

# FUTURE OF CANCER IMPACT IN ALBERTA

SUMMARY



A COLLABORATIVE INITIATIVE FROM THE CANCER STRATEGIC CLINICAL NETWORK • 2022



**Alberta Health  
Services**

Cancer Strategic  
Clinical Network™

**Inspiring solutions.  
Together.**

A close-up photograph of two hands, one larger and one smaller, holding each other in a supportive grip. The hands are positioned in the center-right of the page, with the fingers interlaced. The background is a soft, warm, out-of-focus light, suggesting a bright, sunny day. The overall tone is hopeful and caring.

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## MESSAGE FROM THE FOCI WORKING GROUP

An estimated one in two Albertans will be diagnosed with cancer in their lifetime and at least one in five will die of the disease.

Those are scary statistics, but there are many reasons for us to stay hopeful and optimistic. Every day, Alberta Health Services' Cancer Strategic Clinical Network (SCN) and its many partners lead transformational action to improve care across the cancer continuum in Alberta.

The Future of Cancer Impact (FOCI) in Alberta Working Group was assembled by the Cancer SCN to collect and analyze what is known about cancer in Alberta and to determine what the future likely holds in terms of incidence, prevalence, mortality and survival. This generous and collaborative group of people included Albertans who have experienced cancer first-hand, experts in various cancer-related domains across the continuum, and other key

strategic partners. The wealth of knowledge contributed by these individuals was further strengthened through the active involvement of many other subject matter experts, contributors and reviewers.

The FOCI in Alberta report is a comprehensive exploration of cancer in Alberta and includes current and projected data, as well as clinical and technical interpretations and recommendations. It identifies gaps and opportunities for knowledge generation and implementation that may inform future priorities for cancer research.

We have developed this summary report to uphold our commitment to engage and involve groups and individuals beyond the scientific and clinical community. Cancer impacts us all, and we want the

findings and insights of this important work to be available and accessible to everyone.

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.

Sincerely,



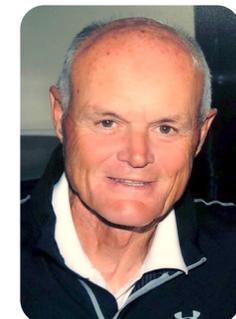
**Dr. Darren Brenner**  
FOCI Working Group  
Co-Chair



**Dr. Paula Robson**  
FOCI Working Group  
Co-Chair

Five years ago, I was told I had tongue cancer. As I moved through treatment, I noticed researchers actively evaluating and working to improve the level of care. We all know there is on-going work to cure cancer, but these researchers were working on every aspect of cancer care and recovery.

My interest in their work led me to participating on the FOCI in Alberta Working Group. I am proud to be one of several cancer patient advisors contributing to this report and to know that communicating my experience is helping to build understanding and ultimately transform cancer care in Alberta.



**Adam Brown**  
Patient Advisor on  
the FOCI Working Group

## INTRODUCTION

Cancer impacts the lives of Albertans, the healthcare system, our communities and our world. As the number of new cases continues to grow, and as more people survive their diagnoses, we need to prepare Alberta's cancer system for the future.

In 2013, Alberta Health published *Changing our Future; Alberta's Cancer Plan to 2030*. This document is a long-term strategic plan aimed at accelerating action on preventing more cancers, curing more cancers, and reducing suffering of people affected by cancer. Much progress has been made since that report was released, but equally as much has changed in the provincial health services' landscape.

The impact of cancer will only continue to grow in Alberta. To meet this rising demand, considerable long-term planning and investment are needed to equip Albertans with a future-ready workforce and cancer care system.

We need to accelerate exploration, implementation, and evaluation of innovative models of cancer care that can adapt to increasing and changing demands. There is also a critical need for additional enhancement to Alberta's cancer data environment. Finding effective ways to monitor trends in cancer incidence,

prevalence, mortality and survival, will go a long way to proactively identifying and addressing emerging issues across all segments of the population.

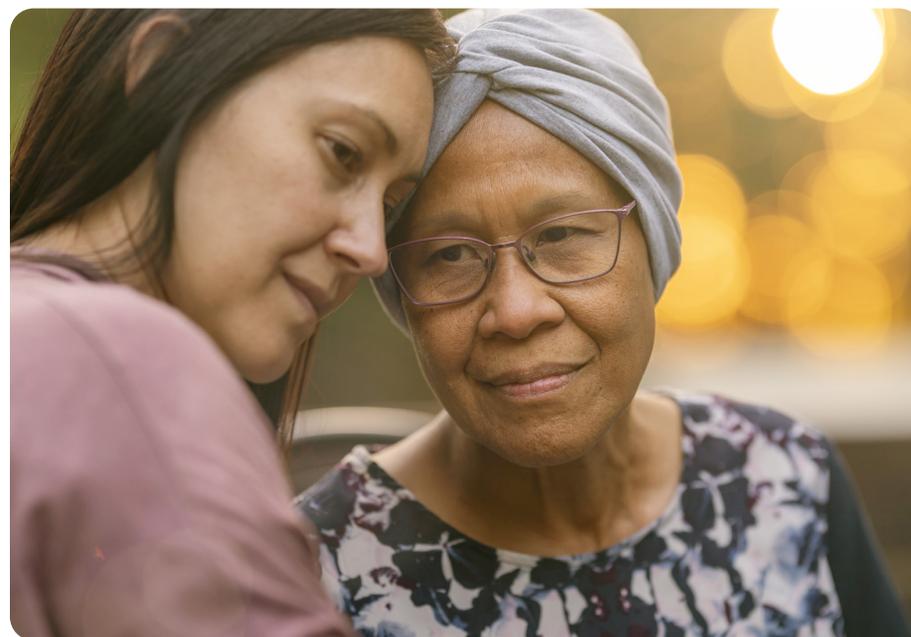
In alignment with the strategic priorities outlined in *Alberta Health Services' Cancer Strategic Clinical Network's Transformational Roadmap 2020–2024*, the Cancer SCN initiated the development of the Future of Cancer Impact (FOCI) in Alberta report to stimulate renewed discussion, planning and action around the future of cancer control in Alberta over the next two decades.

### *FOCI in Alberta puts forward:*

- Projections of cancer incidence, prevalence and mortality in Alberta over the next decade.
- Estimates of the numbers of cancers that may be preventable if risk factors were modified.
- Insights related to the provision of cancer care across the continuum including prevention

and screening, diagnosis, treatment, as well as supportive, palliative and end-of-life care.

- Emerging trends in alternative models of care and needs of special populations.



