

Third All Ireland Cancer Statistics Report



Dr David Donnelly, Dr Joe Harford, Dr Anna Gavin and Dr Harry Comber at the launch of the 3rd All Ireland Report in Dublin.

The third All Ireland Cancer Report was launched by the Minister for Health & Children for the Republic of Ireland, Ms Mary Harney T.D., at the Royal College of Physicians of Ireland in Dublin on the 24th April 2009. The report entitled Cancer incidence, mortality, treatment and survival in the North and South of Ireland: 1994-2004, was compiled by the Northern Ireland Cancer Registry, based at Queen's University, and the National Cancer Registry of Ireland, in Cork. This is the third collaborative report between the NICR and the NCRI and examines more information, including treatment and survival patterns, than ever before.

The report revealed that each year over 21,000 people across Ireland were diagnosed with some form of cancer between 2000 and 2004, with the most common forms of cancer being breast, colorectal, prostate and lung. Total incidence rates were 10.0% lower for males and 2.2% lower for females in Northern Ireland compared with the Republic of Ireland. The difference, for men, was mainly due to differences in prostate cancer diagnosis. The report also showed that mortality rates were around 4% lower in Northern Ireland for men and women.

Overall the number of cancers has increased due to population growth and ageing and for some cancers such as prostate and breast cancer as a result of increased detection. However there have been improvements in survival for breast, colorectal and prostate cancer recorded over the last decade while for no cancers did survival rates fall. As a result cancer death rates have fallen between 1994 and 2004, although there are still approximately 11,000 deaths from cancer each year, many of which could be prevented through reductions in tobacco and alcohol use and the uptake of healthier diets.

The full report is available online while a summary is also available in booklet form at www.qub.ac.uk/nicr

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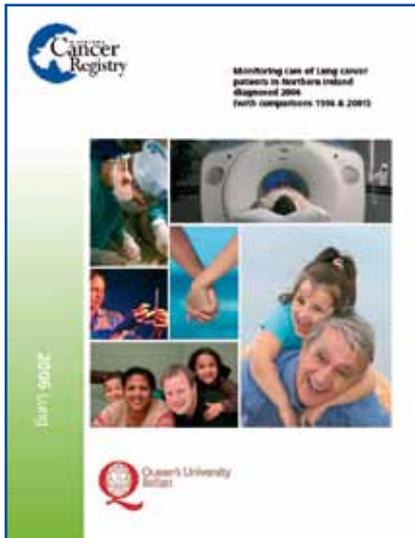
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Ms Mary Harney T.D. speaking at the launch of the 3rd All Ireland Report on Friday 24 April 2009 in Dublin

**2007 data available
end of July at
www.qub.ac.uk/nicr**

Launch of Lung Audit Report



The report documents for the first time the patterns of care for 834 lung cancer patients in N. Ireland who were diagnosed in 2006, and also includes, for comparison, the results of the audit carried out by the Registry for lung cancer patients diagnosed in 1996 & 2001. There was evidence that risk factors for men appear to be declining, mainly smoking, however not so for women where incidences rates have remained constant. In addition, people resident in areas classified with high socio-economically deprivation have a higher risk of getting lung cancer. Many of the lung cancers patients presented with other smoking-related diseases (33% had



Above - Dr Anna Gavin, Mr Michael McGimpsey, Dr Liz Mitchell, Professor Gorman and Mrs Heather Monteverde

Below - Dr Finian Bannon, Dr Anna Gavin, Mrs Dorothy McVeigh and Mrs Heather Monteverde jointly launching two lung reports at Queen's University Belfast on Friday 3 April 2009



heart disease, and 29% had chronic obstructive pulmonary disease). Waiting times for receiving a CT scan, or seeing a respiratory physician were reduced, and 28% of patients received the relatively new sophisticated PET scan. Sixty-four percent of patients were considered by a team of health professionals at a multidisciplinary team meeting. Patients in 2006 experienced a slightly better one-year survival at 27% compared to those in 1996 and 2001 at 23%. Despite these survival improvements, survival still remains very low and, as this disease is caused by smoking (92% of patients had a history of tobacco use), the best way of reducing the burden of this distressing disease in the community is to reduce tobacco use.

