



# **National Strategy for Accelerating Genetic and Genomic Medicine in Ireland**

## **Strategy Implementation Plan for 2023**

April 2023

## 1. Introduction: Background and Context

### 1.1 Background and Context

In May 2022, the Strategic Programmes Office, Office of the Chief Clinical Officer within the HSE commenced work on the development of a National Genetics and Genomics Strategy for Ireland<sup>1</sup> in collaboration with the Department of Health (DoH). A National Genetics and Genomics Strategy Steering Group and four Working Groups were established to drive the collaborative and inclusive development of Ireland's first National Strategy for Genetics and Genomics. Over 100 experts, a number of patient representatives, patient advocates, the DoH, and other key stakeholders contributed to the work with patient and public involvement at the heart of the strategy's co-creation. The [National Strategy for Accelerating Genetic and Genomic Medicine in Ireland](#) was published in December 2022.

In alignment with Sláintecare, this National Strategy outlines our approach for developing a sustainable patient and family centred genetics and genomics service that can be accessed equitably across the country and across the lifespan of patients. The service is to be supported by strong governance, a skilled workforce, pioneering research and innovation, and trusted partnerships.

The development and implementation of the National Strategy will take place over the next five years and beyond. This implementation plan for the National Strategy is based on ten priority deliverables to be achieved in 2023 as outlined in section 3.1 of this plan. The thirteen **strategic areas of focus** of the strategy outline the way forward for genetic and genomic services in Ireland over this five year timeframe and beyond, and these are mapped to the following five interconnected **priority themes**:

1. Coordinating a national approach to genetics and genomics,
2. Ensuring Patient and Public Involvement (PPI) and Partnerships,
3. Building the genetics and genomics workforce for the future,
4. Enhancing genetic and genomic clinical services, and
5. Strengthening infrastructures to drive advances in genetics and genomics.

In September 2022, the Minister for Health announced that €2.7 million in funding had been secured for the initial implementation phase of the National Strategy in 2023. This initial funding will be directed towards the provision of frontline resources and the establishment of the new National Office for Genetics and Genomics. Additions to the frontline workforce will include clinical geneticists, genetic counsellors, and genetic resource associates. Appendix 1, outlines the activities and outputs of the implementation plan for 2023.

### 2.1 Strategic Areas of Focus

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<sup>1</sup> Health Service Executive (2022). National Strategy for Accelerating Genetic and Genomic Medicine in Ireland. Retrieved from <http://bit.ly/3INQDHk>  
April 2023

Table 1. 13 Strategic areas of focus for the development of genetic and genomic services

Coordinating a national approach to genetics and genomics	1	A national office for genetics and genomics will be established in 2023 under the governance of the HSE and will provide oversight and a standardised approach to the delivery of the genetics and genomics service as outlined in the National Strategy for Accelerating Genetic and Genomic Medicine in Ireland.
	2	The Department of Health will engage with stakeholders across the clinical, academic, research, and non-profit sector to identify gaps in Irish policy and legislation. This engagement, in conjunction with wider public consultation, will be used to inform future legislative and policy action.
Ensuring Patient and Public Involvement (PPI) and partnerships	3	A national education and communication programme will be developed and implemented in 2023 to raise awareness of genetics and genomics and increase genetic and genomic literacy amongst patients and the public.
	4	Building and maintaining public trust and engagement will ensure sustainability and impact positively on service, research, and policy developments. Meaningful partnerships with the public will be established to ensure that the public and patient voice is at the heart of implementation of the strategy and in the design and development of any new services or initiatives.
	5	There will be a national approach to ensure that standardised guidance on consent for genetic and genomic clinical and research purposes is harmonised and developed in line with relevant guidelines and legislation.
Building the genetics and genomics workforce of the future	6	A National Genetics and Genomics Workforce Plan will be developed in 2023 to support the recruitment, retention, education, and career development of the current and future genetics and genomics workforce
Enhancing genetic and genomic clinical services	7	A suite of measures that ensure the delivery of safe, high-quality care will commence in 2023, and processes will be implemented to monitor performance against agreed targets to drive quality improvement.
	8	Locally integrated, multidisciplinary, patient and family centred care pathways will support the continued transition of genetics and genomics into mainstream healthcare by building on existing services, collaborative networks, and expertise to enhance service delivery in a manner that is efficient, equitable, and in accordance with the Sláintecare vision.
	9	Equitable, timely, and evidence-based availability of genetic and genomic tests and technologies in clinical practice will be improved through a coordinated and standardised national approach. The development of a National Test Directory will commence in 2023.
Strengthening infrastructure to drive advances in	10	The national office will work with services to enhance existing laboratory infrastructure and informatics services to promote the development and use of innovative technologies for testing, sample tracking, and reporting.

