The National Cancer Registry Ireland (NCRI) was established in 1991 and has produced national figures on cancer incidence since 1994 (1). Most tumour registrations are based on ‘active’ data collection, whereby, trained Electronic Cancer Data Registrars (eCDRs), generally based in hospitals around the country, access a range of data sources to follow up all new cancers and register all relevant patient, tumour and treatment details on the NCRI Cancer Registration System (CRS).

Hospital histopathology reports provided to the NCRI shortly after diagnosis comprise the bulk of the information, providing data on approximately 88% of all new cases. Most histopathology reports are provided to NCRI in electronic format from 23 histopathology laboratories (currently approaching 90% of all histopathology reports). These reports together with some remaining hardcopy histopathology received are manually validated by the eCDRs and additional field entry performed.

Information on non-microscopically (clinically) diagnosed tumours is registered mainly from other hospital sources, principally the Hospital Inpatient Enquiry systems (HIPE) as well as records from radiotherapy and oncology departments, medical charts, hospital cancer databases etc. Most cases (≥ 95%) are initially registered in this way. Hospital systems and/or medical notes are accessed to provide information on e.g. clinical and pathological staging, (neo) adjuvant therapy & status. The main non-hospital source of case information is death certificate data. The NCRI is provided with all death certificates from the Central Statistics Office (CSO). All tumours initially notified by death certificate (DCI) are followed up with the hospital of death and most tumours are subsequently found in other data sources. These are registered as active tumours. Only a small percentage of tumours (<1%) 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.

Although tumour data from histopathology reports is registered almost immediately after diagnosis, data from other sources can take longer to obtain. This, together with essential tumour validation and data quality assurance, means that the NCRI normally produces definitive statistics for case data a minimum of 2 to 3 years following the end of year of diagnosis. Between 90 to 95% of breast, colorectal and prostate cancers are microscopically verified and are therefore registered within three months. However up to 20% of lung and 35% of pancreatic cancers are diagnosed clinically and it may take longer to register these cancers.

Incident tumours 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 (IARC). Tumour 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 NCRI and subsequently assigned to an electoral district (ED). This data can be used by NCRI 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.

NCRI has progressed access to other electronic data sources within hospitals with a view to using these to update tumour registrations. All data electronically or manually inputted is manually verified by the eCDRs.

For relevant legislation see:

(1) 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 <https://www.ncri.ie/> for publications and data downloads