

# N. Ireland Cancer Registry

Centre for Public Health, Queen's University Belfast, Mulhouse Building,  
Grosvenor Road, Belfast, BT12 6DP  
Website [www.qub.ac.uk/nicr](http://www.qub.ac.uk/nicr)



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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

## Cancer Care in Northern Ireland: A decade of change



Left to right: Professors Patrick Johnston, Robin Davidson, Michel Coleman, Dr E Rooney, Professor Sir Peter Gregson, Dr Anna Gavin, Mr Edwin Poots MLA, Mr Tom Diamond, Mrs Deirdre Fitzpatrick, Mr Anthony Hegarty, Dr Lisa Ranaghan, Dr David Donnelly, Dr Mary Drake and Dr Michael McBride at the 'Cancer Care in Northern Ireland: A decade of change' conference held in the Great Hall (Queen's University Belfast) on 27 February 2012.

Prompted by the publication of the Campbell report in 1996, the last fifteen years has seen considerable change in the services provided to cancer patients in Northern Ireland. This review resulted from the work of many clinicians, service planners and patients who worked together with the aim of improving cancer services and included a recommendation that the Northern Ireland Cancer Registry (NICR) monitor changes in service provision over time.

To meet this request NICR undertook a series of audits to document any changes in cancer services and provide snapshots of activity levels within particular years. The first phase of these audits looked at changes between 1996 and 2001, while the second phase also examined the situation in 2006.

Given the volume of information available in these audits, a short summary of the key results has been produced and was presented on 27<sup>th</sup> February 2012 at a conference organised by NICR, supported by the Guidelines Audit and Implementation Network (GAIN) and the Public Health Agency (PHA).

The conference, which had the broad theme of 'A Decade of Change in Cancer Services' was held in the Great Hall of Queen's University Belfast. It was chaired by Dr Eddie Rooney, the Chief Executive of the Public Health Agency, with introductions by Professor Sir Peter Gregson, the Vice-Chancellor of the University, and Mr Edwin Poots MLA, the Minister for Health Social Services and Public Safety. *Continued on page 2*

2010 Data is available at  
<http://www.qub.ac.uk/research-centres/nicr/CancerData/OnlineStatistics/>



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### Forthcoming Event – International Cancer Conference - Cork

The 34<sup>th</sup> annual meeting of the International Association of Cancer Registries will take place from 17-19 September 2012 in Rochestown Park Hotel, Cork. This is followed by the ENCR Meeting – 19-20 September 2012.

Early bird registration closes 31 July and online registration closes 9 September 2012 see:-  
[www.iacr2012.org/](http://www.iacr2012.org/)

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In addition to the short summary of changes in cancer services, two new audits on pancreatic cancer and leukaemia and lymphoma were also launched by their authors, along with support from clinicians who work with patients with these cancers. Michel Coleman, Professor of Epidemiology and Vital Statistics in the London School of Hygiene and Tropical Medicine and guest speaker, covered international comparisons of cancer survival including information on the International Cancer Benchmarking Partnerships work (see page 3).

Closing the conference Dr Michael McBride the Chief Medical Officer reflected on the findings of the audits and identified the key issues facing cancer services in Northern Ireland over the next decade.



I-r Mrs D Fitzpatrick, Mr T Diamond, Dr D Donnelly, Mr A Hegarty, Dr A Gavin, Professor M Coleman, Dr M Drake and Dr L Ranaghan at the launch of the Decade of Change Summary, Pancreatic Cancer Audit and Leukaemia and Lymphoma Audit.

## Care of Pancreatic Cancer Patients in Northern Ireland



I-r Mrs D Fitzpatrick and Mr T Diamond at the launch of the Pancreatic Cancer Audit Report

A NICR regional audit of pancreatic cancer patients diagnosed in 2001 recommended that one specialist Pancreatic Cancer Team be identified for N. Ireland, with one hepatopancreatobiliary (HPB) unit. Through the Northern Ireland Cancer Network (NICaN), surgeons have been working to rationalise services. NICR carried out a re-audit to determine if care and outcome for pancreatic cancer patients has changed, by comparing the care received by pancreatic cancer patients diagnosed in 2007 with those diagnosed in 2001. Data were collated on 152 patients diagnosed in 2001 and 173 in 2007. More patients in 2007 presented to fewer hospitals, whilst presenting symptoms and duration differed little. In 2007, more patients had relevant blood tests, fewer were investigated by ERCP and more had CT scan.

In 2007 almost  $\frac{3}{4}$  of patients had stage recorded (52% in 2001). More patients were recorded as having had a Multidisciplinary Team meeting (MDT) (47% vs 13%) in 2007 and had a preoperative surgery plan recorded (96% vs 22%).

