

Surveillance and Health Status Assessment

Cancer Surveillance

Childhood Cancer



February 2011

2008 Report on Cancer Statistics in Alberta

March 12, 2012

ERRATUM: Childhood Cancers, 2008 Report on Cancer Statistics in Alberta

There was an error on the graphs in the **Incidence and Mortality** section (pages 8-11) where the age-standardized rates on the y-axis of each graph are labeled as "Rate per 100,000".

These should be labeled as "Rate per 1,000,000".

This report has been updated with the correct information.

Acknowledgements

This report was made possible through Alberta Health Services, Surveillance and Health Status Assessment, Cancer Surveillance and the many contributions of staff and management across Alberta Health Services as well as external agencies and individuals.

The authors wish to thank individuals working in the following AHS departments and partner agencies for their contributions to this report: Decision Support Strategies, Alberta Cancer Registry, Alberta Health and Wellness and Statistics Canada. Contributions included provision of information, analysis and interpretation, and assistance with consultation sessions and communication of the report.

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Suggested Citation:

Cancer Surveillance: 2008 Report on Cancer Statistics in Alberta. Edmonton: Surveillance and Health Status Assessment, Alberta Health Services, 2010.

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Purpose of the Report

Cancer Surveillance, a specialized team within Surveillance and Health Status Assessment, Alberta Health Services actively contributes to Becoming the Best: Alberta's 5-year Health Action Plan and the goal to create the best-performing publicly funded health system in Canada. This is accomplished by conducting cancer *surveillance* through the collection, integration, analysis and dissemination of cancer related data and information.

The report is designed to provide comprehensive and detailed information regarding cancer in Alberta. It will help support health professionals, researchers and policy makers in the planning, monitoring and evaluation of cancer-related health programs and initiatives. It will also be a useful education tool for the general public and media.

Navigating the Report

This document provides information on childhood cancer statistics in Alberta. Details about individual cancer types are available within separate documents. The words highlighted in *dark blue* are terms described in detail within the <u>Glossary</u>.

Data Notes

In this document, the term "cancer" refers to *invasive cancers* unless otherwise specified. It is important to note that this document contains both actual and estimated data; distinctions are made where applicable. The numbers published in this report should be considered provisional, as a few cases and deaths may be registered in subsequent years. The data in this report reflect the state of the Alberta Cancer Registry as of August 6, 2010.

Incidence *rates* presented in this document exclude non-melanoma skin cancer cases (basal and squamous). Although approximately 30% of the *malignant* cancers diagnosed among Albertans each year are non-melanoma skin cancer, these *tumours* are generally not life-threatening and are inconsistently reported and coded inconsistently across registries; therefore non-melanoma skin cancer is rarely included in cancer registry reports.

For detailed descriptions about data sources and how they affect data presented in this report, please see the **<u>Data Sources and Quality</u>** section.

Summary

- In the period 2008, **116** children aged 0 to 14 years old were diagnosed with cancer in Alberta. The most common cancers were leukemias (32%) followed by central nervous system tumors (19%), lymphomas (13%) and neuroblastomas (9%).
- In 2008, 15 children aged 0 to 14 years old died from childhood cancer in Alberta. The most common cancer causes of death in children were central nervous system tumors (37%) followed by leukemias (30%), neuroblastomas (9%) and renal tumors (6%).
- As of December 31, 2008, approximately 670 children aged 0 to 14 years were alive who had previously been diagnosed with cancer in Alberta and 1,945 Albertans aged 0 to 99 were survivors of childhood cancer.
- Since 1988, childhood cancer **incidence rates have increased** for children aged 0 to 14 years old.
- Since 1988, childhood cancer **mortality rates have been stable** for children aged 0 to 14 years old.
- Five-year observed survival proportion for all childhood cancers in Alberta is **80%** for those diagnosed between 2006 and 2008.

Childhood Cancer in Alberta

Childhood cancers are relatively rare in Alberta. In this report, childhood cancers are defined as invasive cancers that affect children up to and including the age of 14. Childhood cancers account for 0.8% of all new cancer cases (excluding non melanoma skin cancer) diagnosed in Alberta in 2008. Although childhood cancers are rare, they have a profound impact on families and communities. In addition, childhood cancers as they age.¹

Childhood cancers are classified differently than adult cancers. As with adults, the classification of childhood cancer is based on both tumor morphology and cancer site. However, greater emphasis is placed on morphology rather than site, as compared to adults where greater emphasis is placed on site. In this report, childhood cancers are classified according to the International Classification of Childhood Cancer, third edition².

