

# N. IRELAND Cancer Registry



Centre for Clinical and Population Sciences, Queen's University Belfast, Mulhouse Building, Grosvenor Road, Belfast BT12 6BJ. Website: [www.qub.ac.uk/nicr](http://www.qub.ac.uk/nicr)

PROVIDING INFORMATION ON CANCERS FOR RESEARCH, PLANNING AND EDUCATION

ISSUE 13 JULY 2007

## 3rd All Ireland/NCI Cancer Consortium Conference



Queen's University  
Belfast



*Signing of the Memorandum of Understanding in Belfast: Mr Paul Goggins MP, Health Minister for Northern Ireland – Dr John Niederhuber, Director NCI – Tanaiste Mary Harney TD, Minister for Health and Children, Republic of Ireland.*

The 3rd All Ireland/NCI Cancer Consortium Conference took place 12-15 November 2006 at the Waterfront Hall in Belfast, to celebrate seven years of collaboration on cancer research and care on the island of Ireland supported by the U.S. National Cancer Institute. The conference was organised by a committee chaired by Dr Anna Gavin, Director of N. Ireland Cancer Registry. The meeting provided the occasion for the signing of an updated Memorandum of Understanding which defines this cooperative arrangement for the future. At the conference 470 delegates heard from over 50 speakers on the latest developments in cancer prevention (including the new HPV vaccine), pharmacogenomics, radiation oncology, nursing research, biomarkers, target discovery, drug development and palliative care. There were over 90 poster presentations in the areas of Cancer Epidemiology, Cancer Prevention, Cancer Service Organisation, Cancer Treatments, Supportive and Palliative Care. Those who attended also enjoyed a varied and entertaining social programme.

Thanks are due to the organising committee, speakers and the conference sponsors: Department of Health, Social Services & Public Safety Northern Ireland; Eastern Health & Social Services Board; National Cancer Institute; Department of Health & Children, Republic of Ireland; Research & Development Office; All Ireland Cancer Foundation; Belfast City Council; Beechvale; Queen's University Belfast; Health Research Board; Action Cancer; Almac; Institute of Public Health in Ireland; Irish Cancer Society; Ulster Cancer Foundation.

### 3rd All-Ireland Report

The N. Ireland Cancer Registry in collaboration with the National Cancer Registry (Ireland) recently secured funding from the Department of Health & Social Services Northern Ireland and the Department of Health & Children Republic of Ireland for a two-year project to produce a detailed report on cancer in Ireland. Work will commence in July 2007 with a completion date of June 2009.

### Also in this issue

- 1 MDM Support
- 2 New Version of NICR Registration System
- 3 Cancer Audits
- 4 Tumour Registration Training
- 5 Report on the Survival of Cancer Patients
- 6 NICR News
- 7 Recent publications

The results of a recent re-abstraction study to check data quality are on our website [www.qub.ac.uk/nicr](http://www.qub.ac.uk/nicr)

### Date for your diary

Launch of the '2nd N. Ireland Cancer Survival Report' will take place on Thursday 4 October 2007 at the Great Hall, Queen's University, Belfast.

## Registry Reviews

In November 2007 the Registry will undergo a Peer Review process with a strategic review in early 2008. This is part of the governance of the Registry as set out in the Agreement between the funding authority the DHSSPSNI and the host organisation Queen's University Belfast. Reports, when available, will be posted on the website [www.qub.ac.uk/nicr](http://www.qub.ac.uk/nicr)

**2005 data**  
available end of July  
[www.qub.ac.uk/nicr](http://www.qub.ac.uk/nicr)

# MDM Support

Dr Lisa Ranaghan and Mr Giulio Napolitano have, with the N. Ireland Cancer Network (NICaN) tumour subgroups, developed a multidisciplinary meeting (MDM) management system to facilitate the MDM process. These clinical databases not only enable the permanent recording of tumour-specific data required by minimum datasets, including cancer stage, but also the multidisciplinary management decisions from discussions of cancer patients. Systems are now available for haematology, upper GI, lung, breast, neurooncology, colorectal and head and neck cancers and include facilities for site specific staging and the monitoring of cancer waiting times. The Registry is also involved in training of MDM co-ordinators in the use of the system.

