

# 2016 BC Cancer Registry Annual Report

Special Focus: Cancer Survivors in British Columbia

## ABOUT THE BC CANCER AGENCY

The BC Cancer Agency, an agency of the Provincial Health Services Authority, provides a comprehensive cancer control program for the people of BC in partnership with regional health authorities. This includes prevention, screening and early detection programs, research and education, and care and treatment.

## THE MISSION OF THE BC CANCER AGENCY IS

#### THIS REPORT

- To reduce the incidence of cancer
- To reduce the mortality rate of people with cancer
- To improve the quality of life of people living with cancer

This report has been prepared by members of the BC Cancer Agency's Population Oncology Portfolio. Please note that report numbering has changed to represent the year of release instead of the year of data collection. For this reason, there is no 2015 report.

This publication is available from the BC Cancer Agency website at: http://www.bccancer.bc.ca/health-professionals/professional-resources/ bc-cancer-registry

## CITATION

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## DR. MALCOLM MOORE, PRESIDENT – BC CANCER AGENCY



I am pleased to share with you the 2016 BC Cancer Registry Report.

The BC Cancer Registry is a database of all new cancers diagnosed in BC residents since 1969 and a vital resource for our cancer control efforts in the province. The Registry provides us important data to understand the impact of cancer on our population. It provides data on the numbers of British Columbians who are affected by cancer each year, how our health system has improved survival rates from cancer, and allows us to look at current trends and ahead to the future so that we can plan care for the entire province of British Columbia.

In this year's report, Registry data have been used to provide detailed information on the growing population of cancer survivors in BC. This highlights the value of provincial cancer registries which can provide information on specific issues that are important within the cancer control system. Having better data to characterize this growing population will help our Agency and our partners across the province plan and evaluate programs and services to meet the diverse needs of this group.

I would also like to acknowledge the efforts of those who contributed to the creation of this publication including Ryan Woods, Marilyn Borugian and an advisory group that helped shape the content of this report and included Stuart Peacock, Mary McBride, Winson Cheung, Karen Blain, and Lisa McCune, all from the BC Cancer Agency.

#### RYAN WOODS, SCIENTIFIC DIRECTOR – BC CANCER AGENCY REGISTRY

It is a pleasure to present to you this year's BC Cancer Registry Annual Report. It has been a busy year for the BC Cancer Registry and this report describes some of the projects that have been initiated recently within or using data from the Registry.

As in past years, this year's report includes a brief special feature, with some supporting data from the BC Cancer Registry; the topic of this year's focus report is cancer survivors in British Columbia. This is an important topic for British Columbia given that today, there are more than 122,000 British Columbians living in our province who have been diagnosed with cancer in the past decade – this is about 2.7% of our province's population. The number of cancer survivors in our province has grown steadily with the growth and aging of our population; at the same time, cancer survival rates have increased for most common cancers further increasing the number of British Columbians who have survived a diagnosis of cancer. Thus, this is an important group of individuals for us to characterize and understand.

Several of the short features in this year's report highlight how Registry data are used in a number of diverse and impactful research projects. Some of these projects have provided evidence to motivate new programs for those affected by cancer; others aim to assess the economic impact of cancer at both the health system and patient level. This is exciting to see the research community continue to find creative approaches to use the cancer registry platform to generate new knowledge in very relevant and important areas of research. As noted by Dr. Moore, our survivorship special focus report benefitted substantially from input and suggestions from a small advisory committee to whom we are very grateful.

I hope you will find this year's report informative and interesting.



### INTRODUCTION

The special focus within this year's report highlights how the high quality data resources of the British Columbia Cancer Registry (BCCR) can be used to better understand the growing population of cancer survivors in our province. Additionally, we have presented some examples of how the Registry data, together with a wide range of other data resources. can be utilized to look broadly across populations and generate new knowledge that helps inform policies and cancer control actions to benefit the growing number of cancer survivors in British Columbia (BC).

As this report will describe, the number of people who are alive in BC today with a prior diagnosis of cancer is increasing in our population. Why is this? There are in fact several contributors to this increase: *Population Growth*: The population of BC is increasing. Over the past decade, the population of our province has increased by about half a million people (from 4.2 million in 2006 to an estimated 4.7 million in 2016 (BC Stats 2015). This larger population is expected to be associated with more cancers and thus more people that have survived a previous cancer diagnosis. The population of BC is forecast for continued growth to about 5.6 million people by 2030.

*Aging:* As shown in our 2013 Annual Report, the aging of our population has resulted in a significant increase in the annual number of new cancer cases being diagnosed in BC. This trend is predicted to continue over the coming years as the number of seniors in our province increases by close to half a million people by 2030.

*Improved Cancer Survival*: The survival rates for people diagnosed with cancer have improved for many common cancers. These improvements in cancer survival are related to improvements in cancer treatments, and the benefits of early detection primarily brought about by cancer screening programs. This trend to improved survival means British Columbians diagnosed today with cancer are likely to live longer lives after their diagnosis than in the past. The CONCORD-2 study (Allemani, Weir et al. 2015) described in the BC Cancer Registry 2014 Annual Report showed a trend towards increasing survival for many common cancers examined within that study. Figure 1 shows CONCORD-2 survival results for a selection of adult cancers as well as for childhood leukemia. The 5-year relative survival rate for prostate cancer in BC men was estimated to be almost 94% for the most recent period studied; for women diagnosed with breast cancer the 5-year rate had reached 88% in the most recent period. Childhood acute lymphoblastic leukemia (ALL) survival has improved by more than 10% over the study period to 93%. Although lung cancer survival remains poor (17%), this also represents an improvement from the rate observed in the first study period (14%).

In summary, the increasing number of individuals expected to survive a diagnosis of cancer over the coming years in our province suggests this is an important and timely topic for research, both provincially and nationally. Within this year's report, we have highlighted some key research in this area which we believe will contribute to the knowledge base for new provincial cancer control strategies.



Figure 1. British Columbia 5-year relative survival rates for selected cancers

## CHARACTERIZING THE SURVIVOR POPULATION

How do we count and characterize cancer survivors? Estimates of how many people are alive today in British Columbia who have previously been diagnosed with cancer, are generally derived from cancer prevalence statistics. The prevalence of a disease is the number of people who are alive and have been diagnosed with a disease at a fixed date. called the *index date*, which for this report is January 1, 2014. Additionally, most reports of prevalence limit the individuals counted to those diagnosed in a fixed period prior to the index date. For this report, unless otherwise noted, the statistics quoted represent individuals alive on January 1, 2014 who were diagnosed with cancer in the 10 years prior to that date.

