

# Oceania



# Australian Capital Territory

## Registration area

The Australian Capital Territory (ACT) covers an area of approximately 2400 km<sup>2</sup> and is surrounded on all sides by the state of New South Wales (NSW). Almost all the ACT residents live in metropolitan Canberra, although 85% of the Territory's land mass is devoted to national park, nature reserves, pine plantations and properties. The population at the most recent census in 2001 was 311 947, which represents 1.6% of the Australian's population. The estimated median age in 2001 was 32 years.

## Cancer care facilities

The ACT Health oversees general health care in the region in partnership with the service providers. The ACT has a comprehensive range of cancer prevention, early detection, treatment, community care and palliative services available to the local community, in both the public and private sectors. The Canberra Hospital is the principal cancer care provider in the ACT and surrounding NSW region, and offers expertise in surgery, medical and radiation oncology and haematology services. The Canberra Hospital is active in cancer research and clinical trials.

There is a strong network of consumer and carer support groups and the Cancer Council ACT is well supported by service providers and the ACT community.

## Registry structure and methods

The cancer registry is the agency established under the Public Health (Cancer Reporting) Regulations gazetted in 1994, to receive notification of cancer in the ACT. Previously, the NSW Cancer Registry had been collecting data for the ACT since 1972, although notification was voluntary.

The ACT Health funds the registry, which is located at the Canberra Hospital in Woden in ACT. Since the regulations came into effect in July 1994, notification of malignant neoplasms has been mandatory for all ACT hospitals (public, private and day), radiotherapy departments, pathology laboratories, hospice facilities and nursing homes. Currently, data are received from 18 sources. These are all

paper notifications, with the exception of the Department of Radiation Oncology at the Canberra Hospital and one private hospital in the ACT. The forms are collated and forwarded onto the NSW Cancer Registry, which processes all new cases of cancer for the ACT. Data on deaths from cancer is obtained from the ACT Registrar of Births, Deaths and Marriages.

## Interpreting the results

Under the current arrangements, it is unlikely that any referred cases will be missed. Before 1994, voluntary reporting led to a dramatic under-reporting of cancer cases. Since 1994, the reporting of cancer cases has improved steadily to a level at or near 100%. For example, the age-standardised rate for malignant melanoma of the skin for males was 30.6 in the 1998–92 statistics, and 40.7 in the 1994–96 statistics.

## Use of the data

The registry monitors the incidence and trends in cancer for ACT residents. With regard to the small numbers involved in the ACT cancer statistics, data on incidence and mortality are analysed in five-year blocks and reported every two years.

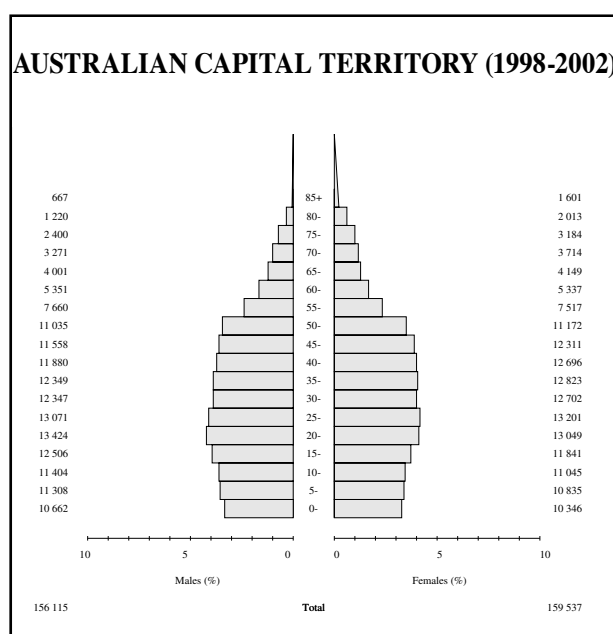
Record information is made available to approved medical researchers engaged in studies that are considered by the ACT Health Ethics Committee to be of importance to the community.

## Source of population

1991, 1996 and 2001 are census populations, adjusted for under-enumeration and Australian residents temporarily overseas. The intercensal estimates are obtained from the previous census by advancing age and allowing for births, deaths and immigration. They are adjusted in the light of the succeeding census. Ref: Australian Bureau of Statistics. Population by age and sex: Australian States and Territories June 1992 to June 1997. ABS Catalogue no. 3201.0(1997) Canberra, Australian Bureau of Statistics.

## Multiple primary rules used

IACR rules (2004) on CI5 IX period.



# Australia, New South Wales

## Registration area

The NSW Central Cancer Registry covers the population of New South Wales. There were 6 686 644 residents in 2003; of these, two thirds live in the capital city, Sydney. NSW is the most populated of the six federated states, with 34% of the population of Australia. The area of NSW is 801 400 Km<sup>2</sup> (309 433 square miles), comprising 10.4% of the total area of Australia. Geographically, the Western Slopes of the Tablelands and the Western Plains occupy two thirds of the State, but most of the population lives in the east, with 74% living in the adjacent coastal cities of Sydney, Newcastle and Wollongong.

At 30 June 2003, 20% of the population was aged under 15 years of age, 67% between 15 and 65 and 13% 65 years and older. By comparison, in 1972, the first year of registration of cancer in New South Wales, 9% of the population was aged over 65 years.

In the 2001 Census, 4 450 772 people (70.5%) stated that they were Australian-born. This compares with 4 394 326 people (73.3%) in the 1996 Census and 4 284 568 (75.1%) in the 1991 Census.<sup>1</sup> The number of people born overseas in the 2001 Census was 1 474 987 (23.4%) compared with 1 388 849 (23.2%) in the 1996 Census and 1 286 847 (22.5%) in the 1991 Census. Of those born overseas, the three main countries of birth in the 2001 Census were the United Kingdom 275 130 (4.4%), New Zealand 105 708 (1.7%) and China (excludes Special Administrative Region and Taiwan Province) 85 363 (1.4%).

## Cancer care facilities

There are 9 metropolitan and rural Area Health Services responsible for providing cancer services. These Area Health Services provide hospital inpatient, outpatient and community health care and specialist Cancer Care Centres for their residents. Radiotherapy and chemotherapy services are predominantly outpatient and provided in specialist Cancer Care Facilities. Cancer services are also provided by private facilities.

Notification of malignant neoplasms is a statutory requirement and currently operates under the authority of the Public Health Act of 1991. All public and private hospitals, departments of radiation oncology, nursing homes and pathology laboratories, outpatient departments and day procedure centres are required by law to notify the NSW Central Cancer Registry when cancer is diagnosed or treated by them.

## Registry structure and methods

The NSW Central Cancer Registry is managed and funded by the NSW Cancer Institute on behalf of the NSW Health Department. There are 19 full-time-equivalent staff employed at the Registry. These include a manager, operations coordinator, coding supervisor, data quality

manager, biostatistician, analyst programmer, medical adviser, medical coders and data entry clerks. The Registry maintains a register of cases of cancer diagnoses since 1972. The information collected includes name, address, date of birth, country of birth, clinical details about the cancer, the notifying institution and doctor. All information sent to the Registry is kept confidential, held under security and protected by the Public Health Act. Presently there is an initiative to develop clinical cancer registries to collect TNM staging and treatment information. These are being piloted in 5 of the 9 Area Health Services.

Forty percent of all notifications are received electronically; the remaining notifications and pathology reports are paper based.

Death registrations are provided by the Registrar of Births, Deaths and Marriages and received regularly. Coded death registrations are also received from the Australia Bureau of Statistics. The Registry routinely matches cancer cases against deaths in Australia from all causes.

## Interpreting the results

As notification is mandatory and provided through a number of different sources (on average, four notifications per case), the level of enumeration is likely to be high. Indicators of data quality support this assertion, with only 1.4% of cases registered as death certificate only and 88% of all cases histologically verified.

