Annual Operational Report

April 2025

Northern Ireland
Cancer Registry

Providing Cancer information for Planning, Development, Research & Education

Table of Contents

GLOSSARY

Acronym	**Definition**
AHP	Allied Health Professionals
AllCaN	All-Ireland Oesophageal Cancer Network
APG	All Party Group
AQs	Assembly Questions
BSO	Business Services Organisation
CaPPS	Cancer Patient Pathway System
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
DHSS	Department of Health & Social Services
DoH	Department of Health
DPIA	Data Privacy Impact Assessment
ECIS	European Cancer Information System
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
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
LIMS	Laboratory Information Management System
MBC	Metastatic Breast Cancer
MCD	Minimum Cancer Dataset
MGUS	Monoclonal Gammopathy of Undetermined Significance
NCRAS	National Cancer Registration Service
NI	Northern Ireland
NICaN	NI Cancer Network
NICC	NI Cancer Centre
NICR	NI Cancer Registry
NICRCSP	NI Colorectal Cancer Screening Program
NIHAP	NI Health Analytics Platform
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 Version 4
ORECNI	Office for Research Ethics Committees Northern Ireland
PAS	Patient Administrative System
PGJCCR	Patrick G. Johnston Centre for Cancer Research
PHA	Public Health Agency
PPI	Patient and Public Involvement
PQs	Parliamentary Questions
QUB	Queen’s University Belfast
RAG	Research Advisory Group
RD	Rapid Datasets
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 2024 - March 2025). 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 to ISO27001 standards,
- Analyse data to support NICR's role as provider of official statistics for cancer incidence, prevalence, and survival,
- Develop Routes to Diagnosis 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, subject to funding,
- 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.

NICR is supported by a Steering Group (Management), which oversees the work of the Registry and a Council, appointed by the Steering Group, which advises the Director and the Steering Group on matters such as NICR outputs and Council which 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).

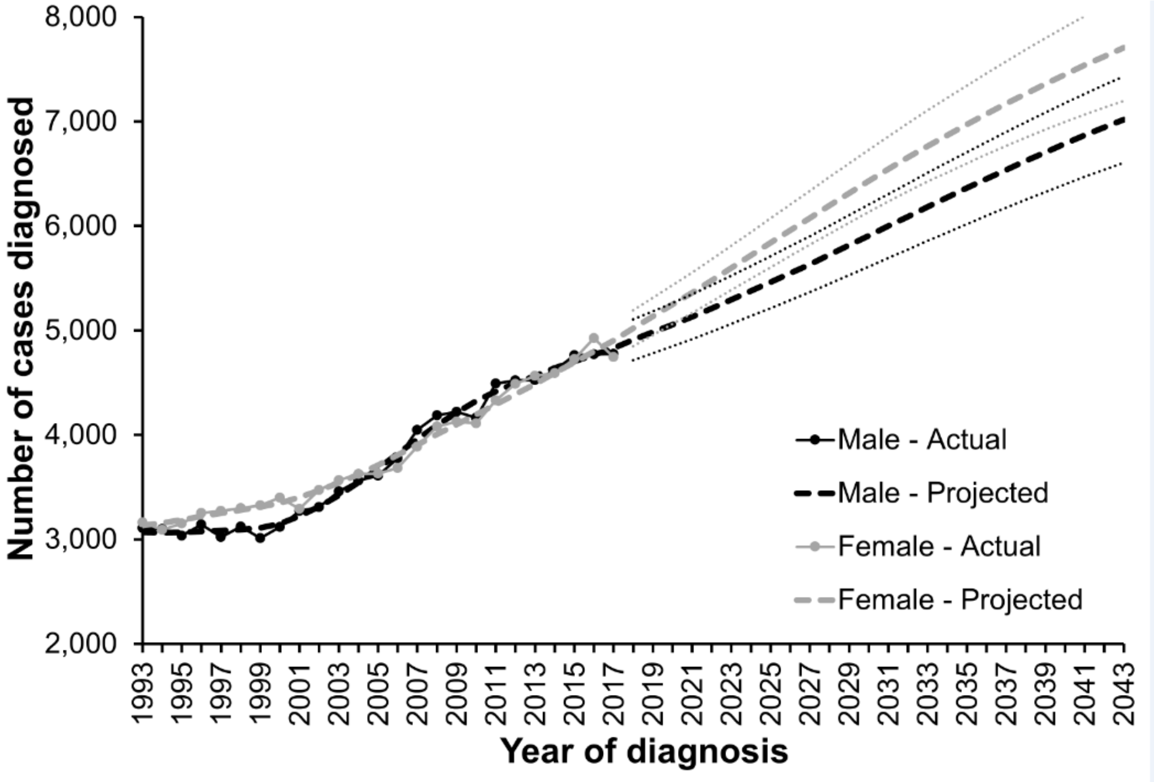
Cancer registry processes include data acquisition, linkage, quality assurance and analysis to ensure that data on cancers and premalignant diseases are fit for purpose including:

- 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 NI cancer burden in NI and cancer prevention.

In 2021 NI had an estimated population of 1,904,500 people. Excluding non-melanoma skin cancer (NMSC) on average 10,061 cancers were diagnosed each year during 2017-2021 (13,6821 cases per year including NMSC). At the end of 2021 there were 71,412 cancer survivors (excluding NMSC) residing in NI who had been diagnosed in the previous 25 years (i.e. 1997-2021) (104,458 including NMSC).

Cancer incidence is increasing, 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 2021 this had risen to 10,513 cancer cases, an increase of 68%. 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 the NICR began in 1994, the number of data items 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 which have been staged are shown in Figures 2a and 2b, increasing from only 1,087 in 1993 to 7,958 in 2020, which represents an increase from just over 10% in 1993 to almost 70% in recent years (Figure 2a/2b).