***By 2040, Alberta will see an estimated 33,773 new cases of cancer diagnosed every year.***

# ALBERTA'S CANCER ECOSYSTEM



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



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)

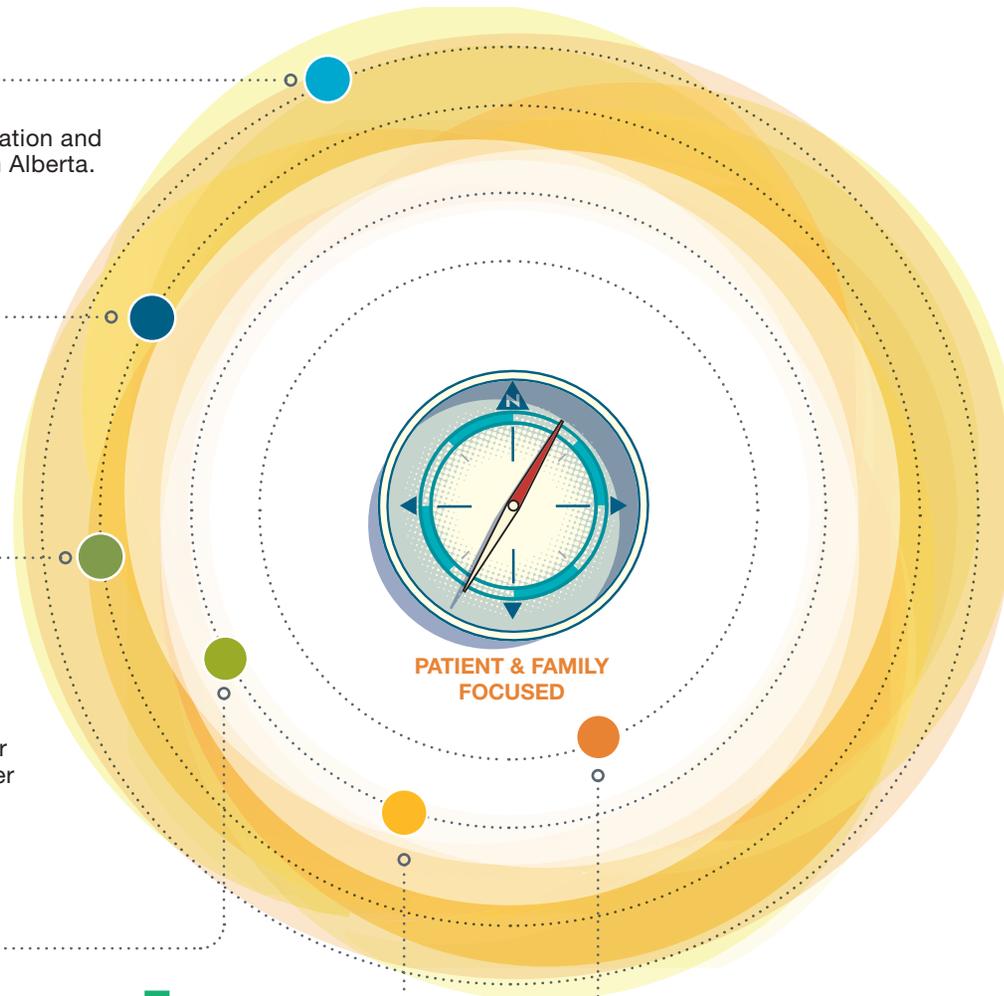
The Cancer SCN is part of the fabric of cancer prevention, treatment and care in Alberta. It is a broad network of patients, health experts and community partners, with a mandate to improve experiences and outcomes of Albertans who face cancer, and to address the increasing burden and high costs to the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



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

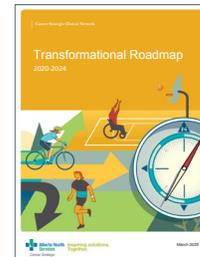
The following strategic plans laid the groundwork for Future of Cancer Impact (FOCI) in Alberta



Changing our Future – Alberta's Cancer Plan to 2030



Alberta's Strategic Clinical Networks: Past, Present, Future



Cancer SCN's Transformational Roadmap 2020-2024

## THE FOCI REPORT

Designed for a broad range of stakeholders, Future of Cancer Impact (FOCI) in Alberta provides an updated summary of key cancer statistics, an overview of cancer services in Alberta today, and insight into cancer-related topics, including the cost of cancer care and health equity.

FOCI in Alberta also provides recommendations for integrated research and enabling infrastructure that could support faster evolution of cancer care in Alberta to better address future challenges.

The report is intentionally foundational and designed to stimulate discussions with key stakeholders to support the identification of short, medium and long-term areas of focus.

Some of these areas will be within the purview of Alberta Health Services' Cancer Strategic Clinical Network (SCN), while others will be best led by partners within the system.

With the report complete, the Cancer SCN will now undertake extensive engagement and consultation with cancer leaders and key strategic partners across Alberta, with the goal of achieving consensus on future cancer-related priorities for the health system.



*This Future of Cancer Impact (FOCI) in Alberta – Summary provides a condensed snapshot of the broader report. Please refer to the complete report for more comprehensive analysis and information, citations, data tables, figures and more.*

