

Cancer Registration

The National Cancer Registry Ireland (NCRI) was established in 1991 and has produced national figures on cancer incidence since 1994.ⁱ Most registrations are based on 'active' data collection whereby trained Tumour Registration Officers (TROs), based in hospitals around the country, access a range of data sources to identify all new cancer cases and register all relevant patient, tumour and treatment details. Hospital pathology reports provided to the Registry shortly after diagnosis comprise the bulk of the information providing data on approximately 85% of all new cases. Most pathology reports are registered manually by the TROs but data is also provided to the Registry in electronic format from eight pathology laboratories (currently approaching 36% of all pathology reports).

Information on non-microscopically diagnosed cases is registered mainly from other hospital sources, principally the Hospital Inpatient Enquiry systems (HIPE) as well as records from radiology and oncology departments, medical charts, hospital cancer databases etc. Most cases ($\geq 95\%$) are initially registered in this way.

Hospital systems and/or medical notes are accessed to provide information on clinical staging, chemotherapy, occupation, marital status and smoking status, general practitioner and GP referral date.

The main non-hospital source of case information is death certificate data. The Registry is provided with all death certificates from the Central Statistics Office (CSO). All cases initially notified by death certificate are followed up with the hospital of death or the certifying doctor and most cases are subsequently found in other data sources. These are registered as active cases. Only a small percentage of cases ($<3\%$) remain classified as notified by death certificate only (DCO), in keeping with international standards.

Follow up of patients is passive, where cancer cases are linked to death certificate information provided regularly by the Central Statistics Office and the General Registers Office. The current censor date (the date to which all patients are followed up) is 31st December 2013.

Although case data from pathology reports is registered almost immediately after diagnosis, data from other sources can take longer to obtain. This, together with essential case checking and data quality assurance, means that the Registry normally produces definitive statistics for case data a minimum of 2 to 3 years following the end of year of diagnosis.ⁱⁱ Currently the completeness of cancer registration for all invasive cancers diagnosed to end 2009 is estimated to be 97%. For certain sites the Registry can provide reliable figures within six months of year of incidence. 99% of breast, 95% of colorectal and 94% of prostate cancers are usually microscopically verified and are therefore registered within a couple of months. However up to 20% of lung and 38% of pancreatic cancers are diagnosed clinically and it may take longer to register these cancers.

Incident cases are coded according to the third edition of the International Classification of Diseases for Oncology (ICD-O3). Before analysis, data is audited using international audit protocols from the International Association for Research on Cancer. Case data are recoded to the equivalent International Classification of Diseases version 10 (ICD10) and results are presented according to the single or grouped ICD10 codes relevant to each cancer.

The address of each cancer patient at the time of diagnosis is recorded by the Registry and subsequently assigned to an electoral district (ED). This data can be used by the Registry to study geographical patterns and suspected cancer clusters.

While the number of cases for certain sites may be available at an early stage, complete information on treatments and staging are obtained from the medical records of the patients. This type of information will normally only be made available 2 to 3 years after the year of incidence, in keeping with international standards.

The Registry is also examining other electronic data sources within hospitals, such as cancer databases and radiotherapy databases with a view to using these to update registrations.

ⁱFor relevant legislation see

S.I. No. 19/1991 The National Cancer Registry (Establishment) Order, 1991

S.I. No. 293/1996: The National Cancer Registry (Establishment) Order, 1991 (Amendment) Order 1996
Health (Provision of Information) Act, 1997

ⁱⁱ See <http://www.ncri.ie> for publications and data downloads.