

# N. Ireland CANCER REGISTRY

providing information on cancers for research and education

Division of Epidemiology, The Queen's University of Belfast



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## Assuring Quality

■ The quality of data held in the N. Ireland Cancer Registry is the key to its future. The Registry receives data electronically from many sources.

The major ones are:

- 1 The Pathology system.
- 2 Patient Administration System.
- 3 Death records.

The programme for data quality enhancement is briefly outlined below:

1. All duplicate patients/tumours must be identified. We are working with AT&T, the providers of our system, on routines to achieve this. This will be supplemented by selected manual checks.

2. The data received from Pathology laboratories and PAS systems have been analysed separately with feedback to the Providers, including information on perceived accuracy. We are very grateful for the useful comments received from these sources.

3. Death Certificates Only (D.C.O.) registrations. This is an unfamiliar term for most of you but is a recognised term, among cancer registry staff. Throughout the world this is used as one measure of case ascertainment and data quality in a registry. Many of the deaths notified to our registry for 1993 will have occurred in patients in whom cancer was diagnosed many years previously. The G.P. records of such patients held in

Central Services Agency are being manually examined to determine date of diagnosis. The procedure also checks the diagnosis for those diagnosed in 1993. This project will continue to examine data for each year for the Registry.

4. Pathology records for breast, cervix and colon cancer will be double checked manually to determine if they represent primary cancer or recurrence.
5. A selection of cases with only a PAS record will have hospital records checked to verify diagnosis, date of diagnosis etc.
6. The electronically collected data will be compared with the old card system, for one year, to ascertain accuracy and completeness.

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## The Computer System Implementation Team

■ We finally went live with the new computer system on 4th February 1997 (the photograph shows the joint NICR/AT&T Istel implementation team at the sign-off meeting). However, during the testing phase a number of problems were identified. Apart from two significant issues concerning patient/tumour duplication and code mappings, most of the problems were minor ones. These problems have been listed and our supplier (AT&T Istel) has given assurances that they will be addressed.

To date, a number of routines have been developed to identify patient duplicates and merge tumour duplicates. Currently, the system is being modified to address the issue of code mappings (ICD10 codes ↔ ICD9 codes ↔ ICD0-1 codes ↔ Snomed topography and morphology codes). Both ourselves and Trent Cancer Registry are pursuing a solution and we expect this issue to be resolved by this summer. Then the NICR will be in a position to produce incidence figures for cancers identified within the Northern Ireland population.

Finally, we are in the process of configuring a modem link between the Registry and our data providers. This will enable them to securely "email" cancer data directly onto a PC within the Registry. We are piloting PC-based encryption software as part of this exercise. Thanks are extended to all in Directorate of Information Services for their continued efforts and support. NICR invites anyone interested in viewing the system to contact **Colin Fox**, IT Manager.



Dr Richard Middleton, Data Manager NICR; Mark Whitelegg, AT & T Project Manager; Colin Fox, IT Manager NICR; Dr Anna Gavin, Director NICR; Chris Carrigan, AT & T Development Manager; Simon Abbott, AT & T Account Manager and Breige Torrains, Administrator NICR.



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7. The N. Ireland Cancer Registry database will be checked against existing registries. Fortunately, we have registries for leukaemia/lymphoma, colorectal cancer and melanoma. These will be examined to compare completeness and quality of data.
8. At a later stage the N. Ireland Cancer Registry database will be checked against international standards set by the Survival Epidemiology and the End Results (SEER), and the International Agency for Research on Cancer (IARC).

This is an outline of a very detailed programme and our timescales, although ambitious, indicate we should have our first Incident Report by the end of 1997-early 1998.

## ■ Finding the unknown

The N. Ireland Cancer Registry receives data electronically from a number of sources.

