

N. IRELAND Cancer Registry



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



North/South Research Meeting

The N. Ireland Cancer Registry (NICR) and the National Cancer Registry of Ireland (NCRI) meet regularly to discuss common areas in cancer research. The work currently includes cross-border study of oesophageal cancer and Barrett's oesophagus risk factors, an investigation of breast cancer - patterns North and South and the production of the second All-Ireland Cancer Incidence Report which will be prepared by Joe Campo, who has worked previously at the Washington State Cancer Registry, USA. Joe will spend one year in Ireland based at the National Cancer Registry in Cork. We look forward to the launch of this second All-Ireland Report expected mid 2004. ■



North/South Research Meeting in Dublin 3 April 2003.

Dr Richard Middleton, NICR; Dr Denise Catney, NICR; Miss Pauline Monaghan, NICR; Dr Liam Murray, NICR; Dr Harry Comber, NCRI; Dr Sandra Deady, NCRI; Miss Martina Roche, NCRI; Dr Paul Walsh, NCRI and Dr Anna Gavin, NICR.



Joe Campo

New Telephone Number for NICR

Please note that the **NICR has a new telephone number, 028 90632573**. If you know the extension of the person you wish to speak to in the NICR just prefix the extension with 028 9063.

<i>Dr Richard Middleton, Data Manager</i>	<i>028 90632574</i>
<i>Mr Colin Fox, IT Manager</i>	<i>028 90632724</i>
<i>Ms Deirdre Fitzpatrick, Biostatistician</i>	<i>028 90632728</i>
<i>Dr Denise Catney, Biostatistician</i>	<i>028 90632571</i>
<i>Miss Wendy Hamill, Office Manager</i>	<i>028 90635041</i>

All-Ireland Cancer Conference October 19th-22nd 2003 Rochestown Park Hotel, Cork.

This multidisciplinary conference will offer the cancer care and research communities in the USA, and both parts of the island of Ireland, an opportunity to come together with cancer experts from around the world. It will provide updates on developments in cancer care and research and a forum for the exchange of views and ideas.

For further information contact Dr Harry Comber, National Cancer Registry, Elm Court, Boreenmanna Road, Cork. Tel: +353 21 4318014 Fax: + 353 21 4318016 Email: h.comber@ncri.ie ■

ALSO IN THIS ISSUE

- | | | |
|--|---|---|
| 1. Cancer Registry Links with Primary Care | 5. RACC Project Update | 9. Tumour Staging |
| 2. Finbar Study | 6. Cancer Fellows Update | 10. Trends in Incidence 1993-2000 |
| 3. PSA Testing in Northern Ireland | 7. European Network of Cancer Registries Course on Automated Cancer | 11. Tobacco Toll Increasing in N. Ireland's Women |
| 4. IT Update | 8. Pain Management | 12. Future Reports |

CANCER REGISTRY LINKS WITH PRIMARY CARE

Comparison of "Data Retrieval in General Practice Project" & the NICR

The GP "Data Retrieval in General Practice Project" (DRGP) is run by the Department of General Practice at Queen's University. The project uses the MIQUEST approach to extract information from the clinical systems of participating practices. Forty-three practices currently participate in the DRGP project, representing approximately 15% of the Northern Ireland population.

As a pilot study, to enhance the NICR data quality, we have been looking at the quality of information held in the clinical systems of a subset of DRGP practices and our own data. With the permission of the GPs concerned, we have received basic diagnostic information on their cancer patients and have been able to match this with our own data. Preliminary results suggest that there is good agreement in the two data sources with the vast majority of cancer patients occurring in both data sets. It has enabled both the GP Retrieval Project and the NICR to quality assure their data. Thanks to Dr. Brendan O'Brien, Dr Colm Rafferty and Ms. Hazel Grandier for their facilitation of this project. ■

GPs Help with Cleaning Data (1993-2000)

We were always aware that some of the data held by the NICR were based on a "hospital admission only" electronic registration. The quality of these is usually fairly good, but errors can occur either through mis-coding or the cancer being only "suspected" rather than proven. Normally we are able to confirm the cancer diagnosis by referral to hospital notes. Occasionally the notes of the patient are not available in the hospital concerned. To get around this problem we wrote to the patients' GP to ask them to confirm the cancer diagnosis. The response was an impressive 86%, and many thanks to the GPs who sent us the information.

Of the 576 patients whose information we received back from GPs, 110 (19.1%) did not have a tumour of any type, 36 (6.2%) had a non-malignant tumour and 61 (10.6%) were prevalent cases.