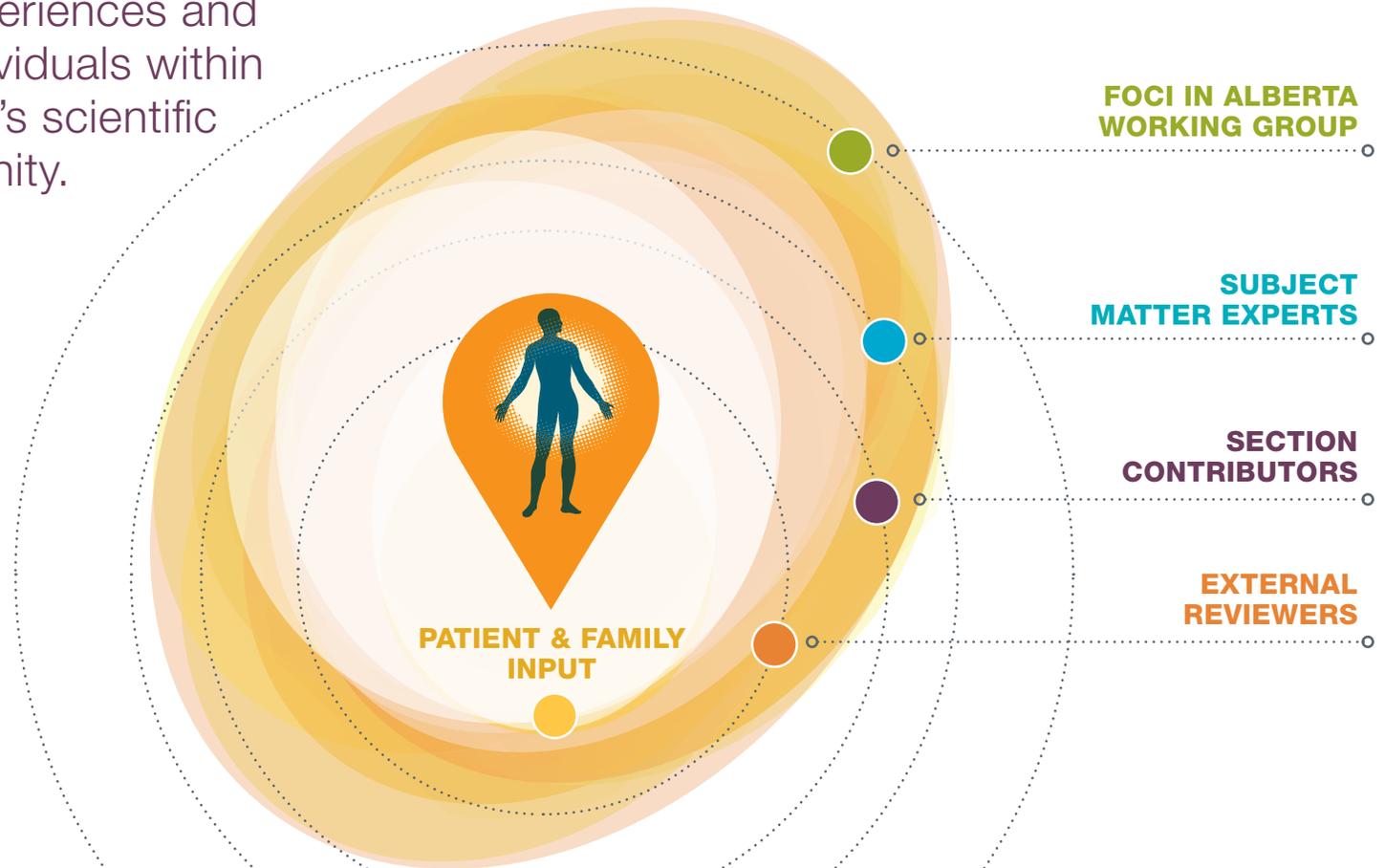
## ENGAGEMENT

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.



## 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

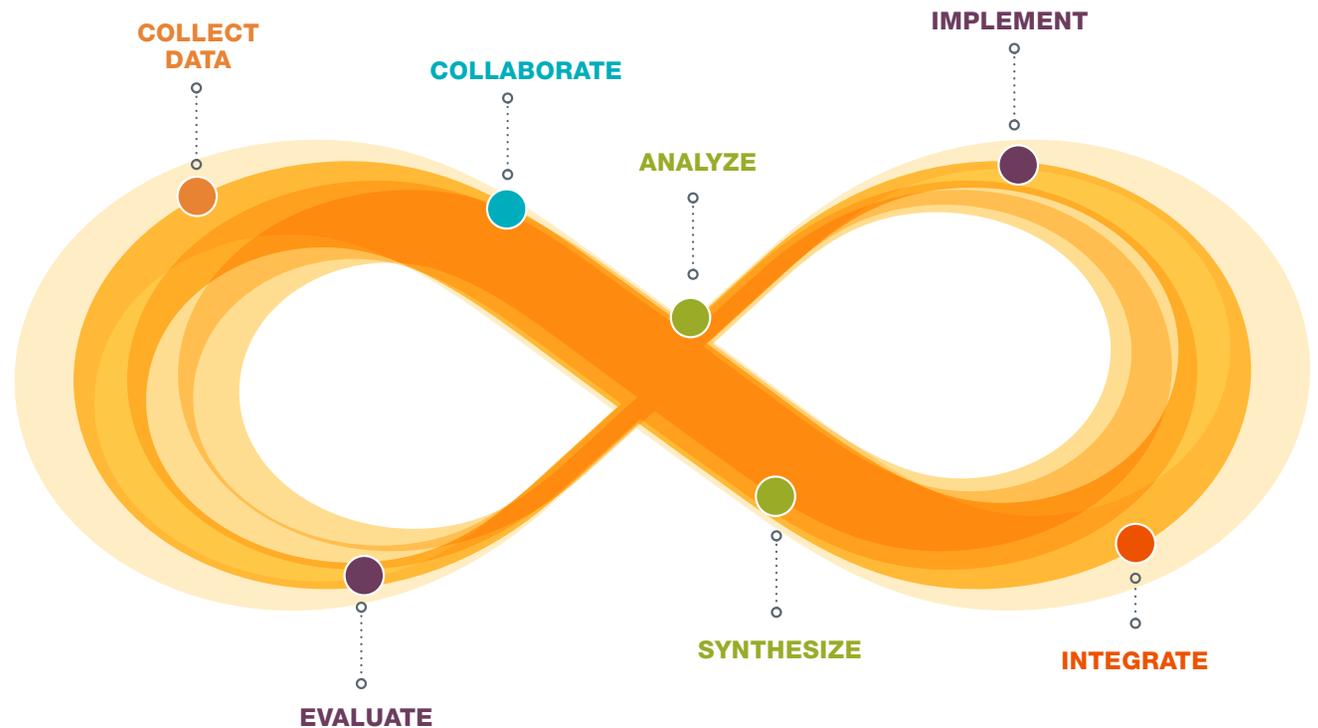
examining cancer incidence, prevalence, mortality and survival was collected and analyzed to generate projections and estimates of future impact.

**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.

## WHERE WE'RE GOING...



## THE BIG PICTURE: CANCER INCIDENCE, PREVALENCE AND MORTALITY

Accelerating innovation in Alberta's healthcare system requires us to translate the best available evidence into action.

Current and projected cancer data is essential in planning and preparing to meet the needs of Albertans when it comes to prevention and screening, diagnosis, treatment and support

services, now and in the future. This information is also crucial in the design of future cancer prevention and control programs and research, as well as setting priorities for health promotion activities and policy.

In this section of the summary, we provide up-to-date estimates on **cancer incidence, prevalence** and **mortality** in Alberta up to the year 2040.



## CANCER INCIDENCE IN ALBERTA

The number of new cancer cases occurring each year is an important measure of cancer impact for populations and healthcare systems. Past trends and population projections can be used to predict incidence in the future, and long-term projections are essential for healthcare resource planning.



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

- 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).
- 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 PREVALENCE IN ALBERTA

Understanding cancer prevalence in Alberta is essential in resource planning for diagnostics, treatments, patient care resources, follow-ups and survivorship supports.