The Lung Cancer Audit report was jointly launched with a complimentary report sponsored by Macmillan Cancer Support which documents the experiences of patients and their carers as they live with a diagnosis of lung cancer.

The Macmillan Report 'Patients' and carer's experiences of living with lung cancer in Northern Ireland' supports the need for the implementation of a lung cancer information pathway. This would facilitate a systematic, co-ordinated and equitable approach to the provision of information. The pathway should address the potential information needs of carers also.

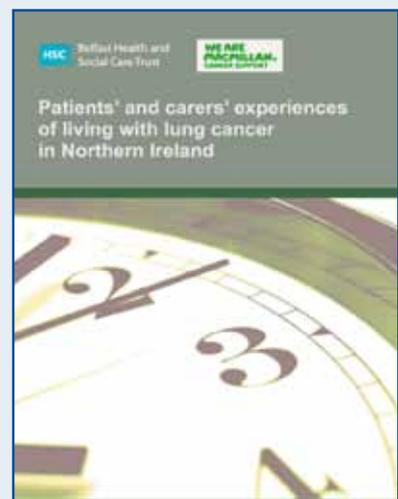
It highlighted the need for a "key worker" type role to help promote effective co-ordination and continuity of care. This would also help to prevent the feelings of

isolation and abandonment that some patients experience.

It recommended that:

- All patients and carers should have access to professionals who can provide expert advice re financial/social issues.
- Strategies/interventions which address nutritional issues and anxiety, fatigue and breathlessness management, should be introduced at an early stage in the patient's disease trajectory.
- The role of carers should be given greater recognition and their needs should be assessed at regular intervals.
- There should be equitable provision and ease of access to support services for carers, which address their practical, social and emotional needs.

- Bereavement support services for lay carers should be developed.
- There needs to be greater emphasis on implementing strategies to raise awareness of the early signs of lung cancer for both health care professionals and the general public.



Trends in Cancer Incidence

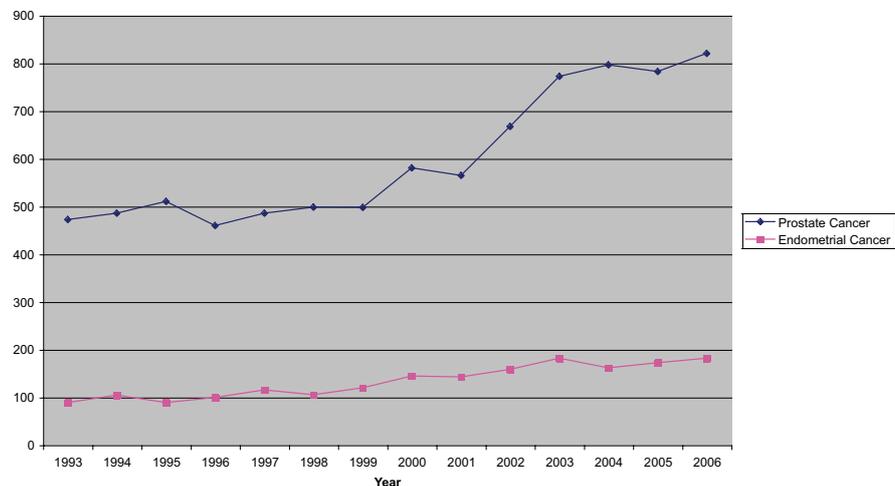
As Cancer is a disease mainly of the elderly, with an increasing older population the number of new cancer cases each year is rising in Northern Ireland from 8,392 in 1993 to 10,070 in 2006. Whilst over a quarter of all new cancer cases are non-melanoma skin cancers, there has been a steady increase in numbers of cancers at various cancer sites.

Cancer increases can also be explained by improved methods of cancer screening and detection, changing lifestyles and environmental changes.

Perhaps the most dramatic rise is that in Prostate cancer which in 1993 there were 473 new cases whereas in 2006 there were 821, nearly twice that of 1993. The reason behind the dramatic rise is the increased use of PSA testing to detect this cancer.

Skin Melanomas have also nearly doubled from 182 cases in 1993 to 259 in 2006. This probably reflects increased exposure to UV light which may also explain the similar rise in non-Melanoma skin cancers.

