N. IRELAND Cancer Registry

Northern Ireland Cancer Registry

Annual Operational Report

April 2023

Providing information on Cancer for Research, Planning, Service Monitoring and Education

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 2022 - March 2023). 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.

The Operational Report comes at a time of positive changes in the Registry;

- Queen's University Belfast (QUB) has made significant investment refurbishing NICR's accommodation which has enhanced collaborative working between staff and external researchers while ensuring high levels of data security,
- The IT system, which has been in place for 20 years, is in the process of replacement,
- We welcome new staff including Cancer Intelligence Officers (CIOs) and the new Interim Director.

Contents

GLOSSARY 4

1. INTRODUCTION 6
    - 1.1 Background 6
    - 1.2 NICR Vision 9
    - 1.3 NICR Purpose 9
    - 1.4 NICR Values 9
    - 1.5 NICR Objectives 9
    - 1.6 Ethics and compliance with Data Protection 10
    - 1.7 NICR engages with patients by: 11
    - 1.8 NICR links with the public by: 11
    - 1.9 NICR links with clinical teams by: 11
    - 1.10 NICR links with researchers through: 11
    - 1.11 NICR engages with policy makers by: 12
    - 1.12 Information Security 12
2. METHOD OF OPERATION 14
    - 2.1 Data Sources 14
    - 2.2 Diseases Registered 15
3. REGISTRY IT SYSTEM 19
    - 3.1 Background 19
    - 3.2 Method of Data Processing 19
4. REGISTRY OUTPUTS 20
    - 4.1 Official Statistics 20
    - 4.2 Cancer Factsheets 20
    - 4.3 Research Publications 20
    - 4.4 Information Requests 20
    - 4.5 Reports 21
    - 4.6 Other Uses of Registry Data 21
    - 4.7 Research Projects 21
5. ISSUES OF CONCERN AND CHALLENGES FOR NICR 23
    - 5.1 Lack of a Legislative Framework for Disease Registration 23
    - 5.2 Access to Data Sources 23
    - 5.3 IT System 23
    - 5.4 Annual Funding 24
    - 5.5 Funding for Audits 24
    - 5.6 Staffing and Succession Planning 24
6. NICR RESOURCES 25
    - 6.1 Current staff and funding 25
    - 6.2 Allocations from PHA 26
    - 6.3 Other funding 26

Update on Actions for 2022-2023 27

NICR Key Priorities 2023-2024 30

REFERENCES 33

APPENDIX A: Steering Group, Council and Research Advisory Group Membership and Role 35

APPENDIX B: Patient Information Leaflet 37

APPENDIX C: Performance Indicators for 2020 38

APPENDIX D: Peer reviewed publications 39

APPENDIX E: Requests for Information 41

APPENDIX F: NICR Media 43

GLOSSARY

Acronym	Definition
BSO	Business Services Organisation
APG	All Party Group
AQs	Assembly Questions
BO	Barrett's Oesophagus
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
ENCR	European Network Cancer Registries
EPD	Enhanced Prescribing Database
ER	Estrogen Receptor
GAIN	Guidelines and Audit Implementation Network
GDPR	General Data Protection Regulation
GRONI	General Register Office 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
KPIs	Key Performance Indicators
LIMS	Laboratory Information Management System
LSHTM	London School of Hygiene and Tropical Medicine
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
NINIS	NI Neighbourhood Information Service
NIPCLR	NI Premalignant Cervical Lesions Register

NMSC	Non-Melanoma Skin Cancer
NWCC	North West Cancer Centre
OAC	Oesophageal Adenocarcinoma
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
SEHSCT	South Eastern Health and Social Care Trust
SMILE	Stratified Mucin-producing Intraepithelial Lesion
SPPG	Strategic Planning and Performance Group
TNM	International Union Against Cancer TNM Classification of Malignant Tumours
UAT	User Acceptance Testing
UKIACR	UK and Ireland Association of Cancer Registries

1. INTRODUCTION

1.1 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). The agreement sets out the terms by which the University maintains and operates a register of incident cancers. NICR staff are employees of QUB and financial regulation, staff appraisals, discipline and recruitment are as per QUB policies. NICR has had regular peer reviews to ensure quality and advice on direction, with the last review (2018) available here.

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 was established with clinical, scientific and patient representation – implementation of this Group and its activities was subsequently delayed and it was 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:

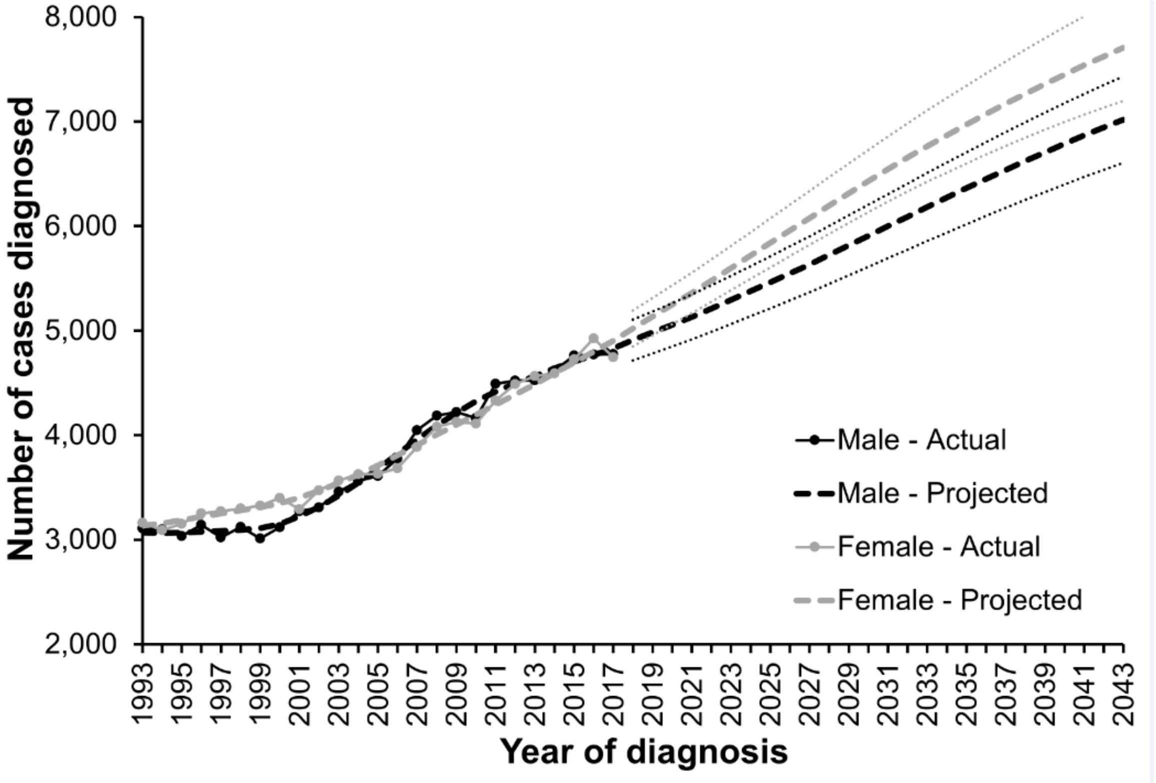
- The provision of annual official statistics on cancer incidence, prevalence and survival,
- Disease surveillance,
- Planning and administration of cancer related health care,
- Monitoring and audit of cancer related health and health care provision and outcomes,
- Provision of information to the Genetics 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 9,843 cancers were diagnosed each year during 2016-2020 (13,684 cases per year including

NMSC). At the end of 2020 there were 69,168 cancer survivors (excluding NMSC) residing in NI who had been diagnosed in the previous 25 years (i.e. 1996-2020) (102,027 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 2020 this had risen to 9,273 cancer cases, an increase of 48%, (an additional 3,172 cases of NMSC). 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 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

