FUTURE OF CANCER IMPACT IN ALBERTA

MAIN REPORT

Alberta Health Services
Cancer Strategic
Clinical Network™

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Executive Summary

Cancer has a major impact on the lives of Albertans, our communities, and our health care system. In 2013, Alberta Health published *Changing our Future; Alberta's Cancer Plan to 2030*, a long-term strategic plan that aimed to accelerate action towards preventing more cancers, curing more cancers, and reducing the suffering of people affected by cancer.

Much progress has been made in the decade since that plan was published, but equally much has changed in the provincial health services landscape. The goal of this document, Future of Cancer Impact (FOCI) in Alberta, is to stimulate renewed and well-informed discussion, planning, and action around the future of cancer in Alberta over the next two decades. Designed for a broad range of stakeholders, FOCI in Alberta provides an updated summary of key cancer statistics, an overview of how cancer services are organized in Alberta today, and insight into related topics pertaining to models of cancer care and health equity. It offers recommendations for integrated research and actions that will prepare Alberta to address future challenges in cancer care.

FOCI in Alberta was instigated by the Cancer Strategic Clinical Network (SCN) and its execution was guided by a multi-disciplinary and multi-jurisdictional Working Group co-chaired by Dr. Paula Robson, Scientific Director of the Alberta Health Services' Cancer Strategic Clinical Network and Dr. Darren Brenner, Associate Professor at the University of Calgary. Subject matter experts and external collaborators were engaged throughout the development process, contributing information and ideas, reviewing draft material, and validating the overall content. Finally, the draft report was made available online in Fall 2022, and over 1,500 cancer stakeholders throughout Alberta were invited to validate the content and provide feedback on the recommendations.

Overview

FOCI in Alberta is presented in three sections: cancer data and trends; cancer diagnosis, treatment, and care; and cancer in context.

The first section (Chapters 1-4) on cancer data and trends describes statistics on cancer incidence, prevalence, mortality, and survival, both now and expected by 2040. These comprehensive data will allow us to monitor future patterns so we can identify where progress is being made and where there is room for improvement.

The second section (Chapters 5-10) focuses on the cancer care continuum, including prevention and screening, diagnosis, treatment, cancer management costs, supportive care, and palliative and end-of-life care. Each chapter provides an overview of current state, with recommendations for additional research, enabling infrastructure and actions to help cancer care providers in Alberta prepare for the future.

The third section (Chapters 11-14) provides an overview of models of cancer care in Alberta and includes information and recommendations relating to health equity in cancer care, childhood cancer in Alberta, and enabling factors for improving research and data infrastructure in Alberta.

Approach

FOCI in Alberta presents a descriptive analysis of the future impact of cancer in Alberta. Data and information were gathered using quantitative, qualitative, and participatory techniques.

- Historical and up-to-date data examining cancer incidence, prevalence, mortality and survival were collected and analyzed to generate projections and estimates of future impact until 2040.

- Reviews of published and grey literature were completed to obtain relevant data and information around topics of interest.

- Stakeholders and experts throughout Alberta, within and beyond Alberta Health Services, were consulted and engaged in developing, reviewing, and validating materials for each chapter.

Appendix 7 includes a description of the data sources, reference material, and estimation and projection tools used in the development of FOCI in Alberta.

Key Findings and Recommendations

Cancer data and trends

Current and projected data on cancer incidence, prevalence, mortality, and survival are essential for planning purposes and ensuring adequate infrastructure and resources are in place for cancer screening, diagnosis, treatment, and support services, now and in the future. In addition, these data provide the foundation for informing the design of future cancer prevention and control programs and research, as well as priorities for health promotion activities and policy.

Continued steady growth in the number of Albertans being diagnosed and living with cancer means that current cancer diagnosis, treatment and care systems may not be sustainable. **The incidence of cancer in Alberta has increased over the past 30 years with 22,215 cases projected to occur in 2021. By 2040, this number is expected to grow to 33,773.** Projected increases in **cancer prevalence** in Alberta will pose a considerable impact on the utilization of health care services, and as cancer survival is projected to improve, a larger proportion of people with cancer will require long-term follow-ups and supportive care. **One- two- and five-year prevalence is projected to rise to 31,339 cases, 60,004 cases and 131,660 cases, respectively, by 2040.** Overall, **cancer survival** continues to improve in Canada and Alberta, providing insights into the effectiveness of prevention and screening, as well as use of robust clinical treatment guidelines.

Given the projected increases in numbers of people being diagnosed and living with cancer, Alberta must accelerate exploration, implementation, and evaluation of innovative models of cancer care that can adapt to increasing and changing demands. **Careful and intentional planning around resource demands and intensity will be needed to ensure the continued provision of safe and high-quality care provided to Albertans facing cancer.** Detailed and concerted efforts dedicated to forecasting future resource needs, including workforce planning, will be essential to ensure optimal operation of Alberta's cancer care system as the numbers of new cases and numbers of people living with cancer continue to grow year on year.

There is also a critical need to further enhance **Alberta's cancer data environment** with the establishment of systematic and appropriately resourced approaches to monitoring trends in cancer incidence, prevalence, mortality, and survival, to proactively identify and address emerging issues. Recommendations for enhancement include:

- Implementation of a systematic approach to cancer epidemiology and monitoring, as well as ongoing evaluations of impacts of innovations in screening programs, cancer prevention, and other cancer control initiatives.

- Implementation of systems to support the ethical collection and use of population-level data for measures of equity, diversity, and inclusion within the cancer control environment.

- Reduced time lag in data collection and release to evaluate system and patient-level impacts of disruptive events, such as those due to COVID-19, or other future health system perturbations.

- Enhanced linkage between Alberta Cancer Registry and treatment databases and evaluation of changes in models of care on intermediate and longer-term outcomes.

- Increased capacity to analyze and interpret economic data to support analyses of impacts of changes in cancer incidence, mortality, and survival.

- Additional research into the optimal, long-term management of surveillance to maximize outcomes and system efficiency.

Additional efforts should be made to ensure that there is a systematic approach to examining regular reports on cancer survival in Alberta and taking action to address the findings when appropriate. Updated comparisons of survival statistics across Canada and with other international jurisdictions will also help identify targets for further action.

Cancer prevention, screening, diagnosis, treatment, and care
Providing safe and high-quality cancer care requires early and streamlined cancer prevention and screening efforts, more efficient processes and supports for diagnosis,

use of appropriate and timely treatment plans, as well as systems that focus on holistic, person-centered care at all stages of each Albertan's cancer experience.

Prevention at all levels is a powerful tool to reduce the impact of cancer in Alberta. An estimated 36 per cent (6,100 cases) of cancer cases diagnosed in Alberta in 2015 were attributable to modifiable risk factors including lifestyle, environmental exposures, and infections. More work is required to help prioritize the design, implementation and evaluation of novel interventions targeting these risk factors, with the potential to reduce the future impact of cancer in Alberta substantially.

Population-based **screening** programs play a key role in early cancer detection and outcomes. Pre-cancerous cells and cancers detected early typically have better clinical outcomes compared to cancers diagnosed at later stages. In addition, more treatment options are available for early-stage cancers. Currently in Alberta, cancer screening participation rates are not meeting targets and the rates differ across zones and subsets of the population, highlighting issues around availability, accessibility, and acceptability of screening. Furthermore, organized population-based screening programs exist only for breast, cervical and colorectal cancers. More research is needed in priority areas such as reducing the variation in cancer screening rates, equitable access to cancer prevention and screening programs, patient engagement in cancer prevention and screening research, and improved methods for prevention research implementation and mobilization.

Streamlining cancer **diagnosis** is likely to have major downstream effects, such as earlier stage at diagnosis, less complex therapy, and better survival. Ongoing efforts in Alberta to streamline cancer diagnosis through the Alberta Cancer Diagnosis (ACD) initiative should continue to be supported. ACD is an opportunity to expedite cancer diagnosis, minimize the use of the emergency departments and hospital admissions for diagnostic procedures, create a "safety net" for unattached or complex patients by providing a most responsible provider until a cancer diagnosis is confirmed, and improve the number of, and access to, non-medical and community-based psychosocial supports.

After diagnosis, a wide range of **treatments** is offered at 17 cancer centres and other hospitals across Alberta to support those affected by cancer. The most common types of treatment (used alone or in combination) are radiation therapy (with external beam radiation therapy, brachytherapy and radiosurgery), systemic therapy (with chemotherapy, hormone therapy and immunotherapy including CAR-T cell therapy), and surgery. New developments are leading to the progressive adoption of precision oncology and targeted approaches to treat cancer in Alberta. Future research opportunities include expanding access to clinical trials, developing more comprehensive approaches to assessing outcomes for trial participants and those exposed to different lines/modes of cancer treatment in routine care, learning how to enhance cancer care to meet the evolving needs and expectations of patients and families, and understanding more about how to optimize patient outcomes and experiences.

The already high **financial burden of cancer** on patients and their families could see an increase as the number of people diagnosed with cancer rises and the health care system is subject to growing capacity and financial pressures. Research is required in Alberta to explore and assess the direct and indirect financial burden of cancer treatment on Albertans and the health system. Future research should focus on evaluating patient care pathways to optimize patient outcomes and values and evaluate potential impacts of delays or gaps in treatment or care.

Supportive care refers to the range of services needed by patients diagnosed with, or waiting for a diagnosis of, a serious illness that go beyond medical, surgical and radiation interventions. Given the steady rise in cancer incidence, and promising trends that show people with cancer now live longer, there is an urgent need to better integrate and coordinate supportive care services to establish more seamless connections for patients and families.

The Provincial **Palliative and End-of-Life** Innovations Steering Committee (PPAL/EOL ISC) oversees the development and implementation of high-performing, publicly funded Palliative and End-of-Life Care (PEOLC) programs in Canada. The goal is to achieve a

level of high-quality service that provides equity, choice, dignity, and care supports for patients and their families, clinicians, and care providers, all within a person-centered model. Provincially, nationally, and internationally, extensive research continues to occur to address challenges and advance knowledge in various areas related to PEOLC. Some of this work is cancer specific, while other research has taken a more holistic approach that focuses on the overall advancement of the palliative approach to care for anyone living with a serious illness.

Cancer in context

Understanding the ways in which people with cancer can be cared for, and how their needs vary based on age, geography, socio-economic status, sex, gender, race, ethnicity, and culture, is crucial in providing the best possible cancer care to Albertans.

In order to adapt appropriately to our future context, Alberta's cancer care system must enhance its efforts to use evidence and a learning health system approach to develop, test and implement innovative models of care. Current models of care that focus on specialists and in-hospital treatments are not sustainable moving forward. Modern models of cancer care to explore further include virtual health care, and home- and community-based care.

Although there have been great improvements in cancer incidence and mortality in recent decades, these improvements likely have not occurred equally for all groups. In Canada, these disparities reflect the historical and political treatment of Indigenous groups, inattention towards racialized populations as well as sexual and gender minorities, and a failure to account for the challenges faced by those with a low socio-economic status or mental illness, and a lack of attention to age-related changes and concerns. A common thread running through these recommendations is the lack of data collection and availability for these populations. There is a great deal of value in developing and implementing ethical processes for collecting and using Alberta-specific data on individuals with mental health disorders, Indigenous peoples, racialized individuals, sexual and gender minorities, and various age groups to identify where resources are needed in the cancer care continuum.

Next Steps

Alberta is well placed to meet the challenges ahead. Significant progress has been made on the strategies outlined in *Changing our Future: Alberta's Cancer Plan to 2030*, and we have a strong foundation thanks to our provincial approach to providing high-quality and safe cancer treatment and care, a robust cancer data ecosystem, a thriving cancer research community and a strong network of health system and community stakeholders dedicated to improving outcomes and experiences for people in Alberta who are facing cancer.

However, FOCI in Alberta provides evidence to suggest that more work is required if we are to be ready to face the challenges imposed by a yearly increase in numbers of people being diagnosed and living with cancer. FOCI in Alberta is intended as a call to action for everyone in Alberta who will face cancer in some way, specifically to catalyze discussion about how Alberta:

EXPLORES novel approaches to implementing what we know about cancer prevention, screening, risk reduction, and treatment;

IMPROVES how patients and their loved ones are supported during diagnosis, treatment, supportive, palliative and end-of-life care, with an emphasis on communication, value, coordination of care, education and access to appropriate help at the right time;

OPTIMIZES the cancer workforce and care infrastructure to ensure that there is sufficient capacity and expertise, and that human and facility resources are used appropriately to deliver care that is safe and of the highest possible quality;

ENHANCES Alberta's cancer data ecosystem to help identify and address existing and emerging issues for people affected by cancer; and finally,

BUILDS CAPACITY to explore, design, implement and evaluate innovative models of cancer care that ensure care is equitable, safe, sustainable and accessible for all people living in Alberta.

Together we will work towards an Alberta where most cancers are prevented, more cases of cancer are cured, and the suffering of people affected by cancer is dramatically reduced.

ALBERTA'S CANCER ECOSYSTEM

Alberta is the government department that sets policy, legislation and standards for the health system in Alberta.

Alberta Health Services

Alberta Health Services (AHS) is the provincial health agency tasked with delivering health services to Albertans.

Strategic Clinical Networks (SCN)

With SCNs, Alberta Health Services brings together people who are passionate and knowledgeable about specific areas of health, challenging them to find new and innovative ways of delivering care to provide better quality, better outcomes and better value for every Albertan.

Alberta Health Services' Cancer Strategic Clinical Network (SCN)

The Cancer SCN is part of the fabric of cancer prevention, treatment and care in Alberta. It is a broad network of patients, health experts and community partners, with a mandate to improve experiences and outcomes of Albertans who face cancer, and to address the increasing burden and high costs to the health system.

PATIENT & FAMILY FOCUSED

Cancer Care Alberta

Cancer Care Alberta (CCA) provides expert care for patients through diagnosis to survivorship. It sets the direction for cancer care in Alberta while supporting patients to not only survive but to thrive, living well with cancer and beyond – all on a foundation of world class research.

Primary Care

Primary Care refers to the services in the community that support our day-to-day health needs, often accessed through family doctors, nurse practitioners, pharmacists, nurses, dietitians, etc. In Alberta, most primary healthcare is organized and delivered through Primary Care Networks (PCNs) and their member clinics.
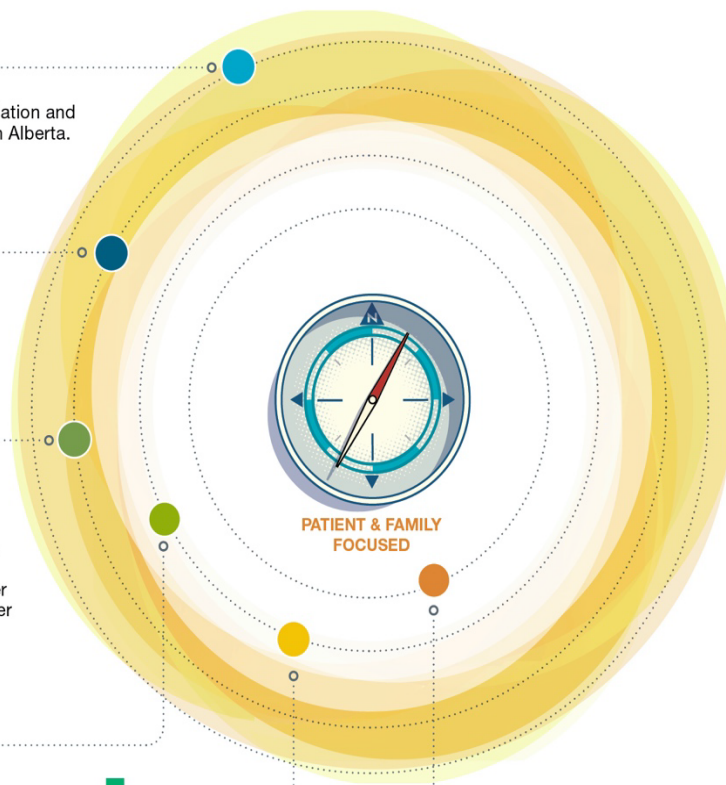
PLANNING AHEAD

The following strategic plans laid the groundwork for Future of Cancer Impact (FOCI) in Alberta

Changing our Future – Alberta's Cancer Plan to 2030
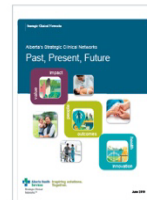
Alberta's Strategic Clinical Networks: Past, Present, Future
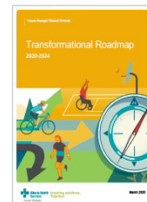
Cancer SCN's Transformational Roadmap 2020–2024

ENGAGEMENT

Future of Cancer Impact (FOCI) in Alberta has been a collaborative effort, designed to collect and reflect the knowledge, experiences and perspectives of individuals within and beyond Alberta's scientific and clinical community.

The FOCI in Alberta Working Group participated in initial discussions, provided input on scope and areas of focus, and shared valuable feedback. Subject matter experts and advisors helped in the definition of the approach, contributed information and ideas, reviewed material and validated the overall content.

Patients and families are at the heart of cancer care.

To align the values of the report with patients and families, those with first-hand knowledge were included in the working group.

FOCI IN ALBERTA
WORKING GROUP

SUBJECT
MATTER EXPERTS

SECTION
CONTRIBUTORS

EXTERNAL
REVIEWERS

PATIENT & FAMILY
INPUT
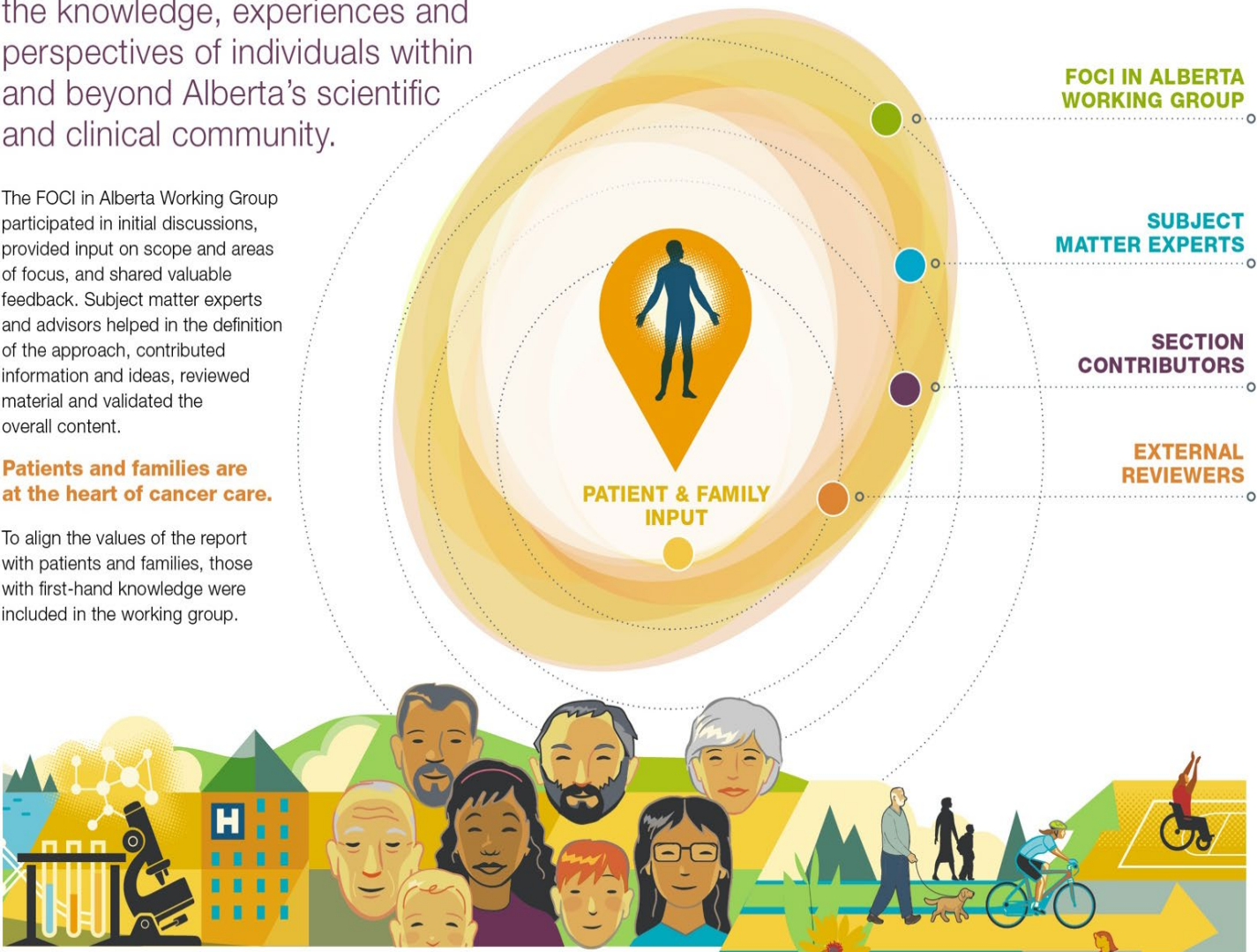
THE FOCI APPROACH

Future of Cancer Impact (FOCI) in Alberta is intended as both a catalyst and a resource to bolster Alberta's drive towards innovation and quality improvement across the entire cancer continuum.

The work involved collating and synthesizing existing evidence to articulate the current and future state of cancer care in Alberta, and identifying gaps and opportunities.

Historical and up-to-date data examining cancer incidence, prevalence, mortality and survival was collected and analyzed to generate projections and estimates of future impact.

Literature reviews of both published and grey literature were completed to obtain relevant data and information around topics of interest.

Stakeholder engagement and collaboration were integral in the planning, development, review and validation of the data, concepts and ideas put forward in the report.

Alberta-specific programs and research were sought out and given priority consideration.

COLLECT DATA

COLLABORATE

ANALYZE

IMPLEMENT

SYNTHESIZE

INTEGRATE

EVALUATE

WHERE WE'RE GOING...

REVIEW CURRENT LANDSCAPE

IDENTIFY GAPS AND OPPORTUNITIES

INFORM ACTION
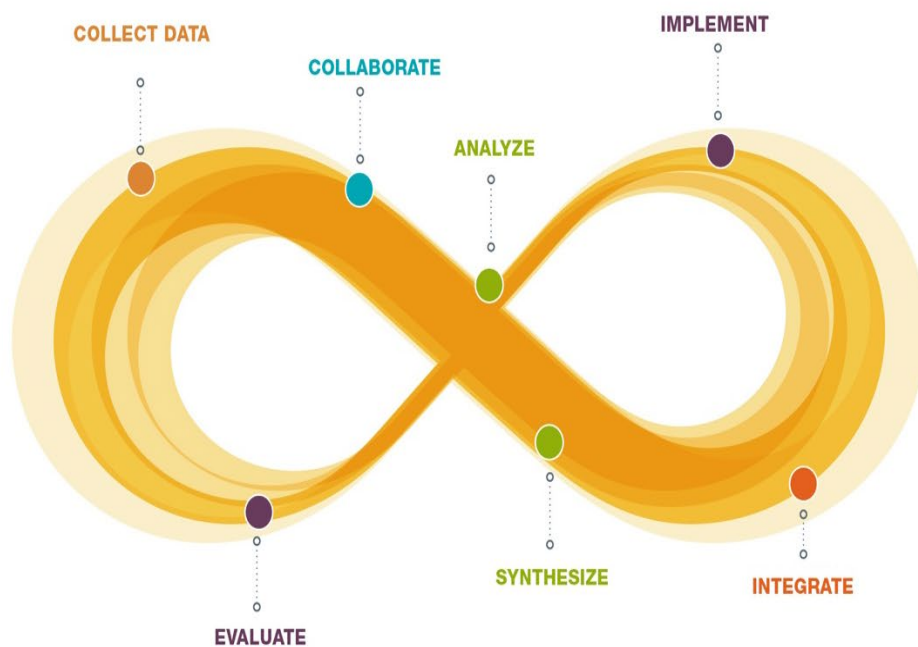
I.   Cancer data and trends

Current and projected data on cancer incidence, prevalence, mortality and survival are essential for planning purposes and ensuring adequate infrastructure and resources are in place for cancer screening, diagnosis, treatment and support services now and in the future. In addition, these data provide the foundation for informing the design of future cancer prevention and control programs and research as well as priorities for health promotion activities and policy. In this section, we provide up-to-date estimates on cancer incidence, prevalence, mortality and survival in Alberta up to the year 2040.

Summary of evidence needs and research gaps

In Alberta, we are fortunate to have access to high-quality, population-level cancer data. In this section, we highlight how these data can be used to estimate the future impact of cancer in Alberta in terms of incidence, prevalence, mortality and survival. We also provide recommendations about how to enhance the current cancer data infrastructure further, ensuring that it will be well placed to support future needs for evidence generation, innovation and evaluation.

- Implementation of a systematic approach to cancer epidemiology and monitoring, with the goal of proactively identifying and taking action on trends and disparities in cancer incidence, mortality and survival, as well as impacts of innovations in screening programs, cancer prevention, and other cancer care initiatives

- Population-level data for measures of equity, diversity and inclusion within the cancer care and data environment. This will allow exploration and evaluation of the impact of inequalities across the cancer care spectrum that are presently believed to exist but difficult to quantify. These should include clinical data that incorporate measures of race, ethnicity, sex, gender, age, health and functional status and socio-economic status. As this is an issue in all cancer registries in Canada, the Canadian Cancer Society is currently co-leading a pan-Canadian cancer data strategy with the Canadian Partnership Against Cancer (CPAC) that focuses on enhancing data collection, integration and use to improve cancer care and outcomes for all people in Canada. A similar strategy should be prioritized in Alberta as these data are crucial for understanding disparities in cancer care, resource access and outcomes.

- Given the varying needs and concerns of people with cancer at various ages and life stages, it is critical to consider the age distribution in current and future cancer incidence, prevalence, mortality, and survival.

- Data to characterize the current and changing environmental impacts on cancer in Alberta and Canada. With the often long latency between environmental exposures and cancer development, studies of environmental exposures have previously been challenging at the population-level. To facilitate these studies, data resources

continue to be developed and investigated studies. The [Canadian Census Health and Environment Cohorts](#) (CanCHECs) and the [CanPATH](#) cohorts will be invaluable to evaluate known, novel and emerging environmental exposures.

- Reduced time lag in data collection and release to evaluate system and patient-level impacts of disruptive events, such as those due to COVID-19, or other future perturbations to the health system

- Improved linkage between registry and treatment databases and evaluation of prevention and screening activities in terms of intermediate and longer-term outcomes

- Increased capacity to analyze and interpret economic data to support analyses of impacts of increasing incidence, mortality and survival on provision of cancer care across the continuum

- Additional research into the optimal, long-term management of surveillance to maximize outcomes and system efficiency. As cancer survival is projected to improve, a larger proportion of people with cancer will require long-term follow-ups and supportive care for recovery. The demand for these types of services will increase in the future.

Chapter 1: Cancer incidence

Key findings

- The number of incident cancer cases in Alberta is projected to increase by 29% from 2020 to 2030 and by 56% from 2020 to 2040, while the age-standardized incidence rate is projected to decrease by 3% over this same period.

- It is projected that the top 10 cancer sites will account to approximately 33,773 cases of cancer diagnosis in Alberta by the year 2040.

- Breast, lung, prostate, and colorectal cancer are the most common cancers in Alberta in 2020, and they are expected to remain so in 2040, attributing to 47% of all cancer cases.

- From 2020 to 2040, the largest absolute increases in annual incidence are projected for breast cancer (2,255 additional cases), lung cancer (1,019 additional cases), melanoma (790 additional cases), prostate cancer (774 additional cases) and colorectal cancer (699 additional cases).

Recommendations

- Projected declines in the overall age-standardized incidence rate suggest that prevention initiatives are working. Support expanded cancer prevention efforts in the areas of tobacco smoking, obesity, physical inactivity, and alcohol consumption to further reduce cancer incidence rates.

- While prevention efforts will continue to have a positive impact on reducing incidence rates overall and for certain cancers, the numbers of new cancer cases will continue to increase over the next two decades. Plan and prepare the health care system for the projected increase in cancer cases, beginning with detailed examination of the workforce, equipment, and infrastructure needs.

- Greater participation in population-based screening programs is likely to have a positive impact on mitigating the increasing incidence of cancer in Alberta. Implement targeted approaches with specific populations to improve prevention and screening.

- Develop a systematic approach to monitoring trends in incidence, augmented with additional socio-demographic variables. Integrate data systems to identify and address issues and changes as they emerge.

Cancer incidence is the number and rate of new cases of cancer diagnosed each year.

Background

In Alberta, 1 in 2 people will develop cancer in their lifetime.[1] The number of new cases of cancer occurring each year (incidence) is an important measure of cancer impact for populations and health care systems. Past trends in the incidence rates of cancer and population projections can be used to predict the number of new cases of cancer that will occur in the future.

Long-term projections of cancer incidence are essential for health care resource planning including screening, diagnosis and treatment of cancer. Early diagnosis of cancer is important, since the earlier a cancer is diagnosed the greater probability of survival and less aggressive treatment – minimizing long-term side effects. Given that screening for certain cancers (e.g., breast, colorectal, cervical and lung cancers) as well as adequate diagnostic practices may lead to the detection of cancer at earlier stages, it is important that there are sufficient resources for those cancer services. All types of cancer generally require some form of treatment including surgery, radiation, chemotherapy and, in some cases, palliative care. The needs and concerns of people with cancer at various ages and life stages may vary. It is therefore important to have an

estimate of the number of cancer cases overall and for specific tumor types and age groups, to ensure that there are adequate and appropriate treatment resources and personnel to provide care.

Projecting cancer incidence is also important for informing cancer care programs to better target and prioritize prevention initiatives. Identifying the cancer sites that are projected to have the largest increases in cases, and consideration of the age distribution of new cancer cases, allows cancer care programs to allocate resources to prevention initiatives that are likely to have the greatest impact on incidence and mortality. The systematic examination of age-standardized cancer incidence rates over time can provide estimates of the impact of established and novel prevention initiatives and provide evidence of emerging or increasing prevalence of exposure to cancer risk factors that require further research. Consideration of differences in incidence rates across age groups is needed to appropriately tailor prevention and screening programs.

The incidence of cancer in Alberta has increased over the past 30 years with 22,215 cases projected to occur in 2021.[1] Since 1998 there has been a 120% increase in the number of new cancer cases with most of the increase attributed to population growth and aging.[1] The increasing number and proportion of older adults in our cancer population may present unique needs and concerns that must be considered in resource planning. The most commonly diagnosed cancers in Alberta are breast, prostate, lung and colorectal cancers, which account for a combined 50% of new cases.[1] Given the large increase in the number of cancer cases in Alberta over the past 30 years, it is important to determine if this trend will continue and to what magnitude. In addition, it is important to determine which cancer sites have the largest increases in incidence to inform specific resource planning.

In this chapter, we project the incidence of all cancers combined and the top 10 cancer sites separately in Alberta to 2040.

Analytic approach

Cancer incidence data in Alberta from the years 1998 to 2018 by cancer site, sex and five-year age group were acquired from the Surveillance & Reporting group within

Cancer Care Alberta, Alberta Health Services. Future incidence rates and absolute cases were estimated using the Canproj statistical tool, which was developed in Alberta and is used nationally.[2] Additional details on Canproj, and the methodology and analytic approach used to calculate and discuss cancer incidence are presented in Appendix 3.

Projected cancer incidence

It is estimated that the overall number of incident cancer cases in Alberta is projected to increase by 29% from 2020 to 2030 and by 56% in 2040, with slightly larger proportional increases for females compared to males (Table 1; Figure 1). Under this projected scenario, there will be an estimated total of 33,773 incident cancer cases by 2040 in Alberta, with 16,846 occurring among males and 16,927 among females. Further efforts to discuss projected incidence would benefit from considering age distribution of cancer cases. In 2019, 54% of new cancer cases in Alberta occurred in people aged 65 years or older, and 26% occurred in those aged 75 years or older.[3]

Table 1. Projected cancer incidence overall and for the top 10 sites by sex in the years 2030 and 2040 in Alberta

	Total					Males					Females				
	2020	2030	Change %	2040	Change %	2020	2030	Change %	2040	Change %	2020	2030	Change %	2040	Change %
All	21,615	27,929	29.2	33,773	56.2	10,919	13,853	26.9	16,846	54.3	10,696	14,076	31.6	16,927	58.3
Breast*	3,278	4,513	37.7	5,533	68.8	NA	—	—	—	—	3,278	4,513	37.7	5,533	68.8
Lung	2,608	3,259	25.0	3,627	39.1	1,265	1,610	27.3	1,920	51.8	1,343	1,649	22.8	1,707	27.1
Prostate	2,526	2,752	8.9	3,300	30.6	2,526	2,752	8.9	3,300	30.6	NA	—	—	—	—
Colorectal	2,167	2,463	13.7	2,866	32.3	1,214	1,321	8.8	1,506	24.1	953	1,142	19.8	1,360	42.7
Bladder	1,083	1,471	35.8	1,760	62.5	850	1,179	38.7	1,419	66.9	233	292	25.3	341	46.4
Melanoma	902	1,329	47.3	1,692	87.6	487	780	60.2	1,056	116.8	415	549	32.3	636	53.3
Lymphoma	957	1,254	31.0	1,458	52.4	537	716	33.3	832	54.9	420	538	28.1	626	49.0
Kidney	783	1,158	47.9	1,445	84.5	522	802	53.6	1,001	91.8	261	356	36.4	444	70.1
Thyroid	679	1,013	49.2	1,248	83.8	187	279	49.2	338	80.7	492	734	49.2	910	85.0
Uterus	729	968	32.8	1,190	63.2	NA	—	—	—	—	729	968	32.8	1,190	63.2

*While males do get breast cancer, it is rare and not among the top cancer sites for males.
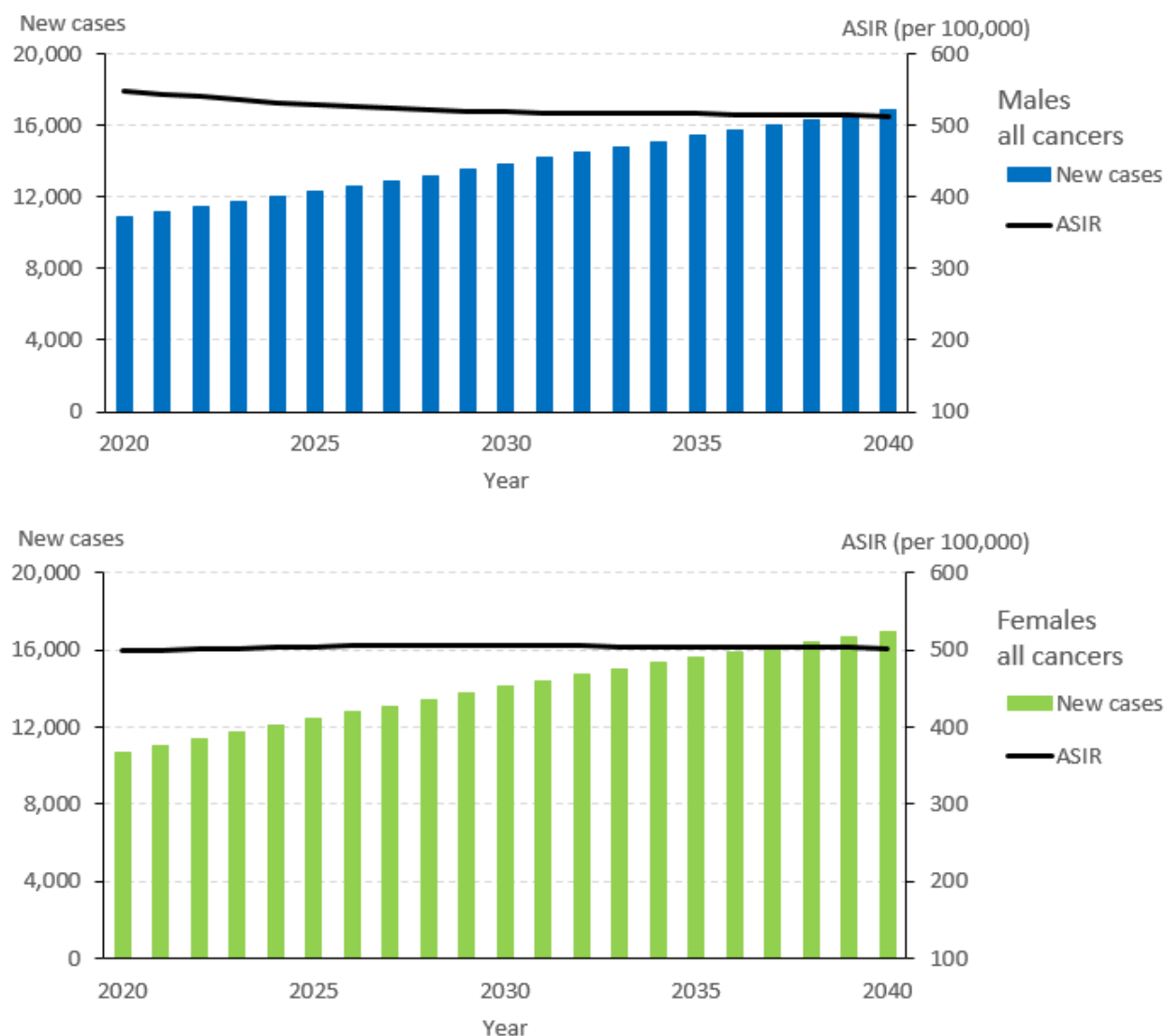
Figure 1. New cases and the age-standardized incidence rate (ASIR) for all cancers, 2020–2040

From 2020 to 2040, the largest absolute increases in the annual incidence are projected for breast cancer (2,255 cases), lung cancer (1,019 cases), melanoma (790 cases), prostate cancer (774 cases) and colorectal cancer (699 cases). Among males, the largest absolute increases are projected for prostate cancer (774 cases), lung cancer (655 cases), melanoma (569 cases) and bladder cancer (569 cases), while the largest

absolute increases for females are projected for breast cancer (2,255 cases), uterine cancer (461 cases), thyroid cancer (418 cases) and colorectal cancer (407 cases).

Among specific cancer sites, the largest relative increases in the number of incident cases by 2040 are projected for melanoma, kidney cancer and thyroid cancer, while the smallest relative increases are projected for prostate cancer, colorectal cancer and lung cancer. Among males, the largest relative increases are projected for melanoma, kidney cancer and thyroid cancer, while the smallest relative increases are projected for colorectal cancer and prostate cancer. Among females, the largest relative increases are projected for thyroid cancer, kidney cancer and breast cancer, while the smallest relative increases are projected for lung cancer and colorectal cancer.

While the overall number of incident cases of cancer in Alberta in 2040 is projected to increase from 2020, the age-standardized incidence rate (ASIR) is projected to decrease by 3% over the 20-year period (Table 2, Figure 2). By 2040, the ASIR is projected to decrease by 6% for males but increase by 1% for females. The ASIR is projected to decrease by greater than 15% for lung, prostate and colorectal cancers, but increase by more than 10% for thyroid cancer, kidney cancer, melanoma and breast cancer. When comparing changes in the ASIR by sex, the decrease in the colorectal cancer rate for males is projected to be greater compared to the rate for females (-21% vs. -11%), while the decrease in the lung cancer rate is projected to be greater in females (-39% vs. -17%) and bladder cancer (-28% vs. -15%). In terms of the increasing ASIRs, the increase for kidney cancer is projected to be greater for males (26% vs. 8%). Rates of melanoma are projected to increase for males and decrease for females.

Table 2. Projected age-standardized cancer incidence rates (per 100,000) overall and for the top 10 sites by sex in the years 2030 and 2040 in Alberta

	Total					Males					Females				
	2020	2030	Change %	2040	Change %	2020	2030	Change %	2040	Change %	2020	2030	Change %	2040	Change %
All	523.68	512.0	-2.2	507.8	-3.0	548.5	519.1	-5.4	513.4	-6.4	498.1	504.7	1.3	502.0	0.8
Breast*	154.1	166.1	7.8	173.0	12.3	—	—	—	—	—	154.1	166.1	7.8	173	12.3
Lung	63.83	56.5	-11.4	50.4	-21.0	65.7	58.9	-10.4	56	-14.8	61.9	54.1	-12.6	44.7	-27.8
Prostate	123.7	102.0	-17.5	101.2	-18.2	123.7	102	-17.5	101.2	-18.2	NA	—	—	—	—
Colorectal	52.88	45.9	-13.2	44.0	-16.7	61.1	50.9	-16.7	48.5	-20.6	44.4	40.8	-8.1	39.5	-11.0
Bladder	28.16	27.1	-3.7	25.1	-10.8	45.1	44.2	-2.0	41.2	-8.6	10.7	9.6	-10.3	8.7	-18.7
Melanoma	21.03	23.4	11.3	23.5	11.6	22.7	27	18.9	29.1	28.2	19.5	19.7	2.1	17.7	-8.3
Lymphoma	23.40	22.9	-2.2	21.2	-9.3	27.2	27	-0.7	24.9	-8.5	19.5	18.7	-4.1	17.5	-10.3
Kidney	18.8	21.3	13.3	22.6	20.2	25.3	29.6	17.0	31.9	26.1	12.1	12.8	5.8	13.1	8.3
Thyroid	15.64	19.5	24.9	21.3	36.5	8.6	10.6	23.3	11.2	30.2	22.9	28.7	25.3	31.7	38.4
Uterus	34.3	36.8	7.3	37.0	7.9	NA	—	—	—	—	34.3	36.8	7.3	37	7.9

*While males do get breast cancer, it is rare and not among the top cancer sites for males.
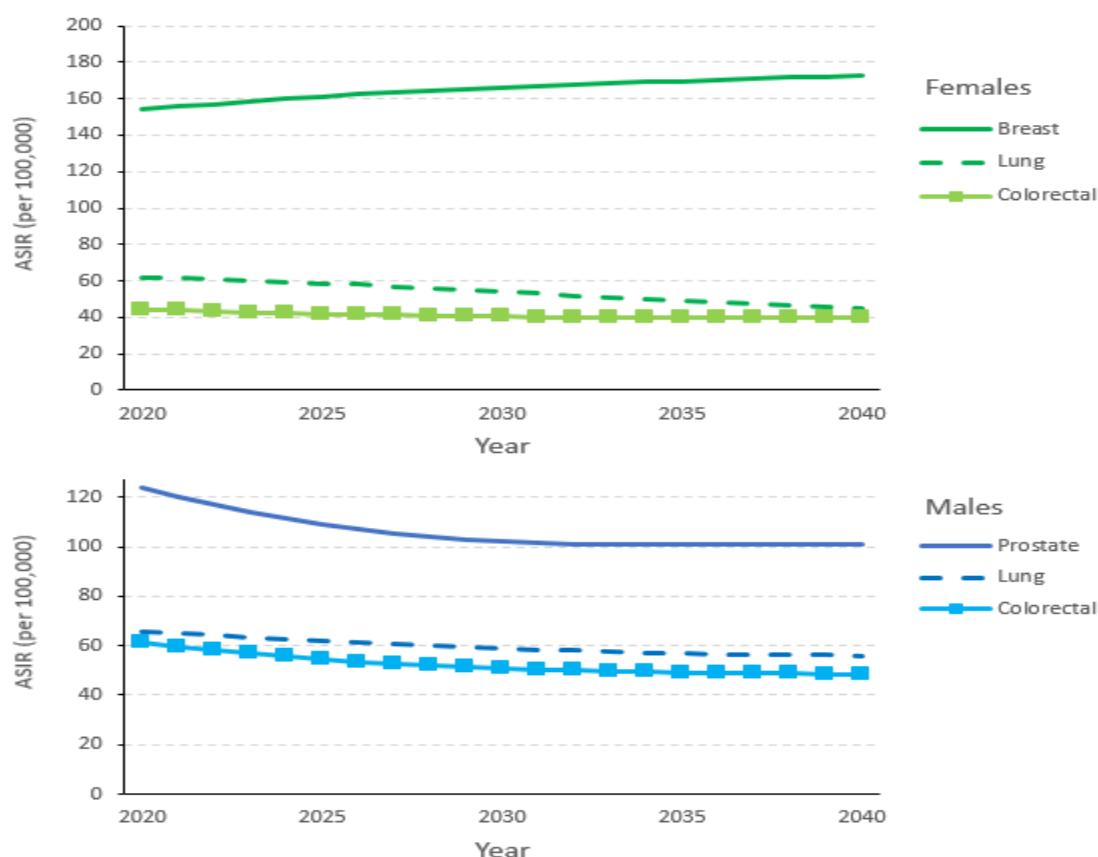
Figure 2. Age-standardized incidence rates (ASIRs) for the most common cancers in females and males

Interpretation and recommendations

From 2020 to 2040, the number of annual cancer cases in Alberta is projected to increase considerably from 21,615 to 33,773 cases with slightly greater increases for females. These increases are driven primarily by an aging population and population growth. The increasing number and proportion of older adults in our cancer population will present unique needs and concerns that must be considered in resource planning. In addition to a large increase in overall cases, the incidences of each of the top 10 most common cancer sites in Alberta are projected to increase considerably with the largest increases projected for breast cancer, lung cancer, melanoma, prostate cancer and colorectal cancer.

The large increase in cancer cases overall will require an increase in resources dedicated to screening, diagnosis and treatment. While a large proportion of breast cancers are already detected at early stages, the large projected increase in breast cancer will require screening to be scaled up to ensure cases continue to be detected at early stages. Similarly, increases in the incidence of colorectal cancer and lung cancer may require increased investment in screening and diagnostics. The large increase projected for melanoma will likely require increases in melanoma-specific treatment resources as well as personnel, such as dermatologists, to ensure early diagnosis and appropriate care. Beyond those cancer sites, thyroid and kidney cancers are projected to have large relative increases in incidence, which may require some upscaling of treatments for those cancers. Given these increases will represent a growing number and proportion of older adults in the cancer population, ensuring appropriate assessment and supportive management of age-related concerns throughout the cancer care trajectory is paramount to ensure appropriate diagnostic and treatment decision making and support optimal outcomes.

From 2020 to 2040, the ASIR of cancer overall is projected to decrease by 3%, which shows progress is being made in the prevention of several leading cancers. However, there is variation by sex with a considerable decrease projected for males (-6%) but a slight increase projected for females (1%). The projected increase for females is primarily driven by an increase in the incidence rate of breast cancer, which is likely a

product of an increase in the prevalence of risk factors such as obesity, physical inactivity and alcohol consumption,[4] as well as changes in protective factors (pregnancy and breast feeding).[5,6] Initiatives targeting these risk factors may help to attenuate the increasing incidence of breast cancer.

ASIRs for some of the commonly diagnosed cancers are declining, which reflects success in cancer care activities around primary prevention (tobacco for lung and bladder cancers), changes in detection practices and increases in participation in population-based screening programs. The ASIR for lung cancer is projected to decrease considerably with a greater decrease for females. The projected decrease for lung cancer can be explained by reductions in the prevalence of smoking, and the larger decrease for females can be explained by the delayed decrease in the prevalence of smoking compared to males.[7] Similarly, the ASIR for bladder cancer is projected to decrease and is also likely a product of decreasing smoking prevalence. While these projected decreases demonstrate that cancer care activities around tobacco are working, there is more to be done given that 72% and 39% of lung and bladder cancer cases, respectively, have been attributed to tobacco smoking.[4] The projected decrease in prostate cancer is primarily due to a decrease in the use of the prostate-specific antigen (PSA) test, which is no longer recommended for males over 75 or asymptomatic males of all ages in Canada.[8] The ASIR for colorectal cancer is projected to decrease for both males and females, which can likely be attributed to the uptake in colorectal screening. However, the colorectal cancer screening uptake remains suboptimal in Alberta (~60%) with room for improvement. In addition, the prevalence of certain risk factors for colorectal cancer, including obesity and physical inactivity, continues to increase in Alberta.[4] Given that these are some of the most common cancer sites, continued efforts to decrease the prevalence of smoking, obesity and physical inactivity, as well as efforts to increase the uptake of colorectal screening, will be important for reducing the impact of cancer in Alberta in the coming years.

Among less common cancer sites, including melanoma, kidney cancer, thyroid cancer and uterine cancer, ASIRs are projected to increase by 2040. The increase in the ASIR for melanoma is projected for males only and may indicate increasing poor sun safety

behaviors among males.[9] Preventive initiatives for promoting sun safety behaviors, particularly interventions that are effective for males, will be important in reducing this projected increase for melanoma. Obesity is a risk factor for uterine, kidney and thyroid cancers, and it is plausible that the projected increase in obesity is partially responsible for the projected increases in ASIRs for these cancers.[10] Given the importance of obesity in the etiology of more common cancer sites, initiatives to reduce the prevalence of obesity should be a top priority. The increase for thyroid cancer may also be attributable to overdiagnosis; efforts to address this issue should be considered.[11]

Given the higher cancer incidence rates in older age groups, particular attention must be paid to targeted communication related to prevention and awareness of signs and symptoms to promote early diagnosis, as well as integration of appropriate frameworks to inform decision-making related to screening decisions, among older adults.

Conclusions

The overall number of incident cancer cases in Alberta is projected to increase considerably by 2040, so additional resources dedicated to screening, early detection, diagnosis, treatment and care will be required. Despite an increase in the absolute number of cancer cases, the ASIR is projected to decrease slightly, indicating some success in cancer care programs and screening. However, ASIRs for some cancer sites are projected to increase, which highlights the importance of allocating resources to primary and secondary prevention programs. Coordinated and sustained efforts to reduce the prevalence of tobacco smoking, obesity, physical inactivity and alcohol consumption, as well as greater participation in population-based screening programs, are likely to have a positive impact on mitigating the increasing incidence of cancer in Alberta. These efforts cannot be directed solely at individuals; there must be ongoing exploration of the roles played by social and environmental factors in influencing behavior and passive exposures that are likely to affect cancer risk. Robust approaches to monitoring of incidence must continue, augmented by additional data that will help advance understanding of potential disparities by cancer type and socio-demographic variables. There is also a need for more research to advance our understanding of how to implement and evaluate effective cancer prevention programs at the levels of

individuals, communities and workplaces, and public policy. Finally, it must be recognized that while coordinated and sustained prevention efforts will have a positive impact on reducing incidence rates overall and for certain cancers, the numbers of new cancer cases will continue to increase over the next two decades, with an increasing proportion of older adults. The health care system needs to prepare now for the projected increase.

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Chapter 2: Cancer prevalence

Key findings

- From 2000 to 2019, the one-year limited-duration prevalence of all cancers in Alberta increased by 85% from 9,627 to 17,810.

- Breast and prostate cancers account for 17% and 15%, respectively, of all prevalent cases, followed by colorectal cancer (10%) and lung cancer (9%).

- From 2019 to 2040, the 1-, 2-, and 5-year prevalence is expected to increase from 17,180 to 31,339 cases (1-year prevalence), from 33,020 to 60,004 cases (2-year prevalence), and from 70,687 to 131,660 cases (5-year prevalence), respectively.

- Compared to the prevalence rates in 2019, the relative increases in one- two- and five-year prevalence rates are 8%, 11% and 13%, respectively. This reflects the impact of improved survival rates, so that more people with cancer are living longer.

- The current four most prevalent cancers – breast, prostate, colorectal and lung cancers – will continue to be the most prevalent in 2040. However, the 5-year prevalence of colorectal cancer will surpass prostate cancer as the second most prevalent cancer in 2034.

Recommendations

- The projected increases in cancer prevalence will pose a considerable impact on the utilization of services. Undertake planning to optimize the cancer care workforce.

- The proportion of people living with cancer has been growing due to considerable improvements in cancer care. Examine and understand the needs of people living longer with cancer and explore innovative ways of delivering care.

Background

In this chapter, we present the projection of limited-duration prevalence of all cancers combined as well as the 10 most common cancer types in Alberta to 2040. Cancer prevalence is an important measure of cancer impact in a population. It is an estimate of

the proportion of people who are alive and have been diagnosed with cancer either recently or in the past. An increasing trend in cancer prevalence could indicate an increase in cancer incidence, an increase in cancer survival, or a combination of both. Therefore, cancer prevalence is a composite indicator of cancer incidence, mortality and survival. Understanding cancer prevalence in a population is essential in the resource planning for diagnostics, treatments, patient care resources, follow-ups and survivorship supports.[1-3] Recently, estimated and projected cancer prevalence have received more attention, as the proportion of people living with cancer has been growing due to considerable improvements in cancer care. Most people with cancer require treatment, long-term monitoring for recurrence and screening for other cancers. They also carry an increased risk of permanent impairment or disability.[1] Projections of cancer prevalence provide useful information in predicting the demand for future cancer-related health care and social services, and in planning for anticipated challenges.[4]

Analytic approach

Details on the methodology and analytic approach are presented in Appendix 3.

Current cancer prevalence – different trends in rates between sexes and among cancer types

From 2000 to 2019, the one-year prevalence of all cancers in Alberta increased by 85% most commonly diagnosed cancers, breast and prostate cancers were the most prevalent, with 3,094 and 2,585 cases, respectively (one-year prevalence) in 2019. In 2018, In 2018, in considering 5-year prevalence, those aged 60 years and older accounted for 66% of prevalent cases and those aged 70 years and older accounted for 37% of prevalent cases.[5] Breast and prostate cancers accounted for 17% and 15%, respectively, of all prevalent cases, followed by colorectal cancer (10%) and lung cancer (9%). Together, these four cancers accounted for 50% of all prevalent cases, and the 10 cancers with the highest incidence accounted for more than 75% of all prevalent cases in 2019.

Cancer prevalence is a measure of the number of people alive at a specific point in time, in a given population, who were previously diagnosed with cancer.

Table 3. Cancer prevalence and age-standardized prevalence rates (number of prevalent cases per 100,000) of the 10 most commonly diagnosed cancers in Alberta in 2000 and 2019

Sex	Cancer Type	One-Year Prevalence		Two-Year Prevalence		Five-Year Prevalence	
		2000 N (ASPR)	2019 N (ASPR)	2000 N (ASPR)	2019 N (ASPR)	2000 N (ASPR)	2019 N (ASPR)
Males	Prostate	1,747 (193.9)	2,585 (134.4)	3,267 (361.7)	4,960 (258.5)	6,617 (742.6)	11,323 (598.5)
	Colorectal	650 (69.9)	975 (53.5)	1,161 (126.5)	1,852 (101.1)	2,199 (245.8)	4,232 (234.1)
	Bladder	356 (39.1)	691 (40.8)	653 (71.6)	1,322 (78.1)	1,370 (151.8)	2,922 (175.2)
	Lung	372 (40.6)	669 (38.2)	580 (62.6)	1,063 (61.0)	860 (92.7)	1,816 (103.6)
	Melanoma	203 (19.2)	526 (29.0)	406 (38.5)	953 (52.9)	794 (74.2)	1,971 (109.1)
	NHL	190 (16.7)	465 (25.1)	352 (32.1)	836 (44.8)	691 (64.3)	1,789 (96.4)
	Kidney	173 (18.0)	374 (18.8)	326 (32.6)	748 (38.1)	633 (62.3)	1,691 (86.9)
	Thyroid	60 (4.9)	152 (7.5)	113 (9.1)	309 (15.0)	205 (16.6)	698 (33.9)
	All	5,032 (525.4)	8,898 (477.1)	8,953 (933.9)	16,317 (874.5)	17,310 (1,823.2)	34,895 (1,879.7)
Females	Breast	1,620 (142.1)	3,094 (154.8)	3,232 (284.5)	5,991 (300.0)	6,907 (614.0)	13,366 (673.9)
	Lung	344 (31.4)	916 (46.3)	540 (49.8)	1,553 (78.2)	844 (78.1)	2,693 (136.0)

	Colorectal	537 (50.7)	743 (38.5)	887 (83.1)	1,395 (72.4)	1,736 (163.5)	3,163 (164.3)
	Uterus	286 (26.6)	662 (32.6)	561 (52.1)	1,265 (62.4)	1,262 (117.4)	2,863 (140.8)
	Melanoma	200 (15.7)	429 (21.1)	403 (31.9)	864 (42.7)	895 (70.1)	1,802 (89.8)
	Thyroid	154 (11.2)	419 (20.0)	268 (19.8)	855 (40.9)	613 (45.2)	1,984 (95.4)
	NHL	165 (14.7)	339 (17.3)	300 (26.7)	637 (32.3)	620 (54.5)	1,410 (71.6)
	Kidney	124 (11.0)	182 (9.2)	199 (17.4)	380 (19.1)	415 (36.9)	883 (43.8)
	Bladder	98 (9.1)	179 (9.3)	205 (18.8)	368 (19.1)	475 (43.6)	802 (41.9)
	All	4,595 (403.8)	8,912 (446.9)	8,406 (737.3)	16,703 (836.4)	17,172 (1,507.2)	35,792 (1,796.7)
Both	Breast	1,620 (72.9)	3,094 (76.8)	3,232 (146.3)	5,991 (149.2)	6,907 (317.0)	13,366 (336.8)
	Prostate	1,747 (87.6)	2,585 (64.5)	3,267 (163.4)	4,960 (124.0)	6,617 (331.8)	11,323 (285.5)
	Colorectal	1,187 (59.6)	1,718 (45.1)	2,048 (102.7)	3,247 (85.1)	3,935 (199.7)	7,395 (195.6)
	Lung	716 (34.8)	1,585 (42.1)	1,120 (54.7)	2,616 (69.5)	1,704 (83.2)	4,509 (119.8)
	Melanoma	403 (16.8)	955 (24.2)	809 (34.0)	1,817 (46.3)	1,689 (69.9)	3,773 (96.1)
	Bladder	454 (22.2)	870 (23.7)	858 (42.0)	1,690 (46.1)	1,845 (90.5)	3,724 (102.7)
	NHL	355 (15.6)	804 (20.8)	652 (29.1)	1,473 (38.0)	1,311 (58.6)	3,199 (82.6)
	Uterus	286 (13.9)	662 (16.2)	561 (27.2)	1,265 (31.2)	1,262 (61.1)	2,863 (70.5)
	Kidney	297 (14.2)	556 (13.6)	525 (24.3)	1,128 (27.9)	1,048 (48.4)	2,574 (63.6)
	Thyroid	214 (7.8)	571 (13.2)	381 (14.2)	1,164 (26.8)	818 (30.4)	2,682 (61.9)
	All	9,627 (449.6)	17,810 (451.9)	17,359 (809.4)	33,020 (836.9)	34,482 (1,609.5)	70,687 (1,798.4)

ASPR, age-standardized prevalence rate; NHL, non-Hodgkin lymphoma

Despite a large increase in cancer prevalence from 2000 to 2019, the age-standardized prevalence rate (ASPR) remained largely unchanged for all cancers in Alberta (450 to 452 per 100,000). In contrast, the two- and five-year ASPRs saw a 4% and 12% increase, respectively, from 2000 to 2019. Among the 10 most commonly diagnosed cancers, thyroid cancer showed the greatest relative increase in ASPR. Lung cancer showed the largest absolute increase in ASPR. In contrast, a large decrease in ASPR was observed for prostate and colorectal cancers. Additional detailed prevalence data for males and females by the top ten cancer sites in Alberta can be found in Table 3.

