

# Macmillan-NICR Partnership: Cancer Data Landscape in Northern Ireland April 2018



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## 1. Abbreviations

ADRC-NI Administrative Data Research Centre-NI

BNF-British National Formulary

BSO-Business Services Organisation

CaPPS- Cancer Patient Pathway System

COIS- Clinical Oncology Information System

CPES- Cancer Patient Experience Survey

CSU- Central Survey Unit

CRUK-Cancer Research UK

EH-Endometrial Hyperplasia

EPD-Enhanced Prescribing Database

FoBt- Faecal Occult Blood test

GRO- General Registrar's office

HSC- Health and Social Care

HESA- Higher Education Statistics Agency

ICBP- International Cancer Benchmarking Partnership

ISO-International Organisation for Standardisation

LAPCD- Life After Prostate Cancer Diagnosis

LCI- Local Cancer Intelligence

LFS-Labour Force Survey

MDT-Multi-disciplinary team

MGUS-Monoclonal Gammopathy of unknown significance

NICR-Northern Ireland Cancer Registry

NICaN- Northern Ireland Cancer Network

NILS- Northern Ireland Longitudinal Study

NCRAS-National Cancer Registration and Analysis Service

OPCS-4- Office of Population Censuses and Surveys. *Classification of Surgical Operations* (Version 4)

ORECNI- Office of Research Ethics for Northern Ireland

PAS- Patient Administration System

PCUK- Prostate Cancer UK

PHA- Public Health Agency

PSA-Prostate Specific Antigen

TCFU-Transforming Cancer Follow-up

QA- Quality Assurance

QARC-Quality Assurance Reference Centre

QUB- Queen's University Belfast

SOA- Super-output areas

UKAICR- UK and Ireland Association of Cancer Registries

## 2. Macmillan-NICR Partnership

Macmillan Cancer Support and the N. Ireland Cancer Registry (NICR) entered into 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 the 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.

### 2.1 Macmillan-NICR Partnership Aims and Objectives

**Aim:** The partnership aims to deliver insightful analysis of Northern Ireland cancer 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 Northern Ireland, 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 Northern Ireland, 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 Northern Ireland.
- To align NI-specific analysis with the aims and objectives of Macmillan's strategy for Northern Ireland, and to add richness and contextual information to UK-wide programmes of work such as the Macmillan-NCRAS workplan.
- To influence the commissioning and delivery of cancer services in Northern Ireland 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.

## 2.2 Current Workstreams

These objectives are currently being covered within Workstreams 1-4

- Workstream 1: GP Federations

The aim of workstream 1 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 of workstream 2 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 of workstream 3 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 proposed aim for workstream 4 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 Northern Ireland. 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 Northern Ireland. The information currently available online is for cancers diagnosed between 2010 and 2014 and it is due to be updated to include 2015 in early 2018, using a tailored aggregated data extract from the NICR.

### 2.3 Future Workstreams

- Workstream 6: Administrative Data Research Centre-NI Data Linkage Project

The proposed aim for workstream 6 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 proposed aim for workstream 7 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 Northern Ireland's five Trusts in March 2016, in order to profile this patient group and better understand their cancer pathway before and after their contact(s) with AO.

### **3. Information Available**

The Macmillan-NICR partnership work mainly focuses on data that are currently held at the NICR (see appendix A regarding NICR sources).

#### **3.1 NICR Data**

The NICR has data on all cancers and most premalignant diseases at population level since 1993. It has approval of the NI ethical committee (ORECNI;15/NI/0203) and is registered with the Data Protection Act - Registration Number (QUB): Z6833827.

##### **3.1.1 Diseases Registered**

The Registry receives notification of all new cases of primary malignant neoplasms (ICD10 C00-C97), carcinoma *in situ* and neoplasms of uncertain behaviour from regional systems including hospital and laboratory systems. Information is also collected about benign neoplasms of the brain and other CNS. The registry also receives notifications on various pre-malignant conditions including Barrett's Metaplasia, Colorectal polyps, endometrial hyperplasia and Monoclonal Gammopathy of unknown significance (MGUS). It also receives information on all Prostate Specific Antigen (PSA) tests performed in NI.

##### **3.1.2 Data Sources**

The NICR acquires notifications of likely cancer diagnoses in the population electronically from pathology laboratories, hospital discharges (Patient Administration System; PAS) and death registrations (General Registrar Office; GRO). Data sharing agreements exist with these data providers. The cases identified are validated as true cancers by checking clinical records including the Multidisciplinary Team datasets provided by the Cancer Patient Pathway System (CaPPS), the Clinical Oncology Information System (COIS), Lab Centre Records and by note review. Datasets are then anonymised for analysis. Data received from Business Services Organisation (BSO), the Radiotherapy System (ARIA), and QARC (Quality Assurance Reference Centre) supplement the notifications by adding staging, radiotherapy/chemotherapy treatments, updates to demographic information, such as GP, address and death data and screening histories for breast, cervix and colorectal cancers.

### **3.1.3 General Registrar Office (GRO) Death Registrations**

Data from GRO in Northern Ireland are used to:

1. Identify death certificate initiated cases by the NICR not obtained from the clinical or laboratory sources. The proportion of cases that are picked up by death certificate only (DCO) is very low at 0.3% indicating a high level of case ascertainment by the NICR.

2. Provide a basis for calculating survival. Death records will hold one primary cause of death and up to ten underlying causes of death. It is important to note that the underlying causes of death are not co-morbidities alone at the point of death but are factors that contributed to the death.

