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**06 June 2024**

**PQ 24194/24**

**To ask the Minister for Health the current provision for and future development of a genetic database for national cancer services and oncology treatment; and if he will make a statement on the matter -Neasa Hourigan**

Dear Deputy Hourigan,

The Hereditary Cancer Model of Care (MOC), launched in June 2023, focuses on the clinical services required for the identification of cancer predisposition and for the ongoing management of those with a predisposition. A multidisciplinary Implementation Steering Group, Chaired by The National Director of the National Cancer Control Programme (NCCP), is in place to guide implementation of the MOC. A number of sub-groups are being convened to progress implementation of key thematic areas, including Thematic Area 6: Data Requirements and IT Infrastructure. Once convened, the work of the data and IT subgroup will include:

- Exploring the role of virtual patient assessment within hereditary cancer services
- Identifying the IT infrastructure required to enable the implementation of the MOC, including a genetic counselling network and referral to a national specialist genetics MDT
- Examining potential data capture options with the National Cancer Information System
- Engaging with the National Genetics and Genomics Office (NGGO) in relation to development of registries for cancer predisposition
- Agreeing minimum datasets for common presentations and cancer predispositions
- Agreeing key performance indicators for the delivery of specialist cancer genetics and Regional Cancer Predisposition Services

The approach taken to IT infrastructure will need to align with that taken by the NGGO, regarding wider services, laboratory test results and patient registries. The NGGO was established in 2023 to drive implementation of the National Strategy for Accelerating Genetic and Genomic Medicine in Ireland. The Specialist Cancer Genetics Service represents a core component of overall clinical genetics services in Ireland. The NGGO will provide governance for the Specialist Cancer Genetics Service in collaboration with the NCCP. The NGGO is responsible for coordinating a national approach to genetics and genomics, supporting the development of a skilled genetic and genomic workforce (including genetic counsellors),

enhancing clinical services for patients and families, and strengthening laboratory and data infrastructure to drive advances in genetic and genomic medicine services.

Implementation of the Hereditary Cancer Model of Care and the National Strategy for Accelerating Genetic and Genomic Medicine in Ireland will be multi-year projects requiring adequate funding and resourcing.

Yours sincerely,

*Dr. Heather Burns*

Dr Heather Burns

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