



## National Genetics and Genomics Implementation Steering Group

### APPROVED MINUTES/ACTIONS

#### Meeting Details:

<b>Date:</b>	15 May 2024
<b>Location:</b>	MS Teams
<b>Time:</b>	11:30-13:00hrs
<b>Chair:</b>	Dr Colm Henry
<b>Members:</b>	See Appendix A

#### Agenda Items:

Item	Discussion
1	<p><b><u>Welcome, Apologies, Review of Actions and Minutes</u></b></p> <p><i>Welcome:</i> Dr Colm Henry (Chief Clinical Officer, Chair) welcomed the members to the National Genetics and Genomics Implementation Steering Group meeting</p> <p><i>Apologies:</i> Dr Eppie Jones, Ms Deridre McNamara, Prof Mary Day, Ms Martina Burns, Prof Eilish Hardiman, Ms Eleanor Masterson, Ms Marie Culliton, Ms Oonagh Ward and Ms Avril Daly</p> <ul style="list-style-type: none"> <li>The meeting was quorate. The quorum for meetings of the ISG is outlined in Appendix A.</li> </ul> <p><i>Review of Actions:</i> Actions from the previous meeting were reviewed with updates against ongoing actions outlined in Appendix B.</p> <p><b><i>Review of Minutes:</i> The minutes of the last ISG meeting on the 14 of February 2024 were approved.</b></p>
2	<p><b>Amendments to the ISG Terms of Reference</b></p> <p>Ms Helen Shortt notified the members of the changes to the Terms of Reference, and these were agreed. Prof Risteárd O’Laoide raised a query on the governance structure for the NGGO. Ms Helen Shortt will discuss this with Prof O’Laoide offline.</p> <p><b>Action 2024/05:</b> Ms Shortt to meet with Prof O’Laoide to discuss his query on NGGO governance structure</p>
3	<p><b>Updates</b></p> <p>Dr Emma McCann presented the further progress on the National Genomics Medicine Service (NGMS) operating model,</p> <ul style="list-style-type: none"> <li>Amendments to the draft of the operating model</li> <li>An options appraisal workshop to determine key requirements for the location of a National Genomic Medicine Centre was held on the 11 of April with stakeholders from National Clinical Programmes and Regional Health Areas. The outcome of the workshop was that the preferred option for the location of a National Genomic Medicine Centre is to locate the centre on an existing hospital site In May 2024, the Executive Management Team (EMT) gave approval for NGGO to commence designing the designation process for the determination of a location.</li> </ul> <p>Dr Richard Hagan presented the update on the National Genomic Test Directory, Workshops have taken place with input from many specialties. The attendees also shared the test directory information with other colleagues and NGGO is still receiving feedback. The first draft version of the test directory for Rare and Inherited diseases to be completed by Q2 2024 In December 2023, an implementation plan for the operationalisation of the test directory was approved by EMT. To progress this development, the NGGO sought approval from ISG to proceed with the development of an expressions of interest for an interim central pre- and post-analytical service as a first phase in the development of laboratory infrastructure.</p>

