



Northern Ireland Cancer Registry Newsletter

Volume 24: July 2018



The N.Ireland Cancer Registry was recently peer reviewed by representatives from European Network of Cancer Registries (ENCR), Queen’s University Belfast, the N.Ireland Public Health Agency and the N.Ireland Cancer Network (NICaN) Patient Forum.

L-R; Prof Ken Mills, Chair NICR Steering Group; Dr Elizabeth Van Eycken, Director, Belgium Cancer Registry, (ENCR rep); Janine McCann, N.Ireland Cancer Consumer Research Forum; Dr David Morrison, Director, Scottish Cancer Registry; Dr Anna Gavin, Director NICR; Dr Lesley Anderson, Acting Deputy Director NICR; Prof Donna Fitzsimmons, Head of Nursing and Midwifery, QUB Representative; Dr Louise Herron, PHA Representative.

Their report is due in Summer 2018.



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ISO27001 certification

ISO27001 certification in Information Security Management continues to be monitored and improved in the Registry with ongoing internal audits ensuring the compliance with the policies and procedures as set out in the accredited security management system. The Registry is currently preparing for an external surveillance audit in early August 2018.

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Official Statistics

On Tuesday 13th March 2018 the N. Ireland Cancer Registry published the latest official statistics on cancer incidence, survival and prevalence in N. Ireland up to the year ending December 2016. (<http://www.qub.ac.uk/research-centres/nicr/CancerInformation/official-statistics/>).

Alongside the release of the official statistics, we have produced 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 some key cancer statistics. We also provide summary statistics for cancer sites by geographical area.

Cancer statistics are located in the one centralised location to aid accessibility of the data: <https://www.qub.ac.uk/research-centres/nicr/CancerInformation/official-statistics/ByGeography/>.

Key Findings

- Over the last ten years the number of cancer cases has increased from 4,044 among men and 3,885 among women in 2007 to 4,629 among men and 4,817 among women in 2016. In addition there were 2,722 cases of Non-melanoma skin cancer (NMSC) in 2002 and 3,798 in 2016. This increase is largely due to an increasing number of older people in the population as cancer rates increase with age. There are currently an estimated 61,038 people living in N.Ireland with a cancer diagnosis as of December 2016.
- The most common cancers diagnosed among males between 2012 and 2016 were prostate (24% of all cancer in males), colorectal (14%) and lung (14%) while the most common cancers among women were breast (30% of all cancer in females), lung (13%) and colorectal (11%) (See Figure 1).
- In 2016 the number of lung cancer cases in women has surpassed the number of cases in men for the first time (Figure 2). After adjusting for the age and size of the population, age-standardised incidence rates of lung cancer have been declining in men by 0.8% per year while rates have been significantly increasing by almost 5.8% per year in women since 2010. This is reflective of historical smoking trends in men and women.
- Net survival rates, which take account of background mortality, are improving in recent years:
 - **55%** of all cancer patients survived five years after diagnosis for patients diagnosed between **2006-2010** compared to **44%** five year survival for patients diagnosed **1993-2000**.
 - Five-year net survival rates for patients diagnosed between 2006 to 2010 were as follows: female breast (81.7%), colorectal (57.6%), prostate (88.7%), lung (10.4%). These survival rates have all shown improvement compared to patients diagnosed in the period 1993 to 2000, although gains in lung cancer survival were slight.
 - Marked improvements were observed in leukaemia and oesophageal cancer survival, likely a reflection of improvements in treatments.

Official Statistics

(continued)

