

3. Cancer registration in Ireland

3.1. The National Cancer Registry Board

The National Cancer Registry Board was established by the Minister for Health in 1991, by Statutory Instrument.⁸ Its functions were laid down in its Establishment Order as follows:

1. to identify, collect, classify, record, store and analyse information relating to the incidence and prevalence of cancer and related tumours in Ireland;
2. to collect, classify, record and store information in relation to each newly diagnosed individual cancer patient and in relation to each tumour which occurs;
3. to promote and facilitate the use of the data thus collected in approved research and in the planning and management of services;
4. to publish an annual report based on the activities of the Registry;
5. to furnish advice, information and assistance in relation to any aspect of such service to the Minister.

The second National Cancer Registry Board was appointed by the Minister for Health in October 1996, to hold office until October 2001. The membership of the current Board is:

- Dr. Elizabeth Keane (Chairperson), Director of Public Health, Southern Health Board, Farm Centre, Dennehy's Cross, Cork; nominated by the Minister for Health and children
- Professor Alun Evans, Division of Epidemiology of The Queen's University of Belfast, Mulhouse Building, Grosvenor Road, Belfast, BT12 6BJ; nominated by the Faculty of Public Health Medicine of Ireland
- Professor James J. Fennelly, Consultant Oncologist, St. Vincent's Private Hospital, Herbert Avenue, Dublin 4; nominated by the Royal College of Physicians of Ireland
- Professor Bernadette Herity, Department of Epidemiology and Public Health, University College, Dublin, Belfield, Dublin 4; nominated by the Irish Cancer Society
- Professor Aine Hyland, Department of Education, University College, Cork; nominated by University College, Cork
- Dr. Tony Holohan, Deputy Chief Medical Officer, Department of Health, Hawkins House, Hawkins St., Dublin 2; appointed by the Minister for Health and children
- Professor Niall O'Higgins, Department of Surgery, St. Vincent's Hospital, Elm Park, Dublin 4; nominated by the Royal College of Surgeons in Ireland
- Dr. Martin Rouse, Medical Centre, Emmet House, Clonmel, Co. Tipperary; nominated by the Irish College of General Practitioners
- Dr. Kieran Sheahan, Consultant Pathologist, St. Vincent's Hospital, Elm Park, Dublin 4; nominated by the Faculty of Pathology of the Royal College of Physicians of Ireland
- Dr. Niall Tierney, Former Chief Medical Officer, Department of Health, Hawkins House, Hawkins St., Dublin 2; appointed by the Minister for Health and Children.

3.2. History

3.2.1. The Southern Tumour Registry

Population-based cancer registration began in Ireland in 1975 with the Southern Tumour Registry, which was set up in Cork and Kerry as the result of an initiative by local clinicians, pathologists and epidemiologists. Funding for the Registry was provided by the Irish Cancer Society, and its first full year of cancer incidence recording was in 1977. The Registry had a close association with University College, Cork from its beginning, through its clinical teaching departments and also through the Departments of Social Medicine and of Statistics. The Heads of the latter Departments, Professors JP Corridan and MA Moran, provided epidemiological and technical support to the Registry, and were both founder members of the Registry Committee. For 17 years, the Southern Tumour Registry collected and analysed cancer incidence data for Cork and Kerry, and was the only comprehensive, population-based cancer registry in Ireland, serving a population of over 500000. The establishment and success of the National Cancer Registry owes much to the pioneering work of those who set up, funded and administered the Southern Tumour Registry. The National Cancer Registry became responsible for data collection in Cork and Kerry late in 1991. An extensive review of the data collected by the Southern Tumour Registry up to 1990 has been published.⁹ The data of the Southern Tumour Registry is held by the National Cancer Registry and is available to researchers.

3.2.2. The National Cancer Registry

The establishment of a National Cancer Registry was one of the main recommendations of an expert group set up by the Minister for Health in November 1984 to investigate a suspected excess of leukaemia deaths on the eastern seaboard.¹⁰ A working group on a National Cancer Registry was appointed by the Minister in 1988 and, acting on the recommendations of this group, the Minister established the National Cancer Registry Board in 1991. The Board assumed responsibility for the work of the Southern Tumour Registry in November of that year. Plans for national cancer registration were produced by the Board in 1992, and full registration of all cancers in the country began on January 1st, 1994.

