



# Scottish Strategic Network for Genomic Medicine

Annual Report 2022/23





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# Executive Summary

Welcome to the first 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.

The SSNGM was launched in August 2022 following the recognition of the need to have a strong, robust decision-making structure for genomic medicine in Scotland. During the past 10 months the SSNGM has been operationalised to replace the previous Scottish Genomics Leadership Group and has been working on the delivery of our year one key objectives as outlined in this report.

The SSNGM has had excellent engagement with our genomics stakeholders across Scotland, many of whom have joined working groups which have been established as part of our work for this year. We worked closely with the Genomics Policy team, the Chief Scientist Office and the Chief Scientific Officer from Scottish Government to drive forward a new vision for genomic medicine for Scotland.

A Genomic Transformation Team has also been established as part of the SSNGM to work closely with the four regional genomics laboratories located in Aberdeen, Dundee, Edinburgh and Glasgow on a programme of transformational change. This work will be key to the delivery of our future genomic services in Scotland.

Our major area of development for this year is the delivery of a published Genomics Strategy for Scotland. Significant scoping work for the development of this strategy has already been undertaken and we look forward to publishing this later in the year.

The SSNGM would like to thank all our stakeholders who have shared our journey over the past 10 months 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 2022 to 31 March 2023.

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 have been Clinical Lead for Germline and Rare Disease in the Scottish Strategic Network for Genomic Medicine (SSNGM) for less than a year, but in that time the Programme Team have made remarkable progress in facilitating strategic consideration and decision making. There are thousands of different rare diseases, but adding them all together, more than 1 in 20 people in Scotland are affected by a rare medical condition. The majority have a genetic cause. An effective genomic strategy is therefore essential to improve diagnosis for people affected by rare conditions and facilitate both research and treatment.

Over the past 6 months we have developed the Scottish Genomic Testing Advisory Groups (SG-TAG) to oversee the introduction of new and essential genomic tests in Scotland. We are rapidly developing effective mechanisms for involvement of people with rare conditions in the design of our policy. Many people are involved in key working groups, with the aim of publishing the first Genomics Strategy for Scotland in the Autumn this year, rapidly followed by an implementation plan in late 2023.

With so many advances in genomics and the understanding of Rare Diseases, we plan to support the development of world leading diagnosis and management for affected people within the Scottish NHS.

# Forward

## Dr Patricia Roxburgh - Lead Clinician for Somatic Cancer

As Clinical Lead for cancer genomics in the newly formed Scottish Strategic Network for Genomic Medicine, I am proud by the progress made by the Network team in the short life of the group. There has been transformation, at pace, in Scotland's four genomics laboratories with a focus on the four key areas of demand optimisation, data standardisation, workforce planning and cancer pathways.

Furthermore, the Network has brought together stakeholders from academia, NHS, third sector and industry to work alongside the Scottish Government genomics policy team, in a series of working groups, to shape the overall policy for Scotland. The strategy will align closely with cancer policy and a patient pathway focus will be facilitated by collaboration with the Scottish Cancer Network and the Managed Service Network for Children and Young People with cancer.

