# Operational Plan
# April 2022 – March 2023

## *N. Ireland Cancer Registry*

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

## CONTEXT

Annually the Northern Ireland Cancer Registry (NICR) produces an operational plan which sets out the Registry's role, direction and priorities for the year ahead. This includes an overview of the Registry's achievements from the previous year, in this case April 2021 - March 2022. 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 Business Plan comes at a time of positive changes in the Registry;

- The IT system of 20 years is in the process of a major upgrade,
- Queen's University Belfast (QUB) has provided the NICR with a significant upgrade to the accommodation which will enhance collaboration working between staff and with external researchers ensuring a high level of data security,
- We look forward to welcoming new staff, Cancer Intelligence Officers (CIOs) and a new Director.

## Contents

## GLOSSARY

| Acronym | Definition |
|---|---|
| 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 |
| CRG | Clinical Reference Group |
| CRUK | Cancer Research United Kingdom |
| DHSS | Department of Health & Social Services |
| DoH | Department of Health |
| ECR | Electronic Care Record |
| ENCR | European Network Cancer Registries |
| EPD | Enhanced Prescribing Database |
| ER | Estrogen Receptor |
| GAIN | Guidelines and Audit Implementation Network |
| GDPR | General Data Protection Regulation |
| GRO | General Register Office |
| GRONI | General Register Office NI |
| HCN | Health & Care Number |
| HER2 | Human Epidermal Growth Receptor 2 |
| HSC | Health & Social Care |
| IACR | International Association of Cancer Registries |
| 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 |
| LIMS | Laboratory Information Management System |
| LSHTM | London School of Hygiene and Tropical Medicine |
| MGUS | Monoclonal Gammopathy of Undetermined Significance |
| NMSC | Non-Melanoma Skin Cancer |
| NI | Northern Ireland |
| NICaN | NI Cancer Network |
| NICE | National Institute for Health & Care Excellence |
| NICR | NI Cancer Registry |
| NINIS | NI Neighbourhood Information Service |
| NIPCLR | NI Premalignant Cervical Lesions Register |
| 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 |
| PCUK | Prostate Cancer UK |
| PGJCCR | Patrick G. Johnston Centre for Cancer Research |
| PHA | Public Health Agency |
| PIs | Performance Indicators |
| PR | Progesterone Receptor |
| PSA | Prostate Specific Antigen |
| QUB | Queen’s University Belfast |
| RISOH | Regional Information System for Oncology and Haematology |

| | |
|---|---|
| RQIA | Regulation and Quality Improvement Authority |
| SACT | Systemic Anti-Cancer Therapy |
| SMILE | Stratified Mucin-producing Intraepithelial Lesion |
| TNM8 | International Union Against Cancer TNM Classification of Malignant Tumours Eighth Edition |
| TVO | Tumour Verification Officer |
| UKIACR | UK and Ireland Association of Cancer Registries |
| YPAST | Young People and Adult Screening Team |

# 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 and premalignant conditions in patient's resident in a defined population. The N. Ireland Cancer Registry (NICR) is one of five cancer registries that cover the populations of Great Britain and Ireland. All of the registries use common definitions and processes and share the same main objective; to deliver timely, comparable and 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 requirement for clinicians to notify new cancer diagnoses and limited resources.
The NICR was established in 1994 (complete registrations from 1993), to provide information on cancers occurring in the NI population for the purposes of research, education, planning and evaluation of services. Following the Review of Public Administration, the funding for the Registry moved from a five-year cycle with the DHSS to an annual cycle with the Public Health Agency (PHA).
The Registry is the subject of an agreement between the PHA and Queen's University Belfast (QUB) (available on request). The agreement sets out the terms by which the University contracts to establish, maintain and operate a register of incident cases of cancer. Financial regulation, staff appraisals, discipline and recruitment are as per QUB policies. The NICR has the option of regular reviews to ensure quality and advice on direction. The last review (2018) is available here on the NICR website.
The Registry 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 relating to the Registry, particularly its outputs. The Council 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 but will be merged with the Council from 2021 onwards. (See Appendix A for membership of Steering Group, Council and Research Advisory Group).

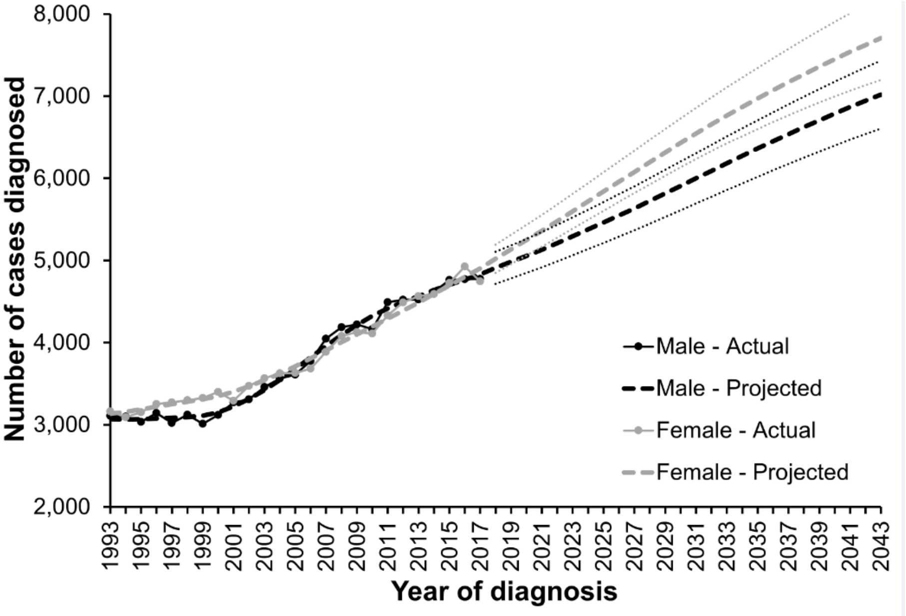
Cancer registry processes include data acquisition, linkage, quality assurance and analysis to ensure that data on cancers and premalignant diseases are fit for purpose including:

- 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,
- The provision, in a confidential setting, of information to Genetics Counselling Services for those with potential predisposition to certain cancer types,
- Quality assurance of population-based screening programs,
- Investigation of alleged cancer clusters,
- Provision of data for and undertaking research into prevention, patterns and trends and outcomes of cancer, approved by research ethics committees when required,
- Improving awareness of the cancer burden in NI and its prevention.

In 2020 NI had an estimated population of 1,895,500 people. Excluding non-melanoma skin cancer (NMSC) on average 9,861 cancers were diagnosed each year during 2015-2019 (13,823 cases per year including NMSC). At the end of 2019 there were 68,361 cancer survivors (excluding NMSC) residing in NI who had been diagnosed in the previous 25 years (i.e. 1995-2019). Including NMSC, there were 101,445 survivors at the end of 2019.

Cancer incidence is increasing, with the increase predicted to continue, largely due to the ageing population among which cancer risk is higher. In 1993 there were 6,265 cancer cases (excluding NMSC) diagnosed. By 2019 this had risen to 10,219 cancer cases, an increase of 63%, with an additional 4,311 cases of NMSC. It is predicted that there will be 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 requiring collection has increased from 44 in 1993-96 to almost 200 in recent years. This number varies greatly depending on the tumour site and whether a clinical audit is being undertaken.

As the NICR looks to the future we foresee an increase in the quantity of data we will be required to process and collect as diagnostic methods improve, with more emphasis on patient pathway analysis and individual tumour level data. Examples of extra data requirements include viral involvement, biomarkers and disease progression. We have started to monitor the impact of COVID-19 on cancer services, the cancers diagnosed, their method of presentation, stage and survival.

In addition, there have been, and continue to be, changes to the IT systems supporting health service activity. The most significant for cancer registration is the roll out of the Regional Information System for Oncology and Haematology (RISOH) and the planned introduction of an integrated patient record through the EPIC based Encompass project which is due for roll out over the next five years.

After much effort we have received data from RISOH and the SACT datasets. These datasets are very important to enable completion of several important areas such as stage at diagnosis and the fact and detail of treatment on all patients required for production of cancer intelligence and official statistics for the population of NI.

## 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 the population of 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 we hold,
- Work with all 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 enable the NICR's role as provider of official cancer incidence, prevalence and survival statistics for NI,
- Facilitate the monitoring of the impact of cancer screening services in NI,
- Provide appropriate information on cancer for ad hoc queries including investigation of alleged cancer clusters,
- Undertake and assist audits of cancer treatments, services and outcomes, and recommend improvements in cancer services where appropriate,
- Facilitate planning of cancer services for prevention, diagnosis, cure and care,
- Promote, facilitate and undertake research into cancer causes, prevention, treatments, outcomes, care and survivorship,
- Publish scientific reports and research articles relating to cancer,
- Promote professional and public awareness about cancer,
- Link nationally and internationally to promote cancer registration and increase understanding and management of cancer.

## 1.6 Ethics and compliance with Data Protection

In October 2020, the NICR had their approval renewed for a further five years for its databases 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.

The NICR is a registered data controller under Queen's University Belfast with the Information Commissioner's Office - Registration Number: Z6833827 and has undertaken a review to ensure compliance with the UK (General Data Protection Regulation) GDPR and other relevant data protection laws. This has taken significant resources, and ongoing maintenance of these and ISO27001 requires designated audits and a trained staff member to oversee the process.

The NICR has data sharing agreements in place to facilitate the receipt of data from the NI Health and Social Care Trusts, Business Services Organisation and the Young People and Adult Screening Team (YPAST). The Registry does not seek individual level 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 since then have been awaiting development of the regulations which may affect the operation of the NICR.

All identifiable data are held in a highly secure area of the registry and are 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:

- Facilitate 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, avoid double counting,
- Enable linkage to other databases e.g. screening for evaluation,
- Enable accurate data for the Genetic Advice Service,
- Facilitate recall exercises. For example, the NICR previously helped the Department of Health (DoH) with the identification of patients who may have been at increased risk of breast cancer following radiation therapy for lymphoma. These patients were then offered a mammogram.

### 1.7 NICR engages with patients by:

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

### 1.8 NICR links with public by:

- The Registry has a leaflet reflecting current practice, and a poster to inform patients, clinicians and the public about the work of the NICR. 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),
- In 2014, a video was developed to inform a wider audience of the work of the NICR which is available at here,

There is public awareness of the NICR through the 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 (e.g. BBC Official Statistics Lung Cancer Launch),

- The Registry has an active Twitter account sharing relevant information on various cancer sites during key awareness days along with updates on Registry publications.

### 1.9 NICR links with clinical teams by:

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

### 1.10 NICR links with researchers through:

- The Director and current Acting Deputy Directors being academic research staff in QUB,
- Provision of designated area within the 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 availability 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 queries, parliamentary questions and data requests from Trusts, PHA and DHSS,
- Attendance at relevant NI Assembly Health Committee events,
- Working with N. Ireland Cancer network (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.

NICR engaged actively in providing data for the development of the 2021 Cancer Strategy and monthly reports on the impact of COVID-19 on Cancer Services.

## 1.12 Information Security

The NICR operates a very high level of security, which has been independently audited and certified to meet the standard of ISO27001:2013 Information Security Management achieved in May 2017 and recertified in February 2020 until May 2023. This is regularly audited internally and externally throughout the year

Information security controls include physical measures such as video surveillance, staff card access only, 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.
We operate logical controls by means of a User Access control system which incorporates a tiered system of access to various physical areas of the Registry with only designated staff in the area where patient identifiable data are used to verify registrations. Similarly, analysts have a designated area for working with anonymised patient level data. The recent COVID-19 pandemic necessitated home working, and this was accommodated while adhering to all security controls with development of a home working policy.

Data security is further enhanced for Registry access procedures with designated hot desks for researchers using anonymised Registry data and a visitor identification and login system with badges coded to indicate levels of access. Phones and electronic devices are left at reception when external researchers access the Registry hot desk facility.

