Operational Plan
April 2021 – March 2022

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 2020 - March 2021. 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.

Contents

GLOSSARY

Acronym	Definition
AO	Acute Oncology
BSO	Business Services Organisation
CaPPS	Cancer Patient Pathway System
CCRCB	Centre for Cancer Research and Cell Biology
CGIN	Cervical Glandular Intraepithelial Neoplasia
CIN	Cervical Intraepithelial Neoplasia (grades 1-3)
CISM	Certified Information Security Management
COIS	Clinical Oncology Information System
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 N. Ireland
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
ISACA	Information Systems Audit and Control Association
LAPCD	Life After Prostate Cancer Diagnosis
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
NIMC	NI Multi-morbidity Cohort
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
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 and collation of data relating to the diagnosis and treatment of cancer and premalignant conditions in patients 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:

- 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 2019 NI had an estimated population of 1,893,667 people. Excluding non-melanoma skin cancer (NMSC) on average 9,629 cancers were diagnosed each year during 2014-2018 (13,452 cases per year including NMSC). At the end of 2018 there were 65,722 cancer survivors (excluding NMSC) residing in NI who had been diagnosed in the previous 25 years (i.e. 1994-2018). Including NMSC, there were 97,807 survivors at the end of 2018.

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 2018 this had risen to 9,897 cancer cases, an increase of 58%, with an additional 4,142 cases of NMSC. It is predicted that there will be 14,238 incident cancer cases (excluding NMSC) by 2040 (Figure 1).

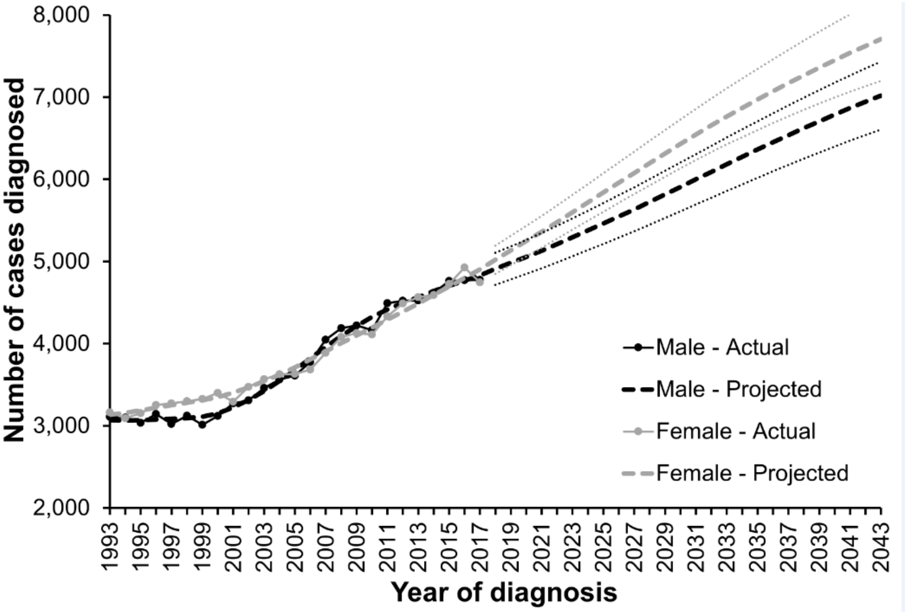


Figure 1: Cancer incidence projections for NI (excluding NMSC)

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 recurrence. We will also be able to monitor the impact of COVID-19 on cancer services and the impact on 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 relatively recent 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. Despite many efforts we have very limited data from RISOH and therefore are unable to complete several important areas such as stage at diagnosis, the fact and detail of treatment on all patients. This is a serious problem for the production of cancer intelligence for the population of N.Ireland and also the official statistics.

1.2 NICR Vision

To continually improve cancer intelligence in NI.

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 received approval 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 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, patient information can be removed from the NICR database and the organisation providing data to the NICR is informed of the patients Health & Care Number (HCN) so a block can be placed, preventing any further notifications reaching the NICR. We would retain the anonymised fact of the cancer for alleged cluster investigation. No such requests have been received since the Registry was launched in 1994. Information on opt 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 look forward to the development of the regulations which may affect the operation of the NICR.

All identifiable data are held in a highly secure area and are available to 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 Council Steering Group 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, which was recently updated to reflect current practice, a poster available 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 Lung Cancer article)
- The Registry has a very 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)
- 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
- 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)
- 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 Public Health Agency (PHA) on specific Projects e.g. 2019-2020 Breast Treatment Services as required by the Department of Health (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. Our designated staff member, who monitors information security to ensure compliance with ISO27001 accreditation, has a Certificate in Information Security Management Principles and was awarded the ISACA Certified Information Security Management (CISM) badge in February 2018.

Information security controls include physical measures such as video surveillance, lockable outer doors, 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 has necessitated home working and this has been 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 database is held on a standalone server within a highly secure area. This server has no connectivity to any external networks and levels of access are 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.

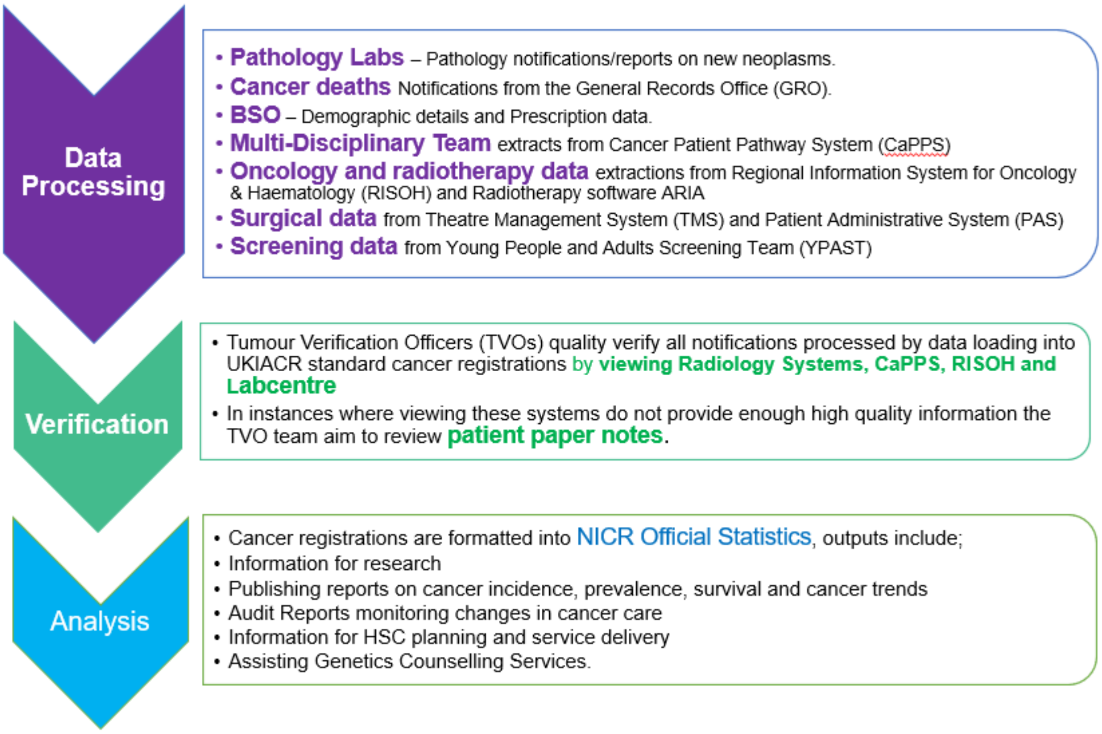
We have a policy of daily backups of the Registry system and regular backups for those working external to the system.

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 Young People and Adults Screening Team (YPAST)

- Tumour Verification Officers (TVOs) 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 TVO team aim to review **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 Tumour Verification Officer (TVO) 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. We are continuously researching innovative methods such as Natural Language Processing and machine learning to identify and enrich data for cancer registration and research.

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, can 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 as an extract from PAS hospital discharge data using OPCS4 procedure codes supplemented by extracts received from the Clinical Oncology Information System (COIS), which the TVO team read to extract relevant information. From April 2017 the Regional Information System for Oncology and Haematology (RISOH) has replaced COIS. The transfer from COIS to RISOH has been problematic for the NICR, as only patients who were alive had their annotation notes uploaded as a part of the move. The NICR actively worked with BSO and Belfast Trust Staff and now have reinstated access to COIS. The NICR does not currently have access to the same level of data from RISOH that COIS provided; however, we are working with BSO to ensure appropriate availability of data and the possibility of acquiring a historical clinical data set.

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 more recently (from 2018) the new North West Cancer Centre based in the Altnagelvin Hospital site within the Western Health and Social Care Trust. 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 the two 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 worldwide, and now includes information on more than 24,000 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. In 2019, a dedicated Barrett's research Patient and Public Involvement group was established, comprising four patients affected by this condition, and who meet quarterly to guide this research.

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 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 to date has focused on piloting different formats for the dataset, establishing the data fields to collect, and liaising with potential end users of the data to ensure its

accessibility and usefulness. Currently data for CIN3, CGIN and SMILE is available for all 2019 and most of 2018. Future work is focused on maximising data accuracy and completeness as well as increasing the scope to include CIN2.
Current funding: Lynsey Courtney Foundation

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 RQIA (previously GAIN).

