



The Israel National Cancer Registry: Completeness and Timeliness of Data

Results of a National Survey

EXECUTIVE SUMMARY*

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Objectives

The main objectives of this national survey were: to assess, separately, the completeness of cancer case ascertainment in the National Cancer Registry in Israel (INCR) as of 2005 and the degree of completeness of the 2005 incidence data; to evaluate the timeliness of the registry data; to evaluate the completeness of reporting to the INCR by medical institute and the sources of reporting therein; to identify issues requiring training of employees in the health care system who are involved in reporting cases to the registry; to improve the quality of future reporting and to identify potential problems in the field, in the era of continual advancement of technology.

Methods

Data on reportable cases diagnosed and/or treated in 2005, and documented by medical records departments, pathology and cytology laboratories, and oncology and hematology institutes of 39 medical institutions in Israel (32 hospitals, 5 private pathology laboratories and 2 community clinics), were independently collected and matched against the INCR database. Unmatched cases (cases that were not present in the INCR database) were followed back to verify their reportability. Matched cases, i.e. cases that were present in the INCR database, but for which there was disagreement between the topography or morphology code recorded in the INCR and that documented in the diagnosis sources or coded by the survey staff, were further investigated to determine whether they represented additional primary cases not previously recorded in the registry. Cases that did not meet the criteria for inclusion in the survey and duplicate records were dropped from the analysis. Percent completeness of casefinding was calculated by different variables as the final number of cases found to be present in the registry divided by the total number of reportable cases ascertained in the independent survey process, multiplied by 100.

Key findings

Completeness of casefinding

- Out of a total of 59,557 reportable cases identified through the survey, 23,246 were new cases first diagnosed in 2005, that is, incident cases. Ninety-three point seven percent of the total number identified and 91.6% of 2005 incident cases had a matched cancer record in the national cancer registry.

- For the five-year period prior to 2005, percent completeness of casefinding of the INCR data ranged between 96.5% of incident cases identified through the survey for 2000 to 94.7% of incident cases identified for 2004. Completeness of casefinding increased with time elapsing since the date of diagnosis, a well-known finding in most cancer registries around the world, as reports of cancer cases may continue to be received well after the date of diagnosis.
- Completeness of INCR data varied according to category of diagnosis (types of diagnoses according to tumor behavior), cancer site, sources from which data were collected, number of tumors per patient, and age, in both the total cases collected and in the 2005 incident cases. The distribution of the 2005 incidence cases according to the various characteristics as well as the completeness, were in most cases similar to that of the total cases identified, though numbers were understandably smaller.
- Ninety-five point two percent of invasive malignancies, 84.1% of carcinomas in situ and 60.5% of benign and borderline tumors of the brain and central nervous system identified through the survey had a matching cancer record in the INCR database. The corresponding figures for the 2005 incidence cases separately were 94.0%, 78.1%, and 53.9%, respectively.
- Completeness of the cancer registry with respect to invasive solid malignancies was 96.8%. For hematologic malignancies, completeness was 88.0%. The corresponding figures for the 2005 incidence cases separately were 95.8% and 83.4%, respectively.
- In more than half of the invasive solid malignancies group the percentage of completeness was very high (95% to 100%). This group includes the majority of diagnoses occurring most commonly in the Israeli population, with the exception of cancer of the prostate, melanoma of the skin and cancer of the kidney (93.4%, 94.5%, 94.5% of all diagnoses, respectively, and 90.6%, 92.9%, and 92.5% respectively for 2005 incidence cases).
- Most of the incompleteness in the invasive solid malignancies group was found in cancer of the eye, in both the total number of cases in the survey and in the 2005 incident cases separately (67.7% and 50.7%, respectively); however the number of cases is not high (158 cases, 67 diagnosed in 2005).
- Of hematologic malignancies, chronic myeloproliferative disorders and myelodysplastic syndromes were the most likely to be underrepresented

