

# The Northern Ireland Cancer Registry

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## SUMMARY

*The Northern Ireland Cancer Registry was evaluated using a 5% sample of all cancers diagnosed histologically in 1983 as the standard for comparison. The overall registration rate was low. Two years following histological diagnosis only 63% of the cancers were registered and 19% of these were notified solely by the Registrar General's office. In a subgroup of patients who were known to have died by the time of the study, only 49% of the cancers were registered while the patient was alive. A further 30% of cases were registered only after death and 21% of cases went unregistered. There was no significant variation in registrations by area, by hospital or by age group. There was a considerable variation in registration rate by disease group. A low level of awareness among hospital doctors about the Northern Ireland Cancer Registry was postulated as a reason for the low levels of registrations received. This was investigated through a postal questionnaire. A response rate of 51% was achieved after two postings. Both the response rate and level of knowledge varied by grade and speciality of the doctor. Only 43% of responders knew of the existence of the cancer registry and only 2% registered patients more often than once a year. Possible methods for improving the system are discussed.*

## INTRODUCTION

Cancer is an important disease. In developed countries it is second only to heart disease as the most commonly registered cause of death. In Northern Ireland, approximately 3,000 individuals die annually from cancer and this accounts for one-sixth of all deaths. The local Hospital Activity Analysis records cancer as the reason for almost 8% of hospital admissions. The total cost of cancer to the Health Service and society is enormous but unquantified. In our daily lives we are brought into increasing contact with carcinogens and so an accurate data base is essential to identify, monitor and ultimately reduce exposure to these hazards. The evaluation of interventions such as screening and health education requires accurate data. Adequate information is also required by those responsible for planning health services.

Mortality data reflect cancer prevalence less and less well as cancers are diagnosed earlier and treated more effectively than in the past. Cancer registration schemes, by collecting information on all cancers diagnosed in an area, provide a method of monitoring cancer incidence and prevalence within a population. Cancer has been registered in Northern Ireland since 1959. The

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registry is located in a civil service department at Castle Buildings, Stormont and receives registrations from hospital doctors who complete cards for their cancer patients, and from the Registrar General's office which provides a list of registered cancer deaths.

Information on approximately 80,000 cases has been gathered by the registry, but until now neither the completeness of registration nor the accuracy of the data have been evaluated. It is staffed by 1.5 whole time equivalent clerical officers with minimal input from senior civil servants. It does not have its own computer. It costs about £25,000 per annum and produces only one document, a bulletin which does not analyse or interpret the data gathered.

## **METHODS**

In 1985 an evaluation of the registry was performed using cancers diagnosed histologically during 1983 as the standard for comparison. This was a valid standard, as it represented the most complete and accurate source of cancer cases and there was no linkage between the records of the histology laboratories and those of the cancer registry.

A 5% random sample, stratified by laboratory, was selected ( $n = 358$ ) from all cancers diagnosed in 1983. Identification details and information about the cancer were extracted by the author from laboratory records and hospital notes. The cancer registry files were then manually searched to ascertain whether the patient had been registered by 31 July 1985 and, if so, whether this occurred during life or solely from the Registrar General's returns after death. The accuracy of the recorded diagnosis was also assessed.

Since, in N. Ireland, doctors are the main source of registrations it was decided to investigate the level of awareness about the registry among hospital doctors. This was investigated by a postal questionnaire sent to each hospital doctor of registrar grade and above, who might diagnose or treat cancer patients. The questionnaire was designed to obtain information on the respondent's grade, specialty, knowledge of the cancer registry, the method by which such knowledge was gained, the frequency of registration by the respondent and whether the registry could be of use to them in their work or research. A space was left for comments. The questionnaire was posted along with an information sheet about the registry, a registration card and a prepaid return envelope. All non-responders were reminded after ten weeks had elapsed. Analysis of the questionnaires was performed using the SPSS computer package on a minicomputer. The exercise was evaluated by comparing the number of registrations received by the registry before and after the questionnaires were distributed. The levels of registration for 1986 were also compared to previous years.

## **RESULTS**

The sample of 358 cancer cases contained 52% males and 48% females. Overall 225, (63%) of patients were registered, 44, (12%) of the sample were registered solely from the Registrar General's returns, accounting for 19% of total registrations. Inaccuracies in the recorded site of tumour was noted in less than 1% (2) of registered cases.

