

# N. IRELAND Cancer Registry

Department of Epidemiology & Public Health, Queen's University of Belfast



Providing information on cancers for research, education and planning of services.

## Review

The second review of the N. Ireland Cancer Registry was undertaken 28th & 29th May. The highly skilled review team led by Professor Sir Donald Acheson, included two members of the previous review team, Professor Patrick Johnston, Department of Oncology, QUB and Mr Roger Black, Head of Scottish Cancer Intelligence Unit. The review team were impressed at the progress made over the five years since the last review and in particular the Registry's portfolio of research projects.

The team made eight recommendations which should facilitate the future development of the Registry.



Back Row: Professor Patrick Johnston and Mr Roger Black

Front Row: Dr Margaret Boyle, Professor Sir Donald Acheson and Dr Anna Gavin

## Protecting Personal Information

A consultation paper is available at [www.dhsspsni.gov.uk/publications](http://www.dhsspsni.gov.uk/publications) with responses by 30 September 2002.



## Cancer Care Ireland 2002



A major international two day conference covering many aspects of cancer prevention, diagnosis and care will take place in Belfast on Monday 14th and Tuesday 15th October 2002 in the Waterfront Hall, Belfast.

Invited speakers include Dr Tom Fahey, Clinical Vice-President, Memorial Sloan Kettering Cancer Centre; Professor Mike Richards, National Cancer Director, England; Dr Gregory Curt, Clinical Director, National Cancer Institute; Dr Douglas Weed, Chief, Office of Preventive Oncology, Division of Cancer Prevention, NCI; Professor Michel Coleman, Professor of Epidemiology and Vital Statistics and Head of

the Cancer and Public Health Unit, London School of Hygiene & Tropical Medicine; Peter Tebbitt, Chairman, National Council for Hospices and Specialist Palliative Care Services; Professor Bob Haward, Cancer Studies, Leeds; Dr Dan Sullivan, Associate Director, Biomedical Imaging Programme, National Cancer Institute; Professor Jessica Corner, Professor of Cancer and Palliative Care, University of Southampton; and Dr Kenneth Anderson, Dana-Farber Cancer Institute.

They will be joined by many local experts from the island of Ireland for various symposia including sessions on lung cancer, breast cancer, nursing, molecular research and colorectal cancer. A special cancer prevention seminar will be chaired by Wendy Austin, BBC broadcast journalist.

Themes include: Cancer survival differences across the developed world – what can be inferred?

Cancer outcomes in UK and Ireland – inferior treatment or late presentation.  
Cancer guidance – does it work in practice?

A full programme for this exciting conference is available by contacting Mrs Gail Henry, email: [cancerconference2002@beeches.bmc.n-lhs.uk](mailto:cancerconference2002@beeches.bmc.n-lhs.uk) or The Beeches Management Centre, Belfast BT7 3EN Tel: (44) 028 90 644811

Abstracts for poster presentations by 31 August 2002.

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# First Northern Ireland Cancer Survival Statistics Unveiled

Five-year Survival Breast Cancer 78%

Better than expected survival for malignant melanoma at 90%

Survival for women with oesophageal cancer in Northern Ireland better than most places in Europe

Northern Ireland's first cancer survival report, which was launched on 4 September 2001, details survival of patient's aged 15-99 who were diagnosed with malignant cancers. Information relates to patients diagnosed 1993-96 and followed up to 1999. Analysis was done on all serious cancers and excluded non-melanoma skin cancer which has an excellent survival. Overall women's survival was better than men's: Relative survival at one-year was 58% for men and 66% for women while at five-years it was 38% and 51% respectively.

## COMPARISONS WITH ELSEWHERE

Survival rates for cancer in Northern Ireland were similar to the Republic of Ireland for many diseases and in many cases better than the rest of the UK. However, it is likely that when current survival rates for other Northern European countries such as Denmark are calculated, Northern Ireland will lag behind. Professor Roy Spence, Surgeon, Belfast City Hospital and Chair of the N. Ireland Cancer Registry's Council, speaking at the launch, said "We are delighted to have, for the first time, survival figures for Northern Ireland. With the recent changes in

cancer services in Northern Ireland I am extremely hopeful we will see improvement in the next report."