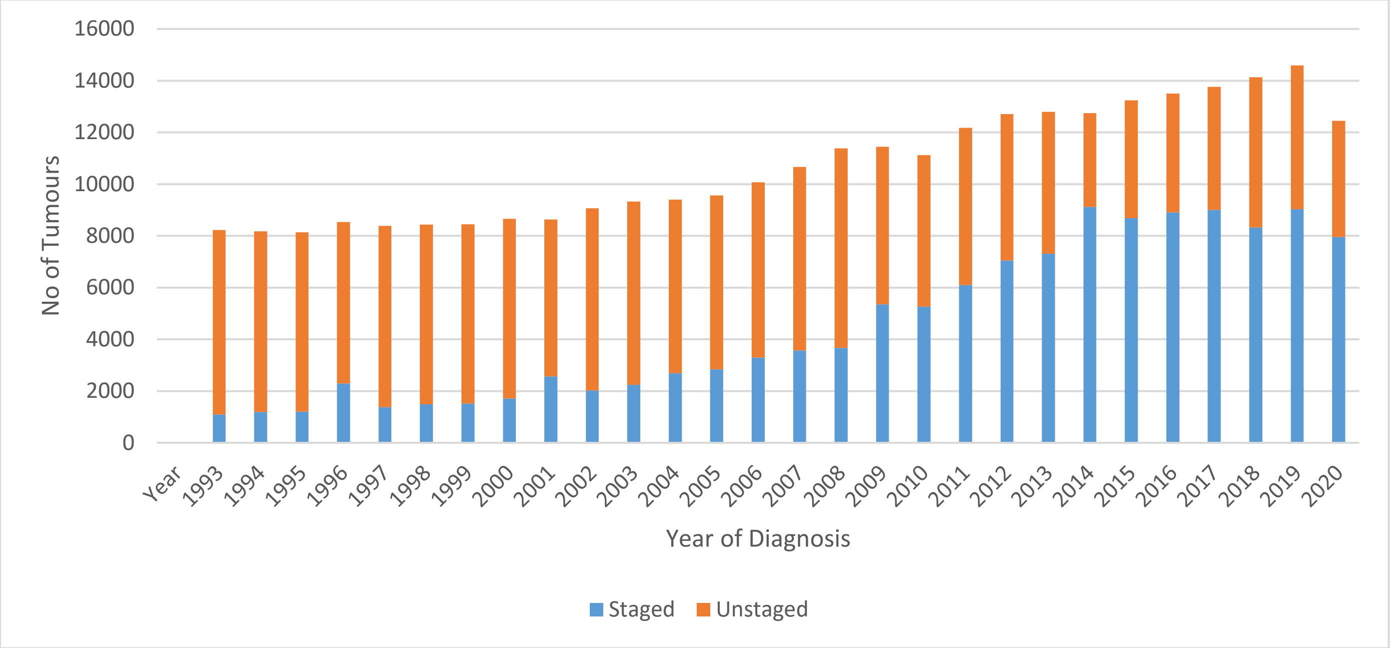
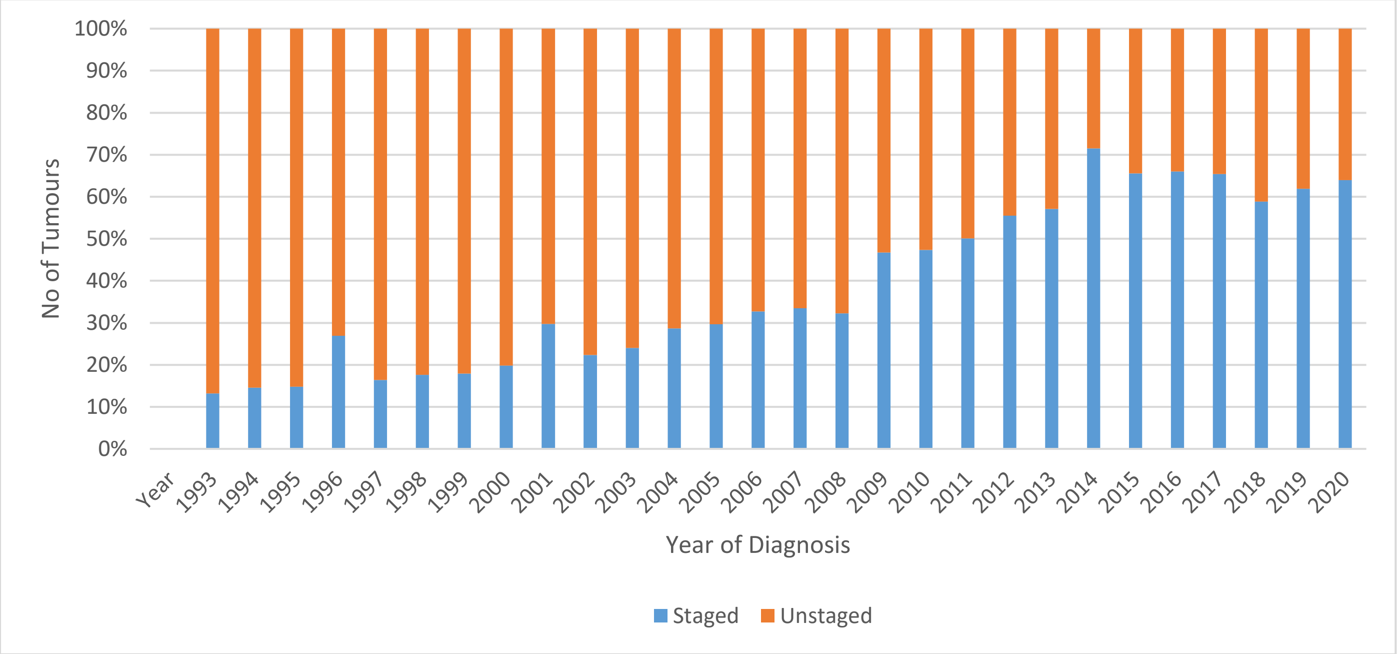


Figure 2b: Malignant Cancers Staged vs Unstaged



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 bio-markers 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, which is due to begin roll out later this year in SEHSCT.

We eventually received data from RISOH in the form of monthly downloads of Systemic Anti-Cancer Therapy (SACT) in January 2021. These datasets are very 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 BSO CITRIX upgrade for third party access.

1.2 NICR Vision

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

1.3 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.

1.4 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.

1.5 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.

1.6 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. 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.

1.7 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.

1.8 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.

1.9 NICR links with clinical teams by:

- Attending NI Cancer Network (NICaN) Board meetings,
- Attending NICaN site specific Clinical Reference Group (CRG) meetings (14 cancer site groups, each with several meetings per year),
- Attending the Encompass Cancer Care Decision Group (meetings every two weeks),
- 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.

1.10 NICR links with researchers through:

- The Interim 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 of adaptations from official statistics, audit reports and peer reviewed publications,
- Training of junior researchers through summer studentships and facilitation of undergraduate and postgraduate dissertation project work.

1.11 NICR engages with policy makers by:

- 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 NICaN on specific projects,
- Working with PHA on specific projects e.g., 2019-2020 Breast Treatment Services as required by the DoH,
- Providing timely information on the impact of COVID-19 on cancer services via regular reports,
- Providing data for development of the 2022-2032 NI Cancer Strategy,
- Participation in the DoH Cancer Data Steering Group and Cancer Strategy Steering Group,
- Development of Routes to Diagnosis on behalf of the DoH.

1.12 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 May 2023. 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.

2. METHOD OF OPERATION

2.1 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:

Prescriptions

The Enhanced Prescribing Database (EPD), managed by Business Services Organisation (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.

2.2 Diseases Registered

NICR registerable tumours are:

- Invasive malignancies including NMSC (ICD 10: 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).

The 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 worldwide, and now includes information on more than 24,500 incident cases diagnosed in Northern Ireland between 1993 and 2018. Barrett's oesophagus is a pre-cursor condition for oesophageal adenocarcinoma and the register has provided data for publications of international standing[8-10]. 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 the surveillance of Barrett's oesophagus patients. 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 Prof. 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).

In 2019, a dedicated NI Barrett's research Patient and Public Involvement (PPI) group was established and is comprised of five patients affected by the condition. The PPI group meet quarterly to guide research and at their first meeting in June 2019, identified an 'unmet' need for evidence-based information on Barrett's oesophagus at diagnosis. Over the past two years, the PPI group together with the NI Barrett's research team have co-produced a patient information leaflet which has received very positive feedback from both patients and clinical staff. The final leaflet has been disseminated to endoscopy clinics in NI and the co-production of the leaflet is currently being written up as a scientific paper.

