

N. IRELAND Cancer Registry



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Providing information on cancers for research, planning and education.



4th REPORT LAUNCH



May 2004 is the tenth anniversary of the re-establishment of the N. Ireland Cancer Registry and to mark this a comprehensive report on cancer in Northern Ireland for the period 1993-2001 has been produced. This is the fourth report from the Registry and a full copy is available on request or at website www.qub.ac.uk/nicr.

For the first time in Northern Ireland we now have information on the prevalence of cancer, that is the number of people who are alive having had a diagnosis of cancer. Cancer as it relates to deprivation and cancer treatments are described. Deprived areas experience more cancers of the lung, cervix and stomach than average but less cancer of the breast or skin. Survival was compared for two periods;

1993-95 and 1996-99. The Registry are pleased to announce that cancer survival for breast, ovary and colon cancer improved between these two periods. There were increased levels of breast cancer and cancer of the uterus in females but falling deaths from breast cancer in females and lung cancer in males.

Stage Matters!

I commenced my post as the Tumour Staging Co-ordinator for the N. Ireland Cancer Registry on 2 February 2004, an appointment funded for 2 years by the four Health & Social Services Boards. My remit is to promote the recording of tumour staging data within the cancer centres and units (without increasing the workload of cancer clinicians) and to establish a reliable system for transferring this information electronically to the Registry.

We all know that stage matters, but it doesn't have to be time consuming and tedious. We are therefore developing an electronic (book-free) tumour staging tool to be accessed on hospital intranets, which will enable clinicians/histopathologists to select tumour



site, input T, N & M variables and, at the click of a mouse, a stage group will be calculated. This will be particularly useful for calculating stage group for breast tumours by condensing the 100 possible TNM combinations into more manageable stage groups.

The Registry hopes to soon achieve electronic transfer of staging data from the histopathology reports by the creation of specific fields within 'Masterlabs' to hold T, N & M variables and also from COIS in which such fields already exist.

Dr Lisa Ranaghan
Tumour Staging Co-ordinator, NICR

The 2nd All Ireland Cancer Report due September 2004

This report, funded by the Department of Health and Children (ROI) and the Department of Health and Social Services (NI) will feature the major cancers. It will cover data 1998-2001 to complement the first All Ireland report. It will include incidence, mortality, survival and trend information from 1994-2000. Incidence and mortality rates for each of the District Councils in Northern Ireland and each of the Counties in the rest of Ireland will be compared. Dr Joe Campo, from the Washington State Cancer Registry, was seconded for one year to work on this project with Dr Comber and Dr Gavin. He indicated that in addition to the report significant supplementary information would be available on the web page of each Registry.

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Investigation into Cancer Incidence in the vicinity of Cranlome Telecommunications Mast

In December 2002, a telecommunications mast situated in the Upper Cranlome Road area of Ballygawley, County Tyrone was felled. People living near the mast believed it to be responsible for an alleged cluster of cancer cases in the area (2001-2002). The felling of this mast came after two similar incidents in England in the preceding months. In February 2003, Dungannon and South Tyrone Borough Council asked the NICR to conduct a full investigation into cancer incidence in the vicinity of the telecommunications mast. The results of this investigation (summarised below) were presented to Dungannon Council by Dr Denise Catney and Dr Anna Gavin on Thursday 6th May, 2004.

In order to validate the alleged cancer cases in the area of Cranlome mast, the NICR database was used. Then, with the help of Ordnance Survey Northern Ireland, any additional and unreported cancer cases occurring within a 5km radius of the mast were highlighted. The risk of cancer was investigated, not only in the immediate vicinity of the mast (circles of radius 1, 2, 3, 4, 5km from the mast), but also in the wider Ballygawley electoral ward area and Dungannon & South Tyrone Borough Council area. Due to the rural nature of the area encompassing the alleged cluster, it was appropriate to compare the number of cancers observed in each of these areas with the numbers diagnosed not only in the general population of Northern Ireland but also in the more rural population of Dungannon district council.