More patients received surgery, which was carried out in fewer hospitals by fewer surgeons. Surgery with curative intent was centralised in one hospital with over  $\frac{3}{4}$  performed in the Mater Hospital. Half of patients in 2007 had a referral to oncology (33% in 2001). In 2007, there was increased referral to dietician, specialised HPB nurse, palliative care specialists/team and occupational therapist. There was however no significant improvement in survival detected between 2001 and 2007, with poor 2-year survival at 1% and 3% respectively.

These results have been fed back to service providers and clinicians. Report available at [www.qub.ac.uk/nicr](http://www.qub.ac.uk/nicr)

## Leukaemia and Lymphoma Audit

This audit was funded by the Guidelines Audit and Implementation Network (GAIN) and was the first detailed look at the pathway from referral through diagnosis, staging, treatment and outcomes of treatment for patients (adults and children) diagnosed with Leukaemia and Lymphoma in Northern Ireland in 2008.

The audit included 225 patients with Non-Hodgkin lymphoma, 51 with Hodgkin lymphoma and 73 patients with acute leukaemia and chronic myeloid leukaemia.

The full audit report is available from [www.qub.ac.uk/nicr](http://www.qub.ac.uk/nicr)



I-r Mr Anthony Hegarty, Dr Mary Drake and Dr Lisa Ranaghan at the launch of the Leukaemia and Lymphoma Audit Report



## Audit of Ovarian and Cervical Cancers

The NICR regularly conducts audits of the process of care for major cancers, with the first phase of these audits including ovarian and cervical cancer. However the data in this audit is now ten years old and considerable changes have occurred in the NHS since then. A new audit has thus been undertaken by NICR with funding from GAIN. It examines data from 2010 and includes many data items not included in the previous audit (particularly for cervical cancer). In addition a modified approach to data collection has been applied. Previously all data were collected by manual examination of clinical notes. This audit has for the first time used several electronic sources including the Cancer Patient Pathway System (CaPPS), with manual examination of notes undertaken to fill in data items that were not available from these sources. Despite these changes the objective of this audit remains the same "To document the presentation, treatment, care and outcomes of ovarian and cervical cancer patients diagnosed in N. Ireland in 2010 and compare that with similar data from 1996 and 2001". The data for ovarian cancer should also fulfil the needs of the International Cancer Benchmarking Partnership. The audit report is expected to be launched later this year.

## National Audits

This year all 5 Trusts in N. Ireland have submitted data to the National Lung Cancer Audit 'LUCADA'. This monitors the care pathway for lung cancer patients in England, Scotland, Wales & N. Ireland from initial diagnosis to treatment. The report is available from: [http://www.ic.nhs.uk/webfiles/Services/NCASP/audits%20and%20reports/NHS\\_IC\\_Lung\\_Cancer\\_AUDIT\\_2011\\_Interactive\\_PDF\\_V1.0.pdf](http://www.ic.nhs.uk/webfiles/Services/NCASP/audits%20and%20reports/NHS_IC_Lung_Cancer_AUDIT_2011_Interactive_PDF_V1.0.pdf)

## Northern Ireland Colorectal Polyp Register

The Northern Ireland Colorectal Polyp Register work has produced some unexpected but fascinating results in the past year. Following up patients who had a polypectomy between 2000 and 2005 for up to 11 years has shown that colorectal cancer risk remains significantly elevated compared with the general population, despite having undergone this intervention at a pre-cancerous stage. Even more concerning, patients diagnosed with hyperplastic polyps (which were previously thought of as 'safe') were at an increased risk of colorectal cancer too. These findings have major implications for surveillance and clinical management of these patients, and were the subject of an invited Keynote presentation by Dr Helen Coleman at the Cancer Focus Northern Ireland (formerly Ulster Cancer Foundation) AGM in November 2011. Dr Coleman is now preparing these findings for journal publications, and the 'first phase' of the Colorectal Polyp Register work will be completed late 2012.

## NAEDI Project

In September 2011, NICR was successful in a competitive funding call by the CRUK National Awareness & Early Diagnosis Initiative (NAEDI) to undertake a large study to identify targets for interventions to promote earlier cancer diagnosis. This study aims to identify factors that discriminate between early and later death in patients with lung or colorectal cancer using a retrospective case control study of 2,400 patients diagnosed in Northern Ireland between 2008 and 2011.

Patient identification and data collection will rely on NICR databases as well as GP/hospital note review. Data will be gathered and analysed for cases (600 lung, 600 colorectal with survival less than 2 months) and controls (600 lung, 600 colorectal with survival between 6 months and 2 years). Results should assist identification of population subgroups and service factors for targeting earlier diagnosis efforts and may identify subgroups for molecular based investigation. Work began in April 2011 and the study will run for three years.

## International Cancer Benchmarking Partnership



The International Cancer Benchmarking Partnership is an international study of differences in cancer survival and the reasons for such differences. It involves 12 jurisdictions (including Northern Ireland) on 3 continents and is studying lung, colorectal, breast and ovarian cancer through 5 modules of epidemiology, patient knowledge and attitudes, primary care influences, patient delays and treatment differences.