Projected cancer prevalence – increasing short- and long-term prevalence

Under the projected scenario, we will see a gradual increase in cancer prevalence in Alberta by 2040 (Figure 3). The one- two- and five-year prevalence will rise to 31,339 cases, 60,004 cases and 131,660 cases, respectively, while the ASPRs will increase to 486, 930 and 2,028 per 100,000, respectively. Comparing 2040 to 2019, 1-year, 2-year, and 5-year prevalence will rise by 76%, 82%, and 86%, respectively. (31,339-17,810)/17,810 = 76% increase in 1-year prevalence (60,004-33,020)/33,020 = 82% increase in 2-year prevalence, and (131,660-70,687)/70,687 = 86% increase in 5-year

prevalence. By 2040, we project that the one-year ASPR of all cancers in females (496) will exceed the ASPR in males (483), which aligns with the projection that the gap between the cancer incidence rates in males and females will close (Figure 3).
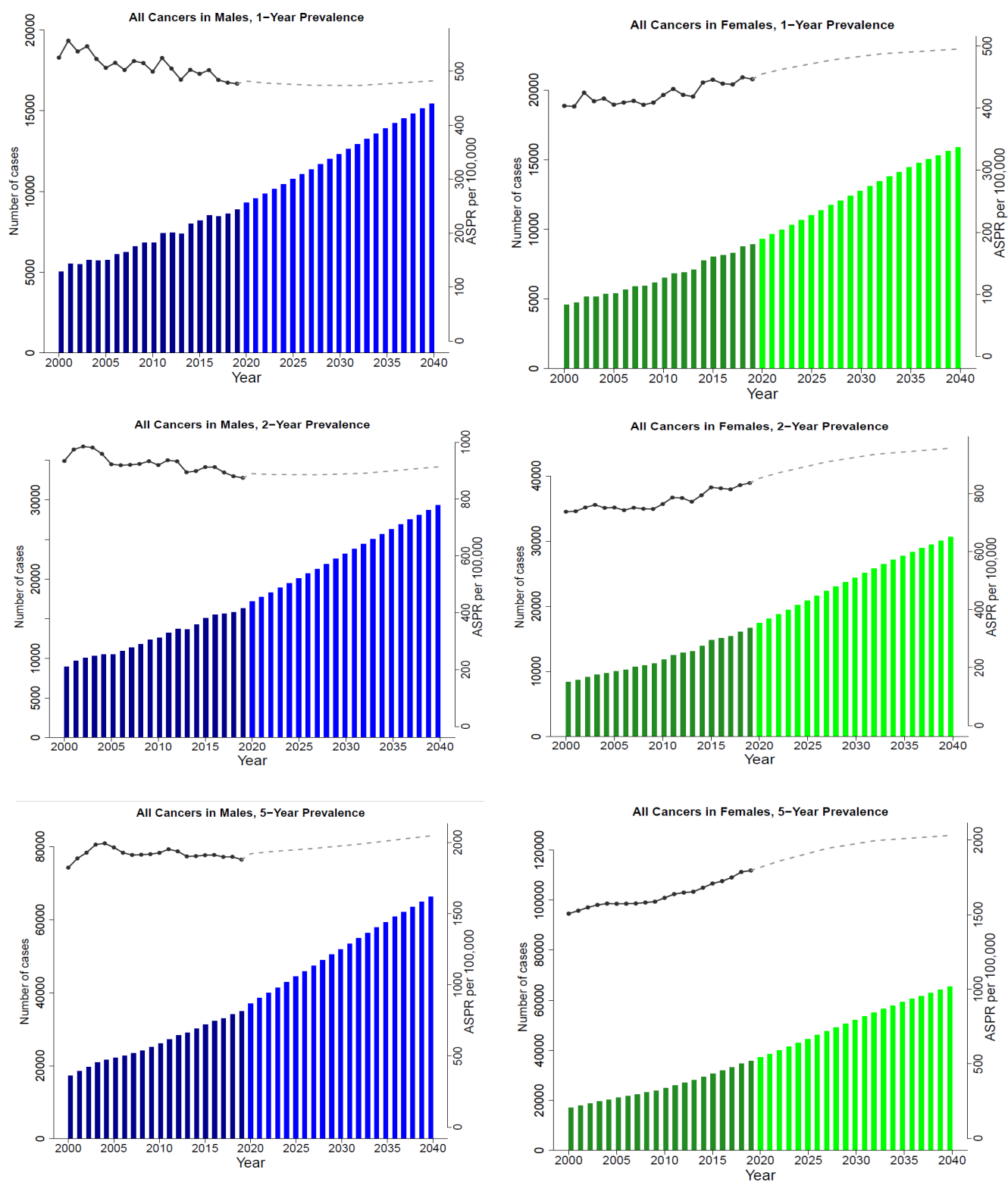
Figure 3. The past and projected cancer prevalence and the age-standardized prevalence rate of all cancers in Alberta, 2000–2040, by sex and duration

Table 4. Projected cancer prevalence and age-standardized prevalence rates (number of prevalent cases per 100,000) of the 10 most commonly diagnosed cancers in Alberta, in 2030 and 2040

Sex	Cancer Type	One-Year Prevalence		Two-Year Prevalence		Five-Year Prevalence	
		2030 N (ASPR)	2040 N (ASPR)	2030 N (ASPR)	2040 N (ASPR)	2030 N (ASPR)	2040 N (ASPR)
Males	Prostate	2,673 (99.5)	2,919 (88.9)	5,150 (192.1)	5,618 (171.0)	12,070 (449.0)	13,174 (399.9)
	Colorectal	1,333 (51.7)	1,748 (55.5)	2,744 (106.1)	3,666 (116.0)	6,266 (243.9)	7,799 (244.1)
	Bladder	1,049 (42.3)	1,275 (39.1)	1,988 (80.4)	2,422 (74.3)	4,632 (187.5)	5,807 (177.3)
	Lung	984 (38.4)	1,250 (37.6)	1,547 (59.0)	1,825 (54.7)	2,767 (106.0)	3,364 (100.9)
	Melanoma	684 (25.3)	872 (27.1)	1,328 (49.2)	1,708 (52.9)	3,193 (117.1)	4,211 (130.3)
	Kidney	661 (26.5)	851 (26.4)	1,199 (48.2)	1,524 (47.2)	2,438 (97.8)	3,034 (94.1)
	NHL	620 (24.2)	752 (23.7)	1,119 (43.7)	1,314 (41.4)	2,569 (100.7)	3,067 (96.1)
	Thyroid	264 (9.9)	335 (10.9)	529 (20.0)	680 (22.3)	1,252 (47.5)	1,651 (54.0)
	All	12,320 (473.9)	15,448 (482.5)	23,182 (888.6)	29,352 (913.9)	51,904 (1,976.8)	66,308 (2,048.7)
Females	Breast	4,402 (168.1)	5,463 (174.5)	8,463 (323.5)	10,525 (336.3)	18,682 (714.8)	23,369 (744.8)
	Uterus	1,014 (38.8)	1,351 (43.4)	2,034 (77.4)	2,754 (88.0)	4,980 (187.2)	6,377 (193.8)
	Colorectal	944 (36.4)	1,169 (37.0)	1,817 (70.1)	2,296 (73.0)	4,012 (152.9)	5,042 (158.9)
	Lung	1,221 (43.1)	1,324 (36.7)	2,141 (75.6)	2,378 (65.9)	4,369 (154.1)	5,250 (146.2)
	Melanoma	622 (24.5)	761 (26.3)	1,254 (49.1)	1,549 (53.2)	2,690 (106.5)	3,230 (110.0)
	Thyroid	499 (18.6)	627 (19.1)	973 (36.0)	1,254 (37.5)	2,216 (82.3)	2,932 (87.0)
	NHL	439 (17.0)	528 (17.0)	1,080 (40.8)	1,388 (41.7)	2,180 (82.7)	2,682 (80.4)
	Kidney	297 (11.5)	369 (11.9)	578 (22.6)	730 (23.7)	1,422 (54.2)	1,804 (58.3)
	Bladder	264 (9.7)	315 (9.0)	509 (18.6)	609 (17.2)	1,056 (38.3)	1,215 (34.0)
	All	12,763 (483.7)	15,890 (495.6)	24,397 (925.1)	30,652 (957.0)	52,124 (1,976.5)	65,351 (2,032.5)
Both	Breast	4,402 (84.1)	5,463 (86.6)	8,463 (161.8)	10,525 (166.8)	18,682 (358.2)	23,369 (369.8)
	Colorectal	2,348 (45.0)	3,099 (49.1)	4,779 (91.3)	6,421 (101.3)	11,246 (214.2)	14,176 (217.8)
	Prostate	2,673 (48.8)	2,919 (44.1)	5,150 (94.2)	5,618 (84.9)	12,070 (219.3)	13,174 (197.8)
	Lung	2,206 (40.7)	2,574 (36.9)	3,688 (67.6)	4,203 (60.5)	7,136 (130.8)	8,614 (124.0)
	Melanoma	1,313 (24.9)	1,590 (23.3)	2,497 (47.4)	3,030 (44.4)	5,688 (108.0)	7,022 (102.3)
	Bladder	1,099 (21.2)	1,379 (21.2)	2,279 (43.7)	2,912 (44.0)	4,618 (88.7)	5,716 (86.3)
	Uterus	1,118 (21.2)	1,379 (21.2)	2,092 (39.6)	2,567 (39.2)	4,785 (90.9)	5,999 (91.0)
	NHL	981 (18.3)	1,241 (19.3)	1,906 (35.5)	2,438 (38.0)	4,614 (84.5)	6,015 (93.2)
	Kidney	944 (18.1)	1,169 (18.4)	1,817 (34.8)	2,296 (36.1)	4,012 (76.1)	5,042 (78.8)
	Thyroid	886 (17.1)	1,096 (18.3)	1,783 (34.1)	2,229 (36.9)	3,943 (76.2)	4,881 (80.8)
	All	25,083 (475.6)	31,339 (486.2)	47,579 (900.9)	60,004 (929.9)	104,029 (1,962.5)	131,660 (2,027.5)

ASPR, age-standardized prevalence rate; NHL, non-Hodgkin lymphoma

The current four most prevalent cancers – breast, prostate, colorectal and lung cancers – will continue to be the most prevalent cancers in 2040. However, colorectal cancer will surpass prostate cancer as the second most prevalent cancer (Figure 4). These four cancers will account for 45% of the prevalence of all cancers in 2040. Similar patterns are also observed for the projected two- and five-year prevalence. Among the four most prevalent cancers in females, the ASPR of breast cancer will continue to rise and be the dominant cancer, whereas the ASPR of lung cancer will decrease to 37 per 100,000

and be surpassed by uterine and colorectal cancers, which are projected to increase respectively to 43 and 37 per 100,000 in 2040 (Table 4). Among the four most prevalent cancers in males, the ASPR for prostate cancer is projected to rapidly decrease, mostly due to a decreasing trend in cancer incidence. In contrast, the ASPRs of colorectal, bladder and lung cancers will only change slightly.
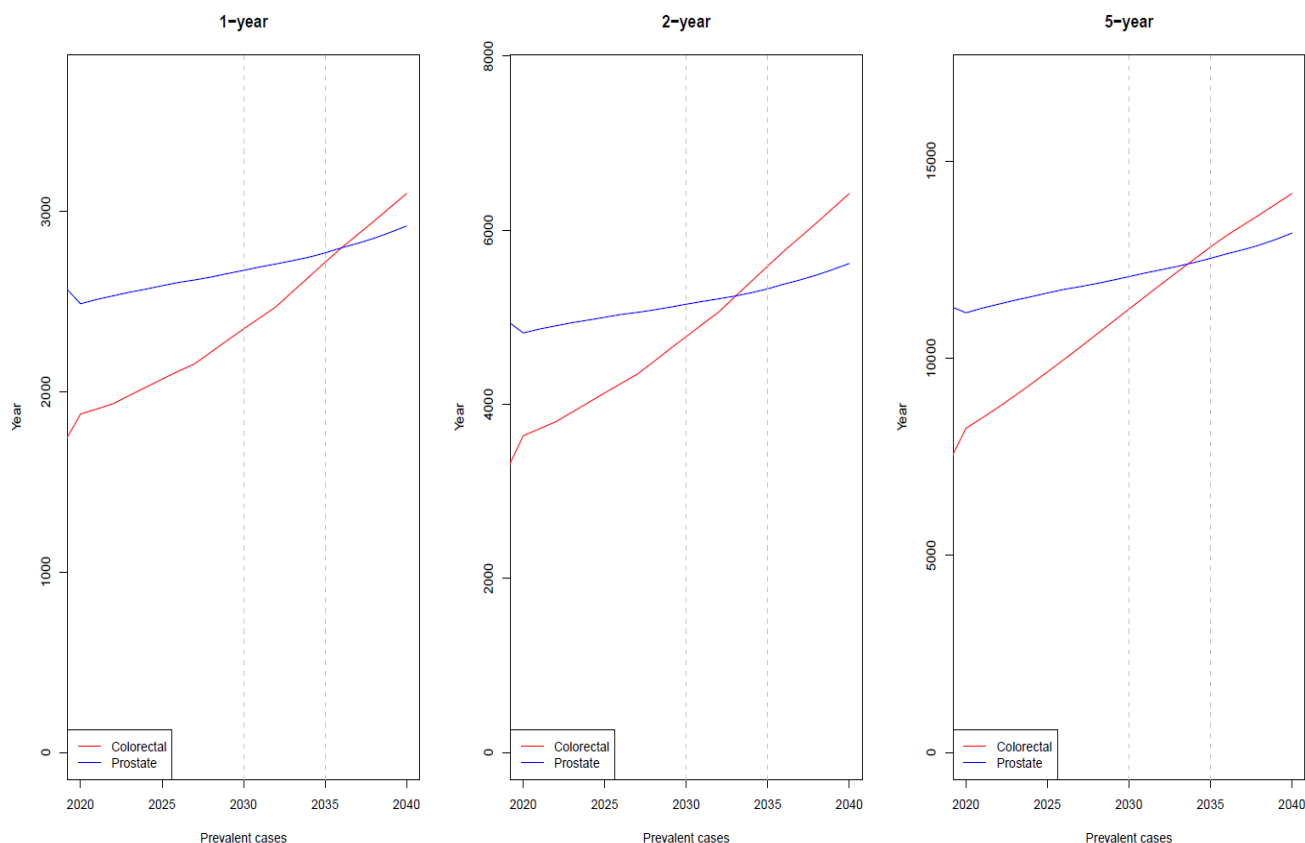
Figure 4. 1-, 2-, and 5-year prevalence of colorectal and prostate cancers from 2020-2040.

Among the other most common cancer types in Alberta, we projected a large relative increase in the one-year ASPRs of thyroid and kidney cancers in both sexes (Table 4). From 2019 to 2040, the ASPRs of thyroid and kidney cancers in males will increase by about 45% and 44% respectively, whereas in females, the ASPRs of these cancers will increase by 32% and 29% respectively.

Differences by sex, age and cancer type

Among females under the age of 45, breast and thyroid cancers are the most prevalent cancers, and the proportion is projected to slightly increase in the future (Figure 5). While the proportion of melanoma, lung and uterine cancers will remain similar, colorectal cancer in this age group is projected to increase from 6% to 13% during the projection period. Taken together, the prevalence of these six cancers is projected to increase from 65% in 2020 to 77% in 2040. Among females aged 45 to 64 years, breast is the dominant cancer type, accounting for 40% of overall prevalence. Uterine, colorectal, melanoma, thyroid and lung cancers are similar in proportion, summing to about 32% of overall prevalence in females. The proportions of these cancers are projected to remain similar from 2020 to 2040, although there is a small increase projected in the proportion of colorectal cancer and a small decrease in lung cancer. Among females aged 65 and over, the proportion of the six most prevalent cancers is similar to that of the 45–64 age group. However, for females aged 65 and over, the proportion of lung cancer is much higher than in the younger age groups. In contrast, thyroid cancer comprises only a small proportion.
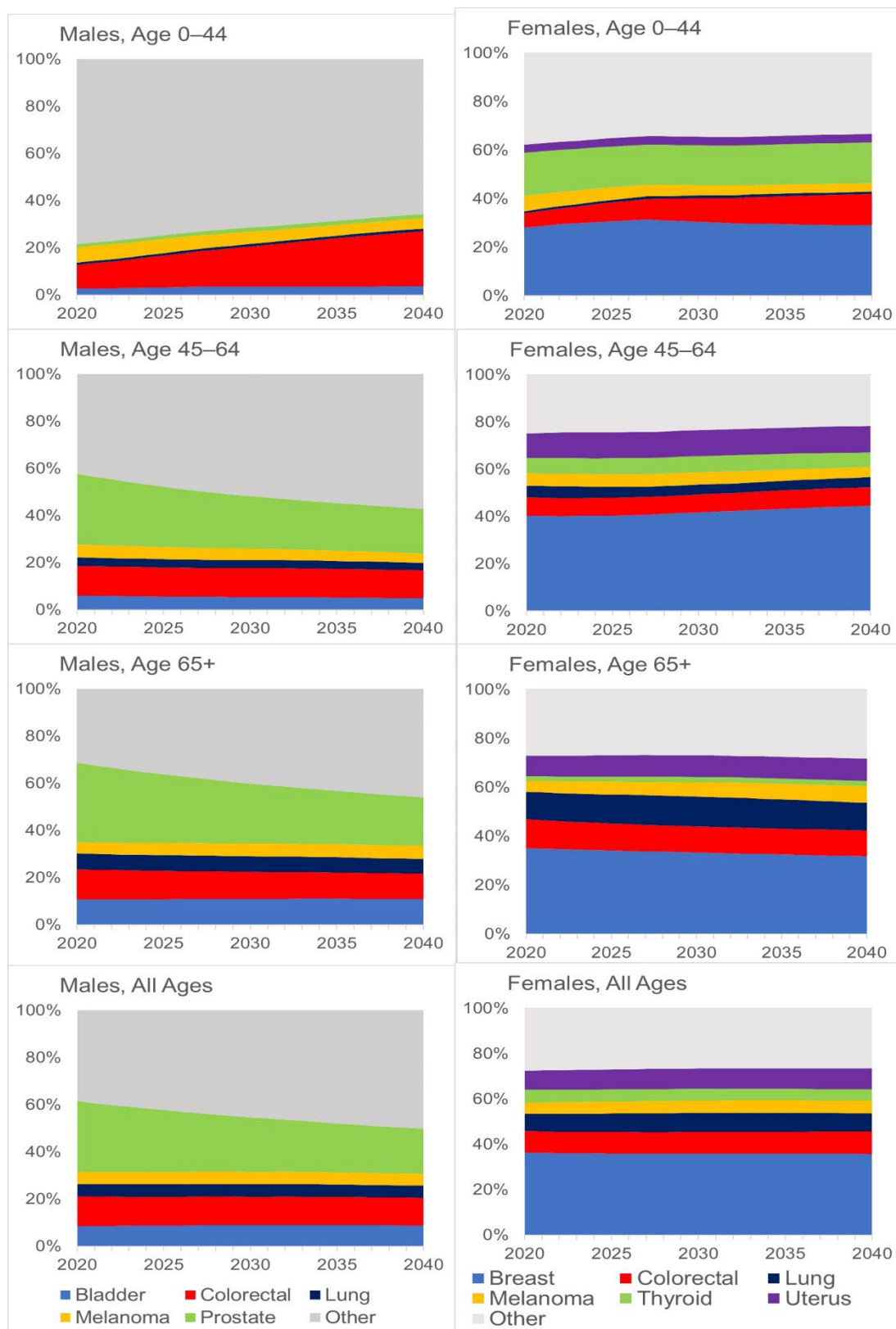
Figure 5. Projected five-year prevalence distribution of the common cancer types in Alberta, 2020-2040, by age group and sex

Among males under the age of 45, colorectal cancer and melanoma are the most prevalent cancers, accounting for 12% and 6% respectively of all cancers. The four most commonly diagnosed cancers in males (prostate, colorectal, bladder, lung) comprise only 20% of all prevalent cancer cases. Similar to females under 45, a moderate increase in the proportion of colorectal cancer from 10% to 13% is projected in males. Among males aged 45 to 64, prostate cancer was the most prevalent cancer in 2020 (28%), although it is projected to decrease to 17% by 2040. The proportions of colorectal cancer, bladder cancer, lung cancer and melanoma are expected to remain stable. Among males aged 65 and over, the five most commonly diagnosed cancers (prostate, colorectal, bladder, lung and melanoma) made up 66% of all cancer prevalence in 2020, and are projected to decrease to 59% by 2040. This is mainly attributable to a decrease in the prevalence of prostate cancer. In this age group, the proportions of lung and bladder cancers are projected to increase significantly compared to the younger age groups.

For the age distribution among breast, prostate, colorectal and lung cancers, these cancers are dominated by patients aged 65 and over. Only a very small proportion of prostate and lung cancers occur in patients under the age of 45. Our projection suggests that the proportion of patients under 65 will increase in colorectal cancer and decrease in lung, prostate, and other cancers.

Interpretation and recommendations

Cancer prevalence is often reported as period-specific prevalence and prevalence rates, which incorporate the time elapsed since diagnosis. In this chapter, we have reported one- two- and five-year prevalence and the ASPR. Different prevalence periods are often used as a proxy for specific care needs, because the length of time since cancer diagnosis is closely associated with the phase reached along the cancer care continuum. For example, the first year for people who develop cancer is usually associated with diagnosis, chemotherapy, radiation therapy, surgery and hospitalization. In the first two years, services would likely include primary treatment and supportive care for recovery from the effects of treatment. The next three years would usually include follow-up visits with close clinical assessment for recurrence or development of

another cancer. At any time point, some patients will experience recurrence or progression and require additional treatment and/or supportive care. Therefore, the one- two- and five-year prevalence will capture different needs for health care utility, with considerable overlap.

We projected that the cancer prevalence in females will exceed that in males, although the ASPR will remain similar. In comparison to the projected cancer incidence and mortality trends in Alberta (see *Chapter 1: Cancer incidence* and *Chapter 3: Cancer mortality*), we observed that the incidence rates are projected to increase in females and decrease in males, whereas the mortality rates will decrease in both sexes. This is in alignment with these cancer prevalence projections, in which the increasing trend is more prominent in females.

From 2000 to 2019, we observed that the ASPRs of thyroid and lung cancers increased, whereas the ASPR of prostate cancer decreased. For thyroid cancer, the increase is mainly due to the increased diagnosis of small papillary cancers of the thyroid, which has emerged as a global issue.[6,7] For lung cancer, because the age-standardized incidence rate has been declining among males and remains steady in females,[8] the increase in prevalence is possibly attributable to improved survival. For example, the Alberta Thoracic Oncology Program aims to provide rapid, high-quality and multidisciplinary evaluation of people suspected to have lung cancer, which leads to quicker diagnosis and treatment, and therefore survival. The decrease in the ASPR of prostate cancer is probably associated with screening guidelines which recommend against using the prostate-specific antigen (PSA) test to screen for prostate cancer.[9]

Aside from all cancer prevalence, projections for each of the major cancer types help us in understanding the disease impacts and the requirements for the provision of care. The cancers that are projected to increase in the one-year ASPR are breast, colorectal, kidney, melanoma, thyroid and uterine cancers. Bladder cancer and non-Hodgkin lymphoma will remain stable, while lung and prostate cancers will decrease in the one-year ASPR. In contrast, projection of the five-year ASPR demonstrates that most of the top ten cancers, except for prostate cancer, are likely to increase. The decreasing five-

year ASPR in prostate cancer is mainly attributable to a projection of decreasing cancer incidence. Since 2000, the prostate cancer incidence rate in Canada has declined by about 30%.[10] This decreasing trend is projected to further decrease by 2040.

Although the lung cancer incidence rate is the second highest of the top ten cancers in Alberta, the prevalence rate ranks only fourth after breast, prostate and colorectal cancers. This is because lung cancer has a lower survival rate than the other three cancers. Therefore, when comparing cancer prevalence of different types, it is important to take both incidence and survival into account.

The prevalence distribution of age groups in major cancer types carries some important messages. The 65+ age group accounts for 50% of all cancers in females and 43% in males, and this age group has a much higher proportion of lung, prostate and colorectal cancers relative to younger age groups. Moreover, the 65+ age group shows a trend towards increasing proportions of lung cancer and melanoma by 2040. It is therefore important to have a plan for resource allocation to respond to this trend. For colorectal cancer, females under age 65 and males aged 45-64 show an increasing trend in the proportion by 2040. This projection is consistent with the observations that the incidence rate of colorectal cancer is on the rise in Canada.

Conclusions

The projected increases in cancer prevalence in Alberta will pose a considerable impact on the utilization of health care services. As cancer survival is projected to improve, a larger proportion of people with cancer will require long-term follow-ups and supportive care. The demand of services in this regard will increase in the future. Additional research into the optimal management of long-term surveillance to maximize outcomes and system efficiency is needed. We project an increasing trend of colorectal cancer prevalence in younger age groups, which calls for more attention. Increasing trends of lung, melanoma, and other cancer prevalence in older adults calls for attention to age-related concerns. In particular, there is a need for ongoing monitoring and better data to help us understand more about cancer prevalence in Alberta.

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Chapter 3: Cancer mortality

Key findings

- The overall number of deaths due to cancer in Alberta is projected to increase by 21% from 2020 to 2030 and by 49% from 2020 to 2040.

- An estimated 9,849 Albertans will die from cancer in 2040, with 5,433 deaths among males and 4,416 among females.

- Lung, colorectum, breast and prostate cancers are the leading causes of death in Alberta in 2020, and they are expected to remain so in 2040, attributing to 45% of all cancer deaths.

- While the overall number of cancer deaths in Alberta is projected to increase between 2020 and 2040, the age-standardized mortality rate (ASMR) is projected to decrease by 19% over the 20-year period.

- Among the leading cancers, the primary reasons for the decrease in cancer-related mortality are attributable to reductions in smoking (lung and bladder cancers), improvements in screening (colorectal cancer), and treatment advances (breast and prostate cancers).

Recommendations

- The largest increases in mortality are projected for the top five most common cancer sites. Target improved primary prevention and population-based screening programs for the most common cancers to reduce the mortality associated with these cancers.

- Among the most common cancers, decreases in cancer-related mortality are partly attributable to treatment advances. Invest to develop/implement/evaluate novel therapies and overall advances in treatment and treatment pathways.
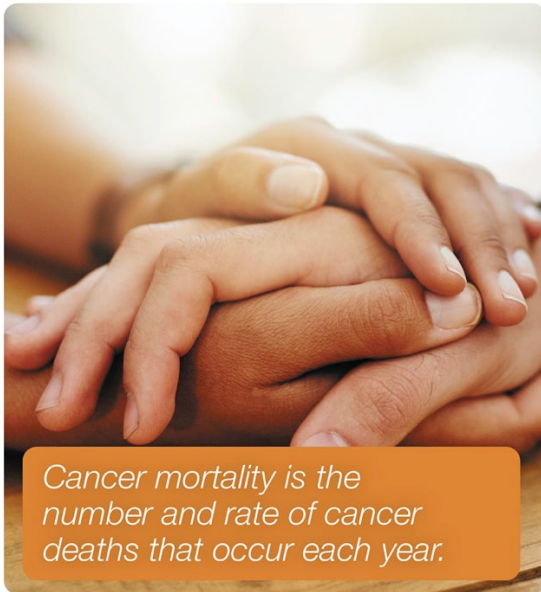
Cancer mortality is the number and rate of cancer deaths that occur each year.

Background

In Alberta, 1 in 4 males and 1 in 5 females will die from cancer.[1] Cancer mortality is an important measure of the impact of cancer in a population since it quantifies the number of deaths that were a direct cause of cancer. Past trends in the mortality rates of cancer and population projections can be used to estimate the number of cancer deaths that will occur in the future.

Long-term projections of cancer mortality are essential for health care planning, for health policy efforts and for guiding future research allocations. Identifying the cancer sites that are projected to account for the greatest number of deaths allows primary and secondary prevention programs to be prioritized, treatment resources to be allocated, and research areas to be determined to reduce the impact of cancer mortality. In addition, examining cancer mortality over time allows the progress in reducing cancer deaths to be measured and helps determine the relative importance of cancer compared to other causes of death. A decreasing trend in cancer mortality could indicate a decrease in cancer incidence, an increase in cancer survival (earlier diagnosis or improved treatment), or a combination of both. Mortality rates are seen as a better indicator of progress than incidence or survival since they combine these

metrics and because mortality is less affected by biases resulting from changes in diagnostic practices.

Cancer mortality in Alberta has been steadily increasing, with 6,701 cancer deaths projected for 2021.[1] Since 1998, there has been a 33% increase in cancer-related mortality, with similar increases in males and females,[1] and dramatic increases in mortality with age.[2] The most common cancer-related deaths in Alberta are from lung cancer, colorectal cancer, breast cancer and prostate cancer, accounting for 49% of cancer deaths.[1] Given the large increase in the number of cancer deaths in Alberta, it is important to determine if this trend will continue and to what magnitude. Consideration of differences in cancer mortality across age groups is critical to inform quality improvement initiatives that optimize outcomes across age groups. In addition, it is important to determine the cancer sites with the largest increases in mortality for specific resource planning. Further, the examination of age-standardized mortality rates (ASMRs) over time provides an indication of success in reducing mortality and helps to identify areas for improvement.

In this chapter, we project the mortality rates of the top 10 most common cancer sites in Alberta to 2040.

Analytic approach

Details on the methodology and analytic approach are presented in Appendix 3.

Projected cancer mortality

The overall numbers of deaths due to cancer in Alberta are projected to increase by 21% by 2030 and 49% by 2040, with slightly larger proportional increases for males compared to females (Table 5; Figure 6). Under this projected scenario, we projected there will be 9,849 cancer deaths in 2040 in Alberta, with 5,433 occurring among males and 4,416 among females. In 2040, the leading causes of cancer deaths are projected to be cancers of the lung, colorectum, breast and prostate, accounting for 45% of all cancer deaths. Among males, the leading causes of cancer deaths are projected to be cancers of the lung, prostate and colorectum, while for females they are projected to be cancers of the lung, breast and colorectum (Figure 7).

Table 5. Projected cancer mortality overall and for the top 10 sites in Alberta by sex in 2030 and 2040

	Total					Males					Females				
	2020	2030	Change %	2040	Change %	2020	2030	Change %	2040	Change %	2020	2030	Change %	2040	Change %
All	6,603	8,002	21.2	9,849	49.2	3,530	4,300	21.8	5,433	53.9	3,073	3,702	20.5	4,416	43.7
Lung	469	1,770	10.9	1,954	22.4	832	965	16.0	1,144	37.5	764	805	5.4	810	6.0
Colorectal	731	850	16.3	1,070	46.4	426	513	20.4	645	51.4	305	337	10.5	425	39.3
Breast*	469	572	22.0	702	49.7	—	—	—	—	—	469	572	22.0	702	49.7
Prostate	393	474	20.6	655	66.7	393	474	20.6	655	66.7	—	—	—	—	—
Bladder	172	228	32.6	316	83.7	120	152	26.7	211	75.8	52	76	46.2	105	101.9
Lymphoma	232	261	12.5	286	23.3	132	154	16.7	177	34.1	100	107	7.0	109	9.0
Kidney	159	197	23.9	250	57.2	58	102	17.6	147	44.1	33	57	35.1	103	80.7
Uterus	114	167	46.5	220	93.0	—	—	—	—	—	13	114	46.5	220	93.0
Melanoma	91	120	31.9	153	68.1	58	76	31.0	96	65.5	33	44	33.3	57	72.7
Thyroid	23	34	47.8	43	87.0	10	15	50.0	18	80.0	57	13	46.2	25	92.3

*While males do get breast cancer, it is rare and not among the top cancer sites.
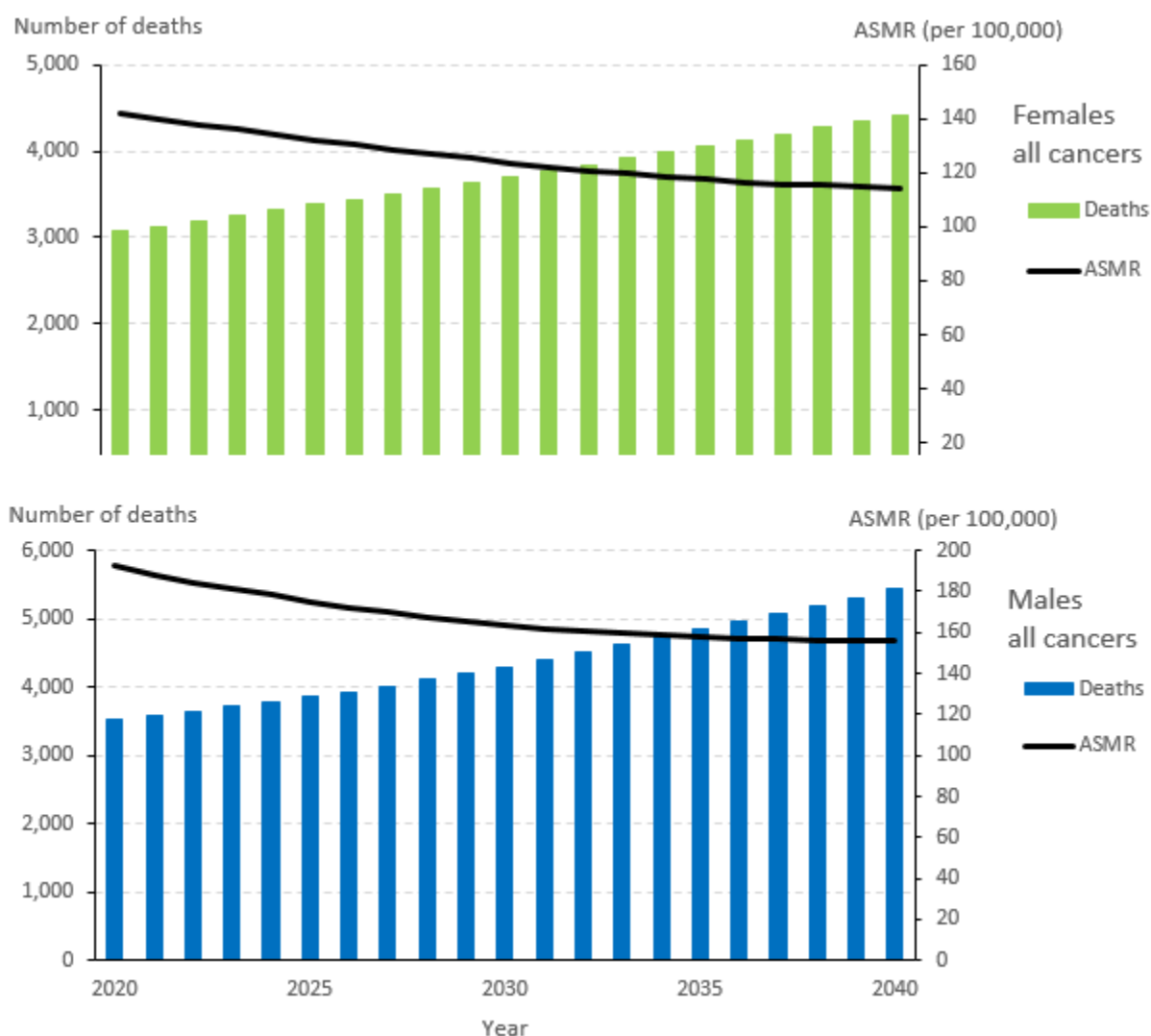
Figure 6. Cancer deaths and age-standardized mortality rates (ASMRs) for all cancers, 2020–2040
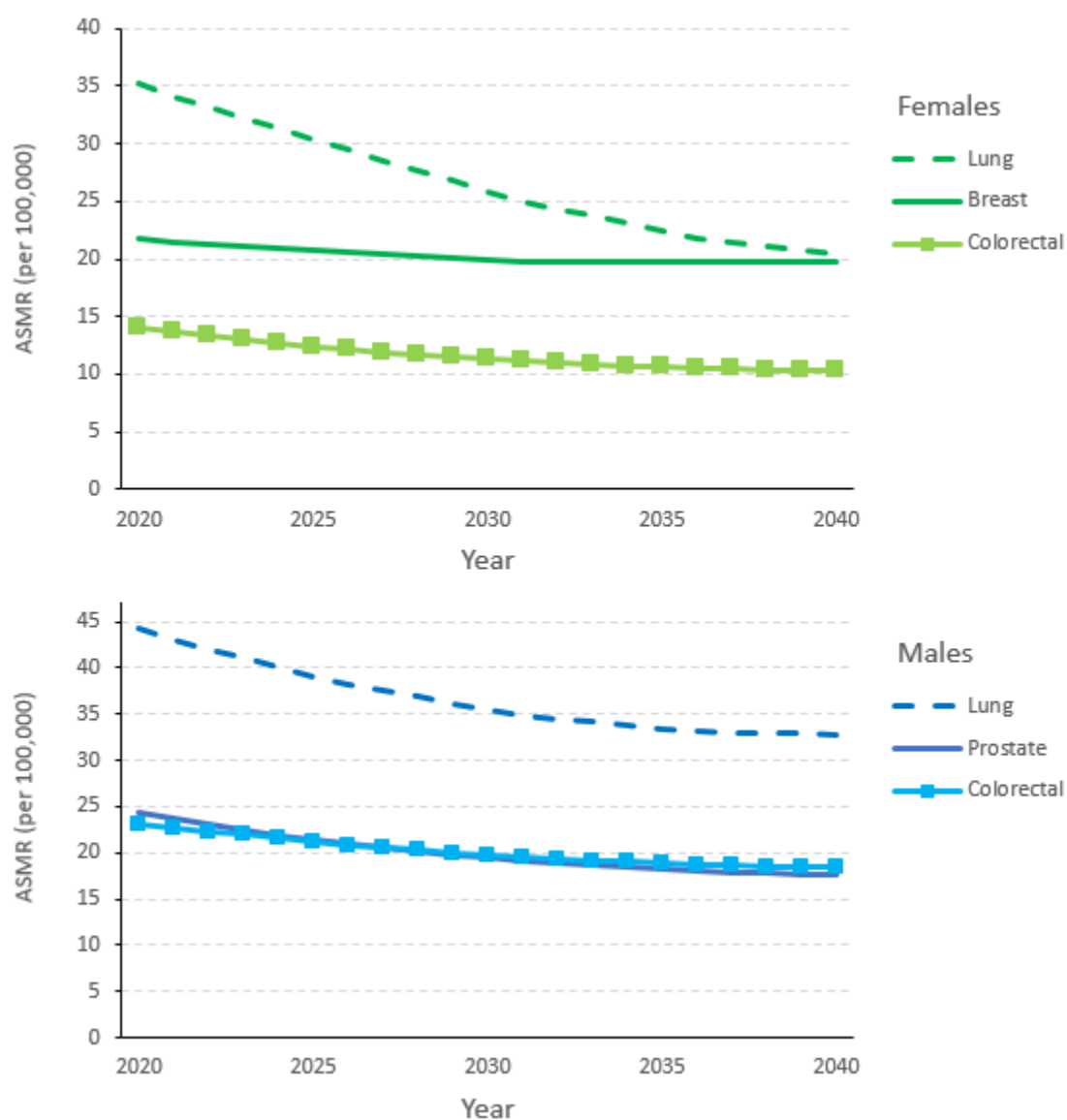
Figure 7. Age-standardized mortality rates (ASMRs) for the most common cancers in females and males

From 2020 to 2040, the largest absolute increases in annual mortality are projected for lung (358 cases), colorectal (339 cases), prostate (262 cases), breast (233 cases) and bladder (144 cases) cancers. Among males, the largest absolute increases are projected for lung (312 cases), prostate (262 cases), colorectal (219 cases) and bladder (91 cases) cancers, while the largest absolute increases for females are projected for breast (233 cases), colorectal (120 cases), uterine (106 cases) and bladder (53 cases) cancers.

Among specific cancers, the largest relative increases in the number of cancer deaths by 2040 are projected for uterine, thyroid and bladder cancers, while the smallest increases are projected for lung cancer and lymphoma. Among males, the largest relative increases are projected for thyroid, bladder and prostate cancers, while the smallest increases are projected for lymphoma and lung cancer. Among females, the largest relative increases are projected for bladder, uterine and thyroid cancers, while the smallest increases are projected for lung cancer and lymphoma.

While the overall number of cancer deaths in Alberta in 2040 is projected to increase from 2020, the age-standardized mortality rate (ASMR) is projected to decrease by 19% (Table 6). The ASMR is projected to decrease by more than 20% for lymphoma, lung cancer, prostate cancer, and colorectal cancer, but remain stable for melanoma (-2%) and thyroid cancer (0%) and increase for uterine cancer (12%). When comparing changes in the ASMR by sex, males are projected to have a larger decrease for bladder cancer and kidney cancer, while females are projected to have a larger decrease for lung cancer, lymphoma, and colorectal cancer.

Table 6. Projected age-standardized cancer mortality rates (per 100,000) overall and for the top 10 sites in Alberta by sex in 2030 and 2040

	Total					Males					Females				
	2020	2030	Change %	2040	Change %	2020	2030	Change %	2040	Change %	2020	2030	Change %	2040	Change %
All	167.4	143.8	-14.1	135.3	-19.2	192.3	163.6	-14.9	156.1	-18.8	141.8	123.5	-12.9	114.1	-19.5
Lung	39.8	30.8	-22.8	26.7	-33.0	44.3	35.5	-19.9	32.8	-26.0	35.2	25.9	-26.4	20.4	-42.0
Colorectal	18.7	15.6	-16.4	14.4	-22.9	23.2	19.8	-14.7	18.4	-20.7	14	11.3	-19.3	10.3	-26.4
Breast*	21.8	20.0	-8.3	19.8	-9.2	—	—	—	—	—	21.8	20.0	-8.3	19.8	-9.2
Prostate	24.3	19.4	-20.2	17.6	-27.6	24.3	19.4	-20.2	17.6	-27.6	—	—	—	—	—
Bladder	4.84	4.3	-11.7	4.1	-15.9	7.2	6.1	-15.3	5.7	-20.8	2.4	2.4	0.0	2.4	0.0
Lymphoma	6.02	4.7	-21.7	3.8	-36.7	7.4	6.0	-18.9	5.0	-32.4	4.6	3.4	-26.1	2.6	-43.5
Kidney	4.02	3.5	-12.6	3.4	-16.5	5.4	4.6	-14.8	4.3	-20.4	2.6	2.4	-7.7	2.4	-7.7
Uterus	5.2	5.6	7.7	5.8	11.5	—	—	—	—	—	5.2	5.6	7.1	7.7	11.5
Melanoma	2.31	2.3	-2.3	2.3	-2.3	3	2.9	-3.3	2.9	-3.3	1.6	1.6	0.0	1.6	0.0
Thyroid	0.55	0.5	0.0	0.5	0.0	0.5	0.5	0.0	0.5	0.0	0.6	0.6	0.0	0.6	0.0

*While males do get breast cancer, it is rare and not among the top cancer sites.

Interpretation and recommendations

The projected increase in cancer-related mortality is driven by increases in the incidence of leading cancers, which is primarily a product of an aging population and population growth. Therefore, attention to the unique needs and concerns of older adults with cancer may also be paramount to optimizing outcomes, including frameworks to support screening decisions,[3] assessment to support appropriate treatment decision making, and supportive interventions addressing age-related concerns and management of comorbidities to promote treatment completion and optimal outcomes.[4] In addition to the large increase in overall cancer mortality, the number of deaths related to each of the top 10 most common cancer sites in Alberta is projected to rise with the largest increases projected for lung, colorectal, prostate, breast and bladder cancers. Given that the largest increases in mortality are projected for the top five most common cancer sites, it is important to target these cancer sites for

prevention efforts and to improve screening uptake for relevant cancers. In addition, early detection, advances in treatment and novel therapies for late-stage disease are required to reduce the impact of mortality associated with cancer in Alberta.

The examination of ASMRs over time can provide estimates of the potential impact of the combination of preventive initiatives, screening and improvements in treatment. In addition, the examination of ASMRs by cancer site, and across age groups, over time could help demonstrate the impact of preventative initiatives, screening, and treatment in particular tumor sites and various age groups, and support the identification of areas that merit future research can help identify areas that merit future research. From 2020 to 2040, the ASMR of cancer overall is projected to decrease by 19%, which reflects reductions in the age-standardized incidence rate (ASIR) of cancer as well as improvements in early detection and treatment. Among the leading cancer sites, the largest decrease in ASMR is projected for lung cancer, which is largely attributable to decreases in the ASIR of lung cancer as a result of reductions in the prevalence of tobacco smoking.[5] Beyond reducing smoking, the five-year survival associated with lung cancer remains under 20%,[6] highlighting the importance of improvements in treatment and advances in targeted screening of high-risk populations to reduce the mortality impact of lung cancer. While the largest projected decrease in ASMR is observed for lung cancer, the smallest decrease is projected for breast cancer, which is a product of the projected increase in the ASIR. A reduction in the ASMR is still projected, which is a testament to improvements in earlier detection from screening (mammography)[7] and considerable improvements in the treatment of breast cancer. Preventive efforts are likely to have the greatest impact on further reducing the mortality associated with breast cancer.

Among the leading cancers, prostate cancer is projected to have the second largest decrease in ASMR, which is a reflection of reductions in incidence and continued improvements in the treatment landscape for prostate cancer. Colorectal cancer is also projected to have a considerable decrease in the ASMR by 2040. This is likely a product of screening, which can reduce incidence by detecting precancerous polyps and improve survival by detecting colorectal cancer at earlier stages of disease. Bladder

cancer is projected to have a considerable decrease in the ASMR, which may largely be attributable to decreases in incidence from reductions in smoking.

Of the top 10 most common cancer sites, uterine cancer is the only cancer that is projected to have an increase in the ASMR. This increase is likely a product of a projected increase in incidence, but also a lack of improvement in the treatment of uterine cancer. Despite improvements in early detection and treatment of advanced melanoma, the ASMR is projected to decrease only marginally due to the large increase in incidence that is projected. This underscores the importance of primary prevention for the reduction of mortality associated with melanoma in Alberta. Among less common cancers, lymphoma is projected to have a large decrease in the ASMR by 2040. This large decrease can be attributed to improvements in diagnosis, classification of subtypes and advances in treatment for this heterogeneous group of cancers. In considering the ASMR, it is important to remember that absolute differences in cancer mortality rates over time may differ across age groups, calling for innovative strategies to address these differences.

Conclusions

The overall number of cancer-related deaths in Alberta is projected to increase considerably by 2040. Despite an increase in the absolute number of cancer-related deaths, the ASMR is projected to decrease substantially, indicating success in primary prevention, screening, detection and treatment. Among the leading cancers, the primary reasons for the decrease in cancer-related mortality are attributable to reductions in the prevalence of smoking (lung and bladder cancers), improvements in screening (colorectal cancer), and treatment advances (breast and prostate cancers). Efforts to continue the primary prevention of common cancers, promote increases in the participation rates for population-based screening programs, and to support the development of novel therapies and overall advances in treatment are imperative to reduce cancer mortality in Alberta.

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Chapter 4: Cancer survival

Key findings

- Among cancers that were examined, the one-year and five-year net survival were highest for colorectal cancer and lowest for pancreatic cancer in both males and females in Alberta from 1995 to 2014.

- Five-year net survival increased over time in both males and females for colorectal, esophageal, lung, pancreatic and stomach cancers.

- One-year and five-year net survival in Alberta were similar to Canadian values for all cancers, except stomach cancer, where survival was lower in Alberta.

- Among cancers that were examined, the absolute percent change in five-year net survival from 1995–1999 to 2010–2014 was greater for males than females in colorectal (10% vs. 9%), pancreatic (7% vs. 4%) and stomach (6% vs. 3%) cancers, and was greater for females than males in esophageal (12% vs. 4%) and lung (8% vs. 7%) cancers.

Recommendations

- Accurate and reliable data can be used by physicians, researchers, public health planners and policymakers to reduce the future impact of cancer. Create a data monitoring system that can report on cancer survival in a timely fashion to highlight improvements or gaps in outcomes.

- Survival is improving for several cancers, likely due to increased participation in and access to screening programs, technological advances in diagnosis and staging, and wider access to novel therapeutic approaches. Continue to support implementation of focused screening and therapy programs.

- Identifying biomarkers as targets for novel cancer therapies may substantially improve survival. Enhance infrastructure for the implementation and evaluation of molecular diagnostics to support targeted and other novel therapeutic approaches.

- Access to advanced radiotherapy treatment technology (e.g. Linac-MR, MR-simulation, protons, etc.) promises improved treatment options for some cancers that may lead to higher survival and/or reduced treatment toxicity (and corresponding improved quality of life). Continue to support development and implementation of these advanced technologies.

- Greater efforts are needed for cancers where survival remains poor, including lung, esophageal and pancreatic cancer. Encourage continued research investment in high-fatality cancers.

Background

Population-based cancer survival data complements incidence and mortality data to inform policy development and the allocation of health care resources and areas of focus for research to lower the impact of cancer. Survival statistics reflect the patient diagnosis, treatment, journey, impact of health care and outcomes, which are not fully captured by incidence or mortality. One metric to quantify cancer survival is age-standardized net survival, which is the probability of surviving a specified time period (usually one, five or 10 years) after diagnosis, taking into account underlying mortality. It approximates cancer survival in the absence of other causes of death. One-year survival represents survival during treatment and reflects stage of diagnosis. Five-year survival represents survival after treatment and typically reflects those who have been "cured" of disease. Ten-year survival reflects long-term survivorship. Age-standardized net survival facilitates comparisons across populations and over time because it accounts for differences in the underlying risk of death and age distribution of the populations being compared.

Comparing cancer survival statistics and their changes over time across populations is essential for health care systems to evaluate progress made in early detection strategies, the effectiveness of treatments and the delivery of cancer care services. Such comparisons are also fundamental to highlight disparities in survival across populations and why they exist.

Survival rates have improved for many cancer sites over the past 20 years in Alberta. On February 4, 2021, World Cancer Day, the 2021 Report on Cancer Statistics in Alberta (ROCSIA 2021) was published with survival trends for the 10 most common cancers in Alberta. According to this report, five-year survival improved for lung, breast, prostate, colorectal, bladder, non-Hodgkin lymphoma, melanoma, thyroid, uterus, and kidney and renal pelvis cancers between 1998–2000 and 2016–18 (Table 7).[1] Similar improvements on the national level for these cancer sites and others were reported in Canadian Cancer Statistics 2019.[2]

Table 7. Five-year age-standardized net survival for Alberta by cancer site in the periods of 1998-2000, 2004-2006, 2010-2012, and 2016–2018

Cancer Site	1998-2000	2004-2006	2010-2012	2016-2018
Bladder	75%	77%	81%	82%
Breast	87%	87%	90%	90%
Colorectal	58%	62%	65%	68%
Kidney	61%	62%	67%	70%
Lung	13%	14%	18%	24%
Melanoma of skin	84%	84%	87%	89%
Non-Hodgkin's lymphoma	55%	63%	72%	72%
Prostate	90%	93%	92%	92%
Thyroid	84%	87%	92%	96%
Uterus	78%	81%	86%	83%

Adapted from ROCSIA (2021) [3]

Comparing population-based net survival among countries and other geographic regions can help assess the overall effectiveness of a country's health care system to deliver services to all people with cancer and cancer survivors. As part of the International Cancer Benchmarking Partnership (ICBP), the Cancer Survival in High-Income Countries (SURVMARK-2) project provided an overview of cancer survival across seven high-income countries comprising Australia, Canada, Denmark, Iceland, New Zealand, Norway and the United Kingdom (UK).[4] Even among high-income countries with similar universal health care systems, cancer survival is reported to be high in Canada.[4] ICBP SURVMARK-2 showed that survival continued to improve across all countries over the period of 1995–2014, especially in cancers with poor prognoses, such as esophageal, stomach and lung cancers.[4] However, over the study period, larger survival improvements were observed for patients younger than 75 years at diagnosis than for those aged 75 years and older.[4] This project provides evidence that the uniform improvements in cancer survival are likely the direct consequence of major health care reforms and technological advances that have enabled earlier diagnosis, more effective and tailored treatment, and better patient management than in previous periods.[4] Evaluating the metrics of survival among Albertans in the context of

other high-performing countries can inform where changes can be made along the cancer care pathway spectrum to improve survival.

In this chapter, we complement the ROCSIA 2021[1] and highlight the current evidence on changes in survival rates for seven common cancer sites (esophagus, colon, rectum, colorectal, stomach, lung and pancreas) overall, by sex and by age groups in Alberta. We also compare cancer survival in Alberta with other provinces and countries for each cancer site. This synthesis uses data from ICBP SURVMARK-2, from which there is only data for esophageal, colon, rectal, colorectal, stomach, lung and pancreatic cancers. We aim to point to areas where evidence-based reform is required to improve detection, diagnosis, and treatment of cancer sites and where research is needed to develop better treatments.

Analytic approach

Details on the methodology and analytic approach are presented in Appendix 3.

Cancer survival in Alberta

Survival by sex and age

One-year and five-year net survival were highest for colorectal cancer and lowest for pancreatic cancer in both males and females in Alberta from 1995–1999 to 2010–2014. Five-year net survival increased over time in both males and females for colorectal, esophageal, lung, pancreatic and stomach cancers (Figures 8 and 9).
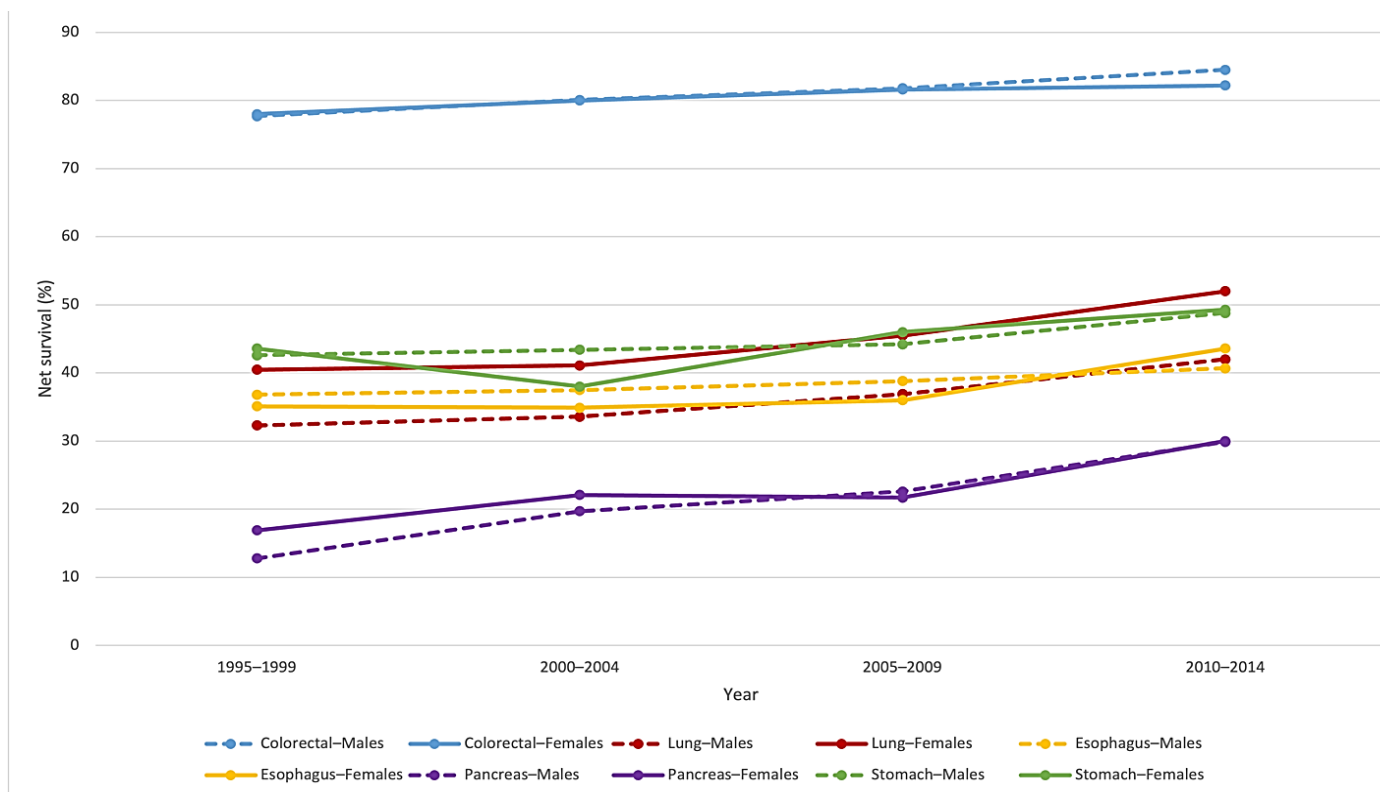
Figure 8. Trends in age-standardized one-year net survival (%) in five-year periods by sex and cancer site
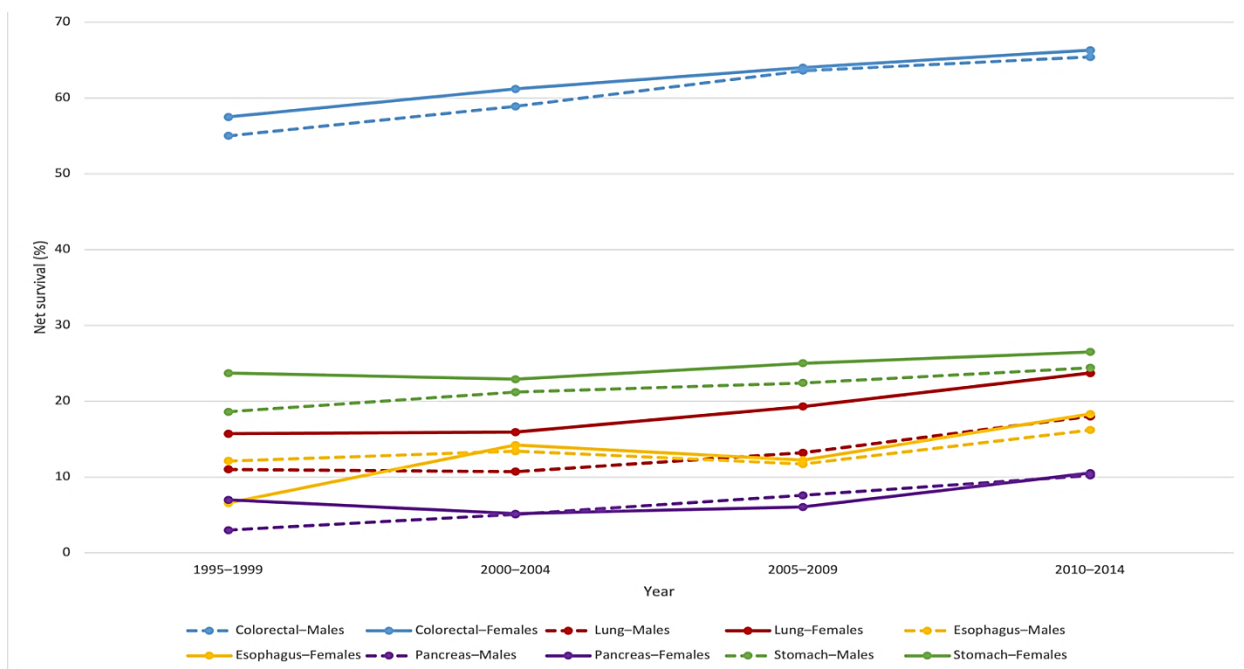
Figure 9. Trends in age-standardized five-year net survival (%) in five-year periods by sex and cancer site

Differences in five-year net survival between sexes for all cancer sites were most apparent in early periods (2000–2004 and earlier), with females having better survival. Differences between sexes diminished over time, except for lung cancer, in which survival in females has been higher than in males for every five-year period from 1995 to 2014 (Figure 9). The absolute percent change in five-year net survival from 1995–1999 to 2010–2014 was greater for males than females in colorectal (10% vs. 9%), pancreatic (7% vs. 4%) and stomach (6% vs. 3%) cancers but was greater for females than males in esophageal (12% vs. 4%) and lung (8% vs. 7%) cancers (Figure 10). The relative percent change in five-year net survival from 1995–1999 to 2010–2014 was greater for males than females in colorectal (19% vs. 15%), lung (64% vs. 51%), pancreatic (243% vs. 50%) and stomach (31% vs. 12%) cancers but was greater for females than males in esophageal cancer (179% vs. 34%) (Figure 11).

Figure 1010. Absolute percent change in five-year net survival (%) by sex and cancer site 1995–1999 to 2010–2014
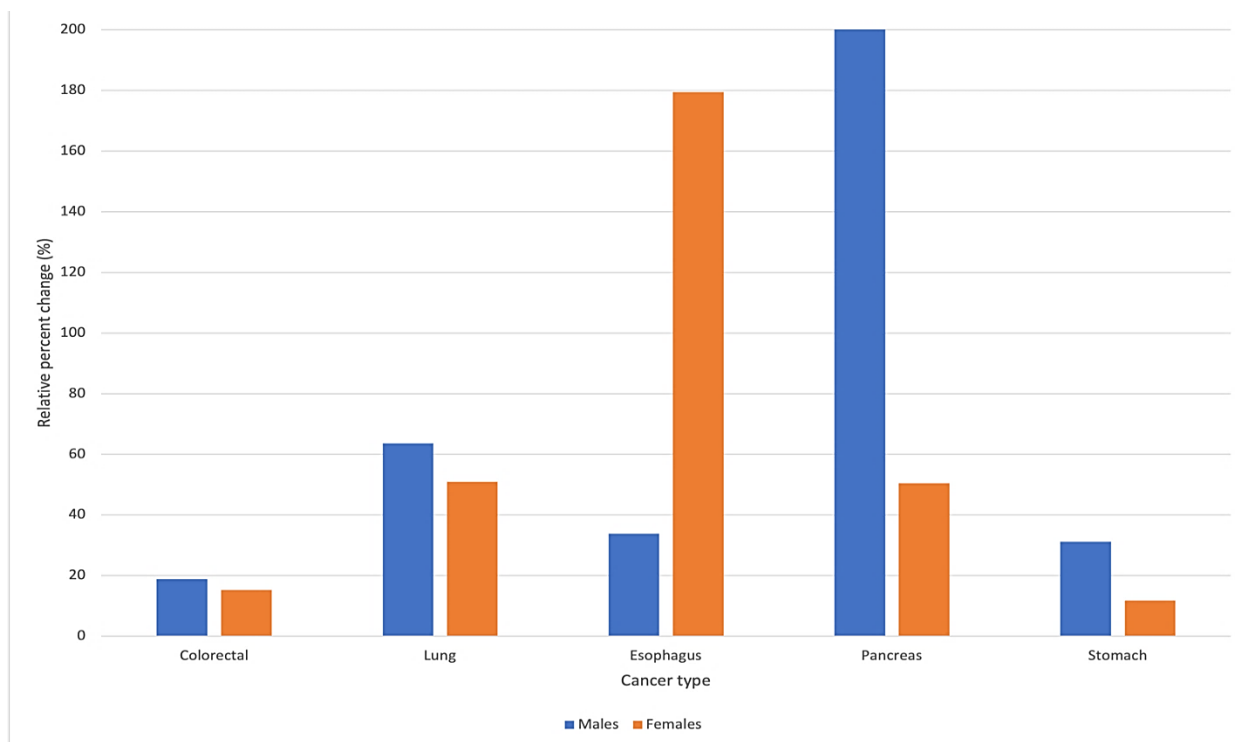
Figure 1111. Relative percent change in five-year net survival (%) by sex and cancer site 1995–1999 to 2010–2014

Although for some cancers, one- and five-year survival was higher in some older than younger age groups, for all cancer types, one- and five-year survival declines with increasing age in 2010-2014 (Figures 12a–e and 13a–e). However, the differences among age groups were greater for some cancers than for others. The absolute percent change in five-year net survival was highest for colorectal, esophageal, lung, pancreatic and stomach cancers in those aged 15–54 years (Figure 14). The relative percent change in five-year net survival was highest for colorectal and stomach cancers in those aged 15–54, pancreatic cancer in those 65–74, and esophageal and lung cancers in those aged 75+ (Figure 15).
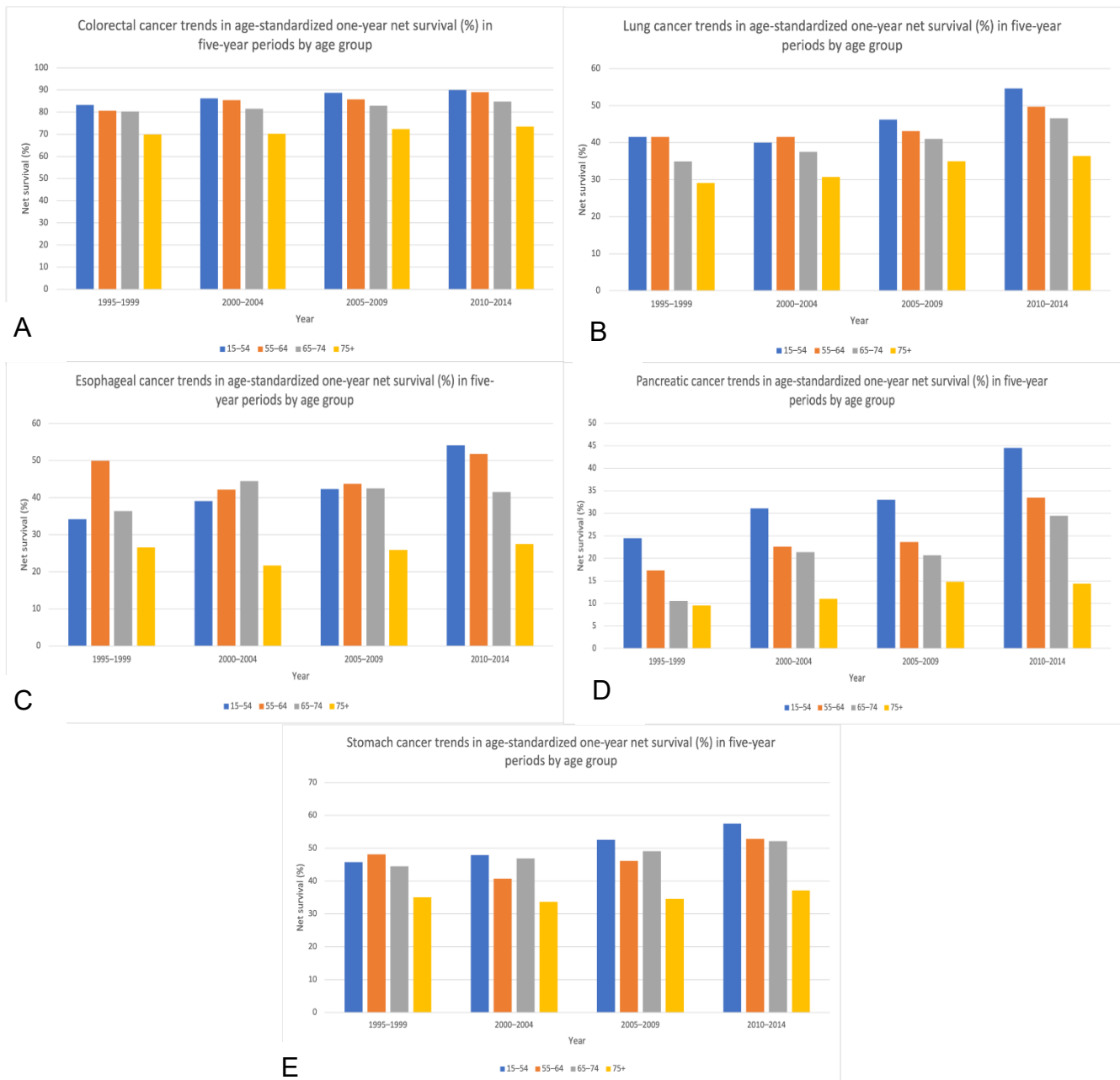
Figure 12a–e. Trends in age-standardized one-year net survival (%) in five-year periods by age group and cancer site.

