neither reputational concerns nor commercial interests are alone sufficient to outweigh the value of transparency in how PPP initiatives are conducted.**
- **Arguments in favour of public transparency and openness are especially compelling when PPPs involve sharing population health data sets, collected in public systems, funded by tax resources, and when PPPs are defended on the grounds of public benefit.**
- **Partners should consider if these features apply to a proposed PPP.**

Summary

- **Health Data Science will disrupt Medicine**
- **Complexity of how we develop transparent approaches to value exchange**
- **Shared learning opportunity with the Data Research Hub programme**



OPINION

Pepper...and Salt



WORLD NEWS

Science-Fiction
Writer Ursula K. Le Guin
Dies at 88



WORLD NEWS

The Internet Is Filling
Up Because Indians Are
Sending Millions of ...



Leadership can be learned.
See you in class.



MUHTAR KENT
CHAIRMAN OF THE BOARD,
THE COCA-COLA COMPANY



LESSONS IN LEADERSHIP

LEARN MORE

LIFE

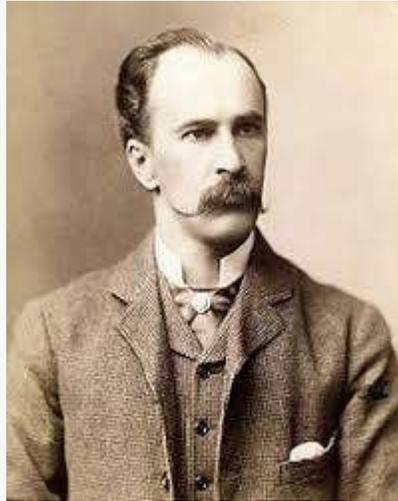
The New Einsteins Will Be Scientists Who Share

From cancer to cosmology, researchers could race ahead by working together—online and in the open

By Michael Nielsen

October 29, 2011





HDRUK
Health Data Research UK



The best preparation for tomorrow
is to do today's work superbly well

William Osler

July 12th 1849-December 29th 1919

Thank you for listening!

From Policy to Practice: the NHS strategy for making better use of data for research

Baroness Dido Harding, Chair of NHS Improvement

What constitutes a fair partnership for using NHS data?

Dr Natalie Banner, Lead, Understanding Patient Data

Panel Discussion - Upholding the ethos of the NHS: the purposes, benefits and values of using health data

Chaired by Professor Carol Dezateux CBE FMedSci, Professor of Clinical Epidemiology and Health Data Science at Queen Mary University London

Upholding the ethos of the NHS: the purposes, benefits and values of using health data

Panellists:

- Dr Natalie Banner, Lead, Understanding Patient Data
- Hilary Newiss, Chair, National Voices
- Dr Aisling Burnand, Chief Executive, Association of Medical Research Charities
- Amy Darlington, Involvement and Engagement Lead, OneLondon LHCRE
- Professor Sir Jonathan Montgomery, Professor of Healthcare Law, University College London

The use of AI could eventually speed up diagnosis, as images can be analysed within seconds by the computer algorithm.

Sara Hiom, director of cancer intelligence and early diagnosis at CRUK, told the BBC: "This is promising early research which suggests that in future it may be possible to make screening more accurate and efficient, which means less waiting and worrying for patients, and better outcomes."



Helen Edwards had breast cancer in her 40s

Upholding the ethos of the NHS: the purposes, benefits and values of using health data

Panellists:

- Dr Natalie Banner, Lead, Understanding Patient Data
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- Dr Aisling Burnand, Chief Executive, Association of Medical Research Charities
- Amy Darlington, Involvement and Engagement Lead, OneLondon LHCRE
- Professor Sir Jonathan Montgomery, Professor of Healthcare Law, University College London

The values of data

Professor Bryan Williams, Chair of Medicine at University
College London and Director of UCL Hospitals NIHR
Biomedical Research Centre

Preparing NHS data sets for entering commercial partnerships

Dr Pearse Keane, Associate Professor, Institute of Ophthalmology,
University College London



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Realising the value of health data – Industry perspective

Prof. Carole Longson, Chief Scientific Officer, ABPI

Life Sciences Industrial Strategy – Sector Deal 2

‘Improved use of high quality, cost-effective healthcare data presents an opportunity to make the UK the home of data-driven life sciences research, innovation and development – and in so doing improve outcomes for patients and the NHS’

ABPI Health Data Strategy aims

- **Help shape** the debate on health data and the development of a world class health data infrastructure
- **Describe** what type of data infrastructure supports the government’s ambition to make the UK more attractive for investment in life sciences R&D
- **Help develop** industry friendly systems so that health data is managed in a trusted way, and accessed and analysed at pace
- **Collaborate** with government to fully enable the use of health data by the life science industry, covering all phases of the product value chain

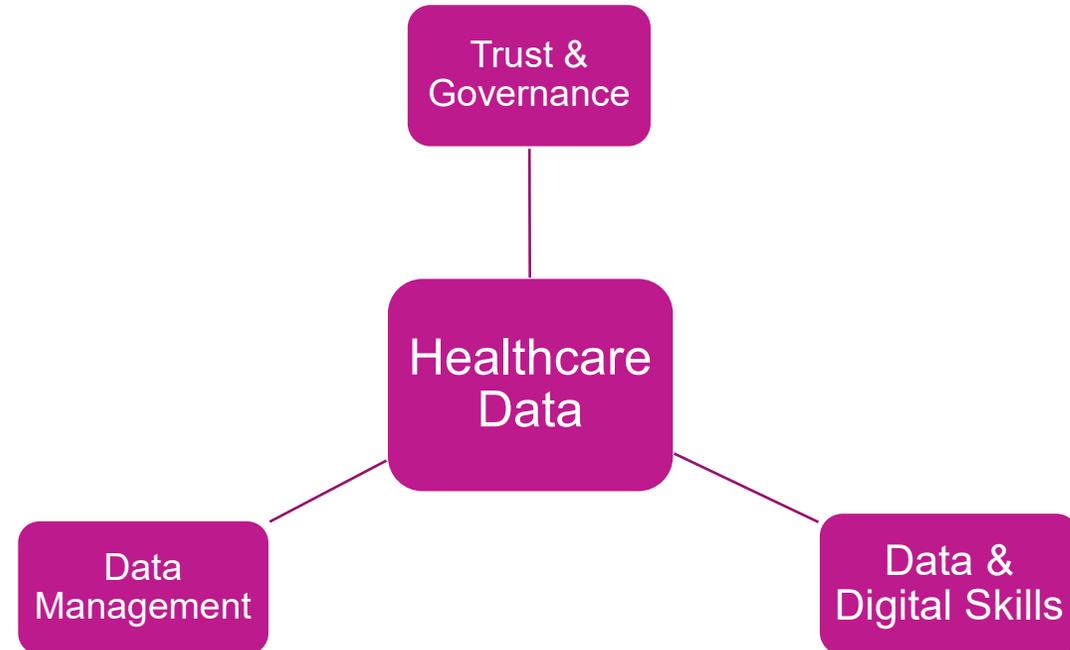
Research, discovery, development and delivery to patients

Unlocking the Promise of UK health data will support life science innovation

Industry recognises the potential of UK health data to achieve **three goals**:

- To improve **patient outcomes**
- To increase the **efficiency** of the NHS
- To support the **development of new medicines and other technologies**

Three key aspects:



Perspectives on trust and confidence

Patients and the public must have trust and confidence that their private information will be used only in the way that they choose, securely protected carefully governed

