



# KEEPING PACE WITH CANCER

## Accelerating access to genomic testing through the NHS Genomic Medicine Service

### Background

The following provides a summary of the findings of the Future Health report, sponsored by Johnson & Johnson, *Keeping pace with cancer: accelerating access to genomic testing through the NHS Genomic Medicine Service (GMS)*. The report assessed progress in expanding access to genomic testing for cancer through the NHS GMS and was published in June 2024.



### About the NHS GMS

The NHS GMS seeks to provide genomic testing for rare diseases and cancer for all eligible patients across England. The service was launched in 2018 and NHS England's most recent genomic testing strategy *Accelerating Genomic Medicine in the NHS* was published in 2022.<sup>i</sup>

The genomic tests available are included within a single national testing directory and delivered through a set of seven regional Genomic Laboratory Hubs (GLHs).

### Regional Genomic Laboratory Hubs

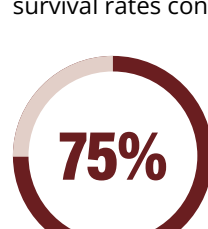
- North East and Yorkshire
- North West
- East
- Central and South
- North Thames
- South East
- South West



Geography	Patient Population	NHS Trusts	NHS ICSs
North East and Yorkshire	8 Million	34 NHS Trusts	4 ICSs
North West	7 Million	34 NHS Trusts	4 ICSs
Central and South	10 Million	45 NHS Trusts	14 ICSs
East	8 Million	32 NHS Trusts	13 ICSs
North Thames	7 Million	36 NHS Trusts	11 ICSs
South East	8 Million	29 NHS Trusts	8 ICSs
South West	4 Million	18 NHS Trusts	7 ICSs

### The GMS and cancer testing

The number of new cancer cases in the UK is set to reach half a million by 2040.<sup>ii</sup> Despite some progress, UK cancer survival rates continue to lag behind other countries including Australia, Canada and Norway.<sup>iii</sup>



The 2020 Richards Review into diagnostics noted the need to expand genomic testing for cancer to meet the NHS Long Term Plan commitment to diagnose 75% of people with cancer at stage one or two by 2028.<sup>iv</sup> As science advances and our understanding of the disease increases, genomic testing presents an opportunity to make new progress in the earlier diagnosis; and improved and more personalised treatment of cancer.

### Summary of different types of genomics tests for cancer

**Single gene testing**

- Tests for a single defined genetic variant in a specific gene
- Can provide a rapid, cost-effective diagnosis. However if initial clinical suspicion is incorrect this can lead to delays in diagnosis as sequential single gene testing has to be undertaken

**Panel testing**

- Gene panels are collections of genes that have been grouped for testing, enabling simultaneous sequencing of all the genes known to cause a particular disease, syndrome or phenotype.
- When compared to sequential single gene testing and whole genome sequencing it is a fast and cost-effective option. However there is more clinical interpretation of results required than in a single genetic test placing requirements on the system

**Whole genome sequencing**

- Sequencing an individual's whole genome
- The cost of this testing is the most expensive, though costs are falling. It can help identify novel genetic causes of disease

### Report findings - more genomic testing, but evidence of system pressures

**13.5%** There is evidence that testing capacity within the NHS Genomic Medicine Service is increasing, with a 13.5% increase in overall genomic tests conducted across six months of recorded data.

**22%** For cancer the number of genomic tests has risen more quickly, with a 22% increase over the same period.

**174 per 100,000** The volume of testing per population served by each GLH varies. North Thames GLH is conducting the highest estimated number of genomic tests, 174 per 100,000 population each month. By contrast the East and South East GLHs are carrying out the fewest, 107 and 109 estimated tests per 100,000 population respectively each month.

**26% since 2021** The number of approved tests on the National Genomic Test Directory is increasing. The number of approved tests for solid tumour cancers has increased by 26% since 2021.