The results of the analyses indicated that levels of cancer in the Ballygawley area (1993-2001) were significantly lower than expected when compared with Northern Ireland levels and were not significantly different from levels experienced in the area of Dungannon district council. Further to this, cancer incidence rates in the Cranlome area (including the townlands of Cranlome and Ballynahaye) were not significantly different from rates encountered at Northern Ireland level or Dungannon district council level. Also, there was no evidence of an excess of cancer cases in non-administrative areas adjacent to the mast

(specifically those areas encompassing circles of radius 3km and 3km-5km from the mast).

A comprehensive review of the literature to date revealed that the overwhelming majority of scientists believe that exposure to radiofrequency radiation below guidelines does not cause adverse health effects to the general population. Notably, the cancers diagnosed over the two-year period of interest (2001-2002), in the vicinity of Cranlome mobile phone mast, were of a variety of sites, each with different risk determinants. Indeed the diversity of the cancers diagnosed in the area serves as evidence against the existence of a common source or carcinogenesis. [N.B. the occurrence of several types of cancer in a group of people or a geographic area generally does not constitute a cancer cluster].

After thorough investigation it was concluded that the Cranlome area did not have statistically higher rates than Dungannon or Northern Ireland, nor was there an apparent, significant, increasing trend in the rates. In summary, there was no evidence of a cancer cluster in the nearer or wider Cranlome area.

The report into the alleged cancer cluster in the vicinity of Cranlome Telecommunications Mast is available for download from our website at www.qub.ac.uk/nicr.

RACC Update

The Research & Development Office have funded Miss Pauline Monaghan to research the effect of the Campbell Report on cancer services and patient outcomes in Northern Ireland. So far this has included a major data cleaning and validation exercise. The descriptive comparisons have been presented to several groups where interactive discussions and feedback have been incorporated into the data structure.

Registry staff are currently completing a descriptive breast cancer paper which compares certain indicators of quality of care as well as patient differences between the years 1996 and 2001. The overall findings from this paper suggest that breast cancer services are moving in the direction outlined in the Campbell report. Work has also started on a hypothesis-driven breast paper which will formally investigate the effect of the main recommendations of the Campbell report on selected outcomes e.g. survival. The above work will be carried out for the other major cancer sites.

A project with the health economics department of the University of Ulster is ongoing, where the RACC data is being used to assess the cost of cancer in N.Ireland using a model established in the UK. The RACC data is also providing invaluable supplementary information for a retrospective audit of lung cancer patients in 2001 (pre PET). This information will be compared to data from 2004 in patients who received a PET scan prior to treatment.

In addition to the research work being carried out using the RACC data, the NICR have recently recruited Mr John Hughes and Mrs Heather Kinnear to help to produce audit reports for services feedback to the Health Boards and Trusts. The NICR hope to establish a system where useful data can be fed back to clinicians about their own patients. The RACC data would initially provide an excellent source to pilot this scheme

The Registry plans to undertake similar audit work for pancreatic cancer. This has been facilitated by Mr Damian Mole. Funding has been achieved from the Northern Ireland Council for Postgraduate Medical and Dental Education to part fund a similar study in the management of thyroid cancers which will fulfil one recommendation of the report on endocrine cancers presented recently to RACC.

Research on Prostate Cancer

Staff from the Registry, in collaboration with Patrick Keane a Urologist from the Belfast City Hospital, have examined levels of Prostate Specific Antigen testing in Northern Ireland. This was published in the BJU International 2004: 95, 730-734 and found that between 1990 and 1999 there were almost 166,000 PSA tests performed on almost 85,000 men. This means that over a third of men aged over 50 had at least one PSA test. The authors concluded that PSA screening is taking place against evidence based advice. Further work in this area is planned to survey General Practices to determine reasons behind a 100 fold variation in PSA testing by General Practice. Another project funded by the R&D Office will study the natural progression of a slightly raised PSA test.

IT Update

Our System User Group has recently expanded to include 3 new registries who will be implementing our cancer registration application software. In addition to the N. Ireland Cancer Registry (NICR), Trent and Thames, the Northern & Yorkshire Cancer Registry and Information Service (NYCRIS), Merseyside & Cheshire Cancer Registry (MCCR) and the North Western Cancer Registry have all confirmed their intention to implement automated cancer registration using the PRAXIS system - the new name for our software.

