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Organizational Guidance for the Care of Patients with Central Nervous System Tumours in Ontario: Consensus Recommendations

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Organizational Guidance for the Care of Patients with Central Nervous System Tumours in Ontario: Consensus Recommendations

Section 1: Recommendations

GUIDELINE OBJECTIVES

To provide guidance for the organization and delivery of healthcare services for adult patients with primary central nervous system (CNS) tumours in Ontario.

The goal is to ensure that all patients in Ontario have access to comprehensive CNS tumour services, regardless of their place of residence. Specifically, to ensure appropriate coordination of concurrent services (surgery, chemotherapy, radiotherapy, and supportive care) within a province-wide CNS tumour program, including:

- Appropriate clinician/health professional skill set, experience, and qualifications
- Case review at multidisciplinary case conferences (MCCs)
- Access to expert multidisciplinary resources (including allied health/psychosocial oncology)
- Care as close to home as possible
- Access to clinical trials

INTRODUCTION

In 2020, it was estimated that over 4500 Ontarians would be diagnosed with, and nearly 3500 Ontarians die from, a CNS cancer [1].

Primary CNS tumours are a heterogenous group of malignant and nonmalignant tumours with varied trajectories ranging from noninvasive and surgically curable gliomas, to more common highly invasive and incurable glioblastomas. CNS tumour care must be multidisciplinary, as well as tailored to individual patients, requiring surgery, radiation therapy, and chemotherapy input into a proposed treatment plan for the most responsible physician to consider. Diagnosis often relies on specialized imaging and laboratory testing, including histological examination, immunohistochemistry, cytogenetics and, increasingly, next-generation sequencing. Tumour identity at the molecular level can have a profound effect on determination of treatment approach and on patient outcomes. For example, patients diagnosed with adult-type low-grade gliomas that possess a mutation in the isocitrate dehydrogenase (IDH) gene may have an expected long overall survival, in contrast to the poor overall survival associated with patients diagnosed with a low-grade glioma and adult-type IDH wild type. Therefore, in patients with IDH-mutant low-grade glioma, treatment decisions regarding surgery, chemotherapy, and radiation therapy may have profound effects on the patient's quality of life measured in years or even decades. The principles of rare tumour management hold true particularly for benign but aggressive tumours of the CNS. For example, although the molecular alterations observed for chordoma or craniopharyngioma may not yet have a significant impact on decisions relating to upfront management, initial surgery offers the best chance for cure or tumour control and should be undertaken only at centres of experience to maximize the therapeutic outcome. Postoperatively, decisions regarding radiation therapy are complex and can have long-lasting impacts on a patient's quality of life and chance for cure or disease control, and eligibility for experimental systemic therapy reserved for recurrence. Lastly, the recognition that the adolescent and young adult population may harbour distinct molecular alterations that can allow for systemic therapies rather than traditional surgical and radiotherapeutic approaches [2-4], further highlights the need for an organized care pathway for patients in Ontario with CNS cancers.

No organizational guidance currently exists at the provincial level to ensure the delivery of coordinated, high-quality, whole-person care for patients with CNS tumours. This includes requirements for clinician experience/qualifications, expert allied health care, and access to all essential components of CNS tumour care.

Over the past decade in Ontario, the footprint of centres offering care for patients with primary brain tumours has expanded, with the goal of diminishing the burden for patients to access high-level, high-quality CNS tumour care. This effort has been tempered by recognition of the rarity of many of these diseases, and by the complexity of treatment and care, particularly given increasingly specialized and sophisticated radiation and surgical techniques, and additional options for targeted systemic therapies. Guidance is needed to ensure quality of care and coordination of services across sites. The delivery of CNS tumour care at centres without sufficient resources places patients at risk of inappropriate treatment decisions, suboptimal service delivery or fragmented care, inequitable access to care, poor outcomes, and increased hospitalization [5-7].

TARGET POPULATION

This guideline focuses on adult patients with primary CNS tumours (glioma and other primary parenchymal neoplasms, sellar lesions, and skull-base lesions and meningioma) and their caregivers. This guideline does not apply to patients with brain or spinal metastases, sarcomatous tumours of the CNS, or pediatric patients with CNS tumour, as care considerations for these patients have been addressed by previous or parallel guideline efforts. For organizational guidance on brain metastases, please see the related Ontario Health (Cancer Care Ontario) (OH (CCO)) organizational care guideline for stereotactic radiosurgery treatment of brain metastasis [8]. Tumours included within this organizational care guideline are summarized in Table 1-1.

Table 1-1. Central nervous system primary tumours

Gliomas and other primary parenchymal neoplasms	Sellar lesions	Skull-base lesions and meningioma
Low-grade glioma	Pituitary adenoma	Convexity meningioma
High-grade glioma	Parasellar meningioma	Anterior fossa lesions
Germ cell tumours	Craniopharyngioma	Middle fossa lesions
Medulloblastoma	Optic pathway glioma	Posterior fossa lesions
Ependymoma		
Hemangioblastoma		
Pineal tumours		

INTENDED USERS

Stakeholders include all Ontario Regional Cancer Programs and affiliated centres that deliver CNS tumour care (primary brain tumours), as well as programs that plan to provide CNS tumour care in the future. Specifically, this document is intended for administrators responsible for developing, implementing, and maintaining CNS tumour programs and for the oncology health care professionals who interact with and care for patients with CNS tumours.

GUIDELINE QUESTIONS

1. What are the centre requirements for the organization and delivery of care for adult patients with CNS primary tumours?

2. What are the recommended staff requirements and expertise required by medical/surgical, nursing, and allied healthcare professionals to provide optimal care for patients with CNS primary tumours?

Case Scenario 1
A 26 year-old man has a seizure while at dinner with his husband. He is taken by ambulance to a local hospital emergency department, where he is given a benzodiazepine and loaded with phenytoin. A computed tomography (CT) scan is performed, demonstrating a hypodensity in the left frontal lobe, which is concerning for a primary brain tumour. Neurosurgery is consulted through CritiCall (the provincial emergency system designed to allow family doctors and emergency physicians access to urgent neurosurgical consultation), and per their instructions, arrangements are made for an urgent magnetic resonance imaging (MRI) scan. He is seen in the neurosurgery clinic the next day. Because of the location of the tumour, arrangements are made for him to undergo an awake craniotomy with speech mapping. Surgery is uncomplicated. Hematoxylin and eosin analysis of his tumour is consistent with a low-grade glioma. Post-operative imaging shows a substantial reduction in tumour burden, with some residual FLAIR signal adjacent to the speech centre. Molecular analysis performed at the CNS Partner Site's sister CNS Network Centre reveals ATRX loss consistent with a grade 2 IDH-mutant astrocytoma, prompting the tumour board to recommend upfront adjuvant therapy. He is referred to an academic neuro-oncology centre and the radiation oncologist and neuro-oncologist advise that he undergo radiation therapy with concurrent and adjuvant chemotherapy. He tolerates treatment well and remains seizure-free as he is transitioned from phenytoin to levetiracetam. He remains under surveillance in the neuro-oncology clinic with repeat imaging planned at three-to-six month intervals.

Case Scenario 2
A 76 year-old woman is brought by her family to her local emergency department with a two-month history of progressive behavioural change. CT imaging shows a large left frontal brain tumour. Neurosurgery is consulted through CritiCall. The patient is transferred to a neurosurgical centre, where she undergoes urgent MRI, revealing what appears to be a glioblastoma. She is taken to surgery soon after, and a gross total resection is performed. Pathology analysis shows an IDH wild type glioblastoma and MGMT promoter unmethylated. At tumour board review, the consideration of referral to an academic neuro-oncology centre that can offer a clinical trial for patients with unmethylated disease is suggested. The patient and her family are given the news and guided toward options on next steps. They decide against the clinical trial, stating instead that they would like to have standard care at a hospital nearer home. She is referred to a local CNS Partner Site that is able to deliver adjuvant chemotherapy and radiation to patients with IDH wild type high-grade glioma.

CARE SETTINGS

In Ontario, the care of adults with CNS tumours is provided in a variety of settings. These settings are defined in this guideline as *CNS Network Centres*, *CNS Partner Sites*, and *other* *hospital sites*. Factors influencing where a patient receives care may include where the patient lives, the type of tumour, and the complexity of associated treatment and care. Some treatments for CNS tumours must be delivered from a CNS Network Centre – a specially designated centre of experience that is usually an academic hospital and affiliated cancer centre. Specialized care may also be provided from CNS Partner Sites - hospitals with oncology expertise that do not have all subspecialties on site. Care decisions depend on multi-disciplinary input supported through partnership with a CNS Network Centre, for example, through a joint MCC (also called tumour board). Other hospital sites may conduct initial investigations and provide routine and supportive care to limit the extent to which the patient needs to travel.

Building relationships among CNS Network Centres, CNS Partner Sites, and other hospital sites is imperative to ensure that patients with CNS primary tumours receive the best possible person-centred care. In recognition of the complexity and specificity of care needs of patients with CNS tumours, sites starting to offer CNS tumour care need to align with, and be mentored by, established CNS Network Centres. In this guideline, use of the term "access to" refers to the ability of a site to access services through an agreement or partnership with another facility.

The Working Group recognizes that a relationship exists between higher practice volumes and improvement in outcomes, however, insufficient data exist to make specific recommendations regarding target volumes for annual number of surgical, radiation, or systemic therapy cases with respect to CNS tumours.