Analysis by area of residence showed that 7.4% of the sample lived in the Western Health and Social Services Board, 23.6% in the Northern Board, 18.5% in the Southern Board and 50.4% in the Eastern Board. The Western Board was significantly under-represented in the sample ( $p < 0.01$ ). The age distribution showed most cases in the older age groups, in keeping with the

epidemiology of cancer. In each age group the proportion of cases registered with the cancer register was similar.

The data were analysed by hospital of diagnosis. Only three hospitals contributed 50 or more patients to the sample: the Belfast City Hospital had 69% of its cancer patients registered with 3% of these registered solely from death certification. The respective percentages for the Royal Victoria Hospital were 61% and 7%, while for the Ulster Hospital, Dundonald, they were 56% and 6% (Table I).

TABLE I  
*Measure of registration by source hospital (hospital of initial attendance)*

<i>Hospital</i>	<i>Absolute frequency in sample</i>	<i>Percentage of sample registered with cancer registry prior to death</i>	<i>Percentage of sample registered with cancer registry only by Registrar General's returns</i>	<i>Percentage of sample not registered</i>
Royal Victoria	72	54%	7%	39%
Belfast City	74	66%	3%	31%
Ulster	50	50%	6%	44%
Craigavon Area	24	54%	8%	38%
Forster Green	10	70%	10%	20%
Waveney	12	33%	25%	42%
Mid Ulster	11	55%	9%	36%
Whiteabbey	14	64%	0%	36%
Altnagelvin	11	55%	9%	36%
Others	80	47%	15%	38%

There was considerable variation in registration by site of disease. Over half (54%) of skin malignancies, 82% of cancers of the cervix (more severe than CIN III), nearly half (46%) of the myelomas and half (50%) of the leukaemias went unregistered. Of the disease groups with sufficient cases to allow reliable comparisons, lymphomas, lung and breast malignancies had the highest percentage registered before death (Table II).

The completeness of registration did not vary significantly between the four health boards: the Eastern Board had the highest registration (66%), while the Western Board had the lowest (58%). The contribution of the Registrar General's returns to the total registrations was assessed. This was the only source of registration in 44 cases, (19%) of all registered cases. Of the total sample of 358 cases, 128 (36%) were known to be dead, 24 (6.7%) were known to be alive and in 206, the status was unknown. Four-fifths (79%) of those known to be dead were registered. Only 49% were registered during life and 30% were registered only after death via the Registrar General's office. Of the 24 persons known to be alive, 54% were registered by the cancer registry (Table III). Therefore, there was a failure of registration in 21% of the subgroup of patients who were known to be dead and 37% of all cancer patients.

TABLE II  
*Distribution of registration by disease groups*

<i>Diagnosis</i>	<i>Absolute frequency in sample</i>	<i>Percentage of sample registered with cancer registry prior to death</i>	<i>Percentage of sample registered with cancer registry only by Registrar General's returns</i>	<i>Percentage of sample not registered</i>
<i>Malignancies</i>				
Lung (ICD 162)	20	75%	5%	20%
Gastrointestinal tract (ICD 140–159)	80	50%	24%	26%
Skin (ICD 172–173)	67	46%	0%	54%
Breast (ICD 174)	42	76%	2%	22%
Lymphomas including Hodgkins (ICD 200–202)	14	86%	0%	14%
Cervix (ICD 180)	17	18%	0%	82%
Lip, oral cavity, vocal cord, larynx and nasopharynx (ICD 140–149 and 161)	18	67%	0%	33%
Bladder (ICD 188)	25	64%	8%	28%
Prostate (ICD 185)	18	50%	11%	39%
Leukaemia and myelofibroais (ICD 204–208)	18	33%	17%	50%
Ovary and vagina (ICD 179, 181–184)	12	50%	8%	42%
Myeloma (ICD 203)	11	55%	0%	46%
Others (thyroid, testis, kidney, brain secondary malignancies)	16	50%	6%	44%

