

N. Ireland Cancer Registry Newsletter



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PROVIDING INFORMATION ON CANCERS FOR RESEARCH, PLANNING AND EDUCATION
The N. Ireland Cancer Registry is funded by the Public Health Agency for Northern Ireland



2011 Data is available at

<http://www.qub.ac.uk/research-centres/nicr/CancerData/OnlineStatistics/>

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Living With and Beyond Cancer



Pictured back row l-r; Dr Johnny Price, Consultant Gynae-Oncologist, Belfast Trust, Ms Nicola Porter, Guidelines & Audit Manager, Guidelines & Audit Implementation Network, Dr Jonathan Browne, GP Advisor, Macmillan Cancer Support NI front row l-r; Dr David Donnelly, Biostatistician, N. Ireland Cancer Registry, Dr Lisa Ranaghan, Medical Advisor, N. Ireland Cancer Registry, Dr Anna Gavin, Director, N. Ireland Cancer Registry, Professor Sir Peter Gregson, Vice-Chancellor, Queen's University Belfast and Mrs Heather Monteverde, General Manager NI, Macmillan Cancer Support.

The "Living with and beyond cancer" conference, organised by the N. Ireland Cancer Registry in conjunction with Macmillan Cancer Support was held in the Great Hall of Queen's University Belfast on Thursday 2 May 2013.

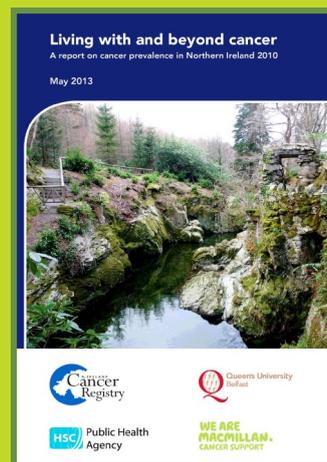
At that conference the first report on cancer prevalence in Northern Ireland 2010 was launched along with the results of a new audit on ovarian and cervical cancer. Dr Gavin spoke about the work of the N. Ireland Cancer Registry while commentary on the two reports was provided by Dr David Donnelly and Dr Lisa Ranaghan, also of the N. Ireland Cancer Registry.

The report launches were supported by a variety of speakers including a welcome by Professor Sir Peter Gregson, the Vice-Chancellor of the University. Dr Johnny Price spoke about current and future trends in the management of ovarian and cervical cancer with a personal story from a cancer patient about living with a cancer diagnosis. This was followed by Dr Jonathan Browne addressing the value of prevalence data to primary care. The conference was chaired by Heather Monteverde, General Manager of Macmillan Cancer Support in Northern Ireland, with closing remarks provided by Dr Michael McBride, the Chief Medical Officer for Northern Ireland.

A special thanks must go to Macmillan Cancer Support for sponsoring the launch and the publication of the cancer prevalence report and to the Guidelines and Audit Implementation Network who supported the audit of ovarian and cervical cancer in Northern Ireland.

Living with and beyond cancer: A report of cancer prevalence in Northern Ireland 2010

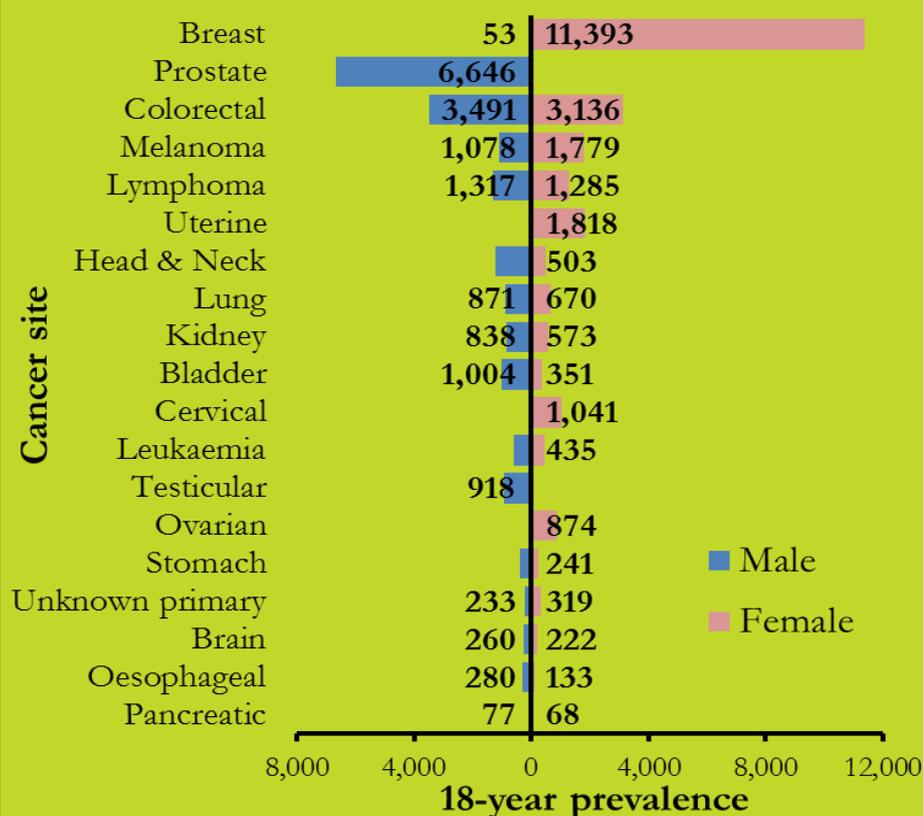
Produced by the N. Ireland Cancer Registry, in association with Macmillan Cancer Support, the “Living with and beyond cancer” report provides the first detailed picture of cancer prevalence in Northern Ireland, which is defined as the number of living people who have ever had a cancer diagnosis. 69,377 people in Northern Ireland were living with a diagnosis of cancer made within the last 18 years at the end of 2010. This includes figures for the rarely fatal Non-melanoma Skin Cancer (NMSC). Excluding this cancer, the number of people who are living in Northern Ireland following a diagnosis made within the last 18 years was 45,265.



