# An Assessment of the Completeness and Timeliness of the Israel National Cancer Registry

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**ABSTRACT**

**Background:** The Israel National Cancer Registry (INCR) was established in 1960. Reporting has been mandatory since 1982. All neoplasms of uncertain/unknown behavior, in situ and invasive malignancies (excluding basal and squamous cell carcinomas of the skin), and benign neoplasms of the brain and central nervous system (CNS) are reportable.

**Objectives:** To assess completeness and timeliness of the INCR for cases diagnosed or treated in 2005.

**Methods:** Abstractors identified cases of in situ and invasive malignancies and tumors of benign and uncertain behavior of the brain and CNS diagnosed or treated in 2005 in the files of medical records departments, pathology and cytology laboratories, and oncology and hematology institutes in 39 Israeli medical facilities. Cases were linked to the INCR database by national identity number. Duplicate cases, and those found to be non-reportable were excluded from analysis. Completeness was calculated as the percent of reportable cases identified by the survey that were present in the registry. Timeliness was calculated as the percent of reportable cases diagnosed in 2005, which were incorporated into the registry prior to 31 December 2007.

**Results:** The INCR's completeness is estimated at 93.7% for all reportable diseases, 96.8% for invasive solid tumors, and 88.0% for hematopoietic tumors. Incident cases for the calendar year 2005 were less likely to be present in the registry database than those diagnosed prior to 2005.

**Conclusions:** Completeness and timeliness of the INCR are high and meet international guidelines. Fully automated reporting will likely improve the quality and timeliness of INCR data.

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tumors, 84.6% for hematopoietic malignancies). Subsequent to these findings, the INCR undertook systemic actions to improve the completeness of registry data, including training of registrars working within the registry and in reporting facilities and amending the regulation specifying the disease categories and facilities for which reporting to the INCR is mandatory.

We conducted an independent case ascertainment survey of reportable disease diagnosed or treated in Israeli medical facilities during calendar year 2005 to evaluate the completeness and timeliness of the INCR.

## PATIENTS AND METHODS

### THE ISRAEL NATIONAL CANCER REGISTRY

The INCR is a population-based registry that was founded in 1960. Reporting of malignant diseases (excluding non-melanoma skin cancers) and benign neoplasms of the brain and central nervous system (CNS) has been required by law since 1982. The registry covers citizens and permanent residents of the State of Israel, a population of approximately 9 million in 2018 [5], but does not capture diagnoses for refugees, tourists, residents of the Palestinian Authority, or citizens abroad.

The INCR relies on reporting facilities to supply documentation for reportable cases, such as hospital discharge records, pathology and cytology reports, patient listings from oncology and hematology institutes, and death certificates. INCR tumor registrars record diagnosis date, source of information, topography and morphology according to the International Classification of Diseases for Oncology (ICD-O-3) [6], grade, size of tumor, treatment provided, and stage according to the Surveillance, Epidemiology and End Results (SEER) Summary Staging manual [7]. The process of receiving and screening documents and coding cases for a calendar year requires approximately 24 months.

Israeli citizens and permanent residents receive an identity number at birth or at immigration. This number facilitates the extraction of personal information from the National Population Register. The National Health Insurance Law of 1995 entitles every Israeli to a basic basket of healthcare services that is updated annually and includes oncology care and approved screening tests [8].

Cancer registry data are an essential element of public health activities related to cancer prevention and control [1]. Objective measures of the quality of cancer registry data include comparability, timeliness, validity/accuracy, and completeness [2,3]. A survey of completeness of the Israel National Cancer Registry (INCR) for 1991 [4] estimated completeness of the registry data at 92.9% for invasive malignancies (94.2% for solid

