

# N. Ireland Cancer Registry Newsletter

July 2016

## Excellent Results for NICR in UKIACR Performance Indicators



Staff from the N. Ireland Cancer Registry celebrating the excellent results in UKIACR Performance Indicators

The United Kingdom and Ireland Association of Cancer Registries (UKIACR) strive to improve quality assurance of data through the development of annual national Performance Indicators (PIs). These PIs enable comparisons of timeliness, quality and data completeness for England, Scotland, Wales, Northern Ireland and the Republic of Ireland. The information is collated and an annual report produced, consisting of a series of datasets, with accompanying explanatory commentary from each of the Registries.

In previous years, the PIs were collated on malignant tumours (excluding non-melanoma skin (NMS) cancers) and in-situ tumours of the breast and cervix only. This year data quality indicators were collated for all registerable tumours, which included all in-situ tumours and tumours of uncertain behaviour, as well as benign tumours of the brain, other parts of the central nervous system and teratomas of testis. In addition to collecting information on more tumours, a wider range of quality indicators were collected this year, such as tumour grade, proportions of stage I and II patients receiving any treatment, cases treated with Watch & Wait/Active Monitoring, cases treated with palliative care, and completeness of bowel screening information.

Continued page 2



### This Issue

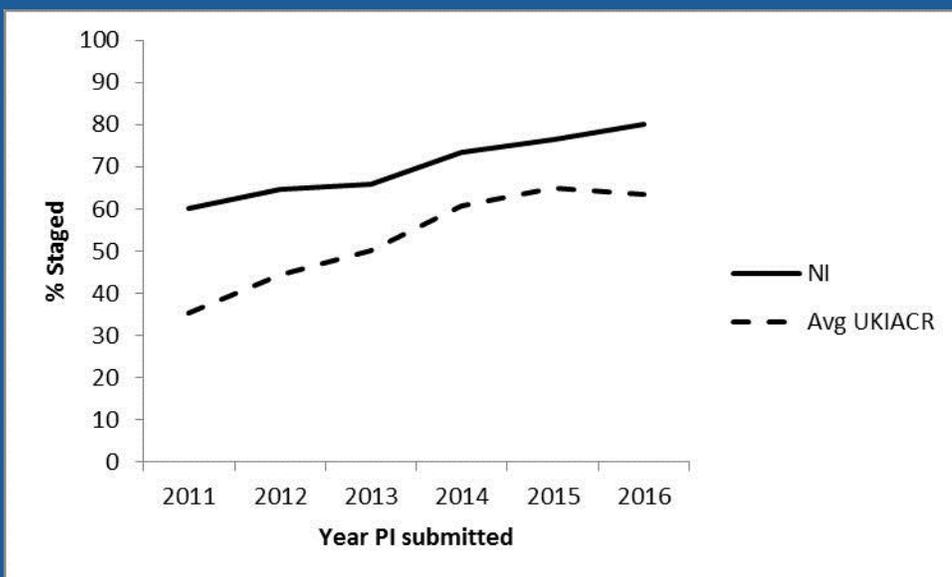
	Page
UKIACR Quality & Performance Indicators	1-2
NICR Website	2
Official Statistics	3
Audits	4-5
Health & Social Care (Control of Data Processing) Act (Northern Ireland) 2016	5
Cancer Registration Training	5
Research	6-9
Collaborative Research	10-13
Presentations at Conferences	14
International Visitor	14
Summer Studentships	15
CanStaging	16
Publications	17-18
Cancer Survival Course	18
ISO27001	19
Cancer Registration System	19
Staff News	20

# United Kingdom and Ireland Association of Cancer Registries Quality and Performance Indicators



In March, the PIs were submitted for just over 17,000 tumours diagnosed in Northern Ireland in 2014. The N. Ireland Cancer Registry (NICR) attained exceptionally high levels of quality across each of the key measures and in many instances, achieved the highest within the UK and Ireland. Of particular note was 80.0% of malignant cancers (excluding NMS cancer) were staged compared to the UKIACR average of 63.5% (Figure 1). This was an increase on last year and the highest submitted amongst each of the jurisdictions. Additionally, NICR performed well having a low level of notification of cases where a death certificate was the only source of information (0.68% NI vs 1.01% UKIACR average) and a high level of recording of tumour grade for malignant tumours (52.9% NI vs 47.54% UKIACR average).

Figure 1: Percentage of all malignant tumours (excluding NMS cancer) with valid staging over time



Also highlighted in the PIs were areas for improvement, for example, NICR submitted limited information on the percentage of patients treated with Palliative Care and no information on treatment with Watch & Wait/Active Monitoring. A source for this has now been identified and will be completed in future submissions. Patient's ethnicity was also a demographic that NICR was unable to submit as it is currently poorly completed on hospital systems but hopefully this will improve.

The excellent NICR PIs reflects the huge effort staff in Trusts and the NICR take in ensuring that the information they collect is as accurate as possible.

Details of latest PIs for NICR may be found on [NICR website](http://www.qub.ac.uk/nicr) ([www.qub.ac.uk/nicr](http://www.qub.ac.uk/nicr)).

## NICR Website

In 2015, staff from the N. Ireland Cancer Registry (NICR) set-up a working group, Conan Donnelly, Samantha Jameson, Alan McCrorie (Summer Student), Eileen Morgan, Eamon O'Callaghan, and Jacqui Napier, to re-design the website. The website working group decided it needed updating to make it more user friendly for visitors, easily accessible on smartphones, tablet computers and touch screen laptops. The decision was to reconfigure both content and design reducing the sections of information from 8 to 4.

Each of the 4 sections and subsections can be accessed from the front page. Working in conjunction with Content Management System (CMS) developer Peter Crowther, the new design (shown right) was developed. Comments were gathered from both NICR and Centre for Public Health (CPH) staff prior to the website going live, and their suggestions were incorporated into the content and design. To date we have had in the region of 10,000 visits to our new website.

You can see our new website at [www.qub.ac.uk/nicr](http://www.qub.ac.uk/nicr). Further changes will be implemented in the coming months.



Feedback is welcome and can be left using the feedback link in the footer on the bottom of the website page.

# Official Statistics

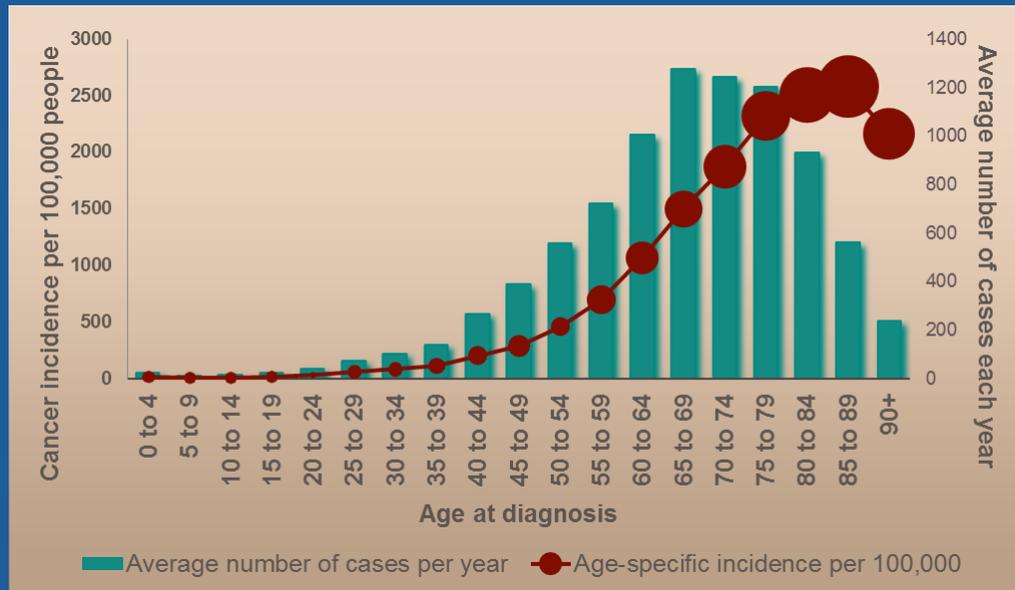
In 2011 the N. Ireland Cancer Registry was designated by the then Minister of Health as the producer of Official Statistics on the incidence, prevalence, survival and mortality of cancer in Northern Ireland.

On Tuesday 22 March 2016 the N. Ireland Cancer Registry (NICR) published the latest **official statistics** on cancer incidence, survival and prevalence in Northern Ireland up to the year ending December 2014. Alongside the release of the official statistics, we have produced a suite of **factsheets** for the four most common cancers (more factsheets will be available later in the year), 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 plan to continue to build on these enhancements over the next year to enhance public understanding of the burden of cancer in Northern Ireland.

## Key Findings

- Over the last ten years the number of cancer cases has increased between 2005 and 2014 from 3,619 to 4,486 among men and 3,648 to 4,454 among women. This is largely due to an increasing number of older people in the population with the incidence of cancer increasing with age (see diagram).
- Survival rates are improving in recent years: **54%** of all cancer patients survived five years after diagnosis for patients diagnosed between **2005-2009** compared to **43%** five year survival for patients diagnosed 1993-1999.

