





Northern Ireland Cancer Registry Newsletter

Volume 23: August 2017



The NICR is delighted to announce that after many months of planning, training and information sessions the Registry has been accredited with the ISO27001 Certification in Information Security Management. ISO27001 is an internationally accredited and recognised standard that looks at how security of the information assets within the Registry is managed and implemented. These controls, which take the form of policies, procedures, technical and logical provisions, are externally audited by an accredited organisation to

ensure that the procedures we have put in place meet the standard required and that we are observing these policies and procedures in our day to day operations. As we had been complying with best practice to the greater extent there was generally a positive attitude toward any changes and it was felt that the standard simplified the protocols rather than causing any undue stress or additional work. By now the system is well embedded and in June we received our certification. The certification lasts initially for three years and is continually monitored and audited both internally and externally by the certification body. As far as we can tell we are the first Cancer Registry in Ireland and the UK to have achieved this certification, and we consider this a great achievement for our staff, in addition to assuring our stakeholders and data providers that we are keeping-up with industry standards in the security of the sensitive data under our protection.

Contents

Page 1: ISO27001

Page 2: Official Statistics

Page 3: Quality and performance indicators

Ongoing Research

Page 4: Life after Prostate Cancer Diagnosis

Page 5: An Evaluation of the Lung and Breast Cancer Awareness Campaign in Northern Ireland

Page 6: Research Study Using Anonymised Northern Ireland Cancer Registry Data to Determine the Effects of Commonly Prescribed Beta-Blockers on Cancer Survival

Page 6: Do Commonly Prescribed Medications Improve Cancer

Page 7: MGUS Registry (Monoclonal gammopathy of undetermined significance)

Page 8: Infectious Agents in Progression from Barrett's Oesophagus to Oesophageal Adenocarcinoma, a Nested Case Control study within the Northern Ireland Barrett's Register

Page 8: Surgical Under-Treatment of Older Adult Cancer Patients

Page 9: Macmillan Cancer Support

Page 10: CaPPS Study

Page 11: Lung Cancer Audit

Page 12: Head and Neck Cancer Audit

Page 13: IT Update, CanStaging Tool

Page 15: Recent Publications

Page 18: Erasmus Student

Page 19: Staff News

Official Statistics

On Tuesday 7 March 2017 the N. Ireland Cancer Registry published the latest official statistics on cancer incidence, survival and prevalence in N. Ireland up to the year ending December 2015. (http://www.qub.ac.uk/research-centres/nicr/CancerInformation/official-statistics/). Alongside the release of the official statistics, we have produced a suite of fact sheets for a number of cancer sites, as well as a summary factsheet for all cancers (excluding non-melanoma skin cancer), to provide some explanation and context for some key cancer statistics. We now provide summary statistics for different cancer sites by geographical location to improve the accessibility of the data with cancer site statistics located in the one centralised location: https://www.qub.ac.uk/research-centres/nicr/CancerInformation/official-statistics/ByGeography/.

Key Findings

Over the last ten years the number of cancer cases has increased from 3,786 among men and 3,681 among women in 2006 to 4,650 among men and 4,606 among women in 2015 (excluding 3,641 cases of Non-melanoma skin cancer). This increase is largely due to an increasing number of older people in the population as the incidence of cancer increases with age. There are currently 58,586 people living in Northern Ireland with a cancer diagnosis as of December 2015.

Survival rates are improving in recent years:

54% of all cancer patients, diagnosed between **2005-2009**, survived five years after diagnosis compared to **42%** survival for patients diagnosed 1993-1999.



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 assurance 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, Northern Ireland (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 2015 (more than 17,000 tumours in N. Ireland, 632,493 in UK & Republic of Ireland), which included all cancers, in-situ tumours and tumours of uncertain behaviour, as well as benign tumours of the brain, other parts of the central nervous system and teratoma of testis.

This UKIACR PI data demonstrated a continued trend of improvements in data completeness and quality. The indicators demonstrate that cancer incidence continues to increase year on year for the majority of cancer types, in particular large increases were seen in head and neck cancer, malignant melanoma and breast in-situ. Death certificate only (DCO) rates are below the 2% target for the UK and Ireland overall, and in particular for NI (DCO 0.5%). Across each of the jurisdictions improvements can be seen in terms of the completeness of grade of differentiation and stage at diagnosis, with NI having the highest level for each at 61% and 82% respectively.

The quality and timeliness of data held by cancer registries in the UK and Ireland continues to improve with areas highlighted for action for particular cancer registries to improve data completeness. There were no areas targeted for action for the Northern Ireland Cancer Registry (NICR). These excellent results for NICR reflect the huge effort staff make to ensure that the information collected is accurate and as complete as possible.

