

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



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## Major Cancer Conference for Belfast

The Annual UK Association of Cancer Registries Conference will be hosted in Belfast 23-24 November 2000 in the Wellington Park Hotel. Broad themes for the Conference are 'Deprivation and cancer', 'Familial cancer registration' and 'Cancer survival'.

Our keynote speakers are Professor Michel Coleman, Professor of Epidemiology and Vital Statistics and Head of Cancer and Public Health Unit at the London School of Hygiene and Tropical Medicine and Professor Mike Richards, the National Cancer Director for England better known as the Cancer Tzar.



### UCF PUBLIC LECTURE

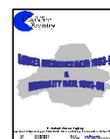
Professor Richards will deliver the first Ulster Cancer Foundation sponsored Cancer Registry lecture which will be open to the public on 23 November 2000. By then the new National Cancer Programme should be published. Professor Richards has outlined the broad goals of this programme:

- 1 Focus on saving lives through better detection, prevention and treatment of cancer.
- 2 Improving the quality of life for patients by addressing quality of care, reducing delays and improving outcomes.
- 3 Addressing inequalities in the incidence and care of cancer.

A detailed programme for the conference will be available by the end of the summer on our web site: [www.qub.ac.uk/nicr/intro.htm](http://www.qub.ac.uk/nicr/intro.htm). □

## New Data

The Registry's 1996 incidence data is available on our web page at [www.qub.ac.uk/nicr/intro.htm](http://www.qub.ac.uk/nicr/intro.htm)



The patterns are similar to that for previous years with few trends except for breast cancer which has seen an increase in numbers from 752 cases in 1993 to 873 cases diagnosed in 1996. This is likely to reflect increased detection of earlier lesions through the breast screening programmes. At the same time deaths from breast cancer have fallen between 1993 and 1998 from 331 to 297 per year. Histological verification for breast cancer has improved over the last 4 years from 88% to 94%.

Our measures of data quality continue to improve with a percent of cases registered by death certificate only very low at 1.3% and over 80% of tumours having a microscopic verification.

\* After skin cancer the major contributions to cancer in women were breast cancer accounting for 19% of female cancers, colon cancer 7% and lung cancer 7%. In men lung cancer accounted for 13% of cases, prostate for 11%, colon 7%, while rectum, stomach and kidney cancers each accounted for 4% of the cases.

The tables on the web page include age-standardised rates and numbers of new cases by Health Board and District Council.

### CANCER SURVIVAL

For the first time ever we will have population based, 5-year cancer survival data for those diagnosed in 1993 and 1994. This will enable us to compare our outcomes with those of other countries and over time. The Survival Report is due late 2000. □

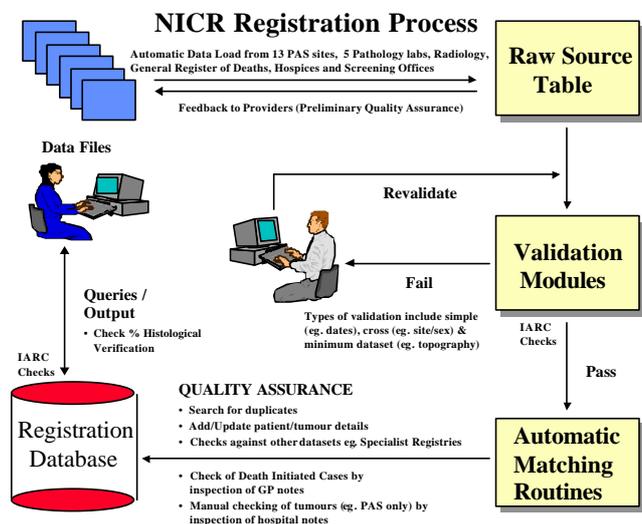
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# Data Blitz



The Registry staff are making a valiant effort to have 7 years incidence data available by 2001, this will cover the period 1993-1999 and will involve a period of intensive work by Registry staff with the help of medical records department in all hospitals. Our process of operation is outlined below.



Data are received electronically from 13 hospital Patient Administration Systems, 5 Pathology Laboratories, 8 Radiology sites and the Registrar General's Office. These become part of our raw source data and are passed through various automatic validation rules which cross check site and sex, dates and minimum dataset. We also have various automatic matching routines which allow us to add data to existing cases or create new ones.

