

# N. IRELAND Cancer Registry



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Providing information on cancers for research, planning and education.



## 2nd All Ireland Cancer Report

The 2nd All-Ireland cancer report, produced collaboratively by the N. Ireland Cancer Registry and the National Cancer Registry (Ireland) was launched 1st September 2004. It examined data from both regions to assess cancer incidence and mortality on the island of Ireland. The report focused on cancers that are life-threatening, represent a substantial burden to the general population and could be prevented or cured. Additionally, all childhood cancers and lymphoma were profiled since these are often a concern to the public, researchers and policy makers. (Each year there are over 19,000 new cancer cases and 11,000 cancer deaths throughout Ireland).

As well as supporting an extension of the smoke free workplace initiative to Northern Ireland the report recommended that the Republic increase its breast cancer screening services. While breast cancer is the leading cause of death for women across Ireland, mortality rates in Northern Ireland, where screening programmes are well established, have fallen by more than 20 per cent between 1994 and 2000. In the Republic breast cancer mortality rates were the same in 2000 as they were in 1994.

The report revealed that incidence and mortality rates for prostate cancer in the Republic of Ireland are significantly higher than those in Northern Ireland. Increased PSA testing may be responsible for the rise in incidence rates as well as the variation in rates between regions. The report pointed out that the benefits of prostate cancer screening are unclear. Added to this uncertainty is the widespread and growing use of PSA tests. Further research into this has been

facilitated by a grant from the Northern Ireland Research & Development Office and the Health Research Board, Ireland.

The report revealed that for childhood cancers, incidence and mortality rates are the same or lower than the rates in the EU and the US. The five year survival rate for all children in Ireland is essentially the same as in the US and better than in Europe.

The report was jointly funded by the Department of Health, Social Services and Public Safety, Northern Ireland and the Department of Health and Children in the Republic. It was compiled by Joe Campo who spent a year on secondment from the Washington State Cancer Registry, USA.

The full report and summary are available on websites [www.qub.ac.uk/nicr](http://www.qub.ac.uk/nicr) and [www.ncr.ie](http://www.ncr.ie)



At the launch of the 2nd All Ireland Cancer Report.

Dr Jim Kiely, Chief Medical Officer, Ireland; Mr Joe Camp, Researcher; Dr Anna Gavin, Director, N. Ireland Cancer Registry; Dr Harry Comber, Director, National Cancer Registry, Ireland; Dr Henrietta Campbell, Chief Medical Officer, Northern Ireland and Professor Peter Gregson, Vice-Chancellor, Queen's University, Belfast

### ALSO IN THIS ISSUE

1. Cancer Survival Collaborations
2. Research Update
3. Fellowship Awarded
4. Staging Update
5. RACC Reports
6. ICT Security Improvements
7. European Automated Cancer Registration
8. Staff News

# CANCER SURVIVAL COLLABORATIONS

The N. Ireland Cancer Registry is providing data for several European wide collaboration studies examining cancer survival. These include:

**1. EUROCARE**, a research collaboration established in 1989, which currently involves population-based cancer registries in 20 European countries. Northern Ireland is now in a position to join the collaboration and results are expected by summer 2006.

**2. CONCORD study - completion of Phase 1 in 2005**  
The CONCORD study was designed to compare population-based survival from cancers of the breast (women), large bowel and prostate between Europe and North America, by extending the geographic comparisons of the EUROCARE study.

It is expected that CONCORD comparative analyses of cancer survival will cover about 80 territories in 27 countries on four continents. Datasets have now been received from the USA, Canada, Australia and Japan, as well as from many registries throughout Europe.

Northern Ireland have already submitted data. Results of analysis are also expected in 2006.

### 3. UK & Ireland Cancer Survival Project

The aim of the UK & Ireland Cancer Survival Project is to produce, for the first time, comparable cancer survival rates for NI, ROI, Scotland, England and Wales, resolving various discrepancies in data preparation, analysis and presentation in the process. Analysis for this project is now complete and results will be published in Autumn 2005.

### 4. Cancer Atlas of Britain and Ireland

The atlas which includes data from Wales, Scotland, England, and for the first time, Northern Ireland and the Republic of Ireland published by ONS and launched 5 July 2005. This is available on the ONS website [www.statistics.gov.uk](http://www.statistics.gov.uk).

