Genomics strategy and implementation in the NHS in England

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Genome Canada leaders' roundtable on the future of genomics in Canada
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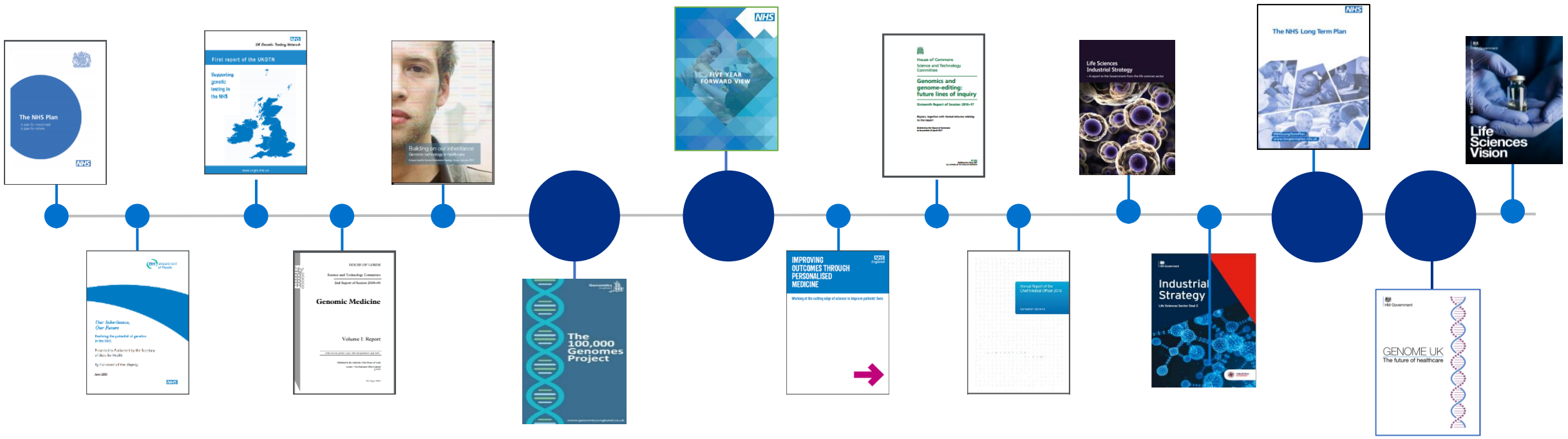
Developing the strategy

History of political and strategic buy-in over the last 10 years



Key commitments

- 1m WGS (Industrial Strategy)
- 500k WGS in UK Biobank
- 100K Genomes Project
- ~1.5 million other genomic tests
- 500k WGS in NHS
- Ongoing NHS GMS investment
- 5 Million Early Detection Cohort
- GENOMICC and COVID research
- Genomics England investment – newborns, cancer tech, diversity

Delivery enabled by whole genomics ecosystem

NHS

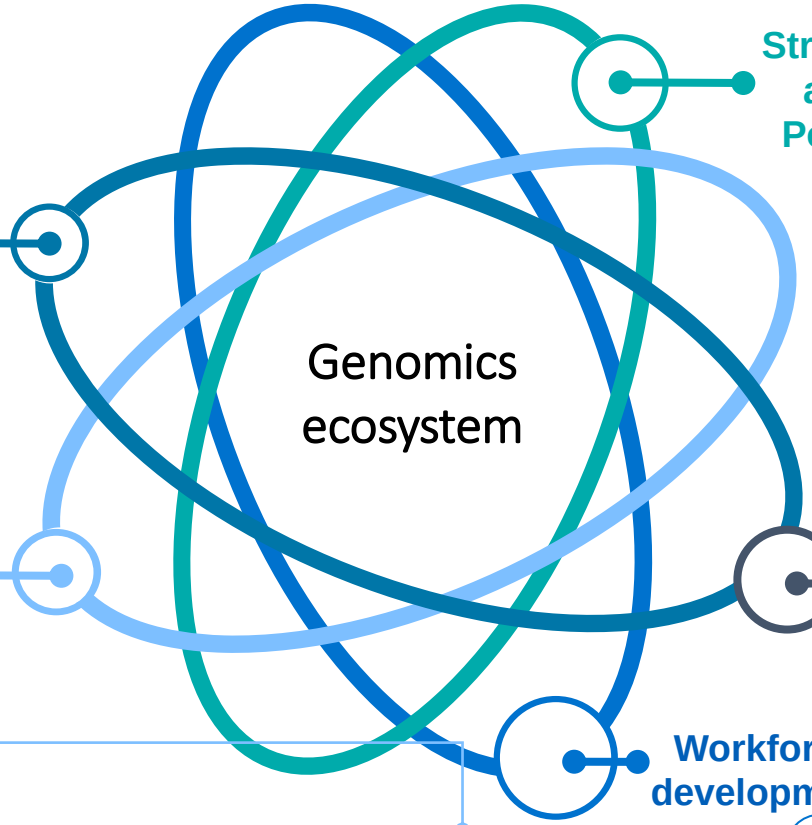
NHSX
Support NHS and care organisations to digitise their services and connect systems through technology

HRD UK
Unite the UK's health and care data to enable discoveries that improve people's lives

NHS Digital
Supplies data to the health service and provides technological infrastructure

Genomics England
Partners with the NHS to deliver WGS service and provide Trusted Research Environment to enable access to genomic data to drive scientific discovery and accelerate its translation into patient care.

NIHR
Delivers world-leading health and social care research. All NHS sites connected through our national network.



Government: *Department of Health (DHSC) and Office for Life Sciences (OLS)*
Funds provision through the NHS and research in England. Office for Life Sciences (OLS) is part of DHSC and BEIS and has set the10-year strategy for sector

NHS England and NHS Improvement
Responsible for setting the overall strategy and commissioning services, including genomics

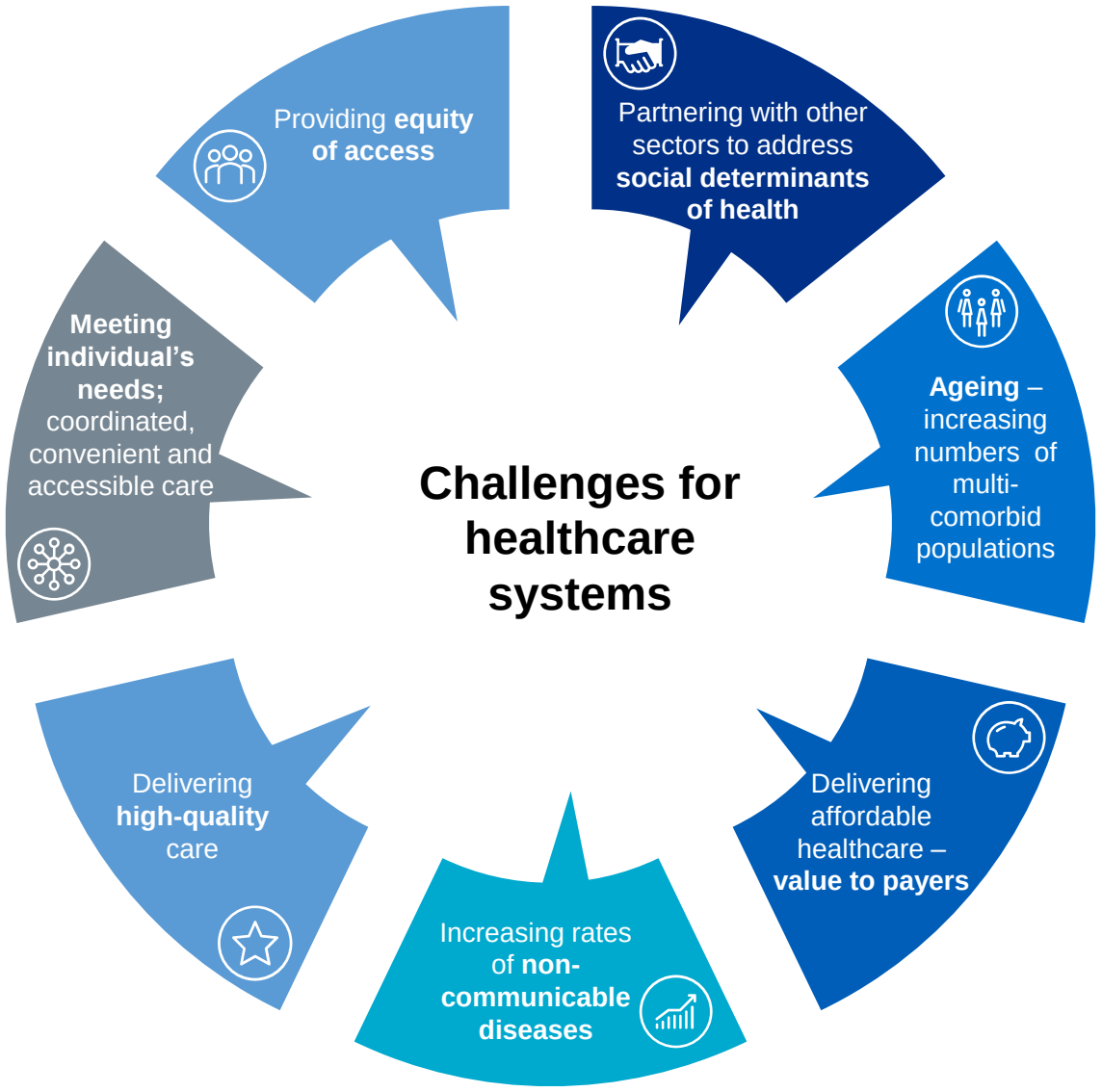
Integrated Care Systems and NHS Trusts
Delivery of NHS services for defined populations

UK Research and Innovation
Work with partners to shape a dynamic, diverse and inclusive system of research and innovation in the UK

Academic Health Science Networks
Connect NHS, academics, local authorities, third sector and industry to spread innovation at pace and scale

Health Education England (HEE)
Responsible for the development of a multi professional workforce to meet the demands of a rapidly expanding service

Drivers for change – the need to address healthcare challenges



The future direction for healthcare systems will require a balanced focus between:

