Operational Plan 2020-2021

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 2019 - March 2020. 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
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
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
NCRAS	National Cancer Registration and Analysis Service
NMSC	Non Melanoma Skin Cancer
NI	Northern Ireland
NICaN	N. Ireland Cancer Network
NICE	National Institute for Health & Care Excellence
NICR	N. Ireland Cancer Registry
NINIS	N. Ireland Neighbourhood Information Service
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
QARC	Quality Assurance Reference Centre
QUB	Queen's University Belfast
RISOH	Regional Information System for Oncology and Haematology
RQIA	Regulation and Quality Improvement Authority
TNM8	International Union Against Cancer TNM Classification of Malignant Tumours Eighth Edition
TVO	Tumour Verification Officer
UKIACR	UK and Ireland Association of Cancer Registries

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 population 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 on the NICR website (http://www.qub.ac.uk/research-centres/nicr/).

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. (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 2018 NI had an estimated population of 1,881,641 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 twenty-five 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).

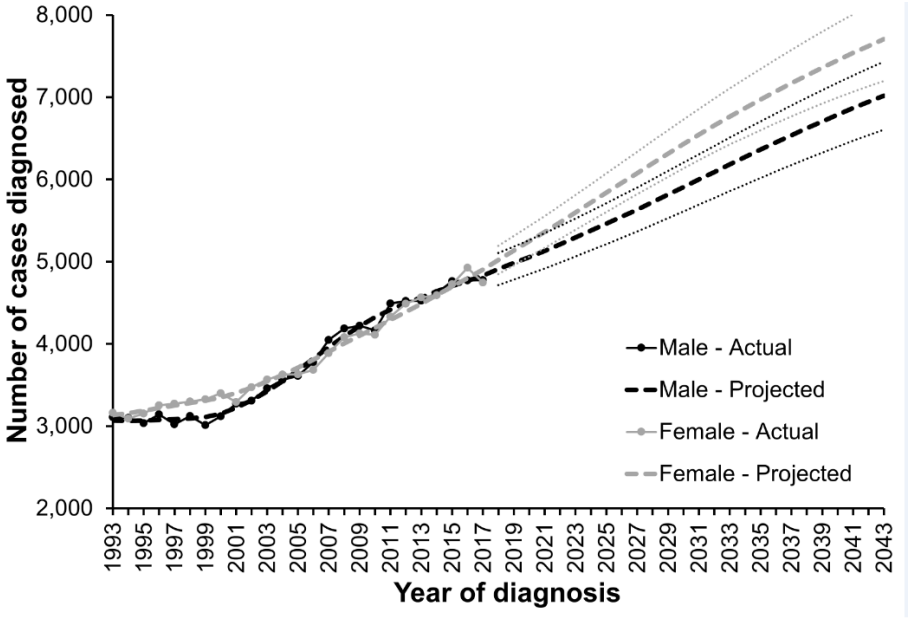


Figure 1: Cancer incidence projections for NI (excluding non-melanoma skin cancers)

Since the NICR began in 1993, 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 or not 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.

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, evaluation and planning.

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

The NICR has approval for its databases from the Office for Research Ethics Committees NI (ORECNI) Reference 15/NI/0203. An application for renewal is due mid-2020. Each research project using non-routine data is required to have separate ethical approval.

The NICR is registered under QUB with the 1984 Data Protection Act - Registration Number (QUB): Z6833827 and has undertaken a review to ensure compliance with the 2018 General Data Protection Regulations (GDPR) under QUB's registration. 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 with each of the NI Health and Social Care Trusts for data provision and with the Quality Assurance Reference Centre (QARC) for data on screening. 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 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).

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 www.qub.ac.uk/nicr.
- 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. http://www.bbc.co.uk/news/uk-northern-ireland-41273132).

1.9 NICR links with clinical teams by:

- Attending each NI Cancer Network (NICaN) Board meetings
- Attending each NICaN site specific Clinical Reference Group (CRG) meetings (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.

1.10 NICR links with researchers through:

- The Director and current Acting Deputy Director 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, undergraduate and postgraduate dissertations.

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 eg 2019-2020 Breast Treatment Services as required by the Department of Health (DOH).

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. 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 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 N Ireland Health & Social Care Trusts, QARC (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.

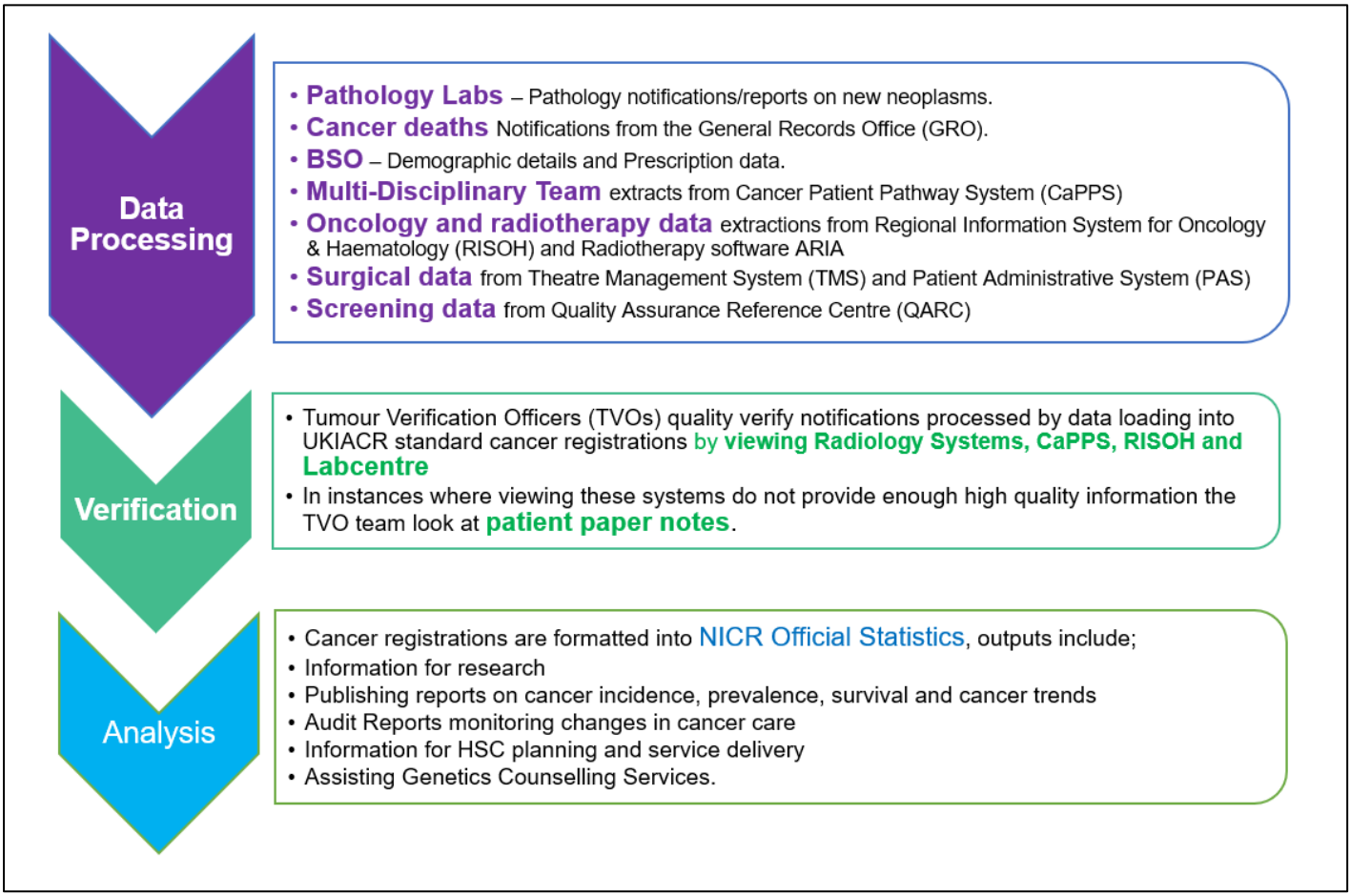
The NICR database is held on a standalone server within a highly secure area. This server has no connectivity to any external networks and levels of access are controlled by the use of biometric (fingerprint) authentication and passwords. Access is dependent on the user permission level – for example, 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.

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 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



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. We are exploring opportunities to use machine learning to identify key items for registration.

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 this 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 2 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.

Data Quality
In order to be assured 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.

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)
- Premalignant neoplasms of the cervix
- Hydatidiform mole
- 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 13,000 incident cases diagnosed in Northern Ireland since 1993. Barrett's Oesophagus is a pre-cursor condition for oesophageal adenocarcinoma and the register has provided data for publications of international standing. Current funding: Cancer Research UK; Historic funding sources: Cancer Focus NI http://www.cancerfocusni.org

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 http://www.ncbi.nlm.nih.gov/pubmed/26082403 in relation to type of polyps, and findings show that elevated cancer risk remains in patients who have undergone polypectomy. 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 http://www.cancerfocusni.org/

Endometrial Hyperplasia (EH)

This is a new population-based register of Endometrial Hyperplasia cases (PI: Prof Helen Coleman). 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.
Historic funding sources: 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.
Current funding source: Cancer Research UK/ Northern Ireland Department for the Economy PhD studentship

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 is capable of contributing to the international debate[14-23]. *Specific projects to clean and match the data held were funded via GAIN and RQIA.*

3. 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). 2017 staging for NICR data is 85.3%. 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. The report for the 2018 dataset will be available officially in summer 2020. Unfortunately The Republic of Ireland did not submit data for comparison due to the introduction of new IT systems and resource constraints. It is also likely that the COVID 19 pandemic may make it difficult for the full report on the 2018 dataset to be jointly completed by the UKIACR for its official date in summer 2020.

Data from the NICR registry have been accepted for Cancer Incidence in Five Continents (since volume VII published 2002), Concord International Cancer Survival Studies, International Cancer Benchmarking Partnership (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].

4. REGISTRY IT SYSTEM

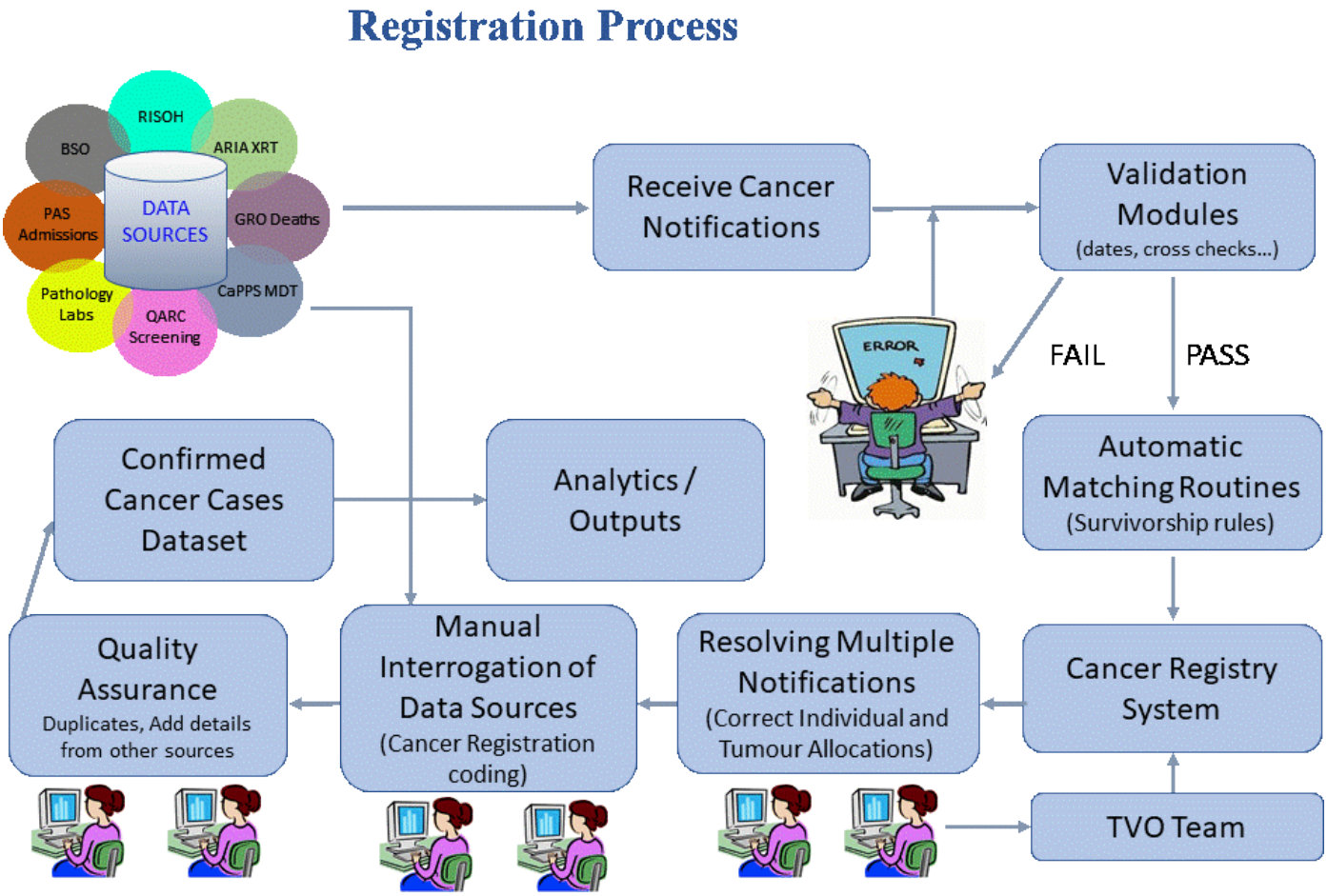
4.1 Background

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.

4.2 Development of a new Registry IT System

The registry developed a range of options which were discussed at the Registry Steering Group and while they recognised the need for a substantial investment the favoured option was to retain many of the features of the existing system such as automatic tumour matching while upgrading the system using a mix of in house resource and external consultancy.
The system development project plan was developed in April last year and is scheduled to run over a two year period. The project is currently running broadly according to the original plan. To date functionality has been developed to provide the patient and tumour matching modules in the original PRAXIS system although these will need further refinement. The developer is currently working with the business areas to create user interfaces which map the processes of the tumour resolving and data enrichment functions in the Registry. Database structures and data transfer mechanisms are also under development.
The project plan has been adjusted slightly to include some additional tasks to develop Admin/Super-user functionality interfaces. The application is estimated to be complete for the end of 2020. However as this coincides with PI's/Official Stats, User acceptance testing will be limited for the first few months of 2021. A full parallel rollout is scheduled for March 2021 with system go-live scheduled for April/May 2021.

4.3 Method of Data Processing



5. REGISTRY OUTPUTS

5.1 Official Statistics

Annually the NICR produce the Official Statistics on the incidence, prevalence and survival of cancer in NI. The Official Statistics for 2017 registrations were published on 12 March 2019 alongside the latest statistics on cancer mortality which are provided by General Registrar's Office Northern Ireland (GRONI).

Official Statistics for 2018 registrations were published 2 April 2020.

Cancer statistics for 34 cancer sites (including all cancers, with and without non-melanoma skin cancer) are available for viewing and download on the NICR website https://www.qub.ac.uk/research-centres/nicr/CancerInformation/official-statistics/.

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 constituency) and deprivation quintile. Cancer incidence trends and survival statistics spanning 1993-2018 are also available.

In 2017 Computer Science students worked with the NICR to enhance the accessibility of the Official Cancer Statistics on the NICR website http://www.med.qub.ac.uk/canstats.

5.2 Cancer Factsheets

The website, through its cancer factsheets, continues to be well used (see http://www.qub.ac.uk/research-centres/nicr/Publications/Factsheets/ and Appendix D for examples).
We now have 21 factsheets updated annually as new official statistics are released.
Detailed clinical factsheets are also prepared for the NICaN clinical groups upon request.

5.3 Information for General Practice

The NICR have prepared information at General Practice Federation level on cancer incidence, prevalence, emergency presentation (see http://www.qub.ac.uk/research-centres/nicr/Publications/MacmillanNICRPartnership/ .

5.4 Research Publications

Since January 2019, 16 peer reviewed publications using registry data have been produced (102 since January 2013) (Appendix E). Most recent scientific articles have a lay summary sheet, available at http://www.qub.ac.uk/research-centres/nicr/Publications/peer-reviewed-publications/.

