Data for R&D
PROGRAMME

NHS

Data for R&D Vision

By 2025, have a world leading NHS-wide health data research infrastructure that enhances patient care, sustains the NHS and supports innovation.

Why are we shifting from data sharing to data access?

Public confidence

Data access provides much better security and enables increased transparency of how data is used.

NHS and DHSC

Enables better use of data to support population health management **decisions**, resource **planning**, and monitoring deployment of new **innovations**.

Researchers

Datasets can be securely linked with results, shared in a non identifiable way.

Setting national policy

Policy principles

12 high level guidelines that will guide our approach to SDEs. Published in recent Data Strategy.

Technical capabilities specification

Defines technical capabilities required of SDEs, including security, functionality, access and data management.

Roadmap

A guidance document that explains the transition to SDEs. How the SDE guidelines, tech spec and accreditation should be implemented and over what timeline.
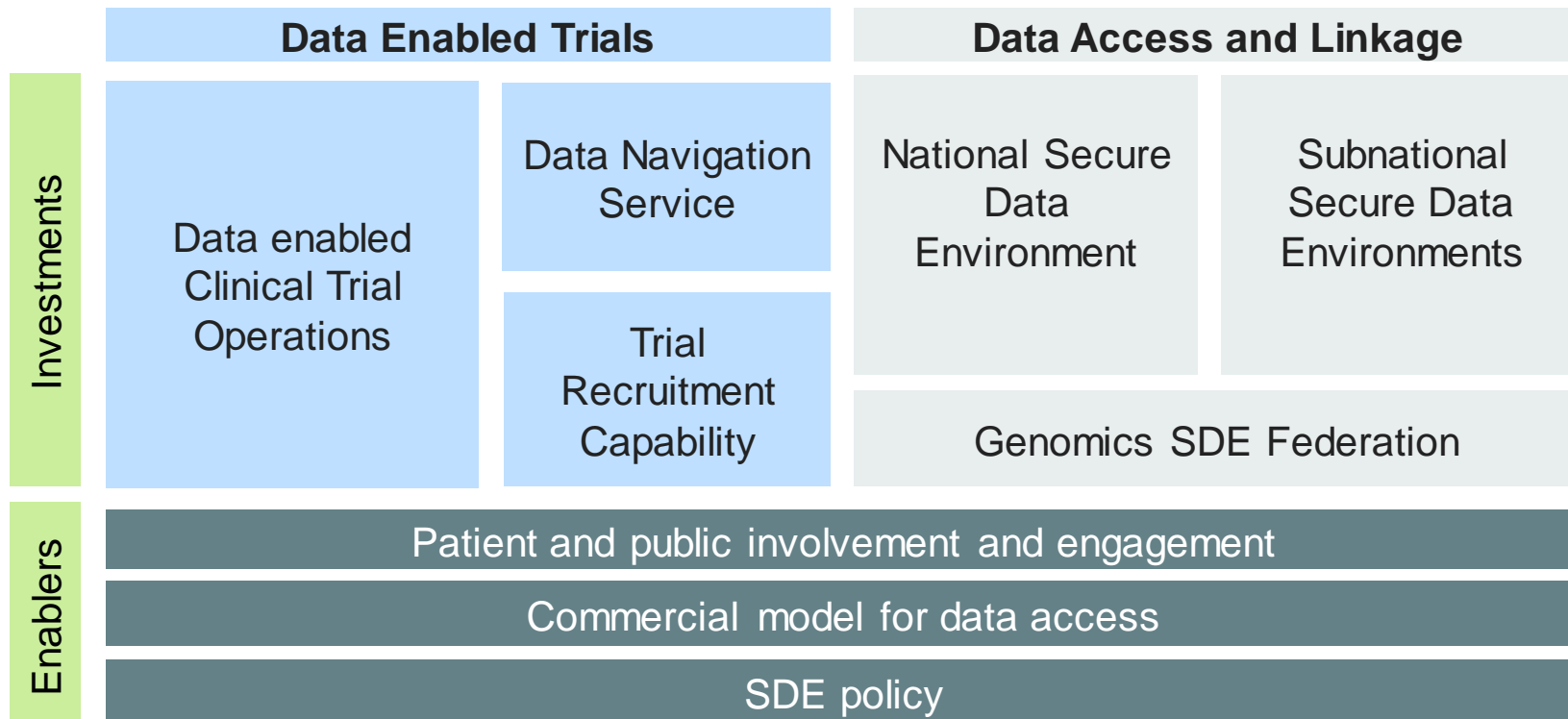
Accreditation framework

Details Information Governance standards that SDEs must adhere to, and how this will be assessed and monitored.