Recommendation 1.1

CNS Network Centre

The CNS Network Centre is an academic hospital and/or cancer centre that must provide the full spectrum of services for patients with CNS tumours, including the specialties of neurosurgery, neuroradiology, neuropathology, neuro-oncology or medical oncology with CNS fellowship training, and radiation oncology with CNS fellowship training or its equivalent. A CNS Network Centre may be composed of one or two closely situated facilities with a formal connection.

CNS Partner Site

The CNS Partner Site is a hospital that should provide a subset of services for patients through a shared-care model, and liaise with CNS Network Centres to share portions of care. Depending on circumstances, CNS Partner Sites may have specialized expertise for specific tumours or in specific services/disciplines. A CNS Partner Site should include a CNS radiation oncologist or a radiation oncologist with sufficient training and competence to treat CNS malignancies, and a neuro-oncologist or medical oncologist with CNS fellowship training either on site or as part of the MCCs.

Other Hospitals

Other hospitals are local hospitals without specific CNS tumour oncology expertise. These hospitals play a critical role in performing initial investigations, administering treatments determined by specialists, and providing supportive, palliative, and follow-up care.

Recommendation 1.2

CNS Partner Sites that care for patients with CNS tumours should establish formal connections with CNS tumour CNS Network Centre to access specialized expertise and services, which must include access to virtual MCCs.

Recommendation 1.3

Many CNS tumours are rare and practice volumes will depend on local conditions. Sites should have sufficient patient volume to maintain competency and safety.

MINIMUM SERVICES FOR ALL PATIENTS WITH CNS TUMOURS

Recommendation 2.1

All patients with CNS tumours must have access to the following services (on-site or through CNS Partner Sites or CNS Network Centres):

- Diagnostics with neuropathology expertise including advanced molecular diagnostics
- Imaging (MRI, CT, other imaging) with neuroradiology expertise including MR perfusion
- Treatment (neurosurgery, CNS radiotherapy (including fractionated radiotherapy for CNS tumours (1.8-3.0Gy/day), fractionated stereotactic radiotherapy (1.8-3.0Gy/fraction), single fraction and hypofractionated radiosurgery [For the technical requirements specific to radiosurgery and fractionated radiosurgery (also referred to as Hypofractionated Stereotactic Radiotherapy/Radiosurgery), please refer to the PEBC Organizational Guideline for the Delivery of Stereotactic Radiosurgery for Brain Metastases in Ontario], and medical oncology/neuro-oncology)]
- Access to clinical trials (all patients should have the opportunity to access clinical trials)
- Review at MCC

Recommendation 2.2

In addition to services listed in Recommendation 2.1, CNS services provided by the following areas of health care must be available or accessible:

- Neurology
- Nursing (patient education, symptom management, supportive care, coordination, and navigation)
- Allied health/Psychosocial Oncology
    - Mental Health (Psychiatry, Psychology)
    - Social work (counseling, caregiver and patient's dependents supports, information regarding home support, transportation [local and distant], and funding assistance)
    - Rehabilitation (Occupational therapy, Physiotherapy, Speech language pathology)
    - Nutrition (Dietitian)
- Palliative and end-of-life care (including medical assistance in dying)
- Patient coordination and communication (Most Responsible Physician [MRP] and continuity of care)

Many of the services listed above may be provided in community settings (e.g., private clinic or home care), particularly for outpatients receiving post-hospital care. Services in the outpatient environment may require out-of-pocket payment or private insurance.

Services with the full spectrum of CNS tumour specialty care are provided on-site by CNS Network Centres. CNS Partner Sites provide a subset of services and access to more specialized services through a shared-care model. Table 1-2 shows the services recommended for the CNS Network Centre and CNS Partner Sites. "Access to" at a site means that local expertise might be available on site; if not, a CNS Partner Site must liaise with a CNS Network Centre, or a site might need to liaise with a specialty hospital to access a particular service.

Table 1-2. Services recommended by site

Recommendation	Service	CNS Network Centre	CNS Partner Site
Recommendation 2.3	Diagnostics (pathology and radiology)	Neuropathology Advanced molecular diagnostics, brain mapping Neuroradiology Advanced imaging protocols Dynamic contrast protocols	Pathology and radiology Access to neuropathology and neuroradiology
Recommendation 2.4	Medical/neuro-oncology	Yes	Yes
Recommendation 2.5	Radiation oncology	CNS radiation oncology	Radiation oncology Access to CNS radiation oncology
Recommendation 2.6	Surgery	Neurosurgery	Access to
Recommendation 2.7		Neurosurgery (with specific training in endoscopy)	Access to
Recommendation 2.8		Skull-base neurosurgery	Access to
Recommendation 2.9		ENT	Access to
Recommendation 2.10		ENT rhinology	Access to
Recommendation 2.11		Neuro-ophthalmology	Access to
Recommendation 2.12		Neuro-otology	Access to
Recommendation 2.13	Endocrinology	Yes	Access to
Recommendation 2.14	Neurology	Yes	Access to
Recommendation 2.15	Nursing	Specialized oncology nursing	Specialized oncology nursing
Recommendation 2.16	Nurse Practitioner	Yes	Access to
Recommendation 2.17	Social work	Social worker with CNS expertise	Social worker with access to social worker with CNS expertise
Recommendation 2.18	Physiotherapy	Yes	Access to
Recommendation 2.19	Occupational therapy	OT with CNS expertise	OT with access to OT with CNS expertise
Recommendation 2.20	Rehabilitation	Access to	Access to
Recommendation 2.21	Speech language pathology	Yes	Access to
Recommendation 2.22	Nutrition	Yes	Access to
Recommendation 2.23	Palliative and end-of-life care	Yes	Access to
Recommendation 2.24	Mental health (psychology and psychiatry)	Yes	Access to

Services are provided on-site unless otherwise noted. CNS=central nervous system; ENT=ear, nose, and throat; NA=not applicable; OT=occupational therapy

Patient Coordination and Communication

The treatment journey following diagnosis with a CNS tumour can be a complex and disorienting experience for patients. Coordination is vital to ensuring the smooth transition between stages of care (e.g., diagnosis, surgery, adjuvant therapy, and surveillance). Ideally, an advisory service would be available throughout a patient's cancer/tumour journey that would cross different treatment specialties and locations and provide continuity and a single point of contact for information and advice [9, 10]. While such an advisory service does not currently exist in Ontario, resources are available for patients and caregivers and advice is provided on ways to enhance patient continuity of care.

The development of the role of MRP to effectively engage with patients within each service is encouraged, as is following the recommendations on maintaining continuity of care from person-centred care guidelines [11].

Most Responsible Physician

Recommendation 3

The MRP is an established role in cancer care. The MRP is responsible for a patient during a distinct stage of care (e.g., diagnosis, surgery, adjuvant therapy, and surveillance).

- A physician clearly identified to the patient should have responsibility for directing and coordinating the care and management of an individual patient at a distinct phase of care.
- An MRP should be identified for each service (e.g. surgery, radiation oncology, oncology) that interacts with a patient. The appropriate clinician to fill the MRP role should be determined at the local institutional level.
- Patients with CNS tumours will often receive care from more than one healthcare provider and at more than one healthcare institution. The MRP is the designated point of contact for patients, caregivers, and relatives and ensures the proper transfer of care between specialties and facilities.

Continuity of Care

All patients in Ontario with CNS tumours should have person-centred medical care. Because stages of care may be dispersed across healthcare providers and centres, optimal coordination of care is required. While individual services may effectively assist and communicate with patients and caregivers about matters relevant to their specialties, many issues that patients have identified as important may not be addressed. These (often practical) issues transcend one particular service or health professional's purview, and affect the entire patient care journey. Areas in which patients may need guidance include transportation and parking, long-distance travel to access specialized care, navigation of health care sites, and access to local support groups or online forums.

Person-centred care should be provided as outlined in the OH (CCO) person-centred care guideline [11]. The guideline provides specific recommendations for continuity of care, which include transition points through all phases of the care continuum.

Continuity of Care Recommendations from OH (CCO) Person-centred Care [11]

Assess each patient's requirement for continuity of care and their preference for how that requirement will be met. This may involve the patient seeing the same healthcare professional throughout a single episode of care, or ensuring continuity within a healthcare team.
For patients who require a number of different services (for example, services in both primary and secondary care, or different clinics in a hospital), ensure effective coordination and prioritization of care to minimize the impact on the patient.

Ensure clear and timely exchange of patient information: • between healthcare professionals in the circle of care (particularly at the point of transitions in care) • between the healthcare team and community services (with the patient's consent, in accordance with the Freedom of Information and Protection of Privacy Act [FIPPA]).
All staff directly involved in a patient's care should introduce themselves to the patient.
Inform the patient about: • who is responsible for their care and treatment • the roles and responsibilities of the different members of the healthcare team • the communication about their care that takes place between members of the healthcare team.
Give the patient information about what to do and who to contact in different situations, such as out of hours or in an emergency.

INITIAL ASSESSMENT

The care journey for patients with a CNS primary tumour is often precipitated by either a medical crisis and presentation to the emergency department or a progressive issue that ultimately requires referral by the family doctor. While imaging often provides a presumptive diagnosis, confirmation of diagnosis typically occurs with harvest of diagnostic tissue at surgery performed at a neurosurgical centre. Post-surgical primary assessment is conducted by a CNS-specific MCC. In some cases, patients may also be reviewed before surgery based on the findings of imaging (e.g., suspected chordoma).