## Table 1. Numbers of British Columbia cancer survivors, by age group and sex (as of January 1, 2014)

Age Group	Females	Males	Total
0-19	418	503	921
20-39	2,377	2,034	4,411
40-59	16,514	9,187	25,701
60-79	29,532	36,017	65,549
80 - 99	11,504	14,027	25,531
Total: All ages 0-99	60,345	61,768	122,113

Cases diagnosed 2004-2013

Although it is possible to provide statistics for individuals diagnosed in the more distant past, it can be challenging for registries to follow-up such cases for vital status (e.g. as some people leave the province). Longer term statistics can be more affected by the small number of such people lost to follow-up each year that when added together over a long period of time can distort some of the statistics. Thus, for this report, we have generally focused on characterizing those diagnosed in the past decade, but have included a short section on "longer term" survivors which includes individuals whose diagnosis was up to 20 years prior to the index date. More detailed explanations of the statistical methods as well as a definition of what is considered "cancer" for this report can be found in Appendix I.

#### Current Survivors – by Age and Sex

As of January 1, 2014 there were more than 122,000 individuals living in British Columbia who had been diagnosed with cancer in the ten-year period prior to that date. Table 1 shows the breakdown of this group of individuals by their current age and sex. This group is nearly evenly split between males (51%) and females (49%); more than half of the group (54%) is presently between the ages of 60 and 79 years. An interesting difference between the sexes is the larger number of female survivors in the 40-59 age group; this results from the relatively large number of breast cancer

diagnoses in this age group (higher than most male cancers in the same age group), who have a generally good prognosis. The subsequent larger number of survivors among males in the 60-79 age group reflects the later age at diagnosis for prostate cancer which accounts for a high percentage of the male cases.

### Current Survivors – Types of Cancer

The cancer survivors described above have been diagnosed with more than 127,000 cancers (Table 2) in the ten-year period prior to January 1, 2014; this number exceeds the actual number of survivors as some individuals have had more than one type of cancer diagnosed over that period. Table 2 shows the numbers of different specific tumour types that have been diagnosed in the current survivor population; cancers of a specific type are only counted once per person, even if the individual is diagnosed more than once with the same cancer. More than 25,000 cases of prostate cancer have been diagnosed in this group, the most common cancer in males and overall. Breast cancer is the most common diagnosis for the female survivors with almost 25,000 women having been diagnosed with this cancer. The other cancers represented in the table are those for which there are at least 3,000 individuals in the survivor population with such a prior diagnosis. Additional data are presented in Appendix I, Table A1.

Looking at Table 2, it may appear that some cancers are disproportionately represented in either the male or female survivors. For example, 76% of the bladder cancers in our survivor population have been diagnosed in male survivors; 75% of the thyroid cancers have been diagnosed in the female survivors. It is important to remember that this largely reflects a difference in the annual number of new cases (incidence) of these cancers between males or females rather than a significant survival difference. Other factors that could affect this difference are differences in the age at diagnosis, cancer stage or other cause mortality between males and females.

## Table 2. Most common cancers diagnosed among BC cancer survivors by sex.

	E	M - I	Tatal
Cancer Group	Females	Inales	Iotal
Prostate	0	25,300	25,300
Breast	24,444	166	24,610
Colorectal	7,061	8,654	15,715
Melanoma (Skin)	3,447	3,687	7,134
Bladder	1,629	5,166	6,795
Lung	3,339	2,756	6,095
Non-Hodgkin Lymphoma	2,705	3,198	5,903
Uterus	5,095	0	5,095
Leukemia	1,488	2,336	3,824
Kidney	1,099	1,992	3,091
Thyroid	2,293	769	3,062
Oral	977	2,033	3,010
All Cancers	62,567	65,059	127,626

#### Current Survivors – Time since Diagnosis

Characterizing the survivor population in terms of their time since cancer diagnosis is also important as this generally describes where this population is in their survivorship journey. For example, individuals closer in time to their cancer diagnosis might more frequently access oncology-specific services; over time they may transition to relying solely on their primary care physician for their health needs.

Data by time since diagnosis can be relevant to assist in the planning of health care needs and to consider what supports might be needed for patients at different periods post-diagnosis. Table 3 describes the same individuals from Table 2 in terms of their time since cancer diagnosis. Of the roughly 122,000 individuals diagnosed with cancer in the past ten years, about 20,000 of these people are within one year of their diagnosis; and approximately one-third of the individuals are within two years of their diagnosis. The remaining individuals are split almost evenly between the other two time intervals with approximately 40,000 individuals (33%) more than three but within five years since diagnosis and another almost 45,000 people (37%) more than five years but within ten years of diagnosis.

#### **Longer-term Survivors**

The last row of Table 3 includes a group of longer-term survivors diagnosed between 10 and 20 years prior to January 1, 2014 (1994-2003); this group includes almost 49,000 British Columbians. This last group of longer-term survivors includes slightly more females (53%) than males (47%), which is in contrast to the other rows in the table where there are slightly more males than females. This last row suggests that there are more than 170,000 British Columbians that are alive in our province that have been affected by a cancer diagnosis in the past 20 years; this number is almost as large as the combined population of the cities of Kamloops and Kelowna.

	Females		М	ales	Both Sexes	
Years Since Diagnosis	#	Cumulative #	#	Cumulative #	#	Cumulative #
≤ 1 year	9,883	9,883	10,376	10,376	20,259	20,259
>1 year to 2 years	8,360	18,243	8,631	19,007	16,991	37,250
> 2 years to 5 years	19,874	38,117	20,279	39,286	40,153	77,403
>5 years to 10 years	22,228	60,345	22,482	61,768	44,710	122,113
Longer-term survivors						
>10 years to 20 years	25,889	86,234	22,936	84,704	48,825	170,938

Table 3. Numbers of cancer survivors, by sex and years since diagnosis (as of January 1, 2014).

Cases diagnosed 1994-2013

#### Current Survivors – Cancer-Specific Summaries

In this section we have chosen to characterize more completely the survivors of a few specific types of cancer, selected to highlight the diversity by cancer type, and the resulting difficulty in interpreting information that is based on "all cancers".

