



Study of completeness of registration at the Estonian cancer registry

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Every cancer registry should be able to quantify the level of completeness of registration. The current study describes a routine quality control procedure in the Estonian Cancer Registry (ECR) for assessing the completeness of registration. The registry's database was compared with the databases of the Tartu University Lung Clinic and the Maarjamõisa Hospital of the Tartu University Clinics, and active retrieval to obtain missing cancer cases diagnosed in 1998 was carried out. The overall completeness of case ascertainment based on this study was 90.8%. As a result of this procedure, 67 cases of malignant neoplasms (1.1% of the total number of incident cancer cases for 1998) and 11 cases of other reportable neoplasms were detected and recorded at the ECR. Cancers of the lung, thyroid gland and prostate were most frequently under-notified. For these sites, the number of cancer cases for 1998 for Estonia as a whole increased 2.6%, 11.8% and 2.2%, respectively. To conclude, the existence of electronic databases is a positive development, but cancer registrars still need to employ labour-intensive methods to validate diagnostic

codes and to decide whether to include in the ECR cases found by active retrieval. Based on the findings of our study, which is the first one of its kind in Estonia, the completeness of cancer reporting varied by cancer site, and it appeared to be a substantial concern for several sites. *European Journal of Cancer Prevention* 12:153–156

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European Journal of Cancer Prevention 2003, 12: 153–156

Key words: cancer, registration completeness, Estonian Cancer Registry

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Received 17 June 2002 Accepted 13 September 2002

Introduction

Completeness of registration can be defined as the extent to which all the incident cancers occurring in a target population are included in the registry's database (Parkin *et al.*, 1994). Ideally, completeness should be close to 100%, so that a comparison of incidence rates between registries reflects true differences in cancer risk, not artefacts of the registration process (Parkin *et al.*, 1994, 2001). Cancer registry databases are extensively used in clinical and epidemiological research, and it is becoming increasingly necessary to assess the quality of the data (Lapham and Waugh, 1992; Brewster, 1995; Harvei *et al.*, 1996). Every cancer registry should be able to quantify the level of completeness at which it operates (Nwene and Smith, 1982). Only a few studies have been conducted to assess the completeness of registration (Dickinson *et al.*, 2001), and almost none in the cancer registries of Eastern Europe.

Advances in medical informatics provide an important opportunity to improve the quality and completeness of cancer registries. Electronic databases with diagnostic codes are now frequently available in hospitals at the local level and sometimes at the national level. These health system databases are mostly designed for administrative purposes and there are remarkably few data about their

relative accuracy (Cooper *et al.*, 1999). They may not be well suited for research or disease monitoring without careful scrutiny (Middleton *et al.*, 2000).

The present paper describes a routine quality-control procedure introduced at the Estonian Cancer Registry (ECR) for assessing the completeness of registration: a regular comparison of the registry's database with the hospital databases.

Cancer registration in Estonia

Estonia is situated on the Baltic Sea coast and has an area of 45 000 km² and a population of 1.4 million. From 1940 to 1991 the country was part of the USSR. The ECR was started in 1978, but retrospective incidence data are available from 1968 (Thomson *et al.*, 1996). The process of cancer registration at the ECR has been fully described (Rahu, 1997). In brief, reporting on cancer cases is a statutory obligation, according to which the physicians and pathologists are obliged to notify the ECR of all new cancer cases that come to their attention, using a standard data submission form. Of all the tumours registered, 72.8% are notified by physicians, 24.7% by both physicians and histopathology departments and 2.0% are detected on autopsy. The DCO cases comprise 0.5% (data for 1998). Reportable cancers include malignant

tumours (ICD-10 (World Health Organization, 1992): C00–C97) and *in situ* carcinomas (D00–D09). In addition, tumours of benign and uncertain behaviour of meninges, brain, other parts of the central nervous system and of intracranial endocrine glands (D32–D33, D35.2–D35.4, D42–D43, D44.3–D44.5) must be also reported.

In 1998, 5891 cancer patients diagnosed in Estonia were registered at the ECR by the end of January 2001 (Aareleid and Mägi, 2001). This study was undertaken in August 2001 to determine completeness of registration at the ECR, by comparing it with the health system databases from two big hospitals. Ethics approval was granted by the Ethics Committee of the University of Tartu (protocol no. 84/22).

Materials and methods

ECR cancer data for 1998 were compared with hospital discharge data from Maarjamõisa Hospital, and the medical insurance data file from the Lung Clinic by electronic linkage of their data with the ECR and by active retrieval of missed records deemed eligible for registration.

The Maarjamõisa Hospital and the Lung Clinic both operate as part of the Tartu University Clinics, serving mainly the population of southern Estonia, which accounts for about one-third of the Estonian population.