The *Table 13-1* provides an overview of childhood cancers in Alberta. Explanations and further details on New Cases, Age-Standardized Incidence Rates, Deaths, Age-Standardized Mortality Rates and 5-Year Observed Survival rate can be found in relevant sections of this report.

Five-year observed survival proportion for all childhood cancers in Alberta is 80% for those diagnosed between 2006 and 2008.

* Year range represents the period over which the most recent significant trend was observed.

Table 13-1: New Cases and Deaths and Three-Year Moving Average Age-Standardized Incidence Rates (ASIRs)^{*†} and Mortality Rates (ASMRs)^{†‡}, Ages 0-14, Alberta, 2004-2008

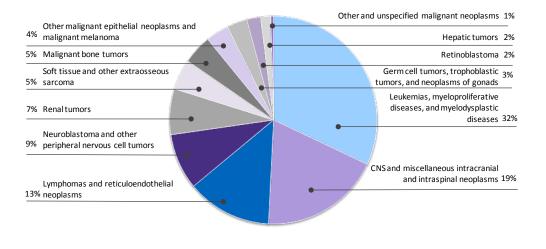
2008				
Diagnostic Group	New Cases (five-year)	ASIRs	Deaths (five-year)	ASMRs
	501	167.8	86	30.2
I. Leukemia	162	58.8	26	9.7
a. Lymphoid	130	45.1	16	5.6
b. Acute Myeloid	19	8.6	5	2.0
II. Central Nervous System	95	30.1	31	10.2
a. Ependymoma	13	3.6	5	0.5
b. Astrocytoma	48	14.3	13	5.1
c. Intracranial & Intraspinal Embryonal	20	6.7	9	3.1
III. Lymphoma	67	20.1	3	1.5
a. Hodgkin Lymphoma	27	7.4	0	0.0
b. Burkitt Lymphoma	12	3.1	2	1.0
c. Non-Hodgkin Lymphoma	25	8.1	1	0.5
IV. Neuroblastoma & Other PNC	44	13.6	8	2.6
a. Neuroblastoma & Ganglioneuroblastoma	42	12.7	8	2.6
V. Soft Tissue	24	6.1	4	1.6
a. Rhabdomyosarcoma	11	2.1	3	1.1
VI. Renal Tumours	36	15.4	5	1.0
a. Nephroblastoma	35	14.9	4	0.5
VII. Malignant Bone	23	7.5	3	1.1
VIII. Other Malignant Epithelial	13	4.5	2	1.0
IX. Germ Cell Tumours and Other Gonadal	16	4.5	1	0.5

[†]Standardized to 1991 Canadian Population

^{*} ASIR and ASMRs are rates per 1,000,000

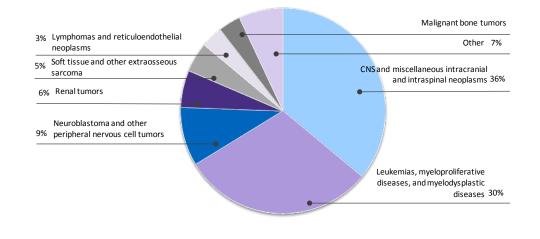
Data Source: Alberta Cancer Registry, Alberta Health and Wellness

Figure 13-1: New Cancer Cases, Ages 0-14, Alberta, 2004-2008



Data Source: Alberta Cancer Registry

Figure 13-2: Childhood Cancer Deaths, Ages 0-14, Alberta, 2004-2008



Data Source: Alberta Cancer Registry

Prevalence

The *prevalence* of a disease is defined as the number of people currently living with that disease. In this section of the report, the cancer prevalence is presented in two ways: the number of children (0-14 years old) alive as of December 31, 2008 who had ever been diagnosed with cancer, and the number of people aged 0-99 years who had ever been diagnosed with cancer in childhood (age 0-14 years).

Prevalence is a useful indicator of the impact of cancer on individuals, the healthcare system and the community as a whole. Although many cancer survivors lead healthy and productive lives, the experience can have a strong impact on the physical and emotional well-being of individuals and their families. The cancer experience can also result in the continued use of the healthcare system through rehabilitation or support services, as well as loss of work productivity that can affect the whole community.