### **3.1.4 Screening Data (Breast, Bowel and Cervical)**

Screening data are exchanged annually with the Quality Assurance Reference Centre (QARC) within the Public Health Agency, which is responsible for supporting the commissioning and quality assurance (QA) of the breast, cervical and bowel cancer screening programmes in Northern Ireland. This helps identify cases picked up at screening and also interval cancers which occur between screening rounds.

#### **3.1.4.1 Breast Screening Programme**

The Breast Screening programme commenced in 1988 with a three-yearly population based call and recall of women aged 50-65 years being in place since 1993. In March 2009 the screening age was extended to 50-70 years. Data on breast cancers identified through the screening programme are received on an annual basis from 1993 and recorded in the main registry dataset.

#### **3.1.4.2 Bowel Screening Programme**

The Bowel Screening programme commenced roll-out across NI in April 2010. It offers Faecal Occult Blood test (FoBt) to both men and women aged 60 to 74 years and had full population coverage in January 2012. Data on both malignant and benign colorectal neoplasms identified through the screening programme are received on an annual basis from 2010 and recorded in the main registry dataset.

### **3.1.4.3 Cervical Screening Programme**

A regional Cervical screening office was established in NI in 1989 and had full population coverage, including all women aged 20-64 years in a regular call/recall system by 1993. In January 2011 following expert advice, the Northern Ireland Cervical Screening programme adopted screening intervals in line with the national screening programme. Women in NI are now offered screening every three years from the age of 25 until 49 and every five years for women aged 50-64 years. Data on cervical cancer and in situ cervical lesions identified through the screening programme are received on an annual basis and recorded in the main registry dataset.

### **3.1.5 Analysis**

For each workstream within the Macmillan-NICR partnership work, an anonymised extract from the Registry is prepared for analysis by the NICR researcher funded by Macmillan. Further information on the variables included in these anonymised extracts is available in Appendix B. The preparation of the extract includes the use of Postcode information to derive Trust, Local Government district and Assembly area of residence and Deprivation Quintile. In order to assign deprivation quintile at an individual level, super output areas (SOA), or census output areas of NI, are assigned to each patient based on their postcode of usual residence at diagnosis. The patient is then assigned, through their SOA, to a socio-economic deprivation quintile based on the SOA's 2010 Income domain of the Multiple Deprivation Measure. The 2017 Multiple Deprivation Measure is available from the NI Statistics and Research Agency ([www.nisra.gov.uk](http://www.nisra.gov.uk)).

### **3.1.6 NICR Audit Database**

The audit database results from specifically funded audits to monitor the investigation, treatment, care of and survival of cancer patients diagnosed in NI in various specific years since 1996. This database contains more detailed data than routinely available in the areas of: 1. Referral and presentation 2. Patient factors- lifestyle, family history, co morbidities and symptoms 3. Investigations, in particular pre-operative investigation techniques and tumour stage 4. Treatments 5. Patient survival 6. Multidisciplinary team meetings 7. Timelines from referral to presentation, investigations, and treatment 8. Surgeon case volumes 9. Patient information and follow up care. The findings of the audits and collaboration with clinicians and the Northern Ireland Cancer Network (NICaN) have led to service improvement.

The NICR audit database includes data on:

- Breast Cancer 1996, 2001, 2006 and 2012 (*Audit subset of patients diagnosed Sept-Dec 2012*)
- Lung Cancer 1996, 2001, 2006 and 2014 (*Audit subset of patients diagnosed Sept-Dec 2014*)
- Colorectal 1996, 2001 and 2006
- Prostate 1996, 2001 and 2006
- Ovary and Cervix 1996, 2001 and 2010
- Oesophagus and Stomach 1996, 2001,
- Thyroid 2001/2002 & 2004/2005
- Pancreas 2001 and 2007
- Upper GI 2005
- Malignant Melanoma 2006
- Leukaemia and Lymphoma 2008
- Bladder cancer 2010 & 2011

### **3.2 Datasets that can be linked to the main NICR dataset**

There are several datasets that are available within the registry that can potentially be linked to the main registry dataset (Appendix A) to provide additional information on prescriptions, co-morbidities and treatments.

#### **3.2.1 Prescriptions database**

The Enhanced Prescribing Database (EPD) contains detailed information in relation to all primary care prescriptions dispensed to cancer patients in Northern Ireland since March 2008. The dataset therefore is a source of information on the level of morbidity within the cancer patient population in NI. This database is owned and managed by BSO. The NICR receives limited information from the Enhanced Prescribing Database including the class of drug prescribed and month of prescription.

#### **3.2.2 Co-morbidity database**

The NICR has received PAS downloads of hospital discharge records which include all hospital admissions since 1 January 2006 for cancer patients to determine patient co-morbidities.

### **3.2.3 Treatment data**

#### **3.2.3.1 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 have been defined by the UK and Ireland Association of Cancer Registries (UKIACR) Analysis group).

#### **3.2.3.2 Chemotherapy**

Chemotherapy data is available as an extract from PAS hospital discharge data using OPCS4 procedure codes and also through extracts from COIS. Going forward from April 2017 it is hoped that the NICR will continue to receive notifications of chemotherapy treatments through the Regional Information System for Oncology and Haematology (RISOH).

#### **3.2.3.3 Radiotherapy**

Radiotherapy data are available as an extract from the Radiotherapy machines (through the Ariasystem) from the Northern Ireland Cancer Centre within the Belfast Trust and North West Cancer Centre within the Western Trust.