We have secure data transfer with encrypted email facilities through hscni.net for communication with NI Health & Social Care Trusts, YPAST (screening services) and external research organisations in addition to nhs.net email for communication and data transfers between NICR and other UK organisations, for example, the Health Trusts in England and Wales.

The NICR is developing a new IT system to replace the praxis system originally developed 20 years ago. Access to the current NICR system is controlled by the use of biometric (fingerprint) authentication and passwords. Access is dependent on the user permission level – for example, external researchers will have access only to folders necessary for their work, while data entry staff do not have access to administrative functions such as reference table maintenance.

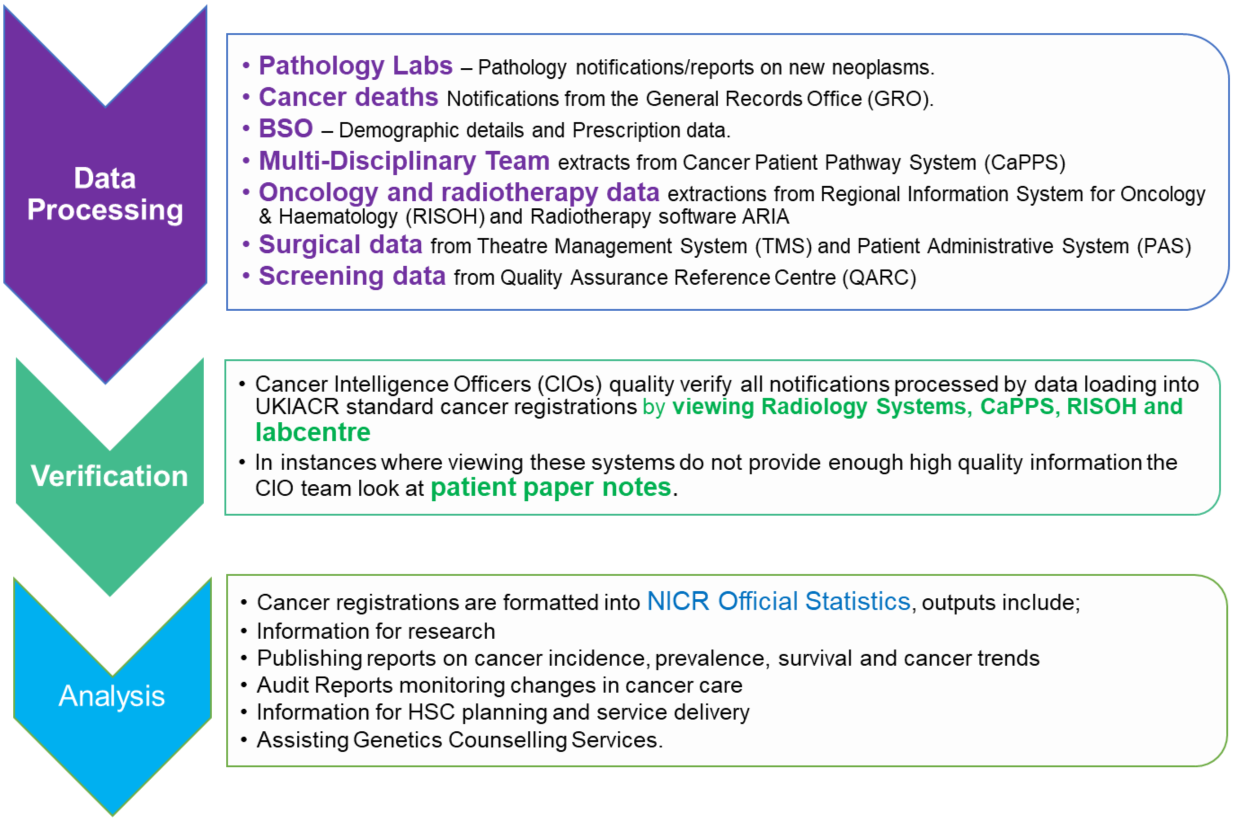
We have a policy of daily backups of the Registry system and regular backups for those working external to the system.

## 2. METHOD OF OPERATION

### 2.1 Data Sources

The NICR acquires notifications of likely cancer and pre-malignant diagnoses in the population electronically from pathology laboratories, hospital admissions and discharges from the Patient Administration Systems (PAS) and General Records Office (GRO) death registrations received via the DoH using cancer and premalignant disease specific ICD10 Coding and Topography coding.

*Figure 2: Process of How NICR Data Sources Are Turned into Outputs*



- **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 Theatre Management System (TMS) and Patient Administrative System (PAS)
- **Screening data** from Quality Assurance Reference Centre (QARC)

- 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 look at **patient paper notes**.

- Cancer registrations are formatted into NICR Official Statistics, outputs include;
- 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.

The NICR Cancer Intelligence Officers (CIO) staff have access to full pathology text reports and part of their work in resolving requires that they read 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 included above the NICR has access to datasets on:

***Prescriptions***

The Enhanced Prescribing Database (EPD), managed by Business Services Organisation (BSO), contains detailed information in relation to all primary care prescriptions dispensed to patients in NI since March 2008. The dataset therefore can be used to source limited information on the level of morbidity within the cancer patient population in NI. As medications can treat a range of conditions, the use of prescriptions to define specific comorbidities is limited. Information on specific cancer treatments such as hormone therapy for breast cancer, are also be captured through the EPD.

***Comorbidities***
Since 1 January 2006, the NICR has received PAS downloads of hospital admission and discharge records for cancer patients, in order to identify patient comorbidities.

***Surgery***
Surgery data are available as an extract from the PAS hospital discharge data using Office of Population Censuses and Surveys Classification of Surgical Operations (Version 4.4) (OPCS4) codes. Curative surgical codes for Cancer Registration have been defined by the UK and Ireland Association of Cancer Registries (UKIACR) Analysis group.

***Chemotherapy***
Chemotherapy data are available from PAS hospital discharge data using OPCS4 procedure codes and are supplemented by extracts received from Regional Information System for Oncology and Haematology (RISOH).

***Radiotherapy***
Radiotherapy data are available as an extract from the ARIA system. NICR have agreements in place to receive these data from both Belfast and the North West Cancer Centre. Limited radiotherapy notifications are also received through PAS hospital discharge data using OPCS4 procedure codes, however, the more detailed data to include fractions, prescription, treatment site, start and end dates are received directly from both radiotherapy centres.

***Primary Care data***
NICR is charged a fee by BSO for review of GP records of deceased patients where there is no other source of information to verify the diagnosis (death certificate initiated cases). Unfortunately, the NICR does not have access to the primary care dataset, the Electronic Care Record (ECR), at this time.

## 2.2 Diseases Registered

The NICR registerable tumours are ICD 10: C00-C97, D00-D09, D37-D48, D29.2, D32, D33, D35.2, D35.3 and D35.4. This includes all invasive malignancies including non-melanoma skin cancer, all in-situ lesions, benign brain and testicular conditions and neoplasms of uncertain or unknown behaviour. We also aim to collect recurrence and clinical data when appropriate.

The NICR also registers the following premalignant diseases:

- Barrett’s Oesophagus,
- Colorectal polyps,
- Endometrial Hyperplasia,
- Monoclonal Gammopathy of Undetermined Significance (MGUS),
- High grade CIN, CGIN and SMILE
- Prostate Specific Antigen (PSA).

See below for 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[1-9]. The register is the foundation for a large body of epidemiological, clinical, and biomarker research, now led by Professor Helen Coleman and 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 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).

In 2019, a dedicated NI Barrett's research Patient and Public Involvement (PPI) group was established and is comprised of five patients affected by this condition. The PPI group meet quarterly to guide this 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 will be disseminated to all endoscopy clinics in NI.

Current funding: Cancer Research UK; 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[10-13]. A joint molecular epidemiology study with Vanderbilt University, TN, USA, is ongoing using this resource to identify biomarkers for advanced recurrent adenomas.

Historic funding sources: Cancer Focus NI

### *Endometrial Hyperplasia (EH)*

This is an update of a population-based register of Endometrial Hyperplasia cases diagnosed between 2008-2014, which will be extended to 2020 (PI: Dr Úna McMenamin). The register will improve our understanding of the prevalence of concurrent Endometrial Hyperplasia and cancer diagnoses and allow estimations of cancer risk in Endometrial Hyperplasia patients who do not undergo hysterectomy. The results will facilitate women to make informed treatment choices following an Endometrial Hyperplasia diagnosis. The Register has recently been used to evaluate the impact of the COVID-19 pandemic on the pathological diagnoses of endometrial hyperplasia in NI and continued monitoring will be conducted. 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 these services. Work this year has included: completing 2018 to 2020 data collection for CIN3, CGIN and SMILE; quality assuring the data collected to maximise accuracy and completeness; assessing the feasibility of collecting additional data fields; and providing data for use in a QUB student's PhD. Future work is focused on standardising the methods for data collection; investigating ways of integrating with the new NICR database (CENTRIS) to maximise efficiency; and starting the routine collection of CIN2 data.
Current funding: Lynsey Courtney Foundation

*CIN = cervical intraepithelial neoplasia (grades 1-3); CGIN = cervical glandular intraepithelial neoplasia; QUB = Queen's University Belfast; SMILE = stratified mucin-producing intraepithelial lesion*

### *Prostate Specific Antigen (PSA)*

This is a population-based database of all PSA tests performed in NI biochemistry laboratories since 1993 and is used to supplement information on prostate cancer cases. It is a valuable research resource for understanding the relationship between PSA levels in men's blood and their risk of developing benign prostatic disease and/or malignant prostate cancer. PSA testing as a method for prostate cancer diagnosis is highly controversial, and this population-based resource has contributed to the international debate[14-23]. Specific projects to clean and match the data held were funded by Regulation and Quality Improvement Authority (RQIA) (previously GAIN).

## MEASURES OF DATA QUALITY

Our datasets are compared annually to those of England, Scotland, Ireland and Wales via the UKIACR. These reveal high quality NICR data, with the highest proportion of cancer staging compared to other UK and Ireland registries, and with staging above 80% from 2015 onwards (see Appendix C). 2020 staging for NICR data is 82%. Other indicators, for example numbers of death certificate only registrations (which account for 0.3% of invasive malignancies registered excluding non-melanoma skin cancers) and microscopically verified cases (which account for 86.3% of invasive malignancies registered excluding NMSC) indicate the high quality of the Registry's data.

Data from the NICR have been accepted for Cancer Incidence in Five Continents (since volume VII published 2002), Concord International Cancer Survival Studies, ICBP and EUROCARE with minimal requirements for data cleaning once quality checks have taken place.

The NICR has twice offered General Practitioners the opportunity to check data held by NICR on their patients. There was good uptake of this offer and results indicated a high level of data quality within the NICR[24].

### ***Data Quality***

In order to be assured of data quality there is a need within the NICR structure to have a CIO lead on data quality to maintain current levels of quality and check datasets for the performance indicators (UKIACR), while ensuring accurate updates of historic records.

## 3. REGISTRY IT SYSTEM

### 3.1 Background

The NICR is currently updating a legacy registration database system (PRAXIS) 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.