Population Health

Focus on improvements to population health

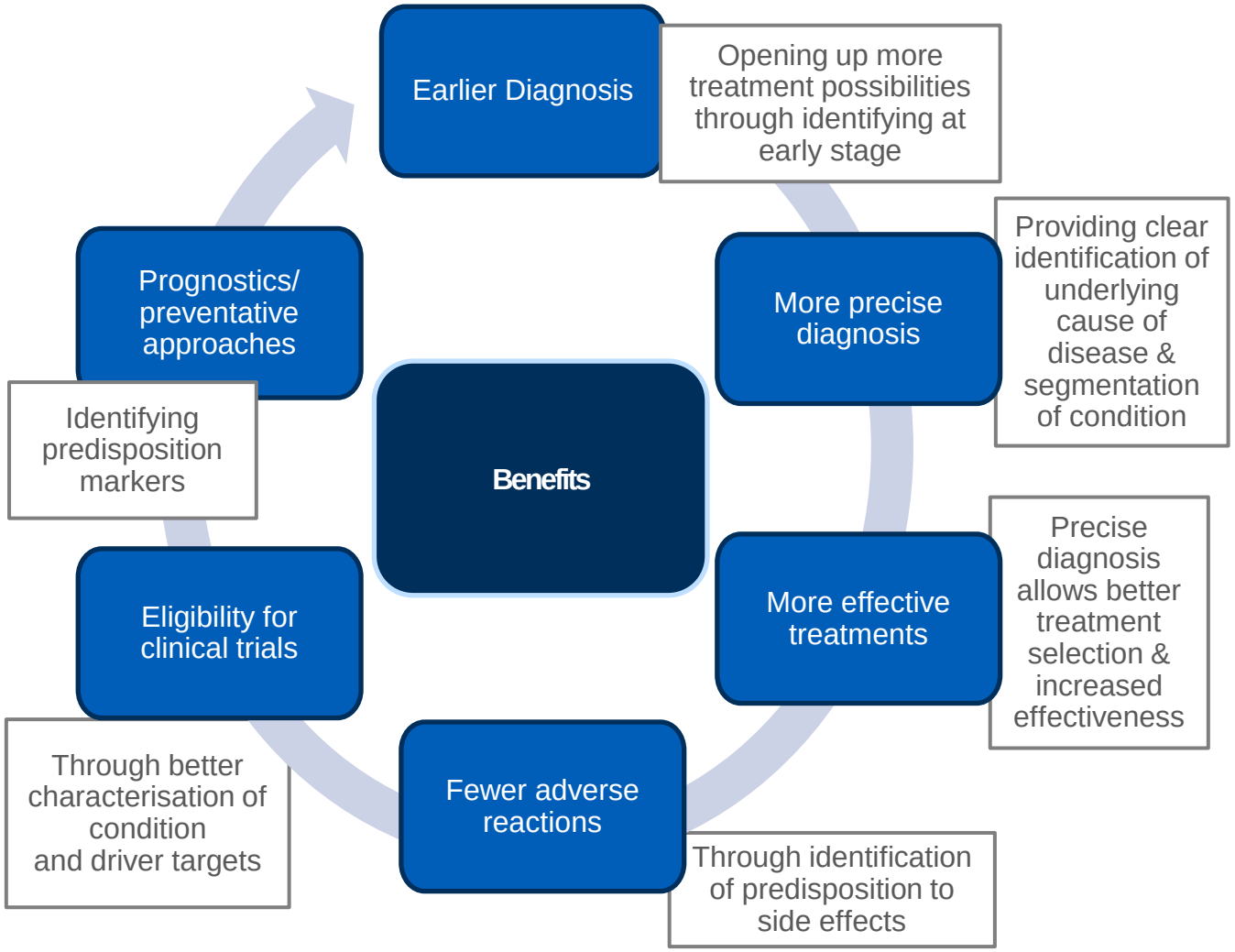
- A step change in prediction and prevention of disease
- Earlier diagnosis of disease
- Enhanced screening and prediction
- Influencing lifestyle choices

Personalised Care

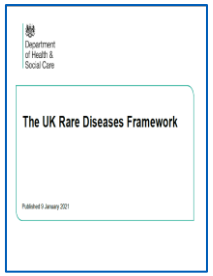
Increasing personalisation and management approaches

- Tackling the limits of 'one size fits all' medicine & blockbuster drugs
- Medicines optimisation
- Managing adverse drug reactions
- Identification of new targets and treatment approaches
- Improving outcomes

Genomics driving improvements for patients



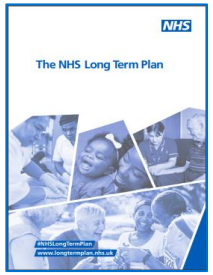
Supports delivery of disease specific strategies:



UK Rare Disease Framework has four key priorities:

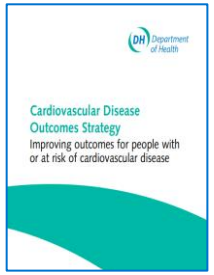
- Helping patients get a **final diagnosis faster**
- **Increasing awareness** among healthcare professionals
- **Better coordination** of care
- Improving access to **specialist care, treatments and drugs**

An action plan will be published to support implementation



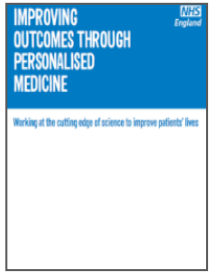
NHS LTP ambitions for cancer:

- by 2028, **55,000 more people each year will survive** their cancer for five years or more; and
- by 2028, **75% of people with cancer will be diagnosed at an early stage** (stage one or two)



DHSC Cardiovascular Outcomes Strategy:

- Focus on **prevention** through risk minimisation and genomics
- Support **early detection**
- **Reduce premature deaths** from cardiovascular disease
- Ensure **equity of access** to services



Improving Outcomes through Personalised Medicine

10-year framework for delivery of personalised medicine across the NHS, including:

- improved p**rediction and prevention** based on predisposition
- more **precise (and prompt) diagnosis** based on cause
- **targeted interventions** through the use of companion diagnostics to personalise effective treatments

Genome UK Strategy

NHS

Published in **September 2020**, Genome UK sets out how the genomics community will work together to harness the latest advances in genetic and genomic science, research, and technology for the benefit of patients

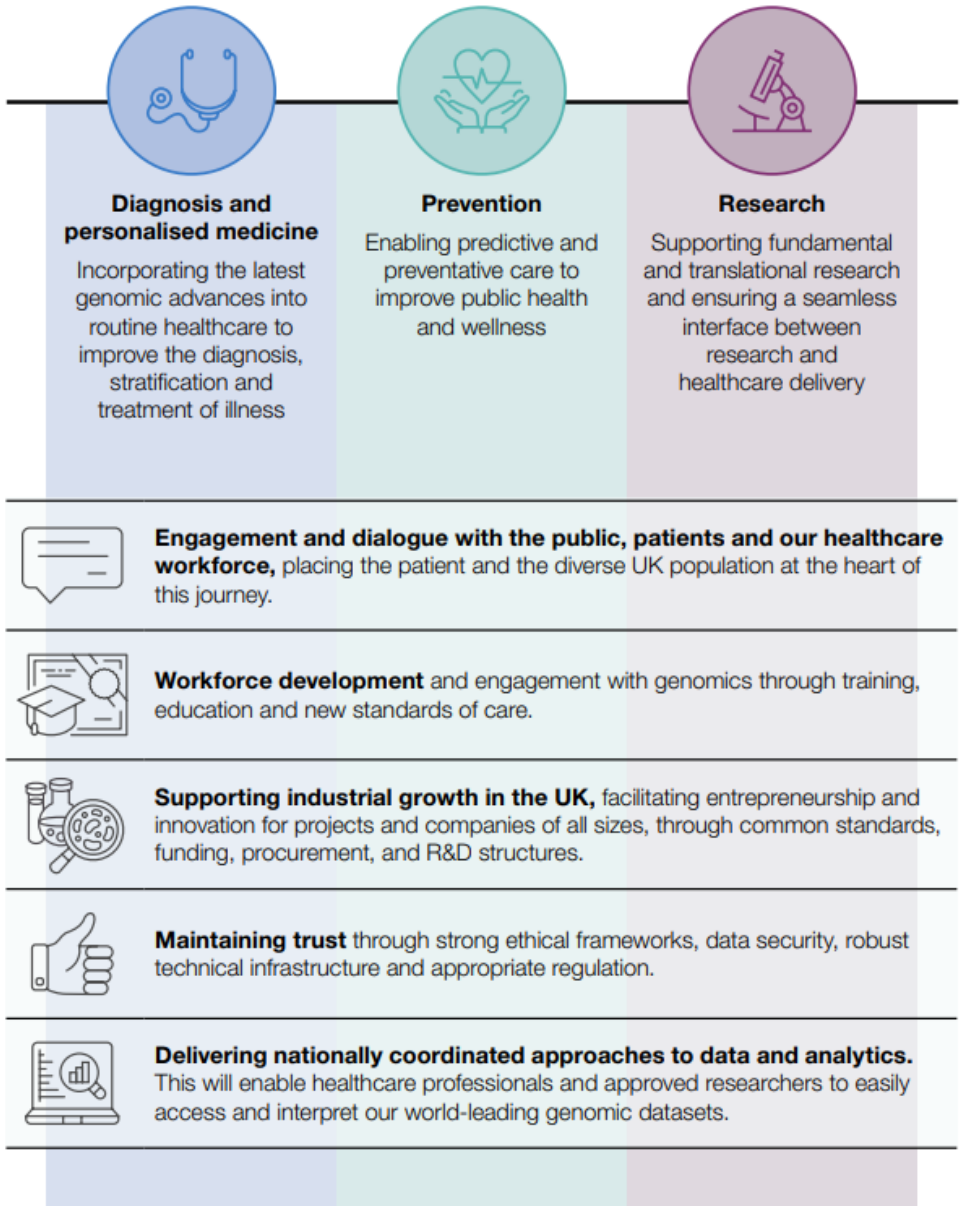
Vision
To create the most advanced genomic healthcare ecosystem in the world, where government, the NHS, research and technology communities work together to embed the latest advances in patient care.

