



N. Ireland CANCER REGISTRY

Issue 1

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



October 1995

CANCER REGISTRY

It is a great delight and privilege to write a preface to a new chapter in the history of cancer registration in Northern Ireland. A cancer registration scheme was established in 1959 on the initiative of the Faculty of Medicine, QUB and the former Northern Ireland Hospitals Authority. On the reorganisation of the HPSS, Health & Personal Social Services in 1973 the ownership passed to the Department of Health. The original scheme was based on notification to a central registry of patients diagnosed as having cancer. Notification was to be made by hospitals and general practitioners, but GP entry was discontinued in the early years of the scheme.

Given the importance of cancer as a health problem it was disappointing to receive a report in 1985 indicating that only 60% of cancers were likely to be recorded in the registry. Part of the problem related to the system being an 'add on' rather than an integral part of routine patient recording and also that many clinicians were unaware of the registry's existence.

The Ulster Cancer Foundation (UCF) in 1988 brought forward proposals for establishing a much more effective registration process based on new developments in the HPSS - PAS systems and laboratory and radiology records. The proposals were developed from national and international experience in the field. It was also interesting that such concepts were being set up in the Republic of Ireland and this forms a basis for further co-operative activity. Other dedicated registry's have been set up by specific clinical groups, e.g., melanoma, leukaemia and colorectal cancer. The experience gained in these areas will complement very considerably the work of the overall concept.

The Registry is now moving to a new phase of activity which will, I hope, provide a focus and resource throughout the Province and beyond. Not only will we be better informed in important areas of health, from prevention and promotion to curative intervention, but also be able to conduct research on credible data to enlarge our understanding of cancer as a disease. This new initiative has come at a crucial time in the HPSS with the new emphasis on 'evidence based' health care. I believe that the output will show a handsome return on investment.

A New Era

A new Northern Ireland Cancer Registry has risen like a phoenix from the original Cancer Registry established in 1959. The new Registry is part of the Department of Epidemiology and Public Health in Queen's University, Belfast and is located in the Mulhouse Building on the Royal Victoria Hospital complex. It is funded by a grant from DHSS and the Ulster Cancer Foundation.

Cancer registration is advocated by the World Health Organisation to provide information on incidence, new cases, prevalence and survival data. Efficient management of the substantial resources required for the prevention, diagnosis, cure and care services for cancer is only possible where there is accurate and timely information about the need for and use of services.

It is estimated that one in three of the population will develop a cancer sometime in their life. Cancer causes almost one in four (3,500), deaths in Northern Ireland each year and it is estimated there are over 8,000 new cases diagnosed annually here.

The Registry will enable us to provide information on trends of new cases and provide estimates of the number of patients who, in the future, are likely to require specific treatment. The information will allow us to evaluate existing services such as the Breast Screening Service and Health Promotion Programmes. It will allow researchers in Northern Ireland to collaborate internationally in research into the causes and treatments of cancer. It is planned the Registry will use information already on computer databases within the Health Service. It aims to collect information in an accurate and timely fashion with strict regard to confidentiality with the aim of producing information to facilitate research, education and the planning of services for people with cancer.

The main sources of information will be hospital patient administration system and laboratory information.

The Registry will also link closely with existing disease specific tumour registries, the Breast Screening Service, Cervical Screening Service and Death Registrations. The Registry will be piloting its systems during 1995 with the aim of producing incident information by the end of 1996.

Inside This Issue

1. Management Group Members
2. Aims & Objectives
3. Council Group Members
4. Logo Competition Winner

5. Making I.T. Work
6. Research News
7. Data Request Service
8. Interval Breast Cancer Project
9. Presentation of Photocopier
10. Who's Who



Members of the Management Group of the Northern Ireland Cancer Registry

Back row, left to right: Dr. R. Atkinson, Department of Oncology, QUB; Mr. R. Beckett, Acting Assistant Secretary, DHSS; Mr. O. Gillespie, Deputy Principal, DHSS; Professor Alun Evans, Department of Epidemiology & Public Health, QUB. Front row left to right: Dr. A. Gavin, Director, Northern Ireland Cancer Registry; Dr. M. Boyle, Senior Medical Officer, DHSS; Dr. A. Telford, Director of Public Health, SHSSB; Ms. B. Torrans, Administrator, NICR. Other members include: Mr. M. Wood, Director, Ulster Cancer Foundation and Professor R. McClelland, Director, School of Clinical Medicine, QUB. The role of the Management Group which meets approximately five times per year is to oversee the work of the Registry.

