

Scottish Strategic Network for Genomic Medicine

Annual Report 2023/24





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Executive Summary

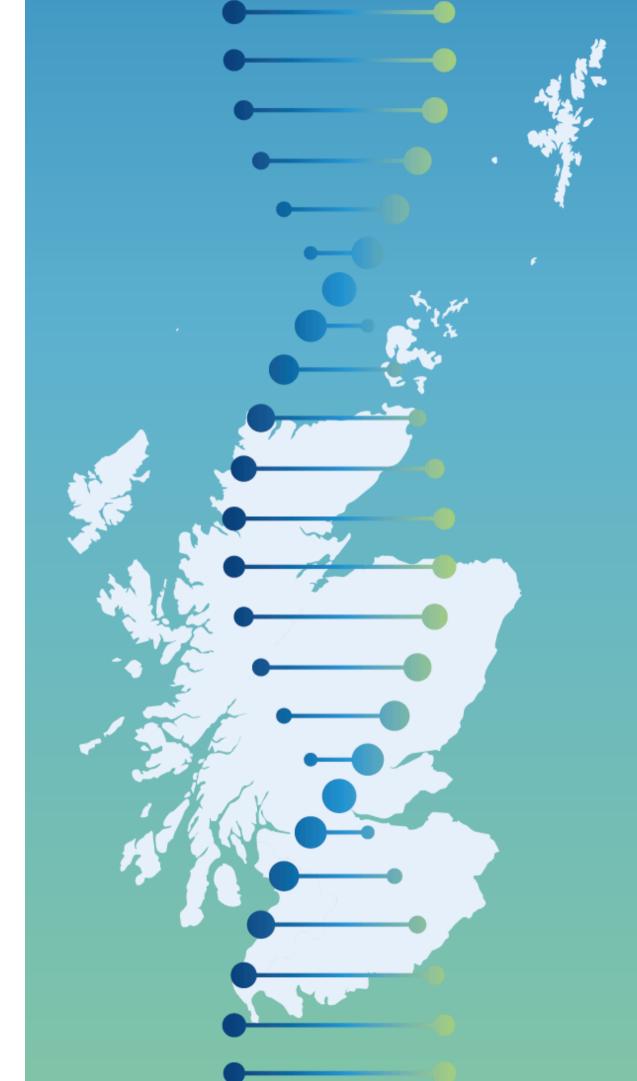
Welcome to the second annual report of the Scottish Strategic Network for Genomic Medicine (SSNGM). The SSNGM is a collaborative National Strategic Network that works across geographical and organisational boundaries to support a 'Once for Scotland' approach to the planning, design and delivery of an integrated, person-centred service for the delivery of genomic healthcare.

This year the SSNGM has moved to business-as-usual for the delivery of key network processes.

- The network website was launched (<u>https://www.genomics.nhs.scot/</u>) and contains important information about the network, including our Scottish Genomic Test Directories.
- The Scottish Genomics Test Advisory Groups (SG-TAG) for Cancer and for Rare and Inherited Disease are now operational and we have received multiple submissions for consideration of new genomic tests for Scotland.
- A new Patient Involvement Advisory Group (PIAG) has also been established to ensure our citizens have a voice in our genomics services in Scotland.

In addition, we have initiated work on industry engagement and have established a SSNGM Horizon Scanning Group which will help with the planning and future delivery of our service.

The Genomics Transformation Team has continued to work closely with the four regional genomics laboratories located in Aberdeen, Dundee, Edinburgh and Glasgow on a programme of transformational change. Key work areas this year have focussed on laboratory genomics workforce, the implementation of 11 new cancer genomic testing pathways, demand optimisation to help manage the increasing demand for genomic testing and data standardisation for benchmarking.

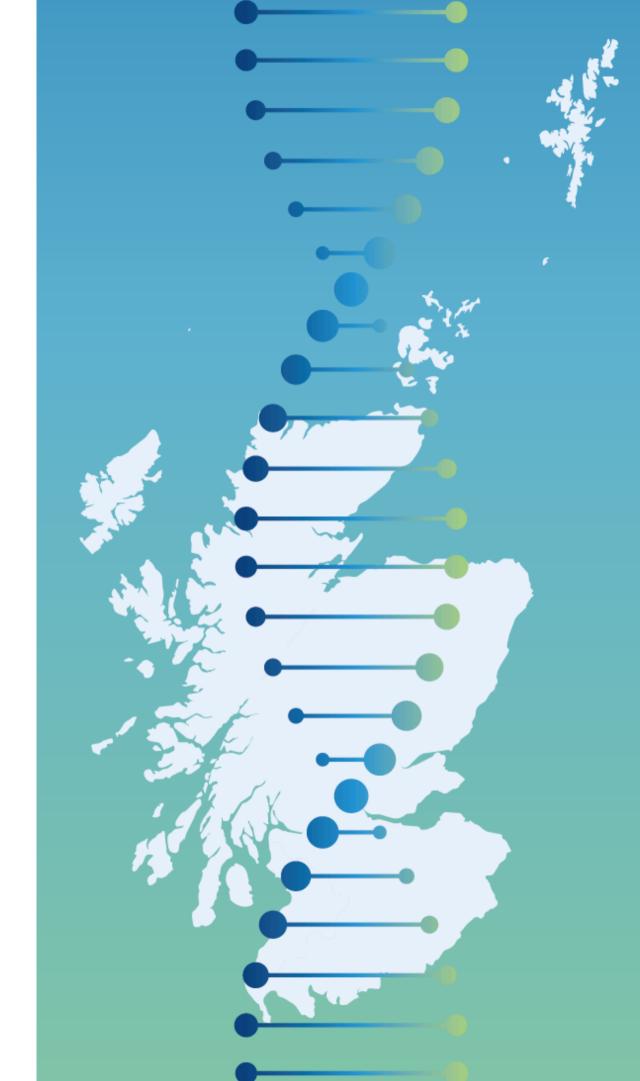


Executive Summary Continued

The network has had excellent engagement across these work areas from laboratory staff and clinical users of the services. In February 2024 a new Genomics Laboratories Transformation Delivery Plan for 2024 to 2026 was ratified by the SSNGM Oversight Board and detailed workplans which cover finance, delivery model, workforce, bioinformatics, data and digital and innovation are in development.