Hence the newly reconstituted PRAXIS user group has 6 registries. The user group will report to the PRAXIS Board with regard to all matters relating to IT and the PRAXIS system, including funding requirements. Furthermore, a PRAXIS coordinator is to be appointed to provide technical support and advice to the user group and manage projects involving both commercial suppliers and internal sub-groups spawned from the main PRAXIS user group to address specific requirements.

The new structure is shown opposite. It includes some sub-groups which have been set up to address specific needs:-

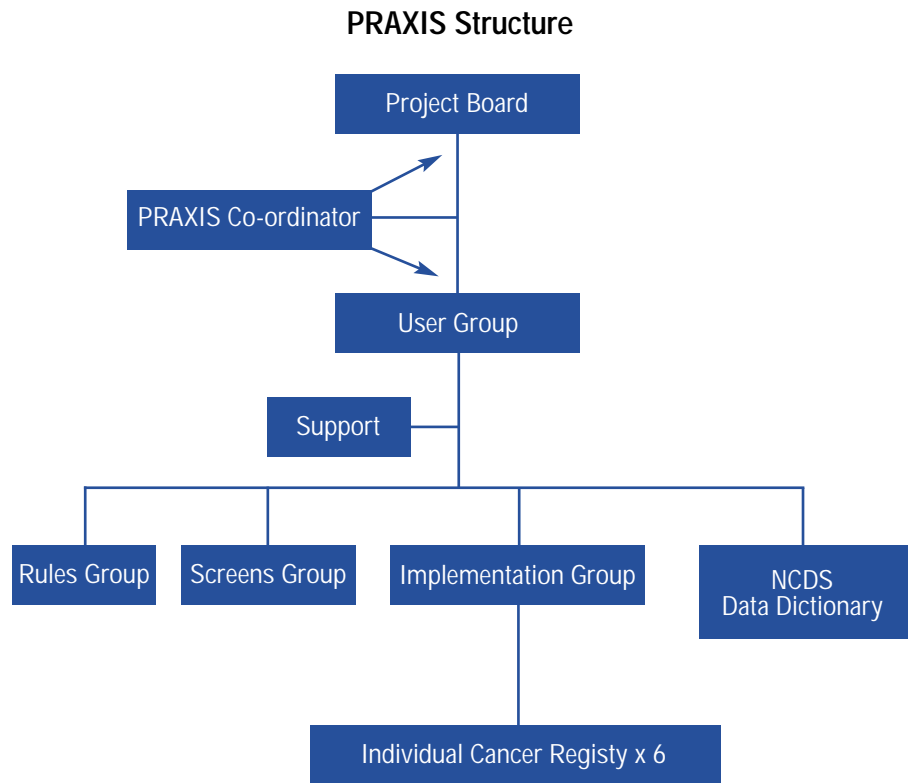
Work is progressing on modifying our database to cope with the new National Cancer Data Set (NCDS) items. In the NICR we have identified a subset of the NCDS which we do not receive from our own hospital and laboratory data providers. We are currently investigating whether we can get such data from local systems.

A prototype screen development for PRAXIS has just been completed in conjunction with WMS (Wealth Management Software, our commercial partner, who also have the contract for a new UK-wide breast screening system). The prototype is currently being evaluated, the intention being to replace the out-dated character-based screens with a full Windows-style interface.

The implementation group are currently assisting the new registries with the implementation of the PRAXIS software - particularly with respect to data conversion from their existing registration systems.

Finally, the Rules Group have been tasked with producing a common library resource for

all PRAXIS registries. The resource will contain data validation and quality checks in use at each PRAXIS registry, along with business rules (patient/tumour matching and data consolidation/merging rule), processes and practices. The intention is to provide a common resource for automatic cancer registration which can be shared, not just between PRAXIS registries, but for the benefit of all other UK and European/World cancer registries.