Prioritisation
Focussed on three key areas and supporting cross cutting themes to drive societal benefit

Coordination
Implementation co-ordination group with representation from 4 countries of UK to support coordinated implementation

HM Government

GENOME UK
The future of healthcare



Ambitions included in the strategy

Diagnosis & personalised medicine

- **Sequence 500,000 genomes** and create the most advanced genomic healthcare system in the world
- Establish a proof-of-concept programme, led by Genomics England in partnership with the NHS, to **explore next-generation approach for the diagnosis and treatment of cancer**, integrating multiple data sources
- **Sequence pathogens** quickly and easily using point of care sequencing technology, helping us control outbreaks and fight antimicrobial resistance

Prevention

- Continue to develop a **public health and screening system** that uses genomics to intensify screening and interventions in those at high risk
- Formulate a clear evidence-based position use of **polygenic risk scores** at scale in the health service
- Explore how genomic testing can continue to be best used in **reproductive medicine to support parents to make informed choices**

Research

- Ensure that clinical genomic testing and genomics research contribute to **powerful national data resources and maximising impact**
- coordinate the UK's existing and future genomics ecosystem, enabling **ground breaking-research at scale** for the benefit of patients
- Achieve **greater diversity within our reference genomes**, and future genome-wide association studies (GWAS) will reflect the UK's diverse populations

Workforce

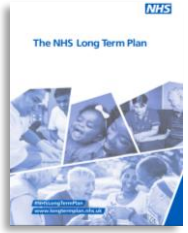
- ensure that all new graduating doctors, nurses, midwives, pharmacists, allied health professionals, dental and relevant nonclinical staff have a **level of awareness and knowledge of** genomics that is relevant to their role
- Ensure that the healthcare science workforce continues to have **advanced genomic training and education** within their programmes

Data

- Establish a **clear set of standards** for genomic and health data
- Develop systems to enable **federated access to data for research** use to enable comparisons across multiple datasets

Strategy to implementation in the NHS

NHS Long Term Plan implementation



Ambition for patients

- **Have the best start in life**
- **Delivering world-class care for major health problems**
- **Supporting people to age well**

Delivery of the ambitions

- **Give people more control over their health and care**
- **Preventing illness and tackling health inequalities**
- **Backing our workforce**
- **Better use of data and digital technology**
- **Value for taxpayers' money**

Genomics commitments

- NHS Genomic Medicine Service will sequence **500,000 whole genomes by 2023/24**.
- Improving recruitment to clinical trials and supporting research

- **Targeted investment** in innovation

Technology

Children & Young people

All **children with cancer** to be offered WGS

Seriously-ill children likely to have genetic disorder to be offered WGS

Earlier diagnosis
Access to personalised care

Cancer

Extended access to molecular diagnostics
Genomic testing routinely offered to all people with cancer

Research

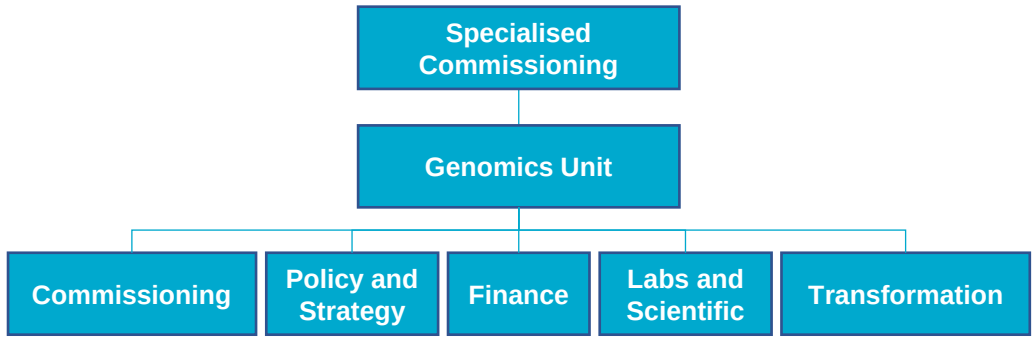
Linking and correlating genomic, clinical data and patient data Provide routes to new treatments, diagnostic patterns and help patients make informed decisions about their care

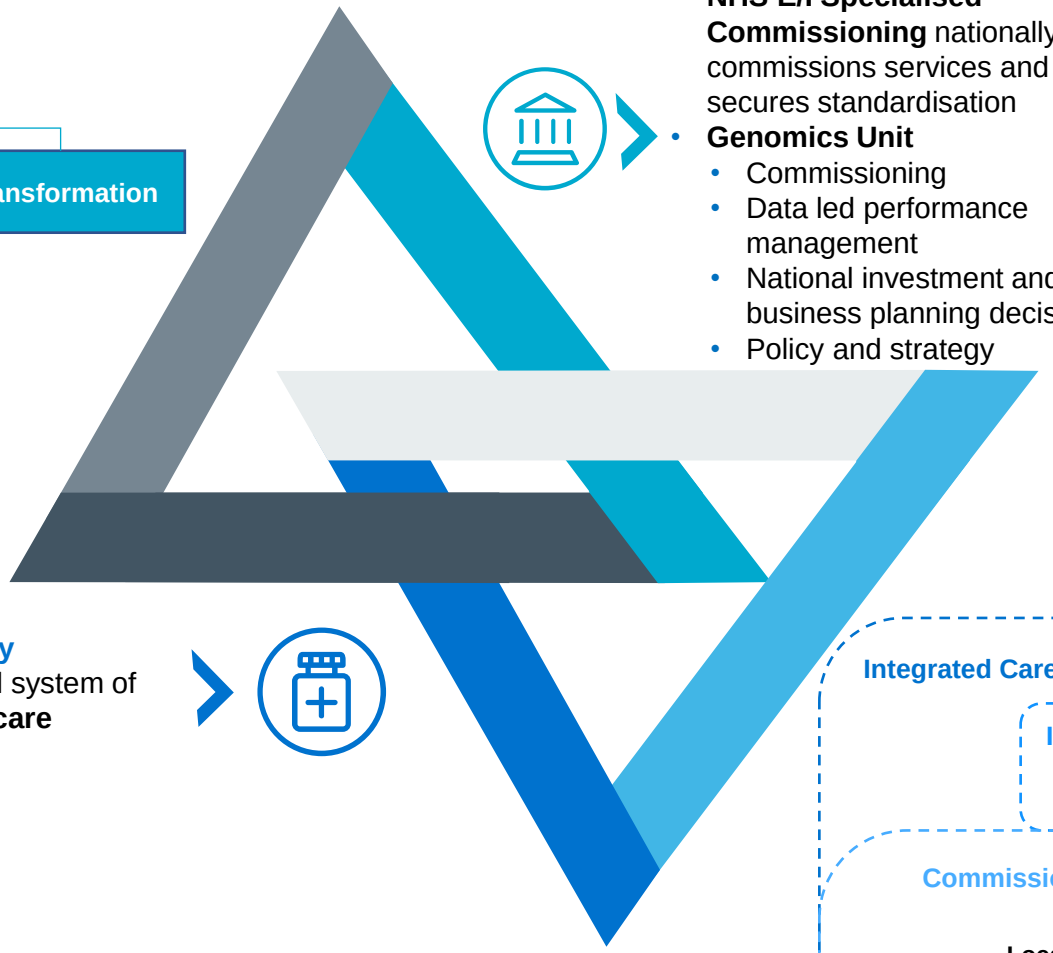
Expanding access to genomic testing for **FH**

Cardio-vascular

Early detection and treatment
Rapid identification of high-risk conditions

Strength of the NHS to delivery of genomics strategy





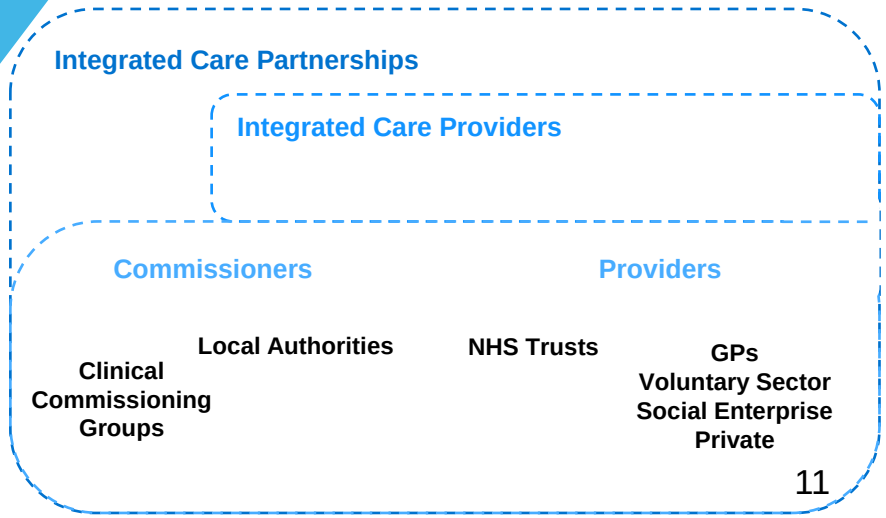
- **National Commissioning**
  NHS E/I Specialised Commissioning nationally commissions services and secures standardisation
- **Genomics Unit**
  - Commissioning
  - Data led performance management
  - National investment and business planning decisions
  - Policy and strategy

- **Provide direction** through mandating approach, messaging and system to accountability
- Link to **broader system priorities** such as cancer, rare diseases, medicines access and personalised medicine
- Use commissioning to enable **adoption of new technologies,** aligning outcomes with improvements and negotiating ahead of outcome of study
- **Collaborative working** has been strengthened by the pandemic experience

- Can work at a **whole system level**
- **Longitudinal health records**, inclusive of primary and secondary care, can be leveraged to enhance delivery of individual clinical care and improve health outcomes at population level
- Ability to **adopt at scale**, coordinate and consolidate to drive efficiency and value for money

NHS system delivery

- Integrated national system of **universal health care coverage**



Proof of concept

100,000 Genomes Project: political buy in

The NHS "urgently" needs to develop the tools and expertise needed to take advantage of a revolution in genetic testing, June 2011