The SSNGM worked closely with our Scottish Government Genomics Policy Team this year on the development of Scotland's first Genomics Strategy. The strategy sets out an ambitious five year plan to transform and deliver increased capacity for our genomic services across Scotland and was published alongside an initial one year implementation plan on the 19th April 2024. The SSNGM will continue to work with Scottish Government and other key stakeholders to support the implementation of our genomic medicine strategy for Scotland.

Over the past 12 months the SSNGM has continued to have excellent engagement from our genomics stakeholders across Scotland, many of whom participate in our working groups. We would like to take this opportunity to thank all of them for sharing our journey by engaging with our work, offering advice and support and by joining our transformational or strategic working groups.





Introduction

The aim of the Annual Report is to provide stakeholders with an update on the work of the Network, focusing on key achievements during the financial year from 1 April 2023 to 31 March 2024.

Achieving the progress outlined in the Annual Report would not have been possible without the energy, time, advice and expertise invested by Network stakeholders.

The Network Programme Team would like to take this opportunity to thank members for their commitment and contributions, with special thanks to those who have given their time to chair Network work streams, as well as to Scottish Government for their continued support.



Forward

Dr Jonathan Berg - Lead Clinician for Rare Disease

"I was very pleased to see the publication of the first Genomics Strategy for Scotland, outlining a commitment to develop a robust national genomic medicine service. The implementation plan, that has been published to acompany the strategy, is a key start in the journey to improving diagnostic testing for rare genomic disorders in Scotland. The Scottish Strategic Network for Genomic Medicine is also working together with key stakeholders, improving links to the Scottish Clinical Genomics Forum, and developing a Patient Involvement Advisory Group. These links will allow us to integrate genetic testing effectively into clinical management pathways for patients across Scotland.

I welcome this report which describes the progress made to date, and outlines the next steps in taking the strategy forward."

Forward

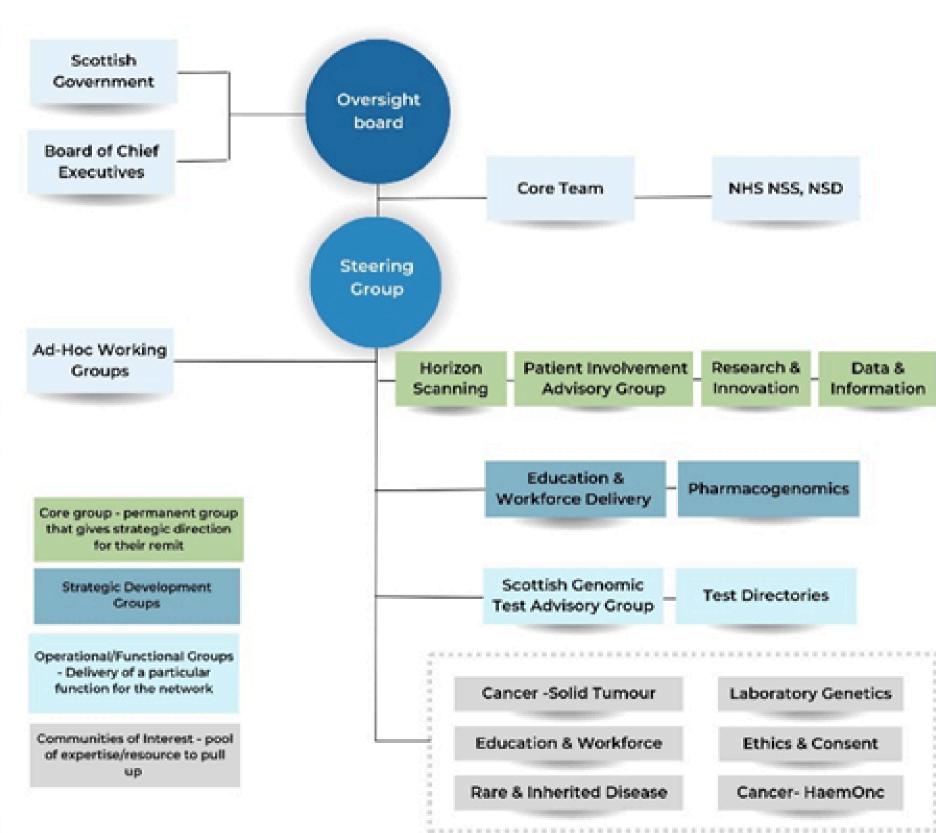
Professor Patricia Roxburgh - Lead Clinician for Somatic Cancer

"This year the genomics network has continued to work in partnership with the cancer networks (both regional and national) to develop appropriate testing pathways for patients. Furthermore work has continued to embed engagement of all cancer relevant disciplines in genomics network processes to ensure that testing pathways are feasible and fit for purpose.

I am delighted that this year has seen the publication of the first genomics Strategy for Scotland which sets out a vision for genomic testing services that will allow us to prevent and optimally treat cancer patients."