#### Breast and Prostate Cancers

Breast and prostate cancers are good examples of cancers with both high incidence and high survival rates. The first row of Table 4 shows those alive within one year of diagnosis, and this roughly approximates the annual incidence for these cancers. There were over 3,200 women and almost 2,900 men within 1 year of their diagnosis of breast and prostate cancer respectively. For each subsequent interval, the numbers of survivors for these two cancers are fairly similar: there are approximately 3,000, 8,000 and 10,000 survivors of each cancer in the periods for 1-2, 2-5 and 5-10 years from diagnosis respectively. However the age distribution for the survivors of these two cancer shows some differences. A greater percentage (33%) of the female breast cancer survivors are younger (age < 60) reflecting the earlier age at diagnosis of breast cancers compared to prostate cancer (only 7% are age < 60). More than one quarter of prostate cancer survivors were greater than 80 years of age; the fraction of breast cancer survivors in this age group was significantly lower (17%).

## Table 4. Numbers of breast and prostate cancer survivors, by years since diagnosis and current age(as of January 1, 2014).

	Female Breast Cancer		Male Pro	state Cancer	Age Distribution		
Years Since Diagnosis	#	Cumulative #	#	Cumulative #		Female	Male
						Breast	Prostate
≤ 1 year	3,246	3,246	2,887	2,887	% < 60	33%	7%
>1 year to 2 years	2,992	6,238	3,002	5,889	% 60-79	50%	68%
> 2 years to 5 years	8,347	14,585	8,610	14,499	% 80+	17%	25%
> 5 years to 10 years	9,859	24,444	10,801	25,300	_		

#### Colorectal Cancer

The data presented in Table 5 characterize colorectal cancer survivors in BC. There are slightly more male survivors (55%) compared to females and this pattern is apparent for each time period post-diagnosis; this reflects the higher incidence of colorectal cancer in men. The age distribution of colorectal cancer survivors in BC shows that approximately 1 in 6 of these individuals is under the age of 60. The incidence of colorectal cancer in younger adults has been increasing in recent years across Canada, including here in BC, and thus this group of younger survivors might be expected to grow over the coming years. About one third of colorectal cancer survivors is more than 80 years of age, with a slightly higher fraction of females in this over 80 age group.

Table 5. Numbers of colorectal cancer survivors, by years since diagnosis, sex and current age (as of January 1, 2014).

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Colorectal	Females		Males		Age Distribution		n
Years Since Diagnosis	#	Cumulative #	#	Cumulative #		Females	Males
≤ 1 year	1,243	1,243	1,554	1,554	% < 60	16%	15%
>1 year to 2 years	1,039	2,282	1,298	2,852	% 60-79	49%	57%
> 2 years to 5 years	2,222	4,504	2,784	5,636	% 80+	35%	28%
> 5 years to 10 years	2,557	7,061	3,018	8,654	-		

#### Lung Cancer

Lung cancer (Table 6) is an example of a cancer with relatively high incidence and generally poor prognosis. As a result, in comparison to some of the cancers described above, there are fewer lung cancer survivors in BC. Of note, there are very few longer-term survivors (those between 5 and 10 years from diagnosis) with just more than 1,400 such individuals; this contrasts with the more than 5,500 colorectal cancer survivors represented in this same period since diagnosis. The age distribution of current lung cancer survivors in BC is similar for males and females with the majority (more than 60%) between the ages of 60 and 79 and approximately one quarter of the individuals older than 80 years of age.

Table 6. Numbers of lung cancer survivors, by years since diagnosis, sex and current age (as of January 1, 2014).

Lung	Females		Males		Age Distribution		n
Years Since Diagnosis	#	Cumulative #	#	Cumulative #		Females	Males
≤ 1 year	969	969	879	879	% < 60	14%	12%
>1 year to 2 years	603	1,572	526	1,405	% 60-79	63%	61%
> 2 years to 5 years	932	2,504	748	2,153	% 80+	23%	27%
>5 years to 10 years	835	3,339	603	2,756	-		

#### Bladder Cancer

The majority of bladder cancer survivors are male (76%, Table 7) owing to the much higher incidence of these tumours in men compared to women. Bladder cancer survivors, like colorectal cancer survivors in BC, are fairly evenly distributed across the three periods representing < 2, more than 2 but within 5, and more than 5 but less than 10 years since diagnosis. Bladder cancer survivors include a significant proportion of individuals older than 80 years of age; the age distribution of bladder cancer survivors is similar across the sexes.

Table 7. Numbers of bladder cancer survivors, by years since diagnosis, sex and current age (as of January 1, 2014).

Bladder	Females		Males		A	ge Distributio	n
Years Since Diagnosis	#	Cumulative #	#	Cumulative #		Females	Males
≤ 1 year	262	262	912	912	% < 60	13%	10%
>1 year to 2 years	239	501	754	1,666	% 60-79	52%	54%
> 2 years to 5 years	518	1,019	1,747	3,413	% 80+	35%	36%
>5 years to 10 years	610	1,629	1,753	5,166	_		

## CHILDHOOD AND ADOLESCENT CANCER SURVIVORS

One group where characterizing longer-term survivors is of great importance is survivors of childhood and adolescent cancers. For Table 8 we present numbers of individuals alive in BC on January 1, 2014 who were previously diagnosed with a cancer between the ages of o and 19. In this table we have included those diagnosed between 10 and 20 years before the index date of Jan 1, 2014; this group of longer term survivors represent about 46% of the cumulative total. Our data suggest that there were over 2,500 children or adolescents diagnosed with cancer in the last 20 years who are living today in BC.

This group of individuals previously diagnosed with cancer is of particular importance to characterize because research has shown that children who have undergone cancer treatments are at higher risk of future health effects resulting from their cancer treatment. In the Featured Survivorship Research section of this report we describe a body of research that aims to identify these late effects of cancer treatment in BC children and some of the specific provincial initiatives that have been developed to address this group's unique needs.

Table 8. Numbers of childhood cancer survivors, by sex and years since diagnosis (as of January 1, 2014).

	Females		٨	Nales	Both Sexes	
Years Since Diagnosis	#	Cumulative #	#	Cumulative #	#	Cumulative #
≤ 1 year	69	69	102	102	171	171
>1 year to 2 years	70	139	76	178	146	317
> 2 years to 5 years	186	325	238	416	424	741
>5 years to 10 years	285	610	360	776	645	1,386
>10 years to 20 years	538	1,148	626	1,402	1,164	2,550

Cases diagnosed 1994-2013

## GROWING NUMBERS OF SURVIVORS

How has the number of cancer survivors in our province changed over time?