Northern Ireland's participation in the International Cancer Benchmarking Partnership is progressing well. Further analysis of international registry data has been carried out in Module 1 to determine the importance of stage and treatment at diagnosis in explaining differences in cancer survival. As part of Module 2, which aims to assess the importance of cancer awareness and beliefs in cancer survival differences, a Public Health Agency funded survey of over 2,300 over 50 year olds in Northern Ireland has also been undertaken contributing to over 20,000 participants internationally. The Public Health Agency has also supported the delivery of Module 3 of the study which investigates differences in attitudes, beliefs and behaviours in primary care with almost 1,000 GPs surveyed in Northern Ireland during Spring and Summer of 2012.

Significant progress has also been made in the planning of Module 4 which will compare diagnostic and treatment delays across participating jurisdictions, work in NI has been funded by the Guidelines Audit and Implementation Network (GAIN) Northern Ireland, Macmillan and the Public Health Agency and project planning is at an advanced stage. Ethical approval has been granted in Northern Ireland and the survey of approximately 700 patients will commence in the summer. The NICR aims to participate in the remaining module, a high resolution audit of cancer treatment. This work is in the early planning stages with preparatory work funded by the Public Health Agency with the study expected to begin in early 2013.

## Breast Cancer Research

Janine Glover a PhD Student from the Centre for Health Improvement, Queen's University Belfast, and Dr Finian Bannon of the N. Ireland Cancer Registry (NICR) Centre for Public Health have published a study examining the trends of benign carcinoma in situ (CIS) lesions of the breast in the UK and the Republic of Ireland (ROI). Ninety percent of CIS lesions are 'ductal' of which 30% will progress to invasive breast cancer. Data on women were collected from cancer registries and the analysis was carried out in NICR. The study showed that from 1990 to 2007 in the UK the increase in incidence rate of CIS was 5.9% per year among screen-eligible women (50-64 years of age), and in ROI this was 11.5% over the years 1994-2007.

In regions where it was possible to identify screened-women, it was shown that the increase in CIS came primarily from screen-detected cases. Much of the UK had breast screening before 1990, so the increase is likely due to a combination of the following factors: better population screening coverage, improvements in screening methods, or increased uptake rates of screening. However, risk factors, such as those that affect invasive breast cancer rates, are contributing also; these include, prescribing of hormonal replacement therapy, fertility trends in the community, and postmenopausal obesity.

The NICR routinely collects information on CIS in women through pathology reports, and matches information from the screening service or Northern Ireland Quality Assurance Reference Centre to see which patients have been screened. This linkage is useful for evaluating the effectiveness of the breast screening programme in Northern Ireland. The full title of the paper is: "Glover JA, Bannon FJ, Hughes CM, *et al.* 2012. Increased diagnosis and detection rates of carcinoma in situ of the breast. *Breast Cancer Research and Treatment Journal*".

## 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



This UK Prostate Cancer Charity study aims to measure the impact of investigation and treatment for prostate cancer on the physical and psychosocial health of men in Ireland. The island of Ireland provides an interesting area of study as prostate cancer has increased markedly but more so in the Republic of Ireland compared with N. Ireland. By working with local prostate cancer support groups, a questionnaire was developed to detect the physical and psychosocial effects of a prostate cancer diagnosis where two different healthcare systems are in operation. Acute and late physical effects and quality of life will be measured for men receiving different treatments up to 15 years after diagnosis. This 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. It will establish a cohort of treated men for further long term study and provide reports for service providers, patient groups and also peer reviewed publications. Men face difficult choices regarding investigations and treatment for prostate cancer. This study will provide information on levels of side effects and help to guide men in their decision making.

### (Study 1) Treatment Impact Study

Ethical and research governance approvals have been obtained and a questionnaire has been devised, pre-tested and printed. The study has been adopted by the National Cancer Research Nurse Network (NCRN) who have done an excellent job in checking patients against the inclusion criteria. Eligibility checking has been split into 3 stages. The first of these is checking information on the Cancer Oncology Information System (COIS) in the hospitals and this has been completed across all 5 Trusts and 1,500 questionnaires have been posted out to eligible men. The response rate so far has been excellent. We are currently experiencing a high volume of phone calls on the Freephone facility set up to assist men in the completion of the questionnaire. The second stage of the eligibility checks involves a patient note review and this is currently ongoing. The final stage of eligibility checks includes patients who have not attended the hospital in the last 18 months and this will be done via the patients' GP. This stage is planned for the summer months of 2012 and will be facilitated by the Northern Ireland Primary Care Network who have also adopted the study. We hope to start analysing data early in 2013. A Public Health Summer Studentship has been made available to assist with coding questionnaire data and entering data onto the study database during the summer of 2012.