genetics and genomics	11	A National Centre of Excellence in Genomic Testing and Bioinformatics will be established as a single entity which will sit under the governance of the HSE.
	12	The national office will review existing genetic and genomic data capacity and capability and work toward the establishment of a secure, scalable, and accessible data and analytical infrastructure to support clinical service delivery, bioinformatics, data access, and research.
	13	Engagement, collaboration, and partnership with international organisations, industry, government, and academic partners will be key to enhancing Ireland's research ecosystems. Procedures, processes, and guidelines will be developed to support the translation of advances in genetics and genomics into current and future clinical practice

## 2. Vision and Guiding Principles

### 2.1 Vision for Genetics and Genomics

The vision for Irish genetics and genomics is to develop a patient and family centred service that aligns with the values of Sláintecare through its focus on equity of access and enhanced patient outcomes. This service will cover the patient lifespan and be available across the Regional Health Areas (RHAs). It will be supported by strong governance, a skilled workforce, innovative research, and trusted partnerships. The development of this strategy and its implementation over the next five years, and beyond, is a key step in delivering this vision.

### 2.2. Guiding Principles

The National Strategy is underpinned by eight key principles which will be the focus of the work throughout the implementation phase:

- **Patient and family centred:** Services will be delivered in an integrated patient and family centred manner.
- **Responsiveness:** Given the speed at which the fields of genetics and genomics are progressing, we will remain agile and adaptable to advances in scientific knowledge and tools and their clinical and research application.
- **Ethically grounded:** The use of personal data will meet the highest ethical principles for clinical practice and research and reflect the voice of the citizens of Ireland.
- **Trusted:** Effective governance will ensure that genetic and genomic clinical services and research are delivered in a manner that fosters trust and builds public and patient confidence in genetic and genomic medicine.
- **Empowering:** Patients and their families will be empowered to make informed decisions about the use of genetic and genomic tests and health data in the delivery of their care.
- **Inclusive and accessible:** Clinical genetics and genomics and research will be equitable, inclusive, accessible, responsive, and respectful of diversity in society.

- **Evidence-based and cost-effective:** The translation of advances in genetics and genomics into healthcare services will be evidence-based and in the best interest of our patients, while remaining cost-effective and reducing waste.
- **Collaborative:** To advance knowledge and fuel innovation in genetics and genomics, we will work collaboratively, both nationally and internationally for the benefit of patients.

### 3. Genetics and Genomics Strategy Implementation Plan Development

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#### 3.1 Genetics and Genomics Implementation Taskforce

A time-limited taskforce was established from January to February 2023 to contribute to the development of an implementation plan and roadmap to achieve 10 priority deliverables for 2023, these include;

1. Development and agreement of the implementation plan and governance structures;
2. Establishment of an Implementation Steering Group for Genetics and Genomics to lead and drive the implementation of the National Strategy;
3. Establishment of a National Office for Genetics and Genomics and manage the recruitment of associated roles;
4. Manage the recruitment for frontline workforce roles, funded through the 2023 estimates process;
5. Development of a targeted communications programme to improve public and patient literacy;
6. Continue to collaborate internationally through participation in the 1+Million Genome (1+MG) European project;
7. Participate in the Genomic Data Infrastructure (GDI) project;
8. Development of a National Genetic and Genomic Workforce Plan;
9. Development of a National Test Directory for Genetics and Genomics;
10. Review of existing genetic and genomic data capacity and capabilities.

