

Standard-documentation Meta information

(Definitions, comments, methods, quality)

on

Cancer Statistics / Austrian Cancer Registry

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Executive Summary

Population-based cancer registries are important data sources for health policy, health reporting and scientific research. Cancer registries provide information about incidence, survival and prevalence of cancer. As the registry's quality is mainly determined by its completeness of case ascertainment, a major aim is to collect all cancer incidences. Therefore the notification of newly diagnosed cancer cases to the Austrian National Cancer Registry is mandatory by law for all Austrian hospitals.

For reasons of quality assurance and control of completeness each hospital has to report the first contact with a cancer patient. In addition, all deaths of cancer patients have to be submitted as well. From this follows that in most cases more than one registration form is submitted per patient. This approach usually leads to several notifications per patient. When entering a cancer notification form into the cancer registry, the patient must be identified in the registry. As clearly defined personal identifiers, as e.g. the social insurance number, are not available for all registry entries the registrar has to decide on the basis of name, date of birth, gender and place of residence whether the person in question is already included in the registry or if the person must be entered as a new case. If, in this search, the patient is found in the inventory, the current report is assigned to this person. In accordance with international guidelines on multiple primaries it is checked whether the present report is another notification of an already existing tumour or if the report describes a new tumour. If these rules lead to multiple tumours the data entered are checked once more and, if necessary, investigated in detail by the registrar. After having entered all data of the notification form a plausibility check is performed and the data of all available individual reports per person are combined to enable an evaluation on the tumour level.

Four of the nine Austrian federal provinces (Carinthia, Salzburg, Tyrol and Vorarlberg), hold regional cancer registries carrying out data collection in close cooperation with the hospitals and, above all, with their pathologies. As providers of services to medical institutions the regional registries administer the data of cancer patients and arrange for the transmission of cancer reports to Statistics Austria. Quality control is performed in co-operation with Statistics Austria, while research is made from the respective registry.

Completeness and timeliness are two important criteria for the assessment of statistical quality often reciprocally related. As the change in the number of cancer incidences is a long-term process completeness is usually preferred if necessary. Quite often, up to five years are between the year under review and the year of publication when internationally compared. With regard to completeness it should be considered that **the obligation to report is restricted to hospitals**. Ambulances outside hospitals and primary care are not obliged to report. For most tumours, this will not be a significant problem as, usually, transfers to hospitals take place almost immediately; with some kinds of tumours, however, under-coverage does incur. This is why, in correspondence with international recommendations, data on selected diseases are not published. Of the malignant neoplasms of the skin, which very often are diagnosed in the primary care sector, only the malignant melanoma is published. As patients with a malignant melanoma are in most cases transferred to a hospital for further treatment, adequate completeness may be presumed for this disease. In tables dealing with the overall cancer incidence, this is clarified by the note "without other malignant neoplasms of the skin (C44)". In general, all kinds of tumour which may be diagnosed and treated outside hospital represent a critical factor with regard to the completeness of the registry.

Persons resident in Austria who are treated abroad exclusively cannot be captured as the legal obligation to notify cancer cases to the Austrian National Cancer Registry applies to health institutions in Austria only. However, this group of persons is supposed to be rather small, and its quantitative importance should not be overestimated. To assess completeness of the registry, the DCO rate – among others – is calculated. The percentage of DCO cases (Death Certificate Only) of all cancer incidences gives a – although very limited – notion of completeness. If the share of persons having died of cancer and not included in the registry before is above 10% of the overall cancer incidence a significant under-coverage must be

assumed. At present, this is still the case in some of the Austrian federal provinces, which is why regional comparisons must be interpreted very cautiously.

Cancer Statistics (Cancer Registry) – Main Features	
Subject Matter	Newly diagnosed cancer diseases; Personal details as well as type, localization and lethality of cancer disease, this means of all carcinoma, all sarcoma, all malignant diseases of the haematopoietic system and reticuloendothelial system
Population	All cancer diseases among Austrian residents (around 36,000 to 38,000 per year)
Type of statistics	Registry; Borderline case between primary and secondary statistics
Data sources/Survey techniques	Registration forms for all cancer reporting institutions. Causes of Death statistics.
Reference period or due day	Year of diagnosis
Periodicity	Yearly
Survey participation (in case of a survey)	Obligatory
Main legal acts	Krebsstatistikgesetz BGBl. Nr. 138/1969 ; Krebsstatistikverordnung BGBl. Nr. 171/1978 .
Most detailed regional breakdown	Municipality. Publication only on federal level for reasons of data protection.
Availability of results	Publication: t + 2 years
Other	According to the reporting obligation, only cancer cases in out- or inpatient wards of a hospital can be recorded. The publication, which takes the living systems of the database into account, is started after processing all cancer registration sheets, research on obvious deficiencies of recent years and matching with causes of death. (Smaller) revisions of publicized figures can effect earlier reporting periods.