



## Implementation Steering Group for Genetics and Genomics Strategy

### APPROVED MINUTES/ACTIONS

#### Meeting Details:

<b>Date:</b>	04 September 2024
<b>Location:</b>	MS Teams
<b>Time:</b>	12:30pm-1:30pm
<b>Chair:</b>	Prof Martin Cormican
<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> Prof Martin Cormican (HSE, National Clinical Lead Laboratory Services Reform) is chairing the meeting covering Dr Colm Henry.</p> <p><i>Apologies:</i> Dr Colm Henry, Prof Eileen Treacy, Dr Philippa Ryan Withero, Prof Risteárd Ó Laoide, Martina Burns</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><b>Review of Actions:</b> Actions from the previous meeting were reviewed.</p> <p><b>Review of Minutes:</b> HS brought the following two typographical errors in the draft minutes; Item 4, second bullet point, under WG07, to change from industrial evolvement to industrial involvement, and, also under Item 4, second last bullet point, the Genome of Europe, should read November 2023 and not November 2024. These changes were accepted, and the minutes of the Implementation Steering Group meeting of 10 July 2024 were approved.</p>
2	<p><b>NGGO Five Year Plan</b></p> <p>CH presented the NGGO Five Year Plan that sets out how the strategy will be implemented over a five-year period. A number of assumptions were made in setting out the plan including the availability of funding and approvals.</p> <p>This high-level plan will enable the NGGO to commence detailed planning for each element and will be a foundation for annual plans for the next five years. As an example, CH presented the laboratory and bioinformatics element of the plan calling out the importance of interconnectivity and interdependencies between each part of the plan.</p> <p>MCor welcomed the clarity provided by the plan, including timelines. MCor advised that due to the detailed information provided in the plan, he requested that the members of the ISG be given time to review before approval is given. MCor recommended a period of 1 week for ISG members to provide feedback on the plan to the NGGO.</p> <p>VW agreed.</p> <p><b>Action:</b> NGGO to circulate to the ISG members the 5-year plan in a simplified version. The plan will include a timeline of 1 week for members to provide any questions, observations, or comments.</p>
3	<p><b>Risk Register</b></p> <p>HS presented the NGGO Risk Register consisting of 4 risks. HS noted the Register was written at a point in time when the NGGO was set up and it has not been revised specifically since then and was not necessarily orientated towards the delivery of the strategy. HS recommended to the ISG that the NGGO re-write the risk register to the context of the Five-Year Plan.</p> <p>MCor agreed that the current Risk Register needs to be replaced by one that is aligned to the plan.</p> <p>MC thanked HS for the update and said that she sees the risk register as critical to be able to develop the plan as well, making sure the plan encompasses the risks and that any amber and red items are being</p>

Item	Discussion
	<p>mitigated. MC offered help to support the development of the Register as she is of the view that the risks identified in the register should also inform the plan.</p> <p>HS thanked MC for her guidance thus far and acknowledged the value of her assistance if MC was in a position to give the NGGO her time.</p> <p>HS said that the NGGO would contact MC once a draft risk register has been prepared. MC noted the power of several risks being red and the importance of ensuring mitigation.</p> <p>MCor noted the NGGO will be trying to ensure the risk register, and the plan are correctly aligned and not an exercise in downgrading any of the high-level risks that have been identified. The Chair requested the plan and the risk register be available for the next meeting to assure the ISG that they are both aligned, and they would both be presented in this way at future meetings. HS noted the challenge of achieving this request but assured the ISG of the NGGO's best efforts.</p> <p>AD said that she fully agrees with MC and offered her support to the NGGO for this action.</p> <p><b>Action:</b> Re-write NGGO risk register and align with the Five-Year Plan and bring it back to the next ISG meeting.  <b>Action:</b> Note support offered from AD &amp; MC in the development of the risk Register</p>
4	<p><b>Programme Update,</b></p> <p>CH presented the 2024 Priority Deliverables Status Report</p> <ul style="list-style-type: none"> <li>• <b>Deliverable No 1:</b> Version 1 is on track for completion at the end of 2024. Version 1 will focus on the clinical specialties of metabolic medicine, mitochondrial lipids conditions, cardiology, and ophthalmology. The next step will be for Version 1 to be operationalized with an expected date of end Quarter 2 2025. Further expansion of the Test Directory will be undertaken thereafter, also on a specialty basis.</li> <li>• <b>Deliverable No. 2:</b> CH advised NGGO will continue to work with the National Doctor Training Programme on an updated review of the clinical genetics workforce with a view to publishing it at the end of the year. Work is ongoing on the business case for Genetic Counsellor grade codes. The development of a workforce plan will be informed by detailed planning associated with the clinical plan model and the phases of development of laboratory infrastructure as set out in the Five-Year Plan.</li> <li>• <b>Deliverable No 3:</b> There has been no Comms &amp; PPI working group meeting since the last ISG meeting. A meeting is scheduled for Tuesday 10 September, it is intended at this meeting discussions on ways of working for the future will be concluded. Other agenda items for the meeting include bodies of work for the remainder of 2024 and into 2025 associated with the HSE Genomic Health Literacy Report. The NGGO continues to engage with the Adelaide Health Foundation on their report on genetics in Ireland and on the possibility of shared work to develop further education for health workers.</li> <li>• <b>Deliverable No. 4:</b> the NGGO continues to develop the genetics and genomics service.</li> <li>• <b>Deliverable no. 5:</b> The NGGO has submitted a proposal to the CCO for support to progress a Bioinformatics Road map. The NGGO continues to engage with the Department of Health on longer-term infrastructural developments.</li> <li>• <b>Deliverable No. 6:</b> The Department of Health will provide a verbal update on the 1+MG project.</li> </ul> <p>HS noted an action arising from the previous ISG meeting regarding the request for the NGGO to consider consulting with children. As an agreed action, the NGGO will bring this proposal to the Communications and PPI Working Group. Children's Health Ireland has offered the Youth Advisory Group for the purposes of consultation if this is agreeable to the Working Group.</p>



