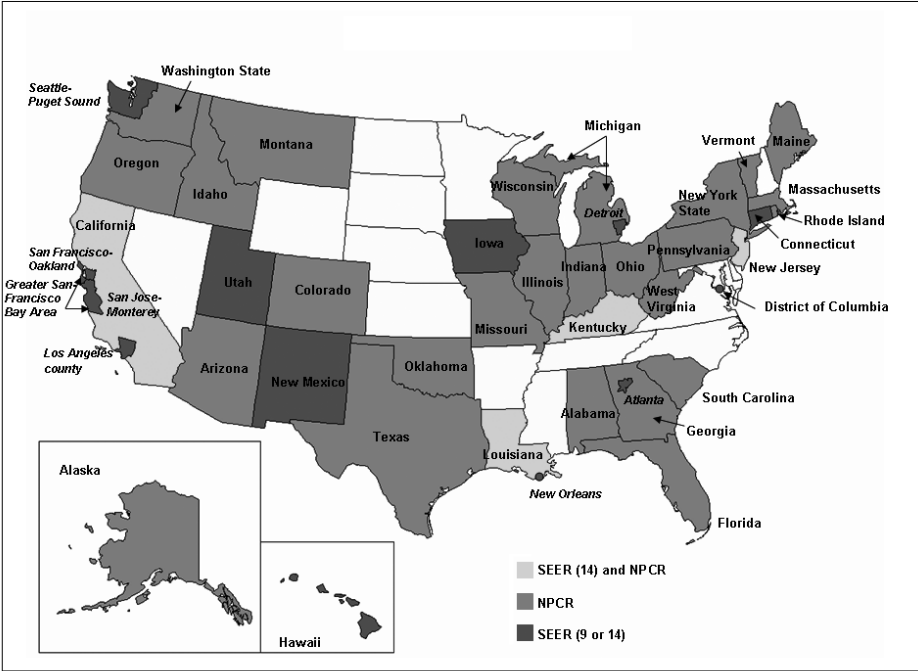


North America

Canada



United States of America



Canada (Excluding Quebec, Yukon and Nunavut)

Since 1969, Statistics Canada, Canada's central statistical agency, has collected population-based cancer incidence data. Starting with the 1992 data year, these data have been compiled by the Canadian Cancer Registry (CCR), replacing the event-oriented National Cancer Incidence Reporting System that existed from 1969 to 1991. The CCR provides national incidence and survival information required for cancer control. Reporting of cancer data by the ten Canadian provinces and two territories is coordinated by the Canadian Council of Cancer Registries, which includes representatives from each of the provincial and territorial cancer registries, Statistics Canada, and the Public Health Agency of Canada.

Registration area

Canada is the second-largest country in the world, with an area of 9 984 670 km² extending from longitude 53° to 141° W and from latitude 42° to 83° N. It is bounded to the west by the Pacific Ocean and Alaska, to the north by the Arctic Ocean, to the east by the Atlantic Ocean and to the south by the United States.

In 2001, the population of Canada numbered 31 110 565, of whom 25.5% were under 20 years of age and 12.6% aged 65 or over. Most Canadians live in a corridor about 300 km wide along the southern border. Almost one third of the population is concentrated in the metropolitan areas of Toronto, Montreal and Vancouver.

Between 1991 and 2001, Canada attracted 1 830 680 new immigrants (almost 6% of its population). Ontario attracted 55.8% of the new arrivals, followed by British Columbia (20.2%), Quebec (13.4%) and Alberta (7.1%). Almost one fifth of all Canadians are foreign-born.

Canada is an ethnocultural society. In 2001, visible minorities constituted 13.4% of the population. Of these, the largest three groups are: Chinese (25.8%), South Asian (23.0%), Black (16.6%), and Filipino (7.7%). English is the mother tongue of 58.5% of the population and French is the mother tongue of 22.6% of the population. The major religious denominations are: Catholic (42.9%), United Church (9.6%), and Anglican (6.8%). The aboriginal population of Canada (accounting for 3.4% of the population) is primarily comprised of North American Indians, Métis, and Inuits.

Registry structure and methods

The patient-oriented Canadian Cancer Registry evolved from the event-oriented National Cancer Incidence Reporting System¹ established in 1969. The Canadian Cancer Registry is an administrative survey. Beginning with cases diagnosed in 1992, cancer incidence figures collected by provincial and territorial cancer registries have been reported to the Canadian Cancer Registry, which is maintained by Statistics Canada. The Canadian Cancer Registry has been developed to provide

Canadian incidence and survival information required for cancer control. The Canadian Cancer Registry forms a personal information bank that is listed in the annual publication *Info Source: Sources of Federal Government Information*.

The Canadian Cancer Registry is a collaborative effort between the thirteen Canadian provincial and territorial cancer registries and the Health Statistics Division of Statistics Canada.

The Canadian Cancer Registry is a dynamic database of all Canadian residents alive or dead who have been diagnosed with cancer. The function of the Canadian Cancer Registry is to produce standardised and comparable cancer incidence data for each newly diagnosed primary site of cancer. The

Canadian Cancer Registry system records the kind and number (incidence) of primary cancers diagnosed for each person over a number of years until death. The advantage of this system is that longitudinal data are available for each cancer patient. New primary cancers occurring for previous cancer patients are identified. The patient data are linked annually to the Canadian Mortality Database so that the date, place and cause of death of every cancer patient are eventually known.

In addition to information on cancer incidence, data are available about the characteristics of patients as well as about the nature and frequency of their tumour(s). Since patients' records remain active on the Canadian Cancer

Registry until confirmation of their death, survival rates for the various forms of cancer can be calculated.

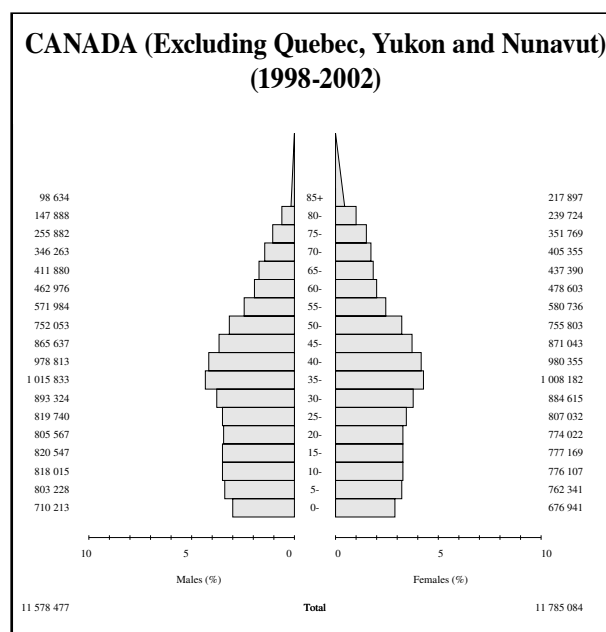
The Canadian Cancer Registry also employs specialised internal record linkage software for detecting duplicate records and for clearing death records. These procedures are done annually. Conflicting information and other problems with the cancer data are resolved through consultation with the reporting provinces and territories.

Use of the data

The annual publication *Canadian Cancer Statistics* is produced by the Canadian Cancer Society, the National Cancer Institute of Canada, the Public Health Agency of Canada, Statistics Canada, the Provincial/Territorial Cancer Registries and Health Canada. The estimates are calculated through extrapolation of cancer incidence data from the National Cancer Incidence Reporting System (NCIRS, 1969–1991) and the Canadian Cancer Registry. Also, non-nominal data for all Canadian registries are published annually by NAACCR in *Cancer Incidence in North America*.

Source of population

Estimates of Population by Age and Sex for Canada, the Provinces and the Territories (1998–2003).



Canada, Alberta

Registration area

Alberta is one of the Prairie Provinces of Canada. Its area of 661 688 km² lies between latitudes 49° and 60° W. The Alberta Cancer Registry covers the population of the 9 Regional Health Authorities within the province of Alberta. The population estimated for Alberta in 1999 consisted of 1 466 696 females and 1 497 933 males.

Alberta has a multi-ethnic population; half of the population are of British extraction, the remainder including people of other European, Asian and Native American origins.

Cancer care facilities

Cancer care is provided and administered by the Alberta Cancer Board in two major treatment centres, four associate and eleven community cancer treatment centres throughout the province. The two major tertiary centres, the Cross Cancer Institute, in Edmonton and the Tom Baker Cancer Centre, in Calgary provide radiotherapy, systemic therapy, and limited surgical procedures. The associate and community cancer centres provide chemotherapy services.

Registry structure and methods

The Alberta Cancer Board's Division of Population Health and Information operates a number of cancer prevention, screening and surveillance initiatives on behalf of the organisation. Several organisation-wide services are also coordinated by this Division, which maintains the Alberta Cancer Registry under the directorship of Dr. Heather Bryant. The Alberta Cancer Registry operates out of the two tertiary cancer centres. Calgary is responsible for the southern half of the province while Edmonton maintains data for the northern half. The Registry staff is involved in coding and abstracting, entering data into the collaborative stage program, research projects, and quality assurance activities. Completeness of cancer cases is very high in the Registry; however, passive follow-up to find additional cases includes record linkage with Alberta Vital Statistics and an ongoing case ascertainment project with the Alberta Health Registration file.

Provincial legislation mandates the registration of all reportable cancers from diagnostic facilities and medical practitioners within Alberta. The Alberta Cancer Registry primarily uses a passive case-finding approach. Pathology, cytology, and operative cytology reports as well as reports from scans, x-rays, etc. with the mention of cancer are sent to the registry. The province is in the process of implementing a provincial electronic health record, which will improve the accuracy of patient demographic information as well as provide timelier access to the reports previously outlined. In addition, Alberta Vital Statistics provides an electronic file each month of all individuals dying in the province, which

enables the Registry to identify patients who have died from cancer or cancer patients dying from other causes.

The Alberta Cancer Registry maintains routine computerised and manual quality assurance data reviews of specific variables on a monthly, quarterly, and yearly basis as required. Mechanisms have also been established to measure the quality of registry-collected variables with respect to completeness, accuracy, and timeliness. The Alberta Cancer Registry received the Gold Standard awarded by the North American Association of Central Cancer Registries (NAACCR) for 1998, 1999, 2000, 2002, 2003, and 2004 incidence data. For 2001 data, silver certification was awarded.

Use of the data

The Alberta Cancer Registry publishes or is involved in the development of several documents on cancer incidence and mortality in Alberta. Publications include the annual report, *A Regional Picture of Cancer in Alberta* (for the Regional Health Authorities), *A Snapshot of Cancer in Alberta*, and various monographs.

The registry is the key source of information for service provision planning by the Alberta Cancer Board, its host agency. Information on cancer within each regional health authority in Alberta is also released to them for planning services. The registry provides data to the screening programs to allow for quality assurance and follow-up of mammography and cervical screening.

The Cancer Registry also has a close relationship with the Alberta Cancer Board's clinical database, which enhances data analysis opportunities.

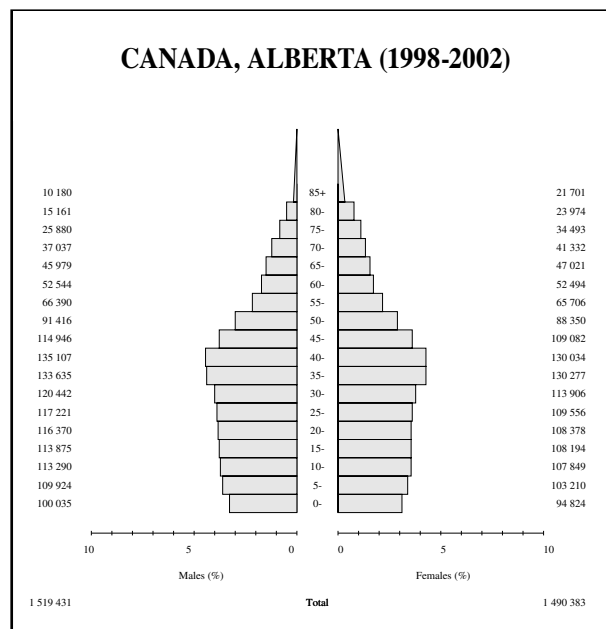
We also respond to over 100 requests for information from the Registry each year. Many of these requests involve the use of Registry data for population or clinical research questions. Examples of this include the use of registry data to invite participants into intervention trials, or studies of the use of complementary therapies for cancer treatment. All research projects must be approved by the Research Ethics Board prior to initiation, and the registry, rather than the investigator, is the usual originator of contact with the individual. Registry data has also been included in several multi-centre studies, and the Alberta Cancer Registry has combined registry data with other research data to examine the projected impact of the use of Hormone Replacement Therapy in the population.

Source of population

The population-at-risks by sex and age from 1998–2003 have been estimated using the adjusted intercensal or postcensal estimates based on the 1996 Census, as provided by the Population Estimates Section, Demography Division, Statistics Canada.

Multiple primary rules used

IACR rules (2004) on historical data



Canada, British Columbia

Registration area

The registry covers all of British Columbia (BC) (926 492 km²), the most westerly province of Canada, bordered by Alberta to the east and by the Pacific Ocean to the west. Most of the population is concentrated in the southwest corner of the province, where the climate is the mildest.

The proportion of immigrants in the population has increased by 1.3% from 17.7% for the 1991–1995 period to 19.0% for 1996–2001. Currently, most immigrants to BC come from Asia, in particular China, Taiwan, India, Hong Kong, the Philippines and South Korea. Based on the 2001 census, 56% of British Columbians belong to a single ethnic origin and 44% to more than one. The largest group of visible minorities within British Columbia is the Chinese, followed by South Asians. Aboriginal people comprised 4.4% of the population in 2001.

The top three industries within British Columbia are retail trade, health care and manufacturing, with the largest component of the working population employed in clerical and sales occupations.

Cancer care facilities

Cancer diagnostic services are provided through general hospitals and specialty clinics. Cancer therapy is provided through a mix of dedicated cancer facilities and general hospitals. The BC Cancer Agency (BCCA), a provincial government agency responsible for cancer care, control and research in British Columbia, operates four regional cancer centres that have close links with local hospitals. Radiation therapy is provided exclusively through the four regional cancer centres. The regional cancer centres also provide approximately 50% of cancer chemotherapy services, with the remainder provided through the Communities Oncology Network, a collaborative voluntary partnership with 19 Community Cancer Centres, 6 Community Cancer Services and 12 Consultative Clinics across BC, in conjunction with the Regional Cancer Centres and the Systemic and Radiation Programs. The Network also supports appropriate delivery of cancer patient care and support in 33 other Community Hospitals.

Registry structure and methods

The registry is part of a combined population-based registry and clinical database maintained by the BCCA. The registry has monitored the impact of cancer on the BC population since 1969. For many years it was mandatory to report cancer cases; however, legislation passed in 1987 authorised the registry to obtain relevant information without the provision of mandatory reporting.

The registry received notification of 95% or more of the cancer cases diagnosed in the province by submission of pathology reports from hospital laboratories or following attendance at one of the four BCCA Cancer Centres, where

about 61% of cancer cases are treated or seen at some point. The registry receives listings of all deaths in the province from the BC Vital Statistics Agency. Follow-up is performed to obtain complete registration information and documentation on all cases.

The personnel consists of a director and a scientific director, one senior, one supervisor and eight health record technicians.

Interpreting the results

The Screening Mammography Program of BC (SMPBC) was established in 1988 through the BC Cancer Agency to reduce breast cancer mortality through early detection. From 2000–2004 (inclusive), 1 134 806 examinations were performed for 512 372 women, and 4627 breast cancers were diagnosed (overall cancer detection rate of 4.1 per 1,000).

The BCCA's Cervical Cancer Screening Program was the first organised programme in the world to screen for cervical cancer. In BC, approximately 71% of women age 20 to 69 were screened in a recent 30-month period. The cervical screening programme is credited with an 85% reduction in the number of BC women getting cancer of the cervix and for reducing cervical cancer deaths by 75% since the 1950s.

The Hereditary Cancer Program (HCP) is a result of the BCCA and the BC Provincial Medical Genetics Program working together to

provide information and genetic counselling for individuals and families with a strong history of cancer.

PSA screening for prostate cancer became common in the early 1990s although it is not a publicly funded service. Rates of prostate cancer peaked in 1993 and have declined since then.

Use of the data

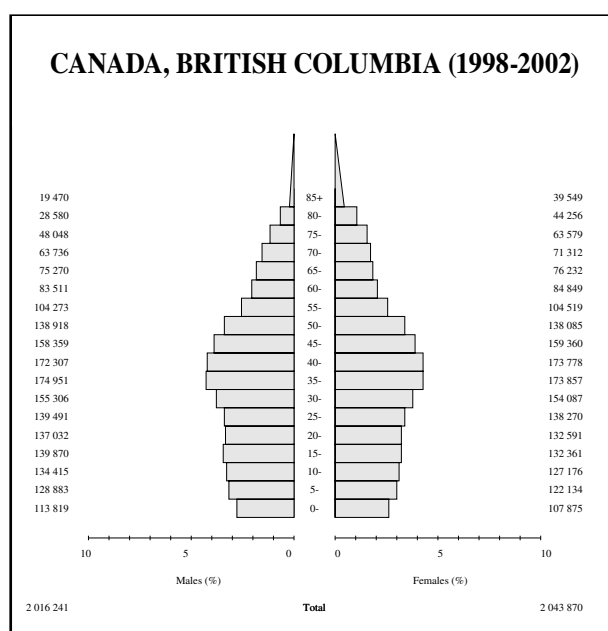
The registry was originally set up to monitor cancer incidence and mortality in the province, but is now extensively used for health services planning and epidemiological research. Registry data are used as a source of cases for surveys and case-control studies, and as outcome data for cohort studies of occupational groups. Registry statistics and estimates of future incidence trends have also been used in conjunction with clinic referral data for cancer services, budgeting and facilities planning.

Source of population

The population-at-risks by sex and age from 1998–2003 have been estimated using the adjusted intercensal or postcensal estimates based on the 1996 Census, as provided by the Population Estimates Section, Demography Division, Statistics Canada.

Multiple primary rules used

IACR rules (2004) on CI5 IX period.



Canada, Manitoba

Registration area

Manitoba is a province located in central Canada, bordered to the east by Ontario and Hudson Bay, to the west by Saskatchewan, to the north by Nunavut and the Northwest Territories and to the south by the American states of North Dakota and Minnesota. It lies between latitude 49° and 60° N and longitude 90° and 102° W. The altitude varies from sea level to 823m, and the province covers an area of 649 950 km².

At the time of the 2001 census, 72% of the population was urban, with 60% living in the capital city of Winnipeg. Manitoba is ethnically diverse. Approximately 13.6% of all residents were Aboriginal (Native Americans 60.2%; Métis 37.9%; Inuits 2.3%). A similar number had immigrated from other countries. Of the 133 660 immigrants, 47.5% were born in Europe and 30.3% were born in Asia. The majority of Manitobans reported British (36.7%), French (12.6%) and/or other European (48.0%) heritage.

Cancer care facilities

CancerCare Manitoba is a provincial cancer agency with a mandate to coordinate all aspects of cancer control in Manitoba. Direct patient care involves the provision of treatment services, including outpatient-based radiation therapy at one centre in the major urban centre (Winnipeg), chemotherapy and breast screening mammography. The cancer agency partners with other community care facilities to provide cancer services through the Community Cancer Programs Network, an innovative program for delivering cancer care—primarily chemotherapy—in local communities throughout the province. *Supportive activities* include cancer-related consultation services for other healthcare providers and the development of standards for the delivery of cancer care in Manitoba, as well as the facilitation of cancer-related education, surveillance and research activities.

Registry structure and methods

Manitoba has one of the longest standing cancer registries in the world. It was started in 1937, although it did not become fully population-based until 1956. The registry is located within the Department of Epidemiology and Cancer Registry at CancerCare Manitoba. It is funded via CancerCare Manitoba by Manitoba Health, the provincial health department. The registry staff include the manager,

eight cancer registrars, a quality assurance technician, a senior cancer registrar, three clerks and an administrative assistant. Three of the staff are Certified Tumor Registrars. Staff from the epidemiology section of the department also provide support for the registry (four epidemiologists and six analysts); the epidemiology staff are also extensively involved in research, much of which revolves around the cancer registry and linkage to other population-based datasets.

Reporting of cancer has been mandated by law since 1956. Case finding is passive, and multiple sources of ascertainment are used. These include physician notifications, pathology and cytology reports, and hospitalisation, mortality and autopsy records. Cancer registrars collect, classify and maintain

comprehensive information on cancer patients. Quality control is an important part of cancer registration in Manitoba, and the registry has been consistently certified by NAACCR for the past eight years.

Interpreting the results

The cancer statistics presented in this volume may be influenced by diagnostic and early detection technologies. The most significant effect is expected to be increased breast cancer incidence resulting from the establishment of the provincial breast screening programme in 1995. An organised cervical cancer screening programme was initiated in 1999. Opportunistic screening for prostate and colorectal cancer occurs, but the magnitude of these practices—and therefore

the effect on cancer incidence rates—remains unknown.

Use of the data

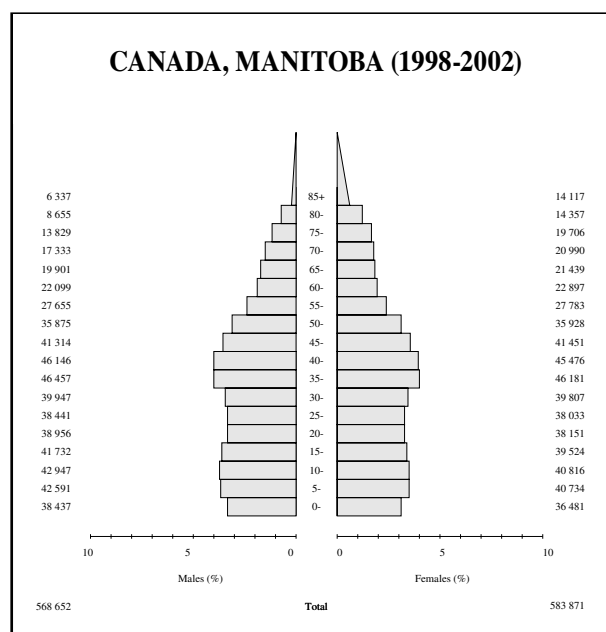
The data are used to answer questions relating to the whole spectrum of cancer control in Manitoba. They are also used for surveillance, research, evaluation, planning and teaching purposes and to provide diagnostic confirmation and treatment-related information to healthcare providers.

Source of population

The population-at-risks by sex and age from 1998–2003 have been estimated using the adjusted intercensal or postcensal estimates based on the 1996 Census, as provided by the Population Estimates Section, Demography Division, Statistics Canada.

Multiple primary rules used

IACR rules (2004) on CI5 IX period.



Canada, New Brunswick

Registration area

The New Brunswick (NB) registry covers the population of seven regions and eight Regional Health Authorities within the province. The provinces of Quebec, Nova Scotia and the state of Maine, USA border NB. The population at the most recent census (2001) was 729 498. About 50.4% of the population lives in urban areas (>1000 and no fewer than 400 persons per km²). There are seven cities, none of which has a population greater than 100 000.

In New Brunswick, religious makeup as reported by the Statistics Canada 2001 census is reported as 54% Catholic, 37% Protestant and 8% with no religious affiliation. Men account for 49.4%, of whom 6% are over 65 years of age, compared to women, 50.6% and 8% respectively. Ethnicity is reported predominantly as Canadian and then French, English and Irish.

Cancer care facilities

Medical treatment of cancer focuses on four modalities: surgery, medical oncology, radiation and supportive services. Paediatric oncology cases are generally referred to Nova Scotia or Quebec for initial consultations with a paediatric oncologist. There are two major radiation-based cancer centres located in the southern part of the province in the cities of Moncton and Saint John. In 1993, the second radiation facility was added in Moncton.

Chemotherapy is administered in the major centres and in 12 outreach centres. There is a provincial Breast Cancer Screening Program that was rolled out in 16 facilities in NB in 1995 to service asymptomatic women between the ages of 50 and 69. There is decentralised cervical screening in NB.

There is no organized prostate screening. PSA testing is ordered at the discretion of the urologist or family physicians in the regions.

Registry structure and methods

The registry is a population-based central cancer registry located in Saint John, NB. The registry is funded by the Department of Health and overseen by Provincial Epidemiology Services (PES), which is located in the city of Fredericton.

The registry is staffed by 4 permanent employees, one PES person who serves as liaison between the coding staff and several internal and external parties, such as Statistics Canada, NAACCR, and the Public Health Agency of Canada. The Director of the registry is Director of the Provincial

Epidemiology Services and the Provincial Epidemiologist for NB.

The NB registry uses passive case-finding predominantly from pathology laboratories, radiation and haematology centres, death registrations, autopsies and data from other provincial registries. An electronic linkage is conducted annually between Vital Statistics and the registry database to reconcile missing death information and to identify cases where there is a mention of cancer on the death certificate but no abstract is found in the registry database.

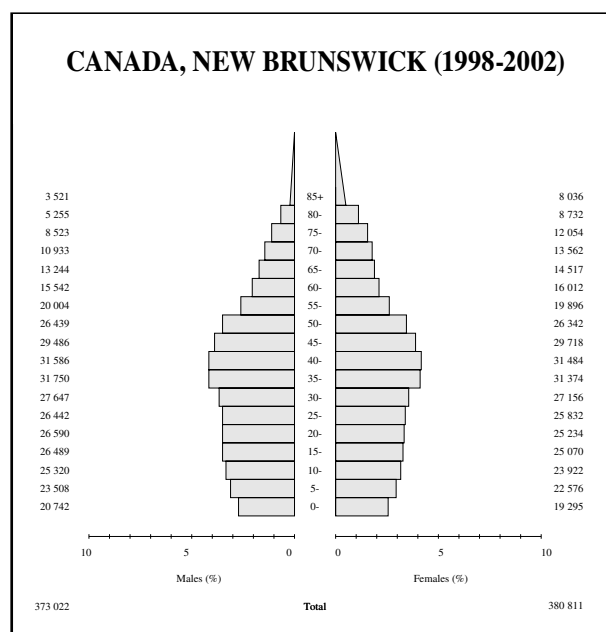
The cancer registry is a patient- and disease-oriented database. Persons may have more than one type of tumour in the database, and the rules governing multiple primary tumours are those of the CCR and SEER. NB also registers basal and squamous cell carcinoma of the skin, one of each, per person per lifetime since 1989.

The AJCC TNM classification method is currently used to assign stage to breast cancer cases.

Authorization to submit patient-specific information is derived from Section 21(1), regulation 92-84 of the Hospital Services Act of NB.

Interpreting the results

NAACCR has awarded silver certification to the NB Cancer Registry for years 1997, 1998, 1999, 2000, 2002, and 2003, and gold in 2001. Incidence is grouped according to the Surveillance, Epidemiology and End Results (SEER) Groups for Primary site of ICD-0-3.



Use of the data

The registry prepares a five-year report of cancer incidence and mortality, highlighting trends and changes by region and community. Some special studies of survival of registered cancer cases (breast), as well as epidemiological research, have been carried out. Policymakers use our data to assess the need for specialized oncology services in the regions and to assess costs on insurance reimbursements for various drugs and equipment related to cancer.

Source of population

The population-at-risks by sex and age from 1998–2003 have been estimated using the adjusted intercensal or postcensal estimates based on the 1996 Census, as provided by the Population Estimates Section, Demography Division, Statistics Canada.

Multiple primary rules used

IACR rules (2004) on CI5 IX period.

Canada, Newfoundland and Labrador

Registration area

The Registry covers the whole of the province of Newfoundland and Labrador, which lies on the east coast of Canada. The island of Newfoundland is surrounded by the Atlantic Ocean. Labrador is bounded by the Atlantic to the east and the province of Quebec to the west and south. The landmass of the province extends between 47 and 61° N and longitudes 52 and 76° W. The altitude varies from sea level to 1600m in the interior of Labrador. The total area is 371 634 km².

The population according to the 2000 census was 554 076 and in 1991 the population was 568 475. The decrease in population is the result of the net outflow due to migration to other provinces.

Registry structure and methods

The Provincial Cancer Registry was started by the Department of Radiotherapy of St. John's General Hospital in 1954. In 1974, the registry came under the jurisdiction of the Newfoundland Cancer Treatment and Research Foundation (NCTRF). NCTRF was dissolved in 2005 and is now under one of four Regional Integrated Health Authorities. The Newfoundland Cancer Registry is a part of the Provincial Cancer Care Program, Eastern Health, formed on 1 April 2005. Eastern Health is the largest integrated health network in Newfoundland and Labrador, serving a regional population of more than 290 000 and offering unique provincial programs and services. The new health region extends west to Port Blandford and includes all communities on the Avalon, Burin and Bonavista Peninsulas. There are more than 80 hospital, health care centres, long-term care facilities and community care sites.

The Provincial Cancer Registry is located within the Dr. H. Bliss Murphy Cancer Centre, in St. John's. There are regional programs in Corner Brook, Grand Falls-Windsor, St. Anthony and Gander, and regional clinics at the Burin Peninsula Health Centre, Burin; Captain William Jackman Memorial Hospital, Labrador City; and Melville Hospital,

Happy Valley-Goose Bay. The Registry is staffed by a full-time director, a manager, a part-time programmer analyst and three full-time health record professionals.

The process for cancer registration is through an Electronic Pathology reporting system (E-Path). The Cancer Registry receives pathology reports electronically from six pathology laboratories through a HL7 interface. Each report is filtered using the ICD-0-3 auto-coding engine. The automated filtering logic examines the topography and morphology codes, and then based on registry reporting requirements selects reports for submission to the registry. E-path has improved the timeliness, completeness and consistency of pathology information.

Cancer is not a reportable disease in our province; the Cancer Act provides a legal mandate for the Provincial Cancer Care Program to establish and maintain a cancer registry.

Interpreting the results

The Cancer Registry is in the process of reactivating a provincial death clearance process. We have purchased a software package (Linkage Wiz) to assist with this process.

Use of the data

The data are used to answer questions relating to the whole spectrum of cancer control in Newfoundland and Labrador. The data are also used for surveillance, research, evaluation, planning

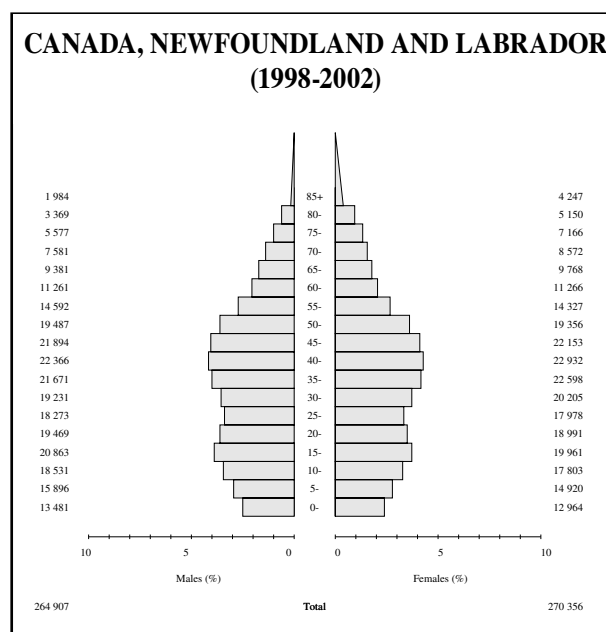
and to provide diagnostic confirmation and treatment-related information to healthcare providers.

Source of population

The population-at-risks by sex and age from 1998–2003 have been estimated using the adjusted intercensal or postcensal estimates based on the 1996 Census, as provided by the Population Estimates Section, Demography Division, Statistics Canada.

Multiple primary rules used

IACR rules (2004) on CI5 IX period.



Canada, Northwest Territories

Registration area

The area covered by the registry is the one of the largest in Canada, yet is sparsely populated. The Northwest Territories (NWT) comprises the area north of the 60th parallel, lying between the Yukon Territory and the Beaufort Sea to the west and Nunavut to the east. The Arctic Ocean forms the northern border, which reaches as far as the 83rd parallel.

All forms of malignancy have been reportable in the Northwest Territories since late 1980. However, the very extensive circumpolar geographical area, which constitutes this jurisdiction, results in an additional reliance on diagnostic service and reporting and may also affect completeness. It should be noted that collection of cancer data was initiated in the late 1950s.

In 2003 the population of NWT was about 42 406 persons living in some 32 communities, half of which had populations of fewer than 500 residents. One-quarter of the population is under 15 years of age. Health programmes and services were provided by eight health and social services authorities and/or boards, reflecting ten official language groups in four ethnic categories (Dene, Inuit, Metis, and non-Aboriginal). Half of the population are Aboriginal people.

Cancer care facilities

In NWT it is possible to perform biopsies, but all diagnostic laboratories are based in Alberta, Canada. It is possible to perform chemotherapy and hormone therapy in the Territories, but there are no radiotherapy departments in the area.

Registry structure and methods

The NWT Cancer Registry is maintained by two registry staff within the Population Health Division, Department of Health and Social Services, Government of the Northwest Territories. These consist of one coder and one analyst. Two are in the process of training to code and we are in the process of having the Alberta Cancer Registry administer the database.

Most formal health services and programmes are provided through community health centres staffed by nurses

and visited by itinerant physicians. Three hospitals provide second-line specialist services. However, most tertiary-level services are offered outside the jurisdiction.

All cancers are registered using a form that must be completed by the treating physician at the time of diagnosis. Also, the contract with out-of-territory laboratories requires that a copy of pathology reports indicative of cancer be forwarded to the Registrar. Other sources of information result from an active search of vital statistics, discharge summaries and physicians' notes. The principal sources of information on cancer cases are laboratory reports and discharge summaries. Death certificates are retrieved from the Northwest Territories Vital Statistics office in Inuvik.

Informal evaluations are performed to ensure validity and completeness.

Interpreting the data

In 1999, Nunavut separated from the Northwest Territories. Over time we have gained services for mammography and are now able to provide chemotherapy and hormone therapy treatment. Since last year, we now have an oncologist that comes to the territories on a monthly basis.

There is an organized screening programme for breast cancer in the Yellowknife region, and PSA testing is common in our population.

Use of the data

The registry is not currently involved in epidemiological

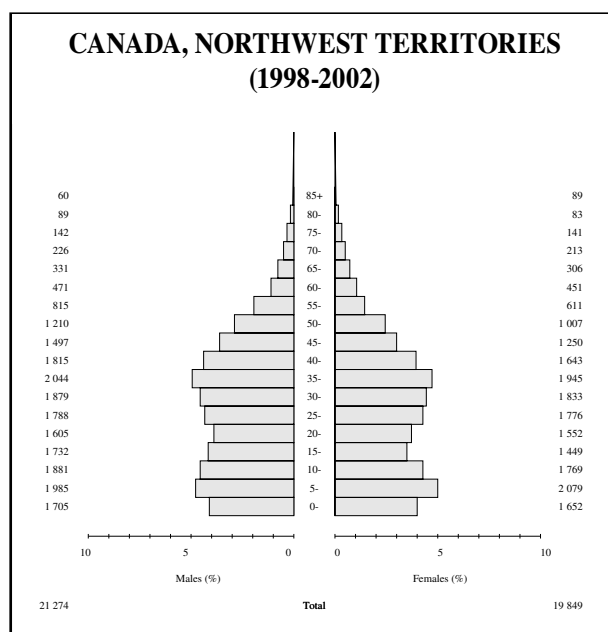
research beyond the production of routine statistics, but policymakers use our cancer registry data for planning and evaluation of health services.

Source of population

The population-at-risks by sex and age from 1998–2003 have been estimated using the adjusted intercensal or postcensal estimates based on the 1996 Census, as provided by the Population Estimates Section, Demography Division, Statistics Canada.

Multiple primary rules used

IACR rules (2004) on CI5 IX period.



Canada, Nova Scotia

Registration area

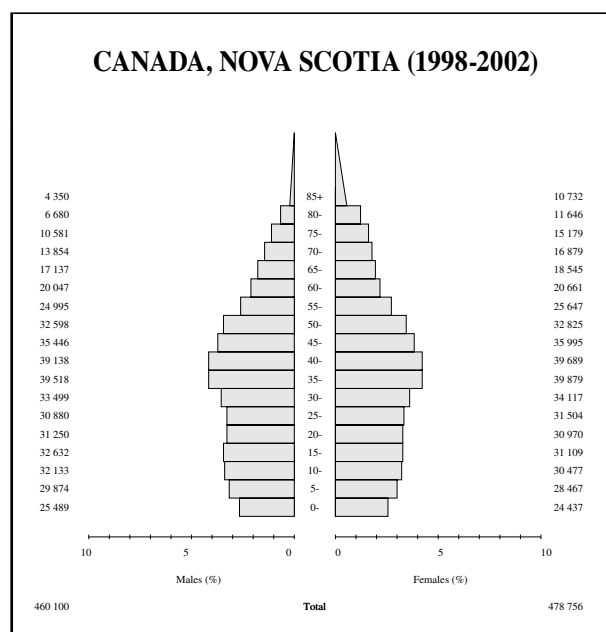
The registry covers the whole of the province of Nova Scotia, one of the three Maritime Provinces of Canada, lying to the south of the St. Lawrence River, east of the Gulf of Maine and south of the provinces of New Brunswick and Prince Edward Island. Although joined to New Brunswick by a central peninsula to the north, it is separated from Prince Edward Island by the Northumberland Strait; to the south, west and east lies the Atlantic Ocean. Most of the province is less than 200m above sea level, the highest point being at 529m in Cape Breton. The province covers an area of 55 491km².

At the 2001 census, the total population of Nova Scotia was 932 389, of which 45% report to be of United Kingdom origin, and 16% French while just over 3% indicate North American Indian. Some 40% of census respondents indicate multiple ethnic origins. The active labour force (443 000) was employed in the following categories of industry: manufacturing, 9.3%; construction 6.1%; primary industry (agriculture, fishing, forestry, mining), 4.2%. Almost 80% report being involved in service-related industries (e.g. trade; finance, healthcare, government, education). In 2001, 56% of the population described itself as urban and 44% as rural dwellers. Over 95% of the population who report religion on the census indicate Christian, while 11% did not respond.

Cancer care facilities

All residents of Nova Scotia are covered by a publicly funded comprehensive health insurance scheme. This includes access to family physician and hospital-based care. Many residents have supplemental insurance programs for costs not covered by the public system (e.g. prescription drugs). Since 1993, all residents are assigned a unique health card number that remains with them for life and aids in the maintenance of an unduplicated patient index. Health care is administratively managed and delivered by district health authorities (DHAs). Cancer care is highly centralised, with coordination occurring under a provincial cancer program. There are two main provincial cancer centres that operate satellite facilities across the province for oncology specialist referral and follow-up. Approximately 60% of all patients have some contact with a centre or satellite clinic at diagnosis.

The Nova Scotia Cancer Registry (NSCR) is operated as part of the provincial cancer program and funded by government. It is physically located in Halifax, at a site within the largest district health authority. A total of 12 FTE's are in place (registrars, analytic, administrative staff). Two cancer centres that operate as part of DHAs also have on-site abstracting staff who submit cases to the registry. Cancer has been a reportable disease by law since 1964. The main reporting sources include hospital health record departments (since 1964), pathology/cytology laboratories (since 1964), cancer centres since 1981 (includes all radiotherapy delivery), death record linkage (since 1969) and more recently, screening of visits at targeted clinical areas (e.g. haematology clinics).



Interpreting the results

The NSCR is active in the Canadian Council of Cancer Registries and is a full member of the North American Association of Central Cancer Registries, including participation in the annual certification program. In the five-year period covered by this data submission, several studies were carried out to review case completeness and demonstrated excellent results. New processes have been put in place to target out patient haematological diagnoses. During and at the end of each calendar year, a series of edit checks ensure the quality of data, which are then submitted to Statistics Canada to become part of the Canadian Cancer Registry.

Use of the data

The registry prepares an annual report of cancer incidence and provides this data to users, highlighting trends and changes. A major monograph is produced every five years, and includes incidence, mortality, survival, projections and prevalence analyses. Ad-hoc queries are frequently received and responses provided. Data are also made available for research purposes to ethically-approved studies.

Source of population

The population-at-risks by sex and age from 1998–2003 have been estimated using the adjusted intercensal or postcensal estimates based on the 1996 Census, as provided by the Population Estimates Section, Demography Division, Statistics Canada.

Multiple primary rules used

IACR rules (2004) on CI5 IX period.

