



BY EMAIL ONLY

Deputy Emer Currie
Dáil Éireann
Leinster House
Kildare Street
Dublin 2

20th October 2025

PQ 53935/25- To ask the Minister for Health in view of 20,000 clinical genetic tests being sent to laboratories abroad, if she will clarify the way in which patient data is handled by each laboratory provider in the interests of transparency and good governance; and if she will make a statement on the matter.

Dear Deputy Currie,

The National Genetics and Genomics Office (NGGO) was established in 2023 under the governance of the HSE to provide oversight and a standardised approach to the delivery of genetics and genomics service as outlined in the National Strategy for Accelerating Genetic and Genomic Medicine in Ireland.

The National Strategy was developed through a collaborative process involving a wide range of stakeholders. This included public representatives, clinicians, academia, industry and international experts, ensuring that the National Strategy reflects both best practice and the specific needs of the Irish healthcare system.

At present, individual hospitals are responsible for accessing genomic testing services provided by laboratories abroad. HSE laboratory services across all domains including clinical genetics are aware of their obligations in relation to privacy and confidentiality of patient data. The HSE Strategic Plan for Laboratory Services emphasises the need for compliance with data protection, this is reinforced by medical laboratory testing being accredited to the ISO 15189 quality standards that guide the operation of HSE laboratories.

Ireland is a participant in the Genomic Data Infrastructure (GDI) Project developing the data infrastructure to deliver the vision of the 1+Million Genomes Initiative to enable secure access to human genetic data across national borders, in order to improve research and clinical practice. The NGGO is working towards the establishment of a secure, scalable, and accessible data and analytical infrastructure to support clinical service delivery, bioinformatics, data access, and research in line with the objectives of the National Strategy for Accelerating Genetic and Genomic Medicine in Ireland.

I hope this provides you with some assistance.



Yours sincerely

Catherine Harvey
General Manager
National Genetics and Genomics Office