Annual Operational Report

April 2026

Northern Ireland Cancer Registry

Providing Cancer Information for Planning, Development, Research & Education

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GLOSSARY

Acronym	Definition
ACF	Academic Clinical Fellowship
AHP	Allied Health Professionals
AICRI	All-Island Cancer Research Institute
AllCaN	All-Ireland Oesophageal Cancer Network
APG	All Party Group
AQs	Assembly Questions
BSO	Business Services Organisation
CaPPS	Cancer Patient Pathway System
CEO	Chief Executive Officer
CGIN	Cervical Glandular Intraepithelial Neoplasia
CIN	Cervical Intraepithelial Neoplasia (grades 1-3)
CIO	Cancer Intelligence Officer
COIS	Clinical Oncology Information System
COSD	Cancer Outcomes Services Dataset
CPH	Centre for Public Health
CRG	Clinical Reference Group
CRUK	Cancer Research United Kingdom
DCO	Death Certificate Only
DHSS	Department of Health & Social Services
DoH	Department of Health
DPIA	Data Privacy Impact Assessment
DSAs	Data Sharing Agreements
ECIS	European Cancer Information System
EH	Endometrial Hyperplasia
EMR	Endoscopic Mucosal Resection
ENCR	European Network Cancer Registries
EPD	Enhanced Prescribing Database
FTE	Full Time Equivalent
GDPR	General Data Protection Regulation
GRONI	General Register Office NI
HRB	Health Research Board
HDRUK	Health Data Research UK
HSENI	Health and Safety Executive NI
HSC	Health & Social Care
HSCIMS	Health and Social Care Inequalities Monitoring System
HSCNI	Health & Social Care NI
ICBP	International Cancer Benchmarking Partnership
ICD03	International Classification of Diseases for Oncology Third Edition
ICD10	International Classification of Diseases and Health Related Problems Tenth Revision
ISMS	Information Security Management System
JCRC	Johnston Cancer Research Centre
LLNI	Leukaemia & Lymphoma NI
MBC	Metastatic Breast Cancer
MCD	Minimum Cancer Dataset
MGUS	Monoclonal Gammopathy of Undetermined Significance

MHLS	Medicine Health Life Sciences
NCRAS	National Cancer Registration Service
NCRI	National Cancer Registry Ireland
NHS	National Health Service
NI	Northern Ireland
NIBR	NI Barrett's Oesophagus Register
NICaN	NI Cancer Network
NICC	NI Cancer Centre
NICR	NI Cancer Registry
NICRCSP	NI Colorectal Cancer Screening Program
NIHAP	NI Health Analytics Platform
NIPCLR	Northern Ireland Premalignant Cervical Lesions Register
NISRA	Northern Ireland Statistics and Research Agency
NMSC	Non-Melanoma Skin Cancer
NWCC	North West Cancer Centre
N/S	North/South
OPCS4	Office of Population Censuses and Surveys Classification of Surgical Operations V.4
ORECNI	Office for Research Ethics Committees Northern Ireland
PAS	Patient Administrative System
PHA	Public Health Agency
PIs	Performance Indicators
PPI	Patient and Public Involvement
PQs	Parliamentary Questions
QUB	Queen's University Belfast
RAG	Research Advisory Group
RD	Rapid Datasets
RFA	Radiofrequency ablation
RISOH	Regional Information System for Oncology and Haematology
RPA	Review of Public Administration
RQIA	Regulation and Quality Improvement Authority
SACT	Systemic Anti-Cancer Therapy
SMILE	Stratified Mucin-producing Intraepithelial Lesion
SBC	Secondary Breast Cancer
SOP	Standard Operation Procedure
SPPG	Strategic Planning and Performance Group
UAT	User Acceptance Testing
UCSD	University of California San Diego
UKIACR	UK and Ireland Association of Cancer Registries
UKRI	UK Research and Innovation

INTRODUCTION

1.1 Context

The Northern Ireland Cancer Registry (NICR) produces an Annual Operational Report which sets out the Registry's role, direction, and priorities for the year ahead and an overview of the Registry's achievements from the previous year (April 2025 - March 2026). It holds to the vision, purpose and values set out in the NICR 5-Year Strategic Plan (April 2019 – March 2024) approved by the NICR Steering Group.

1.2 Background

Cancer registries are responsible for the collection, collation and analysis of data relating to the diagnosis and treatment of cancer in patients resident in a defined population. NICR is one of five cancer registries that cover the populations of Great Britain and Ireland. These registries use common definitions and processes and share the same main objective; to deliver timely, comparable high-quality cancer data. In 1959, the Northern Ireland (NI) Department of Health & Social Services (DHSS) established a paper-based cancer registry. This was largely incomplete due to the lack of requirement on clinicians to notify new cancer diagnoses and the limited resources allocated to its function.

NICR was established in 1994 to provide information on cancers (from 1993) in the NI population for the purposes of research, education, planning, and evaluation of services. Following the Review of Public Administration (RPA), funding for the Registry moved from a five-year cycle with DHSS to an annual cycle with the Public Health Agency (PHA) in 2009.The Registry operates under an agreement between the PHA and Queen's University Belfast (QUB) (available on request) which sets out the terms by which the University maintains and operates a register of incident cancers. NICR has had regular peer reviews to ensure quality and advice on direction, with the last review (2018) available here.

1.3 NICR Vision

To continually improve cancer intelligence in NI for the benefit of patients.

1.4 NICR Purpose

To provide accurate, timely information on cancers and pre-malignant conditions occurring in NI for official statistics, research, education, service planning, monitoring, and evaluation.

1.5 NICR Values

- Ensure high quality data with complete ascertainment of cases,
- Protect the confidentiality of the data held,
- Work with those who aim to reduce cancer burden in our society,
- Work together as a team,
- Value and develop our staff,
- Engage with patients and their representatives,
- Provide value for money.

1.6 NICR Objectives

- Collect and confidentially store accurate, timely and comprehensive data on cancers and selected pre-malignant conditions occurring in the NI population,
- Uphold patient and carer confidentiality using strict data security measures,
- Analyse data to support NICR's role as provider of official statistics for cancer incidence, prevalence, and survival,
- Develop Routes to Diagnosis data for cancer patients in NI,
- Facilitate monitoring of the impact of cancer screening services in NI,
- Provide appropriate information for ad hoc cancer queries including investigation of alleged cancer clusters,
- Undertake and assist audits of cancer treatments, services, and outcomes, and recommend improvements in cancer services where appropriate,
- Facilitate planning of cancer services for prevention, diagnosis, cure, and care,
- Promote, facilitate, and undertake research into cancer causes, prevention, treatments, outcomes, care, and survivorship,
- Publish scientific reports and research articles relating to cancer,
- Promote professional and public awareness about cancer,
- Link nationally and internationally to promote cancer registration and increase understanding and management of cancer.

The NICR is supported by a Steering Group (Management), which oversees the work of the Registry and a Council, appointed by the Steering Group. The Council advises the Director and the Steering Group on matters such as NICR outputs and provides a mechanism for the Registry to link with its key stakeholders twice annually. In 2019 a Research Advisory Group (RAG) was established with clinical, scientific, and patient representation – this Group and its activities were merged with the Council in 2021. (See Appendix A for membership of Steering Group, Council and Research Advisory Group).

Cancer registry processes include data acquisition, linkage, quality assurance and analysis to ensure that data on cancers and premalignant diseases are fit for purpose including:

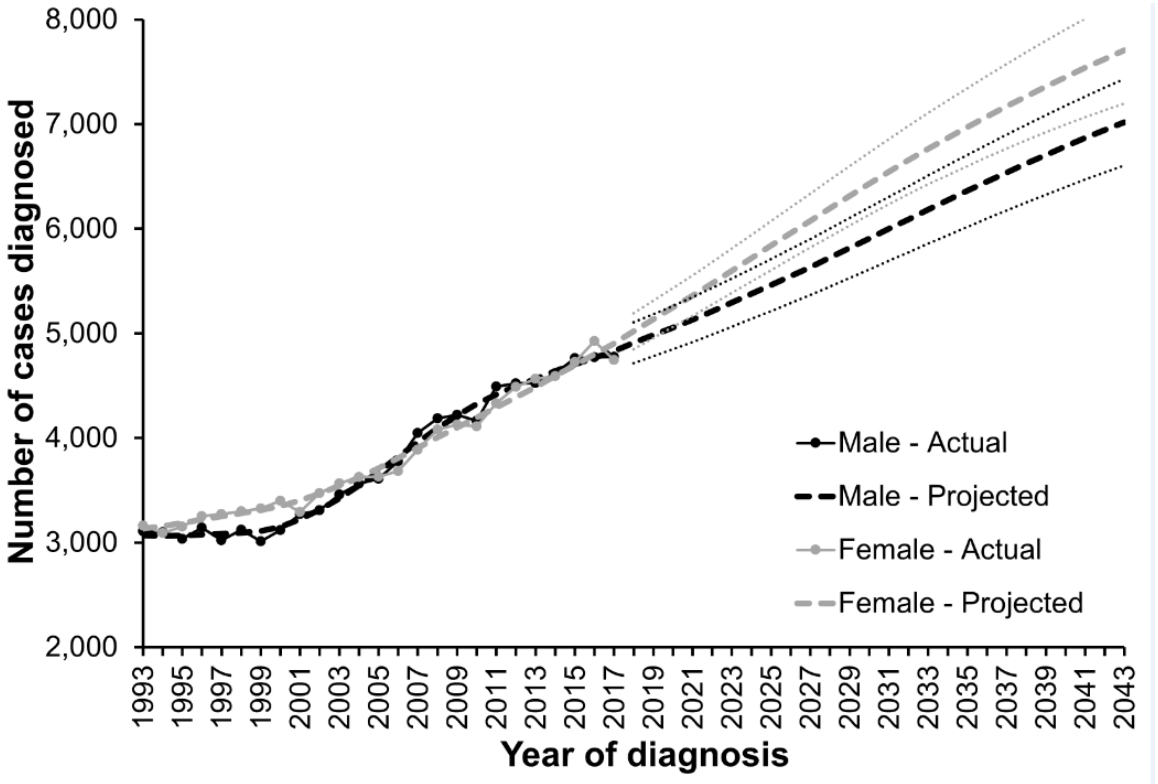
- The provision of annual official statistics on cancer incidence, prevalence, and survival,
- Disease surveillance,
- Planning and administration of cancer related health care,
- Monitoring and audit of cancer related health and health care provision and outcomes,
- Provision of information to the Genetics Counselling Services on those with potential predisposition to certain cancer types,
- Quality assurance of population-based screening programs,
- Investigation of alleged cancer clusters,
- Provision of data for, and undertaking research into, prevention, patterns and trends and outcomes of cancer, approved by research ethics committees when required,
- Improving awareness of the cancer burden and cancer prevention in NI.

In 2022 NI had an estimated population of 1,910,500 people. Excluding non-melanoma skin cancer (NMSC), on average 10,319 cancers were diagnosed each year during 2018-2022 (14,171 cases per year including NMSC). At the end of 2022 there were 73,994 cancer survivors (excluding NMSC)

residing in NI who had been diagnosed in the previous 25 years (i.e. 1998-2022) (107,619 including NMSC).

Cancer incidence is increasing in NI, with the increase predicted to continue, largely due to an ageing population amongst whom cancer risk is higher. In 1993 there were 6,265 cancer cases (excluding NMSC) diagnosed. By 2022 this had risen to 10,856 cancer cases, an increase of 73%. It is predicted this will increase to 14,238 incident cancer cases (excluding NMSC) by 2040 (*Figure 1*).

Figure 1: Cancer incidence projections for NI (excluding NMSC)



Since NICR began in the 1994, the number of items data collected and processed has increased substantially from 44 in 1993-96 to almost 200 in recent years. This number varies depending on tumour site and whether a clinical audit is undertaken. Alongside this increase in cancer cases the level of detail and complexity of cancer data of has increased dramatically. For example, the number and proportion of cancer cases (excluding NMSC) which have been staged are shown in Figures 2a and 2b, increasing from only 1,088 in 1993 to 9,273 in 2022, which represents an increase from 17.4% in 1993 to 85.4% in 2022 (*Figure 2a/2b*).