Based on the tissue diagnosis, the MCC engages in complex decision-making to formulate a treatment plan that could involve second-look surgery, radiotherapy, or systemic therapy. Selected treatments may be delivered at a CNS Partner Site; however, the complexity and rarity of a case may prompt a recommendation toward adjuvant treatment being delivered at a CNS Network Centre (Table 1-3).

Multidisciplinary Case Conferences

MCCs ensure that each patient case is discussed in a multidisciplinary forum with appropriate expertise to generate an appropriate treatment plan. Participation in MCCs is a mechanism by which to ensure that 1) CNS Partner Sites have immediate access to experienced teams at CNS Network Centres; 2) referral pathways required by interdisciplinary care are streamlined; and 3) collegiality and understanding within and between disciplines are fostered. Videoconferencing allows partnering with another hospital that offers a specific disease site MCC or geographically distant partner hospitals.

More information about MCCs is available from the OH (CCO) website including an MCC standards document and several guideline-based clinical tools [12].

Recommendation 4

As per OH (CCO) guidelines for all cancer cases, all CNS primary tumour patient cases should be discussed at CNS-specific MCCs around the time of diagnosis and at progression/recurrence. MCC review is particularly critical for patients with CNS tumours, who often harbour rare tumours that require multi-disciplinary treatment.

Due to the nature of these diseases, engagement of palliative care early in the patient's journey is important. It is recommended that palliative care be considered/referred at the time of MCC. **Every MCC should define how palliative care physicians/teams will be engaged/consulted**. For example, consider palliative care team MCC attendance or clearly define how access to consultation with a palliative care physician/team will be completed near the time of diagnosis

SUBSEQUENT THERAPY

The cancer journey is one part – if sometimes a dominant and defining one – of an individual's life. This guideline has been developed to speak to the elements of the care system specific to the diagnosis and management of CNS primary tumours. These structures are not meant to replace the other pillars of support in a patient's life journey, such as family, community, and other primary caregivers (including a patient's family doctor), nor can they be reasonably expected to do so. Table 1-3 shows the sites that should provide services to patients with specific CNS primary tumours. Recognizing the complex and rare nature of most of these tumours, the services are almost all provided at CNS Network Centres. CNS Network Centres and patients also depend on CNS Partner Sites, which have developed appropriate expertise to provide some of these services, and other hospitals, which constitute a critical part of the support network for patients on the cancer journey.

Table 1-3. Central nervous system tumour specialized services for subsequent therapy

Recommendation	**CNS Tumours**		**CNS Network Centre**	**CNS Partner Site**
Recommendation 5.1	**Glioma and other parenchymal neoplasms**	IDH mutant gliomas Germ cell tumour Medulloblastoma Ependymoma Hemangioblastoma Pineal tumours	●	
Recommendation 5.2		Glioblastoma	●	●
Recommendation 5.3	**Sellar lesions**	Pituitary adenoma Parasellar meningioma Craniopharyngioma Optic pathway glioma	●	
Recommendation 5.4	**Skull-base lesions and meningioma**	Convexity meningioma Anterior fossa lesions Middle fossa lesions Posterior fossa lesions	●	

IDH=isocitrate dehydrogenase

PROVIDERS OF CNS TUMOUR CARE

The following health professionals in Table 1-4 may be involved to a greater or lesser extent in the care of patients with CNS tumours. The minimum qualifications and training requirements for professionals in Ontario are described for each provider.

Table 1-4. Central nervous system tumour healthcare providers

Recommendation	**Health Professional**	**Qualifications**
Surgery		
Recommendation 6.1	Neurosurgeon	Certified in Neurosurgery by the Royal College of Physicians and Surgeons of Canada (RCPSC) or other internationally recognized program or licensing board. Clinical training experience in the breadth of the discipline of Neurosurgery (vascular and endovascular, spinal, functional, neuro-

		oncology, peripheral nerve, radiosurgery, and pediatric neurosurgery) [13].
Recommendation 6.2	Skull-base surgeon	Royal College certified in Neurosurgery or Otolaryngology – Head and Neck Surgery or other internationally recognized program or licensing board plus a clinical fellowship within neurosurgery or head and neck surgery covering advanced training in treating lesions in and around the base of the skull [14, 15].
Recommendation 6.3	Neuro-ophthalmologist	Usually Royal College certified in Neurology, Ophthalmology, or both or other internationally recognized program or licensing board. Neuro-ophthalmology is a required part of the curriculum in all ophthalmology and neurology residency programs [16]. Also suggested a fellowship in neuro-ophthalmology [17].
Recommendation 6.4	Rhinologist – Head and Neck Surgeon (Ear, Nose, and Throat [ENT])	Royal College certified in Otolaryngology – Head and Neck Surgery or other internationally recognized program or licensing board [18] plus advanced training in Rhinology [19].
Recommendation 6.5	Neuro-otologist (also neurotologist)	Royal College certified in Otolaryngology – Head and Neck Surgery or other internationally recognized program or licensing board [20]. Also suggested a clinical fellowship in Medical & Surgical Otology/Neurotology [21].
Pathology		
Recommendation 6.6	Pathologist	Royal College certified in Anatomical Pathology or other internationally recognized program or licensing board [22].
Recommendation 6.7	Neuropathologist	Royal College certified in Neuropathology or other internationally recognized program or licensing board. At least 2 years of training in neuropathology including pediatric neuropathology, forensic pathology, and muscle and nerve neuropathology and has enhanced knowledge and skill in the pathology of CNS tumours [23].
Radiology		
Recommendation 6.8	Radiologist	Royal College certified in Diagnostic Radiology or other internationally recognized program or licensing board [24].
Recommendation 6.9	Neuroradiologist	Royal College certified in Diagnostic Radiology or other internationally recognized program or licensing board and completion of an accredited program in Neuroradiology, or equivalent. Enhanced knowledge and skill in performing cerebral and spinal angiography and CT, percutaneous spinal intervention, MRI, ultrasound, plain film radiology, and interventional neuroradiology/endovascular

		therapy related to the brain, head, neck, and spine [25].
Medicine		
Recommendation 6.10	Neurologist	Royal College certification in Neurology or other internationally recognized program or licensing board. Clinical training experiences in the breadth of the discipline of Neurology, with skill and experience in Neuro-oncology obtained from a formal clinical fellowship or substantial clinical training at an expert centre [26].
Recommendation 6.11	Endocrinologist	Royal College certification in Internal Medicine or Pediatrics or other internationally recognized program or licensing board plus Royal College certification in Endocrinology and Metabolism [27].
Medical Oncology		
Recommendation 6.12	Medical Oncologist	Royal College certification in Internal Medicine and completion of post-graduate training in Medical Oncology (after completion of Internal Medicine) is required, or accreditation from an internationally recognized program or licensing board. Has enhanced knowledge and skill in Neuro-oncology obtained from a formal clinical fellowship or substantial clinical training at an expert centre [28].
Recommendation 6.13	Neuro-oncologist	Royal College certification in Neurology and completion of post-graduate training in Neuro-Oncology is required, or accreditation from an internationally recognized licensing board [29]. OR Medical Oncologist (as above) with enhanced knowledge and skill in Neuro-oncology obtained from a formal clinical fellowship or substantial clinical training at an expert centre.
Radiation Oncology		
Recommendation 6.14	Radiation Oncologist	Royal College certification in Radiation Oncology or accredited by an internationally recognized program or licensing board [30].
Recommendation 6.15	CNS Radiation Oncologist	Royal College certification in Radiation Oncology or accredited by an internationally recognized program or licensing board [31]. Enhanced knowledge and clinical training in the treatment of patients with CNS tumours obtained through a fellowship in CNS cancer radiotherapy is required [8].
Recommendation 6.16	Medical Physicist	Graduate degree in Medical Physics, Physics, Science with Physics as a major, or another field deemed acceptable by the Board of the Canadian College of Physicists in Medicine. Certified by the Canadian College of Physicists in Medicine or an equivalent

		national or international certification agency [32].
Recommendation 6.17	Medical Radiation Therapist	Bachelor's degree in Medical Radiation Sciences plus an advanced college diploma. Certified by the Canadian Association of Medical Radiation Technologists or an equivalent national or international certification agency [33].
Recommendation 6.18	Medical Dosimetrist	Bachelor's degree in Medical Radiation Sciences plus an advanced college diploma, and completion of the Canadian Dosimetry Certificate program from the Canadian Association of Medical Radiation Technologists [34].
Nursing		
Recommendation 6.19	Oncology Nurse	Bachelor's degree in nursing (BScN) and successful completion of the registration exam of the College of Nurses of Ontario (RN) [35]. Certification by the Canadian Nursing Association in Oncology Nursing (C)anada (CON(C) is recommended [36] and expertise in CNS cancers (medical and surgical), palliative care, epilepsy, and psychosocial oncology, depending on area of involvement in CNS tumour care.
Recommendation 6.20	Nurse Practitioner	Master's degree in nursing with NP adult specialty or primary health care certification and RN(EC) registration with the College of Nurses of Ontario [37]. Hospital or patient care experience in CNS tumours. Certification by the Canadian Nursing Association in Oncology Nursing (C)anada (CON(C) is recommended [36].
Allied Health & Rehabilitation/Psychosocial Oncology		
Recommendation 6.21	Social Worker	Master's degree in social work (MSW) and registered with the Ontario College of Social Workers and Social Service Workers (RSW) [38]. Hospital or patient care experience in CNS tumours.
Recommendation 6.22	Physiotherapist	Master's degree in physiotherapy and registered with the College of Physiotherapists of Ontario [39].
Recommendation 6.23	Occupational Therapist	Master's degree in occupational therapy and completion of the National Occupational Therapy Certification Examination and registered with the College of Occupational Therapists of Ontario [40]. Hospital or patient care experience in CNS tumours.
Recommendation 6.24	Speech Language Pathologist	Master's degree in speech language pathology from a Canadian university program accredited by the Council for Accreditation of Canadian University Programs in Audiology