#### **3.2.3.4 Hormone Therapy**

Data on whether a patient registered on the NICR database has been prescribed a drug classified as a hormone antagonist within the British National Formulary (BNF) are available from the enhanced prescribing database held at BSO.

### **3.3 Population tables and life tables**

Population tables are made up of midyear population estimates received on an annual basis from the Northern Statistics and Research Agency (NISRA) available at <https://www.nisra.gov.uk/statistics/population/mid-year-population-estimates>). The population tables are used for the calculation of age-standardised incidence rates.

Life tables for a given calendar period and geographic region within NI are derived from mortality data (number of deaths, population, by age and sex) and updated annually using data received from the General Registrar's Office for Northern Ireland.

### **3.4 Other relevant databases**

#### **3.4.1 PSA database**

The Registry also holds a database on patient's PSA test levels. This database is a population-based database of all PSA tests performed in NI biochemistry laboratories. The database is used to identify/ confirm cases without pathology and is also linked to information on prostate cancer patients. Consequently, 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.

#### **3.4.2 National Clinical Research Network EDGE system**

This system records trials and participating patient details for consented patients.

### **3.5 NICR Pre-Malignant Registers**

The main purpose of the NICR databases is the monitoring of cancer and premalignant lesions for the population to inform service planning, undertake evaluation of cancer services, provide information for professionals, provide anonymised data for international comparisons of outcomes (e.g. survival) and facilitate and undertake research. As part of this work the NICR holds four pre-malignant registers: Barrett's Oesophagus, Colorectal polyps, endometrial hyperplasia, Monoclonal Gammopathy of unidentified significance (MGUS).

#### **3.5.1 Northern Ireland Barrett's Register (NIBR)**

The Northern Ireland Barrett's oesophagus Register is one of the largest population-based registers of Barrett's worldwide, and now includes information on >13,000 incident diagnoses in Northern Ireland since 1993. Barrett's oesophagus is a pre-cursor condition for the cancer, oesophageal adenocarcinoma and the register has provided data for publications of international standing.

*Historic funding sources: the UK Medical Research Council, Cancer Focus Northern Ireland, NI HSC R&D Office, and Cancer Research UK.*

### **3.5.2 Colorectal Polyps Register**

The Colorectal Polyp Register includes information on all polyp diagnoses since 2000 in Northern 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, Tennessee, USA, is ongoing using this resource to identify biomarkers for advanced recurrent adenomas.

*Historic funding sources: Cancer Focus Northern Ireland.*

### **3.5.3 Endometrial Hyperplasia (EH) Register (Endometrial Cancer)**

This new project aims to establish a population-based register of Endometrial Hyperplasia cases within the Northern Ireland Cancer Registry (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 cases who do not undergo hysterectomy. The results will allow women to make informed treatment choices following an Endometrial Hyperplasia diagnosis.

*Current funding sources: Queen's University Belfast International PhD Studentship.*

### **3.5.4 Monoclonal Gammopathy of unidentified significance (MGUS) Register (Haematological Malignancies)**

This pre-malignant blood disorder commonly precedes multiple myeloma. This population-based database facilitates surveillance and assessment of the impact of MGUS on patient outcomes such as rate of progression to cancer and subsequent survival.

*Current funding Sources: Cancer Research UK*

## **4. Potential linkage to other Datasets**

There are several datasets held outside the registry with which there may be the potential for linkage to the main NICR dataset, subject to additional ethical and research governance approvals (Appendix B). These datasets include the Northern Ireland Cancer Patient Experience Survey and Northern Ireland Longitudinal study. There is the potential to link registry data to administrative datasets such as Northern Ireland Census data through the Administrative Data Research Centre-NI and/or health datasets, such as Enhanced Prescribing Database through the Honest Broker Service.

#### **4.1 Northern Ireland Cancer Patient Experience Survey**

The Cancer Patient Experience Survey (CPES) was issued for the first time in Northern Ireland in 2015. The survey was sent to 5,388 patients who were having treatment for their cancer in hospitals over a defined six-month period. The purpose of the survey is to get the views of patients on the care they received and how they can be improved.

The survey was carried out by researchers from Quality health for the Public Health Agency (PHA) and Macmillan Cancer Support. Public reports were produced that included the anonymous survey findings and benchmarked Northern Ireland against similar surveys carried out in England and Wales.

The Northern Ireland CPES is currently being repeated. Subject to appropriate ethical and data governance approvals, there would be the potential to link the survey data to NICR data in order to understand and analyse patients' responses in the context of the wider history of cancer diagnosis, treatment and follow-up.

#### **4.2 Northern Ireland Longitudinal Survey (NILS)**

The Northern Ireland Longitudinal Study (NILS) is a large-scale, representative data-linkage study created by linking data from the Northern Ireland Health Card Registration system to the 1981, 1991, 2001 and 2011 Census returns and to administrative data from other sources. These include vital events registered with the General Register Office for Northern Ireland (such as births, deaths and marriages) and the Health Card registration system migration events data.

