Operational Plan 2018-19

N. Ireland Cancer Registry

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

CONTEXT

Annually the 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 for April 2017 - March 2018. It holds to the vision, purpose and values set out in the 5-Year Strategic Plan (April 2013 – March 2018) which will be updated following the NICR Review on June 4th and 5th 2018. This year the business plan also provides information for those tasked with performing the review.

Contents

GLOSSARY

Acronym	Definition
ADRC-NI	Administrative Data Research Centre N. Ireland
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
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
LCI	Local Cancer Intelligence
LIMS	Laboratory Information Management System
LSHTM	London School of Hygiene and Tropical Medicine
MGUS	Monoclonal Gammopathy of Undetermined Significance
NCI	National Cancer Institute
NCRAS	National Cancer Registration and Analysis Service
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 Operatives Version 4
ORECNI	Office for Research Ethics Committees Northern Ireland
PAS	Patient Administrative System
PCUK	Prostate Cancer UK
PHA	Public Health Agency
PI	Principal Investigator
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
TNM8	International Union Against Cancer TNM Classification of Malignant Tumours Eighth Edition
TMS	Theatre Management System
TVO	Tumour Verification Officer
UICC	The Union for International Cancer Control
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 Northern 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 N. Ireland 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 N. Ireland Cancer Registry (NICR) was established in 1994 (complete registrations from 1993), to provide information on cancers occurring in the N. Ireland 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 advise on direction. The last review (2008) 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 (see Appendix A for membership of Steering Group and Council).

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 patients with potential predisposition to certain cancer types
- Investigation of alleged cancer clusters
- Provision of data for and undertaking research into prevention, patterns and trends and outcomes of cancer, when required approved by research ethics committees
- Improving awareness of the cancer burden in N. Ireland.

Our population is 1,810,863 and our cancer incidence last year, excluding non-melanoma skin cancer, was 9,447 cancers. At the end of 2016 there were 61,038 people residing in N. Ireland surviving a cancer, excluding non-melanoma skin cancer, that were diagnosed between 1993 and 2016.

Cancer incidence is increasing and this is predicted to continue, largely due to the ageing population where cancer risk is higher. In 1993 there were 6,274 incident cancer cases excluding non-melanoma skin cancers; by 2016 this had risen to 9,446 cancer cases plus 3,798 cases of non-melanoma skin cancer – an increase in numbers of 19% overall. By 2035 it is predicted that there will be 14,148 incident cancer cases excluding non-melanoma skin cancers. (Figure 1).

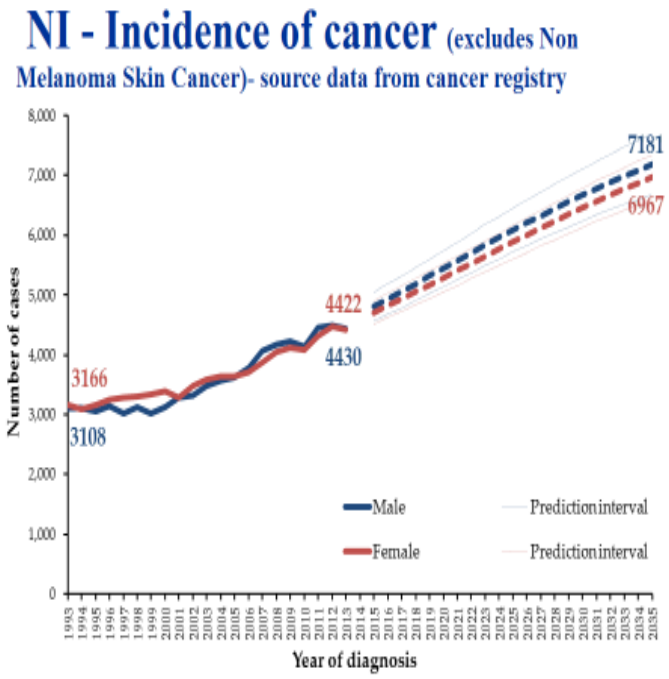


Figure 1: Cancer incidence projections for N. Ireland

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 N. Ireland.

1.3 NICR Purpose

To provide accurate, timely information on cancers and pre-malignant conditions occurring in the population of N. Ireland for official statistics, research, education, service monitoring and service 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 N. Ireland 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 N. Ireland
- Facilitate the monitoring of the impact of cancer screening services in N. Ireland
- Provide appropriate information on cancer for ad hoc queries
- 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 control of cancer.

1.6 Ethics and compliance with Data Protection

The NICR has approval for its databases from the Office for Research Ethics Committees N. Ireland (ORECNI) Reference 15/NI/0203. 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 is currently undertaking a review to ensure compliance with the 2018 Data Protection Regulations (GDPR) under QUB's registration by May 25th 2018.

We have agreements with each of the N. Ireland Health and Social Care Trusts for data provision and with the Quality Assurance Reference Centre (QARC) for data on screening. We do not require individual level consent for data collection however, if requested, the method for removal of patient data is to notify the organisation providing data to the NICR of the relevant Health and Social Care Number (HCN) which would place a block to prevent any notifications reaching the NICR. 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:

- Provision of information through the NICR website and patient information leaflets, posters and screen shots in clinical areas accessed by patients
- Patient representation on the NICR Council and steering groups for specific projects
- Cancer charity involvement in the work of the NICR
- Including patients in report launches.

1.8 NICR links with clinical teams by:

- Attending N. Ireland Cancer Network (NICaN) Board meetings
- Attending NICaN site specific Clinical Reference Group 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 and Steering Group
- Providing information for genetics counselling requests.

1.9 NICR links with researchers through:

- The Director and Acting Deputy Director being academic research staff in QUB
- 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.

1.10 NICR engages with policy makers by:

- Providing information for the Knowledge Exchange website related to official statistics (http://www.knowledge.hscni.net/Resources/ContentDetail/1013)
- Providing timely and accurate answers to NI Assembly queries, parliamentary questions and data requests from Trusts, PHA and DHSS
- Attendance at NI Assembly Health Committee events
- Working with NI Cancer Network (NICaN) on specific projects.

1.11 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. 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 staff cease 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.

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.

We have secure data transfer with encrypted email facilities and hscni.net & nhs.net for communication with the Health and Social Care Trusts and QARC.

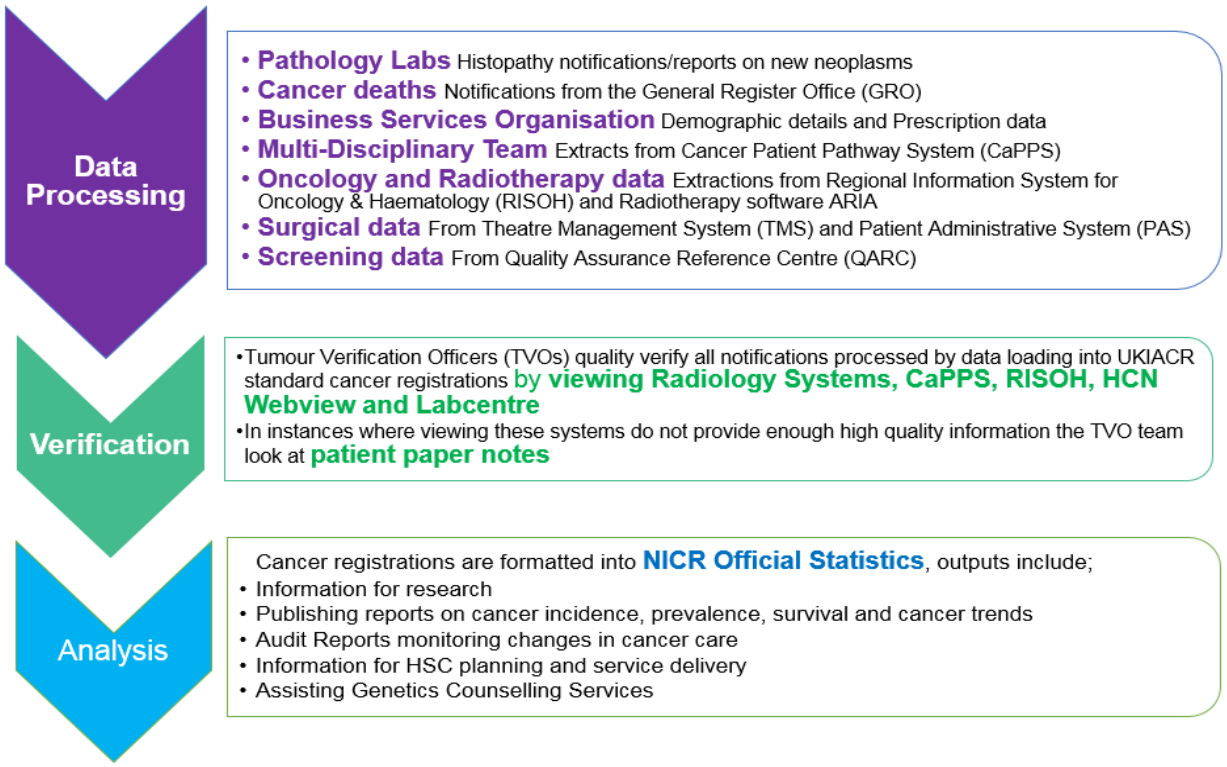
The NICR database is held on a stand alone server within a highly secure area. This server has no connectivity to any external networks and levels of access are controlled by the use of biometric (fingerprint) authentication and passwords. Access is dependent on the user permission level– for example; 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 diagnoses in the population electronically from pathology laboratories, hospital admissions and discharges from the Patient Administrative System (PAS) and death registrations from the General Register Office (GRO) using cancer and premalignant disease specific ICD10 Coding and Topography coding.

Process of How NICR Data Sources Are Turned Into Outputs



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 Northern Ireland since March 2008. The dataset therefore can be used to source limited information on the level of morbidity within the cancer patient population in N. Ireland. As medications can treat a range of conditions the use of prescriptions to define specific comorbidities is limited. Information on specific cancer treatments 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) (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 and is supplemented by extracts received from the Clinical Oncology Information System (COIS), which the TVO team read to extract any 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 sent across as a part of the move. The NICR are liaising with Belfast Trust to try and gain access to both COIS and RISOH systems going forward, however there are ongoing legal complications between the software providers and the Trusts that need to be resolved to gain access. The NICR does not, as yet, 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.

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

2.2 Diseases Registered

The NICR registerable tumours are ICD 02: C00-C97, D00-D09, D37-D48, D29.2, D32, D33, D35.2, D35.3, 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 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

Plans are in place to submit an application to Cancer Research UK to substantially expand the pre-malignant registries. See below for detail on the researcher led pre-malignant registries.

NI Barrett's Oesophagus
The N. Ireland 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[1-9].
Historic funding sources: Cancer Focus N. Ireland.

NI Colorectal polyp
This Register includes information on all colorectal polyp diagnoses since 2000 in N.Ireland. This resource has been used to investigate the risk of cancer in relation to type of polyps, and findings show that elevated cancer risk remains in patients who have undergone polypectomy. A joint molecular epidemiology study with Vanderbilt University, TN, USA, is ongoing using this resource to identify biomarkers for advanced recurrent adenomas[10-13].
Historic funding sources: Cancer Focus N. Ireland

Endometrial Hyperplasia
This is a new population-based register of Endometrial Hyperplasia cases (PI: Dr 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

Prostate Specific Antigen (PSA)
This is a population-based database of all PSA tests performed in N. Ireland 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].

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 a steady improvement from 80% for 2014 registrations, 82% for 2015 and 85% for 2016 data. Other indicators, for example numbers of death certificate only registrations (which account for 0.4% of invasive malignancies registered excluding non-melanoma skin cancers) and microscopically verified cases (which account for 85.3% of invasive malignancies registered excluding non-melanoma skin cancers). These measures indicate the high quality of the Registry's data. The report for the 2016 dataset will be available officially in June 2018. Unfortunately due to the introduction of new IT systems, Wales and Ireland did not submit data for comparison. *Current indicators: (*Appendix C*).*

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.

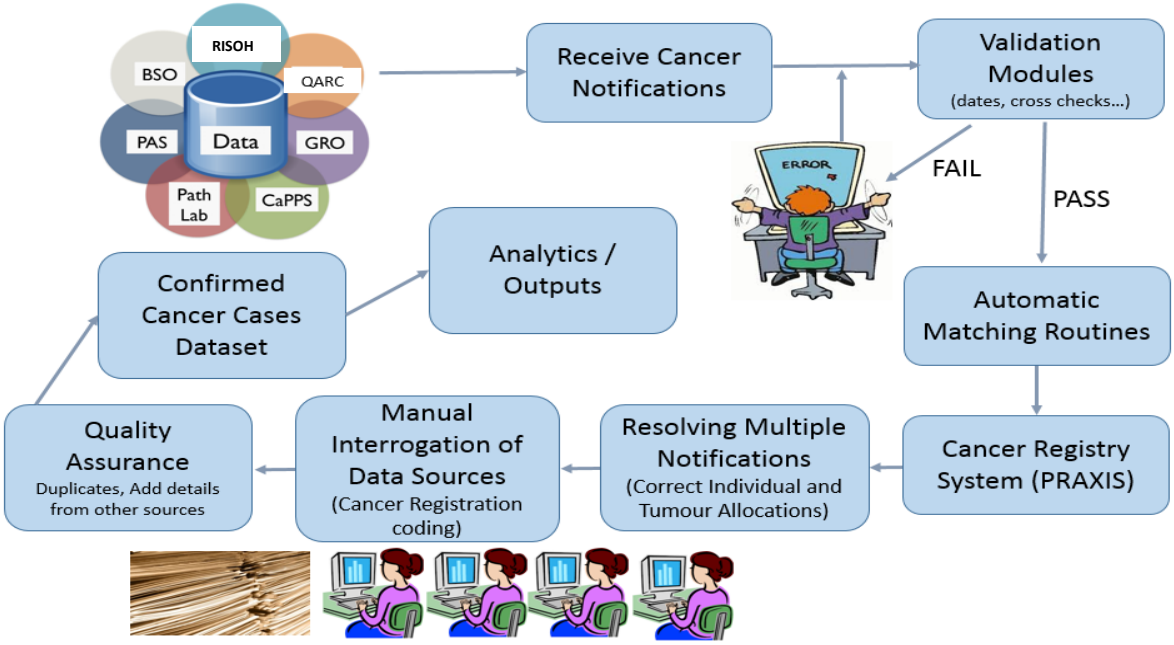
The NICR has twice offered General Practitioners the opportunity to check data held by NICR on their patients. There was good uptake of this offer and results indicated a high level of data quality within the NICR[24].

4. REGISTRY IT SYSTEM

4.1 Background

The NICR 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 choose to use the Encore registration system. This left N. Ireland as the sole user of the PRAXIS system which has many benefits, such as automated data linkage routines, which have not been fully replicated in newer systems.
PRAXIS retains only limited in-house (NICR) support and development. 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 to the latest version of the database management software (Caché). The registration system is however in need of a major redevelopment to facilitate the impending changes to cancer coding (such as SNOMED-CT coding of pathology data due around 2021) and the future requirement to collect, record and analyse molecular data. An options paper is currently being drafted to explore the viable options required in order to build a system on a readily available and fully supported architecture (e.g. ASP.Net/SQL).

4.2 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 N. Ireland. The Official Statistics for 2016 registrations were published on 13 March 2018 alongside the latest statistics on cancer mortality which are provided by GRONI.

Cancer statistics for 34 cancer sites are available for viewing and download on the NICR website.

These statistics detail the average incidence over a rolling five year period by geographical areas (Health and Social Care Trust, local government district and Assembly constituency) and deprivation quintile. Cancer incidence trends and survival statistics spanning 1993-2016 are also available.

This year 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, with its cancer factsheets by site from the official statistics, continues to be well used (see http://www.qub.ac.uk/research-centres/nicr/Publications/Factsheets/ and Appendix D for example).
We now have 13 factsheets updated annually as new official statistics are released.
Detailed clinical factsheets are also prepared for the NICaN clinical groups upon request (Appendix E).

5.3 Information for General Practice

The NICR have prepared information on General Practice cancer incidence, prevalence, emergency presentation (see http://www.qub.ac.uk/research-centres/nicr/Publications/MacmillanNICRPartnership/ and Appendix F for example).

5.4 Research Publications

Since January 2017, 25 peer reviewed publications using registry data have been produced (76 since January 2013) (Appendix G). 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 handles two main types of information request: general requests and genetic requests. General requests cover a broad spectrum from statistical information to complex research requests. During 2017, 97% of 146 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 2017 the NICR completed 98% of 151 genetic information requests within this time-frame (Appendix H). Within N. Ireland, the NI Clinical Genetic Service has a designated nurse who has 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.

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 need (Appendix I for aims and objectives).
- NICR staff have been Principal Investigators 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, the other more recent UK wide Life After Prostate Cancer Diagnosis study in conjunction with Movember, with results on 35,000 prostate cancer patients and 3,000 men without prostate cancer as a comparator group (Appendix J for summary).
- NICR continues to provide clinical data to approved NI Biobank studies as required.

Projects facilitated within NICR by external researchers

- The value of adjuvant radiotherapy on survival and recurrence in triple negative breast cancer: an international pooled meta-analysis. Lead: Dr M O'Rourke
- Commonly prescribed drugs and their association with cancer progression: a data linkage study (breast, colorectal, lung, prostate, ovarian, oesophageal and stomach cancer). Lead: Dr C Cardwell
- Population study of contralateral breast cancers in Northern Ireland with Dr S McIntosh and Dr C McIlmunn
- Under- treatment of lung cancer in older patients with Dr F Bannon
- Population estimate of burden of non-melanoma skin cancer in N. Ireland with Dr O Dolan and Dr A Alani
- Impact of waiting times on outcomes for cancer patients with Dr R Barry
- Regional variation in use and performance of "Urgent Suspected Cancer" referrals – a combined analysis using Northern Ireland and Scottish data with Dr P Murchie

- Study of clinical management and outcomes of pT1 staged colorectal cancer with Dr H Coleman
- Three population-based studies of molecular pathology epidemiology biomarkers for colon cancer survival with Dr H Coleman
- Beta-adrenergic receptor expression and beta-blocker use: association with breast cancer survival and prognosis with Dr C Cardwell
- Assessment of viral agents in Barrett's oesophagus and oesophageal adenocarcinoma pathway. Lead: Dr LA Anderson.

5.9 Audits

The Registry undertook a suite of audits measuring changes to cancer services from 1996 when they were reorganised. 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, comparing N Ireland patient outcomes with that of the rest of the UK, published in 2017.

The NICR commenced an audit of the completeness of the fields in the Multidisciplinary Team meeting Cancer Patient Pathway System (CaPPS) tool, starting with lung and head and neck, results of which were presented to the relevant NICaN Clinical Groups and NICaN Board (Appendix K). The audit of CaPPS highlighted the poor completion of many clinical fields. Since a presentation of this at the NICaN Board, a CaPPS Review Group has been established with the goal to increase clinical data input and clinician engagement. Since then, improvements have already been seen in field completeness. The NICR Clinical Liaison is a member of the CaPPS user group to advance upgrades to the system.

We are currently auditing the use of PSA tests in General Practice, analysing 800,000 records of PSA tests on approximately 200,000 men. The aim of this work is 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.