		and Speech-Language Pathology (CACUP-ASLP) and registered with the College of Audiologists and Speech-Language Pathologists of Ontario (CASLPO) [41].
Recommendation 6.25	Nutritionist/Dietitian	Bachelor's degree in nutrition/dietetics/food science from a Canadian university program and completion of a practicum program accredited by the Partnership for Dietetic Education and Practice. Successful completion of the Canadian Dietetic Registration Examination [42].
Recommendation 6.26	Psychologist	Doctoral degree in clinical psychology. Registered with the College of Psychologists of Ontario [45]. Clinical neuropsychology is a specialty stream within clinical psychology training. Has special expertise in the applied science of brain-behavior relationships.
Recommendation 6.27	Psychiatrist	Royal College certification in psychiatry or accredited by an internationally recognized program or licensing board [46]. Subspecialty of neuropsychiatry provides enhanced knowledge of neurological mechanisms of mental illnesses.
Palliative Care		
Recommendation 6.28	Palliative Medicine Physician	Completion of a Royal College-accredited program in adult Palliative Medicine or accredited by an internationally recognized program or licensing board [43] or Certificate of Added Competence from the College of Family Physicians of Canada [44]. The role of Nurse Practitioner may also apply to palliative care.
Primary Care		
Recommendation 6.29	Primary Care Physician	Successful completion of an approved training program and the Certification Examination in Family Medicine of the College of Family Physicians of Canada (CFPC) [47]. Primary care physicians are responsible for the overall health of the patient and are vital to the continuity of care throughout the patient's cancer journey. Although not involved in the day-to-day treatment of the cancer patient, the primary care physician has an important role in post-treatment supportive care and may be actively involved at other stages of care. Primary care physicians are included in all communications. The role of Nurse Practitioner may also apply to primary care.

CNS=central nervous system; CT=computed tomography; MRI=magnetic resonance imaging

FUTURE CONSIDERATIONS

Virtual care in cancer care in Ontario has existed in a limited form, but its adoption has accelerated during the COVID-19 pandemic. OH (CCO) has recently completed a guideline and evidence summary of relevant literature on virtual care in patients with cancer [48, 49].

Feedback from both patient and clinician groups made it clear that there is a need for development of the role of patient navigator. While this need might be relevant for all cancer care, CNS tumour care is a particularly complex landscape that requires excellent communication across many healthcare services. The role of patient coordinator is that of an intermediary between the patient and the healthcare system. The patient coordinator should be a dedicated health professional or team that serves as a liaison between the patient and various health professionals and is available to offer practical advice and assistance to the patient throughout their care journey. Potential patient coordinator responsibilities are:

- to be a point of contact for the patient or family at all times through the care journey.
- to be familiar with the patient’s file.
- to refer the patient to the most appropriate health professional to answer a specific question.
- to assist the patient in processing information received from various health professionals.
- to provide the patient with information about local support groups, online forums, Facebook groups (e.g., Brain Tumour Foundation of Canada), and travel assistance (e.g., Hope Air).
- to assist the patient with accessing community health and social services supports.
- ideally, to assist the patient with care transitions across healthcare facilities.

Organizational Guidance for the Care of Patients with Central Nervous System Tumours in Ontario: Consensus Recommendations

Section 2: Guideline Methods Overview

This section summarizes the methods used to create the guideline

THE PROGRAM IN EVIDENCE-BASED CARE

The Program in Evidence-Based Care (PEBC) is an initiative of the Ontario provincial cancer system, Ontario Health (Cancer Care Ontario) (OH (CCO)). The PEBC mandate is to improve the lives of Ontarians affected by cancer through the development, dissemination, and evaluation of evidence-based products designed to facilitate clinical, planning, and policy decisions about cancer control.

The PEBC supports the work of Guideline Development Groups (GDGs) in the development of various PEBC products. The GDGs are composed of clinicians, other healthcare providers and decision makers, methodologists, and community representatives from across the province.

The PEBC is a provincial initiative of OH (CCO) supported by the Ontario Ministry of Health (OMH). All work produced by the PEBC is editorially independent from the OMH.

GUIDELINE DEVELOPERS

This guideline was developed by the Organizational Guidance for the Care of Patients with CNS Tumours GDG (Appendix 1), which was convened at the request of OH (CCO) Disease Pathway Management.

The project was developed using a formal consensus process described in detail below. It was led by a small Working Group of the GDG, which was responsible for reviewing the evidence, drafting the guideline recommendations, and responding to comments received during the document review and consensus process. The Working Group included experts in neurosurgery, neuro-oncology, radiation oncology, and health research methodology. Other members of the Organizational Guidance for the Care of Patients with CNS Tumours GDG served as the Expert Panel and were responsible for the review and approval of the draft document produced by the Working Group by means of a consensus process. Conflict of interest declarations for all GDG members are summarized in Appendix 1, and were managed in accordance with the *PEBC Conflict of Interest Policy*.

GUIDELINE DEVELOPMENT METHODS

The steps in the guideline development process are outlined in Appendix 2.

Literature Search

The purpose of the guideline was to provide guidance for the organization of CNS tumour care in Ontario. A search for recent guidelines was conducted to determine whether any organizational guideline existed that could be endorsed. The following resources, agencies, and guideline developers were searched:

- Guidelines International Network Library

- ECRI Guidelines Trust
- Canadian Partnership Against Cancer - Cancer Guidelines Database
- CPG Infobase: Clinical Practice Guidelines
- TRIP Database
- National Institute for Health and Care Excellence (NICE)
- Scottish Intercollegiate Guidelines Network (SIGN)
- European Association of Neuro-Oncology (EANO)
- American Society of Clinical Oncology (ASCO)
- European Society for Medical Oncology (ESMO)
- National Comprehensive Cancer Network (NCCN)
- Ontario Health (Cancer Care Ontario) (OH [CCO])
- Cancer Care Nova Scotia
- Cancer Care Manitoba
- Alberta Health Services
- BC Cancer Agency
- Agency for Healthcare Research and Quality (AHRQ)
- Canadian Agency for Drugs and Technologies in Health (CADTH)

Guidelines from three developers (NCCN, EANO, NICE) that pertained to CNS tumours were identified and examined for their potential for endorsement. However, none of these guidelines could be endorsed as documents providing organizational guidance for CNS tumour care in Ontario.

The NCCN guideline focused on aspects of management (diagnostics, treatment, and follow-up), but not the organization or infrastructure required for caring for patients with CNS tumours [50]. The EANO guidelines focused on individual tumours [51, 52] or specific aspects of organizational care, such as end of life [53]. A guidance document from NICE contained some organizational recommendations, but these were closely aligned with the health system in the United Kingdom and were not applicable to the healthcare environment in Ontario [10]. There were, however, some concepts from NICE including multidisciplinary teams and key workers that informed the development of recommendations for the Ontario guideline.

The Working Group members were aware of other OH (CCO) organizational guidance documents from radiation therapy and head and neck cancer that were similar in purpose to the goals of this document [8, 54], as well as provincial service plans for sarcoma, leukemia, and complex hematology [55-57].

Because of a scarcity of evidence to support organizational guidance for CNS tumour care, a consensus-based approach using a modified Delphi process was used to establish the soundness of the recommendations.

GUIDELINE REVIEW AND APPROVAL

Patient and Caregiver-Specific Consultation Group

Three patients/caregivers participated as a Consultation Group for the GDG. They reviewed copies of the project plan and draft recommendations and provided feedback on comprehensibility, appropriateness, and feasibility to the Working Group's Health Research

Methodologist. The Health Research Methodologist relayed the feedback to the Working Group for consideration.

Expert Panel

The Expert Panel included clinicians from diverse specialties involved in the care of patients with CNS tumours (neurosurgery, neuroradiology, skull-base surgery, radiation oncology, medical oncology, neuro-oncology, palliative care, neuropathology, pediatric oncology, nursing, social work, and administration). The Expert Panel performed the role of a consensus panel.

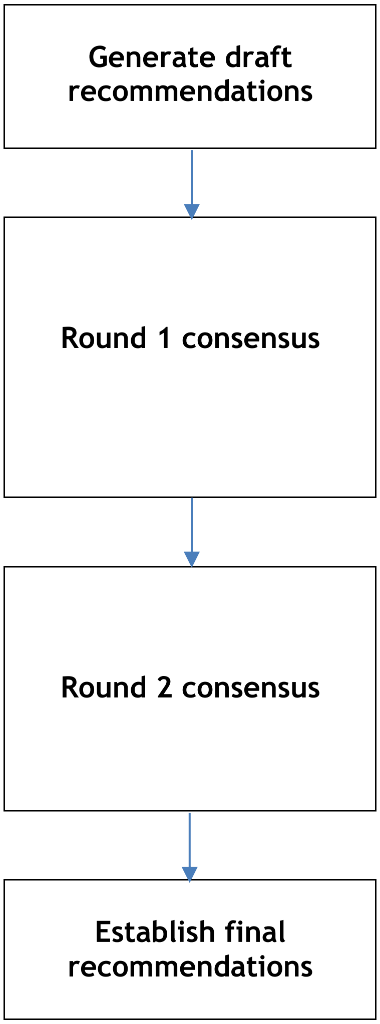
Consensus process

A modified Delphi process was used to review and reach consensus on the draft recommendations. The steps in the planned process are outlined in Figure 2-1. The process followed the methodology proposed by ASCO [58]. The Expert Panel participated in a two-round consensus process, facilitated by an online survey. The consensus threshold was defined as 75% or more of respondents having registered agreement or strong agreement in favour of the recommendation.

