

# N. Ireland CANCER REGISTRY

providing information on cancers for research and education

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



Issue 2  
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## 1st Report Launch

■ While the rest of the world watched Bill Clinton and his entourage, including the motor cavalcade, on his visit to Northern Ireland, the Cancer Registry launched its first report - "*Cancer Deaths in N. Ireland - An Analysis of Patterns and Trends*".

Despite the stiff competition the launch was attended by a veritable Who's Who of the local medical world. Sir Donald Acheson, former Chief Medical Officer of England and Wales and Northern Ireland's Chief Medical Officer, Dr Henrietta Campbell, both spoke of the need for quality information on cancer. Sir Donald was clearly impressed at the layout and content of the report. He remarked particularly on the Health Gain messages included at the end of each section.



Above: Dr Anna Gavin, Director, NICR - Sir Donald Acheson, former Chief Medical Officer of England and Wales - Dr Dermot O'Reilly, Deputy Director, Health and Health Care Research Unit - Dr Henrietta Campbell, Chief Medical Officer for Northern Ireland.



The report has been circulated to each consultant in Northern Ireland, all General Practices, each College of Nursing, Health Board Trusts, local libraries and cancer charities. Each Cancer Registry throughout the world has also received a report. These have, in turn, provided the N. Ireland Cancer Registry with reports and international data which could be of use in future research. This report has marked the re-launch of the N. Ireland Cancer Registry in a very positive way.

Left: NICR Staff - Mr Colin Fox, IT Manager - Miss Lorraine Crichton, Secretary - Miss Breige Torrans, Administrator - Miss Nuala Brady, Researcher - Dr Anna Gavin, Director and Sir Donald Acheson, former Chief Medical Officer of England and Wales.

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# N. Ireland Cancer Registry New Computer System

■ Phew !! After a detailed evaluation phase, we have finally opted for a computer system for cancer registration in Northern Ireland - it is the system developed by AT&T Istel Ltd and currently used by the Thames Cancer Registry.

The system has also been recently purchased by the Trent Cancer Registry and a user group comprising these registries may soon be set up. This system will allow automatic entry and processing of data and provide facilities for data analysis as well as an ability to extract data for analysis in other software packages, such as Geographical Information Systems (GIS) and statistical software.

Recently, our Project Board gave us the OK to purchase the system along with appropriate hardware. At this point the Registry would like to acknowledge the invaluable advice of Mr Roland Beckett, Department of Health and Mr Gerry Gault, Directorate of Information Systems (DIS) and also thank the DHSS for funding.

For the computer whizz kids, the preferred hardware platform is a Digital Equipment Alphaserver model 400 4/233 MHz processor, with a 1GB system disk, a 4.2GB internal disk, 64MB of memory and the Digital UNIX operating system (OSF1). The application will reside on this machine and serve 6 client PCs - these will act as terminal links to the database. However, they will also enable data analysis to be done using the packages SPSS for Windows and Microsoft Excel, which will reside on each PC. The network will be implemented using Pathworks software, supplied by Digital Equipment. It is planned that the network will be configured by July 1996 and the complete system will be operational by October 1996.

The Registry would like to thank Richard Duffin, Noel Breen, David Bryce and Niall Murphy from DIS for their work in developing a common data extraction module for the Registry.

Finally, the Registry would also like to acknowledge the work of Mr Joe Beattie (DIS) on this project. Joe was our IT consultant and provided invaluable knowledge, expertise, helpful advice and 'craic' to the Project Team and the Registry in general.



When we "go live" with the system, we would welcome anyone with an interest in the Registry to come along and see it in action.

Contact: *Colin Fox*, IT Manager.

Computer Group - Mr Eamon O'Hagan, Systems Manager, Dept. of Epidemiology & Public Health - Mr Colin Fox, IT Manager, NICR - Dr Anna Gavin, Director, NICR - Miss Breige Torrans, Administrator, NICR and Mr Joe Beattie, Senior Systems Analyst, DIS.

## What we collect

■ The aim of the NICR is to provide information on cancer by gathering data on all patients diagnosed with a malignant growth. The main basis of our information is pathology reports. In some cases which do not have a pathology report we rely on a clinical diagnosis obtained from other sources such as Hospital Patient Administration Systems (PAS) or death certificates. All information sources are matched to gain the most information on each case.