Northern Ireland Cancer Registry

AIM

To provide accurate, timely information on cancers occurring in the population of Northern Ireland to enable research, planning and education so the burden of disease may be reduced.

OBJECTIVES

These are to:

1. Collect, analyse and store accurate, timely and comprehensive data on cancer.
2. Uphold patient and carer* confidentiality.
3. Facilitate and undertake research into cancer causes, treatments and outcomes.
4. Facilitate planning of cancer services for prevention, diagnosis, cure and care.
5. Assist professionals in audit of treatments, outcomes, etc.
6. Promote professional and public education in cancer causes, prevention, treatment and outcomes.
7. Publish scientific reports and papers relating to cancer in Northern Ireland.
8. Link nationally and internationally to increase understanding and control of cancer.
9. Review activities and programmes of the Registry regularly to ensure the provision of high quality data on cancer.
10. Provide appropriate information on cancer for *ad hoc* queries.

* Carers - Professionals or institutions involved in the screening, diagnosis, cure or care of people with cancer.

These objectives will be reviewed every two years.



Members of the Council of the Northern Ireland Cancer Registry at its inaugural meeting in November, 1994

Pictured above are: front row, Dr. Frank Kee, Consultant Public Health Medicine, NHSSB; Professor Gary Love, Professor of Medicine, RVH; Dr. Harry Comber, Director, National Cancer Registry, Ireland; Dr. Philip Donaghy, Consultant Public Health Medicine, EHSSB. Second row, Dr. Anna Gavin, Director, Northern Ireland Cancer Registry; Dr. Henrietta Campbell, Chief Medical Officer, DHSS; Professor Alun Evans, Department of Epidemiology & Public Health, QUB; Dr. Zareena Desai, Haematology, Belfast City Hospital. Third row, Dr. Ronnie Atkinson, Oncology, Belfast City Hospital; Dr. William McConnell, Director of Public Health, WHSSB; Professor Ciaran Woodman, Director, Centre for Cancer Epidemiology in Manchester; Mr. Roy Spence, Surgeon, Belfast City Hospital; Mr. John Moorehead, Director, Northern Ireland Colo-rectal Registry; Dr. Jeffrey Robertson, Cytology, Belfast City Hospital.

Other members of the Council not included in the picture are: Dr. Russell Houston, Radiotherapy, Belvoir Park Hospital; Dr. Anne-Marie Telford, Public Health, SHSSB; Professor Peter Toner, Pathology, RVH; Mr. Derek Baker, DHSS; Dr. John Price, Obstetrics & Gynaecology, BCH; Mr. Robin Johnston, Urology, BCH; Professor Philip Reilly, General Practice.

Dr. David Stewart, recently appointed as Director of Public Health in the EHSSB has replaced Dr. Philip Donaghy on the Council.

The role of the Council is to advise the Director and the Management Group on the achievement of the Registry's aims. This includes making best use of the data and enhancing opportunities for research.

The Registry aims to provide accurate, timely information on cancers occurring in the population of Northern Ireland to enable research planning and education so that the burden of disease may be reduced.



The logo of the Northern Ireland Cancer Registry was designed from an idea by Paul Stouthers, a student at Lurgan College of Further Education. It is symbolic of the Cancer Registry's role in adding to knowledge about cancer in Northern Ireland. Another student provided inspiration about the layout of letter heading, compliment slips, etc.

Pictured here are Mr. Paul Stouthers and Mr. Sean White, Lurgan College and Dr. Anna Gavin and Ms. Breige Torrains, N. Ireland Cancer Registry.

Making I.T. Work

In the past, only limited data was recorded on cancer registration cards which were then entered on computer and filed within the DHSS. In the current information era there is an increased demand for the collection of greater

and more enhanced data. The present age of high technology and state-of-the-art computer systems can contribute to a more efficient method of data collection and storage for the purposes of registration of cancer incidence in Northern Ireland. In addition, exciting new developments in computer software can provide an effective means for analysing such data for the purposes of research, planning, education and the improvement of health care services.

Since the inception of the new registry, it was recognised that computing technologies could

be usefully employed to assist and improve the process of cancer data registration and subsequent data analysis. Consequently, the Registry has embarked on a major two-year computerisation project, to enable the efficient storage of cancer data and provide an effective platform for the strategic use of that data. Mr. Colin Fox, the IT Manager for the Registry, is responsible for the management of the project.