### (Study 2) Prostate Investigations Study

The study Protocol and Questionnaire is currently being finalised and being prepared for an application to ethics in July 2012 along with research governance. Pre-application research governance procedures have been put in place and contact has been made with the Research Managers in each Trust and the urology nurses who will facilitate giving men questionnaires when they attend urology clinics. Pre-testing of the questionnaire has taken place with groups of men attending local support groups and appropriate modifications have been made. Men will be surveyed at two time points – before their biopsy and again about 4 weeks after their biopsy (after having received the biopsy results but before any active treatment has commenced). A Masters in Public Health student will perform some qualitative work to complement the responses gained via the questionnaires.

It is anticipated that both studies will run parallel during 2012 and results will be available late 2013. If there are any queries regarding this research please contact the Principal Investigator, Dr Anna Gavin or the Research Co-Ordinator, Dr Heather Kinnear (Tel: 028 9063 2618) or email [h.kinnear@qub.ac.uk](mailto:h.kinnear@qub.ac.uk)



## What enables cancer patients to die at home?

The Palliative and End of Life (EoL) Care Strategy for Northern Ireland (NI) (DHSSPSNI 2010) highlights that a feature of good EoL care is enabling patients to die in their place of preference. Unfortunately not all cancer patients achieve this. In Northern Ireland (NI), 46% of cancer patients die in hospitals whilst 34% die at home. A previous NI study funded by Cancer Focus Northern Ireland (previously known as the Ulster Cancer Foundation) of hospital cancer deaths found issues of low recording of preferred place of death, late diagnosis and ill patients unfit for transfer home. This new Cancer Focus Northern Ireland funded study proposes to examine the other side of the coin:

What factors facilitate people to die at home? We will be adopting the same methodology as that used in London for the QUALYCARE study, carried out by the Cicely Saunders Institute, King's College London. The QUALYCARE study examines the quality of care provided to people in their last stages of life and is intended to help improve the care provided by local services.



It involves contacting the people who registered the death of a relative or friend. By analysing the views of families and friends on the care their deceased relative received, we may be able to ascertain why some people received care which met their needs and preferences, while others did not. We will compare the experience of patients who died at home with those who died in institutional settings. It is hoped that the study will advance understanding of costs and consequences to patients and families of dying at home, hospital or hospice, and help improve patient care. The QUALYCARE study is running successfully in London and has collected information from over 600 participants. A Northern Ireland specific study will investigate the factors associated with place of death within this specific environment, and enable comparisons between patients' experience in Northern Ireland and those in London. By comparing two regions with very different demographic and cultural backgrounds, we will be able to gain a better understanding of the importance of these factors in home death and, more generally, enhance our understanding of the demographics of dying, attitudes to end of life care, the care environment and cost of care, all research priorities highlighted in the DHSSPSNI EoL Care Strategy. Additionally, this proposed study will build upon the QUALYCARE London study by linking the NI data to clinical data from the NICR database, to identify disease factors associated with home and institutional death. The QUALYCARE study will commence in Northern Ireland in June 2012.

Pictured l-r Dr Natalia Calanzani, London study researcher, Dr Anna Gavin, NI Principal Investigator, Dr Barbara Gomes, London study co-ordinator and Mrs Deirdre Fitzpatrick, NI study co-ordinator during a visit to the Cicely Saunders Institute in London

## The Northern Ireland Barrett's Oesophagus Register

Dr Helen Coleman and Dr Shivaram Bhat have had a very successful year working on the Barrett's register. Some of the highlights include:

- Research led by Dr Coleman that demonstrated a higher risk of progression to cancer in Barrett's oesophagus patients who smoke. This research was published in the highest ranking gastroenterology journal in the world, *Gastroenterology*. The research has received much attention worldwide with the journal devoting a separate 'Covering the cover' article together with a press release, demonstrating the importance of this work.
- Dr Coleman has had further success with research published in the *European Journal of Epidemiology* showing a rising incidence of Barrett's oesophagus in the population – one of the few population based studies examining this important trend.
- Another research study drew worldwide attention. This research, led by Dr Bhat, was published in the *Journal of the National Cancer Institute*, and demonstrated a low risk of progression to cancer in Barrett's oesophagus patients. This research was subsequently highlighted by the medical website *Medscape* as one of the top 10 gastroenterology research studies of 2011 worldwide.
- Lastly, with the help of two QUB students Blanaid Hicks and Grace Kennedy undertaking summer studentships, the Barrett's register has been updated which will allow further studies to be carried out examining the link between Barrett's oesophagus and oesophageal cancer.

## N. Ireland Cancer Registry Staging Tool: Available on request via the European Network of Cancer Registries Network [ENCR]

The N. Ireland Cancer Registry, with licence from Springer Healthcare, LLC, has developed a Microsoft Access-based Staging Tool. The tool calculates TNM and other site-specific cancer staging classifications from the basic features of the patient's disease (e.g. tumour size or number of lymph nodes involved), entered by the user in a controlled fashion. The tool has been updated to version 7 of TNM.