## Incidence of cancer cases in Northern Ireland in 2014 by age at diagnosis



### PROSTATE CANCER

NUMBER OF CASES PER YEAR (2010-2014)			NUMBER OF DEATHS PER YEAR (2010-2014)		
Male	Female	Both sexes	Male	Female	Both sexes
1,049	-	1,049	251	-	251

FIVE-YEAR SURVIVAL (2005-2009)			22-YEAR PREVALENCE (2014)		
Male	Female	Both sexes	Male	Female	Both sexes
87.6%	-	87.6%	1,923	1,923	3,846

**INCIDENCE**

In 2014-2015 there were 1,049 men diagnosed with prostate cancer each year. The risk for men of developing a prostate cancer up to the age of 75 was 1 in 12.

**Incidence trends**

Year	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014
Male	843	885	972	1,024	1,117	964	1,061	1,072	1,030	1,119

Over a ten year period from 2005 to 2014 the number of prostate cancer cases in men has increased from 843 to 1,119. Prostate cancer incidence rates in men have increased during 1995-2008 by an average of +4.5% per year, and then have decreased by -3.2% from 2009-2014. Incidence rates of prostate cancer have increased internationally. This is primarily a result of the widespread use of prostate specific antigen (PSA) testing which is a blood test that is used as a diagnostic approach to detect prostate cancer at an early stage but which also detects very slowly growing cancers that would never cause any problems or symptoms in a man's lifetime.

### LUNG CANCER

NUMBER OF CASES PER YEAR (2010-2014)			NUMBER OF DEATHS PER YEAR (2010-2014)		
Male	Female	Both sexes	Male	Female	Both sexes
626	529	1,155	544	397	941

FIVE-YEAR SURVIVAL (2005-2009)			22-YEAR PREVALENCE (2014)		
Male	Female	Both sexes	Male	Female	Both sexes
10.0%	11.4%	10.5%	1003	924	1927

**INCIDENCE**

In 2014-2015 there were 626 male and 529 female patients diagnosed with lung cancer each year. The lifetime risk of developing a lung cancer was 1 in 20 for men and 1 in 24 for women.

**Incidence trends**

Year	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014
Male	559	576	602	624	621	600	627	607	605	640
Female	395	389	423	430	462	482	485	535	521	574
Both sexes	954	965	1,025	1,054	1,083	1,082	1,112	1,132	1,126	1,214

Over a ten year period the number of lung cancer cases increased from 954 among men and 395 among women in 2005 to 640 among men and 574 among women in 2014.

After accounting for the increasing number of older people in the population, lung cancer incidence rates decreased among men during 1993-2014 by an average of 0.2% per year. However for the same period, female incidence rates increased by an average of 0.1% per year between 1993 and 2009 and 0.2% per year between 2010 and 2014. These patterns reflect historic smoking trends, the much increased risk factor for lung cancer, with increasing rates of smoking among males and increasing rates among females influencing trends.

### COLORECTAL CANCER

NUMBER OF CASES PER YEAR (2010-2014)			NUMBER OF DEATHS PER YEAR (2010-2014)		
Male	Female	Both sexes	Male	Female	Both sexes
682	537	1,219	276	194	470

FIVE-YEAR SURVIVAL (2005-2009)			22-YEAR PREVALENCE (2014)		
Male	Female	Both sexes	Male	Female	Both sexes
55.3%	57.5%	56.3%	4279	3655	7934

**INCIDENCE**

In 2014-2015 there were 682 male and 537 female patients diagnosed with colorectal cancer each year. The lifetime risk of developing a colorectal cancer was 1 in 19 for men and 1 in 31 for women.

**Incidence trends**

Year	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014
Male	571	570	641	589	605	654	682	742	676	655
Female	425	470	512	503	494	534	533	536	574	530
Both sexes	996	1040	1153	1092	1099	1188	1215	1278	1250	1185

Over a ten year period the number of colorectal cancer cases increased from 973 among men and 613 among women in 2005 to 655 among men and 530 among women in 2014.

After accounting for the increasing number of older people in the population, colorectal cancer incidence rates among males and females during 1993-2014 have remained constant.

### BREAST CANCER

NUMBER OF CASES PER YEAR (2010-2014)			NUMBER OF DEATHS PER YEAR (2010-2014)		
Male	Female	Both sexes	Male	Female	Both sexes
0	1283	1283	0	306	306

FIVE-YEAR SURVIVAL (2005-2009)			22-YEAR PREVALENCE (2014)		
Male	Female	Both sexes	Male	Female	Both sexes
-	80.9%	-	-	13,963	-

**INCIDENCE**

In 2010-2014 there were 1,283 female patients diagnosed with breast cancer each year. The lifetime risk of developing a breast cancer was 1 in 11 for women.

**Incidence trends**

Year	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014
Female	1079	991	1186	1179	1231	1217	1288	1322	1287	1394

Over the last ten years the number of breast cancer cases in women has increased from 1079 in 2004 to 1293 in 2014.

After accounting for the increasing number of older people in the population, breast cancer incidence rates in women have increased during 1993-2014 by an average of +1.2% per year.

### ALL CANCER (EXCLUDING NMSC)

AVERAGE NUMBER OF CASES PER YEAR (2010-2014)			AVERAGE NUMBER OF DEATHS PER YEAR (2010-2014)		
Male	Female	Both sexes	Male	Female	Both sexes
4,426	4,393	8,819	1,923	1,923	3,846

FIVE-YEAR SURVIVAL (2005-2009)			21-YEAR PREVALENCE (2014)		
Male	Female	Both sexes	Male	Female	Both sexes
52.3%	55.7%	53.6%	24,386	31,315	55,701

**INCIDENCE**

From 2010 to 2014, on average, there were 4,426 male and 4,393 female patients diagnosed with cancer each year including Non-Melanoma Skin Cancer (NMSC). There were an additional 1,846 male and 1,524 female patients diagnosed with NMSC. The lifetime risk of developing a cancer (including NMSC) was 1 in 3 for men and 1 in 3 for women.

**Incidence trends**

Year	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014
Male	3,830	3,793	4,061	4,173	4,223	4,145	4,444	4,521	4,520	4,488
Female	3,808	3,889	3,814	4,088	4,112	4,221	4,387	4,388	4,386	4,431
Both sexes	7,637	7,682	7,875	8,261	8,335	8,366	8,831	8,909	8,906	8,919

Over the last ten years the number of cancer cases has increased from 3,819 among men and 3,848 among women in 2005 to 4,486 among men and 4,454 among women in 2014. This increase is largely due to an increasing number of older people in the population.

After accounting for our aging population, cancer incidence rates increased among males during 1993-2014 by an average of 1.2% per year, with evidence of a slowing from 2011-2014. From 1993-2014, female incidence rates increased steadily by an average of 0.7% per year.

# Audits

## Monitoring care for female breast cancer patients in Northern Ireland diagnosed 2012 (with comparisons to 1996, 2001 and 2006)



The report “Monitoring care for female breast cancer patients in Northern Ireland diagnosed 2012 (with comparisons to 1996, 2001 and 2006)” was published in February 2016. The audit aimed to document the presentation, treatment and outcomes for female breast cancer patients diagnosed in 2012 and compare with similar data collected in 1996, 2001 and 2006. This audit was funded by *Guidelines and Audit Implementation Network (GAIN)* which is now located within The Regulation and Quality Improvement Authority (RQIA).

Data on all female breast cancers diagnosed in 2012 were available from the N. Ireland Cancer Registry (NICR) database (n=1,279 after exclusion of Ductal Carcinoma In situ ((n=133), death certificate only registrations (n=1) and patients with insufficient information recorded (n=7)). We sought additional clinical information on patients diagnosed between September and December 2012 (Audit subset (n=411) from the Cancer Patient Pathway System (CaPPS) and the Clinical Oncology Information System (COIS). These data were extracted by Tumour Verification Officers (TVOs) for resolution and validation.