The aim of the Registry is to register all cancers incident since January 1st, 1994, in persons resident in the Republic of Ireland. It has also registered deaths due to cancer since that time, and records the deaths, from whatever cause, of patients diagnosed as having cancer since January 1st, 1994. There is no compulsion, either legal or administrative, on individuals or institutions to supply the Registry with data. The right of individuals or organisations to refuse to supply the Registry with data has posed a problem since our establishment, and is a serious threat to our ability to provide truly comprehensive national cancer statistics. To date, we have been able to work around isolated refusals, with no effect on the completeness of registration. However, the current situation is untenable in the long term.

3.3. Characteristics of the catchment area

3.3.1. Geography and climate

The catchment area of the Registry is the Republic of Ireland. A separate registry covers Northern Ireland and reports on cancer there.¹¹

The Republic of Ireland is situated between 51°30' and 55°30' N and between 6°0' and 10°40' W. The total land area is 70282 km², with a long indented coastline of 3169 km. The highlands are mainly coastal, with a central limestone plain, and the country does not rise above 1040 m at any point. The climate is temperate and oceanic, with average winter temperatures between 4°C and 7°C, and summer temperatures between 14°C and 16°C. Yearly rainfall is highest on the mountains of the west and lowest in the east midlands.

3.3.2. Population

The population at the last census (1996) was 3626087 (see Section A2.7). The population profile is younger than the European average, with a high dependency ratio. The current rate of population increase is estimated at about 1.2% per annum.¹²

3.4. Data collection methods

3.4.1. Sources of data

Reporting to the Registry is voluntary, and data collection is mainly active. The only information received passively at present is on notification forms returned by general practitioners. However, pilot studies of electronic data capture from pathology departments have begun. All other information is actively gathered by eighteen nurses trained in cancer registration methods who are employed by the Registry with the title of Tumour Registration Officer (TRO). These TROs are based in hospitals around the country (see Appendix 3 for a list of TROs and contact numbers). Each is responsible for gathering cancer data from a group of hospitals, and from other sources within a designated geographical area. Within their catchment areas, they liaise with hospital pathology and haematology laboratories, special clinics, hospital administrators and medical records staff, Hospital Inpatient Enquiry (HIPE) and casemix staff, and any other persons they consider to be a useful source of cancer registration data. They also maintain links with public health nurses, hospices and nursing homes in the community.

Hospital sources

Most cases (97%) were first recorded in hospital. This proportion has gone up very slightly between 1994 and 1998. The predominant source of notification of cases (81% of the total) was from reports provided by pathology departments within hospitals (Table 3.1). The Hospital Inpatient Enquiry (HIPE) has become a more important source of information, with the proportion of cases reported from this source increasing from 6% in 1994 to 11% in 1998.

Table 3.1 First source of notification of cases

| | YEAR OF INCIDENCE | | | | | | | | | |
|-----------------------------|-------------------|------------|--------------|------------|--------------|------------|--------------|------------|--------------|------------|
| | 1994 | | 1995 | | 1996 | | 1997 | | 1998 | |
| hospital sources | cases | % of total | cases | % of total | cases | % of total | cases | % of total | cases | % of total |
| pathology | 15591 | 82% | 15374 | 82% | 15831 | 81% | 15957 | 80% | 15625 | 79% |
| HIPE | 1080 | 6% | 1500 | 8% | 1676 | 9% | 1958 | 10% | 2230 | 11% |
| radiotherapy | 232 | 1% | 256 | 1% | 221 | 1% | 86 | <1% | 113 | 1% |
| other inpatient | 786 | 4% | 529 | 3% | 746 | 4% | 869 | 4% | 938 | 5% |
| other outpatient | 654 | 3% | 414 | 2% | 377 | 2% | 426 | 2% | 374 | 2% |
| all hospital sources | 18343 | 96% | 18073 | 97% | 18851 | 97% | 19296 | 97% | 19280 | 97% |
| non-hospital sources | | | | | | | | | | |
| death certificates | 364 | 2% | 369 | 2% | 350 | 2% | 198 | 1% | 204 | 1% |
| GP | 81 | <1% | 76 | <1% | 109 | 1% | 115 | 1% | 128 | 1% |
| other/unknown | 276 | 1% | 166 | 1% | 221 | 1% | 262 | 1% | 233 | 1% |
| all cases | 19064 | | 18684 | | 19531 | | 19871 | | 19845 | |

All Irish residents are entitled to free inpatient and outpatient hospital services. These services may be provided in publicly owned hospitals administered by the regional health boards, in independently owned and managed hospitals, known as voluntary hospitals, which are funded directly by the Department of Health, or in private hospitals. A substantial number of patients elect for private treatment, which is available in public and voluntary hospitals, as well as in private hospitals, which cater exclusively for private patients. Patients can be referred by their general practitioner to any hospital of their choice in the country. Cancers were registered at 115 hospitals in Ireland. The distribution of caseload varied widely between these centres (Table 3.2). Fewer than 10 cases per year per hospital were diagnosed in 9 hospitals; at the other end of the scale five hospitals saw more than 1000 new cases per year. Half of the national cancer workload was accounted for by 12 hospitals.

