

Keynote: transforming healthcare through data & research

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Department
of Health &
Social Care



Transforming healthcare through data & research

AI & Data 2023



Mandate for change

We are delivering a range of ambitions across life sciences, research, and data-driven innovation



NHS Long Term Plan
January 2019



Saving and Improving Lives
March 2021



Life Sciences Vision
July 2021



Genome UK
March 2022

UP TO £260M FOR NHS-LED
HEALTHCARE RESEARCH
AND TO EXPAND LIFE SCIENCES
MANUFACTURING IN THE UK

**Up to £200 million to boost NHS
healthcare data research**
March 2022



Goldacre review
April 2022

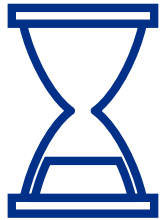


Data Saves Lives Strategy
June 2022

Independent report
**Commercial clinical trials in the UK: the
Lord O'Shaughnessy review - final report**
Updated 20 May 2023

**James
O'Shaughnessy's Clinical Trials
Review**
May 2023

Why are we shifting from data sharing to data access?



Current processes slow down how quickly researchers and analysts can access data and find out new information, stifling innovation.



The current process is complicated and difficult for researchers and innovators to navigate.
It is hard for the public to understand and challenge how their health data is being used.



A reliance on data dissemination is not reflective of best practice data security and protection. This limits the richness and quality of datasets available to researchers and innovators.



Large-Scale Public Engagement Plans

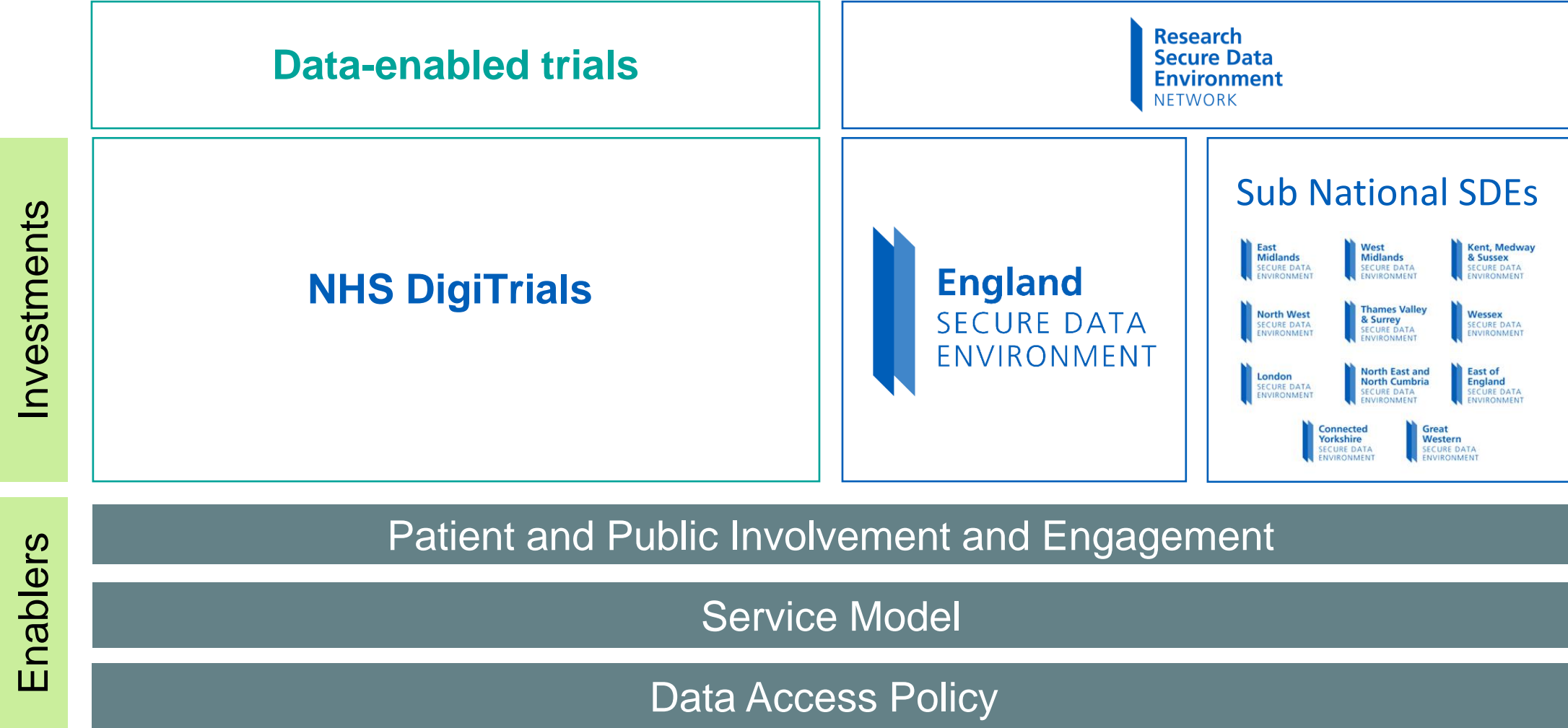
- Around **£2 million** is currently allocated to spend on public engagement workstreams, including large-scale engagement. This was recently announced via a **press release**, and information is available on **Transformation Directorate webpages**.
- Deliberative engagement will run from early 2024 into 2025, in a similar format that was delivered by OneLondon. Large-scale engagement will cover a variety of topics, including the development of **trust products** committed to in Data Saves Lives, reform of the **National Data Opt-Out**, plus governance and access rules for **Secure Data Environments**.
- These deliberations will support development and delivery of programmes including the **NHS Research SDE Network** and the **Federated Data Platform**, building on specific programme engagement.



A decorative graphic on the left side of the slide. It features a series of purple dots arranged in a grid-like pattern that tapers off towards the top left. Below this, there are three overlapping, downward-pointing arrow shapes in shades of teal and green. At the bottom left, there are three parallel diagonal stripes in green, teal, and blue.

Data for R&D PROGRAMME

Programme overview



RECRUITMENT PILOTS



Opportunity to apply for one of up to 4 available pilot recruitment programmes released by the Data for R&D programme.