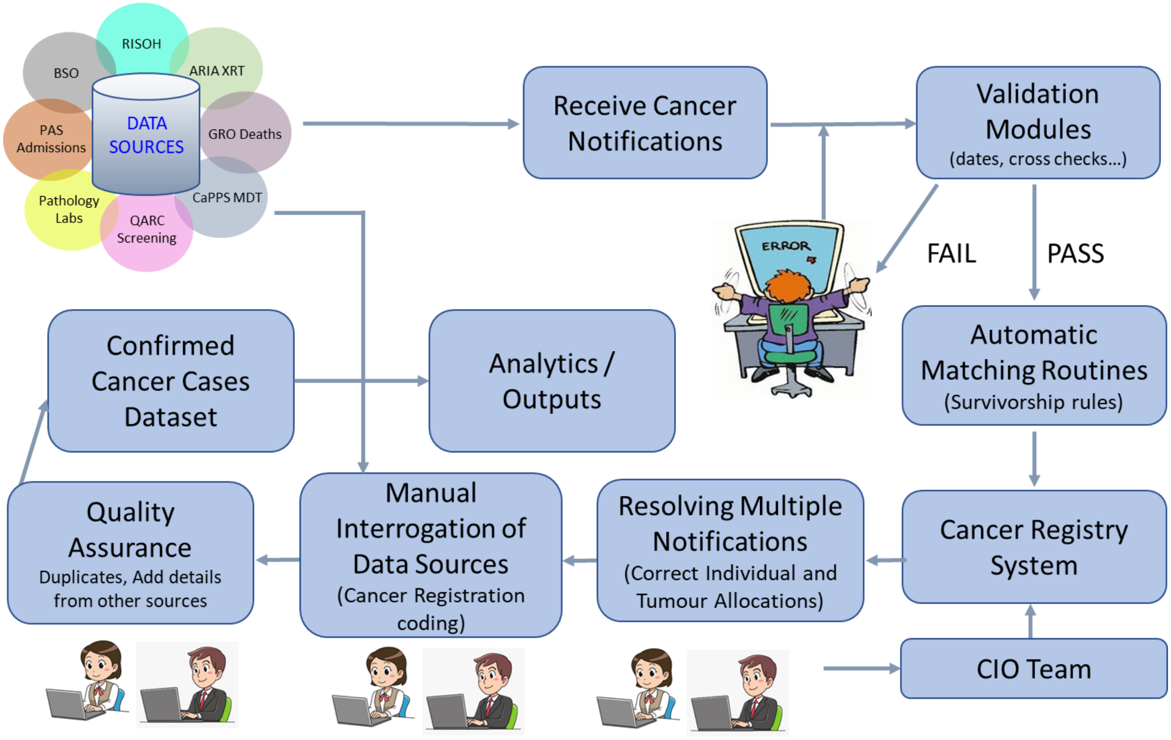
However, the underlying architecture is difficult to further develop using in-house resources and the availability of outside resource is limited and costly as few have expertise in the underlying platform, Caché.

In 2017, to alleviate the risk of system failure, PRAXIS was upgraded using inhouse IT skill to the latest version of the database management software (Caché 2016). The redevelopment aimed to facilitate the impending changes to cancer coding (such as SNOMED-CT coding of pathology data as part of the implementation of the new Laboratory Information Management System (LIMS)) and the future requirement to collect, record and analyse molecular data and record recurrences.

We are currently working with a local IT company CODEC who successfully tendered to replace PRAXIS with a system that is easily supported and developed. It will a Cloud based solution, using newer technologies such as MS Dynamics and Power BI, and have the ability to hold information on disease progression, similar to that collected in other UK registries.

### 3.2 Method of Data Processing

Registration Process



# 4. REGISTRY OUTPUTS

## 4.1 Official Statistics

Annually the NICR produce the Official Statistics on the incidence, prevalence and survival of cancer in NI. The Official Statistics for 2019 registrations were published on 16 September 2021 alongside the latest statistics on cancer mortality which are provided by General Register Office Northern Ireland (GRONI). The 2020 data were provided initially for lung cancer on March 15th, 2022, as there is considerable interest in the impact of COVID-19 on cancer services. Additional site information will be available in May. The official statistics will continue to include specific reports related to COVID -19.

Cancer statistics for 41 cancer sites (including all cancers, with and without NMSC) are available for viewing and download on the NICR website

These statistics detail the average incidence over a rolling five-year period by geographical areas (Health and Social Care Trust, Local Government District and Assembly Area) and deprivation quintile. Cancer incidence trends and survival statistics spanning 1993-2019 are also available.

## 4.2 Cancer Factsheets

The website, through its cancer factsheets, continues to be well used (see examples here).
We now have 41 factsheets updated annually as new official statistics are released.
Detailed clinical factsheets are also prepared for the NICaN clinical groups upon request.

## 4.3 Information for General Practice

The NICR have prepared information at General Practice Federation level on cancer incidence, prevalence, emergency presentation (see here).

## 4.4 Research Publications

Since January 2021, 17 peer reviewed publications using registry data have been produced (134 since January 2013) (Appendix D). Most recent scientific articles have a lay summary sheet, available here.

## 4.5 Information Requests

NICR handle two main types of information request: general requests and genetic requests.
General requests cover a broad spectrum from statistical information to complex research including investigation of alleged cancer cluster requests. During 2020, 98% of 46 general requests for information were completed within the recommended 20 working days.

Genetic requests largely come from Genetic Counselling Services across 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 held responsible for the confidentiality, use and security of the data. Consent must be received by the NICR before data are released. The target for genetic requests is a response within 10 days and in 2020 the NICR completed 100% of 128 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 Registry staff ensured data for all genetic requests were completed on time.

### 4.6 Reports

The 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 produced two clinical audit reports, oesophago-gastric and colorectal cancers.

### 4.7 Other Uses of Registry Data

- Regular feedback of cancer cases to the screening services for their quality control
- Annual updates for the local cancer intelligence tool launched by Macmillan Cancer Support in 2016. (See here),
- Annual updates for Cancer Research UK to populate UK wide cancer statistics concerning cancer incidence, mortality, survival, and risk factor dataon their webpage.

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

- 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).

### 4.8 Research Projects

***Facilitated by NICR staff***

- Macmillan Cancer Support and the NICR established a partnership in April 2016 with the goal of using cancer data to improve understanding of the impacts and costs of cancer and its treatment across the whole of a patient's cancer journey. Part of the role of the partnership is also to provide information at local level to facilitate better understanding of local needs and strategic priorities, while predicting future needs (extended to end 2022),

- The NICR director has been Principal Investigator in two Prostate Cancer UK (PCUK) funded surveys of men after diagnosis and treatment for prostate cancer, one All-Ireland study - with results for 3,384 men, and the other more recent UK wide Life After Prostate Cancer Diagnosis study in conjunction with Movember, with results on over 35,000 prostate cancer patients and 3,000 men without prostate cancer as a comparator group. This project formally ended in March 2019 with a launch of results in Leeds on 19th March 2019 and Belfast 26th March 2019. Publication of research papers continues, see NICR website for details of the publications,
- NICR continues to provide clinical data to approved NI Biobank studies as required,
- The NICR is an active member of DataCan which aims to enhance timely use of data,
- Premalignant conditions related research.

### *Projects facilitated within NICR by external researchers 2021/22*

- Clinical trial emulation for evaluating the effectiveness of surgery for improving lung and colorectal cancer patient outcomes,
- Identifying risk factors for lethal prostate cancer in a Northern Irish population-based study,
- Data-driven precision medicine in Bone Health management for patients with Metastatic Prostate Cancer,
- Investigating the validity of algorithms to identify smouldering myeloma in a cancer registry database,
- A population-based investigation into risk factors and surveillance strategies for endometrial hyperplasia and cancer,
- Epidemiology and treatment outcomes of endometrial hyperplasia and cancer: A population-based investigation using routine administrative data,
- The epidemiology of gastrointestinal pathology diagnoses: focus on serrated colorectal neoplasia.
- Audit of Pathology Data from the Northern Ireland Bowel Cancer Screening Programme (2010-2020),
- Demographic profile of oesophago-gastric cancer patients in NI,
- Head and Neck Cancer Epidemiology in Northern Ireland, analysis of data from the Northern Ireland Cancer Registry,
- COVID RT – assessing the impact of COVID-19 on radiotherapy in the UK: A National Cancer, Research Institute Clinical and Translational Radiotherapy Research Working Group (NCRI CTRad) study,
- Audit of recurrence of T1N0M0 laryngeal squamous cell carcinoma.

## 4.9 Audits

The Registry has in the past undertaken a suite of audits measuring changes to cancer services from 1996 when they were reorganised as a result of the Campbell Report. These have resulted in 21 reports, making recommendations for service improvement (each report is available on the NICR website). Also, the data contained within each audit report facilitated media opportunities, aimed at promoting cancer prevention and early detection messages, whilst also raising the profile of the NICR and QUB.

The most recent completed audits include:

1. The use of PSA tests in General Practice funded by RQIA, analysing 800,000 records of PSA tests on approximately 200,000 men. The aim of this work was to document PSA testing patterns, and feedback information to GPs with a view to encouraging adherence to NICE guidance which recommends that PSA testing is only undertaken when patients present with symptoms. RQIA Website: https://rqia.org.uk – June 2018,
2. An audit of Head and Neck Cancers discussed by Clinicians – April 2019,
3. Mesothelioma – 2020,
4. International Audit of Childhood Cancer,
5. An audit of Colorectal cancer funded by PHA – Available Spring 2022,
6. Funding from Regulatory and Quality Improvement Authority (RQIA) and OG Cancer NI has enabled undertaking of an audit of Oesophageal and Stomach cancers during 2020 – Published November 2021,
7. We plan and to undertake audit of Pancreatic cancer and research into Breast cancer presentation, treatments and outcomes funded by Breast Cancer Now in the near future.

# 5. ISSUES OF CONCERN/CHALLENGES FOR NICR

Below is a list of challenges that the NICR faces over the coming years:

## 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 which has been raised in the Cancer Strategy.

## 5.2 Access to Data Sources

After some time, data from RISOH and SACT have been provided to NICR for cases up to February 2022. The Registry is still awaiting Read-Only access to the RISOH system to facilitate confirmation of diagnosis and obtain essential data on treatment and that needed for staging. We are concerned that the move to Encompass will lead to similar problems with securing data access.

### Mandation of Minimum Dataset for Cancer Registration

Currently, unlike in England, there is no mandated minimum cancer dataset required from Trusts in NI. The development of a minimum dataset was a recommendation from the recent Registry review and Cancer Strategy and should be facilitated by the introduction of Encompass. This will require input from NICR staff.

## 5.3 IT System

The NICR is currently replacing its legacy registration database system (PRAXIS) with one that will be more easily developed and supported using in-house resources.

The replacement system will have the capacity to record additional important data such as disease progression, molecular markers and will have an integrated reporting tool using Power BI.

It is hoped that with additional funding further enhancements may be made such as integration of the cancer staging tool, inclusion of key performance indicators required for local/national audit and extension to the premalignant registers.

## 5.4 Annual Funding

The NICR is currently funded by the PHA, but the University considers this an annual grant. However, following discussions within QUB agreement has been reached that all NICR staff will be made permanent members of staff following their probation period.

There are still difficulties in staff retention and recruitment as posts can only be advertised on a short-term basis. Long term planning is required.

## 5.5 Funding for Audits

National audits provide a mechanism to benchmark local services with providers outside of NI. It requires comparisons of patient level datasets using similar methodologies and the rigorous collection of datasets.

There is a strong desire among cancer clinicians, the NICaN, the PHA and the Health and Social Care Board that NI datasets for cancer patients are available for comparison with those of National Audits. The NICR 2018 Review made recommendations about exploring how NICR can support Clinical Audits. The NICR has recently undertaken audits of colorectal cancer and oesophageal cancer. These were funded on an ad hoc basis by the PHA/RQIA/OG Cancer NI. Regular funding is required.
Planned audits of pancreatic cancer has been funded by NI Panc with research on breast cancer diagnosis, treatment and outcome pre and post covid have been funded by Breast Cancer Now.

### 5.6 Succession Planning

Job roles within the Registry are very specialised. We are a small team and there are risks of losing skills as staff leave for other posts or retire. Additional resource for work shadowing and training of new staff is required to reduce the risk of loss of expertise in this small group. The post of Director will become vacant July 2022. Processes to begin recruitment and advertisement for replacement have been initiated. Two Acting Deputy Directors have been appointed, as of September 2020, to help aid the forthcoming transition period. It is disappointing that the director post has been advertised as interim for two years and not permanent.