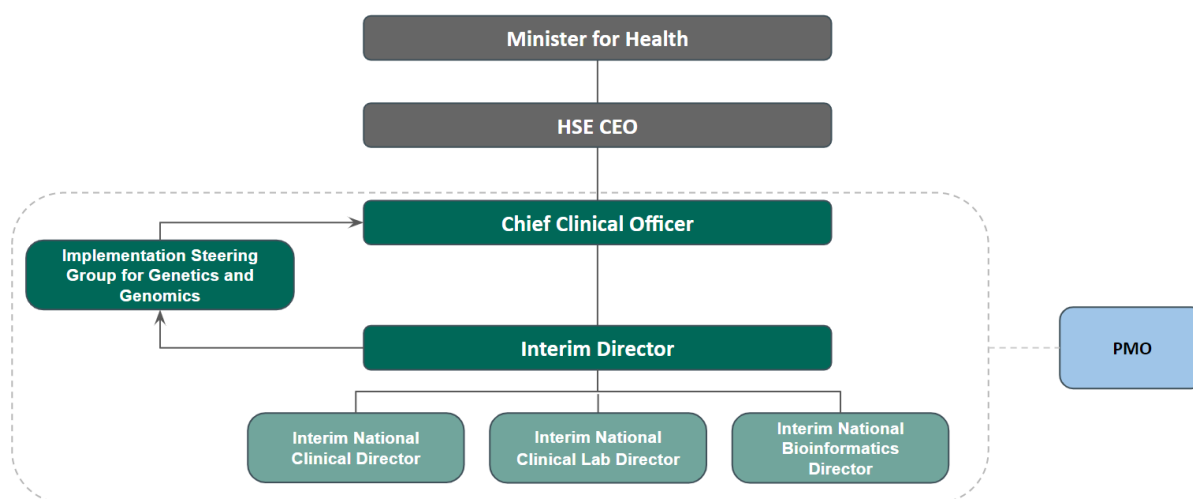
There are three main outputs of this implementation planning phase; 1) development of a governance structure that will see the establishment of an Implementation Steering Group for Genetics and Genomics to ensure a solid foundation for progressing implementation within the strategy lifecycle, while working towards the achievement of the longer term vision; 2) establishment of defined Workstreams to progress the 10 priority deliverables in 2023, and 3) development of an implementation plan that will support the delivery of the National Strategy in 2023.

#### 3.2 Implementation Steering Group for Genetics and Genomics

A governance structure is required to ensure a solid foundation for progressing implementation within the strategy lifecycle, while working towards the achievement of the longer term vision. To achieve this vision, an Implementation Steering Group for Genetics and Genomics has now been established. Their role is to lead and drive forward the implementation of the National Strategy for Accelerating Genetic and Genomic Medicine in Ireland as per the implementation plan. The group

will provide leadership and oversight to the implementation activities as well as monitor and report on the progress of the implementation plan. Figure 1., illustrates the Strategy Implementation Governance Structure.

Figure 1. Strategy Implementation Governance



## 4. Overview of Workstreams for 2023

To progress the work to achieve the 10 priority deliverables for 2023, the Implementation Plan Taskforce identified four main Workstreams, each aligning to a strategic area of focus. The priority activities and outputs for each Workstream are further detailed in section 5.

