Northern Ireland Cancer Registry Newsletter

Volume 25: July 2019

In March 2019, a 5 year Study on Life After Prostate Cancer Diagnosis came to an end. The results were launched at 2 events, one in Leeds and a second in Belfast. More details on pages 4-5.

ISO 27001 certification

ISO 27001 certification in Information Security Management continues to be monitored and improved in the Registry with ongoing internal audits. This ensures 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 2019.

Contents

Official Statistics

Official Statistics on cancers diagnosed in Northern Ireland during 1993-2017 were published on 12th March 2019. This release provides details of the number of cancer cases diagnosed each year (incidence), patient survival after one and five years and the number of people living with cancer in NI at the end of 2017 (prevalence). The detailed information, along with summary factsheets, are available on the NICR website at:

http://www.qub.ac.uk/research-centres/nicr/CancerInformation/official-statistics/

Key facts and figures from the release include:

- There were 9,401 (4,691 male, 4,710 female) people diagnosed with cancer on average each year during 2013-2017 excluding non-melanoma skin cancer (NMSC). There were also on average 3,720 cases of NMSC diagnosed each year.

- The most common cancers diagnosed in 2013-2017 in men were prostate cancer (24%), lung cancer (14%) and bowel cancer (14%) among men, and among women breast cancer (30%), lung cancer (13%) and bowel cancer (11%).

- Over the last ten years the number of cancer cases excluding the very common Non Melanoma Skin Cancer (NMSC) which is rarely fatal, has increased by 15% from 8,269 cases in 2008 to 9,521 cases in 2017. These increases are largely due to our ageing population. After removing the effect of changes in the age and size of the population, over time cancer incidence rates in males decreased during 2009 to 2017 by an average of 0.7% per year. In contrast, cancer incidence rates in females have shown a continuous increase by an average of 0.8% per year since 1993.

Trends in cancer incidence rates by sex: 1993-2017
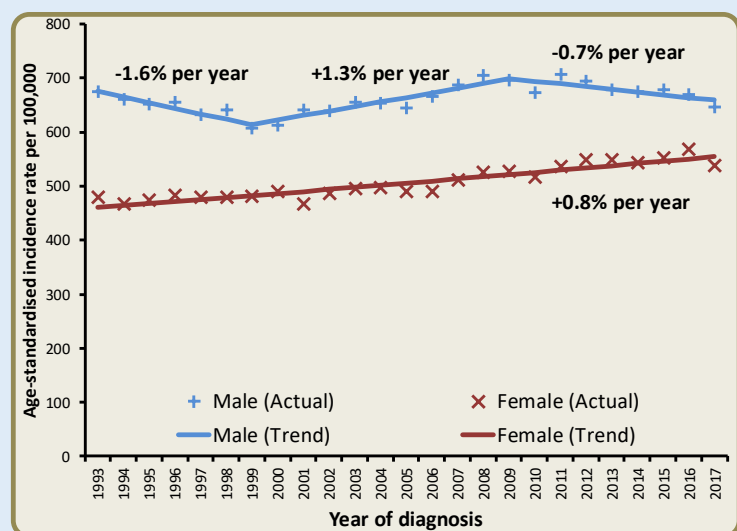
Official Statistics

(continued)

- One-year net survival after cancer diagnosis was 71%, while five-year net survival was 56%. However, over one in five (22%) patients died within six months of diagnosis and survival varied considerably by cancer type, with best survival for testis and melanoma and poorest survival for lung, liver and pancreas.

Five-year net survival for patients diagnosed in 2007-2011 by sex and cancer type
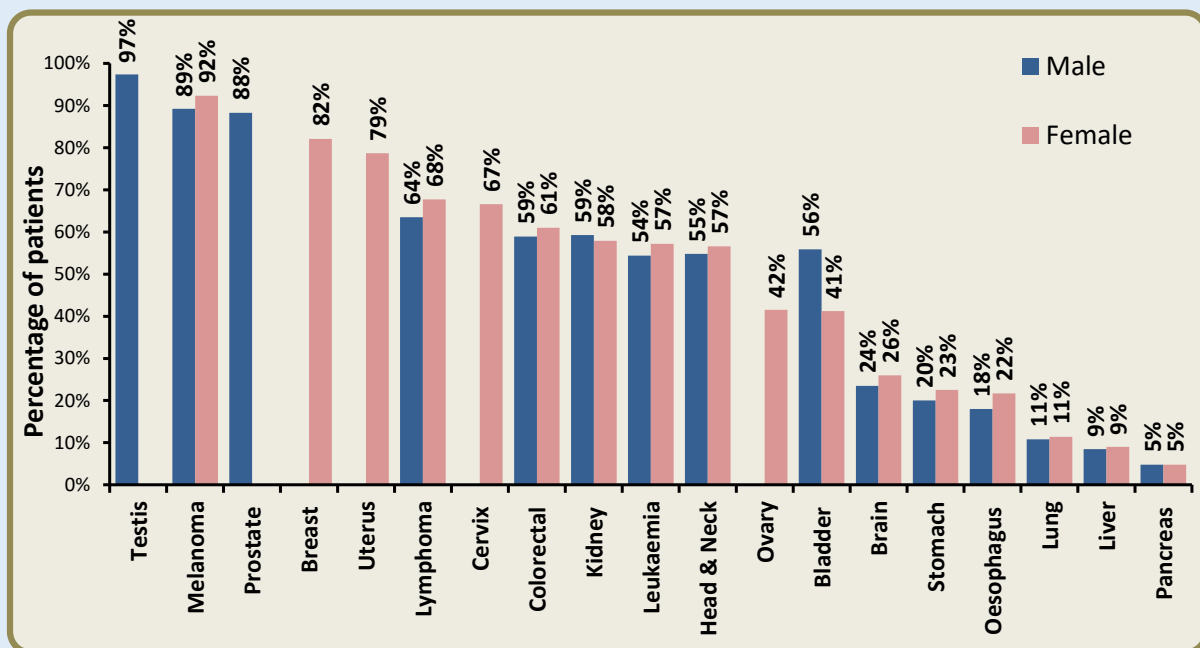
- There were significant improvements in five-year survival between 1993-1996 and 2007-2011 for male lung , prostate, kidney and oesophageal cancer, and among both sexes for bowel cancer, myeloma, lymphoma and leukaemia.

