Transforming care for the future

Professor Sue Hill @CSOSue
Chief Scientific Officer for England

Date 2017

The National Health Service (NHS) in numbers

Semi-integrated system providing care to 55 million population, seeing 1 million patients every 36 hours.
All organisations/ individuals have significant power to operate autonomously to support their populations & individual patients

NHS England

>7500
Family Doctor practices
(GPs)

153
Hospital organisations
(general & specialist)

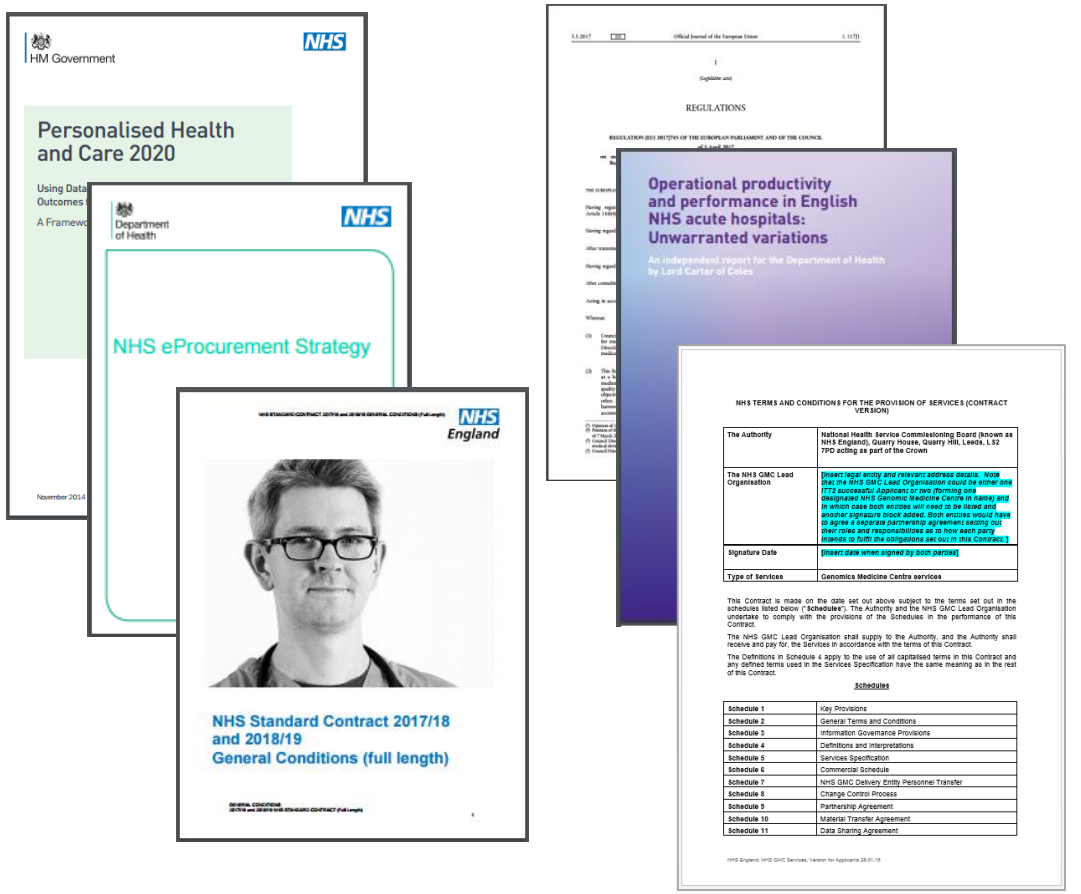
209
Clinical Commissioning Groups
(managing & planning care)

89
Mental Health & other providers

1.3 million staff
inc >675,000 qualified clinical staff

A mandate for systematic improvement of identification & tracking for patient benefit