MEASURES OF DATA QUALITY

Our datasets are compared annually to those of England, Scotland, Ireland and Wales via the UK and Ireland Association of Cancer Registries (UKIACR). These reveal high quality 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). 2018 staging for NICR data is 81.7%. 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 TVO 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

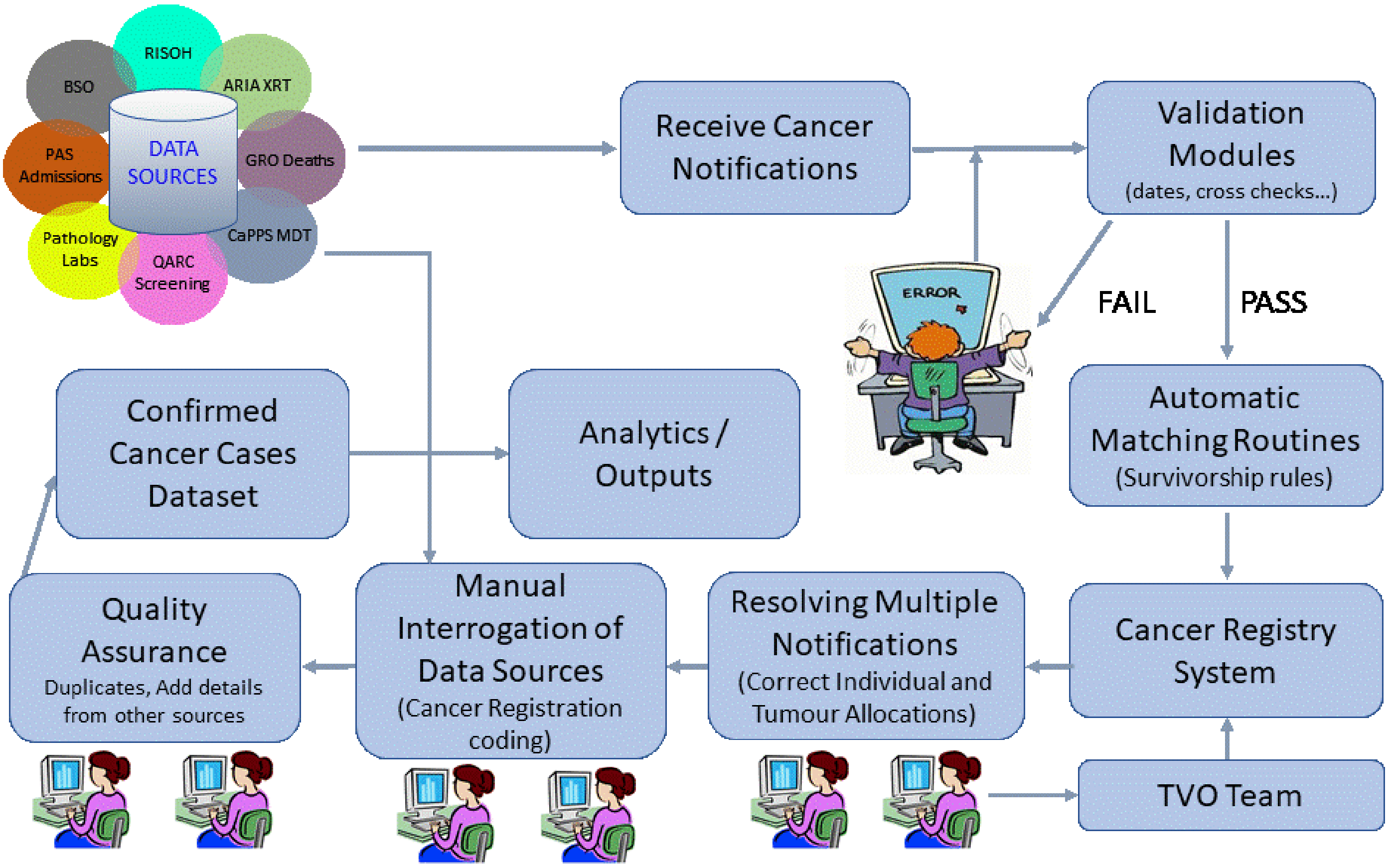
3.1 Background

The NICR currently uses a legacy registration database system (PRAXIS) developed in the 1990's by a commercial company and later supported by a conglomerate of Cancer Registries in the UK. These registries ceased using PRAXIS when the eight English cancer registries combined and instead choose to use the Encore registration system. This left NI as the sole user of PRAXIS, a system which has many benefits, such as automated data linkage routines, which have not been fully replicated in newer systems. Historically PRAXIS required only limited in-house (NICR) support while development was not supported. 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 to the latest version of the database management software (Caché 2016). The registration system is currently undergoing a major redevelopment 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), due around 2021) and the future requirement to collect, record and analyse molecular data and record recurrences.

The Registry is currently exploring opportunities and technologies for a suitable platform to rebuild cancer registration applications which will allow enhancements in the collection, processing and reporting of cancer data in Northern Ireland. Additional investment is required to enable full development.

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 2018 registrations were published on 2 April 2020 alongside the latest statistics on cancer mortality which are provided by General Register Office Northern Ireland (GRONI). The 2019 data should be available late 2021.

Cancer statistics for 34 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 1993-2018 are also available.

4.2 Cancer Factsheets

The website, through its cancer factsheets, continues to be well used (see examples here).
We now have 21 factsheets updated annually as new official statistics are released. It is planned to add new data to the 2019 factsheets.
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 2020, 14 peer reviewed publications using registry data have been produced (116 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 49 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 84 genetic information requests received from outside Northern Ireland within this timeframe (Appendix F). 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 40 reports covering survival, cancer incidence and survival trends, All-Ireland statistics and an All-Ireland Cancer Atlas with colleagues in the National Cancer Registry of Ireland. (See here).

4.7 Other Uses of Registry Data

- Regular feedback of cancer cases to 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 cancer statistics on their webpage
- Provision of data for national/international projects; Cancer Incidence in Five Continents, EUROCARE, UK Cancer Survival Project-London School of Hygiene and Tropical Medicine (LSHTM), National Cancer Dataset Repository, Local Cancer Intelligence Commissioning Tool, Northern Ireland Neighbourhood Information Service (NINIS) and Prevalence Projections for the UK, CONCORD 2 and 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.

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 2020/21

- Identifying risk factors for lethal prostate cancer in a Northern Irish population-based study: Dr Emma Allott, PGJCCR, QUB
- Northern Ireland Multi-morbidity Cohort (NIMC): Measures of multi-morbidity and its impact on mortality: Prof Dermot O'Reilly/Dr Corina Miller CPH, QUB
- CRUK National Cancer Incidence and Mortality Dataset 2018
- Water and Soil Contamination and Awareness on Breast Cancer in Young Women (WASABY) – Cancer Registry, Milan, Italy
- The Descriptive Epidemiology of Male Breast Cancer in Northern Ireland (1993-2018): Dr Nick Orr, PGJCCR, QUB
- The epidemiology of cervical intraepithelial neoplasia 3 (CIN3) in Northern Ireland: Dr Finian Bannon/Sarah Alawi, CPH, QUB
- Clinical trial emulation for evaluating the effectiveness of surgery for improving lung and colorectal cancer patient outcomes : Dr Finian Bannon/Shengsi Chu, CPH, QUB
- Mortality of patients from Northern Ireland, treated for uveal malignant melanoma by the Sheffield Ocular Oncology Service: Dr Hibba Quhill, Sheffield Teaching Hospital NHS Foundation Trust.

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 19 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 was an audit of lung cancer, published 2017 which compared NI patient outcomes with that of the rest of the UK. An audit of Colorectal cancer funded by PHA is expected Spring 2021.
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. This report is due Autumn 2021.

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. We expect to undertake audits of pancreatic and breast cancers 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 now that the NI Assembly has been restored. 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.

5.2 Access to Data Sources

The introduction of RISOH in 2018 has reduced Registry access to the fact and regimen used in chemotherapy despite agreement from Trusts and numerous requests and meetings with RISOH Staff and Board. We are also concerned that the move to Encompass will lead to further problems with data access. The Registry requires Read-Only access to the RISOH systems to provide treatment data and facilitate data completeness and staging.

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

While updates and developments to the current IT system are ongoing this is likely to require significant additional resources. The recent Registry review 2018 recommended an immediate injection of £60,000 to facilitate its development.

Further planned developments include:

- Update the treatment files and death files with NICR number/HCN so that the data may be easily matched against PRAXIS
- Collate the audit datasets into single datasets for each tumour group as many are still held by the analysts.
- Ensure audit data is on PRAXIS
- Create a system for logging and tracking requests which will include request forms, governance documents, staff induction and a record of the data items sent
- Create a facility for the receipt and transfer of genetic requests
- Ensure tumours are coded to both ICD10 and ICDO3 to facilitate international data submissions
- Run IACR/ENCR data quality tools on a regular basis
- Ensure the Common directory holds only pseudonymised data files
- Remove duplicate patients from PRAXIS
- Convert the T and M snomed codes to ICD10 and ICDO3
- Incorporate the ICDO3 version 2 updates
- Incorporate CaPPs as an automated source for cancer registrations
- Create a system which fully records the basic data needed to register cancers and integrates with premalignant registrations.

5.4 Annual Funding

The NICR is currently funded by the PHA, but the University considers this an annual grant. This leads to difficulties in staff retention and recruitment as posts can only be advertised on a short-term basis. Long term planning is impossible.

Currently for 2020/21, approximately 93% of funding was spent on staff. Detail of the amount of funding for each forthcoming year arrives late meaning planning for the forthcoming year is hampered. There are also additional pressures of incremental staff pay awards. In the 2019/2020 budget the PHA provided additional funds to cover the increased pension contributions.

Following discussions within QUB agreement has been reached that all NICR staff will be made permanent members of staff following their probation period.

5.5 Reorganisation of Staff Duties

Reorganisation of staff duties to take account of:

- Changes to NICR over the past 25 years
- The increased work associated with compliance with Information Governance and GDPR
- The increasing number and complexity of registrations taking account of international standards and rules and new datasets e.g. biological biomarkers etc.
- Increasing and more complex data requests for research.

5.6 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 an audit of colorectal cancer and one on oesophageal cancer is underway. These were funded on an ad hoc basis by the PHA/RQIA/OG Cancer NI. Regular funding is required.

5.7 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.

