



Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

HSE Board Briefing Template

Subject: Development of a National Genetics and Genomics Strategy for Ireland
Submitted for meeting on: November 25th
Name & title of author: Deirdre McNamara, Director of Strategic Programmes, Office of the CCO
Why is this information being brought to the Board's attention? The purpose of this report is to update the board on the progress relating to the development of the National Strategy for Genetics and Genomics and to present the strategy draft to the board for approval ahead of publication.
Is there an action by the Board required, if so, please provide detail? Yes, the strategy draft is being presented to the board for noting and support ahead of the publication and launch on December 13 th .
Please indicate which of the Boards objectives this relates to; <ul style="list-style-type: none">• The development and implementing of an effective Corporate Governance Framework, incorporating clinical governance and a performance management and accountability system; <input checked="" type="checkbox"/>• Developing a plan for building public trust and confidence in the HSE and the wider health service; <input checked="" type="checkbox"/>• Ensuring the HSE's full support for and implementation of the Government's programme of health reform as set out in the Sláintecare Implementation Strategy; <input checked="" type="checkbox"/>• Exercising effective budgetary management, including improving the value achieved with existing resources and securing target saving, with the objective of delivering the National Service Plan within Budget. <input checked="" type="checkbox"/>
Brief summary of link to Board objectives. The development of a National Genetic and Genomic Strategy for Ireland is a critical requirement in order to safeguard the future health and wellbeing of the citizens of Ireland. It is essential for ensuring clinical governance and accountability within genetics and genomics services. The establishment of a National Genetics and Genomics Office will ensure that there is a central body accountable for the progression of the National Strategy with effective organisational alignment and good governance. To achieve a good governance structure, the National Office will work with the Department of Health, HSE and other key stakeholders to ensure developed structures align and complement already established services and programmes relating to genetics and genomics. There has been extensive public interest in the development and enhancement of genetic and genomic services in Ireland. To further engage with the public, patients and the Healthcare Workforce, a series of interactive webinar sessions have been held since June. These engagements have provided an opportunity for individuals to voice their lived experiences, as well as their feedback and vision for the National Strategy, which has significantly benefited the Strategy development process. As the Strategy nears the implementation phase in 2023, there will be ongoing engagement with the public, patients and Healthcare Workforce. A communication plan will be developed to support this which will build public trust and confidence in the HSE and the wider health service. The establishment of the National Genetics and Genomics Office and the supporting PMO team will enable services to be developed in alignment to the Sláintecare reform goals and principles and ensure equitable

access to genetic and genomic services across the country. To achieve this, the programme will continue to work closely with the Department of Health, HSE Board and other key stakeholders to ensure alignment to Sláintecare.

The implementation of the National Genetics and Genomics Strategy will lead to the enhancement of the current genetic and genomic services in Ireland through a more cost-effective service i.e. via streamlined patient pathways, a national test directory and more efficient use of resources, thus improving the value achieved with existing resources and securing target saving. To ensure effective budgetary management throughout the development and implementation of the Strategy, the National Office will regularly update the HSE Board, EMT and Office of the CCO to ensure financial projections and targets are within budget.

Background - provide context in order to ensure that the Board fully understands the issue.

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. A Steering Group was established, chaired by expert advisor Dr Mark Bale to develop a single National Strategy for Genetics and Genomics in Ireland, encompassing care provided across acute, primary and community settings and spanning all ages. Dr Bale has a research background in microbial genetics previously leading on a number of emerging healthcare science areas, including the NHS 2012 Human Genomics Strategy which became the NHS 100,000 Genomes Project.

The development of the strategy is in collaboration with the Department of Health and the membership of the Steering and Working Groups includes representatives from a range of clinical specialties in Ireland, academic, patient representatives, international experts and industry in the area of genetics and genomics.