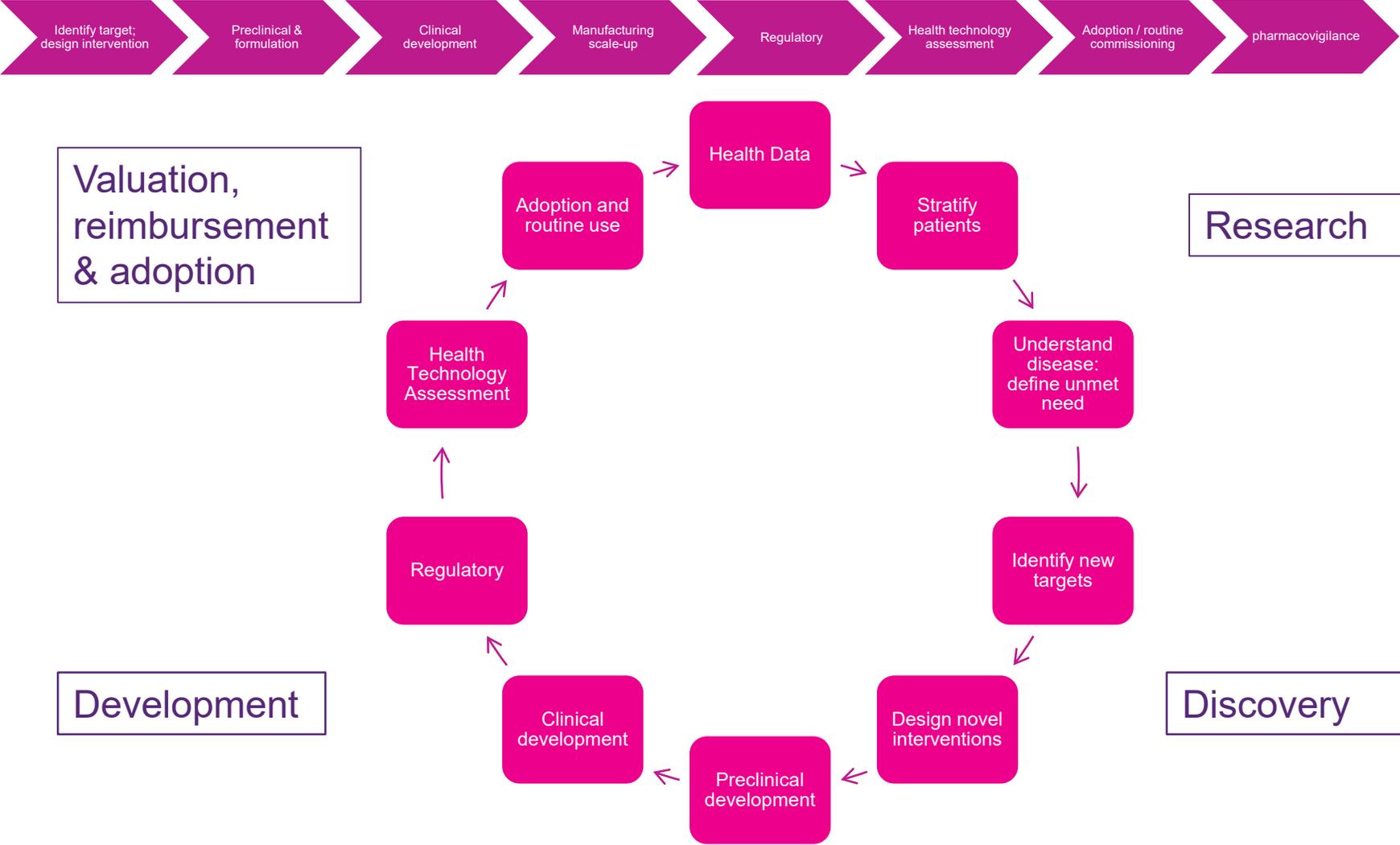
The pharmaceutical industry has decades of experience in collecting and handling specified health data in clinical trials. Outcomes are routinely published of analyses on aggregated, anonymised datasets

3 pre-requisites for trusted **governance**

- Greater **public understanding** of how health data is used by companies to support research
- Robust **protections** for people's private information
- Clear **processes** to share the benefits of research using health data

Five principles have been published; industry is broadly supportive

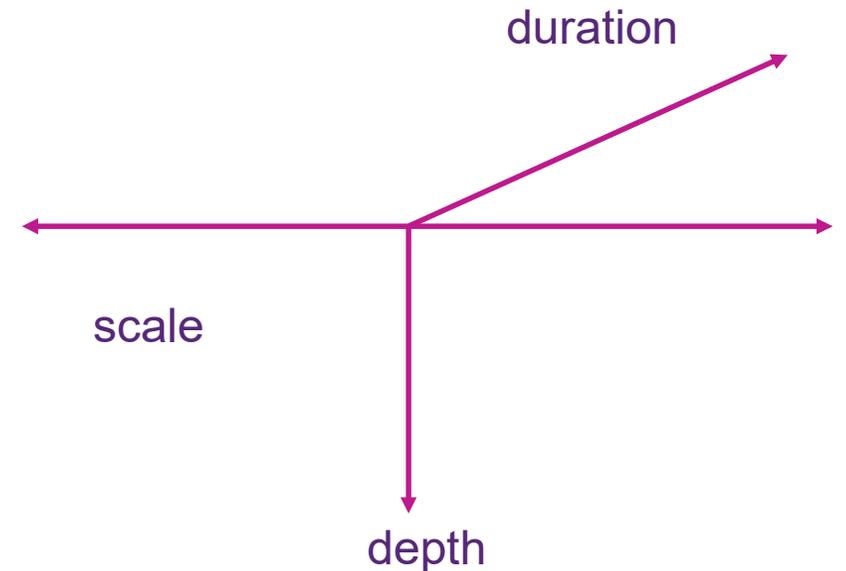
The use of health data spans the entirety of the development and use of new medicines



Harnessing the opportunities

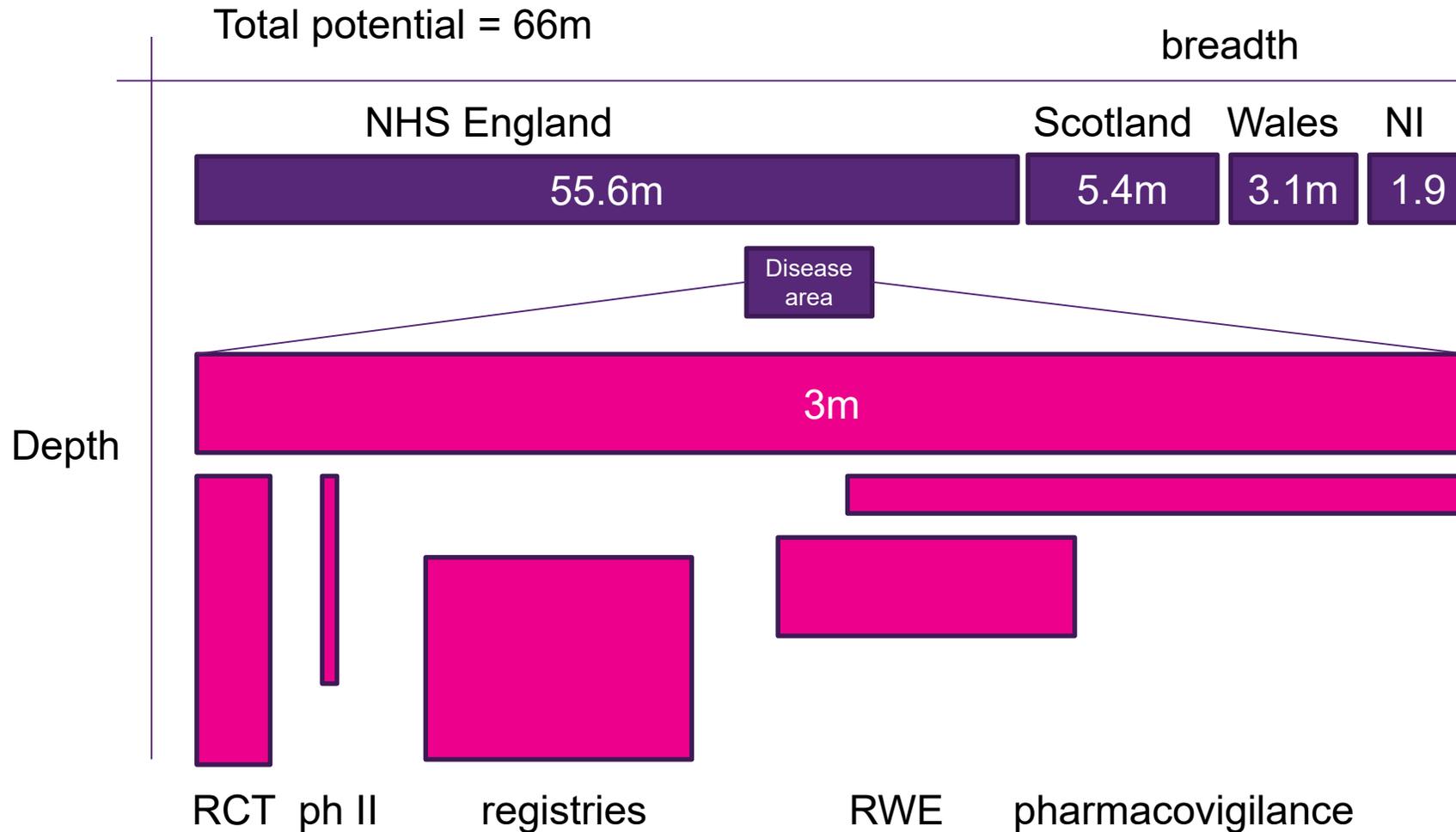
Health Datasets typically have **three dimensions**

- **Scale** – the number of patients
(with consistent data)
- **Depth** – the volume of data
(consistently collected on each patient)
- **Duration** – the longitudinal duration of consistent follow-up