Selection process for access to the DigiTrials recruitment service will be open to all sectors and follow a robust application process that will allow us to award a place on the programme



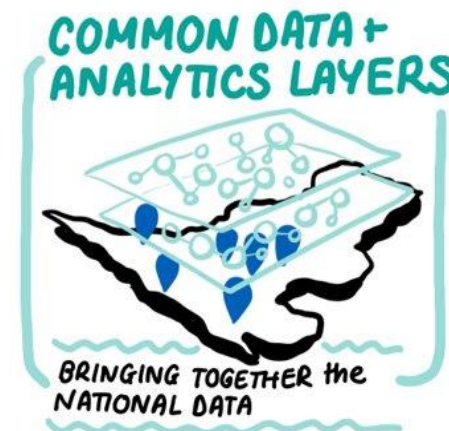
Streamlining secure
access to the world's largest
linked health datasets



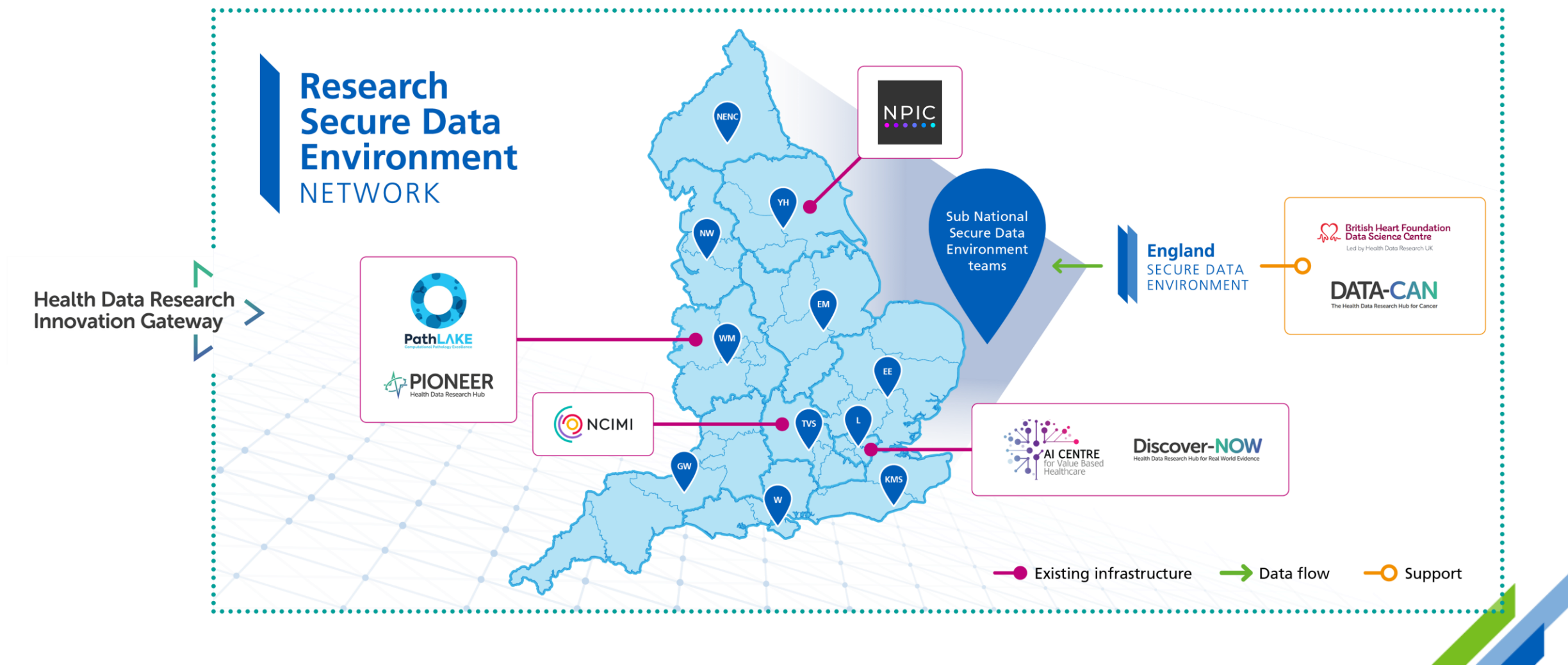
National Scale Data for R&D

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

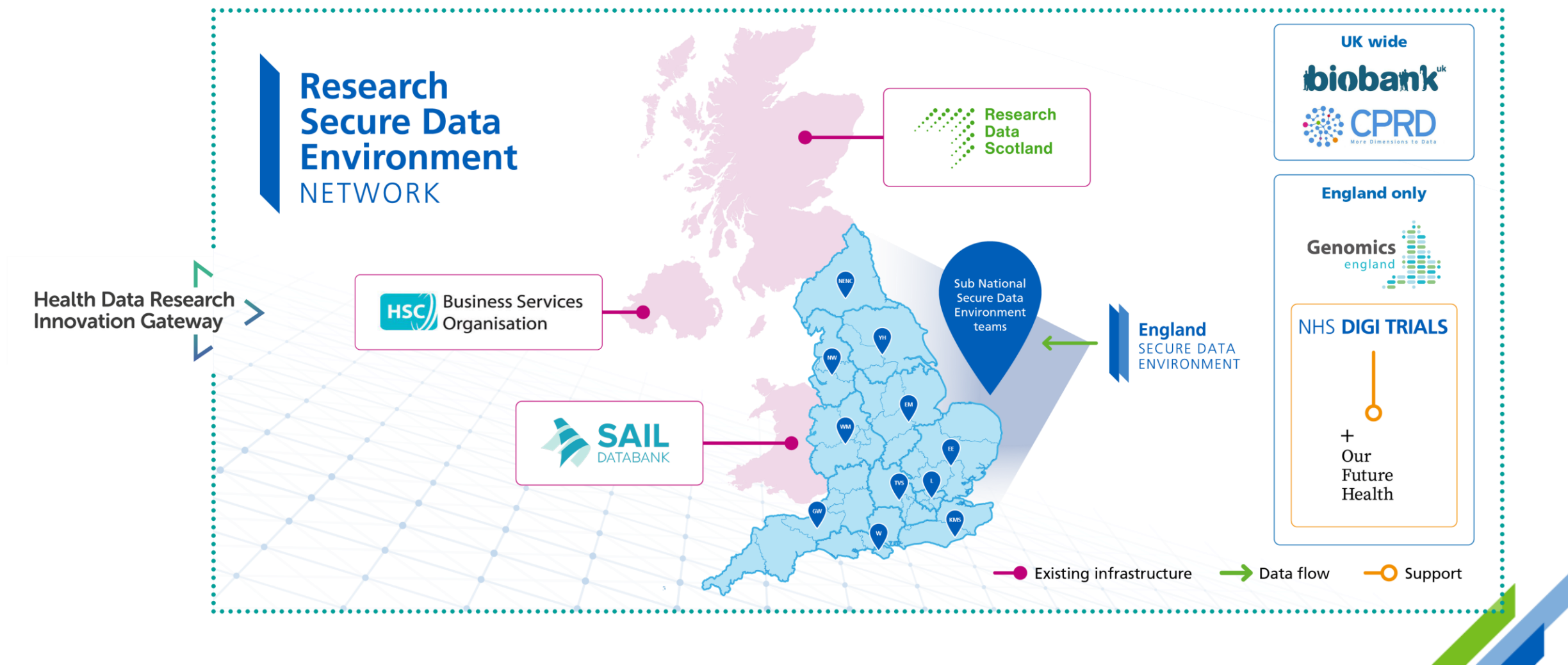
- Full coverage of rich multimodal data across imaging, pathology, genomics and structured data sets
- NHS and academic partnerships for delivery spanning >200 staff
- 40 industry projects already underway