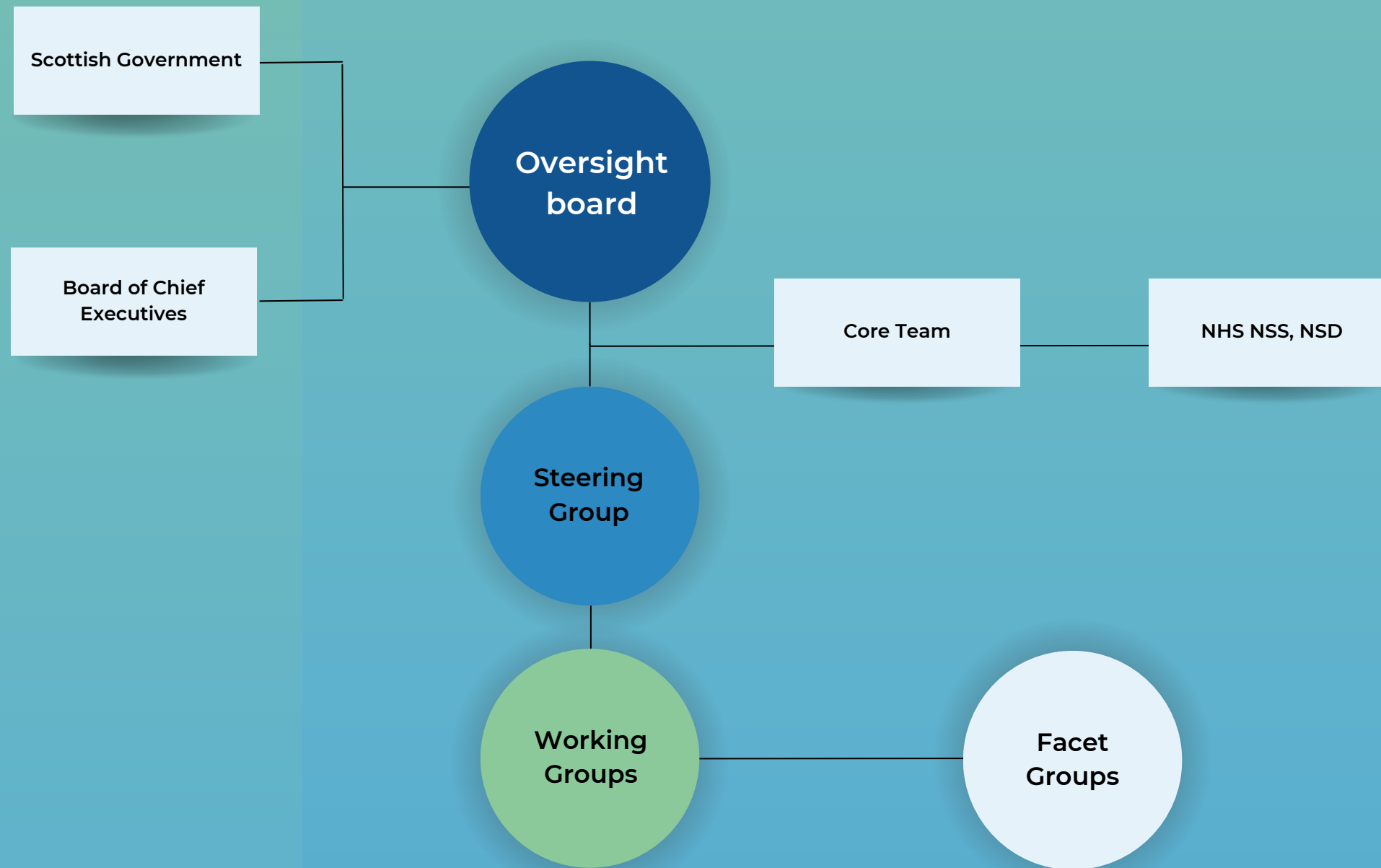
I am delighted to work with the network team to shape a genomics testing service which delivers the quality and breadth of genomic tests that cancer patients require.

Importantly, I am keen to ensure that our vision is for an innovative and world leading service that will support clinical research participation for patients across Scotland.





# Governance Structure



## Network Oversight Board

The inaugural meeting of the Scottish Strategic Network for Genomic Medicine Oversight Board chaired by Professor Jann Gardener (Chief Executive, NHS Lanarkshire) was held on August 17, 2022. 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 Dr 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 mission 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.