Note: Figures 12a–e have different y-axis values.
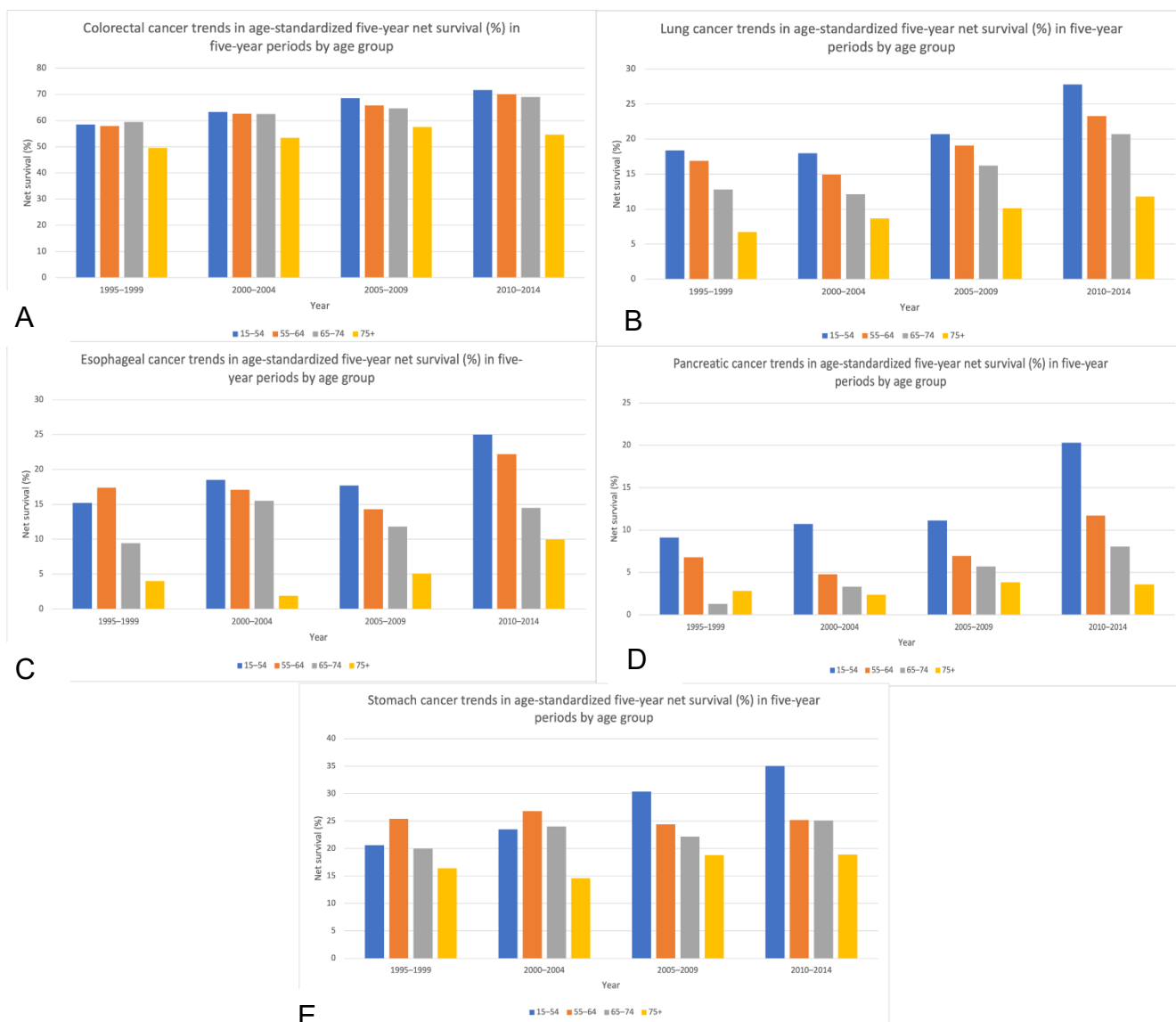
Figure 13a–e. Trends in age-standardized five-year net survival (%) in five-year periods by age group and cancer site
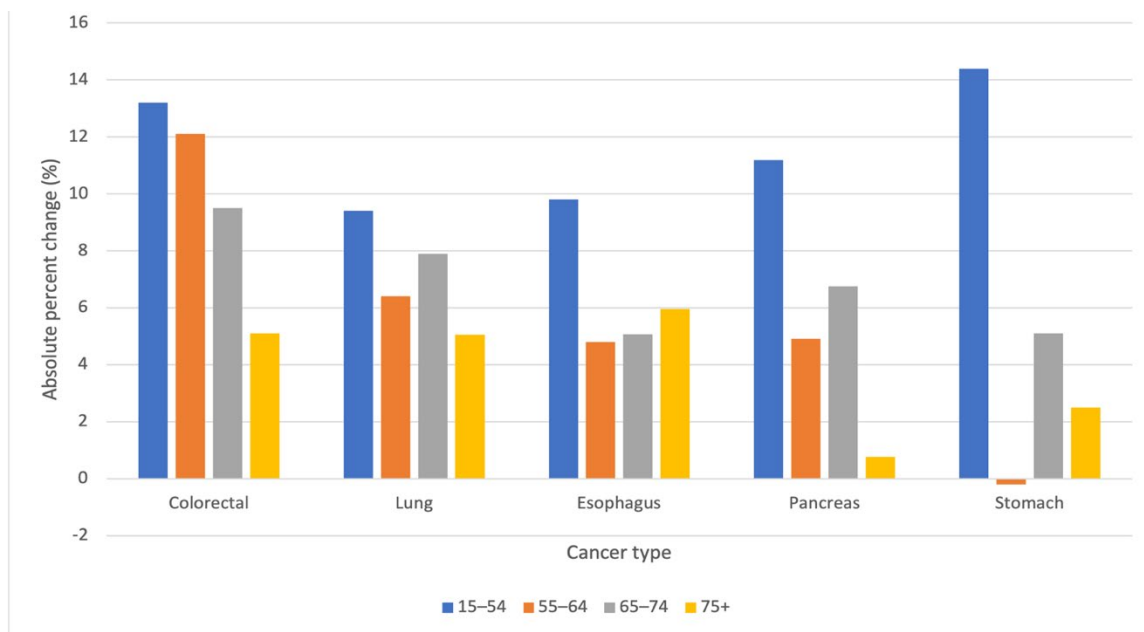
Figure 14. Absolute percent change in five-year net survival (%) by age group and cancer site 1995–1999 to 2010–2014
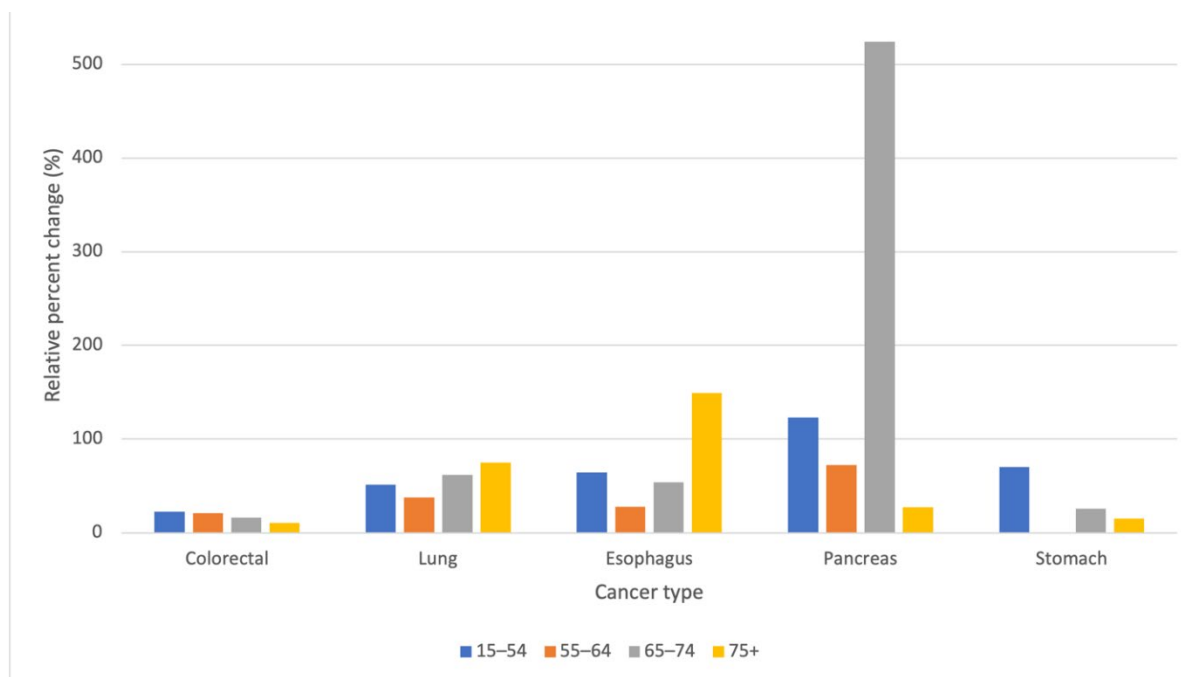
Figure 15. Relative percent change in five-year net survival (%) by age group and cancer site 1995–1999 to 2010–2014

Alberta compared to Ontario, British Columbia, Canada, Australia and the United Kingdom

Compared to British Columbia (BC), one-year and five-year net survival rates in Alberta were similar for all cancers; compared to Ontario, survival in Alberta was lower for colorectal and stomach cancers in 2010–2014 (Figures 16a–e, 17a–e and Table 8). Compared to Canada, one-year and five-year net survival rates in Alberta were similar for all cancers, except stomach cancer, where survival was lower in Alberta. Survival in Alberta was lower than in Australia for all cancers except lung cancer and was higher than the UK for all cancers except esophageal cancer (Figures 16a–e, 17a–e and Table 8). The absolute percent changes of five-year net survival from 1995–1994 to 2010–2014 were greatest in Australia for lung (8.0% in Australia; 7.8% in Alberta) and pancreatic (8% in Australia; 6% in Alberta) cancers but were greatest in the UK and Ontario for esophageal (8% in the UK; 6% in Alberta) and stomach (9% in Ontario; 5% in Alberta) cancers, respectively (Figure 18). The relative percent changes of five-year net survival from 1995–1994 to 2010–2014 were greatest for the UK in all cancer sites (Figure 19).

Table 8. Five-year age-standardized net survival for Alberta, Ontario, BC, Canada, Australia and the UK by cancer site in the period of 2010–2014

Cancer Site	Alberta	Canada*	Australia	UK	Ontario	BC
Colorectal	65.6%	67.1%	70.9%	60.0%	68.7%	66.5%
Esophagus	16.6%	16.3%	23.2%	16.2%	16.5%	19.1%
Lung	20.9%	21.7%	21.3%	14.8%	22.3%	21.3%
Pancreas	10.3%	11.1%	14.3%	7.9%	12.2%	10.6%
Stomach	25.2%	29.8%	32.8%	20.8%	32.7%	26.5%

BC, British Columbia; UK, United Kingdom
*Quebec is excluded, as cases diagnosed in Quebec from 2011 onward have not been submitted to the Canadian Cancer Registry.
Note: Red indicates survival is lower in Alberta and non-overlapping 95% confidence intervals (Cis). Yellow indicates survival estimates with overlapping 95% CIs. Green indicates survival is higher in Alberta with non-overlapping 95% Cis.

A Colorectal cancer trends in age-standardized one-year net survival (%) in five-year periods by geography

B Lung cancer trends in age-standardized one-year net survival (%) in five-year periods by geography

C Esophageal cancer trends in age-standardized one-year net survival (%) in five-year periods by geography

D Pancreatic cancer trends in age-standardized one-year net survival (%) in five-year periods by geography

E Stomach cancer trends in age-standardized one-year net survival (%) in five-year periods by geography

Figure 1616a–e. Trends in age-standardized one-year net survival (%) in five-year periods by geography and cancer site
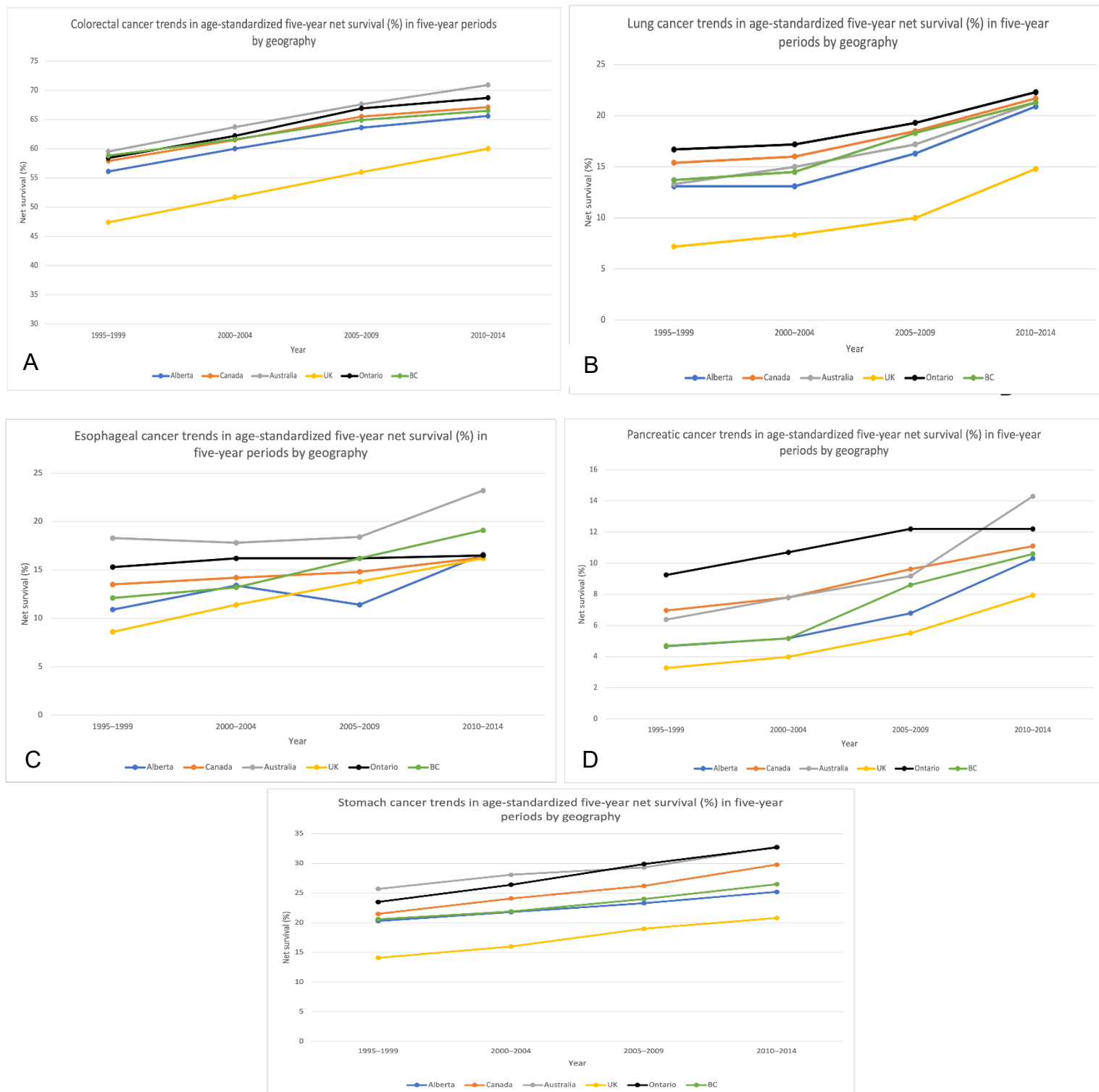
Figure 1717a–e. Trends in age-standardized five-year net survival (%) in five-year periods by geography and cancer site

Alberta Health Services
The Future of Cancer Impact in Alberta
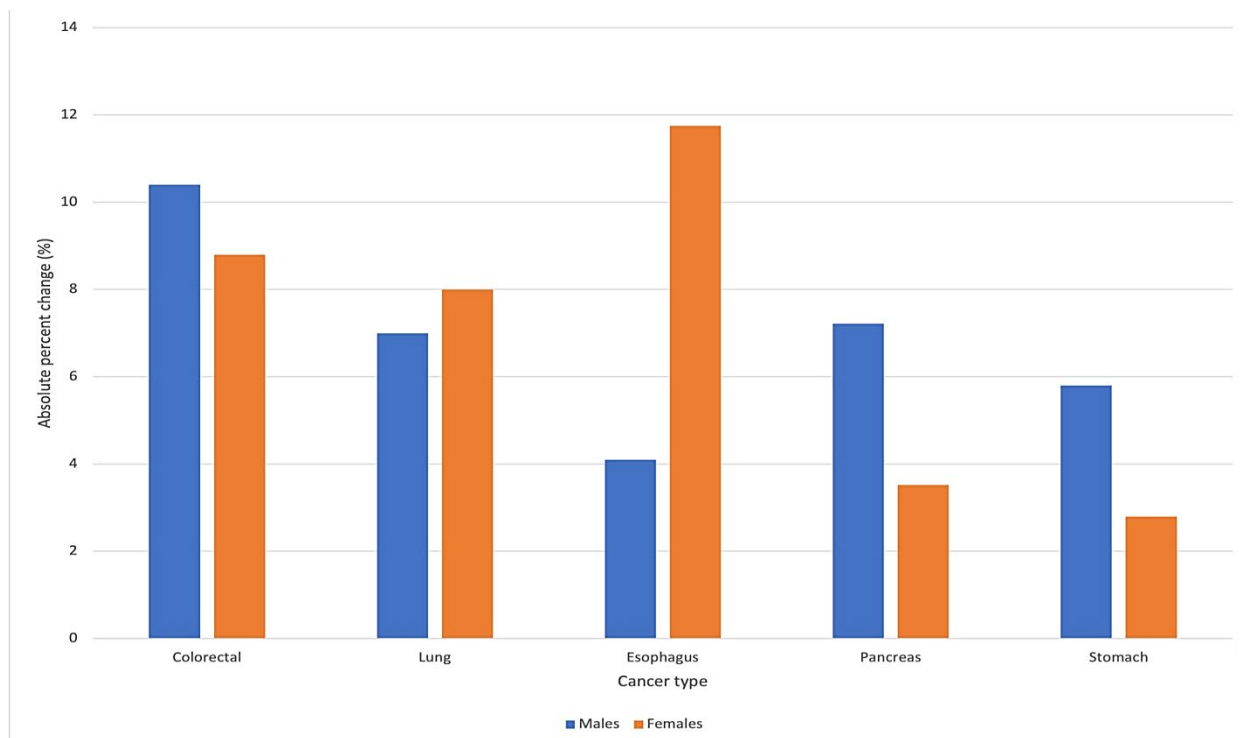
Last revised: April 12, 2023
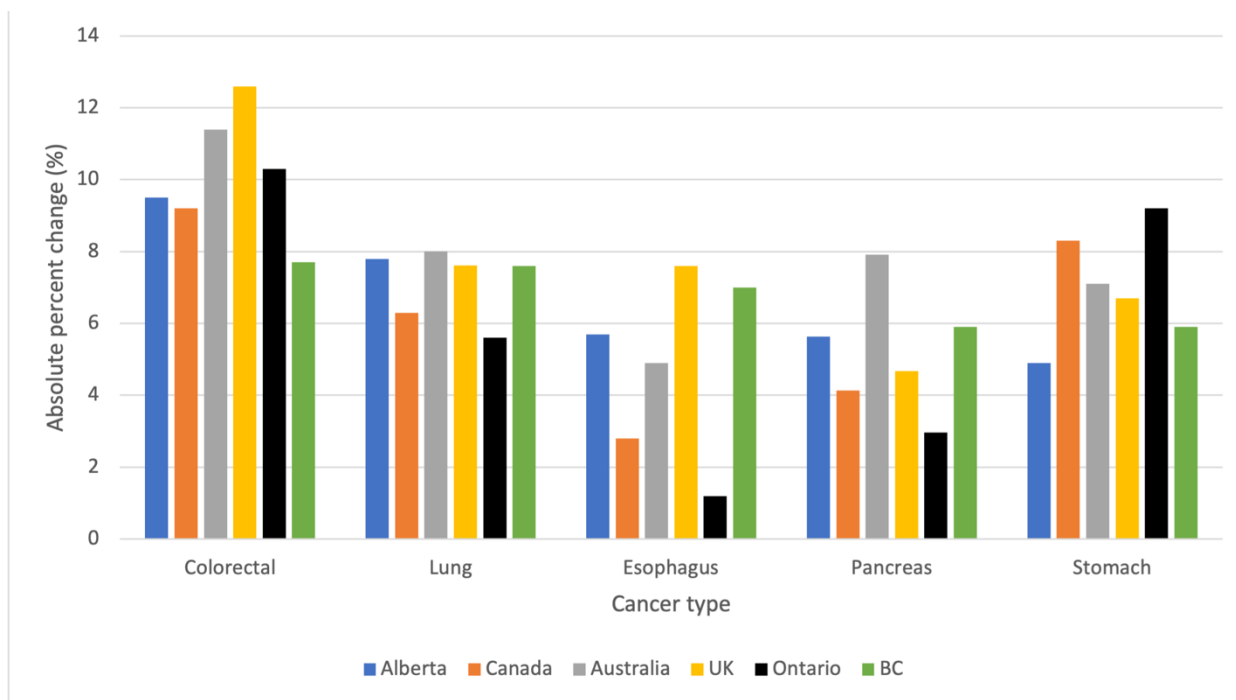
Figure 1818. Absolute percent change in five-year net survival (%) by geography and cancer site 1995–1999 to 2010–2014
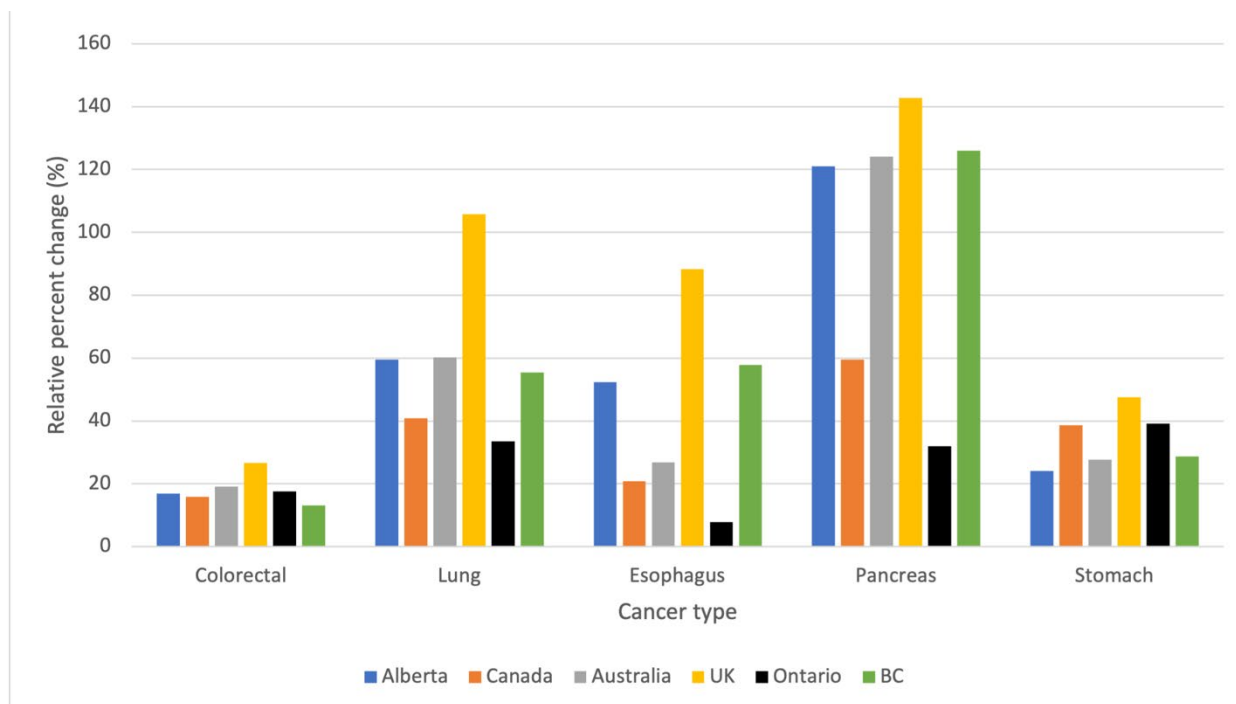
Figure 19. Relative percent change in five-year net survival (%) by geography and cancer site 1995–1999 to 2010–2014

Interpretation and recommendations

Monitoring cancer survival trends is arguably one of the most important uses of population-based cancer registry data. The quality of cancer registry data affects the validity of evidence generated from these data and transparent reporting of findings. Accurate and reliable data can be used by physicians, researchers, public health planners and policy-makers to reduce the future impact of cancer. Lifetime follow-up and linkage with vital statistics are also important aspects of cancer survival data collection and serve in the evaluation of the efficacy of health systems, disparities in care and long-term effects of treatment.

Overall, there were improvements in survival rates for all types of cancer among both males and females of all age groups in Alberta between the periods of 1995-1999 and 2010-2014. However, there was one exception to this trend, as individuals aged 55-64 with stomach cancer experienced worse five-year net survival as time progressed. Improvements in survival for all cancer types were observed for both sexes and all age groups in Alberta from 1995–1999 to 2010–2014. This is likely the direct consequence of public health policies to increase participation in and access to population-based screening for cancers with organized programs, technological advancements to improve diagnosis and staging, and wider access to novel and combination therapies. Survival declined with increasing age and improvements over time were most notable for age groups <75 years. Although this pattern may be expected, disparities in cancer survival among older adults calls for critical attention to strategies that optimize care and address age-related concerns, such as supporting inclusion in clinical trials to inform appropriate treatment decision making,[5] coordinated and integrated care to ensure optimal management of comorbidities throughout the cancer continuum,[6,7] geriatric assessment to inform tailored plans for oncologic treatment and supportive interventions.[8] In general, Alberta was outperformed in survival by Australia for most cancers, except lung for which survival was similar in Australia and Canada. Conversely, Alberta outperformed the UK for most cancers, with the exception of esophageal cancer, for which survival was similar. International differences in access to early detection strategies, diagnostic services, treatments and health care systems

probably explain some survival variations between Alberta and other countries. Differences in coding, classification and cancer registry practice across jurisdictions and countries are currently being investigated to determine their impact on international survival differences.[9]

In this synthesis, cancer survival in Alberta was highest for colorectal cancer. The implementation of the fecal occult blood test (FOBT) and fecal immunochemical test (FIT) as part of province-wide colorectal screening in Alberta has contributed to improvements in survival.[10] Alberta's participation rate in colorectal cancer screening has increased from 36% in 2008 to 67% in 2020. Males experienced slightly greater improvements in survival, particularly in rectal cancer, than females, which may be due to the fact that survival in these cancers has historically been higher for females than males. Improvements are likely attributable to increased participation in screening and changes in lifestyle behaviors that are linked to survival, including smoking, alcohol consumption, red meat consumption and physical inactivity.[11] Many cases are still diagnosed at stages three and four;[12] however, increased participation in screening programs, which were only implemented in 2009, should result in earlier detection and survival improvements. Further, newer targeted therapies against BRAF-mutated cancers, which are associated with poor colorectal cancer survival, are likely to be beneficial.[13] Despite notable successes, survival remains poor for cancers of the lung, esophagus, pancreas and stomach, and improvements are needed.

Lung cancer was the only cancer type in this synthesis where net survival was higher for females than males in every five-year period from 1995–1999 to 2010–2014. This may be related to differences in smoking status – including type, volume and frequency – between males and females. Although daily smoking behavior has declined in Canadian males and females since 1965, males are more likely than females to be daily smokers.[14] Small cell lung cancer (SCLC) is rare among non-smokers and grows fast and spreads more easily than non-small cell lung cancer (NSCLC). The distribution of SCLC and NSCLC in males and females may in part explain survival differences. Smokers also respond more poorly to treatment than never-smokers.[15,16] Despite decreases, further efforts to control tobacco use are still needed to reduce the impact of

lung cancer. Early detection strategies for lung cancer are also a critical component of improving survival. Almost one-half of cases are diagnosed stage IV, which helps explain why lung cancer has among the lowest survival rates.[12] Currently, there are no organized lung cancer screening programs in Canada. In Alberta, pilot studies have taken place and are continuing to assess the feasibility of screening programs for high-risk individuals.[17] This would allow for detection at early stages when the cancer may respond better to treatment. Minor differences in survival between Alberta and the rest of Canada are likely attributable to slight variations in stage at diagnosis and frequency of NSCLC compared to SCLC. In BC, a lung cancer screening program has been approved and it is expected the first participants will undergo screening in 2022.

One- and five-year net survival from pancreatic cancer was the lowest among all cancer types. As the pancreas lies deep within the abdomen, pancreatic cancer typically progresses without causing any symptoms and is only detected when it becomes symptomatic at advanced stages. Like lung cancer, the majority of cases are diagnosed at stage IV with poor prognosis.[12] Around 80% of newly diagnosed patients present with locally advanced or metastatic pancreatic cancer when curative surgery is not feasible.[18] Further, surgery of the pancreas is highly complex and involves a high risk of complications.[19] More recent chemotherapy options, including gemcitabine alone, gemcitabine plus nab-paclitaxel, and FOLFIRINOX, have certainly led to large improvements in one-year survival but improvements in five-year survival are still needed. Advances in early detection strategies will improve response to treatment and thus survival from pancreatic cancer, but no effective screening programs exist for this site. This stresses the importance of developing novel treatment strategies and modifying currently available options to optimize survival. Research studies are being undertaken to directly compare gemcitabine plus nab-paclitaxel and FOLFIRINOX in an effort to identify optimal treatment regimens. Further, investigating the use of chemotherapy alone or with radiation prior to surgery may increase the likelihood of completely removing the cancer with surgery. Identifying biomarkers as targets for novel therapies may also substantially improve survival.

Limitations

These results should be interpreted with caution. Net-survival is a population-based measure and does not reflect an individual's survival with cancer. Despite the methodologic rigour of SURVMARK-2, differences in registration practices may account for variation in survival between countries. Finally, SURVMARK-2 did not have available data for ovarian cancer and therefore survival trends for this cancer site could not be assessed.

Conclusions

Overall, cancer survival continues to improve in Canada and Alberta, providing insights into the effectiveness of screening and use of robust clinical guidelines regarding treatment. Greater efforts are needed for cancers where survival remains poor, including lung, esophageal and pancreatic cancer. Additional work is needed to address clear disparities in survival associated with age and other sociodemographic variables. Early detection strategies are already having a positive impact on colorectal cancer survival. The ability to detect cancer early allows for better treatment response, which is particularly important in lung, esophageal, pancreatic and stomach cancers where the majority of diagnoses are in metastatic stages and surgery is no longer possible. Continued research efforts are greatly needed to identify potential biomarkers for targeted screening and treatment or for developing prediction tools for risk stratification. Such efforts will better suit the individual needs of patients, particularly when population-based protocols for screening or generic treatments do not work. It is yet to be determined whether precision-based medicine is feasible in a universal health care system in terms of cost, access and improving outcomes. Access to advanced radiotherapy treatment technology (e.g. Linac-MR, MR-simulation, protons, etc.) promises improved treatment options for some cancers that may lead to higher survival and/or reduced treatment toxicity (and corresponding improved quality of life). Additional efforts should be made to ensure that there is a systematic approach to examining regular reports on cancer survival in Alberta and taking action to address the findings when appropriate. Updated comparisons of survival statistics across Canada and with other international jurisdictions will also help identify targets for further action.

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II. Cancer diagnosis, treatment and care

Understanding the needs of patients throughout diagnosis, treatment and care is important to ensure resources are allocated to optimize outcomes and experiences of people facing cancer. Early and streamlined diagnosis, appropriate and timely treatment plans, as well as holistic, person-centered care throughout the cancer care continuum are all important factors. In this section, we provide an overview of cancer diagnosis, cancer treatment, treatment costs, supportive care, palliative care and end-of-life care resources in Alberta. We highlight the rapidly changing landscape in clinical care and management and identify several areas for growth and advancement in the future.

Summary of evidence needs and research gaps

When discussing current and future trends in cancer, it is important to mention the growing pressure on the cancer system to care for an increasing number of people diagnosed with cancer, and to absorb the increasing price of drugs and cost of care in general. We need to explore novel approaches to implementing what we know about cancer prevention and risk reduction, and we need to discuss improvements on how people are supported during diagnosis, treatment, supportive and end-of-life care, with an emphasis on communication, coordination of care, education and access to appropriate help at the right time. Additional priorities in the different areas of cancer care include:

Prevention and Screening

- Knowledge-translation-focused initiatives for cancer prevention through modifiable risk factors such as smoking, sun exposure, alcohol consumption, healthy diet, exercise, weight control and vaccination for cancer-causing viruses

- Additional data to support implementation and evaluation of new screening programs such as lung cancer screening and HPV testing

- Ongoing systematic approaches to monitoring uptake of all organized screening programs at the population level, and also for different sub-groups of the population

Diagnosis

- Enhanced integration of cancer screening and diagnostic data with cancer outcomes and health economics data to support ongoing monitoring and evaluation of the impact of new and existing diagnosis pathways on stage at diagnosis, treatment patterns, patient experience, survival and cost-effectiveness/feasibility
- Enhanced capacity to use existing research platforms such as the OncoSim[1] framework, and development of novel approaches to generate useful metrics for diagnosis pathways and the emerging Alberta Cancer Diagnosis Program

- Development, implementation and evaluation of novel communication and education strategies for patients, primary care practitioners, specialists and other stakeholders to support navigation throughout diagnosis, expedite diagnosis and streamline decision-making
- Expansion of psychosocial support and supportive care services for patients going through diagnosis, and development of novel approaches to evaluate the impact on patient experience in the diagnostic interval
- Creation of a research framework based on the emerging Alberta Cancer Diagnosis Initiative to support future studies of novel diagnostic tests

Treatment

- Enhancement of existing health services research efforts and capacity to better meet the needs of Cancer Care Alberta and other key stakeholders in generating real-world evidence evaluating the impacts of novel and routine cancer therapies on health service utilization, adherence to treatment guidelines, patient outcomes and costs/value of cancer care
- Exploration of the feasibility of expanding current clinical trials programs to increase opportunities for participation and collect additional outcome measures, while streamlining pathways towards Phase I and II trials of 'made in Alberta' novel therapies.
- Development of new techniques and approaches in health technology assessment, decision analysis, health economics and statistics to deal with the new challenges posed by the growing drive towards precision oncology[2]
- Utilization of existing expertise to implement a robust research framework for collecting and using patient reported outcomes and experience measures to support design and evaluation of changes in treatment regimens and new models of cancer care
- Establishment of a robust set of indicators related to the full range of cancer services in Alberta to ensure that quality care is provided across all aspects of

quality including acceptability, accessibility, appropriateness, effectiveness, efficiency, equity and safety

Costs

- Creation and implementation of a health economics research framework for cancer to support evaluation of new and evolving patient care pathways and treatment guidelines. The framework should encompass health system and patient/family considerations as follows:
    - Value re-assessment studies that examine the extent to which approved therapies are meeting projected efficacy thresholds and therefore cost-effectiveness in the real-world setting. This is particularly essential with high-cost targeted therapies and immunotherapies
    - Evaluation of potential cost savings for biosimilars and other off-patent therapies
    - Evaluation of the cost-effectiveness of implementing new models of care, including but not limited to changes from resource-intensive in-person visits to virtual models of care
    - Studies to advance understanding of the costs to patients/families associated with the management of cancer, with emphasis on those experiencing the highest impacts on financial health
    - Assessment of Alberta's cancer outcomes and treatment/care costs compared with other provinces to determine areas of success and areas of opportunity for increased efficiency

Supportive care

- Examination of novel ways of enhancing access to supportive care for patients throughout Alberta during and after treatment, regardless of where they live
- Exploration of the expansion of psychosocial support and supportive care services for patients going through diagnosis, and development of novel

approaches to evaluate the impact on patient experience in the diagnostic interval

- Supports for appropriate decision making related to screening, diagnostic testing, treatment, and surveillance informed not by chronological age alone, but by a broad assessment of health and functional status, social supports and resources, and patient/family priorities, values, and goals for care

Palliative, end-of-life care

- Enhanced capacity to access, use and interpret data to advance understanding of access and timing of referrals to palliative and end-of-life care (PEOLC) services for patients diagnosed with cancer
- Advanced understanding of the intersectional impact of the social determinants of health on targeted palliative and end-of-life care needs of vulnerable populations, and development of novel strategies to address needs that are culturally sensitive and appropriate
- Determination of best practices for public and health care professional education, and exploration of how emerging tools (e.g. Connect Care's patient portal) and other approaches could be used to better support advance care planning
- Supports for in-home deaths

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Chapter 5: Cancer prevention & screening

Key findings

- Approximately 40% (6,100 cases) of cancer cases diagnosed in Alberta in 2015 were attributable to modifiable lifestyle, environmental and infectious risk factors, such as tobacco smoking, sun exposure, residential radon exposure and air pollution.

- Based on modelling studies, thousands of cancer cases could be avoided in the future with changes made today.

- Cancer screening participation rates are not meeting targets and the rates differ across health zones and subsets of the population, highlighting issues around availability, accessibility and acceptability of screening.

Recommendations

- Modifiable risk factors that could be targets for primary cancer prevention include tobacco smoking and human papillomavirus (HPV) infections. Prioritize population-based HPV testing and lung cancer screening programs.

- Cancer screening participation rates are not meeting targets and the rates differ across health zones and subsets of the population in Alberta, highlighting issues around availability, accessibility, and acceptability of screening. Improve promotional and recruitment strategies to address low participation rates in cancer screening. Physician-linked programs can be especially valuable as they allow physicians to empower and promote among eligible patients.

- Support research in the following priority areas: reduction of the variation in cancer screening, equitable access to cancer prevention and screening, patient engagement in cancer prevention and screening research, and methods for prevention research implementation and mobilization of what is known about how to reduce the risk of cancer in Alberta.

Background

Improvements in treatment have led to increased survival from many types of cancer in recent years. However, to reduce cancer incidence and mortality, prevention remains an essential first step.

In this chapter, we provide an overview of preventive measures that are primary (environmental and behavioral changes, increased access to immunization, etc.),

secondary (population-based cancer screening) and tertiary (reducing morbidity through behavior, treatment, etc.). We then provide more details on primary and secondary prevention in Alberta including estimates of the number of cases of cancer that could be prevented in the province by changing behaviors and implementing various prevention scenarios. We also provide an overview of currently available cancer screening programs as well as gaps in screening and current initiatives in cancer prevention in Alberta. This information is crucial for prioritizing prevention strategies and screening programs to reduce the impact of cancer in Alberta.

Prevention overview

There are three levels of cancer prevention: primary, secondary and tertiary (Figure 20; Table 9). Interventions at each of these levels can decrease the number of cancer diagnoses. In principle, these three levels of prevention should work in concert to reduce the impact of cancer. For example, for the first time ever, the World Health Organization has launched a global strategy to eliminate cervical cancer.[1] This goal can be achieved in a lifetime by meeting the following prevention targets by 2030:

- Primary prevention: 90% of females fully vaccinated with the HPV vaccine by 15 years of age.
- Secondary prevention: 70% of females screened using a high-performance test by age 35 and again by 45. This goal was set with low- to middle-income countries in mind. In Alberta, more frequent screening is used.
- Tertiary prevention: 90% of females identified with cervical disease receive treatment (90% of females with pre-cancer treated and 90% of females with invasive cancer managed).
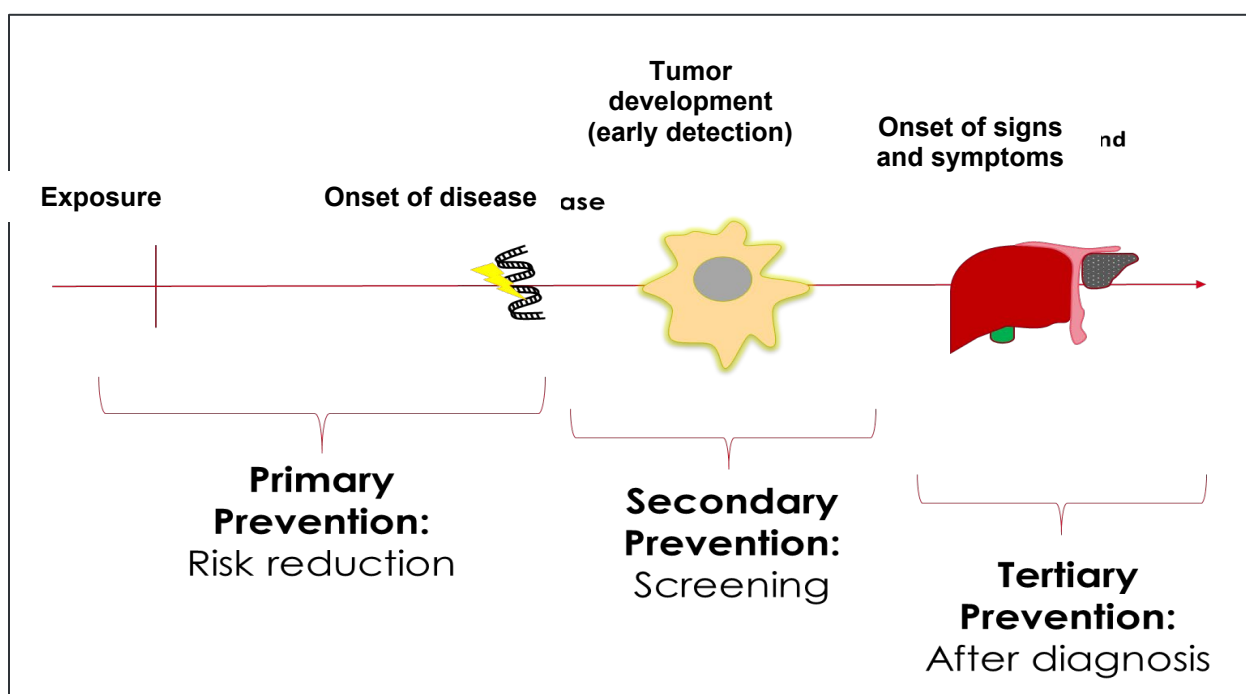
Figure 20. Levels of cancer prevention

Table 9. Summary of the levels of cancer prevention

Level	Target Population	Aim	Examples of Public Health Strategies
Primary	Healthy individuals	Reduce the risk of developing cancer	HPV immunization; public health messaging to reduce alcohol intake; tax increases on tobacco products; walkable communities; access to healthy foods; sun safety for outdoor workers; reducing radon exposure
Secondary	Individuals with subclinical forms of cancer	Detect cancer or pre-cancerous cells early	Cancer screening (FIT test, Pap test, mammogram)
Tertiary	Symptomatic patients (post-diagnosis)	Reduce severity of cancer and associated conditions or symptoms	Rehabilitation through diet, physical activity, medication, etc.

Primary prevention

Primary prevention involves reducing people's risk of ever developing cancer. Therefore, the target for this level of prevention is cancer-free individuals. Various non-modifiable and modifiable risk factors for cancer have been identified. The International Agency for Research on Cancer's (IARC) Monographs[2] and the Continuous Update Project[3] by the World Cancer Research Fund (WCRF) and the American Institute for Cancer Research identify modifiable lifestyle, environmental and infectious risk factors with known, probable, convincing or sufficient evidence of an association with cancer. Examples of modifiable risk factors that could be targets for primary prevention include tobacco smoking, red and processed meat consumption, sun exposure, residential radon exposure, human papillomavirus (HPV), hepatitis B vaccination and many others. Immunizations for HPV as well as campaigns aimed at sun safety and smoking cessation programs are all forms of primary prevention. Screening for both cervical cancer and colorectal cancer has also been shown to reduce the incidence of these cancers through identifying and treating pre-cancerous lesions.

Secondary prevention

In cancer prevention, secondary measures involve detecting cancer early through population-based cancer screening programs. Secondary prevention targets healthy-appearing individuals with no noticeable signs of disease. In most Canadian provinces and territories, including Alberta, screening programs have been implemented for colorectal, breast and cervical cancers. Screening is typically advised based on age at the population level, as well as for individuals at especially high risk. Emerging frameworks inform appropriate shared decision making for screening among older adults based on health status and risk, rather than age alone.[4] For example, the Alberta Colorectal Cancer Screening Program recommends screening with the fecal immunochemical test (FIT) every one to two years in asymptomatic individuals between the ages of 50 and 74 at average risk.

Tertiary prevention

The goal of tertiary prevention is to prevent the progression, recurrence or metastasis of cancer, which can lead to mortality from cancer. Through tertiary prevention, the

severity of the cancer and its associated symptoms or conditions can be reduced to improve the patient's quality of life. Strategies can include treatment, physiotherapy, diet, physical activity and participation in support groups.

Primary prevention

Cancer prevention through behavioral changes – results from the Alberta Population Attributable Risk (PAR) study

The Alberta PAR study was conducted to estimate the proportion of cancer in Alberta in 2015 attributable to modifiable lifestyle and environmental risk factors and infections. Population-based data on risk factors as well as cancer incidence data were used to generate these estimates. Approximately 40% (6,100 cases) of cancer cases diagnosed in Alberta in 2015 were attributable to modifiable risk factors (Figure 21). Lifestyle factors accounted for the highest proportions of preventable cases, specifically tobacco smoking (16%), lack of physical activity (5%) and excess body weight (3%). An estimated 83% of lung cancer, 52% of bladder cancer, 45% of colorectal cancer, 26% of female breast cancer and 5% of prostate cancer were attributable to modifiable risk factors.

Figure 21. Cancer cases in Alberta in 2015 attributable to modifiable lifestyle factors

By making changes now, we can prevent cancer cases in the future:

- If trends in tobacco smoking were to continue unchanged, 89,720 cancer cases diagnosed in Alberta between 2020 and 2038 would be due to tobacco. However, if the prevalence of smoking tobacco were reduced to 5% (currently 16% in females and 24% in males) between 2020 and 2035, 3,890 cancer cases in Alberta could be prevented by 2038.

- Currently 50% of Albertans are overweight, but if by 2032 this number were reduced by 25%, 7,325 cancer cases could be prevented by 2038.

- If trends in sun exposure were to continue, 11,125 melanoma skin cancer cases diagnosed in Alberta between 2020 and 2038 would be due to sun exposure, of

which 1,490 could be prevented if indoor tanning, sunburns and sunbathing were reduced by 50%.

- If current trends were to continue, 18,290 cancer cases diagnosed in Alberta between 2020 and 2038 would be due to alcohol consumption and 7,290 of those cases could be prevented if Albertans reduced their consumption to no more than two drinks per day for males and no more than one drink per day for females.

Approximately 4% of cancers in Alberta are attributable to infections including HPV, *helicobacter pylori,* Epstein-Barr virus and hepatitis B and C. Population-based immunization for HPV and hepatitis B and C can greatly reduce the number of cancers attributable to these infections.

Primary prevention initiatives in Alberta

Existing programs and initiatives available/ongoing in Provincial Population and Public Health (PPPH) that support action on the modifiable risk factors for cancer primary prevention:

- Tobacco – The Tobacco Vaping and Cannabis Program (TVCP) provides text, email and phone support for those ready to quit smoking through the AlbertaQuits helpline at no cost for all residents of Alberta [Phone | AlbertaQuits](). They also provide a virtual and in-person group counselling sessions [QuitCore support groups | AlbertaQuits]() at no cost to Albertans to equip them with the tools and skills they need to quit using tobacco.
- Alcohol – AHS Addictions and Mental Health (AMH) is committed to the Alberta Alcohol Strategy [Alberta Alcohol Strategy | Alberta Health Services]() that is intended to prevent and reduce the harm associated with alcohol use by developing a culture of moderation. AMH also supports health professionals in their important role in promoting health perceptions, attitudes, and behaviors towards alcohol use through the Alcohol and Health Series [Alcohol & Health Series | Alberta Health Services](). AMH Research Hub provides a partnership between professionals, community organizations, ministries, patients and other

stakeholders to reduce alcohol related harms in Alberta [Addiction & Mental Health Research Hub | Alberta Health Services](#)

- Physical Activity and Sedentary Behavior - The Provincial Physical Activity and Sedentary Behavior Team (PPASB) work towards improving the health and wellbeing of all adult Albertans through the promotion of physical activity and the reduction of sedentary behavior [Physical Activity & Sedentary Behavior | Alberta Health Services](#) through the implementation of an Active Workplace Audit Toolkit, UWALK and WalkABle Alberta.

- AHS Nutrition and Food Services promotes healthy eating by supporting people in Alberta where they live, work, learn and play. Resources for improving healthy eating environments are provided for workplaces, schools, early learning and childcare centres and the community [Healthy Eating Starts Here | Alberta Health Services](#).

- Sun Safety – PARISC Framework – In 2018 AHS together with our 17 partners launched the Provincial Approach to Reducing the Incidence of Skin Cancer (PARISC) Framework in Alignment with Alberta's Cancer Plan to 2030. The project's ambitious long-term goal is to shift cultural and social norms in favor of UVR risk reduction, similar to the successes we have seen in reducing tobacco use over the last 15 years through a similar approach to integrated action. As of 2019 14 strategies have been initiated through collaboration with AHS, research and community partners [AHS-6215_PARISC_Framework_AUG15_SS.indd (healthiertogether.ca)](#)

Since 2013, Alberta Health Services' Population and Public Health innovation team for cancer prevention and screening, funded by a restricted grant from Alberta Health, has taken a coordinated approach to developing innovations for cancer prevention and screening that create healthy individual behaviors, enhance community and organizational supportive environments, and strengthen policy and system. High achieving jurisdictions have accomplished reduced cancer rates by systematically inspiring public action and integrating prevention and screening opportunities into people's everyday lives. This includes the places where they live, learn, work, play and

seek health care.[5] Primary prevention and participation in cancer screening are not only determined by decisions made by individuals concerning their own health -but are also highly influenced by the environments in which people live their lives and the way that environment shapes norms, expectations and opportunities concerning health. Determinants of health, including the conditions in which people live, work, learn, heal and seek health care, are essential for sustainable improvements in health and reductions in cancer incidence.[6] For the last several years, AHS has developed and tested interventions based on the population health approach. These interventions are organized around key settings in rural and Indigenous communities, workplaces, and health services, and provide a mechanism to integrate multiple interventions and strategies across the different levels of intervention identified in the Ottawa Charter for Health Promotion.[6]

Community-led cancer prevention

To prevent cancer and chronic disease and ensure health system sustainability, it is essential to create community environments that support healthy lifestyle choices. Community-based programs that focus on preventing modifiable risk factors have been shown to produce a significant return both financially and in health savings (Prevention Institute, 2008). The Healthy Communities Approach is one such successful approach that was adapted to create the Alberta Healthy Communities Approach (AHCA).[7,8] The approach includes a 5-step approach including community capacity and supportive environment assessment tools, evidence-based strategy kits that promote sustainable, cancer preventing action based on unique community needs, priorities and assets. The approach includes a Hub, which is a self-sustaining online platform created to help communities to learn from each other, mentor each other and build on each other's successes. The Hub has been accessed well over 80,000 times since it was launched in September 2017. Evidence informed tools, data and guidance to help communities through the process are available on HealthierTogether.ca (link: Home - Alberta Healthy Communities Hub (healthiertogether.ca)). Data-based profiles of community health, based on multiple sources of data and designed with and for use by community coalitions (not public health experts) are also available to inform planning and

prioritizing of health and wellness initiatives by communities (link: Comprehensive Cancer Prevention Profiles - Resources - Home - Alberta Healthy Communities Hub (healthiertogether.ca)).

Thirty-six rural communities have engaged with the AHCA. Among the 16 that to date have completed the full cycle of planning and actions, 12 improved their supportive environments for physical activity, 12 focused on improving UVR protection, 11 undertook initiatives to promote healthy eating (Figure 22), 10 for mental health and two for tobacco reduction. These changes have the potential to support healthy behaviors among the 83,839 individuals living in those 16 communities.
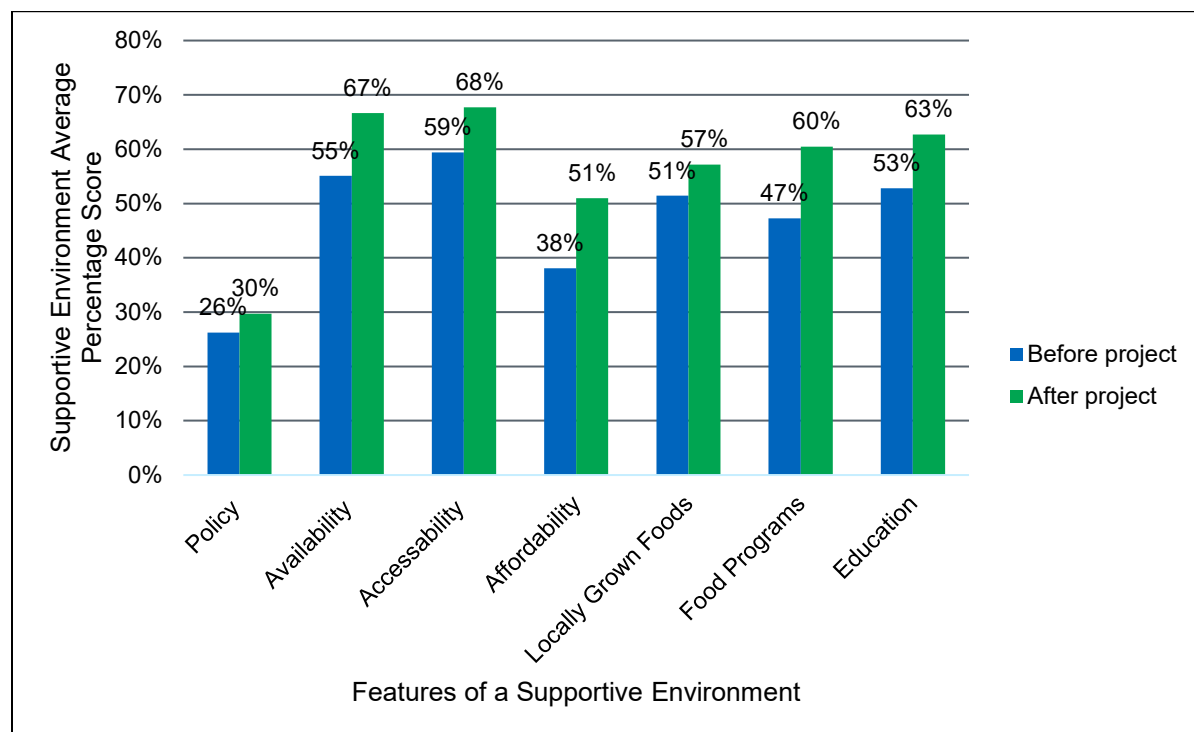
Figure 22. Average supportive environment results from the SUCCESS tool for healthy eating before and after communities participated in the pilot project (n=11)

Workplaces

With approximately 2.5 million people in Alberta in the workforce, the workplace represents an excellent setting to address cancer risk factors. The World Health Organization considers workplace health promotion a strong investment for preventing

cancer and chronic diseases. Comprehensive programs that promote and create an enabling environment for healthy employee behaviors are needed (i.e. tobacco-free policies; safe and healthy working environments; and good corporate practices). Based on earlier pilot work, in which 50 workplaces of various sizes across Alberta worked to promote the health of their employees, the Healthier Together Workplaces program was developed. Accessible without cost online to any Alberta workplace, the program and tools at HealthierTogether.ca (link: https://workplaces.healthiertogether.ca/) guide workplaces to strengthen employee health and wellness and create a stronger culture of health at work. A graduated AHS Certificate of Recognition program was developed to enable workplaces to achieve progressive award levels of AHS recognition for their accomplishments in promoting the health and safety of their employees. Workplaces have promoted the health of their employees through developing policies and taking action in areas such as promoting smoking cessation, UVA protection and physical activity, to name a few (Figure 23).
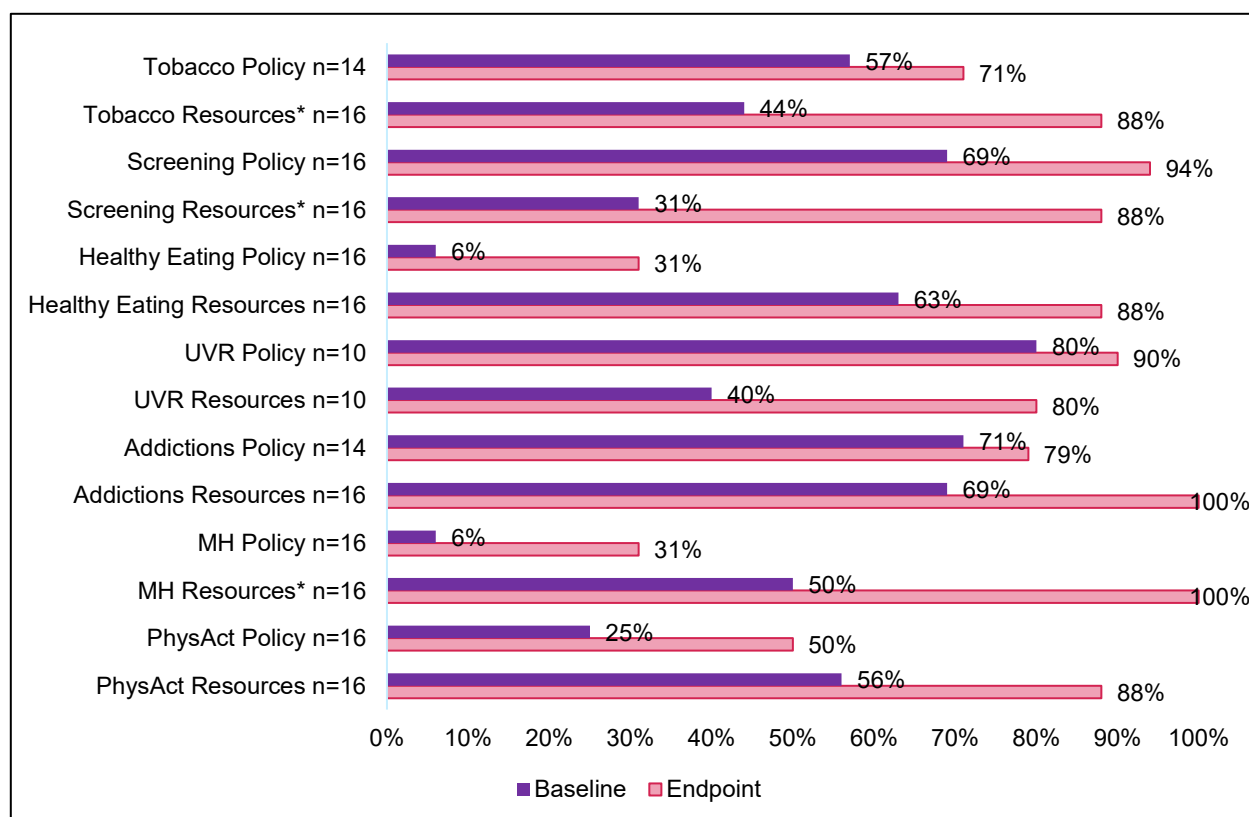
Figure 23. Changes in the Policies and Program/Resources at pre/post BHBB for 16 workplaces.
Note: The following increases were statistically significant: tobacco resources at $p=0.039$ ($p<0.05$); screening resources at $p=0.011$ ($p<0.05$); and mental health resources at $p=0.0078$ ($p<0.01$).

Virtual/Information environment

Reducing cancer and chronic disease risk factors through individual behavior change requires support of Albertans with the right information at the right time. We know that people who live in Alberta are three times more likely to seek information about cancer and chronic disease prevention online than they are to discuss this with their primary care provider.[9] This means it is essential that we meet people in Alberta where they are at with an approach that informs, motivates, and supports individuals to improve their risk factor-related behaviors.

