

## Health Minister Visits the Registry for the Launch of Upper GI Report



Professor James McElroy, Professor Gerry McCormac and Dr Anna Gavin welcomed Mr Michael McGimpsey, Health Minister to the N. Ireland Cancer Registry

Mr Michael McGimpsey, Health Minister for Northern Ireland visited the N. Ireland Cancer Registry on 17 April 2008 to launch an audit report on Upper GI Cancers and see the work of the N. Ireland Cancer Registry.

### Upper GI Report

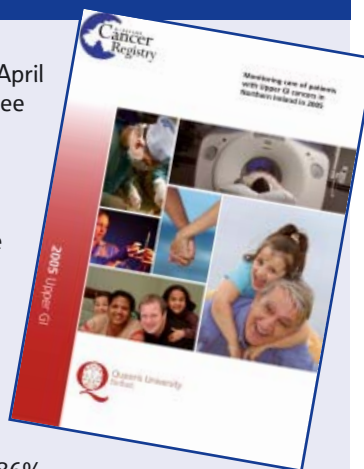
The report launched by the minister noted that there have been some remarkable changes in the delivery of oesophageal and stomach cancer services over the ten years to 2005 with:

- Trends of earlier symptom reporting,
- Increased use of new technology e.g. PET scanning,
- Improved recording of stage to 78% (oesophageal) and 86% (stomach),
- Increased discussion of patients at Multidisciplinary Team Meetings (MDM),
- Increased referral to dieticians, a very important service for patients whose nutrition has been compromised by the disease,
- Increased oncology referral (66% patients).

In all years, low numbers of procedures were still performed in many hospitals and there are still too many operators – 13 surgeons operated on 65 oesophageal cancer patients in 2005. For stomach cancer 23 Consultant Surgeons, 14 of whom did single operations, performed 54 procedures.

There was evidence of improved patient selection for radical intervention with subsequent improvements in survival for oesophageal cancer resection patients; this trend, however was not seen for stomach cancer patients. Despite the increase in Multidisciplinary Team Meeting activity, only 60% of oesophageal cancer and 40% of stomach cancer patients had their case discussed. The target is for all patients to have such a discussion. The report concluded that the development of services is ongoing and is a credit to those working with these difficult diseases that such progress had been made and recommended further audits.

The Registry wish to thank the NICaN Upper GI Subgroup and Mr Roy McMullan, Chair, N. Ireland Oesophageal Patients Group for their input to the report.



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### Coming Soon

- Melanoma audit report – available shortly, this includes data on 248 patients diagnosed with malignant melanoma of skin in 2006.
- 3rd All Ireland Cancer Report – in preparation – expected early 2009

### Date for your diary

4th All Ireland Cancer Conference  
Sunday 30 November – Wednesday  
3 December 2008 – Four Seasons  
Hotel, Dublin. For information on  
registration and general enquiries,  
please contact: Orla Cahalane,  
Conference Partners Ltd

Tel + 353 1 296 72 50 or  
Email [orlac@conferencepartners.ie](mailto:orlac@conferencepartners.ie)

2006 data available  
end of July at  
[www.qub.ac.uk/nicr](http://www.qub.ac.uk/nicr)

# Registry Peer Review



Reviewers and observers; Mr Chris Carrigan, National Co-ordinator Cancer Registries (England), Ms Lucy Ellis-Brookes, Network Information Manager (Avon, Somerset and Wilts), Mr Roy McMullan, Service User, Dr Julia Verne, Director (SWPHO & SWCIS), Mr Mike Vincent, Service User, Ms Sheila Pass, Registration Manager (NYCRIS), Dr Elizabeth Davies, Senior Lecturer – Cancer Registration (Thames), Mr Andy Smith, Head of IT (Trent Cancer Registry) with Dr Anna Gavin Director N. Ireland Cancer Registry