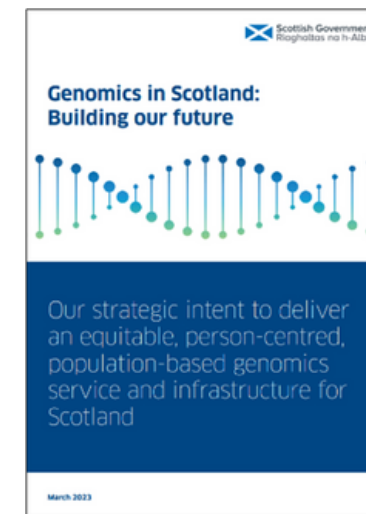
# Strategy Progress



# Strategy Progress

## A Genomics Strategy for Scotland

The development of a Genomics Strategy for Scotland is a key priority of the SSNGM. In March 2023 the Scottish Government published the first in a series of documents outlining our shared vision and commitment to the development of genomic medicine to improve the health of patients in Scotland. [Genomics in Scotland: Building our Future](#)



## Strategic Working Groups

Strategic working groups have been mobilised with excellent engagement from key stakeholders across Scotland. Our working groups are considering key recommendations for inclusion in the Strategy, due for publication in September 2023 and will outline our 5 year vision for Scotland. In December 2023 we will publish a 1 year implementation plan to enable key priorities to be delivered from April 2024.