A cross check of these sources for 1993 identified 935 patients with a cancer diagnosis notified solely from death certificates. We expect many of these patients have had their cancer diagnosed many years previously. A meticulous project examining the GP records of these "death certificate initiated" patients is ongoing. Carmel Canning and Pat Donnelly have already examined all these records from 1993. This has yielded 509 newly diagnosed cancer cases (approximately 5% of all cancer registrations in 1993). For the most part these have been elderly patients who

did not attend hospital, or only attended as outpatients. We have also been able to verify the information on the Death Certificates and the basis of the diagnosis.

The N. Ireland Cancer Registry is grateful to the DHSS who have funded the start of this major quality assurance programme.



**Pat Donnelly**  
Tumour Verification  
Officer



**Carmel Canning**  
Tumour Verification  
Officer

## The Interval Cancer Project

■ **The Interval Cancer Project, on behalf of the N.I. Breast Screening Programme, is now nearing completion.**

Project worker Nuala Brady has been visiting hospitals throughout Northern Ireland to check patient details, essential in defining "interval cancers". These cancers, diagnosed in the three-year interval between breast screening episodes, must be primary (not a recurrence of an earlier tumour) and invasive. Thanks are extended to all Medical Records staff who have helped Nuala in this task.

The next stage in the project will see a review of patient's mammograms (breast x-rays) by radiologists. Interval cancers can belong to several categories:

*true interval*  
*mammographically occult*  
*false negative*  
*unclassifiable*

Results of this work will be published in due course and will be of interest to all those involved in the detection and treatment of breast cancer.

## Cork Visitors

■ **The National Cancer Registry for Ireland was established in January 1994 to collect cancer incidence and mortality data for all 26 counties. Cancer incidence for Cork and Kerry had been collected prior to that time.**

The Registry is located in Cork and its

Director, Dr Harry Comber and staff visited the N. Ireland Cancer Registry recently. This provided an opportunity to exchange information and update on developments. Dr Comber is a regular visitor to the Registry as a member of the Council.

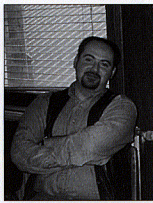


Dr Harry Comber, Director, National Cancer Registry (NCR) Cork; Miss Fiona Dwane, Administrator, NCR; Mr Colin Fox, IT Manager, N. Ireland Cancer Registry (NICR); Mrs Pat Donnelly, Tumour Verification Officer, NICR; Mrs Carmel Canning, Tumour Verification Officer, NICR; Dr Anna Gavin, Director, NICR; Dr Richard Middleton, Data Manager, NICR; Miss Breige Torrains, Administrator, NICR; Mrs Mary Chambers, Supervisor, NCR; Mrs Eleanor Crowley, Systems Manager, NCR; Mr James Reid, Epidemiologist, NICR; Miss Nuala Brady, Researcher, NICR and Miss Eilish Manley, Data Input Clerk, NCR.

## Melanoma- Research Continues

■ **Dr Pauline Pedlow's** research into malignant melanoma has been funded for another year by the Ulster Cancer Foundation. This will enable Pauline to continue her follow-up of melanoma cases diagnosed between 1984 and 1988 for five year's survival. Dr Pedlow's paper on Cutaneous Malignant Melanoma in Northern Ireland has been accepted for publication as a short report in the British Journal of Cancer. She is also travelling to Australia to present a poster entitled "Changes in the Presentation, Incidence and Pathogenesis of Cutaneous Malignant Melanoma in Northern Ireland" at the 4th World Conference on Melanoma in Sydney, Australia, 10-14 June 1997.

On a general note a strategy on malignant melanoma in Northern Ireland will soon be published by DHSS.



**Mr James Reid**  
Epidemiologist/Statistician

Formerly from the Ulster Business School at Jordanstown where he worked on a joint project with EHSSB under the auspices of Marketing Belfast Work in a study of air pollution and ill-health in Belfast. His interests include disease mapping, spatial analysis and Geographical Information Systems (GIS).