#### **4.3 Potential Datasets available for linkage through ADRC-NI**

##### **4.3.1 Northern Ireland Census**

The Census collects information about the characteristics of individuals and households in Northern Ireland. It takes place every 10 years with the previous census being held in 2011 and the next census due to take place in 2021. The census questionnaire collects socio-economic and demographic information for all individuals and households throughout Northern Ireland. The topics covered include:

- Age, sex and marital status
- Religion and community background
- Family, household or communal establishment type

- Housing, including tenure, number of rooms and amenities
- Country of birth, ethnicity and nationality
- Educational qualifications
- Economic activity, occupation, industry and socio-economic classification
- Migration (from October 2001 onwards)
- Limiting, long-term illness, self-reported general health, care-giving and specific (self-reported) health condition
- Travel to work and place of study

#### **4.3.2 BSO data**

The Business Services Organisation were established to provide a broad range of regional business support functions and specialist professional services to the health and social care sector in Northern Ireland. The BSO Information and Registration Unit includes staff seconded from the Northern Ireland Statistics and Research Agency (NISRA) and highly-skilled staff from within the Family Practitioner Services team. The Unit has a Service Level Agreement (SLA) with the HSC Board which is reviewed on an annual basis to reflect changing customer needs and what can be delivered within resources. BSO provides support and information to both internal and external customers including General Medical, Dental, Ophthalmic and Pharmaceutical services in Northern Ireland. The Honest Brokers Service within BSO is a recognised 'safe haven' for securely matching datasets. A 'safe haven' is an environment where population based research, statistical analysis and data matching can be carried out with the risk of identifying individuals is minimised, i.e. a place where research can be done on sensitive data so that the risk of disclosure is reduced by controlling who can have access to the 'safe haven', what data they can analyse and what outputs can be taken away. A 'safe haven' can be accessed either physically or virtually, but a key characteristic is that researchers can only keep their results and even the results are screened to ensure that no disclosive data are released. The 'safe haven' within the Honest Brokers Service in BSO can only be accessed physically.

BSO datasets that are available to be linked include:

- Dental claims data
- Dental Registrations data
- Enhanced Prescribing database (EPD)
- Ophthalmic claims data
- GP Patient Registration data

### **4.3.3 Department for Employment and Learning (DEL) data**

The Higher Education Statistics Agency (HESA) – the official agency for the collection of information on publicly funded Higher Education institutions in the UK – provides DEL with details on student enrolments and qualifications gained at Northern Ireland (NI) Higher Education institutions and also for NI domiciled students at UK Higher Education institutions in each academic year. They also provide details of the destination of leavers from Higher Education six months after graduation.

### **4.3.4 Central Survey Unit (CSU) data**

The Central Survey Unit (CSU) is the official social survey group within NISRA. The Unit is involved in the design and management of social surveys and provides a survey research service to the public sector. The CSU carry out a variety of continuous surveys on a range of topics for governing departments including the Continuous Household Survey and the Labour Force Survey.

#### ***4.3.4.1 Continuous household survey***

The questionnaire consists of both a household interview and an individual interview with each person within the sample aged 16 years and over. Both the household and individual questionnaires consist of core items that are included each year. Core items include household and individual demographics, accommodation, tenure, migration, internet access, environmental issues, domestic tourism, participation in sports, art and leisure, employment status, employment activity, educational qualifications, health and section 75 classifications.

#### ***4.3.4.2 Labour Force Survey***

The Labour Force Survey (LFS) is a continuous household survey. The main purpose of the survey is to provide information on the labour market, including employment, unemployment and economic activity rates. It also covers a range of related topics, such as income, qualifications, training and disability.

## **5. Published Information and reports**

### **5.1 NICR Website**

The NICR website was redesigned in 2015 to improve accessibility and encourage user interaction. The Official statistics for cancer in Northern Ireland including incidence, prevalence and survival are published online in March each year. Cancer mortality statistics from the General Registrars Office (GRONI) are also published at this time. There is a lag time of

approximately 15 months following the end of a given year i.e. the current official statistics available for cancers diagnosed between 1993-2015 were published in March 2017. Alongside the release of the official statistics, the NICR produces a suite of fact sheets for a number of cancer sites, as well as a summary factsheet for all cancers (excluding non-melanoma skin cancer), to provide some explanation and context for key cancer statistics. The NICR also provides summary statistics for different cancer types by geographical location to improve the accessibility of the data with cancer site statistics located in the one centralised location.

## **5.2 NICR reports**

The NICR has produced a number of reports on trends cancer incidence (i,ii), prevalence (iii) and survival (iv) for people diagnosed with cancer in Northern Ireland.

### References

- (i) *Donnelly, D and Gavin, AT (2015) Cancer Incidence trends 1993-2013 with Projections to 2020 and 2035.*
- (ii) *Donnelly, D and Gavin AT (2014) Cancer Statistics by Local Government District: Patients diagnosed in Northern Ireland during 2008-2012.*
- (iii) *Donnelly, D and Gavin AT (2013) Living with and beyond cancer: A report of cancer prevalence in Northern Ireland in 2010.*
- (iv) *Donnelly, D and Gavin AT (2007) Survival of cancer patients in Northern Ireland 2003-2004*

### 5.3 Local Cancer Intelligence (LCI) Tool

In collaboration with the NICR (NICR), Macmillan Cancer Support has developed the Local Cancer Intelligence (LCI) tool to help understand the changing cancer population across the HSC Trusts, Local Government District areas and tumour groups within Northern Ireland. It combines NICR and Macmillan data to provide a quick and easy user-friendly way of getting headline figures on numbers, needs and experience to show what the changing cancer story means. The data for the LCI tool have been provided from routinely available anonymised statistics on cancers occurring in Northern Ireland and is updated annually as new data becomes available. Data on cancer incidence, prevalence and survival for 1993-2014 is currently included in the LCI tool at <https://lci.macmillan.org.uk/>. The data on the site is due to be updated to include 2015 in early 2018.