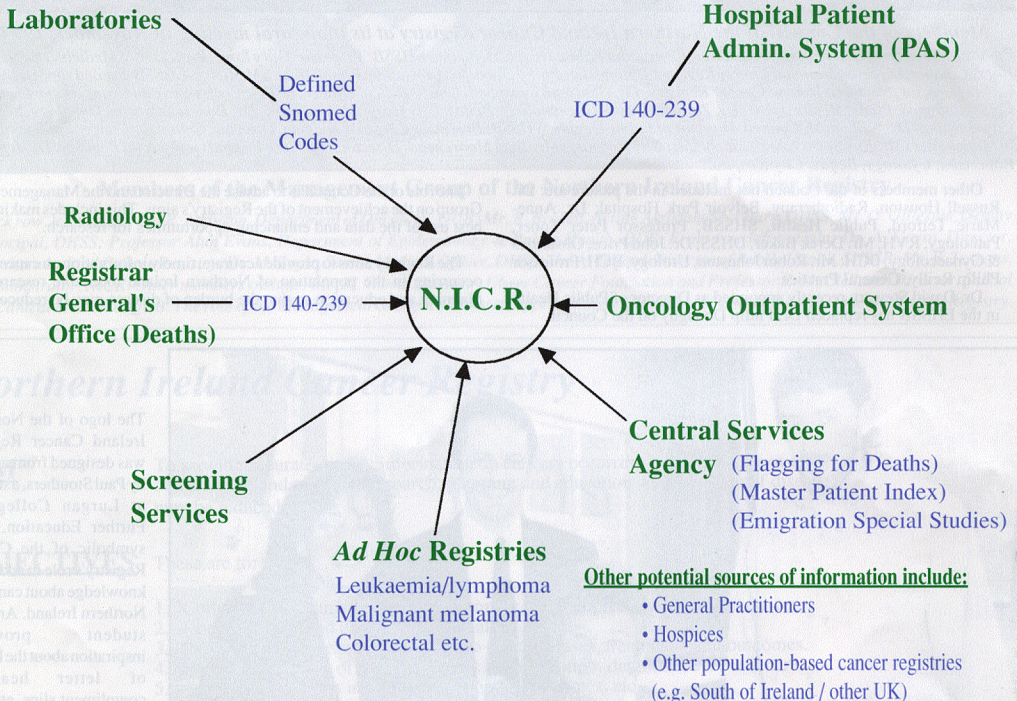
Much of the cancer data is already stored on computers within various hospital and laboratory information systems. The Registry

CANCER INFORMATION SUPPLIERS

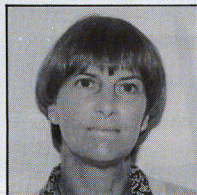
Data on all types of Cancer Incidence will be received in electronic format from the following sources on a regular basis and stored in a computerised database system.

This data will be used for the purposes of research, health care, planning and education.

The system will be used to manage the data in order to compile statistical reports on cancer incidence, treatment and care in Northern Ireland.