Figure 2a: Malignant Cancers Staged vs Unstaged

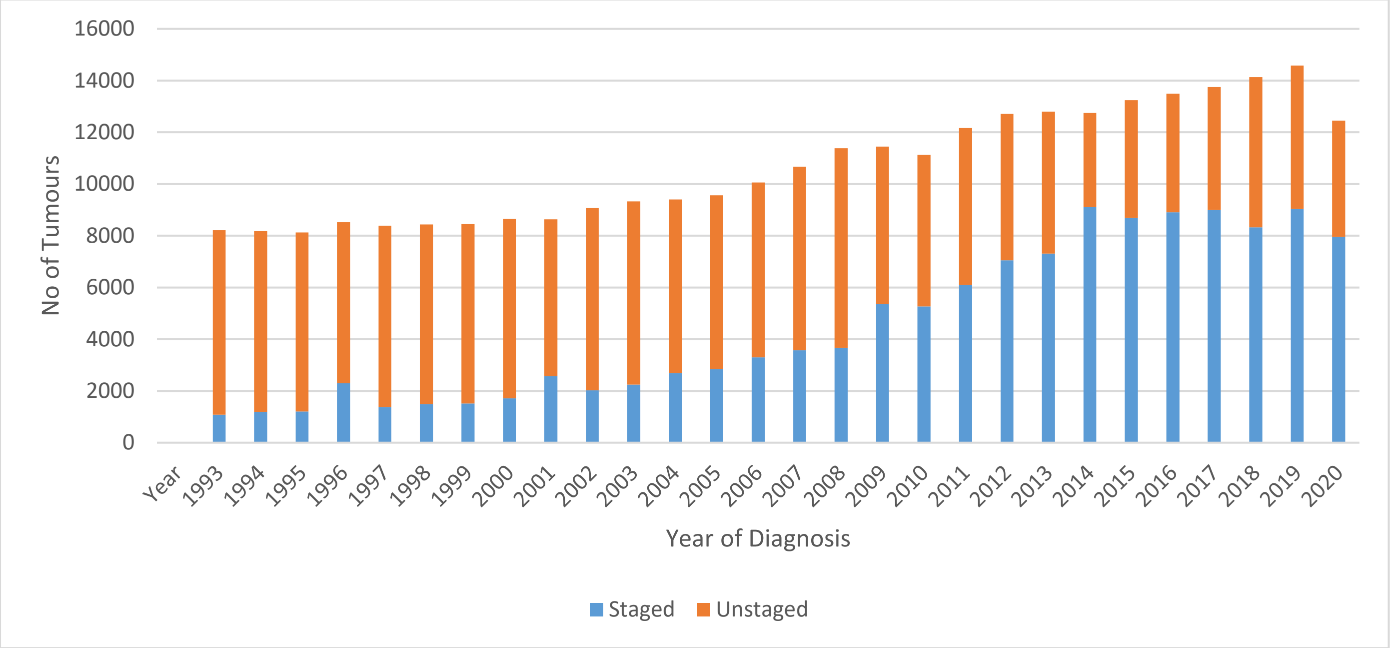
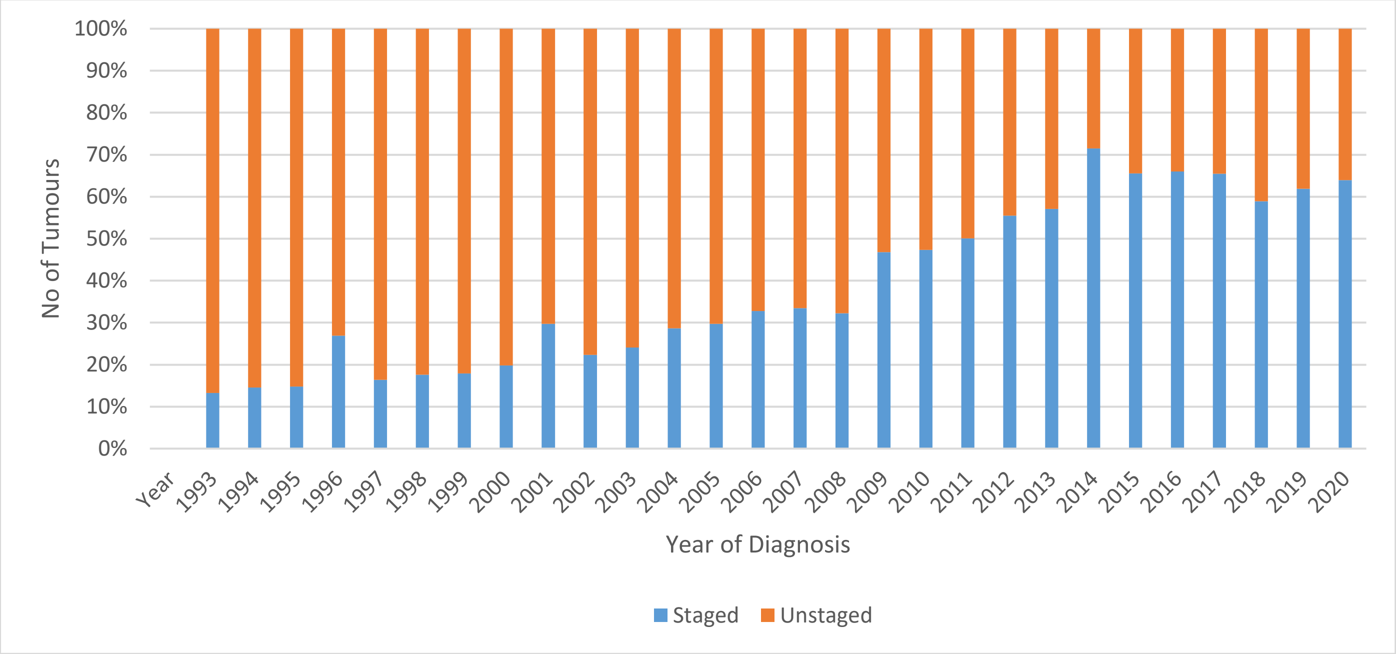


Figure 2b: Malignant Cancers Staged vs Unstaged



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. We have monitored the impact of COVID-19 on cancer services, cancers diagnosed, method of presentation, stage and survival via reports published on a monthly basis.

In addition, there continues to be change and development with health service IT systems, the most significant for cancer registration being the planned introduction of the Encompass integrated patient record, with the roll out to all Trusts due to be completed by Autumn 2025.

We receive data from RISOH in the form of monthly downloads of Systemic Anti-Cancer Therapy (SACT). These datasets are important to enable completion of treatment details on all patients for production of cancer intelligence and official statistics. Unfortunately, we still have not obtained read-only access to RISOH despite NICR's data access agreements with the Trusts. This access is essential for confirmation of NICR data on diagnosis, stage and treatment and disease progression. We are awaiting access since RISOH replaced COIS in 2018 and have been advised this will be granted following the Business Services Organisation (BSO) CITRIX upgrade for third party access.

1.7 Ethics and compliance with Data Protection

In October 2020, NICR had their ethical approval for its databases renewed for five years from the Office for Research Ethics Committees NI (ORECNI), Reference 20/NI/0132. Work is currently underway to renew the NICR ethics which is due this year. Each research project using non-routine data is required to have separate ethical approval.

NICR is a registered data controller under Queen's University Belfast 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 to facilitate receipt of data from NI Health and Social Care Trusts, Business Services Organisation, 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 the exemptions introduced to address opt-out for cancer registration in in England should be applied.

All identifiable data are held in a secure area of the registry, available to only a small group of Registry staff for data verification and addition of specified 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,
- Attendance at Metastatic Breast Cancer report launch at Stormont,
- Attendance at Farm Community Network event.

1.9 NICR links with the public by:

- NICR has a leaflet and a 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 was developed to inform a wider audience of the work of the NICR which is available here,
- Public awareness of NICR through NI media by regular appearance of staff on TV and radio interviews highlighting cancer statistics and changes in survival, while encouraging early detection of cancers (Appendix F),
- NICR has an active Twitter account sharing relevant information on various cancer sites during key awareness periods along with updates on Registry publications.

1.10 NICR links with clinical teams by:

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

1.11 NICR links with researchers through:

- The Director and current Acting 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,
- Working collaboratively with local, national, and international researchers on externally held grants,
- Publication using official statistics, audit reports, in peer reviewed publications,
- 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, with second report due to be fulfilled soon,
- Providing timely information on the impact of COVID-19 on cancer services via regular reports,
- Providing timely and accurate answers 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 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 February 2020 until October 2024. Compliance is audited throughout the year both internally and externally.

Information security controls include physical measures such as video surveillance, staff card access system, alarms triggered out of hours and door codes which are changed regularly and immediately after a member of staff ceases NICR employment. There are a number of administrative controls implemented by means of various policies and procedures (available in Registry). These are included in regular staff training in addition to having their implementation 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 patient level data and a

separate designated hot desk facility for external researchers using anonymised Registry data are available. Phones and electronic devices are left at reception when external researchers access the Registry hot desk facility.
Staff can avail of hybrid working but while working off site, staff must adhere to security controls as per 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 NHS organisations. The 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 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, 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 by following cancer registration guidance ensure the availability of accurately coded population-based cancer data for NI. CIOs have access to full pathology text reports and part of their resolving work requires reading 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 datasets on:

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 information on co-morbidities within the cancer patient population in NI, through the use of prescriptions for specific comorbid conditions.

Comorbidities

Since 1st January 2006, NICR has received PAS 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 the Regional Information System for Oncology and Haematology (RISOH).

Radiotherapy

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

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

- Barrett's Oesophagus,
- Colorectal polyps,
- Endometrial Hyperplasia,
- Monoclonal Gammopathy of Undetermined Significance (MGUS),
- High grade CIN, CGIN and 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 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 between 1993 and 2021. The register is the foundation for a large body of epidemiological, clinical, and biomarker research, now led by Professor 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 CRUK)
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 and the current biomarker studies, which use the NIBR as a sampling frame, aim to: (i) explore the potential of a biomarker for assessing molecular age of Barrett's (led by Professor Helen Coleman in collaboration with Dr Kit Curtius, UCSD and Professor AJ McKnight, CPH) and (ii) identify biomarkers associated with progression to oesophageal adenocarcinoma (led by Dr Richard Turkington and Professor Helen Coleman). Preliminary findings of the Barrett's register update will be presented as a poster at British Society Gastroenterology Conference, 24-26 June 2025, Glasgow.

All-Ireland Barrett's oesophagus Collaboration (funded by Breakthrough Cancer Research) In January 2023, Breakthrough Cancer Research launched the All-Ireland Oesophageal Cancer Network (AllCaN Oesophageal), investing €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 (Queen's University Belfast) and Prof. Juliette Hussey (Trinity St. James's Cancer Institute). This unique cross-border collaboration links six major academic institutions (and their associated hospitals) across the island of Ireland. This will enable for the first time the bringing together of information from the Northern Ireland 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 (three PhD students, an MPH student and a Research Fellow from QUB) and PPI Panel with representatives from across the Island of Ireland. The inaugural AllCaN oesophageal symposium was held at Trinity Translational Medicine Institute, Trinity College Dublin, St. James's Hospital on 23rd October 2024. The AllCaN symposium comprised of presentations and panel discussions within the main themes: Prevention and Intervention and Targeted Diagnostics and Novel Therapeutics. In summer 2025, the Northern Ireland Barrett's register will host a Breakthrough Cancer Research Summer Scholarship student exploring the disease trajectory for patients diagnosed with dysplasia not initially meeting the current criteria for endoscopic treatment. A poster of preliminary findings from this All-Ireland work were presented at Irish Association of Cancer Research Conference 5-7 March, Belfast.