Governance Structure

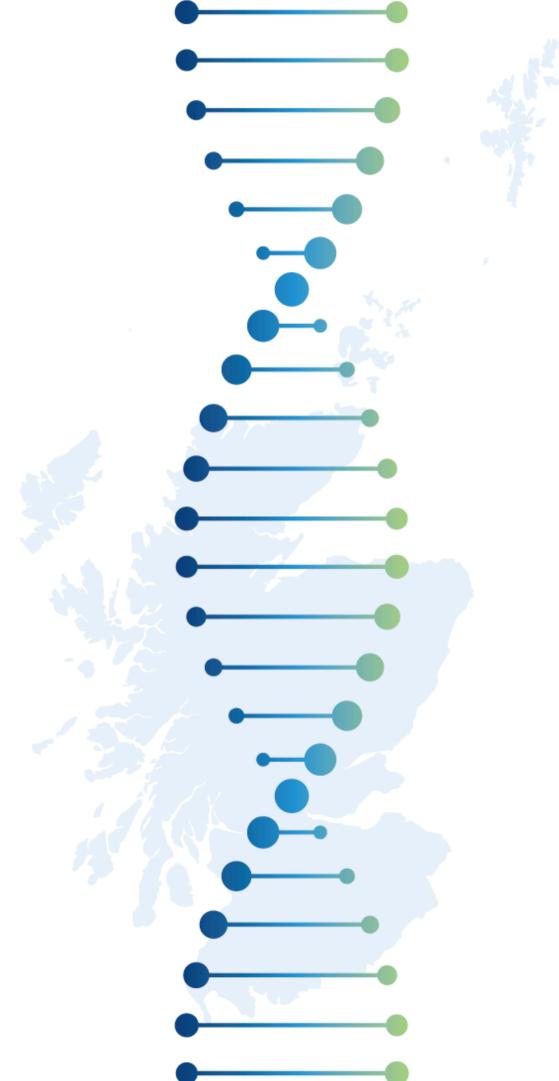


Network Oversight Board

The meetings of the Scottish Strategic Network for Genomic Medicine Oversight Board are chaired by Professor Jann Gardener (Chief Executive, NHS Lanarkshire) The aim of the board is to provide national strategic leadership and decision making in genomics health and social care laboratories in Scotland, based on the most up to date evidence and in line with strategic local, regional and national NHS strategy and Scottish Government priorities.

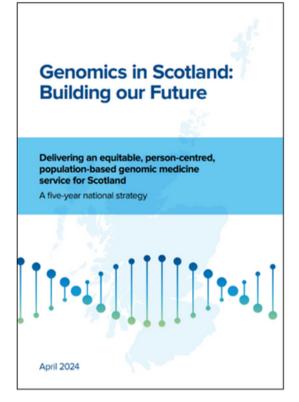
Network Steering Group

The Scottish Strategic Network for Genomic Medicine Steering Group is co-chaired by Prof Patricia Roxburgh and Dr Jonathan Berg, the Network Lead Clinicians. The Steering Group is responsible for the operational oversight of the Network and reports to the Network Oversight Board. The purpose of the group is to work across geographical and organisational boundaries to support Health Boards with a 'Once for Scotland' approach to the planning, design, and delivery of genomics care in Scotland.



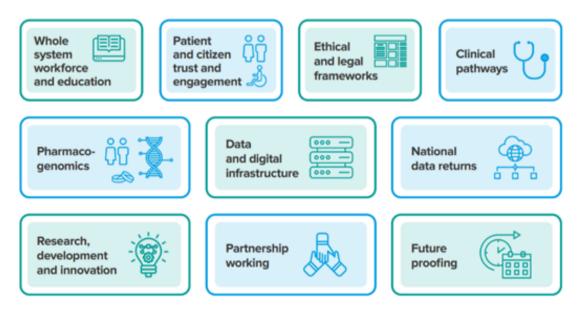
Strategy Progress

Publication of a Genomic Medicine Strategy



The development and publication of a Genomic Medicine Strategy for Scotland has been a key priority and workstream for the SSNGM over the past 12 months. This resulted in the publication of our first Genomic Medicine Strategy in April 2024, Genomics in Scotland: Building our Future. The strategy sets out an ambitious five year national approach to the delivery of an equitable, person-centred, population-based genomic medicine service for Scotland.

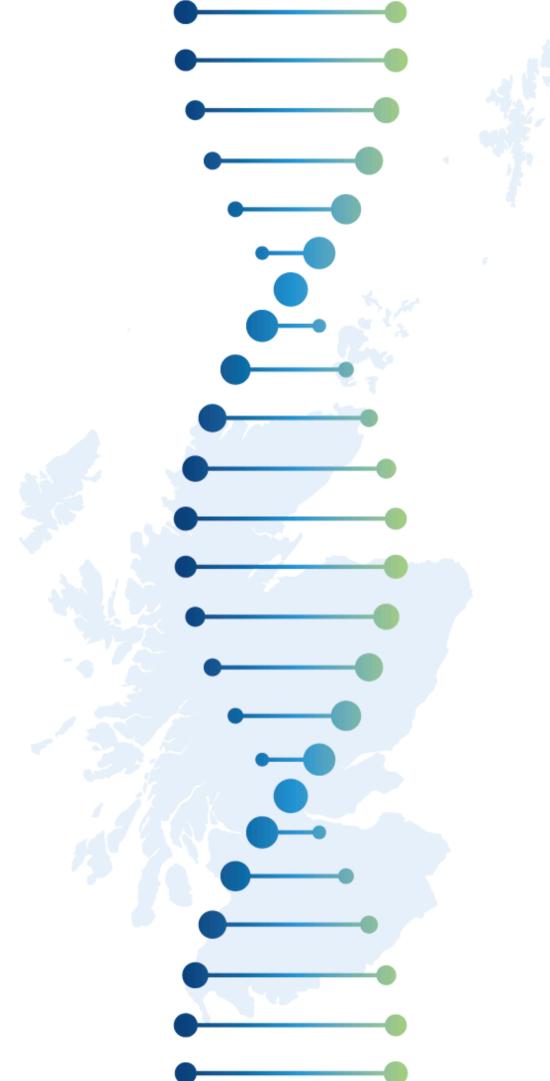
The strategy, through thirteen overarching strategic aims, is intent on improving access to genomic building testing and strong foundations (set out to the right) to Scotland take full allow to advantage of developments in genomic medicine going forward.