Figure 1: Incidence of cancers in N.Ireland in males and females, 2012-2016

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

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

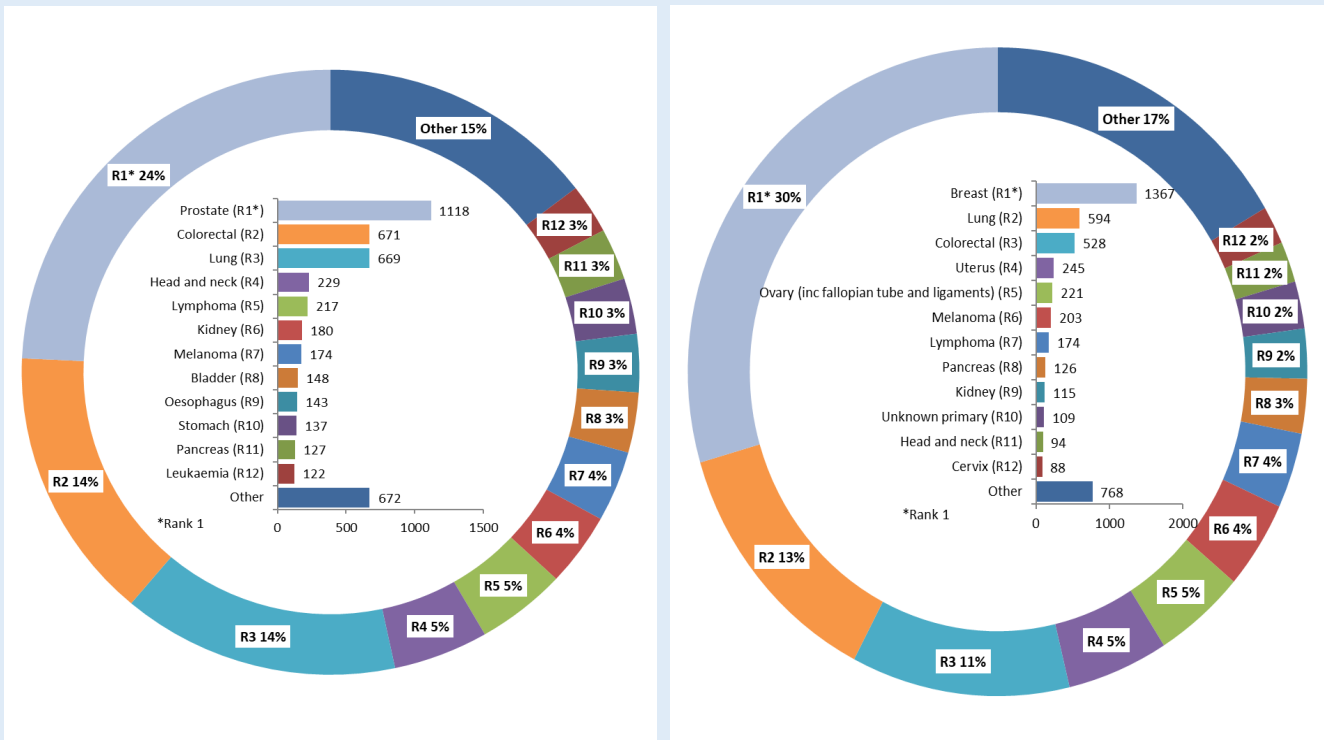
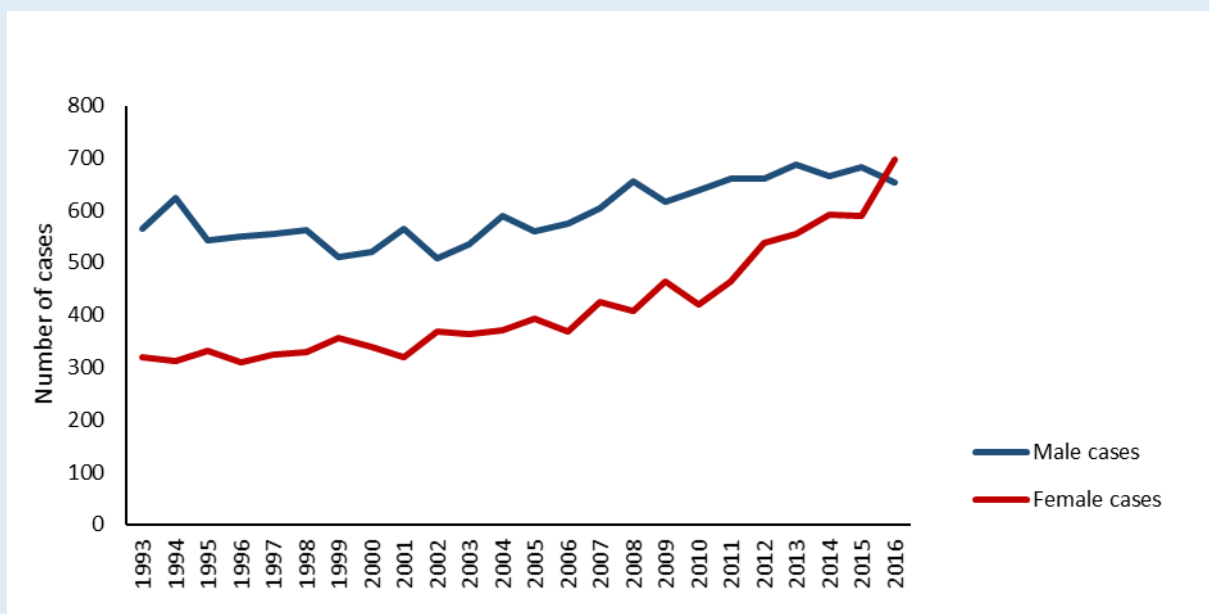


Figure 2: Trends in lung cancer incidence rates by sex: 1993-2016



UK and Ireland Association of Cancer Registries Quality and Performance Indicators

The United Kingdom and Ireland Association of Cancer Registries (UKIACR) strive to improve quality of data through the development of Performance Indicators (PIs). The UKIACR PIs are carried out annually and enable comparisons of timeliness, quality and data completeness for England, Scotland, Wales, N. Ireland (NI) and the Republic of Ireland. This year due to software updates on cancer registration systems in Wales and Ireland, only England, Scotland and NI took part in 2018 for the 2016 dataset. The information is collated and an annual report produced, consisting of a series of datasets, with accompanying explanatory commentary from each of the Registries.

Data quality indicators were collated for all registerable tumours diagnosed in 2016 (more than 17,300 tumours in NI), which included all cancers, in-situ tumours and tumours of uncertain behaviour, as well as benign tumours of the brain, other parts of the central nervous system and teratoma of testis.

This UKIACR PI data demonstrated a continued trend of improvements in data completeness and quality. The indicators demonstrate that cancer incidence continues to increase year on year for the majority of cancer types. In particular large increases were seen in head and neck cancer, malignant melanoma and breast in-situ. Death certificate only (DCO) rates are below the target (lower than 2%) for the UK and Ireland overall, and in particular for NI (DCO 0.4%). Across each of the jurisdictions improvements can be seen in terms of the completeness of grade of differentiation and stage at diagnosis, with NI having the highest level for each at 64% and 85% respectively.

The quality and timeliness of data held by cancer registries continues to improve with areas highlighted for action for particular cancer registries to improve data completeness. These excellent results for the N.Ireland Cancer Registry (NICR) reflect the huge effort staff make to ensure that the information collected is accurate and as complete as possible.

The detail of the latest Performance Indicators for NICR may be found at: <http://ukiacr.org/kpis>

Ongoing Research

Life after Prostate Cancer Diagnosis (LAPCD) Funded by Prostate Cancer UK and MOVEMBER

Life After Prostate Cancer Diagnosis

With more men now surviving five or more years following a diagnosis of Prostate Cancer it is important to consider the quality of survivorship.

The Life After Prostate Cancer Diagnosis (LAPCD) project is a UK wide project involving the University of Leeds, Queens University Belfast, University of Southampton, Oxford Brookes and National Cancer Registries of England, N.Ireland (NI), Scotland and Wales. It has the aim of investigating the quality of life of prostate cancer survivors. The study looks at men's physical, emotional and social wellbeing and associated factors. Patients were

identified by the four UK cancer registries, with a survey sent to men diagnosed with prostate cancer in the previous 18-42 months. The survey included questions on the patients characteristics (e.g. marital status, ethnicity), treatment received (e.g. surgery, radiotherapy), general health, specific outcomes (e.g. urinary, sexual and bowel functioning), and psychological issues (e.g. mental wellbeing, social and financial concerns). The men who responded to this survey in England were resurveyed at a second time point to determine if their symptoms or concerns had changed. 35,823 men with prostate cancer throughout the UK responded to the first survey (a 60.8% response rate) making it the biggest study of patient reported outcomes yet completed.