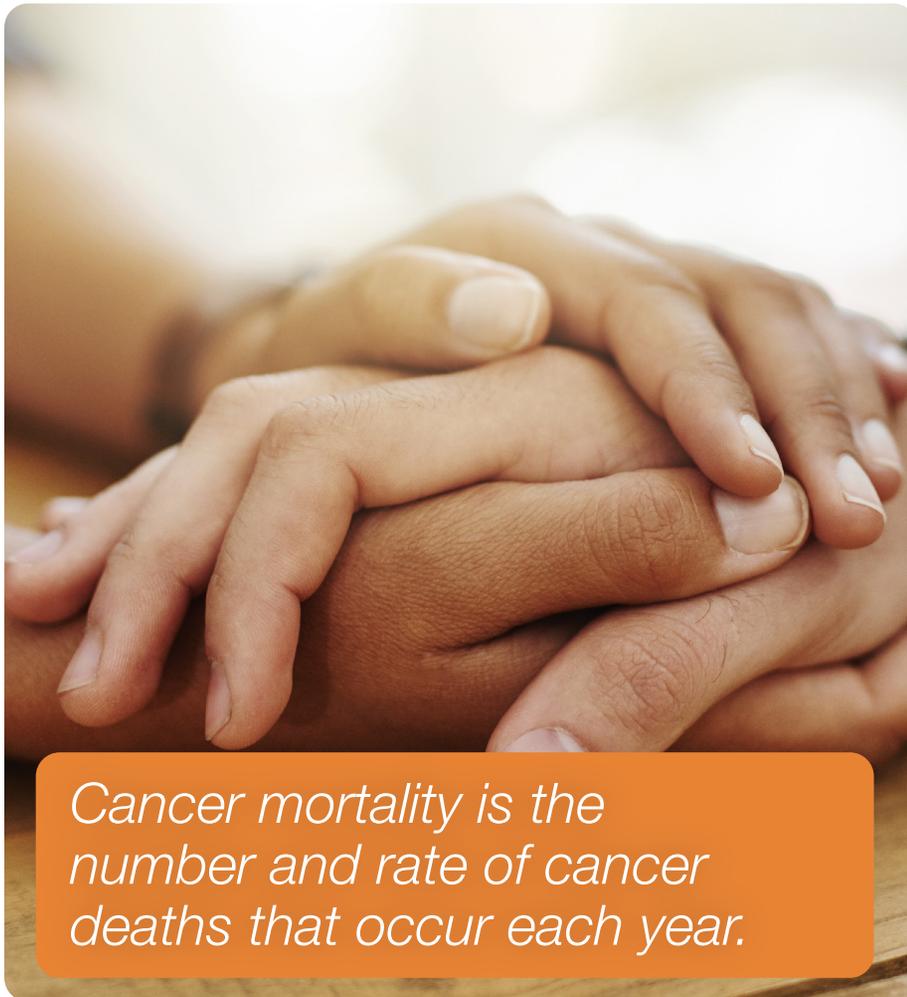


*Cancer prevalence is a measure of the number of people alive at a specific point in time, in a given population, who were previously diagnosed with cancer.*

- 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.
- 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.

## CANCER MORTALITY IN ALBERTA

Cancer mortality is an important measure of the impact of cancer in Alberta. Past trends and population projections in mortality rates of cancer can be used to estimate the number of cancer deaths that will occur in the future.



- 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).
  - 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.
- Age-standardized mortality rate (ASMR)** is the rate of deaths that would occur in a given population, accounting for the age and gender make-up of that population. This standardization supports the comparison of mortality rates across places and time.

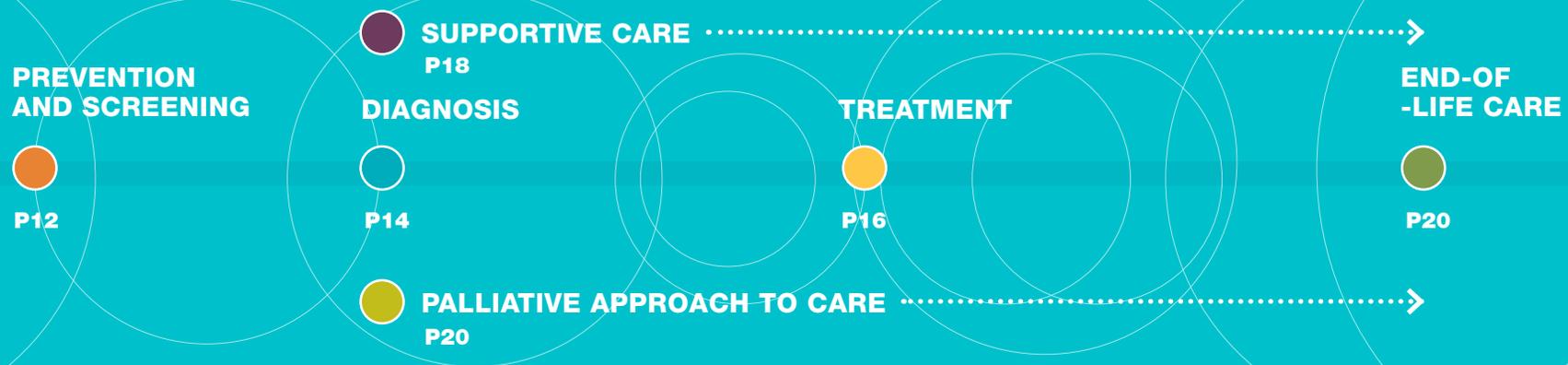
## THE CANCER EXPERIENCE

Understanding the needs of patients throughout diagnosis, treatment and care is important to ensure optimal outcomes and experiences, while effectively managing and allocating resources.

Early and streamlined diagnosis, appropriate and timely treatment plans, as well as holistic, person-centred care throughout the cancer continuum, are all critical to providing the highest quality of care possible.

The following section provides an overview of **cancer prevention and screening, diagnosis, treatment, 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.



*A cancer experience is not linear. Every patient's journey is different and can involve multiple cycles through the various stages of care.*



## PREVENTION AND SCREENING

# Prevention is the essential first step in reducing cancer incidence and mortality.

There are three levels of cancer prevention: primary (risk reduction), secondary (screening), and tertiary (preventing negative outcomes after diagnosis). In principle, these three levels of prevention should work together to decrease cancer incidence and reduce the impact of cancer.

Primary prevention is key to reducing people's risk of ever developing cancer. This involves avoiding or minimizing lifestyle, environmental and infectious risk factors, like smoking, sun exposure, residential radon exposure, human papillomavirus (HPV), hepatitis B, alcohol consumption, sub-optimal diet, inactivity, and many others.

Primary care is a natural environment for the promotion of healthy behaviours, as well as being the main access point for cancer screening.

Secondary prevention involves detecting cancer early through population-based cancer screening programs. In Alberta, organized screening programs have been implemented for individuals considered to be at average risk for colorectal, breast and cervical cancers. Pilot programs are also underway to screen for lung cancer among higher risk populations.

Tertiary prevention involves activities to prevent the recurrence and progression of disease once a cancer has been diagnosed. These activities may include clinical management of the disease, as well as the adoption and implementation of healthy choices and approaches to minimize the risk of recurrence.



**Alberta Healthy Communities Approach (AHCA)** is a collaborative initiative that works to create environments where making the healthy choice is the easier choice.

**Alberta Screening and Prevention (ASaP)** helps primary care providers keep their patients up-to-date on key screening and prevention practices for chronic diseases and cancer.

**Population, Public and Indigenous Health (PPIH)** within Alberta Health Services advances key priority areas and drives innovative health approaches through the advocacy of health equity, health promotion, and disease promotion for all Albertans.

**screeningforlife.ca** is designed to give Albertans the information they need to make informed decisions about cancer screening.