The detail of latest Performance Indicators for NICR may be found at:

http://www.qub.ac.uk/research-centres/nicr/CancerInformation/data-quality/

Ongoing Research

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



LAPCD project team, pictured at their recent meeting in Belfast: Senior research staff from Oxford Brookes, University of Southampton, University of Leeds, Public Health England, Prostate Cancer UK, Welsh Cancer Intelligence and Surveillance Unit, Scottish Information Services Division and the Northern Ireland Cancer Registry worked with the Project's User Advisory Group, chaired by Mr Hugh Butcher with Mr John Keenan as a local representative and the Clinical & Scientific Advisory Group Chaired by Prof Peter Selby.

Prostate cancer is the most common cancer in men in the United Kingdom, however, treatments can impact on the men's quality of life and also the quality of life of their partners/ spouses. This project aims to find out what effect prostate cancer has on men's physical, emotional and social wellbeing, as well as exploring the impact on their families. The combined results should lead to a detailed picture of what life is like for men with prostate cancer across the UK. Information will be gained on how circumstances can change over time, what helps the men cope with any problems and what gaps there are in support and care services.

The multi-centre study is being led by Prof Adam Glaser, University of Leeds and Dr Anna Gavin, N. Ireland Cancer Registry. Men living in Northern Ireland who were diagnosed with prostate cancer between 1st December 2012 and 31st November 2014 were surveyed in June and July last year. They were asked about a range of general cancer specific and prostate cancer specific outcome measures. The topics covered included urinary and bowel functioning, sexual functioning, psychological and social well-being as well as physical social and financial concerns.

The men who responded to this survey are being resurveyed in July and August 2017 to compare their answers and see if their symptom or concerns have changed.

Men in England, Scotland and Wales were surveyed last year with responders also surveyed again this year. A further second group of men living in England diagnosed between 1st November 2014 and 31st October 2015 will be surveyed this year. This separate group can be used to monitor changes to treatment and services over time and to test online survey acceptance.

Towards the end of 2016, a survey similar to the one sent to men diagnosed with prostate cancer, was posted to men in Northern Ireland without prostate cancer. These individuals were aged matched within a 5 year band, to those on the LAPCD. This general population study should allow for the hypothesis testing that significant differences in health outcomes in prostate cancer patients exist when compared to the general population.

To date we have had responses from 35,823 men with prostate cancer (England, Scotland, Wales and Northern Ireland) and 2,955 men without prostate cancer; analysis is ongoing with results expected later in the year.

An Evaluation of the Lung and Breast Cancer Awareness campaign in Northern Ireland

Niamh McKeating (supervised by Dr Finian Bannon) is a medical student at Queen's University Belfast completing an intercalated Masters of Public Health. This project, within the NICR using anonymised data, will inform Niamh's dissertation.

In 2015 the Public Health Agency (PHA) organised a cancer awareness campaign focusing on breast and lung cancer in Northern Ireland. These campaigns aimed to increase awareness of cancer symptoms and encourage the public to present to their GP. The lung campaign focused on cough as a key symptom of lung cancer. The breast campaign focused on skin and nipple changes. These campaigns, were based on research and used multiple media outputs including television, radio, newspapers, posters and magazines.

Using data from the NICR, this project aims to determine whether awareness of these symptoms led to more people presenting with earlier stage disease which could lead to improved 1 year survival. One year survival and stage distribution of breast and lung cancer cases during the selected campaign impact period will be compared with the same calendar months in previous years. The project will also investigate trends in levels of breast and lung cancer by month over recent years to identify any changes in incidence around the campaign periods. The project will design a template impact model to estimate the proportion of the population who could benefit from these campaigns. This work can be used to inform the development of future PHA cancer awareness campaigns. Results will be presented to the PHA in Autumn 2017.

Research Study Using Anonymised Northern Ireland Cancer Registry Data to Determine the Effects of Commonly Prescribed Beta-Blockers on Cancer Survival



Findings from experimental and observational studies have suggested beneficial effects of beta-blockers (cardiovascular medications commonly prescribed to treat angina, arrhythmia, high blood pressure, heart failure, recurrent heart attack, glaucoma and anxiety) on cancer survival via inhibition of the beta-adrenergic signalling pathway.