An additional and unique component of the study was the completion of an additional survey of men in NI without prostate cancer who had a similar age profile to the prostate cancer survivors. By asking these men the same questions we can determine whether prostate cancer survivors have a significantly different quality of life than similar men in the general population. Results from this study have now been published and show that urinary, bowel and sexual dysfunction are common among older men in the general population (see figure above). Any studies of patient reported outcomes must therefore take this into consideration when assessing the impact of treatment for prostate cancer, otherwise adverse treatment effects may be overestimated.

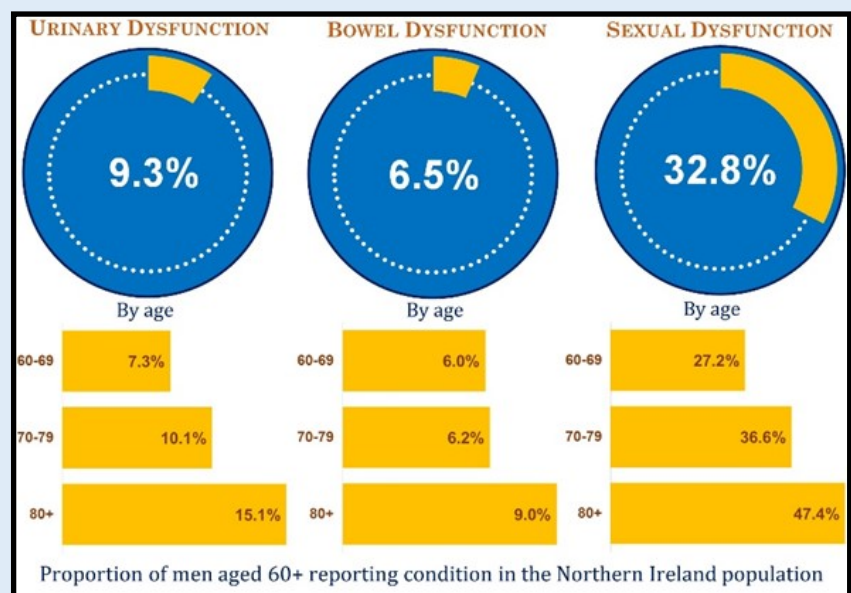
Results from the primary survey of prostate cancer survivors will be released over the next six months, with a wide range of topics covered including:

•Variations in patient reported outcomes by stage at diagnosis and treatment type

•Social distress among prostate cancer survivors and the factors associated with severe distress

•Regional variations in quality of life of prostate cancer survivors

•A toolkit with information for the public and clinicians will soon be available

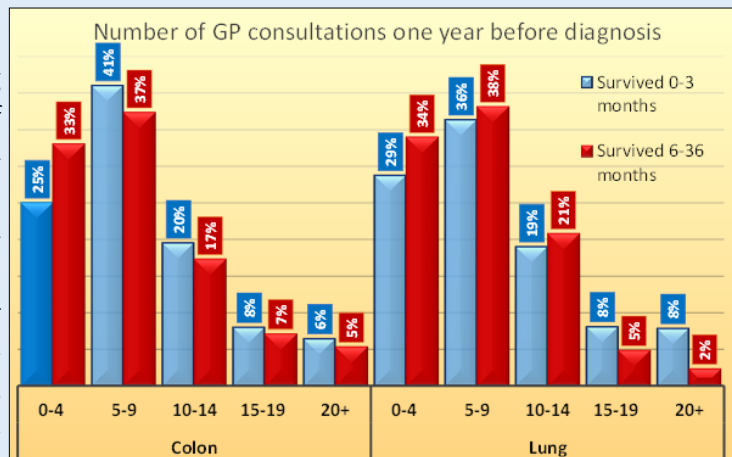


Early and moderate survival from colon and lung cancer

Lung and colon cancer are two of the most common cancers in Northern Ireland, with five-year survival from these cancers approximately 9% and 56% respectively. Survival from these cancers has been slowly improving, but further gains could be achieved by earlier diagnosis as survival from these cancers varies considerably depending upon the stage at diagnosis.

The Targeting Early Diagnosis Interventions Study was conducted from June 2012 to March 2016 as a PhD project and resulted

in a wealth of data being collected with the purpose of investigating ways to improve early detection of lung and colon cancer by comparing patients who survived less than three months to those who survived between six months and three years from diagnosis. Over the next six months we will be conducting further investigation of this dataset in order to extract new information from it. The results will

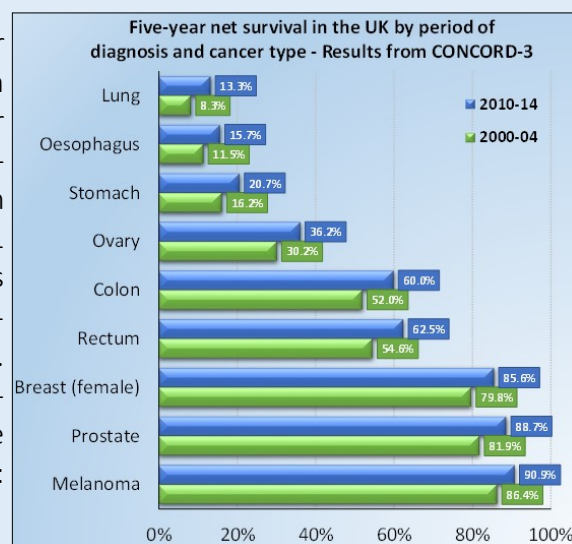


be used to produce a research report fully describing the characteristics of colon and lung cancer patients who survive short and moderate periods of time. Such characteristics include socio-demographic factors, GP visit history (e.g. number of consultations in last year, see figure right), symptoms reported to GPs, investigations (e.g. CT scans and X-rays), treatment type and tumour characteristics.

It is hoped that this unique project will provide insight into why some cancer patients are diagnosed at a very late stage and thus only survive a short time after diagnosis.