### 4.1 Workstream 1: Genetics and Genomics Operating Model

Strategic area of focus: *Coordinating a national approach to genetics and genomics and building the genetic and genomic workforce for the future.*

This Workstream involves the establishment of the National Office for Genetics and Genomics and how it will operate to improve coordination of genetics and genomics in Ireland. The initial priority is to recruit interim roles and key staff within the National Office. They will work with HSE leads to recruit the additional frontline clinical staff funded in the 2023 National Service Planning process. The Workstream will also progress genetic and genomic coordination activities including a clinical education and engagement programme, a multidisciplinary workforce plan, and the scoping of laboratory infrastructure requirements, accreditation and regulation.

### 4.2 Workstream 2: Communications and Stakeholder Engagement

Strategic area of focus: *Ensuring Patient and Public Involvement (PPI) and Partnerships.*

This Workstream will have close engagement with patients, patient advocacy groups, the healthcare workforce and the wider public. To ensure PPI is embedded throughout the implementation, it will establish patient representation within the National Office and across each Workstream. A key output is the development of a Communications Programme to guide further communications, engagement and PPI activities. The Workstream will also ensure appropriate links with other initiatives in Ireland and internationally.

### 4.3 Workstream 3: Testing Guidance and Directory

Strategic area of focus: *Enhancing genetic and genomic clinical services.*

This Workstream will enhance genetic and genomic clinical services through the development of national genetic and genomic testing guidance, test directory methodologies and governance, in line with international best practice.

### 4.4 Workstream 4: Data and Bioinformatics

Strategic area of focus: *Strengthening infrastructure to drive advances in genetics and genomics.*

This Workstream will strengthen genetic and genomic data and bioinformatic infrastructures through international engagement and development of a national genetic and genomic data and technology roadmap.

## 5. Priority Activities and Outputs for Implementation in 2023

The four identified Workstreams will be tasked with the following core activities and outputs for 2023. As the work progresses, sub-groups will be assigned to progress the work. Table 2-5 below outline the priority activities and outputs for implementation in 2023.

### 5.1 Workstream 1: Genetics and Genomics Operating Model

*Table 2. Genetics and Genomics Operating Model Workstream - Core Activities and Outputs*

No.	Activities	Due (2023)
1.	Progress recruitment activities for posts funded through the 2023 National Service Planning which include frontline staff and key roles for National Office for Genetics and Genomics	Q1
2.	Scope laboratory infrastructure requirements, accreditation and regulation	Q2
3.	Progress multidisciplinary workforce plan informed by the model of care and recruitment approach	Q2-Q4
Outputs		

1.	Develop an operating model of how genetic and genomic services will be delivered in Ireland	Q2
2.	National Office established	Q2
3.	Commence education and engagement programme to improve genetic and genomic literacy for healthcare workers	Q2
4.	Key roles in post i.e. National Office roles, Genomic Resource Associate, Clinical Geneticists, Genetic Counsellors and all frontline workforce roles funded in NSD 2023 recruited	Q3
5.	Workforce plan published	Q4

## 5.2 Workstream 2: Communication and Stakeholder Engagement

*Table 3. Communications and Stakeholder Engagement Workstream - Core Activities and Outputs*

No.	Activities	Due (2023)
1.	Establish patient representation on the ISG and across all workstreams	Q1-Q4
2.	Collaborate with other communication programmes for patients and citizens e.g. IPPOSI	Q1-Q4
3.	Collaborate with 1+ Million Genomes Initiative and other appropriate international networks	Q1-Q4
4.	Communicate with stakeholders including public, patients and healthcare workers	Q1-Q4
5.	Develop a communications programme to guide further communications, engagement and PPI activities	Q2
Outputs		
1.	Strengthened approach to communications, stakeholder engagement and PPI activities	Q1-Q4
2.	Communications programme for 2023 delivered	Q4



### 5.3 Workstream 3: Testing Guidance and Directory Workstream

*Table 4. Testing Guidance and Directory Workstream - Core Activities and Outputs*