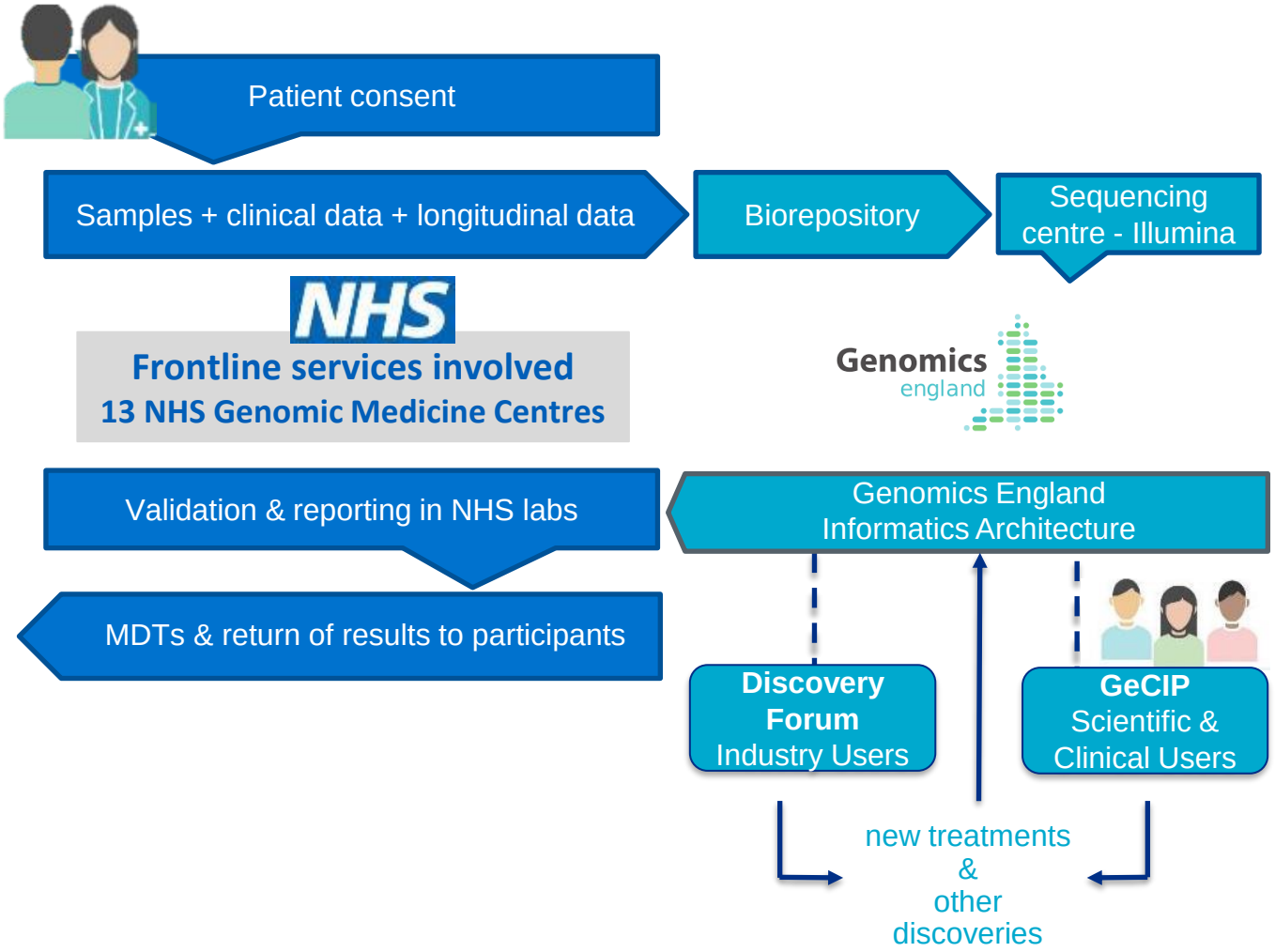
The 100,000 Genomes Project was announced by the Prime Minister, December 2012

An Olympic Legacy

Genomics England was announced by the Secretary of State for Health at NHS 65th Anniversary Celebrations, July 2013

Strategic approach and infrastructure

- Co-ordinating genomic knowledge to make the UK a **world leader**
- Sequencing 100,000 genomes to **advance genomic knowledge**
- Turning genomic knowledge into **health interventions**
- Ensuring the NHS **workforce is skilled & able** to deliver for patient benefit
- Using genomic knowledge for **prevention & health protection**



107,513 genomes available in the Research Environment

- **33,333** cancer
- **74,180** rare disease

122,945

Samples collected and received at the UK Biocentre

Creating direction | **Leading transformation** | **Building readiness**

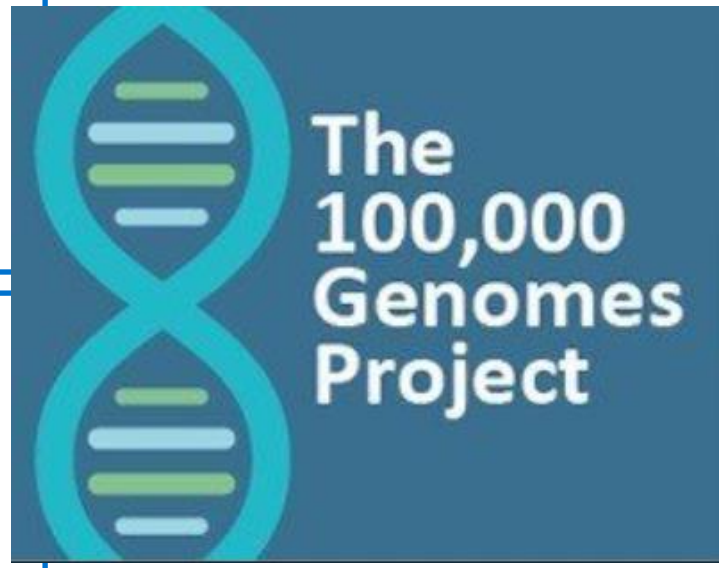
Outcomes for participants

Key findings

- Rare disease – **1,200 disorders with unmet need**
- Diagnostic yield **overall 20%** in rare disease including:
  - **55% in Cystic Kidney disease**
  - **51% in Osteogenesis Imperfecta**
- Cancer – **24 cancer types** included and total of 18,500 participants
  - **50%** of all cancer participants to have a **known actionable or potentially actionable gene identified –** tumour specific early phase clinical trials

Activities to complete 100,000 Genomes Project

- Ensure all participants receive **additional findings** both secondary looked for findings and pharmacogenomic profiles
- Review the evidence on reanalysis
- Ensure continued feedback of learning and further determine variants of unknown significance
- Ensure participants can continue to be involved in future developments



NHS Genomic Medicine Service

Whole system transformation in genomics in the NHS

	Issue	Action
	**Variation in access**	National commissioning and finance mechanisms to ensure standardisation and service stability: • **Secured funding for infrastructure** • **National standards and specifications for delivery of services** • **Regular assurance monitoring**
	**Dispersed infrastructure**	Comprehensive clinical and organisational infrastructure to deliver consistent, high quality genomic medicine. Key components of infrastructure include: • **Consolidated laboratory infrastructure** • **Standardised clinical pathways** • **Embedded workforce, education and training**
	**Lack of performance data**	Performance monitoring to ensure service is being delivered in line with expected standards • **Benchmarking to understand trends between GLHs** • **Monitor access to testing and improve equitability** • **Inform future commissioning arrangements and understand where additional actions or support may be required**
	**Clinical leadership concentrated in clinical genetics**	A dedicated multidisciplinary clinical leadership across the system • **Drives and delivers leadership and partnership at all levels including a bottom-up approach to learning and embedding** • **Collaborative governance, system leadership and strategic partnership**
	**Embedding of innovation and new technologies**	• **Significant NHS investment in 100,000 Genomes Project** as proof of concept for whole genome sequencing as part of routine clinical service – set up of 13 NHS Genomic Medicine Centres, extensive clinical leadership and pathway transformation • Infrastructure to support rapid adoption of new technologies for example long read sequencing technology and liquid biopsy
	**Lack of IT connectivity**	Developed understanding of fundamental need for data sharing – while ensuring confidence in confidentiality and data security • **Created NHS informatics and data infrastructure for genomics** • **Brought multiple systems together to collate and curate clinical data for an individual** • **Developed a rich clinical dataset with standard nomenclature and data models (HPO, SNOMED CT)** • **Established national database of consented and deidentified genomic (WGS) and clinical data**

Building the infrastructure: NHS Genomics Medicine Service

Overarching aim:

To enable the NHS to harness the power of genomic technology and scientific advances to improve population health and patient outcomes

Key principles:

- Be **clinically and scientifically led**
- Have **patients and public involved** at all levels
- Ensure **equity of access** for all patients
- Have a **standardised** model of delivery and commissioning across the country
- **Be responsive** to innovation and new technologies
- Inform and drive change using **data led insights**

The NHS Genomics Medicine Service Pathway

NHS England and NHS Improvement: Commissions and funds services and is responsible for national oversight, assurance and direction

7 NHS Genomic Medicine Service Alliances: Responsible for multidisciplinary clinical leadership to embed genomic medicine across end-to-end pathways

Collaboration with Health Education England to support workforce development, training and education

1. **Patient is referred for genomic testing by 'mainstream' clinicians or clinical genetics service**

2. **7 NHS Genomic Laboratory hubs perform genomic testing, analysis and interpretation and feed back results to clinicians**

3. **Genomics England National Genomic Research Library – consented patient data currently for WGS**

Informed by the National Genomic Test Directory that covers full repertoire of genomic testing

- **Secured national provision for WGS testing**
- **WGS bioinformatics provided by Genomics England**

Enables ongoing research and discovery from approved researchers, academia and industry

Clinical Genomics Services support complex care and other clinical teams. They provide input into genomic MDTS

*Currenting updating the clinical genomics service specification

Delivering the full breadth of genomic testing with horizon scanning

The testing strategy

NHS GMS and National Genomic Test Directory has a deliberate focus on the **whole continuum of genomic testing.** To keep pace with **scientific and technical developments** the Test directory is updated annually through the Test Evaluation Working Groups and review of evidence submitted through consultation.