Global surveillance of trends in cancer survival 2000–14 (CONCORD-3)

The N.Ireland Cancer Registry provided data for the third CONCORD study. Results published in The Lancet in January 2018 included survival for 18 common cancers involving 37.5 million cancer patients diagnosed during 2000-2014, from 322 population-based cancer registries in 71 countries. For most cancers, five-year survival is highest in the USA, Canada, Australia, New Zealand, Finland, Iceland, Norway, and Sweden. Survival trends are generally increasing, but international differences remain very wide. The full results from the study can be found here: [http://dx.doi.org/10.1016/S0140-6736\(17\)33326-3](http://dx.doi.org/10.1016/S0140-6736(17)33326-3)

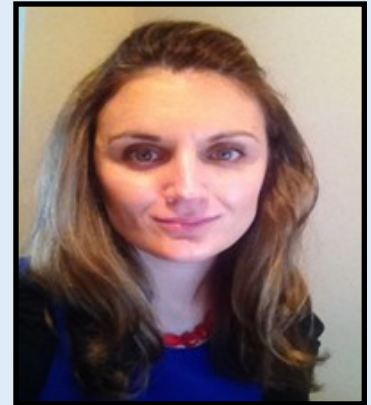


What is the true burden of skin cancer?

Recent trends in incidence of non-melanoma skin cancer pathology reports in Northern Ireland.

Dr Angela Alani, Specialist Trainee in Dermatology has been working to assess the incidence and disease burden of Non-Melanoma Skin Cancers (NMSC) in N.Ireland between 2010-2015. This project is supervised by Dr Collette Mc Court and Dr Olivia Dolan, Consultant Dermatologists at the Royal Victoria Hospital and supported through the N.Ireland Cancer Registry (NICR) working alongside Dr Eileen Morgan, Mrs Deirdre Fitzpatrick and Dr Anna Gavin.

This project was accepted as an oral presentation at the British Association of Dermatologists, Edinburgh July 2018.



Globally the incidence of NMSC is increasing¹. In the UK suspected skin cancers account for a significant proportion of dermatology referrals received from primary care. Many patients have more than one skin cancer. Cancer registration practices vary across the U.K. Due to limited resources, many do not collect data on NMSC. However registries including the NICR report only the first Basal Cell Carcinoma (BCC) or Squamous Cell Carcinoma (SCC) per person thus underestimating the true burden¹.

The work involves measuring the frequency of all NMSC Pathology reports 2010-2105 to indicate workload, incidence and trends of NMSC. This data will assist in the commissioning of Dermatology services to meet current and future needs.

The results showed that between 2010-2015 6,671 SCC, 17,980 BCC and 284 cases of other NMSC were reported (n=18,120 male; n=10,572 female cases of NMSC). Rates of pathology NMSC reports have increased in both males (BCC +5.6%; SCC +4.8%) and females (BCC +4.2%; SCC +2.9%) annually.

This study reports the true rates of all pathologies of NMSC in NI and highlights the steep rise of NMSC annually. Dermatology departments within the UK are already under pressure coping with the rising numbers of patients with skin cancer. This has a knock-on effect on patients with inflammatory skin disease, who wait longer for a routine referral. With an aging population, multiple primary tumours in affected individuals and a steep increasing incidence of NMSC there is an urgent need to plan future services while also encouraging prevention through taking care in the sun and avoiding ultraviolet exposure from sunbeds.

1. Lomas A, Leonardi—Bee. J, Bath-Hextall F. A systematic review of worldwide incidence of non-melanoma skin cancer. BJD 2012; 166:1069-1080.

Pathways to cancer diagnosis: Monitoring variation in the patient journey across Northern Ireland

Dr Finian Bannon of the *Centre of Public Health, Queen's University Belfast*, and Dr Conan Donnelly of the *National Cancer Registry of Ireland* in conjunction with *Business Services Organisation, Health and Social Care N. Ireland (HSCNI)* have received a £100,000 grant from the UK-based charity, *The Health Foundation*, to categorise and quantify the different pathways to diagnosis (e.g. screening, emergency presentation and GP referrals) that N.Ireland (NI) cancer patients take. The study will adopt pioneering work by Public Health England that showed poorer survival for patients who are diagnosed through an emergency pathway compared to screening, two-week waits, or routine referral.



The aim of the work is to provide evidence to direct policy and practice for improving cancer survival by producing 'routes-to-diagnosis' statistics for NI. By monitoring trends in diagnostic pathways, this collaboration has the potential to monitor an important intermediate outcome of several early diagnosis interventions in NI such as the Public Health Agency 'Be Cancer Aware' campaign and changes to GP cancer referral guidelines. In doing so this work will provide an important tool for decision makers in the cancer control arena to improve patient outcomes supported by collaborative engagement between QUB and HSCNI analysts.

The NICR is supplying the primary data on the cancer patient population to which information, needed to assign patients to different pathways, housed in the BSO Warehouse and will be confidentially linked and the patient records anonymised. Two analysts in the BSO Safe Haven will generate statistics on routes-to-diagnosis, at various levels of granularity, for various population sub-groups (geographic health area, disease, service-related factors, and socio-economic deprivation) that are valid and reliable. A steering group, comprising of GP, Public Health Agency and other involved agencies with patient/voluntary sector stakeholders has been established to ensure the study has policy-relevance and it is hoped that annual production of 'routes-to-diagnosis' statistics will be maintained after the end of the project.

More detail on the project can be found at: <https://www.health.org.uk/programmes/advancing-applied-analytics/projects/pathways-cancer-diagnosis-monitoring-variation>

Quantifying surgical under-treatment in older adult lung cancer patients in Northern Ireland

Mr Abdul Qadr (PhD student) and Dr Finian Bannon (Medical Statistics Lecturer) from the Center for Public Health at Queen's University Belfast are investigating surgical under-treatment of older adult cancer patients. Surgical rates in elderly patients are much lower than in younger patients. However, to demonstrate under-treatment, it is necessary to account for reasons that both contra-indicate surgery and are more common in elderly patients. By linking Northern Ireland Cancer Registry (NICR) data to the 2011 census data through the N.Ireland Longitudinal Study (NILS) (28% of NI population) and the Administrative Data Research Center N. Ireland (ADRC-NI, 100% of NI population), the analysis will adjust for the three main surgical contraindications: disease stage, comorbidity and frailty.