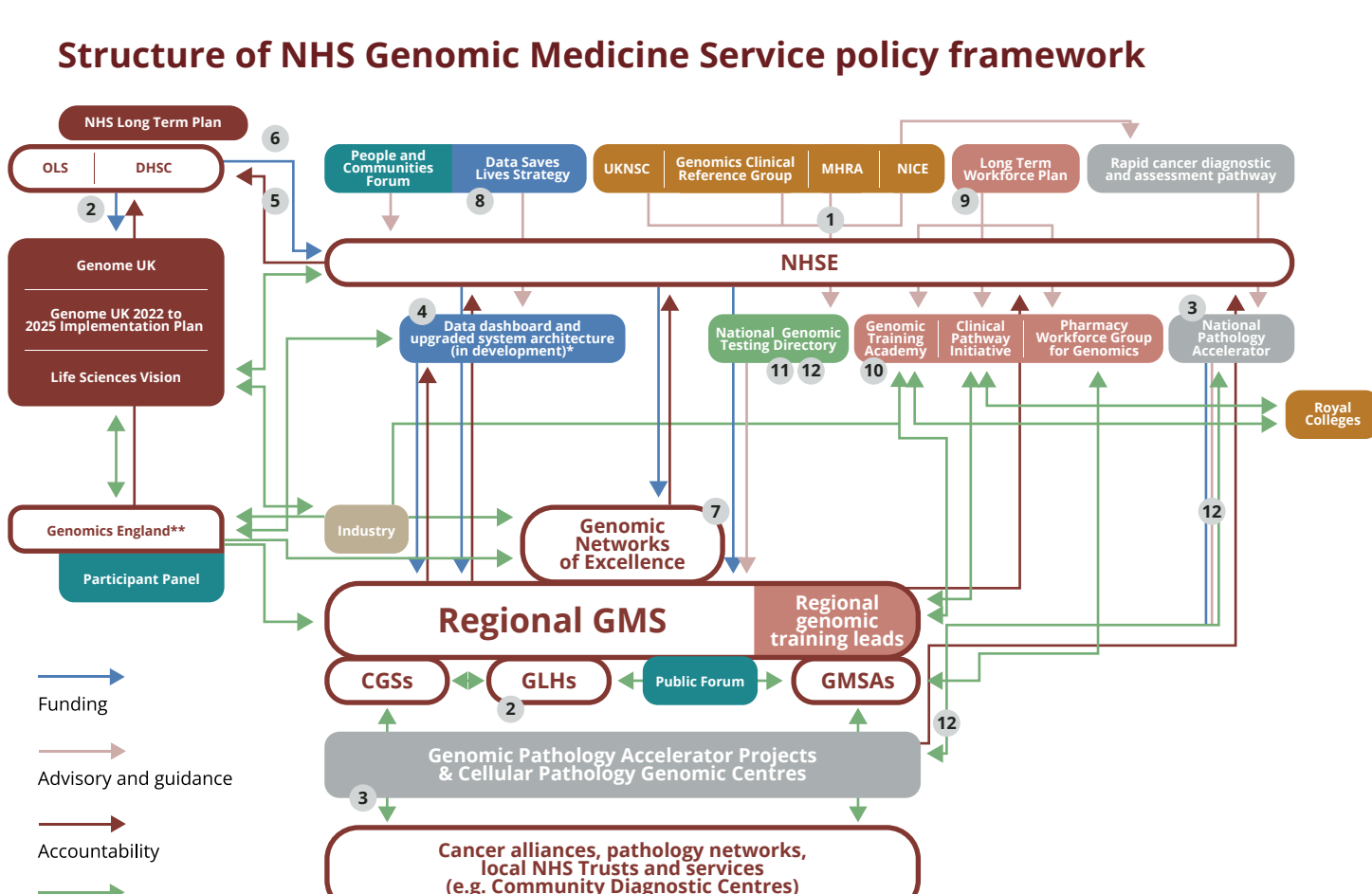
Correspondence within the NHS GMS and regional data published by GLHs shows a series of pressures and challenges facing the system in meeting national turnaround time targets for tests. Slow turnaround times can impact diagnoses, treatment and result in poorer patient outcomes.<sup>v</sup>

## Opportunities and recommendations for action

There are a number of policy opportunities and initiatives that can support the continued development and increased capacity of the NHS GMS:

