REPORT

Objectives & Priorities for the Coming Years by Cancer Type

A RECOMMENDATION PROJECT

Quebec
Cancer Coalition

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Introduction

The Quebec Cancer Coalition was founded in 2001 to be a strong voice for people affected by cancer and to help improve Quebec's healthcare system. Made up of more than 70 non-profit organizations representing all types of cancer across every region of the province, the Coalition advocates for the rights and interests of patients, survivors, and caregivers. For over 20 years, its members have shared a common vision: to unite against cancer and work to improve public health through a healthcare system centred on the needs of those affected by the disease.

In 2025, the Coalition invited its Patient Association Members to participate in a key initiative: drafting cancer-specific recommendations that outline priorities and objectives for the next 10 years.

Following the *États généraux de la lutte contre le cancer* and the unanimous commitment of all political parties to a 10-year cancer plan, the Coalition set out to support this strategy with concrete, actionable proposals. The result is a set of detailed recommendations, organized by cancer type, to help guide the implementation of this plan.

The goal of this project is to provide a clear overview of the steps needed—cancer by cancer—to reduce incidence rates in Quebec, while offering decision-makers a practical tool to guide action within the healthcare system, for patients and their families.

This final report presents recommendations aimed at reducing cancer incidence, mortality, and morbidity, while also improving the quality of life of those living with cancer. It has been submitted to the government as a contribution to the development and implementation of Quebec's cancer action plan.

Project Objectives

01 Provide a comprehensive overview of the necessary measures, by cancer type, to reduce cancer incidence and mortality in Quebec.

02 Serve as a reference tool for decision-makers when implementing measures that involve the healthcare system and improving the lives of people affected by cancer.

03 Highlight the priorities and expertise of our member organizations, who work tirelessly to ensure that the voices and needs of those affected by cancer are heard and prioritized.

Our Participating Members

Lung Cancer Canada / Cancer Pulmonaire Canada — Awareness. Support. Education. / Sensibiliser. Soutenir. Éduquer.

Cancer du rein Canada / Kidney Cancer Canada

Quebec Breast Cancer Foundation

Craig's Cause Pancreatic Cancer Society

PROCURE Cancer – Prostate

Myeloma Canada

Cancer Colorectal Canada / Colorectal Cancer Canada

braintumour foundation of Canada

Bladder Cancer Canada / Cancer de la vessie Canada

Ovarian Cancer Canada

Leukemia & Lymphoma Society of Canada®

hpv global action / vph action globale

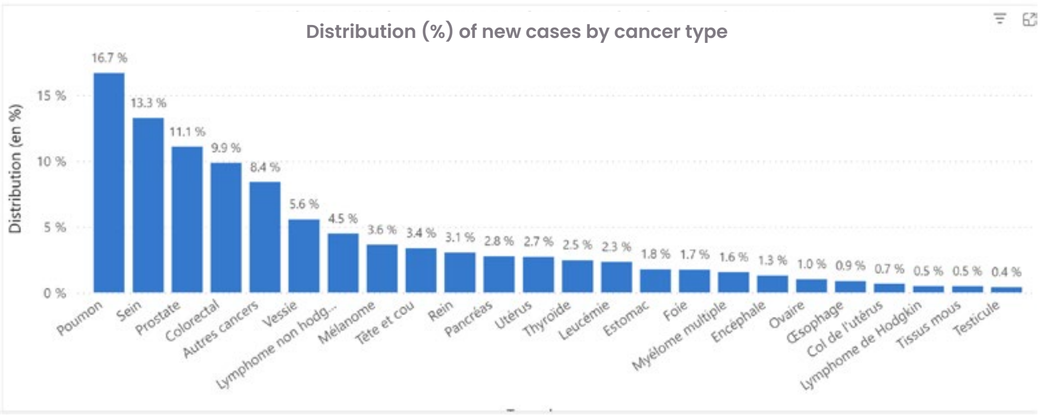
save your skin foundation / La Fondation sauve ta peau

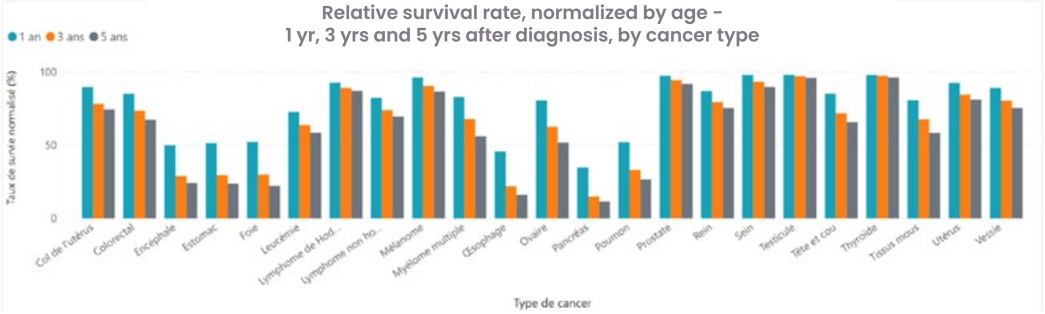
Cancer Statistics in Quebec

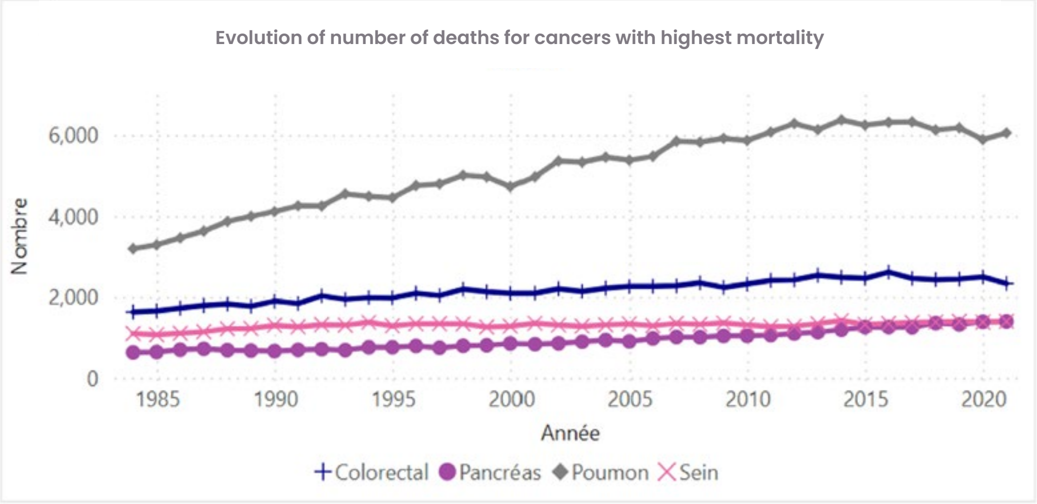
DATA FROM 2021

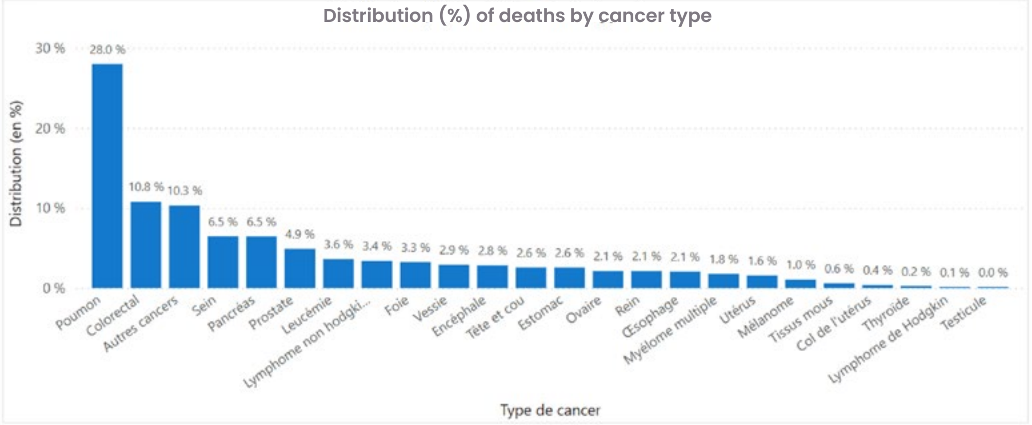
Cancer Type	New cases per year	Deaths by year
Lung	10,264	6,051
Breast	8,154	1,399
Prostate	6,813	1,057
Colorectal	6,064	2,331
Bladder	3,420	627
Non-Hodgkin's Lymphoma	2,759	729
Leukemia	1,435	782
Hodgkin's Lymphoma	306	28
Melanoma (skin)	2,237	223
Kidney	1,881	463
Pancreas	1,703	1,396
Multiple Myeloma	954	383
Brain	791	610
Ovarian	623	463
Cervical	406	81
Head and neck	2,067	553
Uterus	1,666	338
Thyroid	1,514	51
Stomach	1,089	552
Liver	1,070	703
Esophagus	537	444
Soft tissue (sarcoma)	299	127
Testicular	257	7
Other cancers	5,162	2,229
TOTAL	**61,471**	**21,627**

The graphics in this report are pulled from the dashboards of the Registre québécois du cancer, available exclusively in French.
The original data can be accessed here.


Distribution (%) of new cases by cancer type


Relative survival rate, normalized by age -
1 yr, 3 yrs and 5 yrs after diagnosis, by cancer type


Evolution of number of deaths for cancers with highest mortality


Distribution (%) of deaths by cancer type

Lung Cancer

Recommendations by

LUNG CANCER CANADA
AWARENESS. SUPPORT. EDUCATION.
CANCER PULMONAIRE CANADA
SENSIBILISER. SOUTENIR. ÉDUQUER.

Recommendations formulated in collaboration with:
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Co-chair, Lung Cancer Canada Medical Advisory Committee
Eva Dobozy Person Living with Lung Cancer

Introduction

Lung cancer is a disease that transcends boundaries, affecting smokers and non-smokers alike, as well as people of all ages, genders, and backgrounds. While tobacco use remains the leading cause, anyone with lungs can develop lung cancer. **It is the most commonly diagnosed cancer in Canada and the leading cause of cancer-related deaths.**

Lung cancer occurs when cells in the lung tissue grow uncontrollably, forming tumours that disrupt the lungs' ability to supply oxygen to the bloodstream. In advanced stages, it often spreads to other parts of the body (metastasis), complicating treatment. Due to the lack of pain receptors in the lungs, symptoms typically appear only after the disease has progressed. These symptoms vary depending on the tumour's type, size, and location.

Lung cancer is divided into two main types:

01. **Non-Small Cell Lung Cancer (NSCLC):** This is the most common type, making up 80–85% of cases, with subtypes like adenocarcinoma, squamous cell carcinoma, large cell carcinoma, and large cell neuroendocrine tumours. Some NSCLC cases are characterized by specific genetic mutations such as EGFR, ALK-Positive, or ROS1-Positive.
02. **Small Cell Lung Cancer (SCLC):** This less common type represents about 15% of cases. SCLC is an aggressive cancer that spreads quickly throughout the body.

In addition to these primary types, other rare cancers can affect the lungs, such as mesothelioma, Pancoast tumours, and carcinoid tumours.

Context — Reality & Impact on the Quebec Population

Lung cancer remains a pressing public health issue in Quebec, profoundly affecting individuals, families, and the healthcare system. In 2023, an estimated 11,474 Quebecers were diagnosed with lung cancer, including 5,427 men and 6,047 women, making it the leading cause of cancer-related deaths in the province.

Quebec has one of the highest smoking rates in Canada, with approximately 17% of adults reporting regular tobacco use. While tobacco use remains the primary risk factor for lung cancer, the disease does not discriminate; it affects both smokers and non-smokers across all demographics. However, the stigma surrounding lung cancer often leaves patients and their families feeling marginalized, especially as lung cancer is often associated with smoking. This stigma can discourage individuals from seeking help or discussing their diagnosis openly, adding a layer of psychological distress to the physical challenges of the disease.

Lung cancer's tendency to remain asymptomatic in its early stages contributes to delayed diagnoses, with nearly 70% of cases identified only after the disease has advanced. At this stage, treatment becomes more complicated, and survival rates decrease. The disease disrupts the lungs' ability to oxygenate the body, leading to debilitating symptoms and significant challenges in daily living.

The impact of lung cancer in Quebec underscores the urgent need for comprehensive public health strategies. These should include robust prevention campaigns, particularly targeting smoking cessation; education and awareness for both the public and primary care; early detection through screening programs; access to innovative treatments; and strong support systems for patients and caregivers. Addressing these needs is essential to reducing lung cancer's prevalence, overcoming stigma, and improving outcomes for those affected.

Stakeholders to Consider & Priority Populations

Key Stakeholders

01. Government and Public Health Authorities

Quebec Ministry of Health and Social Services (MSSS) and the Institut national de santé publique du Québec (INSPQ) lead public health efforts, cancer treatment, and policy.

02. Healthcare Providers

- Oncologists, pulmonologists, family doctors, nurses, and palliative care teams are central to diagnosis, treatment, and patient care.
- Radiologists and pathologists play key roles in diagnosing and staging the disease.

03. Non-Governmental Organizations (NGOs) and Advocacy Groups

Lung Cancer Canada (including its Medical Advisory Committee), Canadian Cancer Society, and local advocacy groups work to raise awareness, provide patient support, and promote policy change.

Priority Populations

01. Smokers and Former Smokers

Smokers remain the largest group at risk for lung cancer, but former smokers still face a significant risk, particularly those with a history of heavy smoking.

02. Non-Smokers

There is a rising incidence of lung cancer among non-smokers, often linked to environmental factors (i.e. radon), second-hand smoke, or genetic mutations.

03. Indigenous Populations

Indigenous communities experience disparities in healthcare access and lung cancer outcomes, with higher smoking rates in some groups.

04. Women

Increasing numbers of women, especially non-smokers, are being diagnosed with lung cancer, highlighting the need for targeted prevention and awareness.

05. Low-Income and Vulnerable Groups

Socioeconomic barriers affect access to screening, early diagnosis, and treatment, making this group a priority for intervention.

Existing and Missing Supports for Patients and Their Families

While Quebec offers essential cancer care services, substantial gaps remain in early psychological support, system navigation, and post-treatment care. Addressing these gaps is crucial to improving the quality of life and survival outcomes for lung cancer patients and their families across the province.

Existing Supports

01. Support from NGOs

Organizations such as Lung Cancer Canada and the Canadian Cancer Society provide crucial information, counseling, and community-building initiatives, helping to reduce stigma and support patients and caregivers.

02. Palliative and End-of-Life Care

Quebec's palliative care services, including home-based options, offer symptom management and psychological support for both patients and their families, ensuring comfort at the end of life.

Supports Needed

01. Psychosocial and Psychological Support

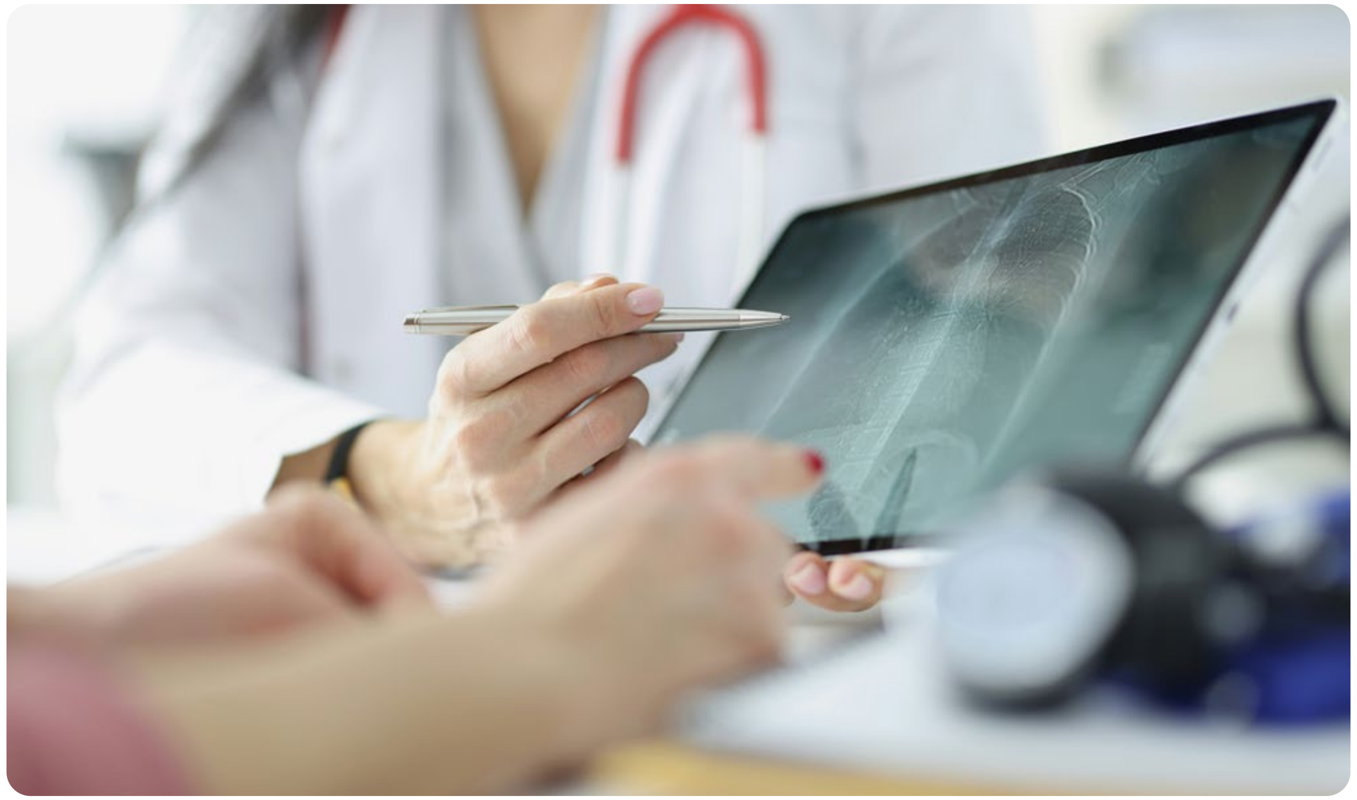
- Lung cancer takes an emotional toll on patients and their families, yet there is a shortage of tailored psychological services for those that require them.
- Expanding resources for mental health support—including counseling, peer support groups, and caregiver respite—is critical.
- Culturally sensitive services must be available in multiple languages, particularly in Quebec, where the linguistic reality presents unique challenges for patients who only speak English or French.

02. Clarity in Treatment Expectations and Communication

- Lung cancer patients often lack clear information about their diagnosis, treatment options, and what to expect during and after treatment.
- Enhanced communication between healthcare providers and patients is essential, ensuring all patients receive information that is accessible, easy to understand, and reflective of their language and cultural needs.

03. Navigating the Healthcare System

- Patients and their families frequently struggle to navigate the complex healthcare system.
- Dedicated patient navigators are needed to guide them through treatment pathways, coordinate care, and ensure timely access to services such as biomarker testing, clinical trials, and supportive care programs.
- Patient navigators can also provide clarity on patients' rights and connect them with community resources.



04. Financial Strain

- Despite existing financial assistance programs, the costs of lung cancer treatment, transportation, and daily living remain a significant burden for many patients and families.
- Expanding financial support programs to cover home care services, travel subsidies, and other essential needs is necessary to reduce this strain.

05. Post-Treatment and Survivorship Care

- Many lung cancer patients face long-term challenges after treatment, including physical, emotional, and social adjustments.
- Survivorship care must focus on empowering patients to return to their regular lives by emphasizing their abilities rather than limitations.
- A comprehensive care plan should include follow-up health monitoring, physical rehabilitation, and resources for managing ongoing health concerns.
- Programs that support a return to work, physical activity, and social engagement can help survivors rebuild their lives with confidence.
- Patients need clear, actionable information and education to navigate post-treatment life effectively and regain independence.

06. Support Outside Hospital Care

- Access to home healthcare services and support for daily activities remains limited, particularly in rural and underserved areas.
- Expanding home care services, reducing wait times for biomarker testing, and addressing regional disparities are critical to improving patient care and equity.

Objectives to Aim For in Quebec to Reduce Incidence, Reduce Mortality & Better Support Patients (Performance indicators to be measured over the next 10 years)

Objective 1: Build Awareness, Reduce Stigma, and Enhance Primary Care Education

Rationale: A foundational barrier to driving meaningful change in lung cancer care is the stigma and misconceptions surrounding the disease, particularly the judgment tied to its causes. This stigma often prevents lung cancer from being viewed with the same urgency and empathy as other cancers, delaying support, intervention, and prioritization. We must change the conversation and emphasize that it doesn't matter what caused the cancer. Every patient deserves equal compassion, access to care, and the chance for better outcomes.

Public education is essential to dismantle these harmful perceptions, combat stigma, and emphasize that lung cancer can affect anyone—smokers and non-smokers alike. Increasing understanding of risk factors, symptoms, and the importance of early detection not only encourages earlier intervention but also fosters a more supportive environment for those affected. Additionally, improving education for primary care providers is critical to ensure lung cancer is considered earlier in the diagnostic process. Too often, lung cancer is overlooked as a potential diagnosis, leading to delays that result in later-stage discoveries when treatment options are more limited. Educating primary care professionals on risk factors, symptoms, and screening guidelines is key to reducing diagnostic delays and improving patient outcomes.

Short-Term Indicators (1–2 Years)

01. Launch province-wide public awareness campaigns to educate about lung cancer, reduce stigma, and highlight early warning signs and risk factors.

02. Partner with community organizations to promote understanding of lung cancer symptoms and encourage timely medical consultations.

03. Develop and distribute training modules for primary care providers focusing on early lung cancer detection, including symptom recognition and appropriate referral pathways.

04. Monitor increases in public awareness and primary care provider knowledge through surveys and feedback tools.

05. Include stigma reduction and early detection education in at least 50% of lung cancer-related initiatives.

06. Evaluate the reach and effectiveness of campaigns and training annually.

Medium-Term Indicators (3–5 Years)

01. Achieve a measurable 20% improvement in public perception of lung cancer, as recorded in surveys.

02. Integrate stigma reduction and early detection training into continuing education for healthcare providers, particularly family physicians and nurse practitioners.

03. Track a 15% decrease in the average time from symptom onset to diagnosis, as reported by patients.

04. Increase participation in lung cancer advocacy events by 30%.

05. Collaborate with media outlets to sustain long-term awareness efforts, including stories highlighting the importance of early detection.

06. Implement school-level programs to educate youth on lung health, stigma, and the importance of early symptom recognition.

Long-Term Indicators (6–10 Years)

01. Establish stigma-free lung health as a societal norm, reflected in surveys and focus groups.

02. Embed lung cancer awareness into routine health campaigns in Quebec, with messaging tailored to the province's linguistic and cultural realities.

03. Increase lung cancer screening participation rates among high-risk groups by 50%.

04. Achieve a 25% reduction in the time to diagnosis by ensuring primary care providers prioritize lung cancer earlier in differential diagnoses.

05. Eliminate stigma and late diagnosis as reported barriers to seeking or receiving care.

06. Evaluate awareness and primary care education initiatives as drivers for earlier-stage lung cancer diagnoses and improved survival rates.

Objective 2: Ensure Equitable Access to Early Detection

Rationale: Early diagnosis through screening is essential for improving lung cancer outcomes and survival rates. Screening needs to become a standard practice, integrated into routine healthcare for high-risk individuals, much like mammograms for breast cancer or colonoscopies for colorectal cancer. Expanding access to screening and overcoming barriers—such as cost, awareness, and stigma—will help detect the disease at earlier, more treatable stages. By establishing and broadening screening programs across Quebec, particularly among high-risk populations, the province can significantly reduce the number of cases diagnosed at later, more difficult-to-treat stages.

Short-Term Indicators (1–2 Years)

01. Expand existing screening programs to include more at-risk individuals.
02. Address gaps in screening program awareness with targeted outreach in underserved regions.
03. Collect baseline data on lung cancer screening participation by region.
04. Improve screening referral rates through healthcare provider education.
05. Develop patient education materials on the benefits of screening.

Medium-Term Indicators (3–5 Years)

01. Increase screening participation rates by 25% across all high-risk populations.
02. Expand mobile screening programs to rural and underserved areas.
03. Ensure 90% of screening participants receive results within 14 days.
04. Address regional disparities by adding at least five new screening sites.
05. Introduce initiatives to encourage follow-up on screening abnormalities.

Long-Term Indicators (6–10 Years)

01. Achieve universal access to lung cancer screening for all eligible Quebecers.
02. Standardize wait times for screening results and follow-ups across the province.
03. Increase early-stage diagnoses of lung cancer by 50%.
04. Reduce lung cancer mortality rates by at least 20% through improved early detection.
05. Continuously evaluate and adapt screening programs to maintain high participation rates.

Objective 3: Improve Access to Biomarker Testing and Personalized Treatment

Rationale: Biomarker testing is essential for personalized lung cancer treatment. By addressing barriers to timely access and standardizing testing processes, Quebec can ensure that more patients receive the most effective treatments, improving survival rates.

Short-Term Indicators (1–2 Years)

01. Standardize wait times for biomarker testing to under 14 days.
02. Establish clear provincial guidelines for molecular testing.
03. Address resource gaps in pathology labs to handle biomarker testing demands.
04. Improve education for healthcare providers on biomarker testing and its importance.
05. Track regional disparities in biomarker testing access and address priority areas.

Medium-Term Indicators (3–5 Years)

01. Ensure at least 90% of eligible lung cancer patients receive biomarker testing.
02. Expand resources in testing facilities to eliminate regional inequities.
03. Integrate biomarker testing as a standard step in all lung cancer treatment plans.
04. Develop a provincial reporting system for testing wait times and outcomes.
05. Foster collaboration between labs and hospitals to streamline testing processes.

Long-Term Indicators (6–10 Years)

01. Achieve universal biomarker testing access within acceptable wait times.
02. Increase access to targeted therapies for patients identified through testing.
03. Improve 5-year survival rates through expanded use of personalized medicine.
04. Reduce delays in connecting patients to appropriate treatments after testing.
05. Continuously innovate and improve biomarker testing methods to keep pace with advancements.

Objective 4: Expand Support Beyond Hospitals

Rationale: The emotional and financial toll of lung cancer can be as severe as the physical challenges of the disease. Expanding support services ensures that patients and their families have access to resources to navigate the emotional, practical, and financial challenges of diagnosis, treatment, and survivorship. Comprehensive support networks not only enhance quality of life and care but also alleviate stress, ensuring that financial or emotional barriers do not impact treatment adherence or overall well-being. These supports are vital at every stage of the lung cancer journey, fostering resilience and promoting better outcomes for patients and caregivers alike.

Short-Term Indicators (1–2 Years)

01. Launch community-based support programs for patients and families.
02. Develop and distribute patient-friendly navigation tools for the healthcare system.
03. Train healthcare providers to offer holistic support beyond clinical care.
04. Establish partnerships with non-profits to provide financial and psychosocial support.
05. Collect data on patients' non-clinical needs to guide resource allocation.

Medium-Term Indicators (3–5 Years)

01. Establish province-wide patient navigation services as a standard offering.
02. Increase funding for community-based lung cancer support initiatives by 30%.
03. Reduce reported financial burdens for patients by 20% through enhanced assistance programs.
04. Expand mental health services for lung cancer patients and caregivers.
05. Build a comprehensive resource directory accessible to all Quebecers.

Long-Term Indicators (6–10 Years)

01. Ensure equitable access to support services across urban and rural areas.
02. Integrate patient and family voices into program development.
03. Reduce caregiver burnout rates by 30% through targeted initiatives.
04. Create a sustainable model for continuous funding of community supports.
05. Evaluate long-term impact of support programs on patient outcomes and quality of life.

Objective 5: Advance Research and Access to Clinical Trials

Rationale: Clinical trials are essential for advancing lung cancer treatments and improving outcomes for the broader lung cancer community. Increasing patient participation ensures access to cutting-edge therapies while accelerating the development of innovative treatments. In Quebec, addressing language barriers is critical — ensuring that confidentiality agreements and protocols are translated into French promptly to avoid delays for patients. Greater emphasis must be placed on the pivotal role of clinical trials in providing novel and important anti-cancer therapies. This includes increasing public and healthcare provider awareness, streamlining enrollment processes, and improving logistical support for patients. By prioritizing these actions, Quebec can expand access to transformative therapies and position itself as a leader in lung cancer research and innovation.

Short-Term Indicators (1–2 Years)

01. Increase patient awareness of and enrollment in clinical trials by 10%.
02. Streamline trial start-up processes to reduce delays.
03. Address regulatory inefficiencies in trial approval processes.
04. Launch educational campaigns to highlight the importance of clinical trials.
05. Track barriers to trial access and prioritize areas for improvement.

Medium-Term Indicators (3–5 Years)

01. Expand the number of available lung cancer trials in Quebec by 30%.
02. Improve patient participation rates in clinical trials by 25%.
03. Reduce administrative delays in trial setup by 50%.
04. Develop collaborations with international research networks.
05. Increase equitable trial access across regions, particularly in underserved areas.

Long-Term Indicators (6–10 Years)

01. Position Quebec as a global leader in lung cancer research.
02. Achieve universal awareness of clinical trial opportunities among eligible patients.
03. Integrate clinical trial participation as a key component of standard care pathways.
04. Ensure innovative treatments reach patients faster through optimized trial processes.
05. Establish Quebec as a hub for groundbreaking lung cancer research and innovation.

Conclusion — Our Vision for the Future

Quebec's Vision: A Future Free from Lung Cancer Stigma

In the next decade, Quebec will lead the fight against lung cancer by championing early detection, equitable care, and cutting-edge treatments. By addressing stigma, promoting awareness, and closing critical gaps in care, we can transform outcomes for patients, families, and communities across the province.

A Culture of Awareness and Compassion

Public campaigns will erase stigma and foster openness about lung cancer, emphasizing that anyone with lungs can get lung cancer. Greater awareness will ensure those affected receive the same compassion as individuals impacted by other cancers. Comprehensive screening programs will reduce late-stage diagnoses, while educating primary care providers will expedite earlier detection and intervention.

Equitable and Timely Care

Every patient, regardless of location or background, will have access to advanced diagnostics, including biomarker testing, within standard wait times. Personalized treatment pathways based on patient needs will ensure better outcomes and equitable care across Quebec.

Comprehensive Support Beyond Hospitals

Patients and caregivers will be supported by networks of psychosocial, financial, and practical resources, addressing the emotional and logistical challenges of lung cancer. Community-based programs will extend care beyond hospitals, empowering patients to focus on what they can do.

Driving Research and Innovation

Quebec will invest in research, fostering advancements in therapies, screening technologies, and clinical trials. Streamlined regulatory processes and increased patient participation will position the province as a leader in global lung cancer innovation.

Measurable Reductions in Lung Cancer Burden

Sustained efforts in prevention, early detection, and equitable care will lead to measurable reductions in lung cancer incidence and mortality. Quebec will become a model for lung cancer care, inspiring change across Canada and beyond.

Grounded in equity, innovation, and compassion, Quebec's commitment will create a future where lung cancer is no longer a death sentence but a challenge that can be overcome. Together, we will build a province where every individual impacted by lung cancer has access to the care, support, and hope they deserve.

LUNG CANCER CANADA
AWARENESS. SUPPORT. EDUCATION.
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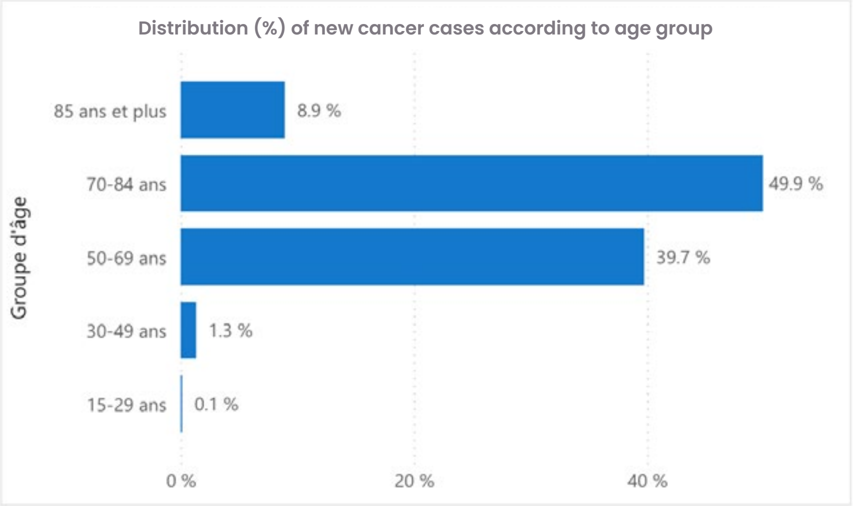
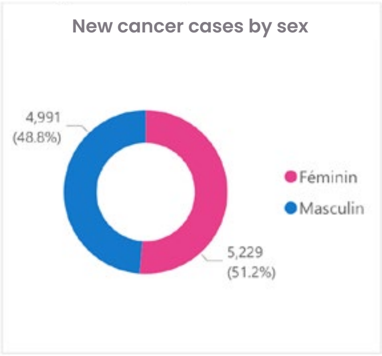
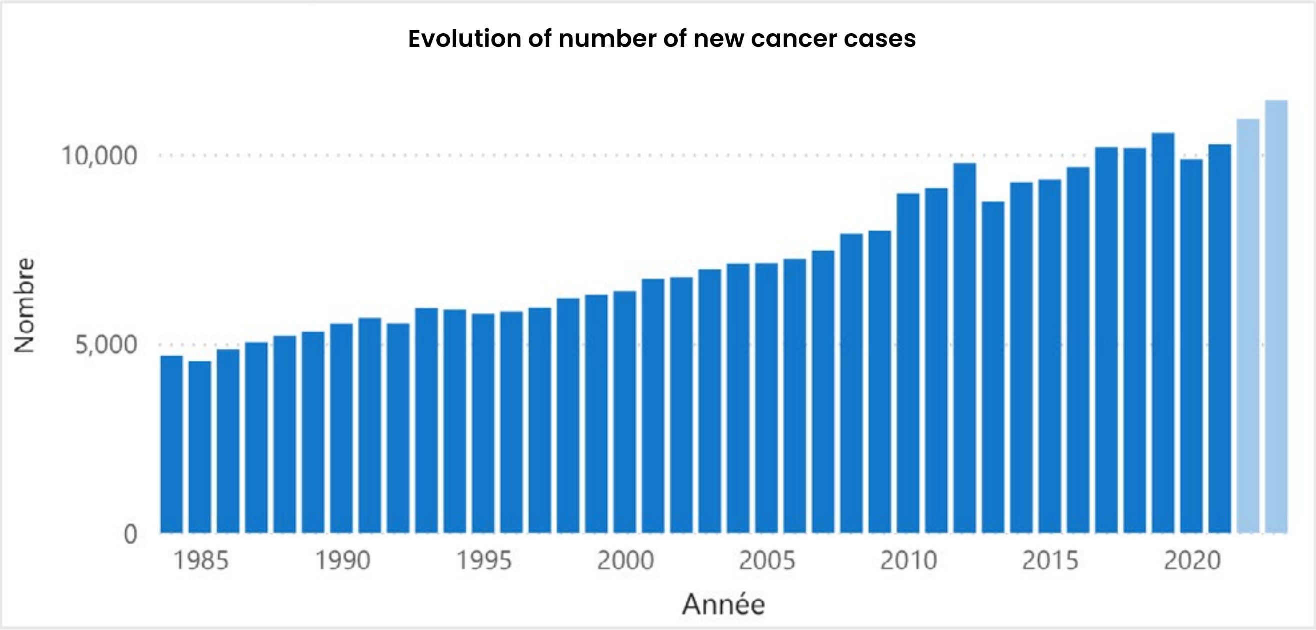
Lung Cancer Statistics in Quebec



New cancer cases
10,264





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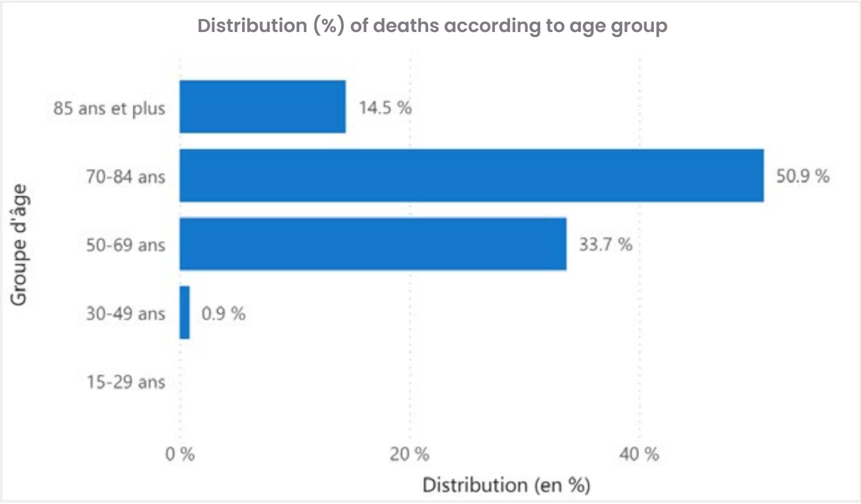
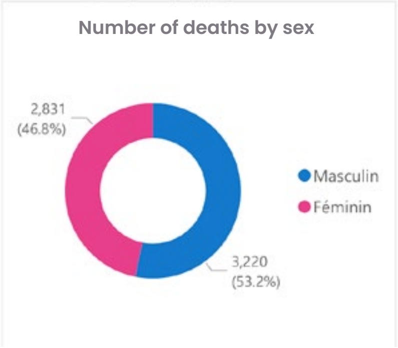
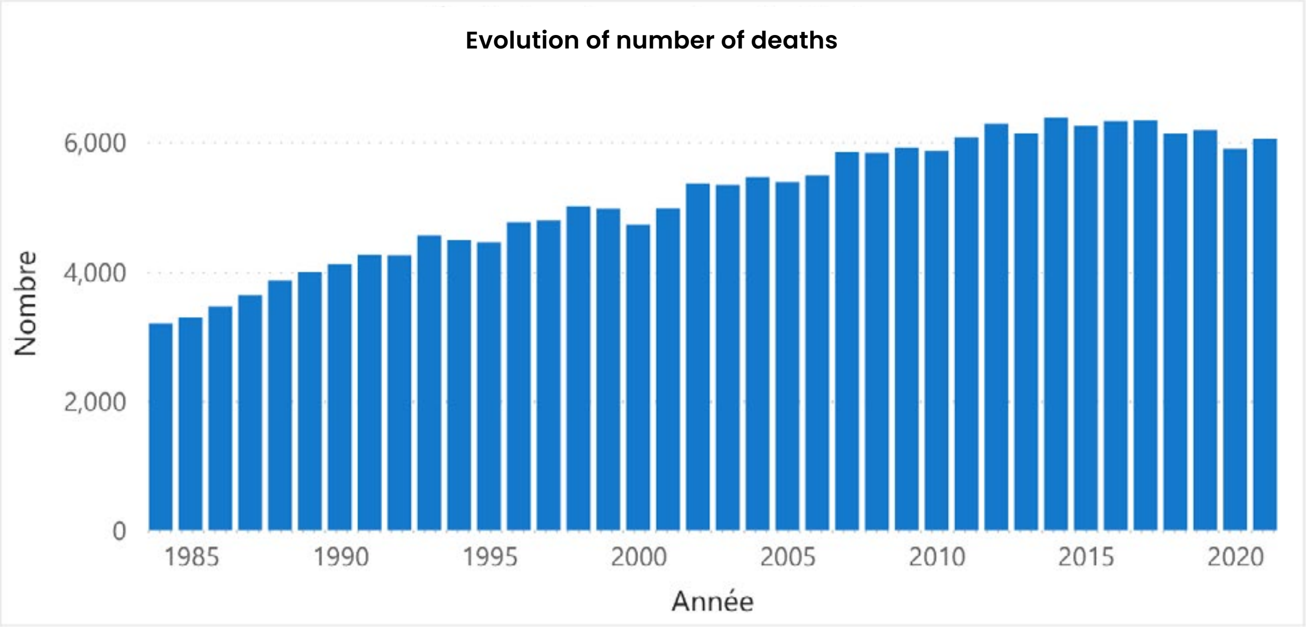


Number of deaths
6,051





Breast Cancer

Recommendations by

Quebec
Breast Cancer
Foundation

These recommendations reflect feedback collected from over one hundred patients following the Forum Santé des Seins (2024)

Introduction

There are several types/subtypes of breast cancer. Here are the main ones and their abbreviations:

ER+/-: estrogen positive/negative

PR+/-: progesterone positive/negative

HR+/-: hormone positive/negative (ER or PR)

HER2+/-: positive/negative for HER2 overexpression

HER2 low: new status, with very slight overexpression of HER2. Until very recently, this type of breast cancer was considered HER2-negative.

TNBC: triple negative, 3 times negative for the classic markers (above), namely estrogen (ER), progesterone (PR) and HER2.

Ductal carcinoma: tumour located in the lactiferous ducts

Lobular carcinoma: tumour located in the lobules

In situ: localized tumour (stage 0)

Ki-67: a marker for assessing tumour cell growth rate

Basal-type breast cancer: a type of breast cancer similar to TNBC, but with modified proteins that are different from triple-negative. It is most often an infiltrating ductal breast cancer.

BRCA 1/2: genes whose mutations will play a role in the development of breast cancer in particular, as DNA repair and control of cell division are no longer carried out adequately, thus increasing the risk of breast cancer.

ATM / CHEK2 / PALB2: other genes in which mutations will have a major impact on increasing the risk of developing breast cancer

BI-RADS A/B/C/D: category indicating breast density. Low breast density for categories A and B, high for categories C and D. This indicates the composition of the breast. A predominantly fatty breast is not very dense, whereas a predominantly glandular breast is very dense. This will have an impact on imaging and the ability to detect a tumour on mammography, as well as on the risk of developing breast cancer (dense = increased risk).

Context — Reality & Impact on the Quebec Population

One woman in eight will be affected by breast cancer during her lifetime, and one woman in thirty-six will die from it. In Quebec, more than 8,000 new cases are expected in 2021.

Breast cancer is the 1st most common cancer in women, and the 2nd leading cause of cancer-related death (after lung cancer). Most cases occur in women, but 1% of breast cancers affect men.