The cancer that most people are living with is NMSC due to its high incidence and excellent survival rates. After this, prostate cancer is the most prevalent among men (6,646 men) while 11,393 women are living in N. Ireland having had a diagnosis of breast cancer. Lung cancer, which is one of the most commonly diagnosed cancers, is only the ninth most prevalent cancer due to its poor survival rate (871 men and 670 women).

The number of male cancer survivors (excluding NMSC) increased by 6.2 per cent per year between 2002 and 2010, while for females the increase was 3.2 per cent per year. The greatest percentage increase between 2002 and 2010 was among male prostate and oesophageal cancer patients, while among females the greatest percentage increase was for uterine and kidney cancers.

Figure 1. 18-Year Prevalence of cancer in Northern Ireland 2010



This report lets us see that cancer is no longer a death sentence for everyone who receives a diagnosis. There are many people in Northern Ireland with cancer who live their normal lifespan. Importantly the information in this report will help those working to improve services for those living with cancer.

The increases in cancer prevalence can be attributed to several factors, including an increasing number of cancers diagnosed as the population ages, the increasing rise in lifestyle-related risk factors including obesity, and also changes in diagnostic procedures for example the rise in diagnosis of prostate cancer due to PSA testing. In addition, improvements in survival related to treatment advances and screening and also reductions in the number of deaths from other diseases such as heart disease have also contributed to the increase in the number of cancer survivors.

The report is available online at www.qub.ac.uk/nicr

Pictured above l-r: Dr David Donnelly, Biostatistician, N. Ireland Cancer Registry, Dr Anna Gavin, Director, N. Ireland Cancer Registry, Dr Jonathan Browne, GP Advisor, Macmillan Cancer Support NI, Professor Sir Peter Gregson, Vice-Chancellor, Queen's University Belfast and Mrs Heather Monteverde, General Manager NI, Macmillan Cancer Support.

Ovarian and Cervical Cancer Audit

Conclusions

Patients with ovarian and cervical cancer in N. Ireland are managed by well functioning local and regional specialist multidisciplinary teams which record cancer stage and treatment plans and communicate very well with patients and secondary care. The majority of gynaecological cancer surgery in 2010 was performed by specialist gynae-oncology surgeons in the regional centre at Belfast City Hospital in keeping with regional clinical management guidelines. However as with any service, improvements may be made.

The considerable proportion (28%) of ovarian cancer patients had an emergency admission via A&E is in keeping with late presentation. Late stage at presentation was particularly evident in older patients.

Over a third of ovarian cancer patients and 46% of cervical cancer patients received their first treatment more than 62 days from initial hospital referral.

14% of cervical cancer patients were over age 70, the majority of whom presented with late stage disease and had no record of a cervical smear.

Recommendations

1. Reasons for late presentation especially in the elderly need further study.
2. A public awareness campaign highlighting the key symptoms of ovarian cancer in post-menopausal women should be considered.
3. The pathways for ovarian and cervical cancers should be explored to speed up this process.
4. There should be increased awareness among clinicians of cervical cancer as a possible diagnosis in older women.
5. The value of the current screening programme to detect early changes which may lead to cancer should continue to be highlighted.

Pictured back row l-r; Dr Johnny Price, Consultant Gynae-Oncologist, Belfast Trust and Dr Jonathan Browne, GP Advisor, Macmillan Cancer Support NI

front row l-r; Dr Lisa Ranaghan, Medical Advisor, N. Ireland Cancer Registry, Dr Anna Gavin, Director, N. Ireland Cancer Registry, Ms Nicola Porter, Guidelines & Audit Manager, Guidelines & Audit Implementation Network and Professor Sir Peter Gregson, Vice-Chancellor, Queen's University Belfast



Bladder Audit

A new audit of bladder cancer patients in Northern Ireland is being undertaken by the N. Ireland Cancer Registry (NICR) with assistance from clinicians. This is supported by the Guidelines and Audit Implementation Network (GAIN). Northern Ireland (NI) has significantly lower age-standardised 1-year relative-survival rates from bladder cancer in females (67.98%) than the UK (78.85%) and Europe (83.31%), which persists to five-year survival (Source: EUROCORE 4). This survival deficit has been highlighted in the Public Accounts Committee Report (2010) on the Performance of the Health Service in Northern Ireland (Northern Ireland Assembly 2010. Ref: NIA 35/09/10R) and has prompted Northern Ireland Cancer Network (NICaN) to stress the value of completing a urology group audit of bladder cancer survival.