The impact on the overall database was small (less than 0.5%), but it did improve our data so that important analysis such as the effects of deprivation and survival can be carried out with a greater degree of accuracy. ■

the
finbar
study

The finbar (Factors INfluencing the Barrett's Adenocarcinoma Relationship) study is an All-Ireland case-control study looking at epidemiological and genetic (hereditary) risk factors involved in the development of oesophageal adenocarcinoma (OAC) and Barrett's oesophagus (BO), a pre-malignant condition of the oesophagus.

Recruitment commenced in March 2002 and so far approximately 360 people have taken part from all over Ireland. Each person is interviewed by one of the researchers, based in Belfast, Dublin and Cork, and asked a number of questions using a computerised questionnaire to obtain details about previous medical conditions, medication usage, diet, lifestyle factors and their psychological profile. In addition measurements such as height, weight and blood pressure are taken along with a sample of blood. Over the forthcoming year the researchers will continue to recruit people from throughout Ireland with the intention of seeing at least 900 people in total.

The analysis of the questionnaire data should hopefully be available in September 2004 with the results of the genetic analysis to follow. It is hoped that the findings of this study will improve our knowledge of the risk factors involved in the development of oesophageal adenocarcinoma so that this cancer may be prevented in the future. First publication: Mortality in Barrett's oesophagus: results from a population based study L A Anderson, L J Murray, S Murphy, D Fitzpatrick, B T Johnston, P Watson, P McCarron, A Gavin Gut 2003; 8: 1081-1084. ■

Prostate Specific Antigen Testing in Northern Ireland - Practice does not meet Department of Health advice

Prostate Specific Antigen (PSA) Testing in Northern Ireland - Practice does not meet Department of Health advice.

The Guidance

Current evidence does not support a national screening programme for prostate cancer. (Ref 1 & 2).

Current screening technologies (including the PSA test) have a limited accuracy that could lead to a positive result for those without the disease. Follow up procedures could thus cause unnecessary harm such as incontinence and impotence to healthy individuals. The introduction of a prostatic cancer screening programme at present carries an unacceptable risk of causing more harm resulting than good.

The National Screening Committee has considered the evidence for introducing screening for prostate cancer and concluded that at this time and with current technology, there is no evidence of benefit resulting from population screening. This recommendation has been accepted by Department of Health Ministers.

The Chief Medical Officer, Dr Henrietta Campbell, in a recent circular HSS(MD)20/97 on this matter concluded that "Population screening for prostate cancer, including the use of prostate specific antigen (PSA) as a screening test, should not be provided by the HPSS or offered to the public until there is new evidence of an effective screening technology for prostate cancer."

Health and Social Services Boards and General Practitioners were asked not to introduce or plan the purchase of population screening for prostate cancer until the National Screening Committee recommends an effective and reliable procedure.

References

1. Selley S, Donovan J, Faulkner A, Coast J, Gillatt D. Diagnosis, management and screening of early localised prostate cancer. *Health Technology Assessment 1997; 1(2)*.
2. Chamberlain J, Mella J, Moss S, Brown J. The diagnosis, management, treatment and costs of prostate cancer in England and Wales. *Health Technology Assessment 1997; 1(3)*.

It was noted that the guidance does not affect the clinical management of men presenting with symptoms of prostatic disease.

Some men, anxious about prostate cancer, may request a PSA test. Before testing they should be properly informed about the probable benefits and harms of the PSA test. Evidence based information developed for the Prostate Cancer Risk Management Programme is available at www.nelc.org.uk/docs/psa/pdf/psa_3.PDF which will assist men making an informed decision regarding this test.

Current Practice

Thanks to the good will and time afforded by the laboratories and GPs who verified the test results, and using a unique database of PSA tests it has been established that by 1999, one third of all men in Northern Ireland aged 50, or over, had at least one PSA test. The proportion of tests initiated from GP practices increased from 47.2% to 67.0% (1993-1999), while the average age of those having one test fell significantly (65.6 to 61.9 years, $p < 0.001$). Test rates varied 100-fold across general practices throughout Northern Ireland, a factor not explained by deprivation, practice size or population density. These figures support the theory that some PSA screening tests are taking place in Northern Ireland. We hope to extend this work to look at why the PSA test was performed, follow up patients with a raised PSA level and hopefully explain the variation in GP practice.

IT UPDATE

Infrastructure

Some significant changes have been made to the IT function within the NICR. We have a new server replacing the ageing Unix server. The IT team received training in the Windows 2000 server operating system and subsequently configured the new server to operate using this system. Our software suppliers, Intersystems, have redeveloped their older Open M/MSQL database product into a modern object-based post-relational database management system known as Caché. Thus, a major project was undertaken towards the end of 2002, to convert the NICR registration system to run on Caché. This was successful and in conjunction with the new server, has resulted in significant gains in performance. The NICR can process much more information in a timely manner and this will greatly assist us in our attempts to become more current with our information outputs.