# 6. NICR RESOURCES

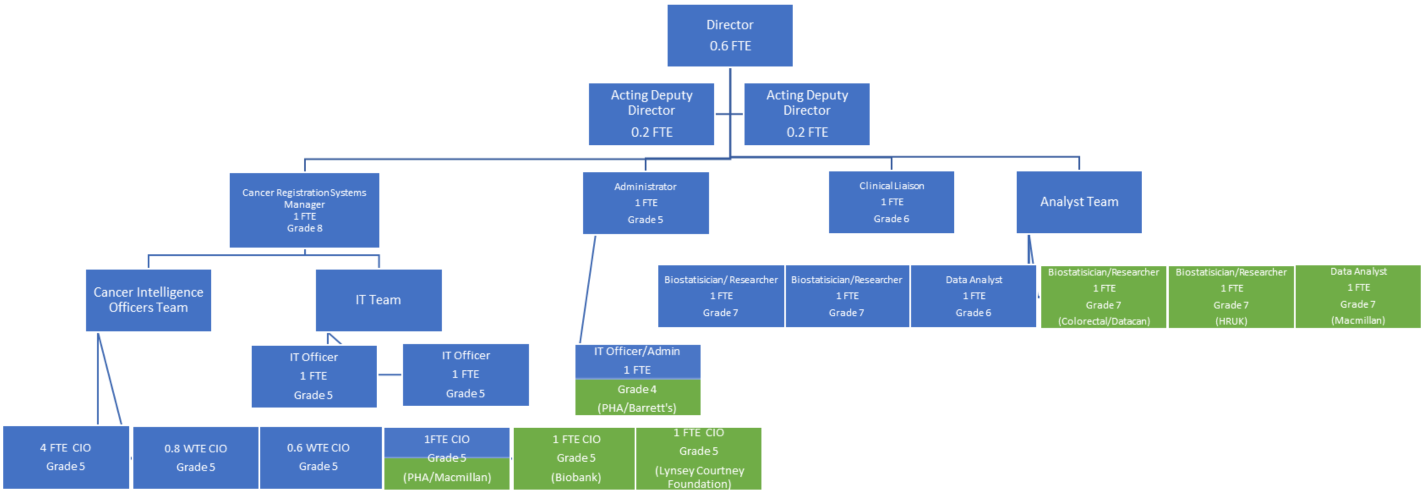
## 6.1 Current staff and funding

The NICR is currently funded by the PHA for the central business of running a population-based cancer registry, with the University considering this an annual grant. Budget for 2021-2022 was £878,673. In most years over 90% of the allocated budget is spent on salaries. The financial year 2021-2022 was unique with a senior staff post part time and several vacant due to staff changes. There was also less funds used for travel due to lack of travel during Covid -19. This provided an opportunity to invest the savings in upgrading of the IT system.

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 2022-2023.

*Figure 3: Current PHA/Grant funded staff 2021-2022*



**FTE = Full Time Equivalent**
**Colour code; Blue = PHA, Green = Grant funding**

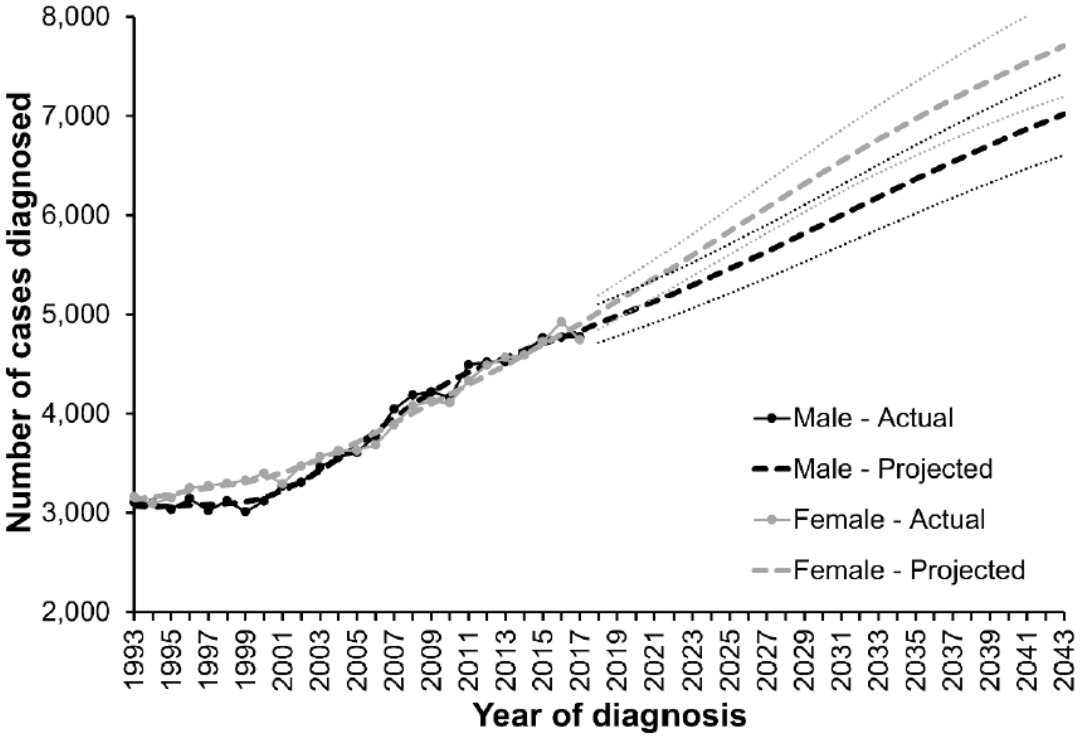
In Addition;

- Cancer Focus funds a Health Economist to work with the NICR and the Patrick G. Johnston Centre for Cancer Research (PGJCCR). The funding for this sits with PGJCCR,
- Macmillan fund 1 FTE Researcher and 0.5 FTE CIO,
- NI Biobank fund 1 FTE CIO,
- RQIA funded an audit of Oesophageal cancers 2020-2021 - report published November 2021. This audit also received £10,000 funding from an Oesophageal Cancer Charity, OG Cancer NI,
- Work on enhancing data available on cervical cancer premalignant disease was funded by a local charity – Lindsay Courtney Foundation,
- NI Panc funding Pancreatic Audit,
- Breast Cancer Now funding Breast Cancer audit for 2019-2020 data.

However due to an increasing number of cancers with increased complexity of the information to be recorded, the NICR will require additional data verification and analytical support and a more sustainable model of funding.

We wish to have an Audit team to work on a rolling cycle of audits with the major sites audited at least every five years with comparisons to data in national audits (£100,000 approx. of above costs).

*Figure 4. Actual and Projected Cancer cases diagnosed in NI (ex NMSC)*



## 6.2 Allocations from PHA

**Table 1: Allocation from PHA**

| Funding from Public Health Agency | Funding 2016/17 | Funding 2017/18 | Funding 2018/2019 | Funding 2019/2020 | Funding 2020/2021 | Funding 2021/2022 |
|---|---|---|---|---|---|---|
| Total Core Work | **£820,112*** | **£820,112*** | **£ 823,560** | **£844,973** | **£861,444** | **£878,673** |

*£10,000 top-sliced by PHA for NICR's contribution to ICBP Phase 2

Funding for 2022-2023 is not yet defined, we plan to work on the same funding as 2021-22 in the meanwhile.

## 6.3 Other funding

In addition to the allocation from the PHA the Registry has six current research projects; DataCan (funds with CCCRB), Macmillan, Heart Research UK and CIN2 (funded by Lindsey Courtney Foundation) and 2 audit projects, Breast and Pancreatic (funded by Breast Cancer Now and NI Panc) (Table 2).

**Table 2: Research/Audit Expenditure relating to projects active during the period 1 April 2016 – 31 March 2022**

| | Funder | Start Date | End Date | Total Budget | Expenditure up to 31/03/22 | Balance c/f 2021-2022 |
|---|---|---|---|---|---|---|
| | | | | | | |
| **Colorectal Audit** | PHA | 01/11/19 | 31/03/20 | £81,531 | £81,531 | £0 |
| **Oesophageal Audit** | RQIA | 01/10/20 | 31/09/21 | £30,000 | £30,000 | £0 |
| **Oesophageal Audit** | OG Cancer NI | 01/10/20 | 31/09/21 | £10,000 | £10,000 | £0 |
| **CIN2** | Lindsey Courtney Foundation | 01/07/19 | On-going | £26,782 | £26,782 | £0 |
| **Macmillan** | Macmillan since 2016 | 01/01/21 | 31/12/22 | £135,000 | £78,707 | £56,293 |
| **Cardiovascular Disease** | Heart Research UK | 01/01/20 | 31/12/22 | £149,991 | £66,266 | £83,725 |
| **Breast Audit** | Breast Cancer Now | 01/05/22 | 30/04/24 | £229,126 | £0 | £229,126 |
| **Pancreatic Audit** | NI Panc | 01/08/21 | 31/05/22 | £26,363 | £500 | £25,863 |

# Update on Actions proposed for 2021-2022

### Table 3: Update on Key Priorities 2021-2022

Colour code: Green = completed, amber = ongoing

| Targets 2021/2022 | Update |
|---|---|
| ***Goal 1 – Data Outputs*** | |
| a. Produce Official statistics by August 2021 | Provided September 2021 for 2019 data |
| b. Extend the statistics dataset available to Registry researchers to include variables such as:<br>- Treatment within a year of diagnosis – Start Date, Chemo, Radio, Surgical procedure code<br>- ER, PR and HER2 status where applicable<br>- Comorbidities (Elixhauser or Charlson score)<br>- Site coded to both ICD10 and ICDO3 | Chemo and Radio data achieved February 2022<br>Achieved |
| c. Provide updated Factsheets online for major cancers. Include Emergency Presentation in factsheets | 41 Factsheets prepared from Official Statistics Emergency Presentation included for the first time |
| d. Review presentation of statistics in line with needs | Needs to be reviewed |
| e. Better lay presentation of NICR data through data visualization products to present Factsheets. Investigate how other registries present data | Updated outputs in Official Statistics |
| f. Provide data for UK and Ireland Cancer Registry Performance Indicators<br>- Achieve a high level for Cancers staged<br>- Include screening data | Available March 2022<br>See https://www.ukiacr.org/kpis<br>82% staged |
| g. Provide information on the impact of COVID-19<br>- Impact on Pathologically diagnosed cases – continued<br>- Impact on Emergency Presentation<br>- Impact on Stage at Diagnosis and Cancer Survival | - Monthly reports<br>- MSc Project, prize winners Poster ENCR Conference, Paper drafted for publication |
| h. Facilitate requests for Information and Genetic Requests within defined timescales | 46 General Requests completed within timescales<br>128 Genetic Requests completed within timescales |
| i. Facilitate Research Related Requests, including any requests for data releases<br>- Establish a mechanism to log requests | - To be undertaken when licensing is in place for new IT system |

| Targets 2021/2022 | Update |
|---|---|
| - Establish monthly meetings for streamlined processing of requests requiring datasets<br>- Organise biannual meetings of the Research Advisory Group as part of Council meeting | - 2 meetings organised |
| j. Continue to investigate Routes to Diagnosis and Impact on Survival | Presentation by screening included in Official Statistics where appropriate<br>Emergency Presentation included in Official Statistics |
| k. Work to establish relevant data for Cardio-oncology | Project ongoing funded by Heart Research UK |
| l. Apply for funding to undertake additional population based audits e.g. breast cancer, pancreatic cancer | Breast Cancer research funded by Breast Cancer Now to commence May 2022<br>Pancreatic audit funded by NI Panc commenced March 2022 |
| m. Apply for one Research Grant | Successful applicant to Breast Cancer Now |
| n. Provide Data as required for International Studies, e.g. CONCORD, EUROCARE etc | Provided within timescale |
| o. Facilitate medical/research staff with access to relevant Registry datasets within confidential and ethical guidelines | 12 projects facilitated despite constraints due to COVID |
| ***Goal 2 – Data Acquisition and Quality*** | |
| a. Achieve full read only access to RISOH and SACT extracts | Achieved February 2022 |
| b. Ensure Registry needs are considered in roll out of Encompass | NICR Staff attend ENCOMPASS meetings |
| c. Run IACR/ENCR data quality tools on a regular basis | Achieved |
| d. Collate the audit datasets into single datasets for each tumour group as many are still held by the analysts | Ongoing – to be completed by March 2022 |
| e. Ensure tumours are coded to both ICD10 and ICDO3 to facilitate international data submissions | Achieved |
| f. Work to ensure relevant data from Health Service systems e.g. LIMS is achieved | NICR has established links with the Encompass and LIMS projects |
| g. Investigate adding recurrence algorithm | Recording of disease progression will be possible in the new IT system |
| ***Goal 3 – IT System*** | |
| a. Continue Development of IT system | Ongoing with Tender awarded |
| b. Incorporate the Cancer Staging Tool into the Registry IT system | Future consideration with IT redevelopment |
| c. Expand database to include additional items e.g. HER2, ER, PR, PSA | Incorporated in IT development remit |