6. NICR RESOURCES

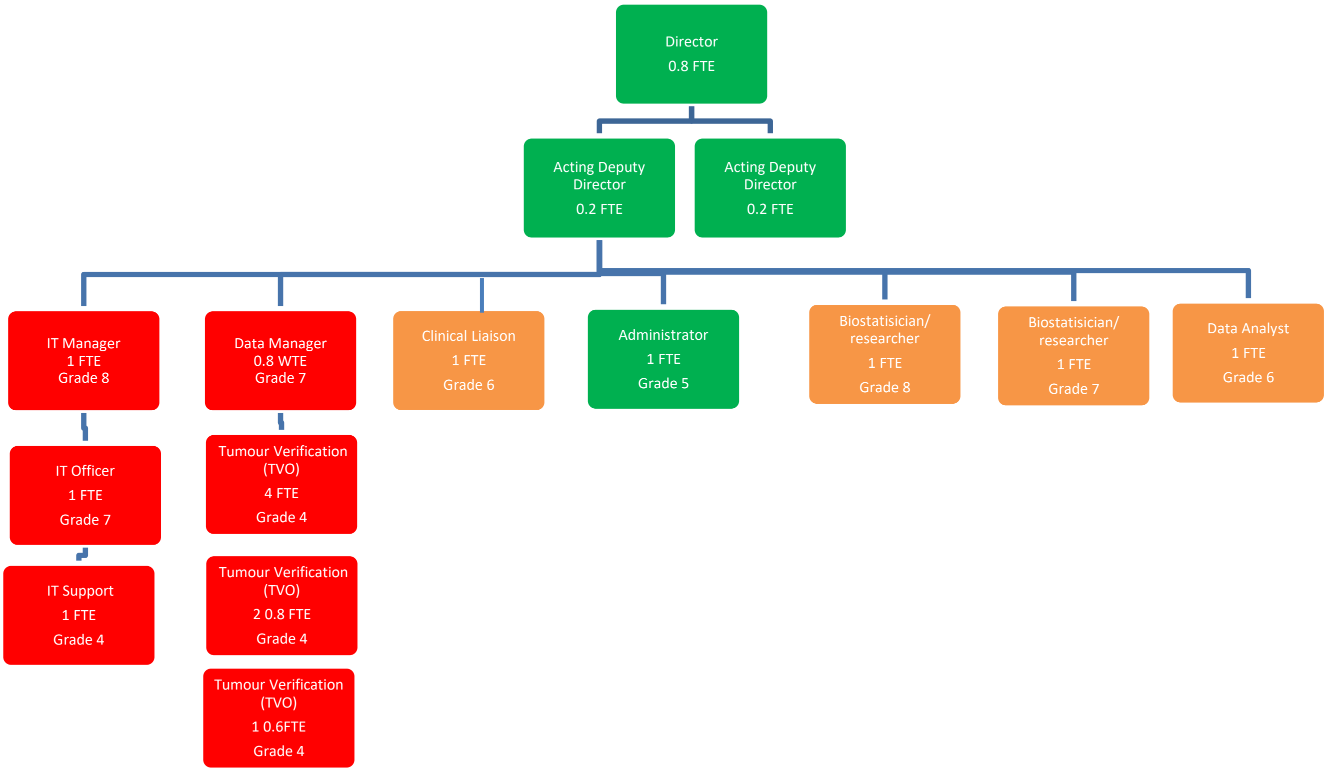
6.1 Current staff and funding

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 2020-2021 was £861,444 with 93% spent on staff salaries.

The Registry submits research and audit grant applications to various funding bodies and, if successful, undertake specific research/audit projects.

Discussions are ongoing with PHA and we await the budget allocation for 2021-2022.

Figure 3: Current PHA funded staff 2020-2021



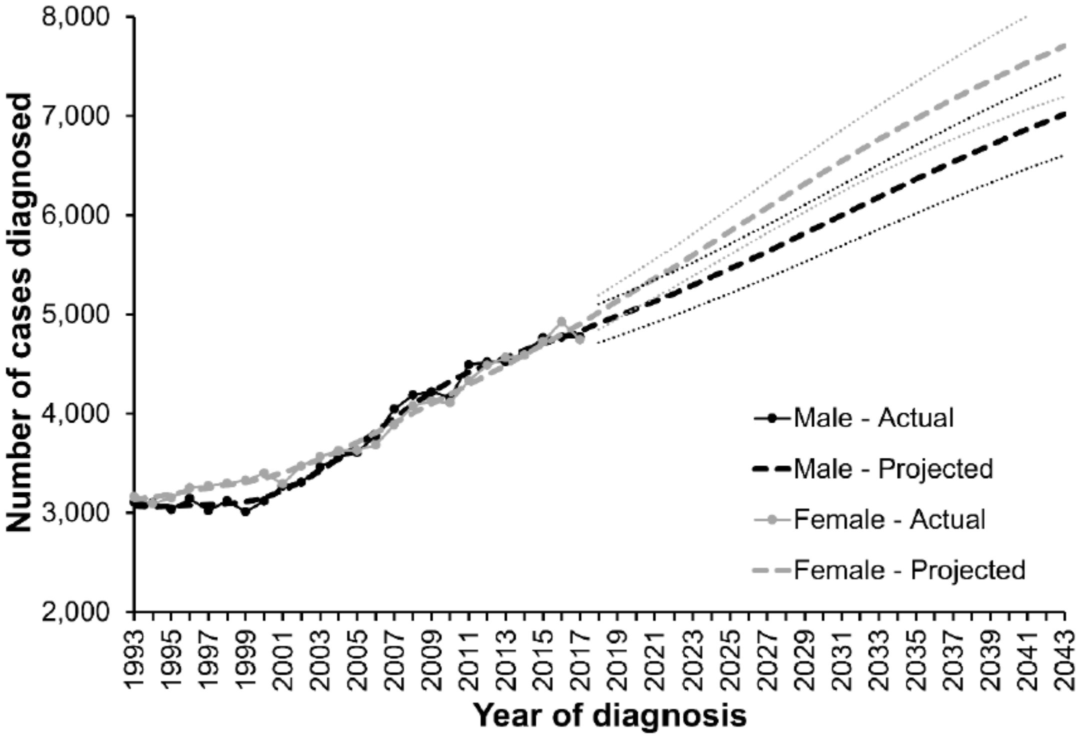
FTE = Full Time Equivalent
Colour coded to reflect Data Security Access Zones within the Registry

In Addition;

- Cancer Focus funds a Health Economist to work with the NICR and the Centre for Cancer Research and Cell Biology (CCRCB). The funding for this sits with CCRCB
- Macmillan fund 1 FTE Researcher and 0.5 FTE TVO
- NI Biobank fund 1 FTE TVO
- The PHA provided additional funding to undertake a Colorectal Audit in 2019/20
- RQIA has funded an audit of Oesophageal cancers 2020-2021 - report due Autumn 2021. This audit also received £10,000 funding from an Oesophageal Cancer Charity, OG Cancer NI.

Significant changes to pension contributions for Staff Grade 6 and above added £12,043 to 2019/2020 budget and an additional £9,225 in 2020/2021. The budget allocation for 2020-2021 included an uplift of £16,471 to provide for these pension increases.

	Basic	Pension	NI	Total	Difference	Cumulative pension effect on NICR budget	
19/20	£653,349	£123,134	£65,641	£788,650			
20/21	£665,367	£135,177	£63,618	£864,162	£75,512	10%	£75,512
21/22	£683,358	£144,402	£65,688	£893,448	£29,286	3%	£104,798
22/23	£701,095	£153,756	£67,564	£922,415	£28,967	3%	£133,765



However, the current resources are not adequate to fulfil the roles of a modern Cancer Registry. Like all cancer registries, the NICR is working on collating data on an increasing number of required data items for an increasing number of cancers with constrained resources. To maintain current standards of data, and cope with increasing numbers of cancers and 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.

To cope with the workload and to enable a better Registry structure the following funding uplift is required. The estimated costs of posts below include National Insurance and Pension contributions and QUB 12.5% overhead:

- 1 FTE director (current post funded 0.2 by retirement) cost could be recovered from assistant director post
- New Post of Registry manager from vacant grade 8 IT post, five TVOs re-grading to grade 5 – current grade 4 estimated £19,664

- One new TVO for audit £38,832 estimate for audit. To be funded from audit related grants
- New data quality lead from within current TVO staff current grade 4 expected grade 6, £10,035
- New training lead from within current TVO staff grade 6 from current grade 4, £10,035
- Review of grade 4 IT post likely to grade 5, £3,443
- Additional statistician grade 7 (£57,331) to cope with the increased demands from complexity of data requests and needs for official statistics, cluster investigations, audits and to reduce risks to the Registry outputs. To be financed from audit specific funding.

Total required for restructure is £43,177 (£19,664 +£10,035 + £10,035 + £3,443) with £96,163 (£57,331 and £38,832) from grants including for audit.

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).
Succession planning for IT post while facilitating urgent time limited work on development of the Registry IT system.

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
Total Core Work	**£820,112***	**£820,112***	**£ 823,560**	**£844,973**	**£861,444**

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

6.3 Other funding

In addition to the allocation from the PHA the Registry has four current research projects DataCan (funds with CCCRB), Macmillan, Heart Research UK and CIN2 (funded by Lindsey Courtney Foundation) and one audit project Oesophageal (funded by RQIA and OG Cancer NI) (Table 2).

Table 2: Research/Audit Expenditure relating to projects active during the period 1 April 2016 – 31 March 2021

	Funder	Start Date	End Date	Total Budget	Expenditure up to 31/03/21	Balance c/f 2020-2021
Macmillan	Macmillan since 2016	01/01/21	31/12/22	£241,226	£0	£0
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	£15,000	£15,000
Oesophageal Audit	OG Cancer NI	01/10/20	31/09/21	£10,000	£0	£10,000
CIN2	Lindsey Courtney Foundation	01/07/19	On-going	£26,782	£13,391	£13,391
Cardiovascular Disease	Heart Research UK	01/01/20	31/12/22	£149,991	£28,522	£121,469

7. NICR Achievements 2020-2021

The list of NICR achievements in 2020/21 are highlighted in Table 3.