**Figure 1.** Case ascertainment and initial data processing, Israel National Cancer Registry completeness survey
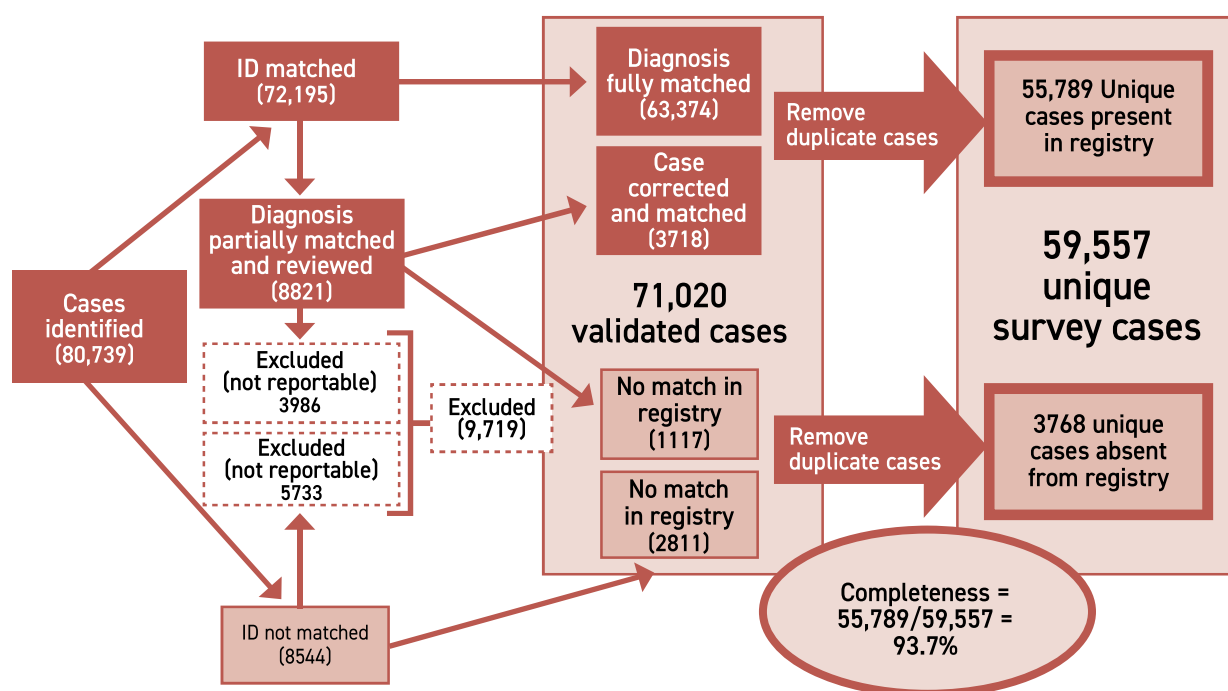


**INDEPENDENT CASE ASCERTAINMENT**

Prior to conducting the survey, the INCR contacted 39 Israeli medical institutions to explain the survey process and request access to the files of the pathology, hematology, oncology, and medical records departments. Data collection commenced at the end of 2008 and continued through 2012. Trained medical students conducted site visits during which they identified and abstracted information according to a standard format. The survey focused on in situ and invasive malignant disease and tumors of benign and uncertain behavior of the brain and CNS documented in discharge summaries of inpatient admissions for calendar year 2005, records of outpatient hematology and oncology visits during calendar year 2005, and pathology reports generated by hospital and community laboratories in March, August, and December of 2005. Case-finding was tailored to the record-keeping practices in each department, and involved both computerized and manual searches for cases meeting criteria for inclusion. Case-finding in hematology departments also involved review of the results of bone marrow examinations and flow cytometry. Tumor registrars assigned ICD-O-3 morphology and topography codes to each case. Information from multiple sources was reconciled to produce a single observation for each reportable case. In the event that more than one diagnosis was identified for a single person, the International Agency for Research on Cancer (IARC) multiple primary cancers rules [9] were used to determine whether these diagnoses represented a single case or distinct multiple cases.