TABLE III  
*Performance of cancer registry for live and deceased persons*

	<i>Alive on 1 January 1985</i>	<i>Deceased by 1 January 1985</i>	<i>Total sample (2 years following histological diagnosis)</i>
Registered during life	13 (54%)	62 (49%)	182 (51%)
Registered only from death certificates	—	39 (30%)	44 (12%)
Not registered	11 (46%)	27 (21%)	132 (37%)
<b>Total</b>	<b>24</b>	<b>128</b>	<b>358</b>

A cross-check was made between the sample and death certificates for 1983 which mentioned cancer, to identify those cases which were wrongly classified as alive by the cancer registry. Of the 128 persons known to be dead, 10 (8%) were incorrectly classified as alive by the registry; three of these errors were the result of doctors failing to complete death certificates accurately so that cancer was not recorded as a cause of death.

The total number of questionnaires posted to hospital doctors was 803. The initial response rate was 38%, which increased to 51% on remailing. The response rate varied between specialties as follows: general medicine 59%, obstetrics and gynaecology 48%, surgery 45%, psychiatry 54%, accident and emergency 53% and anaesthetics 40%. These differences were statistically significant ( $\chi^2 = 14.98$ , 3 df,  $0.05 > p > 0.01$ ).

The response rates also varied significantly by grade of staff:- associate specialists 32%, registrars 41%, senior registrars 58%, consultants 53% ( $\chi^2 = 22.3$ , 3 df,  $p < 0.001$ ).

The level of knowledge about the cancer registry among hospital doctors was low. Only 175 responders (43%) were aware of the registry, of these, 84% stated they had learned about it from a letter or circular, 10% from a colleague and less than 1% from a lecture. Knowledge of the cancer registry varied with the timing of response to the questionnaire: of the 304 initial responders 36% knew of the registry while the figure for the 101 subsequent responders was 64%. Knowledge of the registry also varied significantly by grade of staff. Of those who responded, only 14% of registrars, 10% of senior registrars and 24% of associate specialists knew of it, whereas 60% of consultants were aware of its presence ( $\chi^2 = 82.8$ , 3 df,  $p < 0.001$ ). (Fig 1).

There were also significant differences in the levels of knowledge among the various specialties. The highest level was in those working in obstetrics and

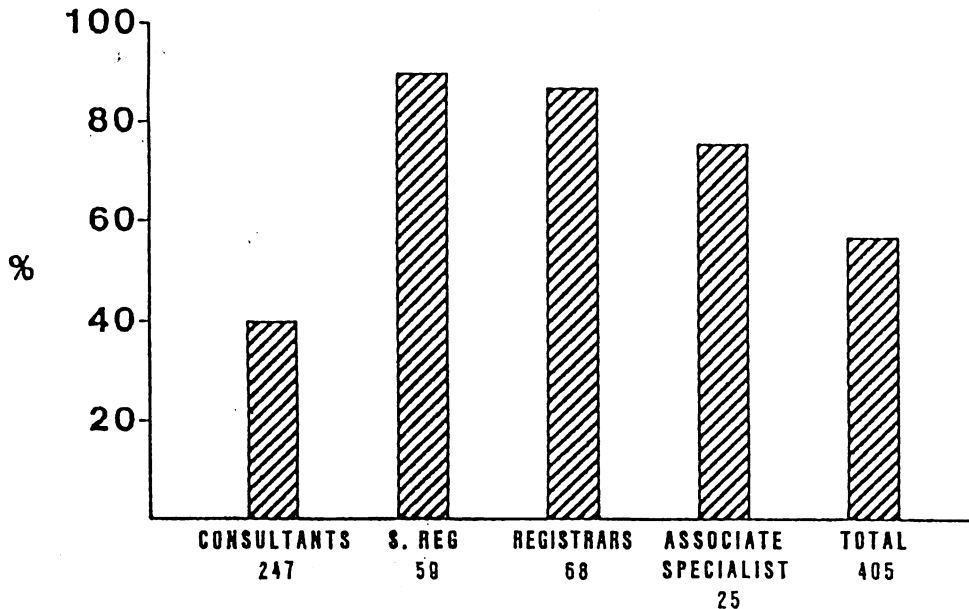


Fig 1. Percentage of responders who were unaware of the cancer registry (by grade of staff)

gynaecology (69%). Only 30% of psychiatrists, 41% of surgeons and 40% of those working in medical specialties were aware of the cancer registry ( $\chi^2 = 22.3$ , 3 df,  $p < 0.001$ ). (Fig 2).