There has been an organized screening program since 1998 (PQDCS), with few changes to the criteria since its inception. Every woman in Quebec between 50 and 74 receives a letter every 2 years inviting her to undergo a mammography (the letter serving as a medical prescription). In Quebec, the participation rate is around 63% (while the government target is 70%). There is currently no consideration of risk in Quebec's screening policy.

Access to mammography in Quebec varies. Depending on your geographic location, waiting times may vary from 1 week to over 35 weeks in some regions. COVID also had a direct impact on the PQDCS, which was interrupted for several weeks before gradually resuming in the various regions.

Stakeholders to Consider & Priority Populations

Key Stakeholders

- Ministry of Health & Social Services (MSSS):
  - Programme Québécois de cancérologie (PQC)
  - Quebec breast cancer screening program (PQDCS)
  - INSPQ
  - INESSS
  - CIUSSS-CISSS
  - CRID-CDD-CCSR
- Community organizations/interest :
  - Quebec Breast Cancer Foundation
  - Canadian Cancer Society
  - Quebec Cancer Foundation
  - Regroupement des organismes communautaires en oncologie (ROCO)
  - Quebec Cancer Coalition
  - Quebec Breast Cancer Action
  - Audace au féminin
  - McPeak-Sirois Group

Priority Populations

- There is a need to assess risk in order to identify those at greater risk. Today, only age and/or family history and/or breast density are taken into account in the notion of risk, and no screening program is dedicated to this population.
- Related to this is the need for risk assessment in certain communities (black communities, indigenous communities, LBGTQ communities, etc.).
- People with poor prognosis cancers such as stage 4 and triple-negative breast cancer need the focus of research
- Post-breast cancer, and all the support provided during the stages following active treatment, is a major gap to be bridged (management of side effects over the long term, fear of recurrence, adoption/maintenance of healthy lifestyle habits, return to work).
- Support for family and friends is also a major issue, and one that is rarely addressed.

Existing and Missing Supports for Patients and Their Families

Existing Supports

- Extensive province-wide support services such as 1 855-561-ROSE
- Numerous educational and awareness-raising events
- Many existing breast cancer resources for patients
- Peer support resources such as https://rubanrose.org/en/support-me/support-services/peer-support/peer-support-services-and-resources/

Supports Needed

- Clarity on resources
- Accurate, timely and appropriate referral to resources
- More resources dedicated to loved ones
- Better access to psychological follow-up in Quebec
- Better access to sexology services in Quebec
- Better access to genetic testing in Quebec
- More standardized use of PROMs to measure Quality of Life indicators.

Objectives to Aim For in Quebec to Reduce Incidence, Reduce Mortality & Better Support Patients

(Performance indicators to be measured over the next 10 years)

Prevention:

- Promote prevention through education on risk factors, particularly modifiable risk factors that can be influenced: alcohol and tobacco consumption, a healthy, balanced diet, physical activity and a sedentary lifestyle.
- Continued investigation of new/future risk factors, such as exposure (endocrine disruptors, fine particles, pollutants...)

Short Term: Large-scale educational campaign on the notion of risk for breast cancer

Medium Term: Listing of new proven risk factors for breast cancer

Long Term: Ban on carcinogenic substances in over-the-counter products

Screening :

- Reduce delays in access to screening imaging
- Just as targeted treatments and precision medicine are used today, we should aim for targeted screening, based on the notion of individual risk, with adapted screening approaches.
- Continue to study innovations in screening technologies, notably with artificial intelligence, in order to find alternative solutions to the current "gold standard", which is mammography (liquid biopsy, odor analysis, virtual twins, etc.)

Short Term: PQDCS based on individual risk. Reduce wait times for PQDCS.

Medium Term: Pilot project on a new screening technology

Long Term: New "gold standard" in screening

Access to healthcare:

- Improve access to genetic/molecular testing
- Reduce access time to new therapies
- Obtain socio-demographic and economic data

Short Term: Systematic collection of socio-demographic and economic data to improve inequalities in access to care.

Medium Term: Improve access to new therapies by setting up a drug validation process like in Europe (access in parallel with discussions). Improve access to genetic & molecular testing for breast cancer. Improve access to genetic counselors for hereditary mutations (eg. BRCA).

Treatment :

- Continue research into increasingly targeted therapies with the fewest side effects for patients.
- Develop and harmonize the use of PROMs. Avoid multiplying projects using different technologies and/or tools that ultimately deliver the same functionality.

Short Term: Setting up a single, harmonized real-world registry. Improve access to new targeted therapies and those that can enable people to continue to live their normal lives (eg. work).

Medium Term: Consideration of PROMS in the evaluation of new therapies

Support :

- Develop post-cancer services (including for caregivers)
- Improve and harmonize referrals to existing resources at the right time.
- Increase the duration of employment insurance

Short Term: Increase employment insurance coverage to 52 weeks following a cancer diagnosis Support patient’s return to work if desired with existing ressources like www.CancerAndWork.ca.

Medium Term: Harmonize implementation of a referral process to existing resources

Conclusion —
Our Vision for the Future

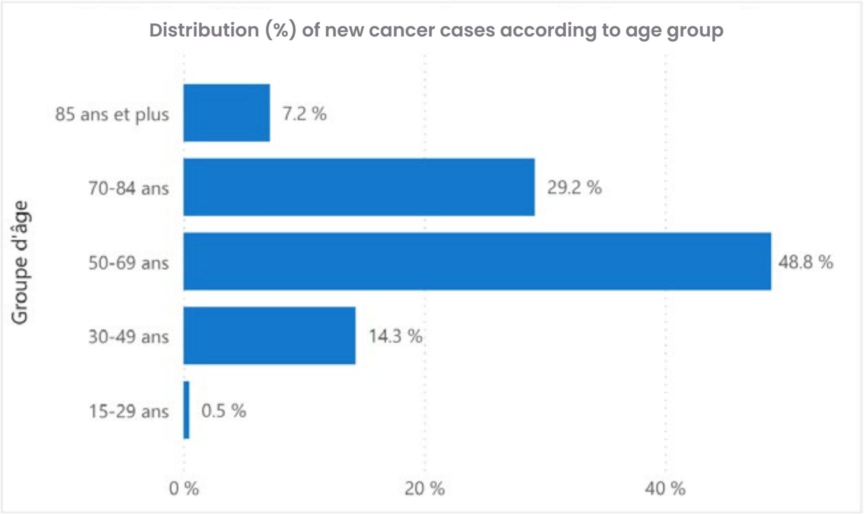
There will be more and more breast cancers, among people of all ages and stages, which means that there will be more and more breast cancer survivors. The specific needs of these people will need to be taken into account throughout the treatment process and over the long term (post-treatment side effects, return to work, much longer life expectancy for stage 4 patients, etc.).

Our vision:

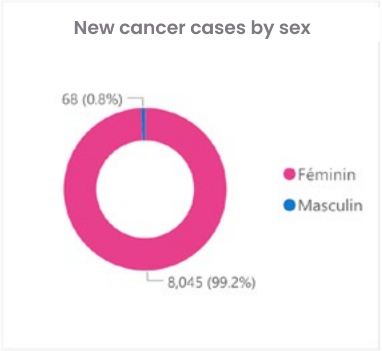
- Targeted screening (based on risk), just as therapies are targeted today.
- A new breast cancer screening technology
- Better access to preventive genetics
- Faster access to innovative treatments
- Improved treatment for breast cancers with poor diagnosis
- Increased eligibility for employment insurance during illness
- Increasing and adapting services for the post-cancer period (including for relatives)
- Unique harmonization of referrals to existing resources: the right resource, at the right time, for the right person.

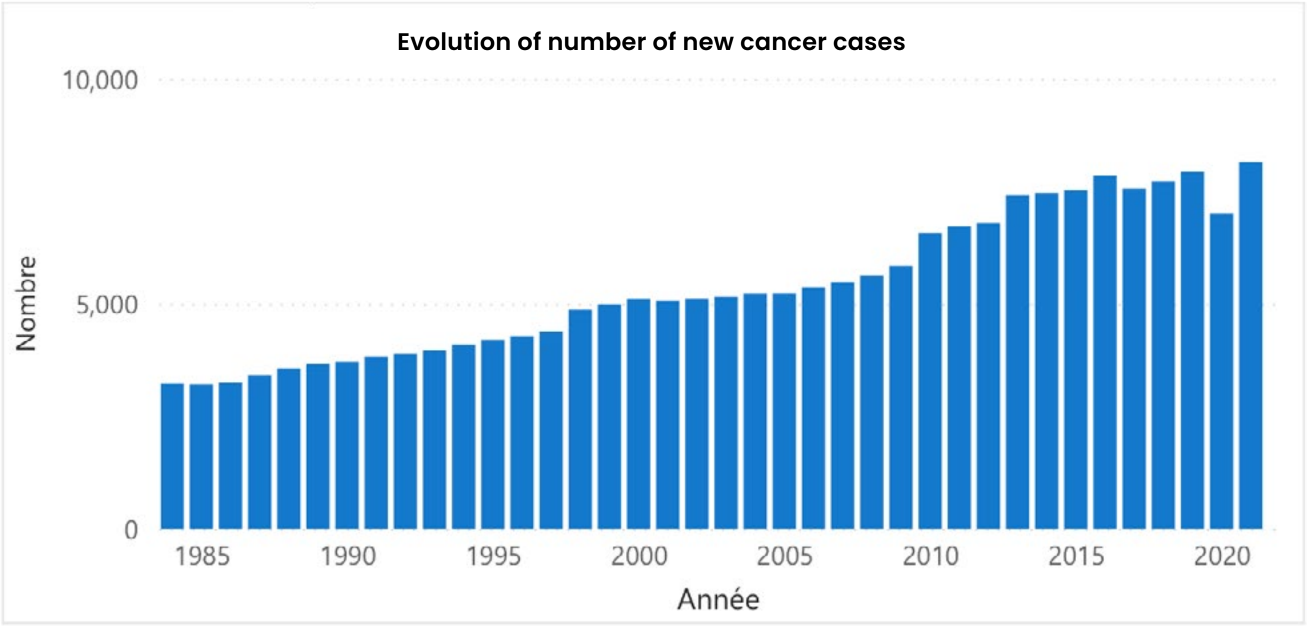
Quebec
Breast Cancer
Foundation

Breast Cancer Statistics in Quebec



New cancer cases
8,154





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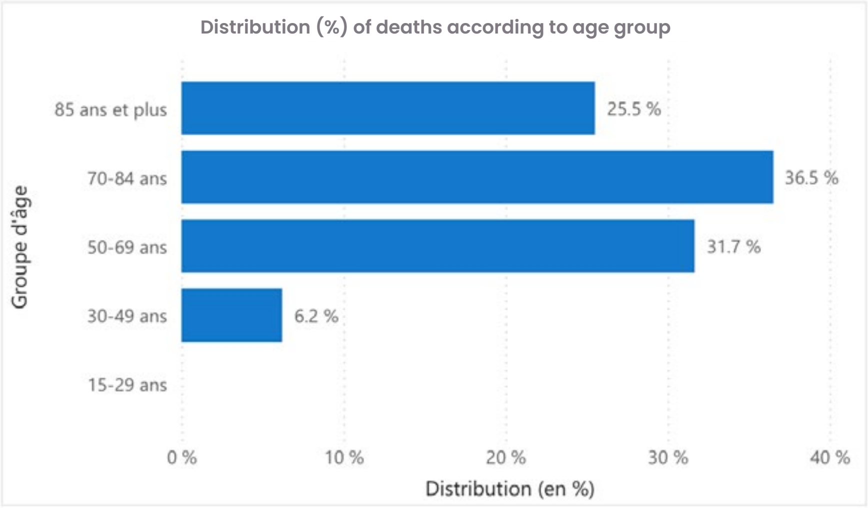
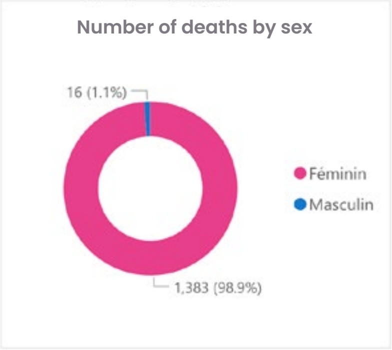
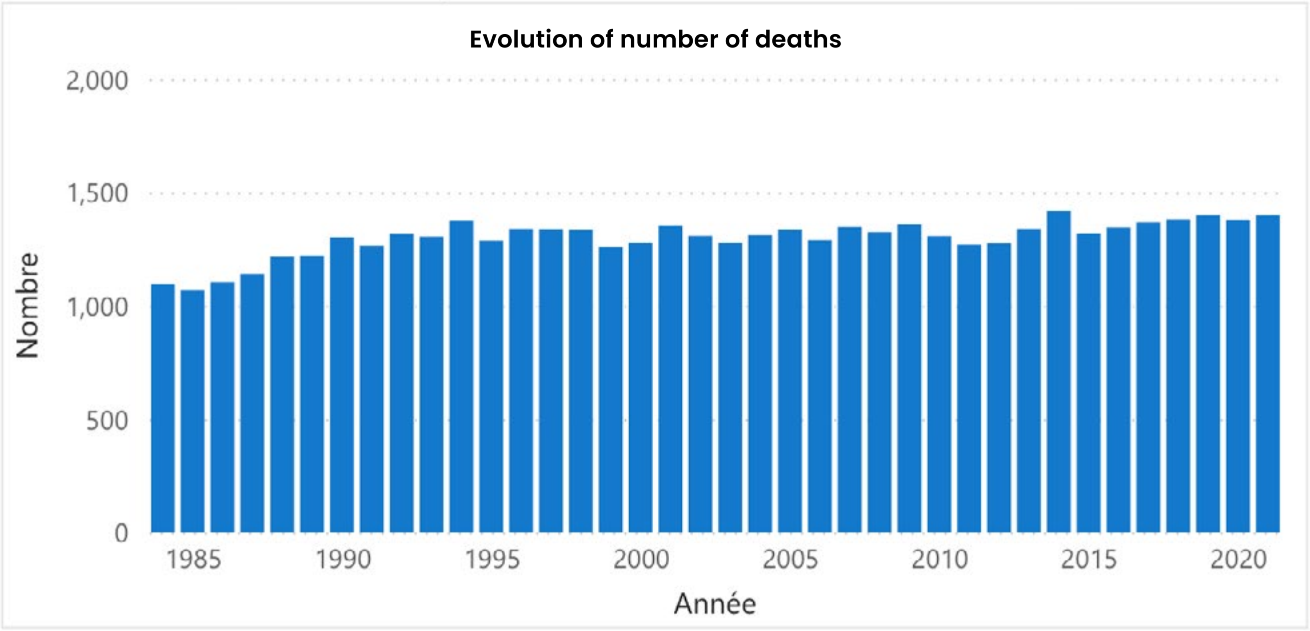
The original data can be accessed here.



Number of deaths
1,399





Prostate Cancer

Recommendations by

PROCURE
CANCER – PROSTATE

These recommendations were formulated following analysis of the questions and concerns of Procure's medical hotline.

Introduction

PROCURE is a charity dedicated to the fight against prostate cancer. Since 2003, we have been raising awareness and supporting men affected by this disease, as well as their families, by offering information, education and support resources.

With a 7-day-a-week toll-free medical hotline staffed by medical professionals specialized in uro-oncology, we're able to respond quickly to patients' concerns and questions.

Recognized by the Canadian Urological Association (CUA) and the Quebec Urological Association (QUA) (authorities on prostate cancer), everything we produce is approved by a validation committee of medical specialists.

PROCURE is also actively involved in advancing research, understanding and treatment of prostate cancer. We are a key player because:

- We maintain an ongoing dialogue with healthcare professionals and forge links with top-level collaborators in the field of scientific research;
- We provide researchers with samples and data from the PROCURE Biobank, world-renowned for its collection of high-quality biological samples, as well as for its valuable data on men with prostate cancer.

Context — Reality & Impact on the Quebec Population

Reality

Prevalence and incidence - Prostate cancer is the most common cancer in men. In Quebec, as in the rest of Canada, it accounts for 20% of all new cases of cancer in men. According to statistics, nearly one man in seven will be diagnosed with prostate cancer in his lifetime, making it a major public health concern.

In Quebec

- 18 men are diagnosed with cancer every day
- Approximately 7,089 new cases of prostate cancer each year
- 3rd leading cause of cancer deaths in men

The Main Risk Factors

- Age (50+)
- Family history
- Ethnic origin, with black men at greater risk

Types of prostate cancer - Prostate cancer can progress slowly or aggressively, with varying impacts on patients' health. Treatments available include active surveillance, surgery, radiotherapy and hormone therapy, but each option presents its own side effects and challenges.

It usually presents no symptoms in its early stages, making it difficult to detect. However, it is entirely curable if diagnosed early, as long as it is still localized to the prostate and treatment is initiated promptly. This underlines the importance of screening men aged 50 and over.

Impact on the Quebec Population

01. MENTAL AND EMOTIONAL HEALTH:

A prostate cancer diagnosis can have significant psychological effects, both for patients and their loved ones. Anxiety, depression, stress linked to the unknown, undesirable side effects are all common reactions, and the support of complementary experts is essential to accompany patients in their care trajectory.

02. ECONOMIC LOAD:

Prostate cancer entails significant costs for the healthcare system, both in terms of treatment and follow-up care. In addition, patients may face loss of income due to inability to work during treatment or recovery. The earlier a diagnosis is made, the lower the economic impact.

03. AWARENESS-RAISING AND EDUCATION:

Initiatives such as PROCURE play a crucial role in providing credible information between treatments or appointments. This enables patients to be well informed, make informed decisions and play an active role in managing their health.

04. SUPPORT NETWORK:

Community resources play an essential role in helping men cope with the challenges associated with this disease. For PROCURE, this means awareness programs, a medical assistance service and open discussions on men's health.

Given an aging population and the fact that prostate cancer mainly affects men over the age of 50, we can expect an increase in diagnoses in the coming years. This trend raises concerns about patients' quality of life during and after treatment.

PROCURE Survey - In May 2022, an online survey commissioned by PROCURE and conducted by Léger revealed that 50% of the 263 patients treated for prostate cancer identified the management of side effects - with erectile dysfunction and incontinence topping the list - uncertainty, and maintaining a positive attitude as the main challenges.

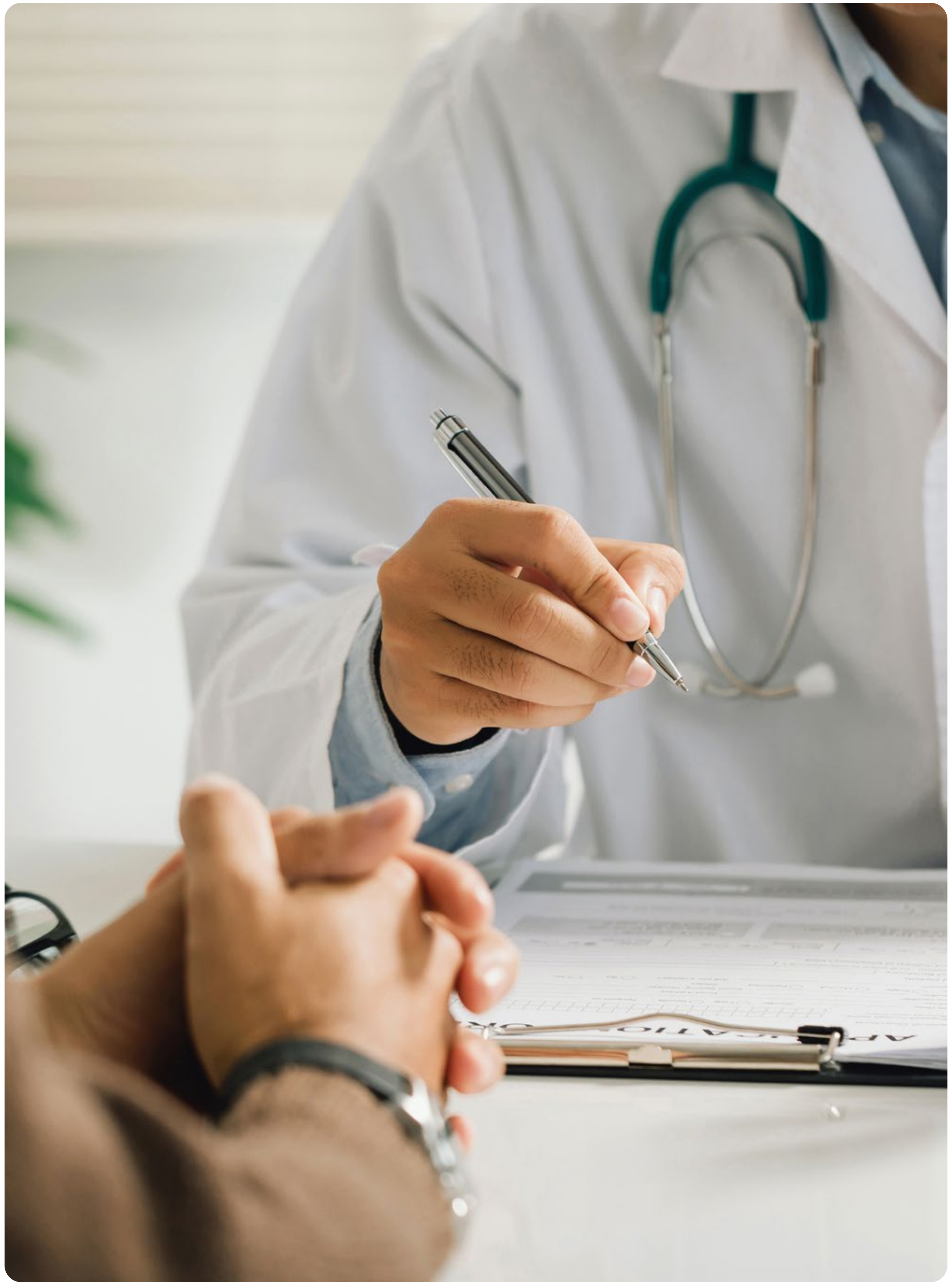
Stakeholders to Consider & Priority Populations

Stakeholders

- CUA - Canadian Urological Association
- AUQ - Que bec Urological Association
- College of physicians
- FMOQ - Quebec Federation of General Practitioners
- FMSQ - Federation of Medical Specialists of Quebec
- AMSMNQ - Association of Nuclear Medicine Specialists
- OIIQ - Ordre des Infirmières et Infirmiers du Québec
- AQIO - Association of Nurses in Oncology
- AQPP- Quebec Association of Pharmacists Owners
- APQ - Quebec Pharmacists Association
- Other professional orders such as:
  - Sexologists
  - Psychologists
  - Physiotherapists
  - Kinesiologists
- Community organizations
- Quebec Government
  - MSSS - CISSS, CIUSSS
  - INESSS
  - Revenu Québec

Priority Populations

- Men aged 50 and over:
  - A PSA test coupled with a rectal examination can detect abnormalities before symptoms appear.
- Black men or men with a family history:
  - Screening from the age of 45 is recommended because of the increased risk.
- Men with a genetic mutation such as BRCA:
  - A screening strategy is recommended towards the end of the thirties.
- Caregivers: partner, family:
  - Resources are needed to support and answer the questions of partners and families.



Existing and Missing Supports for Patients and Their Families

Existing Supports for Prostate Cancer Patients & Their Loved Ones

SUPPORT LINES

Some organizations, such as PROCURE, offer support where patients and their loved ones can ask questions, obtain information about the disease and receive support. These services are often available free of charge. PROCURE offers a medical support telephone line for free by dialing 1-855-899-2873.

ONLINE EDUCATIONAL RESOURCES

Websites and digital platforms offer information on a wide range of topics related to prostate cancer, treatment options, side effects and recovery. Educational videos, guides and fact sheets help patients to better understand their disease and play an active role in their treatment.

SUPPORT GROUPS FOR PATIENTS AND THEIR FAMILIES

Support groups, both face-to-face and online, enable patients and their loved ones to share experiences, concerns and advice. These groups encourage self-help and help people find comfort in similar situations. (More remote regions may not have access to these groups in person).

DIGITAL HEALTH MANAGEMENT TOOLS

The digital health record enables patients to track their care, record appointments and treatments, and centralize medical information to facilitate follow-up. When used, this tool improves communication between patients and healthcare professionals.

Missing or Inadequate Supports

GREATER ACCESS TO COMPLEMENTARY PROFESSIONALS

Although services do exist, it's often difficult to access them in the public sector. In the private sector, financial coverage is often inadequate, particularly when it comes to care with psychologists, sexologists and physiotherapists. These services are not always reimbursed by the RAMQ, limiting access for patients and their loved ones who need them throughout their journey.

CARE COORDINATION BETWEEN HEALTHCARE PROFESSIONALS

Coordination between different levels of care (family doctor, urologist, oncologist and other experts) can be deficient, leading to gaps in care. A system where all medical information automatically follows the patient through each stage of treatment would be beneficial, reducing the administrative burden on patients. Systematic use of the digital health record could, among other things, help track the patient's file and centralize medical information to facilitate follow-up. Several patients confirm that this tool improves communication between patients and healthcare professionals when used.

FINANCIAL SUPPORT TO TREATMENT OF ERECTILE DYSFUNCTION FOLLOWING PROSTATE CANCER

Patients can face significant costs associated with erectile dysfunction treatments such as penile pumps, intravenous injections and oral medications that are not covered by insurance. Including these treatments in basic coverage would ease the financial burden.

ACCESS TO THERAPEUTIC INNOVATIONS

Despite advances in prostate cancer treatment, access to certain innovative therapies, such as targeted or radiopharmaceutical treatments, is still difficult and highly uneven across the province. Providing and standardizing access to these treatments is a necessity to ensure that all patients can benefit from the best options.

Objectives to Aim For in Quebec to Reduce Incidence, Reduce Mortality & Better Support Patients (Performance indicators to be measured over the next 10 years)

PROCURE's proposed objectives for Quebec are to improve the incidence and mortality of this cancer, and to provide better support for patients.

Short-Term Objectives: 1-2 years

01. SCREENING PRACTICES

- Ensure that screening practices are consistent with the College of Physicians and the recommendations of the Canadian Urological Association.
- Encourage men aged 50 and over, as well as those with risk factors or genetic mutations, to discuss screening with their doctor.

02. ACCESS TO EFFECTIVE, RELEVANT AND INNOVATIVE TREATMENTS

- Accelerate approval of new treatments: Facilitate access to innovative therapies, such as radiopharmaceuticals, targeted treatments and precision medicine.
- Standardize access to the latest therapeutic innovations for prostate cancer, such as precision medicine, targeted treatments, nuclear medicine and radiopharmaceuticals.

03. USE AVAILABLE TOOLS

Educate medical staff on the proactive use of patient health records. By encouraging this use, patients can more easily keep track of their medical records.

04. ACTIVE PARTICIPATION OF PEOPLE AFFECTED BY CANCER

Increase participation of men with prostate cancer in public forums and health policy consultations.

Medium-Term Objectives 3-5 years

01. CARE AND SUPPORT SERVICES THROUGHOUT THE TRAJECTORY

- Following prostate cancer, integrate erectile dysfunction treatments into basic coverage and ensure reimbursement of pumps, oral treatments and injections.
- Facilitate access to complementary professionals and ensure RAMQ-covered sessions (sexologists, psychologists, specialized physiotherapists, kinesiologists).
- Ensure better coordination between different levels of care (family doctor, urologist, oncologist) to avoid gaps in care.
- Use of the patient's health record for better management of patient information

02. ACCESS TO EFFECTIVE, RELEVANT AND INNOVATIVE TREATMENTS

- It should be mandatory for all healthcare professionals to record patient information in an electronic file.
- Keep prostate cancer-specific performance indicators up to date, such as survival rates, time to diagnosis, and patients' quality of life after treatment.

Conclusion — Our Vision for the Future

In conclusion, our proposed objectives define concrete actions for the short and medium term, while paving the way for an ambitious vision for the future of prostate cancer care. By harmonizing screening practices and facilitating access to patient data and innovative treatments, we aim to make Quebec a model for cancer care.

One of our key objectives is to ensure that every human being, regardless of background or geographical location, has access to the best technologies and the most appropriate care for his or her situation. A key component of this vision is to ensure that a patient's complete medical record is accessible (regardless of treatment location) throughout his or her care pathway, and automatically. This continuous monitoring of medical data will enable better coordination of care, reducing errors and delays in treatment.

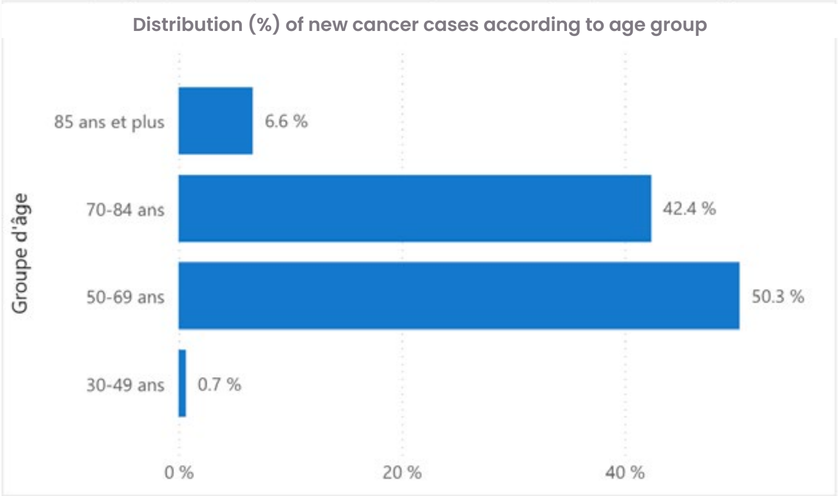
We also envision a future where men and their families actively participate in decisions concerning their health, supported by quality educational resources and seamless care.

This vision for the future must also include special attention to the incorporation of complementary professionals who can provide psychological and physical support for patients.

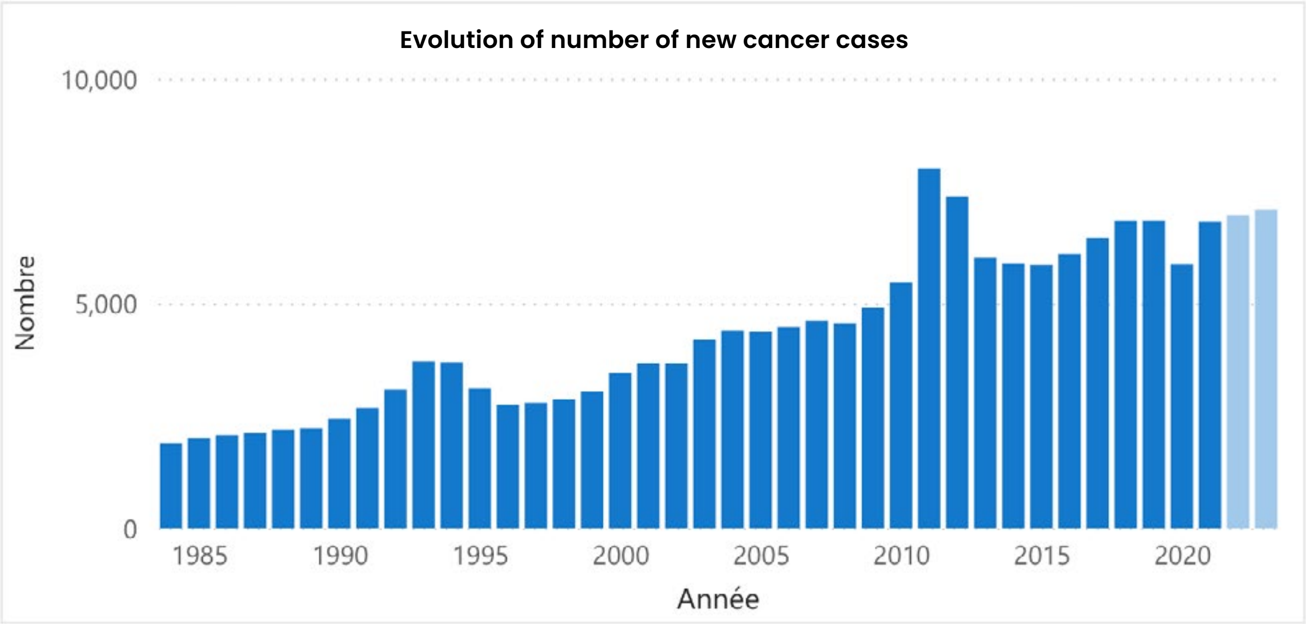
In our view, by pursuing these efforts, we are building a more equitable, innovative healthcare system focused on the well-being of Quebec men affected by prostate cancer.

PROCURE
CANCER – PROSTATE

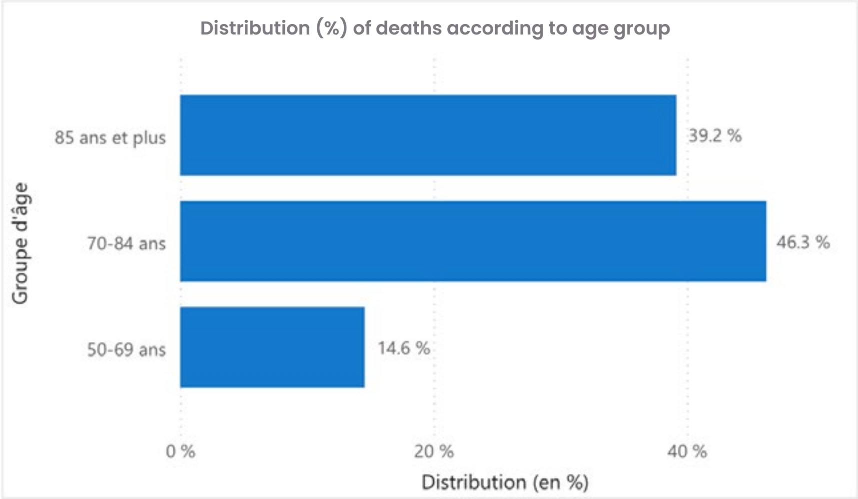
Prostate Cancer Statistics in Quebec


Distribution (%) of new cancer cases according to age group

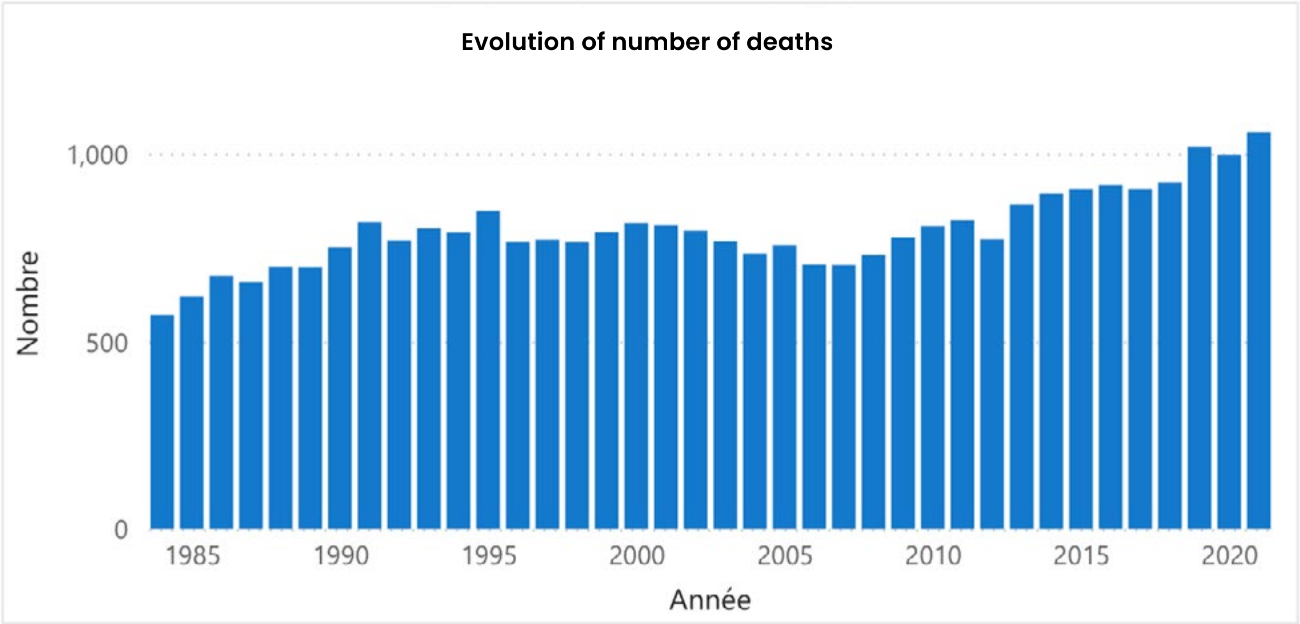
New cancer cases
6,813


Evolution of number of new cancer cases

The graphics in this report are pulled from the dashboards of the Registre québécois du cancer, available exclusively in French.
The original data can be accessed here.


Distribution (%) of deaths according to age group

Number of deaths
1,057


Evolution of number of deaths

Colorectal Cancer

Recommendations by

CANCER COLORECTAL CANADA
COLORECTAL CANCER CANADA

These recommendations reflect the information and contributions of various patients gathered at the many round tables organized by Colorectal Cancer Canada.

Introduction

Colorectal cancer encompasses two types of cancer: colon cancer (large intestine) and rectal cancer (the last segment of the large intestine). These two types of cancer share many characteristics and are collectively known as 'colorectal cancer'.

In general, colorectal cancer spreads quite slowly, and can remain in the colon or rectum for several months, even years. Most cases of colorectal cancer develop from polyps (mushroom-like growths). Some polyps are flat, making them more difficult to detect. Although most polyps are benign, some can become cancerous as they evolve. Polyps can take 8 to 10 years to develop into cancer.

Over time, the benign polyp may grow through some or all of the tissue layers that form the colon and rectum and become malignant, invading nearby tissues and structures. Over time, the malignant tumour cells can enter the blood and lymphatic systems, spreading to other parts of the body and causing cancer to develop in these organs. A cancer that spreads to a distant organ is said to have metastasized; the liver and lungs are common sites of metastasis. Metastatic colorectal cancer is sometimes known as advanced colorectal cancer or stage IV colorectal cancer.

A screening test is used to check for the presence of colorectal cancer in the asymptomatic population. These are individuals who show no signs or symptoms of the disease. Screening asymptomatic people for colorectal cancer and removing one or more benign polyps can prevent colorectal cancer or, in the case of a polyp that has already developed into cancer, cure it if detected in time in 90% of cases. Early-stage cancers do not always present symptoms, which underlines the importance of participating in a regular colorectal cancer screening program. When a person shows signs or symptoms, they are referred for diagnostic testing to determine the source of the problem, rather than being screened.

Abbreviations Associated With Colorectal Cancer:

CRC: colorectal cancer

EAOCRC: early age onset colorectal cancer

mCRC: metastatic colorectal cancer

MSI H: High microsatellite instability

dMMR: defective mismatch repair system

Context — Reality & Impact on the Quebec Population

Colorectal cancer is the second most frequently diagnosed cancer and the second most deadly cancer in Quebec. We estimate that 7,300 individuals will be diagnosed with colorectal cancer in 2024, up from the previous year, and 2,600 will die from it. Colorectal cancer affects both men and women, and according to statistics issued by the Canadian Cancer Society, we project that by 2024 :

- 4,100 men in Quebec will be diagnosed and 1,450 will die.
- 3,200 women in Quebec will be diagnosed and 1,150 will die.

Approximately 8% of new cases of colorectal cancer will be diagnosed in individuals under 50, a segment of the population facing the most rapid increase in new diagnoses. However, 78% will occur in the target population aged 50 to 74, for whom participation in screening is recommended.

It's worth noting that in the USA, the age for early detection has been lowered to 45, as the fastest-growing subgroup of patients is rectal cancer patients aged 28 to 39. In fact, according to a report published in 2024 by the American Cancer Society, colorectal cancer has gone from being the fourth leading cause of cancer death in men and women under 50, twenty years ago, to first in men and second in women.

The first screening test for those at average risk - individuals aged 50 to 74 with no first-degree relatives diagnosed with colorectal cancer - the fecal occult blood test (FOBT), is a simple, non-invasive home test, also known as the "FIT" test.

After making some progress prior to the pandemic, Quebec unfortunately has fallen back, failing to reach its target of 60% colorectal cancer screening among people aged 50 to 74. In fact, Quebec has a colorectal cancer screening rate of less than 40%, and is the only province in which an organized colorectal cancer screening program has not been fully implemented. Most screening is opportunistic, proposed by health professionals. Individuals without a family doctor may be poorly informed about the screening test, although since 2024 access to the FOBT has been made more accessible through access points in Covid-19 vaccination centers, even in the absence of a family doctor. While this is a step in the right direction, there are nevertheless constraints to this process.

In addition, accessibility of the test varies from region to region, for a variety of reasons. Awareness, education and access to the FOBT test may unfairly prejudice underserved populations such as First Nations, Inuit and Métis.

When a person receives a positive FOBT result, he or she must undergo a colonoscopy for further examination within 8 weeks. However, the waiting list for a colonoscopy remains long and, at present, it is not possible to guarantee all individuals a colonoscopy within this timeframe. Although Quebec appeared to be closing what was already a significant gap, over 90,855 (GESTRED-37000 and 37100, March 2023) too many people are still waiting for a colonoscopy today. Lack of qualified personnel and budgetary constraints contribute to the difficulty of expanding access to colonoscopy and limit the possibility of increasing access in the public health network.

There is also a disparity between public and private system follow-up. During the pandemic, the private healthcare network was mobilized to relieve overcrowding in the public system, which could help reduce today's colonoscopy backlogs.

Stakeholders to Consider & Priority Populations

Stakeholders

- Quebec population
- Patients and their caregivers
- Patient groups
- Community organization in oncology
- Family doctors
- Clinical nurses
- Health and Social Services Ministry (MSSS)
- Pharmacists
- Gastroenterologists
- Oncologists
- Santé Québec
- Researchers
- Dieticians
- Psychosocial practitioners
- Private endoscopy clinics

Priority Populations

Early Detection

Efforts to raise awareness of colorectal cancer and the importance of participating in screening, carried out in collaboration with patient groups and public stakeholders, are essential to reach as many people as possible.

Priority populations are average-risk individuals aged 50 to 74, as well as all high-risk individuals, such as :

- Individuals with a family history of colorectal cancer
- Individuals with a family history or personal history of a related syndrome, such as Lynch syndrome or familial adenomatous polyposis (FAP).
- Individuals with inflammatory bowel disease, such as Crohn's disease or ulcerative colitis

It's important to note that high-risk individuals should consult a health professional and be referred to a specialist for personalized follow-up and to determine the best steps to take.