A preliminary analysis of the NI lung cancer patients diagnosed during 2010-14 indicated that elderly patients (≥ 75 years of age) with operable disease (Stage 1-3) and good performance status (ECOG 0-2) receive less surgical treatment than their younger (< 75) counterparts, and that eight more elderly patients would be alive at 2-years had they received the same surgery rates as the younger patients adjusted for their clinical characteristics. Abdul gave an oral presentation of this work in June at the Public Health England 2018 conference: "Cancer Services, Data and Outcomes conference" entitled: Quantifying surgical under-treatment in older adult lung cancer patients in Northern Ireland.

This study is relevant because with longer life expectancy, more elderly patients are presenting with cancer, and there is now evidence that they may not receive treatment in accordance with guidelines, or as much as younger patients. The percentage of people aged over 75 is projected to increase by 5% in the UK, between 2016 and 2039.

The linkage of data from NICR, NILS and ADRC facilitates research hopes to quantify potential under-treatment, and helps shape health-care policy to benefit elderly cancer patients.

Macmillan Cancer Support



The N.Ireland Cancer Registry (NICR) Macmillan Partnership is now in its third year. Over the last year, the partnership has funded work in six main areas:

1. Transforming Cancer Follow-up

Increasing breast cancer incidence and survivorship has placed increasing pressure on the healthcare system in N.Ireland (NI). There was also a growing recognition that the current model of follow-up could be more efficient and effective. This led to an interest in new models of breast cancer follow-up. In January 2012, Transforming Cancer Follow Up (TCFU) commenced across all five Health and Social care (HSC) Trusts. TCFU is a Self-Directed Aftercare (SDA) pathway system that includes patients best able to understand the new system. Women assigned to SDA receive yearly mammograms and follow-up through holistic nurse led clinics. They also have access to a rapid access phone line which enabled them to be referred back into the system and seen within two weeks if required. The NICR study has shown that the women assigned to TCFU are, as expected, younger and diagnosed at an earlier stage when compared to women in the NI breast cancer population. There were also no differences in deprivation between those assigned to the programme and the NI breast cancer population.

2. Breast Cancer Recurrence

This work aims to develop a standardised method to document recurrences and is running alongside work being carried out within the National Cancer Registration and Analysis Service for England (NCRAS) to develop an algorithm for identifying recurrences using routine cancer registration data. Work on documenting recurrences of breast, colorectal and ovarian cancer in NI has begun with follow up to 2017.

3. Emergency Admissions

In recent years there is increased interest in the place and timing of end-of-life care for cancer patients. An examination of emergency hospital admissions for end-of-life cancer patients may indicate gaps in routine cancer care. The NICR has previously investigated reasons why cancer patients die in acute hospitals (1) and factors enabling cancer patients to die at home (2).

(1) Why do cancer patients die in acute hospitals (2011) N.Ireland Cancer Registry Report. Available at <http://www.qub.ac.uk/research-centres/nicr/FileStore/PDF/NirelandReports/Filetoupload,532199,en.pdf>

(2) Dying with cancer- Perspectives of Bereaved Relatives and Friends (2015) N.Ireland Cancer Registry Report. Available at <http://www.qub.ac.uk/research-centres/nicr/FileStore/PDF/NirelandReports/Filetoupload,532185,en.pdf>

Preliminary findings have shown that almost three quarters (73.7%) of people dying of cancer have at least one emergency admission in their last year of life with 1 in 12 (7.9%) people having at least four emergency admissions. The preliminary findings were presented as a poster at the PHE/ NCRAS Cancer Data, Service and Outcomes Conference held in Manchester 20-21 June 2018 and will be presented in an oral session at the European Network of Cancer Registries Conference in September 2018.

Macmillan Cancer Support *(continued)*



4. Cancer Data Landscape in NI document

A landscaping document describing the current Cancer Data Landscape in NI has been developed. The document is available on the NICR website (<http://www.qub.ac.uk/research-centres/nicr/Publications/MacmillanNICRPartnership/>)

5. Acute Oncology

The Acute Oncology Service was established in NI in 2016 and rolled out across all HSC Trusts in 2017. Acute Oncology Services provide a single point of hospital contact for advice/support and bring together expertise from many disciplines including: oncology, palliative care, haematology, acute and emergency medicine, surgery, radiology, microbiology and pathology amongst others. The referral guidelines for the Acute Oncology service are:

- Patients who are receiving or who received any anti-cancer therapy (including radiotherapy or systemic therapy) within the last six weeks and who are admitted with potential complications from treatment.
- Patients with complications from a previously diagnosed cancer whether they have received recent treatment or not.
- Patients with a previously undiagnosed cancer who are found to have a confirmed or suspected malignancy for which there is no obvious primary site after a preliminary set of investigations.

The NICR study aims to document patterns of use of this service.

6. GP Federations

Factsheets with cancer incidence and prevalence for each of the 17 GP Federations in NI have been developed and are now available on the NICR website alongside (<http://www.qub.ac.uk/research-centres/nicr/Publications/MacmillanNICRPartnership/>) a summary report which includes age-standardised incidence rates and comparisons between GP Federations. Copies for the host federation have been mailed to each practice.

Macmillan Poster Conference June 2018

Registry staff attended a Macmillan organised regional event 'Learning from our Macmillan Colleagues: A Poster Conference' on 19th June in Hilton Hotel Templepatrick. The event brought together Macmillan colleagues to share their research findings from various areas of work and to discuss potential initiatives and approaches that could be implemented to improve patient experience and well-being following a diagnosis of cancer. The NICR presented posters on 2 projects entitled: 'Investigating Characteristics of Women with Breast Cancer Recurrence in NI' and 'Emergency Admissions for Cancer Patients in the Last year of life in NI.'