Dr Michael O'Rorke, supported through a Cancer Research UK (CRUK) population research committee postdoctoral fellowship [A16601], is examining whether incidental use of beta-blockers following a breast cancer diagnosis impacts on cancer survival. Michael's study includes a sample of over 1,200 women diagnosed with breast cancer in Northern Ireland between 2009 and 2013, and involves the anonymised linkage of clinical data from the Northern Ireland Cancer Registry (NICR) and beta-blocker drug use from the Northern Ireland Enhanced Prescribing Database (NIEPD). Uniquely, Michael has linked this data to archived diagnostic breast cancer tissue from the five Health and Social Care Trusts across Northern Ireland. This has enabled the examination of beta-adrenergic receptor expression (a protein on the surface of the patient's tumour on which beta-blocker drugs interact). Ultimately, this study will help determine whether beta-blockers would be useful additions to the standard treatments for breast cancer patients and highlight tumour characteristics likely associated with poorer prognosis.

Research: 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 Mc Menamin, Dr Andrew Kunzmann and Dr John Busby, 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 within the secure Honest Broker Service, this information was combined with population-wide data on prescriptions from the Northern Ireland Enhanced Prescribing Database (NIEPD). Analysis of this data is currently ongoing and results will be disseminated through publication in relevant medical journals and presentation at conferences both locally and nationally. 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.

MGUS Registry (Monoclonal Gammopathy of Unknown Significance)

Dr Charlene McShane, a Cancer Research UK Population Science Postdoctoral Fellow at the Centre for Public Health, QUB is currently undertaking a three-month research placement at the National Cancer Institute, Washington DC, USA. For the last two years, Charlene has worked with staff within the Northern Ireland Cancer Registry to establish a confidential population-based register of a premalignant blood disorder called monoclonal gammopathy of undetermined significance (MGUS). This blood disorder commonly precedes multiple myeloma, a blood cancer. While at the National Cancer Institute, Charlene is working with Dr Ruth Pfeiffer, a world leading expert in risk prediction models. Upon her return to Northern Ireland, Charlene will use her newly acquired skills to develop a risk prediction model for MGUS progression to cancer using the data housed within the Northern Ireland MGUS register. Charlene's visit to the USA was supported by a Cancer Research UK Research Travel Award.



Infectious Agents in Progression from Barrett's Oesophagus to Oesophageal Adenocarcinoma, a Nested Case Control Study within the Northern Ireland Barrett's Register



Dr Andrew Kuntzmann is currently using anonymised linked data from the NI Barrett's oesophagus register and N. Ireland Cancer Registry to identify Barrett's oesophagus patients who progressed to oesophageal adenocarcinoma (cases) and matched controls with Barrett's oesophagus who did not progress to oesophageal adenocarcinoma. As part of the work, the team have requested tissue samples to assess whether the presence of viral agents in

Barrett's tissue is linked with risk of progression to oesophageal adenocarcinoma.

Surgical Under-Treatment of Older Adult Cancer Patients

Mr Abdul Qadr (PhD student) and Dr Finian Bannon (Medical Statistic Lecturer) from the Center for Public Health at Queen's University Belfast are investigating surgical under-treatment of older adult cancer patients. Patients over 70 should have a comprehensive geriatric assessment to ensure that objective measure of life expectancy, and not age per se, is informing clinical decisions (International Society Geriatric Oncology guidelines), yet the surgical rates in elderly patients are much lower than in the younger. To demonstrate under-treatment, it is necessary to account for reasons that both contra-indicate surgery and are more common in elderly patients. By securely linking Northern Ireland Cancer Registry (NICR) data to the Northern Ireland Longitudinal Study (NILS) census database (28% of NI population), the analysis will adjust for the three main surgical contraindications: stage, comorbidity and frailty.

From NICR, 1,700 breast, 1,500 lung, and 1,500 colorectal cancer patients will be confidentially linked to the NILS data. The NICR dataset will bring patients' tumour stage, treatment modality, and comorbidity information. The NILS dataset will assist with self-report health information on frailty (e.g. Q22, 2011 Census) and comorbidity (Q23, 2011 Census), ethnicity, and socio-economic factors.

The study is important because with longer life expectancy, more elderly patients are presenting with cancer, and there is evidence that they may not receive treatment in accordance with guidelines. The number of people over 65 is projected to increase by 40% in NI, between 2010 and 2025.

The linkage of data from NICR and NILS will facilitate research that will quantify potential under-treatment, and shape health care policy to benefit elderly cancer patients.