**INITIAL DATA PROCESSING**

Survey cases were linked to the INCR database by national identity number, and diagnoses present in the two files were compared. Cases were classified as fully matched, partially matched, or unmatched. Fully matched cases were present in the registry database with ICD-O-3 topography and morphology codes consistent with those assigned by the survey. Partially matched cases were present in the registry database with ICD-O-3 topography or morphology that were inconsistent with those assigned by the survey. Partially matched cases were reviewed to resolve disagreements between the details of the diagnosis as recorded by the survey and in the registry database, and to determine whether these cases were present in the registry or represented new diagnoses for an existing patient. Unmatched cases were checked against the National Population Register for errors in the national identity number and were reviewed to verify that they represented reportable diagnoses. Cases first diagnosed in 2005 were classified as "incident", while those first diagnosed prior to 2005 were classified as "prevalent".

**COMPLETENESS AND TIMELINESS**

Completeness was calculated as the proportion of survey cases that were present in the registry. Timeliness was calculated as the proportion of 2005 incident cases for which the first clinical documentation was incorporated into the registry database prior to 1 January 2008.

## RESULTS

### COMPLETENESS

The survey identified 80,739 cases. Linkage to the registry database resulted in 63,374 full matches, 8821 partial matches, and 8544 non-matches. Review of partial and non-matches resulted in reclassification of the case as "non-reportable" in 9719, and a corrected diagnosis with a subsequent full match in 3718, resulting in 71,020 validated reportable cases identified by the survey. Removal of duplicates resulted in a final tally of 59,557 unique cases among 56,768 patients. Most (68.5%) cases were identified through one source only (e.g., pathology laboratory, medical records department, hematology institute, oncology institute) while 21.2% were found at two, and 10.1% in three.

For 55,789 cases, a corresponding case was found in the cancer registry database at the time of data processing (overall survey completeness = 93.7%) [Figure 1]. Of the remaining 3768 cases, 28.2% were matched to an individual present in the registry, but the diagnosis identified in the survey differed from that in the database. Survey cases supplied by only one source were less likely than cases identified at more than one source to be present in the registry database (92.1% completeness for cases derived from one source, 96.7% for cases from two sources, 97.6% for cases from three sources, and 98.0% for cases from four sources). Of cases identified through a single source, completeness was highest for those identified in oncology departments (96.9%) and lowest for those identified only in hematology department records (84.2%). While completeness for all cases identified in pathology laboratories was 86.%, cases identified in hospital laboratories were more likely to have been captured by the registry than those identified in community laboratories (90.6% vs. 77.0%, respectively).

Of the 59,557 reportable cases identified through the survey, 23,246 were diagnosed in 2005 (incident cases) and the remaining 36,311, prior to 2005 (prevalent cases). Completeness was 91.6% for incident cases and 95.0% for prevalent cases. For prevalent cases diagnosed between 2000 and 2004, percent completeness ranged from 96.5% of those diagnosed in 2000 to 94.7% of those diagnosed in 2004. Nearly 2% of all cases and 3.4% of incident cases matched to the registry database were registered with a diagnosis year that was later than that confirmed by the survey.

Nearly 95% of malignant tumors identified by the survey were present in the registry. Completeness was highest for invasive malignancies (95.2%) and lower for in situ tumors and borderline/benign tumors of the brain and CNS (84.1% and 60.5%, respectively). Invasive solid tumors were captured more frequently in the registry than hematopoietic and lymphoid neoplasms (96.8% vs. 88.0%, respectively). Among hematopoietic neoplasms, completeness was lowest for chronic myeloprolif-

erative disorders (51.5%) and highest for Hodgkin's lymphoma and non-Hodgkin's lymphoma (95.6% and 94.6%, respectively) [Table 1]. Within the category of invasive solid tumors, completeness was highest for tumors of the breast, colon, rectum, and stomach [Table 2].

### TIMELINESS

Of 23,246 incident cases identified by the survey, 21,286 matched a corresponding case in the registry. Of these, 20,876 were entered into the registry database as of 1 January 2008, and 410 (1.9%) at a later date. Taking into consideration the incident cases identified by the survey for which a later year of diagnosis was recorded in the database, timeliness was 86.7% for all incident cases and 89.1% for incident invasive cases.