## RESEARCH UPDATE

### *The Finbar Study*

This all-Ireland case control study funded by the NI Research and Development Office, the Health Research Board, Ireland and the Ulster Cancer Foundation has completed recruitment. 227 cases of oesophageal adenocarcinoma, 224 Barrett's oesophagus patients and 260 normal controls have been enrolled into the study. The data are currently being analysed and papers will soon be submitted to high scientific journals. Preliminary findings were presented at Digestive Diseases Week in Chicago, USA in May 2005. The study has also been included in a National Cancer Institute Consortium of case control studies of Barrett's oesophagus and oesophageal adenocarcinoma (BEACON).

### *The Extension of the NI Barrett's Oesophagus Register*

This study, funded by the NI Research and Development Office, is well underway. Data abstractors from the NICR are undertaking case note reviews of patients on the register to confirm the presence of Barrett's oesophagus and collect clinically relevant data. The extension of the register will enable the risk of cancer in Barrett's oesophagus to be better characterised.

### *The North/South Prostate Specific Antigen Study*

This study, is a collaborative project between NICR and the National Cancer Registry, Ireland (NCRI). It is funded by the NI

Research and Development Office and the Health Research Board, Ireland and has commenced with the appointment of research assistants in NCRI (Dr Frances Drummond) and NICR (Ms Amanda Black). The two year study will examine patterns of PSA testing in NI and ROI with the aim of determining whether differences in the use of PSA testing were responsible for differences in the trends of prostate cancer incidence between the two areas during the 1990s, i.e. increasing incidence in ROI but relatively stable incidence in NI, while prostate cancer mortality remained stable in both areas.

### *The PSA Follow-up Study*

This study funded by the NI Research and Development Office aims to follow-up a group of men from Northern Ireland who had PSA tests done in the mid 1990's. Mr David Connolly, Specialist Registrar in Urology is co-ordinating the study. The study aims to quantify the risk of prostate cancer in men who have moderately raised PSA levels.

### *Pancreatic Cancer Case Control Study*

This all-Ireland case control study of pancreatic cancer, which is a collaboration with the NCRI and clinicians from throughout Ireland, is in the planning stages. An application for funding to the Ulster Cancer Foundation was successful.

# 5 YEAR ACADEMIC FELLOWSHIP AWARDED

Dr Lesley Anderson recently completed her PhD in cancer epidemiology and has been working at the NICR



as a research fellow since August 2004. Dr Anderson is the first person to be awarded a 5 year academic fellowship in cancer prevention at Queen's University Belfast, which is due to commence shortly. She has also been awarded a very prestigious cancer prevention fellowship from the National Cancer Institute, Maryland, USA which will be incorporated into the first 3 years of the academic fellowship. She will complete a Masters in Population Health Based Evidence from the University of Manchester before going to the National Cancer Institute for 27 months. On her return she will be working within the Centre for Clinical and Population Sciences in the field of cancer epidemiology.

## Update: Electronic tumour staging tool - Dr Lisa Ranaghan

Our electronic tumour staging tool is currently being upgraded by the Registry IT staff prior to its launch on the Cancer Centre network. As a web-based program, multi-user access is possible and TNM updates can be managed centrally. This process should be completed by September 2005.

## RACC Update

There has been good progress made on the Regional Advisory Committee on Cancer project investigating the impact of the reorganisation of cancer services in Northern Ireland on care pathways. To date, audit reports for 3 main cancer sites: Oesophagus & Stomach, Breast and Prostate have been published. A further two, Lung and Colon & Rectum, are almost complete with the remainder due by the end of 2005. Data analysis is currently being undertaken for Pancreatic cancer while Ovary & Cervix and Thyroid will be analysed later this year. 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.

The reports each contain patient stories in addition to detailing the patient care pathway. They also have a detailed section on staging.

### Key findings for the 3 completed audits are as follows:

#### 1 Oesophagus & Stomach

- The process of centralisation of oesophageal cancer surgery had progressed with increasing surgical specialisation evident.
- Recording of multidisciplinary team meetings, treatment plan, stage and discussion of diagnosis with the patient had improved, but further improvement is necessary in this area.

#### 2 Breast

- The process of specialisation has progressed with waiting times reduced.
- There was better use of diagnostic tools eg. Oestrogen receptor status which had resulted in better targeting of treatment, and although staging practices had improved, further work is required.
- Recruitment to clinical trials had improved.

