

DATA-CAN

The National Health Data Research Hub for Cancer

December 2019

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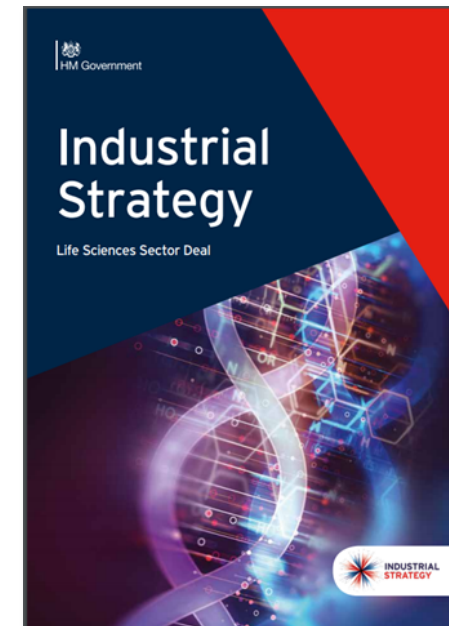
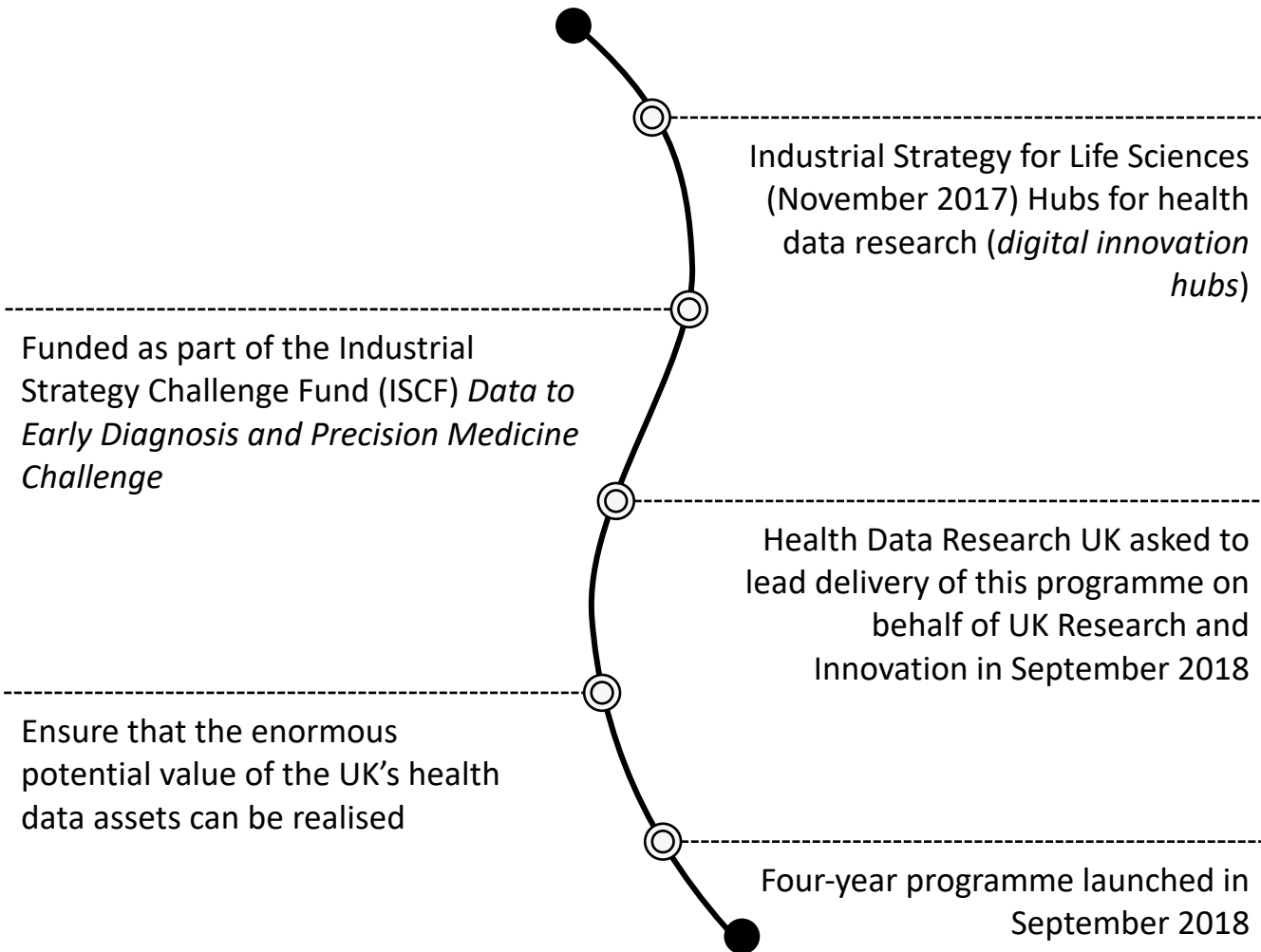
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Where this all started...