- Stage at diagnosis remains the biggest factor influencing cancer survival. For example, five-year survival was 18% for late stage breast cancer, compared to 99% for early stage breast cancer.

- At the end of 2017 there were 63,413 people living in NI who had been diagnosed with cancer since 1993. The most common (prevalent) types were prostate cancer, with 10,337 men living after diagnosis, and breast cancer, with 15,995 women living after diagnosis.

Life After Prostate Cancer Diagnosis Launch

Results from the Life After Prostate Cancer Diagnosis study were launched on 19th March 2019 in Leeds and 26th March 2019 in Belfast. This Movember/Prostate Cancer UK funded study was designed to investigate the quality of survival of men living in the UK 18-42 months after diagnosis of prostate cancer.

Some of the LAPCD team speaking at the launch in Leeds on the 19th March 2019

Speakers at the launch in Belfast on the 26th March 2019 with Dr Michael McBride, Chief Medical Officer

The research team organised a postal survey sent to men throughout the UK between October 2015 and November 2016. A total of 35,833 men out of the 58,930 invited responded. Key findings thus far from the study include:

Health-related quality of life: Men were asked to rate their overall health on a scale of 0-100. Across the UK, the average self-assessed health score was 77. Men most commonly reported problems with pain/discomfort (42%), usual activities (38%), mobility (36%) and anxiety/depression (34%), and were least likely to report problems with self-care (14%). 62% of men reported at least one problem on any of these five domains measured.

Functional outcomes: Just under half of men reported moderate/big bother with sexual problems in general, despite four out of five men reporting poor/very poor sexual function. Smaller proportions of men reported moderate/big problems with their bowel or urinary function, while just under a quarter of men reported moderate/big problems with lack of energy and one in ten reported problems with depression.

Life After Prostate Cancer Diagnosis Launch

(continued)

Functional problems (Moderate/Big)

Fatigue

22%

Leaking urine
(more than once per day)

13%

Urgency of bowel movement

9%

Poor sexual function

81%

Bother with functional problems (Moderate/Big)

Depression

9%

Urinary problems

13%

Bowel problems

8%

Sexual problems

45%
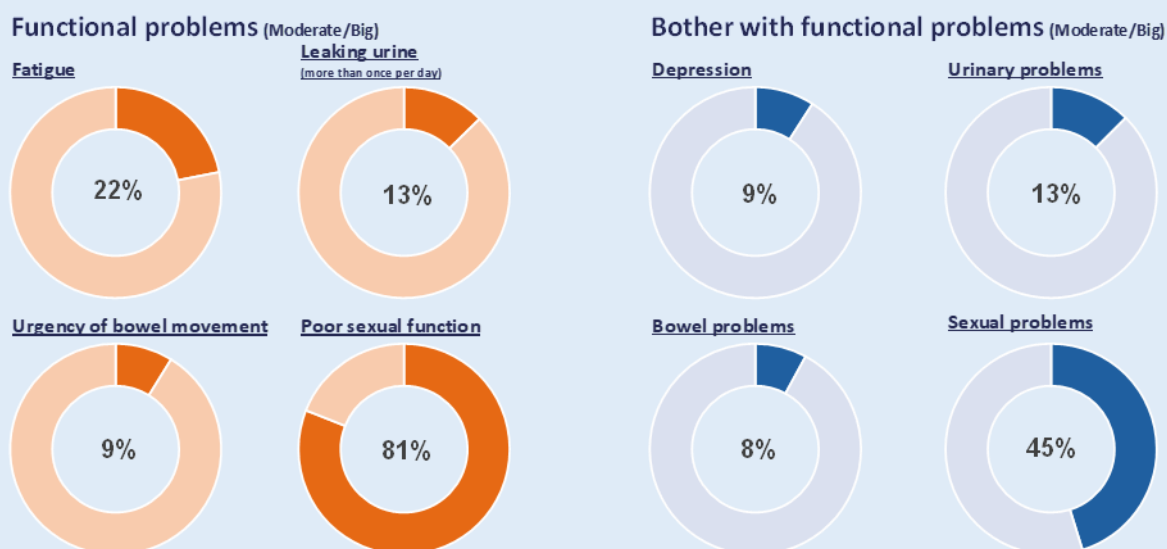
Regional variations in quality of life: After taking account of regional variations in treatment and other clinical and socio-demographic factors, significantly poorer health than the UK average was reported in Wales, Scotland, South Yorkshire and North-East & Cumbria, while significantly better health was reported in South-East London, East of England and Kent & Medway. In addition reporting of specific functional problems varied across the UK.

