Barry Henegan TD
Independent
Leinster House
Kildare Street
Dublin 2

email: barry.heneghan@oireachtas.ie

7th August 2025

PQ 41153/25
To ask the Minister for Health the steps being taken to fund and implement the hereditary cancer model of care in Ireland, with particular reference to improving genetic testing and surveillance for those at risk of inherited cancers like pancreatic cancer; and if she will make a statement on the matter.

PQ 41154/25
To ask the Minister for Health the number of patients diagnosed with pancreatic cancer who were referred for genetic testing following diagnosis, in each of the past five years, in tabular form; and if she will make a statement on the matter.

PQ 41155/25
To ask the Minister for Health the estimated proportion of pancreatic cancer patients with inherited genetic mutations who are currently receiving access to genetic testing, counselling, and tailored treatment plans; and if she will make a statement on the matter.

PQ 41156/25
To ask the Minister for Health if she will provide an update on the current resourcing of the hereditary cancer model of care within the National Cancer Strategy; if she will outline the additional funding being considered to ensure national access to this service; and if she will make a statement on the matter.

Dear Deputy Henegan,

Hereditary cancer services include the identification of inherited cancer predisposition and the ongoing management of those with a predisposition. An NCCP-led multi-disciplinary advisory group developed a Hereditary Cancer Model of Care, as the blueprint for improved access, quality and governance of hereditary cancer genetics services in Ireland.

Since its publication in 2023, implementation has progressed via:

- Hereditary Cancer Steering Group to oversee implementation of the Model of Care
- Hereditary Cancer Working Group for Networked Services and Multidisciplinary teams
- Hereditary Cancer Model of Care Implementation Mainstreaming Sub-group
- Development of accredited HSEland training modules for healthcare professionals

- Development of patient and clinician information resources for Lynch Syndrome
- Clinical workshops to develop an inherited cancer chapter for Irish national genomic test directory for rare and inherited disease

In line with the implementation of the Model of Care, systems are being put in place to implement mainstreaming of cancer genetic testing. This refers to a model where testing for a cancer predisposition gene is integrated into oncology services, for those with a personal cancer diagnosis. This approach is also being adopted across many other non-cancer specialties, as a means of increasing access to genetic testing for patients. Mainstreamed pathways enable more timely access to cancer predisposition gene tests for patients with cancer, as part of the standardised management of cancer care, and in line with nationally agreed criteria and protocols.

In practice, this means that pre-test counselling and consent processes for cancer predisposition gene tests in those with a diagnosis of cancer (diagnostic/ discovery testing) are undertaken by a member of the clinical cancer team caring for the patient and much sooner in the patient pathway. Referral to a specialist clinical genetics professional is then usually reserved for those patients found to have a pathogenic or uncertain variant, or patients with a suspected cancer predisposition syndrome or complex family histories. The mainstreamed approach saves time, is a more efficient use of resources and provides continuity of knowledge for both the treating clinicians and the patient.

We anticipate that this mainstreamed approach, supported by a national testing directory and education initiatives, will improve access to appropriate genetic testing among those with a diagnosis of cancer, including those with a diagnosis of pancreatic cancer.

At this point, there is no national collection of data in relation to the underlying cancer diagnosis of those who are undergoing genetic counselling, testing or management of cancer predisposition. This data is therefore not available in relation to those with a diagnosis of pancreatic cancer.

Funding for the implementation of the Hereditary Cancer Model of Care is sought via the annual service planning process. Relevant new posts to support the hereditary cancer model of care including genetic testing and surveillance in the 2025 service plan included two genetic counsellors, four Advanced Nurse Practitioners, three administrative posts (one to support national MDTs, two to support regional services) and two medical oncology posts with a special interest in cancer genetics. It is acknowledged that significant further investment will be required, particularly in relation to sufficient diagnostic capacity (radiology, pathology and endoscopy) to provide surveillance for those identified with an inherited predisposition to cancer.

Yours sincerely,

Dr Caitríona McCarthy
Consultant in Public Health Medicine (MCRN 22360), NCCP
National Cancer Control Programme