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**UNDERSTANDING NORTHERN IRELAND'S CANCER POPULATION**

**THE CANCER STORY IS CHANGING.**

In collaboration with the N. Ireland Cancer Registry (NICR), Macmillan Cancer Support has developed this Local Cancer Intelligence tool to help you understand your changing cancer population. It details what the changing cancer story means for your area by giving you headline information on numbers, needs and experiences.

According to the NICR, there are an estimated 55,721 people living with cancer in Northern Ireland. By 2030 there could be 93,000. [Learn more about Local Cancer Intelligence](#)

#### View local statistics

View statistics for Northern Ireland by Health or Social Care Trust or Council area.



Health and Social Care Trust



Local Council

All Northern Ireland »

## **6. Current gaps in knowledge/access to data and areas of challenge for the NICR**

### **6.1 Recurrence and Metastatic disease**

Recording recurrence (whether local or distant metastases) can be difficult as there are no ICD-10 codes available for recording a local recurrence and recurrence is not routinely recorded within the NICR main dataset. However, the NICR have developed a working procedure for recording breast cancer recurrence to be agreed by the Northern Cancer Network (NiCaN) with working procedures for other tumour sites to follow and have been working closely with the CaPPS user group to promote the introduction of a specific field for recurrence data entry going forward. The NICR will present the working procedure to the NiCaN Breast clinical reference group for 'sign-off' in Early 2018. The Macmillan-NICR Partnership is contributing to a Public Health England (PHE) led initiative to develop and test algorithms for recording and reporting recurrence of selected cancer types.

### **6.2 Outcomes beyond survival**

NICR staff have been principal investigators in two Prostate Cancer UK (PCUK) funded surveys of men after diagnosis and treatment for prostate cancer, (see LAPCD under research below). However, other than this there is currently little information available for other cancer sites on patient outcomes following treatment including consequences of treatment and other co-morbidities following treatment e.g. anxiety and depression, quality of life and the impact that cancer diagnosis and treatment has on the ability to carry out usual everyday activities (e.g. work) in the short-term and long-term. Access to more detailed prescription data (including the actual drug prescribed) as well as census and benefits data through the ADRC-NI would be invaluable in helping us to better understand the impact that a cancer diagnosis has on the 'whole person'. This work could also include data linkage to help understand other characteristics of the cancer population in Northern Ireland including ethnicity, housing status and education level (in particular of people diagnosed with cancer under the age of 25 years).

### **6.3 Primary care data**

The NICR has access to clinical records for cancer patients to verify diagnosis, staging, etc, The Registry has agreements to view GP records of deceased cancer patients also to check fact and date of diagnosis. The NICR has offered GPs the opportunity to check their data held on cancer patients against data held by the NICR; there was a good take up of this offer and results indicated a high level of data quality within the NICR (i).

(i) Kearney, TM, Donnelly, C, Kelly, JM, O'Callaghan, EP, Fox, CR, Gavin, AT (2015) Validation of the completeness and accuracy of the Northern Ireland Cancer Registry. *Cancer Epidemiology*: 39:3:401-404

## **6.4 Legislation**

The Health and Social Care (Control of Data Processing) Act received Royal Assent in April 2016. The Act provides a framework to enable the use of health and social care information for health and social care purposes which are in the public interest.

The Act is broadly similar to the provision which exists in England and Wales. However, because of the integrated nature of health and social care in Northern Ireland, the Northern Ireland act covers health and social care information (which in turn cover cancer registration). The Northern Ireland Act also contains some provisions about opt out and places an obligation on the Department of Health to publish a Code of Practice on the processing of information.

The detail will be contained in subordinate legislation which will cover how the provisions of the Act will be implemented. Regulations will have to be drafted and consulted upon before being scrutinised and debated by the Northern Ireland Assembly however this has been delayed due to lack of a working Assembly.

The lack of a legal framework for use of health and social care information for health and social and care purposes which are in the public interest has been a challenge for the NICR and has previously prevented the submission of anonymised Northern Ireland cancer data to UK wide audits of cancer services for specific cancer sites.

## **7. Research studies**

### **7.1 Life After Prostate Cancer Diagnosis (LAPCD) study**

The multi-centre UK wide study is being led by Prof Adam Glaser, University of Leeds and Dr Anna Gavin, NICR. It follows a similar All Ireland study also funded by PCUK 2011-2015).

For LAPCD, men living in Northern Ireland who were diagnosed with prostate cancer between 1st December 2012 and 31st November 2014 were surveyed in June and July 2016. They were asked about a range of general cancer specific and prostate cancer specific outcome measures. The topics covered included urinary and bowel functioning, sexual functioning, psychological and social well-being as well as physical, social and financial concerns. This project aims to find out what effect prostate cancer has on men's physical, emotional and social wellbeing, as well as exploring the impact on their families. The combined results should lead to a detailed picture of what life is like for men with prostate cancer across the UK. Information will be gained on how circumstances can change over time, what helps the men cope with any problems and what gaps there are in support and care services. To date 35,823 men with prostate cancer (England, Scotland, Wales and Northern Ireland) and 2,955 men

without prostate cancer (*general population cohort; Northern Ireland only*) have completed the survey. This general population cohort should allow testing of whether significant differences in health outcomes in prostate cancer patients exist when compared to the general population. Analysis is currently underway with results expected in early 2018. The men who responded to the first survey are being resurveyed in July and August 2017 to compare their answers and see if their symptom or concerns have changed.