Each research project requires different combinations of these dimensions

Health data has scale, depth and duration



Snapshot of UK industry investment in and use of healthcare data



Flatiron

For maximum utility, cancer datasets need to capture each patient's stage at diagnosis, every treatment cycle (including the specific treatments delivered), and each patient's responses and outcomes. Few health datasets anywhere in the world capture this kind of detail

US company Flatiron created a unique dataset of around two million patients with cancer, which was bought by biopharmaceutical company Roche in 2018

Flatiron's value was generated not by the sheer volume of information in its database, but instead by the way in which each entry in its database was meticulously curated to develop a clinical research-grade dataset, in an enormously labour-intensive process

Examples of the challenges in discovering UK health data

In 2017, a global biopharmaceutical company looking for cancer-related health data was incorrectly informed that comprehensive, national health data was available. However, after six months it became clear that the data available was incomplete and low-quality, particularly regarding prescription data. The delay in accessing the data meant that it was nearly impossible to have the quality issues addressed

In 2019, a global CRO requested data on the number of specific patients attending UK hospitals so that the UK could be included as a potential site for a global clinical trial. However the data took so long to arrive that the UK was not included as a possible location

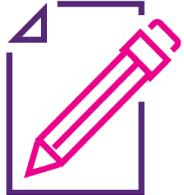
Case studies provided in confidence to the ABPI

Developments

Industry recognises that government initiatives are moving in the right direction, through the Life Sciences Industrial Strategy, NHS Digital, NHSX, and HDR UK:



UK Health Data Research Alliance



Health Data Research Hubs



Health Data Research Innovation Gateway

If these initiatives achieve what they have set out to do, the UK health data landscape can demonstrate improvements that will enable us to unlock the promise that UK health data can offer

Thank you

For any questions please contact Vicky Hayes,
Director, CSO Office vhayes@abpi.org.uk

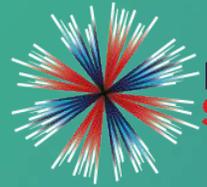
Panel discussion: Perspectives on sustainability opportunities across the Health Data Research Hubs

Chaired by Dame Julie Moore DBE, Professor of Healthcare Systems, Warwick University



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Health Data Research UK



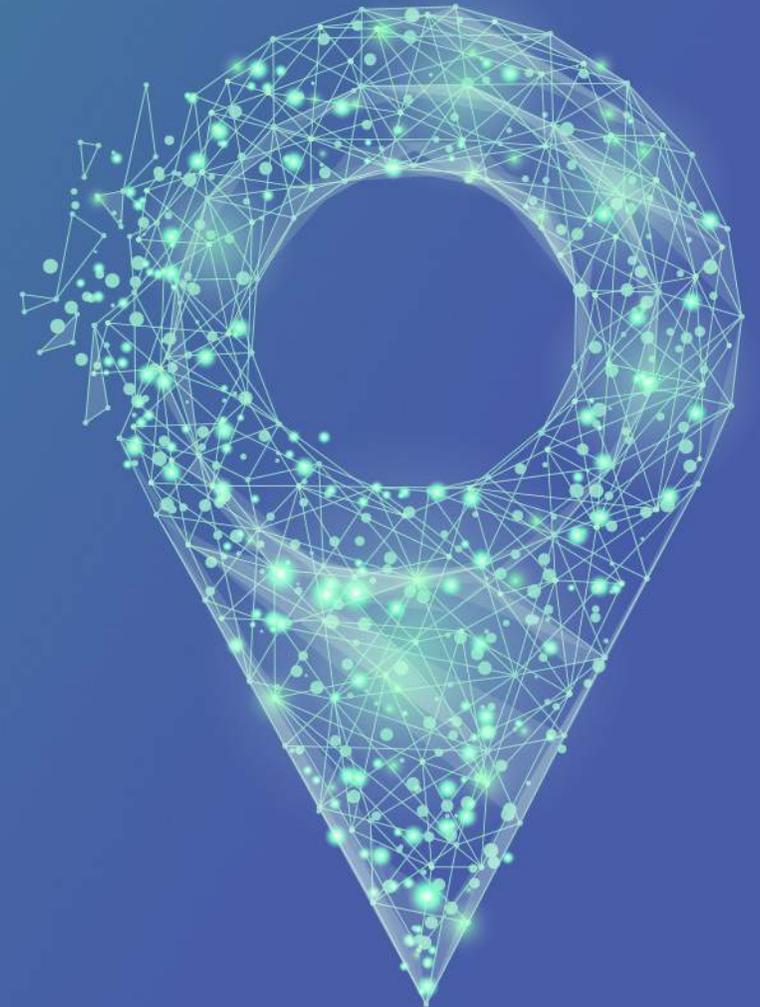
**INDUSTRIAL
STRATEGY**

UK Research
and Innovation

Health Data Research Hubs

Overview and use cases

January 2020



DATA-CAN – The Health Data Research Hub for Cancer

Hub Director: Dr Charlie Davie

DATA-CAN founding partners: UCLPartners, Queens University Belfast, University of Leeds, The Leeds Teaching Hospitals NHS Trust, Genomics England, IQVIA

Overview

- DATA-CAN is a UK-wide partnership that aims to unlock the power of health data to improve cancer care. We make high-quality health data more accessible for cancer researchers, clinicians and other health professionals
- Patients, the public and health professionals are at the heart of what we do. Working in partnership we aim to ensure that health data is used transparently and responsibly, and that the benefits are returned to the NHS and the wider UK community

Service

- Advisory: helping researchers understand UK cancer data & how it can be used
- Curation: assessing quality, linking data, adding/completing key data fields
- Partnerships: creating longitudinal linked primary and secondary datasets for patient approved research

DATA-CAN is not a data controller. All data access is subject to data controller and patient approval.

Example Use Cases

- Understanding how current cancer treatments are used and what could predict response (using anonymized information about cancer types, treatments, outcomes, progression, response, adverse reactions)
- Measuring how experimental treatments perform in the real world (using anonymised data on outcomes after a clinical trial has finished, or within managed access programmes)
- Feasibility study of genetic research and recruitments (using anonymized information about cancer gene mutations, treatments and outcomes)

Discover-NOW

Health Data Research Hub for Real World Evidence

Discover-NOW

Hub Director: Dr Axel Heitmueller

Our partners

Technology partners



Industry partners



NHS, Academic and Third Sector Partners



Data and Research Partners



Overview

- Historically health research has predominantly used data to look retrospectively. Through safe and secure curation of patient information, Discover-NOW is disease agnostic and can be used as a platform to provide leading clinicians, researchers and scientists with access to de-identified linked patient information at scale in near to real time. Through trusted and appropriately governed access it will enable them to look prospectively to identify new patterns in disease thus helping us to better manage many conditions and, in some cases, prevent them happening in the first place. It is a unique partnership to revolutionise the way health information is used to treat and prevent disease in the future
- Discover-NOW has the potential to benefit millions of people, however, we will only realise these benefits if we have the support and trust of our communities and wider population. We are therefore proud to be partnering with OneLondon Local Health Care and Record Exemplar programme in delivering one of the most progressive public engagement programmes in the UK to build trust and confidence in how health information is used. It is only through working in partnership with our communities that we will understand their expectations with regards to how their information should be used, enabling us to design a Hub that operates in line with these, thus building trust

Service

- Discover-NOW is curating a unique single-point, streamlined access to de-identified real-world data, providing unrivalled scale and depth with a real-world, real-time integrated health data source
- Supporting efficient patient uptake into clinical trials and cohort identification through combining North West EHealth FARSITE technology with the Discover-NOW integrated data sets and a population of patients pre-consented for contact for research
- Create an efficient interoperable information source search tools using reducing the barrier of dataset access and novel data linkage whilst providing value in health economics, delivery and policy
- Enable a high-performance analytical environment allowing efficient high demand analysis of longitudinal integrated care records, genomic data, passively and actively collected smart device data, and using cutting edge machine learning tools

Example Use Cases

- Routine clinical dataset to compare Hba1c with different oral hypoglycaemics prescribed – descriptive analysis of a cohort ➤ Real-world evidence for industry to inform new product regulatory submissions and build economic and clinical evidence, post market surveillance of products
- Type 2 Diabetes exemplar** – Linking clinical data (EHR) with patient generated data (PRO, wearables, personal tracking) & real-world outcomes data (hospitalisation, cost to system etc) to enrich the Discover-NOW dataset. A real world intervention in T2D can then be identified and evaluated using this data set. ➤ Connected and enriched data changes to support health and value outcomes using real world data as evidence.
- Researchers can **link images** from scans or pathology datasets to **longitudinal integrated** care records, and deploy machine learning to on this large dataset to **better understand** long term outcomes and complications of interventions ➤ Using machine learning to analyse large complex datasets that wouldn't have previously been feasible, to derive new learning and insights.