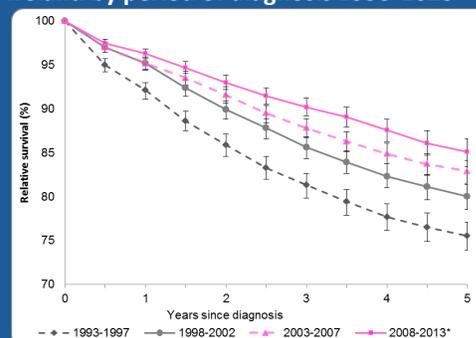
Over half (56%) of patients diagnosed in 2012 came from GP referrals and almost one third (29.9%) were referred through the breast screening programme. Over half (52%) presented with a breast lump with a further one third (33.6%) presenting asymptotically. Overall 7 out of 10 women had a sentinel node biopsy in 2012 compared with 21% in 2006. As a result the invasive procedure, axillary node clearance, fell from 82% in 1996 to 45% in 2012. Three quarters (76%) of women were diagnosed at early Stage I or Stage II disease (39% Stage 1, 37% Stage II, 13% Stage III and 5% Stage IV (6% unknown)). All patients were discussed at a Multi-Disciplinary Team (MDT) meeting. Use of endocrine treatments increased to 84% in 2012 from 78% in 2006. 90% of women had surgery, 49% of these having mastectomy, 51% breast conserving surgery. A higher proportion (62%) of women of screening age had breast conserving surgery when compared with older or younger women (approx. 40%). Primary reconstruction following mastectomy was recorded for 14% of women overall, 20% in patients resident in Belfast Trust and South Eastern Trust areas and much lower for those resident in other Trusts. In 2012, 95% of patients were diagnosed on day of presentation. 93% had surgery within 62 days, 70% within 31 days and 25% within 14 days. Overall, survival for breast cancer patients has improved significantly since 1996. Specifically comparing 1993-1997 diagnosed patients with those diagnosed 1998-2002, 10-year survival increased from 66% to 72%. 2-year observed survival increased from 84% to 89% for all breast cancer patients. Survival improvements were most marked for older

women (65+ years) and those with late Stage IV disease. Some but not all of this improvement is because of general improved health care and survival. Recorded clinical trial enrolment was higher than for previous years at 14% and 13% of women were offered a genetic referral in 2012. The report made the following recommendations:

- Differences by Trust in breast reconstruction should be investigated.
- Awareness needs to be raised of the less common symptoms such skin changes as these account for about 10% of presentations.
- Differences in the assessment of oestrogen and progesterone receptor status by age at diagnosis and age at presentation should be investigated.
- The proportions of patients having surgery within 62 days of diagnosis in 2012 audit subset were similar to that observed in previous audit years, however there was a decrease in proportions of patients receiving surgery within 31 days of diagnosis in 2012. This may be due to new treatments or investigations carried out before surgery in 2012 and warrants further investigation.
- A review of records to assess the proportion of patients commencing on aromatase inhibitors that received a DEXA scan in line with the NICE Clinical Guideline for breast cancer care (2009), showed that only half of patients starting on Aromatase Inhibitors had a DEXA scan recorded. This observation may be a true reflection of clinical practice or may be due to unavailability of this information within the electronic records searched. This should be investigated further for clarification.

The audit report and summary are available to download from NICR website: [www.qub.ac.uk/nicr](http://www.qub.ac.uk/nicr).

**Figure 1: Relative Survival from breast cancer in Northern Ireland by period of diagnosis 1993-2013**



\*Estimates using period analysis (Brenner et al.1997)

Research Team: Dr Victoria Cairnduff, Mrs Deirdre Fitzpatrick, Dr Anna Gavin, Mrs Bernadette Anderson and Mrs Clare Marks.

# Lung Cancer Audit

The Guidelines & Audit Implementation Network (GAIN) have funded the N. Ireland Cancer Registry (NICR) to undertake an audit of lung cancer to:

1. Compare progress in service provision with historic audits carried out 1996, 2001 and 2006.
2. Compare with UK wide lung audits published on LUCADA
3. Determine if lung cancer care is consistent with recently adopted NI Clinical Management guidelines V4.2 for investigation and treatment.
4. Provide data for the International Cancer Benchmarking Partnership Module 5, a high resolution study of cancer treatment with the aim of exploring reasons for international difference in cancer survival. (see <http://info.cancerresearchuk.org/spotcancerearly/ICBP/#News>)
5. Make recommendations for further service improvement.

Lung cancer numbers continue to increase, in 2014 1,214 cases were diagnosed. Rates increase in females by 1.5% per year while rates in males are decreasing by 0.7% per year.

Many cases are diagnosed late. Over half of cases are late stage IV (42%) or unstaged (14%). It is important that we monitor the presentation, investigation, treatments and outcomes including survival for these patients at population level to enable us to make recommendations to improve the patients' outcomes. We expect to have results by early 2017.

## Health & Social Care (Control of Data Processing) Act (Northern Ireland) 2016

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 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. The practical aspects of the process will also need to be established. It may therefore take anything up to a further 2 years to get the system up and running.

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 our Act covers health and social care information. The Northern Ireland Act also contains some provisions about opt out and places an obligation on the Department to publish a Code of Practice on the processing of information.

The Registry wish to offer thanks to Chris Matthews whose hard work was essential in achievement of this Act.

## Cancer Registration Training

On 3rd and 4th March 2016 the N. Ireland Cancer Registry (NICR) Data Manager, Deirdre Fitzpatrick along with TVOs Jacqui Napier, Jackie Kelly, Marsha Magee, Paula Darragh and Sinead Lardner attended the 5<sup>th</sup> National Cancer Registration Service Annual Training Event in Leeds, England. This was a large training event organised by Public Health England with the objective of bringing all the UK and Ireland Registries together to network, share information and provide training for cancer coding. This was an insightful two days for our NICR staff.

The team had informative lectures on the registration software system used by the English cancer registry (ENCORE). This has various datasets which are fed into its registration system such as Cancer Waiting Times and Cancer Outcomes and Services Dataset (COSD). The COSD dataset contains information on each aspect of each patient's pathway. This increased quantity, and more varied patient pathway information, has increased the scope of patient pathway information required for UKIACR Performance Indicators (PI's). This made us in Northern Ireland think about how we obtain our clinical information for cancer registrations and how we can further build on the information that we already routinely collect to help enhance our PI's. The staff fed ideas to the NICR strategy meeting with further insight on what we need to achieve in the future to build on our current cancer registration performance.

The programme included a presentation of current findings from the National Lung Cancer Audit (LUCADA) and the process of published peer reviewed research to NICE guidelines. The staff also received focused training on ICD03 coding and data quality assurance as part of the event.

# Research

## Long term mortality among children and young people who survive cancer in Northern Ireland

While survival rates for childhood cancers are excellent it is known that these patients have an increased risk of death from disease recurrence and other causes. We undertook a study to investigate patterns, trends and survival of cancers in children and young people in Northern Ireland.

We examined anonymised data from the N. Ireland Cancer Registry (NICR) on cancer incidence including non-malignant brain tumours for children and young persons aged 0-24 years diagnosed in Northern Ireland during the 21 years 1993-2013. We examined trends and survival up to the end of 2013 with excess mortality calculated at one and five years after first cancer diagnosis.

We found that 2,633 children and young people were diagnosed with cancer, 1,386 (52.6%) male and 1,247 female with 1,139 (43.3%) aged 0-14 years. While trends of cancer incidence increased over time they did not reach statistical significance except in the 15-24 years age group for males and females combined. The most common cancers for age 0-14 years were brain, eye and central nervous system and leukaemia with skin (including non-melanoma skin cancer) the most common in the 15-24 years age group. 59 patients (2.2%) had a record of a second cancer. Survival was high at 90.7% after 1 year, better among females than males and similar for older and younger groups. Although mortality in children is low overall, there was an excess mortality 24.7% (22-27.5)  $p < 0.001$  at one year and 7.3% (5.5-9.2)  $p < 0.001$  for those who survived 5 years. Excluding the primary cancer there was an excess mortality for one year survivors, with deaths twice that of the background level (SMR= 2.2 (1.3-3.0)  $p = 0.005$  and although one and a half times background levels at 5 years the excess mortality was not significant 1.5 (0.6-2.3  $p = 0.269$ ).

We concluded that while survival from childhood cancers is excellent this work in common with larger studies highlights the need for ongoing monitoring of cancer survivors. Preventable skin cancer was identified as a problem in young adults.

Thanks to Dr David Donnelly who completed this work when working in the Registry.

## NAEDI Project Identifying Targets for Intervention to Promote Earlier Diagnosis of Cancer



This study was established in 2012 following an award from the CRUK National Awareness & Early Diagnosis Initiative to investigate factors associated with dying within three months from a diagnosis of lung or colon cancer. Data collection is now complete and results for colon cancer have been presented in several fora including the National Cancer Intelligence Conference in Belfast, June 2015. The study highlighted several target groups for improving outcomes including older patients and those from the most deprived communities, those unmarried or living alone and those with dementia or psychiatric conditions. Distinctly different diagnostic pathways were observed among those who died early with many more General Practice consultations in the last few months before diagnosis compared to those who died after some time.

The study also investigated patterns in use of the 'red flag' referral in General Practice to assess the potential for use of these metrics as indicators of quality in cancer diagnosis in General Practice and their relationship with cancer mortality. There was little evidence of an association between referral rates and cancer mortality although patients registered to Practices with higher referral rates did seem to have significantly higher odds of early disease.

Work is ongoing to prepare papers for publication and complete analysis of the lung study.

# Research

## Life After Prostate Cancer Diagnosis: A UK wide study of Patient Reported Outcomes



The Life after Prostate Cancer Study (LAPCD) was launched in 2015. This study offers men with prostate cancer across the United Kingdom a unique opportunity to give their feedback on their treatment experience and how it affected/affects their lives over time. Men will be asked through surveys and interviews to share their experiences. Participating men's partners will also be asked if they would like to take part in an interview to talk about how their partner's diagnosis of prostate cancer affects them. The data collected will then be compared with that collected from men without prostate cancer in an ethically approved normative study which will also be administered in Northern Ireland (NI). This part of the study will test the hypothesis that significant differences in health outcomes in prostate cancer patients exist when compared to the general population. Individuals in the normative study will be age matched within a five year band, and also matched on socio-economic quintile to those on the LAPCD.