Table 3.2 Average number of new cancer cases diagnosed in acute hospitals, per hospital per year, 1994 – 1998

| cases per hospital | number of hospitals |
|--------------------|---------------------|
| 0 – 10 | 9 |
| 10 – 50 | 13 |
| 50 – 100 | 8 |
| 100 – 200 | 19 |
| 200 – 500 | 23 |
| 500 – 1000 | 3 |
| > 1000 | 5 |
| total | 80 |

14% of new cases were diagnosed in private hospitals, and 83% in public hospitals (Table 3.3). The remainder were not seen in hospital or were diagnosed abroad. The proportion of cancers diagnosed in private hospitals has gone from 13% in 1994 to 16% in 1998.

Table 3.3 Cancers diagnosed; by hospital type

| hospital type | 1994 | 1995 | 1996 | 1997 | 1998 |
|---------------|------|------|------|------|------|
| private | 13% | 14% | 14% | 16% | 16% |
| public | 86% | 85% | 84% | 83% | 83% |
| other | 2% | 2% | 2% | 1% | 1% |

Table 3.4 shows the distribution of new cancer cases, by hospital of diagnosis, among the health board areas. Almost 50% of all new cancers were diagnosed in hospitals in the ERHA. This distribution did not vary significantly between 1994 and 1998.

Table 3.4 Cancers diagnosed per year; by location of hospital

| health board of diagnosis | no. of cases | % of total |
|---------------------------|--------------|------------|
| EHB/ERHA | 9044 | 47% |
| MHB | 658 | 3% |
| MWHB | 979 | 5% |
| NEHB | 941 | 5% |
| NWHB | 918 | 5% |
| SEHB | 1290 | 7% |
| SHB | 3228 | 17% |
| WHB | 1925 | 10% |
| non-hospital cases | 415 | 2% |
| all cases | 19399 | |

In most cases, patients were diagnosed in the health board in which they lived (Table 3.5). In total, 83% of patients were diagnosed in their health board of residence. However, in the Midland and North Eastern Health Boards, only 56% of patients were diagnosed within the health board; most of the remainder were diagnosed in the Eastern Regional Health Authority (ERHA).

Table 3.5 Cancers diagnosed: by area of residence and hospital of diagnosis

| health board of residence | HEALTH BOARD OF DIAGNOSIS | | | | | | | | all areas | % of patients diagnosed in HB of residence |
|---------------------------|---------------------------|------|------|------|------|------|-------|------|-----------|--|
| | ERHA | MHB | MWHB | NEHB | NWHB | SEHB | SHB | WHB | | |
| ERHA | 35.4% | 0.1% | 0.0% | 0.1% | 0.0% | 0.0% | 0.0% | 0.0% | 36.1% | 98.1% |
| MHB | 1.9% | 3.2% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 0.5% | 5.7% | 55.6% |
| MWHB | 0.9% | 0.0% | 4.9% | 0.0% | 0.0% | 0.2% | 0.6% | 0.6% | 7.6% | 64.2% |
| NEHB | 3.2% | 0.0% | 0.0% | 4.6% | 0.0% | 0.0% | 0.0% | 0.0% | 8.1% | 56.6% |
| NWHB | 1.2% | 0.0% | 0.0% | 0.1% | 4.5% | 0.0% | 0.0% | 0.2% | 6.3% | 72.5% |
| SEHB | 2.5% | 0.0% | 0.1% | 0.0% | 0.0% | 6.4% | 0.8% | 0.0% | 10.1% | 63.0% |
| SHB | 0.4% | 0.0% | 0.0% | 0.0% | 0.0% | 0.0% | 15.1% | 0.0% | 16.2% | 93.6% |
| WHB | 1.0% | 0.0% | 0.0% | 0.0% | 0.2% | 0.0% | 0.0% | 8.6% | 10.0% | 85.8% |
| all areas | 46.6% | 3.4% | 5.0% | 4.9% | 4.7% | 6.7% | 16.6% | 9.9% | | 82.6% |

Death certificates

Death certificates were the most important non-hospital source of cases (1.4%). However, the importance of death certificates as a primary source of case notification has been decreasing, from 1.8% of 1994 cases to 0.9% of 1998 cases. The Registry, at present, does not register a case based on death certification alone, but only after the diagnosis has been confirmed from another source. Our reason for doing this is that almost all cases which first come to our attention from death certificates have turned out to pertain to pre-1994 incident cases. On the basis that almost all current death certificate only (DCO) cases are likely to pre-date the establishment of the Registry, we have decided to exclude them for the present (see section A2.3). The sites of these cancers, and the number of cancers at each site, are shown in Table A2.10.