The N. Ireland Cancer Registry was peer reviewed using the review mechanism which is mandatory in England see [www.cquins.nhs.uk](http://www.cquins.nhs.uk) A copy of the Peer Review Report which was very favourable is available at [www.qub.ac.uk/nicr](http://www.qub.ac.uk/nicr). It summarised that the Review Team was ***“impressed by the remarkable achievements made by the Northern Ireland Cancer Registry since its inception 13 years ago. Over that time, it has established an active cancer intelligence service, firmly embedded in health service provision in Northern Ireland. It is making a real difference to the delivery of patient care and acts as a support and catalyst to clinicians, charities and decision makers.”***

It also identifies concerns, further considerations and examples of good practice. These are outlined below.

The reviewers were concerned about the lack of a clear legal framework for cancer registration in N. Ireland. They identified that further considerations should be given to:-

- Including audit work and continued development of MDT databases.
- Expanding staff numbers and skill mix to maintain the cancer intelligence function.
- Negotiating Service Level Agreements (SLAs) to improve access to Trust held data.

It identified the following themes of good practice against all topics examined:-

- The high level of engagement with a wide range of stakeholders and the proactive approach to disseminating work and results into the public domain.
- Evidence of strong governance arrangements, financial and managerial, supported by a well established proactive approach to securing additional funding.
- Proactive and innovative use of electronic data sources to enhance the quality and completeness of their database.
- The extensive and wide range of outputs using the Registry’s data, through audit and epidemiological reports, peer reviewed publications and by the Registry’s international research collaborations.
- The high level of stakeholder engagement.
- The use of Tumour Verification Officers to consolidate audit and quality assurance by reference to medical case notes.
- The electronic derivation of staging information and the Quality Assurance process in place to validate the scores.

We in the Registry wish to thank all who have helped us over the past 14 years, especially the members of the Registry Management Group and Council and those who helped us in relation to this review.



# MDT System - Innovation in Oncology Award 2007

Registry staff Mr Giulio Napolitano and Dr Lisa Ranaghan won the 2007 N. Ireland Innovation in Oncology Award. They developed an electronic system for the Multidisciplinary Team process. It records the clinical team's decisions on cancer investigations, diagnosis, stage and treatment plan during their regular clinical meetings. This system improves the quality and completeness of information collected, especially stage of tumour. Communication among professionals, especially in primary care, has improved by

the immediate generation of letters. The system also helps monitor cancer waiting times.

The judges felt this project had the potential to improve multidisciplinary management of all cancer patients in Northern Ireland. Development is already under way for a province wide web-based integrated system.

Thanks to the four Health Boards and the Department of Health which have funded this project and to the NI Medical Review who organised the event.



## Colorectal Polyp Register (Dr Khaled Kasim)



Dr Kasim, a trained public health doctor with a PhD in Epidemiology, has joined the Registry on an Ulster Cancer Foundation funded project to establish a colorectal polyp register for Northern Ireland.

### This work will allow us to learn:

- The age and sex distribution of patients with polyps and the rate of recurrence.
- The occurrence of colorectal cancer over time in this group.
- What factors are associated with development of malignancy for example polyp type, size, location, multiple polyps?
- Whether there has been a shift in stage of colorectal cancer at diagnosis over this time period?
- What patterns of surveillance are employed in patients with colorectal polyps and what are the estimated costs of surveillance?

- What impact the national bowel cancer screening programme will have on the diagnosis of colorectal polyps after 2009 in N. Ireland?

Ms Arlene Spiers, Chief Executive of the Ulster Cancer Foundation said that the proposed research is of major public health and clinical importance.

“The development of the polyp register will advance our understanding of colorectal cancer and will provide invaluable information on the effectiveness of the NHS bowel cancer screening programme. It also holds potential to add to the international literature on the natural history of bowel cancer.”