The LAPCD study is significant, as prostate cancer remains the most common cancer in men in the United Kingdom. As a result of prostate cancer treatment, men often experience physical symptoms such as impotence, incontinence, hot flashes/flushes and psychological conditions like depression which can result in a reduced quality of life after prostate cancer.

In England 111 Trusts agreed to participate in the survey which represents over 85% of the total number of Trusts in England. Mail out of the surveys in England commenced in October 2015 and was completed in March 2016. To date, over 30,000 completed surveys have been

returned, giving a return rate of over 60%. Qualitative interviews have also been completed with a sub section of this population. This first cohort of men will be re-surveyed early 2017.

Ethical approval has been granted for the study in NI and all five trusts in NI have agreed to participate. The survey in NI began to be mailed out in July 2016, to approximately 2,000 men diagnosed with prostate cancer between 1 December 2012 and 30 November 2014. All seven Health Boards in Wales and all fourteen in Scotland are also participating. The Welsh and Scottish project teams hope to begin mail out at beginning of the summer. The devolved nations hope to emulate the success of England in achieving a high response rate.

A poster on the LAPCD study was presented at the International Agency for Research on Cancer Conference June 2016 in Lyon, France. Professor Eila Watson (Oxford Brookes University) and Dr Penny Wright (University of Leeds) also presented a poster on this research at the International Psycho-Oncology Society Congress in Dublin and the European Oncology Nursing Society.

### News

We are delighted to announce that Dr Therese Kearney (project manager of the LAPCD study, devolved nations) delivered a healthy baby girl in February and we welcome Dr Oonagh McSorley to the LAPCD team who will be fulfilling Therese's role until her return next year.

## Agreement for NICR to link with the Administrative Data Research Centre



The N. Ireland Cancer Registry (NICR) has agreed in principal to provide datasets for specific ethically agreed projects within the secure structures of the **Administrative Data Research Centre for Northern Ireland (ADRC -NI)**. The (ADRC-NI) is one of the four centres across the UK, working in partnership with Queen's University, Belfast, Ulster University and the Northern Ireland Statistics Research Agency (NISRA). It is charged with the remit of increasing access to routine administrative data for approved research projects undertaken by accredited researchers.

The Centre works with government departments in Northern Ireland – including Employment & Learning, Education, Health & Social Care, Agriculture, Environment, Social Development and Justice – to understand more about issues such as unemployment, ill health, education and our benefits-related culture.

# Research

## International Cancer Benchmarking Partnership (ICBP)



### ICBP Phase 1

Over the last year the N. Ireland Cancer Registry (NICR) has continued to progress work on Phase I of the International Cancer Benchmarking Partnership (ICBP), a programme of work aiming to document and explain international cancer survival variation for lung, breast, colorectal and ovarian cancers. The ICBP is 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 involves 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 after diagnosis. Module 2 examined population awareness of symptoms. Module 3 reported on differences in primary care. Module 4 aims to determine pathway delays to cancer diagnosis in patients diagnosed with breast, colorectal, lung or ovarian cancer. Each jurisdiction aimed to collect data for 200 symptomatic cancer patients in each of the four cancer sites. Questionnaires were also sent to GPs of consenting patients to confirm diagnostic route, treatment and dates, and information on secondary care received was collected from hospital records.

Data collection is now completed for breast, colorectal and lung cancer patients with 358 breast cancer patients (121 screen-detected), 277 colorectal cancer patients (54 screen-detected) and 215 lung cancer patients consenting to take part in the study. Data collection for ovarian cancer patients is ongoing in Northern Ireland with data collected on 90 ovarian cancer patients to date. The module 4 protocol paper "An investigation of routes to cancer diagnosis in ten international jurisdictions, as part of the International Cancer Benchmarking Partnership; survey development and implementation" has been accepted for publication in BMJ Open.

Analysis of the international breast cancer dataset and preparation of paper of the breast cancer results is currently in progress with a total of 3,488 breast cancer patients included in the analyses. Data cleansing and calculation of time intervals has been carried out by applying hierarchical 'data rules'. Routes to diagnosis were described and key time intervals were compared using quantile regression. The findings have shown good agreement for patient questionnaire items, and response rates were comparable with similar questionnaires across jurisdictions. Further papers are expected.

### ICBP Phase 2

ICBP phase 2 has started, building on the successes and learning from ICBP phase 1. To date, 19 jurisdictions in 5 countries have confirmed their involvement in phase 2. These are:

- Canada – Canadian Partnership Against Cancer on behalf of: Alberta, British Columbia, Manitoba, Ontario, Prince Edward Island, Quebec, New Brunswick, Newfoundland, Nova Scotia and Saskatchewan.
- United Kingdom – CRUK, England, Scotland, Wales, and Northern Ireland.
- Australia – New South Wales, Victoria and Western Australia
- Ireland.
- New Zealand.

Negotiations are continuing with several other countries.

The new cancers to be studied are liver, pancreas, oesophagus and stomach in addition to lung, colon, rectum and ovarian, which were included in phase 1.

Four additional research topics have been identified after extensive consultations with the ICBP Programme Board and cancer experts across jurisdictions. These topics are:

1. Access to diagnostics and investigations e.g. capacity, workforce, use, location, guidelines, quality, cost;
2. Access to treatment and related factors e.g. specialisation / centralisation, quality of treatment, innovation (e.g. research intensity, uptake of novel treatments);
3. Cancer patient care pathways e.g. standardised clinical pathways, typical costs, who pays for what and
4. Structure of health systems e.g. role of clinicians, interface between primary and secondary care.

The proposed new research modules will:

- Use data from existing sources (as far as possible) with a view to minimising local costs.
- Be led by researcher teams/consortia appointed through a competitive bid process.
- Include a feasibility study as the first step, to ensure data is available in all jurisdictions to undertake leading edge research.

# Research

## International Cancer Benchmarking Partnership (ICBP) Phase 2 cont'd

- Involve greater collaboration between all research teams.
- Aim to produce more outputs: reports, recommendations and peer-reviewed papers, to ensure all ICBP knowledge is shared.

The International Agency for Research on Cancer (IARC) has started gathering data for an updated survival analysis which covers all cancer sites across participating jurisdictions from 1995 to 2014. Primary and secondary care clinicians from a range of jurisdictions with expertise across ICBP cancers are being nominated by the Programme Board at present. These clinical committees will convene as virtual groups and use teleconference to communicate when required to ensure phase 2 work is clinically relevant and includes local intelligence and considerations.

The main research questions are:

- Does the extent to which **cancer patient pathways** are articulated, structured and monitored contribute to international differences in cancer outcomes?
- How does the **organisation and structure of health systems** impact on the type of the care cancer patients receive, and their outcomes? Does variation in **access to diagnostics and post-diagnostic tests** impact observed differences in international cancer outcomes?
- Does variation in **access to optimal treatment** impact observed differences in international cancer outcomes?

The research briefs have been drafted to reflect key considerations and basic principles for ICBP phase 2, include:

- Potential to impact on policy and practice with research outputs.
- Exploration of areas requiring further understanding - especially in light of phase 1 findings and feedback from ICBP board members. Use of existing administrative data wherever possible.
- Development of methodologies and analyses which are feasible and do not require significant additional financial commitments for local delivery among participating jurisdictions.

If you have any questions or would like more information on the ICBP, please visit their website at [www.icbp.org.uk](http://www.icbp.org.uk) or email the team at [icbp@cancer.org.uk](mailto:icbp@cancer.org.uk).

## N. Ireland Cancer



## Registry—Macmillan Cancer Support Collaboration

A partnership between the N. Ireland Cancer Registry (NICR) and Macmillan Cancer support commenced on 1 April 2016 and will support the employment of a researcher and Tumour Verification Officer (TVO) within the NICR. The aim of the partnership is to deliver insightful analysis of Northern Ireland cancer data to support the improved design, testing and implementation of better models of care, to identify gaps and opportunities to enhance data collection and analysis for improved outcomes for people living with and beyond cancer in Northern Ireland.

The NICR-Macmillan partnership forms part of a larger UK wide analytical partnership initiative with partnerships already established between Macmillan Cancer support and National Cancer Registration and Analysis service (NCRAS) Public Health England, which commenced 2012, Scottish Cancer Registry and Information Services Division (ISD), Scotland which commenced July 2015.

The partnership in Northern Ireland will take place in two phases: Phase I (April 2016 - March 2017) will involve: the analysis of routine registration data of breast cancer patients placed on the transforming cancer follow-up programme with comparisons to all patients diagnosed with breast cancer in Northern Ireland, analysis of Primary Care Federation Cancer profiles and work to establish a method for routinely collecting and reporting breast cancer recurrence and metastases routinely. We will also investigate information availability on consequences of treatment work (including pelvic radiotherapy and cardiotoxicity). The objectives for Phase II (April 2017- March 2018) of the partnership are to be established in January 2017. In terms of outputs of the NICR-Macmillan partnership to date, a report examining mortality and long-term effects among children and young people who survive cancer in Northern Ireland has been prepared and has been submitted to the Ulster Medical Journal with a poster presented on this at the International Association for Research on Cancer meeting in June 2016.