## Use of the data

An annual statistical report is published that provides information on the number of new cases and deaths by counts, rates and trends over time. The Registry contributes to the prevention, planning, control and treatment of cancer in the population of NSW by providing timely accurate data and the evaluation of both breast and cervical screening programs. It contributes to national and international publications and a variety of specialist reports by cancer site. In addition, there are a number of other reports on specific cancer sites, risk factors and cancer survival in NSW in progress. Tabulated data is made available through a web based reporting module that can be accessed at [www.statistics.cancerinstitute.org.au](http://www.statistics.cancerinstitute.org.au).

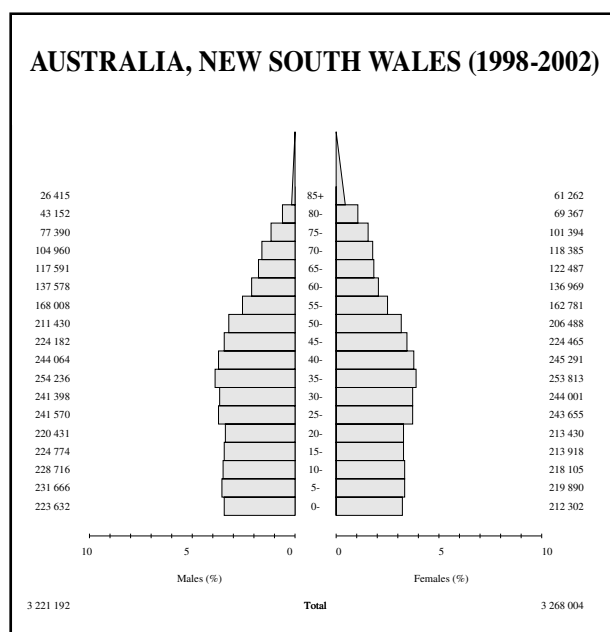
Unit record information is made available to approved medical researchers engaged in studies that are considered by the NSW Cancer Institute Ethics Committee and the Department of Health Ethics Committee to be of benefit to the wider community.

## Source of population

Estimated resident population data – June 1998–2002.

## Multiple primary rules used

IACR rules (2004) on CI5 IX period.



# Australia, Northern Territory

## Registration area

The Registry was established in 1981 to cover the entire population of the Northern Territory, a sparsely settled area of 1.4 million square kilometres in central and northern Australia. The population of the Northern Territory increased from 122 000 in 1981 to 203 000 in 2005. Seventy-five percent live in five urban areas.

The population has a very young age distribution, with only 5% of the population aged over 65 years, although the over-65 population is increasing at a faster rate than are younger age-groups. Twenty-nine percent of the population are Indigenous Australians, most of whom live in small, remote communities.

## Cancer care facilities

There are six hospitals, including two referral hospitals, and a well-developed private health care system in the larger towns.

There has been some improvement in cancer diagnostic and treatment services since the establishment of the Registry. A breast cancer screening service commenced operation in 1994 and a cervical screening register in 1996. The extent of PSA testing is not known. A specialist medical oncologist commenced practice in the NT in 1991 and a haematologist in 2006, but other specialist oncology services are provided by visiting specialists from interstate; there is no specialist cancer treatment centre or radiotherapy facility.

Patients requiring treatment not available locally are transferred to specialist treatment centres in an interstate capital city. There is an extensive network of primary health care centres in remote communities.

## Registry structure and methods

The Registry is located within and fully funded by the Health Gains Planning Branch of the state health department and staffed by one full-time research assistant. Data processing, coding and database maintenance are performed under contract by the South Australian Cancer Registry. Data analysis and publication are performed by Health Gains Planning Branch staff.

Notification of cases from the three pathology laboratories in the NT and the Registry of Births, Deaths and Marriages has been mandatory under the Cancer (Registration) Act since 1991. The Registry also performs active case detection from hospital inpatient morbidity data and follow-up from hospital medical records and medical practitioners for incomplete notifications.

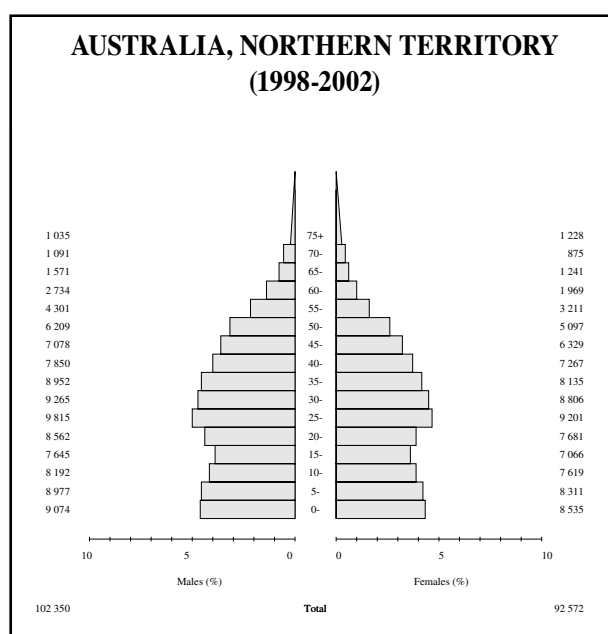
Death registration in the NT is complete. The Hospital Morbidity Dataset is complete for the five public hospitals. There is a well-established system to exchange data with interstate

cancer registries for cases notified in one state but resident in another at the time of diagnosis. There have been no substantial changes to case definitions or coding practices since 1991.

## Interpreting the results

Prior to 1991, case ascertainment is estimated to have been only about 60% complete. A data quality audit of the register estimated that since 1991, case ascertainment has been less than 3% incomplete, in comparison with registration rates of other Australian registries. Incidence rates for Indigenous people under-estimate actual cancer incidence by approximately 18% because of mis-classification of indigenous status (Indigenous people incorrectly identified as non-Indigenous).

Indigenous Australians (Aborigines and Torres Strait Islanders) have a very different pattern of cancer incidence and survival at specific cancer sites than other Australians, with much higher incidence of some cancers but lower incidence of others, and lower cancer survival. Cancer incidence and mortality statistics are published separately for Indigenous and non-Indigenous people. Among Indigenous Australians, smoking prevalence is very high (over 50% of adults are current smokers), as is consumption of alcohol at dangerous levels; the prevalence of chronic infection with Hepatitis B virus is also high, but Pap test participation rates are relatively low. The prevalence of smoking and consumption of alcohol at dangerous levels is also higher among non-Indigenous people in



the NT than for the total Australian population.

## Use of the data

Because of the small number of cases registered each year, the registry produces statistical reports only every few years. The Registry participates in a small epidemiological research program focussing predominantly on issues relating to cancer in Indigenous Australians and performance of local cancer diagnosis and treatment services. In recent years Registry data have been increasingly used for health service planning purposes, particularly in consideration of the feasibility of establishing a radiation oncology service within the Northern Territory.

## Source of population

Estimated Resident Population, based on five-years census. Australian Bureau of Statistics. 3228.0 – Demographic Estimates and Projections: Concepts, Sources and Methods, 1995. Catalogue No 3228.0. (available at <http://www.abs.gov.au/AUSSTATS/abs@.nsf/DSSbyCollectionid/FCEF74DBECB94037CA256BD000274964>).

## Multiple primary rules used

IACR rules (1990 and 2000).

# Australia, Queensland

## Registration area

The Queensland Cancer Registry collects data relevant to the State of Queensland, which occupies the northeastern portion of the Australian continent. Queensland is the second-largest of the six Australian states and has the largest habitable area. Queensland boasts a subtropical to tropical climate.

The Queensland population of 3 522 044 (2001) is 19% of the total population of Australia. Queensland's population is the least centralised of all the mainland states of Australia.

Aboriginal and Torres Strait Islander people represent approximately 3.1% of the total population. Approximately 70% of the population are of Christian denomination.

