

1 Introduction

Cancer is a notifiable disease in all States and Territories and is the only major disease category for which an almost complete coverage of incidence data is available. Cancer is also a major cause of death in Australia. If this situation is to be changed, good information on the occurrence of different types of cancer, the characteristics of patients, and survival and mortality is essential. Such information facilitates the monitoring of trends and the impact 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 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.

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. Spread to other parts of the body occurs 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. They can cause serious damage by destruction, crushing or blocking.

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. 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 cancer-destroying drugs (chemotherapy) or ray treatment (radiation therapy). The growth of some cancers can also be controlled through hormone therapy.

The treatment approach 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 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. Some State and Territory cancer registries have been operating for nearly 30 years and obtain their information from hospital, pathology, radiotherapy and physician records (Appendix D). It was not until 1982, however, that cancer registration was universal in Australia (data were published in *Cancer in Australia 1982* (Giles, Armstrong & Smith 1987)). Before then, there was no registration in some States and in some others registries covered only particular areas, hospitals or cancer sites.

The 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 (NCSCCH) 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 NCSCCH. This provides a facility for compiling data produced by individual State and Territory registries on a continuing basis.

The aim of the NCSCCH 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;

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

The NCSCH receives data from individual State and Territory cancer registries on cancers diagnosed in residents of Australia. This commenced with cases first diagnosed in 1982. The data items provided to the NCSCH by the State and Territory cancer registries enable record linkage to be performed and the analysis of cancer by site and behaviour.

The NCSCH 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 which permits examination of the data in greater depth. The section 'Related publications' sets out the range of publications based on these data.

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

Australian Institute of Health and Welfare
 National Cancer Statistics Clearing House
 Attention: Dr Chris Stevenson
 GPO Box 570
 Canberra ACT 2601
 Phone: (02) 6244 1041
 E-mail: chris.stevenson@aihw.gov.au

Other sources of data on cancer

In addition to the NCSCH, the AIHW holds several other national databases containing cancer-related data. Many factors determine and influence health. Indeed, the dominant view presently is a 'multicausal' one, in which disease, disability and (ultimately) death are to be seen as the result of the interaction of human biology, lifestyle and environmental (including social) factors, modified by healthcare interventions. Therefore, while the main focus of this report is the presentation of cancer incidence and mortality data, it also includes summary data from these other databases which contribute to a more complete picture of cancer in Australia.

Figure 1 presents a conceptual framework for health (AIHW 2002a). Disability, disease and death are aspects of health and wellbeing, and can be seen as the result of a complex interplay of many factors described as individual or environmental. These causes and effects can be modified to various degrees by health protection, prevention and promotion, or by treatment and rehabilitation; in the end stages of life, palliation services feature. Such interventions are supported by human and material resources, including essential information via research, monitoring and evaluation.

The incidence and mortality data presented in this report contribute to the parts of the framework under 'Health, functioning and wellbeing'. The data in Chapter 5 (multiple causes of death, survival, screening and treatment) extend the coverage of this part of the framework. Chapter 5 also contributes to the 'Resources' part of the framework with a

discussion of the health workforce implications for cancer and to the 'Determinants of health' part of the framework with a discussion of cancer-related risk factors.

