

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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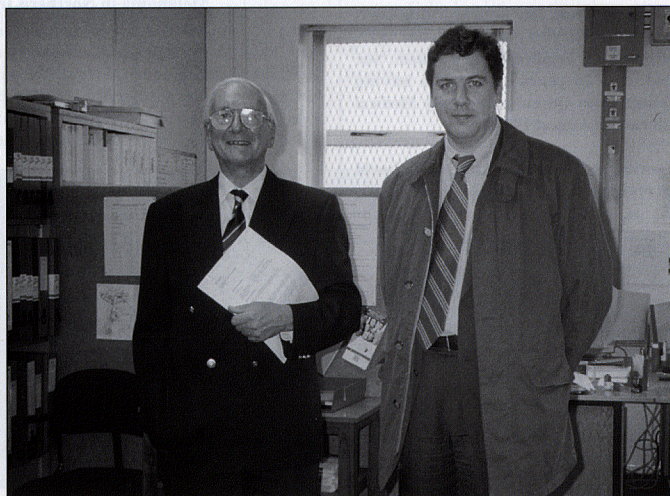
Review Team Impressed

■ The N. Ireland Cancer Registry was reviewed in 1997 by experts in the field of cancer and cancer registration. These were Dr Mary Cotter, Welsh Office; Professor Charles Gillis, Scotland; Professor Patrick Johnston, Department of Oncology, Queen's University Belfast and Mr Roger Black, previously from the International Association for Research on Cancer and, more recently, in the Scottish Cancer Registration scheme. They had the task of "reviewing progress to date in establishing an active cancer registry for Northern Ireland and to facilitate the strategic development of the N. Ireland Cancer Registry". The Registry was visited twice by the review team who emphasised that the fundamental business of the registry was to ensure that good quality data was collated for the purposes of disseminating information to those involved in public health, commissioners of cancer care, health care providers, clinicians and other interested parties. The team provided a detailed six page report commenting on the

Registry's establishment, physical and human resources, the method of data collection, the computer system, Registry's quality assurance and data quality programme, confidentiality, information and research output. They concluded as follows:

"The Review Team is convinced that the N. Ireland Cancer Registry is on course to deliver cancer incidence data for 1993-1996, given the manual procedures recommended. The team were most impressed by the dedication, skill and effectiveness of each of the individuals encountered, and look forward to seeing the registry as an important contributor to cancer care and research in Northern Ireland."

The review team made 13 recommendations, all of which have been taken into account in planning for the Registry's development over the next five years.



Professor Charles Gillis and Mr Roger Black.

■ Dr Carolyn Harper, a Specialist Registrar in Public Health Medicine, joined the Registry staff in October 1997 through a half-time secondment from the Eastern Health and Social Services Board. The Registry is grateful to the Board for Carolyn's input. Her main areas of work included:

- designing a research proposal to evaluate the re-organisation of cancer services in N. Ireland;
- implementing the Registry's quality assurance programme, in particular, assessing the accuracy of data from the Patient Administration System, death certificates and pathology reports;
- writing relevant sections of the Registry's first Incidence Report.

Carolyn will follow up her period with the N. Ireland Cancer Registry with a one year study placement at the North Californian Cancer Registry. Part of her work there will be supported by a grant from the Ulster Cancer Foundation. Carolyn has also been awarded a prestigious U.K. Faculty of Public Health Medicine B.A.C.P. travel award for this study. She was also jointly awarded the 1998 Stevenson Prize for her presentation of her work in the Registry.

The Registry hopes to attract other Specialist Registrars and Public Health Practitioners in the future as we have found Carolyn's secondment most valuable.



Dr Carolyn Harper.

PHD Student



Mrs Rosemary Bergin.

■ Rosemary Bergin joined the N. Ireland Cancer Registry team in October 1997 at the start of her 3 year PhD project.

Library

■ Agnes Craig has been working part-time in the Registry since October 1997, setting up a detailed library system. She has over 25 years experience having retired from Queen's University Medical Library in August 1997.

Specific requests for information should be sent in writing to NICR.



Miss Agnes Craig.

