



National Genetics and Genomics Implementation Steering Group

APPROVED MINUTES/ACTIONS

Meeting Details:

Date:	14 February 2024
Location:	MS Teams
Time:	15:30 -16:30hrs
Chair:	Dr Colm Henry
Members:	See Appendix A

Agenda Items:

Item	Discussion
1	<p><u>Welcome, Apologies, Review of Actions and Minutes</u></p> <p><i>Welcome:</i> Dr Colm Henry (Chief Clinical Officer, Chair) welcomed the member to the National Genetics and Genomics Implementation Steering Group</p> <p><i>Apologies:</i> Dr Eppie Jones, Ms Deidre McNamara, Prof Mary Day, Ms Martina Burns, Prof Eilish Hardiman Ms Eleanor Masterson and Mr Christopher Ryan</p> <ul style="list-style-type: none"> The meeting was quorate. The quorum for meetings of the ISG is outlined in Appendix A. <p>The members confirmed approval for the amendments to the Terms of Reference on two new members, Prof Martin Cormican and Ms Avril Daly.</p> <p><i>Review of Actions:</i> Actions from the previous meeting were reviewed with updates against ongoing actions outlined in Appendix B.</p> <p>Review of Minutes: The minutes of the last ISG meeting on the 23 of November 2023 were approved.</p>
2	<p>Programme Update:</p> <p>Dr Mark Bale presented an update on the 2023 deliverables and the 6-deliverable focused for 2024. The draft 'Annual Implementation Report 2024' was circulated to the members in advance of the meeting. Dr Bale asked if anyone had any queries or requests for changes. Mr Muiris O'Connor requested an adjustment in the governance structure of the ISG as shown in the terms of reference, and (appendix of) Implementation report. Mr O'Connor suggested that the Department of Health sit between the CCO and the Minister for Health. Dr Henry and Dr Bale both agreed to this request.</p> <p>The ISG members approved the Annual Implementation Report 2024.</p> <p>Action FEB 01: NGGO to change the governance structure on the ISG TOR showing DoH sit between CCO and the Minister for Health.</p>
3	<p>Workforce Planning:</p> <p>Dr Emma McCann provided an overview of the Workforce Plan with the focus in the areas of</p> <ul style="list-style-type: none"> The Main Stream Workforce: The NGGO has commenced a set of Webinars and Master Classes that are due for completion in April 2024. NGGO has presented to colleges and will be engaging with them on future developments Workforce Planning: NGGO attended the recent DoH Workforce planning event in January. Dr Henry requested a timeline on the NGGO workforce planning and the 2025 estimates process. NGGO has commenced engagement with HSE Strategic Workforce Planning and Intelligence Unit. Dr Philippa Withero highlighted the need for sustainable plan into the future, which will take account of roles that are not in existence today and will be developed for the future with necessary professional development support Ms. Catherine Harvey advised NGGO are currently developing the 5-year workforce plan for completion this year. NGGO will proceed with the estimate process for 2025 based on the review of the current workforce and gaps within the service. Prof Risteárd ÓLaoide advised NCCP to assist in the estimates to ensure synergies with the programmes. He highlighted the lack of consultants. <p>Action Feb 02: NGGO to provide a draft timeline on the Workforce Plan</p> <ul style="list-style-type: none"> Specialised Genetics: NGGO's plan is to look at how we use this workforce to the maximum efficiency and provide them with the right tools to deliver in a cost-effective manner. The Specialised Genetics workforce will include doctors, nurses, pharmacists, HSCP's and other staff that work with Genomics patients.

