HDRUK
Health Data Research UK

INDUSTRIAL STRATEGY | UK Research and Innovation

Improving the use and utility of UK routine data

UK-Japan symposium on data-driven health
26 February 2020, London

25 February 2020

The Academy of Medical Sciences

AMED 国立研究開発法人 日本医療研究開発機構 Japan Agency for Medical Research and Development

JSPS

The Next 15 minutes

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The Academy of Medical Sciences
AMED
国立研究開発法人 日本医療研究開発機構
Japan Agency for Medical Research and Development
JSPS

- Gearing an entire country for quality health care, research and innovation
- Data Science as a Catalyst for Change
- With big data goes big responsibilities

The 4th Industrial Revolution

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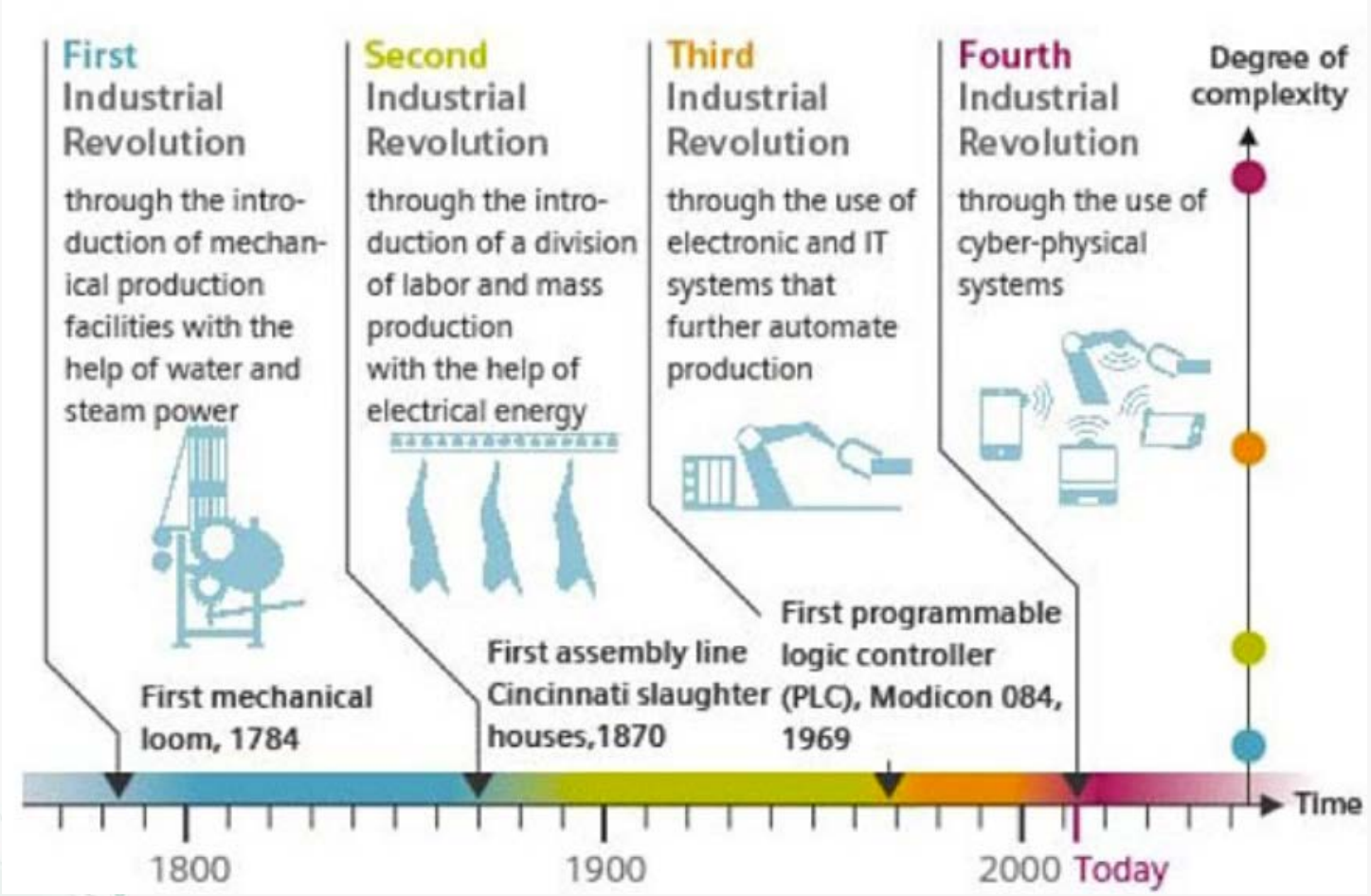
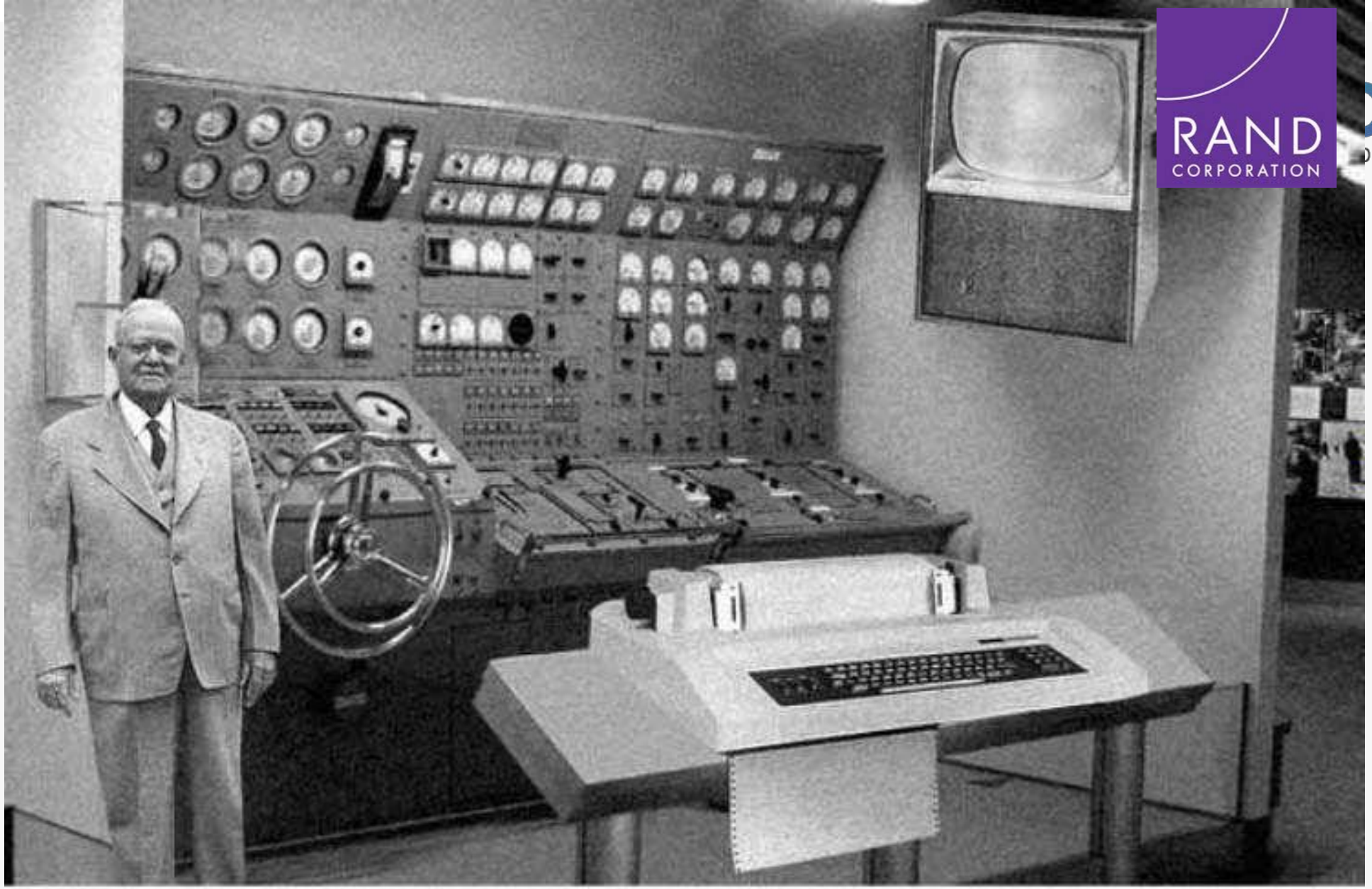
WORLD ECONOMIC FORUM