# Publications

## Launch of Survival Report

Survival of Cancer Patients in Northern Ireland: 1993 – 2004 shows relative survival rates have improved in both males and females diagnosed from 1997 - 2000 compared with 1993 -1996. Between 1993 and 2004, there was a drop of 1.3 per cent in male death rates and 0.8 per cent in female death rates. The study also included Eurocare 4 data which allows comparison of information between 83 cancer registries in 22 European countries. The inclusion of Northern Ireland for the first time in this study is in itself a very important development as it allows direct comparison of our survival with that from other countries. Full report available on request from N. Ireland Cancer Registry or online at [www.qub.ac.uk/nicr](http://www.qub.ac.uk/nicr) Thanks to NISRA who facilitated the secondment of Dr Donnelly to work on this report.



Dr Elizabeth Mitchell, Deputy Chief Medical Officer, Department of Health, Social Services and Public Safety Dr Anna Gavin, Director, N. Ireland Cancer Registry and Dr David Donnelly, Biostatistician, N. Ireland Cancer Registry at report launch on 4 October 2007.

## THYROID REPORT

This report audited the care of 168 thyroid cancer patients diagnosed over four years 2001/2 and 2004/5. Working with clinicians involved in the treatment of thyroid cancer, the following recommendations were made:

- Management of thyroid cancer – a complex clinical scenario – 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.

The Registry wish to thank the clinicians who helped with this report and the patients whose stories, contributed anonymously, are included.



All reports are available from our website [www.qub.ac.uk/nicr](http://www.qub.ac.uk/nicr) or in hard copy by contacting the Registry on Tel 028 9063 2573

## Peer Reviewed Publications

- Gormley G, Connolly D, Catney D, Freeman L, Murray LJ and Gavin A. *Reporting of research data by GPs: a cautionary tale for primary care researchers* - Family Practice 2008 25(3):209-212; doi:10.1093/fampra/cmn013
- Connolly D, Black A, Gavin A, 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;17(2) February 2008

## Patient Information Leaflet

The N. Ireland Cancer Registry is in the process of finalising a patient information leaflet 'About Cancer Registration' which will be made available in hospitals, GP surgeries, cancer charities, and on-line. It is planned that this will be incorporated into a generic information pack which NICaN are developing for patients. It will be accompanied by additional information on the Registry website - Frequently Asked Questions at [www.qub.ac.uk/nicr](http://www.qub.ac.uk/nicr)

### A Future Legislative Framework for Cancer Registration

The N. Ireland Cancer Registry is registered under the Data Protection Act and is funded by the Department of Health to undertake its work. It is however becoming increasingly difficult to guarantee smooth transfer of data on all patients without some form of legislation which allows secondary use of patient health data. This is recognised by the

recently established Privacy Advisory Committee for N. Ireland. A recommendation has been made to the N. Ireland Department of Health, Social Services and Public Safety to explore setting up a legislative framework to cover cancer registration. This is a move welcomed by the Cancer Registry as it would ensure data and allow full use of Registry data while still protecting patient confidentiality.

## Welcome

Welcome to our new staff

Ms Adeline Kell, Data Abstractor, Leukaemia & Lymphoma

Ms Ruth Kerr, Data Abstractor, Leukaemia & Lymphoma

Dr Khaled Kasim, Research Assistant on the Colorectal Polyp Register

## Farewell

Dr Ann Smith, Biostatistician

## Congratulations

Congratulations also to Julie McConnell on the birth of her son Sean Michael on Tuesday 26 February 2008

# IARC Collaboration



Dr Philippe Autier and Dr Mathieu Boniol, International Agency for Research on Cancer were joined by Dr Harry Comber, Ms Anne-Elie Carson and Dr Frances Drummond, National Cancer Registry Ireland; Professor Liam Murray and Dr Marie Cantwell, Cancer Epidemiology and Prevention Research Group; Dr Anna Gavin and Dr Richard Middleton, N. Ireland Cancer Registry and Mr David Connolly, Urologist for the second day of a two day symposium to work on common areas for cancer research. Work is progressing on skin cancers, prostate cancer and breast cancer.