



National Genetics and Genomics Implementation Steering Group

APPROVED MINUTES/ACTIONS

Meeting Details:

Date:	10 July 2024
Location:	MS Teams
Time:	11:30am-13:00pm
Chair:	Prof Ristéard Ó Laoide
Members:	See Appendix A

Agenda Items:

Item	Discussion
1	<p><u>Welcome, Apologies, Review of Actions and Minutes</u></p> <p><i>Welcome:</i> Prof Ristéard ÓLaoide (National Director, NCCP) welcomed members to the Genetics and Genomics Implementation Steering Group and advised that the CCO had requested him to chair the meeting.</p> <p><i>Apologies:</i> Dr Colm Henry, Dr Emma McCann, Mr John O'Neill, Prof Eileen Treacy, Dr Philippa Ryan Withero, Ms Martina Burns and Ms Marie Culliton</p> <ul style="list-style-type: none"> The meeting was quorate. The quorum for meetings of the ISG is outlined in Appendix A. <p>Review of Actions: Actions from the previous meeting were reviewed. Ms Helen Shortt informed the meeting of two changes to membership of the ISG, Ms Eilish Hardiman, Strategic Programme Director for CHI replacing the CHI Chief Executive Ms Grace Rothwell, Interim National Director, Access & Integration replacing Prof. Mary Day, National Director, Acute Operations.</p> <p>In response to a question from the Chair, Ms Shortt confirmed the Terms of Reference were finalised.</p> <p>Review of Minutes: The minutes of the last ISG meeting for the Genetics and Genomics Implementation Programme on the 15 of May 2024 were approved.</p>
2	<p>Programme Update</p> <p>Ms Helen Shortt presented the 2024 Priority Deliverables Status Report</p> <ul style="list-style-type: none"> Deliverable No 1: NGGO is progressing with the Test Directory. Dr Richard Hagan advised a draft document will be completed by the end of Q4 and noted feedback from the specialties has been positive. Dr Hagan thanked Ms Hardiman for her offer of support in regard to input from specialties and will contact her if support is required. Deliverable No. 2: Ms Shortt advised the NDTP is reviewing the Clinical Genetics Workforce 2019 document and the date for completion of the review will be advised at the next ISG meeting. The Genetic Counsellor working group is developing a business case for Genetic Counsellor grade codes and a proposed pay structure. A strategic workforce plan will be completed through ongoing service development planning including assessing requirements for phases 1 & 2 of developing laboratory capacity and the output of clinical service design. A consultation will take place on clinical service design with input being sought from service users via the Communications and PPI Working Group and other stakeholders. <p>Engagement has commenced with the Department of Health (DoH) on the Estimates process.</p> <p>In response to Prof ÓLaoide's request that the NGGO link with other programmes, NCCP and NWIHP, as part of the estimates process, Ms Shortt advised that engagement has taken place, and agreement has been reached on principles for how future Genetic Counsellor posts will work.</p> <p>In response to Ms Hardiman's question on NGGO engagement with the new Regional Executive Officers on service planning, Ms Shortt advised that NGGO will engage with the Regional Executive Officers when a more structured plan has been developed and discussed with the DoH.</p>