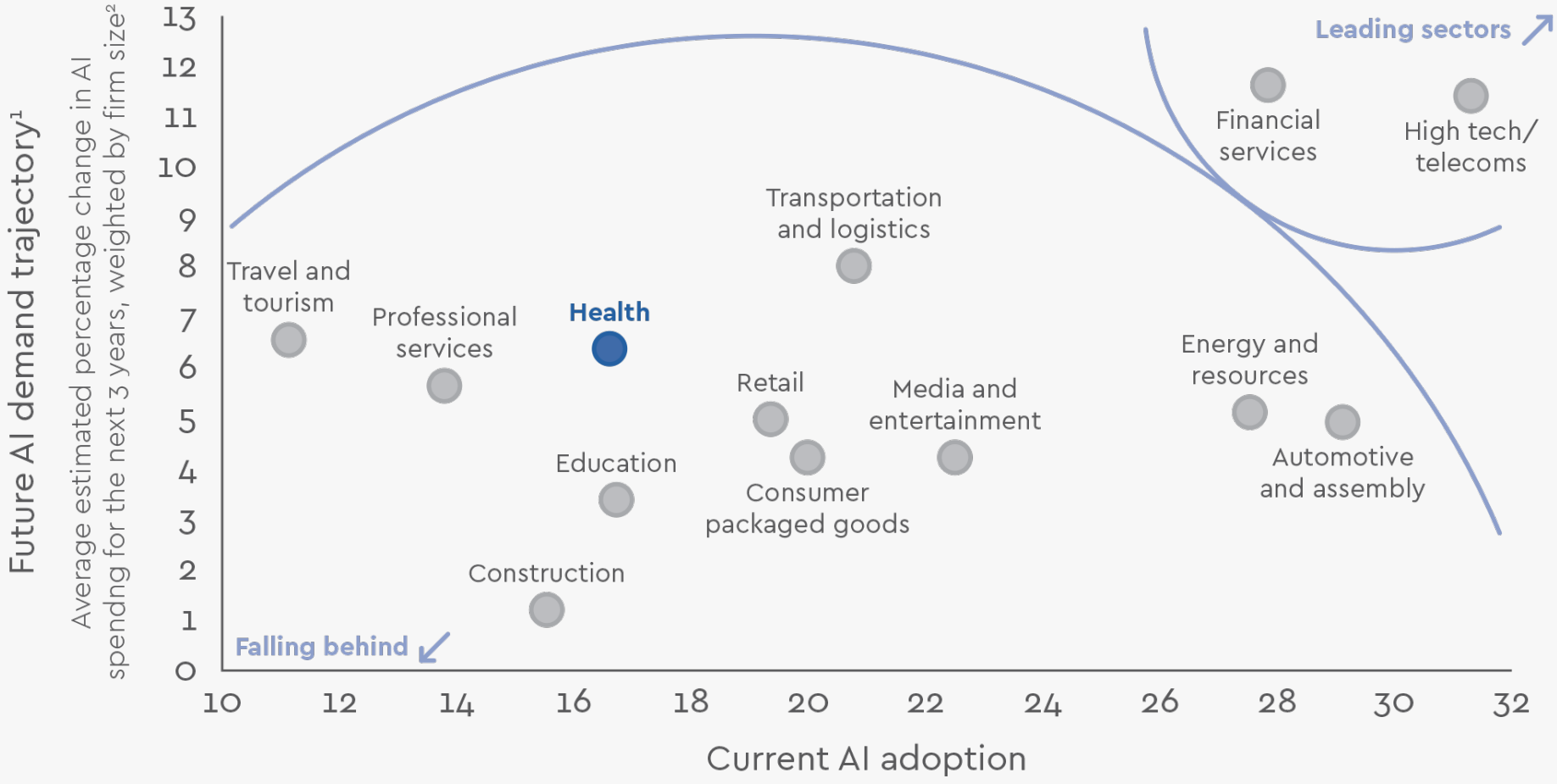


Scientists from the RAND Corporation have created this model to illustrate how a "home computer" could look like in the year 2004. However the needed technology will not be economically feasible for the average home. Also the scientists readily admit that the computer will require not yet invented technology 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.

RAND CORPORATION

DRUK Data Research UK

Sectors leading in Data Science and AI adoption today



Percentage of firms adopting one or more AI technologies at scale or in a core part of their business, weighted by firm size²

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.

HDR UK
Health Data Research UK

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.

About Us

HDRUK
Health Data Research UK

Operating Model

- Ten Funders - **we are not a funder**
- Separate legal entity, tiered structure,
- Wellcome Trust base – **not a data controller**
- **"Lean"**

Substantive Scientific Sites

- Science, leadership, NHS partnership and delivery

Single set of Terms and Conditions for collaborations

- Core platforms, inter-operability, standards, governance, meta-data dictionaries
- Partnership – coordinating and associate ROs
- £37M now £120M Initial Investment

Early days!

- - 520 days old;UK Biobank 4894 days old

MRC Medical Research Council
British Heart Foundation
Chief Scientist Office
EPSRC Engineering and Physical Sciences Research Council
E·S·R·C Economic & Social Research Council
Ymchwil Iechyd a Gofal Cymru Health and Care Research Wales
HSC Public Health Agency Research and Development
NHS National Institute for Health Research
wellcome

Partnerships at scale

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

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

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

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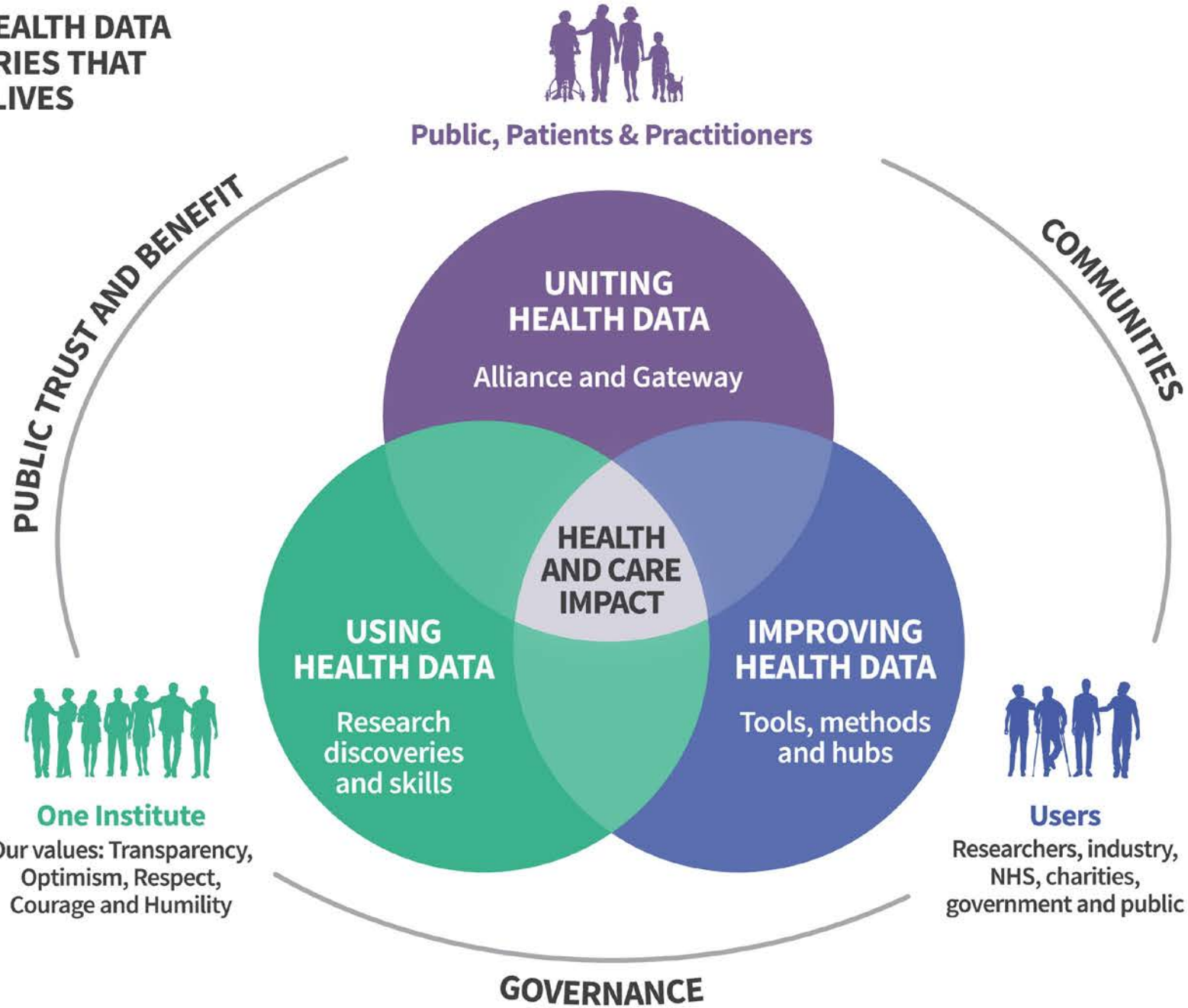
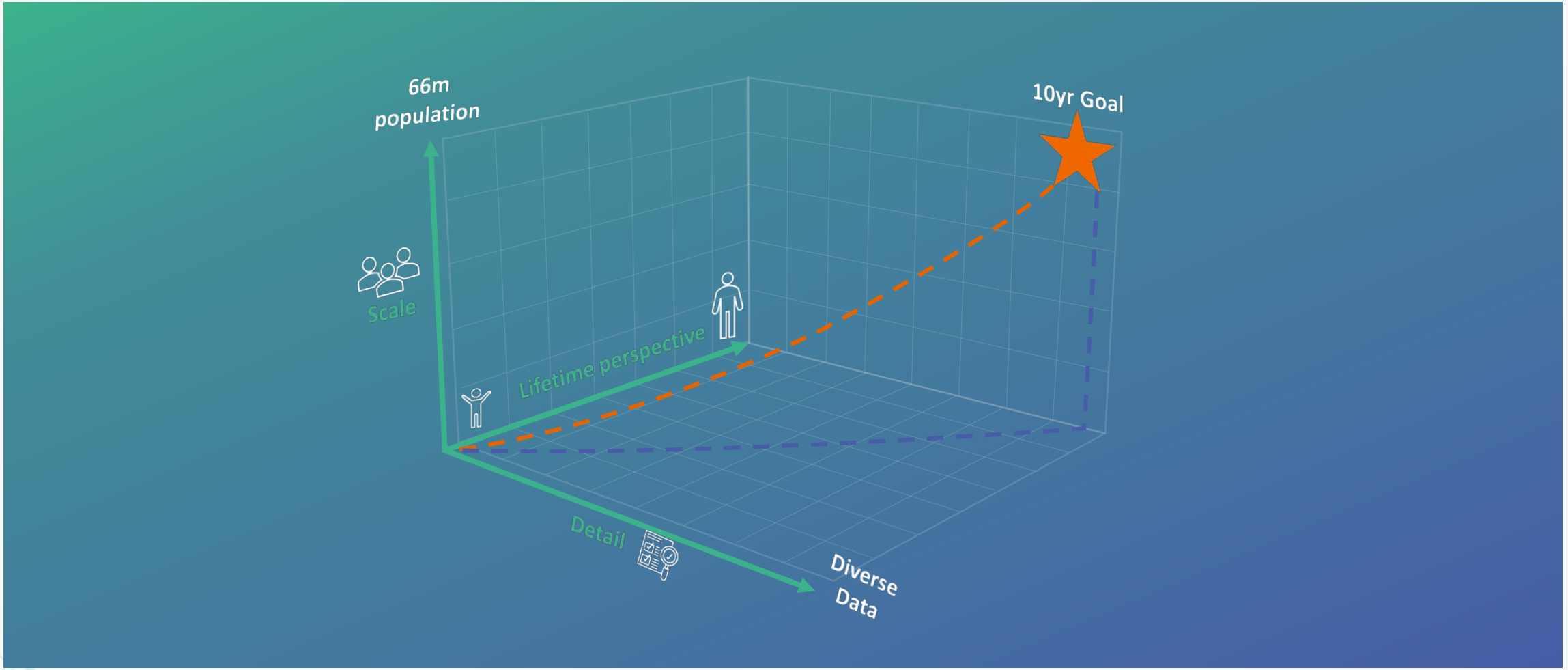


