REPORT

Objectives & Priorities for the Coming Years by Cancer Type

A RECOMMENDATION PROJECT

Quebec Cancer Coalition

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

brain tumour 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**

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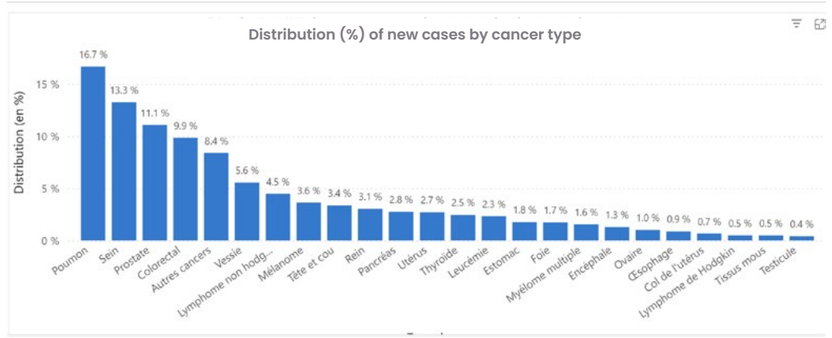
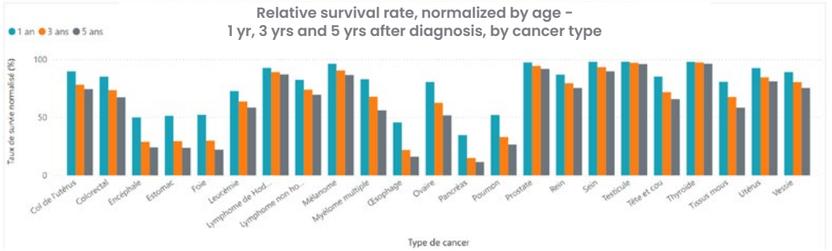
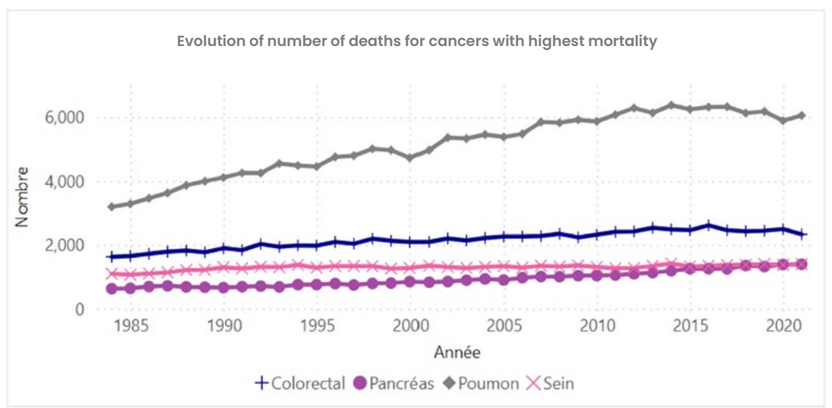
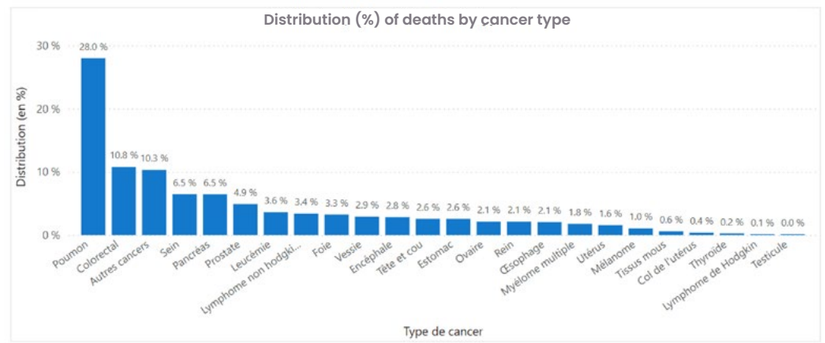
The original data can be accessed here.









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.