Published alongside the strategy was an initial <u>1 year implementation plan for 2024-2025</u>.







Transformation Progress

Transforming Genomics Laboratories Demand Optimisation

This transformational working group was established in October 2022 to work across the Genomic Medicine landscape in Scotland to ensure demand for genomic testing is optimised by engaging with all stakeholders to create the foundation for more integrated service functions, by improving communications between services and referrers, reducing variability in testing guidance and developing the genomic test directories for Scotland.

The group has been working closely with each service to establish national test directories, national gatekeeping for referral systems including those used by Primary and Secondary Care, the test requests from non-clinical routes (i.e. research, quality assurance or assessment) and scope audits for focus areas.

2023/24 Deliverables:

•Baselined draft dataset for test directory developed for wider application.

•National guidance for referral criteria in test directory

•National gate-keeping of testing implemented

- •Focus areas of suboptimal demand in each centre
- identified and audits initiated
- •Atlas of variation deprioritised

2024/25 Planned Deliverables:

•Review what testing needs to stop. •Reduce sub-optimal testing by auditing areas of focussed demand in all centres and implement improvement measures where appropriate. •Develop education material for medics to ensure no unnecessary testing.



•Produce guidance for testing acceptance linked to test directory.



Transforming Genomics Laboratories Laboratory Data Standardisation

This transformational working group was established in October 2022 to form agreement across the Genomic Medicine laboratories in Scotland for the standardisation of national data collection, recording and reporting to NSD, to create the foundation for more integrated service functions in future work. This includes aligning genomics terms nationally to be implemented in several initiatives including inclusion in the National LIMS development programme, the development of national genomics test directories and reporting to national bodies for bespoke data capture such as PHS and NSD.

The group has been working closely with each service laboratory to contextualise, map and review their data systems including those of data generation, management and analysis, the data types, fields and items being collected and the reporting mechanisms.

2023/24 Deliverables:

- Development of a glossary of terms for genomics initiated to support the standardisation across the four centres
- Disease/Indication names mapping to Mondo Disease Ontology now included in National LIMS
- Mondo mapping to test directory initiated

2024/25 Planned Deliverables:

- laboratories.

- internationally.



•Implement and utilise standardised datasets across all four

•Implement standardised reporting of datasets. •Deliver standardisation of clinical terminology. •Ensure that the standardisation of Scottish datasets is intelligible

•Benchmarking of genomic centres activity. •Inform service delivery modelling and accurate costings.

Transforming Genomics Laboratories Laboratory Workforce Planning

This transformational working group was established in October 2022 to analyse the current workforce, determine future workforce needs, identify the gap between the present and the future, and implement solutions to support Genomics Laboratories to deliver their mission, goals, and strategic plan.

2023/24 Deliverables:

•Implemented a system that allows establishment data to be benchmarked.

•Agreed 22 new national job titles to support standardisation across the 4 laboratories.

•Defined the roles and responsibilities of laboratory staff supporting the development of standardised job descriptions.

•Created genomics job profiles aligned to the national job profiles for Healthcare Scientist (HCS) bands 2-7.

•Created draft national job descriptions for Healthcare Scientist (HCS) bands 2-7.

•Obtain NHS HR Directors approval to proceed with a national NHS Job Evaluation Process and therefore the ability to evaluate Genomic Laboratories job descriptions nationally.

2024/25 Planned Deliverables:

•Complete a skill mix reprofiling exercise to maintain a highly skilled workforce that meets the laboratory service demands. •Review staffing structure for the laboratories, benchmarking against comparable laboratories to support the generation of a national work

force plan.

•Understand the impact of developments in Digital Infrastructure and Bioinformatics on the future workforce requirements including the efficiencies in staffing.

•Support the undertaking of a national job evaluation process for all new drafted job descriptions.





Transforming Genomics Laboratories Prioritised Cancer Pathways

This transformational working group was established in October 2022 to understand the current status of the 11 prioritised pathways and to determine an implementation plan that results in the introduction of the 11 pathways into business as usual.

The transformation team have supported establishment of multiple subgroups, membership of the which include Oncologists, Pathologists and Clinical Scientists. These subgroups review the clinical and testing pathways to align with a 'Once for Scotland' approach standardising diagnostic and therapeutic targets, referral criteria, turnaround times and reporting requirements.

2023/24 Deliverables:

•Implementation of 6 prioritised pathways supported by launch communication plan.

January 2024 – DPYD, Endometrial, Ovarian BRCA1/2 and Prostate BRCA 1/2

February 2024 – AML NPM1 MRD

Standardisation work initiated on the costing model terminology to support future pathway costing exercises across the four laboratories.
5 subgroups established to support implementation of the remaining pathways in line with a live implementation plan.

•Draft process established to support future service delivery planning utilising a national 'Once for Scotland' approach.