Users

BREATHE – The Health Data Research Hub for Respiratory Health



Hub Director: Aziz Sheikh

BREATHE partners: Imperial College London, Nottingham University Hospitals NHS Trust, Swansea University, University of Leicester, Queen Mary University of London, King's College London, Asthma UK, British Lung Foundation, NHS Waltham Forest CCG, Greater London Authority, Respi, StormID, Tiny Medical Apps, Novartis Pharmaceuticals UK, BreatheOx, GE Healthcare Finnamore Partners and Optimum Patient Care.

Overview

BREATHE will help navigate respiratory health datasets from across the UK; creating a digital resource where trained, approved experts can securely access respiratory data on an unprecedented scale and use these to support efforts to transform respiratory health for people from all areas of the UK. The datasets will accelerate studies in asthma, Chronic Obstructive Pulmonary Disease, Interstitial Lung Disease and lung infections. We will provide curated definitions of phenotypes with data dictionaries, meta-data, genome-wide association results and individual level data, through the Secure Anonymised Information Linkage (SAIL) Databank. These will have utility for epidemiological and health services research as well as genomic studies.

Service

Through long term partnerships or specific projects, BREATHE offers:

DATA CONSULTANCY

- Wide-ranging academic and clinical expertise to navigate the availability and utility of datasets for research, innovation and Respiratory health services

EXPERT DATA SERVICES

- Facilitate access to multiple well-curated datasets including clinical interpretation and data analysis
- Bespoke analysis of third-party datasets integrated with BREATHE datasets

PATIENT ENGAGEMENT

- Access to expert respiratory patient opinion on study design and protocol development

PRODUCTS

- Leverage collective use of BREATHE industry partners devices and platforms

Example use cases that we will build on

- Patient inhaler usage: Collaboration with AstraZeneca linking smart inhaler data with routine healthcare data within the SAIL Databank. This should help to understand how patients use their inhalers and improve their health outcomes.
- Strategic Respiratory Genomic collaboration with GSK, which aims to use genomics for target identification and validation.
- Collaboration with Orion Pharma in phenome-wide association studies to inform drug safety and target validation (including respiratory).
- PhD programme on Genomic Epidemiology and Public Health Genomics funded by the Wellcome Trust, including training partnerships with GSK, AstraZeneca, Genentech and Pfizer

Gut Reaction – Health Data Research Hub for Inflammatory Bowel Disease

Hub Director: Prof. John R. Bradley

Gut Reaction partners: Leeds Teaching Hospitals NHS FT, Newcastle Hospitals NHS FT, Pennine Acute Hospitals NHS FT, Liverpool University Hospitals NHS FT, Royal Devon and Exeter NHS FT, Western General Hospital NHS Lothian, Salford Royal Hospital NHS FT



Overview

- Gut Reaction is underpinned by patients enrolled in the NIHR BioResource who have consented for their health records to be accessed for research in the public interest
- Crohn's disease and ulcerative colitis, the main forms of IBD, cause debilitating symptoms affecting ~ 0.5 million people in the UK, and costing UK health budgets ~ £1.5 Billion each year. Treatment is with steroids, immunosuppressants and antibody therapies, but outcomes vary. Over 70% of patients with Crohn's and 15% with colitis ultimately require major surgery. There is an urgent need to better understand why patients respond differently to treatments to improve outcomes and reduce healthcare costs

Service

Data applications via the NIHR BioResource.

- Datasets available include:
 - Case Report Forms
 - Lifestyle questionnaire data
 - Genomic data
- ... and for a subset of c.8,000 patients:
 - Electronic Health Record (EPR)-Pathology ; Dx Imaging results / reports ; Commissioning Datasets (CDS) ; Prescribing, discharge summaries, OP letters

Example Use Cases

- Identifying potential participants with active disease in defined locations to support recruitment to a commercially sponsored phase 2 randomized, double-blind, placebo-controlled study in Crohn's Disease; an access fee has been charged per site
- Industry has provided an educational grant to support the NIHR IBD Bioresource
- Genetic predictors of loss of response to anti-TNF therapy. Data has identified an HLA marker associated with development of antibodies to the key anti-TNF therapies infliximab and adalimumab. The commercially funded study is using data on genetics, prescribing, labs and treatment outcomes to determine if the marker correlates with *loss of response* and identify additional genetic markers to improve the prediction model. Patients at risk can be started on concomitant immunomodulators to reduce risk of loss of response, thereby saving NHS costs

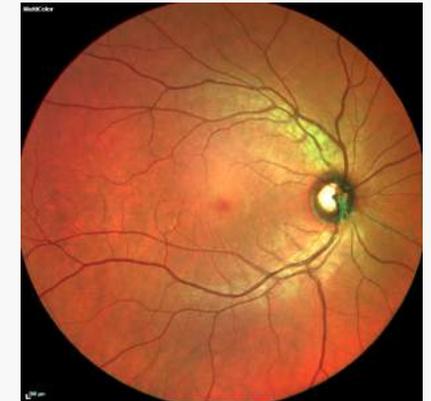
INSIGHT – Health Data Research Hub for Eye Health

Hub Director: Prof Alastair Denniston

INSIGHT partners: University Hospitals Birmingham NHS Foundation Trust, Moorfields Eye Hospital NHS Foundation Trust, University of Birmingham, Google Health UK, Roche, Action Against Age-Related Macular Degeneration

Overview

- INSIGHT is focused on eye diseases such as age-related macular degeneration and glaucoma, and its application to wider health, including diabetes and dementia – the exciting new field of ‘oculomics’
- INSIGHT is the largest ophthalmic imaging database in the world; it will support advanced analytics to develop new insights in disease detection, diagnosis, treatment and personalised healthcare
- INSIGHT is underpinned by public trust, with patients and public at the heart of all we do



Service

- Data access services
 - Single timepoint vs refreshed version-controlled dataset(s)
- Image analytics
- Epidemiological/RWE studies (ACES tool)
- ‘Virtual’ trials
- Model development (conventional/ ML/AI)
- AI interventions – development and validation; independent testing

Example Use Cases

Personalised healthcare in eye health

- Age-related Macular Degeneration is the leading cause of blindness in the UK. By combining longitudinal retinal images, treatment history and outcomes, the INSIGHT dataset can support the development of models/algorithms for **faster triage, stratification of treatment and personalization of care**

Oculomics – the eye as a window into systemic health

- Many changes in general health including dementia are associated with changes in the eyes. By linking retinal images to hospital episode statistics and other systemic data sources, INSIGHT can support the development of **novel diagnostic tests and biomarkers for the detection and monitoring of diseases in the community**

NHS DigiTrial – Health Data Research Hub for Clinical Trials

Hub Directors: Prof Martin Landray (Oxford) and Tom Denwood (NHS Digital)

NHS DigiTrial partners: University of Oxford Big Data Institute, NHS Digital, Microsoft, IBM

Overview

- NHS DigiTrial provides data, expertise and infrastructure to enable efficient and high-quality clinical trials
- Key benefits are increased opportunities for participation in research, reduced cost of developing new treatments, reduced drug costs to the NHS and improved quality of information to patients and their doctors
- The service is designed around the needs of clinical trialists and patients, who will be engaged and involved throughout - including active participation in key decisions
- The service will operate on a "cost recovery plus" model to ensure sustainability and to support on-going service development



Service

- First phase delivers a feasibility service to enable a rapid assessment of the number and location of patients who meet key eligibility criteria
- Available from March 2020 using hospital data with 6 other datasets added by March 2021
- Includes flexible outputs with a range of visualisation tools to support efficient trial planning
- Further phases (subject to funding) to support recruitment, communications and outcomes tracking

Example Use Cases

- **Early feasibility** - Querying national data sets to determine the feasibility of enrolling UK patients into a global clinical trial
- **Protocol refinement** - Detailed and complex queries to enable a study protocol to be fine-tuned using a range of detailed inclusion and exclusion criteria across a number of different data sets
- (Data access is subject to legal and risk-based controls to ensure public trust)

PIONEER – The Health Data Research Hub for Acute Care

Hub Director: Dr Elizabeth Sapey

Pioneer partners: University of Birmingham, University Hospitals Birmingham NHS Foundation Trust, University of Warwick, West Midlands Ambulance Service, Insignia Medical Systems, Birmingham Women’s and Children’s Hospital, Birmingham City University

Overview: Linking acute care health data across providers to innovate this challenged NHS sector

- Acute Care is any unplanned healthcare contact, provided by primary care, community services, 111/999, ambulances and hospitals
- The NHS is facing unmanageable demand across data-siloed acute care services, with 218 patient contacts per minute
- PIONEER will integrate data of how, where and why acutely unwell people access/use health services, enabling innovative companies to develop, test and deliver advances in care, in partnership with NHS service providers, researchers and patients
- Ageless, disease agnostic and multi-morbid cognisant, PIONEER will collate all acute care contacts across 9 NHS providers in depth, supplemented with >150 national hospitals for scalability
- Patients and the public at the executive heart of PIONEER, with engagement, involvement, transparency and guidance
- Robust governance through a Data Access Committee with a responsive data platform to provide curated data at scale and pace