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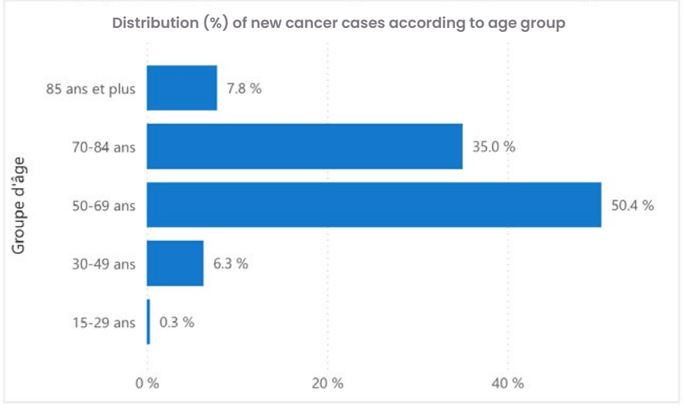
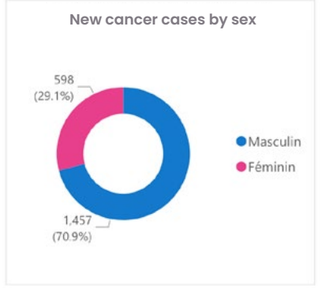
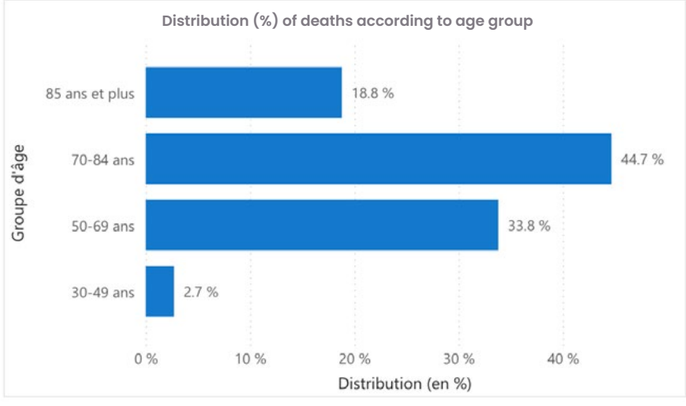
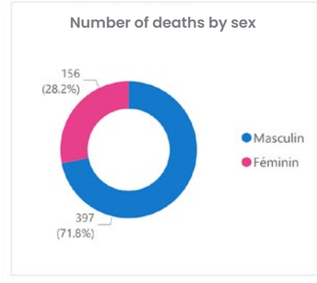
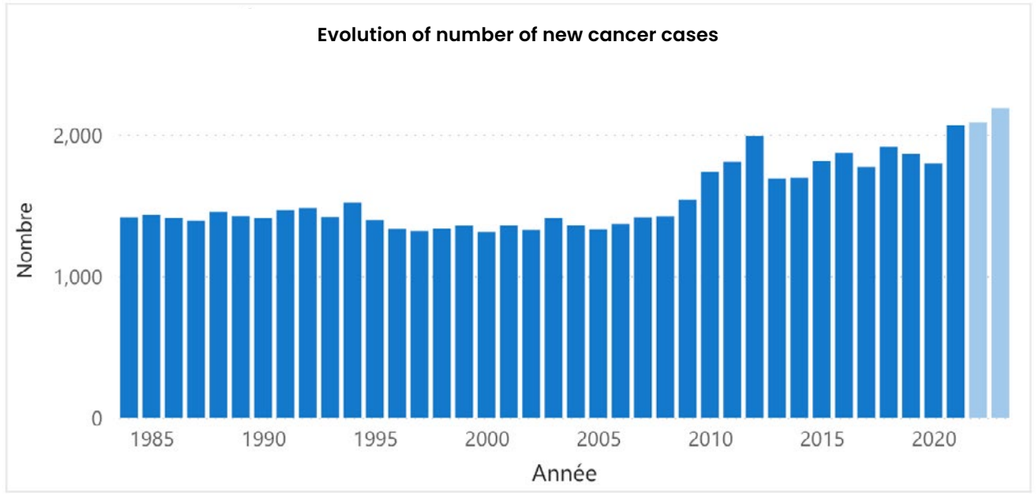
Brain Cancer Statistics in Quebec

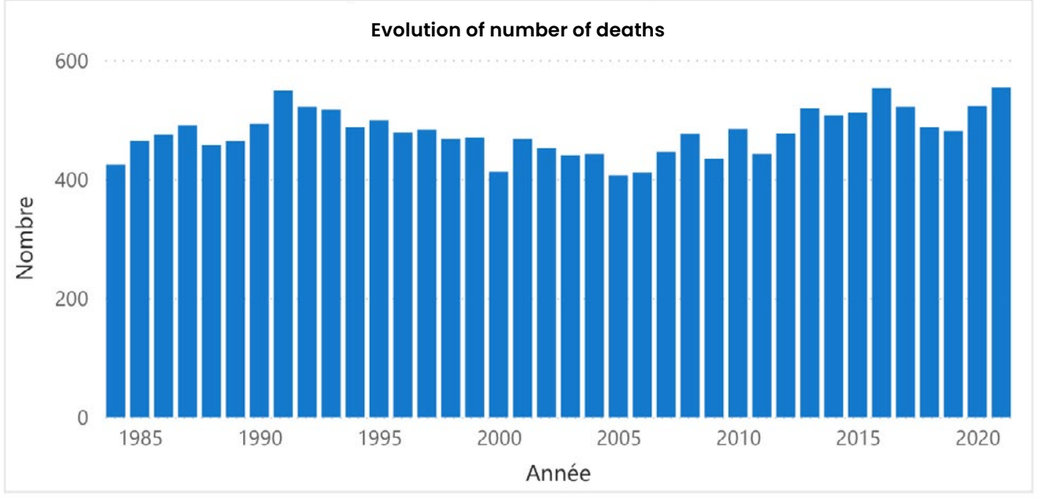












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