The next step is checking patient records of any cases without confirmatory pathology. This allows us to identify patients diagnosed years previously, which we call prevalent cases, and gain additional information from cases notified to us by death certificate only. In addition many pathology records are also checked. This quality assurance process is time consuming but necessary to maintain the high standard of data in the Registry. We are grateful for the co-operation of the Medical Records Departments for this work.

Finally then, we have our registration database which is subject to the International Association of Research on Cancer (IARC) data quality checks before the data is deemed complete. Over the next year we will be undertaking this process for the years 1997, 1998 and 1999 to enhance the timeliness of our data. □

## RACC Audit Project

Has the Reorganisation of Cancer Services made a difference?

The Cancer Registry is in the final stages of part one of a regional 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. Staff have collected data for 1996 by review of hospital records. It is planned that with funding a similar exercise will take place for the year 2001 to determine whether the changes recommended in the Campbell Report – 'Cancer Services Investing for the Future' have made a difference to the care of patients with cancer. A big thanks to all the Medical Records Departments for their help with this project. □

## All Ireland Cancer Incidence Report

One initiative strongly supported by the National Cancer Institute Conference last autumn was the production of the first All Ireland Cancer Incidence Report. This report will use data already acquired by the Registries in the North and South and should be available by the autumn of this year. Currently working on the project is Dr Paul Walsh. □

## North American Association Of Central Cancer Registries Meeting - New Orleans

### Report by Dr Richard Middleton

"I was very fortunate to be able to attend the NAACCR Meeting in New Orleans, last April. Despite the very hot and humid weather, we had a very successful conference. There are currently several new developments in Cancer Registration such as implementation of new SNOMED codes for the morphology and topography of tumours. The American Joint Committee on Cancer has also issued new guidelines on the staging of certain tumours. There are also a number of exciting new developments in the field of computerisation of cancer registration records.

It was extremely useful to renew contacts with those who had attended the National Cancer Institute All Ireland Conference in Belfast in October of last year. In addition I was able to meet researchers throughout the USA and Canada with similar work interests. These contacts may prove useful in the development of future joint projects.

I also attended the NAACCR Course 'Central Cancer Registries: Design, Management and Use', which I found very stimulating. The course covered a wide range of topics from basic epidemiology, total quality management to cancer patient follow-up. It gave me many new insights, which I hope will prove useful in the future." □

*Richard Middleton  
Data Manager*



## New Staff

The Registry is very pleased to welcome the following new staff.

**Dr Liam Murray** as Senior Lecturer, responsible for promoting the Research Agenda of the Cancer Registry. Liam is half time between the Cancer Registry and the Department of Epidemiology and Public Health. He is trained in Public Health and has previously undertaken research in the following areas:



- Epidemiology of *Helicobacter pylori* infection
- Relationship between chronic infection (especially *Chlamydia pneumoniae* and *Helicobacter pylori*) and cardiovascular disease.
- Community based randomised controlled trial of the effect of eradication of *Helicobacter pylori* on dyspeptic symptoms and health service utilisation for dyspepsia.
- The epidemiology of coeliac disease in Europe.
- Investigation of trends in and tracking of behavioural and lifestyle (e.g. fitness, physical activity, diet, smoking etc.) risk factors for cardiovascular disease risk in adolescent and young adult populations – the Young Hearts project. Genetic determinants of arterial compliance, blood pressure and cardiovascular disease risk in early adulthood.
- Environmental and genetic determinants of peak bone density.
- Randomised controlled trial of the effectiveness of hip protectors in preventing hip fractures in the elderly living in nursing and residential homes.
- Seasonality in birthweight and relationships between birthweight and development of risk of cardiovascular disease. □



**Mr Tom Wylie** has joined our IT staff for a change of career from the Finance Department in the Royal Victoria Hospital. Tom has quickly got to grips with the database and is learning the intricacies of MUMPS computer language while proving a great asset for the Cancer Registry. □

**Mrs Deirdre Fitzpatrick** our new Biostatistician carries on the work of James Reid who has moved to the N. Ireland Housing Executive. Deirdre has a background in pure and applied mathematics and a MSc in computational science. She has previously worked in the Department of Agriculture and is currently analysing our data for survival. □



## Cluster Busters

### Investigation of Alleged Cancer Clusters:

Vigilant individuals will often be concerned that a population has a higher rate of disease than they would expect. Part of this suspicion may reflect the increasing frequency with which cancer is diagnosed in our population.