Our 10-year ambition for scale



Improving the use and utility of UK routine data
A Robust UK Health Data Research Infrastructure

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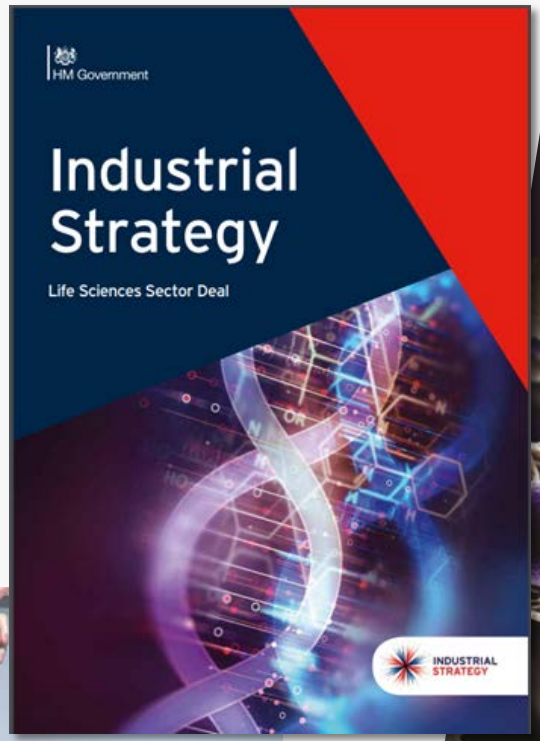
HDRUK Health Data Research UK

- 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



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

HDRUK
Health Data Research UK

Gearing up the UK for quality health care, research and innovation

Enabling data science and innovation as a catalyst for change

But with big data comes with big responsibilities!

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

HDRUK
Health Data Research UK

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

abpi Bringing medicines to life

Pistoia Alliance

CATAPULT Medicines Discovery

Office for Life Sciences

NHS National Institute for Health Research

amrc ASSOCIATION OF MEDICAL RESEARCH CHARITIES

Inspired by global collaborations

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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.

BIOLOGY PHYSICS ETHICS INFORMATICS ENGINEERING CHEMISTRY

W3C®

S.W.I.F.T.

GSMA™

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

NHS England | CPRD | GIG CYMRU NHS WALES | Genomics england | Public Health England | HDRUK Health Data Research UK | NHS Digital | HSC Public Health Agency Research and Development | ISD Scotland | NHS National Services Scotland | RCGP Royal College of General Practitioners Research & Surveillance Centre

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

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

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

Scale: High quality data with UK-wide coverage

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

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

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

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

A strong public advisory board

Patient, carer and public voice embedded in governance via Public Advisory Board


Kush Kanodia


Rachel Plachcinski


Margaret Rogers


Ben Johnson


Sarah Brooke


Claire Cooper


Angela Coulter


Colin Wilkinson

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

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TRUSTWORTHY USE OF DATA

PATIENTS

UK HEALTH DATA RESEARCH ALLIANCE

Uniting the UK's health data

UK Health Data Research Alliance

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

Convened by HDRUK Health Data Research UK

HEALTH DATA RESEARCH HUBS

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

HEALTH DATA RESEARCH INNOVATION GATEWAY

Finding and accessing nationally aggregated, usable data

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

Operated by HDRUK Health Data Research UK

USERS:
Researchers, Industry, NHS, Charities and Government

PATIENT AND PUBLIC BENEFIT

What we have been doing since September 2018

Four-year programme launched in September 2018

UK Health Data Research Alliance launched in February 2019

DIH prospectus launched May 2019

7 Hubs launched September 2019 and started 1 October 2019

BREATHE Health Data Research Hub · DATA-CAN The Health Data Research Hub for Cancer · Discover-NOW Health Data Research Hub for Real World Evidence · Gut Reaction Health Data Research Hub · INSIGHT Health Data Research Hub · PIONEER Health Data Research Hub · NHS DigiTrial

Milestone 1 met by 100% hubs 31 December 2019

Livestreamed event: Realising patient and NHS benefits from health and care data: From policy to practice 22 January 2020

Health Data Research Innovation Gateway

Gateway MVP launch with >400 datasets February 2020

Gateway Rapid Development Task January – March 2020

September 2018 · 2019 · 2020

Design & dialogue September 2018 – April 2019

amrc · Pistoia Alliance · NHS National Institute for Health Research · Office for Life Sciences · abpi · CATAPULT Medicines Discovery · NIHR Research Design Service North East and North Cumbria

11 Sprints March 2019 – Dec 2019

Industry engagement events UK, US, Europe October 2019 onwards

27 Alliance members announced January 2020

Alliance Symposium 4 February 2020

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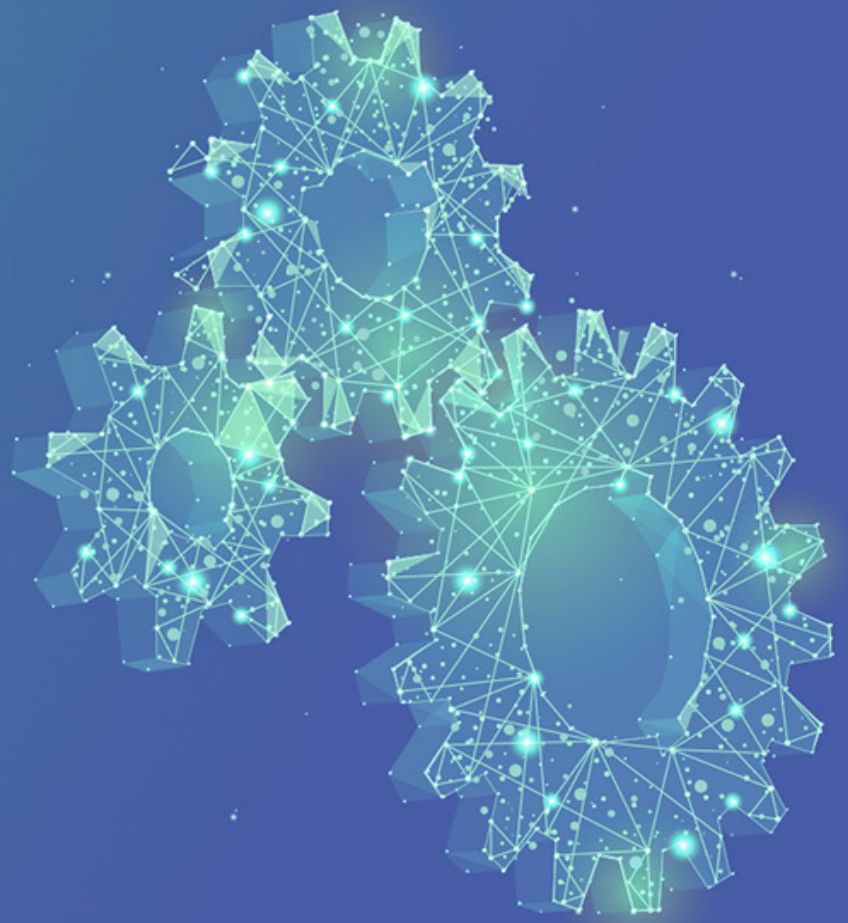
Alliance



Strategic Partnerships – NHS Digital

- Noel Gordon, Sarah Wilkinson, Tom Denwood

- Priority areas:
  - Joint strategy on research data services
  - Infrastructure
  - Training
  - Trials
  - Governance

UK Health Data Research Alliance

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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.

Knotty Issues

- *Information governance data access*
- *Data quality*
- *Sustainability and commercial models*
- *Meaningful public engagement*
- *Technology strategy and standards*
- *Inter-operability*