Table 3: Update on NICR achievements in 2020/2021

Targets 2020-2021	Update
Goal 1 – Provide accurate, timely data on cancers and premalignant disease in N. Ireland	
a. Launch official statistics of cancer incidence, prevalence and survival statistics for patients diagnosed in 2018 by April 2020 and provide at that time a suite of derived site specific factsheets for the NICR website	Launched 2nd April 2020
b. Investigate the datasets available to monitor the impact of COVID 19 on cancer patients	Monthly reports on Pathologically diagnosed cancers produced
c. Prepare the data for 2019 data for launch as official statistics in 2021	Due August 2021
d. Provide accurate Northern Ireland cancer datasets for international comparison including new call for Concord Venus Project	Data provided
e. Enhance staging data available on each patient to maintain goal of high overall staging (85% achieved for 2016 data). Estimated 85% for 2017 diagnosed patients and 82% for 2018 data	Difficulties arose with access to RISOH and access to datasets during remote working and disruption to QUB systems
f. Develop a Registry Manager – oversight role	Ongoing
g. Continue to enhance links with Business Services Organisation (BSO), Trusts, General Register Office (GRO) and screening services to enhance data available on cancer registrations i.e. pathology, treatment and co-morbidity data	Progress has been made in receiving relevant prescribing data from BSO which we hope to obtain annually
h. Consolidate links with RISOH system to ensure relevant clinical information is available to NICR	Not achieved
i. Consolidate link to Radiology systems to enable the interrogation of imaging reports	Data now received from Altnagelvin Radiology site
j. Work on updating the cancer factsheets so they become more interactive in the online version	Ongoing – additional factsheets developed
k. Further investigate the provision of appropriate and faster network links to Health & Social Care (HSC) network	Leased line has been provisioned, as staff are off site it is unsure if link to HSC has improved but access to network remotely has greatly improved
l. Review historical data to assess and correct map to/translate from previous versions of coding systems used to record cases.	Ongoing – All data are currently coded to ICD10

Targets 2020-2021	Update
This work is essential for accurate measurement of trends, projections and investigation of alleged clusters	but work is still needed to recode to ICDO3
m. Work to ensure data from new upcoming NHS systems, to include the laboratory system (Laboratory Information Management System - LIMS) and ENCOMPASS, is accessible to NICR by 2021	Ongoing
n. Assess the Registry resource requirements to maintain current standards of timeliness, completeness and accuracy in views of increasing numbers of cancer cases	Ongoing
o. Provide data for UKIACR annual Performance Indicators within timescale	Provided
p. Aim to review NICR TVO work practice to introduce “Patient Ownership” where all notifications about cancers occurring in each patient are resolved at patient level	Reviewed and accepted not always possible to adopt this method due to timeline of receipt of data
Goal 2 – Protect the confidentiality of the data	
a) Maintain ISO27001 Certification in Information Security Management for NICR	Renewed February 2020
b) Ensure staff training is maintained	All up to date
c) Ensure research projects adhere to the NICR & QUB Research and GDPR directives	All achieved
d) Ensure that all relevant research projects have ethical approval prior to commencement	Ethical approval for NICR reviewed October 2020 for five years (Ref 20/NI/0132)
e) Ensure that the move associated with accommodation decant and refurbishment within QUB achieves maximum security and assures data confidentiality	Delayed
f) Ensure that the new IT ‘CENTRIS’ maintains data confidentiality	Ongoing
g) Investigate remote working options during COVID-19	Achieved with no reduction in Data Security
h) Develop a home working policy	Developed
Goal 3 – Upgrades to the Registry IT System and extend its capacity to store data items	
a) Continue developments of PRAXIS replacement (CENTRIS) in house	Delayed – resource required
b) Expand database to include additional items e.g. HER2, ER, PR, PSA, molecular markers, recurrences and others are recorded on the patient record	Achieved – PRAXIS has been updated to facilitate recording of this information
c) Work with existing breast and colorectal cancer datasets to extract and analyse information on recurrences	Ongoing
d) Adapt the current IT system to record TNM 8	Achieved
e) Integrate the cancer staging tool assessment and addition to CENTRIS	Staging Tool developed, launch expected Spring 2021

Targets 2020-2021	Update
f) Create safe and secure remote working environment for staff, to allow access for processing and analysis of data to be completed on internal systems without moving data outside the Registry systems	Developed
Goal 4 – Provide a cancer intelligence service	
a) Introduce full ICDO3 & TNM8 coding	Achieved
b) Answer all data requests within time limits of 20 days for general requests and 10 days for genetic requests	Achieved
c) Continue to facilitate the Northern Ireland Clinical Genetics Service access to NICR datasets and provide a similar service to those outside of NI as per protocols	Achieved
d) Feedback research findings to relevant partners and associated patient groups	Achieved
e) Ensure website is kept up to date	Achieved
f) Enhance visibility of Official Cancer Statistics on webpage	Achieved
g) Work to achieve additional resources to provide Northern Ireland data for peer review and national audits Oesophageal and Pancreatic Cancer Audits	Ongoing
h) Work to provide information for outcomes of care as required by PHA, NICaN and Trusts	Ongoing
i) Produce updated cancer factsheets from Official Statistics 2018 data with additional clinical data added for specific cancer sites	Factsheets provided and on NICR web April 2020
j) Maximise use of media to promote NICR, messages of cancer prevention and early detection	3rd April 2020 – Official statistics covered by article in Belfast Telegraph, COVID-19 impact data BBC Radio Ulster March 17th 2021
k) Registry to investigate providing information on route to diagnosis and various other relevant metrics e.g. survival related to this	Ongoing
l) Ensure each NICaN Clinical Reference Group and NICaN Board have attendance from NICR	Achieved
m) Ensure a lay summary of all Research Papers are included on NICR webpage	Achieved
Goal 5 – Facilitate planning and monitoring of cancer services in NI including Audits	
a) Ensure audit and research findings are disseminated to key organisations/individuals to encourage implementation of recommendations	Achieved
b) Provide Core Audit required Datasets to Encompass	Supplied the COSD specification used in England
c) Work to achieve resources to ensure that NI data are included in national audits	Ongoing
d) Enhance availability of information on website and dissemination of data and reports through other online partners	Achieved

Targets 2020-2021	Update
e) Provide copies of all publications to PHA	Achieved
f) Work with clinicians, NICaN/PHA to achieve inclusion of NI data in National Clinical Audits	Ongoing
Goal 6 – Undertake and present internationally recognised research	
a) Apply for at least one research grant	Macmillan achieved
b) Submit six papers for peer review in high impact journals	14 papers published
c) Implement the Research Request Policy with a single route for requests via Research Advisory Group. Develop a tracking system to monitor requests to ensure timeliness of response	Not achieved – Goal for 2021/2022
d) Research Advisory Group to meet twice a year	Revised arrangement to merge with Council meeting from May 2021 onwards
e) Ensure Data Governance for all data requests and projects	Achieved
f) Ensure NI provide relevant data for International Cancer Benchmarking Partnership (ICBP) studies	Achieved
g) Work to maximise outputs from Patient Reported Outcomes Measures (Life after Prostate Cancer Diagnosis - LAPCD) Study (externally funded)	Papers continue to be published – four in 2020
h) Submit abstracts and attend relevant conferences	COVID-19 impacted
i) Work with NI Biobank and local researchers to enhance use of NICR data for scientific study	Ongoing
j) Work with Macmillan to promote understanding of Recurrence, Cardio-oncology and Bone Health after a cancer diagnosis. Provide new information for Acute Oncology (AO) Services and Emergency Admissions of Cancer Patients in their last year of life	Macmillan work temporarily halted due to Macmillan halting funding for eight months
Goal 7 – Ensure the Registry provides value for money	
a) Manage annual budget from Public Health Agency and provide accurate updates on spending with reference to the increased numbers of cases and increased data items being collected	Managed
b) Achieve temporary increase in budget to enable restructuring of NICR as outlined in this business plan	Not achieved
c) Manage budgets from research grants	Achieved
d) Implement and monitor cost recovery/administrative policy to ensure resources are available for time consuming requests	Ongoing
e) Involve staff in planning of targets for 2020/2021	Staff away day did not happen due to COVID-19 but staff kept informed online
Goal 8 – Ensure the sustainability of the Registry	
a) Establish active contingency plans in case of loss of accommodation/operating system or staff	Updated March 2021
b) Develop Standard Operating Procedures for NICR work	31 SOPs developed

Targets 2020-2021	Update
c) Work to achieve the regulations for the Health and Social Care Secondary Use of Data 2016 Act legislation to cover disease registration	Work continues
d) Ensure staff are trained to a high level for their work	Achieved
e) Maintain a high registry profile locally and internationally	Achieved – needs ongoing work
f) Achieve additional resources to cope with the increased workload, staff costs (pensions and increments) and complexities of data items	Not achieved
g) Organise opportunities to highlight the work of the Registry to external groups	Needs further work
h) Work to achieve succession planning for Registry posts	Ongoing – two temporary Deputy Directors appointed
i) Maintain a risk register for the Registry for discussion at each Steering Group meeting	Achieved
j) Work with funders and QUB to have an updated contractual agreement for the NICR	Not achieved
k) Minimise disruption to ongoing work during decant and refurbishment and off site working due to COVID-19 pandemic	Achieved – due to excellent work by Data Manager and IT Staff
Goal 9 – Ensure good links with patients and their representatives	
a) Continue to involve patients and their representatives in our Council, Steering Group, Research Advisory Group and in Registry work and research	Achieved
b) Continue to involve patients as speakers/invitees at launch of reports	No report launches due to COVID-19
c) Ensure that the Patient Information leaflet and poster is available on the internet and areas where cancer patients are treated	Achieved
d) Continue to enhance the NICR website to better disseminate and improve access to NICR data to improve public understanding of cancer in Northern Ireland	Achieved
e) Ensure data available to the public on cancer in NI are up to date and accurate	Achieved
Goal 10 – Promote expertise of data acquisition and analysis	
a) Use expertise of data acquisition and analysis for promotion of data availability for other diseases	Working on a research project to identify Cardiac Disease impact on Cancer treatments on the heart. Funded by Heart Research UK
b) Link nationally and internationally to promote cancer registration and increase understanding and control of cancer including promoting cancer staging tool	Achieved
c) Provide data for UKIACR Performance Indicators	Achieved

Targets 2020-2021	Update
d) Work to have Cancer Staging Tool tested and disseminated internationally	Achieved
Goal 11 – Provide an environment for education and training	
a) Offer training slots to undergraduate/postgraduate students, Public Health trainees and F2 doctors	Working with; - One BSc student on Male Breast Cancer - Two Global Health MPH students
b) Raise awareness of the Cancer Registry within the University and beyond	Ongoing
c) Maintain international links on new developments in cancer registration and cancer research	Ongoing
d) Facilitate medical/research staff with access to relevant registry datasets within confidentiality and ethical guidelines	Ongoing – see page 14 for list of projects
e) Ensure the Registry environment and processes support education and training while maintaining data security	Achieved – increase use of designation of Registry environment to facilitated data security