Malignant Melanoma Registration To Continue



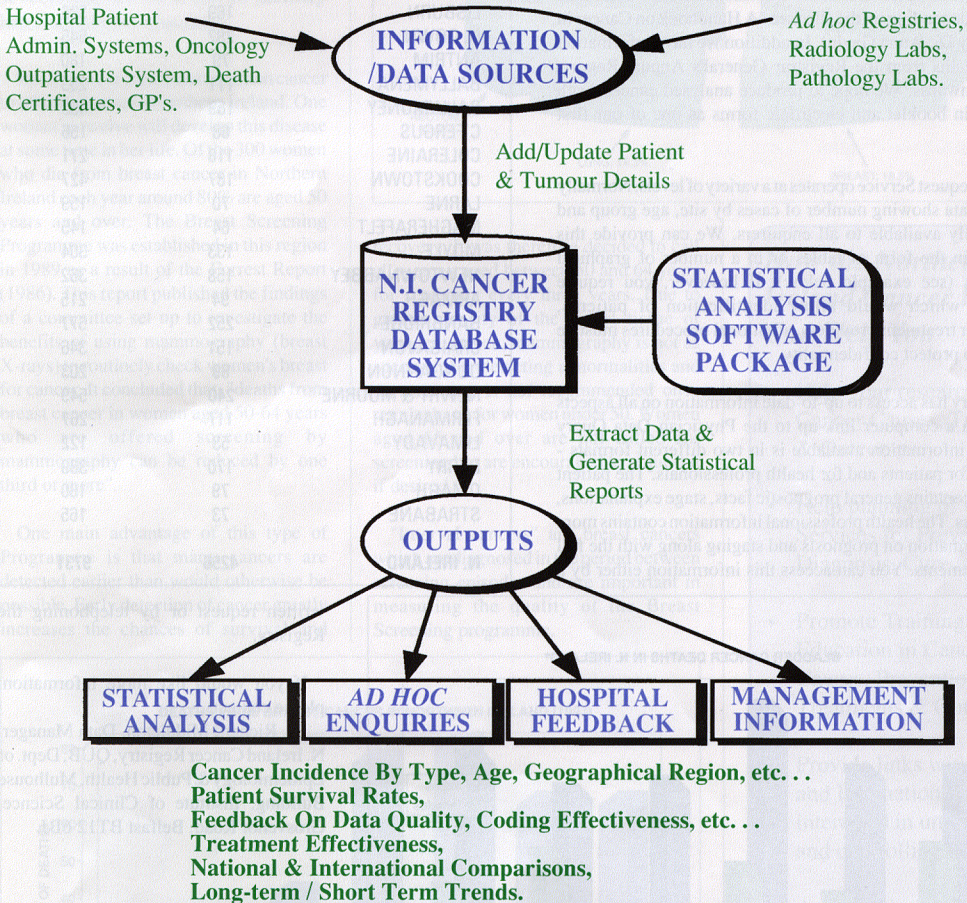
Dr. Pauline Pedlow has been re-awarded a grant from the Ulster Cancer Foundation to continue her work recording detailed information on people in Northern Ireland with malignant melanoma. Dr. Pedlow was recently awarded an MD by Queen's University for her work in this area. This will continue the work summarised in the Wolfson Foundation report published June, 1995. Dr. Pedlow will be based in the N. Ireland Cancer Registry and work co-operatively with the Department of Oncology of Queen's University, Belfast.

will receive this data from various sources, as shown in the diagram ("Cancer Information Suppliers") below. This information will be extracted from the various systems and supplied in electronic format (via floppy disks and/or tape) on a regular basis. Currently, we are in the process of receiving one year's pilot data from the main information sources to initially assess it's quality in terms of accuracy and completeness. Any system developed for the Registry will need to be flexible since, in future, the data may be directly received via computer networks.

The Registry is currently evaluating a number of computer database system options presently employed by other registries in the UK and Ireland - namely, Thames, Wales and Southern Ireland. The preferred option will be that which most closely satisfies the requirements of the Northern Ireland Registry operation (see diagram). The system will possess such features as automated data entry and validation checks, database enquiry and data extraction and a training database to enable registry staff to gain expertise in it's use. In addition, the Registry is also considering the most appropriate IT

arrangement for the system - hardware, software and networking arrangements. Additional software packages will be integrated to enable statistical analysis of data extracted from the database. Furthermore, the system will provide a major resource for research studies in the field of cancer epidemiology. The results of such research will be published in reports and in national and international journals and will provide a basis for enhancing health care planning and education with regard to cancer in Northern Ireland.

N. IRELAND CANCER REGISTRY - OPERATION



Report On Cancer Deaths In Northern Ireland



Cancer deaths have been increasing by 1.4% per year. In 1912 there were 1,224 deaths rising to 3,624 in 1993. Death information is published each year by the Registrar General's Office but this has not been analysed collectively or interpreted for Northern Ireland. Dr. Dermot O'Reilly has been working in the Registry since April 1995 to produce the first research report from the Registry. The report will be published in Autumn 1995.

Data Request Service

The Northern Ireland Cancer Registry welcomes requests for information on cancer in Northern Ireland from organisations and individuals. Requests should be addressed to the Director, preferably in writing, outlining briefly the title of the study, its aims and purpose, proposed methodology and details of the information required. We will attempt to return the data you require as soon as possible to meet any deadlines you may have.

At present the Registry holds cancer registration data collected from 1959. The completeness of this information is low - estimated at 60%-80% depending on the site (see "A Handbook on Cancer in N. Ireland" by Dr. Anna Gavin). In addition we have information on cancer deaths from the Registrar General's Annual Reports from 1911 onwards. We hope to produce analysed cancer death information in booklet and electronic forms as one of our first publications.