Current funding: *Breakthrough Cancer Research (AllCaN network) and Oesophageal Cancer Fund*; Historic funding sources: *Cancer Research UK* (N.Ireland 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 however there is currently no routine screening for endometrial cancer. Endometrial hyperplasia is a recognised precursor to endometrial cancer, which if detected and treated, can help to prevent malignant progression. Little is known on the population incidence of endometrial hyperplasia, or which patients are most at risk of progressing to endometrial cancer.

The Northern Ireland Endometrial Hyperplasia Register has been developed within the NICR, which is the first of its kind in the UK. This research is currently funded by a UKRI Fellowship awarded to Dr Úna McMenamin. The Register consists of approximately 3,000 incident endometrial hyperplasia cases diagnosed from 2008-2020, identified from review of endometrial biopsy pathology reports. Preliminary findings from the Register suggest that there has been a reduction in the rate of endometrial hyperplasia diagnoses from 2008-2019, with further reductions in 2020, likely due to the COVID-19 pandemic. The reduction could not be fully explained by reductions in endometrial sampling and may reflect greater pathological subspecialisation over time, amongst other reasons. This study was recently presented at the Irish Society of Gynaecological Cancer session within the International Gynaecologic Cancer Society Conference in Dublin, October 2024, as well as the Irish Association for Cancer Research Annual Conference in March 2025. Pathology reports for 2021-2023 have recently been reviewed and will be used to update the Register while planned linkage to external datasets will further populate the Register with important clinical information (such as hormonal treatments and surgical procedures) to evaluate long-term outcomes, including progression to endometrial cancer.

Rachel Daffy, 3rd year QUB Biomedical Science student, has recently conducted her final year research project evaluating the quality of the data collected within the Endometrial Hyperplasia Register. The results showed a high rate of inter-observer agreement overall, for example, data extracted on the type of endometrial hyperplasia had an 'almost perfect' agreement between raters. The project has generated important evidence around the quality of the data collected within the Register and will be used to inform future publications.

Importantly, these research studies include clinical input from gynaecologists and gynaecological pathologists, as well as Public and Patient Involvement (PPI) from two patients affected by endometrial hyperplasia. One of the PPI representatives contributed to a panel discussion on the theme of "Empowering Women's Health in Cancer Prevention and Early Detection" as part of the recent Professor Liam Murray Cancer Epidemiology Symposium at Queen's University Belfast in January 2025.

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 Professor Helen Coleman).

MGUS (Monoclonal Gammopathy of Undetermined Significance)

Requires funding to be developed.

NI Premalignant Cervical Lesions Register

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

CIN = cervical intraepithelial neoplasia (grades 1-3)

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 low percentage of death certificate only registrations (which account for 1% of invasive malignancies registered, excluding NMSC) ,
- NI has a high percentage of microscopically verified cases (which account for 84.8% 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.

REGISTRY IT SYSTEM

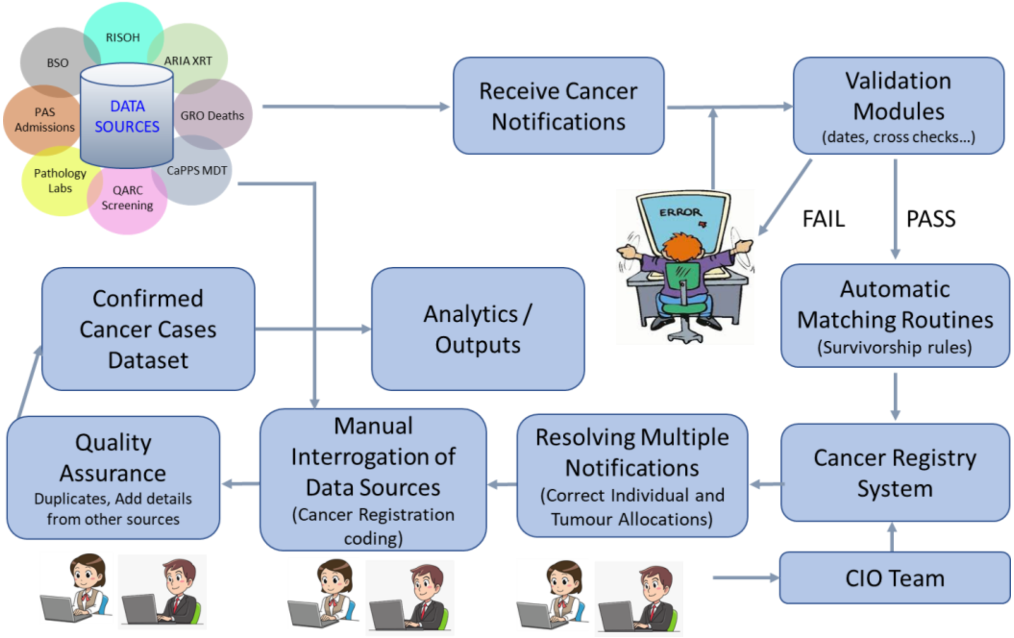
3.1 Background

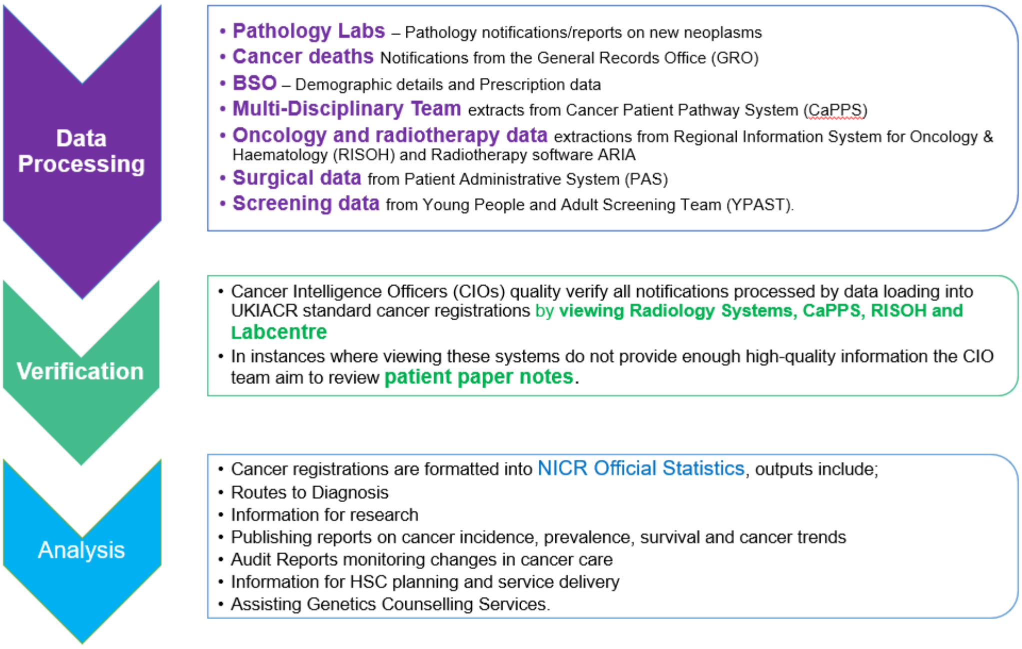
NICR are currently updating a legacy cancer registration database system (PRAXIS) which was developed in the 1990's. The PRAXIS system has many benefits, such as automated data linkage routines, which have not been fully replicated in other newer systems. However, the underlying architecture is difficult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

Registration Process





- **Pathology Labs** – Pathology notifications/reports on new neoplasms
- **Cancer deaths** Notifications from the General Records Office (GRO)
- **BSO** – Demographic details and Prescription data
- **Multi-Disciplinary Team** extracts from Cancer Patient Pathway System (CaPPS)
- **Oncology and radiotherapy data** extractions from Regional Information System for Oncology & Haematology (RISOH) and Radiotherapy software ARIA
- **Surgical data** from Patient Administrative System (PAS)
- **Screening data** from Young People and Adult Screening Team (YPAST).

- Cancer Intelligence Officers (CIOs) quality verify all notifications processed by data loading into UKIACR standard cancer registrations by **viewing Radiology Systems, CaPPS, RISOH and Labcentre**
- In instances where viewing these systems do not provide enough high-quality information the CIO team aim to review **patient paper notes**.

- Cancer registrations are formatted into NICR Official Statistics, outputs include;
- Routes to Diagnosis
- Information for research
- Publishing reports on cancer incidence, prevalence, survival and cancer trends
- Audit Reports monitoring changes in cancer care
- Information for HSC planning and service delivery
- Assisting Genetics Counselling Services.