| Targets 2021/2022 | Update |
|---|---|
| d. Update the treatment files and death files with NICR number/ HCN so that the data may be easily matched against PRAXIS | Partially complete |
| e. Ensure audit data is on PRAXIS | Part of the data migration remit of new system |
| f. Initiate development of processes for creating a system for logging and tracking requests which will include request forms, governance documents, staff induction and a record of the data items sent | This work can commence when licensing is in place for the new IT system – May 2022 |
| g. Initiate development of processes for creating a facility for the receipt and transfer of genetic requests | This work can commence when licensing is in place for the new IT system – May 2022 |
| h. Ensure the Common directory holds only pseudonymised data files | To be completed by December 2022 |
| i. Remove duplicate patients from PRAXIS | Ongoing |
| j. Convert the T and M snomed codes to ICD10 and ICDO3 | Completed |
| k. Incorporate the ICDO3 version 2 updates | Incorporated in IT development remit |
| l. Incorporate Cancer Patient Pathway System (CaPPs) as an automated source for cancer registrations | Incorporated in IT development remit |
| m. Initiate development of processes for creating a system which fully records the basic data needed to register cancers and initiate processes for long-term integration of premalignant registration data integrates with premalignant registrations | Incorporated in IT development remit |
| ***Goal 4 – Enhance Registry Infrastructure*** | |
| a. Manage budgets | All budgets managed |
| b. Implement Cost Recovery when appropriate | Nil for 2021-2022 |
| c. Update Cost Recovery policy | Policy to be reviewed and updated |
| d. Maintain Risk Register | Maintained and presented at alternating Steering Group meetings |
| e. Review and update Registry Business Continuity Plan to incorporate, loss of Coding and Cyber Attacks on QUB systems | To be reviewed by new IT members of staff |
| f. Commence Staff restructuring | TVO staff regraded to CIO in recognition of skill |
| ***Goal 5 – General*** | |
| a. Ensure Registry input to Development for the Health and Social Care Secondary Use of Data legislation in April 2016 | Lobbying has continued |
| b. Lobby for Cancer Minimum Datasets to be developed and provided by Trusts | Has been included as part of Cancer Strategy |

| Targets 2021/2022 | Update |
|---|---|
| c. Ensure all Data Access Agreements are up to date | Achieved |
| d. Maintain ISO27001 accreditation | Achieved |
| e. Ensure data confidentiality is maintained with accommodation upgrade | Achieved and enhanced |
| f. Work to achieve updated contract between QUB/PHA | Ongoing |
| g. Actively engage in succession planning for key posts | IT posts successfully recruited, Director post advertised |
| ***Goal 6 – Registry Profile*** | |
| a. Establish NICR public engagement team of 3-4 staff members, including having representation on PGJCCR Public engagement committee | Due to COVID19 no opportunities to get involved |
| b. Increased promotion of NICR as provider of cancer data within the university and the HSCNI | Registry actively involved with development of Cancer Strategy and linked with all NICaN groups |
| c. Tailored presentations of data at CRGs and regularly send to clinicians across tumour groups | Ongoing |
| d. Encourage partnerships with clinical researchers | Ongoing |
| e. Raise awareness of the types of information the Registry can produce | Achieved with production of new information on<br>- Routes to Diagnosis in Official Statistics<br>- Cardiac Disease in Cancer Patients |
| f. Maintain an active Twitter account, monitored through impressions data from Tweets and number of followers etc | 31 Tweets during the past year |
| g. Have regular press releases | Press releases issued for Official Statistics release September 2021 and March 2022 and Cancer Staging Tool August 2021 |
| h. Maximise use of media | Articles in;<br>BBC NI Facebook<br>BBC Newsline<br>BBC Radio Ulster Evening Extra<br>Irish News<br>Belfast Telegraph<br>Belfast Newsletter<br>Derry Journal |
| i. Ensure input to the International Projects such as International Cancer Benchmarking Partnership | Ongoing |
| j. Ensure Registry leaflet/poster/website are up to date | Maintained |

| Targets 2021/2022 | Update |
|---|---|
| ***Goal 7 – Students/Training*** | |
| a. Offer training opportunities to F2 doctors, Public Health Trainees, undergraduate and MSc/MPH students | Provided training 1 undergraduate student on Male Breast Cancer, 2 MSc/MPH students on work related to COVID-19 |
| b. Ensure all staff have access to appropriate training and opportunities for development | Achieved |
| c. Ensure all staff have annual Personal Development Reviews | All achieved |
| d. Ensure organisation of Registry facilities best use of resources, staff talent while meeting the demands of increased numbers and complexities of registrations, and increased data items such as recurrences and biological markers | Achieved |
| e. Ensure Standard Operating Procedures are up to date | Achieved |
| f. Work to achieve succession planning for Registry posts | Ongoing |
| g. Pursue grading of TVOs | Achieved |
| ***Goal 8 – Patient Involvement*** | |
| a) Ensure Patients/their representatives are integrated into Registry activities e.g.: | |
| - Council Memberships | - 2 meetings annually |
| - Charity representation on Steering Group | - Cancer Focus |
| - Involvement in report launches etc | - No report launches |
| - Provision of information when requested | - Ongoing |

# NICR Key Priorities 2022-2023

The key priorities for 2022/2023 are:

1. Provide accurate, timely data on cancers in NI for official statistics by September 2022 for patients diagnosed in 2020,
2. Commence work on 2021 diagnosed cancers to launch 2023,
3. Provide data on the impact of COVID-19 on cancer services,
4. Continue to provide a data request service including for genetic requests and alleged cancer clusters within timeframes,
5. Provide NI datasets for international comparisons e.g. Eurocare, Concord, ENCR, ICBP,
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,
7. Maintain our ISO27001 Certification in Information Security Management,
8. Continue with upgrades to the Registry IT System and extend its capacity to store data items,
9. Enhance datasets available to and recorded by the Registry e.g. comorbidities, tumour markers, recurrences and premalignant diseases,
10. Continue to undertake feedback to clinicians,
11. Work with clinicians, RQIA, NICaN, local charities and PHA to undertake local audits and achieve inclusion of NI data in National Clinical Audits,
12. Provide data for UKIACR annual Performance Indicators,
13. Maintain up to date, accessible and accurate information on cancer available for the public, charities, media etc,
14. Continue to work with external researchers to enhance cancer research in NI,
15. Ensure Standard Operating Procedures are kept up to date,
16. Identify key roles and best structure for NICR including Post to cover Clinical audits and new Director Post,
17. Work to meet the targets of the Breast Cancer Now grant application,
18. Ensure the budget is used to provide the Business Plan targets,
19. Prepare for NICR review as recommended by the NI Cancer Strategy,
20. Ensure Patient Involvement,
21. Collate the audit datasets into single datasets for each tumour group.

As happens every year the Registry also undertakes work in addition to that in the business plan to meet the dynamic nature of cancer services.

In 2021/22 this included:

- Monthly reports monitoring the impact of COVID-19 on pathologically diagnosed cancers which will continue,
- Intense work for Cancer Strategy which provided new information on cancer projections, and analysis of comorbidities and second cancers,
- Ensuring continued business during remote working linked to the COVID-19 pandemic.

The Registry will continue to strive for additional resources from grants, and by seeking a more sustainable model of funding for the NICR 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 2022-2023**

| Targets 2021/2022 | Proposed Actions |
|---|---|
| **1.** Provide accurate, timely data on cancers in NI for official statistics by September 2022 for patients diagnosed in 2020 | Continue to launch Official Statistics on a phased basis to have all provided by September 2022 with<br>- Factsheets<br>- Reports<br>- Including Routes to Diagnosis |
| **2.** Commence work on 2021 diagnosed cancers to launch 2023 | - Relevant data ready for Analysts by Mach 2022 |
| **3.** Provide data on the impact of COVID-19 on cancer services | - Include as special report on Official Statistics releases<br>- Provide new data on stage at diagnosis and emergency presentation impact |
| **4.** Continue to provide a data request service including for genetic requests and alleged cancer clusters within timeframes | - Instigate an electronic Request Monitoring Service |
| **5.** Provide NI datasets for international comparisons e.g. Eurocare, Concord, ENCR, ICBP | - By due dates |
| **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 | - Work with PHA to identify contact person for RISOH<br>- Ensure Registry is represented on Encompass meetings |
| **7.** Maintain our ISO27001 Certification in Information Security Management | - Train new staff member<br>- Undertake regular internal audits<br>- Successfully complete an external audit |
| **8.** Continue with upgrades to the Registry IT System and extend its capacity to store data items | - Write a business case for required additional funding<br>- Ensure ethics, Data Sharing Agreements etc reflect the changes<br>- Work to achieve inclusion of Cancer Staging Tool<br>- Expand database to include additional items e.g. HER2, ER, PR, PSA |

| Targets 2021/2022 | Proposed Actions |
|---|---|
|  | - Update the treatment files and death files with NICR number/ HCN so that the data may be easily matched<br>- Ensure audit data is on new IT system |
| **9.** Enhance datasets available to and recorded by the Registry e.g. comorbidities, tumour markers, recurrences and premalignant diseases | - Achieve additional resource to identify recurrences<br>- Provide new data on dementia/stroke in cancer patients<br>- Continue to work on impact of heart disease in cancer patients<br>- 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 each NICaN Board and CRG |
| **11.** Work with clinicians, RQIA, NICaN, local charities and PHA to undertake local audits and achieve inclusion of NI data in National Clinical Audits | - Report on Pancreas<br>- Continue to gather and analyse breast information<br>- Appoint dedicated Audit Lead Analyst<br>- Ensure KPIS match those of other nations |
| **12.** Provide data for UK annual Performance Indicators | - For 2020 data by due date |
| **13.** Maintain up to date, accessible and accurate information on cancer available for the public, charities, media etc | - Regular Tweets<br>- Media linked with Official Statistics<br>- Media linked with audit reports |
| **14.** Continue to work with external researchers to enhance cancer research in NI | - Offer summer student placement<br>- Provide Hot Desks for external researchers |
| **15.** Ensure Standard Operating Procedures are kept up to date | - Annual review of each SOP<br>- Ensure all relevant areas has a SOP |
| **16.** Identify key roles and best structure for NICR including Post to cover Clinical audits and new Director Post | - Clinical Audit post appointed<br>- Induction for new Director<br>- Maximise Staff training |
| **17.** Work to meet the targets of the Breast Cancer Now grant application | - Regular meetings of Project Management Group |
| **18.** Ensure the budget is used to provide the Business Plan targets | - Quarterly monitoring of Budget<br>- Update and implement cost recovery policy |

| Targets 2021/2022 | Proposed Actions |
|---|---|
|  | - Apply for one Research/Audit grant<br>- Prepare Business Case for IT system enhancement |
| **19.** Prepare for NICR review as recommended by the NI Cancer Strategy | - Ensure all required documentation is up to date<br>- Maintain Risk Register<br>- Update Business Continuity Document<br>- Updated contract PHA/QUB regard the Registry |
| **20.** Ensure Patient Involvement | Ensure Patients/their representatives are integrated into Registry activities e.g.:<br>- Council Memberships<br>- Charity representation on Steering Group<br>- Involvement in report launches etc<br>- Provision of information when requested |
| **21.** Collation of existing audit datasets to facilitate future audits and inclusion in the new IT system | Collate the audit datasets into single datasets for each tumour group |