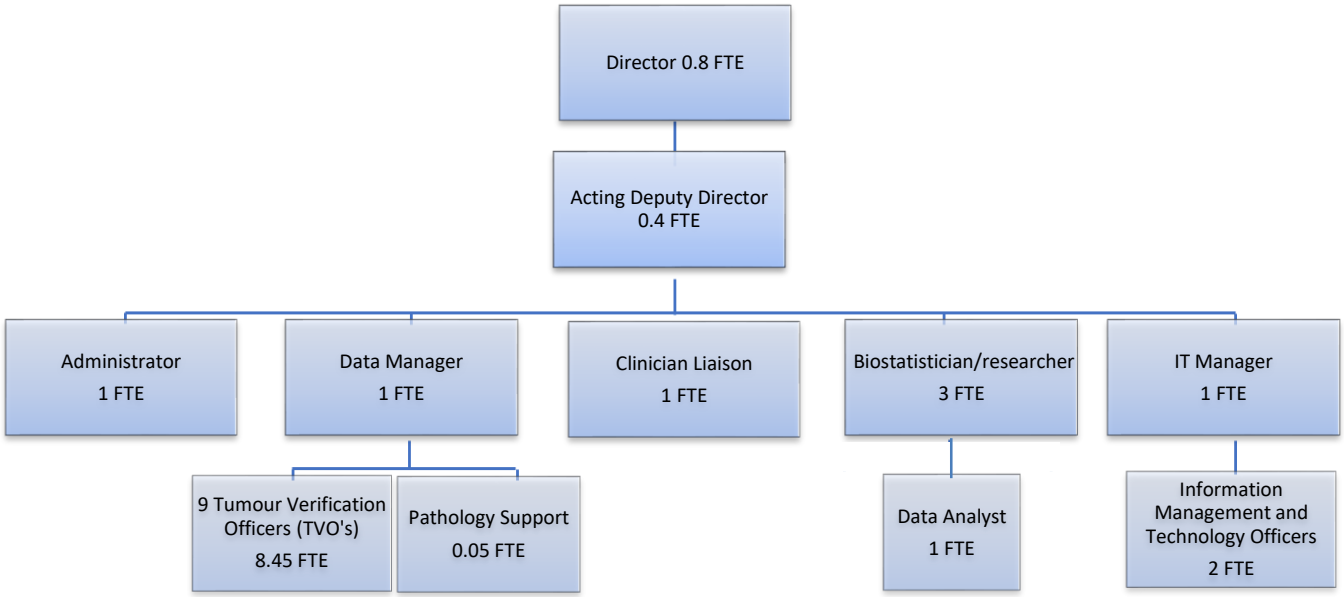
6. INTERACTION WITH THE PUBLIC

The Registry has a leaflet, which was recently updated to reflect current practice, and poster available to inform patients, clinicians and the public about the work of the NICR. These are displayed in cancer centres/units/GP surgeries and available on 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.

Staff from the NICR have a profile in the NI media with regular appearance 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).

7. NICR RESOURCES

Staff
(FTE= full time equivalent)



Cancer Focus has funded a recently appointed Post Doctoral Health Economist to work with the Northern Ireland Cancer Registry and the Centre for Cancer Research and Cell Biology (CCRCB).

8. FUNDING

8.1 Annual Budget

The NICR is currently funded by the Public Health Agency (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 past three years at £820,112 with a significant proportion of the budget (88%) for staff salaries, 97% 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).

The Registry also submits research and audit grant applications to various funding bodies and if successful undertake specific research/audit projects.
This year we have had a letter of reassurance from Mrs V Watt, Chief Executive of the PHA re continuation of Registry funding but not the final amount.

8.2 Allocation from PHA

Table 1: Allocation from PHA

Funding from Public Health Agency	Funding 2014/15	Funding 2015/16	Funding 2016/17	Funding 2017/18	Funding 2018-2019
Total	**£801,778**	**£809,796**	**£820,112***	**£820,112***	**£884,627 (projected as required for status quo but not allocated)**

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

Table 2: Breakdown of allocation from PHA

Funding from Public Health Agency	Funding 2014/15	Funding 2015/16	Funding 2016/17	Funding 2017/18
Salaries	£684,315	£682,201	£674,030	£710,610
Overheads	£68,958	£67,792	£65,439	£72,527
Non-Pay	£48,505	£59,803	£70,643	£26,975
Total	**£801,778**	**£809,796**	**£810,112**	**£810,112**

8.3 Other funding

In addition to the allocation from the PHA the Registry has several research/audit projects (Table 3) these are used to fund work by NICR staff not funded by the PHA.

Table 3: Research/Audit Expenditure Relating to projects active during the period 1 April 2017 – 31 March 2018*

	Start Date	End Date	Total Budget	Expenditure up to 31/03/18	Balance C/F 2017/18
[1]GAIN Lung Audit	01/02/15	31/03/17	£26,800	£26,800	£0
[2]PCUK PROMS UK Study of Patient reported outcomes	01/11/14	31/12/18	£540,982 (part of £1.2million grant with University of Leeds)	£507,858**	£32,200
[3]Macmillan	01/04/16	31/03/20	£241,226	£101,272	£139,954
[4] Prostate Specific Antigen audit of use in primary care	01/04/17	31/06/18	£22,552	£22,552	£0

* Budgets for April – March financial years for specific research projects are not available as start dates vary and projects run over variable timeframes.

** Includes payment to Scotland. Wales will also receive payment for staff and services for this project from the budget held by NICR in QUB.

9. RECENT DEVELOPMENTS

Stroke Registry – The Director of the NICR is Principal Investigator on a grant to establish a population based Stroke Registry within the physical environment of the NICR, estimated start date set for October 2018. Grants are also being submitted to develop a similar register of heart disease.

10. ISSUES OF CONCERN/CHALLENGES FOR NICR

Below are a list of challenges that the NICR faces over coming years.

10.1 Lack of a Legislative Framework for Disease Registration

We are awaiting a legislative framework for cancer registration in N Ireland. In April 2016 a Bill on Secondary Use of Health and Social Care Data received Royal Assent. However with no active government the regulations have yet to be drafted before consultation and final approval.

10.2 IT System

The current IT system no longer receives any consolidated support or development and has therefore fallen behind in terms of serviceability and support. The underlying architecture is difficult to further develop using in-house resources and the availability of outside resource is limited. The application is in need of a major redevelopment in order to build a system which retains the advantages of the current IT system on a readily available and fully supported architecture. This is likely to require significant additional resources.

10.3 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.
Funding has remained stable over the past 3 years and now 97% is spent on staff. The amount of funding for each forthcoming year arrives late meaning that planning for the forthcoming year is hampered.

10.4 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 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 basic skill set for a TVO post as this is very different to the skill set required for a clerical post, and we then have to often advertise externally. This process can take up to one year.
- The work of a TVO is complex, with decision making based on data from several different clinical systems. We are currently consolidating evidence for a review of the post grading within QUB.
- The lack of opportunity to gain a professional qualification in disease registration similar to which is available in the USA is also an issue.

10.5 Maintaining Access to Data Sources

- Currently, unlike in England, there is no mandated minimum cancer dataset required from Trusts in NI.
- We face challenges to ensure continued access to datasets as systems change within the Trusts.
- Compliance with the General Data Protection Regulations (GDPR) may raise further difficulties for data access as data access agreements are refreshed.
- Unfortunately, access to COIS was ended abruptly in April 2018 – negotiations are ongoing to acquire this historical clinical dataset. We are working to assess the availability of data from the COIS replacement system, RISOH.
- Gaining access to Primary Care Electronic Care Record (ECR) also remains a challenge. 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 would 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 and in the determination of risk prediction modelling from premalignant disease to cancer.
- We link with BSO and would like to have Safe Haven status to enable access to electronic records instead of having to request paper notes.

10.6 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 is currently the basis of an audit of PSA testing in General Practice.
- However, following recent discussions with Primary Care and the N. Ireland 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 information on the PSA database.

10.7 Exclusion of Northern Ireland Data in National Audits

- National audits provide a mechanism to benchmark services with providers outside of N Ireland. It requires comparisons of patient level datasets using similar methodologies. There is a strong desire among cancer clinicians, the NI Cancer Network (NICaN), the Public Health Agency and Health and Social Care Board that NI datasets for cancer patients are included in National Audits. The National Audits in question are: National Lung Cancer Audit, National Bowel Cancer Audit, National Head and Neck Cancer Audit and National Oesophago-Gastric Cancer Audit. There is also a National Prostate Cancer Audit.

- 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 as we await an active political Assembly.
- The NICR has been involved in NI cancer audits with the most recent lung audit including comparisons with data from the rest of the UK without transfer of patient level datasets. The NI Cancer Networks Clinical Reference Groups (CRGs), which deal with cancers for which there is a national audit ongoing, have expressed positive interest in having NI data included. 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.
- The accrual of data from the CaPPS systems could provide a mechanism to facilitate N Ireland's inclusion in national audits. Lung and Head and Neck teams already record the required amount of data for the minimum audit dataset. The data however are stored in many systems and formats which will require a lot of time to assemble. The other cancer site Clinical Reference Groups (CRGs) have accepted that they need to agree a minimum dataset and start collecting key clinical data items, however they expressed that with their current work-loads they will require additional resources to help them. The CRG's expressed concerns that by not being a part of a National Audit their surgical registration is at risk.

10.8 Accommodation

The NICR is located in accommodation identified by QUB for refurbishment, to facilitate the designation of secure areas. Any changes need to ensure ongoing confidentiality of datasets while future proofing for expansion.

10.9 Succession Planning

Job roles within the Registry are very specialised. We are a small team and there are risks of losing specialisation as staff leave for other posts or retire. Additional finance for work shadowing and training of new staff is required to reduce the risk of loss of expertise in this small group.

10.10 Coping With Increased Burden Of Registrations And Increased Requirements For Data Items

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 analytical support and a more sustainable model of funding.

The list of NICR achievements in 2017/18 are highlighted in Appendix L.

11. FOCUS FOR 2018/19

The key Registry priorities for 2018/19 identified below, are to ensure the needs of the PHA, NICaN, the upcoming Registry review and also 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 next 5 Year Strategic Plan April 2018 – March 2023 will be based on recommendations from the forthcoming registry review.

***The key priorities for 2018/19 are to*:**

- Provide accurate, timely data on cancers in N. Ireland for official statistics by March 2019 for patients diagnosed in 2017
- Maintain our ISO27001 Certification in Information Security Management certification
- 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
- Continue to undertake feedback to clinicians on CaPPS data fields to enhance quality of data items recorded
- Prepare for Registry review June 2018
- Work with clinicians, NICaN and PHA to achieve inclusion of NI data in National Clinical Audits
- Provide data for UKIACR 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
- To 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.

Achieving these targets, in the face of increasing numbers of cancers and the increased complexity of the information to be recorded, will require additional staffing in all areas. Therefore the Registry will continue to strive for additional resources from grants, and by seeking a more sustainable model of funding for the NICR.

Goals

Goal 1 – Provide accurate, timely data on cancers and premalignant disease in N. Ireland

Key Actions

- Launch official statistics of cancer incidence, prevalence and survival statistics for patients diagnosed in 2017 by March 2019 and provide at that time a suite of derived site specific factsheets for the NICR website.
- Provide accurate Northern Ireland cancer datasets for international comparison.
- Enhance staging data available on each patient to maintain goal of high overall staging (85% achieved for 2016 data).

- 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.
- Consolidate links with RISOH system to ensure relevant clinical information is available to NICR.
- Consolidate link to Radiology systems to enable the interrogation of imaging reports.
- Ensure that the NICR has continued look up access to the historic COIS dataset.
- Further investigate the provision of appropriate and faster network links to HSC network.
- 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.
- Assess Registry resource requirements to maintain current standards of timeliness, completeness and accuracy in views of increasing numbers of cancer cases.
- Provide data for UKIACR annual Performance Indicators within timescale.

Goal 2 – Protect the confidentiality of the data

Key Actions

- Maintain ISO27001 Certification in Information Security Management for NICR.
- Ensure staff training is maintained.
- Ensure research projects adhere to the NICR & QUB Research and GDPR directives.
- Ensure that all relevant research projects have ethical approval prior to commencement.
- Pursue achievement of accommodation with QUB to ensure data confidentiality.
- Link with Privacy Advisory Committee and BSO regarding future of historic PSA database.

Goal 3 – Continue with upgrades to the Registry IT System and extend its capacity to store data items

Key Actions

- Write a business case to identify best outcome.
- Identify budget for Praxis support/minor developments.
- Expand database to include additional items e.g. HER2, ER, PR, PSA, and others are recorded on the patient record.
- Investigate recurrence algorithm and if possible build into Praxis.

Goal 4 - Provide a cancer intelligence service

Key Actions

- Introduce full ICDO3 & TNM8 coding.
- Answer all data requests within time limits of 20 days for general requests and 10 days for genetic requests.
- Continue to facilitate the Northern Ireland Clinical Genetics Service access to NICR datasets.
- Feedback research findings to relevant partners and associated patient groups.
- Ensure website is kept up to date.
- Enhance visibility of Official Cancer Statistics on webpage.

- Work to achieve additional resources to provide Northern Ireland data for national audits and peer review eg National Lung, Bowel, Prostate and Oesophago-gastric Cancer Audits.
- Work to provide information for outcomes of care as required by PHA, NICaN and Trusts.
- Produce updated cancer factsheets from Official Statistics 2016 data with additional clinical data added for specific cancer sites.
- Maximise use of media to promote NICR, messages of cancer prevention and early detection.

Goal 5 – Facilitate the planning and monitoring of cancer services in N. Ireland

Key Actions

- 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.
- Ensure audit and research findings are disseminated to key organisations/individuals to encourage implementation of recommendations.
- Work to achieve resources to ensure that N. Ireland data are included in national audits.
- Enhance availability of information on website and dissemination of data and reports through other online partners.

Goal 6 – Undertake and present internationally recognised research and audits

Key Actions

- Work with clinicians, NICaN/PHA to achieve inclusion of NI data in National Clinical Audits.
- Apply for at least 1 research grant.
- Submit 8 papers for peer review in high impact journals.
- Enhance the completeness and quality of the Prostate Specific Antigen database and complete PSA study (externally funded).
- Ensure N. Ireland provide relevant data for International Cancer Benchmarking Partnership (ICBP) studies.
- Work to maximise outputs from a Patient Reported Outcomes Measures (Life After Prostate Cancer Diagnosis - LAPCD) Study (externally funded).
- Maximise outputs from and use of LAPCD related study for baseline population urological symptoms (externally funded).
- Submit abstracts and attend relevant conferences.
- Work with NI Biobank and local researchers to enhance use of NICR data for scientific study.
- 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
    - Commence work with ADRC-NI to study outcomes
    - Continue to provide information on Recurrence.

Goal 7 - Ensure the Registry provides value for money

Key Actions

- 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.
- Manage budgets from research grants.
- Implement and monitor cost recovery/administrative policy to ensure resources are available for time consuming requests.
- Involve staff in planning of targets for 2018/2019.
- Ensure that the development of the NI Stroke Registry does not negatively impact on current NICR resources, including staff.

Goal 8 – Ensure the sustainability of the Registry

Key Actions

- Prepare for Registry Review in 2018.
- Work with Registry funders and QUB to ensure arrangements reflect the long-term nature of Cancer Registration.
- Inform and support relevant stakeholders in the development of the regulations for the Health and Social Care Act – now expected 2019.
- Ensure staff are trained to a high level for their work.
- Maintain a high registry profile locally and internationally.
- Achieve additional grant income.
- Organise opportunities to highlight the work of the Registry to external groups.
- Work to achieve succession planning for registry posts.
- Develop a risk register for the Registry.

Goal 9 – Ensure good links with patients and their representatives

Key Actions

- Continue to involve patients and their representatives in our Council, Steering group and in Registry work.
- Include a patient representative in the NICR Review 2018.
- Involve patients as speakers/invitees at launch of reports.
- Develop new Patient Information Leaflet to reflect detail of legislative framework for cancer registration when available.
- Continue to enhance the NICR website to better disseminate and improve access to NICR data to improve public understanding of cancer in Northern Ireland.
- Provide regular inputs to the Knowledge Exchange website/database.
- Ensure data available to the public on cancer in N. Ireland are up to date and accurate.

Goal 10 – Promote expertise of data acquisition and analysis

Key Actions

- Use expertise of data acquisition and analysis for promotion of data availability for other diseases.
- Link nationally and internationally to promote cancer registration and increase understanding and control of cancer including promoting cancer staging tool.
- Provide data for UKIACR Performance Indicators.

Goal 11 – Provide an environment for education and training

Key Actions

- Offer training slots to undergraduate/postgraduate students and Public Health trainees.
- Raise awareness of the Cancer Registry within the University and beyond.
- Maintain international links on new developments in cancer registration and cancer research.
- Facilitate medical/research staff with access to relevant registry datasets within confidentiality and ethical guidelines.
- Ensure the Registry environment and processes support education and training while maintaining data security.

REFERENCES

1. Bhat SK, McManus DT, Coleman HG, Johnston BT, Cardwell CR, McMenamin U, Bannon F, Hicks B, Kennedy G, Gavin AT, Murray LJ. Oesophageal adenocarcinoma and prior diagnosis of Barrett's oesophagus: a population-based study. Gut 2015;64(1):20-5.

2. Coleman HG, Bhat SK, Murray LJ, McManus DT, O'Neill OM, Gavin AT, Johnston BT. Symptoms and endoscopic features at Barrett's esophagus diagnosis: implications for neoplastic progression risk. Am J Gastroenterol 2014;109(4):527-34.

3. Bird-Lieberman EL, Dunn JM, Coleman HG, Lao-Sirieix P, Oukrif D, Moore CE, Varghese S, Johnston BT, Arthur K, McManus DT, Novelli MR, O'Donovan M, Cardwell CR, Lovat LB, Murray LJ, Fitzgerald RC. Population-based study reveals new risk-stratification biomarker panel for Barrett's esophagus. Gastroenterology 2012;143(4):927-35.e3.

4. Coleman HG, Bhat S, Johnston BT, McManus D, Gavin AT, Murray LJ. Tobacco smoking increases the risk of high-grade dysplasia and cancer among patients with Barrett's esophagus. Gastroenterology 2012;142(2):233-40.

5. Bhat S, Coleman HG, Yousef F, Johnston BT, McManus DT, Gavin AT, Murray LJ. Risk of malignant progression in Barrett's esophagus patients: results from a large population-based study. J Natl Cancer Inst 2011;103(13):1049-57. Erratum in: J Natl Cancer Inst. 2013;105(8):581.

6. Coleman HG, Bhat S, Murray LJ, McManus D, Gavin AT, Johnston BT. Increasing incidence of Barrett's oesophagus: a population-based study. Eur J Epidemiol. 2011 Sep;26(9):739-45. doi: 10.1007/s10654-011-9596-z.

7. Anderson LA, Murray LJ, Murphy SJ, Fitzpatrick DA, Johnston BT, Watson RG, McCarron P, Gavin AT. Mortality in Barrett's oesophagus: results from a population based study. Gut 2003;52(8):1081-4.

8. Murphy SJ, Anderson LA, Mainie I, Fitzpatrick DA, Johnston BT, Watson RG, Gavin AT, Murray LJ. Incidence of colorectal cancer in a population-based cohort of patients with Barrett's oesophagus. Scand J Gastroenterol 2005;40(12):1449-53. Erratum in: Scand J Gastroenterol 2006;41(2):247.

9. Murray L, Watson P, Johnston B, Sloan J, Mainie IM, Gavin A.Risk of adenocarcinoma in Barrett's oesophagus: population based study. BMJ 2003;327(7414):534-5.

10. Coleman HG, Loughrey MB, Murray LJ, Johnston BT, Gavin A, Shrubsole MJ, Bhat SK, Allen PB, McConnell V, Cantwell MM.Colorectal cancer risk following adenoma removal: a large prospective population-based cohort study. Cancer Epidemiol Biomarkers Prev 2015; 24(9):1373-80.