Canada, Ontario

Registration area

The Ontario Cancer Registry is the largest patient-specific population-based cancer registry in Canada. Operated by Cancer Care Ontario (CCO) since 1964, it covers the entire province of Ontario. The population at most recent census (2001) is approximately 11.4 million people, with over 80% of the population living in urban centres. The major racial/ethnic groups in Ontario are: European 80.9%, South Asian 4.9%, Chinese 3.7%, Black 3.6%, Aboriginal 1.7%, Filipino 1.3%, Latin-American 0.9% and other 3.0%

Cancer care facilities

Cancer Care Ontario is the principal adviser on cancer issues for the Provincial Government. CCO is responsible for long-term planning of the cancer care system and coordination of cancer prevention and control activities and programmes (cancer surveillance, prevention, screening, diagnostic services, treatment, supportive care and research) in Ontario.

CCO does much of its work through 14 Regional Cancer Programs, which are geographically aligned with Ontario's health planning regions (called Local Health Integration Networks, or LHINs). The 12 Integrated Cancer Programs are located in major urban centres, and serve as the hub of the Regional Cancer Programs. CCO continues to directly manage the Ontario Breast Screening Program and the New Drug Funding Program.

Registry structure and methods

The registry operates under CCO's Informatics Unit. CCO's operating expenses were approximately \$460 million in FY 2005/06, and it currently has approximately 330 employees, including planners, scientists, analysts, statisticians, clinical and non-clinical managers, technicians and other professionals.

Cancer registration in Ontario is passive, relying almost completely on electronic records collected for other purposes. Close to one million source records are submitted to the OCR each year. Since 1979, the OCR has relied on four major data sources: hospital discharge (including day surgery) summaries that include a diagnosis of cancer; pathology reports with any mention of cancer; records of patients referred to the Integrated Cancer Programs; and death certificates for all underlying causes of death.

While cancer is not a legally reportable disease in Ontario, the Cancer Act provides a legal mandate for Cancer Care Ontario to establish and maintain a cancer registry. Further, under the Cancer Act, any information about a registered case must be kept confidential and not be used or disclosed for any purpose other than

for compiling statistics or carrying out medical or epidemiological research. Under the 2004 Personal Health Information and Privacy Act, CCO is also mandated to use this information for planning and management of the cancer system in Ontario.

Interpreting the results

Because of changes in diagnostic practices or rules of coding and registration, interpretation of temporal trends must be done with caution. For example, with the introduction of ICD0-2 in Ontario in 1993, borderline ovarian tumours were now registered as invasive neoplasms; this increased incidence by about 30%. But with the introduction of ICD0-3 in 2002, the classification of borderline tumours reverted from malignant to uncertain behaviour. Thus, incidence seemingly fell by 30%.

Limitations in the range of registered tumours may limit comparability. For example, the Ontario Cancer Registry does not register non-malignant brain tumours, non-melanoma skin cancers, or in-situ cancers, nor is there registration of other cancer precursors (e.g. adenomatous polyps of the colorectum).

Limitations in the accuracy and timeliness of registering and reporting actual incident cases may also be critical factors. For example, annual incidence data are generally not considered final and reported publicly until approximately

18–24 months following initial diagnosis. This may be a limitation for researchers who desire more rapid reporting. Problems in coding consistency and classification constancy may also occur.

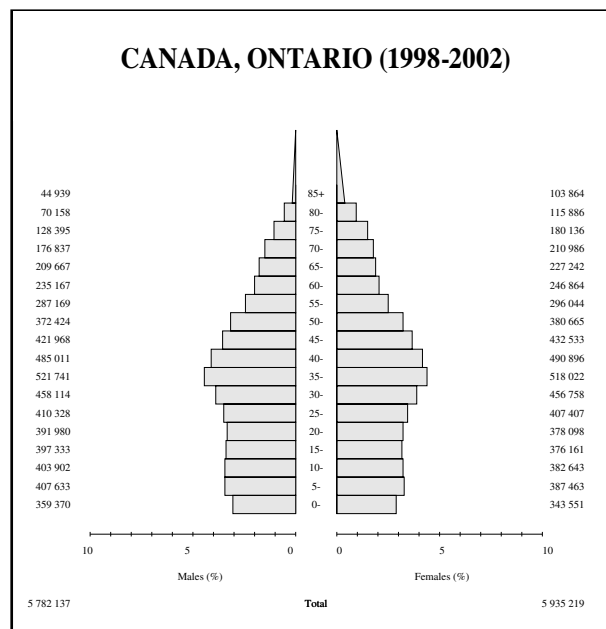
Further, new methods of screening and diagnosis can also change patterns of incidence. With rapid diffusion of new methods (e.g. PSA screening introduced in Ontario in 1989) incidence may increase dramatically, often within months, and may distort assessment of the underlying risk of cancer, or present a sudden increase in demand for the cancer system.

Use of the data

The OCR is an invaluable resource for conducting epidemiological studies, and is also used to follow up patients or individuals who may have been exposed to risk factors.

The OCR can also be used to help evaluate the effectiveness of screening programmes. The Ontario Breast Screening Program links its database to the OCR in order to confirm diagnoses of cancer in the screened population, identify interval cancers and verify vital status.

Over the 1990s, use of the OCR expanded to include health care utilisation studies. The availability of data regarding utilisation of hospitals and cancer clinics by



cancer patients as well as details regarding treatment (e.g. surgical procedures) provides researchers with a useful tool in performing these studies.

Finally, with the evolution of CCO into Ontario's planning agency for cancer services, there has been a substantial investment in modern statistical methods of forecasting, as applied to predicting future incidence, survival, prevalence and mortality, over the short (3–5 yrs) and medium (10–15 yrs) terms.

Source of population

The population-at-risks by sex and age from 1998–2003 have been estimated using the adjusted intercensal or postcensal estimates based on the 1996 Census, as provided by the Population Estimates Section, Demography Division, Statistics Canada.

Multiple primary rules used

IACR rules (2004) on CI5 IX period.

Canada, Prince Edward Island

Registration area

The registry covers all of Prince Edward Island, the smallest province of Canada, which is situated to the southwest of the Gulf of St. Lawrence, lying between longitudes 62° and 65° W and latitudes 46° and 48° N. The island covers an area of 5684 km².

The population according to the 2001 census was 135 294, with 60 675 being urban and 74 619 being rural. A preliminary population count on 1 July 2005 showed a population of 138 113 on PEI. The male to female breakdown from the 2005 population estimates that 67 198 are men and 70 915 are women. Of these, 11 993 of the females and 12 459 of the males were under age 15. A large majority of the population of PEI is of British Isles origins, followed by French origins. A smaller number are of other European origins.

The primary employment by industry are service sector jobs followed by agriculture and fishing.

Cancer care facilities

The PEI Cancer Registry was formerly part of the Provincial Health Services Authority and is now a division of the Department of Health under the Queen Elizabeth Hospital (QEH) and the PEI Cancer Treatment Centre (PEICTC). Hospital organisation and practice are based on a comprehensive government-organised health insurance scheme. There are no private hospital facilities. Treatment services are provided at the Queen Elizabeth Hospital in the PEI Cancer Treatment Centre. Satellite clinics are held at the Prince County and Kings County Memorial Hospitals, providing medical oncology services. Diagnostic services include CAT scan and MRI, both of which are located in the Diagnostic Imaging Department of the QEH adjacent to the PEICTC. Radiation treatment on a Linear Accelerator became available on Prince Edward Island in October 2003. Previously all radiation treatments delivered on PEI were via a Cobalt 60 machine. All radiation treatment necessitating a Linear Accelerator required travel to another province prior to this time. There is an organised Breast Screening program in PEI. There is no formalised colorectal screening program. PSA testing and colorectal screenings are done at the discretion of the physicians.

Registry structure and methods

The PEI Cancer Registry commenced with cancer collection in 1969 and has been submitting cancer data nationally to Statistics Canada since then. The registry personnel consist of the director (medical oncologist), the manager (1FTE) and a health records technician (.5 FTE). The PEI Cancer Registry is not currently involved in any epidemiological research projects but did participate in the National Enhanced Cancer Surveillance study.

The main source of data for the registry is pathology reports with a diagnosis of cancer, copies of which are sent

to the registry from the provincial pathology laboratory. The registry has 98% completeness using the Canadian I/M ratio. The percentage of microscopically confirmed cases for PEI was 93% for the 2003 data submission year. Additional data necessary for cancer registration are obtained from the outpatient cancer treatment centre charts and hospital charts. Physicians and nursing homes are also contacted as needed to obtain information. Electronic sources of data available to the cancer registry staff include the radiology information system, and the laboratory case management system. Death lists are sent from Vital Statistics to the registry monthly. All deaths with mention of cancer are researched and followed back to ensure all cases are registered. Death certificates as the only source of information

comprise a very small number of registrations due to the rigorous follow-up procedures; in fact for the 2003 data submission year there were no cancer registrations in which death certificates were the only source of the cancer registration data.

The registry staff follows up on any cases that require further information for registration. The small size of the province and the accessibility of information enable staff to complete cases with a very high degree of quality. The implementation of an electronic health record in the spring of 2007 will further enhance the ability of the registry to follow up cases for further information.

The registry started to collect staging information on all breast and colorectal cancers starting with cases diagnosed in

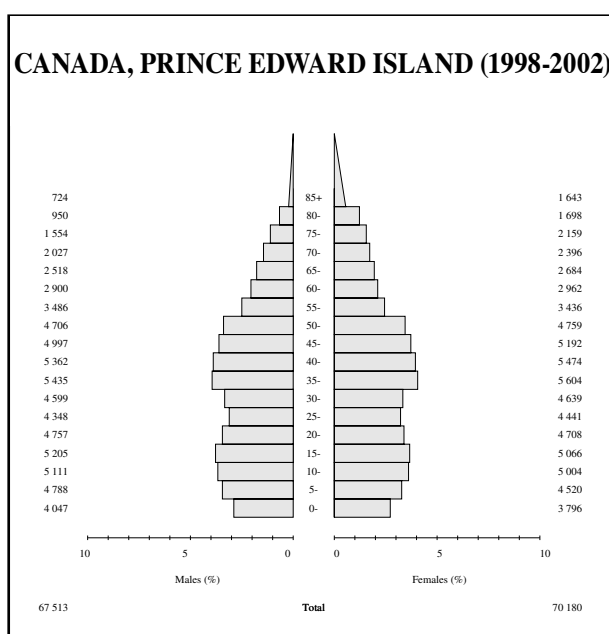
2003. Staging information on all lung and prostate cancers was added for diagnosis year 2005 with the expectation of stage collection on the whole incidence file in future years. The time frame for this is financial/human resource dependant. The registry staff has received formalised training on the staging of breast, colorectal and lung cancer using the Collaborative Stage method of data collection, with prostate and head and neck sites completed in September 2006 and 2007 respectively. The manager of the registry has been very involved in the national implementation of stage collection and is currently one of six Canadian staging specialists providing training to other cancer registrars. The manager of the cancer registry keeps the statistics for cancer incidence as well as all workload statistics for the PEICTC, which are used by policymakers for future planning of required health services.

Source of population

The population-at-risks by sex and age from 1998–2003 have been estimated using the adjusted intercensal or postcensal estimates based on the 1996 Census, as provided by the Population Estimates Section, Demography Division, Statistics Canada.

Multiple primary rules used

IACR rules (2004) on historical data.



Canada, Saskatchewan

Registration area

The registry includes all of Saskatchewan, a province of 651 903 km² located between Alberta to the west, Manitoba to the east, the Northwest Territories to the north and the USA to the south. Saskatchewan is between latitudes 49 and 60 N and longitudes 102 and 110 W. Most of the province is at or above 300m altitude, and the majority of the population live in the southern half of the province.

Among provinces, Saskatchewan ranks sixth in population with 990 930 people according to the 2006 census estimate. The population of Saskatchewan is of mixed ethnic origin. More than 40% of inhabitants trace their ancestry to the British Isles. The next largest ethnic groups claim German, French, Ukrainian, American Indian, Metis and Scandinavian ancestry. Indigenous peoples, mainly Cree, Assiniboine, and Chipewyan account for 17.3% of the population.

Approximately 64% of the population resides in cities of more than 5000 inhabitants, including Saskatoon (237 017) and the provincial capital, Regina (200 854).

Cancer care facilities

The Saskatchewan Cancer Commission Act of 1930 authorised a commission to establish a cancer control program in Saskatchewan. In 1979, the Saskatchewan Cancer Foundation Act established a new organisation to replace the Cancer Commission. The Saskatchewan Cancer Agency is now responsible for treatment, prevention and early detection programs, research, and education services. The Agency maintains two clinics, the Allan Blair Memorial Clinic in Regina and the Saskatoon Cancer Centre in Saskatoon, which provide radiotherapy, chemotherapy and follow-up services. The Agency also has two Cancer Patient Lodges associated with the clinics, a Health Research Division, a Screening Program for Breast Cancer, a Prevention Program for Cervical Cancer, as well as an Education Division. The Screening Program for Breast Cancer was established in 1990 and the Prevention Program for Cervical Cancer began in 2003.

Registry structure and methods

The province is covered by a universal comprehensive health insurance plan. The Cancer Foundation Act mandates that all cancers be reported to the Agency. This reporting structure captures approximately 95% of our case ascertainment. The other 5% is captured through death certificate notification received monthly from the Vital Statistics branch of Saskatchewan Health. The Saskatchewan Cancer Agency is funded by the Saskatchewan Government. The Registry is staffed by 10 FTE cancer registrars, 2 supervisors, 1 coordinator and the director.

Complete computerised information is available on all cancers diagnosed since 1967. There are currently about 212 200 patients and about 281 000 case records on the database. The registry also records follow-up information on approximately 36 000 clinic examinations per year and 25 000 physician reports

each year. All cancer cases in the database are coded according to ICD-O-3. Causes of death from cancer are coded using ICD-10, and non-cancer causes of death up to 1999 remain as ICD-9. In 2005 the Registry started using Collaborative Staging for breast and colon cancers. In 2006 additional cancer sites will have collaborative staging applied to them. The Saskatchewan Cancer Registry is a member of the Canadian Council of Cancer Registries and the North American Association of Central Cancer Registries (NAACCR). Our data are submitted annually to the Canadian Cancer Registry and the NAACCR.

The quality of the registry data is maintained through internal edit processes at the point of data entry as well as yearly processing of edit checks. Edits are also conducted by Statistics Canada/Canadian Cancer Registry and NAACCR on the data we submit to them for quality, accuracy, timeliness and completeness. Statistics Canada now produces a "report card" each year; both the Statistics Canada report and the NAACCR report outline our results and subsequent areas for improvement.

Patient follow-up has been active since 1932. Every case diagnosed (excluding non-melanoma skin cancer) is reviewed at least annually either through an examination at one of the clinics or through our follow-by-mail program, which sends letters to family/referring physicians at regular intervals for 10 years minimum. Although this program is still used as a method of survival/recurrence analysis, it now also helps ensure continuity of patient care once the patient

is discharged from the Clinic. The response rate to these letters is approximately 98%. The Registry began performing an active follow-back process on all registered DCO cases in 2002.

Interpreting the results

The vast majority of the population is involved in farming, which may result in higher exposure to pesticides, herbicides, fungicides etc. Recent literature also suggests a link between cancer and diabetes; if substantiated this could have a huge impact on our First Nations population that have a higher rate of diabetes.

Use of the data

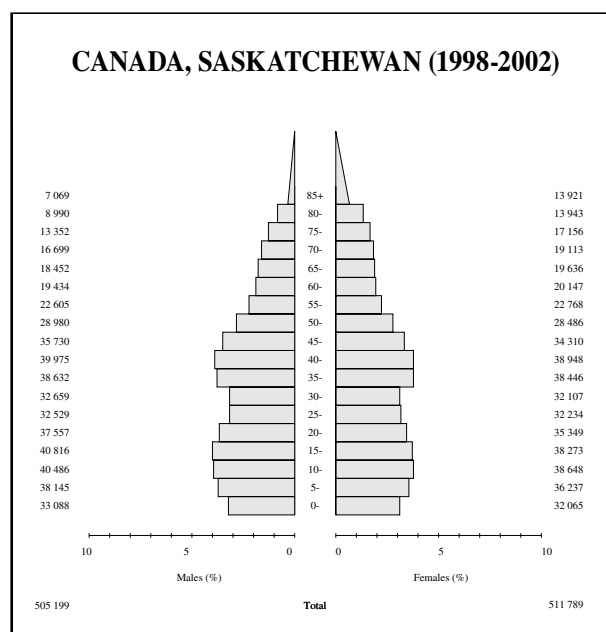
The Cancer Agency will be producing its third annual Cancer Control Report this year. The information in the registry also supports Agency planning for cancer control services and is also used as an information source for various research studies.

Source of population

The population-at-risks by sex and age from 1998–2003 have been estimated using the adjusted intercensal or postcensal estimates based on the 1996 Census, as provided by the Population Estimates Section, Demography Division, Statistics Canada.

Multiple primary rules used

IACR rules (2004) on CI5 IX period.



USA, Alabama

Registration area

Alabama is located on the southern coast of the United States. The state is divided into 67 counties, and the state's largest city is Birmingham, located in the central region of the state. Among the 50 states, Alabama ranks 30th in size, covering 52 423 square miles. According to the 2000 U.S. Census, it the 23rd most populous state, with 4 447 100 residents, and the state's population is projected to increase to 4.8 million by 2010 (Alabama Dept. of Industrial Relations). According to the Census Bureau, Alabama is considered an urban state with 55 percent of its population living in an urban setting and 45 percent in rural areas. Nearly every county in Alabama has some rural population, even the most densely settled counties, but some sparsely settled counties have no urban population at all.

Residents of Alabama are predominantly white (71.1%), with a significant African-American population (26.0%). Hispanics make up 1.7% of the state's population, though Birmingham has been ranked 6th among US cities with the fastest growing Hispanic population (http://apha.confex.com/apha/133am/techprogram/paper_112388.htm). Asians make up 0.7% of the state's population, and Native Americans 0.5%. Alabama has a large number of prime workforce-age residents, with 29% of the state's population between ages 25 and 44.

Cancer care facilities

Cancer is a reportable disease under Alabama Act 95-275. There are 55 healthcare facilities in the state that have fully staffed and functioning cancer registries, along with 54 non-registry facilities who utilise independent CTR contractors to capture and report cancer data. In addition, there are 22 free-standing treatment centres, 36 physicians or physician groups and 13 pathology laboratories that currently report to the ASCR.

Full-service cancer health care is provided by many hospitals in Alabama including two academic teaching facilities. Physicians also deliver limited diagnostic and treatment services in office settings. There are 25 free-standing cancer centres (including radiation centres) and clinics that also provide a full scope of therapeutic options for their patients.

Registry structure and methods

The ASCR is housed in the Bureau of Health Promotion and Chronic Disease of the Alabama Department of

Public Health. The ASCR staff comprises 12 permanent employees, including an Administrative Director, a Program Manager, an Epidemiologist, an Operations Analyst, and four Regional Coordinators (RC), three of which also have additional functions within the registry such as Completeness Coordinator, Quality Assurance Coordinator, and Education Coordinator. In addition, the ASCR has a Death Clearance and Research Coordinator, two case finding auditors and an Administrative Assistant.

The ASCR is supported through Federal funds under the US Centers for Disease Control and Prevention's National Program of Cancer Registries (NPCR). The ASCR does not currently receive any state funds except through support from five county health departments, which provide office space for regionally-based staff.

Electronic reporting is currently being phased in with pathology labs and physician groups. All other reporting sources report via the ASCR's secure website. Thirty-eight of these healthcare facilities are certified by the American College of Surgeons and report approximately 80% of Alabama's incidence.

Interpreting the results

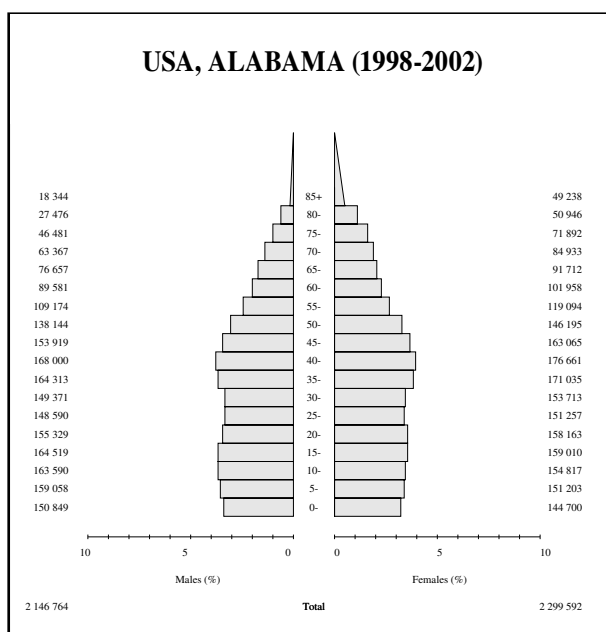
Alabama has captured at least 95% of its expected caseload over the past several years, and is proud to provide a high quality, statistically useful database.

Screening programs are offered through hospitals,

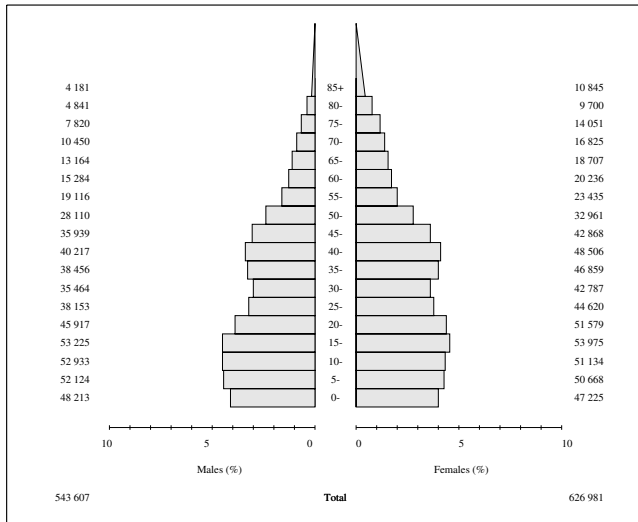
physicians and community organisations such as the American Cancer Society for sites such as breast, skin, colorectal, and prostate. The Alabama Breast and Cervical Cancer Early Detection Program (ABCCEDP) offers screenings for breast and cervical cancers. Prostate Specific Antigen (PSA) testing is a common practice used by healthcare providers in Alabama.

Use of the data

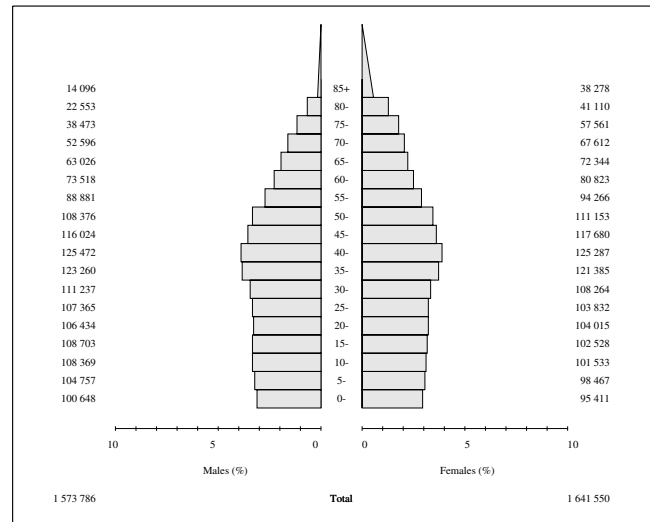
The ASCR, in conjunction with the American Cancer Society's Alabama Affiliate Office, prepares an annual report of cancer incidence, highlighting trends and changes, as well as the efforts of Alabama's Comprehensive Cancer Control Program. In addition, the ASCR collaborates with researchers and Principal Investigators across Alabama and around the US on special data linkages and research projects addressing issues from cancer prevalence to disparities in care. The ASCR limits participation in such activities to twelve open research projects at any given time.



USA, ALABAMA: BLACK (1998-2002)



USA, ALABAMA: WHITE (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.

USA, Alaska

Registration area

The Alaska Cancer Registry (ACR) covers the population of the State of Alaska, the northernmost state in the United States. Alaska represents 16% of the total land area of the country, but only 0.2% of the country's population. The population at the most recent census (2000) was 626 932. The state is divided into 27 county-equivalent areas of municipalities, boroughs, and census areas. Most of the state is rural and sparsely populated. About 42% of the population lives in the Municipality of Anchorage (260 283), although Anchorage represents only 0.3% of the land area of the state. The top five county-equivalent areas in the state (Municipality of Anchorage, Fairbanks North Star Borough, Matanuska-Susitna Borough, Kenai Peninsula Borough, and Juneau Borough) make up 77% of the state's population and represent only 9.2% of the land area. The statewide population is 73.5% White, 17.2% Native Alaskans or American Indians, 5.1% Asian or Pacific Islanders, and 4.3% Black.

Cancer care facilities

General healthcare in the state is provided by 24 hospitals, numerous health clinics, and many private practitioners. Because the Anchorage Municipality has the highest population, it also has the highest number of healthcare facilities, including four hospitals. In rural areas, many boroughs/census areas only have one hospital, and some have no hospitals. Alaska Natives are provided healthcare at no cost at a central hospital in Anchorage.

Registry structure and methods

ACR is located in the city of Anchorage, and is part of the Alaska Department of Health and Social Services, Division of Public Health, Section of Chronic Disease Prevention. It is funded mostly by the US Centers for Disease Control and Prevention (CDC) through the National Program of Central Cancer Registries (NPCR), and partly by the state health department. ACR is staffed by a full-time manager, three full-time registrars, and a full-time data analyst. Several full-time administrative clerks provide part-time support for the program.

Cancer is a reportable disease by state law; a hospital, physician, surgeon, or other healthcare facility or provider diagnosing, screening, or providing treatment for a cancer patient is required to report to the registry. The annual caseload for ACR is approximately 2000 consolidated cases per year. ACR receives about 50% of its case reports (source records) electronically from hospitals in the standard NAACCR Record Layout. Electronic cases are also received from other state central cancer registries in the United States with which ACR has data exchange agreements (currently ACR has 30 of these agreements). The rest are manually abstracted in-house by the registrars. The manual case reports consist of hardcopy medical records sent to the registry by hospitals, private physicians, and pathology laboratories.

Manual case reports are also generated as a result of casefinding audits of hospitals and death clearance. Casefinding audits are conducted by reviewing the medical disease index from the hospital for a given time period for cancer cases and removing cases that have already been reported by the hospital. The remaining cases are researched by the registrars, and new cases are added to the registry. Death clearance is performed by comparing a list of all Alaska resident cancer deaths for a given time period against the registry database and removing death cases that have already been reported by other sources. The remaining cases are researched by the registrars, and new cases are added to the registry.

Quality control is performed on the data on a regular

basis. All new cases need to pass at minimum the "NPCR Required", "NPCR Supplemental", and "Site/Type-Over-rides - Missue" Edit Sets of the current NAACCR Edits Metafile. In addition, during the annual NAACCR and CDC Calls for Data, the data submission file must pass specific Edits Sets specified by NAACCR and CDC at the time of data submission. Also during the Calls for Data, ACR runs specific database queries to check for data quality.

Interpreting the results

There are no unusual geographical, clinical, or coding factors that influence incidence rates. However, the Alaska Department of Labor publishes annual population estimates for Alaska that are

different from those published by the federal government (CDC's National Center for Health Statistics). The incidence and mortality rates ACR generates are based on federal government's population data.

Use of the data

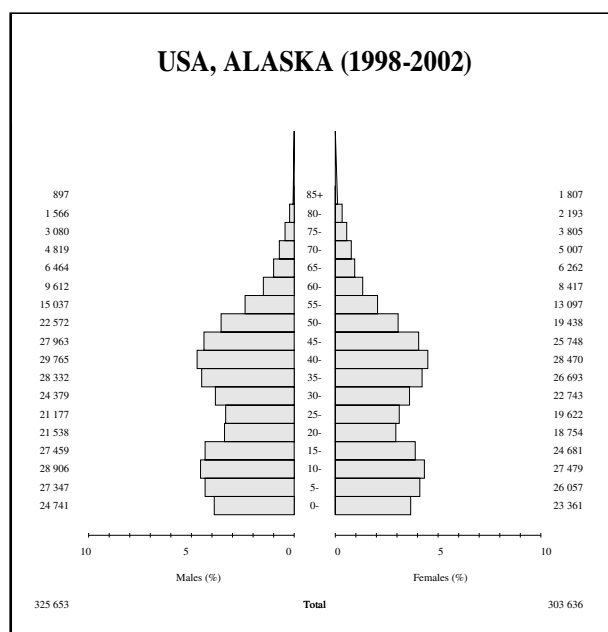
ACR prepares an annual report of cancer incidence and mortality. Data are submitted annually to NAACCR and CDC for use in multi-registry databases and data reports. In addition, registry data are regularly requested by members of the US Congress, the Alaska state legislature, researchers, physicians, researchers, and the general public.

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.



USA, Arizona

Registration area

The Arizona Cancer Registry covers the population of the State of Arizona in the United States of America. Arizona is located in the west in the Rocky Mountain region. The population at the most recent population census projection (2005) was 5.8 million. About 89% of the population lives in urban areas (>5000 population). Arizona has the second largest state concentration of Native Americans in the United States, comprising 5% of the population. The racial breakdown of the population in Arizona is: White Non-Hispanic 60%, Hispanic 29%, and all other races, Non-Hispanic 11%.

Cancer care facilities

General health care in the region is provided by private practitioners, clinics, and hospitals. Health insurance is used by 82% of the population to pay for health care. Most health insurance is private, non-governmental insurance (75%) of healthcare coverage. The amount the insurance plan pays varies greatly between health plans. The remainder of health insurance is provided by the government. There are both hospital and freestanding radiotherapy departments in Arizona.

Registry structure and methods

The registry is located in Phoenix, Arizona, the state capital. The registry receives its funding from state legislature appropriations to the Arizona Department of Health Services. Enhancement funds are provided through the National Program of Cancer Registries (NPCR) from a US Centers for Disease Control and Prevention cooperative Agreement. The registry is staffed with 13 FTE's and comprises three sections, Operations, Data, and Training.

The ACR is considered a population-based surveillance system that collects, manages, and analyses information on the incidence, survival, and mortality of persons having been diagnosed with cancer. Arizona Revised Statute §36-133 mandates the reporting of cancer cases in the state of Arizona. Reporting rules (Arizona Administrative Code Title 9, Chapter 4) require hospitals, clinics, and physicians to report cases to the ACR. The registry also collects information from pathology laboratories. All hospitals are required to perform follow-up on cases. All data reported from hospitals is electronic. The registry also performs a linkage with vital records on the death certificate file. The registry also performs case ascertainment reviews and reabstracting studies at hospitals. The registry has 17 data exchange agreements with other US states, including all bordering states.

The sections of the registry are as follows: The Operations section processes incoming case information from hospitals, clinics, and physicians. The quality assurance program is a comprehensive program that includes reviewing data to ensure

completeness and accuracy, visual editing and immediate and batch editing. The staff also collects cases from facilities that do not report directly to the registry, including hospitals with fewer than 50 beds and pathology laboratories.

The Data section analyses the incidence, mortality and survival of people diagnosed with cancer in Arizona. It provides this data to cancer support organizations and government agencies as well as to researchers, members of the medical community and the public. The section also audits reporting hospitals, to identify areas for improvement when abstracting and reporting cases.

The training section plans and administers a statewide training program for registry staff, reporting facilities including

hospital and clinic personnel, and physicians and their staff. In addition, the training section develops written materials such as brochures and newsletters. Finally, it is also responsible for keeping cancer registry and reporting facility staff updated of coding and regulatory changes.

Interpreting the results

The rate of cancer in Arizona is stable, with rates of increase and decline following United States trends. Arizona age-adjusted incidence rates of cancer are generally lower than the overall United States cancer rates. Completeness of data coverage is between 90 and 95%. Arizona has organised screening programs for breast, cervical, and colorectal cancer. Over half of all men over age 40

yrs are screened for prostate cancer using the PSA test.

Use of the data

The registry prepares an annual report of cancer incidence, highlighting trends and changes. The registry also is involved in research studies that have been approved by our Human Subjects Review Committee. Data are used for comprehensive cancer control planning; to respond to concerns in the community about cancer; to assist in the identification of geographic regions of the state that need intervention programs or epidemiologic research, detection, and prevention; to perform epidemiologic studies; and to provide biostatistics and epidemiologic information to the medical community.

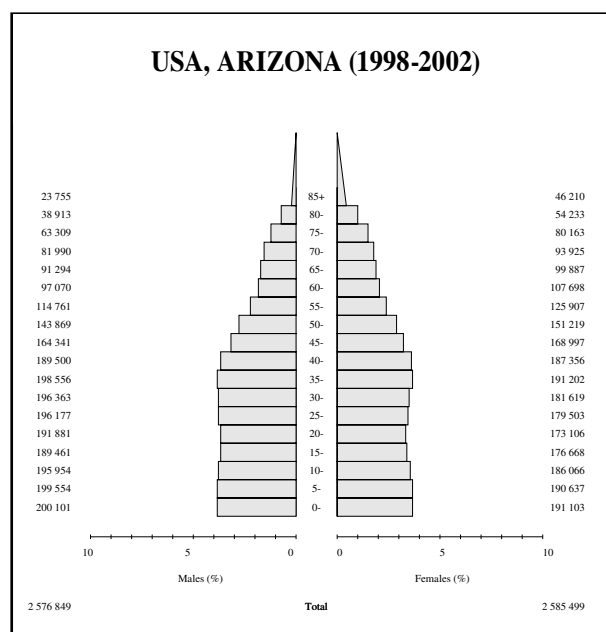
Source of population

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.



USA, California

Registration area

The California Cancer Registry (CCR) is a collaborative effort between the California Department of Public Health Cancer Surveillance and Research Branch, the Public Health Institute, and ten Regional Cancer Registries. These Registries encompass all of California's approximately 156 000 square miles (404 000 km²). All cancers, with the exception of basal and squamous cell skin cancers and in situ cervical cancers, diagnosed among California's 34 043 198 residents are considered reportable cancers. California is not only the most populous state in the United States, but also the most ethnically diverse, with substantial Hispanic, African-American, and Asian-American populations in addition to a large non-Hispanic White population. There are also a wide variety of religious affiliations, socioeconomic levels, and sociocultural characteristics within California.

Cancer care facilities

Health care in California is provided by a variety of health care facilities, including approximately 422 acute care hospitals, 42 radiation therapy centres, 308 free-standing surgery centres, and numerous healthcare clinics. This care is supplemented by more than 80 000 physicians, both general practice and those specialising in oncology.

Registry structure and methods

Legislation declaring cancer to be a reportable disease in California became effective in 1985. Statewide collection of cancer cases began in 1988 under the Statewide Cancer Reporting Law. Additionally, state law mandates that hospitals and physicians report all cancer diagnoses to their Regional Registry. While recent legislation has made all CCR data variables confidential, CCR has always considered personally identifying information to be confidential.

The Central Registry of the CCR is located in Sacramento, California; there are eight Regional offices throughout California, housing the ten Regional Registries. All of California participates in the Surveillance, Epidemiology, and End Results (SEER) Program, although there are three separate SEER Registries within California. The San Francisco Bay Area Registry became a SEER Registry in 1973, with four adjacent counties added in 1992. The registry in Los Angeles County became a SEER Registry in 1992. The remaining areas of California, known as the Cancer Registry of Greater California, became a SEER Registry in 2000. The CCR also participates in the National Program of Cancer Registries (NPCR) at the US Centers for Disease Control and Prevention (CDC) and annually submits statewide data for inclusion in the NPCR Cancer Surveillance System. The CCR database currently contains

approximately 2.5 million records for cases diagnosed 1988 forward, and adds approximately 150 000 new cases to the database each year.

The Central Registry in Sacramento houses numerous research scientists, quality control staff, IT programmers, and fiscal and administrative support staff. Additionally, each Regional Registry maintains their own office of epidemiologists, research scientists, certified tumour registrars and support staff.

The CCR combines elements of an active and a passive surveillance system at both the Regional and Central Registry levels. Active follow-up includes letters to physicians and telephone calls to patients. Passive follow-up involves

computer linkages to vital statistics, voter registration, credit records and medical resources. These various surveillance systems have allowed CCR to follow up over 95% of patients.

Over 90 percent of cancer reports are received electronically from hospitals, using hospital-based computer software supported by the CCR. Regional Registry staff also routinely review the records of outpatient radiation and surgery centres, as well as all non-hospital based pathology laboratories to identify unreported cases. Physicians complete cancer reports of patients diagnosed or treated in non-hospital facilities. All CCR data are edited for completeness and accuracy and then are checked

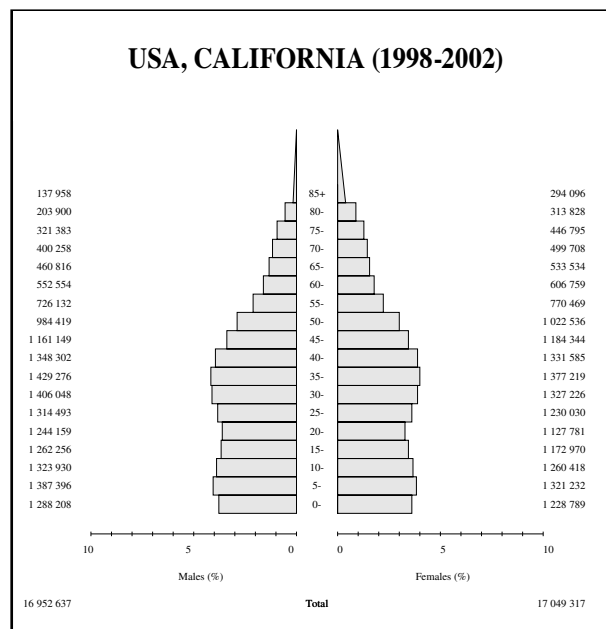
by computer for allowable codes and compatibility between different data fields. Regular audits are conducted at selected hospitals to check for completeness and accuracy.

Interpreting the results

The CCR makes efforts to identify persons who resided in California at the time of diagnosis, but were diagnosed or treated in another state. California has case-sharing agreements not only with neighbouring states, but also with many states throughout the nation. While there have been no changes in the area covered by the CCR, the population in California has steadily increased since its 1988 inception. Efforts to improve screening rates among immigrant and low-income populations through community outreach programs have increased over the years. Cancer incidence in California is similar to that in other parts of the United States; however an aggressive anti-smoking campaign has resulted in the dramatic reduction in smoking-related cancers in recent years.

Use of the data

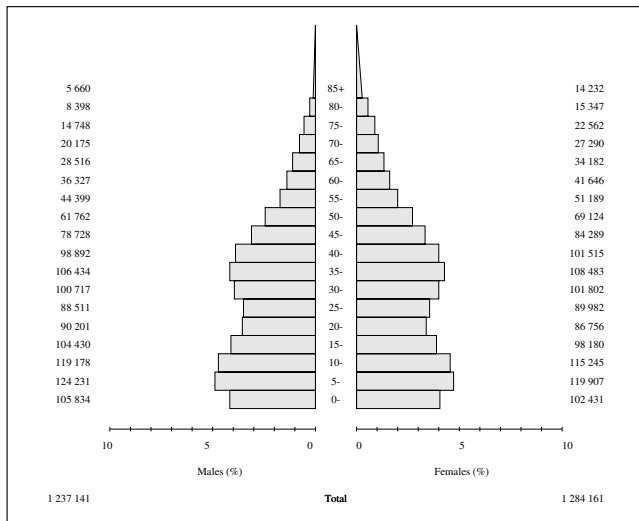
The CCR produces an annual report of cancer incidence and mortality in California for all of the major cancer sites. This report lists rates by year of diagnosis, sex, race/ethnicity, and age. Additionally, each Regional Registry produces an



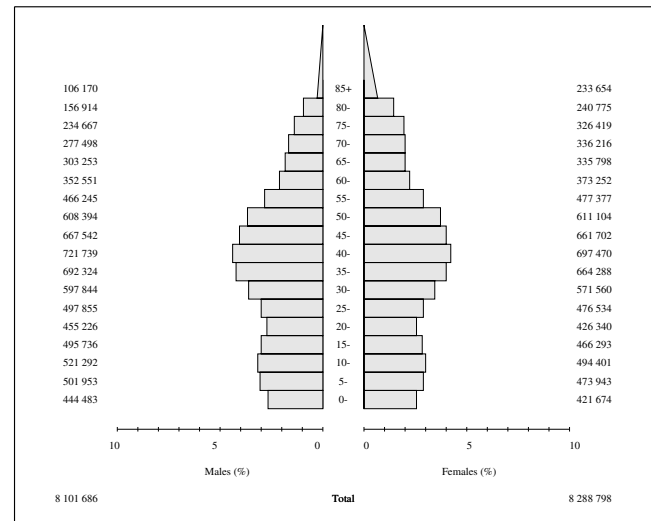
annual report that lists rates by county. CCR data is used by researchers throughout the United States to investigate causes of cancer, survival, quality of care, tumour characteristics and treatment. Since 1988, researchers in California have used CCR data in 450 funded studies and have published

nearly 1700 articles using CCR data. CCR data also are used by policymakers and currently are being utilised by California's cancer control planning organisation to measure the burden of cancer in California and evaluate interventions to reduce incidence and mortality.

