

Appendix 1. About The Western Australian Cancer Registry

Appendix 1A. Overview and technical issues

History and role

The Western Australian Cancer Registry is a population-based cancer registry established in 1981. The Health (Notification of Cancer) Regulations 1981 require the reporting of cancers diagnosed by pathologists, haematologists and radiation oncologists; the current version can be found in **Appendix 2E**. The Registry was established in recognition of the potential importance of reliable population-based cancer data in the planning of services and in the prevention and treatment of cancer.

Surveillance of cancer extends beyond State and national boundaries and this Registry cooperates with other State registries and the National Cancer Statistics Clearing House (NCSCCH) (a central cancer data collection for the whole of Australia based at the Australian Institute of Health and Welfare in Canberra). Data are also provided to the International Agency for Research on Cancer in Lyon, France, for inclusion in Australian statistics published nationally and world-wide.

The Registry is a member of the Australasian Association of Cancer Registries (AACR) which includes all Territory and State cancer registries, and the International Association of Cancer Registries (IACR). The AACR meets regularly to discuss matters such as common coding systems, comparability of data between areas in Australia and involvement in Australia-wide cancer research projects.

Registry scope

The Western Australian Cancer Registry reports on cancers and other neoplasms diagnosed in persons while resident in Western Australia. A separate register is maintained for recording asbestos exposure and other history for all cases of mesothelioma. In practice, the Registry records available information about cancers diagnosed elsewhere, in Western Australians, as this is often vital to the interpretation of new reports or mortality information.

As in other Australian cancer registries, information concerning tumours diagnosed in Western Australia in persons ordinarily resident elsewhere in Australia, is sent to the relevant State or Territory cancer registry, and is not included in Western Australian incidence statistics.

Cancer deaths in current or former Western Australian residents are recorded when possible, regardless of place of death or address at diagnosis, to facilitate survival analysis. However, in routine tables of mortality, geographic location is based on place of residence at time of death rather than on the place of death. Accordingly, the Registry's mortality statistics routinely include only deaths, in Western Australia, of persons resident in Western Australia at the time. In contrast to incidence, mortality reports include deaths due to all non-melanoma skin cancers.

Legislative basis

The Registry acts with the delegated authority of the Executive Director of Public Health with respect to the Health (Notification of Cancer) Regulations 1981. These, as amended in February 1996, require the notification of *in situ* neoplasms and all non-melanoma skin cancers other than basal cell and squamous cell carcinomas, as well as all invasive malignancies and benign CNS tumours (see **Appendix 2E**).

Sources of data

Most notifications are received from pathology laboratories, which supply pathology reports on paper or computer data files. The electronic notification system relies on the tumour codes or "notify Registry" flags generated by pathologists to select the reports which reach the Registry, and it is believed that this has enhanced the completeness of reporting from the larger hospital laboratories. Radiation oncologists also notify patients treated for cancer.

In-house linkage routines are used to link pathology and mortality data files to the Registry to permit creation of new records, or the updating of date, place and cause of death information. Additional cancer registrations are obtained from the remaining (unmatched) mortality records after electronically scanning the written cause of death and other fields on a data file. Data are now obtained from the W.A. Registrar-General's Office via the Data Linkage Unit in the Health Information Centre. Records are created on the Cancer Registry for persons with these previously-unrecorded tumours, and efforts are then made to obtain independent verification of tumour details. Those for which no supporting information can be obtained after research are treated in subsequent reports as "death certificate only" (DCO) tumours.

Additional information including country of birth and Aboriginality or indigenous status, can often be obtained, from extracts of the W.A. Hospital Morbidity Data System (HMDS) files, or via on-line access to a Patient Master Index maintained in Perth Metropolitan Area government hospitals.

Data handling and maintenance

The Registry still maintains paper records for individual cases, although as pathology reports are increasingly being received in electronic form, on-screen-only coding is still being considered. A computer software re-engineering process is currently in progress.