REGISTRY OUTPUTS

4.1 Official Statistics

NICR produces official statistics for incidence, prevalence, and survival of cancer in NI. Official Statistics for cancer registrations are published in two phases. Statistics on patients diagnosed with all cancer types in 1993-2021, both separately and combined, were released in May 2024. Updated statistics on lung, breast, colorectal, upper gastrointestinal cancer, and melanoma were then released in November 2024. Statistics for 42 cancer types (including all cancers, and NMSC) are 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 Northern Ireland Cancer Registry (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 the following 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 first Routes to Diagnosis report for patients diagnosed in 2018-2020 was released in June 2024, with annual updates to this data planned. The next update, to include patients diagnosed in 2018-2021, will be released in April 2025.

4.3 Cancer Factsheets

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

4.4 Research Publications

Since April 2024, 9 peer reviewed publications using NICR data have been produced (165 since January 2013) (Appendix D) which includes published acknowledgments of NICR data in conference abstracts and posters. 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 alleged cancer clusters. During 2024, all 28 general requests for information were completed within the 20 working days target.

Genetic requests largely 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 for genetic requests is response within 10 working days and in 2024 the NICR completed all 105 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. During COVID-19 restrictions NICR staff ensured all genetic requests were completed on time.

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 Cancer Research UK to populate UK wide cancer statistics concerning cancer incidence, mortality, survival and risk factor data on their webpage,
- Provision of data for national/international projects
    a. ICBP International Cancer Survival Phase 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 2024-2025

- Dr Damien Bennett, Helen Mitchell, and BSc Summer Student Emma McBride – Routes to Diagnosis dataset,
- Dr Damien Bennett, Helen Mitchell, and BSc Summer Student Nicole Lowans - Quantifying the impact of COVID-19 on breast cancer services and patients,
- Helen Mitchell and BSc Summer Student Deepika Sankari Gnanabharathi – Chemotherapy data analysis project.

Projects facilitated within NICR by external researchers 2024-2025

Name	Study Title	Supervisor
Anna Blair	Understanding the malignant potential of gastric metaplasia of the oesophagus: a population-based study	Helen Coleman
Erin McGrattan	Identifying characteristics of asymptomatic oesophageal cancer and Barrett's oesophagus patients to inform novel prevention and early detection opportunities	Helen Coleman
Lauren McVicker	Epidemiology and treatment outcomes of endometrial hyperplasia and cancer: A population-based investigation using routine administrative data	Una McMenamin
Rachel Daffy	A Quality Assessment of the Northern Ireland Endometrial Hyperplasia Register	Una McMenamin
Sasha Palmer	Investigating Routes to Bladder Cancer Diagnosis in Northern Ireland	Dan Middleton
Rawan Hattab & Claire Delargy	Investigating geospatial risk factors of cancer	Dan Middleton
Aoife Sweeney	Estimating the prevalence of dementia and Lewy body disease in Northern Ireland cancer patients	Joe Kane
Jack Murphy	Mechanistic underpinnings of risk factors for fatal prostate cancer	Emma Allot
Maeve McAllister	Impact of COVID 19 on Head and Neck Cancer in NI	Finian Bannon
Didar Dyussetayev	Epidemiological study to evaluate the impact of the Northern Ireland Colorectal Cancer Screening Program (NICRCSP)	Finian Bannon
Olivia Adair	Progression of adenomas within NI	Ethna McFerran
Naomh Gallagher	Mental Health and Cancer Patients in NI	Damien Bennett/Helen Mitchell
Emma McBride	Routes to Diagnosis – further analysis	Summer Student 2024
Vinay Murali Prasad	Analysis of NI Pancreatic Cancer 2019-2020 Audit data	Summer Student 2023

4.9 Audits

The Registry has previously completed a range of clinical audits evaluating the pathway of cancer patients to cancer services since 1996. 22 reports have been produced to date, 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.

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. 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. NICR now receives monthly downloads of SACT, however, despite appropriate governance being in place, NICR is still awaiting Read-Only access to RISOH to facilitate confirmation of diagnosis and obtain essential data on treatment needed for staging. Going forward, we are concerned the move to Encompass will lead to similar problems with securing access to data required for cancer registration. Disruption to existing data flows mean 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 (COSD – Cancer Outcomes Services Dataset) required from Trusts in NI. The development of a minimum dataset was a recommendation from the recent Cancer Strategy and the latest NICR peer review. 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 agreed. The development of a NI level MCD will require 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 integration of the cancer staging tool, 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 to allow recording of recurrences, as described above. 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 are receiving end of contract notifications and being offered other posts in the university via 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 the rigorous collection of datasets. There is strong support across a range of stakeholders (cancer 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 21 audits. However, funding for each audit comes from various external sources such as RQIA and charities. For example, the current Breast Cancer COVID Impact Audit is funded by Breast Cancer Now and the Metastatic Breach 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. Budget for 2024-2025 was £1,087,215, 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 the budget allocation for 2025-2026.

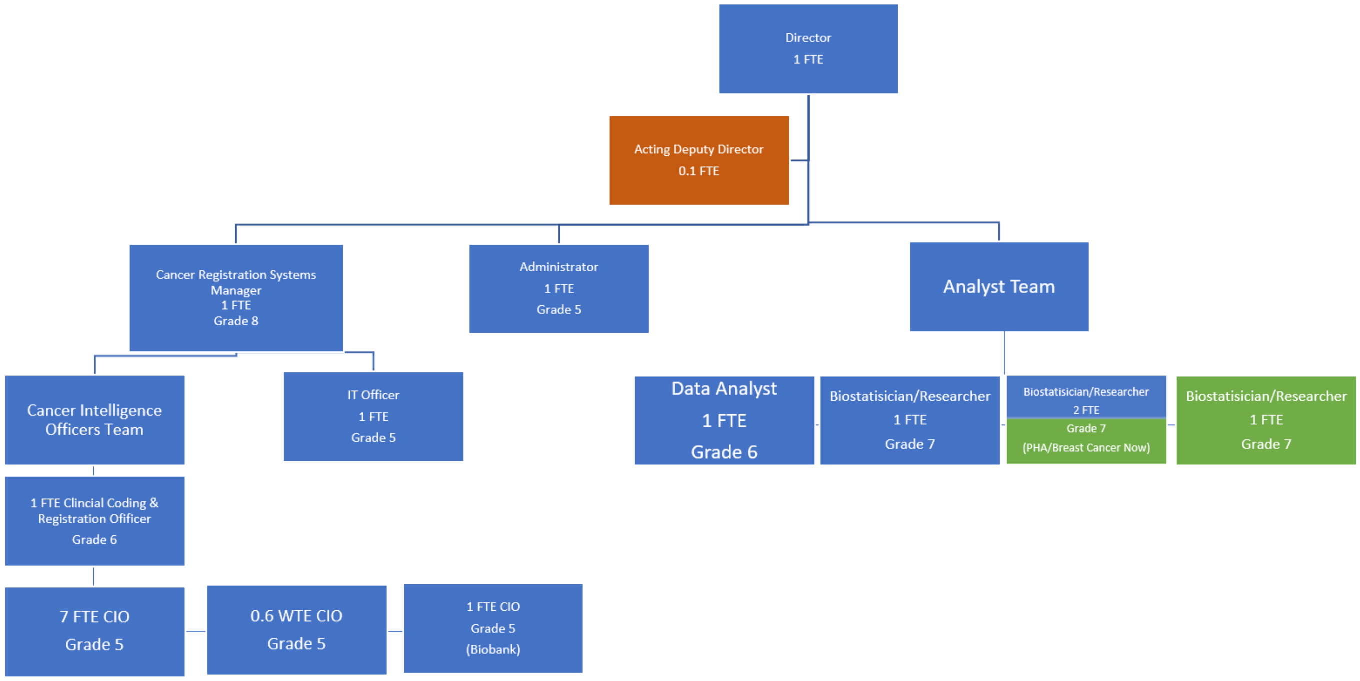


Figure 3: Current PHA/Grant funded staff 2023-2024

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 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 2019/2020	Funding 2020/2021	Funding 2021/2022	Funding 2022/2023	Funding 2023/2024	Funding 2024/2025
Total Core Work	£844,973	£861,444	£878,673	£913,293	£945,633	£1,087,215
Routes to Diagnosis					£77,967	
International Cancer Benchmarking Partnership					£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 2025-2026 is not yet confirmed.*

6.3 Other funding

In addition to the allocation from PHA, NICR has gained support for other research projects including; Heart Research UK, two audit projects, Breast and Pancreatic (funded by Breast Cancer Now and NI Panc). Cancer Focus has also recently agreed to support a Secondary Breast Cancer Research Audit (Table 2).