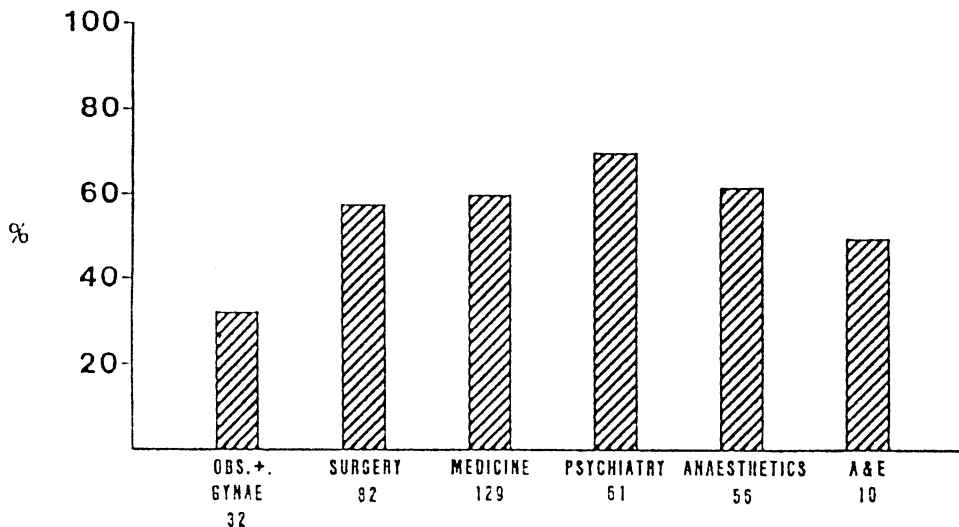


Fig 2. Percentage of responders who were unaware of the cancer registry by speciality

Responders were asked how often they registered cancer patients. Over two-thirds (69%) replied that they had never registered a cancer patient, 11% registered cases occasionally, while only 2% registered cases more often than once a year. Over half (51%) of responders thought the registry could be useful in their work or research, while 32% did not.

Responders were asked who they thought should be responsible for submitting registrations. The majority (53%) thought consultants should register cancer patients, 21% thought clerical staff should perform the task, while 28% thought it should be the responsibility of junior medical staff (in a few cases all three options were chosen and so the total is greater than 100%).

The majority of responders added at least one comment to the questionnaire. Many were surprised to discover that the registry existed and that it was dependent on their co-operation (Table IV). In addition to the popular comments, a few felt the registry should be closed. Many felt it should be reorganised and in particular, that it should be computerised to include information from histology laboratories. A few complained about the potential extra work that cancer registration would involve. Following the distribution of the questionnaire the number of registrations increased transiently, but this rise was not sustained.

## DISCUSSION

The routine recording of basic information on cancer patients is intended to provide information on the frequency of different types of cancer and on survival following diagnosis and treatment. It also may alert researchers to environmental hazards. However, the value of a cancer registry is highly dependent on the accuracy and completeness of the recorded data. If a population-based registry is

TABLE IV  
*Responders' comments*

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1. Education: increased and widespread education of medical staff about the cancer registry is required.
  2. Registration card design: should request more information.
  3. Registration card availability: problems in obtaining cards at ward level.
  4. Responsibility: many different opinions were expressed about who should actually register patients. A fee per registration was advocated by a few.
  5. Feedback: an annual report containing data interpretation in addition to tables of registration was suggested.
  6. Organisation: it is difficult to obtain access to the data contained in the registry.
  7. Cost: the value for money was questioned.
  8. Relevance: some questioned the value of a cancer registry to clinical medicine.
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to be of real epidemiological value it should aim to register 90% of all malignant disease occurring within the area it serves.<sup>1</sup> Incompleteness of ascertainment of new cases leads to an underestimation of the incidence rate and may result in false assumptions about trends.<sup>2</sup>

The level of completeness of registrations (63%) found in this study is low when judged by these criteria, and by comparison with other cancer registries which have evaluated their performance and published results. In north-west England, registration completeness was found to be 94% (ranging from cervix, 81% to ovary, 98.5%).<sup>3</sup> Using morbidity data in Scotland, Haddow<sup>4</sup> showed that completeness of registration ranged from 40% to 90% between areas. The relative contribution of total registrations derived solely from death certificates in Northern Ireland was calculated as 19%, which is higher than the figure of 7.7% calculated by Nwene<sup>3</sup> for north-west England and reflects the generally low levels of registrations by doctors.