## **7.2 International Cancer Benchmarking Partnership (ICBP)**

The ICBP was originally in phase I a partnership of 12 jurisdictions (New South Wales and Victoria [Australia], Alberta, British Columbia, Manitoba, Ontario [Canada], Sweden, Denmark, Norway, England, Wales and Northern Ireland). Module 4 also includes Scotland. The study began in 2009 and has involved 5 modules of work. Module 1 examined survival for breast, lung, colorectal and ovarian cancers for all involved countries using similar methods. It found lower survival rates in the UK countries and Denmark than other areas especially 1 year from diagnosis. Module 2 examined population awareness of symptoms. Module 3 reported on difference in primary care. Module 4 aims to determine pathway delays to cancer diagnosis in patients diagnosed with breast, colorectal, lung or ovarian cancer. Data collection is now completed for all four cancer sites in module 4 and international analysis and preparation of papers is currently underway. It is estimated that results for Breast and Colorectal cancer will be submitted for publication in early 2018 with the results for Lung and Ovarian cancer estimated to be submitted for publication in Summer 2018.

Phase 2 of the ICBP has expanded to include 19 jurisdictions including Canada (10 jurisdictions), United Kingdom (England, Scotland, Wales and Northern Ireland), Australia (3 jurisdictions), Ireland and New Zealand.

The new cancers to be studied are liver, pancreas, oesophagus and stomach in addition to lung, colorectal and ovarian which were included in phase I.

Four additional research topics have been identified for phase II These topics are:

- Access to diagnostics and investigations e.g. capacity workforce use, location, guidelines, quality, cost
- Access to treatment and related factors e.g. specialisation/centralisation, quality of treatment, innovation (e.g. research intensity, uptake of novel treatments)
- Cancer patient care pathways e.g. standardised clinical pathways, typical costs, who pays for what and

- Structure of health systems e.g. role of clinicians, interface between primary and secondary care.

### **7.3 Qualycare-NI study**

The QUALYCARE-NI study funded by Cancer Focus Northern Ireland examined the end of life care of cancer patients in Northern Ireland, with an aim to establish key factors that enable cancer patients to remain at home. The method and questionnaire were based on a similar study by Cicely Saunders Institute, Kings College London. In Northern Ireland the study was facilitated by the Northern Ireland Statistics and Research Agency (NISRA) to maintain patient and responder confidentiality. Participants completed a questionnaire seeking their views on the care received in the three months before their relative died. 467 questionnaires were completed and the information provided has been analysed and reported in the final study report available at (<https://www.qub.ac.uk/research-centres/nicr/FileStore/PDF/NIrelandReports/Filetoupload,532185,en.pdf>).

### **7.4 Targeting Early Diagnosis Interventions (TEDI) study**

In 2012, the NICR initiated a project to investigate the factors associated with dying within 3 months of a diagnosis of lung or colon cancer. This study was funded by the Cancer Research UK (CRUK) National Awareness and Early Diagnosis Initiative. The study involved a comprehensive note review of GP records to review patient characteristics and pathways to diagnosis. Almost 25,000 GP and hospital episodes for over 2000 patients were recorded. The results identify target populations for promoting early diagnosis and will provide evidence to inform improvements to early cancer diagnosis in primary care. Colorectal cancer data have been analysed and published, with the lung cancer dataset has yet to be analysed. *There is currently no analytical resource available with the NICR core team to carry out this analysis.*

## Appendix A: N. Ireland Cancer Registry

### A1.1 N. Ireland Cancer Registry Background

The N. Ireland Cancer Registry (NICR) was established in 1994 (has full population coverage from 1993) and is funded by the Public Health Agency and located in Queen's University Belfast. The Registry is responsible for the production of Official Statistics on cancer incidence, prevalence and survival in Northern Ireland and provides evidence to help inform decision making about cancer services. This work uses data provided by patients and collected by the health service as part of their care and support. The aim of the NICR is to provide accurate, timely information on cancers occurring in the population of NI for research, planning and education so that the burden of disease may be reduced and the experience of patients and their outcomes improved.