2024/25 Planned Deliverables:

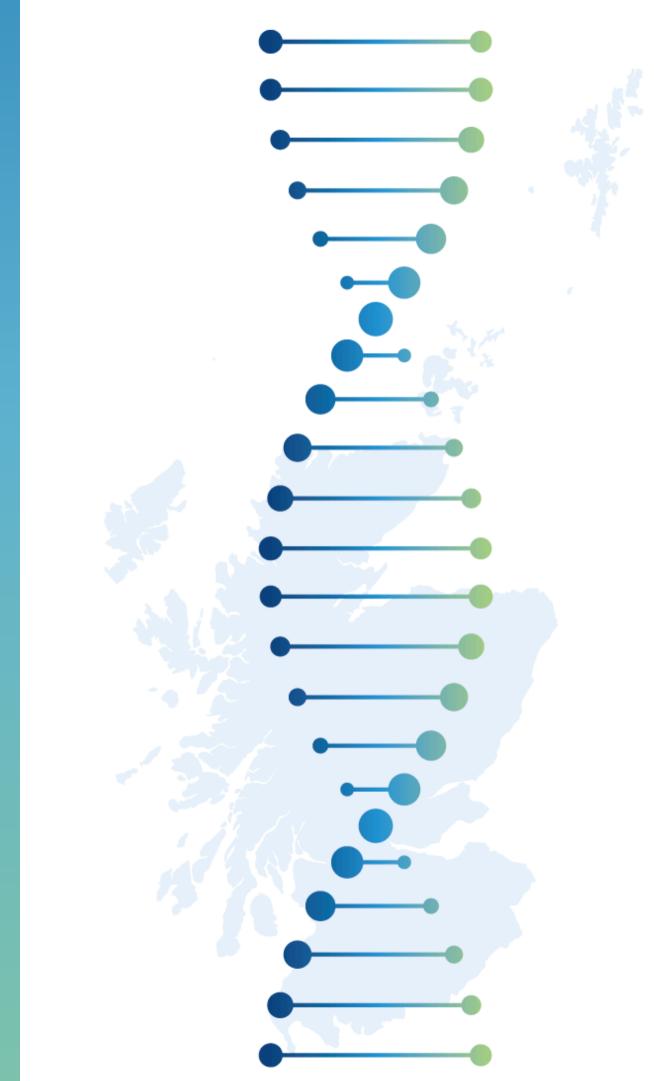
Implementation of remandancess provided for all S
Review of laboratory consupport reinvestment an
Formalise processes for the four laboratory sites.



•Implementation of remaining 5 prioritised cancer pathways with access provided for all Scottish patients.

- •Review of laboratory costings to identify efficiency savings to support reinvestment and future planning.
- •Formalise processes for new test service delivery planning across the four laboratory sites.

Laboratory Transformation Next Steps





Transformation Delivery Plan 2024-26

Initially the SSNGM Transformation Team formed four operational groups focussed on Laboratory Data Standardisation, Demand Optimisation, Genomics Laboratories Workforce Planning and Implementation of New Cancer Pathways. In March 2024 the Transformation Team developed a two-year Genomics Laboratories Transformation Delivery Plan.

The delivery plan has six key transformation themes for which opportunities for improvement have been identified:

- Finance
- Service Delivery Model
- Laboratory Workforce
- Bioinformatics
- Data and Digital
- Innovation

The combined work to implement the objectives of the Scottish Government strategy and the delivery plan will be key to deliver the transformation required to achieve our vision.

Our Vision

"Transform the Genomic Laboratories to deliver an optimised, efficient service which offers an equitable, person centred and population-based genomics service and infrastructure for the people of Scotland."



2024/25 Planned Deliverables

Transformation Theme	Delive
Finance	Implement pan-Scotland costings template for ge commissioned service.
Service Delivery Model	Develop and drive forward a 2-year plan to optim capacity, manage demand and future proof services resource.
	Conduct an options appraisal in conjunction with managers to identify potential future delivery mod
Laboratory Workforce	Understand the current workforce model and are
Bioinformatics	Map and scope existing bioinformatics and deve

verable

genomics services which will directly link to the

timise current service delivery models to increase rvice delivery through efficient use of current

ith the laboratory heads, directors and service nodels.

areas for skill mix reprofiling.

velop in parallel with service delivery modelling.

2024/25 Planned Deliverables

Transformation Theme	Delivera
<section-header></section-header>	Generate a national standardised genomics glossa Develop a test directory database that is standardis Align to an international genomics disease ontology Develop a standardised activity unit. Options analysis of solutions for a centralised data Options analysis for a common data environment a data storage solution.
Whole Genome Sequencing	Scope the clinical need for whole genome sequence Conduct an options appraisal of potential delivery r Understand the infrastructure requirements for the
Pharmacogenomics	Work with the ANIA pathway to implement national Scope the clinical need and projected demand for projected demand

able

sary.

lised, interrogable and integrate-able.

gy.

a store for NHS genomic data.

aligned to the service delivery model and

ncing for cancer and inherited and rare disease.