The Maarjamõisa Hospital discharge database is primarily set up for administrative purposes.

The Lung Clinic was chosen for linkage because the number of cancer notifications from this clinic fell by about a half compared with 1997, which suggested a decline in the completeness of notification. Medical insurance data represent reimbursement claims for hospital stays. These are handled by the Sickness Fund, which implements the medical insurance system introduced in Estonia since 1992 (Nielsen, 2001).

The discharge database of the Maarjamõisa Hospital contained data on patients with a discharge diagnosis of malignant, benign or *in situ* neoplasm, or neoplasms of uncertain or unknown behaviour (ICD-10 C00–C97, D00–D48). The insurance database of the Lung Clinic contained information about patients diagnosed with malignant tumours (ICD-10 C00–C97).

The hospital databases were linked with the ECR database by computerized probability matching, using first name, surname, date of birth and ICD code as matching variables, to find out whether all reportable tumours for that period had been registered at the ECR. Clerical checking was carried out to resolve cases in

which the automated matching could not definitely indicate a successful match.

Patient identification data and codes of diagnoses for cases missing from the ECR database were sent to the hospitals. The statistics departments of the hospitals were asked for permission to review the case notes. An ECR staff member (MM) then visited the hospitals and reviewed the case notes. If the diagnosis of cancer for a specific case was confirmed by her as a result of reviewing the case notes, she filled in a notification form and the case was registered at the ECR.

Results

The Maarjamõisa Hospital discharge database for 1998 contained 699 records of individuals whose diagnosis appeared to be eligible for cancer registration at the ECR. Of these, 640 (96.6%) were classified in the discharge summary as having a malignant tumour, 43 (6.2%) as having a benign neoplasm or neoplasm of uncertain or unknown behaviour of the meninges, brain or other parts of the CNS (D32–33, D43), and 15 patients had neoplasm of uncertain or unknown behaviour of intracranial endocrine glands (D35.2–35.3; D44.3–44.5). One patient had carcinoma *in situ*.

Of these 699 registrable cancer patients, 621 (88.8%) were already registered at the ECR at the time of review, seven months later, and 78 were unregistered. After review of the case notes, 48 (6.9%) of these unregistered patients were found to be eligible for cancer registration (Table 1). For 18 of these patients, the notification form had actually been completed by the doctor and left in the medical record, rather than sent to the ECR.

For all 48 unregistered cancer patients a notification was filled in and the case was registered at ECR.

Of the remaining 30 initially considered to be eligible for cancer registration, a diagnostic coding error was detected for 20 patients, and case notes could not be retrieved for 10 patients (Table 1). Typical coding errors included: another disease coded as a tumour, benign tumour coded as a malignant or *in situ* carcinoma, wrong site code (e.g. skull instead of brain), metastasis coded as a primary (e.g. breast cancer metastasis in orbital bone coded as malignant neoplasm of the eye). Tumours of the central nervous system, prostate and digestive organs were most frequently unreported (Table 2).

The Lung Clinic data file contained information on 200 patients diagnosed in 1998. Of these, 146 (73%) had been registered at the ECR by 31 January 2001. Among the 54 who were not registered, 30 patients were found to be eligible for cancer registration, diagnostic coding errors were found in 8, a cancer diagnosis could not be firmly

Table 1 Distribution of cancer cases missing from the ECR as a result of data linkage and search for these cases at Maarjamõisa Hospital and Lung Clinic

Type/site of the neoplasm	Notification completed	Medical record not found	Coding error	Uncertain diagnosis	Total
The Maarjamõisa Hospital Malignant neoplasm (C00–C97)	37	6	15	–	58
<i>In situ</i> neoplasm (D00–D09)	–	–	1	–	1
Benign neoplasm of meninges, brain, and other parts of CNS (D32–D33)	8	2	–	–	10
Benign neoplasm of other and unspecified endocrine glands (D35.2–D35.4)	1	2	1	–	4
Neoplasm of uncertain or unknown behaviour of meninges, brain, and other parts of CNS (D42–D43)	2	–	3	–	5
Total	48	10	20	–	78
Lung Clinic Malignant neoplasm (C00–C97)	30	12	8	4	54

Table 2 Cancer cases by primary site obtained from Maarjamõisa Hospital and Lung Clinic by active retrieval

Primary site	ICD-10	Maarjamõisa Hospital	Lung Clinic
Pharynx, other lip, and oral cavity	C14	1	–
Digestive organs	C15–C26	6	–
Lung	C34	1	18
Mediastinum	C38	1	–
Mesothelioma	C45	–	2
Prostate	C61	7	–
Bladder	C67	3	–
Brain, malignant	C71	6	–
Thyroid gland	C73	–	8
Primary site not specified	C80	2	1
Lymphoma	C81–C85	4	1
Myeloma	C90	2	–
Lymphoid leukaemia	C91	4	–
Central nervous system, benign	D32–D33	8	–
Hypophysis (pituitary), benign	D35.2	1	–
Central nervous system, uncertain behaviour	D42–D43	2	–
Total		48	30

established in 4. The medical records of 12 patients (22.2% of all patients whose records suggested eligibility for cancer registration) could not be located (Table 1).