In the first round of consensus, the Expert Panel members received an email with links to the draft guideline document and an online survey. In the survey, the panel members rated their level of agreement with each recommendation on a five-point Likert scale, ranging from “strongly agree” (1), through “neither agree nor disagree” (3), to “strongly disagree” (5). The first-round feedback was analyzed, and the percent agreement, median score, and overall response rate were calculated for each recommendation. The results were distributed to the Working Group and the members revised the initial recommendations that did not meet the consensus threshold.

In the planned second round of consensus, the Expert Panel members would have received the draft guideline, the results of the first consensus round, and the modified recommendations, for which they were asked to rate their level of agreement. In this case, consensus was reached in Round 1 and we did not execute Round 2.

Figure 2-1. Planned Consensus Process



Working Group

- Define questions
- Conduct guideline review
- Formulate recommendations

Expert Panel

- Receive draft guideline and online survey
- Rate level of agreement on 5-point scale with each recommendation and provide comments

Working Group

- Revise recommendations not reaching consensus

Expert Panel

- Receive draft guideline, results of the first consensus round, and online survey with modified recommendations
- Rate level of agreement for each of the modified recommendations and provide comments

Working Group

- Review consensus results and establish final recommendations

Report Approval

This guideline was reviewed and approved by the Scientific Director of the PEBC. The methodology used for this guideline was a formal consensus agreement and no formal evidence search and synthesis methods were used. The recommendations are based on the collective expertise and experience of the participants in the consensus process.

External Review

Feedback on the approved draft guideline was obtained from content experts through professional consultation. Members of Canadian Neuro-Oncology (CNO), clinicians and allied health professionals who care for patients with CNS tumours, and other potential users of the guideline were contacted and asked to provide feedback on the guideline recommendations through a brief online survey.

DISSEMINATION AND IMPLEMENTATION

The guideline will be published on the OH (CCO) website and may be submitted for publication to a peer-reviewed journal. The professional consultation of the external review is intended to facilitate the dissemination of the guideline to Ontario practitioners. Section 1 of this guideline is a summary document to support the implementation of the guideline in practice. OH (CCO)-PEBC guidelines are routinely included in several international guideline databases including the CPAC Cancer Guidelines Database, the CMA/Joule CPG Infobase database, ECRI Guidelines Trust, NICE Evidence Search (UK), and the Guidelines International Network (GIN) Library.

ACKNOWLEDGEMENTS

The Organizational Guidance for the Care of Patients with CNS Tumours GDG would like to thank the following individuals for their assistance in developing this report:

- Katharina Forster, Sarah Kellett, Lorraine Martelli, Sheila McNair, Emily Vella, Jonathan Sussman, and Caroline Zwaal for providing feedback on draft versions.
- Thanansayan Dhivagaran for conducting a data audit.
- Sara Miller for copy editing.

Organizational Guidance for the Care of Patients with Central Nervous System Tumours in Ontario: Consensus Recommendations

Section 3: Consensus Process and Internal and External Review

INTERNAL REVIEW

The guideline was evaluated by the Patient and Caregiver-Specific Consultation Group, the GDG Expert Panel, and the PEBC Report Approval Panel (RAP) (Appendix 1). The results of these evaluations and the Working Group's responses are described below.

Patient and Caregiver-Specific Consultation Group

Two patients and one caregiver participated as Consultation Group members for the Working Group. They reviewed the draft guideline and provided feedback on its comprehensibility, appropriateness, and feasibility to the Working Group's Health Research Methodologist. The main comments from the Consultation Group are summarized in Table 3-1.

Table 3-1. Summary of the Working Group's responses to comments from the Patient and Caregiver Consultation Group

Comments	Responses
It is not clear how host and partner sites are integrated and how they provide easier access. Will they have joint tumour boards?	In the care settings section, we noted the importance of MCCs in establishing connections between host sites and partner and other hospital sites.
Caregivers should be included in the target population.	We have included caregivers wherever patients are mentioned.
Virtual care was raised as an important feature.	Virtual care is a timely topic but not directly discussed in this guideline. This issue needs to be addressed at a higher level than is feasible in this document. We comment on it in future considerations and note that OH (CCO) is currently developing guidance in this area.
The availability of assistance (including after-hours) is important to patients and caregivers. Desire for a patient coordinator role, separate from the MRP.	The Working Group acknowledges the importance of this role to patients and caregivers but notes that this position transcends the domain of CNS tumours. Rather than recommend for the creation of the position, the Working Group encourages adherence to the recommendations in the OH (CCO) guideline on person-centred care. Furthermore, the specific responsibilities as envisioned by the Patient-Caregiver Consultation Group are described in this guideline under Future Considerations.
The wording for the recommendation on MCCs indicates that cases should discussed at CNS-specific MCCs before post-surgical treatment and after recurrence. Shouldn't the patient be discussed before ANY treatment, including surgery?	We have changed the recommendation to "CNS primary tumour patient cases should be discussed at CNS-specific MCCs around the time of diagnosis and at progression/recurrence." The case scenarios should also help illustrate the timing of tumour board review.

Some services important to patients are not included: Funding assistance, exercise, medical assistance in dying (MAID), emergency care, virtual care, physical assistance (including transportation), at home assistance, second opinion, specialized allied health care (e.g., physiatrist).	The Working Group acknowledges the importance of these items to patients. Several are likely covered by the various services we have discussed while others may be less commonly available.
Examples were given of lack of continuity of care (e.g., contact phone numbers constantly answered by different people with no knowledge of the patient's details so all information had to be repeated each time.	The hope is to address such situations by following the guidance of person-centred care and the roles of MRP and patient coordinator.
With respect to the MRP, ideally there should be at least one doctor, one nurse, and one social worker.	According to our recommendation, there is an MRP associated with each service or stage of care. It may not be possible to have an "MRP Team" or that particular configuration.
Transitions between services and from the cancer system to the primary care physician are a concern for patients/caregivers. Patients should be able to contact the MRP with a concern even after they transition to a different stage of care, and even they leave the cancer system. Primary care physicians need education to be able to care for a patient CNS tumour without having to send them to the emergency department.	We indicate the MRP ensures the proper handover of care between specialties and facilities. We indicate that primary care physicians are a recognized member of the patient's care team and have an important role in post-treatment supportive care. They may be actively involved at other stages.

Expert Panel Review and Approval

Thirty-four healthcare professionals were invited to join the Expert Panel; 28 agreed to participate. The consensus survey was sent on August 13, 2021 to each Expert Panel member by email. The draft of the guideline document was also attached.

Twenty-four panel members completed the first round of the consensus survey (Appendix 1). The healthcare professions represented in the Expert Panel were neurosurgery (n=3), medical oncology or neuro-oncology (n=2), radiation oncology (n=6), pathology (1), radiology (1), nursing (n=1), palliative care (n=1), social work (n=1), and operations (n=4). Four Ontario Provincial Heads/Quality Leads for systemic treatment, radiation treatment, pathology and laboratory medicine, and surgical oncology also completed the survey.

Consensus Survey Results

The level of consensus agreement was strong for the recommendations. Each recommendation had a percent agreement of 75% or more, meeting the consensus threshold. The data are shown in Table 3-2.

Table 3-2. Consensus Survey Score Frequencies and Percent Agreement

Rec #	Rec Description	1 Strongly agree	2 Agree	3 Neither agree nor disagree	4 Disagree	5 Strongly disagree	Not applicable	# respondents	% agreement	Median score
1.1	CNS Network Cente/CNS Partner Site/other definitions	11	10	2	1			24	91.7	2
1.2	CNS Partner Site & other hospitals connections	19	5					24	100	1
1.3	Practice volumes	15	5	4				24	83.3	1
2.1	Required services	19	5					24	100	1
2.2	Additional services	17	6	1				24	95.8	1
2.3	Diagnostics	13	8	3				24	87.5	1
2.4	Medical/Neuro-oncology	12	11	1				24	95.8	1.5
2.5	Radiation oncology	12	10	2				24	91.7	1.5
2.6 to 2.12	Surgical services	13	8	2	1			24	87.5	1
2.13	Endocrinology	11	11	2				24	91.7	2
2.14	Neurology	11	10	2	1			24	87.5	2
2.15	Nursing	13	9	2				24	91.7	1
2.17	Social work	19	5					24	100	1
2.18	Physiotherapy	14	7	2	1			24	87.5	1
2.19	Occupational therapy	14	7	2	1			24	87.5	1
2.20	Rehabilitation	11	7	5	1			24	75	2
2.21	Speech language pathology	13	6	5				24	79.2	1
2.22	Nutrition	11	12	1				24	95.8	2
2.23	Palliative & end-of-life care	19	4	1				24	95.8	1
2.24	Mental health	14	9	1				24	95.8	1
3	MRP	13	8	2	1			24	87.5	1
4	MCCs	16	5	2	1			24	87.5	1
5.1 to 5.2	Glioma and Glioma - IDH wild type	7	11	2	3	1		24	75	2