To examine this question, we compared cancer prevalence statistics from a decade ago to current statistics. We specifically looked at the numbers of individuals who were alive on January 1, 2004 and diagnosed with cancer in the decade prior to that date, and compared this to the number alive on January 1, 2014 and diagnosed in the decade prior to that (Table 9). The full tabular comparison by cancer site and sex is in Appendix I (Table A1), and selected sites are shown graphically below.

It is immediately apparent from the last row of Table 9 that the number of cancer survivors has grown dramatically in BC. In 2004, we

estimated that more than 89,000 cancer survivors were living in BC; this number has grown to more than 122,000 people based on our most recent data (an increase of 37%). Although the distribution of cancers survived by these individuals doesn't immediately look too different between the 2004 and 2014 data (Table A1), some cancer survivor populations have grown considerably. For example, there were more than 24,000 breast cancer survivors in 2014 compared with more than 18,000 in 2004 (~30% increase); over this period there was an increase of approximately 5,000 colorectal cancer survivors in BC (up to about 15,700 survivors in 2014). This increase is due to both aging and growth of our population, but also to better survival.

	Females		Males		Both Sexes	
Age Group	2004	2014	2004	2014	2004	2014
0-19	379	418	457	503	836	921
20-39	2,081	2,377	1,561	2,034	3,642	4,411
40-59	13,559	16,514	7,698	9,187	21,257	25,701
60-79	19,289	29,532	25,697	36,017	44,986	65,549
80 - 99	8,781	11,504	9,982	14,027	18,763	25,531
All ages 0-99	44,089	60,345	45,395	61,768	89,484	122,113

Table 9. Numbers of cancer survivors by age group and sex – January 1, 2004 compared with January 1, 2014.

Figure 2 compares numbers of cancer survivors for 2004 and 2014 for selected cancer types, side-by-side. In Part A, for all cancers, the increase from 2004 to 2014 is over 36%, similar for males and females. Parts B and C show that the increases over that period for breast and prostate cancer survivors were about 30% and 25% respectively.



Figure 2. Change in numbers of cancer survivors by sex and cancer type – January 1, 2004 to January 1, 2014.

In Part D, the combined increase for colorectal cancer survivors was 44%, however when broken out by sex, reveals a greater increase among males (48%) than females (39%). Another example of a large increase in the number of survivors is lung cancer (Part E, 47%), but in this case, the difference by sex goes the other direction, with a larger increase among females (54%) than males (40%). Finally, Part F shows the considerable difference between males and females with respect to the number of bladder cancer survivors. There are considerably more male bladder cancer survivors than female in both time periods, and the increase from 2004 to 2014 is much larger, 28% for males compared with 11% for females.



## SURVIVORSHIP SUMMARY

Planning for the needs of cancer survivors requires population-level information. This year's BCCR report highlights the distribution of cancer survivors by age, sex, cancer type and time since diagnosis; these data demonstrate that the numbers of cancer survivors can differ quite significantly according to these factors. The population in this report, diagnosed in the ten years prior to the January 1, 2014 index date, is almost evenly split between males and females, and over half are presently in the 60-79 year age group. However, there are considerable differences within this broad group of all cancer survivorsdepending on the specific type of cancer they have been diagnosed with in the past. These differences have important implications for research and practice including identifying research priorities and developing care guidelines and programs for patients as they continue from active treatment to survivorship care.

With the expected continued growth of the survivor population, data about this population helps to identify additional programs needed to meet this group's diverse and sometimes complex needs. Today, the BC Cancer Agency, through its portfolio on patient experience and inter-professional practice, offers a number of important services, one example of which is the new program and medical clinic for survivors of childhood cancer, the Adult Childhood Cancer Survivors program described in the next section. Data from the BCCR were utilized in developing the knowledge base that informed the need for and development of the program.

Development of survivorship guidelines, standards of care, protocols and programs are typically cancer site specific. Understanding the intricacies of the survivor population in BC can greatly assist with prioritizing our activity and tailoring the programs to the unique populations.

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## CHILDHOOD, ADOLESCENT AND YOUNG ADULT CANCER SURVIVOR CARE

Submitted by:

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- Clinical Professor,
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  Co-Lead, Survivorship,
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Due to the increasingly successful treatment of individuals diagnosed with cancer before age 25, a growing survivor population is emerging. Depending upon their age at the time of diagnosis and the treatment they received, these survivors are at higher risk for a number of serious health conditions, including: new cancers; damage to multiple organs; and problems with memory, thinking and understanding (known as neurocognitive problems). Many of these problems are severe or life-threatening. However, at present, knowledge regarding lifetime impacts is incomplete. There is a need to ascertain the risks and predictors of late effects among these survivors over time, and determine resource needs in health, education, and other areas, in order to develop and evaluate strategies for long term management and support; educate both survivors and those that provide support on risks and management; and identify new problems as the survivors age and treatments change.

CAYACs research team



This year we are delighted to highlight a body of important research conducted over fifteen years, using BC Cancer Registry data to achieve a better understanding of the cancer survivor population in BC, and to inform the design and implementation of a program to address the ongoing needs of childhood, adolescent and young adult cancer survivors (CAYACS).

The story began in the late 1990s, with a new program proposal led by BC Cancer Agency epidemiologist Mary McBride to better understand the growing population of childhood and young adult cancer survivors. The BC Cancer Registry provides information about cancer cases province-wide, with high standards of accuracy and ongoing quality assurance. By leveraging this high quality data resource and linking it to other existing population-based data resources with health, education and employment outcomes, McBride and colleagues were able to support their research goals and lay the crucial groundwork leading to eventual policy changes and funding advances for survivor care.

Data linkage methodology has important differences from more traditional and better-known laboratory- and clinic-based research. First, use of existing registries and datasets is cost-effective, timely and comprehensive. Second, the BC Cancer Registry and many other population-based datasets have a long history, and will be maintained into the future to allow identification of new risks, evaluation of long-term outcomes, and assessment of effectiveness for survivor care management strategies. Record linkage methodology using population registries addresses some of the limitations of other cohort studies, in particular the comprehensive subject identification, completeness of recruitment, completeness and recency of follow-up, the need for costly maintenance of a cohort over time, and potential for bias in data collection of outcomes. Population-based files of vital events. cancer, and health care utilization in Canada are available and have successfully been utilized for many years for health-related studies.