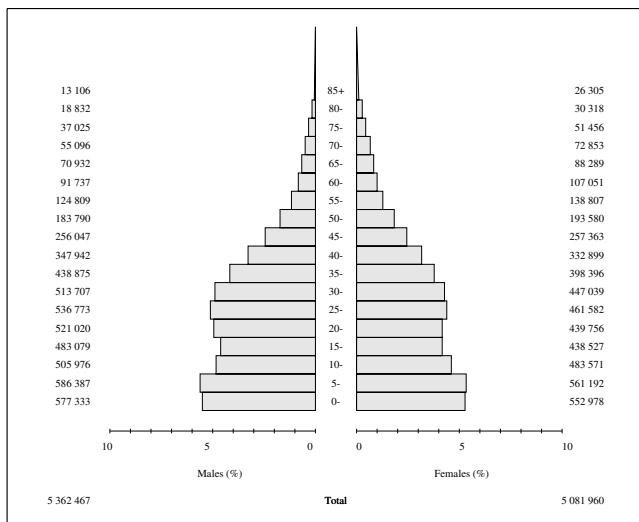
USA, CALIFORNIA: BLACK (1998-2002)



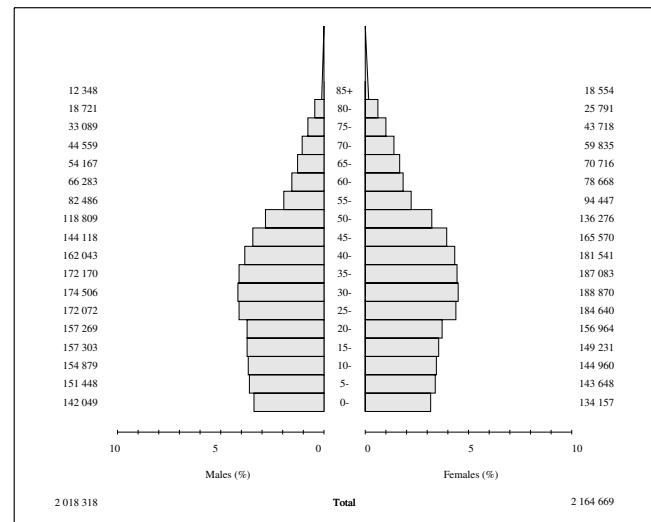
USA, CALIFORNIA: NON-HISPANIC WHITE (1998-2002)



USA, CALIFORNIA: HISPANIC WHITE (1998-2002)



USA, CALIFORNIA: ASIAN AND PACIFIC ISLANDER (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.

USA, California, Greater San Francisco Bay Area

Registration area

The registration area includes nine counties (Alameda, Contra Costa, Marin, Monterey, San Benito, San Francisco, Santa Clara, San Mateo, Santa Cruz) in northern California, USA. The US Census counted 6 516 923 persons living in the region in the year 2000. Compared to other parts of the USA, this area is noteworthy for its racial/ethnic diversity, with substantial Hispanic, Chinese, Filipino, and other Asian populations. The majority of the population lives in the urban San Francisco Bay Area, which includes a major financial centre as well as the "Silicon Valley" centre for technology innovation and industry. Overall levels of education and income are higher than USA averages and accordingly, cost of living tends to be higher in the Greater San Francisco Bay Area than in other parts of the USA.

Cancer care facilities

Healthcare services in this region, including cancer screening, diagnosis and treatment, are provided mostly by private hospitals and physicians, but also by publicly funded hospitals, clinics and public health agencies. At least 61 hospitals and over 21 000 physicians treat cancer patients in the region and two major academic cancer centres are located in the region. In addition, there are a number of free-standing radiation centres, surgery centres, and pathology laboratories involved in cancer diagnosis and treatment. A significant proportion of residents receive managed health care services through health maintenance organizations.

Registry structure and methods

The Greater Bay Area Cancer Registry, with a staff of about 50, is operated by the Northern California Cancer Center (NCCC), founded in 1974 as an independent consortium centre for cancer research in Northern California. The registry has been part of the Surveillance, Epidemiology and End Results (SEER) Program of the National Cancer Institute since 1973 and has contributed data to the statewide California Cancer Registry since 1988. Cancer registry efforts at NCCC also include a population-based registry covering four counties south of the Bay Area (Santa Clara, Santa Cruz, San Benito, Monterey) that have been included in the SEER program since 1992 and the California Cancer Registry since 1988. Data from these two registries have been combined to create the Greater San Francisco Bay Area region shown in this volume. In total, this registry contains well over 700 000 incident cases and processes about 30 000 incident cases annually. The registry collects data not only on incident cancer diagnoses but on diagnostic procedures, tumour characteristics (including stage, grade and tumour markers), treatment and survival time. Each patient is given a unique identifying number and multiple primaries designated by sequence number. All patients reported to the registry are followed both actively and passively for vital status to monitor survival time. Active follow-up consists of letters to physicians. Passive follow-up involves computer linkages to vital statistics, voter registration, credit records and medical resources. Through these methods, the registry maintains current follow-up information for over 95% of cancer patients.

Cancer has been a reportable disease by California state mandate since 1987. This law requires that hospitals report to regional registries such as NCCC all cancer diagnoses occurring in their facilities and that physicians report cancers not diagnosed in a hospital. Well over 90% of cancer registry reports are received electronically from hospitals. The registry supports a hospital-based

computerised reporting system allowing each hospital to collect, maintain, and easily transmit registry-reportable information and facilitating editing by cancer registry staff. Quality assurance procedures implement SEER and NAACCR standards for visual and computerized editing, reabstractions and audits.

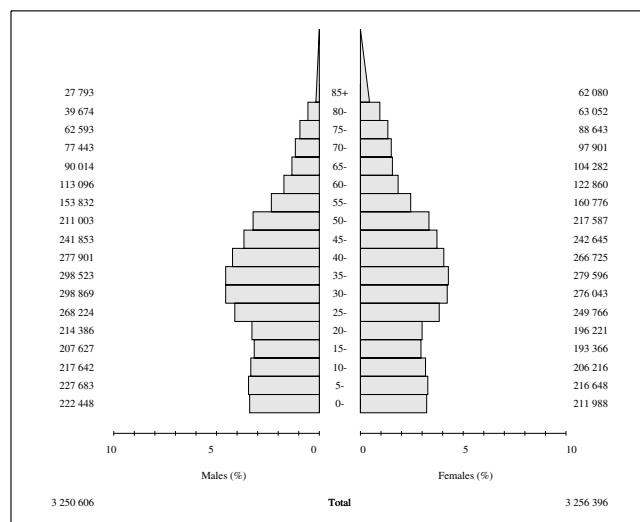
Interpreting the results

The registry identifies cases residing in the Bay Area but who are diagnosed or treated elsewhere through well-established data sharing programs with neighbouring cancer registries. The registry is also linked semi-annually to California vital statistics records in order to identify persons for whom cancer is mentioned on the death certificate but not already reported to the registry. It is estimated that over 98% of cancer diagnoses in region residents are captured by the registry.

Use of the data

Registry data are used primarily for investigating trends in cancer incidence, survival, tumour characteristics and treatment, thus providing a critical resource for monitoring the burden of cancer in the region. Data are routinely combined with California Cancer Registry and SEER program data for larger surveillance efforts. A number of investigators apply each year to access cancer registry information needed to carry out analytic epidemiologic studies of many different cancer types and outcomes. The large and diverse population has made this registry a valuable resource for epidemiologic research into the genetic and environmental causes of cancer, as well as for cancer control interventions and healthcare planning efforts.

USA, CALIFORNIA, GREATER SAN FRANCISCO BAY AREA (1998-2002)



Source of population

July 1 county population estimates by age and sex; postcensal estimates based on 2000 United States Census.

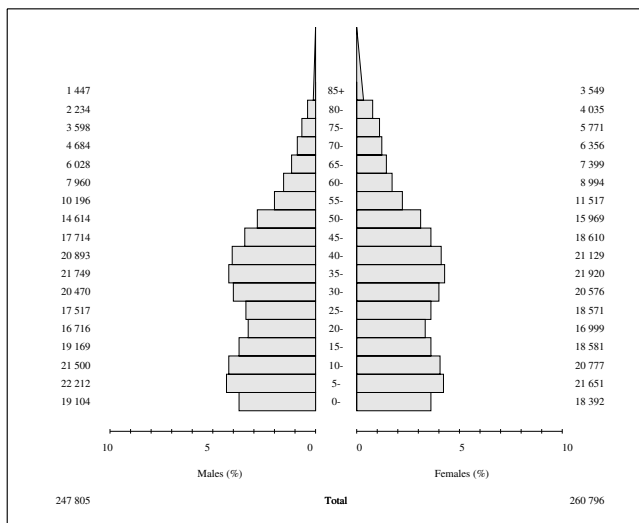
Multiple primary rules used

IACR rules (2004) on CI5 IX period.

Notes on the data

This is not the same as the sum of the other groups presented.

USA, CALIFORNIA, GREATER SAN FRANCISCO BAY AREA: BLACK (1998-2002)



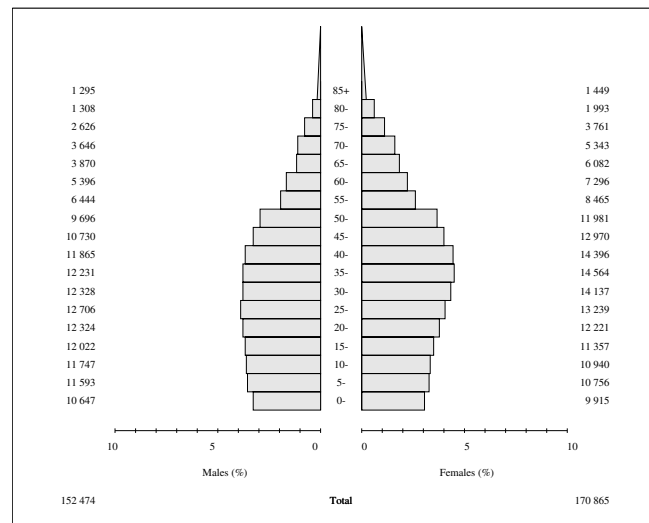
Source of population

July 1 county population estimates by age, sex and race; postcensal estimates based on 2000 United States Census.

Multiple primary rules used

IACR rules (2004) on CI5 IX period.

USA, CALIFORNIA, GREATER SAN FRANCISCO BAY AREA: FILIPINO (1998-2002)



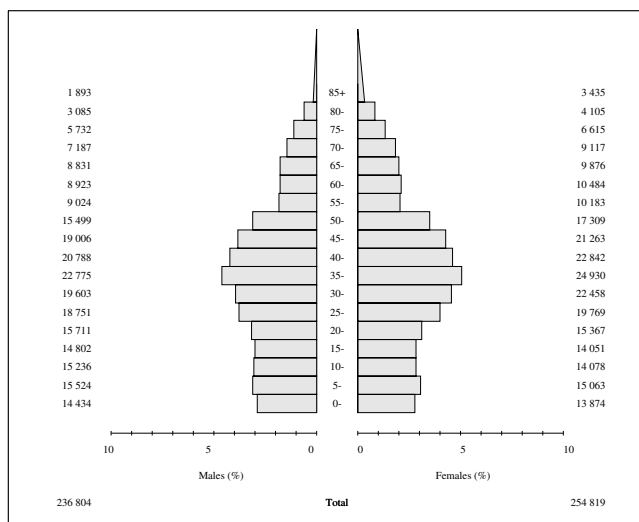
Source of population

July 1 county population estimates by age, sex and race; postcensal estimates based on 2000 United States Census.

Multiple primary rules used

IACR rules (2004) on CI5 IX period.

USA, CALIFORNIA, GREATER SAN FRANCISCO BAY AREA: CHINESE (1998-2002)



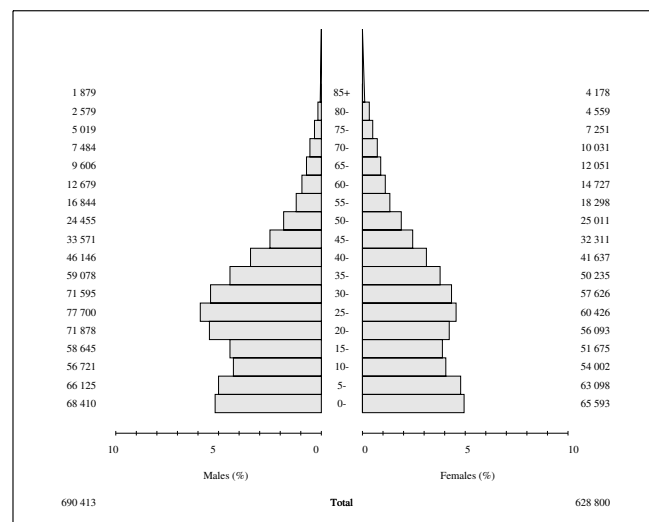
Source of population

July 1 county population estimates by age, sex and race; postcensal estimates based on 2000 United States Census.

Multiple primary rules used

IACR rules (2004) on CI5 IX period.

USA, CALIFORNIA, GREATER SAN FRANCISCO BAY AREA: HISPANIC WHITE (1998-2002)



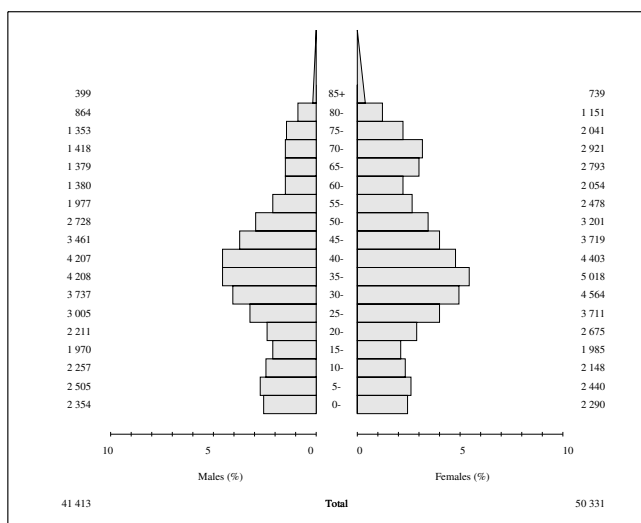
Source of population

July 1 county population estimates by age, sex, race, and Hispanic origin; postcensal estimates based on 2000 United States Census.

Multiple primary rules used

IACR rules (2004) on CI5 IX period.

USA, CALIFORNIA, GREATER SAN FRANCISCO BAY AREA: JAPANESE (1998-2002)



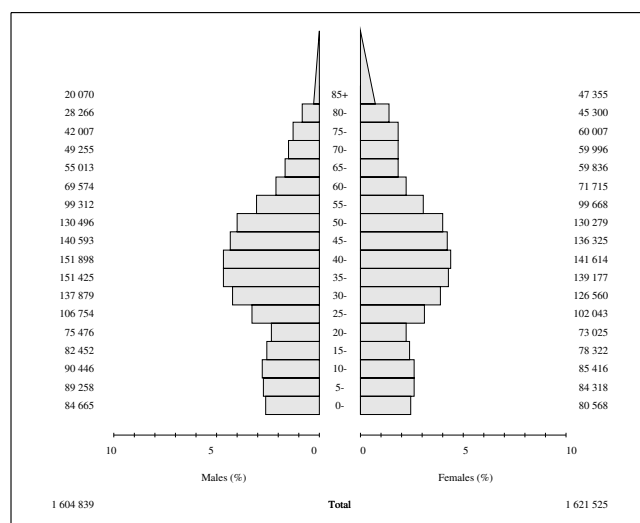
Source of population

July 1 county population estimates by age, sex and race; postcensal estimates based on 2000 United States Census.

Multiple primary rules used

IACR rules (2004) on CI5 IX period.

USA, CALIFORNIA, GREATER SAN FRANCISCO BAY AREA: NON-HISPANIC WHITE (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.

Multiple primary rules used

IACR rules (2004) on CI5 IX period.

USA, California, Los Angeles County

Registration area

Los Angeles County is an urban area covering more than 10 000 km² and has the largest population of any county in the United States, with nearly 9.5 million residents in the 2000 census. Among these residents are more than four million self-declared Latinos including more than three million Mexicans, 38 000 Puerto Ricans, 38 000 Cubans and sizeable populations representing various Central and South American countries. There are nearly one million blacks in the county and between 100 000 and 400 000 each of Japanese, Chinese, Koreans and Filipinos. Other major south-east Asian groups include Vietnamese, Asian Indians, Cambodians and Thais. There is wide variation in socio-economic as well as socio-cultural characteristics in the county.

Registry structure and methods

The Cancer Surveillance Program (CSP) of Los Angeles County was started at the University of Southern California in 1970 as part of an epidemiology and biostatistics program. In June 1987, the CSP became one of the ten regional registries of the population-based California Cancer Registry. This registry, established by California law in 1985, places the obligation for identifying and abstracting cancer cases on those facilities where cancer is diagnosed or treated.

The CSP combines elements of an active and a passive surveillance system. Under the active surveillance component, CSP personnel systematically screen pathology reports and other relevant files at all hospitals and free-standing pathology laboratories, as well as some treatment facilities, to obtain pathology reports for each cancer patient diagnosed or treated. For passive surveillance, each hospital or other reporting facility completes a full abstract, including stage and treatment information on every cancer patient diagnosed and/or treated at that facility. For each cancer patient, over 200 data items including disease or medical variables, demographics and administrative descriptors are coded and computerised.

The responsibility for completing reporting at some hospitals is contracted back to the CSP; currently about 9% of all hospital reports in Los Angeles County are so reported. All of the completed abstracts are record-linked by the CSP to the pathology reports obtained under active surveillance to assure that an abstract is completed on every histologically verified cancer case.

Before 1992, linkage with the State of California death tapes was the only means of passive follow-up. However, beginning with 1992 diagnoses, the CSP instituted complete follow-up as a function of its new affiliation with the National Cancer Institute's Surveillance, Epidemiology and End Results (SEER) Program. Follow-up data are collected by record linkages with multiple sources as well as incorporating active follow-up information provided by hospitals.

Manual and computerised record linkages are performed separately with a variety of external data sources, using a sophisticated probabilistic methodology. Multiple primaries are noted by a tumour sequence number. Each data item is checked as an allowable code, and selected interfield checks are performed.

Interpreting the results

Los Angeles County has more than 100 hospitals and clinics, many of them providing screening programs. The availability of cancer screening programs can, in some instances such as PSA for prostate cancer, result in increasing incidence rates.

Cancer mortality rates may not be directly related to cancer incidence rates due to several factors including migration.

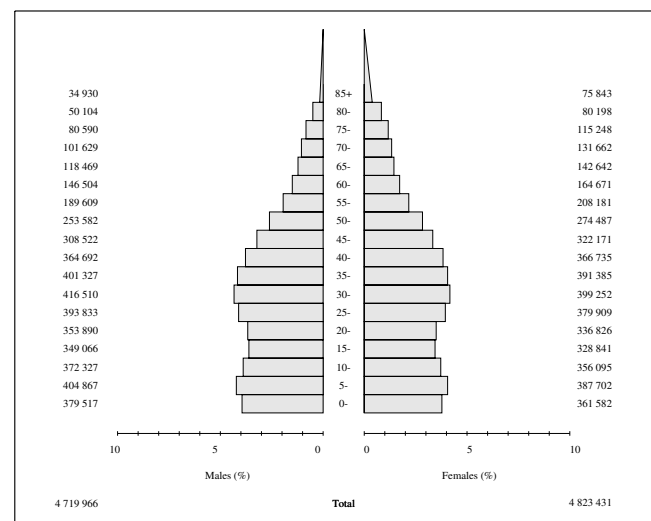
Differences in classifying cancers by primary site between incidence and mortality data sources may also differentially affect incidence and mortality rates. Furthermore, a cancer may be reported as a cause of death when in fact it is a site of metastasis from other cancer(s).

Race/ethnicity information for cancer incidence is based primarily on information contained in the patient's medical record. Race/ethnicity for cancer deaths, on the other hand, is based on information on the death certificate, which may not always be based on information provided by next-of-kin. The reporting of race/ethnicity in either system may be influenced by the racial/ethnic distribution of the local population, by local interpretation of data collection guidelines, and other factors. Some differences in race/ethnicity-specific rates likely reflect biases of classification rather than true differences in risk.

Use of the data

The CSP is one of the most productive cancer registries in the world, in terms of scientific contributions toward understanding the demographic patterns and the etiology of specific cancers. More than 850 publications using CSP data have been contributed to scientific journals. The registry supports a large ongoing body of research funded mainly by the National Cancer Institute. The CSP also prepares an annual report of cancer incidence and mortality in Los Angeles County and other monographs monitoring the trends and patterns of cancer among the County's populations. As a service to the community, the CSP provides community-wide or hospital-specific data on cancer occurrence. The CSP responds to requests from concerned residents, community physicians, or from the County and State health departments seeking assistance in investigating perceived cancer risks from environmental exposures.

USA, CALIFORNIA, LOS ANGELES COUNTY (1998-2002)



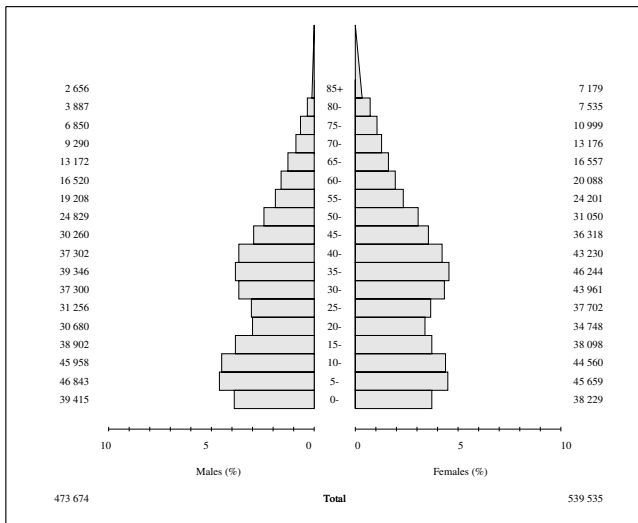
Source of population

July 1 county population estimates by age, sex, race, and Hispanic origin; postcensal estimates based on 2000 United States Census.

Multiple primary rules used

IACR rules (2004) on CI5 IX.

**USA, CALIFORNIA, LOS ANGELES COUNTY:
BLACK (1998-2002)**



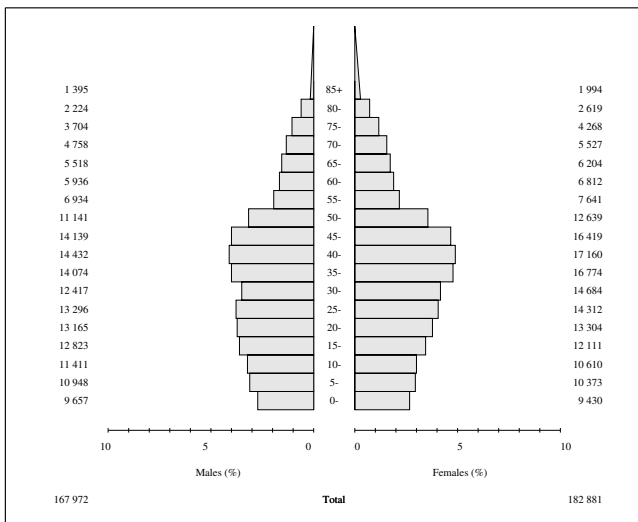
Source of population

July 1 county population estimates by age, sex, race, and Hispanic origin; postcensal estimates based on 2000 United States Census.

Multiple primary rules used

IACR rules (2004) on CI5 IX period.

**USA, CALIFORNIA, LOS ANGELES COUNTY:
CHINESE (1998-2002)**



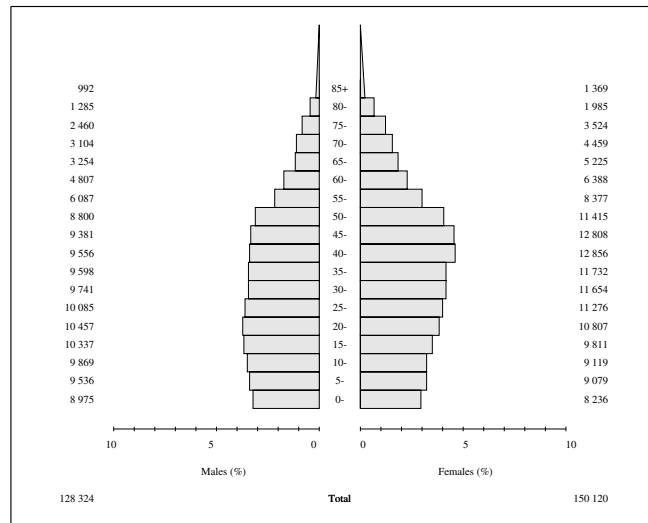
Source of population

Census 2000. Because the US 2000 Census allowed multiple selection of race categories, there are two ways of counting the population for a given race group: one is the minimum count, which consists of individuals who reported that particular race as their only race, the other is the maximum count that includes individuals who reported that race alone as their only race, as well as individuals who reported that race in combination with other race(s). The population counts included in this file are the simple averages of the minimum and maximum counts for each of the age-sex-race-specific groups.

Multiple primary rules used

IACR rules (2004) on CI5 IX period.

**USA, CALIFORNIA, LOS ANGELES COUNTY:
FILIPINO (1998-2002)**



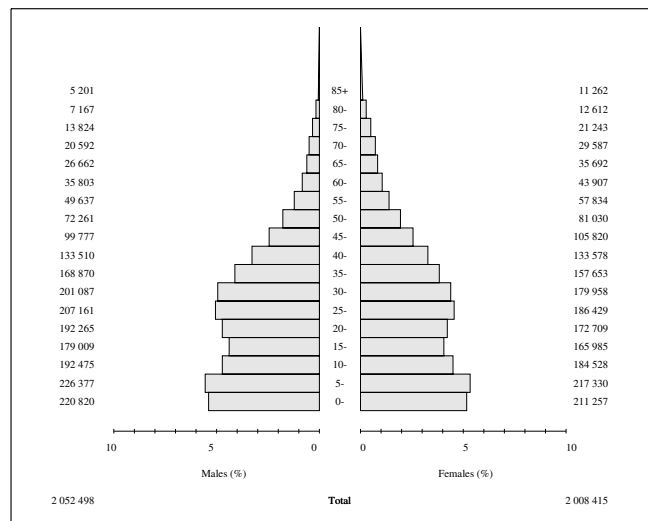
Source of population

Census 2000. Because the US 2000 Census allowed multiple selection of race categories, there are two ways of counting the population for a given race group: one is the minimum count, which consists of individuals who reported that particular race as their only race, the other is the maximum count that includes individuals who reported that race alone as their only race, as well as individuals who reported that race in combination with other race(s). The population counts included in this file are the simple averages of the minimum and maximum counts for each of the age-sex-race-specific groups.

Multiple primary rules used

IACR rules (2004) on CI5 IX period.

**USA, CALIFORNIA, LOS ANGELES COUNTY:
HISPANIC WHITE (1998-2002)**



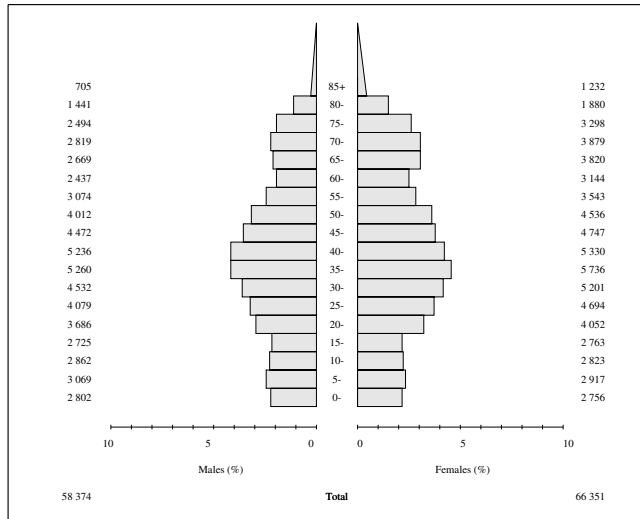
Source of population

July 1 county population estimates by age, sex, race, and Hispanic origin; postcensal estimates based on 2000 United States Census.

Multiple primary rules used

IACR rules (2004) on CI5 IX.

**USA, CALIFORNIA, LOS ANGELES COUNTY:
JAPANESE (1998-2002)**



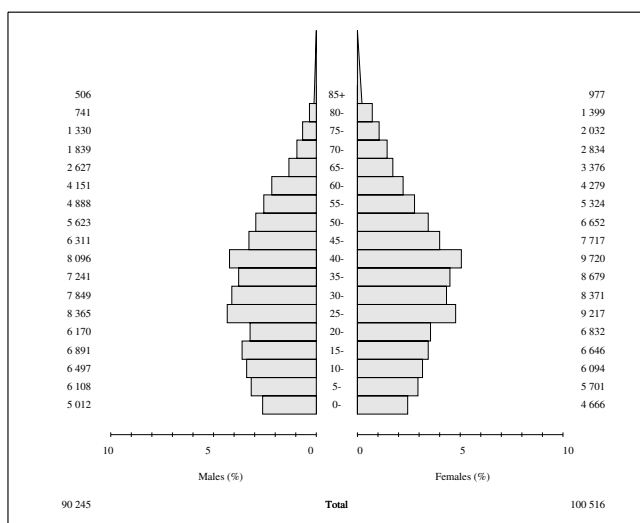
Source of population

Census 2000. Because the US 2000 Census allowed multiple selection of race categories, there are two ways of counting the population for a given race group: one is the minimum count, which consists of individuals who reported that particular race as their only race, the other is the maximum count that includes individuals who reported that race alone as their only race, as well as individuals who reported that race in combination with other race(s). The population counts included in this file are the simple averages of the minimum and maximum counts for each of the age–sex–race–specific groups.

Multiple primary rules used

IACR rules (2004) on CI5 IX period.

**USA, CALIFORNIA, LOS ANGELES COUNTY:
KOREAN (1998-2002)**



Source of population

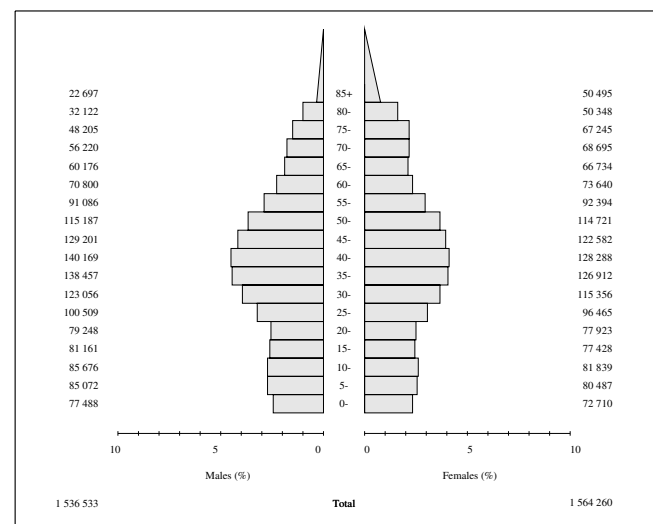
Census 2000. Because the US 2000 Census allowed multiple selection of race categories, there are two ways of counting the population for a given race group: one is the minimum count which consists of

individuals who reported that particular race as their only race, the other is the maximum count that includes individuals who reported that race alone as their only race, as well as individuals who reported that race in combination with other race(s). The population counts included in this file are the simple averages of the minimum and maximum counts for each of the age–sex–race–specific groups.

Multiple primary rules used

IACR rules (2004) on CI5 IX period.

**USA, CALIFORNIA, LOS ANGELES COUNTY:
NON-HISPANIC WHITE (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.

Multiple primary rules used

IACR rules (2004) on CI5 IX period.

USA, Colorado

Registration area

The Colorado Central Cancer Registry (CCCR) covers the population of the entire state of Colorado (United States). The state is composed of 64 counties with a total population of approximately 4.3 million.

Cancer care facilities

Colorado has 75 inpatient facilities around the state that provide most cancer care; most are privately operated, 2 are public institutions, and 3 are military facilities. Colorado also has many free-standing surgery and radiation therapy facilities, as well as a large network of cancer care specialty clinics that provide radiation and chemotherapy services. Private oncology practitioners also provide care in their offices.

Registry structure and methods

The registry is located in Denver, the capital of Colorado. The registry is funded mostly by federal funds through the US Centers for Disease Control and Prevention's National Program of Cancer Registries (NPCR) and receives some support from state funding. The registry is staffed by 11.5 FTEs: a Director, 2 statisticians, 1 administrative assistant, 1 data quality and training coordinator, and 6.5 registrars.

Hospitals in Colorado with 50 beds or more must actively report their cancer cases to the Colorado Central Cancer Registry. Staff from the Central Registry travel to smaller facilities once per year to collect data. The CCCR also receives data reports from numerous

pathology labs and some of the free-standing radiation and surgery centres. Annually, the CCCR links its database with the official death file for Colorado to obtain follow-up information, and to identify potential missed cases.

Interpreting the results

Colorado has no special characteristics that influence incidence rates.

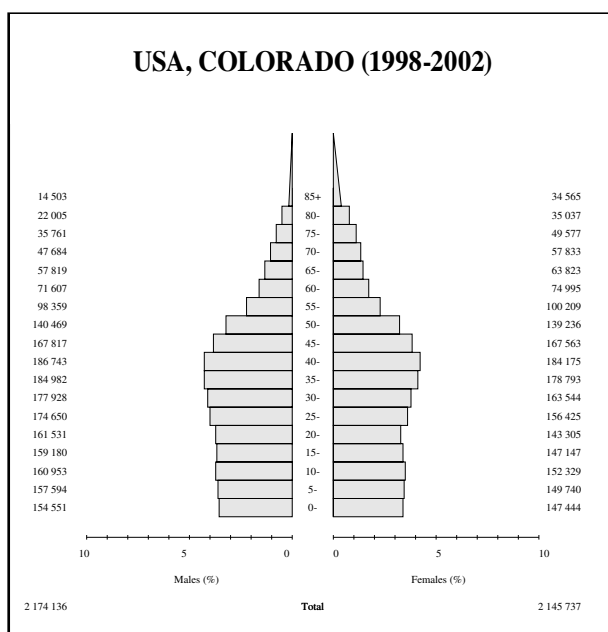
Use of the data

The CCCR produces an annual report of incidence and mortality. In alternate years, the report includes survival statistics and county-level data. The data are published on the internet and can be queried interactively. The CCCR data are also used for many special studies, including epidemiologic studies, clinical studies, environmental risk analyses, cancer control program evaluation, cancer care facility market analyses, and citizen inquiries.

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.

USA, Connecticut

Registration area

The Connecticut Tumor Registry (CTR) covers the entire State of Connecticut, which is bounded by Massachusetts to the north, Rhode Island to the east, Long Island to the south and New York to the west. It lies between latitudes 41° and 42° N and longitudes 71° and 73° W. The total registration area is 12 973 km². At the 2000 census, the population of Connecticut was 3.4 million, composed of 82% white, and 9.1% black. Approximately 9.4% of the Connecticut population is Hispanic, the majority of Puerto Rican origin.

Cancer care facilities

Health care related to cancer is provided predominantly by hospitals in Connecticut, but reciprocal reporting agreements with surrounding states also identify some cases. Most patients suspected to have cancer who are first seen in facilities outside of a hospital are likely to be referred to a hospital for testing and/or treatment.

There are 32 acute care hospitals in the state of Connecticut. All hospitals have diagnostic radiology services; in addition there are many free-standing radiology facilities located throughout the state, operated by hospitals or by private companies. Approximately one third of Connecticut's hospitals have therapeutic radiology facilities. In addition, there are a number of free-standing radiation therapy centres, three of which are privately operated; the remainder are associated with a "parent" hospital.

Registry structure and methods

The CTR is located in the Connecticut Department of Public Health in Hartford, Connecticut. The CTR is funded by the State of Connecticut and the federal government. Since 1973, the registry has participated in the Surveillance, Epidemiology and End Results (SEER) Program sponsored by the National Cancer Institute (NCI). The registry is staffed by over 20 full-time employees including an epidemiologist, research analyst, supervisor, coders, quality control staff and office support personnel.

The CTR is primarily a hospital-based reporting system. All hospitals in Connecticut are required by public health legislation to report incident cases, along with follow-up and treatment information, to the registry. Reports containing pre-coded data are prepared by hospital-based tumour registrars and submitted, either on paper, diskette or electronically, to the registry. In 1981, this reporting mandate was extended to include private pathology laboratories. The CTR also has reciprocal cancer-reporting agreements with all the adjacent states and several other states. This allows for the identification of Connecticut residents whose cancers are diagnosed or treated in other states.

In an effort to increase the accuracy, timeliness and completeness of reporting to the CTR, the registry has implemented a quality control plan. This calls for biannual audits and annual re-abstracting audits of hospitals, regular detailed analysis of reporting errors received by the CTR, regular quality and quantity reports of CTR staff productivity, and training workshops for in-house and hospital registrars.

All death certificates that mention cancer are reviewed and checked against the CTR for prior registration. Follow-back is initiated on all death certificates that do not match to a patient in the registry database.

From its inception in 1941, the CTR has maintained lifetime follow-up on all tumours. Follow-up information is primarily obtained from the hospitals. Follow-up information is also obtained from periodic linkages with the Connecticut mortality files, State of Connecticut motor vehicle license files, the Medicare files of the Centers for Medicare and Medicaid Services, and the Social Security Administration. Although not legislatively mandated to report cancer cases to the CTR, physicians have also been contacted as part of follow-up activities.

To ascertain completeness, we monitor hospitals submissions on a monthly basis; we also send field staff to the pathology departments of all hospitals to perform case-finding audits. All case submissions received from each hospital and private

laboratory are visually edited by the CTR's coding and abstracting staff.

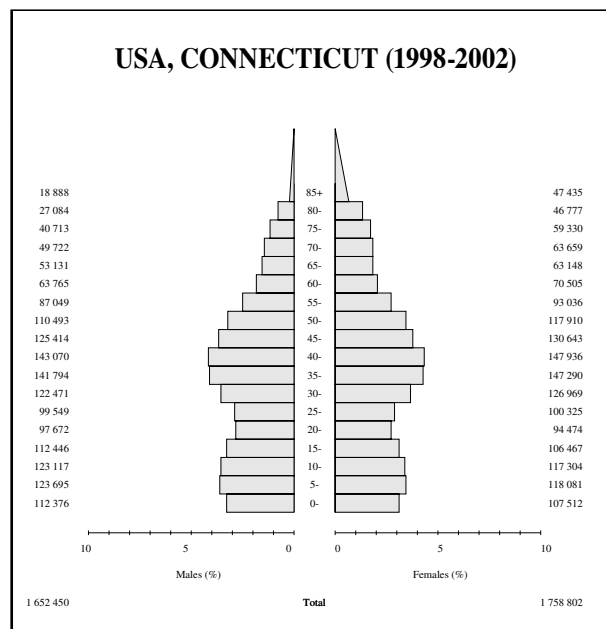
Interpreting the results

Lack of reporting of cancer diagnoses from physicians may result in under-ascertainment, mainly for certain cancers treated and diagnosed solely in physicians' or dermatopathologists' offices. The possibility of use of out-of-state pathology laboratories also requires periodic examination.

Use of the data

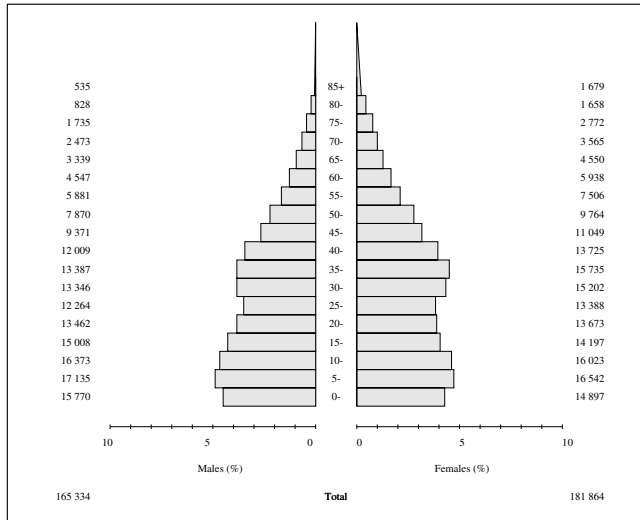
CTR's database contains statistical information on cancers diagnosed since 1935, the earliest year among registries in the USA.