Rec #	**Rec Description**	**1 Strongly agree**	**2 Agree**	**3 Neither agree nor disagree**	**4 Disagree**	**5 Strongly disagree**	**Not applicable**	**# respondents**	**% agreement**	**Median score**
5.3	Sellar lesions	9	12	2	1			24	87.5	2
5.4	Skull base lesions	9	11	2	1	1		24	83.3	2
6.1	Neurosurgeon	14	6	3	1			24	83.3	1
6.2	Skull-base surgeon	15	5	4				24	83.3	1
6.3	Neuro-ophthalmologist	12	9	3				24	87.5	1
6.4	Rhinologist	11	11	2				24	87.5	2
6.5	Neuro-otologist	10	9	5				24	79.2	2
6.6	Pathologist	13	9	1	1			24	91.7	1
6.7	Neuropathologist	17	4	3				24	87.5	1
6.8	Radiologist	15	9					24	100	1
6.9	Neuroradiologist	15	7	2				24	91.7	1
6.10	Neurologist	13	10	1				24	95.8	1
6.11	Endocrinologist	13	9	2				24	91.7	1
6.12	Medical oncologist	11	13					24	100	2
6.13	Neuro-oncologist	14	8	1	1			24	91.7	1
6.14	Radiation oncologist	15	9					24	100	1
6.15	CNS radiation oncologist	15	8		1			24	95.8	1
6.16	Medical physicist	14	8	1			1	24	91.7	1
6.17	Medical radiation therapist	12	10	1			1	24	91.7	1.5
6.18	Medical dosimetrist	12	10	1			1	24	91.7	1.5
6.19	Oncology nurse	10	14					24	100	2
6.20	Nurse practitioner	13	11					24	100	1
6.21	Social worker	12	11	1				24	95.8	1.5
6.22	Physiotherapist	9	11	3	1			24	83.3	2
6.23	Occupational therapist	9	11	3	1			24	83.3	2
6.24	Speech language pathologist	11	10	2				23	91.3	2

Rec #	Rec Description	1 Strongly agree	2 Agree	3 Neither agree nor disagree	4 Disagree	5 Strongly disagree	Not applicable	# respondents	% agreement	Median score
6.25	Nutritionist/Dietitian	12	11					23	100	1
6.26	Psychologist	10	10	3				23	87	2
6.27	Psychiatrist	10	12	1				23	95.7	2
6.28	Palliative medicine physician	11	11		1			23	95.7	2
6.29	Primary care physician	12	10	1				23	95.7	1

Although the recommendations did not require revisions based on consensus threshold, the Expert Panel members made several comments that the Working Group wished to address. The main themes that emerged from the comments were requests for clearer definitions and descriptions of CNS Network Centres and CNS Partner Sites and the role of specialty hospitals, care provided in the community, and training requirements of certain healthcare providers. The comments and responses are summarized in Table 3-3.

Table 3-3. Summary of the Working Group's responses to comments from the Expert Panel

Comments	Responses
CNS Network Centre & CNS Partner Sites	
Do all host sites provide care for every type of tumour? Even the very rare or ones requiring very subspecialty care? What are the minimum criteria to be a partner site?	Host sites should have the full complement of services to care for patients with CNS tumours. We recognize that some CNS cancers are very rare requiring expertise that may be only available at selected host sites or even at a partner site. The Working Group added case scenarios to illustrate the interactions and relationships of different centres.
Specialty hospitals	
There are hospitals in large urban centres that only provide specialized neurosurgery but do not have all the medical oncology / radiation oncology services. The partner site definition does not address these hospitals.	Specialty hospitals would be considered partner sites with specific expertise that would liaise with a host site to access the full spectrum of care. We acknowledge that a specific specialty may reside at a particular hospital (e.g., specialized neurosurgery) and in these cases the

	host site without that expertise might refer patients to the partner site for that service.
Volumes	
How is this going to be monitored or managed? Who decides what a “sufficient volume” is? It is more important to be familiar with the recommended treatment, be it a drug or radiotherapy; so, sufficient volumes to administer that treatment may be more important than specific volumes for a specific tumour type, as many treatments are similar in CNS for a variety of different entities, as long as they have accessed the expertise of a host centre to determine the recommended treatment and follow up. It is likely that host sites with all of the expertise listed will have reasonable volumes of patients with common CNS tumours. Collaboration with more specialized, higher volume sites should be encouraged for more moderate sized sites with options for provincial multidisciplinary rounds for rare tumour discussion. The volumes are driven by disease prevalence. I am not sure that the titles partner sites and other sites based on volume is realistic or reasonable provided they capture the majority of cases in the region they serve.	It is generally accepted that patient outcomes are better in high-volume centres for most patient interventions. The designations of host and partner were based on recent captured treatment volumes in Ontario from a survey of expertise at Ontario sites. We changed the recommendation wording slightly to reflect this.
Minimum services	
Does this mean centres categorized as partner sites can offer a broad spectrum of primary neurosurgical management within a multidisciplinary setting with host neurosurgical sites being accessible as complex cases warrant this? The guideline may be misleading in that only 'host' sites are able to perform treatment within the surgical sites listed. Sub-specialty neuro disciplines such as neuro-otology and skull-base neurosurgery may not be available in smaller partner site communities despite having fully experienced and equipped neurosurgery and ear, nose, and throat (ENT). Does this assume that the surgery is only performed at the host site? Are all these surgeries feasible at all host sites? How would a site be classified if there is only access to certain "other" surgical sub-specialties (i.e., ENT but not otology, etc). Neurosurgical input from those neurosurgeons practicing within partner sites within a fully equipped and experienced neuro surgical team plays an integral role in care in non-academic or evolving academic programs	The Working Group is addressing these questions about surgery by illustrating issues with case scenarios. Services that can be provided at partner sites should be delivered but having a close relationship with a host site ensures that advice and expertise regarding more complex care is available.

Do the specialties “on site” at the host centre and “access to” at the partner centre 'infer' that the specialty only need be available at a host site or…does 'access to' mean that local expertise is an appropriate option if available?	The Working Group agrees that in certain cases local expertise is an option and explained further what “access to” means in the text preceding Table 1-2.
Social work personnel at host site should have CNS expertise and social work personnel at the partner site should have access to that specialized personnel at the host site. Occupational therapy personnel at host site should have CNS expertise and available for consultation by occupational therapists at partner sites or in the community.	We made these modifications to social work and occupational therapy.
Physical therapy/occupational therapy will be provided at the site that does the surgery, but unlikely at partner sites or other hospitals. Need to access as outpatients – private clinic or home care.	We added a statement about outpatient services in the community setting.
Subsequent therapy	
Is the recommendation really talking about "subsequent" therapy or the role of surgery?	The Working Group maintains that the label “subsequent therapy” best describes the recommendations in this section. Chemotherapy and radiotherapy would be the main features of subsequent therapy.
Allied health and inpatient/outpatient services	
While the framework does cover care settings for the acute management of CNS tumours, patients also continue to get care in community- based health care settings. I think this should be acknowledged. Primary care physicians/NPs continue to provide care for concurrent illnesses as well as often supporting management of complications of the tumour or its treatment. Palliative care is also often provided in community settings, including home and hospice in addition to hospital-based services.	The Working Group agreed that the guideline should address services in the community to outpatients with CNS tumours because a great deal of primary and allied health care as well as palliative and end-of-life care is provided outside of hospitals. We added a description in Recommendation 2.2.
Why is primary care not included? Their role is (and/or should be) significant?	Primary care physicians are included in all communications and are recognized as a member of the patient’s care team. We noted this in the description of Palliative Care Physician training and expertise.
Easy access to a stand-alone hospice setup for the best possible end-of-life care is an absolute need across the province. This is very patchy at the moment. There should be inpatient palliative care settings as well as strong linkages with community palliative care program.	The Working Group expects that host centres would have inpatient palliative care settings and agree that there should be access to community palliative care programs by partner sites that have no or limited inpatient palliative care.
Access to a neuro-psychologist should be available at each host site, and access to same should be available to partner sites. A neuro-psychologist provides and expertise and support	The Working Group feels that the rarity of the specialty makes it infeasible to require a neuro-psychologist at all host sites.

for patients with CNS tumours that is different than a general psychologist.	
Psychology and psychiatry will not be available in many places. Are these crucial services for these patients, more than the other components?	The Working Group expects that host centres would have psychology and psychiatry services on site and agree that partner sites that have limited mental health services should have access to such programs.
Psychology/psychiatry are services patients might have access to as inpatients, but with high volumes it is difficult to access in a timely manner as outpatient. If the compensation model addressed this maybe centres could gain access to dedicated individuals for just patients with CNS tumours.	We changed most of the allied health services to “access to” under partner sites. The Working Group understands that some services will not necessarily be on-site at a partner hospital and may need to be accessed at local hospitals or in the community.
Most Responsible Physician	
I am not clear why we specifically need to say an MRP is required for CNS tumors - isn't it the same for all cancer care?	We added words indicating MRP is a role that exists beyond patients with CNS tumours.
In addition to the MRP, a navigator assigned to each patient would be ideal. Someone that can help the patient from the beginning of the diagnosis to resolution. Patient needs to be helped with having a clear main point of contact should be for questions and concerns. This is challenging with multiple "MRPs". A major problem for patients is navigating this complex landscape. A single site when possible, with multidisciplinary care available at each visit would likely be best approach. Three MRPs is already confusing. I struggle with the idea of "one" MRP for patients who may also have multiple other medical issues. Is it possible to specify the MRP is related to the cancer, the primary care physician retaining a role for other health conditions (though even then can be a challenge for things like pituitary tumours, where endocrinology may also have a key role). It is certainly critical, however, for there to be excellent communication for patients and families about who to contact for what issues. There also need to be very clear and simple lines of communication for all members of the care team to communicate.	The Working Group recognizes the need for the role of patient navigator – a single point of contact for patients and caregivers to obtain information and guidance. The Patient-Caregiver Consultation group also strongly urges the creation of such a role. In the meantime, the Working Group encourages adherence to the guidance recommended in the Person-centred Care guideline [5]. Continuity of care recommendations from this guideline are included in this document.
Multidisciplinary Case Conference	
Make sure the MCC isn’t too prescriptive or dictatorial. The role should be for the various disciplines to advise the referring physician on best possible care. Potential in the bigger centres to have a large number of patients per week with recurrent	We have modified the recommendation slightly. The best practice would be to see all patients. The Working Group encourages that sites aspire to have MCCs at progression/recurrence.