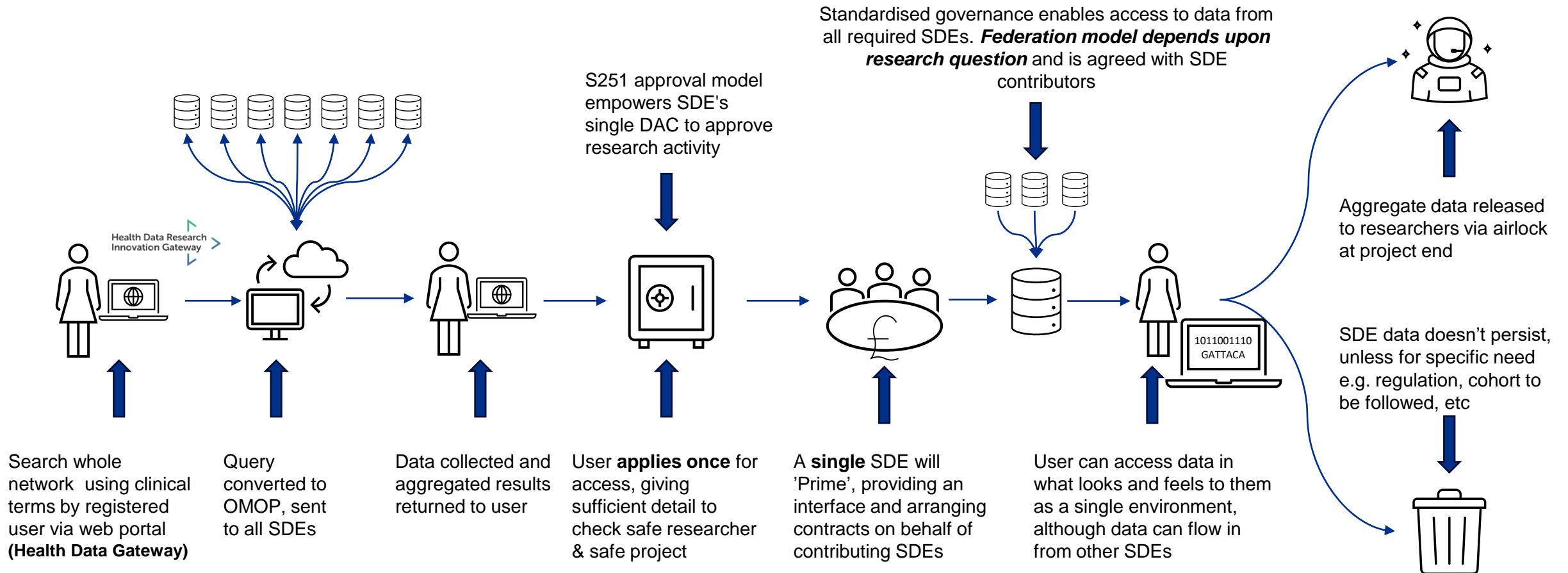
The NHS Research SDE Network



Docking in with the ecosystem



Multi-SDE Research



Introducing the NHS SDE Network 'Collection'

<https://www.healthdatagateway.org/collectioncategories/secure-data-environments-sde>

The NHS Research Secure Data Environment Network

The NHS Research Secure Data Environment (SDE) Network is made up of 12 SDEs who provide secure access to healthcare data for research and innovation.

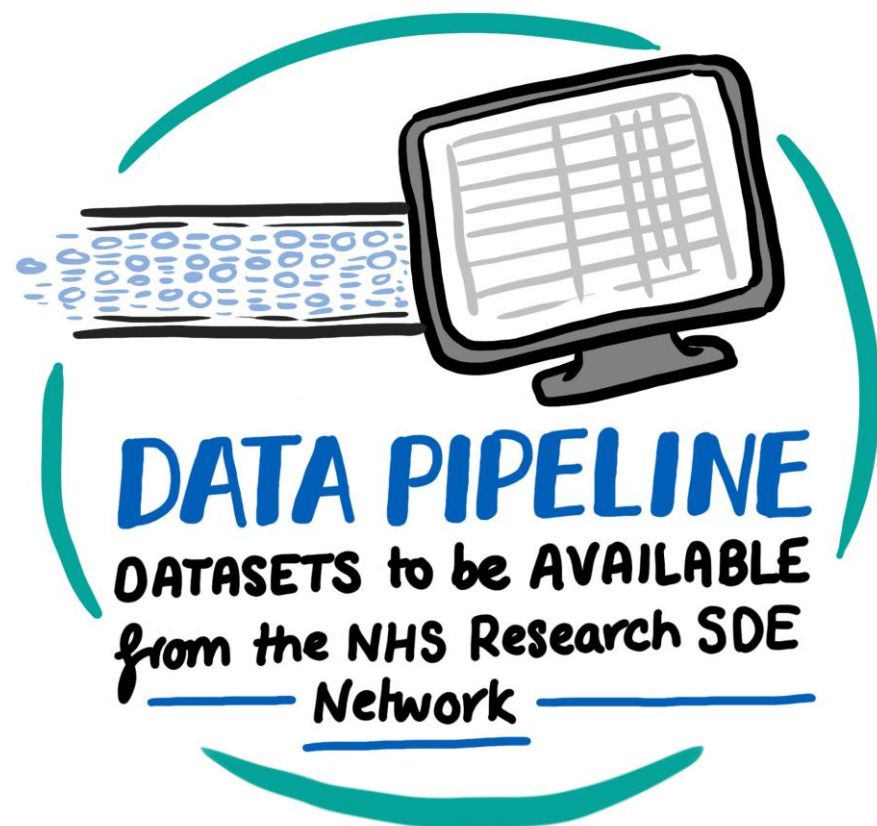
What is the NHS Research Secure Data Environment (SDE) Network?