- in the cancer registry, with a completeness of 51.1% of all cases in the survey, and 51.5% of 2005 incident cases.
- Among in situ carcinomas, completeness was lowest for in situ carcinoma of the uterine cervix; 69.3% completeness for all cases in the survey, and 56.7% for 2005 incidence cases.
 - The most commonly occurring non-malignant tumors of the brain and central nervous system identified in the survey were meningiomas, which constituted 70.8% of all tumors in this category. Only 65.0% of these cases were present in the cancer registry database. Of cases diagnosed in 2005, meningiomas comprised 69.5% of non-malignant tumors of the brain and central nervous system, and only 59.0% of tumors were present in the cancer registry database.
 - Data completeness increased significantly with the increase in number of data sources. The highest completeness (98.0%) was seen for cases identified from four separate sources, and the lowest (92.1%) for cases identified from a single reporting source. The corresponding figures for 2005 incidence cases were 98.2% and 85.1%, respectively.
 - Data completeness was highest for cases identified through oncology institutes records alone. For these cases, 96.9% of the total cases in the survey and 97.5% of 2005 incident cases had a matched cancer record in the registry database. In contrast, data completeness was lowest for cases identified through hematology institutes alone. The completeness of cases identified by hematology institutes alone is much lower for the 2005 incidence cases (66.5%) compared with the total number of cases identified in the survey (84.2%)
 - Among cases identified on the basis of pathology reports alone, completeness varied with the type of pathology laboratory. 90.6% of those from hospital pathology laboratories and 77.0% of those from community pathology laboratories had a matched cancer record in the registry database. Completeness figures for 2005 incidence cases were 87.3% and 71.6%, respectively. This finding suggests incomplete reporting to the INCR by non-hospital-based pathology laboratories.
 - Cancer cases occurring in patients with multiple primary malignant neoplasms (two or more) were significantly less likely to appear in the cancer registry database than those in patients with a single diagnosis (90.9% vs 93.9% respectively for all cases, and 86.0% vs. 91.7%, respectively for 2005 incidence cases). This finding suggests incomplete registration of new cancer diagnoses in patients already present in the registry.

- Data completeness varied by the age of the patient at the time of diagnosis. The lowest percentages of completeness of case ascertainment in the young age groups (up to age 39) was observed among those aged 20-29 and 30-39 (90.4% and 92.6%, respectively), and in the oldest age groups – among those aged 80-89 and 90 and over (90.5% and 88.6%, respectively). A similar picture was also observed for the 2005 incidence cases, which also has the lowest percentages of completeness among those aged 20-29 and 30-39 (86.1% and 89.4%, respectively), and among those aged 80-89 and 90 and over (88.2% and 86.8%, respectively).
- Gender was not found to be associated with data completeness.
- In examining medical records, we found room for improvement in the documentation of a medical history of cancer, as presented in the Health Ministry's 1989 Directive on the subject. Inadequate documentation of medical history jeopardizes the accuracy of cancer incidence estimates for a given calendar year and the performance of quality control activities. Missing information on year of diagnosis reduces completeness estimates for the year under scrutiny.

Timeliness

Timeliness of the data is reflected by the time required by the registry to publish incidence data for a given calendar year. An internationally accepted standard is for cancer cases to be registered within two years of diagnosis. Thus, registry incidence data for calendar year 2005 would be expected to have been complete and ready for analysis by the end of 2007. As stated above, 91.6% of cases diagnosed in 2005 that were identified through our survey were present in the registry database at the time the survey was conducted. However, when examining these cases, we found that as of the beginning of 2008, 5.4% of them were not included in the registry's listing of cases diagnosed in 2005. In 3.4% of cases, the recorded year of diagnosis was mistakenly recorded as later than 2005, and in 1.9% of cases, the year of diagnosis was correctly recorded as 2005, but the case was first registered in the database in 2008 or later. When subtracting these cases that were present in the national cancer registry at the time of the survey but were not recorded in a timely manner, we find that when the 2005 incidence data were first published by the registry in 2008, data completeness for that calendar year was 86.7%. This finding raises concerns regarding the timeliness of registration of cases.

Completeness of reporting

Examination of the completeness of reporting by the different medical institutions was carried out on the basis of cases found only in one medical institution (and not in any other medical institution), and according to the specific source of data collection (medical record departments, pathology laboratories, etc.) in each medical institution; i.e. cases found in only one medical institution, by a single data source (and not by any other data source) in that medical institution.

- Completeness of reporting by institution varied from 42.2% to 100% (in an institution with a very small number of reportable cases).
- Completeness of reporting was lowest for cases diagnosed in institutions with 501-700 beds (91.9%) and highest for institutions with less than 100 beds (97.6%).
- Completeness of reporting was highest from institutions in the Northern District (94.9%) and lowest from institutions in the Central District (92.9%).
- There is no difference in the percentage of reporting between government/municipal hospitals and Clalit Health Services hospitals (93.6% and 93.7%, respectively), but the percentage of reporting from private hospitals is lower (92.0%). The lowest percentage (67.2%) was found in community clinics of the Clalit Health Services, but the number of cases was small and the data were collected from only two clinics, with a large difference between them in the percentage of reporting (97.9% and 42.2%, respectively). A low percentage of reporting (77.0%) was also found in private pathology laboratories in the community.
- When examining completeness of reporting by specific source of data collection in each of the medical institutions, it was found that in most institutions the problem of completeness is concentrated in the hematology institutes (reporting ranges from 100.0% to 42.2%), although in some hospitals, problems were also found in the medical records department (range 100.0%-83.0%). In certain institutions, problems exist also in pathology laboratories (range 97.0%-48.0%) and oncology institutes (100.0%-90.2%).