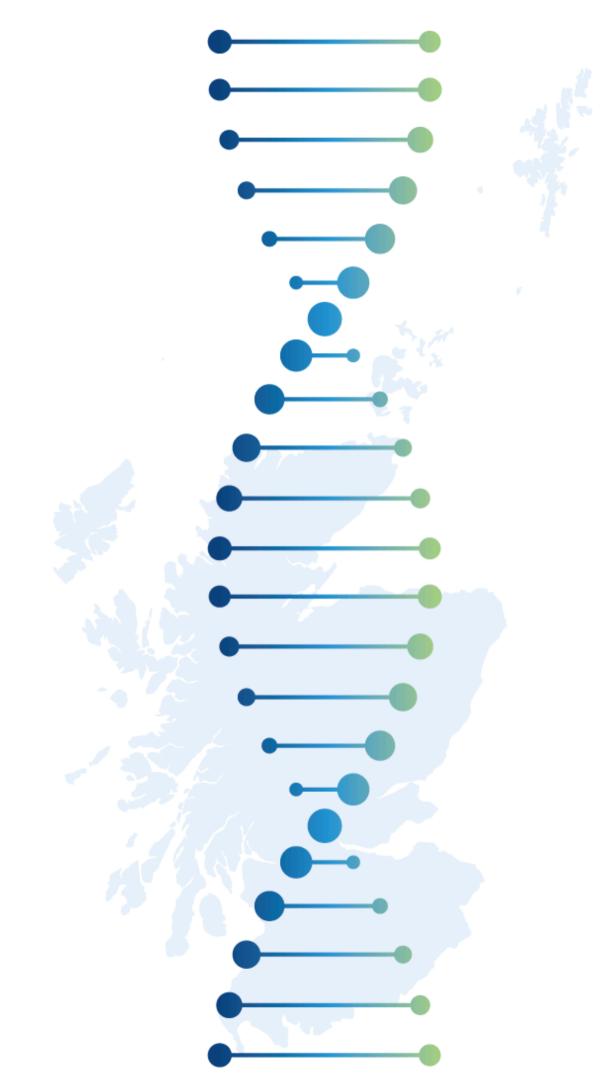
models.

e delivery of WGS.

al testing for CYP2C19 in stroke patients.

pharmacogenomics testing.

Significant progress has been made in achieving network's deliverables since last year's annual report. We have carried forward the workforce & education, online test directories and data related deliverables into the current year's focus areas to ensure continuity and highlight the commitment to achieving those goals.



Deliverable



Establishment of new genomic test request process that is nationally agreed and creates ideal solutions with robust processes that are patientcentred and take a "Once for Scotland" approach. Progress/Next steps

Progress: The Scottish Genomic Test Advisory Groups (SG-TAG) for cancer and for rare & inherited diseases (R&ID) were launched in November 2023 land December 2023, respectively. These SG-TAGs processes are fully operational and paperless, based on Windows 365 applications. Since launch, two cancer submissions and one R&ID submission have successfully undergone the SG -TAG process. Next: Implementation of an SG -TAG process for Pharmacogenomics.

Implement new process to manage updates to Cancer and R&ID Scottish test directories.

Progress: The new process was launched and communicated with stakeholders in January 2024.



Improvement







A once-for-Scotland approach to service delivery that is robust and streamlined, using realistic medicine principles, promotion of best practice, along with benefits for patients and clinical staff. A sustainable process using virtual meetings, digital applications and evaluation processes resulting in faster turnaround times for new test approval. In addition the process is environmentally friendly, reducing carbon footprint and enables real-time updates and better visibility of requests.

The Test Directories process streamlines the implementation of changes reducing risk of errors, provides quality assurance, facilitates the documentation of changes, making it easier to track changes.

Deliverable



Establishment of new Horizon Scanning process

Progress/Next steps

Progress: The group has been operational since October 2023 with Terms of Reference agreed. The group is now in the process of gathering information to form the baseline and support prioritisation of new initiatives within each of the horizon scanning workstreams.

Next steps: Within the workstreams the group will develop reporting and prioritisation processes to support decision making at Horizon Scanning meetings.

Progress: KPIs have been established and categorised by Theme, Network and Business as Usual. KPIs for 2023/2024 were regularly tracked, and a reporting system has been developed.

Next steps: Create a Dashboard for enhanced KPI visualisation in Q1. Plus explore the introduction of KPIs to monitor new clinical pathways.



Implement Network Key Performance Indicators (KPIs)





Provide a platform for future planning and review of developing technologies, emerging SMC approvals, new tests, and changing resources to meet supply and demand.

The Network KPIs allow for greater understanding of the quality of our work. The KPIs will be monitored and used to evaluate the performance of the Network in achieving our objectives and enabling rapid quality improvements.



Establish engagement plan with Cancer Regional Networks to support and empowered engagement with the cancer community.

Progress/Next steps

Progress: A communication plan between SSNGM and Cancer Regional Managers has been agreed upon. SSNGM has produced two Cancer Genomic Newsletters, one in winter 2023 and the other in spring 2024. Enhanced communications have supported the development of 5 short life working groups to support delivery of the prioritised cancer pathways.

Next steps: Review the communication plan in June 2024.

Establishment of Patient Involvement Advisory Group (PIAG) **Progress:** A PIAG group has been established, and the Terms of Reference have been agreed ; the group has two co-chairs representing cancer and also rare and inherited disease. Initial meetings have taken place to promote ways of working within the group. The chairs will regularly attend SSNGM Steering Group meetings.

Next steps: Set up regular meetings and agree on workplan objectives.



Engagement with stakeholders







Provides a forum for collaborative working and addressing issues that require national consensus among partners through engagement.

Provides a forum for dialogue between healthcare professionals and patients and people with lived experience ensuring that genomic services are more responsive to patient needs and preferences, resulting in improved healthcare outcomes.

