



COUNTING ON CANCER REGISTRY

Many cancers are avoidable and treatable. The broad purpose of cancer registration is to help assess the impact of malignant diseases on the community and the measures taken to control them. Cancer registration also provides a reservoir of data which can be used for case series or analytic epidemiological studies.

As cancer is the second most frequent cause of death (after cardiovascular diseases) in Australia, there is a major need for relevant data to assess impact and to plan strategies for prevention and treatment services. Information on cancer morbidity and mortality is of increasing importance because, as cardiovascular disease becomes less common and life expectancy increases, the number of cases of cancer increases.

In NSW, notification of cancer has been a statutory obligation under the Public Health Act for all hospitals and radiotherapy units since 1971, and for pathologists since 1985. Notification of all cancer deaths is provided by the NSW Registrar of Births, Deaths and Marriages. Analysis of survival with cancer requires, in addition, regular information on *all* deaths in NSW.

The NSW Central Cancer Registry was established in 1971 as a population-based registry, and began data collection in January 1972. In 1986, management of the Registry was transferred from the NSW Department of Health to the NSW Cancer Council.

Although hospital morbidity statistics and death certificates can provide some useful information on cancer epidemiology, the only effective method of obtaining cancer incidence data is considered to be universal registration of cancer cases. In particular, data are needed on different types of cancer, patient characteristics, survival and mortality.

The importance of cancer registration is indicated by the fact that many countries and States now have cancer registries. Every Australian State and Territory is covered by cancer registration and most have legislation making notification compulsory.

State-wide cancer registration using a total enumeration as a method of investigation has advantages and limitations. The advantage is that the total picture in the State can be appreciated, reliable data on rare cancers and small areas can be obtained, and a large number of cases can be accumulated for use in case series or analytic individual-based epidemiological studies of causation or control.

The limitations of total enumeration methods are that it is difficult to control data quality, and many important variables — such as tobacco smoking and occupational history — cannot be collected at all. Cancer registration should therefore focus on what can

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Counting on Cancer Registry

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be achieved by this method, and discard data items which have low completion rates and/or are thought to be inaccurate.

It is doubtful whether detailed data on staging and treatment methods can be collected reliably at central level. Hospital-based cancer registries or follow-up studies on a sample of Cancer Registry data can be used to collect additional information.

Cancer registration has a primarily statistical purpose which is aimed at prevention, or future control and treatment methods, and does not benefit the individuals with cancer who are registered. Thus cancer registration differs from registration of births/deaths/marriages because there is no legal necessity and benefit for affected individuals and their families which is attached to registration of cancer.

Cancer registration also differs from registration of diseases such as tuberculosis, because such registers are actively used for individual case follow-up and contact tracing. In these circumstances cancer registration should impose the least burden possible on those who are required to supply information since there is no direct benefit for patients, their families or health care providers.

Hospital-based or area-based cancer registries in NSW are evolving and could become a useful source of information on survival for various cancers for different treatment protocols, since accurate data in this amount of detail can only be collected locally.

The organisation and funding requirements of a cancer registry are related to:

- (a) the number of cancers occurring in the community it serves — which is a function of the age-specific incidence and age structure of the population;
- (b) the intensity of treatment and number of reporting sources — which have a multiplier effect on (a); and
- (c) the size of the data base — which is related to the number of cancers registered per year and the length of the collection.

The difficulties with cancer registration seem to increase geometrically (rather than linearly) with increasing size, unless accompanied by a high level of automation and compromises concerning data items and accuracy.

OBJECTIVES OF THE NSW CENTRAL CANCER REGISTRY

1. Overall objectives

To contribute to the prevention, control and treatment of cancer in the population of NSW, in particular, and human populations, in general, by the supply of timely and accurate data based on a total enumeration of cases of cancer in NSW — which meets statutory requirements and the needs of users.

2. Specific objectives

2.1 Objectives related to characteristics of the data collection

Priority 1: A complete enumeration of all incident malignant neoplasms in NSW, except BCC and SCC

of the skin (but including SCC of the lip, vulva, penis and anus), and except carcinoma-in-situ.

Priority 2: Timeliness of the data.

Priority 3: Accuracy in the variables collected.

Priority 4: Dead or alive status current for each individual registered (for survival analysis).

Priority 5: Completeness of variables which are to be collected on each case.

Priority 6: Compatibility of the data with other State registries in Australia and internationally.

2.2 Objectives related to acquisition of data

2.2.1 Reporting and data items will be kept to a minimum. In some instances, only the first contact, death and new primary cancers will be reported from hospitals and radiotherapy departments.

2.2.2 Data acquisition will become as automated as possible. Thus data supplied by institutions should be in electronic form.

2.2.3 Data should be obtained on all incident cancers in NSW using hospital inpatient records, pathology reports, radiotherapy department records and cancer deaths from the Registrar General. Outpatient records will also be used when possible.

2.2.4 Data on non-cancer deaths will be obtained weekly from the Registrar General to calculate survival.

2.2.5 Improvement in quality of peripheral coding of cancer data will be encouraged so internal coding or recoding can be minimised.

2.3 Objectives related to data processing

(a) add to the database new cancer cases from various sources

(b) minimise double registration

(c) add relevant data items, edit existing data to improve accuracy, and document alive/dead status in cases already registered.

2.3.1 Computer programs will be developed which will match data tapes from data suppliers with the Cancer Registry data base, and then automatically add to or edit existing data, add new cases if no match occurs, and reject the information for semi-automated processing by operators if near matches are detected.