Biobank/NICR Partnership

The Northern Ireland Biobank (NIB) is a cancer specific biobank and was awarded full ethical approval in August 2011 (ORECNI Ref: 16/NI/0030) for the collection of surplus tumour and non-tumour control tissues and associated biospecimens from patients with a suspected or confirmed diagnosis of cancer. NIB has two 'strands' to its workflows, namely the prospectively and retrospective collections. The NIB prospective collection targets colorectal, breast, prostate, gynaecological, lung, head and neck and haematological malignancies with linkage to robust de-identified clinico-pathological data. Donation to the prospective collection is voluntary and requires written informed consent from patients. The retrospective collection relates to the ethical and governance approvals in place to allow NIB to access the NHS tissue pathology diagnostic archives. This allows NIB to retrieve defined cohorts of cancer tissues for ethically approved studies which are anonymised and made available in a timely manner for scientifically sound translational research activities.

The Northern Ireland Cancer Registry (NICR) supports the NIB's work by linking anonymised clinical and pathological information stored on the NICR database with samples requested for particular NIB ethically approved studies. All data are examined and extracted in a confidential setting under agreed ethical and governance approvals. Data linkage is achieved via the use of a pseudonymised number; no personal identifiers are ever released to NIB studies.

The NICR has completed over eight data requests for NIB between 2017 and 2018 covering lung, oesophageal and breast cancers.

The NIB/NICR partnership has recently been strengthened through allocation of more NIB funding which will allow employment of a full TVO resource rather than 0.5WTE in the NICR.

CanStaging:

An Online Free Cancer Staging tool

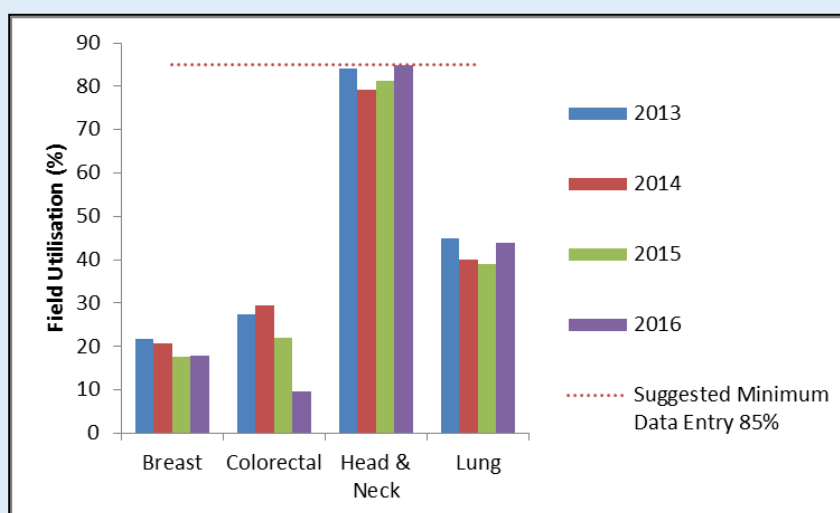
The Cancer Staging Tool is recognised as having enormous potential to harmonise cancer staging. Discussions are ongoing to determine the feasibility of:

1. Upgrading to take account of recent changes to staging, namely TNM8
2. Having the system available offline as Cancer Registries find accessing the internet to use this tool may compromise data security

CaPPS Study

The Cancer Patient Pathway System (CaPPS) was implemented in 2009 to facilitate Multi-Disciplinary Meetings (MDMs). It is a region wide system for N.Ireland and it monitors Cancer Waiting Times (CWTs), facilitates audit and aids communication between members of the MDM and primary care. It is also a valuable data source for cancer registration. The N.Ireland Cancer Registry (NICR) undertook an audit which showed high levels of completeness for mandatory data items for CWTs, however low levels of data completeness for clinical data items. The audit showed variation in data input between Health and Social Care (HSC) Trusts and it also showed variation between cancer sites. The graph below shows the variation of clinical completeness by site for MDT agreed stage.

CaPPS Data Completeness for 'MDT Stage' 2013-2016



The results of the audit were presented to the NICaN Board. The NICaN Board group then subsequently agreed that a CaPPS Review Group should be set up to review CaPPS and put forward recommendations as to how data entry can be improved. A NICR representative is involved in this group

ICBP

The International Cancer Benchmarking Partnership (ICBP) is a partnership of clinicians, academics and policymakers. They work together to understand how and why cancer survival varies between countries/jurisdictions. In the first phase it focused on breast, colorectal, lung and ovarian cancers, and included Australia (New South Wales and Victoria), Denmark, Norway and Sweden, Canada (Alberta and British Columbia, Manitoba and Ontario), England, N.Ireland, Scotland and Wales. A jurisdiction briefing for N.Ireland is available on the NICR website:

<http://www.qub.ac.uk/research-centres/nicr/research-audits/current-research/international-cancer-benchmarking-project/Publications/>

Phase 2 of the ICBP is well underway addressing survival difference for liver, oesophagus, stomach and pancreas as well as lung, colorectal and ovarian cancers as studied in Phase 1. It includes more countries including New Zealand, Republic of Ireland, all of the UK, Norway and Denmark, Western Australia and New Brunswick, Newfoundland, Nova Scotia, Prince Edward Island, Quebec and Saskatchewan from Canada have all joined. The N.Ireland Cancer Registry continues to play an active part.

N. Ireland Cancer Registry Cancer Registration System

Since the upgrade in April 2017, PRAXIS has been stable. The data dictionary has been expanded with new fields added to enable the recording and storage of additional data items, including molecular markers and ICDO3 coding. However, two major issues remain with the system. Firstly, the user interface is quite old in terms of its technology base and is at risk of failing with newer versions of Microsoft Windows. Secondly, the system still contains some legacy data structures which would need conversion. Therefore the NICR recently conducted an options appraisal which was submitted to our Steering Group. Essentially the preferred option is to proceed with a hybrid solution, retaining the functionality of the existing system, particularly the patient and tumour matching logic and the data survivorship rules but moving to a more modern platform such as SQL Server. Some work has been completed on translating the data structures (including the data) into a SQL Server database. The next stage is to appoint a developer to build the back-end program code containing much of the automated processing functionality which underpins the current system and develop a suitable user interface.