NICR Key Priorities 2021-2022

The key priorities for 2021/2022 are:

1. Provide accurate, timely data on cancers in NI for official statistics by August 2021 for patients diagnosed in 2019
2. Commence work on 2020 diagnosed cancers to launch 2022
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 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
17. 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 2020/21 this included:

- Monthly reports monitoring the impact of COVID-19 on pathologically diagnosed cancers
- 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 2021-2022

Targets 2021/2022	Update
Goal 1 – Data Outputs	
a. Produce Official statistics by August 2021	
b. Extend the statistics dataset available to Registry researchers to include variables such as: - Treatment within a year of diagnosis – Start Date, Chemo, Radio, Surgical procedure code - ER, PR and HER2 status where applicable - Comorbidities (Elixhauser or Charlson score) - Site coded to both ICD10 and ICDO3	
c. Provide updated Factsheets online for major cancers. Include Emergency Presentation in factsheets	
d. Review presentation of statistics in line with needs	
e. Better lay presentation of NICR data through data visualization products to present Factsheets. Investigate how other registries present data	
f. Provide data for UK and Ireland Cancer Registry Performance Indicators - Achieve a high level for Cancers staged - Include screening data	
g. Provide information on the impact of COVID-19 - Impact on Pathologically diagnosed cases – continued - Impact on Emergency Presentation - Impact on Stage at Diagnosis and Cancer Survival	
h. Facilitate requests for Information and Genetic Requests within defined timescales	
i. Facilitate Research Related Requests, including any requests for data releases - Establish a mechanism to log requests - Establish monthly meetings for streamlined processing of requests requiring datasets - Organise biannual meetings of the Research Advisory Group as part of Council meeting	
j. Continue to investigate Routes to Diagnosis and Impact on Survival	
k. Work to establish relevant data for Cardio-oncology	
l. Apply for funding to undertake additional population based audits e.g. breast cancer, pancreatic cancer	
m. Apply for one Research Grant	
n. Provide Data as required for International Studies, e.g. CONCORD, EUROCARE etc	
o. Facilitate medical/research staff with access to relevant Registry datasets within confidential and ethical guidelines	
Goal 2 – Data Acquisition and Quality	
a. Achieve full read only access to RISOH and SACT extracts	

Targets 2021/2022		Update
b.	Ensure Registry needs are considered in roll out of Encompass	
c.	Run IACR/ENCR data quality tools on a regular basis	
d.	Collate the audit datasets into single datasets for each tumour group as many are still held by the analysts	
e.	Ensure tumours are coded to both ICD10 and ICDO3 to facilitate international data submissions	
f.	Work to ensure relevant data from Health Service systems e.g. LIMS is achieved	
g.	Investigate adding recurrence algorithm	
Goal 3 – IT System		
a.	Continue Development of IT system	
b.	Incorporate the Cancer Staging Tool into the Registry IT system	
c.	Expand database to include additional items e.g. HER2, ER, PR, PSA	
d.	Update the treatment files and death files with NICR number/ HCN so that the data may be easily matched against PRAXIS	
e.	Ensure audit data is on PRAXIS	
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	
g.	Initiate development of processes for creating a facility for the receipt and transfer of genetic requests	
h.	Ensure the Common directory holds only pseudonymised data files	
i.	Remove duplicate patients from PRAXIS	
j.	Convert the T and M snomed codes to ICD10 and ICDO3	
k.	Incorporate the ICDO3 version 2 updates	
l.	Incorporate CaPPs as an automated source for cancer registrations	
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	
Goal 4 – Enhance Registry Infrastructure		
a.	Manage budgets	
b.	Implement Cost Recovery when appropriate	
c.	Update Cost Recovery policy	
d.	Maintain Risk Register	
e.	Review and update Registry Business Continuity Plan to incorporate, loss of Coding and Cyber Attacks on QUB systems	
f.	Commence Staff restructuring	

Targets 2021/2022		Update
Goal 5 – General		
a.	Ensure Registry input to Development for the Health and Social Care Secondary Use of Data legislation in April 2016	
b.	Lobby for Cancer Minimum Datasets to be developed and provided by Trusts	
c.	Ensure all Data Access Agreements are up to date	
d.	Maintain ISO27001 accreditation	
e.	Ensure data confidentiality is maintained with accommodation upgrade	
f.	Work to achieve updated contract between QUB/PHA	
g.	Actively engage in succession planning for key posts	
Goal 6 – Registry Profile		
a.	Establish NICR public engagement team of 3-4 staff members, including having representation on PGJCCR Public engagement committee	
b.	Increased promotion of NICR as provider of cancer data within the university and the HSCNI	
c.	Tailored presentations of data at CRGs and regularly send to clinicians across tumour groups	
d.	Encourage partnerships with clinical researchers	
e.	Raise awareness of the types of information the Registry can produce	
f.	Maintain an active Twitter account, monitored through impressions data from Tweets and number of followers etc	
g.	Have regular press releases	
h.	Maximise use of media	
i.	Ensure input to the International Projects such as International Cancer Benchmarking Partnership	
j.	Ensure Registry leaflet/poster/website are up to date	
Goal 7 – Students/Training		
a.	Offer training opportunities to F2 doctors, Public Health Trainees, undergraduate and MSC students	
b.	Ensure all staff have access to appropriate training and opportunities for development	
c.	Ensure all staff have annual Personal Development Reviews	
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	
e.	Ensure Standard Operating Procedures are up to date	
f.	Work to achieve succession planning for Registry posts	
g.	Pursue grading of TVOs	
Goal 8 – Patient Involvement		
a)	Ensure Patients/their representatives are integrated into Registry activities e.g.:	

Targets 2021/2022	Update
- Council Memberships - Charity representation on Steering Group - Involvement in report launches etc - Provision of information when requested	

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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, CCRCB 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 Andrew Galway	Lay Representative
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
Debbie Keatley	Lay Representative
Dame Joan Harbinson	Lay Representative
Dr Collette McCourt	Belfast HSC Trust, Dermatologist
Dr Deirdre Donnelly	Belfast HSC Trust

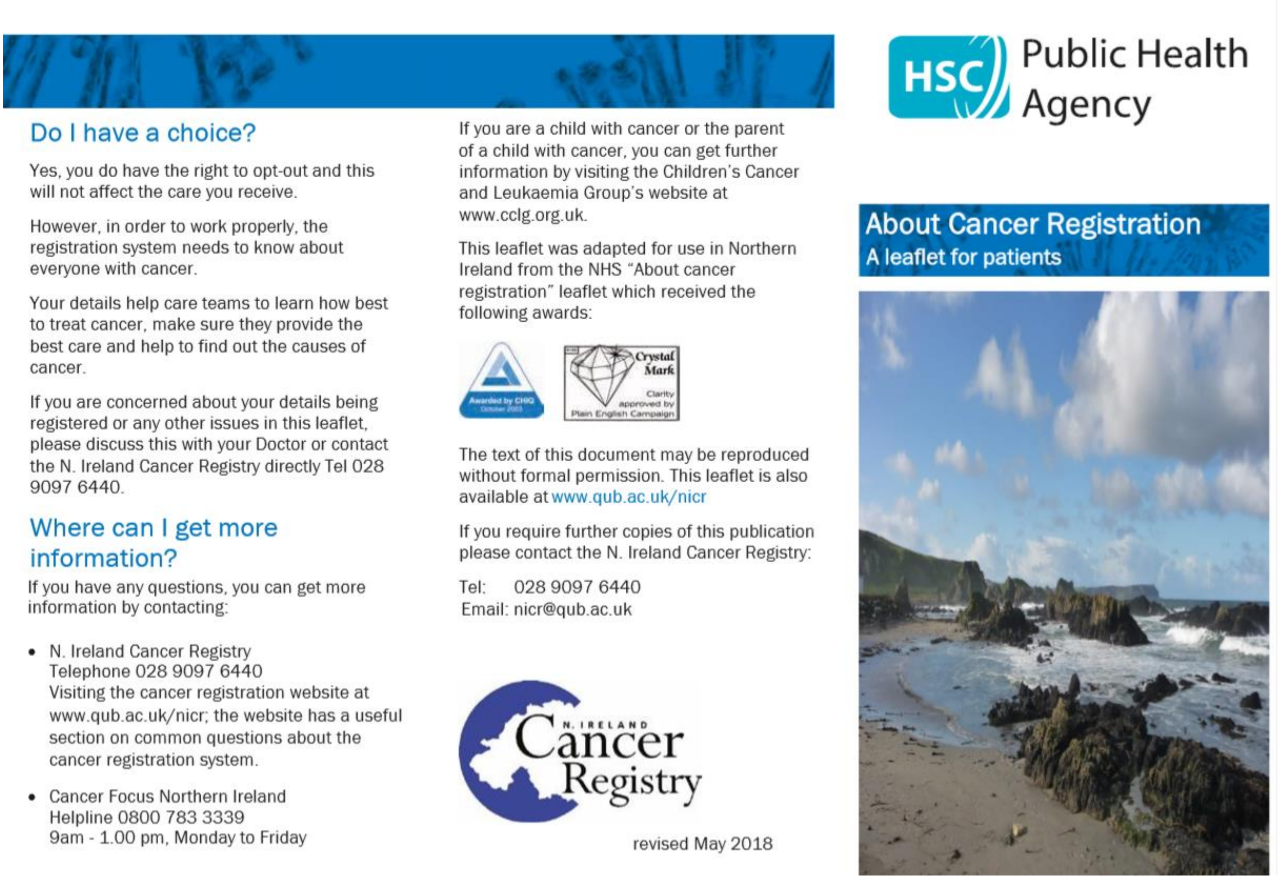
With attendance from Registry Director, Deputy Director and relevant staff required for the agenda.

Research Advisory Group

Role is to review Data Information requests received to the Registry to ensure they have a scientific rationale, appropriate methodological approach and are covered by the existing ethics approval held by the NICR.