11. Santin S, Murray L, Prue G, Gavin A, Gormley G, Donnelly M. Self-reported psychosocial needs and health-related quality of life of colorectal cancer survivors. European Journal of Oncology Nursing 2015; 19; 336-342.

12. McClements J, Fitzpatrick D, Campbell WF, Gavin A. Changes in Management and outcome of patients with rectal cancer in Northern Ireland: 1996-2006. Colorectal Disease 2014;16(2):O58-65.

13. Maringe C, Walters S, Rachet B, Butler J, Fields T, Finan P, Maxwell R, Nedrebø B, Pahlman L, Sjövall A, Spigelman A, Engholm, Gavin A, Gjerstorff ML, Hatcher J, Johannesen TB, Morris E, McGahan CE, Tracey E, Turner D, Richards MA, Coleman MP & The ICBP Module 1 Working Group. Stage at diagnosis and colorectal cancer survival in six high-income countries: a population-based study of patients diagnosed during 2000-2007. Acta Oncol 2013;52(5):919-32.

14. Connolly D, Van Leeuwen PJ, Bailie J, Black A, Murray LJ, Keane PF, Gavin A. Daily, monthly and seasonal variation in prostate specific antigen levels and the association with weather parameters. Prostate Cancer and Prostatic Diseases, March 2011, doi:10.1038/pcan.2010.37.

15. van Leeuwen PJ, Connolly D, Tammela TLJ, Auvinen A, Kranse R, Roobol MJ, Schröder FH, Gavin AT. Balancing the harms and benefits of early detection of prostate cancer. Cancer 2010, doi: 10.1002/cncr.25474.

16. Van Leeuwen PJ, Connolly D, Gavin A, Roobol MJ, Black A, Bangma CH, Schroder FH. Prostate cancer mortality in screen and clinically detected prostate cancer: Estimating the screening benefit. Eur J Cancer 2010, doi:10.1016/j.ejca.2009.09.008.

17. Connolly D, Black A, Murray LJ, Nambirajan T, Keane PF, Gavin A. Repeating an abnormal prostate-specific antigen (PSA) level: how relevant is a decrease in PSA?. Prostate Cancer and Prostatic Diseases, March 2009, doi:10.1038/pcan.2008.37.

18. Connolly D, Black A, Murray L, Nambirajan T, Keane PF, Gavin AT. The utility of prostate – specific antigen velocity thresholds in clinical practice: a population – based analysis. British Journal of Urology International, June 2008, doi: 10.1111/j.1464-410X.2008.07470.x.

19. Connolly D, Black A, Gavin AT, Keane PF, Murray L. Baseline prostate-specific-antigen level and risk of prostate cancer and prostate-specific mortality: diagnosis is dependent on the intensity of investigation. CEBP, February 2008, doi: 10.1158/1055-9965.EPI-07-0515.

20. Connolly D, Black A, Murray L, Napolitano G, Gavin AT, Keane PF. Methods of calculating prostate-specific antigen velocity. European Urology, October 2007, doi: 10.1016/j.eururo.2006.12.017.

21. Carsin AE, Drummond FJ, Black A, van Leeuwen PJ, Sharp L, Murray LJ, Connolly D, Egevad L, Boniol M, Autier P, Comber H, Gavin AT. Impact of PSA testing and prostatic biopsy on cancer incidence and mortality: comparative study between the Republic of Ireland and Northern-Ireland. Cancer Causes and Control, September 2010, doi: 10.1007/s10552-010-9581-y.

22. Gormley GJ, Catney D, McCall JR, Reilly PM, Gavin AT. Prostate-specific antigen testing: uncovering primary care influences. British Journal Urology International, November 2006, doi: 10.1111/j.1464-410X.2006.06481.x.

23. Gavin AT, McCarron P, Middleton RJ, Savage G, Catney D, O'Reilly D, Keane PF, Murray LJ. Evidence of prostate cancer screening in a UK region. British Journal of Urology International, online March 2004, DOI: 10.1111/j.1464-410X.2003.04716.x

24. Kearney TM, Donnelly C, Kelly JM, O'Callaghan EP, Fox CR, Gavin A. Validation of completeness and accuracy of the Northern Ireland Cancer Registry. Cancer Epidemiol 2015. doi: 10.1016/j.canep.2015.02.005. Epub 2015 Mar 12.

APPENDIX A: Steering Group and Council Membership and Role

NICR Steering Group
Role of Steering Group as revised 8th February 2012

a) Agreeing to 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 N. Ireland Cancer Network

Membership 2018

Prof Ken Mills (Chair)	QUB
Ms Cara Anderson	HSC Board, Asst Director Commissioning (Cancer & Pathology)
Ms Lyn Benson	HSC Board, Financial Accounts & Governance
Dr Martin Eatock	NICaN, Medical Director
Ms Roisin Foster	Cancer Focus NI, CEO of this cancer charity
Dr Aidan Cole	Clinician
Dr Louise Herron	Public Health Agency

Attended by registry director and deputy director.

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
Prof Roy Spence (ex Chair)	Belfast HSC Trust
Dr Neil Anderson	Belfast HSC Trust
Ms Margaret Carr	Cancer Research UK
Dr Olivia Dolan	Belfast HSC Trust
Dr Andrew Galwey	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 Maurice Loughrey	Pathologist Belfast HSC Trust
Dr Seamus McAleer	Oncologist QUB
Dr Shane McKee	Consultant in Clinical Genetics Belfast HSC Trust
Ms Heather Monteverde	Macmillan Chief Executive, N. Ireland
Prof Joe O'Sullivan	Radiotherapist Belfast HSC Trust
Miss Rosemary Rainey	Lay representative
Dr Michael Reilly	Western HSC Trust
Dr Keith Rooney	Consultant in Cancer Centre

With attendance from registry director, deputy director and relevant staff required for the agenda.

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 90976440.

Where can I get more information?

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

- Cancer Focus Northern Ireland
  Helpline 0800 783 3339
  9am - 1.00 pm, Monday to Friday
- 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.

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:

Crystal Mark
Clarity approved by Plain English Campaign

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

Tel: 028 90976440
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 processes and procedures.

BM TRADA

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, CancerB7, Cancer Research UK, GIST Support UK, It's In the Pipe, 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

Executive Summary

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

Indicator	Country average (population)	Country average (country)	England	Scotland	Northern Ireland
Stability: Percentage change (%) for all cancers (C00-C97 ex. C44) in 2016 compared with 2013-2015	**0.2%**	**-0.4%**	0.6%	4.1%	2.2%
Registry Creep: Percentage (%) for all cancers (C00-C97 ex. C44) of 2015 registrations at 31/01/2018 compared with registrations at 31/01/2017	**1.3%**	**2.1%**	1.1%	3.0%	2.1%
Staging: Proportion (%) of all cases (C00-C97 ex. C44) with valid known stage registered out of all 2016 registered cancers (C00-C97 ex. C44)	**80.6%**	**77.9%**	81.9%	67.2%	84.7%
Average of Core Patient Information Complete: Average percentage (%) of all cancers (C00-C97 ex. C44) registered with demographic information	**98.5%**	**94.3%**	99.1%	96.3%	87.5%
Average of Core Tumour Information Complete: Average percentage (%) of all cancers (C00-C97 ex. C44) registered with tumour information	**97.3%**	**96.2%**	97.4%	96.5%	94.6%
Diagnosing Hospital Known: Percentage (%) of all cancers (C00-C97 ex. C44) registered with an organisation of diagnosis	**97.2%**	**91.7%**	98.0%	93.5%	83.6%
Death Certificate Only (DCO) Rates: Percentage (%) of all cancers (C00-C97 ex. C44) registered as a DCO	**0.5%**	**0.4%**	0.5%	0.2%	0.4%

Zero Day Survivors: Percentage (%) of all cancers (C00-C97 ex. C44) registered with the date of death equals the date of diagnosis	**1.2%**	**0.9%**	1.3%	0.6%	0.7%
Microscopically Verified: Percentage (%) of all cancers (C00-C97 ex. C44) that are microscopically verified	**85.2%**	**84.8%**	85.3%	83.9%	85.3%
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%	1.2%	1.5%
Grade: Percentage (%) of all cancers (C00-C97 ex. C44) registered with a known grade	**60.2%**	**61.1%**	60.2%	58.6%	64.4%
Treatment: Percentage (%) of all cancers (C00-C97 ex. C44) registered with any treatment	**87.1%**	**79.2%**	88.9%	69.5%	NA
Breast Screening Data: Percentage of breast cancer (C50) cases from 2015 screen detected for ages 50-64	**45.1%**	**48.1%**	44.3%	51.4%	48.4%
Cervical Screening Data: Percentage of cervical cancer (C53) cases from 2015 screen detected for ages 25-60	**32.0%**	**37.7%**	30.0%	45.3%	NA
Bowel Screening Data: Percentage of bowel cancer (C18-C20) cases from 2015 screen detected for ages 60-69	**24.9%**	**25.9%**	24.6%	27.1%	NA

APPENDIX D: Factsheets from Official Statistics

ALL CANCER (EXCLUDING NMSC)

AVERAGE NUMBER OF CASES PER YEAR (2012-2016)[1]			AVERAGE NUMBER OF DEATHS PER YEAR (2012-2016)		
Male	Female	Both sexes	Male	Female	Both sexes
4,607	4,632	9,240[1]	2,238	2,036	4,274
FIVE-YEAR SURVIVAL (2006-2010)			**24-YEAR PREVALENCE (2016)**		
Male	Female	Both sexes	Male	Female	Both sexes
53.1%	56.4%	55.1%	26,686	34,352	61,038

[1] Mean yearly incidence data for period 2012-2016 has been rounded to nearest integer, and thus some numbers in tables will not add to give the exact total.

INCIDENCE

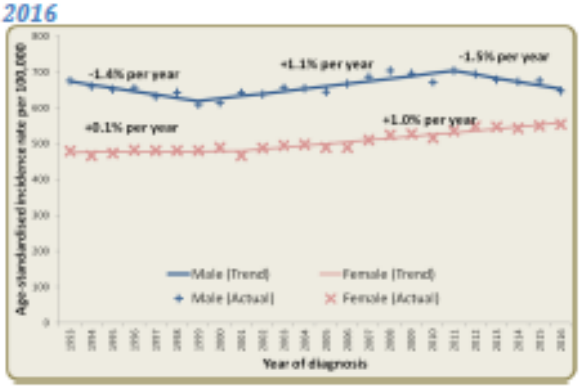
From 2012 to 2016, on average, there were 4,607 male and 4,632 female patients diagnosed with cancer each year excluding Non-Melanoma Skin Cancer (NMSC). There were an additional 2,124 male and 1,594 female patients diagnosed with NMSC. The lifetime risk of developing a cancer (excluding NMSC) was 1 in 3.5 for men and 1 in 3.7 for women.

Incidence trends

Table 1: Incidence of cancer by sex and year of diagnosis: 2007-2016

	2007	2008	2009	2010	2012	2012	2013	2014	2015	2016
Male	4,044	4,181	4,219	4,156	4,483	4,520	4,529	4,614	4,745	4,629
Female	3,885	4,075	4,127	4,110	4,328	4,488	4,561	4,583	4,712	4,817
Both sexes	7,929	8,256	8,346	8,266	8,811	9,008	9,090	9,197	9,457	9,446

Figure 1: Trends in cancer incidence rates by sex: 1993-2016



Over the last ten years the number of cancer cases (excluding non melanoma skin cancers) increased between 2007 and 2016 from 4,044 to 4,629 among men and 3,885 to 4,817 among women. This increase of 15% in men and 24% in women (19% overall) is largely due to increasing numbers of older people in the population. After accounting for our aging population, cancer incidence rates increased among males during 1999-2011 by an average of 1.1% per year, followed by a decrease of 1.5% between 2011-2016. From 2001-2016, female incidence rates increased steadily by an average of 1.0% per year.

1

Incidence and age

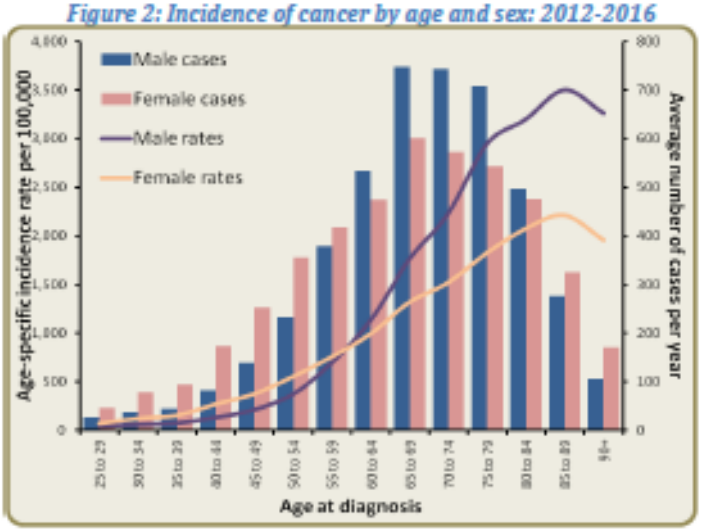
The risk of developing cancer increases with age, with over 60% of cancers occurring in those aged over 65 and incidence rates greatest for those aged 80-89 in both men and women.

Table 2: Average number of cancers diagnosed per year by sex and age: 2012-2016

Age (years)	Male	Female	Total
0 to 49	385	698	1,083
50 to 64	1,144	1,247	2,391
65 to 74	1,491	1,173	2,664
75 and over	1,587	1,514	3,102
All ages	4,607	4,632	9,240

Due to rounding of yearly averages, 'All ages' may not equal the sum of age categories in tables.

Figure 2: Incidence of cancer by age and sex: 2012-2016



Cancer site

Cancer can occur in many different parts of the body, some more common than others and with considerable variation between males and females. The most common cancers among males between 2012 and 2016 were prostate, colorectal, lung, head & neck and lymphomas (Fig. 3) while the most common cancers among women were breast, lung, colorectal and uterine cancer (Fig. 4).

Figure 3: The most common cancers (excluding NMSC) diagnosed in men: annual incidence 2012-2016

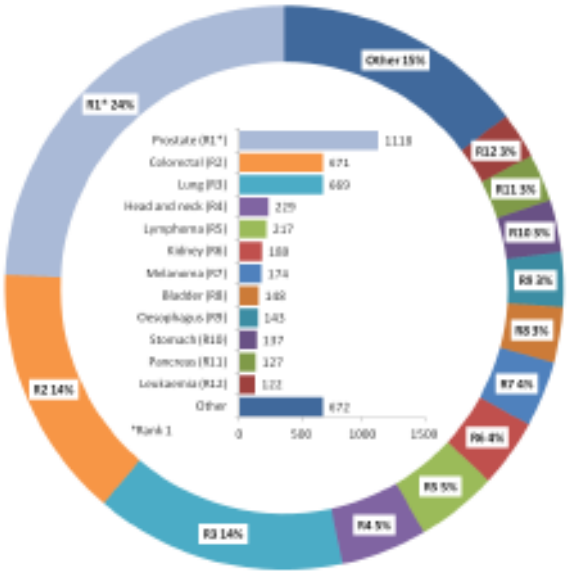
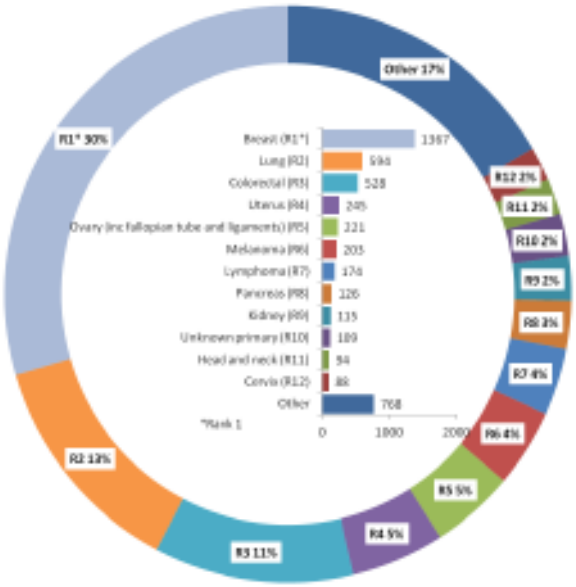


Figure 4: The most common cancers (excluding NMSC) diagnosed in women: annual incidence 2012-2016



Age at diagnosis by cancer site 2012-2016

Age at diagnosis varied by cancer site. Overall half of cancer patients were diagnosed before the age of 69 years (median age) with median age at diagnosis higher among males (70 years) than females (68 years). In men, the median age ranged from 35 years for testicular cancer to 75 years for bladder cancer. In women, the median age ranged from 41 years for cervical cancer to 78 years for stomach cancer. The most common cancers, breast cancer among females and prostate cancer among males, had a median age at diagnosis of 63 years and 70 years, respectively.

Figure 5: The median age of male cancer patients by cancer site

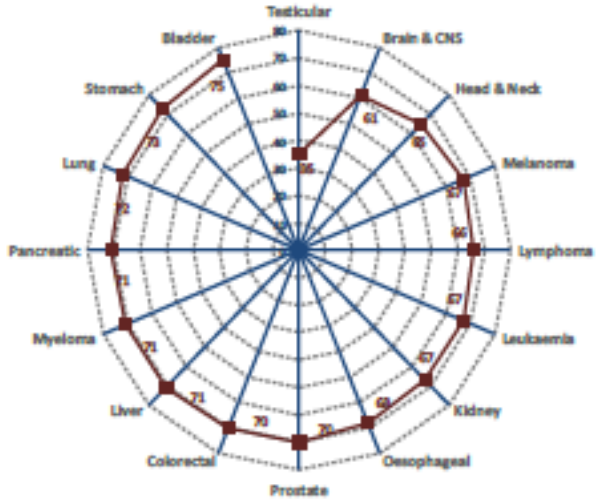
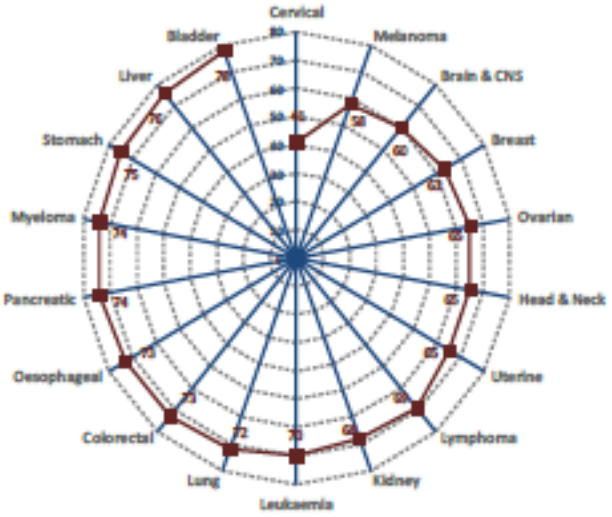


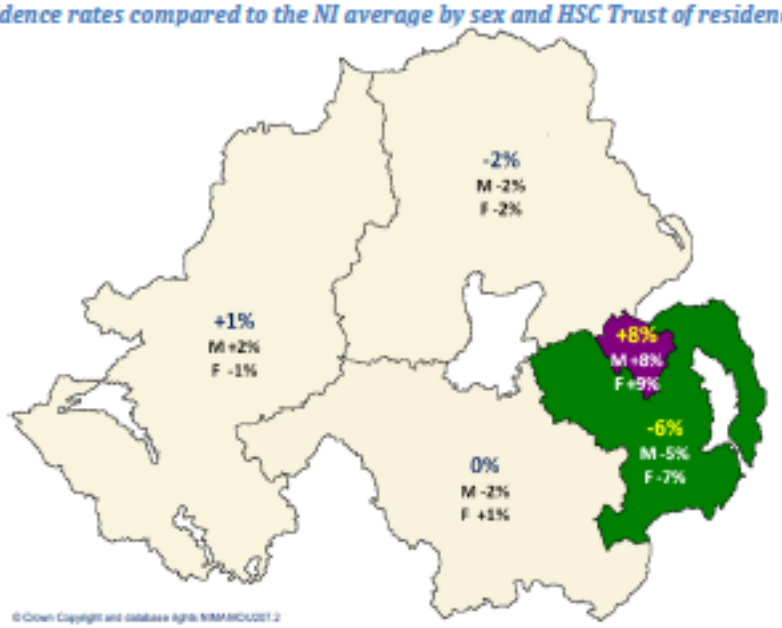
Figure 6: The median age of female cancer patients by cancer site



Incidence by Trust area

Incidence rates of cancer (excluding NMSC) in 2012-2016 were 8% higher among people living in Belfast HSCT area than the NI average. Rates were lower than the NI average for those living in the South-Eastern Trust area.

