

N. IRELAND

Cancer Registry



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

Providing information on cancers for research, planning and education.



2004 Data Available
End of July
www.qub.ac.uk/nicr

Date for Your Diary

3rd All Ireland Cancer Conference

13-15 November 2006

Working together to reduce the burden of cancer in Ireland

The 3rd All Ireland Cancer Conference, will take place at the Waterfront Hall 13-15 November 2006.

It will offer a wide range of topics, from basic research through cutting edge clinical practice to survivorship. World experts will present the state of the art in Ireland and the USA in most areas of cancer research and practice. The programme includes sessions on:

- cancer – state of the science
- cancer prevention
- biomarkers
- prostate cancer
- cancer deprivation – advocacy
- palliative care and quality of life

- advances in cancer care
- nursing and clinical trials
- pharmacogenomics
- new frontiers in haematological malignancies
- target discovery and drug development
- radiation oncology
- funding cancer research

The conference serves as an opportunity to reflect upon past accomplishments but, more importantly, to plan for future activities.

This conference is being organized on behalf of Ireland-Northern Ireland-National Cancer Institute (Washington DC) Cancer Consortium which was formed through a Memorandum of Understanding in 1999. Since the signing of that document, much

has been accomplished as the parties have worked together to enhance the island's ability to conduct world-class cancer research and thereby improve cancer prevention and cancer care for all the people of Ireland.

The cost of registration at the conference is being kept low to encourage attendance, early booking is advised.

POSTER ABSTRACTS SHOULD BE SUBMITTED BY 8 September 2006 in categories of epidemiology, prevention, basic science, treatment, survivorship, palliative care, service organisation.

Website: www.happen.co.uk/aicc2006

Sponsors



Pancreas Report Launch



Mr Lloyd McKie, Surgeon and Dr Anna Gavin, Director N. Ireland Cancer Registry, at the launch on 30th March 2006 of the audit report on Pancreatic Cancer, the sixth report in a series of eight. This report recommends that:

- One specialist Pancreatic Cancer Team should be identified for Northern Ireland. All Trusts and GPs should be informed of this and have information on referral and advice protocols.
- There should be one hepatopancreatobiliary unit for Northern Ireland which should forge links with other similar centres outside Northern Ireland.
- Research into the cause of pancreatic cancer and possibilities for earlier detection eg.via tumour markers should be funded.

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RESEARCH UPDATE

The finbar study

The first paper¹ from this all-Ireland case control study of oesophageal adenocarcinoma (OAC) examines the apparent protective effect of aspirin and non-steroidal anti-inflammatory drugs against the development of Barrett's oesophagus and OAC. Other papers are in preparation or have been submitted for review to scientific journals. Two research grants have been submitted to NI Research and Development Office to fund further analyses within the finbar study. The second meeting of National Cancer Institute Consortium of case control studies of Barrett's oesophagus and OAC (BEACON), which includes the Irish finbar study, was held in Los Angeles on 19th and 20th May 2006. Plans for pooling some of the data and specimens from the participating studies are underway.

1. Anderson LA, Johnston BT, Watson RG, Murphy SJ, Ferguson HR, Comber H, McGuigan J, Reynolds JV, Murray LJ. Nonsteroidal anti-inflammatory drugs and the esophageal inflammation-metaplasia-adenocarcinoma sequence. *Cancer Res.* 2006;66(9):4975-82

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 NICR are midway through case note reviews of patients on the register to confirm the presence of Barrett's oesophagus and collect clinically relevant data. Pathological data have been received to enable the register to include data up to the end of 2005. This register will allow further study of the risk of adenocarcinoma of the oesophagus in people with Barrett's oesophagus.

The North/South Prostate Specific Antigen Study

This collaborative project between NICR and the National Cancer Registry, Ireland (NCRI) is approaching the end of its first year. Relevant

PSA and prostate biopsy data is being collected in both Northern Ireland and the Republic of Ireland. The project aims to determine whether differences in the use of PSA tests underlie the differences in prostate cancer incidence between the two areas i.e. an increasing incidence in ROI but relatively stable incidence in NI. Prostate cancer mortality is stable in both areas.

The PSA follow-up study

This study funded by the NI Research and Development Office is following a group of men from Northern Ireland who had PSA tests done in the mid 1990's. Dr David Connolly, Surgeon, is co-ordinating the study. The study aims to quantify the risk of prostate cancer in men who have moderately raised PSA levels. The study should be complete at the end of 2006.

Pancreatic Cancer Case Control Study

This all-Ireland case control study of pancreatic cancer, which is a collaborative effort with NCRI and with clinicians from throughout Ireland, has received initial funding from the Ulster Cancer Foundation and the Health Research Board, Ireland. It is anticipated that the study will start in July 2006.