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	<p>Genetic Councilors meet with NGGO, they provided information on their initial work, and NGGO will continue to engage with them</p> <p>The National Training Doctors Programme (NDTP) is to meet with NGGO on the current clinical genetics training scheme and how this can grow.</p> <p>Dr Henry raised a question on the shape of the product. Dr McCann advised based on her experience she would like a service delivered within the health regions with links with specialists to ensure genetics services are available across the country. This would ensure peer support and resilience within the service and the ability to deliver to the whole country.</p>
4	<p>Communications and Stakeholder Engagement</p> <p>Ms Aisling Cusack provided an update on the communications project started at the end of 2023. Amárach Research are currently holding focus groups and in-depth interviews over the next 2 / 3 weeks. The information obtained will then be analysed with Amárach delivering a report by the end of Q1. In Q2 NGGO will consider the recommendations provided through the research and in Q3/Q4 develop communications material to address any information gaps identified.</p>
5	<p>Testing Guidance and Directory</p> <p>Dr Richard Hagan presented the update on the Testing Guidance and Test Directory</p> <ul style="list-style-type: none"> • Testing Directory <p>Dr Hagan confirmed the title of the Test Directory, <i>National Genomic Test Directory for Rare and Inherited Disease</i></p> <p>Pilot Workshop with Renal took place in December 2023, with positive feedback received.</p> <p>3 larger specialty workshops to take place in February, with the clinical leads to then discuss within their network of colleagues and patient representatives and provide feedback. End of Q2: all information will be collated, and draft versions of the Test Directory for Rare and Inherited Disease, and the Testing Guidance Handbook will be developed</p> <p>NGGO are engaging with NHS England on mirroring their test directory.</p> <p>Dr Henry discussed the integration of the National Test Directory for Rare and Inherited Disease with NCCP cancer genetics test directory to ensure people are directed to the correct site and this will assist in the development of plans for repatriating tests. Prof ÓLaoide advised that NCCP used the NHS directory as a template and are engaging with the NGGO office. Dr Hagan informed him he is meeting with NCCP to discuss this matter further.</p> <p>Mr Muiris O'Connor requested that only one directory could be developed. Dr Hagan advised that the current outlook would be for both testing documents to be shown side by side on the one website Dr.McCann recommended for both documents to be alongside each and supported the NCCP development of the Cancer genetics test directory with NGGO support as they have the expertise in the clinical relevance of tests.</p> <p>Dr Henry highlighted the importance of the testing directory to patients and families. Ms Avril Daly commented on the information provided today and how important and relevant Dr McCann's overview was and the value of looking at both the need now and into the future.</p> • Testing Guidance <p>The Testing Guidance handbook is running parallel with the Testing Directory and a draft document will be developed by the end of Q2</p>
6	<p>Genomics Laboratory Capabilities</p> <p>Dr Richard Hagan presented an overview of the current laboratory capabilities.</p> <ul style="list-style-type: none"> ○ Deloitte report last year on model 4 hospitals on what testing and samples they do and send out ○ Significant gaps in much of the data received from hospitals on sample send outs. ○ The test directory will provide an assessment of tests/samples being requested ○ Clinical risk currently exists – possible that the most suitable tests and laboratories are not being selected ○ Crumlin provided comprehensive breakdown of their test data <p>Ms Marie Culliton advised the National Maternity Hospital completed a similar project and is happy to share the information with NGGO</p> <p>Ms Margaret Cuddigan acknowledged from a patient perspective it is great to see data starting to be used</p> <p>Action Feb03: Ms Marie Culliton to share data from the National maternity Hospital</p>
7	<p>1+MG Project and the National Mirror Group Update</p> <p>Ms Ailish Kelly provided an update on the 1+MG project. The topics covered included:</p> <ul style="list-style-type: none"> ○ Upcoming meetings for the 1+MG National mirror Group/ Genomic Data Infrastructure Europe – 1+MG Special Group ○ The new 1+MG Roadmap 2023-2027