# Collaborative Research

## Local Cancer Intelligence Northern Ireland

In collaboration with the N. Ireland Cancer Registry (NICR), Macmillan Cancer Support developed a [Local Cancer Intelligence Tool](#) (LCI) to help understand Northern Ireland's changing cancer population across the HSC Trusts, council areas and tumour groups. It combines NICR and Macmillan data to provide a quick and easy user-friendly way of getting headline figures on numbers, needs and experiences 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. The most recent data on cancer incidence, prevalence and survival for 1993-2014 is currently included in the LCI tool.

The most recent statistics show that there are an estimated 55,721 people living with cancer (excluding Non-melanoma skin cancer) in Northern Ireland. On average (between 2010 and 2014) there were 8,819 cases diagnosed each year (4,426 males and 4,393 females). By 2030, it is estimated that there could therefore be 93,000 people living in Northern Ireland after a cancer diagnosis.

The LCI tool allows users to go into more detail, through the facility to filter the data shown in each chart by gender, age group, cancer type etc. and to download the underlying data as a spreadsheet or image:

HOW TO ACCESS IT (<http://lcini.macmillan.org.uk/>)

### 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 »](#)

### Trends

Sex: Both      Cancer type: All cancers ex NMSC (C00-C43 & C45-C97)      [Update chart](#)

Number of cases from cancer and cancer incidence rates by single year, 1993-2014 - Northern Ireland  
N. Ireland Cancer Registry (NICR) published 2016

2007  
New cases: 7,935  
Rate: 582

Filtered by - Sex: Both sexes, Type: All cancers ex NMSC (C00-C43 & C45-C97)  
■ New cases    ● Rate

Trends allow you to see a pattern of what has happened over a historical period of time. These rates are based on the year in which an individual is diagnosed with cancer.

**LOCAL CANCER INTELLIGENCE NORTHERN IRELAND**      **WE ARE MACMILLAN. CANCER SUPPORT**

All Northern Ireland    Health and Social Care Trusts    Council areas    Cancer types    About    FAQs    Contact us

Home - All Northern Ireland

## CANCER IN NORTHERN IRELAND

This page shows the data available to review for cancer statistics covering Northern Ireland as a whole, including all Health and Social Care Trusts and Council areas.

Select from the options below for more detailed data sets:

### Prevalence >

At the end of 2014, around **55,721** people in Northern Ireland were living up to 22 years after a cancer diagnosis.

This could rise to an estimated **93,000** by 2030.

22-year Prevalence by time since diagnosis

### Incidence >

Between 2010 and 2014, there was an average of **592** new cancer diagnoses for every 100,000 people per year. \*

### Mortality >

Between 2010 and 2014, an average of **288** people in every 100,000 died from cancer each year. \*

### Survival >

Between 2005 and 2009, net survival rates for cancer across all of Northern Ireland were:

6 months survival: **77%**  
One-year survival: **70%**  
Five-year survival: **54%\*\***

### Patient Experience >

**92%** of people rated their overall care as excellent or very good in the 2015 Northern Ireland Cancer Patient Experience Survey (CPES).

### Stage at diagnosis >

Between 2010 and 2014:

**22%** of people were diagnosed at Stage I.      One-year survival for people diagnosed at Stage I was **95%**

**18%** of people were diagnosed at Stage IV.      One-year survival for people diagnosed at Stage IV was **33%**

### Population and deaths

In 2014, Northern Ireland had a population of **1,840,498**

[More population information](#)

\* European age-standardised incidence rate using the European Standard Population 2013.  
\*\* Net survival of cancer patients diagnosed

[Learn more about the rates we use in our FAQs](#)

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**WE ARE MACMILLAN. CANCER SUPPORT**

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In collaboration  
 Cancer Registry  
The data for this tool was extracted from N. Ireland Cancer Registry's (NICR) website. The N. Ireland Cancer Registry is located in Queen's University Belfast and is funded by the Public Health Agency.

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# Collaborative Research

## Population-based biomarker studies of bowel cancer survival

Mr Ronan Gray (Surgical registrar and PhD student) and Dr Helen Coleman (Lecturer) from the Cancer Epidemiology and Health Services Research Group at Queen's have been using Registry data as a basis for a study investigating factors associated with survival in locally advanced (Stage 2 and 3) bowel cancer. Survival information for these cases has been combined with features such as medication use at the time of diagnosis, smoking status, co-morbidity and treatment.

This large population-based dataset has subsequently been matched to tumour samples within the Northern Ireland Biobank. Using this fully anonymous resource, the research team are able to address important questions such as (i) whether levels of protein expression in patients' tumour samples or (ii) the presence of certain mutations in tumour DNA can predict response to commonly prescribed medications that may have anticancer properties (e.g. aspirin or cholesterol lowering drugs known as statins). The resource that has been created to answer these types of questions is extremely valuable in the quest to deliver so-called *personalised cancer treatment* and forms the basis for a new area of research known as *molecular pathology epidemiology* research.

Ronan and Helen are just two members of the large team behind this research initiative, which includes collaborators from the Centre for Public Health (led by Professor Liam Murray), Centre for Cancer Research and Cell Biology (led by Professor Manuel Salto-Tellez), and the Belfast Health and Social Care Trust, most notably one of the Registry's own pathology advisors, Dr Maurice Loughrey. This is a great example of the N. Ireland Cancer Registry and Northern Ireland Biobank facilitating world-class research that will hopefully benefit patients here and further afield.



## Pre-malignant disease register: Monoclonal Gammopathy of Undetermined Significant (MGUS)

Multiple myeloma (MM) is the third most common blood cancer in the UK with 5,497 cases diagnosed in 2013. Despite significant advances in treatment, MM remains incurable. Almost all cases of MM are preceded by monoclonal gammopathy of undetermined significance (MGUS). MGUS, is a plasma cell disorder which has been reported to progress to MM and associated blood cancers at a rate of 0.5-1.5% per year and this risk has been reported to remain elevated up to 25 years post diagnosis. Identifying individuals with a higher risk of progression is therefore crucial to improving patient outcomes as well as reducing burden on healthcare systems around the world.

Dr Charlene McShane (CRUK Population Science Research Fellow) and Dr Lesley Anderson (Lecturer) from the Centre for Public Health, Queen's University Belfast are collaborating with the N. Ireland Cancer Registry (NICR) to establish a population-based register of MGUS in Northern Ireland. Cancer Research UK has awarded Dr McShane a personal fellowship to undertake this research study.

To identify MGUS cases, all protein electrophoresis investigations with a detectable paraprotein carried out in Northern Ireland are retrospectively being reviewed and linked to the NICR. Individuals with a previous or concurrent blood cancer will be excluded from the MGUS register. The MGUS register will also be securely linked to a number of datasets housed within the NICR to investigate important patient outcomes such as survival.

Once the register is established, Drs McShane and Anderson will use it to determine the incidence and prevalence of MGUS within Northern Ireland and to investigate the rate of, and factors associated with progression to myeloma and other blood cancers. The register will also be used to develop a new risk stratification tool to stratify MGUS patients by risk of progression.

# Collaborative Research

## NI-Biobank



The link between the Northern Ireland BioBank (NIB) and the N. Ireland Cancer Registry (NICR) is now firmly established. The NIB is an institution which hosts and distributes a collection of well defined, quality assured biological samples to support translational research programmes in Northern Ireland and beyond. The NICR now collects clinical information from the NICR databases relating to the patients from whom they have collected particular tumour samples from such as; age, date of diagnosis, how they were diagnosed, tumour stage at diagnosis, treatment and whether or not they had a recurrence etc. The molecular information and clinical information associated with each sample is then used for molecular based population based studies with the hope of finding new biomarkers. The discovery of new biomarkers will in turn help with further biomedical research to develop innovative biomedical diagnostic procedures for tumours, and create better targeted therapies for cancer patients. All this work is ethically approved and data are anonymised for analysis.

The NICR is currently working with the NIB to establish a link to send automated anonymised clinical data associated with each tumour sample directly to the NIB electronically. The NIB have funded half a TVO's salary to help collect anonymised clinical data for more detailed studies, and to help with quality assurance of clinical data already stored with the NIB.

## Do commonly prescribed medications improve cancer survival?

Some studies in cancer patients suggest that medications widely used in the prevention and treatment of common conditions (such as cardiovascular disease, diabetes and bone disease) may have unintended beneficial effects on cancer progression and may actually improve survival. These studies however are not conclusive and few have had detailed information on how advanced the cancer is at diagnosis and what cancer treatments the patients received.