Education & Workforce



Data & Information



Germline/ Rare Disease



Solid Tumour



Haematology



Prevention



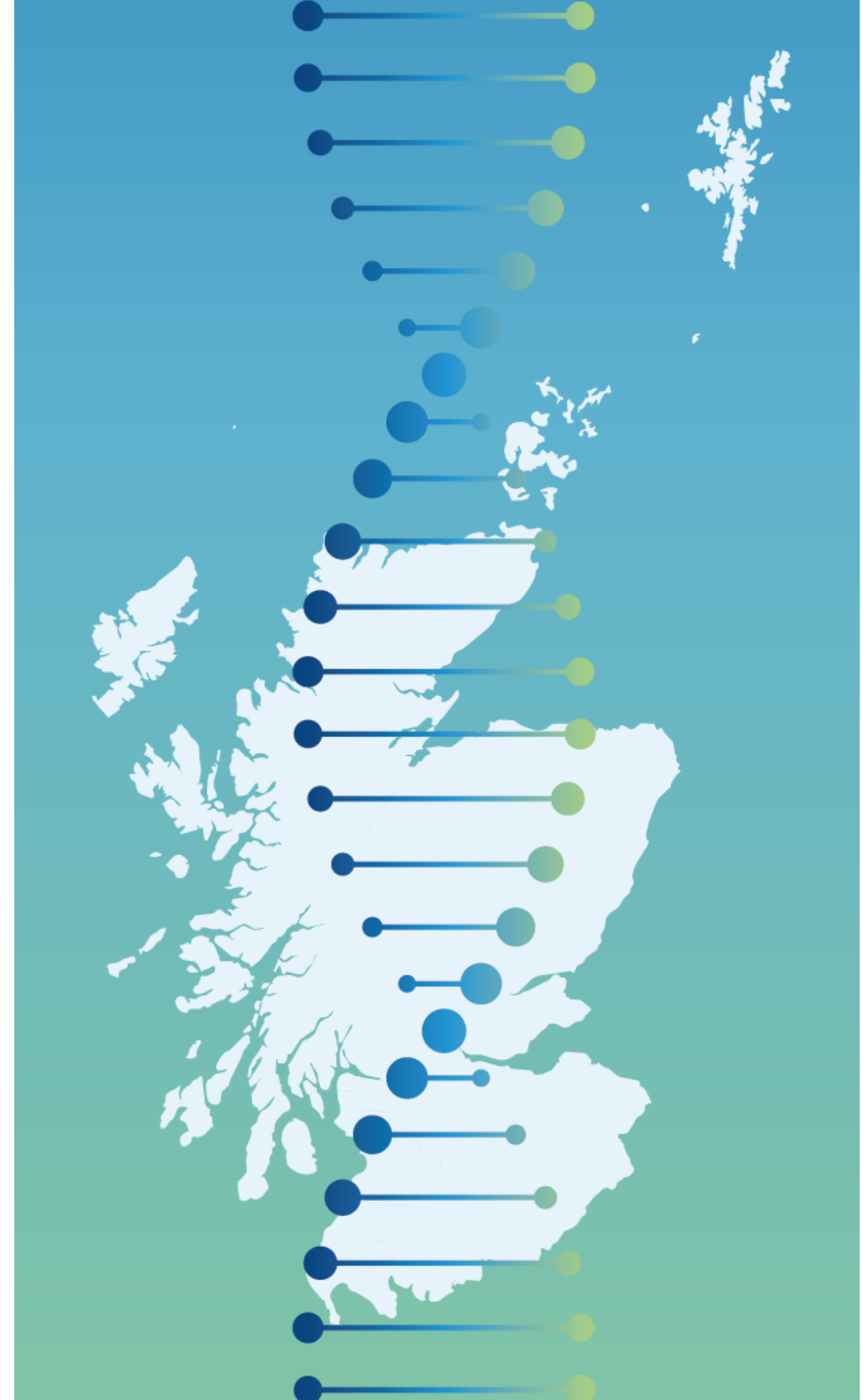
Research & Innovation



Public Engagement & Awareness



Pharmacogenomics





# Transformation Progress



# Transforming Genomics Laboratories Laboratory Data Standardisation

The Laboratory Data Standardisation Transformational Working Group was established to form agreement across the Genomic 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.

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. The group has also worked in the context of a National LIMS module in development for genomics. A standardised dataset to be included in the build.



## 2022/23 Deliverables:

- A glossary of terms for genomics is under development supporting standardisation across the four laboratories.
- Disease/indication names are being aligned to the international Mondo Disease Ontology.
- New workload units under development for inclusion in annual reports will support financial profiling and benchmarking.
- Stakeholder engagement with the four nations to support standardisation at a UK level.



## 2023/24 Deliverables:

- Develop standardised nomenclature, definitions, and parameters for data across all laboratories.
- Develop a standardised data collection mechanism and reporting template for laboratories to report comparable information to NSD.



# Transforming Genomics Laboratories Demand Optimisation

The Demand Optimisation Transformational Working Group was established to work across the Genomic Medicine landscape in Scotland to ensure Demand Optimisation by engaging with all stakeholders to create the foundation for more integrated service functions.

The group has been working closely with each service to contextualise, map and review referral systems, the test directories in Scotland and across the UK and scope an atlas of variation.

## 2022/23 Deliverables:

- Test directory digitisation completed across Cancer and Rare & Inherited disease. This exercise will support the development of a new online test directory and atlas of variation the ability to identify gaps in service provision.
- Review of referral criteria to provide assurance of the correct service demand and delivery.
- Review of gatekeeping practices across all laboratories to standardise for a unified national approach.



## 2023/24 Deliverables:

- Map the current demand in all areas of test requests and referrals to genomic laboratories and develop an atlas of variation.
- Review the atlas of variation and develop a mechanism for implementing change in areas of concern.
- Review test directory tests and make recommendations for the appropriate realignment and retirement of certain tests.





# Transforming Genomics Laboratories Laboratory Workforce Planning

This Laboratory Workforce Planning Transformational Working Group was established to analyse the current workforce, determine future workforce needs, identify the gap between the present and the future, and implement solutions so that Genomics laboratories can deliver on their aims, objectives and strategic plan. The working group have created a data establishment template that supports benchmarking between the four laboratories.

The transformation team have supported ongoing discussions around the current NHS Job Evaluation process and the ability to evaluate national job descriptions. This work will be a significant step in the nationalisation of laboratory job descriptions.