The first Steering Group meeting took place on the 12th of May and governance includes four working groups;

1. Policy, Communications and Engagement led by Deirdre McNamara and Muiris O'Connor
2. Infrastructure and Data led by Prof Mark Lawler and Prof Walter Kolch
3. Clinical Practice and Innovation led by Prof Owen Smith and Prof Risteárd Ó Laoide
4. Workforce and Collaboration led by Prof Michael Gill and Prof Brendan Loftus

There have been a number of reports to date which all point to the need for a national strategy and plans to develop and strengthen genetics and genomics services in Ireland. The HSE committed to the establishment of a Steering Group, chaired by an international expert. The purpose of the National Genetics and Genomics Strategy Steering Group is to develop a single national strategy for genetics and genomics in Ireland.

The strategy seeks to determine:

- A patient centered model of care, aligned to the RHA's and mainstream clinical practice
- The scope and scale of Ireland's genetics and genomic ambition
- The clinical and research priorities
- Plans for international collaboration and partnerships
- Plans for strengthening of the existing clinical and laboratory services in Ireland.

The strategy seeks to address the following key issues:

- Improved patient journey and end-to-end integrated pathways of care
- Governance structures and legislative requirements

- Ethical principles and data privacy and security
- The required infrastructure, equipment and ICT data processing
- Staffing resources and training requirements.

Recent Programme Activities & Key Updates

Since the circulation of the previous summary update to the HSE board:

- (1) Drafting of the National Genetics and Genomics Strategy is now complete; during this process we have received over 70 recommendations and 800 comments from over 100 contributors. The Steering Group met on November 16th for the final strategy sign off.
- (2) In November, the Strategy was submitted to the office of the CCO, HSE EMT and the Department of Health's Management Board. A presentation on the strategy was delivered to the DoH Management Board, they welcomed the continued efforts and work to date contributed to the development of the strategy and expressed the need to progress to the implementation planning phase.
- (3) A presentation on the strategy was delivered to the Safety and Quality sub-committee of the HSE board on the 15th of November. The feedback from the committee was positive, a suggestion was made to evaluate the experience of the patient advocates involved in its development and this will be actioned in the coming weeks.
- (4) A launch date for the publication of the strategy is scheduled for December 13th.
- (5) The Minister for Health announced €2.7M in funding set aside for the initial implementation phase of the National Strategy in 2023. A press release was issued on September 30th to provide an update on the Town Hall meeting and confirmation of the funding that was secured for 2023.
- (6) The Irish Platform for Patient Organisation, Science and Industry (IPPOSI) presented 'The Verdict of the Citizens' Jury on the Future Use of Genomics in Ireland' report which was published on October 11th, was presented at the October 13th Steering Group meeting.
- (7) Engagement internationally has continued, and a meeting with Northern Ireland was held during October. The purpose of this meeting was to gain insight into their experience of implementation. The Steering Group Chair represented Ireland in the 'Beyond One Million Genomes Maturity Level Model Workshop' (B1MG MLM) in Lisbon in October. A presentation on the National Genetic and Genomic Strategy and the results of the MLM pilot assessment were discussed. Ireland was commended on their ability to actively engage with the public, patients and advocacy groups in development, as other EU countries found this challenging. The Minister subsequently wrote to the project commissioner requesting a change in Ireland's status from an observer country to a stakeholder for this initiative.
- (8) Members of the Steering Group met with Fran Thompson, Chief Information Officer on 27th October to review and agree 'the way forward' in relevant sections of the Strategy document, particularly in relation to Strengthening Infrastructures to Drive Advances in Genetics and Genomics.
- (9) A series of patient advocacy and healthcare professional engagement webinars were held in the months of June, July, August, September and October. There has been considerable interest from patients, patient advocacy organisations and the healthcare workforce relating to the development of the National Genetics and Genomics Strategy and over 110 queries have been received since June.
- (10) Fundamental to the successful development of a National Genetics and Genomics Strategy is patient and public involvement. There are 11 patient representatives across the programme with two members on the Steering Group. To date, each patient representative has provided invaluable insight and recommendations to the strategy document process.
- (11) An industry Engagement Survey was launched in October and shared widely with industry stakeholders identified through a comprehensive market research exercise. The purpose of this survey was to understand the capabilities and expertise in genetics and genomics that exist across Ireland and to gain understanding regarding the current use of technologies in genetics and genomics. The responses received which will help to inform implementation planning.