New registrations and updates are made on a locally-designed computerized multi-user database installed on an IBM-compatible microcomputer network. In general, cancer cases are recorded with one demographic record for each person with a separate, linked, record for each tumour. Records which are incomplete or which are found to be inaccurate in the light of new information are progressively updated, and the data are thus subject to continual enhancement until the time of any final update such as that following confirmation of death information. Registry records that are duplicates of existing cases are now handled by cross-referencing to the "valid" case, rather than deletion, minimizing the repetition of "detective" work if more information later comes to hand.

Statistics are produced from database extracts using the Registry's own incidence and mortality rates calculation system and a variety of other statistical and graphics software packages. Software for routine statistical reports is constantly being developed and upgraded to reflect changes in coding systems, geographical area boundaries and the types of information requests received. The vast majority of tables in this report are created directly from this in-house software.

Where resources permit, customized tabulations using similar area and age group subdivisions are available to anyone who makes a request.

Coding practices

General

The coding of tumour data is based on the International Classification of Diseases for Oncology (ICD-O) which originated as an extension of Chapter II (Neoplasms) of the Ninth Revision of the International Classification of Diseases (ICD-9); which is superseded by ICD-10.

ICD-O permits separate coding of topography ("site"), morphology ("tissue") and behaviour, and thus allows a more comprehensive characterization of some tumours than the single-code ICD-9 and ICD-10 classification system. Topography and morphology codes in this report are from ICD-O third edition (2000) (ICDO-3),^a following the successful conversion of software, and translation of historical data in 2003.

In general, for incidence reporting, leukaemias, lymphomas and other lymphohaematopoietic malignancies are grouped on the basis of morphology codes, as for cutaneous melanoma, Kaposi sarcoma and mesothelioma, while others are tabulated on the basis of topography, or location. This Registry does use Behaviour code "6" to indicate tumours of unknown primary site.

For the sake of consistency in reporting of incidence and mortality data, causes of death are coded to morphology (lymphohaematopoietic malignancies, Kaposi sarcoma and mesothelioma) and topography (others). Melanoma deaths are coded to the ICD-10 code, C43x, to distinguish them from deaths due to non-melanoma skin cancers (C44x). In accordance with IACR guidelines adopted by AACR, melanomas of unknown primary site are treated as primary skin melanoma for tabulation purposes.

Diagnoses in non-Western Australian residents are excluded from incidence reporting routines but are recorded for reference. A system of 'aliasing' duplicate or otherwise invalid records allows ongoing reconciliation of old and current data, necessary for follow-up studies.

Cancer Registry mortality reporting has been based on death certificate coding performed within the Registry since 1990. Reconciliation with coding by the Australian Bureau of Statistics was once a useful monthly process but ABS has failed to support this since 2005. This exchange was extremely important, as annual ABS-coded mortality files are normally not released until well into the year following death, which is, in some cases, a delay of almost 2 years.

Multiple tumours

Two or more discrete tumours of different (3-character) sites in any individual are counted separately for the purposes of incidence statistics. However, in accordance with international practice, similar tumours arising in sites coded with the same first three characters are counted as one.

This, in effect, means that a person who has two similar tumours diagnosed, even many years apart, is reported only once in incidence statistics. This applies even when tumours arise in paired organs, e.g. lung or breast and are regarded as truly separate, unless the tumour types are different enough to permit both to be counted. Groups of types considered to be different, for the purposes of allowing the counting of more than one tumour of the same "site", are based on those in Jensen *et al* (1991).^b

WACR now uses the ICDO-3-based table as promulgated by the International Association of Cancer Registries. xxWebsite address. Using these rules, for example, a squamous cell carcinoma of the lung and an adenocarcinoma of the lung arising at any time will both be counted in incidence statistics. Lymphohaematopoietic malignancies are treated differently,

^a World Health Organization (2000) *ICD-O: International classification of diseases for oncology* (Third Edition). WHO, Geneva.