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, CCRCB
Dr Nick Orr	QUB, CCRCB
Dr Chris Cardwell	QUB, CPH (Statistician)

APPENDIX B: Patient Information Leaflet



Do I have a choice?

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

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

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

If you are concerned about your details being registered or any other issues in this leaflet, please discuss this with your Doctor or contact the N. Ireland Cancer Registry directly Tel 028 9097 6440.

Where can I get more information?

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

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

If you are a child with cancer or the parent of a child with cancer, you can get further information by visiting the Children's Cancer and Leukaemia Group's website at www.cclg.org.uk.

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

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

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

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

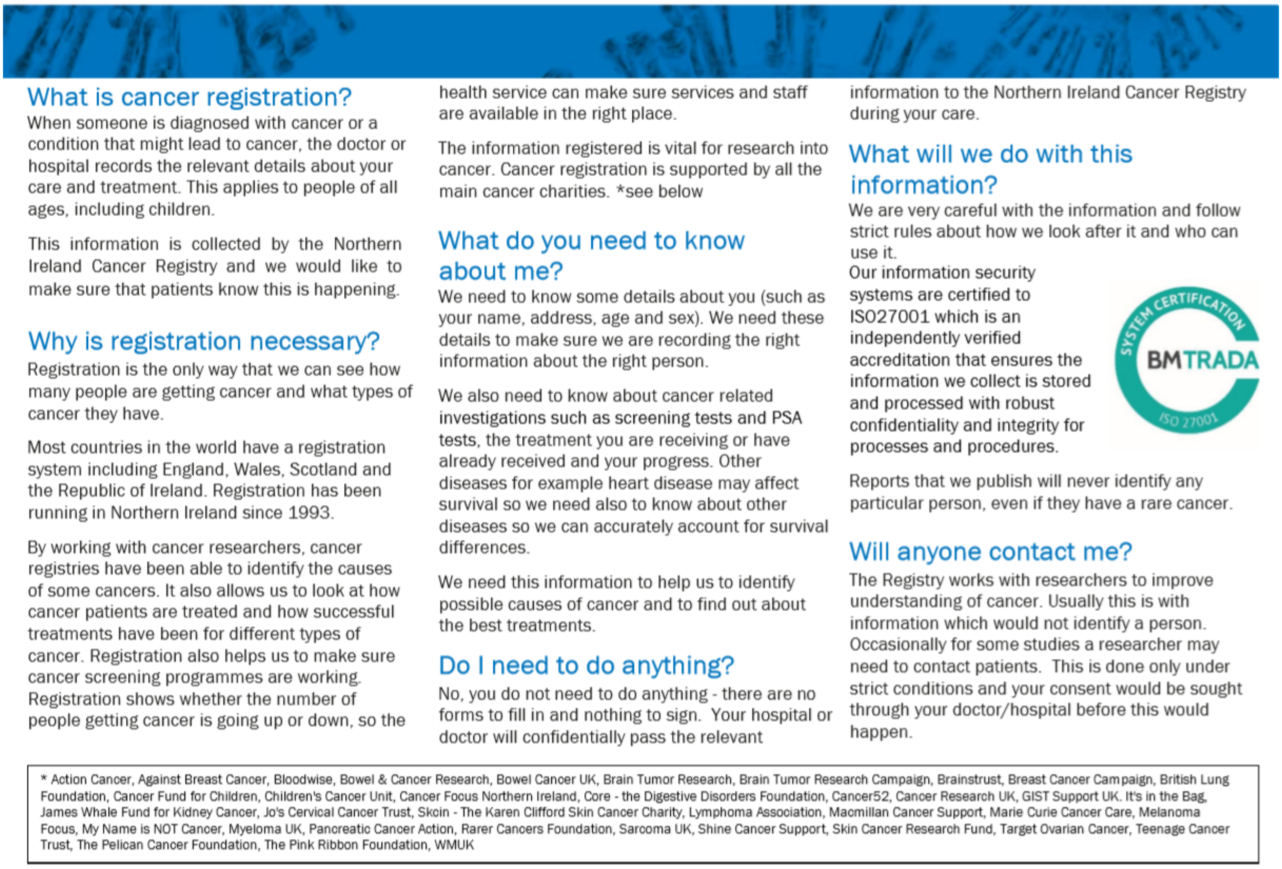
N. IRELAND Cancer Registry

revised May 2018

HSC Public Health Agency

About Cancer Registration

A leaflet for patients



What is cancer registration?

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

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

Why is registration necessary?

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

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

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

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

What do you need to know about me?

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

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

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

Do I need to do anything?

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

What will we do with this information?

We are very careful with the information and follow strict rules about how we look after it and who can use it.
Our information security systems are certified to ISO27001 which is an independently verified accreditation that ensures the information we collect is stored and processed with robust confidentiality and integrity for processes and procedures.

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

Will anyone contact me?

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

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

APPENDIX C: Performance Indicators for 2018

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

Indicator	**Country average (population)[1]**	**Country average (country)[1]**	**England**	**Scotland**	**Northern Ireland**	**Wales**
Stability: Percentage change (%) for all cancers (C00-C97 ex. C44) in 2018 compared with 2015-2017	**4.1%**	**3.8%**	4.1%	4.6%	2.3%	4.1%
Registry Creep: Percentage (%) for all cancers (C00-C97 ex. C44) of 2017 registrations (extracted between 31/12/19 and 20/04/2020) compared with registrations extracted between 02/02/2019 and 01/03/2019[6].	**1.3%**	**1.6%**	1.2%	1.9%	2.8%	0.3%
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]	**79.9%**	**77.2%**	81.3%	67.6%	80.4%	79.6%
Average of Core Patient Information Complete: Average percentage (%) of all cancers (C00-C97 ex. C44) registered with demographic information[3]	**98.6%**	**96.9%**	99.2%	96.3%	100.0%	92.0%
Average of Core Tumour Information Complete: Average percentage (%) of all cancers (C00-C97 ex. C44) registered with tumour information[4]	**97.3%**	**96.9%**	97.5%	96.4%	96.7%	97.1%
Diagnosing Hospital Known: Percentage (%) of all cancers (C00-C97 ex. C44) registered with an organisation of diagnosis	**97.9%**	**96.7%**	98.3%	94.1%	-	97.7%
Death Certificate Only (DCO) Rates: Percentage (%) of all cancers (C00-C97 ex. C44) registered as a DCO[5]	**0.6%**	**0.6%**	0.6%	0.2%	0.3%	1.2%

Zero Day Survivors: Percentage (%) of all cancers (C00-C97 ex. C44) registered with the date of death equals the date of diagnosis[5]	**1.2%**	**1.0%**	1.2%	0.5%	0.5%	1.9%
Microscopically Verified: Percentage (%) of all cancers (C00-C97 ex. C44) that are microscopically verified	**84.8%**	**84.3%**	85.1%	82.4%	85.7%	84.1%
Non Specific Codes: Percentage (%) of all cancers (C00-C97 ex. C44) that are microscopically verified with non specific morphology codes	**1.2%**	**1.1%**	1.2%	0.9%	1.6%	0.7%
Grade: Percentage (%) of all cancers (C00-C97 ex. C44) registered with a known grade	**60.0%**	**60.9%**	59.9%	59.7%	63.0%	60.9%
Treatment: Percentage (%) of all cancers (C00-C97 ex. C44) registered with any treatment	**88.2%**	**85.6%**	88.8%	85.6%	-	82.5%
Breast Screening Data: Percentage of breast cancer (C50) cases from 2017 screen detected for ages 50-64	**49.1%**	**51.3%**	48.7%	50.1%	-	55.1%
Cervical Screening Data: Percentage of cervical cancer (C53) cases from 2017 screen detected for ages 25-60	**23.6%**	**23.8%**	22.1%	49.3%	-	0.0%
Bowel Screening Data: Percentage of bowel cancer (C18-C20) cases from 2017 screen detected for ages 60-69	**4.3%**	**19.0%**	0.0%	29.4%	-	27.5%

APPENDIX D: Peer reviewed publications

NICR Publications 2020-2021

2020

1. **The 'Good Friday Agreement' and cancer research on the island of Ireland: Evidence for the impact of a tripartite cancer research partnership**
   Lewison, G., **Gavin, A**., McCallion, K., McDermott, R., Sullivan, R. & Lawler, M.
   27 Feb 2020, In: European journal of cancer (Oxford, England: 1990). 129, p. 15-22 8
   www.doi.org/10.1016/j.ejca.2020.01.014

2. **Cancer incidence projections in Northern Ireland to 2040**
   Donnelly, D. W., **Anderson, L. A**., & **Gavin, A**.,
   24 Apr 2020, In: Cancer Epidemiology Biomarkers & Prevention.
   www.doi.org/10.1158/1055-9965.EPI-20-0098

3. **A Qualitative Exploration of Prostate Cancer Survivors Experiencing Psychological Distress: Loss of Self, Function, Connection, and Control**
   Matheson, L., Nayoan, J., Rivas, C., Brett, J., Wright, P., Butcher, H., **Gavin, A**., Glaser, A., Watson, E. & Wagland, R.
   01 May 2020, In: Oncology Nursing Forum. 47, 3, p. 318-330 13 p.
   www.doi.org/10.1188/20.ONF.318-330

4. **Colon and rectal cancer survival in seven high-income countries 2010-2014: variation by age and stage at diagnosis (the ICBP SURVMARK-2 project)**
   Araghi, M., Arnold, M., Rutherford, M. J., Guren, M. G., Cabasag, C. J., Bardot, A., Ferlay, J., Tervonen, H., Shack, L., Woods, R. R., Saint-Jacques, N., De, P., McClure, C., Engholm, G**., Gavin, A. T.,** Morgan, E., Walsh, P. M., Jackson, C., Porter, G., Møller, B. & 5 others.
   01 Jun 2020, In: Gut.
   http://dx.doi.org/10.1136/gutjnl-2020-320625

5. **Can different definitions of date of cancer incidence explain observed international variation in cancer survival? An ICBP SURVMARK-2 study**
   Myklebust, TA., Andersson’ T., Bardot, A., Vernon, S., **Gavin’ A., Fitzpatrick, D**., Jerm’ MB., Rutherford, M., Parkin’ DM., Sasieni, P., Arnold’ M., Soerjomataram, I., Bray, F., Lambert, PC., Møller,B.
   13 June 2020, In: Cancer Epidemiology
   https://doi.org/10.1016/j.canep.2020.101759