## DISCUSSION

An independent case ascertainment survey of the INCR yielded a completeness estimate for cases diagnosed or treated in calendar year 2005 of 93.7% (94.8% for all malignancies, 96.8% for invasive solid tumors, and 88.0% for hematopoietic malignancies). Although this finding suggests an improvement in registry completeness since the previous survey in 1991, we were unable to perform a formal comparison of the results of the two surveys because of differences in survey methodology and coding practices.

Timeliness of the 2005 data was estimated at 86.7%. The delay in identifying and registering a subset of cases of reportable disease is reflected in our finding that percent completeness for 2005 incident cases was 3.4% lower than that of prevalent cases. While the database is continuously updated as new cases are reported, delays in registering cases affect the utility of the data for health care planning and research purposes.

We found that data completeness varied with diagnosis category. Because diagnosis and treatment of invasive solid malignancies frequently involves hospital admission, biopsies, and surgical procedures, it is expected that completeness for these diagnoses would be high in a registry whose principal sources of diagnosis information are pathology reports and discharge records. In contrast, capture is more difficult for those hematopoietic malignancies for which confirmation by pathology is not required or that are treated entirely on an outpatient basis. Consequently, completeness for Hodgkin's and non-Hodgkin's lymphomas was considerably higher than that for chronic myeloproliferative disorders and myelodysplastic syndromes. Cancer types diagnosed at a more advanced stage or in other situations when biopsy or resection may not be clinically warranted are also less likely to be captured. We also noted incomplete registration of new cancer diagnoses in patients already present in the registry, perhaps due to a failure of reporting institutions or registry personnel to identify these diagnoses as new cases, rather than recurrences of previous illnesses.

Assessment of completeness of cancer registry data is an essential component of registry operations. The Cancer Incidence in Five Continents (CI5) program of the IARC and the International Association of Cancer Registries collects and publishes cancer incidence data from 290 registries in 68 countries throughout the world. CI5 uses several methods to assess the completeness of data supplied by participating registries, including: analyzing historical data to verify that incidence rates are stable over time, comparing incidence rates between populations, verifying that age-specific incidence rates follow the expected pattern, tracking rates of childhood cancer incidence, calculating the proportions of microscopically verified and

death certificate only (DCO) cases, and calculating the ratio of cancer mortality to incidence [10]. Similar programs monitoring the completeness of cancer registries exist in North America and Europe [11-13].

Several reports of the results of registry-wide completeness assessments have been published [14-18]. Most relied on independent data sources, including hospital discharge registries [14,18], outpatient clinic and general practitioner databases [15], or a combination of sources [17]. One exception was the work of Larsen et al. [16], which classified cases present in the registry on the basis of the number of sources for each and used the capture-recapture method to estimate the true number of cases in the population for the period from 2001–2005. Regardless of specific methodology, estimates of the completeness of national population-based cancer registries ranged from 96–100%, but in all cases completeness for hematopoietic malignancies was lower than that for all malignancies combined [14-18]. Our overall completeness estimate (93.7%) was somewhat lower than others reported in the literature. However, our survey actively identified cases from a wide range of sources, rather than relying only on inpatient data and is therefore likely to have produced a more accurate completeness estimate than those derived from other studies. Our finding of underreporting of hematopoietic malignancies was consistent with other published studies.

**STRENGTHS OF THE STUDY**

This study had a number of strengths that contributed to the value of its findings. Israel is a small country and it was therefore feasible to actively survey every facility reporting to the registry. This comprehensiveness is in contrast to published completeness surveys of other national registries, which have generally relied on data from a limited number of external sources. The inclusion in the survey of outpatient pathology laboratories and hematology and oncology clinics increased the likelihood of identifying cases diagnosed and treated in the community, which may be missed in surveys focusing only on inpatient facilities. The availability of a unique population identifier allowed linkage of survey cases to the registry database.