■ **The average annual numbers of deaths recorded for major sites has been updated following the production of the Registry report: "Cancer Deaths in N. Ireland: An Analysis of Patterns and Trends" which covered the period 1989-1993. The updated figures relate to the period 1991-1995 and Table 1 provides a breakdown by Board and District Council area. As in the original report, the figures relate to deaths in which cancer was cited as the first cause of death on the death certificate.**

Extending this to include mention on any of the four additional causes of death on the certificate gives a better appreciation of the total burden of cancer in the population and its mortality toll. The 'any cause' column reflects the extra cancer burden identified in this way. Table 2 illustrates the percentage increase in cancer deaths by gender and site recorded by using the additional cause of death information and illustrates significant variation by site, reflecting differences in site-specific burdens and death certification practices. For further information please contact the Registry.



**Table 1. Average numbers of annual deaths 1991-1995**  
*All Cancers ICD 140 - 239*

Board	District Council	Males		Females	
		Cancer 1st Cause	Cancer Any Cause	Cancer 1st Cause	Cancer Any Cause
<b>Eastern</b>	ARDS	75.4	84.2	74.6	84.8
	BELFAST	436.0	486.2	409.6	460.8
	CASTLEREAGH	79.6	88.4	79.2	87.2
	DOWN	58.2	68.2	60.0	67.6
	LISBURN	91.2	104.4	89.6	98.8
	NORTH DOWN	84.2	95.2	93.6	106.4
	<i>Totals</i>	<i>824.6</i>	<i>926.6</i>	<i>806.6</i>	<i>905.6</i>
<b>Northern</b>	ANTRIM	43.0	48.4	39.0	41.8
	BALLYMENA	58.6	66.4	59.0	66.2
	BALLYMONEY	25.2	30.0	22.0	25.4
	CARRICKFERGUS	35.4	39.8	37.4	40.4
	COLERAINE	62.2	69.4	62.6	68.8
	COOKSTOWN	27.8	31.4	20.2	24.2
	LARNE	36.8	41.2	33.6	37.6
	MAGHERAFELT	36.8	41.6	26.8	30.0
MOYLE	19.0	22.6	17.4	19.8	
NEWTOWNABBEY	81.2	90.8	86.2	94.6	
<i>Totals</i>	<i>426.0</i>	<i>481.6</i>	<i>404.2</i>	<i>448.8</i>	
<b>Southern</b>	ARMAGH	47.6	55.2	47.8	52.8
	BANBRIDGE	37.8	42.0	35.8	39.0
	CRAIGAVON	72.6	81.6	75.8	86.6
	DUNGANNON	47.0	53.6	43.4	48.0
	NEWRY/MOURNE	92.6	102.6	84.8	95.4
	<i>Totals</i>	<i>297.6</i>	<i>335.0</i>	<i>287.6</i>	<i>321.8</i>
<b>Western</b>	FERMANAGH	65.6	77.8	50.0	55.6
	LIMAVADY	29.6	31.6	24.4	28.6
	DERRY	95.6	108.0	92.0	103.8
	OMAGH	41.2	46.2	37.8	41.6
	STRABANE	41.2	45.0	35.6	38.2
<i>Totals</i>	<i>273.2</i>	<i>308.6</i>	<i>239.8</i>	<i>267.8</i>	
N.I. Deaths		1,821.4	2,051.8	1,738.2	1,944.0

*All cancers by Board and District Council using (a) 1st cause only and (b) any cause.*

**Table 2. Percentage increase in average number of deaths per annum (1991-1995), selected sites, by gender**

Males		Females	
Lung	6.17	Breast	20.80
Prostate	26.18	Lung	5.82
Colon	16.23	Colon	14.99
Stomach	6.92	Stomach	10.61
Pancreas	5.83	Ovary	10.33
Rectum	16.13	Pancreas	5.43
Oesophagus	9.36	Rectum	16.54
Bladder	29.70	Oesophagus	9.16
Non-H Lymphoma	13.85	Non-H Lymphoma	15.11
All Cancers	12.65	Cervix	10.56
		Bladder	28.86
		All Cancers	11.84

## Research Advisory Group

■ We are moving quickly to having quality assured data as a basis for research.