Data from the registry are included with those from other SEER registries in the NCI's annual publication entitled Cancer Statistics Review. This document is used by the NCI as part of the process of setting priorities for research on the prevention and treatment of cancer in the US population. The data the CTR collects are also used to identify priorities and target prevention and control activities in Connecticut, educate the public and health professionals about specific cancer risks, trends and treatments, monitor

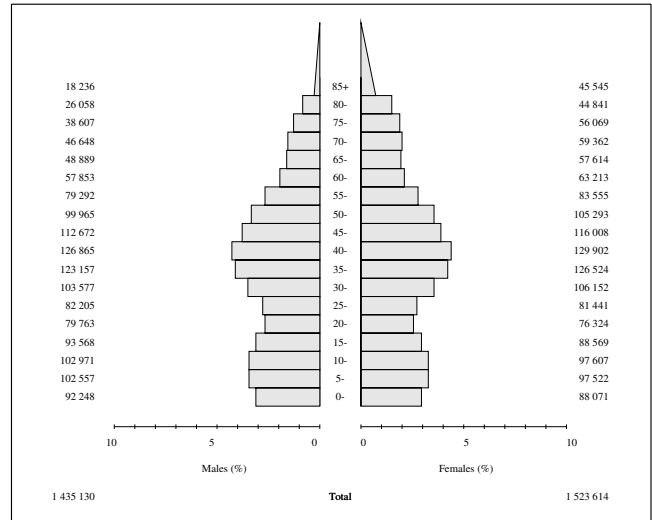


cancer incidence and trends and aid research studies. Data from the CTR have been used in hundreds of scientific publications by researchers worldwide, including the Pratt and Whitney Brain Cancer Study. <http://www.dph.state.ct.us/>. Incidence rates in Connecticut are routinely reported in various monographs produced by the CTR.

USA, CONNECTICUT: BLACK (1998-2002)



USA, CONNECTICUT: WHITE (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.

Multiple primary rules used

IACR rules (2004) on CI5 IX period.

USA, District of Columbia

Registration area

The District of Columbia Cancer Registry (DCCR) operates within the DC Department of Health (DOH) and serves a total population of 572 059 (2000 census) District residents. The District population consists of about 60% African-Americans, 31% Caucasians and the remainder from other racial/ethnic backgrounds. The gender distribution is 47% males and 53% females. In addition, the District's area hospitals provide cancer diagnosis and treatment to residents from the surrounding jurisdictions (Maryland and Virginia).

Cancer care facilities

The District of Columbia has 3 teaching hospitals, 1 specialty hospital for children, 2 federal hospitals, and 3 other hospitals. All of the hospitals provide diagnostic and treatment services for cancer patients. Almost all of the radiotherapy departments are located in a hospital facility. Almost all of the District's private practitioners are associated with at least one of the hospitals where cancer patients receive diagnostic and/or treatment services.

Registry structure and methods

The District of Columbia Cancer Registry (DCCR) is located within the DC Department of Health (DOH) and is funded partly by the US Centers for Disease Control and Prevention's National Program of Cancer Registries (NPCR), which pays the salaries of 3 staff members and a contractor. The DOH pays the salaries of 2 staff members, one of whom is the Program Director.

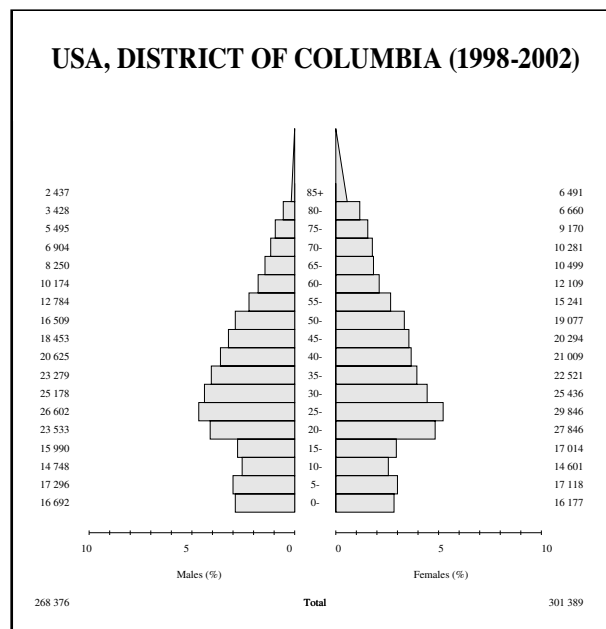
Data collection is passive notification of pre-coded data from the hospitals through electronic means (e.g. diskette, CD-ROM, etc.).

The principal sources of information on cancer cases are the hospitals. The District does not have any freestanding

pathology laboratories. Death registration is performed by the State Center for Health Statistics where the DCCR obtains a death tape to match the registry database. Death certificates received at the registry are manually entered into the registry's database. For verification, registry staff performs a follow-up by contacting the physician signing the certificate or the institution listed on the certificate where the patient might have died.

Interpreting the results

The number of cases for the District of Columbia has been on a steady decline since the 2000 diagnosis year. Almost all of the decline can be attributed to a decrease in the population. PSA testing is common.



Use of the data

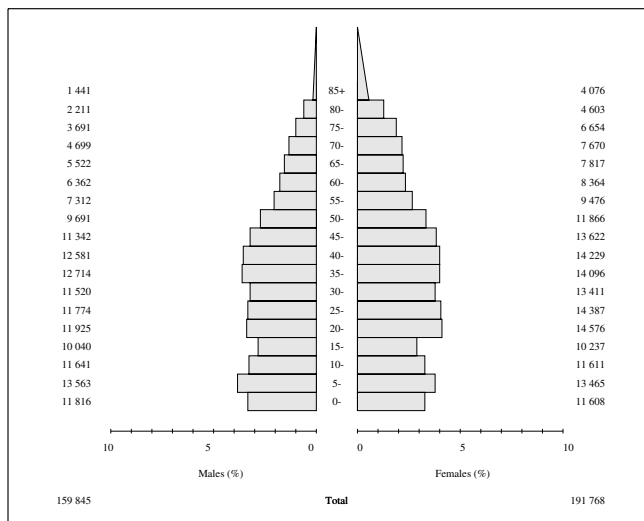
The DCCR prepares and publishes an annual report of cancer incidence and mortality. The DCCR collaborates with the George Washington University on a number of cancer research studies. Some recent titles include:

1. The Association of SES with Breast Cancer Incidence, Grade & Stage at Diagnosis Among Caucasian & African American Women in Washington, D.C.
2. The Role of Race and Poverty in Determining Breast Cancer Patterns in the District of Columbia.
3. Using Demographic Data to Improve Breast Cancer Screening and Education in Underserved DC

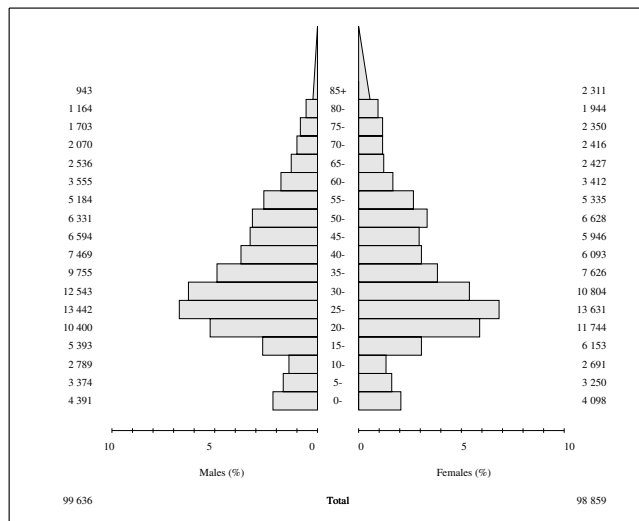
Communities.

In addition, the DCCR also collaborates with other independent researchers by providing data, or performing data linkage of its data with other databases. The DCCR also performs statistical reviews for the Comprehensive Cancer and Breast Cancer Programs.

**USA, DISTRICT OF COLUMBIA:
BLACK (1998-2002)**



**USA, DISTRICT OF COLUMBIA:
WHITE (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.

USA, Florida

Registration area

The Florida Cancer Data System (FCDS) is a legislatively mandated, statewide population-based registry covering a population of approximately 16 million. The State is comprised of 67 counties. Approximately 95% of the population (~15 million) live in 38 counties designated as Urban by the 2003 Beale codes. The remaining 29 counties are classified as Rural.

Cancer care facilities

There are over 230 primary care facilities reporting data to FCDS. Additionally, data are collected from over 350 ambulatory care facilities, 800 pathology laboratories, the State of Florida Vital Statistics, the State of Florida discharge database and inter-state data exchange agreements.

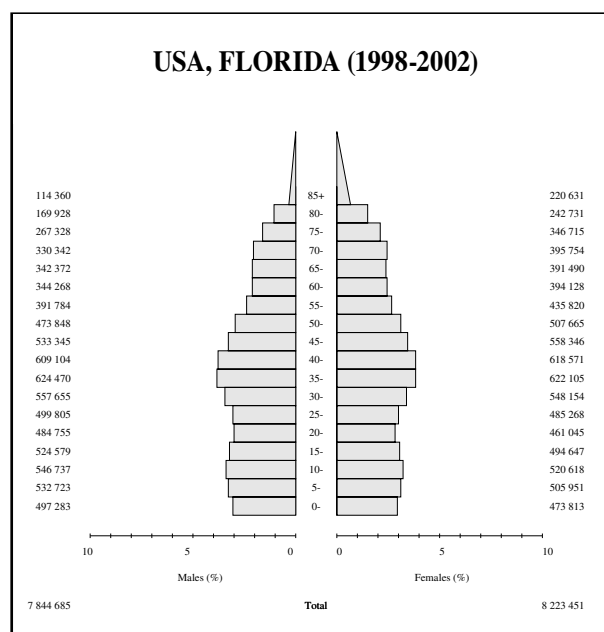
Registry structure and methods

The FCDS is a joint project of the Florida Department of Health and the University of Miami Miller School of Medicine (UMMSM). The UMMSM has operated the FCDS since its inception in 1981 under contract with the DOH.

FCDS is part of the US Centers for Disease Control and Prevention's National Program of Cancer Registries (NPCR) and is nationally certified by the North American Association of Central Cancer Registries (NAACCR) at its highest level, gold certification. Gold certification is conferred on central

registries that meet or exceed all standards for completeness, timeliness, and quality.

Data collected and coded by the FCDS are in accordance with national standards as put forth by the NAACCR. To code primary site (typography and morphology), the FCDS uses the International Classification of Diseases – Oncology, 3rd edition (ICD-O-3). During the study time period, the national staging criteria were revised. Tumours diagnosed between 1998 and 2000 were staged using the SEER General Summary Stage 1977. Tumours diagnosed between 2001 and 2002 were staged under the SEER General Summary Stage 2000 schema. Both schemas as presented in Table 2 categorise stage of disease as in-situ, local, regional or distant, but the site-specific conversion was not necessarily a one-to-one conversion within and between the regional and distant categories. However because regional and distant staged breast cancer were combined into 'late stage', the revised coding schema had no effect on this analysis, and the year-specific stages could be combined into a common stage variable.



Interpreting the results

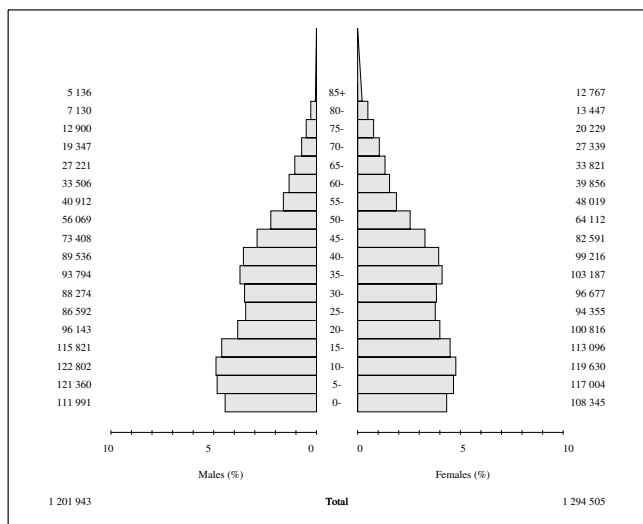
The FCDS collects in excess of 95% of cancer cases among Florida residents.

Use of the data

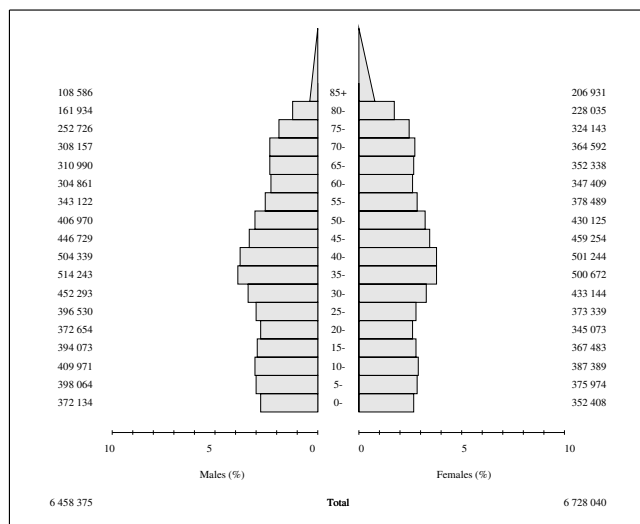
The FCDS prepares an annual report of cancer incidence, highlighting trends and changes, and maintains a web site for dissemination of

tabular data. Additionally, data are provided for researchers.

USA, FLORIDA: BLACK (1998-2002)



USA, FLORIDA: WHITE (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.

USA, Georgia

Registration area

The Georgia Comprehensive Cancer Registry is a population-based cancer registry covering the population of the entire state of Georgia. The population as of the most recent census projection (2000) is 8 186 453. Based on the 2000 census 65.1% of Georgia population is white, 28.7% black or African American, 2.1% Asian, 0.3% American Indian and Alaska Native, 0.1% Native Hawaiian and Other Pacific Islander, and 2.4% other race. Additionally 5.3% of the Georgia population is of Hispanic or Latino origin. The majority (80%) of Georgians live in urban areas, while 20% live in areas classified as rural.

Cancer care facilities

For each cancer case, facilities are required to report information such as sex, race and date of birth; cancer diagnostic information such as primary site, histology, grade, and date of diagnosis; diagnostic confirmation and stage information such as SEER summary stage 2000 and Extent of Disease (EOD); and treatment information related to first course of treatment such as surgery, radiation, chemotherapy, hormone and other treatment. Additionally information is collected on the patient's vital status.

Registry structure and methods

The Georgia Comprehensive Cancer Registry (GCCR) is located in the Georgia Department of Human Resources, Division of Public Health in Atlanta, Georgia. The registry is funded by the state of Georgia and the federal government. Since 1995, the GCCR has participated in the National Program for Cancer Registries (NPCR) that was established by the US Centers for Disease Control and Prevention (CDC).

The GCCR registry covers the entire State of Georgia, which is bounded by Tennessee and North Carolina to the north, Alabama to the east, Florida to the south, and South Carolina to the west. Reports are prepared by cancer registrars located in hospitals with more than 100 licensed beds and submitted to the central registry. The GCCR's five regional coordinators are responsible for abstracting cancer reports for facilities with less than 100 licensed beds. Independent

pathology laboratories submit their pathology reports electronically, and small pathology laboratories whether in-state or out-of-state may submit a photocopy of their pathology reports. Since 2001, the GCCR has conducted a yearly electronic match with the Georgia Hospital Discharge database to identify potential missed cases. Cases identified are researched by the GCCR regional cancer coordinators for reportability; identified missed cases are the responsibility of the facility to report. Additionally, the GCCR conducts death linkage with the State of Georgia death file, and follow-up of missed cases is done via hospitals, nursing homes, hospice and next-of-kin. Additionally the GCCR regional cancer coordinators conduct yearly casefinding audits on a sample

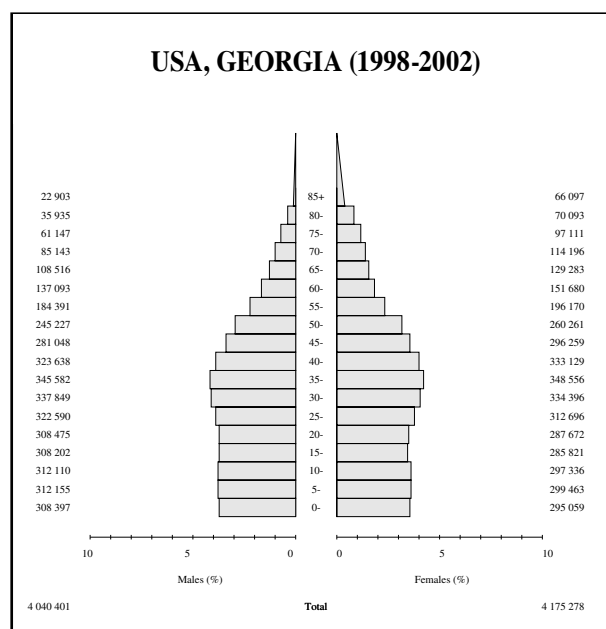
of hospitals. During these audits cancer registrars check on missed cases in hospital departments of medical records, pathology, radiology, outpatient department, and other hospital sources.

Since 1995 all healthcare providers in the state of Georgia have been required to report specific information on all cancers in their patient population to the Georgia Comprehensive Cancer Registry. This includes all facilities providing diagnostic evaluations and/or treatment for cancer patients, including hospitals, outpatient surgical facilities, laboratories, radiation therapy and medical oncology facilities, and physician's offices. In addition, reporting agreements are maintained with neighbouring

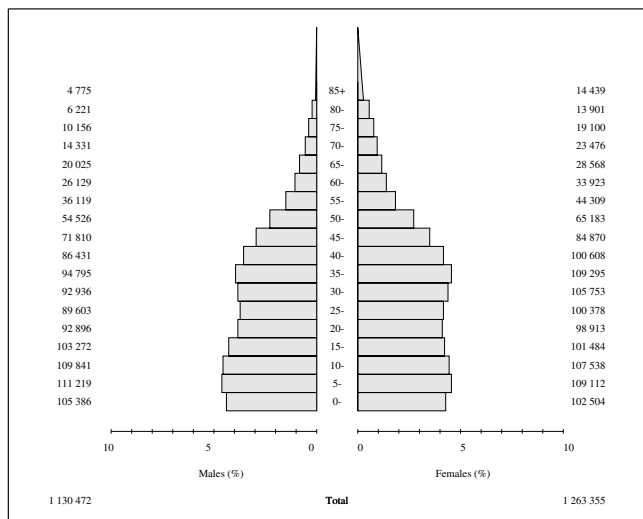
states so that Georgia residents who are diagnosed or treated in out-of-state facilities can be identified.

Use of the data

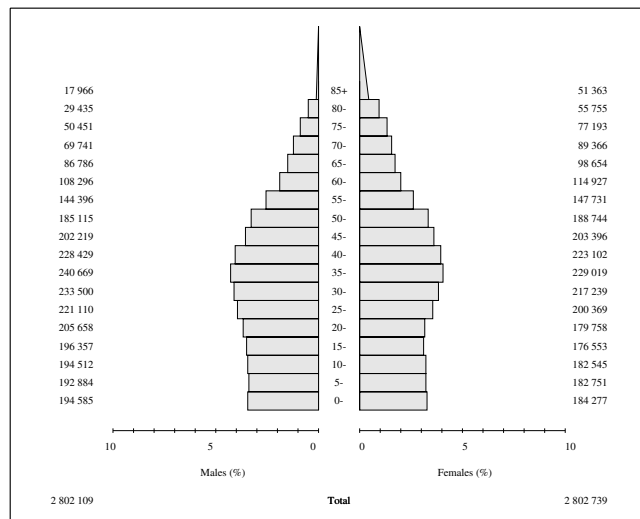
The registry prepares an annual report of cancer incidence and mortality, highlighting trends and changes. Special reports on breast, cervical, colorectal, lung, prostate, and childhood cancers are prepared on an annual basis. GCCR annual reports, cancer incidence and mortality analysis are available at <http://health.state.ga.us/programs/gccr>. Cancer data are analysed regularly to meet the needs of the state-wide Georgia Comprehensive Cancer Control Program. The GCCR provides qualified researchers with cancer data to assist in investigating their proposed studies, and responds to various data requests and cancer cluster for the public.



USA, GEORGIA: BLACK (1998-2002)



USA, GEORGIA: WHITE (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.

USA, Georgia, Atlanta

Registration area

The Metropolitan Atlanta Registry records cancer diagnosed in residents of five contiguous counties (Clayton, Cobb, DeKalb, Fulton and Gwinnett) surrounding the state capital of Atlanta, Georgia. Covering an area of 4500 km², the metropolitan Atlanta area is situated in the southeastern United States at latitude 33° N and longitude 84° W. The population in 2000 was estimated to be 2 914 587, of which 54% were white, 36% were black, 4% were Asian and 6% were other races. Approximately 6% of the population were Hispanic. The combined population of these 5 metropolitan Atlanta counties comprised 36% of the entire population of Georgia (159 counties). The area has one of the fastest-growing populations in the USA, with an increase of 737 546 (33.8%) between 1990 and 2000. Atlanta lies at an altitude of over 320m and enjoys a temperate climate with 4 distinct seasons. Air pollution is a growing problem, particularly during summer months.

Registry structure and methods

The Georgia Center for Cancer Statistics (GCCS), a division of the Department of Epidemiology in the Rollins School of Public Health at Emory University, was founded in 1976 to provide population-based incidence data for a 5-county region in the southeastern USA as part of the National Cancer Institute's Surveillance, Epidemiology and End Results (SEER) Program. Metropolitan Atlanta was a logical choice, since it had been included in the First, Second and Third National Cancer Surveys. Since its inception the population covered by the registry has increased dramatically, but the geographical boundaries have not changed.

The GCCS also operates the Rural Georgia SEER Registry and carries out the day-to-day operations of the Georgia Comprehensive Cancer Registry. It collaborates with the SEER Program of the National Cancer Institute, the Cancer Control Program of the State of Georgia and the National Program of Cancer Registries at the Centers for Disease Control and Prevention on these cancer registry projects. The registry is staffed by over 25 full-time employees including epidemiologists, data abstractors, quality control editors, data analysts and other support staff.

Cancer is a reportable disease in the state of Georgia. The Metropolitan Atlanta Registry combines both active and passive case-finding and reporting systems. Most of the hospitals and free-standing pathology laboratories in

the area identify and electronically transmit their cases to the registry on a monthly basis. Registry field staff actively identify and collect cases from radiation therapy facilities, large physician practices and other selected facilities without the ability to report data electronically.

Patient follow-up is primarily conducted through hospital cancer registries, treating physicians and record linkage against a variety of available data sources. Death certificates are obtained electronically on a monthly basis and are used to supplement case-finding and update patient follow-up. Data are processed at the registry using software developed by in-house staff. Extensive automated and visual editing is performed on the data to enhance and ensure quality. Both case-finding and re-abstraction audits are periodically performed at facilities reporting data.

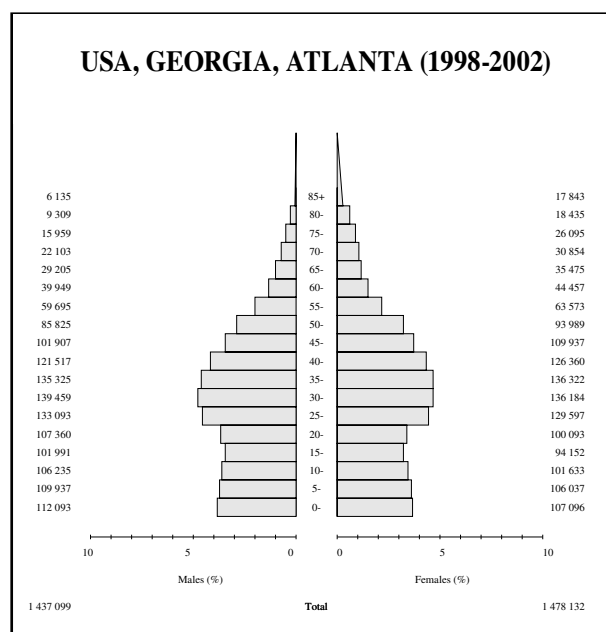
Interpreting the results

The Metropolitan Atlanta Registry actively shares data with the Georgia Comprehensive Cancer Registry to help ensure complete case ascertainment and treatment information on residents of the 5-county catchment area diagnosed and/or treated elsewhere in Georgia. Case sharing agreements with Georgia's bordering states also exist. For selected cancers that may be solely diagnosed and treated in the physician's office setting, incidence records may be missing from the registry due to a general lack of reporting

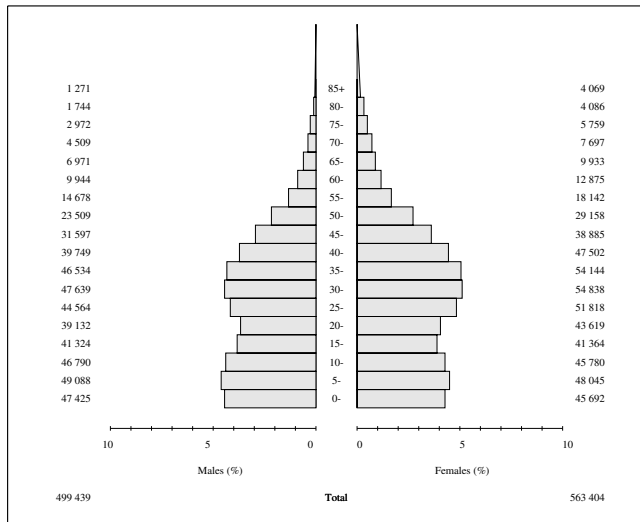
by physicians throughout the state.

Use of the data

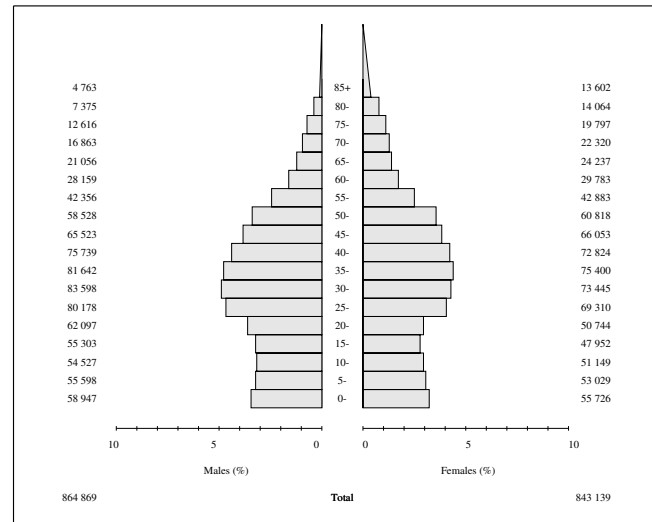
The Metropolitan Atlanta Registry submits data on an annual basis to the National Cancer Institute's SEER Program and the Center for Disease Control and Prevention's National Program of Cancer Registries, in collaboration with the Georgia Comprehensive Cancer Registry. A number of population-based descriptive and analytical epidemiological investigations have been conducted through the registry. Several of these have focused on factors, which may relate to the observed high incidence and low survival rates for cancer among blacks. These studies have included cancers of the prostate, breast, pancreas, esophagus, ovary, colon, rectum and multiple myeloma. Registry data extensively support the research of faculty within the Rollins School of Public Health at Emory University as well as many other researchers throughout the state.



USA, GEORGIA, ATLANTA: BLACK (1998-2002)



USA, GEORGIA, ATLANTA: WHITE (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.

Multiple primary rules used

IACR rules (2004) on CI5 IX period.

USA, Idaho

Registration area

According to the US Census Bureau (internet release 22 December 2006), Idaho's total resident population for 1 July 2006 was 1 466 465. Idaho is the 4th fastest growing state since the 2000 Census. Idaho ranks 3rd among the 50 states plus the District of Columbia in terms of the proportion of the population aged 18 and under, and 41st in terms of the proportion of the population aged 65 and older (2000 Census). The majority of Idahoans are non-Hispanic whites; Hispanics and Native Americans are the two largest minority groups, comprising 8.9% and 1.6% of Idaho's population, respectively (2004).

Idaho ranks near the bottom of states on several demographic measures that have been shown to be related to lower rates of cancer screening and later stage at diagnosis. Idaho is a large geographical state of 82 413 square miles, and over one third of Idaho counties are classified as frontier with less than 6.0 persons per square mile. The rural character of Idaho combined with severe winters in much of the state pose difficulties with access to cancer care.

Cancer care facilities

Thirty-seven hospitals routinely provide cancer diagnosis and/or treatment. There are seven hospitals in Idaho that have approved cancer programs from the American College of Surgeons Commission on Cancer. Seven hospitals offer radiotherapy, and there is one free-standing radiation facility in Idaho.

Registry structure and methods

The Cancer Data Registry of Idaho (CDRI) is a population-based, statewide cancer registry that collects incidence and survival data on all cancer patients who reside in the state of Idaho or who are diagnosed and/or treated for cancer in the state of Idaho. Idaho has one of the oldest cancer registries in the United States. Established before the National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) Program, the Cancer Data Registry of Idaho (CDRI) has functioned since 1969 and has been population-based since 1971.

Since 1969, CDRI has been supported with state funding by a dedicated fund from a portion of Idaho's tobacco tax. Since 1994, CDRI has enhanced cancer registry operations and increased utilisation of cancer registry data with National Program of Cancer Registries (NPCR) funding administered by the US Centers for Disease Control and Prevention (Public Law 102-515).

CDRI is staffed by six employees, including a vice president of operations and registry services, a director, an epidemiologist, a database coordinator and two cancer data controllers.

Both hospital-based registrars and central registry personnel conduct active and passive follow-up of cancer patients. CDRI conducts an annual linkage with vital records to obtain survival data as well as determine cancer cases that were not identified through other sources.

CDRI has worked since 1999 with the Northwest Portland Area Indian Health Board (NPAIHB) on probabilistic linkages between cancer registry, tribal registry and Indian Health Service administrative data to improve the accuracy of cancer statistics among Native Americans in Idaho.

Interpreting the results

CDRI has achieved NPCR and North American Association of Central Cancer Registries (NAACCR) standards for data completeness, timeliness and quality since 1993; for the last ten years of submitted data (1995–2004) CDRI has achieved the NAACCR Gold Standard. Idaho data are included in USCS and CINA.

In 2004, Idaho was twelfth-worst in the nation for men aged 40 and older who have not had a prostate specific antigen (PSA) test within the past two years, according to the Behavioral Risk Factor Surveillance System (BRFSS).

Use of the data

CDRI data are used for many purposes, including surveillance of cancer incidence rates, program planning and evaluation,

quality assurance, measurement against clinical guidelines and benchmarks, central registry systems development, responding to requests for information from hospitals, media and the public, and public health practice.

CDRI data are used in approved projects for use in epidemiologic and translational studies. In 2006 CDRI was funded to participate in the CDC/ORC Macro study "Accuracy of Cancer Mortality Measured by Death Certificates." CDRI worked with NPAIHB to link tribal registries to CDRI data to improve quality of race-specific incidence rates and used linked data in studies.

Published reports of cancer incidence and mortality are available on the CDRI web site at: www.idcancer.org.

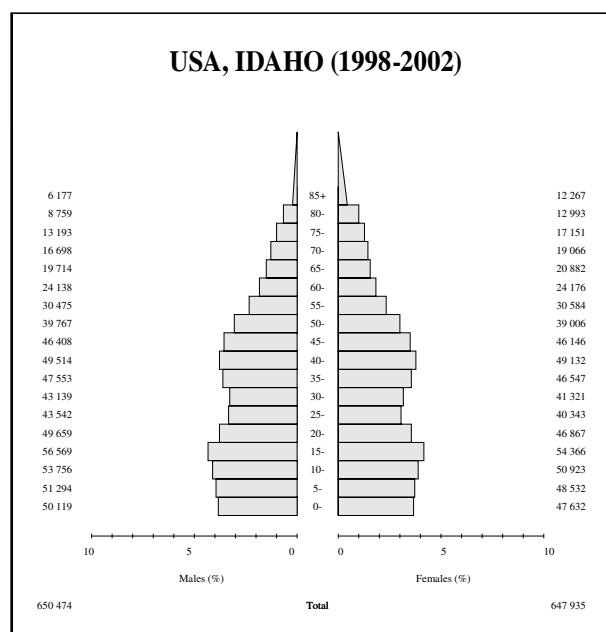
Source of population

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.



USA, Illinois

Registration area

The Illinois State Cancer Registry covers the population of the State of Illinois, USA. The population at the most recent census was 12 439 738, with an urban population of 12 378 679 and a rural population of 61 059. Eighty percent of the population is white, 16% African American, and 4% of the Illinois residents reported themselves as some other race; 12% of the population is Hispanic or Latino.

Cancer care facilities

Throughout Illinois cancer patients are treated at hospitals, ambulatory surgery centres, out-patient non-hospital facilities that house radiation therapy equipment, physician's offices and chemotherapy centres. The size of the hospitals varies from large teaching and university-based hospitals to small rural community hospitals. There are two NCI-designated Comprehensive Cancer Centers in Illinois. About 6% of the Illinois residents visit hospitals in other states for diagnosis and treatment.

Registry structure and methods

The Illinois State Cancer Registry is housed in the Illinois Department of Public Health, Division of Epidemiologic Studies and state law provides the authority for collection of cancer incidence cases.

The state accounts for one third of the Registry funding, and the other two thirds is funded by the US Centers for Disease Control and Prevention's National Program of Cancer Registries (NPCR). The registry receives reports from over 400 facilities, and 97% of the reports are received in electronic format.

All hospitals are visited at least once every five years for casefinding. Re-abstracting studies will be performed online within the next year, and online abstracting will also be available. Death clearance is performed as a casefinding tool, and data exchange is performed with 12 other US states.

There are 23 staff supporting the registry and include a PhD, MD Medical Director, along with 11 certified tumour registrars (including registry manager, trainer and QC manager), 3 database support staff, 1 data use coordinator, 2 registry operations staff, 1.75 clerical support staff, 2.5 epidemiologists and 1.75 research support staff. The registry performs all activities required by the National Program of Cancer Registries and has been certified as a gold standard registry by the North American Association of Central Cancer Registries for the past 9 years.

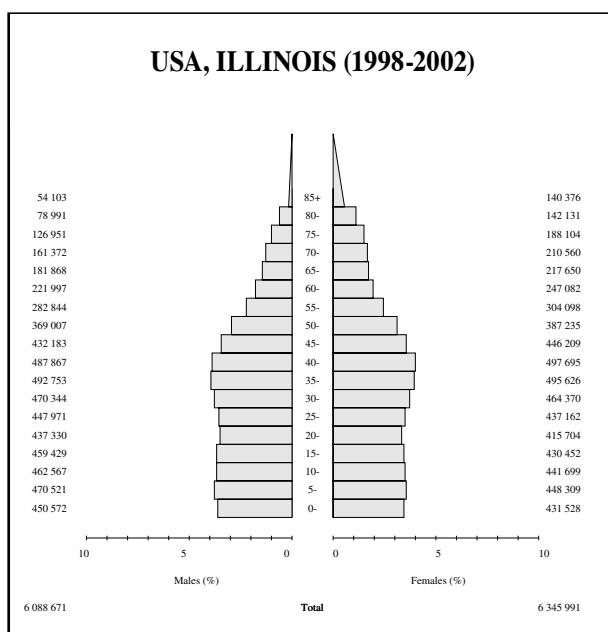
Interpreting the results

The completeness of reporting for the Illinois State Cancer Registry is estimated to be 100%. However, melanomatous cancers of the skin and prostate cancer are estimated to be under reported.

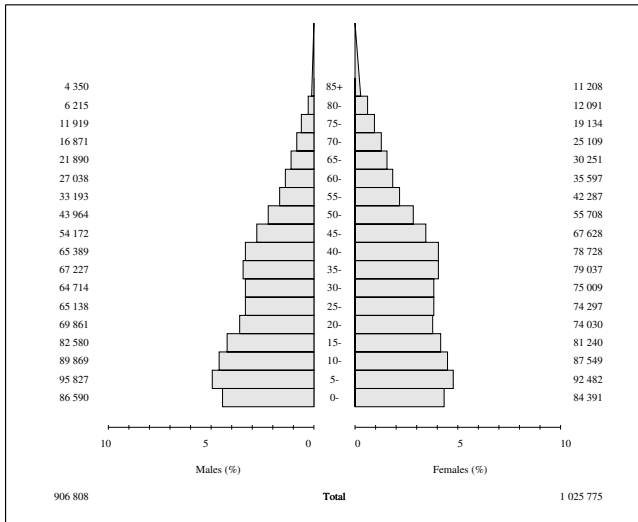
Use of the data

The registry provides yearly annual reports at the state and county levels; a public dataset file with data at state, county and postal code levels; an interactive query system of all public data on the Department's web site; access to confidential data by researchers through application and IRB review;

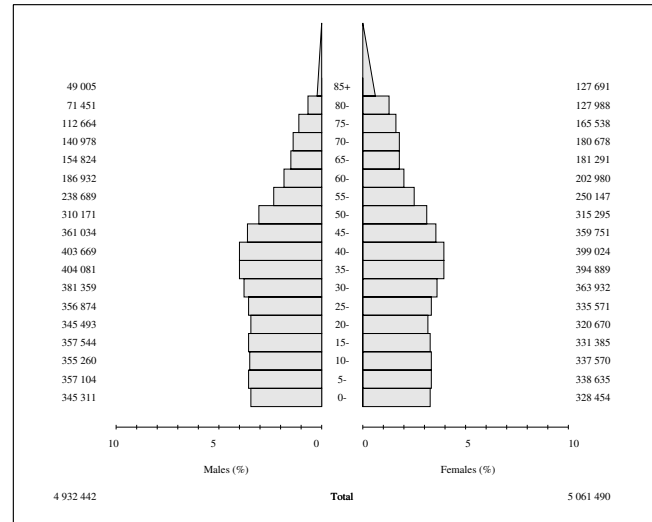
cluster investigations; quality control reports to reporting facilities; linkage with the Department's Breast and Cervical cancer program and the State's death certificates and various non-confidential data requests from reporting facilities.



USA, ILLINOIS: BLACK (1998-2002)



USA, ILLINOIS: WHITE (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.

USA, Indiana

Registration area

The Indiana State Cancer Registry covers the population in the state of Indiana, USA. The population at the most recent census (2000) was 6 080 485. The majority of the population (85.8%) is white, non-Hispanic. Non-Hispanic Black or African Americans comprise 8.3% of the population, Hispanics of any race 3.5%, and all other non-Hispanics 2.3%. The majority of the population (70.8%) resides in urban areas with 56.1% of the total population living in areas with more than 50 000 residents. Although 29.2% of the population lives in rural areas, only 2.1% of the total population live on farms. Surveys from 1990 suggest that about 87.5% of the population is Christian (Catholic 16%), about 7.4% is nonreligious, about 0.3–0.4% is Jewish, about 0.1% is Muslim, and the others belong to a variety of religions. Approximately 14% of the population has no health insurance, 24% has government-sponsored health insurance, and 63% has private health insurance (59% through their employers).

Cancer care facilities

Approximately 44 of the approximately 120 acute care hospitals in Indiana have a cancer program approved by the Commission on Cancer/American College of Surgeons. Patients also receive cancer care in a variety of outpatient settings, such as ambulatory surgery centres, radiation therapy centres, cancer clinics, home care, private physician offices, and other locales.

Registry structure and methods

The registry is located within the Indiana State Department of Health, and is funded through state and federal funds from the US Centers for Disease Control and Prevention's National Program of Cancer Registries (NPCR). The registry is staffed by a director, three full-time cancer registrars, one full-time software programmer/analyst, one grant coordinator, and one secretary.

The registry collects data from approximately 120 hospitals throughout the state plus additional surgery centres, radiation centres, pathology laboratories, and physician offices. Cancer registry records are matched electronically with death certificates every year. Unreported cancer cases identified through this death clearance process are followed back and added to the registry as either a new case or a Death Certificate Only (DCO) case.

Cancer is a reportable disease by state statute. Most cases are reported electronically by hospitals using various cancer registry software programs. Case-sharing agreements are in place with the four surrounding states (MI, OH, KY, & IL) and approximately 14 other states.

Numerous quality control procedures are performed on all incoming data using electronic and manual edit checking procedures.

Interpreting the results

Estimates of completeness of case ascertainment are made using the NAACCR method, which compares the ratio of incidence rates to mortality rates for over a dozen cancers, and compares this ratio with the ratio calculated for areas covered by SEER.