Figure 2a: Malignant Cancers (ex NMSC) Staged vs Unstaged

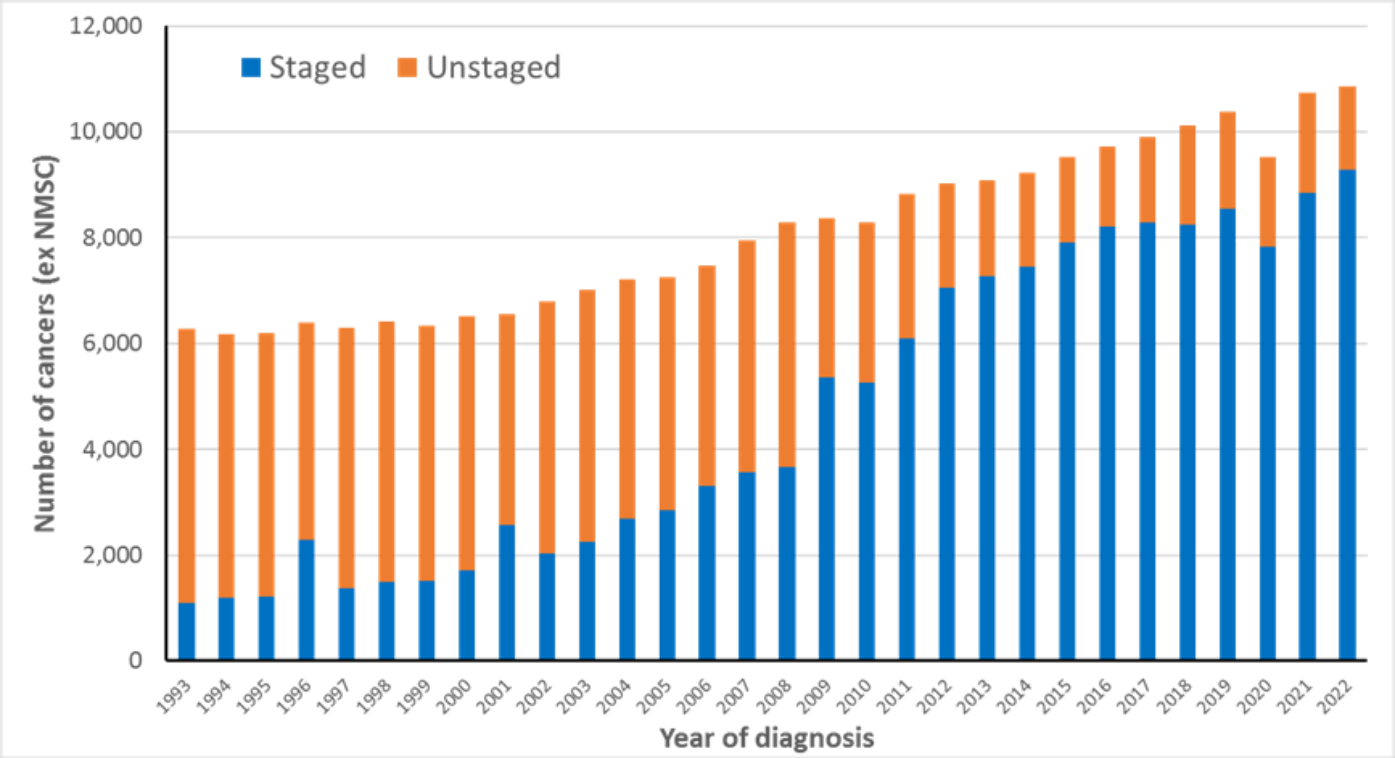
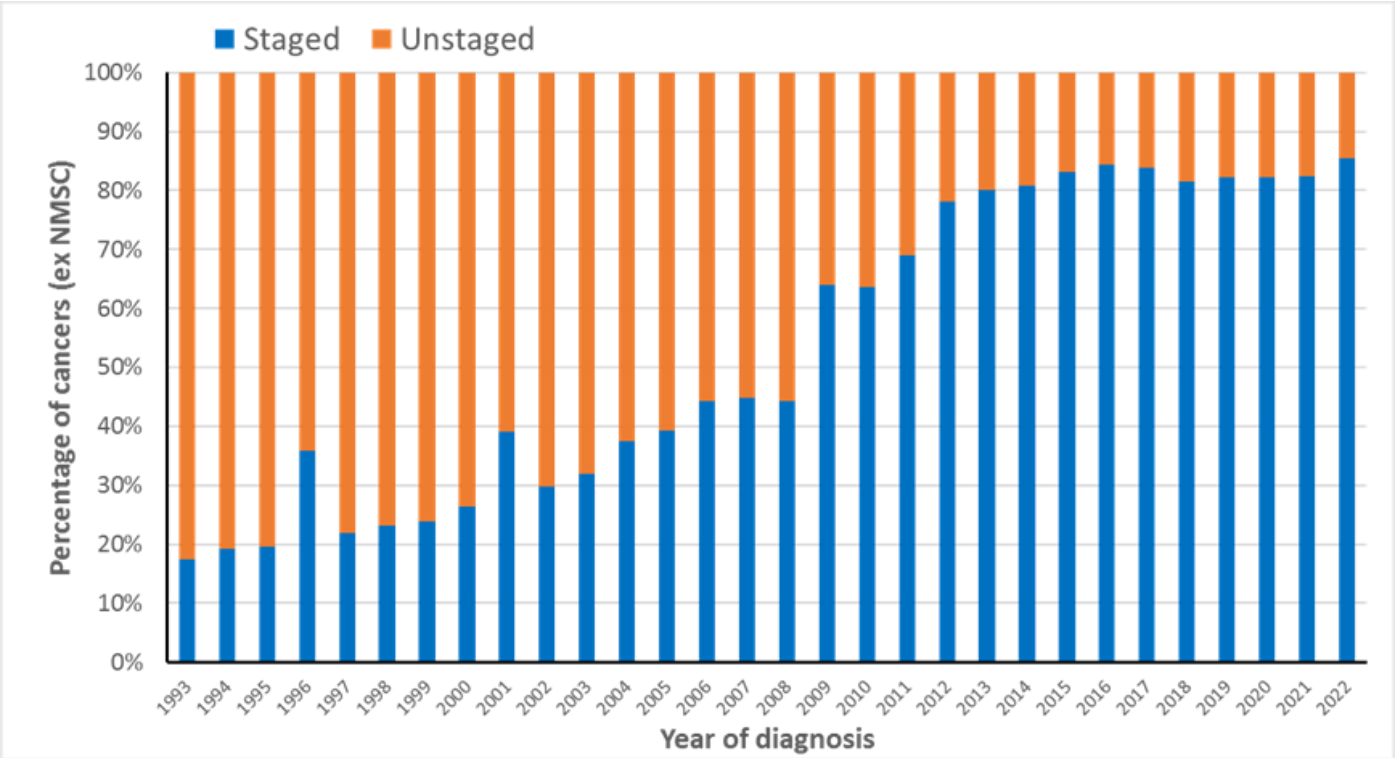


Figure 2b: Malignant Cancers (ex NMSC) Staged vs Unstaged



As NICR looks to the future we anticipate an increase in the quantity of data available to collect and process as diagnostic methods improve, with more emphasis on patient pathway analysis and individual tumour level data. Examples of extra data requirements include viral and biomarkers and data on disease progression.
The introduction of Encompass completed May 2025 should provide opportunities for better access to relevant data.

We receive data from Regional Information System for Oncology and Haematology (RISOH) in the form of monthly downloads of Systemic Anti-Cancer Therapy (SACT). These datasets enable completion of treatment details for production of cancer intelligence and official statistics.

1.7 Ethics and compliance with Data Protection

In August 2025, NICR had ethical approval for its databases successfully renewed for five years from the Office for Research Ethics Committees NI (ORECNI), Reference 25/NI/0104. Research projects using non-routine data require separate ethical approval.

NICR is a registered data controller under QUB with the Information Commissioner's Office (Registration Number: Z6833827) and has undertaken a Data Privacy Impact Assessment (DPIA) to align with UK GDPR (General Data Protection Regulation) and other relevant data protection laws. In addition, NICR has achieved ISO27001 accreditation for its information security management system (ISMS), which is maintained by a NICR staff member to oversee compliance and completion of regular internal audits.

NICR has data sharing agreements (DSAs) to facilitate receipt of data from NI Health and Social Care Trusts, Business Services Organisation (BSO), and the PHA Cancer Screening Service. The Registry does not seek individual patient consent for data collection. However, if requested, we would retain the anonymised fact of the cancer but remove the patient's identifiable information from the NICR database. No such requests have been received since the Registry was launched in 1994. Information on opting out is included in the patient information leaflet (Appendix B).

We welcomed the Health and Social Care Secondary Use of Data legislation in April 2016 and have been awaiting development of the regulations which may affect the operation of the NICR. The potential adverse impact that blanket patient opt-out may have on completeness for a population-based cancer registry like NICR needs to be considered and exemptions such as was introduced to address opt-out for cancer registration in England should be applied.

All identifiable data are held in a secure area of the registry, accessible to only a specific group of Registry staff for data verification which allows addition of specific clinical information such as cancer stage.

Patient identifiable data are required to:

- Allow validation of data received from multiple sources,
- Enable linkage of cases for follow up e.g., death records for survival, multiple tumours in same patient and to avoid double counting,
- Enable linkage to other databases e.g., treatment, screening,
- Support the Genetic Advice Service,

- Facilitate recall exercises. For example, the NICR previously helped the Department of Health (DoH) to identify patients who were at increased risk of breast cancer following radiation therapy for lymphoma with these patients subsequently offered screening mammograms.

1.8 NICR engages with patients by:

- Patient representation on the NICR Steering Group and Council,
- Cancer charity funding of research in NICR,
- Presenting NICR information to cancer patient groups,
- Including patients in report launches and studies.

1.9 NICR links with the public by:

- Production of a leaflet and poster to inform patients, clinicians, and the public about its work. These have been distributed widely across NI for display in cancer centres/units/GP surgeries/charities and are available on the NICR website (Appendix B),
- A video informing a wider audience of the work of NICR is available here,
- Public awareness of NICR through NI media via a variety of appearances and engagement with TV, radio, print and social media, highlighting key cancer data and statistics and encouraging early detection of cancers (Appendix F).

1.10 NICR links with clinical teams by:

- Having clinicians as active members of the NICR Council and Steering Group,
- Working with clinicians on research projects as collaborators, advisors, and/or funded participants e.g., for pathological verifications,
- Providing information for genetics counselling requests,
- Attending NI Cancer Network (NICaN) site specific Clinical Reference Group (CRG) meetings,
- Involvement in cancer audits – developing funding applications, determining the datasets to be collected, interpretation of results and making recommendations,
- Providing feedback to cancer screening services for quality assurance and improvement purposes.

1.11 NICR links with researchers through:

- The Director and Deputy Director being academic research staff in QUB,
- Provision of designated area within NICR for researchers to access anonymised datasets,
- Inclusion of local, national, and international researchers on specific research projects,
- Preparation of joint applications for research grant funding,
- Provision of data through data requests and data available on the NICR website,
- Providing data to international consortia for international studies e.g., Eurocare, Concord, International Cancer Benchmarking Partnership (ICBP), Cancer Incidence in V Continents, Benchista, ECIS,
- Working collaboratively with local, national, and international researchers on externally held grants,
- Peer reviewed publications using data from official statistics, audit reports,

- Training, mentoring and support of junior researchers through summer studentships and facilitation of undergraduate and postgraduate dissertation project work.

1.12 NICR engages with policy makers by:

- Development of Routes to Diagnosis on behalf of the DoH,
- Providing timely and accurate responses to NI Assembly Questions (AQs), Parliamentary Questions (PQs), and data requests from Trusts, PHA and DoH,
- Attendance at relevant NI Assembly Health Committee events (e.g., All Party Group (APG) on Cancer),
- Working with Strategic Planning and Performance Group (SPPG) and PHA on specific projects e.g., SACT Dashboard development,
- Invite policy makers and relevant stakeholders to visit the NICR (Appendix G),
- Presentations made at DoH Radiotherapy Services Workshop and Health and Safety Executive NI (HSENI) Conference,
- Providing data for development of the 2022-2032 NI Cancer Strategy.

1.13 Information Security

The NICR operates a high level of security, which has been independently audited and certified to meet the ISO27001:2013 Information Security Management standard in May 2017 and recertified in May 2023. Compliance is audited both internally and externally.

Information security controls include physical measures such as video surveillance, staff card access system, alarms triggered out of hours and access removed after a member of staff ceases NICR employment. There are several administrative controls implemented through various policies and procedures (available in Registry). These are included in regular staff training and are regularly audited.

A user access control system provides a tiered system of access to various physical areas of the Registry with only approved staff allowed in areas where patient identifiable data are used to verify registrations. A designated area for NICR staff working with anonymised data and a separate designated hot desk facility for external researchers using anonymised data are available. Phones and electronic devices are left at reception when external researchers access the hot desk facility. Staff can avail of hybrid working but while working off site, staff must adhere to security controls as outlined in the NICR Home Working Policy.