Table 2: Research/Audit Expenditure relating to projects active during the period 1 April 2016 – 31 March 2024

	Funder	Start Date	End Date	Total Budget	Expenditure up to 31/03/25	Balance c/f 2025-2026
Cardiovascular Disease	Heart Research UK	01/01/20	31/12/24	£149,991	£149,991	£0
Breast Cancer COVID-19 Impact Audit	Breast Cancer Now	01/05/22	30/04/24	£229,126	£146,850	£82,276
Secondary Breast Cancer Research Audit	Cancer Focus	01/04/23	31/03/25	£60,000	£51,628	£8,372

Table 3: Update on Key Priorities for 2024-2025

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

Targets 2024/2025	Updates
1. Develop Routes to Diagnosis data and outputs	- Report launched at NICR 30th Celebrations – June 2024
2. 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
3. Respond to requests from the family genetic services within a timely manner	- All requests responded to within the appropriate timescale; 28 general requests, 104 genetics
4. Provide NI datasets for international comparisons and collaborations e.g., ICBP, Eurocare, Concord, ENCR	- CRUK Incident and Mortality dataset - HSCIMS dataset - Blood Cancer UK All submitted by agreed dates
5. Seek to acquire clinical information on oncology patients by acquiring full read-only RISOH access as per Trust agreements	Access to Encompass makes this less of an issue
6. Seek to ensure NICR requirements are met by future HSC systems e.g., Encompass/LIMS	- Read only access to Encompass secured for CIOs - Still awaiting data downloads from Encompass which is impacting official stats release
7. Maintain ISO27001 Certification in Information Security Management	- New standard, ISO 27001 (2022) successfully implemented in May 2024.
8. Implement new Registry IT System and ensure it is fully operational for staff	- User Acceptance Testing (UAT) of the new IT system is underway. - End of year money secured for short term support, but funding is required for ongoing support.
9. Enhance and improve NICR data outputs and seek to tailor for individual stakeholders	- Review how other registries and data providers present and use data. - Engaged with stakeholders regarding NICR data outputs ie ○ SACT dashboard (SPPG/PHA) ○ Radiotherapy service review (DoH)
10. Provide data for UKIACR annual Performance Indicators	- NICR data submitted and included in UKIACR PIs
11. Provide data on the impact of COVID-19 on cancer services	- Data was incorporated with Official Statistics release
12. 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

Targets 2024/2025	Updates
13. Ensure Standard Operating Procedures are kept up to date	- Review of NICR SOPs ongoing
14. Ensure NICR Director Post is secured on permanent basis	- NICR Director Post now a full time QUB post, however the Director’s time is split 80/20 between QUB/PHA
15. 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
16. 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
17. Explore resources needed to collect additional NICR data items as per ENCR recommendations (e.g., comorbidities, tumour markers, recurrences)	- Determine process for additional data item collection, quantify resources required and explore possibly funding sources
18. Secure resources to allow collection of CIN II and NMSC data in line with UKIACR counterparts and ENCR recommendations	- Explore potential funding sources for additional data collection
19. Work with clinicians, RQIA, NICaN, local charities and PHA to secure funding to undertake audits	- Investigate potential funding sources to support regular ongoing clinical audits - Secure funding for Blood and Skin cancer audits
20. Investigate development of rapid datasets (RDs) – using CAPPs and SACT data	- Undertake exploratory QA exercise using existing NICR data sources in line with practice in other Registries - Scope development of rapid dataset for NI and investigate quality issues, including strengths and weaknesses - Encompass data delaying release
21. Increase awareness of the opportunities NICR data can provide	- NICR work showcased at 30th Anniversary event in the Great Hall, with the Health Minister, CMO and DoH/PHA officials in attendance. NICR Staff attendance at; - The Cancer Data Steering Group - Cancer Strategy Steering Group - CPH Cancer Epidemiology Research Group - Attendance at Clinical Reference Groups (CRGs) - Media engagement (see Appendix F) - New staff within stakeholder groups invited to visit the NICR
22. Expand on secondary cancer research audit	- Explore research funding proposals based on SBC work

Table 4: NICR Key Priorities 2025-2026

Targets 2025/2026	Proposed Actions
1. Provide complete, accurate data on cancers in NI for official statistics by March 2026 for patients diagnosed in 2023	- Release Official Statistics by March 2026
2. Develop Routes to Diagnosis data and outputs	- Produce Routes to Diagnosis data for 2022
3. Respond to general data and information requests within a timely manner	- 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	- Monitor timeliness of responses to genetic requests
5. Provide NI datasets for international comparisons and collaborations e.g., ICBP, Eurocare, Concord, Benchista	- Datasets to be submitted by agreed dates
6. Seek to ensure NICR requirements are met by future HSC systems e.g., Encompass	NICR staff will continue to seek access to Encompass data from relevant parties
7. Maintain ISO 27001 Certification in Information Security Management	- Undertake regular internal audits to ensure confidence with NICR ISO policies.
8. 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)
9. 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 regarding NICR data outputs
10. 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
11. 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
12. Ensure Standard Operating Procedures are kept up to date	- Undertake review of NICR SOPs as processes develops at least annually
13. Ensure NICR Director Post is maintained on permanent basis and filled 100%	- Work with NICR Steering group, QUB, and PHA to ensure target is achieved

Targets 2025/2026	Proposed Actions
14. 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
15. 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
16. Explore resources needed to collect additional NICR data items as per ENCR recommendations (e.g., comorbidities, tumour markers, recurrences)	- Determine process for additional data item collection, quantify resources required and explore possible funding sources
17. Secure resources to allow collection of CIN II and NMSC data in line with UKIACR counterparts and ENCR recommendations	- Explore potential funding sources for additional data collection
18. Work with clinicians, RQIA, NICaN, local charities and PHA to secure funding to undertake audits	- Investigate potential funding sources to support regular ongoing clinical audits
19. Investigate development of rapid datasets (RDs) – using CAPPs and SACT data	- Integrate Encompass data into development of rapid dataset for NI
20. Increase awareness of the opportunities NICR data can provide	Membership of - Maintain media engagement (see Appendix F) - Ensure new staff within stakeholder groups are invited to visit the NICR - CPH Cancer Epidemiology Research Group - Attendance at Clinical Reference Groups (CRGs) - Radiotherapy Review Group - HDRUK Big Data for Complex Disease - AICRI Programme Board - ICBP Programme Board
21. Expand on secondary cancer research audit	- Explore research funding proposals based on MBC work to expand to other sites
22. Expand on current breast cancer inequalities work to other sites	- Explore if methodology can be applied to other sites - Explore research funding proposals based on this work
23. Link with Biobank	- Attend NI Biobank meetings
24. Develop N/S Research projects	- Complete work on All Island Atlas - Explore other N/S opportunities
25. Timeliness of Official Statistics	- Resources required to support production of official statistics in a timely manner
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)	- Ensure NICR systems integrate with NIHAP, and staff engage with relevant stakeholders

REFERENCES

1. A Cancer Strategy for Northern Ireland 2022-2032; Published March 2022, Department of Health for Northern Ireland. https://www.health-ni.gov.uk/publications/cancer-strategy-northern-ireland-2022-2032

2. ENCR endorsement of the ICD-O-3.2 coding. The IARC/WHO ICD-O Committee has updated the draft ICD-O-3.1 classification, with new morphology codes and terms from the 4th series of WHO Classification of Tumours (Blue Books). The new version ICD-O-3.2, published in April 2019, is recommended for use from 2020.

3. Northern Ireland Cancer Registry, 2025. Routes to diagnosis 2018-2021. Available at: www.qub.ac.uk/research-centres/nicr

4. Centre for Public Health. Pathways to a cancer diagnosis 2012-2016. Queen's University, Belfast 2020. https://pure.qub.ac.uk/en/publications/pathways-to-a-cancer-diagnosis-monitoring-variation-in-the-patien

5. Elliss-Brookes L, McPhail S, Ives A, et al. Routes to diagnosis for cancer - determining the patient journey using multiple routine data sets. Br J Cancer 2012; 107:1220-6. https://pubmed.ncbi.nlm.nih.gov/22996611/

6. Public Health England. Routes to diagnosis 2006-2016: Technical document. Available at http://www.ncin.org.uk/view?rid=3965. Accessed Jan 2024.

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.

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
Mr Gareth Irwin	Health and Social Care Trust Clinician
Dr Louise Herron	PHA
Ms Louise Dunlop	QUB, Governance
Dr Emma Allott	QUB, PGJCCR

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.