The Indiana State Department of Health (ISDH) has a Breast and Cervical Cancer Program through the Centers for Disease Control and Prevention (CDC), which provides funding and guidelines for the program. This program provides mammograms and Papanicolaou testing for low-income women ages 40–65. The ISDH organizes the annual Black & Minority Health Fair, which occurs in conjunction

with the Indiana Black Expo Summer Celebration. Free PSA testing is offered as one of a number of screening tests for chronic diseases. There is information available about screening for other cancers, including breast cancer, cervical cancer, and colon cancer, though these screenings are not generally offered at the fair. Outside of ISDH, there are many public and private organisations offering free or low-cost screenings for breast, cervical, prostate, and colon cancers.

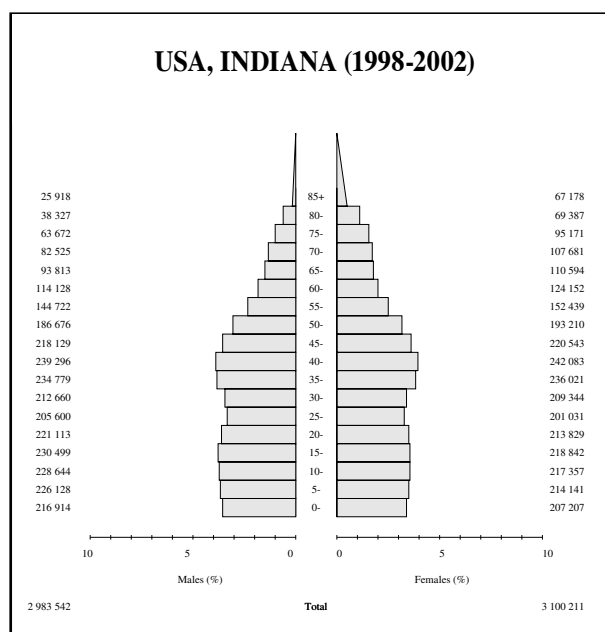
Self-reported information from the 2004 Indiana Survey of the Behavioral Risk Factors Surveillance System indicates that an estimated 48.9% of Indiana men age 40 or above have had a PSA test within the past 2 years. This is lower than

the nationwide (USA) average of 51.8%. In Indiana, only an estimated 55% of men age 40 or over report ever having had a PSA test.

Indiana is second highest in the USA in the percentage of current smokers (27.3% of the population age 18 or older). Both tobacco growing and coal mining are fairly common occupations in southern Indiana.

Use of the data

The Cancer Registry supports the Comprehensive Cancer Control program with data used both in educational publications and to provide an evidence base for the planning and implementation of strategies. The registry prepares an annual report of cancer incidence. Cancer registry data are also matched with data from the Breast and Cervical Cancer Early Detection Program annually. Cancer registry data are provided to the Shared Information Pathology Network project at Regenstrief Clinic in Indianapolis quarterly. Data are also used to respond to numerous unscheduled requests for data from other sources. Neither the registry nor any other programs or divisions in the ISDH does epidemiological cancer research beyond producing routine statistics. However, the Indiana State Cancer Registry makes its data available to bona fide researchers in both public and private organisations.



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.

USA, Iowa

Registration area

The state of Iowa is located near the geographical middle of the United States and is part of its agricultural "heartland". Iowa is bordered on the north by Minnesota, the south by Missouri, the east by Illinois, and the west by Nebraska. The total area is about 145 800 km² with elevation ranging between 146 and 505m above sea level.

Ninety-two percent of the land area in the state is devoted to agriculture, ranking the highest in the USA among its 50 states. Agricultural exposures include pesticides, fertilizers, fuels and oils, animal viruses, organic solvents, engine exhausts and paints. These may influence cancer incidence in this population, but likely not as strongly as lifestyle factors like tobacco use, alcohol consumption and overweight/physical inactivity.

Iowa had a 2000 population of 2 926 324, a 3.6% increase over its 1970 population. The population aged 65 years and older increased from 12.4% in 1970 to 14.9% in 2000. The principal ethnic group is Northern European, with Germans, Danes and Swedes accounting for a large segment of the population. The 2000 population is 93.9% white with 2.1% blacks, 1.3% Asian/Pacific Islander, 0.3% American Indian/Alaskan Native, and 2.4% other or more than one race. Over 80% of Iowa residents are native-born. The population is primarily Christian, the most prevalent religions being Roman Catholic, Lutheran, and Methodist.

Cancer diagnostic and treatment services are widely available to the entire Iowa population through both in-state and out-of-state facilities. These include surgery, radiation therapy, chemotherapy, and other treatment modalities such as immunotherapy. Radiation oncology services are provided as in-hospital facilities as well as stand-alone facilities. These types of diagnostic and treatment services have increased over time and have been accompanied by increasing numbers of medical, surgical, and radiation oncologists.

Registry structure and methods

Cancer data collection for the entire state of Iowa began in 1969 with the Third National Cancer Survey sponsored by the National Cancer Institute (NCI). With the completion of the survey in 1971, no further funding for cancer registration was available and 1972 data are incomplete. In 1973 the State Health Registry of Iowa, frequently referred to as the Iowa Cancer Registry, became part of the NCI Surveillance, Epidemiology and End Results (SEER) Program. The area covered by the Registry has not changed since 1969, and includes all 99 counties in the state of Iowa.

Cancer became a reportable disease in Iowa in 1982. The Iowa Department of Public Health has designated responsibility for cancer data collection to the Registry. Cancer data for Iowa

residents are obtained from 154 hospitals, clinics, and pathology laboratories located both within the state and bordering the state. Cancer data are exchanged with other states.

Data are collected by Hospital Cancer Registrars and by 20 field staff employed by the Registry to cover specified geographic areas. The field personnel visit hospitals and other facilities in their areas and abstract data using laptop computers. The Registry's remaining 30 full-time employees work in the central office where they edit the data, consolidate multiple reports for the same cancer, perform follow-up, respond to data requests, and conduct research.

Since 1969, there have been changes in case definition and coding. These are documented in revisions to coding manuals and extent of disease classifications, provided at <http://www.seer.cancer.gov/tools/codingmanuals>.

The International Classification of Disease for Oncology is used to assign codes for topology, morphology, and tumour behaviour. The Registry is currently using the 3rd edition of ICD-O.

The Registry uses active and passive follow-up activities to obtain survival data. Passive follow-up activities include computerized linkage of data with death certificate information, driver's license data, and Medicare information provided by the Centers for Medicare & Medicaid Services.

Active patient follow-up is conducted annually.

Quality control activities, including computer edits, statistical comparisons, and visual review of data, occur daily. Site-specific re-casefinding and re-abstracting are also performed on a regular basis.

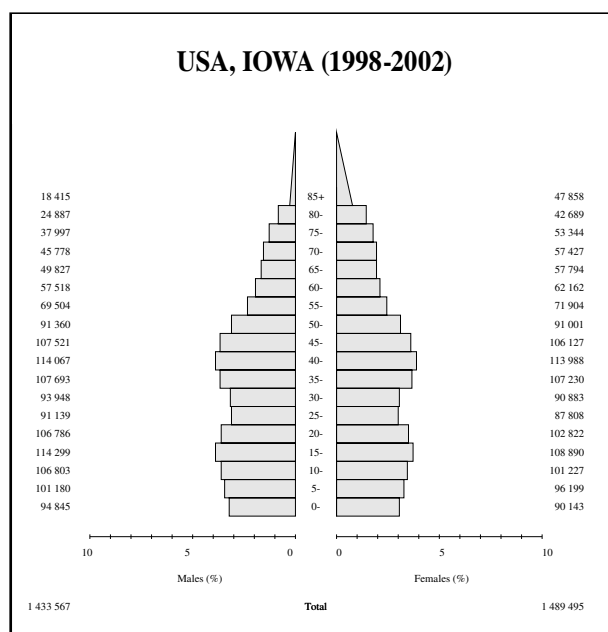
Interpreting the results

Although some Iowans who leave the state for care are not identified and missed, ascertainment is thought to be about 99%. The Iowa Cancer Registry successfully follows over 98% of all patients into the current year.

Use of the data

The Registry functions as a collaborative program with the Iowa Department of Public Health. Many University of Iowa researchers have used Registry data. Registry data have also been used extensively in a number of local, national and international epidemiological studies.

Policymakers look to the cancer registry to provide information regarding the burden of cancer and time trends in cancer incidence, stage of disease at diagnosis, survival, and mortality. To this extent, they are currently used to address and assess cancer prevention and control issues. Occasionally, the data are also used to determine certificate



of need requests for new medical facilities and equipment in selected geographic areas of the state.

Source of population

Annual census projection based on the 2000 Census, prepared by the US Bureau of the Census.

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.

USA, Kentucky

Registration area

The Kentucky Cancer Registry (KCR) is a population-based central cancer registry for the entire state of Kentucky. According to the 2000 U.S. Census, the population of Kentucky was approximately 4 042 000. Of that, 75.1% are White, 12.3% are Black and the remaining 12.6% are American Indians, Alaska Natives, Asian, Hawaiian Natives, Pacific Islanders or other races.

Cancer care facilities

All health care facilities in Kentucky that diagnose or treat cancer patients are required to report cancer cases to KCR. Facilities that are also required to report cancer cases include freestanding treatment centres, non-hospital (private) pathology laboratories, and physician offices.

Registry structure and methods

KCR has been collecting data on incident cases of cancer since 1991, when the State General Assembly approved legislation requiring mandatory reporting of all cases of cancer to the registry. The legislation provided recurring funding for staff, travel and computer equipment. KCR also receives funding from the US Centers for Disease Control and Prevention (CDC) through the National Program of Cancer Registries (NPCR) and the National Cancer Institute's Surveillance Epidemiology and End Results (SEER) program. KCR employs three Regional Coordinators to work with larger institutions and four Regional Abstractors that work with smaller hospitals in order to ensure the quality, accuracy, timeliness of the data reported.

The larger hospitals (those diagnosing or treating more than 100 new primary cancer cases annually) are required to have their own tumour registrar(s). These larger hospitals are divided into three geographic regions. The three Regional Coordinators employed by KCR spend one day each month in each of these larger facilities providing additional training, re-abstracting cases for quality control and helping the hospital-based registrars prepare reports from the data. The smaller hospitals (those diagnosing or treating fewer than 100 new primary cancer cases annually) are divided

into four regions and assigned to one of four Regional Abstractors employed by KCR. The Regional Abstractors record and report information on all cases of cancer seen in these smaller institutions. The KCR Regional Coordinators and Regional Abstractors are required to be Certified Tumor Registrars (CTRs) or become CTRs within two years of their date of employment.

Interpreting the results

Data from KCR have been submitted to the North American Association of Central Cancer Registries (NAACCR) for an objective evaluation of completeness, accuracy and timeliness each year since a formal certification program was established in 1997. In each year (1999–2001), KCR received the highest level of NAACCR certification available (Gold). KCR has also submitted its data for inclusion in the Cancer in North America (CINA) publication. A registry must have complete data for the most current five-year period before their data can be evaluated for inclusion in the CINA combined rates. KCR data have been included in the CINA combined rates each year since five years of KCR data became available.

Use of the data

KCR data are used to initiate cancer control programs, evaluate intervention activities, or conduct epidemiological research. KCR data have been used in preparing hundreds

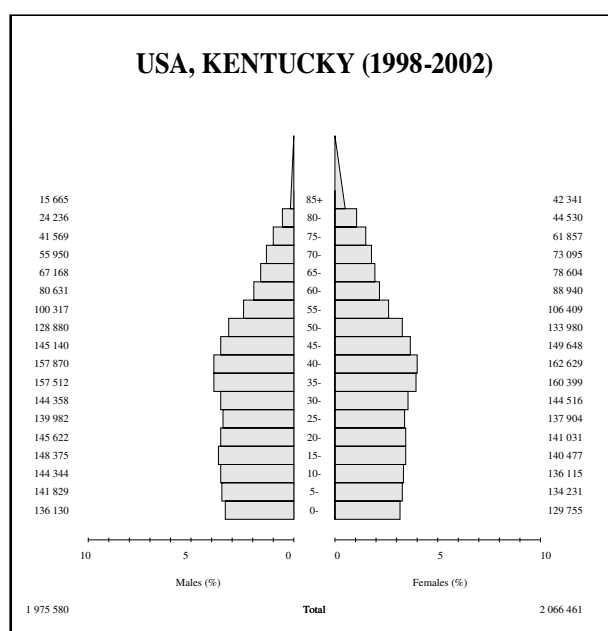
of research projects and proposals. Also, data from KCR are presented each year to cancer councils in 15 Area Development Districts (groups of counties) covering the entire state. These District Cancer Councils use the data from KCR to identify specific types of cancer that occur in their area at substantially different rates compared to state and US rates.

Source of population

July 1 county population estimates by age, sex, race, and Hispanic origin; postcensal estimates based on 2000 United States Census.

Multiple primary rules used

IACR rules (2004) on CI5 IX period.



USA, Louisiana

Registration area

Louisiana belongs to what is historically known as the “Deep South” of the US, a warm and flat section of the country. The 2000 Louisiana population of 4 468 976 is 63.9% white and 32.5% African-American. Louisiana has less racial diversity than the nation, with 1.2% Asians, 2.4% Latin Americans, and 2.6% foreign-born. One population group unique to the state is the Cajuns, descendants of French-Canadians who live in central and southwest Louisiana.

Per-capita income and graduation rates for high school and college well below the national levels reflect Louisiana’s low socioeconomic ranking in the US. The percentage living below the poverty level is 50% higher in Louisiana than nationally. Louisiana is unusual, however, in its dedication to providing free medical care through a statewide system of ten public hospitals.

Cancer care facilities

During the years 1998–2002 cancer diagnostic care and treatment were available at approximately 125 inpatient hospitals in Louisiana. The cancer programs at 29 hospitals and one cancer treatment centre were accredited by the Commission on Cancer. Radiotherapy services were available at most of these facilities, located in the larger cities throughout the state. One notable change in medical practice has been the rise of freestanding outpatient surgery facilities. Only a handful existed in Louisiana in 1998–2002, but two dozen are open now.

Registry structure and methods

The Louisiana Tumor Registry (LTR) was established in 1974 to monitor cancer incidence in the three-county area of Greater New Orleans. Its catchment area gradually expanded to include the entire state by 1988. The LTR participates in both the US Centers for Disease Control and Prevention’s National Program of Cancer Registries and the National Cancer Institute’s Surveillance, Epidemiology, and End Results (SEER) Program.

The LTR comprises a central office and eight regional offices. The LSU Health Sciences Center operates the LTR central office and three of the regional offices while local academic and medical organisations with cancer research and treatment interests coordinate the activities of the remaining five regions.

The registry staff in early 2005 numbered 54, with 18 of those in the central office. The LTR staff included 23 Certified Tumor Registrars, and the central office, housed in the Louisiana State University in New Orleans, had a research/technical team that included 4 doctorate degrees and 6 Master’s degrees.

Louisiana law requires all licensed healthcare providers to report cancer cases who receive medical services for cancer. Because the LTR is considered a public health authority, it is exempt from the patient consent requirement of the HIPAA legislation.

Most incident cases are identified in hospitals. One fourth of the hospitals in Louisiana operate cancer registries, and these report about two thirds of new cases. Registrars from the LTR regional offices screen and abstract at the remaining hospitals. The LTR follows the reportability guidelines of the SEER Program and the CDC National Program of Cancer Registries and the coding guidelines of the SEER Program.

Non-hospital sources of reportable cancer cases include

pathology laboratories, radiation and dermatology clinics, and one-day surgery facilities. Pathology reports from both hospital and freestanding laboratories, including out-of-state labs, are screened, and all positive reports are followed back to the diagnosing healthcare provider to obtain the required information. Death certificates also identify a small number of cases, and these too are followed back to the diagnosing physician or hospital if possible.

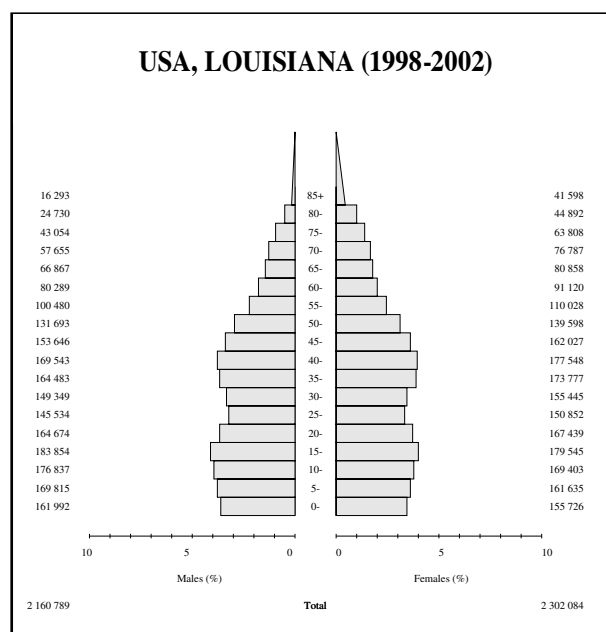
Industry in Louisiana

Although the state’s economy traditionally relied on agriculture, Louisiana is now the second-largest refiner of petroleum in the US, and manufactures a quarter

of the nation’s petrochemicals. Over 25 000 people are employed in chemical manufacturing and another 14 000 in shipbuilding. The presence of 100 large petrochemical facilities has given rise to concerns about excess cancer incidence among workers and residents there. The LTR publishes comparisons of cancer incidence rates in the industrial corridor from Baton Rouge to New Orleans with those for the state and the nation in its annual *Cancer in Louisiana* series. Although monitoring environmental indicators remains the responsibility of the federal Environmental Protection Agency and the state Department of Environmental Quality, the LTR collaborates with the Louisiana Office of Public Health in investigating reports of excess cancer incidence in specific areas.

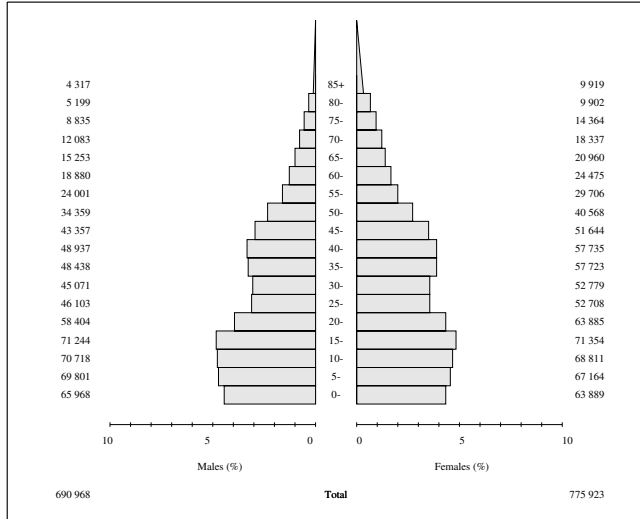
Use of the data

Louisiana incidence and mortality data are published annually in *Cancer in Louisiana* and are available on the registry website: <http://publichealth.lsuhscc.edu/tumorregistry>. In addition, they are incorporated into several databases on the Web: the CDC/NCI’s State Cancer Profiles, the CDC’s WONDER, and the North American Association of Central Cancer Registries’ CINA+. The LTR cooperates with outside researchers investigating the correlations between

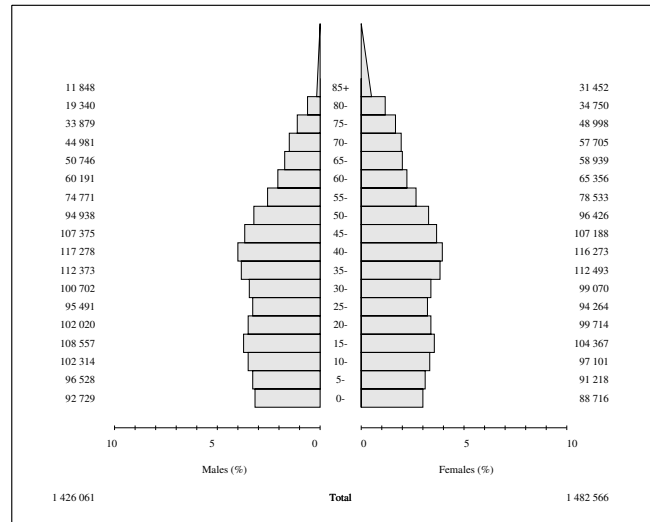


cancer incidence and workplace exposures or lifestyle risk factors and with the Louisiana Office of Public Health in investigations of potential cancer “clusters.” LTR staff members also participate in patterns-of-care studies for the CDC and the SEER Program, as well as publishing numerous descriptive epidemiology articles.

USA, LOUISIANA: BLACK (1998-2002)



USA, LOUISIANA: WHITE (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.

Multiple primary rules used

IACR rules (2004) on CI5 IX period.

USA, Louisiana, New Orleans

Registration area

The New Orleans region, comprising three counties in southeast Louisiana in the American Deep South, had a population of 1 007 369 in 2000. Of these, 99% were considered urban dwellers. The average per capita income of metropolitan New Orleans was slightly higher than the state average, but the state per capita income is 22% lower than the national level. The area's population is approximately 44% African American and 53% white, with only a small presence of Asians or American Indians. About 5% of the population is of Hispanic origin.

Cancer care facilities

Cancer registration in the three-county area of Greater New Orleans began in 1974. The New Orleans Regional Registry, which also documents cancer incidence in eight surrounding counties, has a staff of six full-time employees and a supervisor. Of these, five are Certified Tumor Registrars.

Diagnosis and treatment for cancer during the period 1998-2002 was available at 18 hospitals in Greater New Orleans. Eight offered cancer programs approved by the Commission on Cancer, and a few others had extensive cancer services as well. Radiotherapy was available only at these large facilities.

Registry structure and methods

Although the Louisiana Tumor Registry (LTR) encompassed only the New Orleans area in 1974, its catchment area expanded incrementally, covering the entire state in 1988. The LTR participates in both the U.S. Centers for Disease Control and Prevention's National Program of Cancer Registries and the National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) Program.

The LTR comprises a central office and eight regional offices. The LSU Health Sciences Center operates the LTR central office and three of the regional offices, while local academic and medical organizations with cancer research and treatment interests coordinate the activities of the remaining five regions.

Louisiana law requires all licensed healthcare providers to report cases that receive medical services for cancer, whether a resident of the state or not. Because the LTR is considered a public health authority, it is exempt from the patient consent requirement of the HIPAA legislation.

Most incident cases are identified in hospitals. One fourth of the hospitals in Louisiana operate cancer registries, and these report about two thirds of the new cases. Registrars from the LTR regional offices screen and abstract at the remaining hospitals. The LTR follows the reportability guidelines of the SEER Program and the CDC National Program of Cancer Registries, abstracting

all data items required by these programs as well as other data items.

Non-hospital sources of reportable cancer cases include pathology laboratories, radiation and dermatology clinics, and one-day surgery facilities. Pathology reports from both hospital and freestanding laboratories, including out-of-state labs, are screened, and all positive reports are followed back to the diagnosing healthcare provider to obtain the required information. Death certificates also identify a small number of cases, and these too are followed back to the diagnosing physician or hospital.

For cancer cases diagnosed in its area, each regional office abstracts, consolidates, and edits data and documents survival through active follow-up. The central office consolidates and edits data from the regional registries, monitors completeness of case ascertainment, exchanges case reports with other states, obtains survival information through data linkages, and analyzes and interprets the statistical information derived from the data.

Both regional registries and the central office evaluate case completeness on an ongoing basis by comparing each facility's case counts with those for previous years. The LTR conducts case-finding audits throughout the state, as do the major funding agencies (the CDC and the SEER Program). Abstractors from the central and regional offices participate in national reliability studies at least biennially to evaluate their coding expertise, and samples of cases prepared by hospital registrars are re-abstracted to appraise their accuracy.

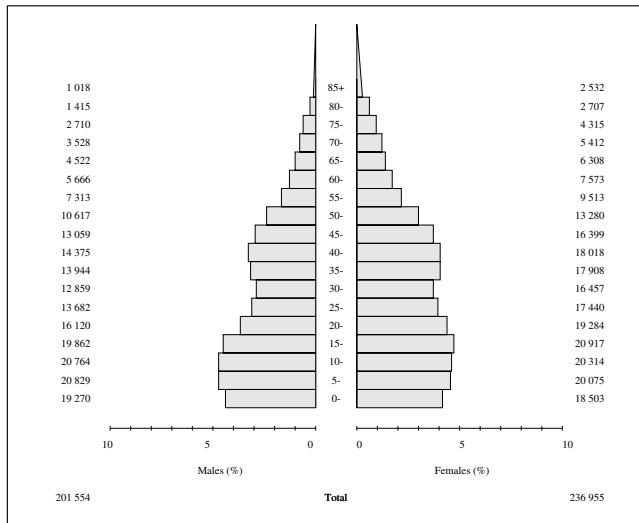
The LTR follows the coding guidelines of the SEER Program. Over time, some changes have been adopted nationwide to reflect changes in the understanding of cancer and in treatment modalities. These include the transition from the First Edition to the Third Edition of the ICD-O manuals and from the SEER 1977 staging manual to the SEER 2000 staging manual, as well as updates to the treatment codes.

Use of the data

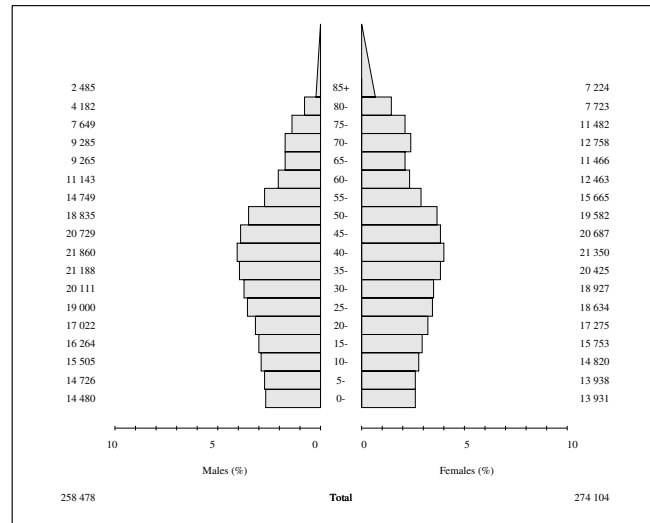
Louisiana incidence and mortality data are published annually in the LTR's *Cancer in Louisiana* series and are available on the registry website: <http://publichealth.lsuhs.edu/tumorregistry>. In addition they are incorporated into several databases on the Web: the CDC/NCI's State Cancer Profiles, the CDC's WONDER, and the North American Association of Central Cancer Registries' CINA+.

The LTR cooperates with outside researchers studying correlations between cancer incidence and workplace exposures or lifestyle risk factors, and with the Louisiana Office of Public Health in investigations of areas with possible high rates of cancer incidence. In addition, LTR staff participates actively in patterns-of-care studies for the CDC and the SEER Program, as well as publishing numerous descriptive epidemiology articles.

**USA, LOUISIANA, NEW ORLEANS: BLACK
(1998-2002)**



**USA, LOUISIANA, NEW ORLEANS: WHITE
(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.

Multiple primary rules used

IACR rules (2004) on CI5 IX period.

USA, Maine

Registration area

The Maine Cancer Registry covers the entire population of the state of Maine in the United States of America. According to the 2000 US Census, 58% of the population lives in a rural area. About 82% are Christian, while 17 % classify themselves as non-religious. About 97% of the population is Caucasian.

Cancer care facilities

Health care in Maine is provided by 37 hospitals and many private physician offices. Of the 37 hospitals, 11 have approved cancer care programs. The availability of care is more prominent in the more populous southern regions of Maine. Citizens in northern Maine may have to drive further to obtain appropriate cancer care.

Registry structure and methods

The registry is located in Augusta, the state capital. The registry is staffed by 6.5 full-time employees, two of whom are certified tumour registrars. Funding for the central registry is a 3:1 match between federal dollars from the US Centers for Disease Control and Prevention's National Program of Cancer Registries (NPCR) and state dollars. Cancer is a reportable disease according to state law. The majority of our cases are reported by hospitals on a routine basis. These data are supplemented by required physician reporting, active case-finding at Maine's one independent pathology laboratory, and review of death certificates with a mention of cancer. Death registry information in Maine is very complete and accessible. Maine also has data exchange agreements with all bordering states and other states where Maine residents tend to vacation during the winter. The Maine Cancer Registry has a quality control program, and the resulting data meet the highest standards for data quality.

Interpreting the results

Maine's cancer incidence database meets the highest standards for quality, completeness, and timeliness. The registry database is 100% complete for the data years of interest. Screening for prostate, colon, breast, and cervical cancer have increased but remain largely opportunistic. Environmental concerns in Maine include high levels of arsenic in private well water, and high radon air concentrations in Maine homes, as these chemicals occur naturally in Maine's geography. Maine is also home to a shipbuilding company that used asbestos in the past.

Use of the data

The registry prepares an annual report of cancer incidence and includes mortality from the state's vital statistics office. Annual reports may also include information on trends and stage at diagnosis. Maine does not operate a follow-up registry, so survival studies are not produced. Data are used for program planning and evaluation. Maine's database has also been used in special studies of bladder cancer, cervical cancer, colon cancer treatment, and quality-of-life surveys.

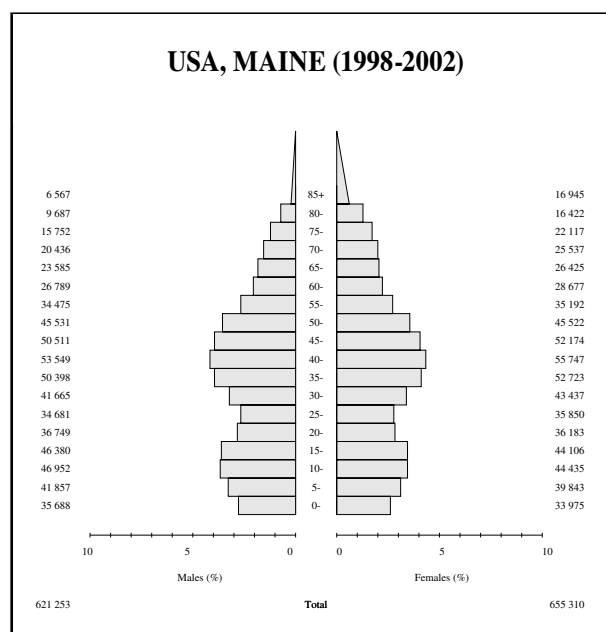
Source of population

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.



USA, Massachusetts

Registration area

The Massachusetts Cancer Registry (MCR) covers the population of the Commonwealth of Massachusetts. The population at the most recent US Census (2000) was 6 349 097. The population is represented as follows: 84% White non-Hispanic; 5% Black non-Hispanic; 7% Hispanic; 4% Asian non-Hispanic; .02% Native American non-Hispanic.

Cancer care facilities

The MCR collects reports of newly diagnosed cancer cases from multiple sources. In 2003, 70 Massachusetts acute care hospitals, 3 medical practice associations, 5 laboratories, 1 radiation/oncology facility, dermatologists and urologists reported to the MCR.

Registry structure and methods

The MCR is located within the Center for Health Information, Statistics, Research and Evaluation (CHISRE), Massachusetts Department of Public Health (DPH). The MCR is 75% funded by the US Centers for Disease Control and Prevention's National Program of Cancer Registries (NPCR), and 25% by the Commonwealth of Massachusetts. The Registry's staff include a director, assistant director of registry operations, an administrative assistant, 9 operations staff (quality assurance and data acquisition), 3 epidemiology staff, and 3 geographic information systems/special project staff.

The MCR follows all CDC/NPCR program requirements for data collection and reporting. We are certified by the North American Association for Central Cancer Registries (NAACCR) and have received their gold standard for completeness, quality and timeliness for the past several years.

Interpreting the results

As noted above, the MCR collects reports of newly diagnosed cancer cases from multiple sources, including acute care hospitals, medical practice associations, laboratories, radiation/oncology facilities, dermatologists and urologists reported to the MCR. Reports from dermatologists' offices and dermatopathology laboratories, particularly on cases of melanoma, have only been collected by the MCR since 2001. Reports from urologists' offices have only been collected by the MCR since 2002. Currently, the MCR collects information on *in situ* and invasive cancers and benign tumors of the brain and associated tissues. The MCR does not collect information on basal and squamous cell carcinomas of the skin.

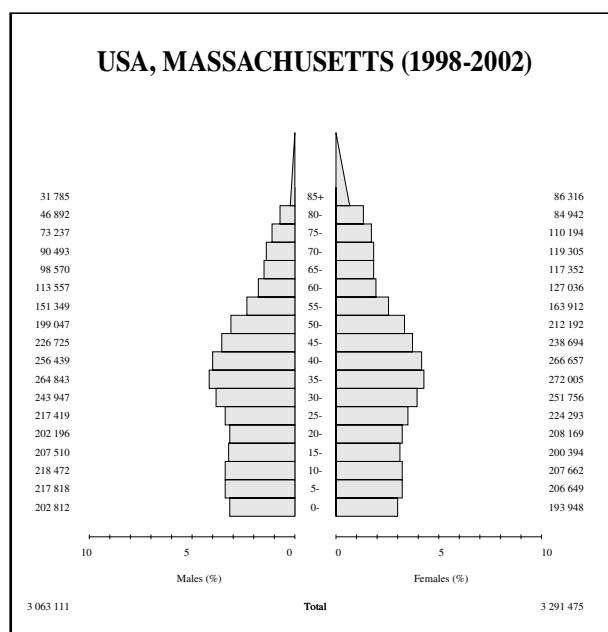
The MCR also collects information from reporting hospitals on cases diagnosed and treated in staff physician

offices when this information is available. Not all hospitals report this type of case, however, and some hospitals report such cases as if the patients had been diagnosed and treated by the hospital directly. Collecting this type of data makes the MCR's overall case ascertainment more complete. The cancer types most often reported to the MCR in this manner are prostate cancer and melanoma.

In addition, the MCR identifies previously unreported cancer cases through death certificate clearance to further improve case completeness. When possible, the MCR obtains additional information on these cases through follow-up activities with hospitals, nursing homes and physicians' offices. Otherwise, a cancer-related cause of death recorded

on a Massachusetts death certificate is the only source of information for a cancer case. As a result, these cancer cases identified through death certificates are poorly documented and have not been confirmed by review of complete clinical information. These cases, however, comprise less than 3% of all cancer cases in this report.

There are organised screening programs at the state level for breast, cervical and prostate cancer. According to data from the behavioural risk factor survey (BRFS), a questionnaire administered randomly to the state, 57.9% of men over 50 had a prostate specific antigen PSA in the past year. Additionally, 65.4% of men over 50 had a digital rectal exam (DRE).



Use of the data

The MCR produces two annual reports: *Cancer Incidence and Mortality in Massachusetts* (providing information on cancer incidence and mortality for the state as a whole), and *Cancer Incidence in Massachusetts: City and Town Supplement* (providing information on cancer incidence for Massachusetts' 351 cities and towns). We also produce special reports on a periodic basis, such as *Data Report on In Situ Breast Cancer in Massachusetts*, *Data Report on Colorectal Cancer in Massachusetts*, *Childhood Cancer in Massachusetts, 1990-1999*, *Cancer in Massachusetts Women, 1989-1998: Data Report*, and *Selected Cancers in Massachusetts Men, 1982-1996*.

Data are available to the public via MassCHIP, the MDPH's online information service that provides community-level data (<http://masschip.state.ma.us>), and at Massachusetts Cancer Information Online, a website that allows users to access a variety of local, state and national cancer information in three ways—by age, by geography and by type of cancer (<http://www.mass.gov/dph/cancer>). MCR reports are also posted on the program website (<http://www.mass.gov/dph/bhsre/mcr>).

The MCR receives approximately 10-15 requests for data each month. Data are used by other DPH programs for

program planning and evaluation, and by external researchers for epidemiologic studies. MCR staff provide support and consultation to other DPH programs and outside agencies.

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.

USA, Michigan

Registration area

This Registry covers the State of Michigan within the United States of America. The state of Michigan is approximately 82% white, 12% black, 4% Asian and 2% Native American. The state is roughly 3% Hispanic.

Cancer care facilities

Diagnostic and treatment services for cancer are widely available throughout the state. Radiotherapy services are widespread and generally readily available in population centres, with some access issues in rural areas.

Registry structure and methods

The registry is located within the Department of Community Health for the State of Michigan. It is staffed using 12 full time equivalent positions. The registry is funded in part by the US Centers for Disease Control and Prevention's National Program of Cancer Registries (NPCR).

Data collection is passive, with routine auditing of reporting by health facilities using CTRs.

Eighty-five percent of case reports are submitted electronically. Reports are received largely from hospitals and regional cancer registries. Reporting is supplemented by

pathology laboratories, clinics, physicians and dentists. Resident case exchange agreements are in place with 19 other states.

The registry is located within the vital records office with ready access to death information.

Reporting is required by law. Case information is confidential and protected by law. Improper use or release of the information is a crime.

Registry quality, completeness, accuracy and timeliness are monitored through ongoing routine auditing of reporting facilities, with independent assessments of quality conducted annually by NAACCR and by CDC.

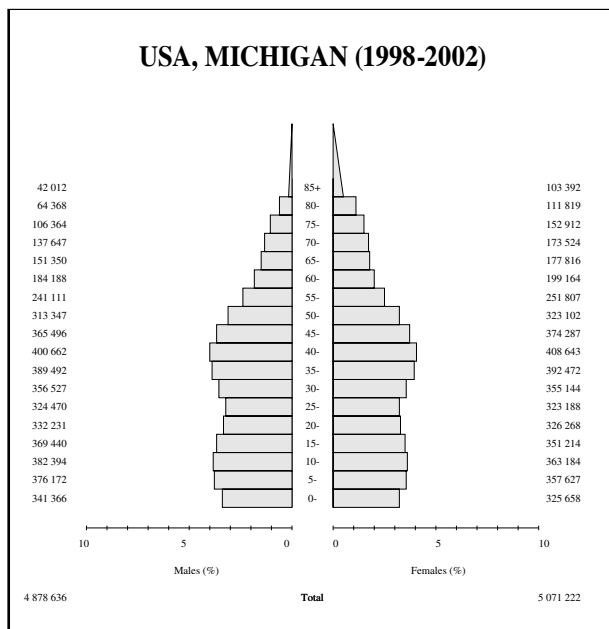
Interpreting the results

Breast and cervical cancer screening programs for the uninsured are in place throughout the state. Screening prevalence for breast and cervical cancer is reasonably high by US standards, and PSA testing is common in the

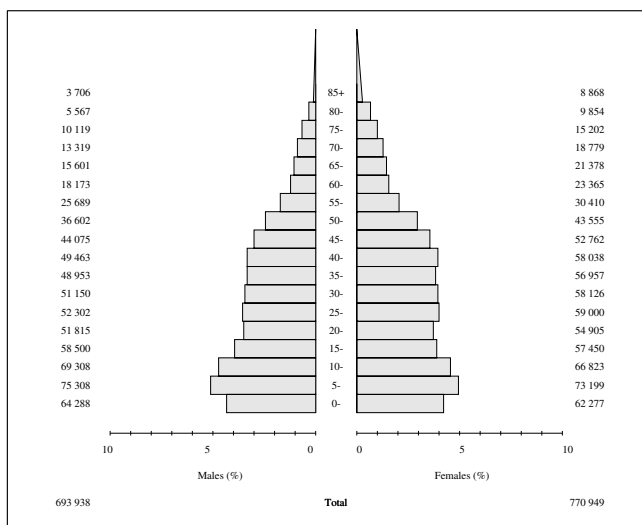
population.

Use of the data

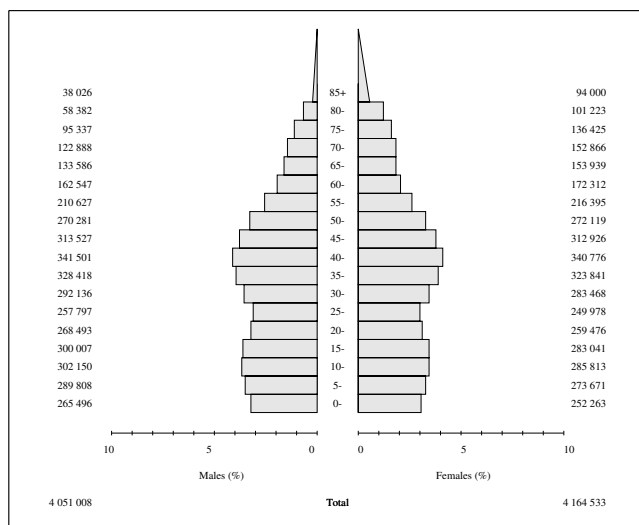
Registry data are used for reporting incidence, extent of disease, and survival. Data are also used in research, and for planning and evaluation of health services.



USA, MICHIGAN: BLACK (1998-2002)



USA, MICHIGAN: WHITE (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.