Figure 7: Cancer incidence rates compared to the NI average by sex and HSC Trust of residence: 2012-2016



Significantly higher than average

Significantly lower than average

Incidence by deprivation

Some geographical variation is due to a relationship between cancer and socio-economic deprivation. Cancer incidence is higher in the most deprived communities in Northern Ireland though this varies significantly by cancer site. Incidence of cancer of the head & neck, oesophagus, stomach, lung, pancreas, male-colorectal, and cervix are higher in more deprived areas while incidence of breast, melanoma, non-melanoma skin and prostate cancer are higher in the least deprived communities.

Figure 8: All cancer incidence rates compared to the NI average by sex and deprivation quintile: 2012-2016

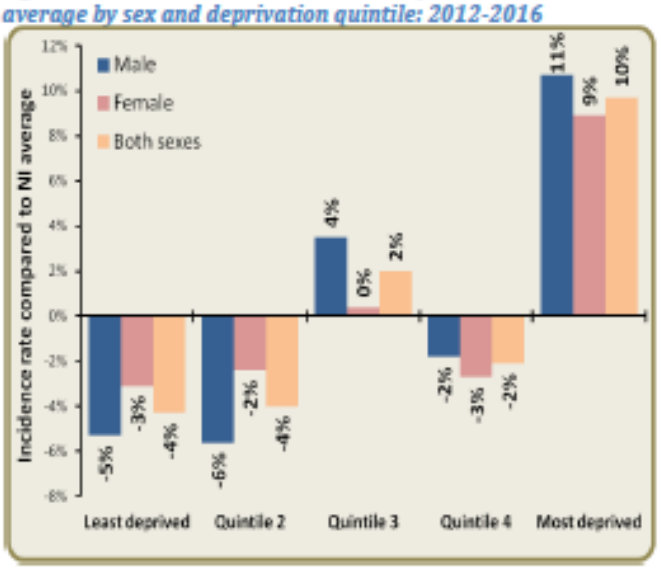


Table 3: The relationship between cancer incidence rates and socio-economic deprivation

Incidence rates higher in deprived than affluent areas	No significant relationship	Incidence rates higher in affluent than deprived areas
Head & neck, oesophagus, stomach, lung, pancreas, male-colorectal, cervix	Kidney, Liver, Myeloma, Uterus, Ovary, Testes, Lymphoma, Leukaemia, Bladder	Breast, Melanoma, Non-melanoma skin, Prostate

SURVIVAL

Overall survival

The net survival was 70.5% at one year, and 55.1% at five years for patients diagnosed in 2006 to 2010.

Table 4: Five-year survival by sex: patients diagnosed 2006-2010

Time since diagnosis	Diagnosed 2006-2010		
	Male	Female	Both sexes
6 months	76.9%	78.0%	77.6%
1 year	69.2%	71.5%	70.5%
5 years	53.1%	56.4%	55.1%

Survival Trends

Five-year net survival from cancer has improved, increasing from 38.3% to 53.1% for men and from 48.0% to 56.4% for women, when we compare patients diagnosed from 1993 to 2000 to those diagnosed from 2006 to 2010.

Table 6: Five-year survival by period of diagnosis and sex

Period of diagnosis	Male	Female	Both sexes
1993-2000	38.3%	48.0%	43.6%
2001-2005	47.0%	52.7%	50.2%
2006-2010	53.1%	56.4%	55.1%

Survival and cancer site

Survival varied by cancer site with estimates of five-year (age-standardised) net survival for male patients diagnosed 2006-2010 ranging from 5.0% for pancreatic cancer to 97.8% for testicular cancer. Among females five-year (age-standardised) net survival ranged from 4.9% for pancreatic cancer to 92.8% for non-invasive brain cancer. Comparisons of five-year survival for patients diagnosed 2005-2009 to those diagnosed 1993-2000 show survival improvements for all cancers except bladder cancer in both females and males. Three (breast, colorectal and prostate) of the four most common cancers showed strong improvement.

Table 7: Five-year age-standardised net survival of patients diagnosed 2006-2010 compared to patients diagnosed 1993-2000 by site

	1993-2000		2006-2010	
Site (ICD10 code[1])	Male	Female	Male	Female
All Cancers excluding NMSC (C00-C43,C45-C97)	38.3%	48.0%	53.1%	56.4%
Bladder (C67)	59.9%	48.5%	57.6%	43.4%
Brain and other CNS (C70-C72,C75.1-C75.3)	16.3%	22.0%	24.0%	24.8%
Breast (C50)	-	75.9%	-	81.7%
Cervix (C53)	-	58.4%	-	63.0%
Childhood cancer (C00-C97,ex C44)	73.6%[3]	75.1%[3]	76.4%[3]	84.2%[3]
Colon (C18)	50.5%	52.1%	57.3%	58.0%
Colorectal (C18-C20)	49.6%	51.1%	56.9%	58.6%
Head and Neck (C00-C14; C30-C32)	53.0%	48.1%	54.4%	56.0%
Hodgkin Lymphoma (C81)	75.9%[3]	78.2%[3]	86.9%[3]	73.8%[3]
Kidney (C64)	49.3%	51.2%	56.9%	54.7%
Leukaemia (C91-C95)	34.1%	35.2%	52.0%	54.8%
Lip, Oral Cavity & Pharynx (C00-C14)	46.2%	42.3%	51.3%	52.5%
Liver & Intrahepatic Bile Ducts (C22)	4.9%	4.9%	6.7%	10.7%
Lung, Bronchus & Trachea (C33-C34)	8.0%	9.4%	10.1%	11.0%
Lymphoma (C81-C86)	44.6%	49.8%	62.1%	66.7%
Malignant Melanoma (C43)	85.5%	90.8%	89.6%	92.0%
Multiple Myeloma (C90)	27.3%	35.0%	49.3%	51.6%
Non-Hodgkin Lymphoma (C82-C85)	42.3%	48.8%	60.2%	66.9%
Non-Invasive Brain (D32,D33.0-D33.4,D35.2-D35.4,D42,D43.0-D43.4,D44.3-D44.5)	87.2%	85.9%	90.7%	92.8%
Oesophagus (C15)	8.9%	15.8%	19.2%	20.3%
Ovary (including fallopian tube and ligaments) (C56-C57.7)	-	36.9%	-	40.8%
Pancreas (C25)	2.2%	2.7%	5.0%	4.9%
Prostate (C61)	63.5%	-	88.7%	-
Rectum (C19-C20)	47.4%	48.4%	56.0%	59.9%
Stomach (C16)	15.6%	17.2%	18.6%	21.2%
Testis (C62)	94.5%[3]	-	97.8%[3]	-
Ill defined, secondary and unspecified sites (C76-C80)	6.8%	9.7%	11.6%	10.4%
Uterus body (endometrium) (C54-C55)	-	64.7%	-	77.6%

1 The classification of different tumours codes see: International Statistical Classification of Diseases and Related Health Problem to cancer types, e.g. lung is done using ICD10 codes. For a listing and explanation of ICD10 topography or site s, Tenth Revision, World Health Organisation, Geneva. Or view online at http://apps.who.int/classifications/icd10/browse/2010/en#/II

2 Not-applicable

3 Survival estimate is not age-standardised because of small numbers of patients diagnosed in the period

Mortality

Mortality statistics are provided by the Northern Ireland General Registrar's Office. In 2012-2016 there were on average 2,256 male and 2,043 female deaths from malignant cancer each year. The most common cause of cancer death among males was lung cancer followed by prostate cancer and colorectal cancer (Fig. 9), while among women the most common cause of cancer death was lung cancer followed by breast cancer (Fig. 10).

Figure 9: The most common cancer deaths in men: average annual deaths 2012-2016. Multiple myeloma, mesothelioma, and malignant melanoma included in 'other'.

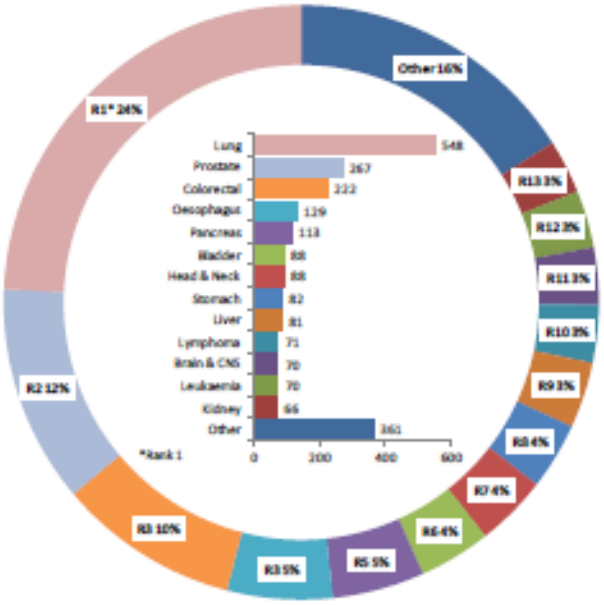
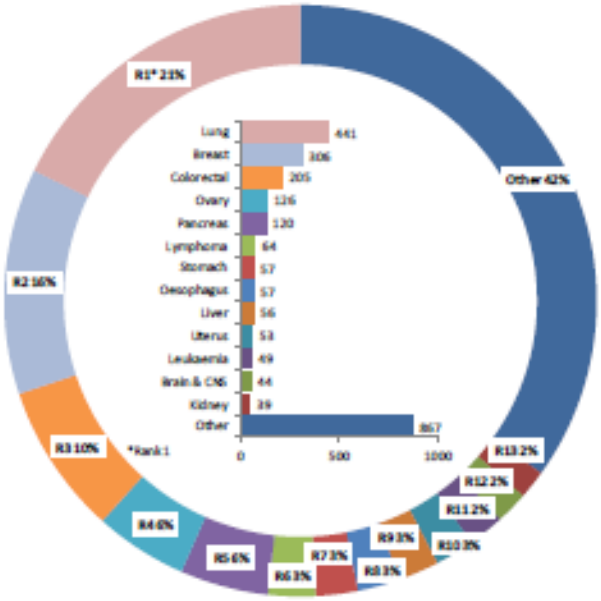


Figure 10: The most common cancer deaths in women average annual deaths 2012-2016. Bladder, multiple myeloma, head and neck, cervix, malignant melanoma included in 'other'.

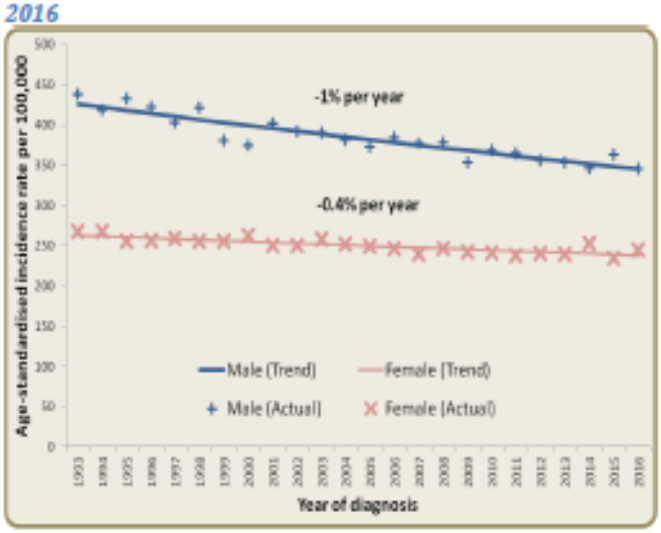


Mortality trends

Over the ten years to 2016 the number of cancer deaths increased by 16% from 2,024 among men and 1,795 among women in 2007 to 2,298 among men and 2,122 among women in 2016 (14% increase in men, 18% in women)

When adjusted for age and population change, cancer mortality rates during 1993-2016 decreased per year by 1.0% in males, and 0.4% in females. Trends in cancer death varied by cancer site. Among men, mortality rates decreased for lung, prostate and colorectal cancer. Among women, mortality rates decreased for breast and colorectal cancer but increased for lung cancer.

Figure 11: Trends in cancer mortality rates by sex: 1993-2016



PREVALENCE

At the end of 2016 there were 61,038 people living in NI who had been diagnosed with cancer within the previous twenty-four years (Table 8). Of these, 43.7% were male, 47.4% were aged 70 and over and 10.9% had been diagnosed in the previous year.

Table 8: Number of people living with cancer at the end of 2016 who were diagnosed within the past twenty-four years by time since diagnosis

Sex	Age at end of 2016	Time since diagnosis				24-year Prevalence
		0-1 year	1-5 years	5-10 years	10-24 years	
Male	0-69	1,741	4,622	3,219	2,971	12,553
	70+	1,540	4,267	4,063	4,263	14,133
	All ages	3,281	8,889	7,282	7,234	26,686
Female	0-69	2,075	6,221	5,258	5,980	19,534
	70+	1,272	3,737	3,552	6,257	14,818
	All ages	3,347	9,958	8,810	12,237	34,352
Both sexes	0-69	3,816	10,843	8,477	8,951	32,087
	70+	2,812	8,004	7,615	10,520	28,951
	All ages	6,628	18,847	16,092	19,471	61,038

Among men, prostate cancer was the most prevalent cancer accounting for 37% of total prevalence (Fig. 12). This was followed by colorectal cancer (18%) and lymphoma (7%). Among women, breast cancer (45%) was most prevalent followed by colorectal cancer (11%) and malignant melanoma (8%) (Fig. 13).

Figure 12: The number of male cancer patients alive on 31st December 2016 diagnosed since 1993 (24-year prevalence) by cancer site

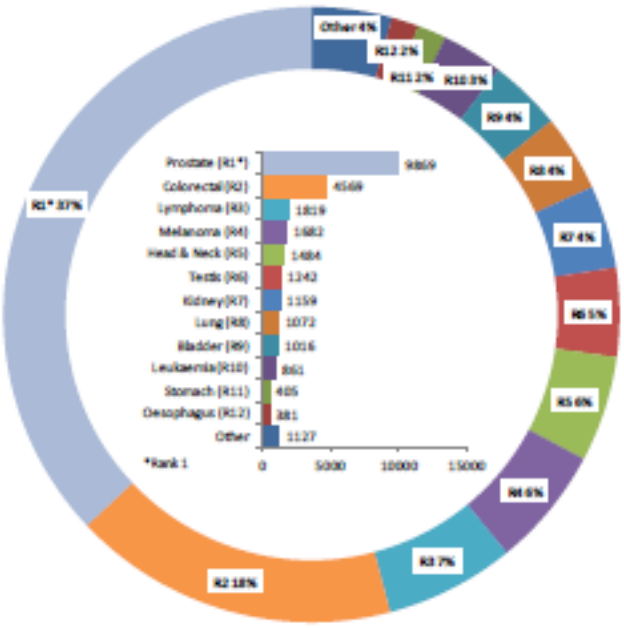
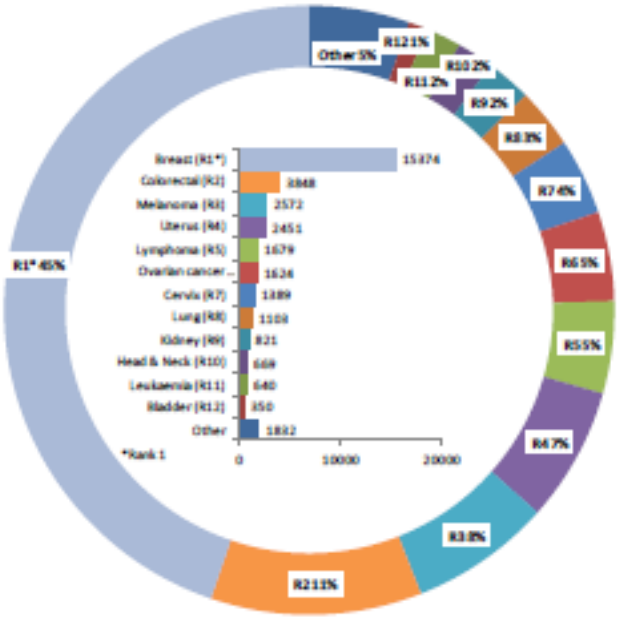


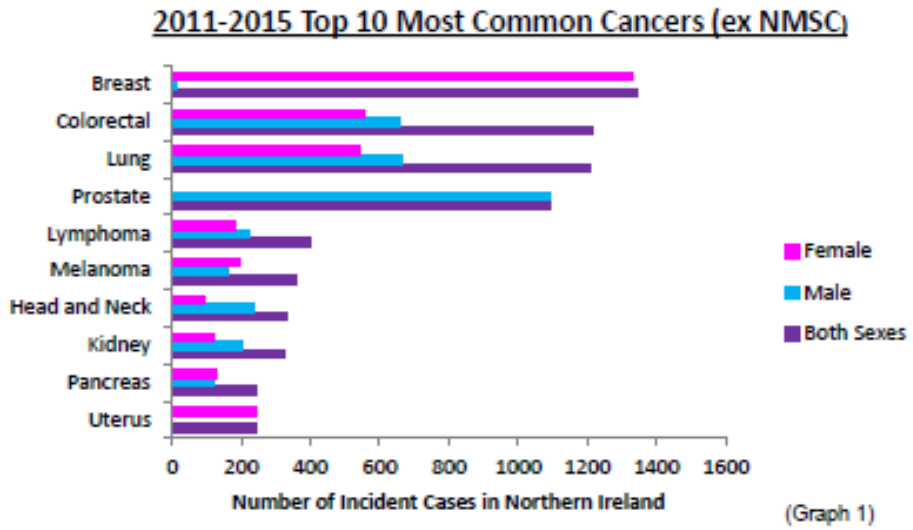
Figure 13: The number of female cancer patients alive on 31st December 2016 diagnosed since 1993 (24-year prevalence) by cancer site



APPENDIX E: Example Clinical Factsheet

Colorectal Cancer Statistics

A supplementary report provided by the NI Cancer Registry (NICR) for the Colorectal CRG



(Graph 1)

Colorectal Cancers represent the 2nd most common type of cancer diagnosed between 2011 and 2015 in Northern Ireland (NI) (ICD10 C18 & C20) Excluding Non-melanoma-skin cancer which had 3,641 cases in 2015. The table below shows the average anatomical distribution of malignant cases covered by the Colorectal NICaN CRG as per the 2011-2015 NICR Official Statistics.