Accuracy of death certificates

The accuracy of death certificates as a source of notification of cancer is questionable. In matching death certificates with registered cases, we have noticed significant discrepancies between the cause of death as given on the death certificate and the cancer as registered by the National Cancer Registry. In all of these cases, we have gone back to the original medical record to attempt to confirm the diagnosis.

The effects of inaccurate death certification are discussed in section A2.4.

Other sources of registrations

General practitioners

Cancer cases are also notified to the Registry by general practitioners. The number of cases is quite small (Table 3.1) at 0.5% of the total, although this is increasing. However, notification by GPs is a valuable check on the completeness of registration from other sources, and is our only source of information on non-fatal cancer cases treated solely by GPs.

Cancer screening

From 1994 to 1998 no organised cancer screening programme existed in Ireland. However, informal screening for cervical, and to a lesser extent, breast and some other cancers, took place (Table 3.6). Most screen-detected cancers were carcinoma in situ of the cervix; however, when invasive cancers only are considered, almost equal numbers of cervical and breast cancers were detected by screening. Apart from in situ cervical cancer, screening accounted for a negligible fraction of the cancers diagnosed.

Table 3.6 Cancers detected by screening

| | cases detected by screening | % of cancers at this site which were detected by screening | % of all screen-detected cancers |
|--|-----------------------------|--|----------------------------------|
| all cancers (including in situ) | | | |
| cervix | 2607 | 89.7% | 55.8% |
| breast | 180 | 6.2% | 2.1% |
| prostate | 34 | 1.2% | 0.6% |
| colon | 17 | 0.6% | 0.3% |
| lung | 15 | 0.5% | 0.2% |
| skin | 15 | 0.5% | 0.0% |
| other sites | 39 | 1.3% | 0.1% |
| all sites | 2907 | 100% | 3.0% |
| invasive cancers | | | |
| cervix | 163 | 39.5% | 18.3% |
| breast | 143 | 34.6% | 1.8% |
| prostate | 34 | 8.2% | 0.6% |
| colon | 13 | 3.1% | 0.2% |
| lung | 15 | 3.6% | 0.2% |
| skin | 13 | 3.1% | 0.0% |
| other sites | 32 | 7.7% | 0.1% |
| all sites | 413 | 100% | 0.5% |

3.5. Data processing

3.5.1. Data entry

Data is entered directly onto laptop computers by the TROs. The TRO enters or updates data under three headings: patient, tumour and treatment information (Table 3.6). Some of this information comes from the pathology report or other source of initial notification, but most is extracted from the patient's records when these become available to us, usually some months after discharge. The date, cause and place of death are entered by linkage with death certificates and the ward/DED data by linkage of the address with a national address database.

With the introduction of a new Registry computer system, we plan to extend the dataset to include information on waiting times, tumour markers and extended treatment codes (see Appendix 4). We also hope to extend the scope of linkage to the HIPE system.

Table 3.7 Data collected

| PATIENT | TUMOUR | TREATMENT |
|--|---|----------------|
| name–surname, first name, maiden name | source of notification | treatment type |
| address | method of presentation | treatment date |
| other address(es) | GP | hospital |
| ward/district electoral division of residence* | hospital | consultant |
| GMS number | consultant | |
| RSI number | medical record number | |
| date of birth | incidence date | |
| sex | age at incidence | |
| smoking status | topography | |
| marital status | morphology | |
| occupation | grade | |
| occupational status | behaviour | |
| alive or dead* | method of diagnosis | |
| date of death* | TNM stage | |
| cause of death* | basis of staging | |
| place of death* | residual disease | |
| | sites of metastases | |
| | histology date, lab, pathologist and reference number | |

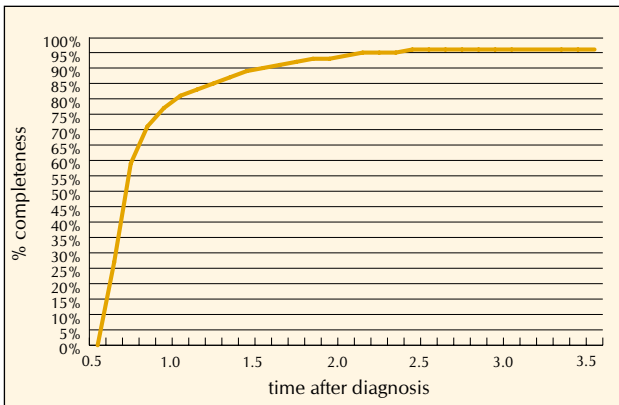
* added by data linkage

3.5.2. Quality control

The Registry carries out internal quality control checks on the data throughout collection and processing. Additional, more detailed, checks have been carried out during the past year for this report and as part of the process of preparing the data for an upgraded computer system.