USA, Michigan, Detroit

Registration area

The Metropolitan Detroit Cancer Surveillance System (MDCSS) covers three adjacent counties in southeastern Michigan in the United States (US) of America. Metropolitan Detroit is between longitudes 82° and 83° W and latitudes 42° and 43° N. These three counties, Wayne, Oakland and Macomb, comprise 42% of the overall population of the state of Michigan. The total population of the Metropolitan Detroit area, according to the 2000 US Census was 4 043 467. Of this total, 2 784 071 (68.8%) persons were Caucasian and 1 011 038 (25.0%) persons were African American. Of the total population, 118 641 (2.9%) persons were of Hispanic origin. The City of Detroit is the major urban centre of this area. In the City of Detroit, 12.3% of the population was Caucasian and 81.6% was African-American, with 5.0% of the total being of Hispanic descent. The Metropolitan Detroit area is culturally diverse, with representation from Arabic, Polish, Greek, Italian, German, English, Irish and Scottish ancestry. The area is heavily industrialised, being the centre of the United States automobile manufacturing industry. The total registration area is 5094 km².

Cancer care facilities

The MDCSS began in 1949 as a pathology registry for 25 collaborating hospitals. In 1960, the MDCSS became a central statistical resource for these 25 hospitals, providing reports comparing the experience of each hospital with the entire group of collaborating hospitals. In 1969 the MDCSS became the designated arm of the Michigan Department of Community Health (MDCH) for collection of cancer information in the Metropolitan Detroit area. In this same year, the MDCSS was organised in its current form to participate in the Third National Cancer Survey for the years 1969–1971. In 1973 the MDCSS became one of the founding participants in the National Cancer Institute's (NCI) Surveillance, Epidemiology and End Results (SEER) Program.

Registry structure and methods

In 1976, the MCF became a member of the NCI-funded Comprehensive Cancer Center in Detroit along with Wayne State University (WSU) and the Detroit Medical Center. In 1995, all programs of the Comprehensive Cancer Center were consolidated under the name of the Barbara Ann Karmanos Cancer Institute (KCI). The Director of KCI reports to the Dean of the WSU School of Medicine and the Comprehensive Cancer Center's Programs are administered by the School of Medicine.

We have a staff of 35 in abstracting, 14 in editing, 5 in follow-up and 4 in IT who handle case finding, abstracting, editing, follow-up and computer issues. In addition, there are over 40 individuals working in research.

The MDCSS provides both incidence and survival reporting for the Metropolitan Detroit area. Data are collected by the MDCSS abstracting staff from area hospitals, private pathology laboratories, radiation therapy facilities and selected clinics and physician offices. These facilities include those located within Metropolitan Detroit, as well as facilities outside the area, which routinely provide care for cancer patients who reside in the MDCSS registration area. Both passive and active follow-up are maintained for

all cases. Re-admissions to hospitals are also abstracted for follow-up data. Death certificates for the State of Michigan, and for other states that are primary retirement areas for local residents, are linked by computer tape each quarter to provide up-to-date information on new deaths and causes of death.

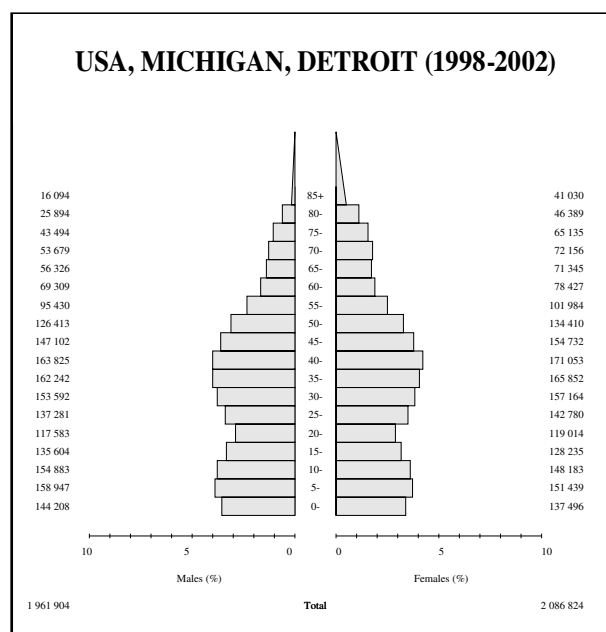
The completeness and accuracy of our data are evaluated both by the SEER program and internally on a routine basis. The Metropolitan Detroit Cancer Surveillance System routinely scores in the top 5 of all SEER registries nationally.

Interpreting the results

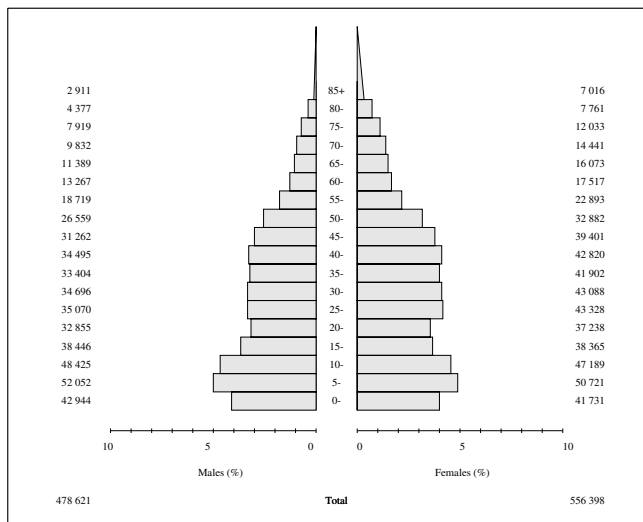
Besides the metropolitan Detroit area being highly industrialised, the area is also home to a plant that was involved in the processing of vermiculite contaminated with asbestos.

Use of the data

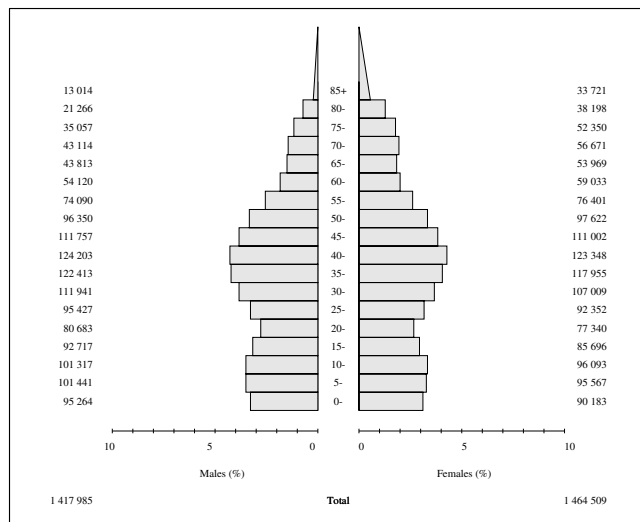
From 1973 through 1978, the MDCSS and the Metropolitan Detroit SEER Program were essentially data collection operations, with minimal reporting of descriptive data. Development of a research program in cancer epidemiology began in 1979. Cancer epidemiology evolved into a major research program with a current focus on racial disparities in risk and survival. The Metropolitan Detroit SEER data are utilised extensively for descriptive and analytic epidemiology. The data are also utilised by local health departments, the Michigan Department of Community Health and area health professionals for planning, evaluation and educational purposes. Community concerns regarding cancer risk are also addressed through use of MDCSS data.



USA, MICHIGAN, DETROIT: BLACK (1998-2002)



USA, MICHIGAN, DETROIT: WHITE (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.

Multiple primary rules used

IACR rules (2004) on CI5 IX period.

USA, Missouri

Registration area

The Missouri Cancer Registry (MCR) covers the population of the state of Missouri, located in the middle of the United States and having as its eastern border the Mississippi River. The majority of Missouri's 5.5 million people live in two major metropolitan areas (Kansas City and St. Louis) and five minor metropolitan areas. The remainder of the state consists of small towns and rural areas.

Cancer care facilities

Over 85% of annual cancer incidence cases are reported by hospitals, of which there are 126 in Missouri, including four Veterans Affairs (VA) hospitals and two military hospitals. Most of the remaining cases are reported by long-term care facilities, ambulatory surgery centres, freestanding cancer clinics and treatment centres, pathology laboratories and physician offices/groups that diagnose or treat cancer or through case-sharing agreements with 18 other states. The states of Kansas, Illinois and Texas contribute the largest number of data exchange cases.

Registry structure and methods

MCR is a joint endeavour of the University of Missouri and the Missouri Department of Health and Senior Services (DHSS). It is located on the campus of the University of Missouri-Columbia and is housed in the School of Medicine, Department of Health Management and Informatics (HMI). The primary funding source for operating the registry is the US Centers for Disease Control and Prevention's National Program of Cancer Registries (NPCR) through a contract between the University and DHSS. The registry's operations director is also a member of the HMI faculty. Registry staff include 9.25 Certified Tumor Registrars (CTR's), 3 health program specialists or assistants, 2.25 technical staff (data base manager and IT support), a half-time statistician, 1 support staff and 2 part-time graduate research assistants. The registry also receives support from four DHSS staff members who are partly funded by CDC-NPCR.

Data collection from hospitals is 80–85% automated. Approximately 5% of the cases are received as copies of medical records, which are then abstracted by MCR staff. Another 5% are submitted by non-hospital facilities (surgery centres, radiation centres, physician offices and nursing homes); most of these cases are submitted on paper but MCR is piloting web-based reporting of prostate cancer and

melanoma skin cancer by physician offices. Another source is death certificates. Death information for Missouri residents who died in Missouri is available both in an electronic file and as a paper record through a Memorandum of Understanding with DHSS's vital records unit. Death information for Missouri residents that die elsewhere is available from some but not all states. MCR staff conduct death clearance and follow-back on in-state cancer deaths not matched in the registry database; the number of new cases identified only through death certificates is <3% for data from 1998–2003. MCR staff process over 45 000 records annually. After case consolidation, this yields approximately 28 000 Missouri incident cases.

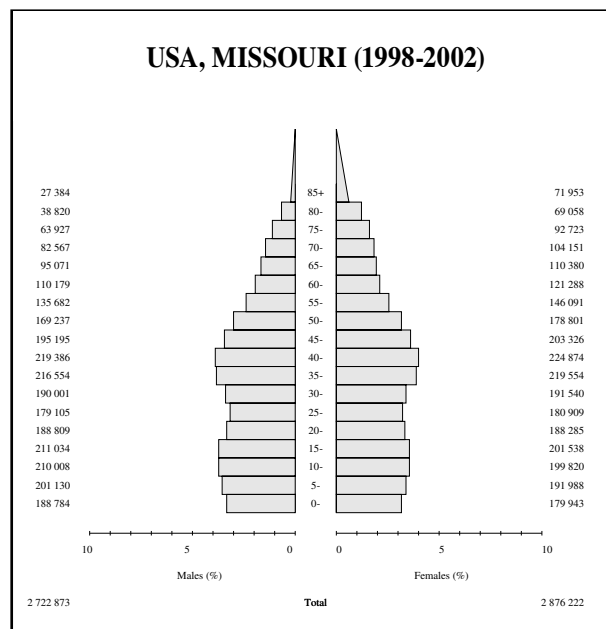
Quality control is an ongoing process at MCR. All records receive an initial review and an additional in-depth review. Before each call for data, all cases are run against GenEdits and Interrecord Edits and corrections made prior to submission. Quality control is also part of each data request. Prior to finalising the data request, the data are reviewed for accuracy. In addition, reports are produced whenever necessary to look at possible errors that have been identified through the review process.

Interpreting the results

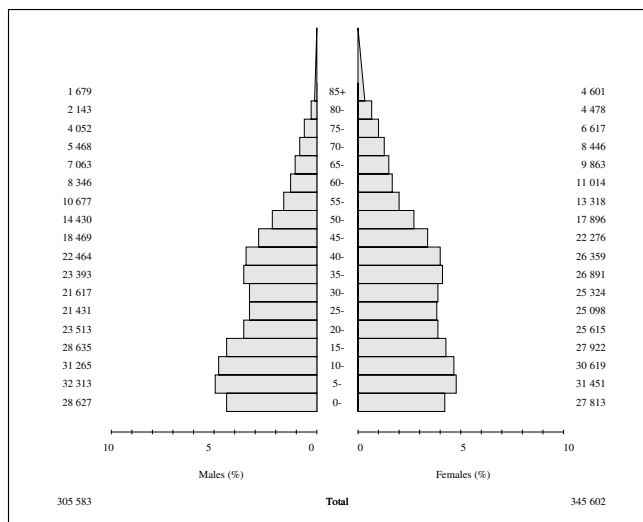
MCR data meet NPCR standards and North American Association of Central Cancer Registry (NAACCR) criteria for timeliness completeness and quality. While MCR data are more than 95% complete (i.e., >95% of expected cases are available within 24 months of the close of a diagnosis year), some sites are less complete. Less than 60% of expected melanoma skin cancer cases were reported annually through 2003. In 2004, MCR initiated reporting of melanoma skin cancers by physicians; this has resulted in increased reporting of these cases. Prostate cancer cases were also underreported. In 2005, Missouri became one of eight states funded by CDC-NPCR to pilot web-based reporting of prostate cancers by physicians. We hope to see an increase in reporting of these cases in 2006.

Use of the data

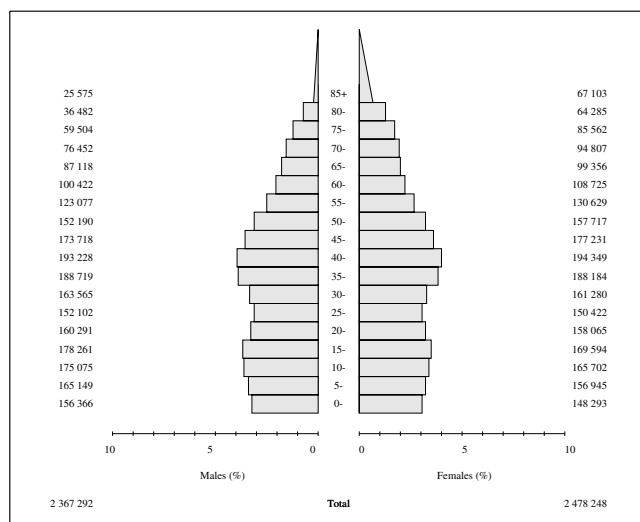
Missouri incidence data are used for program planning and evaluation, epidemiological studies, cancer cluster investigations, annual reports and a variety of other purposes. Missouri incidence data are available online at <http://www.dhss.mo.gov/cancerMICA/> by site, race, age group and geographic unit.



USA, MISSOURI: BLACK (1998-2002)



USA, MISSOURI: WHITE (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.

USA, Montana

Registration area

The Montana Central Tumor Registry (MCTR) is a population-based registry covering the entire State of Montana. The MCTR was started in 1979 by the Montana Tumor Registry Act. About 60% of the state is actually prairie in the Great Plains. Montana is primarily rural. The state ranks fourth among US states in size but has a relatively low population and consequently a very low population density. The race of Montanans is about 92% Caucasian and 6% American Indian.

Cancer care facilities

Montana has 4 American College of Surgeons cancer approved programmes; Benefis Healthcare in Great Falls, St. Patrick Hospital in Missoula, St. Peter's Hospital in Helena, and Billings Clinic in Billings. Other cancer-related facilities include: St. Vincent's Hospital in Billings, Bozeman Deaconess Hospital in Bozeman, St. James Community Hospital in Butte, and Kalispell Regional Hospital in Kalispell.

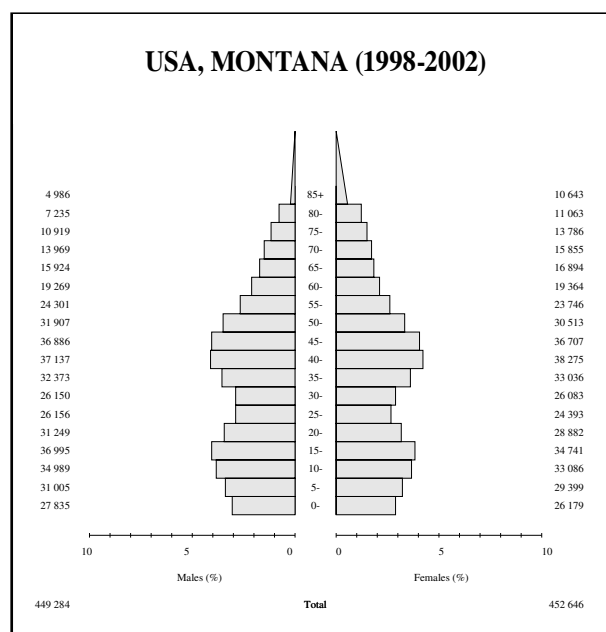
Registry structure and methods

The MCTR is housed in the Montana State Department of Public Health and Human Services, Division of Public Health and Safety, Bureau of Chronic Disease Prevention and Health Promotion, Cancer Control Section. Financial support includes about 20% of the budget covered by State funds and about 80% of the budget covered by Federal support through the US Centers for Disease Control and Prevention's National Program of Cancer Registries (NPCR). MCTR staff include: 1 Cancer Epidemiologist, 1 Program Manager, 1 Administrative Support/Follow-up, and 2 Quality Assurance Technicians. Data collection is passive, with each facility responsible for abstracting and reporting its own cancer cases. MCTR staff do not abstract for any facility. The principal sources of information on cancer cases are hospitals, radiation centres and independent pathology

laboratories. MCTR has access to all death certificates from the Office of Vital Statistics on a quarterly basis. Quality control procedures are being developed. Presently, the MCTR undergoes a casefinding, data quality, and timeliness audit by the CDC once every 5 years.

Interpreting the results

The population in Montana is growing and grew almost 10% in 2005. Prior to that, the population increased about 3% since the year 2000. Diagnostic and treatment facilities for cancer patients are increasing, and several cancer treatment facilities are seeking ACoS approval. Montana has breast and cervical cancer screening and a health assistance programme, and PSA testing is common in the population.



Use of the data

The MCTR publishes an annual report that presents topics on incidence rates, mortality rates, incidence by sites, stage at diagnosis, rates by counties, risk and associated factors, age-specific incidence rates, and ten-year trends. Data are used for individual requests for information and are used for cancer cluster investigations. The registry is not currently involved in epidemiological research beyond the production of routine statistics, but the Montana Comprehensive Cancer Program routinely uses our cancer registry data.

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.

USA, New Jersey

Registration area

New Jersey is located on the east coast of the United States, bordered by the states of New York, Pennsylvania, and Delaware. In 2000, the population of the state of New Jersey comprised over 8.4 million inhabitants. Of these, 13.6% were African American, 13.3% were Hispanic and 5.7% were Asian. The median household income, according to the 2000 census, was US\$55 146 (in 1999 dollars). Of the population over 16 years of age, 64.2% are in the labour force.

Cancer care facilities

A total of 76 in-state hospitals report to the registry on a monthly basis via e-mail to a secure, encrypted e-mail server. The proximity of New Jersey to prestigious cancer centres in neighbouring states attracts many residents to seek diagnosis and treatment outside the state. Over 10 000 case reports are received annually from out-of-state sources through reciprocal reporting agreements with other states.

Registry structure and methods

Cancer Epidemiology Services (CES) is located in the Division of Epidemiology, Environmental and Occupational Health Services. CES is financed by both state and federal sources, including the US Centers for Disease Control and Prevention's National Program of Cancer Registries (NPCR). There are 42 full-time equivalent staff working in the unit on cancer registry and cancer surveillance activities. Certified Tumor Registrars (CTRs) are employed in all aspects of the registry operations including data collection, quality assurance, reporting and analysis.

The majority of cases are reported by hospitals throughout the state. Abstracting, coding and data entry are conducted at the hospital level by CTRs directly from source records and reported electronically to the central office. All health care facilities are required by law to report cancer cases electronically within three months of discharge or six months of diagnosis or face a penalty. Hospitals are required to report all cases of cancer, regardless of in- or out-patient status. Reporting from non-hospital facilities accounts for a small but growing number of cases. The majority of non-hospitalised cases are reported by 16 independent pathology laboratories. Other sources include 117 surgery centres and 9 free-standing radiation treatment centres. Reports are also received from nursing homes,

psychiatric facilities and rehabilitation facilities. Physicians and dentists are required to report non-hospitalised cases. Matching of the registry database with the Department's AIDS registry and the Breast and Cervical Cancer Early Detection Program have resulted in the identification of cases.

Quarterly record linkages are performed between the registry database and the state death file. A built-in death certificate match system links and updates cancer registry records with death information. Linkages are also performed with individual state tax return files, hospital discharge files, motor vehicle driver's license files, the federal Centers for Medicare and Medicaid Services, Social Security Administration, and National Death Index to obtain follow-up information.

Interpreting the results

New Jersey has Gold Certification Status from NAACCR. The data quality assurance programme is a continuous multi-faceted programme of checks and balances, performed by highly skilled CTRs with years of quality control experience. Other components include consistent application of computerised edits, systematic review of problem cases, re-abstracting and re-coding studies centred in hospitals, feedback and training programmes for hospital staff, documentation of policies and procedures, and case-finding audits.

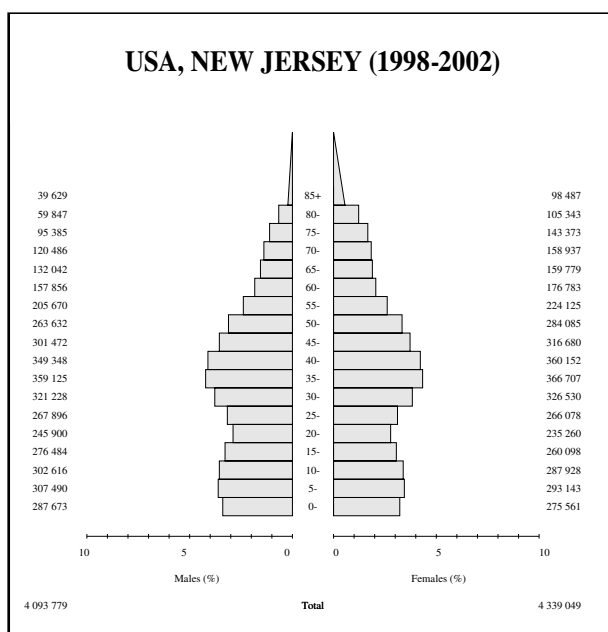
Definite and possible duplicates are electronically generated and resolved by staff. Computerised programs are used to identify multiple

primary cancers for review.

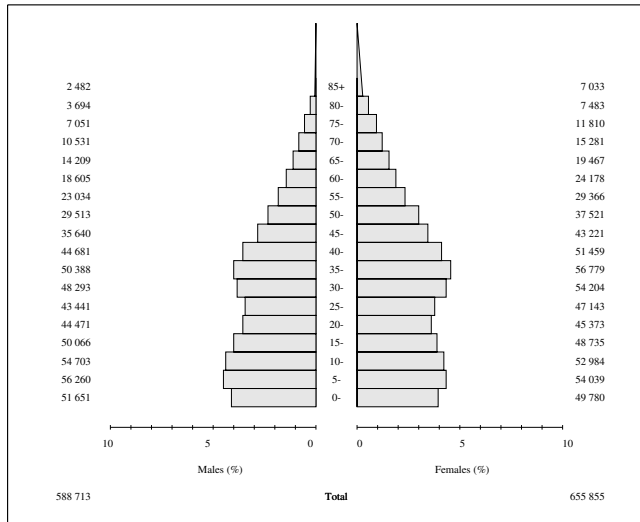
Use of the data

The Cancer Surveillance Program, staffed by epidemiologists and a statistician, monitors cancer incidence trends, disseminates data, and responds to citizens' concerns about cancer. The staff have published a variety of registry reports, including a report on trends in cancer incidence and mortality, cancer survival, cancer prevalence, an in-depth analysis of prostate cancer, breast cancer, colon and rectum cancer, and childhood cancer.

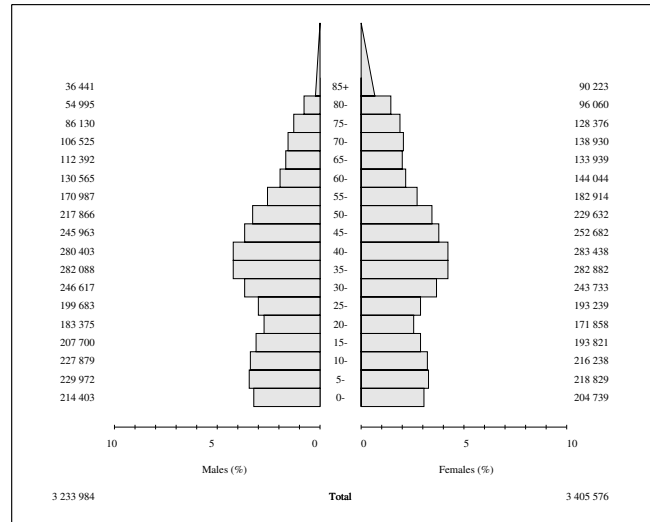
The data are employed in a wide range of activities including applications in cancer control and prevention, aetiological studies, policymaking, and epidemiological research. Registry data were also used to define baseline measures for the general and special populations in the state to establish public health objectives for the next decade.



USA, NEW JERSEY: BLACK (1998-2002)



USA, NEW JERSEY: WHITE (1998-2002)



Source of population

2000 Census of the United States, prepared by the US Bureau of the Census.

Multiple primary rules used

IACR rules (2004) on CI5 IX period.

USA, New Mexico

Registration area

With an area of 314 926 km², New Mexico is the fifth largest state in the USA. Located in the southwest of the country (latitude 30° to 37° N), it has extensive high desert and mountain terrain, the altitude ranging from 859 to 4010m above sea level. Rainfall and humidity are low.

Its population is about 1.9 million, of whom approximately one third live in the Albuquerque metropolitan area; the remainder live in small cities or in villages. The population come from diverse ethnic backgrounds: 42% have Spanish and/or Mexican-American heritage (Hispanics); 9.5% are American Indians (Navajo, Pueblo, Apache); 1.9% are Black; about 1% are Asian; the remaining 45% are non-Hispanic white of European descent. A sizeable subgroup of New Mexico's Hispanic population traces its ancestry to Spanish soldiers and colonists who settled in New Mexico during the 17th and 18th centuries. Median levels of education and per capita income are in the lowest decile of the 50 states.

Cancer care facilities

An overwhelming majority of cancer patients in New Mexico are diagnosed and treated at one or more of seven medical facilities that support cancer programmes accredited by the American College of Surgeons. Cancer-related care is also provided by several private oncology and radiation-oncology practices affiliated with the latter medical facilities. Some New Mexico residents receive cancer-related care in neighbouring states; the registry has longstanding agreements with central cancer registries in all bordering states to routinely receive reports on diagnosis or treatment of New Mexico residents.

Registry structure and methods

Cancer reporting has been required (but not enforced) by a State Health Agency regulation since 1922. The New Mexico Tumor Registry, located at the University of New Mexico Cancer Research and Treatment Center in Albuquerque, began operation in 1966 and became the official cancer data repository for the State Health Agency in 1975. Registry funding initially came from the New Mexico Regional Medical Program and since 1973 primarily from the National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) Program.

The registry abstracts and follows all cases of known malignancy. Multiple primaries are counted separately by assigning sequence numbers within the records of individual patients. Patients entered into the registry system are followed for life.

Some of the larger hospitals employ tumour registrars, and abstractors from the central registry travel to other hospitals and clinics throughout the state to review and abstract cancer patient records. The majority of the registry's

cases are registered from hospital admission and outpatient records. Other methods of casefinding are used to obtain information on cancer cases not seen in reporting hospitals. Radiation therapy records and death certificates are reviewed regularly.

Medical chart data are entered directly onto diskettes using a software package assembled locally, allowing collection of supplemental data items of special interest to individual hospitals and physicians. It also allows each hospital to analyse its own 30+ year complete dataset and to compare it with a statewide analytical dataset. Data from the abstractors' diskettes are edited, linked and merged into the master file.

Abstracted cases are reviewed for thoroughness and accuracy. The file is ordered by the computer-generated accession numbers, but can be sorted by any item of data. Numerous routine crosschecks are made to eliminate duplicate cases.

Interpreting the results

Cancer surveillance in New Mexico is conducted according to prevailing standards promulgated by the SEER Program and the North American Association of Central Cancer Registries (NAACCR). As such, the data have been subject to the same changes in definitions and coding as other registries that abide by SEER and NAACCR standards. The Registry's geographic area of coverage

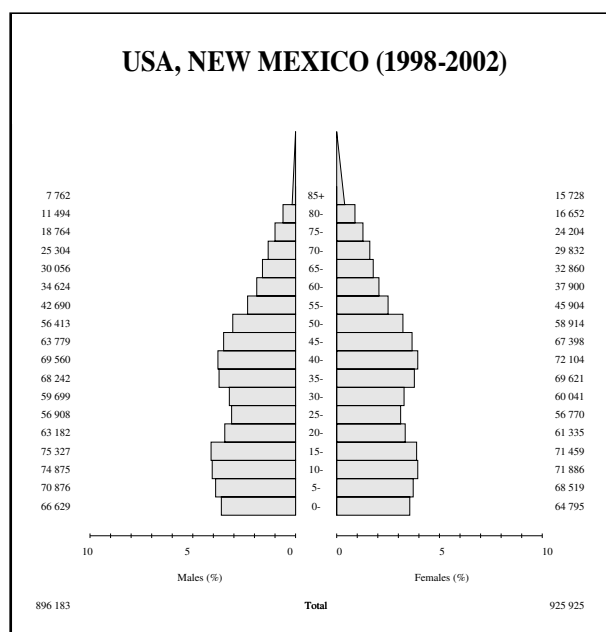
has remained constant since it initiated statewide coverage in 1969.

Because incidence rates vary by cancer primary site among the State's three largest racial/ethnic groups, New Mexico data must not be considered in aggregate, that is, without stratification by race/ethnicity. Descriptive epidemiological analyses have shown that Hispanics and American Indians have lower rates than the non-Hispanic white population for skin, breast, endometrium, lung and colorectal cancers, and higher rates for stomach, uterine cervix, kidney and gallbladder cancers.

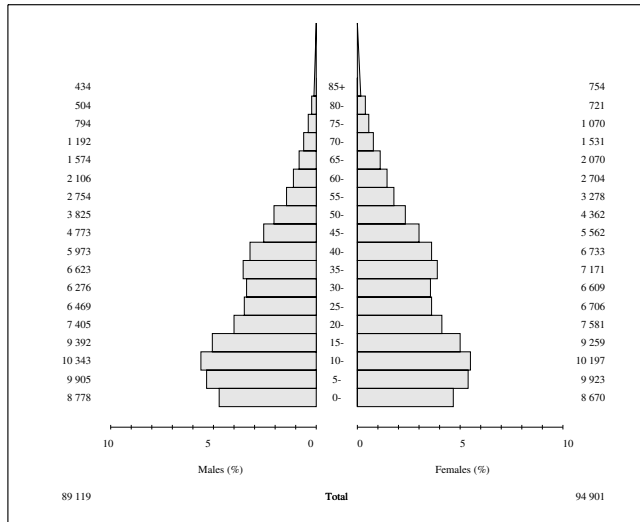
Use of the data

Periodic reports are sent to participating hospitals and individual physicians. The registry also handles over 100 special requests for cancer data annually. The registry has been a casefinding source for a variety of population-based case-control studies relating to cancer etiology. It has also been used to monitor patterns of cancer care and survival in relation to factors such as ethnicity, age and marital status.

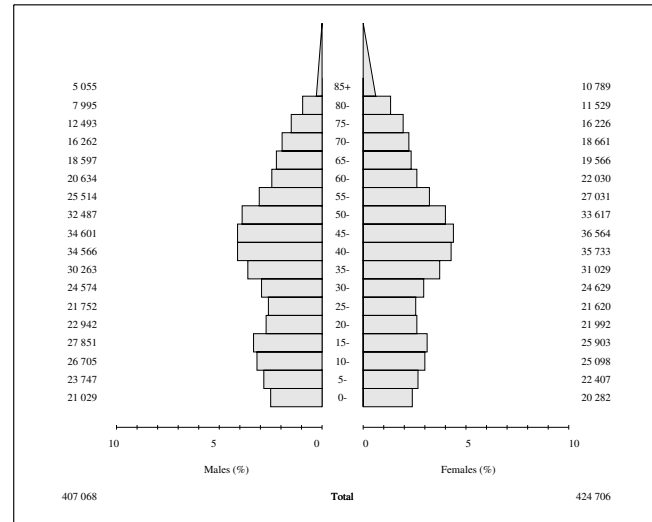
The development of new techniques for investigating molecular and cellular changes in preserved tissue specimens has created requests for the registry to help select cases that have documentation of different clinical courses and outcomes.



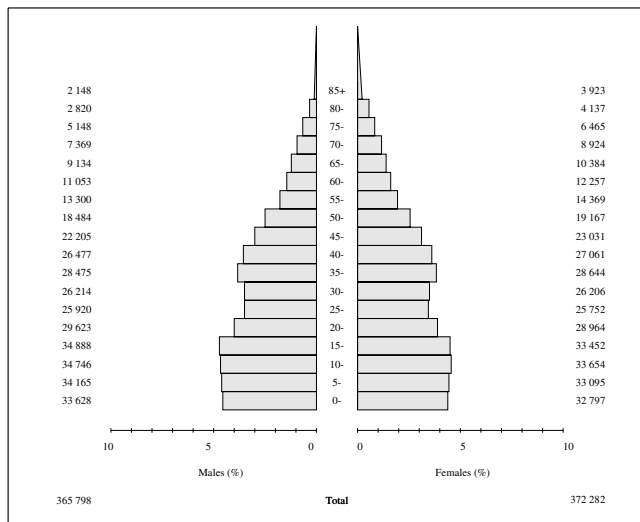
**USA, NEW MEXICO: AMERICAN INDIAN
(1998-2002)**



**USA, NEW MEXICO: NON-HISPANIC WHITE
(1998-2002)**



USA, NEW MEXICO: HISPANIC WHITE (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.

Multiple primary rules used

IACR rules (2004) on CI5 IX period.

USA, New York State

Registration area

The New York State Cancer Registry (NYSCR) contains reports on all malignant tumours (except basal cell and squamous cell skin cancers), most *in situ* lesions, and certain benign tumours. The Registry, the second oldest state tumour registry in the United States, has had mandated cancer reporting since 1940, when the registration area covered the entire state except New York City. Beginning in 1973, the reporting mandate was extended to include New York City. The Registry has been population-based since 1976.

The population of New York State was 18 976 457 in the year 2000, according to the U.S. census; the estimated population for 2004 is 19 227 088. In 2000, about 90% of the population lived in metropolitan areas; 62% were Non-Hispanic Caucasians, 16% were African-Americans, 15% were Hispanics (of any race), 0.4% were American Indians and 5.5% were Asians (including Pacific Islanders).

Cancer care facilities

Residents of New York State have access to more than 250 acute-care hospitals, including 22 Community Hospital Comprehensive Cancer Care facilities located throughout the State and three National Cancer Institute-designated Comprehensive Cancer Centers. In addition, many freestanding healthcare facilities and private physicians diagnose and treat cancer. There are 54 Ambulatory Surgery Centers and 12 Veterans Administration Hospitals that also provide cancer services.

Registry structure and methods

The Registry is located within the New York State Department of Health (NYSDOH), and is funded partly by the NYSDOH and partly by the National Program of Cancer Registries. The Registry has a director, field staff, coding staff, quality assurance staff, research scientists, computer programmer analysts, and geo-coding and secretarial support staff; 22 staff members are Certified Tumor Registrars.

Law mandates cancer reporting with full personal identifiers. The NYSCR uses passive notification of reports from more than 300 sources including hospitals, pathology and cytology laboratories, radiation treatment centres, ambulatory surgery centres, and state vital records. Data are received electronically in the NAACCR (North American Association of Central Cancer Registries) format and are mostly pre-coded. Many quality checks, including single field range and validity edits as well as interfield edits, are routinely applied to the data and much time and effort are devoted to elimination of duplicate case reports.

New York State law mandates reporting of mortality, and death certificates are electronically matched against Registry files. Cancer deaths not previously reported to the Registry are followed back to hospitals and physicians for

complete diagnostic information. To further assure complete reporting, cases diagnosed and/or treated in 16 other states are identified through reciprocal reporting agreements.

In order to provide detailed geographic information for cancer surveillance and cancer mapping, attempts are made to geo-code the addresses of all cancer cases to the county, postal code and census block level.

In order to evaluate the quality and completeness of cancer reporting, the Registry conducts routine audits at hospitals throughout the state. Staff from the Field Services Unit also compare the number of cases reported to the number of cancer-related hospital discharges for consistency. Results are used to target the location and content of statewide educational and training programs.

Interpreting the results

The registration area for the Registry has been constant since 1973. Although no new class of sources of cancer case reports was added during 1998–2002, ambulatory surgery centres have been added as sources more recently.

Changes in cancer screening patterns have had a large impact on the number of cancer cases diagnosed in New York State. According to the Behavioral Risk Factor Surveillance System telephone survey, the percentage of persons aged 50 years or older who ever had colorectal cancer screening grew from 56.6% in 1996 to 67.8% in 2002. By 1997 (the most recent available data), 74.6% of New York women aged

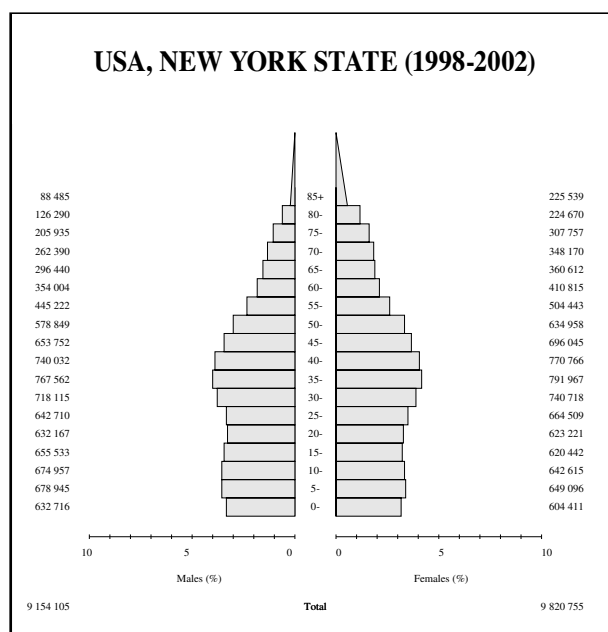
fifty or older had had a mammogram and clinical breast exam within the previous two years; 77% of men aged fifty or older had ever had a prostate specific antigen (PSA) test.

Use of the data

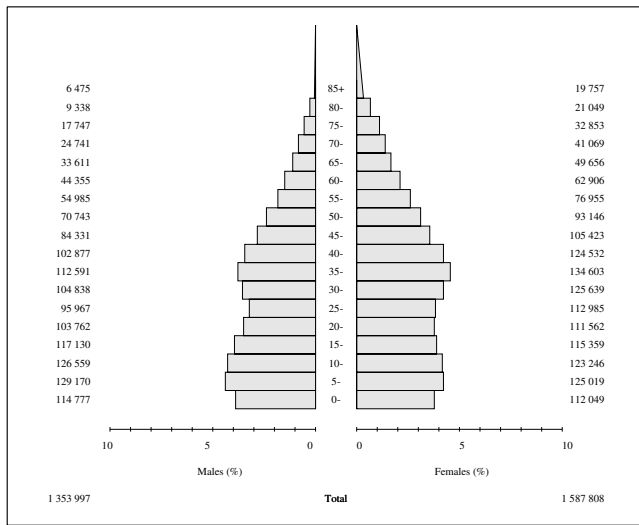
The Registry prepares an extensive annual report of cancer incidence and mortality. The most frequently requested tables are produced in a printed volume, whereas the entire report is available on our Web site: <http://www.health.state.ny.us>.

Within the New York State Department of Health, Registry data are used extensively for cancer surveillance and for program planning. The Cancer Surveillance Program has access to the database for use in investigating possible cancer clusters and addressing community concerns. The Cancer Screening Research and Evaluation unit uses Registry data for programme evaluation, targeting and prioritisation. The Health Department provides cancer education and awareness programs and funds screening for breast, cervical and colorectal cancer for under- or uninsured individuals.

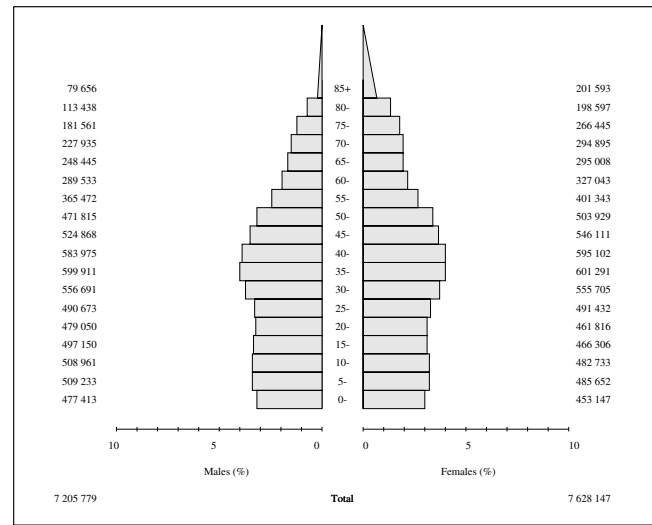
Cancer Registry data are routinely provided to other organisations within the state for planning and evaluation of health services, grass-roots advocacy, and generating etiologic hypotheses. In addition, the Registry is utilised by researchers nationwide for a variety of epidemiological studies.