A Research Advisory Group has been established to promote the development of a research agenda for the N. Ireland Cancer Registry. The new population based N. Ireland Cancer Registry is in a pivotal position to facilitate research on:

1. Cancer genetics.
2. Gene-environment interactions.
3. Genetics of survivorship.
4. The changes and development of cancer services.

Cancer research received a boost of interest following the recent visit of Professor George Radda, Head of the Medical Research Council.

We await developments with interest.

The members of this group are: Professor Paddy Johnson, Oncology Department, Belfast City Hospital; Professor Alun Evans, Division of Epidemiology; Queen's University; Dr Anna Gavin, N. Ireland Cancer Registry; Dr Frank Kee, Consultant in Public Health Medicine; Dr Chris Patterson, Statistician, QUB; Mr Roy Spence, Surgeon, Belfast City Hospital and Dr Seamus McAleer, Oncologist, Belvoir Park Hospital.

## The Community Health Index Number

The Community Health Index Number (CHI) is considered a unique identifier in Northern Ireland. The N. Ireland Cancer Registry has been able to monitor the use of the CHI number for cancer patients from the various PAS sites throughout the Province. Its use has remained remarkably consistent with little variation

between 1993 and 1995. While the average for Northern Ireland remains about 30% the range is from less than 3% to almost 97%. This is a valuable additional identification number for the N. Ireland Cancer Registry and we would encourage PAS data coders to complete this information in as many cases as possible.

### Use of CHI Number

PAS	1993	1994	1995
	%	%	%
Altnagelvin	14.80	16.30	10.60
Sperrin/Lakeland	2.78	4.54	4.53
Belfast City	14.60	14.20	11.80
Lagan Valley	23.80	23.80	27.20
Green Park	95.50	96.60	91.60
Mater	10.83	12.24	12.09
UNDAH	4.67	4.05	2.14
Royal Group	7.98	9.37	6.98
United	12.43	13.63	12.66
Causeway	17.40	16.51	16.73
Daisy Hill	55.83	56.79	54.19
South Tyrone	76.61	74.45	72.90
Craigavon	46.40	50.10	51.70
N. Ireland	29.20	30.20	28.86

Source: N. Ireland Cancer Registry  
April 1997

## Cancer Registry Review

A team of experts have been invited to review progress to date in establishing an active Cancer Registry for Northern Ireland, and to facilitate the strategic development of the N. Ireland Cancer Registry. This fulfils part of the agreement under which the Registry is established in Queen's University, Belfast, and receives funding from the DHSS.

The review team are expected to report in late summer 1997. This detailed review is welcomed by the staff of the Registry, who see it as vital for the future development of the Registry. The members of the review team are: Dr Mary Cotter, previously Director of the Welsh Cancer Registry; Dr Charles Gillis, Director of the West of Scotland Cancer Registry; and Professor Paddy Johnston, the newly appointed Professor of Oncology at Queen's University, Belfast.



## New Staff

**Susan Shields**  
Part-time Secretary who  
joined the Registry in  
November 1996.

## Scholarship

■ The Registry is offering a 3 year PhD Scholarship beginning 1 October 1997. The successful student will carry out their research programme on the new cancer database. There will be an emphasis on genetic epidemiology of cancers. This scholarship is possible thanks to a voluntary contribution to a Belfast City Hospital Trust Fund of which the N. Ireland Cancer Registry has been a benefactor.

## Cancer Services - Investing for the Future

■ Working groups from each of the four Boards are considering the implementation of the recommendations of the Campbell Report published in May 1996. The primary objective of this development is to ensure that patients with cancer receive uniformly high quality care. This will be achieved where the management of patients with cancer is undertaken by specialists working together in teams. Enhanced communication with local GPs and other providers is considered crucial. There is also a focus on the development of specialist palliative care teams. It recognises the role of the N. Ireland Cancer Registry in providing information on cancer.

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

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