Corrective actions taken by the cancer registry as a result of the survey

- Changes were made to the Reporting Regulations of 1982. The changes took effect on April 29, 2012. The main change in the regulation was the extension of the reporting requirement to sources outside the hospitals.
- Data from a private pathology laboratory in the community that did not previously report to the national cancer registry have been registered. The laboratory was first identified during the survey activities. .
- A unique project was carried out to obtain complete data on the incidence of Chronic Lymphocytic Leukemia (CLL) in Israel, by actively monitoring new cases diagnosed in 2011-2012. The work was carried out in collaboration with Dr. Rosa Ruchelmer (Department of Hematology, Shaarei Zedek Hospital), on behalf of the CLL Study Group in Israel.
- A meeting was held with representatives of the Clalit Health Services and Maccabi Health Services regarding reporting to the National Cancer Registry. It was agreed to cross-check the data on cancer patients in Clalit and Maccabi with the cancer registry data twice a year to complete cases that are known to them and are not registered in the National Registry database.
- An advisory committee was formed to address the issue of reporting of hematologic malignancies, in order to improve reporting, with an emphasis on reporting from the community.
- A meeting was held with Prof. Yaakov Peer, Director of the Department of Ophthalmology at the Hadassah Medical Center, on the subject of eye cancer cases. It was agreed to transfer the relevant data file to the National Cancer Registry.
- The requirement to report to the National Cancer Registry has been reconfirmed in private pathology laboratories in the community and in hematology institutes.
- It was decided to include a team from the National Cancer Registry in the quality control activities carried out in hospitals by the Medical Administration Division of the Ministry of Health in order to monitor the implementation of the requirement to report cancer cases to the INCR. The quality of reporting will also be monitored.

Recommendations

- To formulate a directive to be published in the framework of the regulations published by the Medical Administration Division, requiring the systematic registration of malignant diseases in the oncology and hematology institutes, that includes the obligation to code diagnoses according to ICD-O-3 (Internal Classification of Diseases for Oncology), as accepted in cancer registries and in oncology institutes around the world.
- With respect to pathology and cytology laboratories, to formulate a directive requiring that the pathology and cytology reports include, in addition to the text description of the final diagnosis, coding of the diagnosis according to the most recent version of the Systematized Nomenclature of Medicine (SNOMED), as accepted in pathology institutes around the world.
- To re-issue a directive of the Director-General of the MOH, such as the directive published in 1989, setting out the requirements of reporting cancer cases and the medical record, in order to improve medical documentation in this field.
- To employ advanced online technologies: electronic reporting, including from pathology laboratories.
- To cross-link data from other existing cancer databases, including data collected in research projects in specific ambulatory clinics that treat cancer patients in the hospital setting, with the National Cancer Registry database, for the benefit of all parties.
- To develop effective procedures to cross-link data between databases.
- For pathology institutes/laboratories, to include the requirement of reporting to the National Cancer Registry in the criteria for receiving a license from the Ministry of Health.
- To continue to run basic courses on registration and medical information relating to of cancer, for personnel involved in the registration and reporting of cancer cases both in hospitals and in the community.
- To continue to hold two-year training activities, including workshops on various subjects in the field of cancer.
- To develop the position of Certified Tumor Registrar (CTR) as existing in the US and elsewhere in the world.
- All of the recommendations mentioned above should also improve data timeliness. However, concurrent with these activities, the Registry

should also consider using the American model for estimating the real-time incidence rates in a given year in Israel.¹

- To perform quality control activities of registry data completeness indices as part of the ongoing work plan of the Israel Center for Disease Control, rather than as a project carried out once in ten years.
- To employ permanent and specifically appointed personnel to plan and implement quality control activities.

- ¹A special model for delay adjustment developed by the US National Cancer Institute (NCI) that predicts the incidence of cancer for a given year, based on the cumulative trends of previous years.