Diagnostic Tests

Anyone experiencing symptoms or changes in bowel habits should discuss them with their family doctor or clinical nurse as soon as possible, to determine the causes and, if necessary, undergo **colorectal cancer screening** as soon as possible. A priority sub-group is people under 50.

Existing and Missing Supports for Patients and Their Families

To develop a resilient healthcare system, we need to ensure that adequate planning is in place to ensure that capacity issues are not a barrier to timely and equitable treatment. The approach to colorectal cancer and cancer in general in Quebec must start with a major investment in prevention and the implementation of a population-based colorectal cancer screening program, as it is not only more cost-effective, but colorectal cancer is certainly easier to prevent than to treat and eventually cure.

We need to ensure timely and equitable access to prevention and screening strategies, diagnostic tests, including molecular profiling, and effective cancer treatments. Once diagnosed, we need to ensure that patients have rapid and equitable access to molecular profiling and clinical trials to provide early access to some of the latest innovations, and to ensure that they have recourse to the best treatment for their situation. Therefore, we need to encourage investment in clinical trials in Quebec as they become an integral part of clinical practice.

Access to psychosocial and mental health support for cancer patients and their caregivers is essential, and currently poses a serious challenge for cancer patients trying to cope with the realities of their illness, both during and after treatment. Caregivers are thrust into roles that require them to manage complex medical tasks, provide emotional support and take on additional domestic responsibilities, often with little or no formal training.

Despite their essential role, support systems for family carers remain limited, with few resources to help them cope with the emotional burden and demands of caregiving. Many lack access to mental health services, respite care and peer support networks, leaving them feeling alone and unsupported during and after their loved ones' treatment. It is therefore essential to integrate systematic support for family caregivers into oncology care to ensure their well-being and quality of life, as well as that of their loved one with cancer, and to improve their ability to act more effectively on the patient's behalf.

Financial stress resulting from the inability to work, for both patient and caregiver, is a major concern for most patients undergoing treatment or receiving palliative care. This stress can also result from the cost of treatment or related services. Patients and caregivers need financial support, as the economic burden of colorectal cancer in Canada, as well as in Quebec, is considerable. The direct costs of colorectal cancer in Canada, i.e. out-of-pocket expenses for patients and their families, such as co-insurance, deductibles and costs of non-reimbursed services or treatments, have been estimated at around $364 million in 2021. A significant proportion of these costs are attributed to Quebec patients.

Patient groups play an essential role in supporting patients and their caregivers at all stages of their care trajectory - whether diagnosis, treatment, palliative care or survivorship - and are complementary to the services offered by healthcare professionals at our medical facilities. Those affected by the disease could benefit greatly from a systematic referral process, or greater recognition by the public health system of the importance of involving patient groups from the moment of diagnosis, in order to achieve the best outcomes for patients, caregivers and their loved ones.

Patient groups are unsupported and rely on donations and grants from charitable organizations. They are an essential part of our healthcare system, often called upon by the public, government agencies and healthcare professionals to provide services free of charge. They need recognition and financial support to meet growing patient demand.

Gaps in support identified by patients and caregivers:

- High demand for mental health and psychosocial services during and after treatment for patients and their families.
- Need for additional nutritional assessment and support to avoid malnutrition in cancer patients.
- Navigation and access to clinical trials in Quebec and across Canada, as trials are not always conducted in the province.
- Lack of support and guidance in returning to work.
- Lack of services during the survival period to deal with psychosocial and physical after-effects.
- Lack of support specific to the early onset of colorectal cancer (EOCRC), e.g. in terms of reproductive and sexual health, intimacy, relationships, fighting cancer with children, etc.
- Additional support for patient care at home.
- Additional support for palliative care
- Lack of services to help navigate life after the death of a loved one, especially for young adults facing different issues.
- IT tools/systems for patient care and remote monitoring.

Objectives to Aim For in Quebec to Reduce Incidence, Reduce Mortality & Better Support Patients

(Performance indicators to be measured over the next 10 years)

Short-Term Targets: 1-2 Years

01. Implementation of a population-based organized screening program

02. Integrating community oncology organizations/patient groups into oncology care

03. Reaching recommended screening and follow-up times for colonoscopy and treatment initiation

04. Increasing participation in FOBT to stabilize and/or reduce incidence

05. Equitable and rapid access to comprehensive genomic profiling and precision drugs across the province

Medium-Term Targets : 3-5 Years

01. Achieve a minimum 60% participation rate in FIT test (Fecal Immunochemical Test)

02. Launch of a specialized oncology center for CRC patients

03. Reducing health disparities

04. Developing multidisciplinary care teams

05. Lowering the screening age to 45

Long-Term Targets : 6-10 Years

01. Increased 5-year survival rate for CRC patients

02. Increase the percentage of CRC survivors reporting a good quality of life five years after treatment.

- Setting up a protocol and long-term follow-up programs for survivors

03. Reduction in the incidence rate of colorectal cancer per 100,000 inhabitants.

04. Developing guidelines for psychosocial care in oncology

- Integrating psychosocial care into routine oncology practice
- The implementation of a systematic assessment procedure for depression, anxiety and distress in CRC patients at the time of diagnosis and during treatment (e.g., before surgery, after chemotherapy).

The Objectives Are As Follows:

A) Impact Prevention & Reduction

- Raise awareness of the disease and the importance of screening among average- and high-risk individuals
- Increase disease awareness among people under 50
- Reduce incidence by identifying early-stage cancers and precancerous lesions through screening programs (e.g. colonoscopies, fecal occult blood tests).
  - Facilitating access to FOBT and colonoscopies
  - Increasing the role of nurses and pharmacists in test distribution
  - Harmonizing distribution from one region to another
- Reduce incidence by focusing on populations most likely to develop CRC.
- Reduce the number of new cases of colorectal cancer through sustained efforts in prevention and early detection.
- Systematically reach the Quebec population aged 50 and over
- Implement screening programs and increase capacity to perform colonoscopies.

B) Reduce Mortality & Improve Quality of Life

- Ensure that symptoms are not overlooked by family doctors - better recognition and rapid action on their part.
- Reduce mortality by reducing waiting times for diagnostic tests and treatment
- Reduce mortality by detecting cancers at an early stage, when they are easier to treat.
- Ensure availability and equitable access to the most effective treatments, including clinical trials as first-line treatments.
- Address inequalities in care and reduce the gap in colorectal cancer outcomes (incidence and mortality) between different socio-economic or racial groups and underserved populations.

C) Better Support for Patients & Caregivers

- Integrating psychosocial care into routine oncology practice for both patient and caregiver
- Helping patients access drugs and treatments, as well as funding opportunities to access these treatments, including clinical trials.
- The implementation of a procedure for the systematic assessment and treatment of depression, anxiety and distress in colorectal cancer patients at the time of diagnosis, during treatment and post-treatment (e.g., before surgery, after chemotherapy).
- Improve support by ensuring that patients benefit from timely follow-up and care coordination.
- Improve patient support by ensuring high-quality care and communication.
- Improving patient support by responding to the need for holistic care and complementary services.
- Improving patient support by involving community oncology organizations in the care trajectory
- Improve long-term support by ensuring that survivors receive the physical, mental and emotional care they need.
- Improving support for caregivers
- Improve survivors' support and general condition by implementing a protocol and long-term follow-up programs for survivors.

Recommendations:

SYSTEMATICALLY REACH THE QUEBEC POPULATION AGED 50 AND OVER

In order to systematically reach the Quebec population aged 50 and over, the system put in place will have to respect the confidentiality of the data in each file. Ideally, we'd like to have a computer system that would automatically identify and contact Quebecers reaching the age of 50. Targeted citizens would receive an invitation to be screened, as well as the necessary instructions for the tests to be carried out.

- Implement screening programs and operations. Launch the Quebec Colorectal Cancer Screening Program and allow pharmacies to distribute FOBT tests as an additional strategy.
- Closer follow-up to reduce absenteeism at colonoscopy appointments
- Use automated calls, messages or e-mails. In Quebec, we have the opportunity to contact individuals easily in order to reach people aged 50 and over. These practices may be considered intrusive and disturbing by the public, but COVID-19 with Clic Santé has shown us that they can be very effective and produce positive results.

CENTRALIZE DATA COLLECTION ACROSS THE PROVINCE VIA A CENTRALIZED COMPUTER SYSTEM

Draw inspiration from the National Endoscopy Database (NED), a centralized database deployed in 2013 under the Joint Advisory Group in the UK that offers real-time endoscopy tracking and uniform screening for everyone, while ensuring the quality of colonoscopies performed. Responsibility for communicating results and sharing data in a centralized system must be accompanied by appropriate follow-up with patients. Consideration could be given to integrating screening by region, a strategy used in other provinces that seems to have proved successful. This solution could help to cope with limited resources.

- All doctors should have the same reporting template, which would facilitate the work of all professionals. Hospitals would then be obliged to make the results data available for analysis, in order to assess the indicators and quality of these tests.
- Create a database and make it available to doctors so that they can consult it while maintaining confidentiality.
- Industry manufacturers could be further involved in accelerating and integrating reporting and standardizing screening processes. Here are some ways in which they can contribute:
  - Supplying equipment
  - The industry is involved at software level and could collaborate to ensure cohesion and better exchange of information between hospitals, although it could be complex, bringing everyone together on the same centralized server.
  - Investigate the possibility of industry playing a role in physician training and standardization.

MAKE QUEBECERS AWARE OF THE IMPORTANCE OF SCREENING AND INCREASE THE AWARENESS OF FOBT TESTING

We need to ensure that relevant information is publicized to make the target population and primary care physicians aware of the importance of participating in FOBT screening and the ways in which they can obtain it. To reach as many people as possible, we need to work on several fronts at once, ensuring that we don't focus solely on one category of the population (families, healthcare professionals or patient groups, for example) or one profession among those working in the healthcare system. Closer collaboration between associative stakeholders, especially patient groups, is essential. However, it is important not to forget the central role that family doctors, nurses and clinical nurses can play. Each must have the necessary documentation to inform their patients.

- Modernize approaches and advertising in partnership with patient groups: develop and implement a digital campaign mobilizing platforms like Facebook, or other social media to more precisely target various audiences with personalized approaches.
- Deploy poster campaigns in partnership with patient groups to promote the FOBT test. Posters should be placed in key locations, such as pharmacy counters, public washrooms and hospital environments.
- Develop a multi-platform awareness campaign. Efforts must be both digital and traditional to reach and raise awareness among people aged 50 and over.
- An awareness campaign should also cover professional audiences, especially front-line workers such as GPs and nurses.
- Design a new social campaign to raise awareness of colon cancer and the FOBT test. In order to increase the success of this campaign, it would first be advisable to address issues of accessibility to the test.
- An example of a relevant awareness campaign could be to give the patient the responsibility of going to a website for information, using a QR code, for example.
- Multiply collaborations between the various players, and don't hesitate to publicize them in joint campaigns.
- It is often the case that government and other key players with significant credibility among the population, such as healthcare professionals and patient groups, act as silent partners in campaigns they fund. Highlighting their participation and collaboration would be beneficial for:
  - Increase message persuasiveness.
  - Break the taboo surrounding the FOBT test by generating interest and positive emotions, by identifying an influential person who talks about his or her own experience and publicizing it. We need to find an example for the general public (e.g. Ryan Reynolds and Katie Couric in the U.S. and George Thurston in Canada).

FACILITATING ACCESS TO FOBT TESTS

The MSSS has already made progress by making the FOBT test available at vaccination centers and through ClicSanté. In some remote regions, pharmacists have the power to prescribe the test. While this is a step in the right direction, nurses (not only those working in vaccination centers) and pharmacists should be allowed to prescribe the test in all regions, and make it available in pharmacies.

- A regulatory change should be made to allow greater pharmacist involvement. How this is to be implemented has yet to be defined, but this alternative can certainly be considered. Particular care will need to be taken in the pharmaceutical community to ensure that the test is only offered to eligible patients. To do this, we need to ensure access to quality training, as well as a clear process. We need to make the tests more accessible and available in several healthcare establishments, and harmonize the type of distribution and operation from one region to another.
- Facilitate access to telemedicine for follow-up of test results. - Think about follow-up with a partner patient group approach. Patients are increasingly well-informed about the illnesses that can afflict them, and they want to feel they have a stake in the solutions put in place. We need to facilitate their participation and collaboration.
- Continue to improve screening methods and evaluate the best technologies for cancer screening.

EASIER ACCESS TO COLONOSCOPY

Improving existing infrastructures and opening endoscopy centers on weekends remain the most effective ways of tackling the problem, according to many players. This may involve opening dedicated centers outside hospitals. The aim is to get closer to the population and simplify the process. But there's a staff shortage to deal with:

- The private sector should be more involved, and all procedures should be covered by RAMQ/PQC/MSSS, even if colonoscopies are performed privately. Public-private collaboration is essential if we are to catch up. Standardization of data collection must apply to all stakeholders involved.
- Deploy dedicated colonoscopy clinics to avoid overloading hospitals and doctors.
- Create specialized clinics and specific time slots for the management of next steps following positive tests, in all regions, although once again the lack of human resources may act as a brake or limitation. Dedicated centers would help bypass the cumbersome administrative procedures and often outdated or inadequate infrastructures of the hospital network.

REDUCING SCREENING INEQUITIES AND PRIORITIZING CLIENTS MOST AT RISK FOR FOBT TESTING AND COLOSCOPIES

There is already an inequity in access to healthcare. We must be careful not to widen it, and work to reduce it.

- Target high-risk and medium-risk patients first, to reduce the likelihood of cancer.
- Ensure that we have a system capable of systematic and accessible follow-up with patients, and the capacity to welcome them into the system.
- Organize the data collected so that each doctor can consult them confidentially.
- Launch demonstration projects to standardize test taking and analysis
- Implement a quality control mechanism for FOBT/ITF tests and colonoscopies to ensure confidence in the system.
- Create a specialized committee to ensure transparent and equitable training of professionals. This committee could also be responsible for monitoring the quality of tests (it would seem that this solution is currently of being implemented, piloted by the Quebec College of Physicians).
- Standardize colonoscopy tests and training courses to make them more accessible and improve quality control.
- Be inclusive and leave no one behind, especially populations from marginalized groups and those living in regions far from major centers.
- Find the best program to standardize screening processes. The objectives of the test are not the same everywhere and for all specialists. What's more, training is not standardized, which creates problems between the different centers in Quebec. Standardization is necessary to ensure a coherent itinerary for patients and the quality of tests.

Conclusion — Our Vision for the Future

The future of colorectal cancer care in Quebec is one of hope, innovation and patient-centred equity. Our vision is one where colorectal cancer no longer represents a significant threat to public health, where early detection, effective treatment and comprehensive support enable every person affected by this disease to live a full and healthy life. We aspire to a future where incidence rates are radically reduced, mortality is minimized and patients not only survive, but thrive during and after treatment; through strong partnerships between healthcare providers, researchers, patient groups and communities.

To achieve this, we need to prioritize prevention and early detection. Widespread and accessible screening programs will be at the heart of our approach, particularly for high-risk populations. We envisage screening becoming a routine healthcare activity, stimulated by public awareness campaigns and supported by modern diagnostic technologies. Early-stage colorectal cancer is often very well treated, and through early detection we aim to catch more cases when they are most curable, rather than at stage III, IV.

It's also important to improve treatment outcomes. Advances in personalized medicine, where therapies are tailored to each patient's unique genetic and molecular profile, will revolutionize care. We foresee a future where colorectal cancer treatment will be highly individualized, with less invasive and more targeted therapies that will reduce side effects and improve survival rates. Continued research and collaboration between medical institutions, biotech companies and government will be essential to push back the boundaries of what is possible in colorectal cancer treatment.

Beyond medical care, our vision recognizes the vital role of psychosocial support for patients and their loved ones. We envision a holistic approach that integrates mental, emotional and practical support into the cancer care journey. Every patient should benefit from mental health services, peer support and resources to help them overcome the difficulties associated with a colorectal cancer diagnosis. This support must continue long after treatment, as survivors face unique challenges in post-cancer life, including fear of recurrence and ongoing physical and emotional repercussions.

Equity will underpin all aspects of this vision. Disparities in colorectal cancer outcomes - based on socio-economic status, geographic location or racial origin - will be eliminated. This will require targeted programs to ensure equal access to prevention, treatment and support services for all.

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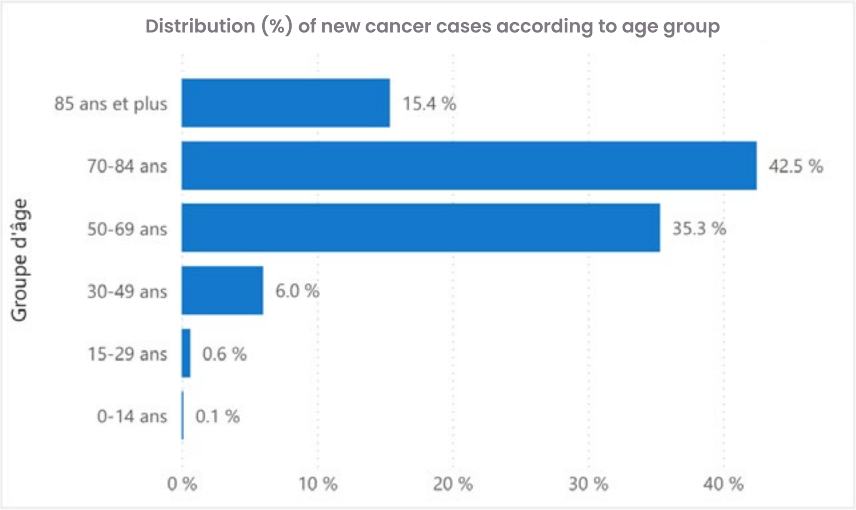
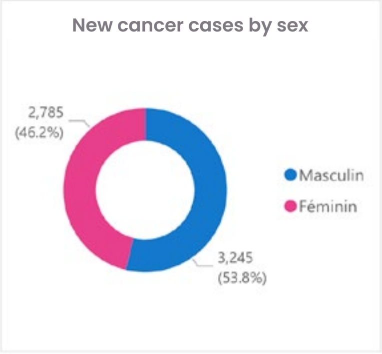
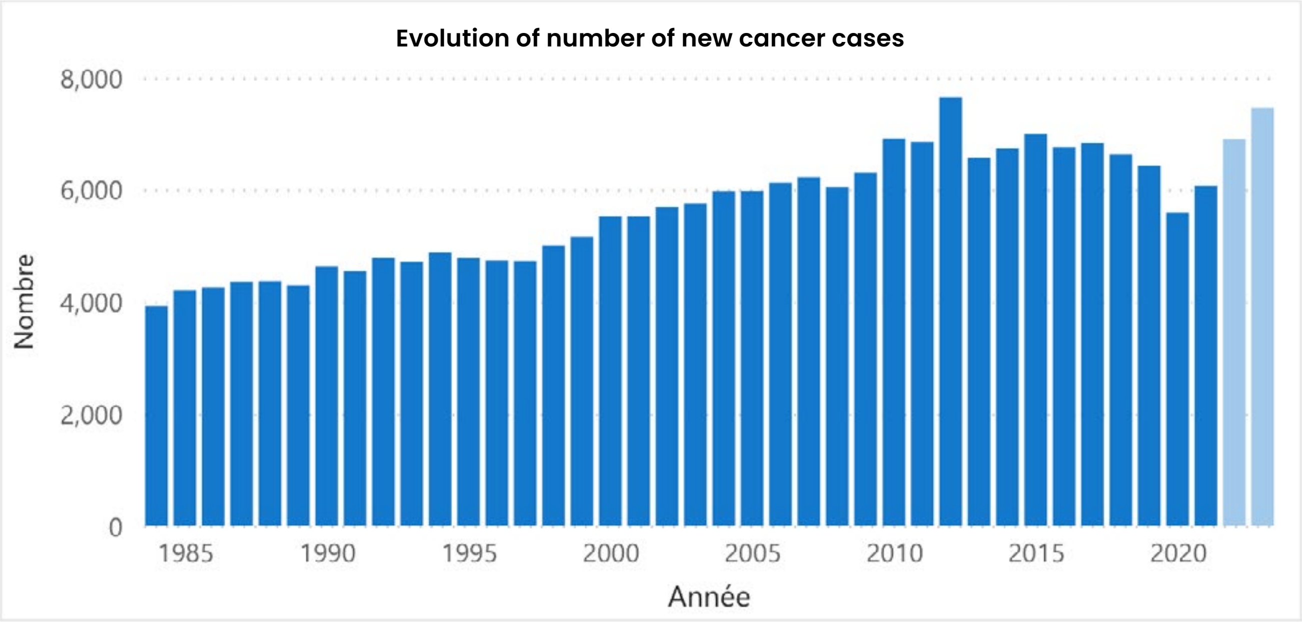
Colorectal Cancer Statistics in Quebec

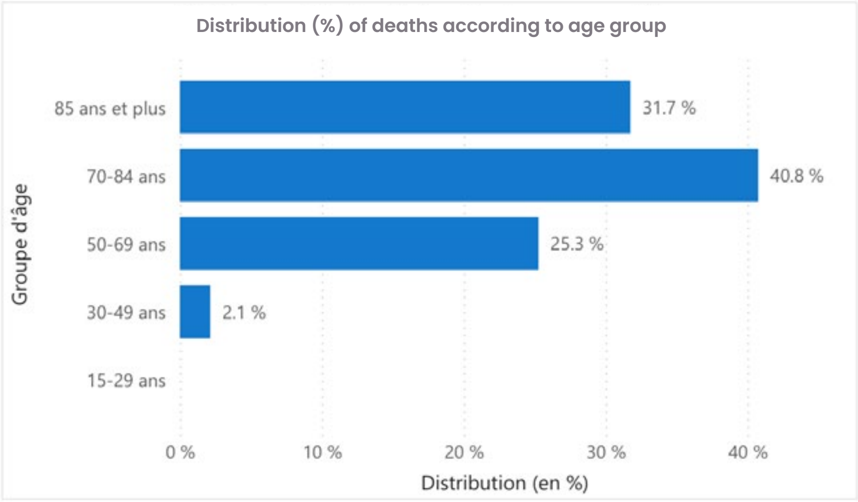

Distribution (%) of new cancer cases according to age group

New cancer cases
6,064

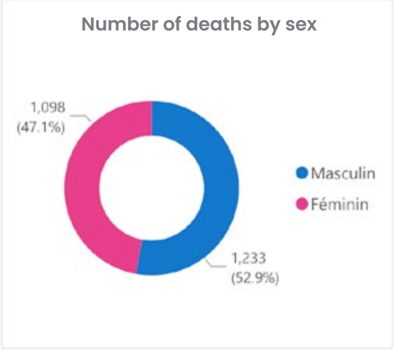

New cancer cases by sex

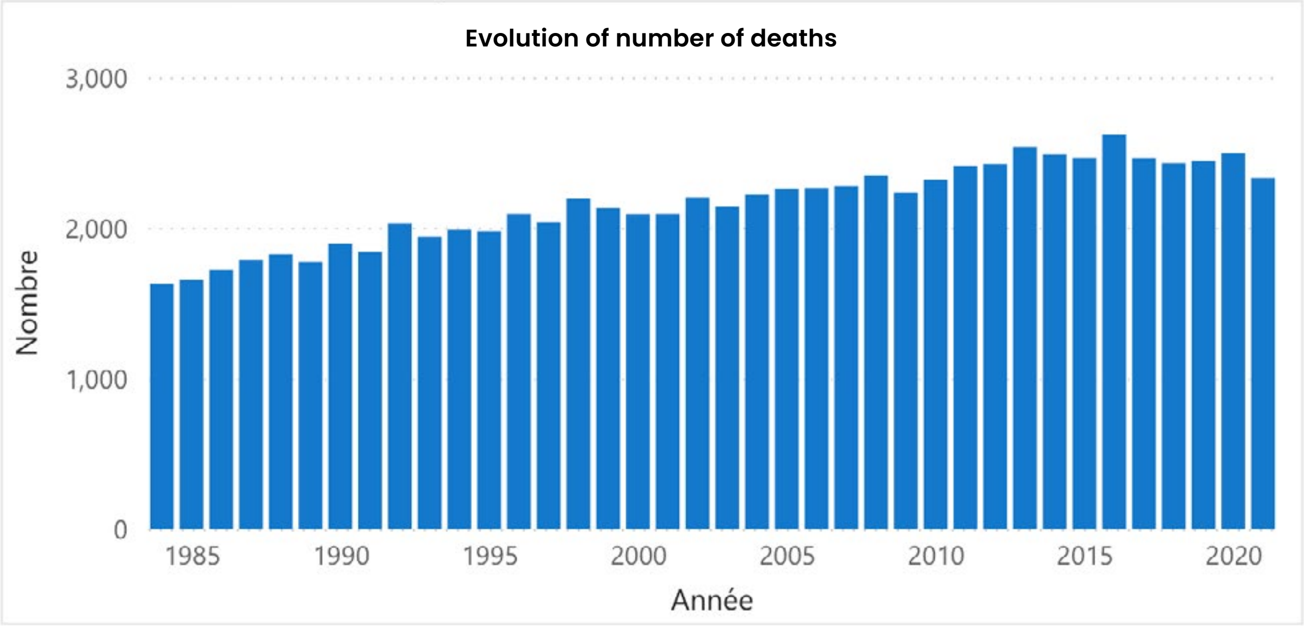

Evolution of number of new cancer cases

The graphics in this report are pulled from the dashboards of the Registre québécois du cancer, available exclusively in French.
The original data can be accessed here.


Distribution (%) of deaths according to age group

Number of deaths
2,331


Number of deaths by sex


Evolution of number of deaths

Bladder Cancer

Recommendations by

BLADDER CANCER CANADA
CANCER DE LA VESSIE CANADA

Recommendations formulated in collaboration with:
Dr. Claudio Jeldres (MD, Msc, FRCSC)
Eddie Maleterre Patient partner

Introduction

Bladder cancer is the fifth most common cancer in Canada, with around 13,400 cases diagnosed each year. It is the fourth most common cancer in men and eighth in women. Bladder cancer occurs when abnormal cells in the bladder begin to grow uncontrollably. The most common bladder cancer is called urothelial carcinoma. It develops in the urothelial cells lining the urethra, bladder, ureters (tubes connecting the kidneys to the bladder), renal pelvis and other organs. Other forms of bladder cancer include squamous cell carcinoma, adenocarcinoma, small cell carcinoma and sarcoma.

Approximately 90-95% of urothelial cancers occur in the bladder and can be divided into 3 types:

- **Non-muscle-invasive bladder cancer:** around 75% of bladder cancers are non-muscle-invasive at diagnosis. This means that the cancer cells are found only in the inner wall of the bladder, and have not grown through the inner wall into the deeper muscular layer of the bladder. The recurrence rate for this cancer is 60-70%, and around 20% of cases progress to muscle-invasive cancer.
- **Muscle-invasive bladder cancer:** around 25% of bladder cancers are muscle-invasive at diagnosis. This means that the cancerous tumours have grown through the bladder wall and into or through the bladder muscle. In most cases, this type of cancer is treated by surgery to remove the bladder, called a "radical cystectomy", and create a new urine outlet, called a "urinary diversion".
- **Metastatic or advanced bladder cancer:** cancer is considered "metastatic" when the abnormal cells of an invasive muscle tumour spread beyond the bladder to other parts of the body, such as the pelvic lymph nodes, urethra or ureters, or to neighbouring organs or tissues. When bladder cancer metastasizes, it usually reaches the liver, lymph nodes, lungs and bones. Around 10-15% of patients are diagnosed at an advanced stage, also known as stage IV.

An exception to urothelial cancer is urothelial carcinoma of the upper tract, a cancer that develops in the excretory cavities of the kidney (also known as the renal pelvis) or ureter and requires a different therapeutic approach.

Diagnostic measures for bladder cancer depend on the case and facility, and may include urinary cytology, cystoscopy, CT scans, ultrasound, or transurethral resection of the bladder tumour (TURBT). The treatment plan established by the physician depends on the stage and classification of the tumour(s), which are determined by a pathologist. These treatments include:

- additional TURBTs
- Bacillus Calmette-Guérin (BCG) therapy
- intravesical chemotherapy
- radical cystectomy
- trimodal therapy
- systemic chemotherapy
- targeted therapy
- radiotherapy
- immunotherapy

Context — Reality & Impact on the Quebec Population

In Canada, over 80,000 people are currently living with bladder cancer. Every day, 37 people are diagnosed with the disease. By 2024, some 3,160 people in Quebec will have been diagnosed with bladder cancer, including 2,300 men (73%) and 860 women (27%). For the same year, an estimated 730 Quebecers will die of bladder cancer, i.e. 520 men and 210 women. As already mentioned, bladder cancer has a high recurrence rate, which means that those diagnosed will require extensive follow-up with urologists and oncologists, even in the absence of signs of the disease. For all patients, these follow-ups are a lifelong commitment, and it's crucial to remain vigilant.

Smoking is the most common risk factor for bladder cancer, and the Canadian government estimates that a smoker is up to six times more likely to develop bladder cancer than a non-smoker. The 2022 Canadian Tobacco and Nicotine Survey (CTNS) shows that 12.3% of the Quebec population currently identify themselves as smokers, and 28.1% as former smokers. It's important to note these statistics, because a population with a higher number of smokers means that bladder cancer is becoming an increasingly prevalent health problem.

Finally, the typical profile of a bladder cancer patient is that of an older male. According to Statistics Canada's 2021 census profile, 20.6% of the Quebec population is now aged 65 and over. Thanks to modern medicine, life expectancy is certainly being extended, and this raises concerns about the potential increase in the number of cases of bladder cancer.

Stakeholders to Consider & Priority Populations

Bladder cancer is a complex and constantly evolving disease. As mentioned earlier, the profile of the typical bladder cancer patient has long been that of an older male, with a history of smoking or heavy exposure to toxic chemicals. However, every day at Bladder Cancer Canada (BCC), we hear from patients who don't fit this profile. It is also important to consider various factors shaping the bladder cancer landscape, such as exposure to different air pollutants and chemicals. These factors influence the stakeholder map and need to be taken into account when considering priority populations and key players.

When it comes to the future of bladder cancer treatment, research and innovation can be divided into four categories:

- **Proximity to key players:** These are the stakeholders with the most power/influence and the greatest level of interest.
  - Healthcare professionals and scientists: It's crucial to work closely with urologists, oncologists and researchers to keep abreast of innovative treatment methods, new patient studies and evolving standards of care. As a patient organization that connects directly with the newly diagnosed, we need to be able to disseminate the latest information on bladder cancer, which requires working closely with medical staff.
  - Bladder cancer patients: BCC is a highly responsive organization that adapts to the needs of bladder cancer patients. Our founders' mission was to improve patient support, and to do that we need to know what patients need and respond accordingly. This requires constant communication with bladder cancer patients to understand the resources we can develop to best support them through diagnosis, treatment and life despite bladder cancer.
  - Pharmaceutical companies: The pharmaceutical world is on the lookout for new therapies and drugs to treat bladder cancer. This industry funds innovative research and clinical trials for the development of medical solutions. It's very important to be aware of ongoing clinical trials and any gaps in research.
- **Maintaining interest:** This is aimed at stakeholders with a high level of power and influence, but a lower level of interest.
  - Quebec government: The provincial government is responsible for approving drug coverage and supply reimbursement programs. It's important to advocate for our patients' needs at this level, while remaining aware of any provincial changes that could impact our community.
  - Government of Canada: We need to keep abreast of federal decisions regarding treatments approved by the Canadian Medicines Agency (CMA). Drug approvals will affect the resources available to our community and lead to questioning of these innovative therapies.
- **Information transmission:** In consideration of stakeholders whose needs must be anticipated and met, with a high level of interest but less power.
  - High-risk populations: There are a few known causes of bladder cancer, such as smoking, radiation exposure and exposure to certain chemicals (e.g. benzene) found in certain occupations. These occupations include leather workers, hairdressers, mechanics and painters, as well as agricultural workers. It's important that people working in these fields know the risk factors for bladder cancer, and are aware of the signs and symptoms of the disease. If detected early, bladder cancer is highly treatable and offers a range of management options.
  - Family physicians: Make sure they are aware of the signs and risks of bladder cancer, and refer any patient with these symptoms to urology.
- **Monitoring and dissemination:** This is for stakeholders with whom we need to maintain regular contact, even though they have less power and a lower level of interest.
  - Other patient organizations and coalitions: It's important to stay in touch with other patient organizations, especially those associated with bladder cancer. This will also present networking and partnership opportunities to amplify our respective voices.

Existing and Missing Supports for Patients and Their Families

Bladder Cancer Canada (BCC) offers a range of free programs for patients and caregivers, most of which are available online.

Here are the existing supports offered by BCC:

- **One-to-One Peer Support Program:** Our specially trained volunteers, who have also been touched by bladder cancer, offer unique perspectives and understanding to help patients and family caregivers over the phone. We match callers with a volunteer whose experience most closely resembles their own to provide perspective and reassurance. For example, if someone is facing a radical cystectomy and has to choose between two bypass options, we might put them in touch with two different volunteers to explain daily life with a bypass.
- **Information line:** Our information line allows callers to connect with Bladder Cancer Canada by phone or e-mail to obtain useful resources and information, access support programs and get advice on finding answers to their questions. Our helpline is available Monday to Friday, between 9 a.m. and 5 p.m.
- **Support groups:** Welcoming, non-judgmental platforms where patients and caregivers can share their concerns, challenges and questions with others diagnosed with bladder cancer. We currently offer 12 different support groups, 2 of which are run in French. Most groups meet virtually, although some have adopted a hybrid model and occasionally meet in person.
- **Online discussion forum:** The forum allows individuals to ask questions and share their experience anonymously, 24 hours a day, 7 days a week, with our online community, moderated by bladder cancer survivors. The forum features a wide range of discussion topics and offers a safe space to ask questions and hear about others' experiences.
- **Educational resources:** We offer educational programs through our patient guides, informative webinars and patient education events.
    - We currently offer 6 different guides, providing valuable information and advice to help individuals understand their bladder cancer treatment after diagnosis. These guides are available in English, French, Chinese, Punjabi, Spanish and Hindi. They are available on our website as free downloads, or can be ordered and shipped in hard copy, free of charge.
    - We host monthly educational webinars on a variety of topics based on the needs and interests of our community. These webinars feature guest speakers such as ostomy nurses, urologists, social workers and more. Our webinars are recorded and available for viewing on our website or YouTube channel. These webinars support the education and empowerment of patients, caregivers and their loved ones.
    - BCC holds in-person patient education events twice a year in different cities. These events allow the bladder cancer patient community to connect and attend engaging presentations by some of the most experienced healthcare professionals.
- **Website:** The BCC website features information on diagnosis, treatment, staging and classification, clinical trials, "Tools, Tips and Information", and more. The site is designed to help patients better understand their diagnosis and feel empowered in their medical decisions.
- **Resources for healthcare professionals:** BCC is committed to raising awareness and providing support for patients by also helping healthcare professionals. For example, we have designed diagnostic information sheets that provide urologists with a tool to visually educate their patients about the stage and classification of their bladder cancer, as well as the treatment plan. These sheets provide comprehensive information on the diagnostic procedures and types of treatment proposed for their cancer. Another tool we've created for healthcare professionals is the "How to" guide for the Disability Tax Credit (DTC), published in early 2024. This guide provides step-by-step instructions on how to complete the DTC, so that physicians and nurse practitioners can help their patients living with urinary diversion access the financial compensation to which they are entitled.

BCC has also identified certain areas where support is lacking, and we are actively working to fill these gaps:

- **Increased awareness of the signs and symptoms of bladder cancer:** General practitioners and family doctors are often the first line of medical contact for those presenting with symptoms of bladder cancer. Unfortunately, these signs are sometimes confused with those of a bladder or urinary tract infection (UTI), delaying diagnosis and treatment. To help raise awareness of bladder cancer, we are currently working on a brochure on hematuria - the presence of blood in the urine - which is the most common symptom, affecting over 80% of patients.
- **Government funding:** Although bladder cancer is the fifth most common cancer and the most expensive to treat due to its high recurrence rates, it ranks 21st out of the 24 most common cancers in terms of funding. At BCC, we receive no government funding, and our efforts depend entirely on the generosity of donors.
- **Equitable access:** Ensuring equitable access to healthcare in urban and rural areas. Many patients currently have to travel to urban centers for treatment, often incurring travel, accommodation and other expenses during their stay. What's more, for some patients, travel time and conditions are significant practical difficulties, given their illness.

Objectives to Aim For in Quebec to Reduce Incidence, Reduce Mortality & Better Support Patients

(Performance indicators to be measured over the next 10 years)

Short-Term Objectives: 1-2 Years		
Indicator	**Objective**	**Actions**
Increased awareness campaigns - for the general public.	Increase public awareness of bladder cancer prevalence, early signs and symptoms, treatment options, recurrence rates and services offered by patient organizations such as BCC.	— Use media and social networks, networking, community events and partnerships to raise general awareness of bladder cancer. — Encouraging patient advocacy in the medical field.
Increased awareness campaigns - for healthcare professionals.	Increase family physicians' awareness of the early signs and symptoms of bladder cancer, such as hematuria.	— Direct awareness campaigns for family doctors. — Inform new residents/graduate physicians of the services offered by patient organizations via educational brochures and presentations.
Enhanced patient navigation services.	Provide patients with a complete understanding of their diagnosis, their treatment plan and all available resources (in and out of hospital, via patient organizations).	— Ensure that hospital sites have a list of available resources, either within the healthcare system or through trusted patient organizations specializing in bladder cancer.
Ensure a sufficient supply of BCG for the administration of full doses of treatment to patients.	Guarantee an uninterrupted supply of BCG to meet all patient needs full induction doses.	— Determine forecast BCG requirements. — Protecting the BCG supply chain. — Prepare for unforeseen needs.
Ensure access to BCG supplies throughout the province, particularly in small community hospitals and clinics.	Ensure that all patients, regardless of where they live in the province, have access to the same medical treatments, in this case BCG therapy.	— Ensure that supply is equitably distributed, taking into account the needs of rural areas and small community hospitals. — Establish sites in more remote areas for BCG administration, so that patients can access treatment locally without having to travel long distances.

Medium-Term Objectives : 3-5 Years

Indicator	Objective	Actions
New immunotherapy treatments for first-line response to advanced urothelial carcinoma.	Develop immunotherapies with favorable outcomes for patients with advanced (metastatic) bladder cancer.	— Highlight research gaps and focus funding in these development areas. — Expansion of clinical trials for innovative therapies.
Further development of early detection methods.	To develop non-invasive testing methods that can be used effectively to detect bladder cancer at an early stage in any setting (urban or rural).	— Research and development of a non-invasive, accessible and inexpensive test. — Testing the test method in a clinical trial setting. — Refinement of the test method to correct any problems. — Awareness and marketing campaign on the availability of the test to physicians.
Increased availability of clinical trials and patient participation in them for the advancement of medicines and research.	Inform patients about the importance of clinical trials and provide advice on how to locate them.	— Educational webinars. — Complete website with links to search engines. — Video vignettes focusing on quality of life and everyday issues, with resources from: occupational therapy, physiotherapy, psychotherapy, ostomy therapy, nutritionist, etc.
Access to innovative therapies in non-metropolitan areas.	Ensure that patients across the country have equitable access to healthcare, including new innovative therapies, procedures and diagnostic measures.	— Developing educational materials for rural community health centers. — Improve the continuous learning resources available to healthcare professionals.
Increased awareness among high-risk populations and professions of the signs and symptoms of bladder cancer and of occupational risks.	Raise awareness among population groups who may be at greater risk of developing bladder cancer because of their occupation.	— Identify at-risk populations, such as those regularly exposed to hazardous materials.

Long-Term Objectives 6-10 Years

Indicator	Objective	Actions
More collaborative care models.	Collaborative care models integrating cutting-edge research, urologists, oncologists, social services and patient organizations. This would create an integrated approach to a bladder cancer diagnosis, and provide patients and their loved ones with a comprehensive support network to guide them from diagnosis to treatment, and to continue their lives despite bladder cancer.	— Create communication channels between healthcare professionals. — Develop methods for monitoring coordinated patient care.
Public health initiatives, such as smoking cessation programs and incentives.	Government-led and funded initiatives to improve health at the provincial level.	— Engage public health decision-makers in creating awareness campaigns. — Campaigns to identify the direct correlation between smoking and bladder cancer.
Continued development of new immunotherapies as first-line treatments for advanced urothelial carcinoma.	Ongoing development of immunotherapies with favorable results for those with advanced (metastatic) bladder cancer.	— Identify gaps in research and focus funding in these development areas. — Expansion of clinical trials for innovative therapies.
Implementation of new early detection methods and standardization of their use.	Develop a new standard of care integrating the implementation of new methods and tools for early detection.	Systemic approach to incorporating new testing methods and standards of care throughout the province.
Ongoing advances in minimally invasive surgical procedures.	Ongoing development of new minimally invasive laparoscopic and robotic procedures with favorable patient outcomes.	— Ongoing research and development of laparoscopic and robotic surgery. — Technological advances in the medical field.

Conclusion — Our Vision for the Future

Bladder Cancer Canada's vision for the future is a world where bladder cancer is a thing of the past. Our mission has three crucial elements:

01. Providing support to bladder cancer patients and their teams in dealing with the day-to-day problems associated with the disease.

02. Raising awareness of bladder cancer among the general public and the medical community.

03. Fund research to improve the diagnosis, treatment and eradication of bladder cancer.

We work to achieve this mission through the efforts of volunteers across Canada and with the support of physicians on our Medical Advisory Board. Our core values are based on respect, compassion and integrity; putting people first and making a significant impact in their lives; creating connections with patients and building relationships with key players in the bladder cancer field; valuing and developing employees and volunteers; fostering action; promoting diversity and inclusion; and challenging ourselves to accept failure and new ideas.

This document was reviewed by Dr. Claudio Jeldres (MD, MSc, FRCSC, member of the Medical Advisory Board of Bladder Cancer Canada) and Eddie Maleterre (Bladder Cancer Canada volunteer and patient).