Service

- Data tailored to need
- Flexible: disease/condition; multi-morbidity; drug/device specific; interactions
- Bespoke curation
- A mirror image of an acute care health environment
- Analysis, algorithm development, testing, validation
- Access to clinicians, patients to co-create & road test
- Rapid progression through innovation pipeline

Example Use Cases

- **Pathway innovation tackling diagnostic delay.** 25% of cancers and 20% of chronic diseases are diagnosed in the Emergency department at a late stage after multiple presentations. PIONEER will identify critical points where innovation will enhance early diagnosis and treatment
- **Personalised therapy and sub-populations of response.** PIONEER will be able to identify adverse reactions for new therapeutics, sub populations who respond (or not) to current interventions, identifying where new approaches, biomarkers, devices or pathways should be implemented
- **Self management software for chronic diseases with acute flares.** PIONEER will provide insight into scale, a sandbox to develop algorithms for implementation, end user evaluation and validation to accelerate adoption

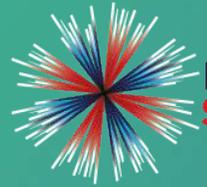


Perspectives on sustainability opportunities across the Health Data Research Hubs

Panellists:

- Dr Charlie Davie, Director, DATA-CAN
- Dr Axel Heitmueller, Director, Discover-NOW
- Professor Aziz Sheikh OBE FRSE FMedSci, Director, BREATHE
- Professor John Bradley, Director and Dr Mary Kasanicki, Gut Reaction
- Professor Alastair Denniston, Director, INSIGHT
- Professor Martin Landray, Director, NHS DigiTrial
- Dr Elizabeth Sapey, Director, PIONEER

HDRUK
Health Data Research UK



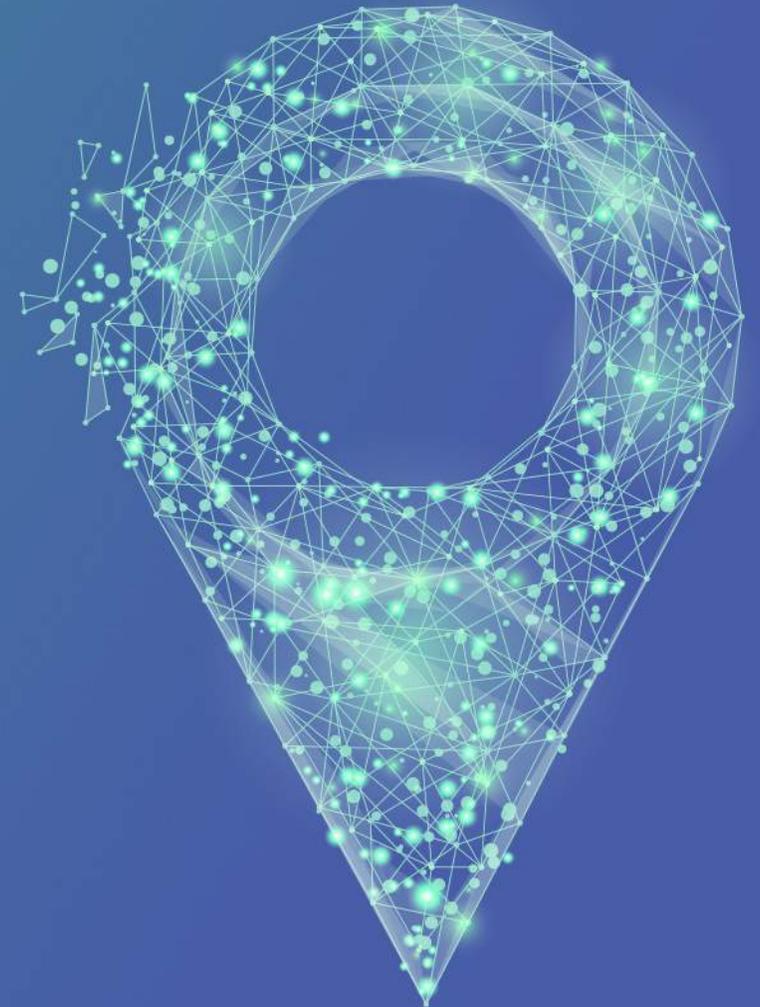
**INDUSTRIAL
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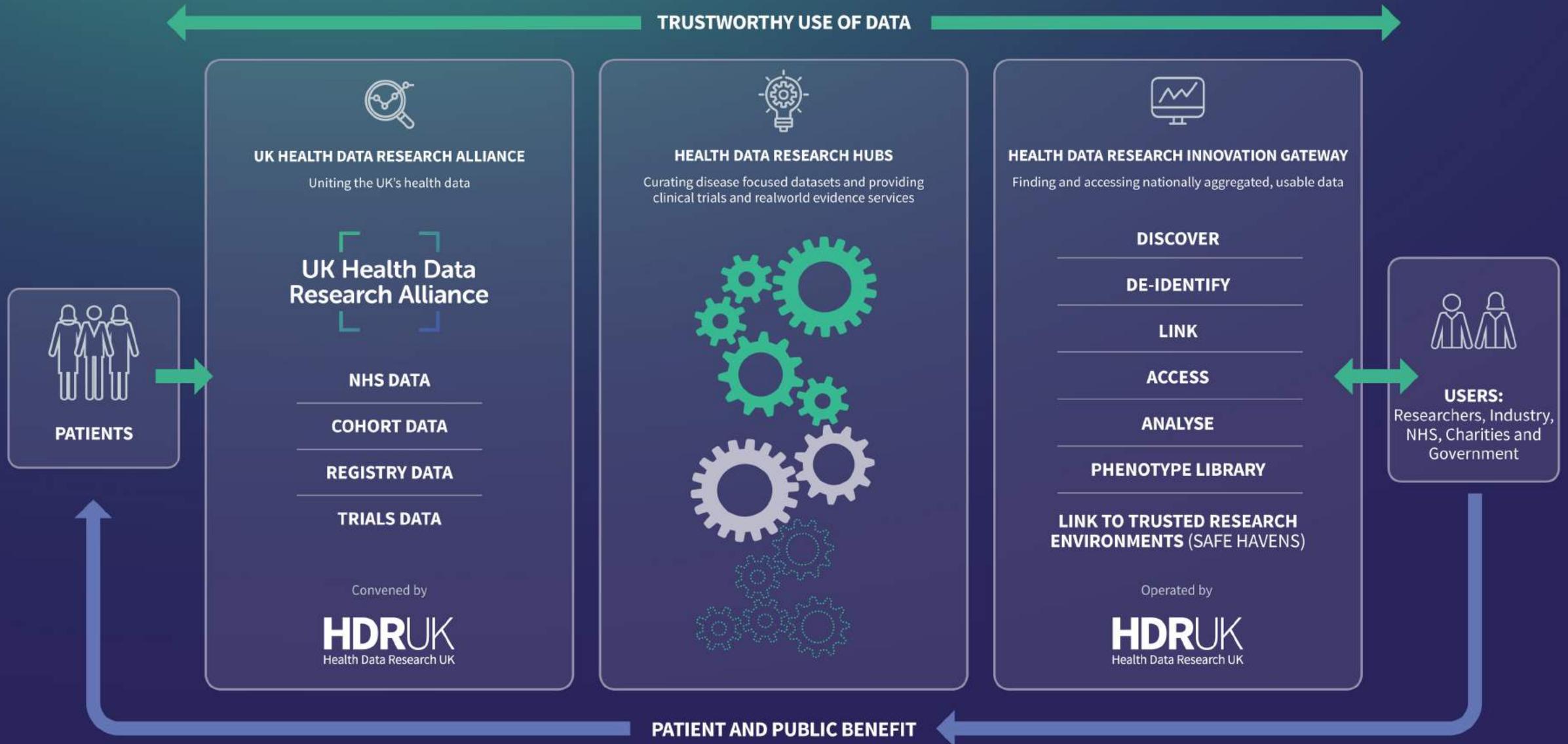
UK Health Data Research Infrastructure – a proposed commercial framework

Caroline Cake

22 January 2019



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



Hubs support a wide array of use cases

Development of **algorithms** for faster triage, stratification of treatment and personalization of care in **Macular Degeneration**
INSIGHT

Querying of national data sets to determine the feasibility of enrolling UK patients into a **global clinical trial**
NHS DigiTrials

Linkage of clinical data (EHR) with patient generated data (PRO, wearables, personal tracking) & real-world outcomes data (hospitalisation, cost to system etc) to identify a **real-world intervention in Type 2 Diabetes**
Discover-NOW

Linkage of smart inhaler data with routine healthcare data to understand how patients use their **inhalers** and improve their health outcomes
BREATHE