Cancer Incidence 1993-2006 for Prostate and Endometrial Cancers



As the population becomes more overweight, we are seeing an increase in cancers that have been associated with obesity. In particular, endometrial cancer in women has increased from 89 in 1993 to 182 in 2006.

A more detailed study of cancer trends in Northern Ireland which includes comparisons with the Republic of Ireland and other countries, can be found in our most recent publication "Cancer in Ireland 1994-2004: a summary report" which is available on our website: www.qub.ac.uk/research-centres/nicr/Publications

Business Plan

The N. Ireland Cancer Registry has since its inception produced an annual business plan. The format of this has changed keeping with the requirement of our current funders the Department of Health & Social Services. The business plan gives an overview of the work of the Registry, giving progress based on last years goals and objectives, it sets long and short term goals, provides a basis for the work of the Registry. A copy of the business plan will be available on our web page shortly at www.qub.ac.uk/nicr

Under the Review of Public Administration the funding for the Registry has moved from the Department of Health to the new Agency for Public Health and Social Well-being.

Cancer Referrals

The Northern Ireland Cancer Registry has analysed the cancer waits datasets supplied by the HSC Trusts and compiled an analysis of cancer referral patterns across Northern Ireland based on a total of 26,601 patients referred with a suspected cancer between September 2007 and August 2008.

The annual referral rate in Northern Ireland as a whole was 15.1 referrals per 1,000 members of the population. Overall referral rates for females (19.5) were almost twice that of males (10.4). Breast cancer accounted for 28.9% of all referrals, followed by skin cancer (15.6%), lower

gastrointestinal (13.6%) and urological (9.7%) cancers.

Referral rates in the Northern Board were higher than from any other Board areas by approximately 50% for both males and females. Variations in referral rate between Health Boards however may be a result of incomplete capture of all referrals in the Cancer Waits system. There was no difference in overall referral rate between the most affluent and most deprived deprivation quintiles.

Out of the 26,601 suspected cancers during Sept. 2007 – Aug. 2008 there were 6,903 confirmed cancers (26.0%). This percentage

was higher for males than females (Male: 36.9%, Female: 20.2%). The yield of actual adult cancers from referrals was lowest for breast cancer (15.5%), skin cancer (16.5%), head and neck cancer (17.1%) and lower gastrointestinal cancer (24.1%). The highest yield was from haematological cancer (80.5%) and lung cancer (63.1%).

The 6,903 confirmed cancers made up 71% of the total expected by NICR. Excluding 683 skin cancers (6,220) the number of confirmed cancers was 89% of the annual total expected (excluding NMSC and melanoma). This finding is encouraging as it predicts this as a valid source of timely data for the Cancer Registry.

Cancer Survivorship

In Oct 2006, Olinda Santin (3rd Year PhD Student) commenced a PhD in epidemiology and health services research designed to measure the health and social care needs and quality of life of cancer survivors. The project comprises several components including a policy review of cancer survivorship and a qualitative investigation of stakeholders' views and understanding of survivorship. The major component of the study, a collaboration with the Cancer Registry, involved mailing over 600 cancer survivors, requesting them to report their health and social care needs as a consequence of living

with cancer. The data from this study are currently being analysed to examine:

- the health and social care needs of colorectal cancer survivors, including service provision gaps
- quality of life of cancer survivors
- the relationship between quality of life and health and social care needs
- factors that influence health and social care needs such as cancer stage and time since diagnosis

This study will advance our knowledge about the issues faced by people after their treatment for

cancer has been completed, the nature and extent to which needs are being met and the quality of life experienced by cancer survivors. Olinda's PhD research is supervised by Michael Donnelly, Liam Murray and Anna Gavin.



Leukaemia Lymphoma Data

Ruth Kerr and Adeline Kell who previously worked for the Leukaemia Lymphoma Registry worked with the Cancer Registry for several months during 2008. During that time Ruth and Adeline were extremely helpful in assisting to improve the Registry's Leukaemia and Lymphoma data by accessing laboratory

information and transferring their skills and knowledge to other staff, we found their help invaluable. Ruth and Adeline have since transferred to other posts within Queens University School of Nursing and we would like to take this opportunity to thank them for all their hard work and wish them well.