HealthierTogether.ca (link: Healthier Together (alberta.ca)) is now the place where all AHS prevention-oriented websites have started to come together as a single source of prevention information for the people of Alberta. Using the HealthierTogether.ca website

as a central info hub – public campaigns have been initiated to promote primary cancer prevention actions. The HPV Decision Aid (link: http://hpvtool.healthiertogether.ca/a decision-aid), designed to inform and motivate people who are undecided about getting HPV vaccination, has been accessed by nearly 7,000 people and has provided important insights for future vaccine hesitancy interventions for both parents of children aged 12-17 and adults 18-26 seeking the vaccine for themselves.[10] A single social-media campaign to promote smoking cessation information and resources on HealthierTogether.ca resulted in almost 700 new registrations with the AlbertaQuits smoking cessation program.

Health services

Primary care is a natural health services environment for promotion of healthy behaviors for primary cancer prevention as well as being the main access point for cancer screening. The Alberta Screening and Prevention (ASaP) maneuvers for primary care providers to help their patients stay up to date on key screening and prevention practices for chronic diseases and cancer are well-established and widely practiced in Alberta. In recent years, an extension of the ASaP program (called ASaP+) was developed to include screening, brief intervention and referral for several modifiable factors such as tobacco use, excessive alcohol use, overweight, insufficient physical activity and low consumption of vegetables and fruit. ASaP+ was tested over 2 years in 5 clinics from 4 different Primary Care Networks across Alberta resulting in nearly 54,000 screens for modifiable factors and over 2,500 supportive interventions for patients identified with elevated risk. An ASaP+ Change Package, hosted on the Alberta Medical Association's Accelerating Change Transformation Team website (https://actt.albertadoctors.org/) allows primary care providers to independently use the tools and resources of ASAP+ to guide health promotion and disease prevention practices in relation to patients' modifiable factors.

Because Indigenous people have a higher prevalence of cancer modifiable risk factors, there is a tremendous need for innovative health system practices that identify people who are at risk and support them to address these factors. To that end, ASaP was also adapted specifically for settings where a greater proportion of patients are Indigenous

and this adapted program has been taken up by clinics in Calgary and Edmonton that focus on serving Indigenous people.

Health care providers occupy a unique position of trust and expertise with most people, with respect to health issues, so health care encounters provide special opportunities to engage patients in primary (and secondary) prevention and encourage screening.

Smoking cessation is an important part of cancer treatment. Research[11,12] has demonstrated a strong return on investment since tobacco can interfere with cancer chemotherapy, and contribute to cancer recurrence or development of new cancers subsequent to treatment. In the last several years the Provincial Population and Public Health program, in partnership with Cancer Care Alberta developed, tested and operationalized a program for use by cancer treatment centres in Alberta to refer patients who use tobacco to specialized cancer-patient focused smoking cessation support services provided by AlbertaQuits (www.albertaquits.ca).

Hospitalization or ambulatory care clinic visits offer another opportunity to intervene with patients to promote primary prevention and screening. In recent years, a screening, brief intervention and referral (SBIR) approach – to identify and intervene with patients at increased risk of cancer in relation to several modifiable factors - has been piloted in several Alberta hospitals in both urban and rural settings. These pilots have demonstrated the feasibility and acceptability (to clinicians and patients) of the approach to integrating prevention-promoting practices into regular care in acute and ambulatory care settings. With the progressive roll out of Connect Care (AHS' unified EMR) over the next couple of years – an opportunity exists to spread this practice more widely through its integration into clinical workflows related to Connect Care.

Cancer prevention through cancer screening

Cancer screening programs in Alberta

There are organized cancer screening programs (Table 10) in Alberta for breast, colorectal and cervical cancers. These free programs are offered to specific target populations. Mobile clinic sites are also available for those in rural communities.

Table 10. Current cancer screening programs in Alberta

Cancer Site	Target Population	Test	Recommended Frequency
Breast	Females 50 to 74 years of age at average risk	Mammogram	Every two years
Cervix	Females 25 years of age and older, or three years after becoming sexually active, whichever is later	Pap test	Every three years
Colorectal	People 50 to 74 years of age at average risk	FIT test	Every one to two years
	People with a first-degree relative who had colorectal cancer and/or high-risk polyps	Colonoscopy	Dependent on risk factors and results of previous colonoscopies

Breast cancer screening

In breast cancer screening, mammograms (X-rays of the breast) are used to detect early signs of cancer in females with no symptoms. The mammogram can find abnormalities in the breast that cannot be felt by the patient or health care provider. If an abnormality is found in a screening mammogram, a diagnostic follow-up is recommended. Since the introduction of breast cancer screening in Canada in the 1990s, the mortality rate for female breast cancer has been declining.[13] The percentage of patients surviving five years after a breast cancer diagnosis is significantly higher for early-stage breast cancer compared to late-stage disease (Table 11).

Table 11. Five-year breast cancer survival by stage

Stage	Five-year relative survival
1	99%
2	90%
3	72%
4	26%

Source: Cancer Research UK (2021).[14] Note: These numbers only apply to the stage of cancer at diagnosis. These statistics come from Canadian sources as well as other countries that are likely to have similar outcomes as in Canada.

Females between the ages of 50 and 74 years should receive a mammogram every two years, or as decided by the patient and their health care provider. In 2018–2019, 65% of females aged 50 to 74 in Alberta had a screening mammogram within a 30-month period.[15] In addition, in Alberta, breast cancer (BRCA) gene tests are available for

those who are concerned they may have a BRCA gene mutation due to family history. These tests can determine if someone has a higher risk of breast and ovarian cancer (as well as prostate and pancreatic) cancer by detecting mutations in the BRCA1 and BRCA2 genes.[16] Albertans can discuss their concerns regarding BRCA gene mutations with their primary care provider to determine if a gene test is recommended.

Cervical cancer screening

More than 90% of cervical cancers can be prevented with regular Papanicolaou (Pap) tests and follow-up. A Pap test is used to check cells collected from the cervix for abnormalities. If abnormal cells are found, additional tests may be recommended including additional Pap tests, HPV tests or a colposcopy. HPV reflex testing is used to triage certain abnormal Pap test results. Almost all cervical cancer cases are caused by HPV. Cervical cancer screening can detect pre-cancerous lesions or invasive cervical cancer early, and therefore reduces the incidence and improves the clinical outcomes of invasive cervical cancer cases (Table 12). As mentioned above, there is now a global initiative to eradicate cervical cancer[1] by employing all three levels of prevention.

Table 12. Five-year cervical cancer survival by stage

Stage	Five-year relative survival
1A	93%
1B	80%
2A	63%
2B	58%
3A	35%
3B	32%
4A	16%
4B	15%

Source: Canadian Cancer Society (2021).[17] Note: These numbers only apply to the stage of cancer at diagnosis. These statistics come from Canadian sources as well as other countries that are likely to have similar outcomes as in Canada.

In Alberta, women are recommended to start Pap tests at age 25 or three years after becoming sexually active, whichever is later. In 2017–2019, 64% of women aged 25–69 in Alberta had a Pap test within a 42-month period.

Colorectal cancer screening

In Alberta, the FIT test is used to detect blood in the stool that is not visible. If blood is found in the stool sample, a colonoscopy is usually recommended. During a colonoscopy, a scope with a light and video camera on the end is inserted through the anus to inspect the lining of the colon and rectum. If polyps are found, they are removed during the procedure and sent to a lab to check for pre-cancerous cells or cancer. As shown with both breast cancer and cervical cancer, survival in early-stage colon and rectal cancers is much better compared to diagnosis at a later stage (Table 13).

Table 13. Five-year colon cancer and rectal cancer survival by stage

Cancer site	Stage	Five-year relative survival
Colon	1A	92%
	2A	87%
	2B	65%
	3A	90%
	3B	72%
	3C	53%
	4	12%
Rectum	1A	88%
	2A	81%
	2B	50%
	3A	83%
	3B	72%
	3C	58%
	4	13%

Source: Canadian Cancer Society (2021).[18] Note: These numbers only apply to the stage of cancer at diagnosis. These statistics come from Canadian sources as well as other countries that are likely to have similar outcomes as in Canada.

Individuals between the ages of 50 and 74 years at average risk should get screened for colorectal cancer using a FIT test every one to two years, but health care providers may refer their patients for screening at age 40 years or younger if they are considered high risk. A colonoscopy is the recommended screening test for Albertans considered to be at a high risk. In 2018–2019, 39% of Albertans aged 50–74 had completed a FIT test at least biennially. When both methods of screening for colorectal cancer are considered, 56% of screen-eligible Albertans aged 50–74 had a FIT test and/or a colonoscopy in the past five years.

Newer recommended cancer screening approaches

Lung cancer

Lung cancer is by far the leading cause of cancer mortality in Alberta, accounting for about 1 in 4 cancer deaths.[19] If lung cancer is diagnosed at stage 1, the three-year survival is 71%, but survival is reduced to just 5% if it is diagnosed at stage 4. Unfortunately, about 50% of lung cancers are diagnosed at stage 4 and only 21% are diagnosed at stage I.[20] As of November 2021, there are no organized screening programs for lung cancer in Canada, but opportunistic screening is occurring in six provinces, including Alberta, using low-dose computed tomography (LDCT).[21] Screening for lung cancer is recommended by the Canadian Task Force on Preventive Health Care for adults aged 55–74 years who currently smoke or who have quit within 15 years and smoked 30 pack years (number of packs of cigarettes smoked per day multiplied by the number of years smoked). A Canadian study estimated that lung cancer screening using LDCT for high-risk individuals in Canada could prevent 5,000 to 11,000 lung cancer deaths over a lifetime.[22] In Alberta, screening activities have been part of a research study to support organized lung cancer screening and, as of September 2020, British Columbia was the first province to announce the implementation of a lung cancer screening program by 2022.[23]

HPV primary screening

HPV tests are now available that detect the presence of the HPV types that are considered high risk. The HPV test is more sensitive than the Pap test. In addition, HPV self-sampling kits can be made available to reduce access barriers for screening. In Canada, there are currently no organized programs using HPV as a primary screening test. CPAC has called for the HPV test to replace the Pap test as the primary cervical cancer screening tool in Canada.[24]

Bladder cancer screening

Although there is no standard or routine screening for bladder cancer, various tests have been studied as potential screening methods for the disease. Urinalysis is used to detect red blood cells in a sample of urine (hematuria). However, this test has not been shown to be useful for routine screening and is typically only performed for people with

a high risk of bladder cancer or as part of a general health check-up.[25] In more recent years, urine tests for tumor markers have been explored. These tests include: UroVysion™, which detects chromosome changes; bladder tumor-associated antigen (BTA) tests; ImmunoCyt™, which detects substances such as mucin and carcinoembryonic antigen (CEA) in urine cells; and NMP22 BladderChek® which detects a protein called NMP22 (nuclear matrix protein 22) in urine. In addition, cystoscopy and cytology are used to screen for bladder cancer in patients who have had bladder cancer in the past.

Gaps in cancer prevention

Although a great deal of progress has been made in cancer prevention in Alberta, gaps remain in terms of actions that can be taken to reduce the incidence of cancer across the province.

Vaccination

The HPV vaccination uptake rates in Alberta have been increasing, but they are still not at the level required for the elimination of cervical cancer in Alberta. Since 2008, the HPV vaccine has been part of a school-based immunization program for grade 5 females and was made available to grade 9 females in 2009. In 2014, the program was expanded to include grade 5 and grade 9 males. From 2008 to 2014, 169,259 Albertans received one or more doses of the HPV vaccine, with 84% of them receiving a publicly funded vaccine.[26] The uptake rates increased in the target population over the study period, which is an encouraging sign for the future. In the 2016/17 school year, the HPV vaccine uptake in grade 5 females for the first dose was 76% but it decreased to 67% for the third dose.[27] Many jurisdictions in Alberta have now moved to a two-dose schedule, as this approach has been shown to be effective.

Residential radon exposure

Radon is a radioactive gas that is undetectable by the human senses and dilutes quickly to non-hazardous concentrations in the outside air. However, modern buildings can capture, contain and concentrate radon to unnaturally high levels that emit DNA-damaging radiation at cancer-causing doses. The lungs are the primary point of

exposure, and long-term inhalation of high concentrations of radon is causatively linked with lung cancer in both smokers and never-smokers. It is important to recognize that radon exposure in Alberta is among the highest in the world, and that newer residences contain higher levels relative to mid-20th century equivalents.[28] Indeed, 1 in 10 Alberta homes built in the 1970s exceeds the maximum tolerated radon exposure limits set by Health Canada, while this is 1 in 4 for new properties (built in 2020). This exposure issue has a solution, as radon mitigation is both effective and permanent, involving minor home renovations typically completed within two days at costs comparable to replacing a few windows. Radon testing programs have been in operation in Canada since the 1990s; however, only a relatively small proportion of the Alberta population has ever performed a radon test at a property they live in, and only about one-third of those who find they are at risk will take action to mitigate it. Increased awareness regarding the dangers of radon exposure and solutions are needed to reduce the incidence of lung cancer caused by radon gas in Alberta.

Screening adherence

Breast, colorectal and cervical cancer screening programs in Alberta are available to anyone who meets the eligibility criteria for screening. However, participation rates differ – sometimes greatly – between Alberta Health Services' Zones, which highlights the need for programs aimed at improving adherence in those zones. For all screening programs, the participation rates are lowest in the North zone, where there are more rural and remote communities. For example, in 2018–2019, 65% of females aged 50–74 had a screening mammogram within a 30-month period in Alberta; however, participation rates ranged from 57% in the North zone to 67% in the South zone. In addition, none of the zones met the screening mammogram target participation rate of 70%, although rates have increased since 2013–2014, when the overall participation rate for Alberta was 63%.

For cervical cancer screening, the results are similar. Participation rates for Pap tests were 64% in 2017–2019 but ranged from 56% in the North zone to 66% in the Calgary zone. Again, none of the zones met the target participation rate of 80% and participation rates have decreased since 2011–2013, when the rate was 68% for Alberta.

Participation rates for biennial FIT tests in Alberta are quite low. In 2018–2019, 39% of Albertans aged 50–74 had a FIT test at least biennially, which ranged from 36% in the North zone to 42% in the South zone. These participation rates are significantly below the 60% target. The rates are higher, at 56%, when both the FIT and colonoscopy methods of screening for colorectal cancer are considered and range from 51% in the North zone to 59% in the South zone. Very little change has been observed for FIT and colonoscopy participation rates since 2014.

Screening equity

In Canada, the publicly funded health care system aims to provide equitable care for all. However, in general, screening participation rates are low among low-income individuals; First Nations, Inuit and Métis individuals; new immigrants; those living in rural and remote communities; and the LGBTQ2S+ populations.[29] Barriers to cancer screening exist at both system and individual levels. For Indigenous groups, sexual minorities and new immigrants, a lack of sensitivity in care can deter participation in screening programs. For example, sex and gender preferences for the screening provider and an understanding of the patient's language and culture are important factors that are often not taken into consideration in these groups.[30] In addition, access to screening continues to be an issue for those in low-income, racialized and Indigenous communities due to barriers such as lost wages, lack of childcare and limited resources in remote communities. In Alberta, mobile screening clinics have been established to serve rural and remote communities for breast, colorectal and cervical cancer screening, but barriers remain for other cancer sites and communities not served by the mobile clinics.

According to the limited data specific to First Nations, Inuit and Métis communities, participation rates for cancer screening (especially colorectal cancer screening) are lower among these groups than for non-Indigenous people in Canada.[31] In Alberta, screening programs work with Indigenous communities and primary care groups to raise awareness of cancer risk and screening. However, awareness strategies alone cannot bridge this disparity. Significant resources including accessible screening centres are required, especially for First Nations, Inuit and Métis communities.

In Alberta, the Creating Health Equity in Cancer Screening project aims to better understand sociodemographic and spatial barriers to cancer screening. The project involves a three-phase community engagement approach. In phase one, the Pampalon deprivation index was used to identify target communities in Calgary and data were analyzed to investigate how material and social deprivation influences screening rates. In phase two, the public were engaged to determine barriers and facilitators to cancer screening within underserved communities. Phase three is in progress and focuses on the implementation and evaluation of collaborative interventions.[32]

Interpretation and recommendations

Prevention at all levels is a powerful tool to reduce the impact of cancer in Alberta. An estimated 40 % (6,100 cases) of cancer cases diagnosed in Alberta in 2015 were attributable to modifiable risk factors including lifestyle, environmental and infections. These comprehensive results can help inform and prioritize policy and interventions targeting these risk factors, with the potential to reduce the future impact of cancer in Alberta substantially.

Population-based screening programs play a key role in early cancer detection and outcomes. Pre-cancerous cells and cancers detected early have much better clinical outcomes compared to late-stage cancers. In addition, more treatment options are available for early-stage cancers. Unfortunately, cancer screening participation rates are not meeting targets and the rates differ across health zones and subsets of the population, highlighting issues around availability, accessibility and acceptability of screening. To address low participation rates, more promotional and recruitment strategies need to be introduced. Advertising, recall letters, social media campaigns and physician-linked correspondence programs are all strategies to promote screening in Alberta. Physician-linked programs such as Alberta Netcare can be especially valuable as they allow physicians to see the screening status of eligible patients. Recruitment methods differ for each screening program in terms of physician or self-referral. To increase participation rates, Albertans should be made aware that access to screening programs is available through self-referral directly to the service provider. In addition,

the introduction of population-based HPV testing and lung cancer screening programs should be prioritized.

Research Recommendations

In 2020, Cancer Research & Analytics commissioned a project [33] aimed to identify cancer prevention and screening research gaps and opportunities, and involved interviews and round tables with key stakeholders.

There were two distinct areas of future work: (1) Discovery– what we need to know more about and (2) Support and mobilization – what we need to implement.

Discovery

Six research priorities emerged as gaps and opportunities in cancer prevention and screening research:

1. Reducing the variation in cancer screening
2. Equitable access to cancer prevention and screening
3. Equitable access to cancer prevention and screening (Indigenous focus)
4. Patient engagement in cancer prevention and screening research
5. Methods for research mobilization (knowledge translation)
6. Mobilization of research priorities and implementation (knowledge translation)

Sample targeted priorities include:
- Deepen the understanding of nature/scope of barriers to cancer screening at the individual, provider and system level, specific to the Alberta context.
- Identify criteria and approaches to tailoring screening programs for sub-populations (especially for marginalized populations).
- Understand how a multi-pronged approach (i.e., health equity/social determinants of health lens) impacts cancer incidence, morbidity and mortality in Indigenous peoples.
- Explore how effective patient engagement can inform more equitable access to screening and prevention interventions.
- Enhance knowledge translation efforts by raising awareness of existing knowledge translation tools, resources and methodological training
- Identify best practices for data monitoring, measurement and sharing.
- Enhance opportunities to evaluate short-term successes that enable rapid knowledge mobilization within specific contexts.

Support and Mobilization

Four overarching themes related to enhanced coordination emerged:

1. Evidence
2. Exchange
3. Equity
4. Engagement

Sample targeted priorities to leverage include:
- Partner with organizations already focused on patient engagement to build capacity for communities to actively participate in research in a sustainable manner.
- Develop a white paper on incentives for enhancing health promotion and prevention in primary care settings, and enabling family doctors to actively participate in research and knowledge translation interventions
- Undertake a knowledge, attitudes and beliefs study of Alberta's population to understand the current state regarding cancer prevention and screening in the province.

"A more coordinated effort between research, policy and practice professionals may help advance some of the research priorities. This underscores the critical importance of working together now to address current research gaps and inequities. It also serves as an opportunity to build momentum among all cancer care stakeholders to create a comprehensive and coordinated approach for a healthier Alberta – where the aim is to have most cancers prevented."

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Chapter 6: Cancer diagnosis

Key findings

- Evidence shows that organized initiatives to facilitate cancer diagnosis, expedite cancer staging, imaging, and referrals are effective in reducing wait times and improving the patient experience, as well as using health system resources more efficiently.

- Improving cancer diagnosis may have major downstream effects, such as earlier stage at diagnosis, less complex therapy, and better survival rates.

- The Alberta Cancer Diagnosis (ACD) Initiative aims to establish a comprehensive provincial cancer diagnosis program that will anchor all cancer diagnosis pathways and ensure essential components are available including: 1) centralized referral and triage with closed loop communication to primary care providers; 2) supports to meet navigation, education, psychosocial and symptom control needs of patients; 3) facilitated appropriate diagnostic tests and specialist referrals; 4) measurement and reporting framework for ongoing quality improvement.

Recommendations

- The ACD initiative will anchor all cancer diagnosis pathways and establish a single point of access for patients and providers. Develop a research framework to support the ACD initiative, with an emphasis on person-centered care, outcomes and experiences, and value for the health system.

- Molecular diagnostics are becoming more widely used to stratify cancers for prognosis and to guide treatment. Enhance infrastructure for molecular diagnostics to support the movement towards multi-target sequencing for most cancers in the province. Molecular diagnostics would also benefit from a research infrastructure developed to support the ACD.

- Leveraging existing research platforms such as the OncoSim framework may be helpful to fill research and evaluation gaps regarding cancer diagnosis. Expand outcome reporting to allow for greater understanding of the effectiveness of diagnostic programs and to help to justify continued or expanded governmental support.

Background

The Canadian Strategy for Cancer care (2019-2029)[1] described the importance of a streamlined approach to cancer diagnosis (Priority 2: "Diagnose cancer faster, accurately and at an earlier stage"), citing the importance of "rapid access to appropriate diagnosis for those suspected of having cancer." Early detection of cancer

is associated with reduced patient distress, improved treatment effectiveness and, ultimately, improved patient outcomes.[2-4] Achieving early diagnosis is a complex endeavor due to the complexities of diagnostic pathways.[5]

The diagnostic phase of cancer care can be separated into three distinct time periods: symptom appraisal, help-seeking and diagnostic intervals (Figure 24).[6] Symptom appraisal and help-seeking intervals occur before contact with the health system. The appraisal interval recognizes the time between a patient's detection of symptoms and the perception that they need to discuss these symptoms with a health care provider. The help-seeking interval is the time from perceiving a reason to discuss symptoms to the first consultation with a health care provider. This is different from organized screening programs where the goal is to identify cancer in patients before symptoms appear. Once a patient interacts with the health care system to investigate symptoms or for follow-up on an abnormal screening result, the diagnostic interval begins. Generally, this interval will start with the first clinical consultation, typically with a family doctor or urgent care provider, and it then proceeds with laboratory and diagnostic imaging testing, possible specialist referrals, and ultimately tissue biopsy through invasive procedures such as endoscopy, surgery or CT/ultrasound guided biopsies via interventional radiology to establish a cancer diagnosis.[6]
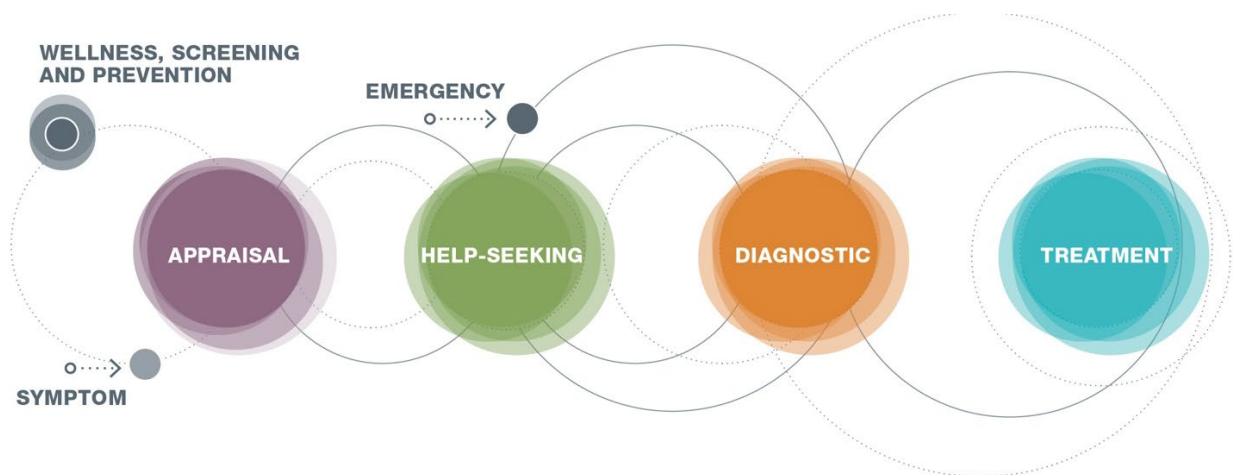
Figure 24. Categorization of the diagnostic interval and its' associated delays

Delays associated with the patient, or the health system can prolong the diagnostic interval. Patient delay, such as patient inaction or late action in seeking medical attention, occurs during the period between an individual's first awareness of a symptom and their first clinical consultation.[7] Health system delays are related to the inherent complexities of the diagnostic process related to system inefficiencies including variable access to specialists and testing, and limited coordination of care.[8-11] The diagnostic interval is particularly vulnerable to delays as it comprises multiple steps and involves a range of health care providers. Therefore, strategies that aim to increase the efficiency and quality of care during the entire diagnostic phase could significantly impact key cancer outcomes such as stage at diagnosis, survival, and patient experiences.

In Alberta, studies of the diagnostic interval have demonstrated a lot of variability. Common cancers such as breast, non-small cell lung (NSCLC) and colorectal cancers are plagued by multifaceted and complex diagnostic processes.[12-15] In 2016, it was reported that breast cancer had a median diagnostic interval ranging from four to 37 days for screen- and symptom-detected cancers,[14] and those with NSCLC could experience delays in diagnosis of up to 148 days.[12] For colorectal cancer, it was reported in 2018 that the patient interval ranged from 21 to 49 days, the diagnostic interval could range from 27 to 76 days, and the total time from first symptom to treatment ranged from 77 to 168 days.[13,15] Of note, these data may not completely reflect the delays seen in cancer diagnosis today, owing to the implementation of new programs – to be discussed – geared towards reducing these delays. The length of the diagnostic interval may have far-reaching consequences and has been shown to affect both the patient experience and survival. Patients have reported high psychological stress prior to their cancer diagnosis that often stems from avoidable delays, worry about their deteriorating health status or a misunderstanding of the diagnostic process.[16]

With an understanding of the importance of an efficient diagnostic interval and the potential consequences of delays, strategies for improvement are a priority. In this chapter, we will offer an overview of the multifaceted diagnostic phase of cancer care in

Alberta, including the perspectives of both patients and health care providers, and review various initiatives to accelerate the diagnostic phase.[17] This information will help to identify any gaps in our knowledge and provide opportunities to improve.

Diagnostic phase of cancer care[17,18]

Background

In 2019 the Alberta Health Services (AHS) Cancer SCN partnered with the Institute of Health Economics to identify and describe existing cancer diagnosis initiatives in Canada and internationally.[17] Two qualitative studies and a survey were then conducted to explore experiences and perspectives of patients/families and healthcare providers when going through the diagnosis process.[16,19,20] Further, CPAC conducted an environmental scan that aimed to identify interventions that improve the patient experience during the diagnostic interval.[18]

Patient and physician perspectives

The diagnostic phase remains a critical part of a patient's cancer experience and is associated with distress and uncertainty while waiting for a cancer diagnosis. Needs for more information about the diagnostic process, as well as navigation and support were expressed strongly by research participants. Through an understanding of the patient's perspective, a lack of information is the main driver for patient distress during the diagnostic phase, and interventions to improve the patient experience are likely to be important.

Understanding the experiences of the primary care physicians (PCP) and specialists involved in the diagnostic phase is also important. Findings from the qualitative study done in Alberta confirmed that the process of cancer diagnosis is deeply complex.[19] PCPs are often involved in the first patient experience, and both the PCPs and specialists included in the study identified that PCPs carry a weight of responsibility, which is further complicated by the diagnostic workup process including determining which tests are needed, deciding how to provide timely access to patients, and the challenges in contacting specialists for advice or referral. The PCPs and specialists mentioned they often feel disconnected from each other thus hindering communication.

Further, limited education and training on cancer screening and diagnosis were often cited as some of the main reasons for delay and complication, and patient trajectories typically improved and were more expeditious once specialists become involved in the diagnosis process. Finally, physicians also noted that the existing pathways for cancer diagnosis were helpful, and there was a strong call to develop similar pathways for other cancer types.

The environmental scan conducted by CPAC largely aligned with these studies and ultimately summarized the challenges to early cancer diagnosis that exist in the Canadian system.[18] These challenges included barriers in primary care (lack of knowledge about the diagnostic process); wait times for diagnosis, often associated with limited health system resources; communication challenges, where PCPs are unable to effectively communicate with specialists, or patients feel they were not provided with enough information or the information was inaccurate; transportation barriers that make it difficult for patients to access services; and, finally, patient concern or embarrassment that prevents them from seeing a health care provider.

Current initiatives to improve the diagnostic interval

The Institute of Health Economics (IHE) literature review yielded 21 reports of various initiatives to facilitate cancer diagnosis – internationally, nationally and within Alberta. Ten of the programs were international (England, Wales, Denmark, Norway, Sweden, Ireland and New Zealand), seven were in other provinces within Canada (Ontario, Manitoba, Saskatchewan, British Columbia, Quebec and Newfoundland) and the remaining four were in the province of Alberta. Generally, the programs were characterized as either an integrated care pathway or a diagnostic assessment program (DAP).

The initiatives included in the IHE's environmental scan shared many components including the use of urgent referral criteria, having centralized and coordinated diagnostic services, the involvement of patient navigators, aiming for benchmark or targeted wait times, and others.[17] Evaluation criteria were diverse across the programs, and the only outcome with consistent and significant improvement was a reduction in

wait time throughout the diagnostic interval. Overall, most initiatives were able to reduce wait times by anywhere from several days to several weeks. Furthermore, the specific costs and subsequent cost savings could not be fully described due to a near complete lack of reporting on these metrics. Any new initiatives developed in Alberta must include metrics for reporting on patient and provider experiences, as well as value.

Summary of current or ongoing programs within Alberta

Prostate Cancer Centre Rapid Access Clinic[21]

In 2005, the Prostate Cancer Centre Rapid Access Clinic (RAC) opened as the first facilitated cancer diagnosis initiative in Alberta. As a single-site regional program located in Calgary, all patients with suspected prostate cancer can be referred and receive timely access to a urologist for an expedited diagnostic process. The RAC offers support and information regarding treatment options as well as integrated post-treatment care. The program's wait time targets are especially important, where the time from referral to first specialist appointment is one to two weeks, followed by one to two weeks for biopsy. As a diagnostic assessment program, it does not provide nurses or PNs.

Lethbridge Breast Program[22]

In 2006 a single-site, regional, diagnostic assessment program was implemented in Lethbridge that aims to support all patients with suspected breast cancer. The program provides timely access to assessments, diagnostic imaging, and treatment services. It also provides access to psychological support and information, with the aim to improve the patient experience.

Alberta Thoracic Oncology Program[23]

With the support of provincial stakeholders (thoracic surgeons, pulmonologists, nurse practitioners and radiologists), the Alberta Thoracic Oncology Program (ATOP) was developed in 2013. The ATOP was supported by the provincial government and Alberta Health Services and took form as a multi-centre initiative with sites in Calgary and Edmonton. The program involves an urgent referral criterion and offers coordinated diagnostic services, patient navigators and multidisciplinary teams. It is the first program

to provide "straight-to-test" access to diagnostic services for primary care providers, nurse practitioners and radiologists, for those patients with suspected stage IV disease. While the two sites are managed independently, the program receives oversight from an executive group and working group to maintain a standard level of care between each site.

Provincial Breast Health Initiative[24,25]

The Provincial Breast Health Initiative was established by the Cancer SCN in 2016. This initiative led to the establishment of two care pathways to accelerate the diagnostic process of patients with suspected breast cancer. The Comprehensive Breast Care Program[24] was first established in 2017 in Edmonton. This program provides virtual services to patients with suspected or newly diagnosed breast cancer. The Calgary Breast Health Program was established in 2018,[25] and it provides in-person services for those with suspected or newly diagnosed breast cancer. Both programs expedite the diagnostic phase of cancer care using specific diagnostic imaging and prompt referrals. Further, the programs aim to improve the patient experience with patient navigators who can coordinate diagnostic tests and specialist appointments and provide early support to patients. Finally, the programs use benchmarks and wait time targets to create an efficient diagnostic interval for all patients.

In progress: provincial colorectal cancer and lymphoma diagnosis pathways[26]

In August 2020, the Cancer SCN released a statement that both colorectal cancer and lymphoma will be next to receive diagnostic assessment programs. It noted that colorectal cancer and lymphoma both had a high proportion of patients who were diagnosed during hospital admissions in Alberta. Based on the success of the other programs in Alberta, a new initiative was formed that will aim to expedite and support symptomatic patients suspected of colorectal cancer and lymphoma by co-designing and implementing cancer diagnosis pathways.

The colorectal cancer pathway will include urgent assessment criteria; rapid staging investigations; and access to navigation, education, and psychosocial support from the point of suspected disease. As of August 2020, two specific programs were being

developed to identify high-risk patients who require urgent investigation for colorectal cancer. The first is the High-Risk Rectal Bleeding (HRRB) program that will refer patients with new onset, worsening or persistent visible blood in their stool to the pathway. Referred patients will have their medical history assessed and undergo a physical exam and baseline investigations. Then, depending on these results, the patients would either be referred for an urgent colonoscopy or to a low-risk rectal bleeding program that is soon to be operational. The second program is an Iron Deficiency Anemia pathway that follows a similar path to the HRRB program and ends up in an accelerated referral to endoscopy.

The lymphoma pathway was implemented in November 2020 and allows for the identification of patients experiencing lymphadenopathy with suspicious test findings. It includes standardized imaging, radiologist-facilitated diagnostic investigations and psychosocial support for patients at the time of suspicion. The pathway describes clear routes depending on the findings from clinical examination and standard imaging. The pathway provides criteria for what constitutes a possible malignancy, as well as other possible explanations for the observed symptom profiles. Overall, the program will hope to improve patient and provider experiences, reduce in-hospital diagnoses and shorten the length of the diagnostic interval.

Alberta Cancer Diagnosis Initiative

The Alberta Cancer Diagnosis Initiative is a partnership between Albertans, primary care and the SCN. The purpose of the initiative is to design a better cancer diagnosis experience for Albertans by streamlining cancer diagnosis, improving continuity between primary/specialist care and optimizing support for Albertans. To ensure this initiative is successful, various groups are being engaged including various age groups, those living in rural and remote settings, Indigenous peoples, sexual and gender minorities, people with disabilities and people experiencing homelessness. The goal is to design a comprehensive operational plan for a centralized and coordinated cancer diagnosis program, which will provide timely diagnosis, consistent processes for accessing appropriate tests and referrals and coordinated resources with the elimination of unnecessary tests and hospital visits.

COMPREHENSIVE GENOMIC PROFILING: A CORNERSTONE OF PRECISION ONCOLOGY
Decrease in methods per sample. Increase in data per sample.

CURRENT → **NEXT** → **FUTURE**

Single Biomaker Analysis:
"Step by Step Diagnostics"
- Patient populations are tested for specific biomarkers using IHC, PCR, FISH, etc.
- Biosamples getting limited

NGS Panel Testing:
- Specific patient populations are tested with specific entity dependent panels, e.g. lung adenocarcinoma

Comprehensice Genomic Profiling:
- NGS replaces conventional methods
- "Single Test on Single Sample"

Comprehensive genomic profiling (CGP) is a next-generation sequencing (NGS) approach that uses a single assay to assess hundreds of genes including relevant cancer biomarkers, as established in guidelines and clinical trials, for therapy guidance.

Molecular diagnostics in Alberta: the past, the present, and future

Rather than only diagnosing cancer based on site and histology, molecular diagnostics are becoming more and more common to subgroup cancers for prognosis and to guide treatment. Molecular tests in the realm of diagnostics can be used for several purposes including the diagnosis of hereditary cancer syndromes, subgrouping of cancers for stratified prognosis and treatment selection, as well as use of circulating DNA or other tumor-derived molecules for early diagnosis, surveillance, and recurrence.

Among cancer patients, the assessment of hereditary cancer syndromes based on a germline mutation can be used to determine treatment options as well as to determine the potential risk of a second malignancy. Among healthy individuals (family members), testing for specific familial gene mutations can help identify individuals at an elevated risk for developing specific cancers, which can help guide preventive measures, as well as surveillance for early diagnosis of potential cancers. The most common examples of hereditary driver mutations are TP53 for multiple cancer sites, and BRAC1 and BRAC2 genes for breast and ovarian cancers.[27-29] Another example is the mutation in one of

the DNA mismatch repair genes (MLH1, MSH2, MSH6, and PMS2), resulting from Lynch syndrome, the most common cause of inherited colorectal cancer.[30] In Alberta as of March 22, 2021, every new diagnosis of colorectal cancer is now eligible for reflexive screening for Lynch syndrome using immunohistochemistry for the antibodies PMS2 and MSH6.[31] Additional molecular pathology testing and immunohistochemistry are completed if screening results are abnormal.

Among patients with a cancer diagnosis based on site and histology, the classification of cancer further into molecular subtypes is becoming increasingly common to inform on prognosis and to guide tailored treatment decisions. One of the first examples of this was in breast cancer, where tumors were prognostically grouped based on the expression of estrogen and progesterone receptors through the use of immunohistochemistry methods.[32] This classification system was later updated with the inclusion of the HER2 amplification and overexpression.[33] The method to identify subtypes in breast cancer has been further improved using gene expression assays, which allow for more accurate and granular subtypes.[34]

Several cancer sites including brain, colon, lung, thyroid, melanoma and high-grade serous carcinoma can have specific somatic mutations that are diagnostic, prognostic, or predictive (Table 14). The presence of these mutations is typically detected through the use of PCR testing. In addition, copy number alterations are frequently detected with FISH in hematological and brain cancer. However, as the understanding of tumor biology improves, there is a paralleled recognition of new prognostic and predictive mutations for several cancer sites, which has shifted many of these individual tests to Mass Array panels or next generation sequencing. Importantly, large hotspot pan-tumor panels of approximately 50 genes have been validated and will be implemented in the future. Table 14 displays all of the molecular tests in service or planed in Alberta by cancer site and includes the target, the methodology, testing site, and if the test is diagnostic, prognostic, or predictive. Several additional Next Generation tests and platforms are being evaluated and are likely to impact clinical care in the future. Careful consideration around the required resources for these transformative approaches to clinical care is needed at all levels of governance.

DRUG COVERAGE

The Outpatient Cancer Drug Benefit Program in Alberta covers the cost of drugs needed for systemic cancer therapy.

HEALTH CANADA ASSESSES: QUALITY, SAFETY AND EFFICACY

CADTH REVIEWS: CLINICAL AND COST-EFFECTIVENESS

1 For a drug to be added to the benefit program, first Health Canada assesses it, while the Canadian Agency for Drugs and Technology in Health (CADTH) reviews it.

CONSIDERED BY ALLIANCE

2 Recommendations resulting from these assessments are then considered by the pan-Canadian Pharmaceutical Alliance (pCPA), of which Alberta is a member.

COMMITTEE REVIEWS: SCIENTIFIC, THERAPEUTIC, CLINICAL AND SOCIO-ECONOMIC MERITS

3 The Expert Committee on Drug Evaluation and Therapeutics then review the drug.

FINAL DECISION BY HEALTH MINISTER

4 They provide advice to the federal Health Minister, who makes the final decision.

Enablers

- A team of engaged and qualified molecular pathologists and lab scientists
- Integration with the Provincial Tumor Teams and Anatomic Pathology Specialty Interest Groups
- Coordination with the Genetics & Genomics group through a joint discipline council
- Affiliation with the University of Calgary and the University of Alberta
- Access to Connect Care, a centralized and standardized Electronic Medical Record (EMR) system
- Relocation of Molecular Pathology Labs to the new Calgary Cancer Center building in 2023
- Established network between AHS Pharmacy and Alberta Health for companion diagnostics funding, which allows for a small percentage of the drug cost to be allocated to APL Molecular Pathology labs when a new targeted therapy is approved by the government of Alberta.

Challenges

- 20% increase in Molecular Pathology test volume

- Fixed operational budget for APL
- A disconnect between AHS funding for translational and clinical research (Precision Oncology Hub, University of Calgary), advances in clinical care, and molecular laboratory diagnostics
- No identifiable sources of funding for non-targeted therapy applications of genomics in cancer. This could include patient's risk stratification using genetic information, which is important for adjuvant therapy and follow up strategy.
- Closure of the HUB Lab in Edmonton with no alternative plan for infrastructure and equipment
- Emergence of CPSA accredited private and semi-private labs to fill in the need for advanced diagnostics (e.g. Oncohelix, CardiAi, Institute for Genomics and Molecular Diagnostics)
- Difficult to keep pace with advances in cancer biomarker testing in other jurisdictions in Canada

With the continuing emergence of prognostic and predictive biomarkers, the use of hotspot pan-tumor panels is projected to increase. The use of these panels will help to improve decision-making and ultimately patient outcomes, but many challenges will emerge including higher costs, and increased need for capacity to ensure tests results are interpreted and disseminated in an efficient manner for appropriately timed care.

Table 14. Alberta Cancer Genomics Initiative 2020-2023

Assay	Technology	Number of genes	Status	Utility	Type	Cost per Test (30% overhead for non-APL cases not included)
Lung, Colon, Melanoma Liquid Biopsy Panel *Applications: Anti-EGFR resistance, Insuffcent Tissue, Monitoring*	Mass-Array	6	Currently Available	Predictive	commercial	$400
Myeloid DNA/RNA Panel *Applications: Acute Myeloid Leukemia, Myelodysplatic Syndrome, Myeloproliferative Neoplams*	NGS	69	Currently Available	Diagnostic, Prognostic, Predictive	commercial	$870
Oncomine Focus Assay DNA/RNA Panel *Applications: Lung Tumors - North*	NGS	52	Currently Available	Predictive	commercial	$550
Archer Lung Tumor RNA Panel *Application: Lung Tumors - South*	NGS	17	Currently Available	Predictive	custom	$620
Pan-Solid Tumor Fusion RNA Panel *Applications: Fusion Gene detection*	NGS	103	Currently Available	Diagnostic, Prognostic, Predictive	custom	$670
Pan-Solid Tumor Biomarkers DNA Panel *Applications: Point mutations, copy number alterations, LOH, MSI, TMB-High screening*	NGS	130	In development	Diagnostic, Prognostic, Predictive	custom	$500
Pan-Solid Tumor Liquid Biopsy Panel *Applications: Advanced metastatic cancers*	NGS	70	In development	Prognostic, Predictive	custom	$2,000
Lymphoma DNA panel *Applications: Chronic Lymphocytic Leukemia, IgH Somatic Hypermutation, Clonality*	NGS	TBD	In development	Diagnostic, Prognostic, Predictive	custom	TBD
Comprehensive DNA/RNA Profiling *Applications: HRD score, TMB score, Clinical Trials Enrollment*	NGS	500	In planning	Diagnostic, Prognostic, Predictive	commercial	$1,500
Gene Expression Profiling *Applications: Breast cancers, lymphoma subtyping*	Nanostring Ncounter	Variable	In planning	Prognostic, Predictive	custom	$350

	Immediate clinical need
	Immediate clinical trial need
	Long term research and development

Conclusions and recommendations

Success in the implementation of existing diagnostic programs has been linked to continuous stakeholder involvement, strong clinical leadership, a multidisciplinary approach and, most importantly, support from provincial health systems and the government.

Moreover, the Alberta Cancer SCN has begun to develop and implement the Alberta Cancer Diagnosis Initiative.[35] This initiative will address the major gaps previously discussed regarding the continuum of cancer care. Specifically, this initiative will anchor all cancer diagnosis pathways and establish a single point of access for patients and providers. This means that patients will have direct access to timely diagnosis and support navigating the system, and providers will experience consistency in the processes for accessing appropriate tests and referrals, and enhanced communication to expedite and support patients.

Further platform research such as the OncoSim[36] framework may be helpful to fill these research and evaluation gaps. Better outcome reporting would allow for greater understanding of program effectiveness and help to justify continued and expanded governmental support.

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Chapter 7: Cancer treatment

Key findings

- The most common types of treatment (used alone or in combination) are radiation therapy, systemic therapy, and surgery.

- Biomarker-guided targeted therapies with small molecules and immunotherapies or antibody-drug conjugates are being used more frequently to treat cancer in Alberta and around the world, which may lead to better outcomes but also higher costs. Increased health human resources are also needed to manage patients on these therapies.

Recommendations

- Implement a robust research framework for collecting and using patient reported outcomes and experience measures to support design and evaluation of current and new treatments as well as current and novel models for delivering care.

- Establish a robust set of quality indicators related to the full range of services available in Alberta with equity considerations and ensure that quality care is provided across all aspects of quality including acceptability, accessibility, appropriateness, effectiveness, efficiency, equity and safety.

- Clinical trials allow researchers to discover new ways in which to prevent, diagnose, treat, and manage cancer, thus helping to improve patient outcomes. Expand access to clinical trials.

- Develop comprehensive approaches to assessing outcomes for trial participants and those exposed to different lines/modes of cancer treatment in routine care.

- Investment in radiation oncology research has led to the development of world-leading technology and treatment protocols. Prioritize continued investment in these directions to ensure Albertans receive the highest quality care, in a timely manner.

Background

It has been estimated that there were 21,615 new cancer cases and 6,701 cancer deaths in Alberta in 2020 and 2021 respectively. There are approximately 150,000 Albertans living with or beyond cancer, who were diagnosed in the past 25 years. Cancer mortality is decreasing over time, compared to 1999, mortality rates have decreased 32% in males and 29% in females. Although some of the improvements in

cancer mortality have resulted from prevention and early detection, treatment advances also have reduced death rates over the preceding decades.

In this chapter, we focus on the treatment stage of the cancer continuum. We describe treatment patterns and cancer services in Alberta, discuss emerging trends in cancer treatment, and present a summary and recommendations to fulfill future treatment requirements for the Alberta population. We offer an explanatory synthesis of different sources referring to cancer treatment in Alberta. The section on cancer services and treatment patterns brings together documents by Cancer Care Alberta (CCA) and Alberta Health Services (AHS), including internal frameworks and reports, websites and dashboards. The section on emerging trends in cancer treatment is based on interviews with key informants, a Google search, and a selective search in the academic literature. Keywords related to the different trends presented in this section were used to identify sources. Sources providing relevant insights into general information on the topic, with emphasis on recent trends and relevant to the Alberta context, were reviewed and synthesized for inclusion in this chapter.

Cancer treatment patterns

Cancer treatment can have different goals depending on the type of cancer, stage of cancer and patient preferences or characteristics. Treatment can be curative or non-curative. In the latter category, treatment may be given to attempt to control the cancer, or it may be given to ease symptoms or provide pain control.[1] In the past, curative cancer treatment depended upon detecting cancers at an early stage, and then using effective local treatments such as surgical resection and/or radiotherapy. These strategies remain the mainstay of treating localized solid tumor malignancies.

Types of treatment offered to patients diagnosed with cancer in Alberta include radiation therapy, systemic therapy, hematopoietic stem cell transplantation, and surgery. The different treatments can be used alone or in combination with other treatments. The different treatments are discussed separately in this section. Drug benefit programs and funding related to treatment are discussed later on in this section.

Radiation therapy[2,3]

Overview

Radiation therapy uses high-energy radiation beams to kill or shrink tumors. More than 50% of all cancer patients will receive radiation at some point in their cancer journey. In Alberta five centres offer radiation therapy, the two tertiary centres: the Cross Cancer Institute and the Tom Baker Cancer Centre (soon to be replaced by the new Calgary Cancer Centre), the Jack Ady Cancer Centre, the Central Alberta Cancer Centre, and the recently opened Grande Prairie Cancer Centre. Collectively these centres deliver >10,800 courses of radiation therapy every year.

Types of radiation therapy

Radiation can be delivered in different ways. In external beam radiation therapy, the radiation is most often generated in a machine called a linear accelerator and typically delivered to patient over multiple treatments, often over a period of weeks. Advanced imaging techniques and the capacity to create complicated intensity patterns of radiation enable the delivery of very high doses of radiation to very precise targets while avoiding or reducing the amount of radiation to those healthy tissues most sensitive to side effects. In some cases, the radiation can be delivered with sub-millimetre precision. Alternatively, radiation can be delivered from an internal source in a technique known as brachytherapy. In some cases, small radioactive sources are permanently implanted in the patient and slowly deliver the radiation over time, while in others the source is temporarily inserted through a catheter. Often brachytherapy can be delivered as an outpatient procedure.

Infrastructure requirements

For the reliable delivery of radiation to cancer patients across Alberta the following dedicated infrastructure is essential.

1. *Radiation therapy equipment*

    Linear accelerators (linacs) are the backbone of external beam radiation therapy programs across the province. There are roughly 25 linacs operational in Alberta, each capable of approximately 40 treatments per day. Other related equipment

includes brachytherapy remote afterloaders; radioactive source inventories; orthovoltage machines for superficial treatments; Gamma Knife Icon or linac-based units used for high precision intracranial radiosurgery; and linac-MRI machines that enable highly advanced image guidance in radiation therapy. Each machine requires considerable dedicated medical physics support and quality control equipment. The operational lifespan of a linac is approximately 10 years, after which maintenance and repair times increase considerably. Therefore, continual capital planning and investment is required to maintain treatment capacity. More radiation therapy equipment will also be needed to increase treatment capacity in the future to keep pace with the expected rise in the number of Albertans diagnosed with cancer.

2. *Dedicated imaging equipment*

Dedicated computed tomography (CT) machines known as CT simulators provide the primary images for planning radiation therapy treatments. Dedicated magnetic resonance imaging (MRI) simulators use more sophisticated imaging techniques to improve target and soft tissue delineation and are becoming the new standard for some types of radiation therapy planning. In addition, for some tumor sites, diagnostic positron emission tomography (PET) with concurrent CT (PET-CT) or MRI (PET-MRI), and diagnostic MRI are also necessary to accurately determine the extent of a patient's cancer, and for tracking the progress during treatments.

3. *Radiation therapy planning and administrative systems*

There are two dedicated radiation oncology record systems in Alberta, one for Northern Alberta and another for Southern Alberta, that interface with the provincial Connect Care patient medical record systems. These systems calculate radiation doses, optimize treatment plans, and record and verify delivery including tracking any daily imaging taken. The systems are upgraded regularly at approximately two- to three-year intervals. Correct operation of these systems requires detailed understanding of the algorithms used and management from the medical physics teams in the province. Treatment

planning calculations are so critical that independent calculation software is also necessary to confirm the primary system results. Moving forward in the next decade, software that partially automates tasks such as identifying and delineating organs on medical images, and treatment plan optimization, is likely to become standard in the field.

Radiation oncology teams

The delivery of any radiation therapy treatment is a highly technical process, requiring tightly integrated cooperation from a broad team of professionals. As with many healthcare professions, at the time of writing, recruitment for these specialized positions in Alberta is a challenge. Recent peer-reviewed modeling work has shown that current staffing levels are falling short of benchmarks established prior to the pandemic.

Radiation oncologists

A Radiation Oncologist is a physician who specializes in the management of malignant and benign tumors, and other conditions with radiation therapy. Typical training for a radiation oncologist is five-year residency training after medical school and requires certification qualifications in Radiation Oncology and an Alberta medical license to practice. Many radiation oncologists also perform specialized fellowship training following their residency. Their role involves diagnosing cancer and determining when radiation therapy is an appropriate treatment, the prescription of radiation and development of treatment plans, administering radiation therapy, monitoring patients, and closely integrating with the cancer care team to provide comprehensive care to cancer patients.

Medical physicists

Medical Physicists are scientist-clinicians who have completed a specialized graduate degree in medical physics, a minimum two-year residency, and national board certification examinations. They are experts in the medical applications of physics in radiation oncology, diagnostic radiological imaging, magnetic resonance imaging, and nuclear medicine, being certified in one of these subspecialties. Medical physicists are responsible for: the safe and accurate operation of radiation oncology and imaging

infrastructure (linear accelerators, Gamma Knife, brachytherapy afterloaders, linac-MRI machines, CT simulators, treatment planning systems, MRIs, CTs, PET machines, mammography units, etc.); commissioning of new equipment; protocol development; oversight of quality control programs; clinical investigations and problem solving; research; development; training; and teaching. In radiotherapy, medical physicists are also responsible for the accuracy of delivered radiation doses; imaging medical physicists ensure optimal image quality for diagnosis. Medical physicists also have a primary role in technological innovation, and the implementation and management of these new technologies.

Dosimetrists

Dosimetrists are experts in the planning of radiation therapy treatments. Typically, treatment planning is an area of specialization for radiation therapists. Dosimetrists usually have several years of work experience in radiation therapy before beginning dedicated planning training while working toward national dosimetrist certification. They are responsible for using dedicated treatment planning software to design and plan a radiation therapy treatment course, integrating patient-specific instructions from radiation oncologists with specific goals and constraints.

Radiation therapists

Radiation Therapists are a subset of medical radiation technologists who specialize in the delivery of therapeutic radiation to patients. Their education is typically a four-year degree in radiation therapy followed by successful completion of a national certification exam. Radiation therapists are responsible for the safe and accurate delivery of radiation to patients in accordance with the prescription and treatment plan, accurate imaging of patients both for planning at the time of simulation and during treatments in accordance with daily set protocols, patient education, tracking patient progress and providing patient care. In addition to dosimetrists, there are other specialized roles within radiation therapy requiring additional training. Brachytherapists are experts in the delivery of brachytherapy to patients, and often work closely with surgical resources and provide post-surgical care. MR enhanced practice radiation therapists have trained and

been certified to allow them to assist with MR-simulation and MR-guided treatment delivery.

Specialized nursing in radiation oncology

Radiation oncology also requires specialized nursing staff. In most cases these individuals are registered nurses (RNs) with additional hands-on training specific to radiation oncology. Responsibilities of these nurses include patient education and navigation, assessment and monitoring, administering medications to manage side effects of the treatment or improve comfort with the treatment process, coordinating with other treatment professionals, and patient advocacy.

Recent advances in radiation therapy

Radiation therapy is one of the most technologically challenging medical treatments, and its technology is constantly evolving in sophistication and complexity. A few of the many recent advancements are highlighted to suggest future directions in this field.

Linac-MR

The medical physics team in Edmonton has been pursuing the integration of a linear accelerator with a magnetic resonance imaging device for over a decade, and have now begun clinical trials. They have designed and constructed a world-leading device that offers the opportunity for unparalleled image guidance for tumor-targeting. This major advance in radiation therapy is expected to lead to increased cure rates and/or reduced rates of radiation treatment toxicities. The new Calgary Cancer Centre will also have two MR-linac machines purchased from a commercial vendor. This exciting technology requires highly specialized expertise in both traditional radiation oncology and MRI technologies.

Proton therapy

Intensity-modulated proton therapy is the most conformal technique of external beam radiation therapy available to eligible patients. High-energy proton beams produced with a cyclotron can treat tumors while substantially reducing the volume of surrounding nearby normal tissues receiving significant dose, compared to traditional and MR-integrated linacs. Proton therapy can be used to treat tumors sites throughout the body

with extended margins over a period of weeks (similar to linacs), or treat brain and upper spinal tumors with limited or no margins over one day to one week (complementing our existing Gamma Knife radiosurgery program). Proton therapy is most useful for patients being treated with curative intent and having an expected survival beyond five years, in particular children and young adults. There are no clinical proton therapy facilities available in Canada and eligible patients from Alberta must travel to the United States for treatment, often for nearly two months.

Artificial intelligence and automation

Over the coming decade it is expected that many routine tasks in the radiation oncology treatment planning and delivery workflow will become automated, leading to improved efficiencies, enabling higher volumes of patient throughput, and potentially reducing wait times. As one example, a time-consuming task performed is "contouring" – the process of outlining specific organs and tissues on imaging data sets (slice-by-slice) in the treatment planning software. Radiation therapy centers in Alberta are currently exploring the implementation of software using artificial intelligence to partially automate this process, which will free up dosimetrists and radiation oncologists to focus time on other areas of patient care. Automation of workflows, facilitated by developments in planning software and/or new linac delivery technologies, also increases opportunities to implement **advanced adaptive radiotherapy** - adjusting treatment during the course of radiotherapy in response to anatomical changes, further optimizing personalized radiotherapy delivery.

Hypofractionation

In recent years, clinical trials have demonstrated similar outcomes for some tumor sites with radiation treatment courses using fewer treatments of higher doses, called hypofractionation, compared to traditional treatment courses spread out over several weeks. For example, the Fast Forward protocol for breast cancer radiotherapy has reduced the number of treatment visits to the cancer centre from 25 or 16 down to 5. Hypofractionation, in combination with highly conformal radiotherapy delivery techniques such as volumetric arc radiotherapy, can also limit the risk of adverse treatment-related events; use of specialized radiation delivery techniques (including

radiosurgery, proton therapy, or Linac-MR) for SBRT may help further limit adverse events for some tumor sites.

Stereotactic body radiotherapy

Stereotactic body radiotherapy (SBRT), sometimes called stereotactic ablative radiotherapy (SABR), is the highly precise delivery of very high radiation doses using on-board imaging technology on the treatment unit to small tumors located in the body. This treatment was derived from similar technology called stereotactic radiosurgery (SRS) that is used to treat tumors in the brain. While SBRT was originally developed to treat primary cancers with curative-intent, such as early-stage lung and prostate cancers, this treatment is also now used to treat patients with 5 or less metastatic tumors in different locations within the body. Cancers that have spread to spine, non-spine bone, lung, liver, adrenal glands, or lymph nodes in the abdomen or pelvis may be eligible for SBRT treatment. SBRT also can lead to better outcomes and fewer side effects compared to conventional radiation therapy.

Systemic therapy

Systemic therapy uses substances that travel through the bloodstream, reaching and affecting cancer cells that have spread to parts of the body far away from the original (primary) tumor. Systemic therapy includes chemotherapy, hormone therapy and immunotherapy.[4] Chemotherapy (traditional or standard chemotherapy) uses cytotoxic drugs to slow the growth of cancer cells or destroy them.[5] Hormone therapy (a type of targeted therapy) uses drugs to block or alter hormones that can slow or stop the growth of certain cancers.[5] Immunotherapy boosts or changes the immune system and works so it can find and attack cancer cells.[5] Immunotherapy is an emerging cancer treatment and is further discussed in the *Immunotherapies* section below. A recent population-based study of 28,485 individuals with advanced cancer in Alberta by Dr. Darren Brenner and Dr. Winson Cheung (submitted), reported that the proportion of patients who initiated systemic therapy was 43%. After restricting to individuals referred to a medical oncologist (n=16,661), the proportion who initiated systemic therapy was 70%.

Advances in systemic therapy have resulted in significant improvements in cancer survival rates over the past few decades.[6] Systemic combination cytotoxic chemotherapy regimens initially developed in the 1970-80s continue to cure only a small number of advanced stage cancers such as lymphomas, testicular and a small proportion of ovarian cancers.[7] The effectiveness of adjuvant chemotherapy to improve survival rates for resected stage 2-3 breast cancer and colon cancers was proven in the 1980-90s. Adjuvant chemotherapy is currently also used after resection of stage 2-3 carcinomas of the lung, bladder, stomach, and pancreas. Pre-operative chemotherapy (or concurrent chemoradiotherapy) is currently used for selected patients with advanced stage breast, bladder, rectal, head and neck, and some other carcinomas to increase the chances of successful resectability and help guide post-operative adjuvant chemotherapy based upon pathological response rates to the pre-operative treatment.[8] High dose myeloablative chemotherapy and hematopoietic stem cell transplantation was shown to cure or improve survival rates for selected patients with relapsed leukemia (allogeneic donor stem cells), lymphoma and myeloma (autologous patient-derived stem cells) in the 1980-90s.[9,10]

Breast and prostate cancers have unique sensitivity to hormonal therapies, and several agents have been introduced over the past few decades to exploit this fact including tamoxifen and fulvestrant estrogen receptor modulators, aromatase inhibitors, and CDK4/6-inhibitors used in combination with these agents for estrogen receptor positive breast cancer, and anti-androgens and LHRH agonists for prostate cancer.[11,12] Molecular oncology research identified other targets for drug therapies, of which the first highly effective examples in the 1990-2000s were Rituximab and Trastuzumab monoclonal antibodies for CD20+ lymphomas and HER2+ breast cancer, respectively, as well as the small molecular oral inhibitor of the BCR-ABL1 oncoprotein in chronic myeloid leukemia called Imatinib.[13,14] A new monoclonal antibody, Daratumumab, has demonstrated significantly improved outcomes for myeloma.[15] Numerous other molecular biomarker-guided treatments have since been adopted as standard of care over the past 20 years; these typically target driver mutations common to specific cancer types including Alectinib or Crizotinib (ALK+ lung cancer), Axitinib or

Cabozantinib (VEGFR for renal cell cancer), Dabrafenib or Trametinib (BRAF+ melanoma), Entrectinib (ROS1+ lung cancer), Ibrutinib (BTK CLL), Lapatinib or Tucatinib (HER2+ breast cancer), Niraparib or Olaparib (PARP for BRCA1/2+ breast or ovary cancers), Osimertinib (EGFR+ lung cancer), and Venetoclax (BCL2 CLL).[16] Recent analyses conducted by Brenner et al., demonstrate the profound impact that molecular testing has had on cancer patient outcomes in Alberta using EGFR and metastatic non-small cell lung cancer as an example. In this study, Brenner at al., observed that among patients diagnosed in the pre-*EGFR* testing period, the 6-month, 1-year, and 2-year survival probabilities were 0.39 (95% CI: 0.38-0.41), 0.22 (95% CI: 0.21-0.23), and 0.09 (95% CI: 0.08-0.10), while the survival probabilities for patients diagnosed in the post- *EGFR* testing period were significantly improved at 0.45 (95% CI: 0.43-0.46), 0.29 (95% CI: 0.27-0.30), and 0.16 (95% CI: 0.15-0.17), respectively (Figure 25).
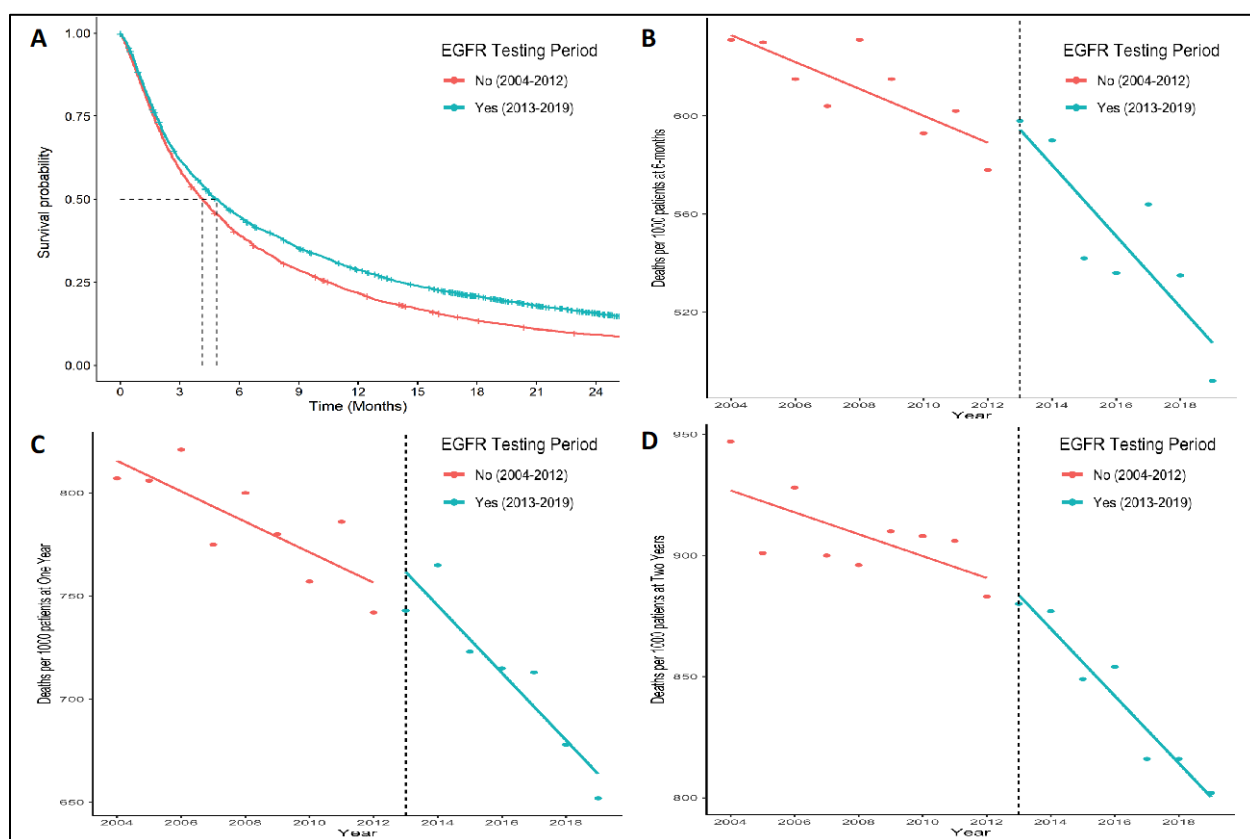
Figure 25. Metastatic NSCLC survival pre and post initiation of EGFR testing in Alberta (A) Overall survival by *EGFR* testing period. (B) Interrupted time series: Deaths per 1,000 patients 6-months after diagnosis (cumulative risk of death) before and after the initiation of *EGFR* testing in Alberta. (C) Interrupted time series: Deaths per 1000 patients one-year after diagnosis (cumulative risk of death) before and after the initiation of *EGFR* testing in Alberta. (D) Interrupted time series: Deaths per 1000 patients two years after diagnosis (cumulative risk of death) before and after the initiation of *EGFR* testing in Alberta.