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	<ul style="list-style-type: none"> • Deliverable No. 4: Ms Shortt advised a meeting took place with the DoH in June. The vision for the National Genomics Medical Centre (NGMC) that includes clinical, laboratory and bioinformatics services was discussed. Engagement between NGGO and DoH is ongoing as part of the annual service planning process. • Deliverable no. 5: The NGGO currently does not have a director of bioinformatics, and this is a challenge for the completion of Deliverable 5. Ms Shortt advised that she is engaging with St James Hospital regarding a secondment to a full-time post and will provide an update at the next ISG meeting. • Deliverable No. 6: Ms Shortt advised the NGGO participates in the 1+MG Working Groups. NGGO will continue to support the GOI and GDI infrastructure projects as required. <p>Ms Hardiman queried the RAG status of priority deliverable 5, 4 and 2 and if the ISG members could support the NGGO in managing the associated challenges. Ms Shortt advised Dr Colm Henry approved the secondment of a Bioinformatics Director on a full-time basis and, once in place, a Bioinformatics director will support Deliverable 5.</p> <p>Priority deliverables 4 & 2 are progressing however, the development of a workforce plan requires input from the laboratory capacity and clinical service design workstreams. The Genetic Counsellor working group is continuing to develop a business case for grade codes. Ms Shortt advised that the NGGO will continue to work with the DoH and REOs on proposals for developments in 2025.</p> <p>Ms Cuddigan highlighted the positive meeting with Dr Colm Henry and the PPI group in July, and requested information on what are important wins for priority deliverable no. 2, and how this will be communicated.</p> <p>In response to requests from Ms Hardiman and Ms Cuddigan for information and timelines for key deliverables 2,4, and 5, Ms Shortt agreed to provide this information at the next ISG meeting.</p> <ul style="list-style-type: none"> • Recruitment – Frontline Posts, Ms Shortt advised in May 2024, 5 frontline posts were confirmed to proceed to recruit, and notification was sent to REOs. Children's Health Ireland (CHI) will recruit for the services in the South & Mid-West regions. Dr Emma McCann is engaging with Beaumont Hospital on governance for the Senior Genetic Counsellor post. • Risk Log, Ms Shortt presented the 2 highest scoring risks on the Log. These two risks are in relation to the absence of a Bioinformatics Director and the corresponding challenge for the NGGO to deliver on that aspect of the Strategy. Ms Shortt recommended leaving the rate as currently stated until the post is filled. Ms Cuddigan requested the entire Risk Log be presented at the next ISG meeting. <p>Action: NGGO to provide information and timelines for key deliverables 2,4, and 5 at the next ISG meeting Action: NGGO to present the full Risk Log at the next ISG meeting.</p>
3	<p>Communications, Public and Patient Involvement, Ms Shortt presented an update on priority deliverable No 3,</p> <ul style="list-style-type: none"> • PPI Group: The Communications and PPI Working Group met in May and used a roundtable approach to identify key themes to support a more effective way of working. A further meeting is planned to agree actions and work plans. Dr Colm Henry met with PPI group in July and information on current NGGO plans was shared. The next Communications and PPI Working Group is scheduled for 10 September. • Amárach: the Amárach report was made available to the ISG for comment and will be circulated to the PPI group for feedback and to inform the work of the group. • Adelaide Health Foundation (AHF): A number of discussions have taken place between the NGGO and AHF in regard to the potential for a collaboration to develop an online education programme for healthcare staff with limited genomic literacy. • Education Courses: NGGO partnered with the RCSI to develop education material for staff and is now engaging with the HSE LanD development team on developing this into an online course to include some form of accreditation. <p>In response to Ms Hardiman's query on the sustainability of AHF funding, Ms Shortt advised discussions with AHF were at an early stage and further clarification on the potential output and funding was necessary prior</p>

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	<p>to proceeding.</p> <p>Ms Hardiman recommended including children and young people in consultations given the prevalence of rare diseases diagnosed and treated in this age cohort. Ms Hardiman acknowledged the PPI Group could deliberate on how this could be achieved.</p> <p>Prof ÓLaoide asked if the Amárach Report is freely accessible. Ms Shortt advised that it will be made available to the Communications and PPI Working Group and then it will become a part of the HSE library.</p> <p>Action: PPI Group to review participation of children and young people</p>
4	<p>1+MG project and the National Mirror Group update, Ms Aideen Dowling, DoH presented updates on the 1+MG,</p> <ul style="list-style-type: none"> • Update on Meetings <ul style="list-style-type: none"> Belgian Presidency Conference 28/29 May 2024: discussion on the converging tectonic technologies in future healthcare 1+MG Special Group 30 of May 2024: all member states attended 1+MG Irish Mirror Group 07 June 2024: Brussels meeting discussed the complexity of genomic landscape and how lessons can be learned due to the different points of members. The request from the Commission to draft a metro map on clarity of synergies to reduce duplication. Some Member States have drawn down funding from DGI, Technical Support Instruments (TSI). If the Commission approves the draft metro map, DoH could consider a development of an Irish metro map where it could support the link in with other Member States to benefit the Irish learning and lessons learned. DoH are working on the citizen outreach and the importance of this work. Ms Dowling presented a dialogue model highlighting government departments, experts, trade and industry and PPI in the center. It is important for continuous dialogue on how trust in Genomics is built. • 1+MG Working Group Changes, <ul style="list-style-type: none"> WG01: refocused to National Mirror Groups, it will focus on best practice for setting and running National Mirror Groups and governance. WG07: changed from Industrial involvement to new working group Healthcare Implementation. It will look at implementation of Genomic Medicine in healthcare, Citizen/Patients outreach, (literacy and communication). Network of policymakers, health authorities, and HCPS which will understand the challenges and promote genetic medicine and healthcare. WG10: Common and Complex Diseases will merge with old Working Group 12 Genome of Europe to form Population Genetics. Working together to choose aspects of Genome of Europe and the polygenic risk scores will be a significant development. WG12: Introduce new Working Group Pharmacogenetics, will bring together a network of scientists and healthcare professionals in harmonies efforts in testing and healthcare implementation trajectories. This working group will be important to the Genomic Data Infrastructure (GDI) regarding user scenarios, requirements and experience. <p>1+MG Key Outputs: Ms Dowling advised of the recommendations, guidelines, best practices in the areas of,</p> <ul style="list-style-type: none"> Data governance & ELSI Data models & quality Sequencing guidelines Technical infrastructure Genomics into healthcare Use cases National implementation <p>Ms Dowling advised it is a very useful resource for Member States to use for learning and best practices.</p> <ul style="list-style-type: none"> • Genome of Europe (GOE) <ul style="list-style-type: none"> In November 2023 DoH in collaboration with RCSI, who are leading out on Irelands Genome of Ireland (GOI) project submitted an application for Ireland's co-fund 50% to the European Commission. The European Commission approved the funding and GOI have now submitted an application to the Health Research Board (HRB) for the national balance of the fund. • Next 1+MG National Mirror Group & 1+MG Groups