Macmillan Cancer Support



The N. Ireland Cancer Registry has established a formal collaboration with Macmillan Cancer Support which funds a programme of work covering three main areas :

1. Transforming Cancer Follow Up (TCFU)

This initiative was introduced firstly for breast cancer services across NI to deliver more effective follow-up. It not only aimed to improve the patient experience by addressing broader health and well-being issues, but aimed to make more effective use of resources. Historically patients were routinely reviewed for years, often by both surgeons and oncologists. Growing numbers of patients presenting and remaining in the system had resulted in significant delays in follow up appointment times. To address this, additional clinics were frequently commissioned (e.g. 65 in one year) at additional cost.

TCFU provided the opportunity to redesign systems and processes to make them more effective. A risk stratified approach to follow up was introduced, with over 61% of patients now allocated to self-directed aftercare pathways. This has released thousands of appointments according to an evaluation undertaken by Price Waterhouse Cooper, allowing clinicians to spend more time with more complex patients, such as those with recurrence and new patients, while also coping with the increased number of breast cancer referrals.

Duplication of appointments between surgery and oncology being also reduced by 45%. Annual review mammograms have been decoupled from out patient clinic appointments by being booked in advance, which has reduced the number of times patients attend hospital. In addition, mammograms are now delivered on time and the results communicated quickly to the patient and their GP. This process has been shown to reduce anxiety experienced by patients as they receive their results quicker than the traditional pathway.

To address the impact of cancer and its treatment on the person, breast care nurses now undertake holistic assessment of patient needs, providing them with relevant information including signposting them to support services in the community, and teaching them breast self-examination. A rapid access process has been set up should patients need to get back into the system. This risk stratified approach to follow up is now being rolled out and adapted across Northern Ireland for other cancer sites.

2. GP Federations

Nineteen Federations covering all GP practices in Northern Ireland have been formed. Information on cancer incidence, mortality and prevalence by cancer type has been analysed for each Federation as part of this Macmillan funded work.

Macmillan Cancer Support

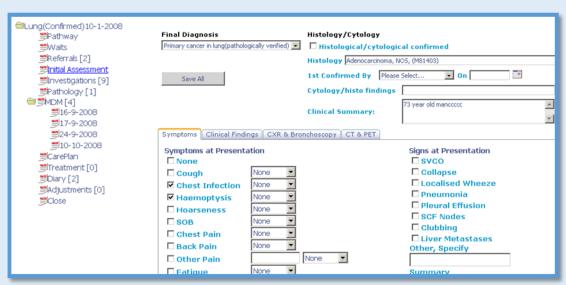
(continued)

3. Cancer Recurrence

This work aims to develop a standardised method to document recurrences. Work on documenting recurrences of breast, colorectal and ovarian cancer has begun with follow up to 2017.

CaPPS Study

The Cancer Patient Pathway System (CaPPS) was implemented in 2009 to facilitate Multi-Disciplinary Meetings (MDMs). It is a region wide system for Northern Ireland and it monitors Cancer Waiting Times (CWTs), facilitates audit, and aids communication between members of the MDM and primary care. It is also a valuable data source for cancer registration. This picture below shows an example of clinical and diagnostic data which can be entered into the system. The data entry fields are cancer site specific.



Cancer incidence has increased by 10.9% since 2009, however, possibly linked to increased workload, data entry in key CaPPS clinical fields has been falling. The NICR undertook an audit to quantify CaPPS data entry reporting back to clinicians.

The NICR has also adapted site specific factsheets containing 2015 Official Statistics with addition information on clinical data entry into CaPPS. These have been prepared and distributed to the following Clinical Reference Groups: Thyroid, Head & Neck, Upper GI & Hepatobiliary, Colorectal, Sarcoma, Urology and Skin.

The Factsheets to date have been well received and have proved useful in helping decisions regarding feasibility to enter clinical trials, specialist MDM requirements and time resource allocations, while also helping to provide background and context to business cases.

Of note, their Head & Neck Cancer Team have recorded an increase in clinical data entry since the feedback began, with key fields such as Performance Status increasing from a zero base to 85%. Another issue that has been identified is a need for further education regarding the CaPPS system for all MDM members as not all clinicians are aware of the abilities of CaPPS or the fields that are available.

There are now plans to update the CaPPS system to better aid data entry, to ensure clinical relevance and to capture recurrence data.

Lung Cancer Audit

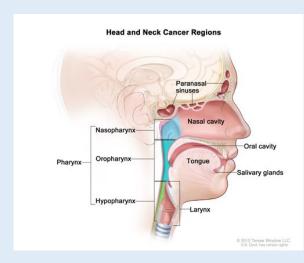
This Lung Cancer audit compared data from NI patients with the UK National Lung cancer Audit (NCLA). Lung cancer is a devastating disease with poor overall survival and the number of lung cancer cases continues to increase in Northern Ireland. In 2014, 1,226 patients had a lung cancer diagnosis, a 37% increase from 2006 lung cancer registrations. The increase was three times greater for women (78%) than men (25%).

