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9th July 2025

PQ 34960/25 To ask the Minister for Health her Department's plans to increase funding and resources for a hereditary cancer model of care.

PQ 34961_25 To ask the Minister for Health the actions her Department is taking to establish oversight for the implementation of the hereditary cancer model of care.

PQ 34963_25 To ask the Minister for Health the actions she is taking to ensure workforce development, as recommended in the national cancer control programme in the hereditary cancer model of care, HSE national cancer control programme.

PQ 34964_25 To ask the Minister for Health the actions her Department is taking to ensure there is patient information and supports for those under the hereditary cancer model of care.

PQ 34965_25 To ask the Minister for Health the actions her Department is taking to provide patient information and supports, as recommended in the national cancer control programme in the hereditary cancer model of care, HSE national cancer control programme.

PQ 34966_25 To ask the Minister for Health the actions her Department has taken to identify the IT infrastructure required to enable the implementation of this hereditary cancer model of care, including genetic counselling network and referral to national specialist genetics multi-disciplinary teams.

Dear Deputy Brabazon,

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, the following implementation activities have been established:

- 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

A table is provided below which summarises progress in implementation to date, according to the relevant thematic areas.

Funding for the implementation of the Model of Care is sought via the annual service planning process. Relevant new posts 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.



Overview of Implementation Progress

Thematic Area	Initiative	Progress	Start Date
1: Establish oversight for the implementation of the Hereditary Cancer Model of Care	Hereditary Cancer Steering Group	<ul style="list-style-type: none"> Group established and chaired by the NCCP National Director, Prof Risteárd Ó Laoide Met three times Membership includes broad representation from clinicians (medical, nursing, genetic counsellors, psychology), patient representatives, National Genetics and Genomics Office (NGGO), Dept of Health, National Cancer Registry Ireland, NCCP programmes. Conflict of Interest Compliance: Completed by Steering Group members. 	11.12.2023
	Collaboration with NGGO	<ul style="list-style-type: none"> Regular meetings between NGGO/NCCP are quarterly Collaborative work includes service planning & test directory 	18.04.2024
2. Development of networked services and MDTs	Hereditary Cancer Working Group for Networked Services and MDTs	<ul style="list-style-type: none"> Group established and has met four times Prof Karen Cadoo appointed as chair and Dr Lynda McSorley as deputy chair Progressing development of template job descriptions Project is underway on National MDTs configuration and pathways e.g. development of a SOP for the National MDTs. Consideration given to MDT's for paediatrics, AYA, adult solid tumour and adult haemato- oncology Mainstreaming was agreed as a priority area. A mainstreaming subgroup has been established to progress the operational aspects (see below). 	20.03.2024
	Hereditary Cancer MoC Implementation Mainstreaming Sub-group	<ul style="list-style-type: none"> Generic genetic testing consent form has been drafted. Awaiting patient representation feedback HSEland training for those delivering mainstreamed pathways is under development, see below Discussion on implementation support for regional services is ongoing. 	04.09.2024
3. Healthcare professional education & training; workforce development	Cancer Genetic Testing E-Learning	<ul style="list-style-type: none"> Four e-learning modules to enhance mainstream cancer genetic testing knowledge are under development. Module 1 and 2 are currently being finalised. <p>Module 1 - Fundamental of Cancer Genetics Module 2 – Obtaining Informed Patient Consent Module 3 – Cancer Genetic Testing for BRCA Module 4 – Cancer Genetic Testing for Lynch syndrome</p>	Q4 2022

4. Clinical guidance and pathway development	Lynch Syndrome Clinical Advisory Group	Guidance previously agreed on universal tumour testing of colorectal, endometrial, and specific ovarian cancers for Lynch Syndrome. Support will be required in implementation of guidance and incorporation of mainstreamed germline testing for Lynch syndrome.	TBC
	Inherited cancer chapter for genetic test directory	<ul style="list-style-type: none"> Group established, chaired by Prof Andrew Green, to agree an Inherited Cancer chapter for the National Genomic Test Directory for Rare and Inherited Disease One workshop specific to testing in paediatric populations and three broader workshops have been held 	
5. Patient information and supports	Lynch Syndrome Subgroup	<ul style="list-style-type: none"> Patient information group has been established for Lynch Syndrome A Lynch syndrome section has now been published on the HSE.ie Health A to Z section. Five Leaflets have been developed and are at the design stage <ol style="list-style-type: none"> Lynch syndrome - Information for patients and families Bowel (colorectal) cancer in Lynch syndrome –Information for patients and families Gynaecological cancer in Lynch syndrome – Information for patients and families Q&A Lynch syndrome Bowel (colorectal) cancer and genetic testing in Lynch syndrome <p>Leaflets will be available to order from healthpromotion.ie</p>	Q4 2022
6. Data requirements and IT infrastructure	Registries workshop	<ul style="list-style-type: none"> Initial workshop was held on Friday April 11th 2025 to explore the population data collection for cancer predisposition. Approximately 30 people participated. Presentations were given from the SJH pilot project, the Irish National Health Intelligence Unit and the English Lynch Syndrome Registry. Outputs from the workshop will be shared in a report and next steps to be agreed. 	



Yours sincerely,

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National Cancer Control Programme