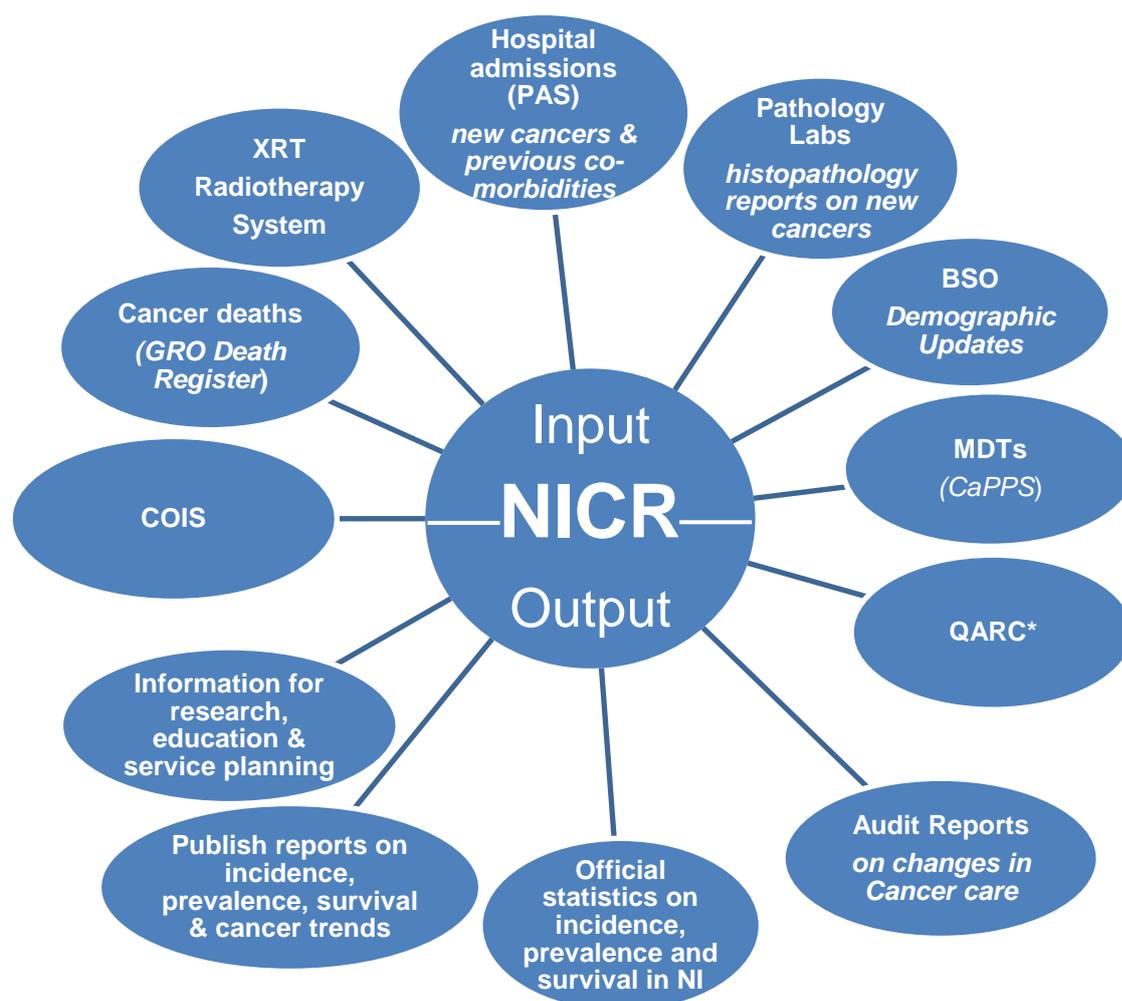
The objectives of the registry are:

- To collect and confidentially store accurate, timely and comprehensive data on cancers and pre-malignant disease occurring in the Northern Ireland population.
- Uphold patient and carer confidentiality
- Analyse data to provide for the Registry's role as provider of official cancer incidence, prevalence and survival statistics in Northern Ireland.
- Provide appropriate information on cancer for ad hoc queries in a timely manner.
- 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, treatment and outcomes.
- Link nationally and internationally to promote cancer registration and increase understanding and control of cancer.

The NICR has approval for its databases from the Office for Research Ethics Committees Northern Ireland (ORECNI) Reference 15/NI/0203. It is registered with the Data Protection Act - Registration Number (QUB): Z6833827. Each research project that uses registry data has separate ethical approvals. A leaflet and poster are available to inform patients, clinicians and the public about the work of the NICR. In 2014, a video was developed to inform a wider audience of the work of the NICR available at [www.qub.ac.uk/nicr](http://www.qub.ac.uk/nicr).

The method for removal of patients' data if requested is to notify the organisation providing data to the Registry of the relevant Health and Social Care Number so a block can be placed to prevent notification to the NICR.

## A1.2 N. Ireland Cancer Registry (NICR) Method of Operation



\*Registry provides data to quality assure Cancer Screening Services and to facilitate the work of the Clinical Genetics service (QARC = Quality Assurance Reference Centre).

## A1.3 UK and Ireland Association of Cancer Registries (UKIACR) Performance Indicators

Each year all five of the cancer registries in the UK and Ireland extract data relating to a number of performance indicators to allow comparisons of the timeliness, quality and completeness of their data. This information is collated centrally and an annual report is published.

The measures that make up the annual performance indicators include:

- Stability of incidence in the current year compared to the average of the three previous years
- Completeness of data items such as known date of diagnosis, date of birth, identification number, ethnicity and tumour behaviour code

- Completeness of screening category for breast, bowel and cervical cancers
- Completeness of stage at diagnosis by cancer type and morphology
- Proportion of death certificate only (DCO) cases
- Proportion of patients whose morphology code is non-specific, proportion of microscopically verified cases, the mortality to incidence ratios
- Proportion of tumours that have any treatment where treatment would be expected (i.e. childhood, early stage)

The performance indicators for the most recent year of published data (2015) have shown a DCO rate of 0.3% (*below the target of 2.0%*), a high microscopic verification rate (86.7%; *similar to that observed across other UKIACR registries*), a high proportion (82.4%) of tumours staged (*above the target of 70%*) and that 61% of tumour have a grade recorded (*above UKAICR average of 55.1%*) which continue to highlight the consistently high quality data held within the N. Ireland Cancer Registry.

#### **A1.4 ISO27001 Certification**

In June 2017, the NICR was accredited with the ISO27001 Certification in Information Security Management. ISO27001 is an internationally accredited and recognised information management standard that looks at how security of the information assets within the NICR are managed and implemented. These controls, which take the form of policies, procedures, technical and logical provisions, are externally audited by an accredited organisation to ensure that the procedures we have put in place meet the standard required and that we are observing these policies and procedures in our day to day operations. The certification lasts initially for three years and is continually monitored and audited both internally and externally by the certification body.