POORER THAN UK AVERAGE

Urinary, Sexual, Bowel, Hormonal

Urinary incontinence

Urinary irritation, Bowel, Hormonal

Hormonal

Sexual

Urinary incontinence

BETTER THAN UK AVERAGE

Bowel, Hormonal

Sexual

Urinary, Hormonal

Sexual

Urinary irritation, Sexual, Hormonal

Urinary incontinence, Bowel, Sexual, Hormonal

Urinary incontinence, Sexual, Hormonal
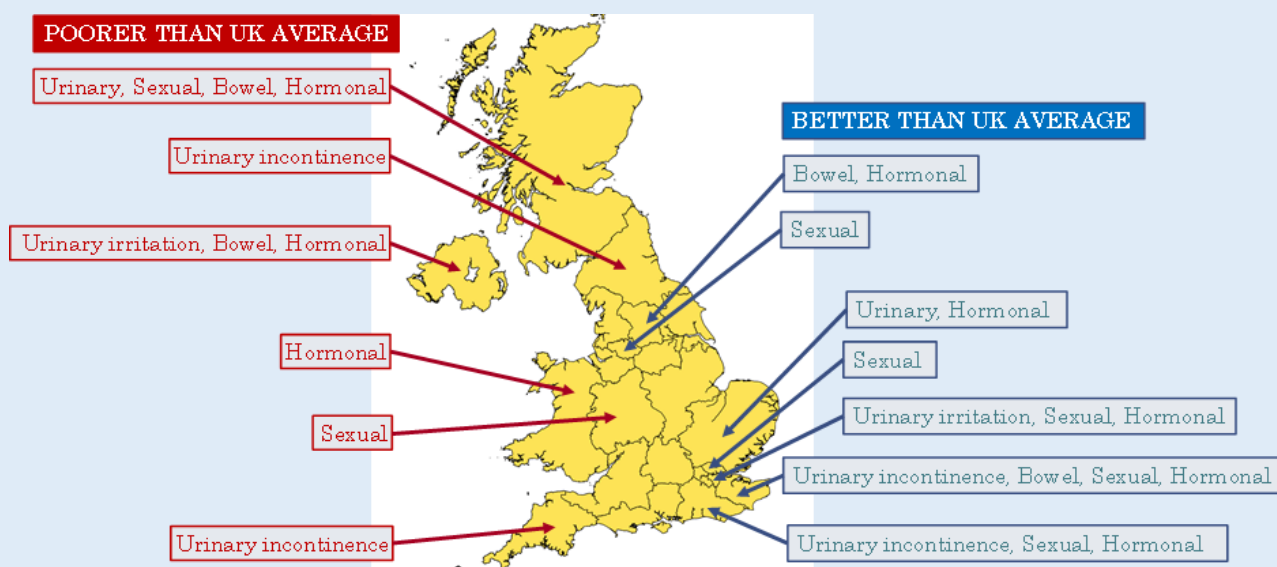
While the study has now finished, further results will be published in the coming months and an online information service using the data will be available via the Prostate Cancer UK web site (https://www.lifeafterprostatecancerdiagnosis.com/). A full list of publications available to date from this study are listed in the publications section of this newsletter.

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, NI 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.

Data quality indicators were collated for all registerable tumours diagnosed in 2017 (more than 17,000 tumours in NI), which included all malignant tumours, 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 excellent and well below the target (lower than 2%) for the UK and Ireland overall, and in particular for NI (DCO 0.3%). Across each of the jurisdictions, improvements can be seen in terms of the completeness of grade of differentiation, with NI having the highest level at 65.6%.

STAGING, which is important for comparisons of survival and information on early diagnosis initiatives, was recorded for 2017 data at 85.3%, the highest of all registries measured.

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. We will make further efforts to increase information on treatments received.

The detail of the latest Performance Indicators are due to be published for NICR in late summer 2019 and may be found at: http://ukiacr.org/kpis

Ongoing Research

Dr Hannah McKenna

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

Dr Finian Bannon and Dr Hannah McKenna of the Centre of Public Health, Queen's University Belfast, in conjunction with Mr Martin Mayock, Mr Alan Harbinson, Mr Scott Mathieson and Mr Neil Marsden from the Information Unit in Business Services Organisation, Health and Social Care N. Ireland (HSCNI), have utilised cancer data provided by the NICR to categorise and quantify the different pathways to diagnosis (e.g. screening, emergency presentation and GP referrals) that NI cancer patients take. The study adopts pioneering work by Public Health England suggesting that route to diagnosis is important in cancer outcomes, enhancing current knowledge on diagnostic procedures as acting as an important predictor of survival.