## RANGE OF SURVIVAL

Like many countries survival from different cancers is different - while five-year survival for malignant melanoma (90%) and breast (78%) are high, at the other end of the scale there is very poor survival for lung cancer (8%), oesophageal (9%) and stomach cancer (17%). These latter cancers are all related to tobacco use. Dr Etta Campbell, Chief Medical Officer, said "We need to continually work to reduce tobacco consumption among our population."

## SURVIVAL BETTER IN WOMEN AND YOUNG PEOPLE

Among the other findings of the report are that relative survival is lower for elderly patients than for younger patients, even when figures are adjusted for higher levels of background disease in older people.

Commenting on the findings Dr Anna Gavin, Director of the N. Ireland Cancer Registry said



"This report provides a benchmark against which improvements will be measured. The higher than expected survival for malignant melanoma indicates the impact of health promotion programmes, early detection and co-ordinated treatment."

## TOBACCO TOLL

Overall cancer incidence and death rates in men are falling, driven by the fall in lung cancer and colorectal cancer. Among women however, the number of deaths has fallen to a lesser degree. There has been no change in the number of cases of cancer among women and the fall seen in deaths and cases from lung cancer in men has not been repeated in women.

The report is dedicated to the memory of Professor Gary Love, a former Dean of the Faculty of Medicine at Queen's University, Belfast.



There has been an increase in the incidence of cancer of the oesophagus (gullet) in Western countries in the last 30 years. This is due to a large increase in one particular type of oesophageal cancer called adenocarcinoma. This type of cancer has usually reached an advanced stage when it is diagnosed by doctors and has a poor prognosis, with most patients surviving for less than a year after diagnosis. Oesophageal adenocarcinoma (OAC) is linked to an inflammatory condition affecting the lower

oesophagus called Barrett's Oesophagus (BO). However, only a small proportion of people with BO develops OAC. Heartburn and acid reflux appear to be the most important factors involved in the development of BO:

Heartburn/Acid reflux ► Barrett's oesophagus (BO) ► Oesophageal adenocarcinoma (OAC)

The Finbar Study (Factors INfluencing the Barrett's Adenocarcinoma Relationship) is a large epidemiological and genetic study designed to look at possible risk factors involved in the above diseases. Researchers from the N. Ireland Cancer Registry and the National Cancer Registry, Ireland are recruiting people from all over Ireland over the next 2 years and will compare three different groups of people: those with OAC, those with BO and 'normal' healthy people to serve as controls. Those who agree to take part will be visited by one of the researchers involved in the study. They will be asked to complete a questionnaire that enquires about possible risk factors such as heartburn, medications, diet and smoking. Measurements such as height and weight are recorded, and finally a blood sample is taken. This will be used to examine genetic (hereditary) risk factors that may be important in these conditions. It is hoped that the information gained from this study will help improve our understanding of this cancer so that its diagnosis, treatment and ultimately patient survival can be improved in the future.

## the finbar study

Study researchers are:

### Northern Ireland

Dr Seamus Murphy  
Specialist Registrar in Gastroenterology

Miss Lesley Anderson  
PhD student

Dr Liam Murray  
Consultant in Public Health Medicine and  
Senior Lecturer, N. Ireland Cancer Registry

### Southern Ireland

Miss Siobhan Reynolds  
Research nurse (Cork)

Mrs Majella Gallagher  
Research nurse (Dublin)

Dr Harry Comber  
Director, National Cancer Registry, Ireland

The project receives funding from the Research & Development Office and the Health Research Board.