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

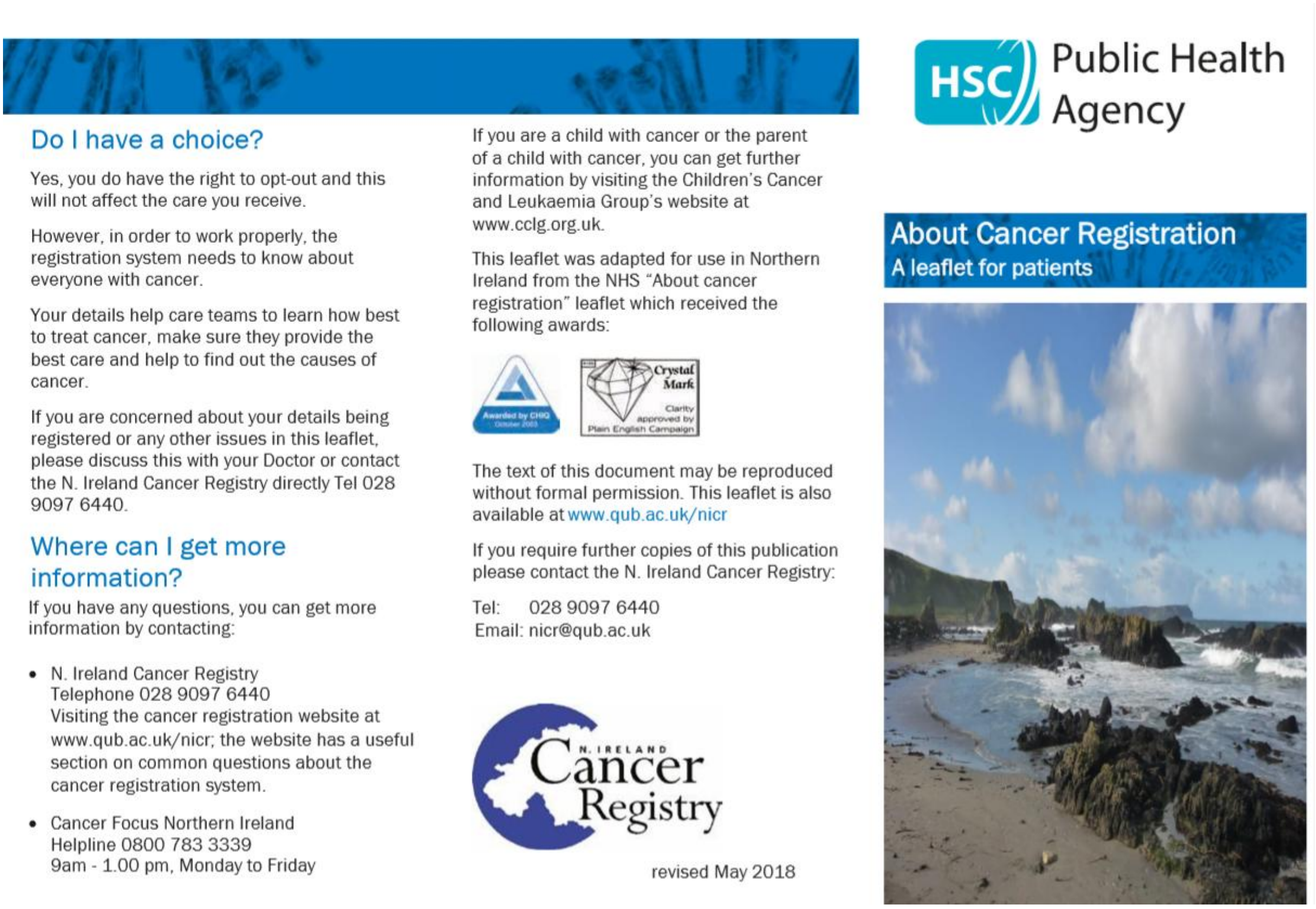
With attendance from Registry Director, Deputy Director and relevant staff required for the agenda.

Research Advisory Group

Role is to review 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 the NICR. The RAG joins the bi-annual NICR Council Meetings with extraordinary meetings convened to review Data Information requests when required.

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, PGJCCR
Dr Nick Orr	QUB, PGJCCR
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 to 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 N. Ireland Cancer Registry directly Tel 028 9097 6440.

Where can I get more information?

If you have any questions, you can get more information by contacting:

- N. Ireland Cancer Registry
Telephone 028 9097 6440
Visiting the cancer registration website at www.qub.ac.uk/nicr; the website has a useful section on common questions about the cancer registration system.
- Cancer Focus Northern Ireland
Helpline 0800 783 3339
9am - 1.00 pm, Monday to Friday

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 and Leukaemia Group's website at www.cclg.org.uk.

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

The text of this document may be reproduced without formal permission. This leaflet is also available at www.qub.ac.uk/nicr

If you require further copies of this publication please contact the N. Ireland Cancer Registry:

Tel: 028 9097 6440
Email: nicr@qub.ac.uk

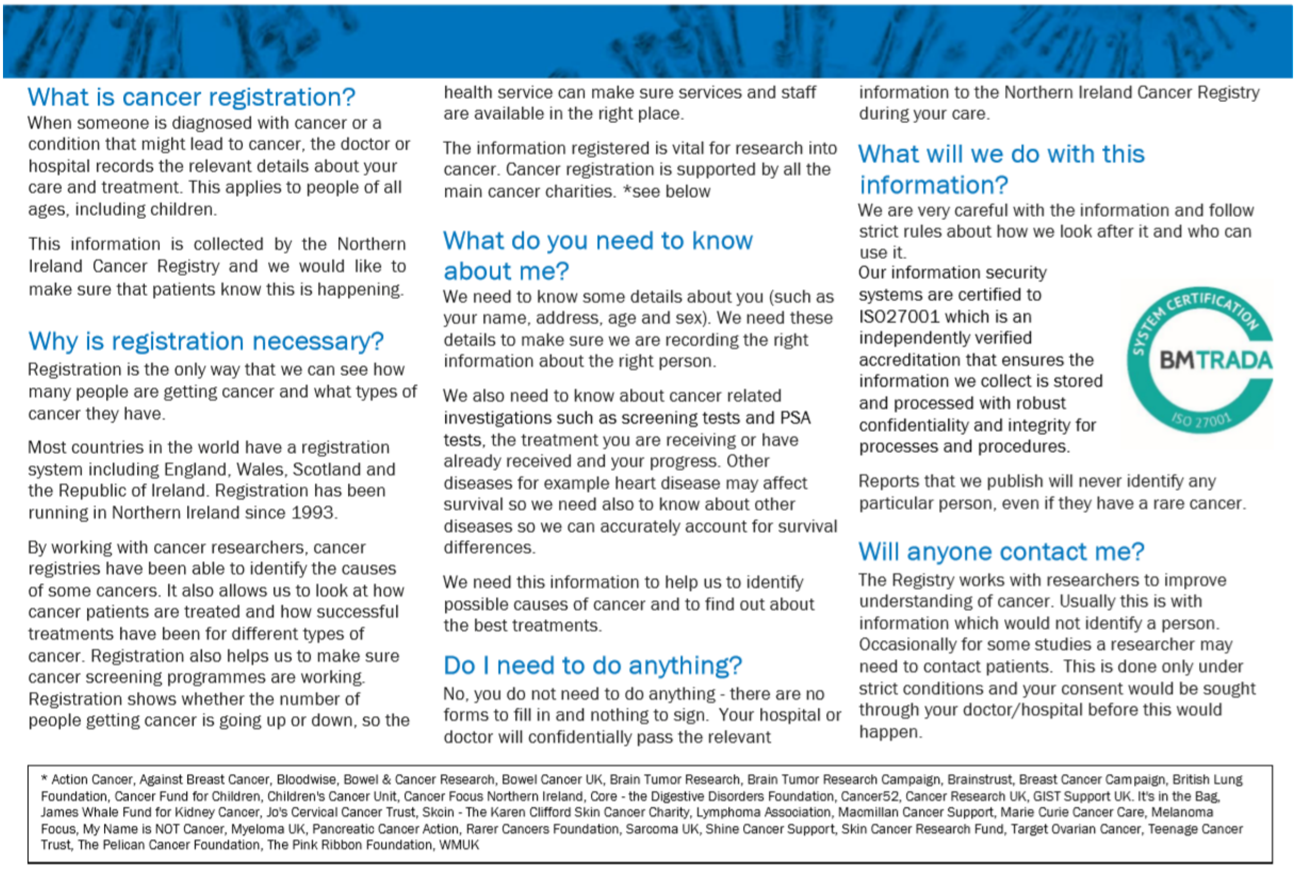
N. IRELAND Cancer Registry

revised May 2018

HSC Public Health Agency

About Cancer Registration

A leaflet for patients



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 registration system 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 below

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 PSA tests, the treatment you are receiving or have already received and 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 to 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.

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.

Our information security systems are certified to ISO27001 which is an independently verified accreditation that ensures the information we collect is stored and processed with robust confidentiality and integrity for processes and procedures.

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 which 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.