The aim of the work was to provide evidence to identify patterns and trends in routes to diagnosis and how they link with patient outcomes, therefore impacting policy and practice for improving cancer survival. The NICR supplied the primary data on the cancer patient population to which patient pathway information was confidentially linked in the BSO's Regional Data Warehouse and anonymised. Two analysts in the BSO Research Safe Haven generated statistics on routes-to-diagnosis for various population sub-groups (geographic health area, disease, service-related factors, and socio-economic deprivation). Results have been circulated around the steering group, comprising of GPs, Public Health Agency and other involved agencies with patient/voluntary sector stakeholders. The steering group have provided a policy perspective on results based on their expertise on how NI health services are meeting the challenges of early cancer diagnosis.

Debbie Keatley, a member of NI Cancer Research Consumer Forum, said: "I know how important early diagnosis can be. When I was diagnosed with breast cancer it had already spread to nearby lymph nodes. For me, this meant that as well as surgery and radiotherapy I also needed chemotherapy. If I had been diagnosed earlier I might not have needed this and while I'm grateful to be a cancer survivor, I live with the consequences of treatment. As a patient advocate I meet many people living with long-term effects that really impact their day-to-day life and I have lost too many friends whose cancer could not be cured. I'm really thrilled to be involved in this work being done in Northern Ireland - from speeding up diagnosis to improving patient care; making the most of the data we already have can help save lives."

It is anticipated that annual production of 'routes-to-diagnosis' statistics will be maintained after the end of the project. The work has been presented at the 'Advancing Analytics Workshop' held in Birmingham in November 2018, and has been accepted for presentation at the Royal Statistical Society Annual Conference due to be held in Belfast in September 2019.

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

Prof Helen Coleman
Northern Ireland Barrett's Register

The update of the Northern Ireland Barrett's oesophagus register, funded by a Cancer Research UK Career Establishment Award to Prof Helen Coleman, is continuing at a great pace thanks to the efforts of Mr Sean Morrison. Over 12,000 pathology reports have been reviewed in the first year of the grant. Work will continue for review of 2015-2018 reports over the next year. The team are also delighted to welcome Dr Victoria Cairnduff as a postdoctoral research fellow overseeing the management of the register during this grant, starting in August 2019. The update of the register will allow Prof Coleman, Dr Cairnduff and the wider study team to investigate up-to-date trends in diagnoses of Barrett's oesophagus, low and high grade dysplasia, and oesophageal adenocarcinoma in the modern treatment era, when some patients are now treated with endoscopic therapies.

Cancer Research UK International Symposium on Oesophageal Cancer, London

Several researchers who utilise Northern Ireland Barrett's Register data for their research attended this International conference held at the Royal Institute in London in April, 2019. Several posters were presented from Northern Ireland researchers, showcasing our world-leading research in this area. Pictured are Prof Helen Coleman, Dr Úna McMenamin and Dr Haydee Jordao, who are based in the Cancer Epidemiology Research Group in the Centre for Public Health.

Mr Abdul Qadr

Quantifying under-treatment in older adult lung and colorectal 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 under-treatment of older adult cancer patients. Treatment rates in older patients are much lower than in the younger. However, to demonstrate under-treatment, it is necessary to account for reasons that both contra-indicate treatment receipt and are more common in elderly patients. By linking NICR data to the 2011 census data through the Northern Ireland Longitudinal Study (NILS) (28% of NI population), the analysis will adjust for the three main surgical contraindications: stage, comorbidity and frailty.

A preliminary analysis of the NI lung patients diagnosed during 2010-14 indicated that elderly patients (≥75 years of age) of 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 2018 at the Public Health England conference: "Cancer Services, Data and Outcomes conference". A significant improvement was made to this work by incorporating radiotherapy and chemotherapy episode information which indicated that older patients received less treatment than younger patients, and that 4.5 extra deaths is expected among every 100 older patients due to under-treatment. This finding was presented at the National Cancer Research Institute in November 2018.

We have extended our work to examine the potential for surgical under-treatment in older colorectal cancer patients, by retrospectively comparing differences in stage-specific surgery rates and net survival in both young and older patients, over two time periods; 2000-2007 and 2008-2015, spanning 16 years. We discovered that the rate of curative surgery dropped by about 3% in the elderly compared to the 2.5% increase in the young. In addition, a lower increase in 2-year net survival in the elderly (5.9% vs 7.5%) compared to the young was possibly driven by the lower surgery rate, highlighting potential surgical under-treatment. This inequality was more evident in stage 4 disease patients.

These studies are 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 and NILS facilitates research that will quantify potential under-treatment, and helps shape health-care policy to benefit older cancer patients.

