



Príomhoifigeach Cliniciúil
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BY EMAIL ONLY

Deputy Denis Naughten
Dáil Éireann
Leinster House
Kildare Street
Dublin 2

29th October 2024

PQ40696/24 To ask the Minister for Health the steps being taken to ensure that all samples for familial genomic testing are sent to the same laboratory, be it in Europe or the United States, from hospitals here in Ireland; and if he will make a statement on the matter.

PQ 40697/24 To ask the Minister for Health if he is aware that a risk assessment submitted to the HSE in 2010 identified increasing clinical risk with the dispatching of genomic samples to multiple laboratories outside this jurisdiction; the actions taken to date to ameliorate these risks; and if he will make a statement on the matter.

Dear Deputy Naughten,

Many thanks for your representation.

The HSE recognised the need to develop a strategy for genetics and genomics and the National Strategy for Accelerating Genetic and Genomic Medicine in Ireland was published in 2022. Many stakeholders including patients and staff contributed to its development. The strategy identifies several key strategic areas of focus that, when achieved, will transform existing services including genetic and genomic testing. The HSE's National Genetics and Genomics Office (NGGO) is working to achieve these strategic objectives.

These key strategic areas of focus include:

- Coordinating a national approach to genetics and genomics
- Development of a National Test Directory for genetic and genomic tests

As part of coordinating a national approach to genetics and genomics and progressing a National Test Directory, the NGGO will publish the first version of the National Genomic Test Directory in early 2025. This will provide advice to clinicians and laboratories on the genetic and genomic tests suitable for specific clinical specialties.

In addition, and in 2025, the NGGO will seek expressions of interest from HSE and voluntary hospitals to set up and provide a National Genomic Processing Service that will support operationalizing the Test Directory. This will include the routing of processed samples to the appropriate laboratory. The development of this service is funding dependent.



In addition, and in 2025, a procurement for genetic and genomic tests will be undertaken and the outcome will ensure genetic and genomic tests will be available from laboratories that conform to recognized laboratory quality standards.

Taken together, these developments will begin to ameliorate risks associated with genetic and genomic tests and will see a national, standardised approach to genetic and genomic testing commenced which will include steps taken to ensure samples for genetic and genomic tests are directed to approved laboratories.

I hope this provides you with some assistance.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Sharon Hayden', written in a cursive style.

Sharon Hayden
General Manager
Office of the Chief Clinical Officer