Completeness of registration

Figure 3.1 Completeness of cancer registration up to three years after diagnosis



Many methods are available for checking the completeness of cancer registration, none of which can do more than give an indirect estimate of completeness. The most accurate method is comparison against a completely independent registration system, something which is not available in Ireland. The Registry approach to data collection is to use every possible source of notification. Two indirect methods, however, suggest a high level of completeness. A simple capture-re-capture method⁴ (Table 3.8) suggests a completeness of around 96%. A more complex survival model¹³ suggests that registration completeness has reached an asymptotic level of just over 96% at 2 years after diagnosis (Figure 3.1).

Table 3.8 Estimation of completeness using death certificate notifications

| | |
|-----------------------|--|
| registered alive (a) | 61344 |
| registered dead (b) | 42848 |
| unregistered dead (c) | 3241 (including DCO) |
| completeness | $\frac{a + b + c}{a + b + c + \frac{ac}{b}}$ 95.9% |

Histological verification of diagnosis

Histological verification is a strong guarantee of the accuracy of the data. The level of verification in Ireland is quite high by international standards.¹⁴

Table 3.9 Basis of diagnosis

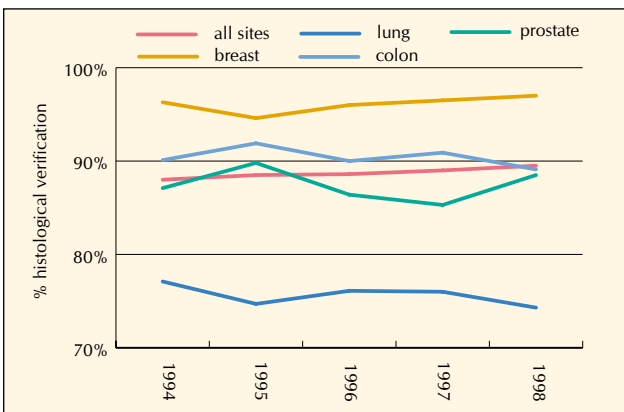
| | NUMBER OF CASES | | | | | | % of all registrations |
|-----------------|-----------------|-------|-------|-------|-------|-------------|------------------------|
| | 1994 | 1995 | 1996 | 1997 | 1998 | 1994 – 1998 | |
| histology | 15448 | 15034 | 15758 | 16079 | 16070 | 78389 | 80.8% |
| histology other | 453 | 580 | 589 | 569 | 588 | 2779 | 2.9% |
| cytology | 330 | 263 | 310 | 361 | 406 | 1670 | 1.7% |
| bone marrow | 422 | 546 | 539 | 561 | 586 | 2654 | 2.7% |
| blood film | 131 | 115 | 103 | 118 | 111 | 578 | 0.6% |
| imaging | 924 | 993 | 1106 | 1159 | 1202 | 5384 | 5.6% |
| clinical | 1180 | 1005 | 944 | 928 | 732 | 4789 | 4.9% |
| post-mortem | 30 | 38 | 26 | 22 | 18 | 134 | 0.1% |
| other/not known | 146 | 110 | 156 | 74 | 132 | 618 | 0.6% |
| all cases | 19064 | 18684 | 19531 | 19871 | 19845 | 96995 | 100.0% |

The overall level of histological verification has been increasing steadily since 1994, from 88.0% to 89.5% in 1998 (Table 3.9, Table 3.10). However, this trend has not been uniform for all sites (Table 3.10; Figure 3.2). As can be seen, the level of histological verification is quite low for some sites, such as lung cancer.