However, despite the increase in numbers, lung cancer services here have demonstrated marked improvements over time and these have been accompanied by improvements in survival. The disease is more common in deprived populations linked to the levels of tobacco use.

Recommendations include focusing on smoking prevention and promotion of earlier presentation.

The report with all its findings will be formally launched on 15th September 2017.

Head and Neck Cancer Audit



As part of an academic foundation programme placement Dr Conor McKenna undertook an audit of head and neck cancer in Northern Ireland, Using anonymised Northern Ireland Cancer Registry data the incidence, prevalence, survival and mortality trends from 1993-2013 for the three main sites of head and neck cancer in Northern Ireland; larynx, oral cavity and oropharynx cancer were examined. There was a decrease in the incidence rate of larynx cancer for men but not for women between

1993 and 2013. There has been a statistically significant increase in incidence rate of oropharynx cancer for both men and women between 1993 and 2013. Head and neck cancer is more common in areas of deprivation.

From 2009-2013 there were on average 22 male and 11 female deaths from oral cavity cancer, 7 male and 5 female deaths from oropharynx cancer and 19 male and 5 female deaths from larynx cancer each year. At the end of 2013 there were 671 people living in Northern Ireland who had been diagnosed with larynx cancer, 513 people with oral cavity cancer and 319 with oropharynx cancer diagnosed since 1993.

This study also examined presentation, referral and management of head and neck cancers diagnosed in 2013. Understanding the local epidemiology and management of these cancers will help inform local head and neck cancer public health strategies and resource planning for head and neck cancer services in the future. Work from this audit has been presented at the Irish Otolaryngological Society, British Association for Head and Neck Oncology and the European Network of Cancer Registries.

N. Ireland Cancer Registry Cancer Registration System

The IT system which underpins the cancer registration process in N. Ireland, before a recent upgrade, was running on an unsupported platform. After a period of testing the new version of the system, Praxis went live on 27th April 2017. The system now operates on modern hardware employing the latest version of the database management system on which the cancer registration application was developed. In addition, the system is running in a modern virtual server environment for improved business continuity. The upgrade will enable further development and expansion of the system, previously not possible with the older version.

Cancer registries are being tasked with collecting a more detailed and sophisticated dataset. Therefore, future plans for the system include enhancing the user interface, expanding the data dictionary and adding in new functionality to enable the use of new coding classifications.

CanStaging:

An Online Free Cancer Staging tool

The tool is a collaboration between NICR, the Global Initiative for Cancer Registry Development and the Union for International Cancer Control (UICC) TNM Core Group, supported by International Agency for Research on Cancer (IARC). The online tool currently has over 60 subscribed users in more than 50 countries worldwide and provides an automated facility for the staging of cancers based on a number of clinical inputs relating to the tumour, such as tumour size and nodal status. Following consultations with users the tool has expanded to include translations into Spanish, Portuguese and French. With further languages due to be added in the future, including German, Azerbaijani and Chinese.

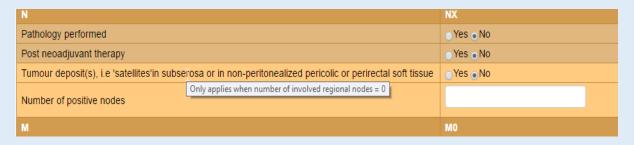
(continued over)

Significant improvements in access speeds have also been made. Other enhancements include the addition of functionality to add prefixes to the TNM stage values and a help facility in the form of 'Tooltips'. Currently the tool supports the staging of breast, cervix, colorectal, lung and prostate cancers but it is hoped that more sites will be added over time.

Correspondence and applications for access should be directed to nicr@qub.ac.uk or alternatively c.fox@qub.ac.uk. The free tool can be accessed via the following webpage which also has the application form: http://go.qub.ac.uk/CanStaging



Main Screen



Example of 'ToolTips'

Publications (1st April 2016-30th July 2017)

Bannon F, Cairnduff C, Fitzpatrick D, Blaney J, Gomes B, Gavin, A, Donnelly, C. Insights into the factors associated with achieving the preference of home death in terminal cancer: a national population-based study. *Palliative & Supportive Care*, 2017. *in press*

Donnelly C, Cairnduff V, Chen JJ, Kearney T, Fitzpatrick D, Fox C, Gavin A. The completeness and timeliness of cancer registration and the implications for measuring cancer burden. *Cancer Epidemiology* 2017;49: 101-107 doi: 10.1016/j.canep.2017.05.007