In January 2023, Breakthrough Cancer Research launched the first All-Ireland Oesophageal Cancer Network (AllCaN Oesophageal) and has invested €1 million in Oesophageal Cancer research on the island of Ireland with the aim of significantly improving early detection and survival of the disease. The work of the AllCaN Oesophageal network 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 across the island of Ireland (Trinity College Dublin, Queen's University Belfast, University College Cork, Royal College of Surgeons in Ireland, University College Dublin, and University of Galway – along with their associated hospitals, the National Cancer Control Programme, the Belfast HSC Trust and Industry partners) and 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 for studying this disease. Both a training network for early career researchers and PPI Panel will also form integral parts of the AllCaN network. More information on the AllCaN network and highlights from the launch can be found at https://www.qub.ac.uk/News/Allnews/featured/first-all-ireland-cancer-network-launched-world-cancer-day.html and https://www.youtube.com/watch?v=YoYswYU0T4Q

Current funding: *Cancer Research UK* (N.Ireland Barrett's Register update), *Breakthrough Cancer (AllCaN network)* ; Historic funding sources: Medical Research Council, the HSC R&D Office Northern Ireland and *Cancer Focus NI*

NI Colorectal polyp

This Register includes information on all colorectal polyp diagnoses since 2000 in NI. This resource has been used to investigate the risk of cancer in relation to type of polyps, and findings show that elevated cancer risk remains in patients who have undergone polypectomy[11-14]. A joint molecular epidemiology study with Vanderbilt University, TN, USA, is ongoing using this resource to identify biomarkers for advanced recurrent adenomas.

The NICR team have also been strengthening links with the NI Bowel Cancer Screening programme (BCSP) pathology database, with analysis undertaken by postdoctoral research fellow Dr Ray Carragher under the leadership of Dr Maurice Loughrey and NICR Deputy Director Professor Helen Coleman. This one-year project in 2022 was funded by the Belfast Health and Social Care Trust Charitable Funds. Publications on pathology reporting trends are planned, in collaboration with the relevant stakeholders of the BCSP.

Historic funding sources: Cancer Focus NI

Endometrial Hyperplasia (EH)

The Northern Ireland Endometrial Hyperplasia Registry is a population-based register of Endometrial Hyperplasia cases diagnosed between 2008-2020. Dr Úna McMenamin (Principal Investigator) is leading a multidisciplinary, international research programme with three main research aims (below):

1. Expansion of the UK's first population-based endometrial hyperplasia register.
2. Determine the impact of non-surgical, fertility-sparing therapies on future cancer risk and reproductive outcomes in endometrial hyperplasia patients.

3. Investigate long-term clinical outcomes according to treatments in women diagnosed with endometrial cancer.

Following development of the UK's first population-based endometrial hyperplasia, analyses found that endometrial hyperplasia incidence trends among women aged 18-85 years old was stable during the years 2008 to 2020. These data also display a consistent decreasing trend in endometrial incidence rate from a peak of 35/100,000 woman-years in 2014 to 16/100,000 woman-years in 2020. Likewise, decreasing EH incidence trends were observed in women who did not undergo hysterectomy when stratified by menopausal status. The consistent reduction trends in all performed analyses may show a truly reduction on EH incidence and EH cases.

Currently, we are applying for ethical approval to link the endometrial hyperplasia dataset to external datasets such as (I) Patient Administration System to obtain information on surgical therapy following endometrial hyperplasia diagnosis (II) Enhanced prescribing dataset to obtain information on dispensed hormonal drugs (III) Deaths register, to obtain date and cause of death and (IV) Northern Ireland Maternity System for information on pregnancies and births following a diagnosis of endometrial hyperplasia and endometrial cancer.

These results will help women make informed treatment choices following Endometrial Hyperplasia diagnosis.

*The register builds on previous work led by Professor Helen Coleman.

Historic funding sources: UKRI Future Leaders Fellowship, Queen's University Belfast International PhD Studentship.

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.

Historic funding source: Cancer Research UK / Northern Ireland Department for the Economy PhD studentship

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 Northern Ireland. 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.

We are very grateful to the Lynsey Courtney Foundation for their generous donations which have allowed the work to date.

Current funding: No current source of funding

CIN = cervical intraepithelial neoplasia (grades 1-3)

MEASURES OF DATA QUALITY

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 83.5% of invasive malignancies registered, excluding NMSC).

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

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

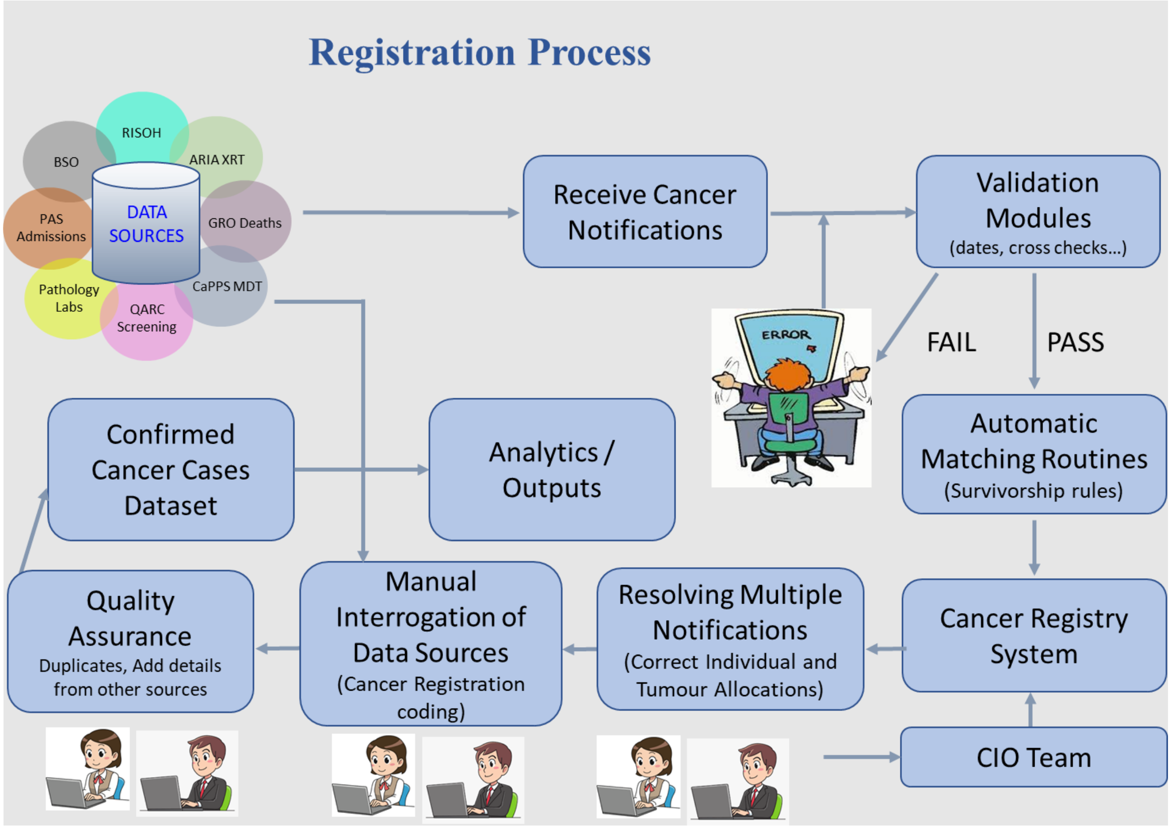
3. REGISTRY IT SYSTEM

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



4. REGISTRY OUTPUTS

4.1 Official Statistics

NICR produces official statistics for incidence, prevalence and survival of cancer in NI. Due to the COVID-19 pandemic, Official Statistics for 2020 cancer registrations were published in four releases throughout 2022 (March, May and December) and early 2023 (February). Statistics for 41 cancer types (including all cancers, and NMSC) are available at NICR website.