## PREVENTION AND SCREENING

### FINDINGS

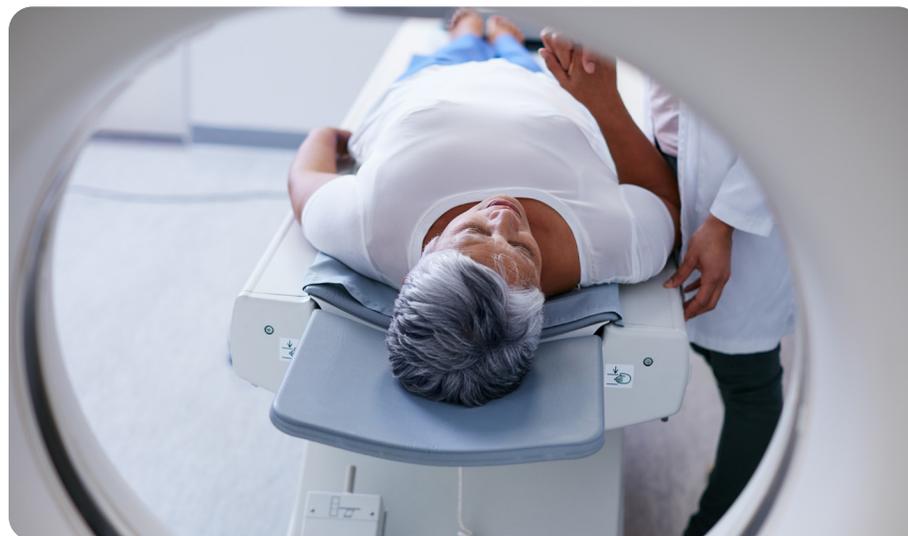
- Approximately 40% (6,100 cases) of cancer cases diagnosed in Alberta in 2015 were attributable to modifiable lifestyle, environmental and infectious risk factors, such as tobacco smoking, sun exposure, residential radon exposure and air pollution.
- Based on modelling studies, thousands of cancer cases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

### FUTURE FOCUS

- 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.



**A recent study found that over 40 per cent of cancer in Alberta can be linked to risk factors that are within our control.\***

**Population-based screening** is a test offered to everyone in a target group. Screening involves simple tests to look for changes or early signs of a disease in people who do not have symptoms.

**Knowledge-translation initiatives** are the activities involved in moving research from the laboratory, the research journal and the academic conference, into the hands of people and organizations who can put it to practical use.

\* results reported in the Alberta Population Attributable Risk (PAR) study

## DIAGNOSIS

# A diagnosis of cancer forever changes a person's life. It impacts families, friends, work and education.

Early diagnosis of cancer is important to help reduce patient distress, increase the chances of a lower stage of the cancer at diagnosis, improve treatment effectiveness and ultimately, improve patient outcomes.

Cancers can be detected via screening programs or as a result of symptoms reported by patients and investigated using specific imaging or laboratory tests. There is a clear need for adequate resourcing of cancer

diagnostic services, as well as the design, implementation and evaluation of streamlined and coordinated systems to ensure that patients are diagnosed in a timely manner.

Cancer diagnosis can be separated into three distinct intervals – self-appraisal (i.e. patient awareness of symptoms), help-seeking and diagnostic – often followed by treatment.

Alberta is a leader in developing and implementing new cancer diagnosis pathways. Patients who experience earlier and more streamlined cancer diagnoses will likely have their cancer diagnosed at an earlier stage, less complex treatment and better survival. Additional research to discover, validate, implement and evaluate new diagnostic tests, pathways and approaches, will help further reduce the impact of cancer in Alberta.

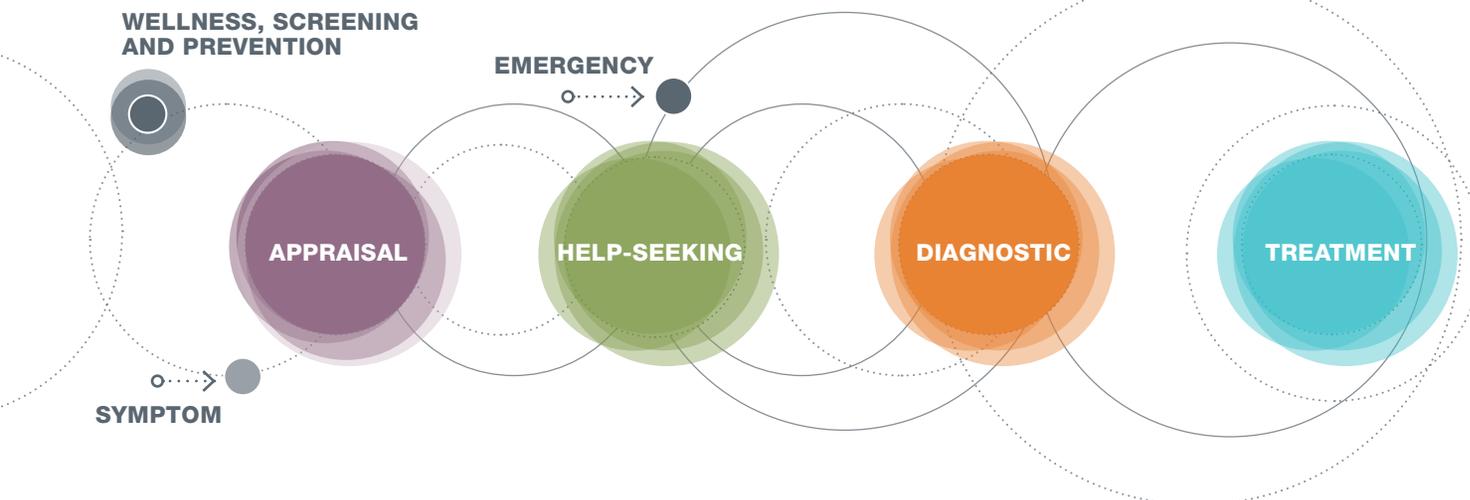
A **Cancer Diagnosis Pathway** is an evidence-based care process coordinated by Primary Care to expedite and support symptomatic patients during the diagnostic interval.

In Alberta, all diagnostic pathways will increasingly integrate **molecular diagnostics** to subgroup cancers for prognosis and to guide treatment. At its most basic, this involves analyzing the unique genetic elements found in our cells to detect the presence of cancer, flag an increased risk of cancer, diagnose a certain cancer type, and plan and evaluate treatment.

**Between 2012-2017, 30% of cancer patients in Alberta were diagnosed through presentation at an Emergency Department.\***

\* recent study published in *The Lancet Oncology*

### CANCER DIAGNOSIS INTERVALS



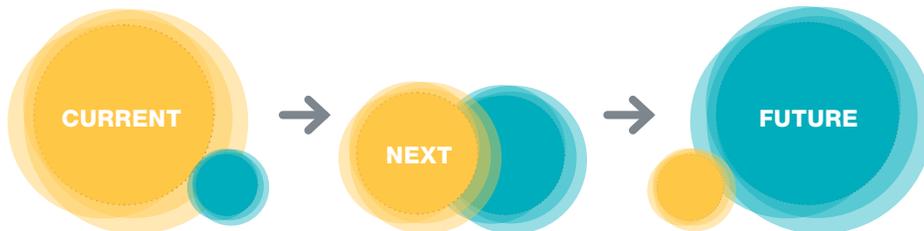
## DIAGNOSIS

### 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.

### COMPREHENSIVE GENOMIC PROFILING: A CORNERSTONE OF PRECISION ONCOLOGY

Decrease in methods per sample. Increase in data per sample.