Research Update

The N. Ireland Cancer Registry has received a grant from the Ulster Cancer Foundation to undertake a study of 'Why do Cancer Patients die in Acute Hospitals?' The latest figures for Northern Ireland show that 32% of cancer deaths occur at home, 49% occur in hospital with 10% occurring in hospices and 8% occurring in nursing homes. This study which has received ethical approval plans firstly to use routine administrative data and then for patients who die in hospital to examine their hospital records and determine factors associated with their disease, their stay in hospital etc. with the view to providing a report with recommendations and a peer review publication. The study is supported by a multi-agency project advisory group. Data collection has already commenced and the first reports from this work are expected in the middle of 2010.

The N. Ireland Cancer Registry is also working on the final stages of two reports documenting the care of patients diagnosed in 2006 with either prostate or colorectal cancer. These will compare the services with those already documented in 1996 and 2001, monitor the changing care of cancer patients resulting from the review of cancer services in the 1990's. Similar work on breast cancer is also ongoing.

Student placements

Timothy Vennard, a placement student studying for a BSc degree in Computing & Information Technology at Queen's University Belfast, completed a one year placement with the Registry in August 2008. His main duties were to assist with IT function of the Registry. During his time he performed PC troubleshooting and configuration work and enhanced various in-house databases (such as the requests for information system and the inventory database).

The Registry also had two summer placement students organised through Queen's Job shop. Tsvyata Gavrilova Donova, a native of Bulgaria and studying psychology at Queen's University Belfast, investigated demographic and treatment factors influencing the survival of patients suffering from oesophagus or stomach cancer.

Catherine Reaney, from Co. Down who was doing a masters in *Mathematics and Statistical & Operational Research* at Queen's, analysed data from patients who had melanoma skin cancer; the factors she investigated included age, sex, lesion location, and tumour characteristics. Both summer students brought dedication and enthusiasm to the Registry.

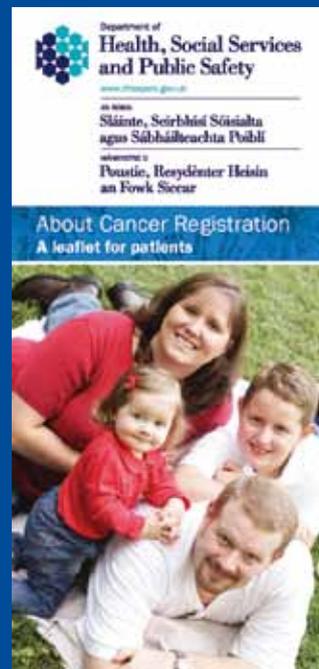
Bethan Holland, a student at Queen's University of Belfast, came to the Registry in February to complete her final year project. Bethan was studying for a BSc in Mathematics and Statistics and undertook a project within NICR. We wish her well in her future career.

Northern Ireland Link with Tumour Bank (NITB) Initiative

The NICR will be assisting in the setting up of a Biobank. Biobanks are organised collections of biological samples linked with well defined data sets and provide an important resource to support biomedical research programmes such as the development of molecular biomarkers. Biomarkers have the potential to open up new diagnostic, prognostic and disease monitoring tools, vital for the detection and treatment of cancer. NICR will be involved in managing the NITB information system and the associated hardware/network configuration, including providing advice on aspects of security. NICR will also with agreements link cancer registration data, including pathology data to the tumour bank data set. Integration with the N Ireland Virtual Tissue Archive (NITVA) containing high resolution images of the samples is also planned for the NITB.

Patient Information Leaflet

The Department of Health & Social Services have funded printing of leaflets which inform the public about the role of the cancer Registry. This leaflet is specific for Northern Ireland and replicates an initiative in the rest of the UK. Its development was encouraged by the new Privacy Advisory Committee for Northern Ireland. Full copies of the leaflet are available in the Cancer Centre, Cancer Units and General Practices. Copies of the leaflet may be downloaded from the N. Ireland Cancer Registry web site www.qub.ac.uk/nicr



The NICR goes to the UN!