Table 3.10 Changes in level of histological verification, 1994 to 1998

| | % HISTOLOGICAL VERIFICATION | | | | | |
|-----------|-----------------------------|-------|-------|-------|-------|-------------|
| | 1994 | 1995 | 1996 | 1997 | 1998 | 1994 – 1998 |
| all sites | 88.0% | 88.5% | 88.6% | 89.0% | 89.5% | 88.7% |
| lung | 77.1% | 74.7% | 76.1% | 76.0% | 74.3% | 75.6% |
| breast | 96.3% | 94.6% | 96.0% | 96.5% | 97.0% | 96.1% |
| colon | 90.1% | 91.9% | 90.0% | 90.9% | 89.1% | 90.4% |
| prostate | 87.1% | 89.8% | 86.4% | 85.3% | 88.5% | 87.4% |

Figure 3.2 Changes in level of histological verification, 1994 to 1998



Completeness of data items

Table 3.11. Percentage of "unknown" or "not specified" values

| data item | percentage of "unknown" or "unspecified" cases |
|------------------------|--|
| site (C80.9) | 3.6% |
| morphology (M-8000/3) | 8.9% |
| basis of diagnosis | 0.6% |
| method of presentation | 3.6% |

Most tumour and patient variables were available to a high level of completeness (Table 3.11). One important exception, however, was staging information. The Registry attempts to collect staging information on all cancers to which the TNM system applies. The TNM system covers 59% of all registered cancers, the major exceptions being all non-invasive cancers, non-melanoma skin cancers and leukaemia.

For all stageable cancers, a T stage was recorded for 71.2%, an N stage for 49.1% and an M stage for 48.5% (Table 3.12). The level of staging varied for the common cancers, from breast cancer, with 91% of T stage, to prostate, which had only 46% of T stage recorded. The level of N stage was more variable, from 82% of breast cancers to only 13% of prostate. Recording of M stage was poorer overall, but with much less variation between sites.

As a consequence of missing TNM information, a summary stage (i.e. I, II, III, IV) could be derived for a relatively low percentage of cancers. Apart from lymphoma, where TNM staging does not apply, the highest level of summary stage was for colorectal cancer (59%). The absence of staging data for many cancers makes the interpretation of treatment and survival data much more difficult. From our experience of dealing with medical records over many years, we would strongly urge the introduction of a standard minimum dataset for cancer patients and the inclusion in all cancer medical records of a standard form for recording this information.

Table 3.12 Completeness of staging information for common cancers

| | PERCENTAGE OF CASES WITH A KNOWN STAGE | | | summary stage |
|-----------------------|--|-------|-------|---------------|
| | T | N | M | |
| all stageable cancers | 71.2% | 49.1% | 48.5% | |
| colorectal | 83.4% | 72.1% | 63.0% | 58.7% |
| breast | 91.5% | 82.5% | 53.6% | 50.3% |
| lung | 55.1% | 39.4% | 42.5% | 37.1% |
| prostate | 46.3% | 13.0% | 45.3% | 28.5% |
| lymphoma | | | | 80.7% |
| stomach | 60.1% | 49.3% | 56.1% | 49.9% |
| bladder | 70.6% | 25.8% | 33.2% | 23.2% |
| melanoma | 80.9% | 27.6% | 25.1% | 21.7% |

3.6. Availability of Registry data

3.6.1. Reports and datasets

The Registry wishes to make its data as widely available as possible, within the restraints imposed by maintaining confidentiality. The material published here may be reproduced freely, but the Registry must be cited as the source, and any alterations, omissions and interpretations of the data must be identified as having been made by the author. A summary of this report, many of the data tables and the basic dataset from which the report has been written, are available on the Registry website at www.ncri.ie.

Subsets, or further analyses, of the data may be obtained by any interested person by applying in writing to the Registry. Data from the Southern Tumour Registry (Cork and Kerry) for the period 1977 to 1993 are available on the same basis. The data may be provided either as cross-tabulations or as individual data records, as appropriate. No information which could identify an individual patient, institution or health care worker will be released without their consent. This service is free to individuals or institutions who contribute data to the Registry; a charge will be payable by others for the time taken in producing the information. We would be particularly interested in hearing from individuals or institutions within the healthcare system who might wish to use Registry data routinely for performance review.

3.6.2. Confidentiality

While wishing to facilitate researchers and others, the Registry must place the highest priority on maintaining the confidentiality of all patients. Data collection and processing is subject to high levels of physical and electronic security and all staff must sign binding undertakings with regard to the absolute confidentiality of any material they encounter. No information is ever published or released by the Registry in a format which could identify a patient, except with that patient's consent or where the information has been requested by a doctor who is caring for the patient.

The full text of the Registry's policy on confidentiality is available by post from the Registry, or on our website at www.ncri.ie/confid.htm

3.7. Research Programme

The Registry has an active research programme, covering the aetiology, diagnosis, treatment and outcome of cancer, as well as methodological problems in cancer epidemiology. This programme is supported by direct funding from the Department of Health and Children, by project grants from the Health Research Board and the Northern Ireland R&D Office, and by support from the Ireland-Northern Ireland-National Cancer Institute Consortium. We also welcome proposals for collaborative research.