#### 3 Prostate

- Rates of radical prostatectomy and radical radiotherapy increased markedly.
- Recording of Gleason score improved considerably.
- Although more patients were referred to oncologists, there was little evidence that multidisciplinary meetings had taken place.
- Observed survival improved between 1996 and 2001 but this is likely to reflect lead time bias due to increased PSA testing and the age shift. Patients diagnosed in 2001, on average, were younger by 3 years than those diagnosed in 1996.

The reports documented patient delays in presenting with symptoms. One in 12 women with breast cancer had symptoms for more than one year before presentation. This highlighted the need to raise population awareness about symptoms.

For oesophageal and stomach cancers it was recognised that the high rate of emergency presentations pose difficulties for those trying to reorganise services.



# ICT Security improvements, updates and research

## ICT Security improvements, updates and research

### Improvements

A server room with a dedicated power line and ventilation system has been provided so that the risk of faults due to fluctuations in the mains power and in the environmental temperature is minimized.

A secure, stand alone link to the HPSS network has been installed.

### Research

Our efforts in enhancing ICT Security and protecting patients' data have been rewarded by the publication of a Letter, Mole D; Fox C; Napolitano G. *Electronic data protection: procedures need drastic improvement*, BMJ 2005;330:537. In this some issues concerning the ICT Security practices adopted by a small sample of Northern Ireland consultants are highlighted.

## System Developments

The PRAXIS user group (consisting of Thames, Trent, Northern & Yorkshire, Mersey, North Western and N Ireland Registries) is working closely with commercial partners Wealth Management Software to complete the first phase of development of graphical user interfaces for the system by end of July 2005. This will provide new screens for manually registering new cases of cancer and amending data on existing cases.

It is anticipated that the second phase of the development, the batch processing functionality, will begin in September 2005.

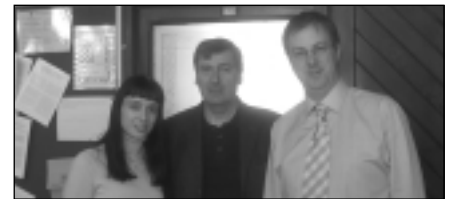
## New Data

Meanwhile, significant modifications have been made to the data dictionary of the system and the back-end database software. These modifications will allow for much more data to be held – for example, on patient waiting times, care plans and the patient pathway in general. In England, it will be mandatory to provide cancer registries with many new data items, hence the drive for change and need for PRAXIS to be capable of processing and storing the new data. In Northern Ireland, it would appear from a survey completed by the NICR, that many of our data provider systems cannot supply much of the new data. However, NICR will at least have the capability to cope with such data if it becomes available in the future.

Finally, NICR are leading a project on behalf of our partner registries, to document the rules used by the PRAXIS system to register cancers. Such rules are logic based and involve such functions as data validation, patient and tumour matching and data consolidation. NICR are currently documenting the existing rules used within PRAXIS with a view to agreeing consistent standards across all PRAXIS registries. Eventually, it is intended that the results of this work will be shared and made available to all UK cancer registries.

## European Automated Cancer Registration

We are continuing to forge links with other registries in the UK and Europe who are currently, or hope to do more of their cancer registration in an automated fashion. The NICR is a co-founder of the ENCR Automated Cancer Registration Group and members of the group visited the Registry to discuss future plans. The group hopes to expand its work through offering courses, facilitating visits to registries and providing a framework for standardisation of automated registration practices.



### Pictured are:

Dr Ariana Znaor, Croatia National Institute of Public Health and heads the Croatia Cancer Registry where they are currently working on ways to improve automated cancer registration.

Dr Lorenzo Simonato, Institute of Health, University of Padova, Italy. He is a leader in this field having set up automated cancer registration in several regions in the North East of Italy.

Mr Chris Carrigan, National Co-Ordinator for Cancer Registration in England. Chris, in a previous post, was responsible for installing and helping us to develop the automated registration system used by the NICR today.

## STAFF NEWS

As part of the initiative supported by the Ireland/Northern Ireland/National Cancer Institute Consortium on Cancer, Dr Richard Middleton has secured a place on the National Cancer Institute "Principles and Practice of Cancer Prevention and Control" course held in Washington DC USA this July

Congratulations to Pauline Monaghan on the birth of her son Thomas Steven on 29 December 2004.

Congratulations also to Julie McConnell on the birth of her daughter Meave on 20 March 2005.