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	<p>In response to a question from the Chair, CH advised the first version of the Test Directory will most probably be a hard copy with a link that is available online.</p> <p>HS noted the publication of Version 1 of the Test Directory will provide an opportunity for the NGGO to communicate the work of the office and will allow questions on when and how the Directory will become operational.</p>
	<p><b>1+MG Project &amp; The National Mirror Group</b></p> <p>Mr. John O'Neill, DoH presented updates on the 1+MG Project &amp; The National Mirror Group,</p> <ul style="list-style-type: none"> <li>• The next 1+MG meeting of the special group is scheduled for September 27<sup>th</sup> and a further meeting scheduled for November that will coincide with the Genomic Data Infrastructure (GDI) General Assembly meeting.</li> <li>• The next Mirror Group meeting is planned to take place in November. The Department has appointed reps to WG 1, WG 7, and WG 12. The Department hopes to engage with all the relevant working groups for feedback on current working streams and would welcome suggestions in that regard, in terms of engagement and carrying that forward.</li> <li>• The Department continues to work with colleagues in the HRB in terms of progressing co-funding of Genome of Ireland project. As mentioned previously, there has been a positive decision from the European Commission in terms of contributions to Genome of Europe project, which then must be matched by a national contribution which is currently being considered.</li> </ul> <p>MCor summarized today's discussion and requested ISG members to review the Five-Year plan and to provide comments, suggestions, or questions. If the ISG members do not respond, it will be assumed that there are no major concerns with the plan.</p> <p>EH asked the Chair if membership and terms of reference for the ISG could be considered at the next meeting. A request was also made for members to receive presentations in advance of future meetings.</p> <p>The Chair agreed for the terms of reference and membership to be considered for the next meeting.</p> <p>MCor noted the goal of getting materials out to members before meetings but acknowledged this was not always possible. However, the NGGO will certainly try their best in the future.</p> <p><b>Action:</b> Add membership and ISG Terms of Reference to the agenda for next meeting  <b>Action:</b> NGGO to ensure presentations were available to ISG members in advance of meetings where possible</p>
5	<p><b>Next Meeting Date &amp; AOB</b></p> <p>CC said by way of AOB that she will be leaving the HSE, and that Carol Ivory will represent Access and Integration on the ISG in the future.</p> <p>MCor wished CC all the best and welcomed CI to the group.</p> <p>Next meeting is to be held virtually on Wednesday 30<sup>th</sup> October at 11:30-13:00hrs via MS Teams</p>



### Appendix A – Members

Quorum	50% of members for discussions and recommendations	
Members In Attendance	Prof Martin Cormican (MCor)	HSE, National Clinical Lead Laboratory Services Reform (Chair)
	Helen Shortt (HS)	HSE, Assistant National Director, National Genetics and Genomics Office
	Dr Emma McCann (EMcC)	HSE, Interim Clinical Director, National Genetics and Genomics Office
	Dr Valerie Walsh (VW)	HSE, Economist, National Finance Division
	Ms Oonagh Ward (OW)	HRB, Head of Research and Innovation Infrastructures
	Mr John O'Neill (JON)	DoH, Principal Officer, Research Policy & Innovation Unit
	Ms Aideen Dowling (AD)	DoH, Assistant Principal Officer, Research Policy
	Ms Ailish Kelly (AK)	DoH, Assistant Principal Officer, Research Policy
	Ms Avril Daly (AD)	Patient Representative
	Ms Eilish Hardiman (EH)	CHI, Strategic Programme Director
	Ms Catherine Clarke (CC)	HSE, Assistant National Director, Access & Integration
	Ms Carol Ivory (CI)	HSE, Access & Integration
	Ms Margaret Cuddigan (MC)	Patient Representative
	Pat Mulhare (PM)	HSE, National Laboratory Services Reform

Non-members In Attendance	Ms Pauline Sargent	HSE, Administrator, National Genetics and Genomics Office
	Ms Catherine Harvey (CH)	HSE, Programme Manager, National Genetics and Genomics Office
	Mr James Kelly	HSE, Research, National Genetics and Genomics Office

Members Not In Attendance	Dr Colm Henry	HSE, Chief Clinical Office, Chair
	Prof Risteárd Ó Laoide	NCCP, Director
	Dr Richard Hagan	HSE, Interim Clinical Laboratory Director, National Genetics and Genomics Office
	Ms Eleanor Masterson	HSE, Chief Architectural Advisor, Estates
	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

Description	Owner(s)	Date Raised	Action Date
NGGO to circulate to the ISG members the 5-year plan in a simplified version. The plan will include a timeline of 1 week for members to provide any questions, observations, or comments	NGGO/ISG Members	04/09/2024	30/10/2024
Replace current NGGO risk register and align with the implementation plan	NGGO	04/09/20/24	30/10/2024
Note support offered from AD & MC in the development of the risk Register	NGGO	04/09/20/24	30/10/2024
Review membership and ISG Terms of Reference for next meeting	NGGO	04/09/20/24	30/10/2024
Send reading materials in advance of meetings where possible	NGGO	04/09/20/24	30/10/2024