References

Bladder Cancer Canada. (n.d.). Home. Bladder Cancer Canada.
https://bladdercancercanada.org/en/

Bladder Cancer Canada. (2023). Bladder Cancer Canada 2024-2027 strategic plan.
https://bladdercancercanada.org/wp-content/uploads/2023/11/Bladder-Cancer-Canada-2024-2027-Strategic-Plan.pdf

Brenner, D. R., Gillis, J. L., Demers, A., Ellison, L. F., Billette, J. M., Zhang, S. X., Liu, J., Woods, R. R., Finley, C., Fitzgerald, N., Saint-Jacques, N., Shack, L., & Turner, D. (2024). *Projected estimates of cancer in Canada in 2024.* CMAJ, 196(9), E615-E623. https://doi.org/10.1503/cmaj.240095

Canadian Cancer Statistics Advisory Committee in collaboration with the Canadian Cancer Society, Statistics Canada and the Public Health Agency of Canada. Canadian Cancer Statistics 2023. Toronto, ON: Canadian Cancer Society; 2023.

Health Canada. (2023). Canadian tobacco and nicotine survey: 2022 detailed tables [Table 2]. Government of Canada.
https://www.canada.ca/en/health-canada/services/canadian-tobacco-nicotine-survey/2022-summary/2022-detailed-tables.html#tbl2

Health Canada. (n.d.). Smoking and bladder cancer. Government of Canada.
https://www.canada.ca/en/health-canada/services/health-concerns/tobacco/legislation/tobacco-product-labelling/smoking-bladder-cancer.html

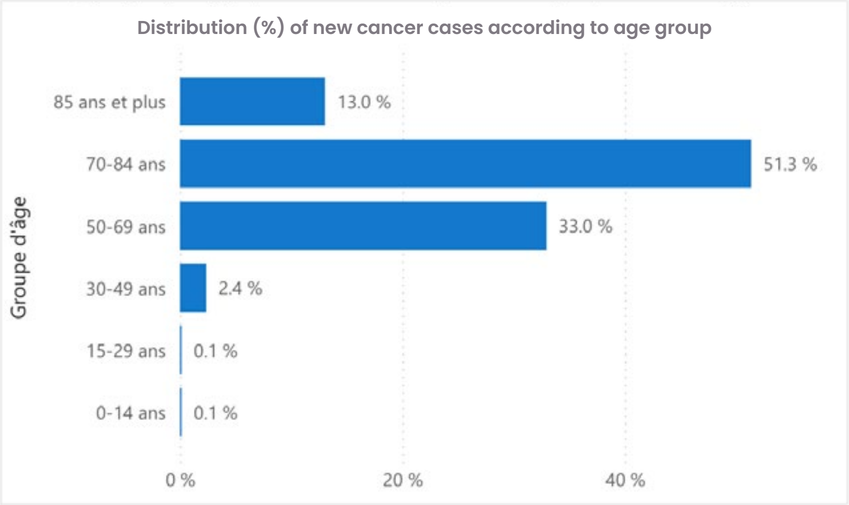
Institut national d'excellence en santé et en services sociaux (INESSS). (2024). Modalités optimales d'organisation et de prestation des soins et services liés à la cystectomie radicale au Québec.
https://www.inesss.qc.ca/en/publications/publications/publication/modalites-optimales-dorganisation-et-de-prestation-des-soins-et-services-lies-a-la-cystectomie-radicale-au-quebec.html

Quebec. (n.d.). Données sur le cancer [*Data on cancer*]. Gouvernement du Québec.
https://www.quebec.ca/sante/systeme-et-services-de-sante/organisation-des-services/donnees-systeme-sante-quebecois-services/donnees-cancer

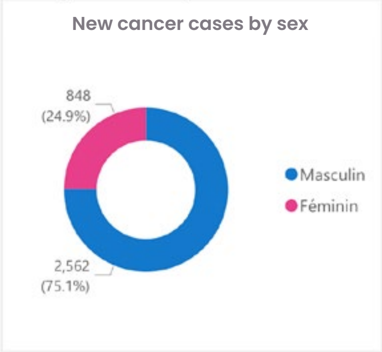
Radio-Canada. (2023). Un test de détection du cancer de la vessie développé à l'Université de Sherbrooke [*A bladder cancer detection test developed at the University of Sherbrooke*]. ICI Radio-Canada.
https://ici.radio-canada.ca/nouvelle/1974095/cancer-vessie-detection-test-universite-sherbrooke

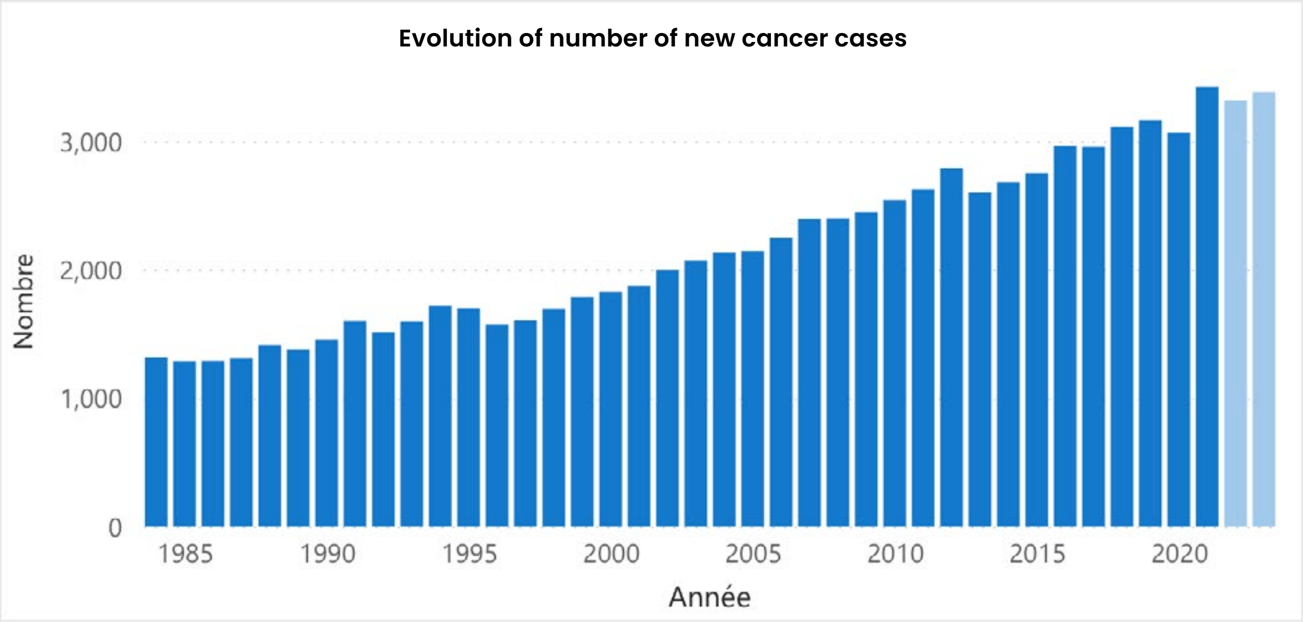
Statistics Canada. (2021). *Census profile, 2021 census of population: Quebec* [*Data table*]. *Government of Canada.*
https://www12.statcan.gc.ca/census-recensement/2021/dp-pd/prof/details/page.cfm?Lang=E&SearchText=Quebec&DGUIDlist=2021A000224&GENDERlist=1,2,3&STATISTIClist=1,4&HEADERlist=0

Bladder Cancer Statistics in Quebec



New cancer cases
3,420





The graphics in this report are pulled from the dashboards of the Registre québécois du cancer, available exclusively in French.
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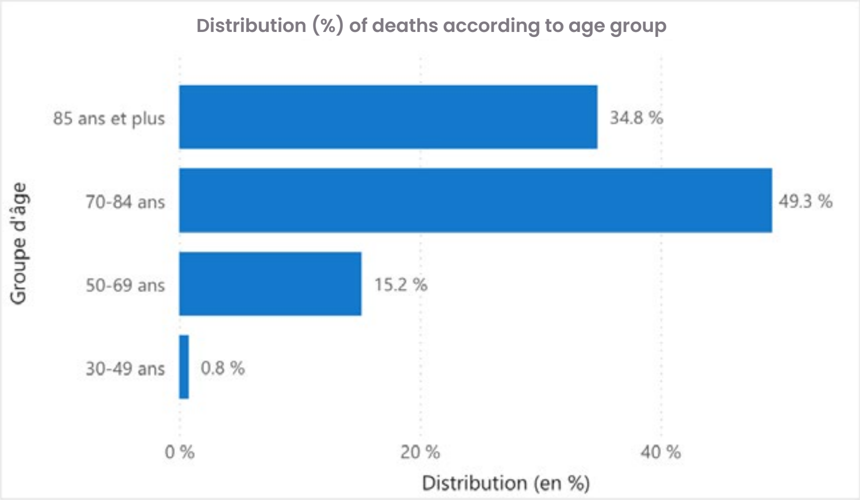
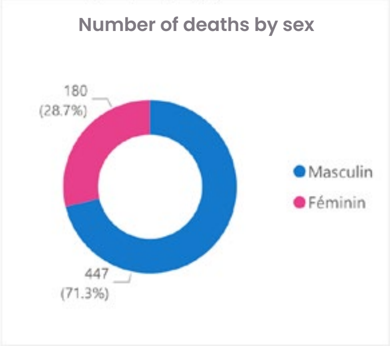
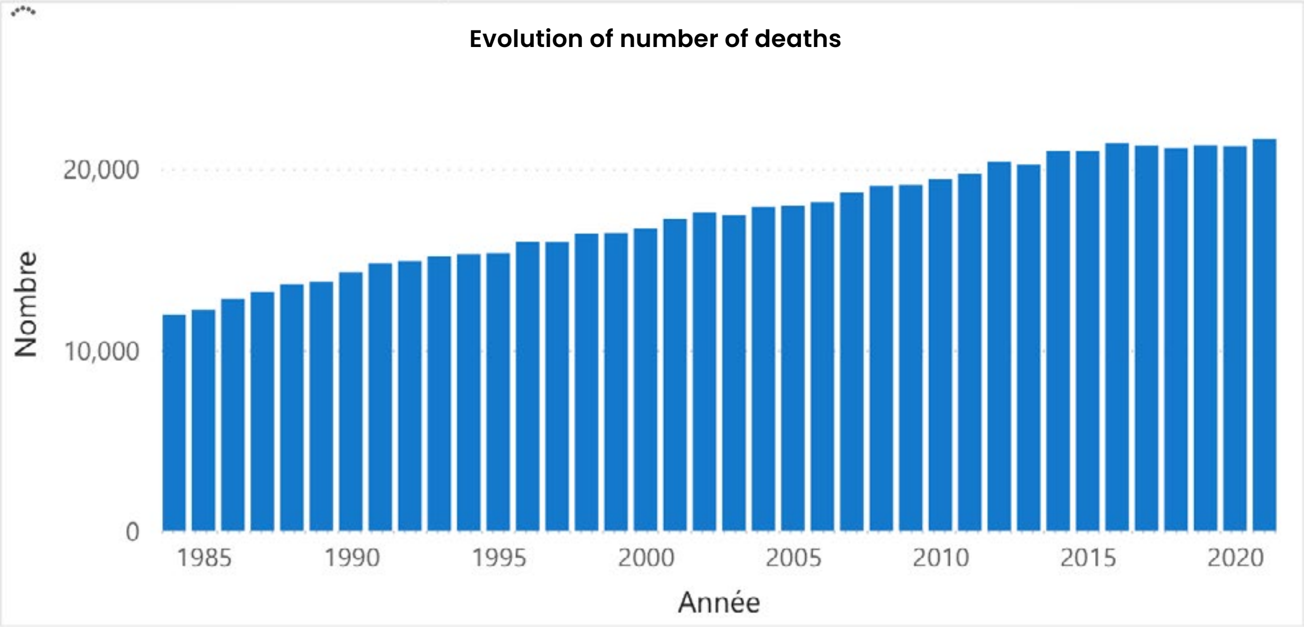


Number of deaths
627





Blood Cancers — Leukemia & Lymphoma

Recommendations by

LEUKEMIA & LYMPHOMA SOCIETY OF CANADA®

These recommendations reflect information gathered from research and recent blood cancer experience surveys designed by the Leukemia & Lymphoma Society of Canada.

Introduction

There are 137 types of blood cancers and related disorders. These cancers affect the blood cells, bone marrow, lymph nodes, and other parts of the lymphatic system. They include leukemias, lymphomas, myelomas, and less common cancers such as myelodysplastic syndromes (MDS) and myeloproliferative neoplasms (MPN).

- Blood cancers can affect anyone, at any age, at any time, without warning.
- The exact causes are unknown, but a diagnosis can have immediate and life-changing effects on individuals, families, and communities.
- Blood cancers are the fifth most common type of cancer in Canada.
- Leukemia is the most common cancer among children.
- Lymphoma is the most common cancer among adolescents and young adults (ages 15–24).

Although each type of blood cancer is different, they often share common symptoms, including:

- Severe fatigue, night sweats or fevers, unusual bruising or bleeding, persistent infections, unexplained weight loss, painless lumps in the neck, and bone pain.

According to 2020 estimates in Quebec:

- There were 5,000 new cases (incidence)
- Approximately 9,500 people were living with a blood cancer (prevalence)

Most blood cancers are chronic. While they cannot be cured, they can often be managed with daily medication. Others are acute and require urgent, intensive treatment.

Available treatments—especially for acute cases—are often very invasive and include chemotherapy, radiation, stem cell transplants, and CAR-T therapy. These treatments can lead to significant side effects.

Blood cancers are treated by hematologists, who specialize in diseases of the blood and related systems.

Context — Reality & Impact on the Quebec Population

Blood cancers are complex, and their symptoms are often vague, overlapping, or non-specific. Many resemble less serious illnesses like the flu, which can lead to misdiagnosis or delayed diagnosis—sometimes with life-threatening consequences.

One of the treatment options for some blood cancers is a stem cell transplant. When a match cannot be found within the family, finding a donor becomes difficult and highly stressful. This procedure is also extremely invasive and requires patients to be isolated for extended periods, sometimes months, to avoid infection. This physical isolation can take a serious toll on mental health and wellbeing.

Beyond the disease itself, patients also face the challenge of navigating Quebec's healthcare system, which is marked by staff shortages and limited access to timely care and treatment.

Despite these difficulties, we are at a pivotal moment in blood cancer research. Advances in technology and groundbreaking treatments have ushered in a new era of hope, collaboration, and momentum. Thanks to research, blood cancers have seen the largest gains in cancer survival since the early 1990s:

- Non-Hodgkin lymphoma: 5-year survival has risen from 49% to 68%
- Multiple myeloma: from 27% to 44%
- Leukemia: from 43% to 59%

However, access to new medications remains a major challenge. In Canada, the recommendations of INESSS and Canada's Drug Agency (CDA) don't always align. For instance:

- Tafasitamab (for DLBCL) received a positive recommendation from INESSS but was rejected by CDA.
- Polatuzumab (also for DLBCL) received a positive CDA recommendation but a negative one from INESSS.

Pharmaceutical-sponsored Patient Support Programs (PSPs) have become a critical access point for many patients who cannot get coverage through public systems.

Everyday Struggles

For many people living with blood cancer, just getting to their medical appointments is a challenge. Some face impossible choices, like deciding between feeding their family or attending treatment — and appointments are often cancelled as a result.

Because many blood cancers are chronic, patients must cope with the reality of living with cancer over the long term, including:

- Managing relapses
- Taking medication for life
- Ongoing follow-ups with specialists
- Navigating the healthcare system indefinitely

This long-term journey brings its own burdens:

- Many are unable to return to work due to fatigue and the frequency of medical visits, leading to financial instability.
- Long wait times for follow-ups are common.
- Employers often struggle to understand the unpredictability of chronic illness and relapses.
- Loved ones may not grasp the reality of living with an "invisible" illness.
- Active surveillance (also called "watchful waiting") can cause ongoing stress and anxiety, despite being a legitimate medical approach.

The Impact of COVID-19

Blood cancer patients are immunocompromised, putting them at greater risk of infections. The COVID-19 pandemic severely affected this population, increasing the demand for support, services, and advocacy.

The pandemic delayed cancer screenings, diagnoses, and treatments — which has had serious consequences for survival, quality of life, and hospital admissions. It also had a profound psychological impact, increasing levels of stress, depression, loneliness, and social isolation for people living with cancer.

Social isolation has been shown to worsen quality of life and can trigger symptoms like pain, fatigue, and cognitive difficulties. Researchers have found that cancer patients are experiencing stress levels similar to those of PTSD, especially heightened fears of disease progression or recurrence.

Even as COVID cases decline and vaccination rates rise, people with blood cancer remain at risk due to reduced immune responses to vaccines. They must continue to limit contact with others, wear masks, and socially distance—measures that protect them physically but worsen their emotional burden.

This added psychological weight has created an urgent need for more resources to educate, support, and connect this vulnerable community.

Systemic Gaps

The pandemic also exposed long-standing gaps in care and support for blood cancer patients. It revealed the urgent need for better services and stronger advocacy to ensure timely and equitable access to care, treatments, and information for all people affected by blood cancers.

In Summary: Navigating the healthcare system, accessing treatment, and finding support can be overwhelming. If you don't know who to contact or where to turn, critical opportunities and resources may be missed. That's why improving awareness, coordination, and support services is more important than ever—for every person living with blood cancer.

Stakeholders to consider & Priority Populations

Key Stakeholders

- Programme Québécois de cancérologie
- INESSS / RAMQ
- Elected officials and civil servants
- Coalition of Community Organizations in Oncology (ROCO)
- Quebec Cancer Coalition
- Quebec Cancer Foundation
- Other non-profit organizations
- Cancer Centers

Priority Populations

- Pediatric and AYA
- Advance Cancer
- Palliative Care
- Indigenous population
- LGBTQ2S+ community
- Seniors

Existing and Missing Supports for Patients and Their Families

Existing Supports

- Several community organizations in blood cancer (SLLC, Myeloma Canada, Lymphoma Canada, MPN Network, AMAAC, Leucan, etc.) which can advance research, offer support services, information, education, defense of rights.
- Some cancer centers have information centers (Partner Space (HMR), Lévis Information Center, etc.)
- Some centers have psychosocial teams (but not all).
- Pediatric centers are more equipped than adults.

Supports Needed

- Practical programs (financing)
- Help with transportation
- More advocacy for access to services and treatments
- Psychosocial support in hospitals
- Support for siblings and loved ones

Objectives to Aim For in Quebec to Reduce Incidence, Reduce Mortality & Better Support Patients (Performance indicators to be measured over the next 10 years)

Because blood cancers can strike anyone, at any age, at any time, without warning and that the cause of blood cancers is unknown, it is, for now, difficult to work on the incidence and mortality. But keep funding research can really help with the mortality and survival rate.

Our Strategic Plan:

Curing blood cancer and improving the quality of life of people affected by blood cancer and their families. Being the leading provider of services, funding for research, and partner to the community of people with blood cancer:

01. Assess and evolve programs and services addressing gaps in to attract new users

02. Leverage healthcare professionals and allied health to connect people affected by a blood cancer with LLSC

03. Build rapport and partnerships with advocacy and research funding allies

Short Term Indicators

Access Indicators

01. Reduce time to listing between Health Canada approvals to listing by RAMQ. In some cases, the time from Health Canada approval to listing is more than 700 days.
02. Alignment between CDA and INESSS. Many times, the INESSS submissions are after the CDA submissions. Perhaps the submissions can happen concurrently.
03. INESSS commitment to NetZero.

Improve Wait Times

The average wait time for tests in Quebec is significant. As mentioned above, blood cancer patients are waiting for follow-up tests to monitor for progression.

Some opportunities for improvement include:

04. Increasing Capacity: Adding more sessions in hospital and/or exploring out of cancer centre solutions
05. Public-Private Partnerships: Collaborating with private healthcare providers to increase capacity. For example, can some blood tests and labs be done in community settings to reduce both patient travel time and in-hospital resources?

Patient Navigation Services

06. Increase the number of patients accessing patient navigation services to help them through the cancer experience. For example, implement a province-wide patient navigation program that connects newly diagnosed patients with trained navigators that can also connect them to psychosocial services and patient organizations.

Medium Term Indicators

RWE Protocols Developed

01. Develop real-world evidence protocols on to collect the end points required for funding decisions.
02. Complete data infrastructure that will allow data collection needed to make decisions on drug efficacy.
03. 5-Year Survival Rates: Improve the 5-year survival rates for common cancers (e.g., breast, lung, colorectal cancer). For example, aim for a 5% increase in survival rates through improved treatment protocols and early detection.

Improve Alignment Between CDA and INESSS

04. Continue to improve alignment between CDA and INESSS. Targeted therapies and personalised medicine mean that new treatments may only be suitable for very small groups of patients. In order to gather enough information and data to make RWE decisions, CDA and INESSS must commit to additional alignment.
05. INESSS and CDA decisions – potentially for CDA to make decisions on reimbursement and INESSS to focus on implementation?

Patient Reported Outcomes

06. Enhance patient-reported outcomes measures (PROMs) to assess the quality of life and satisfaction of cancer patients.
07. Explore patient-reported outcomes that are beyond those identified in trial. As treatments are implemented, outcomes not captured in trials but are meaningful to patients are identified.

Cellular Data Access

08. Currently cellular data in Canada is amongst the most expensive in the developed world. As health records and health management increasingly moves online, patient organizations should band together to join voices in finding solutions to reducing cost. This helps set patients up for success as partners in their cancer experience.

Long Term Indicators

Prevention and Risk Management

01. Many cancers such as blood cancers have occupational hazards. Develop monitoring and prevention procedures for these cancers can reduce incidence rates

System Integration

02. In Alberta, MyHealth is a tool that allows Albertans to access their health records and centralizes all the results. A similar system in Quebec can help communication between healthcare providers, patient insight and management of multiple morbidities.

Genomic Testing

03. Reflex testing – As more and more tumours have treatments that rely on molecular information, ensure system readiness to prepare for reflex testing upon diagnosis
04. Next Generation Sequencing and Panels – currently panels may not optimally allow testing for multiple tumour sites in the same " batch ". This means that labs may be waiting to fill a tray of the same tumour type before testing. Advancing technologies that allow for multi-panel testing may increase efficient
05. Investing in blood-based testing – instead of biopsies, in 6 – 10 years, genomic testing should all be done with liquid biopsies
06. Re-testing on progression – many tumours develop acquired mutations. Cancer should be moving towards a model where tumours are tested regularly – and on progression at minimum in order to develop a truly personalized approach to treatment.

Health Equity

07. Remote regions of Quebec, new immigrants and those with social constraints on health do not have the same access to treatment, outcomes and use services at a lower rate than urban, more educated counterparts. Targeted programs need to occur in order to advance health equity.

Conclusion — Our Vision for the Future

The vision for cancer care in Quebec is where cancer patients can be supported and thrive instead of just being alive.

Patients cannot thrive unless they are supported. Quebec needs to build an infrastructure of survivorship with faster access to support, mental health and going back to work services.

The cancer system also needs to modernize the cancer care system and future proof this system.

Major opportunities for modernization are in data development and management. The availability of data and the correct data is key to making healthcare decisions. The data must include real-patient data points not measured in trials but have significant real-life impact on outcomes.

In order to thrive, Quebec needs to addressing disparities in cancer care. There is a focus on ensuring that all individuals, regardless of their socio-economic status, gender identification, minority affiliation or geographic location, have equal access to high-quality care. This involves expanding services and personalizing services to promote health equity.

Research also plays a key role. In order to achieve the vision, research needs to evolve and expand beyond the traditional model where only "ideal" patients are included in trials.

Key to this vision is the coordination of efforts amongst patient organizations in advocating for a common vision in Quebec.

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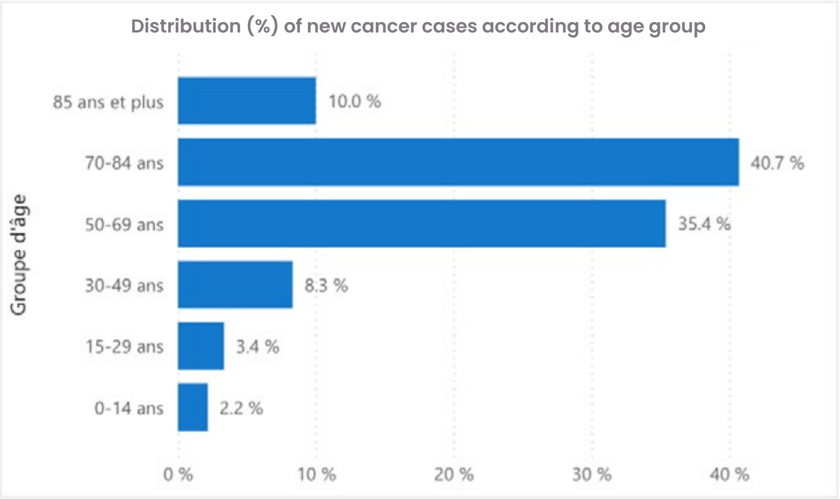
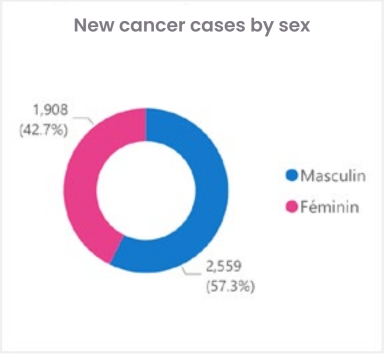
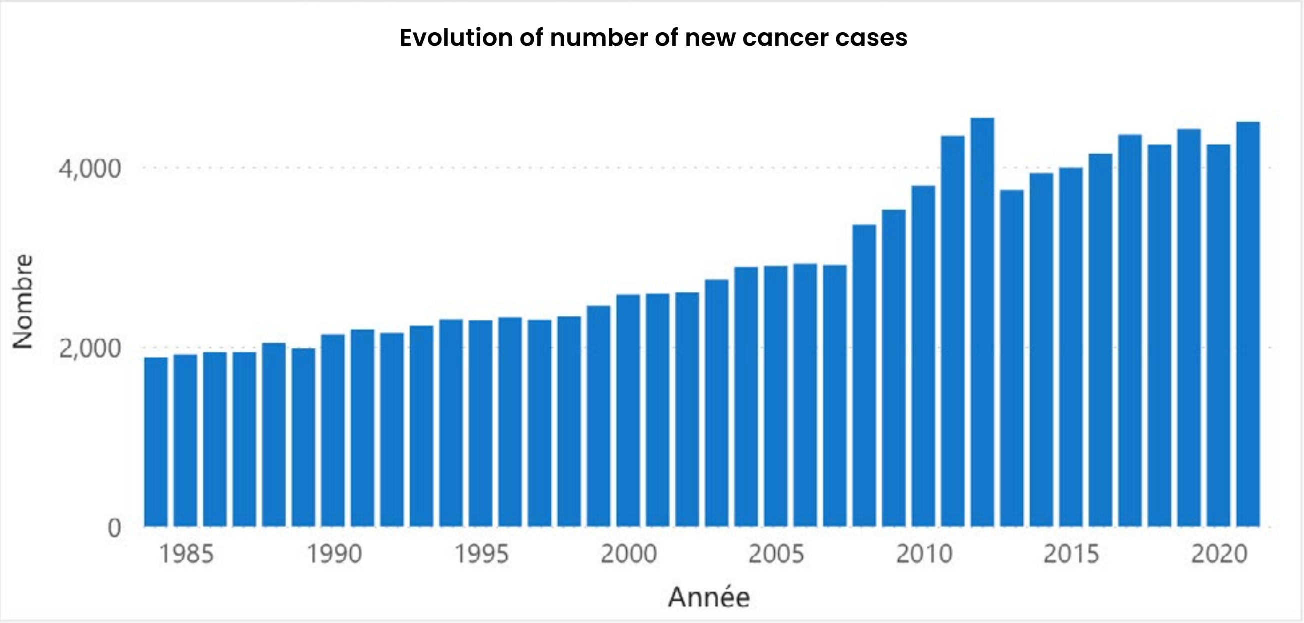
Blood Cancers (Leukemia & Lymphoma) Statistics in Quebec

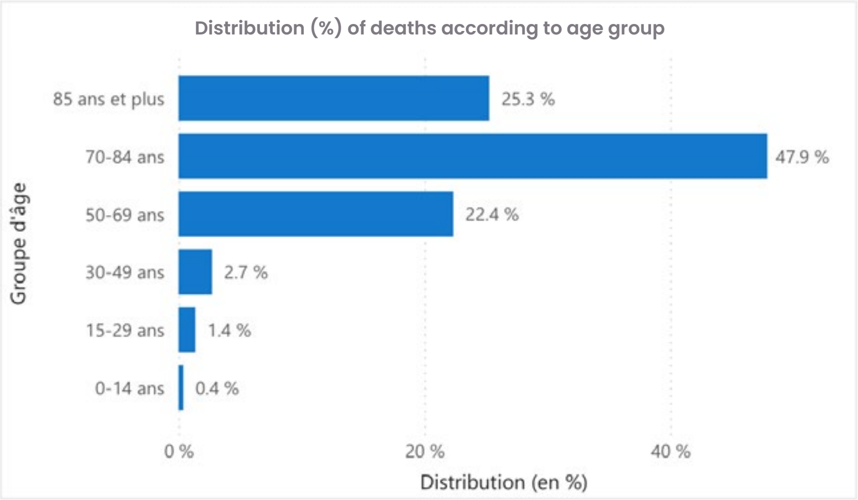

Distribution (%) of new cancer cases according to age group

New cancer cases
4,500

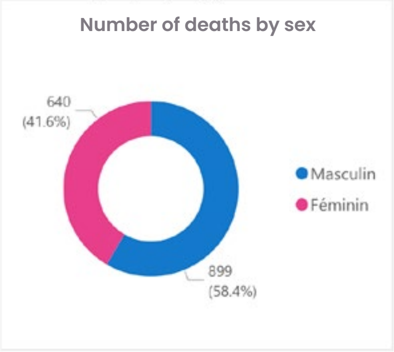

New cancer cases by sex

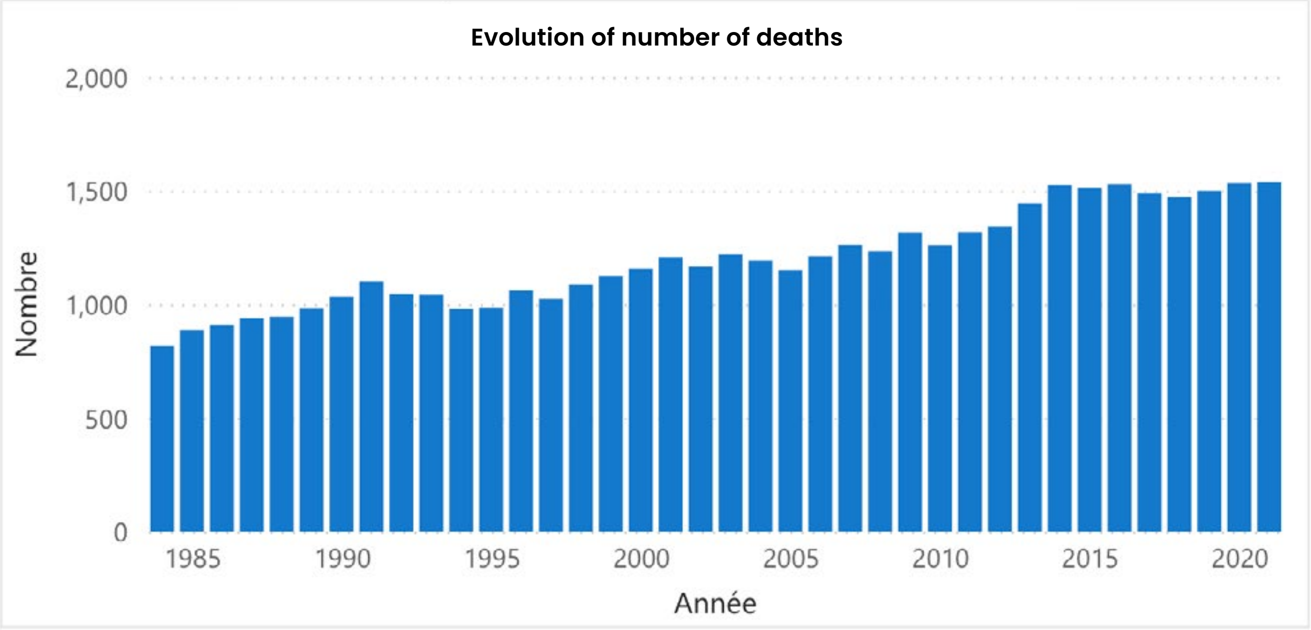

Evolution of number of new cancer cases

The graphics in this report are pulled from the dashboards of the Registre québécois du cancer, available exclusively in French.
The original data can be accessed here.


Distribution (%) of deaths according to age group

Number of deaths
1,539


Number of deaths by sex


Evolution of number of deaths

Skin Cancer — Melanoma

Recommendations by

save your skin FOUNDATION
LA FONDATION sauve ta peau

Introduction

Types of Non-Melanoma Skin Cancer (NMSC)

Basal cell carcinoma (BCC): BCC represents about 80% of NMSC cases. It is correlated with sun exposure, and therefore most often manifests in sun-exposed areas, and primarily affects older Caucasian populations. Most BCCs appear as red, pink, or pearly white sores or elevated bumps on the skin.

Squamous cell carcinoma (SCC): is the second most common skin cancer, and develops in sun-exposed areas, burn, and wound sites. It develops in the squamous cells, which are thin, flat cells that appear in the skin's surface. SCC often appears as red sores, which may bleed, and large, red, scaly patches.

Merkel cell carcinoma (MCC): Merkel cell carcinoma develops in merkel cells, which are found in hair follicles and deep in the epidermis. MCC usually develops in sun-exposed areas, though it is able to develop anywhere on the body, and often spreads (or metastasizes). MCC generally appears in a firm, raised, and non-painful bump that may be red or purple in colour. If MCC spreads, more lumps may appear in the area or lymph nodes may swell.

Types of Melanoma

Melanoma is the most aggressive form of skin cancer. It starts in the melanocyte cells in the skin, which produce melanin (the polymer that causes the colour in hair, skin, and eyes. Melanoma is most often identified through the

manifestation of new moles (though not all moles are cancerous), or changes in the size, shape, or colour of an existing mole. The Canadian Cancer Society estimates that in 2024, 11,300 Canadians will be diagnosed with melanoma and 1,300 will die from the disease (Brenner et al.). Melanoma is prone to metastasis and is staged on the 1-4 scale, like most other cancers. There are four types of melanomas. 70% of melanomas are superficial spreading melanomas, which usually develop on the central areas of the body (legs, trunk, arms) and spread outward or downward into the skin. Nodular melanoma makes up approximately 15-20% of melanomas: it presents as a raised growth from the skin, always grows downward into the skin, and most often develops on the chest, back, or face. 10-15% of melanomas are lentigo maligna melanomas, which usually develops in older people; it often grows outward radially across the surface of the skin, taking the form of a flat patch with an uneven border that is tan, brown, or black in colour. Acral lentiginous melanoma, which comprises less than 5% of melanomas, is not related to sun exposure and is most common in people with darker skin. It often develops under the nails, on the soles of the feet, or the palms of the hands. There are also three types of melanoma that do not start in the skin: mucosal lentiginous melanoma (develops on the mucosa/mucous membrane or organ linings and is not related to sun exposure), desmoplastic melanoma (develops in the dermis (inner layer of skin), or the connective tissue surrounding the mucosa; a skin-coloured lump that often develops on the upper back, head, or neck, and grows down into the skin), and uveal/ocular melanoma (more below).

Ocular/Uveal Melanoma: ocular melanoma, often referred to as uveal melanoma, is an extremely rare form of melanoma that develops in the eye. The cause of ocular melanoma is unknown, however having fair skin and light eyes can increase the risk. This cancer does not cause vision problems as a symptom and can only be detected by an optometrist. Ocular melanoma has an extremely high rate of metastasis, usually to the liver. Please note that, while the terms ocular and uveal melanoma are often used interchangeably, they are not equivalent, as uveal melanoma technically only refers to melanoma occurring in the uvea (the middle layer of the eye).

Relevant Terms & Abbreviations:

NMSC: Non-melanoma skin cancer

CBC: Basal cell carcinoma

CSC: Squamous cell carcinoma

CCM: Merkel Cell Carcinoma

ABCDEs of melanoma: to use to identify suspicious moles to be checked by a dermatologist: asymmetry, borders (inconsistent), colour, diameter, evolution

Radial growth: spread of skin cancer outward, across the surface of the skin

Vertical growth: spread of skin cancer down into the skin

Melanocytes: The cell that produces melanin, which contributes colour to skin and hair.

Context — Reality & Impact on the Quebec Population

A Few Statistics

- Skin cancer accounts for at least 40% of all new cancer cases in Canada.[1]
- Approximately 90% of non-melanoma skin cancers are associated with exposure to the sun's ultraviolet (UV) rays.[2]
- There are more new skin cancers each year than breast, prostate, lung and colon cancers COMBINED.[3]
- Among teenagers and young adults (aged 15 to 29), melanoma ranks fourth among newly diagnosed cancers.
- Skin cancer is on the rise in Quebec, with 138% increased chance of developing melanoma between 2009 and 2019.[4]
- Over the years, melanoma incidence rates have risen by 44% worldwide, and associated mortality rates by 32%.[5]

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[1] https://cancer.ca/fr/cancer-information/cancer-types/skin-non-melanoma/risks

[2] Koh HK, Geller AC, Miller DR, Grossbart TA, Lew RA. *Prevention and Early Detection Strategies for Melanoma and Skin Cancer: Current Status*. Arch Dermatol. 1996;132(4):436 -443. https://jamanetwork.com/journals/jamadermatology/article-abstract/557666?redirect=true

[3] "About Skin Cancer" Save Your Skin Foundation. https://saveyourskin.ca/thefacts-2/

[4] "Tableau de bord - Statistiques du Registre québécois du cancer." Gouvernement du Québec. 11 Novembre 2023. https://app.powerbi.com/view?r=eyJrIjoiNjc2ZTAxNmMtMWFiMi00NDIwLTg0MzYtOTY2OTIzMDliYjA2IiwidCI6IjA2ZTFmZTI4LTVmOGItN-DA3NS1iZjZjLWFlMjRiZTFhNzk5MiJ9

[5] https://www.mcgill.ca/channels/fr/channels/news/cancer-de-la-peau-lincidence-du-melanome-en-hausse-au-canada-339957

Non-Melanoma Skin Cancer

The Canadian Cancer Society (CCS) designates non-melanoma skin cancer as the most commonly diagnosed cancer among Canadians. NMSC is so common that statistics are not regularly kept for this type of cancer, as these are usually removed on site at provider offices.

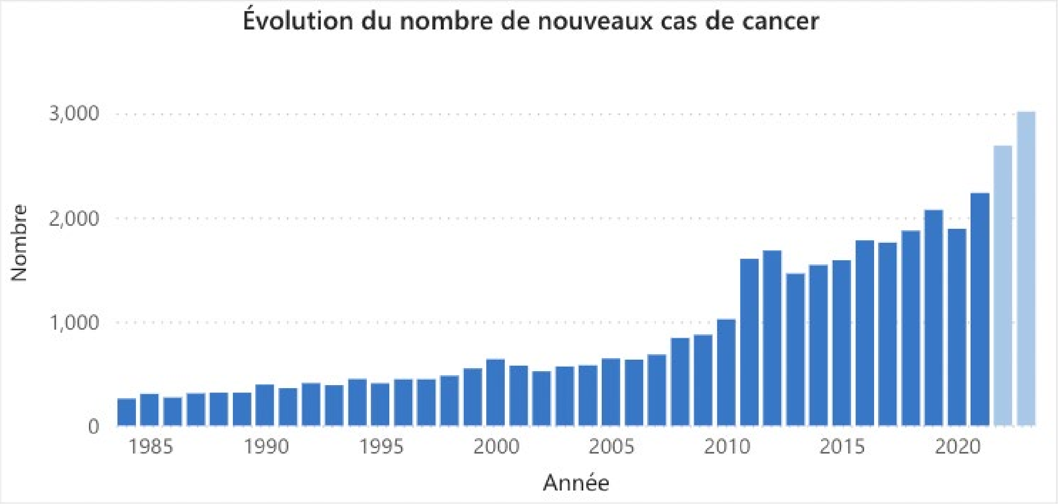
Melanoma

A 2022 article published by McGill University cited cutaneous melanoma as the most deadly cancer, causing 1.9% of all cancer-related deaths in men and 1.2% in women (McGill University, "Melanoma map shows skin cancer is on the rise in Canada").

The Canadian Cancer Society (CCS) projects that in 2024, there will be 11, 300 new cases of melanoma and 1, 3000 deaths from melanoma in Canada (Brenner et al.). While specific statistics regarding cancer in Quebec are largely unavailable to CCS, Brenner et al. "used estimates derived from locally estimated scatterplot smoothing to the 2006–2017 reference period" to include Quebec in these estimates (par. 8).

In their 2023 cancer statistics publication, CCS further notes that cancer mortality rates are generally lower in the western provinces and Ontario, and higher in Quebec and the eastern provinces (2023, 54). CCS was also able to project age-standardized mortality rates for melanoma in 2024 in Quebec, which they calculated to be 3% in males and 1.8% in females (2023, 53).

The Registre québécois du cancer keeps cancer statistics in Quebec via dashboards. As per the figure below (Evolution in number of new cancer cases), they estimate that there has been a 1.5-2x increase in melanoma cases in the 2010s relative to the 2000s, with projections continuing to rise. They also noted that, while it has historically been the case that more men than women are diagnosed with melanoma yearly, a larger increase in diagnosis rates was seen in women.



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The last year of published data from the Registre québécois du cancer was 2021, in which they recorded 2, 237 new cases of melanoma, a remarkably high incidence rate relative to the rest of Canada. Their projected incidence for 2023 was 3, 016 (above).

Save Your Skin Foundation ran two patient reported experience measures surveys on the impacts of the COVID-19 pandemic which included a separate French language survey for the Quebec population (2020, 2021). The results of the 2020 survey indicate that Quebecois cancer patients generally experienced the same anxieties around contracting COVID, including from medical facilities, in their immunocompromised state and ambivalent feelings towards the transition to telehealth care. The most notable divergence between the English and French language surveys sent out across Canada in 2020 was that Quebec patients saw a much higher rate of postponed surgeries than in the rest of the country (5.88% in the English survey, 16.67% in French).