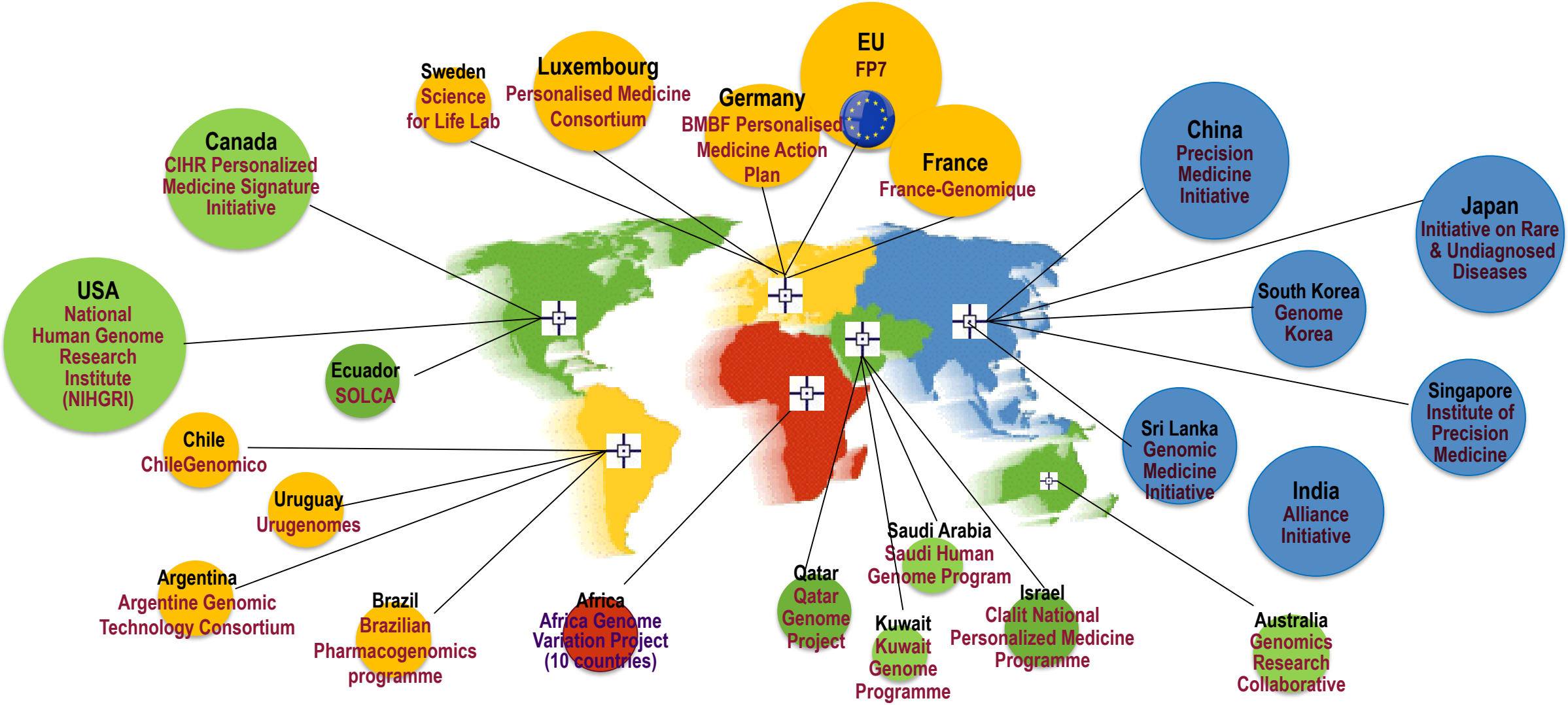
- Modern healthcare requires increasing standardisation, streamlining of ways of working & driving through of innovation
- The Department of Health & NHS has recognised the importance of identification & tracking across **product, person** & **place**
- This, in turn, improves patient safety and efficiency & sustainability of services
- GS1 standards are now mandated through the National Information Board strategy, the e-Procurement Strategy and the NHS Standard Contract
- New EU regulations on medical devices & in-vitro diagnostics require GS1 implementation for tracking
- Significant initiatives such as the NHS Operational Productivity review and the NHS contribution to the 100,000 Genomes Project specification mandate the use of GS1 standards



Genomic Medicine: a focus around the world

NHS England

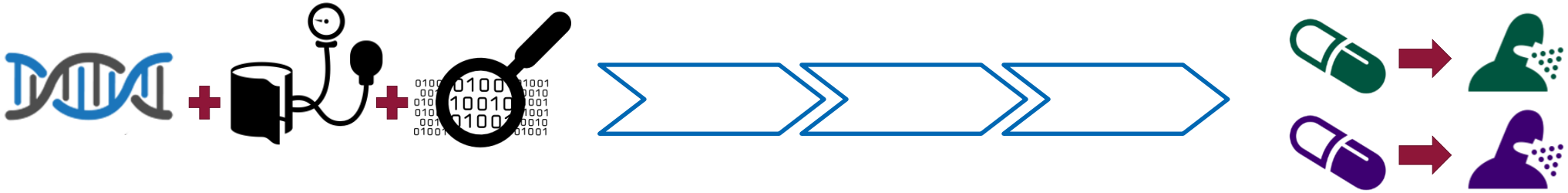
Countries across the globe – in both developed & developing world – are conducting a range of genomic medicine initiatives, recognising the importance of this technology to future healthcare. This diagram shows *some* of the initiatives taking place.