Measurement of how **experimental treatments perform** in the real world (using anonymised data on outcomes after a clinical trial has finished, or within managed access programmes)
DATA-CAN

Use of data on genetics, prescribing, labs and treatment outcomes to determine if an HLA marker **correlates** with loss of response to anti-TNF therapy
Gut Reaction

Identification of **adverse reactions** for a new therapeutic, and subpopulations who respond (or not) to current interventions, to identify where new approaches, biomarkers, devices or pathways should be implemented
PIONEER

Principles for Participation align behaviours and intent

Summarised principles:

1. Demonstrate active and ongoing engagement with **patients and the public**
2. Encourage the **availability and use** of data for research and innovation that serves **public interest** purposes, while promoting the protection of **privacy and data security**.
3. Make data Findable, Accessible, Interoperable and Reusable (**FAIR**)
4. Adhere to the GA4GH Foundation Principles and Core Elements for Responsible Data Sharing and use a proportionate approach to the governance of data access based on the five “**safes**” (Safe projects; Safe people; Safe settings; Safe data; Safe outputs)
5. Maximise the benefits of data for research and innovation through **non-preferential access** to data
6. Establish **mutually beneficial** ways of working in partnership in line with principles set out in the Life Sciences Sector Deal
7. Work collaboratively to increase **harmonisation, transparency** and reduce the complexity of data sharing arrangements
8. Contribute to a **joined-up and UK-wide** health data offer for researchers in all sectors

A practical commercial framework is needed for the hubs

1. Promote **public trust** through transparency of commercial arrangements
2. Improve the data access **user experience** through a consistent and clear model for users
3. Ensure that commercial arrangements serve the **public interest**
4. Provide a common language and enable Hubs and other organisations to **collaborate and learn** from each other as they develop sustainable business models



In the future, commercial terms will be made transparent through the Gateway

HDRUK
Health Data Research UK



Health Data Research
Innovation Gateway

Explore & Discover our 414 health datasets from across the UK.

Search and explore information about these datasets. If you have an OpenAthens account, you can log in to enquire about access to these datasets for research and innovation.

[Continue as a guest](#)

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The proposed Commercial Framework accommodates use and outcome-based approaches

Use-based		Outcome-based	
Data Access	Data Service	Share of cost saving	Share of revenue
Description			
Fee for accessing data and data products	Charge for specific data services required to fulfil the user's request	Agreed proportion of cost savings shared with the data custodian attributable to use of the data	Agreed proportion of revenue in product or company shared with the data custodian
Variants			
<ul style="list-style-type: none"> • Frequency of payment: one-off, yearly, other • Free or discounted services for a defined or unlimited period e.g., basic level of service • Fee stratified by dataset quality level • Fee stratified by type of user or data use 	<ul style="list-style-type: none"> • Charge per service type • Charge per time required to provide service • Charge stratified by type of user or data use 	<ul style="list-style-type: none"> • Proportion of cost savings realised by partner • Discounted services for the data custodian/NHS for products developed using the data 	<ul style="list-style-type: none"> • Multiple one-off fees linked to product sales/milestones • Royalty/revenue share from products developed using the data • Profit share: portion of the profits generated by partner • IP ownership share • Equity share/Golden share

Many organisations currently focus on use-based elements

Use-based		Outcome-based	
Data access	Data service	Share of cost saving	Share of revenue
   			

Hubs models will differ according to their strategic choices

Strategic choices

- What sources of sustainability does the hub have? e.g., from other funders
- What type of public benefit is the hub seeking to generate through its business model, for example, encouraging innovation and/or returning financial benefit to the NHS?
- Who can access the data, and what are the access guidelines?

Hubs will need to have their **patient and public advisors closely involved in their strategic decision making** as they develop their model and work with the appropriate regulatory bodies, including the Health Research Authority

Working groups: Questions

1. Given the types of use cases that the hubs are envisaging, what are the benefits and risks associated with the proposed Commercial Framework, and have we missed any important elements?
2. How should we engage and involve members of the public, patients and practitioners in the ongoing development and delivery of this approach?

Working groups: Format

- Each group will be facilitated to focus on the 2 questions we have posed
- 45 minutes discussion – then brief report back from the facilitators before the next break

Breakout group details

The coloured dot on your badge indicates your group and room.

- Group 1 - **Yellow**, Wolfson Room (Ground Floor)
- Group 2 - **Red**, Laurie Landeau Room (Ground Floor)
- Group 3 - **Purple/Pink**, Curie Room (Basement)
- Group 4 - **Green**, Franklin Room (Basement)
- Group 5 - **Blue**, Ann Rylands Room (First Floor)

The secretariat will help you find your room.

Working groups: Colleagues viewing live stream

Please feel free to provide your input and responses to these questions by emailing us at events@hdruk.ac.uk

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Break-out session

Chaired by Caroline Cake, Chief Operating Officer and Deputy Director at Health Data Research UK



Network: 41PortlandPlace-Guest
WifiCode: HelloFellow1

Working groups: Question 1

Given the types of use cases that the hubs are envisaging, what are the benefits and risks associated with the proposed Commercial Framework, and have we missed any important elements?

Working groups: Question 2

How should we engage and involve members of the public, patients and practitioners in the ongoing development and delivery of this approach?

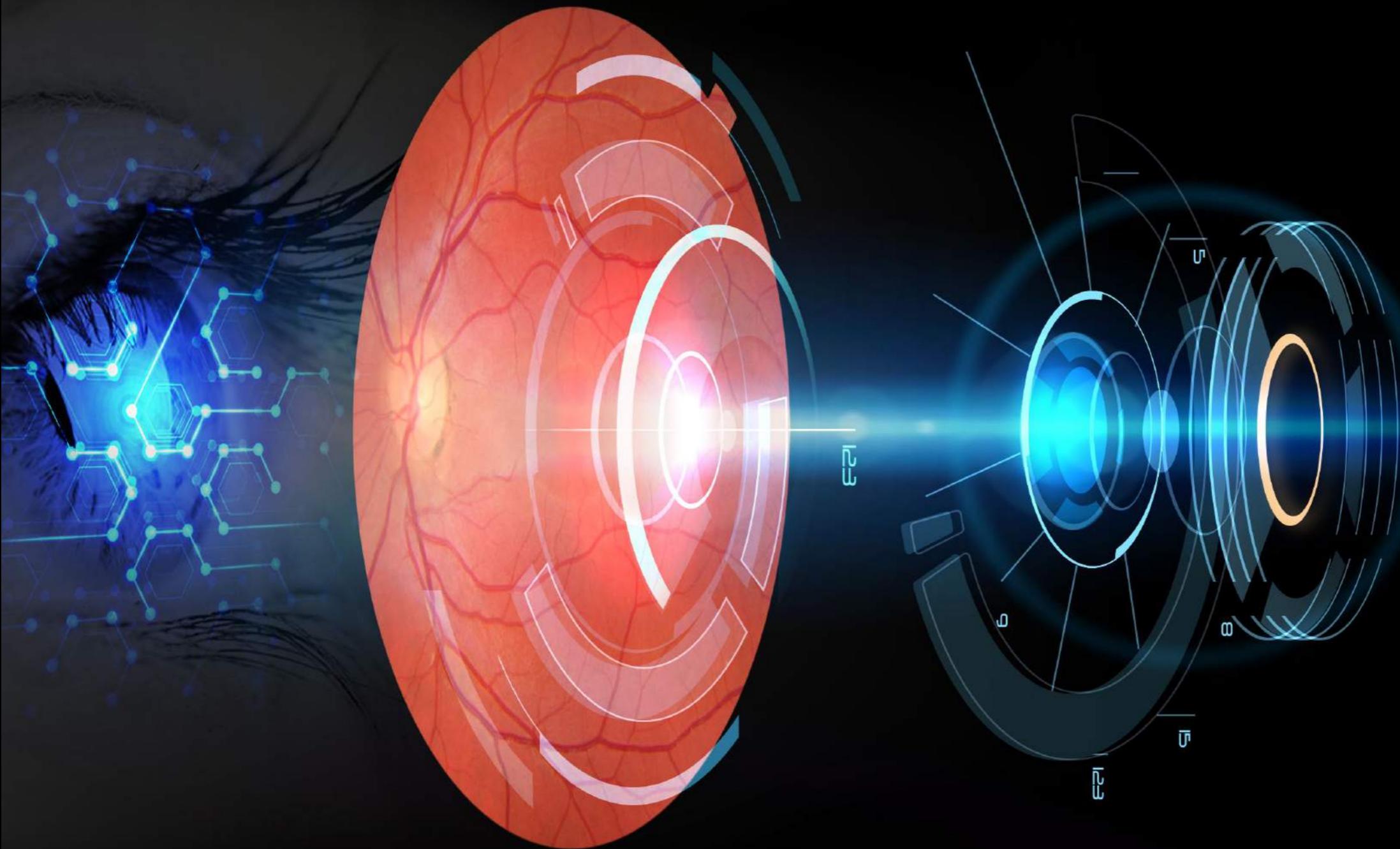
Review of key themes and additional discussion