To investigate this further, Dr Úna McMenamin and Dr Andrew Kunzmann, researchers from the Centre for Public Health, are carrying out a large study to investigate if the use of common medications (including low-dose aspirin, statins, blood pressure lowering medications, bisphosphonates and metformin) are associated with longer survival in cancer patients. So far, the researchers, along with NICR staff, have collated detailed clinical and tumour information for patients diagnosed with breast, colorectal, lung, prostate, ovarian, oesophageal and stomach cancer between 2009 and 2014 within the NICR. Using novel record linkages, which maintain patient confidentiality, this information will be combined with population-wide data on prescriptions from the Northern Ireland Enhanced Prescribing Database (NIEPD). The findings from this study will help determine if these medications, which are commonly prescribed and well tolerated, could be useful additions to cancer therapy.

This work is funded through a HSC Research and Development, Public Health Agency funded National Institute for Health Research (NIHR) Career Development Fellowship obtained by Dr Chris Cardwell (Centre for Public Health) and the Health Research Board.

## Hiding in plain sight?: the potential for beta-blockers to reduce breast cancer mortality



Some studies have suggested that women with breast cancer taking beta-blocker medications after diagnosis, for the treatment of certain cardiac conditions or high blood pressure, may have improved survival. However, few studies have examined whether the presence of beta-adrenergic receptors in the tumour tissue (the target protein of the beta-blocker medications) has any additional effect on breast cancer mortality.



Funded through a Cancer Research UK population research fellowship, Dr Michael O'Rorke has been using data available within the N. Ireland Cancer Registry, with linkages to archived tumour tissue and prescription information in these women, to investigate the impact of beta-blocker medications and tumour beta-adrenergic receptor expression on breast cancer survival.

This unique study will provide insight into the use of beta-blockers, a commonly prescribed and well tolerated medication, as a potential therapy in breast cancer patients, and will also help outline the relevance of beta-adrenergic receptor expression on prognosis and survival.



# Collaborative Research

## Contralateral breast cancer risk study

Following a diagnosis of breast cancer, the incidence of a contralateral breast cancer (CBC) is around 0.5% per annum, or 10 - 15% over the 20 years following an initial diagnosis. This risk provides an additional significant source of concern for women newly diagnosed with breast cancer. In fact, the rate of contralateral prophylactic mastectomy (CPM) for a unilateral breast cancer is on the rise despite a general decline in CBC incidence. CPM carries a significant increase in the rate of post-operative complications, in addition to the psychosocial effects of a bilateral mastectomy.

Currently, there is no reliable method by which the CBC risk of a woman with a new breast cancer diagnosis can be estimated. We know that risk factors for CBC include young age of initial diagnosis and family history of breast cancer. We have developed a plan for studying this risk. The N. Ireland Cancer Registry will collaborate with the NI Biobank to identify samples of tumours from archival tissue, which will be used to compare primary and contralateral tumours at a genetic and molecular level. This will provide an in-depth understanding of the relationship between these tumours allowing us to examine whether women with a particular genetic background, or those who develop a specific subtype of primary breast cancer, are at higher risk of developing a CBC.

This potential study has three main aims. Examination of the genetic relationship between primary and CBC would help to establish whether it is possible to distinguish between a true second primary versus a recurrent/metastatic lesion. This information would have important implications in terms of clinical management decisions for these patients. Additionally, gene sequencing for mutations in breast cancer predisposition genes in the germline DNA of these women would investigate whether there are frequently occurring previously unrecognised genetic drivers in the development of CBC. Immunohistochemical subtyping of these tumours would complement and enhance this data, providing a fuller understanding of the relationship between primary and contralateral tumours.

This research has the potential to significantly inform the counselling process of a woman who has been diagnosed with a primary breast cancer. Quantification of CBC risk would undoubtedly assist in providing a personalised approach to her surgical management decision and impact on her subsequent quality of life.

Dr Colin McIlmunn

**Research supervised by Mr Stuart McIntosh and Dr Kieran Savage in CCRCB.**

## Audit: ovarian mucinous borderline tumours

Clinical histopathologists from Belfast Health and Social Care Trust and researchers in the Centre for Public Health, QUB, are using N. Ireland Cancer Registry data to audit the diagnosis and outcomes of ovarian mucinous borderline tumours in Northern Ireland. The team will review historical cases of this condition to understand better why, in some rare cases, the disease recurs after surgery. They will investigate elements of clinical histopathology practice, morphological features and patient characteristics that may suggest a higher risk of recurrence. The audit aims to improve patient care by reviewing histopathological practice and identifying ways of delivering continuous quality improvement.

Dr Declan Bradley

## F2-Placement

I worked as an Academic F2 within the Centre for Public Health from December 2015 – April 2016. At medical school in the University of Manchester, through placements in Clinical Oncology and ENT-Head and Neck Surgery, I developed an interest in head and neck cancer research, pre-clinical and clinical, motivating me to pursue an Academic Foundation Programme. Prior to commencing my academic post in the Centre for Public Health I had been in a busy clinical placement within the Northern Ireland Cancer Centre as an Oncology F2 doctor. This exposed me to the inpatient experience of cancer patients within Northern Ireland and renewed my interest in head and neck cancer patients and their care. My four-month research placement was principally undertaken with the N. Ireland Cancer Registry (NICR). The purpose was to produce a detailed report on head and neck cancer in Northern Ireland encompassing the incidence, prevalence, mortality and survival of head and neck cancer patients from 1993-2013. I also carried out a detailed audit of care for patients with larynx, oropharynx and oral cavity cancers diagnosed in 2013, looking at patient characteristics, referral process, MDT management and outcomes. The friendly and supportive working environment in the Northern Ireland Cancer Registry allowed me to work effectively towards my research aims. They provided training in data protection and confidentiality and I was able to utilise the strong academic and clinical links of the NICR to produce a good piece of work which I have submitted for presentation at an international conference. Their wealth of information on cancer registrations across all the Health and Social Care Trusts allowed me to take a broad view of head and neck cancer across all of Northern Ireland, an important feature for a relatively uncommon group of cancers. I found the staff to be very welcoming and encouraging and their input and concentrated expertise helped to shape the scope of my work.

I would, without reservation, recommend the NICR as a research environment for future academic foundation trainees and indeed any clinician/scientist with an interest in local cancer epidemiology and patterns of care.

Conor McKenna F2 Doctor

# Presentations at Conferences

Research from the N. Ireland Cancer Registry (NICR) was presented at the following conferences:

1. UKCRC Conference – Edinburgh, November 2015.
2. All Ireland Cancer Conference – Belfast, 10-13 May 2015.
3. Cancer Outcomes Conference – Belfast, 8-10 June 2015.

## Oral Presentations:

- Features of the diagnostic pathway associated with early death from colon cancer: A nested case control study in a UK region. Mr Conan Donnelly
- Prostate Cancer: Prostate cancer patient reported outcomes - Does more investigation and treatment result in better health? Dr Anna Gavin

## Poster Presentations:

- Cancer Screening Programmes – public knowledge and beliefs in Northern Ireland.
- Men's experience of a prostate biopsy is associated with health-related quality of life.
- Challenges in measuring the diagnostic and treatment interval within Northern Ireland; ICBP module 4.
- A population level study of clinical trial participation among cancer patients in Northern Ireland.
- HPV prevalence and type-distribution in cervical cancer and premalignant lesions of the cervix: a population-based study from Northern Ireland.
- Establishing a population-based register of Monoclonal Gammopathy of Undetermined Significance (MGUS) in Northern Ireland.
- Cancer Incidence Projections to 2035 in Northern Ireland.
- Improving access to curative therapies in lung cancer for Northern Ireland.
- Personal and Public Involvement in Cancer Registry Research – The Northern Ireland Model.
- Factors associated with Palliative Outcomes among cancer patients in a UK region.
- Factors associated with terminally-ill cancer patients achieving their preference to die at home.
- Life After Prostate Cancer Diagnosis (LAPCD).
- Prevalence and predictors of procedure-related distress in men undergoing prostate biopsy.
- Challenges of establishing a population-based patient-reported outcomes study (PROMs) using national cancer registries across two jurisdictions; The Prostate Cancer Treatment, your experience (PiCTure) Study.
- Do men regret undergoing a diagnostic prostate biopsy?
- Physical side-effects in men undergoing prostate biopsy: an all-Ireland study.

# International Visitor

From mid February 2016 I did a three month internship for my PhD at the N. Ireland Cancer Registry (NICR). I am a second year PhD student living in the south of the Netherlands and working at the Netherlands Comprehensive cancer organization (IKNL) which is responsible for the Netherlands Cancer Registry. My PhD is about



the quality of care among patients with oesophageal and gastric cancer. During my stay in Belfast at the NICR I mainly worked together with Dr Helen Coleman and Prof Liam Murray who are lecturers and researchers in Queens University Belfast. Together with Dr Anna Gavin and other medical specialists we investigated the risk of a 'missed' oesophageal adenocarcinoma or high grade dysplasia among patients with a Barrett's oesophagus at time of their diagnosis.

On 8th April I presented the results from this study at the 10th National Barrett's symposium in London. During my stay in Belfast I worked on the manuscript and I would like to publish the results of the study later in 2016. Furthermore, during my stay, I followed the global short cancer course for one week at Queen's University Belfast. I attended lots of seminars and journal clubs. I have learned to perform analysis in STATA as I usually perform analysis in SAS and I helped at the fund raising coffee morning for oesophageal cancer research. Oh and I got involved in another study about seasonal trends in diagnoses of Barrett's oesophagus and oesophageal adenocarcinoma. So, I think I had some productive months in Belfast.