The NHS Research Secure Data Environment (SDE) Network is made up of 12 SDEs who provide secure access to healthcare data for research and innovation. Network members include the NHS England SDE and 11 Sub National SDEs:

- East Midlands
- East of England
- Great Western
- Kent, Medway and Sussex
- London
- North East and North Cumbria
- North West
- Thames Valley and Surrey
- Wessex
- West Midlands
- Yorkshire and Humber

The network ensures there is secure access across England to healthcare data for approved research projects led by academics, industry organisations or NHS employees such as clinical researchers.



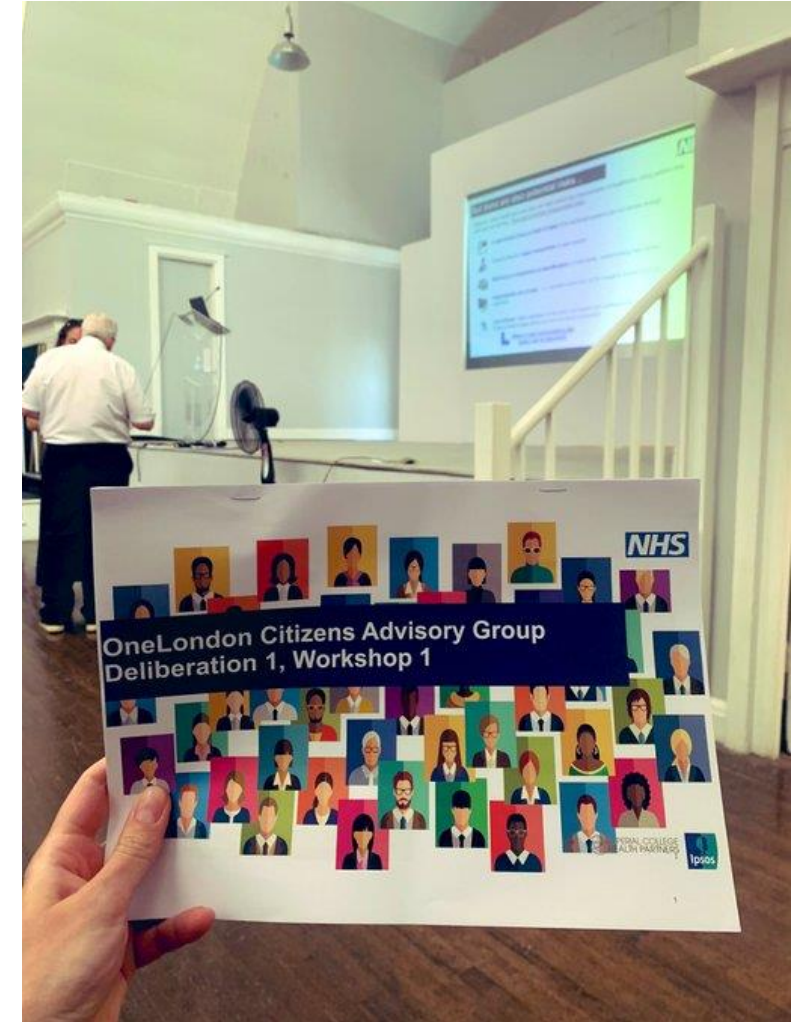


Data Type	Population Coverage, million							SDEs with Data Type by Jan-25
	Oct-23	Jan-24	Apr-24	Jul-24	Oct-24	Jan-25	Trend	
A. Demographics and wider determinants	24.9	34.7	34.7	43.4	43.4	54.2		10
B. Primary Care	6.9	22.2	27.3	33.9	33.9	40.1		8
C. Prescribing	6.1	21.4	22.7	39.3	41.9	43.7		10
D. Vaccines	-	6.2	6.2	11.3	16.4	26.9		4
E. Referrals	2.6	8.8	12.0	23.7	23.7	36.7		6
F. Secondary Care (Clinical Systems)	9.9	14.9	17.2	31.6	31.6	42.6		10
G. Secondary Care (Payment + Performance)	15.2	27.8	30.9	44.4	46.3	50.1		10
H. Emergency, Urgent, and Out of Hours Care	12.2	20.1	22.2	31.4	33.9	43.6		9
I. Maternity and neonatology	13.1	24.1	24.7	32.9	36.1	44.9		9
J. Cancer Specific	13.7	27.3	28.6	33.7	36.3	46.0		9
K. National Disease Registries and Audits	10.0	10.0	10.0	10.0	15.1	23.0		4
L. Intensive Care Units / Critical Care Units	9.4	12.2	13.5	20.9	20.9	20.9		4
M. Diagnostics (Results and Reports)	5.1	11.4	12.4	29.9	32.6	35.4		8
N. Diagnostics (Images)	7.0	7.0	18.5	18.7	25.8	29.6		7
P. Physical and Physiological Measurements	3.0	10.8	12.1	19.5	19.5	19.5		5
Q. Genomics	2.5	9.8	9.8	26.2	26.2	26.2		4
R. Mental Health	8.2	18.3	21.2	28.9	31.5	36.7		7
S. Community Care	14.2	34.6	39.7	39.7	39.7	41.4		8
T. Local Authority	5.2	13.6	16.6	16.6	16.6	28.8		7
U. Continuing Health Care	-	-	-	-	-	12.3		2
V. Shared Care Record	-	2.6	6.8	13.0	15.9	15.9		4
W. PROMS	3.2	9.4	9.4	9.4	14.5	14.5		3
X. Disease Registry (Research)	9.7	12.2	14.5	18.0	18.2	19.6		5
Y. Other Data Types	3.2	5.9	5.9	5.9	5.9	7.0		3