The audit aims to document care of all 400 bladder cancer patients diagnosed in 2010 & 2011, establish baselines and determine whether they are in keeping with the guidelines outlined in European Association of Urology Guidelines. The audit is a patient case note review using data from the following electronic sources; Patient Administration System (PAS), Clinical Oncology Information System (COIS), radiology information, and Cancer Patient Pathway System (CaPPS) supplemented with information following note review by Registry Tumour Verification Officers. The audit will track the patient journey including referral, first consultant appointment, investigations, diagnosis, treatment, and after care. Detailed information will be collected on symptoms and co-morbidities at the time of diagnosis, diagnostic testing and tumour staging, and types of treatment. The audit will also record timelines along the key stages of the patient journey in order to identify service improvements that could lead to earlier diagnosis and treatment, and better patient survival. Analysis is ongoing with a report due late 2013.

Living with and beyond Prostate Cancer:

A study of the impact on men of increased and variable investigation and treatment of prostate cancer in the Island of Ireland funded by Prostate Cancer UK, R&D Office N. Ireland and the Health Research Board, Dublin

This All-Ireland study aims to measure the impact of investigation (prostate biopsy) and treatment for prostate cancer on the physical and psychosocial health of men. Acute and late physical effects and quality of life have been quantified for men receiving different treatments up to 15 years post diagnosis (Treatment Impact Study). The second phase of the study will provide a better understanding of the psychological effects of having a prostate biopsy comparing patient outcomes by area and by intensity of investigation (Prostate Investigations Study).

Treatment Impact Study (Study 1)

Almost 7,000 men diagnosed with primary, invasive, prostate cancer (C61) 1-15 years ago, identified through cancer registries in Northern Ireland (NI) and Republic of Ireland (RoI), received a postal questionnaire during 2012. 3,577 men returned completed questionnaires (~58% response rate), making this one of the largest ever studies of prostate cancer survivors worldwide.

Differences in treatment modalities were observed; prostatectomy was more common in RoI, hormone therapy and radiotherapy were more common in NI. Pre-treatment urinary symptoms were common in this early sample. Post treatment side effects were also common and these included incontinence, impotence, loss of sexual desire, sweats/hot flushes, changes in breast tissue, bowel problems and depression. Post treatment levels of regret varied depending on the treatment modality and current ongoing side effects.

Predictors of low health related quality of life (HRQoL) were investigated. In a subset of the first 1,344 respondents, HRQoL fell with increased time since diagnosis. Men who had other medical conditions (in addition to their cancer) and those whose treatment side-effects were more severe than they had expected also had lower HRQoL. Some treatments were more likely to result in lower HRQoL than others. In addition, men with ongoing urinary incontinence and impotence were more likely to have low HRQoL.

Of the men who received the questionnaire, 13% in both RoI and NI used the Freephone which helped to achieve an understanding of issues concerning prostate cancer survivors and increased response rates due to resolution of confusions and facilitation of questionnaire completion.

This study is quantifying, for the first time, a population-based picture of prostate cancer treatment side effects on the island of Ireland, and the impact of these on men's lives. This data will be valuable in guiding men's decision-making processes in the future, in informing the debate on prostate cancer screening, and informing strategies to identify those likely to require additional support post-treatment.

The treatment study has established a cohort of treated men for further long term study.

The full results are expected November 2013.

Prostate Investigations Study (Study 2)

As rates of prostate specific antigen testing in the population rise, so also do rates of prostate biopsy. Some of the men who have a prostate biopsy will have a diagnosis of prostate cancer but most will not. The biopsy itself is an invasive procedure and some men have side effects. Few studies have attempted to quantify these side-effects or explore other ways in which undergoing a prostate biopsy might impact on men and their lives. We are currently inviting men who attend urology clinics for a prostate biopsy to complete questionnaires at two time points - before their biopsy and again about 6 weeks later, after they have received the biopsy results but before any active treatment has commenced.

It is anticipated that recruitment will continue to mid-summer 2013, after which data analysis and report write up will take place. This study will quantify the associated regret with having had a prostate biopsy and will provide information for men so that informed decisions can be made in the future.

The research team are:

Dr Anna Gavin, Dr Heather Kinnear and Dr David Donnelly, N. Ireland Cancer Registry.

Dr Linda Sharp, Dr Frances Drummond, and Mr Eamonn O'Leary, National Cancer Registry, Ireland.

Administrative support provided by Mrs Audrey Craven-Lynn, N. Ireland Cancer Registry and Joanne Clooney, National Cancer Registry, Ireland.