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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 Ken Mills (Chair) | Associate Director for Undergraduate Teaching, PGJCCR QUB |
| Ms Cara Anderson | HSC Board, Asst Director Commissioning (Cancer & Pathology) |
| Ms Lyn Benson | HSC Board, Financial Accounts & Governance |
| Dr Kathryn Boyd | NICaN, Medical Director, from February 2020 |
| Mr Richard Spratt | Cancer Focus NI, CEO of this cancer charity |
| Dr Aidan Cole | Health and Social Care Trust/QUB Clinician |
| Dr Louise Herron | Public Health Agency |
| Ms Louise Dunlop | QUB Governance |

## 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 |
| Ms Janice Preston | Macmillan |
| Dr Michael Reilly | Western HSC Trust |
| Ms Rosemary McAnerney | Lay Representative |

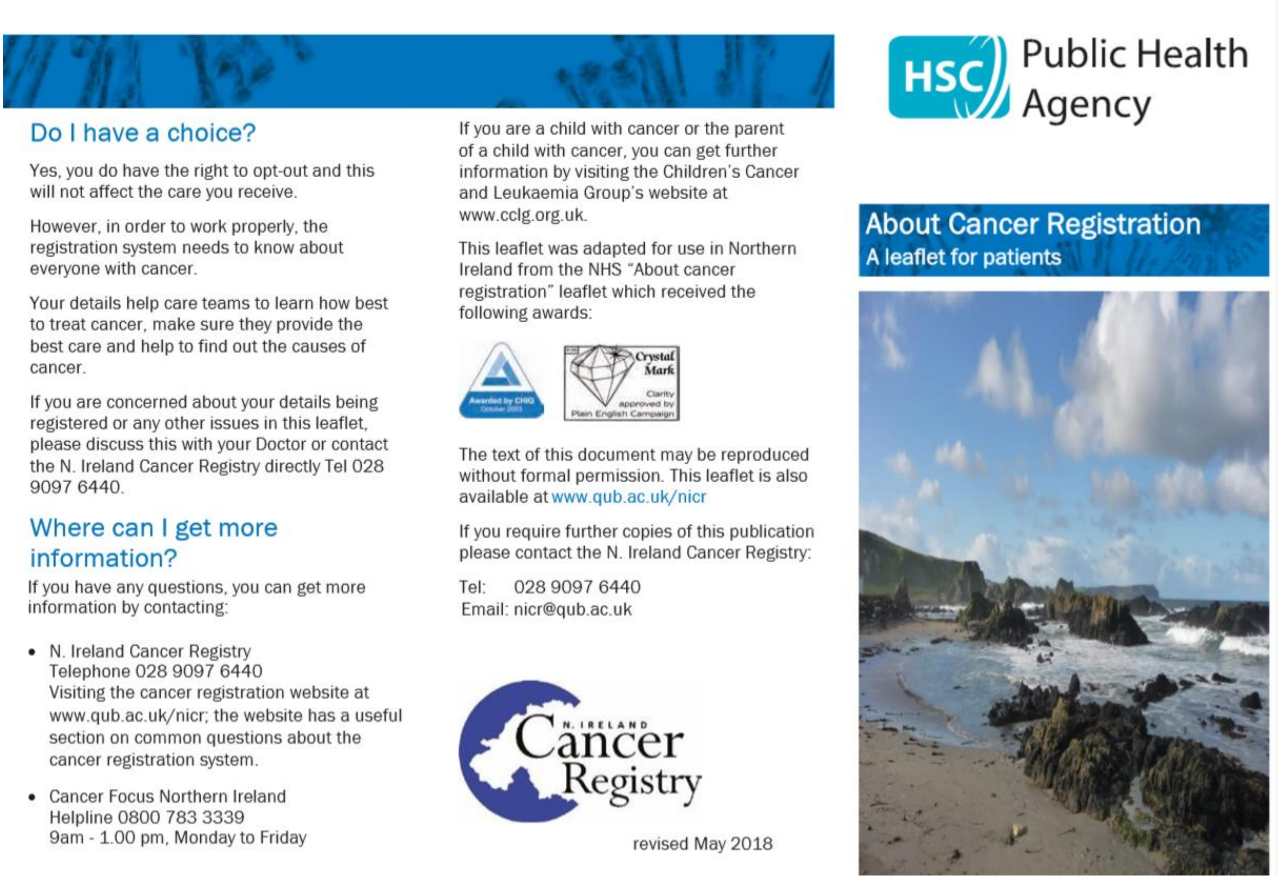
With attendance from Registry Director, Deputy Director and relevant staff required for the agenda.

## 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:

Awarded by CHIQ October 2003

Crystal Mark
Clarity approved by Plain English Campaign

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

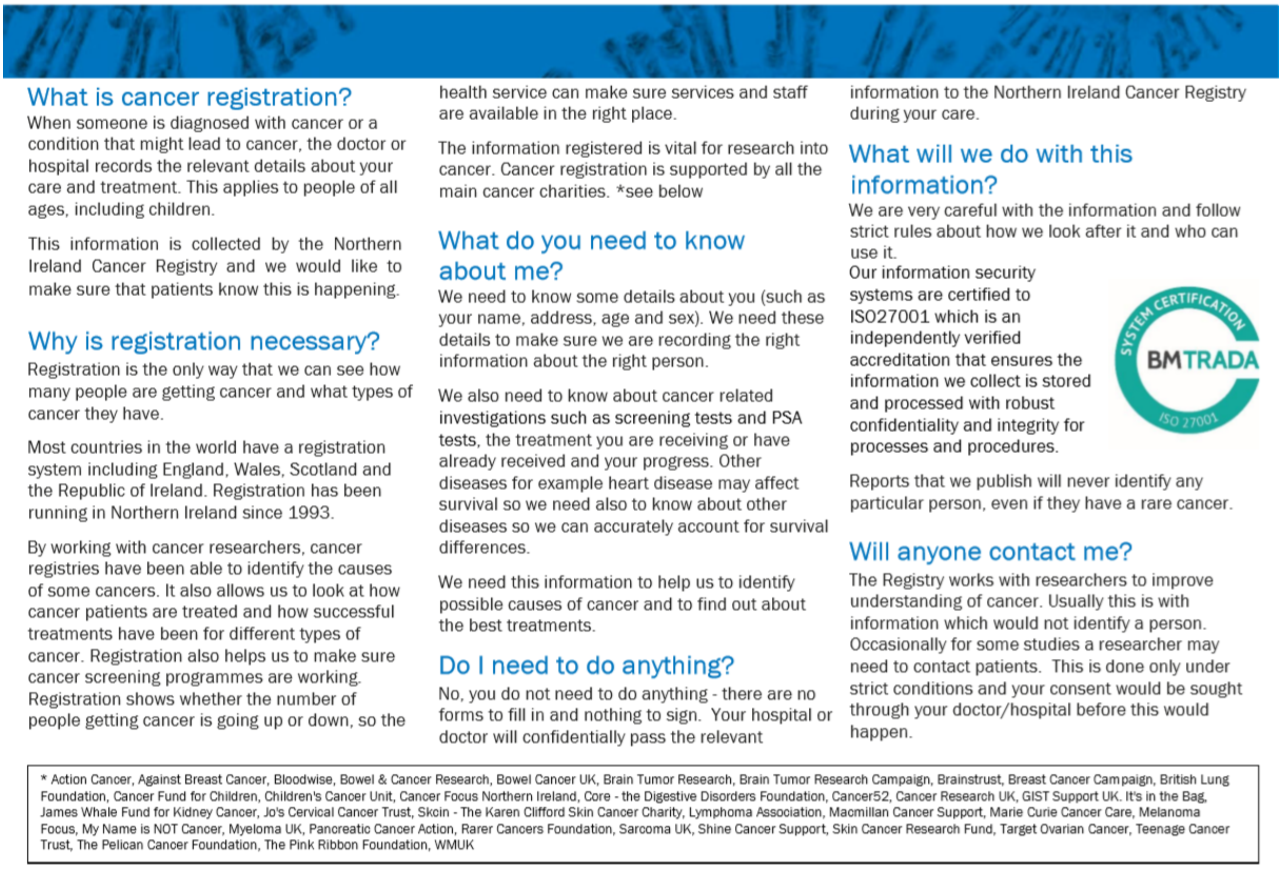
N. IRELAND Cancer Registry

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.

SYSTEM CERTIFICATION BMTRADA ISO 27001

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** 2020 report on **2018 diagnoses** | **Northern Ireland 2021 report on 2019 diagnoses** |
|---|---|---|
| **Stability:** Percentage change (%) for all cancers (C00-C97 ex. C44) compared with previous three years | 0.6% | 3.3 |
| **Registry Creep:** Percentage (%) for all cancers (C00-C97 ex. C44) registrations (extracted between 31/12/19 and 20/04/2020) compared with registrations extracted between 02/02/2019 and 01/03/2019[6]. | **2.6%** | 1.4% |
| **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] | 🟩 **85.3%** | 🟩 82.0% |
| **Average of Core Patient Information Complete:** Average percentage (%) of all cancers (C00-C97 ex. C44) registered with demographic information[3] | 100.0% | 100.0% |
| **Average of Core Tumour Information Complete:** Average percentage (%) of all cancers (C00-C97 ex. C44) registered with tumour information[4] | 97.2% | 96.9% |
| **Diagnosing Hospital Known:** Percentage (%) of all cancers (C00-C97 ex. C44) registered with an organisation of diagnosis | 98.1% | - |
| **Death Certificate Only (DCO) Rates:** Percentage (%) of all cancers (C00-C97 ex. C44) registered as a DCO[5] | 🟩 **0.3%** | 🟩 0.6% |
| **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%** | 🟩 0.6% |
| **Microscopically Verified:** Percentage (%) of all cancers (C00-C97 ex. C44) that are microscopically verified | **86.3%** | 85.8% |

| | | |
|---|---|---|
| **Non Specific Codes:** Percentage (%) of all cancers (C00-C97 ex. C44) that are microscopically verified with non specific morphology codes | **1.6%** | 2.6% |
| **Grade:** Percentage (%) of all cancers (C00-C97 ex. C44) registered with a known grade | **65.6%** | 59.7% |
| **Treatment:** Percentage (%) of all cancers (C00-C97 ex. C44) registered with any treatment | **71.9%** | 84.5% |
| **Breast Screening Data:** Percentage of breast cancer (C50) cases screen detected for ages 50-64 | **NA** | 52.0% |
| **Cervical Screening Data:** Percentage of cervical cancer (C53) cases screen detected for ages 25-60 | **NA** | 63.1% |
| **Bowel Screening Data:** Percentage of bowel cancer (C18-C20) cases screen detected for ages 60-69 | **NA** | 18.8% |

# APPENDIX D: Peer reviewed publications

## NICR Publications 2020-2021

### 2021

1. **Experiences of Support for Sexual Dysfunction in Men With Prostate Cancer: Findings From a U.K.-Wide Mixed Methods Study**
   Watson, E., Wilding, S., Matheson, L., Brett, J., McCaughan, E., Downing, A., Wright, P., Cross, W., Selby, P., Butcher, H., Glaser, A., **Gavin, A**. & Wagland, R., 26 Feb 2021, In: The journal of sexual medicine.
   https://doi.org/10.1016/j.jsxm.2020.12.017