Programme Engagement

Enhanced stakeholder engagement

- Strategic Partners meeting with membership bodies, will now shift to a formalised **Steering Group**
- New Data Subcommittee of **Life Sciences Council**.
- Individual quarterly meetings for **key membership groups**, please work with ABHI, ABPI, BIA, TechUK and AMCR
- Launch of the programme supported **national public engagement on the use of health data**. The majority of this funding will be spent on “large-scale public deliberations”, similar to the methodology successfully used by OneLondon .



Powered by Data

Objectives	Approach	Impact
<ol style="list-style-type: none">1. Increase public awareness of how NHS data is used and the benefits.2. Increase public confidence in the use of NHS health data for purposes beyond direct care.3. To build a partnership of stakeholder organisations and help them to showcase the importance of patient data to their work.	<ol style="list-style-type: none">1. A social media campaign2. Focused on building understanding3. Encouraging emotional4. Showing how NHS data is behind amazing work in a variety of settings5. Focused on the outcomes of the data use.6. Partnership approach and chance to showcase partner organisations	<ol style="list-style-type: none">1. Around one in thirteen of the population of England has watched a Powered by Data video all the way through2. 28m impressions on social media3. 4.3m video views4. Support to allow secure access to NHS data by other organisations to improve patient care increased from 63% in June to 66% in August



Our next film

Premiere of the first edit



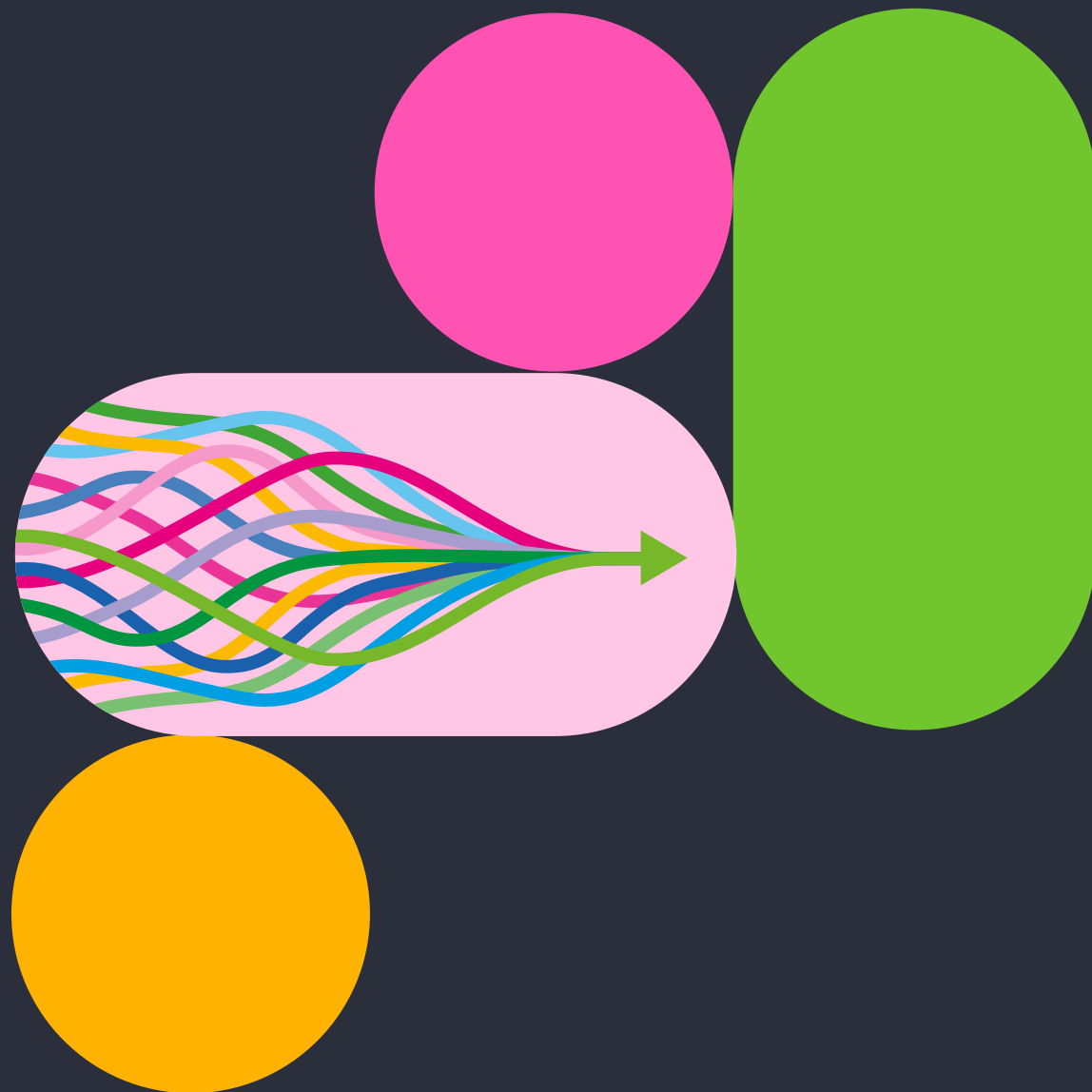
Thank You

Genomics – linking clinical care and research

Dr Rich Scott

Acting CEO, Genomics England

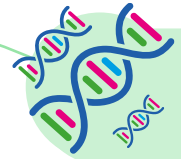
30 October 2023





Our vision is a world
where **everyone** benefits
from genomic healthcare

Timeline condensed version



2013

Launch of the 100,000 Genomes Project



2015

First patients diagnosed as a result of the 100,000 Genomes Project



2018

The 100,000th genome is sequenced



2020

- GenOMICC COVID-19 study established
- Launch of the Genome UK strategy
- First whole genome sequenced in the NHS GMS