Average Number of Incident Cases by Anatomical Site 2011-2015

Anatomical Site ICD10 C17.0-C21.8	Average Number of Cases 2011-2015
Small Intestine	46
Caecum	180
Appendix	29
Ascending Colon	130
Hepatic Flexure	46
Transverse Colon	74
Splenic Flexure	27
Descending Colon	46
Sigmoid Colon	253
Overlapping & Unspecified Colon	44
Rectosigmoid Junction	63
Rectum	321
Anus	5
Anal Canal	17
Overlapping Lesion of Rectum, Anus, & Anal Canal	6
Total	1287

(Table 1)

Colorectal Cancer Statistics

Incidence of Colon (ICD10 C18 & C20) and Rectal Cancer by Year of Diagnosis: 2006-2015

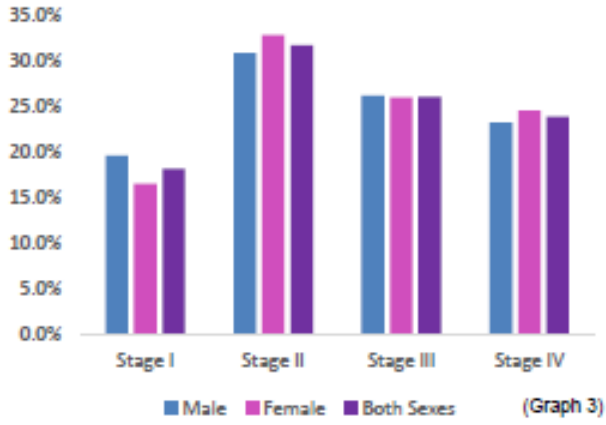
	2006	2007	2008	2009	2010	2011	2012	2013	2014	2015
Colon	684	780	721	718	792	826	837	876	838	774
Rectum	276	302	316	291	302	341	365	309	292	297
Total	960	1082	1037	1009	1094	1167	1202	1185	1130	1071

(Table 2)

N.B. In 2015 total percentage of screen detected bowel cancers (ages 60-69) in Northern Ireland = 27%

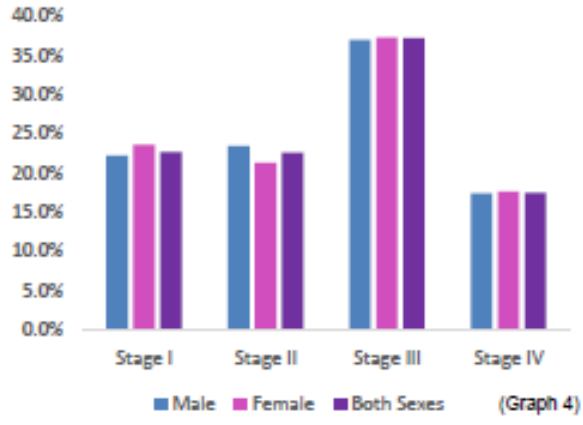
Graphs 3 and 4 below show the average stage distribution of incident cases diagnosed in NI between 2011 and 2015.

Average Stage at Diagnosis: Colon Cancer 2011-2015



(Graph 3)

Average Stage at Diagnosis: Rectal Cancer 2011-2015



(Graph 4)

Percentage of Colorectal Cancer cases Microscopically Verified 2011-2015

Site of Diagnosis	*Colon*	*Rectum*
Cases Microscopically Verified (%)	88.7%	94.7%

(Table 3)

Morphology and Grade of Microscopically Verified Colorectal Cases 2011-2015

Site	Morphology	% Cases Morphology	Grade 1	Grade 2	Grade 3	Grade Unknown
Colon	Adenocarcinoma	91.4%	4.0%	50.7%	9.7%	35.6%
	Mucinous Adenocarcinoma	7.2%	1.6%	41.2%	17.1%	40.1%
Rectum	Adenocarcinoma	96.4%	2.3%	43.9%	5.3%	44.8%

(Table 4)

Survival

Net Age Standardised Net Survival Estimates of Colon (C18) Patients

Diagnosed: 1993-2014

Sex	Year of Diagnosis	Number of cases	6 months	1 Year	5 Year
Male	1993-1999	2040	79.2%	71.5%	49.6%
	2000-2004	1471	78.7%	73.3%	50.7%
	2005-2009	1808	82.0%	76.1%	55.7%
	2010-2014	2146	85.6%	80.9%	
Female	1993-1999	2147	79.3%	71.5%	50.5%
	2000-2004	1414	80.5%	73.8%	53.8%
	2005-2009	1642	80.1%	72.2%	57.0%
	2010-2014	1867	84.3%	78.1%	
Both sexes	1993-1999	4187	79.2%	71.4%	50.2%
	2000-2004	2885	79.6%	73.6%	52.4%
	2005-2009	3450	81.1%	74.4%	56.3%
	2010-2014	4013	85.0%	79.7%	

(Table 5)

Net Age Standardised Net Survival Estimates of Rectal Cancer (C20) Patients

Diagnosed: 1993-2014

Sex	Year of Diagnosis	Number of cases	6 months	1 Year	5 Year
Male	1993-1999	976	84.7%	75.5%	47.1%
	2000-2004	758	85.3%	76.8%	49.8%
	2005-2009	929	90.0%	83.1%	56.4%
	2010-2014	995	89.8%	84.7%	
Female	1993-1999	731	85.6%	77.9%	46.3%
	2000-2004	532	84.9%	79.0%	53.9%
	2005-2009	525	88.7%	82.9%	57.6%
	2010-2014	604	90.6%	85.1%	
Both sexes	1993-1999	1707	85.0%	76.5%	46.6%
	2000-2004	1290	85.1%	77.7%	51.4%
	2005-2009	1454	89.3%	82.8%	56.7%
	2010-2014	1599	90.2%	84.9%	

(Table 6)

Colorectal Cancer Statistics

UK and Irish Cancer Registries collect treatment data for each cancer case for up to six months post-date of diagnosis. Tables 15 and 16 below shows how each Nation within the UKIACR compares for treatments delivered up to six months post-date of diagnosis and for data completeness of stage and grade of cancer.

2015 Lower GI Cancer Registry Performance Indicators

	UKIACR Average	England	Scotland	Wales	Northern Ireland	Republic of Ireland
Grade Data Completeness	**75.9%**	80.2%	79.6%	61.6%	**83.8%**	74.2%
Stage Data Completeness	**81.6%**	89.7%	73.2%	81.1%	**92.2%**	71.9%
% of Microscopically Verified Cases	**90.0%**	89.1%	88.8%	84.4%	**93.0%**	94.9%
Surgical Procedure	**66.0%**	66.0%	64.9%	56.8%	**82.8%**	59.5%
Radiotherapy	**11.8%**	12.6%	11.6%	8.5%	**13.3%**	13.0%
Chemotherapy	**28.5%**	32.5%	30.0%	24.7%	**28.5%**	26.8%

(Table 7)

Lower GI CaPPS Module Data Entry 2015-2016

CaPPS Data Item	2015	2016	National Audit Requirement
MDT Agreed Stage	6.7%	10.8%	Required Field
Performance Status (ECOG)	0.0%	0.0%	Required Field
Operability Code	3.3%	2.7%	Required Field
First Definitive Intent	26.2%	39.7%	Required Field
Clinical Exam Findings	55.1%	49.9%	-
Main Tumour Site	2.3%	2.0%	Required Field
First Degree Relative	2.2%	0.0%	-
MRI Date & Summary	0.0%	0.0%	-
Endoscopy Date & Summary	0.0%	0.0%	-
Other Imaging Date & Summary	0.0%	0.0%	-
Barium Enema Date & Summary	0.0%	0.0%	-
Colonoscopy Date & Summary	0.0%	0.0%	-
Colonoscopy Complications	0.0%	0.0%	-
Reason Colonoscopy Incomplete	0.0%	0.0%	-

(Table 8)

Table 8 shows poor data entry in CaPPS for Lower GI specific fields. It also shows poor data entry for MDT Agreed Stage, Performance Status, Operability Code, and First Derivative Intent. Operability Code has data items describing whether or not a patient is fit for surgery, and reasons why a patient may not be fit for surgery. First Definitive Intent describes a patient's pathway e.g. radical –curative, palliative anti-cancer etc.

This report was written by Sinéad Lardner - clinical advisor to the NICR, and Official Statistics provided by Dr Eileen Morgan. If you would like further information feel free to contact via email S.lardner@qub.ac.uk, or for more general queries nicr@qub.ac.uk

The N. Ireland Cancer Registry is funded by the Public Health Agency. *This work uses data provided by patients and collected by the NHS as part of their care and support.*

APPENDIX F: Primary Care Federation Information

Antrim GP Federation

This factsheet presents information on cancer incidence and prevalence in the Antrim GP Federation to provide those working with cancer some idea of the number of patients diagnosed each year, the ages of these patients, the type of cancer they have had and how many patients are living with and beyond a cancer diagnosis between 1993-2015. It forms part of a larger report produced as part of the Macmillan-NICR partnership to describe the cancer profiles of the 17 GP Federations in Northern Ireland (NI). The full report can be accessed at http://www.qub.ac.uk/research-centres/nicr/. The data are reported based on GP federation of care rather than GP federation of residence i.e. patients registered at GP practices in the Antrim GP Federation area and not based on their home address. Also were data are presented for 'All cancers' this excludes Non-Melanoma Skin cancer.

Table 1.Summary statistics for all cancers (excluding Non-Melanoma Skin Cancer) in Antrim GP Federation area

	Males	Females	Both Sexes
New Cases diagnosed per year (2011-2015)	294.6	283.8	578.4
10 year prevalence	1265	1440	2705
23 year prevalence	1679	2163	3842

Incidence

- There were on average 578 cases of all cancers excluding Non-Melanoma Skin Cancer (NMSC; C00-C97 ex.C44) diagnosed each year between 2011-2015.

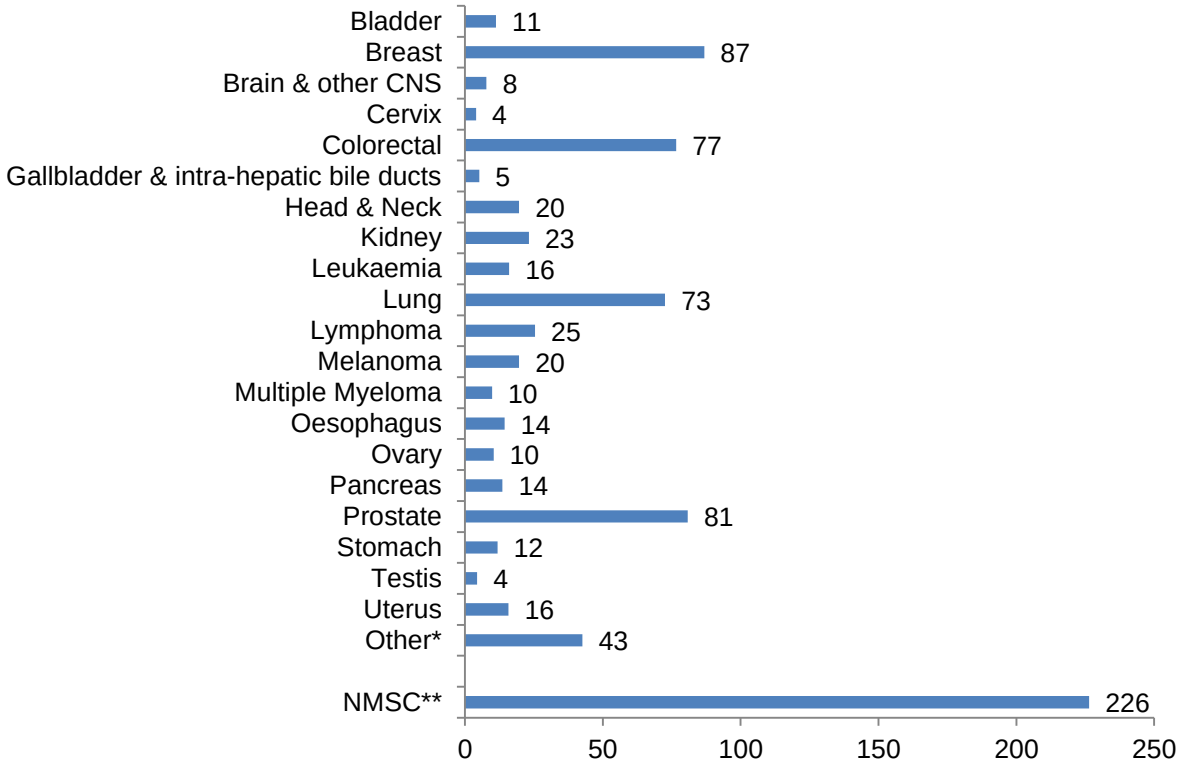


Figure 1. Average number of cases of specific cancers diagnosed each year between 2011-2015 in patients registered in Antrim GP Federation area.

- In 2011-2015 there were on average 87 cases of invasive breast cancer, 81 cases of prostate cancer, 77 cases of colorectal cancer and 73 cases of Lung cancer and 226 cases of Non-Melanoma Skin Cancer diagnosed each year.

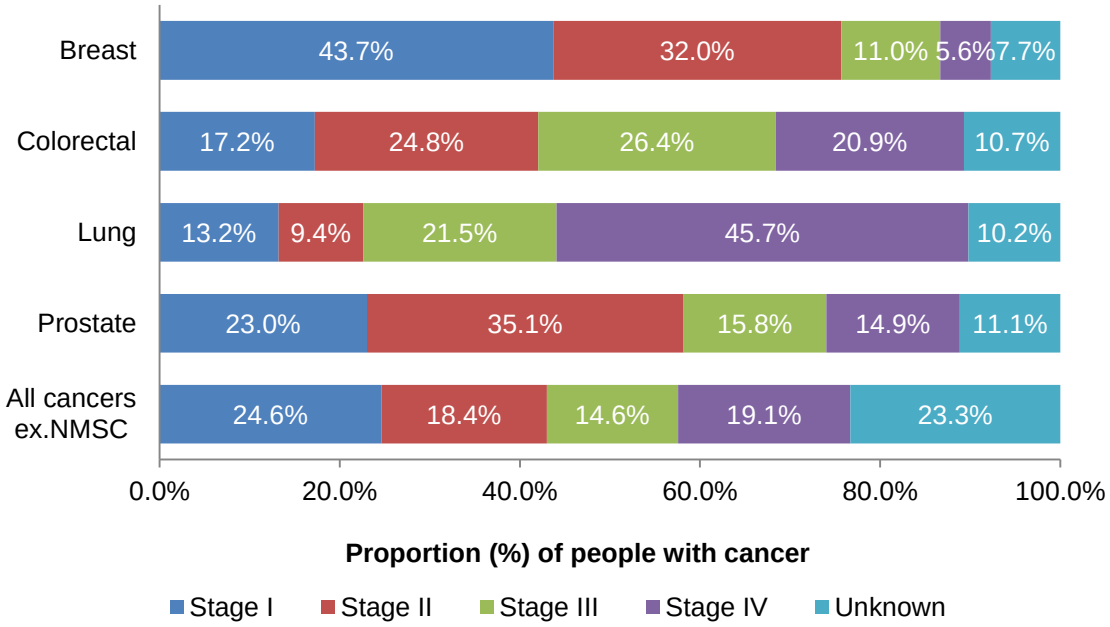


Figure 2. Proportion (%) of cases diagnosed between 2011 and 2015 by specific cancer site and stage at diagnosis in Antrim GP Federation area.

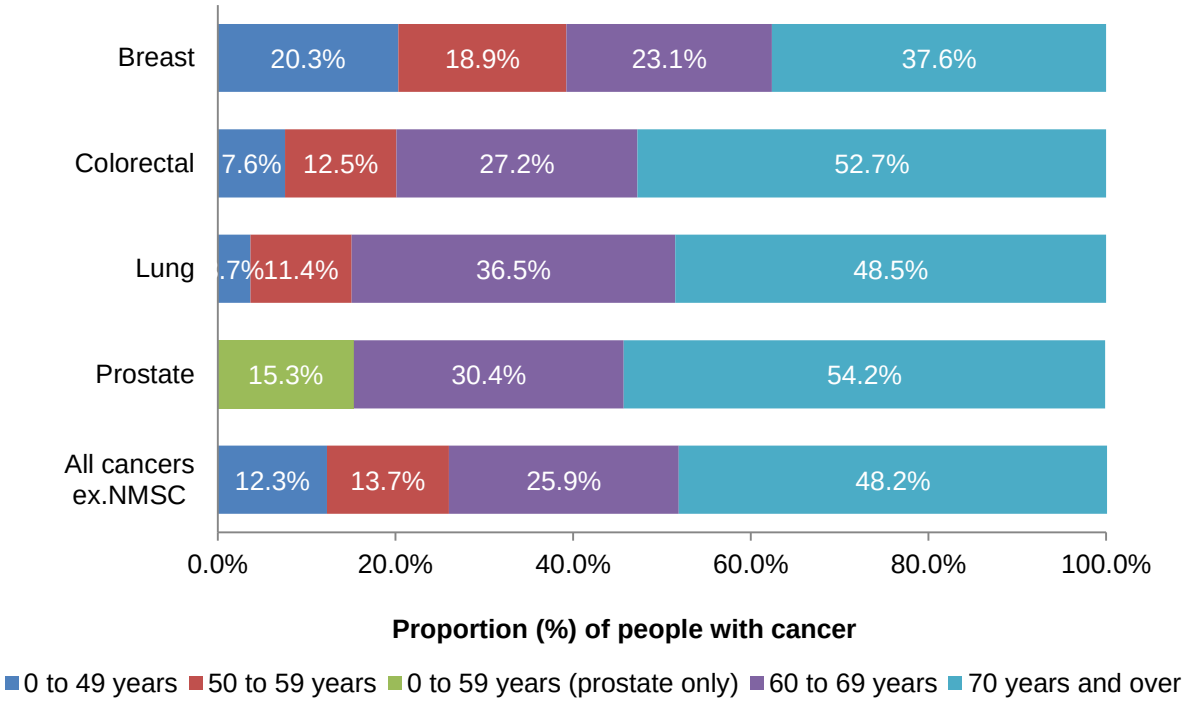


Figure 3. Proportion (%) of cases diagnosed between 2011 and 2015 by specific cancer site and age at diagnosis in Antrim GP Federation area.

Prevalence

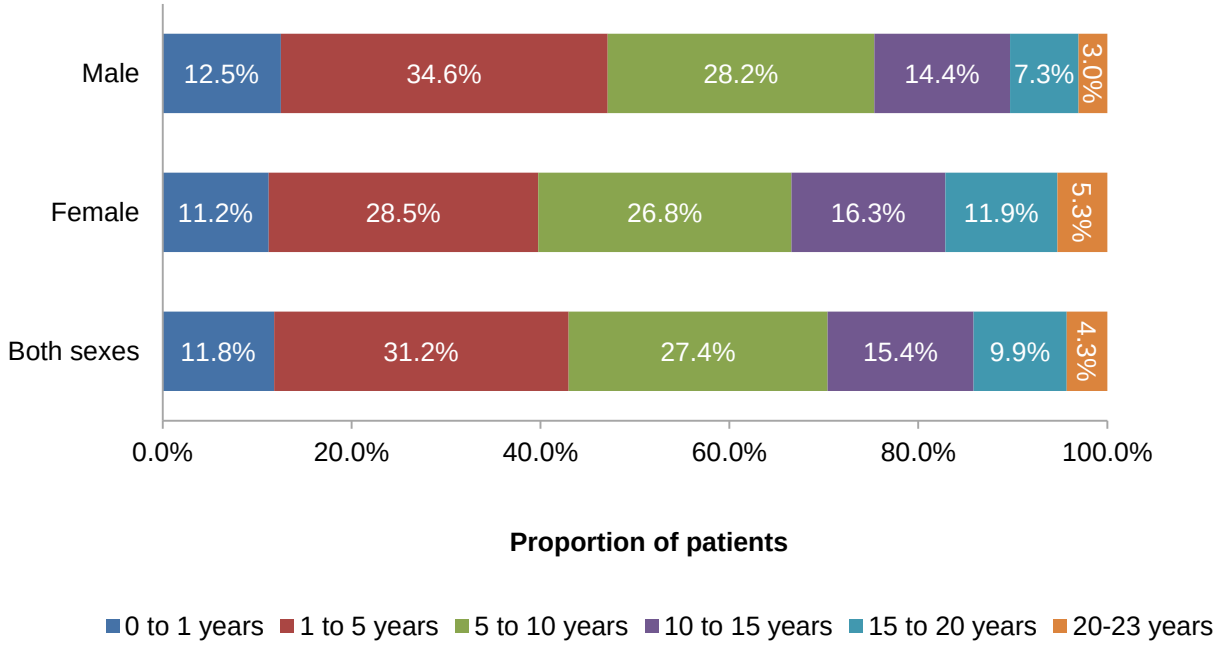


Figure 4. 23-year prevalence of all cancer (excluding NMSC) by sex and time from diagnosis in Antrim GP Federation area.

