N. IRELAND
Cancer Registry
providing information on cancers for research, education and planning of services
Issue 7 August 2001

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

All-Ireland Report

The Ministers for Health Ms Bairbre De Brun and Mr Michael Martin, Dr Rick Klausner, Director, National Cancer Institute (NCI) USA, Dr Etta Campbell and Dr Jim Kiely, Chief Medical Officers launched the first All Ireland Cancer Incidence Report, 1 May 2001.

This is a concrete example of co-operation within the initiative launched 3 October 1999 between the National Cancer Institute of the United States, the Departments of Health of Northern Ireland and the Republic of Ireland to enhance cancer research in Ireland and promote international dialogue in the control of cancer.
Both registries have worked closely since their establishment to secure agreement on issues such as case definitions and coding conventions to ensure that the two databases are compatible.

Speaking at the launch Ms De Brun identified that the report will provide a useful baseline reference on cancer for years to come. The report's author Dr Paul Walsh says that by combining the data the power to examine trends and patterns have been increased while data quality has been enhanced.

Major Findings

1. Cancer Rates are 30% Higher in Men than Women

This pattern is common to many western populations due to differences in sex specific cancers. Some cancers occur more commonly in men e.g lip, oesophagus, stomach, lung, kidney and bladder. Many of which are strongly linked to tobacco usage, which is higher in men. Tobacco related cancers have poor survival, which is reflected in the death rates for men, about 50% higher than those of women. Men may also present later when there is less chance of a cure
We would like to investigate these pattern in an All-Ireland survival report.

Dr H Cambpell, Ms B De Brun, Mr M Martin, Mr J Keily at the launch of the All Ireland Report

2. We have higher than EU average lung cancer rates in women.

This is likely to reflect historic tobacco consumption.

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- CONFERENCE -
Data Protection & Confidentiality

The 1998 Data Protection Act, GMC Guidance, Implications for Doctors, Administrators and Managers

Hilton, Templepatrick
Thursday 25 October 2001

Speakers - Michel Coleman (Professor of Epidemiology LSHTM), Ms Sandra Cavill (Office of Data Protection Registrar), Ms Jane O'Brien (General Medical Council), Mr Phil Walker (Head of Confidentiality Issues, DoH), Dr Nick Gaunt (Clinician), Ms Ruth Boardman (Lawyer)
Booking form and further details are available on our web site. (see page 4)

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3. Urban populations have 10% higher rates of cancer in females and 15% higher rates of cancer in males.

This pattern was consistent North & South. This pattern is similar to that found in other Western/developed countries. There are two main linked reasons for this: - Deprivation and Tobacco Use. Urban areas have large pockets of deprivation which is associated with higher rates of cancer (and other diseases). The reasons include poorer diet and in particular higher rates of tobacco use and exposure to environmental tobacco smoke among deprived populations. This is an area we would like to investigate further and in particular to document any survival differences which exist geographically and by socio-economic groups.

4. Oesophageal cancer is high in Northern Ireland and Republic of Ireland compared with EU average.

Oesophageal cancer is linked with tobacco use, alcohol use and a diet with low levels of fresh fruit and vegetables. There is scope for health gain here through health education and health promotion.

5. Breast cancer accounted for 1/5 cancer deaths in women.

The population based breast screening programme which detects cancers at an earlier stage combined with advances in therapy have resulted in a fall in breast cancer deaths.

Dr Harry Comber, Dr Paul Walsh, Dr Anna Gavin and Dr Rick Klausner at the launch of All Ireland Report

6. Overall cancer rates 6-7% higher in Northern Ireland.

These consist of the following major groups:

- Colorectal cancer – males and females – consistent finding which requires further research
- Lung - males and females – represents higher historical rates of tobacco use.
- Skin melanoma – requires further research
- Stomach – linked with tobacco use, urbanisation/ deprivation and Helicobactor pylori infection.

Report and Summary are available on our web site: www.qub.ac.uk/nicr/intro.htm

IT Developments

After several journeys and some configuration work, the move from Mulhouse to Riddel Hall was finally completed in March and consequently the Registry system is once again fully operational.

The main work has been on two fronts. Firstly, a significant effort has been put into processing 1997-99 data through the system. Secondly, there has been significant collaborative effort with the Trent and Thames Registries to rationalise the systems. Each Registry uses the same system but in different ways. A support server has been installed at Sheffield (within the Trent Registry) with copies of the three versions of the system (NICR, Trent and Thames). Software was developed in order to compare main aspects of the system between the three versions. This has been completed and currently we are finalising a set of core system objects which will be common to all three registries. When each Registry adopts this core system, support and future development activities can be more easily coordinated.