UK Research
and Innovation

2,700 people



350 organisations

in the UK and globally
across NHS, industry
and academia



35



Events

32

Interviews with Businesses



abpi
Bringing medicines to *life*



Pistoia Alliance

CATAPULT
Medicines Discovery

Office for
Life Sciences

NHS
National Institute for
Health Research

NIHR | Research Design Service
North East and
North Cumbria



Genomics
england

NHS
The Leeds
Teaching Hospitals
NHS Trust



UNIVERSITY OF LEEDS



QUEEN'S
UNIVERSITY
BELFAST

What we've heard



The UK has **good health data resources**, but these can be **difficult to identify and access**



Data research and innovation takes place outside of the UK because of the **difficulty in working with UK data**



Members of the public support research using health data, where this is **transparent and leads to benefits to the NHS**

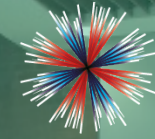


We need to be **clear and concise** on the benefits, risks and how these will be managed



We need to **involve patients and the public** throughout the process

HDRUK
Health Data Research UK



**INDUSTRIAL
STRATEGY**

UK Research
and Innovation



HDRUK: delivering on what patients expect and what industry, NHS and academic data users want



INDUSTRIAL
STRATEGY

UK Research
and Innovation



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



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



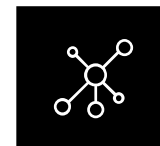
Access: Single, easy-to-use route to data



