

N. Ireland CANCER REGISTRY

providing information on cancers for research, education and planning of services

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



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First Incidence Report launched

■ On February 23, 1999 staff from the N. Ireland Cancer Registry were in jubilant mood as they were joined by many hundreds of well-wishers at the launch of their first incidence report. The Belfast City Hospital lecture theatre was crammed with many people who had helped in the production of this report. These included those who had helped us set up our computer system, acquire the data and facilitate the quest for data quality through searches of notes from the Central Services Agency and the hospitals throughout Northern Ireland.

Professor George Bain, Vice-Chancellor of the University, introduced the launch saying that although the Registry had been established for less than five years, it had broken all records in having produced three years of high quality incidence data within a short timescale. He identified that the report represents a major achievement which will become a foundation for cancer research in Northern Ireland into the next millennium.

Other speakers on the programme included Dr Henrietta Campbell, Chief Medical Officer, who welcomed the report which she said marked the beginning of a new era in cancer surveillance for our population. She identified the many ways the Registry could impact on health care from monitoring the effectiveness of prevention programmes, through facilitating audit and research while providing information on trends in cancer, survival patterns and outcomes of care.

Dr Linda Caughley described the Cancer Registry's role in the monitoring and evaluation of the breast and cervical cancer screening programmes. Professor Patrick Johnston, with Professor Frank Kee, highlighted the importance of the Registry's role in research both at clinical and population level.

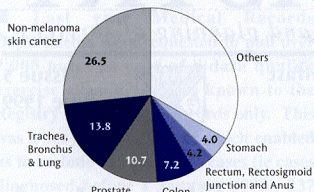
The report includes measures of data quality and we are happy to report they were of a high international standard. In addition the data compared well with that found in specific cancer research projects already

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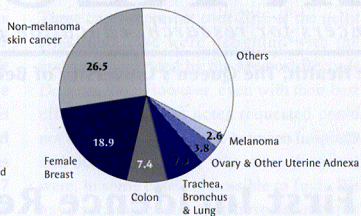


Professor Gary Love, Chair of Council of NICR, Professor Frank Kee, Department of Epidemiology & Public Health, Professor George Bain, Vice-Chancellor, QUB, Dr Anna Gavin, Director, NICR, Dr Henrietta Campbell, Chief Medical Officer and Dr Linda Caughley, member of Council of NICR.

**MALE
% 1993-95**



**FEMALE
% 1993-95**



Breast Cancer

There are 820 cases of female breast cancer, 6 male cases, per year with a 12% increase between 1993 and 1995. It is difficult to examine trends with just 3 year's data even for a more common cancer such as breast cancer. Nevertheless, this is a statistically significant rise which may reflect better detection with the new mammographic screening programme. Breast cancer deaths represent 40% of incidence. The Registry

carried out in Northern Ireland on, for example, breast, cervix, lung and melanoma.

The report, which was funded by DHSS was distributed to all consultants, general practices, each pharmacy and library throughout Northern Ireland. Copies were also sent to each Cancer Registry throughout the world. The report is available on the internet <http://quis.qub.ac.uk/nicr/intro.htm>.

Report Highlights

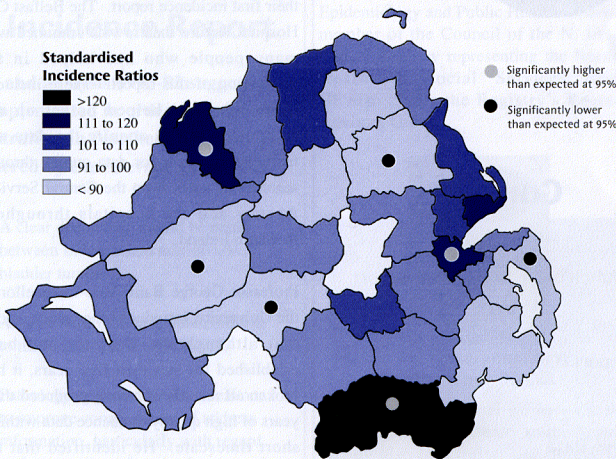
Levels of kidney, colon and rectal cancer in men and women here are the highest in the British Isles, as is oesophageal cancer in men. Lung cancer accounts for 11% of cases but 22% of deaths indicating high case fatality. Skin, on the other hand, accounts for over a quarter of all cases but less than 3/1000 cancer deaths, 6% of people with cancer have more than one cancer in their lifetime. This figure of 6% is the same as the Republic of Ireland.