Chaired by Professor Sir John Tooke FMedSci, Chair of Collaboration for the Advancement of Sustainable Medical Innovation (CASMI) and Professor Andrew Morris CBE FRSE FMedSci, Director of Health Data Research UK

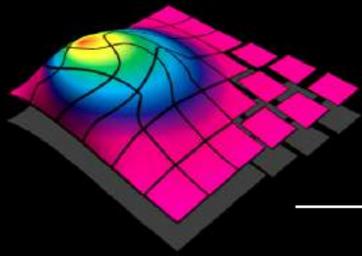
Closing remarks

Professor Sir John Tooke FMedSci, Chair of Collaboration for the Advancement of Sustainable Medical Innovation (CASMI)
Professor Andrew Morris CBE FRSE FMedSci, Director of Health Data Research UK

Preparing NHS Datasets for Commercial Partnerships



Pearse Keane
Moorfields Eye Hospital and
UCL Institute of Ophthalmology

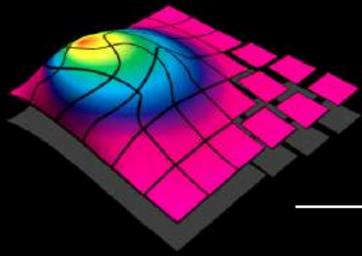


Background

Associate Professor
UCL Institute of
Ophthalmology

Consultant
Ophthalmologist
Moorfields Eye Hospital





The Problem

OPHTHALMOLOGY SURPASSES ORTHOPAEDICS IN ANNUAL ATTENDANCE FIGURES

The latest statistics from NHS Digital reveal that ophthalmology outpatient activity was greater than any other specialty in 2017–2018

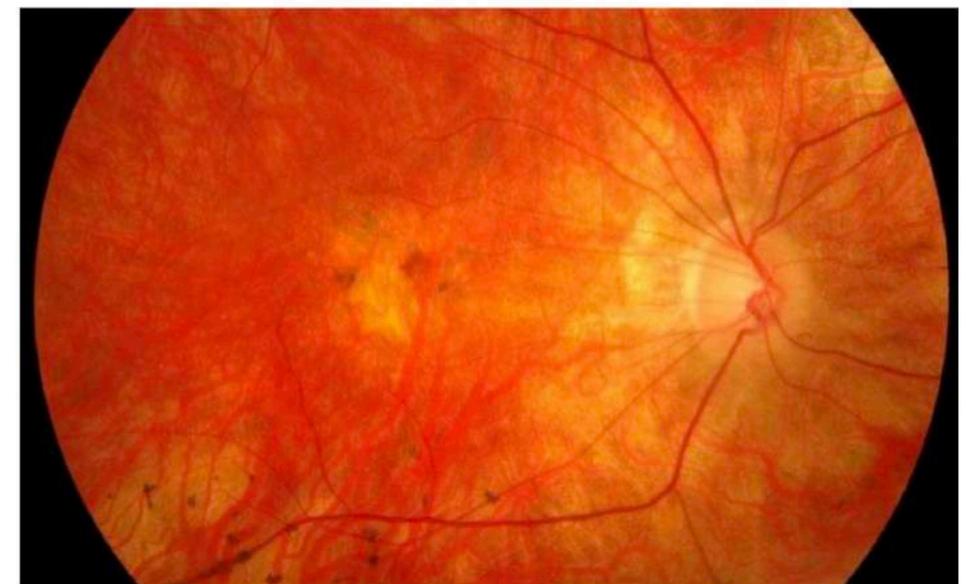
17 Oct 2018 | by Selina Powell

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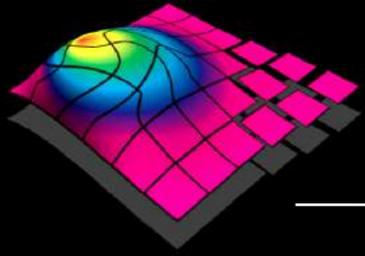
News

Patients are going blind because of long NHS delays, investigators warn



Charities warned that a growing national crisis was leaving patients in danger of visual impairment

January 2020

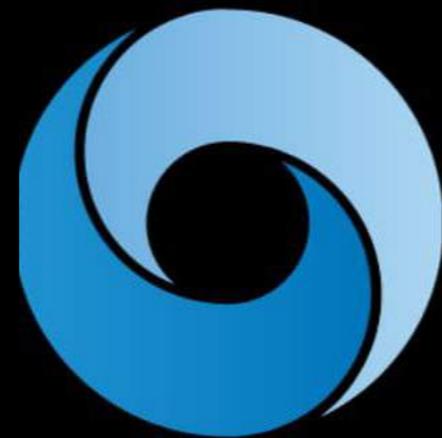


July 2016

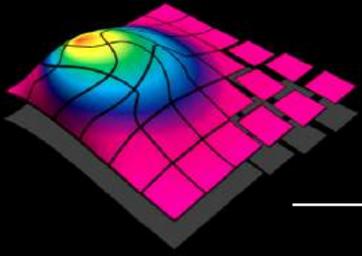
Moorfields Eye Hospital



NHS Foundation Trust



DeepMind

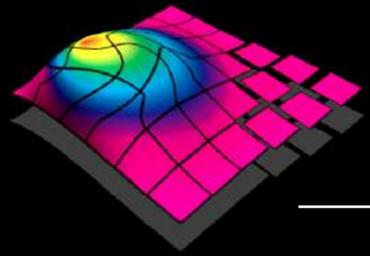


July 2015



- 1. Datasets Quantity and Quality**
- 2. Technical Feasibility**
- 3. Ethical / Governance Requirements**

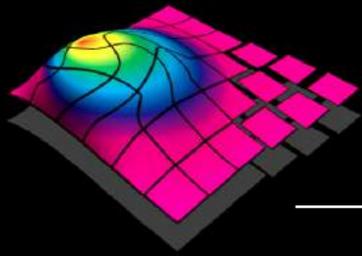




When all questions answered...



*Research
Collaboration
Agreement*



Website

Home > Your eye health > DeepMind Health research partnership > DeepMind Health Q&A

DeepMind Health
research partnership

DeepMind Health Q&A

Latest updates -
DeepMind Health

Partnership video -
DeepMind Health

Eye conditions

Looking after your eyes

Yes EYE Can

Yes Eye Did

Anatomy of the eye

DeepMind Health Q&A

How did the partnership come about? 

What will the project involve? 

What is the project trying to achieve? 

How long will the project last? 

How much data has DeepMind been given access to? 

Do patients have to give their consent for their data to be used? 

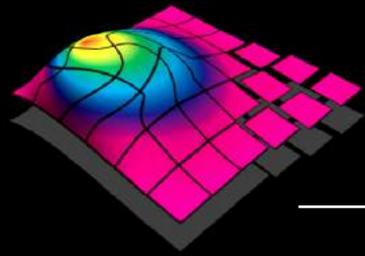
What are the data protection measures in place for this project? 

Will any further patient information be shared between Moorfields and DeepMind in future? 

How can patients be sure that no identifiable data is being shared with DeepMind? 

What processes are in place to ensure the data transferred to DeepMind is only ever seen by the research team? 

What approvals has DeepMind been given for this research project? 



Research Protocol

F1000Research

F1000Research 2016, null:null Last updated: 10 JUN 2016



STUDY PROTOCOL

Automated analysis of retinal imaging using machine learning techniques for computer vision

Jeffrey De Fauw¹, Pearse Keane¹, Nenad Tomasev¹, Daniel Visentin¹,
George van den Driessche¹, Mike Johnson¹, Cian O Hughes¹, Carlton Chu¹,
Joseph Ledsam¹, Trevor Back¹, Tunde Peto², Geraint Rees³, Hugh Montgomery⁵,
Rosalind Raine⁴, Olaf Ronneberger¹, Julien Cornebise¹

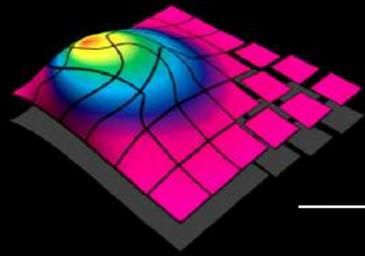
¹Google DeepMind, London, EC4A 3TW, UK

²Moorfields Eye Hospital NHS Foundation Trust, London, EC1V 2PD, UK

³Alexandra House University College London, Bloomsbury Campus, London, WC1N 3AR, UK

⁴Department of Applied Health Research, University College London, London, WC1E 7HB, UK