The total number of children living in Alberta is approximately 670,000⁴, or about one fifth of the Alberta population. As of December 31, 2008, approximately **663** children (0-14 years old) were alive who had previously been diagnosed with cancer. Also **1,945** Albertans aged 0 to 99 had survived a childhood cancer.

Incidence and Mortality Counts

Incidence counts are the number of new cancer cases diagnosed during a specific time period in a specific population. In this section of the report, incidence counts refer to the number of new childhood cancers (children aged 0-14) diagnosed in Alberta between 2004 and 2008.

Mortality counts describe the number of deaths attributed to childhood cancer during a specified period of time in a specific population. In this section of the report, mortality counts refer to the number of deaths due to childhood cancer (children aged 0-14) in Alberta between 2004 and 2008, regardless of date of diagnosis.

The *Figures 13-1* and *13-2* illustrate the proportion of new cancer cases and cancer deaths by cancer type.

Between 2004 and 2008, in total 501 childhood cancer cases were diagnosed in Alberta. The most commonly diagnosed childhood cancers were leukemia (32%), central nervous system cancers (19%), and lymphoma (13%); these cancers accounted for 64% of all childhood cancers (*Figure 13-1*). Of the 162 childhood leukemia diagnoses, 130 cases (80%) were lymphoid leukemia and 19 cases (12%) were acute myeloid leukemia. Of the 67 children diagnosed with lymphoma, 27 cases (40%) were Hodgkin lymphoma, 12 cases (18%) were Burkitt lymphoma, and 25 cases (37%) were non-Hodgkin lymphoma.

Of the 86 childhood cancer deaths between 2004 and 2008, 36% were attributable to central nervous system cancers, 30% to leukemia and 9% to neuroblastoma (*Figure 13-2*). These three cancers account for 75% of all childhood cancer deaths.

Incidence and Mortality Rates

Incidence rates are the number of new cancer cases diagnosed per 1,000,000 population in a specific time period. *Mortality rates* are the number of deaths per 1,000,000 population in a specific time period.

In order to compare cancer incidence or cancer mortality over time or between populations, *age-standardized incidence rates (ASIRs)* or *agestandardized mortality rates (ASMRs)* are presented. These are weighted averages of *age-specific rates* using a standard population. These rates are useful because they are adjusted for differences in age distributions in a population over time, which permit comparisons of cancer incidence or mortality among populations that differ in size, structure and/or time period. ASIRs and ASMRs give the overall incidence and mortality rates that would have occurred if the population of Alberta had been the same as the standard population. In this report the Canadian 1991 population is used as the standard population.

Three-year moving averages are used to smooth out year-to-year fluctuations so that the underlying trend may be more easily observed. They are calculated based on aggregating three years of data. Agestandardized incidence rates (ASIRs) and age-standardized mortality rates (ASMRs) are presented as three-year moving averages. This smoothing of trends is especially important when the number of cancer cases per year is relatively small, where year-to-year variability can be quite large.

Incidence and mortality can be affected by the implementation of public health prevention or screening strategies that either prevent disease or find cancer in its early *stages* when treatment is generally more successful, the development of cancer treatment programs that may impact chances of survival, and research innovations.

The *Figures 13-3* to *13-8* show incidence and mortality trends in Alberta. Separate analyses for both incidence and mortality are shown in subsequent sections. The statistical significance of the trends was determined by using Joinpoint⁵ and is described in the text accompanying each graph. Joinpoint models are based on yearly agestandardized rates; hence there may be slight differences in the rates presented in the text (from Joinpoint model) and the graphs (where ASIRs and ASMRs are shown as three-year moving averages). In 2007, the three-year moving average ASIR for childhood cancer was 167.8 per 1,000,000 childhood population.

Childhood cancer ASIRs have increased significantly since 1988 (*Figure 13-3*). From 1988 to 2008, childhood cancers ASIRs have increased by an average annual increase of 1.3% in Alberta.

In 2007, the three-year moving average ASMR for childhood cancer was 30.2 per 1,000,000 childhood population.

Childhood cancer ASMRs have not significantly changed since 1988 (*Figure 13-3*).

In 2007, the three-year moving average ASIR for childhood cancer in boys was 181.8 per 1,000,000 population of boys.

Childhood cancer ASIRs for boys have increased significantly since 1988 (*Figure 13-4*). From 1988 to 2008, childhood cancer ASIRs in boys have increased by an average annual increase of 1.2% in Alberta.