Age and Cancer

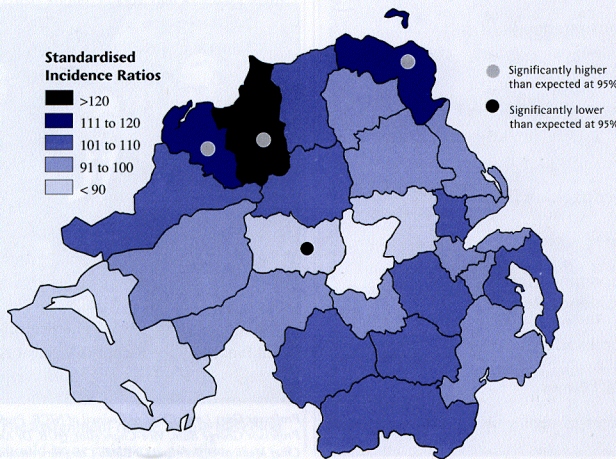
We think of cancer as a disease of old age but 8% of male and 11% of female cancers occur in those under 45 years. We have a 1/3 chance of developing cancer by age 75, a 1/4 chance if skin cancers are excluded.

Cancer of the testis, cervix and melanoma occur in younger ages with half of cases less than 33, 47 and 54 years respectively. Prostate, stomach, colon and bladder cancers tend to occur much more in older people. Half of prostate cancers occur in those over the age of 75 years.

All Age Male Standardised Incidence Ratios (SIRs) by District Council 1993-95, All Cancers (excluding non-melanoma skin cancers)



All Age Female Standardised Incidence Ratios (SIRs) by District Council 1993-95, All Cancers (excluding non-melanoma skin cancers)





Dr Harry Comber, Director, National Cancer Registry, Miss Clare Macmahon, OBE BSc MIBiol FLS, President of the Ulster Cancer Foundation, Dr Anna Gavin, Director, N. Ireland Cancer Registry, Mr James Reid, Epidemiologist, NICR, Miss Breige Torrains, Administrator, NICR.

can monitor practice. We have noted improvement in recording the stage for breast cancer from 1993-95.

Malignant Melanoma

Malignant melanoma accounts for 160 cases per year. It is twice as common in females than males. However, levels in women are falling while they rise in males. Cases occur at a younger age in women, 1/3 under 40 compared with men, 1/5 under 40 years. In women with falling numbers overall there is a shift which could reflect early detection and the impact of health promotion programmes with falling levels of invasive disease and rising levels of *in situ* disease.

Variations within Northern Ireland

The report includes maps displaying differences in disease rates within Northern Ireland. These are statistically significant but we must be cautious in their interpretation. Not all cancers had an address which could be allocated to a District Council and with only three year's data these could represent year-to-year natural variations. For all cancers Belfast, Derry and Newry & Mourne District Councils had higher than expected levels of cancers in men, while Derry and Limavady had higher than expected levels in women.

Next Report

■ The next report on cancer incidence will be an All-Ireland report covering the period 1994 - 96 inclusively and should be available in early 2000. This will represent significant collaboration between the N. Ireland Cancer Registry and the National Cancer Registry of Ireland on data quality analysis and interpretation.

1996 Data

■ The Cancer Registry has been notified electronically of cancer cases recorded in 1996 from pathology laboratories, the PAS system and the Registrar General's office. Those cases identified only from death certification have been double-checked against GP records to check the diagnosis and its date.

The next major exercise is the checking of records which have been notified to us from the single source hospital PAS. This will include a mix of prevalent cases, ie those diagnosed before 1996, cases in people who normally live outside of Northern Ireland and errors in coding.

We are grateful to the staff of all the Medical Records Departments who fit the note extraction into an already busy schedule. The notes are checked in the Medical Records Department by trained Tumour Verification Officers from the Cancer Registry. Data for 1996 should be available in early 2000. A similar exercise then begins for the next year 1997.

Contingency Plan

■ The Registry have been working on the detail of a plan we hope will never be used. This is a contingency plan for rescue of our system and the data in the event of the Cancer Registry being destroyed, for example, by fire.