Continuum of Genomic Testing

Disease focussed → **Informing treatment decisions** → **Population based** → **Predictive** → **Horizon scanning**

Targeted Testing	Panels (10s-100s of genes)	Exome Sequencing	Whole Genome Sequencing
For known causes of genetic disease eg Huntington's Disease	*Small and Extensive Next Generation Sequencing*	*Standardising rapid NICU/PICU testing* - *Fetal Exome testing* - *Interim testing while WGS established*	*Looking across the genome for diagnostic, therapeutic and predictive information*

Examples in Cancer	Aim to test **30,000 patients/year**. Biomarker testing including for **BRCA and Lynch Syndrome**	Standardising cancer panels for pan-solid tumours – high throughput cutting edge technology Referrals from all providers Establish transport pathways	Phase 1: 3 cancers, including all **paediatric** Phase 2: pilot **triple negative breast** and **high grade serous ovarian cancer**
Examples in Rare Disease	Cascade testing for **Familial Hypercholesterolaemia**.	NGS gene panel standardised across England for 323 panel tests	Phase 1 – **21 rare disease conditions** Phase 2 – additional **25 rare disease conditions**

Core testing – delivered by all 7 GLHs → **Specialist testing** – delivered by between 2-5 GLHs with specialist knowledge for interpretation → **National provision** – one provider for the whole country

Developing the testing strategy

National Genomic Test Directory outlines the testing strategy for the NHS and has a deliberate focus on the **whole continuum of genomic testing.**

Strategy

Covers **over 3,000 rare disease** and **majority of solid and haem-onc cancers**

Strategy to move away from single gene testing to **more comprehensive DNA and RNA panel testing** through to whole exome and whole genome sequencing to drive efficiency and productivity

Developed **through review of scientific and clinical evidence**

Supported by **clinical leadership and patient and public involvement**

Evidence

Evidence from the 100,000 Genomes Project and other national and international studies supported the implementation of WGS in routine clinical care.

WGS clinical indications chosen based on:

- **clinical assessment** – based on current and emerging evidence relating to analytic and clinical validity, and optimal testing technology
- **operational assessment** – technical requirements, laboratory infrastructure, equity of access, pathway implications, cost and affordability elements and commissioning requirements

Investment and oversight

Commissioned and funded nationally to provide clarity and ensure equityy of access – required investment decision

Mandated for use in all NHS GLHs to ensure standardisation

Collect data to enable benchmarking between GLHs

Test Directory is updated annually to keep pace with **scientific and technical developments** from evidence submitted by NHS, academia, industry, patient groups

POLYCYSTIC KIDNEY DISEASE

Problem

- ‘1 in 500 people affected with PKD – autosomal dominant
- Renal failure tends to occur in middle age
- Tolvaptan can slow progression of renal failure if you detect people early enough

Solution:

- PKD1 and PKD2 are the main genes
- PKD2 tends to be milder
- PKD1 is technically really tricky to sequence so most families don’t have a genetic diagnosis
- Lots of PKD diagnoses were made through 100,000 Genomes Project

Impact:

Having a genetic diagnosis helps with:

- Predicting progression and medicine
- Working out who in next generation needs monitoring (without the genetics can’t be sure until 30 that someone isn’t affected)
- Reproductive options such as PGD

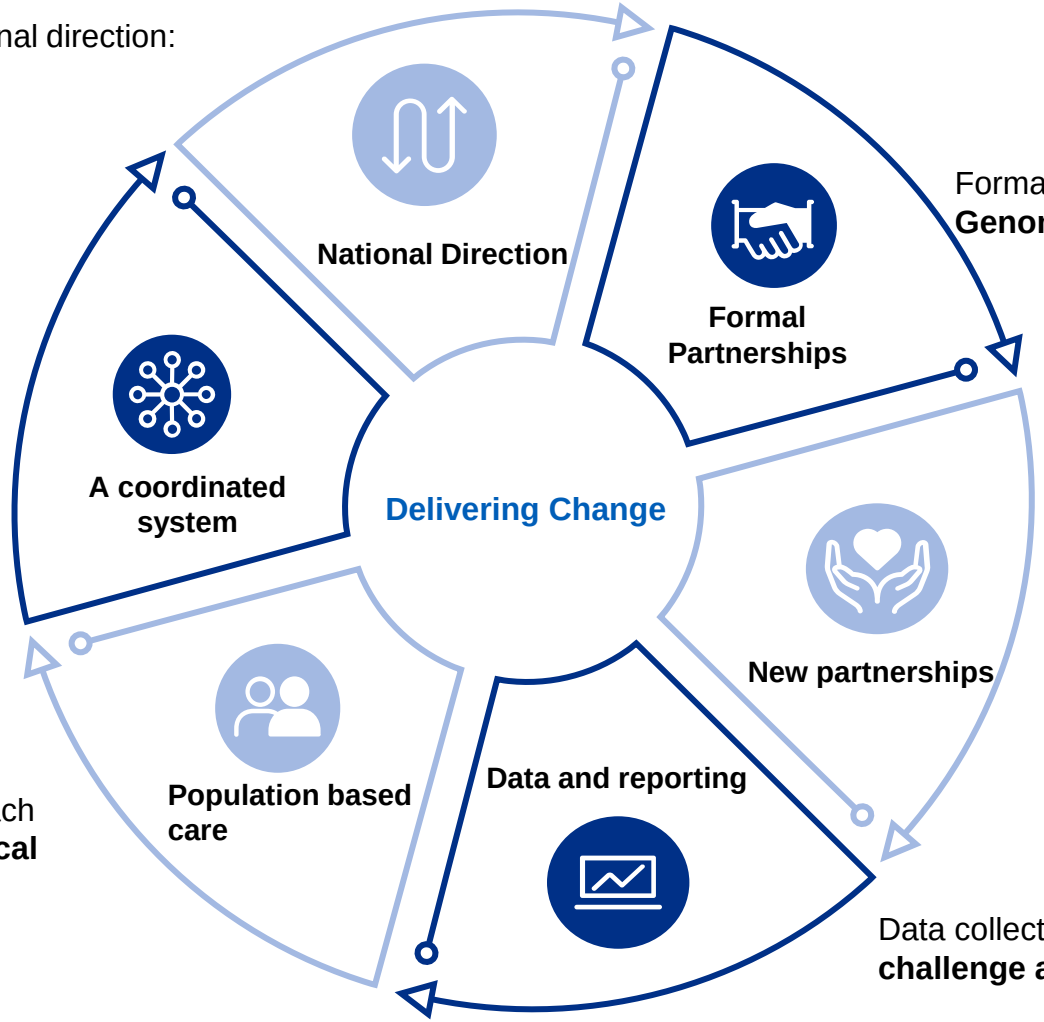
WGS testing now increasingly being arranged by renal physicians with support from clinical genetics

Governance, leadership and partnership – a multi-layered approach

NHS E/I Genomics Unit provide national direction:
- Service specifications
- Protocols Quality monitoring

Shared governance and risk
- Dives and delivers leadership and partnerships **at all levels**
- Works **across boundaries** – national, local, clinical, organisational, participants and local innovation bodies.

NHS Genomic Laboratory Hubs and NHS GMS Alliances
- Provide **population-based care** across organisational boundaries
- Drive local service and professional networks, each with **Medical, Scientific, Operational and Clinical leadership**



Formal partnerships between **NHS England and Genomics England**

NHS GMS Alliances working across the geography to bring together **Alliance Networks** engaging all Integrated Care Systems, Trusts, Cancer Alliances, AHSNs Primary Care Networks, pathology networks etc.

Data collection and performance reporting to **drive challenge and change**

NHS Genomic Medicine Service Alliance

7 NHS Genomic Medicine Service Alliances across the country, aligned to the geographies of the NHS GLHs, providing:

NHS System Level

Working with all partners across a geography; includes the ICS, Cancer alliances, regional NHSE/I teams and local clinical leadership and partnership with key partner boards. Governance links with the Genomic Laboratory Hubs.

Clinical Leadership

Genomic medicine focused 'Supra regional' clinical directorates

- Engage with clinical leaders, advocates, and champions across a geography
- Creation of clinical genomic senates and other advisory structures

Transformation

Service models and projects to drive embedding of genomics:

- Local and National approach
- 7 key national transformation projects and multiple projects running in the regions