5.5 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 2019, 100% of 71 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 worldwide services. 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 2019 the NICR completed 100% of 107 genetic information requests received from outside Northern Ireland within this time-frame (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.

5.6 Reports

The NICR has produced 27 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. (http://www.qub.ac.uk/research-centres/nicr/Publications/).

5.7 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 2015 (http://lcini.macmillan.org.uk)
- 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 expected late 2020.

5.8 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. Macmillan have indicated their wish to extend this partnership for a further two years.

- 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. Work however is ongoing on publications.

- NICR continues to provide clinical data to approved NI Biobank studies as required.

Projects facilitated within NICR by external researchers

- Incident and mortality dataset for 2017 – CRUK: Dr Yannis Kotritsios
- UK Neuroendocrine Study – PHE: Tracey Genus
- Emergency Admissions at End of Life-Costs Analysis – CPH: Dr Ethna Ferran
- NI Health and Social Care Inequalities Monitoring System Cancer Dataset – DoH: Hannah Blakely
- UK wide analysis of liver cancer – NCRAS, PHE: Anya Burton
- National Mesothelioma Audit – Royal College of Pathologists: Rachel Tebay
- A population-based study of the relationships between synchronous breast cancers – opportunities for personalised surgery: Dr G Dobson & Dr S McIntosh
- Surgical under-treatment of older adult lung, colorectal and breast cancer patients: Dr A Q Akinoso-Imran & Dr Finian Bannon
- Pathways to cancer diagnosis – Monitoring variation in the patient journey across Northern Ireland: Dr H McKenna & Dr Finian Bannon
- Identifying the immunological subtypes of pancreatic adenocarcinoma and determining if these have prognostic significance in terms of disease free and overall survival: Dr A McGuigan
- The International Breast Cancer Intervention Studies: Prof J Cuzick
- Factors influencing emotional wellbeing and mental distress in older men in Northern Ireland and UK men who become unemployed and retire early following diagnosis of prostate cancer - Findings from the Population-based Life After Prostate Cancer Diagnosis (LAPD) Study: Dr D Bennett & Dr B Clarke
- National Registry for Radiation Workers: Dr Richard Haylock
- Children, Teenage and Young Adults (CTYA) cancer statistics annual report 2019: Dr Lucy Irvine
- Invasive, In-situ and thin melanoma in Europe-How and where are they increasing: Dr S Rosso
- Review of Breast Treatment in Northern Ireland for Department of Health

5.9 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 resulted in 19 reports, making recommendations for service improvement (each report is available on the NICR website www.qub.ac.uk/nicr). 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. In 2019 the NICR received additional funding from the PHA to undertake an audit of colorectal cancer. A report is expected late 2020. Funding was also received from Regulatory and Quality Improvement Authority (RQIA) to undertake an audit of Oesophageal cancers during 2020.
Data has also recently been provided for a UK wide audit of Mesothelioma.

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 GP's 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

6. ISSUES OF CONCERN/CHALLENGES FOR NICR

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

6.1 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.

6.2 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 recommended an immediate injection of £60,000 to facilitate its development.

6.3 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 2019/20, approximately 93% of funding was spent on staff. Detail of the amount of funding for each forthcoming year arrives late meaning that planning for the forthcoming year is hampered. There are also additional pressures of (1) incremental staff pay awards and (2) a significant rise in employer contributions and pension increases in 2020/2021 and 2021/2022 which cannot be avoided. In the 2019/2020 budget the PHA provided additional funds to cover the increased pension contributions.

6.4 Current Recruitment Processes Related to Grading of Tumour Verification Officer (TVO) Staff

- Recruitment of staff is via QUB Personnel Department. The annual nature of the funding means that positions can only be advertised as short-term maximum 12 month contracts in the first instance with potential for renewal. This restricts the field of applicants.
- Recruitment processes are slow, often taking several months, as within QUB guidelines the positions are advertised on the QUB redeployment intranet. If unsuccessful the QUB Boarding Scheme, a scheme whereby clerical staff are recruited in batches based on generic clerical job descriptions, is consulted. Usually those on the Boarding Scheme do not have the skill set for a TVO post as this is very different to that required for a clerical post, and we then must often advertise externally. This process can take up to one year.
- The work of a Tumour verification Officer (TVO) is complex, with decision making based on data from several different clinical systems. Considerable knowledge of anatomy, physiology and cancer registration rules is required which takes extensive continuous training. We are currently consolidating evidence for a review of the post grading within QUB.
- Recently Public Health England developed an accreditation for their Tumour Registrars. However, the course and accreditation is based on their Encore Registration system and not transferable to Northern Ireland. However, they have extended access to their online cancer registration training site, MylearningSpace, and also opened attendance to their annual training conference to NICR staff. Both of these have been invaluable training resources for NICR staff, ensuring a communal approach to cancer registration.

6.5 Maintaining Access to Data Sources

- 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 review and should be facilitated by the introduction of Encompass. This will require input from NICR staff.
- We face challenges to ensure continued access to datasets as systems change within the Trusts. This was highlighted by the change from COIS to RISOH. We are concerned that the introduction of Encompass will result in further difficulties for the NICR in accessing datasets essential for accurate and timely registration of cancers. The introduction of regulation for Secondary Use of Data will hopefully take place soon and help the situation.
- Compliance with the General Data Protection Regulations (GDPR) has significantly increased the work of the NICR in relation to data processes, development of data access agreements etc. This requires additional resource.
- Gaining access to Primary Care Electronic Care Record (ECR) would enable a more efficient and complete registration system. However, this is currently not possible. The ECR was introduced under strict terms of only being available for direct Patient Care and holds information on all primary care consultations. Access to this system would be very beneficial to the NICR as it could provide additional information such as lifestyle factors (smoking history, alcohol consumption), signs and symptoms, delays in access to diagnosis, anthropometric data (e.g. body mass index) and detailed information on co-morbidities which are important in determining aetiology and delays, evaluating impact on prognosis, adjustment to survival calculations and in the determination of risk prediction modelling from premalignant disease to cancer. These data, if recorded, are currently available to NICR staff through access to clinical notes, which is time consuming/expensive but is required for clinically meaningful audits and to enable national comparisons.
- We would like to have Safe Haven status to ensure continued access to clinical information required for cancer registration.

6.6 Loss of Historic PSA Database

- The NICR has recorded information on all PSA tests occurring in the population since 1993. This has facilitated research and publications which have added to the debate about PSA testing for prostate cancer ([refs 14-23]). It was recently the basis of an audit of PSA testing in General Practice.
  However, following recent discussions with Primary Care and the NI Privacy Advisory Committee, the NICR has been advised that it can only hold anonymised data on PSA tests, except for patients with prostate cancer. This is because those people on the database have not had the option to 'opt out'. We are in further negotiation about this and have adapted the patient information leaflet to include the PSA database. We await clarification via the regulations for Secondary Use of Data 2016 Act.

6.7 National 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. 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 Audit. There are National Audits for Lung Cancer, Bowel Cancer, Head and Neck Cancer, Oesophageal Cancer and Prostate Cancer.

- However, as it currently stands, despite the achievement of Royal Assent for a Health and Social Care Secondary Use of Data legislation in April 2016, we do not have active legislation to cover such data transfers. This issues has been actively raised with the current Minister of Health.
- The NICR has been involved in local NI cancer audits with the recent Lung audit and Head and Neck audits and an ongoing Colorectal audit including comparisons with data from the rest of the UK without transfer of patient level datasets. The NI Clinical Reference Groups (CRGs), have expressed positive interest in having NI data available for comparison. The NICR, which already records many clinical aspects, could with additional resources, prepare datasets and reports enabling NI data to be compared in national audits.
- NICaN cancer site Clinical Reference Groups (CRGs) have accepted that they need to agree a minimum dataset and begin collecting key clinical data items; however they expressed that with their current workloads, they will require additional resources to help them. The CRG's expressed concerns that by not having their data a part of a National Audit their surgical registrations are at risk. Audit minimum datasets are included in the CaPPS MDT system however, these are not mandated fields so were not completed. We are actively working with Encompass to ensure minimum cancer datasets are included.

6.8 Accommodation

The NICR is located in accommodation identified by QUB for refurbishment, to facilitate the designation of secure areas and modern working. Changes agreed will ensure ongoing confidentiality of datasets while future proofing for expansion. The decant is planned for late 2020, with the expectation that the redevelopment of the current NICR accommodation and the additional floor space will provide a more open plan, adaptable environment in 2021. This reflects a delay due to the COVID-19 pandemic.

6.9 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. A recommendation from the review is the development of Standard Operating Procedures (SOPs). A list of SOPs to be drawn up was developed at the March 2019 planning day (see Appendix G). While some have been completed, others remain for action over the next year 2020-2021.

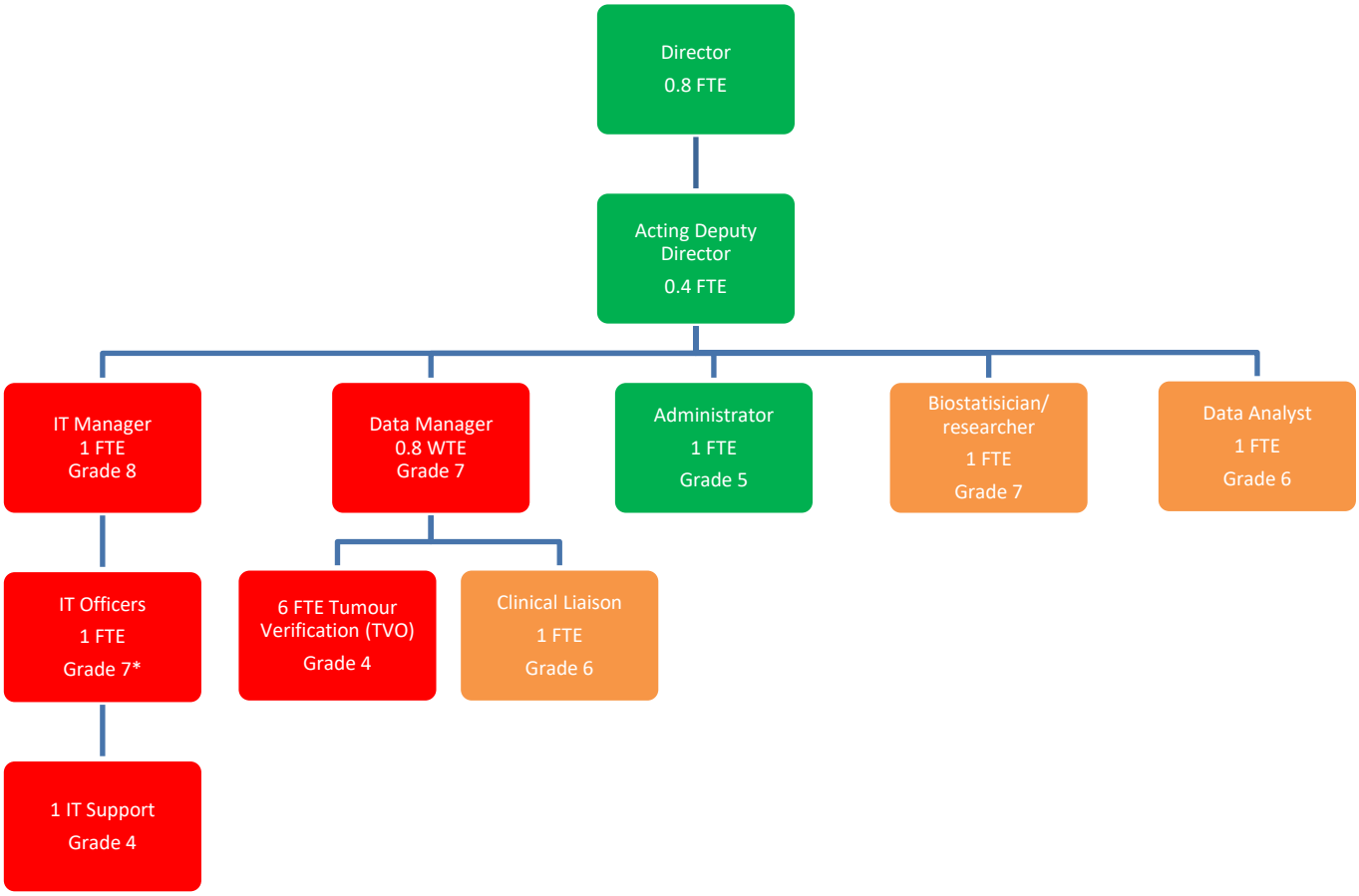
The post of Director will become vacant August 2022 and there is an urgent need to advertise for an acting deputy director as the current post holder is moving to another academic institution.

7. NICR RESOURCES

7.1 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. This funding has remained stable over the three years 2015-2018 at £810,112 with a significant proportion of the budget now spent on staff salaries, 93% including 12.5% overhead to the University on staff (except Director and acting deputy Director who are directly involved in teaching, supervision and University administrative duties). In 2018/19 the NICR received an uplift £13,448 with an additional uplift of £21,413 in 2019/20 to cover the increase of University Staff pensions contributions.
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 2020-2021.

Figure 1: Current PHA funded staff 2019-2020



***with project specific acting up allowance for system development**
WTE = Whole Time Equivalent
FTE = Full Time Equivalent

In Addition

- Cancer Focus has funded a recently appointed Post-Doctoral 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 – contract paused due to COVID-19
- NI Biobank fund 1 FTE TVO

- The PHA provided additional funding to undertake Colorectal and Mesothelioma Audits in 2019/20 and RQIA has funded an audit of Oesophageal cancers 2020-2021 likely to commence October 2020

In 2019/2020 and again in 2020/2021 there will be significant changes to pension contributions for Staff Grade 6 and above. This is will add £12,043 to 2019/2020 budget and an additional £9,225 in 2020/2021. The budget allocation for 2019-2020 included an uplift of £21,413 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.

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

To cope with the workload and to enable a better Registry structure the following funding 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 data manager estimated at grade 8, £19,815 from within existing staff compliment and funding
- 5 TVOs re-grading to grade 5 – current grade 4 estimated £19,664
- 1 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
- 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 funded from Audit grants.

Total required for restructure is £59,549 (£19,815 + £19,664 +£10,035 + £10,035) 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.

7.2 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
Total Core Work	**£820,112***	**£820,112***	**£ 823,560**	**£844,973**

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

7.3 Other funding

In addition to the allocation from the PHA the Registry has two live research/audit projects (Macmillan and Colorectal) (Table 2).

Table 2: Research/Audit Expenditure relating to projects active during the period 1 April 2018 – 31 March 2020

	Start Date	End Date	Total Budget	Expenditure up to 31/03/20	Balance c/f 2020/21
Macmillan*	01/04/16	31/03/20	£241,226	£220,787 (£20,439 returned to Macmillan)	£ 0
Colorectal Audit	01/11/19	31/03/20	£81,531	£81,531	£0
Oesophageal Audit**	01/10/20	31/09/21	£30,000	£0	£30,000

* Macmillan have indicated they wish to extend the contract for a further 2 Years but are currently unable to undertake this expenditure

** Delayed until Autumn 2020 due to the COVID-19 pandemic

8. KEY PRIORITIES FOR 2020/2021

The list of NICR achievements in 2019/20 are highlighted in Appendix H.

The key priorities for 2020/2021 are:

1. Provide accurate, timely data on cancers in NI for official statistics by April 2020 for patients diagnosed in 2019.
2. Continue to provide a data request service including for genetic requests and alleged cancer clusters within timeframes.
3. Provide NI datasets for international comparisons e.g. Eurocare, Concord, ENCR, ICBP.
4. 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.
5. Maintain our ISO27001 Certification in Information Security Management certification
6. Continue with upgrades to the Registry IT System and extend its capacity to store data items.
7. Enhance datasets available to and recorded by the Registry e.g. comorbidities, tumour markers, recurrences and premalignant diseases.
8. Continue to undertake feedback to clinicians.
9. Work with clinicians, RQIA, NICaN and PHA to undertake local audits and achieve inclusion of NI data in National Clinical Audits.
10. Provide data for UKIACR annual Performance Indicators.
11. Maintain up to date, accessible and accurate information on cancer available for the public, charities, media etc.
12. Continue to work with external researchers to enhance cancer research in NI.
13. Contribute to the development of the NI Cancer Strategy 2020.
14. Develop a suite of Standard Operating Procedures for the Registry.
15. Review job profiles to identify key roles and best structure for NICR.
16. 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 2019/20 this included;

- Intense work for Cancer Strategy which provided new information on cancer projections, and analysis of comorbidities and second cancers.
- A significant piece of work for DHSS required PHA work on Breast Cancer Treatment.
- Provision of data for a UK Mesothelioma audit.
- Working at short notice to undertake an audit on Colorectal Cancers.
- Preparation for 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.