Item	Discussion
	<p>Dr Colm Henry highlighted the importance of this objective for NGGO in this year as the first step in building the foundation for testing stability.</p> <p>Prof O’Laoide queried the operationalisation of the test directory and how this is going to be structured. Dr Hagan replied that operationalisation of the test directory will be done in phases. The development of the pre- and post-analytical service will provide information on tests being sent away. The NGGO and NCCP to include this item on the agenda for their next meeting.</p> <p>In response to Dr Eileen Tracy’s question on interim biobanking arrangements, Dr Hagan advised biobanking was not included in this interim phase.</p> <p>Ms Helen Shortt highlighted the development of the pre- and post-analytical service will require human resources and these will be put forward as an Estimates 2025 submission. The expectation is the interim service will commence in 2025.</p> <p>Prof Martin Cormican asked for clarity on the approach to updating the test directory, and how changes to tests would be added incrementally. Dr Hagan advised the test directory workshops were about clinical indications, eligibility criteria and the specialties ordering tests. Dr Hagan clarified the use of the term ‘incrementally’ as referring to the addition of specialties and the tests agreed for each specialty as opposed to looking to incrementally add tests.</p> <p>Dr Henry advised that a proposal for a live directory should be considered in order to produce a dynamic approach to adapt and change information as it comes on board.</p> <p><b>Action 2024/06:</b> NGGO and NCCP meeting to include agenda item ‘pre- and post-analytical service’.  <b>Action 2024/07:</b> NGGO to review the concept of a live test directory.</p>
4	<p><b>Communications and PPI Working Group</b></p> <p>Ms Catherine Harvey noted a letter from the patient representatives of the Communications &amp; PPI working group in relation to progression of strategy implementation was sent to Dr Henry. A response was issued addressing issues highlighted and included an offer for Dr Henry to meet the group.</p> <p>The next meeting of the working group is scheduled for 30 May and has been designed to engage with members in a workshop format to determine together the remit of the working group and identify future ways of working.</p> <p>NGGO to engage with the CCO’s Office to agree a date to meet with the PPI Group.</p> <p>Dr Henry highlighted the importance of patients and parents’ input and the interest generated from public representatives regarding frontline appointments. Dr Henry requested the NGGO provide the Steering Group with details of the funding and posts provided to date. It was agreed to add the status of posts as a standing item to the agenda.</p> <p>Ms Margaret Cuddigan thanked Dr Henry for his response to the letter and noted the importance of a meeting with the PPI group. Ms Cuddigan highlighted the importance to the PPI group of Steering Group meetings that provide information on the development of services. Ms Cuddigan requested the Steering Group receive information on progress against the implementation plan.</p> <p>Prof O’Laoide sought information on the status of posts outside Dublin and highlighted the importance of approval for these posts. NGGO will provide an update.</p> <p><b>Amárach Report</b>  The first draft of the report has focused on the health literacy needs of adults and parents of children attending services in prenatal, cancer and rare diseases. The NGGO is reviewing the draft report and is seeking further clarity on some of the details and findings. The next step will be to work with HSE Communications and the Communications and PPI working group on the development of educational materials.</p>

Item	Discussion
	<p>Dr Henry welcomed Ms Helen Shortt as the new Assistant National Director who is now in a full-time post within the NGGO.</p> <p><b>Action 2024/08:</b> NGGO to engage with Dr Henry’s office in facilitating a meeting with the PPI group  <b>Action 2024/09:</b> NGGO to forward a summary of the status of posts to the members</p>
<p>5</p>	<p><b>Programme Update</b></p> <p>Ms Catherine Harvey presented an update on the priority deliverables for the period of March and April. Ms Harvey noted that deliverables 1,3 and 4 have already been discussed.</p> <ul style="list-style-type: none"> <li>• <b>Deliverable no. 2: NGGO</b> completed an assessment of the specialised genetic and genomic workforce and carried out a survey of genetic counsellors to obtain a better understanding of the current workforce. The NGGO also met with the National Doctors Training Programme to request an update of their 2019 report.</li> </ul> <p>This analysis will assist in the Estimates process for 2025. NGGO has commenced engagement with NWIHP and NCCP to develop a shared approach to ensure a specialised workforce across the services and geography.</p> <ul style="list-style-type: none"> <li>• <b>Deliverable no.5:</b> due to the interim director’s absence there has been no further development.</li> <li>• <b>Deliverable no.6:</b> NGGO is continuing to collaborate with the 1+MG working groups and GDI-IE.</li> </ul> <p><b>Risk Log</b>  Ms Harvey presented two risks to the steering group and advised this will be a standing agenda going forward. Ms Cuddigan raised a question regarding the input the Steering Group should have in the escalation of risks. Ms Shortt agreed to present mitigating actions against high scoring risks for the next meeting.</p> <p><b>Action 2024/10:</b> Ms Shortt to present mitigating actions against high scoring risk a the next ISG meeting  <b>Action 2024/11:</b> Risk log to become standing item</p>
<p>6</p>	<p><b>1+MG Project and the National Mirror Group Update</b></p> <p>Mr John O’Neill introduced the newly set up Research Policy and Innovation Unit of the Department of Health (DoH) and team of Ms Aisling Kelly and Aideen Dowling. The Unit will work closely with the HSE and HRB and met with the NGGO team last week.</p> <p>Mr O’Neill provided a brief update,</p> <ul style="list-style-type: none"> <li>• The 1+MG special group will meet on the 30 May in Brussels, DoH will be represented.</li> <li>• Genome of Europe (GOE) application has been successful, the drafting stages and work is ongoing through Health Research Board (HRB)</li> <li>• The 1+MG Mirror group will meet at the end of June</li> </ul> <p>Dr Henry welcomed Mr O’Neill and his team.</p>
<p>7</p>	<p><b>Next Meeting Date &amp; AOB</b></p>