## 2022/23 Deliverables:

- Implemented a system that allows establishment data to be comparable between years, job titles and laboratory locations.
- Reviewed 72 different job descriptions across the four laboratories against the national defined job profiles.
- Agreed 22 new national job titles to support standardisation across the 4 laboratories.
- Created a draft job description template as the basis for all new job descriptions going forward.



## 2023/24 Deliverables:

- Define the roles and responsibilities of laboratory staff supporting the development of standardised job descriptions and allowing accurate resource to be identified for introduction of new tests.
- Develop a proposal that allows national training and competency to be taken forward creating a resilient workforce that is agile



# Transforming Genomics Laboratories

## Prioritised Cancer Pathways

The Prioritised Cancer Pathways Transformational Working Group was established to understand the current status of the 11 prioritised cancer pathways and determine an implementation plan that results in the introduction of these pathways into business as usual.

The working group have continued to monitor the implementation progress across the four Scottish laboratories defining timelines for implementation. The transformation team have supported ongoing discussions around service delivery models that are aligned with the 'Once for Scotland' approach achieving great success with the 2022/23 deliverables.



## 2022/23 Deliverables:

- Funding applications have been approved by Scottish Government for recruitment of staff and procurement of reagents to support the implementation of the prioritised pathways.
- Up to date status report and implementation plan for 11 prioritised pathways. The plan provides equity for the patients of Scotland.
- Standardised costing model developed to support a national approach to cost evaluation. This model will provide robust data for future business case applications and service reviews.
- National process map templates and approach agreed to support service reviews.



## 2023/24 Deliverables:

- Implementation of the 11 prioritised cancer pathways with equitable access across Scotland.
- Review of laboratory costing models to identify efficiency savings to support reinvestment and future planning.
- Established processes for service delivery planning across the four laboratory sites.

# Facet Groups



SSNGM has 13 facets which cover key areas, as shown in the diagram. In August 2022 SSNGM wrote to genomics community members who had completed the April 2022 Genomics Survey, to provide guidance on the remit of the facet groups. Facets are currently used as a resource of expertise which can be called upon to help with the work of the network. Colleagues allocated to a facet may have been asked to join a working group to help deliver key work areas for the network. The network has identified that some facets should be lay dormant for a period of time. The priorities of the network have continued to develop and grow over time and in response to this the SSNGM core team are planning to review the remit of the facet groups in June 2023.

# Network Deliverables 2022/23





# Network Deliverables 2022/23



Governance



Continuous Improvement

Deliverable



## Establish Oversight Board and Steering Group

**Replacement for the Molecular Pathology and Genetic Evaluation Panels** - to create ideal solutions with robust processes that are patient-centred and take a “Once for Scotland” approach.

Progress/Next steps



**Progress:** The SSNGM Oversight Board was formed, and the first meeting was held on August 17, 2022. The board is chaired by Prof Jann Gardner, BCE NHS Lanarkshire.

The SSNGM Steering Group was established, and the first meeting was held on October 6, 2022, co-chaired by Network Clinical Leads.

**Progress:** Two new groups established, the Scottish Test Advisory Group (SG-TAG) Cancer and Germline and Rare Disease, with their own framework and membership.

**Next Steps:** Finalisation of electronic application and review system and launch as business as usual.

Benefits



Effective Network structure that is organised, resourced and governed to deliver its agreed objectives, as agreed with Scottish Government, NHS Boards, and others as required.

Streamlined process, new ways of working, supporting realistic medicine principles, promoting best practice and advantages for the patients and clinical staff. Environmentally sustainable process with all meetings held virtually and digital application and review process.

# Network Deliverables 2022/23

## Deliverable



**Establish Digital Test Directory**  
- to offer an online platform that allows users to view all commissioned genomic tests in Scotland.

## Progress/Next steps



**Progress:** The SSNGM test directories for Germline and Rare Disease and Molecular Pathology were published online. The directories have been digitised and a plan to develop an online directory initiated.