The table below shows a list of the tumours we are currently collecting. It is based on an agreed list produced by the United Kingdom Association of Cancer Registries. In broad outline we collect all malignant neoplasms (SNOMED behaviour code 3), all metastatic tumours, all 'in situ' neoplasms including CIN III, tumours of uncertain behaviour (SNOMED behaviour code 1) and a number of important benign tumours.

As we obtain our information electronically, we can collect information on a number of other important pre-cancerous tumours. These, whilst not being formally part of the Cancer Registry, will be a valuable resource to researchers in the future.

We would, of course, welcome any comments on the list and, in particular, whether there are any other tumours we should be collecting.

### Types of Neoplasms Collected by N. Ireland Cancer Registry

▼  
All Malignant Neoplasms

All 'in situ' Neoplasms (includes CIN III)

All Neoplasms uncertain or unknown behaviour

Certain Benign Tumours (eg. Brain, Endocrine, Glands, Colon and Rectum)

Other Conditions (eg. Asbestososis, CIN I, CIN II)

# Ulster Cancer Foundation Grant Awards



## Malignant Melanoma

The Ulster Cancer Foundation has been very supportive of the N. Ireland Cancer Registry. This year they have re-awarded a grant to support a malignant melanoma project to continue adding to a 10 year old database of cases with a view to monitoring outcomes. Information from the earlier Wolfson Study and the study funded by the Ulster Cancer Foundation has been

published in the Wolfson Report (June 1995). Postholder Dr Pauline Pedlow.

## Epidemiologist/Statistician

From August 1996, thanks to a grant from the Ulster Cancer Foundation, the Registry will be able to employ an Epidemiologist/Statistician. This person will enhance the analytical skills of the Registry team. The first major task will be analysis of information for our first report of cancer incidence in 1997. Currently 30% of the Registry's funding is provided by the UCF. The other major funder is the DHSS.

## Project Worker

Fiona Moore is examining cancer deaths occurring in District Council areas for the Cancer Registry. Fiona has a degree in Psychology and Sociology and plans to pursue a career in health promotion.



Fiona Moore

## Interval Breast Cancer Project - Update

■ Year one of this two-year research project, funded by the N. Ireland Cancer Registry and the Breast Screening Programme, has seen the successful collection of data from hospitals, screening centres and pathology laboratories.

We now have a list of women born between 1922 and 1947 who have had a diagnosis of cancer of the breast since the beginning of the Northern Ireland Breast Screening Programme in 1989. By comparing this list with data held on the Screening Unit's database it will be possible to group these cancers as "screen-detected", ie picked up at screening, or "non-screen-detected". Further analysis will define those cancers which occurred in the three-year interval between each call for screening. These cancers will then be more closely investigated to ensure the quality of the Screening Programme.

Project Worker, Nuala Brady, would like to take this opportunity to thank all those who have co-operated with the Cancer Registry in connection with this important project. Your help is greatly appreciated!

Please contact Nuala at the Registry with any queries regarding the Interval Breast Cancer Project.

## Pathologist Joins Team

Dr Jeffery Robertson has recently retired after many years of service both overseas and in Northern Ireland. Dr Robertson has volunteered his services as a visiting pathologist for the N. Ireland Cancer Registry. This will ensure a high standard of data from the Registry.



## The Burden of Cancer in N.Ireland

	Cancer* Admissions	Cancer Total Bed Days	Total Admissions All Causes
1986	7,838	99,365	226,676
1987	8,793	104,088	216,049
1988	10,369	126,335	221,145
1989	11,810	117,994	259,281
1990	13,433	130,835	279,634
1991	16,626	149,795	307,987
1992	17,162	143,243	323,218
1993	20,124	148,687	341,666
1994	21,518	152,492	385,392
1995**	20,700	147,128	411,461

\*ICD Codes 140-239 (excluding benign neoplasms 210-229)

\*\*Provisional Data

Coverage 1986-90 was 80-90%

Coverage 1990 onwards 95% approximately except coverage 1992 = 88%

Source HAA 1986-1988

HIP 1989-1995

Data acquired independently by the N. Ireland Cancer Registry from the Patient Administration System (PAS) for 1993 indicates there were 20654 cancer admissions. These represent 97.4% of officially recorded hospital activity for cancer and account for 10,389 patients.