A limited number of NICR staff use hscni.net email accounts for secure communication and transfer of data with the NI Health & Social Care. Similarly, nhs.net email accounts are in place for communication and data transfers between NICR and National Health Service (NHS) organisations. The Health and Social Care NI (HSCNI) encrypted email service is used to securely transfer data to external research organisations.

NICR is working with an external IT company to develop a new IT system to replace PRAXIS, the NICR's current system originally developed 20 years ago. The new system is being developed using modern database technologies which will be more easily supported and developed going forward.

METHOD OF OPERATION

2.1 Diseases Registered

NICR registerable tumours are:

- Invasive malignancies including NMSC (ICD10: C00-C97),
- In-situ lesions (ICD10: D00-D09),
- Benign brain and testicular conditions (ICD10: D32, D33, D35.2, D35.3, D35.4 and D29.2),
- Neoplasms of uncertain or unknown behaviour (ICD10: D37-D48).

2.2 Data Sources

NICR acquires cancer and pre-malignant diagnoses via electronic downloads from pathology laboratories, integrated patient health records, hospital inpatient records, multi-disciplinary team meeting databases and death registrations.

NICR Cancer Intelligence Officers (CIO) use these sources to extract complex clinical information such as cancer staging and following cancer registration guidance ensure the availability of accurately coded population-based cancer data for NI. CIOs have access to full pathology reports, and part of their resolving work requires reading detailed reports to obtain full staging and diagnostic information that may not be available from electronic downloads or not coded to cancer registration standards.

In addition to the data sources above NICR has access to other datasets such as:

Prescription data

The Enhanced Prescribing Database (EPD), managed by BSO, contains detailed information on primary care prescriptions dispensed to patients in NI since March 2008. The dataset is used to identify specific cancer treatments such as hormone therapy for breast and prostate cancer. It also provides limited prescription information regarding co-morbidities within the cancer patient population in NI.

Comorbidities

Since 1st January 2006, NICR has received PAS (Patient Administrative System) downloads of hospital admission and discharge records for cancer patients, which provide hospital-based records of patient comorbidities.

Surgery

Curative surgical codes for cancer registration have been defined by the UK and Ireland Association of Cancer Registries (UKIACR) Analysis group. NICR uses Office of Population Censuses and Surveys Classification of Surgical Operations (Version 4.4) (OPCS4) codes to extract surgical data from PAS hospital discharge data.

Chemotherapy

Chemotherapy data are available from PAS hospital discharge data using OPCS4 procedure codes and are supplemented by extracts received from RISOH.

Radiotherapy

NICR receives radiotherapy treatment data from both the Northern Ireland Cancer Centre (NICC) and the North West Cancer Centre (NWCC), as well as limited radiotherapy notifications received through PAS hospital discharge data using OPCS4 procedure codes.

Premalignant Registers

NICR also holds the following premalignant disease registers which depend on external grant funding:

- Barrett's Oesophagus,
- Colorectal polyps,
- Endometrial Hyperplasia (EH),
- Monoclonal Gammopathy of Undetermined Significance (MGUS),
- High grade Cervical Intraepithelial Neoplasia (CIN), Cervical Glandular Intraepithelial Neoplasia (CGIN)
- Stratified Mucin-producing Intraepithelial Lesion (SMILE).

These important premalignant registers were highlighted in the NI Cancer Strategy 2022-2032[1], which advised that "***expansion of the precancerous databases would enable improved patient outcomes***." Action 11 from the Strategy recommended creation of "***surveillance systems for conditions where there is clear evidence regarding the pre-malignant potential of a particular condition to ensure people are not lost to follow up.***"

See below for further detail on the researcher-led pre-malignant registries.

NI Barrett's Oesophagus

The NI Barrett's Oesophagus Register (NIBR) is one of the largest population-based registers of Barrett's oesophagus (a pre-cursor condition to oesophageal adenocarcinoma) worldwide and now includes information on more than 28,000 incident cases diagnosed in Northern Ireland since 1993. The register is the foundation for a large body of epidemiological, clinical, and biomarker research, now led by Prof. Helen Coleman's team, that has informed clinical guidelines for surveillance of Barrett's oesophagus patients and provided data for publications of international standing.

Barrett's Register Epidemiological update and Biomarker studies (funded by Cancer Research UK)

The current epidemiological work aims to investigate trends in diagnoses of Barrett's oesophagus, and progression to dysplasia and oesophageal adenocarcinoma, now that new endoscopic treatments such as Endoscopic Mucosal Resection (EMR) and Radiofrequency ablation (RFA) are available. Endoscopic treatment data for dysplastic Barrett's oesophagus patients are currently being updated in a collaboration with Dr David Johnston (Clinical research fellow), Dr Zara Kirkwood (ACF), Prof. Richard Turkington and the Clinical Gastroenterology teams at the Belfast Health and Social Care Trust.

A number of biomarker studies are also ongoing , which use the NIBR as a sampling frame, which aim to: (i) explore the potential of a biomarker for assessing molecular age of Barrett's (led by Prof. Helen Coleman in collaboration with Dr Kit Curtius, UCSD and Prof. AJ McKnight, CPH) and (ii) identify biomarkers associated with progression to oesophageal adenocarcinoma (led by Prof. Richard Turkington and Prof. Helen Coleman).

All-Ireland Barrett's oesophagus Collaboration (funded by Breakthrough Cancer Research)

In 2023, Breakthrough Cancer Research launched the All-Ireland Oesophageal Cancer Network (AllCaN Oesophageal), investing over €1 million to enhance early detection and survival of oesophageal cancer. AllCaN oesophageal is led by Prof. Jacintha O'Sullivan (Trinity St. James's Cancer Institute) and co-led by Prof. Helen Coleman (QUB) and Prof. Juliette Hussey (Trinity St. James's Cancer Institute). This will enable, for the first time, bringing together of information from the NI and Republic of Ireland Barrett's oesophagus registries (over 34,000 patients) to answer important epidemiological questions using one of the largest platforms available worldwide. The AllCaN network also hosts a training network for early career researchers and PPI Panel with representatives from across the Island of Ireland. This research was showcased at the **Breakthrough Cancer Research Open Exhibition '*Cancer Revolution: Science, Innovation and Hope*'** in St. Stephen's Green shopping centre, Dublin, launched in August 2025.

Student projects

The NIBR continues to support a number of student projects, including **Dr Erin McGrattan** who passed her **PhD viva** subject to minor corrections in November 2025. Erin's thesis was titled 'Characteristics of Asymptomatic Barrett's Oesophagus and Oesophageal Cancer Patients to Inform Novel Prevention and Early Detection Opportunities', supervised by Prof. Helen Coleman, Prof. Richard Turkington and Dr Victoria Child, and was funded by the Brian Conlon Foundation. Three undergraduate students were also hosted in 2025: **Anna Blair** (Year 3 Biomedical Sciences dissertation project and an externally funded summer studentship from Breakthrough Cancer Research), and two Centre for Public Health summer studentships in Summer 2025 for **Aksh Sharma** (Year 2 Medical student) and **Marianne Toal** (Year 3 Medical student).

Current funding: *Breakthrough Cancer Research (AllCaN network) and Oesophageal Cancer Fund, Brian Conlon Foundation*; Historic funding sources: *Cancer Research UK* (NI Barrett's Register update 2011-2021), Medical Research Council, the HSC R&D Office Northern Ireland and *Cancer Focus NI*.

NI Colorectal polyp

NI Colorectal polyp register was updated until 2023 and awaits further funding.

Endometrial Hyperplasia (EH)

Endometrial cancer is the most commonly diagnosed gynaecological cancer in developed countries, yet there is currently no routine screening programme. Endometrial hyperplasia is a recognised precursor to endometrial cancer, and timely detection and treatment can prevent malignant progression. However, population-level data on the incidence of endometrial hyperplasia and factors influencing progression to cancer remain limited.

The Northern Ireland Endometrial Hyperplasia Register has been established within NICR and is the first register of its kind in the UK. The Register is currently funded through a UK Research and Innovation Future Leaders Fellowship awarded to Dr Úna McMenamin. It includes approximately 3,000 incident cases of endometrial hyperplasia diagnosed between 2008 and 2022, identified through review of endometrial biopsy pathology reports.

Preliminary analyses indicate a reduction in rates of endometrial hyperplasia diagnoses over time. This decline was not fully explained by changes in endometrial sampling and may reflect increasing pathological subspecialisation and suspension of gynaecological services during the COVID-19 pandemic. Findings have been disseminated at national scientific meetings, including the All-island Forum on Cancer Data (Belfast, January 2026) and the Irish Association for Cancer Research Annual Conference (Galway, February 2026). Pathology reports from 2023 onwards are currently under review to update the Register. Planned linkage to external datasets will enable the capture of key clinical information, including hormonal treatments and surgical procedures, to support evaluation of long-term outcomes such as progression to endometrial cancer.

Additionally, two studies have recently examined the relationship between endometrial hyperplasia and endometrial cancer. In the first, 66.5% of endometrial cancers in patients with hyperplasia were diagnosed within three months of the hyperplasia diagnosis, indicating a high prevalence of concurrent malignancy. Atypical hyperplasia was associated with a three-fold increased risk of having cancer diagnosed at the same time. In the second study, women with endometrial cancer who had a prior diagnosis of hyperplasia were younger, more likely to present with early-stage, low-grade tumours, and experienced better survival outcomes. Improved survival was largely attributable to earlier stage at diagnosis. This research was informed by patient and public involvement (PPI) representatives and clinicians, ensuring relevance to patients and clinical practice.

Taken together, this research will generate robust population-level evidence to inform diagnostic, treatment, and surveillance strategies for women with endometrial hyperplasia with the ultimate aim of better informing clinical decision-making between women and their health care professionals.

Current funding: *UKRI Future Leaders Fellowship*, *Northern Ireland Department for the Economy PhD studentship;* Historic funding sources: *Queen's University Belfast International PhD Studentship* (this register builds on previous work led by Prof. Helen Coleman).

MGUS (Monoclonal Gammopathy of Undetermined Significance)

This pre-malignant blood disorder commonly precedes multiple myeloma. This population-based database which is under construction will facilitate surveillance and assessment of the impact of MGUS on patient outcomes, such as rate of progression to cancer and subsequent survival. Requires funding to be developed.

NI Premalignant Cervical Lesions Register

The Northern Ireland Premalignant Cervical Lesions Register (NIPCLR) was established in 2020. The aim is to construct a database containing information about all histologically verified high grade premalignant (in situ) cervical lesions diagnosed in NI. This resource can be used to monitor incidence and prevalence, improve understanding of the diagnosis, treatment and progression of these lesions, evaluate the impact of screening and vaccination programmes and the effect of the coronavirus pandemic on the provision of services.

Work has included: standardising methods of data collection; reviewing the feasibility of deriving resection depth information from pathology reports; and starting the routine collection of CIN2 data. This pilot register has also been used as a basis for a PhD thesis chapter.

Due to the lack of regular funding, work on this project stopped in May 2022. Despite this, much of the data will continue to be collected through the core work of the main registry, and the NICR team will consider how to further enhance this pilot work and identify possible sources for further funding. With forthcoming changes to the range of premalignant lesions that are registrable, and potentially greater flexibility in the fields which can be collected with CENTRIS, it may mean that a separate premalignant register is no longer necessary to fulfil the aims.

The establishment of this register was possible due to generous funding from the Linsey Courtney Foundation. The European Network of Cancer Registries (ENCR) has recommended that Cancer Registries collect CIN2 and CIN3 data[2], but NICR are only currently funded to collect CIN3 data.

Current funding: No current source of funding

2.3 Measures of Quality Data

NICR dataset quality are compared annually to England, Scotland, Wales, and Ireland via the UKIACR which have shown NICR data quality to be of a high standard. For example:

- NI has the highest proportion of cancers staged (above 80%) from 2015 onwards (see Appendix C),
- NI has a high percentage of microscopically verified cases (which account for 84.8% of invasive malignancies registered, excluding NMSC),
- NI has a low percentage of death certificate only (DCO) registrations (which account for 1% of invasive malignancies registered, excluding NMSC).

Data from NICR have been included in numerous international comparative studies and these organisations have had to undertake minimal data cleaning, due to the quality of NICR data:

- ICBP,
- EUROCARE,
- Cancer Incidence in Five Continents,
- Concord International Cancer Survival Studies,
- Benchista.