The detail of these Key Priorities 2020-2021 is included in the following Table 3:

Table 3: Targets of NI Cancer Registry for 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	
c) Prepare the data for 2019 data for launch as official statistics in 2021	
d) Provide accurate Northern Ireland cancer datasets for international comparison including new call for Concord Venus Project	
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	
f) Develop a Registry Manager – oversight role	
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	
h) Consolidate links with RISOH system to ensure relevant clinical information is available to NICR	
i) Consolidate link to Radiology systems to enable the interrogation of imaging reports	
j) Work on updating the cancer factsheets to they become more interactive in the online version	
k) Further investigate the provision of appropriate and faster network links to Health & Social Care (HSC) network	
l) Review history data to assess and correct map to/translate from previous versions of coding systems used to record cases. This work is essential for accurate measurement of trends, projections and investigation of alleged clusters	
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	
n) Assess the Registry resource requirements to maintain current standards of timeliness, completeness and accuracy in views of increasing numbers of cancer cases	
o) Provide data for UKIACR annual Performance Indicators within timescale	
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	
Goal 2 – Protect the confidentiality of the data	
a) Maintain ISO27001 Certification in Information Security Management for NICR	
b) Ensure staff training is maintained	
c) Ensure research projects adhere to the NICR & QUB Research and GDPR directives	

Targets 2020-2021	Update
d) Ensure that all relevant research projects have ethical approval prior to commencement	
e) Ensure that the move associated with accommodation decant and refurbishment within QUB achieves maximum security and assures data confidentiality	
f) Ensure that the new IT 'CENTRIS' maintains data confidentiality	
g) Investigate remote working options during COVID-19	
h) Develop a home working policy	
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	
b) Expand database to include additional items e.g. HER2, ER, PR, PSA, molecular markers, recurrences and others are recorded on the patient record	
c) Work with existing breast and colorectal cancer datasets to extract and analyse information on recurrences	
d) Adapt the current IT system to record TNM 8	
e) Integrate the cancer staging tool assessment and addition to CENTRIS	
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	
Goal 4 – Provide a cancer intelligence service	
a) Introduce full ICDO3 & TNM8 coding	
b) Answer all data requests within time limits of 20 days for general requests and 10 days for genetic requests	
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	
d) Feedback research findings to relevant partners and associated patient groups	
e) Ensure website is kept up to date	
f) Enhance visibility of Official Cancer Statistics on webpage	
g) Work to achieve additional resources to provide Northern Ireland data for peer review and national audits Oesophageal and Pancreatic Cancer Audits	
h) Work to provide information for outcomes of care as required by PHA, NICaN and Trusts	
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
k) Registry to investigate providing information on route to diagnosis and various other relevant metrics e.g. survival related to this	
l) Ensure each NICaN Clinical Reference Group and NICaN Board have attendance from NICR	
m) Ensure a lay summary of all Research Papers are included on NICR webpage	

Targets 2020-2021	Update
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	
b) Provide Core Audit required Datasets to Encompass	
c) Work to achieve resources to ensure that NI data are included in national audits	
d) Enhance availability of information on website and dissemination of data and reports through other online partners	
e) Provide copies of all publications to Public Health Agency	
f) Work with clinicians, NICaN/PHA to achieve inclusion of NI data in National Clinical Audits	
Goal 6 – Undertake and present internationally recognised research	
a) Apply for at least 1 research grant	
b) Submit 6 papers for peer review in high impact journals	
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	
d) Research Advisory Group to meet twice a year	
e) Ensure Data Governance for all data requests and projects	
f) Ensure NI provide relevant data for International Cancer Benchmarking Partnership (ICBP) studies	
g) Work to maximise outputs from Patient Reported Outcomes Measures (Life after Prostate Cancer Diagnosis - LAPCD) Study (externally funded)	
h) Submit abstracts and attend relevant conferences	
i) Work with NI Biobank and local researchers to enhance use of NICR data for scientific study	
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	
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	
b) Achieve temporary increase in budget to enable restructuring of NICR as outlined in this business plan	
c) Manage budgets from research grants	
d) Implement and monitor cost recovery/administrative policy to ensure resources are available for time consuming requests	
e) Involve staff in planning of targets for 2020/2021	
Goal 8 – Ensure the sustainability of the Registry	
a) Establish active contingency plans in case of loss of accommodation/operating system or staff	
b) Develop Standard Operating Procedures for NICR work	
c) Work to achieve the regulations for the Health and Social Care Secondary Use of Data 2016 Act legislation to cover disease registration	
d) Ensure staff are trained to a high level for their work	
e) Maintain a high registry profile locally and internationally	

Targets 2020-2021	Update
f) Achieve additional resources to cope with the increased workload, staff costs (pensions and increments) and complexities of data items	
g) Organise opportunities to highlight the work of the Registry to external groups	
h) Work to achieve succession planning for registry posts	
i) Maintain a risk register for the Registry for discussion at each steering group meeting	
j) Work with funders and QUB to have an updated contractual agreement for the NICR	
k) Minimise disruption to ongoing work during decant and refurbishment and off site working due to COVID-19 pandemic	
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	
b) Continue to involve patients as speakers/invitees at launch of reports	
c) Ensure that the Patient Information leaflet and poster is available on the internet and areas where cancer patients are treated	
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	
e) Provide regular inputs to the Knowledge Exchange website/database	
f) Ensure data available to the public on cancer in NI are up to date and accurate	
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	
b) Link nationally and internationally to promote cancer registration and increase understanding and control of cancer including promoting cancer staging tool	
c) Provide data for UKIACR Performance Indicators	
d) Work to have Cancer Staging Tool tested and disseminated internationally	
Goal 11 – Provide an environment for education and training	
a) Offer training slots to undergraduate/postgraduate students, Public Health trainees and F2 doctors	
b) Raise awareness of the Cancer Registry within the University and beyond	
c) Maintain international links on new developments in cancer registration and cancer research	
d) Facilitate medical/research staff with access to relevant registry datasets within confidentiality and ethical guidelines	
e) Ensure the Registry environment and processes support education and training while maintaining data security	

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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 Services Boards, Health and Social Care Trusts, Provider Organisations and the NI Cancer Network

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
Ms Roisin Foster	Cancer Focus NI, CEO of this cancer charity *until June 2020
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 Heather Monteverde	Macmillan Chief Executive, NI *until June 2020
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.

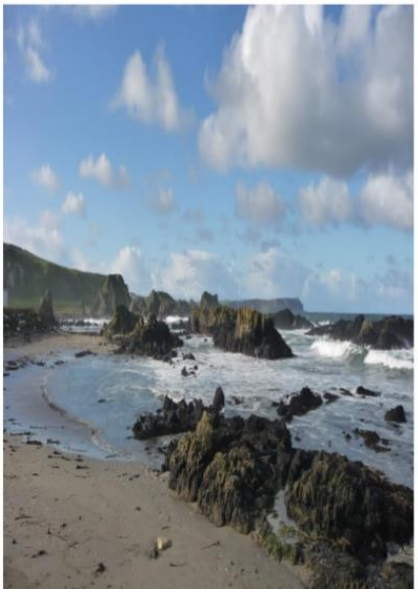
Prof Lesley Anderson	QUB, CPH
Dr Edward Goodall	NI Cancer Research Forum
Ms Dorianne Finlay	NI CRUK & Marie Curie
Ms Ashley Hurst	NI Cancer Research Forum
Dr Cherith Semple	Ulster University
Dr Nicola Armstrong	PHA
Dr Aidan Cole	Health and Social Care Trust/QUB
Dr Charlene McShane	QUB, CPH
Dr Olinda 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

HSC Public Health Agency

About Cancer Registration

A leaflet for patients



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:

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

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 2017

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

Indicator	Country average (population)	Country average (country)	England	Scotland	Wales	Northern Ireland
Stability: Percentage change (%) for all cancers (C00-C97 ex. C44) in 2017 compared with 2014-2016[1]	**0.2%**	**0.0%**	0.3%	-0.8%	-0.3%	0.6%
Registry Creep: Percentage (%) for all cancers (C00-C97 ex. C44) of 2016 registrations between 02/02/2019 to 01/03/2019 compared with registrations at 31/01/2018[7].	**1.6%**	**2.4%**	**1.4%**	**4.0%**	**1.6%**	**2.6%**
Staging: Proportion (%) of all cases (C00-C97 ex. C44) with valid known stage registered out of all 2017 registered cancers (C00-C97 ex. C44)[2]	**80.6%**	**78.6%**	**81.9%**	**67.5%**	**79.7%**	**85.3%**
Average of Core Patient Information Complete: Average percentage (%) of all cancers (C00-C97 ex. C44) registered with demographic information[3]	**98.6%**	**96.9%**	99.3%	96.5%	91.9%	100.0%
Average of Core Tumour Information Complete: Average percentage (%) of all cancers (C00-C97 ex. C44) registered with tumour information[4]	**97.3%**	**96.9%**	97.4%	96.1%	97.1%	97.2%
Diagnosing Hospital Known: Percentage (%) of all cancers (C00-C97 ex. C44) registered with an organisation of diagnosis	**97.7%**	**96.9%**	98.2%	93.0%	98.2%	98.1%
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%**	**1.3%**	**0.3%**
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%**	**1.3%**	**0.5%**	**1.6%**	**0.6%**

Microscopically Verified: Percentage (%) of all cancers (C00-C97 ex. C44) that are microscopically verified	**84.8%**	**84.3%**	**85.1%**	**82.1%**	**83.4%**	**86.3%**
Non Specific Codes: Percentage (%) of all cancers (C00-C97 ex. C44) that are microscopically verified with non specific morphology codes	**1.2%**	**1.3%**	**1.2%**	**1.1%**	**1.5%**	**1.6%**
Grade: Percentage (%) of all cancers (C00-C97 ex. C44) registered with a known grade	**59.6%**	**61.3%**	**59.4%**	**59.0%**	**61.1%**	**65.6%**
Treatment: Percentage (%) of all cancers (C00-C97 ex. C44) registered with any treatment	**86.6%**	**78.4%**	**89.2%**	**68.0%**	**84.8%**	**71.9%**
Breast Screening Data: Percentage of breast cancer (C50) cases from 2016 screen detected for ages 50-64[6]	**42.2%**	**48.2%**	**40.8%**	**48.0%**	**55.8%**	**NA**
Cervical Screening Data: Percentage of cervical cancer (C53) cases from 2016 screen detected for ages 25-60[6]	**28.6%**	**38.0%**	**25.6%**	**50.4%**	**NA**	**NA**
Bowel Screening Data: Percentage of bowel cancer (C18-C20) cases from 2016 screen detected for ages 60-69[6]	**4.4%**	**19.2%**	**0.0%**	**29.2%**	**28.4%**	**NA**

APPENDIX D: Factsheets from Official Statistics

All cancers excluding non-melanoma skin cancer [NMSC]

Number of cases per year (2014-2018) [1]			Number of deaths per year (2014-2018) [1]		
Male	Female	Both sexes	Male	Female	Both sexes
4,810	4,819	9,629	2,304	2,096	4,400
Five-year net survival (2009-2013)			**25-year prevalence (2018)**		
Male	Female	Both sexes	Male	Female	Both sexes
54.3%	58.5%	56.6%	28,937	36,785	65,722

Incidence

During 2014-2018:

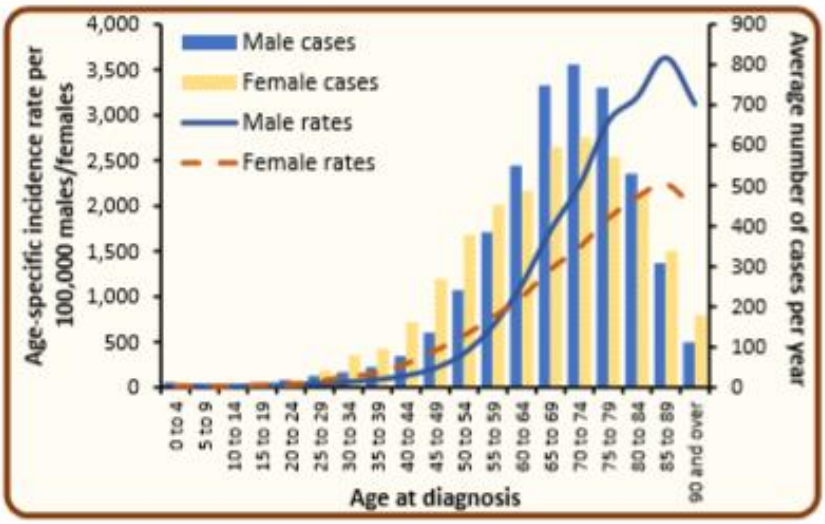
- There were 4,810 male and 4,819 female cases of cancer (ex NMSC) diagnosed each year.
- There were 670.3 male and 554.1 female cases of cancer (ex NMSC) per 100,000 males/females diagnosed each year.
- Cancer (ex NMSC) made up 68.5% of all male cancers, and 75.0% of all female cancers.
- The risk of developing cancer (ex NMSC) before the age of 75 was 1 in 3.5 for men and 1 in 3.7 for women.

Incidence by sex and age at diagnosis: All cancers (ex NMSC) 2014-2018[1]

During 2014-2018:

- The median age at diagnosis was 70 for men and 68 for women.
- Cancer risk increased with age, with 67.4% of men and 58.0% of women aged 65 years or more at diagnosis.
- 11.4% of cases were diagnosed among those aged under 50.

Age at diagnosis	Average cases per year		
	Male	Female	Both sexes
0 - 49	390	706	1,096
50 - 64	1,176	1,319	2,497
65 - 74	1,550	1,216	2,766
75 +	1,694	1,577	3,272
All ages	4,810	4,819	9,629



Incidence by sex and year of diagnosis: All cancers (ex NMSC) 2009-2018

- Among males the number of cases of cancer (ex NMSC) increased by 9.6% from an annual average of 4,388 cases in 2009-2013 to 4,810 cases in 2014-2018.
- Among females the number of cases of cancer (ex NMSC) increased by 11.3% from an annual average of 4,329 cases in 2009-2013 to 4,819 cases in 2014-2018.

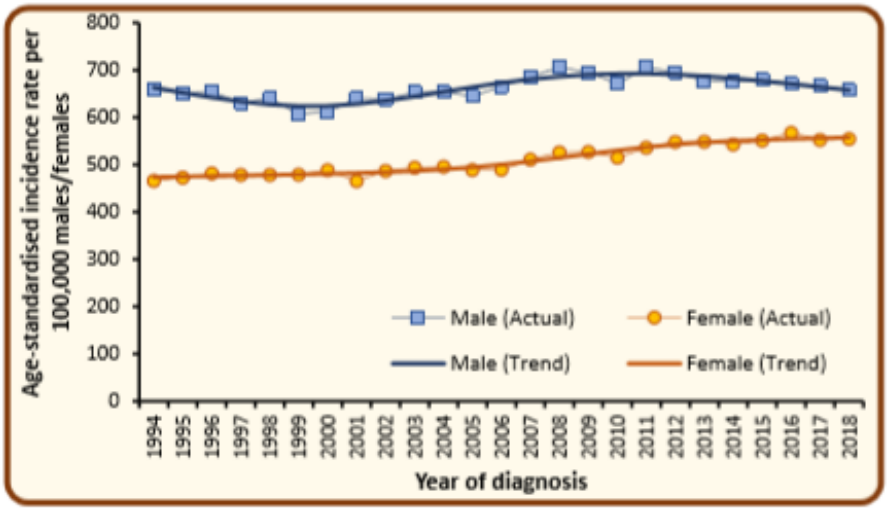
	2009	2010	2011	2012	2013	2014	2015	2016	2017	2018
Male	4,223	4,162	4,492	4,535	4,527	4,634	4,770	4,789	4,923	4,934
Female	4,133	4,111	4,332	4,494	4,576	4,593	4,729	4,937	4,874	4,963
Both sexes	8,356	8,273	8,824	9,029	9,103	9,227	9,499	9,726	9,797	9,897

1. Annual averages based upon several years have been rounded to the nearest integer. Sums of numbers in table rows or columns may thus differ slightly from the given total.
NMSC: Non-melanoma skin cancer

Trends in age-standardised incidence rates by sex: All cancers (ex NMSC) 1994-2018

- Among males age-standardised incidence rates of cancer (ex NMSC) decreased by 2.8% from 689.3 per 100,000 person years in 2009-2013 to 670.3 cases per 100,000 persons years in 2014-2018. This difference was statistically significant.

