



Brain Tumour Foundation of Canada

Submission to: Canadian Partnership Against Cancer (CPAC)

For

Refresh to the Canadian Strategy for Cancer Control (CSCC)

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NOTE: BTFC is willing to be named as an input provider to the CPAC consultation process

Brain Tumour Foundation of Canada (BTFC) is pleased to submit the following response to the Canadian Partnership Against Cancer (CPAC) relating to refreshing the *Canadian Strategy for Cancer Control*.

Q1. What do you see as the main benefits of Canada’s cancer control strategy in a system where health care is mostly a provincial/territorial responsibility?

A1. In an era of increasing fiscal restraint, the provinces and territories will be looking to evidence-based guidelines to inform their funding decisions. A cancer control strategy can provide consensus on the types of interventions that support the best possible outcomes for cancer patients. As patients live longer and with more treatment options available, provinces and territories will be looking to a national organization to help them shape essential services and programs.

A cancer control strategy can also provide a consistent, ongoing mechanism for translating research and registry evidence into priorities for cancer care and prevention. This can help provinces and territories to evaluate their existing practices, set national standards for practice, and identify significant gaps in access to care.

Q2. What would you say are the biggest cancer control challenges Canada will face over the next 10 years?

A2. Brain Tumour Foundation of Canada regularly surveys our patient, caregiver and health care professional network to discern their priorities and experiences in accessing care. From this survey and additional experience working with this community, we can identify the following challenges:

The Demand for Reliable and Consistent Data

Those that administer cancer care are increasingly calling for evidence-based recommendations. If national standards for cancer control are to be achieved, CPAC needs to draw from consistent and reliable registry data on ALL types of cancer.

To date, Canada has relied on data from several American and Canadian data resources to guide Canadian research and programming for brain tumours data that is incomplete and not a true reflection of Canada’s brain tumour community.

Access to reliable enumerative data is essential to monitoring and, ultimately, controlling cancer across the country. In alignment with the collection of cancer statistics for more common cancer diagnoses, BTFC urges that the Strategy place the highest level of importance on counting a wider variety of cancers nationally in order to track prevalence and incidence, as well as gauge equitable access to treatment.

Equitable Access to Care

Once a patient has been diagnosed, piloting through the network of care is both stressful and complicated, especially if one begins the journey from a place that is geographically distant from a major hospital network. Even once evidence-based guidelines for care are in place, the reality is

patients face varying wait times and available services across the country. Where services exist, the information and assistance they receive in accessing these resources varies widely.

Listening to our community, BTFC has identified equitable access to cancer care as one of our primary advocacy efforts for our next strategic cycle.

Currently, BTFC is mapping patient access to the primary and most common treatment for malignant brain tumours. Our preliminary data shows that although this oral chemotherapy treatment has been standard of care for more than a decade, access varies widely as does the intervention used by health professionals to ensure patients receive their treatment in a timely manner. The impact of this varied access on patient treatment outcomes is unknown.

BTFC understands that even with a national pharma care approach, challenges will continue to exist in equitable access to cancer care across the country. It is essential that future guidelines and recommendations for cancer control be accompanied by an *accurate understanding and mapping of access to care across the country*. This includes the realities of marginalized groups and remote areas. Policy must align with clinical practice.

In the next ten years, patients and their families need tools to help ensure they can access available care in a timely and consistent manner (e.g. health system navigators, online resources). These tools are essential to ensuring cancer control outcomes are achieved.

Chronic Care Needs

BTFC has witnessed an incredible shift in treatment over the last ten years. Those with malignant brain tumours are living longer and with better quality of life. The shift in innovative treatment has not been accompanied in a shift in care. Our members often lack access to adequate occupational therapy, rehabilitation services, physiotherapy, and the psychosocial support needed to help them live well with their disease.

A challenge for cancer control in the next ten years will be ensuring that evidence continues to inform the lifecycle of care management for those with cancer. This goes beyond managing survivorship but examining how chronic care needs are dealt with for those on active treatment over a long period of time. There is an opportunity to examine multi-disciplinary models for disease management.

A strong national strategy needs to reflect the reality of health care provision in Canada and ensure that the experience of every Canadian – regardless of tumour type, geography, or ability – is addressed over the entire lifecycle of care.

Q3. In 10 years' time, what does success look like? How will we know this strategy worked?

A3. A more holistic cancer control strategy will result in fewer reported gaps in care, more consistent services that span the lifecycle of care, and more consistent data across disease sites to help inform ongoing work.

BTFC feels success will also be represented by more inclusive partnership with patient-led organizations to help inform and support ongoing work.

Q6. Where would you say Canada is on the balance of attention and resources between (1) investing in researching and developing new solutions and modalities; (2) ensuring everyone has equitable access to existing services and (3) ensuring sustainability for future generations?

A6. The value of responsible investment into new medications and treatment options is invaluable to improving screening and treatment, as well as ensuring the highest quality of life during the traumatic and life-changing period of treatment. In addition to federal scientific investments, BTFC has undertaken landmark investments in research from the lab as well as in providing funding opportunities to emerging research and technologies. In Canada, cancer researchers continue to rely on both federally supported research organizations and on supplemental funding from charitable organizations like BTFC.