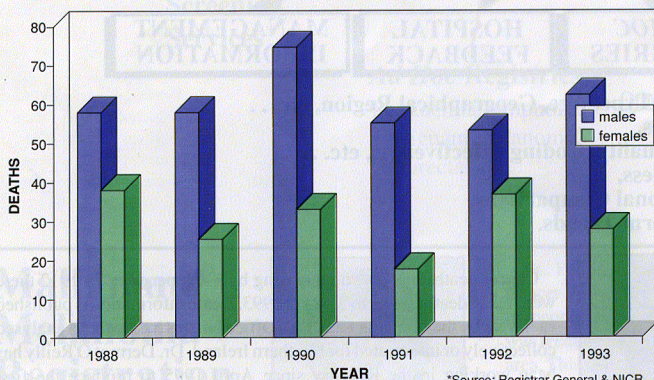
The Data Request Service operates at a variety of levels. Normally aggregated data showing number of cases by site, age group and sex are readily available to all enquirers. We can provide this information in the form of tables or in a number of graphical presentations (see example below). If however, you require information which would allow identification of patients, consultants or treatment providers, additional procedures must be carried out to protect confidentiality.

The Registry has access to up-to-date information on all aspects of cancer via a computer link-up to the Physician Data Query system. The information available is in two different formats - information for patients and for health professionals. The patient information contains general prognostic facts, stage explanations, and treatments. The health professional information contains more detailed information on prognosis and staging along with the full range of treatments. You can access this information either by a

Deaths and Estimated New Cancer Cases by District Council Area N. Ireland

COUNCIL	Average Annual Deaths 1989-93	Estimated New Cases
ARDS	147	336
BELFAST	892	2040
C'REAGH	158	361
DOWN	113	259
LISBURN	169	386
N. DOWN	282	645
ANTRIM	79	180
BALLYMENA	111	253
BALLYMONEY	189	433
C'FERGUS	68	156
COLERAINE	118	271
COOKSTOWN	187	427
LARNE	70	159
MAGHERAFELT	64	145
MOYLE	133	304
NEWTOWNABBEY	158	362
ARMAGH	94	215
BANBRIDGE	252	577
CRAIGAVON	151	346
DUNGANNON	89	203
NEWRY & MOURNE	240	549
FERMANAGH	117	267
LIMAVADY	53	122
DERRY	170	389
OMAGH	79	180
STRABANE	73	165
N. IRELAND	4256	9731

BLADDER CANCER DEATHS IN N. IRELAND*



written request or by telephoning the Registry.

If you would like more information, please contact:

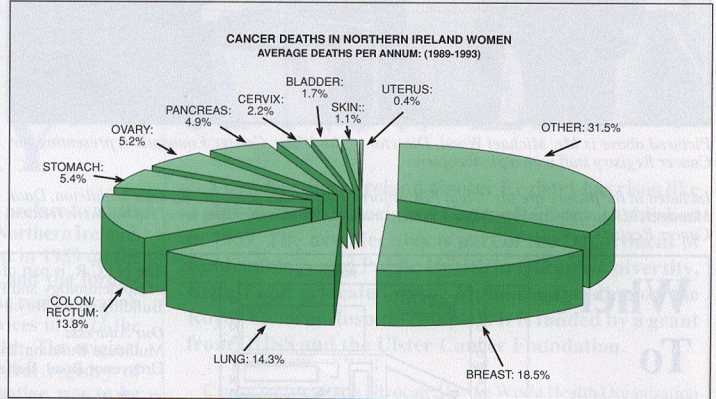
Dr. Richard Middleton, Data Manager,
N. Ireland Cancer Registry, QUB, Dept. of
Epidemiology & Public Health, Mulhouse
Building, Institute of Clinical Science,
Grosvenor Road, Belfast BT12 6BJ.

Interval Cancers And The Breast Screening Service

A Quality Assurance Project has been jointly financed by the Breast Screening Programme in Northern Ireland and the newly re-established Northern Ireland Cancer Registry. Project Worker Nuala Brady hopes to draw together information from several sources in order to identify interval breast cancers.