- Among females age-standardised incidence rates of cancer (ex NMSC) increased by 3.5% from 535.5 per 100,000 person years in 2009-2013 to 554.1 cases per 100,000 persons years in 2014-2018. This difference was statistically significant.

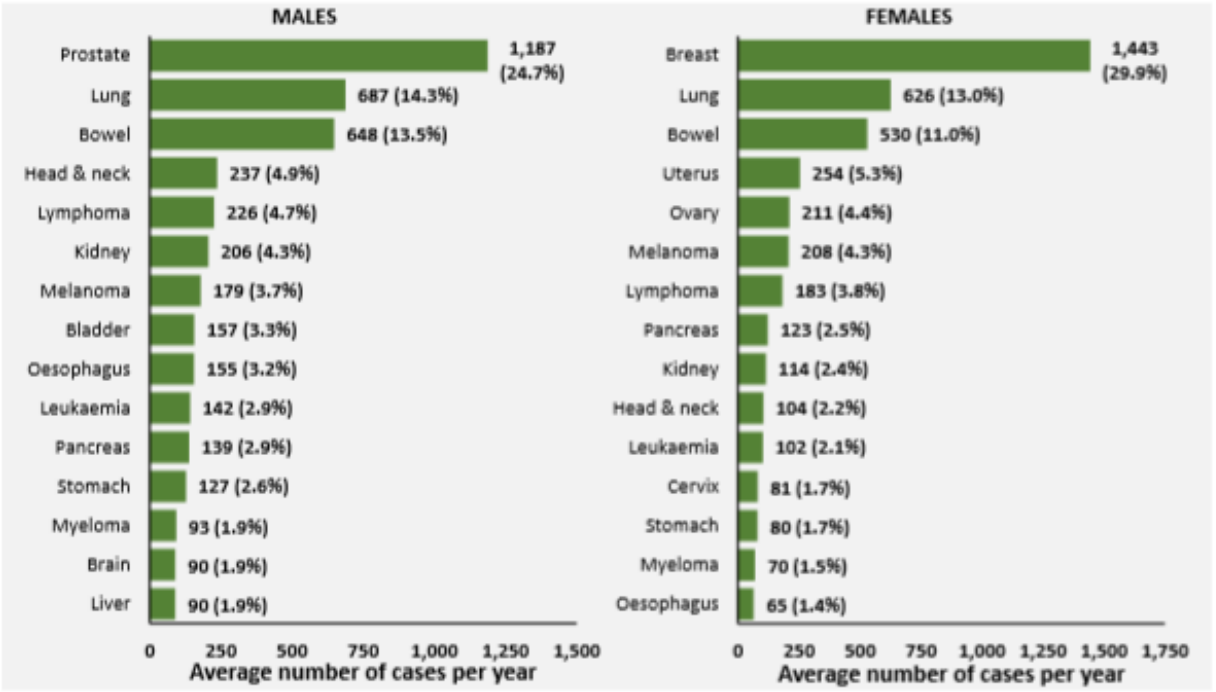


Age-standardised incidence rates illustrate the change in the number of cases within a population of a fixed size and age structure (2013 European Standard).

They thus represent changes other than those caused by population growth and/or ageing.

Incidence by sex and cancer type: All cancers (ex NMSC) 2014-2018[1]

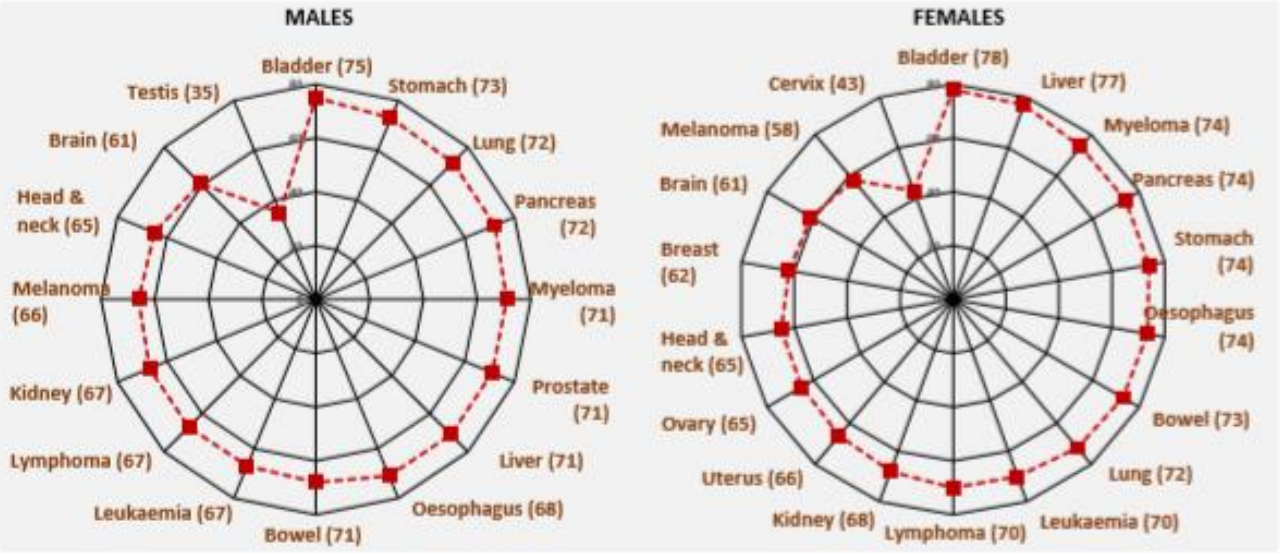
The most common cancer types among men (excluding NMSC), were prostate cancer (24.7%), lung cancer (14.3%) and bowel cancer (13.5%), while the most common cancer types among women (excluding NMSC) were breast cancer (29.9%), lung cancer (13.0%) and bowel cancer (11.0%).



1. Annual averages based upon several years have been rounded to the nearest integer. Sums of numbers in table rows or columns may thus differ slightly from the given total.
NMSC: Non-melanoma skin cancer

Median age at diagnosis by sex and cancer type: All cancers (ex NMSC) 2014-2018[1]

The median age at diagnosis for most cancer types during 2014-2018 was 65 years or more. Exceptions include testicular cancer (35) and brain cancer (61) among males, and cervical cancer (43), melanoma (58), brain cancer (61) and breast cancer (62) among females.



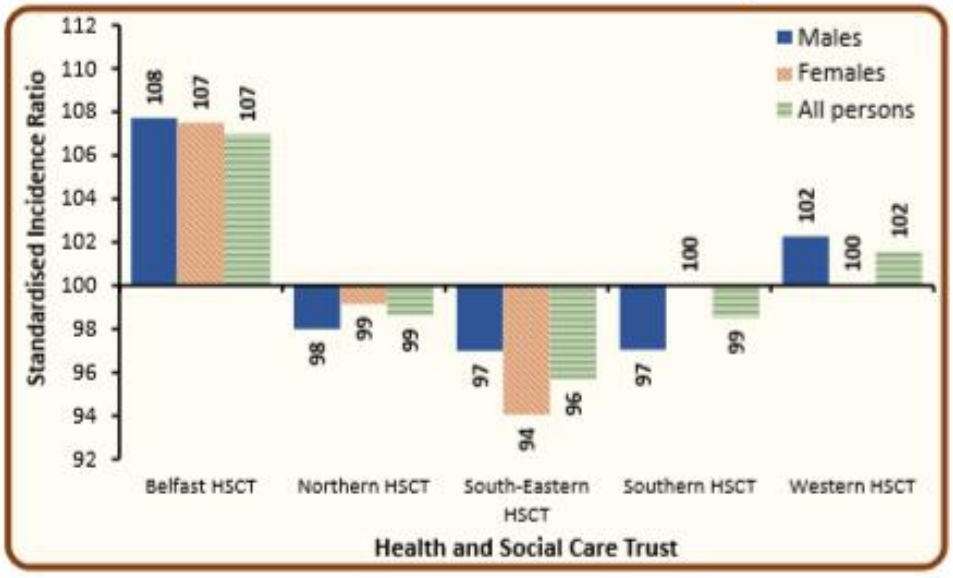
Incidence (cases and rates) by sex and Health and Social Care Trust (HSCT): All cancers (ex NMSC) 2014-2018[1]

The annual number of cases during 2014-2018 varied in each HSCT due to variations in population size and age (see table).

After accounting for these factors, incidence rates (see figure):

- in Belfast HSCT were significantly higher than the NI average.
- in Northern HSCT did not vary significantly from the NI average.
- in South-Eastern HSCT were significantly lower than the NI average.
- in Southern HSCT did not vary significantly from the NI average.
- in Western HSCT did not vary significantly from the NI average.

Health and Social Care Trust	Average cases per year		
	Male	Female	Both sexes
Belfast HSCT	915	992	1,907
Northern HSCT	1,258	1,259	2,517
South-Eastern HSCT	978	941	1,919
Southern HSCT	876	893	1,769
Western HSCT	782	734	1,516
Northern Ireland	4,810	4,819	9,629



Standardised incidence ratios compare incidence rates in each HSC Trust with the Northern Ireland incidence rate.

A value above 100 means that incidence rates in that HSC Trust are greater than the Northern Ireland average.

This measure takes account of population size and age structure. Differences are thus not a result of these factors.

1. Annual averages based upon several years have been rounded to the nearest integer. Sums of numbers in table rows or columns may thus differ slightly from the given total.
NMSC: Non-melanoma skin cancer, HSCT: Health and Social Care Trust

Incidence (cases and rates) by sex and deprivation quintile: All cancers (ex NMSC) 2014-2018[1]

The annual number of cases during 2014-2018 varied in each deprivation quintile due to variations in population size and age (see table).

After accounting for these factors, incidence rates (see figure):

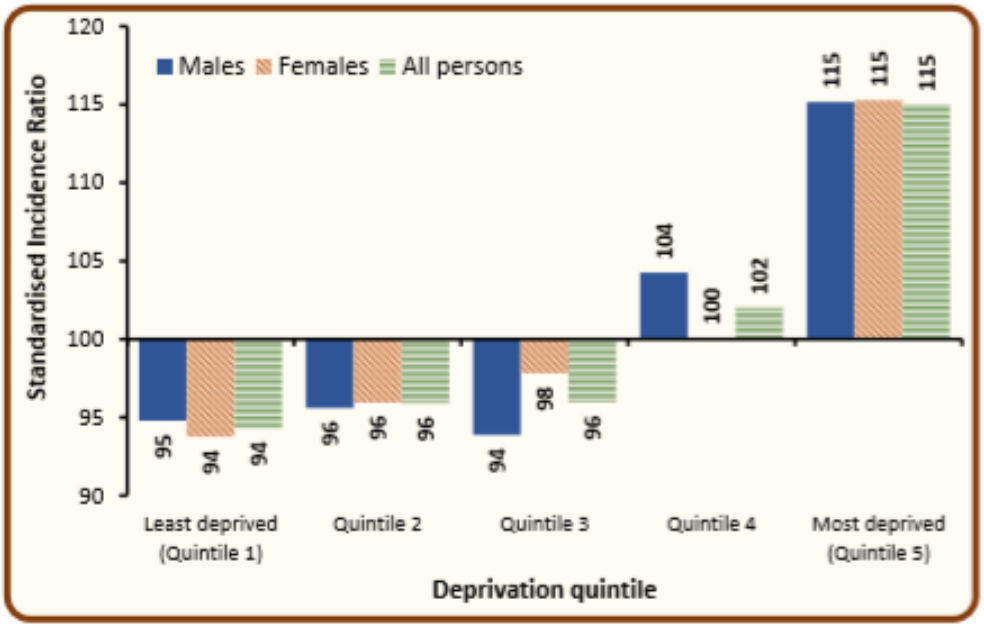
- in the most socio-economically deprived areas were 15.0% higher than the NI average.
- in the least socio-economically deprived areas were 5.7% lower than the NI average.

Deprivation quintile	Average cases per year		
	Male	Female	Both sexes
Least deprived (Quintile 1)	958	959	1,918
Quintile 2	979	968	1,947
Quintile 3	961	977	1,937
Quintile 4	1,004	970	1,974
Most deprived (Quintile 5)	908	944	1,852
Northern Ireland	4,810	4,819	9,629

Standardised incidence ratios compare incidence rates in each deprivation quintile with the Northern Ireland incidence rate.

A value above 100 means that incidence rates in that deprivation quintile are greater than the Northern Ireland average.

This measure takes account of population size and age structure. Differences are thus not a result of these factors.



Incidence by sex, cancer type and deprivation quintile: All cancers (ex NMSC) 2014-2018

While cancer incidence is higher in the most deprived communities overall, the relationship between cancer and socio-economic deprivation varies by cancer site. During 2014-2018:

- Incidence of head and neck cancer, oesophageal cancer, stomach cancer (male only), bowel cancer (male only), liver cancer, lung cancer, cervical cancer, kidney cancer (female only) and unknown primary cancer (female only) was higher in the most deprived areas than the NI average.
- Incidence of melanoma, prostate cancer and brain cancer (male only) was higher in the least deprived areas than the NI average.

Incidence rates higher in most deprived areas than NI average	Incidence rates higher in least deprived areas than NI average	Incidence rates not higher than the NI average in either the most or least deprived areas[2]
• Head and neck cancer	• Melanoma	• Pancreatic cancer
• Oesophageal cancer	• Prostate cancer	• Breast cancer
• Stomach cancer (male only)	• Brain cancer (inc. CNS) (male only)	• Uterine cancer
• Bowel cancer (male only)		• Ovarian cancer (inc. fallopian tube)
• Liver cancer		• Testicular cancer
• Lung cancer		• Bladder cancer
• Cervical cancer		• Lymphoma
• Kidney cancer (female only)		• Myeloma (inc. plasma cell)
• Unknown primary cancer (female only)		• Leukaemia

1. Annual averages based upon several years have been rounded to the nearest integer. Sums of numbers in table rows or columns may thus differ slightly from the given total.

2. These cancers can still vary in other ways by geographic area and/or deprivation quintile (e.g. by being higher than average in the middle deprivation quintile).

NMSC: Non-melanoma skin cancer, CNS: Central Nervous System

Survival

- 70.0% of patients were alive one year and 49.1% were alive five years from a cancer (ex NMSC) diagnosis in 2009-2013. (observed survival)
- Age-standardised net survival (ASNS), which removes the effect of deaths from causes unrelated to cancer, was 72.5% one year and 56.6% five years from a cancer (ex NMSC) diagnosis in 2009-2013.
- Five-year survival (ASNS) for patients diagnosed in 2009-2013 was 54.3% among men and 58.5% among women.
- Estimates for survival (ASNS) of patients diagnosed during 2012-2016 are 73.6% one year, and 57.6% five years from diagnosis.

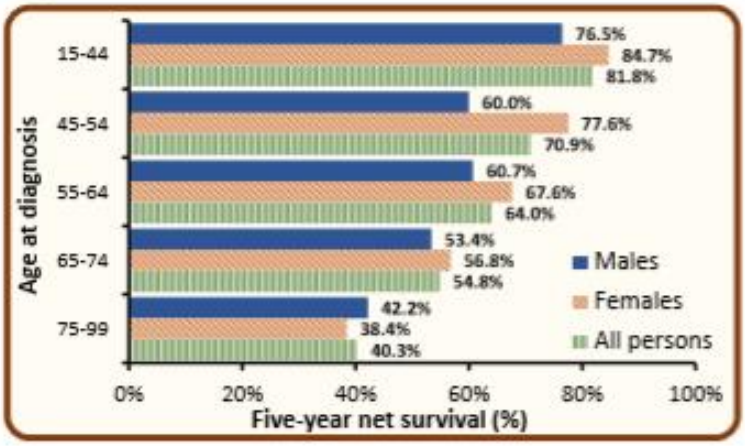
Period of diagnosis[1]	Gender	Observed survival		Age-standardised net survival	
		One-year	Five-years	One-year	Five-years
2009-2013	Male	67.9%	45.1%	71.2%	54.3%
	Female	72.1%	53.2%	73.3%	58.5%
	Both sexes	70.0%	49.1%	72.5%	56.6%
2012-2016 estimates	Male	69.6%	47.0%	72.9%	56.0%
	Female	72.4%	53.1%	73.8%	58.5%
	Both sexes	71.0%	50.1%	73.6%	57.6%

Observed survival is the proportion of patients still alive one/five years after diagnosis. However, in this measure patients may have died from causes unrelated to their cancer.