Some of our current projects are:

- National audit of waiting times of public patients with lymphoma, breast, colorectal, prostate and lung cancer
- The consistency, appropriateness and effectiveness of treatments for breast, colorectal, prostate and lung cancer
- The use of geographical tools to study variations in cancer incidence
- Circumstances prior to referral of patients with colorectal cancer to a specialist by their GP (collaboration with Department of General Practice, UCC)
- National study of geographical variation in skin cancer incidence (collaboration with Dr. John Bourke, South Infirmary/Victoria Hospital, Cork)
- Trend analysis and prediction of short-term trends in cancer mortality rates since 1950
- Cancer incidence in renal transplant patients (collaboration with the departments of renal medicine and dermatology, Beaumont Hospital)
- Differences in stage and survival from breast cancer between Ireland and Northern Ireland
- An atlas of cancer incidence and mortality in Ireland and Britain (collaboration with Office of National Statistics, UK)
- CONCORD project—cancer survival in Europe and North America (multi-centre collaboration)
- Development of name and address stabilisation algorithms for matching purposes
- Case-control study of adenocarcinoma of oesophagus (with NI Cancer Registry).

4. Patient data items

The information collected by the Registry mainly pertains to tumours and their treatment, but a limited set of patient data is also collected. As the Registry has no facilities for data linkage with other national datasets such as census or occupational registers, the patient data presented here is that which can be extracted from clinical medical records. As such, it is necessarily limited and sometimes of unproven validity. Because of these limitations, data on individual cancer sites for patient variables such as occupation and smoking have not been described.

The 96995 registered cancers were diagnosed in 92106 patients, 1.05 cancers per patient.

4.1. Occupational status

Table 4.1 Occupational status

| occupational status | FEMALE | | MALE | |
|---------------------|----------|-----|----------|------|
| | patients | % | patients | % |
| employed | 3087 | 6% | 4599 | 10% |
| self-employed | 292 | 1% | 1643 | 4% |
| housewife | 18174 | 38% | 29 | < 1% |
| religious | 572 | 1% | 554 | 1% |
| retired | 12003 | 25% | 23279 | 52% |
| student | 404 | 1% | 344 | 1% |
| unemployed | 1058 | 2% | 2093 | 5% |
| other/unknown | 11922 | 25% | 12053 | 27% |
| all patients | 47512 | | 44594 | |

The National Cancer Registry collects some information on occupational status from medical records. Inevitably, because of the priorities of medical record keeping and the fact that many of the patients are beyond retirement age, detailed occupational information is often missing.

Over half of the patients were described as either "retired" or "unknown". Most men were recorded as "retired", while most women were described as "housewife", an occupation without a recognised retirement age.

These categories can be directly compared to those used for "principal economic status" in the 1996 census (Table 4.2). As expected the "retired" were over-represented among cancer patients and there was a significant number of "unknown".

Table 4.2 Observed and expected principal economic status

| | FEMALE | | | MALE | | |
|---------------|----------|----------|------|----------|----------|------|
| | observed | expected | SIR | observed | expected | SIR |
| at work | 3951 | 9205 | 43% | 6796 | 15619 | 44% |
| unemployed | 1058 | 2129 | 50% | 2093 | 4635 | 45% |
| student | 404 | 406 | 99% | 344 | 259 | 133% |
| home duties | 18174 | 29637 | 61% | 29 | 231 | 13% |
| retired | 12003 | 9037 | 133% | 23279 | 27167 | 86% |
| other/unknown | 11922 | | | 12053 | | |
| all patients | 47512 | 50415 | 94% | 44594 | 47912 | 93% |

4.2. Smoking status

This is recorded, if available, from the medical records. Information on smoking was available for 64% of patients (Table 4.3). Forty-five per cent of men and 28% of women were recorded as current or ex-smokers. No accurate age-specific national data are available for comparison.

Table 4.3 Smoking behaviour

| | FEMALE | | MALE | |
|--------------|----------|------------|----------|------------|
| | patients | % of total | patients | % of total |
| smoker | 9643 | 20.3 | 12727 | 28.5 |
| ex-smoker | 3441 | 7.2 | 7170 | 16.1 |
| non-smoker | 18185 | 38.3 | 11831 | 26.5 |
| unknown | 16243 | 34.2 | 12866 | 28.9 |
| all patients | 47512 | | 44594 | |

4.3. Marital status

Table 4.4 shows the marital status of patients with registered cancers. Information was available on 92% of patients. Fifty-eight percent of men and 44% of women were married. Far more women were widowed, due to their greater life expectancy.