The 23- year prevalence represents all patients diagnosed with cancer during 1993-2015 who are still alive at the end of 2015. Other prevalence measures commonly used, which depend on the diagnosis period considered, include:

- One year prevalence (patients diagnosed in 2015) which at the end of 2015 was 453 (210 males and 243 females).

- Five year prevalence (patients diagnosed 2011-2015) which at the end of 2015 was 1651 (791 males and 860 females).

- Ten year prevalence (patients diagnosed 2006-2015) which at the end of 2015 was 2705 (1265 males and 1440 females).

- Twenty-three year prevalence (patients diagnosed 1993-2015) which at the end of 2015 was 3842 (1679 males and 2163 females).

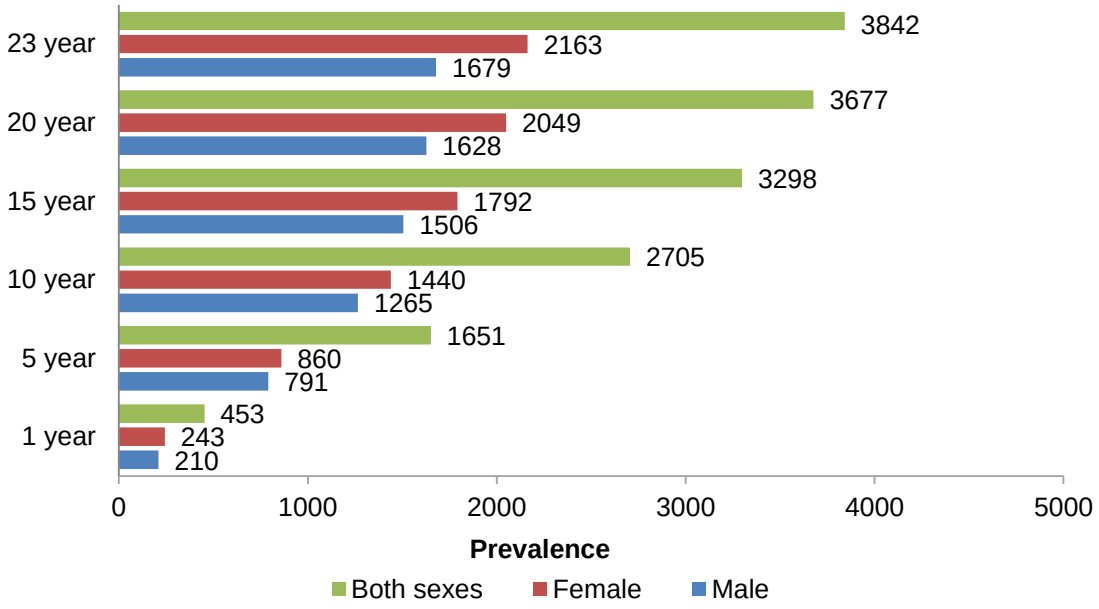


Figure 5. 23 year prevalence (based on time since diagnosis) for all cancers (excluding NMSC) by sex in Antrim GP Federation area.

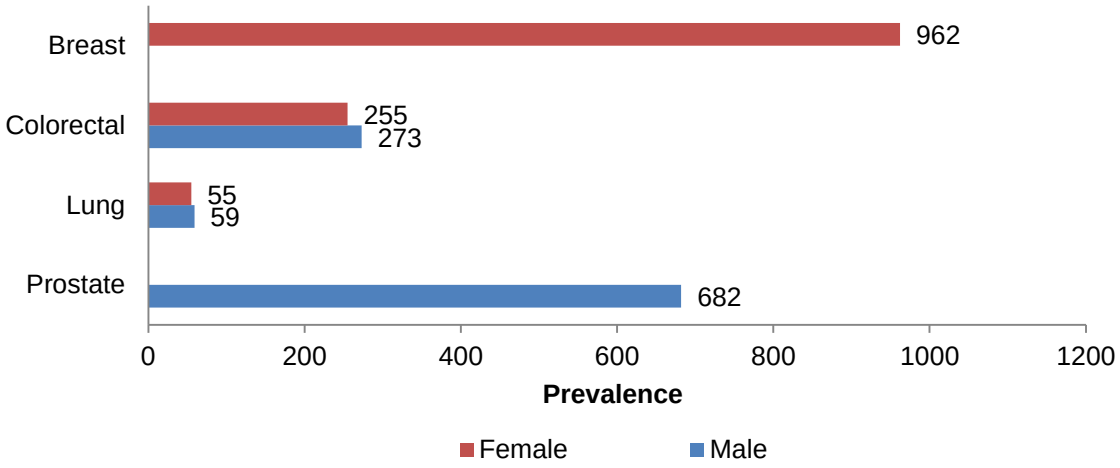


Figure 6. 23-year prevalence (number of patients) for all cancers (excluding NMSC) by sex and cancer site in Antrim GP Federation area.

At 31st December 2015, of those people living up to 23 years after a cancer diagnosis (excluding non-melanoma skin cancer) in the Antrim GP Federation:

- Over half (59.5%) had been diagnosed with Breast, Prostate, Colorectal or Lung cancer.
- 2163 were females and of these over 4 in 10 females (44.5%) had, had a diagnosis of Invasive Breast Cancer (ICD10 C50).
- 1679 were males and of these 4 in 10 males (40.6%) had, had a diagnosis of Prostate Cancer (ICD10 C61).

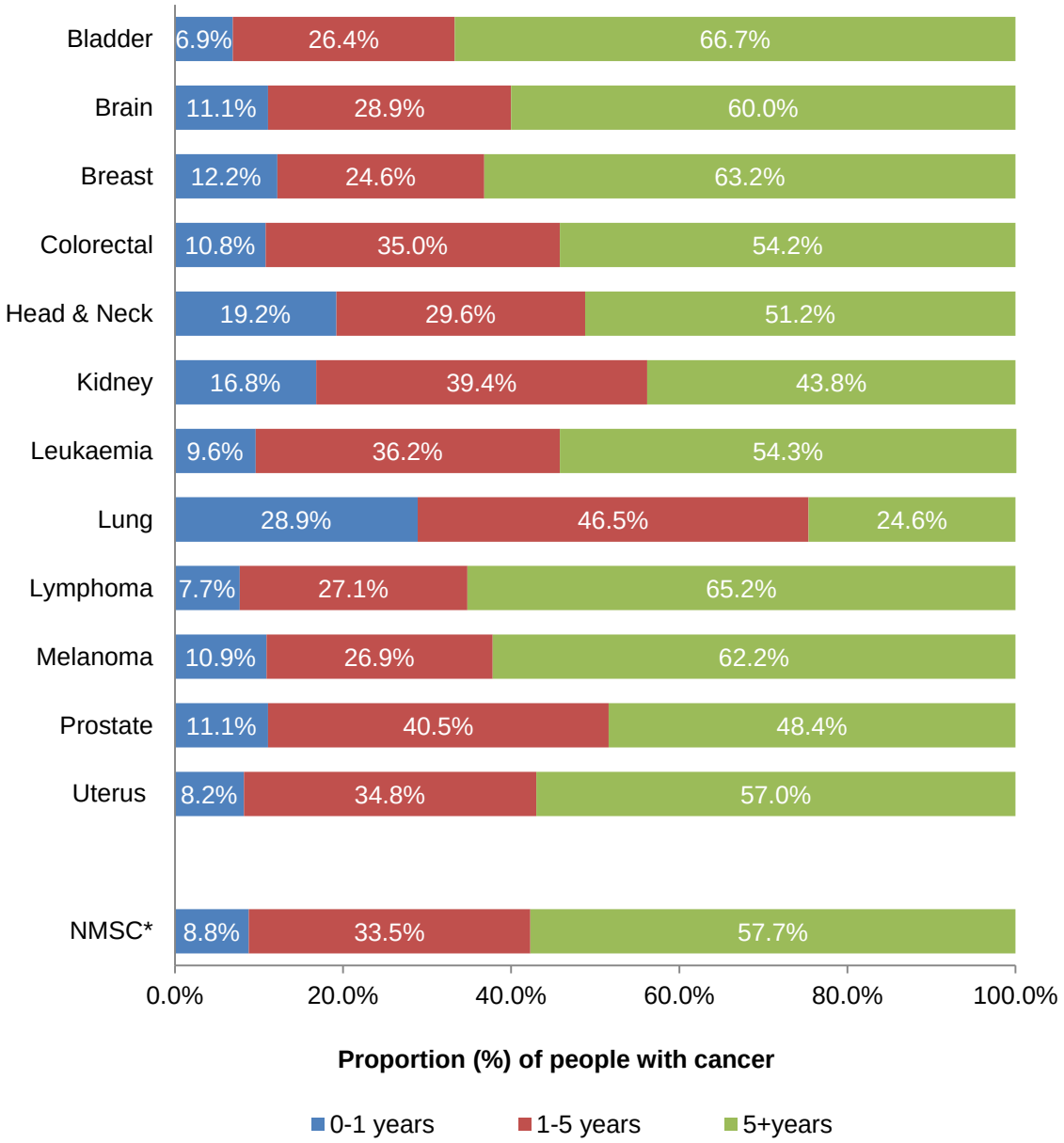


Figure 7. 23-year prevalence for all cancers (excluding NMSC) by cancer site and time since diagnosis in Antrim GP Federation area.

At 31st December 2015, of those people living up to 23 years after a cancer diagnosis (excluding non-melanoma skin cancer) in the Antrim GP Federation:

- Two thirds of patients diagnosed with Bladder (66.7%), Lymphoma (65.2%), Female Breast (63.2%) and Melanoma (62.2%) were diagnosed more than five years previously.

- Over half (54.2%) colorectal cancer patients were diagnosed within the last five years.

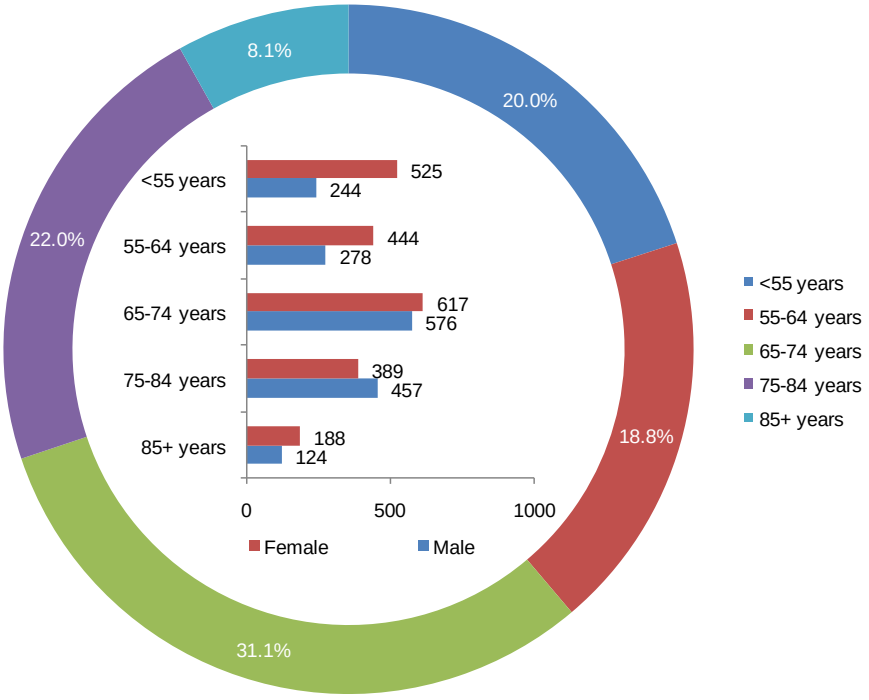


Figure 8. 23-year prevalence of all cancers (excluding NMSC) by age at end 2015 in Antrim GP Federation area.

- 8 out of 10 (80.0%) of patients diagnosed with all cancers excluding NMSC between 1993-2015 and alive at end of 2015 were aged 55 years or over at 31st December 2015 with one in five (22.0%) of patients aged between 75 and 85 years.

Acknowledgements

This work has been undertaken by the N. Ireland Cancer Registry as part of the Macmillan-NICR Partnership funded by Macmillan Cancer Support. The N. Ireland Cancer Registry is funded by the Public Health Agency and is hosted by Queen's University, Belfast. This work uses data provided by patients and collected by the health service as part of their care and support. 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

APPENDIX G: Peer Reviewed Publications

(Available via our web page www.gub.ac.uk/nicr)

1 January 2017/31 March 2018 Peer Reviewed Publications

1. Sharp L, Morgan E, Drummond FJ, Gavin A The psychological impact of prostate biopsy: Prevalence and predictors of procedure-related distress Psycho-Oncology 2018: 27:500-507. doi.org/10.1002/pon.4521
2. Steentjes L, Siesling S, Drummond FJ, van Manen JG, Sharp L, Gavin A Factors associated with current and severe physical side-effects after prostate cancer treatment: What men report European Journal of Cancer Care 2018: 27:e12589. doi.org/10.1111/ecc.12589
3. Sacchetto L, Zanetti R, Comber H, Bouchardy C, … , Gavin A, … , Morgan E, … Trends in incidence of thick, thin and in situ melanoma in Europe European Journal of Cancer 2018: 92:108-118. doi.org/10.1016/j.ejca.2017.12.024
4. Drummond FJ, Gavin AT, Sharp L Incongruence in treatment decision making is associated with lower health-related quality of life among prostate cancer survivors: results from the PiCTure study Supportive Care in Cancer 2017: :1-10. doi.org/10.1007/s00520-017-3994-z
5. Maguire R, Hanly P, Drummond FJ, Gavin A, Sharp L Regret and fear in prostate cancer: The relationship between treatment appraisals and fear of recurrence in prostate cancer survivors Psycho-Oncology 2017: 26:1825-1831. doi.org/10.1002/pon.4384
6. Matheson L, Watson EK, Nayoan J, Wagland R, Glaser A, Gavin A, Wright P, Rivas C A qualitative metasynthesis exploring the impact of prostate cancer and its management on younger, unpartnered and gay men European Journal of Cancer Care 2017: 26:e12676. doi.org/10.1111/ecc.12676
7. Keinan-Boker L, Silverman BG, Walsh PM, Gavin AT, Hayes C Time Trends in the Incidence and Mortality of Ovarian Cancer in Ireland, Northern Ireland, and Israel, 1994-2013 International journal of gynecological cancer : official journal of the International Gynecological Cancer Society 2017: 27:1628-1636. doi.org/10.1097/IGC.0000000000001079
8. Morgan E, Drummond FJ, Coyle C, Sharp L, Gavin AT Physical after-effects in men undergoing prostate biopsy in routine clinical practice: Results from the PiCTure study Urologic Oncology: Seminars and Original Investigations 2017: 35:604.e11-604.e16. doi.org/10.1016/j.urolonc.2017.06.003
9. Donnelly C, Quaife S, Forbes L, Boylan J, Tishelman C, Gavin A Do perceived barriers to clinical presentation affect anticipated time to presenting with cancer symptoms: An ICBP study European Journal of Public Health 2017: 27:808-813. doi.org/10.1093/eurpub/ckx064
10. Minicozzi P, Innos K, Sánchez M-J, Trama A, … , Gavin A, Fitzpatrick D, ... Quality analysis of population-based information on cancer stage at diagnosis across Europe, with presentation of stage-specific cancer survival estimates: A EUROCARE-5 study European Journal of Cancer 2017: 84:335-353. doi.org/10.1016/j.ejca.2017.07.015
11. Storm H, Engholm G, Mägi M, Aareleid T, … , Gavin A, Donnelly C, ... Geographical variability in survival of European children with central nervous system tumours European Journal of Cancer 2017: 82:137-148. doi.org/10.1016/j.ejca.2017.05.028
12. Donnelly C, Hart N, McCrorie AD, Anderson L, Donnelly M, Murchie P, Gavin A Knowledge or noise? Making sense of General Practitioners' and Consultant use of 2-week-wait referrals for suspected cancer British Journal of Cancer 2017: 117:597-603. doi.org/10.1038/bjc.2017.213
13. Donnelly C, Cairnduff V, Chen JJ, Kearney T, Fitzpatrick D, Fox C, Gavin A The completeness and timeliness of cancer registration and the implications for measuring cancer burden Cancer Epidemiology 2017: 49:101-107. doi.org/10.1016/j.canep.2017.05.007
14. Gatta G, Capocaccia R, Botta L, Mallone S, ... , Gavin A, … Burden and centralised treatment in Europe of rare tumours: results of RARECAREnet—a population-based study The Lancet Oncology 2017: 18:1022-1039. doi.org/10.1016/S1470-2045(17)30445-X
15. Gray RT, Loughrey MB, Bankhead P, Cardwell CR, McQuaid S, O'Neill RF, Arthur K, Bingham V, McGready C, Gavin AT, James JA, Hamilton PW, Salto-Tellez M, Murray LJ, Coleman HG Statin use, candidate mevalonate pathway biomarkers, and colon cancer survival in a population-based cohort study British Journal of Cancer 2017: 116:1652-1659. doiorg/101038/bjc2017139

16. Steliarova-Foucher E, Colombet M, Ries LAG, Moreno F, ... , Gavin AT, … International incidence of childhood cancer, 2001–10: a population-based registry study The Lancet Oncology 2017: 18:719-731. doi.org/10.1016/S1470-2045(17)30186-9
17. Donnelly CB, Wotherspoon AC, Morris M, Wilson RH, Chen JJ, Cairnduff V, Morgan E, Devlin A, Gavin AT A population-level investigation of cancer clinical trials participation in a UK region European Journal of Cancer Prevention 2017: 26:s229-s235. doi.org/10.1097/CEJ.0000000000000373
18. Dal Maso L, Tavilla A, Pacini F, Serraino D, … , Gavin A, Donnelly C, … Survival of 86,690 patients with thyroid cancer: A population-based study in 29 European countries from EUROCARE-5 European Journal of Cancer 2017: 77:140-152. doi.org/10.1016/j.ejca.2017.02.023
19. Bonaventure A, Harewood R, Stiller CA, Gatta G, ... , Fitzpatrick D, Gavin A, … Worldwide comparison of survival from childhood leukaemia for 1995–2009, by subtype, age, and sex (CONCORD-2): a population-based study of individual data for 89 828 children from 198 registries in 53 countries The Lancet Haematology 2017: 4:e202-e217. doi.org/10.1016/S2352-3026(17)30052-2
20. Roulston A, Campbell A, Cairnduff V, Fitzpatrick D, Donnelly C, Gavin A Bereavement outcomes: A quantitative survey identifying risk factors in informal carers bereaved through cancer Palliative Medicine 2017: 31:162-170. doi.org/10.1177/0269216316649127
21. Matz M, Coleman MP, Carreira H, Salmerón D, ... , Fitzpatrick D, Gavin A, ... Worldwide comparison of ovarian cancer survival: Histological group and stage at diagnosis (CONCORD-2) Gynecologic Oncology 2017: 144:396-404. doi.org/10.1016/j.ygyno.2016.11.019
22. Matz M, Coleman MP, Sant M, Chirlaque MD, ... , Fitzpatrick D, Gavin A, ... The histology of ovarian cancer: worldwide distribution and implications for international survival comparisons (CONCORD-2) Gynecologic Oncology 2017: 144:405-413. doi.org/10.1016/j.ygyno.2016.10.019
23. Coyle C, Morgan E, Drummond FJ, Sharp L, Gavin A Do men regret prostate biopsy: Results from the PiCTure study BMC Urology 2017: 17:11. doi.org/10.1186/s12894-016-0194-y
24. Gray RT, Cantwell MM, Coleman HG, Loughrey MB, Bankhead P, McQuaid S, O'Neill RF, Arthur K, Bingham V, McGready C, Gavin AT, Cardwell CR, Johnston BT, James JA, Hamilton PW, Salto-Tellez M, Murray LJ Evaluation of PTGS2 expression, PIK3CA mutation, aspirin use and colon cancer survival in a population-based cohort study Clinical and Translational Gastroenterology 2017: 8:e91. doiorg/101038/ctg201718

Reports

Care of lung cancer patients in N. Ireland diagnosed 2014 (with comparisons to findings reported 1996, 2001 and 2006 and in the National Lung Cancer Audit for patients diagnosed 2014). McKee C, Savage G and Gavin A T. N. Ireland Cancer Registry 2017. Available at http://www.qub.ac.uk/nicr March 2017.