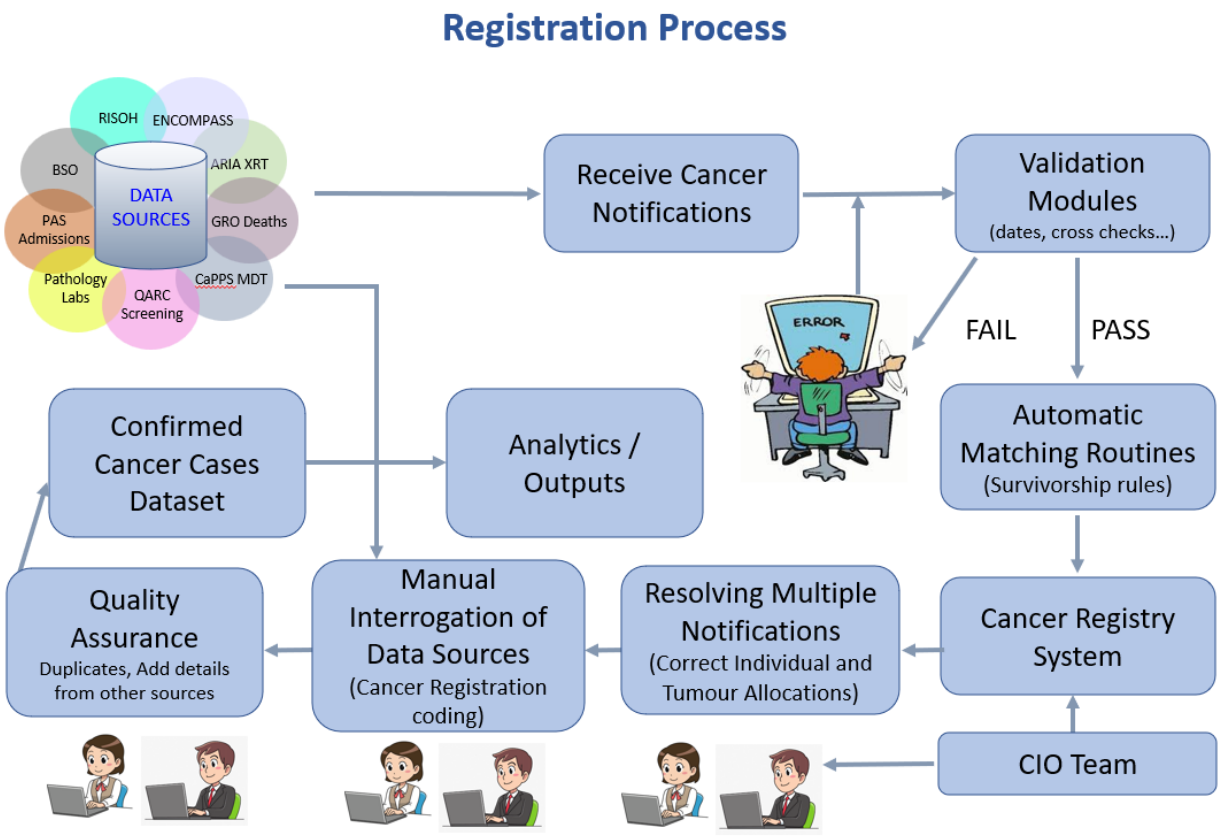
REGISTRY IT SYSTEM

3.1 Background

NICR are currently updating a legacy cancer registration database system (PRAXIS) which was developed in the 1990's. The PRAXIS system has many benefits, such as automated data linkage routines, which have not been fully replicated in other, newer systems. However, the underlying architecture is difficult to develop further, and the system is currently unsupported.

We are currently working with a local IT company (CODEC) who successfully tendered to replace PRAXIS with a system that is more easily supported and developed. It will be a Cloud based solution, using newer technologies such as MS Dynamics and Power BI, and will have the ability to record information on disease progression.

3.2 Method of Data Processing



REGISTRY OUTPUTS

4.1 Official Statistics

NICR produces official statistics for incidence, prevalence, and survival of cancer in NI. Official statistics for cancer registrations in 1993-2022 were published in two phases. Statistics on lung, breast, colorectal, upper gastrointestinal cancer, and melanoma were released in November 2024, with statistics on all other cancer types (including all cancers combined) released in July 2025. Overall statistics for 42 cancer types (including all cancers and NMSC) were included as part of these releases and are available from the NICR website.

Key characteristics presented for each cancer type include incidence trends and breakdowns of incident cases by patient demographics (e.g. sex and age), geographical areas (e.g. Health and Social Care Trust, Local Government District and Parliamentary Constituency), socio-economic deprivation and tumour characteristics (e.g. stage). Survival and prevalence statistics by key characteristics are included alongside the latest statistics on cancer mortality, with death data provided by the General Register Office Northern Ireland (GRONI).

4.2 Routes to Diagnosis

In March 2022, the Department of Health launched a new Cancer Strategy for Northern Ireland[1] which set the direction for cancer services for the 10 years between 2022 and 2032. Action 5 of this strategy aims to – "***Establish routes to diagnosis reporting and analysis on a regular basis to monitor changes to help improve diagnostic pathways and outcomes for patients"***.

In 2023 the NICR was funded by the DoH to develop a routes to diagnosis project[3] with the aim of providing an indication of the key event in each cancer patient's pathway that most directly led to their cancer diagnosis. Initially piloted in NI in 2020 using data from 2012-2016[4], which was in turn based upon a project which has been running in England since 2012[5,6], this exercise classifies every case of cancer registered in NI as having one of eight Routes to Diagnosis.

The data required to assign this classification comes from several sources. The core data on cancer patients is collected by the NICR. This data is linked to hospital episode data (both inpatient and outpatient) from PAS, referral data from the Cancer Patient Pathway System (CaPPS) and data supplied by the three cancer screening programmes in NI (bowel, breast, and cervix).

The translation of this wealth of data into a single route to diagnosis is based upon the algorithm developed by the National Cancer Registration and Analysis Service (NCRAS) in England[5,6]. This process works by initially assigning an endpoint based upon the hospital episode that occurred closest to diagnosis, and then working backwards to the event most likely to be the main referral source with certain key events, such as screening, given priority over others.

The second Routes to Diagnosis report for patients diagnosed in 2018-2021 was released in April 2025. The next update, to include patients diagnosed in 2018-2022, will be released in April 2026.

4.3 Cancer Factsheets

There are 42 factsheets updated annually as part of the official statistics release. These are available on the NICR website.

4.4 Research Publications

Since April 2025, 14 peer reviewed outputs using NICR data have been produced (179 since January 2013) (Appendix D). Most NICR recent scientific articles have a lay summary sheet, available here.

4.5 Information Requests

NICR handle two main types of information request: general and genetic requests.
General requests cover a broad range from descriptive statistical information to more complex analysis including investigation of suspected cancer clusters. During 2025, 40 out of 48 general requests for information were completed within the 20 working days target.

Genetic requests generally come from Genetic Counselling Services across the UK and Ireland, but requests are also received from services worldwide. Release of data is guided by UKIACR policy which requires a named registered medical practitioner to be responsible for the confidentiality, use and security of the data. Consent must be received by NICR before data are released. The target response for genetic requests is 10 working days and in 2025 the NICR completed all 156 genetic information requests received from outside NI within this timeframe (Appendix E). Within NI, the Clinical Genetic Service has a designated nurse who manages these requests using special status access to NICR datasets for cancer genetics patients.

4.6 Reports

NICR has produced 43 reports covering survival, cancer incidence and survival trends, All-Ireland statistics and an All-Ireland Cancer Atlas with colleagues in the National Cancer Registry of Ireland (see here).

4.7 Other Uses of Registry Data

- Regular feedback of cancer cases to regional cancer screening services for quality assurance and improvement,
- Annual updates for CRUK to populate UK wide cancer statistics concerning cancer incidence, mortality, survival and risk factor estimates on their webpage,
- Provision of data for national/international projects;
    a. ICBP International Cancer Survival Phases 1, 2 and 3 (see here),
    b. CONCORD, (see here)
    c. Benchista, (see here),
    d. EUROCARE (see here),
    e. Cancer Incidence in Five Continents (see here),
    f. European Cancer Information System (ECIS) (see here),
    g. UK Cancer Survival Project-London School of Hygiene and Tropical Medicine (see here).
- Provision of data on the impact of COVID-19 on cancer services (see here),

- Health and Social Care Inequalities Monitoring System (HSCIMS) (see here).

4.8 Research Projects

Facilitated by NICR staff 2025-2026

- Dr Damien Bennett, Dr Lorenzo Stella, Helen Mitchell, and Data Analytics MSc student Jessica Santizo Galicia - Outpatient appointment before cancer diagnosis analysis project,
- Dr Damien Bennett, Dr Lorenzo Stella, Helen Mitchell, and Data Analytics MSc student Andrea Serrano Santos - Radiotherapy data analysis project,
- Dr Damien Bennett, Helen Mitchell, and undergraduate Medical Summer Student Josias (Grace) Nyele - Scoping project on Super Survivors.

Projects facilitated within NICR by external researchers 2025-2026

Name	Study Title
Anna Blair	Understanding the malignant potential of gastric metaplasia of the oesophagus: a population-based study – *Supervisor Prof Helen Coleman*
Erin McGrattan	Identifying characteristics of asymptomatic oesophageal cancer and Barrett's oesophagus patients to inform novel prevention and early detection opportunities – *Supervisor Prof Helen Coleman*
Aksh Sharma	Understanding the malignant potential of gastric metaplasia of the oesophagus: a population-based study – *Supervisor Prof Helen Coleman*
Marianne Toal	Understanding the malignant potential of gastric metaplasia of the oesophagus: a population-based study – *Supervisor Prof Helen Coleman*
Ying Yang	Epidemiological research of colorectal and gastric cancer – *Supervisor Prof Helen Coleman*
Lauren McKenna	Epidemiology and treatment outcomes of endometrial hyperplasia and cancer: A population-based investigation using routine administrative data – *Supervisor Dr Una McMenamin*
Rachel Daffy	A Quality Assessment of the Northern Ireland Endometrial Hyperplasia Register – *Supervisor Dr Una McMenamin*
Jack Murphy	Mechanistic underpinnings of risk factors for fatal prostate cancer – *Supervisor Dr Emma Allott*
Ella Shields	Impact of comorbidity on prostate cancer outcomes in Northern Ireland: A population-based study using the Charlson Comorbidity Index (CCI) – *Supervisor Dr Emma Allott*
Ishrar Rafid	Epidemiology of prostate cancer and co-occurring other primary cancers among men in Northern Ireland. – *Supervisor Dr Emma Allott*
Sasha Palmer	Investigating Routes to Bladder Cancer Diagnosis in Northern Ireland – *Supervisor Dr Dan Middleton*
Rawan Hattab & Claire Delargy	Investigating geospatial risk factors of cancer – *Supervisor Dr Dan Middleton*
Meg Wallace	Investigating environmental risks for bladder cancer – *Supervisor Dr Dan Middleton*
Tracy Sloane	A forgotten cancer: investigating the aetiology of oesophageal squamous cell carcinoma in the UK – *Supervisor Dr Dan Middleton*
Didar Dyussetayev	Epidemiological study to evaluate the impact of the Northern Ireland Colorectal Cancer Screening Program (NICRCSP) – *Supervisor Dr Finian Bannon*
Mayuri Raje	Can we identify chemotherapy induced neurotoxicity using real world data? – *Supervisor Dr Blanaid Hicks*
Anhukrisha Karthikeyan & Laura Agnew	Describing the Use of Targeted Cancer Therapies in Northern Ireland: Patterns and Patient Characteristics – *Supervisor Dr Blanaid Hicks*
Lucas Keyes	Exploratory Study of Cancer in Facioscapulohumeral Muscular Dystrophy: A Population-based study using the Northern Ireland Cancer Registry – *Supervisor Grace McMacken*
Zara Kirkwood & David Johnston	Endoscopic Eradication Therapy for Dysplastic Barrett's Oesophagus and Low–Stage Oesophageal Adenocarcinoma; Predictive Indicators and Risk Factors for Disease Recurrence.
Andrea Serrano Santos	Exploring the Link Between Socio-Economic Deprivation and Cancer Incidence in Northern Ireland – *Supervisor Dr Ethna McFerran*
Erin Fitzsimons-West	Survey of breast cancer management during pandemic (NI/ Ireland Specific); Health inequalities for patients with breast cancer- healthcare provider perspective. – *Supervisor Dr Charlene McShane / Dr Damien Bennett / Prof Frank Kee*
Stephanie Craig	A novel role for oral inflammatory disease and the oral microbiome in the early detection of cancer – *Supervisor Prof Dan Longley*
Kifa Mohammad	A novel role for oral inflammatory disease and the oral microbiome in the early detection of cancer – *Supervisor Dr Stephanie Craig*
Shaima Abujaber	Exploring Epidemiological Trends and Patient Experience in Head and Neck Cancer – *Supervisor Prof Gerry McKenna & Dr Amanda Willis*

4.9 Audits

The Registry has previously completed a range of clinical audits evaluating the pathway of cancer patients to cancer services since 1996. To date, 22 reports have been produced, making recommendations for service improvement, with each report available on the NICR website. Highlighting audit findings has provided media opportunities which allowed cancer prevention promotion and messaging around early cancer detection as well as raising the profile of NICR and QUB.