The second COVID-19 impact survey from 2021 had similar results, with consistency across both language groups other than reports of greater delays in medical imaging from the Quebec respondents (8.11% in English, 33.33% in French).

Although we were unable to find Quebec-specific incidence rates for ocular/uveal melanoma, the Canadian Cancer Society reports that in 2019 (the most recent update year), 325 Canadians were diagnosed with eye cancer ("Eye Cancer Statistics"). While it is not possible to accurately determine which percentage of these occurrences were in Quebec, Ghazawi et al. reported in their study of uveal melanoma incidence in Canada that British Columbia and Saskatchewan saw disproportionately high diagnosis rates relative to the rest of Canada, suggesting that Quebec is not in the highest contributors to incidence of ocular/uveal melanoma in Canada (The British journal of ophthalmology vol. 103,12 (2019), "Uveal melanoma incidence trends in Canada: a national comprehensive population-based study).

Stakeholders to Consider & Priority Populations

Those above middle age: The highest priority population to consider in Quebec for melanoma diagnoses are those above middle age, with the Registre québécois du cancer reporting that in 2021, 42.2% of melanoma diagnoses were in people between 50 and 69 years of age and 32.1% were in people between 70 and 84 years of age. As previously noted, rates of melanoma diagnoses in Quebec women are also increasing faster than in men, which is likely related to the increasing age of demographics that were less aware of the risks of high UV exposure and therefore more likely to tan and/or not practice general sun safety.

Youth and teens are less likely to be sun safe without parental intervention; aggressive sun burns in youth are also associated with increased risk of skin cancer later in life. Teens especially are more likely to intentionally tan, further increasing risks of skin cancer.

Occupational workers and **outdoor athletes** are also at higher risk for developing skin cancer based on their increased UV exposure from being outside.

Fair-skinned people and those with a history of skin cancer in their families are genetically at increased risk of melanoma.

Other stakeholders to consider in terms of care option accessibility and reimbursement approval include **providers, the pharmaceutical industry, and regulatory bodies** such as the *Institut national d'excellence en santé et services sociaux (INESSS)*. Government stakeholders are also able to assist in creating public awareness opportunities and financial grants.

Existing and Missing Supports for Patients and Their Families

Save Your Skin Foundation (SYSF) offers completely bilingual informational content, patient and survivor support resources. Newsletters, which contain updates on the melanoma treatment landscape and news and upcoming events from Save Your Skin Foundation are available in French, as is all social media content. All patient-oriented resources created by SYSF are available in French, and every survey SYSF creates to gather patient-reported experience measures is also created in French to gather Quebec perspectives.

Quebec Cancer Foundation has a suite of resources for Quebecers facing all types of cancer. These include hotlines for patients to reach oncology consultants, support groups, information about cancers, and access to therapies such as art therapy, guided meditation, yoga, and massage therapy. They also offer a telephone peer matching service and online portal for teens and young adults.

Association du cancer de l'Est du Québec offers information guides and support to residents of Eastern Quebec who are fighting cancer.

Hope and Cope is a Quebec organization that offers resources for those at every stage of the cancer continuum, including survivors and caregivers. Services include peer mentors, support groups, rehabilitation and nutrition, and informational lectures and webinars.

Canadian Cancer Society has resources available for patients, caregivers, families, and health professionals. There is extensive information about all cancer types on their website and their Cancer Information Service is available in both English and French.

AIM at Melanoma is an American group that includes limited Canadian resources; this includes lists of melanoma specialists in Canada, including Quebec.

Melanoma Canada offers various informational and support resources to Canadians, with the educational resources available in both English and French.

Ocumel Canada is an initiative of SYSF that aims to provide information and support for Canadians with ocular melanoma. All information on this website is available in French and all webinars are translated.

Le Centre hospitalier de l'Université de Montréal (CHUM) offers a brief fact sheet about ocular melanoma on their website.

While Quebec has a substantial collective of cancer support resources, there is no Quebec-based foundation that specifically serves melanoma and skin cancer patients, or ocular/uveal melanoma patients, with SYSF offering the most resources for Quebec patients with these diseases. Given the increasing rates of melanoma survival, melanoma patients are also in need of increased resources related to survivorship. There are also significantly fewer support resources for caregivers than for patients. Ongoing gaps in cancer support also include individualized financial assistance and resources to support cancer patients applying for government disability benefits and navigating employment law-related situations and fertility/family planning-related resources. Finally, there is need for additional support for ocular/uveal melanoma patients, as the rareness of this cancer means there are limited resources available.

Objectives to Aim For in Quebec to Reduce Incidence, Reduce Mortality & Better Support Patients

(Performance indicators to be measured over the next 10 years)

Short term objectives

01. Gathering of melanoma patient-related experience measures to gain an assessment of information and resource availability for melanoma, NMSC, ocular/uveal melanoma patients in Quebec
  — One survey per population every two years

02. Development of informational resources for patients on fertility issues, applying for government disability programs, and other resources related to taking time off work

03. Continued network-building of government stakeholders to proclaim May as melanoma month and endorse sun safe behaviours and melanoma awareness throughout Quebec

04. Appeals to government and other donors (charitable, corporate) to sponsor sustainable sunscreen dispensers in public areas

05. Media push of public safety announcements regarding melanoma awareness, sun safety, and skin checking, including network television, social media advertisements, and billboards

Medium term objectives

01. Development of sun safety task forces in school boards, universities, athletic societies, and occupational worker unions

02. Increased awareness and implementation of precision medicine in melanoma care

03. More reciprocal relationship between providers and patient groups: patient group/psychosocial support informational brochures being readily available in doctors' offices

04. The unfolding of the pan-Canadian Health Data Strategy would increase access to health data for patients and ease of movement between providers; patient groups can support this work through ongoing endorsements and patient education

05. Development of psychosocial support systems specifically for caregivers, young melanoma patients, and those with ocular/uveal melanoma

Long term objectives

01. Continued campaigning to the Institut national d'excellence en santé et services sociaux (INESSS) for reimbursement of a variety of innovative treatments that are equitably available and appropriate for a variety of different cases and medical histories

02. Continued efforts towards sun safety awareness to decrease melanoma and NMSC diagnoses rates in the long term

03. Increased availability and options for care of ocular/uveal melanoma

04. Sustainable financial support for patients who face geographical barriers to care, and/or care options being available in a broader range of geographic areas

05. Sustainable placement of sunscreen dispensers in public areas throughout Quebec

Conclusion — Our Vision for the Future

We would love to see a future with meaningful changes for melanoma in the areas of prevention and education and across the cancer care continuum. As a highly preventable cancer, public education about melanoma is essential to lowering melanoma incidence rates and the burden of melanoma on the public health system. In the most ideal circumstance, the general public would be aware of the correlations between UV exposure and the development of skin cancers, and therefore practice sun safety (wearing sunscreen, UV protective clothing, seeking shade) when they are out in the world. In our vision of the future, the public would be supported in this endeavour with sunscreen dispensers being available in parks and other public areas, designated shade sites, and federal or provincial sun safety public awareness initiatives. Furthermore, public service announcements about self-checking your skin, and how to check others' skin, would also be shared in the media and in print form at doctors' offices; skin-checking would be as well-known as checking for breast or testicular lumps. While skin checks do not prevent melanoma, earlier discovery reduces mortality and healthcare burden, especially when paired with expedited access to dermatologists and general practitioners with mole identification training.

Public awareness information about melanoma, ideally, would highlight the increased risk of the disease in the elderly, outdoor athletes and occupational workers, and fair-skinned people, and highlight the dangers of unprotected sun exposure (either naturally or in tanning beds) as teens. These prevention and early diagnosis measures would also emphasized in Quebec and the Maritime/Atlantic provinces, which have higher melanoma incidence rates than the rest of Canada. In terms of ocular melanoma, greater awareness surrounding this rare cancer would influence the public to be vigilant regarding their annual eye exams and to ask their optometrists about ocular melanoma.

When patients are diagnosed with melanoma, non-melanoma skin cancer, and ocular melanoma, we hope for a future where they are offered timely and appropriate care, alongside adequate psychosocial and financial support. In the most ideal scenario, genetic testing for precision care would be covered by insurance, readily available to patients, and patients would be aware of this option. The diagnosis-to-care pipeline would be swift, and care would be available in a wider range of geographical areas and have increased reimbursement rates. From diagnosis to survivorship, patients with these diseases would have access to a holistic support network that would include nurse navigators, mental wellness and psychosocial supports, and increased data accessibility. Gaps in this area for melanoma patients currently include survivorship support, financial and legal resources, fertility and family planning support, resources for young melanoma patients, caregivers, and those living with ocular/uveal melanoma. In Quebec specifically, there is no designated support organization for melanoma, non-melanoma skin cancer, or ocular melanoma patients. This gap is currently being filled by Save Your Skin Foundation. Ideally, patient reported experience measures surveys would be conducted on a regular basis and categorized by the different areas of the cancer care continuum, with the results of these surveys being shared with government, industry, and medical care stakeholders.

References

Brenner DR, Gillis JL, Demers A, Ellison LF, Billette JM, Zhang SX, Liu J, Woods, RR, Finley C, Fitzgerald N, Saint-Jacques N, Shack L, Turner D, pour le Comité consultatif canadien sur les statistiques du cancer. "Estimations projetées du cancer au Canada en 2024." CMAJ 2024 May 13;196:E615-23. doi: 10.1503/cmaj.240095.
Cet article est le fruit de la collaboration entre la Société canadienne du cancer, Statistique Canada et l'Agence de la santé publique du Canada en matière de statistiques canadiennes sur le cancer.

Comité consultatif des statistiques canadiennes sur le cancer, en collaboration avec l'Institut canadien du cancer. Société canadienne du cancer, Statistique Canada et l'Agence de la santé publique du Canada. Le cancer au Canada Statistiques 2023. Toronto, ON: Société canadienne du cancer ; 2023.

"Statistiques sur le cancer de l'oeil." Société canadienne du cancer. Web. Lien:
https://cancer.ca/en/cancer-information/cancer-types/eye/statistics. Consulté le 14 juillet 2024.

Ghazawi, Feras M et al. "*Uveal melanoma incidence trends in Canada: a national comprehensive population-based study*". The British journal of ophthalmology vol. 103,12 (2019): 1872-1876. doi:10.1136/bjophthalmol-2018-312966.

Université McGill, "*Melanoma map shows skin cancer is on the rise in Canada*". Lien:
https://www.mcgill.ca/newsroom/channels/news/melanoma-map-shows-skin-cancer-rise-canada-339957.
20 juin 2022. Consulté le 14 juillet 2024.

"Statistiques du Registre québécois du cancer." Gouvernement du Québec.
https://app.powerbi.com/view?r=eyJrIjoiNjc2ZTAxNmMtMWFiMi00NDIwLTg0MzYtOTY2OTIzMDliYjA2IwidCI6IjA2ZTFmZTI4LTVmOGItNDA3NS1iZjZjLWFlMjRiZTFhNzk5MiJ9. Consulté le 14 juillet 2024.

https://cancer.ca/fr/cancer-information/cancer-types/skin-non-melanoma/risks

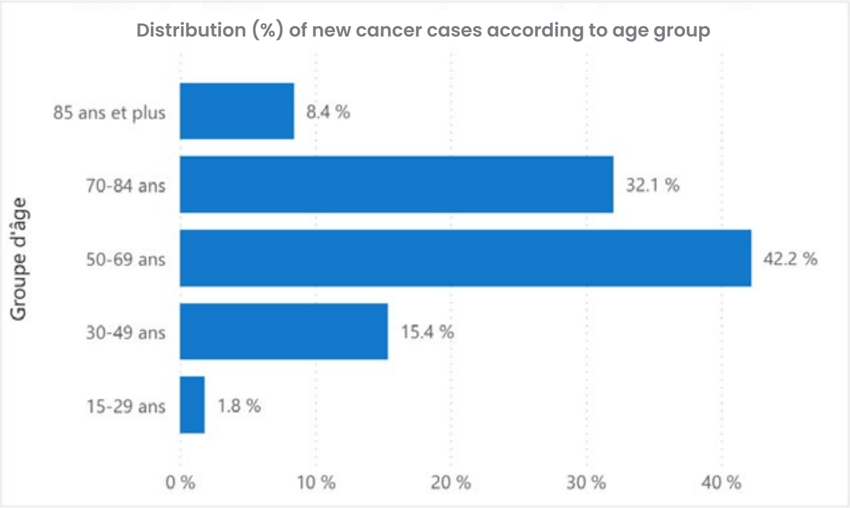
Koh HK, Geller AC, Miller DR, Grossbart TA, Lew RA. *Prevention and Early Detection Strategies for Melanoma and Skin Cancer. Current Status*. Arch Dermatol. 1996;132(4):436 -443.
https://jamanetwork.com/journals/jamadermatology/article-abstract/557666?redirect=true

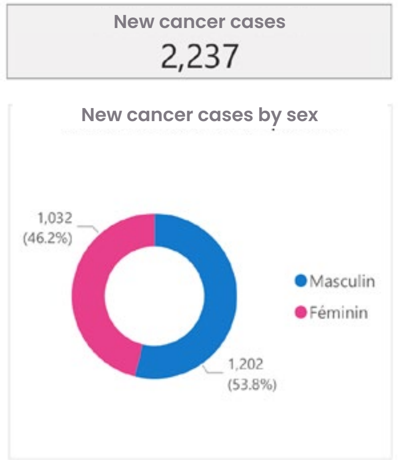
"*About Skin Cancer.*" Save Your Skin Foundation. https://saveyourskin.ca/thefacts-2/

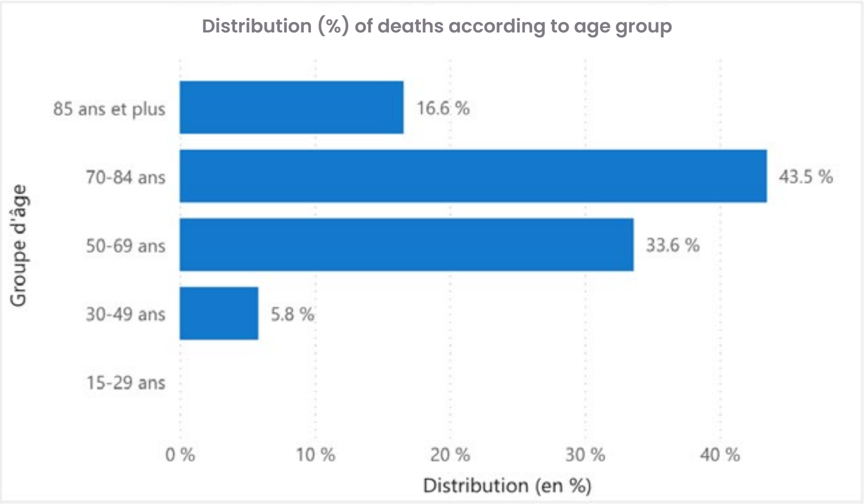
"Tableau de bord - Statistiques du Registre québécois du cancer. " Gouvernement du Québec.
11 Novembre 2023. https://app.powerbi.com/view?r=eyJrIjoiNjc2ZTAxNmMtMWFiMi00NDIwLTg0MzYtOTY2OTIzMDliYjA2IiwidCI6IjA2ZTFmZTI4LTVmOGItNDA3NS1iZjZjLWFlMjRiZTFhNzk5MiJ9

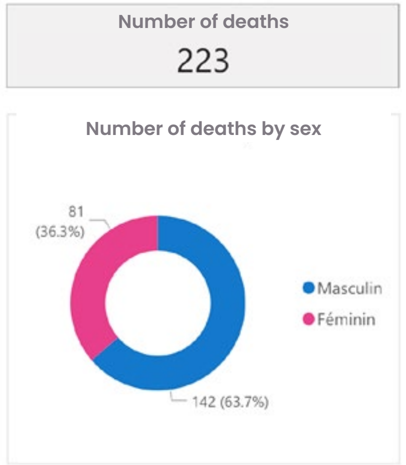
https://www.mcgill.ca/channels/fr/channels/news/cancer-de-la-peau-lincidence-du-melanome-en-hausse-au-canada-339957

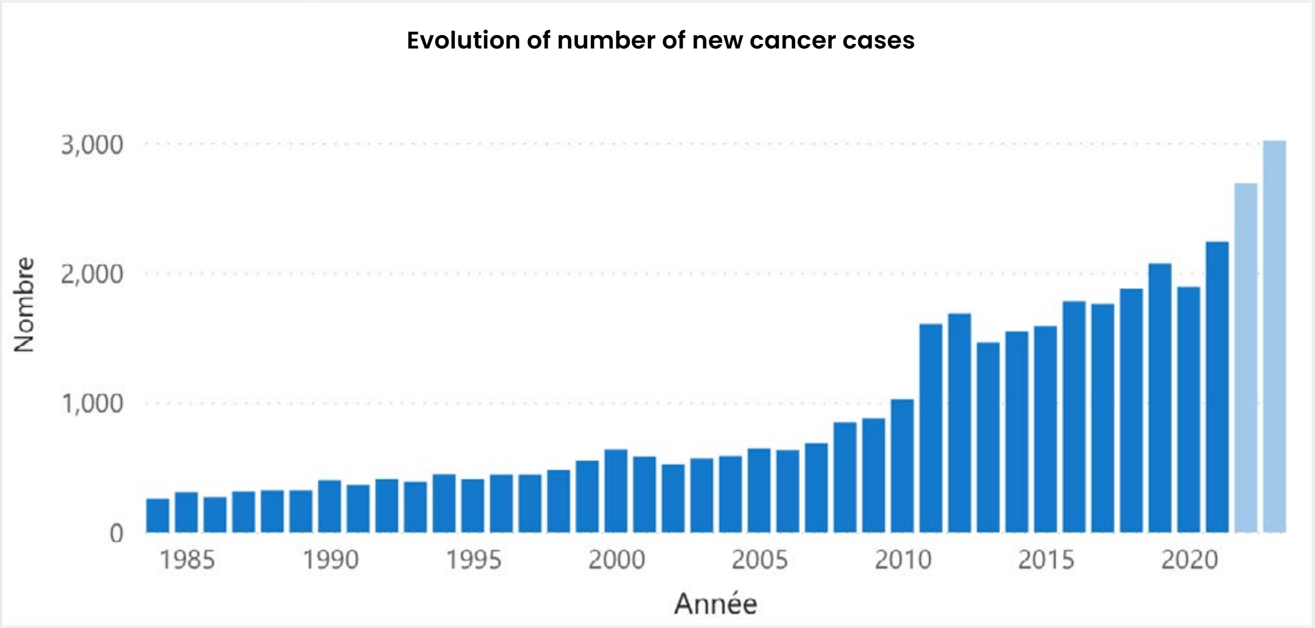
Skin Cancer (Melanoma) Statistics in Quebec

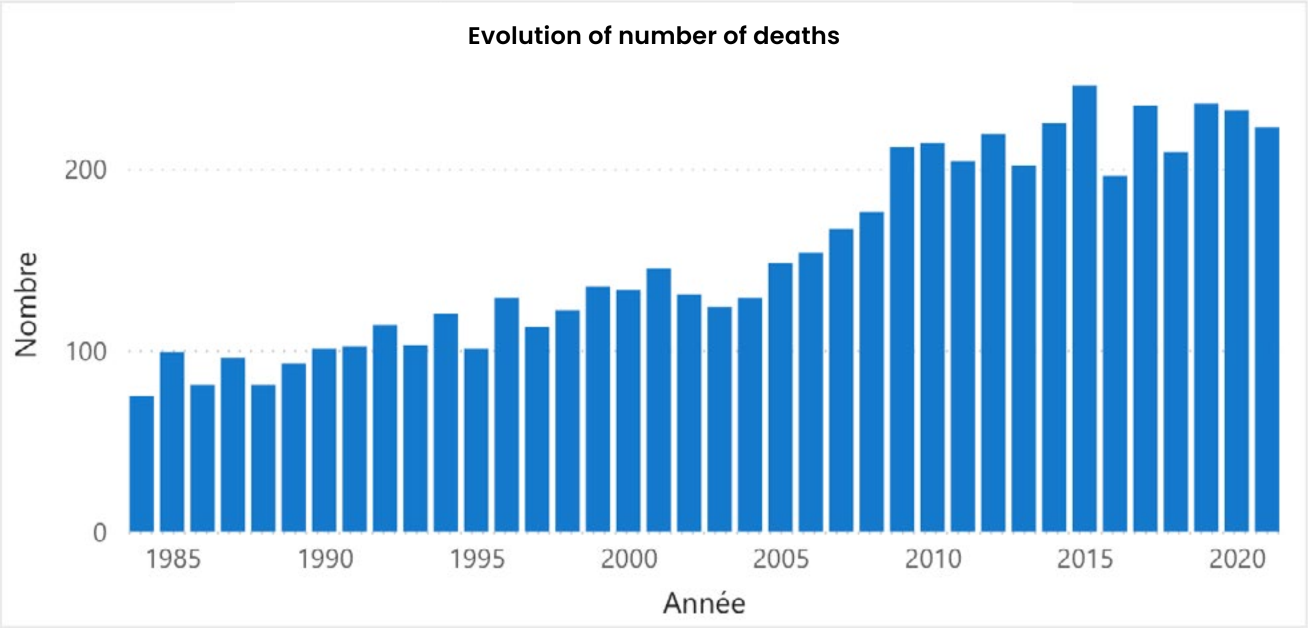












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The original data can be accessed here.

Kidney Cancer

Recommendations by

Cancer du rein CANADA
Kidney Cancer CANADA

Recommendations formulated in collaboration with:
Dr Patrick Richard Medical Oncologist
Dr Vincent Castonguay Medical Oncologist
Yves Nadeau Patient partner

Introduction

Kidney cancer is a unique type of cancer with specific characteristics. Screening for kidney cancer is challenging because, in many cases, there are no signs or symptoms until the tumour becomes quite large. Many of the symptoms associated with kidney cancer—such as a palpable mass, flank pain, or blood in the urine—may only appear once the cancer has progressed. Therefore, kidney cancer is often diagnosed quite late, at an advanced stage of the disease, which can reduce the effectiveness of treatment.

Fortunately, most kidney cancer patients do not fall into this category. Most are diagnosed incidentally, meaning the cancer is discovered while the person is undergoing testing for another condition—such as an ultrasound, a CT scan, or another imaging test.

The term "kidney cancer" refers to various types of cancer classified based on their appearance under a microscope—what is known as the "histological type." The most common histological type, found in about 70% of patients, is clear cell renal cell carcinoma, followed by chromophobe and papillary cell types.

Treatment for localized kidney cancer includes active surveillance, ablation (either radiofrequency or cryoablation), or surgery (partial or radical nephrectomy). Treatment for metastatic kidney cancer, in the first line, generally consists of a combination of immunotherapies or an immunotherapy paired with a targeted therapy. Subsequent lines of treatment usually involve targeted therapies.

Chemotherapy is not effective for kidney cancer. There is currently no screening test for kidney cancer.

Context — Reality & Impact on the Quebec Population

From the urology perspective, over the past two years in clinical settings, an increasing number of patients are presenting with locally advanced or even metastatic kidney cancer. This is mainly due to imaging delays, which are largely the result of the COVID pandemic. These delays have led to patients presenting with larger tumours and more advanced cancers than what was seen four years ago, before the pandemic. This phenomenon is not unique to kidney cancer—it also affects prostate and bladder cancers. There have been more delays in accessing family physicians, more delays for imaging tests, and now that the system has reopened, many people are being diagnosed at once, leading to a patient influx. This is based on perception, as we do not yet have data to prove this theory. It is also possible that we've forgotten how busy things already were before COVID, but there's a general feeling that everything is happening all at once.

It's also noted that in urology, access to operating rooms remains limited and restricted, mainly due to a shortage of staff, which is a problem in most hospitals. Patients may be treated within "unacceptable" timeframes. What we currently consider an acceptable delay is, in reality, not very acceptable—every patient diagnosed with cancer wants quick access to information about their condition and wants to begin treatment quickly. These delays create anxiety and challenges for both patients and physicians—doctors would treat their patients tomorrow if they could.

From the oncology perspective, there are also delays in imaging and diagnostic biopsies. This access issue is believed to be less related to COVID and more to a growing demand for imaging services. This growth stems from:

01. an aging population, and

02. in medical oncology, access to more treatments, which means more imaging—more long-term survivors, more patients on therapy, and more patients requiring closer monitoring.

Kidney cancer is a prime example—thanks to new treatments, patients are now followed for an average of 6 to 8 years. There are also more patients eligible for treatment, including older patients, as our population continues to age. Furthermore, non-oncological conditions requiring monitoring or managing treatment toxicity also increase imaging needs. Together, these factors rapidly increase demand and place pressure on access to diagnostic technologies, operating rooms, and in some settings, medical oncologists and treatment rooms. This is a Quebec reality: rising needs with limited resources.

When it comes to access to medications, Quebec is well-positioned. Initially, approval and access to adjuvant therapy for kidney cancer were challenging, but these issues have fortunately been resolved. The treatment is now listed as an exceptional drug, bringing us in line with other provinces.

This reality is echoed by our patient partner, who is connected with the day centre at Maison Michel Sarrazin. He has observed a noticeable increase in cancer diagnoses since 2022–2023. He was already undergoing treatment during COVID, so for him, not much changed—in fact, he found that treatments and imaging appointments moved more efficiently; things moved faster in the hospital. Today, however, exams are more difficult to schedule. There are significant delays, and often the oncologist must intervene to expedite appointments. According to the patient partner and discussions with other patients, the typical three-month interval is now often pushed to four or even five months.

Stakeholders to Consider & Priority Populations

Involve the pharmaceutical industry in rare diseases. There should be collaboration between physicians and the pharmaceutical industry for research on rare diseases—for scientific purposes, and not solely for financial gain. In the case of kidney cancer, most efforts are directed toward the "clear cell" subtype, which is the most common. However, more attention must be given to rare histological subtypes. Research on rare subtypes has increased, but further attention and effort are needed to better understand, manage, and treat them.

Greater study and use of genetics in the diagnosis and treatment of kidney cancer. Quebec does not have a robust program for genetic syndromes. We must improve referrals of eligible patients to medical geneticists. In the case of kidney cancer, we should recommend genetic screening for metastatic or high-risk patients, as there is a higher proportion of patients with genetic mutations. This could influence the management of the disease. Ontario's Reflex genetic screening program should be implemented in Quebec, and applied to kidney cancer more broadly—not just in the limited way it is currently done.

Radiation oncology is increasingly becoming a stakeholder in the treatment of both localized and metastatic kidney cancer.

Ensure equitable and improved access to care in remote regions. Increase research capacity—not just in Montreal.

Existing and Missing Supports for Patients and Their Families

Among existing supports are patient associations and pivot nurses. However, the presence of pivot nurses and the roles they play vary greatly from one region to another. There are inconsistencies in access to home care and palliative care. There is a growing need for early access to palliative care. For example, a patient with kidney cancer and bone metastases often requires regular follow-up with the palliative care team throughout their metastatic illness.

Access to psychological support through the public system is difficult unless one goes through the private sector. This limited access is due to systemic issues at all levels. There is too much focus on treating the disease and not enough on treating the patient as a whole. Psychological support has always been difficult to access because it is not prioritized. While cancer must be treated, the system does not recognize the broader impact of cancer. If patients do not actively seek help through patient associations, they are often left to manage on their own. There is a "dehumanization" of care—patients are treated on a conveyor belt. We need advocacy groups to defend this point. The patient must be treated as a whole—body, mind, and soul.

Every hospital should have its own support group where patients and families can meet with a professional therapist to discuss their situation and share their experiences. Patient associations do important work, but they are limited in the services they can provide. A local support group would help families who need someone to listen, to share with, and to provide respite for caregivers. The system must be improved in this regard.

Caregivers are often forgotten—the entire health-care support system is designed to help the patient. Caregivers struggle just as much, if not more, because of the burdens placed on them. While we all acknowledge the role of caregivers and their need for support, few services are actually available to help them. There is clearly a lack of support for caregivers. It is only when the caregiver's physical health is threatened due to the stress of caregiving that a family doctor may step in.

We must make the diagnostic process more seamless—from localized to metastatic stages. There are many questions, and access to biopsies is complicated. Supporting the patient through the diagnostic journey would be beneficial.

In Quebec, patient information is decentralized. There are patient organizations and hospitals, but Quebec lacks a central cancer authority like BC Cancer or CancerCare Ontario. Centralization helps ensure that information and support are consistent and not dependent on where a person lives. For example, remote regions do not have the same access to information about specific treatments, oncology pharmacists, or brochures. There is a need to make patient support more equitable and ensure resources are accessible to everyone, everywhere.

There is a lack of support for navigating the reimbursement of oral medications, which can sometimes be very difficult to access. There are inequities across regions in this area as well—not all hospitals have an on-site navigator or pharmacy technician. For some medications not included in standard pathways, oncologists need a navigator to help them navigate the different levels—RAMQ, private insurance, and access programs—in order to secure treatment for their patients. Physicians or patients alone would struggle to achieve this.

Objectives to Aim For in Quebec to Reduce Incidence, Reduce Mortality & Better Support Patients

(Performance indicators to be measured over the next 10 years)

There are no major or modifiable risk factors for kidney cancer, so the only intervention that could have some impact is genetic disease screening—better screening and monitoring of patients with a genetic syndrome.

Consider implementing a baseline preventive ultrasound and follow-up ultrasounds every three years for screening family members with a first-degree relative diagnosed with kidney cancer. In addition, it is important not to lose sight of follow-up for patients under surveillance for renal masses.

To reduce mortality, it would be beneficial to shorten the time to diagnosis and referral. The time required for approval and reimbursement of new oncology medications should also be accelerated. Drug approval in Quebec still takes longer than in European and American jurisdictions.

There should be broader access to minimally invasive treatments and an increased proportion of patients receiving partial nephrectomy rather than radical nephrectomy.

Performance Indicators:

- Time between the imaging request and the actual imaging
- Time between imaging and consultation with the urologist or oncologist
- Time to surgical intervention
- Time to access treatment for metastatic kidney cancer

Issues and Concerns for the Next 10 Years:

- Will there be enough nurses—in operating rooms and treatment units?
- Will there be sufficient access to urologists and oncologists? If not, who will follow up with patients?
- First-line treatment is generally ensured, but the number of patients receiving subsequent lines of treatment will be a quality indicator.

Over the next 10 years, the government should commit to ensuring that patient support and treatment access are equitable across all regions.

Conclusion — Our Vision for the Future

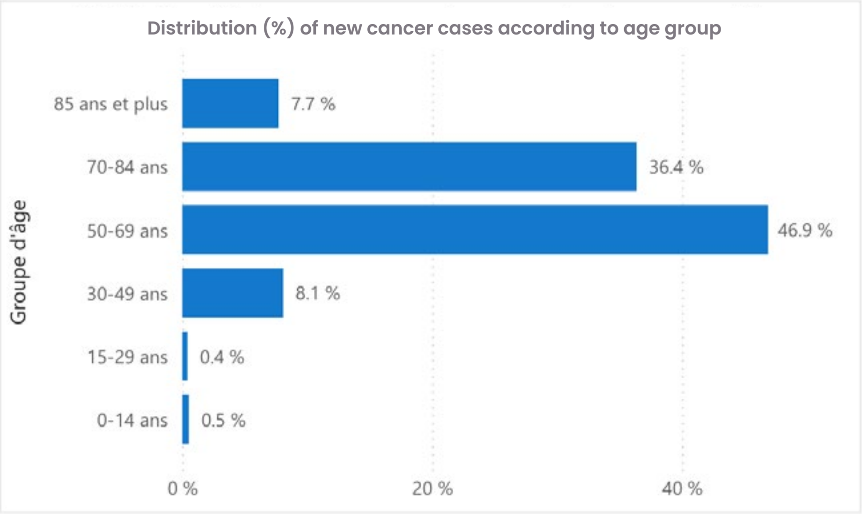
A better approach to care means addressing the whole person—not just the cancer—body, mind, and soul. While we are making progress in improving access to treatment, we are not improving how we treat the patient as a whole. Patient advocacy groups recognize this need, but the healthcare system does not. We must improve the patient journey and their overall survival.

The healthcare system must evolve toward a more holistic model of care. More thought leaders and health professionals need to take the initiative to move in this direction. This also means the government must play an active role. First, the government must recognize the importance of this shift and invest accordingly.

Continue clinical research. Continue improving the management of localized kidney cancer with treatments that are increasingly less invasive and morbid. Continue research that aims to improve treatment quality and move toward a cure. In the medium term, we will begin using the word “cure” when discussing metastatic clear cell kidney cancer.

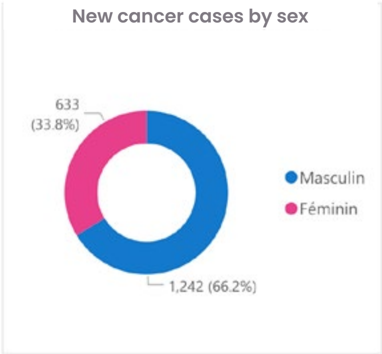
Cancer du rein CANADA Kidney Cancer CANADA

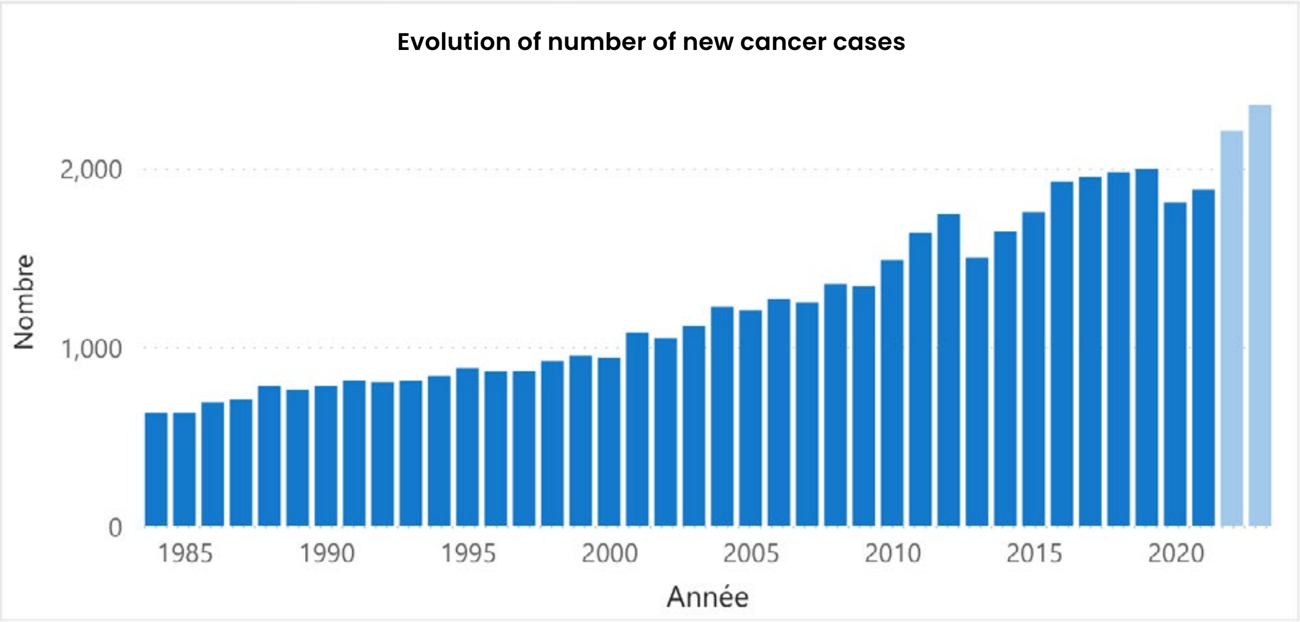
Kidney Cancer Statistics in Quebec



New cancer cases

1,881





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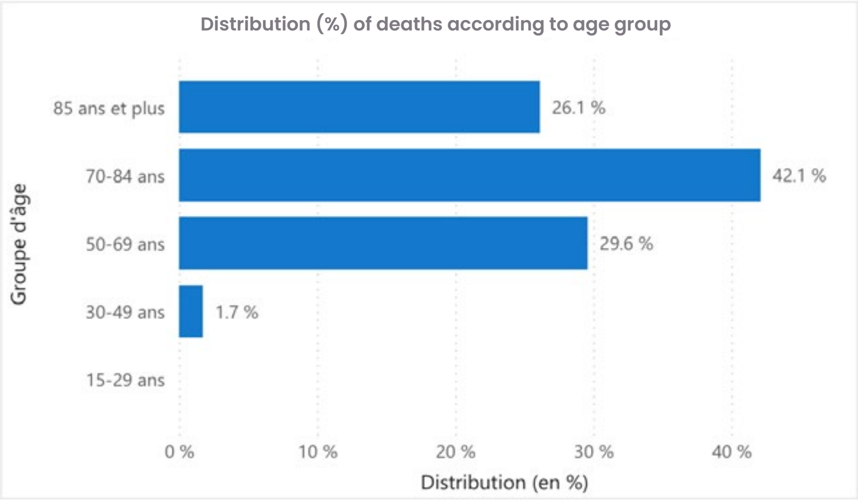
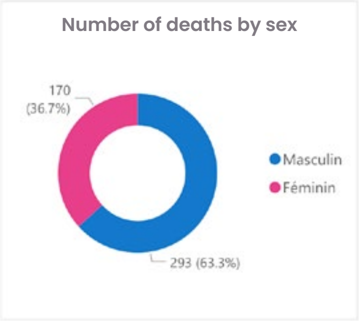
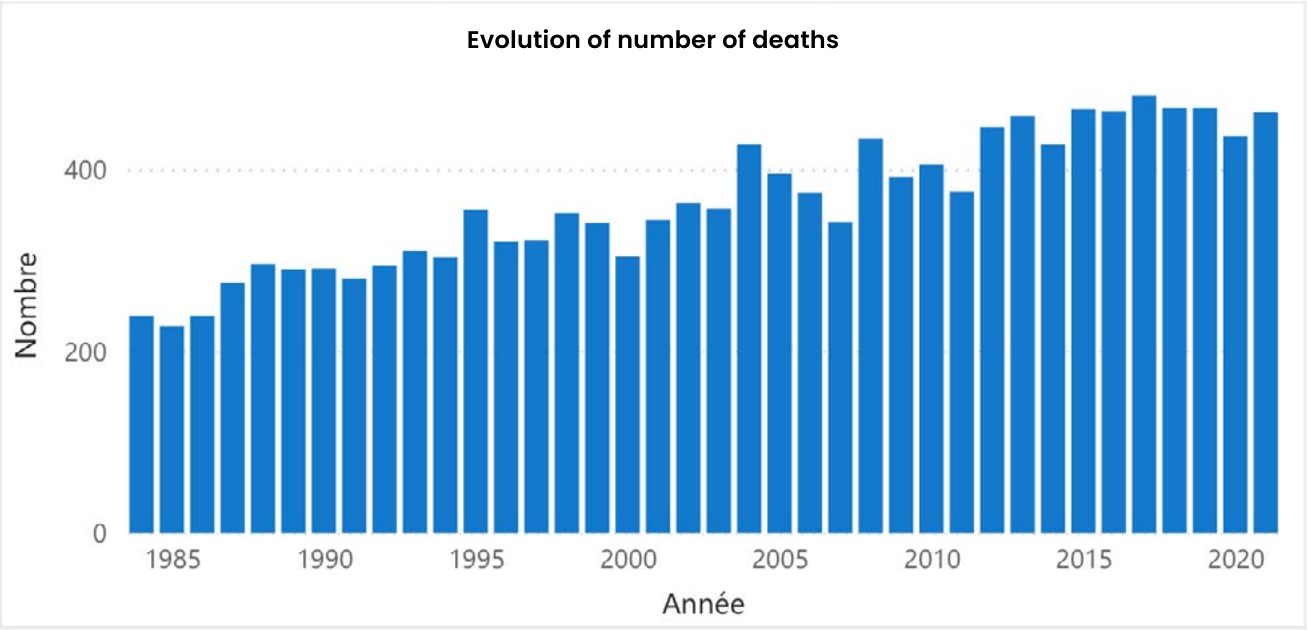


Number of deaths

463





Pancreatic Cancer

Recommendations by

Craig's Cause
Pancreatic Cancer Society

Introduction

Pancreatic Cancer - What Is It?

Pancreatic cancer is a particularly aggressive malignancy that develops in the tissues of the pancreas, an organ situated behind the lower part of the stomach. The pancreas has two main functions: producing insulin and glucagon to regulate blood sugar levels (endocrine function) and secreting digestive enzymes (exocrine function).

Statistics

Pancreatic cancer (PC) is the eleventh most diagnosed cancer in Canada but is the third leading cause of cancer-related death with a five-year survival rate of just 10%, depending on the province the patient resides in. This means that in Canada, in 2024, it is projected that 7100 Canadians will be diagnosed with pancreatic cancer and 6100 Canadians are projected to die from their pancreatic cancer diagnosis.

Pancreatic cancer is projected to be the second leading cause of cancer-related death in the next two years.

Why Is Pancreatic Cancer So Deadly?

Although pancreatic cancer is an uncommon malignancy of the gastrointestinal system, pancreatic cancer is one of the most aggressive and lethal malignancies, characterized by its late-stage diagnosis and poor prognosis. The most prevalent form, pancreatic ductal adenocarcinoma (PDAC), accounts for approximately 95% of cases. Another type, pancreatic neuroendocrine tumours (PNETs), is less common but can have a more favourable prognosis if detected early. Despite advancements in cancer research, the five-year survival rate remains alarmingly low due to the absence of effective screening methods and the non-specific nature of early symptoms, which often leads to misdiagnosis.

Treatment

Despite more substantial improvements in survival rates with other major cancers, there has been relatively low improvement in PC survival, since 1998.

Although surgical resection may be curative, only 15-20% of patients are diagnosed with early-stage resectable disease. Empiric chemotherapy and radiotherapy approaches have only led to incremental improvements in survival rates despite decades of research, largely due to treatment resistance. Regardless of a patient's candidacy for curative treatment (i.e. surgery), integrated holistic management approaches have been proven critical towards minimizing symptoms and improving quality of life. Common treatments to extend life and improve quality of life include chemotherapy and radiation. Patients who are able to have surgical resection may also receive neoadjuvant chemotherapy or adjuvant chemotherapy.