To date, cancer care research investment has been more heavily weighted on clinical developments than on system or program innovation. From the BTFC patient survey, it was clear that patients lack equitable access to care across the country – from 1st line chemotherapy treatment to psychosocial care to rehabilitative care and survivorship. BTFC discovered a significant lack of supplemental system data that could help inform and substantiate our survey findings. The implementation of distress screening was a positive step, but much more needs to be done to ensure the collection of real-time data in hospital screening and assessment methods that can better illustrate how gaps in cancer care occur.

To ensure sustainability, a cancer control strategy must align with additional policy initiatives such as a national pharma care strategy and a palliative care strategy. The most significant risks to achievable cancer care outcomes cannot be addressed by one organization. BTFC would like to see stronger collaboration of CPAC with other national organizations on practical, health equity projects that address drug funding parity, transportation gaps, and financial barriers to care.

Q7. The challenges faced by vulnerable populations are often at the local level (at the intersections of cultural, socio-economic, geographic and other factors). How can a national strategy contribute to addressing these pervasive yet locally variable challenges?

A7. A national strategy must engage with local practitioners and patient-led organizations to ensure the challenges of regions and sub-populations are accounted for. A national strategy can only contribute to addressing local variables by issuing guidelines and strategies that can be adapted or reflective of local needs. Regional representatives are key not just to informing a strategy but for implementing it as well. Many national organizations like BTFC engage with local practitioners and patients to help inform the experience of care and local variables. *Well-established partnerships can lend local expertise to implementation that can help diminish barriers and ensure strategies can be realized.*

Q8. What are the aspects/elements/components of cancer control that could best be addressed if all jurisdictions work together in a coordinated way as opposed to alone or bilaterally? Examples may include: a. Long-standing and complex challenges like inequities in access and outcomes that require unified solutions involving multiple sectors and players. b. Roll-out of new programs or modalities (e.g., lung cancer screening) that would benefit from coordinated planning and implementation with consistent application of standards and joint monitoring and evaluation. c. Others?

A8. If improved coordination is achieved, there are three potential areas of cancer control that could be addressed:

Improved National Cancer Registry

In 2018, our community loudly spoke out that every diagnosis of brain tumour must be counted. We agreed – that is why BTFC, in partnership with Brain Canada, has funded a **Canadian Brain Tumour Registry Project**, which will be officially launched in 2019. This initiative and other similar efforts will need the support of a range of organizations to ensure data is reported consistently and across jurisdictions. Pathways to reporting need to be mandatory and clear. There is great potential to better monitor the experience of cancer patients and identify opportunities for system improvement overall with a more robust and complete registry. To achieve this succinctly will need the guidance and leadership of a national organization.

Equitable Access to Standard Cancer Treatment

Those who are diagnosed with the most common form of malignant brain tumours have an internationally recognized standard of care – a generic chemotherapy drug that has been shown to both lengthen periods of survivability and improve quality of life. For more than 10 years, this therapy has been the primary choice of treatment for oncologists and it continues to show significant outcomes progression free survival. There is no alternative 1st line therapeutic option for this group of patients.

Access to this standard therapy varies widely in Canada because it is an oral chemotherapy agent, and in many provinces and territories it continues to be a prescription drug and the responsibility of the patient. Although the national pharma care strategy holds promise of bring parity to cancer drug funding in Canada, there are no guarantees that equity to standard cancer treatment will result.

With new treatments and medications for malignant brain tumours years away, BTFC will be relying on a national organization like CPAC to align with other national efforts and urge its national counterparts to work towards cancer drug funding parity in Canada. Universal standards of care cannot be achieved without universal access to basic cancer treatment.

Guidelines for Chronic Cancer Care

Apart from a few large academic centres, most cancer centres across the country lack rehabilitative or chronic care programs for cancer patients. With progression free survival timelines increasing, there is more urgent need to extend standards of care beyond systemic therapy and acute care to chronic care models. This type of programming cannot be provided by patient organizations alone.

BTFC believes that the view of cancer care needs to be expanded to include rehabilitative services, broader psychosocial support and family care. It will need the leadership of CPAC to bring a new vision for cancer care forward and work with regional partners to recognize the impact of expanded programming on disease recurrence risks and outcomes.

Question 9: As a partner in cancer control, where do you see yourself playing leadership or supporting roles in implementing the refreshed strategy?

The Problem with Estimation

With an estimated 55,000 Canadians living with a brain tumour today, and with a further estimated 27 new diagnoses every day in Canada, BTFC has long recognized that there is an inherent deficiency with relying on estimates. In the past, health care professionals in brain/CNS oncology have largely relied on metrics derived from the United States transposed on the Canadian population. BTFC has determined that this data is insufficient.

Since 2011, BTFC has invested in the genesis of a Brain Tumour Registry Project (BTRP). With the inclusion of the BTRP into the larger network of the Canadian Cancer Registry, the data gathered will be a turning point for the effective allocation of research funding and provide a real-time tracking tool for geographical incidence, prevalence and survivability data surrounding brain tumours in Canada.

BTFC aims to take a leadership role in adding brain tumour-specific data into the pool of data that is currently being collected for other cancers in the hope of directing research, programs and supports to areas of the country and to population segments that need them most in order to tangibly and meaningfully contribute to the strategic goals of the Strategy. Through this work, every brain tumour will count.

We would like to thank CPAC for the opportunity to share our insights into ways that the national cancer control strategy can be refreshed to achieve important objectives over the next 10 years. We have sent encouragement throughout our networks for the patients, caregivers, researchers and allied health professionals that we represent to submit their own perceptions of cancer control to inform your work. We look forward to the warm reception of your report.