What is genomic medicine?

- Conventional medicine works backwards from symptoms and tests to come to a diagnosis – often with a ‘one size fits all’ approach to treatment

- Genomic medicine builds an **analysis of the underlying cause** of a condition – combining sequencing of an individuals DNA with other diagnostic & clinical information. Knowing the root cause allows the selection of the most appropriate and effective intervention for that individual



- Genomic medicine allows individuals to get **earlier, better** treatment, that is tailored to their **precise** needs, improving outcomes and being more efficient for healthcare systems

WHY NOW? Huge advances in sequencing technology and computer power are allowing the analysis of whole human genomes at a speed and affordability never seen before

Genomics and the UK: leading the world

Jun 2000: UK PM Tony Blair & US President Bill Clinton announce **first draft from Human Genome Project** *(UK facilities were major contributor to HGP)*

Dec 2012: UK PM David Cameron announces a paradigm shift in the way the NHS will use genomics, **committing the UK to sequencing 100,000 whole human genomes** from patients with rare/inherited diseases & common cancers

Sep 2015: NHS England Board announce **NHS-wide strategic approach to personalised medicine** building on the NHS's status as one of the most advanced healthcare systems in the world in genomic medicine and the evolving legacy of the 100,000 Genomes Project

The **UK is a world-leader** in genomic medicine, having been involved in the field since the initial Human Genome Project

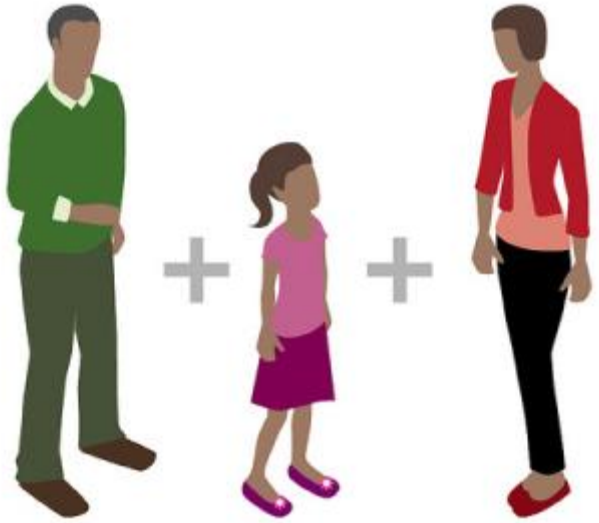
The 100,000 Genomes Project is **unique globally in its scale, scope and number of services** that it brings together.

The Project will form the basis of a Genomic Medicine service for the entire **55 million population** served by the NHS in England

The 100,000 Genomes Project – NHS requirements

90,000 samples from patients with common cancer & rare diseases

Rare disease



Blood sample required from the patient and, in some cases, from their close relatives