Key characteristics presented for each cancer type include incidence trends and breakdown of incidence 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 also included alongside the latest statistics on cancer mortality, with death data provided by the General Register Office Northern Ireland (GRONI).

Specific COVID impact reports for each cancer type were released alongside the annual official statistics comparing incidence, survival and mortality in 2020 with that of 2018-2019, providing a novel and rapid assessment of the impact of COVID -19 on cancer patients and their care in NI.

4.2 Cancer Factsheets

There are 41 factsheets updated annually as new official statistics are released via our website.

4.3 Research Publications

Since January 2022, 13 peer reviewed publications using NICR data have been produced (147 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.

4.4 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 2022, 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 2022 the NICR completed all 70 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.

4.5 Reports

NICR has produced 42 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). In the past year we have published two clinical audit reports on Oesophago-Gastric and Colorectal cancers.

4.6 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. International Cancer Benchmarking Partnership (ICBP) International Cancer Survival Phase 1 and 2.
  b. Cancer Incidence in Five Continents,
  c. EUROCARE,
  d. European Cancer Information System (ECIS),
  e. Cancer Risk in Childhood Cancer Survivors,
  f. UK Cancer Survival Project-London School of Hygiene and Tropical Medicine (LSHTM),
  g. National Cancer Dataset Repository, Local Cancer Intelligence Commissioning Tool,
  h. Northern Ireland Neighbourhood Information Service (NINIS),
  i. Prevalence Projections for the UK,
  j. CONCORD,
  k. Benchista

- A UK wide report on cancers in children and young people (released March 2021),
- Provision of timely data on the impact of COVID-19 on cancer services,
- Health and Social Care Inequalities Monitoring System (HSCIMS).

4.7 Research Projects

Facilitated by NICR staff

- Macmillan Cancer Support and NICR established a partnership in 2016 to improve understanding of the impacts and costs of cancer and its treatment across the patient's cancer journey. Part of the role also provided information at local level to facilitate better understanding of local needs and strategic priorities and predicting future needs.
- Prof Anna Gavin, Helen Mitchell and MSc Student Ben Alford worked to examine the Impact of COVID-19 on emergency hospital admissions for NI cancer patients, with a paper published in BMC Cancer in August 2022[15]. This data will be updated to identify incident and prevalent cases in 2020.
- Prof Anna Gavin and Helen Mitchell worked with Global MPH student Jennifer McLean to compare the impact of COVID -19 on pathologically diagnosed lung, colorectal and breast cancers between NI, the Netherlands and New Zealand, with a paper to be submitted in Spring 2023.

- The NICR Director and Helen Mitchell have been supervising a BSc student Cherry Stevenson, who is helping investigate cancer patients admitted to hospital with COVID-19 from March 2020-Dec 2021. This work will be compared against cancer patients admitted to hospital without COVID-19 and will examine factors such as age, length of stay and method of admission.
- The NICR Director is supervising Nkiruka Leona Sunday, Global Masters and Public Student whose draft dissertation title is ‘Limitations in cervical cancer control and screening in Nigeria – lessons from population-based analysis of women with cervical cancer in NI.’

Projects facilitated within NICR by external researchers 2021/22

- Pre-existing Dementia or Stroke associated with Less Treatment and Poorer Survival in UK Cancer Patients – Findings from a Population-Based Study (Rory Jackson, 2nd Year Medical Student),
- An evaluation of the proportion of endometrial cancer patients with a prior diagnosis of endometrial hyperplasia and its influence on survival outcomes: a population-based study,
- Understanding the molecular age of Barrett’s oesophagus in a population-representative sample of patients,
- Molecular biomarkers to predict progression of Barrett’s Oesophagus (BO) to Oesophageal Adenocarcinoma (OAC),
- Smouldering Multiple Myeloma: Validation of a Detection Algorithm in a Northern Ireland Dataset and Impact on National Statistics,
- Trends in incidence and survival of head and neck cancer patients in Northern Ireland by demographic factors,
- Pilot development of R Shiny Data Dashboards for routine NICR outputs,
- The Role of Infectious Agents in Progression from Barrett’s Oesophagus to Oesophageal Adenocarcinoma,
- Performing an emulated clinical trial in observational audit data to test prostate cancer patient interventions - a feasibility study.

4.8 Audits

The Registry has previously completed a range of clinical audits evaluating the pathway of cancer patients to cancer services since 1996. 21 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:

1. Audit of Oesophageal and Stomach cancers – funded by RQIA and OG Cancer NI – published in November 2021,
2. Audit of Colorectal cancer – funded by PHA – published in November 2022,
3. Audit of Pancreatic cancer – funded by NI Panc – report due Spring 2023,
4. Audit of Breast Cancer COVID-19 Impact – funded by Breast Cancer Now – Data collection ongoing, report due Spring 2024

5. 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 National Cancer Registration Service (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. These have now been provided to NICR for cases up to July 2022. 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, GAIN and charities. For example, the recently completed audits of colorectal cancer and oesophageal cancer were funded on an ad hoc basis by the PHA/RQIA/OG Cancer NI. The current audit of pancreatic cancer is funded by NI Panc, whilst research on breast cancer diagnoses, treatment and outcomes pre and post covid have been funded by Breast Cancer Now. 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

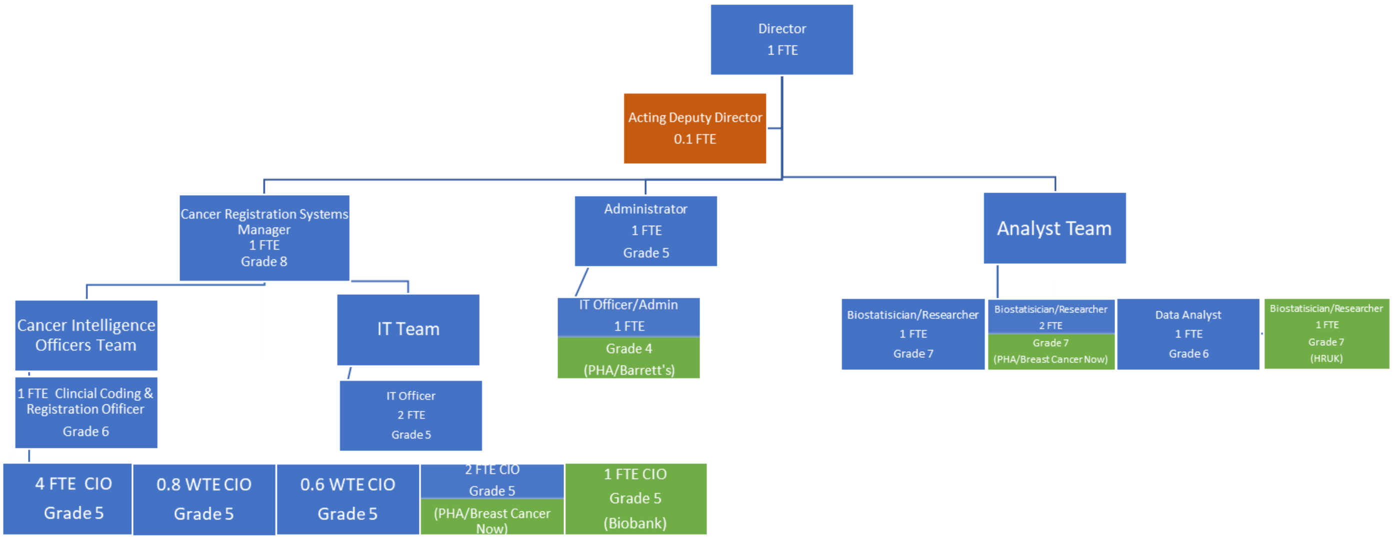
NICR has a relatively small team of highly specialised staff, often with long experience. Although staff turnover is low and staff are very committed, there are risks as staff retire or leave for other posts. Additional resources to allow work shadowing and training of new staff would reduce the risk of skills and expertise loss in this small group. The post of Director has been filled however this is only on an interim basis and a permanent appointment should be made.

6. 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 2022-2023 was £913,293, with over 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 2023-2024.