The Lung MDT Meeting (Belfast City Hospital) uses the MDM system. It was visited by representatives from the Department of Health, London who are working closely with Dr Mike Richards, the Cancer Tzar, Mr Chris Carrigan, National Co-ordinator Cancer Registries (England) and Ms Di Riley Associate Director Cancer Waiting Times National Cancer Action Team who reported:

“The lung MDT demonstrated many excellent areas relating to data collection tools and associated

processes, and we were particularly impressed with the following:

- Commitment and support from the entire MDT team, to improving the MDT, and maximising the use of available information electronically for that purpose.
- Total integration of the MDT Coordinator within the MDT team and recognition of the role.
- Collection of data ‘real-time’ to supplement data already entered into the system by the MDT coordinator/clinical teams.
- Projection of the MDT ‘Proforma’ to enable all the team to review information available for a patient and to validate/verify/update this, and, importantly to use this information when discussing a patient’s treatment plan.
- Combining the use of the MDT Data system with pathology/radiology system images, and other hospital systems e.g. PAS to enhance each discussion.
- Combining data collection with associated hospital processes, such as the creation of GP/onward referral letters, MDT minutes and records to go into the patient’s case notes.”

## Retirement



### Mrs Carmel Canning

Carmel was a Tumour Verification Officer with the Registry for ten years and contributed greatly to enhancing data quality. She is missed by her colleagues who wish her every happiness in her retirement.

## Welcome

**Dr Caughley** who recently retired from her position as a Histopathologist in Belfast Link Labs kindly agreed to take over Dr Jeffrey Robertson’s role in the Registry. We look forward to working with her and, like Dr Robertson, she will be working in a voluntary capacity.



### Ms Olwyn Dawson

A new Tumour Verification Officer has joined the Registry initially to work on a Barrett’s oesophagus study.



## New Version of NICR Registration System

Significant development work on the NICR registration system (known as the PRAXIS system) has been ongoing for the last 2 years.

We are currently implementing PRAXIS version 10 and have completed the data migration task. In addition to rebuilding all the data translation and validation routines, the next stage will involve re-definition of the rules to determine which pieces of data to keep to yield an accurate consolidated tumour registration. It is also planned to enhance the tumour matching algorithm and extend the code translations available within the system.

The data dictionary of the new system has been significantly extended to incorporate the National Cancer Data Set for England. This will benefit NICR by enabling the Registry to link audit data (such as provided by the RACC projects) and Multidisciplinary Team Meeting (MTM) data when it becomes available...watch this space!

Colin R Fox – IT Manager

# CANCER AUDITS (1996 & 2001 data)

The project investigating the impact of the reorganisation of cancer services in Northern Ireland for patients diagnosed in 1996 and 2001 is almost complete with the last report in the current series in its final stages. Since December 2005, audit reports for Cervix & Ovary have been published and Thyroid is currently with the printers. Published reports are available from our web site [www.qub.ac.uk/nicr/racc](http://www.qub.ac.uk/nicr/racc) or from the Registry.

Thanks to the clinicians who helped in the interpretation of data and writing of the final reports.

## OVARY AND CERVIX REPORT LAUNCH

### Key Findings are as follows: Cervix & Ovary (1996 compared with 2001)

- Evidence of centralisation and increased surgical specialisation in ovarian cancer services.
- Patients were more likely to have serum tumour markers and CT scans.
- Shorter delay from referral to first seen for ovarian patients.
- Improved survival for Stage III ovarian cancer patients.
- Increased use of chemoradiation for cervical cancer patients.
- Slightly increased delay from diagnosis to first treatment for cervical cancer patients.

### Thyroid Audit (2001/2 and 2004/5) recommendations include:

- The management of thyroid cancer requires input from various specialists in a regional multidisciplinary team meeting setting.

- Protocols for investigation and follow-up of thyroid cancer patients should be developed and their use audited.
- The use of fine needle aspiration should be further audited.

### New Audit Studies Underway

A new series of studies are planned to monitor cancer services for patients in Northern Ireland using data from 2005/2006. We plan to audit most of the sites from the first series as well as Melanoma and Head & Neck. This will allow comparisons to be made over a 10-year period. The first of the second series (Stomach & Oesophagus) is nearing completion and the key findings are as follows:

### Stomach & oesophagus (2005)

- There was a trend of earlier symptom reporting.
- Between 1996 and 2005 the use of CT scanning increased and was reflected in better initial staging assessments.
- The recording of stage TNM in the clinical notes showed a marginal improvement for stomach cancer only between 1996 and 2005.
- Intra-operative staging practices improved substantially between 1996 and 2005.
- Recording of multidisciplinary team meetings increased dramatically yet by 2005 only 61% of oesophageal and 42% of stomach patients had this recorded in their notes.
- There was evidence of improved patient selection for radical intervention.
- There was an improvement in survival for oesophageal cancer patients detected between 1996 and 2005, driven by improved selection of patients for surgery.
- There was, however, no evidence of service centralization.