No.	Activities	Due (2023)
1.	Collaborate with the Irish National Accreditation Board (INAB) to support and streamline accreditation processes	Q2
2.	Develop a comprehensive national test directory methodology	Q3
3.	Develop national genetic and genomic testing guidance in line with international best practice	Q3
4.	Establish governance processes for regular reviewing and updating of the test directory	Q2-Q3
5.	Collaborate with patient representatives and advocacy groups to inform the development of testing guidance and the national test directory	Q2-Q4
Outputs		
1.	Existing genetic and genomic lab capacity baselined	Q2
2.	Genetic testing guidance published	Q3
3.	National test directory methodology and process developed, agreed and published	Q4
4.	National test directory progressed according to published methodology and process	Q4

### 5.4 Workstream 4: Data and Bioinformatics

*Table 5. Data and Bioinformatics Workstreams - Core Activities and Outputs*

No.	Activities	Due (2023)
1.	Participate in the Genomic Data Infrastructure (GDI) steering committee	Q1-Q4
2.	Collate international examples of genetic and genomic data and technology infrastructures	Q2
Outputs		
1.	National genetic and genomic data and technology roadmap developed	Q4
2.	Engage with the GDI Steering Group to inform scope and capabilities to be developed (e.g. technology, data infrastructure, data sharing, research etc.)	Q4

## 6. Conclusion and Next Steps

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The activities to achieve the 10 priority deliverables for 2023 have already commenced with the appointment of the Interim Director for the National Office for Genetics and Genomics, establishment of the Implementation Steering Group for Genetics and Genomics and progression of recruitment activities for Interim roles covering clinical, laboratory and bioinformatics. They will form the initial core of the National Office for Genetics and Genomics as well as being responsible for mobilisation of the four Workstreams.

Appendix 1., outlines the activities and outputs for 2023 to successfully implement the National Strategy for Accelerating Genetic and Genomic Medicine in Ireland. To ensure transparency and open channels of communication, the Interim Director will provide sufficient updates to the Implementation Steering Group for Genetics and Genomics on the progress of work from the four Workstreams and associated sub-groups. Regular updates will be provided to the HSE Executive Management Team and HSE Board on the progress of key activities and deliverables on a monthly basis, or as requested. The Communications Programme will also outline the required Patient and Public Involvement (PPI) activities to ensure patients, patient advocates, the public and the healthcare workforce are regularly updated on the progress of strategy implementation as well as providing an opportunity for these key stakeholders to engage in the implementation process. These activities will be communicated via the Communications and Stakeholder Engagement Workstream.

## Appendix.1., National Strategy for Accelerating Genetic and Genomic Medicine in Ireland: Implementation Plan - Activities and Outputs for 2023

Workstream	Strategic Area of Focus	No.	Specific Output/Activity	Lead Responsible	Due (2023)
Genetics and Genomics Operating Model	Coordinating a national approach to genetics and genomics and building the genetics and genomics workforce for the future	1.1	<b>Output:</b> Develop an operating model of how genetic and genomic services will be delivered in Ireland, addressing key elements including an overview of services organisation design, and location and interaction model between key stakeholders	Interim Director/ Interim Clinical Director/ Interim Clinical Laboratory Director	Q2
		1.1.1	<b>Activity:</b> Collate and benchmark against international operating models	Interim Director	Q2
		1.1.2	<b>Activity:</b> Collaborate with patient representatives and advocacy groups to identify how Patient and Public Involvement (PPI) can be incorporated into the Genetics and Genomics Operating Model workstream	Interim Director	Q1-Q4
		1.1.3	<b>Activity:</b> Engage with the public, patient representatives and advocacy groups to help identify the needs to be prioritised for service users and their families (e.g. understanding the service users' experience of accessing genetic and genomic services).	Interim Director	Q1-Q4
		1.2	<b>Activity:</b> Progress multidisciplinary workforce plan informed by the model of care and recruitment approach	Interim Director	Q2-Q4
		1.2.1	<b>Activity:</b> Decide on approach to developing a workforce plan	Interim Director	Q1
		1.2.2	<b>Activity:</b> Commence development of an education and engagement programme to improve genetic and genomic literacy for healthcare worker	Interim Director	Q2
		1.2.3	<b>Activity:</b> Establish working group with board representation from national programmes and representation from the genetics and genomics workforce	Interim Director	Q2