In 2007, the three-year moving average ASMR for childhood cancer in boys was 37.0 per 1,000,000 population of boys.

Childhood cancer ASMRs in boys have not significantly changed since 1988(*Figure 13-4*).

In 2007, the three-year moving average ASIR for childhood cancer in girls was 153.1 per 1,000,000 population of girls.

Childhood cancer ASIRs for girls have increased significantly since 1988 (*Figure 13-5*). From 1988 to 2008, ASIRs for childhood cancer in girls have increased by an average annual increase of 1.6% in Alberta.

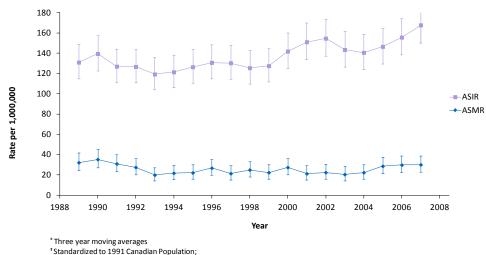
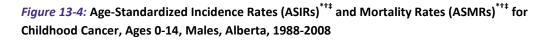
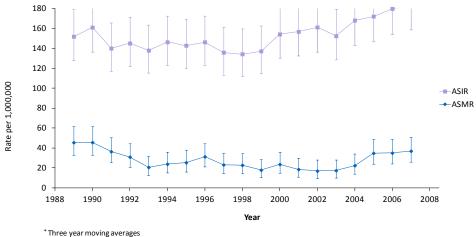


Figure 13-3: Age-Standardized Incidence Rates (ASIRs)^{***} and Mortality Rates (ASMRs)^{***} for

Childhood Cancers, Ages 0-14, Both Sexes, Alberta, 1988-2008

Data Source: Alberta Cancer Registry, Alberta Health and Wellness

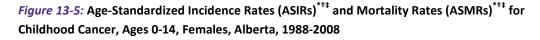


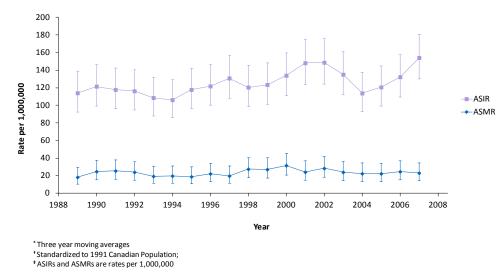


* Standardized to 1991 Canadian Population; * ASIRs and ASMRs are rates per 1,000,000

Data Source: Alberta Cancer Registry, Alberta Health and Wellness

^{*} ASIRs and ASMRs are rates per 1,000,000.





Data Source: Alberta Cancer Registry, Alberta Health and Wellness

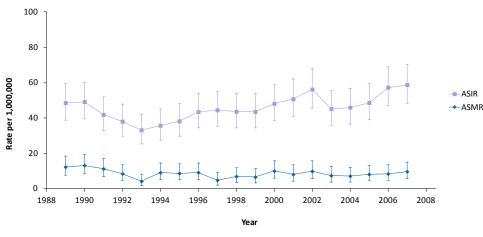


Figure 13-6: Age-Standardized Incidence Rates (ASIRs)^{***} and Mortality Rates (ASMRs)^{***} for Childhood Leukemia, Ages 0-14, Both Sexes, Alberta, 1988-2008

* Three year moving averages * Standardized to 1991 Canadian Population; * ASIRs and ASMRs are rates per 1,000,000

Data Source: Alberta Cancer Registry, Alberta Health and Wellness

Surveillance and Health Status Assessment Cancer Surveillance In 2007, the three-year moving average ASMR for childhood cancer in girls was 23.0 per 1,000,000 population of girls.

Childhood cancer ASMRs for girls have not significantly changed since 1988(*Figure 13-5*).

In 2007, the three-year moving average ASIR for childhood leukemia was 58.8 per 1,000,000 childhood population.

Childhood leukemia ASIRs have not significantly changed since 1988 (*Figure 13-6*).

In 2007, the three-year moving average ASMR for childhood leukemia was 23.0 per 1,000,000 childhood population.

Childhood leukemia ASMRs have not significantly changed since 1988 (*Figure 13-6*).

In 2007, the three-year moving average ASIR for childhood cancers of the central nervous system (CNS) was 30.1 per 1,000,000 childhood population.