Some of the important knowledge gained to date relates to health outcomes and healthcare utilization among childhood and young adult cancer survivors, of whom 40% had late-occurring conditions leading to hospitalization, nearly twice the risk as the general population. It was also found over a 3-year study period that over 90% of survivors saw a family physician, with 49% more visits than the general population. The research was able to demonstrate that diagnosis and treatment affected healthcare utilization, but factors such as region of residence and socioeconomic status, which relate to inequities in access to care, did not affect utilization in general. A key finding was that a minority of survivors were receiving guideline-based follow-up care, in the absence of a formal follow-up program. Based on these results and survivor concerns, in 2014 the

BC Government asked BC Cancer Agency and BC Children's Hospital to provide recommendations for strategies for evidence-based care of these survivors. The research results informed both the development of strategies, and a business case; and in January of 2015, the Government announced funding for the BC Cancer Agency to implement a risk-stratified program, the Adult Childhood Cancer Survivors (ACCS) program, that would provide appropriate care depending on risks of later health problems, and a smooth transition for patients from pediatric cancer care to ongoing follow-up care.

For more information on cancer survivor resources and services, visit the BC Cancer Agency's website, at http://www.bccancer.bc.ca/ health-professionals/professionalresources/survivorship-primary-care.

### COMMENTS FROM STAKEHOLDERS

#### Survivor

"I think the impact has actually been stronger as an adult than as a teen... I find it harder to process things. Like, it just takes me a little bit longer; I'm a little bit slower than the average student."

#### Dr Terry Lake, BC Minister of Health

"In BC, we have had great success treating childhood cancers. Our survival rates are a testament to the world class care offered at BC Children's Hospital and the BC Cancer Agency. However, this special group of survivors requires ongoing follow-up care as they are at higher risk for a number of serious health conditions. This funding will further support the transition to follow-up care so this group of cancer survivors can be supported in having a long and healthy future."

## ECONOMIC OUTCOMES FOR CHILDHOOD CANCER SURVIVORS

#### Submitted by:

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The number of childhood cancer survivors has been rapidly increasing over the last three decades due in part to substantial improvements in treatment. The percentage of cancer patients diagnosed between ages 0-19 who lived five years or more post-diagnosis, increased from 56% during the 1970s to 81% for cases diagnosed between 1990 and 1995. This improvement in survival has resulted in a growing population of childhood cancer survivors in Canada, and many of the childhood survivors are now adults living with late adverse effects of treatment compromising their future physical, cognitive, or psychosocial health, as well as employment.

There is growing evidence suggesting that the late effects of chemotherapy, radiotherapy, and surgery could be severe or life-threatening, however, little is known about the economic well-being of childhood cancer survivors. The studies that have been done on economic well-being have focused on adult cancer survivors. This study, using CAYACS Program data linked to income data, examines the annual earnings of cancer survivors diagnosed before age 25 over a 29 year period (1982-2010) to determine the impact of cancer diagnosis and treatment on long-term income. The cohort included 3,958 survivors with over 106,777 person-years of follow-up.

Mean income was observed to be lowest for those surviving Central Nervous System cancers and highest for those surviving Germ Cell cancers and Lymphoma. Survivors who underwent radiotherapy treatment went on to earn significantly less than those who had not undergone such treatment. Cancer survivors for all types of cancer earned significantly less than the general population.

The use of linked administrative databases allows researchers to address such important non-health outcomes for a more complete picture of survivorship challenges.

## NAACCR GOLD CERTIFICATION

In 2015 the BC Cancer Registry received some great news. The Registry received a gold certification status from the North American Association of Central Cancer Registries (NAACCR) for the first time in almost 20 years of data evaluations. NAACCR is an independent body located in the United States that evaluates the quality and completeness of data for central cancer registries across the US and Canada. Based on the assessment completed by NAACCR of our 2012 cancer incidence data, our case completeness rate (meaning the % of all cancers in the population they estimate our registry has captured) is now almost 98%.

Improving the case-capture rate for the cancer registry has been a consistent challenge for several years. A major reason for the cancer registry's success this past year has been the support of the Ministry of Health which has facilitated greater access to information about patients hospitalized in the province for cancer. Access to this information has helped the Registry staff identify



cases that were not previously reported to the Registry, track down the relevant documentation and complete the registration of these cases. The Ministry of Health has further supported the Registry by establishing a long-term information sharing agreement to provide these data on a regular basis, permitting these processes to become established as part of regular Registry operations.

BC Cancer Registry Operations team

#### Most Common Cancers, 2013 BC Males

Cancer	# New Cases
Prostate	2,975
Lung	1,566
Colorectal	1,817
Bladder (includes in situ)	1,012
Non-Hodgkin Lymphoma	600
Melanoma (skin)	630
Kidney	393
Leukemia	469
Oral	405
Pancreas	361

- In 2013, there were 12,970 cancers diagnosed in BC males; 49% of these were cancers prostate, colon, rectum or lung
- In 2013, 5122 BC males died of cancer. Of these deaths, 1138 were due to lung cancer

#### Most Common Cancers, 2013 BC Females

Cancer	# New Cases
Breast	3,421
Lung	1,576
Colorectal	1,482
Uterus	741
Melanoma (skin)	489
Non-Hodgkin Lymphoma	509
Ovary	378
Bladder (includes in situ)	303
Pancreas	352
Leukemia	313

- In 2013, there were 12,071 cancers diagnosed in BC females; 54% of these were cancers breast, colon, rectum or lung
- 2013 marks the first year that BC females recorded more lung cancer cases and deaths than BC males.
- In 2013, 4474 BC females died of cancer of which 1139 died of lung cancer

### **MOST COMMON CANCERS**

#### TRENDS IN CANCER RATES FOR COMMON CANCERS

#### Incidence

- Prostate cancer incidence in males continues to decline in BC from its peak in the 1990's, possibly due to decreases in PSA testing.
- Lung cancer incidence continues to decline in the province with the age-standardized incidence rate for lung cancer now lower than the rate for colorectal cancer in BC males.
- The rate of oral cancers in males was decreasing in BC up until about the year 2000 when it started to increase. The previous declining trend was likely the result of smoking cessation successes however the recent increasing trend likely reflects an increase in HPV-associated oral cancers (see 2014 BC Cancer Registry Annual Report).