Coyle C, Morgan E, Drummond FJ, Sharp L, Gavin A. Do Men Regret Prostate Biopsy: An observational study. Results from the PiCTure Study Decisional Regret following Prostate Biopsy. *BMC Urology* 2017 17:11.doi: 10.1186/s12894 -016-0194-y

Roulston A, Campbell A, Cairnduff V, Fitzpatrick D, Donnelly C, Gavin A. Bereavement outcomes: a quantitative survey identifying risk factors in family carers bereaved through cancer. *Palliative Medicine* 2017;31(2);162-170 doi: 10.1177/0269216316649127.

Downing A, Wright P, Wagland R, Watson E, Kearney T, Motttram R, Allen M *et al.* Life after prostate cancer diagnosis –protocol for a UK wide patient reported outcomes study. *BMJ Open* 2016 6:e013555.doi:10.1136/bmjopen-2016-013555.

Steentjes L, Siesling S, Drummond FJ, van Manen JG, Sharp L, Gavin A. Factors associated with current and severe physical side-effects after prostate cancer treatment: What men report. *European Journal of Cancer Care* 2016, 1-13 doi: 10.1111/ecc.12589.

Donnelly DW, Gavin AT. Mortality Among Children And Young People Who Survive Cancer In Northern Ireland. *Ulster Med J* 2016;85(3):158-163.

Cardwell CR, Pottegård A, Vaes E, Garmo H, Murray LJ, Brown C, Vissers PAJ, O'Rorke M, Visvanathan K, Cronin-Fenton D, De Schutter H, Lambe M, Powe DG, van Herk-Sukel MPP, Gavin A, Friis S, Sharp L, Bennett K. Propranolol and survival from breast cancer: A pooled analysis of European breast cancer cohorts. *Breast Cancer Res.* 2016; 18: 119. doi: 10.1186/s13058-016-0782-5.

Publications (1st April 2016-30th July 2017)

Gavin AT, Donnelly D, Donnelly C, Drummond FJ, Morgan E, Gormley GJ, Sharp L. Effect of more intense investigation and treatment of prostate cancer on survivor's physical symptoms, psychological wellbeing and health related quality of life: a two country observational study. *BMJ Open.* 2016; 6(12): e012952. Doi: 10.1136/bmjopen-2016-012952

Sharp L, O'Leary E, Kinnear H, Gavin A, Drummond FJ. Cancer-related symptoms predict psychological wellbeing among prostate cancer survivors: results from the PiCTure study. *Psycho-Oncology*. 2016 Mar;25(3):282-91. doi: 10.1002/pon.3909. Epub 2015 Aug 6.

Drummond FJ, O'Leary E, Gavin A, Kinnear H, Sharp L. Mode of prostate cancer detection is associated with the psychological wellbeing of survivors. Results from the PiCTure study. *Support Care Cancer*. 2016;24(5):2297-307. doi: 10.1007/s00520-015-3033-x..

Donnelly CB, Wotherspoon AC, Morris M, Wilson RH, Chen JJ, Cairnduff V, Morgan E, Devlin A, Gavin AT. A population-level investigation of cancer clinical trials participation in a UK region. Accepted by European Journal of Public Health May 2017. doi: 10.1097/CEJ.000000000000373.

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* 2016;88(7):1262-1270. doi: 10.1002/jmv.24447

Lawler M, Gavin A, Salto-Tellez M, Kennedy RD, Van Schaeybroeck 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* 2016;122(5):664-673; doi: 10.1002/cncr.29814.

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* 2016;26(1):29-35 doi: http://dx.doi.org/10.1093/eurpub/ckv112 ckv112 First published online: 16 June 2015 (IF 2.591)

Publications (1st April 2016-30th July 2017)

Rivas C, Matheson L, Nayoan J, Glaser A, Gavin A, Wright P, Wagland R, Watson E. Ethnicity and the prostate cancer experience: a qualitative metasynthesis. *Psychooncology*. 2016;25(10):1147-1156. doi: 10.1002/pon.4222.

Ahmed K, Kyte D, Keeley T, Efficace F, Armes J, Brown JM, Calman L, Copland C, Gavin A, Glaser A, Greenfield DM, Lanceley A, Taylor R, Velikova G, Brundage M, Mercieca-Bebber R, King MT, Calvert M. A Systematic Evaluation of Patient-Reported Outcome (PRO) Protocol Content and Reporting in UK Cancer Clinical Trials: the EPiC Study Protocol" *BMJ Open* 2016;6:e012863 doi:10.1136/bmjopen-2016-012863

Napolitano G, Marshall A, Hamilton P, Gavin AT. Machine learning classification of surgical pathology reports and chunk recognition for information extraction noise reduction. *Artif Intell Med.* 2016;70:77-83. doi: 10.1016/j.artmed.2016.06.001.