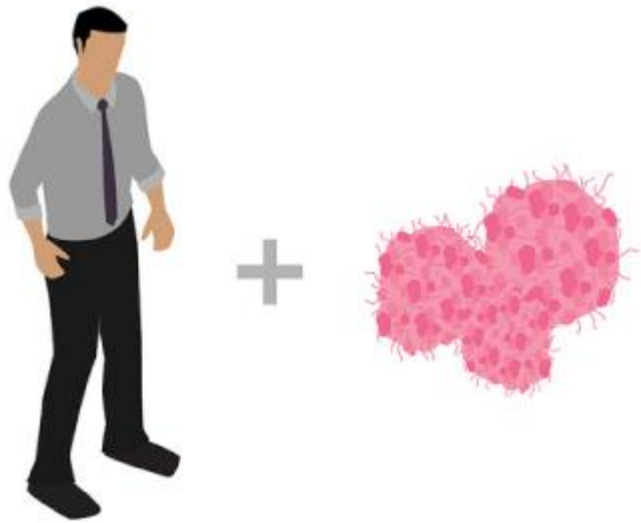
DNA

Plasma

Serum

RNA

Cancer

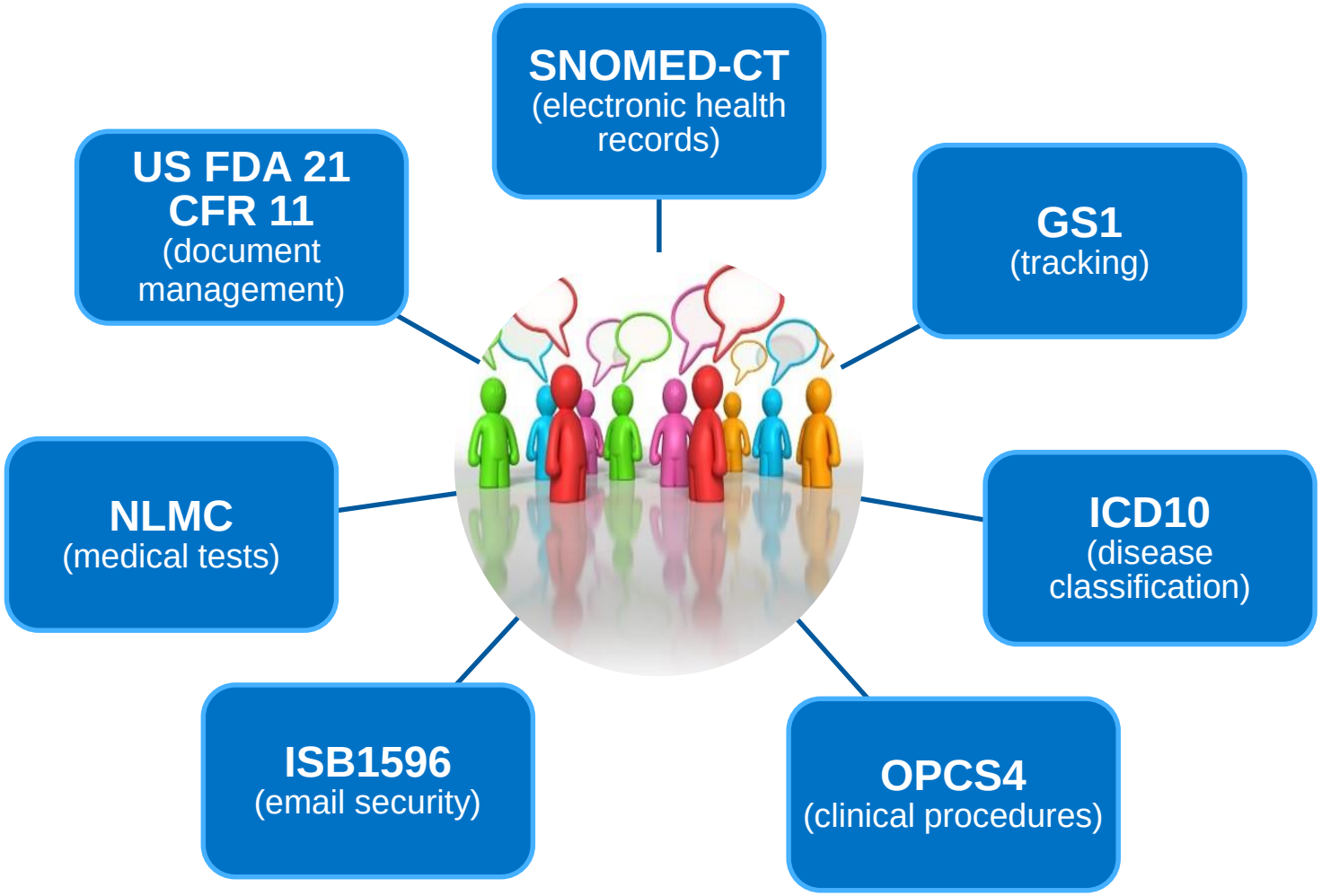


Blood sample required from patient, and tissue sample from their tumour

Linked through to clinical & diagnostic record

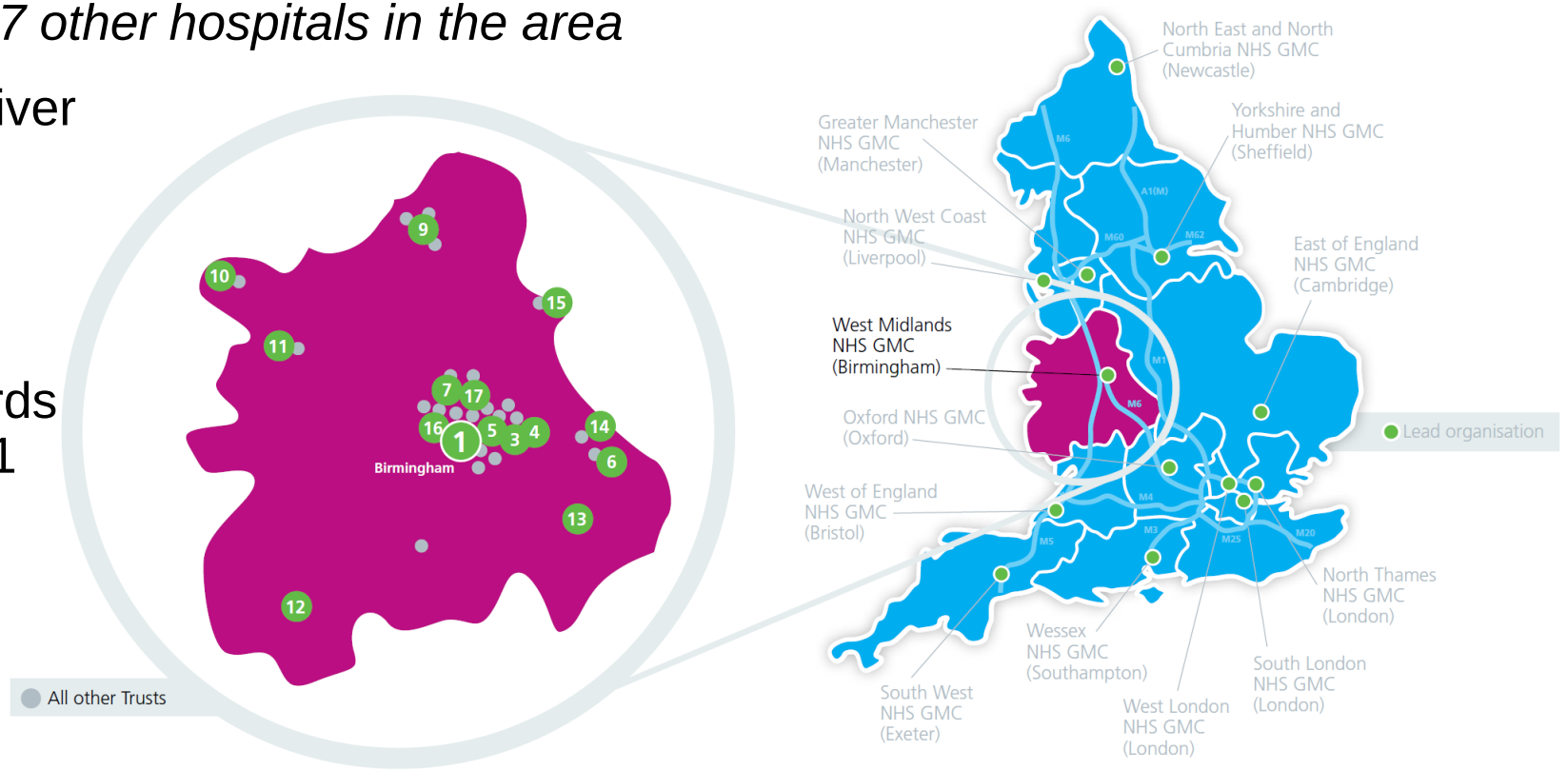
Speaking a common language

- Standardisation and comparability is essential for Genomic Medicine
- The 100,000 Genomes Project contract mandates a range of national & international standards, including those listed in the diagram



NHS Genomic Medicine Centres - the service infrastructure

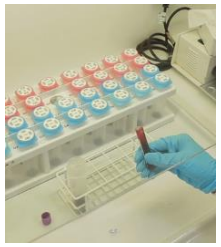
- **13 NHS Genomic Medicine Centres** coordinating care for populations of ~3-5 million
- Each GMC has a **lead organisation** for contracting and performance management and formal partnerships with local hospitals – *eg West Midlands NHS GMC is led by QE Hospital Birmingham, operating with 17 other hospitals in the area*
- NHS GMCs contracted to deliver against a **very precise specification & common protocols** to ensure consistency, including:
  - Clear information standards inc mandating use of GS1
  - EQA scheme



The genomic medicine sample journey

Patient samples go on a journey across the country - so it's crucial to have a common national identification and tracking system to uniquely identify and locate individual samples