## Cancer care facilities

Specialist cancer treatment is primarily provided by the major Brisbane hospitals (Princess Alexandra Hospital, Mater Misericordiae Hospital, Royal Brisbane and Womens Hospitals and the Greenslopes and Wesley Private Hospitals) with large regional hospitals (e.g. Townsville and Rockhampton hospitals) also providing specialised treatment. In addition, some oncology specialists visit patients at regional centres. Radium treatment is available at Townsville and Brisbane.

## Registry structure and methods

The registry is located at the Queensland Cancer Fund and is funded and managed by the Queensland Department of Health. The registry has a core of eight clinical coding staff as well as a number of temporary staff to undertake supplementary projects.

Data collection for the Queensland cancer Registry commenced on 1 January 1982. The registry operates under an Act of Parliament that requires compulsory notification of all cancer patients in Queensland to the registry from all hospitals (public, private, psychiatric) and nursing homes. In addition, it is compulsory for all pathology laboratories to provide pathology reports mentioning cancer to the registry. Death certificates are accessed where the cause of death is cancer and also for cancer patients dying of causes other than cancer.

Arrangements for completion of forms vary according to the type of hospital. Resident medical staff and medical records staff are involved in the larger hospitals, medical superintendents and nursing staff at smaller hospitals.

## Interpreting the results

A number of new initiatives have been undertaken in recent years. Quality assurance reviews have been conducted on cause of death coding from the Australian Bureau of Statistics. A review comparing cancer notifications against the hospital morbidity collection has been conducted and indicated under-reporting. The registry is able to obtain access to electronic pathology reports for all public hospitals, and is currently

working on accessing other pathology laboratory results electronically. Access to the electoral roll with date of birth has been gained, which assists in identifying patients still alive, and the registrar of births, death and marriages has introduced date of birth and indigenous identifier to the death certificates.

There is population-based, coordinated screening for breast and cervix, and about 30% of men older than 50 yrs have a PSA test in any specified year.

## Use of the data

While the QCR doesn't undertake an epidemiological research itself, it does provide data for researchers wishing to undertake epidemiological research. Policy makers also use our cancer

registry data for planning and evaluation of health services.

## Source of population

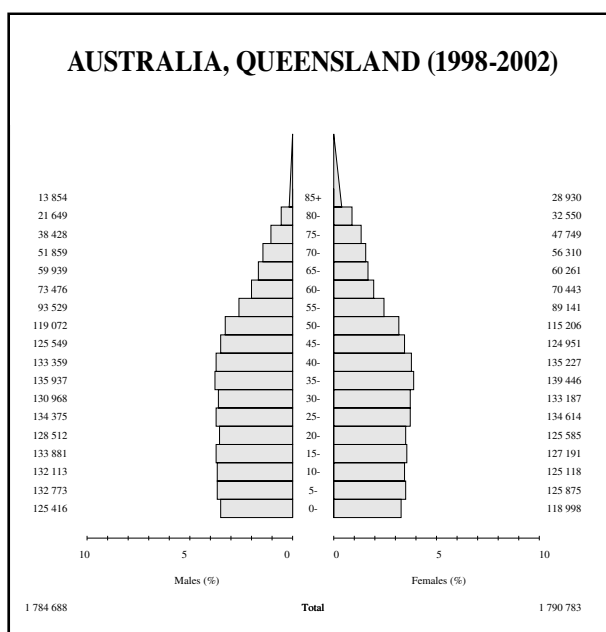
Australian Bureau of Statistics. 2001 Census of Population and Housing, Selected Social and Housing Characteristics for Statistical local Areas 2015.3.

## Multiple primary rules used

IACR rules (2004) on CI5 IX period.

## Notes on the data

C44 does not include basal cell or squamous cell carcinoma.



# South Australia

## Registration area

South Australia is a state in the Australian federation of six states and two territories. It is situated between 26° and 38° S and 129° and 141° E, and covers a total area of 984 375 km<sup>2</sup>. Over one third of this area is desert, and over half of the state is devoted to extensive pastoral pursuits.

Approximately 99% of the population lives south of the 32<sup>nd</sup> parallel, and a high proportion of the population lives in or around the coastal state capital city, Adelaide.

South Australia has a multicultural population with increasing immigration from many overseas countries. The Cancer Registry records Country of Birth and Race (whether Caucasian, Indigenous, Asian or "Other").

## Registry structure and methods

The South Australian Cancer Registry started in 1976, on a voluntary basis, but since 1977 notification of cancer has been a statutory obligation (without penalty) for all hospitals and pathology laboratories in South Australia. Hospitals are required to report all cases of cancer (except non-melanotic skin cancers) within one calendar month of the patient's commencing radiotherapy, the patient's discharge from the hospital and/or death of the patient in the hospital. Pathology laboratories are required to send copies of reports of all cases of cancer within one calendar month of the finalisation of the pathology report.

Registry staff consists of a Manager and five cancer registry project officers.

The system of notification varies among hospitals depending on hospital size, staffing and types of record systems. In general, the responsibility lies with medical records officers in public hospitals and managers in private institutions. The multiple notifications received are linked and a file is created for each patient. Checks are available to the registry from death certifications and pathology reports. Cases from such sources that are not reported by hospitals are followed up.

Information collected includes country of birth, race, occupation, Breslow thickness and Clark level for melanoma and tumour diameter and nodal status for breast cancer.

The registry staff regularly telephone, visit or write all hospitals to obtain information on inadequately reported cases and cases identified from pathology laboratory reports. Patients' medical advisers may be consulted by letter or telephone if case discrepancies are not resolved by other means. An annual cross-linkage checks cancer registry live cases with the Registrar of Deaths' main deaths file to see whether any cancer cases have died of a condition other than cancer. Cancer deaths are detected on a monthly basis by electronically

searching the current file of death certificates obtained from the Registrar of Births, Deaths and Marriages. Hospitals or treating medical advisers are consulted when a cancer death certificate is received for someone not already known to the registry. All Australian registries communicate regularly with each other about cases who have moved interstate.

Ascertainment checks to find unreported cases are performed at least every six months by comparing hospitals' inpatient separation data with the registry's files. An annual data validation check is performed in addition to the routine editing and validation procedures incorporated into the data entry software.

Since 1987, a system of hospital-based (clinical) registries has been established in major teaching hospitals in South Australia. Special liaisons have been established with the hospitals' departments to facilitate the follow-up of patients by clinicians and to enable them to evaluate clinical aspects such as treatment outcomes in relation to disease stage and important prognostic factors. The relevant clinical areas own these hospital-based registries, but significant interaction with the population-based registry is required for case ascertainment and data provision.

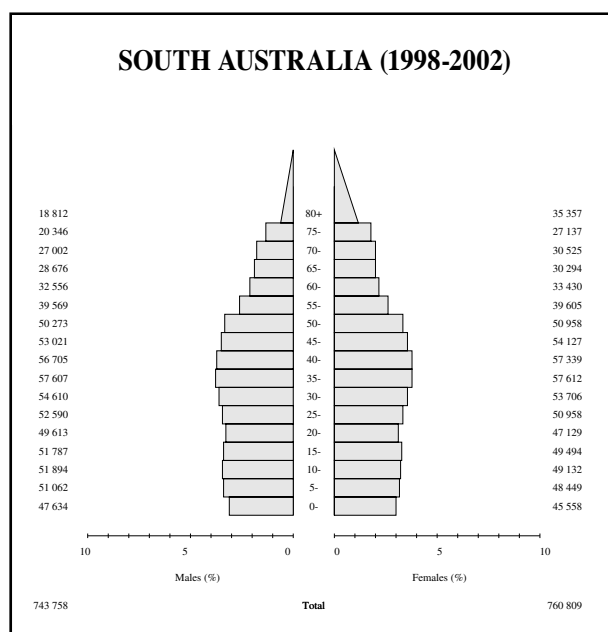
## Use of the data

The primary objective of the registry is to describe the nature and extent of cancer in South Australia, to monitor cancer incidence, mortality and survival, and to evaluate spatial and sub-population differences. Registry publications on cancer in South Australia are current, timely and well-received locally, interstate and overseas.