6. **International trends in oesophageal cancer survival by histological subtype between 1995 and 2014**
   Morgan, E., Soerjomataram, I., **Gavin, A. T.,** Rutherford, M. J., Gatenby, P., Bardot, A., Ferlay, J., Bucher, O., De, P., Engholm, G., Jackson, C., Kozie, S., Little, A., Møller, B., Shack, L., Tervonen, H., Thursfield, V., Vernon, S., Walsh, P. M., Woods, R. R. & 6 others,
   17 Jun 2020, In: Gut.
   http://dx.doi.org/10.1136/gutjnl-2020-321089

7. **Esophageal Columnar Metaplasia in Childhood: A Population-Based Case Series Analysis**
   Twohig-Bennett, L., **Coleman, H. G., Cairnduff, V.**, McManus, D. T., Murray, L. J., **Gavin, A. T**. & Johnston, B. T.,
   18 Jul 2020, In: Digestive Diseases and Sciences.
   https://doi.org/10.1007/s10620-020-06462-5

8. **Cumulative financial stress as a potential risk factor for cancer-related fatigue among prostate cancer survivors**
   Lu, L., **Gavin, A.,** Drummond, F. J. & Sharp, L.,
   01 Aug 2020, In: Journal of Cancer Survivorship.
   https://doi.org/10.1007/s11764-020-00906-7

9. **Strategies for living well with hormone-responsive advanced prostate cancer—a qualitative exploration**
   Matheson, L., Nayoan, J., Rivas, C., Brett, J., Wright, P., Butcher, H., Jordan, P., **Gavin, A**., Glaser, A., Mason, M., Wagland, R. & Watson, E.,
   06 Jul 2020, In: Supportive Care in Cancer.
   https://doi.org/10.1007/s00520-020-05594-8

10. **Influence of deprivation and rurality on patient-reported outcomes of men living with and beyond prostate cancer diagnosis in the UK: a population-based study**
    Smith, L., Downing, A., Norman, P., Wright, P., Hounsome, L., Watson, E., Wagland, R., Selby, P., Kind, P., Donnelly, D., Butcher, H., Huws, D., McNair, E., **Gavin, A**. & Glaser, A. W.,
    01 Sep 2020, (Accepted) In: Cancer epidemiology.
    https://doi.org/10.1016/j.canep.2020.101830

11. **The experiences and needs of couples affected by prostate cancer aged 65 and under :a qualitative study**
    Collaço, N., Wagland, R., Alexis, O., **Gavin, A.,** Glaser, A. & Watson, E. K.,
    24 Sep 2020, In: Journal of Cancer Survivorship.
    https://doi.org/10.1007/s11764-020-00936-1

12. **Age disparities in stage-specific colon cancer survival across seven countries: an ICBP SURVMARK-2 population-based study**
    Pilleron, S., Charvat, H., Araghi, M., Arnold, M., Fidler-Benaoudia, M. M., Bardot, A., Guren, M. G., Tervonen, H., Little, A., O'Connell, D. L., **Gavin, A**., De, P., Aagaard Thomsen, L., Møller, B.,

Jackson, C., Bucher, O., Walsh, P. M., Vernon, S., Bray, F. & Soerjomataram, I., 02 Oct 2020, In: International Journal of Cancer.
https://doi.org/10.1002/ijc.33326

13. **Exploring the impact of cancer registry completeness on international cancer survival differences: a simulation study**
    Andersson, T. M-L., Rutherford, M. J., Myklebust, T. Å., Møller, B., Soerjomataram, I., Arnold, M., Bray, F., Maxwell Parkin, D., Sasieni, P., Bucher, O., De, P., Engholm, G., **Gavin, A**., Little, A., Porter, G., Ramanakumar, A. V., Saint-Jacques, N., Walsh, P. M., Woods, R. R. & Lambert, P. C., 09 Dec 2020, In: British Journal of Cancer.
    https://doi.org/10.1038/s41416-020-01196-7

2021

14. **The impact of excluding or including Death Certificate Initiated (DCI) cases on estimated cancer survival: A simulation study**
    Andersson, T. M-L., Myklebust, T. Å., Rutherford, M. J., Møller, B., Soerjomataram, I., Arnold, M., Bray, F., Parkin, D. M., Sasieni, P., Bucher, O., De, P., Engholm, G., **Gavin, A**., Little, A., Porter, G., Ramanakumar, A. V., Saint-Jacques, N., Walsh, P. M., Woods, R. R. & Lambert, P. C., 10 Jan 2021, In: Cancer epidemiology. 71, Pt A, p. 101881
    https://doi.org/10.1016/j.canep.2020.101881

APPENDIX E: Requests for Information

Requests for Information

The NICR provided data and information for 133 requests in 2020, 49 (37%) general requests and 84 (63%) genetic requests (excluding local genetic requests) (***Figure 4***). A nurse from the Medical Genetics department deals with local genetic requests.

In 2020, 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 5***).

39% of general requests were received from academic researchers and charities (combined) (***Figure 6***).

On average general requests took 218 minutes to complete but ranged from 10 minutes to 3360 minutes (56 hours). Genetic requests took 33 minutes to complete however ranged from 10 minutes to 120 minutes. 98% of general requests were received via email (***Figure 7***) although 100% of genetic requests were received by letter (***Figure 8***).