Sample collected from patient at local hospital



Initial processing in local laboratories

Samples collated by NHS GMC lead organisation

National Sequencing facility, Cambridge

Samples stored at UK Biobank

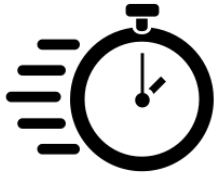
Associated patient data

National Genomic Data Centre

The importance of GS1 to Genomic Medicine

The size & scope of project means we need to have clear and effective sample tracking that operates on a consistent national basis

Genomic samples have particular ethical sensitivity given the extent of information they can provide about an individual



Effective genomic medicine requires prompt processing, results and action

These concerns mean that patients have particularly high expectations that their samples are not delayed or misplaced

Analysis of tracking data & any ‘bottlenecks’ provides useful management information for the refinement of new clinical pathways

The GS1 journey: North West Coast GMC

BEFORE

- Before the 100,000 Genomes Project, sites used their own local system for identification and tracking of clinical samples
- Laboratory staff were required to transcribe information – with senior colleagues monitoring for errors
- Tracking system less robust – with greater risk of samples misplaced in transit

"Improvements such as GS1 build in efficiencies and allow things to run more smoothly, improving services. This allows us to improve skill mix and make much better use of precious healthcare resources"

Programme Director, NWC NHS GMC

NOW

- Cross GMC adoption of GS1 sample tracking system
- Information is only entered once, with GS1 system updating information in each location - Sample booking & monitoring can be carried out by lower-grade staff, minimising errors & freeing up scientists for other tasks
- Globally unique identifiers avoid confusion and patient safety risks
- Precise location of any given sample can be determined from multiple locations
- Common pathways for ***all*** samples into labs – spreading GS1 further across the system

Driving broader transformation in the NHS

Developments around 100,000 Genome project has led to wider transformation in local health systems

- **Addenbrooke's Hospital, Cambridge** have implemented barcode labelling for all samples *(not just genomic samples)* **eliminating 99.9% of sample errors**.
  The hospital already used GS1 for high-value medical devices, improving delivery time and device utilisation. Work continues to ensure full GS1 compliance in the labs and build on other developments such as robotic sample handing and the EPIC EPR system.
- Together these have seen a **six-fold increase in sample processing** from 20m samples per year to 120m samples per year.

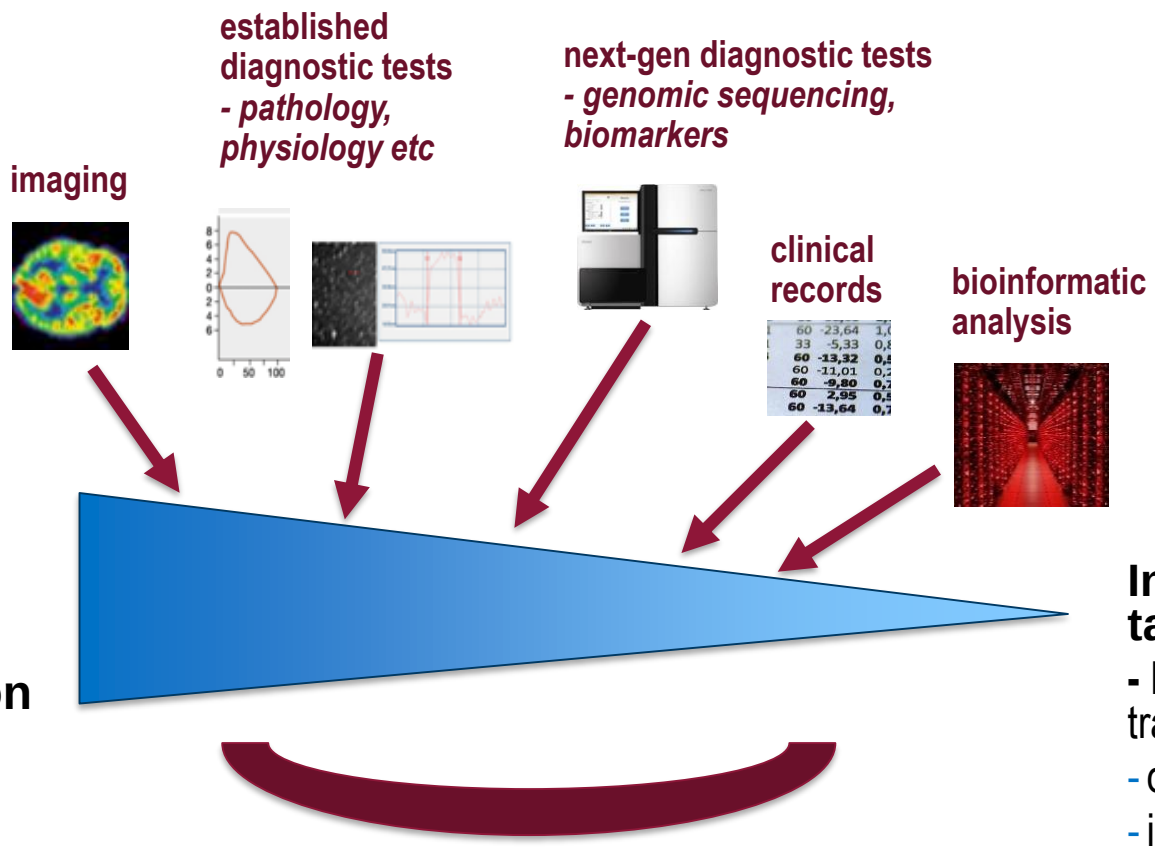
Many NHS GMCs have improved their GS1 uptake.