The data are used extensively for monitoring the burden of cancer in the community and evaluating the effectiveness of cancer control and prevention programmes, for example breast and cervical cancer screening, and of clinical services. PSA testing is also common within the population. Other international, national and local bodies also use the data extensively for their cancer prevention, cancer control, clinical services and/or research activities. The Cancer Council South Australia is one local organisation that uses registry data heavily in its activities.

An analysis of survival has provided valuable information for the entire South Australian community, and has served as a standard comparison for intra-hospital survival studies. The data are now sufficient for ten-year relative survival rates to be calculated based on the proportion of survivors from 1977 in the patient group, as related to the proportion of survivors in a similar group of people without the disease.

Cancer registry data also are used in investigating perceived cancer clusters in various geographical areas.



These perceptions usually arise from a citizen or group of citizens concerned about their local environment.

Other cancer epidemiology and statistics endeavours are supported, such as the National Malignant Mesothelioma Project, National Paediatric Cancer Registry, the National Cancer Statistics Clearing House and various *ad hoc* international, national and local projects.

**Source of population**

The mid-year 2000 population was estimated by the Australian Bureau of Statistics, based on the 1996 census, and advancing age and allowing for migration, births and deaths.

**Multiple primary rules used**

IACR rules (2004) on CI5 IX period.

# Australia, Tasmania

## Registration area

Tasmania, the smallest state of Australia, is a group of islands of 68 114 km<sup>2</sup>, about 0.9% of the total area of Australia, lying between 40° and 43°S, and having a temperate climate. The principal industries are aquaculture, viticulture, mining and forestry. Secondary industries include textile, confectionery, beer and beverages, zinc and aluminium smelters, and vegetable and milk processing. Tourism is also a major industry in Tasmania. Waterpower stations provide nearly all the electricity generated in the state. Wood fires used for home heating produce smoke in populated areas during the winter. A degree of heavy metal pollution of river waters occurs in some areas.

Only 2.5% of Australia's population reside in Tasmania. Tasmania is the most decentralised state in Australia, with almost 60% of people living outside the capital city statistical division. Like the national population, that of Tasmania is ageing with an increasing proportion of the population aged 65 years and over. Tasmania is the least diverse population in multicultural terms of all the states in Australia with 95.5% of the population born in Australia, the USA, the UK, New Zealand and South Africa. Three percent of the population are of indigenous origin.

## Cancer care facilities

Tasmania is well served by oncology services. The three main population regions all have a public hospital system as well as a number of private hospitals. There are two radiation oncology units in the state.

## Registry structure and methods

The Tasmanian Cancer Registry was established in 1977 as a population-based registry covering the state. The registry was set up for the purpose of providing the state government with accurate cancer incidence and mortality statistics and to provide the capacity to monitor cancer trends. In July 1988 the responsibility for the operation of the cancer registry was transferred from the Department of Health and Human Services to the Menzies Research Institute, University of Tasmania, Hobart.

Cancers were proclaimed as notifiable diseases in December 1992, and since then cancer has had a legislative basis. The registry is assisted by an Advisory Committee. The registry staff currently comprises a director, manager, two medical coders and a clerical assistant.

All the pathology laboratories in the State send the registry copies of histopathology, cytology and cell marker reports of cancer. Notification of cancer forms are supplied by the two radiation oncology clinics. Private and public hospitals notify diagnoses of cancer to the registry upon discharge of patients or provide a computerised listing of cancer cases periodically by electronic

transfer. Death certificates of Tasmanian people are reviewed for mention of cancer as a cause of death. Since 1994 breast and cervix cancer screening programs have been undertaken in Tasmania, and listings from these sources are available to check against registry records. In the 1990s, the increase in the incidence of prostate cancer coincided with a greater use of PSA testing. Incidence peaked in 1995 before declining. Interstate registries supply data to the Tasmanian Cancer Registry on Tasmania residents who seek treatment interstate or who move interstate at some time after cancer diagnosis.

The Tasmanian Cancer Registry collects and registers non-melanoma skin cancers (NMSC) on a register established in 2001 for this purpose. Currently NMSC registrations are complete from 1978 to 2004.

To help achieve high data quality and case ascertainment, data are obtained from multiple sources including pathology laboratories, hospitals and the Registrar of Births, Deaths and Marriages. Most registered cases include data from both a pathology laboratory and a hospital service (inpatient or radiation oncology clinic). Where information received is insufficient to enable complete registration, active follow-up is undertaken by contacting treating doctors, pathology laboratories and medical records departments. In addition, the National Cancer Statistics Clearing House (NCSCCH) in the national capital, Canberra, collates all State and Territory data and checks for duplicate

registrations across two or more States.

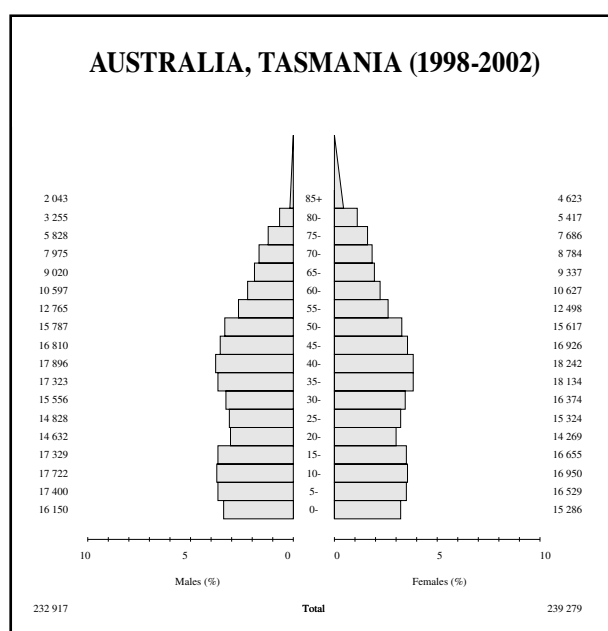
Prior to the year 2000 cases were not accepted by the registry on the basis of death certificate only. Each death certificate is actively followed up to ascertain the time and place of diagnosis and to verify the diagnosis, and the percentage of death certificate only cases registered since 2000 is 1% per annum.

## Use of the data

The registry publishes a report each year showing the number of new cases of cancer in Tasmania, and each cancer registry in Australia sends information to the NCSCCH which publishes a national report. More detailed information is made available to the State Government healthcare institutions, healthcare professionals and health researchers to plan cancer education, treatment and research. In ethically approved research projects, identified data from the cancer registry may be released to researchers.

## Source of population

1996 and 2001 are Census populations, adjusted for under-enumeration and Australian residents temporarily overseas. The intercensal estimates are obtained from the previous census by advancing age and allowing for births,





deaths and migration. They are adjusted in the light of the succeeding census. Ref.: Australian Demographic Statistics, Australian Bureau of Statistics, Cat. No. 3101.0, Dec. 1996–2001. Allen DN, Tasmanian Year Book 1996, Australian Bureau of Statistics, Cat. No. 3101.6, 1996.

**Multiple primary rules used**  
IACR rules (2004) on historical data.

**Notes on the data**  
C44 not available.

# Australia, Victoria

## Registration area

The Victorian Cancer Registry covers the State of Victoria, the second most populous State in the Australian Commonwealth, situated in the southeastern corner of the continent and bounded to the north by New South Wales and to the west by South Australia. The estimated population in 2004 comprised 4 962 970 persons, of whom 19% were under 15 years and 13% were aged 65 years or more. One in four Australians lives in Victoria, and almost three quarters of these live in the Melbourne Metropolitan Area with most of the remainder in small provincial cities. The average population density is 22 persons/km<sup>2</sup>, ranging from <2 in the Wimmera to over 400 in Melbourne.