Dr Phillip Dunne

Molecular risk stratification in patients with T1 colorectal cancer

There are approximately 1.4 million cases of colorectal cancer (CRC) annually[1] worldwide. In Northern Ireland, this equates to approximately 1,200 cases each year (NICR data 2018). CRC risk is strongly related to age, as more than 70% of patients diagnosed with CRC are over the age of 65 years.

Reduction in CRC mortality will largely involve three approaches: prevention (reduce incidence), screening (detect earlier disease) and treatment optimisation (better response). Working in partnership with NICR, Dr Philip Dunne, Prof Helen Coleman and Dr Maurice Loughrey aim to exploit a fundamental change in CRC epidemiology, stemming from recent implementation of bowel cancer screening (BCS), as while the majority of sporadic CRC cases are diagnosed at a more advanced stage of disease, 42% of BCS-detected cancers are diagnosed at stage I (Figure 1)[2].

Dr Dunne and the team hypothesises that within early stage lesions there are so called "born-to-be-bad" tumours with highly aggressive traits, which would otherwise not be diagnosed until the metastatic stage, where 5 year survival remains below 10%, but due to BCS these asymptomatic tumours are being detected much earlier. Importantly, histological assessment of resected T1 tumour tissue is unable to reliably distinguish these aggressive lesions from the vast majority of T1 cases that are non-aggressive, therefore some patients have an unidentified risk of metastatic spread.
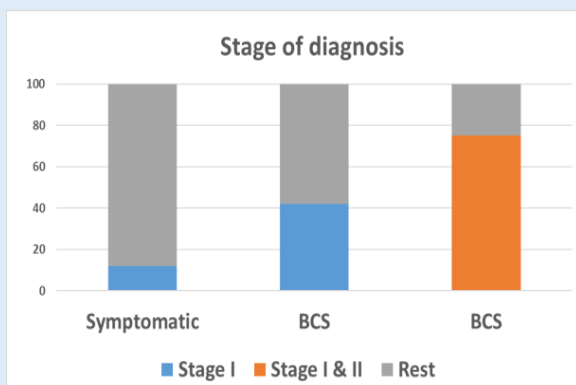
Figure 1: Bowel cancer screening (BCS) by testing for faecal occult blood is aimed at identifying people who appear healthy, but may be at increased risk of developing CRC. The results from the first 1 million cases indicates that the CRC landscape has changed, with 42% of new BCS cases being stage I compared to only 12% prior to BCS, and 75% being stage I/II. As the BCS eligibility age continues to drop (from 65 initially to potentially 50), early-stage diagnoses are expected to rise further.

The choice between local excision (LE) versus surgical resection in early-stage CRC is highly contentious and represents a major clinical issue. Current risk stratification for T1 tumours at the highest risk of having lymph node or distant metastatic spread are based on primary tumour histological features, however the positive predictive value such histological discrimination is limited, therefore some patients with T1 tumours undergo major surgery without any clinical benefit. This is particularly relevant in rectal cancer, where radical resection is associated with significant mortality (up to 6.5%) and morbidity (30–68%), including sepsis, permanent/temporary stoma and diminishing quality of life. Therefore the development of a robust molecular histology classifier to aid in surgical decision-making could be used to prioritise patients at highest risk for more extensive surgery. Conversely, non-aggressive early-stage cancers may only require limited surgery or endoscopic resection alone, with emphasis on organ-preservation in order to avoid surgical co-morbidities and reduce impact on quality-of-life.

Using molecular data (RNA and DNA profiling) generated from a new T1 CRC cohort; identified with the help of Deirdre Fitzpatrick (NICR) and retrieved via the Northern Ireland Biobank with funding from the MRC and CRUK S:CORT programme (https://www.scort.org.uk/), Dr Dunne and his team have identified potential biomarkers for these aggressive "born-to-be-bad" tumours. The team now hope to expand on their pilot data. Using the NICR services to retrieve anonymous data, Dr Dunne and the team have conducted a wider search for T1 samples in Northern Ireland with a minimum of 5 year follow-up and known clinical outcomes, with a view to future sample retrieval for molecular and histological profiling.

1. Arnold M, Sierra MS, Laversanne M, Soerjomataram I, Jemal A, Bray F. Global patterns and trends in colorectal cancer incidence and mortality. Gut. 2017;66(4):683-691. doi: 10.1596/978-1-4648-0349-9_ch2 [doi].
2. Logan RF, Patnick J, Nickerson C, et al. Outcomes of the bowel cancer screening programme (BCSP) in england after the first 1 million tests. Gut. 2012;61(10):1439-1446. doi: gutjnl-2011-300843 [pii].

Dr Andrew McGuigan

Investigation of the association between immunological biomarkers of pancreatic cancer and disease specific outcome measures

This project aims to identify features in pancreatic cancer that better determine how long patients will survive after treatment. To do this we will analyse the individual make-up of pancreatic tumours archived in the Belfast Trust laboratory. The NICR has enabled us to identify relevant patients and provide demographic and survival data essential for the project. To date, details of 281 patients have been found in the registry and I am working to update their staging information to the TNM8. The corresponding pathology numbers will be used to identify tumour tissue from the laboratory and analysis of this will begin in the next few months.