The most recent audits include;

- Breast Cancer COVID-19 Impact – funded by Breast Cancer Now,
- Metastatic Breast Cancer Research Audit – funded by Cancer Focus NI,
- Lymphoma Audit – funded by LLNI & Blood Cancer UK.

Breast Cancer Now – COVID-19 Impact Audit

In 2022 NICR received a grant from Breast Cancer Now to undertake a study on the impact of COVID-19 on breast cancer patients. The quantitative audit component, led by Helen Mitchell and Sinead Hawkins, covered approximately 2200 patients diagnosed in March - December 2018 and 2020. Analysis is now complete and the final report will be published in 2026. A methodology paper was published in PLOS One in September 2025.

The mixed methods component of this project is led by Dr Charlene McShane, Dr Lynne Lohfeld and assisted by Dr Meena Sharma at the CPH. The online patient survey had over 2,000 responses and analysis is being undertaken by Dr Meena Sharma with a publication due to be submitted in early 2026. Analysis of patient interviews conducted by Dr Lynne Lohfeld is underway and a draft publication being prepared.

Metastatic Breast Cancer Research Audit

Cancer Focus supported the NICR to develop the first ever metastatic breast cancer (MBC) research audit in Northern Ireland. Progressive cancer events are not routinely recorded in most cancer registries, including NI. For patients initially diagnosed with locoregional breast cancer (i.e. stages I-III) there is no specific health service data collected by registries on the numbers of patients who subsequently develop progressive or recurrent metastatic breast cancer. NICR has undertaken a three-phase process to deliver on an MBC audit.

Phase 2 of this project is to improve accuracy of MBC diagnosis timing using a range of datasets available to the cancer registry. Each of these datasets have been evaluated and a hierarchical model was developed to identify the earliest identified date of MBC for patients. Results of this phase will be released in 2026.

Breast Cancer – Inequalities Audit

Prof. Chris Cardwell and Dr Charlene McShane, along with Dr Damien Bennett, NICR and CPH staff, have investigated if some women in NI experience inequalities in breast cancer care and outcomes, thanks to funding from Breast Cancer Now. NICR staff have successfully developed novel linkages with BSO and the Northern Ireland Statistics and Research Agency (NISRA) datasets to allow investigation of the impact of, for example, mental health problems, remote living, and socio-economic status on stage at diagnosis and survival outcomes. An online survey and qualitative interviews will also be conducted of a sample of breast cancer patients to understand how inequalities impact on their experiences of living with a breast cancer diagnosis.

A paper examining the impact of mental health conditions on breast cancer outcomes has been published in Breast Cancer Research and Treatment. A paper investigating house value as an individual measure of socio-economic status has been submitted to Breast Cancer Research and Treatment and a paper examining the impact of travel times to from GP and treatment centres and breast cancer outcomes has been submitted to Cancer Causes and Control. Furthermore, a paper is currently being developed which examines the impact of health inequalities on breast cancer outcomes. Posters were presented for both mental health conditions and breast cancer outcomes studies at the ENCR Conference, where the mental health the poster was awarded ENCR Best Poster, and at the All-Island Forum on Cancer Data. Poster presentations were also given for the house value and breast cancer outcomes study at the UK Interdisciplinary Breast Cancer Symposium, where it was awarded Best Poster. In addition, Dr Sarah Baxter was awarded the Prof. Dermot O'Reilly Prize for the manuscript "Stage at diagnosis and breast cancer specific mortality in breast cancer patients treated with antidepressants, anxiolytics, and antipsychotics: a population-based cohort study from Northern Ireland".

Haematological cancer report and lymphoma audit

Leukaemia and Lymphoma NI and Blood Cancer UK have supported the NICR in developing a two-part research and audit project on haematological cancers in NI. This includes a detailed epidemiological report, presenting information on blood cancers beyond the scope of routine NICR reporting, and an audit report benchmarking lymphoma cancer care in NI against clinical quality performance indicators from across the UK.

This project's epidemiological report will include the latest incidence, prevalence and survival statistics, as well as future projections and geographical mapping for haematological cancer in NI. In addition to leukaemia, lymphoma and myeloma, this will include specific analysis of chronic myeloproliferative disorders, myelodysplastic syndrome and other immunoproliferative diseases, and detailed subgroups of each condition where appropriate.

The lymphoma audit report has been enabled by collaboration with haematologists via the NICAN CRG. Data collection is underway to enable benchmarking of haematological care outcomes in NI against Public Health Scotland's National Lymphoma Quality Performance Indicators, and performance indicators from the National Cancer Audit Collaborating Centre (NATCAN) National Non-Hodgkin's Leukaemia Audit.

ISSUES OF CONCERN AND CHALLENGES FOR NICR

Some of the challenges that the NICR faces over the coming years are outlined below:

5.1 Lack of a Legislative Framework for Disease Registration

We are awaiting a legislative framework for cancer registration in NI. In April 2016, a Bill on Secondary Use of Health and Social Care Data received Royal Assent. This will require regulations to be drafted before consultation and final approval. The Minister of Health has been actively lobbied on this matter, and this has been raised in the Cancer Strategy[1]. Although NICR welcomes the legislation, there should be exemption for opt out from cancer registration similar to that in England. From a cancer registration perspective, a useful reference is from England where exemption from Type 2 objections was provided by Ministerial direction in 2016 for data required for cancer registration data as applied to the NCRAS. Our concern is that offering a single, blanket opt-out for patients for all their healthcare data (e.g., via Encompass etc) may mean a significant drop in cancer cases and cancer data being available for cancer registration, which will make trend analysis and comparisons inaccurate and accurate investigation of cancer clusters impossible. Cancer registration depends on complete, continuous, and consistent data on all cancer patients.

5.2 Access to Data Sources

Access

Cancer registration depends on a continuous and consistent supply of data from a variety of sources to ensure complete and accurate recording of cancers in NI. When RISOH replaced COIS, it took four years to receive oncology treatment data. Following the move to Encompass, we have experienced similar problems securing access to data required for cancer registration. Disruption to existing data flows may result in delays or gaps in cancer registration, which undermines confidence in data and outputs.

Minimum Cancer Dataset (MCD) for Registration

Currently, unlike in England, there is no mandated minimum cancer dataset (Cancer Outcomes Services Dataset (COSD)) required from Trusts in NI. The development of a minimum dataset was a recommendation from the NI Cancer Strategy (2022) [1] and the NICR peer review (2018). COSD is used by the cancer registry in England (NCRAS) to provide much of the data items required for national audit. Adopting a similar approach in NI would help facilitate timely audit and allow for benchmarking with other regions. Although it may be possible to embed these fields within Encompass, this has not yet been implemented. Development of a NI level MCD should involve input from NICR staff.

5.3 IT System

NICR are currently replacing its legacy registration database system (PRAXIS), which has been in operation for 20 years. The replacement system will have the capacity to record additional data such as disease progression and molecular markers and will allow enhanced reporting. It is hoped that additional funding will allow further enhancements such as inclusion of key performance indicators required for local/national audit and extension to premalignant registers.

Recording of disease progression

Recording of disease progression (including recurrences, secondary and metastatic cancers), will require development of the IT system. However, this will not mean NICR staff will be able to begin recording disease progression as NICR is funded to record primary disease only. Substantial additional staff would be required to record disease progression. Recruitment and training of these staff would also take some time. A Secondary Breast Cancer Research Audit funded by Cancer Focus should allow NICR to assess some of the practical issues associated with the process.

5.4 Annual Funding

NICR is currently funded by the PHA, but the University considers this an annual grant.
There are still difficulties in staff retention and recruitment as posts can only be advertised on a short-term basis, usually one year. Therefore after 6 months staff receive end of contract notifications and are offered other posts in the university via the QUB redeployment portal. Long term planning is required to attract and retain staff.

5.5 Funding for Audits

Audits provide a mechanism to benchmark local services against best practice guidelines and also with providers outside NI. It requires comparison of patient level datasets using similar methodologies and rigorous collection of datasets. There is strong support across a range of stakeholders (clinicians, NICaN, PHA, SPPG etc) for better audit data. The NICR 2018 Peer Review made recommendations about exploring how NICR can support clinical audits. The NICR has a strong record of undertaking local audit since 1996 and to date has published 22 audits. However, funding for each audit comes from various external sources such as charities and RQIA. For example, the current Breast Cancer COVID-19 Impact Audit is funded by Breast Cancer Now and the Metastatic Breast Research Audit is funded by Cancer Focus NI – both of which are cancer charities. Regular funding is required to allow an ongoing cycle of regular audits by experienced NICR staff, which will retain staff skilled in data collection and analysis.

5.6 Staffing and Succession Planning

NICR has a relatively small team of highly specialised staff, often with long experience. Although staff turnover is low and staff are very committed, there are risks as staff retire or leave for other posts. Recruitment and retention of IT staff has been problematic, with currently only a single IT officer in post. Additional resources to allow work shadowing and training of new staff would reduce the risk of skills and expertise loss in this small group. The CIOs have a very specialist skill set which takes extensive training. As a result, these posts are difficult to fill. The post of Director has been made permanent, however this is only on the basis of 80% QUB and 20% PHA. Arrangements need to be made for the backfill of 20% which will be challenging.

NICR RESOURCES

6.1 Current staff and funding

NICR is currently funded (as a population-based cancer registry) by the PHA, with the University considering this an annual grant. The budget for 2025-2026 was £1,157,884, with almost 90% spent on salaries. The Registry submits research and audit grant applications to various funding bodies and, if successful, undertake specific research/audit projects. Discussions are ongoing with PHA, and we await budget allocation for 2026-2027.

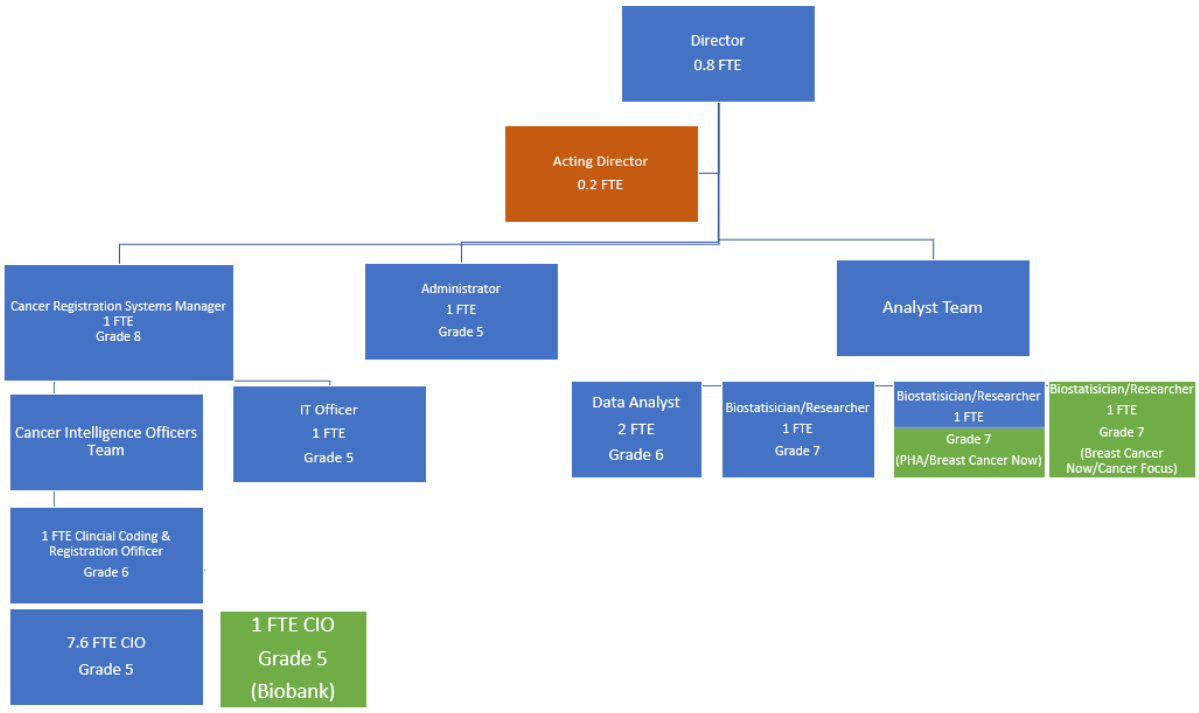


Figure 3: Current PHA/Grant funded staff 2025-2026

FTE = Full Time Equivalent
Colour code; Blue = PHA, Green = Grant/Additional funding, Amber = CPH

Regarding figure 3:

- NI Biobank currently fund 1 FTE CIO,
- Breast Cancer Now fund a 2-year COVID-19 impact audit for 2018 & 2020 – 2x 0.5 FTE Analysts,
- Routes to Diagnosis funded by PHA fund 1 FTE Researcher.