#### Single Biomarker 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

#### Comprehensive 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.

### FUTURE FOCUS

- 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.

#### Alberta Cancer Diagnosis (ACD) Initiative

There is currently no overarching provincial system to streamline diagnosis of all cancers in Alberta. Alberta Health Services' Cancer Strategic Clinical Network (SCN) identified this as an area of focus and in December 2021, launched the Alberta Cancer Diagnosis (ACD) initiative.

#### The program is designed to:

- Anchor all existing and new cancer diagnosis pathways.
- Establish a single point of access for patients and providers.
- Improve timely diagnosis and increased support for patients navigating the system.
- Enable consistent processes for primary care physicians to access appropriate tests and referrals.

## TREATMENT

# There are different goals for cancer treatment depending on the type and stage of cancer, and on the patient's unique needs and preferences.

The objective of treatment is often to completely remove or eradicate all cancer cells from a patient's body, but it can also be used to control the cancer or to ease symptoms and pain.

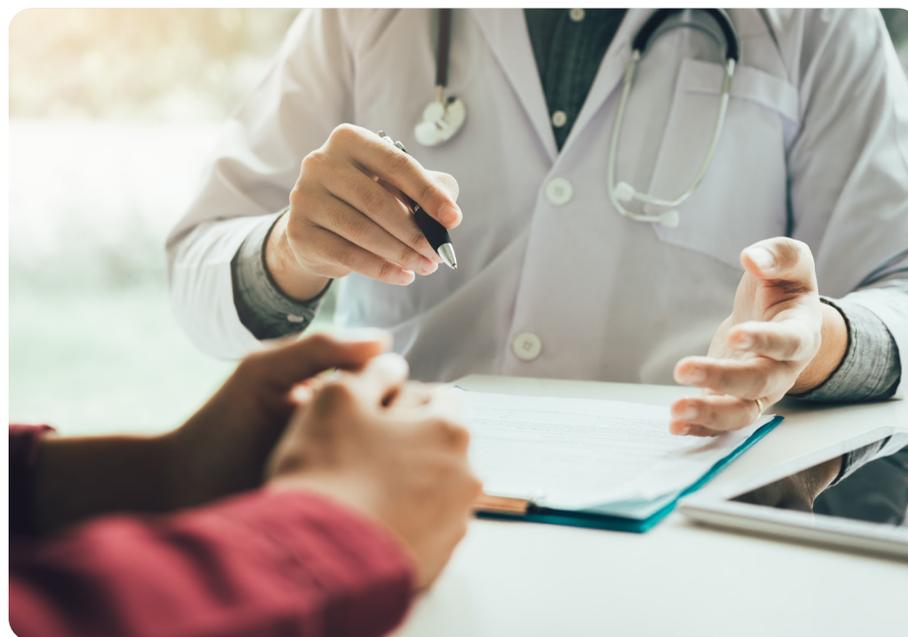
The most common types of treatment (used alone or in combination) are radiation therapy, systemic therapy (with chemotherapy, hormone therapy and immunotherapy), hematopoietic stem cell transplantation, and surgery.

Across the province, precision oncology and targeted therapies to treat cancer are being quickly adopted. These include targeted therapies and current advances in immunotherapies such as monoclonal antibodies, immune checkpoint inhibitors, and T-cell transfer therapies (e.g., TIL therapy and CAR T-cell therapy).

Patients and families affected by cancer in Alberta have access to a wide range of treatments and therapies, which are provided

through cancer centres, hospitals and other care settings. Cancer Care Alberta (CCA) has 17 cancer centres located across Alberta, including two tertiary, four regional and 11 community cancer centres.

Regional and community cancer centres are located within regional hospitals or health centres and allow patients to stay closer to home while having access to a range of treatments and care options.



In 2020/21, Alberta had approximately 1,000 patients enroll in clinical trials at the Cross Cancer Institute and the Tom Baker Cancer Centre.

Collectively, the research teams at these two tertiary cancer centres opened 75 new trials and provided over \$30 million worth of drugs to cancer patients.

## TREATMENT

### 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.

### FUTURE FOCUS

- 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.

**Biomarker testing** (also called tumour testing, tumour profiling or tumour genetic testing) finds changes in a patient's cancer that could help target their cancer treatment.

**Biologic drugs** come from living organisms or from their cells. They are often made using biotechnology. Examples of biologic drugs include insulin, growth hormones and antibodies.

**Biosimiliars** are drugs that are similar to the original biologic, with no meaningful differences in terms of quality, safety or treatment efficacy, but are less expensive.



## SUPPORTIVE CARE

# A cancer diagnosis affects not only a person's physical health but also their mental, emotional and spiritual well-being.

Cancer can affect other aspects of personal and family life as well, such as loss of income, social isolation, and the inability to drive or perform household tasks.

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. It includes physical, emotional, social, psychological, cultural, informational, spiritual and practical support for patients and their families.

In Alberta, Cancer Care Alberta (CCA) provides supportive care services to people with a diagnosis of cancer and who are referred to a CCA facility. Complementary medical support, such as managing the side effects of treatment, concurrent conditions or disease-related symptoms, is often handled outside the formal cancer care system by Primary Care. As well, Home Care and community paramedics may offer medical care and support with activities of daily living.

In addition, there are thousands of community resources that patients and families can access for supportive care. Alberta is home to over 26,000 not-for-profit groups and community-based services. The challenge is making sure that everyone is aware of all the available resources and that linkages to these supports are made as they are needed.

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.

More 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 allow Alberta to effectively support its citizens with cancer, and their families, well into the future.



**The Patient's Medical Home (PMH)** is a model subscribed to by Alberta's Primary Care Networks, the Alberta Medical Association (AMA), and the Alberta College of Family Physicians, which works to manage the holistic health and social needs of Albertans. The underlying principle of the PMH is to have the family physician be the most responsible provider and coordinator of medical care, as well as be a key connection to resources focused on social needs.

In the context of cancer, 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 patients and their families.

To learn more, visit [acfp.ca/advocacy/patients-medical-home](https://acfp.ca/advocacy/patients-medical-home).

## SUPPORTIVE CARE

### 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.

### FUTURE FOCUS

- 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.



## PALLIATIVE AND END-OF-LIFE CARE

# Together, 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 those living with advanced cancer.

**Palliative care** aims to improve quality of life for those facing a life-limiting or life-threatening illness. It focuses on the prevention and relief of suffering, by means of early identification, comprehensive assessments and appropriate interventions.

**End-of-life care** is provided to patients and their families when they are closer to death and may include a higher-degree of interdisciplinary services and assessments, such as anticipatory grief support and pain and symptom management.

Alberta has been recognized nationally as a leader in providing an integrated and innovative range of PEOLC programs and services that spans across a variety of care settings. This includes tertiary palliative care, pediatrics and palliative home care.

We have an integrated approach to end-of-life care that is delivered across the province through both stand-alone hospices and embedded hospice beds within supportive living and long-term care facilities.