Melanoma Strategy Launch

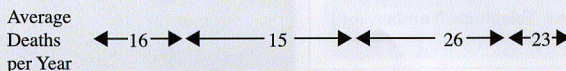
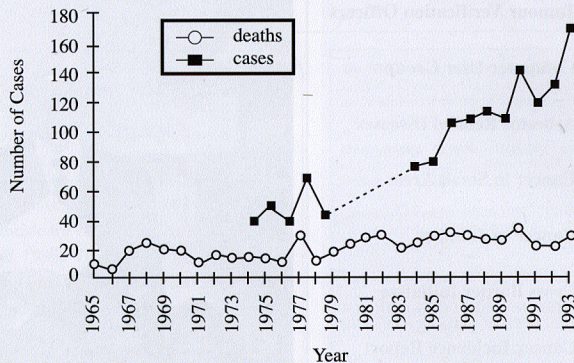
■ The Chief Medical Officer, Dr Henrietta Campbell, welcomed the multi-agency approach outlined in the strategy for the prevention, diagnosis and treatment of malignant melanoma and other skin cancers in Northern Ireland. Many agencies, including the Cancer Registry, were involved over the past three years in workshops, consultation and the production of the strategy. It builds on the work of the "Northern Ireland Care in the Sun Health Promotion Group" which began educational programmes in 1990. Their alliance with the "Northern Ireland Melanoma Study Group", which considers the epidemiology management and research of melanoma, identified the

need for such a strategy. The strategy fits with points 5 and 7 of the European 10 point code against cancer:

- (5) "Avoid excessive exposure to the sun and avoid sunburn, especially children"
- (7) "See a doctor if you notice a lump, a sore which does not heal, a mole which changes in shape, size or colour or any abnormal bleeding".

Skin cancer accounts for about a quarter of all cancers, 3,500 cases each year in Northern Ireland. Most of these are completely cured by removal and never recur. One in 12 of these cancers however,

Melanoma in Northern Ireland 1965-1993: Incidence and Deaths



Note: Information on incident cases not available pre 1974 or 1979-1983.

continued

is more serious malignant melanoma. There are about 160 new melanoma cases each year causing an average of 25 deaths. Compared to other skin cancers, melanomas tend to occur in younger people. About half (45%) of melanomas occur in those under 60 compared with 1/5th of other skin cancers. Unfortunately, as the population ages and we continue to sunbathe, the number of skin cancers, including melanoma, is expected to increase. The aim of this strategy is to reduce morbidity and mortality from skin cancers, especially malignant melanoma in Northern Ireland. The objectives are:

1. To increase awareness about care in the sun.
2. To encourage good sun care practice.
3. To increase awareness about the early signs of skin cancer and the need for prompt attention, especially of malignant melanoma.
4. To ensure all skin cancers, especially melanomas are detected and treated at an early stage.
5. To encourage evidence based treatment of malignant melanoma.
6. To promote research into knowledge, attitudes, behaviour and the epidemiology of skin cancer.

The strategy is aimed at professionals and identifies four priority areas for action.

- i. Primary prevention by education.
- ii. Secondary prevention by early detection and intervention.
- iii. The achievement of treatments according to agreed evidence based guidelines to achieve health gain.
- iv. Audit and research to monitor the effects of this strategy.

Copies of the strategy have been distributed although further copies should be available from the Health Promotion Resource Service at the numbers given below:

EHSSB Telephone 01232 321313

NHSSB Telephone 01266 635575

SHSSB Telephone 01861 412532

WHSSB Telephone 01504 865127

Tumour Verification Officers

■ Our Tumour Verification staff are currently visiting all hospitals in Northern Ireland to compare the information we receive electronically with that in the patient record. This involves examination of over 5,000 records for the period from 1993-1995. Our thanks are due to the many hospital record staff who have helped us in this important project. At the time of going to press four new TVO's have been appointed.



Fleda Surgeon, Marina Bleakley, Patricia Donnelly and Carmel Canning - Tumour Verification Officers.

4th Computer User Group Meeting

■ The N. Ireland Cancer Registry hosted the 4th Computer User Group meeting which took place on Friday 27th March. The group comprises of the Thames, Trent and N. Ireland registries. Employing a common computer system, the group was formed to address issues relating to automated cancer registration using the system. To date, much of the work has involved the resolution of implementation problems. However, opportunities exist for future improvement of the system and automated cancer registration in general.

This meeting was well attended, and it is planned to hold 3 or 4 meetings per year, each registry taking it in turn to host the meeting. Colin Fox (IT Manager - NICR and Chairman of the Group) initially helped to set up the group. At the end of the meeting Colin handed over the role to Alan Waterhouse of Trent who will co-ordinate the Groups's activities over the coming 18 months.