User Group and Other Activities

One of the recommendations of the recent NICR review was the conduction of a separate review of the IT function. Work on this is progressing in conjunction with Trent and Thames Registries, who use a similar system.

Issues being explored are:

- Flexible support arrangement that could include the provision of a system development resource
 - Connections with the HPSS network
 - An audit of IT security
- The Directorate of Information Systems (DIS) is assisting us with this task.

We are also exploring enhancements to the system which could enable us to hold more clinical, pathological and treatment data.

Security

AUTHENTICATION BY FINGERPRINTS

A new system for users authentication has been implemented in the NICR, using fingerprint identification. This feature, together with file encryption practice for sensitive data, further raises the security standard for the NICR. For further details contact the IT Manager.

With the help of Jacqui O'Neill, our current University of Ulster placement student, we have developed an application for the permanent and true deletion of files from disks. ■

Regional Advisory Committee on Cancer - RACC Project

The RACC Project is a study investigating the impact of the reorganization of cancer services in Northern Ireland. Our trained staff have been collecting patient information on several cancer sites and we are pleased to report that the collection of data is reaching completion. We have recruited Pauline Monaghan, a statistician, to analyse this data. This post is funded by the R & D Office. Preliminary results have been presented to several groups of clinicians and the feedback from these discussions has been very useful. Our aim is to finalise the datasets for each of the cancer sites in 1996 and 2001, giving us a complete 'picture' of the two years. The data will then be interrogated, studying trends, workload, quality of recording, associations and survival, to document any changes that have occurred and research the reasons behind such change. ■

We have recruited Miss Pauline Monaghan as a researcher in the NICR. Pauline's background is in statistics and she will be working on the RACC project.



Cancer Fellows Update

Dr Peter McCarron is in Italy undertaking a masters in genetic epidemiology, a key area identified in the recent NICR review. He is also working with IARC on cancer trends in industrial countries.

Dr Paul Walsh has also returned from the NCI and is working on a range of projects at the NCRI including, analyses of All-Ireland breast cancer data (rates, stage and surgery) in relation to differences in availability of mammographic screening.

The second round of Epidemiology Fellows was re-advertised in the autumn of 2002 and Dr Deirdre Cronin was appointed. She will be based in Cork and will spend a year at the NCI, commencing June 2003. ■

European Network of Cancer Registries Course on Automated Cancer Registration Lyon 7-10th July 2003

The NICR is a founder member of the ENCR Automated Cancer Registration Group. One of the areas of work of this group is to improve and give guidance to other European Cancer Registries wishing to set up automated cancer registration. This year the group has organised a course in Lyon for computer and data managers to facilitate their use of electronic data.

Dr Richard Middleton, Data Manager of the NICR is part of the faculty for the course. ■

PAIN MANAGEMENT

The Department of Health, Social Services & Public Safety (DHSSPS)

produced a document entitled "General Palliative Care Guidance for Control of Pain in Patients with Cancer" in May 2003. This document is intended to be a practical clinical guideline for the control of pain in patients with cancer. Its target group is hospital staff, primary care team members and nursing home staff. It can be accessed via the internet = www.dhsspsni.gov.uk. The DHSSPS also produced a leaflet for patients entitled "Managing Your Cancer Pain in Hospital and at Home". ■

Tumour Staging

We are pleased to announce a 2-year project, working with consultants in the Trusts throughout Northern Ireland, to enhance the quality of data available on staging for the NICR. This post is funded by the four Health & Social Services Boards. The stage of a cancer is the main predictor for survival. Standardised information on stage is necessary to compare outcomes over time, by geographical area and by care provider. Currently there is poor recording of staging data, for example, only 64% of rectal tumours had Dukes Stage recorded in the notes in 2001 and only 10% had TNM recorded. This 2-year project, to promote the use and recording of cancer staging data in Northern Ireland, will involve working with lead cancer clinicians and other clinical groups who audit current practice and staging, assess training needs in relation to staging cancers and develop training materials and courses. Initiatives to encourage the recording of staging and the transfer of that information to the NICR will also be explored. It is hoped to have a person in post by October 2003. ■

Trends in Incidence 1993-2000

The NICR, which monitors the level and survival of cancer in Northern Ireland, has just released data for the time period 1993-2000, see web page www.qub.ac.uk/nicr. There are 8,500 people diagnosed annually with cancer here, of which about a quarter are skin cancers. If detected early, these can be successfully treated and rarely cause death. Therefore, excluding non-melanoma skin cancer, there are over 6,000 serious cancers diagnosed here each year.