⁵Institute of Sport, Exercise and Health, London, W1T 7HA, UK



Patient-Centred Research

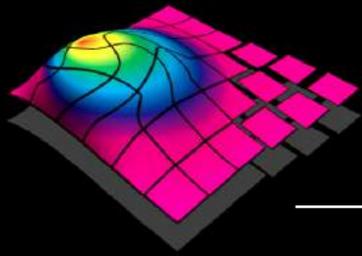


Macular Society

*Royal National
Institute for the Blind*

Fight For Sight UK

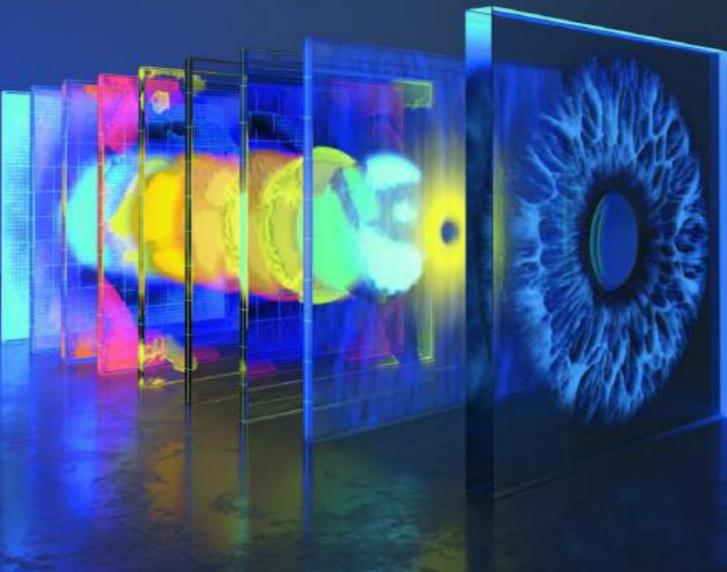
Patient Engagement Event, Sept 2016



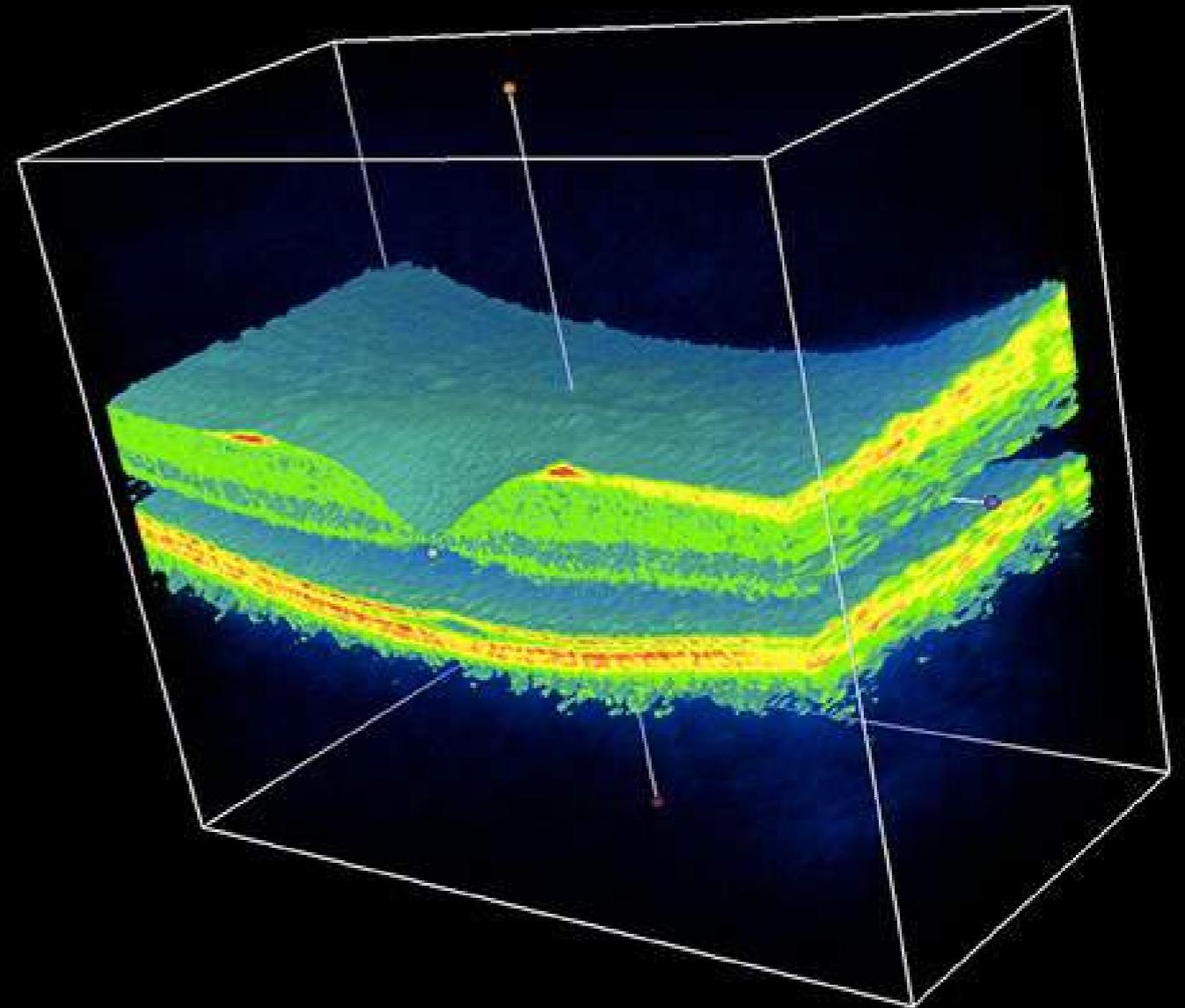
September 2018

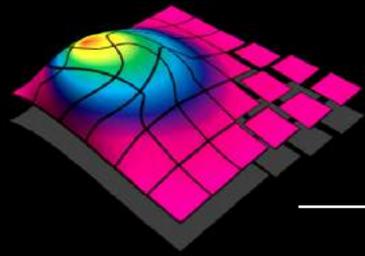
nature
medicine

SEPTEMBER 2018 VOL 24 NO 9
www.nature.com/naturemedicine



AI accelerates diagnosis
NAD⁺ biosynthesis and high-risk hospitalizations
Targeted microbiome therapy for thrombosis





Value-Back?

1. Reputation

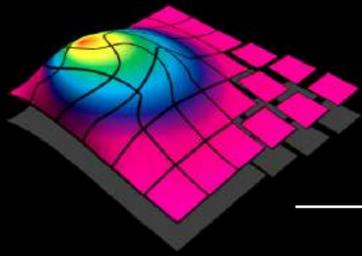
2. Talent

3. Free Use of Algorithm

4. Peer-reviewed Publications

5. Research Grants

6. Technical Infrastructure and Experience



The AlzEye Study

**3 million plus OCT volumes in
>300,000 patients >40 years**



What is HES?

- Hospital Episode Statistics (HES): Data warehouse that contains details of:
 - Inpatient admissions (1989/90 – present)
 - Outpatient appointments (2003/4 – present)
 - Accident and Emergency (A&E) attendances (2007/8 – present)
- Record based system that covers all NHS Trusts in England



hal
@halhod

I've covered health data for a while, including the Deepmind/Royal Free story, and have never seen any team "dot is and cross ts" quite like @pearsekeane and @sktywagner have. the potential for their system is mindblowing, and they're building it while respecting patient rights

5:22pm · 20 Dec 2019 · Twitter Web App

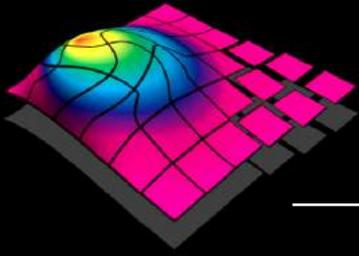
1 Reply 3 Retweets 9 Likes



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and a BP of 150/85 mm Hg.

Photo Library

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An AI Pipeline for the NHS

INSIGHT

Health Data Research Hub for Eye Health

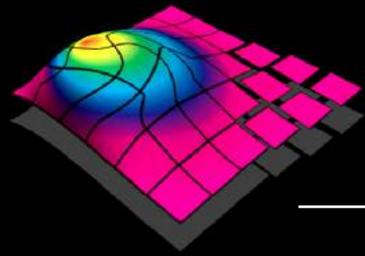
INSIGHT is focused on eye disease and its application to wider health, including diabetes and dementia. It will use anonymised large-scale data and advanced analytics, including artificial intelligence, to develop new insights in disease detection, diagnosis, treatments and personalised healthcare.



INDUSTRIAL
STRATEGY

UK Research
and Innovation





Next Steps?

1. Towards Implementation
2. INSIGHT Health Data Research Hub
3. Independent Research Programme
4. Reinventing the Eye Exam!

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