USA, NEW YORK STATE: BLACK (1998-2002)



USA, NEW YORK STATE: WHITE (1998-2002)



Source of population

Modified Census and census estimates: NCI modification of U.S.Census Bureau population estimates. See <http://seer.cancer.gov/popdata/>

Multiple primary rules used

IACR rules (2004) on historical data.

USA, National Program of Cancer Registries (NPCR)

Registration area

The United States Centers for Disease Control and Prevention (CDC) provides financial and technical support to Public Health Departments (or their designees) for the operation and maintenance of population-based cancer registries in 45 states, the District of Columbia and 3 US territories (Palau, Puerto Rico, and Virgin Islands): 27 to collect data for cases diagnosed beginning in 1995; 13 to collect data for cases diagnosed beginning in 1996; 4 to collect data for cases diagnosed beginning in 1997; and the remaining 5 to collect data for cases diagnosed either beginning in 1999 or 2000. The remaining 5 states—Connecticut, Hawaii, Iowa, New Mexico, and Utah—receive federal support from the National Cancer Institute's (NCI) Surveillance Epidemiology and End Results (SEER) Program. In addition, SEER supports metropolitan area cancer registries in the states of California, Georgia, Michigan and Washington. These metropolitan area registries report their incidence data both to the National Cancer Institute and to the statewide NPCR-funded cancer registries and, thus, these data are included in the NPCR statewide database. The NPCR programme covers 96% of the US population. In 2000, SEER began to provide support for the operations of cancer registries in California, Kentucky, Louisiana and New Jersey. These four registries report their incidence data to both CDC and NCI.

To be eligible for inclusion in this volume of *Cancer in Five Continents*, NPCR-funded cancer registries had to consent and had to report data that met stringent criteria for incidence reporting as established by CDC (see below). Incidence data from 31 cancer registries reported to CDC as of January 2005 (Alabama, Alaska, Arizona, California, Colorado, District of Columbia, Florida, Georgia, Idaho, Illinois, Indiana, Kentucky, Louisiana, Maine, Massachusetts, Michigan, Missouri, Montana, New Jersey, New York, Ohio, Oklahoma, Oregon, Pennsylvania, Rhode Island, South Carolina, Texas, Vermont, Washington, West Virginia, Wisconsin), covering 83% of the U.S. population, met these criteria and are included. Each registry is featured separately in this report.

Registry structure and methods

Participating cancer registries transmit data to CDC using a standardised record layout and coding system documented by the North American Association of Central Cancer Registries. The data files are updated annually beginning with the diagnosis year for which the cancer registry first received federal support (e.g. 1995 or later). Reportable cases include all malignant and in situ neoplasm as defined in ICD-0, excepting most non-melanoma skin cancers and in situ cervical cancer. Neither the patient's name nor the name of the reporting facility is provided to CDC. Upon arrival at CDC, the data undergo evaluation prior to publication and use.

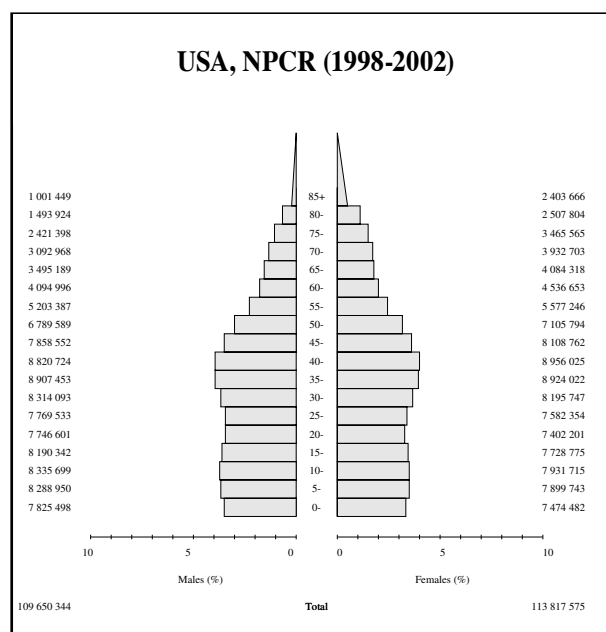
Data included in this report are from statewide or metropolitan area cancer registries that have high quality cancer incidence data for 1998–2002 as demonstrated by meeting the following data quality criteria for all cancer sites combined:

- Case ascertainment is 90% or more complete. The registry data include at least 90% of the expected cases where the expected cases are estimated by using methods developed by the North American Association of Central Cancer Registries.
- No more than 5% of cases are ascertained solely on the basis of a death certificate.
- No more than 3% of cases are missing information on sex.

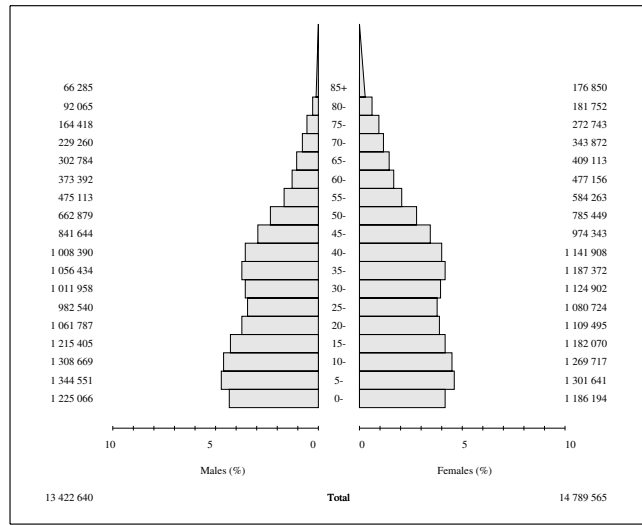
- No more than 3% of cases are missing information on age.
- No more than 5% of cases are missing information on race.
- At least 97% of the registry's records passed a set of single-field and inter-field computerised edits.

Use of the data

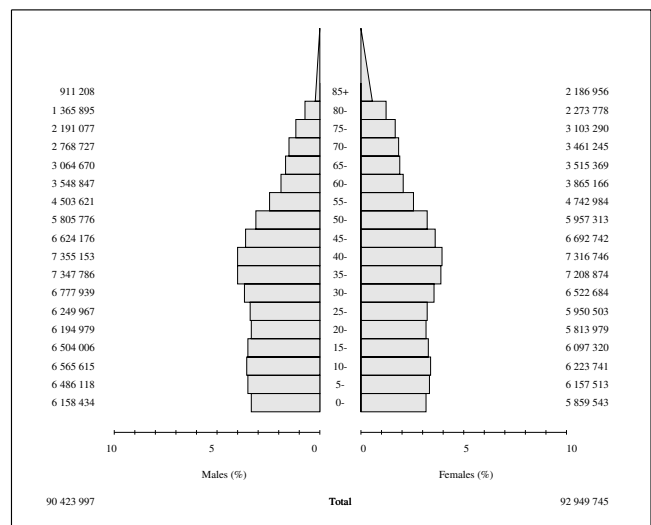
CDC and NCI annually publish the *United States Cancer Statistics* report, beginning with cases diagnosed in 1999 forward. These federal cancer statistics are also made available to the public and cancer control planners through public use and restricted access data sets. In addition, several monographs and reports on special topics have been published.



USA, NPCR: BLACK (1998-2002)



USA, NPCR: WHITE (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.

USA, Ohio

Registration area

Ohio's cancer registry covers a population of over 11 000 000 residents. The state has large metropolitan areas of over 1 000 000 as well as rural areas. Manufacturing, agriculture, and business are all important factors in Ohio's economy and play roles in the lifestyles of Ohioans.

Cancer care facilities

Ohio has two National Cancer Institute designated Comprehensive Cancer Centers: Case Western Reserve University in Cleveland and The Arthur G. James Cancer Hospital in Columbus. The state has over 160 other hospitals, most of which offer cancer treatment services.

Registry structure and methods

The registry, established by Ohio law in 1991, is in the Ohio Department of Health and is funded by the US Centers for Disease Control and Prevention's National Program of Cancer Registries (NPCR) and by the State of Ohio.

Staff include 13 cancer registrars, four administrative staff, and two IT staff members.

Cancer data are reportable by law for all who diagnose and/or treat cancer patients, including pathology laboratories. Some data are submitted on paper, but increasingly data are submitted in electronic formats, either on diskettes or via email in encrypted files. The OCISS recently opened a Web-based system for reporting and is enrolling the larger reporting sources to use it at this time. This is the mode of reporting that the registry is promoting, as it automates much of the processing of data as they are submitted.

Principal sources of information on cancer cases are the hospitals, free-standing radiation centres, and ambulatory

surgery centres. Physicians' offices and pathology laboratories also report data. The pathology laboratories are seen as increasingly good sources of initial cancer data as electronic means for them to report are developed.

Death certificates are available for the death clearance procedures that are performed annually. The Bureau of Vital Statistics, where the death certificates are housed, is a part of the Department of Health, where the Registry is housed.

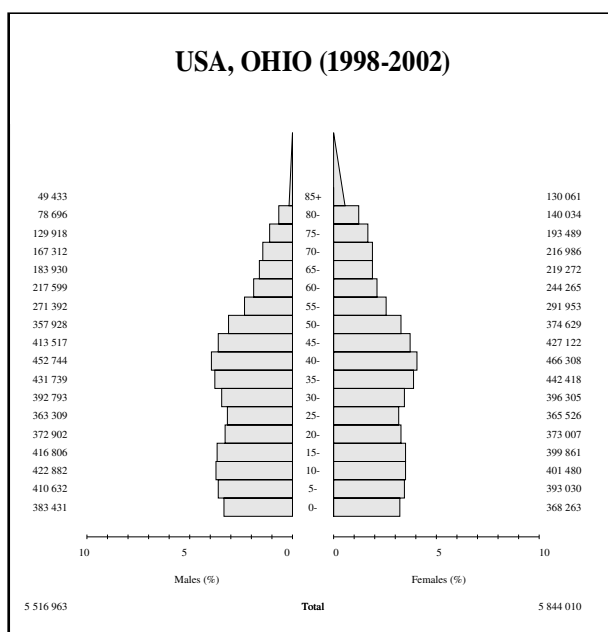
Automated editing processes are part of the database software used by the Registry and of the Web-based reporting system recently put into operation. Quality control procedures are attended to on a daily basis by OCISS registrars. Evaluation of data by two national organisations each year also comprises part of quality control.

Use of the data

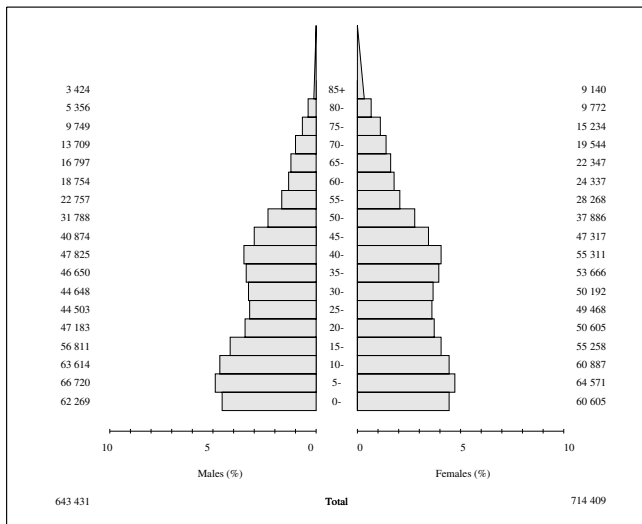
Reporting of incidence, extent of disease, survival: The registry produces an annual report and posts data in the Data Warehouse at the Ohio Department of Health's website. In addition, several "fact sheets" are published each year for different types of cancers. These are available on the registry's website or in paper form. Data are also submitted to the National Program for Cancer Registries and to the North American Association for Central Cancer Registries, both of which publish annual reports and post data to web sites.

Research use: Registry data are accessed by researchers several times each year, often including Institutional Review Board approvals for confidential data.

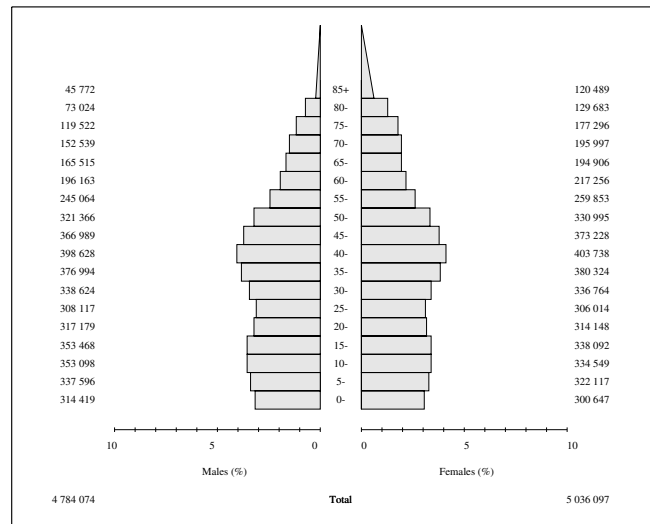
Planning and evaluation of health services: Local health departments use registry data to perform surveillance studies and to support funding efforts to provide screening and other cancer-related services.



USA, OHIO: BLACK (1998-2002)



USA, OHIO: WHITE (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.

USA, Oklahoma

Registration area

The Oklahoma Central Cancer Registry covers the population of 77 counties within the state of Oklahoma, in the central United States. The population at the most recent census (2000) was 3 450 654. About 65% of the population lives in urban areas (>2 250 000 inhabitants).

Cancer care facilities

General health care in the state is provided predominantly by private practitioners and hospitals. This includes 17 facilities that have been designated as Approved Cancer Programs by the American College of Surgeons Commission on Cancer.

Registry structure and methods

The registry is located within the Oklahoma State Department of Health, and is funded partly by the US Centers for Disease Control and Prevention's National Program of Cancer Registries (NPCR), and partly by the state health department. The registry is staffed by a surveillance coordinator, nine full-time registrars, an administrative assistant and a part-time epidemiologist.

The OCCR utilizes automated data collection via electronic media to receive an average of 31 000 cancer reports per year from approximately 230 active sources of data such as cancer hospitals, general hospitals, teaching hospitals, pathology laboratories, freestanding oncology centres, mammography centres, ambulatory surgery centres, Indian Health facilities, some dermatologists' and urologists' offices, and the vital statistics office of the Oklahoma State Department of Health, along with data sharing with surrounding states.

Registrars within individual facilities involved in diagnosis and treatment of cancers identify and abstract information on cases of cancer, diagnosed by all methods, among residents of the state.

Interpreting the results

OCCR is obtaining 96% of the incident cancer cases in Oklahoma each year, of which 2% are Death Certificate Only cases. An additional 4% is believed to be diagnosed and/or treated but not reported to OCCR, or may be attributable to error in the method of estimating completeness.

Use of the data

OCCR publishes a quarterly report of Chronic Disease Service Data Analysis, or an article focussing on a specific topic around cancer important for Oklahoma. Data are presented to interested groups, including but not limited to Comprehensive Cancer, Indian Health Services, College of Public Health, and the Oklahoma State Legislature, and OCCR has instituted and maintains a queryable cancer data website (<http://www.health.ok.gov/stats/cancer/>).

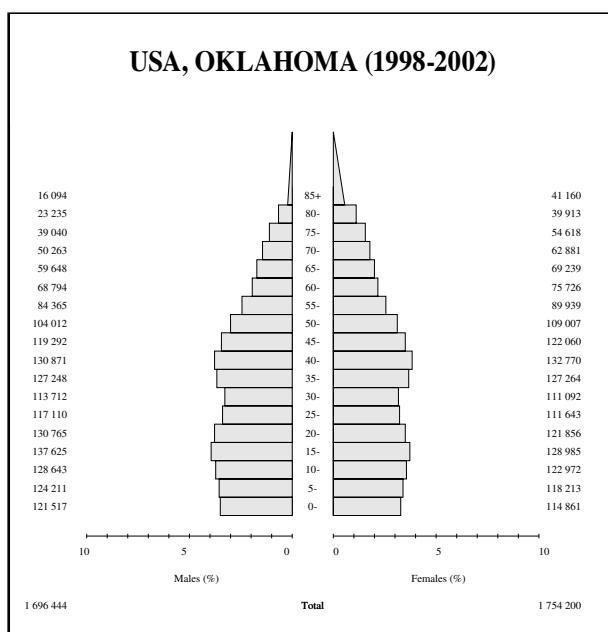
Source of population

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.



USA, Oregon

Registration area

The Oregon State Cancer Registry (OSCaR) is a population-based registry covering the state of Oregon. Oregon, located in the northwestern United States, is about 360 miles long and 261 miles wide. The population in the 2000 census was 3 421 399 and is estimated to have increased to 3 594 586 by 2004. About 70% of the population lives in urban areas. The racial make-up is approximately 87% White, 3% Asian, 1.6% Black and 1.3% American Indian/Alaska Native (approximately 7% are some other race or two or more races).

Cancer care facilities

Cancer care in the state is provided predominantly by 56 hospitals. Of these, 18 have American College of Surgeons Commission on Cancer-approved cancer programs. Additional services are provided at ambulatory surgery centres, freestanding cancer treatment facilities, physicians' offices and clinics around the state.

Registry structure and methods

The registry is located within the Health Promotion and Chronic Disease Prevention section of the Oregon Department of Human Services, along with the Oregon Breast and Cervical Cancer Early Detection Program and the Oregon Comprehensive Cancer Control Program. Funding for the registry comes through a cooperative agreement with the US Centers for Disease Control and Prevention's National Program of Cancer Registries (NPCR). The program manager, one office-support staff, five certified cancer registrars and three research analysts staff the registry.

Information processed by OSCaR comes from a variety of sources including: hospital cancer registries, state cancer registries, ambulatory surgery centres, physician offices, vital statistics, pathology laboratories, hospital medical record departments and the US Census Bureau. Approximately 75%

of Oregon's cancer cases are collected by certified tumour registrars (CTR) in established hospital cancer registries and are reported to OSCaR. The statewide population-based cancer registry collects the remaining 25% from non-registry hospitals, outpatient clinics, physician offices, and neighbouring state registries diagnosing or treating Oregon residents. The annual process of death clearance identifies missed cases by comparing the Registry database with Oregon death certificates. The majority of cases identified through death clearance are subsequently reported by one of the above-mentioned sources. Remaining cases are recorded as death certificate only cases.

Interpreting the results

OSCaR consistently exceeds the NPCR standard of ascertaining 95% of expected cases based on the North American Association of Central Cancer Registries case completeness calculation.

Use of the data

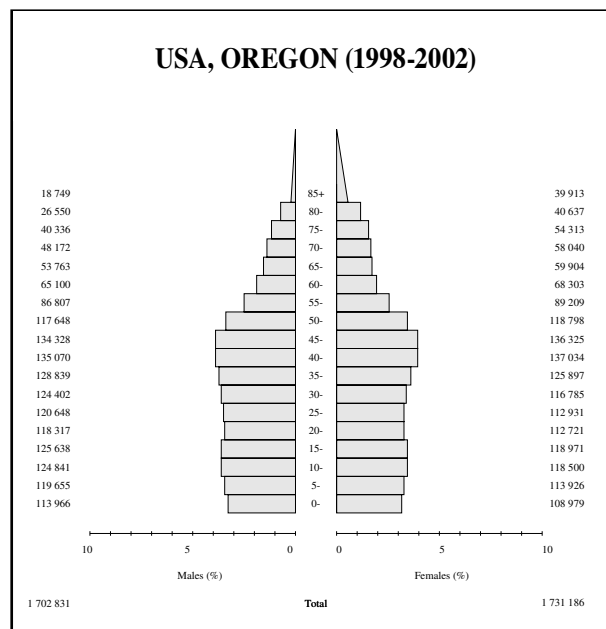
The registry prepares an annual report of cancer incidence and mortality highlighting cancer risks, screening and trends. Other cancer control programmes use registry data for planning and evaluation. The registry also collaborates with local and national researchers on a variety of special studies designed to reduce the burden of cancer in Oregonians.

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.



USA, Pennsylvania

Registration area

The Pennsylvania Cancer Registry covers the population of the entire state and has been collecting statewide cancer data since 1985. In Pennsylvania, racial categories other than White made up 13.5% of the total population in 2004, compared to 11.5% in 1990, 9.6% in 1980, and 9.0% in 1970. Of the 1 674 223 residents other than White in 2004, 77.7% identified themselves as Black. The number of Asian/Pacific Islanders in the state increased by 9.2% between 2000 and 2004, and by 77% between 1990 and 2004. The number of black residents increased by 6.3% between 2000 and 2004, and by 19.4% between 1990 and 2004. The number of Hispanics in Pennsylvania increased by 81 464 (20.7%) between 2000 and 2004. Between 1990 and 2000, the number of Hispanic residents increased by almost 70%. Pennsylvania Hispanics tend to be much younger than white, black or even Asian/Pacific Islander residents. The 2004 median age for Hispanics was 24.9, compared to 31.7 for Asian/Pacific Islanders, 31.1 for Blacks, and 39.9 for Whites.

Cancer care facilities

Cancer cases are reported by all acute care hospitals in Pennsylvania. Interstate data exchange is conducted regularly with all contiguous states as well as Florida and Michigan. Other non-hospital sources where patients are diagnosed or treated for cancer also report to the PA Cancer Registry, including freestanding pathology laboratories, radiation therapy centres and physicians' offices.

Registry structure and methods

The PA Cancer Registry operates in the Pennsylvania Department of Health, and is funded by the state and the US Centers for Disease Control and Prevention's National Program of Cancer Registries (NPCR).

Fifteen staff work directly on PA Cancer Registry operations (8/15 are CTRs); two additional statistical support staff generate cancer reports and statistics; 1 IT staff provides computer support; 1.5 epidemiologists perform analysis of cancer data.

The PA Cancer Registry uses the CDC Registry Plus cancer data system; uses active casefinding from all reporting sources and passive follow-up through death clearance. PA Cancer Registry has received NAACCR Gold Certification for approximately six years.

Principal sources of information on cancer cases include acute care hospitals, freestanding pathology laboratories, radiation therapy and cancer centres, physicians' offices, and death certificates.

Death certificate files (with personal identifiers) are used annually to conduct death clearance by linking to update existing cancer cases with death information, and by identifying cancer deaths not included in the registry.

Cancer is a reportable disease in Pennsylvania as mandated by the Pennsylvania Cancer Control, Prevention, and Research Act (Act 224) and Department of Health Regulations regarding communicable and non-communicable diseases. According to Act 224, information collected by the

Cancer Registry is confidential but can be used for medical research as approved by the PA Department of Health Policy.

The PA Cancer Registry uses national and local edits metafiles to edit data to meet national and local standards; conducts casefinding and re-abstracting audits at reporting hospitals; performs special studies to check data and identify potential quality issues used to improve data and train staff; and requests feedback from data users to improve data and increase usability of data.

Interpreting the results

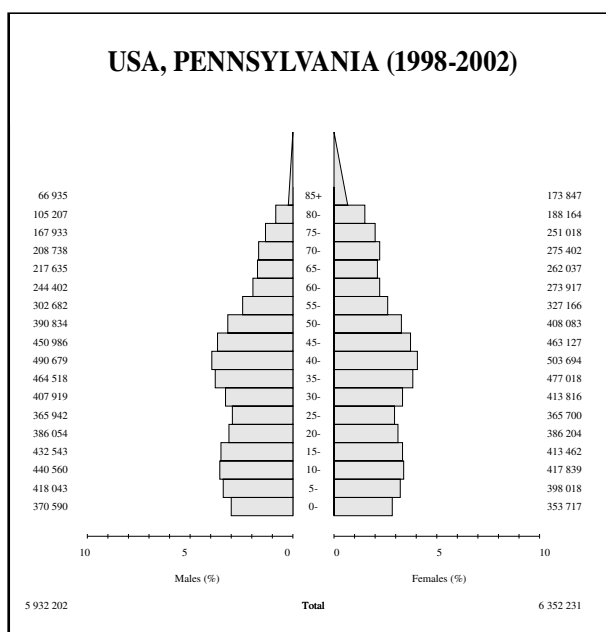
There has been a shift in diagnosis and treatment of certain types of cancer from inpatient to outpatient facilities.

The only recent change in case definition and coding is the addition of benign brain and CNS tumours to reportable diagnoses effective in 2004. Pennsylvania participates in the CDC Breast and Cervical cancer screening program.

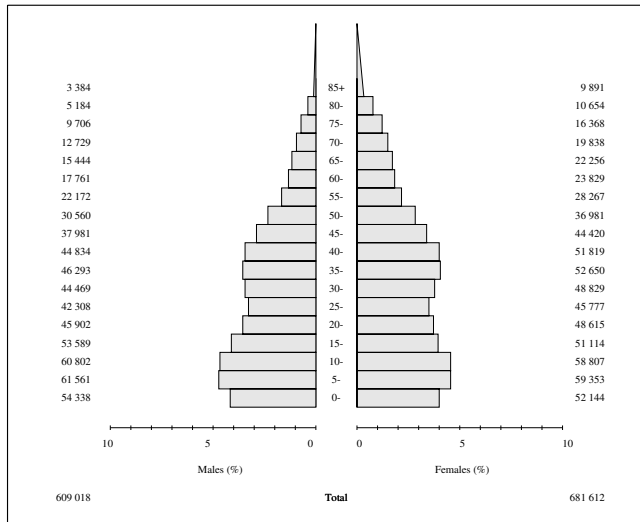
In the 2004 Behavioral Risk Factor Surveillance System (BRFSS) survey, 78% of Pennsylvania men aged 50 and older said that they had ever had a prostate-specific antigen blood test to detect the presence of prostate cancer.

Use of the data

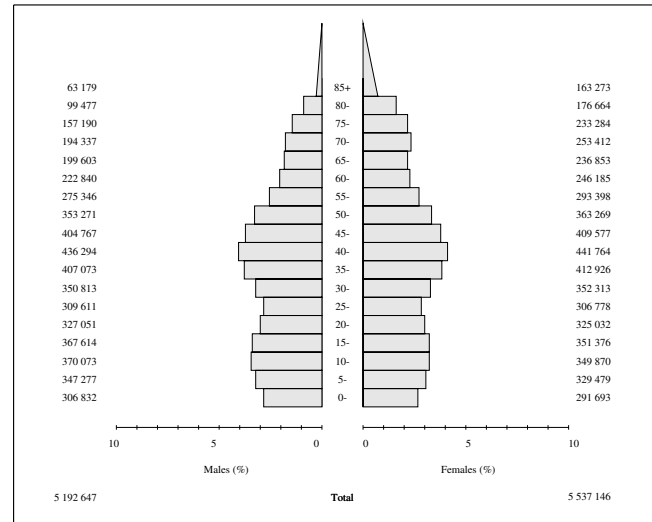
Incidence, extent of disease, and survival data are produced and made available on PA Department of Health website at www.health.state.pa.us/stats. Cancer data are used for medical research studies as approved by the PA Department of Health, and we receive numerous requests for hospital-specific data, which is used to evaluate their services.



USA, PENNSYLVANIA: BLACK (1998-2002)



USA, PENNSYLVANIA: WHITE (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.

USA, Rhode Island

Registration area

The Rhode Island Cancer Registry, an administrative unit of the Rhode Island Department of Health (RIDOH), covers the population of the State of Rhode Island and Providence Plantations in the Northeastern region of the United States. The population at the most recent census (2000) was 1 048 000. About 85% of the population lives in urban areas; roughly 10% are of recent immigrant status.

Cancer care facilities

General health care in the region is provided by 10 privately funded acute care hospitals, one federally funded acute care (veterans') hospital, 25 community health centres (for primary care), and several hundred private physician offices (for primary and specialty care). All eleven hospitals provide cancer care; all have Cancer Care Committees. Nine of the eleven acute care hospitals have American College of Surgeons-approved cancer programs. In addition, the state is served by two freestanding radiotherapy centres.

Registry structure and methods

The Rhode Island Cancer Registry (RICR) is a population-based cancer registry established in 1985. It began collecting reports of newly diagnosed cancers on 1 October 1986. Under Rhode Island law, all newly diagnosed cases of cancer and of benign tumours of the brain and central nervous system are reportable to the Rhode Island Cancer Registry. The Registry is funded by the State and by the US Centers for Disease Control and Prevention's National Program of Cancer Registries (NPCR). It is run collaboratively by the Rhode Island Department of Health (HEALTH) and the Hospital Association of Rhode Island (HARI). There are 5 persons employed: a Registry Manager, 2 Registrars (CTR), a Data Manager and an epidemiologist. The profile of the principal sources of information are as follows: 85–90% of case reports are received from 11 acute care hospitals; ~10% of case reports are "developed" from pathology reports; ~5% of case reports are "developed" from death certificates (1–2% "death certificate only" cases).

In Rhode Island, all cancer registries (including 11 hospital-based tumour registries and the central registry) conform to data collection standards adopted by the American College of Surgeons (*FORDS*). Data are transmitted electronically from hospital registries and other reporting sources to the central registry and vice versa. The Rhode Island Cancer

Registry is a member of the North American Association of Central Cancer Registries (NAACCR), and conforms to NAACCR standards for central registry operations, including data reporting, editing and transmission.

Interpreting the results

Data from the Rhode Island Cancer Registry have consistently met NAACCR quality control standards for inclusion in national and international aggregates of cancer incidence. Reporting completeness exceeds 95 %, with less than 3% of cases being reported on the basis of death certificates only (DCO). During the 1990s, Rhode Island experienced surges in screening for cancers of the breast (clinical breast exam and mammogram), cervix (pelvic exam and Pap test), colon-rectum (faecal occult blood and endoscopy), and prostate (PSA), resulting in increases in the incidence of cancers of the breast, cervix and prostate, and a decrease in the incidence of cancer of the colon-rectum (because of the removal of pre-cancerous lesions).

Rhode Island is a highly urbanised state, best compared with highly urbanised areas such as cities. Historically, Rhode Island has had an "urban cancer profile," with higher incidence of cancers related to tobacco and alcohol use, cancers related to diet, and cancers of the female breast and of the prostate.

Use of the data

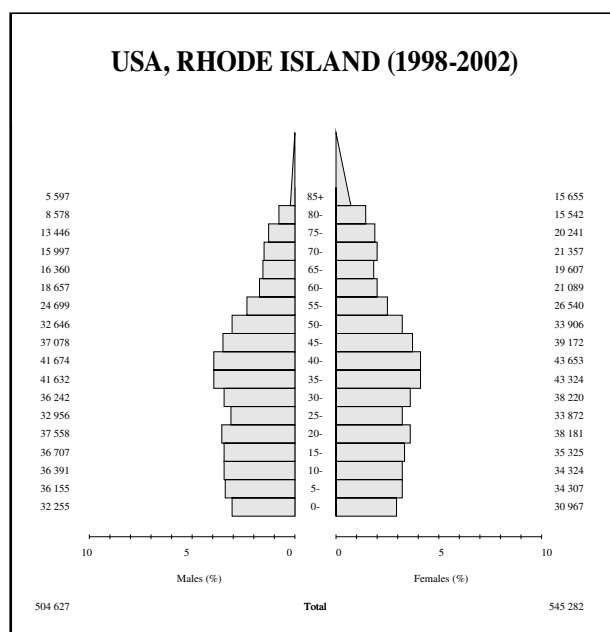
The Registry produces official cancer statistics for Rhode Island, including an annual report posted on the RIDOH website, and also supplies cancer data to researchers (strict guidelines are used to protect patient confidentiality so that individuals cannot be identified). Special studies are performed regularly to support the planning and management of cancer control efforts in the state, and also to assist with environmental health risk assessments.

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.



USA, SEER

Registration area

Participants in the Surveillance, Epidemiology, and End Results (SEER) Program were selected on the basis of their ability to operate and maintain a population-based cancer reporting system and for their population sub-groups, which were of special epidemiological interest. The SEER Program now covers over one fourth of the United States (US) population. Data are available back to at least 1975 from the SEER 9 areas (States of Connecticut, Iowa, New Mexico, and Utah) and metropolitan areas San Francisco-Oakland (California), Detroit (Michigan), Seattle-Puget Sound (Washington), and Atlanta (Georgia)), which represent about 10% of the total US population. The SEER 14 areas (States of Connecticut, Iowa, New Mexico, Utah, Kentucky, New Jersey, and Louisiana and metropolitan areas Greater California (San Francisco-Oakland and San Jose-Monterey) (California), Los Angeles (California), Greater California (California excluding SF/SJM/LA), Detroit (Michigan), Seattle-Puget Sound (Washington), and Atlanta plus Rural Georgia (Georgia)) cover 26.1% of the US population. The data are considered fairly representative of the US population with respect to selected demographic variables. With regard to race, rural blacks are under-represented, whereas other minority populations such as Chinese, Japanese, Hawaiians and American Indians are over-represented. Over 350 000 new cases of *in situ* and invasive cancers are added each year to the SEER database. In addition to contributing to SEER, many of the SEER areas report data separately for their own registry in this volume.

Registry structure and methods

The SEER Program is a continuing project of the Surveillance Research Program of the US National Cancer Institute (NCI). The Program was initiated in 1973 as an outgrowth of the End Results Program and the three National Cancer Surveys and The National Cancer Act of 1971, which mandated the collection, analysis and dissemination of data useful in the prevention, diagnosis and treatment of cancer. The participating regions were selected principally for their ability to operate and maintain a population-based cancer

reporting system and for their epidemiologically significant population subgroups.

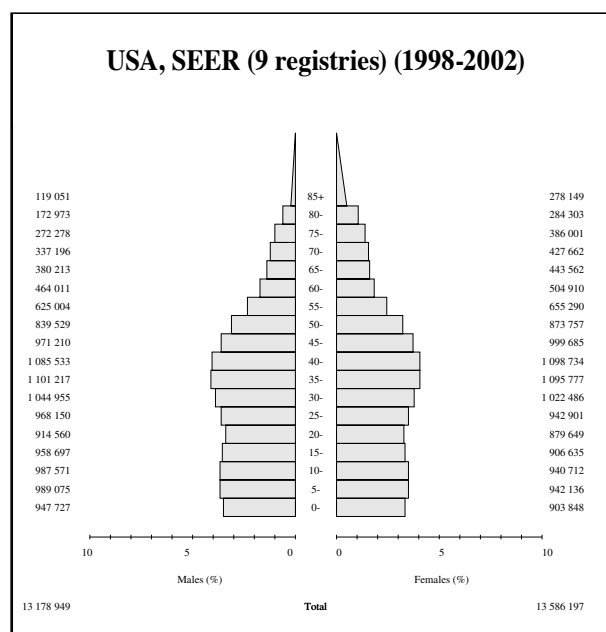
The Program aims to determine the incidence and survival of cancer in selected geographical areas in relation to demographic and social characteristics of the population and to estimate annual cancer incidence for the US. Trends in incidence by site and histology are monitored, as are survival and trends in survival. Studies are conducted to identify etiological factors that can possibly reveal groups of the population at high or low cancer risk, which may be defined by social, occupational, environmental, dietary or other characteristics. Geographical information systems are developed for use with SEER and other population-based central cancer registries in the USA through linkage with small area demographic census data and national surveys on health behaviours, risk factors and environmental exposures for use in cancer control and surveillance research.

Data for publication are transmitted by the participants to NCI 22 months after the end of each calendar year. All malignant and *in situ* neoplasms as defined in ICD-O are collected except for basal and squamous skin cancers since 1973, *in situ* and CIN III of the cervix uteri since 1996, and PIN III since 2001. SEER registries must collect information about extent of disease, first course of therapy, and follow-up. Neither the patient's name nor the name of the hospital is provided to NCI.

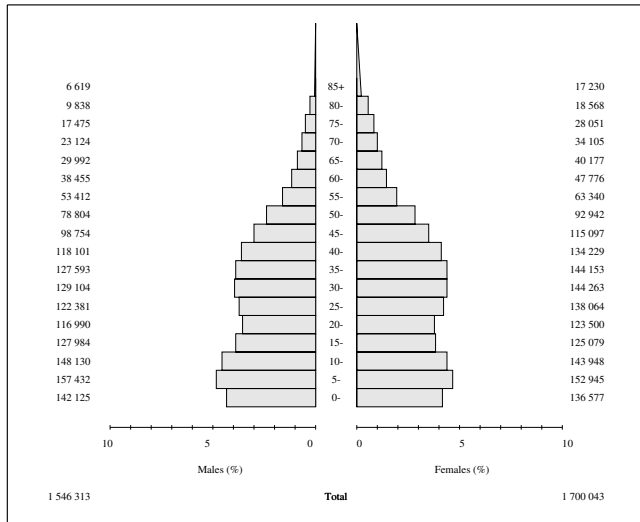
The SEER Program conducts studies to evaluate quality and completeness of data, and provides specialist training for personnel.

Use of the data

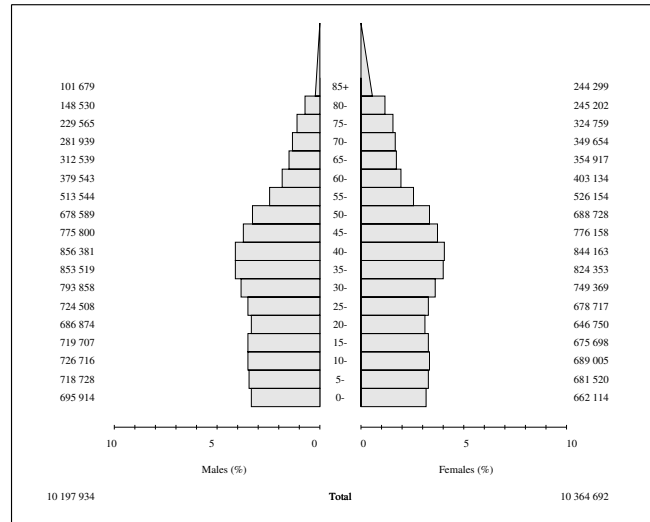
Updated annually and provided as a public service in print and electronic formats, SEER data are used by thousands of researchers, clinicians, public health officials, legislators, policymakers, community groups, and the public. Each year since 1985, the NCI has published a 'SEER Annual Cancer Statistics Review' (www.seer.cancer.gov/publications), which comprises principally SEER cancer incidence and survival data, and cancer mortality data from the National Center for Health Statistics. In addition, data are made available on the SEER home page (www.seer.cancer.gov) and via SEER*Stat software on a client-server and CD-ROM.