Since the registry's inception in 1982, the population has both grown and aged, and the mix of immigrants has altered from predominantly European to growing numbers from Asia, South America and Africa. The newest migrant groups tend to be younger and, therefore, contribute little to cancer incidence. At the 2001 census, 24% of the population was described as being overseas born. Of these 1 080 344 persons, 15% were from the United Kingdom, 4% from New Zealand, 7% from Italy, 4% from Greece, and 4% from Vietnam. The remainder originated in China, India, Sri Lanka, Malaysia, Germany, former Yugoslavia and other European countries, and small numbers from Asia, South America, Africa and Oceania.

Almost 70% of Victorians were Christians (28% Catholic) with less than 1% each of Muslim, Jewish, Buddhist, Hindu and other religious denominations; one third stated no religion.

Because of its low latitude and highly susceptible population Victoria has a high incidence of skin cancers. No other cancer risk factors are particularly prominent; smoking has long been in decline but obesity is increasing.

## Cancer care facilities

Victoria's medical care system is a mix of private and public sectors. In 2003–4 it had a well-established system of 144 public hospitals with several specialist oncology units including Radiation Oncology centres, and one large hospital dedicated to cancer treatment, for a total of 11 950 public hospital beds. In addition there were 135 private hospitals containing 6674 beds. A mix of public hospital departments and private laboratories provided pathology services. In the last two decades there has been some de-centralisation of treatment services, especially radiotherapy.

Victoria has organised screening programmes for breast and cervical cancer and bowel cancer screening is being introduced. Since the early 1990s the use of the PSA test has become widespread, though this is not supported by cancer agencies or the government.

## Registry structure and methods

The Victorian Cancer Registry was established in 1940 by the Anti-Cancer Council of Victoria (as it was then known). Since legislation was passed in December 1982, cancer notification has been compulsory for all hospitals and pathology laboratories in Victoria, and fully population-based coverage was achieved in 1982. The registry is central to Cancer Council Victoria's cancer control programme, and is housed in its Cancer Control Research Institute in Melbourne. The registry is also funded by the Department of Human Services, Victoria. The Registry has a staff of 20: medical coders and clerical staff, a consultant pathologist, registrar and deputy registrar, director, information manager and administrative support from the Cancer Epidemiology Centre.

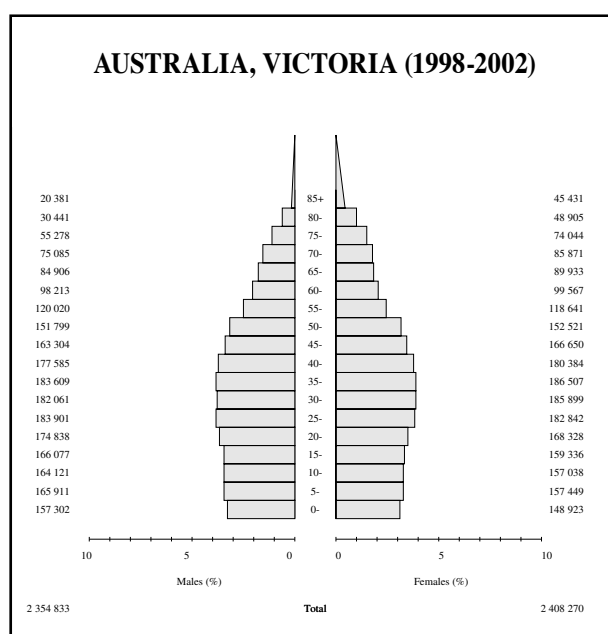
The registry is largely a passive notification system, receiving reports from around 250 hospitals and 50 pathology labs in Victoria and exchanging non-resident data with neighbouring states. Hospital data are received on handwritten forms, computer printouts or increasingly in electronic format. Notifications from pathologists are usually full copies of pathology reports in computer readable format. Over 70 000 notifications are processed for each year of incidence data. Other data sources include details of all death certificates supplied on magnetic tape by the Registrar of Births, Deaths and Marriages. Some active

follow-up is pursued for cases in specialist sub-registers e.g. for *in-situ* and small invasive breast cancers, CNS neoplasms, childhood cancers, and prostate cancers.

The Victorian Cancer Registry adheres to IACR definition and coding recommendations; all data from 1982 have been recoded according to IACR rules. Data are rigorously computer-checked for validity and consistency, and routine checks are regularly conducted on the entire file. Data quality is assured by matching pathology reports with hospital registrations for cases where diagnosis was based on histological confirmation. There are no plans for a formal review of completeness or accuracy. Periodic record linkage with other administrative databases has confirmed virtually complete casefinding. For death certificate only registrations, correspondence is sent to the signatory doctor to confirm diagnosis. The registry only contacts patients directly within the context of research study recruitment.

## Use of the data

The registry produces regular statistical reports and overviews of its accumulated data. It also produces a regular pamphlet, CANSTAT, a topical epidemiological digest of cancer facts and figures. Registry data are used to assess the extent of the cancer epidemic and to monitor trends, particularly in



cancers targeted by prevention programs (skin, lung, breast and cervix). The registry also facilitates cancer management surveys by identifying random samples of patients and sending their treating doctors questionnaires regarding care patterns. Cancers surveyed in this way have included breast, bowel, prostate, lung, and testis, rectum, ovary and bladder. One of the registry's most important functions is to facilitate epidemiological research. In addition to epidemiological analysis of registry data, the registry is used to follow up cancer events in cohort studies, to identify cases for case-

control studies, and to confirm cancer occurrence in population-based studies.

**Source of population**

Mid-year estimated resident population (ERP) by age group and sex; Australia, States and Territories. Australian Bureau of Statistics Cat. No. 3201.0 ([www.abs.gov.au](http://www.abs.gov.au)).

**Multiple primary rules used**

IACR rules (2004) on CI5 IX period.

# Western Australia

## Registration area

The Western Australian population of is approximately 10% of the total population of Australia. Western Australia now has a high proportion of migrant inhabitants; 69% of the population were born in Australia, 22% in New Zealand, and 18% in Europe (including the UK). Approximately 3% of the population are Aboriginals, for whom life expectancy is on average between 15 and 20 years less than for non-Aboriginal persons.

The Registry covers the entire State of Western Australia, an area of 2 525 500 km<sup>2</sup>, almost one third of the total area of Australia. The State lies between latitude 13° and 35°S and longitude 113° and 129°E and extends approximately 2400 km from north to south. The northern third of the State lies within the tropics where desert or near-desert conditions prevail over some 900 000 km<sup>2</sup> and population density is sparse. Population distribution overall is extremely uneven; 73% of the population live in the capital city Perth, in the south of the State

The State's economy has diversified, and it is now a leading producer of several key minerals. Heavy manufacturing is relatively insignificant, but light manufacturing is widespread. Air pollution has not been a major problem in Western Australia; however, there has been increasing public concern over the possible effects of industry, to which the Cancer Registry has had to devote significant time in recent years.

## Cancer care facilities

Cancer therapy is concentrated in the Perth metropolitan area, the major (government-operated) teaching hospitals and several private clinics acting as referral centres for country areas.

## Registry structure and methods

Reporting of cancer in Western Australia became a statutory obligation in August 1981 with the establishment of the population-based Western Australian Cancer Registry. Notifications are received from pathologists and radiation oncologists. Scope includes all malignancies and *in situ* neoplasms other than primary cutaneous BCC and SCC, and includes benign CNS tumours.

The WACR has the equivalent of 6 full-time staff who handle preparation, linkage, coding and entry of data, as well as administrative and statistical reporting functions. A detailed statistical report is produced each year and includes incidence and mortality rates and "most common cancer types" data, while other analyses such as survival and geographic-area analysis are periodically included.

Registry staff have access to medical records departments of major public hospitals to allow collection of

additional data when necessary; enquiries are also made of private pathology laboratories and medical practitioners in case of need. Mortality information is routinely searched for outcomes of known cases, and additional cases are recorded—then subjected to the routine enquiry process—when a death certificate indicates a cancer in an individual previously unknown to the Registry. Search and matching routines are now fully computerised.

For selected cancers, additional data (such as level and depth for melanomas) are stored in linked data files. The database is a relational structure consisting of individual linked Dbase3+ files controlled by a locally-developed program using the Clipper5 compiler.