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



Scale: High quality data with UK-wide coverage



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

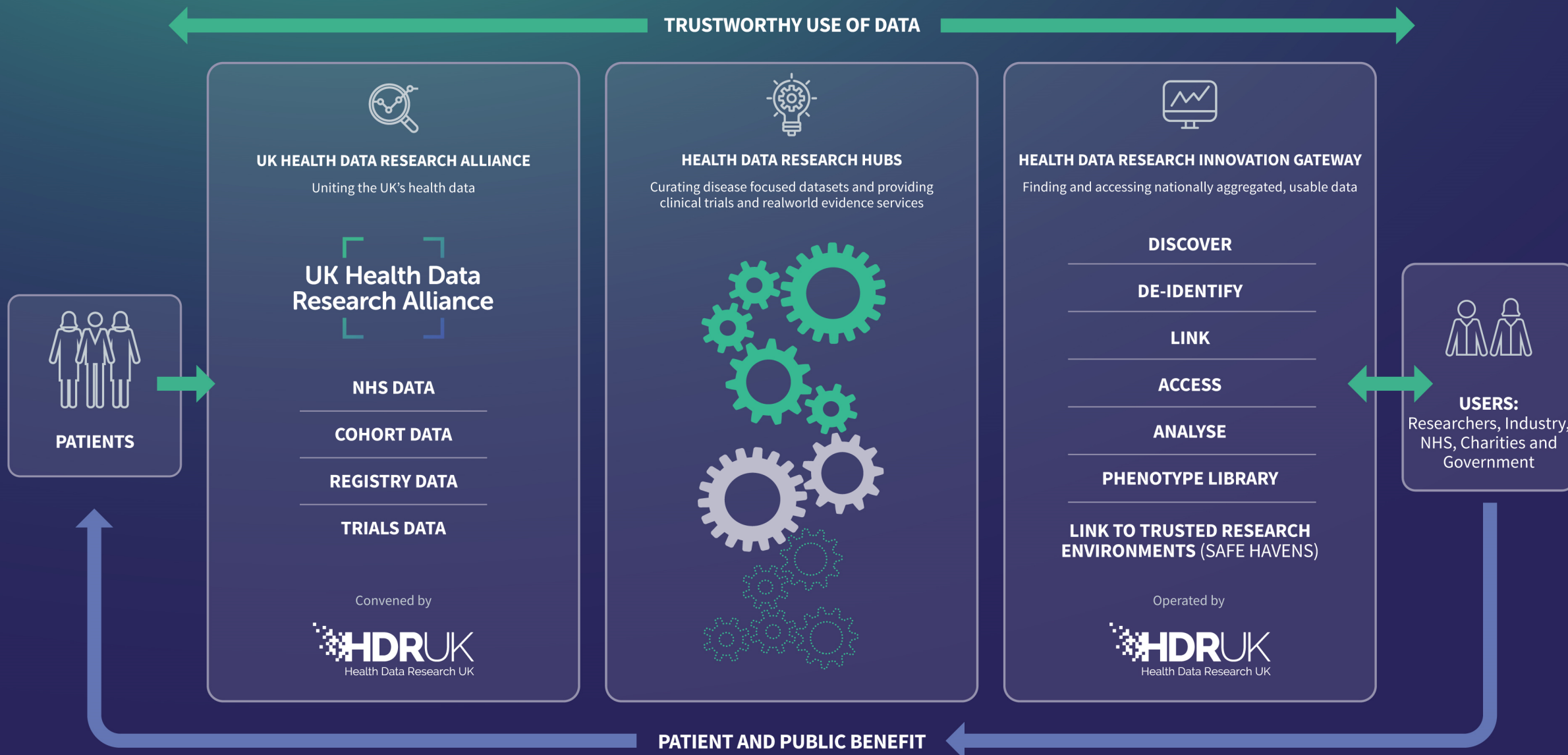
All underpinned by building people's confidence and trust in how data is used



INDUSTRIAL
STRATEGY

UK Research
and Innovation

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



DATA-CAN is the UK's Health Data Research Hub for Cancer



We will make **high-quality health data easily available** for cancer researchers and clinicians.

By connecting data from across the UK and making it easier to use, we will **facilitate research into new treatments** and improvements in care for people affected by cancer.

Working with patients, the public and practitioners, we will ensure that **data is used safely and ethically**, and that the benefits are returned to the NHS and the wider UK community.

Why cancer?

- One in two people will get cancer during their lifetime
- Every year, almost 400,000 new cases are diagnosed in the UK, and cancer costs the NHS £7bn annually
- Using cancer data more effectively could improve cancer survival rates, potentially contributing to saving the lives of 30,000 cancer patients a year and many more around the world

A unique partnership



Support from across the United Kingdom



DATA-CAN : The Vision

DATA-CAN – The Health Data Research Hub for Cancer – aims to unlock the power of data to improve cancer care

What does this mean for industry?