UK Health Data Research Alliance in numbers

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27 Alliance members

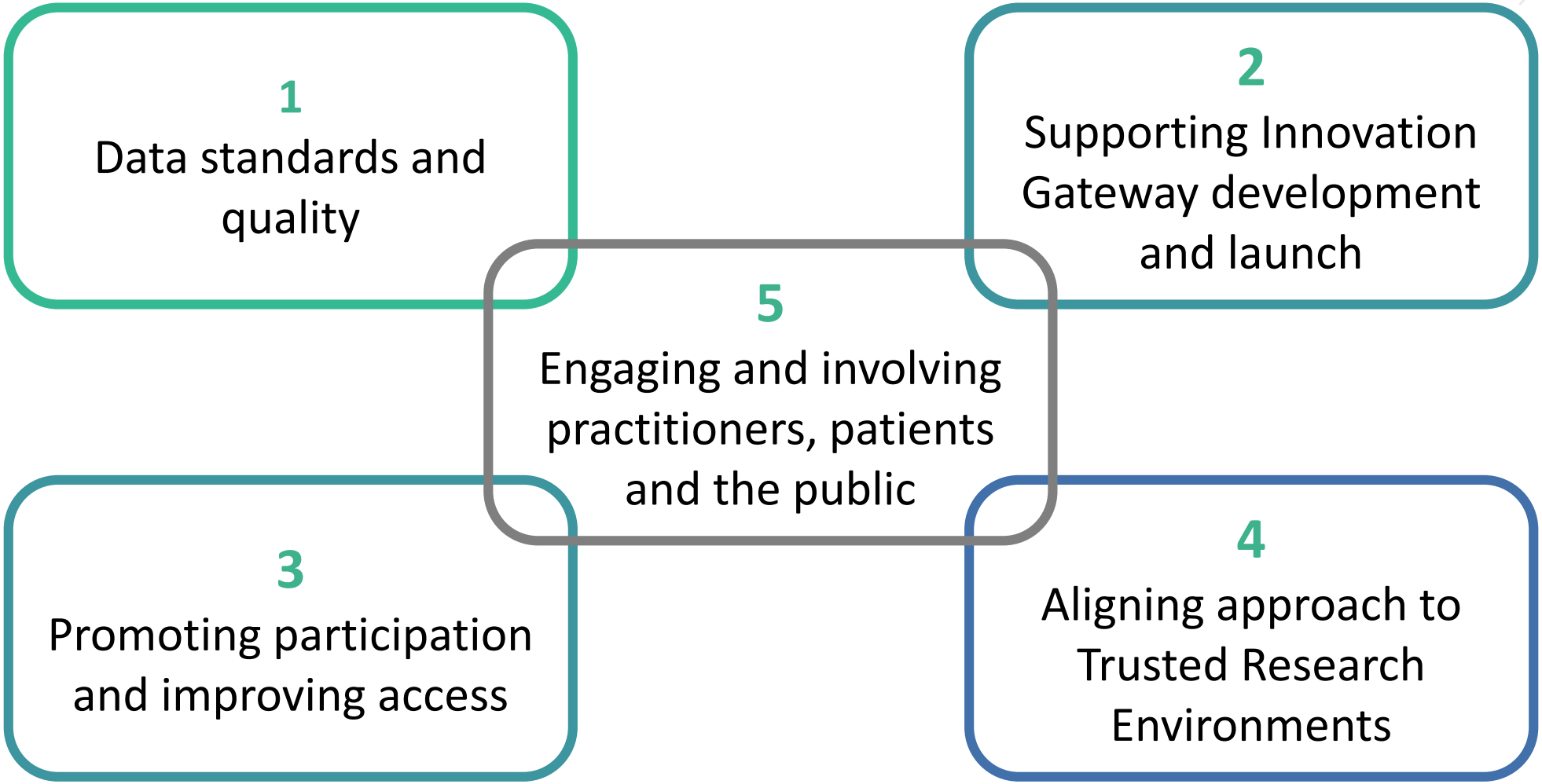
- Barts Health NHS Trust
- Nottingham University Hospitals NHS Trust
- University Hospitals Birmingham NHS Foundation Trust
- Clinical Practice Research Datalink
- Cystic Fibrosis Trust
- The Brain Tumour Charity
- NHS Digital
- NHS England
- NHS Scotland
- NHS Wales
- Health and Social Care Northern Ireland
- NHSX
- Genomics England
- UK Biobank
- National Institute for Health Research (NIHR) Bioresource
- Public Health England
- HQIP
- Royal College of General Practitioners (RCGP) Research and Surveillance Centre (RSC)
- Avon Longitudinal Study of Parents and Children (ALSPAC)
- Guy's and St Thomas' NHS Trust
- UKCRC Tissue Directory and Coordination Centre
- University Hospitals of Leicester NHS Trust
- University College London Hospitals NHS Foundation Trust
- Human Fertilisation and Embryology Authority
- Great Ormond Street Hospital for Children NHS Foundation Trust
- Nottinghamshire Healthcare NHS Foundation Trust
- South London and Maudsley NHS Foundation Trust

5 working sub-groups

- **Data Quality & Standards** convening **>30** data officers
- **Practitioner, Public & Patient Involvement and Engagement** (PPPIE)
- Supporting development of the **Innovation Gateway** with **>400** datasets discoverable
- **Promoting participation and improving access >300** viewers of live streamed event
- Aligning approach to **Trusted Research Environments**

UK Health Data Research Alliance workstreams

UK Health Data Research Alliance



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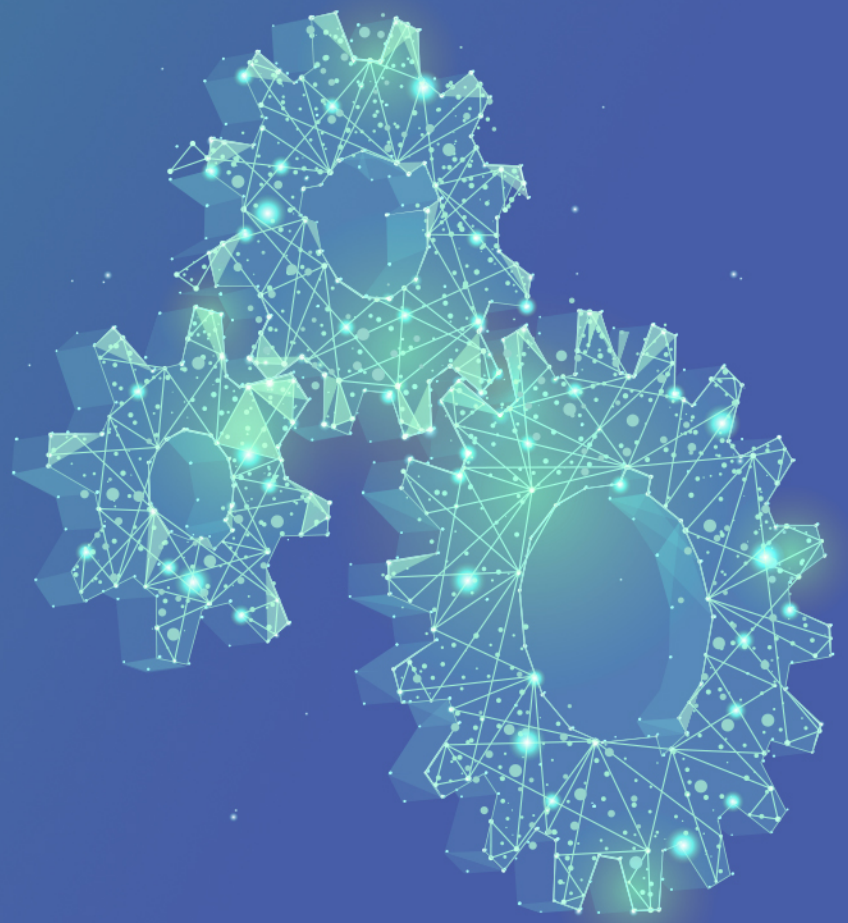
Hubs



Applications will be considered by the panel based on pre-determined criteria

- **Make datasets available** for research, development and innovation across industry, academia and the NHS
- **Curate new or existing data** for research, development and innovation taking place across industry, academia and the NHS
- **Provide services** to meet identified needs for research, development and innovation taking place across industry, academia and the NHS
- **Deliver** against agreed milestones
- Engage with and involve **patients and the wider public**
- Demonstrate **capabilities and partnership**
- Enable **wider impacts** and linkage to the aims of ISCF and the Life Sciences Industry Strategy
- Provide **value for money**

7 Health Data Research Hubs

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BREATHE
Health Data Research Hub

DATA-CAN
The Health Data Research Hub for Cancer

Discover-NOW
Health Data Research Hub for Real World Evidence

Gut Reaction
Health Data Research Hub

INSIGHT
Health Data Research Hub

PIONEER
Health Data Research Hub

NHS DigiTrial

UK Health Data Research Hubs in numbers

100% of the **7** hubs met milestone 1;

involving **>100** organisations from NHS, academia, industry and charities involved

in **22** locations across England, NI, Scotland & Wales

>4 high profile global partnerships

Discover-NOW AstraZeneca

INSIGHT Health Data Research Hub Roche

Gut Reaction Health Data Research Hub

Microsoft

NHS DigiTrial NOVARTIS

6 disease areas prioritised

Cancer
Diabetes
Respiratory health
Inflammatory bowel disease
Eye health
Acute care

Quality of datasets

Level 4: Full technical submission

Demonstrated technical maturity and capability to submit quality metadata

- DATA-CAN
- DiscoverNOW
- INSIGHT
- Gut Reaction

Charity Partners in Hubs

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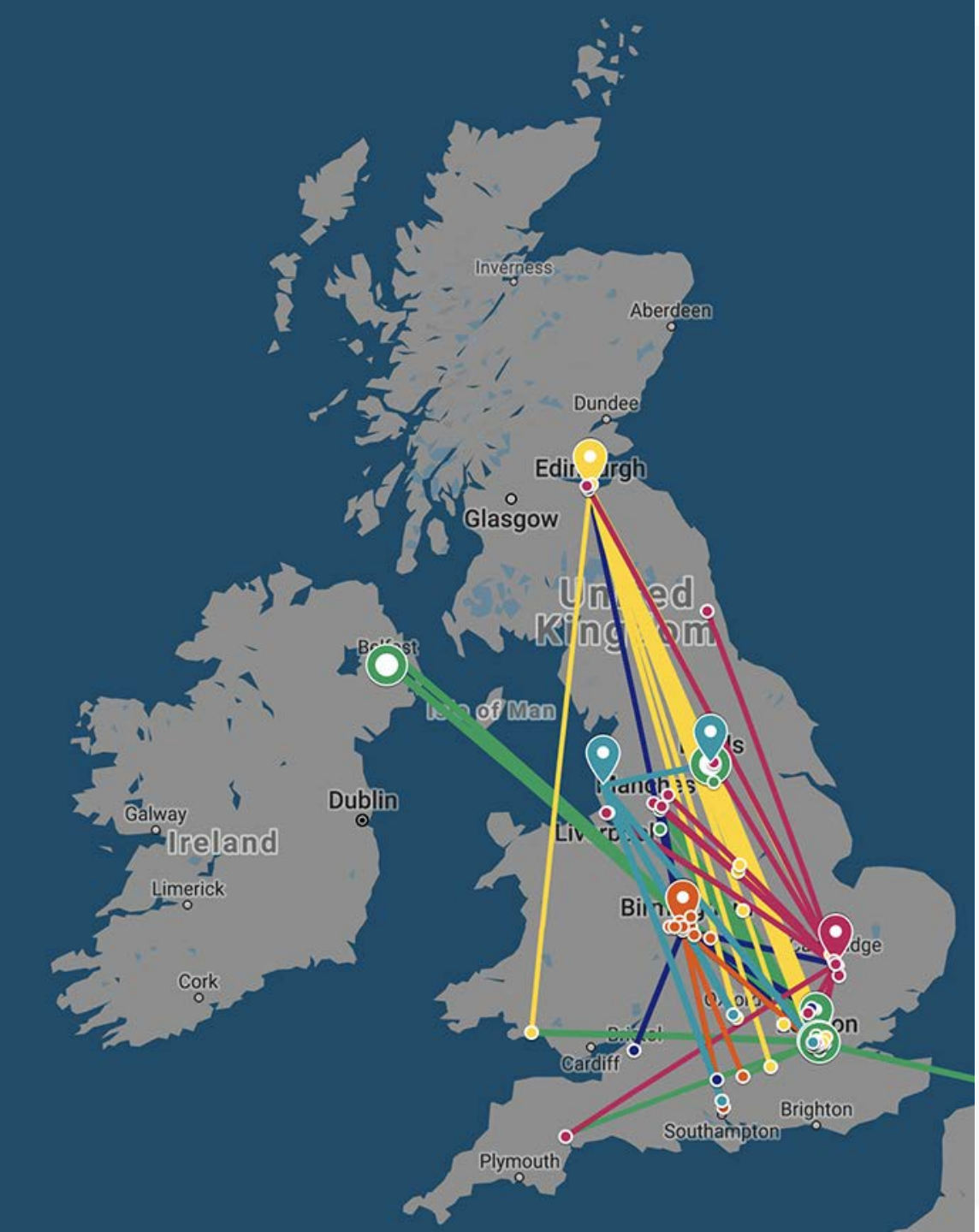
Charities are mobilising the community to share, celebrate and challenge the work of the Hubs; directly supporting research by providing access to data asset; bringing in patient voices