Objectives

1. **Develop an England-wide ecosystem of NHS owned and managed infrastructure** to allow researchers access to secure, high-quality, linked datasets, by:
   - **Expanding the scope, capacity and capability** of a national health data infrastructure platform
   - **Developing a network** of sub-national/regional linked health data infrastructure platforms and services.

2. **Enhance patient and public support and enthusiasm** for use of NHS health data to drive research and development.

3. **Increase clinical trials capacity** by underpinning clinical trial operations with NHS health data, improving the efficiency of clinical trial set up; and increasing the volume of people recruited to participate in clinical trials.

4. **Expand** the ability for researchers to **access a range of genomics datasets through linkage** of sources.

5. **Generate returns to the NHS** by applying commercial principles consistently and coherently across the programme to generate value for the NHS.

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Programme on a page

Data Enabled Trials		Data Access and Linkage	
Data enabled Clinical Trial Operations	Data Navigation Service	National Secure Data Environment	Subnational Secure Data Environments
	Trial Recruitment Capability	Genomics SDE Federation	

Investments

Enablers

Patient and public involvement and engagement

Commercial model for data access

SDE policy

Six use cases

Data for R&D investments are guided by six key, high level use cases

AI/algorithm development (testing, training, and validation)

Clinical trial activities (feasibility, recruitment, efficacy through short- and long-term trial follow up)

Real world studies (safety, effectiveness, cost effectiveness)

Translational research (academic discovery and implementation of discovery into practice)
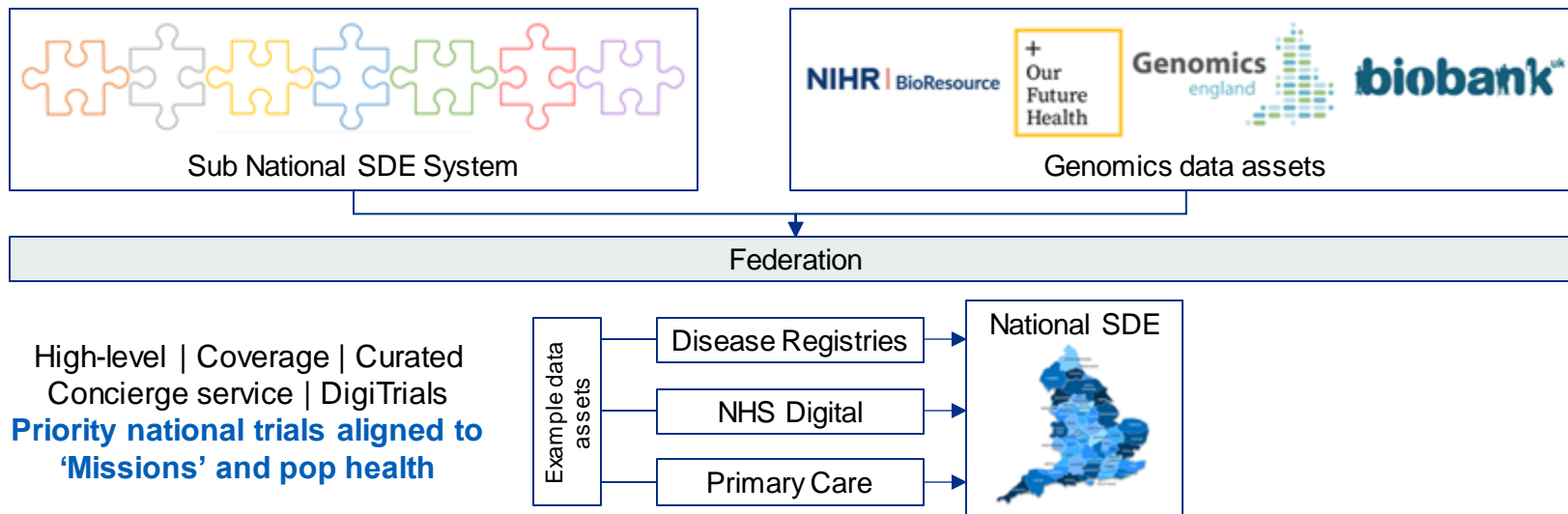
Epidemiological studies (large cohorts for population health research)