For example **North Thames NHS GMC** has delivered GS1 capability across **all the 7 Local Delivery Partners** in its region

Lessons from implementation and benefits

- The project **structured to drive transformation –** working with informatics teams & clinicians from day one.
- We specified leadership and technical **requirements in national contract** and regularly followed up progress to ensure effective implementation
- **Champions in senior management**, particularly in informatics, provide a powerful impetus to adoption and uptake of GS1
- We've **brought people together at a national level** to share good practice and enthusiasm – so driving the pace of implementation
- Ability to use sample flow **information to inform and improve changes** in pathways and protocols
- **Interoperability** has been greatest challenge, particularly where existing information systems are older and organisational **IT infrastructure** poorer
- Where **organisations more digitally mature** implementation is much easier
- **Central investment** from government has been a great enabler

Personalisation – the future of healthcare

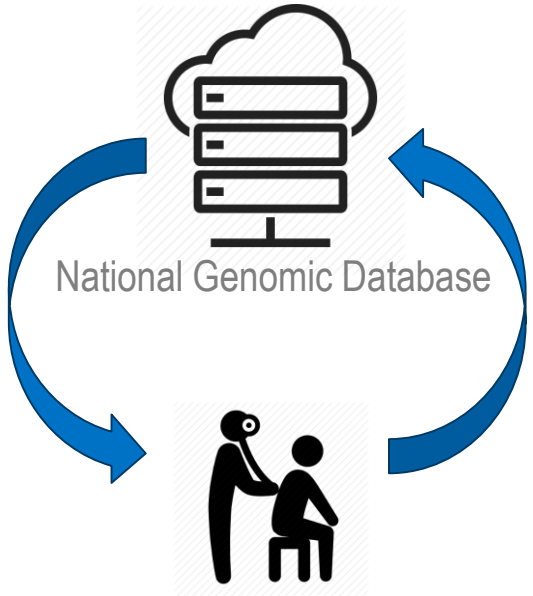


'One size fits all' treatments & intervention

Individually-tailored approach

- Drugs (inc drug tracking)
- devices
- interventions (eg surgery, radiotherapy)