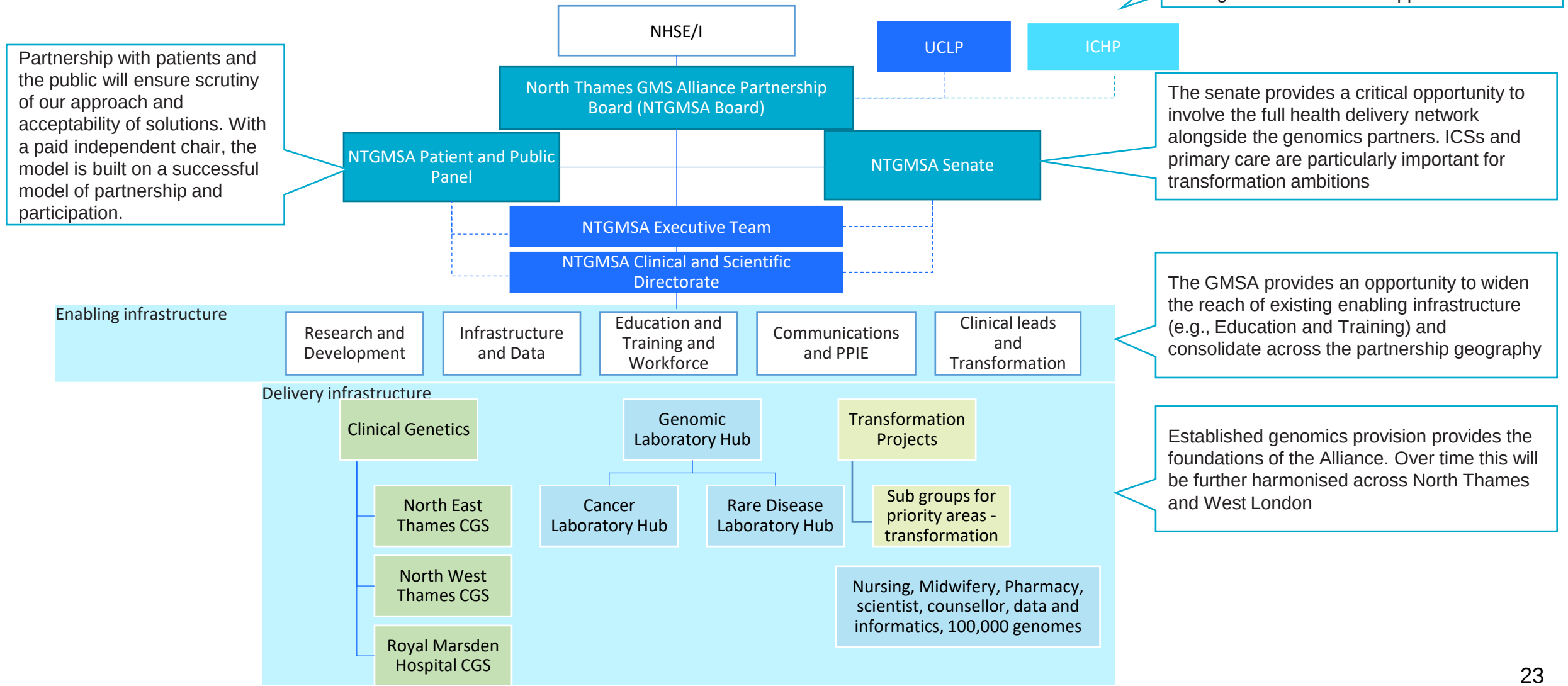
Workforce Development

Working with Health Education England at national and regional levels for appointment of education and training leads by linking needs with priorities.

Cohesive approach | Forward looking | Right people, right place

Example: North Thames NHS GMS Alliance structure

North Thames **population approx. 5 million**
Lead national transformation project on **pathology** and **Lynch Syndrome**



Partnership with patients and the public will ensure scrutiny of our approach and acceptability of solutions. With a paid independent chair, the model is built on a successful model of partnership and participation.

Additional scrutiny and collaboration opportunities from UCLP hosting arrangements and ICHP support

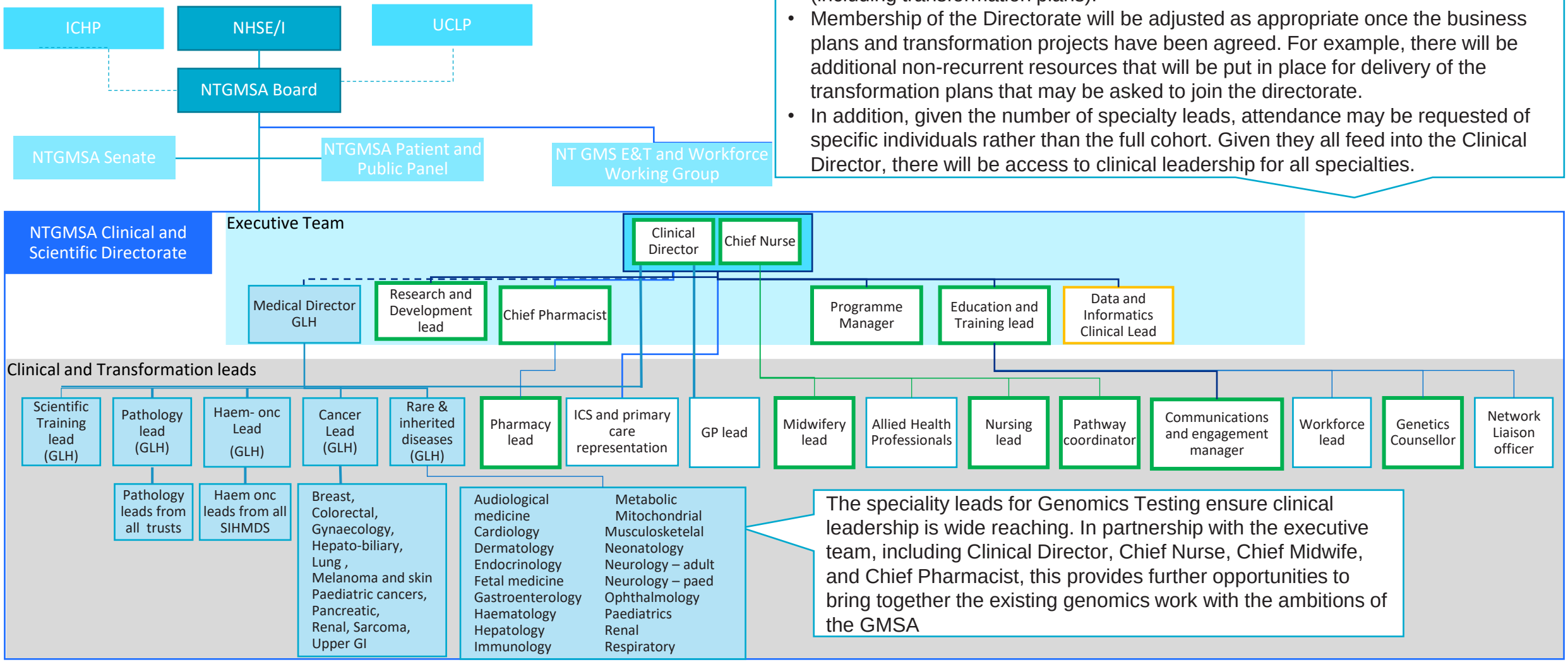
The senate provides a critical opportunity to involve the full health delivery network alongside the genomics partners. ICSs and primary care are particularly important for transformation ambitions

The GMSA provides an opportunity to widen the reach of existing enabling infrastructure (e.g., Education and Training) and consolidate across the partnership geography

Established genomics provision provides the foundations of the Alliance. Over time this will be further harmonised across North Thames and West London

Builds on infrastructure from NHS and 100,000 Genomes Project

- A regional Clinical and Scientific Directorate will enable clinical and scientific partners to work with the executive team to ensure delivery of the business plan (including transformation plans).
- Membership of the Directorate will be adjusted as appropriate once the business plans and transformation projects have been agreed. For example, there will be additional non-recurrent resources that will be put in place for delivery of the transformation plans that may be asked to join the directorate.
- In addition, given the number of specialty leads, attendance may be requested of specific individuals rather than the full cohort. Given they all feed into the Clinical Director, there will be access to clinical leadership for all specialties.



The speciality leads for Genomics Testing ensure clinical leadership is wide reaching. In partnership with the executive team, including Clinical Director, Chief Nurse, Chief Midwife, and Chief Pharmacist, this provides further opportunities to bring together the existing genomics work with the ambitions of the GMSA

Research driving clinical improvements

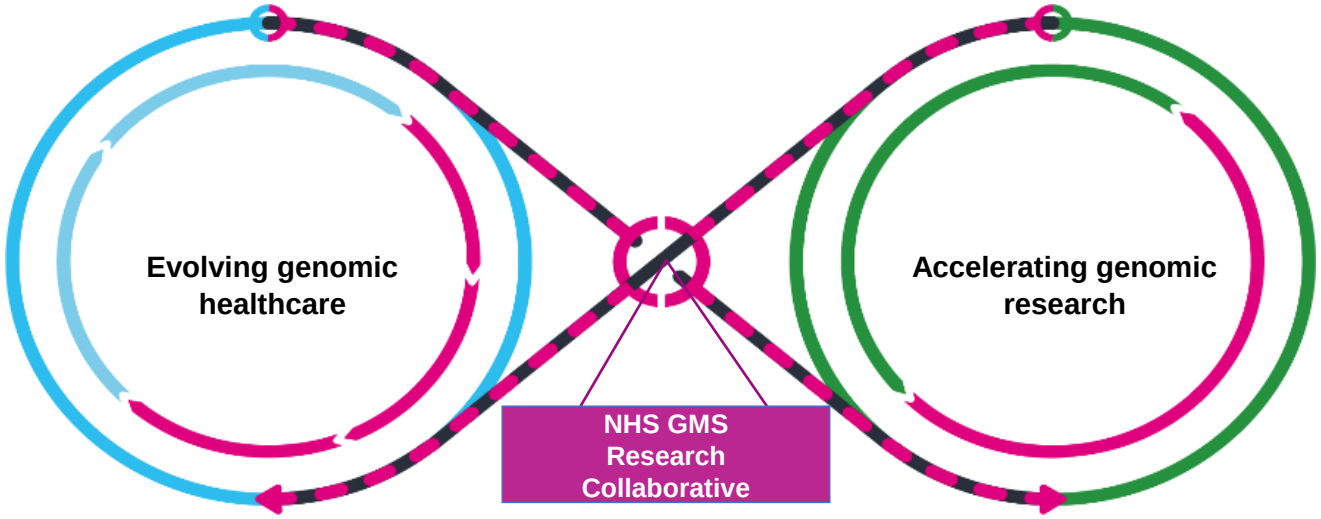
Research driving improvements in clinical care

The single biggest driver of genomic medicine success is the ability to build and create partnerships – within and across organisations and across the globe

Discovery	Translation	Adoption	Spread
• **Discovery of new drugs and genomic variants** • **Exchanging information, sharing resources and best practice**	• **Establishing evidence synthesis against agreed policy domains** • **Proof of concept studies** • **Real world evidence studies** • **Example liquid biopsy / long read sequencing**	• **Reviewing the evidence for commissioning and contracting** • **Trailblazers / early adopters** • **Agreeing common outcome metrics incorporating the design of policy levers**	• **Commissioning and finance alignment** • **Standardisation of services** • **Equity of access**

Evolving genomic healthcare:

- Collaborating with researchers to test and confirm variants
- **141 diagnoses** returned to NHS laboratories since January 2020
- Further **135 variants** undergoing triage to establish suitability for return to the NHS
- Proband diagnosed with **osteogenesis imperfecta** (OI)
- Researchers identified **compound heterozygous variants** in a known OI gene
- One variant was a 1.7Mb deletion, and the other was an intronic **variant predicted to affect splicing**
- Result had **immediate relevance for the next generation in the family**