International Cancer Benchmarking Partnership

Since 2010, Northern Ireland has been an active member of the International Cancer Benchmarking Partnership (ICBP). This unique and innovative global partnership of clinicians, academics and policymakers the first of its kind is seeking to understand how and *why* cancer survival varies between countries/jurisdictions. It includes 12 jurisdictions in 6 countries, Australia, Canada, UK, Denmark, Sweden and Norway and focuses on four cancer sites (breast, lung, colorectal and ovarian cancer). There are 5 areas of research (modules). Each module looks at different aspects of cancer survival to identify possible reasons for differences between partners.

Module 1

Module 1 involves an analysis of the population based cancer registry data from the twelve collaborating jurisdictions collaborating in the ICBP project. Northern Ireland data was submitted in April 2010 and the first results were published in the Lancet in January 2011. Further work in 2011 consisted of an examination of the effect of stage at diagnosis on survival in order to establish the likely cause of lower survival rates. Four site specific cancer papers have been produced and have been submitted to relevant journals. At present, papers on ovarian¹, breast² and lung cancer³ have been published.

For ovarian cancer, differences in stage at diagnosis partly explain international variation in survival, and a more adverse stage distribution contributes to comparatively low survival in Denmark. However, differences in survival also exist within each stage, with lower survival for advanced disease in the UK, suggesting unequal access to optimal treatment.

With regard to breast cancer, low overall survival arose in Denmark due to adverse stage distribution despite stage - normal specific survival in contrast to the UK where stage distribution was typical but stage-specific survival is low.

In lung cancer, while differences in stage at diagnosis explain some of the international variation in overall survival, wide disparities in stage-specific survival exist, suggesting that other factors are also important such as differences in treatment.

The fourth paper on stage at diagnosis and international differences in colorectal cancer survival is due to be published later in the year.

1. *Maringe C, Walters S, Butler J et al. Stage at diagnosis and ovarian cancer survival: Evidence from the International Cancer Benchmarking Partnership. Gynecol Oncol. 2012, 127:75-82.*
2. *Walters S, Maringe C, Butler J et al. Breast cancer survival and stage at diagnosis in Australia, Canada, Denmark, Norway, Sweden and the United Kingdom: a population-based study, 2004-2007. Brit J Cancer. 2013 Feb 28.*
3. *Walters S, Maringe C, Coleman MP et al. Lung cancer survival and stage at diagnosis in Australia, Canada, Denmark, Norway, Sweden and the United Kingdom: a population-based study, 2004-2007. Thorax. 2013 Feb.*

Module 2 & 4 - see page 6

Module 3

The aim of module 3 is to understand international differences in primary care that may impact on cancer survival. This work was funded by the Public Health Agency. A primary care physician survey is ongoing in Northern Ireland and due to be completed shortly. In addition a healthcare systems mapping exercise has also taken place. This will provide insight into variations in systems that might impact on the GP survey and help to analyse emerging trends. This includes looking at which financial and non-financial incentives GPs receive and what their actual diagnostic access is. Results of this module will be published in late 2013.

Module 5

Module 5, currently in its early stages, aims to investigate the contribution of co-morbidity and treatment variation and routes to diagnosis to international survival differences through an in depth audit of the patient care pathway. Partners are currently putting together a 'data map' of available data sources in partner jurisdictions to scope possible linkages/key research questions. In contribution to this, the N. Ireland Cancer Registry (NICR) has undertaken a Public Health Agency (PHA) funded project to enhance its collection of data from electronic data sources. Data proformas have been developed, ethical approval has been attained to access other sources of data on treatment, co-morbidity and investigations and evaluation of the quality and completeness of electronic data sources was undertaken. A report will be presented to PHA later in the year.

Module 2

Module 2's aim was to examine the pattern of differences in cancer awareness and beliefs across the ICBP countries (to see if they mirror survival patterns reported by Module 1). In NI this work was funded by the Public Health Agency and the core work is now complete. Outputs include:

- An internationally validated research measure of cancer knowledge and beliefs called the Awareness and Beliefs about Cancer (ABC), measure. The development of this tool was reported in BMJ in early 2013¹. The ABC will serve in future as a blueprint for researchers in other countries to study their population's awareness and beliefs about cancer.
- In the summer of 2011 more than 19,000 men and women aged 50 and older were interviewed via telephone using the measure in Australia, Canada, Denmark, Norway, Sweden and the UK – resulting in the first robust international comparison of population awareness and beliefs about cancer.
- A Northern Ireland specific report was prepared in the N. Ireland Cancer Registry (NICR) and presented to the Public Health Agency in Spring 2012.