Deliverable



Progress/Next steps



Engagement with stakeholders

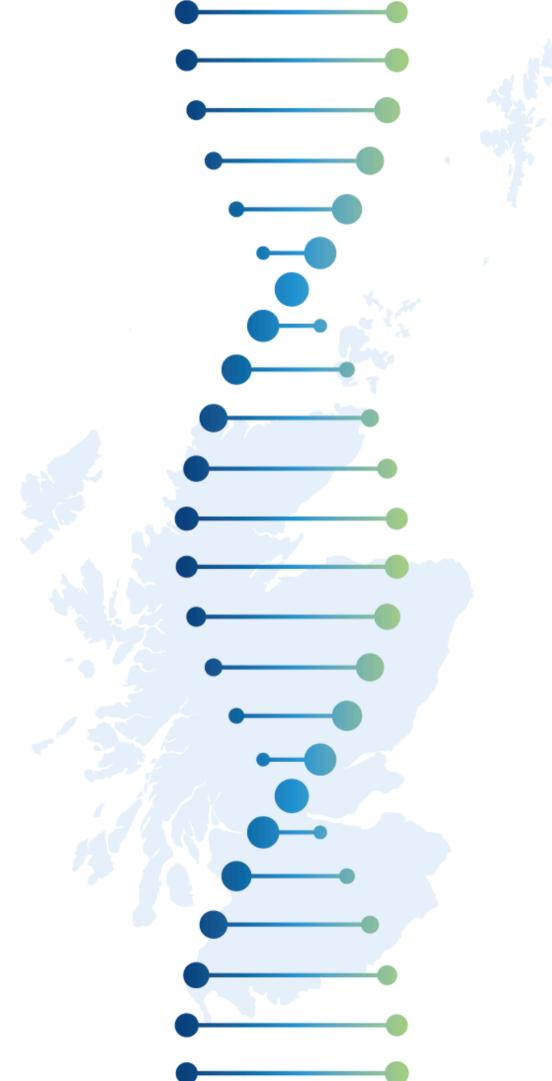
Establish Short-life Working Group to improve communication with Scottish Pathology Network (SPAN) **Progress:** Engagement at the initial meetings has laid the foundation for successful development in this area including joint education sessions between genomics and pathology. The group meets on a bimonthly basis, and the focus areas have been decided upon.

Next Steps: An education programme will be established, with a target date for the first session in Sep 2024.



Benefits

Streamline workflows and ensure joint future planning for cancer patient testing pathways. This collaboration is built on cooperation, shared knowledge and expertise. Engagement at the initial meetings has laid the foundation for successful development in this area including joint education sessions between genomics and pathology and identifying other key areas of joint working for the group.





Establish Workforce and Education Core Group

Progress/Next steps

Progress: The Terms of Reference draft and membership is being con The Network Steering Group agree objectives for the year 2024–2025 Next Steps: Members will be invited, f the first meeting of the group by June

Network Governance and Structure Establish Research & Innovation Core Group

Progress: Work will begin in July 2

Establish Data & Information Core Group Progress: The Terms of Reference is in draft and membership is being considered. The Network Steering Group agreed on objectives for the year 2024–2025. Next Steps : Members will be invited, followed by the first meeting to be scheduled by June 2024.

Complete the requirements of the SSNGM Governance model creating a forum for expertise to support resolution of the current issues/concerns around data and information.



Develop a test directory database that is standardised, interrogable and integrateable

Progress/Next steps

Next steps: Develop a test directory database that is standardised, interrogable and integrateable.



Continuous

Improvement

Progress: Quality checking of the dataset underway and final design of interface under review with Short-life Working Group.

Next steps: The Online Test Directories are scheduled to be launched in Summer 2024.

Horizon Scanning: Develop a system for information to be received by the Horizon Scanning group and for reporting under the key areas of the group.

Work will begin in October 2024.







Improved timeliness of the test directory updates/ changes, providing healthcare professionals the most up to date information.

Improvements to service users providing easy to navigate and searchable genomics tests available in Scotland.

Early identification of emerging new tests and laboratories developments, clinical guidelines with expertise and guidance on prioritisation of resource and funding to ensure best use of both with maximum outputs for clinical users and patients.



Support Scottish Government in development of the framework that supports collaborative work with industry.

Progress/Next steps

Progress: Working with Industry & Pharma is an ongoing effort in close collaboration with the Scottish Government Genomics Policy Team. Working with industry is an important element for our genomics services in Scotland.

Next steps: Scoping how the SSNGM works with industry. A framework will be established in close coordination with the Scottish Government Policy Team.

Support delivery of the year one Implementation Plan via the transformation delivery plan.

Progress: <u>One-year implementation plan</u> was published on 19th April 2024.



Strategic Service Planning and Development







Collaborate with industry and pharma to develop capability and capacity in care whilst obtaining the benefit of the latest technologies and innovations.

Clear communication of the actions, timeliness, and effective execution of strategic activities.





Host an annual event to increase opportunities for engagement with stakeholders Progress/Next steps

Work will begin in May 2024.



Engagement with stakeholders

Conduct stakeholders feedback to gather insights on the effectiveness of network processes and identify areas for improvement.

Work will begin in October 2024.

Develop PIAG Workplan to engage the support of the group for delivery of the year 1 Implementation Plan.

Work will begin in July 2024.





Knowledge sharing, professional development, networking opportunities, stakeholders engagement

Stakeholder feedback provides valuable insights for improving processes, enhancing stakeholders satisfaction, strengthening relationships.

Ensured patient viewpoints are considered in policy decisions, patient centered services



Develop informational materials and resources for stakeholders, such as toolkits, and infographics, to improve their understanding of the BAU network's activities.

Progress/Next steps

Progress: A draft guide detailing the steps involved in submitting the initial online application to the Scottish Genomic Test Advisory Group (SG-TAG) is currently being reviewed.

Next steps: Assess the available resources.



Education, Training, & Workforce Workforce and Education Core Group - Complete a gap analysis of existing education materials available to NHSS.