UK CANCER SURVIVAL STUDY

Population-based cancer survival rates are available separately for Northern Ireland, Scotland, England and Wales, covering a variety of different periods of diagnosis and follow-up. However, it is impossible to compare these survival rates in the four nations directly and survival rates for the UK as a whole have never been produced, despite the fact that such figures have twice been requested in parliamentary questions at Westminster.

The aim of the UK Cancer Survival Study is to produce comparable cancer survival rates for England, Wales, Scotland, Northern Ireland, the UK as a whole and the Republic of Ireland. In doing so, various discrepancies in data preparation, analysis and presentation of survival rates will be resolved, in collaboration with cancer epidemiologists and biostatisticians from all countries. To control for mortality from causes other than cancer, the relative survival rate will be derived. A common criticism of conventional survival analysis is that the survival estimates produced are inevitably out of date and no longer reflect current practice. However, recently-developed statistical methods now enable reasonable estimates to be obtained of survival up to five years (say) of patients diagnosed as recently as one year ago. These so-called "period" survival methods, developed by Dr H Brenner of Germany, will be employed in this study, in addition to the traditional and widely-used cohort method. Resulting estimates of relative survival (for England, Wales, Scotland, Northern Ireland, the UK as a whole and the Republic of Ireland) will be reliable, up-to-date and directly comparable and will be published in Autumn 2004.



Left to right: Miss Lesley Anderson, Dr Wong-Ho Chow, Dr Joseph Fraumeni, Dr Anna Gavin.

Anna Gavin, Director, NICR and Lesley Anderson, PhD Researcher for the finbar study met with Dr Chow, Senior Investigator and Dr Fraumeni, Director in the Division of Cancer Epidemiology and Genetics when they attended the National Cancer Institute Summer Cancer Prevention Programme. They discussed the work of the NICR and the progress and possible collaboration of the **finbar** study (the all-Ireland case-control study examining the aetiology of oesophageal adenocarcinoma and Barrett's oesophagus).



Welcome to our new secretary, **Mrs Susan McGookin** who started with the Registry in November 2003.

Congratulations to **Deirdre and Kieran Fitzpatrick** on the birth of their third daughter Ella. Thanks are due to Deirdre for her significant input into our most recent publication launched 27th May 2004 – A Comprehensive Report on Cancer in Northern Ireland which is available on request or from our website at www.qub.ac.uk/nicr.

VISITORS FROM ABROAD



Dr. Mirari Marquez Cid from the Cancer Registry of Murcia in Southern Spain visited the Registry in March of this year. Dr. Marquez Cid

is responsible for the Information Technology section of the Cancer Registry in Murcia, and is very interested in using Automated Cancer Registration to complement the registration system currently in operation there.

During her visit, she was able to look at our computer system and was particularly interested in our tumour matching algorithm which has a set of rules whereby tumour data relating to the same patient are consolidated to produce the definitive cancer registration. We were also able to load some Spanish data on to our training database, and look at

possible ways of using the electronic sources to enhance quality. The Registry enjoyed Mirari's visit and hope that she gained much from the experience.



As part of the Cancer Registration IARC course in Lyon, we also received a placement visit from **Dr. Pattarawin Attasara**. Dr.

Attasara works in the National Cancer Institute in Bangkok, Thailand and he was also interested in the automated cancer registration system that we use in Northern Ireland. The Registry in Bangkok serves a population of over 11 million people and Dr. Attasara was very interested to apply automated methods to aid the cancer registration process.

Atlas of Cancer Incidence and Mortality in the UK and Ireland

This Atlas will cover 1991-1999 incidence and up to 2000 mortality for 17 sites in males and 18 in females representing just under 90% of all malignancies (excluding Non-Melanoma Skin Cancer). This Atlas will illustrate variations in cancer levels for N. Ireland at Health Board level. In addition to the Atlas the National Statistics website: www.statistics.gov.uk, will have the text of the report and links to data at local level in Excel spreadsheets so it should be possible to click on a map in PDF and obtain the data behind it. Publication date for this has not yet been confirmed but is likely to be late 2004.