Results were published in 2013² and showed that Denmark had the lowest level of barriers to symptomatic presentation, followed by Sweden, Norway, Australia and Canada – and the UK had the highest level of barriers to symptomatic presentation. The UK also reported the lowest awareness that the risk of cancer increases with age. The researchers stated that the number of people in the UK presenting early to their GP with symptoms may rise if public awareness of age-related risk increased and the public's confidence in approaching their GP with possible cancer symptoms were improved. Awareness of cancer symptoms was high and beliefs about cancer outcomes were positive for all of the countries populations studied. Differences between the countries were small. All of the countries reported that approximately eight out of eleven cancer symptoms were recognised by members of the public. All of the countries also reported around nine out of ten people thought that "cancer can often be cured" and seven out of ten disagreed with the statement that "a diagnosis with cancer is a death sentence". Low one year cancer survival does not seem to be explained solely by poor awareness and negative beliefs about cancer. This research provides important information to inform awareness raising interventions in the UK in the future. Further work on investigating factors associated with barriers to presentation to healthcare and on variation in awareness of risk factors between countries is anticipated in the coming months.

1. Simon AE, Forbes LJJ, Boniface D et al. An international measure of awareness and beliefs about cancer: development and testing of the ABC. *BMJ*.
2. Forbes LJJ Simon AE, Warburton F, et al. Differences in cancer awareness and beliefs between Australia, Canada, Denmark, Norway, Sweden and the UK (ICBP): do they contribute to differences in cancer survival? *Brit J Cancer*. 2013.

Module 4

Module 4 of the benchmarking partnership is well underway. This study is looking at four cancer sites: breast, lung, colorectal and ovarian cancer, and is comparing diagnostic and treatment delays across participating jurisdictions in the benchmarking partnership. Work in NI has been funded by Macmillan Cancer Support, the Guidelines Audit and Implementation Network (GAIN) and the Public Health Agency. Data are collected from both the patient (postal questionnaire), their GP (postal questionnaire), and from their secondary care notes. A pilot study was successfully conducted from January 2013 to April 2013, inviting 50 breast, lung and colorectal and 21 ovarian cancer patients. The aims of the pilot study were to test the feasibility of the patient identification process, find out the response rates, and look for any issues with the consent form and questionnaires.

The process of identifying eligible patients was three fold and worked very well. First patients were identified using the new NI Cancer Patient Pathway System (CaPPS) and other relevant electronic resources. Following this check the Northern Ireland Cancer Trials Network Clinical Research Nurses in each of the 5 Health and Social Care Trusts (HSCTs) checked the patients from their HSCT, ensuring that only eligible patients were invited to take part. Finally a vital status check was conducted before any invitations to take part in the study were sent to eligible patients. Patients were contacted between 6 weeks and 5.5 months post diagnosis (the questionnaire had to be completed before 6 months post diagnosis). Response rates were very good, and a freephone number was available for patients to contact the research team if they had any queries.

A few amendments were made based on the pilot study findings. For example, based on response rates it was decided that contacting patients 3 to 5.5 months post diagnosis would be the main study recruitment strategy. Also the questionnaires have been shortened for the main study. These amendments were approved by the ethics committee and the research governance departments in all 5 Health and Social Care Trusts (HSCTs). The main study commenced in late June 2013 and will continue until data on 200 breast, lung, and colorectal cancer patients and 60* ovarian cancer patients has been collected. It is hoped that this study will help determine reasons for delay in cancer presentation and identify time intervals where actions to reduce delays could be focussed.

If there are any queries regarding this research please contact the Principal Investigator, Dr Anna Gavin or the Research Co-Ordinator, Dr Jackie Boylan: Tel: 028 9063 5042 Email jackie.boylan@gub.ac.uk *This is a realistic number to recruit within the study timeframe, however when the study ends recruitment for ovarian patients will continue until 200 is reached.

Identifying Targets for Intervention to promote earlier diagnosis of cancer

The purpose of this study is to investigate ways of improving early detection of lung and colon cancer by comparing patient, clinical, disease and service related factors in people with these cancers who survived less than 3 months to those who survived between 6 months and 3 years from diagnosis. This project has been made possible with funding from the National Awareness and Early Diagnosis Initiative (NAEDI), a collaboration between Cancer Research UK, the National Cancer Action Team, the Department of Health and the National Health Service. Ethical approval has been obtained by Office of Research Ethics in Northern Ireland.

The Study commenced in June 2012, the team have developed a proforma to collect data from a range of electronic sources as well as General Practice records. A pilot data collection exercise took place in the summer of 2012 with 50 records reviewed with a number of improvements to the protocol highlighted for the main study. Cases and matched controls have been selected for the main study and three Tumour Verification Officers are currently employed in collection of data for 2,400 deceased patients diagnosed with cancer between 2005 and 2010. This work has benefited from significant input from Dr Lisa Ranaghan and advice from a Multidisciplinary Steering Group made up of oncologists, surgeons, General Practitioners, Public Health experts, patients and researchers. The project will be completed by May 2015.

Data Quality and Performance Indicators for 2011 data

Indicators of data quality remain high for the N. Ireland Cancer Registry (NICR). One of the measures of this is the number of registrations made from death certificates only (DCO). For 2011, this was 52 cases or 0.6% of total registrations for that year. This is low and compares favourably with other national and international registries. The other major indicator is the number of cases which have a microscopic verification of the cancer (MV). This has continued to improve with a MV rate of 86% for 2011. Whilst this still remains low compared to other registries in Europe and North America, it is well within those recorded in the rest of the UK.