Given the predicted increase in the number of new cancer cases in Alberta, mainly due to an aging and growing population, a plan is needed for increased access to quality PEOLC programs and services, as well as resources for additional care providers.



The **Palliative and End-of-Life Care Alberta Provincial Framework Addendum (2021)** outlines what Alberta has achieved since the development of the Framework in 2014, where we are today, ongoing gaps and challenges, and recommendations for future work.



## PALLIATIVE AND END-OF-LIFE CARE

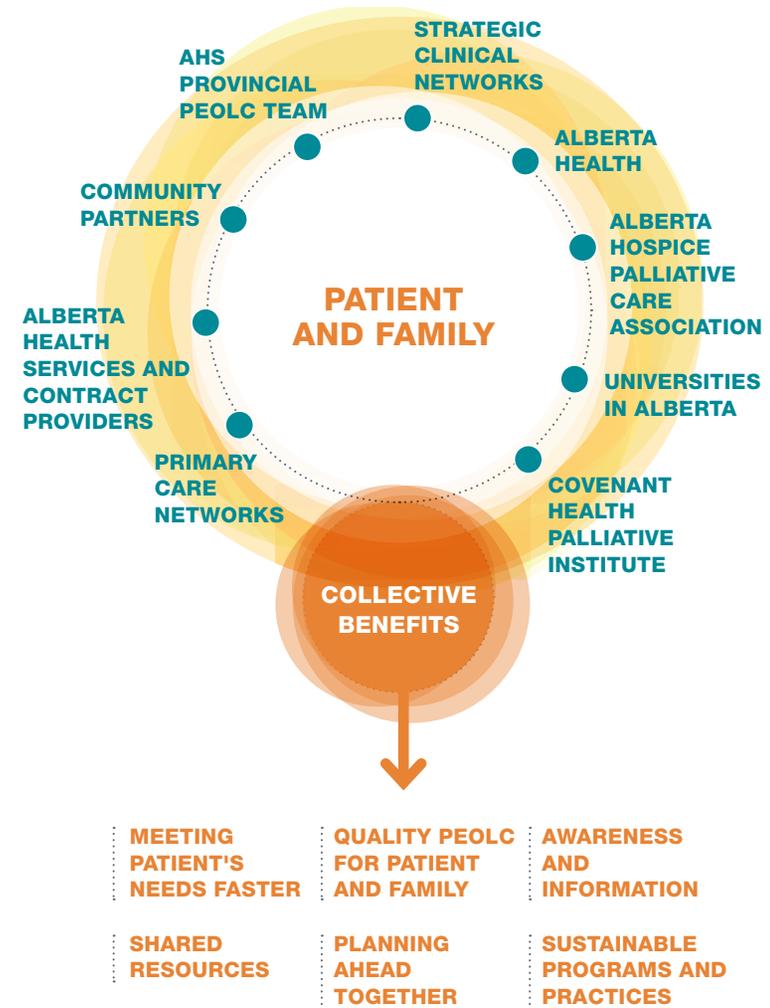
### FINDINGS

- 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.

### FUTURE FOCUS

- 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.

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



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

## CANCER CARE IN CONTEXT

# Future of Cancer Impact (FOCI) in Alberta explores three additional aspects of cancer care in Alberta – **Childhood Cancer, Health Equity** and the **Cost of Care**.

Understanding the ways in which all 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 cancer care to Albertans.

It is important that the cancer care system can adapt appropriately, using evidence and a learning health system approach to develop, test and implement innovative models of care.

In addition to the three topics mentioned above, FOCI in Alberta also looks at different models of cancer care and presents recommendations on how we can enhance Alberta's cancer data infrastructure.

**PREVENTION AND SCREENING**



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## CHILDHOOD CANCER

# Childhood cancer is relatively rare and there is often a good chance of it being cured thanks to advancements in cancer treatment.

Even still, it is the leading cause of disease-related death among children in Canada.

There are currently 500,000 survivors of childhood cancer in North America, many of whom face challenges associated with their treatment. The short-term effects of treatment, including pain and fatigue, are well known, but there is also the possibility of long-term effects. These include delays in fine motor development, persistent stress, emotional challenges and even chronic or life-threatening conditions.

After diagnosis, it has been reported that up to 95 per cent of childhood cancer survivors experience at least one chronic health condition later in life, and over 80 per cent are diagnosed with a chronic or life-threatening condition. Interventions

that may reduce both physical and psychosocial late effects of cancer include reduction of exposure to toxic therapies whenever possible,

toxicity prediction through pharmacogenomics or screening, and enhanced support for children in dedicated survivorship programs.



**Pharmacogenomics** is the study of how a person's unique genetic makeup (genome) influences his or her response to medications.

Research investment in childhood cancer may be quantitatively different from the investment in other cancer research due to its unique characteristics and the individuals being impacted.

## CHILDHOOD CANCER

### FINDINGS

- Alberta follows the national pattern, with 136 children (ages 0–14) diagnosed with cancer in 2018, and an increasing incidence rate since 1998.
- The 2021 Report on Cancer Statistics in Alberta shows that for 2018, the most commonly diagnosed childhood cancers were leukemia (29 per cent), central nervous system (18 per cent), and lymphoma (11 per cent). These three cancers accounted for 58 per cent of all childhood cancers.
- From 2014 to 2018, the most common cancer-caused death in children was central nervous system tumours.
- The five-year observed survival rate for 2018 for all childhood cancers in Alberta was 83 per cent.
- Kids Cancer Care Foundation of Alberta reports that in 2015, there were 1,269 survivors of childhood cancer living in the province, and more than 75 per cent of them were living with at least one chronic health condition due to the cancer treatments they received as children.
- Alberta has the clinical expertise to involve children with cancer in clinical trials, but patient numbers are often too small to trigger the initiation of these studies.

### FUTURE FOCUS

- 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.

**The Women and Children's Health Research Institute (WCHRI)**, a partnership between Alberta Health Services and the University of Alberta, works to close the gap in research focusing on women and children, and brings a multi-disciplinary approach to the closely related areas of women's, children's and perinatal health.

**The Alberta Children's Hospital Research Institute (ACHRI)** works across the University of Calgary, Alberta Health Services and into the community to generate new knowledge in child health, and translate these discoveries into life-saving treatments, practices and policies for a healthier future for children and families.

**The Childhood Cancer & Blood Disorders Program** is a collaborative initiative of ACHRI and the Arnie Charbonneau Cancer Institute. This integrated and interdisciplinary team, led by Dr. Greg Guilcher, aims to advance understanding of the biology and aftereffects of childhood cancers and blood disorders, and to use existing and new knowledge to improve their diagnosis and treatment.

## HEALTH EQUITY

Health equity is achieved when everyone has the opportunity to reach their full health potential and are not disadvantaged by social, economic or environmental circumstances.

Improvements in cancer care in recent decades have had a positive impact on the outcomes for many types of cancer, including better survival rates. These improvements, however, are not consistent for all population groups.