Figure 3: Current PHA/Grant funded staff 2022-2023



FTE = Full Time Equivalent
Colour code; Blue = PHA, Green = Grant 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 0.5FTE CIOs, 1FTE Analyst,
- Heart Research UK fund 1 FTE Researcher until Winter 2023.

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 8).

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
Total Core Work	**£844,973**	**£861,444**	**£878,673**	**£913,293**

Funding for 2023-2024 is not yet defined.

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 2023

	Funder	Start Date	End Date	Total Budget	Expenditure up to 31/03/23	Balance c/f 2023-2024
Cardiovascular Disease	Heart Research UK	01/01/20	31/12/24	£149,991	£95,723	£54,268
Breast Audit	Breast Cancer Now	01/05/22	30/04/24	£229,126	£20,564	£208,562
Pancreatic Audit	NI Panc	01/08/21	31/03/23	£26,363	£26,363	£0
Secondary Breast Cancer Audit	Cancer Focus	01/04/23	31/03/25	£60,000	£0	£60,000

Update on Actions for 2022-2023

Table 3: Update on Key Priorities 2022-2023

Colour code: Green = completed, Amber = ongoing

Targets 2022/2023	Update
🟩 **1.** Provide accurate, timely data on cancers in NI for official statistics by September 2022 for patients diagnosed in 2020	Final release of Official Statistics in February 2023 including - Factsheets - Reports - Data tables - COVID-19 impact reports
🟧 **2.** Commence work on 2021 diagnosed cancers to launch 2023	- Due to IT system upgrade, data access issues and other work pressures launch may not take place till 2024
🟩 **3.** Provide data on the impact of COVID-19 on cancer services	- Monthly updates released up to December 2022
🟩 **4.** Continue to provide a data request service including for genetic requests and alleged cancer clusters within timeframes	- 28 General and 70 Genetic requests responded to within 20/10 day target - Development begun on electronic Request Monitoring Service
🟩 **5.** Provide NI datasets for international comparisons e.g. Eurocare, Concord, ENCR, ICBP	- Datasets submitted
🟩 **6.** Ensure continued access to clinical information on oncology patients by acquiring RISOH downloads/access as per Trust agreements and becoming active in Encompass/LIMS planning. This is very important as PAS and other lab systems which are vital to the Registry processing will be replaced in ENCOMPASS	- RISOH monthly downloads now received. However read only access to RISOH is still not secured. Have been advised it will be possible following an upgrade to Citrix at BSO - NICR represented on Encompass meetings
🟩 **7.** Maintain our ISO27001 Certification in Information Security Management	- New staff member trained - Regular internal audits completed - External audit completed successfully November 2022 - Recertification audit due 1st May 2023
🟩 **8.** Continue with upgrades to the Registry IT System and extend its capacity to store data items	- Business Case submitted to PHA for additional funding
🟧 **9.** Enhance datasets available to and recorded by the Registry e.g. comorbidities, tumour markers, recurrences and premalignant diseases	- Explore additional resources to identify and record recurrences and disease progression - New data on dementia/stroke in cancer patients provided

Targets 2022/2023	Update
	- Work on impact of heart disease in cancer patients ongoing - Continue work on Premalignant Disease including documentation of CIN III and CIN II Cervical lesions
10. Continue to undertake feedback to clinicians	- Registry represented at NICaN Board and CRGs
11. Work with clinicians, RQIA, NICaN, local charities and PHA to undertake local audits and achieve inclusion of NI data in National Clinical Audits	- Colorectal Cancer audit published Oesophageal Cancer audit published - Pancreatic Cancer audit near completion - Breast Cancer Now COVID impact audit underway - Audit Lead Analyst appointed - Ensure KPIs match those of other nations
12. Provide data for UK annual Performance Indicators	- 2020 data submitted April 2022
13. Maintain up to date, accessible and accurate information on cancer available for the public, charities, media etc	- 30 Tweets with 27,517 impressions and 582 engagements. - Media interactions via Twitter, Facebook, BBC Newsline, BBC NI News and local newspapers regarding Official Statistics, COVID Impact on Health Services, Breast Cancer Now Audit, Secondary Breast Cancer Research Audit and Pancreatic Cancer Audit (see Appendix F)
14. Continue to work with external researchers to enhance cancer research in NI	- Two summer student placements via CPH - Hot Desks provided to 13 external researchers
15. Ensure Standard Operating Procedures are kept up to date	- Annual review of each SOP - Ensure all relevant areas have a SOP
16. Identify key roles and best structure for NICR including post to cover Clinical audits and new Director post	- Audit Lead Analyst appointed - New Director in post (although interim position) - Staff training and development continuing
17. Work to meet the targets of the Breast Cancer Now grant application	- Grant application successful and audit commenced May 2022 - Regular meetings of Project Management Group and Steering Group
18. Ensure the budget is used to provide the Business Plan targets	- Quarterly monitoring of Budget - Update and implement cost recovery policy - Breast Cancer Now Audit grant successful - Business Case for IT system support and development submitted to PHA

Targets 2022/2023	Update
19. Prepare for NICR review as recommended by the NI Cancer Strategy	- Ensure documentation is up to date - Maintain Risk Register - Update Business Continuity Document - Update PHA/QUB contract
20. Ensure Patient Involvement	Patients/their representatives are integrated into Registry activities through the likes of: - Council Membership - Charity representation on Steering Group - Provision of information when requested - Audits
21. Collation of existing audit datasets to facilitate future audits and inclusion in the new IT system	- Audit data amalgamations have started. Thyroid complete, breast commenced

NICR Key Priorities 2023-2024

1. Provide complete, accurate data on cancers in NI for official statistics by March 2024 for patients diagnosed in 2021,
2. Develop Routes to Diagnosis data and outputs,
3. Respond to general data and information requests within a timely manner,
4. Respond to requests from the family genetic services within a timely manner,
5. Provide NI datasets for international comparisons and collaborations e.g., ICBP, Eurocare, Concord, ENCR,
6. Seek to acquire clinical information on oncology patients by acquiring full read-only RISOH access as per Trust agreements,
7. Seek to ensure NICR requirements are met by future HSC systems e.g., Encompass/LIMS,
8. Maintain ISO27001 Certification in Information Security Management,
9. Implement new Registry IT System and ensure it is fully operational for staff,
10. Enhance and improve NICR data outputs and seek to tailor for individual stakeholders,
11. Provide data for UKIACR annual Performance Indicators,
12. Provide data on the impact of COVID-19 on cancer services,
13. Continue to work with external researchers to enhance cancer research in NI,
14. Ensure Standard Operating Procedures are kept up to date,
15. Ensure NICR Director Post is secured on permanent basis,
16. Undertake a formal data quality assessment of the NICR data,
17. Secure funding for ongoing collection of data on premalignant diseases,
18. Secure resources needed to collect additional NICR data items as per ENCR recommendations (e.g., comorbidities, tumour markers, recurrences),
19. Secure resources to allow collection of CIN II and NMSC data in line with UKIACR counterparts and ENCR recommendations,
20. Work with clinicians, RQIA, NICaN, local charities and PHA to secure funding to undertake audits,
21. Investigate development of rapid datasets (RDs),
22. Increase awareness of the opportunities NICR data can provide.

Although the Registry will continue to seek additional resources from external sources, a more sustainable model of funding for NICR is required to ensure it continues to provide a cancer intelligence service with high quality, timely, accurate data for service planning and evaluation, research and education.