Item	Discussion
	<ul style="list-style-type: none"> ○ A recent Genome of Europe funding application with a Genome of Ireland component ○ Proposed changes to the 1+MG Working Group structures <p>National Rare Disease Plan</p> <p>Mr Ciarán Murphy presented the National Rare Disease Plan, highlighting</p> <ul style="list-style-type: none"> ○ The Steering Group membership ○ Areas/themes for consideration ○ The preparatory work to date, including a HIQA review of international Rare Disease strategies covering 12 selected countries and Ireland. ○ An update on the progress since the 2014 / 2018 Plan which included recommendations on genetic testing ○ A new Rare Disease Patient Forum and representatives on the Steering Group ○ Next Steps <p>Ms Avril Daly and Prof ÓLaoide highlighted a greater recognition for the need for rare cancers and to consider it going forward with plans.</p>
8	<p>Next Meeting Date & AOB</p> <p>Ms A Daly advised she would report to the patients committee and provide them with a brief update and ensure there is an understanding of the topics discussed today, and both are moving in the same direction.</p> <p>Next meeting is to be held virtually on Wednesday 20 of March by MS Teams.</p>

Appendix A – Members	
Quorum	50% of members for discussions and recommendations
	Dr Colm Henry HSE, Chief Clinical Office, Chair
	Dr Mark Bale HSE, Interim Director, National Genetics and Genomics Office
	Dr Emma McCann HSE, Interim Clinical Director, National Genetics and Genomics Office
	Dr Richard Hagan HSE, Interim Clinical Laboratory Director, National Genetics and Genomics Office
	Ms Marie Culliton HSE, Scientific Lead, National Clinical Programme for Pathology
	Dr Valerie Walshe HSE, Economist, National Finance Division
	Ms Avril Daly Patient Representative
	Ms Margaret Cuddigan Patient Representative
	Prof Martin Cormican HSE, National Clinical Lead Laboratory Services Reform
	Dr Cliona Murphy HSE, National Clinical Director, National Women, and Infants Health Programme
	Prof Risteárd Ó Laoide NCCP, Director
	Prof Eileen Treacy HSE, Clinical Lead, National Rare Disease Office
	Ms Oonagh Ward HRB, Head of Research and Innovation Infrastructures
	Dr Philippa Ryan Withero HSE, Assistant National Director, National HR Integrated Health Workforce Planning
	Ms Ailish Kelly Department of Health, Assistant Principal Officer, Research Policy

Non-members In Attendance	Ms Catherine Harvey	HSE, Programme Manager, National Genetics and Genomics Office
	Ms Christine Daly	HSE, Business Coordinator, National Genetics and Genomics Office
	Ms Aisling Cusack	HSE, Communications Officer, National Genetics and Genomics Office
	Mr James Kelly	HSE, Data Analysis, National Genetics and Genomics Office
	Mr Ciarán Murphy	DoH, Assistant Principal Officer, Rare Disease Policy
	Ms Aideen Dowling	DoH, Assistant Principal Officer, Research Policy
	Mr Muiris O'Connor	DoH, Assistant Secretary, Head of research and Development and Health Analytics



	Mr Pat Mulhare	HSE, National Programme Manager, Laboratory Services Reform
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Apologies:	Dr Eppie Jones	HSE, Interim Bioinformatics Director, National Genetics and Genomics Office
	Ms Deidre McNamara	HSE, National Director, Strategic Programme Office
	Prof Mary Day	HSE, National Director, Acute Operations
	Ms Martina Burns	HSE, Assistant National Director, Office of the Chief Information Officer
	Prof Eilish Hardiman	CHI, Chief Executive Officer
	Ms Eleanor Masterson	HSE, Chief Architectural Advisor, Estates
	Mr Christopher Ryan	DoH, Head of Research Services and Policy

Appendix B – Ongoing / New Actions				
Action #	Description	Owner(s)	Date Raised	Action Date
FEB01	NGGO to change the anagram governance on the ISG TOR showing DoH sit between CCO and the Minster for Health.	NGGO	14/02/2024	20/03/2024
FEB02	NGGO to provide a draft timeline on the Workforce Plan to Dr Colm Henry	NGGO	14/02/2024	20/03/2024
FEB 03	Ms Marie Culliton to share data from the National maternity Hospital	Ms Marie Culliton	14/02/2024	20/03/2024