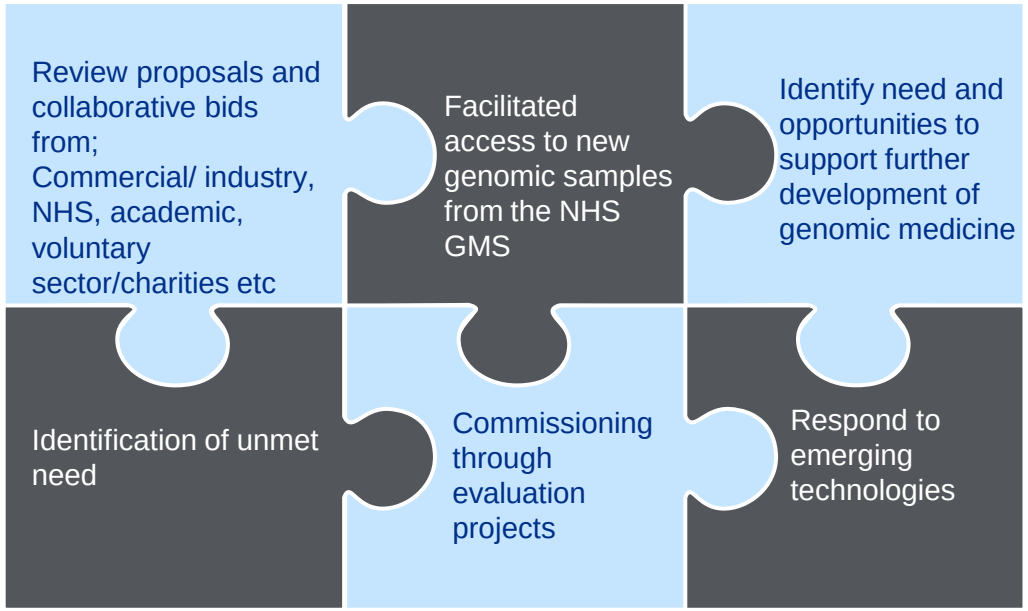
Over 94% of NHS GMS WGS patients consented to data being used for research

Accelerating genomic research:

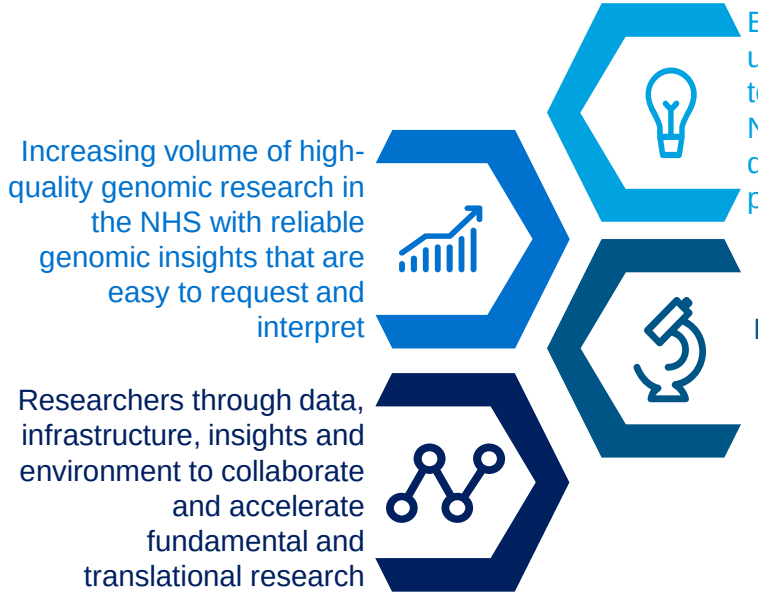
- **95,600** participants recruited as part of 100,000 Genomes Project
- **117,000** genomics in reading library
- **53** petabytes of genomic and medical data
- **32** bioinformatic pipeline workflows
- **21,000** cancer genomic signatures
- **84** academic institutes
- **3,680** registered academic researchers
- **8/10** top pharmaceutical companies
- **160+** publications using GEL assets
- **550** registered GeCIP projects

NHS GMS Research Collaborative

Goals

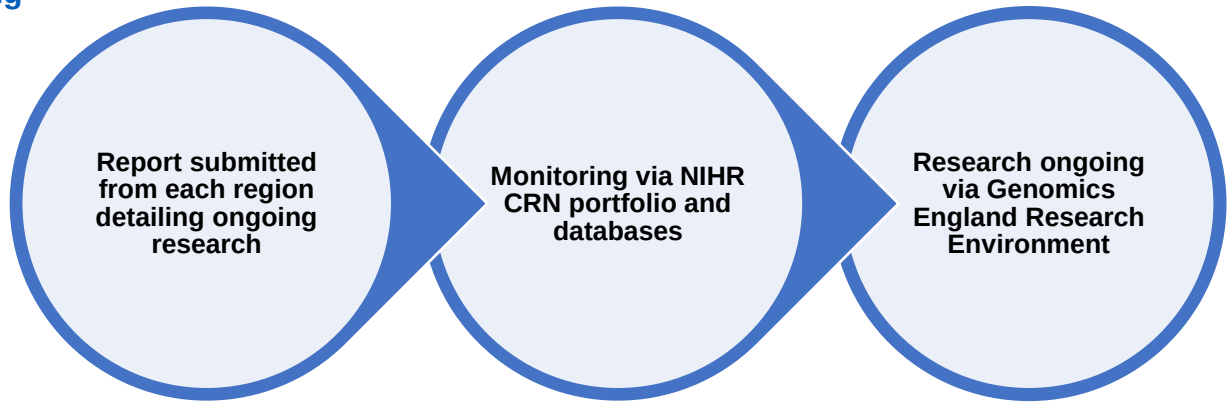


Benefits



Capacity and capability monitoring

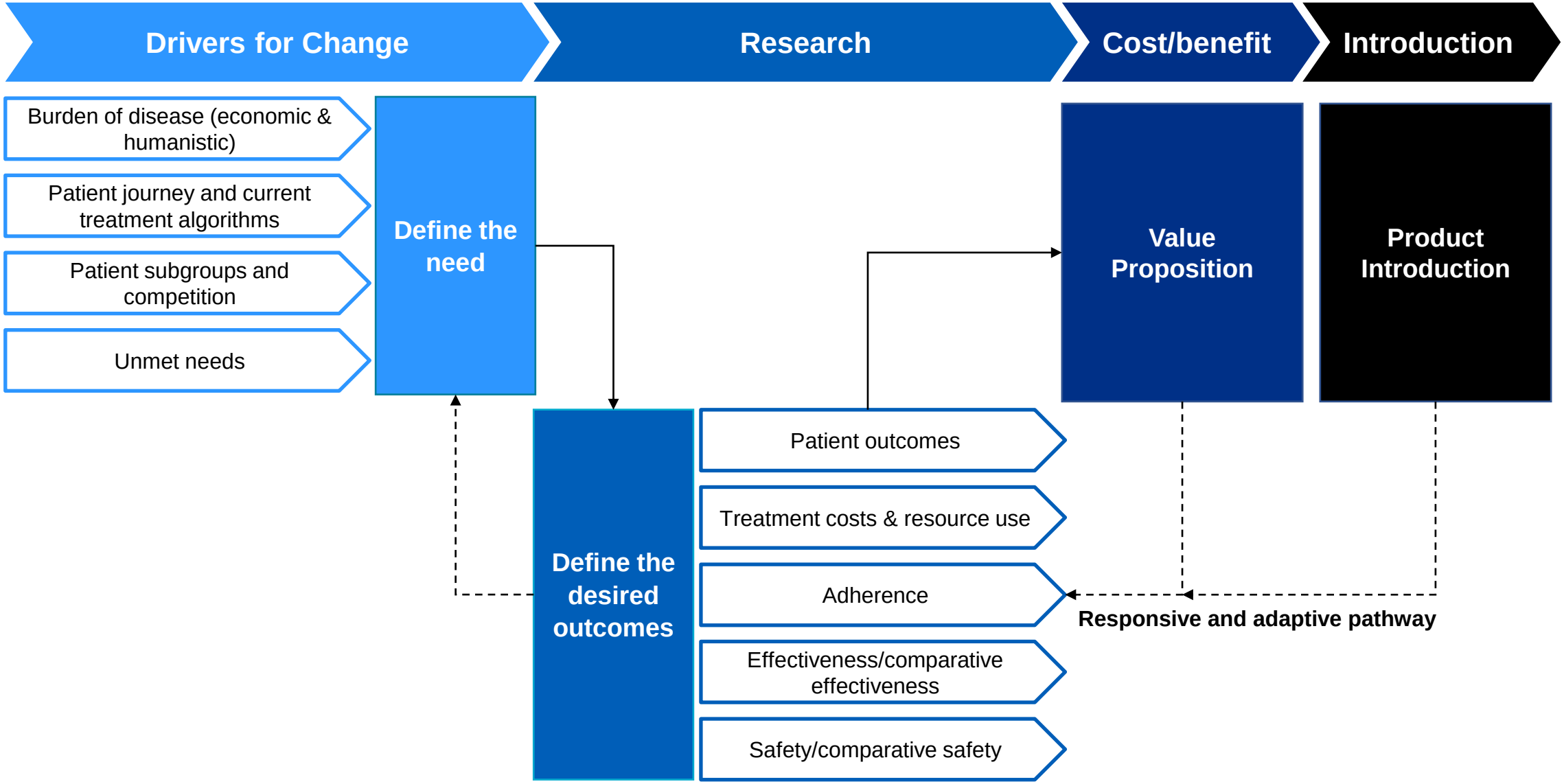
- Understanding genomic research across England to support more strategic approach to use of resources
- Understand capacity of NHS GMS infrastructure to support research projects



323 genomics studies on NIHR CRN portfolio
Engaged in **34** NIHR Programmes
664 NIHR Central Commissioning Facility studies involving genomics