Age-standardised net survival is the proportion of patients who would survive if the patient could not die from causes unrelated to their cancer. This measure is more typically used in studies of cancer survival.

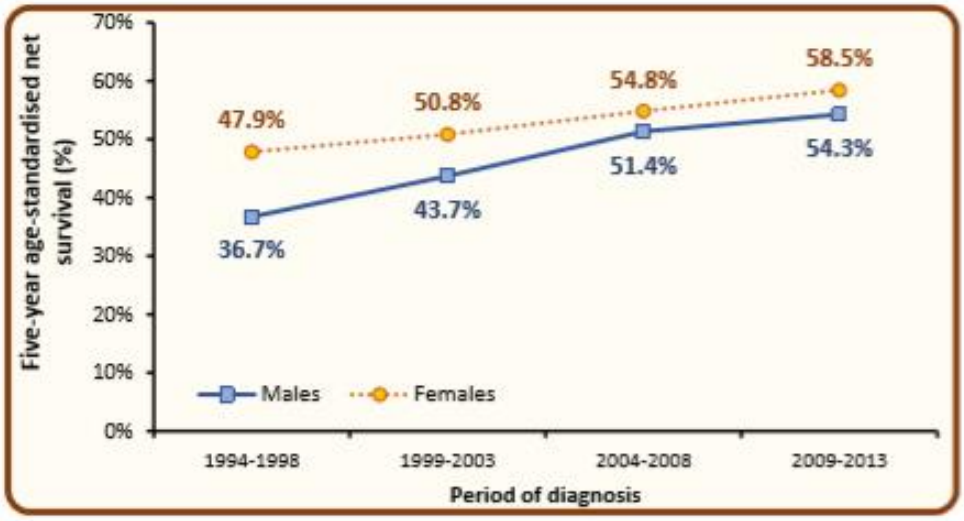
Survival by sex and age at diagnosis: All cancers (ex NMSC) 2009-2013

- Survival from cancer (ex NMSC) is strongly related to age with five-year survival decreasing as age increases.
- Five-year net survival ranged from 81.8% among patients aged 15-44 at diagnosis to 40.3% among those aged 75 and over.
- Five-year net survival among patients aged 75 and over was 42.2% for men and 38.4% for women.



Trends in age-standardised net survival by sex: All cancers (ex NMSC) 1994-2013

- Among men five-year survival (ASNS) from cancer (ex NMSC) increased from 36.7% in 1994-1998 to 54.3% in 2009-2013. This difference was statistically significant.
- Among women five-year survival (ASNS) from cancer (ex NMSC) increased from 47.9% in 1994-1998 to 58.5% in 2009-2013. This difference was statistically significant.

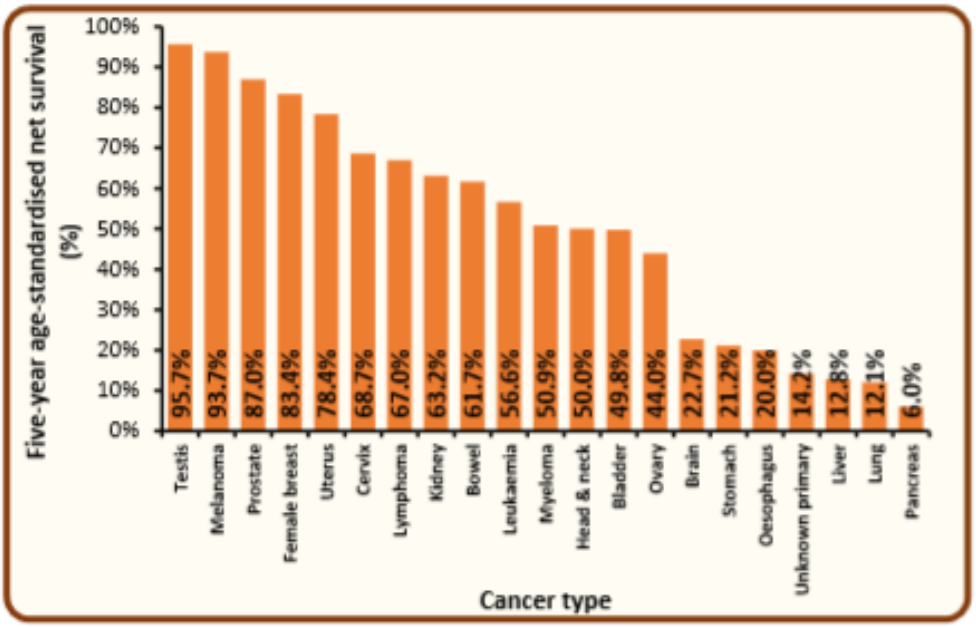


1. Five-year survival for 2012-2016 are estimates as not all patients have five years worth of follow up.

NMSC: Non-melanoma skin cancer, ASNS: Age-standardised net survival

Five-year survival by cancer type: All cancers (ex NMSC) 2009-2013

- Five-year survival (ASNS) for patients diagnosed in 2009-2013 ranged from 95.7% for testicular cancer to 6.0% for pancreatic cancer.
- In particular five-year survival (ASNS) for the most common cancer types was:
  - 83.4% for female breast cancer.
  - 61.7% for bowel cancer.
  - 12.1% for lung cancer.
  - 87.0% for prostate cancer.



Five-year survival by cancer type, sex and period of diagnosis: All cancers (ex NMSC) 2004-2013

- Five-year survival (ASNS) showed significant improvement between 2004-2008 and 2009-2013 for all cancers (ex NMSC) and bowel cancer among males and for all cancers (ex NMSC), bowel cancer and kidney cancer among females.
- Five-year survival (ASNS) did not decrease significantly for any cancer site between 2004-2008 and 2009-2013.

Cancer type	Sex and period of diagnosis			
	Male		Female	
	2004-2008	2009-2013	2004-2008	2009-2013
All cancers (ex NMSC)	**51.4%**	**54.3%***	**54.8%**	**58.5%***
Head and neck cancer	56.0%	49.7%	57.0%	51.3%
Oesophageal cancer	17.0%	19.0%	16.4%	23.4%
Stomach cancer	15.1%	21.0%	21.7%	21.9%
Bowel cancer	53.8%	61.6%*	55.2%	61.9%*
Liver cancer	6.2%	12.2%	5.8%	15.7%
Pancreatic cancer	4.8%	4.7%	4.9%	7.5%
Lung cancer	9.3%	11.2%	11.2%	13.2%
Melanoma	87.4%	90.4%	92.4%	96.0%
Breast cancer			80.7%	83.4%
Cervical cancer			66.1%	68.7%
Uterine cancer			74.6%	78.4%
Ovarian cancer (inc. fallopian tube)			37.6%	44.0%
Prostate cancer	87.7%	87.0%		
Testicular cancer (NS)	98.7%	95.7%		
Kidney cancer	56.4%	60.0%	51.5%	67.4%*
Bladder cancer	58.3%	54.3%	50.8%	39.7%
Brain cancer (inc. CNS)	24.4%	20.9%	26.2%	25.1%
Lymphoma	61.0%	65.0%	64.4%	69.2%
Myeloma (inc. plasma cell)	44.7%	50.8%	51.4%	50.9%
Leukaemia	52.8%	55.0%	52.5%	59.0%
Unknown primary cancer	11.7%	14.0%	10.4%	14.3%

** Represents a statistically significant change over time.*

NMSC: Non-melanoma skin cancer, CNS: Central Nervous System, ASNS: Age-standardised net survival, NS: Not standardised due to small number of cases

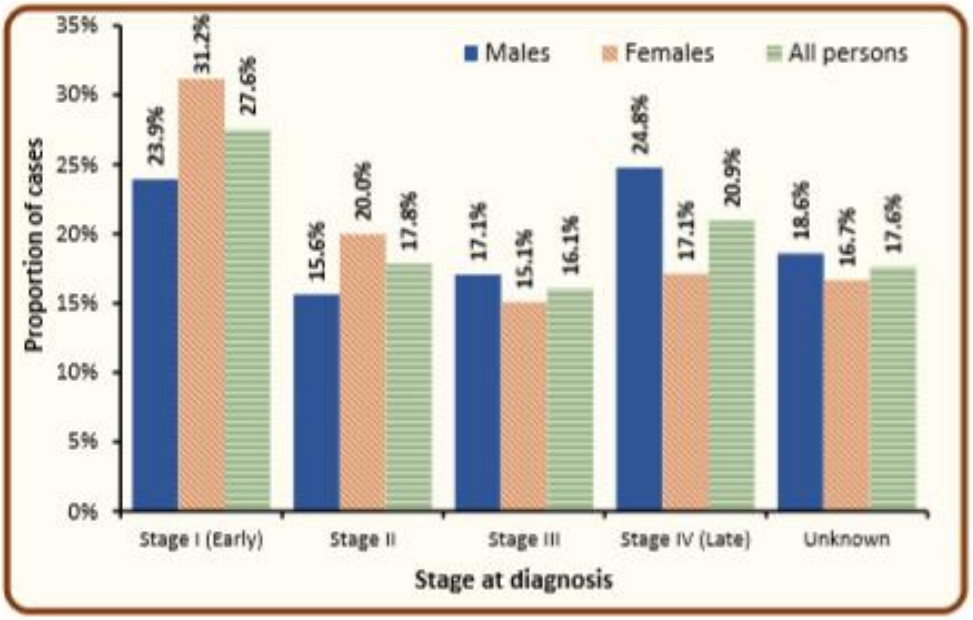
Cancer stage

Incidence by sex and stage at diagnosis: All cancers (ex NMSC) 2013-2017[1]

During 2013-2017:

- 82.4% of cases diagnosed had a stage assigned.
- 27.6% of cases were diagnosed at stage I. (33.5% of staged cases)
- 20.9% of cases were diagnosed at stage IV. (25.4% of staged cases)
- Among cases which were staged, 30.4% of male cases were diagnosed at stage IV, compared to 20.5% of female cases.

Stage at diagnosis	Average cases per year		
	Male	Female	Both sexes
Stage I (Early)	1,132	1,478	2,610
Stage II	740	948	1,687
Stage III	807	715	1,521
Stage IV (Late)	1,171	812	1,983
Unknown	879	790	1,669
All stages	4,729	4,742	9,470



Cancer stage describes the size of a cancer and how far it has grown and spread.

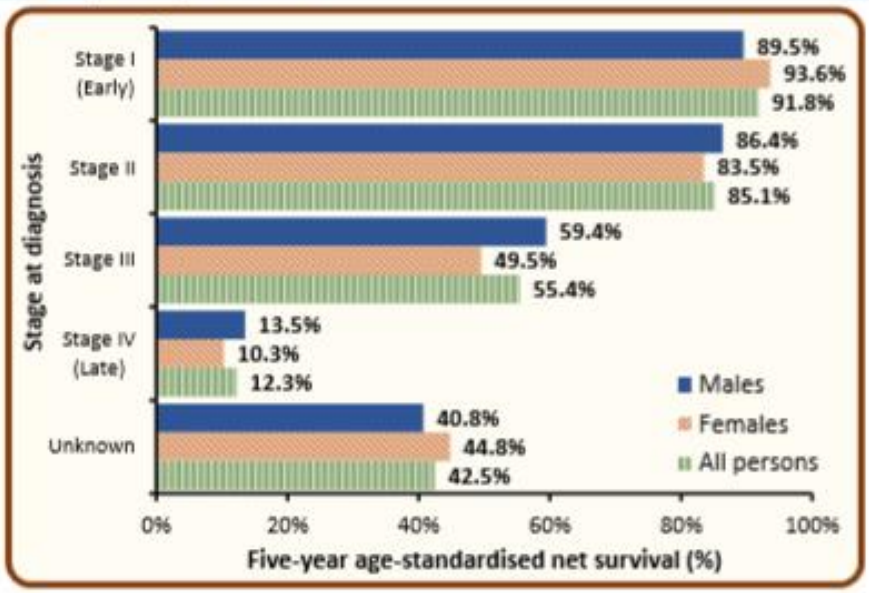
This information is used to help decide what treatments are needed.

The classification used here to stage cancer is the TNM (version 7) classification.

Data on cancer stage in 2018, classified using TNM (version 8), is available online at www.qub.ac.uk/nicr

Survival by sex and stage at diagnosis: All cancers (ex NMSC) 2009-2013

- Stage at diagnosis is one of the most important factors in cancer (ex NMSC) survival with five-year survival decreasing as stage increases.
- Five-year survival (ASNS) ranged from 91.8% for early stage (stage I) disease to 12.3% for late stage (stage IV) disease.
- Five-year survival (ASNS) for unstaged cancer was 42.5%.
- Five-year survival (ASNS) for stage IV cancer was 13.5% for men, compared to 10.3% for women.



1. Annual averages based upon several years have been rounded to the nearest integer. Sums of numbers in table rows or columns may thus differ slightly from the given total.
NMSC: Non-melanoma skin cancer, ASNS: Age-standardised net survival

Prevalence

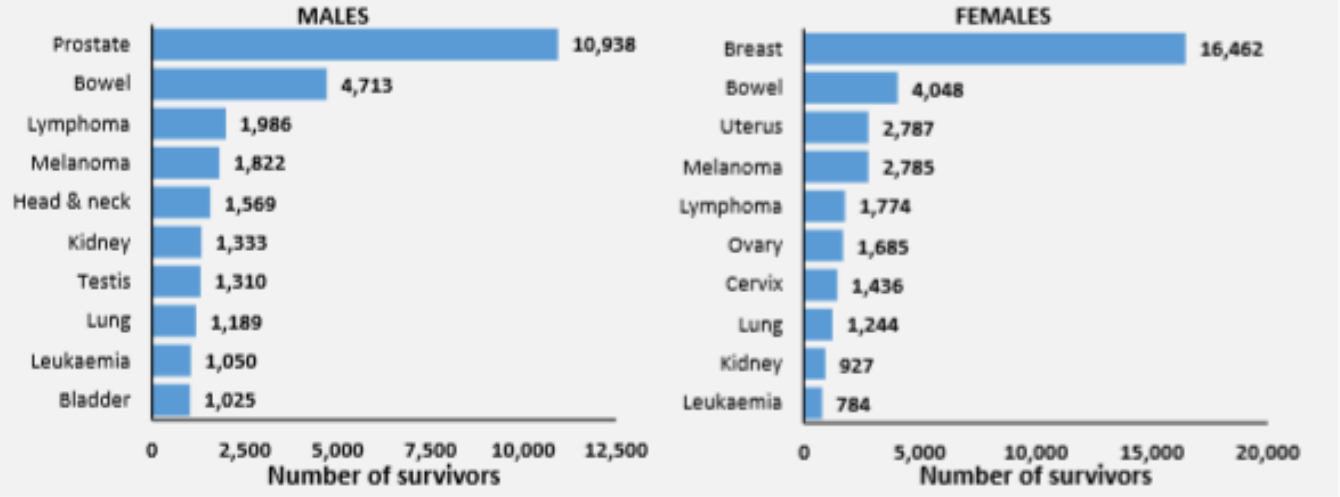
- At the end of 2018, there were 65,722 people (Males: 28,937; Females: 36,785) living with cancer (ex NMSC) who had been diagnosed with the disease during 1994-2018.
- Of these, 44.0% were male, 48.4% were aged 70 and over, and 11.9% had been diagnosed in the previous year.

25-year prevalence refers to the number of cancer survivors who were alive at the end of 2018, and had been diagnosed with their cancer in the previous 25 years (i.e. 1994-2018).