- Increased Government investment in the NHS GMS to build capacity for more genomic testing
- Developing new contracting models to support increased capacity for testing at a local level
- Improved cross organisational horizon scanning for new tests
- Upgrading data and IT infrastructure
- Monitoring how genomic tests for cancer are being used within care pathways and continuing to move towards a 'genomics first' approach to cancer testing
- Monitoring the impact of training initiatives on genomics for NHS staff
- Publishing more regular data and information on service turnaround times

### Structure of NHS Genomic Medicine Service policy framework



- Policy/Delivery organisation
- Life Sciences/Genomics policy
- Advisory/Partnership organisation
- Public/Patient
- Technology/Data policy
- Workforce/Education policy
- Pathway and capacity policy
- GMS testing policy
- Industry

\* Work on the informatics implementation plan is now part of the wider NHSE data/digital policy agenda

\*\* Genomics England delivers the whole genome sequencing programme

This framework should be treated as an outline guide for how policies in the GMS map to different organisations. For example please note that Genomic Networks of Excellence bring together a range of different services and providers - their visual representation here does not fully reflect this.

### Summary table of recommendations

	DHSC	NHSE	Regional GMSs
<b>Accountability and performance</b>	With OLS publish an annual report with metrics on progress in implementing the Genome UK Strategy (5)	Publish monthly performance dashboard for the Genomic Medicine Service (4)	Provide data to support the development of the Genomic Medicine Service dashboard (4)
<b>Capacity</b>	Ensure the Genomic Medicine Service is resourced to deliver the necessary increase in cancer testing capacity required (2,6)	Explore new contracting and funding arrangements to maximise cancer testing capacity between GLHs and other local services (2)	Be enabled to maximise local testing capacity outside of GLHs to improve turnaround times for cancer testing (2)
<b>Pathways</b>	Evaluate the uptake and impact of the GeNotes course (11)	Publish an update on Genomic Pathology Accelerators and Cellular Pathway Genomic Centres by the end of 2024 (3). Ask each GLH to report back on where a small sample of genomic cancer tests from the Test Directory are being used in pathways to identify variation. Use such data to support moves to deliver a 'genomics first' approach to cancer testing (12) Publish data on the uptake and feedback on the GeNotes course (11)	
<b>Horizon scanning</b>		Complete and publish an annual horizon scanning process (with other agencies e.g. NICE and MHRA) for new genomic tests and set out a clear process for updating the Genomic Test Directory 'in year' (1)	
<b>Workforce</b>	Continue to invest in the healthcare science workforce through the NHS Long Term Workforce Plan and ensure that the Genomic Medicine Service has the staff needed to deliver for patients (9)	Regularly review workforce models to ensure they utilise the full capabilities of the workforce including biomedical scientists. (9) Publish the numbers participating in and feedback from participants in genomic training programmes (10)	
<b>Data</b>	Use NHS Productivity Plan to upgrade the IT and data capability of the Genomic Medicine Service. Fund and scale evidenced based solutions developed through the Genomic Networks of Excellence (6)	Invest in the Genomic Medicine Service dashboard (4). Provide quarterly updates on progress in implementing the Data Saves Lives strategy (8)	Collect data on the economic impact of new technological innovations in the Genomic Medicine Service, through Genomic Networks of Excellence (7)

### Further information

For the full report please visit [www.futurehealth-research.com](http://www.futurehealth-research.com)

The independent report *Keeping pace with cancer* was sponsored by Johnson & Johnson and authored by Future Health. The views and conclusion in the report and the infographic are those of Future Health and should be attributed as such. Future Health takes full responsibility for the content of the report and associated publications.

### References

- i <https://www.england.nhs.uk/long-read/accelerating-genomic-medicine-in-the-nhs/>
- ii <https://news.cancerresearchuk.org/2023/11/28/cancer-research-uk-launches-ambitious-manifesto/>
- iii <https://www.ucl.ac.uk/news/2024/feb/uk-cancer-treatment-falls-behind-other-countries#:~:text=Lower%20use%20of%20chemotherapy%20and,15%20years%20behind%20leading%20countries>
- iv <https://www.england.nhs.uk/wp-content/uploads/2020/11/diagnostics-recovery-and-renewal-independent-review-of-diagnostic-services-for-nhs-england-2.pdf>
- v Future Health Research. *Keeping pace with cancer accelerating access to genomic testing through the NHS Genomic Medicine Service*. June 2024