

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, on the characteristics of patients, and on 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 and have a specific function in the body. Occasionally, however, they multiply in an uncontrolled way after being affected by a carcinogen, or after developing from a random genetic mutation, and form a lump 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 less than a year after detection. 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 (e.g. ultraviolet radiation), while others may be a result of inherited genetic faults. It should be noted that for some 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 cut out 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 charity organisations. Some State and Territory cancer registries have been operating for more than 20 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 et al. 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 (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 a facility for compiling data produced by individual State and Territory registries on a continuing basis.

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

The NCSCCH 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.

In 1999 and 2000 there will be an emphasis placed on data development in cancer registry collections. This project will look at the transition of existing collections toward the National Health Data Dictionary (NHDD) standards, where they do not currently comply, and the development of cancer registry specific NHDD definitions.

The NCSCCH 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: Mr Robert van der Hoek
GPO Box 570
Canberra ACT 2601
Phone (02) 6244 1133.

Structure of this report

This report is divided into four major components:

- an introduction and overview of cancer in Australia in 1996;
- summary tables for all cancer sites for 1996;
- a series of data tables for the most common cancer sites, and some less common but topical cancer sites, for 1996;
- appendixes comprising cancer coding system, methods, State and Territory registration features, glossary and reference sections.

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 (1983–1996) and mortality (1983–1997). An international comparison is made for selected cancers.

Summary tables of incidence and mortality for 1996 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.

The series of data tables for the most common or topical cancers in 1996 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 (World Health Organization 1977). All rates are expressed per 100,000 population and, at the Australian level, are directly age-standardised to both the total estimated resident population of Australia at 30 June 1991 and the World Standard Population. 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. Therefore, 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 World Standard Population*.** The NCSCCH is able to provide State and Territory rates that have been age-standardised to the World Standard Population on request or the cancer registries can be contacted directly.

The appendixes include the International Classification of Diseases 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 1996; 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 are available on the Institute's Internet web site <<http://www.aihw.gov.au>>.

If you are unable to access these data via computer then contact the Australian Institute of Health and Welfare for a hard copy.