# NCI Fellowship

Dr Peter McCarron (Northern Ireland) was awarded, along with Paul Walsh (Rep. Ireland) the first Consortium fellowships in cancer epidemiology. He commenced the fellowship in January 2000, taking up his post in the National Cancer Institute, Bethesda, USA where he spent the next 15 months. While there he availed of the numerous training opportunities by participating in epidemiology and biostatistics courses at Johns Hopkins School of Public Health, and he also took part in the NCI five-week Cancer Prevention Course and a one-week course in cancer registration. Dr. McCarron was also involved in several research projects.

In addition, to contributing as co-editor on a SEER Cancer Survival Monograph, this work included investigation of (a) survival differences between blacks and whites with bladder cancer, (b) the association between height and cancer in the Finnish Alpha

Tocopherol Beta-Carotene trial, and (c) the co-incidence of familial melanoma and pancreatic cancer. He is currently completing papers on these studies. Since returning to Belfast he has been involved in a number of on-going projects in the Registry and is currently developing his research interests in cancer, hoping to focus on the genetic epidemiology of, and the early life risk factors associated with, cancer incidence.

The second round of fellowships will be advertised in September 2002. Contact NICR for details.



## Process of Patient Care Survey (RACC Project)

In year 2000 we carried out a prospective study into the patient journey from primary care through to diagnosis and treatments for a number of major cancer sites. This involved the examination of records for all patients diagnosed with cancer of the lung, breast, colon, rectum, ovary and cervix in 1996. As a result we have baseline data on which to monitor changes in patient treatment over time.

This year we are again collecting data for 2001 for the same cancer sites and have also included cancers of the stomach and oesophagus. This will enable us to compare the process of care received by patients over time. The study will identify the changes in patient care initiated by the recommendations of the Campbell Report on cancer patient care in Northern Ireland. Later in the year, we hope to extend the number of cancer sites to include prostate.

The project would not be possible without the tireless efforts of medical record staff pulling the medical records and providing the space for our staff in their very overstretched offices. A big "thank you" to all concerned.

# Trends in Cancer Incidence (1993-99) and Mortality (1984-00) in Northern Ireland

Cancer Registry staff have examined trends in cancers in Northern Ireland, looking for patterns in incidence over the past 7 years and mortality over the past 16 years. The comparisons have been standardised for age and so any changes noted are not due to the ageing population.

### Incidence

- 1) The rate of new cases of cancer in men is decreasing significantly. Between 1993 and 1999, the rate in men fell by 8.9%. However, no significant downward (or upward) trend was found in women.
- 2) For certain sites, significant decreasing trends in cancer incidence were identified:
  - a) For men, lip, oral cavity and pharynx fell by 23.5% and trachea, bronchus and lung by 15.8%
  - b) Pancreatic cancer in women fell by 30.0%
- 3) For certain sites, significant increasing trends in cancer incidence were identified:
  - a) Non-melanoma skin cancer in men rose by 9.0%
  - b) Breast cancer in women rose by 13.1%

### Mortality

- 1) The rate of cancer mortality is decreasing in both men and women. The percentage change between 1984 and 2000 was 10.0% in men and 7.0% in women.
- 2) For certain sites, significant decreasing trends in mortalities were identified:
  - a) Stomach cancer deaths in men and women fell by 39.8% and 41.7% respectively, reflecting the trends experienced by other European countries
  - b) Colorectal cancer deaths in men and women fell by 26.1% and 30.2% respectively
  - c) For men, deaths from bladder cancer and cancer of the trachea, bronchus and lung, fell by 23.5% and 31.2% respectively
  - d) For women, deaths from pancreatic cancer and breast cancer fell by 22.6% and 21.8% respectively.
- 3) For certain sites, significant increasing trends in mortalities were identified:
  - a) Oesophageal cancer deaths in men and women rose by 59.3% and 34.6% respectively
  - b) Liver cancer deaths in men and women rose by 111.8% and 72.0% respectively (Note: poor reliability of liver cancer death information)
  - c) Deaths from non-Hodgkin's lymphoma in men and women rose by 37.1% and 85.7% respectively
  - d) Deaths from trachea, bronchus and lung cancer in women rose by 31.8%, despite men showing almost an equivalent decrease.
  - e) Prostate cancer deaths in men rose by 23.1%.