Disparities in cancer outcomes are preventable and, in many instances, are the result of unnecessary and avoidable differences that are unfair and unjust.

A major determinant of health equity is how income, power, resources,

goods and services are distributed in a population. These factors impact one's risk of being diagnosed with cancer, the care they will receive following a cancer diagnosis, and how likely it is that they will survive.

Alberta Health Services is one of many high-performing health systems around the world who are taking an active role in advancing health equity to improve health outcomes for everyone.



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.

## HEALTH EQUITY

### FINDINGS

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

### FUTURE FOCUS

- 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.

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.

In Alberta, the **Creating Health Equity in Cancer Screening** project aims to better understand sociodemographic and spatial barriers to cancer screening. Sociodemographic factors include age, race, ethnicity, language, etc. and spatial barriers often refer to geographic factors like the distance to healthcare services.

The **Indigenous Wellness Core** is a dedicated program within Alberta Health Services that is focused on innovation, quality improvement and standardization for programs and services for all Indigenous peoples within Alberta.

The **Guide to Cancer Care in Alberta for Newly Diagnosed Indigenous People** was developed to support Indigenous cancer patients and their families, and answer some of the questions they may have.



## COST OF CARE

# Once cancer is diagnosed, a patient may require medical treatment and specialized care for months, if not 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.

Over the past two decades, many new and expensive technologies in

cancer treatment and drugs have seen increased application, including precision medicine, targeted therapy and immunotherapy. The cost of immunotherapy drugs, for example, has shown to be as much as 62 per cent more than conventional chemotherapy drugs.

While people across Canada benefit from publicly funded healthcare, not all aspects of care are fully funded. There can still be a substantial economic impact for people diagnosed with cancer and their families.

Despite ongoing efforts and improvements in the cost-effectiveness of cancer care in Alberta, the growing number of people diagnosed with cancer and the improved survival rates require us to further optimize the cost-effectiveness and value of care. This needs to happen at both the health system and patient/family levels.

The creation and implementation of a health economics research framework for cancer, to support evaluation of new and evolving patient care pathways and treatment guidelines, is imperative.

**A recent study concluded that the economic burden of cancer in Canada, including out-of-pocket costs, travel, parking, and income loss averages, could be more than \$2,500/month per patient.**



## COST OF CARE

### 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).

### FUTURE FOCUS

- 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.

### DRUG COVERAGE

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

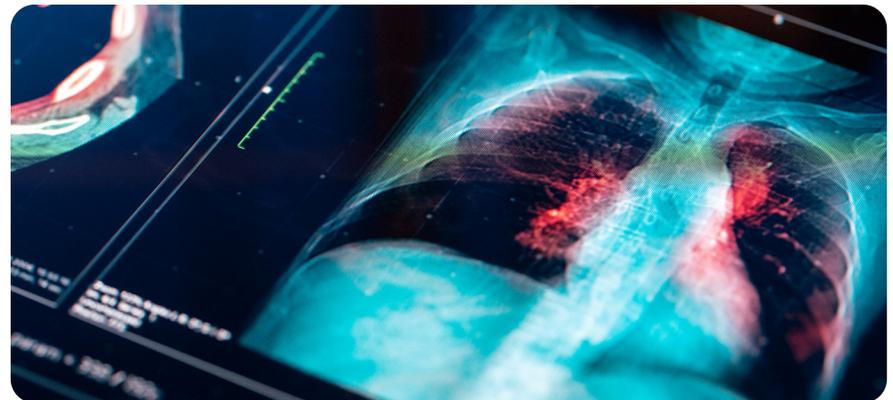


## ALBERTA'S CANCER DATA INFRASTRUCTURE

In Alberta, we are fortunate to have access to high-quality, population-level cancer data.

**Alberta Health Services' Cancer Strategic Clinical Network (SCN) and its partners are continually working to further improve and enhance our cancer data infrastructure. The following are opportunities to support future needs for evidence generation, innovation and evaluation.**

- A systematic approach to cancer epidemiology and monitoring to proactively identify and act on trends and disparities in cancer incidence, mortality and survival, and on the impact of innovations relating to prevention, screening and other cancer control initiatives.
- Population-level data on equity, diversity and inclusion within our cancer control and data environment. This will help to better understand the impact of existing inequalities and could include clinical data that includes measures of race, ethnicity, sex, gender and socio-economic status.
- Accelerate the data collection and communication around the impacts of disruptive events, like those due to COVID-19, or other future disruptions to the health system.
- Improve the link between registry and treatment databases with the evaluation of prevention and screening activities, in terms of intermediate and longer-term outcomes.
- Increase capacity to analyze and interpret economic data to support analyses of the impacts that increasing incidence, mortality and survival has across the cancer care continuum.
- More research, including data to identify cost-effective strategies, on how to best manage increased cancer survivorship to maximize outcomes and system efficiency.
- A data integration strategy that enables and accelerates research both within cancer care and with allied areas of Alberta Health Services. This strategy should engage a broad range of stakeholders across health and data sectors, and will improve patient care through continued collaboration and integrated research.
- Enhance support for the Surveillance & Reporting team within Cancer Care Alberta. This group develops and provides critical analysis and evidence that drives improvements to reduce the burden of cancer on Albertans. Additional support would allow for a broadened scope and improved knowledge translation.



## LOOKING AHEAD

Cancer is a human experience filled with challenges and uncertainty. Fortunately, challenge and uncertainty are also key drivers of curiosity, innovation and progress.

Cancer has a major impact on the lives of Albertans and, consequently, the healthcare system and society as a whole.

While the Future of Cancer Impact (FOCI) in Alberta points to many current and upcoming challenges, it also indicates that our cancer care environment is well-positioned to accelerate progress through meaningful, transformational action.

This report is intended as both catalyst and call to action for

fundors, government, the healthcare community and citizens. It outlines how changes at the policy, practice and personal level, combined with continual evaluation, reflection and investment, can reduce the impact of cancer for Albertans, now and in the future.

When it comes to cancer, it is hard to see the finish line. That said, every step is progress and in Alberta, we have covered much ground and gained promising momentum. Let's keep moving in the right direction.

Now this is not the end.  
It is not even the beginning  
of the end. But it is, perhaps,  
the end of the beginning.

WINSTON CHURCHILL

## TOGETHER, WE CAN...

- Prevent more cancers
- Cure more cancers
- Reduce the suffering of those affected by cancer

## BY FOCUSING ON HOW WE...

- Integrate and enhance access to data
- Improve screening among under-represented groups
- Integrate clinical data, analytics and decision supports
- Prioritize measures of equity and diversity
- Encourage clinical trials
- Support molecular diagnostics
- Implement and monitor novel therapeutics
- Support precision approaches using analytics
- Enhance home-based and virtual care delivery
- Increase execution of supportive care resources
- Support palliative, end-of-life programs with family
- Plan and invest in the cancer care workforce and the cancer care system long-term

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This *Future of Cancer Impact (FOCI) in Alberta – Summary* provides a condensed snapshot of the broader report. Please refer to the complete report for more comprehensive analysis and information, citations, data tables, figures and more.

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