The Cancer Epidemiology and Prevention Research Group

Research being undertaken by NICR staff and allied staff within the Centre for Clinical and Population Sciences (QUB) is to be grouped under the umbrella of a 'Cancer Epidemiology and Prevention Research Group' (CEPRG). This group aims 'to undertake research of clinical and public health relevance aimed at preventing cancer and improving the quality of life and survival of patients diagnosed with cancer'. The studies mentioned above will form part of the work of the group.

THE SMARTER WAY TO DO THINGS (Dr Lisa Ranaghan and Mr Giulio Napolitano)

Web-based tumour staging tool development - Update

This tumour staging tool developed by Dr Lisa Ranaghan and Giulio Napolitano of the Registry aims to promote the recording of cancer minimum dataset tumour staging information by cancer clinicians when they see the patient.

This electronic tumour staging programme, for use with hospitals, provides clinicians with rapid access to an electronic (book-free) method to enter tumour details. These are then automatically staged. This is currently being piloted. When testing is complete it will be hosted on the Belfast City Hospital Intranet.

This project was supported by a grant from each of the four Health & Social Services Boards.

Electronic System for Multidisciplinary Cancer Management

This project has designed an electronic system to record details of the care pathway for multidisciplinary team meeting discussions for use by cancer clinicians within the region. Since May 2005 systems for Haematological, Lung, Oesophagogastric, Colorectal & Breast cancer have been developed and piloted and are now available for use. These systems support the extremely important multidisciplinary management of cancer providing summary data for clinicians automatic referral letters, including letters to GPs. The extracts from these databases are also a rich source of good quality, timely data which will facilitate the production of comprehensive reports on the cancer care pathway. This system also facilitates communication within the team, with other specialists in the referral pathways and back to the GP.

Further details are available from Dr L Ranaghan – e.ranaghan@qub.ac.uk

Quality Assurance of Data

It is a common question asked of a cancer registry, "How do you know your data is any good?" There are a number of quality measures that have been agreed at a national and international level to access data ascertainment and quality. The NICR is constantly looking for new ways to ensure that the information is timely and as accurate as possible. We are part of the UKACRs* Quality Assurance Group which compares data quality throughout the UK and ensures that cancer registries perform the best way possible to provide accurate data.

In addition to the activity of the QA group, we have instigated a policy of re-abstraction of a portion of all our data and compared key registration data items of the re-abstracted information with that on our database. To check the validity of data of registration for the 6,737 malignant cancer cases (excluding non-melanoma skins) diagnosed in 2002, 351 cases representing over 5% of the data base for that year were reviewed by two of our most experienced Tumour Verification Officers Mrs. Bernadette Anderson and Mrs. Carmel Canning. They examined primary source material for these cases which included histopathology reports and patients' medical records.

The result of the project showed that the overall quality of the data was very good and that most of the data items agreed with the data re-abstracted. Problem areas were identified, notably in the "site" and "date of diagnosis" of the tumour. A small number of cases were affected and represent only a few percent of the cases examined. We have altered our procedures accordingly and hope to repeat the process next year on 2003 data.

*UKACR = United Kingdom Association of Cancer Registries

RACC Update

The Regional Advisory Committee on Cancer project investigating the impact of the reorganisation of cancer services in Northern Ireland for patients diagnosed in 1996 and 2001 is nearing completion. Since July 2005, audit reports for a further 3 main cancer sites have been published: Lung, colorectal and Pancreas. The Cervix and Ovary report is almost complete, while further data is being gathered for the thyroid report. Published reports are available from our web site www.qub.ac.uk/nicr/racc or from the Registry.

Key Findings are as follows:

1 Lung (1996, 2001)

- Patients presented earlier and there was evidence of better management by primary care.
- Waiting times had improved.
- Recording of multidisciplinary team meetings had improved.
- There was better use of diagnostic tools resulting in better targeting of treatment.
- Survival improved for surgery patients to 55% observed survival at 2 years reflecting appropriate patient selection.

2 Colorectal (1996, 2001)

- There was better initial and intra-operative staging.
- More patients were being operated on by surgeons with a workload of over 20 patients per year.
- Recording of multidisciplinary team meetings, treatment plan, stage and discussion of diagnosis with the patient had improved.
- The process of specialisation in colon cancer surgery had progressed slightly.
- There had been some specialisation of rectal cancer services.

3 Pancreas (2001)

- A high percentage of patients presented with metastatic disease.
- Survival is very poor with only 10% of patients alive at one year after diagnosis.
- There is a lack of service centralisation – too many surgeons in too many hospitals are performing surgery.



WEBSITE

THE N. IRELAND CANCER REGISTRY's WEBSITE is currently being redesigned to comply with Queen's University guidelines. This will be carried out with the use of a Content Management System (CMS) by Wendy Hamill from the Registry. The redesign will improve the appearance and usability with easier navigation. Provision of up-to-date information through the addition of a news feature will provide information and links to new publications, topics of interest, cancer facts, etc. Feedback is very important to the maintenance and development of

a website and comments are encouraged via completion of an online feedback form.