(12) The HSE Engagement Survey was launched on October 14th and closed on November 4th with 196 responses received. The purpose of this survey was to: better understand how staff will rank the importance of the various key priority areas of focus, and how feasible these various priorities are based on their understanding and experience in their work. The survey findings will be used to help inform implementation planning.

The next steps of the programme are as follows:

- Ongoing engagement with public and patient advocacy groups, healthcare workforce, international experts, academia and industry
- Collation and review of Industry and HSE Engagement Surveys
- Continuation of the monthly Steering Group meetings
- Planned approach to implementation
- Publication and official launch of National Genetics and Genomics Strategy on December 13th 2022
- Implementation of the National Strategy to commence in January 2023.

HSE Timeline of Key Milestones

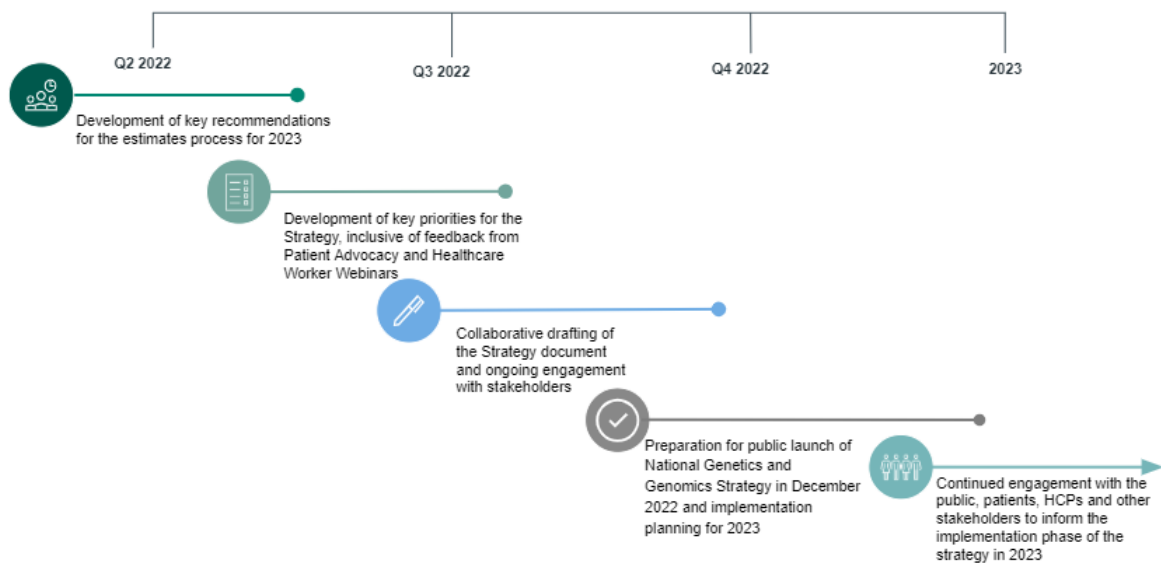


Figure 1: Timeline for the development of the National Genetics and Genomics Strategy

Highlight any implications that the Board should be made aware of in its consideration such as;

The National Genetics and Genomics Strategy has received sign off from the National Strategy Steering Group, the HSE EMT and the DOH management Board. It is planned that it will be published and launched externally on December 13th 2022.

Conclusion:

The Strategic Programmes Office has made significant progress in the development of a National Genetics and Genomics Strategy for Ireland. Despite tight timelines and the complexity of the work to date, the programme has submitted the finalised National Strategy to the office of the CCO, EMT, DoH, the Safety and Quality sub-committee of the board and, as of today, the HSE Board. The publication and official launch of the National Strategy will be held on December 13th.

Recommendation:

The HSE Board is to be updated regularly on the progress relating to the development of the National Genetics and Genomics Strategy and implementation plan as the strategy development reaches this phase in Q1 of 2023.