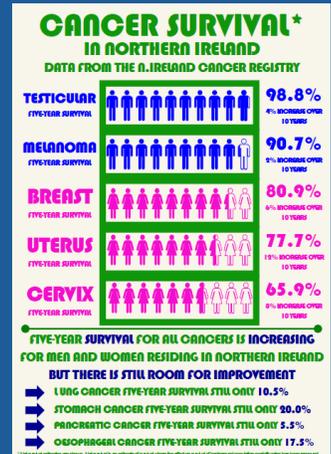
Maybe you are now thinking, 'Did she also see something of our country?' Yes, I did and I fully enjoyed that. What beautiful scenery you have in Northern Ireland and I really like the pubs with live-music. The weather is a disaster but what lovely and friendly people live here. Especially at the NICR! I will miss the coffee breaks and lunch breaks with you. You are such a warm group of people and you have a lot of fun with each other. Oh and I will miss the Tayto crisps, of course, but only cheese and onion. I hope to see you again, cheerio!

Margreet

# Summer Studentships



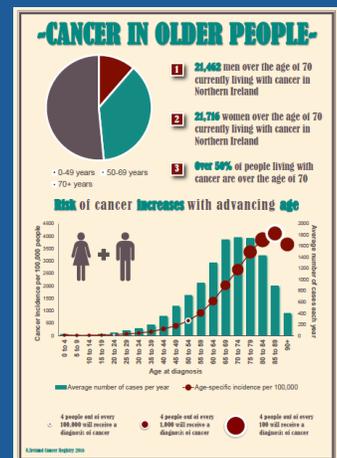
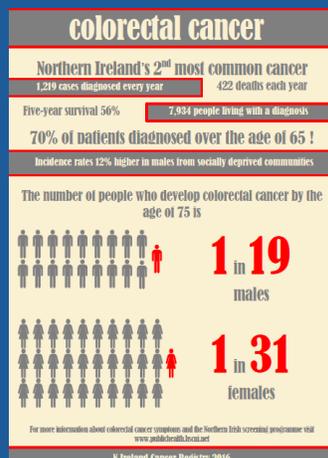
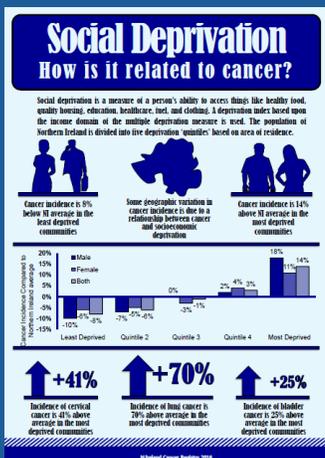
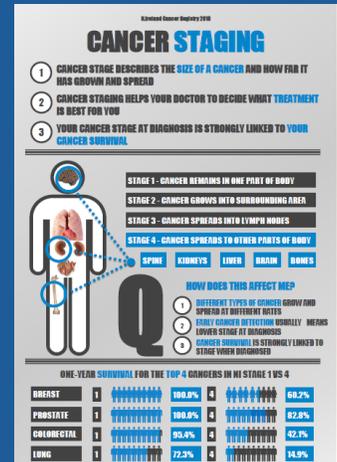
I-r Suzanne Graham, Alan McCrorie, Conor Brown, and Jessica Chen



During the summer of 2015, four undergraduate students joined the team at the N. Ireland Cancer Registry (NICR) to work on various projects using anonymised datasets. Conor Brown, a second year Biomedical Science student, assisted the team in analysing qualitative data from the Northern Ireland Qualycare study and conducted a structured literature review. His work will contribute to a forthcoming research paper investigating the views of carers on the care of dying cancer patients in Northern Ireland. Jessica Chen, a second year medical student was involved in several different work areas including analysis of data from the International Cancer Benchmarking Partnership Module 4 investigation into delays on the pathway to a cancer diagnosis and helped prepare a

questionnaire for the UK wide Life After a Prostate Cancer Diagnosis study. She also assisted in the analysis of data on completeness of cancer registry and is currently helping the team publish this work. Alan McCrorie a fourth year medical student, assisted in the redesign of the NICR website, production of statistical documents, and creation of digital media resources and was involved in a piece of primary care research. He has since written a paper on 'Infographics: Healthcare communication for the digital age' which was published in the Ulster Medical Journal. Both Alan and Conor won awards for their work at the Centre for Public Health student symposium in August 2015. In the short time Conor, Jessica and Alan were with the NICR, they made a

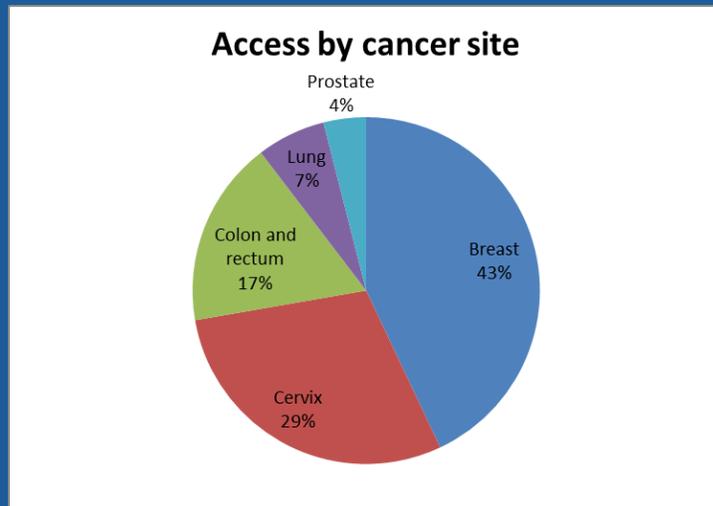
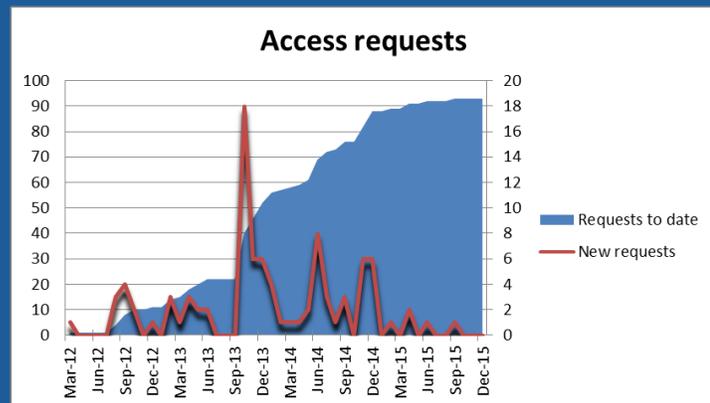
significant contribution to its work. Suzanne worked with Dr Lesley Anderson to further understanding of Barrett's Oesophagus and its role as a precursor of oesophageal cancer. We wish all the students well in the future.



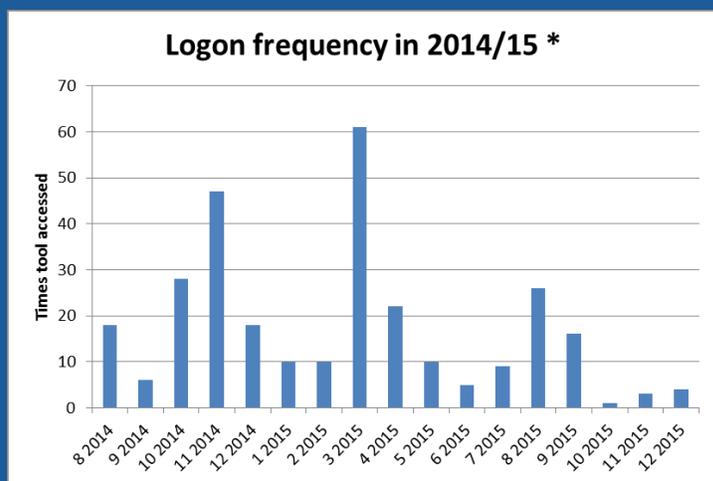
# CanStaging access stats to December 2015

CanStaging (the Cancer Staging Tool) is a tool that calculates TNM, Stage Group and other simplified and/or site-specific cancer staging classifications from the basic features of the patient's disease (e.g. tumour size or number of lymph nodes involved), entered by the user in a controlled fashion.

To request access to CanStaging, please download and complete the [Application Form](#) (available from NICR website).



Countries where at least one organisation has requested access



(\* ) Excluding NICR and IARC access

Algeria	Curaçao	Iceland	Nigeria	South Africa
Argentina	Denmark	India	Pakistan	Spain
Australia	Ecuador	Indonesia	Peru	Switzerland
Azerbaijan	El Salvador	Iraq	Poland	Taiwan
Basque Country	Ethiopia	Ireland	Portugal	Thailand
Belarus	Finland	Italy	Puerto Rico	Tunisia
Belgium	France	Jordan	Qatar	Turkey
Canada	Germany	Kenia	Romania	UK
Colombia	Greece	Luxembourg	Saudi Arabia	Uruguay
Congo	Grenada	Mexico	Slovakia	USA

## Actual usage

These are estimated values: only when users click the 'Submit' button the cancer site information will be saved to the log, but we have found that most of the users simply transcribe stage information as it appears on screen.