Gnanapragasam VJ, Lophatananon A, Wright KA, Muir KR, Gavin A, Greenberg DC. Improving clinical risk stratification at diagnosis in primary prostate cancer: a prognostic modelling study. *PLoS Med.* 2016;2;13(8):e1002063. doi: 10.1371/journal.pmed.1002063. eCollection 2016.

Weller D, Vedsted P, Zalounina, A, Fourkala E, Desai R, Liston W, Jensen H, Barisic A, Gavin A, Grunfeld E, Lambe M, Law RJ, Malmberg M, Neal R, Kalsi, J, Turner D, White V, Bomb M, Menon U,m ICBP Working Group. An investigation of routes to cancer diagnosis in ten international jurisdictions, as part of the International Cancer Benchmarking Partnership; survey development and implementation. *BMJ Open* 2016;6:e009641 doi:10.1136/bmjopen-2015-

Erasmus Student

Mid February 2017 I started with a four month internship at the N. Ireland Cancer Registry. The internship was part of my Master's Thesis from the university of Twente in The Netherlands. My project was about the difference between men diagnosed with prostate cancer by symptoms or by PSA testing. This project was part of the big 'Life After Prostate Cancer Diagnosis' study that is UK wide. I mainly worked with Dr Anna Gavin and Dr Therese Kearney. It was really interesting to work with all researchers at the Registry and from the other nations, and to have Skype meetings with my Dutch supervisors, Prof Sabine Siesling and Dr Jeannette van Manen. During my stay in Belfast I have learned a lot about research; I have learned to analyse data with SPSS and how to write a scientific article, which was not as easy as I thought it would be.

The university funding of my own university gave me the chance to attend the Cancer Data and Outcomes conference in Manchester on the 13th and 14th of June. I really enjoyed this conference, because the talks were really interesting and it was interesting to see what kind of cancer research is performed in the United Kingdom.

I fully enjoyed my stay in Belfast. The Northern Irish people are very friendly.

Although I was only in Belfast for four months, I felt part of the team at the N. Ireland Cancer Registry. I really enjoyed the tea and lunches breaks and I am definitely going to miss those. I also enjoyed the trips I have made in Ireland, which is very beautiful. I have done a lot during my stay, such as I went to Dublin, the Carrick a reed rope bridge, the Giants Cause way, different castles, and walked to the top of Cavehill, which

to those of us from the Netherlands is like a mountain! I also went to different pubs and liked the live-music. I really enjoyed doing my internship at the N. Ireland Cancer Registry, and as a result, I'm coming back later this year to work at the Registry for several months. I'm looking forward to see everyone again!

Linda

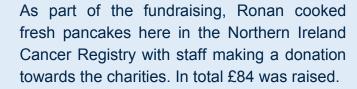
Staff News





Fundraising

Ronan Campbell (IT department) is captain of the Mayobridge Golf Club. This year the club are raising funds for number of local Autism charities (Autism Families, HAND [Help with Autism in Newry and District] and Autism NI), as well as the local Newry and District Gateway club.









European Network of Cancer Registries Conference 2016

Registry staff presented posters and delivered presentations of their work at the biennial conference of the European Network Cancer Registries which took place in Baveno, Italy from the 5th to 7th October 2016. The conference aims to bring together European Cancer Registries so they can share research findings, exchange ideas and best practices and discuss cancer registration issues within their own country. In total, 170 European Cancer Registry representatives, as well as researchers, epidemiologists and clinicians attended the 3-day conference. Delegates were able to view 50 posters, attend 36 oral presentations and enjoyed keynote speeches from Mr Roberto Zanetti, International Association of Cancer Registries; Francesco de Lorenzo, Federation of Cancer Patients Organisations, and Kathy Pritchard-Jones, University College London.