* Action Cancer, Against Breast Cancer, Bloodwise, Bowel & Cancer Research, Bowel Cancer UK, Brain Tumor Research, Brain Tumor Research Campaign, Brainstrust, Breast Cancer Campaign, British Lung Foundation, Cancer Fund for Children, Children's Cancer Unit, Cancer Focus Northern Ireland, Core - the Digestive Disorders Foundation, Cancer52, Cancer Research UK, GIST Support UK. It's in the Bag, James Whale Fund for Kidney Cancer, Jo's Cervical Cancer Trust, Skcin - The Karen Clifford Skin Cancer Charity, Lymphoma Association, Macmillan Cancer Support, Marie Curie Cancer Care, Melanoma Focus, My Name is NOT Cancer, Myeloma UK, Pancreatic Cancer Action, Rarer Cancers Foundation, Sarcoma UK, Shine Cancer Support, Skin Cancer Research Fund, Target Ovarian Cancer, Teenage Cancer Trust, The Pelican Cancer Foundation, The Pink Ribbon Foundation, WMUK

APPENDIX C: Performance Indicators for 2020 and 2021

	Key
🟥	Target not reached or not in line with other registries
🟩	Target attained

Indicator	Northern Ireland 2022 report on 2020 diagnoses	Northern Ireland 2023 report on 2021 diagnoses
Stability: Percentage change (%) for all cancers (C00-C97 ex. C44) compared with previous three years	-8.0%	4.1%
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].	1.0%	2.2%
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]	81.2%	81.8%
Average of Core Patient Information Complete: Average percentage (%) of all cancers (C00-C97 ex. C44) registered with demographic information[3]	99.9%	100.0%
Average of Core Tumour Information Complete: Average percentage (%) of all cancers (C00-C97 ex. C44) registered with tumour information[4]	96.3%	96.6%
Death Certificate Only (DCO) Rates: Percentage (%) of all cancers (C00-C97 ex. C44) registered as a DCO[5]	0.9%	1.0%
Zero Day Survivors: Percentage (%) of all cancers (C00-C97 ex. C44) registered with the date of death equals the date of diagnosis[5]	1.1%	1.0%
Microscopically Verified: Percentage (%) of all cancers (C00-C97 ex. C44) that are microscopically verified	83.4%	84.8%
Non-Specific Codes: Percentage (%) of all cancers (C00-C97 ex. C44) that are microscopically verified with non-specific morphology codes	1.2%	1.2%
Grade: Percentage (%) of all cancers (C00-C97 ex. C44) registered with a known grade	59.6%	60.6%
Treatment: Percentage (%) of all cancers (C00-C97 ex. C44) registered with any treatment	74.8%	85.6%
Breast Screening Data: Percentage of breast cancer (C50) cases screen detected for ages 60-64	44.6%	51.1%
Cervical Screening Data: Percentage of cervical cancer (C53) cases screen detected for ages 25-60	46.3%	45.8%
Bowel Screening Data: Percentage of bowel cancer (C18-C20) cases screen detected for ages 60-69	19.3%	25.6%

APPENDIX D: Peer reviewed publications

NICR Publications April 2024 – March 2025

1. **Impact of the COVID-19 pandemic on breast cancer patient pathways and outcomes in the United Kingdom and the Republic of Ireland – a scoping review**
   Lohfeld, L., Sharma, M., **Bennett, D., Gavin, A., Hawkins, S. T.**, Irwin, G., **Mitchell, H.,** O'Neill, S. & McShane, C. M., 04 May 2024, (Early online date) In: British Journal of Cancer. 8 p.
   https://doi.org/10.1038/s41416-024-02703-w

2. **Long-term survival for lymphoid neoplasms and national health expenditure (EUROCARE-6): a retrospective, population-based study**
   Sant, M., Vener, C., Lillini, R., Rossi, S., Bonfarnuzzo, S., Marcos-Gragera, R., Maynadié, M., Innos, K., Paapsi, K., Visser, O., Bernasconi, A., Demuru, E., Di Benedetto, C., Mousavi, S. M., Blum, M., Went, P., Serraino, D., **Bennett, D**., Sánchez, M-J., De Angelis, R., & 2 others, Jun 2024, In: Lancet Oncology. 25, 6, p. 731-743 13 p.
   https://doi.org/10.1016/S1470-2045(24)00141-4

3. **Skin in the game: the cost consequences of skin cancer diagnosis, treatment, and care in Northern Ireland**
   McFerran, E., Donaldson, S., Dolan, O. & Lawler, M., Mar 2024, In: Journal of Cancer Policy. 39, 7 p., 100468.
   https://doi.org/10.1016/j.jcpo.2024.100468

4. **Cancer data quality and harmonization in Europe: the experience of the BENCHISTA Project - international benchmarking of childhood cancer survival by stage.**
   Lopez-Cortes A, Didonè F, Botta L, Hjalgrim LL, Jakab Z, Canete Nieto A, Stiller C, Zeller B, Gatta G, Pritchard-Jones K; **BENCHISTA Project Working Group**.
   Front Oncol. 2023 Aug 22;13:1232451. doi: 10.3389/fonc.2023.1232451. eCollection 2023.
   https://doi.org/10.3389/fonc.2023.1232451

5. **Survival and Health Care Burden of Children With Retinoblastoma in Europe**
   Gianni Virgili, Riccardo Capocaccia; Laura Botta; **Damien Bennett**, Theodora Hadjistilianou, Kaire Innos, Henrike Karim- Kos, Claudia E. Kuehni, Ursula Kuhnel, Cinzia Mazzini, Adela Canete Nieto, Keiu Paapsi, Mariacristina Parravano, Cécile M. Ronckers, Silvia Rossi, Charles Stiller, Giulio Vicini, Otto Visser, Gemma Gatta, for the EUROCARE-6 Working Group*JAMA Ophthalmol.* Published online October 10, 2024.
   https://doi:10.1001/jamaophthalmol.2024.4140

6. **Collecting long-term outcomes in population-based cancer registry data: the case of breast cancer recurrence**
   Morgan, E ; O'Neill, C; Bardot, A; Walsh, P; Woods, RR; Gonsalves, L; **Hawkins, S**; Nygard, JF; Negoita, S; Ramirez-Pena, E; Gelmon, K; Siesling, S; Cardoso, F; Gralow, J ; Soerjomataram, I; Arnold, M
   JCO Glob Oncol. Published online 31 October 2024;
   https://doi.org/10.1200/GO-24-00249

7. **Estimated incidence and prevalence of metastatic breast cancer in Northern Ireland, 2009 to 2020**
   Hawkins, S. T., Ashok, A., Kelly, J. M., Savage, G., Fitzpatrick, D., Mitchell, H., McBrien, A. & **Bennett, D**., 06 Jan 2025, In: JAMA Network Open.
   https://doi.org/doi:10.1001/jamanetworkopen.2024.53311

8. **Sex differences in survival from melanoma of the skin: The role of age, anatomic location, and stage at diagnosis: A CONCORD-3 study in 59 countries**
   Di Carlo, V., Eberle, A., Stiller, C., **Bennett, D.**, Katalinic, A., Marcos-Gragera, R., Girardi, F., Larønningen, S., Schultz, A., Lima, C. A., Coleman, M. P. & Allemani, C., 25 Feb 2025, In: European Journal of Cancer. https://doi.org/10.1016/j.ejca.2024.115213

9. **International benchmarking of stage at diagnosis for six childhood solid tumours (the BENCHISTA project): a population-based, retrospective cohort study**
   Botta L., Didonè F., Lopez-Cortes A., …. **BENCHISTA Project Working Group**. 9 March 2025 In: Lancet Child Adolesc Health. https://doi.org/10.1016/S2352-4642(24)00302-X

10. **Corrigendum to "Incidence and prognosis of cutaneous melanoma in European adolescents and young adults (AYAs): EUROCARE-6 retrospective cohort results"**
    EUROCARE-6 Working Group, 11 Mar 2025, In: European Journal of Cancer. https://doi.org/10.1016/j.ejca.2025.115295

Other outputs using NICR Data

1. **Endometrial cancer and prior diagnosis of endometrial hyperplasia: a population-based study**
   Authors: McCoy CA, Coleman HG, McShane CM, Bannon FJ, Cardwell CR, McCluggage WG, Wylie J, Quinn D, Sanni OB, Gavin A, Bennett D, McMenamin ÚC.
   Presenting author: Dr Úna McMenamin (on behalf of Chloe McCoy), CPH **POSTER PRESENTATION**

2. **Trends in the incidence of endometrial hyperplasia in a UK population from 2008 to 2020.**
   Authors: Jordão H, Coleman HG, Cardwell CR, McCluggage WG, Wylie J, Quinn D, Sanni OB, Gavin A, Bennett D, McMenamin ÚC.
   International Gynaecologic Cancer Society (IGCS) Conference, Dublin, October 2024
   Presenting author: Dr Úna McMenamin, CPH **POSTER & ORAL PRESENTATION**

3. **Oesophageal Columnar Metaplasia in Childhood: A Population-Based Case Series Analysis (1993-2018) POSTER**
   Lucy Loughrey, Victoria Cairnduff, Damian T McManus, Richard C Turkington, Damien Bennett, Brian T Johnston, Helen G Coleman

4. **Skin in the game: the cost consequences of skin cancer diagnosis, treatment, and care in Northern Ireland**
   McFerran, E., Donaldson, S., Dolan, O. & Lawler, M., Mar 2024, In: Journal of Cancer Policy. 39, 7 p., 100468 **ORAL PRESENTATION x3 + 1 invited talk**

5. **Exploring how time-to-treatment is reported among children and young adults with cancer globally: a scoping review**
   Jeyaraj, A., Bennett, D. & McShane, C., 25 Feb 2025 **POSTER**

APPENDIX E: Requests for Information

Requests for Information

The NICR provided data and information for 133 requests in 2024, 28 (21%) general requests and 104 (79%) genetic requests (excluding local genetic requests) (***Figure 4***). A nurse from the Medical Genetics department deals with local genetic requests.