Due to continued increase in the number of cancers and their complexity, NICR will require additional data verification and analytical support and a more sustainable model of funding (see Figure 1 on page 7).

In the area of clinical audit, an audit team could be developed to work on a rolling cycle with the major tumour sites audited at least every five years with comparisons in national audits.

6.2 Allocations from PHA

Table 1: Allocation from PHA

Funding from Public Health Agency	Funding 2020/2021	Funding 2021/2022	Funding 2022/2023	Funding 2023/2024	Funding 2024/2025	Funding 2025/2026
Total Core Work	**£861,444**	**£878,673**	**£913,293**	**£945,633**	**£1,087,215**	**£1,157,884**
Routes to Diagnosis				**£77,967**		
International Cancer Benchmarking Partnership				**£15,450***	**£15,450***	**£15,450***

* *NICR pay this funding directly to CRUK to allow to the inclusion of Northern Ireland data in the ICBP project.*

Funding for 2026-2027 is not yet confirmed.

6.3 Other funding

In addition to the allocation from PHA, NICR has gained support for other research projects including; All Island Cancer Atlas and two audit projects, Breast Cancer COVID-19 Impact and Metastatic Breast (funded by Health Research Board (HRB), Breast Cancer Now and Cancer Focus NI).

Table 2: Research/Audit Expenditure relating to projects active during the period 1 April 2016 – 31 March 2026

	Funder	Start Date	End Date	Total Budget	Expenditure up to 31/03/26	Balance c/f 2026-2027
Breast Cancer COVID-19 Impact Audit	Breast Cancer Now	01/05/22	30/04/26	£229,126	£146,850	£82,276
Secondary Breast Cancer Research Audit	Cancer Focus	01/04/23	31/12/26	£60,000	£51,628	£8,372
All Island Cancer Atlas	HRB	01/12/24	30/11/27	£92,842	£0	£92,842

Table 3: Update on Key Priorities for 2025-2026

Colour code: Green = completed, Amber = ongoing, Red = not completed

Targets 2025/2026	Updates
1. Provide complete, accurate data on cancers in NI for official statistics by March 2026 for patients diagnosed in 2023	- 2022 statistics were released in November 2024 and July 2025 - We have moved to a single release for 2023 statistics with plans to release in June 2026
2. Develop Routes to Diagnosis data and outputs	Second report released April 2025
3. Respond to general data and information requests within a timely manner	Work continues to develop an electronic Request Monitoring Service to provide better tracking of requests, status, and timeliness
4. Respond to requests from the family genetic services within a timely manner	All 156 requests responded to within the 10-day target
5. Provide NI datasets for international comparisons and collaborations e.g., ICBP, Eurocare, Concord, Benchista, ECIS	Datasets submitted to ECIS & Benchista
6. Seek to ensure NICR requirements are met by future HSC systems e.g., Encompass	A limited extract of data from Encompass was secured for 2023 patients diagnosed/treated within the SET. We continue to seek access to Encompass data that meets the needs of the NICR
7. Maintain ISO 27001 Certification in Information Security Management	External audit successfully completed May 2025
8. Implement new Registry IT System and ensure it is fully operational for staff	CENTRIS UAT is nearing completion and progress has been made regarding its hosting. - *Staff training* - *Complete data migration* - *Parallel testing of CENTRIS and PRAXIS* - *Ensure system is fully supported* - *Investigate further enhancements in line with user requirements* - *Establish ongoing support for IT system (funding required)*
9. Enhance and improve NICR data outputs and seek to tailor for individual stakeholders	NICR website has been enhanced and updated, providing users with easier access to data. Work is ongoing to incorporate dashboards as an additional means of accessing data
10. Provide data for UKIACR annual Performance Indicators (PIs)	NICR data submitted and included in UKIACR PIs
11. Continue to work with external researchers to enhance cancer research in NI	Research collaboration with CPH and Data Analytics Researchers (e.g. Dr Dan Middleton, Dr Finian Bannon, Dr Emma Allott, Dr Ethna McFerran, Dr Adele Marshall)
12. Ensure Standard Operating Procedures are kept up to date	SOPs reviewed and placed on SharePoint in July 2025
13. Ensure NICR Director Post is maintained on permanent basis and filled 100%	Raised at NICR Steering group (4) and NICR Council (2) meetings, with QUB & PHA representatives in attendance

Targets 2025/2026	Updates
14. Undertake a formal data quality assessment of the NICR data	JRC checking software ran on ECIS extract by NICR Analysts. Will rerun on official statistics
15. Secure funding for ongoing collection of data on premalignant diseases	Prof Helen Coleman secured funding for the Barrett's Oesophagus Register via AllCaN
16. Explore resources needed to collect additional NICR data items as per ENCR recommendations (e.g., comorbidities, tumour markers, recurrences)	Raised at Council/Steering Group that NICR is out of step with other registries, but no business case made. Of low priority with other more pressing commitments such as hosting of IT system
17. Secure resources to allow collection of CIN II and NMSC data in line with UKIACR counterparts and ENCR recommendations	- Raised at NICR Steering Group and Council meetings - Further discussions to take place
18. Work with clinicians, NICaN, local charities and PHA to secure funding to undertake audits	Discussions ongoing with LLNI & NIPANC regarding future audits and analysts
19. Investigate development of rapid datasets (RDs) – using CAPPs and SACT data	Awaiting comprehensive extracts from Encompass despite several meetings/emails to relevant personnel
20. Increase awareness of the opportunities NICR data can provide	- Good media engagement maintained (see Appendix F) - CPH Cancer Epidemiology Research Group attended on a regular basis by NICR staff - Participation in Radiotherapy Review Group by NICR Director - Participation in HDRUK Big Data for Complex Disease by NICR Director - Participation in AICRI Programme Board by NICR Director - Participation in ICBP Programme Board by NICR Director - Attendance at Clinical Reference Groups (CRGs) by NICR staff, where possible
21. Expand on secondary cancer research audit	Quarterly Steering Group meetings established to review on-going work and explore opportunities for further research
22. Expand on current breast cancer inequalities work to other sites	Dr Damien Bennett and Dr Chris Cardwell have submitted a joint bid to ESRC to expand inequalities work to other sites
23. Link with Biobank	Meetings attended
24. Develop N/S Research projects	Work has progressed significantly with the All-Island Atlas, following delays setting up appropriate agreements between QUB and NCRI. Explore other N/S opportunities
25. Timeliness of official statistics	Measures to increase timeliness within existing resources have been employed such as no longer collecting some extended registry variables (e.g. ER value, Clinical/pathological size).
26. Ensure seamless transfer from PAS to Encompass	- Involvement in archiving of Trust data when Encompass transfer complete - Attendance at appropriate planning meetings
27. NI Health Analytics Platform (NIHAP)	- Multiple and various discussions ongoing with NIHAP, PHA & BSO regarding possible hosting on BSO platform

Table 4: NICR Key Priorities 2026-2027

Targets 2026/2027	Proposed Actions
1. Provide complete, accurate data on cancers in NI for official statistics by June 2026 for patients diagnosed in 2023	Release official statistics by June 2026
2. Respond to general data and information requests within a timely manner	- Implement new electronic Request Monitoring Service to provide better tracking of requests, status, and timeliness - Review and improve processes with researchers, students and analysts
3. Respond to requests from the family genetic services within a timely manner	Monitor timeliness of responses to genetic requests
4. Timeliness of official statistics	Investigate process and resources required to support production of official statistics in a timely manner
5. Develop Routes to Diagnosis data and outputs	Produce Routes to Diagnosis data for 2022 by June 2026

6. Implement new Registry IT System and ensure it is fully operational for staff	- Undertake comprehensive User Acceptance Testing (UAT) of the new IT system with involvement of NICR staff from each work area
	  - Staff training
	  - Complete data migration
	  - Parallel testing of CENTRIS and PRAXIS
	  - Ensure system is fully supported
	  - Investigate further enhancements in line with user requirements
	- Establish ongoing support for IT system (funding required)
	- Establish hosting platform and secure data output into QUB

7. Maintain ISO27001 Certification in Information Security Management	Undertake regular internal audits to ensure confidence with NICR ISO policies and update policies as required
8. Ensure support & resources for NICR IT systems	- Evaluate current IT infrastructure required to support NICR core functions and data access needs - Establish funding streams for support & maintenance - Liaise with QUB IT
9. Secure appropriate datasets required for NICR function	NICR staff will continue to seek access to data from relevant parties, e.g. Encompass
10. Enhance and improve NICR data outputs and seek to tailor for individual stakeholders	- Review how other registries and data providers present and use data. - Engage with stakeholders, patients, cancer charities & appropriate clinicians regarding NICR data outputs
11. Ensure continuity of existing work processes as a result of transition to CENTRIS	- Any new processes introduced due to move to CENTRIS should not negatively impact NICR core functions

Targets 2026/2027	Proposed Actions
	- Awareness and scoping of adverse impact to official statistics, Genetic Requests and Route to Diagnosis production and provision of data to NI Biobank
12. Ensure access to archive of PAS data for Routes to Diagnosis	Continue engagement with appropriate individuals
13. Ensure NICR systems integrate with BSO, NIHAP	Engage with relevant stakeholders
14. Secure appropriate datasets required for NICR function	NICR staff will continue to seek access to data from relevant parties, e.g. Encompass
15. Provide data for UKIACR annual Performance Indicators	Submit data to UKIACR either by due date or within one month of final release of official statistics
16. Continue to work with external researchers to enhance cancer research in NI	- Provide researchers with: - Datasets from NICR data sources - Secure environment for analysis of NICR data - Advice on data availability/opportunities - Advice and support with data interpretation outputs - NICR Analyst involvement with the CEDAR group
17. Ensure Standard Operating Procedures are kept up to date	- Undertake review of NICR SOPs - Identify new areas that need SOPs
18. Ensure NICR Director Post is maintained on permanent basis and filled 100%	Continue to raise with NICR Steering group, QUB, and PHA to ensure target is achieved
19. Undertake a formal data quality assessment of the NICR data	Set up schedule of data quality assessments with input from NICR staff across various workstreams
20. Secure funding for ongoing collection of data on premalignant diseases	Work with CPH researchers to investigate potential funding sources to support continuity of premalignant registers
21. Premalignant diseases onto CENTRIS	Investigate possibilities for registers to be incorporated into CENTRIS
22. Explore resources needed to collect additional NICR data items as per ENCR recommendations (e.g., comorbidities, tumour markers, recurrences CIN II and NMSC data)	- Explore potential funding sources for additional data collection - Determine process for additional data item collection, quantify resources required
23. Secure funding to undertake audits	Investigate potential funding sources to support regular ongoing clinical audits
24. Investigate development of rapid datasets (RDs) and Dashboards	Integrate data into development of rapid dataset for NI, e.g. Encompass /SACT
25. Provide NI datasets for international comparisons and collaborations e.g., ICBP, Eurocare, Concord, Benchista, ECIS	Datasets to be submitted by agreed dates
26. Improve and increase cross-working and knowledge transfer	Work shadowing & task transfer among different work streams

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APPENDIX A: Steering Group, Council and Research Advisory Group Membership

NICR Steering Group

Role of Steering Group as revised 8th February 2012;

a) Agreeing the Registry's strategic objectives,
b) Providing specialist advice,
c) Agreeing the Registry's development strategy and annual business plan,
d) Being informed about registry performance and advising in setting priorities in improving or enhancing performance,
e) Assisting the Registry in matters of general policy where these impact upon the wider mainstream activity of the NHS, in the Health and Social Services Boards, Health and Social Care Trusts, Provider Organisations and the NI Cancer Network.

The Steering Group meets quarterly.

Membership:

Prof. Mark Lawler (Chair)	Ass. Pro-Vice-Chancellor & Prof. of Digital Health, MHLS Faculty
Ms Jean Frizzell	HSC Board, Financial Accounts & Governance
Mr Richard Spratt	Cancer Focus NI, CEO
Ms Nora Smith	Cancer Focus NI
Mr Gareth Irwin	Health and Social Care Trust Clinician
Dr Louise Herron	PHA
Ms Louise Dunlop	QUB, Governance
Dr Emma Allott	QUB, JCRC

With attendance from Registry Director, Deputy Director and relevant staff required for the agenda.

NICR Council

Role "***to pursue the aims of the Registry and to identify and enhance opportunities for use of the Registry data***" by advising the Director and Steering Group. Frequency of meetings - twice a year. It provides a mechanism to liaise with key stakeholders.