Giulio Napolitano from the Registry is a co-author, with Ralf Barkemeyer from Queen's University Management School, of a paper entitled *The UN Global Compact: Moving Towards a Critical Mass or a Critical State?* The authors applied a medical statistics technique (Kaplan-Meier estimates of a survival function) to analyse and predict compliance levels of member companies of the UN Global Compact – a United Nations initiative to encourage businesses worldwide to adopt sustainable and socially responsible policies – and to report on their implementation. Information extraction and classification techniques, commonly used for the processing of pathology reports, will also be used in a related project. The paper will be presented at the "Social Issues in Management" track of the conference *2009 Academy of Management Annual Meeting*, 7-11 August 2009, Chicago, Illinois, USA (theme: Green Management Matters). The paper has also been selected for the Best Paper Proceedings of the conference. Only around 5% of all the papers accepted for presentation at this very high profile meeting (approximately 6000-7000 delegates are expected) enjoy a space in these proceedings.

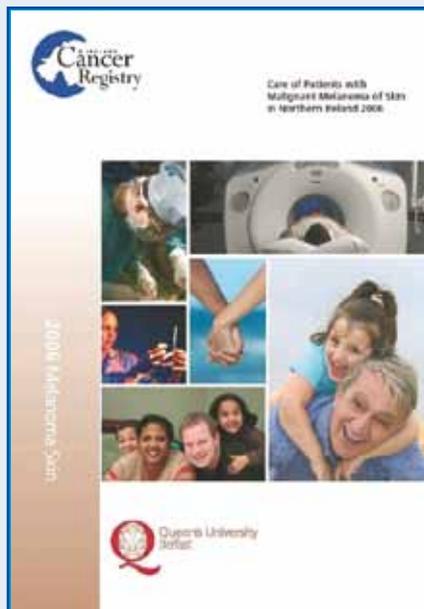
NCI Summer Prevention Scholarship

Dr Finian Bannon, Biostatistician, and Jackie Kelly, Nurse and Tumour Verification Officer have been accepted to attend the 'Principles and Practice of Cancer Prevention and Control' course from 6 – 31 July 2009 at the National Cancer Institute, Washington DC, USA, funded by the HSC R&D function of the Public Health Agency.

Malignant Melanoma Report

The N. Ireland Cancer Registry launched a report on the treatment of Malignant Melanoma, the most serious form of skin cancer in September 2008. Cases of malignant melanoma, a serious type of skin cancer, have almost tripled in Northern Ireland from 80 cases in 1984 to 254 cases in 2006. Patients tend to be younger than those diagnosed with other cancers, with a third of those under 50 at the time of diagnosis and nine under 25.

NICR has worked with local clinicians and the Northern Ireland Cancer Network (NICaN) to produce the report entitled the Care of Patients with Malignant Melanoma of Skin in Northern Ireland 2006. It documents the care that patients received including the hospitals they attended and the number of surgeons who performed operations.



Other findings were that melanoma in Northern Ireland is more common in women than men. In men, 70% of melanomas were on the head, neck and trunk areas, while in women almost half of the lesions occurred on their leg and feet. Unlike other cancers, it is seen more often in more affluent populations than those considered deprived.

The most common symptom of melanoma is an increase in size of the lesion, followed by a change in colour. Patients also reported that the lesion had nodules or bled as well as itching or ulceration.

The good news is that people in Northern Ireland have among the best survival rates for the cancer in Europe, with 98.8% of patients alive one year after being diagnosed. Over a fifth of patients had significant symptoms for over a year which points to the need for professionals to focus even more on highlighting the early signs of melanoma. These include increasing size of a mole or spot to greater than the blunt end of a pencil, a spot which bleeds or is itchy. If people are worried they should contact their GP who will decide if they need further referral."

As exposure to UV radiation from sunshine and sunbeds is the major risk factor for this cancer the advice for prevention is to take care in the sun and to avoid using sunbeds.

The full report can be seen at www.qub.ac.uk/nicr

CaPPS Update

The Cancer Patient Pathway System, a web-based enhancement of the NICR-developed MDT and Waiting Time monitoring systems, has now completed Phase II of its development. The enhancement is funded by the Department of Health and managed by DIS. The additional clinical modules for Urology, Head & Neck, Skin, Upper & Lower GI, Haematology & Neuro-oncology are now being implemented throughout the 5 HSC Trusts, involving trust-wide training of clinicians, clinical nurse specialists, secretarial & clerical staff and all other allied health professionals (radiographers, dieticians, social workers) involved in the cancer patient pathway. The developing team are currently working on the interface with the regional pathology reporting system "Labcentre", which for clinical governance reasons is of vital importance. Interfaces with the new regional web-based radiology system NIPAX and the Oncology prescribing & clinical information system are planned and will follow.