The tool is now available to any of the European Cancer Registries via the ENCR website <http://www.encl.com/fr/>

Demonstration of the staging tool was part of a seminar on Cancer Epidemiology hosted by International Agency for Research (IARC) on 21<sup>st</sup> June in Lyon.

## N. Ireland Cancer Registry and Enhanced Prescribing Database linkage study

A research team from the Centre for Public Health and the NICR are currently working on a study to investigate the effect of a variety of commonly prescribed medications such as aspirin, non-steroidal anti-inflammatory drugs, and certain blood pressure lowering agents on disease recurrence and survival among patients diagnosed with breast, colorectal or lung cancer. The project involves linking data from the NICR to prescription and dispensing information from the Northern Ireland Enhanced Prescribing Database (NIEPD). The NIEPD, which is under the auspices of the Business Services Organisation, Public Health Agency, was established in 2008 and through the use of two-dimensional barcode technology, captures information on dispensed medications in Northern Ireland.

Ethical approval for the study was obtained in September 2011 and data collection is currently ongoing within the NICR. To date, cancer staging and treatment details for almost 3,000 breast cancer patients diagnosed between 2009 and 2010 have been collected. These data will be combined with data from NIEPD to provide a fully anonymised linked dataset which the investigators will use to determine whether cancer patients who receive these commonly prescribed drugs have fewer or delayed recurrences of their cancer and/or survive longer than those individuals who are not prescribed such drugs. It is hoped that this study will help determine whether any of these drugs would be useful additions to current treatments for cancer patients.

## Recent Peer Reviewed Publications (April 2011 – March 2012)

1. Glover JA, **Bannon FJ, Murray LJ**, Cantwell MM, Comber H, **Gavin A** and Hughes CM. Increased diagnosis and detection rates of carcinoma in situ of the breast. *Breast. Epidemiology* January 2012.
2. **Helen G. Coleman**, Shivaram Bhat, Brian T. Johnston, Damian McManus, **Anna T. Gavin, Liam J. Murray**. Tobacco Smoking Increases the Risk of High-Grade Dysplasia and Cancer Among Patients With Barrett's Esophagus. *Gastroenterology Online* November 2011 doi:10.1053/j.gastro.2011.10.034
3. **Donnelly DW, Gavin AT**. Socio-economic inequalities in cancer incidence – the choice of deprivation measure matters. *Cancer Epidemiology online* August 2011, doi:10.1016/j.canep.2011.06.002.
4. **Blaney J**, Crawford G, Elder TR, Johnston G, **Gavin AT**. Hospital Cancer Deaths – Late diagnosis and missed opportunity. *BMJ Supportive & Palliative Care online* August 2011, doi:10.1136/bmjspcare-2011-000036.
5. Autier P, Boniol M, **Gavin AT**, Vatten L. Breast cancer mortality in neighbouring European countries with different levels of breast screening but similar access to treatment: An analysis of WHO mortality database. *BMJ* July 2011 doi: 10.1136/bmj.d4411.
6. Bhat S, **Coleman HG**, Johnston BT, McManus D, **Gavin AT, Murray LJ**. Risk of malignant progression in Barrett's esophagus - results from a large population based study. *JNCI* 2011 doi: 10.1093/jnci/djr203
7. **Coleman HG**, Bhat S, **Murray LJ**, McManus D, **Gavin AT**, Johnston B. Increasing incidence of Barrett's oesophagus: a population-based study. Accepted by *European Journal of Epidemiology* June 2011. doi 10.1007/s10654-011-9596-z
8. Comber H, Deady S, **Montgomery E** and **Gavin AT**. Drinking water fluoridation and osteosarcoma incidence on the island of Ireland. *Cancer Causes Control*, June 2011 doi: 10.1007/s10552-011-9765-0.
9. **Napolitano, G, Ranaghan, E, Middleton R, Fox, C and Gavin A**. Real-time multidisciplinary team meeting management systems: A comparison with paper records for staging completeness and waiting times. *Behaviour and Information Technology*, online May 2011, doi: 10.1080/0144929X.2011.582151.
10. Chaillol I, Boniol M, **Middleton RJ**, Dore JF, Autier P and **Gavin AT**. Seasonality of cutaneous melanoma diagnosis in Northern Ireland with a review. *Melanoma Research*, April 2011, doi: 10.1097/CMR.0b013e328343a619.

## Cancer Patient Information Leaflet

The N. Ireland Cancer Registry has had a patient information leaflet since October 2008.

An updated version has been prepared to reflect the changed sponsorship of the Registry from the Department of Health, Social Services and Public Safety to the Public Health Agency and that the Registry now collects additional information than previously.

