

Establishing baseline data in cancer registration in northern England: implications for Health of the Nation targets

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Abstract

Objective - To assess the completeness and accuracy of cancer surveillance data relevant to *Health of the Nation* targets.

Design - A comparison of locally ascertained data on cancer with recorded cancer registry sources in selected diagnoses.

Setting - The district of South West Durham within the Northern Regional Health Authority.

Patients - All patients with lung, skin, and malignant cervical cancer who were resident and diagnosed in the district or identified in the Northern Region Cancer Registry during the calendar period 1989-91.

Main results - Of 544 cases of cancer identified from all available sources, 448 (95.8%) were registered, ranging from 93.9% for malignant cervical cancer to 96.7% for skin cancer. In 448 cases which were both identified locally and registered, 53 (11.8%) showed disagreements between local sources and register data, involving classification of site and timing of registration. Twenty three cases were identified locally but were not registered, 22 registered but not identified locally, and 51 registered with the casenotes missing locally.

Conclusions - Any real achievement of *Health of the Nation* targets may be masked by changes over time in the accuracy and completeness of information systems. In assessing the achievement or otherwise of targets, it is important to be aware of any differences in the completeness and accuracy of the baseline data compared to future measurements.

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The publication of the *Health of the Nation* has concentrated attention on a number of key areas.¹ For example, one target is to reduce the death rate for lung cancer in those under the age of 75 years by at least 30% in men and 15% in women by the year 2010 (baseline 1990). In skin cancer, the target is a halt in the year on year increase in the incidence by 2005 (no baseline stated) and for invasive cervical cancer the target is to reduce the incidence by at least 20% by the year 2000 (from a 1986 baseline). We wished to investigate a cancer primarily involving an inpatient stay or first registration through death certification (lung

cancer) and one involving diagnosis and treatment in the primary care setting or outpatients (skin cancer). Although *Health of the Nation* targets include breast cancer, organised screening for the resident population of South West Durham Health Authority (the population for study) did not begin until the autumn of 1991. Hence the service received by residents was not systematic and often provided by hospitals from outside the district. In contrast, the cervical screening programme in the district started in October 1987. We therefore decided to investigate only cervical cancer as our example of a cancer with a screening programme for early secondary prevention. We investigated the completeness and accuracy of cancer registration in these three diagnoses.

Subjects and methods

Cases of malignant neoplasm of trachea, bronchus, and lung (ICD-9 162); malignant neoplasms of skin (ICD-9 172-3); and malignant (invasive) neoplasms of the cervix uteri (ICD-9 180) were identified for the residents of South Western Durham Health Authority who had attended the local district general hospital (DGH).

Lung cancer cases were collected from hospital discharge and death data and bronchoscopy outpatient clinic data. For skin cancer, the cases were identified from the histology register of the DGH and for cervical cancer, from DGH discharge and death data and the district cervical cancer call and recall scheme. Data were re-abstracted from these sources and case notes by one investigator (MK), blind to the original registration information.² Registrable cancer was considered to be present if the diagnosis was histologically confirmed or therapeutic decisions for the relevant cancer diagnosis had been taken by a clinician. Cases were collected for the years 1989-91 as the reference period except for skin cancer, for which data in 1989 were not available. Individual cases, identified locally, were matched with the cumulative registered cases in the Northern Cancer Registry for South West Durham residents (including cases who had died) at 30 July 1993, using eight identifying characteristics (table 1).

Results

Of the 471 cases identified locally, 448 (95.1%) were registered, ranging from 91.3% for malignant cervical cancer to 96.5% for skin cancer

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Table 1 Identifying items used for linkage of lung, skin, and cervical cancer cases within the Northern Cancer Registry

General:	Specific:
Surname	Diagnosis (to the third digit of ICD-9) year of diagnosis
First forename	
Additional forenames	
Month of birth	
Year of birth	
Postcode	

(table 2). However, 53 of the 448 (11.8%) registered cases required further investigation since there was not a complete match on all criteria with local information. Nineteen cases of skin cancer and one of lung cancer, identified from local sources and diagnosed during the reference period, had also had a previous cancer of the same morphology and site in previous years. In the local sources, neither the clinician nor pathologist had indicated that this was a recurrence. In the registry data, these 20 cases had been registered in previous years but not during the reference period. In this situation, the need to register a new or second primary cancer was questionable.

Eight cases of skin or lung cancer, diagnosed during the reference period, also had a primary cancer at another site. For these cases, only the non-pulmonary or non-skin site had been registered before or during the reference period. A further eight cases had evidence from local sources, mainly case notes, of primary cancers belonging to ICD-9 162, 172-3, or 180. These eight cases were registered as malignant neoplasm without specification of site (ICD-9 199) because the registry had received vague and inconsistent information from different sources. Three cases were recorded locally as malignant cervical cancer but the registry had received more detailed information which confirmed that the correct registration had been made to non-malignant cervical neoplasm, endometrial cancer, and ovarian cancer respectively. In 14 cases involving the three diagnoses, the registered anniversary date was ascribed to years other than the project reference years. In 10 of these, the difference was about one year and in four cases, the discrepancy was minor but resulted in cases being registered in 1992 rather than 1991.

The register identified 23 cases in South West Durham, fulfilling the original criteria set for the study, which were not identified in local sources but for which case notes were available for investigation. In 12 of these, the local case notes and discharge letters only reported carcinomatosis with an unknown primary, whereas the cancer registry had registered one of the three relevant primary cancers using information from other sources – for example,

death certificates and x ray reports. In 10 cases, the case notes showed little evidence of a neoplasm. These were mainly elderly persons with pneumonia but with neither clinical nor pathological confirmation of a specific cancer. However, each of these patients had died with a cause of death specified on the death certificate as lung cancer and had been registered as such. In one case, the diagnosis should have been registered outside the study reference period and was therefore excluded; thus leaving 22 cases registered but not identified locally. For an additional 51 cases registered as lung, skin, or malignant cervical cancer, the case notes could not be traced locally. These registry diagnoses were accepted as correct making the total number of cases, derived from all available sources, as 544. The estimated overall completeness of registration for all three cancers was 95.8%, ranging from 93.9% for malignant cervical cancer to 96.7% for skin cancer.