Table 4: NICR Key Priorities 2023-2024

Targets 2023/2024	Proposed Actions
1. Provide complete, accurate data on cancers in NI for official statistics by March 2024 for patients diagnosed in 2021	Release Official Statistics in two tranches by March 2024
2. Develop Routes to Diagnosis data and outputs	- Acquire outpatient data to enable analysis of Routes to Diagnosis for patients diagnosed in 2020 - Complete data analysis and develop outputs, such as reports
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, ENCR	Datasets to be submitted by agreed dates
6. Seek to acquire clinical information on oncology patients by acquiring full read-only RISOH access as per Trust agreements	- Liaise with BSO to enable read-only RISOH access once BSO's upgrade for third party access is complete. - Continue to raise this issue at NICR Steering Group meetings
7. Seek to ensure NICR requirements are met by future HSC systems e.g., Encompass/LIMS	NICR staff will - Continue to attend Encompass Cancer Decision Group Meetings - Link with the new LIMS project management team
8. Maintain ISO27001 Certification in Information Security Management	Undertake regular internal audits to ensure confidence with NICR ISO policies to prepare for external audit/recertification in May 2023
9. 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)
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 regarding NICR data outputs

Targets 2023/2024	Proposed Actions
11. 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
12. Provide data on the impact of COVID-19 on cancer services	Reports to be released quarterly, with possibility of less frequent release on review
13. 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
14. Ensure Standard Operating Procedures are kept up to date	Undertake review of NICR SOPs as processes develops and at least annually
15. Ensure NICR Director Post is secured on permanent basis	Work with NICR Steering group, QUB and PHA to secure permanent post
16. 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
17. 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
18. 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
19. 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
20. 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
21. Investigate development of rapid datasets (RDs)	- Undertake exploratory QA exercise using existing NICR data sources in line with practice in other Registries - Seek to develop an initial rapid dataset for NI and investigate quality issues, including strengths and weaknesses
22. Increase awareness of the opportunities NICR data can provide	Membership of - The Cancer Data Steering Group - Cancer Strategy Steering Group - CPH Epidemiology Research Group - Attendance at Clinical Reference Groups (CRGs) - Maintain media engagement (see Appendix F) - Ensure new staff within stakeholder groups are invited to visit the NICR - Host NICR Information Day

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

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)	Associate Pro-Vice-Chancellor and Professor of Digital Health Faculty of Medicine, Health and Life Sciences
Ms Cara Anderson	HSC Board, Asst Director Commissioning (Cancer & Pathology)
Ms Lyn Benson	HSC Board, Financial Accounts & Governance
Dr Kathryn Boyd	NICaN, Medical Director
Mr Richard Spratt	Cancer Focus NI, CEO
Dr Gareth Irwin	Health and Social Care Trust Clinician
Dr Louise Herron	Public Health Agency
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 Margaret Carr	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

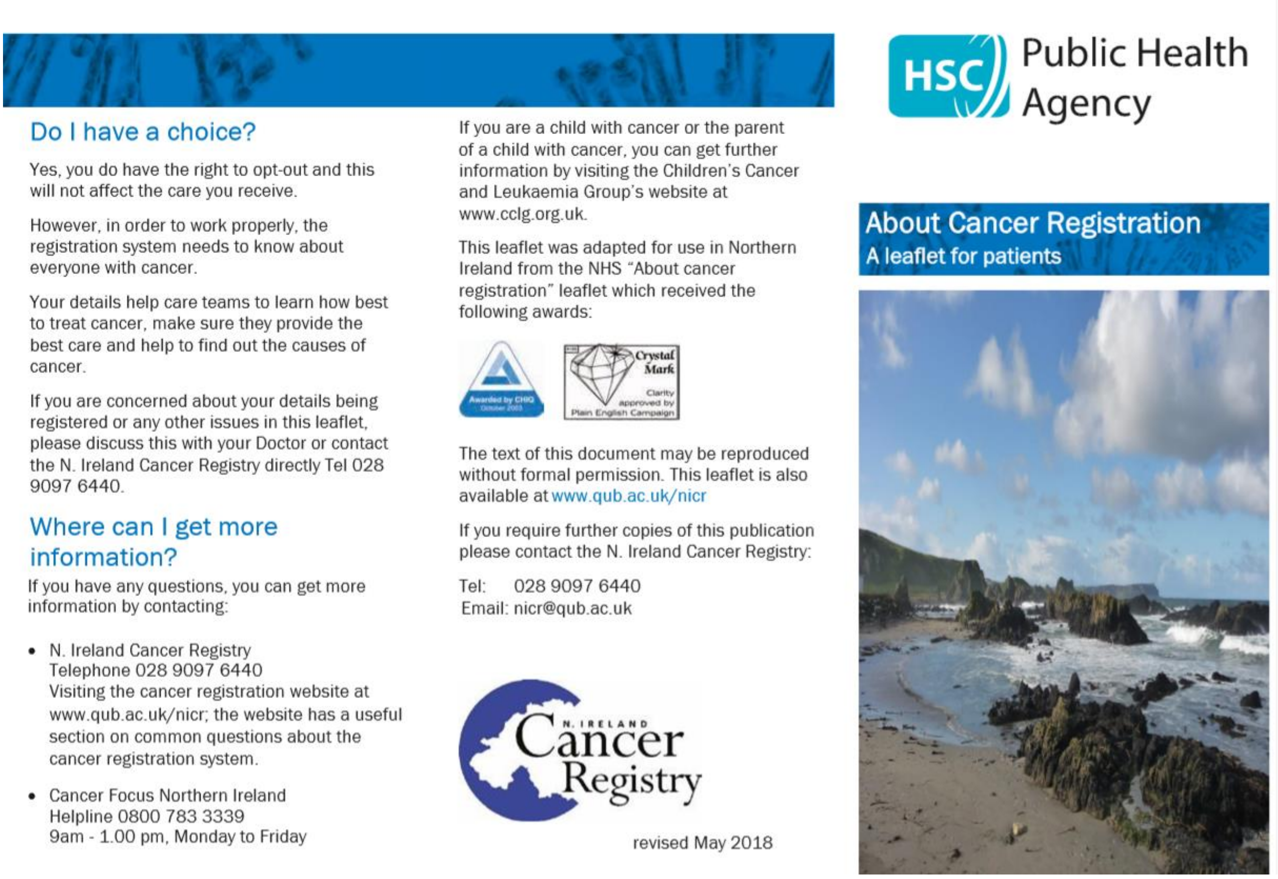
With attendance from Registry Director, Deputy Director and relevant staff required for the agenda.

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 Research Advisory Group join 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