Research presented from N. Ireland Cancer Registry included:

Dr Victoria Carnduff - "Dying with Cancer: perspectives of bereaved friends and relatives" AND "Investigating the Characteristics of Breast Cancer Patients Assigned to Self-directed Aftercare Programme

Dr Eileen Morgan - "Physical After Effects Reported by Men Undergoing Prostate Biopsy. Results from an All-Ireland Study"



NICR Staff (left to right), Ms Sinead Lardner, Dr Victoria Carnduff, Dr Eileen Morgan, Dr Anna Gavin and Mr Colin Fox

Staff News

European Network of Cancer Registries - Joint
Research Centre Training Event on Data Collection &
Comparability, 2017

On 3rd & 4th May 2017, Deirdre Fitzpatrick, Jacqui Napier & Jackie Kelly attended the European Network of Cancer Registries - Joint Research Centre training event on Data Collection and Comparability in Ispra, Italy. Over 50 people attended the event chaired by Harry Comber. The purpose of the course was to bring together registry staff from across Europe to discuss and share cancer registration experience in order to obtain and produce high quality



data. The event was a great opportunity to network with peers, whilst gaining invaluable experience through discussion and practical group work

6th National Cancer Registration and Analysis Service Annual Training Event

On 16th & 17th March 2017 nine Registry staff attended the 6th National Cancer Registration and Analysis Service Annual Training Event at Warwick University, England. The two day event was a mixture of formal presentations and discussion sessions, covering topics such as coding issues, registration practices and data analysis & quality assurance.

These training events ensure all staff are kept up to date with changes that effect the way they interpret and record information from the many clinical data sources. This year data analysts were invited to the event for the first time and found the experience useful in expanding their understanding of extracting, working with data



outputs, in addition to enhancing their knowledge base within their respective fields.

Theme of the Conference Dinner was St Patrick's Day. NICR Staff from left to right Jackie Kelly, Marsha Magee, Jacqui Napier, Deirdre Fitzpatrick, Brid Morris, Clare Marks, Victoria Cairnduff, Gerard Savage and Sinéad Lardner.

Farewell



Susan McGookin (Senior Administration officer and PA for the Director) left the Northern Ireland Cancer Registry in April 2017. Susan had worked in the NICR for 14 years and throughout her time here was a very valued member of staff. Susan has taken up a new post in the Northern Ireland Hospice. We wish her every success.

Rosemary Ward (*Tumour verification officer*) retired from the Cancer Registry in November 2016. Rosemary had worked at the NICR for almost 20 years. She is now relaxing, travelling and spending time with her grandchildren. We wish her a long and very happy retirement.





Dr Oonagh McSorley (*Research Fellow*) worked in the Northern Ireland Cancer Registry on the Life After Prostate Cancer Diagnosis Project from March 2016 to March 2017. Oonagh is a now a lecturer in the School of Nursing and Midwifery. We congratulate Oonagh on her new post and wish her every success.

Dr Conan Donnelly (*Statistician*) worked in the NICR for just over 7 years and contributed greatly to various research projects. Conan was awarded his PhD in December 2016. Conan left the Cancer Registry in March 2017 to take up a senior statistician post at Exploristics. We wish him every success.



New Staff



Welcome to Professor Ken Mills as Chair of the N. Ireland Cancer Registry Steering Committee. He replaces Dr David Stewart who recently retired. Professor Ken Mills is Chair of Experimental Haematology at Queen's University Belfast since 2007 having previously worked at Cardiff and Glasgow University. He is a Fellow of the Royal College of Pathologists and a HCPC registered clinical scientist. His research interests are focused on all aspects of blood cancers and has published over 160 peer-reviewed articles. Prof Mills has been a member of the Steering Group for the Cancer Registry since 2010 and said "I am very pleased to have been appointed Chair of the Steering Group and I wish to pay credit to the Dr David Stewart, the retiring chair, for his excellent guidance of the Cancer Registry and I hope that I can continue and build on that legacy"

Gerard Savage joined the Northern Ireland Cancer Registry in August 2016. He has been working on the Lung Audit which will be launched in the Autumn of this year and further analysis of the PSA database held securely in the NICR.





Laura Dywer joined the Northern Ireland Cancer Registry in March 2017 as a Tumour Verification Officer. Her role is a collaborative post with Northern Ireland BioBank and Macmillan to collect de-identified clinical data that links with Biobank tissue samples requested by researchers and to collect data for various Macmillan projects.



Dr David Donnelly (Statistician) returned to the Northern Ireland Cancer Registry on the 1st June 2017. David will be working on the Life After Prostate Cancer Diagnosis study.



Tracey McTernaghan joined the registry on the 10th July 2017, as Senior Administrator and PA to the Director.



N. Ireland Cancer Registry

Centre for Public Health
Queen's University Belfast
Mulhouse Building
Grosvenor Road
Belfast, BT12 6DP

Tel. +44 (0)28 9097 6028/6440 Email: nicr@qub.ac.uk Web: www.qub.ac.uk/nicr