Time since diagnosis	25-year prevalence								
	Aged 0-69			Aged 70+			All ages		
	Male	Female	Both sexes	Male	Female	Both sexes	Male	Female	Both sexes
0-1 year	1,914	2,391	4,305	1,936	1,606	3,542	3,850	3,997	7,847
1-5 years	4,904	6,636	11,540	5,028	4,220	9,248	9,932	10,856	20,788
5-10 years	3,238	5,377	8,615	4,257	4,004	8,261	7,495	9,381	16,876
10-25 years	3,171	6,253	9,424	4,489	6,298	10,787	7,660	12,551	20,211
0-25 years	13,227	20,657	33,884	15,710	16,128	31,838	28,937	36,785	65,722

25-year prevalence by sex and cancer type: All cancers (ex NMSC) 2018

The most prevalent cancer types among male survivors at the end of 2018 (ex NMSC), were prostate cancer (10,938 survivors) and bowel cancer (4,713 survivors), while the most prevalent cancer types among female survivors were breast cancer (16,462 survivors) and bowel cancer (4,048 survivors).



Mortality

During 2014-2018:

- There were 2,304 male and 2,096 female deaths from cancer (ex NMSC) each year.
- Death from cancer (ex NMSC) made up 30.7% of all male, and 26.3% of all female deaths in Northern Ireland.

Deaths by sex and age at death: All cancers (ex NMSC) 2014-2018[1]

During 2014-2018:

- The median age at death was 74 for men and 75 for women.
- Risk of death from cancer (ex NMSC) was strongly related to age, with 78.4% of men and 76.8% of women aged 65 years or more at time of death.
- 4.7% of cancer deaths (ex NMSC) occurred among those aged under 50.

Age at death	Average deaths per year		
	Male	Female	Both sexes
0 - 49	94	113	207
50 - 64	403	375	778
65 - 74	670	531	1,201
75 +	1,136	1,079	2,214
All ages	2,304	2,096	4,400

1. Annual averages based upon several years have been rounded to the nearest integer. Sums of numbers in table rows or columns may thus differ slightly from the given total.
NMSC: Non-melanoma skin cancer

Deaths by sex and year of death: All cancers (ex NMSC) 2009-2018

- Among males the number of deaths from cancer (ex NMSC) increased by 8.8% from an annual average of 2,118 deaths in 2009-2013 to 2,304 deaths in 2014-2018.

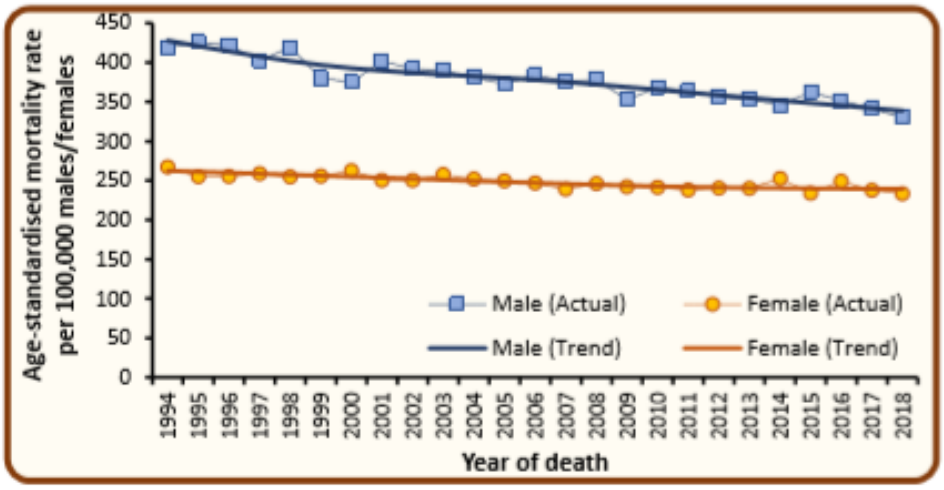
- Among females the number of deaths from cancer (ex NMSC) increased by 9.1% from an annual average of 1,921 deaths in 2009-2013 to 2,096 deaths in 2014-2018.

	2009	2010	2011	2012	2013	2014	2015	2016	2017	2018
Male	1,988	2,119	2,136	2,146	2,203	2,202	2,343	2,339	2,337	2,300
Female	1,864	1,903	1,903	1,959	1,978	2,121	2,000	2,162	2,103	2,093
Both sexes	3,852	4,022	4,039	4,105	4,181	4,323	4,343	4,501	4,440	4,393

Trends in age-standardised mortality rates by sex: All cancers (ex NMSC) 1994-2018

- Among males age-standardised mortality rates from cancer (ex NMSC) decreased by 3.6% from 359.1 per 100,000 person years in 2009-2013 to 346.2 deaths per 100,000 persons years in 2014-2018. This difference was not statistically significant.

- Among females age-standardised mortality rates from cancer (ex NMSC) increased by 0.4% from 240.4 per 100,000 person years in 2009-2013 to 241.4 deaths per 100,000 persons years in 2014-2018. This difference was not statistically significant.



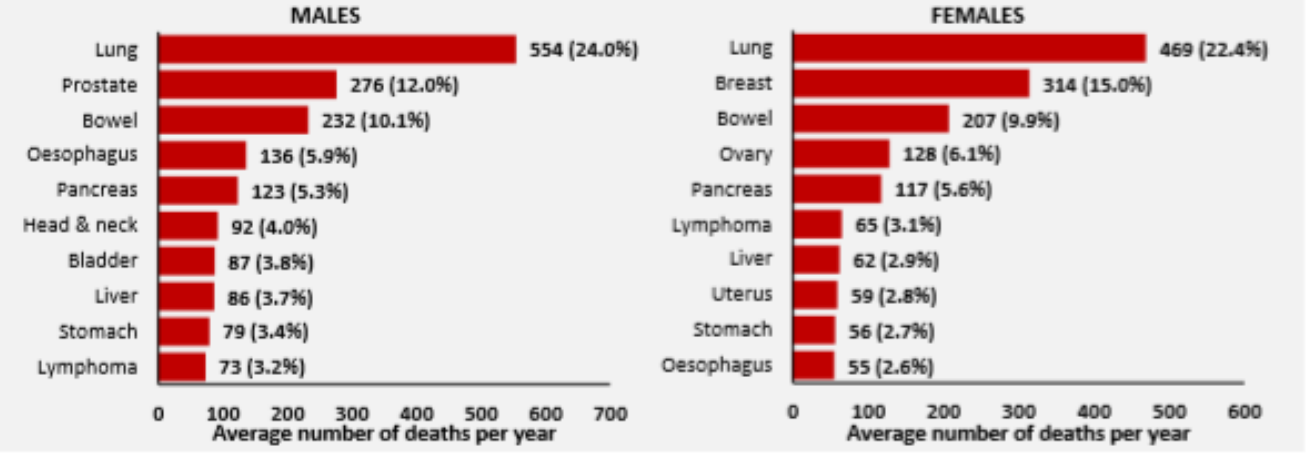
Mortality data are provided by the Northern Ireland General Registrar Office via the Department of Health.

Counts of the number of deaths are based upon the year that death occurred, and upon the primary cause of death only.

Age-standardised mortality rates remove changes over time caused by population growth and/or ageing.

Cancer deaths by sex and cancer type: All cancers (ex NMSC) 2014-2018[1]

The most common causes of cancer death (ex NMSC) among men, were lung cancer (24.0%), prostate cancer (12.0%) and bowel cancer (10.1%), while the most common cause of cancer death (ex NMSC) among women were lung cancer (22.4%), breast cancer (15.0%) and bowel cancer (9.9%).



1. Annual averages based upon several years have been rounded to the nearest integer. Sums of numbers in table rows or columns may thus differ slightly from the given total.
NMSC: Non-melanoma skin cancer

Background notes

Cancer classification: Classification of tumour sites is carried out using ICD10 codes. For a listing and explanation of ICD10 codes see: World Health Organisation at http://apps.who.int/classifications/icd10/browse/2010/en#/II

Population data for Northern Ireland, and smaller geographic areas, are extracted from the NI mid-year population estimates available from the NI Statistics and Research Agency (available at www.nisra.gov.uk).

Geographic areas are assigned based on a patient's postcode of usual residence at diagnosis using the July 2019 Central Postcode Directory (CPD) produced by the NI Statistics and Research Agency (available at www.nisra.gov.uk).

Deprivation quintiles: Super output areas (SOA) are assigned to each patient based on their postcode of usual residence at diagnosis. Using the SOA each patient is assigned a socio-economic deprivation quintile based on the 2017 Multiple Deprivation Measure. The 2017 Multiple Deprivation Measure is available from the NI Statistics and Research Agency (available at www.nisra.gov.uk).

A **crude incidence/mortality rate** is the number of cases/deaths per 100,000 person years in the population. Person years are the sum of the population over the number of diagnosis included.

An **age-standardised incidence/mortality rate** per 100,000 person years is an estimate of the incidence/mortality rate if that population had a standard age structure. Throughout this report the 2013 European Standard Population has been used. Standardising to a common Standard Population allows comparisons of incidence/mortality rates to be made between different time periods and geographic areas while removing the effects of population change and ageing.

A **Standardised Incidence/Mortality Ratio (SIR/SMR)** is the ratio of the number of cases/deaths observed in a population to the expected number of cases/deaths, based upon the age-specific rates in a reference population. This statistic is often used to compare incidence/mortality rates for geographic areas (e.g. Trusts) to the national incidence/mortality rates (i.e. Northern Ireland). An SIR/SMR of 100 indicates there is no difference between the geographic area and the national average.

Confidence intervals are a measure of the precision of a statistic (e.g. lung cancer incidence rate). Typically, when numbers are low, precision is poorer and confidence intervals will be wider. As a general rule, when comparing statistics (e.g. cervical cancer incidence rate in year 2012 vs year 2013), if the confidence interval around one statistic overlaps with the interval around another, it is unlikely that there is any real difference between the two. If there is no overlap, the difference is considered to be **statistically significant**.

Lifetime risk is estimated as the cumulative risk of getting cancer up to age 75/85, calculated directly from the age-specific incidence rates. The odds of developing the disease before age 75/85 is the inverse of the cumulative risk.

Prevalence is the number of cancer patients who are alive in the population on a specific date (31st December 2018 in this report). Since data from the NI Cancer Registry are only available since 1993, prevalence only refers to a fixed term (10 and 25 years in this report). There may be members of the population living with a diagnosis of cancer for more than 25 years.

Observed survival refers to the proportion of patients who survive a specified amount of time from their date of diagnosis. Observed survival considers death from any cause and is not adjusted for the age of the patient. Cause of death may be unrelated to the cancer the patient has been diagnosed with.

Net Survival is an estimate of survival where the effect on survival of background population mortality rates has been removed. It represents the [theoretical] survival of cancer patients if they could only die from cancer-related causes. Age-standardised net survival estimates are the estimates that would occur if that population of cancer patients had a standard population age structure. The age groups and weights used here are those used by international studies such as EUROCARE, an international study group that compares cancer survival among European countries. However, due to the small number of patients in NI, the first two age categories in the standard population are combined.

Mortality: Information relating to cancer mortality is sourced from the General Registrar Office (GRONI) via the Department of Health (NI) and is based upon the date on which death occurs. Results may differ slightly than those produced by the Northern Ireland Statistics and Research Agency (NISRA), which produces deaths data based upon the date on which the death is registered with GRONI.

Further Information

Further data is available from the Northern Ireland Cancer Registry web site: **www.qub.ac.uk/nicr**

Phone: +44 (0)28 9097 6028
e-mail: nicr@qub.ac.uk

Acknowledgements

The Northern Ireland Cancer Registry (NICR) is funded by the Public Health Agency. NICR uses data provided by patients and collected by the health service as part of their care and support.

APPENDIX E: Peer reviewed publications

NICR Publications 2019-2020

2020

1. Wilding S, Downing A, Selby P, **Gavin A**. et al. Decision regret in men living with and beyond non-metastatic prostate cancer in the UK: a population-based patient-reported outcome study. Psycho-oncology Feb 2020. www.doi.org/10.1002/pon.5362

2. Cabasag C. J, Butle, J, Arnold M, **Gavin A**, et al. Exploring variations in ovarian cancer survival by age and stage (ICBP SurvMark-2) : A population-based study. Gynecologic Oncology Jan 2020. www.doi.org/10.1016/j.ygyno.2019.12.047

3. Baden M, Lu L, Drummond F J, **Gavin A**. & Sharp L. Pain, fatigue and depression symptom cluster in survivors of prostate cancer. Supportive Care in Cancer Jan 2020. www.doi.org/10.1007/s00520-019-05268-0

4. Wagland R, Nayoan J, Matheson L, **Gavin A**, et al. Adjustment strategies amongst black African and black Caribbean men following treatment for prostate cancer: findings from the Life After Prostate Cancer Diagnosis (LAPCD) study. *European Journal of Cancer Care Jan 2020.*

2019

5. Menon, U., Vedsted, P., Zalounina Falborg, A.,…Gavin, A. et al. Time intervals and routes to diagnosis for lung cancer in 10 jurisdictions: cross-sectional study findings from the International Cancer Benchmarking Partnership (ICBP). *BMJ Open Nov 2019.* www.doi.org/10.1136/bmjopen-2018-025895

6. Kyte D, Retzer A, Ahmed K,… **Gavin A**. et al. Systematic evaluation of Patient-Reported Outcome protocol content and reporting in cancer trials. *Journal of the National Cancer Institute Nov 2019*. www.doi.org/10.1093/jnci/djz038

7. **Donnelly D**. **W, Vis L C, Kearney T… Gavin A**, et al. Quality of life among symptomatic compared to PSA-detected prostate cancer survivors - Results from a UK wide patient-reported outcomes study. *BMC Cancer Oct 2019.* www.doi.org/10.1186/s12885-019-6164-5

8. Wilding S, Downing A, Wright, P… **Donnelly, D… Gavin, A,** at al. Cancer-related symptoms, mental well-being, and psychological distress in men diagnosed with prostate cancer treated with androgen deprivation therapy. *Quality of Life Research Oct 2019*. www.doi.org/10.1007/s11136-019-02212-x

9. Arnold M, Rutherford M J, Bardot A,…**Gavin A**, et al. Progress in cancer survival, mortality, and incidence in seven high-income countries 1995-2014 (ICBP SURVMARK-2): a population-based study. *Lancet Oncology Sep 2019.* www.doi.org/10.1016/S1470-2045(19)30456-5

10. McBride R, Hicks B, Coleman H… **Gavin, A**., et al. Prognosis following surgical resection versus local excision of stage pT1 colorectal cancer: a population-based cohort study: Surgical resection versus local excision for pT1 colorectal cancer. *Surgeon-Journal of the royal colleges of surgeons of Edinburgh and Ireland 8 Aug 2019.* www.doi.org/10.1016/j.surge.2019.06.004

11. **Donnelly D, Gavin, A**… et al. Regional Variations in Quality of Survival Among Men with Prostate Cancer Across the United Kingdom. *European Urology Jul 2019.* www.doi.org/10.1016/j.eururo.2019.04.018

12. Donnelly C, Hart N,,… **Gavin A**, et al. Predictors of an early death in patients diagnosed with colon cancer: a retrospective case-control study in the United Kingdom. *BMJ Open Jun 2019.* www.doi.org/10.1136/bmjopen-2018-026057

13. Matheson L, Wilding S, Wagland R…. **Gavin A**,… et al. The psychological impact of being on a monitoring pathway for localised prostate cancer: a UK-wide mixed methods study. *Psycho-oncology Jun 2019.* www.doi.org/10.1002/pon.5133

14. Wright P, Wilding S, Watson E, …. **Gavin A,**… et al. Key factors associated with social distress after prostate cancer: Results from the United Kingdom Life after Prostate Cancer diagnosis study. *Cancer epidemiology Jun 2019.* www.doi.org/10.1016/j.canep.2019.04.006

15. Kunzmann A T, Thrift A P, Johnston B. T, McManus D. T, **Gavin A T**,… et al. External validation of a model to determine risk of progression of Barrett's oesophagus to neoplasia. *Alimentary Pharmacology and Therapeutics May 2019.* www.doi.org/10.1111/apt.15235

16. Maguire R, Drummond F J, Hanly P, **Gavin, A** & Sharp, L., Problems sleeping with prostate cancer: exploring possible risk factors for sleep disturbance in a population-based sample of survivors. *Supportive Care in Cancer Jan 2019*; www.doi.org/10.1007/s00520-018-4633-z

APPENDIX F: Requests for Information

Requests for Information

The NICR provided data and information for 178 requests in 2019, 71 (40%) general requests and 107 (60%) genetic requests (excluding local genetic requests) (***Figure 1***). A nurse from the Medical Genetics department deals with local genetic requests.

In 2019, 100% 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 2***).
45% of general requests were received from academic researchers and charities (combined) (***Figure 3***).