Work will begin in October 2024



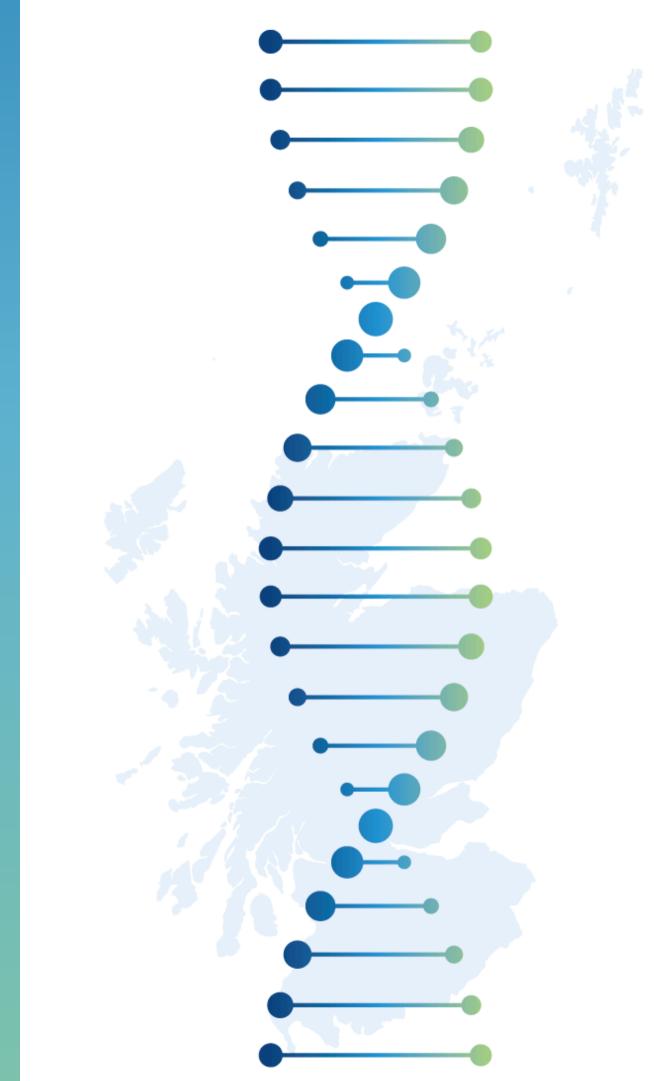




The Network educational materials are visible to as many stakeholders as possible and important news, processes and messages are shared appropriately

Opportunity to understand the current baseline for education material available within NHSS and understand the opportunities available to work with other UK nations to share education materials and resources.

Communication and Engagement



•••

The SSNGM acts as a front door for engagement with clinicians, academics, industry, pharma and many others to deliver a genomics health service for Scotland. Since launching the network in August 2022, the network team have been actively engaging with stakeholders through various meetings, events, presentations, newsletters and other network communications.

We have engaged with Scottish Government Policy teams, other managed clinical and strategic networks, and clinician colleagues across clinical genetics, pathology, oncology, and haematology. The SSNGM has also been actively engaging with the wider genomics community in Scotland including colleagues in the public and private sectors, patient groups, charities, universities, and industry partners. The network has also been regularly engaging with colleagues outside Scotland including colleagues in NHS England, NHS Wales and Health and Social Care Northern Ireland.

Communication and Engagement

Below details some key communication and engagement pieces for the network this year:

Educational Conference

On Thursday 28th September 2023, Precision Medicine Scotland hosted their 10th Anniversary Conference at Strathclyde University in Glasgow. The event was attended by academics, clinicians, healthcare professionals and industry partners form across the UK. The SSNGM was invited as a special guest for the event and held five Genomics Sessions throughout the daylong conference. More information on the conference can be found here.



Newsletters

The SSNGM has received great engagement with the network newsletter averaging 102 in depth reads and 76 quick reads per quarterly newsletter. The SSNGM will continue to develop this and other newsletters to ensure the network is well informed of progress and updates.



Strategy Development

The SSNGM distributed a survey to participants of the Strategic Working Groups to gain feedback and help improve the strategy development process. 73% noted in their response that they were satisfied or very satisfied with the outcomes of process. 73% noted in their response that the communication was effective and/or worked well.

Website

Community specific

An important objective for the SSNGM is to improve communications to specific communities. To promote greater collaboration and information exchange, a specific cancer issue newsletter is being issued from the network. The formation of new working group that will play a key role in enhancing the communication between genomic services and pathology has been established. The SSNGM also continue to work closely with clinical teams to improve clinical pathways for services.



There was an average of 72% attendance at our Oversight Board meetings last year and an average of 62% attendance at our Steering Group meetings for 2023/24. The SSNGM saw positive engagement in our core group meetings last year. 5 meetings were held for the Patient Involvement Advisory Group and 6 meetings took place for the Horizon Scanning group.

The SSNGM website was launched in June 2023. The website will be used to provide a central source of information on the work of the network and wider developments. Our new website address is www.genomics.nhs.scot. Since it's launch, website visits have steadily increased averaging 200 views per month.

MEETthe TEAM





Associate Director National Strategic Networks



Dr Johnathan Berg

Clinical Lead for Germline and Rare Disease



Professor Patricia Roxburgh **Clinical Lead for Somatic** Cancer

Nicola Williams **Consultant Clinical Scientist and** Scientific Lead for SSNGM and **Genomics Transformation Team**



Nelson Grant Portfolio Manager, Genomics **Transformation Team**



Gillian McCarrol Portfolio Manager, Genomics **Transformation Team**





Alija Mustafa Programme Manager, SSNGM



Nicole Carson Assistant Programme Manager, **Genomics Transformation Team**



Shannon Mullen

Programme Support Officer, SSNGM