The web site provides an efficient medium for obtaining our most recent data and now includes cancer incidence (1993-2003), mortality (1993-2003) and 5-year survival rates (1993-1995) and (1996-1999) for the key cancer sites. Pictorial representation of incidence, mortality and survival rates are available in graphical format and are accessed by individual cancer sites, currently via the link 'cancer statistics'.

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Registry publications such as reports and their summaries, together with NICR annual newsletters, and policy documents are all available for download in PDF format from the web page.

For more detailed data analysis, an important addition to the web site is the ability to download a data file containing all incident malignancies between 1993 and 2003. The file consists of sex, year of diagnosis, 5-year age band and is coded by ICD-10. As part of the download process users are required to register online.

A final year QUB Computing student, Emma Montgomery, is developing a system for better access and display of the statistics on the web. This will constitute her final year project and she is being externally supervised by staff from the NICR. The new system will produce customised, aggregated, anonymised cancer statistics on demand, on the basis of a regularly updated subset of the main Cancer Registry Database. Initially only available on the HPSS network, the tool will also allow clinicians and GPs in Northern Ireland to obtain cancer information on the population treated by them. Prof Roy Spence has indicated his support and will help in assessing the tool. The first prototype of the tool should be ready by June/July 2006.

Further details from w.hamill@qub.ac.uk

CANCER TRENDS 1993-2003

Included in this newsletter is a fact sheet on Cancer Trends in Northern Ireland 1993-2003. These show that there are 14% more cases and 40% more cancer deaths in men than women.

While cancer rates are falling in men they remain steady in women. The reduction in tobacco related cancers in men is driving this trend with on average 7 fewer lung cancer cases and 6 fewer lung cancer deaths each year over the period. In females the most dramatic change is in breast cancer with an average of 20 more cases and 5 fewer deaths each year.

Full report available at www.qub.ac.uk/nicr

STAFF NEWS

RETIREMENTS



Patricia Donnelly



Helen Hanlon

Patricia & Helen have been with the Registry as tumour verification officers where they contributed to enhancing the data quality. They will be greatly missed by their colleagues who wish them every happiness in their retirement.

NEW STAFF

Dr David Donnelly, on secondment from NISRA and Dr Finian Bannon are temporary biostatisticians.



Dr David Donnelly



Dr Finian Bannon

CONGRATULATIONS

To Deirdre Fitzpatrick on the birth of her son Frank on 15th January, Denise Catney on the birth of her son Liam 10th March and Heather Kinnear on the birth of her daughter Emma on 6th May.



Mr Eamon O'Callaghan, Mrs Donna Floyd and Mr Gavin Kennedy have joined the team of tumour verification officers.

Visit to the National Cancer Institute

As part of the Ireland/Northern Ireland/National Cancer Institute Consortium on Cancer initiatives on training, I was fortunate to gain a place on the National Cancer Institute "Principles and Practice of Cancer Prevention and Control" course held in Washington DC USA in July 2005. The course was an intensive five week programme which was attended by participants from all over the world. It was extremely informative to look at the different approaches to cancer prevention in the United States and internationally. They were also interested to hear about our programmes of cancer prevention and in particular the Republic's legislation on smoking in public places.

The course enabled me to broaden my knowledge in this increasingly expanding and important field of study. It has also given me the chance to strengthen our links with the NCI. Thanks to the R & D Office who fund this initiative and the NCI for providing this excellent training opportunity.

Richard Middleton
(Data Manager)

N. IRELAND CANCER REGISTRY RECENT PUBLICATIONS

1. *Modelling predictions of cancer deaths in Northern Ireland.* French D, Catney D, Gavin AT. Ulster Medical Journal 2006;75(2):120-125.
2. *Nonsteroidal anti-inflammatory drugs and the esophageal inflammation-metaplasia-adenocarcinoma sequence.* Anderson LA, Johnston BT, Watson RG, Murphy SJ, Ferguson HR, Comber H, McGuigan J, Reynolds JV, Murray LJ. Cancer Res. 2006;66(9):4975-82
3. *Breast Cancer Services – A population based study of Service Reorganisation.* Monaghan P, Murray L, Donnelly M, McCarron P, Spence R, Gavin A. Journal of Public Health 2005 Volume 27:issue 2
4. *Have patients with oesophagitis got an increased risk of adenocarcinoma? Results from a population-based study.* Murphy S, Anderson L, Johnston T, Fitzpatrick D, Watson P, Monaghan P, Murray L. World Journal of Gastroenterology. 2005 Volume 11: no46
5. *Photocarcinogenic risk of narrowband ultraviolet B (TL-01) phototherapy: early follow-up data.* Black RJ, Gavin AT. British Journal of Dermatology 2006 154;p551-577