disease. Does every recurrent GBM need to be discussed at rounds? Also, in terms of timeliness, sometimes the wait for the next MCC meeting is too long and the oncologist and surgeon need to meet sooner.	
Provider qualifications/expertise	
Why is a general and CNS-specific provider listed for pathology and radiology?	Depending where they first present, patients with CNS tumours may be initially reviewed by a general pathologist or radiologist before being referred to a host centre or partner centre with CNS expertise.
Not sure why in the document there is the specification of a CNS Fellowship for Radiation Oncologists in some parts of the document but not for Medical Oncology. A similar standard of training for both disciplines to be considered a CNS Oncologist (medical or radiation) should be in place for both disciplines.	We agree this should be clarified and have added the CNS expertise requirement to medical oncologist.
Medical Oncologist (following internal medicine or pediatrics) with subspecialty training (Fellowship) in neuro-oncology should also be considered a neuro-oncologist.	We added this wording to Neuro-Oncologist.
CON(C) is not a required designation with unionized members in Ontario. It is a preferred designation, but cannot be mandated.	We added that CON(C) designation would be of benefit.
And there are palliative care nurse practitioners. Should that be noted?	We noted for the description of Nurse Practitioner training and expertise.
While the one-year program in palliative medicine was previously dually accredited by both the Royal College and the College of Family Practice of Canada, there are now two separate programs. This creates a challenge if "Royal College accredited program" is the standard moving forward, as the pool of graduating palliative medicine physicians who hold a Year of Added Competency from the College of Family Practice (without the dual accreditation) will grow over time. Can either training be recognized if appropriate experience/expertise.	We noted this in the description of Palliative Care Physician training and expertise.

RAP Review and Approval

One RAP member (PEBC Scientific Director) reviewed this document in January 2022. The RAP approved the document on January 24, 2022.

The RAP reviewer requested more detail on how the actual draft recommendations were synthesized. We responded by making it clear that the guideline was consensus based. We added “Consensus Recommendations” to the end of the title to quickly focus the reader’s attention and establish that the guideline was developed using a consensus process. We also referenced other organizational guidance documents that were used as models for the framework of this guideline.

EXTERNAL REVIEW

External Review by Ontario Clinicians and Other Experts

Professional Consultation

Feedback was obtained through a brief online survey of healthcare professionals and other stakeholders who are the intended users of the guideline. Members of Canadian Neuro-Oncology (CNO), clinicians and allied health professionals who care for patients with CNS tumours, and other potential users of the guideline were contacted by email and asked to provide feedback on the guideline recommendations through a brief online survey. Fifty-nine professionals were contacted. Thirty-two professionals practiced in Ontario and 27 were from outside Ontario.

Nineteen (32%) responses were received. The results of the feedback survey are summarized in Table 3-4. The main comments from the professional consultation and the Working Group's responses are summarized in Table 3-5.

Table 3-4. Responses to four items on the professional consultation survey

	Number 19 (32%)				
General Questions: Overall Guideline Assessment	Lowest Quality (1)	(2)	(3)	(4)	Highest Quality (5)
1. Rate the overall quality of the guideline report.				9	10
	Strongly Disagree (1)	(2)	(3)	(4)	Strongly Agree (5)
2. I would make use of this guideline in my professional decisions.	1		2	6	10
3. I would recommend this guideline for use in practice.				9	10
4. What are the barriers or enablers to the implementation of this guideline report?	See below				

Barriers mentioned by respondents

Qualified healthcare professionals and availability of services:

Are there enough CNS fellowship-trained physicians at existing host sites for these sites to keep their designations?

Are there sufficient neuro-oncologists able and willing to attend partner site MCC rounds?

Access to neuroimaging appropriate for each brain tumour, timely radiology reports.

Limited access to allied health services such as speech language pathology and occupational therapy, even at host sites.

Lack of community palliative care services and providers and other supportive services.

Not all CNS sites will have access to the entire list of recommendations, and this may be seen as a limitation; however, the required resources should be able to be met by all CNS host sites.

Travel:

To avoid traveling long distances, some patients might choose to be treated at a local site without CNS expertise.

Cooperation:

Buy-in from partner and non-academic sites.

How to accomplish in real-time communication between broad multidisciplinary team members across host, partner, and other sites and not cause delays for the patient?

Patient navigator:

Need for patient navigator, particularly to facilitate communication between patient/family and the appropriate MRP.

Education important at all levels – including hospital staff answering phones, emails.

Resources:

Budget, resource allocation.

Enablers mentioned by respondents

The guideline clearly outlines interprofessional team members and their roles.

The guideline provides a framework in which host and partner sites can team up, allowing more high-quality CNS care to take place in the community.

Despite a current lack of CNS fellowship-trained oncologists, the wording of the document clarifies what is needed so that centres can plan to recruit more appropriately trained staff.

Treatment of CNS tumours is already largely confined to a few centres. This guideline will ensure quality is maintained and in some cases, resources may potentially be expanded in response to it. Support from cancer centre leaders and some funding may be necessary to achieve the standard set out in the guideline to the benefit of patients.

Improved platforms for virtual care.

Multidisciplinary teams.

Patient/caregiver advocacy groups, support groups, and foundations.

Although the guidelines have an Ontario focus, they could serve as a model for guidelines outside the province.

Table 3-5. Summary of the Working Group's responses to comments from professional consultation

Comments	**Responses**
It would be helpful to know which centres provide what. Can the current organization of host, partner, and other centres in Ontario be included?	The purpose of the guideline is to recommend the services that should be in place or accessible to patients with CNS tumours. We anticipate that services currently in place will not remain static and liaisons will form between sites to expand services to patients.
This guideline would benefit from the inclusion of a quality framework such as described in the Canadian Quality & Patient Safety Framework for Health Services from the Canadian Patient Safety Institute. Frameworks that highlight integration of care are particularly relevant.	This is an important consideration, but beyond the scope of this initial guideline.
Regarding Nurse Practitioners – the guideline states Adult specialty certification. NPs can be Primary Health Care certified as well.	We have added Primary Health Care certification to the qualifications for Nurse Practitioner.
The classification of brain tumors is not exhaustive. Where, for example would choroid plexus tumors fall? CNS melanocytic tumors? I suggest using the World Health Organization (WHO) CNS5 headings.	This is a valid point; however, we chose not to be exhaustive and refer instead to broad categories to keep the focus on the organization of services. Choroid plexus and CNS melanocytic tumours would fall under other primary parenchymal neoplasms.

Some descriptions of gliomas are not in keeping with WHO CNS5. For example, “patients diagnosed with low-grade gliomas that possess a mutation in the isocitrate dehydrogenase (IDH) gene may have long survival, in contrast to the poor survival associated with patients diagnosed with an IDH wild type low-grade glioma." This sentence does not really make sense in the context of WHO CNS5. Many IDH wild type apparent low grade gliomas are in fact molecular glioblastomas, but there are also IDH wild type low-grade gliomas that are in fact pediatric-type low-grade gliomas (e.g., PLNTY) that have a good prognosis.	We acknowledge this observation and have added “adult-type” to low-grade gliomas and to IDH wild type in this passage in the introduction.
"These principles of rare tumour management hold true, particularly for benign but aggressive tumours of the CNS" – Aren't these opposite concepts? What does benign but aggressive mean?	We disagree. They are not opposite concepts.
I would include access to MAID as an option.	We have included MAID in the section describing end-of-life care in Recommendation 2.2.
The definition of partner sites is quite undefined as most services are "access to". Should partner sites have one or more of CNS sub-specialization on site as stipulated in Recommendation 1.1?	In Ontario, this comment does not apply. CNS care is confined to CNS trained practitioners.
A certain patient volume is needed to maintain competency, without any guidance in the number.	Patient volume has been considered as a metric in other guidelines, but the decision was made not to include in this guideline. Future iterations may be able to target volumes as data become available.
What about Molecular Testing - can/should partner site be able to perform this?	In Ontario, a centralized testing system is used. Five centres serve the province.
What is the role of partner sites with regard to initiation radiology and pathology?	In Ontario, many partner sites have both.
What about long-term follow-up? Can other hospitals take on this role to improve patient accessibility to local care while ensuring that there is a corridor or service between the local hospital and more specialized sites?	We acknowledge that follow-up care should be included in the description of other hospitals and have added to Recommendation 1.1.
If it is not possible to have patient navigators at all sites now, it would be worthwhile to start in some areas of the province. I think that this will show how key these individuals will be to the success of this approach for care of adults with CNS malignancies.	We acknowledge that patient navigator is a resource urged by both patients/families and health care professionals.
While partner sites do not currently all have CNS fellowship-trained medical and radiation oncologists, some have expertise in neurosurgery and due to sufficient volume and clinical experience, they are able to provide evidence-based care to CNS patients.	We agree that some partner sites are well resourced to care for CNS patients and in some cases may offer specialized care not offered at all host sites, as we mention in the section under care settings.