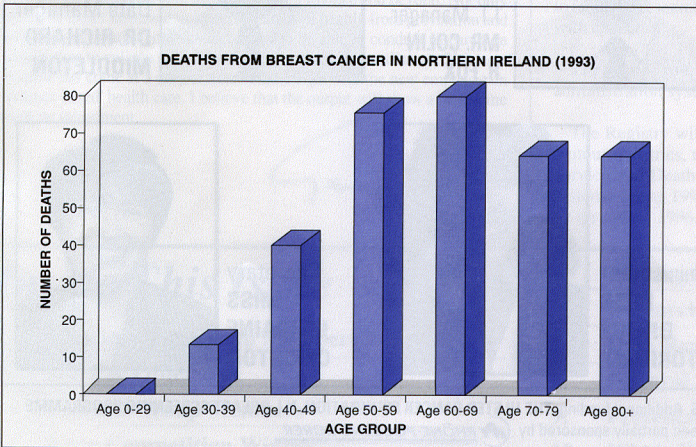
Breast cancer is the most common cancer to affect women in Northern Ireland. One woman in twelve will develop this disease at some time in her life. Of the 300 women who die from breast cancer in Northern Ireland each year around 80% are aged 50 years and over. The Breast Screening Programme was established in this region in 1989 as a result of the Forrest Report (1986). This report published the findings of a committee set up to investigate the benefits of using mammography (breast X-rays) to routinely check women's breast for cancer. It concluded that, "deaths from breast cancer in women aged 50-64 years who are offered screening by mammography can be reduced by one third or more".

One main advantage of this type of Programme is that many cancers are detected earlier than would otherwise be possible. Early detection of cancer greatly increases the chances of survival and



recovery. It was therefore decided to call all women aged between 50 and 64 years for screening every three years. Due to greater density of the breast tissue of younger women, mammography is not as successful in detecting abnormalities and so screening is not recommended on a regular basis for women under 50. Women aged 65 and over are not called for screening but are encouraged to request it if desired.

"Interval cancers" are breast cancers which are diagnosed in the period between screening episodes and are important in measuring the quality of the Breast Screening programme.



How the Northern Ireland Cancer Registry Can Help You

- Help your research into Cancer Causes, Treatments & Outcomes.
- Help planning of Cancer Services for Prevention, Diagnosis, Cure and Care.
- Promote Training & Education in Cancer Causes, Prevention, Treatments & Outcomes.
- Provide links with National and International bodies interested in understanding and controlling Cancer.
- An Information Service on all aspects of Cancer in Northern Ireland through reports, scientific papers and an *ad hoc* query service.

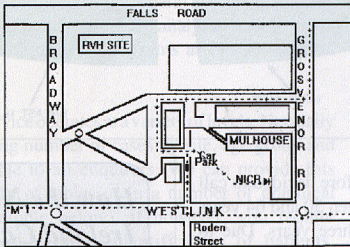


Pictured above is Mr. Michael Wood, Director of the Ulster Cancer Foundation, presenting the Cancer Registry staff with a photocopier.

Included in the picture are Mr. Colin Fox, Information Technology, Dr. Richard Middleton, Data Manager, Ms. Breige Torrans, Administrator and Dr. Anna Gavin, Director of the Northern Ireland Cancer Registry.

The Ulster Cancer Foundation has pursued the vision of a new Cancer Registry for Northern Ireland for many years now and is providing major funding for the Cancer Registry over the next five years. Mr. Wood said an accurate system of cancer registration is essential to enable us to identify the size of the problem; plan new initiatives and monitor progress in reducing the incidence of and death from cancer.

**Where
To
Find
Us!**



The N.I.C.R. 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:
Mulhouse Building, Institute of Clinical Science,
Grosvenor Road, Belfast BT12 6BJ

Our Telephone Number:
(01232) 263136 - Direct Line or (01232) 240503
Ext. 2573 - R.V.H. switchboard

Our Fax Number:
(01232) 248017

Our E.MAIL Address:
NICR@V1.EPH.QUB.AC.UK

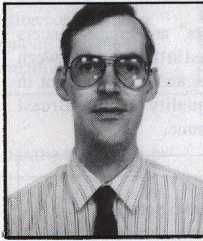
**N. Ireland
Cancer Registry**

WHO'S WHO

QUB - Department of Epidemiology and Public Health



Director
**DR. ANNA
GAVIN**



I.T. Manager
**MR. COLIN
R. FOX**



Data Manager
**DR. RICHARD
MIDDLETON**



Researcher
**MISS
NUALA
BRADY**




Administrator
**MISS
BREIGE
TORRANS**



Secretary
**MISS
LORRAINE
CRICHTON**

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This Newsletter has been partially sponsored by  **RHÔNE-POULENC RORER**