2.3.2 Data entry from written or electronic sources will occur at the time of data receipt or shortly afterwards.

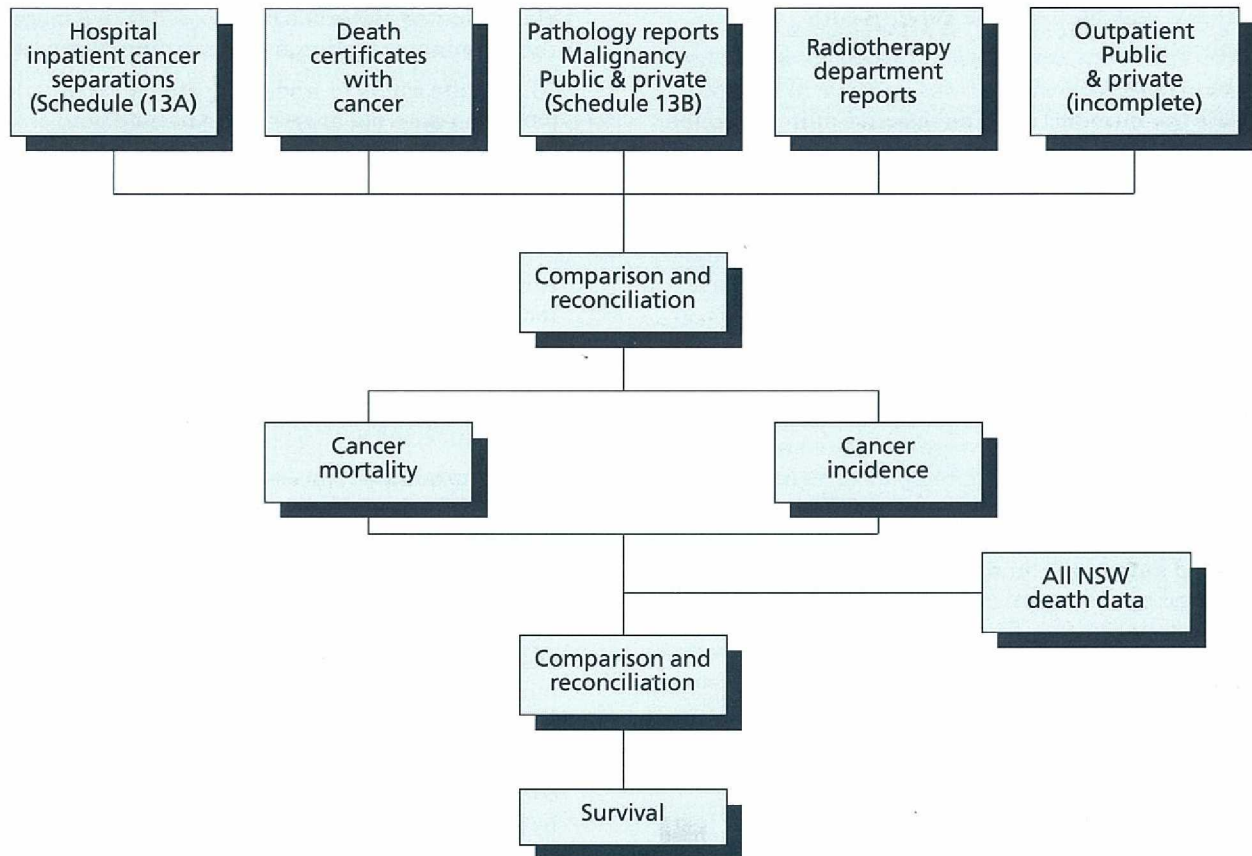
2.3.3 Coding for topography and morphology will be automated.

2.3.4 Geographic coding will include suburb, postcode, legal LGA, statistical subdivision, statistical division, health service area/region and urban/rural for the year of incidence and year of death.

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FIGURE 1

DATA SOURCES —
NSW CENTRAL
CANCER REGISTRY



2.4 Objectives related to data output

These objectives overlap with those of the Cancer Epidemiology Research Unit. Certain functions will be exchanged between the Epidemiology Unit and Registry on a cost recovery basis.

2.4.1 Descriptive epidemiology

Analyse and publish descriptive data concerning cancer incidence and mortality in NSW:

- magnitude of the health problem due to various cancers. This is measured by incidence and mortality rates.
- distribution of various cancers by age, sex and country of birth.
- survival for various cancers by age group, sex and other factors.
- small area differentials in incidence and mortality for various cancers. Small areas include urban/rural, health areas/regions, local government areas, postcodes or appropriate aggregations.
- temporal trends in incidence and mortality from various cancers, and temporal trends in survival.
- patterns of referral for diagnosis and treatment of various cancers (and temporal trends), and patterns of treatment for various cancers (and temporal trends). These aims will require additional ad hoc surveys based on registered cases.

2.4.2 Collaboration with the Cancer Epidemiology Research Unit and other Institutions. This consists of provision of data for:

- more detailed descriptive epidemiological studies related to cancer using subsamples of the Registry data base.
- descriptive-analytic studies of cancer incidence and mortality in relationship to other variables (ecological studies and before-and-after studies).
- analytic epidemiological studies using case control and cohort methodologies.
- case series studies by clinicians, radiotherapists, pathologists or other medical scientists.

2.4.3 Reports and publications

The NSW Central Cancer Registry will publish an annual report of cancer incidence in NSW and reports related to cancer epidemiology derived from routinely collected data sources.

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