APPENDIX H: Requests for Information

Requests for Information

The NICR provided data and information for 297 requests in 2017, 146 (49%) general requests and 151 (51%) genetic requests (excluding local genetic requests) (Figure 1). A nurse from the Medical Genetics department takes care of local genetic requests. In 2017, 97% of general requests for information were completed within the recommended 20 working days and 98% of genetic requests for information were completed within the recommended 10 working days (Figure 2).

44% of general requests were received from academic researchers, cancer registries, charities, and parliamentary questions (combined) (Figure 3). On average general requests took 187 minutes to complete but ranged from 5 minutes to 2400 minutes (60 hours). Genetic requests took 23 minutes to complete however ranged from 5 minutes to 90 minutes. The time taken to complete requests has increased over the past 5 years and this trend is expected to continue as cancer cases increase (Figure 4&5). 79% of general requests were received via email (Figure 6) although 94% of genetic requests were received by letter (not shown).

Figure 1: General and Genetic Requests received 2017

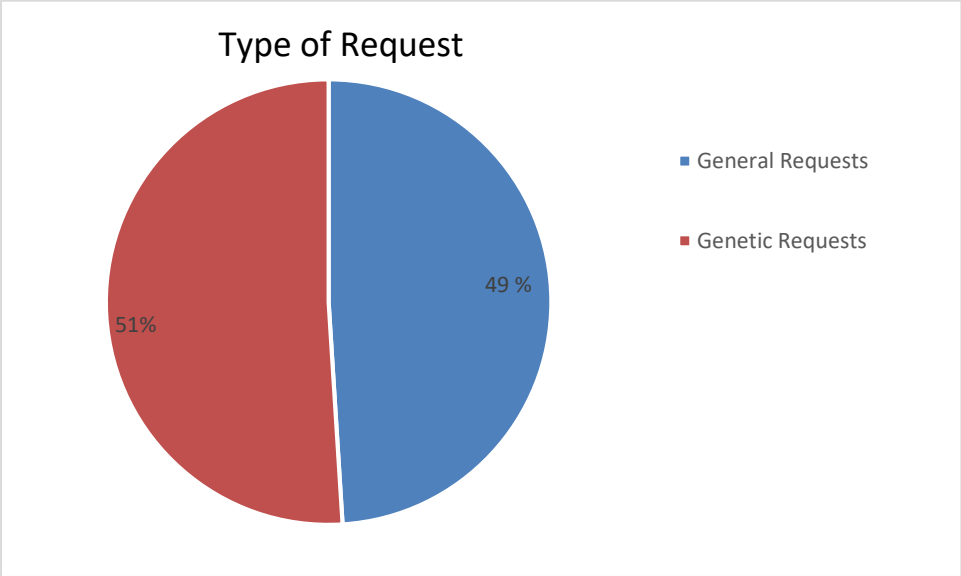


Figure 2: Percentage of requests completed within agreed timeframe

Figure 3: Source of Requests – General

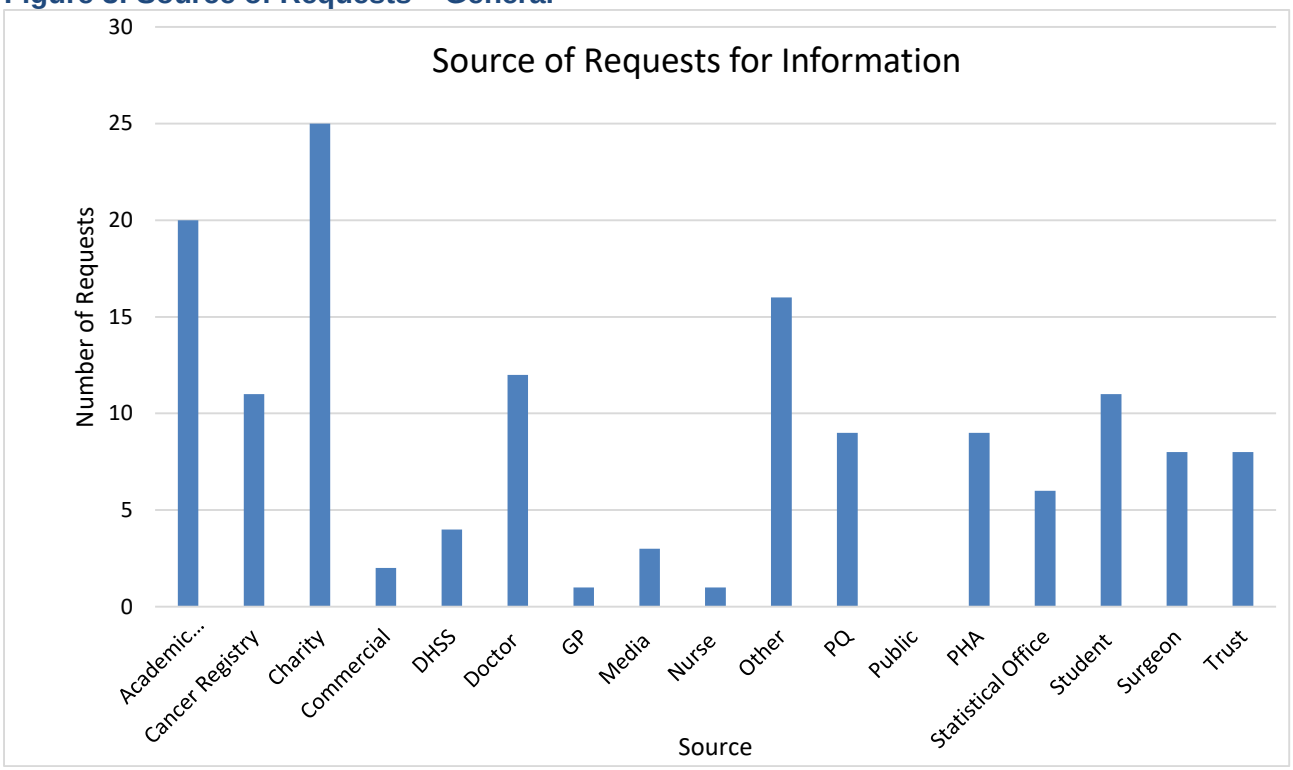


Figure 4: Time Spent on General Requests

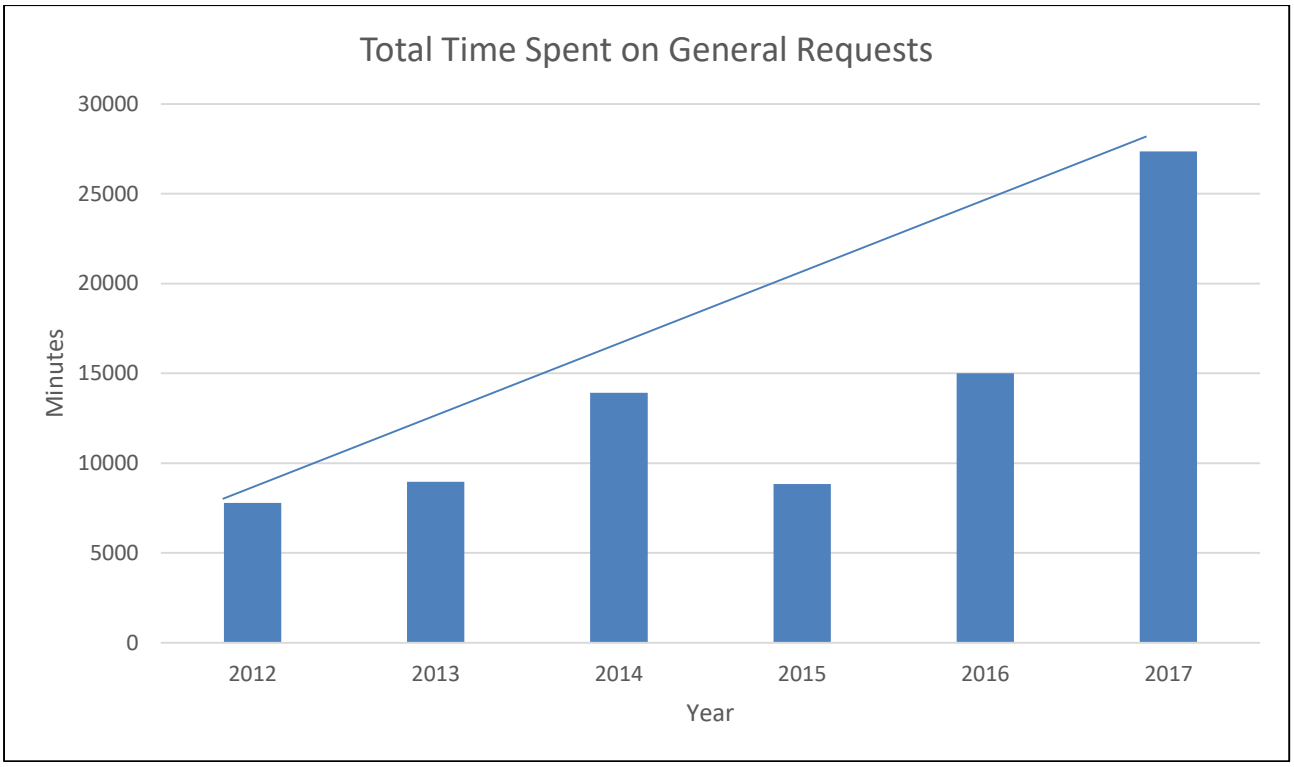


Figure 5: Time Spent on Genetic Requests

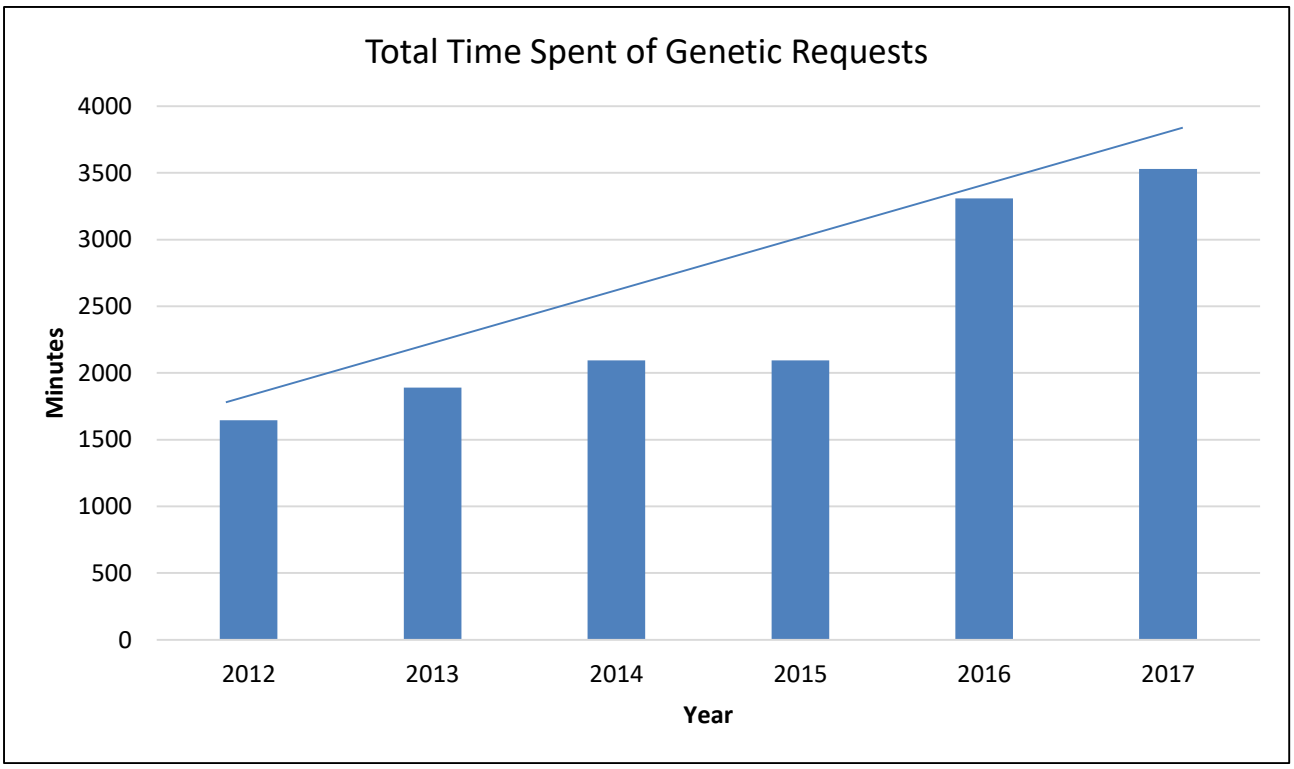
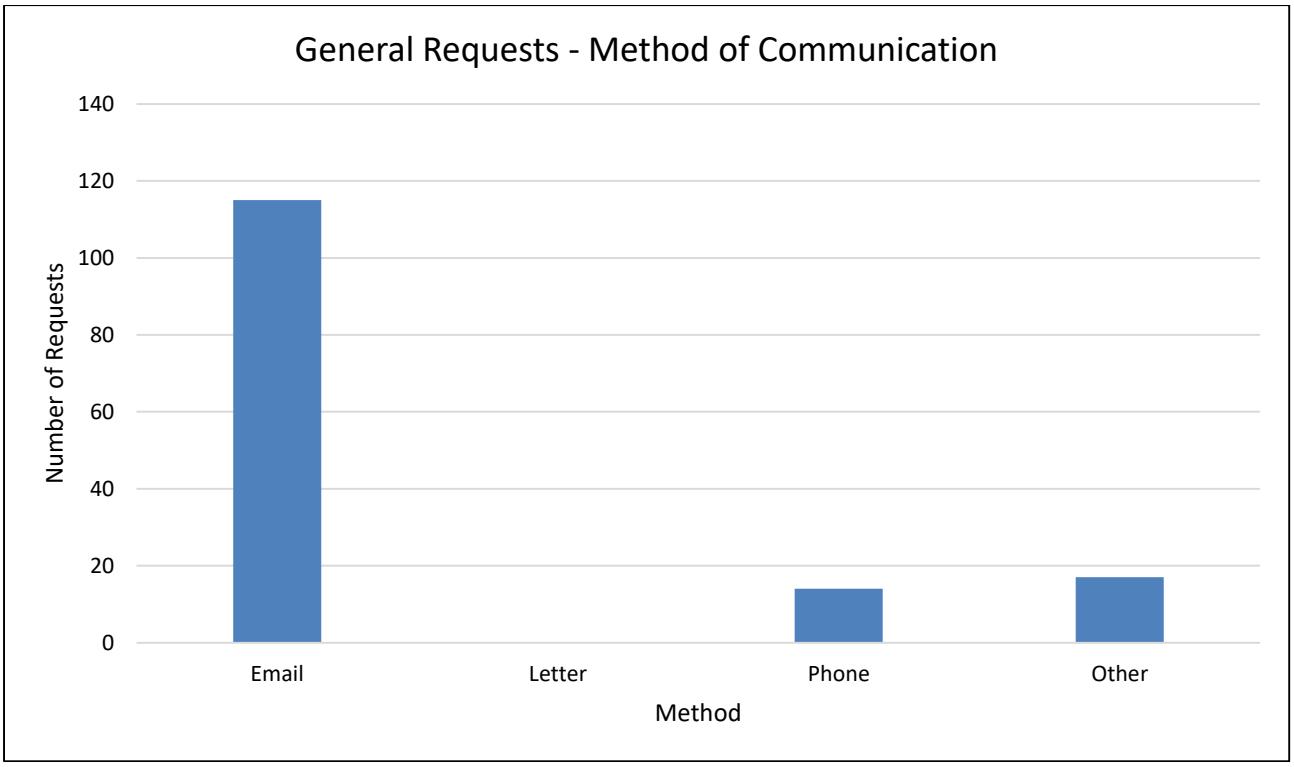


Figure 6: Method of Communication from Requestor – General Requests



APPENDIX I: Macmillan Partnership Aims and Objectives

Macmillan-NICR Partnership Aims and Objectives

Aim: The partnership aims to deliver insightful analysis of N Ireland cancer (NICR) data to support improved design of cancer systems, test and report on implementation of better models of care, and to identify gaps in data availability and opportunities to deliver world class data collection and analysis for improved outcomes for people living with and beyond cancer.

Objectives:

- To deliver insight into the unique characteristics of cancer data in N. Ireland (NI), the opportunities these provide for analysis, and any gaps in availability between NI and other UK nations.
- To understand the needs and outcomes of the cancer population in NI, the health and social impacts of cancer (including cancer recurrence and metastatic disease) and the consequences of its treatment across the cancer journey.
- Through linking and analysing data on clinical outcomes and patient experience, gaining better understanding of the experience of cancer across the health and social care system in NI.
- To align NI-specific analysis with the aims and objectives of Macmillan's strategy for NI, and to add richness and contextual information to UK-wide programmes of work such as the Macmillan-NCRAS work plan.
- To influence the commissioning and delivery of cancer services in NI by delivering relevant, timely and accessible outputs – for example, by providing information on cancer of value to GP Federations and to document the impact of NI specific interventions e.g. Transforming Cancer Follow-up.

These objectives are currently being covered within Workstreams 1-5

- **Workstream 1: GP Federations**

  The aim is to provide information of value to GP Federations (n=17). This has involved preparing factsheets containing aggregated routine registration data on cancer incidence (2011-2015) and prevalence (1993-2015) for each GP Federation, with detail where appropriate on age, stage and deprivation at diagnosis. An overall report including age-standardised incidence rates and comparisons of cancer incidence and prevalence across GP Federation areas has also been prepared.

- **Workstream 2: Transforming Cancer Follow-up**

  The aim is to document the impact of NI specific interventions e.g. Transforming Cancer Follow-up. This has involved analysis of the demography (age at diagnosis, deprivation quintile) and disease characteristics (stage at diagnosis, breast tumour type i.e. Invasive Breast cancer or Ductal Carcinoma In Situ) of breast cancer patients assigned to the Self-Directed Aftercare pathway between 2013 and 2015, with comparisons to the full NI breast cancer population diagnosed between 2011-2015. A final report of the findings is currently in draft with plans also to submit a scientific paper for publication.