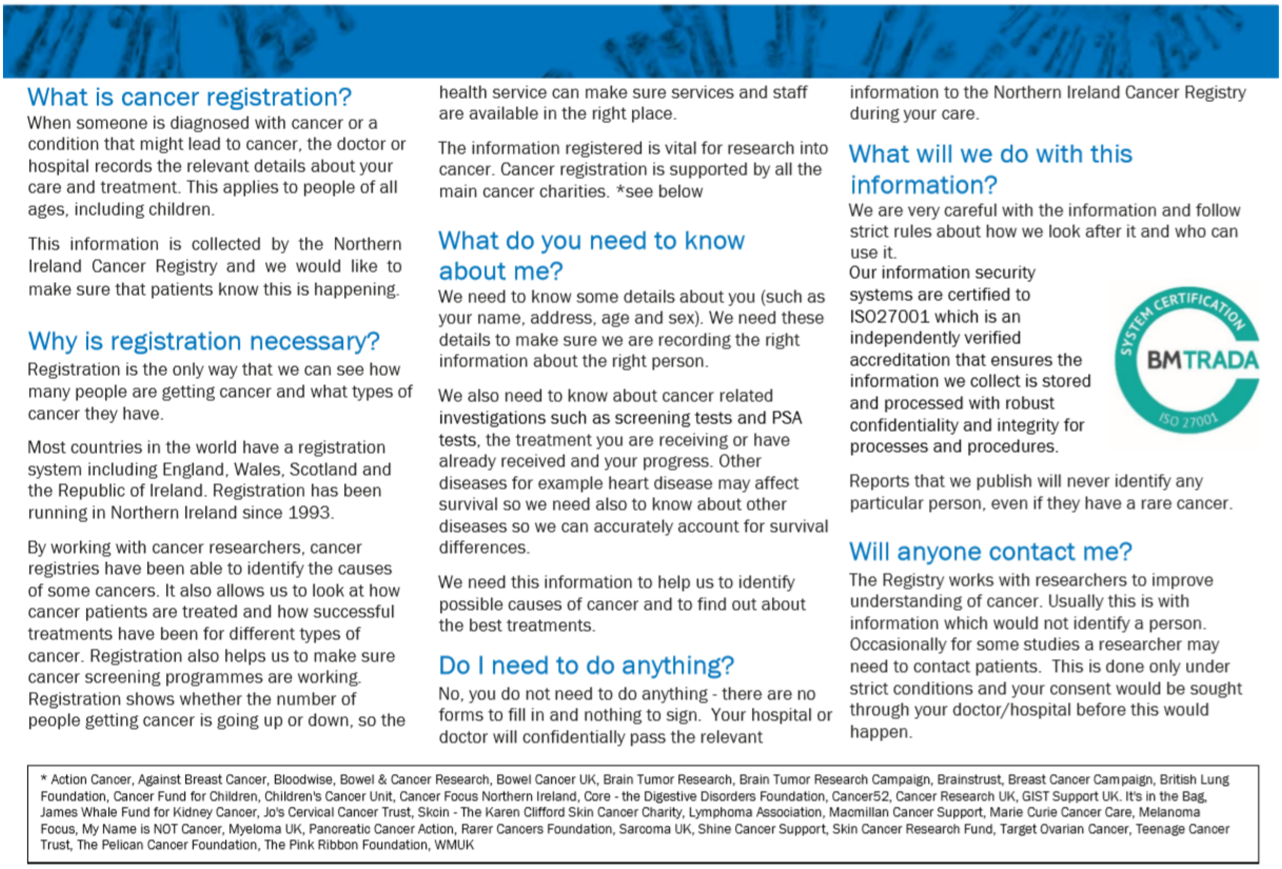
N. IRELAND Cancer Registry

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

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

Indicator	**Northern Ireland** 2021 report on **2019 diagnoses**	**Northern Ireland 2022 report on 2020 diagnoses**
Stability: Percentage change (%) for all cancers (C00-C97 ex. C44) compared with previous three years	3.3%	-8.0%
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].	1.4%	1.0%
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]	82.0%	81.2%
Average of Core Patient Information Complete: Average percentage (%) of all cancers (C00-C97 ex. C44) registered with demographic information[3]	100.0%	99.9%
Average of Core Tumour Information Complete: Average percentage (%) of all cancers (C00-C97 ex. C44) registered with tumour information[4]	96.9%	96.3%
Death Certificate Only (DCO) Rates: Percentage (%) of all cancers (C00-C97 ex. C44) registered as a DCO[5]	0.6%	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]	0.6%	1.1%
Microscopically Verified: Percentage (%) of all cancers (C00-C97 ex. C44) that are microscopically verified	85.8%	83.5%
Non-Specific Codes: Percentage (%) of all cancers (C00-C97 ex. C44) that are microscopically verified with non-specific morphology codes	2.6%	1.2%
Grade: Percentage (%) of all cancers (C00-C97 ex. C44) registered with a known grade	59.7%	59.6%
Treatment: Percentage (%) of all cancers (C00-C97 ex. C44) registered with any treatment	84.5%	67.3%
Cervical Screening Data: Percentage of cervical cancer (C53) cases screen detected for ages 25-60	63.1%	74.0%

APPENDIX D: Peer reviewed publications

NICR Publications January 2022 – March 2023

1. **Epidemiology of multiple myeloma in UK and Republic of Ireland**
   Sharma, M., Anderson, L., **Gavin, A**. & McShane, C., 03 Apr 2022. In British Journal of Haematology
   Meeting abstract.

2. **Risk factors and prognostic implications of diagnosis of cancer within 30 days after an emergency hospital admission (emergency presentation): an International Cancer Benchmarking Partnership (ICBP) population-based study**
   ICBP Module 9 Emergency Presentations Working Group, 06 Apr 2022, In: Lancet Oncology.
   https://doi.org/10.1016/S1470-2045(22)00127-9

3. **The impact of the COVID-19 pandemic on endometrial cancer and endometrial hyperplasia diagnoses: a population-based study**
   Wylie, J, Quinn, D, Donnelly, DW, McCluggage, WG, Coleman, HG, Gavin, A, McMenamin, US. May 2022. In American Journal of Obstetrics and Gynaecology.
   https://doi.org/10.1016/j.ajog.2021.12.259

4. **Diagnostic routes and time intervals for ovarian cancer in nine international jurisdictions; findings from the International Cancer Benchmarking Partnership (ICBP)**
   ICBP Module 4 Working Group, 26 May 2022, In: British Journal of Cancer.
   https://doi.org/10.1038/s41416-022-01844-0

5. **Survival of cancer patients with pre-existing heart disease**
   O'Neill, C., **Donnelly, D. W.,** Harbinson, M., Kearney, T., **Fox, C. R.,** Walls, G. & **Gavin, A**., 04 Aug 2022, BMC Cancer.
   https://doi.org/10.1186/s12885-022-09944-z

6. **Impact of the COVID-19 pandemic on emergency hospital cancer admissions in a UK region**
   Mitchell, H., **Alford, B. S**., **O'Hare, S**., **O'Callaghan, E., Fox, C. & Gavin, A. T**., 04 Aug 2022, In: BMC Cancer.
   https://doi.org/10.1186/s12885-022-09932-3

7. **Early-Onset Cancers in Adults: A Review of Epidemiology, Supportive Care Needs and Future Research Priorities**
   Hamilton, A. C., **Donnelly, D. W., Fitzpatrick, D. & Coleman, H. G.,** 20 Aug 2022, In: Cancers.
   https://doi.org/10.3390/cancers14164021

8. **The global landscape of esophageal squamous cell carcinoma and esophageal adenocarcinoma incidence and mortality in 2020 and projections to 2040: New estimates from GLOBOCAN 2020**
   Morgan, E., Soerjomataram, I., Rumgay, H., **Coleman, H. G**., Thrift, A. P., Vignat, J., Laversanne, M., Ferlay, J. & Arnold, M., 01 Sep 2022, In: Gastroenterology.
   https://doi.org/10.1053/j.gastro.2022.05.054

9. **Impact of patient and public (PPI) involvement in the Life After Prostate Cancer Diagnosis (LAPCD) study: a mixed-methods study**
   Brett, J., Davey, Z., Matley, F., Butcher, H., Keenan, J., Catton, D., Watson, E., Wright, P., **Gavin, A**. & Glaser, A. W., Nov 2022, BMJ Open.
   http://dx.doi.org/10.1136/bmjopen-2022-060861

10. **Incidence and survival of uveal melanoma in Northern Ireland: how incomplete data can skew results in rare cancers**
    Quhill, H., Jefferis, J. M., Rennie, I. G., Salvi, S. M., **Gavin, A., Fitzpatrick, D., Savage, G**., Curragh, D. & Rundle, P., 09 Dec 2022, In: Eye.
    https://doi.org/10.1038/s41433-022-02352-4

11. **Diagnostic pathways for breast cancer in 10 International Cancer Benchmarking Partnership (ICBP) jurisdictions: an international comparative cohort study based on questionnaire and registry data**
    The ICBP Module 4 Working Group, The ICBP Module 4 Working Group, ICBP Module 4 Academic Reference Group, Vedsted, P., Weller, D., Zalounina Falborg, A., Jensen, H., Kalsi, J., Brewster, D. H., Lin, Y., **Gavin, A.,** Barisic, A., Grunfeld, E., Lambe, M., Malmberg, M., Turner, D., Harland, E., Hawryluk, B., Law, R-J., Neal, R. D. & 33 others, 15 Dec 2022, In: BMJ Open.
    http://dx.doi.org/10.1136/bmjopen-2021-059669

12. **Shifting incidence and survival of epithelial ovarian cancer (1995-2014): a SurvMark-2 study**
    Cabasag, C. J., Arnold, M., Rutherford, M., Ferlay, J., Bardot, A., Morgan, E., Butler, J., O'Connell, D. L., Nelson, G., Høgdall, C., Schnack, T., **Gavin, A**., Elwood, M., Hanna, L., Gourley, C., De, P., Saint-Jacques, N., Mørch, L. S., Woods, R. R., Altman, A. D. & 8 others, 19 Dec 2022, In: International Journal of Cancer.
    https://doi.org/10.1002/ijc.34403

13. **Impact of the COVID-19 pandemic on cancer care in Ireland - Perspectives from a COVID-19 and Cancer Working Group**
    O'Reilly, S., Kathryn Carroll, H., Murray, D., Burke, L., McCarthy, T., O'Connor, R., Kilty, C., Lynch, S., Feighan, J., Cloherty, M., Fitzpatrick, P., Falvey, K., Murphy, V., Jane O'Leary, M., Gregg, S., Young, L., McAuliffe, E., Hegarty, J., **Gavin, A**., Lawler, M. & 15 others, , 23 Feb 2023, In: Journal of Cancer Policy.
    https://doi.org/10.1016/j.jcpo.2023.100414

APPENDIX E: Requests for Information

Requests for Information

The NICR provided data and information for 98 requests in 2022, 28 (29%) general requests and 70 (71%) genetic requests (excluding local genetic requests) (***Figure 5***). A nurse from the Medical Genetics department deals with local genetic requests.

