

1 Introduction

Cancer is a notifiable disease in all states and territories. Cancer, excluding non-melanocytic skin cancer (NMSC), is the only major disease category for which complete coverage of incidence data is available. It is also a major cause of death in Australia. Good information on the occurrence of different types of cancer, the characteristics of patients, and survival and mortality facilitates the monitoring of trends and the effects of interventions, and provides a sound basis for epidemiological studies and the initiation of prevention and treatment programs.

What is cancer?

Cancer describes a range of diseases in which abnormal cells proliferate and spread out of control. Other terms for cancer are tumours and neoplasms, although these terms can also be used for non-cancerous growths.

Normally, cells grow and multiply in an orderly way to form tissues and organs that have a specific function in the body. Occasionally, however, cells multiply in an uncontrolled way after being affected by a carcinogen, or after developing from a random genetic mutation, and form a mass which is called a tumour or neoplasm. Tumours can be benign (not a cancer) or malignant (a cancer). Benign tumours do not invade other tissues or spread to other parts of the body, although they can expand to interfere with healthy structures. In 2004 there were 101 registered deaths from benign tumours.

The main features of a malignant tumour (cancer) are its ability to grow in an uncontrolled way and to invade and spread to other parts of the body (metastasise). Invasion occurs when cancer cells push between and break through other surrounding cells and structures. Cancer spreads to other parts of the body when some cancer cells are carried by the bloodstream or the lymphatic system and lodge some distance away. They can then start a new tumour (a secondary cancer) and begin invading again.

Cancer can develop from most types of cells in different parts of the body, and each cancer has its own pattern of growth and spread. Some cancers remain in the body for years without showing any symptoms. Others can grow, invade and spread rapidly, and are fatal in a short period of time. Apart from the cancer's natural behaviour, its effects can also depend on how much room it has before it damages nearby structures, and whether it starts in a vital organ or is close to other vital organs.

Although a number of cancers share risk factors, most cancers have a unique set of risk factors that are responsible for their onset. Some cancers occur as a direct result of smoking, dietary influences, infectious agents or exposure to radiation (for example, ultraviolet radiation), while others may be a result of inherited genetic faults. It should be noted that for many cancers the causes are unknown. While some of the causes are modifiable through lifestyle changes, some others are inherited and cannot be avoided through personal action. However, the risk of death due to particular cancers may be reduced through intensive monitoring of individuals at high risk, reducing external risk factors, detecting and treating cancers early in their development, and treating them in accordance with the best available evidence.

Many cancers can be serious and even fatal. However, medical treatment is often successful if the cancer is detected early. The aim is to destroy the cancer cells and stop them from returning. This can be done by surgery to remove the growth or by other methods such as chemotherapy (cancer-destroying drugs) or radiation therapy. The growth of some cancers can also be controlled through hormone therapy.

Treatment often combines a number of these methods and uses them in stages. The first line of treatment aims to remove as many cancer cells as possible; the second line, which may go on for a long time, aims to ensure that the cancer does not recur.

Cancer surveillance in Australia

National data on cancer deaths have been available since the early 1900s, based on information in medical certificates of cause of death, as provided to the Registrar of Births, Deaths and Marriages in each state and territory. The Australian Institute of Health and Welfare (AIHW) and the Australian Bureau of Statistics (ABS) use these data to report national cause of death statistics. Information concerning cancer deaths and non-cancer deaths of cancer cases is also collected by state and territory cancer registries, based on death certificates and other diagnostic information.

The only effective method of obtaining cancer incidence data is through universal registration of cancer diagnoses. In Australia, cancer registration is required under state and territory legislation. The cancer registrations are collated by cancer registries that are supported by a mix of state and territory government and non-government organisations. The registries obtain their information from hospital, pathology, radiotherapy and physicians' records (Appendix D). The earliest cancer registries have been operating since 1972 but it was not until 1982 that cancer registration was universal in Australia for all states and territories except the Australian Capital Territory. Cancer notification in the Australian Capital Territory was not legislated until 1994 so pre-1994 cancer data for this jurisdiction are considered to be incomplete.

National Cancer Statistics Clearing House

In June 1984 the National Health and Medical Research Council endorsed the concept of a national collection of cancer statistics. In April 1985 the National Committee on Health and Vital Statistics agreed that the National Cancer Statistics Clearing House (NCSCH) should be operated by the then Australian Institute of Health under the supervision of the Australasian Association of Cancer Registries (AACR).

Following the enactment of Commonwealth legislation establishing the then Australian Institute of Health as a statutory body in 1987, and subsequent legislation providing for the protection of confidentiality of records supplied to it, the Institute and the AACR established the NCSCH. This provides an ongoing facility for compiling data produced by individual state and territory registries and identifying cross-border duplicate registrations.

The aim of the NCSCH is to foster the development and dissemination of national cancer statistics for Australia and specifically to:

- enable computation and publication of national statistics on cancer
- allow tracking of interstate movement of cancer cases via record linkage so that the same cancer case is not counted more than once

- facilitate exchange of scientific and technical information between cancer registries and promote standardisation in the collection and classification of cancer data
- facilitate cancer research both nationally and internationally.

The NCSCCH primarily produces reports of national incidence and mortality data. Periodically, analyses of specific cancer sites, cancer histology, differentials in cancer rates by country of birth, geographical variation, trends over time and survival are undertaken on an accumulation of data that permits examination of the data in greater depth.

The NCSCCH is able to make available a broad range of statistical data. Data that may identify individuals may only be released to bona fide researchers after a strict scientific and ethical review process which involves the AACR executive, the AIHW Ethics Committee and the state and territory cancer registries. General database enquiries and enquiries about the release of statistical data should be addressed to:

Health Registers and Cancer Monitoring Unit
 Australian Institute of Health and Welfare
 GPO Box 570
 Canberra ACT 2601
 Phone: (02) 6244 1000
 Email: cancer@aihw.gov.au

Cancer data on the AIHW website

Cancer data on the AIHW website includes the following at <www.aihw.gov.au/dataonline>.

Australian Cancer Incidence and Mortality books

These are newly developed interactive Excel workbooks of tables and graphs by age and sex for 'all cancers' and the major cancers, for incidence from 1982 to 2003 and mortality from 1968 to 2005.

Cancer incidence data cubes

There are two cancer incidence data cubes, one age-specific and the second age-standardised, with data from 1983 to 2003:

- The age-specific data cube includes the number of new cases and age-specific rates for all registrable cancers (International Classification of Diseases, 10th edition (ICD-10) categories C00–C96 excluding NMSC C44) by year of diagnosis, sex and 5-year age groups.
- The age-standardised database includes the number of new cases, age-standardised incidence rates and crude rates by year of diagnosis, sex and age. All rates are expressed per 100,000 persons and are age-standardised to both the Australian 2001 Population Standard and to the World Health Organization's (WHO) new World Population Standard.

General Record of Incidence of Mortality (GRIM) books

The GRIM books (AIHW 2006b) are interactive Excel workbooks that feature mortality data on selected causes of death by age and sex for each year from 1907 to 2005.

National hospital morbidity data cubes

The interactive national hospital morbidity data page contains links to a number of data cubes containing information on the principal diagnoses, procedures and diagnosis-related groups of patients admitted to Australian hospitals. These include patients with a principal diagnosis of cancer. The source of these data is the National Hospital Morbidity Database. This database, compiled by the AIHW from data supplied by the state and territory health authorities, is a collection of records for admitted patients separated from public and private hospitals in Australia.