- **Workstream 3: Breast Cancer Recurrence and Metastases**

  The aim is to identify a method of routinely collecting and reporting recurrence data. This work has been set up to align with the Macmillan-NCRAS programme of work on the development of an algorithm using proxy indicators to identify recurrence, second cancer and metastatic disease. The NICR is currently establishing a dataset of women diagnosed with invasive

breast cancer between 2009 and 2010 and followed up to 2017 in order to test the algorithm once it has been finalised.

- **Workstream 4: Emergency Admission Work**

  The aim is to investigate the number of emergency admissions in the last year of life by age and cancer site using the Patient Administration System (PAS) data for people who died from cancer in 2015. The work will deliver analysis for use in understanding the numbers and types of patients being admitted as emergencies at end of life, determining how many of these admissions are avoidable and influencing for system change accordingly in order to avoid emergency presentations where possible.

- **Workstream 5: Local Cancer Intelligence (LCI) Northern Ireland**

  In 2015, in collaboration with the NICR, Macmillan Cancer Support developed the Local Cancer Intelligence (LCI) tool, a Macmillan-maintained website with interactive, visual representations of key cancer indicators and statistics for NI. It includes aggregated data on cancer incidence, prevalence and survival by tumour group, HSC trusts and Local Government District to help with understanding the changing cancer population in NI. The information currently available online is for cancers diagnosed between 2010 and 2014 and it is due to be updated to include 2015 in mid-2018, using a tailored aggregated data extract from the NICR. http://lcini.macmillan.org.uk/

Proposed Future Workstreams

- **Workstream 6: Administrative Data Research Centre-NI Data Linkage Project**
  The aim is to investigate the consequences of a cancer diagnosis on the 'whole person'. Following the appropriate ethical and research governance approvals, this will involve secure linkage of NICR data with available ADRC datasets.

- **Workstream 7: Acute Oncology work**
  The aim is to investigate the characteristics (age, stage, length of time from diagnosis, cancer type) for people seen by the regional Acute Oncology (AO) service since its establishment across all of NI's five Trusts in March 2016, to profile this patient group and better understand their cancer pathway before and after their contact(s) with AO

APPENDIX J: Summary of LAPCD Research Study

Life after Prostate Cancer Diagnosis Study (LAPCD)

(Joint funded by Prostate Cancer UK and Movember)

- Commenced in 2015 to investigate issues that could affect a men following diagnosis and treatment for prostate cancer
- Surveys sent to approx. 75,000 men diagnosed with Prostate cancer 18-42 months previously (65,000 England & 10,000 devolved nations
- 120 Qualitative interviews carried out
- Methodology paper published in BMJ open

Life After Prostate Cancer Diagnosis (LAPCD) Study - 1st round

www.lifeafterprostatecancerdiagnosis.com

Background and current status

- A UK wide survey of all men diagnosed with prostate cancer who in 2016 were alive 18-42 months after diagnosis
  - 35,800 responses received (c. 61% response rate)
  - Analysis underway
- A second NI wide survey of a sample of 10,000 men aged 40 and over in the general population with the same age distribution of prostate cancer survivors
  - 3,000 responses (c. 30% response rate)
  - Analysis underway
- A third UK wide survey sent to men who responded to the first survey
  - c. 86% response rate
  - Data being cleaned
- A fourth England wide survey sent to fresh cohort of prostate cancer survivors (DeNovo survey)
  - c. 35% response rate
  - Data collection now finished

Publication plans

- General population data
  - Urinary, bowel and sexual dysfunction among older men paper accepted in BJUI
  - Treatment for erectile dysfunction among older men paper to be submitted this week
- Life After Prostate Cancer Diagnosis
  - Lead paper summarizing patient reported outcomes for prostate cancer patients
  - Upon publication, further papers ready to be submitted
    - Social distress
    - Psychological well-being in men with prostate cancer on active surveillance
    - Change in employment status after diagnosis
  - Further papers currently being worked on
    - Sexual function after treatment
    - Predictors of psychological distress
    - Decision regret and involvement in decision making
    - Changes in reported outcomes over time (Analysis of repeat survey)
  - Regional variations in patient reported outcomes

APPENDIX K: CAPPS Completeness Audit

		Breast (%)	Colorectal (%)	Head + Neck (%)	Lung (%)
Demographics	HCN Number	100	99	100	100
	Full Name	100	100	100	100
	Address	100	99	100	100
	Is patient waiting treatment?	100	100	100	100
	Is patient aware of diagnosis?	99	100	97	41
	Sex	100	100	100	100
	Date of birth	100	100	100	100
	Date of death	0	0	0	1
	Cancer Status Code	100	100	100	100
	GP Code	100	99	100	100
Diary Entries	Number of diary entries (n)	3026	3367	922	4035
	Average diary entries per patient (n)	5.9	9.4	10.0	9.8
	Diary entry date completed	100	100	100	100
	Diary actioned date	54	74	80	72
	Diary comments	100	100	100	100
	Last diary entry date	100	100	100	100
	Last diary comments	100	100	100	100
	Last diary actioned date	73	90	99	98
Consultants	Cancer Surgeon	73	74	94	14
	Consultant referred to	71	64	57	0
	Oncologist	6	18	3	0
	Palliative specialist	0	0	0	0
	Physician	12	19	6	0
Investigation	Location	30	57	8	29
	Date expected	1	9	7	10
	Date preformed	56	80	93	97
	Date reported	12	26	1	3
	findings	47	69	79	85
MDT Stage	MDT date of staging	18	10	85	34
	MDT T stage	18	10	85	34
	MDT N stage	15	8	84	33
	MDT M stage	0	1	83	32
Transposed Investigatio	First bronchoscopy date	0	0	0	27
	First CT chest/abdomen/pelvis date	0	0	0	0
	First CT Chest date	0	0	0	0
	First CT date	7	53	58	98
	First CT guided core biopsy date	0	0	0	1
	First CT guided FNA/core/Lung date	0	0	0	4
Referrals	Hospital referred to	100	100	100	100
	Priority type code	95	86	49	69
	Referral ID	100	100	100	100
	Referral date	100	100	100	100
	Primary referral date	100	100	100	100
	Primary referral type	100	100	100	100
	Referral date received	95	86	49	69
	Source of first referral	81	82	75	81
	Referral reason	1	5	13	5
Appointment	Is patient waiting first appointment	100	100	100	100
	Attendance	81	55	66	65
	Date of first appointment	88	64	84	84
	Other appointment date	82	56	68	67
	Appointment hospital - code	82	56	68	67
	Date first seen	100	100	99	99
	Hospital first seen	100	100	99	99

APPENDIX L: Update of NICR Achievements - 2017/18

(Green represents achieved in full, orange partly achieved, red not achieved)

<table>
<tr><th>Targets 2017-2018</th><th>Update</th></tr>
<tr><td colspan="2">Goal 1– Ensure high quality, timely, complete data on cancers and pre-malignant conditions occurring in the population of N. Ireland</td></tr>
<tr><td>a) Launch official statistics of cancer incidence, prevalence and survival statistics for NI patients diagnosed with cancer in 2016 by March 2018.</td><td>Achieved – Staging 85 %</td></tr>
<tr><td>b) Provide accurate NI data for international comparison to UK Data repository</td><td>Achieved</td></tr>
<tr><td>c) Continue to update Registry IT System:
Recurrence algorithm. Expand Database – HER2, ER PR, PSA, others.
Future options for IT system.</td><td>Additional enhancements to data dictionary completed.
Recurrence algorithm requires further input from others.
Options paper being developed to identify future requirements from an IT system.</td></tr>
<tr><td rowspan="5">d) Continue to enhance links with Business Service 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.</td><td>Trust cancer managers on Registry Council meeting – Invited Attended.</td></tr>
<tr><td>Meet with cancer screening services annually – Meetings ✓</td></tr>
<tr><td>Request regular updates to patient information and prescribing data from BSO – Achieved</td></tr>
<tr><td>Request regular death updates from GRO – Achieved</td></tr>
<tr><td>Completed Data Access Agreements in 2017/18: achieved, see below;

<table>
<tr><th>Title of Agreement</th><th>Party Involved</th></tr>
<tr><td>Beta-adrenergic receptor expression and beta-blocker drug use: association with breast cancer survival</td><td>Business Services Organisation, 2 Franklin St, Belfast BT2 8DQ</td></tr>
<tr><td>Quantifying surgical under-treatment in older adult cancer patients</td><td>Business Services Organisation, 2 Franklin St, Belfast BT2 8DQ</td></tr>
<tr><td>Pathways to Cancer Diagnosis</td><td>Business Services Organisation, 2 Franklin St, Belfast BT2 8DQ</td></tr>
</table>
</td></tr>
</table>

Targets 2017-2018	Update	
	Epidemiology and Statistics of Neuroendocrine Tumours: A National Study from 2013 to 2015.	National Cancer Registration and Analysis Service, Public Health England, 5 St Philips Place, Birmingham B3 2PW
	Melanoma Trends in Europe	Piedmont Cancer Registry, of Via San Massimo 24, 10123 Torino, Italy
	Breast cancer data exchange with the NI screening services – to facilitate monitoring of screening services	Quality Assurance Reference Centre (QARC), Public Health Agency
	Colorectal cancer data exchange with the NI screening services - – to facilitate monitoring of screening services	Quality Assurance Reference Centre (QARC), Public Health Agency
	Cervical cancer data exchange with the NI screening services - – to facilitate monitoring of screening services	Quality Assurance Reference Centre (QARC), Public Health Agency
	International Breast Cancer Intervention Study (IBIS)	Dept of Epidemiology, Wolfson Institute of Preventative Medicine, Charterhouse Square, London EC1M6BQ
	Molecular and genetic characterisation of contralateral breast cancer (CBC): opportunities for personalised surgery.	Centre for Cancer Research and Cell Biology, QUB
	Geographic Variations of Leukaemia Incidence in England and Northern Ireland.	Newcastle University, of Newcastle upon Tyne, Tyne and Wear, NE1 7RU
	The Northern Ireland Biobank	Centre for Cancer Research and Cell Biology, QUB
	UK level cancer incidence	Cancer Research UK, Angel Building, 407 St John's Street, London
	UK level cancer mortality	Cancer Research UK, Angel Building, 407 St John's Street, London
	NI Multiple Deprivation Measure	NISRA, Colby House, Stranmillis Ct, Belfast, BT9 5BF
	Increase speed of access to clinical datasets for TVOs further investigation of network links to HSC. Resolved.	
e) Establish new links with RISOH System to ensure relevant datasets are available to NICR.	BSO developed front end. Testing and not satisfactory. Missing data and not in date order.	

Targets 2017-2018	Update
f) Ensure that the NICR has continued look up access to the COIS dataset.	Unfortunately access to COIS was ended abruptly in April 2018 – negotiations are ongoing to acquire this historical clinical dataset
Goal 2 Protect the confidentiality of the data	
a) Retain ISO27001 certification	Regular review and internal auditing by trained staff – Ongoing and external surveillance audit planned for mid-2018
b) Ensure staff training is maintained.	Regular awareness sessions required to maintain standard – Achieved
c) Ensure research projects adhere to the NICR & QUB Research and Data Protection Protocols.	All registry outputs including information requests, general reports, presentations, audits and research papers have adhered to Standard Operating procedure (SOP) on release of data – Achieved
Goal 3 – Continue with upgrades to the Registry IT System and extend its capacity to store data items	
Additional data fields have been successfully added to both the database and the user interface. These have been tested on the test/development system and are currently being replicated on the live system.	
Goal 4 – provide a cancer intelligence service	
a) Answer all data requested within 20 days for general requests and 10 days for genetic requests. Continue to facilitate the Northern Ireland Clinical Genetics Service access to NICR datasets for clinical purposes.	97% of general requests were completed within the recommended 20 working days and 98% of genetic requests within the recommended 10 working days.
b) Feedback research findings to relevant partners and associated patient groups.	All research papers published within calendar period to have 'implications for service' sheet included and shared with PHA/included on NICR website – Achieved.
c) Ensure website is kept up to date.	Relevant items brought to Team meeting – Achieved. Items to web page – Achieved.
d) Work to provide N. Ireland data for national audits and peer review eg Lucada, Oesophago-gastric, Bowel Audit.	Achieved for lung – launched September 2017.

Targets 2017-2018	Update
e) Work to provide information for outcomes of care as required by PHA, NICaN and Trusts.	All requests answered – Achieved.
f) Produce updated cancer factsheets from Official Statistics 2015 data.	Factsheets prepared and available on website – Achieved.
Goal 5 – facilitate the planning and monitoring of cancer services in Northern Ireland	
a) Continue to Evaluate the quality of completion of the Cancer Patient Pathway System (CaPPS) databases at Trust level and feedback to Trusts and NICaN clinical groups and Board.	Audits of fields on CaPPS for breast, colorectal, head and neck and lung modules. Feedback of results to NICaN clinical groups, NICaN board and CaPPS user group. Develop feedback reports for datasets 2015 and 2016 for Upper GI, hepatobiliary and thyroid. Analysis and feedback of CaPPS completeness for Skin and urology.
b) Ensure audit and research findings are disseminated to key organisations/ individuals to encourage implementation of recommendations.	Lung audit report circulated to NICaN clinicians, covered in media, sent to Steering Group members and PHA colleagues. Lack of secretarial support hampered circulation of peer reviewed papers – Achieved.
c) Work to achieve resources to ensure that N. Ireland data are included in national audits.	Not achieved yet, external support required.
Goal 6 – undertake and present internationally recognised research	
a) Apply for 1 research grant.	2 grants awarded - Grant with Macmillan renewed, achieved grant to establish a stroke database/registry
b) Submit 8 papers for peer review in high impact journals.	24 publications submitted for publication – 4 NICR studies, 1 from UK wide LAPCD study, 6 from All-Ireland PICTURE study of prostate cancer outcomes, 11 international projects using NICR data, 2 external researchers using NICR data – Achieved
c) Enhance the completeness and quality of the Prostate Specific Antigen database, up to 2016 and undertake externally funded PSA audit	Relevant datasets received from Trusts. Analysis ongoing. Due for Completion June 2018

Targets 2017-2018	Update
d) Ensure N. Ireland provide relevant data for ICBP Phase 1 and 2.	Data access agreements signed and data provided.
e) Work to maximise outputs from UK PCUK Patient Reported Outcomes Measures (Life After Prostate Cancer) Study for Northern Ireland, Scotland and Wales (externally funded).	1 paper accepted in BJU International. Further papers submitted and/or in preparation. Numerous abstracts submitted and accepted as posters or talks at national and international meetings
f) Maximise outputs from and use of LAPCD related study for baseline of population urological symptoms (externally funded).	Analyst recruited. See (e) above for update on outputs.
g) Submit abstracts and attend relevant conferences.	Cancer Outcomes Conference – Posters presented 2017. International Association of Cancer Registries Meeting – Posters presented.
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 and need to provide funding for ICBP Phase 2 sign up.	Budget managed on target, despite loss of staff with experience and training in that area.
b) Manage budgets from research grants.	Budgets monitored.
c) Involve staff in planning of targets for 2018/2019.	Host NICR Planning & Development Day – Achieved 22/3/18. Staff to contribute to actions/completion dates.
Goal 8 – Ensure the sustainability of the Registry	
a) Prepare for Registry Review March 2018.	Terms of reference and membership agreed.
b) Work with Registry funders and QUB to ensure arrangements reflect the long-term nature of Cancer Registration.	Wording of contract reviewed. Letters of funding available January 2018. Staff working > 4 years will receive permanent contracts with QUB.

Targets 2017-2018	Update
c) Inform and support relevant stakeholders in the development of regulations for Health & Social Care Act.	No progress as no Government.
d) Ensure staff are trained to a high level for their work.	Training needs assessment for each person included in annual appraisal with plan for action.
	Induction booklet for new staff in Registry updated.
e) Maintain a high registry profile locally and internationally.	- Staff attended conference of International Association of Cancer Registries. - Staff Attended cancer outcomes conference. - Staff Attended NCRAS Workshop 17/3/18.
	Information re NICR included on TV Screens in Cancer Centre. Annual Newsletter published July 2017.
	Numerous Media Interactions.
	Ensure relevant staff have media training some staff have had media training in the past.
	Continue on International Association of Cancer Registries Committee – Director elected to European Network Cancer Registries.
f) Organise opportunities to highlight the work of the Registry to external groups.	Liaise with Trust Cancer Managers – ongoing, links have been established.
	Attend NICaN Board and Clinical Groups – 90% attended by NICR rep.
	Website updated, annual newsletter published. Twitter continues to be used to highlight key Registry events.
g) Work to achieve succession planning for registry posts	Ensure staff are trained appropriately so all roles in Registry are covered – Ongoing
	Acting Deputy Director employed for 2 years.
	Public Health Trainee in Registry Aug 17-Jan 18.
	Develop a risk register.
Goal 9 – Ensure good links with patients and their representatives	
a) Continue to involve patients and their representatives in our Council, Steering group and Registry work.	Consumer representation on Steering Group on Council maintained.
	Replacements organised for resignations from Steering group and council, including new chairs organised for both groups.
b) Involve patients as speakers/invitees at launch of reports.	Patients and charities involved in successful launch of the lung cancer audit repo – Achieved.
c) Develop new Patient Information Leaflet to reflect detail of legislative	Leaflet updated while awaiting legislation. In the meanwhile a new print run of the leaflet has allowed us to update the content.

Targets 2017-2018	Update
framework for cancer registration when available.	
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.	34 cancer sites have updated summary statistics available to download – Achieved.
	Prevalence data included in the factsheets – Achieved.
e) Provide regular inputs to the Knowledge Exchange website/database.	Information sent for last official statistics.
f) Ensure data available to the public on cancer in N. Ireland is up to date and accurate.	Data made available for Macmillan re Cancer Toolkit.
	Regular datasets provided to CRUK January 2018.
	Provided regular data to NINIS.
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.	Advice provided to Cerebral Palsy and Rare Diseases registries, achieved funding for stroke database/registry.
	Ethical agreements achieved for colorectal polyps and Endometrial Hyperplasia.
b) Link nationally and internationally to promote cancer registration and increase understanding and control of cancer including promoting cancer staging tool.	Director elected as chair European Network Cancer Registries.
	Director member of International Association of Cancer Registries Executive committee representing European region.
	Attendance of relevant Registry staff at international meetings maintained.
Goal 11 – Provide an environment for education and training	
a) Offer training slots to undergraduate/ postgraduate students and Public Health trainee.	Suitable projects offered to two postgraduate students.
	International student hosted.
b) Raise awareness of the Cancer Registry within the University and beyond.	Collaborate with outside bodies.
	Staff attended Cancer Outcomes Conference, International Association Cancer Registries Conference and presented work of NICR.
	Annual newsletter produced and circulated widely internally in University and beyond.
c) Maintain international links on new developments in cancer registration and cancer research.	Staff attend; - UKIACR. Analysts meeting quarterly. - UKIACR executive meetings quarterly. - UICC teleconference meeting on cancer coding.

Targets 2017-2018	Update
	- NICR dialled into each International Cancer Benchmarking Partnership meeting and contributed to development of reports and scientific papers.
d) One member of staff to attend NCI summer curriculum in cancer prevention.	Researcher attended funded by NI Research and Development Office.
e) Facilitate medical/research staff with access to relevant registry datasets within confidentiality and ethical guidelines.	Visitor Identification System in place. Designated hot desk available.
f) Ensure the Registry environment and processes support data security.	Access codes regularly changed. Registry back up policies followed. All new staff and temporary users had induction to NICR security.