In 2022, 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.

36% of general requests were received from academic researchers and charities (combined) (***Figure 6***).

On average general requests took 134 minutes to complete but ranged from 20 minutes to 630 minutes (10.5 hours). Genetic requests took an average of 22 minutes to complete however this ranged from 10 minutes to 50 minutes.

Figure 5: General and Genetic Requests received 2022

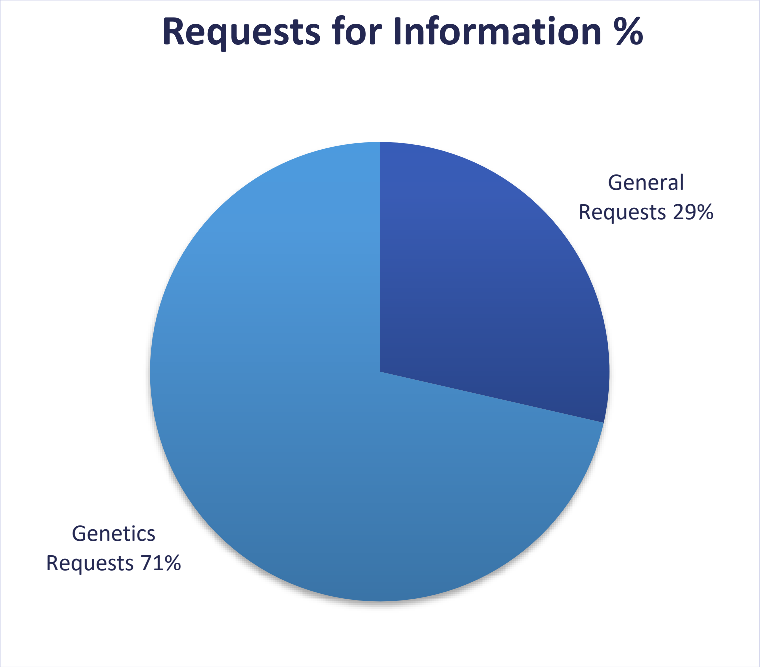
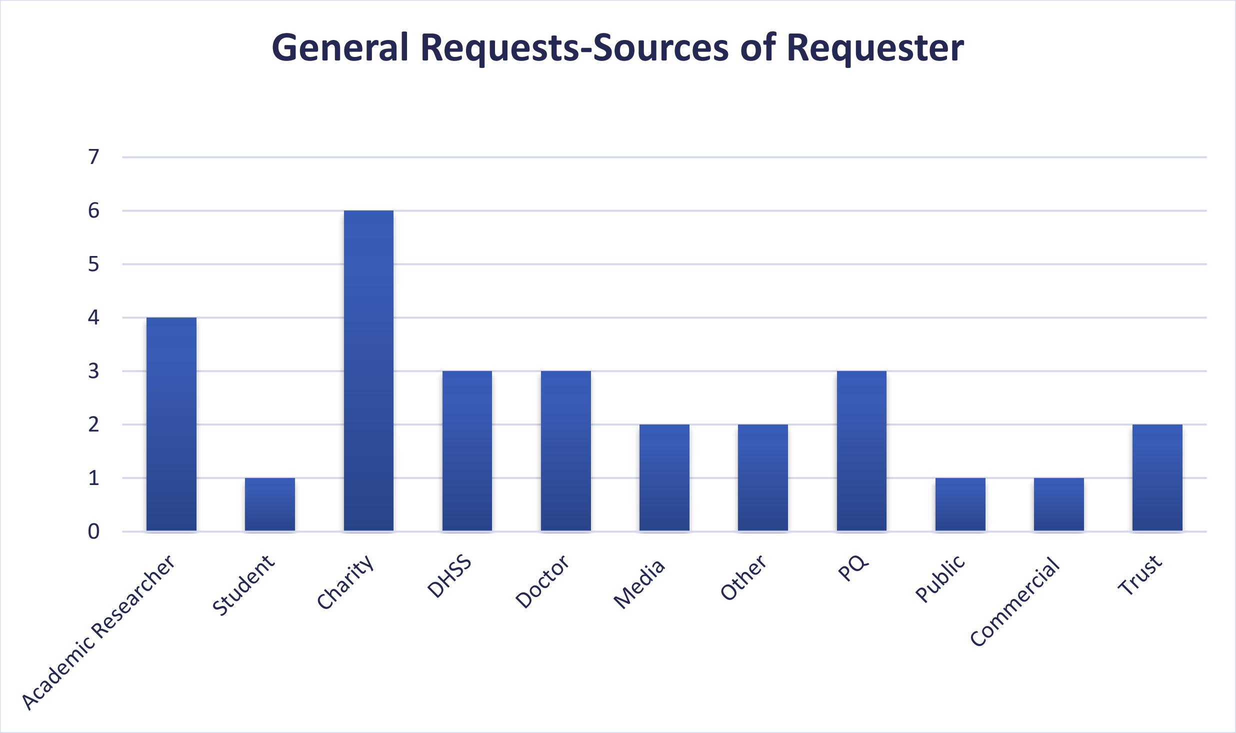


Figure 6: Source of Requests – General



APPENDIX F: NICR Media

Media Interactions April 2022 – March 2023

07-04-2022, Belfast Newsletter
One in four cancer diagnoses in Northern Ireland come after medical emergencies

07-04-2022, Belfast Live
Northern Ireland mum diagnosed with cancer after being told she was 'too over anxious' about symptoms

07-04-2022, Belfast Telegraph
Lurgan mum diagnosed with cancer in A&E told she only had 'hours to live'

27-05-2022, M2 PressWIRE;
The Queen's University : Urinary, Gynaecological, hepatobiliary and pancreatic cancer incidence and survival statistics NI

30-09-2022, Breast Cancer Now
2 in 5 women in the UK do not check their breasts regularly for the signs and symptoms of breast cancer

15-12-2022 ENP Newswire
Queen's University : Breast, colorectal, oesophageal, stomach and head neck cancer incidence and survival statistics NI

04-02-2023, Cork's RedFM
First All-Ireland Cancer Network Launched Today – World Cancer Day

05-02-2023, BBC Online
First All-Ireland Cancer Network launched

07-02-2023, Belfast Newsletter
More than 14,000 cancer cases every year in NI by 2040

09-02-2023, Science Business
Trinity lead network of 'the best minds in Ireland' studying oesophageal cancer

09-02-2023, Irish News
Nearly 10,000 cancer cases diagnosed each year in Northern Ireland

14-02-2023, India Education Diary

Trinity College Dublin’s network of ‘the best minds in Ireland’ studying oesophageal cancer

22-02-2023, BBC Online
Breast cancer: Audit of patients in Northern Ireland to take place

22-02-2023, HEAD TOPICS
Breast cancer: Audit of patients in Northern Ireland to take place

23-02-2023, News Letter (Belfast)
Local charity funds Northern Ireland’s first secondary breast cancer research audit

02-03-2023, Coleraine Chronicle
MLA welcomes breast cancer audit

02-03-2023, Ballymoney Chronicle
MLA welcomes breast cancer audit

02-03-2023, Ballymena Guardian
Ballymena family's donation helps fund vital breast cancer audit

02-03-2023, Antrim Guardian
Ballymena family's donation helps fund vital breast cancer audit