## Appendix B. Variables in Main N. Ireland Cancer Registry Dataset

<b>Variable</b>	<b>Description</b>
<i>Personal Identifier</i>	Unique Identification number
<i>Tumour ID number</i>	Tumour number
<i>HCN</i>	Health and Care number
<i>Sex</i>	
<i>Date of Birth</i>	
<i>Marital Status</i>	
<i>GP at Diagnosis</i>	GP cypher code at time of Diagnosis
<i>Postcode at Diagnosis</i>	
<i>Local Government District at Diagnosis</i>	<b>11 Local Government Districts (2014)</b> (Antrim & Newtownabbey, Armagh, Banbridge & Craigavon, Belfast, Causeway Coast & Glens, Derry & Strabane, Fermanagh & Omagh, Lisburn & Castlereagh, Mid & East Antrim, Mid Ulster, Newry, Mourne & Down, North Down & Ards)
<i>Assembly Area at Diagnosis</i>	<b>18 Assembly Constituency areas (2014)</b> (Belfast East, Belfast North, Belfast South, Belfast West, East Antrim, East Londonderry, Fermanagh & South Tyrone, Foyle, Lagan Valley, Mid Ulster, Newry & District, North Antrim, North Down, South Antrim, South Down, Strangford, Upper Bann, West Tyrone)
<i>Trust at Diagnosis</i>	<b>5 HSC Trusts</b> (Belfast, Northern, South-Eastern, Southern, Western)
<i>Deprivation Index</i>	Currently using 2010 Deprivation index based on postcode at diagnosis but 2016 data (published in 2018) will be using 2017 Deprivation index.
<i>Basis of Diagnosis</i>	The method used to validate the diagnosis during the course of the illness
<i>Screen Detected</i>	
<i>Number of nodes examined</i>	Pathological nodal status- indicates the number of regional lymph nodes that were examined ( <i>invasive breast cancer only</i> )
<i>Number of positive nodes</i>	Pathological nodal status- indicates the number of regional lymph nodes that were examined ( <i>invasive breast cancer only</i> )
<i>Date of Diagnosis</i>	
<i>Age at Diagnosis</i>	
<i>Tumour site (ICD10)</i>	
<i>Laterality</i>	This indicates the laterality or side (e.g. left or right). In paired organs of the body in which the tumour is located.
<i>Morphology</i>	
<i>Tumour Behaviour</i>	
<i>Grade</i>	
<i>Clinical T</i>	T-Clinical stage indicates the extent of spread of the tumour at diagnosis in terms of clinical findings
<i>Clinical N</i>	N-Condition of regional lymph nodes/glands based on clinical examination imaging
<i>Clinical M</i>	M-indicates distant metastases
<i>Pathological T</i>	T- Pathological Stage indicates the extent of the spread of the tumour at diagnosis in terms of pathological findings

<b>Variable</b>	<b>Description</b>
<i>Pathological N</i>	N-Condition of regional lymph nodes/glands based on pathological findings
<i>Pathological M</i>	M-indicates distant metastases
<i>Pathological Tumour size</i>	Pathological tumour size is maximum diameter in mm of the invasive component of the tumour in the fresh or fixed state on the histological preparation.
<i>Overall Stage Duke's</i>	Stage (Colorectal) indicates the extent of spread of the invasive tumour at diagnosis in terms of the pathological and/or clinical findings
<i>Clarke's</i>	This is a measure of depth of invasion of the melanoma into the skin.
<i>FIGO</i>	FIGO stage indicates the extent of spread of the invasive primary tumour for Cervix and ovary at diagnosis in terms of the pathological/clinical findings
<i>Breslow Thickness (mm)</i>	This is a measure of the depth of invasion of the melanoma into the skin in mm.
<i>Gleason Nottingham Prognostic Index (NPI)</i>	The Nottingham Prognostic index (NPI) is used to determine prognosis following surgery for breast cancer. Its value is calculated using three pathological criteria: the size of the lesion; the number of involved lymph nodes and the grade of the tumour.
<i>Date of Death</i>	
<i>Cause of Death</i>	
<i>Survival Status</i>	
<i>Age at follow-up</i>	
<i>Postcode at follow-up</i>	
<i>Local Government District at follow-up</i>	<b>11 Local Government Districts (2014)</b> (Antrim & Newtownabbey, Armagh, Banbridge & Craigavon, Belfast, Causeway Coast & Glens, Derry & Strabane, Fermanagh & Omagh, Lisburn & Castlereagh, Mid & East Antrim, Mid Ulster, Newry, Mourne & Down, North Down & Ards)
<i>Assembly Area District at follow-up</i>	<b>18 Assembly Constituency areas (2014)</b> (Belfast East, Belfast North, Belfast South, Belfast West, East Antrim, East Londonderry, Fermanagh & South Tyrone, Foyle, Lagan Valley, Mid Ulster, Newry & District, North Antrim, North Down, South Antrim, South Down, Strangford, Upper Bann, West Tyrone)
<i>Trust at follow-up</i>	<b>5 HSC Trusts</b> (Belfast, Northern, South-Eastern, Southern, Western)
<i>Deprivation index at follow-up</i>	Currently using 2010 Deprivation index based on postcode at follow-up but from 2016 data published in 2018 will be using 2017 Deprivation index.
<i>GP at follow-up</i>	