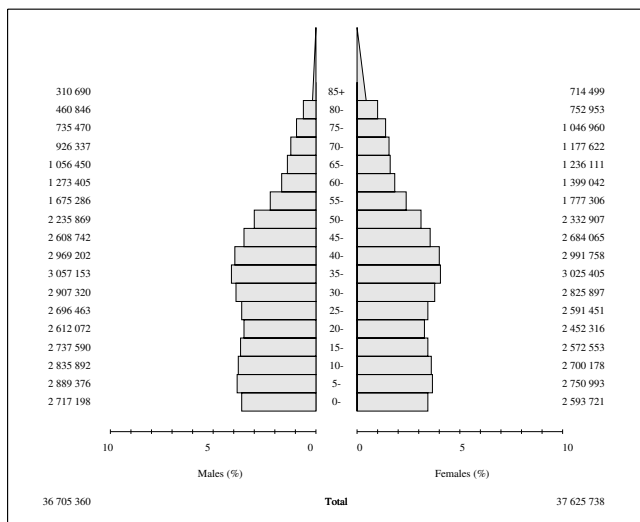
USA, SEER (9 registries): BLACK (1998-2002)



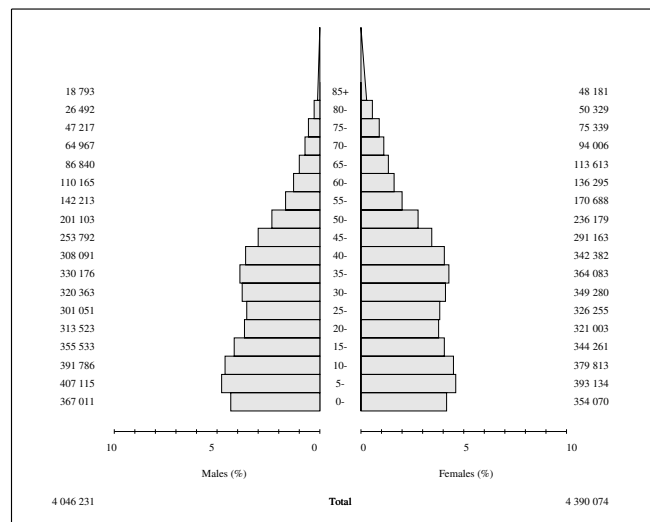
USA, SEER (9 registries): WHITE (1998-2002)



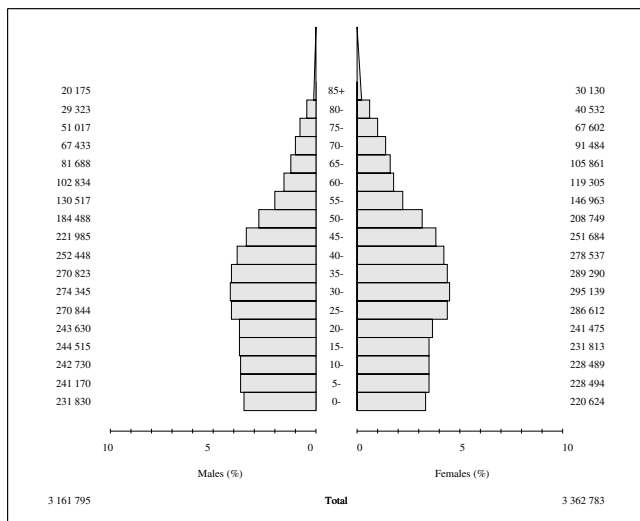
USA, SEER (14 registries) (1998-2002)



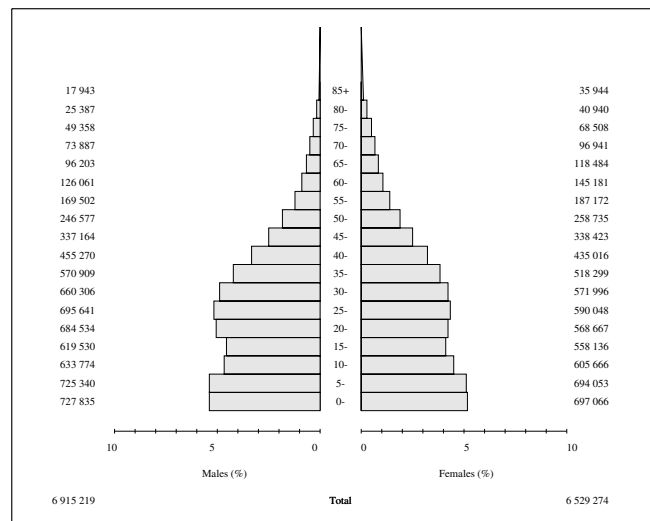
USA, SEER (14 registries): BLACK (1998-2002)



USA, SEER (14 registries): ASIAN AND PACIFIC ISLANDER (1998-2002)



USA, SEER (14 registries): HISPANIC WHITE (1998-2002)



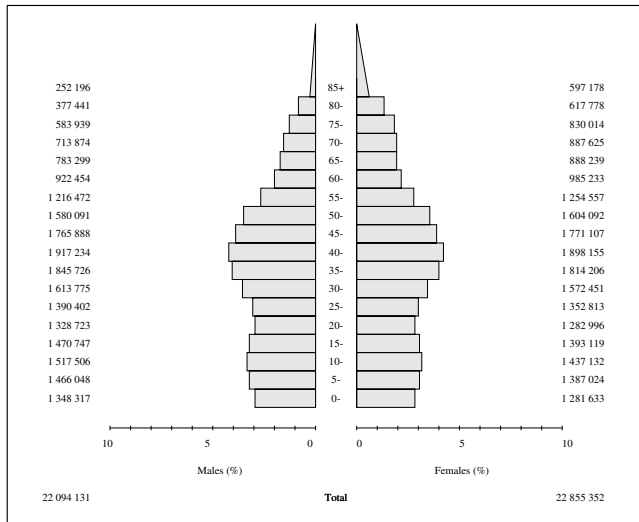
**USA, SEER (14 registries): NON-HISPANIC WHITE
(1998-2002)**

Source of population

July 1 county population estimates by age, sex, race, and Hispanic origin; postcensal estimates based on 2000 United States Census.

Multiple primary rules used

IACR rules (2004) on CI5 IX period.



USA, South Carolina

Registration area

The South Carolina Central Cancer Registry covers the entire state. The state is 60.5% urban and 39.5% rural, comprised racially of 31% African American, 68% Caucasian, and 1% Other Races.

Cancer care facilities

Health care is provided in SC by 65 acute care hospitals, ~35 freestanding surgical and oncology treatment centres, and private oncology practices.

Registry structure and methods

The SCCCR is located at the SC Department of Health and Environmental Control, funded by the US Centers for Disease Control and Prevention's National Program of Cancer Registries (NPCR) and state funds.

The SCCCR is comprised of 17 staff, including the Director, 10 CTRs who perform data coordination and quality control, 4 Master's-level research analysts, database manager and statistician, and administrative coordinator.

The majority of data collection (85%) comes from pre-coded data from hospital registries. The remainder is actively sought by staff from small hospitals, pathology labs, freestanding treatment centres and physicians.

The hospital medical record is the principal source of information on cancer cases. Secondly, pathology reports from reference labs are a contributing source of information.

Access to death certificates (with personal identifiers) is provided by the SC Div of Vital Registry.

Cancer reporting is mandated in SC by the state statute SC Code Section 44-35-10-60. Confidential patient, hospital

and physician identifiers are reported via state statute and protected by this law.

Quality control procedures include visual review of patient abstracted data along with computerised inter-record, intra-record edits. Routine casefinding and quality audits are performed at reporting facilities. Once every five years, the SCCCR undergoes a national data completeness and quality audit. Results of most recent national audit: 97% completeness, 98% accuracy.

The SCCCR has attained Gold Certification for 6 years, and Silver for 2 from the NAACCR certification process since 1997.

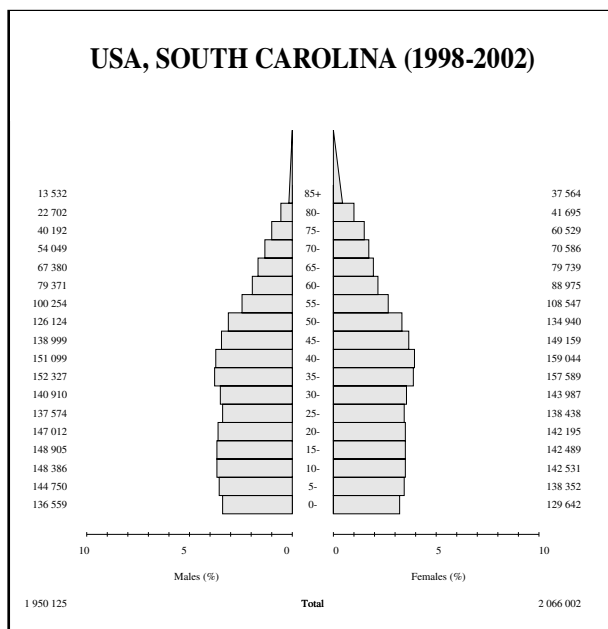
Use of the data

The data are used to report official annual cancer incidence, extent of disease and survival for the state. An annual Cancer Report Card is produced as well as County Cancer Fact Sheets.

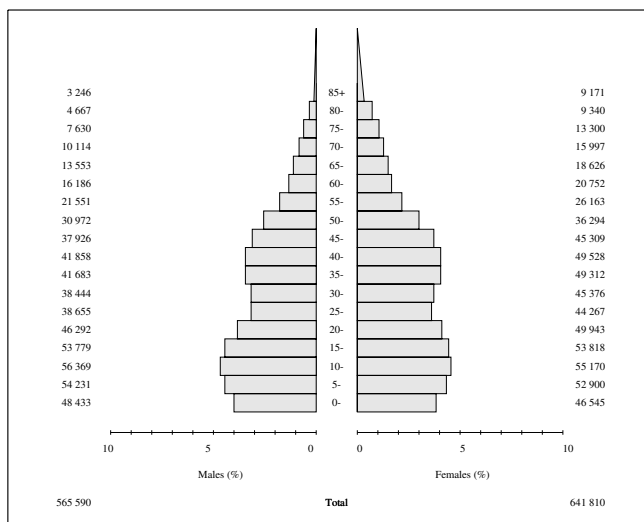
Assessments of community cancer concerns (potential cancer clusters) are carried out with the data.

The data are available through the on-line query system, called SC Community Assessment Network (SCAN). Researchers and the public can create their own query by accessing the cancer module on SCAN. Maps, trend graphs, bar charts and tables are provided.

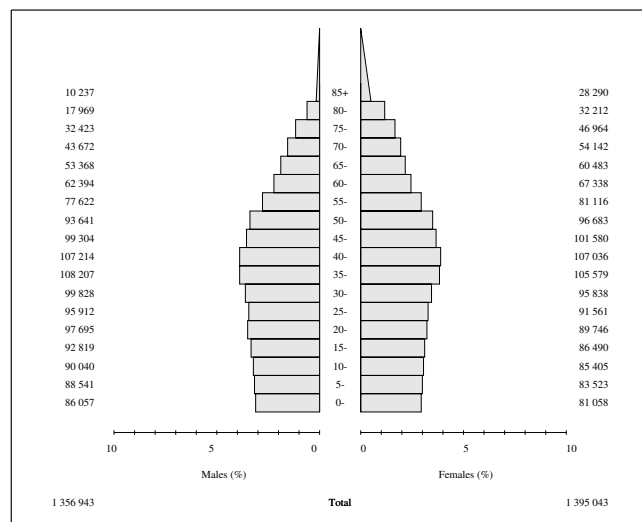
The data are used for research as prescribed by the protocol for data release and approval by the advisory committee. Data are used by multiple university researchers as well as SC medical schools, by state cancer control planners and evaluators, the statewide Cancer Alliance, and the American Cancer Society.



USA, SOUTH CAROLINA: BLACK (1998-2002)



USA, SOUTH CAROLINA: WHITE (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.

USA, Texas

Registration area

The Texas Cancer Registry (TCR) covers the statewide population of Texas, in the south central United States of America. The estimated mid-year 2000 population census was 20 851 820. Although 86% of the population lives in urban counties, these represent only 30.3% of all Texas counties. The 2000 Texas population also shows considerable race/ethnic diversity with 53.1% being non-Hispanic White, 32.0% Hispanic (of any race), 11.6% Black and 3.3% Other Races.

Cancer care facilities

Cancer care in Texas may be provided by a wide variety of facilities, from large medical centres specialising in cancer treatment to community hospitals. The M.D. Anderson Cancer Center in Houston, Texas is a leader with a worldwide reputation in cancer care, as well as research, education and prevention. Numerous other research-based University medical centres and American College of Surgeons Accredited Cancer Programs are found in the state, and provide state-of-the-art cancer diagnosis and treatment.

Registry structure and methods

The TCR is part of the Texas Department of State Health Services (DSHS), and also receives federal funding from the US Centers for Disease Control and Prevention, National Program of Central Cancer Registries (NPCR). The TCR is staffed by 46 full-time state staff and 10 contract staff.

Our cancer data are reported to the TCR primarily by hospitals, but also by cancer treatment centres, pathology labs and medical practitioners.

Cancer case reporting in Texas is required by state law (Chapter 82, Health and Safety Code), and the TCR has specific cancer reporting rules. Cancer death reporting is through the Texas DSHS, Vital Statistics Unit. Cancer case reporting is done electronically for approximately 98% of cases, and 0% of deaths. All personal identifying data are considered confidential, and are used internally by TCR staff for registry operations and approved research purposes. Confidential data may only be released with DSHS Institutional Review Board approval.

Texas Cancer Registry staff work with the cancer reporters to provide training in case reporting as needed, and technical assistance to identify and abstract information on cancer cases. In addition, the TCR has data exchange

agreements with other states to obtain data on Texas residents diagnosed and/or treated out-of-state.

Interpreting the results

We estimate the completeness of our cancer data by predicting the number of cases to be expected each year, based on standard age-, sex-, and race/ethnic-specific rates from another state registry with a similar population to the Texas population. Based on these estimates, we do not produce a final dataset for any given year until the estimated completeness of the data is at least 95%. The average completeness of the entire 1998–2002 dataset is 96.3%.

The population of Texas is unusual in that there is a large

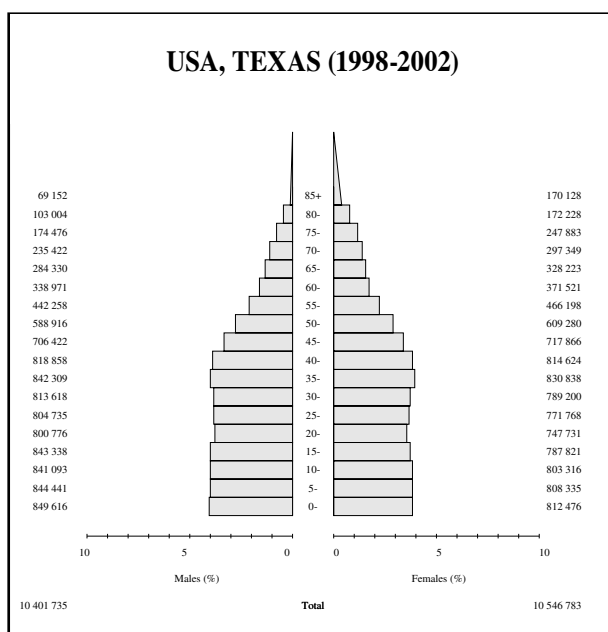
proportion of the total statewide population made up of Hispanics. For most major cancer types, incidence rates in Hispanics are lower than for many other race/ethnic groups, leading to generally lower (overall) incidence rates in Texas than in surrounding states. For this reason, Texas rates are also reported by race/ethnicity.

The goal of the DSHS Breast and Cervical Cancer Control Program is to reduce mortality from breast and cervical cancer in Texas. This program provides free breast and cervical cancer screening and diagnostic services to low-income women with no health insurance at over 200 sites throughout Texas. Since 1991, more than 190 000 women in Texas have received early cancer detection services through this program.

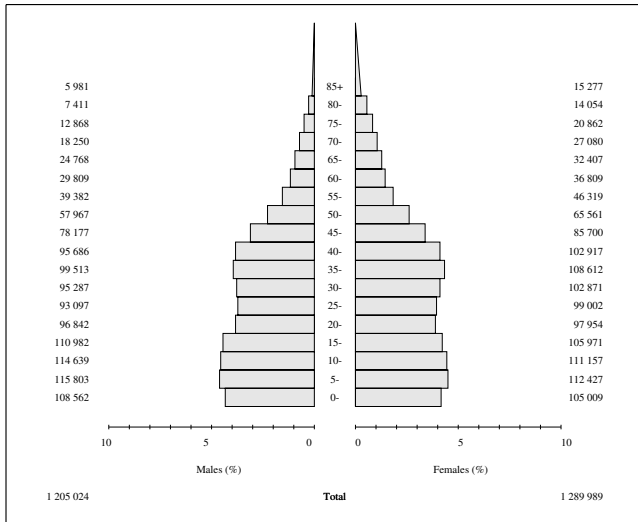
According to the DSHS Texas Behavioral Risk Factor Surveillance System, in 2002, 70% of Texas men 50 years and older had a PSA test within the past five years. Non-Hispanic white men and men 65 and older had higher PSA prevalence rates, while Hispanic males and those with less than a high school education have lower PSA rates.

Use of the data

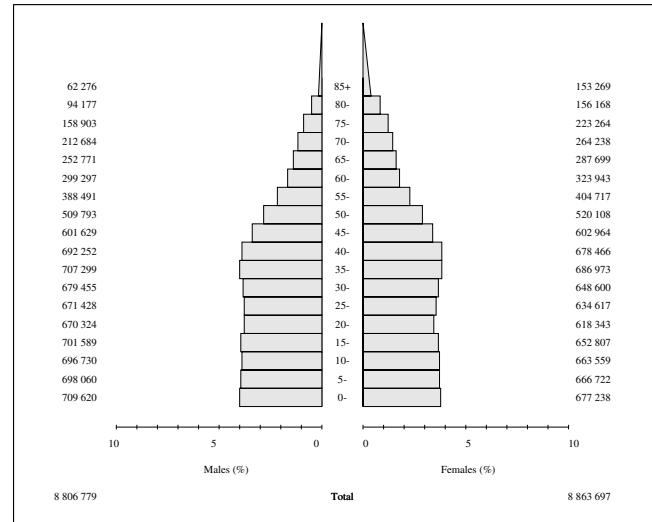
The registry produces an annual report of cancer incidence and mortality, examining race/ethnic differences, trends, and other patterns in statewide cancer data, and maintains tables of average annual rates, published on our website. These data are provided statewide, by sex and race/ethnicity, and by various geographical areas including counties. Also provided are childhood cancer incidence and mortality rates, as well as estimated cases and deaths for future years at the statewide, regional and county levels. Data are also provided to external customers upon request, and have resulted in numerous specialised studies of cancer incidence and mortality, as well as health services studies.



USA, TEXAS: BLACK (1998-2002)



USA, TEXAS: WHITE (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.

USA, Utah

Registration area

The State of Utah covers 299 888 km² and is geographically the 11th largest US state. There were 2 233 169 residents in Utah at the time of the decennial census conducted in 2000. Approximately 89% of Utah residents are white, and 9% are of Hispanic origin (any race). The remaining population comprises American Indians (1.3%), Asians (1.7%), Pacific Islanders (0.7%), blacks (0.8%), and individuals of other racial/ethnic backgrounds (4.2%).

Utah's 2000 birth rate of 21.1/1000 was approximately 47% higher than the national average of 14.4/1000. As a result, the median age of Utah residents was 27.1 years, fully 8 years younger than the national figure of 35.3 years.

Approximately 70% of Utah residents are members of the Church of Jesus Christ of Latter-day Saints (LDS), whose doctrine places a high value on marriage and encourages large families (hence, high fertility rates). The church also discourages consumption of tobacco, alcohol and caffeine, and proscribes premarital sex, profoundly influencing cancer incidence and mortality rates in Utah.

Cancer care facilities

Forty-five health care facilities in Utah routinely provide cancer-related services to state residents. Seven of Utah's largest facilities have ACoS accredited cancer care programmes. Fourteen hospitals in Utah support one or more cancer registrars on their staff, including each of the ACoS-accredited facilities. Six Utah hospitals have radiation therapy units; there are 2 freestanding radiation therapy units in the state.

Registry structure and methods

The Utah Cancer Registry (UCR) has operated since 1966 on a population-based, statewide level. In 1973, UCR became one of the original members of the National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) Program. UCR has continuously participated in the SEER program since that time.

UCR is staffed by 20 employees, including 5 administrative personnel, 1 research coordinator, 2 supervisors, 3 coders, 4 field pathology and hospital abstractors, 1 follow-up coordinator, 3 IT and data support staff, and 1 data entry/file clerk.

Cancer cases are identified and followed using information from hospitals, pathology laboratories, radiation treatment centres, physician offices, nursing homes, vital records, other central cancer registries, and by direct patient contact. Cancer reporting in Utah is mandated by legislation and regulatory rule.

Central registry personnel annually travel to outlying areas to identify and abstract cases in the smaller rural hospitals. The UCR is now advancing toward electronic

pathology reporting and plans to receive some 90% of pathology reports electronically within the next 5 years.

Both hospital-based registrars and central registry personnel conduct active and passive follow-up of cancer patients. For example, registry records are routinely linked with administrative databases, including those maintained by the Centers for Medicare/Medicaid Services and the Utah Department of Public Safety's Driver License Division, and local voter registration files. UCR routinely queries vital records from the Utah Department of Health for information about cancer patients who may have died. In rare instances, death certificates may provide information about cancer cases that were not identified through other sources.

Cancer data are abstracted and coded by both hospital-based registrars and central registry personnel. Hospital-based registrars submit abstracts and pathology reports to UCR, allowing central registry staff to monitor the quality of data and process difficult-to-code items such as extent of disease and site-specific treatment. All electronic records are subjected to various automated edits developed by SEER and other professional organizations. UCR also participates in SEER-sponsored quality control projects.

Interpreting the results

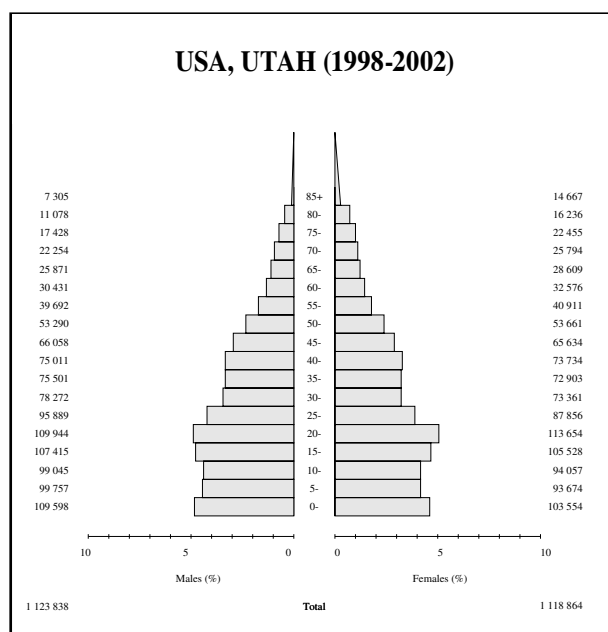
With respect to the 1998–2002 data, the UCR has had consistent coverage, geographically and

demographically. UCR, along with other registries in the SEER Program, changed topography and morphology coding rules from ICD-O-1 to ICD-O-2 for cases diagnosed from 1998–2000 and 2001–2002, respectively. However, these changes in coding rules will not have an effect on the 1998–2002 statistics, as 1998–2000 cases were retrospectively coded using ICD-O-2.

According to data from the Utah Behavioral Risk Factor Surveillance System (BRFSS), as many as 64% (95%CI 61–68%) of men aged 40+ surveyed in 2002 reported a PSA test within the last five years. Therefore, PSA is relatively common in the Utah population.

Use of the data

UCR data are combined with those from other SEER Program participants to monitor cancer trends in the USA. UCR data are also well utilised by independent investigators and the Utah Department of Health for studies of cancer etiology, prevention and control. By combining UCR records with genealogy files and other sources, researchers have made notable contributions in the field of cancer genetics. The registry maintains a web page (<http://ucr.utah.edu>), publishes trends in incidence and mortality annually, and responds to *ad hoc* requests for cancer-related data.



Source of population

Surveillance, Epidemiology, and End Results (SEER) Program (www.seer.cancer.gov) SEER*Stat Database: Populations – Total U.S. (1969–2003) – Linked To County Attributes – Total U.S., 1969–2003 Counties, National Cancer Institute, DCCPS, Surveillance Research Program, Cancer Statistics Branch, released January 2006.

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 except for skin of anus.

USA, Vermont

Registration area

The Vermont Cancer Registry (VCR) covers the population of the State of Vermont. The population at the most recent census (2000) was 608 827. About 38% of the population lives in urban areas (areas designated by the U.S. Census Bureau as Urbanized Areas and/or Urban Clusters); 97% are white, the remainder other races.

Cancer care facilities

General health care in the region is provided predominantly by 15 hospitals, including a Veterans Affairs Medical Center. This is supplemented by private practitioners and one outpatient radiation therapy facility. The Vermont Cancer Center (VCC) is an NCI-designated facility for Phase I, II and III therapeutic clinical trials. VCC and Fletcher Allen Health Care (FAHC) are located in Burlington, the largest city in Vermont, and provide radiotherapy, cancer surgery and chemotherapy services. Patients suspected to have cancer in the primary and secondary care facilities in the registry area are mostly referred to VCC, FAHC, Dartmouth Hitchcock Medical Center in neighbouring New Hampshire, one of the hospitals with comprehensive cancer services in the state, or occasionally to one of the hospitals in Boston, MA or Albany, NY.

Registry structure and methods

The registry is located within the Vermont Department of Health and is funded by the US Centers for Disease Control and Prevention's National Program of Cancer Registries (NPCR) and in-kind support from reporting hospitals. The registry is staffed by a full-time director, a cancer data specialist, a certified cancer registrar and an epidemiologist.

The VCR uses active case finding from 13 non-federal hospital cancer registries, one out-of-state reference pathology laboratory, one radiation therapy centre, 5 dermatologists, 8 urologists, 1 VA hospital, and a small number of other physicians. The cancer registry is linked with the VT death file annually. Non-matches are followed back to identify cases potentially unreported to VCR. These cases identified by death certificates are followed back with hospitals and physicians to either rule out reportability or be reported to VCR. Records that cannot be followed back to source records are accessioned as death-certificate-only cases. Cancer is required to be reported by Vermont health care facilities and healthcare providers. Interstate data exchange agreements exist with all bordering states and Florida.

Electronic editing, visual editing, and hospital auditing are all used as quality assurance strategies.

Interpreting the results

VCR data are estimated to be at least 95% complete, 24 months after the close of the diagnosis year.

Ladies First is a health screening program for Vermont women. Ladies First removes financial barriers, which prevents many women from being screened for breast and cervical cancer.

Use of the data

VCR prepares an annual report of cancer incidence, highlighting trends and changes. Site-specific reports are also published. Because active follow-up is not conducted, survival analyses have not been possible.

The registry is currently involved in the NCI-sponsored New England Study of Environment and Health, which is investigating the possible causes of elevated bladder cancer incidence and mortality in the states of Maine, New Hampshire and Vermont.

VCR data are used for planning and evaluation of cancer control objectives e.g. comprehensive cancer control, detailed incidence/mortality statistics, health event investigations and program evaluation.

For Needs Assessment/Program Planning: VCR completed a project using GIS to identify opportunities for breast cancer screening of income-eligible women. The purpose of the project was

to identify areas where the Ladies First breast and cervical program services are less utilised and enrolment could be increased, particularly for women ages 40–64 who meet eligibility requirements, by examining the current enrolment of Ladies First clients, the distribution of providers and facilities providing services, screening patterns and stage distribution of breast cancers to determine if there were any parallels with areas of lower membership.

The VCR has started routinely evaluating late stage diagnosis of certain cancers (colon, breast, cervical) as a measure of the effectiveness of cancer screening efforts.

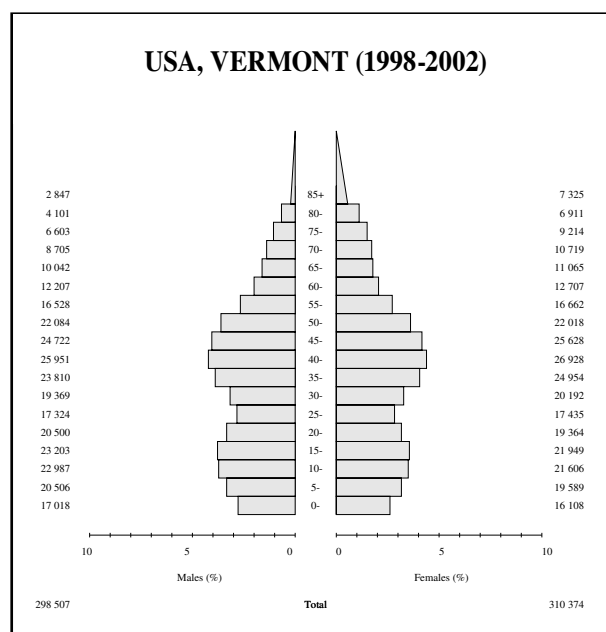
Source of population

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.



USA, Washington State

Registration area

The Washington State Cancer Registry is responsible for cancer case surveillance throughout the State of Washington (USA). The mid-2000 population for Washington State is reported at 5 894 121 of which approximately 49.8% are males, 50.2% females.

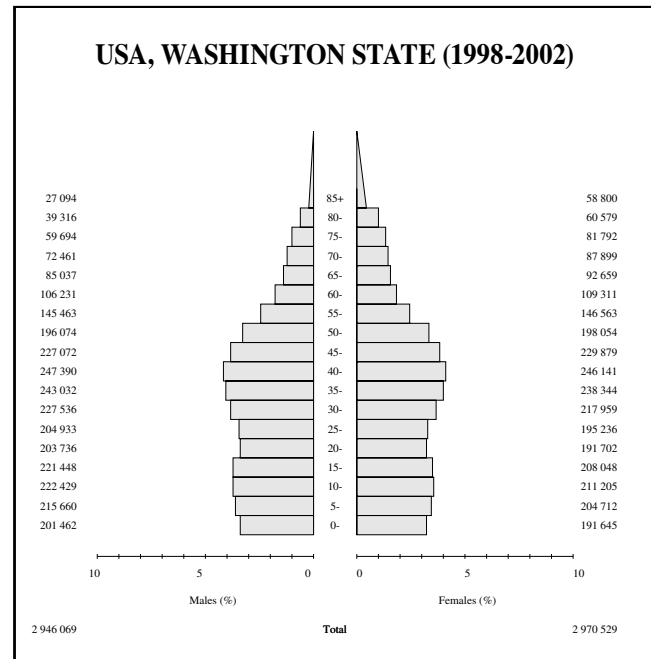
Registry structure and methods

Case information is provided to the State Cancer Registry by healthcare facilities (hospitals, laboratories, physician offices) throughout the state.

The registry is located within the Washington State Department of Health and is funded by the US Centers for Disease Control and Prevention's National Program of Cancer Registries (NPCR) and partly by state funds. The registry is staffed by experienced certified tumour registrars (CTRs) and an epidemiologist.

Use of the data

The registry prepares an annual report of cancer incidence, highlighting trends and changes.



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.

USA, Washington, Seattle

Registration area

The Cancer Surveillance System (CSS) operates under the Surveillance, Epidemiology, and End Results (SEER) program to provide incidence, treatment, and follow-up data on all newly-diagnosed malignancies (except non-melanotic skin cancers and *in situ* cancers of the cervix) occurring in residents of 13 counties of northwest Washington State.

While the geographic area has not changed, the population has grown substantially in size. The CSS reporting area has a population of over 4.2 million (based on 2000 census), which is approximately 70% of the state population. Counties in the reporting area include Clallum, Grays Harbor, Island, Jefferson, King, Kitsap, Mason, Pierce, San Juan, Skagit, Snohomish, Thurston and Whatcom. The CSS reporting area includes four Primary Metropolitan Statistical Areas (PMSAs). Approximately 86% of the people in the CSS reporting area reside in these PMSAs: Seattle-Bellevue-Everett (57.7%), Tacoma (17.5%), Bremerton (5.6%) and Olympia (5.1%). The racial distribution of the population base is as follows (2000 data): 80.4% White, 5.3% Hispanic, 4.2% Black, 7.2% Asian, 1.4% Native American, and 1.5% Other.

Cancer care facilities

Cancer patients have extensive access to diagnostic and treatment facilities throughout the CSS catchment area. The increasing provision of services in outpatient settings has necessitated expansion of activities to make sure that cancers and details about them are not missed.

Registry structure and methods

The registry is located within Fred Hutchinson Cancer Research Center (FHCRC), and is funded primarily by the SEER Program, and partly by the FHCRC and the Washington State Department of Health. The registry is staffed by 28 full-time technical staff members and 9 hourly technical/data processing staff, and 3.5 programming staff, 2 part-time epidemiologists, 1 part-time staff scientist, and 1 part-time administrator.

The CSS registry uses active case finding from over 100 sources of data consisting of cancer hospitals, general hospitals, teaching hospitals, pathology laboratories and the Washington State Bureau of Vital Statistics. All the case finding is performed at the central registry office. Abstraction of medical records is performed by a mix of hospital staff and registry staff. The latter perform abstracting either at the healthcare facilities or via remote access at the central office. All the coding and case consolidation is performed

in the central office by registry staff. Both active and passive follow-up methods are used. Passive follow-up is performed via data linkage with both medical and non-medical source records. Active follow-up consists of annual letters sent to the physicians. Death clearance and unduplication activities are performed annually. The data are submitted annually to the SEER Program and North American Association of Central Cancer Registries (NAACCR), and monthly to the State registry.

As a member of SEER, we annually evaluate the completeness and accuracy of the information recorded.

Interpreting the results

This registry has no circumstances that are particularly different from any other region with a highly-medicalised society.

Use of the data

CSS provides reports to reporting hospitals on a monthly basis. Identifiable information is reported only to the reporting physician or institution, to FHCRC investigators conducting IRB-approved research, and to the state Department of Health as required by law. Statistical reports for publication contain no data identifying patients, physicians or institutions. Non-identifiable data are released to scientists working at the local, regional, national and international level. Aggregate

reports of non-identifiable data, such as incidence rates by county or 5-year survival rates, are provided to the public upon request. The CSS responds to many requests from the local medical and scientific community, registrars, health care administrators, news media, public, Cancer Information Service, and students receiving graduate training in public health sciences.

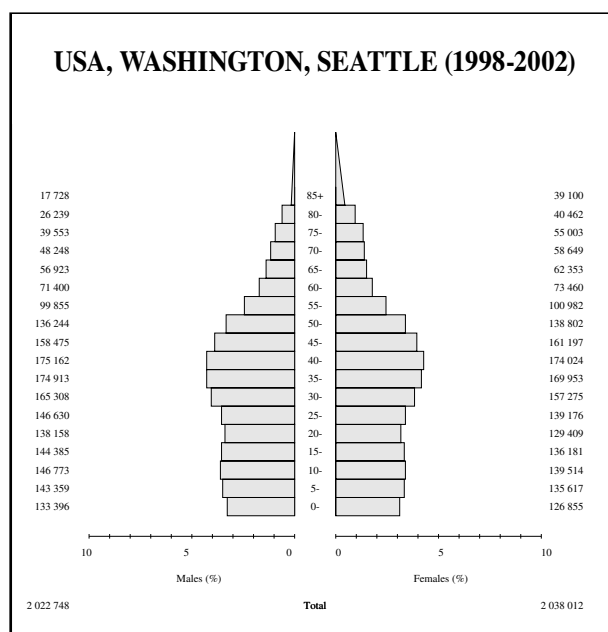
CSS also contributes to collaborative studies involving multiple SEER areas. Data released to SEER are stripped of information which would identify the patient, physician, or reporting institution and is identified only by a unique number assigned by the CSS.

Source of population

July 1 county population estimates by age, sex, race, and Hispanic origin; postcensal estimates based on 2000 United States Census.

Multiple primary rules used

IACR rules (2004) on CI5 IX period.



USA, West Virginia

Registration area

The West Virginia Cancer Registry (WVCR) covers the state of West Virginia, which is the only state that is classified as entirely Appalachian. West Virginia is racially and ethnically homogeneous, with 95% of its population identifying as white and 0.7% identifying as Hispanic. West Virginians have an overall lower educational attainment than the US as a whole, with 75.2% of persons 25 and older having a high school education or higher (80.4% for the US), lower per capita income (\$16 477 compared to \$21 587) and a higher median age (38.9 years compared to 35.3 years). West Virginia is one of the least urban states in the United States, with 46.1% of the state's population living in urban areas.

Cancer care facilities

As of January 2006, 51 of West Virginia's 55 counties were classified by the US Department of Health and Human Services as medically underserved or had medically underserved populations. West Virginia has 57 hospitals, 11 of which have cancer programs approved by the Commission on Cancer. In addition, there are 18 free-standing cancer diagnostic and treatment centres and 7 day surgery centres.

Registry structure and methods

The West Virginia Cancer Registry is part of the West Virginia Department of Health and Human Resources, Bureau for Public Health, Office of Epidemiology and Health Promotion, Division of Surveillance and Disease Control and is funded by the State of West Virginia and the US Centers for Disease Control and Prevention's National Program of Cancer Registries (NPCR). WVCR has 10 full-time staff including 4 cancer surveillance staff, 3 data quality staff, a programmer analyst, an epidemiologist/program director and an administrative professional. WVCR receives electronic reports from hospitals with cancer registries and provides abstracting services to other hospitals as well as free-standing diagnostic and treatment facilities, day surgery centres and large urology and dermatology practices. WVCR also receives pathology reports and conducts annual linkages with death certificates. Cancer is reportable by law in West Virginia.

WVCR performs computerised edits on all data and visual editing on a minimum of 10% of cases from each reporter. Additional data quality studies are performed as indicated by the results of the computerised and visual edits. Hospitals undergo case-finding and re-abstracting audits every five years but may be audited more frequently if systematic problems are found. To maintain quality control, formal studies/evaluations are carried out. West Virginia Cancer Registry data are submitted to NAACCR for evaluation of completeness and quality, and also undergo regular audit by NPCR.

Interpreting the results

West Virginia is known to have relatively high levels of cancer risk factors including tobacco use and obesity in comparison to the US, screening rates for breast and cervical cancer similar to those of the US and colonoscopy and sigmoidoscopy rates lower than those of the US. BRFSS data indicate that PSA testing levels in West Virginia are similar to those in the US as a whole.

Use of the data

The West Virginia Cancer Registry publishes an annual report on cancer incidence and mortality in West Virginia, conducts investigations of possible cancer clusters, performs analyses as needed for special projects, promotes the use of WVCR data in planning and evaluation of cancer control activities and

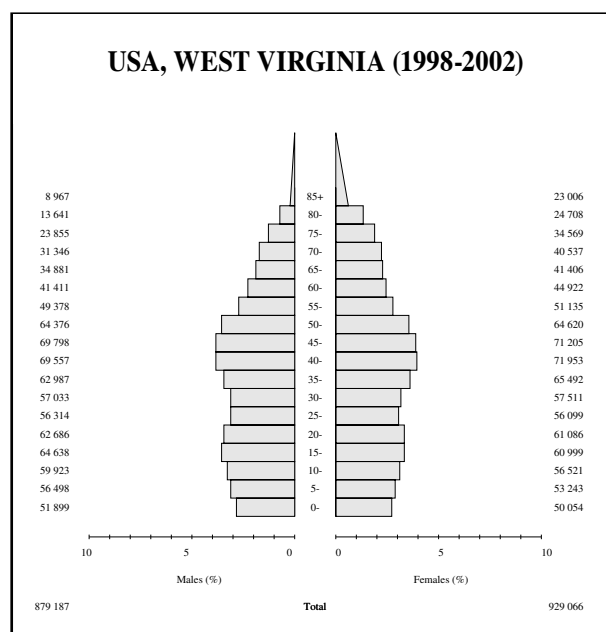
makes de-identified data available to approved researchers.

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.



USA, Wisconsin

Registration area

The Wisconsin Cancer Reporting System (WCRS) covers the statewide population of Wisconsin, USA. The population at the most recent census (2000) was 5 363 675. About 89% of the population is white, 6% African American, 1% American Indian or Native Alaskan, 2% Asian/Pacific Islander and 1% multiple race. Almost 4% are of Hispanic origin.

Cancer care facilities

Wisconsin has approximately 150 hospitals and over 1700 clinics (including radiation therapy centres, health maintenance organisation outpatient clinics and private physician offices) serving its population. Residents living near state borders may cross into other states for their cancer diagnoses and care depending on proximity to the out-of-state facilities and restrictions based on insurance coverage.

Registry structure and methods

WCRS is located within the Bureau of Health Information and Policy, Wisconsin Department of Health and Family Services. It is funded partly by general purpose revenue funds (25%) and by the US Centers for Disease Control and Prevention through the National Program of Cancer Registries (NPCR) (75%). The registry has six full-time staff: a program director, epidemiologist, CTR data editor and state trainer, quality control data and GIS analyst, data processor, office operations assistant and a part time data entry staff person. WCRS collects data (passive data collection) from Wisconsin hospitals, clinics, physician offices and out-of-state hospitals along state borders. These facilities are required to submit data electronically using the NAACCR standard layout or on paper using the WCRS reporting form. Wisconsin also has data exchange agreements with 19 other state central cancer registries, and receives data on Wisconsin residents from those registries annually. WCRS conducts an annual link with the Wisconsin Resident Death File to update death information on cases previously

reported and identify cases not previously reported by the above mentioned sources. Follow up is conducted on the death certificate only cases annually. Cancer is a reportable disease in Wisconsin per Chapter 255.04, Wisconsin statutes. Data submitted to WCRS is processed through a combination of NPCR-required and recommended edits and Wisconsin-specific edits. All cases are edited electronically, and the incoming paper reports are also reviewed manually. WCRS participates annually in the NAACCR Certification Process and has received the Silver or Gold standard for its data every year since 1995.

Interpreting the results

Wisconsin incidence rates overall remain stable but can be influenced by periodic reporting anomalies (e.g. a facility loses cancer reporter and cannot submit for extended period) or inconsistent reporting on residents seen outside of Wisconsin for diagnosis and/or care.

Use of the data

WCRS data are published in an annual report (incidence and mortality rates by site, diagnosis year, race and county, stage at diagnosis). Special site-specific reports are periodically produced. Data are used by researchers for case control studies, linkage studies, and extensively by comprehensive cancer control organisations for planning and prevention strategies.

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.