Staging has continued to improve with 68% of all cancers (excluding NMS) with a full TNM stage. Several sites such as breast and melanoma have over 90% of their tumours staged.

Improvements have occurred due to the use of the clinical oncology system (COIS) and the multi-disciplinary team reporting tool (CaPPS), both of which are available electronically to the NICR.

A fuller report of the data can be seen on the UKACR website.

http://www.ukacr.org/sites/default/files/UKACR_Annual_Report_2013.pdf

Cancer Patient Information Leaflet – Poster

The N. Ireland Cancer Registry has had a patient information leaflet since October 2008. This leaflet was updated in 2012 and the N. Ireland Cancer Registry in conjunction with the Public Health Agency recently produced a poster 'About Cancer Registration' to help inform cancer patients about the N. Ireland Cancer Registry and the cancer registration process.

The leaflet and poster were distributed to GP practices, HSC Trusts, cancer charities and libraries throughout Northern Ireland.

The leaflet, poster and a section on 'Common Questions About the Cancer Registration System' is available for downloading from our website <http://go.qub.ac.uk/wvbbc>.

If you would like copies of the patient information leaflet or poster please contact the Registry via email nicr@qub.ac.uk.



What enables cancer patients to die at home (QUALYCARE-NI Study)

The **QUALYCARE-NI study** is funded by Cancer Focus Northern Ireland and examines the end of life care of cancer patients in Northern Ireland, with an aim to establish key factors that enable cancer patients to remain at home. In September 2012, following ethical approval, the Northern Ireland Statistics and Research Agency (NISRA) identified 1,500 people who had registered the death of someone where cancer was the primary cause of death. NISRA then invited eligible participants to complete a questionnaire asking their views on the care received in the three months before their relative died.

To date 464 questionnaires have been completed and we wish to thank all those who participated, as their views will provide us with valuable information to inform health care professionals on how to best meet the needs of their future patients. The questionnaire information has now been entered, enabling analysis to begin. Preliminary findings have been welcomed by the QUALYCARE-NI Steering Group and were also presented to the 'Living Matters, Dying Matters' Implementation Board, who provide advice on policy and strategy for palliative and end of life care in Northern Ireland. A poster of results will be presented at the Cancer Outcomes Conference, 12-14 June in Brighton. It is hoped that a report will be finalised by November 2013 and made available on our website www.qub.ac.uk/sites/QUALYCARE/, with a summary of the study findings distributed to participants.

International Cancer Conference

The 34th annual meeting of the International Association of Cancer Registries hosted by the National Cancer Registry, Ireland took place from 17-19 September 2012 in Rochestown Park Hotel, Cork. This was followed by the ENCR Meeting 19-20 September 2012.

The conference provided an opportunity for the N. Ireland Cancer Registry to showcase their research to an international audience.

The International Association of Cancer Registries will be holding its 35th meeting in Buenos Aires, Argentina, from 22 to 24 October 2013. The meeting will be hosted by the Instituto Nacional del Cáncer (INC) with the collaboration of the Bahía Blanca Cancer Registry.

Early registration closes on 10 September 2013. Further information can be found at www.iacr2013.com/.

Concord-2

Dr Finian Bannon of the N. Ireland Cancer Registry has been funded by Cancer Focus Northern Ireland to work 6 months in 2013 with Professor Michel Coleman and his team, the Cancer Research UK Cancer Survival Group, in the London School of Hygiene and Tropical Medicine. This period of training will build expertise in the N. Ireland Cancer Registry in advanced statistical techniques, allowing Northern Ireland's net survival statistics to be estimated to the highest international standards. Dr Bannon will work on the CONCORD-2 study which will compare cancer survival in adults with stomach, colon, rectum, liver, lung, breast (women), cervix, ovary, prostate and leukaemia cancer and in children with leukaemia. Data will be supplied by 160 or more cancer registries from 50 countries on patients diagnosed from 1995-2009.



CONCORD
Global surveillance
of cancer survival

CONCORD-2 will establish global surveillance of cancer survival, with a view to further progress in:

1. Identifying large numbers of avoidable premature deaths due to inequalities in cancer survival.
2. Prompting countries to improve their health systems.
3. Evaluate progress to World Cancer Declaration goal of major increase in survival by 2020.

The first CONCORD study was published in *The Lancet Oncology* in 2008¹. It reported survival for breast, colon, rectum and prostate cancer for 1.9 million adults diagnosed from 1990-1994 in 31 countries on five continents. It was the first worldwide analysis of cancer survival, with standard quality-control procedures and analytic methods for all datasets. The study showed that global variation in cancer survival was very wide. Cancer survival was higher in North America, Australia, Japan, and northern, western and southern Europe, and lower in Algeria, Brazil, and Eastern Europe.

In CONCORD-2, information on stage of cancer at diagnosis will be collected for the first time in order to investigate in more depth the reasons for the inequalities in survival between different countries.