- 12 September, BMA House

Health Data Research Hubs Announcement



a. Partnerships spanning across the UK

INSIGHT - https://www.youtube.com/watch?v=BkPXFfetZwM
PIONEER - https://www.youtube.com/watch?v=eibnqYye0og
NHS DigiTrial - https://www.youtube.com/watch?v=dRGrUusoqVE

Example: The Discover Now Hub builds on one of Europe's largest and most diverse, longitudinal linked data sets

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2.3
million population

More than
10
years of historic data

>£20
million invested

6
Terabytes of data

Over
400
ISAs signed with partner organisations

Our partners

Technology Partners

Google IBM discover

Industry Partners

AstraZeneca NOVARTIS janssen

NHS, Academic and Third Sector Partners

Imperial College London · Imperial College Healthcare NHS Trust · amrc · DIABETES UK KNOW DIABETES. FIGHT DIABETES. · North West London NHS Collaboration of Clinical Commissioning Groups

Data and Research Partners

NWEH NorthWest EHealth · medopad · Genomics england · ONE LONDON · dr foster.

Example: Discover Now Hub - Four domains to create a world leading RWE Hub

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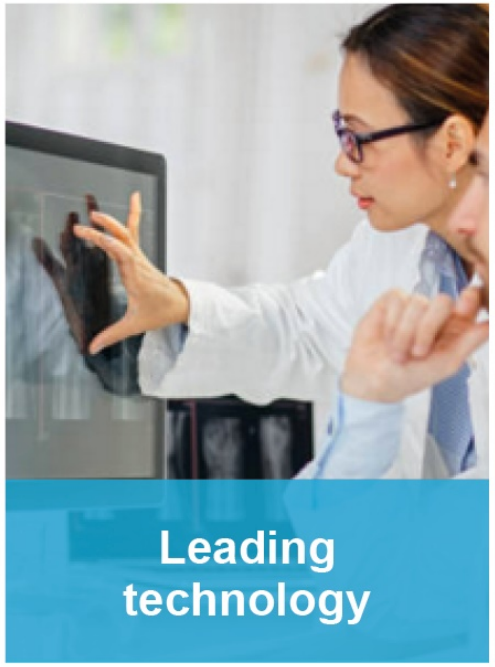
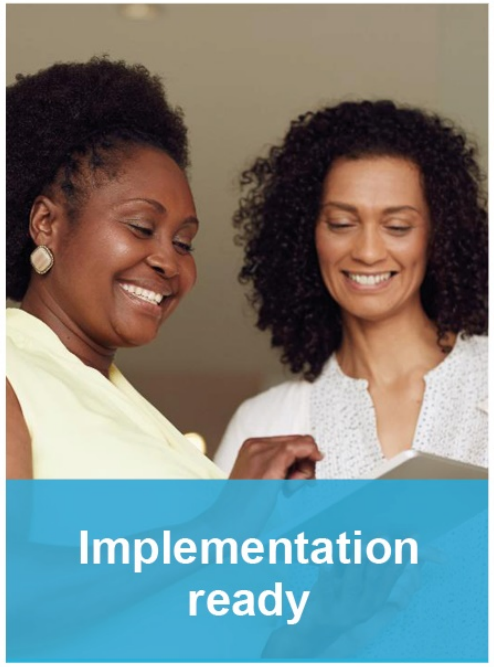
Richer and curated data

- **Additional data** including user generated
- Growing across London from **2.3 to 8 million** lives
- Improved quality of data



Leading technology

- Moving to **near real time** and high performance analytics
- **Single-point, streamlined access** to de-identified real-world data for trials



Implementation ready

- Embedded in a **real-world care eco-system**
- Access to leading KOLs and data and research expertise

Public trust

- Ambitious London wide **deliberative democracy** approach to build trust
- Commitment to be guided by citizens recommendations

Our partners

Technology Partners: Google, IBM, discover

Industry Partners: AstraZeneca, NOVARTIS, janssen

NHS, Academic and Third Sector Partners: Imperial College London, Imperial College Healthcare NHS Trust, amrc, DIABETES UK, North West London NHS

Data and Research Partners: NWEH, medopad, Genomics england, ONE LONDON, dr foster

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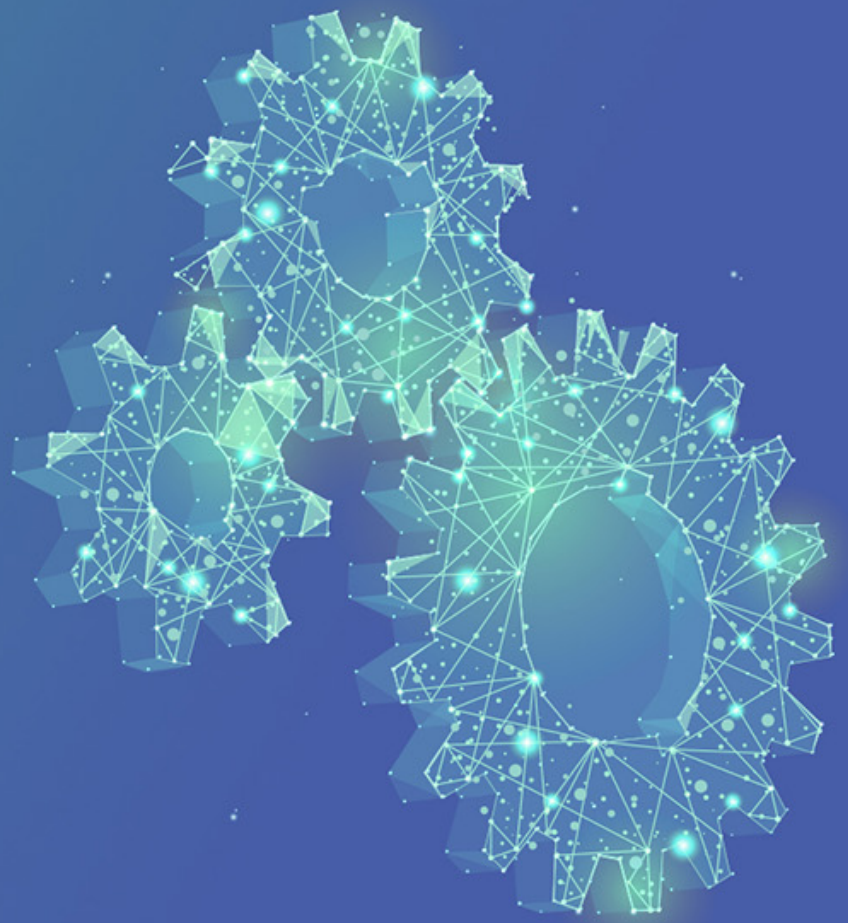
Innovation Gateway



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Operated by HDRUK Health Data Research UK

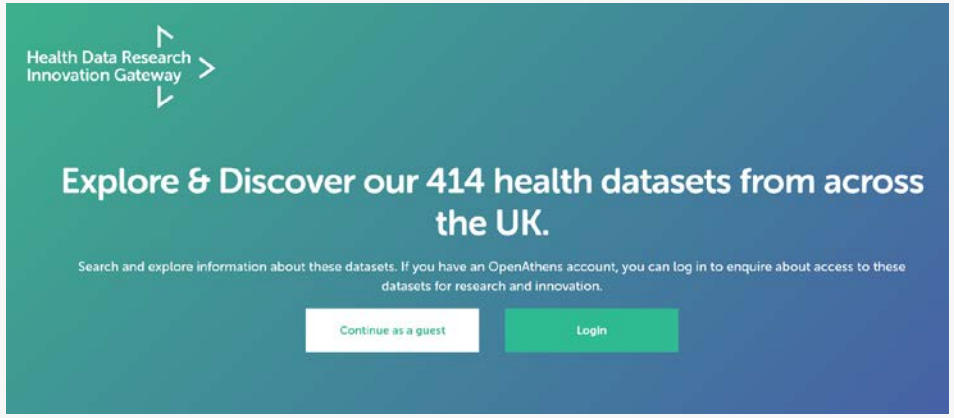
USERS:
Researchers, Industry, NHS, Charities and Government