The most common cancer in males is lung cancer with an average of 561 cases per year. Survival for lung cancer is very poor with only 23% surviving one year and 8% five years.

The most common cancer in women is breast cancer which has seen an average annual

increase in the rates of almost 2%, with the number of cases rising from 762 in 1993 to 964 in the year 2000. Part of this can be attributed to increased activity of the Breast Screening Programme which is picking up cancers at an earlier stage. In addition we have a population with an increasingly older age structure and breast cancer, like most cancers, is more common in older people. The impact of lifestyle factors such as having fewer children, historically less breastfeeding, increasing body mass index and the use of artificial oestrogen, have all contributed to some extent.

Survival for breast cancer is quite good with 92% surviving one year and 78% surviving five years. These figures are based on data from 1993 to 1996 before the introduction of the

Breast Screening Programme. More recent figures indicate an improved survival.

For the first time we are able to examine trends in cancer. In men there has been a significant reduction in lung cancer rates with an average annual fall of over 3%, corresponding to a fall from 572 cases in 1993 to 503 in 2002. This reflects changing tobacco consumption habits among the male population. A similar change was noted in cancers of the lip, oral cavity and pharynx which are also related to tobacco.

Rates for cancer of the colon also fell by an average of 2.5% per year in men but showed no change in women. Unlike in men there were no significant downward trends in any of the female cancers. See table below. ■

Site	ICD-10 coding	% Change in Males ^a	% Change in Females ^a
Lip, oral cavity & pharynx	C00-C14	-5.3 ^c	-1.4
Oesophagus	C15	-2.8	2.8
Stomach	C16	-2.5	-0.7
Colon	C18	-2.6 ^b	-2.1
Rectum, rectosigmoid junction & anus	C19-C21	-1.4	0.4
Colorectal	C18-C21	-2.1 ^c	-1.3
Liver & intrahepatic bile ducts	C22	-3.7	-2.2
Pancreas	C25	-3.2	-2.4
Larynx	C32	-1.6	0.9
Tracheas, bronchus & lung	C33-C34	-3.3 ^c	0.6
Malignant Melanoma	C43	-0.4	-1.9
Non-Melanoma Skins (NMS)	C44	0.8	-1.0
Breast	C50	-	1.9 ^c
Cervix	C53	-	0.7
Uterus	C54	-	5.1 ^b
Ovary	C56	-	1.9
Prostate	C61	-0.2	-
Testis	C62	3.0	-
Kidney	C64-C65	0.7	0.7
Bladder	C67	-0.9	1.2
Brain	C71	-0.3	-1.5
Non-Hodgkin's Lymphoma	C82-C85 & C96	-0.8	3.9
Leukaemia	C91-C95	-1.0	-2.5
All Sites excluding NMS	C00-C96 exc C44	-1.6 ^c	0.8 ^b
All Sites	C00-C96	-1.0 ^c	0.2

a The average annual percentage change in European Age-Standardised Incidence Rates (EASR) over the 8-year period (1993-2000) for each cancer site, has been estimated by fitting a linear regression line to the eight annual age-standardised rates for the period 1993-2000. Thus, for example, breast cancer in Northern Ireland has risen by an average of 1.9% per year over the 8-year period, and this change is highly significant (p<0.01).

b significant increases/decreases P<0.05

c significant increases/decreases P<0.01

Tobacco Toll Increasing In N. Ireland's Women

The number of women diagnosed with lung cancer increased from 320 cases in 1993 to 345 in 2000, the highest year in this period was 1999 with 363 cases. Data from the NICR indicates that only 5% of those with lung cancer record never having actively smoked tobacco. Tobacco is recognised as the major preventable cause of many cancers, particularly lung cancer. It is estimated that 90% of all cases are directly linked with tobacco consumption.

We must further strengthen our efforts to reduce further tobacco consumption among men and address the public health time bomb of smoking among women. This would have significant impact on the numbers of cancers recorded but also reduce morbidity and deaths from heart disease, stroke and chronic lung disease. **Over 90 years ago when smoking was rare among the population there were about a dozen lung cancer deaths recorded, today we have 900.** ■

Future Reports

Part of the role of the NICR is to disseminate information on cancer in Northern Ireland. So, in conjunction with publishing on our website, fact sheets shall be produced containing information such as updates on cancer incidence, mortality and survival, and investigation of cancer trends. Currently work is underway to produce our first report into cancer and deprivation, which shall hopefully be published later this year. ■