Many organisations with historical data already have such a plan in place. Some of the pre-requisites for a contingency plan include having an accurate list of your equipment and contacts, backups of the system, its software and the data which should be held in a coded format in a secure off-site location. Electronic data storage makes this task easy as significant amounts of data can be stored in a bank safe deposit box. Thought also needs to be given to the immediate aftermath with the allocation of roles to retrieve the data and replace the system as soon as possible. We are grateful to the assistance of Joe Beattie, Directorate of Information Systems in this matter. Further information is available from the Registry.

RACC Audit Report

■ The Cancer Registry will be the host organisation for an audit project examining the process and outcome of care for patients diagnosed with lung, breast, colorectal and ovarian cancer in 1996. The project has been funded by the Regional Medical Audit Committee, the Western, Southern and Northern Health Boards and the DHSS. Trained staff will collect the data for 1996 by a review of hospital records. It is

planned that a similar exercise will take place in the year 2001 to determine whether the changes recommended in the Campbell Report 'Cancer Services' Investing for the Future has been implemented. Two nurses with recent acute care experience, preferably in the area of cancer who have experience of extracting data from notes, will be recruited. Further details are available from the Registry.

Feedback on Data Quality

■ Last year Medical Records Departments were requested to pull over 7,000 notes as part of a data quality exercise examining cases known to the Registry from hospital records only. This was a very useful exercise which enabled us to exclude 865 prevalent cases (ie cases diagnosed before 1 January 1993), 237 cases where there was a tumour however the behaviour was not malignant, and over 400 cases which did not have any tumour.

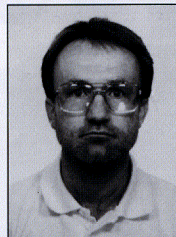
These cases represent over 20% of the notes examined. We were delighted with the assistance provided by the Medical Records Departments. However, even with their best efforts, 18% of the notes requested could not be found. This varied between hospitals and notes of patients who were deceased were, in some cases, impossible to find. We have recommended that hospital records should be stored in a manner so that they are readily accessible and not mislaid. We are preparing a scientific paper reporting the detail of this exercise.

Recommendations from Incidence Report

■ Experience gleaned from data acquisition and analysis 1993-95 suggest that a number of practical measures should be implemented in order to reduce the burden of cancer and enhance cancer registration in Northern Ireland. The following recommendations should be considered by the relevant authorities.

- Tobacco use, which is responsible for the majority of preventable cancers must be addressed in line with the Government White Paper on tobacco control.
- The rising levels of oesophageal cancer in young males requires further investigation and initiatives to reduce alcohol consumption.
- Further research into the aetiology of colon and rectal cancers and the role of diet in Northern Ireland should be conducted.
- The recording of stage at diagnosis for all tumours should be enhanced.
- A Unique Patient Client Identifier should be introduced as soon as possible to improve identification of individuals and avoid duplication.
- Females with suspected breast cancer should have their disease stage, including lymph node status, assessed at diagnosis.
- Pathologically diagnosed CIN III (severe dysplasia) tumours should be consistently coded as SNOMED code M80772.
- A clear distinction should be made between invasive and non-invasive bladder tumours.
- Address information should conform to the British Standard BS6667.
- Pathology systems should endeavour to improve completeness of address information, particularly with regard to the recording of postcodes.
- Haematology bone marrow records should be computerised.
- Trusts should ensure that key data items on stage of disease, occupation and postcode are routinely and accurately collected.
- Hospital records should be stored in a manner so they are readily accessible and not mislaid.
- The radiology departments should routinely use the coding system available to them.
- Barrett's oesophagus should be consistently coded using the internationally agreed SNOMED code M73330.
- The assignment of site within the colon should be as precise as possible.

Staff News



New Professor Appointed

Congratulations to Professor Frank Kee on his appointment to a new chair - Professor of Public Health in the Department of Epidemiology and Public Health. Frank is a member of the Council of the N. Ireland Cancer Registry representing the Northern Health & Social Services Board. He also chairs the Registry's Research Advisory Group.



The Registry Secretary
Miss Wendy Hamill

Since our last newsletter we have recruited Wendy Hamill as secretary to the Registry. Wendy also looks after our library with assistance from Medical library staff.

The NICR is part of The Queen's University of Belfast's Department of Epidemiology and Public Health and is located in the Mulhouse Building on the Royal Victoria Hospital site.

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