PATIENT AND PUBLIC BENEFIT

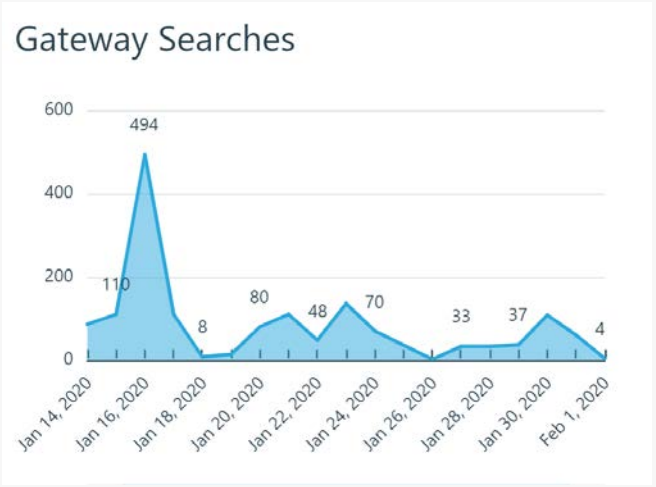
https://healthdatagateway.org/

UK Health Data Research Innovation Gateway in numbers

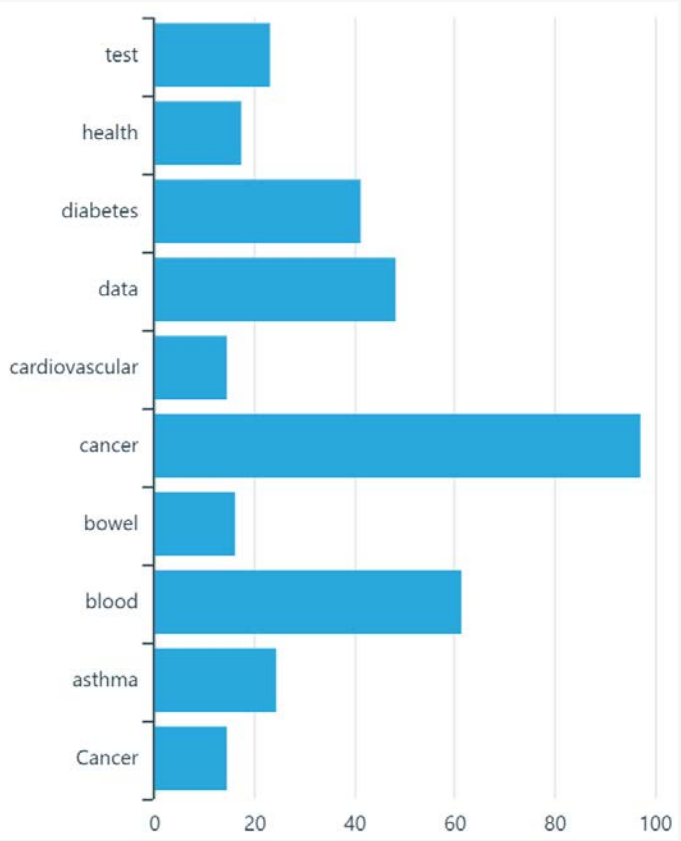
>400 datasets in **Minimum Viable Product**



2,415 searches



Top **10** Gateway searches



16 organisations registered interest for the **Technology Partnership**

7 applied

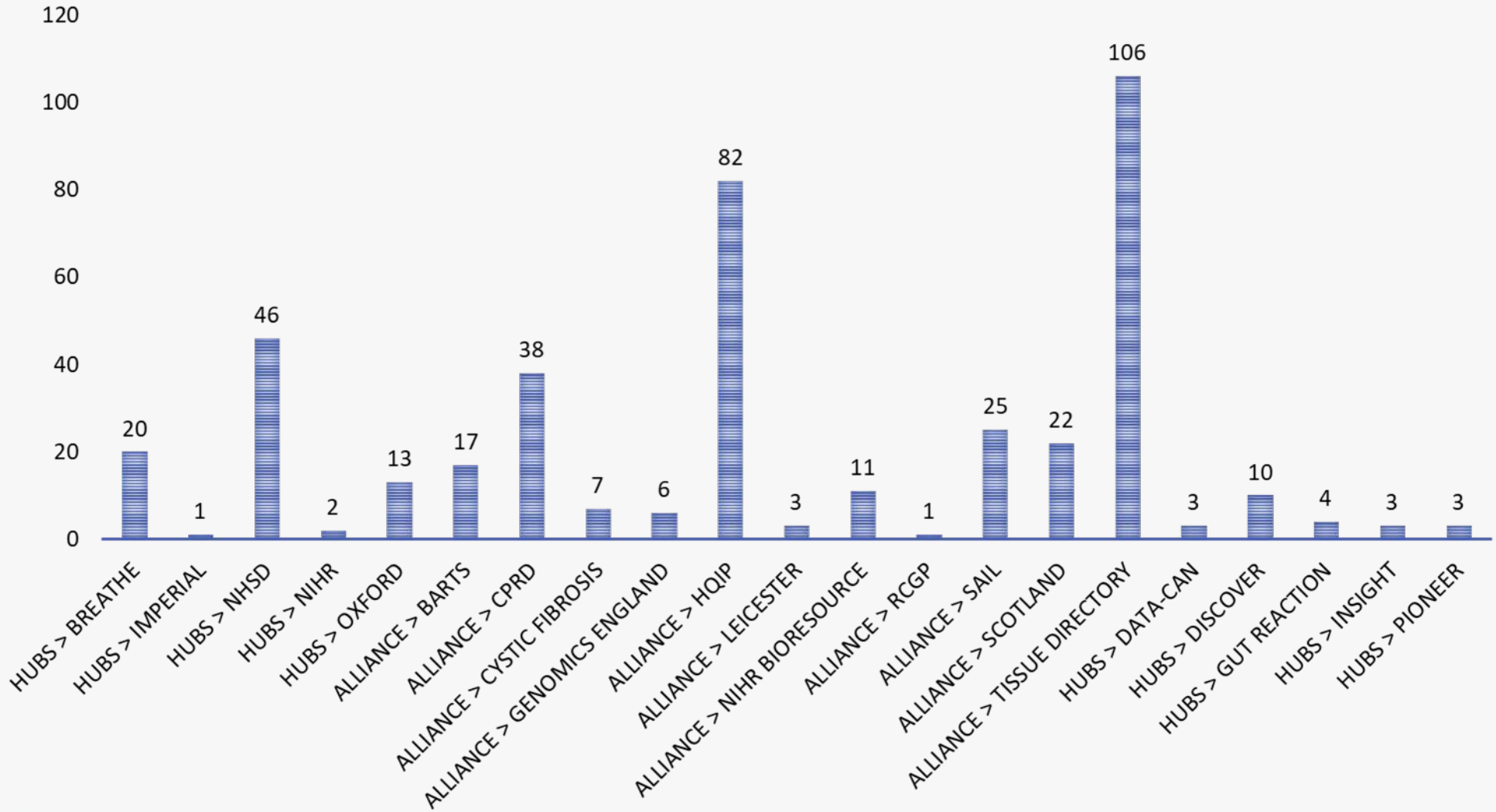
3 selected for Rapid Development Task

2,076 users

Data on 4 February 2020

Where the data has come from

Number of datasets on Gateway, February 2020



Scientific Exemplars

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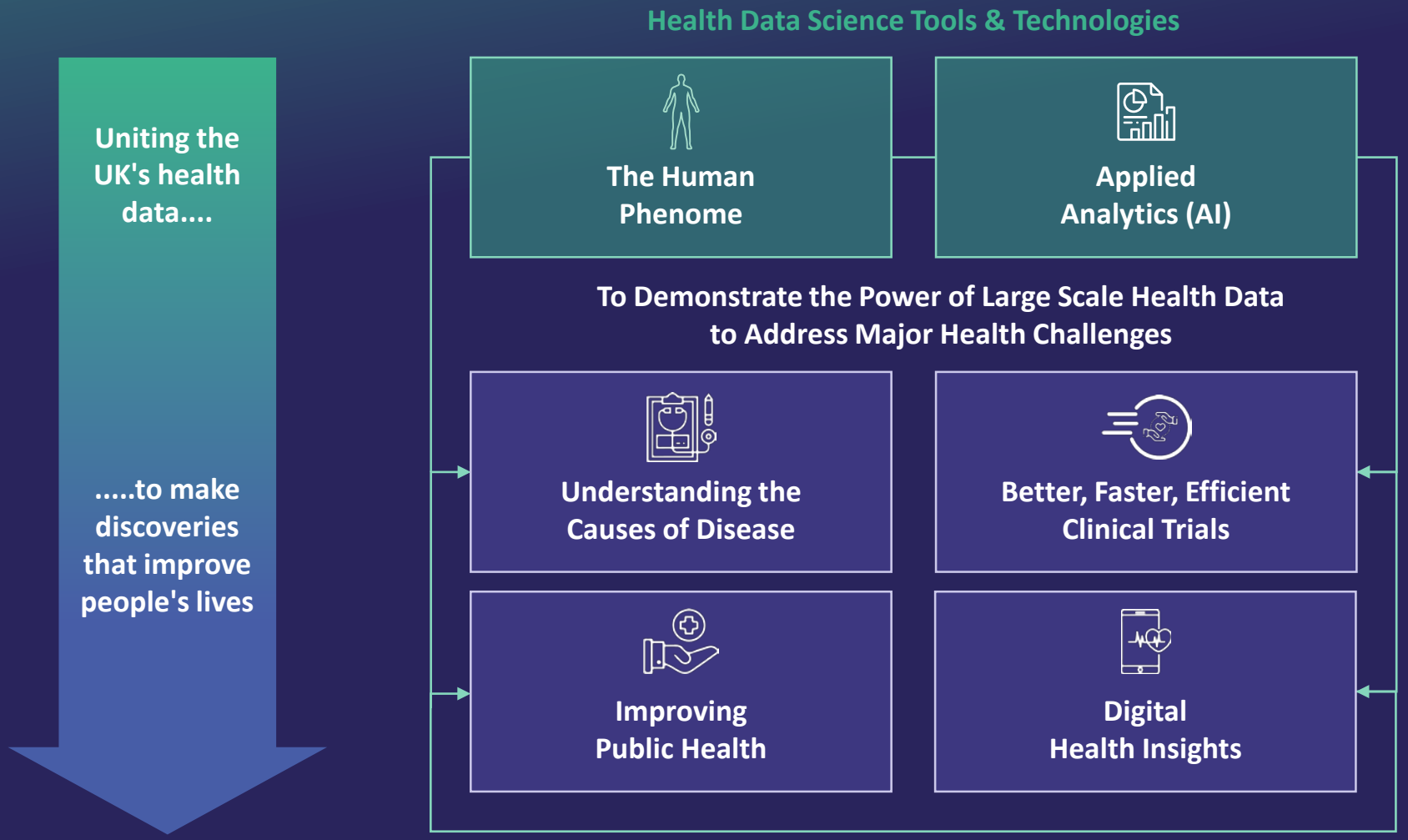