~80%

of clinical trials are
delayed by at least 2-3
months



-3%

UK's share in global
pharma R&D (10% > 7%)



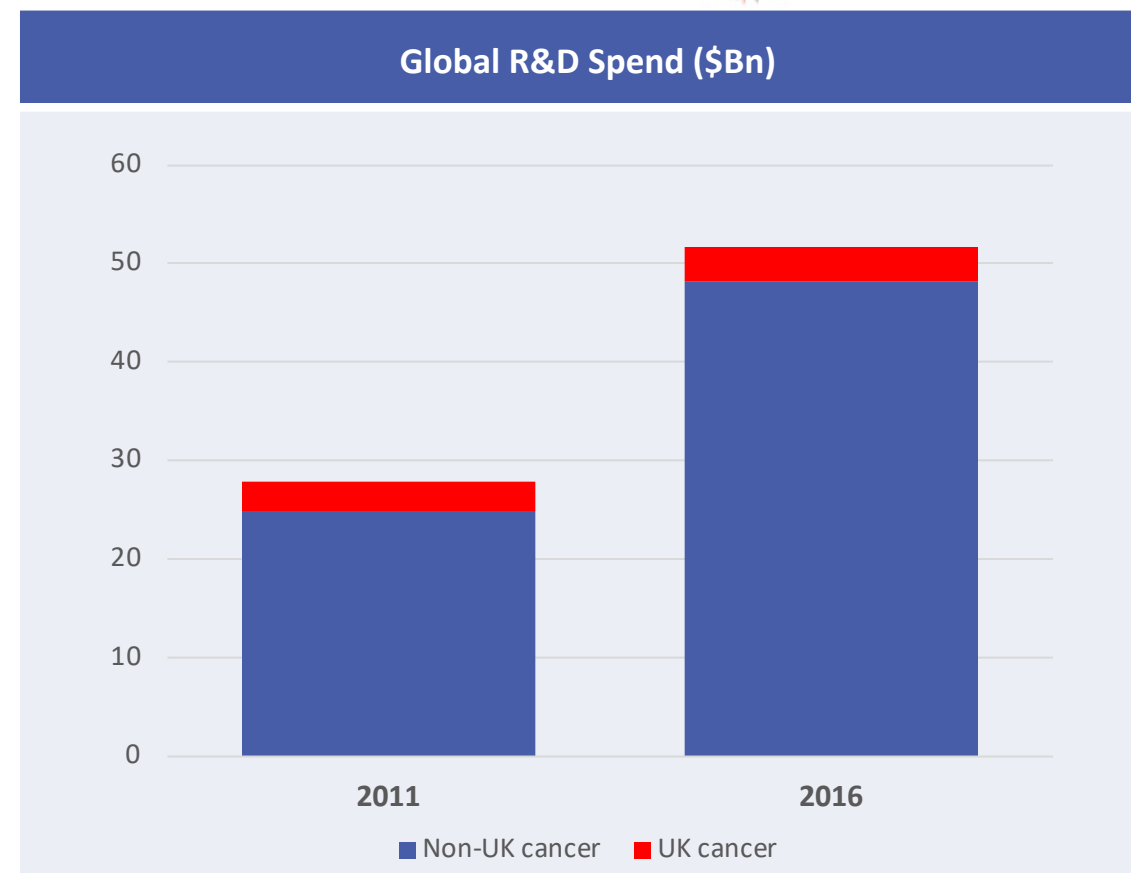
~45%

of protocol delays could
be avoided through
better use of data

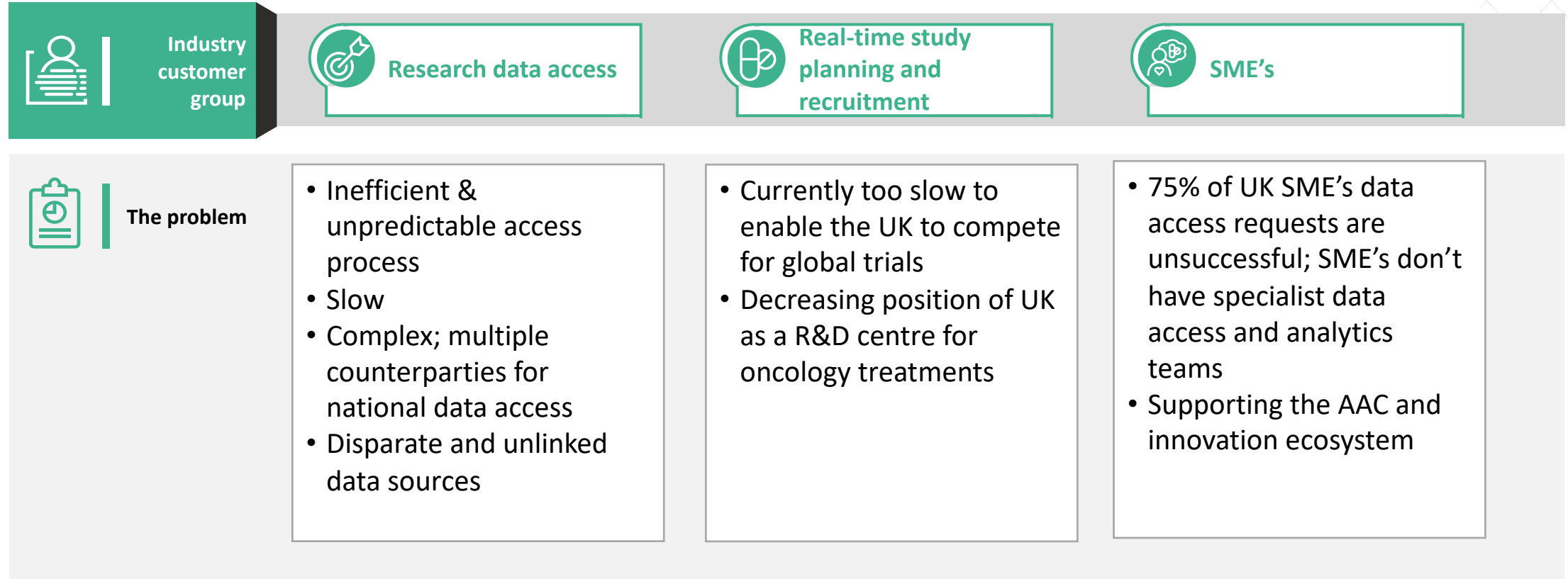


+\$2B

Increase to UK cancer
research returning to the
UK's 2011 % of total R&D
spend



Challenges we have heard from industry



DATA-CAN is working closely with patients, clinicians and the wider NHS



Patients

- Full board members
- Patient panel
- Internationally recognised PPIE leadership



Clinicians

- Lead clinicians at core sites
- 6 NHS clinicians on team



Wider NHS

- NHSX, LHCREs
- NHS data custodians
- Standards
- AHSNs and regional NHS improvement



What DATA-CAN will do

Our vision is to unlock the power of health data to improve the lives of people affected by cancer



Enable and expand UK-
wide cancer dataset
access for research

- Link existing epidemiological datasets
- Enrich with datasets (eg genomics, imaging)