Phil Needham, Deputy Director, Trent Registry; Colin Fox, IT Manager, N. Ireland Cancer Registry; Hannes Botha, Director, Trent Registry; James Reid, Epidemiologist, N. Ireland Cancer Registry; Elizabeth Davies, General Manager, Thames Registry; Jason Hiscox, Database Administrator, Thames Registry; Anna Gavin, Director, N. Ireland Cancer Registry; Shirley Bell, Data Manager, Thames Registry; Chris Carrigan, HBOC and Breige Torrans, Administrator N. Ireland Cancer Registry.

Asbestos Related Diseases in Northern Ireland

■ Asbestos has been used for many years in a wide range of manufacturing and building industries. In Northern Ireland, asbestos was used particularly widely in the ship building process. The hazards to workers using asbestos have been well documented and steps to control its use are now in place. The diseases caused by inhalation of asbestos dust include asbestosis, mesothelioma (a specific type of cancer of the membranes surrounding the lungs and other organs), lung cancer and pleural thickening.

As mesothelioma is invariably a fatal disease with poor prognosis, death rates

give a good approximation for incidence of the disease in the population. Asbestosis on the other hand is much less likely to contribute to death and so mortality data can only give a rough measure of the burden of the disease in the population.

Work carried out by the N. Ireland Cancer Registry, together with the Employment Medical Advisory Service (EMAS) and the Health and Social Care Research Unit has sought to monitor the burden of diseases in the Northern Ireland population. Data on the number of deaths in Northern Ireland which may be attributable to asbestos exposure, age at death and vulnerable

occupational groups, were examined to monitor the extent of the problem in the population and examine trends.

The work has shown that deaths from asbestos related disease may be as high as 100 per year. Those most at risk are men who had been exposed to asbestos many years before in the work place. This is in agreement with the known facts about mesothelioma and asbestosis. The rates of mesothelioma are amongst the highest in the United Kingdom. The rate is comparable to the rates for Strathclyde in Scotland and Rotterdam in the Netherlands, two other areas with a recent history of shipbuilding.

Cancer in Small Areas

The N. Ireland Cancer Registry have recently formalised an agreement for data exchange and co-operative research with the Small Area Health Statistics Unit (SAHSU) based in St. Mary's College, London. SAHSU was established as a UK wide resource in the wake of public concern over an identified leukaemia cluster around Sellafield. It is charged with the specific remit to investigate possible health effects caused by carcinogenic and mutagenic agents in the environment. The DHSS (NI) routinely contribute to SAHSU's budget although, to date, the unit has not conducted investigations in the province due, in the main, to lack of data. The advent in Northern Ireland, for the first time, of reliable incidence data (and more recent data than elsewhere in the UK), due to the work at the N. Ireland Cancer Registry, means that there is now real potential to respond to public concern over putative cancer clusters and to undertake proactive research in the field of geographical environmental epidemiology. Further details of the NICR/SAHSU agreement can be obtained by contacting the Registry.

Cancer in Families

The Registry is interested in exploring the feasibility of collecting information on cancer in families within Northern Ireland.

Please contact the Registry so we may confidentially explore this further.

Cross Border Initiative

The population of the South Armagh and North Louth area have, for many years, raised concerns of increased radiation linked cancers in their area. Research in the 1980s, examining new cases and deaths, did not reveal any clusters. The establishment of cancer registries North and South of the border will allow an ongoing investigation of cancer cases occurring in the North Louth/South Armagh area to address these issues. A collaborative research study will take place involving both registries and the health boards for the areas concerned over the next 2-3 years.

Cancer Incidence Report

■ After 4 hectic years the Cancer Registry plans to produce its first incidence report, hopefully by the end of 1998. This will contain incident data for the years 1993-1995 inclusive and will be available in hard copy and electronically. Further details will be available closer to the time.

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.

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 - RVH switchboard

Our Fax Number: (01232) 248017

N.B: NEW TELEPHONE NUMBERS WILL BE ALLOCATED IN NEXT SIX MONTHS.

E.MAIL address: NICR@QUB.AC.UK

WWW URL address:
<http://quiss.qub.ac.uk/nicr/nicrpg1.htm>