**LIMITATIONS**

The survey and linkage were completed more than 2 years after the end of 2005, and consequently our completeness figure may overestimate the proportion of reportable cases present in the registry within 2 years. The level of automation of clinical data varied widely among institutions, and a range of coding systems were used. Therefore, case finding required the cooperation of the facilities being surveyed, using a strategy tailored to the data management systems of each.

Our results helped to identify several avenues for improvement. Our results suggested systematic underreporting from community laboratories and hematology departments. Undercounting of tumors of benign and uncertain behavior of the

**Table 1.** Percent completeness of the registry database by type of cancer

| Disease Type | All cases (%) | Incident cases only (%) |
|---|---|---|
| Carcinomas in situ | 84.1 | 78.1 |
| Uterine cervix | 69.3 | 56.7 |
| Invasive malignancies | 95.2 | 94.0 |
| Solid invasive malignancies | 96.8 | 95.8 |
| Hematologic malignancies | 88.0 | 83.4 |
| Non-Hodgkin's lymphoma | 94.6 | 91.1 |
| Hodgkin's lymphoma | 95.6 | 95.1 |
| Chronic myeloproliferative disorders and myelodysplastic syndrome | 51.1 | 51.5 |
| Benign and borderline tumors of the brain and central nervous system | 60.5 | 53.9 |
| Meningioma | 65.0 | 59.0 |

**Table 2.** Percent completeness of the registry database by location of invasive solid tumor, for all cases identified in the survey

| Location of Solid Invasive Tumor | Number of cases identified in the survey | Number of cases present in the registry | Percent completeness |
|---|---|---|---|
| Female breast | 9738 | 9583 | 98.4 |
| Colon | 5502 | 5401 | 98.2 |
| Prostate | 5057 | 4725 | 93.4 |
| Urinary bladder | 3502 | 3444 | 98.3 |
| Rectum | 2444 | 2420 | 99.0 |
| Melanoma of the skin | 1742 | 1646 | 94.5 |
| Thyroid | 1433 | 1379 | 96.2 |
| Stomach | 1311 | 1294 | 98.7 |
| Corpus uteri | 1214 | 1180 | 97.2 |
| Cervix uteri | 556 | 540 | 97.1 |
| Other invasive solid tumors | 12635 | 12179 | 96.4 |

brain and CNS indicated a need to educate reporting institutions on the categories of disease requiring reporting to the registry.

The INCR has implemented several interventions aimed at improving registry data, including the following:

- Finalizing the amendment to the law governing reporting to the cancer registry enlarging the scope of mandated reporters to include health funds, community pathology laboratories, and outpatient hematology clinics
- Encouraging reporting facilities to submit reports via a secure server to improve data security and reduce the burden of reporting
- Training for registry staff and reporting facility personnel, including courses in medical coding and tumor registration and workshops on selected topics
- Incorporating measures of completeness of reporting from pathology and hematology departments into the Ministry of Health's periodic hospital inspection program
- Comparing, historically, overall and disease-specific incidence, distribution of cases by facility and calculation of percent DCO and histologically verified cases
- Encouraging reporting facilities to participate in collaborative research and case-finding activities

## Conclusions

Our survey documented a high level of completeness in the INCR, and identified areas needing improvement. In addition to the steps already taken, we regard increased automation of the reporting process and the use of artificial intelligence tools for the initial processing of reports as crucial steps that will allow us to cope with an increasing workload. Continued monitoring of completeness, using a combination of targeted audits, semi-quantitative tools, and comprehensive case ascertainment surveys, is necessary to ensure that the INCR continues to be a high-quality source of cancer incidence data.

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It is not length of life, but depth of life.
Ralph Waldo Emerson (1803-1882),
American essayist, lecturer and poet, and champion of individualism

A man may die, nations may rise and fall, but an idea lives on.
John Fitzgerald Kennedy, (1917–1963),
35th American President, served from 1961 until his assassination in 1963