Hereditary Cancer Model of Care – Implementation Report (April 2025)

1. Introduction

The NCCP Hereditary Cancer Model of Care (MoC) aims to enhance equity of access to genetic services for individuals and families at increased risk of cancer due to inherited predispositions. This report presents progress on national implementation, linked to thematic areas within the MoC. Progress is summarised in the below implementation table.

These activities are framed within the context of the National Cancer Strategy 2017–2023 and focus on improving service delivery, equity of access, HealthCare Professional (HCP) education, and genetic testing for high-risk populations.

The vision of the Hereditary Cancer MoC is that it will provide clarity regarding the structure, governance and test delivery for hereditary cancer services in Ireland. Since the publication of the Hereditary Cancer MoC in April 2023, the following implementation activities have been established:

1. Hereditary Cancer Steering Group to oversee implementation of the MoC.
2. Hereditary Cancer Working Group for Networked Services and MDT’s.
3. Hereditary Cancer MoC Implementation Mainstreaming Sub-group.
4. Development of accredited HSEland training modules for HCPs.
5. Development of patient and clinician information resources for Lynch Syndrome.
6. Clinical workshops to develop an inherited cancer chapter for Irish national genomic test directory for rare and inherited disease.

Table 1: 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	• 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	• 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	• 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	• 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	• Four e-learning modules to enhance mainstream cancer genetic testing knowledge are under development. Module 1 and 2 are currently being finalised. Module 1 - Fundamental of Cancer Genetics Module 2 – Obtaining Informed Patient Consent	Q4 2022

		Module 3 – Cancer Genetic Testing for BRCA Module 4 – Cancer Genetic Testing for Lynch syndrome	
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	• 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	• 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 1. Lynch syndrome - Information for patients and families 2. Bowel (colorectal) cancer in Lynch syndrome –Information for patients and families 3. Gynaecological cancer in Lynch syndrome – Information for patients and families 4. Q&A Lynch syndrome 5. Bowel (colorectal) cancer and genetic testing in Lynch syndrome Leaflets will be available to order from healthpromotion.ie	Q4 2022
6. Data requirements and IT infrastructure	Registries workshop	• 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.	

Table 2 Summary of Recommendation Status

Thematic Area 1: Establish oversight for the implementation of the Hereditary Cancer Model of Care	Status
1.1 Establish a governance and reporting structure aligned to the National Cancer Strategy and National Cancer Control Programme	Complete
1.2 Agree areas for collaboration with the National Genetics and Genomics Office once in place	In progress
1.3 Convene a multi-disciplinary implementation steering group, with clinical leadership and patient involvement	Complete
1.4 Establish relevant working groups for thematic priorities	In Progress
1.5 Agree an overarching governance framework for hereditary cancer service	In Progress
1.6 Appoint Clinical Leads for Cancer Predisposition within regional services	To be started
1.7 Report at minimum annually on progress in implementation	In Progress
Thematic Area 2: Development of networked services and MDTs	
2.1 Define the process(es) by which genetic counselling services can be networked and made accessible regionally	In Progress
2.2 Develop a standardised pathway to a national specialist cancer genetics MDT (adults)	In Progress
2.3 Develop a standardised pathway to a national specialist cancer genetics MDT (CAYA)	In Progress
2.4 Establish a network of regional cancer predisposition leads	To be started
Thematic Area 3: Healthcare professional education and training; workforce development	
3.1 Identify the training needs of staff working in generalist settings	To be started
3.2 Identify the training needs of staff working in regional cancer predisposition services	To be started
3.3 Develop an accredited online programme to meet the minimal learning needs staff working in regional services	In Progress
3.4 Identify or develop further training courses to meet identified needs of staff	To be started
3.5 Work with the National Genetics and Genomics Office, professional training bodies and regulators to develop career pathways in specialist cancer genetics	To be started
Thematic Area 4: Clinical guidance and pathway development	
4.1 Agree the guidance development and approval process, in line with HSE policy, including guidance on laboratory testing	In Progress
4.2 Establish guidance development groups for common presentations and cancer predispositions	To be started
4.3 Ensure patients are involved in the co-design of clinical pathways	To be started

4.4 Agree the process by which international guidance relating to rarer conditions will be approved and disseminated for use in Ireland	To be started
4.5 Agree the platform(s) through which current guidance will be made available to all	To be started
4.6 Highlight critical points in clinical pathways, which should be subject to regular audit	To be started
4.7 Describe resource requirements for implementation of pathways	To be started
Thematic Area 5: Patient Information and supports	
5.1 Establish subgroups for development of patient information, according to common presentations and cancer predispositions	In Progress
5.2 Ensure patients are engaged in the co-design of patient information materials	In Progress
5.3 Consider how best to meet the information needs of underserved populations and those with health literacy challenges	To be started
5.4 Agree or develop platform(s) through which patient information can be most easily accessed	In Progress
5.5 Ensure evaluation of information materials and supports provided	To be started
Thematic Area 6: Data Requirements and IT infrastructure	
6.1 Explore the role of virtual patient assessment within hereditary cancer services	To be started
6.2 Identify the IT infrastructure required to enable the implementation of this model of care, including a genetic counselling network and referral to a national specialist genetics MDT.	To be started
6.3 Examine potential data capture options with the National Cancer Information System	To be started
6.4 Engage with the National Genetics and Genomics Office in relation to development of registries for cancer predisposition	Under review
6.5 Agree minimum datasets for common presentations and cancer predispositions	To be started
6.6 Agree key performance indicators for the delivery of specialist cancer genetics and regional cancer predisposition services	To be started