**Next steps:** The development of an online test directory accessible to all with a maintenance and review framework linked to horizon scanning and the test advisory group process.

## Benefits



The Digital Test Directory will identify all genomic tests commissioned and made available by the NHS in Scotland. The platform, once finalised, will be user-friendly and visually appealing, as well as linked to SG-TAG for live modification once the test is approved and funded.

## Working with Industry and Pharma

**Progress:** Working with Industry & Pharma is a standing agenda item at meetings of the Oversight Board.

**Next steps:** Scoping how the SSNGM works with industry. One industry representative has been identified, scoping the requirements for a second industry representative is underway.

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



**Continuous Improvement**



# Network Deliverables 2022/23



Continuous Improvement



Engagement with Stakeholders

Deliverable



## Develop Network's KPIs

Progress/Next steps



**Progress:** Key Performance Indicators have been established and categorised by Theme, Network and Business As Usual.

**Next steps:** Delivery of Network KPIs with regular monitoring and reporting in 2023/24.

Benefits



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.

## Stakeholders Matrix Analysis

**Progress:** A matrix of Network stakeholders has been developed and reviewed. 57 stakeholders were identified and a communications plan developed for engagement which has been approved by the Steering Group.

**Next steps:** Process engagement with key stakeholders. Implementation of the Network Communication Plan.

The Network stakeholder matrix exercise has identified key stakeholders for engagement by the Network. The communication plan will ensure the most effective communication routes for engaging with all stakeholders are maintained and reviewed.



# Network Deliverables 2022/23



Engagement with stakeholders

Deliverable



**Establish Communication Channels**

Progress/Next steps



**Progress:** The Network newsletter has been established with an average of 144 in depth reads. Several MS Teams channels have been formed and are in use by our members and stakeholders.

**Next Steps:** Review and evaluation of communication channels

Benefits



Provides a forum for partnership working and resolving issues requiring national agreement between partners through collaboration.



Education, Training & Workforce

**Website to store educational resources**

**Progress:** The Network website is in development by the NSS Digital and Security team and includes a section for education.

**Next steps:** Website to be launched by June 2023 with educational resources development ongoing thereafter.

Provides an excellent venue for collaborative working. Provide a space for sharing educational resources across Scotland that is accessible and comprehensive. Increases our influence, establish trust and reputation, and attract new stakeholders.

**SSNGM educational event launch**

**Progress:** Agreed to join the Precision Medicine Scotland (PMS) 10th anniversary conference on the 28th of September 2023. The network team is working with PMS to plan this event.

**Next steps:** Further preparation, content and invited speaker selection.

Develop a greater understanding of the genomics work across Scotland, and the work of the Network for stakeholders, establishing greater and stronger links.



# Network Deliverables 2022/23

## Deliverable



## Progress/Next steps



## Benefits



### Data Standardisation across LIMS

**Progress:** Lab information to digitised directories matching exercise has been carried out.

**Next step:** Lab continuing to update the LIMS.

Standardisation is beneficial for national reporting and benchmarking purposes. Removes need for users or SSNGM to map existing LIMS exports which would be a very time onerous process.

### Electronic test request process for Cancer and Germline tests

**Progress:** The process for Cancer requests is now in the live testing environment stage.

**Next step:** Review and implement as business as usual.

Reduced time and resource need for users and the assessors. Faster turn-around times as large meeting/discussion not required. for approval. Expected to be more resilient than paper based systems and will allow real time updates/allow greater visibility of requests

### Power BI dashboard to track team workload

**Progress:** Power BI dashboard designed for both the Network and Transformation Teams so they can track their progress against targets.

**Next steps:** Monitor and update spreadsheet or dashboard as needed.

Easy to use the visual output to filter to specifics, everything sits on teams/sharepoint so is very accessible.