There are 4 hospital-based cancer registries in Western Australia that collect additional data concerning cancer stage and treatment, and regularly exchange information with the central Registry and hospital registries. This enhances the completeness of WACR data, and provides hospital teams with outcome (survival) information.

## Interpreting the results

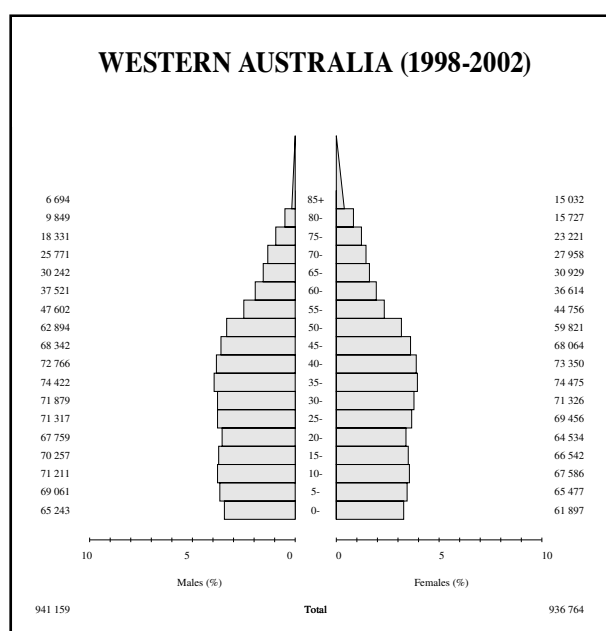
In Western Australian women, around 54% of the target population (50–69 years) are screened for breast cancer and 61% of the target population (20–69) undergo routine Pap smears to detect cervical cancer. Screening for other specific diseases is at present reserved for high-risk families.

Within WACR, data quality is assessed in various ways. For completeness of data, the mortality to incidence ratio is a reasonable indicator and for the 2004 data were 0.33 for males and 0.30 for females. The IARC rules for flagging of non-reportable "multiple primary" tumours are incorporated in the Registry software (recently updated to the current ICDO-3 rules).

Processing of death information has a special status—at the time of death data linkage, each case is reviewed for compatibility of incidence and mortality data, cause of death is coded by registry staff, and letters are sent to doctors or hospitals to resolve outstanding questions. The Registry records cause and date of death when notified of events outside our jurisdiction, so as to facilitate accurate survival analysis and prevalence studies.

## Use of the data

The WACR maintains a comprehensive statistical analysis tool for response to queries, based on a statistical extract which can be updated periodically. Population files are maintained to serve the Department of health administrative boundaries, and a choice of "standard population" weightings is available to meet the needs of both local and International communities.



Data from the WA Cancer Registry are used in a wide variety of research projects, many of which include the contacting of individual persons on behalf of researchers. Use of named data for such purposes is strictly controlled, and the increasing use of Registry data for research purposes is encouraged. The staff support the view that the value of the Registry lies mainly in its being used.

**Source of population**

The estimate of the population-at-risk is based on Australian censuses and Australian Bureau of Statistics inter-censal estimates, making allowance for births and deaths, and migration into and out of the registration area.

**Multiple primary rules used**

IACR rules (2004) on historical data.

# French Polynesia

## Registration area

The registry covers all of the islands of French Polynesia, i.e. 118 main islands distributed over 5 archipelagos, corresponding to a total of 4000 km<sup>2</sup> land area, but spread over an area of ocean the size of Europe.

Seventy-five per cent of the 244 830 inhabitants (Nov. 2002 population census) live on the island of Tahiti, where Papeete is the only real town of the area. The population is young: 40% are aged less than 20 years. In 2002, the birth rate was 19.6%; during the same period, the crude mortality rate was 4.6%, and 6.7% for child mortality.

Census data for 1988 show the following ethnic distribution (information on ethnic groups has no longer been collected after that date): Polynesian and related groups 83%, European and related groups 12%, and Asian and related groups 4%.

The majority of the population is of Christian denominations, mostly Protestant. In 2002, the economically active rate was 58%.

## Cancer care facilities

Health care in French Polynesia is characterised by the co-existence of an important public sector and a free enterprise sector that has greatly increased over the past 10 years.

Healthcare expenses have been evaluated to 420 million euros. Since 1995, all Polynesians have had social healthcare coverage. Moreover, an interaction between preventive and medical care, the improvement of lifestyle and education, and the development of public structures such as drinking-water networks and wastewater treatment have improved the level of health indicators, despite the important rise of diseases linked to lifestyle (diabetes, obesity).

The Polynesian health system on Tahiti Island has one well-equipped university hospital centre with 436 beds, 2 private clinics, one secondary hospital, administered by the Health Directorate, with 44 beds for medico-obstetrics, public community clinics also administered by the Health Directorate and one growing free-enterprise sector with 193 physicians (as at 1 Jan 2007), corresponding to 114 per 100 000 inhabitants in Tahiti.

The global healthcare distribution currently (2007) is of 282 physicians per 100 000 inhabitants in Tahiti, and of 234 per 100 000 over the whole country, the actual distribution being very uneven (84% work on the island of Tahiti).

In addition to the above there are 7 specialised medical clinic departments combining care and prevention: Hygiene and Public Health, Mothers Care, Child Care, School Health, Dental care, Child and Youth Psychiatry, and Alcohol and Drug Addiction.

## Registry structure and methods

The 8<sup>th</sup> Regional Conference of South Pacific Commission Health Directors organised in 1979 in Apia (Western Samoa)

recommended the establishment of a cancer registry in each country of the region. To date, only two island countries have such a registry: Papua New Guinea (since 1958) and Fiji (since 1965). French Polynesia, as well as American Samoa and New Caledonia, immediately showed interest in having a common notification system for cancer cases. Other countries of the region have since adhered to this proposal.

Data collection started in French Polynesia in 1981, with the technical assistance of the South Pacific Commission, UCLA and the University of Hawaii Cancer Research Institute.

The cancer registry of French Polynesia is not an administrative independent body: it is managed by the Health Directorate, under the administrative responsibility of the Director.

Sources of cancer data include: Physicians voluntary notifications, pathology reports from the three existing laboratories, cytology reports from the computerised medical systems (PMSI) of the French Polynesia University Hospital Centre and private clinics, death certificates and the registry of repatriation towards France or New Zealand and the long-diseases registry of the Social Security system.

Some physicians are often reluctant to reveal the names of their cancer patients. However, follow-up of identified cases has improved thanks to the above PMSI.

Data is coded according to Version 3 of the WHO International Classification of Diseases for Oncology. A patient

with two distinct tumours will be entered twice. The crude registry data are analysed on a yearly basis (number of cases declared and distribution). A 5-year synthesis is performed regularly.

## Interpreting the data

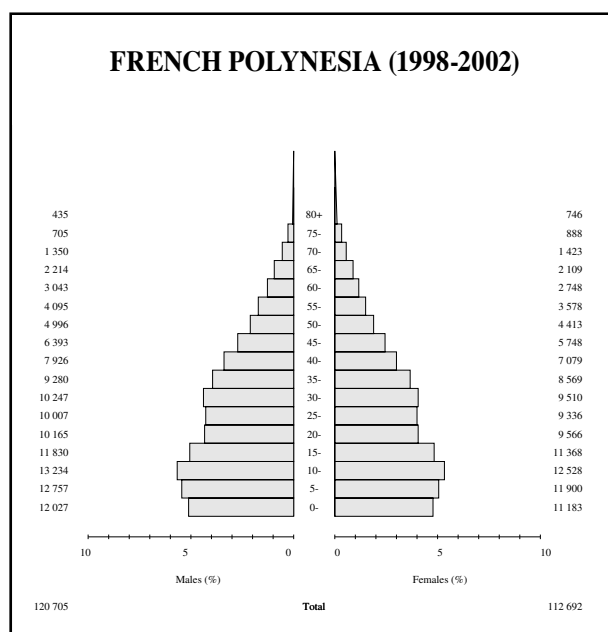
Cancer currently is the second-leading cause of death in Polynesia (23% of certified deaths), following cardiovascular diseases. In the majority of cases, cancer treatment leads to medical repatriation towards France or New Zealand, once the diagnosis has been confirmed by one of the of the country's three pathology laboratories. Only basic chemotherapy protocols and surgery of some tumours take place locally.