Item	Discussion
	<p>Dr Henry confirmed the request for the NGGO to provide an update on the status of posts and highlighted this should be a standing item on the ISG agenda going forward.</p> <p><b>Action: 2024/12:</b> NGGO to included recruitment updates as a standing item on ISG agenda going forward</p> <p>Next meeting is to be held virtually on <b>Wednesday the 10 of July 11:30-13:00hrs.</b></p>

### Appendix A – Members

<b>Quorum</b>	50% of members for discussions and recommendations	
<b>Members In Attendance</b>	Dr Colm Henry	HSE, Chief Clinical Office, Chair
	Ms Helen Shortt	HSE, Assistant National 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
	Dr Valerie Walshe	HSE, Economist, National Finance Division
	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
	Dr Philippa Ryan Withero	HSE, Assistant National Director, National HR Integrated Health Workforce Planning
	Mr John O'Neill	DoH, Principal Officer, Research Policy, and Innovation Unit
	Ms Aideen Dowling	DoH, Assistant Principal Officer, Research Policy
Ms Ailish Kelly	DoH, Assistant Principal Officer, Research Policy	
<b>Non-members In Attendance</b>	Ms Catherine Harvey	HSE, Programme Manager, National Genetics and Genomics Office
	Ms Christine Daly	HSE, Business Coordinator, National Genetics and Genomics Office
	Mr Pat Mulhare	HSE, National Clinical Programme for Laboratory Services Reform
<b>Apologies:</b>	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
	Ms Eilish Hardiman	CHI, Chief Executive Officer
	Ms Eleanor Masterson	HSE, Chief Architectural Advisor, Estates
	Ms Marie Culliton	HSE, Scientific Lead, National Clinical Programme for Pathology
	Ms Oonagh Ward	HRB, Head of Research and Innovation Infrastructures
Ms Avril Daly	Patient Representative	

### Appendix B – Ongoing / New Actions

Action #	Description	Owner(s)	Date Raised	Action Date
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<b>FEB 02</b>	NGGO to provide a draft timeline on the Workforce Plan to Dr Colm Henry <b>Update 15/05/2024:</b> In progress	NGGO	14/02/2024	20/03/2024
<b>FEB 03</b>	Ms Marie Culliton to share data from the National maternity Hospital	Ms Marie Culliton	14/02/2024	20/03/2024
<b>2024/05</b>	Meeting to be arranged for Ms Shortt and Prof O'Laoide to discuss his query on NGGO governance structure	NGGO & Prof O'Laoide	15/05/2024	10/07/2024
<b>2024/06</b>	Meeting to be arranged between NGGO and NCCP on the step processes of phase 1 of the development of the genomic laboratory infrastructure and will include agenda item 'pre- and post-analytical service	NGGO & Prof O'Laoide	15/05/2024	10/07/2024
<b>2024/07</b>	NGGO to review the concept of a live test directory	NGGO	15/05/2024	10/07/2024
<b>2024/08</b>	NGGO to engage with Dr Henry's office in facilitating a meeting with the PPI group	NGGO	15/05/2024	10/07/2024
<b>2024/ 09</b>	NGGO to forward a summary of the status of posts to the members	NGGO	15/05/2024	10/07/2024
<b>2024/10</b>	NGGO to provided detail mitigate responses for high risks at the next ISG meeting	NGGO	15/05/2024	10/07/2024
<b>2024/11</b>	NGGO to included RISK log as a standing item on the ISG Agenda	NGGO	15/05/2024	10/07/2024
<b>2024/12</b>	NGGO to included recruitment updates as a standing item on ISG agenda going forward	NGGO	15/05/2024	10/07/2024