Poster Prize

Dr. Finian Bannon, Biostatistician at NICR, won the *Best Poster Prize at the 24th All-Ireland Social Medicine Meeting in Newcastle Co. Down 20-22 March 2009* with a poster entitled "Lung Cancer in N. Ireland 1996-2006: Changing Care Patterns and Improved Survival" which presented results on information collected on patients who were diagnosed with lung cancer in 2006.

Obituary

Anita Jones (1954-2009)

It was with great sadness that staff of the NICR learned of the passing of our dear friend and colleague Mrs Anita Jones on the 9th April 2009. Anita was formerly a member of staff in the University Health Service and in October 2004 joined the NICR culminating in over 30 years of service.

In Anita's short time with the Registry she made a valuable contribution to a number of studies. She would be the first to volunteer for any task and her work was always exemplary. Anita always had a positive approach and took great pride in her work. Her willingness to help and generous personality enriched the registry. Anita thrived on a challenge and her enthusiasm for problem solving and attention to detail led many to comment that she missed her calling in life as a Private Detective!

Anita touched the hearts of all who knew her. She was cheerful, caring and patient, as long as you weren't holding her back on the road! Her fun loving and mischievous character brought joy to our working day. Anita's unique and colourful personality was reflected in her love of vibrant colours and beautiful flowers, we often joked that one day we would arrive to work to find the office painted pink! This was Anita.

It was an honour to work with and know Anita. She had a tremendous sense of humour. Her ability to find a saying for everything, the twinkle in her eyes and her cheeky smile will always be remembered.

Toodle-pip!



Welcome

Welcome to our new staff

**Mrs Helen Wilson,
Secretary**

Farewell

Ms Breige Torrans

Miss Wendy Hamill

Dr Khaled Kasim

Breige Torrans (early retirement)

Breige Torrans, Registry Administrator took early retirement in Spring 2009 after almost 15 years with the N. Ireland Cancer Registry. Breige was the first member of staff to join Dr Gavin in establishing the Registry in 1994. We all wish Breige a long and happy retirement and thank her for her contribution to the Registry.

Recent Peer Reviewed Publications

- Cantwell MM, Murray LJ, Catney D, Donnelly D, Autier P, Boniol M, Fox C, Middleton RJ, Dolan OM, Gavin AT. Second primary cancer in patients with skin cancer: a population-based study in Northern Ireland. Br J Cancer 100, 174-177.
- Cantwell MM, Forman MR, Middleton RJ, Murray LJ. Association of early life factors and brain tumour risk in a cohort study. Br J Cancer 2008 Sep 2; 99(5): 796-9.
- Connolly D, Black A, Gavin AT, Keane PF, Murray LJ. Baseline prostate-specific-antigen level and risk of prostate cancer and prostate-specific mortality: diagnosis is dependent on the intensity of investigation. Cancer Epidemiol Biomarkers Prev 2008 Feb; 17(2): 271-8.
- Connolly D, Black A, Murray LJ, Gavin AT, et al. Repeating an abnormal prostate-specific antigen (PSA) level: how relevant is a decrease in PSA? Prostate Cancer Prostatic Dis 2008
- Connolly D, Black A, Murray LJ, Gavin AT, et al. The utility of prostate – specific antigen velocity thresholds in clinical practice: a population – based analysis. BTU 2008 Jun; 101(12):1507-12.
- Fleming I, Monaghan P, Gavin A, O'Neill C. Factors influencing hospital costs of lung cancer patients in Northern Ireland. Eur J Health Econ 2008 Feb; 9(1): 79-86.
- Gormley G, Connolly D, Catney D, Freeman L, Murray LJ, Gavin AT. Reporting of research data by GPs: a cautionary tale for primary care. BMC Fam Pract 2008 Jun; 25(3): 209-12.