		1.2.4	<b>Activity:</b> Final review and sign off of the document by the working group, ISG, CCO and EMT	Interim Director/Chief Clinical Officer	Q3
		1.2.5	<b>Activity:</b> Finalise document based on any feedback from review and sign off process	Interim Director	Q3
		1.2.6	<b>Output:</b> Education and engagement programme developed	Interim Clinical Director	Q3
		1.2.7	<b>Output:</b> Workforce plan published	Interim Director	Q4
		1.3	<sup>2</sup> <b>Activity:</b> Progress recruitment activities for posts funded through 2023 national service planning	Programme Manager	Q1
		1.3.1	<b>Activity:</b> Hiring of Interim Director, Interim National Clinical Director, Interim National Clinical Laboratory Director and Interim National Bioinformatics Director	Programme Manager	Q1-Q2
		1.3.2	<b>Activity:</b> Hiring of the Grade VI Communications Officer, General Manager, Programme Manager, Grade VI Research Analyst and Grade VI Business Coordinator	Programme Manager	Q1-Q2
		1.3.3	<b>Activity:</b> Hiring of permanent National Director, National Clinical Director, National Clinical Laboratory Director and National Bioinformatics Director	Programme Manager	Q4
		1.3.4	<b>Activity:</b> Hiring of Clinical Service Development Manager (GM Grade)	Programme Manager	Q3

<sup>2</sup> To note, the activities outlined in 1.3.1 to 1.3.4 of the Genetics and Genomics Strategy Implementation Plan, will include the following recruitment activities;

1. HSE internal processes required to advertise the associated role;
2. advertisement, interview and recruitment of the associated role and;
3. the individual commencing in their associated role.

		1.3.5	<b>Output:</b> Interim National Office established	Programme Manager	Q2
		1.3.6	<b>Activity:</b> Hiring of Genomic Resource Associate	National Programmes/Interim National Office/Hospital site	Q1-Q3
		1.3.7	<b>Activity:</b> Hiring of Clinical Geneticist, approval and sign off of Clinical Geneticist location and job description	National Programmes/Interim National Office/Hospital site	Q2-Q3
		1.3.7.1	<b>Activity:</b> Advertise, interview and extend offers for Clinical Geneticists role	Hospital site/National Recruitment Service	Q3
		1.3.8	<b>Activity:</b> Hiring of Genetic Counsellors, agree location for the six Genetic Counsellor posts and develop job descriptions for Genetic Counsellor roles	National Programmes/Interim National Office/Hospital site	Q1-Q3
		1.3.8.1	<b>Activity:</b> Advertise, interview and extend offers for genetic counsellor roles	Hospital site	Q3
		1.4	<b>Activity:</b> Scope lab infrastructure requirements, accreditation and regulation	Interim National Clinical Lab Director	Q2
		1.4.1	<b>Activity:</b> Collate information gathered on test directories during the strategy development process	Interim National Clinical Lab Director	Q2