Management

One of the critical concerns for patients diagnosed with metastatic disease is the lack of treatment and management of the disease. Most Canadian translational research studies suggest that over 50% of metastatic patients receive no treatment or management of their disease, upon diagnosis. This varies across the different provinces. Stories of patients being sent home to "get their affairs in order," are frequent and do not reflect research recommendations: clinical trials and management of pancreatic cancer increase a patient's quality of life and life expectancy. All patients should receive holistic and supportive care that relies on a multi-disciplinary team of professionals, which even extends beyond the scope of the healthcare community.

A common symptom of pancreatic cancer is weight loss, and as the disease progresses, cachexia can accelerate the loss of muscle mass. Given the frequent and rapid weight loss associated with pancreatic cancer, the role of optimal nutrition in the management of pancreatic cancer can not be overstated, including the incorporation of supplemental enzymes. A 2018 multivariate analysis by De La IglesiaGarcia et al. showed that two factors influenced a patient's survival following a metastatic pancreatic cancer diagnosis—1) receipt of PERT and 2) chemotherapy.

Recent palliative care approaches have integrated oncology care to include patients earlier in the cancer continuum, specifically pancreatic cancer patients, who often receive a very challenging diagnosis. Once again this is often an underutilized specialty but one which provides a significant impact on a patient's quality of life and life expectancy. Palliative care provides a team-based approach that maximizes the care for patients. The inclusion of both, generalist and specialist palliative care specialists, improves patient outcomes.

Lastly, recent research has shown clear links to depression and pancreatic cancer. Depression is common among patients with pancreatic cancer and has significant impacts on a patient's quality of life and potential adherence to treatment and engagement with care. If a patient's depression is left untreated it could negatively impact a patient's outcomes.

Additionally, support from social workers, psychologists, palliative care, pain management specialists etc. are of optimal importance to extend life expectancy and improve the patients overall quality of life.

Early Detection

Early detection is crucial but difficult. Diagnostic imaging techniques like endoscopic ultrasound (EUS), magnetic resonance imaging (MRI), and computed tomography (CT) scans are vital in identifying and staging pancreatic tumours. While biomarkers such as CA 19-9 are not specific enough for early screening, they are useful in monitoring disease progression and treatment response.

Researchers are working to diagnose pancreatic cancer earlier and create personalized treatment plans based on genetics. Technologies like artificial intelligence (AI) and machine learning (ML) can analyze large datasets to spot tumours early, which is crucial since symptoms often appear late.

By understanding the genetic changes linked to pancreatic cancer, doctors can develop targeted therapies tailored to individual patients. Combining early detection with personalized medicine could greatly improve treatment options and outcomes for patients.

Symptoms

Symptoms of pancreatic cancer are often non-specific, leading to frequent misdiagnoses and delays in an accurate diagnosis. Common symptoms of pancreatic cancer include abdominal pain, unexplained weight loss, jaundice (yellowing of the skin and eyes), changes in stool, dark urine and new-onset diabetes mellitus.

Risk Factors

Risk factors for pancreatic cancer include genetic predispositions, such as BRCA1 and BRCA2 mutations, hereditary pancreatitis, and familial pancreatic cancer syndromes. Lifestyle factors like smoking, obesity, and chronic alcohol consumption also play a significant role. Medical conditions like chronic pancreatitis and long-standing type 2 diabetes mellitus (T2DM) further increase the risk. Age is a notable factor, with most cases occurring in individuals over 60, and certain ethnic groups, including African Canadians and Ashkenazi Jews, have a higher prevalence. There is a slight increase of males diagnosed with pancreatic cancer (3800), than females (3300).

Relevant Abbreviations & Lexicon

EUC: endoscopic ultrasound

CT: computed tomography

MRI: magnetic resonance imaging

PDAC: Pancreatic ductal adenocarcinoma

PNETS: pancreatic neuroendocrine tumours PEI - Pancreatic exocrine insufficiency

PERT: Pancreatic enzyme replacement therapy

CA 19-9: Carbohydrate Antigen 19-9 - a tumour marker often elevated in pancreatic cancer patients

HPB surgeon: Hepato- Pancreatico - Biliary surgeon

FOLFIRINOX: A combination chemotherapy regimen used to treat pancreatic cancer, consisting of folinic acid, fluorouracil, irinotecan, and oxaliplatin.

Gemcitabine: a chemotherapy drug used as a treatment for different cancer types, including pancreatic.

Abraxane: a chemotherapy drug used to treat metastatic or advanced staged cancers, including pancreatic

Whipple Procedure: A surgical operation, also known as pancreatoduodenectomy, used to remove part of the pancreas, duodenum, and other nearby tissues in an attempt to treat pancreatic cancer

Neoadjuvant Chemotherapy: Chemotherapy prior to surgical resection

Adjuvant Chemotherapy: Chemotherapy post surgical resection

Cachexia: a syndrome common among late stage cancer patients that alter metabolic activity resulting in muscle protein loss

Context — Reality & Impact on the Quebec Population

Pancreatic cancer is a pressing public health issue in Quebec, mirroring global trends in both incidence and mortality. As the province's population continues to age, the prevalence of pancreatic cancer is expected to increase, underscoring the need for enhanced efforts in prevention, early detection, and treatment. In Quebec, pancreatic cancer remains among the deadliest cancers, with a five-year survival rate of around 10%, consistent with national figures. In 2024, it is projected that 1760 Quebec residents will receive a pancreatic cancer diagnosis, often at an advanced stage due to the disease's typically asymptomatic early progression. This delayed diagnosis significantly contributes to the high mortality rate associated with the disease, which is projected to be 1490 deaths in 2024.

The impact of pancreatic cancer spans all demographics, but it disproportionately affects individuals with lower socioeconomic status, who often face barriers to healthcare access and preventive services. Patients often have to stop working after diagnosis and may require support from partners or family members, meaning they also have to stop working, significantly decreasing household incomes. The financial burden of treatment, which can include surgery, chemotherapy, and palliative care, places tremendous strain on families, potentially leading to widespread economic challenges. Other costs include hospital parking, gas to get to and from appointments, supplements, medications and grocery costs to name a few.

Quebec's healthcare system faces several obstacles in addressing pancreatic cancer, including delayed diagnoses, resource allocation issues, limited research funding, and disparities in access to care. The psychological toll on patients and their families is profound, as the aggressive nature of the disease and poor prognosis often lead to significant emotional distress. While support services such as counselling and support groups are vital, they remain underutilized or inaccessible to many in Quebec.

The COVID-19 pandemic has further complicated the management of pancreatic cancer in Quebec. Diagnostic delays became a major issue as elective procedures and routine screenings were postponed during the height of the pandemic, leading to delays in diagnosis and treatment. Additionally, treatment interruptions were common, with patients experiencing modifications or delays in their chemotherapy or other therapies due to hospital capacity constraints and infection control measures. The pandemic also intensified anxiety and stress among patients and their families, exacerbating the psychological burden of a pancreatic cancer diagnosis.

Stakeholders to Consider & Priority Populations

Addressing pancreatic cancer in Quebec necessitates the coordinated efforts of a diverse array of stakeholders to ensure effective management, research, and support.

At the core of this endeavor are patients and survivors, whose needs and experiences drive the development of tailored support and treatment programs. The role of families and caregivers is equally vital, as they provide essential day-to-day support that underpins patient care, making their well-being crucial to the overall care process.

Healthcare providers—including oncologists, surgeons, primary care physicians, nurses, and palliative care teams—are central to diagnosing, treating, and managing pancreatic cancer. Healthcare institutions must be adequately equipped to address the multifaceted needs of these patients. Research institutions and universities are pivotal in advancing our understanding of pancreatic cancer through rigorous research initiatives.

Non-profit organizations and advocacy groups, such as Craig's Cause Pancreatic Cancer Society, are instrumental in advocating for research funding, patient support, and public awareness. Pharmaceutical and biotechnology companies play a significant role in developing vital medications and treatments. Insurance providers, including both public entities like the Régie de l'assurance maladie du Québec (RAMQ) and private insurers, are essential in covering treatment costs, thus alleviating the financial burden on patients.

Efforts should prioritize several key populations to ensure universal and equitable care and support for pancreatic cancer patients across Canada. High-risk groups, including those with a family history or genetic predispositions, require prioritized screening and preventive measures. The elderly, who experience higher incidence rates, need specialized treatment and support services. African Canadians and Ashkenazi Jews, who face elevated risk levels, must be included as priority populations.

Indigenous communities, with their unique healthcare needs and cultural considerations, necessitate culturally tailored approaches to cancer care. Immigrant and minority communities, who may encounter language barriers and cultural differences, require targeted outreach and culturally sensitive care.

Additionally, cancer survivors need comprehensive long-term follow-up care to address potential late effects of treatment, while children and adolescents in affected families require psychological support to navigate the challenges of a loved one's illness.

Existing and Missing Supports for Patients and Their Families

The World Pancreatic Cancer Coalition recommends that all patients and their families and caregivers are provided information about where to access support, yet patients report high levels of unmet supportive care needs.

Additionally, as pancreatic cancer continues to rise as a leading cause of cancer- related mortality, addressing treatment disparities based on geography, race, and socioeconomic status has become increasingly vital. Initiatives aimed at improving access to care and enhancing early detection can potentially reverse the grim statistics associated with this formidable disease. An example of this is a review that was conducted by Noel and Fiscella that discussed how black and Hispanic patients are more often treated at low-volume institutions and are less likely to undergo surgery.

Craig's Cause Pancreatic Cancer Society offers a variety of specialized, comprehensive programs aimed at empowering patients, caregivers and healthcare professionals. These are a few of the programs:

- **Pancreatic Cancer Guide™** is a virtual, one-on-one meeting with our nurse navigator, who helps patients and caregivers navigate the healthcare system and ensures adequate access to resources and care, ultimately improving patient outcomes and quality of life.
- **The PERT calculator** analyzes the lipase units required to optimize your digestion and will calculate a custom PERT dosage based on your meal or snack.
- **Peers with Pancreatic Cancer** is a support group facilitated by our Nurse Patient Support Manager, where those with pancreatic cancer meet weekly to give and receive support, share stories, and learn about topics chosen by the group.
- **Support4Caregivers™** is an interactive support group for pancreatic cancer patients and caregivers, facilitated by professionals experienced in the unique pancreatic cancer journey.
- **Ask a Doctor™** empowers patients and caregivers with the knowledge, enabling them to navigate the pancreatic cancer journey while self-advocating best practices and clinical trial options.
- **Referral List -** An up to date list of institutions in Canada that have healthcare professionals experienced in treating pancreatic cancer.
- **Clinical Trial Finder -** Helps patients find suitable clinical trials for their cancer treatment and facilitate discussions with their oncologists.

The Canadian Cancer Society has developed a widget that contains a database of all cancer support services within Canada.

Wellspring offers one-on-one peer support services which foster a supportive community for those affected by pancreatic cancer, helping patients and caregivers navigate their journey with understanding and compassion.

The Canadian Digestive Health Foundation provides comprehensive online resources about pancreatic cancer, pancreatic exocrine insufficiency (PEI), and pancreatic enzyme replacement therapy (PERT).

The Clinical Research Organization in Cancer (Q-CROC) enhances cancer clinical research in Quebec by optimizing participant recruitment and supporting healthcare professionals.

Missing Advancements in treatment options for pancreatic cancer have not kept pace with those for other cancers, but efforts continue to adapt, develop and combine approaches to affect change in the difficult-to-treat cancer.

Many non-specialists tasked with treating pancreatic cancer patients, are often ill- informed or are too overburdened with patient caseloads, to be adequately informed on the clinical trials, throughout Canada. The World Pancreatic Cancer Coalition reports that patients who participate in clinical trials have better outcomes and quality of life than those who do not. Eligibility criteria for clinical trials vary with many requiring that patients have not received prior treatment, so it is critical that these options are made available to the patient and thoroughly explored very early after diagnosis.

Precision medicine and immunotherapy are improving the outcomes and quality of life for patients with an array of cancers, though not overly accessible within Canada.

Precision medicine and immunotherapy have the potential to improve the survival of patients with pancreatic cancer. However, progresses have been less significant than for other malignancies.

In the absence of precision medicine, the patient who has a high abundance of the drug targets for the standard chemotherapy will respond more positively while the treatment will not be as effective for patients whose tumours exhibit different profiles.

The Know Your Tumour program in the U.S. provides multi-omic analysis that can help in tailoring treatment based on the actionable molecular profile of each patient's tumour. It was shown in a 2020 report by Pishvaian et al. that matching the treatment to the actionable alterations improved the two-year survival rate by approximately 30%40. However, once again Canadians struggle to access such critical programs, unless through hospitals where pancreatic cancer research is taking place, making it less accessible for most Canadians. If Canadians are not treated at these research hospitals, molecular profiling is available through several organizations but costs many thousands of dollars, making it inaccessible to most.

With increasing resolutions of analysis and research, it is now understood that pancreatic cancer is not a uniform disease at the cellular and molecular levels. This means that the genetic, but also the structural and immunologic landscape of a tumour varies even within the same patient. Perhaps uniquely, the immune system can recognize and react to a variety of tumour cell phenotypes. Although checkpoint- based immunotherapy has been largely ineffective against pancreatic cancer, new cell-based and combination immunotherapies are showing promise in pancreatic cancer. Alone, and in combination with other approaches, strategies to maximize immune cell reactivity hold high potential for the treatment of pancreatic cancer.

Palliative care is often overlooked in the management of pancreatic cancer, with many patients missing out due to public stigma and referral challenges. Despite its benefits in increasing survival rates and improving quality of life, limited resources hinder access.

A team-based approach, integrating generalist and specialist palliative care to enhance patient outcomes and address the stigma is crucial. Advocating for better integration and addressing funding barriers are vital for enhancing patient care.

Would you like to focus on specific strategies or initiatives?

The management of pancreatic enzyme insufficiency (PEI) and diabetes in pancreatic cancer (PC) patients is fraught with challenges. A significant number of these patients suffer from PEI, leading to malnutrition and decreased appetite. Despite the benefits of pancreatic enzyme replacement therapy (PERT) in improving quality of life and survival—comparable to chemotherapy—fewer than 20% of patients receive it, often at inadequate doses. Barriers such as lack of prescription practices, education gaps among healthcare providers, and inconsistent insurance coverage need to be addressed and national guidelines are required for healthcare professionals to follow.

Lastly, national guidelines for the diagnosis, treatment and management of pancreatic cancer create critical challenges, across Canada for both Healthcare Professionals and patients.

A recognized national standard pathway to diagnosis, treat and manage pancreatic cancer would improve patient care and make healthcare systems more efficient. Such a pathway would ensure that patients receive consistent and high-quality care no matter where they are. By streamlining the diagnostic process, these pathways help with the early detection of pancreatic cancer, which is crucial, leading to better patient outcomes and quality of life.

Overall, national pathways for pancreatic cancer would contribute to a more effective and patient-centred healthcare experience.

Objectives to Aim For in Quebec to Reduce Incidence, Reduce Mortality & Better Support Patients

(Performance indicators to be measured over the next 10 years)

Short Term (1 - 2 years)

01. Diagnosing and Screening

Participate in round table discussions and National awareness about the importance of Germline testing and Individualized treatment and care.

02. Value-Based Healthcare

- Measure multidimensional patient
- reported outcomes and experience(PROMs & PREMs) in a standardized way for all patients to optimize their quality of life and trajectory of care.
- Create national, comprehensive pathways for both diagnosis and treatment and management of the disease.

03. Palliative Care

- Campaign addressing myths, to reduce stigmas.
- Create resources for patients

04. PEI/PERT

- Educate HCPs on the influence of PEI and malabsorption on cancer-relatedcachexia, tolerance to treatment, quality of life, and overall survival - Make PERT accessible to all PC patients
- Optimize the efficacy of PERT by widespread adoption of the PERT dosage tool
- Optimize selection criteria for neoadjuvant vs. adjuvant approaches alongside potential resection
- Discuss the advantages and risks of recruiting clinical trials based onpatient eligibility immediately following diagnosis
- Educate patients on the benefits of clinical trial participation compared tostandard of care—reduce the stigma

Medium Term (3 - 5 years)

01. Diagnosing and Screening

- Germline testing for all patients diagnosed with PC with the implementation of oncology clinic-based point- of-care testing covered through provincial healthcare plans and timely return of results for treatment decisions.
- Improve cascade testing in families that harbour a predisposing germline mutation and expand screening opportunities for high-risk individuals across Canada, preferably through an integrated clinical and research program such as PRECEDE.

02. Value Based Healthcare

Increase collaboration among healthcare stakeholders by moving from simple inter - or multidisciplinary care to integrated practice units and make it equitable for all.

03. Palliative Care

All patient with pancreatic cancer and associated difficulties should have a referral to palliative care.

04. Treatment

Support research on optimizing immunotherapy and promote enrollment in clinical trials for neoadjuvant treatment strategies across Canada. By prioritizing these initiatives, we can enhance treatment options and survival rates for PC patients.

Long Term (6- 10 years)

01. Diagnosing and Screening

Continue to optimize machine learning models for better detection of elusive early malignant and high-risk precursor lesion.

02. Palliative Care

Make early palliative care accessible to all patients

03. Treatment

Continue to support research in better selecting systemic therapies for patients to optimize benefit and minimize side effects.

04. Value-Based Healthcare

Continue to incorporate patients and families in care decisions and utilization of integrated care models.

Conclusion — Our Vision for the Future

Craig's Cause Pancreatic Cancer Society is committed to improving the outcome for pancreatic cancer patients and their families. By integrating perspectives from diverse fields, knowledge sharing on innovative treatments and supportive care, we see a hopeful future for improving the quality and length of life for pancreatic cancer patients.

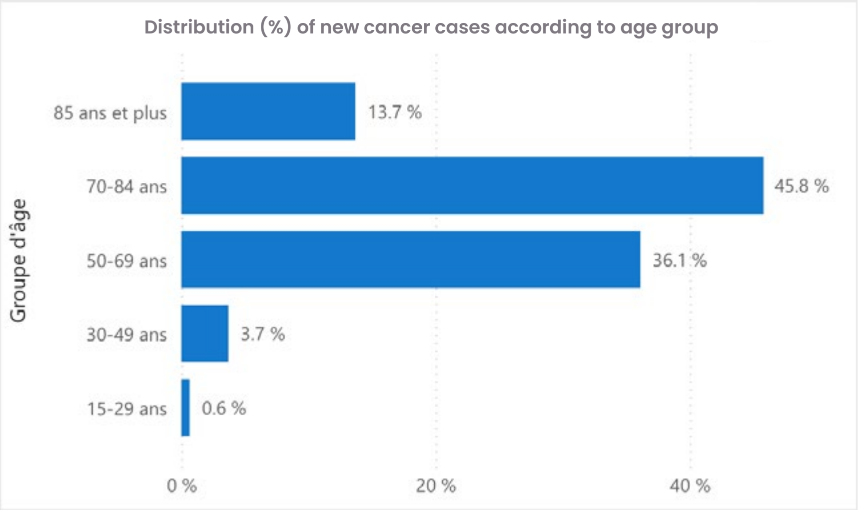
The application of PERT and providing practical insights into its use and benefits plus education on palliative care and the importance of holistic support, including mental health resources, are monumental in the care of pancreatic cancer. Ongoing research efforts, illustrate how funding is directed towards cutting-edge studies in precision medicine and genetic profiling.

Craig's Cause Pancreatic Cancer Society will continue to foster connections amongst healthcare providers, fund collaborative research and optimize patient care through advocacy, education and support The above approach not only promotes comprehensive patient management strategies but also enhances the collective expertise needed to drive advancements in pancreatic cancer care.

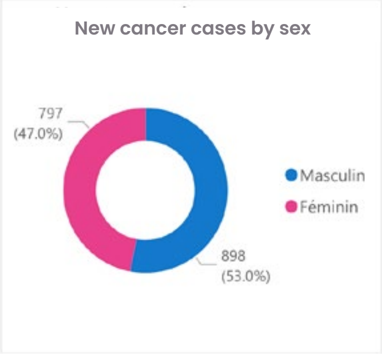
Overall, we are optimistic that pancreatic cancer care and outcomes will improve through implementation of the above and we are committed to being a voice for the pancreatic cancer community.

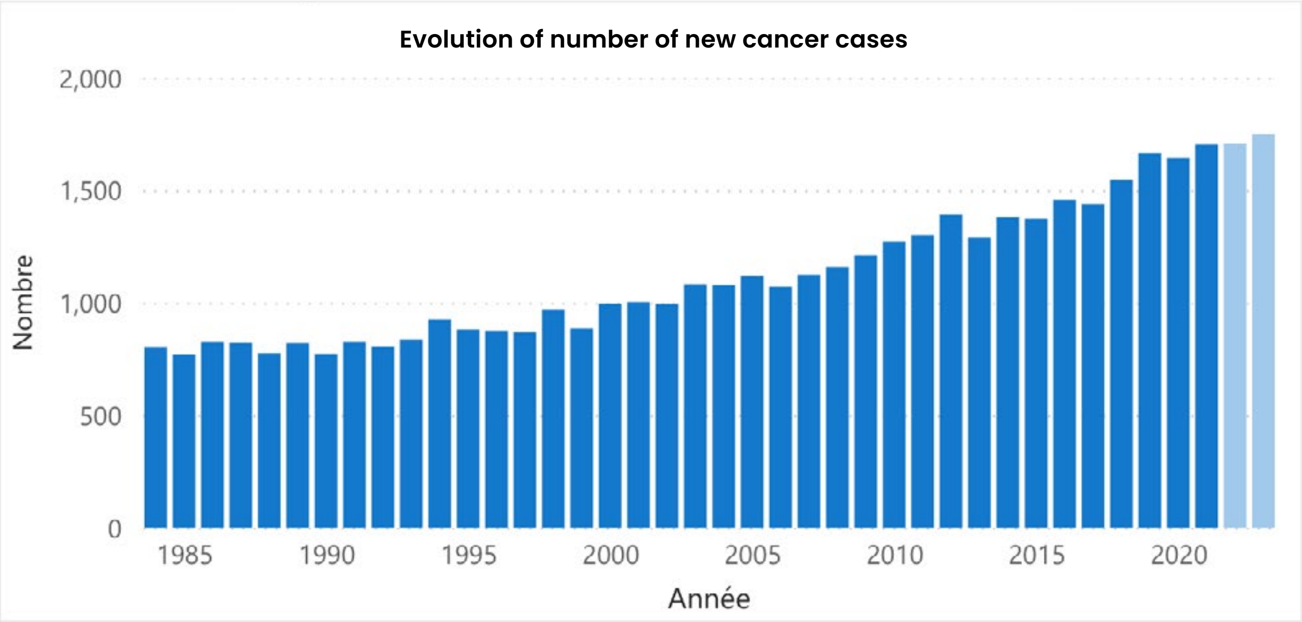
Craig's Cause
Pancreatic Cancer Society

Pancreatic Cancer Statistics in Quebec

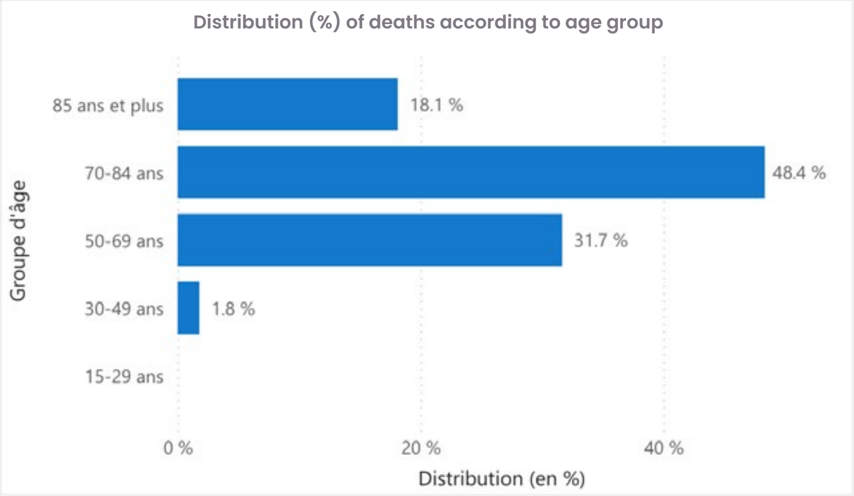

Distribution (%) of new cancer cases according to age group

New cancer cases
1,703

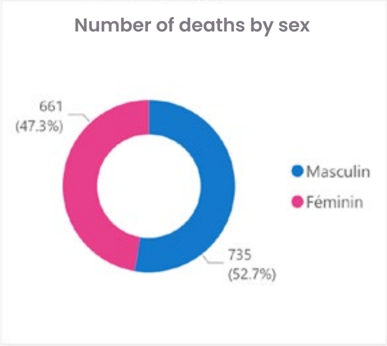

New cancer cases by sex

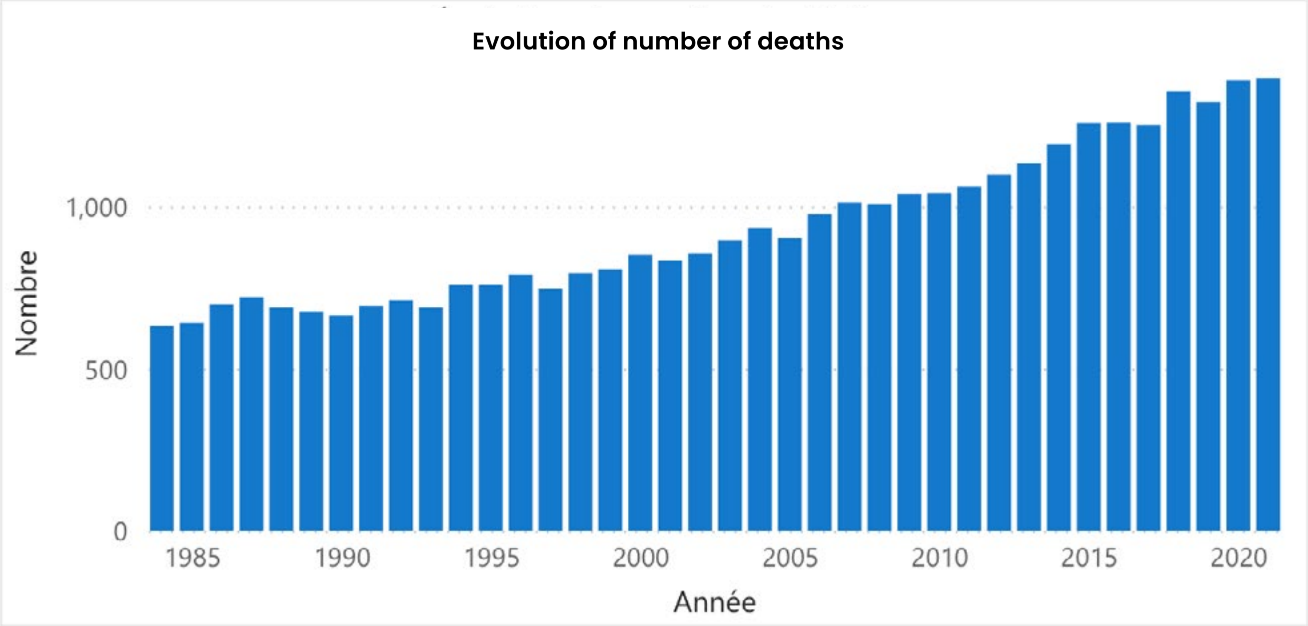

Evolution of number of new cancer cases

The graphics in this report are pulled from the dashboards of the Registre québécois du cancer, available exclusively in French.
The original data can be accessed here.


Distribution (%) of deaths according to age group

Number of deaths
1,396


Number of deaths by sex


Evolution of number of deaths

Multiple Myeloma

Recommendations by

MYELOMA
CANADA

These recommendations were formulated in collaboration with:
Dr. Richard LeBlanc, M.D., FRCPC, Hematologist and medical oncologist, and Gisèle Fournier, patient diagnosed with a multiple myeloma in 2020

Introduction

Abbreviations

MM – Multiple Myeloma

MGUS – Monoclonal gammopathy of undetermined significance

SMM – Smouldering multiple myeloma

CAR T – Chimeric Antigen Receptor T-cell Therapy

Multiple myeloma (also known as myeloma or MM) is the second most common form of blood cancer and remains incurable. Every day, an average of 11 Canadians are diagnosed with myeloma, a number that has been rising steadily since the early 1990s.

Myeloma develops in a type of immune cells called plasma cells, which are responsible for producing antibodies (immunoglobulins) and critical for the effective functioning of our immune system. The cancer develops through a complex, multi-step process, as these plasma cells mutate into malignant myeloma cells.

Myeloma symptoms are often vague, i.e. like fatigue or anemia, bone pain (resulting from bone fractures), and kidney problems. People living with myeloma commonly experience a severely weakened immune system making them more susceptible to to frequent, recurrent - and potentially life-threatening - infections, like COVID-19. For additional complexity, the cancer develops uniquely in each patient, meaning our responses to the same therapies vastly differ, and making myeloma a difficult disease to both diagnose and treat.

Associated disorders and diseases

MGUS and smouldering multiple myeloma

There are precursors to multiple myeloma, the most common of which are monoclonal gammopathy of undetermined significance (MGUS) and smouldering multiple myeloma (SMM), which are typically asymptomatic and do not require treatment. Solitary plasmacytoma(s) (highly localised mass(es of myeloma cells) can also be a precursor of the disease and benefits from radiotherapy. All patients with these precursor diseases should be monitored long-term for potential development of multiple myeloma.

Bone disease associated with myeloma

The most common and debilitating feature of myeloma is the way it affects bones throughout the body. More than 70% of people with myeloma experience bone pain and show signs of myeloma-related bone disease at the time of diagnosis. The majority of people with myeloma will develop myeloma-associated bone disease at some point in their myeloma journey.

Myeloma and kidney disease

People with myeloma have an increased risk of developing kidney disease. At least 20% of people with myeloma show some degree of kidney failure at the time of diagnosis, and up to 50% develop kidney failure during the course of their myeloma. Kidney damage can result from several myeloma-related causes, for example, when the abnormal protein (monoclonal antibody or m- protein) produced by myeloma cells in large quantities blocks the kidneys' excretion channels, dehydration or high calcium levels (hypercalcaemia). Some of the drugs used to treat myeloma can also cause or contribute to myeloma-associated kidney disease.

Infections

People with multiple myeloma are more susceptible to infections. This is due both to the myeloma itself and to the effects of its treatments. Infections are an important cause of morbidity and mortality in people with multiple myeloma. Studies show that infections are a key cause of death following a myeloma diagnosis. Most infections in people with myeloma are caused by viruses and bacteria, although fungal and parasitic infections can also occur.

Some myeloma patients may develop other cancers due to certain myeloma treatments like cyclophosphamide (bladder cancer), and lenalidomide, especially after an autologous stem cell transplant (ASCT). Pregnant persons or those planning to become pregnant should not take thalidomide, lenalidomide or pomalidomide, as these drugs may cause serious birth defects.

AL Amyloidosis

AL amyloidosis is a group of conditions that occur when amyloid, an abnormal protein produced by plasma cells, accumulates in the body's organs. Although around 10-15% of people with myeloma have or develop AL amyloidosis, it is rare for people with amyloidosis to develop myeloma.

Context — Reality and impact on the Quebec population

In 2024, 1,060 new myeloma diagnoses were expected in Quebec, and 450 previously diagnosed Quebecers were projected to die from the disease (Canadian Cancer Statistics, 2024). This is one of the highest population-adjusted incidence rates in the country. It is worth noting that the number of myeloma cases diagnosed in 2020-2021 fell by 8.5% compared to the number of diagnoses in the pre-COVID-19 period. It is critical that Quebec's cancer statistics are updated so that we can assess the pandemic's impact on diagnoses and measure associated treatment delays.

A 2019 analysis of the geographical distribution of myeloma in Canada identified Longueuil, Gaspésie and Saint-Lambert as the regions in Quebec with the highest incidence of myeloma, and these were amongst the top five highest population-adjusted incidence rates across the country.

Risk Factors

Good general health reduces the risk of developing cancer, and this is equally true for myeloma. Certain risk factors may also play a role in the development of myeloma, for example:

- Age is the most important risk factor for multiple myeloma, with 96% of individuals diagnosed after the age of 45.
- Myeloma is NOT hereditary like other cancers such as breast or colorectal can be. Still, the incidence of myeloma is slightly higher in first-degree relatives of people with myeloma (parents, siblings and children), than in the general population.
- The risk of developing myeloma is higher in those who have been diagnosed with MGUS, SMM, have a history of solitary plasmacytomas of the bone, or an autoimmune disease.
- Myeloma is more common in biological males than in biological females.
- The incidence of myeloma is higher in the black population, with men also presenting a higher risk of developing the disease than women.

Exposure to multiple carcinogens (chemicals) involved in the development of myeloma is more common in sectors such as agriculture, manufacturing, transportation, warehousing, and construction. Some key facts that could have a significant impact on future diagnoses:

- During the pandemic, employment in the agricultural sector has increased and was expected to continue growing until 2024. Approximately 52,600 people work in the agricultural sector in Quebec. "... since 2019, agriculture has added 900 jobs with 4,400 additional temporary foreign workers" to the province.
- Field crops (grain corn and soybeans) occupy more than 800,000 ha in Quebec. They are an important source of agricultural income, but also account for the majority of glyphosate-based herbicides (ex. RoundUP) used in the province.
- Glyphosate is also the best-selling herbicide in Quebec. Laval banned glyphosate in the spring of 2021, and Montreal did the same a few months later, banning the use and sale of 36 pesticides, including glyphosate. Quebec City followed suit in mid-2023 with a bylaw banning glyphosate (the main ingredient in RoundUP) and encouraging the use of safer, less toxic biopesticides.
- CAREX Canada data has shown benzene to be the third most common carcinogenic substance to which Quebec workers are exposed, with around 2.1% of workers impacted.
- Quebec recognizes firefighting as a presumptive cause for nine cancers (including kidney, bladder, prostate, skin, and laryngeal cancers, as well as mesothelioma, multiple myeloma, and non-Hodgkin's lymphoma) due to repeated occupational exposure to multiple carcinogens. Multiple myeloma was officially recognized in Quebec in 2016, but only administratively by the CNESST. Full Legal protection for firefighters was not established until 2019. It should be noted that Quebec's requirements regarding the number of years one must be employed as a firefighter to qualify for this protection is higher than in the rest of the country.

Stakeholders to Consider & Priority Populations

Cellular therapies (CTs) offer unparalleled potential to improve outcomes for patients with myeloma and bring us closer to finding a cure for this disease. Ensuring access to these therapies for all eligible myeloma patients is a critical priority. Amongst the stakeholders who will need to take part in discussions surrounding the future of myeloma treatment is, first and foremost, the myeloma community—those living with the disease and their families. In 2019, we launched Myeloma Canada's Research Priority Setting Partnership (RPSP) to survey the Canadian myeloma community and identify the top 10 myeloma research questions most important to them. The first priority research question identified was: 'How can myeloma be cured?', and a question our researchers are working to answer through the development of innovative therapies with increasingly promising therapeutic value, like CTs.

Priority Populations

- Patients with more aggressive disease, biological risk factors, or a poor prognosis. Many patients with multiple myeloma will receive long-term treatments with some side effects but will generally have a good quality of life. These patients often die from other causes such as heart disease or other cancers and should not currently be considered a "priority population" compared to patients who are at high risk of dying within two to four years.
- Patients at risk of dying within 2-4 years are a priority, because we need to develop mechanisms to better identify these individuals so we can minimize the impact of myeloma on their lives, by treating them more quickly and effectively.
- People who are not eligible for autologous stem cell transplant, as they have fewer treatment options
- Workers at risk due to their occupation/work environment (see previous section).
- Young patients for whom existing treatments and support are often unsuitable, as they are mainly designed for older patients. The effects of treatment also have a significant impact on areas of their lives such as fertility and sexuality which are not always addressed by their doctor. Managing the professional and family responsibilities young patients shoulder is also rarely discussed, as myeloma is often considered to be an 'older person's cancer'.
- People living in rural areas or remote regions, which represents 19.5% of Quebecers (2016, CIHI). The Canadian Cancer Society's 2022 report on cancer prevalence describes higher rates of obesity, smoking, and chronic diseases (diabetes, cardiovascular disease) as "lifestyle factors" that may explain the higher incidence of cancer in rural populations. However, other important factors contribute to cancer rates in rural areas, such as social determinants of health (socioeconomic and environmental factors that influence your health) and lack of adequate health services or access to them. These factors may help explain why Canadians living in rural areas are, in general, more likely to suffer from chronic diseases, develop cancer, and have difficulty accessing treatment. Canadians living in rural areas are also more likely to be exposed to dangerous levels of cancer-causing chemicals such as pesticides, which many studies have shown to increase the risk of developing myeloma. In short, Canadians living in rural and remote areas are at higher risk of developing cancer, including myeloma, and often face poorer outcomes due to limited access to health resources.
- First Nations, Métis, and Inuit peoples, who are also among Canadians most at risk due to socioeconomic factors and face limited access to health services. As well, certain immigrant populations who similar risk factors, and/or face difficulty accessing available health services and care due to immigration status, language, or cultural barriers.

Existing and Missing Supports for Patients and Their Families

Pivot nurse/Drug Access Navigator: This role is critical for myeloma patients due to the many (often new and costly) treatments they will need during their illness. These treatments have different dosing schedules and side effects which can be challenging to manage. Crucially, many patients need help navigating the healthcare system and managing potential funding mechanisms (e.g., patient support programs and compassionate use programs offered by the pharmaceutical industry, special medical need/exceptional patient status, private and public insurance).

The fact that Quebec is constantly facing a nursing shortage significantly reduces the amount of time nures can spend with each patient. Patients often find themselves waiting alone, feeling helpless in the face of bureaucratic red tape, and often not knowing who to talk to. The role of medication access coordinators, which is entirely complementary to that of nurse navigators, is not officially recognized and supported in Quebec, although it is elsewhere in Canada. Quebec needs to regulate this status and give medication access coordinators a formal place in the Quebec healthcare system.

Myeloma Canada has seven support groups across Quebec. Myeloma Canada offers a network of support groups across the country, as well as six virtual support groups via Facebook, and MC LOUNGE, which are accessible regardless of location. In addition, we offer a peer support program in collaboration with the FQC, which can be accessed by phone for people who do not have reliable Internet access. Joining a support group is a meaningful way for individuals, whether they are living with myeloma or caring for someone with the disease, to advocate for themselves and others. These groups provide a safe environment where participants can connect with other members of the myeloma community, share their experiences, concerns, and questions with people who understand what they are going through. Support from peers living with myeloma can empower individuals to take charge of their own journey with myeloma, better understand potential challenges, and provide comfort and empathy along the way.

Local community resources. At Myeloma Canada, when our when our community asks for help, we strive to create new solutions, but there are existing models/programs that could address some of their needs. The systematic referral model in the Chaudière-Appalaches region is one such example. We are increasingly confronted with the harsh reality of some patients who are unable to physically get to their treatments due to a lack of resources. While we cannot influence individuals' incomes, we can ensure that when cancer is diagnosed, people will not have to move heaven and earth to find the transportation and housing they need to receive treatment and stay alive. The scope of the existing systematic referral model would enable our organizations to work together to find specific solutions to patients' needs, and should be expanded to additional regions.

Objectives to Aim For in Quebec to Reduce Incidence, Reduce Mortality & Better Support Patients (Performance indicators to be measured over the next 10 years)

Short term:

01. Diagnostic

- Recognition and dissemination of the guidelines for the diagnosis and treatment of multiple myeloma developed by Myeloma Canada and Quebec researchers specializing in multiple myeloma.
- Access to a wider range of publicly-funded diagnostic blood tests.

A tremendous amount of work has already been done to standardize and normalize Canadian and Quebec practices in diagnosis and treatment. However, with the exception of hematologists specializing in myeloma, other health professionals who may be involved in diagnosis or treatment do not always have access to this information. Establishing a standard of care accessible to all these professionals would allow us to provide better care and prevent patients from wandering around for months, seeing an average of three different healthcare professionals before they are diagnosed and able to start treatment. There are also diagnostic tests that can facilitate this work. These minimally invasive tests could identify certain markers that would allow for faster identification of myeloma as the cause of problems patients report during routine examinations. These tests are not automatically funded as part of routine blood tests but should be included for patients aged 50 and over.

02. Evaluation of drug reimbursement

- Shorter time between notice of compliance (NOC) and reimbursement recommendation for new drugs.
- Faster reassessment when a negative recommendation is issued

There are already models in place developed by INESSS's sister organization, CDA-AMC, which specifically address these two issues. Target Zero, for example, aims to improve Canadian patients' access to new drugs that have been proven effective. Target Zero's ambitious goal is to reduce to zero, the time between Health Canada's regulatory approval of a drug and CDA-AMC's recommendation for reimbursement to participating public drug plans. With regard to re-evaluations following refusals, there is a feedback process established by CDA-AMC that gives patient groups, and not just industry, a voice. We do not dispute the independence of INESSS, but we believe it is crucial that the two organizations collaborate and on initiatives such as these, as they directly affect access to treatment and the opportunity for patients to have their views heard and considered.

03. Improved administration of existing treatments

- Availability and support for at-home administration of treatment by subcutaneous injection

Ongoing studies in Alberta are demonstrating the benefits of at-home administration of one of the most common myeloma treatments, bortezomib. This treatment normally requires frequent trips (biweekly) to the hospital. Safe at-home administration significantly improves patients' quality of life, reduces treatment-related travel costs, and frees up nursing staff. Better organization of home care (including treatment administration) would also have a positive impact on reducing overall healthcare costs, in addition to freeing up time and resources that could be reallocated according to community needs.

04. Modification of the circulaires 2000-028 and 2023-015 (2003-012)

Since 2018, we have alerted the government to the problems caused by these circulaires in clinical trials initiated by research groups. These two documents prevent the administration of a treatment in its totality:

- When the treatment includes a drug that cannot be administered in a hospital setting, by requiring healthcare establishments to assume responsibility for the entire treatment when a combination of drugs is prescribed and includes a medical procedure exclusive to the hospital setting (2000-028). This limits access to state-of-the-art treatments if they are not yet listed on the RAMQ's reimbursement list;
- When investigator-initiated clinical studies, unsupported by a pharmaceutical company that would generally cover the cost of all drugs to be administered, use different modes of administration and depend on multiple payers to conduct their studies (2023-015).