Compared to patients who were not tested for an *EGFR* mutation, patients who were *EGFR-* (median survival: 5.20 months; 95% CI: 4.87-5.56) and patients who were *EGFR+* and treated (median survival: 21.37 months; 95% CI: 19.13-24.33) had significantly greater survival with multivariable HRs of 0.72 (95% CI: 0.67-0.77) and 0.32 (95% CI: 0.28-0.37) (Figure 26). No significant difference in overall survival was observed between patients who were not tested and patients who were *EGFR+*, but not treated (Figure 26).
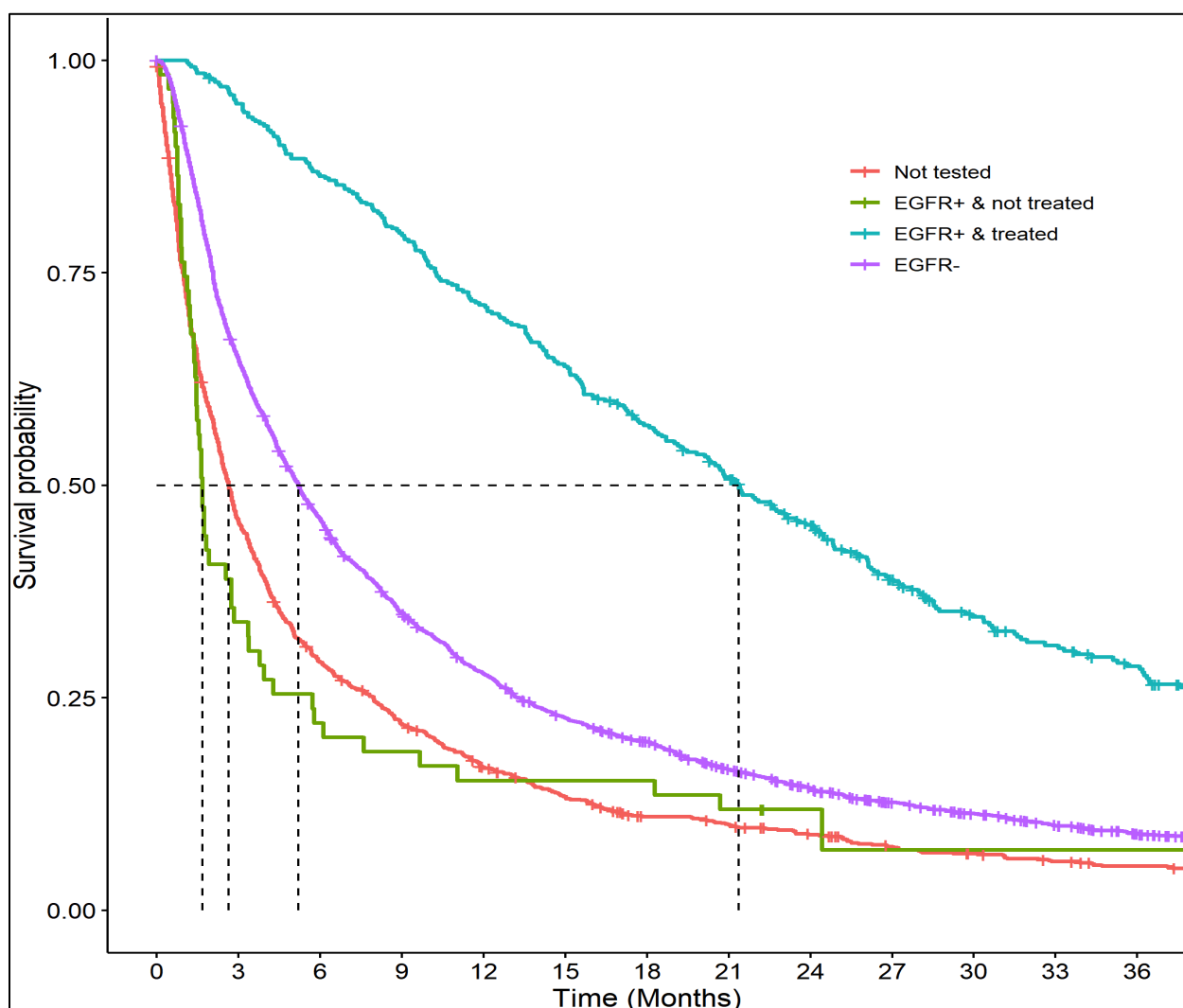
Figure 26. Overall survival by EGFR testing and EGFR status among all patients

This represents a strong example of how a population-based precision oncology program can influence care and outcomes. Among patients who initiated systemic therapy, patients who were tested had improved outcomes compared to those who were not tested. Testing is a proxy for improved diagnostics, management and monitoring as well as the availability of additional therapies. As tumor biology and cancer genetic signaling pathways are better understood, it is likely that greater numbers of effective targeted agents will be developed in the future.

Hematopoietic stem cell transplantation

Hematopoietic stem cell transplantation (also called peripheral blood stem cell or bone marrow transplantation) is a type of treatment that uses high dose intensive chemotherapy with or without total body irradiation to treat sensitive types of cancer, and then rescues the damaged bone marrow by immediately infusing healthy blood stem cells into the patient's body to regrow the marrow and blood cells.[17] The stem cells are usually collected from the blood by a process called apheresis, either from the cancer patient (autologous) or from another person (allogeneic). Allogeneic transplants are most often used to treat cancers of the marrow such as leukemia or myelodysplasia, whereas autologous transplants are most often used to treat cancers such as lymphoma or multiple myeloma.[17] Transplantation is done to significantly improve cancer survival or cure rates, but unfortunately requires 3-4 weeks of hospitalization to manage severe complications. Because Allogeneic transplantation results in transplantation of the donor's immune system, it is associated with risks of longer term immunological toxicities such as graft versus host disease where the new immune system attacks the patients organs such as skin, gastrointestinal tract, and liver.

Cancer surgery

The role of surgery in cancer care

Surgery is a broad area of medical practice and plays a variety of roles in cancer care. [18] The main goal of surgery is the removal of the tumor for curative purposes, which in Alberta is the purpose of 69% of all cancer-related surgeries.[19] Although surgery is often the only treatment for some cancers, it can also be used in combination with radiation therapy and/or chemotherapy. Neoadjuvant therapies are administered before surgery to help reduce the size of the tumor, while adjuvant therapies are administered after surgery to reduce the chance of cancer recurrence.[18]

Other than removal of the tumor for curative purposes, the most common use of surgery in cancer care is for diagnosis and staging of cancer, which represents 24% of all cancer surgeries in Alberta.[19] A biopsy is performed to extract cells from a suspicious area, and a pathologist examines this sample under a microscope and/or performs

some testing to confirm whether there are cancer cells. From a biopsy, the pathologist can also determine the exact type of cancer, and other information useful to develop a treatment plan such as the extent of the cancer (stage), and how abnormal cancer cells appear to be and how quickly they are likely to grow and spread (grade).[18]

Surgery is also used to reduce the risk of developing certain types of cancer. Four percent of cancer surgeries performed in Alberta are done for this purpose.[19] The surgeon removes tissue that is not yet cancerous, but has high risk of becoming cancerous. An example of this type of surgery is prophylactic mastectomy for women with high risk of developing breast cancer. Another role of surgery in cancer care is reconstruction of the body's appearance or function during or after cancer treatment. Reconstructive surgery of this sort represents 3% of cancer surgeries performed in Alberta.[19] Examples of reconstructive surgery include breast reconstruction after mastectomy for breast cancer, and surgery for patients diagnosed with head and neck cancer who required major tissue removal (such as jaw, skin, pharynx or tongue).[20,21] Cancer surgery can also be used for other purposes. These include relieving symptoms and improving quality of life for people with advanced or widespread cancer (palliative surgery), facilitating other cancer treatments (e.g., surgery performed to place a special pump that is used to deliver chemotherapy drugs), or supporting body functions after cancer treatment (e.g., tracheostomy to place a breathing tube, gastrostomy to place a tube to provide a route for tube feeding).[18]

Surgery service delivery

Alberta Health Services directly oversees the provision of cancer surgery services across Alberta. Most major cancer surgery is performed at the 16 major hospital sites in Medicine Hat, Lethbridge, Calgary, Red Deer, Edmonton, Grande Prairie and Fort McMurray; a smaller number of procedures are performed at up to 40 other hospitals across the province, in physician offices, and in a number of Chartered Surgical Facilities. Some highly specialized procedures are performed only at larger sites in Edmonton and Calgary. At these sites, surgeons work closely with oncologists and

other healthcare providers in a multi-disciplinary setting to coordinate the care that patients receive.

Currently, approximately 22,000 cancer-related surgeries are performed in Alberta annually.[22] This amounts to about 440 operations/week, with 350 divided between Calgary and Edmonton, 50-60 in Central Zone, 20-25 in South Zone and 10-15 in North Zone.[23] As shown in Figure 27, the six most common cancer sites where surgery is performed are: breast, bladder, uterus, bowel and colon, prostate, and head and neck.[22] Over the last six years, the number of surgeries related to bladder, uterus, bowel and colon, prostate and head and neck cancers has been fairly stable (except for a significant increase in uterus cancer surgeries in 2016-2017 when compared to 2015-2016).[22] For this same period, the number of breast cancer surgeries has been increasing steadily, with a drop in 2020-2021,[22] which might be related to the interruption of breast cancer screening to asymptomatic patients and the postponement of elective surgeries to alleviate the demand on the healthcare system due to COVID-19 during the pandemic.[24]
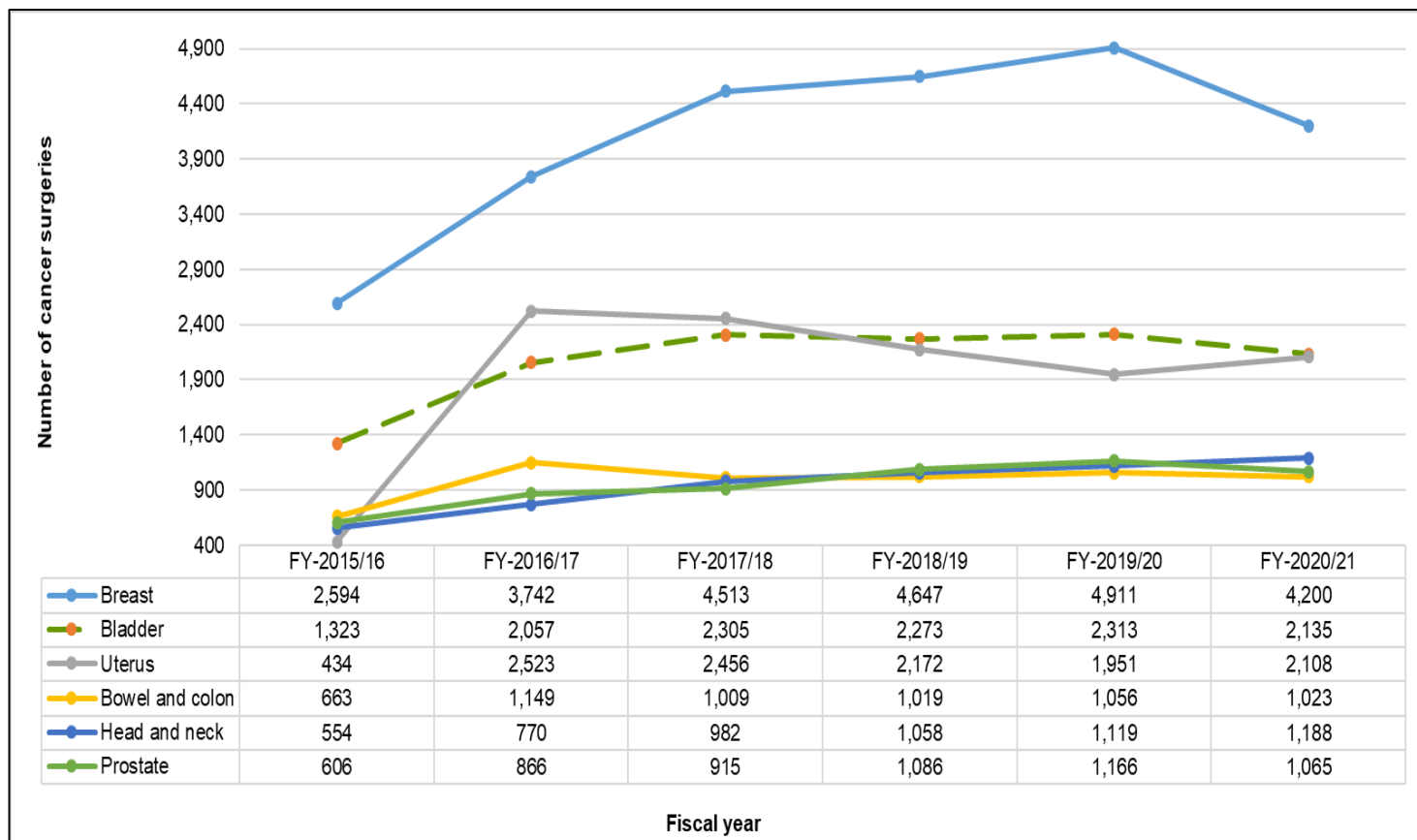
Figure 27. Number of cancer surgeries by cancer type from 2015/16 to 2020/21

	FY-2015/16	FY-2016/17	FY-2017/18	FY-2018/19	FY-2019/20	FY-2020/21
Breast	2,594	3,742	4,513	4,647	4,911	4,200
Bladder	1,323	2,057	2,305	2,273	2,313	2,135
Uterus	434	2,523	2,456	2,172	1,951	2,108
Bowel and colon	663	1,149	1,009	1,019	1,056	1,023
Head and neck	554	770	982	1,058	1,119	1,188
Prostate	606	866	915	1,086	1,166	1,065

Timely access to appropriate surgical care is an area of improvement that has been established as a provincial priority. Alberta uses the Alberta Coding Access Targets System (ACATS) to assess how long each patient waits between when they are ready for surgery and when the surgery is performed. The system is used to measure, monitor and help surgeons manage wait lists for surgery.[25] Each type of diagnosis requiring surgery is assigned a particular code, and each code is assigned a clinically appropriate wait time that represents the maximum time a patient should wait for surgery before complications would be expected to occur. For example, code LR54 is "bowel cancer near complete obstruction", which has a wait time "window" of 2 weeks, which means that the surgery should be performed within a maximum of two weeks of its booking. Of all the cancer surgeries performed in Alberta at present, approximately 40% take place beyond the clinically recommended wait time,[26] which translates into thousands of

patients potentially at risk for stage migration and adverse outcomes [27] with an associated negative economic impact.[28] Surgical wait times in the province have significantly worsened due the COVID-19 pandemic,[24,29] although cancer surgery has continued to be prioritised throughout the pandemic.

Innovations to improve surgery cancer care in Alberta

There are many opportunities within Alberta to improve the delivery of surgical care for patients diagnosed with cancer. A major initiative related to improvements in access to care is the Alberta Surgical Initiative (ASI). The ASI was jointly developed in 2019 by AHS, Alberta Health, Alberta-based surgical specialists, primary care partners, patient advisors and other stakeholders to ensure that all Albertans receive scheduled surgeries within clinically appropriate timelines by 2023.[30] Under the ASI mandate, there are five key strategies that align with the patient's surgical journey to shape demand and manage capacity for surgery in Alberta, and are:

1) Improve provision of specialist advice to family physicians before consultation (referral phase);

2) Improve provision of surgical consultation and recovery, including central access and triage (referral and recovery phases);

3) Improve provision of surgery (surgery phase);

4) Improve care coordination and development of surgical pathways for patients and referring physicians (referral phase); and,

5) Develop strategies and recommendations to support long-term service viability (across all phases).[31]

A key component of ASI is the implementation of an Electronic Referral Solution, a comprehensive provincial platform for electronic referral that allows family physicians to request referrals from their own Electronic Medical Record (EMR) system and track the whole process, from central intake and specialist consultation, through to surgery booking, the operative procedure, hospital discharge, and back to primary care for recovery.[32] Additional components include Pathways and Patient Resources, Speciality Advice, Central Access and Triage, Workflow Optimization, Access Analytics (Path to

Care), Care Transitions, and Pre and Post Surgical Care. These components are part of the Specialty Access Bundle, and result from a partnership between the Surgery and Bone and Joint SCNs, the Primary Health Care Integration Network, Access Improvement and Path to Care team, Zone operational leadership, patient advisors and specialty care physician leaders.[32,33]

Another relevant provincial initiative related to improvements in surgical cancer care in Alberta is the Provincial Breast Health Initiative. The Provincial Breast Health Initiative (*further discussed in Chapter 5*) was launched by the Cancer SCN in 2016, in partnership with the Surgery SCN and CancerControl Alberta (currently Cancer Care Alberta). This initiative brought together patients, providers, and administrators to focus on patients with suspected or newly diagnosed breast cancer and their suboptimal experiences during the diagnostic and treatment phases.[34] The Provincial Breast Health Initiative expedited processes for patients with highly suspicious breast lesions on imaging, improved perioperative care for patients undergoing mastectomy, created new educational supports, enhanced patient navigation, and provided surgical coordination and measurement to improve access and delivery of breast reconstruction.[35] Reporting measures showed a 60% decrease in wait time between a suspicious test result and a confirmed breast cancer diagnosis (from 19 days in 2016 to 6 days in 2018), an increase in same-day mastectomy from 1.7 to 48% (without an increase in complications or hospital readmission rates), and an estimated 831 bed-days released per year.[36,37]

Other innovations which apply to cancer surgery include Surgical Synoptic Reporting, the Safe Surgery Checklist, the National Surgical Quality Improvement Program (NSQI), and Enhanced Recovery After Surgery (ERAS). These programs are highly relevant in the context of cancer care, and demonstrated a reduction in unwanted variability and adverse events, an increase in system efficiency, and improvements in patient outcomes.[38,39]

Cancer services

Cancer treatment in Alberta is offered at cancer centres operated by CCA, AHS, as well as at hospitals where cancer surgery is performed.

Cancer centres

[Cancer Care Alberta](#) is a division within the Cancer Care Alberta & Clinical Support Services portfolio of AHS and comprises cancer professionals and facilities that provide cancer treatment, coordinate supportive care, generate and disseminate educational materials and manage transitions for patients back to their medical home. CCA is also responsible for: 1) the [Alberta Cancer Registry](#); 2) providing cancer data and analytic services in supporting clinical operations, surveillance, quality improvement and research; and 3) conducting and supporting research across the cancer continuum ([Cancer Research & Analytics](#)).

In Alberta, patients with symptoms typically receive initial cancer diagnoses and referrals from primary care and/or the emergency department or hospitals (usually when symptoms are severe). Cancer can also be identified when patients are asymptomatic. It can be detected when the patient undergoes cancer screening or identified incidentally when the patient is examined for concerns other than cancer. For some patients, surgery is the only treatment required and they may not receive treatment with CCA, since most surgeries occur in acute care facilities outside of cancer centres. About two out of three people with cancer receive treatment in CCA facilities, with the most common treatments being radiation therapy and chemotherapy (either alone or in combination with surgery). Immunotherapy is a newer type of treatment that is becoming more common in Alberta (further details above, in the *Immunotherapies* section). Treatment programs within the cancer centres have access to all necessary laboratory and pharmacy facilities for evaluating and treating patients diagnosed with cancer. A wide range of specialist services is also offered, such as psychosocial services, nutrition services, services related to rehabilitation medicine, patient navigation, patient and family education, spiritual care or palliative care/end-of-life care (see *Chapter 9: Supportive care and Chapter 10: Palliative and end-of-life care* for further details). Research is an important enabler for helping improve care, and much of

the work undertaken in CCA is associated with research activities including clinical trials (https://albertacancerclinicaltrials.ca/researchers/funding-for-trials/acct-iit/) and other interventional and observational studies, as well as applied research in person-centered care, health services and real-world evidence research.

CCA has 17 cancer centres, including two tertiary cancer centres, four regional cancer centres and 11 community cancer centres. The regional and community cancer centres are located alongside or within regional hospitals or health centres, and they deliver a range of treatments and care options to patients with cancer as close to home as possible. See Table 15 for a complete list of cancer centres, their location and a map.

Table 15. Cancer centres in Alberta

Name	Location	Map of cancer centres
Tertiary cancer centres		
Cross Cancer Institute	Edmonton	
Tom Baker Cancer Centre	Calgary	
Regional cancer centres		
Grande Prairie Cancer Centre	Grande Prairie	
Central Alberta Cancer Centre	Red Deer	
Jack Ady Cancer Centre	Lethbridge	
Margery E. Yuill Cancer Centre	Medicine Hat	
Community cancer centres		
Barrhead Community Cancer Centre	Barrhead	
Bonnyville Community Cancer Centre	Bonnyville	
Bow Valley Community Cancer Centre	Canmore	
Camrose Community Cancer Centre	Camrose	
Drayton Valley Community Cancer Centre	Drayton Valley	
Drumheller Community Cancer Centre	Drumheller	
Fort McMurray Community Cancer Centre	Fort McMurray	
High River Community Cancer Centre	High River	
Hinton Community Cancer Centre	Hinton	

■ Tertiary cancer centres
◆ Regional cancer centres
● Community cancer centres

Lloydminster Community Cancer Centre	Lloydminster	*Source*: Alberta Health, Government of Alberta, 2012. **Cancer Services**
Peace River Community Cancer Centre	Peace River	

Services provided

Tertiary, regional and community cancer centres provide different types of health care services to patients living with cancer in Alberta. The two tertiary cancer centres provide a wide range of services, and they are the central hubs for local populations and provincially for rarer cancer types, more complex treatments and patients with complex needs (e.g., with multiple comorbidities). In addition, they provide care support, as needed, to physicians and staff at the regional and community cancer centres, and they coordinate care via referrals to other health care providers within CCA or specialist teams within AHS. A list of services and members of the health care team at the different cancer centres is presented in Table 16.

Table 16. Main services available in the different cancer centres in Alberta

Name	Treatments	Other services	Health care team
Tertiary cancer centres			
Cross Cancer Institute Tom Baker Cancer Centre	• Radiation therapy (including brachytherapy) • Chemotherapy • Hormone therapy • Immunotherapy (including CAR T-cell therapy) • Hematopoietic stem cell transplantation	• Patient consultations • Treatment • Education • Palliative and end-of-life care • Supportive care • Post-treatment care	• Oncologists • Medical physicists • Nurse practitioners • Nurses • Radiation therapists • Pharmacists • Patient navigators • Dietitians • Rehabilitation medicine professionals • Psychosocial professionals (social workers, psychologists, psychiatrists) • Spiritual care practitioners • Palliative/end-of-life care professionals • Clerks
Regional cancer centres			

Grande Prairie Cancer Centre[†] Central Alberta Cancer Centre[†] Jack Ady Cancer Centre[†]	• Radiation therapy • Chemotherapy • Hormone therapy • Immunotherapy	• Patient consultations • Treatment • Patient education • Supportive care • Post-treatment care	• Oncologists • Medical physicists • Nurse practitioners • Nurses • Pharmacists • Patient navigators • Dietitians • Psychosocial professionals (social workers) • Clerks
Margery E. Yuill Cancer Centre	• Chemotherapy • Hormone therapy • Immunotherapy		
Community cancer centres			
Barrhead Community Cancer Centre Bonnyville Community Cancer Centre Bow Valley Community Cancer Centre Camrose Community Cancer Centre Drayton Valley Community Cancer Centre Drumheller Community Cancer Centre Fort McMurray Community Cancer Centre High River Community Cancer Centre Hinton Community Cancer Centre Lloydminster Community Cancer Centre	• Chemotherapy • Hormone therapy • Immunotherapy	• Patient consultations • Treatment – once patient has had an initial consultation at a regional or tertiary cancer, has been determined appropriate for treatment at a community cancer centre and has received a treatment plan • Supportive care[‡] • Post-treatment care[‡]	• General practitioners in oncology (GPOs) • Nurses • Pharmacists • Patient navigators • Clerks

Peace River Community Cancer Centre			

† Care teams at the Grande Prairie Cancer Centre, Jack Ady Cancer Centre and the Central Alberta Cancer Centre also include radiation therapists and professionals in rehabilitation medicine. The Jack Ady Cancer Centre has physiotherapy services, and the Grande Prairie and the Central Alberta Cancer Centres have physiotherapy, occupational therapy and speech language pathology services.
‡ At some facilities.

As shown in Table 16, tertiary cancer centres in Alberta provide radiation therapy (including brachytherapy), chemotherapy, hormone therapy, immunotherapy (including CAR-T cell therapy) and hematopoietic stem cell transplantation. Regional cancer centres offer chemotherapy, hormone therapy and immunotherapy. The Jack Ady Cancer Centre and the Central Alberta Cancer Centre also offer radiation therapy. As part of the Radiation Therapy Corridor project that started back in 2008, aiming to have a radiation therapy clinic within a 100 kilometres reach for 92% of Albertans (Alberta's Radiation Therapy Corridor), since December 2021 the Grande Prairie Cancer Centre also offers radiation therapy as an additional treatment option. Community cancer centres provide chemotherapy, hormone therapy and immunotherapy following patient consultation in a tertiary care facility, once the patient has received a treatment plan at that facility.

Cancer and treatment for cancer may cause various symptoms or side effects. These often depend on the type of treatment and drugs used, along with the patient's own reaction to them. Side effects include physical symptoms such as nausea, vomiting, diarrhea and fatigue, and mental or emotional symptoms such as depression and anxiety. Relieving these side effects and symptoms is an important part of cancer care. CCA is a leader in Canada in collecting information about symptom burden from patients undergoing treatment. Patients attending all CCA sites are invited to complete a 'Putting Patients First' form, which is based on the Edmonton Symptom Assessment Scale (revised) (ERAS-r)[40] and the Canadian Problem Checklist[41] Information about these Patient Reported Outcomes (PRO) is entered into a database and used to generate electronic symptom reports, which are used to help monitor trends in symptom

burden for individuals and to help drive referrals for additional support such as dietitians, social workers, psychologists and others.[42]

Supports to manage symptoms and side effects of cancer and cancer treatment may be provided by CCA if they are flagged by patients during visits or by phone. Alternatively, symptoms associated with treatment may be addressed by other stakeholders and partner providers at AHS and in the community, including primary care (community cancer clinics), emergency departments, and the volunteer and not-for-profit sector (see *Chapter 8: Supportive care*). Symptom management for people undergoing active cancer treatment may be suboptimal, and that alternative approaches to providing support may be required.[43]

Service volumes

The Cross Cancer Institute (Edmonton) and the Tom Baker Cancer Centre (Calgary) each has over 13,000 unique patients attending every quarter. During the 2019/20 fiscal year, the Cross Cancer Institute had 378,246 patient visits and the Tom Baker Cancer Centre had 227,299 patient visits.[44] The Cross Cancer Institute provides a wider range of diagnostic imaging and laboratory tests within the facility, while for patients at the Tom Baker Cancer Centre many of these occur within the local acute facility or in the community (situation to change with the opening of the new Calgary Cancer Centre in 2023). During this same fiscal year, the regional cancer centres had a total of 80,155 patient visits.[44] Patients residing in rural Alberta receive an initial consultation at a tertiary or regional cancer centre prior to receiving treatment at the community cancer centres, if appropriate.

Community cancer centres have a considerably smaller number of patient visits when compared to tertiary and regional cancer centres (as a whole they had over 18,000 patient visits in 2019/20).[44] Generally, patients receiving treatment at community cancer centres have a low risk of complications, are treated with the more common treatment regimes and have the more common cancer types including breast, prostate and colorectal cancers.

Transitions and care coordination

Cancer care is often done by separate teams of care providers. During treatment, for example, many people with cancer need to transition from their oncology team at the cancer centre to specialized teams outside of the cancer centre, and then back to their oncology team. That is the case for most patients with cancer receiving surgery, which is typically performed outside of cancer centres and often as part of a regime that also involves other types of treatment such as radiation therapy and chemotherapy, which are performed at cancer centres. It is also the case for cancer survivors who need longer-term support and care such as surveillance for cancer relapse (with clinical assessments, diagnostic imaging studies or molecular genomic diagnostics), management of short- and long-term complications of cancer treatment, cancer rehabilitation, or work to optimize quality of life after treatment (see *Chapter 9: Supportive care and Chapter 10: Palliative and end-of-life care* for further details on care and services in these areas). Care coordination refers to the idea of having separate teams working collaboratively to provide efficient care towards optimal patient outcomes.[45] Care providers from separate teams share information and participate in patient care delivery activities that are aligned with the patient's needs and preferences.[46] A person-centered approach is crucial to care coordination.[47,48] In Alberta, a relevant program enhancing successful transitions and coordination of care is the provincial Cancer Patient Navigation program, which has been in existence since 2012 at the 15 regional and community cancer centres across Alberta.[49] The Cancer Patient Navigation program uses a professional navigation model[50] with specially trained registered nurses who provide a variety of clinical supports and services including psychosocial interventions, coordination of care, health education, case management and facilitation of communication between health systems and the patient.[43,51] Watson et al.[52] have demonstrated that the program, implemented in 15 urban and rural cancer centres across Alberta, could provide tangible, real-time improvements to system functioning, the ability of health care teams to collaborate, and patient and family experience. More work is required to understand how the Patient

Navigation program could be enhanced to support patients and families as Alberta explores new models of care.

Care coordination is not only a challenge during treatment, but also once treatment is complete. After treatment, patients have unique care needs. They may continue to experience physical, psychosocial and functional challenges such as fatigue, anxiety about cancer returning, depression, changes in sexual activity and function, and worries about returning to work or school.[53-56] Despite increasing frameworks and recommendations for interventions that address the specific needs of patients after treatment,[43,57-60] many patients do not receive adequate support as they transition back to their daily lives, and many of their needs remain unmet.[57,61] Results from the [Experiences of Cancer Patients in Transition Study](#) (2016 data), a national survey examining the experiences of over 13,000 people with cancer as they transition from cancer treatment to the broader health system, illustrate the magnitude of this issue. Alberta data (dataset with 1,833 valid respondents) showed that 56% of participants had difficult times after treatment in terms of their ability to live their life the way they wanted to, 15%–22% found help in three to 12 months, and 9%–12% waited a year or more to get help.[62]

Although some patients receive cancer and survivorship care at their cancer centre, this is not the case for the majority of patients in Alberta (and across Canada), especially outside of urban settings. Most patients transition out of the cancer system into the community once they have completed cancer treatment. For some patients, this transition is supported by a treatment summary and a follow-up care plan based on the patient's needs, goals and preferences, but that is not yet widespread practice in Alberta and across the country.[57,63,64] Data from the Experiences of Cancer Patients in Transition Study showed that 55% of participating patients from Alberta (out of 1,456) received a formal written plan for follow-up care from the facility where they received treatment.[62] Transition into the community may be stressful for patients as they may still be experiencing physical symptoms, delayed effects of treatment, uncertainty about their health and fears of cancer recurrence.[65-67] For care providers, the transition is not easy either. They face several patient, health care provider and health care system

barriers including poor coordination, flow of information and communication with the cancer care system;[47,66,68-70] lack of speciality training in providing effective and person-centered follow-up care;[70,71] and a lack of clarity about providers' roles and responsibilities.[47,66,68]

To overcome these challenges, several initiatives are being pursued in Alberta including Living Well after Cancer, a provincial collaboration established in 2020 between CCA, Alberta's Primary Care Integration, and Innovation Network & Community Partners. Living Well after Cancer seeks to improve coordination and continuity of post-treatment care for survivors transitioning from cancer care to primary care.[72] Building on previously developed CCA clinical surveillance guidelines, transition letters, and patient knowledge tools, the goal of this initiative is to: 1) increase awareness of evidence-based survivorship guidelines, knowledge products and self-management resources which support both primary care physicians and cancer survivors; 2) support navigation by utilizing community supports to overcome gaps/barriers to patient support and decrease patients' unmet needs after cancer; and, 3) improve coordination between CCA and primary care by increasing knowledge, building capacity and sharing best practices in transitions and cancer survivorship.[72]

Cancer clinical trials and research

The Cross Cancer Institute and the Tom Baker Cancer Centre are teaching hospitals, and they are linked to the universities of Alberta and Calgary, respectively, with many cross-appointments of clinical staff. Provincial research, with critical contributions to the improved care of people with cancer, benefits from close collaborations of the cancer system with scientists at the [Charbonneau Cancer Research Institute](#) (University of Calgary), the [Cancer Research Institute of Northern Alberta (CRINA)](#) (University of Alberta) and the [Collaborative Health Research Institute in Southern Alberta (CHRISA)](#) (University of Lethbridge).

Clinical trials are a particular type of research study that allows researchers to discover new ways in which to prevent, diagnose, treat and manage cancer.[73] Among many other benefits, these trials help improve patient outcomes by finding innovative drugs to

treat cancer, identifying alternative cancer drugs that require fewer doses and/or cause fewer side effects, and determining lifestyle interventions that enhance cancer treatment received (e.g., nutrition or physical activity). Clinical trials hosted by the Cross Cancer Institute and the Tom Baker Cancer Centre range from international, multi-centre studies to smaller-scale investigator-initiated trial projects conducted by local clinician researchers and scientists. These research projects are integrated into everyday clinical practice and help to continually improve care for patients with cancer across the province. In 2020/21, 1,022 patients were enrolled in clinical trials, with 75 new trials opened within the province. Through running these trials, it has been estimated that over $30M worth of drugs were provided free to clinical trial patients.[74]

Philanthropic organizations, including but not limited to the Alberta Cancer Foundation and the Cure Cancer Foundation, support clinical trials throughout the province. This support provides people with cancer in Alberta the opportunity to participate in a wide range of clinical trials, including investigator-initiated trials that are driven by clinician researchers in the cancer centres. The trials units at both the Cross Cancer Institute and the Tom Baker Cancer Centre are also part of the Canadian Cancer Clinical Trials Network (3CTN), a pan-Canadian initiative that links Alberta's cancer centres with others across the country to improve recruitment as well as the efficiency and quality of academic clinical trials.

Clinical trials are not the only type of research study with a direct impact on improved patient care. Examples of other types of studies that make important and significant contributions to improving patient treatment include health services and real-world evidence research; intervention and observational studies in the realms of psychosocial oncology, nutrition, body composition and physical activity; observational studies enabled by the availability of comprehensive population-based cancer data and biobanking capability; imaging, medical physics and genomics studies that improve how cancers are characterized and treated; and discovery/translational research where questions are driven by an ongoing need to understand more about how tumor biology contributes to responses to treatment.

Drug benefit programs and therapeutic funding

In Alberta, prescription drugs provided during care received in hospitals, auxiliary hospitals and nursing homes are covered under the Alberta Health Care Insurance Plan. In addition, many Albertans have insurance coverage for prescription drugs provided through private supplementary health plans sponsored by their employers, while others have coverage through publicly funded plans.[75] Alberta Health (Ministry of Health, Government of Alberta) offers a number of additional health benefit plans for Albertans which are administered by Alberta Blue Cross and provide prescription drug coverage. These plans include the Non-Group Coverage Program (a premium-based plan available to Albertans under 65 years of age and their dependants), the Coverage for Seniors Program (a premium-free plan available to Albertans 65 years of age and older and their dependants), and the Palliative Coverage Program (for people diagnosed as being in the end stage of a terminal illness or disease and receiving their treatments at home), and several supplementary health benefit plans for low-income Albertans (e.g., Assured Income for the Severely Handicapped, Income Support).[75]

In addition to supplementary health benefits, Alberta Health provides some specialized drug coverage and pharmacy services. Albertans diagnosed with cancer have access to cancer drugs through the Outpatient Cancer Drug Benefit Program. This program provides select medications used in the direct treatment of patients at no cost through specific locations in the province.[75] Drugs covered include those needed in the systemic treatment of patients. Drugs supportive to treatment such as pain and nausea medications are not covered under the Outpatient Cancer Drug Benefit Program, but may be covered with some type of private or provincial health insurance.[75]

Drug funding decisions are complex and need to follow a rigourous evidence-based review process to ensure coverage consistency, equity, and the long-term sustainability of our health system.[76] Health Canada assesses drugs for quality, safety and efficacy, while the Canadian Agency for Drugs and Technology in Health (CADTH) reviews their clinical and cost effectiveness. Recommendations resulting from these assessments are considered by the pan-Canadian Pharmaceutical Alliance (pCPA), of which Alberta is a member. The pCPA capitalizes on the collective negotiation power of the provincial,

territorial and federal public drug plans to achieve enhanced value and consistent coverage for prescription drugs across Canada. Should a drug be successfully negotiated by the pCPA, it will be considered for listing on government-sponsored drug programs at the provincial level. In Alberta, the Minister of Health makes the final decision on changes to the Alberta Drug Benefits List after considering the recommendations of Alberta's Expert Committee on Drug Evaluation and Therapeutics, which are based on the scientific, therapeutic, clinical and socio-economic merits of drug products and devices.[76]

In Alberta, the cost of individual drugs, the number of new agents approved by the Minister of Health and the number of Albertans accessing drug coverage are all increasing. Despite multiple efforts to ensure cost efficiencies, in the last fiscal year (2019/20) Alberta saw an 11% increase in its drug budget, following an increase of 6% in 2018/19 and 2017/18, and an increase of 8% in 2016/17 (C. Chambers, personal communication, January 27, 2021). Figure 28 shows the steady progression of expenditures over time. Advances in systemic therapy have significantly improved survival rates for cancer patients, but are increasingly expensive with annual cancer drug expenditures rising by an additional $50 million/year in Alberta, much of which is currently driven by the increasing use of immune and targeted therapies (C. Chambers, personal communication, February 23, 2022). Appendix 4 presents names of 21 drugs related to immune and targeted therapies that are among the over 150 drugs included in the Outpatient Cancer Drug Benefit Program and accounted for ~80% of the 2020 cancer drug budget in 2020.
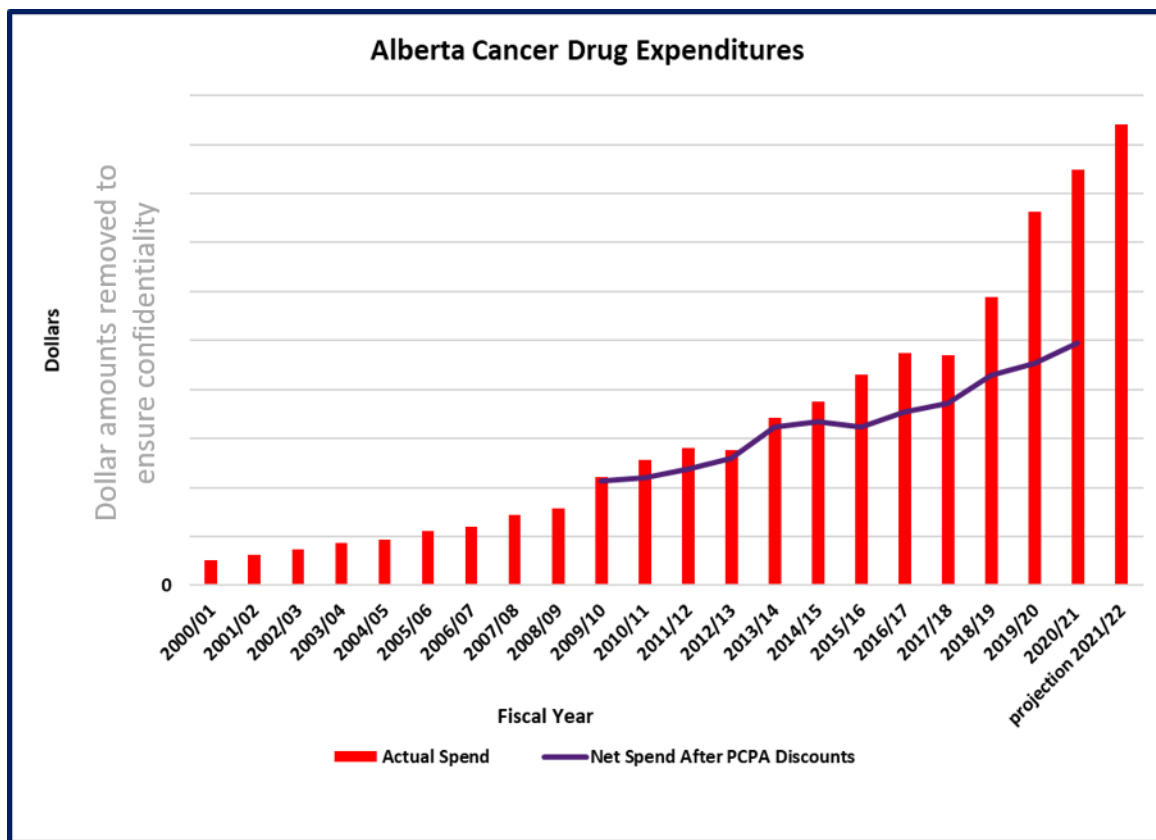
Figure 28. Alberta cancer drugs expenditures from 2000/01 to 2021/22
Source: Personal communication from Carole R. Chambers, B.Sc.(Pharm) MBA FCSHP FISOPP FCAPhO, AHS Pharmacy - Director, Cancer Services. January 2022

Emerging trends in cancer treatment

Cancer treatment is constantly evolving. With a focus on continuous improvement to deliver the highest possible value to patients with cancer, current trends in cancer treatment include the progressive adoption of precision oncology (including targeted therapies and immunotherapies), and the exploration of biosimilars to treat cancer. Appendix 5 lists future systemic treatments for most common cancers identified by Alberta Tumor Team members, which generally include targeted therapies and immunotherapies. While these treatments may help improve cancer survival rates, they are expensive, and need to be evaluated. Studies using real-world evidence to assess the impacts of novel treatments on health service utilization, patient outcomes, and costs/value of cancer care are required.

Precision oncology

Precision medicine (also known as personalized medicine) is a genetic approach to health care that uses a patient's genetic makeup and –in oncology- the genetic makeup of a specific tumor, to support clinicians in defining a particular treatment plan that is more likely to be effective for that specific patient.[77] Using this approach, mutant driver genes in each patient's tumor are identified through cancer genome sequencing and analysis by bio-informatic approaches, to then target the mutant gene products with customized inhibitors. To date, the success of this approach has proven elusive. Such precision medicine approaches have occasionally produced excellent short-term remissions of difficult-to-treat cancers, but long-term disease control is rare because of the difficulty identifying true driver mutations amongst the many others found, access to effective targeted agents, and tumor heterogeneity with clonal evolution of treatment resistant subpopulations.[78] In addition, the widespread adoption of this approach faces important problems.[79,80] Importantly, it encompasses important economic challenges such as costly development, high rates of failure and reduced market size in comparison with the traditional drug development model.[81,82]

More relevant than true individual "personalized medicine" is biomarker-guided therapy, which establishes pathological cancer subtypes that consist of fairly large groups of patients. In biomarker-guided therapy, appropriate targeted therapies are defined based on particular pathological cancer subtypes for cancers that express specific molecular markers (e.g., HER2+ breast cancer, MYC/BCL2 double hit lymphoma, PDL1+ or EGFR+ lung cancer). These cancers are subdivided into common molecular subtypes that can be studied and treated differently (e.g., ER+ vs HER2+ *vs.* triple negative breast cancer, IgHv mutated or unmutated CLL, ABC *vs.* GCB DLBCL).

As the use of biomarker-guided therapies continues to grow, so do the barriers to their use, including the lack of complete and broad understanding about how biomarker testing works and what impact it can have on selecting the most promising cancer treatment options. [83] Measurable residual disease (also known as "minimal residual disease") refers to the number of cancer cells that remain during and after cancer treatment, and is considered a promising prognostic marker to identify individuals at

increased risk of recurrence and who may benefit from further treatment.[84] Measurable residual disease has already been used for several years to guide use of second-line salvage or maintenance therapy for chronic myeloid leukemia (with QPCR for BCR-ABL transcripts in blood to assess adequate response, and stop strategies for molecular complete responders),[85] as well as acute myeloid leukemia and acute lymphocytic leukemia in allogenic stem cell transplantation.[86] Increasing evidence is being generated for chronic lymphocytic leukemia, certain lymphomas, and many other cancers.[87,88]

In Alberta, the [Precision Oncology and Experimental Therapeutics (POET) Program](#) at the University of Calgary, in partnership with the Tom Baker Cancer Centre, has taken on the challenge of developing novel precision diagnostics and therapeutics.[89,90] Similarly, precision health is an institutional priority for the University of Alberta ([Precision Health Strategy](#)), with cancer as a relevant area of focus and several research groups working on advancing the field of precision oncology in cancer care.[91] In October 2021, a consortium of cancer researchers across Alberta, Saskatchewan and Manitoba submitted an application to the [Terry Fox Research Institute Marathon of Hope Cancer Centres Network](#), with the goal of accelerating precision oncology by streamlining approaches to sequencing tumors and sharing clinical and genomic data.

Important parts of precision oncology are targeted therapy and immunotherapy:

Targeted therapies

While conventional cancer treatments such as radiation therapy and chemotherapy focus on killing, damaging or shrinking tumors or cancer cells, targeted therapies zero in on the specific pathways in the development, growth and spread of tumors.[92] Since targeted therapies do less damage to healthy cells, they tend to be less toxic and can be provided to patients with poor performance status who may not be candidates for conventional treatment, they are a major focus of cancer research today.[93,94]

Various targeted therapy drugs, used alone or in combination with other cancer treatments have been approved by Health Canada and are available to patients with cancer in Alberta.[95] In clinical trials, researchers are evaluating the use of targeted

therapies to help prevent the resistance cancer cells can develop to particular therapies when mutating.[96,97] A few of the pathway targets being studied in Alberta-based clinical trials include BCL2, CL2, FLT3, the oncogene KRAS, numerous cyclin-dependent kinases (CDKs), c-MET and mTOR, and the enzymes poly (ADP-ribose) polymerase (PARP) and phosphoinositide 3-kinase (PI3K).[98] For some types of cancer, many patients will have an appropriate target for a particular targeted therapy and thus, will be candidates to be treated with this therapy. For other cancer types, however, a patient's tumor tissue must be tested to determine whether or not an appropriate target is present. The use of targeted therapies may be restricted to patients whose tumor has a specific gene mutation that codes for the target. In addition, sometimes a patient might be a candidate for a targeted therapy only if they meet other specific criteria (for example, their cancer did not respond to other therapies, has spread or is inoperable).

Immunotherapies

Immunotherapy activates certain parts of a person's immune system to fight diseases such as cancer.[99] The various types of immunotherapy work in different ways. Some treatments help the immune system stop or slow the growth of cancer cells, while others help the immune system destroy cancer cells or stop the cancer from spreading to other parts of the body. Immunotherapies are generally associated with better tolerance overall compared to traditional chemotherapy agents,[100] and side effects are usually mild and go away once the body gets used to the drug.[99,101]

Main current types of immunotherapy to treat cancer include monoclonal antibodies, immune checkpoint inhibitors, and T-cell transfer therapy:[99]

Monoclonal antibodies. Monoclonal antibodies are laboratory-made proteins that mimic the immune system's ability to fight off harmful pathogens. Some monoclonal antibodies work by finding a specific antigen (such as a protein) on a cancer cell and then attaching to it.[102] One example of this type of monoclonal antibody is rituximab (Rituxan). Rituxan has demonstrated efficacy in patients with various lymphoid malignancies, including indolent and aggressive forms of B-cell non-Hodgkin's

lymphoma and B-cell chronic lymphocytic leukemia.[103] Similar strategies are being explored for other tumor sites, and will likely be adopted in the future.

Immune checkpoint inhibitors. Immune checkpoint inhibitors are drugs that block checkpoint proteins from binding with their partner proteins, preventing the "off" signal from being sent and allowing the T-cells to kill cancer cells.[99] Immune checkpoint inhibitors are effective in a broad range of cancers, and it is anticipated that their indication will continue to expand to a number of additional malignancies.[104] Currently in Alberta, the use of immune checkpoint inhibitors is approved to treat a number of cancer types, and have improved survival rates for a wide spectrum of cancers that are not traditionally considered chemosensitive such as melanoma and non-small cell lung cancer, as well as many other tumor types including bladder, ovary and kidney. [100,104] As of June 2020, seven immune checkpoint inhibitor agents have been approved and funded for Alberta use.[101]

T-cell transfer therapy. T-cell transfer therapy involves growing and modifying receptors on specific immune cells called T-cells. In large quantities, these modified T-cells have an enhanced ability to strengthen the immune system of a patient and fight against cancerous cells and tumors.[105] The most prominent and common types of T-cell transfer therapy include tumor-infiltrating lymphocyte (TIL) therapy and chimeric antigen receptor (CAR) T-cell therapy:

TIL therapy. TILs are specialized immune cells capable of fighting cancer cells. In TIL therapy, a patient's own TILs are activated and multiplied in the laboratory, and given back to the patient to kill the tumor and help the immune system to respond to the tumor.[105] TIL therapy is still experimental in Canada, with two clinical trials currently underway.[98]

Chimeric Antigen Receptor (CAR) T-cell therapy. CAR T-cell therapy uses receptors on modified T-cells that can detect and attack cancer cells more effectively. It offers improved survival rates for relapsed B-cell lymphoma and myeloma patients, and recently has been reported to give higher cure rates than autologous stem cell transplantation for initial relapse of diffuse large B-cell lymphoma; becoming a new

standard of care.[106,107] Two CAR T-cell therapies have been approved in the Canada for some types of advanced non-Hodgkin lymphoma and myeloma and for children and young adults with acute lymphocytic leukemia.[108] This treatment previously required Alberta patients to travel outside the province or the country, but it is now available in Alberta.[109] In March 2021, the first Albertans received an approved CAR T-cell therapy at the Tom Baker Cancer Centre. In addition, Alberta has a clinical trial to develop a made-in-Alberta CAR T-cell therapy. Alberta is now the third province to offer CAR-T-cell therapy, which is used to treat both children and adults with specific types of leukemia and lymphoma who would otherwise have poor chances of recovery or survival.[110] A handful of additional clinical trials related to CAR T-cell therapy are currently underway in the province.[98]

Biosimilars

Biosimilars are drugs that are similar to the originator biologics (biologics or biologic drugs), with no meaningful differences in terms of quality, safety and treatment efficacy,[111] but less expensive.[112] In Canada, costs for originator biologics have been estimated at more than $25,000 per patient per year, with biosimilar versions costing up to 50% less.[113] As a result, and in the context of rising health care expenses, Alberta and many other jurisdictions are turning their attention to biosimilars.[111,114] Under Alberta's government-sponsored drug plan, the province spent more than $238M in the 2018/19 fiscal year on biologic drugs, and these costs are increasing by an average of 16% every year.[112] Switching to biosimilars will save between $227M and $380M over the next four years once fully implemented.[112] In terms of cancer treatment, within CCA, biosimilars have been incorporated for trastuzumab, rituximab, and bevacizumab. Biosimilar enter the market after the patent and data protection of the original biologics have expired,[115,116] and ongoing work in Alberta should monitor cancer outcomes for patients treated with cancer drug biosimilars.

Conclusions and recommendations

A diagnosis of cancer impacts a person's life immensely. In Alberta, a diversity of services is offered across the province to support those affected by cancer. CCA provides cancer treatment and support for many aspects of the cancer continuum at its 17 cancer centres in partnership with clinical support services (pharmacy, lab, diagnostic imaging), some AH Zone partners (acute, palliative/end-of-life, home care), as well as other health care providers and services including community, primary care and volunteer and not-for-profit organizations. The most common types of treatment (used alone or in combination) are radiation therapy, systemic therapy and surgery. New developments are leading to the progressive adoption of precision oncology to treat cancer in Alberta. The use of targeted therapies and current advances in immunotherapies (monoclonal antibodies, immune checkpoint inhibitors, and T-cell transfer therapies such as TIL therapy and CAR T-cell therapy) offer promising options to many patients who otherwise would have poor chances of recovery or survival. In addition, treatment in Alberta is changing with the introduction of biosimilar drugs. Another relevant trend in cancer care is the growing pressure placed on the cancer system to care for an increasing number of people diagnosed with cancer, and to absorb the increasing price of drugs and health care in general.

Recommendations for research and action to fulfill future treatment requirements for the Alberta population include:

- Establish a robust set of quality indicators related to the full range of services available in Alberta to ensure that quality care is provided across all aspects of quality including acceptability, accessibility, appropriateness, effectiveness, efficiency, equity and safety. Performance metrics need to be developed to quantify and evaluate system improvements achieved from the implementation of emerging trends in cancer treatment. Real-world data should be collected to assess quality. Consideration should be given to collecting baseline data on innovations prior to their implementation to most effectively compare them to standard practice. Additionally, patient-reported outcomes and the net value of innovation adoption should be assessed.

- Use and complement existing expertise to implement a robust research framework for collecting and using patient reported outcomes and experience measures to support the design and evaluation of current and new treatments as well as current and novel models for delivering care. Enhance evaluation of current efforts to improve transitions of care and care coordination to optimize care across the cancer continuum is required.

- Conduct further research into the cost-effectiveness of emerging trends in cancer treatment, and evaluate their advantages compared to traditional treatments in terms of clinical outcomes, patient and health care provider preferences, and system efficiencies in the Alberta context. The costs of cancer therapy are dramatically increasing on an annual basis, and with a likely move to expensive targeted and immune therapies in the future, an acceptable cost-effectiveness benchmark for cancer treatments will need to be established in order to justify treatment funding.

- Explore future research opportunities including the expansion of access to clinical trials, the development of more comprehensive approaches to assessing outcomes for trial participants and those exposed to different lines/modes of cancer treatment in routine care, learning how to enhance cancer care to meet the evolving needs and expectations of patients and families, and understanding more about how to optimize patient outcomes and experiences.

- Investment in radiation oncology research has led to the development of world-leading technology and treatment protocols. Prioritize continued investment in these directions to ensure Albertans receive the highest quality care, in a timely manner.

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Chapter 8: Cancer management costs

Key findings

- The overall direct cost of cancer management in Alberta is estimated to increase from $1.5B in 2020 to $2.3B in 2040 (58% increase).

- The largest portion of costs and increase in costs are projected to relate to continuing care (between six months after diagnosis and up to the period before end-of-life), which was estimated at $0.7B in 2020 and $1.3B in 2040 (71% increase).

- Hematological cancers are estimated to account for the largest estimated direct cost in 2020 and 2024. Together with prostate cancer, hematological cancers account for the largest increase in cost projections for 2040 (69% increase for hematological cancers – $266M in 2020 to $449M in 2040, and 72% increase for prostate cancer -$229M in 2020 to $394M in 2040).

Recommendations

- Focus future studies on evaluating optimal patient care pathways that optimize patient outcomes and value. As part of pathway optimization, the impact of delays or gaps in care should be evaluated.

- Managing cancer through treatment and care is expensive, due to both an increasing number of people diagnosed with cancer and rising price of drugs and care in general. Expand research infrastructure to examine cost-effectiveness of approved therapies as well as potential cost savings for biosimilars and other off-patent therapies.

- Prioritizing long-term planning for routine updating and replacement of capital equipment (e.g. critical treatment machines such as linear accelerators, which have an approximate lifespan of 10 years) will create stability and minimize disruption to patient treatments.

- The safe and accurate delivery of radiation relies on stable staffing of highly trained professionals. Staffing models need to be based on relevant national benchmarks, and efforts for recruitment and retention of highly qualified personnel need to be bolstered in order to maintain the standards of care that Albertans expect.

- Explore and assess the direct and indirect financial burden of cancer treatment on Albertans and the health system.

- Understand costs of cancer care to the Alberta health system and cancer outcomes compared with other provinces to determine areas of success and areas of opportunity for increased efficiency.

Background

Once cancer is diagnosed, the patient may require medical treatment and specialized care for months and often years. As a leading cause of death and disease in Canada, cancer takes a significant toll on the health of patients and survivors, but it also has a high financial impact. The high financial cost of cancer is largely paid by the public health system, but a considerable amount is still paid by the patients diagnosed with cancer and their families.

In this chapter, we describe the projections of future costs associated with the management of cancer care. This chapter has two subsections: a section that presents projected costs by the health system in Alberta for the next 20 years, and a section that discusses the related financial burden imposed on patients and their families.

Analytic approach

Details on the methodology and analytic approach are presented in Appendix 6.