Macmillan Cancer Support

WE ARE MACMILLAN. CANCER SUPPORT

The NICR Macmillan Partnership is now in its fourth year. Over the last year, the partnership has funded work in two main areas:

1. **Emergency Admissions in the last year of life.**

In recent years there is increased interest in the place and timing of end-of-life care for cancer patients, as it is recognised that emergency hospital admissions for end-of-life cancer patients may indicate gaps in routine cancer care. This study aimed to examine the demographic, disease and environmental characteristics of people dying with cancer in 2015, and whether they had an emergency admission recorded in their last year of life. Information on people who died with cancer in 2015 were confidentially and securely linked with Patient Administration System (PAS) episodes relating to emergency admission between 1st January 2014 and 31st December 2015. The findings have shown that almost three quarters (74.2%) 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. Overall this represented 6,035 emergency admissions. Emergency admission was more common in males (75.7%) than females (72.5%; p=0.018), age groups (0-24 years 60.0%, 80 – 89 years 69.2% and over 90 years 58.9% compared with 25-39 years 80.4%,40-49 years 81.4%, 50-59 years, 83.7%, 60-69 years 80.0%, 70-79 years 74.5%, p<0.001) and tumour site. Patients with lymphoma (82.3%), mesothelioma (80.5%), myeloma, (80.0%), brain and CNS (79.8%), leukaemia, (78.5%) and lung cancer (78.0%) were more likely to have an emergency admission compared to patients diagnosed with melanoma (57.1%), connective tissue cancers (55.0%) and Non Melanoma Skin Cancer (45.7%;) (p<0.001). No statistically significant differences in emergency admission by rurality (p=0.082) or deprivation quintile (p=0.708) (based on post-code at time of death) were observed.

Preliminary findings of this work were presented at an oral session at the European Network of Cancer Registries Conference in September 2018 and as a poster at the International Association Cancer Registries conference in Peru, 13-15 November 2018.

The final report is due to be published on the NICR and Macmillan partnership website in August 2019. It is hoped that the findings of this report will inform decision-making around end-of-life care provision for people dying of cancer in Northern Ireland.

Macmillan Cancer Support *(continued)*

2.   **Breast Cancer Recurrence**

Knowledge about cancer recurrence at a population level is important for service providers, patients, researchers and clinicians aiming to increase survival and provide the best treatments possible. However, little is currently known about the number and characteristics of women who develop a recurrence of breast cancer. This work aims to develop a standardised method to document recurrences using routine cancer registration data. In the absence of internationally recognised rules for recording recurrence. A working procedure for recording breast cancer recurrence has been developed by the registry and all women diagnosed with Invasive Breast Cancer in 2009 have been followed up for recurrence until 2017. This dataset will be used to develop an algorithm to identify women with a potential recurrence from routine cancer registration data. The findings of this work to date were presented at the European-US recurrence workshop 11-12th March 2019. The workshop brought together experts in breast cancer recurrence and cancer registration from across Europe and the US to discuss issues relating to recording recurrence at a population level, including standard ways to annotate how a recurrence is detected and how it is progressing.

The findings of this work have also been presented as a poster at the European Network of Cancer Registries conference 26-28 September in Copenhagen and the IACR/NAACR joint conference in Vancouver 9th-13th June 2019.

Biobank/NICR Partnership

The Northern Ireland Biobank (NIB) is a cancer specific biobank which 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 prospective 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 clinic 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 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.

Since July 2018, the TVO team has retrieved, evaluated and recorded data on over 1300 individual cases. The majority of cases required information on relapse of breast and colorectal cancers including the date, site and mode of detection of the recurrence. These requests highlight the increasing importance of the NICR for the provision of cancer relapse data for clinical research projects. Other information requested over the year included smoking and alcohol history, tumour and treatment details for a cohort of patients diagnosed with oral Squamous Cell Cancer of the mouth and also first and second line therapies for a cohort of lymphoma patients.

CanStaging: An Online Free Cancer Staging tool

Work has commenced to upgrade the cancer staging tool. This tool was developed within the NICR in conjunction with the Union for International Cancer Control (UICC) and the International Agency for Research on Cancer (IARC). The tool is currently hosted on the QUB network and is being used by cancer registries in more than 50 countries worldwide. The tool enables the user to automatically derive a stage via manual input of tumour parameters such as tumour size, nodal involvement and metastases. It also has the facility to stage multiple tumours via a batch mode.

Currently the tool provides TNM version 7 staging for breast, colorectal, cervix, lung and prostate cancers but plans are now in place to upgrade the tool to enable staging in the new version 8 of the UICC TNM staging classification system. Furthermore, a standalone version of the tool will be provided for those registries with limited or no access to the internet. Currently the tool is accessed via the QUB network (http://nicancerstaging.qub.ac.uk/tool), however, in order to facilitate future developments, the tool will be moved to the International Association for Research on Cancer (IARC) website. Prospective users need to apply for an account to use the tool – this can currently be done by contacting NICR via email (nicr@qub.ac.uk). Future plans include enhanced language support (currently the tool has support for French, Spanish and Portuguese) and additional tumour sites. Watch this space!