Figure 3. Age-standardized cancer incidence rates in BC males, 1970-2013.

- The lung cancer incidence rate in BC females appears to have peaked since the early 1990's however the declining pattern seen in males has not yet been observed in females.
- Breast and colorectal cancer incidence rates have been fairly stable for the past decade.
- Rates of uterine, melanoma and thyroid cancers have all increased in recent years in BC. The dramatic increase in thyroid cancer incidence has been observed in most of the western world and is believed to be due in large part to greater detection of low-risk, previously undiagnosed tumours.

Figure 4. Age-standardized cancer incidence rates in BC females, 1970-2013.



### Mortality

- In general cancer mortality rate patterns in men have been encouraging in recent years.
- Declining rates continue to be observed for major cancers such as lung, prostate and colorectal.
- Esophageal cancer mortality rates were increasing through the 80's and 90's but appear to have leveled.
- Non-Hodgkin lymphoma mortality continues to decline in BC since the early 2000's when improvements to treatment were realized.

Figure 5. Age-standardized cancer mortality rates in BC males, 1970-2013.



- Mortality rates for common cancers such as breast, colorectal and ovary continue to decline in BC, continuing the encouraging rates seen over the past decades.
- Lung cancer mortality rates appear to have started a declining trend; in the coming years this will be watched with interest to see if this follows the steady declining pattern observed in males.
- As with males, non-Hodgkin lymphoma mortality rates continue to decline due to improvements in treatments for this population.

Figure 6. Age-standardized cancer mortality rates in BC females, 1970-2013.



For more BC Cancer Statistics please visit the BC Cancer Agency website at: http://www.bccancer.bc.ca/health-info/disease-system-statistics/bc-cancer-statistics

## CANCER IN BC FIRST NATIONS PEOPLE

Submitted by:

- Dr. John Spinelli
- Vice President,
- Population Oncology and Distinguished Scientist, BC Cancer Agency
- Professor,
  University of British Columbia

In 2011, the Canadian First Nations, Inuit and Métis Action Plan on Cancer Control Studies identified gaps in cancer control, one of them being a lack of cancer control data specific to First Nations, Inuit and Métis populations (CPAC 2011). Although there have been some recent analyses from different provinces, the results have been variable so that generalization from elsewhere may not be reliable to use in BC. In order to address this gap, the BC Cancer Agency and the First Nations Health Authority (FNHA) have partnered together on a research study. The study is gathering information on cancer incidence, mortality and survival in British Columbia First Nations peoples and comparing it to BC non-First Nations to enhance knowledge of the distribution and extent of cancer in British Columbia registered First Nations peoples. This will aid in the development of a targeted cancer control strategy and will provide valuable baseline cancer surveillance data for BC First Nations population.

Data was obtained from the British Columbia Cancer Registry, Statistics Canada population estimates and the Registered First Nations Client File (FNCF). The FNCF is a cohort of BC Resident First Nations (RFN) people registered under the Indian Act, and their unregistered descendants for whom entitlement-to-register can be determined. It provides a historical database of RFNs resident in BC going back to 1993 and includes identifying information, location and demographic data.

Incidence and mortality rates by 5-year age groups for the period 1993 – 2010 will be calculated by dividing the total number of cases or deaths over all the years in each 5-year age group by the total population estimates over all the years.

The information from this study will help to better understand the differences between First Nations and non-First Nation populations, and to suggest possible steps to address these differences.

Canadian Partnership Against Cancer (2011). Canadian First Nations, Inuit and Métis Action Plan on Cancer Control Studies. Toronto: Canadian Partnership Against Cancer.

## COSTS OF CANCER CARE IN BC

#### Submitted by:

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 Data Linkage Coordinator, BC Cancer Agency; and

Dr. Stuart Peacock,

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  Canadian Centre for Applied
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  (ARCC)
- Distinguished Scientist
  Cancer Control Research,
  BC Cancer Agency

Population-based administrative data is well-suited to costing studies and analysis of cost trajectories and patterns. Investigators from Applied Research in Cancer Control (ARCC) in BC and ON have initiated a study which identifies cancer cohorts using provincial cancer registries to study the costs of cancer in these two provinces. The study is led in BC by Dr. Stuart Peacock and in Ontario by Dr. Claire de Oliveira. This study's objectives include estimating direct medical costs and predictors of these costs for 21 common types of cancer and 4 phases of care using linked administrative data. The study objective was to estimate direct medical costs and predictors of these costs for 21 common types of cancer and 4 phases of care, using linked administrative data in British Columbia and Ontario. Data sources included hospitalizations, physician services, outpatient prescriptions, chemotherapy, radiotherapy, home and community care, and diagnostic procedures.

The study examined cancer costs across four phases of cancer care: pre-diagnosis phase, initial phase, continuing care phase, and terminal phase. Study findings show that for some cancer sites, costs across the phases were consistently high (myeloma, pancreas and brain) or consistently low (melanoma, cervix and prostate). The researchers observed especially high initialphase costs for aggressive cancers, but the same pattern for aggressive cancers was not seen in terminal phase costs; the cost of dying is high across cancer sites.

Overall, the cost estimates tended to be lower for BC than Ontario, however there were unavoidable differences in costing methods for the two provinces, so separating true difference across provinces from those differences related to methods is challenging.

For more information about the Canadian Centre for Applied Research in Cancer Control, please visit their website at cc-arcc.ca.

## BC HEPATITIS TESTERS COHORT – ASSESSMENT OF THE BURDEN OF HEPATITIS C

Submitted by:

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Administrative data sources such as the BC Cancer Registry serve many diverse goals, some reaching beyond traditional cancer surveillance through partnerships with other disease surveillance agencies. One example of such a partnership involves the British Columbia Centre for Disease Control (BCCDC), under the auspices of the Provincial Health Services Agency (PHSA). The BCCDC has undertaken a project to provide more accurate provincial estimates of morbidity, mortality, health outcomes and costs attributable to Hepatitis C virus (HCV) infection.

The cohort is linked to the BC Cancer Registry because chronic HCV infection is associated with an elevated risk of liver cancer and the development of non-Hodgkin's lymphoma, especially B-cell lymphoma. One project goal is to evaluate the effect of treatment with interferon and ribavirin on sustained virologic response and long term outcomes of hepatocellular carcinoma and mortality.