On average general requests took 91 minutes to complete but ranged from 10 minutes to 480 minutes (8 hours). Genetic requests took 23 minutes to complete however ranged from 5 minutes to 60 minutes. 97% of general requests were received via email (***Figure 4***) although 99% of genetic requests were received by letter (***Figure 5***).

***Figure 1*: General and Genetic Requests received 2019**

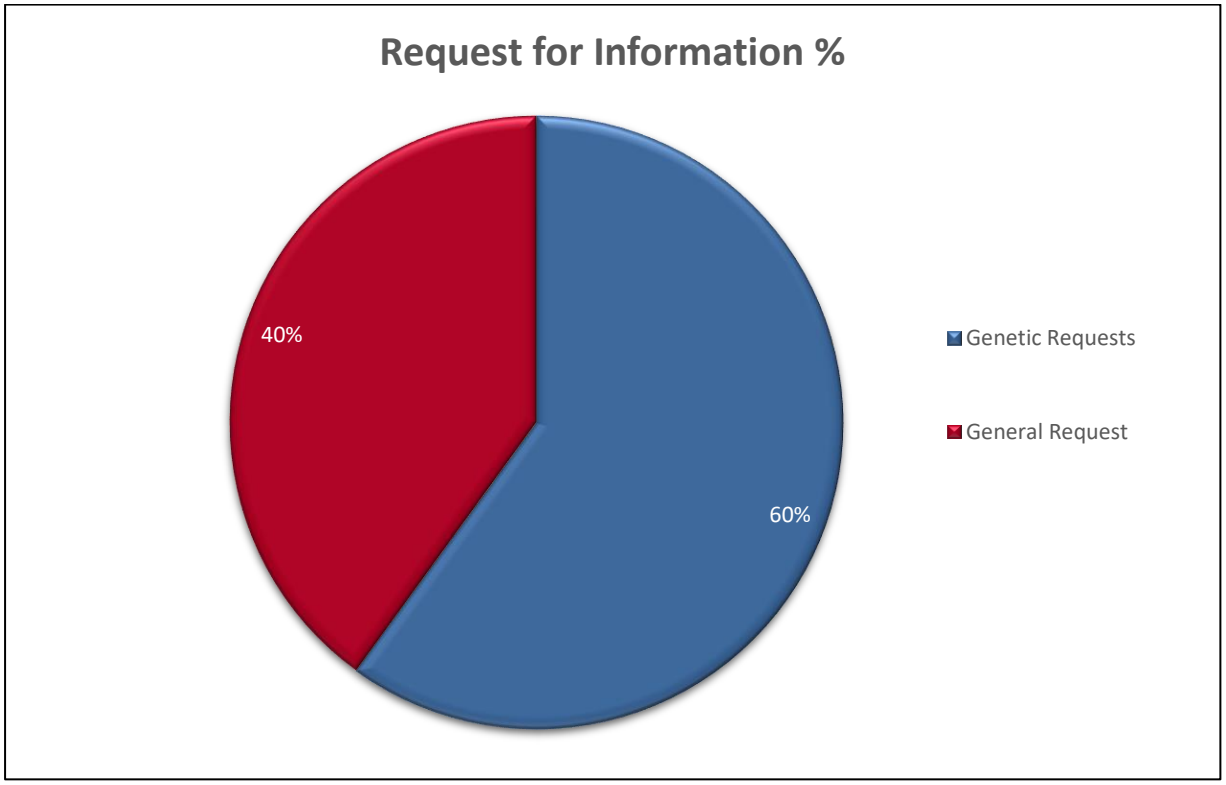


***Figure 2*: Percentage of requests completed within agreed timeframe**

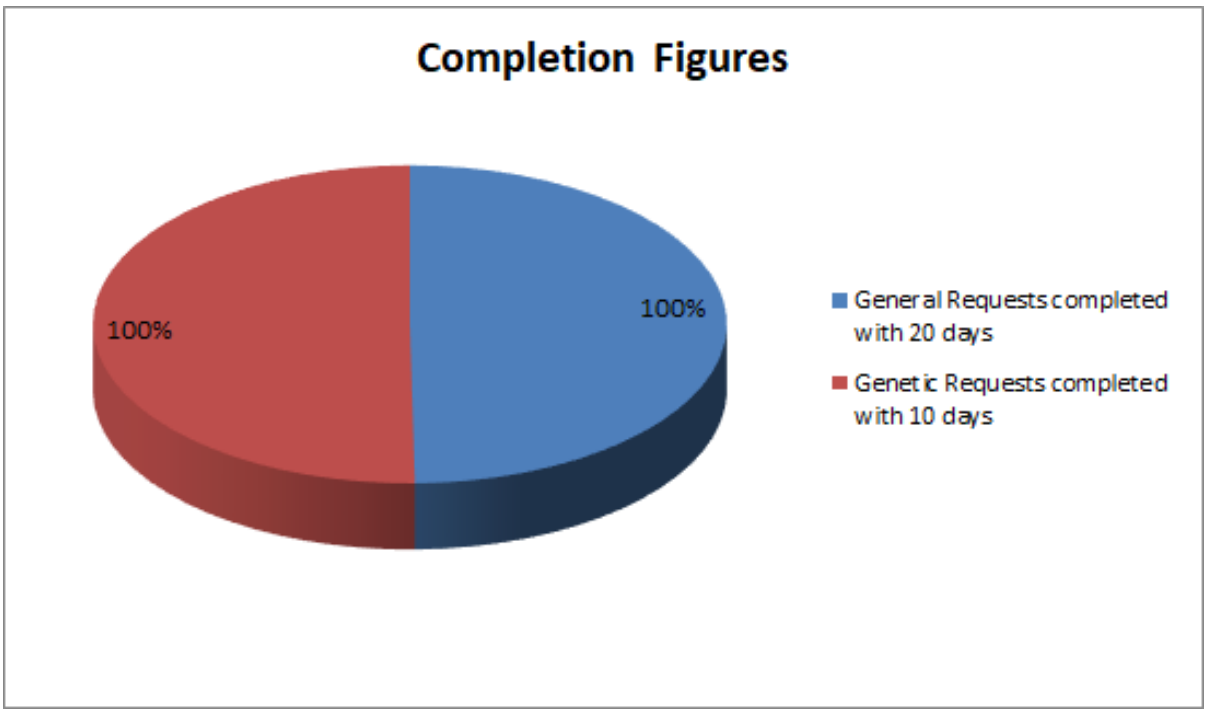


***Figure 3*: Source of Requests – General**

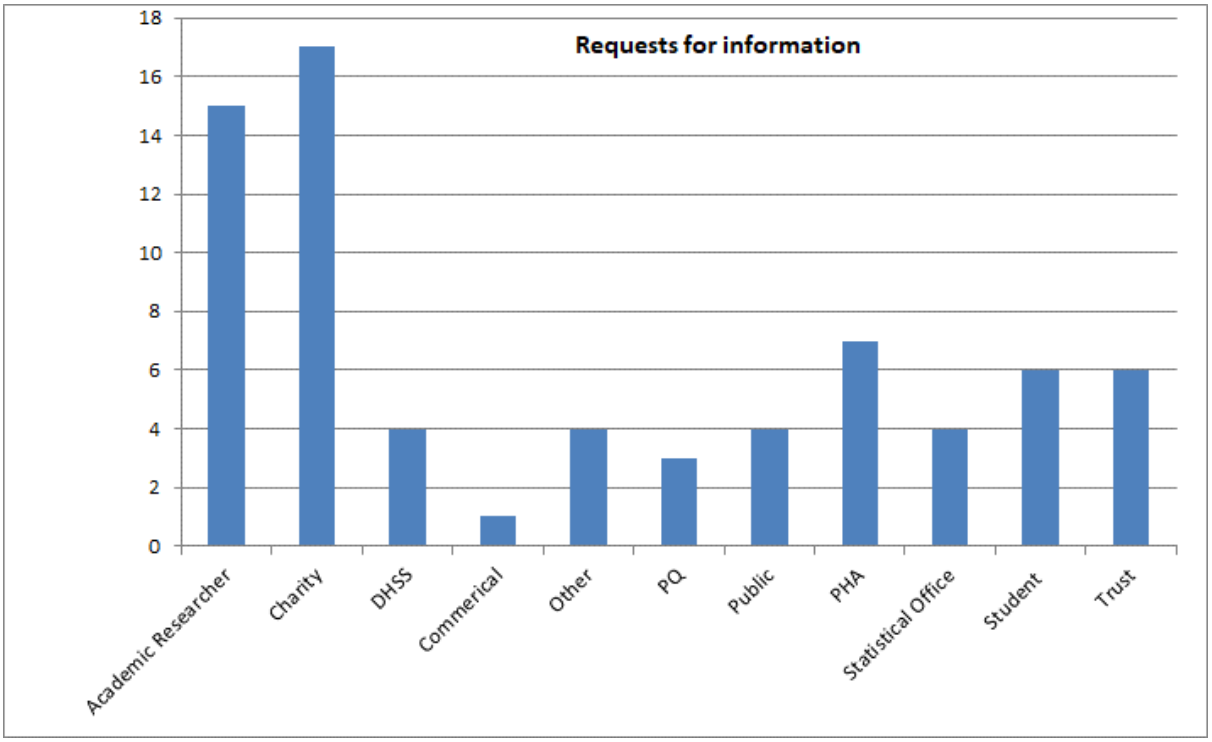


***Figure 4*: Method of Communication from Requestor – General Requests**

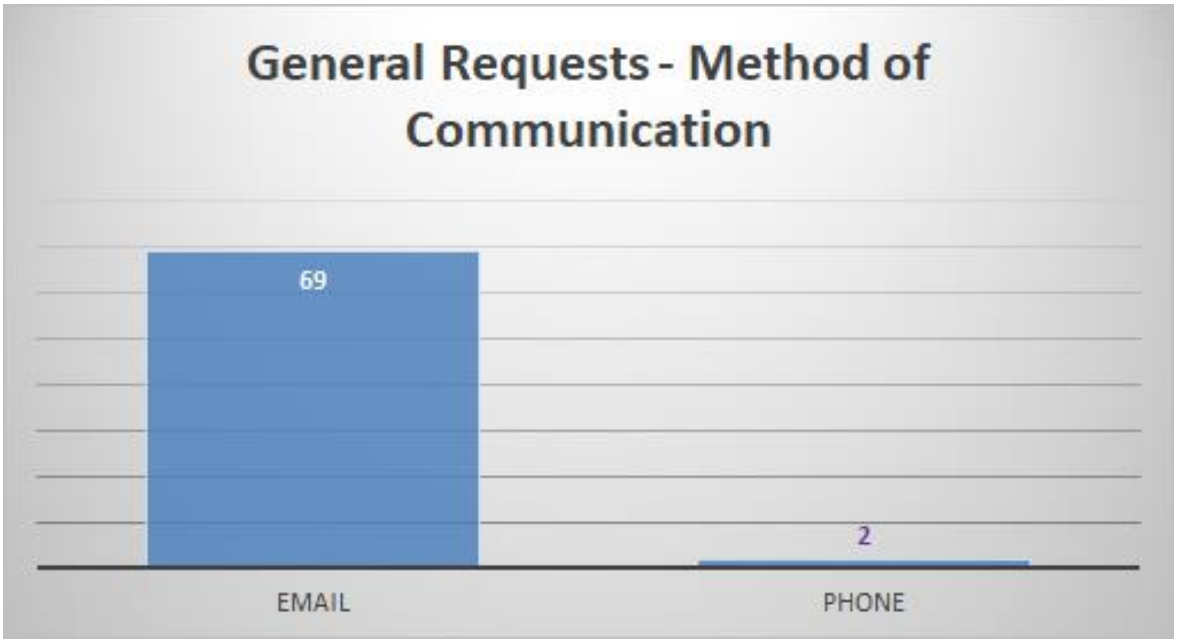
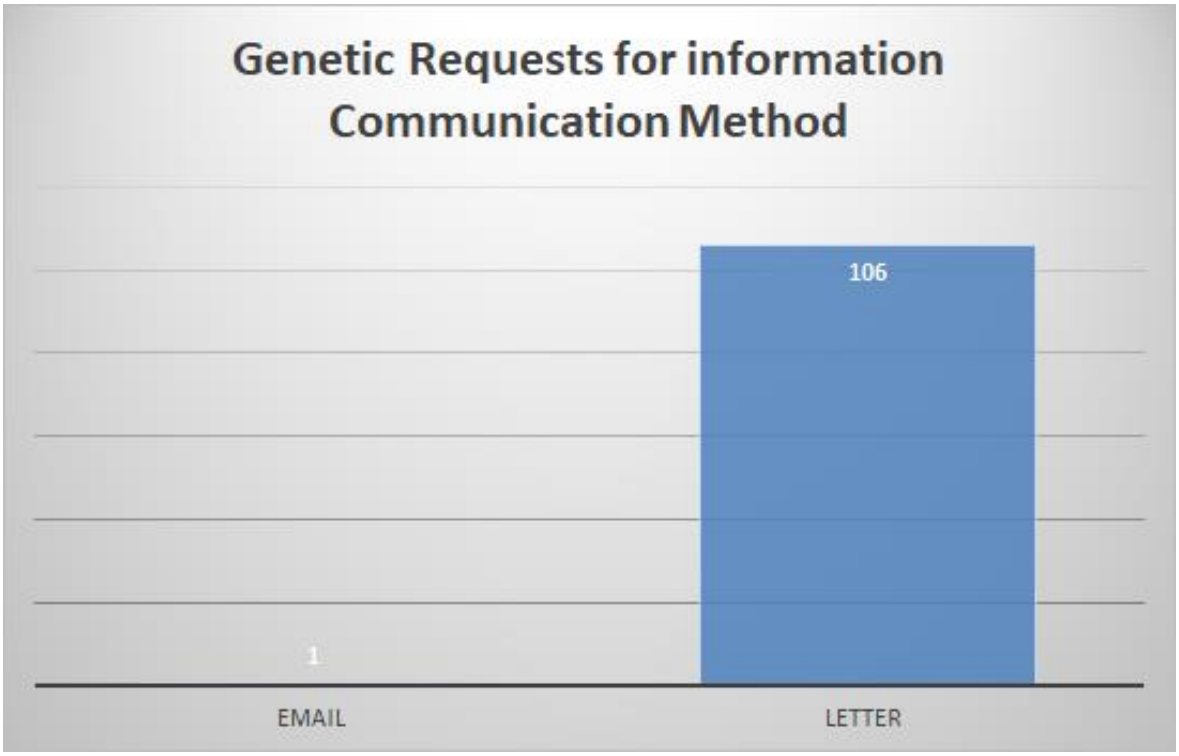


***Figure 5*: Method of Communication from Requestor – Genetics Requests**



APPENDIX G: Standard Operating Procedures (SOPs) to be 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 (eg 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 (eg 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
- Induction of staff – IT element, but not an IT-specific SOP
- Lone Worker

- Fire Testing/Drill Procedure

TVO

- How to input data into PRAXIS
- How to do resolving utilising PRAXIS
- Generic staging (c, p and r staging)
- Staging Version Table by Year of Diagnosis
- TVO Resources eg. Online, Pathology files, TVO rules
- Handling duplicates - copying tumours, cancelling patients
- Biobank protocols- including work allocation, anonymisation, linkage with researchers

- Macmillan protocols- including work allocation, anonymisation, linkage with researchers
- Recurrence protocols
- Refresh Genetics Request protocol
- Handling Deaths batches
- Handling PAS batches
- Creating and sending lists to Hospitals/ BSO- incl. resources required/ data security
- Handling extra-regionals
- Multiple tumours

Office

- Registry Finance
- Petty Cash
- Purchasing
- Travel Requests
- Training Requests
- Grant Applications
- Plan-On Requests
- Confidential Waste
- Visitors
- Staff – Inductions
- Staff – Leave Requests (annual/dependent/maternity)

Media

- Website Updates
- Comms

Research administration

- Signing in/logging on etc
- Ongoing Requests
- Publication/outputs – authorship
- Preparing Official Stats extracts
- Performance Indicators
- Data Acquisition
- Data Workflow (deadlines)
- Cluster Queries with PHA
- Data Extracts
- Geographical analysis work
- TVO Work allocation
- Induction – TVO specific

- Data Quality Checks
- Genetic Requests
- Acknowledgements
- Staff – QUB maternity policy

Deadlines Dates

- Ethics
- Governance
- Agreements

APPENDIX H: Completed achievements from 2019/2020

The key Registry priorities for 2018/19, identified below, were to ensure the needs of the PHA and NICaN were met, and to take account of the QUB Research Strategy; the priorities of which include international research partnerships, achieving excellence and supporting post graduate training to maximise academic, social and economic impacts.