Publications (June 2018-May 2019)

International and UK-wide studies

Eden M, Harrison S, Griffin M, Lambe, M, Pettersson D, <u>Gavin A</u>, Brewster DH, Lin Y, Johannesen TB, Milne RL, Farrugia H, Nishri D, King MJ, Huws DW, Warlow J, Turner D, Earle CC, Peake M, Rashbass J,. Impact of variation in cancer registration practice on observed international cancer survival differences between International Cancer Benchmarking Partnership (ICBP) jurisdictions. *Can Epidemiol 2019 Jan; 58:184-192.* www.doi.org/10.1016/j.canep.2018.10.019

Weller D, Menon U, Zalounina Falborg A, Jensen H, Barisic A, Kari Knudsen A, Bergin RJ, Brewster DH, Cairnduff V, <u>Gavin AT</u>, Grunfeld E, Harland E, Lambe M, Law RJ, Lin Y, Malmberg M, Turner D, Neal RD, White V, Harrison S, Reguilon I, ICBP Module 4 Working Group, Vedsted P,. Diagnostic routes and time intervals for patients with colorectal cancer in 10 international jurisdictions; findings from a cross-sectional study from the International Cancer Benchmarking Partnership (ICBP). *BMJ Open 2018 Nov; 27:e023870.* www.doi.org/10.1136/bmjopen-2018-023870

Ferlay J, Colombet M, Soerjomataram I, Dyba T, Randi G, Bettio M, <u>Gavin A</u>, Visser O, Bray F,. Cancer incidence and mortality patterns in Europe: Estimates for 40 countries and 25 major cancers in 2018. *Eur J Cancer 2018 Nov; 103:356-387.* www.doi.org/10.1016/j.ejca.2018.07.005

Life After Prostate Cancer Diagnosis

Wilding S, Downing A, Wright P, Selby P, Watson E, Wagland R, Donnelly DW, Hounsome L, Butcher H, Mason M, Henry A, <u>Gavin A</u>, Glaser AW,. Cancer-related symptoms, mental well-being and psychological distress in men diagnosed with prostate cancer treated with Androgen Deprivation Therapy. *Quality of Life Research 2019.* www.doi.org/10.1007/s11136-019-02212-x

Donnelly DW, <u>Gavin A</u>, Downing A, Hounsome L, Kearney T, McNair E, Allan D, Huws DW, Wright P, Selby P, Kind P, Watson E, Wagland R, Wilding S, Butcher H, Mottram R, Allen M, McSorely, Glaser AW,. Regional variations in quality of survival among men with prostate cancer across the United Kingdom. *European Urology 2019.* www.doi.org/10.1016/j.eururo.2019.04.018

Wright P, Wilding S, Watson E, Downing A, Selby P, Hounsome L, Wagland R, Brewster DH, Huws D, Butcher H, Mottram R, Kearney T, Allen M, <u>Gavin A</u>, Glaser A. Key factors associated with social distress after prostate cancer: Results from the United Kingdom Life after Prostate Cancer diagnosis study. *Cancer Epidemiol 2019 May; 60:201-207.* www.doi.org/10.1016/j.canep.2019.04.006.

Wagland R, Nayoan J, Matheson L, Rivas C, Brett J, Downing A, Wilding S, Butcher H, <u>Gavin A</u>, Glaser AW, Watson E,. 'Very difficult for an ordinary guy': Factors influencing the quality of treatment decision-making amongst men diagnosed with localised and locally advanced prostate cancer: Findings from a UK-wide mixed methods study. *Patient Educ Couns 2019 Apr; 102:797-803.* www.doi.org/10.1016/j.pec.2018.12.004.

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Downing A, Wright P, Hounsome L, Selby P, Wilding S, Watson E, Wagland R, Kind P, <u>Donnelly DW</u>, Butcher H, Catto JWF, Cross W, Mason M, Sharp L, Weller D, Velikova G, McCaughan E, Mottram R, Allen M, <u>Kearney T</u>, McSoley O, Huws D, Brewster D, McNair E, <u>Gavin A</u>, Glaser AW,. Quality of life in men living with advanced and localised prostate cancer: a UK population-wide patient-reported outcome study of 30000 men. *Lancet Oncol 2019 Mar; 20:436-47*. www.doi.org/10.1016/S1470-2045 (18)30780-0

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Publications (June 2018 - May 2019)

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Posters

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Wilding S, Watson E, Selby P, Cross W, Downing A, Wright P, Wagland R, Donnelly D, Glaser A, Gavin A., Treatment decision regret in men with early-stage prostate cancer: Findings from the UK-wide Life after Prostate Cancer Diagnosis (LAPCD) study. *International Psycho-Oncology Society (IPOS), Hong Kong (China), 2018 Oct*.