The British Columbia Hepatitis Testers Cohort is a surveillance system established under BCCDC's mandate to monitor the health of the population and perform health promotion and health protection activities under the Public Health Act. The cohort includes all individuals tested for HCV or HIV at the BC Public Health Laboratory (BCPHL) or those who have been reported to public health as a case of HCV, Hepatitis B, HIV or active tuberculosis in BC. Linkage with administrative datasets including the BC Ministry of Health (MoH) Client Roster, medical visits, hospitalizations, prescription drug data, cancer registry and mortality data will provide a longitudinal history of infections and outcomes. The BC-HTC includes records from inception (1990) of each dataset to 2012/13with plans for annual updates thereafter. The resulting linked cohort includes data on more that 1.5 million individuals, about a third of BC's 4.6 million population. The 2015 update of the cohort includes about 1.7 million people. The data linkages were approved by the data stewards of the BCCDC, the MoH, the BCPHL, the BC Vital Statistics Agency and the BCCR.

Data from this linked cohort will provide essential information to support development of appropriate prevention and treatment initiatives for HCV. BC-HTC also serves as a model of collaboration and data stewardship to fulfill shared goals of the BCCDC, the BC Ministry of Health, BC Cancer Agency and other health partners.

For more information about the BC Hepatitis Testers Cohort, please visit their website at http://bchtc.med.ubc.ca/ Andreotti, G., Birmann, B. M., Cozen, W., De Roos, A. J., Chiu, B. C., Costas, L., ... Purdue, M. P. (2015). A pooled analysis of cigarette smoking and risk of multiple myeloma from the international multiple myeloma consortium. *Cancer Epidemiol Biomarkers Prev*, 24(3), 631-634.

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## **Population Data BC**





The BC Cancer Registry continues to be an active supporter of Population Data BC, a multi-university resource that facilitates linkages of administrative health data for health research purposes. The BC Cancer Registry has contributed data to this facility for several years and is one of two core holdings of BC Cancer Agency data available to researchers via this platform. BC Cancer Agency staff also support the facility through membership on the Data Stewardship Working Group, as well as by reviewing study applications and providing assistance in understanding and interpreting our data.

Researchers who request access to data at Population Data BC are required to complete a detailed data application, obtain research ethics approval and complete necessary privacy training. Data remain on a secure server, but are available through secure connections to researchers anywhere in Canada. At present, there are more than 30 active research projects using BC Cancer Registry data within this facility. These projects are investigating a diversity of important health research questions. A sample of these include whether certain prescriptions drugs are associated with cancer risk, how to estimate costs associated with cancer in our health system, and study the patterns and quality of care for breast cancer patients in BC.

By making the cancer registry data available in this way, we have made it possible for health researchers to securely access the data and potentially link it to other important health data including hospital separations, physician billings, home and community care information and prescription drugs.

For more information about Population Data BC, please visit their website at www.popdata.bc.ca

## CALCULATION OF CANCER SURVIVOR STATISTICS

The methodological approach to calculating numbers of cancer survivors is based on limited duration cancer prevalence statistics. This approach requires the specification of an index date (here January 1, 2014) which is the date upon which we have counted all individuals who are known to be alive with a prior diagnosis of cancer. The use of limited-duration prevalence statistics means that we are only counting cancers diagnosed within a prespecified period prior to diagnosis. For example, a 2-year limitedduration prevalence estimate counts individuals alive on Jan 1, 2014 who have been diagnosed in the 2 years prior to this date (meaning sometime in 2012 or 2013).

In this report, we have generally computed 10-year limited-duration prevalence statistics and then decomposed those cases into separate groups based on the time interval since diagnosis. Thus the rows in the tables for  $\leq$  1 year, > 1 year to 2 years, > 2 years to 5 years, > 5 years to 10 years represent a decomposition of 10-year limitedduration prevalence statistics.

When counting individuals with a prior diagnosis of cancer, we only include invasive cancers (except in situ bladder which is included) and we have not counted any non-melanoma skin cancers as these are not completely registered in BC. We have further excluded the following cases from all prevalence calculations:

- cases with unknown year of birth or sex;
- cases diagnosed based on death certificate information only;
- cases diagnosed on autopsy on the same date as the date of diagnosis;
- cases where the diagnosis date pre-dates the birth date.

These situations are all extremely rare in generating survivor statistics for the data years included in this report.

We have also chosen to only present data for individuals alive on January 1, 2014 who are between the ages of o and 99 (inclusive). Although there will certainly be some cancer survivors in our province that are older than 99 years of age, these individuals have not been counted in this report. Although the BC Cancer Registry obtains death notifications from the BC Vital Statistics Agency to help us identify prevalent cases of cancer (ie those individuals still alive that have a prior diagnosis) we have some challenges with ascertaining all deaths for our previously registered cases (see note below). As such, some individuals who have deceased appear alive in our database as their death notice has never been received by the Registry. These cases become most apparent in the oldest age groups where the probability of an individual attaining a very high age (e.g. greater than 110 years) is low.

When counting prevalent cases of specific cancers, in the event of multiple cancers of the same kind on a single individual, we include only one cancer per person; we count the time from diagnosis in these cases from the date of the most recent cancer. Thus in these cases, an individual will only count once for example for breast cancer even if they have been diagnosed with breast cancer twice in the past.

Additionally, the tables of "cancer survivors" characterized by various variables (e.g. current age, sex, time since diagnosis) count only a single cancer per person in the case of multiple cancers and include the

The BC Cancer Registry receives regular death notifications from the BC Vital Statistics Agency to enable the calculation of cancer survival, mortality and prevalence statistics. This information is critical to the calculation of cancer prevalence or survivor statistics as to satisfy the definition of a prevalent case of cancer, one must be alive on the date for which the statistics are generated (the index date). Although the Registry receives notifications for all deaths that occur within British Columbia, there is currently no mechanism to report deaths that occur either out of province or outside of Canada. As such, there is some potential for overestimation

most recent cancer where relevant. It is important to note however that Table 2 which counts the numbers of cancers of different kinds in the current survivors would count a given individual twice if they have been diagnosed with two different cancers in their lifetime (e.g. a person diagnosed in the past with both breast and lung cancer will count once in each of these rows in the table and twice in the "All Cancers" total for this table). Thus Table 2 represents a tumour-based prevalence estimate with the limitation that individuals may only count once per each cancer type they have been affected by.

of the numbers of prevalent cases of cancer as a small percentage of individuals who relocate after cancer diagnosis and die out of province, will be identified as still alive in the Registry.