*Ovary and Cervix Report Launch – Dr Yvonne Summers, Oncology – Belfast City Hospital, Professor Patrick Morrison, Genetics – Belfast City Hospital, Mrs Muriel Paterson – Eastern Health & Social Services Council Representative, Dr Linda Caughley, Cancer Screening – Belfast City Hospital, Professor George Kernohan, NHSS Council Representative, Ms Pauline Monaghan, Researcher – QUB, Dr Johnny Price, Gynaecology – Belfast City Hospital, Dr Anna Gavin, Director – N. Ireland Cancer Registry, Professor Roy Spence, Consultant Surgeon – Belfast City Hospital, Ms Janet Moore – DHSS&PSNI, and Ms Sandra McKillop, NICAN.*

## Tumour Registration Training

The NICR runs training courses based on the UKACR training materials for tumour registration staff. The course is modular covering topics including introduction to medical terminology, basic tumour biology, specific tumour sites and treatment and outcome measures. Currently there are 14

modules and, although stand alone, they do follow a pattern. Training materials are provided at no cost.

While the course has been designed for cancer registry staff, we have also had specialist nurses, clinical coders and other support staff attend. These

courses will be very useful for the recently appointed MDT co-ordinators. It is planned to run a full course early autumn 2007 and if you work in a hospital and would be interested in attending one, or all of the courses, please contact me for further details.

*Richard Middleton – Data Manager*

Telephone 028 9063 2577 or  
email: [r.j.middleton@qub.ac.uk](mailto:r.j.middleton@qub.ac.uk)

# Report on the Survival of Cancer Patients in Northern Ireland 4 October 2007

Patient survival is one of the best indicators as to the efficiency of diagnostic and treatment methods in an area. A report from the N. Ireland Cancer Registry due to be launched on 4 October 2007 aims to investigate a range of factors that have the potential to impact on patient survival and thereby allow an assessment of the effectiveness of cancer care in Northern Ireland.

The report presents the results of analysis of patients diagnosed with cancer between 1993 and 2004. It presents survival by sex, age and stage for different periods of diagnosis where information is available and the number of patients is large enough. For the main cancer sites survival for patients who have

already survived a given length of time is examined and investigations into the impact of deprivation and urban/rural factors on survival are conducted. Both traditional and recently developed methodologies are used in the report and the most up to date results from other European countries, USA and Canada are included for comparison.

This publication will be the third report from the N. Ireland Cancer Registry (NICR) detailing the survival of cancer patients in Northern Ireland.

Previous reports are currently available from the NICR web site: [www.qub.ac.uk/nicr](http://www.qub.ac.uk/nicr)

## Recent Publications

### N. Ireland Cancer Registry

- Factors influencing hospital cost of lung cancer patients treatment in Northern Ireland – European Journal of Health Economics, 2007; online awaiting publication.
- Skin cancer trends in Northern Ireland and consequences for provision of dermatology services – British Journal of Dermatology, 2007; 156(6): 1301–1307
- Prostate-specific antigen testing: uncovering primary care influences – British Journal of Urology International, 2006; 98(5): 996-1000
- Addressing a community's cancer cluster concerns – Ulster Medical Journal 2006; 75(3) 195-199

### Cancer Epidemiology & Prevention Research Group (CEPRG) Publications

- Methods of Calculating Prostate-Specific Antigen Velocity. Eur Urol. 2006 Dec 18;
- Risk factors for esophageal adenocarcinoma and Barrett's esophagus – results from the FINBAR study. World Journal of Gastroenterology.2007;13(10): 1585-94.
- A population-based association study of SNPs of GSTP1, MnSOD, GPX2 and Barrett's esophagus and esophageal adenocarcinoma. Carcinogenesis 2007;28(6):1323-8
- Malignancy and mortality in a population-based cohort of patients with coeliac disease or 'gluten sensitivity'. World J Gastroenterol. 2007;13(1): 146-51.
- TP53 and progression from Barrett's metaplasia to oesophageal adenocarcinoma in a UK population cohort. Gut. 2006 Oct;55(10):1390-7.

## Thanks

The Registry wish to thank **Professor Alun Evans** who recently resigned as chair of the Registry Management Group. Professor Evans worked tirelessly with the Ulster Cancer Foundation, Queen's University and the Department of Health in the late 1980s and early 1990s to establish the N. Ireland Cancer Registry. He has chaired the Management Group of the Registry since 1994 and is very pleased with the development of the Registry from its early days. The Registry now plays a vital part in monitoring cancers and works with clinicians, service planning and NICAN to improve service provision.



Thanks also to **Alan Charles**, the DHSSPSNI liaison officer for the Management Group, for all his hard work. We wish him well in his retirement.



**Professor Rod Hay**, Head of School of Medicine who will retire in September, has been a valuable member of the Management Group and we wish him the very best for the future.



**Dr Jeffrey Robertson** – A very special thank you to Jeffrey who volunteered his services to the Registry for many years following his retirement as a pathologist in the Belfast City Hospital. He was an invaluable member of the team and was responsible for setting out protocols for pathology registration.