^b Jensen OM, Parkin DM, MacLennan R *et al* (1991) *Cancer Registration: Principles and methods*. IARC Scientific Publications No. 95, Lyon, France.

being tabulated by morphology, and their discovery in a particular site does not preclude the counting of different types of neoplasms in the same site. The urinary tract is treated as a special case of an "extended site", whereby multiple transitional cell carcinomas of sites C65x to C68x, *including* bladder (C67x), are counted only once in a person.

While these practices govern the reporting of cancers for incidence statistics in accordance with international practice, it is an inescapable conclusion that multiple tumours have separate effects on health, and the best illustration of this is in relation to survival. Cases occur in which a person has a breast carcinoma, and is treated and considered cured, only to die from a second primary breast carcinoma arising many years later. Measuring survival time from the first tumour diagnosis (the "incident" tumour) and ignoring the presence of the second, can lead to a simplistic analysis which falsely underestimates cure rates. To allow better analysis, the Registry now separately records all tumours, and statistics counting tumours, rather than cases, can be provided if required.

This Report uses the "multiple-primary" rules based on the ICDO-3 classification and tumour groupings will differ slightly from those used some previous publications (see Appendix 2F).

"Death certificate only" cancers

Death certificate only (DCO) cancers are those for which no information other than a death certificate is available. From mortality data, records of previously-unknown tumours are created on the Cancer Registry, and efforts are made to obtain independent verification of details. Those for which no supporting information can be obtained after research are treated in subsequent reports as "death certificate only" (DCO) tumours. Up to 60 tumours are followed up in this way each month, and supporting information is eventually obtained for the vast majority. Very few tumour records remain in this category. Tumours of unknown primary site have been consistently more common among DCO cases than among cancers in general.

To achieve such a low proportion of DCO cases, reporting of statistics must be delayed, until most follow-up is complete. Rapid access to death notifications assists the Registry to commence enquiries while information is still accessible. Due to workload issues, DCO cases are now been treated as "resolved" if a compatible hospital discharge record is found, and a special Basis of Diagnosis code of "H" is used.

Lymphomas

ICD-O codes are used for coding lymphomas, however several "in-house" morphology codes are used when the best ICD-O code is too general; these are shown in the footnote to the table in Appendix 2F(b). These codes are converted, when contributing data to others, to the relevant less-specific ICD-O code.

Basis of Diagnosis

Most notifications result from diagnoses made on the basis of tissue examination (histology, cytology, haematology), and these are generally regarded as the most reliable. Their percentage of the total cases is shown in the "TissDx" column of some tables in this report.

^a Breslow A (1970) Thickness, cross-sectional area and depth of invasion in the prognosis of cutaneous melanoma. *Ann Surg* 172, 902-908

^b Clark WH *et al* (1975) The developmental biology of primary cutaneous malignant melanoma. *Seminars in Oncology* 2, 83.

Additional data for specific tumour types

A number of additional data items are collected for some tumours. For primary invasive breast cancer, the Registry records maximum tumour diameter, number of axillary lymph nodes biopsied and the number affected by cancer, whether a tumour is multi-centric, and whether there is associated ductal carcinoma in situ (DCIS) outside the margins of the invasive tumour. For primary skin melanoma, the maximum thickness of the tumour and Clark's level are recorded (Breslow 1970^a Clark *et al* 1975^b), and are used in many of this Registry's reports.

Quality assurance

Data quality is assessed in various ways, both continuous and occasional. On a continuous basis, all coding on pathology reports, and the details entered on the database, are checked by a second member of the Registry staff, and queries are referred to a Registry medical officer. In addition, the Registry database system incorporates various "unusual case" warnings, based on dates, sex, and age. A case-flagging system, based on site and tissue combinations and the rules encapsulated in a modified version of IARC's "Check" routine,⁵ warns of unusual records. A verification code is assigned to records which do not fit the "rules" but which are believed to be correctly coded.