Many clinical trials have not taken place in Quebec because of these two rules and their inflexibility. The circulaire 2023-015 has been amended, without taking into account the recommendations on the funding model that we have made over the years, and the report submitted by the Quebec Cancer Coalition in 2021 on the subject, on which we collaborated.

Now that Catalis-Quebec has become involved in the issue, having been given the mandate to consult stakeholders, we hope to see a result. Over the past 30 years, research has enabled us to better understand myeloma and its underlying pathological processes. This has led to the development and approval of new treatments based on cutting-edge agents that have prolonged the lives of many people with myeloma. The relapsing/refractory nature of the disease and the fact that myeloma remains incurable make clinical trials a valuable treatment option for our community. It is inconceivable that some individuals in the same province, or even country, will never be offered clinical trials as part of their care pathway, and will not be able to make the choice to move on with their lives when options exist.

Medium term:

01. Successful development and commercialization of academic cellular therapies
02. Access to CAR T-cell therapy, regardless of the patient's place of residence

To give Canadians with myeloma the best chance at survival and quality of life, we must expand access to cellular therapies (CTs) for all Canadians with myeloma. To do this, it is imperative that we invest in Canadian research. Canada has the expertise and knowledge to match and even rival international research. It is essential that Quebec and the rest of Canada invest in clinical trials for cellular therapies to treat myeloma developed in Canadian universities and establish point-of-care cellular therapy manufacturing processes and facilities in Canada. We cannot rely solely on the pharmaceutical industry to produce this type of complex therapy. The manufacturing process can take over four weeks, and with what is currently available, very few patients will have access to it. We must be able to offer different options so that as many patients as possible can benefit.

The allocation of commercial clinical trials for CAR T-cell therapy is highly competitive. To date, only five centers have participated in such clinical trials in Canada, Calgary, Hamilton, Montreal, Toronto, and Vancouver. These centers were selected based on the expertise of clinicians and staff, the availability of apheresis units, and the number of centers needed to recruit the patient population required for the trials.

Access to these therapies will not only improve patient outcomes but will also have a positive impact on the healthcare system. This treatment is administered only once and offers prolonged remission, meaning patients can last several months or even years, without the need for additional treatment.

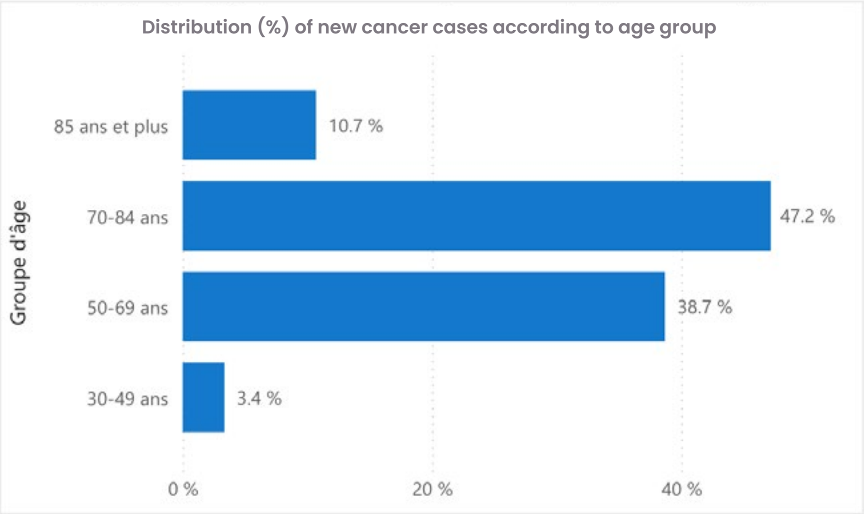
Conclusion — Our Vision for the Future

People with myeloma require comprehensive support to manage the many aspects of their disease and its treatment. More patients are being diagnosed with multiple myeloma each year, and more effective treatment options are prolonging their lives. This has resulted in an increase in prevalence— more people in Quebec are living longer with myeloma than ever before. Most new therapies for myeloma are very expensive, and in order to keep patients alive throughout subsequent lines of treatment, the healthcare system must be prepared to cope with rising costs. Cellular therapies developed in academic settings could help reduce the cost of these treatments, making them more widely available. We need to change the way we think about healthcare.

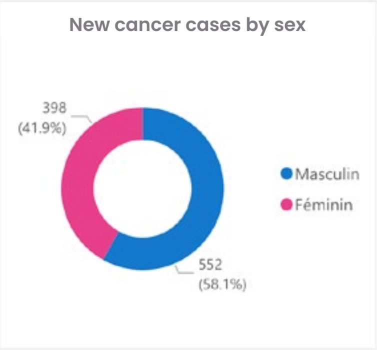
We've already written about what we want to see in the future, in our opinion piece in People with blood cancer manage science, bureaucracy – Toronto Star.

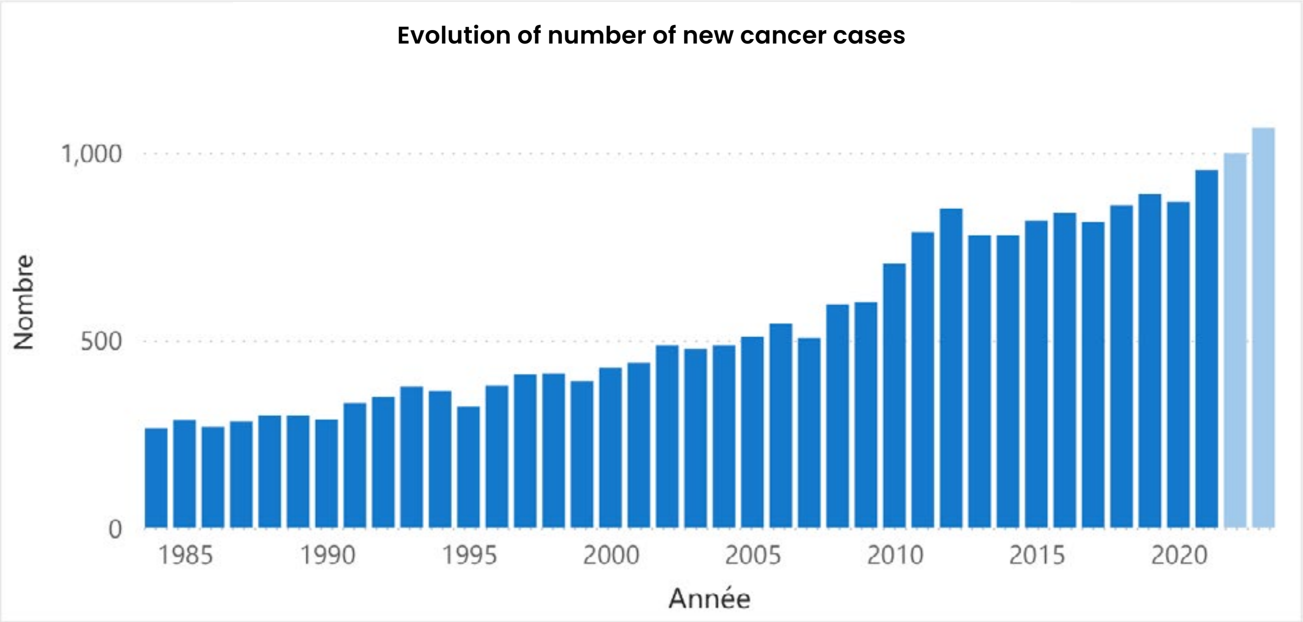
MYELOMA CANADA

Myeloma Statistics in Quebec

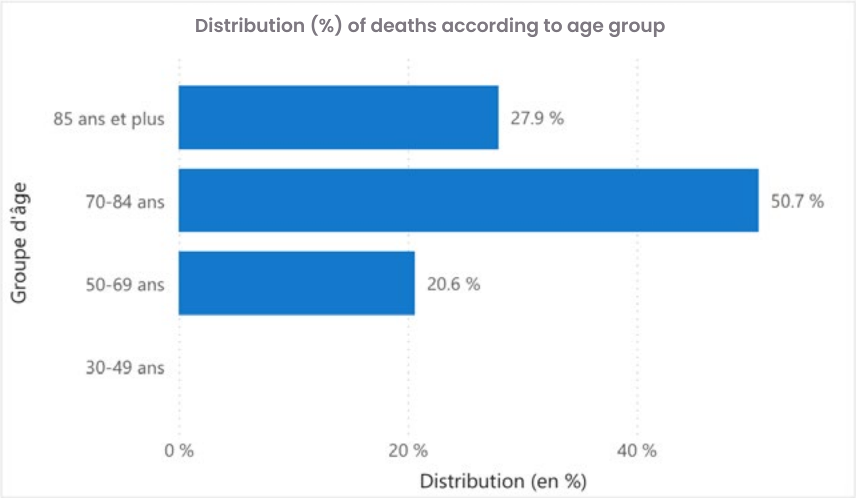

Distribution (%) of new cancer cases according to age group

New cancer cases
954

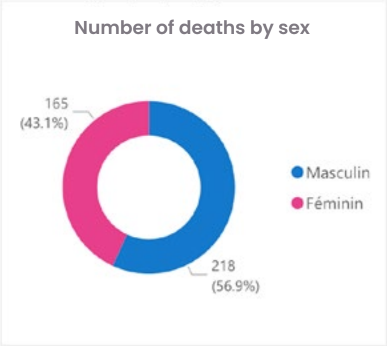

New cancer cases by sex

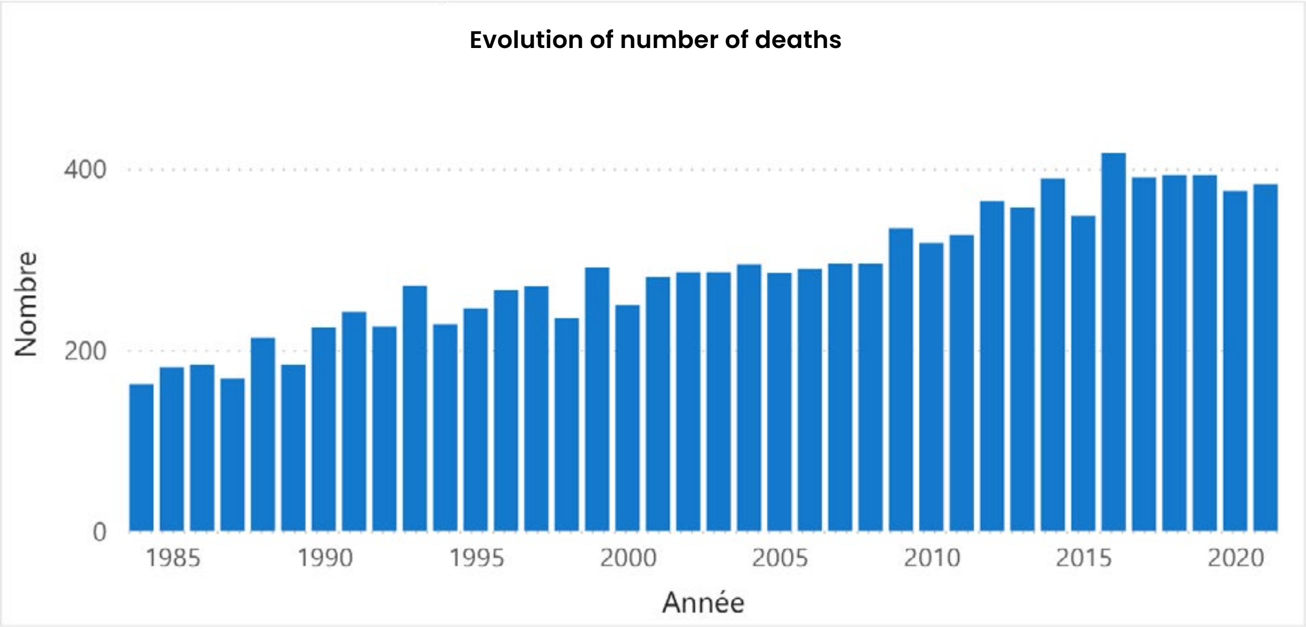

Evolution of number of new cancer cases

The graphics in this report are pulled from the dashboards of the Registre québécois du cancer, available exclusively in French.
The original data can be accessed here.


Distribution (%) of deaths according to age group

Number of deaths
383


Number of deaths by sex


Evolution of number of deaths

Brain Cancer

Recommendations by

braintumour
foundation
OF CANADA

Recommendations formulated in collaboration with:
Dr. David Fortin (and team)
Dr. James Rutka
Max Erenberg Patient partner

Introduction

Brain tumours can be classified as primary or secondary, as well as malignant or non-malignant (benign). Primary brain tumours originate in the brain, while secondary brain tumours occur when cancer spreads to the brain from another area of the body.

In children under the age of 18 years, malignant brain tumours account for 40% of all cases, while 60% of cases are considered non-malignant. Brain tumours can grow, however, and some may progress from a non-malignant to malignant diagnosis over time. The most common types of malignant brain tumours in children include medulloblastoma, high grade glioma (including diffuse intrinsic pontine glioma or DIPG, and diffuse midline glioma or DMG), ependymoma, germ-cell tumours, and embryonal tumours. The most common types of non-malignant brain tumours in children include low-grade glioma, craniopharyngioma, oligodendroglioma, and dysembryoplastic neuroepithelial tumour (DNET).

In adults, the vast majority of patients are diagnosed with a malignant brain tumour, with gliomas comprising approximately 81% of all malignant brain tumour diagnoses. The most common and aggressive malignant brain tumour diagnosis is glioblastoma (GBM), comprising almost 53% of all glioma diagnoses in Canada. A typical glial tumour such as GBM is driven by a minority of cancer stem cells which are highly resistant to conventional treatments, and are highly migratory, thereby invading and permeating other areas of the brain. In the last decade, advances in research on molecular markers and anomalies have improved our understanding of the disease, including modifications to the World Health Organization's classification of central nervous system tumours to update the grading scheme to improve accuracy in diagnosis.

The standard first-line treatment for GBM, called the Stupp protocol, involves an optimal surgical resection, followed by fractionated radiation with concomitant and adjuvant temozolomide (TMZ). With this treatment, the clinical median survival (OS) is 14.6 months, a modest improvement over the previous standard of radiotherapy as monotherapy (12.1 months). However, only a subset of patients respond to this therapeutic modality, while the majority of tumours relapse during treatment or shortly thereafter. As such, the reported progression free survival (PFS) is only 6.9 months.

The estimated incidence of adult glial tumours in Canada is about 6 per 100,000/population. GBM remains by far the most prevalent glial tumour, with an estimated incidence of about 3 per 100,000/population, representing 50% of all glial tumours. GBM is by and large considered one of the most aggressive cancer sites and is the pinnacle of the severity spectrum of this deadly disease.

GBM remains an incurable cancer characterized by systematic relapse and disease progression. At recurrence, there is no standard of care, and few therapeutical options are available since most chemotherapeutic drugs are incapable of crossing the blood-brain barrier (BBB), which lines the wall of the entire cerebral vascular network, rendering many treatments ineffective.

Context — Reality & Impact on the Quebec Population

Over 20% of all children in Canada diagnosed with a brain tumour live in Quebec, placing these children among some of the highest brain tumour incidence rates in the country. Quebec is also a leading province in adult glial tumour incidence rates, marked by an estimated 6.33 cases per 100,000/year, with approximately half of these being glioblastoma.

As the most common and fatal malignant brain tumour diagnosis in adults, GBM requires access to highly specialized care and treatment. Once the disease recurs, few options are available to patients. These cases should all be transferred to specialized facilities for evaluation, as many second or even third-line treatment options are administered in the context of clinical studies which are not offered at peripheral centers.

It is not infrequent to see patients that have been inadequately treated in first instance, due to the initial care being provided by a general practitioner or health care team not specialised in brain tumours. Because of the vast nature of the Quebec territory, general neurosurgeons will often be the first physician to take charge of these complex cases. However, in order to gain access to clinical trials and expert care, patients should be referred to a specialist as soon as the diagnosis is established at imaging. This disease's management is rapidly evolving due to the newly developing field of molecular diagnosis and targeted treatments. However, these new approaches are sometimes overlooked by first-line physicians, initially. Multi-disciplinary teams can be mobilized in these specialized centers to ensure maintenance of the continuum of care.

Regardless of age at diagnosis, brain tumours place an extremely heavy burden on the patient and their family. In addition to the emotional toll, families often require a plethora of supports along the disease continuum, especially in cases where patients experience physical and cognitive decline. In these circumstances, it can be extremely difficult for patients and families to maintain quality of life at home and may require residential supports or hospice. This transition period causes great stress for patients and their families as they navigate a continued decrease in patient functionality without adequate supports and services. Patients without adequate support systems such as family, friends, and community services are further at risk for poor health outcomes and decreased quality of life. It is critical that patients are encouraged to seek support from a variety of sources to help meet their unique needs and to help in navigating the challenges of a brain tumour diagnosis and treatment.

Stakeholders and priority populations in the brain tumour sphere include:

- Patients and families of all ages and backgrounds, including children, young adults, older adults and seniors
- Health Care Providers, including general practitioners, pediatricians, social workers, neuro-psychologists, rehabilitation specialists, and other allied health care providers
- Minority groups and underrepresented populations

Brain Tumour Foundation of Canada (BTFC) is a one of the most established stakeholders to be considered in terms of patient, family, and health care professional supports, research priorities, and education and information. Although a Canada-wide association, it is also well represented in Quebec.

Canadian Cancer Society is another major stakeholder, but with a more generalized approach leaning toward more prevalent cancers. Hence, specifically for brain cancers, BTFC is the preferred representative.

Existing and Missing Supports for Patients and Their Families

At diagnosis, patients are typically managed within the hospital system, as many cases often require a surgical procedure and monitored recovery. During this initial hospitalization period, a multidisciplinary team is deployed around the patient. Based on the patient's needs, health care teams could include rehabilitation specialists, social workers, psychotherapists, and others. These resources, although scarce, are available.

It is often found that when the patient must be discharged that there is a lack of intermediate home and community-based resources supporting the patients and families. We observe that, depending on the territory, services provided by CLSC are extremely variable from one region to another within the province. This heterogeneity in care coverage is sometimes difficult to accept as it produces a discernible difference in terms of quality of support. Consequently, such variability in the availability of off-site care directly impacts whether a patient can be sent back home or not. In cases when the patient must leave the hospital (acute care) but is insufficient to manage independently at home, patients are often left hanging, putting additional pressure on families.

Tertiary care would facilitate access to certain treatments that are not available otherwise. These approaches, although often expensive and not universally effective, can be extremely helpful for some. These tertiary care treatments should be accessible to the few specialized neuro-oncology teams across the province. Stakeholders including Brain Tumour Foundation of Canada are working tirelessly to advocate for timely and equitable access to brain tumour drugs and treatment for Canadian brain tumour patients.

Objectives to Aim For in Quebec to Reduce Incidence, Reduce Mortality & Better Support Patients

(Performance indicators to be measured over the next 10 years)

The population of patients afflicted by primary brain tumours can be divided in 2 different class: low and high grade.

For the low-grade tumour, the advent of new molecular targeting treatments (IDH inhibitor) should allow the postponing of radiation and chemotherapy, hence extending the progression free survival of patients significantly for many years. PFS, in this case, should be the main performance indicator.

For the high-grade tumour, the median survival (MS) is much shorter and should be the referenced performance indicator. A significant extension of the MS for glioblastoma, high-grade IDH-mutated astrocytomas (grade 3 and 4) and IDH-mutated anaplastic oligodendrogliomas should be pursued.

Short Term (1-2 years)

01. More information available along the treatment pathway so patients and families know what to expect and can better prepare.

02. More contact with allied health care professionals, including assistance with re-entry and supports at school and the workplace.

03. Frequent neuro-psychological assessments and monitoring.

04. Access to rehabilitation services throughout the disease trajectory (including pre-operative preparation and rehabilitation).

Performance indicators include:

- Determining and decreasing the morbidity and mortality of children and adults diagnosed with brain tumours in Quebec.
- Determining the neurological outcomes in children and adults diagnosed with pediatric brain tumours in Quebec.

Medium Term (3-5 years)

01. Evidence-informed diet and nutrition education and programming for adults and children.
02. Clinical trials in QC and across the country for pediatrics and adults
    - Potential to partner with the Pediatric Brain Tumour Consortium (could become part of these clinical trials groups in the US or internationally through SIOP)
03. Limiting exposure to radiation therapy, especially in children (in cases where radiation is required, a reduced dose is recommended to limit negative impacts on the developing brain).
04. Optimizing treatment, based on the molecular genetic variations in each patient, including referring patients to a centre that specializes in brain tumour care.
    - The province of Quebec may have the opportunity to invest in proton beam therapy (PBT) to facilitate the administration of more targeted doses of radiation therapy or combination therapies that improve quality of life and overall survival.

Performance indicators include:

- Demonstration of a reduction in morbidity and mortality of children and adults diagnosed with a brain tumour.
- Increasing the use of novel technologies to treat children with brain tumours.
- Increasing the percentage of children placed on ongoing, active clinical protocols.

Long Term (6-10 years)

Improved and updated brain tumour data collection; corroboration with data previously collected through brain tumour or cancer registries to identify trends.

Performance indicators include:

- A reduction in the incidence of both pediatric and adult brain tumours.
- Adaptation of novel radiation delivery strategies (e.g. proton beam therapy).
- Personalized, targeted therapy for all patients with brain tumours.

Conclusion — Our Vision for the Future

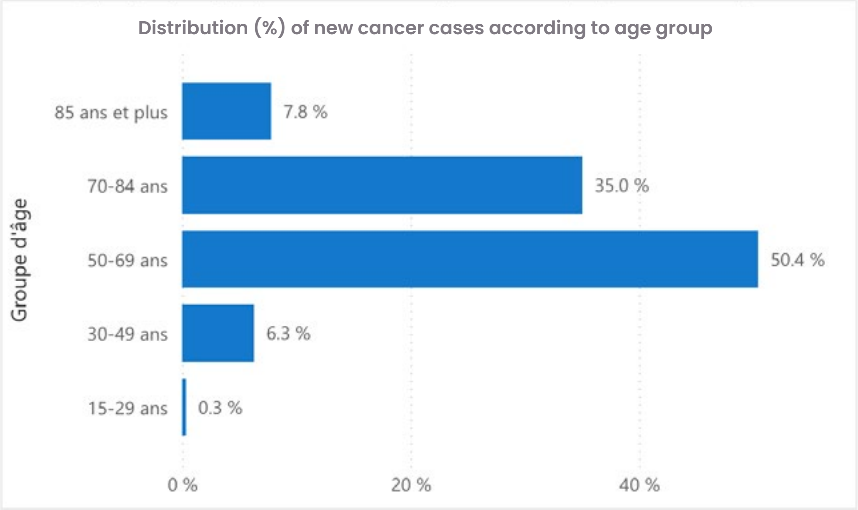
We envision long term goals to include clinical protocol-driven treatment of all cases, the adaptation of advances in neuro-imaging to make a more timely diagnosis of brain tumours, the use of novel technologies (e.g. laser interstitial ablation, MR-guided focused ultrasound, convection enhanced delivery of targeted chemotherapy or immunotherapy) to enhance the extent of resection of brain tumours where indicated using minimally invasive surgery techniques, and improvement in patient transitions from pediatric to adult hospital settings after children reach age 18.

Additionally, future improvement in the care of these patients must include a consolidation in their care. Patients should be treated in specialized integrated centers dedicated to neuro-oncology care, with concentrated tertiary expertise and improved access to specialized high-end treatments and research approaches. Quality of life is at the forefront of the tertiary treatment team's priorities whenever treating these patients, as they are more informed and are better equipped to assist in maximizing quality of life. As the disease is incurable, a significant number of these patients should also be considered for clinical studies, which will be easily achieved in the context of centralized and specialized care in integrated centers. It is also important to grant access to tertiary care available in other countries to these specialized teams that will be better equipped to select the patients that are more susceptible to benefit from these expensive approaches.

We envision a future where a brain tumour is not a life-limiting disease, for anyone, anywhere, regardless of diagnosis or demographics.

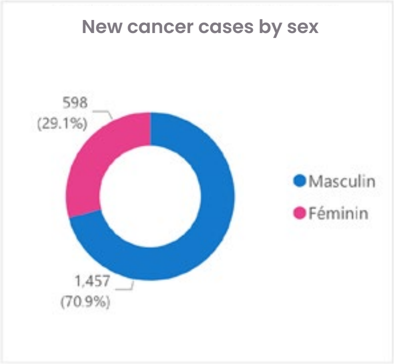
braintumour foundation OF CANADA

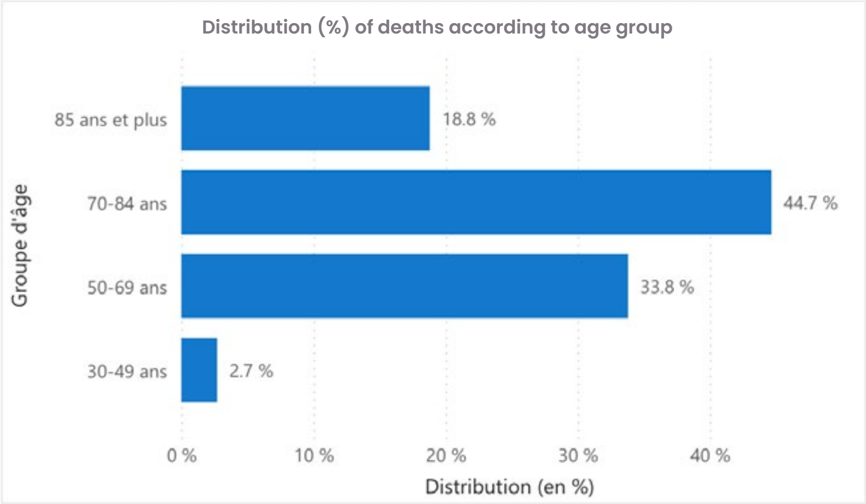
Brain Cancer Statistics in Quebec



New cancer cases

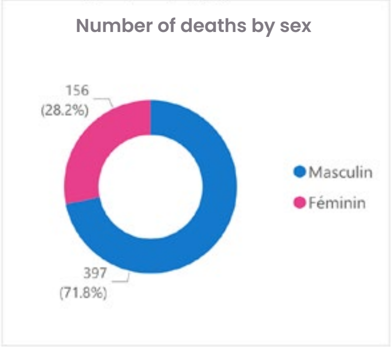
2,067

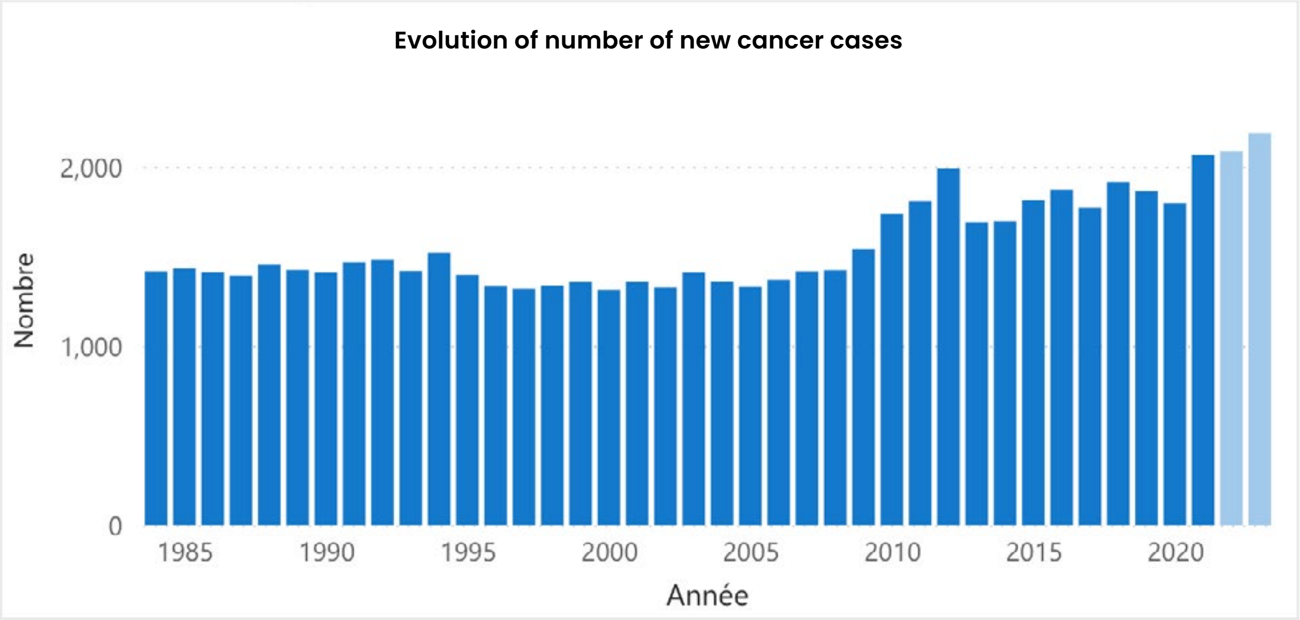


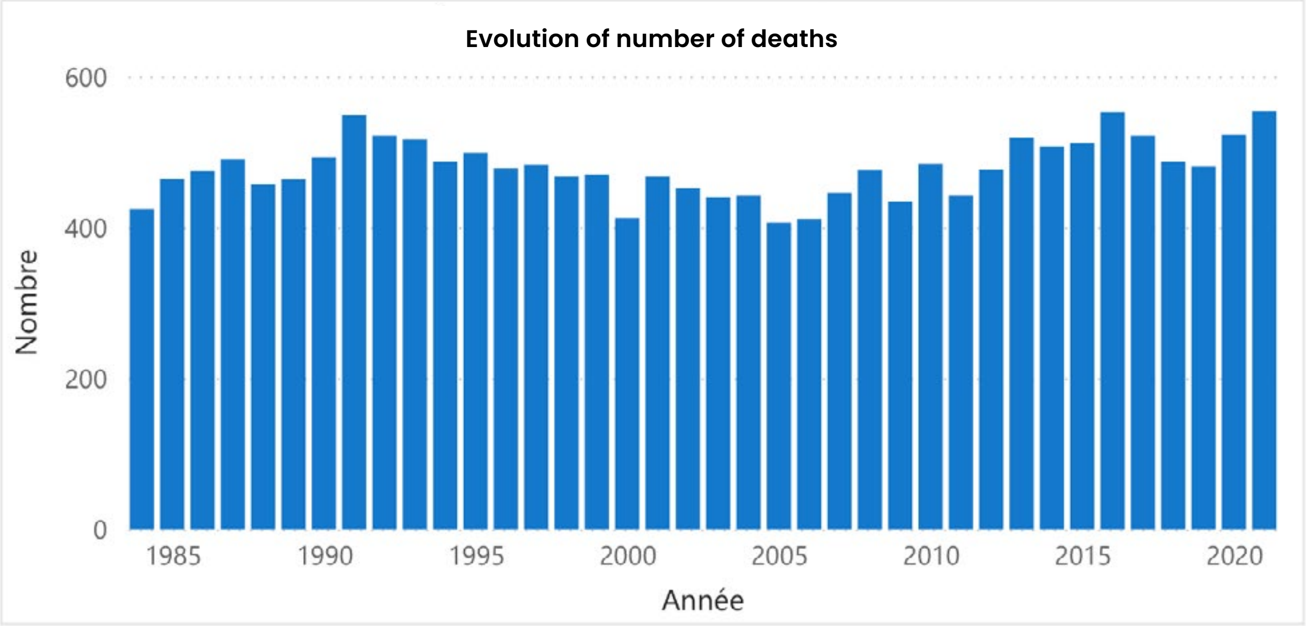


Number of deaths

553







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Ovarian Cancer

Recommendations by

OVARIAN CANCER CANADA

Introduction

Ovarian cancer is the most fatal women's cancer, with a five-year survival rate of only 44%. This means that of the eight women a day who are diagnosed with ovarian cancer in Canada only four will survive five years. **In Quebec, it is projected that in 2024, there will be 670 new diagnoses and 470 deaths.**

There are no screening or diagnostic tests available for ovarian cancer and there is no vaccine to prevent it either. The Pap test does not screen for ovarian cancer. Symptoms are non-specific (e.g., bloating, abdominal pain/discomfort, urinary symptoms, changes in bowel habits) and diagnostic pathways and tools are limited making timely diagnosis extremely challenging.

Ovarian cancer is not one disease, **it is a group of diseases** that are broadly classified according to which type of ovarian cell they start from (epithelial, germ, or stromal). Each of these types of cells may develop into a different type of tumour. This makes the path to scientific discoveries and improved treatments particularly complex.

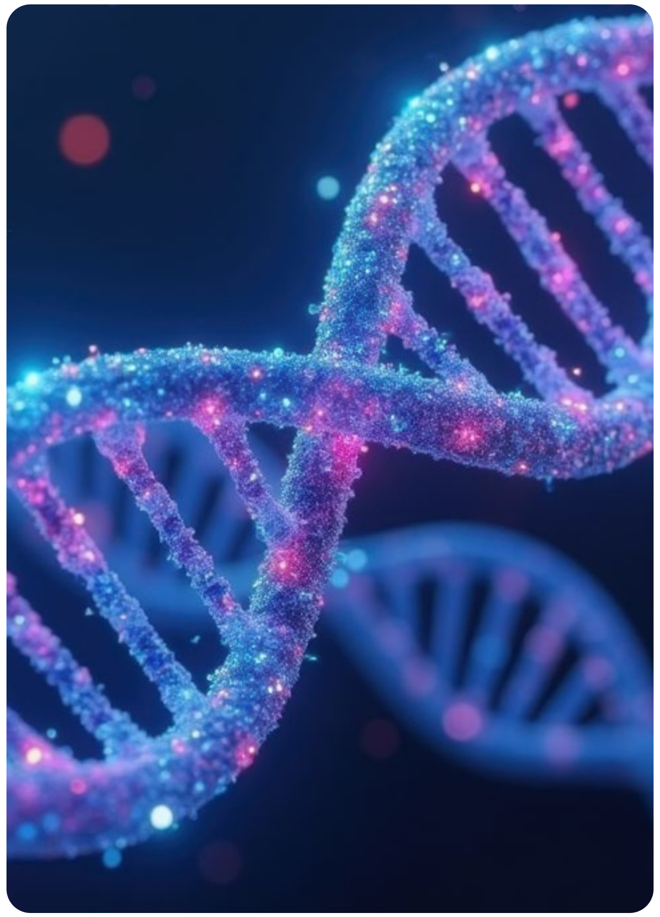
The most common genetic mutations associated with ovarian cancer are in the BRCA1 or BRCA2 genes. These mutations are more common among certain ethnic groups. For instance, those of Ashkenazi Jewish descent, **French-Canadian descent,** or Icelandic/Dutch descent **have an increased risk for ovarian cancer.** The only way to know for sure is to pursue genetic testing.

With very few exceptions, available treatments have not changed significantly since the 1990s. For the **3,000 Canadians diagnosed with ovarian cancer this year,** they will be treated with the same methods, surgery and chemotherapy, and unfortunately these methods are not successful in most patients.

Associated Cancer Types

Associated cancer types include breast, prostate, pancreatic, uterine and colorectal cancer.

If an individual has a family history of the above listed cancer types on their biological mother's or father's side of the family, there is a possibility of a genetic mutation being passed from generation to generation.



Context — Reality & Impact on the Quebec Population

Prevention

Without an effective screening test, **preventing ovarian cancer before it starts is the best chance to save lives now.** With an estimated one in five ovarian cancer cases being linked to inherited genetic mutations, prior knowledge of a mutation can help patients in Quebec take preventative action.

Genetic testing for patients: Gynecologic oncologists should conduct reflex somatic genetic testing to all ovarian cancer patients at the time of diagnosis. **They should be tested for the full panel of ovarian cancer risk genes:** BRCA1, BRCA2, Lynch Syndrome, RAD51C, RAD51D, BRIP1, PALB2. Subsequently germline testing should be conducted when appropriate.

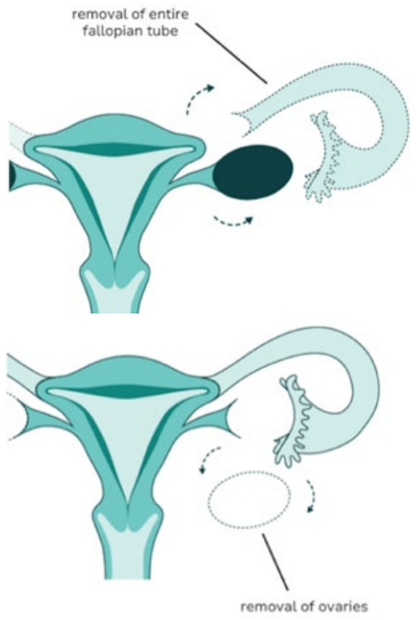
This means that every ovarian cancer patient in Quebec should have their tumour tested to see if there is a mutation in the tumour itself (somatic mutation) and if the result is positive, they should receive a blood test to determine if the mutation is limited to the tumour or inherited from the patient's mother or father (germline mutation).

Identifying a patient's mutation status as soon as possible is vital so that appropriate clinical recommendations can be made to prevent ovarian cancer in her relatives.

Genetic testing for first degree relatives of patients with an ovarian cancer genetic mutation: First degree relatives of patients with an inherited germline mutation should be offered genetic testing so it can be determined if they have inherited the same genetic mutation that increases their risk of ovarian and consider preventative surgery (risk-reducing salpingo-oopherectomy) to stop ovarian cancer before it starts.

Genetic Mutation	Estimated Lifetime Risk of Ovarian Cancer	Recommended Age for RRSO
BRCA 1	39-44% by age 70	35-40 years
BRCA 2	11-18% by age 70	40-45 years
Lynch Syndrome	10-20% by age 70	Timing individualized
RAD51C, RAD51D	11-13% by age 80	Consider at 45-50 years
BRIP1	5-15% by age 80	Consider at 45-50 years
PALB2	3-5% by age 80	Based on family history or >45 years

Risk-Reducing Salpingo-Oophorectomy (RRSO)



This diagram shows the risk reducing surgery for ovarian cancer, which includes the removal of both ovaries and both fallopian tubes. This is called a risk-reducing salpingo-oophorectomy. The reason that the fallopian tubes are also removed is because the most common type of ovarian cancer – which is also the most deadly type – actually originates in the fallopian tubes, not the ovaries.

Genetic testing for those with a family history of certain cancers: Patients with a family history of certain cancers: breast, uterine, colorectal and ovarian have an increased risk of inheriting a genetic mutation that increases their risk of developing these cancers. However, there is a lack of discussion on family history between primary care physicians and patients and **physicians do not always refer patients to genetics counseling and testing when appropriate.** These patients miss out on the opportunity to pursue preventative measures.

Further, there are inconsistency across Quebec regarding genetic testing criteria and wait-times for genetics counseling and testing. In 2019, OCC sent a survey to genetics counsellors at clinics offering cancer genetics services. **Five clinics were in Quebec where some of the longest wait times were reported.** When asked the wait-times for genetic counselling/testing in relatives of women with ovarian cancer. Responses from the five Quebec clinics were: 6-9 months; approximately 2 years; >2 years; 3-4 years; and **one simply responded: "Forever".**

Ovarian Cancer Prevention Task Force

Ovarian Cancer Canada has established the Ovarian Cancer Prevention Task Force (OCPTF) by convening leading experts from across Canada to optimize the pathway to ovarian cancer prevention, emphasizing the critical role of the family physician. The OCPTF has developed two knowledge mobilization resources (available for download here) to support ovarian cancer prevention in the primary care setting, including a one-page handout on how to assess patient risk of ovarian cancer and the associated referral pathways, and a waiting room poster for patients that can be posted by clinic staff.

Diagnosis

In 2022, Ovarian Cancer Canada published the Canadian edition of the Every Woman Study. We received a total of 557 responses from ovarian cancer patients and survivors across Canada, 100 responses were from Quebec.

Quebec compares similarly to the rest of Canada with 85% having experienced at least one ovarian cancer symptom prior to consulting a healthcare provider. However, there were concerning variations in care for respondents in Quebec regarding seeking help for those symptoms and ultimately receiving a diagnosis.

Quebec showed the highest percentage of ER /urgent care consultation in the country and were more likely to be diagnosed with late-stage disease.

- 68% of respondents in Quebec were diagnosed with late-stage disease compared to 59% in the rest of Canada.
- Only 52% of respondents in Quebec consulted a family doctor for their symptom(s) compared to 71% of respondents in other provinces.
- While 35% reported going directly to an ER or Urgent Care setting versus 21% of respondents from other provinces.

Regarding time to diagnosis, 36% of respondents from Quebec were diagnosed in under a month following their first consultations with a healthcare provider, compared to 40% in the rest of Canada. While the short time to diagnosis may seem positive at first glance, respondents diagnosed within a month were 2.5 times more likely to have been diagnosed at late stage.

The third significant finding from Quebec is that **21% of respondents reported that no tests were ordered, and no referral was made by their first healthcare providers** in response to their ovarian cancer symptoms compared to 15% in the rest of Canada, a slightly elevated rate.