The BCCR used to receive notifications of deaths occurring in cancer patients from other Canadian jurisdictions through a data linkage with the National Mortality Database held at Statistics Canada; this process however has been suspended pending the re-development of a national linkage process. The last time a linkage to ascertain deaths that occurred in other Canadian provinces was performed, it included deaths only up to the end of 2010.

## ASCERTAINMENT OF DEATH STATUS

## INCREASE IN CANCER SURVIVORS BY CANCER GROUP - 2004 TO 2014

Table A1 below provides the 2004 and 2014 numbers of cancer survivors for each specific cancer type. Note that some survivors may have had more than one cancer and thus the total in the table of > 127,000 is higher than the number of individuals described in Table 9 (> 122,000).

Table A1. Numbers of British Columbia cancer survivors, by sex and cancer type – January 1, 2004 to January 1, 2014.

	Females		Males		Total	
Cancer Group	2004	2014	2004	2014	2004	2014
Prostate	0	0	20,255	25,300	20,255	25,300
Breast	18,700	24,444	123	166	18,823	24,610
Colorectal	5,067	7,061	5,839	8,654	10,906	15,715
Bladder	1,464	1,629	4,028	5,166	5,492	6,795
Melanoma (Skin)	2,286	3,447	2,429	3,687	4,715	7,134
Lung	2,162	3,339	1,967	2,756	4,129	6,095
Non-Hodgkin Lymphoma	1,792	2,705	2,121	3,198	3,913	5,903
Body of Uterus	3,353	5,095	0	0	3,353	5,095
Leukemia	922	1,488	1,328	2,336	2,250	3,824
Oral	773	977	1,338	2,033	2,111	3,010
Kidney	762	1,099	1,269	1,992	2,031	3,091
Thyroid	1,312	2,293	419	769	1,731	3,062
Cervix	1,203	1,296	0	0	1,203	1,296
Ovary	1,130	1,483	0	0	1,130	1,483
Testis	0	0	1,010	1,223	1,010	1,223
Hodgkin Lymphoma	354	432	462	481	816	913
Stomach	281	346	482	625	763	971
Brain	338	408	418	555	756	963
Larynx	125	102	587	573	712	675
Multiple Myeloma	316	517	359	706	675	1,223
Esophagus	107	150	246	383	353	533
Liver	79	158	266	478	345	636
Pancreas	165	332	160	345	325	677
All Other Cancers	2,699	3,766	2,600	3,633	5,299	7,399
Total Cancers Survived	45,390	62,567	47,706	65,059	93,096	127,626

## Appendix II: Other Materials

## ABBREVIATIONS

ALL	Acute Lymphoblastic Leukemia
BC	British Columbia
BCCDC	British Columbia Centre for Disease Control
BCCR	British Columbia Cancer Registry
BC-HTC	British Columbia Hepatitis Testers Cohort
BCPHL	BC Public Health Laboratory
CAIS	Cancer Agency Information System
CAYACS	Childhood, Adolescent and Young Adult Cancer Survivors
CPAC	Canadian Partnership against Cancer
FNCF	Registered First Nations Client File
FNHA	First Nations Health Authority
HCV	Hepatitis C Virus
МоН	Ministry of Health
NAACR	North American Association of Central Cancer Registries
PHSA	Provincial Health Services Authority
RFN	BC Resident First Nations people

### GLOSSARY

#### **Cancer Incidence**

The number of new cases of a given type of cancer diagnosed in a specified time period. The basic unit of reporting is a new case of cancer rather than an individual patient.

#### **Cancer Incidence Rate**

The number of new cases of a given type of cancer per person in the general population (usually expressed as a rate per 100,000 people).

#### **Cancer Mortality**

The number of deaths attributed to a particular type of cancer in a given time period. Included are deaths of patients diagnosed in earlier years, persons with a new diagnosis during the year, and patients for whom a diagnosis of cancer is made only after death.

#### **Cancer Mortality Rate**

The number of new deaths of a given type of cancer per person in the general population (usually expressed as a rate per 100,000 people).

#### Prevalence

The number of cases alive on a given date (e.g. January 1, 2014) that have been previously diagnosed with cancer. This can be counted as either individuals previously diagnosed with cancer (person-based) or total previous tumours in individuals still alive (tumour-based).

#### Trends

The change in the rate of new cancer cases or deaths in the population over time.

## CANCER SITE DEFINITIONS

Table A2 provides the specific definitions used for the various cancers reported upon in this report. The definitions for each cancer are based on the ICDO-3 site (topography) and histology type (morphology) codes and are provided in right-hand column of Table A2. In this report we include invasive cancers only with the exception of bladder cancer which includes both invasive and in situ cases.

Note: non-melanoma skin cancers are not including in any of the above cancer types as these are not routinely registered in BC at this time.

Note: ICD-O-3 refers to the International Classification of Diseases for Oncology, Third Edition and ICD-10 refers to the International Statistical Classification of Diseases and Related Health Problems, Tenth Revision.

For more information about site groupings used in this report, please contact the BC Cancer Registry using the contact information provided in this appendix.

Table A2. Cancer site groupings used within this report.

ICD-O-3 Site/Type (incidence)
C67
С54-С55
С70-С72
C50
C <sub>53</sub>
C18–C20, C26.0
C15
С64.9, С65.9
Туре 9650-9667
C32
Type 9733, 9742, 9800–9801, 9805–9809, 9820, 9826, 9831–9836, 9840, 9860–9861, 9863, 9865–9867, 9869–9876, 9891, 9895–9898, 9910, 9911, 9920, 9930–9931, 9940, 9945–9946, 9948, 9963–9964 Type 9811–9818, 9823, 9827, 9837 sites C42.0,.1,.4
C22
C34
C44 (Type 8720–8790)
Type 9731-9732, 9734
Type 9590–9597, 9670–9719, 9724–9729, 9735, 9737, 9738 Type 9811–9818, 9823, 9827, 9837 all sites except C42.0,.1,.4
Coo-C14
C56.9
C25
C61.9
C16
C73.9
All other cancer types not identified above
All invasive sites (including <i>in situ</i> bladder)

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### CONTACT INFORMATION

If you would like more information about the BC Cancer Registry and any of our activities, please feel free to contact us. Additionally, if you have any questions or feedback on this report we would be happy to hear from you.

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