Specifically we now collect information on other diseases which cancer patients may have such as diabetes or heart disease as these may help explain differences in treatment and survival.

The new leaflet will be provided at cancer clinics across Northern Ireland and will soon be on our web page ([www.qub.ac.uk/nicr](http://www.qub.ac.uk/nicr)), with a further factsheet of common questions about the cancer registration system.





## NCI Summer Prevention Scholarship

Congratulations to Conan Donnelly who was awarded a HSC R&D award to attend the National Cancer Institute Summer Curriculum in Cancer Prevention taking place in Bethesda USA from 6 July to 3 August. This four-week course of specialised instruction on concepts, issues and applications in the field of cancer prevention will be delivered by world leaders in the field.

Participants will gain a broad-based perspective in terms of resources available, scientific data, quantitative and qualitative methods. This is also an excellent opportunity to meet other researchers, decision makers and practitioners in the field of cancer prevention and control from the rest of Ireland and the National Cancer Institute.

## 3<sup>rd</sup> National Conference on Population-Based Cancer Research in Ireland - 17 November 2011

The 3<sup>rd</sup> National Conference on Population-Based Cancer Research in Ireland took place in Dublin on Thursday 17 November 2011. It was attended by over 130 delegates with 13 high quality oral presentations and 50 poster presentations. The conference was split into three sessions:

1. Aetiology, prevention and early detection,
2. Survivorship and outcomes research,
3. Cancer registration and health services research.

It is planned to host this as an annual event resuming again in autumn 2013, as Autumn 2012 will see the International Association of Cancer Registries annual conference hosted in Cork, Ireland for the first time (17-19 September) (see [www.iacr2012.org/](http://www.iacr2012.org/) for further details).

## Launch of the first All-Ireland Cancer Atlas

The first atlas of cancer risk covering the whole island of Ireland was jointly published on December 9<sup>th</sup> 2011 by the National Cancer Registry, Ireland and the N. Ireland Cancer Registry with the assistance of the University of Limerick and the Centre for Research in Environmental Epidemiology Barcelona.

The atlas describes both the geographical variation in cancer risk on the island and the relationship between cancer risk and socio-economic and demographic factors. Geographic variations in cancer risk are predominantly the result of variations in factors such as tobacco smoking, alcohol drinking, obesity, diet and sexual behaviour. However some of the variation for other diseases may also be attributable to health service provision, such as higher levels of breast screening in NI in the 1990s and more prostate specific antigen testing in RoI. The atlas highlights the need for further research into the factors associated with the development of cancer and for further public education into the cancer risk posed by tobacco, alcohol, poor diet and obesity.

Some of the key findings in the report include:

- For most cancers there was a significant geographical variation in cancer risk, with different patterns evident for different cancers. Higher cancer risk was seen:
  - In coastal and urban areas for both types of skin cancer;
  - In the east of RoI for female breast cancer;
  - Around Cork and in a band running from Donegal to Down for colorectal cancer;
  - In the urban areas of Belfast, Dublin, Derry and Cork, and in Louth, Kildare, Carlow and Wicklow for lung cancer;
  - In the west and north of RoI during 2002-2007 for prostate cancer;
  - In a band running from Dublin to Donegal, excluding the north-east, but including Belfast for stomach cancer;
  - In the south-west for oesophageal cancer, pancreatic cancer, brain cancer and leukaemia;
  - Around Dublin, around Cork, Waterford, Belfast and Sligo for cervical cancer.
- Many cancers showed a relationship to employment and/or educational attainment:
  - The risk of lung, stomach, head and neck and cervical cancer was higher in areas of high unemployment and/or low educational attainment;
  - The risk of cancers of the skin, female breast and prostate was lower in areas of high unemployment and/or high educational attainment.
- People living in more densely populated areas had a higher risk of cancer than those living in more sparsely populated areas.

The Atlas is available at [www.qub.ac.uk/nicr](http://www.qub.ac.uk/nicr) and [www.ncri.ie](http://www.ncri.ie).

## Official Statistics

In March 2012, the Minister for Health included the 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. 2010 incidence statistics are now available.

The NICR is required to comply with the Official Statistics Code of Practice, however, data users should not notice any changes to the Registry services.

## Timeliness of Cancer Registration Data

In December 2011 we had achieved completeness of incidence data for 2010. This is in line with other cancer registries in England and Wales.

We have achieved this through better use of electronic sources in particular the Clinical Oncology Information System (COIS) and the MDT information from the Cancer Patient Pathway System (CaPPS).

## Cancer Patient Pathway System (CaPPS)

Recent enhancements to the Regional Cancer Information System [CaPPS] are:

- Phase II of the Pathology interface is due to be released to the live system. This ensures that all pathology reports are stored in CaPPS and available to the cancer clinicians.
- New drawing tool software has been added to CaPPS. This allows the location of specific tumours to be stored in each patient episode. This will be used in the breast cancer module first and then rolled across other tumour sites such as skin and upper GI.