Projected health system costs

Cancer is a major public health issue and has a significant economic impact on the health care system. Based on OncoSim data for Alberta, and as shown in Figure 29, the overall direct cost of cancer management was estimated to increase from $1.5B in 2020 to $2.3B in 2040 (in 2019 CAD value; 58% increase). Over the projected period, there were relative increases estimated in the cost of all four phases of cancer care (diagnosis, initial treatment, continuing care and terminal care). The largest portion of the cost – and the largest increase in cost – was related to continuing care, which was estimated at $0.7B in 2020 and $1.3B in 2040 (71% increase). Continuing care is associated with expenses incurred for surveillance and active follow-up care, and its increasing cost can be partially attributable to the projected improved survival rate. The second largest portion of estimated cost was for the initial treatment phase, which includes the primary course of therapy and any adjuvant therapy. The projected cost for initial treatment was estimated at $0.4B in 2020 and $0.6B in 2040 (42% increase). Terminal care is related to intensive care services provided at end of life (often palliative

in nature), and was the third most costly phase of care. Terminal care was expected to increase from $0.3B to $0.4B in the projected period (52% increase).
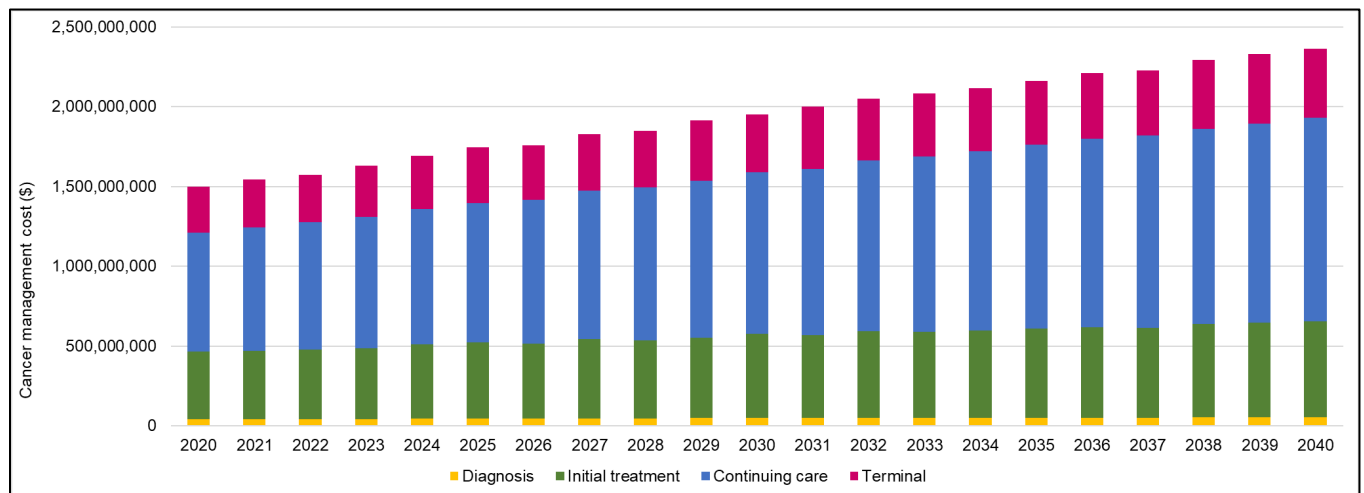
Figure 29. Estimated cancer management costs for all cancers combined in 2020 and projected to 2040

Figure 30 and Table 17 present cost estimates by cancer type. Among the five most prevalent cancer types in Alberta, hematological cancers had the largest estimated direct cost in 2020 ($266M) and 2040 ($449M). Prostate cancer has the second largest estimated cost, and together with hematological cancers had the largest increase in cost projection for 2040, with a 72% increase prostate cancer (from $229M in 2020 to $394M in 2040). For hematological cancers, the projected increase was 69% (from $266M in 2020 to $449M in 2040). Colorectal and breast cancers were projected to have, respectively, a 43% and 24% increase in total cancer management costs by 2040, whereas lung cancer was projected to have a 2% increase. Table 17 further indicates that the increase in the cost of care for prostate, hematological, colorectal and breast cancers had unique patterns. For prostate and hematological cancers, the increase of cost was most prominent in continuing care. In contrast, the increase in the cost of colorectal cancer care was mainly due to initial treatment. For breast cancer, the increase was attributable to both initial treatment and continuing care.
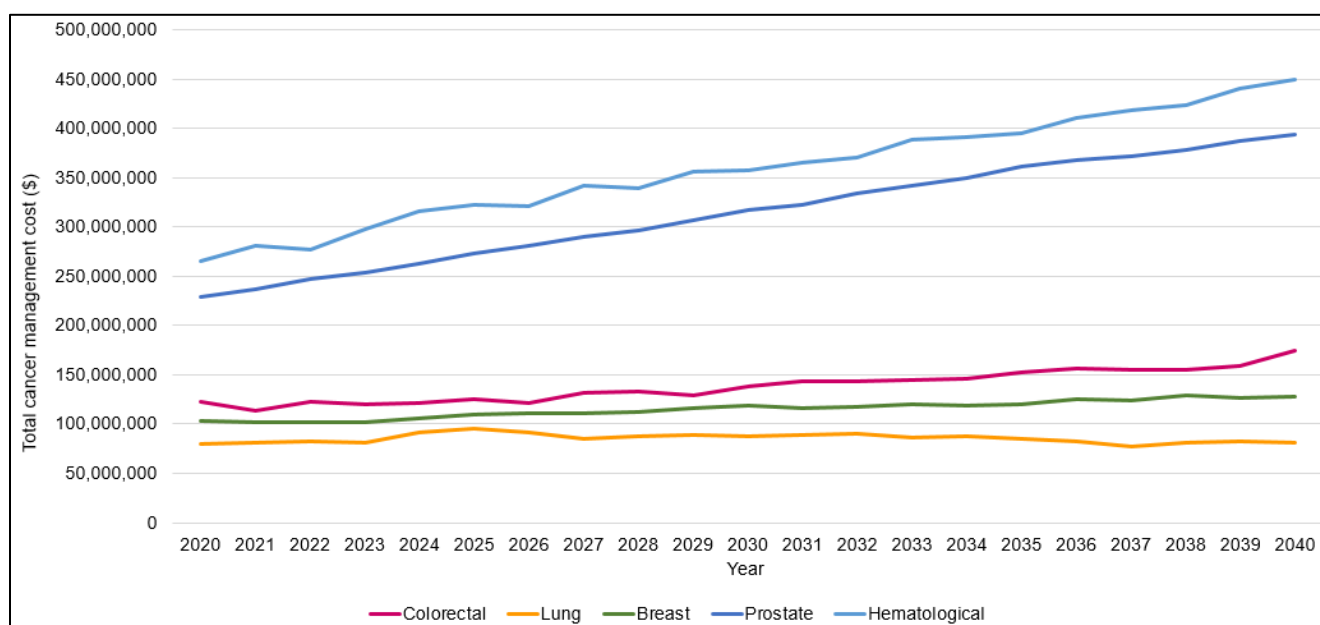
Figure 30. Estimated total cancer management costs for colorectal, lung, breast, and hematological cancers in 2020 and projected to 2040

Table 17. Estimated cancer management costs by phase of care for colorectal, lung, breast, prostate and hematological cancers in 2020 and projected to 2040

Most recent cancer diagnosed	Phase of care	2020 ($)	2040 ($)	Increase (%)
Colorectal	Total	122,056,321	175,089,299	43
	Diagnosis	6,201,577	8,727,560	41
	Initial treatment	94,567,346	138,541,923	47
	Continuing care	11,579,055	15,217,625	31
	Terminal	9,708,343	12,602,192	30
Lung	Total	80,062,069	81,711,799	2
	Diagnosis	16,380,639	17,190,802	5
	Initial treatment	31,786,632	30,011,334	-6
	Continuing care	1,898,700	2,001,810	5
	Terminal	29,996,099	32,507,853	8
Breast	Total	102,936,549	127,829,015	24
	Diagnosis	1,229,619	1,602,038	30
	Initial treatment	58,908,315	69,563,079	18
	Continuing care	29,821,787	41,150,979	38
	Terminal	12,976,829	15,512,920	20
Prostate	Total	229,138,720	394,140,016	72
	Diagnosis	2,425,117	3,486,476	44
	Initial treatment	31,956,724	45,942,674	44
	Continuing care	182,577,250	326,191,828	79
	Terminal	11,657,739	18,074,378	55
Hematological	Total	265,712,085	449,081,750	69
	Diagnosis	3,590,863	5,881,751	64
	Initial treatment	43,251,421	70,847,688	64
	Continuing care	162,869,322	275,116,047	69
	Terminal	55,721,320	96,285,800	73

To account for the increase in costs due to projected population growth, we also reported cancer management cost *per capita*, which is the cost across the projected population. As shown in Figure 31, the overall direct cost for cancer management for each Albertan was estimated to be about $345 in 2020 and almost $460 in 2040. As shown in Table 18, the total management costs for the four major types of cancer were expected to increase, except for lung cancer. The *per capita* cost of prostate cancer was projected to increase from $53 in 2020 to $76 in 2040 (45% increase), in which the continuing care cost increased from $42 to $63 (50%). Similarly, for hematological

cancers, projections showed an increase from $24 in 2020 to $33 in 2040 (42% increase), with an increase from $13 to $20 for continuing care (50%). In contrast, there was a moderate increase in the estimated management cost of colorectal cancer (from $28 to $34; 21%), a small increase for breast cancer (from $24 to $25; 4%) and a decrease for lung cancer (from $18 to $16; -14%).
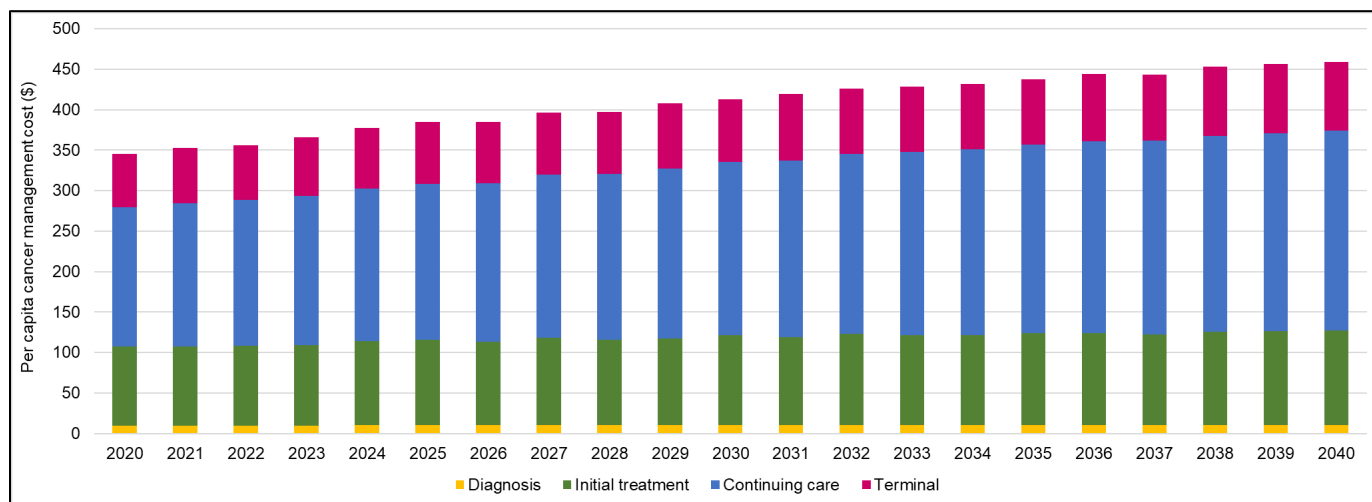
Figure 31. Estimated cancer management costs *per capita* for all cancers combined in 2020 and projected to 2040

Table 18. Estimated cancer management costs by phase of care *per capita* for colorectal, lung, breast, prostate, and hematological cancers in 2020 and projected to 2040

Most recent cancer diagnosed	Phase of care	2020 ($)	2040 ($)	Increase (%)
Colorectal	Total	28.14	33.97	21
	Diagnosis	1.43	1.69	18
	Initial treatment	21.80	26.88	23
	Continuing care	2.67	2.95	11
	Terminal	2.24	2.45	9
Lung	Total	18.46	15.85	-14
	Diagnosis	3.78	3.34	-12
	Initial treatment	7.33	5.82	-21
	Continuing care	0.44	0.39	-11
	Terminal	6.92	6.31	-9
Breast	Total	23.73	24.80	4
	Diagnosis	0.28	0.31	10
	Initial treatment	13.58	13.50	-1
	Continuing care	6.88	7.98	16
	Terminal	2.99	3.01	1
Prostate	Total	52.83	76.47	45
	Diagnosis	0.56	0.68	21
	Initial treatment	7.37	.91	21
	Continuing care	42.10	63.29	50
	Terminal	2.69	3.51	30
Hematological	Total	23.51	33.33	42
	Diagnosis	0.20	0.28	37
	Initial treatment	3.75	5.29	41
	Continuing care	13.20	19.78	50
	Terminal	6.33	7.94	25

The trend in cancer management costs is affected by several factors including changes in population size, changes in cancer incidence rates, changes in cancer mortality rates, and changes in treatment modalities and the associated costs. Our projection of cancer management costs had several limitations:

- OncoSim at present cannot incorporate modifications of the costs over time (including, for example, inflation). Therefore, the cost for each phase and treatment was fixed through the projection period (2020–2040), which is not realistic for many of the associated costs.

- Although OncoSim has two sophisticated models for projecting immigration and interprovincial migration, these models might not be adequate to address the dynamic changes in net migration in Alberta.[1] As a result, the reported *per capita* cost (although adjusted for the projected population growth) might not be accurate.

- Economic values, treatment pathways and drugs involved in the model presented are based on Ontario data, which might be different from those in Alberta.

- OncoSim projects future cancer incidence and mortality based on a statistical model validated on the historical data. However, scientific advances, medical breakthroughs and effectiveness of interventions, which may have great impacts on cancer incidence rates, mortality rates, treatment options, and related survival, which affect the associated cancer management costs, are not accounted for.

- The parameters of cancer costs in OncoSim were based on the publication of de Oliveira et al.[2,3] which used data from a cohort of patients from 1997 to 2007. The treatments of many cancer types have evolved rapidly –and continue to evolve- since then, and OncoSim likely underestimated the treatment costs of some types of cancers. For hematological cancers, for example, treatment costs are significantly increasing due to the use of new targeted and immune therapies (including antibody drug conjugates) as initial therapy, and CAR T-cell therapy as second line for lymphoma and myeloma with stem cell transplantation as third line, as well as targeted therapies and allogeneic transplantation as initial therapy for myeloid malignancies. Targeted therapy and immunotherapy have seen their increased applications in cancer treatment. The cost of immunotherapy drugs, for example, was shown to be 62% more than conventional chemotherapy drugs.[3] In our study, the cumulative cost of first-line chemotherapy for lung cancer from 2020 to 2040 was $337M (19% of the total cost for lung cancer at $1.8B). If all first-line chemotherapies in Alberta were replaced by immunotherapy, we would possibly see $209M more in the drug

cost and a total cost of $2003M. Under such a scenario, the treatment costs would be roughly underestimated by 10%, without considering the changes to the costs of continuing and palliative care that immunotherapy could incur.

Despite the limitations of the methodology, these projections demonstrate the need to continually monitor costs and to develop more sophisticated approaches to modelling that account for attributes that may be peculiar to Alberta's cancer care system.

Financial burden for patients and families

Although in Canada we have publicly funded health care, not all aspects of care are fully funded, and there is a substantial economic burden for people diagnosed with cancer and their families. For example, in Alberta coverage for home care has monthly limits,[4] and certain medications like those that help manage side effects of treatment and some treatment drugs are not funded by Alberta Health.[5] A few Canadian studies have quantified the different economic costs related to cancer treatment incurred by people with cancer and their caregivers.[e.g., 6,7-11] A recent study provides a comprehensive summary of the overall costs and financial burden for patients and families after treatment.[12] In this study, a questionnaire was administered to 901 patients with cancer enrolled in four cancer centres in British Columbia, six in Alberta, one in Saskatchewan, one in Manitoba, six in Ontario and two in the Atlantic provinces. Participants were asked about their monthly out-of-pocket costs (including costs for drugs, home care, home-making, complementary or alternative medicines, vitamins or supplements, family care, accommodations, devices and "other" costs) as well as travel and parking costs, and whether they considered these costs and lost income to be a financial burden for them. The study reported that the mean out-of-pocket cost 28 days after treatment was $518, plus $179 for travel and $84 for parking. One-third of participants (33%) self-reported the burden of out-of-pocket costs was considerable, representing an average of 34% of their monthly income. In addition, the study found that 29% of participants and 26% of caregivers who were working took time off work during the 28-day study period, averaging 18 days for patients and 11 days for caregivers. A crude estimate (based on provincial salary averages) of lost productivity revealed that participants and their families lost on average $209 per day for work

missed, resulting in an average loss of $3,759 in income for patients and $2,402 for caregivers over a month. The study concluded that the approximate national economic burden, including out-of-pocket costs, travel, parking and income loss averages, was $2,514/month per cancer patient. The fact that Alberta has the highest average salary among the provinces included in the study[13] suggests that the estimate for Alberta patients might be higher. On the other hand, factors particular to the Alberta context, such as the high coverage of treatment drugs, might suggest it is lower. Further research specific to Alberta is needed, including cost estimates comprehensive to all cancer types and emerging treatment trends.

The already high financial burden of cancer on patients and their families could see an increase as the number of people diagnosed with cancer rises and the health care system is subject to growing capacity and financial pressures. Patients might experience reduced access to supportive services which, together with the increasing price of drugs and decline in private insurance coverage, might result in a gradually higher burden put on patients and their families.

Conclusions and recommendations

Managing cancer through treatment and care is expensive, and there is growing pressure for an increasing number of people diagnosed with cancer and rising price of drugs and care in general. In Alberta, it is estimated the overall direct cost of cancer management will increase from $1.5B in 2020 to $2.3B in 2040 (58% increase). Recommendations for future research and action concerning the future cost of cancer management for the Alberta population include:

- Studies to evaluate optimal patient care pathways that balance costs and patient outcomes. Of particular note are studies to evaluate futile therapy, unnecessary treatments or procedures, and potential over-treatment.
- Evaluations of cost of delays or gaps in care pathways. Delays and gaps may be potential source of system and cost improvement.
- Value re-assessment studies that examine whether approved therapies are meeting the efficacy thresholds from the initial submissions and therefore cost-

effectiveness in the real-world setting. This is particularly essential with higher-cost targeted therapies and immunotherapies.

- Studies of potential cost savings for biosimilars and other off-patent therapies.

- Assessments of the cost-effectiveness of implementing innovative models of care that can potentially lead to cost savings, such as changes from resource-intensive, in-person visits to a virtual care model. Any cost savings should be evaluated in the context of patient experiences and outcomes.

- Prioritizing long-term planning for routine updating and replacement of capital equipment (e.g. critical treatment machines such as linear accelerators, which have an approximate lifespan of 10 years) will create stability and minimize disruption to patient treatments.

- The safe and accurate delivery of radiation relies on stable staffing of highly trained professionals. Staffing models need to be based on relevant national benchmarks, and efforts for recruitment and retention of highly qualified personnel need to be bolstered in order to maintain the standards of care that Albertans expect.

- Research addressing costs associated with the management of cancer among Albertans with cancer and their family members, with emphasis on those experiencing the highest impacts on financial health.

- Assessment of Alberta's cancer outcomes and management costs compared with other provinces to determine areas of success and areas of opportunity for efficiency.

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Chapter 9: Supportive care

Key findings

- Supportive care is an overarching concept that describes the health care services that people awaiting a diagnosis of cancer, or who already have a diagnosis of with cancer, and their families need beyond anti-cancer medical, surgical and radiation interventions. It can include physical, emotional, social, psychological, cultural, functional, informational, spiritual and practical support for patients and their families.

- According to the Supportive Care Framework, 45%–55% of people with cancer require support beyond introductory coping strategies, classes and other educational materials.

Recommendations

- Alberta has an extensive network of supportive care services, including the volunteer sector, municipal supports, primary care and AHS. Assess the extent to which supportive care access can be tailored to people's needs by leveraging what already exists. Evaluate the impact of supportive care on quality of life.

- An opportunity exists to strengthen and integrate the relationships between the patient's medical home (PMH), community services and supports, and the formal cancer system to meet the medical, emotional, spiritual, and social needs of people with cancer and their families in a comprehensive manner. Optimize integration and better coordination across sectors with the goal of better patient experience and improved outcomes, both at an individual and system level.

Background

When people develop cancer, it has a major impact on their lives. Not only is their physical health affected, but their emotional health and spiritual well-being are affected too. In addition, cancer frequently hinders other aspects of personal and family life as represented by the social determinants of health (e.g., loss of income, social isolation and inability to drive or perform household tasks). To provide holistic, person-centered care to people with cancer, all aspects of health and well-being must be considered.

Supportive care is an overarching concept that describes the health care services people with cancer and their families need beyond anti-cancer medical, surgical and

radiation interventions. It is defined as the provision of necessary services for those living with or affected by cancer to meet all their needs – physical, emotional, social, psychological, cultural, informational, spiritual and practical.[1] By providing these services, anxiety and worry are reduced, physical and social needs are met, quality of life is enhanced, and thereby clinical outcomes are improved.[2]

Research has shown that the majority of non-medical support occurs in the community, provided by family, friends and community resources (e.g., Meals on Wheels, volunteer transportation agencies). Similarly, ancillary medical support such as the management of treatment side effects, concurrent conditions or disease-related symptoms may be handled outside the formal cancer care system by primary care. Home care and community paramedics may help with both medical care and activities of daily living (e.g., bathing, mobilization, medication administration). If supported and well integrated with formal cancer care, the entirety of supports can provide the holistic, person-centered care that individuals with cancer require.

A major consideration, however, is how best to coordinate all the various services: cancer care, primary care, home care or community paramedic, volunteer services, informal caregivers and self-care. While the cancer care system can screen for and identify the needs of people undergoing treatment, it is likely neither feasible nor optimal to have the cancer care system case-manage every individual with cancer by coordinating all the above-noted sectors. This raises the question of who, or which organization, is in the best position to case-manage the complex needs of individuals with cancer.

The Patient's Medical Home model subscribed to by Alberta's Primary Care Networks, the Alberta Medical Association (AMA), and the Alberta College of Family Physicians provides an appropriate foundation to manage the holistic health needs of a person with cancer and to arrange referral to appropriate social agencies or volunteer organizations to meet social needs. Considerable work has already been done within the volunteer and not-for-profit sector, government ministries, municipalities, cancer system supports

and the business community to provide a coordinated approach to supporting Albertans with social needs.

The next sections describe in more detail supports provided by primary care, the cancer-focused volunteer and not-for-profit sector, ethnocultural organizations and the cancer system, including Cancer Care Alberta. Considering what these various groups/sectors offer is important as there may be opportunities for more optimal integration and coordination of supports for patients and families.

Primary care – Patient's Medical Home

The Patient's Medical Home (PMH) refers to a family medicine practice defined by its patients as the place where they feel most comfortable in discussing their personal and family health concerns and where all their health care needs can be addressed.[3] The underlying principle of the PMH is to have the patient's family physician be the most responsible provider and coordinator of medical care. In this role, they work collaboratively with a team of health professionals to coordinate comprehensive health care services and ensure continuity of patient care. Recently, the importance of the social determinants of health has been appreciated by primary care and efforts are underway to introduce screening for social needs. As well, primary care is in the process of introducing social prescribing.[4,5] Social prescribing encompasses screening for needs within the realm of the social determinants of health and then using community health navigators to match people with appropriate resources based on their needs. This more holistic care is in keeping with the principles of person-centered care).[6]

The PMH enables the best possible outcomes for each person, the practice population and the community being served. In the context of cancer, having a PMH allows the cancer system to focus on treatment of the cancer and its direct consequences, while the PMH can help provide the other supports needed by these people and their families. More information about the PMH in the Alberta context is available at https:acfp.ca/advocacy/patients-medical-home/.

Primary Care Networks (PCNs) are groups of family doctors who work with Alberta Health Services (AHS) and other health professionals to coordinate the delivery of primary care services for their patients. Each network has the flexibility to develop programs and provide services in a way that works locally to meet the specific needs of patients (source calgaryfamilymedicine.ca). PCNs improve Albertans' access to a health or medical home. PCNs follow a team-based health care model. Within each of Alberta's 40 PCNs, doctors and health care professionals such as nurses, mental health therapists, social workers and dietitians work collaboratively to provide integrated care for all of a patient's primary health care needs. Contact information for each of Alberta's PCNs is available at https://pcnpmo.ca/alberta-pcns/pages/list.

Many PCNs offer virtual, out-of-hours or same-day care to patients who cannot get in to see their doctor. Thus, when a person with cancer experiences an acute medical problem or side effect, this can often be addressed quickly by primary care. In addition, PCNs offer workshops and educational seminars that are designed to meet the unique needs of their communities and are available to help patients better manage their physical and mental health. An overview of programs and services offered by primary care is presented in Table 19. General information about PCNs and a tool to help Albertans find a family doctor is available at https://albertafindadoctor.ca/.

Table 19. Programs and services offered by primary care

Program/service	Description
Nutrition	• Most PCNs offer nutrition services (and/or have access to AHS Registered Dietitians (RDs) to meet the needs of patients. These may include RDs (one-on-one or group sessions), weight management and healthy lifestyle promotion.
Rehabilitation Medicine	• Many PCNs offer or can refer patients to rehabilitation medicine services which may include geriatric care, care of chronically ill patients, children's services, falls prevention programs, occupational therapy, physical therapy, recreational therapy, respiratory therapy, speech therapy, mobility specialists, pain management clinics, and coordination and linkages with AHS Home Care and non-AHS programs.
Psychosocial Care	• PCNs offer and facilitate a variety of psychosocial supports for patients. Some PCNs have social workers, behavioral health consultants and psychologists on staff.

	• Many PCNs offer psychosocial care in areas that include geriatric and youth mental health, active living, sleep programs, recreation therapy, behavioral change, immigrant and settlement services, refugee clinics, social integration, counselling, mindfulness resources, interpersonal skills, crisis management, case coordination and transition planning.
Patient Navigation	• Most PCNs have established referral processes and partnerships. • Many PCNs have referral coordinators to assist with bookings and to coordinate testing and specialist appointments. Registered nurses and nurse practitioners can assist with provision of care. • Some PCNs also offer services such as discharge planning (from acute care), multidisciplinary teams (which may include doctors, nurses, allied health professionals and pharmacists), chronic disease management, complex care, resource navigators and wellness support workers. • Many PCNs have community health navigators or other linking mechanisms to social agencies and supports. When social needs are identified, people can be linked with the appropriate supports or agencies to have these needs addressed.
Patient and Family Education	• Many PCNs offer health and education seminars for patients and families, access to nurse practitioner and social worker services, chronic disease management (CDM) programming and CDM-registered nurses, pain management education, nutrition workshops, tobacco-use-reduction programs, asthma and COPD management education, referrals to the Alberta Healthy Living Program and disease screening.
Specialty Supportive Care	• PCNs support patient navigation to specialty supportive care. While the availability of specialty supportive care programs and particular services within them varies among PCNs according to local population needs, services offered may include refugee clinics, culturally appropriate care for Indigenous patients, and limited palliative and end-of-life care.

A Home to Hospital to Home Guideline (H2H2H) was recently developed by AHS in partnership with the AMA and Alberta Health to support the transition of care for adult patients between their community and acute care and back to their community. The guideline includes confirmation of the primary care provider in acute care settings, admit notifications to primary care, transition planning, referral and access to community support, transition care planning and follow-up to primary care. This guideline is a

mechanism for better integrating primary care with acute care and addressing the needs of patients in a more coordinated way.

Cancer-focused volunteer and not-for-profit sector

There are many not-for-profit and volunteer agencies whose mandates are to provide services to people with cancer and their families. Examples of local, provincial and national organizations are described in Table 20.

Table 20. Cancer-specific programs and services offered by volunteer and not-for-profit organizations

Program/service	Description
Canadian Cancer Society (CCS)	• National organization that funds research, provides services to those living with cancer, advocates on important cancer-related issues, and educates and empowers people to make healthy choices. • Services include linking patients to community services and transportation, financial assistance, travel and accommodations, hospice palliative resources and other psychosocial supports. • In 2020, CCS had over 20M visitors to its website, with 3,000 people seeking emotional support for suspected cancer. • CCS's Advance Cancer project augments services into local areas, where patients with suspected or newly diagnosed cancer can be referred electronically for psychosocial support.
Wellspring	• Canada-wide network of community-based centres offering free cancer services to any person with any type of cancer. • In addition to in-person support, Wellspring offers an online program – Well on the Web – that provides a variety of online classes to support people with cancer and their caregivers. • There are community centres in Edmonton and Calgary (https://wellspring.ca).
Hospices	• Pilgrims Hospice (Edmonton) provides supportive and compassionate family-centered care to enhance the quality and dignity of life for those diagnosed with a progressive, life-threatening illness as well as solace to those who are bereaved (https://pilgrimshospice.com/). • Sage Centre (Hospice Calgary) provides support to people of all ages living with advanced illness as well as their family members and close friends. It assists people in staying at home as long as they are able (https://www.hospicecalgary.ca/).
Cancer Chat Canada	• Professionally-led online support group for Canadians affected by cancer. • Administered by the University Health Network; relies on donations and community sponsorship to provide services to patients (https://cancerchat.desouzainstitute.com/resources).
Canadian Cancer Survivor Network	• The Canadian Cancer Survivor Network connects patients, survivors and other stakeholder groups with decision-makers and the wider community to engage in discussion and to act on

	evidence-based best practices to alleviate the medical, emotional, financial and social costs of cancer. • The network has partners with a comprehensive list of cancer support groups that span across Canada (https://survivornet.ca/connect/partners/canadian-psychosocial-oncology-partners).

In addition to these well-established cancer-specific organizations, there are many other groups, nationally, provincially and locally, providing social supports which can be accessed by people with cancer and their families. These include transportation, food security and companionship. Complementing these volunteer services, municipalities throughout Alberta also offer many services and supports. Examples include transportation services and housing supports.

Connecting Albertans and service providers with these resources has become much easier since Spring 2020 because COVID-19 has led to enhanced coordination between agencies in Alberta. For example, the 211 helpline (https://ab.211.ca/) is the province-wide resource that enables people or providers to link with a broad spectrum of social supports, both volunteer and formal. 211 can be accessed by anyone in Alberta by phone, text or internet. It has a comprehensive provincial listing of services, both general and specific, available to particular populations. For seniors, CORE Alberta (https://corealberta.ca/) also has connections to senior-specific resources and facilitates coordination within the seniors-serving sector. Volunteer Alberta supports the Alberta Cares Connector (https://www.volunteerconnector.org/), which links agencies seeking volunteers with those willing to volunteer. Since its inception in 2020, the Alberta Cares Connector website has had over 2M visits and has matched over 30,000 people with volunteer organizations.[7]

Within the volunteer health and social services sectors, it is often thought there is a lack of resources, but this may not be the case. Over 25,000 not-for-profit, volunteer and charitable organizations exist in Alberta.[8] Thus, the issue is not so much a lack of resources, but the need for awareness and better coordination of resources.

Further, because of the efforts to coordinate volunteer activities in Alberta, most volunteer organizations are aware of people's holistic needs and are much more likely

to suggest additional connections to clients, as needed. Thus, linking people living with cancer, and their families, to social resources should be considerably easier now than it was in the past. Moreover, with coordination between the volunteer sector, municipalities, primary care and AHS, it should be easier for Albertans to have their medical, emotional, spiritual and social needs met.

Ethnocultural supports

One-third of Albertans are either immigrants or belong to a visible minority. This number is expected to rise to 50% of the Alberta population in the next 15 years. Similarly, in the future, most of the population growth in Alberta is anticipated to occur as a result of immigration.

Newcomers may have challenges in knowing which supports are available and how to access those supports; the medical system in their own country likely functions differently than in Alberta, creating difficulties in navigation. Further, people belonging to different ethnocultural groups may have different values, norms and cultural contexts of health and disease. Language and comprehension barriers can be an issue in the management of disease and related social factors or impacts. It is often a challenge to translate patient information into other languages due to sustainability and the upfront costs. In addition, without proper consideration and appreciation of cultural contexts, we may inadvertently violate norms for certain people. Our process of shared decision-making may be flawed. There may be misunderstandings on the parts of both the patient and the provider. Accordingly, awareness of ethnocultural considerations and a knowledge of ethnocultural resources will contribute to better supportive care for these Albertans.

Many individual ethnocultural organizations help support their members in terms of their social, spiritual and mental health needs. There are also larger umbrella organizations that offer an even wider array of support services. Examples of such organizations include the Mennonite Centre for Newcomers, Jewish Family Services, Catholic Social Services, ActionDignity, Immigrant Services Calgary, the Africa Centre and the Multicultural Health Brokers (Edmonton). As a consequence of COVID-19, many of

these organizations have, in a facilitated manner, banded together to coordinate and cooperate such that by accessing one organization, the entirety of a person's needs are assessed and supports provided by multiple organizations.

Cancer care in Alberta for First Nations, Inuit and Métis

Work is currently underway to enhance the capacity of Cancer Care Alberta and other partners to provide culturally safe care to Indigenous peoples living with cancer and to partner effectively with individuals experiencing cancer, their families and their communities.

Walking Together to Strengthen Indigenous Cancer Care in Alberta (June 2019 to March 2023) is an initiative that is currently focused on changing the stories of the Indigenous peoples' cancer experience in Alberta to support and result in an improved cancer journey. Some key principles have been jointly identified and are being employed to improve the outcomes and experiences of First Nations, Inuit and Métis individuals receiving cancer care in Alberta. These principles include staff engagement, working with communities and building bridges through sharing information, fostering trusting relationships, acknowledging history, and living to the principles and recommendations of UNDRIP (United Nations Declaration on the Rights of Indigenous Peoples) and the TRC (Truth and Reconciliation Commission of Canada).

The Alberta Indigenous Virtual Care Clinic (AIVCC) is a collaborative service delivery innovation that aims to increase access to culturally safe primary care for Indigenous patients and families across Alberta who do not have a primary care medical home. On October 28, 2020, AIVCC opened its doors, providing same-day primary care services to rural and urban First Nations, Métis and Inuit patients and families through a secure telephone and/or video system. AIVCC is staffed by physicians experienced in Indigenous health and cultural safety. This is a joint primary care initiative between Indigenous Services Canada (First Nations and Inuit Health Branch), First Nations Technical Services Advisory Group Inc. (TSAG) and the AHS Indigenous Wellness Program Clinical Alternative Relationship Plan (IWPcARP).

Cancer Care Alberta strives to bridge western medicine in cancer care with traditional Indigenous ways with the aid of Indigenous Cancer Patient Navigators; a service to support patients and families either as an inpatient or an outpatient. An Indigenous Cancer Patient Navigator is a registered nurse who works with and supports First Nations, Métis, and Inuit people impacted by cancer. Once connected to an Indigenous Cancer Patient Navigator a cancer patient and their family will have a partnership to support needs, concerns or questions at any point during their cancer journey.[9]

Workplace supports

Many workplaces offer supportive care services to their employees. These services can include individual counselling, rehabilitation and a variety of other social support services either contracted by the employer or included in employee benefit programs. These programs may help people with cancer and their families deal with the emotional consequences of a cancer diagnosis and treatment.

AHS (as an example) states the health, safety and well-being of its workers are essential in its ability to provide high-quality health care in Alberta. A few of the services offered through the AHS Employee and Family Assistance Program (EFAP) are listed below:

- Live Smart Coaching
- Counselling
- Homeweb
- i-Volve (Cognitive Behavioral Therapy)
- EFAP Resilience APP
- Resilience, Wellness and Mental Resource Guide

Cancer system supports – Cancer Care Alberta

Cancer Care Alberta (CCA) provides supportive care services to people with a diagnosis of cancer and who are referred to a CCA facility.

To organize and provide supportive care services, CCA adopted the tiered model of supportive care developed by Margaret Fitch.[1] The Fitch model was informed by

scholarly evidence; clinical expertise; and patient values, needs and preferences. The review of literature used standardized methodology seeking the highest level of evidence available in the areas of supportive care research to inform an understanding of where the greatest impacts from supportive care may be realized. Widespread consultations were conducted with experts to create CCA's Supportive Care Framework.[10] The Supportive Care Strategic Plan (2019–2022) identifies three key strategic priorities: (1) building capacity for care closer to home; (2) implementing sustainable, innovative and person-centered models of care; and (3) increasing awareness of and access to CCA's supportive care services.

CCA offers a range of programs and services to individuals living in Alberta who have had a cancer diagnosis or have cancer-related concerns. These are listed with a brief description in Table 21. A full description of these programs, services, disciplines and roles can be found in Appendix A of the Supportive Care Framework Report CCA 2016 and Appendix B Guideline Summary, Supportive Care, CancerCare Alberta, 2021. Further information is available on the CCA Supportive Care webpage.

Table 21. Cancer Care Alberta programs and services

Program/service	Description
Rehabilitation Medicine Cancer rehabilitation services provide therapeutic interventions to assist patients and families in preventing or mitigating the physical and psychosocial impact of impairments and functional limitations resulting from cancer or its treatment.	• Provided by physiotherapy, occupational therapy and speech language pathology.
Psychosocial Oncology Psychosocial oncology involves a whole-person approach to cancer care and addresses a range of human needs that can improve or optimize the best possible quality of life for individuals and their families affected by cancer.	• Provided by a variety of professionals within psychosocial oncology including social workers, psychologists, psychiatrists and spiritual care specialists. • Provides support for the social, psychological, emotional, spiritual and functional (practical and rehabilitative) needs throughout the disease trajectory. • Deals with the understanding and treatment of the social, psychological, emotional, spiritual and functional (practical and rehabilitative) aspects of cancer. • A variety of professionals are involved in psychosocial oncology including social workers, psychologists, psychiatrists, spiritual care specialists and drug access coordinators.
Specialized Supportive Care Services Specialized supportive care programs serve particular groups of patients diagnosed with cancer who share unique and complex care needs that cross-tumor groups and disease types.	• Sexual health consultants and other disciplines provide specialized education and counselling services to individual patients and couples – OASIS (Oncology and Sexuality, Intimacy and Survivorship program). • Indigenous Cancer Patient Navigator Program is provided by a specialized oncology registered nurse who offers support, liaison and care coordination to Indigenous peoples in Alberta. • Adolescent and Young Adult (AYA) Oncology Program is cancer care and research focused to meet the needs of young people diagnosed with cancer (18–39 years old). The AYA Patient Navigator Program is offered by a specialized oncology registered nurse. • Specialized navigator roles are funded by the Alberta Cancer Foundation.
Cancer Patient Navigation Patient navigation refers to the process of collaborating with patients and their families to provide	• Patient navigators are registered nurses with oncology expertise who work in collaboration with community resources, acute care services,

	clinical staff, social workers and other allied health providers.
guidance as they transition into the cancer system, through the cancer system and beyond.	• The Cancer Patient Navigation program has generalist cancer patient navigators at the four regional cancer centres and community cancer centres except for the Peace River Community Cancer Centre.
Patient and Family Education Cancer patient and family education is a program aimed at empowering patients and families dealing with cancer with the knowledge and information they need to be full partners in their care.	• A team of patient education specialists works with patient and family advisors and content experts to develop resources and supports. • Classes, workshops and other teaching sessions are delivered in multiple modalities including in-person, by telehealth and via a website.

Collaborative Services	
Nutrition Cancer nutrition services are provided by registered dietitians who report through the AHS Nutrition Services portfolio and are assigned to various CCA sites. Oncology-registered dietitians provide nutritional support to patients diagnosed with cancer.	• Offered at the tertiary cancer centres and regional cancer centres, except the Grande Prairie Cancer Centre.

Although CCA provides a range of high-quality, supportive care, patients can only access these resources once they have a confirmed diagnosis and they have concerns related to their cancer or the side effects of treatment.[11-13] Even then, the average wait time for these services from the point of routine referral can be a couple of months depending on site, service, patient needs and patient preference. We know from research done in Alberta and elsewhere in Canada that waiting for a cancer diagnosis is a time of great distress for patients and families, and there can be a lack of awareness of the range of service offerings and how to access them by not only patients, but also providers.

Cancer research and supportive care

Research is an important component that underpins ongoing improvements in the area of supportive care for people living with cancer.

Some research findings have become translated into standards of care. For example, previous research in the area of screening for distress has resulted in the development of a provincially endorsed and standardized operating process (SOP) that uses the Putting Patients First (PPF) form as part of a standard of care ([Putting Patients First FAQ (albertahealthservices.ca)](#)). The SOP aligns with the principles of person-centered care where the term "person" also includes families and highlights the individual approach that is required to get to know the individual receiving care as a person, not just as a patient or a family member.

There are many other areas of research in the supporting care realm. Some examples include sexual health; geriatric oncology (assessment and management of age-related concerns in cancer care) integrative oncology (eg: mindfulness-based approaches such as acupuncture, complementary therapies; nutrition and body composition);[14-16] support groups and group therapy programs;[17] and exercise programming (eg: Alberta Cancer Exercise Program (ACE),[18] Alberta Moving Beyond Breast Cancer (AMBER),[19] Alberta Physical Activity and Breast Cancer Prevention (ALPHA) Trial,[20] and Reducing the Burden of Breast Cancer in Young Women (Ruby).[21]

Conclusions and recommendations

The annual number of new cancer cases in Alberta is projected to increase significantly, from 21,615 in 2020 to 33,773 in 2040. According to Garvey et al. (2020),[22] there is increasing evidence of the value of augmenting and enhancing supportive care for improving outcomes and experiences for people with cancer. As noted by the Institute of Medicine as far back as 2008, "Today it is not possible to deliver high-quality cancer care without using existing approaches, tools, and resources to address patients' psychosocial health needs. All patients with cancer and their families should expect and receive cancer care that ensures the provision of appropriate psychosocial health services."[23]

The Supportive Care Framework[1] highlights that 45%–55% of people with cancer require support beyond introductory coping strategies, classes and supportive information. In fact, research has shown that outside of formalized health care provider

systems, patients rely heavily on informal support care networks such as family, friends and community organizations.[24] This chapter has highlighted a wide spectrum of psychosocial supports with most of these resources being not-for-profit groups that aim to help patients, families and caregivers deal with psychosocial challenges and social determinants associated with chronic disease, including cancer.

Alberta has a well-advanced PMH model where care and support is coordinated through multidisciplinary teams within a PCN. That said, it is still a challenge for primary care providers to be aware of all the other services that can be accessed outside the PCN. As well, helping patients and their families effectively navigate this complex system and become connected when needs arise is difficult. There is a clear need for more research to understand how best to address these issues, with the goal of helping patients and families to take full advantage of all the supports that meet medical, emotional, spiritual and social needs, thereby resulting in better outcomes.

Alberta's extensive network of services and supports includes the volunteer sector, municipal supports, primary care and AHS. Therefore, the need for supports in cancer is less about building more, but rather better leveraging what already exists. There is also a need for research and innovation to support the development of mechanisms to evaluate the impact that addressing psychosocial factors has on cancer care and survivorship, as well as ways to mobilize promising social interventions into routine care.

Also of note are the supportive care needs patients have as they await a cancer diagnosis. We know from research done in Alberta and other jurisdictions that waiting for a cancer diagnosis is a time of great distress for patients and families. There is no jurisdiction in Canada that offers a streamlined or equitable service that connects patients with supportive care, including psychosocial support or counselling, during the pre-diagnosis phase.

An opportunity exists to strengthen and integrate the relationships between the PMH, community services and supports, and the formal cancer system to meet the medical, emotional, spiritual and social needs of people with cancer and their families in a

comprehensive manner. Alberta can capitalize on its many assets – its people and its infrastructure – to ensure that a comprehensive cancer support system evolves and is sustained. There is urgency in doing this as we anticipate a steady increase in cancer incidence, in numbers of people living longer with cancer, and in survivorship. Further coordination and collaboration of services across sectors will lead to a better patient experience and improved outcomes, both at an individual and system level. This will enable Alberta to effectively support its citizens with cancer, and their families, well into the future.

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Chapter 10: Palliative & end-of-life care

Key findings

- In Alberta, cancer-related and neoplasm-related deaths accounted for approximately 85% of palliative care services. Yet 60% of patients with metastatic gastrointestinal cancers had late (within two months of death) or no palliative care referral.

Recommendations

- In addition to the Alberta Health palliative review, Alberta Health and AHS have prioritized a redesign and evolution of home care to improve quality and access to care for all Albertans. Both of these reviews will inform the work to be done ahead to continue to improve quality access to palliative and end-of-life care (PEOLC). Conduct further research and quality improvement projects to enhance access to quality PEOLC services for people with cancer and non-cancer diagnoses across the province.

- Have research informed by patients, families, and practitioners at a community level, and supported by an enhanced capacity to access, use, and interpret data on service provision and patient needs including those of vulnerable populations.

Background

Palliative and end-of-life care (PEOLC) is a crucial component of improving the quality of life for people living with serious illness. This includes but is not limited to people living with advanced cancer. As a result, this chapter is not cancer specific and rather provides an overview of PEOLC over the past six years in Alberta. It highlights accomplishments that have been made, summarizes a recent current state analysis, and describes the plan for work to be done in the future.

According to the 2021 Report on Cancer Statistics in Alberta, 1 in 2 Albertans will develop cancer in their lifetime and 1 in 4 will die from cancer.[1] The number of new cancer cases in Alberta is expected to increase steadily to about 33,773 in 2040; this is mainly due to the increases in the age and size of Alberta's population. In addition to the predicted increase in cancer diagnoses, data also indicates that non-cancer-related

rates of chronic illness are also increasing.[2] This suggests a need to plan for increased services and providers for PEOLC over time.

There is increasing recognition that the philosophy and principles of PEOLC need to be imbedded into the management of all life-limiting diseases, including but not limited to chronic disease, frailty and cancer illness trajectories.[3] Early access to palliative care is highly effective at reducing emergency department visits and intensive care stays at the end of life.[4,5] In addition, other important outcomes are associated with the palliative approach to care, including but not limited to better quality of life and symptom management.

In Canada, people with cancer diagnoses were three times more likely than patients with non-cancer PEOLC diagnoses to receive palliative care in the last year of their life.[4] In Alberta, cancer-related and neoplasm-related deaths accounted for approximately 85% of palliative care services.[6] However, there is a significant portion of advanced cancer patients in Alberta who do not receive early access to PEOLC services. In Alberta, 60% of patients with metastatic gastrointestinal cancers had late (within two months of death) or no palliative care referral.[7,8] There is a need for more up-to-date estimates of PEOLC referrals and access to services for both patients with cancer and patients with non-cancer diagnoses.

Survey results from key stakeholders such as the Canadian Institutes of Health Research and the Canadian Hospice Palliative Care Association (CHPCA) indicate that the majority of Canadians want to die at home.[4] Despite this, acute care has the largest percentage of deaths per care setting in Alberta. However, between 2010 and 2020, the proportion of Albertans dying in acute care has decreased by 6.3%.[9] This decrease could in part be due to the increasing proportion of Albertans who are supported in dying at home because of the implementation of the Enhancing Care in the Community programs. Some of these programs include, but are not limited to, EMS PEOLC Assess, Treat and Refer (ATR), the 24/7 Palliative Physician On-Call Program and the Rural Palliative Care In-Home Funding Program (described later).

Heightened support for and awareness of programs like palliative home care can increase the proportion of people who are able to stay in their community as they approach end of life. A 2018 Canadian Institute for Health Information report indicated that people who received palliative home care in their last year of life were 2.5 times more likely to die at home than other home care clients. A 2013 study completed by CHPCA found that 75% of Canadians have a preference to die in their home. However, many patients and families prefer death in a hospice setting when faced with the realities of dying.[10] Having a diverse variety of PEOLC supports and services has benefits to the health system, patients and families, and ultimately supports the patient's preferences around the type of care they would like to receive and where they would like to receive it.

Provincially, nationally and internationally, extensive research continues to occur to address challenges and advance knowledge in various areas related to PEOLC. Some of this work is cancer specific, while other research has taken a more holistic approach that focuses on the overall advancement of the palliative approach to care for anyone living with a serious illness. This work will be discussed in more detail later in this chapter.

Foundational definitions

When developing the Palliative and End-of-Life Care Alberta Provincial Framework[3] and the Palliative and End-of-Life Care Alberta Provincial Framework Addendum,[11] the Provincial Palliative and End-of-Life Innovations Steering Committee (PPAL/EOL ISC) agreed on foundational PEOLC definitions for Alberta. Four of these core definitions were selected to be included in this chapter (Figure 32).

Palliative and end-of-life care is defined as a continuum of care from the time of diagnosis of a life-limiting illness through to the time of death and into bereavement. It demonstrates that a palliative approach to care can occur simultaneously with a curative approach or during treatment.

The palliative approach* to care focuses on the person and family, and their quality of life throughout the illness trajectory, in advance of and not just at the end-of-life. A palliative approach to care can occur simultaneously with disease-directed treatment
This includes supporting and managing:
- illness comprehension and coping
- symptoms and functional status
- advance care planning and the patient's preferred method of decision making
- coordination of care
- support for family/caregivers

Palliative care aims to improve the quality of life for patients and families facing the problems associated with a life-limiting illness through the prevention and relief of suffering by means of early identification, comprehensive interdisciplinary assessments, and appropriate interventions.

End-of-life-care is care provided to patients and their families when they are approaching a period of time closer to death, which may be exemplified by an intensification of inter-disciplinary services and assessments such as anticipatory grief support, and pain and symptom management.

*The revised definition of the palliative approach is adapted from the Canadian Hospice Palliative Care Association 2013; Pereira 2008; and Cancer Care Alberta 2018.

Figure 32. Foundational definitions
Definitions from the palliative and end-of-life care Alberta Provincial Framework (pg. 10)[3] and the Palliative And End-Of-Life Care Alberta Provincial Framework Addendum (pg. 10).[11]

Palliative and end-of-life care delivery in Alberta

AHS has an integrated approach to PEOLC that is delivered across Alberta in five geographically defined administrative zones: North, Edmonton, Central, Calgary and South (Figure 33). Calgary and Edmonton are the two main urban centres, and the North, Central and South zones are described as "rural" in nature. There are both stand-alone hospices and embedded hospice beds within supportive living and long-term care facilities across Alberta, with the embedded model becoming more popular. This is partly related to embedded models being more financially viable and cost effective because the operating costs of housekeeping, food services, security and building maintenance are a shared responsibility. The embedded model is part of an integrated approach to capacity

Figure 33. Alberta Health Services zone map

Retrieved from:
https://www.albertahealthservices.ca/assets/about/publications/ahs-ar-2020/zones.html

planning, which encompasses three streams of care: palliative home care, hospice- and community-supported PEOLC beds, and acute care PEOLC designated beds. This approach allows for flexibility and differences in local contexts and geography.

The urban areas of the Calgary and Edmonton zones have access to specialized palliative home care, whereby home care nurses are dedicated solely to the care of PEOLC patients. In suburban and rural areas, a blended model is in place where home care nurses care for both PEOLC patients and non-PEOLC patients; this service is referred to as integrated home care. The Calgary and Edmonton zones have well-integrated and comprehensive PEOLC programs and services including tertiary

palliative care units, which provide interdisciplinary, specialized care to PEOLC patients who require complex symptom management. In addition, the Cross Cancer Institute in the Edmonton zone and the Tom Baker Cancer Centre in the Calgary zone both have cancer pain and symptom teams. Both zones have strong partnerships with community organizations to better address the needs of patients with diverse needs, including people experiencing homelessness and people from Indigenous communities.

Communities in the North, Central and South zones have integrated home care, except for Red Deer and Sylvan Lake, which have specialized palliative home care. Since 2014, these zones have increased interdisciplinary team members, embedded pain and symptom clinics within cancer centres and established a tertiary palliative care unit in Red Deer Hospital. Front-line staff in the Central and South zones have access to specialized palliative care consultation support within their zones. The North zone established a formal palliative care program in 2018, which allowed for more integrated and comprehensive PEOLC services. This is evidenced by an increase in specialized interdisciplinary staff to meet the needs of PEOLC patients in the community.

The Alberta Children's Hospital in Calgary and the Calgary zone pediatric PEOLC program provide support to the Central and South zones. The Stollery Children's Hospital in Edmonton and the Edmonton zone pediatric PEOLC program provide support to the North zone and some parts of the Central zone. The Rotary Flames House in Calgary is the only pediatric stand-alone hospice in Alberta. It has seven beds and provides symptom management, end-of-life care and respite care. Currently, palliative care pediatric patients are supported by the home care teams serving the overall pediatric population. Unlike adult palliative care programs, where the majority of referrals are for patients with advanced cancer, only 22% of pediatric palliative care patients have a diagnosis of cancer.[12] However, referral patterns among various centres in Canada are highly diverse. As of March 16, 2020, there has been a reorganization in AHS and instead of a North–South sector model for pediatrics, there will be a focus on zone operations.

Provincial PEOLC strategic partnerships

The AHS Provincial PEOLC team and the Covenant Health Palliative Institute have a collaborative partnership. Their work is instrumental in advancing PEOLC and advance care planning (ACP) across Alberta and Canada. Under the auspices of the PPAL/EOL ISC, the Palliative Institute led the development of the interdisciplinary PEOLC competencies work. As described in the resulting document:

"15 discipline-specific competency frameworks [were developed] to provide a reference and opportunity for front line clinical staff and volunteers to engage in self-assessment of knowledge, skills, behaviors and attitudes toward palliative care and when caring for a person with a life-limiting illness and their family. These documents can furthermore be used to inform and guide academic curricula, professional development, professional regulatory bodies, continuing education programs and employers."[13]

Along with PPAL/EOL ISC, the zone PEOLC operational dyad group is made up of provincial PEOLC, zone PEOLC operational leadership, pediatric programs and the Palliative Institute. This group meets on a regular basis to share learnings and resources specific to operations and was instrumental in preparing a PEOLC response to COVID-19, advocating for end-of-life visitation and creating ACP goals of care designation (GCD) documents specific to COVID-19.[14]

Cancer Care Alberta and the Provincial PEOLC team also have a collaborative working relationship. There is cross-representation on each other's committees, with connections to the senior provincial director of the Cancer SCN who is also one of the co-chairs of PPAL/EOL ISC. In addition, both groups provide feedback on each other's PEOLC strategies. Figure 34 provides a high-level overview of the partners involved in PEOLC in Alberta.

Partnerships are instrumental in advancing PEOLC and advance care planning (ACP) across Alberta and Canada.

STRATEGIC CLINICAL NETWORKS

AHS PROVINCIAL PEOLC TEAM

COMMUNITY PARTNERS

ALBERTA HEALTH

ALBERTA HOSPICE PALLIATIVE CARE ASSOCIATION

ALBERTA HEALTH SERVICES AND CONTRACT PROVIDERS

UNIVERSITIES IN ALBERTA

PATIENT AND FAMILY

PRIMARY CARE NETWORKS

COVENANT HEALTH PALLIATIVE INSTITUTE

COLLECTIVE BENEFITS

MEETING PATIENT'S NEEDS FASTER

QUALITY PEOLC FOR PATIENT AND FAMILY

AWARENESS AND INFORMATION

SHARED RESOURCES

PLANNING AHEAD TOGETHER

SUSTAINABLE PROGRAMS AND PRACTICES

Adapted from an original infographic within PSH &CC; retrieved from Partnerships in Palliative and End-of-Life Care in Alberta infographic (AHS)

Figure 344. The benefits of partnerships in PEOLC in Alberta
Section retrieved from Partnerships in Palliative and End-of-Life Care in Alberta infographic (AHS)

Overview of palliative and end-of-life care in Alberta

The PEOLC Alberta Provincial Framework[3]

In 2014, the Palliative and End-of-Life Care Alberta Provincial Framework[3] and its patient and family companion document[15] were published by AHS to identify and coordinate activities to fill gaps in PEOLC programs and services in Alberta, and to improve the quality of existing PEOLC programs and services. The framework recommended 36 initiatives to help fill these gaps and to enhance the quality of PEOLC in Alberta. To date, 21 of these initiatives have been completed under the guidance of the PPAL/EOL ISC. These initiatives are discussed in more detail in the next section of this report.

The PPAL/EOL ISC is an advisory committee that has multifaceted representation including, but not limited to, patients and families, primary care providers, interdisciplinary PEOLC operational leaders, provincial PEOLC from seniors health and continuing care, Indigenous representatives, Cancer Care Alberta and SCNs. The goal of the PPAL/EOL ISC is to oversee the development and implementation of high-performing, publicly funded PEOLC programs in Canada under the guidance of the PEOLC Alberta Provincial Framework.

The framework outlined provincial standards to facilitate exceptional services and introduced innovative program solutions with the goal of achieving a level of high-quality service that provides equity, choice, dignity and care supports for patients and their families, clinicians and care providers, all within a person-centered model.

The framework was developed through an academic process with an internationally recognized rapid systematic literature review and examination of the current state in Alberta in 2014.

This current state analysis of PEOLC in Alberta was determined using the following three methodologies:

1. A systematic comprehensive literature review which focused on local, national and international PEOLC programs, services and practices;

2. Consultation and engagement through qualitative analysis using questionnaires and surveys to gather information about existing programs and services; and

3. Data mining and analysis to identify trends, gaps and variations in PEOLC across the province.

Publications identified within the rapid systematic literature review were categorized into three levels (as described in Appendix E of the PEOLC Alberta Provincial Framework): Level I – international or federal (national) level; Level II – province (Canada), territory (Canada, Australia and New Zealand), state (US, Australia) and country (UK: England, Wales, Scotland and Northern Ireland); Level III – lower administrative level; NR – not reported.

The development of the PEOLC Alberta Provincial Framework document was a joint collaboration between the Cancer SCN, the Provincial Seniors Health and Continuing Care program, the division of PEOLC in seniors health, and primary and community care.[3] The work was guided by a provincial PEOLC steering committee consisting of experts in PEOLC across the province. Additionally, patient and family representatives were consulted and provided feedback for this document through specific focus groups and advisory committee engagements, which clearly identified the need for a more public-facing companion document.

PEOLC – a health technology assessment (HTA) report[16]

In addition to implementing the framework initiatives, a need was identified by the PPAL/EOL ISC for information on leading practices to support additional improvements in PEOLC in Alberta. As a result, the PPAL/EOL ISC commissioned the Health Technology Assessment Unit at the University of Calgary and the Health Technology and Policy Unit at the University of Alberta to write a report that provided a comprehensive overview of what was needed for innovative PEOLC programs and services.[16] This work was funded by Alberta Health (Government of Alberta) through the former Alberta Health Technologies Decision Process. This process has since transitioned to the Health Evidence Review process.[17]

The HTA report aimed to answer the following policy question: *What is the most appropriate model to enable equitable access to PEOLC in Alberta whereby the model of care includes elements of appropriate population, care, time, place, provider and cost for PEOLC services across remote, rural and urban sectors, and any variation between zones is informed by evidence? (pg. 31)*

This report utilized two methods:

1. Assessment of the current context of PEOLC in Alberta and synthesis of evidence in the published literature on the required and effective components of PEOLC. This was achieved through completing a review of the current context of PEOLC in Alberta, focus groups with patients and families, and multiple systematic reviews (pg. 4).
2. Creation of an inventory of the ways in which jurisdictions across Canada approach the essential and core elements of palliative care. This inventory was created by surveying people across Canada who were involved in the delivery of PEOLC in a variety of jurisdictions (pg. 4).

This report framed the essential elements of high-quality PEOLC with 14 quality statements. More details on the quality statements can be found by accessing the HTA report.

The PEOLC Alberta Provincial Framework Addendum[11]

In response to the quality statements identified in the HTA report, the remaining outstanding framework initiatives, and the additional current existing gaps and challenges identified by the five geographic zones in Alberta, the PPAL/EOL ISC requested that an addendum to the framework be completed as a refresh after six years. The addendum summarizes where we were and where we are now, and it describes the plan moving forward to refocus and reframe the work that needs to be completed in the years ahead.

The methodology used for the development of the addendum comprised multiple activities. In 2019, the PPAL/EOL ISC examined the gaps identified in the HTA quality

statements and outstanding framework initiatives and categorized them into six themes, which were then prioritized to be addressed if and as resources became available.[11]

The next step included a current state analysis of PEOLC programs and services, as well as gaps and challenges within the zones. This was accomplished through individual meetings between the provincial PEOLC team and each zone, as well as the Covenant Health Palliative Institute and pediatrics. The current state analysis was validated by the zones and programs to inform a high-level summary which can be found on page 4 of the addendum. Further, the zones validated their current gaps and challenges, which were classified into five categories and detailed how they related to the corresponding prioritized themes. As part of the current state analysis, other programming and service gaps and challenges were identified. These recognized the need to increase access to early palliative care and improved symptom control for patients with advanced cancer. In addition, there is a desire to optimize the referrals to pain and symptom clinics embedded within cancer centres.[11]

Completed initiatives in Alberta

Framework initiatives

Alberta has been recognized nationally as a leader in providing an integrated and innovative range of PEOLC programs and services. For example, as outlined in the addendum, the EMS PEOLC Assess, Treat and Refer (ATR) program received both the Canadian Foundation for Healthcare Improvement Innovation Award in Palliative and End-of-Life Care and the Health Quality Council of Alberta Patient Experience Award in 2017. All of the initiatives aim to benefit patients with cancer and non-cancer PEOLC diagnoses.

The following is a summary of the PEOLC Alberta Provincial Framework initiatives that have been completed to date. More information can be found by following the hyperlinks and by visiting the provincial PEOLC website.

- [24/7 Palliative Care Physician On-Call Service](#) to support physicians province-wide who are caring for PEOLC pediatric and adult patients.

- [Provincial PEOLC website](#) as a centralized access point for PEOLC information and resources, inclusive of finding services for patients, families and health care providers.
- [Provincial EMS PEOLC ATR Program](#) to enhance care in the community. The intent of the program is to respond to palliative patients in symptom crisis at home, where they would previously have been calling 9-1-1 for transfer to a hospital. This work is sustained and improved by champions who are part of the Provincial EMS PEOLC ATR Community of Practice.
- Provincially available bereavement program inclusive of a [bereavement package, the White Rose Program and a bereavement directory.](#)
- Provincially available volunteer resource training and facilitator PEOLC manuals, by contacting palliative.care@ahs.ca
- [A Resource Guide for Community Development of PEOLC within Alberta.](#)
- Integrated capacity planning and forecasting model.
- [Patient's Death in the Home Setting Guideline](#), which provides direction for home care providers on how to prepare for and/or approach an expected or unexpected death of a home care patient (in a private home or seniors' lodge).
- Provincial Rural PEOLC In-Home Funding Program, which allows families to access additional patient care within their own community when all other AHS resources have been exhausted.
- [Interdisciplinary PEOLC competencies](#) led by the Covenant Health Palliative Institute that are published and available on their webpage. These competencies are a resource that can be used by front-line clinical staff and volunteers to engage in self-assessment of knowledge, skills, behaviors and attitudes towards PEOLC. This includes a specific section on cultural safety in all 15 discipline-specific competency frameworks.
- Provincially required ACP/GCD [Policy](#) and [Procedure](#) for health care professionals as well as resources and a central [website for both the public and health care professionals.](#)
- Internal AHS ACP/GCD dashboards which have been published using evaluation data to make recommendations for improvement.
- Provincial ACP/GCD Community of Practice made up of champions that sustains and improves ACP/GCD work across the province.
- [Clinical knowledge topics](#) (palliative sedation, ACP/GCD, care of the imminently dying).
- Accreditation Canada Survey 2018.
- Provincial PEOLC policy to meet Continuing Care Health Service Standards.
- Participation in discussions with other provinces and CPAC regarding competency work and advocating for national competencies.

- Identified and established connections with other person-centered initiatives in the province by developing resources such as PEOLC infographics and using agreed-upon common language for terms such as palliative end-of-life care. This information can be accessed by contacting palliative.care@ahs.ca
- PPAL/EOL ISC–endorsed PEOLC indicators and internal AHS provincial dashboards, which are accessible upon permission from the provincial seniors health and continuing care leadership.

Activities external to the PEOLC Alberta Provincial Framework

Innovative projects and programs continue today that aim to improve early access to PEOLC across the province. This chapter aims to highlight some of the key work that is occurring; however, this is not a comprehensive overview.

One of these research initiatives is the Palliative Care Early and Systematic (PaCES) Project co-led by Drs. Ayn Sinnarajah, Jessica Simon, Patricia Tang, Mark Kerba, Sharon Watanabe and Amy Tan, and funded by the Canadian Institutes of Health Research (CIHR), Alberta Health and the M.S.I. Foundation.[18] PaCES aims to improve the quality of life for Albertans with advanced cancer by delivering early and systematic palliative care. A clinical practice guideline on Integrating an Early Palliative Approach into Advanced Colorectal Cancer Care has been published, and the accompanying pathway piloted in Calgary.[8] Work is in progress to extend this initiative to people with other types of cancer across the province.