Childhood CNS cancers ASIRs have not significantly changed since 1988 (*Figure 13-7*).

In 2007, the three-year moving average ASMR for childhood cancers of the CNS was 10.2 per 1,000,000 childhood population.

Childhood CNS cancers ASMRs have not significantly changed since 1988 (*Figure 13-7*).

In 2007, the three-year moving average ASIR for childhood lymphoma was 20.1 per 1,000,000 childhood population (*Figure 13-8*).

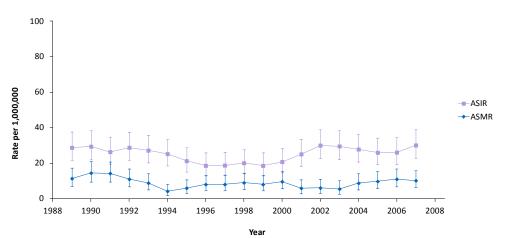
Childhood lymphoma ASIRs have not significantly changed since 1988 (*Figure 13-7*).

In 2007, the three-year moving average ASMR for childhood lymphoma was 1.5 per 1,000,000 childhood population (*Figure 13-8*).

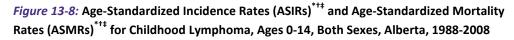
Childhood lymphoma ASMRs have decreased significantly since 1988 by an average annual decrease of 4.9%.

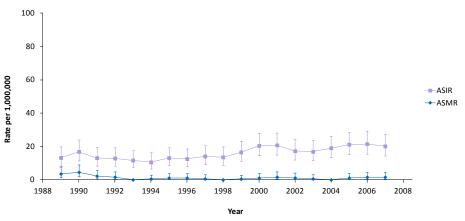
Childhood Cancer Survival

The *observed survival* proportion (OSP) describes the proportion of children diagnosed with a specific cancer who survived through the specific time period. Observed Survival Proportions are estimated by the *cohort method* when complete follow-up data (e.g., at least five years of follow-up to estimate five-year rate) after diagnosis are available. For recently diagnosed cases, whose complete follow-up data are not available, the up-to-date estimates are computed using the *period method*. Only survival following first primary tumors is estimated. Children whose cancer was only identified through death certificate were excluded from the calculation. Survival depends on several factors including the cancer type (most importantly site, stage and morphology at diagnosis), sex, age at diagnosis, health status and available treatments for that cancer. *Figure 13-7:* Age-Standardized Incidence Rates (ASIRs)^{*++} and Mortality Rates (ASMRs)^{*++} for Childhood Cancers of the Central Nervous System, Ages 0-14, Both Sexes, Alberta, 1988-2008



* Three year moving averages * Standardized to 1991 Canadian Population; * ASIRs and ASMRs are rates per 1,000,000. Data Source: Alberta Cancer Registry, Alberta Health and Wellness

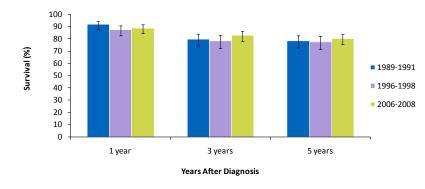




*Three year moving averages
*Standardized to 1991 Canadian Population;
*ASIRs and ASMRs are rates per 1,000,000 not 100,000.

Data Source: Alberta Cancer Registry, Alberta Health and Wellness

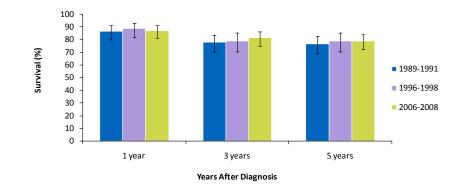
Figure 13-9: Observed Survival Trends for Childhood Cancer, Both Sexes, Ages 0-14, Alberta, 1989-1991^{*}, 1996-1998^{*}, 2006-2008[†]



* Proportions calculated by cohort method, where complete follow-up data are available * Propositions calculated by period method, where complete follow-up data are not available

Data Source: Alberta Cancer Registry, Statistics Canada

Figure 13-10: Observed Survival Trends for Childhood Cancer, Males, Ages 0-14, Alberta, 1989-1991^{*}, 1996-1998^{*}, 2006-2008[†]



* Proportions calculated by cohort method, where complete follow-up data are available * Propositions calculated by period method, where complete follow-up data are not available

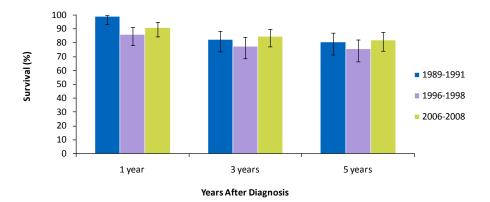
Data Source: Alberta Cancer Registry, Statistics Canada

Five-year observed survival proportions for Alberta children diagnosed with cancer have not changed since 1989-1991. In 2006-2008, five year observed survival was 80% (*Figure 13-9*).