¹Coleman MP, Quaresma M, Berrino F, Lutz JM, De Angelis R, Capocaccia R, Baili P, Rachet B, Gatta G, Hakulinen T, Micheli A, Sant M, Weir HK, Elwood JM, Tsukuma H, Koifman S, E Silva GA, Francisci S, Santaquilani M, Verdecchia A, Storm HH, Young JL; CONCORD Working Group, 2008. Cancer survival in five continents: a worldwide population-based study (CONCORD) 9:730-56.

Official Statistics

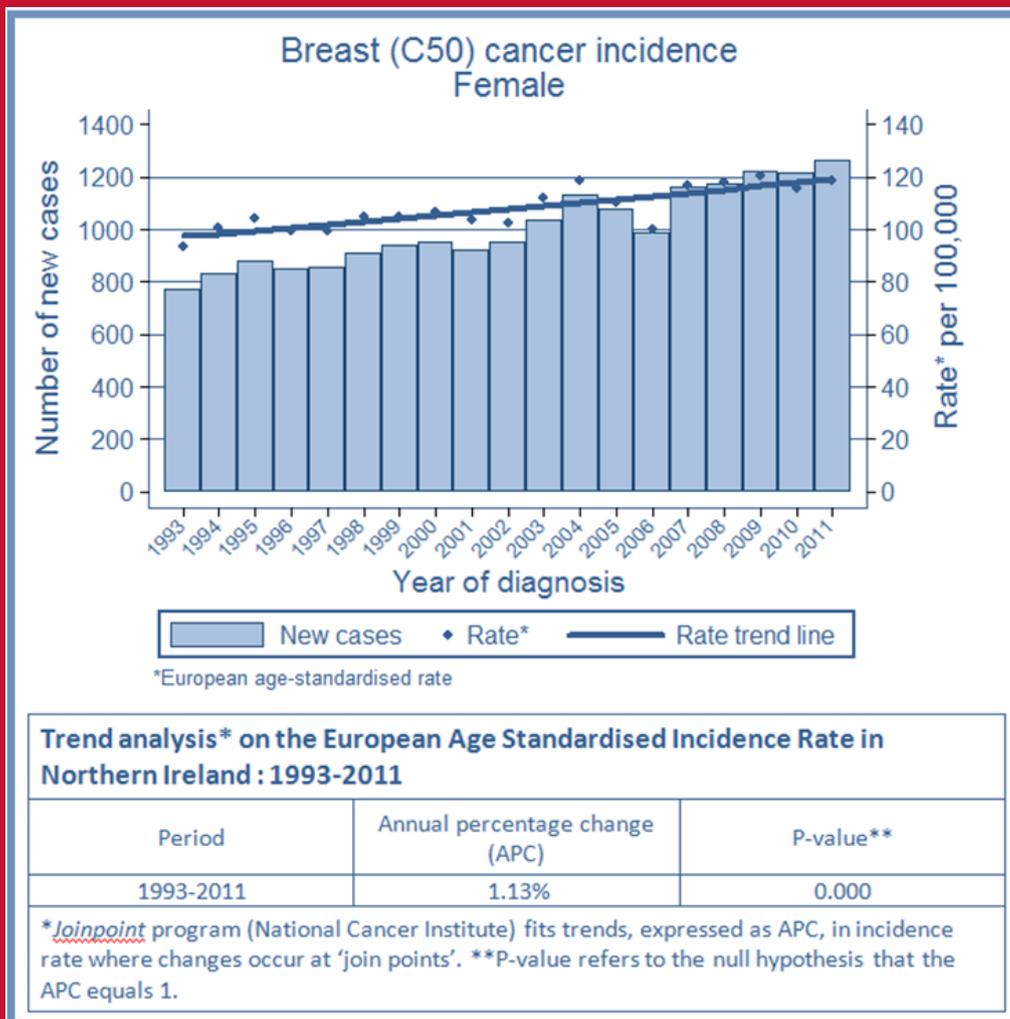
In March 2012, the Minister for Health included the N. Ireland Cancer Registry (NICR) in the official statistics order as a producer of official statistics. This means that the NICR is recognised as the official producer of cancer incidence and survival statistics in Northern Ireland. 2011 incidence statistics are now available. Breast, prostate, lung, colorectal, melanoma, cervix, non-melanoma skin cancer sites have additional incidence tables comparing geographical areas in N. Ireland, socio-economic deprivation areas, and 5-year age bands.

Official statistics are available at: <http://www.qub.ac.uk/research-centres/nicr/CancerData/>

Some key statistics

1. In 2011, 8,686 cancers were diagnosed in people in Northern Ireland (this excludes 3,330 cases of the common but not generally serious non-melanoma skin cancer). The most common types of cancer in men were prostate (n=1007), lung (n=630), and colorectal (n=643). In women, the most common cancer types were breast (n=1208), and colorectal (n=522).
2. From 1995 to 2011, female breast age-standardised cancer rates increased by 1.13% per year (see Figure 2), male malignant melanoma rates rose by 2.7% and female melanoma by 2.5%, female lung cancer rates increased by 0.8% while male lung cancer rates decreased by 1.2%.
3. In 2007-2011, incidence rates were higher in the least deprived areas than the most deprived for female breast, prostate, and malignant melanoma, whereas incidence rates were higher in most deprived areas than the least deprived for male colorectal, cervical, and lung cancer. If the lung cancer incidence rates of the most deprived areas were the same as in the least deprived, there would be 180 fewer cases of lung cancer in women and 220 fewer cases in men diagnosed per year.
4. Five-year survival rates for patients diagnosed from 2002 to 2006 were as follows: female breast (80.1%), colorectal (52.4%), prostate (84.1%), lung (10.8%). These survival rates have all shown improvement compared to patients diagnosed in the period 1993 to 1996.