### *This increase has several causes:*

- Firstly, an aging population, as we live longer we are more likely to develop diseases of old age, including cancer.
- Secondly, competing causes of deaths such as infection has largely been controlled.
- Thirdly, technological advances have improved the accuracy of diagnosis and so we are better at diagnosing cancer when it occurs.
- Fourthly, lifestyle changes, the use of tobacco, a high fat/low fibre diet combined with increased alcohol consumption and reduced levels of exercise has increased our risk of developing cancer.

### *But Beware:*

- It is unlikely that analysis will identify a causal factor: the results can only suggest areas for further investigation.
- Multiple analyses may generate apparent excess risks by chance.
- Small expected numbers may generate apparent excess risks by chance.

It is important to study alleged clusters as this may contribute to the investigation of previously undetected causes of cancer. Information, however, from alleged clusters which have been scientifically investigated indicate that the discovery of an unknown cause of cancer is unlikely.

The Cancer Registry will follow procedures for cluster investigation as outlined by the Ontario Cancer Treatment and Research Foundation.

### *Why there's often a negative result*

The study of individual clusters of disease do not offer many prospects for scientific advance for the following reasons:

- Clusters are usually too small to contribute a useful epidemiology study with adequate control of confounding variables.
- Reported clusters often use vague definitions of disease with cases too varied for useful study.
- Difficulties defining population at risk.
- Poorly characterised, mixed or low concentration of alleged exposure.
- Publicity makes unbiased data collection difficult.

*continued on page 4*

## International Collaboration Enhancing Automated Cancer Registration

Computers have enabled all areas of health care to hold an excellent, readily accessible data on patients. The N. Ireland Cancer Registry relies on the electronic capture of data on all cancer patients in a confidential manner. The two main sources of data that we use, are from hospital discharges and laboratory information. From these two sources, we build up a composite record of the patients' diagnosis and progress using an automated system. We are not unique in this and other cancer registries worldwide are seeking to maintain a database via electronic data capture.

One of the problems for any electronic cancer registry is the duplication of patient and tumour information. Duplication of patient information is peculiar to each geographical registry as there are many common names in Northern Ireland, which would be very rare, or non-existent in England, never mind France or Italy. However, problems concerned with duplication of tumour are universal no matter which country the cancer registry is situated.

### Co-operation to tackle Tumour Duplication

At the last IARC meeting in Lisbon, Dr Middleton met representative of the other electronic based registries with similar experiences to ourselves. After discussion, the area of tumour duplication was identified as one area in which we could share expertise and resources. As a result of this meeting, the European Network, of Cancer Registries ENCR has set up a working group to look at these issues led by Dr Lorenzo Simonato of the Veneto Registry in Italy. The group is looking at rules and standardisation of the procedures involved in the resolution of electronic data capture. Northern Ireland is actively involved in setting up a test database for use on any cancer registry's computer system. It is hoped that the work of this group will aid cancer Registries already using electronic capture and also help those planning to use it. □

## Staff News



We wish **Breige Torrans** a speedy recovery from her recent illness and look forward to having her back with us soon. □

### What If You Think There Is A Cluster?

#### 1. Assessing the Inquiry

- Reported cases must be of sufficient number, minimum 5 cases per unit of analysis, and of the same type or body system.
- A plausible biological association must exist with a suspected exposure.

If it is not possible to analyse in a meaningful way, we will give you general information discussing cancer clusters and specific information on cancer rates and known risk factors which may help them understand what you have observed.

#### 2. Verification of Cases

If it is possible to proceed, then we will verify the data including cases known to the Registry. It will also check any reported cases additional to that known to the Registry. This reduces reporting bias.

#### 3. Analysis

- Statistical analysis will then be undertaken taking account of differing age distributions using:
  - age and sex standardised incidence rates,
  - comparisons of geographical areas under study with similar areas and
  - analysis using special statistical methods designed for the study of spatial, temporal and/or space-time disease clusters in conjunction with the Small Area Health Statistics Unit (SAHSU) in London.

#### We may then recommend one of the following:

- i) no further action
- ii) future surveillance or
- iii) a detailed study, depending on the satisfaction of criteria on statistical significance, biological plausibility and documentation of exposure. □



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.

#### Our Address:

N. Ireland Cancer Registry  
Mulhouse Building  
Grosvenor Road  
Belfast  
BT12 6BJ

**Tel:** 028 9026 3136 or 028 9024 0503 ext 2573

**Fax:** 028 9024 0817

**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)