Gavin A, Cairnduff V, Dwyer L, Fox C, Burns C,. Emergency Admissions for Cancer Patients in Last year of life in Northern Ireland (NI). *IACR Conference, Peru, Nov 2018.*

Cairnduff V, Dwyer L, Lardner S, Anderson L, Burns C, Gavin A,. Investigating characteristics of women with Breast Cancer Recurrence in Northern Ireland (NI). *NIICCAR Conference, Vancouver, June 2019.*

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Watson E, Wilding S, Matheson L, Brett J, McCaughan E, Wilding A, Glaser A, Gavin A, Wagland R,. Access to and experiences of medication, devices, and support for sexual dysfunction in men with prostate cancer: findings from a UK-wide study. *NCRI Conference, Glasgow, Nov 2019*

Brett J, Butcher H, Keenan J, Catton D, Davey Z, Matley F, Watson E, Wright P, Glaser A, Gavin A,. Evaluating the impact of patient and public involvement (PPI) in the Life After Prostate Cancer Diagnosis (LAPCD) Study. *NCRI Conference, Glasgow, Nov 2019*

Conferences

National Disease Registration Training Event

Four TVOs and the Clinical Advisor from the NICR attended the National Disease Registration - Training Event hosted by Public Health England at Heathrow, England on 13th and 14th March 2019.

The event covered the changes in the TNM Classification of Malignant Tumours due to 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. This event also had a session on haematological malignancies and cancer registration presented by Professor David Bowen.

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.

NAACR/IACR annual combined meeting

Dr Lesley Anderson presented "Using Cancer Registry Infrastructure and Linkage to Biobank Facilities to Investigate the Role of Infectious Agents in the Progression from Oesophageal Premalignancy to Cancer" at a combined annual meeting of the North American Association of Cancer Registries and the International Association of Cancer Registries in Vancouver, British Colombia, Canada in June 2019. The conference enabled networking with cancer registry colleagues from across the world.

Conferences

Registry staff gave oral and poster presentations of their work at the bi-annual Scientific Meeting and General Assembly of the European Network of Cancer Registries (ENCR) which took place in Copenhagen, Denmark from the 26th to 28th of September 2018. The conference aimed to bring together European Cancer Registries to share research findings, exchange ideas and best practices and discuss cancer registration issues within their own country. The Conference was co-hosted by the Danish Cancer Society, the ENCR and the European Commission's Joint Research Centre (JRC). The focus of the meeting was data linkage and cancer registries, and was attended by researchers, epidemiologists and clinicians over the three day conference.

Oral presentations of research from NICR/CPH included:

- Hairy Cell Leukaemia: Incidence, prevalence and survival in Europe, findings from RARECARE.NET by Dr Charlene M. McShane.
- Emergency admissions for cancer patients in last year of life in Northern Ireland by Dr Victoria Cairnduff.
- The challenges, methods and benefits of implementing ISO27001:2013 in the NICR by Mr Ronan Campbell.

Data linkage and cancer registries

ENCR Scientific Meeting and General Assembly

26-28 September 2018 · Copenhagen · Denmark

Staff News

New Staff - Welcome

Ashley Levickas (TVO)

Ashley joined the Registry as a Tumour Verification Officer in December 2018 to work on the Macmillan project.

Paul Frew (IT System Analyst)

Paul joined the Registry in June 2019. He will be working on the redevelopment of the Cancer Registration system.

Farewell

Dr Eileen Morgan (Statistician)

Eileen achieved a post at the International Association for Research on Cancer after a three month secondment, working on the International Cancer Benchmarking Partnership results.

We would like to wish Eileen every success in her new role in Lyon.

Dr Victoria Cairnduff (Macmillan Researcher)

Victoria has worked as the Macmillan funded statistician with the NICR for almost four years. She is moving to work within the Centre for Public Health on the Barrett's Register as a post doctoral research fellow.
We wish Victoria every success in her new role.

Staff News

Summer Student

Mr Kenneth Yeung

Kenneth is a 2nd Year Student studying Biomedical Science at QUB. During his 8 weeks with the NICR he will be working to identify the changes in staging from TNM7 to TNM8. This work will be used to update the Cancer Staging Tool in the plan to have this available offline to Cancer Registries internationally.
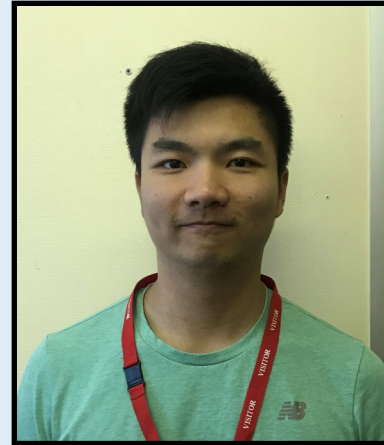
Congratulations!

Congratulations to Dr Helen Coleman who will be promoted to Professor of Cancer Epidemiology in August 2019. With her new baby girl Erin born 19th July, Helen is having an exciting year! Congratulations from all in the Registry.

The Registry also wish to congratulate our colleague Brid Morris-Canter and her husband Phillip on the birth of their son Jamie.

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