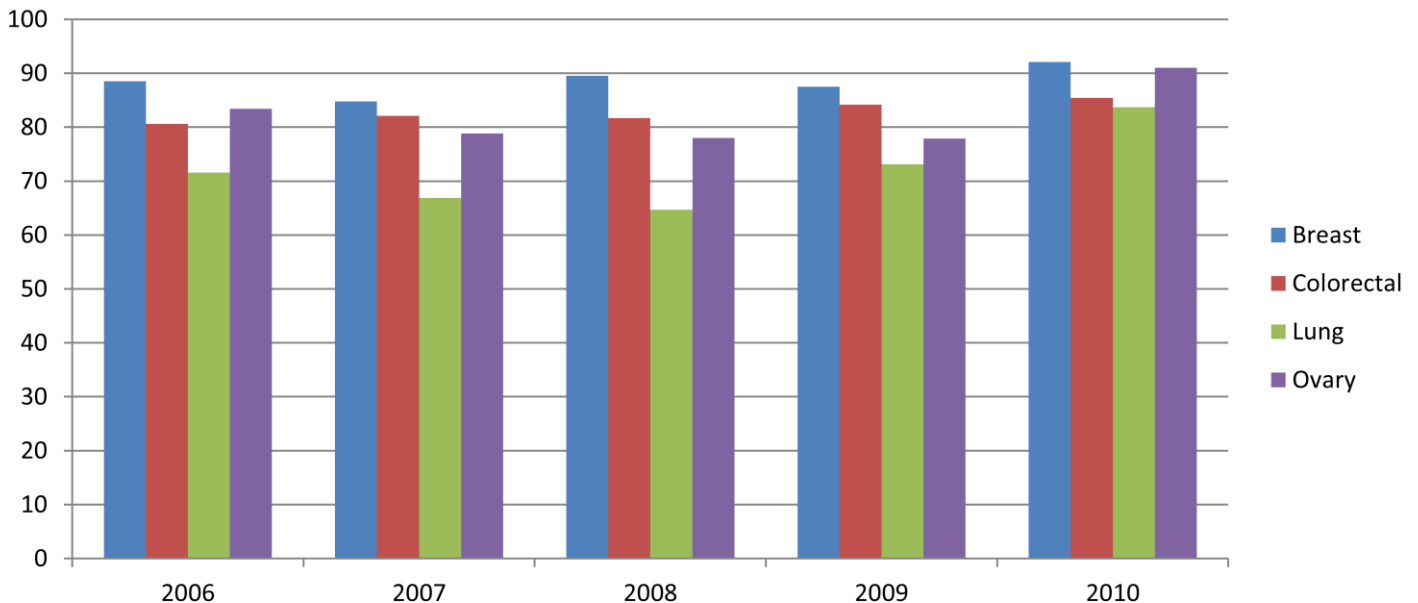
## Staging information held by the Registry

Stage at diagnosis is an important measure for determining cancer outcomes. Our staging for all cancer sites has continued to improve from 62% for 2009 incidence data (excluding non-melanoma skin cancers) to 64% for 2010 data.

This has been accomplished by using the Clinical Oncology Information System (COIS) and the MDT information from Cancer Patient Pathway System (CaPPS), both of which have given us access to information from radiology.

Information from CT, MRI, PET scans etc. are now available routinely and enable us to achieve a complete stage in more cases.

### Percentage of Cancers with full staging for Breast, Colorectal, Lung and Ovary in N. Ireland 2006-2010



As a result of more complete staging information, we are able to look at survival by stage. This will enable better monitoring of patient treatment.



## The National System for Cancer Registration in England - encore

The new national cancer registration system for England (**encore**) is being implemented by all English registries during 2012. The system has been in use with the Eastern Cancer Registration and Information Centre (ECRIC) for a number of years and in 2011 it was selected as the preferred single system to support cancer registration in England.

In March, a group from NICR comprising IT staff and Tumour Verification Officers (TVOs), visited the Trent Cancer Registry with the purpose of viewing the system at work in a live context. Our intention was to learn about how the system worked and to compare it to the current NICR system.

The visit was very useful and the system holds much potential for the future. However, the NICR system (PRAXIS) provides automated tumour matching functionality – a feature not currently in place within Encore. The system does however provide automated patient matching, consolidating a number of patient records from various data sources for registrars to manually construct a tumour registration. Typical data sources include hospital discharge data, pathology data and multidisciplinary team meeting data. The advantage of this approach is that all cancer-related records for patients' received from the various sources, can be viewed at the same time, thereby enabling a more complete registration to be made. In contrast PRAXIS can only process one data source at a time, although it does create the registration automatically, reducing the manual effort required.