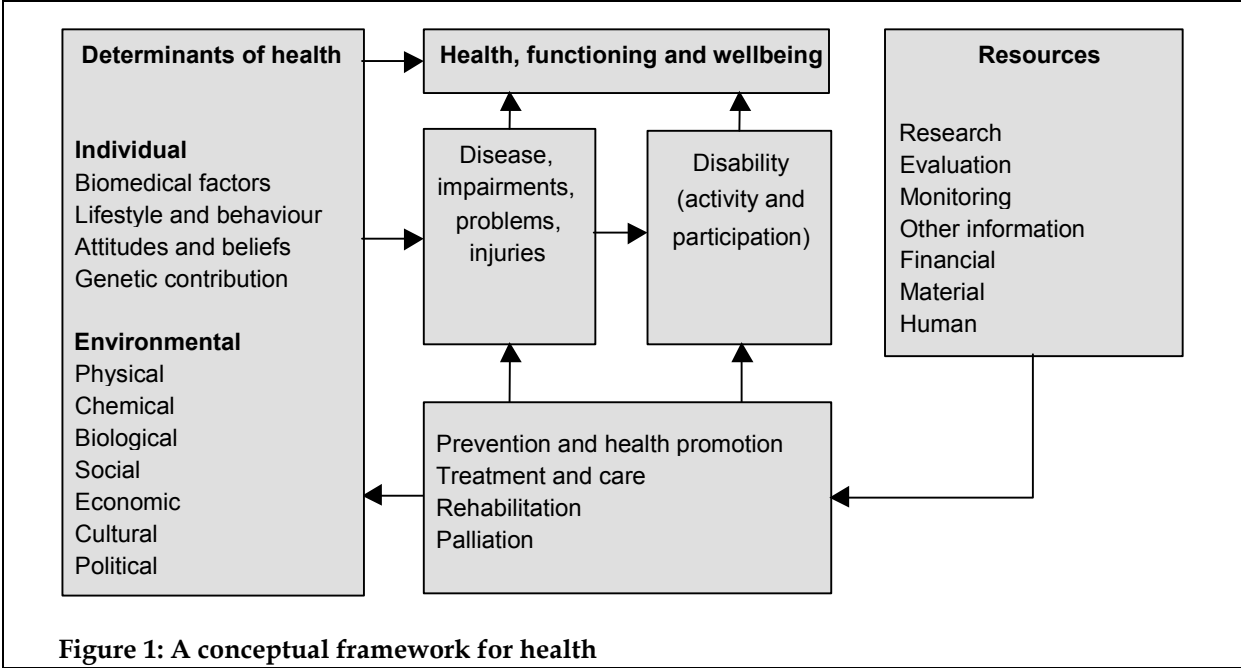


Figure 1: A conceptual framework for health

There are still significant gaps in cancer-related national data collections. For example, there are still no national data collections of hospital outpatient services and only limited data in areas such as palliative care.

Structure of this report

This report is divided into six major components:

- an introduction and overview of cancer in Australia in 1999;
- summary tables of incidence and mortality for all cancer sites for 1999;
- a series of incidence and mortality data tables for the most common cancer sites, and some less common but topical cancer sites, for 1999;
- an overview of some additional sources of data on cancer in Australia covering cancer survival, risk factors, screening, treatment and workforce issues;
- glossary and reference sections;
- appendixes comprising the cancer coding system and methods used in this report and State and Territory registration features.

In addition, a full set of statistical tables are published separately on the AIHW's web site at www.aihw.gov.au. Also on the web site are two interactive data cubes with cancer incidence data for Australia for 1983–1999. An interactive data cube is a multidimensional representation of data. It contains information organised into dimensions to provide fast retrieval of data and cross-tabulation facilities.

Introduction and overview

The overview of cancer in Australia provides a selection of highlights from the data tables. It describes the patterns of cancer incidence and mortality by site, age, sex, and State and Territory. Trends in cancer incidence and mortality are discussed and a series of graphs are provided presenting the most common cancers by sex and age group, and trends in national cancer incidence (1983–1999) and mortality (1983–2000).

Summary tables

Summary tables of incidence and mortality for 1998 for all cancer sites are provided. These tables list numbers of new cases and deaths, and crude and age-standardised incidence and mortality rates for Australia. Cumulative rates are given for incidence, while the mortality tables provide estimates of the person-years of life lost. Sex ratios are presented in both the incidence and mortality tables.

Series of data tables

The series of data tables for the most common or topical cancers in 1999 contain age-specific, crude, and age-standardised incidence and mortality rates for males, females and persons for each cancer site. The order of the tables is based on the International Classification of Diseases 10th Revision (World Health Organization 1992) (Appendix A). All rates are expressed per 100,000 population and, at the Australian level, are directly age standardised (Appendix B) to both the total estimated resident population of Australia at 30 June 1991 and the new WHO World Standard Population (Appendix C). Included in these tables are estimates of the lifetime risk of contracting each cancer, the person-years of life lost and the numbers of each cancer as a proportion of the total (excluding non-melanocytic skin cancers).

The data tables also include average annual numbers of new cancer cases and deaths, and age-standardised incidence and mortality rates for each State and Territory. It should be noted that the State and Territory incidence and mortality rates have been directly age standardised to the total estimated resident population of Australia at 30 June 1991. Particular care should be taken not to compare these State and Territory rates with previous Cancer Series publications – *Cancer in Australia 1989–1990 (with Projections to 1995)*, *Cancer in Australia 1986–1988* or *Cancer in Australia 1983–1985* – where age standardisation used the old World Standard Population. The NCSCCH is able to provide State and Territory rates that have been age standardised to the new WHO World Standard Population on request or State and Territory cancer registries can be contacted directly.

Appendixes

The appendixes include the International Classification of Diseases 10th Revision coding system; a methods section providing formulae, explanations and examples of the techniques used to present the data in the report; population data for Australia for 1999; and a summary table of State and Territory cancer registry characteristics.

This report, together with a comprehensive set of Excel tables for all cancer sites, is available on the AIHW's web site at www.aihw.gov.au/publications/.