Scientific Priorities for 2019/20 and Beyond

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Health Data Science Tools & Technologies

Cathie Sudlow
HDR UK Scotland

Harry Hemingway
HDR UK London

The Human Phenome

Applied Analytics (AI)

Chris Holmes
Alan Turing Institute

To Demonstrate the Power of Large Scale Health Data to Address Major Health Challenges

John Danesh
HDR UK Cambridge

Understanding the Causes of Disease

Better, Faster, Efficient Clinical Trials

Martin Landray
HDR UK Oxford

Ronan Lyons
HDR UK Wales/NI

Improving Public Health

Digital Health Insights

Simon Ball
HDR UK Midlands

The Alan Turing Institute

HDRUK
Health Data Research UK

Applied Analytics

Chris Holmes

APPLIED ANALYTICS (AI)

HDR UK National Text Analytics Resource

HDRUK Health Data Research UK

Leads: Angus Roberts
Richard Dobson
KCL

Start: 1st Oct 2019

End: 31st Mar 2023

Award: £0.65m (3.5yrs)

National involvement:

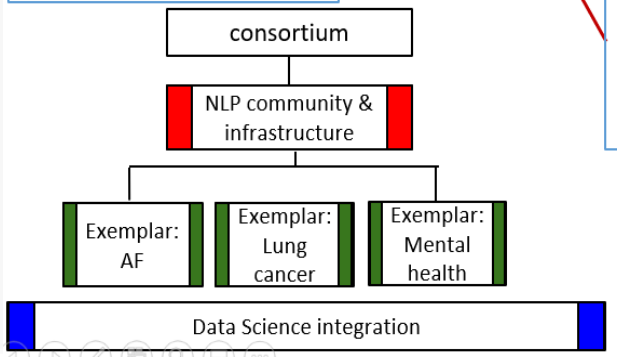
Scotland
Cathie Sudlow (UoE, Neurology/ Epidemiology)
Honghan Wu (UoE, HDR UK Fellow)
Bea Alex (UoE, NLP)

Midlands
Simon Ball (UoB, Digital healthcare)
Georgios Gkoutos (UoB, Informatics)

Cambridge
Nigel Collier (NLP)

London
Richard Dobson (KCL/UCL, Health Info)
Angus Roberts (KCL, NLP)
Robert Stewart (KCL, Psychiatry)
Carol Dezateux (QMUL, Epidemiology)

Wales and NI
Ronan Lyons (Swansea, Epidemiology)
Simon Thompson (Swansea, Data Science)



Main aims:

1) Survey and map clinical Natural Language Processing (NLP) landscape in the context of EHR analysis – in doing so, build NLP community
2) Build a portal for NLP tools, datasets, APIs and standards
3) Develop and test tools in stroke, lung cancer and serious mental illness

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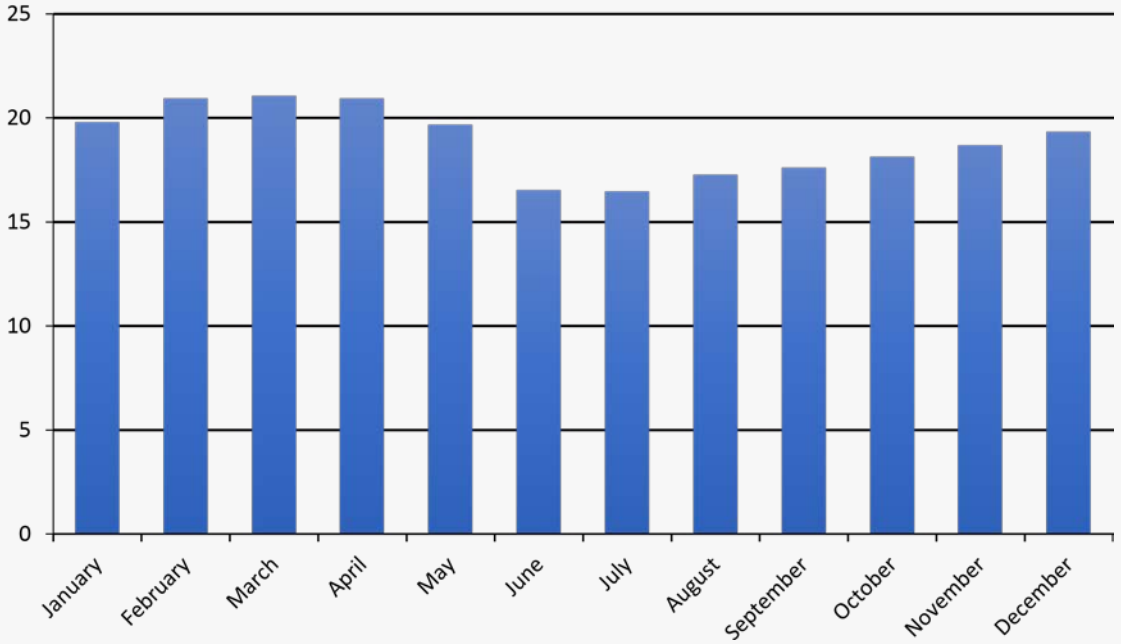
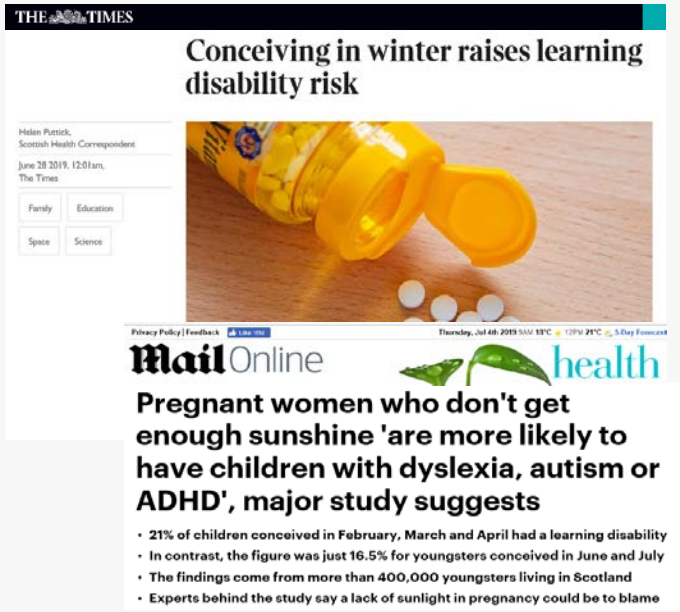
Improving Public Health



Crude prevalence of learning disabilities by month of conception



THE TIMES

Conceiving in winter raises learning disability risk

Helen Puttick, Scottish Health Correspondent

June 28 2019, 12:01am, The Times

Family | Education | Space | Science

Mail Online health

Pregnant women who don't get enough sunshine 'are more likely to have children with dyslexia, autism or ADHD', major study suggests

- 21% of children conceived in February, March and April had a learning disability
- In contrast, the figure was just 16.5% for youngsters conceived in June and July
- The findings come from more than 400,000 youngsters living in Scotland
- Experts behind the study say a lack of sunlight in pregnancy could be to blame

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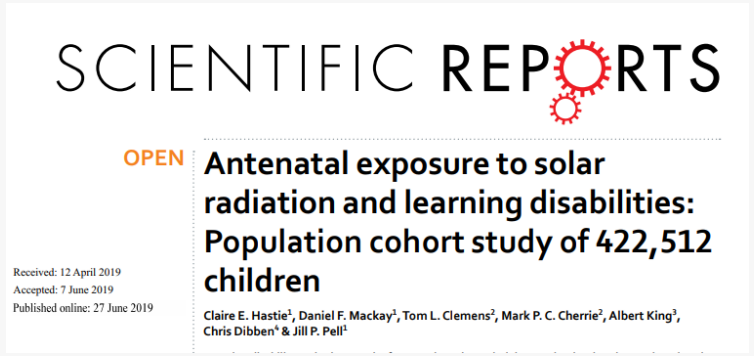
IMPROVING PUBLIC HEALTH

UVB quintile	OR	95% CI	P value
1 Lowest	1.00		
2	0.84	0.80-0.88	<0.01
3	0.61	0.57-0.66	<0.01
4	0.55	0.51-0.60	<0.01
5 Highest	0.50	0.46-0.55	<0.01

Multivariate model of association between whole pregnancy UVB exposure and learning disabilities

Cross-sectoral data linkage:

- Education (school pupil census)
- Health (maternity records)
- Environment (NASA satellites - solar radiation)



SCIENTIFIC REPORTS

OPEN

Antenatal exposure to solar radiation and learning disabilities: Population cohort study of 422,512 children

Received: 12 April 2019
Accepted: 7 June 2019
Published online: 27 June 2019

Claire E. Hastie[1], Daniel F. Mackay[1], Tom L. Clemens[2], Mark P. C. Cherrie[2], Albert King[3], Chris Dibben[4] & Jill P. Pell[1]

IMPROVING PUBLIC HEALTH

HDR UK National Multimorbidity Resource

HDRUK Health Data Research UK

Lead: Colin McCowan St Andrews
Start: 1st Oct 2019
End: 31st Mar 2021
Award: c£1m (1.5yrs)

Main aims:

1) Establishing the current level of Multi-morbidity in the UK
2) Identify key Multimorbidity Clusters
3) Key trajectories of Multimorbidity Development

Scale:

c12 million

Data linkage:

Data Provider	Type	Base Population
Scotland: eDRIS	Hospital Prescribing Disease registries Population spine	5.4m
Northern Ireland	Hospital Prescribing Disease registries Population spine	1.2m
Wales: SAIL	Hospital Prescribing Disease registries Population spine GP	3.5m
CALIBER	Hospital Disease registries GP	10m
Leicester City, Leicestershire & Rutland	GP	1.1m
Discovery (London)	GP Hospital	1.2m