By 2013, the plan is that all the English cancer registries will have gone live with **encore**. There are plans to build on **encore's** strengths by adding a tumour matching algorithm. If this happens, **encore** will represent a very efficient system for cancer registration and one worthy of further consideration for Northern Ireland. The NICR will review developments in **encore** as the year progresses.

## School of Medicine, Dentistry and Biomedical Sciences Annual Celebration of Excellence Award 2012

The School of Medicine, Dentistry and Biomedical Sciences hosted its third Annual Celebration of Excellence on Wednesday 28 March 2012. Dr Anna Gavin and the Staff of the N. Ireland Cancer Registry, Centre for Public Health were awarded a prize for the most Exciting/Innovative Research Programme Introduced/Carried out in Partnership with the NHS or Industry. The Registry staff were delighted with this achievement.



Pictured: Mr Colin Fox, Dr Anna Gavin, Mr Giulio Napolitano, Mrs Audrey Craven-Lynn, Mrs Julie McConnell, Mrs Samantha Jameson, Mrs Bernadette Anderson, Mrs Kate Donnelly, Dr Linda Caughley MBE, Dr Heather Kinnear, Mrs Rosemary Ward, Mrs Susan McGookin, Mrs Michelle McGaughey, Mrs Deirdre Fitzpatrick, Mr Eamon O'Callaghan, Dr Finian Bannon, Dr Richard Middleton, Mr Conan Donnelly, Miss Jackie Kelly and Mrs Donna Floyd. (absent; Dr David Donnelly, Dr Lisa Ranaghan and Dr Patricia McDowell)

## Queen's Anniversary Prize – A Comprehensive Cancer Centre

The work of the N. Ireland Cancer Registry was recognised in the Queen's Anniversary Prize for Higher and Further Education 2011 announced in February 2012.

To quote from the submission "Conquering cancer required a multifaceted approach which matches the complexity of the disease. The University, in collaboration with the Health Trusts, has pioneered strategies to develop services and outcomes for cancer patients by the establishment of the CCC which includes: clinical facilities for treatment and clinical trials in the Clinical Cancer Centre; the Centre for Cancer Research and Cell Biology (CCRCB) and the Cancer Registry."

The Registry's work in monitoring of screening services, research outputs, international links, integrated working with the Health Service to monitor patients care and studies on "Why cancer patients die in hospital?", "The influences on GPs undertaking Prostate Specific Antigen (PSA) tests" and "How Prostate Cancer treatment affects Quality of Life" were highlighted.

The unique population based datasets on Barrett's Oesophagus and Colorectal Polyps and the development and distribution of an automated tool to improve levels of and harmonisation of cancer staging were identified in the successful submission.

The award also recognised the Registry's contribution to the development of the electronic Cancer Patient Pathway System (CaPPS). "Furthermore, working with Health Services an Electronic Cancer Patient Pathway System (CaPPS) was developed. This facilitates the running of clinical Multidisciplinary Teams, where patients are discussed before treatment, provision of regional enhanced data on cancer, speeds up patient management including reducing patient waiting times and times for information back to the patients' GP. The CaPPS system, which was initiated by the University's Registry and developed in collaboration with the health service, has revolutionised the way cancer patients are managed within the health service of Northern Ireland and has facilitated the fast tracking of cancer patients in the health system. This has improved recording patient data such as stage of cancer from 28% to 85% and patient performance ECOG status from 31% to 87% and overall five year patient survival from 56% to 64% from the period 1996-2001 compared to 2004-2009".

### Congratulations

Dr Linda Caughley, who has worked voluntarily with the N. Ireland Cancer Registry since her retirement as a histopathologist was honoured in the New Year's Honours List by Her Majesty Queen Elizabeth II, with an MBE.

Dr Caughley's commitment to the Registry and her highly valued work is an example to others and this achievement is to be applauded.

Dr Caughley is pictured after receiving her MBE at Buckingham Palace on Friday 4 May 2012.



### Congratulations

Dr Anna Gavin is also to be congratulated for her promotion to Reader in the N. Ireland Cancer Registry, Centre for Public Health, School of Medicine, Dentistry & Biomedical Sciences.



### Welcome & Farewell

Michelle McGaughey arrived to the Registry from QUB Information Services and has been working with us from February 2012, to enhance and further develop the Registry's audit databases to support research and other projects within the Registry.



This work funded by the Public Health Agency is now nearing completion. During Michelle's short time in the Registry she has been consolidating the breast, lung, colorectal and bladder proformas into one generic database which will be used to perform audits later in the year. The application will also enable more electronic data capture, thereby reducing the amount of manual interrogation of hospital charts, hopefully reducing the time required for data collection. Michelle has also been supporting research projects through the development of other databases.

Michelle has brought a coordinated approach to the project, liaising with Registry staff to ensure the application meets all requirements.

We have enjoyed having her as part of the team and are appreciative of the work she has completed.