2021

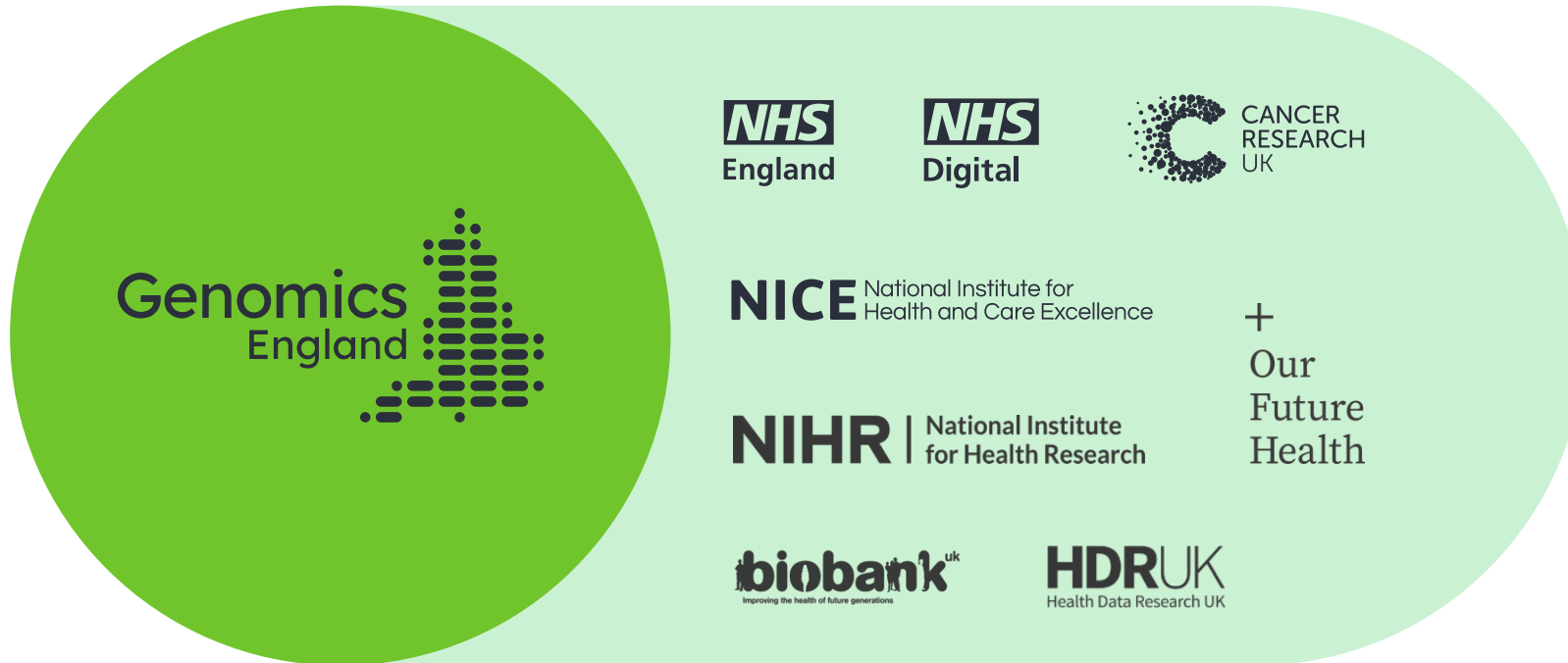
Newborn sequencing pilot and Diverse Data programme announced



2022

The government publishes the Genome UK: 2022 to 2025 implementation plan for England, highlighting our Cancer 2.0 and Diverse Data initiatives and Newborn Genomes Programme

The UK ecosystem



Academia ~4000 researchers

BioPharma & Start-ups

Tech

(e.g., AWS, Nvidia, Lifebit, Congenica)