## Use of the data

The registry's current task is limited to basic descriptive analysis of the distribution by sex and age of the main cancer incidence in French Polynesia.

Sources:

- French Polynesian Institute of Statistics
- Department of Health Care Planning, Health Directorate, French Polynesia
- Cancer Registry of French Polynesia, Health Directorate, French Polynesia



**Source of population**

Estimated annual median population. Institut de la Statistique de Polynésie Française (I.S.P.F.). 2002: General census of the population in French Polynesia, November 2002.

**Multiple primary rules used**

IACR rules (1990).

# New Zealand

## Registration area

New Zealand is situated in the South Pacific Ocean, 1600 km southeast of Australia. It is a long mountainous country surrounded by a large expanse of ocean, and consists of two main land masses: the North Island and the South Island. The total land area (including offshore islands) is 270 534 km<sup>2</sup>. In 2001, 75% of the population lived in the North Island, and more than 30% of the population lived in the Auckland region. New Zealand is one of the most urbanised countries in the world—approximately 85% of New Zealand's 2001 Census usual population count lived in an urban area.

In 2001, 80% of New Zealanders identified as European and 14.7% identified as Maori. The other main ethnic groups were Asian (6.6%) and Pacific Peoples (6.5%).

## Cancer care facilities

Cancer care in New Zealand is predominantly state-funded, supplemented by private hospitals and private practitioners. Cancer surgery and chemotherapy services are provided in the main centres of population; there are six radiotherapy centres.

## Registry structure and methods

The New Zealand Cancer Registry is located in the New Zealand Health Information Service (NZHIS), which is a unit of the New Zealand Ministry of Health in Wellington. The registry has operated since 1948. The New Zealand Cancer Registry is staffed by seven clinical coders and two support staff. Honorary consultants include pathologists, epidemiologists and oncologists.

Since 1994, laboratories have been the primary source of cancer notifications to the New Zealand Cancer Registry. Laboratories are required by law to report any new diagnosis of cancer in New Zealand, excluding squamous and basal

cell skin cancers. Additional data sources include Medical Certificates of Causes of Death, Coroners' Findings, and public and private hospital discharge data received in electronic form.

All cancer registrations are coded by registry staff. Quality control procedures include computerised validation checks at data input, and rigorous edit checks on pre-publication incidence data.

The New Zealand Cancer Registry carries out internal and external audits from time to time. We last had a review by an external auditor in 2005.

## Use of the data

Cancer registry data are used to monitor the burden of disease and to assess the impact of screening programmes, and as a resource for cancer research. The New Zealand Health Information Service produces an annual cancer publication containing information about cancer incidence and trends. The registry provides data for epidemiological research and identifies cases for ethics-approved case-control studies. Cancer registry data is also used by Genetics Services centres to assist in identifying familial cancers. Policymakers use our cancer registry data for planning and evaluation of health services.

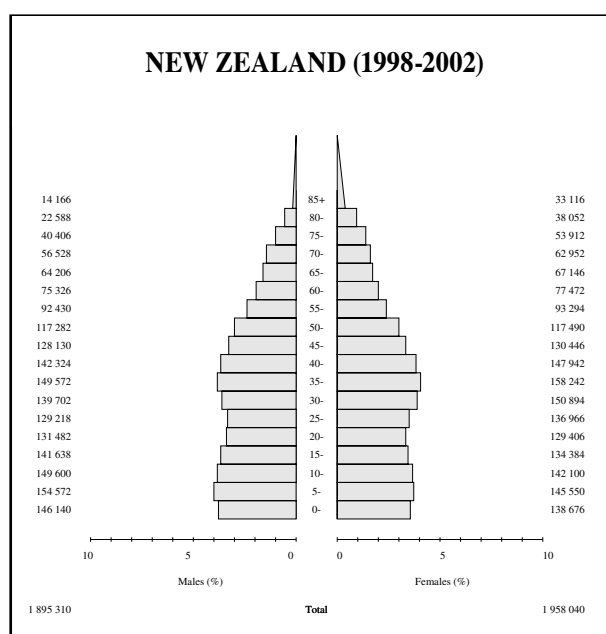
## Source of population

Annual estimates of the "usually resident population"

supplied by Statistics New Zealand, based on a five-yearly census and taking into account births, deaths and migration.

## Multiple primary rules used

IACR rules (2004) on CI5 IX period.





# USA, Hawaii

## Registration area

The Hawai'i Tumor Registry (HTR) is an active cancer surveillance monitoring system for the entire US state of Hawai'i, consisting of 8 major and 124 minor islands, covering 1367 miles from tip to tip. The resident population in 2005 was approximately 1 275 000, with the majority of residents living on the island of O'ahu.

## Cancer care facilities

As the central statewide collection point for cancer data, the HTR receives data from collaborating hospitals maintaining their own hospital-based Tumor Registries. HTR staff also gathers data from other facilities, in addition to cases from oncology clinics, pathology labs, private physicians and radiation oncology facilities. The HTR database currently contains 137 591 reportable resident cases.

## Registry structure and methods

The Hawai'i Tumor Registry (HTR) maintains a database of information on all cases of cancer diagnosed in the State of Hawai'i. It provides complete cancer reporting for the entire state and serves as a resource for nearly all epidemiologic cancer research and cancer control activities in Hawai'i. HTR collects the required SEER demographic and diagnostic items for all malignancies diagnosed in the state. Patients are followed annually during their lifetime. To ensure accuracy, strict quality control and assurance procedures have been established.

The HTR was established in 1960 by the Hawai'i Medical Association (HMA), the Hawai'i State Department

of Health (DOH) and the Hawai'i Pacific Division of the American Cancer Society (ACS). Presently, HTR is jointly operated by the Cancer Research Center of Hawai'i and DOH, and became a member of the National Cancer Institute, Surveillance, Epidemiology and End Results (NCI/SEER) program in 1973. HTR has received its primary financial support from the National Cancer Institute through its Surveillance, Epidemiology and End Results (NCI/SEER) Program, with additional funding from a DOH fee-for-service contract.

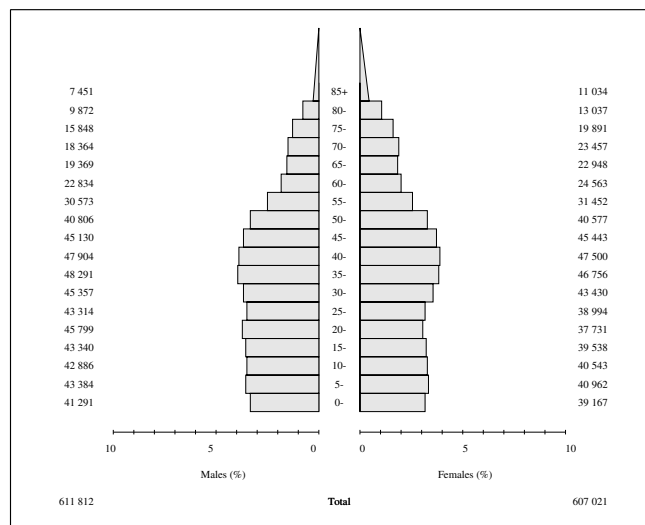
## Interpreting the results

In its years of operation, HTR has been a major source of cancer data and information, locally, nationally and internationally. HTR data collected for diagnosis years 1973–2003 are complete. There is some difference in incidence rates between males and females and among several ethnic groups. Hawai'i is unique in that its population is racially diverse, with no one ethnicity in the majority.