		1.4.2	<b>Activity:</b> Final review and sign off of the Laboratory report by the Implementation Steering Group for Genetics and Genomics	Interim National Clinical Lab Director	Q4
		1.4.3	<b>Output:</b> Laboratory infrastructure report developed	Interim National Clinical Lab Director	Q3
		1.5	<b>Output:</b> Key roles in place - National Office roles, Genomic Resource Associate, Clinical Geneticists, Genetic Counsellors and all frontline workforce roles funded in NSP 2023 recruited	Programme Manager	Q3
Communications and Stakeholder Engagement	Ensuring Patient and Public Involvement (PPI) and partnerships	2.1	<b>Activity:</b> Establish patient representation on the Implementation Steering Group for Genetics and Genomics and across all Workstreams	Interim Director	Q1
		2.1.1	<b>Activity:</b> Collaborate with patient representatives and advocacy groups to identify how Patient and Public Involvement (PPI) can be incorporated into the Communications and Stakeholder Engagement Workstream	Interim Director	Q1-Q4
		2.1.2	<b>Activity:</b> Engage with the public, patient representatives and advocacy groups to help identify the needs to be prioritised for service users and their families (e.g. patient and public awareness of and literacy in genetics and genomics).	Interim Director	Q1-Q4
		2.2	<b>Activity:</b> Develop a communications programme building on the strategy	Interim Director	Q2
		2.2.1	<b>Activity:</b> Establish communications working group	General Manager	Q1
		2.2.2	<b>Output:</b> Communications programme for 2023 delivered	General Manager	Q4
		2.2.3	<b>Output:</b> Strengthened approach to communications, stakeholder engagement and PPI activities	General Manager	Q1-Q4

		2.3	<b>Activity:</b> Collaborate with other communication programmes for patients and citizens e.g. IPPOSI	Interim Director	Q1-Q4
		2.3.1	<b>Activity:</b> Ongoing collaboration with IPPOSI meetings to support knowledge sharing and avoid duplication of efforts	Interim Director	Q1-Q4
		2.3.2	<b>Activity:</b> Ongoing collaboration with other educational programmes as appropriate	Interim Director	Q1-Q4
		2.4	<b>Activity:</b> Collaborate with 1+ Million Genomes Initiative and other appropriate international networks	Interim Director	Q1-Q4
		2.4.1	<b>Activity:</b> Attendance and contributions to the National Mirror Group convened by the DOH to identify which workstreams Ireland is going to join under the 1+MG genome project	Interim Director	Q1-Q4
		2.4.2	<b>Activity:</b> Ensure engagement and input from Ireland into agreed 1+ Million Genomes Initiative' workstreams as appropriate	Interim Director	Q1-Q4
		2.5	<b>Activity:</b> Communicate with stakeholders including public, patients and healthcare workers	Interim Director	Q1-Q4
Testing Guidance and Directory	Enhancing genetic and genomic clinical services	3.1	<b>Activity:</b> Collaborate with patient representatives and advocacy groups to inform the development of testing guidance and the national test directory	Interim National Clinical Lab Director	Q2-Q4
		3.1.1	<b>Activity:</b> Collaborate with patient representatives and advocacy groups to identify how Patient and Public Involvement (PPI) can be incorporated into the Testing Guidance and Directory Workstream	Interim National Clinical Lab Director	Q1-Q4
		3.1.2	<b>Activity:</b> Engage with the public, patient representatives and advocacy groups to help identify the needs to be prioritised for service users and their families (e.g. approach to consent process, accessibility and use of patient health data etc.).	Interim National Clinical Lab Director	Q1-Q4

		3.2	<b>Activity:</b> Collaborate with INAB to support and streamline accreditation processes	Interim National Clinical Lab Director	Q2-Q4
		3.3	<b>Output:</b> Existing genetic and genomic lab capacity baselined	Interim National Clinical Lab Director	Q2
		3.4	<b>Activity:</b> Develop national genetic and genomic testing guidance in line with international best practice	Interim National Clinical Lab Director	Q3
		3.4.1	<b>Activity:</b> Establish a Genetic Testing Guidance/Handbook development group comprising of a diagnostic laboratory technician, a clinical geneticists and a non genetic specialist clinician	Interim National Clinical Lab Director	Q2
		3.4.2	<b>Activity:</b> Carry out review of international approaches to genetic testing guidance	Interim National Clinical Lab Director	Q2
		3.4.3	<b>Activity:</b> Draft Genetic Testing Guidance/Handbook	Interim National Clinical Lab Director	Q2
		3.4.4	<b>Activity:</b> Final review and sign off of the Testing Guidance/ Handbook by the working group, ISG and EMT	Interim National Clinical Lab Director	Q2-Q3
		3.4.5	<b>Output:</b> Genetic testing guidance published	Interim National Clinical Lab Director	Q3
		3.5	<b>Activity:</b> Develop a comprehensive national test directory methodology	Interim National Clinical Lab Director	Q3