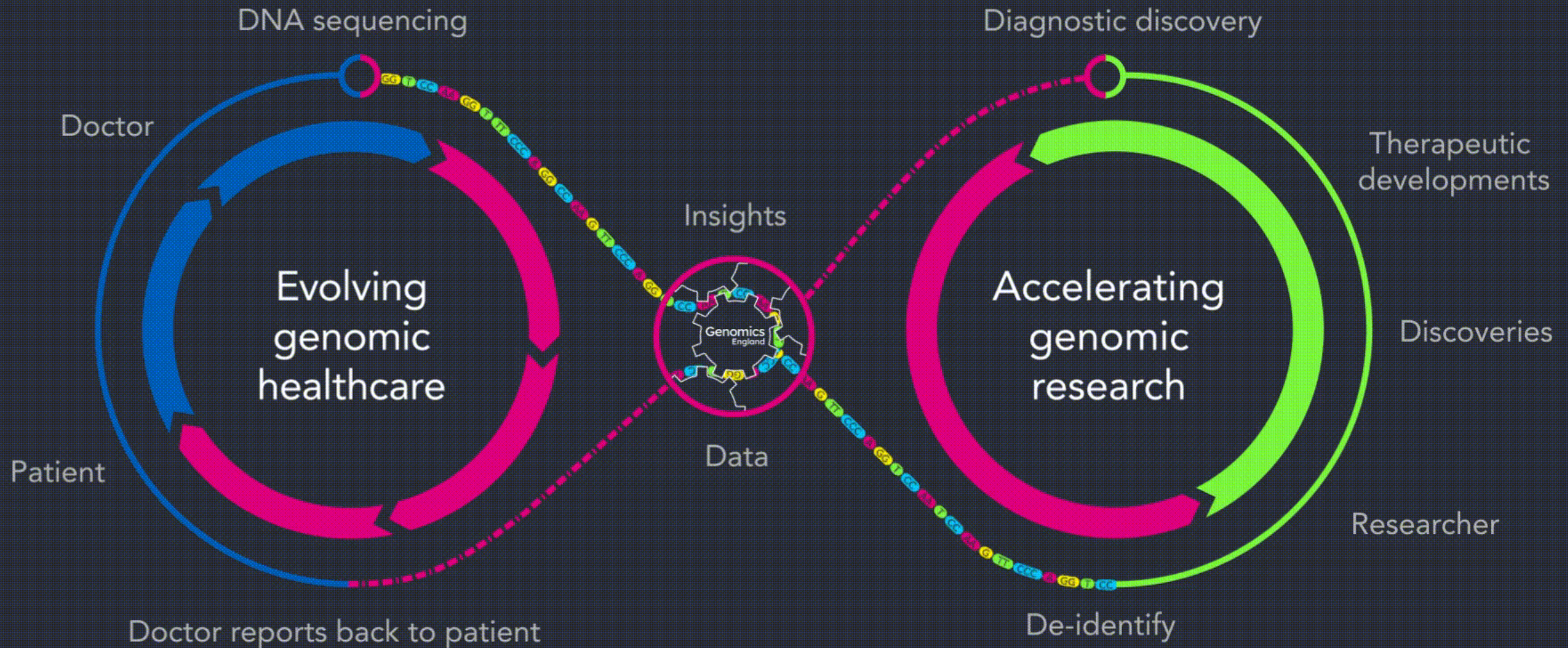
Lab Tech

(e.g., Illumina, Oxford Nanopore)

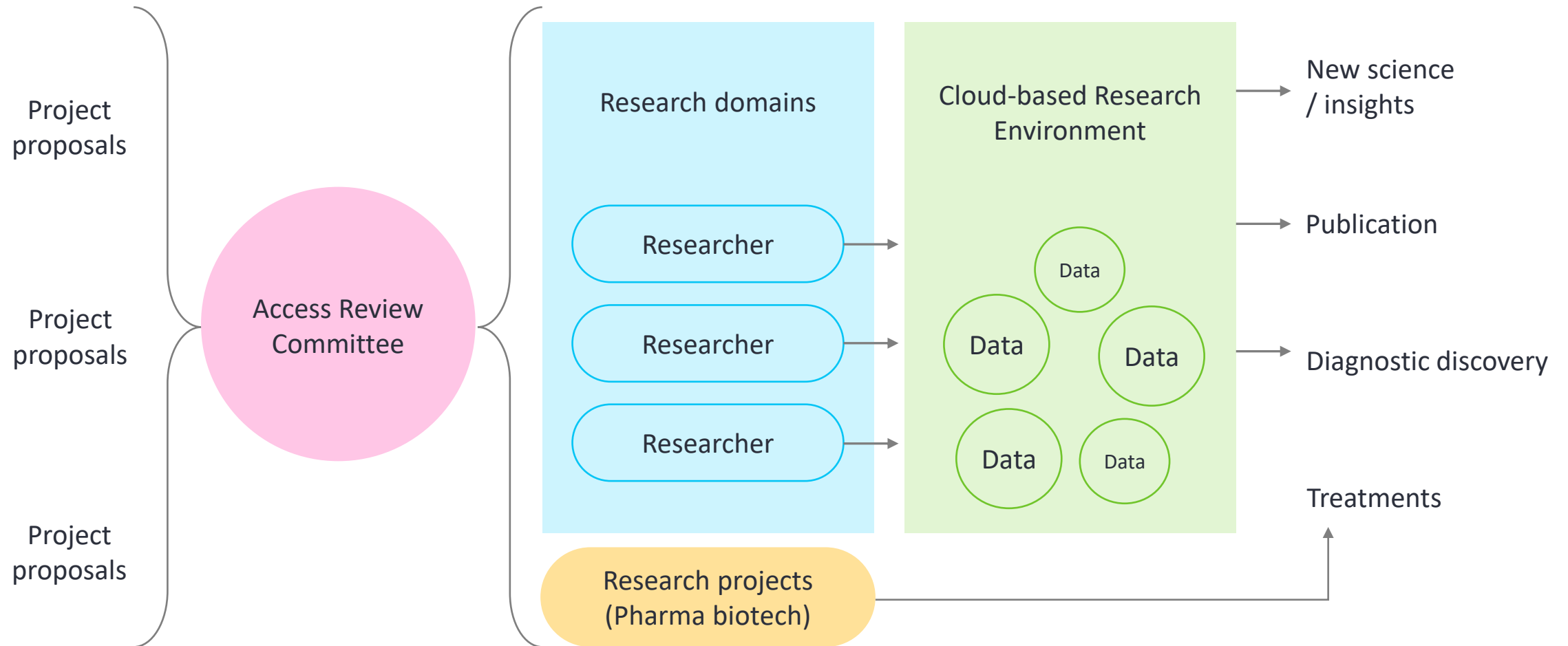
Funders

(e.g., Innovate, BEIS, MRC, CRUK, Wellcome, Lifearc)

Turning science into healthcare, together



How do academics and biotech/pharma co's work with us?