Acknowledgement to Owen Johnston, Strategy & Intelligence Group, DHSS.

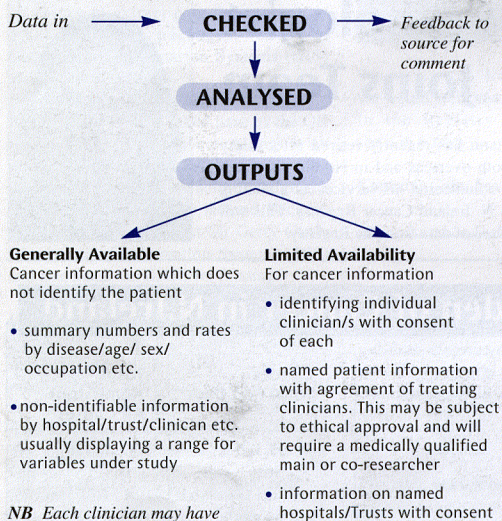
# May We Help You?

■ The N. Ireland Cancer Registry's role is to provide information on cancer for research, education and planning of services. We are keen to assist with enquiries for information. This role will increase as we have more data.

The release of Cancer Registry data must be within the requirements of our Data Protection Act registration and as agreed by those who have provided the data.

The N. Ireland Cancer Registry has an internal document on the policy regarding security, confidentiality and issue of data. This has been approved by the Queen's University and the University of Ulster Ethical Committees and a copy is available on request.

The following diagram outlines the availability of the data from the NICR.



**NB** Each clinician may have access to all information on patients in their care.

If you wish to request information on cancer please contact Dr Richard Middleton, Data Manager.

## In Partnership

NIGIS, the Northern Ireland Geographical Information Systems, is a multi-partner initiative led by Ordnance Survey of Northern Ireland to maximise the efficiency and effectiveness of handling geographical information. This partnership has been extended to include the Northern Ireland Cancer Registry which will avail of the mapping techniques and boundary files available for Northern Ireland. The confidentiality of the data held within the Registry will be maintained while detailed geographical and small area analysis will be enhanced.



Funding Sources: The N. Ireland Cancer Registry is funded by **DHSS**. Additional funding: **The Ulster Cancer Foundation and the N.I. Breast Screening Programme**. This Newsletter has been sponsored by **RHÔNE-POULENC RORER**

## A View to the Future

UCF Epidemiologist/Statistician in Post **July/August 1996**

New Computer System Installed **October 1996**

Electronically acquire: Information from Patient Administration System (PAS) and Pathology Laboratories up to end of 1995. **December 1996**

This should provide approximately 4-5 years of information which will be of higher quality for more recent years. The acquisition of information will then become routine.

Assess Additional Information Sources eg Radiology, Hospices, GP Data Retrieval Project **Ongoing**

Match and Quality Assure Information Received **Autumn 1996**

Feedback of Information to Key Providers **Early 1997**

Report of Cancer Incident Information **Mid 1997**

Updated Deaths and Estimated New Cancer Cases by District Council Area in N. Ireland	Average Annual Deaths 1989-93	Estimated New Cases
ARDS	151	345
BELFAST	907	2073
CASTLEREAGH	158	362
DOWN	116	265
LISBURN	173	395
NORTH DOWN	175	401
ANTRIM	81	186
BALLYMENA	114	260
BALLYMONEY*	44	101
CARRICKFERGUS	70	161
COLERAINE	123	280
COOKSTOWN*	47	107
LARNE	71	162
MAGHERAFELT	65	150
MOYLE*	40	91
NEWTOWNABBNEY	162	369
ARMAGH	96	220
BANBRIDGE*	73	166
CRAIGAVON	153	350
DUNGANNON	90	206
NEWRY/MOURNE	182	415
FERMANAGH	118	271
LIMAVADY	54	123
DERRY	177	406
OMAGH	80	182
STRABANE	75	171
<b>N. IRELAND</b>	<b>3,595</b>	<b>8,217</b>

\* NB The table in Issue 1 had errors for these District Councils. See N. Ireland Cancer Registry Report on Cancer Deaths for further details.

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

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