Discussion

The Northern Region Cancer Registry is population based and, in addition to identifying information on patients, records the site and morphology of reported cancers. The anniversary date during the reference period was defined in order of precedence as the date of starting treatment, the date of first hospital admission, or the date when first seen as an outpatient. The sources of data for the registry in 1989–91 are data from pathology departments submitted by hospital clerks; reports from radiotherapy departments; death certification; data on resident patients transferred from other regional registries; and notifications from other hospital sources. The registration process, however, varies between regional registries as does the proportion of cancers recorded as a result of death certification only.^{3,4} In the northern region, unlike some other regions, there is neither direct control of staff at peripheral data collection points nor the direct employment of peripatetic clerks for data capture purposes.

The concentration on targets and their achievement within the *Health of the Nation* approach will inevitably increase attention on the information systems necessary for evaluative purposes. In these circumstances, continual use of data within systems in itself leads to greater completeness and accuracy through feedback and interchange between users and information suppliers.⁵ One danger is that any real achievement of targets may be masked by changes over time in the completeness of data

Table 2 Completeness of cancer registration for three diagnoses, 1989–91

Diagnostic categories	Registered and identified locally	Identified locally but not registered	Total no of cases identified locally	Completeness of registration of locally identified cases (%)	Registered but not identified locally	Registered but case notes missing locally	Total cases identified from all sources	Overall completeness of registration (%)
Malignant neoplasm of trachea, bronchus and lung (ICD-9 162)	288	16	304	94.7	17	37	358	95.5
Malignant neoplasm of skin* (ICD-9 172-3)	139	5	144	96.5	2	7	153	96.7
Malignant neoplasm of cervix uteri (ICD-9 180)	21	2	23	91.3	3	7	33	93.9
Total	448	23	471	95.1	22	51	544	95.8

* 1990–91 only.

in the information system. A further difference between baseline data and future registration data is that before 1 July 1993, cancer registration was not seen as a mandatory data collection exercise.⁶ In 1993 cancer registration came under the control of the committee for regulating information requirements. It is important, therefore, to be aware of differences in the completeness and accuracy of the baseline data compared with later measurements when assessing the achievement targets.

The study reported here shows that overall cancer registration in cases of these three cancers is high, 93.9% in malignant cervical cancer, 95.5% in lung cancer, and 96.75% in skin cancer. Although in *Health of the Nation*, the lung cancer targets are based on death rates, we have included an assessment of this condition in cancer registration for two reasons. Firstly, as a measure of the success of primary prevention through reduced smoking, complete and accurate incidence data would be preferable to death registration alone. Secondly, a potential danger of target setting exercises such as *Health of the Nation* is that undue emphasis is placed on the specified indicators with the relative neglect of others. We feel that concentrating on death certification alone in lung cancer at the expense of registration data would be unhelpful.

If registration data had been taken at face value for *Health of the Nation* purposes, difficulties might have arisen in interpretation, since the completion rates quoted are subject to the caveats concerning accuracy raised on 53 registrations. One problem includes the decisions that are made about whether a tumour is recurrent, in which situation a new registration should not take place, or whether there is a new primary of the same morphology at the same site. This is particularly a problem in cancers of the skin in which a new tumour of the same morphology occurring at any place on the whole skin surface (same site) creates difficulties in interpretation. A second problem concerns the precision with which the anniversary date is recorded. It seems preferable to select a group of years, perhaps five, for establishing baseline values in order to reduce the effect of discrepancies over anniversary dates. Possibly, for these reasons, the Department of Health, in its recent review of progress with the *Health of the Nation* strategy, has wisely avoided quoting incidence data for these three cancers at this stage.⁷

Much work is currently being carried out by cancer registries to make baseline data complete and accurate, for which they need adequate resources. Given the impetus of the *Health of the Nation* initiative and the critical importance of the baseline data, the relative dearth of recent publications on this topic is surprising. One study, examining the North

Western Cancer Registry for the period 1974–77, found that completeness of ascertainment by the registry was 94% overall but varied with site.⁸ The completeness of cancer registration in England for 1968–85 was assessed by comparison of registry data with the reporting of malignancies in 17 000 women directly to an independent research team. In this study, the completeness of registration was evaluated as 86.5%.⁴ The most recent and relevant investigation, carried out in the North Western Regional Cancer Registry in 1988 and 1989, studied misclassification of invasive cervical cancer by comparing cancer registry data with pathology records.⁹ There was an over-registration of invasive cervical cancer of 3% but this was exceeded by under-registration to the extent that the best estimate of the incidence of the condition for baseline data after adjustments for misclassification, was increased from 16.5 to 18.1 per 100 000 population.

The difficulty of evaluating cancer registration data, especially when using independent morbidity data for comparison, should not be underestimated. For instance in this study, the case notes could not be traced locally for 51 cases who were registered with one of these three cancers. In the future, although hospitals and other provider units are obliged to collect the minimum dataset for cancer registration and forward this to regional registries, there are few financial incentives to do so since this process is not usually linked to district contracts. There is likely to be considerable variation in the extent to which purchasers recognise this problem and write it into contracts. We conclude, therefore, that when assessing the achievement of *Health of the Nation* targets involving cancer registration, particularly in a comparison of districts or other areas, careful consideration of the accuracy and completeness of both the baseline and later measurements is required.

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