Membership:

Mr Jim McGuigan (Chair)	Belfast HSC Trust
Dr Maurice Loughrey (Deputy Chair)	Pathologist Belfast HSC Trust
Ms Barbara Roulston	Cancer Research UK
Dr Brid Farrell	Public Health Agency
Ms Rosemary Rainey	Lay Representative
Dr Jacqueline James	Pathologist QUB and NI Biobank
Prof. George Kernohan	Ulster University
Ms Davinia Lee	Belfast HSC Trust
Dr Claire Lewis	NI Biobank

Dr Seamus McAleer	Oncologist QUB
Ms Janice Preston	Macmillan NI
Dr David Morrison	Director of the Scottish Cancer Intelligence Service
Ms Debbie Keatley	Lay Representative
Dr Collette McCourt	Belfast HSC Trust, Dermatologist
Dr Deirdre Donnelly	Belfast HSC Trust
Dr Deirdre Murray	Director of the Irish Cancer Registry
Dr Gillian Rea	Genetics Services
Mr Gareth Kirk	Action Cancer
Dr Sarah McKenna	Belfast HSC Trust
Dr Michael Reilly	Western HSC Trust

With attendance from Registry Director, Deputy Director and relevant staff required for the agenda.

Research Advisory Group

Role is to review major, difficult or strategic Data Information requests received to the Registry to ensure they have a scientific rationale, appropriate methodological approach and are covered by the existing ethics approval held by NICR. The RAG joins the bi-annual NICR Council Meetings with extraordinary meetings convened to review Data Information requests when required.

Membership:

Prof. Helen Coleman	QUB, CPH
Prof. Ciaran O'Neill	QUB, CPH
Dr Edward Goodall	NI Cancer Research Forum
Ms Dorianne Finlay	NI CRUK & Marie Curie
Ms Ashley Hurst	NI Cancer Research Forum
Dr Cherith Semple	Ulster University
Dr Nicola Armstrong	PHA
Dr Aidan Cole	Health and Social Care Trust/QUB
Dr Charlene McShane	QUB, CPH
Dr Olinda Santin	QUB, School of Nursing Midwifery
Dr Emma Allott	QUB, JCRC
Dr Nick Orr	QUB, JCRC
Dr Chris Cardwell	QUB, CPH (Statistician)

APPENDIX B: Patient Information Leaflet

Do I have a choice?

Yes, you do have the right to opt-out and this will not affect the care you receive.

However, in order to work properly, the registration system needs to know about everyone with cancer.

Your details help care teams learn how best to treat cancer, make sure they provide the best care and help to find out the causes of cancer.

If you are concerned about your details being registered or any other issues in this leaflet, please discuss this with your doctor or contact the Northern Ireland Cancer Registry by calling 028 9097 6440.

Why We Collect Data Without Asking Everyone?

We collect this data without asking each person directly because it would be too difficult - especially during stressful times in healthcare. If people opted out, the data could be incomplete and biased, often missing those who are very ill or disadvantaged. Having full and accurate information helps us track outcomes, avoid duplication, and link with other health services. It also supports vital public health work and improving care for everyone.

There's a very small risk to your privacy and a slight loss of personal control, but the benefits of using health data are far-reaching. It helps us learn more about what causes cancer and how to prevent it, to improve treatments, and protect communities through vital research and health monitoring.

Where can I get more information?

Northern Ireland Cancer Registry
Telephone 028 9097 6440
Visiting the Northern Ireland Cancer Registry website at www.qub.ac.uk/nicr which has a useful section on common questions about the cancer registration system.

Cancer Focus Northern Ireland
Telephone 0800 783 3339 or visit cancerfocusni.org
Monday, Wednesday, and Friday (9.00am - 1.00pm)

If you are a child with cancer or the parent of a child with cancer, you can get further information by visiting the Children's Cancer Unit Charity website at https://childrenscancerunit.com/ or the Cancer Fund for Children website at https://cancerfundforchildren.com/

This leaflet was adapted for use in Northern Ireland from the NHS "About cancer registration" leaflet which received the awards below.

If you require further copies of this publication, please contact the Northern Ireland Cancer Registry:
Tel: 028 9097 6440
E-mail: nicr@qub.ac.uk

Northern Ireland Cancer Registry

HSC Public Health Agency

Revised August 2025

Northern Ireland Cancer Registry

About Cancer Registration

A Leaflet for Patients and Public

HSC Public Health Agency NICR

What is cancer registration?

When someone is diagnosed with cancer or a condition that might lead to cancer, the doctor or hospital records the relevant details about your care and treatment. This applies to people of all ages, including children.

This information is collected by the Northern Ireland Cancer Registry and we would like to make sure that patients know this is happening.

Why is registration necessary?

Registration is the only way that we can see how many people are getting cancer and what types of cancer they have.

Most countries in the world have a cancer registry including England, Wales, Scotland and the Republic of Ireland. Registration has been running in Northern Ireland since 1993.

By working with cancer researchers, cancer registries have been able to identify the causes of some cancers. It also allows us to look at how cancer patients are treated and how successful treatments have been for different types of cancer. Registration also helps us to make sure cancer screening programmes are working. Registration shows whether the number of people getting cancer is going up or down, so the health service can make sure services and staff are available in the right place.

The information registered is vital for research into cancer. Cancer registration is supported by all the main cancer charities. *see adjacent list

What do you need to know about me?

We need to know some details about you (such as your name, address, age, and sex). We need these details to make sure we are recording the right information about the right person.

We also need to know about cancer related investigations such as screening tests and the treatment you are receiving or have already received as part of your progress. Other diseases for example heart disease may affect survival so we need also to know about other diseases so we can accurately account for survival differences.

We need this information to help us identify possible causes of cancer and to find out about the best treatments.

Do I need to do anything?

No, you do not need to do anything - there are no forms to fill in and nothing to sign. Your hospital or doctor will confidentially pass the relevant information to the Northern Ireland Cancer Registry during your care.

Organisations that support cancer registration

- Action Cancer
- Against Breast Cancer
- Asthma + Lung UK
- Bloodwise
- Bowel Cancer UK
- Brain Tumour Research
- Brain Tumour Research Campaign
- Brainstrust
- Breast Cancer Now
- Cancer 52
- Cancer Focus NI
- Cancer Fund for Children
- Cancer Research UK
- Children's Cancer Unit
- GIST Support UK
- GUTS UK
- It's in the Bag
- Kidney Cancer UK
- Leukaemia and Lymphoma NI
- Lymphoma Action
- Macmillan Cancer Support
- Marie Curie Cancer Care
- Melanoma Focus
- Myeloma UK
- NIPANC - Pancreatic Cancer
- Oesophageal NI
- Pancreatic Cancer Action
- Rare Cancer Research Foundation
- Sarcoma UK
- Shine Cancer Support
- Skcin - The Karen Clifford Skin Cancer Charity
- Skin Cancer Research Fund
- Target Ovarian Cancer
- Teenage Cancer Trust
- The Pelican Cancer Foundation
- The Pink Ribbon Foundation
- WMUK

What will we do with this information?

We are very careful with the information and follow strict rules about how we look after it and who can use it.

nqa. ISO 27001 INFORMATION SECURITY MANAGEMENT

The NICR have established and maintain an Information Security Management System (ISMS) which is certified to ISO27001, the highest internationally recognised information security standard.

Reports that we publish will never identify any particular person, even if they have a rare cancer.

Will anyone contact me?

The Registry works with researchers to improve understanding of cancer. Usually this is with information that would not identify a person. Occasionally for some studies a researcher may need to contact patients. This is done only under strict conditions and your consent would be sought through your doctor/hospital before this would happen.

APPENDIX C: Performance Indicators for 2021 and 2022

	Key	
	Target not reached or not in line with other registries	
	Target attained	
Indicator	**Northern Ireland 2023 report on 2021 diagnoses**	**Northern Ireland 2024 report on 2022 diagnoses**
Stability: Percentage change (%) for all cancers (C00-C97 ex. C44) compared with previous three years	4.1%	7.2%
Registry Creep: Percentage (%) for all cancers (C00-C97 ex. C44) registrations (extracted between 31/12/19 and 20/04/2020) compared with registrations extracted between 02/02/2019 and 01/03/2019[6].	2.2%	2.1%
Staging: Proportion (%) of all cases (C00-C97 ex. C44) with valid known stage registered out of all 2018 registered cancers (C00-C97 ex. C44)[2]	81.8%	84.4%
Average of Core Patient Information Complete: Average percentage (%) of all cancers (C00-C97 ex. C44) registered with demographic information[3]	100.0%	100.0%
Average of Core Tumour Information Complete: Average percentage (%) of all cancers (C00-C97 ex. C44) registered with tumour information[4]	96.6%	96.7%
Death Certificate Only (DCO) Rates: Percentage (%) of all cancers (C00-C97 ex. C44) registered as a DCO[5]	1.0%	0.8%
Zero Day Survivors: Percentage (%) of all cancers (C00-C97 ex. C44) registered with the date of death equals the date of diagnosis[5]	1.0%	0.9%
Microscopically Verified: Percentage (%) of all cancers (C00-C97 ex. C44) that are microscopically verified	84.8%	85.1%
Non-Specific Codes: Percentage (%) of all cancers (C00-C97 ex. C44) that are microscopically verified with non-specific morphology codes	1.2%	1.1%
Grade: Percentage (%) of all cancers (C00-C97 ex. C44) registered with a known grade	60.6%	59.3%
Treatment: Percentage (%) of all cancers (C00-C97 ex. C44) registered with any treatment	85.6%	84.9%
Breast Screening Data: Percentage of breast cancer (C50) cases screen detected for ages 60-64	51.1%	50.9%
Cervical Screening Data: Percentage of cervical cancer (C53) cases screen detected for ages 25-60	45.8%	44.6%
Bowel Screening Data: Percentage of bowel cancer (C18-C20) cases screen detected for ages 60-69	25.6%	30.6%

APPENDIX D: Peer reviewed publications

NICR Publications April 2025 – March 2026

Impact of COVID-19 on breast cancer patients and services in a UK region: Protocol for a mixed methods study
Mitchell H, McShane C, **Hawkins S**, Lohfeld L, **Darragh P**, Irwin G, Lowans N, McBrien A, Moss E, O'Neill S, **Roebuck J**, Sengupta S, Sharma M, **Gavin AT, Bennett D**. PLOS One. September 29 2025 https://doi.org/10.1371/journal.pone.0333288

Stage at diagnosis and breast cancer-specific mortality in breast cancer patients treated with antidepressants, anxiolytics, and antipsychotics: a population-based cohort study from Northern Ireland
Baxter, S. M., McShane, C. M., McIntosh, S. A., **Bennett, D.**, Lohfeld, L., Middleton, D. R. S., **Savage, G., Fitzpatrick, D.,** Kane, J., McBrien, A., McCallion, D., **Gavin, A.** & Cardwell, C. R., Aug 2025, Breast Cancer Research and Treatment. https://doi.org/10.1007/s10549-025-07766-8

Lung cancer burden attributable to ambient particulate matter: a nationally representative population-based case-control study
Alhattab, R. A. N., McKinley, J. M., Hunter, R. F., Delargy, C. M., Wallace, S. M., **Bennett, D., Fitzpatrick, D., Mitchell, H.**, McGuinness, B., Scott, A., McKay, G., Bouaoun, L., McCormack, V. & Middleton, D. R. S., 06 Oct 2025. In: British Journal of Cancer. https://doi.org/10.1038/s41416-025-03207-x

Impact of COVID-19 pandemic on healthcare appointments for breast cancer patients in the UK and Republic of Ireland: Preliminary findings of a mixed-methods study
Sharma, Moss B, Lohfeld L, McBrien A, **Bennett D, Gavin A, Mitchell H, Hawkins S,** Irwin G, O'Neill S, Sengupta S, McShane CM. European Journal of Surgical Oncology. 14 May 2025. https://doi.org/10.1016/j.ejso.2025.109963

Skin melanoma survival is improving in Europe, but regional differences persist: Results of the EUROCARE-6 study
Crocetti, E., **Bennett, D.**, Jooste, V., Rossi, S., Maso, L. D., Marcos-Gragera, R., Smits, S., Tina, Z., Xavier, T., Mayer-da-Silva, A., Daubisse-Marliac, L., Lourenço, A., Katalinic, A., Sanchez, M.-J., Vener, C., Mousavi, M., Ziliani, V. & Gatta, G., 19 Oct 2025. In: European Journal of Cancer (Oxford, England). DOI: 10.1016/j.ejca.2025.116061