A report examining these findings in more detail will be produced in 2003.



## Web News

[www.qub.ac.uk/nicr/intro.htm](http://www.qub.ac.uk/nicr/intro.htm)

University of Ulster IT placement student, Stephen Monaghan, has been working on the further development of the N. Ireland Cancer Registry's (NICR) web site over the last few months, under the supervision of Miss Wendy Hamill. The web site has proved to be a valuable resource, so far this year being accessed approximately 3,100 times.

The web site provides an efficient medium for obtaining our most recent data and now includes cancer incidence (1993-1999), mortality (1993-2000) and 5-year survival rates 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 via the link **cancer stats**.

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

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 1999. 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.

The re-design of the NICR web site should now enable easier navigation. All links have been checked and updated, however if you do find a missing link please contact us. A feedback form is also available on the web, we would be grateful if you would take a few moments to fill in your suggestions and comments.

The Registry is grateful for Stephen's input and hopes his time with the Registry proves valuable in attaining his BSc Honours degree in Computer Science.

# Data Protection & Confidentiality Conference



## Speakers at the Data Protection & Confidentiality Conference, Thursday 25 October 2001 at the Hilton Hotel, Templepatrick

Mr Stephen Adams, Project Executive, UPCI; Dr Anna Gavin, Director, N. Ireland Cancer Registry; Mr Phil Walker, Head of Confidentiality Issues, Department of Health England & Wales; Professor Michel Coleman, London School of Hygiene and Tropical Medicine and Office for National Statistics; Mr Michael Thick, Consultant Transplant Surgeon at the Freeman Hospital,

Newcastle; Ms Sandra Cavill, Assistant Commissioner, Information Commissioner's Office; Dr Bill McConnell, Director of Public Health, WHSSB; Ms Jane O'Brien, Head of Standards Section, General Medical Council; Mr Paul Conliffe, Director of Personnel & Corporate Services, DHSSPSNI and Ms Ruth Boardman, Bird & Bird Lawyers

The N. Ireland Cancer Registry organised a successful conference on Data Protection & Confidentiality on 25 October 2001. It was attended by over 200 people. Speakers included Professor Michel Coleman from the London School of Hygiene & Tropical Medicine who delivered the second Michael Wood Lecture "Confidentiality Consent and Public Health - A Modern Dilemma"; Ms Sandra Cavill from the Information Commissioner's Office (previously the office of the Data Protection Registrar) who spoke on data protection and freedom of information; Ms Jane O'Brien from the General Medical Council; and Mr Philip Walker from the Department of Health in London; gave overviews from their specialist areas. Ms Ruth Boardman, Bird & Bird Lawyers spoke on the consequence of non-compliance while Mr Paul Conliffe finished the conference with an overview of developments in Northern Ireland. Thanks go to Dr Bill McConnell, Dr Etta Campbell and Mr Steven Adams for their input on the day. Thanks also to Mark Eustace, Mrs Una Doyle, Dr Margaret Boyle, Dr Tom Gardiner and Dr Claire Willis for their help in planning the conference.

## RETURN TO MULHOUSE

Please note that the Cancer Registry has returned to the Mulhouse Building

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Mulhouse Building, Grosvenor Road, Belfast BT12 6BJ

Tel: (44) 028 90263136 Fax: (44) 028 90248017 Email: [nicr@qub.ac.uk](mailto:nicr@qub.ac.uk)

Web Site: [www.qub.ac.uk/nicr/intro.htm](http://www.qub.ac.uk/nicr/intro.htm)

*Funding for the Cancer Registry is provided by DHSSPSNI*

## New Staff:

### Biostatistician



Dr Denise Catney

### Data Abstractors



Mrs Susan McCracken,  
Mrs Noelle Watson,  
Dr Suzhuang Hong and  
Mr Gary Brownlee.