Finally, a new version of MailSecure encryption software has been released and the NICR, in conjunction with the Directorate of Information Systems, are currently rolling this out to each Trust that provides data extracts to the Registry. This should enhance our means of data acquisition and enable improved security. The IT team has been enhanced with the appointment of Mr Giulio Napolitano who will join the Registry in August and Wendy Hamill, from our secretarial team, who is making her career in computing. Giulio replaces Mr Tom Wylie who has moved to QUB Finance Department.

New Staff

Giulio Napolitano is our new IM&T Officer replacing Tom Wylie who has moved to QUB Finance Department. Giulio has a background in software development applied to database systems. He has skills in Internet-based technologies such as XML. He should prove a useful asset in the further development of the cancer registry system.

Welcome to **Suzhuang Hong**, Data Abstractor, commenced work in the N. Ireland Cancer Registry, June 2001

Research Update

The Registry is working on the following areas:

1. Population-based study of risk of oesophageal adenocarcinoma in Barrett's Oesophagus

This study is a collaboration between NICR and local gastroenterologists, pathologists and surgeons. Previous studies have suggested that Barrett's Oesophagus, (BO), which is a change in the lining of the lower oesophagus following gastro-oesophageal reflux, carries a 30 to 125 fold increased risk of oesophageal adenocarcinoma (OAC), but population based studies have not been performed. In this study data was collected on every oesophageal biopsy (N=15,670) undertaken within Northern Ireland between 1993 and 1999. Patients were classified as having BO or not. Incident oesophageal malignancies occurring at least 3 months after the initial biopsy, were identified by NICR. Standardised incidence ratios for oesophageal malignancy were calculated by comparing NI rates with those of the study population. 18 cancers occurred in 3,053 patients giving a standardised incidence ratio for oesophageal malignancy of 7.7 (95% CI, 4.5 to 12.1). It therefore appears that the risk of oesophageal malignancy in BO may have been substantially overestimated in previous studies. This study was presented at the meeting of the American Gastroenterology Association in Atlanta in May 2001.

2. Association of early life factors and acute lymphoblastic leukaemia: historical cohort study

This study, which has been recently completed, was collaboration between NICR and local paediatric haematologists and oncologists. Birth record data on all live singleton births in NI from 1971-86 (n = 434,933) were obtained and cases of acute lymphatic leukaemia (ALL) were identified among this cohort (n = 188). Birth factors were compared between children who developed ALL and those who did not. Large babies and babies born into low density households had substantially raised risk of childhood ALL while longer gestation, being born into an extended family unit and having a maternal history of miscarriage were protective. Further research examining childhood infections, insulin-like growth factors and cytokine biology is currently being planned. This study has been submitted for publication to the Journal of the National Cancer Institutes (USA).

3. Effect of availability of prostatic specific antigen testing on incidence of prostate cancer in Northern Ireland in the 1990's

Many developed countries have seen dramatic increases in the incidence of prostatic cancer as the result of the introduction of prostatic specific antigen (PSA) testing. Screening using this blood test is not advocated in the UK as there is no evidence that it improves outcome from prostatic cancer. Nevertheless, testing frequently occurs both within primary and secondary care. In this study, all PSA tests performed in NI since it was introduced in the early 1990's were obtained. Rates of testing were compared to incidence of prostatic cancer in the Province. Unlike in the USA, no overall increase in prostatic cancer incidence was observed following the introduction of PSA testing, despite widespread use of the test. The Cancer Registry is currently checking the data and will report on its findings in the Autumn.

4. Breast Cancer Staging

Nuala Hale, a medical student, is undertaking a project with the breast clinicians to improve staging data available to the Registry.
Copies of the latest edition of the TNM staging booklet are available on request from the Registry

Informed Consent

CANCER INFORMATION AT RISK

In late 2000, the UK cancer registration scheme was put at risk by new guidance to doctors from the General Medical Council (GMC). The guidance stated that no identifiable information should be transferred to cancer registries without the patient's explicit consent. As a direct result, some NHS trusts and private hospitals stopped providing data to cancer registries. The GMC subsequently agreed to a period of grace for cancer registries until November 2001, allowing time for appropriate legislation to be passed or systems for seeking and recording consent to be put in place.