Table 4.4 Marital status of patients

| | FEMALE | | MALE | |
|---------------|----------|------------|----------|------------|
| | patients | % of total | patients | % of total |
| married | 21053 | 44.3 | 25818 | 57.9 |
| widowed | 12916 | 27.2 | 5220 | 11.7 |
| single | 8331 | 17.5 | 9326 | 20.9 |
| divorced | 104 | 0.2 | 91 | 0.2 |
| separated | 932 | 2.0 | 594 | 1.3 |
| other/unknown | 4176 | 8.8 | 3545 | 7.9 |
| all patients | 47512 | | 44594 | |

4.4. Occupation (or parent's, or spouse's)

Table 4.5 Main occupational classes of registered patients

| occupational class | FEMALE | | | | MALE | | | |
|---|----------|------------|----------|------|----------|------------|----------|-----|
| | patients | % of total | expected | SIR | patients | % of total | expected | SIR |
| all patients with known occupations | 12974 | 100 | 10099 | 100 | 23087 | 100 | 17779 | 100 |
| farming, fishing and forestry workers | 2126 | 16 | 547 | 303 | 7390 | 32 | 5327 | 107 |
| communication, warehouse and transport workers | 558 | 4 | 115 | 377 | 2212 | 10 | 1418 | 120 |
| building and construction workers | 457 | 4 | 41 | 869 | 2190 | 9 | 1609 | 105 |
| other gainful occupations (incl. not stated) | 1069 | 8 | 876 | 95 | 1724 | 7 | 924 | 144 |
| sales occupations | 973 | 7 | 1210 | 63 | 1091 | 5 | 1426 | 59 |
| personal service and childcare workers | 1542 | 12 | 1376 | 87 | 977 | 4 | 914 | 82 |
| other manufacturing workers | 217 | 2 | 276 | 61 | 849 | 4 | 487 | 134 |
| engineering and allied trades workers | 265 | 2 | 38 | 541 | 746 | 3 | 814 | 71 |
| health and related workers | 1531 | 12 | 1059 | 113 | 637 | 3 | 335 | 146 |
| scientific and technical occupations | 182 | 1 | 88 | 160 | 574 | 2 | 317 | 139 |
| managers and executives | 265 | 2 | 372 | 55 | 521 | 2 | 820 | 49 |
| central and local government workers | 306 | 2 | 291 | 82 | 507 | 2 | 375 | 104 |
| business and commerce occupations | 305 | 2 | 227 | 104 | 470 | 2 | 408 | 89 |
| clerical and office workers | 1284 | 10 | 1799 | 56 | 445 | 2 | 392 | 87 |
| teachers | 816 | 6 | 878 | 72 | 440 | 2 | 414 | 82 |
| religious occupations | 275 | 2 | 94 | 228 | 425 | 2 | 289 | 113 |
| food, drink and tobacco production workers | 137 | 1 | 108 | 99 | 374 | 2 | 269 | 107 |
| electrical trades workers | 91 | 1 | 11 | 657 | 360 | 2 | 292 | 95 |
| Garda Síochána | 101 | 1 | 10 | 821 | 301 | 1 | 111 | 210 |
| other professional workers | 138 | 1 | 192 | 56 | 236 | 1 | 264 | 69 |
| chemical, paper, wood, rubber, plastics, printing | 61 | <1 | 88 | 54 | 223 | 1 | 224 | 77 |
| Army occupations | 62 | <1 | 3 | 1498 | 206 | 1 | 108 | 147 |
| textile, clothing and leather workers | 132 | 1 | 211 | 49 | 128 | 1 | 130 | 76 |
| computer software occupations | 38 | <1 | 90 | 33 | 39 | <1 | 81 | 37 |
| social workers and related occupations | 43 | <1 | 99 | 34 | 22 | <1 | 33 | 51 |

The patient's last occupation, as given in the medical records, was recorded. This information was recorded in fewer than 50% of cases for men and for only 25% of women (Table 4.5). The most frequent occupational category for both males and females was "farming, fishing and forestry workers" as it was in the 1996 census. The percentage of males with cancer describing themselves as farmers (32%) was slightly higher than would be expected from the census data for a group of the same age composition but this may be due to differential reporting of occupation by retired persons. In many cases the observed/expected ratio was very high, reflecting the general unreliability of this data.

Relating occupational data to cancer risk was some of the earliest work in cancer epidemiology. Without such links, new occupational risk factors are difficult to identify. It is unfortunate that no mechanism exists in Ireland to link data on occupation with cancer registration as can be done, for instance, in Denmark. With the wider use of the PPS number, there may be some opportunities for this type of linkage.