2. **Primary liver cancer in the UK: Incidence, incidence-based mortality, and survival by subtype, sex, and nation**
   Burton, A., Tataru, A., Driver, RJ., Bird TJ, Huws, D., Wallace, D., Cross, TJS., Rowe, IA, Alexander, G., Marshall, A., on behalf of the HCC-UK/BASL/**NCRAS Partnership Steering Group**. JHEP Reports 2021.
   https://doi.org/10.1016/j.jhepr.2021.100232

3. **Systematic review of the use of translated patient-reported outcome measures in cancer trials**
   Slade, A. L., Retzer, A., Ahmed, K., Kyte, D., Keeley, T., Armes, J., Brown, J. M., Calman, L., **Gavin, A**., Glaser, A. W., Greenfield, D. M., Lanceley, A., Taylor, R. M., Velikova, G., Turner, G. & Calvert, M. J., 26 Apr 2021, In: Trials. 22, 16 p., 306.
   https://doi.org/10.1186/s13063-021-05255-z

4. **Using the Framework Method for the Analysis of Qualitative Dyadic Data in Health Research**
   Collaço, N., Wagland, R., Alexis, O., **Gavin, A**., Glaser, A. & Watson, E. K., 13 May 2021, In: Qualitative Health Research.
   https://doi.org/10.1177/10497323211011599

5. **Inequalities in the decline and recovery of pathological cancer diagnoses during the first six months of the COVID-19 pandemic a population-based study**
   Hamilton, A. C., **Donnelly, D. W.,** Loughrey, M. B., Turkington, R. C., **Fox, C., Fitzpatrick, D., O'Neill, C. E., Gavin, A. T**. & **Coleman, H. G.,** 01 Jul 2021, In: British Journal of Cancer.
   https://doi.org/10.1038/s41416-021-01472-0

6. **International perspectives on suboptimal patient-reported outcome trial design and reporting in cancer clinical trials: A qualitative study**
   Retzer, A., Calvert, M., Ahmed, K., Keeley, T., Armes, J., Brown, J. M., Calman, L., **Gavin, A.,** Glaser, A. W., Greenfield, D. M., Lanceley, A., Taylor, R. M., Velikova, G., Brundage, M., Efficace, F., Mercieca-Bebber, R., King, M. T. & Kyte, D., 05 Jul 2021, In: Cancer Medicine.
   https://doi.org/10.1002/cam4.4111

7. **International differences in lung cancer survival by sex, histological type and stage at diagnosis; an ICBP SURVMARK-2 Study**
   ICBP SURVMARK-2 Local Leads, 19 Jul 2021, In: Thorax.
   https://doi:10.1136/thoraxjnl-2020-216555

8. **CanStaging+: an electronic staging tool for population-based cancer registries**
   Soerjomataram, I., Ervik, M., **Fox, C., Hawkins, S., Yeung, K.,** Napolitano, G., Tittenbrun, Z., Bray, F. & **Gavin, A.,** Aug 2021, In: Lancet Oncology. 22, 8, p. 1069
   https://doi.org/10.1016/S1470-2045(21)00188-1

9. **Comparison of liver cancer incidence and survival by subtypes across seven high-income countries**
   Rutherford, M. J., Arnold, M., Bardot, A., Ferlay, J., De, P., Tervonen, H., Little, A., Bucher, O., St Jacques, N., **Gavin, A.,** Engholm, G., Møller, B., O'Connell, D. L., Merrett, N., Parkin, D. M., Bray, F. & Soerjomataram, I., 30 Aug 2021,
   In: International Journal of Cancer.
   https://doi.org/10.1002/ijc.33767

10. **Data linkage and pain medication in people with cerebral palsy: a cross-sectional study**
    García Jalón, E. G., Maguire, A., Perra, O., **Gavin, A**., O'Reilly, D. & Thurston, A., Sep 2021, In: Developmental Medicine and Child Neurology.
    https://doi.org/10.1111/dmcn.14854

11. **A summary of the updated report on the incidence and epidemiological trends of keratinocyte cancers in the United Kingdom 2013-2018**
    Kwiatkowska, M. M., Ahmed, S., Ardern-Jones, M. R., Bhatti, L. A., Bleiker, T. O., **Gavin, A.**, Hussain, S., Huws, D. W., Irvine, L., Langan, S. M., Millington, G. W. M., Mitchell, H., Murphy, R., Paley, L., Proby, C. M., Thomson, C., Thomas, R., Turner, C., Vernon, S. & Venables, Z. C., 26 Sep 2021
    https://doi.org/10.1111/bjd.20764

12. **The European cancer burden in 2020: Incidence and mortality estimates for 40 countries and 25 major cancers**
    Dyba, T., Randi, G., Bray, F., Martos, C., Giusti, F., Nicholson, N., **Gavin, A**., Flego, M., Neamtiu, L., Dimitrova, N., Negrão Carvalho, R., Ferlay, J. & Bettio, M., Nov 2021, In: European Journal of Cancer.
    https://doi.org/10.1016/j.ejca.2021.07.039

13. **International variation in oesophageal and gastric cancer survival 2012–2014: differences by histological subtype and stage at diagnosis (an ICBP SURVMARK-2 population-based study)**
    Arnold, M., Morgan, E., Bardot, A., Rutherford, M. J., Ferlay, J., Little, A., Møller, B., Bucher, O., De, P., Woods, R. R., Saint-Jacques, N., **Gavin, A. T**., Engholm, G., Achiam, M. P., Porter, G., Walsh, P. M., Vernon, S., Kozie, S., Ramanakumar, A. V., Lynch, C. & 10 others, , 25 Nov 2021, In: Gut.
    https://doi:10.1136/gutjnl-2021-325266

14. **The Impact of the COVID-19 Pandemic on Barrett's Oesophagus and Oesophago-gastric Cancer**
    Turkington, R., Lavery, A., **Donnelly, D., Gavin, A.**, McManus, D., Cairnduff, V., McShane, C., Johnston, B., **Anderson, L**. & **Coleman, H.,** Dec 2021. In BJS
    https://doi.org/10.1093/bjs/znab430.166

15. **Stability of health-related quality of life and morbidity burden from 18 months after diagnosis of prostate cancer: results of a UK-wide population-based outcome cohort**
    Mason, S. J., Downing, A., Wilding, S., Hounsome, L., Wright, P., Watson, E., Wagland, R., Butcher, H., Kind, P., Selby, P., **Gavin, A.** & Glaser, A. W., 13 Dec 2021, In: Supportive care in cancer: official journal of the Multinational Association of Supportive Care in Cancer.
    https://doi.org/10.1007/s00520-021-06650-7

16. **Impact of the first wave of the COVID-19 pandemic on cancer registration and cancer care: a European survey**
    ENCR Steering Committee, 22 Dec 2021, In: European journal of public health.
    https://doi.org/10.1093/eurpub/ckab214

17. **The Impact of the COVID-19 Pandemic on Endometrial Cancer and Endometrial Hyperplasia Diagnosis: A Population-Based Study**

Wylie, J., Quinn, D., Donnelly, D., McCluggage, W. G., Coleman, H., **Gavin, A**. & McMenamin, Ú., 29 Dec 2021, In: American Journal of Obstetrics and Gynaecology. https://doi.org/10.1016/j.ajog.2021.12.259

# APPENDIX E: Requests for Information

## Requests for Information

The NICR provided data and information for 174 requests in 2021, 46 (27%) general requests and 128 (73%) genetic requests (excluding local genetic requests) (***Figure 5***). A nurse from the Medical Genetics department deals with local genetic requests.

In 2021, 98% of general requests for information were completed within the recommended 20 working days and 100% of genetic requests for information were completed within the recommended 10 working days (***Figure 6***).

40% of general requests were received from academic researchers and charities (combined) (***Figure 7***).

On average general requests took 171 minutes to complete but ranged from 10 minutes to 1920 minutes (32 hours). Genetic requests took 29 minutes to complete however ranged from 15 minutes to 60 minutes. 98% of general requests were received via email (***Figure 8***). 97% of genetic requests were received by email as opposed to letters due to new COVID-19 processes (***Figure 9***).