It was reassuring to find there was no variation in registration by geographical area. Such variations, if present, could lead to false impressions about disease occurrence. Unlike Benn et al<sup>5</sup> this study did not find a significant variation in the completeness of registration for different age groups. The response rate to the questionnaire was low (51%) and may reflect the level of interest among some specialists about cancer registration. This would account for the variation in response rate by specialty. In view of the fact that hospital doctors represent the main source of registration, it is hardly surprising that the registry performs poorly. There are over 7,000 cancers diagnosed histologically in Northern Ireland each year, yet the registry receives details on under 5,000 cases annually.

The means by which responders became aware of the cancer registry will be of interest to those planning to further the education of doctors in this area. Almost all of those who were aware of the Northern Ireland Cancer Registry had learned about it by letter (84%). This method of education about the cancer registry could be pursued but not in isolation; doctors need to know the benefits of cancer registration before they register cases. The fact that very few junior staff but over half of consultants knew of the registry suggests that there has been little or no education about its existence for some years.

There was a strange discrepancy between the small number of doctors who registered cases and the large number (over half) who felt the registry could be of use to them in their work or research. There is not only a general lack of awareness about the registry but also an ignorance among doctors concerning their role in registering cancer patients. This was borne out by the variations in responses to the question about who should register such cases. Each group of staff appeared to be under the impression that some other group was registering the cancer cases. There was not a sustained increase in cancer registrations over the months following this exercise, perhaps because of issues other than levels of knowledge, for example availability of registration cards or poor perception of the value of cancer registration.

The poor registration percentages in general, and for some disease groups in particular, casts doubt on the value of the registry as currently organised. A cancer registry is a valuable tool for researchers in general, and epidemiologists in particular, and so efforts should be made to increase the level and accuracy of registrations. Ultimately this may involve the automatic registration of patients by histology laboratories, but in the meantime the system could be vastly improved if all doctors who diagnose or treat cancer patients register the details. Apart from its use as a research tool, the registry is essential for monitoring cancer incidence. A convincing demonstration of the need for adequate surveillance has been 'the sustained and genuine public concern over the discharge of radioactive waste from Sellafield into the Irish Sea'.<sup>6</sup> The Chernobyl disaster further strengthens the case for improving cancer registration. This work has quantified the shortcomings in the Northern Ireland Cancer Registry and this awareness has already spurred those concerned about the problem to propose an improved system.

For the success of an improved cancer registry, it should use multiple sources of information including hospital doctors, general practitioners, diagnostic facilities including pathology, neuropathology, haematology and immunological laboratories, radiology departments, terminal care hospitals and the Registrar General's office. It should have sufficient resources, including adequate staff numbers and mix to allow analysis and interpretation of data received and engagement in research projects. We look forward to the realisation of such a system in Northern Ireland.

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#### REFERENCES

1. Waterhouse J, Muir C, Shanmugaratnam K et al. Cancer incidence in five continents, vol IV: International Agency for Research on Cancer, Lyon, 1982.
2. Fraser P, Beral V, Chilvers C. Epidemiological surveys on the availability of cancer registration data from regional cancer registries for research. Reports to the advisory committee on cancer registration by the epidemiological units of the London School of Hygiene and Tropical Medicine, 1978.
3. Nwene U, Smith A. Assessing completeness of cancer registration in the north-western region of England by a method of independent comparison. *Br J Cancer* 1982; **46**: 635-9.
4. Haddow AJ. The coverage achieved by the cancer registration scheme in the Western Hospital Region of Scotland in 1965. *Health Bull (Edinburgh)* 1968; **26**: 10-2.
5. Benn RT, Leck I, Nwene UP. *Int J Epidemiol* 1982; **11**: 362-7.
6. Lowry committee (first report). Investigation into patterns of disease with possible association with radiation. Department of Health and Social Services, Northern Ireland, 1986.