National involvement:

Colin McCowan
Jill Pell
Steve Pavis
Frank Sullivan
Albert Tenesa

Bruce Guthrie
Corri Black
Marion Bennie
Chris Dibben
Carole Morris

Anthony Brookes
Keith Abrams
Phil Quinlan
Kamlesh Khunti

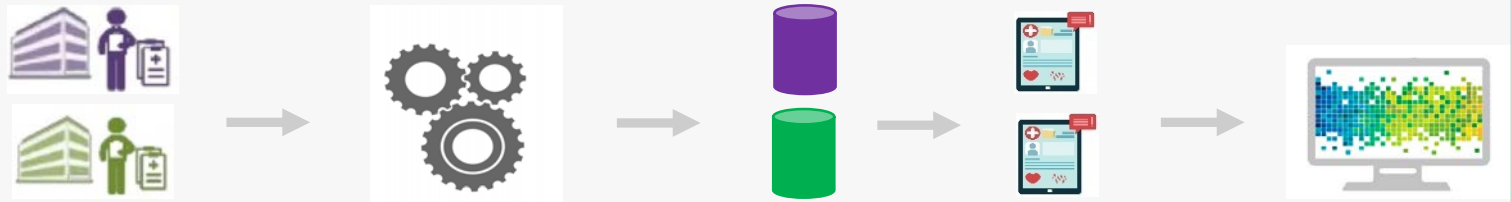
Krish Nirantharakumar
Sophie Staniszewska
Umesh Kadam

Ronan Lyons Dermot O'Reilly
David Ford, Alan Watkins,
Ashley Akbari

Silvia Richardson
Emanuele Di Angelantonio

Danny Alexander
Spiros Denaxas
Carol Dezateux
Aroon Hingorani

Ruth Gilbert
John Robson
Waty Lilaonitkul
Paul Elliot



Data extraction & linking → Harmonisation & standardisation → Storage in CDM → Morbidity coding → Federated analysis

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Health Data Research UK

Better, Faster and More Efficient Clinical Trials

Better, Faster and More Efficient Clinical Trials

HDRUK
Health Data Research UK

Enabling cost-effective clinical trials which exceed the standards required by international regulators and deliver results that improve patient care

Requires digital & regulatory innovation, pre-competitive knowledge sharing, and broad partnerships

20/21 Priorities

- **Development of NHS DigiTrial infrastructure** (with initial focus on Feasibility Service)
- **Building partnerships** with patient groups, medical charities, NIHR CRN, HRA, MHRA, government, tech & pharma
- **Securing further funding** to enable development of other aspects of NHS DigiTrial vision

QQR Deliverables

- **Development of new tools and methods** (e.g. for monitoring clinical trial quality; ascertaining clinical outcomes; and notifying trial participants of the results)
- **Demonstrator trials:** delivered in partnership with academic & commercial organizations; patient & researcher stories; metrics of researcher usage and patient access to trials
- **Changes to regulatory approaches:** new trials regulatory, ethics & information governance policies & practices

Digitally-enabled clinical trials for the NHS

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Addressing major challenges to quality & efficiency

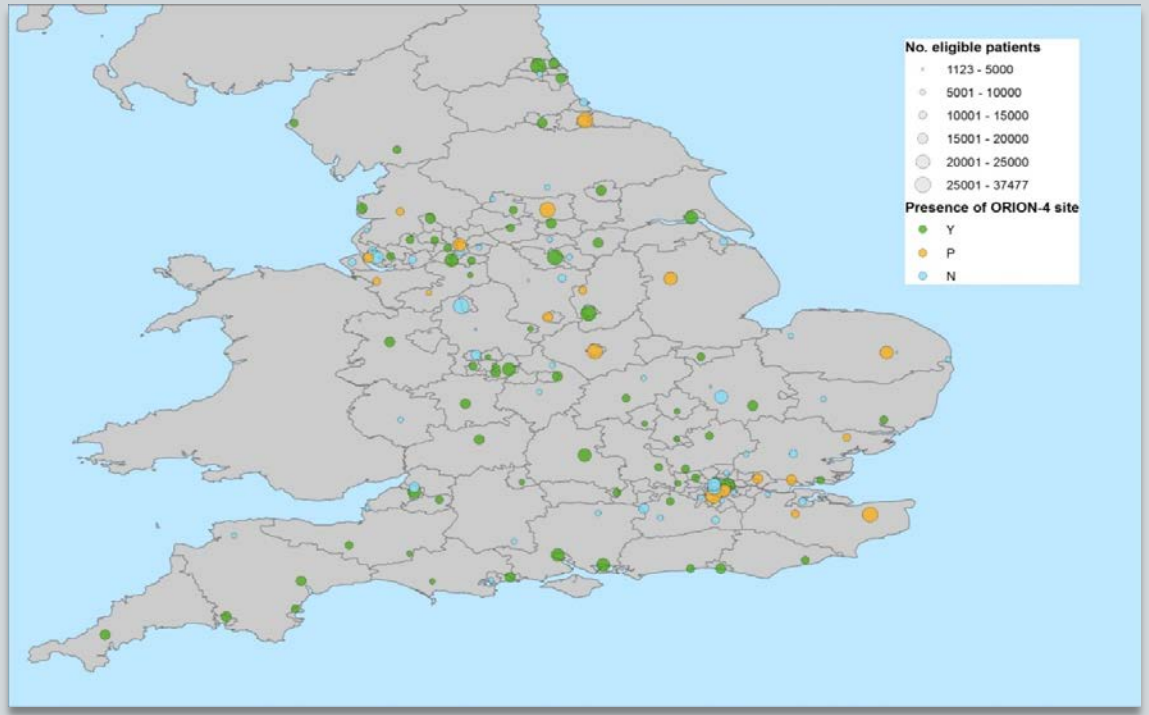
Good design

Feasibility

- Assess number & location of potential participants
- Iteration of protocol & recruitment approach
- Focus efforts & resources

ORION-4

1.5 million people with cardiovascular disease at top 90 hospitals (over 10,000 per hospital) across whole of England



Recruitment ongoing
300,000 invitations
Up to 1000 phone calls/day
Typically >100 pts attending per hospital
(biggest sites district general hospitals along South Coast, Midlands, and North East)

Researchers of the Future! Wellcome PhD Programme

HDRUK
Health Data Research UK

The Alan Turing Institute

News announcement

Wellcome to fund Health Data Research UK and The Alan Turing Institute PhD Programme

16 September 2019

Health Data Research UK, in partnership with The Alan Turing Institute, is to receive funding to support a PhD programme in Health Data Science funded by the Wellcome Trust.

Peter Diggle

Christopher Yau

Strategic partnerships
British Heart Foundation

World-leading **BHF Data Science Hub** that capitalises on the UK's unique data assets to drive research and improve prevention, prediction and treatment of cardiovascular diseases and enhance delivery of care.

- Partnership approved - July 2018
- Submission to BHF April 2019
- Competitive call for Director
- November 2019 launch

Professor Sir Nilesh Samani

Professor Cathie Sudlow

This is just the start. We can achieve a lot more together….

"Alone we can do so little;
Together we can do so much."

Helen Keller

Find out more

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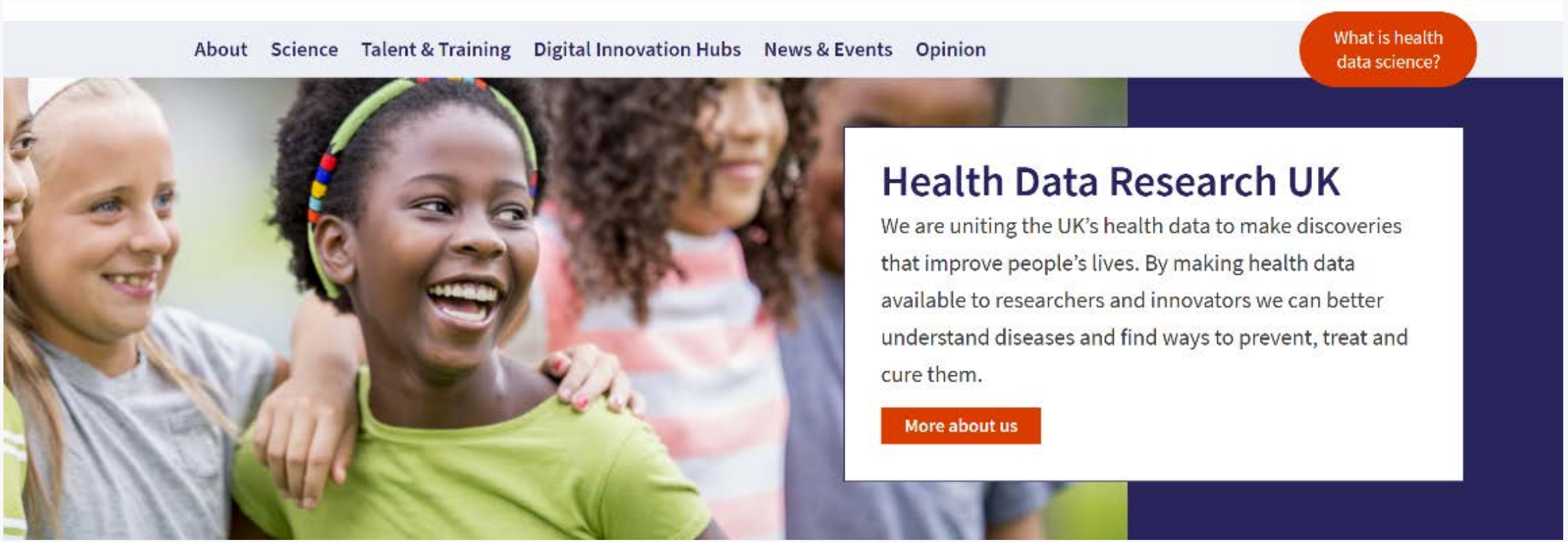
Health Data Research UK



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