Figure 4**: General and Genetic Requests received 2020**

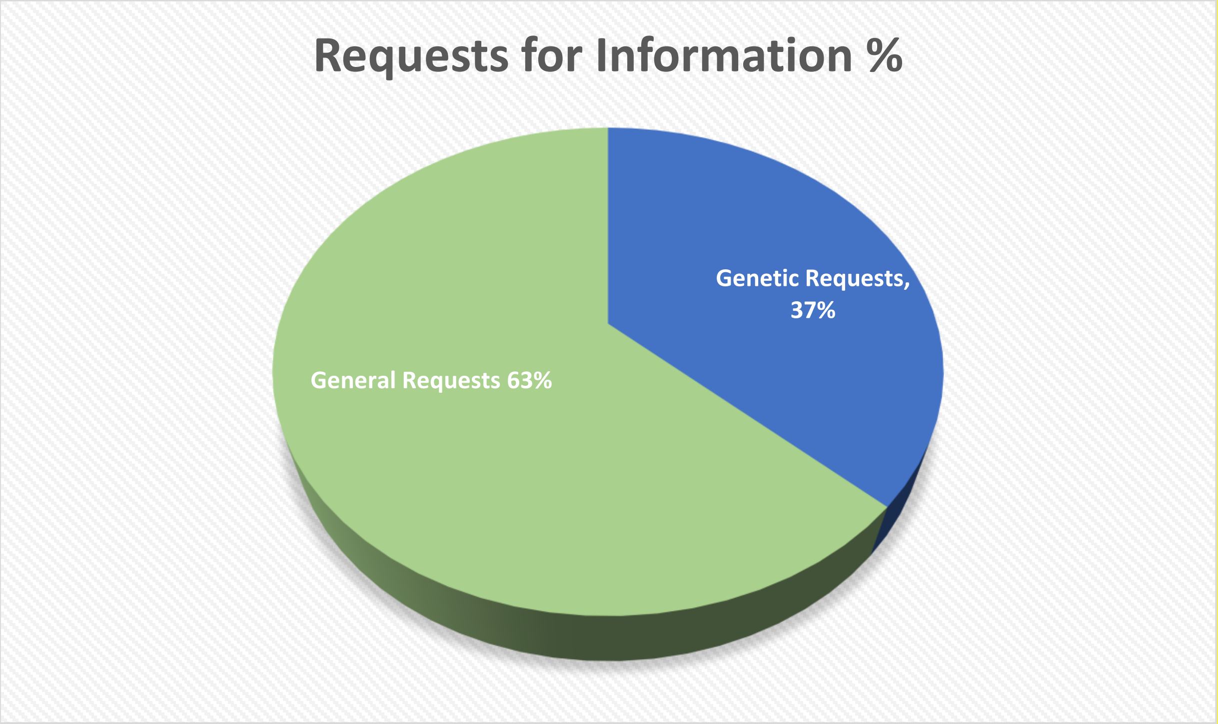


***Figure 5*: Percentage of requests completed within agreed timeframe**

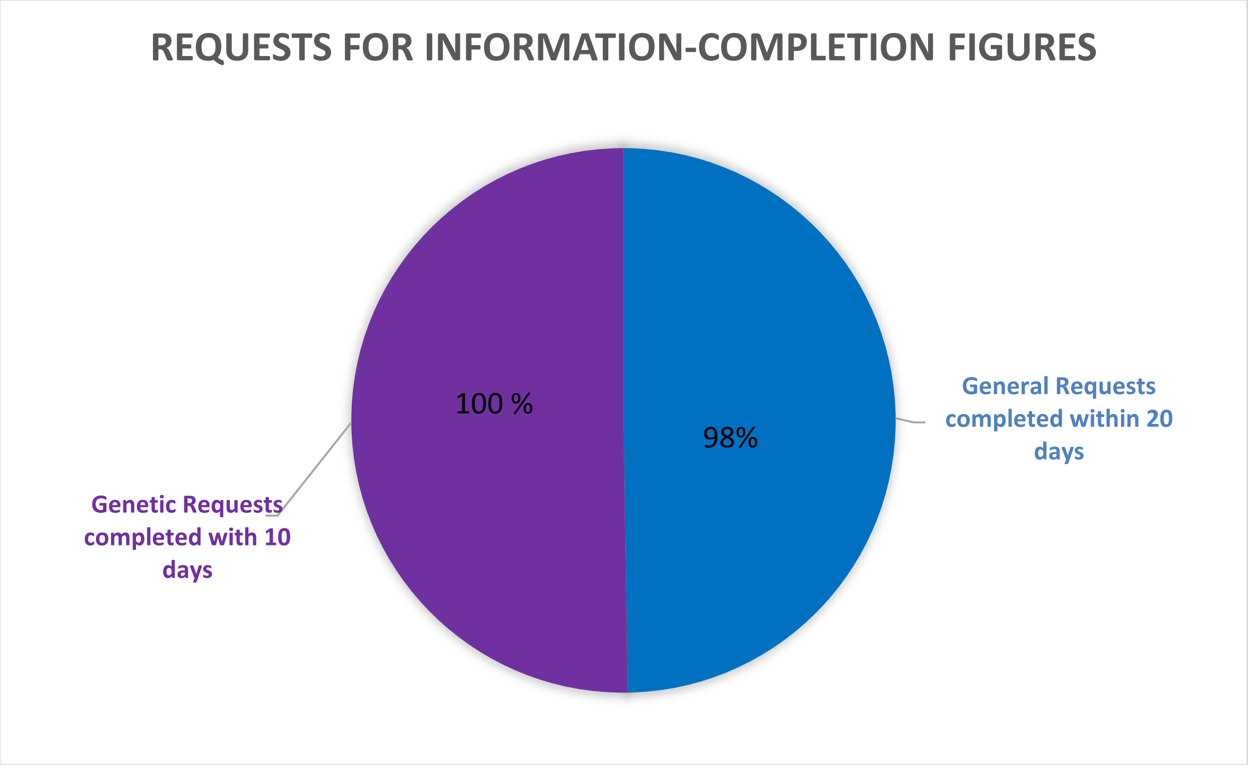


***Figure 6*: Source of Requests – General**

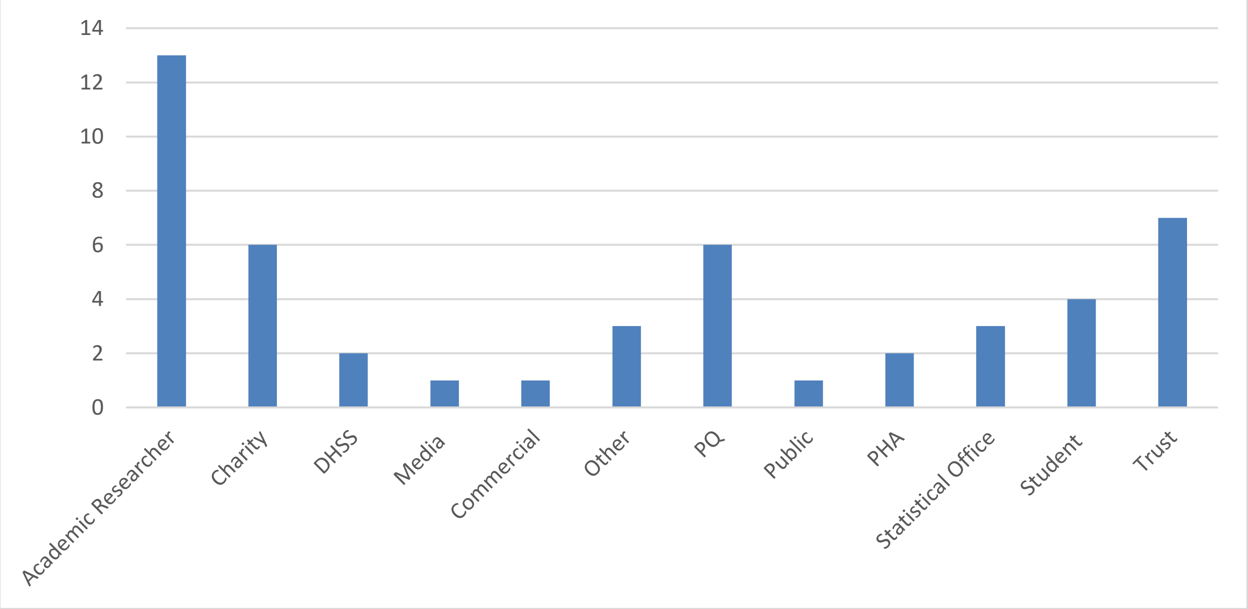


***Figure 7*: Method of Communication from Requestor – General Requests**

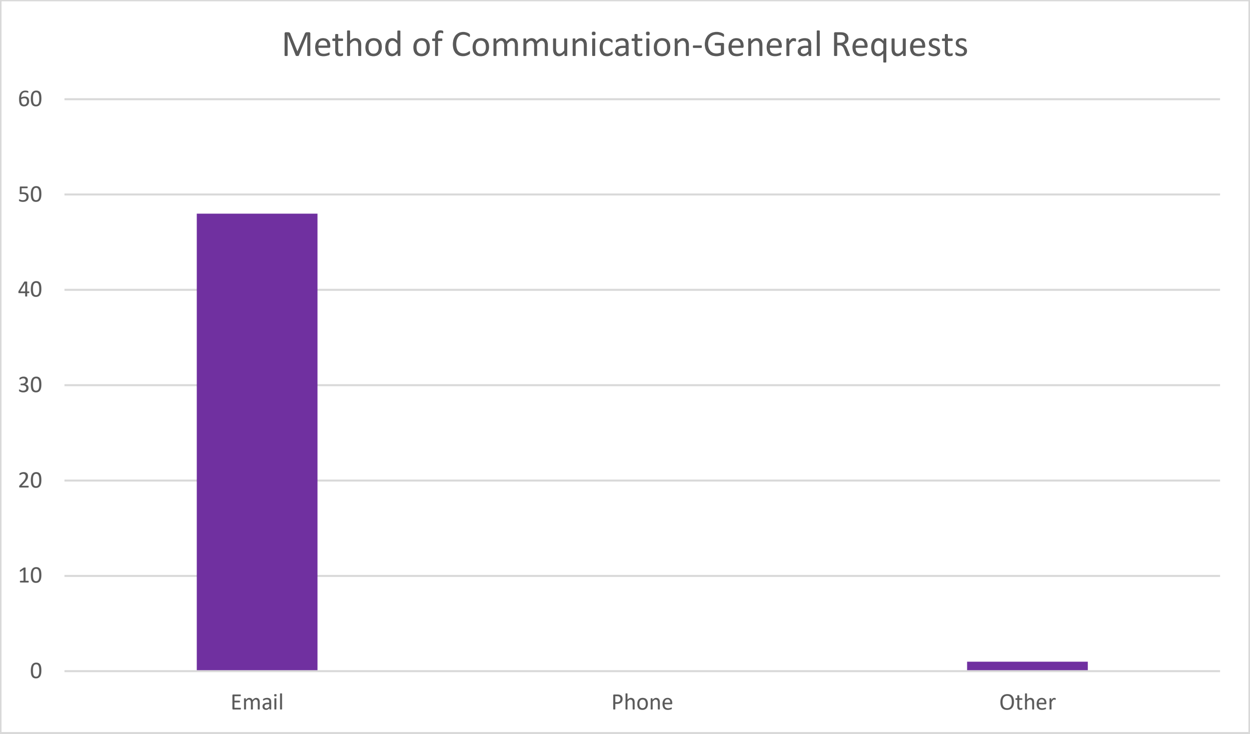
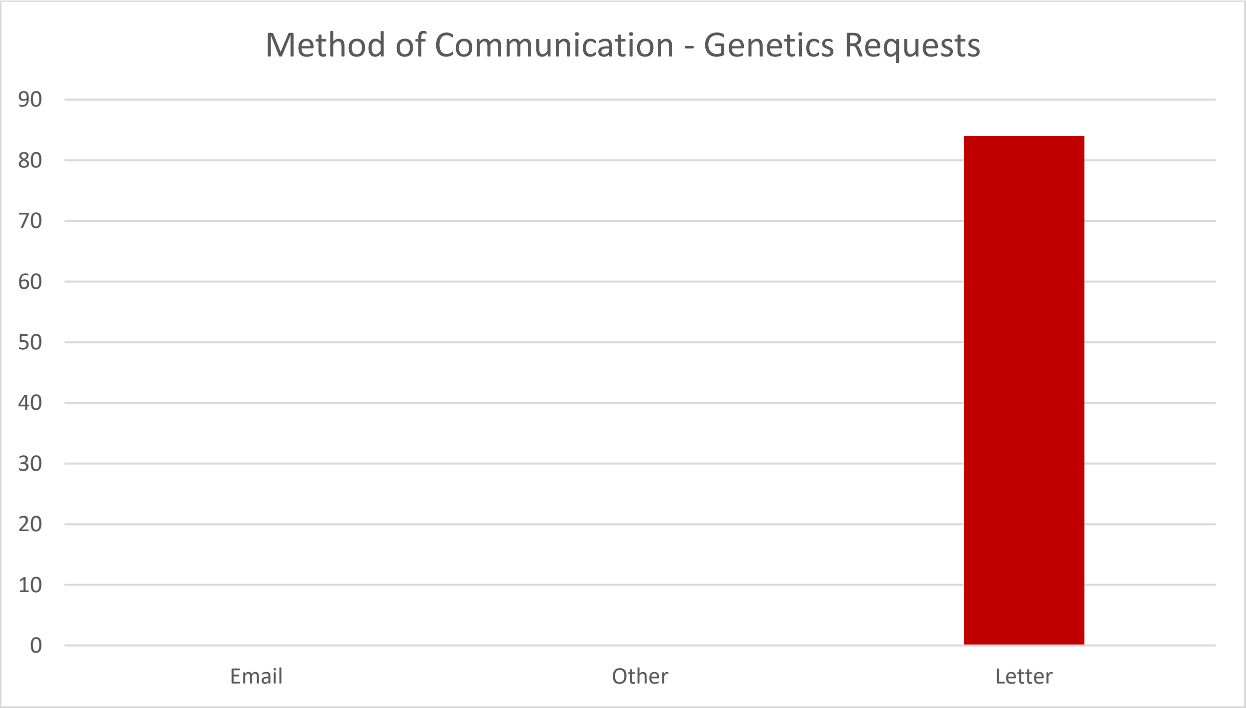


***Figure 8*: Method of Communication from Requestor – Genetics Requests**



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

TVO

- 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
- TVO Work allocation
- Induction – TVO specific
- Data Quality Checks
- Acknowledgements
- Quality Assurance
- Requests for Patient information from NICR database

- Request to remove Patient data from NICR database

Deadlines Dates

- Ethics
- Governance
- Agreements