In 2024, 100% 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.

46% of general requests were received from academic researchers and the DoH (combined) (***Figure 5***).

On average general requests took 166 minutes to complete but ranged from 5 minutes to 180 minutes. Genetic requests took an average of 30 minutes to complete however this ranged from 10 minutes to 160 minutes.

Figure 4: General and Genetic Requests received 2024

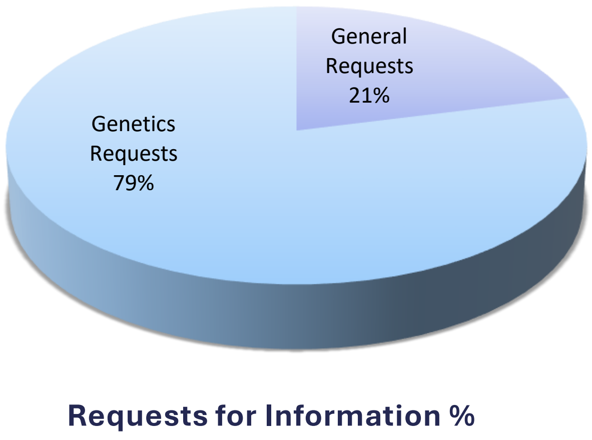
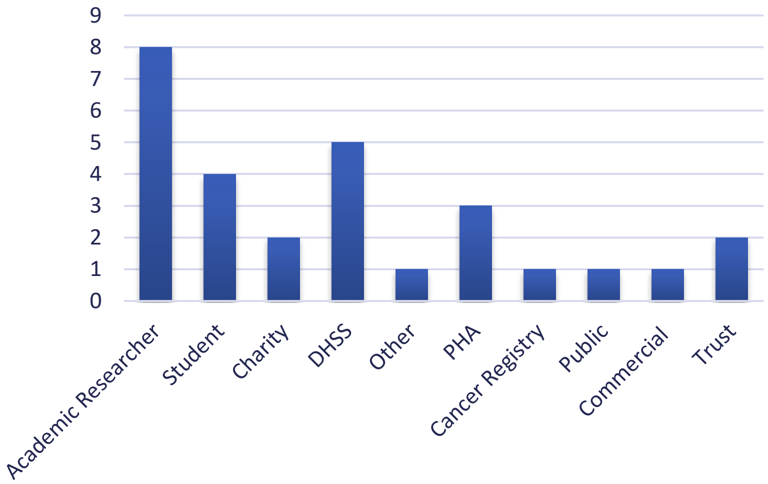


Figure 5: General Requests-Sources of Requester



APPENDIX F: NICR Media

Media Interactions April 2024 – March 2025

May 2024

04/05/2024 British Journal of Cancer
Impact of the COVID-19 pandemic on breast cancer patient pathways and outcomes in the United Kingdom and the Republic of Ireland – a scoping review
22/05/2024 India Education Diary
Report Released: Cancer Incidence and Survival Statistics for Northern Ireland (1993-2021)
23/05/2024 Indian Education News
Report Delivered: Malignant growth Rate And Endurance Insights For Northern Ireland (1993-2021)
24/05/2024 Downtown Radio
Downtown Radio (5/24/2024 6:00:05 PM)
24/05/2024 Downtown Radio
Downtown Radio Belfast (5/24/2024 6:00:00 PM)
24/05/2024 Downtown Radio
Downtown Radio Belfast (5/24/2024 9:00:00 AM)
24/05/2024 Downtown Radio
Downtown Radio (5/24/2024 6:00:00 AM)
24/05/2024 Cool FM
Cool FM (5/24/2024 6:00:00 AM)

June 2024

04/06/2024 News Letter (Belfast)
Red flags 'improve' cancer survival rates
04/06/2024 IrelandLive.ie
Red flag referral and screening routes can improve cancer survival rates – study
04/06/2024 Derry Now
Red flag referral and screening routes can improve cancer survival rates – study
04/06/2024 PA Newswire: Northern Ireland
Advisory: First issued under embargo
04/06/2024 The Irish News (Online)
Red flag referral and screening routes shown to have better cancer survival rates
04/06/2024 The Irish News (Online)
Red flag referral and screening routes shown to have better cancer survival rates
04/06/2024 Belfast Telegraph (Online)
Red flag referral and screening routes can improve cancer survival rates – study
04/06/2024 The Irish News
Red-flag referral 'yielding better cancer survival rates'
17/06/2024 BBC Parliament
Cancer Statistics and Queen's University Research
17/06/2024 BBC Parliament
Recommendations for Cancer Research Funding and Cross-Border Cooperation
18/06/2024 BBC Parliament
Concerning Cancer Diagnosis Trends and Call for Action

18/06/2024 BBC Parliament
All-Island Cancer Research Report and Recommendations
21/06/2024 BBCPARL
"Cross-Border Cooperation Key to Addressing Rise in Cancer Rates in Northern Ireland, Health Minister Prioritizes Strategy"
21/06/2024 BBCPARL
All-Island Cancer Research Report Recommendations
22/06/2024 BBCPARL
Cancer Statistics and Research in Northern Ireland
22/06/2024 BBCPARL
Report Recommends All-Island Approach to Cancer Research and Innovation

July 2024
25/07/2024 British Journal of Cancer
Correction: Impact of the COVID-19 pandemic on breast cancer patient pathways and outcomes in the United Kingdom and the Republic of Ireland – a scoping review
25/07/2024 British Journal of Cancer
Correction: Impact of the COVID-19 pandemic on breast cancer patient pathways and outcomes in the United Kingdom and the Republic of Ireland – a scoping review

October 2024
19/10/2024 The Irish News (Online)
More than 14,000 people to be diagnosed with cancer every year in Northern Ireland by 2040

November 2024
21/11/2024 ENP Newswire
-University Road, Belfast: Lung, bowel, breast, upper gastrointestinal cancer melanoma incidence survival statistics for NI
21/11/2024 M2 PressWIRE
-University Road, Belfast: Lung, bowel, breast, upper gastrointestinal cancer melanoma incidence survival statistics for NI

January 2025
07/01/2025 News Letter (Belfast) Online
Northern Ireland amongst the first in the world to produce estimates of people living with metastatic breast cancer
10/01/2025 News Letter (Belfast)
'Metastatic breast cancer patients are no longer invisible'

February 2025
18/02/2025 BBC Parliament
Queen's University Belfast Conducts Cancer Diagnosis Research for Northern Ireland
21/02/2025 BBC Parliament
Queen's University Belfast Conducts Cancer Diagnosis Research for Northern Ireland
23/02/2025 BBC Parliament
Queen's University Belfast Cancer Diagnosis Research Project

Appendix G: NICR Visits by Policy Makers & Shareholders

Date	Name	Department
2022		
Wed 24th August	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
Thurs 8th September	Dr Kathryn Boyd	Medical Director, NICaN
	Naomi McCay	Network Manager, NICaN
	Lorna Nevin	Nurse Consultant, Palliative Care and Cancer, NICaN/PHA
Tuesday 15th November	Sharon Gallagher	Deputy Secretary for Strategic Planning and Performance Group (SPPG)
Tuesday 22nd November	Wayne Irvine James Taylor	Department of Health
Thursday 15th December	Tomas Adell	Director of Hospital Services Reform
2023		
Monday 9th January	Cynthia Stafford	Ulster University
Tuesday 14th February	Prof Lourda Geoghegan	Deputy Chief Medical Officer, DoH
Thursday 20th April	Craig Donnachie	Department of Health
Friday 24th October	Prof Jayne Woodside	Centre for Public Health Director, QUB
2024		
Monday 15th April	Friends of the Cancer Centre reps x 12	Friends of the Cancer Centre
Monday 4th November	Natalie Dhomen	CRUK
2025		
Wednesday 15th January	Ian Purdy David Smyth Vaughan Purnell	QUB IT Dept