Available external indicators of Registry completeness are all potentially biased in favour of cancers which are more often serious, causing hospitalization or death. Reports from radiation oncologists serve as a useful avenue for checking receipt of reports based on previous pathology specimens, and enables recording of a small number of cancers which were not diagnosed histologically. The Hospital Morbidity System, which records details of all hospitalizations in Western Australia, is another potential source of information regarding Registry completeness.

If trends in incidence, mortality and migration are constant, then the ratio of the number of new cancer diagnoses registered to the number of cancer deaths (mortality to incidence ratio) serves as a crude indicator of completeness.

Uses of Cancer Registry data

Non-identifying data are available for release to interested parties, subject to time constraints, as data files or as finished tables and figures. Only data which do not identify any patient, care provider or institution can be treated in this manner. Release of named information is strictly controlled (see "Confidentiality guidelines") and data can only be released to persons other than the original providers (or other clinicians involved in ongoing care of the individual) with personal consent, or a formal approval from the Confidentiality of Health Information Committee (CHIC) which is responsible to the Minister for Health.

Data are used in a wide variety of research projects, including the recruitment of subjects for descriptive and case-control studies. Specific requests have included data on incidence in specific areas, cancer deaths by location and institution type, melanoma levels and depths, mesothelioma deaths and occupation, teenage cancers, myeloma survival and ocular melanoma. Registry data have been used in a number of studies of cancer incidence, and in a number of national projects, most notably those commissioned by the National Breast Cancer Centre.

In addition to technical and statistical enquiries, the Registry receives general and personal enquiries regarding cancer services and medical problems; these are referred when appropriate to other agencies and treating physicians.

The Registry provides support for four hospital-based cancer registries (HBCRs). In the hospital setting, with clinical and pathological staging and treatment data, the availability of mortality data facilitates the assessment of outcomes using survival analysis.

Appendix 1B. Current issues

Registry staffing and workload

In 2003, a long process seeking reclassification of "Clerical officers" to a higher level, redesignated "Data quality officers", came to a successful conclusion. The resources now available to service the needs of a population of 1.9 million people now include -

Principal Medical Officer/Manager	1.0 fte
Medical Officer/coding adviser	0.2 fte
Data Quality Officers	3.5 fte
Mesothelioma research officer	0.25 fte
Analyst/programmer	1.0 fte

Additional resources used include financial/ Human Resources services, Epidemiology Branch advice on some statistical issues, and production/graphic design services from the Marketing Branch. However all reports such as this are produced primarily within the Registry itself.

Workload is not adequately represented by reported "cancer" totals. In 2005, there were 9151 invasive cancer cases as mentioned earlier in this report. However, in the same year there were 16275 pathology records added to the registry databases, and 20532 records were edited in some way by staff.

Increases in these workload estimates exceed population growth rates, and underscore the need to properly resource disease registries and ensure a continued capacity to deal with the demands of health service planners, researchers, students and the public.

Assessment of current notification system and Regulations

Western Australia is the only Australian State in which there is no legal requirement for the direct notification of cancer diagnoses by hospitals; there is consequently some incompleteness in WA statistics for some cancer types. As a result of two successful "Graduate Officer" placement requests made under a new Department of Health program in 2004, a review and update of a previous assessment of the opportunities for more complete notification based on hospital data for non pathologically-diagnosed cancers, has recently been completed. This Report contains related material in Section 3.2.

These findings are being made available in support of a process of seeking changes to the Health (Notification of Cancer) Regulations 1981 so as to require hospital notification, among other things. Current data systems cannot be used satisfactorily for this purpose as there are 3 key data items - basis of diagnosis, date of diagnosis and place of residence at diagnosis - that are not included. The Registry has participated in consultations concerning a replacement of the (public) hospital Patient Administration System (PAS), and these data items are to be considered when choosing potential replacement systems. It is also likely that changes to the existing PAS may be sought if delays in its replacement are extensive.