Support **NHS delivery
of care**

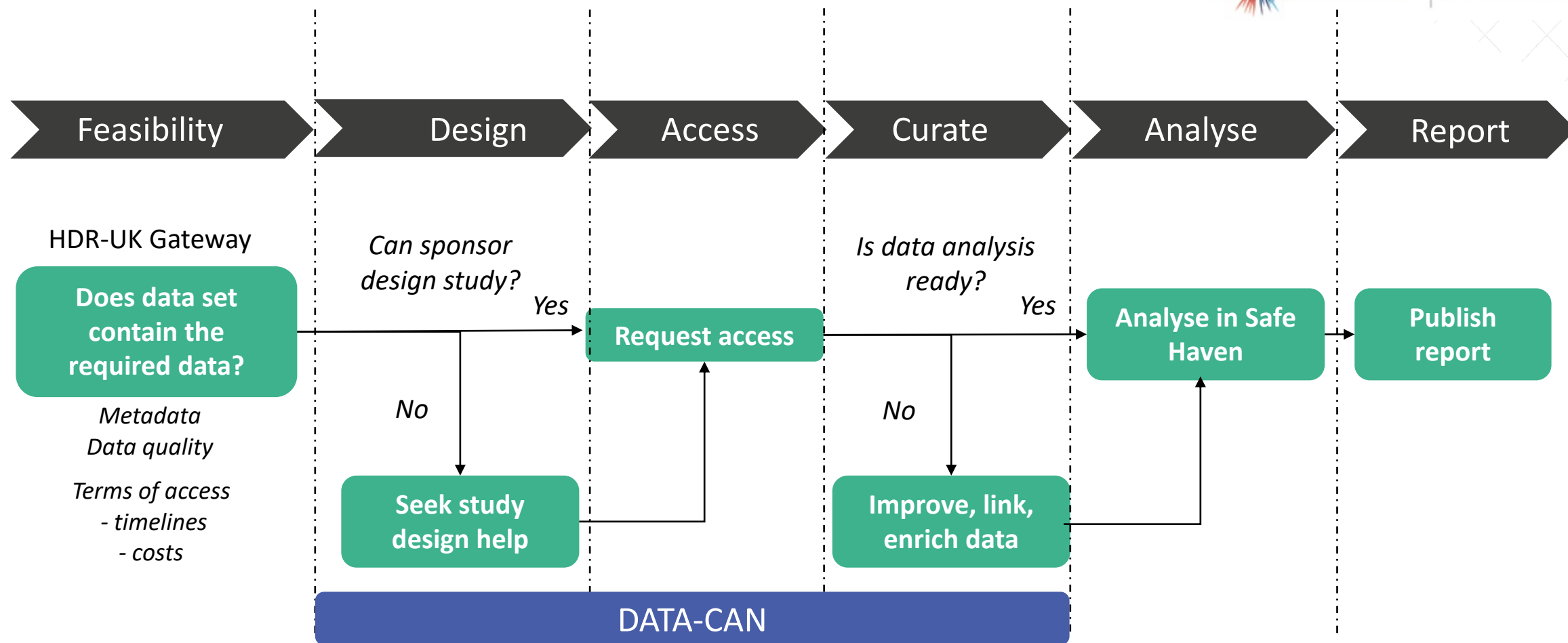
- Track variation in care
- Benchmark against comparable hospitals
- Understand treatment options



Support **clinical study**
design, site selection
and patient recruitment

- Use NHS data to identify potential candidates for local and national clinical trials

DATA-CAN will offer services to help researchers find and access cancer data safely



DATA-CAN will help evolve how research questions can be answered using UK data



Can you get me full clinical phenotype, digital pathology and imaging on patients on 1st-line immune-checkpoint inhibitors in non-small cell lung cancer?