***The key priorities for 2019/20 were to*:**

- Provide accurate, timely data on cancers in NI for official statistics by March 2020 for patients diagnosed in 2018
- Maintain our ISO27001 Certification in Information Security Management
- Continue with upgrades to the Registry IT System and extend its capacity to store data items
- Introduce full ICDO3 and TNM 8 coding
- Enhance datasets available to Registry e.g. comorbidities, tumour markers and premalignant diseases
- Work with clinicians, NICaN and PHA to achieve inclusion of NI data in National Clinical Audits
- Provide data for UKIACR annual Performance Indicators
- Ensure continued access to clinical information on oncology patients i.e. COIS while acquiring RISOH downloads/access as per Trust agreements
- Continue to enhance communication of Cancer Registry data to researchers and public
- Continue to work with external researchers to enhance cancer research in Northern Ireland
- 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.

Update of NICR Achievements – 2019/2020

(Green represents achieved in full, orange partly achieved/on-going, red not achieved)

Targets 2019-2020	Update	
Goal 1 – Provide accurate, timely data on cancers and premalignant disease in N. Ireland		**Date due/completed**
a) Launch Official Statistics of cancer incidence, prevalence and survival statistics for NI patients diagnosed with cancer in 2017 by March 2019.	Completed for 2017 data, on time March 2019	March 2019
	Official Statistics launched 12th March 2019	March 2019
b) Provide accurate Northern Ireland cancer datasets for international comparison.	Not required in this time period	
c) Enhance staging data available on each patient to maintain goal of high overall staging (85% achieved for 2016 data).	HI performance in 2016 dataset, NI currently leading UK in staging rates Awaiting formal results for 2017 dataset	March 2018
	Current Staging 82% - behind this year due to changes TNM7-8, lack of access to current RISOH	March 2019
d) 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.	Data Agreements updated between NICR and Trusts.	
	We now have access to death data. New agreement was required for continued acquisition of death data as NISRA-GRO cannot supply the data to NICR due to not having a legal basis for sharing. Workaround was developed whereby GRO provided the data to the Department of Health and a new agreement between NICR and the DoH enabled NICR to receive the data.	

Targets 2019-2020	Update	
e) Consolidate links with RISOH system to ensure relevant clinical information is available to NICR.	NICR understood that they had a view of RISOH through BOXi updated every fortnight, while this did not show all variables required, we understood that RISOH Project manager in talks with ARIA to get improved access. Subsequently we discovered by chance 2 years later we were still using the original test dataset pulled from RISOH and this this had not been updated. This has serious implications for data quality in NICR outputs	
f) Consolidate link to Radiotherapy systems to enable the interrogation of imaging reports.	On-going - Agreements in place with Western Trust. Data received January 2020	
g) Work to update the Cancer Factsheets online to become more interactive	On-going New Cancer of Unknown Primary (CUP) added	
h) Add Prevention messages to Cancer Factsheets.	Not possible as Factsheets are official statistics – but could be done separately	
i) Ensure that the NICR has continued look up access to the historic COIS dataset.	COIS dataset currently being loaded into Business Objects universe by BSO-IT. Access to this dataset achieved March 2019	
j) Further investigate the provision of appropriate and faster network links to HSC network.	Options were investigated and it was concluded we have the best currently available connection possible without spending significant monies. This is being considered if and when NICR accommodation is refurbished.	
k) 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 - Colin currently sitting on LIMS Project Assurance Group – Good partnership with LIMS team setup, further outreach required for ENCOMPASS team Raised formally with CMO Included as a review recommendation	
l) Assess Registry resource requirements to maintain current standards of timeliness, completeness and accuracy.	Review recommendation to be discussed at Steering Group The additional Pension costs will make it difficult for NICR to meet staff costs within the annual budget – Budget for 2019/2020 confirmed with uplift of £21,413 for unavoidable pension increases.	January 2019

Targets 2019-2020	Update	
in views of increasing numbers of cancer cases		
m) Provide data for UKIACR annual Performance Indicators within timescale.	Outputs for 2018 data expected May 2020.	
Goal 2 – Protect the confidentiality of the data		
a) Maintain ISO27001 Certification in Information Security Management for NICR.	Achieved August 2018. Successful reaccreditation February 2020.	
b) Ensure staff training is maintained.	Achieved. 3 new Auditors trained	
c) Ensure research projects adhere to the NICR & QUB Research and GDPR directives.	All projects comply	
d) Ensure that all relevant research projects have ethical approval prior to commencement.	All projects comply	
e) Pursue achievement of accommodation with QUB to ensure data confidentiality.	Working with Estates Agreement for decant area and refurbishment achieved	
f) Link with Privacy Advisory Committee and BSO regarding future of historic PSA database.	On-going.	
g) Data Sharing Access Agreements.	Agreements reviewed and updated	

Targets 2019-2020	Update	
Goal 3 – Continue with upgrades to the Registry IT System and extend its capacity to store data items		
a) Write a business case to identify best outcome.	Completed – Developer working as part of in house team. Expected new system late 2021	
b) Expand database to include additional items e.g. HER2, ER, PR, PSA, and others are recorded on the patient record.	Completed for the requested data items	
c) Investigate recurrence algorithm and if possible build into PRAXIS.	Recurrence algorithm not yet available from Public Health England Work ongoing in this area supported by Macmillan. Information available on Breast – work being done on Colorectal	
d) Work with the existing breast and colorectal datasets to extract and analyse information on recurrences.	On-going – funded by Macmillan	
e) Adapt the current PRAXIS system to record TNM8.	Completed – additional TNM8 codes added	
Goal 4 – Provide a cancer intelligence service		
a) Introduce full ICDO3 & TNM8 coding.	Completed – ICD03 coding available in live system, additional TNM8 coding added	
b) Answer all data requests within time limits of 20 days for general requests and 10 days for genetic requests.	General Requests to date 71 Genetic Requests to date 107 100% of genetic requests were completed within the 10 day time limit 100% of general requests were completed within the 20 day time limit.	
c) Continue to facilitate the Northern Ireland Clinical Genetics Service access to NICR datasets.	All requests completed within timescales	

Targets 2019-2020	Update	
d) Feedback research findings to relevant partners and associated patient groups.	Work ongoing with Macmillan, Prostate Cancer UK	
e) Ensure website is kept up to date.	On-going	
f) Enhance visibility of Official Cancer Statistics on webpage.	On-going	
g) Work to achieve additional resources to provide Northern Ireland data for national audits and peer review eg National Lung, Bowel, Prostate and Oesophageal Cancer Audits.	Funded to undertake Colorectal, Oesophago-gastric, and Mesothelioma Audits.	
h) Work to provide information for outcomes of care as required by PHA, NICaN and Trusts.	NICR staff actively involved in developing the NI Cancer Strategy. NICR staff involved in Review of PHA review of Breast Cancer Services for Department of Health.	
i) Produce updated cancer factsheets from Official Statistics 2016 data with additional clinical data added for specific cancer sites.	Completed New Factsheets eg Cancer Unknown Primary prepared	
j) Maximise use of media to promote NICR messages of cancer prevention and early detection.	Continue utilising Twitter to promote Official Statistics and key messages Media interactions including Belfast Newsletter, Belfast Telegraph, Cool FM radio station and website, BBC Newsline & Facebook page, Irish News, UTV News	
k) Registry to provide information on routes to diagnosis and various relevant metrics eg survival related to this.	NICR staff involved in Project funded by Health Foundation between QUB (Dr Finian Bannon CPH) and BSO – Also in discussion with CRUK regarding N Ireland involvement in National Cancer Diagnosis Audit	
l) Ensure NICR staff members attend the NICaN clinical Reference Groups and NICaN Board.	On-going – all attended	

Targets 2019-2020	Update	
Goal 5 – Facilitate the planning and monitoring of cancer services in N. Ireland		
a) Continue to evaluate the quality of completion of the Cancer Patient Pathway System (CaPPS) databases at Trust level and feedback to clinicians, Trust NICaN clinical groups and NICaN Board.	CaPPS Audit complete and presented, engaging with CRGs to enhance relevant data inputting	
b) Ensure audit and research findings are disseminated to key organisations/individuals to encourage implementation of recommendations.	Successful launch of Macmillan funded Emergency Admissions report August 2019	
c) Work to achieve resources to ensure that NI data are included in national audits.	£5000 from CRUK – several practices enrolled	
d) Enhance availability of information on website and dissemination of data and reports through other online partners.	On-going	
Goal 6 – Undertake and present internationally recognised research and audits		
a) Work with clinicians, NICaN/PHA to achieve inclusion of NI data in National Clinical Audits.	Still waiting on HSC Secondary Uses of HSC Data - Bill to have detail to include NICR submission to National Audits, NICR has lobbied new Minister of Health	
b) Apply for at least 1 research grant.	Colorectal Audit DataCan Oesophageal Audit	
c) Submit 8 papers for peer review in high impact journals.	1. Epidemiology of basal and cutaneous squamous cell carcinoma in the UK 2013-15: a cohort study. Br J Dermatol 2019. [accepted]	

Targets 2019-2020	Update	
	2. Impact of variation in cancer registration practice on observed international cancer survival differences between International Cancer Benchmarking Partnership (ICBP) jurisdictions. Can Epidemiol 2019 Jan [accepted] 3. Diagnostic routes and time intervals for patients with colorectal cancer in 10 international jurisdictions; findings from a cross-sectional study from the International Cancer Benchmarking Partnership (ICBP). BMJ Open 2018 Nov [accepted] 4. Cancer incidence and mortality patterns in Europe: Estimates for 40 countries and 25 major cancers in 2018. Eur J Cancer 2018 Nov [accepted] 5. Cancer-related symptoms, mental well-being and psychological distress in men diagnosed with prostate cancer treated with Androgen Deprivation Therapy. Quality of Life Research 2019. [in submission process] 6. The challenges on the family unit faced by younger couples affected by prostate cancer; a qualitative study. Psycho-oncology 2019 Feb [in submission process] 7. Urinary, bowel and sexual health in older men from Northern Ireland. BJU Int 2018 Nov [accepted] 8. Factors influencing job loss and early retirement in working men with prostate cancer – findings from the population-based Life After Prostate Cancer Diagnosis (LAPCD) study. J Cancer Surviv 2018 Oct [accepted] 9. Prostate cancer and the impact on couples: a qualitative metasynthesis. Support Care Cancer 2018 Jun; [accepted] 10. Problems sleeping with prostate cancer: exploring possible risk factors for sleep disturbance in a population-based sample of survivors. Support Care Cancer 2019 [in submission process] 11. Insights into factors associated with achieving the preference of home death in terminal cancer: A national population-based study. Palliat Support Care 2018 Dec [accepted]	
d) Enhance the completeness and quality of the Prostate Specific Antigen database and complete PSA study (externally funded).	Achieved Distributed to GP practices and each GP Federation – Considering Peer Reviewed Publication	

Targets 2019-2020	Update	
e) Ensure NI provide relevant data for International Cancer Benchmarking Partnership (ICBP) studies.	On-going	
f) Work to maximise outputs from a Patient Reported Outcomes Measures (Life After Prostate Cancer Diagnosis - LAPCD) Study (externally funded).	On-going	
g) Maximise outputs from and use of LAPCD related study for baseline population urological symptoms (externally funded).	Paper published	
h) Submit abstracts and attend relevant conferences.	Achieved National Disease Registry, Heathrow March 2019 IARC Conference, Vancouver, June 2019 NCRI Conference, Glasgow, October 2019 ENCR Childhood Cancer Workshop, October 2019 ENCR Conference, Italy, November 2019	
i) Work with NI Biobank and local researchers to enhance use of NICR data for scientific study.	On-going	
j) Continue to work with Macmillan to provide information - At Primary Care Federation level - Write up findings from Transform Cancer Follow Up for paper for peer review - A&E admissions last year of life	New Researcher recruited. New contract in negotiation, grant extension expected Health Economic Paper in preparation	

Targets 2019-2020	Update	
- Continue to provide information on Recurrence.		
Goal 7 - Ensure the Registry provides value for money		
a) Provide a paper to PHA outlining the need for additional resources to enable the registry to cope with increased number and complexity of registrations.	Regular meetings now held with PHA	
b) Manage annual budget from Public Health Agency and provide accurate updates on spend with reference to the increased numbers of cases and increased data items being collected.	On-going – Request for uplift with PHA	
c) Manage budgets from research grants.	All on target	
d) Implement and monitor cost recovery/administrative policy to ensure resources are available for time consuming requests.	In place	
e) Involve staff in planning of targets for 2018/2019.	Achieved. Staff Planning Day 29th March 2019. Next planned planning day delayed due to COVID-19 pandemic	
f) Ensure that the development of the NI Stroke Registry does not negatively impact on current NICR resources, including staff.	Under review	

Targets 2019-2020	Update	
Goal 8 – Ensure the sustainability of the Registry		
a) Develop Standard Operating Procedures for NI practices	On-going	
b) Work with Registry funders and QUB to ensure arrangements reflect the long-term nature of Cancer Registration.	On-going	
c) Work to achieve legislative cover for disease registration.	No progress	
d) Work with Registry funders and QUB to ensure arrangements reflect the long-term nature of Cancer Registration.	Included in recommendations of 2018 Review Bid with PHA	
e) Ensure staff are trained to a high level for their work.	On-going Meeting held with all staff in absence of formal appraisal process	
f) Maintain a high registry profile locally and internationally.	Registry Staff attended 5 National and International Meetings (Lyon, London, Cardiff, Vancouver, Milan)	
g) Achieve additional grant income.	Macmillan grant renewed for a further 2 years Grants for Colorectal and Oesophageal audit successful Biobank funded for another year	
h) Organise opportunities to highlight the work of the Registry to external groups.	NICR have attended relevant Stormont All Party Groups and presented at international conferences	
i) Work to achieve succession planning for registry posts.	Deputy Director in Post to be extended a further 2 years. SOPs being developed Raised also as a concern in the Review	
j) Develop a risk register for the Registry.	Reviewed at each quarterly Steering Group meeting	

Targets 2019-2020	Update	
Goal 9 – Ensure good links with patients and their representatives		
a) Continue to involve patients and their representatives in our Council, Steering Group and in Registry work.	Achieved 2 patient representatives included. Membership list for Council under review	
b) Involve patients as speakers/invitees at launch of reports.	Patients included in Prostate LAPCD Launch 26th March 2019 Patients will be included as speakers and invitees	
c) Continue to enhance the NICR website to better disseminate and improve access to NICR data to improve public understanding of cancer in Northern Ireland.	On-going	
d) Ensure the Patient Information Leaflet/Posters is available on the internet and areas where cancer patients are treated.	Distributed and available online	
e) Provide regular inputs to the Knowledge Exchange website/database.	On-going – copies of Official Statistics circulated	
f) Ensure data available to the public on cancer in NI are up to date and accurate.	On-going	
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.	Work started on Cardiovascular Disease dataset	

Targets 2019-2020	Update	
b) Link nationally and internationally to promote cancer registration and increase understanding and control of cancer including promoting cancer staging tool.	On-going Currently Chair of European Network Cancer Registries Actively involved in International Cancer Benchmarking Partnership	
c) Provide data for UKIACR Performance Indicators.	Complete for 2017 data	
Goal 11 – Provide an environment for education and training		
a) Offer training slots to undergraduate/postgraduate students and Public Health trainees.	One summer student due June 2019 Dr Hannah McKenna, Post Doc - Pathways to cancer diagnosis: Monitoring variation in the patient journey across Northern Ireland study Dr Andrew McGuigan, Post Doc - Investigation of the association between immunological biomarkers of pancreatic cancer and disease specific outcome measures	
b) Raise awareness of the Cancer Registry within the University and beyond.	Vice Chancellor visited NICR 15th April 2019 Meetings held Head of School, PHA, NICR	
c) Maintain international links on new developments in cancer registration and cancer research.	On-going	
d) Facilitate medical/research staff with access to relevant registry datasets within confidentiality and ethical guidelines.	On-going	
e) Ensure the Registry environment and processes support education and training while maintaining data security.	On-going NICR accommodation rearranged to accommodate those working with data while ensuring data confidentiality	