A new project being developed is the Cancer Care Alberta Palliative Care Strategy, which focuses on the care of people with cancer with palliative care needs within the broader AHS context. Cancer Care Alberta (CCA) palliative care supports are delivered in various ways to people with cancer across the zones in Alberta. With a growing body of evidence recommending integration of an early palliative approach to care, combined with increasing cancer incidence and longer life expectancies for people with chronic or incurable cancers, there are potentially many more patients who could benefit from palliative care supports at a primary, secondary or tertiary level. The major focus of the CCA Palliative Care Strategy will be to determine the role of CCA within the broader PEOLC framework. In particular, it will describe the needs of the cancer palliative care

population within Alberta, define CCA's core work of the specialist palliative care team and the general palliative care approach for CCA staff and physicians, identify shared care pathways for patients within the zones, and refresh the CCA palliative care model of care and strategic direction.

Another program that aims to improve early access to palliative care is the Integrated Supportive Care Pathway, One:carepath, co-led by Dr. Sara Davison and Dr. Brad Bahler, with the support of Alberta's SCNs, primary care and community partners, and co-funded by the Canadian Institutes of Health Research, Alberta Health Services and Alberta Innovates.[19] One:carepath is an interactive digital decision-support tool with parallel arms for health care providers and patients and their families. This provincial initiative will support care planning in primary care for people who have non-curative lung, heart, liver and kidney disease and/or cancers. The goals of this program are to (1) standardize processes and tools to optimize symptom and crisis management for patients in their medical home; (2) help patients maintain quality of life and functional status, avoid aggressive treatments, where appropriate, and align care with patient preferences and values; and (3) support physicians to identify when patients are transitioning from disease-modifying therapy to a more exclusive palliative care plan as disease progresses.

The Covenant Health Palliative Institute works in collaboration and partnership with the PPAL/EOL ISC and is a key stakeholder in provincial and national PEOLC work. This includes, but is not limited to, advancing PEOLC research on important topics such as evaluating the timing of referral to palliative care consultations for patients with advanced cancer, as well as public engagement and communication regarding advance care planning, and the recently published Interdisciplinary PEOLC Competencies. This work is led by the director and scientific director of the Covenant Health Palliative Institute.

Advance care planning

Advance care planning and goals of care designation (ACP/GCD) is a provincial [policy](#) and [procedure](#)that is required in all settings of care across Alberta. This program

replaced the "resuscitate" *versus* "do not resuscitate" dichotomy that existed in the past and is intended to allow patients to identify their preferences for care, including resuscitation, if they should be in a position where they cannot speak for themselves. To support these challenging conversations, the [Conversations Matter](#) guidebook was developed by AHS and recently updated in eight languages. Further information on ACP for patients, families and health care providers can be found on the [provincial ACP website](#) or on the AHS app, which has a quick reference for ACP planning resources and the recently revised ACP/GCD e-learning module. There is an ACP/GCD Community of Practice comprised of champions across the province to advocate and sustain best practice for ACP/GCD for Albertans.

The [ACP Collaborative Research and Innovation Opportunities](#) (CRIO) program has also completed significant work to advance ACP in Alberta. This work was led by Dr. Neil Hagen, Dr. Jessica Simon and Dr. Konrad Fassbender. ACP CRIO examined the impact that increasing ACP would have on health resource utilization and clinical outcomes. Through this work, nine ACP indicators were identified and validated. These indicators were used as metrics in the last AHS evaluation and built into the provincial ACP/GCD dashboard.

Other projects continue to arise with the goal of promoting ACP for Albertans. An example of this is ACP Alberta, which is a new provincial initiative led by the Palliative Institute. Using the findings from ACP CRIO, ACP Alberta aims to "further integrate ACP into Albertans' lives through collaborative partnerships across multiple sectors including law, financial planning, banking, and insurance."[14] This work is being completed under the auspices of Alberta Health and the Alberta Justice and Solicitor General and is funded by an Alberta Health grant.

Gaps in care and future directions

This section of the chapter provides a high-level overview of the gaps and recommendations to advance PEOLC in Alberta. For more detailed information please refer to the PEOLC Alberta Provincial Framework Addendum.[11]

Gaps in care

The addendum refreshes and refocuses the work to be done ahead. In addition to addressing the gaps and challenges identified by the zones, the PPAL/EOL ISC identified further work that needs to be done with respect to any outstanding framework initiatives and HTA quality statements. The PPAL/EOL ISC categorized this work into six key themes, which are reflected in priority order within the addendum as follows (pg. 6):

1. Education
2. Programs and Services
3. Awareness and Engagement
4. Resources for Care
5. Advance Care Planning/Goals of Care Designation
6. Policy, Procedure and Guidelines

Note: Themes three and four are considered equal priority.

As part of the awareness and engagement theme, the addendum identified the need to develop direct links with primary care networks and family care clinics within local communities and partner with provincial stakeholders, building strong relationships with those who can support the provision of PEOLC in local communities.[11]

Future directions

The timing of the addendum being published aligns with the current Alberta Health palliative review. A report from that review with recommendations to support and enhance PEOLC in Alberta will be forthcoming.

In addition to the palliative review, Alberta Health and AHS have prioritized a redesign and evolution of home care to improve quality and access to care for all Albertans. Both of these reviews will inform the work to be done ahead to continue to improve quality access to PEOLC across the province.

The impact of activities such as Alberta Health's palliative review will need to be considered by the PPAL/EOL ISC when it prioritizes the work for the fiscal year ahead.

Work is divided into five core categories: "givens" (work that must be done); ongoing; participation in other local and provincial work; initiatives on hold; and external initiatives that may have an impact on the PPAL/EOL ISC's work.

One of the "givens" for the provincial PEOLC work plan for 2021/22 is the continued PEOLC response to COVID-19. Another "given" is the continued rollout of Connect Care, which is a provincial clinical information system. Connect Care will enhance a person-centered approach, as patients and families will be able to upload their ACP documents into the patient portal. Patients will also be able to complete symptom assessments electronically in advance of clinic visits. Further, Connect Care has the potential to create stronger linkages between care settings, which will promote continuity of care and system navigation.

Conclusions and recommendations

The PPAL/EOL ISC has been instrumental in guiding the implementation of the initiatives recommended in the framework to date. It has also developed the addendum, which recommends the work needing to be completed in the future. The PPAL/EOL ISC will continue to prioritize annual and long-term activities to enhance quality of and access to PEOLC for patients and families, as well as support health care providers across the province.

System supports and funding are needed to implement the further work recommended in the addendum.

Future research priorities and areas of work

In addition to the work recommended in the addendum, further research and quality improvement projects are needed to enhance access to quality PEOLC services for people with cancer and non-cancer diagnoses across the province. This research should include community-engaged knowledge translation, be informed by patients, families and practitioners at a community level , and be supported by an enhanced capacity to access, use and interpret data on service provision and patient needs including those of vulnerable populations.

The research priorities and areas of work identified in this report for future investment include, but are not limited to:

- Access and timing of referrals to PEOLC services

- Supports for in-home deaths

- More up-to-date estimates of PEOLC referrals and access to services for both patients with cancer and non-cancer diagnoses

- Determining best practices for public education and engagement with Connect Care's patient portal

- Cultural sensitivity training

- Understanding and addressing the intersectional impact of the social determinants of health on targeted PEOLC needs of vulnerable populations

- Public and health care professional engagement with advance care planning

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III.   Cancer in context

Almost half of all Albertans are expected to be diagnosed with cancer, which is the leading cause of death in Alberta, accounting for 26% (6,780) of all deaths in 2019. Therefore, cancer has an enormous impact on the health care system in Alberta. Understanding the ways in which people with cancer can be cared for and how their needs vary based on geography, socio-economic status, sex, gender, age, race, ethnicity and culture is crucial in providing the best cancer care to Albertans. In this section, we provide an overview of the various models of cancer care available in Alberta, equality in cancer care, and cancer screening and prevention practices.

Summary of evidence needs and research gaps

Throughout this report, we have highlighted the impact that cancer has on the Alberta population. Cancer impacts all populations and communities in Alberta, and although the population-level cancer outcomes are generally positive compared to other parts of Canada and the world in terms of incidence, mortality and survival, these metrics are likely to vary across socio-economic status, as well as racial, ethnic and under-represented population groups. In addition, inequalities in terms of access to care are a challenge in Alberta. In particular, more research is needed to improve cancer outcomes and access to resources for those with low socio-economic status, people with mental health conditions, as well as Indigenous populations, racialized groups, new immigrants, sexual and gender minority groups, and those of varying age groups.

To better understand the inequalities in cancer outcomes and access to resources, comprehensive systematically collected data are needed. Currently, information on race, ethnicity, socio-economic status, sexual orientation and gender identity are not collected in the Alberta Cancer Registry. These data are crucial for understanding disparities in cancer care, resource access and outcomes.

As we transition to more models of virtual cancer care, evaluations of patient satisfaction and feedback are needed to ensure optimal patient uptake. Data on patient satisfaction and outcomes by model of care can drive prioritization of which care models are used for various populations and settings.

In addition, research projects are needed in the following areas:

- Understanding the poor outcomes observed in those with concurrent mental illness and cancer, and identifying solutions
- Identifying and addressing barriers to screening due to socio-economic status, geographic location of residence, culture, race, ethnicity, gender identity, sexual orientation, age, and other factors
- Promotion strategies for cancer screening to increase participation rates

- Learning health systems to integrate innovations in science, technology and practice with the goal of improving health system performance and achieving the best possible health outcomes
- Models of care to address workforce shortages, budget restraints, increasing cancer incidence and prevalence and technological advances.
- Models of care that support assessment and management of age-related concerns to facilitate appropriate diagnostic and treatment decision making and ensure optimal outcomes.

For all research projects and initiatives, meaningful engagement with Indigenous peoples, racialized individuals, and sexual and gender minorities, and people belonging to various age groups in the early stages of planning is essential to work towards bridging the gaps and disparities we are observing in cancer care, resource access and outcomes.

Chapter 11: Models of care

Key findings

- Alberta's current cancer care services include prevention, screening, diagnosis, treatment, long-term management, and follow-up delivered by a variety of health care providers.

Recommendations

- As the number of people with cancer and the complexity of treatments increases, it is important that the care system can adapt appropriately. Invest in a detailed workforce plan to address the growing needs of the cancer care system while accounting for recent changes and trends in models of care delivery.

- While virtual care technology has mainly been used to provide care in remote or rural populations, this method of care delivery may be a feasible adaptation across the province regardless of geographic location. Evaluate the impact of virtual care and home care on patient outcomes, experience, and satisfaction.

- Innovations in models of cancer care are needed to support the patient population now and into the future, as the traditional models may no longer be sufficient or sustainable in all settings. Examine the impact of changes in care delivery during the pandemic to understand whether some of the forced changes to care delivery result in similar outcomes that might be more sustainable.

- To work towards the goal of optimizing person-centered care, the health care system in Alberta will need to adopt technology and new processes that continue to put the patient and family needs at the centre of the care, while ensuring that systems are in place to evaluate innovations and adapt as required. Examine how to enhance cancer care to meet the evolving needs and expectations of patients and families, while working to optimize patient outcomes and experiences.

Background

A model of care in oncology outlines the way in which health services are created and provided for patients as they move through the stages of cancer.[1] Given the projected increase in cancer incidence and prevalence, and increasing complexity of treatment and care needs, appropriate delivery of care requires balancing patient needs, health care resources and fiscal constraints. As cancer care becomes more complex, mostly through rapid technological advancement, the methods and models by which cancer

care is delivered are also evolving. Here, we provide a summary of the current models of cancer care in Alberta, discuss recent advancements in these models, and highlight particular gaps and evidence needs to support optimal care delivery in the future.

Alberta's current cancer care services include prevention, screening, diagnosis, treatment, long-term management and follow-up delivered by a variety of health care providers.[2] The Cancer Strategic Clinical Network (Cancer SCN) was formed in 2012 to address the disparities in the cancer system and improve connections between services and programs, while advancing innovation.[2] Presently, the Cancer SCN, alongside its valued partners and stakeholders, is working towards a vision for new models of cancer care in Alberta that can better integrate community support and explore approaches to moving services into the community provided by community-based multidisciplinary teams.[3] This approach aligns with many of the recommendations outlined in the Alberta Health Services (AHS) review completed in 2019.[4]

Overview of models of cancer care across Canada

Specialist-based models

Traditional models in cancer treatment rely on specialist-based models for follow-up cancer care. In a specialist-based model, teams of specialists including medical oncologists, radiation oncologists and surgical oncologists provide consultation, treatment and follow-up care for patients.[1] Specialist-based models of care commonly focus on the surveillance of cancer recurrence and the delivery of specialized services to examine symptoms.[1] A downside of these models is that delivery of care in a highly specialized environment can leave little room to address other important health issues not directly related to the patient's cancer that could also impact long-term health outcomes, such as mental health.[1] These kinds of models may also not make the most appropriate use of specialists' time and skills, as many of the tasks they may perform could be undertaken by individuals in other roles.

Primary care–based models

In a primary care–based model, family physicians or primary care providers deliver follow-up care and monitoring for patients.[5] This model is important for prevention, screening, rehabilitation, supportive and follow-up care, and community- and home-based palliative care. Family physician–led models help manage specific health issues like osteoporosis, cardiac health and depression that may be related to or impacted by cancer therapy. Newer models suggest a transition towards primary care for follow-up cancer care. CPAC recommends optimizing non-oncologist health care professional roles to expand the scope of practice or skills.[6] For example, enabling pharmacists to prescribe certain medications and training non-specialist health care providers in additional cancer care skills. The primary care-based model also provides person-centered care through the implementation of collaborative health care teams. A successful primary care-based model is dependent on addressing challenges faced by family physicians in delivering cancer care and control programs, family physicians' interest in providing follow-up care and the effective integration of cancer care programs into primary care.

Community networks models

This model involves expanding the development of networks and capacity to deliver cancer care to patients in a community setting. A community networks model is also based on a person-centered approach that encourages the collaboration of several health care teams. In 2013, the Government of Alberta released a report on Alberta's Cancer Plan to 2030,[7] which included a recommendation for greater integration of primary health care providers and community services in the provision of cancer-related services. Community-based health and social services were also granted expanded roles in cancer prevention, diagnosis, treatment and follow-up care.

Nurse-based models

A nurse-based model of care involves highly trained oncology nurses who are proficient in a variety of clinical care activities and are heavily involved in follow-up cancer care.[1] Alberta has previously integrated nurse practitioners who either work with physician-led teams or act independently to provide follow-up cancer care. Models that involve nurses

can considerably reduce outpatient workload while maintaining a satisfactory quality of care.[8,9]

Shared-care models

In a shared-care model, patients may be monitored by both an oncologist and a primary care physician.[10] Patients receive both types of care, provided by an oncologist, such as appropriate surveillance for their cancer, and by a family physician for all other health care unrelated to their cancer. In order for this model to function, communication between specialists and primary care physicians is critical; however, if conducted appropriately, patient satisfaction with shared care can be higher than with the usual models of care.[11]

Towards new models of care

Modern models of cancer care are needed to support the patient population now and into the future, as the traditional models described above may no longer be sufficient or sustainable in all settings. As the number of people with cancer increases with a growing and aging population and better patient outcomes and survivorship,[6] it is important to be mindful of the resources available, including financial, staffing and space constraints, and changing patient needs, as we move towards newer models of care in Alberta and Canada. These changes may require adjusting the roles of health professionals in the cancer care workforce, the further adoption of virtual care in appropriate circumstances, and a general focus on the quality of care for people with cancer.

Given the increasing number and proportion of older adults within our cancer population, assessing, and managing age-related concerns to support appropriate diagnostic and treatment decision making and optimize treatment outcomes is paramount. The integration of geriatric assessment and management in cancer care is recommended by the American Society of Clinical Oncology[12] and the National Comprehensive Cancer Network.[13] This involves multidimensional assessment of health status across somatic, functional, and psychosocial domains to inform a personalized oncologic treatment plan and recommendations of non-oncologic

interventions to support management of age-related concerns that may impact cancer outcomes.[14] In a recent systematic review of randomized controlled trials, authors concluded that geriatric assessment can contribute to improved patient experience and outcomes, including improved communication, lower rates of toxicity and complications, improved treatment completion, and increased quality of life and physical functioning during and after treatment.

In the transition towards a new model of care, there will also be adjustments in the cancer care workforce. Alberta's Cancer Plan to 2030[7] addressed this issue as Strategy Eight (Develop a strong cancer workforce to meet the needs of cancer patients and their families). In particular, the strategy addressed the need to explore how the services of health care professionals and community supports could be used better and more appropriately to provide care in an integrated system. Currently, Alberta is facing shortages of specialized cancer care staff including oncologists, medical physicists, radiation therapists, oncology pharmacists, oncology nurses and social workers.[15] A suboptimal cancer care workforce has the potential to lead to longer wait times for treatment or care, increased errors in the delivery of care and overall lower quality of cancer care. Therefore, it may be necessary to increase the capacity of health care professionals beyond cancer specialists.[6]

Expanding the scope of health care providers to deliver services traditionally provided by cancer specialists has been shown in several studies to enhance the quality of patient care.[11,16-18] We see this idea being implemented in newer models but, as the need to expand the present role of health care professionals grows, education and training programs are critical. Over time, care traditionally provided by specialists could be delivered by primary care physicians, nurses or pharmacists. This will require continuing education and training for professionals to take on new or additional expanded scopes of practice. In 2013, Alberta's Cancer Plan to 2030 indicated that optimizing the cancer care workforce through education and training should be a priority going forward.[7] This topic was further reinforced by the AHS review (2019) that recommended the optimization of staffing levels and skill mix across the organization as a whole.[4]

Virtual health care

Virtual care is health care provided through the use of technology including telephone, video call or other online mediums. The use of various forms of virtual care has increased across Canada over the past decade.[19] There are several different terms for virtual care including telemedicine, telehealth, telecare, online health and e-health.[20] While virtual care technology has mainly been used to provide care in remote or rural populations, this method of care delivery may be a feasible adaptation across the province regardless of geographic location. AHS currently provides virtual cancer treatment planning or consultation appointments with patients and providers using this technology and the demand for this service is growing. A recent environmental scan on virtual care conducted by CPAC showed that both patients and providers find virtual visits useful, convenient and cost effective.[21] However, providers still favour in-person visits to build core relationships with patients. In addition, based on a 2018 survey, 74% of respondents would like to use technology for routine touchpoints such as follow-up visits and prescription refills.[22] Expanding virtual care was also a major recommendation in the 2019 review of AHS to provide care to those for whom health care is difficult to access.[4] For many Alberta residents, cancer care can be an ongoing economic burden due to unexpected out-of-pocket costs. Attending an in-person appointment may include travel-related costs, time off from work and childcare expenses, all of which can be prohibitively expensive for many.[23] Virtual care is a possible solution to alleviate some of these additional costs and provide care in rural, remote and underserved areas where there may be further barriers to timely and quality care.

While virtual care may fill some gaps within the current health care system, it is not without disadvantages. It is not possible to conduct every type of health care appointment virtually. Several components of care, such diagnostic procedures, imaging tests and bio-sampling, still require in-person and hands-on approaches. Another disadvantage is that virtual health care is dependent on strong and reliable internet infrastructure for health care providers to connect with, view and speak with patients. Telecommunication companies in Canada may not provide comparable high-speed

internet services in rural or remote settings to those available in urban settings.[24] Interrupted internet connections can result in disruptions and misunderstandings that can affect the quality of care a patient receives. Ensuring that the technological infrastructures to support virtual communication are in place is essential to the viability of providing virtual health care.

Home- and community-based care

Advances in cancer treatment have allowed for increased survival from many types of cancer.[25] Over time, more patients will access the cancer system and require additional services as they transition from completing treatments in hospital to home and/or community-based settings. Transitions in care are "a set of actions designed to ensure the safe and effective coordination and continuity of care as patients experience a change in health status, care needs, health care providers or location (within, between or across settings, including home)."[26] Recently, AHS released guidelines on transitions in care for adult patient populations with a chronic disease.[26] In brief, the report outlines six criteria for successful transition between hospital and home based on a patient's needs. The six criteria are: confirmation of the primary care provider, admit notification, transition planning, referral and access to community supports, transition care planning and follow-up to primary care. Together, these criteria provide a guide for how primary, specialist and community care can work together to improve care for those with chronic diseases such as cancer. A sister report on patient experiences with transitions to care emphasized cooperation, communication, trust, planning and access as important areas for home care transition.[27]

Present challenges

Impact of COVID-19 on cancer care

The onset of the COVID-19 pandemic in early 2020 resulted in unprecedented clinical challenges in the delivery of cancer care. Given the additional risk of infection for patients with cancer, in-person clinical care presented a logistical challenge for cancer screening, diagnosis and treatment.[28,29] Provincial health authorities quickly published clinical practice guidelines that provided recommendations for how to triage those patients who may need services the most acutely, while shifting other services to virtual

care.[30] A Canada-wide survey conducted early in the pandemic response found that 54% of participants had appointments cancelled, postponed or rescheduled and 15% had surgeries or procedures cancelled.[31] The most affected by these changes were those awaiting a potential diagnosis and those newly diagnosed.

In Alberta, cancer screening programs including mammograms, Pap tests, colposcopies and fecal immunochemical tests (FIT) were paused in March 2020 and resumed in June 2020. An estimated 170,000 tests were suspended in that period to prepare for the influx of COVID-19 patients in clinics and hospitals.[32] As a result, there was a 20%–30% drop in the number of new cancer cases diagnosed in the province.[33,34] As the pandemic progressed and health services were brought back online, there was still an observed deficit in numbers of new cancers diagnosed. Between March 2020 and April 2021, there was a 7.8% decrease in cancer diagnoses relative to 2019, despite an expected increase of 3%. The biggest drop in number of diagnoses occurred in April and May 2020 where 500-600 fewer cases were reported compared to the previous year.[35] Of course, this does not mean fewer people developed cancer, only that new cases are likely to be diagnosed at later stages.

While decreases in cancer diagnoses were observed for all types of cancers, the interruption of regular cancer screening programs is expected to have negative consequences in the future, including cancers being detected at later stages, potentially resulting in poorer prognoses for people with cancer. The interruption in screening will also lead to increased pressure on the cancer diagnosis and treatment system. A simulation model exploring scenarios of cancer screening interruptions in Canada projected an increase in cancer cases upon the stable return of cancer screening programs as well as cancer cases being diagnosed at later stages with lower survival and, thus, more cancer-related deaths. Through the simulation model, the long-term impact of breast and colorectal screening interruptions was estimated.[36] A three-month interruption could increase breast and colorectal cancer cases diagnosed at advanced stages (310 and 1,100 more, respectively) and breast and colorectal cancer deaths (110 and 480 more, respectively) between 2020 and 2029. Surgeries, treatments and other forms of cancer care were also delayed.[37] Highlighting the value of the cancer

screening pathway is necessary to safeguard screening as an essential service and to support the cancer screening system's resilience through future health crises.

During the pandemic, colorectal cancer screening capacity in Alberta was reduced, affecting how and when cancers were diagnosed. In total, diagnoses of colorectal cancer reduced by 55% between March and August 2020 when compared to the same months in previous years.[35] For those who were diagnosed with colorectal cancer, patients were more likely to show symptoms of cancer and be diagnosed in urgent care or hospital settings than in previous years. At the same time, the proportion of patients diagnosed through screening pathways dropped during the pandemic compared to other years. This means that more patients were diagnosed at later stages of cancer during the pandemic than would be expected, which can greatly affect survival.[38]

During the pandemic, Cancer Care Alberta moved a considerable volume of traditionally in-person patient appointments to virtual clinics to continue providing care at a safe distance for patients and health care providers. Between April 1 and June 10th, 2020 over 11,000 patients had a virtual visit within CCA, with an average of 43% of visits each week occurring virtually and 67% of patients surveyed indicated they would be interested in receiving virtual care beyond the pandemic.[39] In general, patients were satisfied with their virtual care experience. However, patients reported lower satisfaction in terms of feeling like they could discuss their emotional concerns, that their family and friends could be involved in their virtual care encounter, and that they were connected to resources and/or referrals to support their symptom management and well-being.

Virtual care made it possible for physicians to contact and follow up with patients while being socially and physically distanced to protect patients and providers from possible exposure.[40] In addition, health care organizations transitioned to reduced in-person cancer care by temporarily switching to oral treatment, where possible.[30] However, the lack of in-person care, including appointments for psychological services, physiotherapy and group activities, led to greater anxiety and poor mental health among patients and caregivers.[31]

While it is predicted that the interruptions in cancer prevention and treatment may lead to a spike in cancer cases and deaths, there are gaps in understanding how current cancer programs will be able to adapt to these potential increases once the COVID-19 pandemic subsides. Cancer centres and hospitals may be expected to handle an influx of cancer-related surgeries as well as increased access to treatments, medications and follow-up care. There are also possible gaps with regard to the economic costs of cancer management across Canada after the pandemic with the projections of potentially increased cancer incidence. Treatments and medications for later-stage cancers are generally associated with increased costs and, therefore, costs to the health care system are expected to increase due to the predicted rising incidence of later-stage cancers.[41] There is no doubt that the cancer care system in Alberta has been strained by the COVID-19 pandemic. Planning is crucial to successfully manage the expected future consequences of the pandemic. Specifically, the various models of care described here need to be adapted to meet increasing needs. This massive disruption in the health care system should provide lessons to be learned for the future. Strategies based on these experiences should be implemented to make the system less susceptible in the event of another major health crisis.

Conclusions and recommendations

As the number of people with cancer and the complexity of treatment both increase, it is important that the care system can adapt appropriately. Current models of care that focus on specialists and in-hospital treatments are not sustainable moving forward. Research is required to inform innovation in models of cancer care in Alberta. Furthermore, to work towards the goal of optimizing person-centered care, the health care system in Alberta will need to adopt technology and new processes that continue to put the patient and family needs at the centre of the care, while ensuring that systems are in place to evaluate innovations and adapt as required.[7] AHS and Cancer Care Alberta are already exploring new strategies to address issues of workforce shortages, space requirements and limited funds, while still maintaining a high standard of care for patients, including the adoption of virtual care, home- and community-based treatment, and person-centered models of care.

The emerging field of implementation science is focused on improving the effectiveness and quality of health care through promoting "the systematic uptake of research findings and other evidence-based practices into routine practice."[42] For example, learning health systems integrate innovations in science, technology and practice to improve health system performance and achieve the best possible health outcomes.[43] In the Canadian context, learning health systems have been defined as "dynamic health ecosystems where scientific, social, technological, policy, legal and ethical dimensions are synergistically aligned to enable cycles of continuous learning and improvement to be routinised and embedded across the system, thus enhancing value through an optimized balance of impacts on patient and provider experience, population health and health system costs."[44] The learning health systems approach is attractive, as it addresses some of the main challenges that Alberta's cancer care system is facing, such as strategies for harnessing the power of communities to identify and address questions about delivery of care, the rapid integration of evidence and innovation, as well as ensuring value for patients, providers and the system.

As these changes in models of care occur, continual assessments of patient outcomes in terms of disease-free survival and patient-reported outcomes will be essential to evaluate the impact of changes regardless of whether they are planned or forced due to situations like COVID-19 or other episodic impacts. Furthermore, with additional transition to virtual care platforms, rigorous evaluations of patient satisfaction and feedback are needed to ensure optimal patient uptake. As we emerge from the COVID-19 pandemic, it will also be important to weigh the cost-effectiveness of providing services virtually *versus* in a community, home or one-on-one setting. Despite its challenges, the COVID-19 health crisis has mandated health care providers to explore alternative solutions to the traditional health care model, and we would do well to continue that exploration long after the pandemic is part of our lives.

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Chapter 12: Health equity

Key finding

- Although there have been great improvements in cancer incidence and mortality in recent decades, these improvements have not occurred equitably for all groups.

Recommendations

- Increase collection of Alberta-specific data on vulnerable populations and those previously under-represented in health and population data. Investments should focus on individuals with mental health disorders, Indigenous peoples, racialized individuals, and sexual and gender minorities to identify where resources are needed in the cancer care continuum.

- Investigate methods of establishing long-term staffing stability for smaller, regional radiotherapy cancer centres, to facilitate ongoing equitable access to radiotherapy across the province.

Background

Improvements in cancer care in recent decades have resulted in improvements in outcomes for many cancer types, especially reduced mortality. Between 1984 and 2020, mortality has decreased for lung, prostate and colorectal cancers in males, and breast and colorectal cancers in females.[1] Primary prevention campaigns, such as those urging people who smoke tobacco to quit, have also been effective at lowering the incidence of lung cancer for several decades.[2] However, these improvements are likely not consistent for all population groups. Disparities in cancer outcomes are preventable and are in many instances the result of social and historical hierarchies that can lead to structural discrimination and marginalization. Equity, the overarching theme of this chapter, reflects the need to act on these disparities and create opportunities for everyone to benefit from improvements in cancer care. For the purposes of this report, we will use the definition of equity provided in the Alberta Health Services Provincial Diverse Populations Strategy overview:[3]

Health equity refers to the elimination of the social, economic, and environmental factors that produce inequitable health outcomes among groups. This means that all

persons have fair opportunities to attain their health potential to the fullest extent possible.

A major determinant of health equity is how income, power, resources, goods and services are distributed in a population. These factors are the social determinants of health and are defined as "the conditions in which people are born, work, grow, live and age, and the wider set of forces and systems shaping the conditions of daily life."[4] These factors make a difference in an individual's risk of being diagnosed with cancer, the care that person will receive following a cancer diagnosis and how likely it is that the person will survive. Socio-economic status, an encompassing term that includes education level, income and employment status, is a known predictor of health status in a population. Generally speaking, those with lower socio-economic status are more likely to smoke tobacco and drink alcohol to excess than those with higher socio-economic status, leading to a higher risk of several cancers. The likelihood that someone will be screened for cancer also follows a socio-economic gradient, where those with a lower socio-economic status are less likely to be screened than those with a higher socio-economic status. Underscreening can lead to cancers being diagnosed at a later stage and make them more difficult to treat successfully. Cancer-specific mortality has improved for all socio-economic status groups, but individuals with a lower socio-economic status still fare worse and the disparity between groups is growing larger.[5]

Importantly, all of the elements related to the social determinants of health interact with each other, resulting in greater vulnerability for those who exist at the intersections.[6] For example, racialized migrants in Canada who are female have worse health outcomes than racialized migrants who are male.[7] When cancer outcomes for a given population are examined individually rather than in combination with other identities, the true negative impacts may be masked. Moving forward, any plans to address inequities must also acknowledge that social categories such as ethnicity, sex, gender, age, and socio-economic status are neither independent nor mutually exclusive.[8]

Differences in cancer outcomes by socio-economic status have been well documented elsewhere and there are many other vulnerable groups that will require further attention

in future research. For this section, we have chosen to discuss four populations who are likely to face disparities in cancer care in Alberta: those with mental health disorders or concerns, Indigenous populations, racialized populations, and sexual and gender minorities.

The topics discussed in this section are complex, and a full understanding of these inequities requires the particular perspectives of those with lived experience. By using a reflexive approach, we hope to contextualize the content and recommendations provided in this document. Since the authors do not have lived experience as a racialized person or an Indigenous person in Canada, we collaborated with members of these communities to provide feedback and input on this chapter prior to publication.

Cancer care and mental health

Mental health disorders are common in the Canadian population and most people are affected, either directly or indirectly, by mental illness. In Canada, 20% of adults will experience mental illness in any given year, and people of all ages, education, and income levels can be affected.[9] Severe mental illness (SMI), which includes obsessive compulsive disorder, manic depressive disorder, major depressive disorder, and schizoaffective disorder or schizophrenia, is more prevalent than many may realize. Nearly 5% of people in Alberta are diagnosed with major depressive disorder, almost 2% have bipolar disorder and the prevalence of schizophrenia is near 1%.[10] The suicide rate in Alberta is also among the highest in Canada, with 16 suicides per 100,000 persons in 2015.[10]

Given the prevalence of mental health disorders and their impact on overall health and well-being, mental health is indicated as a priority area by Alberta Health Services. This includes the establishment of the Provincial Addiction and Mental Program, which aims to "improve addiction and mental health patient care and health outcomes in Alberta."[11] Despite this initiative and others,[12] evidence continues to show that individuals with mental illness at all levels of severity are more likely to experience poor health outcomes, including those related to a cancer diagnosis.

Risk factors for cancer may be higher among those with mental illness, as some may develop coping strategies to relieve symptoms, such as smoking, binge drinking and substance abuse[13] and are less likely to participate in leisure-time physical activity.[14] SMIs, in particular, tend to be diagnosed before the age of 25, making these behaviors especially harmful.[15] As a result, individuals with mental illness are at a higher risk for cancers related to smoking, drinking and a sedentary lifestyle. Additionally, there is some evidence that the uptake of cervical,[16] breast[17,18] and prostate cancer screening is lower in those with mental illness compared to those without.[19] Individuals with mental illness may also have more difficulty accessing primary care services regularly.[20] This may be due to mental health symptoms, substance use issues or poverty, or it may be that practitioners are unwilling to take on patients with mental health disorders.[21] This makes it less likely that individuals will receive preventive care and early symptoms of disease may go unnoticed.

Studies from multiple populations have shown higher cancer mortality[22,23] and shorter time between diagnosis and death[24-26] in those with mental illness compared to those without. This association does not appear to be attributable to later stage at diagnosis and is likely the result of events that occur after a person is diagnosed.[27] Some individual-level factors that could lead to higher mortality are a greater prevalence of physical comorbidities (including those caused by antipsychotic, antidepressant and mood stabilizer medications)[28] and lower adherence to treatment protocols.[29] Some studies have found that individuals with mental illness rate their quality of care lower than those without.[22,24,30,31]

A significant number of patients with cancer experience anxiety and depression, and people with certain types of cancer are at a higher risk of mental illness.[32,33] Prevalence of depression among people with cancer ranges from 4% to 49%, with variations by method of assessment and cancer type or severity. Individuals with incurable cancer are more likely to experience depression than those for whom the cancer can be cured.[34] Approximately 13% of patients with lung cancer experience major depression, whereas this rate is 6% among patients with genitourinary cancers.[35] This is compared to the past-year prevalence in the general population of

approximately 4%.[36] Individuals with pre-existing mental health disorders may be at risk of relapse or worsening condition following a cancer diagnosis.[37] The increased presentation of mental health disorders among individuals diagnosed with cancer contributes to the higher rate of suicide and suicidal ideation in this population, particularly within the first year of diagnosis.[38-40] Fortunately, mental health care for people with cancer has grown in priority in the past decade. In Alberta, people with cancer are regularly screened for distress at all major cancer centres and psychosocial support is available for anyone who wants it. These are welcome improvements that indicate recognition of the importance of concurrent mental and physical health care.

Recommendations

These data show a need for more research into the experiences of those with concurrent mental illness and cancer. Despite studies of many populations showing a higher prevalence of depression, anxiety and suicidal ideation among people with cancer than in the general population, there is a dearth of research undertaken in the Canadian context. Fortunately, the mental health of people with cancer is becoming a higher priority, with clinics in Alberta routinely screening patients for distress and providing resources to improve the mental health of people with cancer. Further research should be conducted on the uptake of available resources among people with cancer and referrals to mental health professionals, particularly among those who are diagnosed with less-treatable forms of cancer. People with cancer are now more likely to die from causes other than cancer,[41] so it is increasingly important to study comorbid conditions that may affect survival in this population. Going forward, mental health needs greater attention in cancer care and research is required to understand more about the impact of mental health on cancer outcomes.

Indigenous populations

The Indigenous peoples of Canada include three distinct groups – First Nations, Inuit and Métis (FNIM) – each with unique languages, customs and histories. In 2016, there were nearly 260,000 Indigenous individuals in Alberta, accounting for 7% of the total population. Of the Indigenous populations, 53% are First Nations, 44% Métis and 1% Inuit.[42] While the impacts of colonization for these groups may differ, the effect of 400

years of oppression and disenfranchisement has created "social and material inequities that result in health disparities that persist over many generations."[43] Historically, Indigenous peoples have had a lower rate of cancer than that of the broader population in Canada,[44] but incidence and mortality have been increasing due to systemic and institutional factors, including racism, that have led to lower life expectancy and overall well-being.

As noted in the Canadian Strategy for Cancer Control (2019-2029),[45] Indigenous peoples experience inequities in accessing culturally appropriate cancer care. Recognition of this situation led CPAC to develop "peoples-specific priorities and actions" in the refreshed strategy, with three cross-cutting priorities identified by First Nations, Inuit and Métis as follows: (i) culturally appropriate care closer to home; (ii) Peoples-specific, self-determined cancer care; (iii) First Nations, Inuit or Métis governed research and data systems.

Alberta Health Services has previously acknowledged existing health inequities between Indigenous peoples and the broader population in this province. A publication in 2018 identified some of the health disparities that Indigenous peoples in Alberta may face, including a shorter life expectancy, higher suicide rate and higher rate of infectious diseases.[46] The document recognized the importance of an Indigenous approach to wellness for those who want it, health care capacity in Indigenous communities and alignment with the Truth and Reconciliation Commission of Canada's Calls to Action.[47] The Calls to Action include seven items related to the health of Indigenous peoples in Canada (#18–#24), one of which specifies closing the gaps in health outcomes between Indigenous and non-Indigenous communities. In this report, the goal is to take steps towards that call to action for cancer care specifically.

Within Alberta Health Services, several initiatives are underway to improve cancer care for Indigenous peoples. In January 2020, the organization published "Indigenous Health Commitments: Roadmap to Wellness" describing actions designed to remove barriers to access and improve health outcomes for Indigenous people in Alberta.

In Cancer Care Alberta, the project Walking Together: Strengthening Indigenous Cancer Care in Alberta aims to improving access to health services (primary care and cancer care) for Indigenous people (especially in the north), working to minimize jurisdictional barriers, creating shared understanding between the health system/staff and Indigenous people/communities through collaboration, increasing knowledge sharing and education, and improving supports for Indigenous people experiencing cancer both in the cancer system and in communities.[48] CCA also employs three Indigenous Cancer Patient Navigators based in Calgary, Edmonton and Grande Prairie who work with and support First Nations, Métis and Inuit people impacted by cancer. They bridge western medicine in cancer care with traditional ways by connecting patients and families with Indigenous cultural support workers to facilitate cultural practices, advocating for patients, helping them to answer questions and navigate the health system, connecting them to supportive services and resources, and helping healthcare providers to better understand Indigenous peoples and their cultural ways. [49,50]

The [Indigenous Wellness Core](#) is a dedicated program within AHS that is focused on innovation, quality improvement and standardization for programs and services for all Indigenous peoples within Alberta. It represents one point of contact for all Indigenous health needs and topics including cancer, and is dedicated to strengthening the building of partnerships between AHS and Indigenous peoples in Alberta.[51] Among other areas of service, the Indigenous Wellness Core provides help for Indigenous patients navigating the cancer care system in providing consistent, coordinated care and ensure they feel safe and comfortable in a clinical setting. This role also facilitates the development of culturally sensitive relationships with other health care providers.[52]

Outside the formal health system, it is clear that Indigenous peoples experience disadvantages with regards to the social determinants of health that have been linked to poorer health status, including lower income and employment rates as well as inadequate housing. Contributing factors include socio-economic conditions established by colonial policies like the Indian Act,[53] as well as the cumulative and multigenerational trauma associated with Indigenous children being placed in residential

schools,[54,55] the social welfare system,[56] and the proportionally greater representation of Indigenous peoples in the prison system.[57] These difficulties are further compounded for Indigenous peoples when faced with discrimination and racism in health care settings.[58]

There is currently no well-established, readily accessible database for cancer among Indigenous peoples in Canada, with most evidence coming from provincial or population-based studies. Available evidence shows a higher prevalence of cancer risk factors, including smoking, obesity, and low fruit and vegetable consumption among First Nations living on-reserve.[59] First Nations, Inuit and Métis people are also less likely to participate in cancer screening programs.[54] Reserves, settlements and Métis communities tend to be in remote and rural areas, making it difficult to access screening programs, specialty care and treatment centres that are based in more populated areas, as travel can be prohibitively expensive.[54] There may be other factors in play that require more research, with the caveat that any research must be done in partnership with Indigenous communities.

There is evidence that Indigenous peoples are facing growing cancer incidence and cancer-related deaths. The incidence for several cancers in First Nations populations has surpassed that in the non-Indigenous population, with a significantly higher incidence of colorectal, kidney, cervical and liver cancers.[60] First Nations people have significantly worse survival from many cancer types compared to the broader population and the difference does not appear to be attributable to rurality or income.[61] The leading cause of cancer-related deaths among all Indigenous groups is lung cancer, where mortality is higher in comparison to the non-Indigenous population.[61,62] For instance, Métis people are consistently under-represented in health research, but there is evidence that they have a higher rate of lung cancer than the general population of Alberta.[63] A Canada-wide study found that the incidence of all cancers was significantly higher for Métis females than for non-Métis females.[64] With over 100,000 people in Alberta who self-identify as Métis, this province has a larger population of Métis people *per capita* than any other Canadian province or region.[42]

Recommendations

It is important to note that the factors here, both individual and structural, can be traced back to the effects of colonialism. Therefore, any future research on the health of FNIM people in Canada should commit to creating knowledge that "documents social injustice … and that challenges racism, colonialism and oppression."[65] A disproportionate amount of current research on FNIM people and cancer is dedicated to screening, especially cervical cancer screening. There is a far smaller field of evidence on factors related to primary prevention, stage at diagnosis, treatment delays and other factors which can have a substantial impact on cancer mortality and require further research. Access to care is one of the most crucial determinants of health outcomes for Indigenous peoples worldwide, including in Canada.[66] Mistrust of health care providers and the health care system is an obstacle to accessing health care, and addressing this mistrust is a crucial step in closing the cancer outcomes gap. Individual and systemic racism, discrimination, previous negative experiences, and the historical trauma of residential schools and the "Sixties Scoop" all contribute to the power imbalances that lead to mistrust.[67,68] Building trust between Indigenous peoples and health care providers will require dedicated action. The AHS' Roadmap to Wellness document lays out the Health Commitments to health equity for and with Indigenous peoples in Alberta. It outlines specific goals and actions around people, processes, wise practices and quality outcomes to ensure that AHS can address Indigenous health in a coordinated and comprehensive way.[51]

Researchers interested in Indigenous issues in recent years have grown increasingly aware of the benefits of community-based participatory research; however, much more emphasis should be placed on this practice. Community engagement with Indigenous populations begins long before data collection for a research project. Researchers must be prepared to engage, resource and include Indigenous peoples in any research proposal that involves these populations. Determining the needs of the community must be a collaborative process in which the priorities and outcomes are agreed upon from the onset, and mutual benefits for all parties are transparent and achievable.[69] Further, data collection limits and ownership need to adhere to the First Nations, Inuit and Métis

principles of ownership, control, access and possession; seek Indigenous interpretations of results; and obtain approval for dissemination of results.[69] In general, any research group that wishes to engage with Indigenous communities must recognize that time and energy devoted to relationship building are a key component of a successful project that intends to provide outcomes inclusive of both Western and Indigenous perspectives.

Racialized groups and new immigrants

People of colour account for more than one-fifth of Canada's population,[70] and this proportion is expected to increase to about one-third of the total population by 2036.[71]* Over 300,000 immigrants arrived in Canada in 2018,[72] and 21% of Alberta's residents are immigrants.[42] Emerging evidence during the COVID-19 pandemic has raised consciousness of health inequities by ethnicity in Canada and around the world. In Alberta, the rate of COVID-19 infection was significantly higher in communities with higher proportions of racialized people,[73] and Ontario reported higher incidence, hospitalization and deaths in areas with higher densities of immigrant and racialized populations.[74,75]

Despite the significant population of racialized people in this country and the understanding that experiences of racialization can affect physical and mental health,[76] research on this relationship in Canada is limited. One reason for this neglect is the lack of ethnicity data in Canadian health care databases and registries.[77] In 2013, Alberta Health Services published the Alberta Cancer Plan to 2030 in which it highlighted the need to capture data for stage at cancer diagnosis by ethnicity and socio-economic status.[78] To date, there is no national data collection on ethnicity and cancer incidence or mortality, leaving policy-makers and researchers with unanswered questions. More importantly, the lack of ethnicity or race-based data in Canada severely limits our ability to discuss the effect of ethnicity on health and provide resources for those who may need them most.

While data are limited, there is reason to believe that visible minorities in Canada have different experiences with cancer care that may lead to different outcomes.

Approximately 90% of new arrivals in Canada are immigrants who may demonstrate the so-called healthy immigrant effect. This is a well-documented phenomenon that describes the overall better health status among new immigrants to a country than those who were born in the landed country.[79] However, the advantages enjoyed by new immigrants to Canada tend to fade after about 10 years of arrival in Canada, with significant variations by health outcome, country of birth and area of residence following immigration.[79,80] The reasons for an increased risk of poor health in long-term immigrants include the adoption of unhealthy lifestyle habits common in North America, lack of access to regular health care and lack of culturally appropriate care that may deter participation in the health care system.[81] This care gap is mainly seen in prevention efforts such as cervical and breast cancer screening, which can lead to cancers being diagnosed at a later stage in this population.[82,83] Barriers to screening include lack of physician referral, prohibitive costs associated with transportation and childcare, and stigma or embarrassment.[82,84] For the 10% of newcomers to Canada who arrive as refugees, the healthy immigrant effect is not a given. In fact, the only category for which refugees are healthier than Canadian-born individuals is for females with low-level chronic conditions such as asthma, high blood pressure and arthritis.[85] Despite these differences, research on refugee health in Canada is lacking and deserves far more attention in the future.

The Canadian Institute for Health Information (CIHI) endorsed the collection of race-based and ethnicity data in a publication from 2020 that outlines proposed standards of data collection.[86] Race is a social construct that is politically, historically and socially informed, whereas ethnicity is a construct that refers to a sense of group belonging based on place of birth, cultural traditions, language or religion. Throughout this report, the authors note the importance of integrating race-based and ethnicity data to capture both the experience of being racialized by individuals and institutions as well as factors associated with language or cultural differences. Canadian parlance for capturing the experiences of those of different ethnicities is the broad term "visible minorities," which does not distinguish between people who may have very different experiences. For instance, South Asian immigrants to Canada consistently have lower rates of colorectal

and breast cancer. The highest rates of colorectal cancer are among those from Central Asia and the highest rates of breast cancer are among those from the Middle East and North Africa.[80] Furthermore, ethnicity is often favoured over race in Canadian data collection, which does not capture the full experiences of racialized people in Canada. Individual and institutional anti-Black racism is a key determinant of health inequalities faced by African-Caribbean-Black Canadians and may contribute to reduced cancer survival in this population.[87] Canada's preferred narrative is to set our history apart from the legacy of slavery in America; however, slavery was legal in Canada until 1834 – 30 years after it was abolished in the last Northern states – and the racist ideologies of that time persist in the discrimination of Black people today.[87]

Recommendations

Current evidence indicates a need for future research into the experiences of people of colour in Canada, which reaffirms the necessity for collecting race-based data. Much of the current evidence focuses on immigrants or visible minorities as a collective group, rather than considering the distinct health care experiences of people who are racialized in this country. Specifically, we recommend following the CIHI guidelines for race-based data collection. This includes collecting both ethnicity and race-based data, working with communities to ensure data collection is appropriate and collaborating with communities in the interpretation of the data.[86] While it appears that immigrants are not universally disadvantaged, the intersection of immigration and socio-economic status puts some individuals in a position where prevention and treatment are less accessible. More research on the diversity of experiences within the immigrant population is needed, including further research on the experiences of refugees to Canada. The majority of research on immigrant and visible minority health in Canada is from Ontario, indicating a clear need for Alberta-specific evidence. Nearly 25% of Alberta's population identifies as a visible minority and yet there is a limited understanding of experiences of cancer care and cancer outcomes for people of diverse ethnicities and races in Alberta.

Sexual and gender minority groups

In 2017, 500,000 individuals in Alberta identified as being part of the sexual and gender minority community. This population includes people with diverse sexual orientations

and gender identities including lesbian, gay, bisexual, transgender, gender non-binary, queer, two-spirit and intersex.[88-90] With the growing visibility of sexual and gender minorities has come the understanding that, in many cases, this population may be underserved in the health care system. While there is not a dedicated strategy to address the health needs of people with sexual and gender minority identities, Alberta Health Services recognizes the unmet needs of this population and provides resources for best practices including how to be an ally, using inclusive language, using appropriate pronouns, and terms and phrases to avoid. Despite greater recognition, sexual and gender minority groups may be at a greater risk for some illnesses than cisgender or heterosexual individuals,[91] including certain cancers.[92] This greater risk may be attributable to modifiable primary and secondary prevention factors as well as socio-economic factors.

In general, individuals who identify as sexual or gender minorities tend to have higher rates of smoking, alcohol misuse and receptive anal sex practices than heterosexual cisgender individuals, which are associated with an elevated risk of several cancer types.[93] Lesbian and bisexual women tend to have a higher body mass index and are more likely to be nulliparous than heterosexual women[94] and bisexual women generally report higher unemployment and lower income than both heterosexual and lesbian women.[93] Transgender individuals are less likely to have a regular doctor and more likely to report difficulties in obtaining medical care than cisgender individuals.[93,95,96] These differences increase the risk for several cancer types such as lung, breast, anal, cervical and colorectal cancers.[92] Additionally, men who have sex with men (MSM) still make up half of all those who are living with human immunodeficiency virus (HIV), which increases the risk of several types of cancer.[97]

Despite widespread organized screening programs for many of these cancers, accumulating evidence suggests that sexual and gender minority individuals may be less likely to participate in screening. Lesbian and bisexual women are significantly less likely to be up to date on cervical cancer screening (Pap testing),[98] partially due to misconceptions regarding the risk of human papillomavirus (HPV) infection among women who have sex with women.[92] Transgender women and non-binary individuals

are less likely to participate in both cervical cancer screening and mammography than cisgender women, as these procedures can lead to harmful feelings of gender dysphoria.[99] There is also some concern about ambiguity in screening results for transgender individuals. For instance, Pap tests on transgender men who have been on testosterone are 10 times more likely to have an unsatisfactory result than those on cisgender women, which suggests that some screening procedures could be less effective at detecting early-stage cancers in this population.

It is not clear at this point whether sexual and gender minority individuals are at an increased risk of cancer. Virus-related cancers such as Kaposi's sarcoma, anal cancer and penile cancer have been found among sexual minorities, particularly among MSM who live with HIV. No other cancers appear to have significantly higher incidence in sexual and gender minorities.[100,101] Transgender individuals do not appear to have any higher risk of cancers when taking exogenous hormones, but the research in this field is particularly scarce. Transgender men were found to be more likely to have breast cancer than cisgender men but were no more likely to get breast cancer when compared to cisgender women, and transgender women were less likely to be diagnosed with prostate cancer than cisgender men.[88] The lack of data on cancer incidence among sexual and gender minorities also reduces our ability to understand whether people in these populations have different cancer outcomes than cisgender or heterosexual individuals.

Recommendations

With limited existing evidence regarding cancer care for individuals who identify as sexual or gender minorities, more research is needed to determine the facilitators and risk factors for cancer prevention. This research should include physician attitudes towards the treatment of sexual and gender minorities, with a specific focus on knowledge gaps that could be addressed through further training. These opportunities could help to make steps towards creating an inclusive environment for individuals of all identities. Data from a Canada- and Alberta-specific context is desperately needed as results from the United States cannot necessarily be applied here. Researchers should also examine the feasibility and acceptability of routinely collecting data on patients'

sexual orientation and gender identity, as this will allow for assessment of incidence, disease severity and outcomes in the sexual and gender minority population. Finally, future research should approach this population with an intersectional lens to recognize the unique experience of those sexual and gender minorities who are also racialized, from FNIM populations or in a lower socio-economic position.

Older adults

In Alberta, adults aged 65 and older comprise 54% of new cancer cases, and those aged 75 and older comprise 26% of new cancer cases.[102] Aging is associated with physiological, functional, social, psychological, and existential changes that happen at different times for different people, resulting in vast variation among older adults.[103] Medical co-morbidities and frailty add complexity to the aging process.[104,105] Age-related and disease-related changes have an important impact on cancer and cancer treatment;[104-108] while cancer and cancer treatment also have an important impact on aging[109-111] as well as the management and outcomes of comorbid conditions.[105] In the past 25 years, the number of new cancer cases among Albertans aged 65 and older has more than doubled and the number of new cancer cases among Albertans aged 85 and older has almost tripled. Given that the number of new cancer cases among Canadians aged 65 and older is expected to increase by 68.6% from 2020 to 2040, and that among Canadians aged 75 and older is expected to increase by 114.6% in the same time frame,[112] the need to address the needs and concerns of older adults with cancer is paramount.

Although older adults comprise the majority of our cancer population, important age-based disparities in cancer research,[113-116] treatment,[117-119] and outcomes[120,121] suggest that age-related changes are not adequately addressed in cancer care.

In an analysis of US Food and Drug Administration data from 2005-2015, although adults aged 75 and older comprised about one-third (29% in 2013) of new cancer cases, they only represented only 12% of clinical trial participants.[116] Furthermore, in a recent review of oncologic clinical trials, on average participants were 6.5 years younger than the median age of the related patient population for the related cancer type, a gap

that is widening over time.[122] Older adults may be excluded from clinical trials due to age, functional status, or comorbidity.[122] Therefore, when making treatment decisions, clinicians and patients must often extrapolate from research done with younger, healthier patients and outcomes of importance to older adults, such as functional independence and quality of life, are often lacking.[113,115] Disparities in research extend to studies in supportive and psychosocial oncology care, with relevant tools, measures, and interventions often developed and validated in younger populations with a lack of attention to age-related concerns.[123,124]

Treatment disparities are evident in clear patterns of sub-optimal treatment that have been documented among older adults with cancer, including both undertreatment and overtreatment.[118] These patterns remain even when health status is considered.[119,125]

With respect to outcomes, across high income countries, including Canada, cancer survival is improving more slowly and to a lesser degree for those aged 75 and older.[120] Although often attributed to age or the presence of comorbidities, the impact of inappropriate screening and treatment decisions as well as lack of attention to age-related concerns that impact treatment adherence and tolerance, with a corresponding impact on optimal outcomes, must also be considered.

The factors that may contribute to these disparities are explored by researchers describing ageism in cancer care[126,127] and by those documenting unmet needs among older adults with cancer.[127-131] Unmet needs are reported by older adults during active cancer treatment[128,129] and into survivorship.[130] These unmet needs occur across physical, practical, and emotional domains,[127,130] with older adults expressing particular concern in addressing informational and medical support needs.[128]

In Alberta, programmatic attention to the needs and concerns of older Albertans with cancer and those close to them is lacking. Age-analysis of the 2021 Ambulatory Oncology Patient Satisfaction Survey demonstrated that grouping together all older adults aged 65 years and older obscured lower levels of satisfaction among those aged 75 years and older and/or those 85 years and older on many patient centered

dimensions of care, with significant differences across age groups on the coordination of care domain.[132]

Recommendations

Strategies to support consideration of age-related concerns in research, screening, diagnosis, oncologic treatment, and supportive care are critical to optimizing care for older adults with cancer.

There is a clear need to strengthen the inclusion of older adults in oncologic clinical trials,[115] adapt psychosocial interventions to consider the specific needs of older adults with cancer,[123] and ensure tools and measures are developed and validated with the consideration of older populations.[124] It is also important to recognize that grouping all older adults aged 65 and older together in analyses, particularly in analyses of patient-reported outcome and experience measures, may obscure the needs and concerns of those in older age groups (e.g., those aged 75 and older and/or those aged 85 and older); therefore, more specific age-analysis is recommended.[132] In clinical trials, and other research, it is also important to consider grouping not only by chronological age, but also by data on broader health and functional data collected using standardized geriatric assessment measures.[113,115] There is also opportunity to use innovative trial designs, consider outcomes of importance to older adults such as functional status and quality of life, and optimize use of real-world data to inform treatment recommendations.[113,115]

In screening and prevention, there is a need for targeted communication to promote early diagnosis. There is also an opportunity to integrate established frameworks to inform cancer screening decisions for older adults, ensuring those decisions are based on risk and health and functional status, not chronological age alone.[133]

In clinical cancer care, published guidelines by the American Society of Clinical Oncology,[134] National Comprehensive Cancer Network,[135] and the International Society of Geriatric Oncology[136] recommend assessment of age-related concerns to inform treatment decision making and supportive interventions to optimize outcomes. In a recent systematic review of randomized controlled trials, authors concluded

assessment and management of age-related concerns contributed to improved outcomes, including increased communication satisfaction and goals of care discussions, lower rates of toxicity/complications, improved likelihood of treatment completion, and improved quality of life and physical functioning.[137] Innovative models of care that integrate assessment of age-related concerns early in the cancer trajectory are needed to strengthen care of older adults, with services and resources extending to support of caregivers and family members.[108]

To prepare the cancer care workforce for the shifting demographics in the future cancer population, active strategies are needed. A scoping review conducted in the United Kingdom identified the need for (1) education and training in the assessment, management, and treatment of older adults with cancer, particularly related to comprehensive assessment, treatment decision making, communication skills, and awareness of age-related concerns that impact cancer care; (2) resources and tools to support practice; and (3) integration of skilled staff who understand the aging process.[138]

Older adult survivors themselves call for improvements in service delivery, support, and practical assistance, with particular attention to information/communication, and follow-up care.[131] This will require integrated and coordinated care among cancer care, primary care, other specialists involved in management of comorbidities, and community health and social support networks to promote optimal outcomes for older persons throughout the cancer care trajectory.

Conclusions and recommendations

Although there have been great improvements in cancer incidence and mortality in recent decades, these improvements likely have not occurred equally for all groups. In Canada, these disparities reflect the historical and political treatment of Indigenous groups, inattention towards racialized populations as well as sexual and gender minorities, a failure to account for the challenges faced by those with a low socio-economic status or mental illness, and a lack of attention to age-related needs and concerns. A common thread running through these recommendations is the lack of data

collection and availability for these populations. There is a great deal of value in collecting Alberta-specific data on individuals with mental health disorders, Indigenous peoples, racialized individuals, sexual and gender minorities, and various age groups to identify where resources are needed in the cancer care continuum.

The cultural changes necessary to improve the lives of all Albertans will take time and require the long-term focus that research projects can provide. Future research needs to focus on the following items:

- Ethical collection of data on sexual orientation, gender identity, and race or ethnicity.
- Meaningful engagement with Indigenous peoples in health-related research in the early stages of project planning.
- Investigation of the causes of poor outcomes among those with concurrent mental illness and cancer.
- Identifying and addressing the barriers to screening among those with low socio-economic status.
- Research on health inequities in cancer care with an intersectional-lens approach.
- Investigate methods of establishing long-term staffing stability for smaller, regional radiotherapy cancer centres, to facilitate ongoing equitable access to radiotherapy across the province.

The gaps in cancer care presented here are not unbridgeable. Alberta's health care system has both the foundations and the capacity to provide care to all and – to meet this ideal – we must provide the resources to those who need it most.

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Chapter 13: Childhood cancer in Alberta

> **Recommendations**
>
> - Expand development of new therapies for cancers with higher mortality and relapse rates such as brain tumors and soft tissue sarcomas. Explore novel personalized targeted chemotherapy drugs, precision radiation therapy including proton therapy, and immunotherapies that hold promising results.
>
> - Although Alberta has the required clinical expertise to involve children diagnosed with cancer in clinical trials, patient numbers are often too small to trigger the initiation of these studies, impeding the access by this population to novel therapies. Efforts are required to promote collaboration and to reduce barriers to initiating trials in the pediatric oncology arena. Enhance access to early phase clinical trials and novel therapies in pediatric oncology.
>
> - Children affected by cancer have unique medical and psychosocial needs and require specialized care. Improve access to specialized care, focusing on ensuring that treatment and supports for children diagnosed with cancer are designed specifically to serve this population and available in pediatric-appropriate formulations.
>
> - Interventions that may reduce physical and psychosocial late effects of cancer treatment in children include the reduction of exposure to toxic therapies, toxicity prediction through pharmacogenomics or screening, and enhanced support to survivors in dedicated comprehensive survivorship programs. Enhance understanding of long-term health issues related to childhood cancer and its treatment, and insights into their prevention.

Background

Childhood cancer is relatively uncommon, but remains the leading cause of disease-related death among children in Canada.[1,2] While a diagnosis of cancer is often extremely distressing to those diagnosed and their families, the rate of cure is high due to advancements in cancer treatment.[3] In more economically privileged countries, mortality rates for childhood cancer have declined by more than 50% over the last several decades, resulting in an exponential growth in the number of survivors.[4,5] Currently, there are approximately 500,000 survivors of childhood cancer in North America.[6] These survivors are faced with several challenges associated with

treatment. Treatment has many short-term effects including pain and fatigue, and late or long-term effects including delay in fine motor development, fatigue, and chronic or life-threatening conditions.[7,8] After diagnosis, it has been reported that up to 95% of childhood cancer survivors experience at least one chronic health condition later in life, and over 80% are diagnosed with a chronic or life-threatening condition.[9] In addition, the stress related to a cancer diagnosis often persists during treatment and survivorship.[10,11] As young adults and later in life, this population is at risk of experiencing challenges related their emotional well-being,[12,13] educational attainment, employment, social relationships, intimacy and fertility.[14,15]

In the Cancer in Young People in Canada report by the Public Health Agency of Canada[16] it was described that between 2001 and 2006, childhood cancer was diagnosed at a rate of 152 new cases per million children, an average of approximately 855 cases per year, with incidence rates greater for males than females and almost double for children aged 0 to 4 years when compared to children aged 5 to 14 years. Data also showed that patterns of diagnoses varied greatly between age groups. In infants under the age of one, neuroblastoma accounted for nearly one third of all cases (28.2%), followed by leukemias (17.5%) and central nervous system tumors (16.0%). Among 1 to 4 year old, leukemias accounted for 41.7% of all diagnoses, while among 5 to 9 year old and 10 to 14 year old lymphomas and bone tumors became increasingly common.[16] In terms of health outcomes, an overall diagnosis-related, five-year survival of 81.5% was reported, with differences between age groups and diagnosis. The lowest five-year survival rate was seen for infants diagnosed under the age of one year (77.4%), and for malignant bone tumors (62.0%) and soft tissue sarcomas (71.0%). The largest five-year survival proportions were seen for retinoblastoma (97.0%), carcinomas (91.3%) and lymphomas (91.3%).[16] Results from the Public Health Agency of Canada[16] also demonstrated that approximately 14.6% of children experienced a relapse within five years of diagnosis, being that more frequent among children diagnosed with malignant bone tumors and soft tissue sarcomas than among those diagnosed with other types of cancer (24.9% and 20.4%, respectively).