More data, more complexity



150k+

Genomes sequenced



90+

petabytes
Genomic and
medical data



99+

bioinformatic
pipeline
workflows



7/10

top pharmaceuticals
as partners



80k+

Digital Pathology
images



200+

academic
& clinical
institution



100+

publications
using GEL
data assets



673

research
projects



1,859

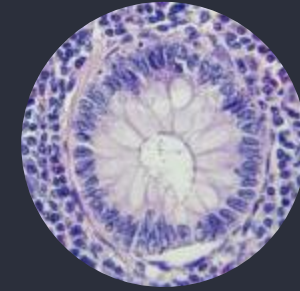
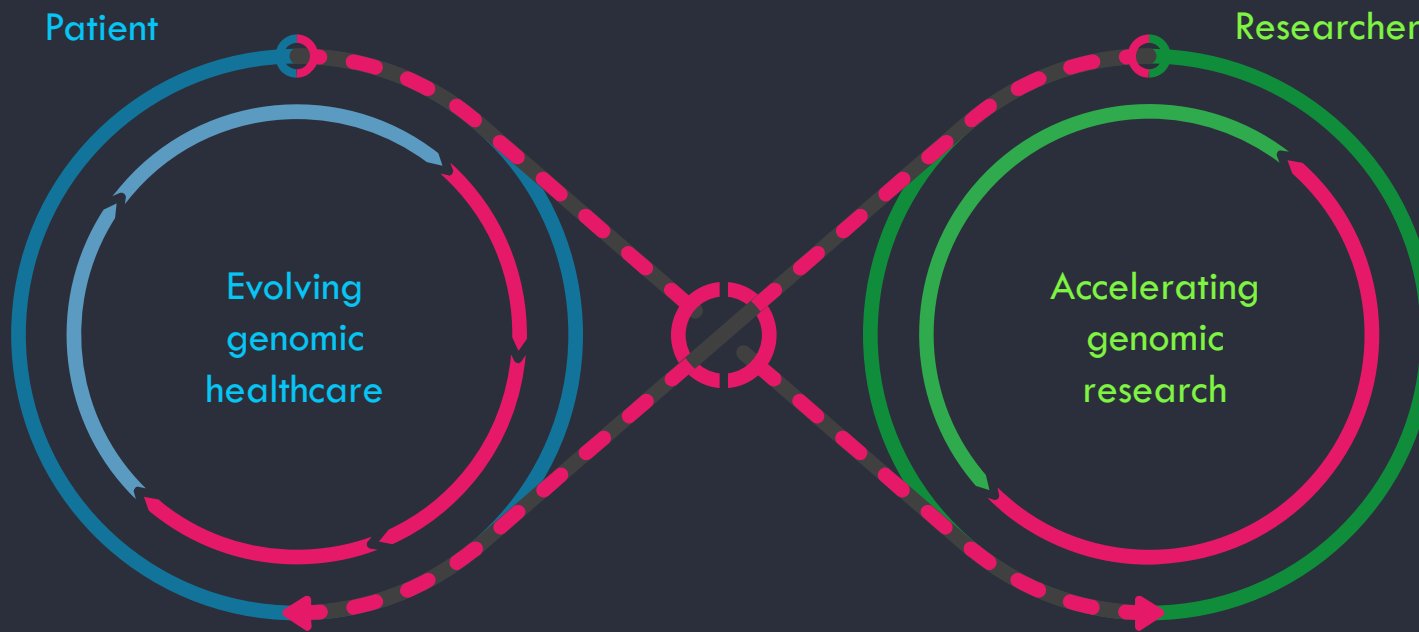
Researchers with access to data
(academic and commercial)



500k

Government target for genomic
interpretations

Research initiatives



Cancer 2.0



Diversity



Newborns

Multimodal Programme

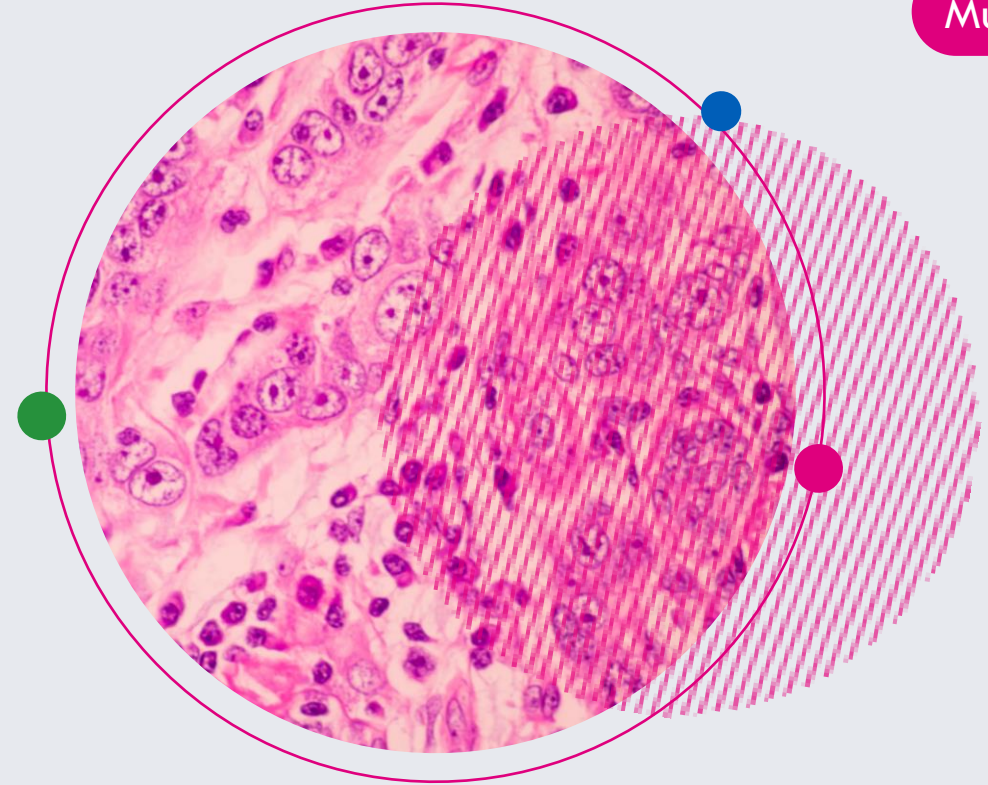
Combining digitised patient imaging data with clinico-genomic data to enable better predictive models of diagnosis, prognosis and response to treatment

Currently:

>80k pathology images

>45k radiology series

Multimodal



Build

Provide the world's largest library of linked genomic, clinical and imaging data

Accelerate

Understanding the utility of morphological changes in cancer and its relationship to genomic sequencing

Enable

Accelerate the way for the NHS to become an entirely digital pathology service

De·coded

100,000 newborn babies will have their genomes sequenced in the UK. It could have big implications for child medicine



by Thomas Page, CSM

5 minutes read · Updated 7:56 AM GMT, Mon March 20, 2023



Foundations for the 'lifetime genome'



All c. 650k new babies annually potentially offered WGS at birth

Genomics underpins early diagnosis and interventions

PRS driven risk stratification and screening

Pharmacogenomics informs prescribing.

Cancer early detection.

Cancer diagnosis and treatment stratification.

Cancer monitoring.

Genomic data stored ready for use 'on the fly' in primary and secondary care to support healthcare though lifetime

Thank you

www.genomicsengland.co.uk



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Dr Richard Scott

Chief Medical Officer &
Deputy CEO, Genomics
England

Chair: Dr Bishoy Dimitri

Director of Clinical Informatics
(CCIO)
Oxford University NHS FT