Such partner sites do refer the patients to academic host sites if it is an unusual tumor or any other specialized intervention is needed. I think academic host sites may also be overloaded with numbers of patients and unable to provide timely care.	
This is a very practical and usable document. Certainly, it can be used to advocate the hospital for resources. Well done. Excellent document. With so many stakeholders, implementation will be difficult but that does not mean that it cannot be accomplished. Overall good guidance document for the management and care of CNS tumors in Ontario.	Thank you.

Post-completion Implementation Review

Following completion of the guideline by the PEBC, the CNS Advisory Group and the CI-DAP initiated a review process to obtain feedback to support the implementation of the guidance. The following groups were consulted: CNS Organizational Guidance Implementation Expert Panel and CNS Organizational Guidance Implementation Advisory Group, both composed of multidisciplinary CNS cancer care experts from across Ontario. Additional comments and feedback from this review resulted in minor modifications which were incorporated. Modifications included: adding the term Psychosocial Oncology to Allied Health; inclusion of disciplines for rehabilitation, mental health and nutrition under the umbrella term Allied Health/Psychosocial Oncology; changing the terms host and partner sites to CNS Network Centres and CNS Partner Sites, respectively; added additional specifications to Diagnostic (advanced molecular diagnostics), Imaging (MR perfusion), and Treatment (CNS Radiotherapy techniques) requirements; updated tumour classifications; added requirement to engage palliative care at the time of MCC; changed Pathologist qualification requirements from General to Anatomical Pathology.

CONCLUSION

The final guideline recommendations contained in Section 1 reflect the integration of feedback obtained through the external review processes with the document as drafted by the GDG Working Group and approved by the GDG Expert Panel and the PEBC RAP.

Subsequent modifications were made to facilitate the implementation of the recommendations in Ontario.

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Appendix 1. Affiliations and Conflict of Interest Declarations

Members of the Organizational Guidance for the Care of Patients with CNS Tumours Guideline Development Group

Name	Affiliation	Declarations of interest
Working Group		
Sunit Das Working Group Chair Neurosurgical Oncology	St. Michael's Hospital Toronto, ON	Honoraria from Medexus for serving as a trainer for Canadian neurosurgeons to introduce them to fluorescence-guided surgery with 5-ALA. Financial support to cover travel and accommodations as a speaker for the Congress of Neurological Surgeons, American Association of Neurological Surgery, and the Society for Neuro-Oncology. Professional earning include billing of OHIP for services involving patients with tumours of the central nervous system. Research support from Alkermes. Published an editorial, commentary, or other clear opinion regarding any of the objects of study. Work published by my group on the effect of osimertinib in patients with EGFR-mutant lung adenocarcinoma and brain metastases was featured by multiple news organizations, e.g. Osimertinib may be beneficial for NSCLC patients with intracranial metastasis. Medscape. Available from: https://www.medscape.com/viewarticle/928043
Garth Nicholas Neuro-oncology	The Ottawa Hospital, Ottawa, ON	None declared
Arjun Sahgal CNS Radiation Oncology	Sunnybrook Health Sciences Centre Toronto, ON	Consulted for ELEKTA, VARIAN, BRAINLAB. Advisor/consultant with AbbVie, Merck, Roche, Varian (Medical Advisory Group), Elekta (Gamma Knife Icon), BrainLAB, and VieCure (Medical Advisory Board) Board Member: International Stereotactic Radiosurgery Society (ISRS) Co-Chair: AO Spine Knowledge Forum Tumor Past educational seminars with Elekta AB, Accuray Inc., Varian (CNS Teaching Faculty), BrainLAB, Medtronic Kyphon, AstraZeneca (Honorarium) Research grants with Elekta AB, Varian Travel accommodations/expenses by Elekta, Varian, BrainLAB

		Dr. Sahgal also belongs to the Elekta MR Linac Research Consortium, Elekta Oligometastases and Gamma Knife Consortia
Cindy Walker-Dilks Health Research Methodologist	Program in Evidence-Based Care McMaster University Hamilton, ON	None declared
Expert Panel		
Margaret Anthes Radiation Oncology	Thunder Bay Regional Health Sciences Centre, Thunder Bay, ON	None declared
Glenn Bauman Radiation Oncology	London London Health Sciences Centre, London, ON	As I provide consultation and treatment services for patients with brain tumours, my professional income could increase or decrease by substantially more than $10,000 per year, depending on the outcome of the guideline
Denise Bilodeau Oncology Social Work	Sunnybrook Health Sciences Centre, Toronto, ON	None declared
Susan Blacker Ontario Palliative Care Co-Lead	Ontario Health (Cancer Care Ontario), Toronto, ON	Received honorarium for Canadian Hospice; presented at Palliative Care Association conference
Michael Chan Neuroradiology	Trillium Health Partners, Mississauga, ON	None declared
Martha Cope Operations Director	Royal Victoria Regional Health Centre, Barrie, ON	None declared
Maureen Daniels Nursing	Princess Margaret Cancer Centre, Toronto, ON	Member of the Board of Directors for Brain Tumour Foundation of Canada; Chair of the Advocacy Committee for Brain Tumour Foundation of Canada; Senior Advisory – International Brain Tumour Alliance (all volunteer positions)
Ryan DeMarchi Neurosurgery	Health Sciences North, Sudbury, ON	None declared
Melissa Diffey Radiotherapy Administration	The Ottawa Hospital Ottawa, ON	Educational services provided to ELEKTA.
Matthew Follwell Radiation Oncology	Royal Victoria Regional Health Centre, Barrie, ON	None declared

Leta Forbes Provincial Head, Systemic Treatment Program	OH (CCO) Toronto, ON	Received speaker fees for a talk about COVID vaccination for the Canadian Association of Medical Oncologists.
Crystal Hann Radiation Oncology	Juravinski Cancer Centre, Hamilton, ON	None declared
Cynthia Hawkins Neuropathology	The Hospital for Sick Children, Toronto, ON	On Editorial Board of WHO 2021 classification which describes classification of brain tumours and required molecular testing to reach these diagnoses; because of my role in the WHO I have given talks to several international audiences to teach the WHO classification to the neuro-oncology community
Norm Laperriere Radiation Oncology	Princess Margaret Cancer Centre, Toronto, ON	Online survey done for Abbvie in fall 2017; Travel support and honorarium from Merck in August 2016
Warren Mason Neuro-oncology	Princess Margaret Cancer Centre, Toronto, ON	Participated in an Advisory Board on GBM sponsored by Galaxo Smith Kline in December 2020. It was a one-time online event and limited to approximately 1 hour/day for 3 consecutive days. The total compensation was 2400 CAD.
Jason Pantarotto Provincial Head, Radiation Therapy Program	OH (CCO) Toronto, ON	None declared
James Perry Neuro-oncology	Sunnybrook Health Sciences Centre, Toronto, ON	None declared
Aaron Pollett Provincial Head, Pathology & Laboratory Medicine Program	OH (CCO) Toronto, ON	None declared
Kesh Reddy Skull-base Surgery	Hamilton Health Sciences, McMaster University, Hamilton, ON	None declared
Jill Rice Palliative Care	Bruyere Continuing Care, Ottawa, ON	Facilitator for Pallium Canada, non-profit developer of palliative care education; Ontario Palliative Care Network clinical co-lead for Champlain and member of an academic alternate funding plan
Ken Schneider Radiation Oncology	Windsor Regional Cancer	None declared

	Program, Windsor, ON	
John Sinclair Neurosurgery	The Ottawa Hospital, Ottawa, ON	Consulted for INTEGRA in 2019.
Janice Stewart Director of Operations and Regional Planning	Odette Cancer Program Sunnybrook Health Science Centre, Toronto, ON	I am the Director of Operations at Sunnybrook Health Science Centre and we receive donations/grants from multiple pharma and device companies (e.g., Phillips, Elekta, Varian) annually to support care, education, and research - many are over $5000. I do not benefit personally from these donations, but they do provide a revenue source for events/research grants, etc. I am certain some of these companies will be relevant business entities during this process. I do not oversee the grants or donations but am aware of them.
Frances Wright Quality Lead, Surgical Oncology Program	OH (CCO) Toronto, ON	Received speaker fees (for community surgical oncology events) - BMS, Roche, Merck. All donated to University of Toronto General Surgical Oncology fellowship program. 2016 unrestricted research grant from Roche for melanoma neo-adjuvant BRAF/ MEK inhibitor trial.
RAP Reviewer		
Jonathan Sussman Scientific Director, Program in Evidence-Based Care, Ontario Health (Cancer Care Ontario) Chair, Department of Oncology McMaster University	Juravinski Cancer Centre, Hamilton, ON	None declared

Members of the Patient Consultation Group

Name	Declarations of Interest
Andrew Boyle	None declared
Janet Fanaki	None declared
Steven Golick	Co-founder and CEO of Canadian Chordoma Network (non- profit, currently inactive); unpaid consultant to Canadian Cancer Society in connection with reviewing grant

	proposals for chordoma research in 2018; led a major fundraiser in 2017 for Canadian Chordoma Network (no compensation other than reimbursement of expenses); Member of the Board and Member of the Community Advisory Board of the Chordoma Foundation (U.S. non-profit); Member of the Quality and the Patient Experience Committee of the board of Sunnybrook Health Sciences Centre

Appendix 2. Guideline Development Flowchart