Health systems research (evaluation of systems or processes, including operational and applied research)
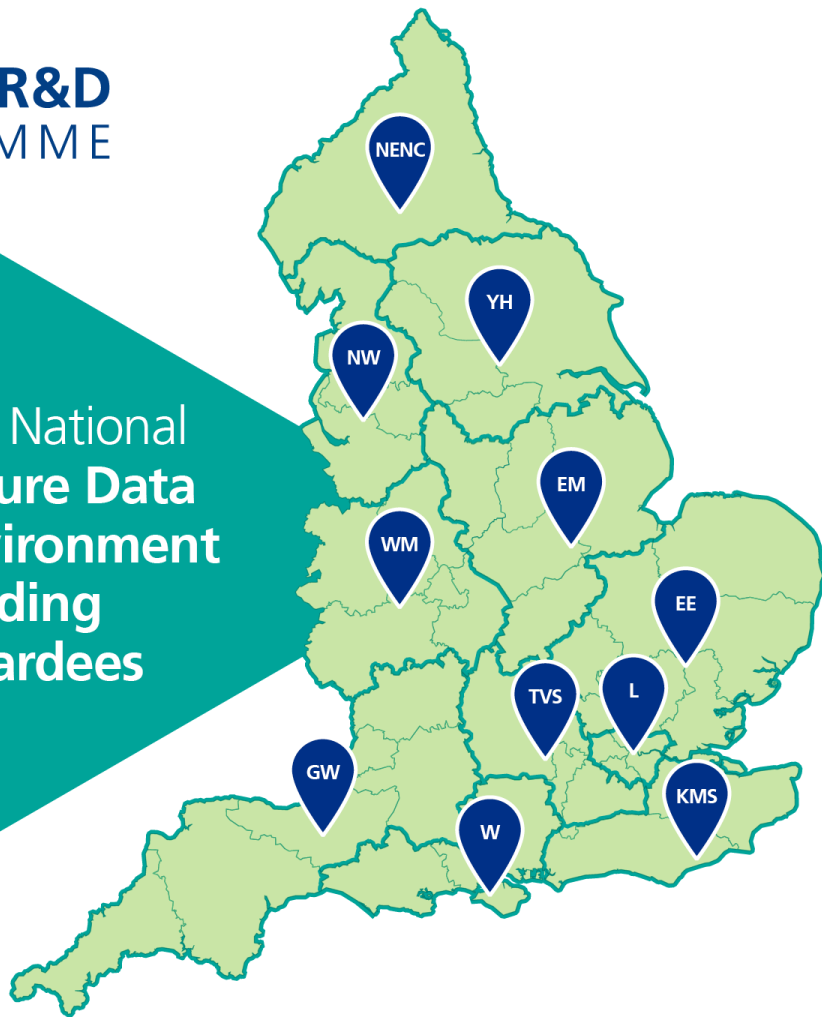
Sub National SDE funding

- Over **£13.5m** 22/23 funding awarded to **11** geographies to develop SDEs that will give full coverage of England, part of a >£100m funding package

- Covering **42** ICSs

- Over **45** initial research projects proposed

- Public-facing communication 9 Dec '22 including blog from Dr Claire Bloomfield

- Expect to see some consolidation over Programme term

- Waves are purely for phasing and not an indicator of quality

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Sub National **Secure Data Environment funding awardees**

EE	East of England
EM	East Midlands
GW	Great Western
KMS	Kent, Medway & Sussex
L	London
NENC	NENC
NW	North West
TVS	Thames Valley & Surrey
W	Wessex
WM	West Midlands
YH	Yorkshire & Humber

Commercial principles development

The CIDC is developing commercial principles to ensure that partnerships for access to data for research and development have appropriate safeguards, and benefit the public and the NHS.

The commercial principles aim to:

Align incentives so that the NHS and companies want to develop innovations that work for patients

Support and encourage worthwhile innovation and research that deliver patient benefit

Speed up negotiations, make them simpler and contracting save costs and support innovation

Ensure that any income is shared fairly across the NHS

Patients expect value return from data:

" 81% of people believe benefits that come from health data partnerships should be distributed across the NHS. "

" Over 60% of people would rather that commercial research organisations have access to health data than society miss out on the benefits these companies could potentially create. "