Data & Information





# Network Priorities 2023/24

# Network Priorities 2023/24



Continuous Improvement



Engagement with stakeholders

## Objective



### Establish Network's Horizon Scanning process

## Progress/Next steps



**Progress:** Scoping for horizon scanning requirements has taken place to include lead clinicians and genomic laboratories.

**Next Steps:** Service mapping to identify what is available, priority level categories to be determined, framework defined, membership established.

## Benefits



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

### Expensive Send Away Test process

**Progress:** The process is currently being discussed between the NSD Commissioning Team and the SSNGM team. The framework is being examined by the network's Scientific Lead and Clinical Lead for any revisions to the guidelines.

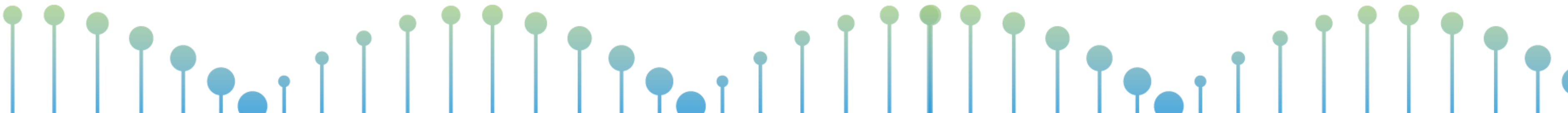
**Next steps:** Agree the framework and supporting material required to launch new process.

Streamlined process supporting the equity of care for the patients of Scotland.

### Communication channels established and in place

Stakeholder engagement plan has been developed and is under evaluation to ensure we deliver on the communication plan.

Deliver appropriate communication in a timely manner to stakeholders. Encourage engagement, discussion and input.



# Network Priorities 2023/24



Engagement with stakeholders



Education, Training, & Workforce

**Objective**

**Progress/Next steps**

**Benefits**

## Establish Patient Panel

**Progress:** Scoping work underway with a range of stakeholders who have experience in large scale public engagement activity.  
**Next steps:** Patient Panel initiated.

Ensure that patients and people with lived experience have more involvement over the services provided by our genomic services.

## Education resources clearly signposted

Following the website's launch, education will have its own tab.

Encouraging the use of new learning approaches, wider circulation of good quality educational resources and creating possibilities for learning.

## Forums for peer support provided for CPD

Following the website's launch, work will begin.

Provide an access to the learning tools, creating possibilities for learning, mental support.

## Workplan has education/workforce activities

**Progress:** The workplan will be based on the already established Theme and Network KPIs.  
**Next steps:** Create a work plan by 31 May.

Work plan lays out a clear path for team to follow in order to achieve the desired goals and objectives, as well as to manage expectations.





# Communication and Engagement



# Communication and Engagement

The SSNGM acts as a front door for engagement with clinicians, academics, industry, pharma and many others to deliver on 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.

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

## Educational Conference

The SSNGM team is collaborating closely with [Precision Medicine](#) in preparation for a joint event on [September 28th, 2023](#), where the network will carry out further targeted stakeholder engagement.

## Newsletters

The SSNGM has received great engagement with the network newsletter averaging [141 in depth 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.

## Website and social media

The SSNGM network website is nearing completion and will be available on or before June 11, 2023. The website address: [www.genomics.nhs.scot](http://www.genomics.nhs.scot). Updates will be provided via the [@NMDNScot](#) twitter account.

## Meetings



# The NSD Team

The Network Programme and transformation Teams comprises of:



**Janis Heaney**  
Associate Director



**Nicola Williams**  
Consultant Clinical Scientist



**Dr Patricia Roxburgh**  
Lead Clinician



**Dr Jonathan Berg**  
Lead Clinician



**Nelson Grant**  
Portfolio Manager



**Gillian McCarrol**  
Portfolio Manager



**Alija Mustafa**  
Programme Manager



**Nicole Carson**  
Assistant Programme Manager



**Kelly Maxwell-Brown**  
Senior Data Analyst