		3.5.1	<b>Activity:</b> Establish a national directory sub group in consultation with NCCP, NRDO, NWIHP and laboratory diagnostics	Interim National Clinical Lab Director	Q2
		3.5.2	<b>Activity:</b> Agree a standardised template for the fields of the national test directory	Interim National Clinical Lab Director	Q2
		3.5.3	<b>Activity:</b> Identify and prioritise specialties for agreement of tests to be included	Interim National Clinical Lab Director	Q2
		3.5.4	<b>Output:</b> National test directory methodology and process developed, agreed and published	Interim National Clinical Lab Director	Q3-Q4
		3.5.5	<b>Output:</b> National test directory progressed according to published methodology and process	Interim National Clinical Lab Director	Q4
		3.6	<b>Activity:</b> Establish governance processes for regular reviewing and updating of the test directory	Interim National Clinical Lab Director	Q2-Q3
		3.6.1	<b>Activity:</b> Develop a standardised evaluation framework for new genetic and genomic tests	Interim National Clinical Lab Director	Q2-Q3
		3.6.2	<b>Activity:</b> Develop a standardised process for review of existing test directory content	Interim National Clinical Lab Director	Q2-Q3
		3.7	<b>Activity:</b> Prioritise other areas for national test directory development	Interim National Clinical Lab Director	Q2

Data and Bioinformatics	Strengthening infrastructures to drive advances in genetics and genomics	4.1	<b>Activity:</b> Participate in the GDI steering committee	Interim National Bioinformatics Director	Q1-Q4
		4.2	<b>Activity:</b> Collate international examples of genetic and genomic data and technology infrastructures	Interim National Bioinformatics Director	Q2
		4.3	<b>Output:</b> National genetic and genomic data and technology roadmap developed	Interim National Bioinformatics Director	Q4
		4.3.1	<b>Activity:</b> Collaborate with patient representatives and advocacy groups to identify how Patient and Public Involvement (PPI) can be incorporated into the data and bioinformatics workflow	Interim National Bioinformatics Director	Q1-Q4
		4.3.2	<b>Activity:</b> Engage with the public, patient representatives and advocacy groups to help identify the needs to be prioritised for service users and their families (e.g. approach to consent process, accessibility and use of patient health data etc.)	Interim National Bioinformatics Director	Q1-Q4
		4.3.3	<b>Activity:</b> Collaborate with the office of the HSE Chief Information Officer (CIO), identifying opportunities for the integration of genetic and genomic data with existing systems (e.g. disease registries, EHRs etc.)	Interim National Bioinformatics Director	Q2-Q4
		4.3.4	<b>Activity:</b> Engage with NCCP, NSS, NWIHP and NRDO and other clinical programmes to inform data and technology roadmap development	Interim National Bioinformatics Director	Q2-Q4
		4.3.5	<b>Output:</b> Engage with the GDI Steering Group to inform scope and capabilities to be developed (e.g. technology, data infrastructure, data sharing, research etc.)	Interim National Bioinformatics Director	Q2-Q4
		4.3.6	<b>Activity:</b> Final review and sign off by the Implementation Steering Group for Genetics and Genomics	Interim National Bioinformatics Director	Q3-Q4

		4.3.7	<b>Activity:</b> Finalise genetic and genomic data and technology roadmap	Interim National Bioinformatics Director	Q3-Q4
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