Five-year observed survival proportions for boys diagnosed with childhood cancer have not changed since 1989-1991. In 2006-2008, five year observed survival for boys diagnosed with childhood cancer was 79% (*Figure 13-10*).

Five-year observed survival proportions for girls diagnosed with childhood cancer have not changed since 1989. In 2006-2008, five-year observed survival for girls diagnosed with childhood cancer was 82% (*Figure 13-11*).

Figure 13-11: Observed Survival Trends for Childhood Cancer, Females, Ages 0-14, Alberta, 1989-1991^{*}, 1996-1998^{*}, 2006-2008[†]



* Proportions calculated by cohort method, where complete follow-up data are available * Propositions calculated by period method, where complete follow-up data are not available

Data Source: Alberta Cancer Registry, Statistics Canada

Further Information

Data Sources and Quality

Most of the data presented within this report are derived from the Alberta Cancer Registry (ACR). The ACR is responsible for recording and maintaining data on all new *primary cancers*, as well as all cancer deaths occurring within the province of Alberta, as mandated by the Regional Health Authorities (RHA) Act of Alberta.⁶

The quality of data collected by any registry is dependent on three factors: comparability, completeness and validity. Firstly, comparability is accomplished by applying standard practices regarding classification and coding of new cases and by using consistent definitions, such as the coding of multiple primaries. To achieve comparability, the ACR employs the International Classification for Oncology (ICD-O-2 for 1988-2000 data and ICD-O-3 for 2001 onwards) to classify all cancers by site and morphology.

Cancer deaths are coded using the International Statistical Classification of Diseases and Related Health Problems (ICD-9 for 1988-2000 data and ICD-10 for 2001 onwards). Childhood cancer death numbers in this report are based on coder cause of death information in the Alberta Cancer Registry; this may slightly vary from the Alberta Vitals Statistics official cause of death (when more information is available to the Alberta Cancer Registry).

Childhood cancer is classified using the International Classification of Childhood Cancers (ICCC). ICCC classification is based on tumour morphology and cancer site with more emphasis on morphology. ICCC classifications are available from Surveillance, Epidemiology and End Results program (SEER):

http://seer.cancer.gov/publications/childhood/iccc.pdf

Secondly, completeness refers to the extent to which all the newly Surveillance and Health Status Assessment Cancer Surveillance diagnosed cancers among Albertan residents are accurately captured by the ACR. The ACR is notified of new cancers by doctors and laboratories throughout the province, who are mandated to report such information. Cancer-related deaths are recorded and validated by the ACR using registry and Alberta Vital Statistics information. Over the years, the ACR has achieved a completeness of over 95%.

Lastly, validity depends on the documentation available and the level of expertise in the abstracting, coding and recording of data within a registry. The ACR has numerous checks on the data to ensure all information is input as accurately as possible. For example, date of diagnosis of cancer must be after the date of birth. There are additional data quality reviews performed on ACR data by the Canadian Cancer Registry and the North American Association of Central Cancer Registries (NAACCR).

Confidentiality and security of personal information are protected by the Regional Health Authority (RHA) Act and the Health Information Act (HIA). The Alberta Cancer Registry maintains the trust of the public, the government, the data provider, and the general public by requiring rigorous confidentiality and security practices, in accordance with the RHA Act and HIA, to access the Registry database. Formal policies on information disclosure are available on request from the Alberta Cancer Registry.

By recording information on cancer cases and cancer-related deaths over the past few decades, the Alberta Cancer Registry has been able to compare cancer statistics in Alberta with other provinces and countries. The Registry also provides information to health care stakeholders throughout the province so that they can plan effective prevention, treatment and research programs.

For many years, the Alberta Cancer Registry has been certified by NAACCR and has achieved a Gold Standard for completeness of the data, timely reporting and other measures that judge data quality.