Today

- NCRAS + SACT to 2017
- Patchy coverage for
 - Digital imaging
 - Primary care



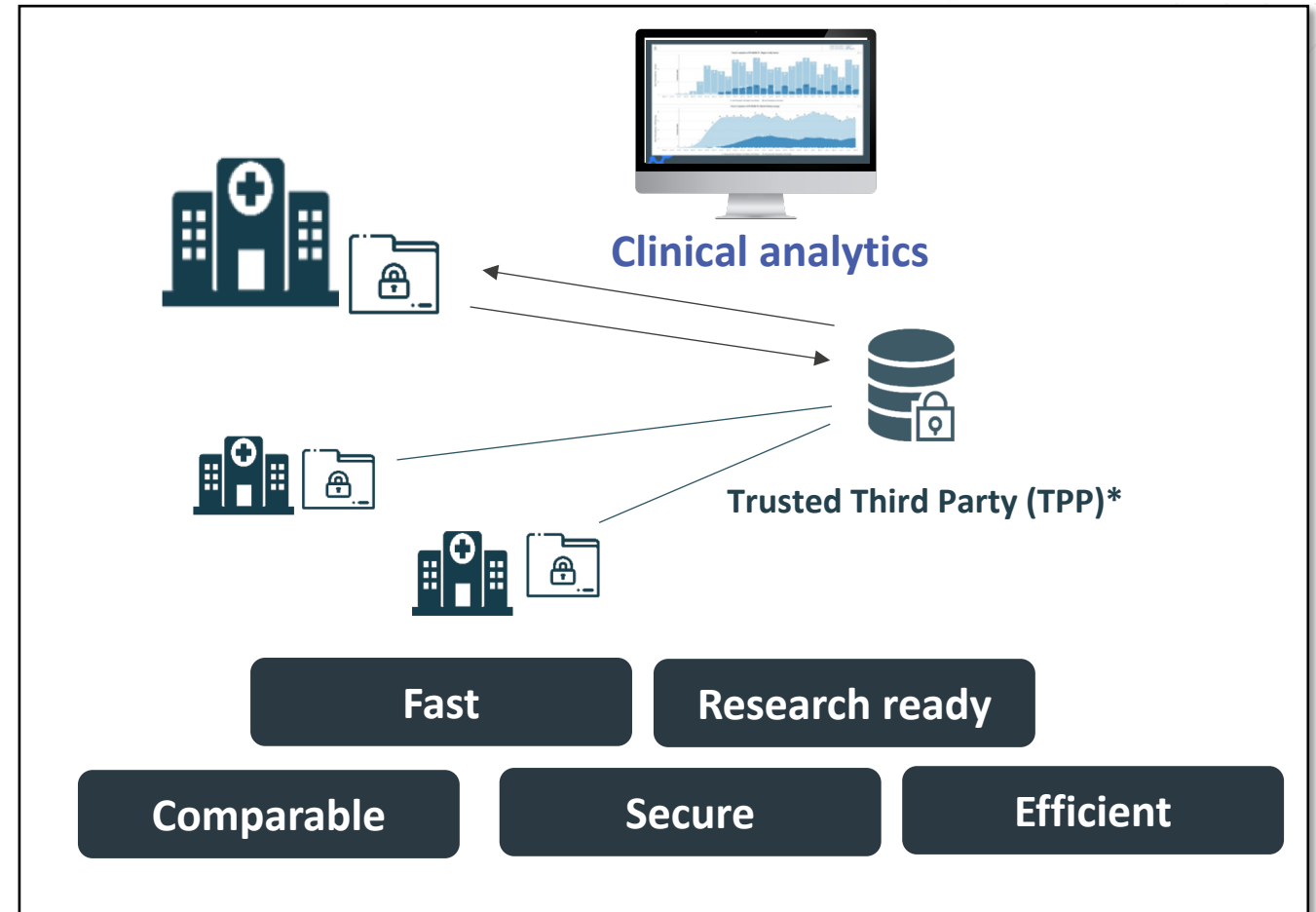
By 2022

- 27M DATA-CAN population
- Digital imaging & pathology from National Digital Imaging hubs
- LHCRE-linked primary care data
- Detailed molecular and genetic phenotype

IQVIA are proud to support DATA-CAN through technology to support priorities



- **European Real World** Oncology data
- **Data sharing** network
- **Automated extracts** from clinical systems
- **120+** centres across **7** countries



* Non-identified data is processed and stored in secure data centres which are certified by government agencies as required in each country, or otherwise comply with industry security standards

How DATA-CAN will help different stakeholders

Patients

- Increase access to clinical trials and support faster development of new cancer treatments
- Ensure patient data is used securely and provides the NHS fair value

NHS

- Identify and address unwanted variation in care
- Benchmark performance against comparable hospitals

Academic researchers

- Increase the availability, linking and quality of clinical data

Industry

- Support access processes
- Reduce the cost of study design and delivery
- Support trial recruitment

Data custodians

- Support access processes
- Help identify supporting technologies

DATA-CAN

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Unlocking the power of health data to improve the lives of patients affected by cancer

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Working together

DATA-CAN video



<https://www.hdruk.ac.uk/infrastructure/the-hubs/data-can/>