Survival of European children, adolescents and young adults diagnosed with haematological malignancies in the period 2000–2013: Results from EUROCARE-6, a population-based study
Trama A, Geerdes EE, Demuru E, De Angelis R, Karim-Kos HE, Troussard X, **Bennett D**, Marcos-Gragera R, Kuehni CE, Liu H, Bernasconi A, Vener C, Guevara M, Zwaan CM, Mayer-da-Silva A, Paapsi K, Ragusa R, Smith OP; EUROCARE-6 Working Group. 06 May 2025, In: European Journal of Cancer. https://doi.org/10.1016/j.ejca.2025.115336

Global variation in patterns of care and time to initial treatment for breast, cervical, and ovarian cancer from 2015 to 2018 (VENUSCANCER): a secondary analysis of individual records for 275 792 women from 103 population-based cancer registries in 39 countries and territories
Allemani C, Minicozzi P, Morawski B, Lima CA, **Bennett D**, Pongnikorn D, Petrova D, Innos K, Girardi F, Galán Alvarez Y, Schaffar R, Dal Maso L, Molinié F, Valkov M, Phillips K, Siesling S, Schultz A, Daubisse-Marliac L, Marcos-Gragera R, Di Carlo V; VENUSCANCER Working Group. 22 Oct 2025. In: Lancet (London, England). DOI: 10.1016/S0140-6736(25)01383-2

Estimating cure and risk of death from other causes of adolescent and young adult cancer patients in Europe
Botta L, Capocaccia R, Vener C, Bernasconi A, Trama A, Didoné F, Demuru E, De Angelis R, Rossi S, Mousavi SM, Peters F, **Bennet D**, Mayer-da-Silva A, Jooste V; EUROCARE-6 WG. 19 April 2025. In: European Journal of Cancer. https://doi.org/10.1016/j.ejca.2025.115443

Prognosis of Breast Cancer in European female adolescents and young adults (AYAs): EUROCARE-6 retrospective cohort results.
Bernasconi A, Toss A, Zattarin E, Mousavi SM, Blum M, Kuehni CE, Katalinic A, Trallero J, Rapiti E, Dal Maso L, Botta L, Rossi S, Peccatori F, Trama A; **EUROCARE-6 Working Group.** 02 May 2025, In: The Breast. https://doi.org/10.1016/j.breast.2025.104472

Long-term survival for myeloid neoplasms and national health expenditure: a EUROCARE-6 retrospective, population-based study
Vener C, Lillini R, De Angelis R, Bonfarnuzzo S, Poirel HA, Trama A, Visser O, Troussard X, Marcos-Gragera R, Maynadié M, Demuru E, Di Benedetto C, Johannesen TB, Solans M, Paapsi K, Guevara M, Mousavi SM, Blum M, Von Moos R, **Bennett D**, Ragusa R, Guilloteau A, McShane CM, Rossi S, Sant M; EUROCARE-6 Working Group. 02 May 2025, In: European Journal of Cancer. https://doi.org/10.1016/j.ejca.2025.115231

Survival of European adolescents and young adults diagnosed with central nervous system tumours and comparison with younger and older age groups: EUROCARE-6 results
McCabe, M., Rossi, S., Cerza, F., Massimino, M., Gianno, F., Spycher, B. D., Marcos-Gragera, R., **Bennett, D.**, Lasalvia, P., Didonè, F., El Karoui, N. J., Ragusa, R., Mayer-da-Silva, A., Mousavi, S. M. & Trama, A., 09 Sept 2025, In: European Journal of Cancer. https://doi.org/10.1016/j.ejca.2025.115661

Chemotherapy and radiotherapy use in patients with lung cancer in Australia, Canada, the UK and Norway 2012-2017: an ICBP population-based study
Barclay ME, McPhail S, Johnson SA, Swann R, Finley CJ, Butler J, Alvi R, Barisic A, **Bennett DB**, Bucher O, Creighton N, Denny CA, Dewar RA, Donnelly DW, Dowden JJ, Downie L, Finn N, Habbous S, Huws DW, Kumar SE, May L, McClure CA, Møller B, Morrison DS, Musto G, Nilssen Y, Saint-Jacques N, Sarker S, Shack L, Te Marvelde L, Tian X, Thomas RJ, Thomson CS, Walton R, Wang H, Wong THT, Woods RR, You H, Zhang B, Lyratzopoulos G; .ICBP Module 9 Lung Study Group, Jul 2025, In: BMJ Oncology. https://doi.org/10.1136/bmjonc-2025-000800

Prognosis of Breast Cancer in European female adolescents and young adults (AYAs): EUROCARE-6 retrospective cohort results.
Bernasconi A, Toss A, Zattarin E, Mousavi SM, Blum M, Kuehni CE, Katalinic A, Trallero J, Rapiti E, Dal Maso L, Botta L, Rossi S, Peccatori F, Trama A; EUROCARE-6 Working Group. **EUROCARE-6 Working Group,** Aug 2025, In: Breast. 82, 104472. DOI 10.1016/j.breast.2025.104472

Other outputs using NICR Data

Impact of COVID-19 pandemic on breast cancer patient experiences of healthcare services in Northern Ireland: findings from a large-scale cross-sectional survey. Bennett, D. UKIBCS, Birmingham. January 2026. **POSTER**

The association of house value with stage at diagnosis and survival in breast cancer patients from Northern Ireland. Bennett, D. UKIBCS, Birmingham. January 2026. **POSTER**

Counting the Seconds: Estimating the time to Metastatic Breast cancer using treatment data. Mitchell, H. UKIBCS, Birmingham. January 2026. **POSTER**

The Incidence of Endometrial Hyperplasia in Northern Ireland: A Population-based Study
McKenna L, Jordao H, Sanni OB, McCoy C, McCluggage WG, Wylie J, Quinn D, Gavin A, Bennett D, Coleman HG, Cardwell CR, McMenamin UC. All-island Forum on Cancer Research (26th-27th Jan 2026), Riddel hall, Belfast. **POSTER**

FREE ELECTRONIC STAGING TOOL FOR POPULATION-BASED CANCER REGISTRIES: CANSTAGING+
Gavin, A. IACR Conference, Izmir, Turkey. November 2025 **POSTER**

The Rise of Early-Onset Cancers - Biology, Causes, and Detection
Russell, A. European Association for Cancer Research-Mark Foundation Joint Conference. Bergamo, Italy 11-13 November 2025. **POSTER**

ESTIMATED TRIHALOMETHANES IN PUBLIC DRINKING WATER AND BLADDER CANCER RISK IN NORTHERN IRELAND
M. Wallace, Northern Ireland Cancer Registry, NICOLA Study Team, D. Middleton. SEGH Conference Belfast, July 2025. **CONFERENCE PRESENTATION**

Trends of prostate cancer stage and grade over a 12-year period in Northern Ireland; a population-based analysis
Murphy, JT. European Association for Cancer Research (EACR), June 2025. Lisbon, Portugal. **POSTER**

APPENDIX E: Requests for Information

Requests for Information

The NICR provided data and information for 204 requests in 2025, 48 (24%) general requests and 156 (76%) genetic requests (excluding local genetic requests) (*Figure 4*). A nurse from the Medical Genetics department deals with local genetic requests.

In 2025, 83% of general requests for information were completed within the target 20 working days and 100% of genetic requests for information were completed within the target 10 working days.

40% of general requests were received from academic researchers and clinicians (combined) (*Figure 5*).

Figure 4: General and Genetic Requests received 2025

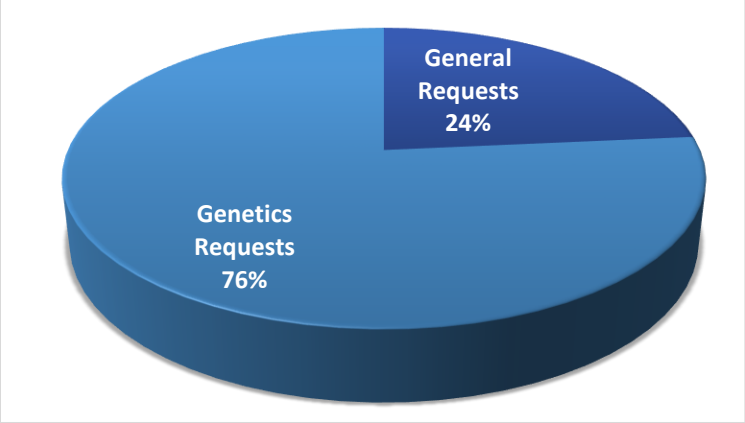
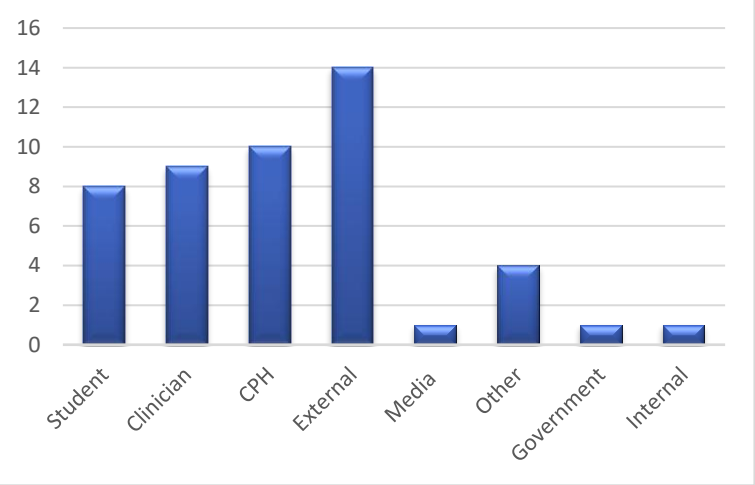


Figure 5: General Requests-Sources of Requester



APPENDIX F: NICR Media

Media Interactions April 2024 – March 2025

Headline	Date	Outlet
"I'm here to walk alongside people and their families at one of the most frightening times of their lives": NI's first pancreatic support nurse	November 2025	The Irish News – ***print & online***
Cancer Focus 2025 Review	December 2025	Cancer Focus Social Media
New Melanoma Study Findings Recently Were Reported by Researchers at Queens University Belfast (Skin melanoma survival is improving in Europe, but regional differences persist: Results of the EUROCARE-6 study)	November 2025	Health & Medicine Daily
Global variation in patterns of care and time to initial treatment for breast, cervical, and ovarian cancer from 2015 to 2018	November 2025	The Lancet
A Grounded Theory of the Lived Experiences of People with Pancreatic Cancer in Northern Ireland: Study Protocol	November 2025	MDPI
New Findings on Lung Cancer from Queen's University Belfast Summarized (Lung Cancer Burden Attributable To Ambient Particulate Matter: a Nationally Representative Population-based Case-control Study: Epidemiology)	November 2025	Disease Prevention Daily
Impact of COVID-19 on breast cancer patients and services in a UK region: Protocol for a mixed methods study	September 2025	PLoS ONE
New Findings from Queen's University Belfast in the Area of COVID-19 Reported (Impact of COVID-19 on breast cancer patients and services in a UK region: Protocol for a mixed methods study)	October 2025	NewsRx COVID-19 Daily
Widower warns of 'sneaky' symptoms of ovarian cancer	June 2025	BBC Radio Ulster *(broadcast)*
		BBC Radio Foyle (*broadcast)*
		Aol.
		BritishBulletin.com
		Yahoo! News
		Finnoexpert

Appendix G: NICR Visits by Policy Makers & Shareholders

Name	Department
2022	
David Curtin	NICaN AHP CRG Lead
Gay Ireland	Head of Cancer Projects, Department of Health
Ceara Gallagher	AHP Consultant, PHA
Nikki Strain	DoH – Cancer Strategy
Dr Kathryn Boyd	Medical Director, NICaN
Naomi McCay	Network Manager, NICaN
Lorna Nevin	Nurse Consultant, Palliative Care and Cancer, NICaN/PHA
Sharon Gallagher	Deputy Secretary for Strategic Planning and Performance Group (SPPG)
Wayne Irvine James Taylor	Department of Health
Tomas Adell	Director of Hospital Services Reform
2023	
Cynthia Stafford	Ulster University
Prof. Lourda Geoghegan	Deputy Chief Medical Officer, DoH
Craig Donnachie	Department of Health
Prof. Jayne Woodside	Centre for Public Health Director, QUB
2024	
Friends of the Cancer Centre reps x12	Friends of the Cancer Centre
Natalie Dhomen	CRUK
2025	
Ian Purdy David Smyth Vaughan Purnell	QUB IT Dept
~40members from Cancer Charities	NI Cancer Charity Coalition
Philip McGuigan Patricia Smith	NI Assembly Health Committee
Stephanie McMullan	LLNI
Nora Smith	Cancer Focus NI
Deirdre Cunningham	Belfast Trust, PHA – Nursing & AHP Directorate
Sarah Christie Katrina Hawker Amrit Kaliasethi Harriet Hall Justine Howe	Macmillan visit