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Publications (July 2017 - June 2018)

(continued)

Drummond FJ, Gavin AT, Sharp L. Supportive medications and interventions received by prostate cancer survivors: results from the PiCTure study. *JCSO* 2017; 15:e309-313

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. *Psychooncology* 2017; 26:1825-1831

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Conferences

International Association of Cancer Registries Conference 2017

Registry staff presented posters and delivered presentations of their work at the annual conference of the International Association of Cancer Registries (IACR) which took place in Utrecht, The Netherlands from the 17th to 19th October 2017. The conference aimed to bring together World Wide Cancer Registries so they can share research findings, exchange ideas and best practices and discuss cancer registration issues within their own country. The Conference was co-hosted by The Belgian Cancer Registry and the Netherlands Comprehensive Cancer Organisation. The theme of the meeting was “Ensuring Quality and Use of Data from Cancer Registries in the 21st Century”. Researchers, epidemiologists and clinicians attended the three day conference. Delegates were able to view 120 posters and attend 45 oral presentations.

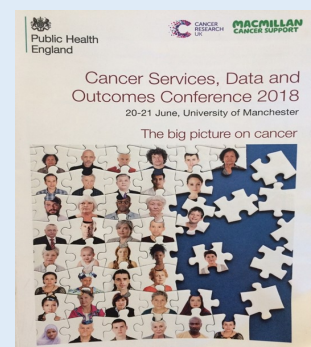


Research presented from NICR included:

- Improving the Completeness of Multidisciplinary Meeting Data
- MDM Data-Entry Feedback Effectiveness
- Cancer Registry Enhancing Datasets for Primary Care
- Melanoma increase in men - a success story?
- Using registry data to investigate the characteristics of breast cancer patients assigned to self-directed aftercare.

PHE Cancer Services, Data and Outcomes Conference, Manchester, 2018

Registry staff attended the Cancer Services, Data and Outcomes Conference on 20th and 21st June 2018 at the University of Manchester. The conference showcased formal presentations on work being done with patient data in order to drive improvements in cancer care and service delivery. The two day event also included workshops which covered a variety of topics ranging from data protection and GDPR to the value of public and patient involvement with PHE's NCRAS. An oral presentation by Abdul Qadr Akinoso-Imran and 7 out of 71 posters displayed at the conference were produced using NICR data.



7th National Cancer Registration and Analysis Service Annual Training Event

Four TVOs and the Clinical Advisor from the NICR attended the 7th National Cancer Registration and Analysis Service and National Congenital Anomaly and Rare Disease Registration Service Training Event at Warwick University, England on 13th and 14th March 2018.

The event covered the changes in the TNM Classification of Malignant Tumours ahead of the move to TNM8 for 2018 registrations as well as the advances in Molecular Genetics and the implications this will have for Cancer Registries in the future. It also focused on the utilisation of the Case of the Week feature on Mylearningspace whereby tumour registrars can test their knowledge, re-enforce registration rules, learn something new and identify learning needs.

This annual event is extremely useful in providing an opportunity to network with other registry staff from the United Kingdom and also to keep up to date with changes in registration practice.

A word from the chair of the N. Ireland Cancer Registry Council, Mr Jim McGuigan

The Need for Cancer Registries in Improving Cancer Outcomes

It is necessary to gather relevant data to understand the causes of cancer and to facilitate detection of cancer at an early and potentially curable stage. Cancer specialists must make clinical decisions based on accurate cancer data regarding pathology and stage. The United States Secretary of the Department of Health and Human Services, Dr. Donna Shalala once noted that "A national system of cancer registries can help us understand the disease better and use our resources to the best effect in prevention and treatment."

We also need these data to follow-up patients for a sufficient length of time following treatment to determine the effectiveness of cancer treatments. Registries uniquely possess tools for the investigating aetiology, diagnosis, and treatment of our patients.

Cancer registries were established in the mid twentieth century and now there are more than 700 cancer registries worldwide. The World Health Organization (WHO) has approved the Global Monitoring Framework on Non-communicable Diseases (NCDs). This framework aims at improving outcomes and includes a commitment to report on cancer incidence and type as an indicator for the 2025 mortality target.

National Cancer Control Plans (NCCPs) require accurate data and aim to effectively utilise resources for prevention, treatment, rehabilitation and palliative care, and help to plan research. To assess cancer control policies, validated data on the cancer burden and how this changes with time are essential.

It is therefore critical to know exactly what is happening at a population level. Population-based cancer registries need a sophisticated structure and support. Registration needs trained individuals working in a highly structured and adequately resourced environment. Experience, discipline and dedication are essential in cancer registries' staff. Planning and investing in cancer services depends on detailed analysis of complex data. The data we use are not abstract, they represent the analysis of the outcomes for individual and groups of real cancer patients.

The N. Ireland Cancer Registry [NICR] is embedded within Queen's University Belfast and is funded by the Public Health Agency [PHA] for N. Ireland (NI). The data from patients are collected by the Health Service. The NICR serves the population of NI and enables us to use locally based evidence to moderate decisions on individual cancer treatment. The Cancer Patient Pathway System CaPPs has improved the management of cancer patients in NI. In most hospital Trusts CaPPs data are recorded during Multidisciplinary Cancer Team [MDT] meetings. However, while CaPPs is widely admired by those who actively use it and those who provide external review of our services, there are problems in some locations where resources prevent the optimal use of CaPPs during patient discussions at MDT meetings. CaPPs provides an excellent basis for assessing the efficiency and accuracy of cancer patients' access to cancer services.

CaPPs can ensure data on cancer patients are included in analyses in combination with the Cancer Registry's PRAXIS system. CaPPs also enables health Trusts to identify deficiencies in assessing rapid access to cancer services.

Data collection over the short-term can also be useful. As an example, there was a significant increase in one year in the incidence of malignant melanoma in males but not in females in NI . During the same year there was a skin cancer awareness campaign, launched by the PHA for NI in 2015 which was targeted at outdoor workers. Updates can therefore be produced quickly to help explain changes in patterns.