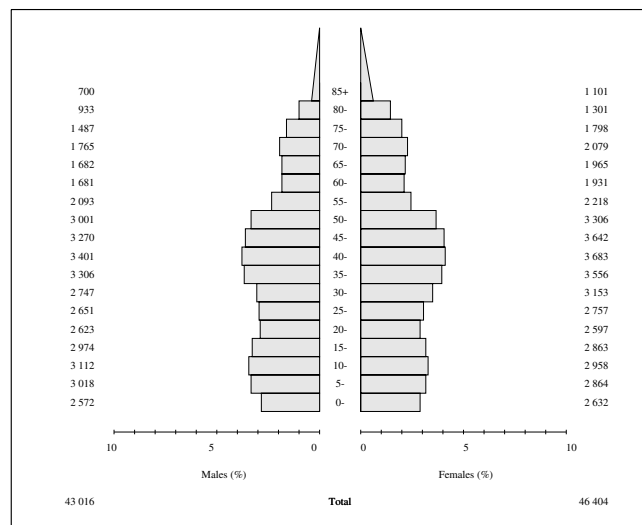
## Use of the data

Hawai'i statistics on a wide variety of malignancies are available to the research community world wide. The most recently available statistical publication, *Hawai'i Cancer Facts & Figures 2003-2004*, is available for download at <http://www.crch.org/Cancer0304.pdf>. The publication provides an overview of cancer, a discussion of the impact of gender and age and racial/ethnic disparities in cancer, and an analysis of six major cancer sites by race/ethnicity.

USA, HAWAII (1998-2002)



USA, HAWAII: CHINESE (1998-2002)



## Source of population

July 1 county population estimates by age, sex, race, and Hispanic origin; postcensal estimates based on 2000 United States Census. The population data include the bridged single-race estimates derived from the original multiple-race categories in the 2000 United States Census. <http://www.seer.cancer.gov/popdata>.

## Multiple primary rules used

IACR rules (2004) on CI5 IX period

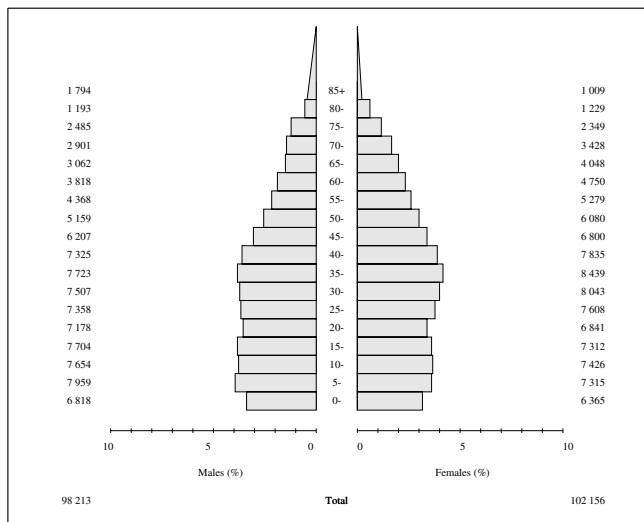
## Source of population

State and County Intercensal Population Estimates : 1990 to 2000. Source: Population Division, U.S. Census Bureau, Washington, DC 20233 (<http://www.hawaii.gov/dbedt/>).

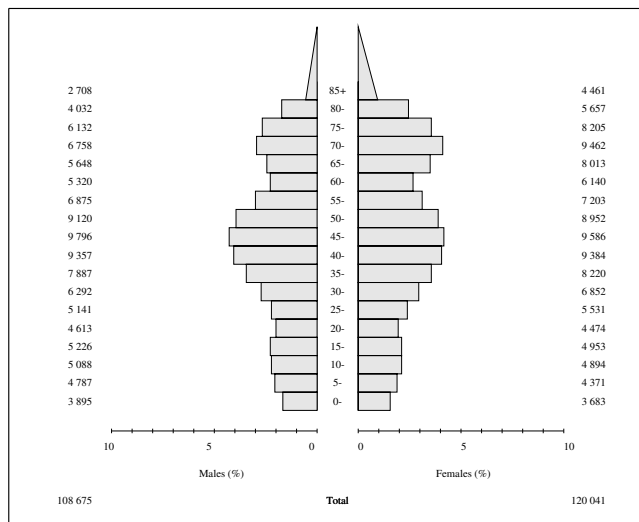
## Multiple primary rules used

IACR rules (2004) on CI5 IX period

**USA, HAWAII: FILIPINO (1998-2002)**



**USA, HAWAII: JAPANESE (1998-2002)**



**Source of population**

State and County Intercensal Population Estimates : 1990 to 2000. Source: Population Division, U.S. Census Bureau, Washington, DC 20233 (<http://www.hawaii.gov/dbedt/>).

**Source of population**

State and County Intercensal Population Estimates : 1990 to 2000. Source: Population Division, U.S. Census Bureau, Washington, DC 20233 (<http://www.hawaii.gov/dbedt/>).

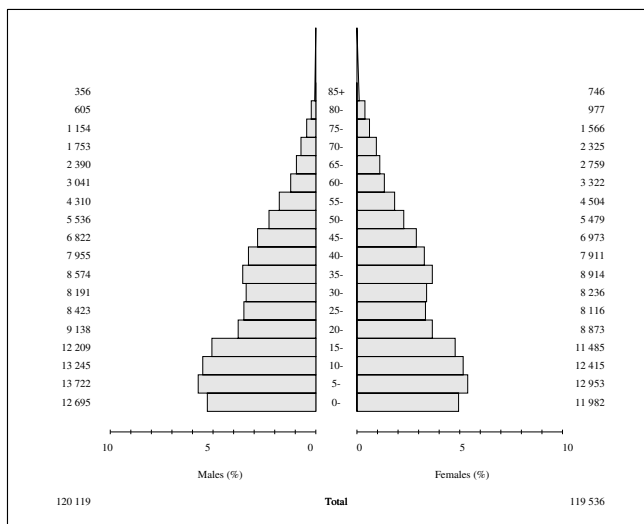
**Multiple primary rules used**

IACR rules (2004) on CI5 IX period.

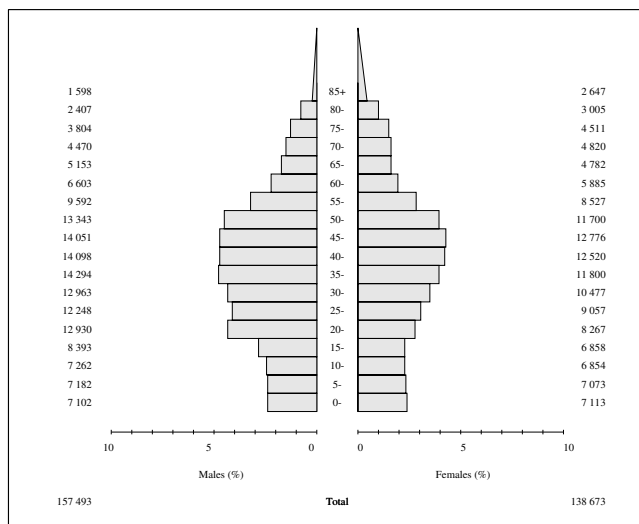
**Multiple primary rules used**

IACR rules (2004) on CI5 IX period.

**USA, HAWAII: HAWAIIAN (1998-2002)**



**USA, HAWAII: WHITE (1998-2002)**



**Source of population**

State and County Intercensal Population Estimates : 1990 to 2000. Source: Population Division, U.S. Census Bureau, Washington, DC 20233 (<http://www.hawaii.gov/dbedt/>).

**Source of population**

July 1 county population estimates by age, sex, race, and Hispanic origin; postcensal estimates based on 2000 United States Census. The population data include the bridged single-race estimates derived from the original multiple-race categories in the 2000 United States Census. <http://www.seer.cancer.gov/popdata>.

**Multiple primary rules used**

IACR rules (2004) on CI5 IX period.

**Multiple primary rules used**

IACR rules (2004) on CI5 IX period.