Valuable Information Source

The national cancer registration scheme is the only available source of information on cancer incidence and survival at population level. Information from cancer registries has shown that survival from most cancers is poorer in this country than in other parts of Europe. This has been one of the major factors influencing government policy on cancer services and leading to the decision to invest in improving the quality of care available. The government has given a commitment that by 2010 cancer survival rates in this country will equal the best in Europe. It will only be possible to monitor progress against this target if the national cancer registration system is protected by appropriate legislation.

Strict Confidentiality

Cancer registries require identifiable data because of the need to link data from many different sources and over long periods of time. Patients can be reassured that registries adhere to strict confidentiality protocols and there have been no recorded breaches over the more than 40 year history of the national scheme.

Informed Consent Unworkable

Experience from other European countries has shown that requiring informed consent for cancer registration does not work and leads to an unquantifiable loss of information. This is not because many patients refuse to allow their data to be transferred although some do and those who refuse may be different from other cancer patients in ways which might, for example, influence survival rates. The main problem is that many patients are never asked for consent. Doctors are reluctant to burden patients with the request at an already stressful time and the default position is to block the transfer of data if consent is not recorded. The resulting loss of information makes comparisons over time or between different geographical areas unreliable. If this happens in the UK we will be unable to reliably monitor trends in cancer survival or evaluate the effectiveness of cancer screening programmes or assess cancer risks in the population.

The Solution

Under Clause 60 Health and Social Care 2001 which recently became law, regulations can be passed allowing transfers of identifiable data without explicit consent for certain specified and controlled purposes. The process will be overseen by a newly established Patient Information Advisory Group, with representatives from bodies such as the GMC, Data Protection Office, the Royal Colleges and patients groups. It is essential that a regulation covering cancer registration is passed as a matter of urgency if the national system built up over many decades is to be preserved for the benefit of current and future cancer patients. It should be noted that any regulation passed under Clause 60 would only apply to England and Wales and not to other parts of the UK.

The DHSSP is dealing with the issue for Northern Ireland.

The United Kingdom Association of Cancer Registries, of which the N. Ireland Cancer Registry is a member, fully endorses the need for much better and more accessible information for cancer patients about the uses that are made of data relating to their illness and will work with the Department of Health to ensure this happens.

GMC Revised Guidance

The GMC have revised their guidance "Confidentiality: Protecting and Providing Information" to reflect changes in law with the introduction of Health & Social Care Act 2001. The new guidance will remove the section on disclosures for research, epidemiology and public health monitoring (separate advice will be published taking account of the Health & Social Care Act 2001). It will also take account of practical difficulties which doctors may face in seeking and recording consent or anonymising data while new systems are being developed.

Professor Gary Love A Sad Loss

Professor AHG Love, Emeritus Professor of Medicine at Queen's University, Belfast, died suddenly while horse-riding on Wednesday, 3 January 2001. He was 66. Gary Love was a person of great charm who was a friend to everybody, always courteous and helpful. He was one of the most outstanding doctors in Northern Ireland and was well known and highly respected in many other parts of the world. Professor Love chaired the Council Meeting for the N. Ireland Cancer Registry. He will be sadly missed by Registry staff.

Professor Roy Spence New Chair of the Council

Professor Roy Spence has been a Consultant Surgeon at the Belfast City Hospital since 1986.

He is also a Senior Lecturer in the Departments of Anatomy, Surgery and Oncology in the Queen's University of Belfast and a Visiting Professor at the University of Ulster. He acquired the Fellowships of the Royal College of Surgeons of Edinburgh and Ireland in 1981. He received an MD Degree from Queen's University in 1984 and an MA Degree in 'Medical Ethics and Law' from Queen's University in 1997. His major clinical interests are as a General Surgeon with a Specialist interest in Breast Cancer and Endocrine Surgery. He has an interest in the organisation of Cancer Services and is Lead Cancer Clinician in the Belfast City Hospital Trust. He is a Council Member of the Ulster Cancer Foundation and Chairs the UCF's Research Advisory Panel.

He was appointed an OBE in the New Year's Honours List, 2001.

We Have Moved

OUR TEMPORARY ADDRESS UNTIL APPROX. FEBRUARY 2002 IS:

N. Ireland Cancer Registry, Department of Epidemiology & Public Health,Riddel Hall, 185 Stranmillis Road, BELFAST BT9 5EE

Tel: (44) 028 9027 4803 or Also our original number of (44) 028 9026 3136 Fax: (44) 028 9027 4804

Email: nicr@qub.ac.uk Web Site: www.qub.ac.uk/nicr/intro.htm

(We will be at the above address for approximately one year and then will return to the Mulhouse Building, Grosvenor Road, Belfast).