In addition to referrals for assessment of possible cancer the effectiveness of screening can be monitored by NICR for breast, cervical and colorectal cancer. Registry data can also ensure that important details of patients' cancer stages or histological grades which ensure comparisons are valid. The NICR has year on year improved the completeness of tumours staged and achieved a level of 84.7% which was well above the UKIACR target of 70%.

Registry data in NI can confirm that the percentage of cancers with recorded grades of disease showed a rate of 64.4%, a rate above the UKIACR average of 60.2%. These parameters are important in facilitating comparisons of cancer outcomes and they are currently not easily provided to the NICR as a loadable field from data feeds but must be manually entered. In particular, attaining high levels of tumour staging and grade in the absence of automated data feeds has been an achievement brought about by the effectiveness of our local cancer registry staff.

There is an adage that when it comes to improving systems any conclusions reached are questionable without accurate details ie "no data, no good".

The optimal treatment of individual cancer patients in NI requires energetic and detailed recording of the data of cancer patients. The use of these data enable us to assess the performance of our health services in the assessment and treatment of patients with cancer.

To find further information on the work and outputs from the NICR visit their webpage www.qub.ac.uk/nicr

Obituary

Our dear friend and colleague, Professor Liam Murray, Centre for Public Health, passed away peacefully, on Friday 12th January following a brave battle with his final illness. The huge attendance at his funeral was testament to how many people thought so highly of Liam. In the Eulogy Liam's character was described as noble, humble, inspiring, collegial, unassuming, fair-minded, generous, scholarly, respectful, approachable, calm, dependable – a gentle man and a real gentleman.

Liam trained in Public Health and worked in Public Health Departments in N.Ireland and in the Epidemiology and Public Health Departments at the University of Bristol. In 1997 he returned to Queens University working in the NICR. He inspired the establishment of the Northern Ireland Barrett's Oesophagus register and an all-Ireland case-control study of oesophageal cancer with a new PhD student, Dr Lesley Anderson, now Acting Deputy Director of the NICR. He was recognised internationally as an academic of great intellect. Over those years people would readily acknowledge that Liam was a man who knew how to get things done and took his job but not himself seriously.

He became head of the Cancer Epidemiology Research Group in the Centre for Public Health leading a team of new researchers to great achievements. In the drive for Globalisation he worked with colleagues in Europe, USA, Vietnam and Malaysia.

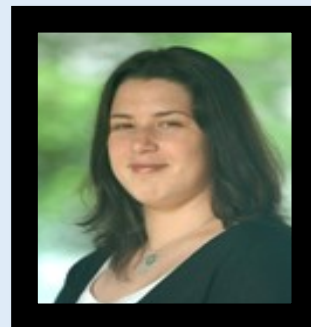
Our heartfelt condolences go to his wife Marylou, his daughters Lois and Evelyn and all the Murray family.



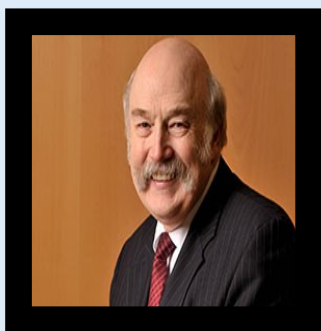
Staff News

Dr Lesley Anderson

Congratulations to Dr Lesley Anderson, who joined the Registry in August 2017 as Acting Deputy Director of NICR, on her recent promotion to Senior Lecturer within the Medicine, Science and Life Sciences faculty. We wish her every success in her new role.



Council



Professor Roy Spence (pictured left) has stepped down as Chair of NICR Council. We would like to take this opportunity to thank him for all his support. Thankfully he remains as an active member of the Council. Mr Jim McGuigan (pictured right) is welcomed as the new Chair of the Council.



New Secretary

Sarah Davidson joined the Registry on 18th December 2017 as Senior Administrator and PA to the Director.

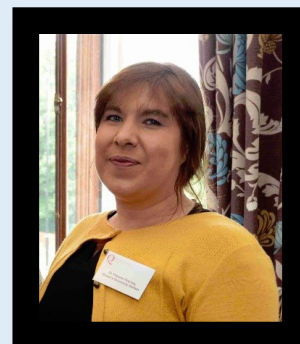


Farewell



Tracey McTernaghan (*Senior Administrator and PA for the Director*) left the Northern Ireland Cancer Registry in August 2017. We wish her every success.

Dr Thérèse Kearney (*Research Fellow*) worked in the Northern Ireland Cancer Registry from November 2013 to March 2018. During her time at the Registry Thérèse was project manager on the International Cancer Benchmarking Partnership (ICBP) and then moved to project manager of Life after Prostate Cancer Diagnosis (LAPCD) project. We congratulate Thérèse on her new post in the Physical and the Regeneration of Connswater (PARC) study and wish her every success.

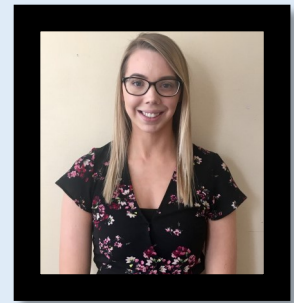


Staff News

Summer Students



Laura Cowan is working on Myeloproliferative Neoplasms (MPNs), a rare group of cancers and their incidence, prevalence and survival across Europe between 1995 and 2007.



Michelle Doherty returned to the Registry to continue work on the audit of PSA use in Primary Care.

NICR Staff Away Day - Mount Stewart

On 23rd March 2018, the NICR had a team away day to the beautiful house and gardens of Mount Stewart. The visit included a tour around the house by our wonderful guide. After lunch, we were met by the head gardener and not even torrential rain could spoil his or our enthusiasm for a walk around the gardens. Thank you to Thérèse Kearney for organising such a great day out for the whole team.



Fundraising

Ronan Campbell (IT department) cooked fresh pancakes in the Northern Ireland Cancer Registry on Pancake Tuesday with staff making a donation towards the NCPSS Childline Appeal. In total £84 was raised.

Congratulations!

The Registry would like to congratulate our colleague Abdul Qadr Akinoso-Imran and his wife Layla on the birth of their second son Yahya. Abdul is a PhD student on the project 'Quantifying under-treatment in older adult cancer patients'.



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