Alberta follows the national pattern, with 136 children (ages 0-14) diagnosed with cancer in 2018, and an increasing incidence rate since 1998.[17] Data from the 2021 Report on Cancer Statistics in Alberta[17] shows that for 2018, the most commonly diagnosed childhood cancers were leukemia (29%), central nervous system (18%), and lymphoma (11%), and that these cancers accounted for 58% of all childhood cancers. Over the period from 2014 to 2018, the most common cancer cause of death in children was central nervous system tumors (35%).[17] In terms of survival, the five-year observed survival rate for 2018 for all childhood cancers in Alberta was 83%, with 14 children dying from cancer.[17] Data from the Kids Cancer Care Foundation of Alberta[18] shows that in 2015, there were 1,269 survivors of childhood cancer residing in the province, and more than 75% of them are currently living with at least one chronic health condition (severe or life-threatening in 30% of cases) due to the cancer treatments they received as children.

Childhood cancer research

Research investment in childhood cancer may be quantitatively different from the investment in other cancers research due to the particularities of this cancer and its affected population. The [Canadian Cancer Research Alliance (CCRC)](#) is an alliance of organizations that work strategically to coordinate and collaborate on most of the cancer research conducted in Canada. Together, these organizations support cancer research that will lead to better ways to prevent, diagnose and treat cancer, and improve survivor outcomes.[19] CCRC has created a database that tracks research investments made in Canada over the past 15 years in cancers affecting childhood and adolescents (0-19 years).[20] Investment figures for the 2005-2019 period.[20,21] showed an upwards trend in recent years, despite a declining rate of children and adolescents participating in therapeutic clinical trials.[22] Data also showed a growing proportion of the overall cancer research investment used in childhood and adolescent cancers over time, which for the latest five-year period (2015-2019) was mostly related to funding programs not specific to childhood and adolescent cancers and related disorders.[20,21]

Research gaps and opportunities in childhood cancer were described in 2021 by Dr. Lindsay Jibb (Hospital for Sick Children (SickKids) and the University of Toronto). Dr.

Jibb and her team were awarded a CIHR grant to engage with children diagnosed with cancer, family members and clinicians across Canada to identify relevant unanswered questions in childhood cancer and survivorship, and determine future research priorities. Themes emerging from responses gathered from participants in Alberta were as follows:

More research and new therapies for cancer types associated with higher mortality and relapse rates such as brain tumors and soft tissue sarcomas. Novel personalized targeted chemotherapy drugs and immunotherapies hold promising results and should be further explored.

Enhanced access to early phase clinical trials and novel therapies. Although Alberta has the required clinical expertise to involve children diagnosed with cancer in clinical trials, patient numbers are often too small to trigger the initiation of these studies, impeding the access by this population to novel therapies. In addition, the small size of the population together with the difficulties related to drug approval processes makes the overall Canadian market somewhat unattractive to study sponsors. Efforts are required to promote collaboration and to reduce bureaucracy associated with initiating trials in the pediatric oncology arena.

Improved access to specialized care. Children affected by cancer have unique medical and psychosocial needs and require specialized care. Efforts need to focus on ensuring that treatment and supports for children diagnosed with cancer are designed specifically to serve this population and available in pediatric-appropriate formulations.

Better understanding of long-term health issues related to childhood cancer and its treatment, and insights into their prevention. Some interventions potentially effective in reducing both physical and psychosocial late effects might include the reduction of exposure to toxic therapies whenever possible, toxicity prediction through pharmacogenomics or screening, and enhanced support to survivors in dedicated comprehensive survivorship programs. An additional relevant component might be the provision of better psychosocial supports to families, friends and caregivers (e.g., peer

support groups, enhanced shared decision-making, navigation) throughout and after treatment.

 In Alberta, there are different examples of leadership in many of these priority areas. An example is the Alberta Children's Hospital Research Institute (ACHRI) at the University of Calgary, in partnership with Alberta Children's Hospital and the Alberta Children's Hospital Foundation. At the intersection of strength and opportunity, ACHRI has created a Program in collaboration with the Arnie Charbonneau Cancer Institute for researchers in [Childhood Cancer and Blood Disorders](). The integrated and interdisciplinary team led by Dr. Greg Guilcher aims to advance understanding of the biology and sequelae of childhood cancers and blood disorders, and to use existing and new knowledge to improve their diagnosis and treatment.[23] Another example is the Women & Children's Health Research Institute (WCHRI), a partnership between the University of Alberta and Alberta Health Services, with core funding from the Stollery Children's Hospital Foundation and the Alberta Women's Health Foundation. Within WCHRI, Dr. Amit Bhavsar is leading a team working to understand the biological processes that result in these adverse drug reactions, and how this can be prevented.[24]

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Chapter 14: Enabling factors for improving research and care in Alberta

> **Key findings**
>
> - In Alberta, population-based chart reviews are possible due to the provincial electronic medical record system. Linking these data to administrative databases can generate a wealth of information.
>
> - Alberta's Strategic Clinical Networks (SCNs) catalyze health system innovation and improvement provincially, through effective partnerships, leadership, and careful priority setting.
>
> - The Cancer SCN's mission is to lead transformation to improve care across the cancer continuum.

Data sources

Alberta is unique in that it has a provincial electronic medical record system. As such, it is possible to conduct population-based chart reviews at the provincial level which contrasts other regions where one can only review charts from a select group of treatment facilities. Therefore, it is feasible to conduct a chart review for the entire province including a total of 17 cancer centres (two tertiary, four regional, and 11 community hospitals). In addition, data captured from chart reviews can be linked to the following administrative databases:

- Discharge Abstract Database (DAD): The DAD database captures information for each instance where an individual has been discharged from an inpatient hospital bed. This database contains International Classification of Diseases, Tenth Revision – Canadian Enhancement (ICD-10-CA) diagnostic codes for the most responsible diagnosis and secondary diagnoses. Information is also captured on procedures that occurred during the hospitalization. Such procedures are coded according to the Canadian Classification of Health Interventions (CCI) system. In addition, information on the date and the duration of the hospitalization are also available as are information on aspects of patient costs such as the resource intensity weight. Data accuracy and quality are assessed on a regular basis by hospital administration and the Canadian Institute for Health Information (CIHI).

- National Ambulatory Care Reporting System Database (NACRS): The NACRS database captures information on all inpatient and outpatient use of ambulatory care services. This database contains ICD-10-CA diagnostic codes and the date

of service. As with the DAD, data accuracy and quality are assessed on a regular basis by hospital administration and the Canadian Institute for Health Information (CIHI).

- Practitioner Claims Database (PC): The PC database captures physician and allied practitioner claims used for reimbursement and shadow-billing purposes that have been processed by the Alberta government. This database includes information such as the processed claim amount, diagnostic codes (ICD-9-CM: International Classification of Diseases, Ninth Revision – Clinical Modification), and health service codes (Canadian Classification of Diagnostic, Therapeutic, and Surgical Procedures).

- Population Registry: This database includes information related to birth and death dates as well as migration out of province for all Albertans with Alberta Health Care Insurance Plan (AHCIP) coverage.

- Pharmaceutical Information Network Database (PIN): The PIN database captures information on all prescription drugs dispensed from community pharmacies in the province. Information within the PIN database is collected from community pharmacists and includes information on the drug name, dose, and quantity dispensed. Complete information from this database is available starting in 2010. While data are available prior to 2010, these data are incomplete since they were collected prior to the enactment of regulations that mandated the collection of pharmacy dispensary records which occurred in 2007.

- ARIA Medical Oncology (MO): The ARIA database consists of electronic medical records for all 17 provincial cancer centres (two tertiary, four regional and 11 community) covering the 4.5 million residents of Alberta. This database contains information related to patient care including systemic therapies (e.g., the date and dose of each agent within each cycle of each chemotherapy regimen), radiation therapy, treatment facility and visits with cancer physicians (including specialty type).

- Alberta Cancer Registry (ACR): Cancer is a reportable disease within the province of Alberta. The ACR captures information on all individuals diagnosed with cancer within the province of Alberta (200,000+ cases). This database also includes information related to cancer morphology and stage which are captured from pathology, physician, and laboratory reports, electronic medical records, along with patient charts. In addition, this database houses information on the date and cause of death along with the last known date of follow-up which are captured via vital statistics and the population registry.

- Data Environment for Cancer Inquiries and Decisions (DECIDe): This data warehouse is currently in development to further improve cancer data access in Alberta. DECIDe will integrate the multiple cancer data systems and map to new Epic EMR data (expected implementation for Cancer Care in November 2022) in an automated, documented, and sustainable way. It will automate the linkage of provincial cancer data that currently involves the time consuming, access, comparison, and analysis of information. With the implementation of Epic (provincial EMR) this will be even more complex, especially for temporal trends across the continuum. DECIDe will provide streamlined access to all cancer patient data from multiple sources by linking and mapping from original treatment data (ARIA MO) to Epic in a standard and documented way. The initial development of DECIDe will include data from ACR, Cancer Surgery Alberta, Patient Reported Outcomes, Alberta Thoracic Oncology Program, ARIA MO (EMR), ARIA Radiation Oncology, and the new EMR (Epic). ACR and ARIA Radiation Oncology will continue to function in the current way to meet operational needs. ACR and ARIA Radiation Oncology data will automatically be integrated into DECIDe and linked to other datasets thereby enabling analytics inclusive of these. It will be directly accessible to approved analysts within Alberta Health Services in order to provide automated dashboards, analysis and high quality extracts to researchers. The subsequent phase (Phase 2 –2022/23) will expand the data holdings to incorporate Alberta's Tomorrow Project and the Alberta Cancer Research Biobank. To our knowledge, this will be the only population-based cancer data warehouse in North America covering the entire population of Alberta (4.4 million in 2021).

Alberta's Strategic Clinical Networks: Supporting health system improvement

Alberta's Strategic Clinical Networks (SCNs) are unique in Canada. They catalyze health system innovation and improvement provincially, through effective partnerships, leadership, and careful priority setting.[1,2]

By design, the SCNs are embedded within a single, integrated health system.[2] This structure enables SCNs to maximize available health resources, assess current practices, and implement health system changes on a provincial scale.[3] Alberta Health Services (AHS) launched its first SCNs in 2012. Currently, there are 11 SCNs and five provincial programs, each focusing on a specific area of health, and comprised of clinicians, patients, operational leaders, government and other stakeholders across the health spectrum (https://www.albertahealthservices.ca/scns/scn.aspx).

All SCNs share the commitment to provide high quality, person-centered and sustainable healthcare to all Albertans, and are united by a common mission: to improve the health of Albertans by bringing together people, research and innovation.[3,4] SCNs develop integrated care pathways, support local and system-wide improvements, and use evidence and measurement to improve patient and family experiences, quality of care, health outcomes, and health system sustainability. The SCN's commitment to patient and stakeholder engagement is an important area of strength. The work of the SCNs supports a learning health system and appropriate, high-value care for every Albertan.[2,3]

Since their inception, the SCN have played an important role in advancing health system improvement, sustainability, and transformation.[5] In terms of value and health system sustainability, a comprehensive analysis of return on investment done in 2015 for the first nine SCN projects showed an estimated cumulative savings of over $43 million, representing a 2:1 return on investment, meaning that every dollar invested in SCN activities produced two dollars in savings.[6] The SCNs have also delivered substantial value by improving patient outcomes, safety, care satisfaction, and quality of life.[3,7] Particular achievements of the SCNs can be found in the 2018 SCN Retrospective document,[6] and the articles included in a 2019 supplement of the Canadian Medical Association Journal (https://www.cmaj.ca/content/191/supplement/S54).

The Cancer SCN

The Cancer SCN was established in 2012 with the mandate to lead health system improvements for Albertans at risk or with a diagnosis of cancer.[8] As established in the Cancer SCN's strategic plan, the 2020-2024 Transformational Roadmap,[9] the Cancer SCN's mission is to lead transformation to improve care across the cancer continuum. The Cancer SCN works with a diversity of stakeholders to improve linkages between services and programs, to translate evidence and data into practice, and to enhance care experiences for patients and families, outcomes and system efficiencies.[9]

Within the AHS organizational structure, the Cancer SCN is in the unique position of being aligned with Cancer Care Alberta (CCA), while being part of the broader SCN family. The alignment with CCA enables collaboration on priority settings and a better understanding of operational issues.[8] Belonging to the SCN family allows the interaction with a wide range of stakeholders, and facilitates collective learning about successful tools and approaches for improving the health of Albertans.[10]

A crucial element of the Cancer SCN is its Core Committee, which includes patient and family advisors, representatives from national and provincial organizations, clinical leaders and experts, researchers, primary care, operational leaders (provincial and zone), community health, industry representatives, provincial cancer foundations, members of provincial and national organizations, and government.[9] Core Committee members work closely with the Cancer SCN leadership to provide important insights into its work. They help identify emerging issues, assist with priority setting, and contribute to planning and solution design. Importantly, Core Committee members are proponents of change, bringing not only a wide range of expertise and experience, but also voices of and access to broader communities that can be mobilized when required to advance innovation and health system improvements.[9]

The Cancer SCN has had many achievements since its inception. A more detailed overview of the Cancer SCN's approach, its major initiatives and outcomes can be found in the Cancer SCN's strategic documents,[9,11] the Cancer SCN article in the 2019 supplement of the Canadian Medical Association,[8] and the Cancer SCN website.

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Appendix 2: Glossary of terms

Age-specific incidence: The proportion of new cancer cases per year within a given age group

Age-standardized (incidence/mortality) rate: The number of cancer cases or deaths occurring in a defined population over a specified period of time after adjusting for age. Because different cancers occur more frequently at different ages, to compare rates among two populations, one has to statistically "adjust" them so they have the same proportions of people in each age group.

Bisexual: A person who is attracted to people of their own and other genders.

Cancer risk (lifetime risk): The probability of developing cancer or dying from cancer across a person's lifetime

Cancer site specific incidence: The proportion of new cancer cases per year within a given body part or organ

Count: The number of cancer cases (primaries) or deaths in a given time period

Cisgender: Individuals whose current gender identity is the same as the sex they were assigned at birth.

Determinants of health (social determinants of health): The personal, social, economic and environmental factors that influence the health of individuals and populations such as income, housing, food security, or social connections

End-of-life care: Care provided to patients and their families when they are approaching a period of time closer to death such as grief support, and pain and symptom management

Ethnicity: The multi-faceted characteristics of a group sharing certain traits in common. Ethnicity is associated with ancestry, cultural traditions and languages. Ethnicity is based on self-identification, whereas race is imposed on a population by society.

First Nations: Refers to the original Peoples of Canada. First Nations people include both Status (a person who is registered as a First Nation or Inuit under the Indian Act) and Non-status (a person who self-identifies but is not registered as a First Nation or Inuit under the Indian Act). The term "First Nation" can refer to an individual, a community (or reserves), or its government (or band councils).

Gay: A person who is attracted primarily to members of the same gender.

Gender non-binary: Individuals who do not identify their gender as either man or woman.

Health equity: The equal opportunity of all persons to reach their best possible health status

Indigenous: Descendants of the original inhabitants of a land or territory. The Canadian Constitution recognizes the following three groups of Indigenous people: First Nations, Métis, and Inuit (FNIM).

Immigrant: A person born outside of Canada who currently resides within the nation and who has sought permanent residence in Canada. Known as landed immigrants, these individuals have been granted the right to live in Canada permanently by immigration authorities.

Incidence (incidence count): The number of new cancer cases during a period of time

Intersectionality: The interconnected nature of social categorizations such as race, class and gender as they apply to a given individual or group, regarded as creating overlapping and interdependent systems of discrimination or disadvantage.

Intersex: A person who is born with any range of sex characteristics that may not fit typical notions of binary male or female bodies.

Inuit: Indigenous peoples of Arctic Canada who self-identify as Inuit.

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Lesbian: A woman who is primarily attracted to other women.

Métis: Peoples of mixed First Nations and European ancestry who identify themselves as Métis and are accepted as such by Métis organizations.

Model of care (care model): The way in which care is provided according to a set of rules, guidelines, principles, tasks and activities

Morbidity: Being ill or unhealthy from a disease or condition

Mortality (mortality count): The number of deaths due to cancer during a period of time

Palliative care: Palliative care aims to improve the goal for patients and families facing the problems associated with a life-limiting illness through the prevention and relief of suffering by means of early identification, comprehensive interdisciplinary assessments, and appropriate interventions

Prevalence: The number existing cancer cases for a population at a given time

Primary cancer site: The tissue or organ in which the cancer originates

Projection: An estimate of cancer incidence or mortality in the future

Queer: An umbrella term sometimes used to refer to the entire sexual- and gender-minority community.

Race: A social construct that is politically, historically and socially informed; contextually dependent; and there is no universal measure for it. People are generally classified into racialized groups based on perceived physical differences such as skin colour and facial features.

Racialized: The process of manufacturing and utilizing the notion of race in any capacity.

Rate: The number of cases or deaths occurring in a defined population over a specified period of time

Refugee: A person who, due to a well-founded fear of being persecuted for reasons of race; religion; nationality; sexual orientation or gender identity; membership of a particular social group; or political opinion; is outside their country of nationality, and is unable to or, owing to such fear, unwilling to avail themself of the protection of that country.

Sex-specific incidence: The proportion of new cancer cases per year within a given sex group

Social determinants of health: The social conditions in which people are born, grow up, live, work and age, including the health system. The range of personal, social, economic and environmental factors that determine the health status of individuals and populations.

Socio-economic status: A measure of social position that may include education level, employment, social class and income.

Survival (observed survival): The proportion of people with a particular cancer who are alive after a given length of time

Stage of cancer: 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.

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

Survival: The proportion of people alive at a given time after the diagnosis of their cancer

Transitions in care: Movement of patients between levels of health care providers or services such as between hospitals and the community or between family doctors and specialists

Transgender: Individuals whose current gender identity differs from the sex they were assigned at birth.

Two-spirit: A person who identifies as having both a masculine and feminine spirit; used by some Indigenous peoples to describe their sexual, gender or spiritual identity.

Virtual care: Care provided in a manner that does not involve physical presence in the same location

Visible minorities: Persons who are identified, according to the Employment Equity Act, as being non-Caucasian in race or non-white in colour. Under the Act, Indigenous persons are not considered to be members of visible minority groups.

Appendix 3: Methodology and analytic approach used in Chapters 1-4

Cancer incidence, prevalence and mortality

Cancer incidence and mortality data in Alberta from the years 1998 to 2018, and limited-duration cancer prevalence data in Alberta from the years 2000 to 2019 by cancer site, sex and five-year age group, were acquired from the Surveillance & Reporting group within Cancer Care Alberta, Alberta Health Services. Future incidence, mortality, and prevalence rates were estimated using the Canproj statistical tool, which was developed in Alberta and is used nationally.[1] Absolute cases of future cancer incidence, mortality and prevalence were estimated based on a medium population growth scenario.[2]

Canproj is an R package that has nine projection models, which include the Nordpred model which incorporates age, drift, period and cohort effects; the age-cohort model; three hybrid models that incorporate age and potentially period effects (age-specific or all ages); a 5-year average model; and Poisson or negative-binomial distribution can be selected for Nordpred, age-cohort, and hybrid age-specific models.

The Canproj package uses a decision tree to determine which model is the most appropriate based on the significance of the variables. Canproj begins with the most complex model (i.e., Nordpred) with age, period, cohort and a drift parameter. Canproj first determines if the cohort variable is significant. If it is significant, Canproj determines if the drift parameter is significant. If both parameters are significant, Canproj selects the Nordpred model to make the projections. If the cohort variable is significant but the drift parameter is not, Canproj selects the age–cohort model. Overdispersion is tested to determine whether Poisson or negative-binomial distribution is selected.[3,4]

If the cohort effect is not significant, Canproj selects one of the hybrid models. The hybrid models take the advantages of the Poisson regression method, the average method, and the joinpoint type methods to fit the best regression model. The estimated

parameters are used to extrapolate future age-specific rates. If the number of cases is too small to run a regression model, a 5-year average is calculated. If the number of cases is big enough, Canproj will fit two models: an age-common trend model (the period trend is common to all age groups) and an age-specific trend model (the period trend is calculated by age group). If the age-specific model has a better fit, this model is selected and overdispersion is tested to select between Poisson or negative-binomial distribution. If the age-common trend model has a better fit, the slope of the common trend variable is then tested to determine if it differs from zero. If it differs from zero, the age-common trend model is used. If it is not different from zero, then only the age variable is used in the model (i.e., hybrid age-only model). Alternatively, users may select individual model that is considered most appropriate for the projection.

Limitations of methodology of Chapters 1-3

The limitations of methodology in the projections of cancer incidence, mortality, and prevalence in Chapters 1-3 pertained to two aspects: data quality and analytic approach.

Data quality

Cancer incidence, mortality, and prevalence data used to project these statistics to 2040 were taken from the Alberta Cancer Registry (ACR). ACR has maintained the highest Gold Certification status from the North American Association of Central Cancer Registries since the inception of gold certification in 2005 and has cancer data of the highest quality. Nevertheless, the occurrence of certain cancer cases or deaths may be registered in subsequent years, and that may influence some of the projected trends. In addition, changes in methods to identify cancer cases over time may have an impact on the number of documented cases, and this may influence subsequent projections. Finally, Statistics Canada's National Death Clearance Overview captures deaths that occur in the Canadian provinces. It has been on hold since 2009 pending legal agreements between Statistics Canada and the provinces and territories. As such, complete follow-up for cases 2009 and later may be impacted until an agreement is reached. This might cause incomplete reporting of cancer deaths, which would lead to

slightly underestimated cancer mortality trend and overestimated cancer prevalence trend.

Analytic approach

We used age-period-cohort models implemented through the Canproj statistical package for the projection of cancer incidence, mortality, and prevalence. The age-period-cohort models rely on assumptions that general historical and recent trends will continue, and these trends may not hold in the real world. Therefore, even though our analysis were based on validated and widely used models, long-term projections involve considerable uncertainty and therefore should be interpreted with caution. For example, a breakthrough in cancer treatment might greatly reduce mortality, leading to a higher prevalence than projected. Changes in cancer screening guidelines may have great impacts in cancer incidence and prevalence, such as observed in prostate cancer. Increased participation in current population-based screening programs (i.e. cervix, breast and colorectal cancer) or introduction of new screening programs (e.g., low-dose CT scan for lung cancer for higher risk individuals) will likely affect both cancer incidence, mortality, and prevalence. Also, the COVID-19 pandemic, or other future disruptive events, will likely have some additional unforeseen impact on patient outcomes that are not accounted for in these models. Furthermore, the projection results can vary considerably, depending on the choice of models. For example, we noticed that the nine models in Canproj led to distinctly different projections for the prevalence of bladder, kidney and thyroid cancers. Consequentially, there is a large degree of uncertainty associated with our projection, which will increase further into the future. We present these data as a set of general scenarios while acknowledging this uncertainty.

Data Definitions

Cancer	ICD-O-3 Site/Histology Type* (Incidence)	ICD-10 (Mortality)
Oral	C00–C14	C00–C14
Esophagus	C15	C15
Stomach	C16	C16
Colorectal	C18–C20, C26.0	C18–C20, C26.0
Liver	C22.0	C22.0, C22.2–C22.7
Pancreas	C25	C25
Larynx	C32	C32
Lung and bronchus	C34	C34
Melanoma	C44 (Type 8720–8790)	C43
Breast	C50	C50
Cervix	C53	C53
Body of Uterus	C54–C55	C54–C55
Ovary	C56.9	C56
Prostate	C61.9	C61
Testis	C62	C62
Bladder (including *in situ* for incidence)	C67	C67
Kidney and renal pelvis	C64.9, C65.9	C64–C65
Brain/CNS	C70–C72	C70–C72
Thyroid	C73.9	C73
Hodgkin Lymphoma*	Type 9650–9667	C81
Non-Hodgkin Lymphoma*	Type 9590–9597,9670–9729, 9735-9738 Type 9811-9818, 9823, 9827, 9837, all sites except C42.0,.1,.4	C82–C86,C96.3
Multiple Myeloma*	Type 9731,9732,9734	C90.0, C90.2
Leukemia*	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 and 9837 sites C42.0,.1,.4	C91–C95,C90.1
All Other Cancers	All sites C00–C80 not listed above (excluding non-melanoma skin cancer)	All sites C00–C80 and C97 not listed above
All Cancers	All invasive sites†‡	All invasive sites ‡

* Histology types 9590–9992 (leukemia, lymphoma and multiple myeloma), 9050–9055 (mesothelioma) and 9140 (Kaposi Sarcoma) are excluded from other specific organ sites.
† Only invasive cancers were included in the incidence analysis except bladder, which also included in in situ.
‡ Basal and squamous skin cancers were excluded from incidence analysis but included in the mortality analysis.

The following cancer types are available in the IHDA and defined by the following ICD codes: Breast Female only (ICD-9: 174; ICD-10: c50) Lung (ICD-9: 1622-1625, 1628, 1629; ICD-10: c34) Prostate (ICD-9: 185; ICD-10: c61) Colorectal (ICD-9: 153, 154, 1590; ICD-10: c20, c260) Bladder (in-situ and invasive) (ICD-9: 188, 2337; ICD-10: c67, D090) NHL (ICD-9: 200, 2020- 2022, 2028; ICD-10: c82-c85,c963) Melanoma (ICD-9: 172; ICD-10: c43) Methods for coding of cancers in the Alberta Cancer Registry have varied through the years. Therefore, caution should be exercised when evaluating trends. Please note the numbers provided in the lists are provisional as some cases may be registered in subsequent years. The Alberta Cancer Registry incidence is dynamic, and case reporting is the legislative responsibility of the physician and/or

laboratory. Case finding methods have changed over time with the additions of new technologies. In particular, starting in 2016 changes in pathology reporting may have caused under-reporting of certain cancer anatomical sites. As these issues are rectified, we have seen fluctuations in cancer incidence. Therefore, caution should be exercised when evaluating trends

Cancer survival

To contextualize cancer survival trends in Alberta among the top-performing countries, published data were retrieved from the ICBP SURVMARK-2 online tool: International Cancer Survival Benchmarking.[5] This tool includes longitudinal population-based data on primary invasive cancers based on International Classification of Diseases-10 (ICD-10) codes, including cancers of the esophagus (C15), stomach (C16), colon (C18-19), rectum (C20), colorectum, pancreas (C25), lung (C33) and ovary (C48.1-2, C56, C57.0) from population-based cancer registries covering 21 jurisdictions in seven countries: Australia (New South Wales, Victoria and Western Australia), Canada and each province, Denmark, Ireland, New Zealand, Norway and the UK (England, Northern Ireland, Scotland and Wales). The data include cases diagnosed in the period 1995–2014.[5]

Net survival was estimated by population-based cancer survival, which was defined as the survival of patients in a defined resident population if cancer was the only possible cause of death, with accompanying 95% confidence intervals (95% CI). Net survival was estimated for each primary site in each jurisdiction and for the Canadian, Australian and UK jurisdictions combined. Net survival at one, three, and five years after diagnosis was computed by age, sex, period and cancer site for each jurisdiction using the Pohar–Perme estimator.[6,7] Age-standardization was carried out using international cancer survival standard weights.[8] The cohort approach was used for 1995–1999, 2000–2004 and 2005–2009, and the period approach was used for 2010–2014.[9]

For this synthesis, we pulled one- and five-year age-standardized net survival estimates (with 95% CIs) in Alberta for all available cancer sites from 1995–2014 in five-year periods: 1995–1999, 2000–2004, 2005–2009 and 2010–2014. We also calculated the

absolute and relative percent change in net survival from 1995–1999 to 2010–2014. Absolute percent change was defined as the absolute difference in net survival between 1995–1999 and 2010–2014. Relative percent change was defined as the difference in net survival between 1995–1999 and 2010–2014, divided by net survival in 1995–1999, then multiplied by 100%. Change in net survival in one- and five-year periods was compared between the seven cancer sites in the overall Albertan population (both sexes, all ages), by sex (male, female) and by age group (15–54, 55–64, 65–74, 75+ years). The absolute and relative percent change from 1995–1999 to 2010–2014 was compared between cancer sites in the overall population and by sex and age group. Within each cancer site, we compared change in net survival in one- and five-year periods between males and females, and between the four age groups. Further, within each cancer site, absolute and relative percent change from 1995–1999 to 2010–2014 was compared between males and females, and between the four age groups. Finally, for each cancer site, we compared change in net survival in five-year periods between Alberta and Ontario, British Columbia, Canada, Australia and the UK. Given the high correlation between colon, colorectal and rectal cancers, this synthesis only reports data on colorectal cancer. Visualizations of net survival comparisons were generated using Microsoft Excel.

Population attributable risk of cancer

Various analyses can be conducted to estimate the impact of primary prevention on cancer incidence in Alberta. We used population attributable risk (PAR) to estimate the proportion of cancer cases in Alberta associated with modifiable risk factors.

To estimate the present and future PAR of cancer in Alberta associated with various modifiable cancer risk factors, data on the prevalence of lifestyle and environmental exposures, and measures of risk between exposure-cancer site pairs and cancer incidence for Alberta, were required. Detailed methods for the PAR approach used here have been reported previously.[10]

Risk estimates

Measures of exposure-cancer risk (relative risks or odds ratios) from the IARC Monographs and the WCRF Continuous Update Project reports for modifiable risk

factors with known, probable, convincing or sufficient evidence of an association with cancer were abstracted. Additional exposure-cancer associations suggested by recent studies were identified through reviews of recently published, high-quality systematic reviews and meta-analyses. We excluded exposures for which the evidence was inconsistent. For risk factors where a summary risk estimate was not available, a meta-analysis of published studies was conducted.

Exposure prevalence

Population-based national health surveys, including the Canadian Community Health Survey (CCHS),[11] the Canadian Health Measures Survey[12] and the Second National Sun Survey[13] were used to estimate the population-level prevalence of lifestyle and environmental exposures among Albertans. For most exposures, we used a latency period of 12–15 years (i.e., we assumed the cancer incidence in 2015 was due to the exposure prevalence in 2000–2003).

For environmental factors (e.g., air pollution, UVR, radon) for which the entire population is exposed, specific methods were used to estimate PAR.[14-16]

Cancer incidence

Cancer incidence data for the year 2015 were obtained from the Canadian Cancer Registry (CCR) at Statistics Canada. Cancers in the CCR are coded using the International Classification of Diseases for Oncology, 3rd Edition (ICD-O-3). The 2015 incidence data were the most recent data available at the time of the study.

- Age standardized rates are calculated over j age strata as: $R = \sum wj \frac{ej}{nj} J j=1$ where ej represents the number of events in the jth stratum, and nj represents the number of individuals in the jth stratum. The standardization weights wj are given by: $wj = nj* / \sum nj J j=1$ where nj* represent the number of people in the jth age stratum in the standard population. The same weights are applied to the crude rates for males, females, and both sexes combined. When an indicator is calculated for a subset of all age strata, standardization weights are rescaled so that they still sum to one.

PAR estimation

For risk factors with prevalence data at the population level, PAR was calculated by Levin's equation[17]

$$PAR = \frac{\sum_x P_x (RR_x - 1)}{1 + \sum_x P_x (RR_x - 1)}$$

where P_x is the prevalence within each category x and RR_x is the RR for each risk category relative to the reference category.

Exposure projections

The future prevalence (to 2032) of active and passive smoking, high body mass index, low physical activity, sedentary behavior, alcohol consumption, red and processed meat intake, and low fruit and vegetable intake were estimated based on data from three cycles of the National Population Health Survey (1994–1998)[18] and five cycles of the CCHS (2000–2011).[11] Using data from 1993–2014, we projected future average air pollution levels to 2036 using Canada-wide historical satellite data from 1993 to 2014. Our projections were based on the assumption that the trend observed from the historical data will continue into the future without reversion.

Cancer incidence projections

Established methods for cancer projections were used as previously described.[19] Cancer incidences for Alberta were projected to 2038 based on 1983–2015 cancer incidence data and the available modelling for projected populations from Statistics Canada. All projected results were evaluated for statistical goodness-of-fit using the Pearson's chi-squared test as well as on-face validity based on expert opinion.

Future avoidable cancer incidence

Potential impact fractions (PIFs) were used to estimate the future preventable impact of cancer in Alberta. Evidence-based intervention targets from the scientific literature were used for estimating PIF under varying scenarios. Depending on whether the intervention targets were assumed to change the prevalence of exposure, the distribution of risk factor or the relative risks, proportions shift, distribution shift or RR shift methods were used to estimate PIF.[10]

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Appendix 4. List of drugs in the Outpatient Cancer Drug Benefit Program that account for most of the cost

The following are drugs in the Outpatient Cancer Drug Benefit Program (including over 150 drugs;[1] that accounted for ~80% of the 2020 cancer drug budget in Alberta (C. Chambers, personal communication, February 23, 2022).

Immunomodulatory drugs (IMiDS)
      Lenalidomide* (myeloma)
      Pomalidomide (myeloma),

Immune therapy (checkpoint inhibitors)
  PD1-inhibitors
      Pembrolizumab* (melanoma, lung, renal, Hodgkin lymphoma, head & neck, bladder)
      Nivolumab* (melanoma, lung, renal, Hodgkin lymphoma, head & neck)
      Durvalumab (lung)
  CTLA4-inhibitor
      Ipilimumab (melanoma)

Monoclonal antibodies
      Daratumumab (myeloma)
      Rituximab* SC (CD20+ lymphoma)
      Trastuzumab* (HER2+ breast and gastric)
      Pertuzumab (HER2+ breast)

Targeted oral small molecules
      Ibrutinib* (BTK-inhibitor for CLL, mantle cell lymphoma)
      Palbociclib (CDK4/6 inhibitor for ER+ breast cancer)
      Osimertinib (EGFR mutated lung)
      Ruxolitinib (janus kinase (JAK) inhibitor for myelofibrosis, polycythemia vera)
      Imatinib* (BCR-ABL inhibitor for CML, ALL with t(9;22), GIST)
      Alectinib (anaplastic lymphoma kinase (ALK)-positive lung)

Dasatinib* (BCR-ABL inhibitor for CML, ALL with t(9;22))

Hormone therapy
Leuprolide* GEL DEPO (prostate, breast)
Abiraterone (prostate)
Enzalutamide* (prostate)

Cytotoxic chemotherapy
Bendamustine* (lymphoma)

Antibody-drug conjugates
Trastuzumab emtansine-Kadcyla (HER2+ breast)

* Drugs included on the World Health Organization Model List of Essential Medicines – 22nd List, 2021. Geneva: World Health Organization; 2021 (WHO/MHP/HPS/EML/2021.02). Licence: CC BY-NC-SA 3.0 IGO. https://www.who.int/publications/i/item/WHO-MHP-HPS-EML-2021.02. The core list presents minimum medicine needs for a basic health-care system, listing the most efficacious, safe and cost–effective medicines for priority conditions.

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Appendix 5. Future systemic treatments for most common cancers

New treatments identified by Alberta Tumor Team members as advances that will likely be implemented between now and 2030 include:

For breast cancer:

ER-/HER2- (triple negative breast cancer):
- PD1 inhibitors (e.g., Pembrolizumab) in early and advanced stage settings
- Poly adenosine diphosphate-ribose polymerase (PARP) DNA repair inhibitors (e.g., Olaparib) – adjuvant therapy for high risk early stage breast cancer patients with BRCA1/2 mutations
- Antibody drug conjugate (e.g., Sacituzumab Govitecan) for advanced stage

ER+/HER2-:
- CDK4/6 inhibitors (e.g., Abemaciclib) with endocrine therapy as adjuvant treatment for high risk node positive ER+/HER2- stage 2-3 breast cancer
- Subsequent lines endocrine therapy: AKT inhibitor (e.g., capivasertib) plus fulvestrant or Selective Estrogen Receptor Degraders (SERDs, e.g., Elacestrant)

HER2+:
- New antibody-drug conjugate (Trastuzumab deruxtecan, T-DXd) to replace trastuzumab emtansine (T-DM1) for advanced stage disease, and possibly early stage indications

For lung cancer:

New targeted therapy agents for actionable mutations in lung cancer. "Liquid biopsy" (genome sequencing on blood to evaluate circulating tumor DNA) is an exciting test that can detect actionable mutations in lung cancer through a blood test. Ongoing studies are examining how to incorporate this in early stage and advanced lung cancer to facilitate personalized medicine.

Targeted Agents:
- Adjuvant osimertinib for EGFR+ early stage NSCLC instead of only advanced stage
- New targeted agents will be used for NSCLC with know driver oncogenes (i.e., EGFR sensitive mutations; ALK; ROS-1, MET exon 14; BRAF V600; RET; EGFR exon 20 resistance, HER2)
  Examples:
  - Capmatinib is active against MET Exon 14–Mutated or MET-Amplified NSCLC
  - Sotorasib to treat advanced KRAS G12C-mutated lung cancer
  - Antibody drug conjugates such as Trastuzumab deruxtecan for HER2+ NSCLC

Immunotherapy:

- Immunotherapy continues to improve survival in advanced stage lung cancer, and likely will be shown effective for use in the adjuvant setting for early stage lung cancer after surgical resection and is also being studied prior to surgery
- New combinations of immunotherapy will likely be used for advanced stage non-small cell lung cancer (NSCLC) such as inhibitors of PD1/PDL-1 and TIGIT (T-cell immunoreceptor with Ig and ITIM domains)
- PD1/PDL1 inhibitors will likely also to be integrated into therapy for small cell lung cancer (SCLC) and mesothelioma. Anti-CD56 CAR T-cell therapy is under study for SCLC

For gastrointestinal cancers:

Rectal cancer:

- Total neoadjuvant therapy (short course RT -> chemotherapy -> surgery) with organ preservation strategies

Metastatic colorectal cancer:

- BRAF inhibitor (e.g., Encorafenib) and EGFR inhibition for BRAF mutated colorectal cancer. Pembrolizumab for DNA mismatch repair deficient colorectal cancer. In the future, more targeted therapies for emerging subsets of colorectal cancer based on molecular profiling such as NTRK fusions and HER2 amplification.

Esophageal cancer:

- Adjuvant nivolumab immunotherapy after chemoradiation and surgery

Metastatic upper GI cancers:

- immunotherapy plus platinum based chemotherapy as well as novel HER2 targeted agents for HER2 positive metastatic upper GI cancers

Hepatocellular carcinoma:

- Durvalumab and tremelimumab immunotherapy

Cholangiocarcinoma:

- Durvalumab with cisplatin/gemcitabine for metastatic disease. More targeted therapies for intrahepatic cholangiocarcinomas based on molecular profiling such as FGFR inhibitors for FGFR fusion positive cancers, ivosidenib for IDH mutated cholangiocarcinoma, TRK inhibitor therapy for NTRK fusion positive cancers

For genitourinary cancers

Prostate:

- Androgen receptor targeted therapy (ARAT) (e.g. abiraterone) for high risk local disease

- Following ARAT therapy, prostate specific membrane antigen PET/CT imaging (PSMA)-directed radiopharmaceutical therapy for advanced disease with the introduction of 177Lu-PSMA and potentially others (Actinium and Thorium, BITE-PSMA)
- Combination or sequencing of PARPi and ARAT therapies in mCRPC in patients with DNA damage repair deficiencies found using genomic sequencing

Transitional Cell Carcinoma (TCC) of bladder, ureter:

- Perioperative immunotherapy PD-1/PD-L1 inhibitor for high risk locally advanced TCC
- FGFR targeted therapy (e.g., Erdafitinib) for metastatic TCC following chemotherapy and pembrolizumab (requires molecular testing for FGFR mutations)
- Antibody-drug conjugate against Nectin-4 (enfortumab vedotin) for metastatic TCC, following chemotherapy and pembrolizumab

Renal cell carcinoma (RCC):

- Adjuvant immunotherapy (e.g., Pembrolizumab) for intermediate/high risk clear cell RCC
- Combination immune and targeted therapies for metastatic RCC such as Nivolumab + ipilimumab, Pembrolizumab + axitinib (VEGF), Nivolumab + cabozantinib (c-Met, VEGFR2, AXL, RET), Pembrolizumab + Lenvatinib (VEGF 1-3, PDGFR, c-Kit, RET, FGFR)

For hematological cancers

- Initial CLL treatment with a finite 1 year course of BCL2 inhibitor (e.g., Venetoclax) + anti CD20 antibody (e.g., Obinutuzumab) or BCL2 inhibitor + BTK inhibitor (e.g., Ibrutinib or Acalabrutinib), with indefinite BTKi therapy reserved for second or third-line therapy with covalent or more likely with more effective non-covalent BTKi (e.g,. Pirtobrutinib)
- CAR T-cell therapy (e,g., axicabtagene ciloleucel or axi-cel), for refractory or early first relapse of DLBCL following RCHOP frontline treatment, replacing salvage chemo and ASCT in this setting.
- Addition of antibody drug conjugate therapy (e.g., polatuzumab vedotin) or bispecific antibody therapy to front-line therapy chemoimmunotherapy for DLBCL
- Novel immune therapy approaches for relapsed DLBCL (e.g., tafasitamab monoclonal antibody with lenalidomide) and bispecific anti-CD20/CD3 antibody therapy (e.g., Mosunetuzumab, Epcoritamab, Odronextamab, or Glofitamab) for third line therapy of indolent lymphoma as well as possible use for relapsed DLBCL
- Immunotherapy with PD1 inhibitor (e.g., Nivolumab or Pembrolizumab) with AVD chemotherapy for high risk Hodgkin lymphoma
- Initial therapy for transplant ineligible myeloma: Daratumumab, Lenalidomide, Decadron
- Initial therapy for transplant eligible myeloma: Dara used with induction and maintenance
- Relapsed myeloma: BiSpecific antibodies, CAR-T, or Venetoclax/Daratumumab if t(11;14)
- Amyloidosis: Dara + CyBorD chemotherapy, and Venetoclax for t(11;14) subtype

For uterine cancer

- Anti-PD-1 monoclonal antibody: Pembrolizumab - in MSI-high/dMMR, Dostarlimab in dMMR, and Lenvatinib + pembrolizumab in MSI-stable/pMMR tumors

For cervical cancer

- Paclixaxel + Carboplatin + Pembrolizumab for metastatic disease. (other anti-PD1 Cemiplimab)
- Tisotumab vedotin (anti-tissue factor ADC) in metastatic disease progressing on chemotherapy

For ovary cancer

- Dostarlimab (anti-PD1) for advanced disease with DNA mismatch repair deficiency (dMMR)
- Pembrolizumab (anti-PD1) for advanced disease with high microsatellite instability (MSI-H), DNA mismatch repair deficiency (dMMR), or high tumor mutational burden (TMB-H)

For Gestational Trophoblastic Neoplasia (GTN)

- Pembrolizumab (anti-PD1) for relapsed metastatic GTN after EMACO chemotherapy

Appendix 6. Methodology and analytic approach used in Chapter 8

Cancer management costs

OncoSim is a web-based microsimulation tool developed by Statistics Canada and maintained by CPAC that evaluates the impact and value of cancer management strategies. OncoSim has four in-depth models for lung, breast, colorectal and cervical cancers, in which individuals of a simulated population are followed up throughout their life course for a chance of developing these four cancers based on determined characteristics including age, sex, smoking (lung cancer), family history of cancer and participation in screening programs. For individuals diagnosed with any of the four cancers mentioned, OncoSim follows up and monitors their survival after diagnosis and treatment. OncoSim also has a less complicated model in which it simulates the incidence, mortality and direct cancer management cost of the 27 most prevalent types of cancer in Canada (in addition to lung, breast, colorectal and cervical cancers). All model parameters related to incidence, mortality, survival, stages, screening and population structure have been estimated using reliable data sources (e.g., Canadian Cancer Registry, Statistics Canada) and calibrated and validated against Canadian cancer data of the past. A more detailed description of OncoSim is available on the CPAC website ([OncoSim – CPAC](#)).

The estimated cost of cancer management in Alberta presented in this chapter is based on a study done in Ontario that reported the estimated main net costs (i.e., cost difference between patients and matched non-cancer control individuals) by phase of care and sex, which were used to estimate five-year and lifetime costs.[1] The phases of care examined in the study were diagnosis (three months before diagnosis), initial treatment (from diagnosis date to six months after), continuing care (between six months after diagnosis and up to 12 months before death) and terminal phase (up to 12 months before death). The diagnosis phase typically involves testing to establish the

cancer diagnosis. Initial treatment includes the primary course of therapy and any adjuvant therapy. Continuing care encompasses ongoing surveillance and active follow-up treatment for cancer recurrence and/or new primary cancers. The terminal phase captures the intensive services, often palliative in nature, provided at end of life.[1] Population-based cost estimates were provided for the entire adult population and based on a comprehensive list of costs incurred by the health system including cost of diagnostic tests and laboratory services; cost of treatment; cost of all physician services (including primary care, specialists and other physicians); cost of outpatient prescription drugs covered by the governmental drug benefit programs; and cost of home care, inpatient hospitalizations and ambulatory care (same-day surgeries, emergency department visits).[1]

To estimate the cancer management costs for each phase of care, we ran a series of OncoSim simulation models. All these models were based on *status quo* assumptions, meaning that model parameters (such as cancer incidence, stages, survival, screening [breast, cervix and colorectal], vaccination [cervix], treatment and population growth) were not modified. Our models were based on the following:

- The future cancer incidence and mortality in Alberta were based on the projection by OncoSim, which might be different from the projections described in *Chapter 1: Cancer incidence* and *Chapter 3: Cancer mortality*;
- The population growth in OncoSim was modelled using its own parameters of birth rate and all-cause mortality rate, which led to a different population projection. For example, OncoSim projected a population in Alberta of 5.2M in 2040, whereas Alberta Health projected a population of 5.9M.[2]
- The participation rates in the existing screening programs would stay the same, and the existing screening and prevention programs would continue to 2040; and
- The lack of a screening program such as a low-dose CT scan for early lung cancer detection would persist to 2040.

The *Financial burden for patients and families* section of this chapter is based on relevant academic literature. We searched and reviewed current, relevant publications

related to the economic cost of cancer incurred on patients and families, and summarized our findings in an explanatory synthesis.

References

1.   de Oliveira C, Pataky R, Bremner KE, Rangrej J, Chan KKW, Cheung WY, et al. Phase-specific and lifetime costs of cancer care in Ontario, Canada. BMC Cancer. 2016;16:1-12.
2.   Government of Alberta. Interactive Health Data Application [Internet]. Edmonton, Alberta, Canada: 2021. [Accessed February 23 2021]. Available from: http://www.ahw.gov.ab.ca/IHDA_Retrieval/

Appendix 7: Summary of Data Sources, Reference Material, and Estimation and Projection Tools

- Data on cancer incidence, mortality and prevalence was acquired from the Surveillance & Reporting group within Cancer Research & Analytics, Cancer Care Alberta, Alberta Health Services.

- Age-period-cohort models were implemented through the Canproj statistical package[1] for the projection of cancer incidence, mortality, and prevalence.

- Data was retrieved from the ICBP SURVMARK-2 online tool: International Cancer Survival Benchmarking Project[2] to contextualize cancer survival trends in Alberta compared to the top-performing countries.

- Population attributable risk (PAR) was used to estimate the proportion of cancer cases in Alberta associated with modifiable risk factors.

- Measures of exposure-cancer risk (relative risks or odds ratios) from the IARC Monographs and the WCRF Continuous Update Project reports were used for modifiable risk factors with known, probable, convincing or sufficient evidence of an association with cancer were abstracted.

- Exposure-cancer associations suggested by recent studies were identified through reviews of recently published, high-quality systematic reviews and meta-analyses.

- For risk factors where a summary risk estimate was not available, a meta-analysis of published studies was conducted.

- Population-based national health surveys, including the Canadian Community Health Survey (CCHS), the Canadian Health Measures Survey and the Second

National Sun Survey were used to estimate the population-level prevalence of lifestyle and environmental exposures among Albertans.

- Cancer incidence data were obtained from the Canadian Cancer Registry (CCR) at Statistics Canada.

- The future prevalence (to 2032) of active and passive smoking, high body mass index, low physical activity, sedentary behaviour, alcohol consumption, red and processed meat intake, and low fruit and vegetable intake were estimated based on data from three cycles of the National Population Health Survey (1994–1998) and five cycles of the CCHS (2000–2011).

- Potential impact fractions were used to estimate the future preventable impact of cancer in Alberta. Evidence-based intervention targets from the scientific literature were used for estimating PIF under varying scenarios.

- A series of OncoSim simulation models were conducted to estimate the cancer management costs for each phase of care.

- Current, relevant publications related to the economic cost of cancer incurred on patients and families were reviewed and summarized.

References

1. Qiu J, Hatcher J, Team C-PW. Canproj—the R package of cancer projection methods based on generalized linear models for age, period, and/or cohort. Technique Report for Cancer Projections Network (C-Proj), Alberta Health Services, Alberta. 2011.
2. Arnold M, Rutherford MJ, Bardot A, Ferlay J, Andersson TML, Myklebust TÅ, et al. Progress in cancer survival, mortality, and incidence in seven high-income countries 1995-2014 (ICBP SURVMARK-2): a population-based study. The Lancet Oncology. 2019;20(11):1493-505.

Appendix 8: Summary of Recommendations

> **Cancer Incidence:** Incidence is defined as the number of new cases of cancer occurring each year and is an important measure of cancer impact for populations and health care systems. The incidence of cancer in Alberta is projected to increase considerably by 2040, driven primarily by an aging population and population growth.

1. Projected declines in the overall age-standardized incidence rate suggest that prevention initiatives are working. *Support expanded cancer prevention efforts in the areas of tobacco smoking, obesity, physical inactivity and alcohol consumption to further reduce cancer incidence rates.*

2. While prevention efforts will continue to have a positive impact on reducing incidence rates overall and for certain cancers, the numbers of new cancer cases will continue to increase over the next two decades. *Plan and prepare the health care system for the projected increase in cancer cases, beginning with detailed examination of the workforce, equipment, and infrastructure needs.*

3. Greater participation in population-based screening programs is likely to have a positive impact on mitigating the increasing incidence of cancer in Alberta. *Implement targeted approaches in specific populations to improve prevention and screening.*

4. Develop a systematic approach to monitoring trends in incidence, augmented with additional socio-demographic variables. *Integrate data systems to identify and address issues and changes as they emerge.*

> **Cancer Prevalence:** Cancer prevalence is defined as the proportion of people who are alive after being diagnosed with cancer either recently or in the past. Projections of cancer prevalence provide useful information in predicting the demand for future cancer-related health care and social services, and in planning for anticipated challenges.

5. The projected increases in cancer prevalence will pose a considerable impact on the utilization of services. *Undertake planning to optimize the cancer care workforce.*

6. The proportion of people living with cancer has been growing due to considerable improvements in cancer care. *Examine and understand the needs of people living longer with cancer, and explore innovative ways of delivering care.*

Cancer Mortality: Cancer mortality quantifies the number of deaths that were a direct cause of cancer. Examining cancer mortality over time allows the progress in reducing cancer deaths to be measured and helps determine the relative importance of cancer compared to other causes of death.

7. The largest increases in mortality are projected for the top five most common cancer sites. *Target improved primary prevention and population-based screening programs for the most common cancers to reduce the mortality associated with these cancers.*

8. Among the most common cancers, decreases in cancer-related mortality are partly attributable to treatment advances. *Invest to develop/implement/evaluate novel therapies and overall advances in treatment and treatment pathways.*

Cancer Survival: Survival statistics reflect the patient diagnosis, treatment, journey, impact of health care and outcomes, which are not fully captured by incidence or mortality. One-year survival represents survival during treatment and reflects stage of diagnosis. Five-year survival represents survival after treatment and typically reflects those who have been "cured" of disease. Ten-year survival reflects long-term survivorship.

9. Accurate and reliable data can be used by physicians, researchers, public health planners and policy-makers to reduce the future impact of cancer. *Create a data monitoring system that can report on cancer survival in a timely fashion to highlight improvements or gaps in outcomes.*

10. Survival is improving for several cancers, likely due to increased participation in and access to screening programs, technological advances in diagnosis and staging, and wider access to novel therapeutic approaches. *Continue to support implementation of focused screening and therapy programs.*

11. Identifying biomarkers as targets for novel cancer therapies may substantially improve survival. *Enhance infrastructure for the implementation and evaluation of molecular diagnostics to support targeted and other novel therapeutic approaches.*

12. Access to advanced radiotherapy treatment technology (e.g. Linac-MR, MR-simulation, protons, etc.) promises improved treatment options for some cancers that may lead to higher survival and/or reduced treatment toxicity (and corresponding improved quality of life). *Continue to support development and implementation of these advanced technologies.*

13. Greater efforts are needed for cancers where survival remains poor, including lung, esophageal and pancreatic cancer. *Encourage continued research investment in high-fatality cancers.*

> **Prevention & Screening:** Cancer prevention includes primary (e.g., environmental and behavioural changes, increased access to immunization), secondary (e.g., population-based cancer screening) and tertiary (e.g., reducing cancer morbidity through behaviour and treatment) measures. Interventions at each of these levels can decrease the number of cancer diagnoses, and they should work in concert to reduce the impact of cancer.

14. Modifiable risk factors that could be targets for primary cancer prevention include tobacco smoking and human papillomavirus (HPV) infections. *Prioritize population-based HPV testing and lung cancer screening programs.*

15. Cancer screening participation rates are not meeting targets and the rates differ across health zones and subsets of the population in Alberta, highlighting issues around availability, accessibility, and acceptability of screening. *Improve promotional and recruitment strategies to address low participation rates in cancer screening.* Physician-linked programs can be especially valuable as they allow physicians to empower and promote among eligible patients.

16. *Support research in the following priority areas: reduction of the variation in cancer screening, equitable access to cancer prevention and screening, patient engagement in cancer prevention and screening research, and methods for prevention research implementation and mobilization of what is known about how to reduce the risk of cancer in Alberta.*

> **Cancer Diagnosis:** Organized initiatives to facilitate cancer diagnosis are effective in reducing wait times, improving the patient experience, and using health system resources more efficiently. Improving cancer diagnosis may also have major downstream effects -- an earlier stage at diagnosis may require less complex therapy and have better outcomes.

17. The Alberta Cancer Diagnosis (ACD) initiative will anchor all cancer diagnosis pathways and establish a single point of access for patients and providers. *Develop a research framework to support the ACD initiative, with an emphasis on person-centered care, outcomes and experiences, and value for the health system.*

18. Molecular diagnostics are becoming more widely used to stratify cancers for prognosis and to guide treatment. *Enhance infrastructure for molecular diagnostics to support the movement towards multi-target sequencing for most cancers in the province. Molecular diagnostics would also benefit from a research infrastructure developed to support the ACD.*

19. Leveraging existing research platforms such as the OncoSim framework may be helpful to fill research and evaluation gaps regarding cancer diagnosis. *Expand outcome reporting to allow for greater understanding of the effectiveness of diagnostic programs and to help to justify continued or expanded governmental support.*

Cancer Treatment: Cancer treatment can have different goals depending on the type of cancer, stage of cancer, and patient preferences or characteristics. CCA provides cancer treatment and support for many aspects of the cancer continuum at its 17 cancer centres in partnership with clinical support services, Zone partners, and other health care providers and services including community, primary care and volunteer/not-for-profit organizations.

20. *Implement a robust research framework for collecting and using patient reported outcomes and experience measures to support design and evaluation of current and new treatments as well as current and novel models for delivering care.*

21. *Establish a robust set of quality indicators related to the full range of services available in Alberta with equity considerations and ensure that quality care is provided across all aspects of quality including acceptability, accessibility, appropriateness, effectiveness, efficiency, equity and safety.*

22. Clinical trials allow researchers to discover new ways in which to prevent, diagnose, treat, and manage cancer, thus helping to improve patient outcomes. *Expand access to clinical trials.*

23. *Develop comprehensive approaches to assessing outcomes for trial participants and those exposed to different lines/modes of cancer treatment in routine care.*

24. Investment in radiation oncology research has led to the development of world-leading technology and treatment protocols. *Prioritize continued investment in these directions to ensure Albertans receive the highest quality care, in a timely manner.*

Cancer Management Costs: As a leading cause of death and disease in Canada, cancer not only takes a significant toll on the health of patients and survivors, but it also has a high financial impact. The high financial cost of cancer is largely paid by the public health system, but a considerable amount is still paid by the patients diagnosed with cancer and their families.

25. Focus future studies on evaluating optimal patient care pathways that optimize patient outcomes and value. *As part of pathway optimization, the impact of delays or gaps in care should be evaluated.*

26. Managing cancer through treatment and care is expensive, due to both an increasing number of people diagnosed with cancer and rising price of drugs and care in general. *Expand research infrastructure to examine cost-effectiveness of approved therapies as well as potential cost savings for biosimilars and other off-patent therapies.*

27. *Prioritizing long-term planning for routine updating and replacement of capital equipment (e.g. critical treatment machines such as linear accelerators, which have an approximate lifespan of 10 years) will create stability and minimize disruption to patient treatments.*

28. The safe and accurate delivery of radiation relies on stable staffing of highly trained professionals. *Staffing models need to be based on relevant national benchmarks, and efforts for recruitment and retention of highly qualified personnel need to be bolstered in order to maintain the standards of care that Albertans expect.*

29. *Explore and assess the direct and indirect financial burden of cancer treatment on Albertans and the health system.*

30. *Understand costs of cancer care to the Alberta health system and cancer outcomes compared with other provinces to determine areas of success and areas of opportunity for increased efficiency.*

> **Supportive Care:** Supportive care is an overarching concept that describes the health care services that people awaiting a diagnosis of cancer, or who already have a diagnosis of with cancer, and their families need beyond anti-cancer medical, surgical and radiation interventions. It can include physical, emotional, social, psychological, cultural, functional, informational, spiritual and practical support for patients and their families.

31. Alberta has an extensive network of supportive care services, including the volunteer sector, municipal supports, primary care and AHS. *Assess the extent to which supportive care access can be tailored to people's needs by leveraging what already exists. Evaluate the impact of supportive care on quality of life.*

32. An opportunity exists to strengthen and integrate the relationships between the patient's medical home (PMH), community services and supports, and the formal cancer system to meet the medical, emotional, spiritual and social needs of people with cancer and their families in a comprehensive manner. *Optimize integration and better coordination across sectors with the goal of better patient experience and improved outcomes, both at an individual and system level.*

> **Palliative & End-of-Life Care (PEOLC):** PEOLC is a crucial component of improving the quality of life for people living with serious illness, including but is not limited to people living with advanced cancer.

33. In addition to the Alberta Health palliative review, Alberta Health and AHS have prioritized a redesign and evolution of home care to improve quality and access to care for all Albertans. Both of these reviews will inform the work to be done ahead to continue to improve quality access to PEOLC. *Conduct further research and quality improvement projects to enhance access to quality PEOLC services for people with cancer and non-cancer diagnoses across the province.*

34. *Have research informed by patients, families and practitioners at a community level, and supported by an enhanced capacity to access, use, and interpret data on service provision and patient needs including those of vulnerable populations.*

> **Models of Care:** A model of care in oncology outlines the way in which health services are created and provided for patients as they move through the stages of cancer. With an aging and growing population, appropriate delivery of care requires balancing patient needs, health care resources and fiscal constraints.

35. As the number of people with cancer and the complexity of treatments increases, it is important that the care system can adapt appropriately. *Invest in a detailed workforce plan to address the growing needs of the cancer care system while accounting for recent changes and trends in models of care delivery.*

36. While virtual care technology has mainly been used to provide care in remote or rural populations, this method of care delivery may be a feasible adaptation across the province regardless of geographic location. *Evaluate the impact of virtual care and home care on patient outcomes, experience and satisfaction.*

37. Innovations in models of cancer care are needed to support the patient population now and into the future, as the traditional models may no longer be sufficient or sustainable in all settings. *Examine the impact of changes in care delivery during the pandemic to understand whether some of the forced changes to care delivery result in similar outcomes that might be more sustainable.*

38. To work towards the goal of optimizing person-centered care, the health care system in Alberta will need to adopt technology and new processes that continue to put the patient and family needs at the centre of the care, while ensuring that systems are in place to evaluate innovations and adapt as required. *Examine how to enhance cancer care to meet the evolving needs and expectations of patients and families, while working to optimize patient outcomes and experiences.*

> **Health Equity:** Disparities in cancer outcomes are preventable and are in many instances the result of social and historical hierarchies that can lead to structural discrimination and marginalization. Equity reflects the need to act on these disparities and create opportunities for everyone to benefit from improvements in cancer care.

39. *Increase collection of Alberta-specific data on vulnerable populations and those previously under-represented in health and population data.* Investments should focus on individuals with mental health disorders, Indigenous peoples, racialized individuals, and sexual and gender minorities to identify where resources are needed in the cancer care continuum.

40. *Investigate methods of establishing long-term staffing stability for smaller, regional radiotherapy cancer centres, to facilitate ongoing equitable access to radiotherapy across the province.*

> **Childhood Cancer in Alberta:** Childhood cancer is relatively uncommon but remains the leading cause of disease-related death among children in Canada.

41. *Expand development of new therapies for cancers with higher mortality and relapse rates such as brain tumors and soft tissue sarcomas. Explore novel personalized targeted chemotherapy drugs, precision radiation therapy including proton therapy, and immunotherapies that hold promising results.*

42. Although Alberta has the required clinical expertise to involve children diagnosed with cancer in clinical trials, patient numbers are often too small to trigger the initiation of these studies, impeding the access by this population to novel therapies. Efforts are required to promote collaboration and to reduce barriers to initiating trials in the pediatric oncology arena. *Enhance access to early phase clinical trials and novel therapies in pediatric oncology.*

43. Children affected by cancer have unique medical and psychosocial needs, and require specialized care. *Improve access to specialized care, focusing on ensuring that treatment and supports for children diagnosed with cancer are designed specifically to serve this population and available in pediatric-appropriate formulations.*

44. Interventions that may reduce physical and psychosocial late effects of cancer treatment in children include the reduction of exposure to toxic therapies, toxicity prediction through pharmacogenomics or screening, and enhanced support to survivors in dedicated comprehensive survivorship programs. *Enhance understanding of long-term health issues related to childhood cancer and its treatment, and insights into their prevention.*