Figure 2: Breast cancer incidence cases and incidence rates in women in Northern Ireland 1993-2011



Recent Peer Reviewed Publications (April 2012 – March 2013)

2013

1. Maringe C, Walters S, Rachet B, Butler J, Fields T, Finan P, Maxwell R, Nedrebø B, Pahlman L, Sjövall A, Spigelman A, Engholm G, **Gavin A**, Gjerstorff ML, Hatcher J, Johannesen TB, Morris E, McGahan CE, Tracey E, Turner D, Richards MA, Coleman MP and the **ICBP Module 1 Working Group**. Stage at diagnosis and colorectal cancer survival in six high-income countries: A population-based study of patients diagnosed during 2000-2007. *Acta Oncol* 2013 Jun;52(5):919-32.
2. Siesling A, Kwast A, **Gavin A**, Baili P and Otter R and **EUROCHIP-3 Workpackage 5**. Availability of stage at diagnosis, cancer treatment delay and compliance with cancer guidelines as cancer registry indicators for cancer care in Europe: Results of EUROCHIP-3 Survey. *Int J Cancer* 2013 Jun15;132(12):2910-7
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NICR Staging Tool presented Internationally

The work of the N. Ireland Cancer Registry (NICR), in partnership with the IARC (International Agency for Research on Cancer) and UICC (Union for International Cancer Control) was presented by Giulio Napolitano in Syracuse (Italy) at the annual meeting of the *Group of Registry and Epidemiology of Cancer in Latin Speaking Countries* (GRELL, 9-10 May 2013). Our development of the NICR Staging Tool into a web-based application was greeted with appreciation and more requests have been received to download the tool, now being used in around twenty organisations in a dozen countries around the world. Cancer staging is important for treatment planning and review of outcomes, including screening, new diagnostic technologies and survival, and the NICR is leading this project to maximise availability, standardisation and comparability of cancer staging internationally.

The NICR was also present at the *World of Health IT Conference & Exhibition, part of the eHealth Week* in Dublin (13-15 May). The NICR Staging Tool and the core mission and activities of the Registry were shown at the stand set up by InvestNI.

Photo: Giulio Napolitano, Senior IM&T Officer, NICR, Presenting the NICR Staging Tool at the World of Health IT Conference & Exhibition, Dublin



Colorectal Polyp Register - Project Completion

In 2012, the Northern Ireland Colorectal Polyp Register benefitted immensely from an additional project undertaken by TVOs Donna Floyd, Rosemary Ward and Kate Donnelly. Donna, Kate and Rosemary performed a case note review of over 400 patients to aid our understanding of why some patients who have had an adenoma or hyperplastic polyp removed still have an increased risk of subsequently developing colorectal cancer. Early results from this work would suggest that this may be partially explained by patients not attending for a follow-up investigation or inadequate visualisation of the bowel (and therefore a potentially missed polyp) at colonoscopy. This work should be submitted for publication in Summer 2013 and our gratitude is extended to Cancer Focus Northern Ireland for their support of the Polyp work.

In addition, Summer 2013 will see NI Colorectal Polyp register researcher, Dr Helen Coleman, donning her cowboy boots to spend a 3 month collaborative research visit in Tennessee, USA! Helen will be working as part of a world-renowned colorectal polyp and cancer research team at Vanderbilt Epidemiology Center, led by Professor Wei Zheng. This will allow important comparisons between USA and Northern Ireland populations to investigate risk factors for recurrent adenomas, and should lead to exciting new research being produced from the polyp register. Yee ha!

Staff News

Dr Jackie Boylan, Karen Green and Clare Marks joined the Registry Autumn 2012. Dr Jackie Boylan, Research Fellow and Karen Green, Clerical Officer are working together on Module 4 of the International Cancer Benchmarking Project. However, Karen has now secured a permanent clerical position in Human Resources, QUB and we would like to wish her all the best in her future career.

Clare Marks, commenced working with Deirdre Fitzpatrick providing clerical support on the QUALYCARE-NI Study and has now taken up a one year post as a Tumour Verification Officer within the Registry.

Mrs Audrey Craven-Lynn joined the Registry in March 2011 to assist with the work of an all-Ireland prostate cancer research study to which she made a valuable contribution. Audrey has now moved to a new role in the Northern Ireland Clinical Research Facility, QUB based in Belfast City Hospital. We would like to wish her all the best in her new position.

Congratulations to Conan and his wife Anna on the birth of their son Michael Pilib Donnelly on Monday 10 June 2013.