In all, among 132 patients whose records at Maarjamõisa Hospital or the Lung Clinic suggested eligibility for cancer registration, 78 unregistered tumour patients (67 malignant tumours and 11 cases of tumours of benign, uncertain or unknown behaviour of intracranial endocrine glands) were detected by means of active retrieval (Table 2). The overall completeness of case ascertainment by

the ECR based on the linkage of databases from these two hospitals was 90.8%. Cancers of the lung and thyroid were the most frequently missed, almost all of these at the Lung Clinic. Diagnostic coding errors were detected in 28 cases. These were mainly misclassification of another disease as a malignant tumour, or of a lung metastasis as a primary site, in all these cases the true primary site had already been notified to the ECR. For four patients, a cancer diagnosis could not be firmly established from the information in the medical records, and the medical records of 22 patients (16.7% of all patients whose records suggested eligibility for cancer registration) could not be retrieved.

Discussion

This project led to a 1.1% increase in the total number of malignant tumours registered for 1998, from 5824 to 5891. Cancers of the lung, thyroid gland and prostate were most frequently under notified. For these sites, the number of cancer cases for 1998 for Estonia as a whole increased 2.6%, 11.8% and 2.2%, respectively.

In addition, 11 cases of tumours of benign, uncertain or unknown behaviour of intracranial endocrine glands were registered as a result of this study. This raised the total number of these neoplasms from 94 to 105, a considerable increase of 10.5%.

Actively retrieving the 78 cases of neoplasms was quite laborious. Another very time-consuming activity was checking the 28 sets of notes where the diagnosis of a neoplasm appeared in the hospital database as reportable to the ECR, but which were 'false positives' (i.e. not neoplasms). The medical case notes of these patients had to be reviewed most attentively, and time spent on each

such case was considerably longer than time spent on each case of active retrieval.

A significant proportion (16.7%) of medical records of patients initially thought to be eligible for cancer registration was unobtainable for review. The proportion was especially high at the Lung Clinic, reaching 22.2%, which is worrying, as patients whose medical records were not obtainable could also have contributed to the level of under notification. As mentioned earlier, the Lung Clinic was chosen for linkage because the number of cancer notifications from this clinic fell by about a half compared with 1997, which suggested a decline in the completeness of notification. The medical records were probably unobtainable because they were either misplaced in the archive or being used for other research projects. The fact that a number of medical records were not available for review is likely to have an impact on the results of the study, as several cancer patients eligible for registration could have been lost.

One of the shortcomings of the study is that we were not able to estimate the completeness of the ECR as a whole. Our study was restricted to two hospitals only, where electronic databases already existed.

In Estonia there is no nationwide hospital discharge registry as there is, for example, in neighbouring Finland (Teppo *et al.*, 1994). In the future it will be possible to include all hospitals in Estonia in this kind of study, as more and more hospitals develop electronic patient discharge databases and a nationwide hospital discharge database is eventually set up.

Yet another means of enhancing the completeness of case ascertainment are notifications from histopathology departments and the linkage of ECR data with the databases from these departments. As can be seen from the above, none of the cancer cases registered at the ECR is notified by histopathology department solely, and only a quarter of all notifications are accompanied by histopathology notifications. Therefore, notifications by histopathology departments could be a considerable resource for increasing the completeness of cancer reporting. Developing electronic pathology databases, of which there are only a few currently existing, and amalgamating these into a nationwide pathology database, would make it possible to carry out data-quality checks by linking it with the ECR data files. This procedure would serve several purposes: in addition to

increasing case completeness it would also enhance the accuracy of cancer information already registered at the ECR.

To conclude, the existence of electronic databases is a positive development, however, cancer registrars still need to employ labour-intensive methods to validate diagnostic codes and to decide whether to include in the ECR cases found by active retrieval. Based on the findings of our study, which is the first one of its kind in Estonia, the completeness of cancer reporting varied by cancer site, and this appeared to be a substantial concern for several sites.

Acknowledgements

The authors are grateful to Professors Michel Coleman (London, UK), David Leon (London, UK) and Mati Rahu (Tallinn, Estonia) for their useful comments on the manuscript. The work was performed in: Estonian Cancer Registry, North Estonian Regional Hospital Foundation Cancer Centre, Hiiu 44, 11619 Tallinn, Estonia.

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