***Figure 5: General and Genetic Requests received 2021***

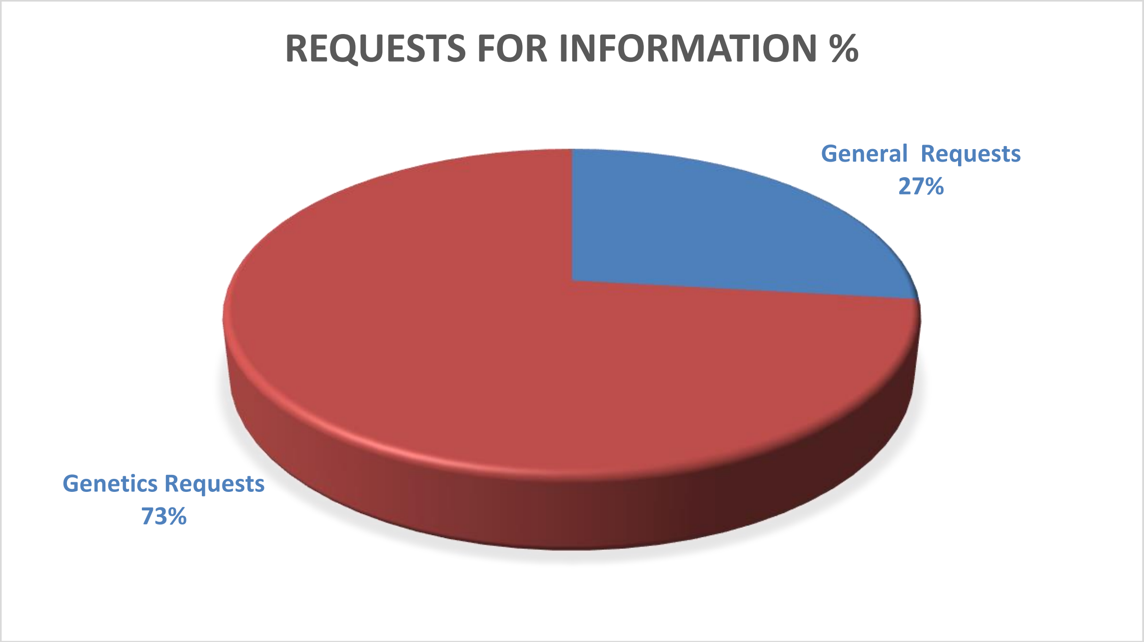


*Figure 6: Percentage of requests completed within agreed timeframe*

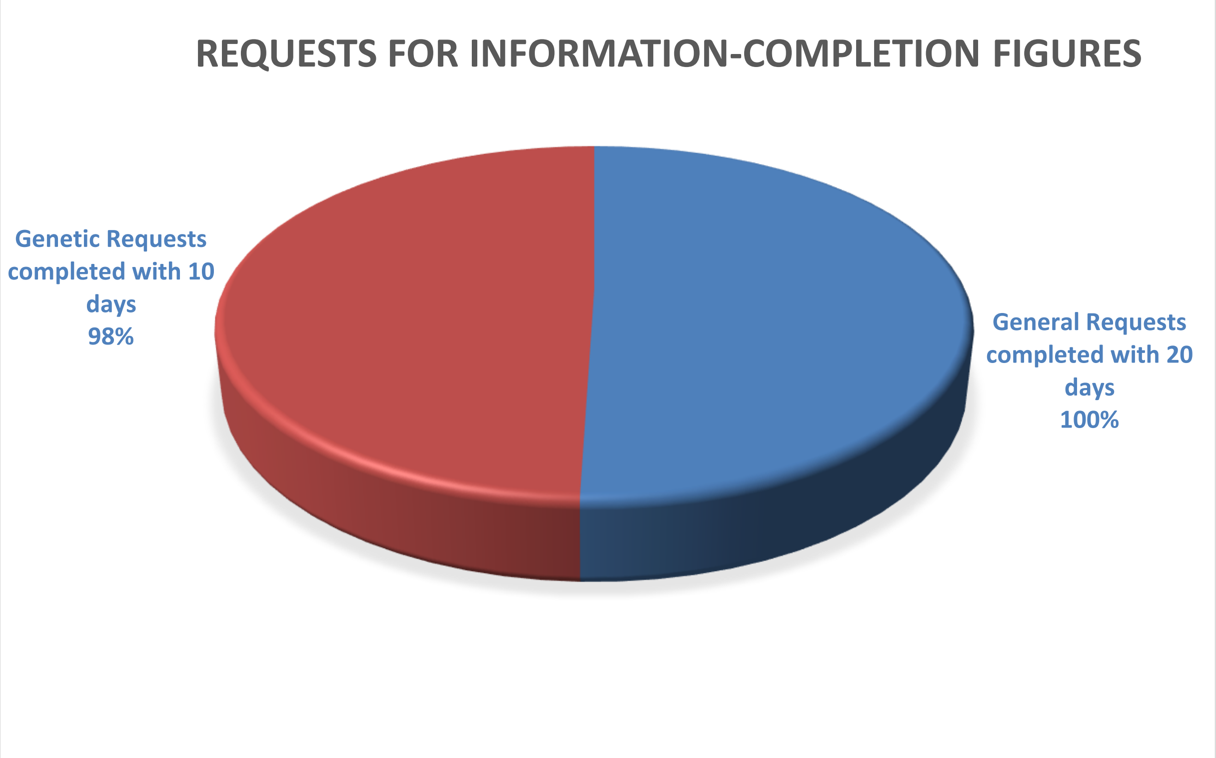


*Figure 7: Source of Requests – General*

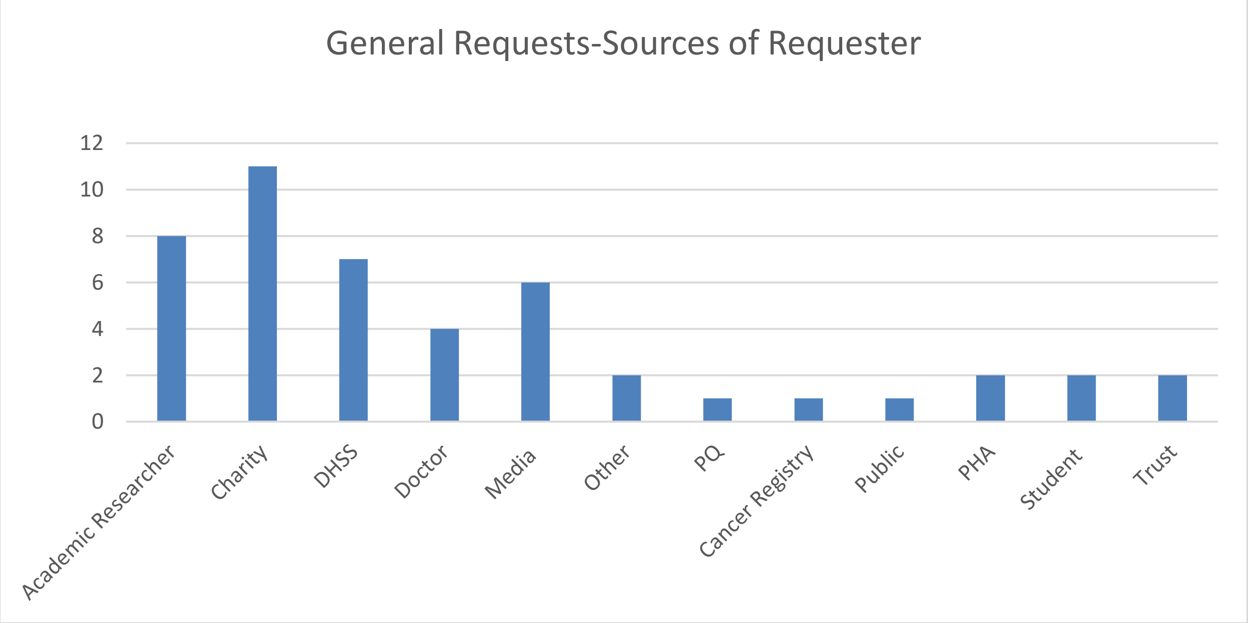


*Figure 8: Method of Communication from Requestor – General Requests*

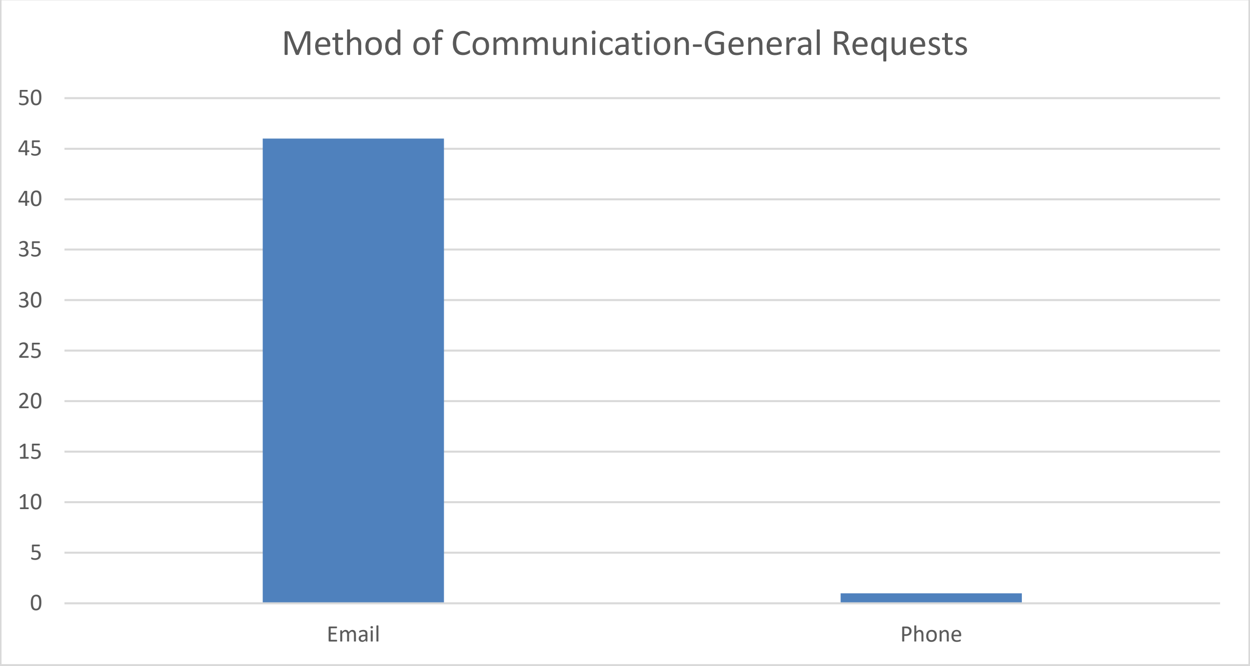
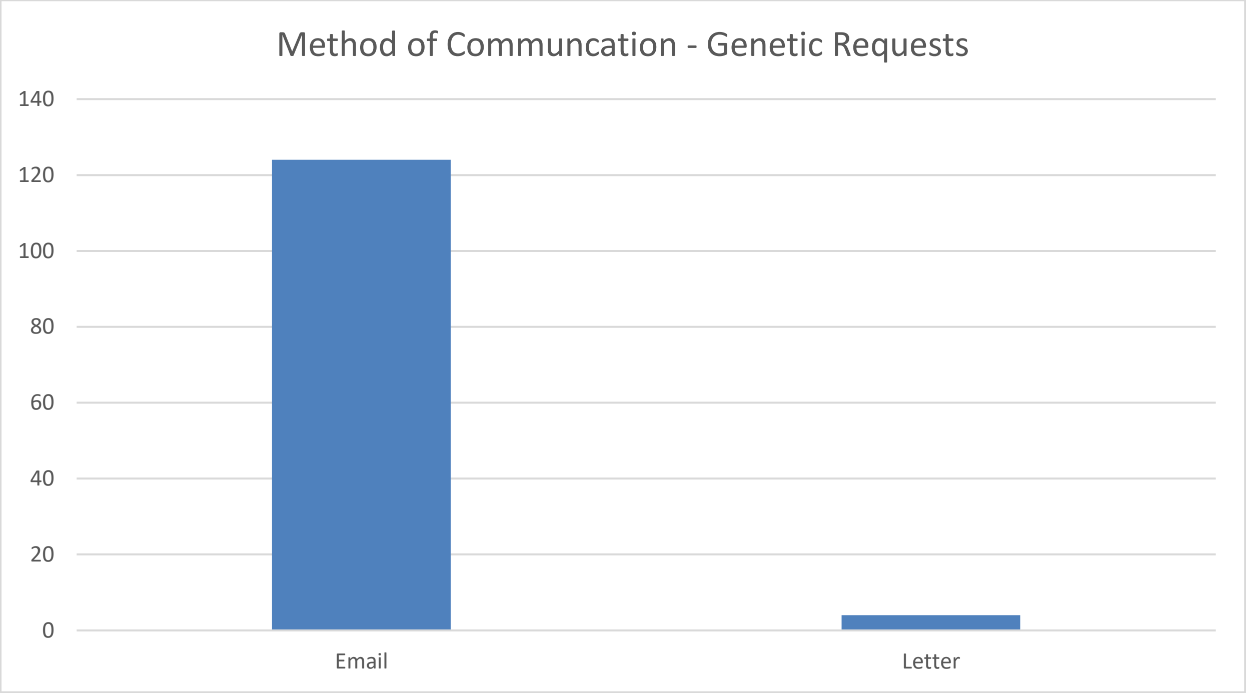


*Figure 9: Method of Communication from Requestor – Genetics Requests*



# APPENDIX F: Standard Operating Procedures (SOPs) developed by NICR

## Information Technology

- Data Acquisition (all sources)
- PRAXIS Data input & processing
    - Pre-processing/cleaning
    - Loading and validation
    - Resolving failed records (GP codes, consultants, T&M -> ICD maps)
    - Maintaining Reference Tables (GP, Consultant, ICD site/morphology etc)
    - Batch processing
    - Managing validations and data survivorship logic
- Dataset specific processing (Deaths, XRT and Chemo treatments, Co-morbidity)
- Creation and display of fields on PRAXIS database
- Creating a separate PRAXIS instance (e.g. for testing)
- List key PRAXIS routines (system routines)
- List key locally developed routines for specific tasks
- Data Extracts and Reports – to cover all variables which may be requested
- Data Transfers
- Server management
- Backup and Restore (all infrastructures)
- Security/Credential management (e.g. door codes, bitlocker, pen drives, alarm users)
- Account creation/deletion (including fingerprinting, active directory, etc)
- Providing access to HSC applications (such as CaPPS, Labcentre, Webview, Radiology etc)
- Asset management
    - Allocation
    - Disposal of equipment
    - Transfer of ownership
- ISO27001 – policies, audits, potential overlap with other SOP's
- Lone Worker
- Remote Working

## CIO

- Creating and sending lists
- Genetic Requests
- Processing Private Pathology reports
- Multiple tumours
- Generic Staging
- Biobank

- Extra regionals
- Resolving
- Macmillan
- Duplicates
- Handling PAS batches
- Handling Death batches

### Administration

- Registry Finance
- Petty Cash
- Purchase Card processes
- Travel Requests
- Plan-On Requests
- Confidential Waste
- Visitors
- Staff – Inductions
- Staff – Leave Requests (annual/dependent/maternity)
- Fire Testing/Drill Procedure

### Media

- Website Updates
- Comms/Twitter updates

### Research administration

- Information requests
- Disclosure control
- Publication/outputs – Authorship
- Official Statistics data
- PIs
- Official Statistics outputs
- Cluster Queries
- Preparing data extracts for analysts/researchers
- Official Statistics release
- CIO Work allocation
- Induction – CIO specific
- Data Quality Checks

- Acknowledgements
- Quality Assurance
- Requests for Patient information from NICR database
- Request to remove Patient data from NICR database

### Deadline Dates

- Ethics
- Governance
- Agreements