Glossary of Terms

Age-specific rates:

The number of new cancer cases or cancer deaths per 100,000 people per year within a given age group.

Age-standardized (incidence/mortality) rates:

A weighted average of age-specific rates using a standard population distribution. They reflect the overall rates that would be expected if the population of interest had an age structure identical to the standard population used to compare cancer rates among populations or identify trends over time.

Benign:

A tumour that is not malignant (i.e. does not spread).

Carcinoma:

A tumour that begins in the skin or in tissues that line or cover body organs.

Childhood cancer:

Cancers diagnosed and cancer deaths in children aged 0-14 at time of diagnosis or time at death respectively.

Confidence intervals:

An indication of the reliability of an estimate. A wide confidence interval indicates less precision and occurs when a population size is small.

Count refers to the number of cases (primaries) or deaths in a given time period. One patient may have multiple primary sites.

Incidence count:

The frequency of new cancer cases during a period of time; often the number of new invasive cases diagnosed in a year.

Invasive cancer:

Cancer with the ability to spread beyond its point of origin.

Life table:

A life table estimates, for people at a certain age, what the probability is that they die before their next birthday. From this starting point, a number of statistics can be derived and thus also included in the table: a) the probability of surviving any particular year of age; b) remaining life expectancy for people at different ages; and c) the proportion of the original birth cohort still alive. They are usually constructed separately for males and females because of their substantially different mortality rates.

Lymphatic system:

A system of vessels that carry lymph between lymph nodes located throughout the body.

Malignant:

Refers to a tumour that invades and destroys surrounding tissues, may spread elsewhere in the body, and is likely to recur after removal; a cancerous tumour.

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Median Age:

The age at which half of the population is older and half is younger.⁸

Metastasis:

Refers to the spread of the original tumour to other parts of the body.

Mortality count:

The number of deaths due to cancer during a period of time.

Observed survival

Observed survival is an estimate of the probability of surviving all causes of death for a specified time interval calculated from the cohort of cancer cases.⁷

Prevalence:

The number of people alive at a specific point in time with cancer. Complete prevalence is the number of people alive today who have *ever* been diagnosed with cancer. In this document, we report complete prevalence.

Primary Site of Cancer:

The tissue or organ in which the cancer originates.¹⁰

Prognosis:

A prediction about the outcome or likelihood of recovering from a given disease.

Projection:

An estimate of cancer incidence or mortality in the future, based on recent historical trends.

Rate:

The number of cases or deaths occurring in a specified time period.

Relative survival:

The survival of cancer patients relative to that of the general population. It is the ratio of observed survival in a group of cancer patients relative to the expected survival of a similar group of people in the general public, matched by age and sex in Alberta.

Stage of cancer:

Refers to the degree of cancer progression and the size of tumor at the time of diagnosis. If the cancer has spread, the stage describes how far it has spread from the original site to other parts of the body.⁸

Surveillance:

Cancer surveillance includes the collection of data, and the review, analysis and dissemination of findings on incidence (new cases), prevalence, morbidity, survival and mortality. Surveillance also serves to collect information on the knowledge, attitudes and behaviours of the public with respect to practices that prevent cancer, facilitate screening, extend survival and improve quality of life.⁹

Survival - Cohort method:

The cohort method provides survival estimates of cases having complete follow-up for the number of years of survival of interest. For example, cases diagnosed in 2001, for which vital status data are available to the end of year 2008, the cohort method may be used to obtain an estimate of five-year survival. The cohort survival represents the actual survival experience of individuals.

Survival - Period analysis:

The period method provides up-to-date survival estimates of recently diagnosed cases considering the survival experience of those cases within the most recent calendar period that allows for the estimation of a given period of survival. For example, to estimate the five year survival for cases diagnosed in 2004-2008, this method considers zero to one year survival experience for cases diagnosed in 2004-2008, one to two year survival experience for cases diagnosed in 2003-2005 who survived at least one year, and so on up to four to five year survival experience for cases diagnosed at least four years.

Three-year moving average:

Three-year moving averages are used to smooth out year-to-year fluctuations in age-standardized rates so that the underlying trend may be more easily observed. They are calculated based on aggregating three years of data.

Tumour:

An abnormal mass of tissue that is not inflammatory, arises without obvious cause from cells of pre-existent tissue, and possesses no physiologic function.

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