Treatment

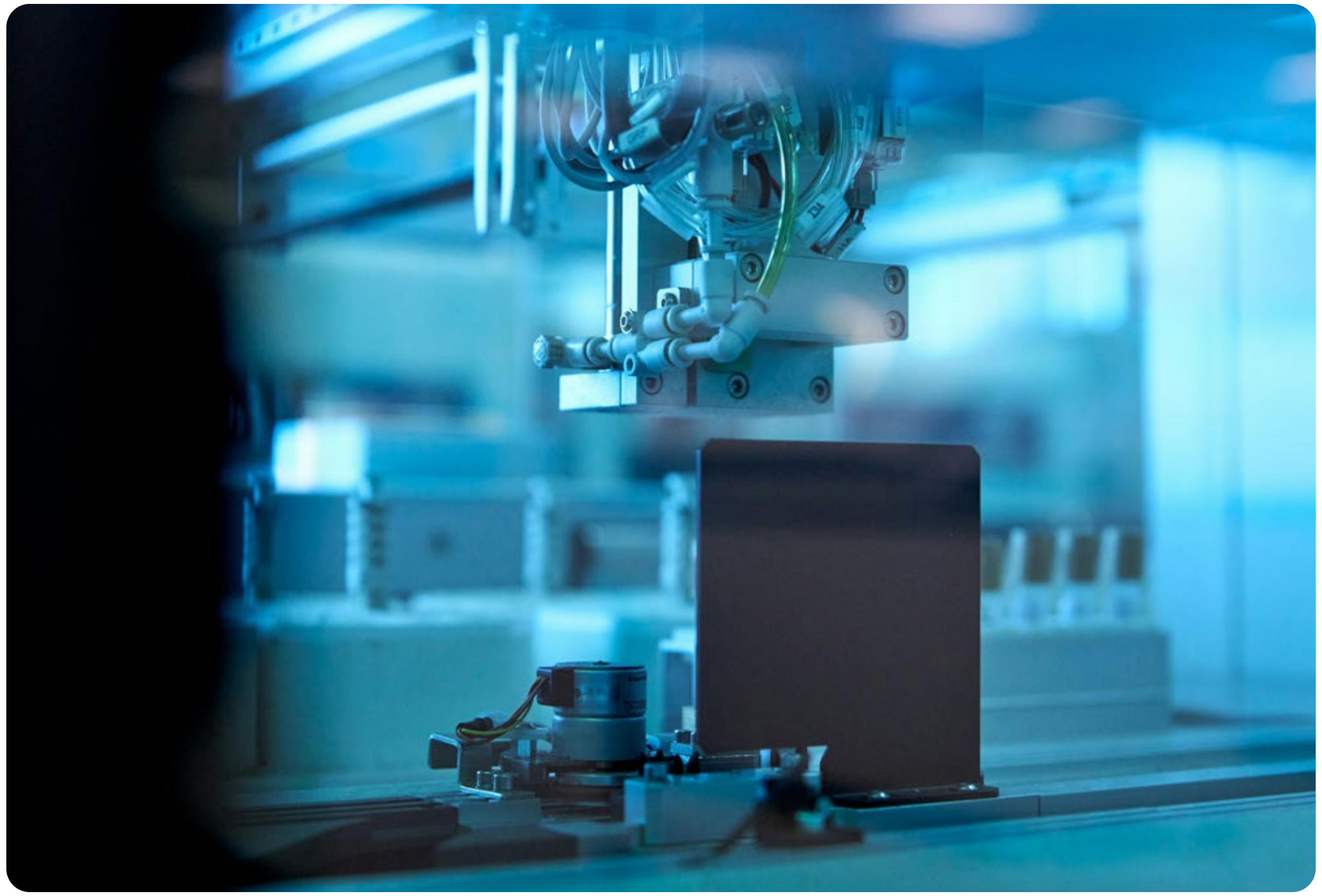
Once diagnosed, standard first-line treatment for most ovarian cancer patients remains cyto-reductive surgery in combination with platinum- and taxane-based chemotherapy. While most patients respond well to chemotherapy initially, most women are diagnosed in stage three or four and develop resistance, eventually succumbing to their disease.

If we want survival outcomes to improve, we must invest in research that will lead to effective treatments.

Drug & Testing Access

Patients must have timely access to ovarian cancer drugs when they become available in Canada. For patients with high-grade serous or endometrioid epithelial ovarian cancer which has low survival rates and limited treatment options, tools such as homologous recombination deficiency (HRD) testing have the potential to help clinicians and patients evaluate potential risks and benefits and "assess the value of pursuing treatment".

We believe that HRD testing has the potential to help inform patients as they weigh the pros and cons of taking a drug that shows variation of progressive free survival depending on BRCA, HRD, and high-risk population status. However, patients should not be denied access to treatments based on results of their HRD testing.



Stakeholders to Consider & Priority Populations

Stakeholders

- Physicians: family doctors, obstetricians/gynecologists, gynecological oncologists, medical oncologists
- Genetic counsellors
- Nurse Practitioners
- Nurses
- Researchers
- Patients
- Provincial and Federal Governments
- Provincial Medical Associations and Provincial Cancer Agencies
  - RGOQ - Regroupement des Gynécologues Oncologues du Québec
  - ROCO - Le Regroupement des organisations communautaires en oncologie
  - AQIO - l'Association québécoise des infirmières en oncologie
- Pharmaceutical Companies

Priority Populations

- Women
- Women living with ovarian cancer/survivors
- Women at increases risk for ovarian cancer/previvors
- Women at average risk for ovarian cancer
- Women with breast cancer
- Trans men and non-binary people born with ovaries
- Patients with an ovarian cancer diagnosis
- Individuals with the BRCA1 or BRCA2 genes.
- Individuals of certain ethnic groups that have an increased risk for ovarian cancer:
  - Those of Ashkenazi Jewish descent,
  - **French-Canadian descent,** or
  - Icelandic/Dutch descent
- Individuals with Lynch Syndrome, also known as hereditary nonpolyposis colorectal cancer (HNPCC)
  - This is an inherited condition that puts people at increased risk for certain types of cancer at a younger age, including but not limited to ovarian, colorectal, and uterine cancers.

Existing and Missing Supports for Patients and Their Families

Ovarian Cancer Canada offers a variety of support programs.

Patient Resource Guide

'Understanding ovarian cancer: A comprehensive patient guide' that has been developed by Ovarian Cancer Canada and a team of experts to support and inform those affected by ovarian cancer. This guide offers reliable, evidence-informed information about ovarian cancer.

This book is available in both hard copy and digital form, in both English and French. To order your free copy, you can scan the QR code.

Self-advocacy Tools

Ovarian Cancer Canada has created self-advocacy tools to support people in their interactions with healthcare providers about ovarian cancer. These tools were co-created in collaboration with our clinical, research and patient partners and intend to fill important gaps.

"Understand Your Risk" Tool: This tool is a digital, interactive, and personalized, and allows for two separate user journeys – a journey for people that are worried they have ovarian cancer right now, and a journey for people that are worried about their risk of developing ovarian cancer in the future. Users are supported in identifying any relevant risk factors, family history, and/or symptoms. Users are also encouraged to consider their needs related to health equity and access and are provided with conversation prompts depending on what their equity needs are. The tool can be accessed here.

Clinical Trials Tool: One of the most common questions Ovarian Cancer Canada received from women in our community is about how to find clinical trials that they may be eligible for. This is because there are so few effective long term treatment options, particularly for those who are platinum resistant. We developed a tool to help women and their families have effective conversations with their oncology teams about clinical trials. The tool can be accessed here.

Support Programs

OVdialogue: Ovarian Cancer Canada's peer support online forum available in both French and English. An active and vibrant community accessible 24/7 where people with ovarian cancer can connect to share information, experiences, and provide support and encouragement for each other.

Les Thé Turquoise: a time for connection and conversation, where women with ovarian cancer can share their stories and learn from one another. They are small group gatherings that take place entirely online, available in both French and English.

One-on-One Peer Support Matching Program: allows those diagnosed with ovarian cancer to connect with others who understand what they are going through. This program can help those newly diagnosed or those who have been living with the disease. Peer Support is available in both French and English. Those diagnosed with ovarian cancer have the opportunity to meet privately with a specially trained Ovarian Cancer Peer Support Volunteer who has also experienced ovarian cancer and knows what they are going through. They meet by telephone or via video conferencing.

Ovarian Cancer Support Group: is a professionally led virtual support group that meet weekly for six weeks. Participants explore relevant themes, including coping with change and have an opportunity to share within and build a community of support.

Ovarian Cancer Support Circle: is a professionally led virtual support group that meets monthly, it is available in both French and English. This is an 'open' group, meaning participants are welcome to join as they are able.

Under the leadership of a healthcare professional, this group provides a community of support to discuss relevant issues such as relationships, sexuality, side effects, anxiety, fertility and other challenges of living with ovarian cancer.

Speaker Series

The Ovarian Cancer Canada Speaker Series features experts from across the country discussing a wide range of topics for women living with ovarian cancer and their families and friends. They are available in both French and English. Examples of topics include genetic testing, managing fear of cancer recurrence, getting to know your oncology pharmacists etc.

In addition to the supports listed above, as the only national charity dedicated to overcoming ovarian cancer, the team at Ovarian Cancer Canada stands shoulder to shoulder with the community affected and we are determined to help save lives. The Ovarian Cancer Canada team spans across Canada and are an available resource.

Missing Supports

Reaching Patients

Ovarian Cancer Canada provides resources and supports for those impacted by ovarian cancer, the challenge is **reaching patients when they need it most** so they can access the resources they need.

Ovarian Cancer Canada welcomes the opportunity to work with the Quebec Government to determine how patients in the province can be made aware of patient organizations and the role they play in their care.

Clinical Trials

An ongoing request from the ovarian cancer patient community is assistance in finding clinical trials for which they are eligible. Clinical trials help connect individuals with new and emerging treatments while ensuring utmost safety and as little risk as possible to participants.

While Ovarian Cancer Canada provides clinical trial content on several pages of our website, a self-advocacy tool, and a chapter in our patient guide patients want individualized assistance and guidance from clinical experts who can connect them with trials both in the local cancer centre and beyond.

Diagnostic Pathway

The Quebec Government does not have an ovarian cancer diagnostic pathway publicly available for patients and clinicians.

Objectives to Aim For in Quebec to Reduce Incidence, Reduce Mortality & Better Support Patients (Performance indicators to be measured over the next 10 years)

Short Term (1-2 years)

01. Patients at risk of an inherited mutation receive timely and optimal genetic counseling and testing.
02. Primary care providers understand their role in ovarian cancer prevention and have effective conversations about risk with those at risk of the disease.
03. The Quebec government has a publicly accessible ovarian cancer diagnostic pathway and patients receive a timely diagnosis.
04. Ovarian cancer patients are informed of the clinical trials for which they are eligible.
05. Patients with high-grade serous or endometrioid epithelial ovarian cancer have access to HRD testing to evaluate potential risks and benefits and "assess the value of pursuing treatment".
06. The Quebec government meets with Ovarian Cancer Canada to discuss investments in ovarian cancer research.

Medium Term (3-5 years)

01. There is no longer inconsistency across the province regarding genetic testing criteria and wait-times for genetics counseling and testing have improved.
02. Increased uptake in prevention opportunities: genetic testing and risk reducing surgery.
03. There is a significant decrease in ovarian cancer patients being seen by an ER or urgent care as their first provider (increase in timely diagnosis starting in the primary care setting vs. acute cases presenting at ERs/urgent care).
04. Ovarian cancer patients are offered and participating in more clinical trials for which they are eligible.
05. Continued and consistent ovarian cancer research investments made by the Quebec government.

Long Term (6-10 years)

01. Continued and steady uptake in prevention opportunities: genetic testing and risk reducing surgery.
02. Family doctors are making appropriate referrals to genetic counselling and testing when a patient comes to them with ovarian cancer symptoms, the ER or urgent care is no longer the first provider.
03. Ovarian cancer patients no longer have to seek out information on clinical trials they are eligible for because this information is readily available to them at their cancer centres.
04. Ovarian cancer patients receive timely access to available tests and treatments.
05. Continued and consistent ovarian cancer research investments made by the Quebec government.

Conclusion — Our Vision for the Future

A future where ovarian cancer is preventable, curable, and **ultimately eradicated.**

Ovarian Cancer is a **top-of-mind issue** in Quebec and across the country where the voice of the ovarian cancer community is heard.

This is achieved through:

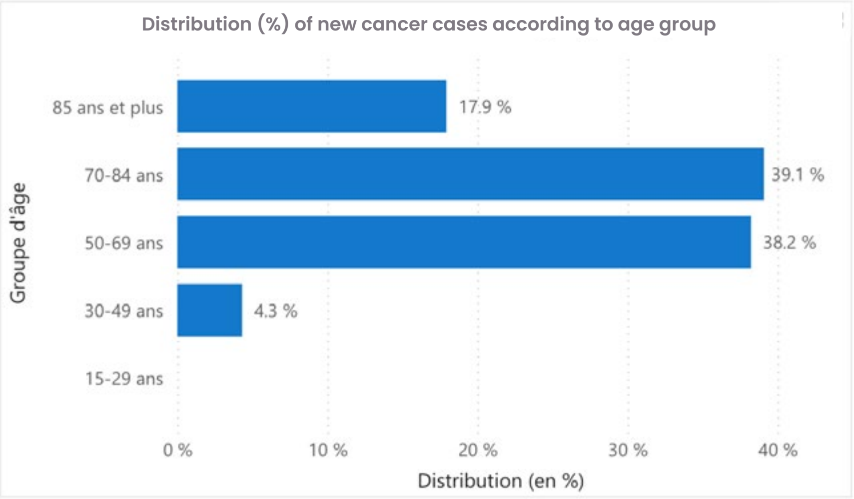
- **Preventing ovarian cancer before it starts,** is the best chance to save lives. Patients in Quebec are aware of their inherited genetic mutations so they can take preventative action.
- Patients receiving a **timely diagnosis** and have **access to treatments.**
- **Improving patient outcomes** through scientific discoveries and research breakthroughs.

Ovarian Cancer Canada stands hand-in-hand with the people experiencing, affected by, or at risk of the disease. **We will not rest** until women are able to live their lives freely, fully, and uninhibited by ovarian cancer.

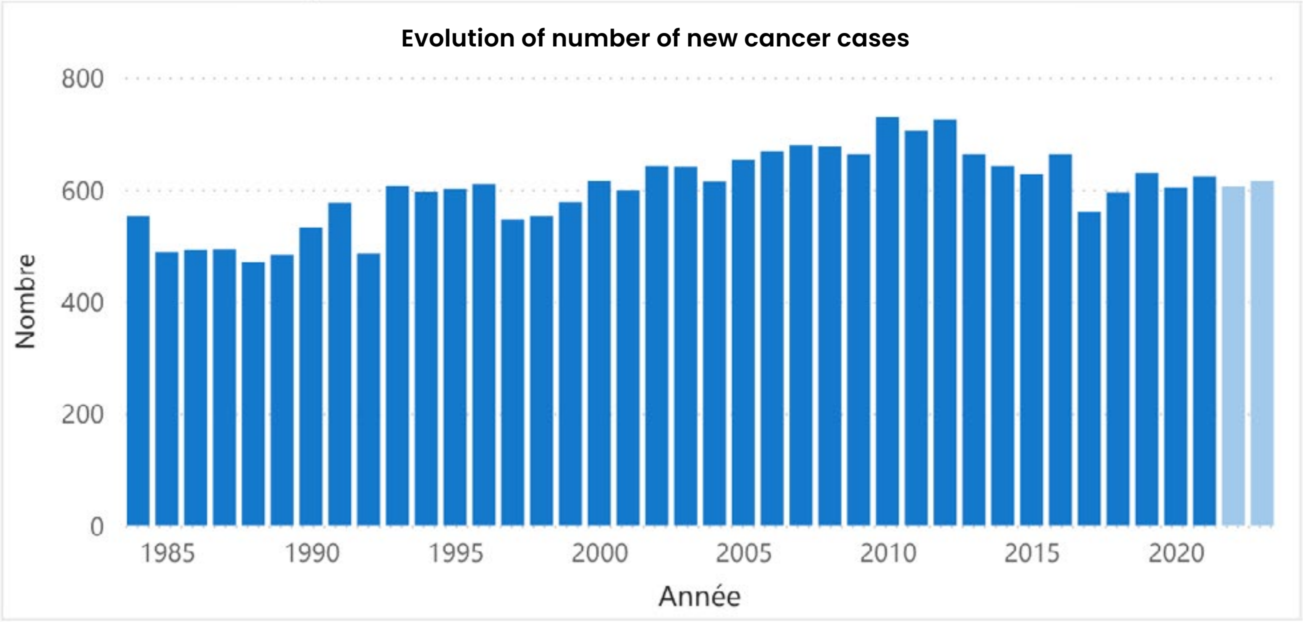
We will continue to take action against ovarian cancer until the number of deaths from this disease is **zero.**

OVARIAN CANCER CANADA

Ovarian Cancer Statistics in Quebec



New cancer cases
623



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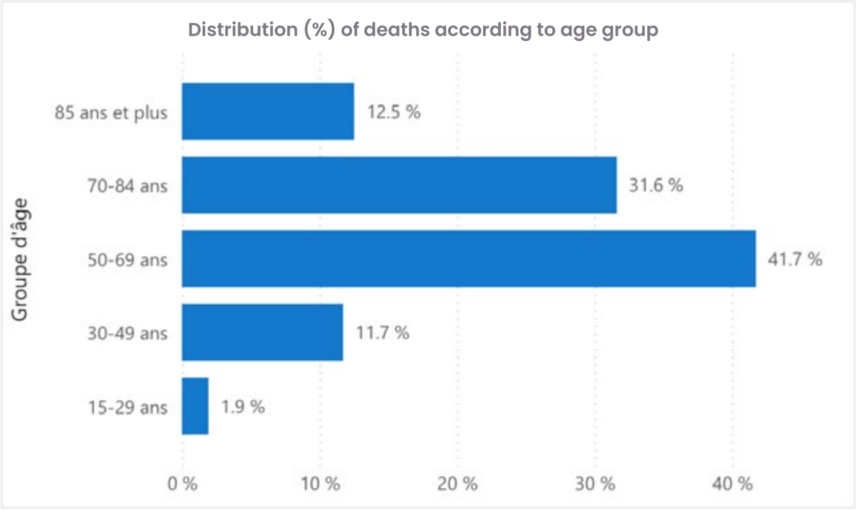
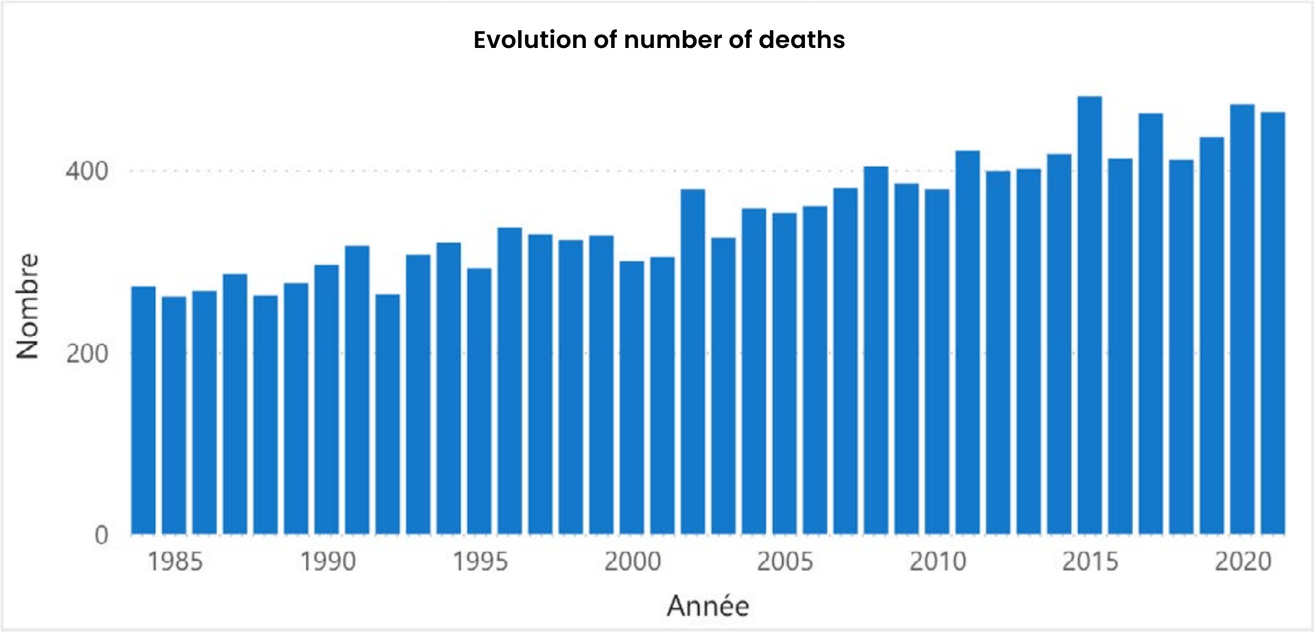


Number of deaths
463



Cervical Cancer

& Other HPV-Related Cancers

Recommendations by

hpv global action
vph action globale

Introduction

Abbreviations

HPV: Human papillomavirus

STI: Sexually transmitted infection

NPO : Non-profit organization

WHO: World Health Organization

Context

Human papillomavirus (HPV) infections are the most common sexually transmitted infections (STI) in the world. Over 80% of the global population will be infected with at least one HPV genotype in their lifetime. The virus is transmitted through sexual contact—via fingers, mouth, or other body parts—even without oral, vaginal, or anal penetration. Although condoms provide effective protection against most STIs and unintended pregnancies, and against HPV in general, they do not cover all genital, anal, and oral surfaces, and therefore do not fully protect against HPV.

HPV causes 9 different types of cancer: cancers of the tonsils and vocal cords, tongue, throat, anus, cervix, vulva, vagina, and penis. Each year in Quebec, 290 new cases of cervical cancer are diagnosed, and 50% of these diagnoses occur in individuals under the age of 50. HPV is the necessary cause of cervical cancer and is present in 40–90% of other anogenital cancers (vagina, vulva, penis, and anus), as well as up to 80% of oropharyngeal cancers.

A high-coverage HPV vaccination program, province-wide standardized screening using the HPV test, and equitable, inclusive policies could eliminate cervical cancer in Quebec. Future policies must aim for a 90% HPV vaccination rate among those under 18, and a 90% screening rate among people with a cervix, using the HPV test.

Context — Reality & Impact on the Quebec Population

Cervical cancer is the only cancer that can be eliminated through vaccination and screening. It is caused by persistent infection with certain high-risk genotypes of HPV. Unlike most cancers, its progression from HPV infection to cancer is slow—often taking 10 to 20 years—allowing for preventive action through screening and vaccination.

The WHO's global strategy to eliminate cervical cancer as a public health problem sets out three main goals for 2030:

- 90% of girls fully vaccinated with the HPV vaccine by age 15
- 70% of women screened using a high-performance test by age 35, and again by age 45
- 90% of women with precancer or cancer receive treatment

These goals have been endorsed by Canada and must be adopted in full by Quebec.

Stakeholders to Consider & Priority Populations

Priority Populations

Eliminating HPV-related cancers requires reducing inequalities in access to healthcare. The following groups, which have historically faced persistent disparities within the Quebec healthcare system and beyond, must be prioritized in this effort.

Socially Vulnerable Populations

First Nations, Inuit, and Métis populations have higher-than-average incidence and prevalence rates of HPV infection. Promoting reconciliation, building trust, and ensuring adequate representation are essential steps in reducing these rates. It is important to highlight that these communities are already leading initiatives to overcome historical barriers and improve the prevention and care of cervical cancer.

HPV incidence and related cancers are also higher among certain populations in Quebec, including people with low income, immigrants and refugees, at-risk youth, and LGBTQ2S+ individuals. It is crucial to fight misinformation, inequality, and barriers to healthcare access. Tailored information, developed by community-based non-profit organizations, must be made available to raise awareness of HPV-related risks and promote the benefits of HPV vaccination.

Rural and Remote Populations

Geographic barriers limit access to screening and vaccination. The deployment of mobile clinics, including for self-screening, could help better serve these populations.

Medically Vulnerable Populations

People with high-grade cervical lesions are at increased risk of recurrence or of developing lesions at other anatomical sites. Administering HPV vaccination directly in colposcopy clinics could maximize treatment effectiveness and improve access for patients already under medical follow-up.

Additionally, it is necessary to invest in the vaccination of underserved populations, ensuring that those not covered by current programs can also benefit from this protection.

Existing and Missing Supports for Patients and Their Families

Lack of Resources

The resources currently available to support patients and their loved ones are often insufficient. In particular, there is a notable lack of alternative resources, such as community-based HPV screening, self-sampling kits available in pharmacies, or online-accessible options. Furthermore, hospitalized individuals do not systematically have access to HPV screening or vaccination during their hospital stay. This lack of screening and vaccination options constitutes a major barrier to comprehensive and effective care.

Post-Treatment Action Plan

It is essential to implement a post-treatment action plan for every patient, including detailed follow-up and recommendations for mental health support, as well as consultations with various professionals such as a psychologist, social worker, nutritionist, sexologist, and kinesiologist. Each patient should receive clear information on how to access these supports, including contact details to book appointments. Pivot nurses or other care coordinators should take the time to explain the importance of these services to ensure holistic and continuous care.

Patient testimonials underscore the importance of this support. For example, one patient shared their experience:

"As a patient, my most confusing moment was literally after the treatment ended. I didn't know what to expect, how to cope, how to handle the fear of the cancer coming back. I felt in limbo. I needed resources, and it would have helped if an action plan had been provided to help me navigate the post-treatment period. For instance: I had no idea about hormone replacement therapy after treatment, but I only knew to ask because I was in a cervical cancer Facebook group where other women were talking about it. That's when I asked my doctor, and she prescribed the medication. I also initiated a bone scan request—again, because it was discussed in the Facebook group—and that's how I discovered I had osteoporosis and osteopenia in my spine and hips (due to radiation). So maybe a checklist should be created to cover the most common side effects of surgery, chemotherapy, radiation? Post-treatment care is just as important as cancer treatment itself."

Another example concerns patients with head and neck cancers, who experience high rates of depression and suicide. These cancers severely affect function and quality of life (especially appearance and the ability to eat), often leading to lasting disability, severe anxiety, and increased suicide risk. Yet most patients do not have access to adequate psychosocial support.

These examples highlight the need for comprehensive and continuous support for patients after treatment. Supportive care must go beyond medical treatment to include thorough follow-up and mental health services to improve patients' quality of life and help them navigate the post-treatment period.

Objectives to Aim For in Quebec to Reduce Incidence, Reduce Mortality & Better Support Patients (Performance indicators to be measured over the next 10 years)

Strategic Objectives

Vaccination

Objective 1: Achieve a 90% HPV vaccination rate among youth under 18 by 2030

Strategy 1: Strengthen school-based vaccination programs

Include cohorts missed during the pandemic by integrating HPV vaccination into the existing online booking portal used for COVID-19 vaccinations. This approach will facilitate access for parents and guardians and optimize existing infrastructure. Integrating this option could also reduce costs—an estimated $2,225 per vaccinated person—by combining avoided medical and indirect costs.

Strategy 2: Deploy mobile vaccination clinics

Launch mobile clinics in rural and remote areas to ensure equitable access to HPV vaccination.

Strategy 3: Provide free and accessible vaccination for vulnerable populations

The biggest barrier to eliminating HPV-related cancers is population-wide vaccine coverage. It is crucial to better target at-risk populations rather than increasing coverage in already well-covered groups. The most vulnerable—such as people who are homeless, Indigenous, refugees/immigrants, those with mental health issues, cancer, or who are immunocompromised—have the lowest coverage levels. There must be a better strategy to increase vaccination in these groups.

Strategy 4: Implement a "once eligible, always eligible" vaccination policy

Individuals who did not receive the publicly covered vaccine when it was first recommended should remain eligible to receive it later.

Strategy 5: Improve education and access to vaccination in a targeted way

Solutions include enhanced education, better structures for vaccine access, and better use of existing resources like pharmacists. It is essential to disseminate more information about where to get vaccinated or find vaccine-related information. Furthermore, cost can be a barrier to vaccination for some. No one should have reduced access to healthcare due to affordability—this must be addressed to increase vaccination rates and eliminate HPV.

Screening

Objective 2: Achieve a 90% HPV screening rate among individuals with a cervix using the HPV test by 2030

Strategy 1: Replace the Pap test with HPV testing as the standard screening method

This transition is critical to improve early detection and cervical cancer prevention. A pilot program is currently underway in Quebec. Lab restructuring and data system updates are essential. Public and healthcare provider support, as well as government commitment, are also crucial. COVID-era nucleic acid testing platforms can ease the transition. A community-led advisory committee including affected individuals should guide this rollout. Vaccination and testing registries must be compatible.

Strategy 2: Make self-sampling HPV tests available in pharmacies

Allow individuals to collect samples at home and submit them via pharmacies or mail. This would simplify and increase access to screening while reducing barriers like travel and appointment logistics.

Strategy 3: Integrate HPV screening into routine healthcare, especially in sexual and reproductive health services

HPV screening education must target both the public and healthcare providers and should be led by non-profits to boost uptake and trust. Self-sampling should be prioritized for under- or never-screened individuals.

Strategy 4: Set up a recall/reminder system for screening

A formal letter-based invitation and reminder system should be established for eligible individuals.

Strategy 5: Establish an expert committee to oversee HPV test implementation

The committee should include public health experts, clinicians, and community representatives to ensure inclusive and effective deployment.

Education & Awareness

Objective 3: Increase awareness of HPV and its risks among the general public and healthcare professionals

Strategy 1: Develop targeted awareness campaigns for at-risk populations

To address the stigma associated with HPV and vaccine hesitancy, it is crucial to implement effective awareness campaigns. These campaigns must include increased education on HPV and the importance of vaccination. Various media should be used to reach a broad audience, including TV ads, streaming platforms such as Tou.TV, Gem, and Netflix, as well as social media and websites. The involvement of non-profit organizations (NPOs) in the creation and dissemination of educational materials is essential to ensure the content is appropriate, relevant, and well understood by the target audience.

Strategy 2: Train healthcare professionals on best practices for HPV prevention and screening

It is imperative to educate healthcare providers so that they are well-informed about HPV-related cancers, particularly head and neck cancers. A better understanding of HPV tests, their sensitivity, and proper use is necessary to improve prevention and early diagnosis. Dentists and oral health professionals must also play a more active role by recognizing signs of HPV-related oral cancers and referring patients to appropriate care. Training should include identifying clinical signs and using screening tools to optimize patient management and reduce stress during screening.

Strategy 3: Collaborate with NPOs to share accurate and accessible information about HPV and vaccines

The government must fund these NPOs to support the development and dissemination of educational content. These organizations play a critical role in ensuring that information is accurate and accessible. Collaboration with pharmacies, healthcare workers, and NPOs will ensure that information on HPV and preventive measures is widely available. It is also recommended to include the pharmaceutical sector in action plans to strengthen the impact of awareness and prevention campaigns.

Strategy 4: Raise awareness among youth through schools

School-based awareness aims to educate youth about HPV, its risks, and prevention options such as vaccination. This includes incorporating HPV education into biology or sexual health classes, organizing interactive workshops with healthcare professionals, and promoting vaccination within schools. Tailoring content by age and educational level is essential to make information accessible and relevant, positively influencing young people's future health behaviours.

Strategy 5: Use social media and digital platforms

Social media and digital platforms offer a powerful way to reach a wide audience—especially young people—by sharing awareness messages about HPV. This strategy includes creating engaging visual content, partnering with influencers, and using platforms like Instagram, TikTok, and YouTube. Interactive campaigns—such as viral challenges and live webinars with experts—aim to educate while encouraging active participation, helping normalize HPV vaccination and sexual health online.

Patient Support

Objective 4: Improve support for patients before, during, and after HPV-related cancer treatment.

Strategy 1: Provide each patient with a post-treatment action plan, including information on mental health resources and required follow-ups

Every patient should receive a detailed plan covering medical follow-up, mental health support, and HPV vaccination. This plan should also include reminders for HPV testing to ensure continuous monitoring and improved post-cancer quality of life.

Strategy 2: Provide alternative screening and vaccination resources accessible in community settings

Improve access to care by offering HPV screening and vaccination points within local communities. A centralized database of patients' medical and treatment histories would allow better coordination among healthcare professionals, ensuring continuity of care and avoiding loss to follow-up.

Strategy 3: Ensure the availability of mental health support services for patients during and after treatment

Ensure the availability of specialized mental health services throughout the cancer treatment process and after. Appropriate emotional and psychosocial support will help patients manage the psychological impact of cancer and recover effectively.

Strategy 4: Create support groups for patients and their loved ones

Establish support groups that encourage sharing of experiences and mutual aid among patients and their families. These groups offer a safe space to discuss challenges associated with cancer.

Strategy 5: Offer ongoing education on post-treatment management

Provide continuous education on managing life after treatment, including information on preventing recurrences, follow-up care, and maintaining overall health, to ensure a complete recovery.

Performance Indicators

Short Term (1–2 years)

01. Increase HPV vaccine coverage to 90% among youth aged 18, in line with the Public Health Program's goals.
02. Expand provincial rollout of HPV testing.
03. Promote self-sampling for HPV testing.
04. Make HPV tests accessible via websites, pharmacies, and community locations.
05. Launch a public education campaign on HPV, including signs and early symptoms of HPV-related cancers.
06. Establish compatible and connected HPV vaccination and testing registries.

Medium Term (3–5 years)

01. Reach over 90% HPV vaccine coverage among 18-year-olds.
02. Ensure proper follow-up for 90% of people with a positive HPV test.
03. Reduce cervical cancer incidence to fewer than 4 cases per 100,000 people.
04. Reduce cervical cancer mortality to fewer than 2 deaths per 100,000 people.
05. Improve access to mental health services for patients with HPV-related cancers.
06. Implement vaccination programs targeting priority populations.

Long Term (6–10 years)

01. Achieve 90% HPV vaccine coverage among 17-year-olds.
02. Reduce cervical cancer rates by 50%.
03. Establish a comprehensive post-treatment support system for all patients.
04. Eliminate healthcare access disparities for priority populations.

Conclusion —
Our Vision for the Future

To eliminate HPV-related diseases, Quebec must actively engage in the fight against misinformation through targeted information campaigns using various media channels to provide accurate data on HPV, its modes of transmission, the effectiveness of the vaccine, and screening. These initiatives will encourage a better understanding of HPV and reduce vaccine hesitancy. Clear, scientifically validated education will promote greater comprehension and help diminish resistance to vaccination.

It is also crucial to reduce inequalities in access to healthcare by focusing on vulnerable populations such as First Nations, Inuit, Métis, rural communities, low-income individuals, immigrants, refugees, at-risk youth, and LGBTQ2S+ communities. Specific programs must be developed for these groups, including expanded vaccine coverage, easier access to screening tests, self-sampling programs, and appropriate psychosocial and sexual health support. Simplifying access to prevention and care—by integrating vaccination into existing healthcare systems—will optimize interventions and strengthen public health.

Achieving a 90% vaccination rate among youth under 18 and a 90% screening rate among people with a cervix is essential. This requires close coordination between public health authorities, healthcare professionals, educators, and communities, along with holistic post-treatment support for patients. By taking these steps, Quebec can envision a future where HPV-related diseases are eliminated, improving the quality of life for future generations.

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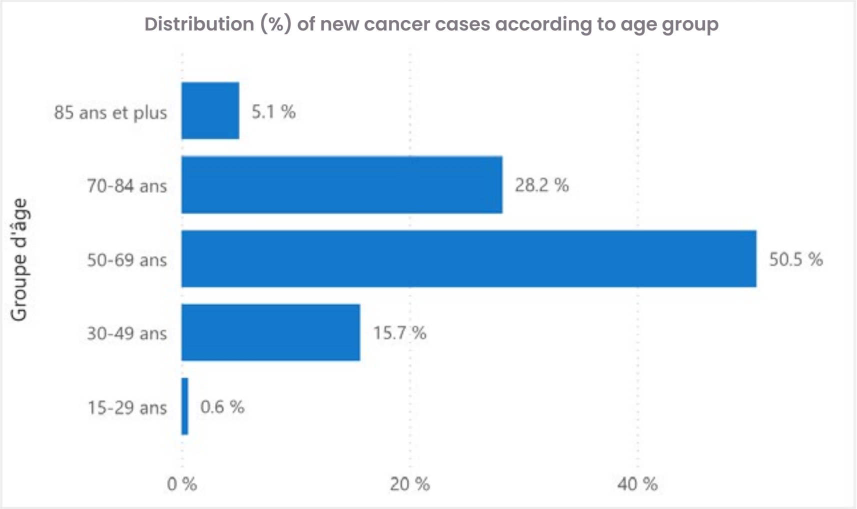
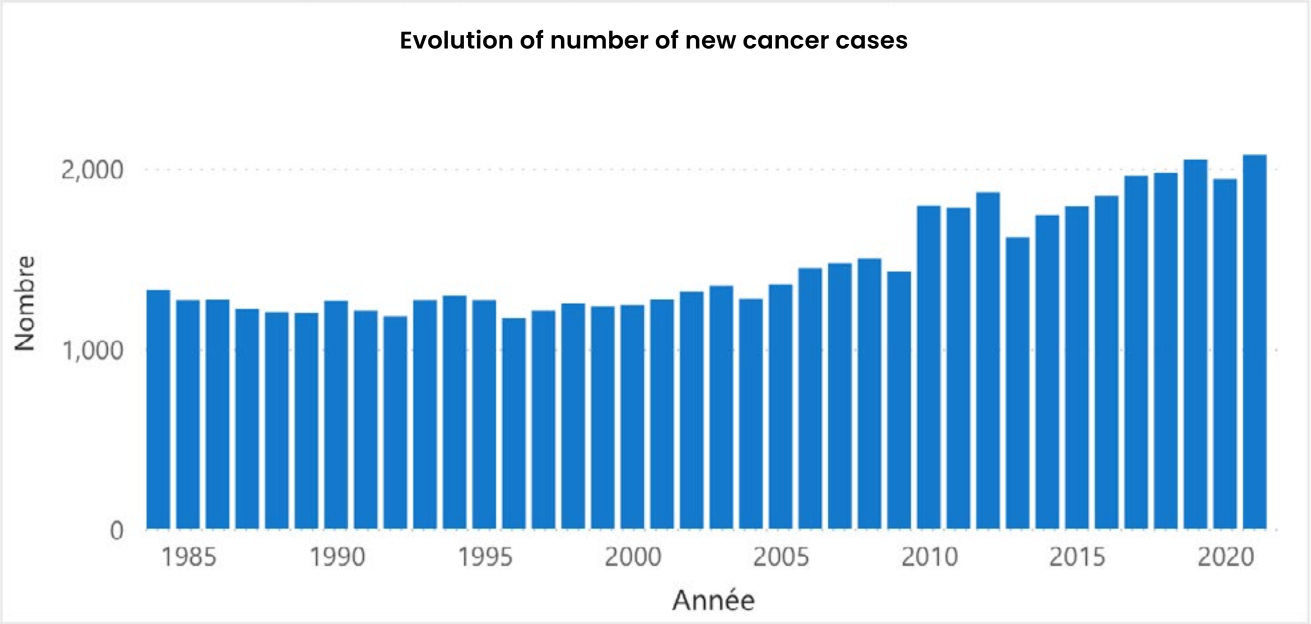
Cervical Cancer Statistics in Quebec



Distribution (%) of new cancer cases according to age group

New cancer cases

2,072



Evolution of number of new cancer cases

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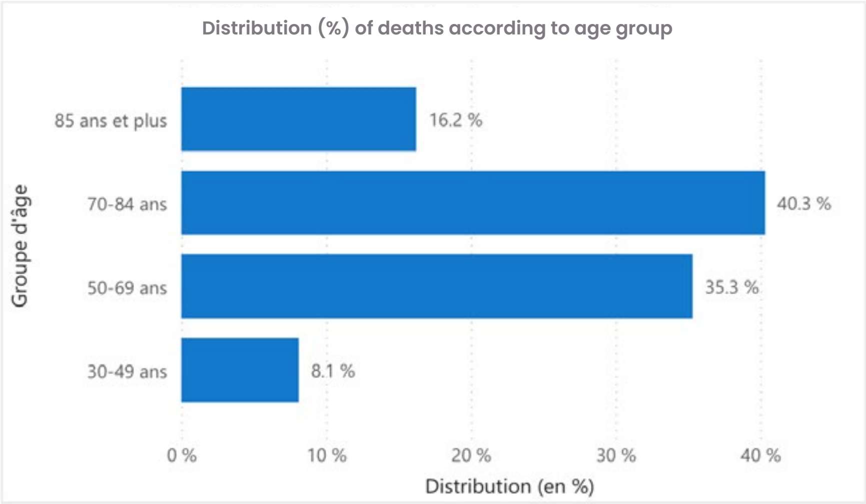
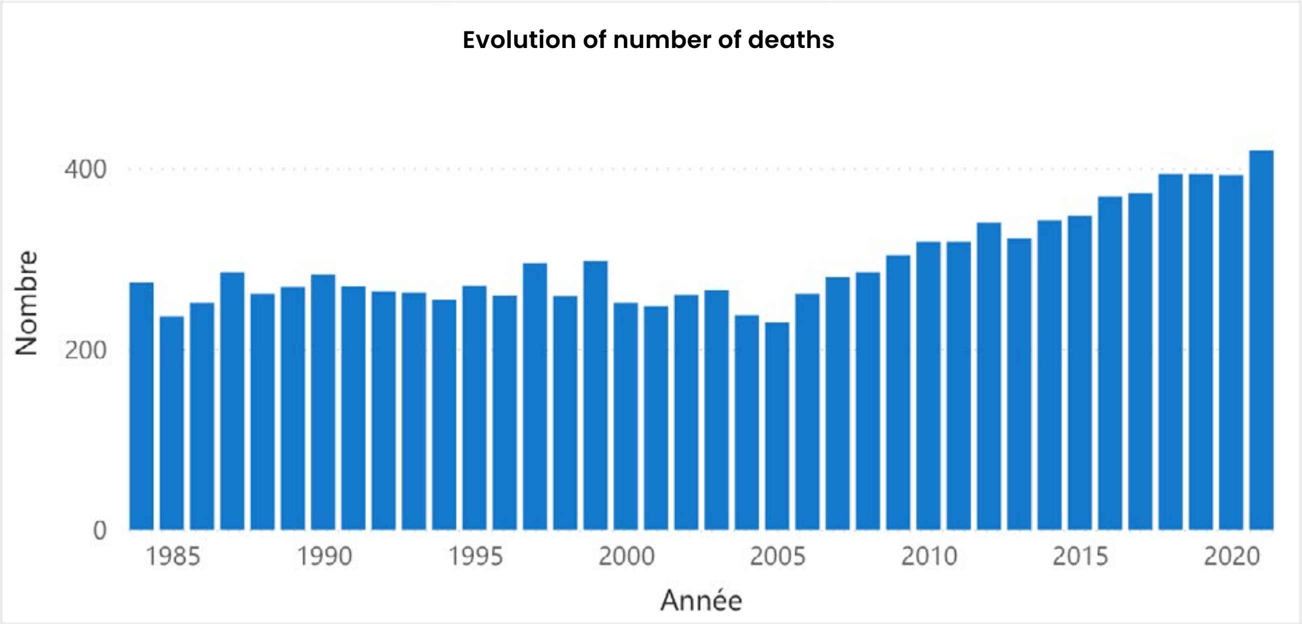
The original data can be accessed here.



Distribution (%) of deaths according to age group

Number of deaths

419



Evolution of number of deaths

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