# Publications

## 1 January 2015 - 31 March 2016 Peer Reviewed Publications

1. Lawler M, Gavin A, Salto-Tellez M, Kennedy RD, Van Schaebroeck S, Wilson RH, Harkin DP, Grayson M, Boyd RE, Hamilton PW, McArt DG, James J, Robson T, Ladner RD, Prise KM, O'Sullivan JM, Harrison T, Murray L, Johnston PG, Waugh DJ. Delivering a research-enabled multistakeholder partnership for enhanced patient care at a population level: The Northern Ireland Comprehensive Cancer Program. *Cancer*. 2015 Dec 22. doi: [10.1002/cncr.29814](https://doi.org/10.1002/cncr.29814).
2. Rose PW, Rubin G, Perera-Salazar R, Almberg SS, Barisic A, Dawes M, Grunfeld E, Hart N, Neal RD, Pirota M, Sisler J, Konrad G, Toftegaard BS, Thulesius H, Vedsted P, Young J, Hamilton W, The ICBP Module 3 Working Group\* (\*includes Dr Anna Gavin). Explaining variation in cancer survival between 11 jurisdictions in the International Cancer Benchmarking Partnership: a primary care vignette survey. *BMJ Open* 2015;5:e007212 doi:[10.1136/bmjopen-2014-007212](https://doi.org/10.1136/bmjopen-2014-007212).
3. Hajdarevic S, Hvidberg L, Lin Y, Donnelly C, Gavin A, Lagerlund M, Pedersen AF, Rasmussen BH, Runesdotter S, Vedsted P, Tishelman C. Awareness of sunburn in childhood, use of sunbeds and change of moles in Denmark, Northern Ireland, Norway and Sweden. *European Journal of Public Health* DOI: <http://dx.doi.org/10.1093/eurpub/ckv112> ckv112 First published online: 16 June 2015.
4. Coleman HG, Loughrey MB, Murray LJ, Johnston BT, Gavin AT, Shrubsole MJ, Bhat SK, Allen PB, McConnell V, Cantwell MM. Colorectal cancer risk following adenoma removal: a large prospective population-based cohort study. *Cancer Epidemiol Biomarkers Prev* (2015) 24(9):1373-80. doi: [10.1158/1055-9965.EPI-15-0085](https://doi.org/10.1158/1055-9965.EPI-15-0085) Epub June 16.
5. Anderson L, O'Rorke M, Wilson R, Jamison J, Gavin A; Northern Ireland HPV Working Group. HPV prevalence and type-distribution in cervical cancer and premalignant lesions of the cervix: A population-based study from Northern Ireland. *J Med Virol* 2015 Dec 17. doi: [10.1002/jmv.24447](https://doi.org/10.1002/jmv.24447).
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# Publications Cont'd

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## 2015/16 Reports

1. Cairnduff V, Gavin A. Monitoring care for female breast cancer patients in Northern Ireland diagnosed 2012 (with comparisons to 1996, 2001 and 2006). N. Ireland Cancer Registry, QUB 2016, 110 pages.
2. Donnelly D. Cancer incidence trends 1993-2013 with projections to 2035. May 2015.
3. Cairnduff C, Fitzpatrick D, Donnelly C, Blaney J, Gavin A. Dying with Cancer: Perspectives of Bereaved Relatives/Friends. May 2015.

## 2015/16 Chapters in Books

1. McKinley J, Ofterdinger U, Palmer S, Jackson C, Gavin A. & Fogarty D. 2015 *Tellus*. Young, M. (ed.). Combining environmental and medical datasets to explore potential associations between environmental factors and health: Policy implications for human health risk assessments. Royal Irish Academy, 7 p. (Chapter in book).

# Cancer Survival: Principles, Methods and Applications

For the week commencing 27 June, Eileen Morgan and Victoria Cairnduff had the opportunity to attend the short course on Cancer Survival: Principles, Methods and Applications at the London School of Hygiene and Tropical Medicine (LSHTM). This annual course is run by the Cancer Survival Group at the LSHTM and is in its 11th year.

The main focus of the course was on population-based cancer survival with population-based data, explained through lectures and also in computer-based practical classes using real data. The main approach used in cancer survival statistics from Registry data is net survival which a lot of the lectures were based on. Net survival is the probability of surviving cancer in the absence of other causes of death. It is a measure that is not influenced by changes in mortality from other causes and, therefore, provides a useful measure for tracking survival across time, and between registries. The course also discussed other aspects of survival data such as missing data and alternative methods such as modelling to investigate factors associated with increased/ decreased survival in cancer patients.

Both Eileen and Victoria found the course very useful.



Participants in the London School of Hygiene and Tropical Medicine (LSHTM) Cancer Survival training course including our very own Eileen Morgan and Victoria Cairnduff - photograph courtesy of LSHTM

# ISO27001 Information Security Management System

This year the Registry have taken the decision to implement the ISO27001:2013 Information Security standard. This internationally recognised and accredited standard looks at all the information assets held within the organisation and assesses the processes and practices to assure that the confidentiality, integrity and availability of data and data assets are adequately maintained. The ISMS is initially and continually audited by an external accredited awarding body to ensure that the organisation is both implementing the policies and procedures that are in place as well as observing a commitment to maintaining continual process improvement by reviewing and updating the policies and procedures in light of emerging technologies and changing circumstances.



## Why do we need it?

To be honest, we don't! We feel that the Registry takes the confidentiality and integrity of the data it collects very seriously and already employs robust policies and procedures in relation to our information security. We already feel we follow, or in some cases, exceed current best practice in relation to our data security. However, there is a perception that this is a self-proclamation of our processes and attaining the ISO27001 accreditation would be externally verified by an independent body. The accreditation could raise the profile of the organisation and offer an extra level of assurance to our stakeholders, partners and above all the patients' from whom we collect the necessary data that allows us to function as a high value organisation in the analysis and reporting of cancer incidence in Northern Ireland. It is also envisaged that the standard could potentially improve the process for ethical approval requirements and similar data governance issues that are potentially time consuming in their own right.

## What is going to change?

As we are already working to best practice in a number of areas then probably not a lot is going to change. While we are going through the process we may uncover some areas that could be improved in terms of information security and therefore the implementation process will allow us to review our current processes in line with current best practice and assess if further action is required in these areas.

## When will this happen?

It is happening!! The project board have allocated 12-18 months for the process which was officially started in November 2015. We have agreed an outline definition of the scope that will be covered by the ISMS are now undertaking the process of building the documentation and preparing for the Risk Assessment that is the integral part of the ISMS. We hope to be ready for certification by April 2017.

# Cancer Registration System

In a significant undertaking much of the Cancer Registry IT infrastructure has been upgraded over the past twelve months and many of the operational servers have been migrated onto virtualised hosting platforms. This has allowed us to provide resilience to the system by creating cloned copies of critical systems with the added benefit of easier backups and quick restoration if required. Work is currently ongoing to upgrade the Cancer Registry application and database to allow us to further modernise the infrastructure and operating systems and also pave the way for the addition of future functionality to meet increasing demands on the Registry to capture and record more information about cancer such as detailed staging, treatment and other patient pathway information. Our IT staff have attended training on Registry applications and database technology and we are confident that, with internal and external support, our staff and systems will continue to maintain and improve the quality and integrity of Cancer registration data in Northern Ireland. We will continue to explore existing and emerging technology options that may provide additional benefit to the Registry.

# Staff News



The N. Ireland Cancer Registry have their very own chef, IM&T Officer Ronan Campbell. Staff in the Registry were treated to a pleasant surprise on Pancake Tuesday this year with home made pancakes cooked before their very eyes. Working diligently behind the scenes the pancake mix was pre-prepared and was cooked up in the registry on Pancake Tuesday and enjoyed by all—yum yum!

Due to the unprecedented success, we may ask for charitable donations for next years event, all are welcome to attend! Booking Essential!

## New Staff

Throughout the last year we welcomed several new appointments to the Registry.



I-r Marsha Magee (TVO), Sinead Lardner (TVO - subsequently Clinical Advisor), Donna Speers (TVO while Brid Morris is on maternity leave), Oonagh McSorley (Project Manager LAPCD while Therese Kearney is on maternity leave), Paula Darragh (TVO) and Deborah Brown—not pictured (statistician temporarily seconded to NICR from NISRA)

## New Arrivals



Brid Morris gave birth to a beautiful baby boy Charlie on Wednesday 19 August 2015.

Conan Donnelly and his wife Anna had a bouncy baby boy Gerard on Monday 14 December 2015.

Therese Kearney gave birth to a gorgeous baby girl, Eimear on Thursday 28 January 2016.



## Farewell

The Registry bid farewell to Dr Lisa Ranaghan and Dr David Donnelly after 18 years accumulative service to the Registry, we wish them both well for their future careers.

As Brid Morris returned from maternity leave (May 2016) we also bid farewell to Donna Speers.

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