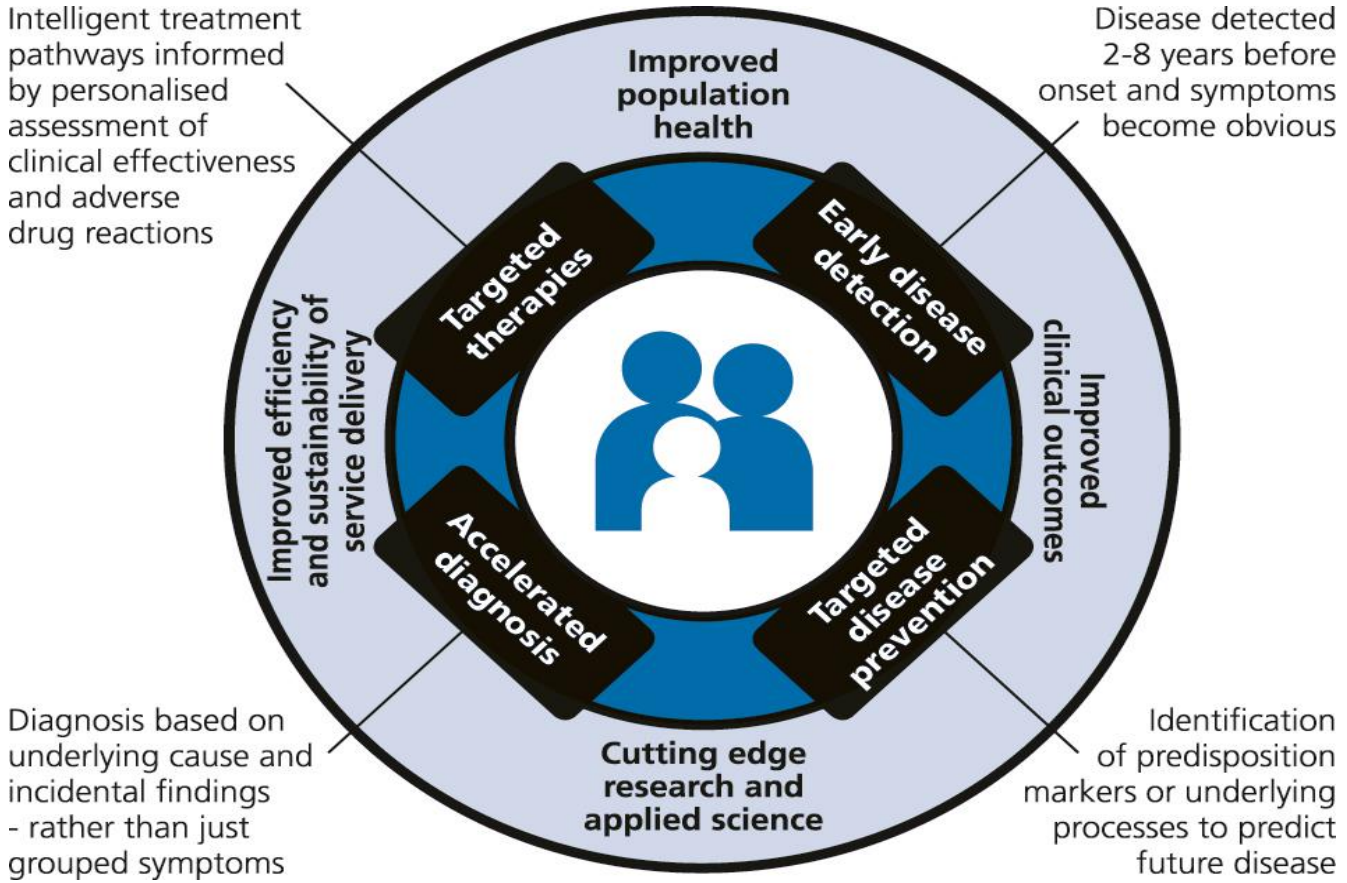
Increasingly precision interventions based upon carefully identified subgroups within the broader population



The diagnosis, treatment and outcomes of every patient builds the information in the National Genomic Database.

This – in turn – informs the recommendations for future patients seeking care

Genomic Medicine: Delivering patient, population & system benefits

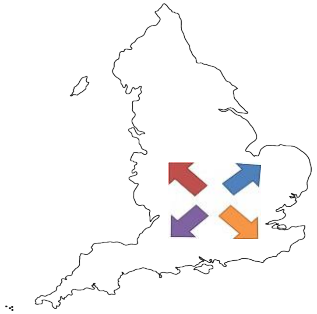


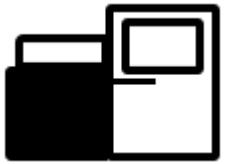
- the ability to improve quality and outcomes
- the ability to address inequalities
- the ability to drive value based healthcare

underpinned by an evolving infrastructure

Where next?

- Roll-out of genomic medicine into mainstream care for entire population
- Supporting the development of an integrated laboratory structure – providing consistent access to the full range of diagnostic expertise, including national specialist centres
- Informing medicines optimisation, including electronic prescribing and medicines administration – tracking the drug history & response for individual patients
- Supporting the roll-out of GS1 to all NHS locations, including family doctors & community pharmacy and across the pathway
- Supporting digital diagnostics service and development of National Genomic Database





Mainstreaming genomic medicine: the UK's 'Moonshot Moment'

NHS England

The New Frontier is here whether we seek it or not.

Beyond that frontier are uncharted areas of science and space…
unsolved problems….
unanswered questions…

It would be easier to
shrink from that new frontier,
to look to the safe
mediocrity of the past…

But I believe that the times
require imagination
and courage
and perseverance

John F Kennedy, 1960