Including clinical trials, genotype/phenotype studies, pharmacogenomics and COVID studies

Using real world evidence to support product introduction



NHS GMS delivery of the genomics strategy

7 NHS Genomic Laboratory Hubs all with high throughput cutting edge technology

203 cancer clinical indications covering majority of solid and haem-onc cancers

357 rare disease clinical indications covering over 3,000 rare diseases

500 gene cancer next generation sequencing panel

Over **323** specialist rare disease panels

600,000 genomic tests performed in England every year

Over **2,000** NHS staff dedicated to the delivery of the NHS GMS

Whole genome sequencing service for **21** rare disease clinical indications and **3** cancers with an average diagnostic yield of 33% - up to 50% in some conditions

250 referrals to rapid Fetal Exome Sequencing Service with diagnosis identified in around **40%** of cases

1,200 referrals to date for national rapid whole exome sequencing for NICU / PICU with diagnostic yield of around **40%**

3 NHS GLHs are delivering a Non-Invasive Pre-Natal Testing (NIPT) service as part of an evaluative roll out

7 NHS Genomic Medicine Service Alliances led by Clinical Directors

7 national genomic transformation projects

26 local genomic transformation projects

Over **200** funded posts in GMS Alliances to support multiprofessional clinical leadership

17 clinical genetics services

Over **920** genomic research projects being supported across the NHS

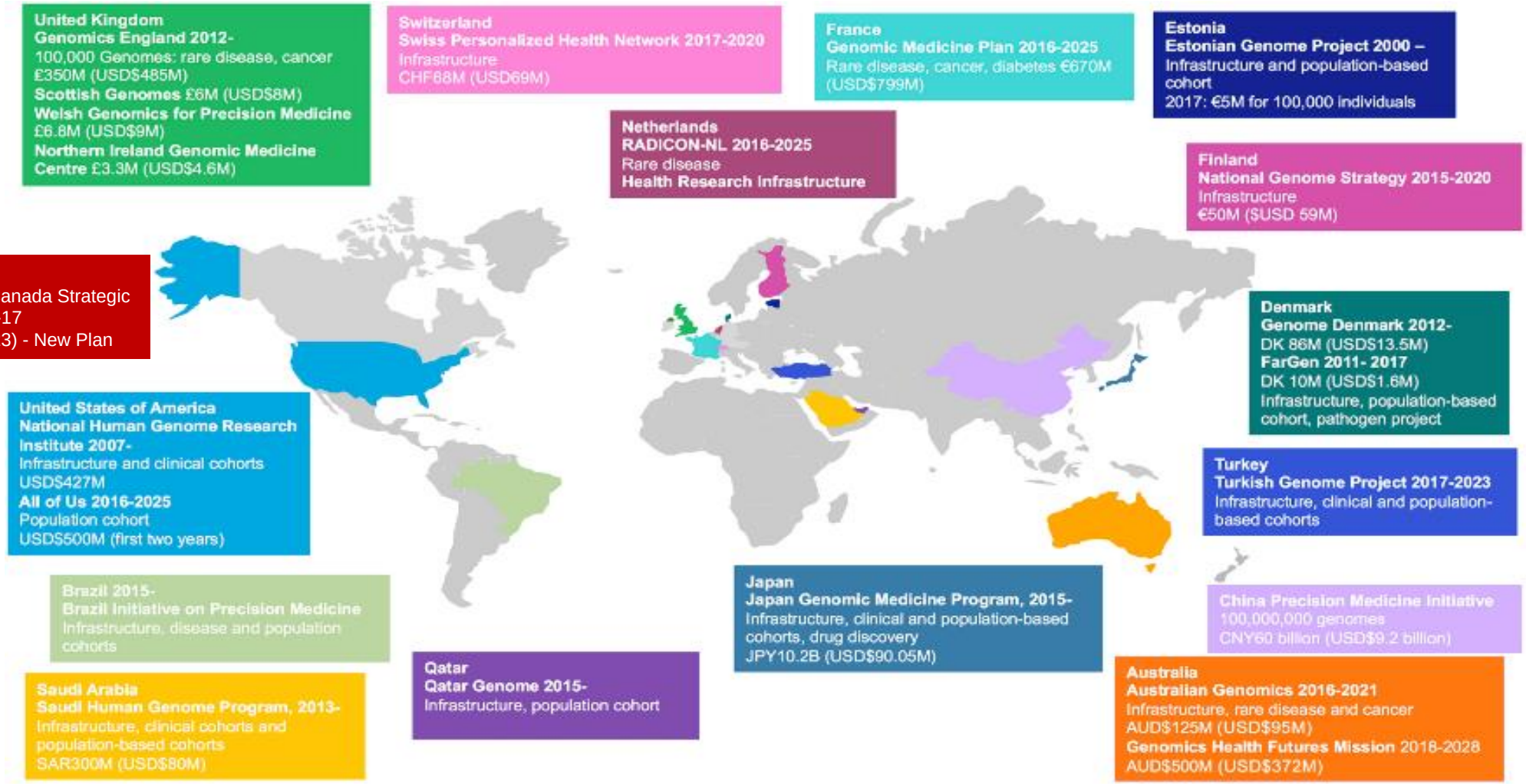
Genomics is a global initiative with opportunities for international collaborations

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

A policy-framing and technical standards-setting organisation, seeking to enable responsible genomic data sharing within a human rights framework

Global Genomic Medicine Collaborative

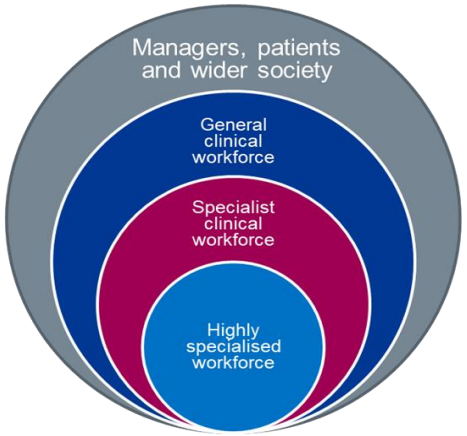
An independent not-for-profit charitable organization identifying opportunities to foster global collaboration to demonstrate value and the effective use of genomics in medicine



Source: STARK, Z., et al. (2019). Integrating genomics into healthcare: a global responsibility. *American Journal of Human Genetics*. Published online 03 01; DOI: 10.1016/j.ajhg.2018.11.014

Ongoing challenges to overcome

Changing end-to-end pathways (engaging clinicians across care spectrum)

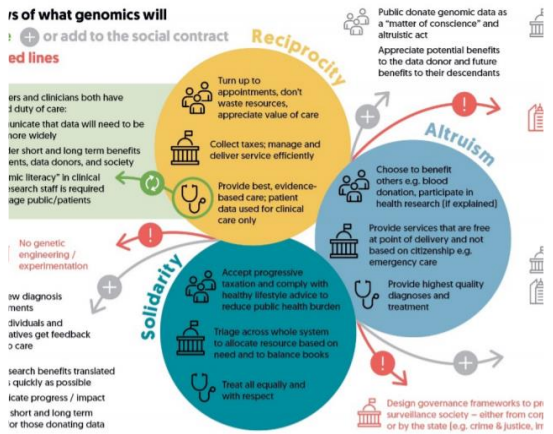


- Expanding existing roles & responsibilities & addressing capacity gaps
- Resources to upskill clinicians & develop genomic literacy
- Formal education & training programmes
- Evolving role of clinical genetics
- Involving all NHS providers
- Embedding genomics and driving change across end-to-end pathways

Working within an ethical framework

- Working at speed of public acceptance
- Choice & consent
- Central role for public
- Ethics of diagnostics can be dynamic – cf HIV testing
- Big questions about when appropriate to carry out WGS within the life course

Retaining & Building public trust



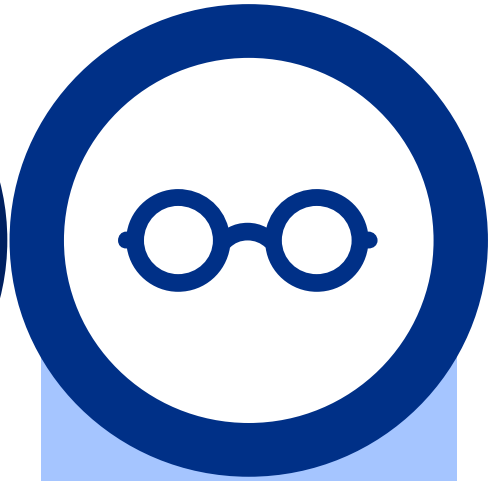
- Creating a societal "contract" for people to share and contribute their genomic data based on reciprocity, altruism & solidarity
- Ensure appropriate governance frameworks

Themes for success for genomics

NHS

Government and senior healthcare leader interest

Demonstrate benefit of genomics to population and also to broader agendas such as life sciences or the economy.



Proof of concept studies

Alignment with strategy and interface between clinical and research.

Support end to end innovation including plans for adoption and scale up.

Building the evidence base for ongoing transformation.

Investment in infrastructure

Co-design with leadership to enable delivery of a high quality, equitable services that offers value for money, efficiency and productivity.

Infrastructure supported by national oversight.

Receiver pull

Build the evidence base to demonstrate benefit of genomics to the system and society.

Engagement with system leaders and alignment with professional networks.

User pull

Co-creation with users through public dialogue.

Demonstrate benefit to the users and opportunities for research and discovery.

Transformation having an impact

Lee Morris

A revolutionary new surgery for a rare inherited retinal disease

Lee Morris underwent Ocular Gene Therapy at Manchester University NHS Foundation Trust in one of the first gene therapy treatments undertaken by the NHS.

Lee had vision problems from birth and at 8 years old was diagnosed with RPE65 retinal dystrophy, a rare inherited retinal condition caused by defects in one of a number of different genes.

Other patients have been given the treatment since at other NHS hospitals and the patients are reporting that their vision is improving well.

Mail Online

'Doctors saved my sight by injecting a gene into my eye': Experts say this cutting-edge technique could one day also help many with age-related vision loss

Thank you for listening!

Keep in touch:

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