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	<p>1+MG National Mirror Group will take place in September (date TBC) The 1+MG Group will take place with the GDI General Assembly in Lisbon from the 19-21 of November 2024</p> <p>Dr R Hagan enquired if the HRB gave a timeline for the process. Ms A Dowling, advised not presently but engagement is ongoing. Ms Dowling highlighted the decision is required by the end of July 2024.</p>
5	<p>Next Meeting Date & AOB</p> <p>Next meeting is to be held virtually on Wednesday 04 September at 11:30-13:00hrs via MS Teams.</p>

Appendix A – Members

Quorum	50% of members for discussions and recommendations	
Members In Attendance	Prof Risteárd Ó Laoide	NCCP, Director (Chair)
	Ms Helen Shortt	HSE, Assistant National Director, National Genetics and Genomics Office
	Dr Richard Hagan	HSE, Interim Clinical Laboratory Director, National Genetics and Genomics Office
	Dr Valerie Walshe	HSE, Economist, National Finance Division
	Ms Margaret Cuddigan	Patient Representative
	Prof Martin Cormican	HSE, National Clinical Lead Laboratory Services Reform
	Ms Aideen Dowling	DoH, Assistant Principal Officer, Research Policy
	Ms Ailish Kelly	DoH, Assistant Principal Officer, Research Policy
	Ms Avril Daly	Patient Representative
	Ms Eilish Hardiman	CHI, Strategic Programme Director
	Ms Eleanor Masterson	HSE, Chief Architectural Advisor, Estates
	Ms Catherine Clarke (attending for Ms Grace Rothwell)	HSE, Assistant National Director, Access & Integration
	Non-members In Attendance	Ms Christine Daly
Members Not In Attendance	Dr Colm Henry	HSE, Chief Clinical Office, Chair
	Dr Emma McCann	HSE, Interim Clinical Director, National Genetics and Genomics Office
	Mr John O'Neill	DoH, Principal Officer, Research Policy, and Innovation Unit
	Dr Cliona Murphy	HSE, National Clinical Director, National Women, and Infants Health Programme
	Prof Eileen Treacy	HSE, Clinical Lead, National Rare Disease Office
	Dr Philippa Ryan Withero	HSE, Assistant National Director, National HR Integrated Health Workforce Planning
	Ms Deidre McNamara	HSE, National Director, Strategic Programme Office
	Ms Martina Burns	HSE, Assistant National Director, Office of the Chief Information Officer
Ms Marie Culliton	HSE, Scientific Lead, National Clinical Programme for Pathology	
Ms Oonagh Ward	HRB, Head of Research and Innovation Infrastructures	



Description	Owner(s)	Date Raised	Action Date
NGGO to provide information and timelines for key deliverables 2,4, and 5 at the next ISG meeting	NGGO	10/07/2024	04/09/2024
NGGO to present the full Risk Log at the next ISG	NGGO	10/07/20/24	04/09/2024
PPI Group to review participation of children and young people.	NGGO	10/07/2024	04/09/2024