

## Guiding principles for adult CNS tumor treatment programs

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### Abstract

Central nervous system (CNS) tumors require specialized care to promote better patient survival outcomes and life quality. Before this paper, there were no published guidelines identifying what constitutes specialized, comprehensive CNS tumor treatment and care in the United States. Consequently, members of several CNS tumor patient advocacy and not-for-profit organizations established a set of Guiding Principles by which adult CNS tumor treatment programs could be evaluated for the availability of specialized services offered. These Guiding Principles for CNS tumor treatment programs are the first tool of its kind in the United States. Patient advocacy and not-for-profit organizations that support the CNS tumor population can use these guiding principles to help patients and their loved ones make more informed decisions about where to seek treatment and care.

### Key Points

- The Guiding Principles are guidelines by which adult CNS tumor treatment programs in the United States can be evaluated for the availability of specialized services offered.
- The Guiding Principles exist to help patients and their loved ones make more informed decisions about where to seek treatment and care and are intended to be an aspirational framework for treatment programs to achieve.
- This tool, established by members of several CNS tumor patient advocacy and not-for-profit organizations, is the first of its kind in the United States.

Every year in the United States, approximately 90,000 people are diagnosed with a primary central nervous system (CNS) tumor<sup>1</sup> and approximately 200,000 are diagnosed with a metastatic (secondary) CNS tumor.<sup>2</sup> CNS tumors are rare, diverse, often difficult to treat, and require specialized care to promote better patient survival outcomes and life quality.<sup>3</sup> However, there are no published guidelines in the United States that identify what constitutes specialized, comprehensive CNS tumor treatment and care. Additionally, while there are several tools available that help individuals identify top medical programs locally or nationally that specialize in treating certain diseases, there are no such tools that identify programs

that offer specialized services for the treatment of CNS tumors. Such tools would assist CNS tumor patients and their loved ones in selecting treatment programs that best meet their needs, as well as serve as a benchmark for treatment and care.

Acknowledging these unmet needs, several CNS tumor patient advocacy and not-for-profit organizations, working both in the United States and internationally, assembled to discuss developing a set of guidelines by which adult CNS tumor treatment programs in the United States could be evaluated for offering specialized, comprehensive treatment and care. Each participating organization believed it important to advocate for CNS tumor patients through this joint effort to provide

patients and their loved ones with guidance and a tool that aids their search for specialized treatment programs. This group was composed of members from the American Brain Tumor Association, The Brain Tumour Charity, Brain Tumor Network, The Collaborative Ependymoma Research Network (CERN) Foundation, Head for the Cure, International Brain Tumour Alliance, Musella Foundation, National Brain Tumor Society, Oligo Nation, Society for Neuro-Oncology, and Southeastern Brain Tumor Foundation. The Society for Neuro-Oncology participated in group discussions but was not a voting party.

## Methodology

This working group met six times, both in-person and virtually, between November 2019 and November 2021. During each meeting, group members identified and discussed elements of expert, comprehensive CNS tumor treatment and care. This group's intent was not to determine whether CNS tumor treatment programs are "centers of excellence," but rather to set guidelines for patients and caregivers to evaluate community and academic programs in terms of sub-specialty clinical practice, technologies and treatments offered, and best practices. Additionally, these guidelines are also intended to be an aspirational framework for treatment programs to achieve.

A variety of evidence-based resources were leveraged for this purpose, including the National Institute for Health and Care Excellence (NICE) guidelines on brain tumors and brain metastases, the European Cancer Organisation's Essential Requirements for Quality Cancer Care for glioma and melanoma, the National Comprehensive Cancer Network's Guidelines for Patients with gliomas, academic articles, and survey data gathered by the American Brain Tumor Association (ABTA) about US-based CNS tumor treatment programs. Several rounds of drafted guidelines were discussed, revised, and voted upon by group members. Additionally, the guidelines were reviewed by notable medical professionals working in the CNS tumor field, including members of ABTA's Clinical Advisory Committee and the Society for Neuro-Oncology External Relations Committee.

## Data

Between March 2019 and July 2020, the ABTA sent surveys to 107 healthcare institutions throughout the United States. Of these, 60 surveys were completed and returned. Institutions were selected to be surveyed based on both internal knowledge or belief that they had a CNS tumor treatment program and prior interactions with the ABTA. These surveys asked a variety of questions about each program's services, including the number of clinical staff members who specialize in CNS tumors, the number of patients treated with CNS tumors, treatment options available, and clinical services offered. This data, in addition to other sources, was leveraged by the working group to draft guidelines for specialized CNS tumor treatment and care.

The number of responses for each data point was between 58 and 60 (variance due to incomplete data on certain surveys). All data gathered in surveys were self-reported by the institutions from which information was requested. These data served as a framework to assess the current state of known CNS tumor treatment programs, aiding in the development of the Guiding Principles.

In October 2021, the treatment program data collected by ABTA was made publicly available on the ABTA website to assist CNS tumor patients and their loved ones in making decisions about where to seek treatment and care.<sup>4</sup> These data are regularly updated on the ABTA website as institutions submit new or updated surveys. The original data set that was used to inform the authors' work can be seen in [Table 1](#).

## Proposed Guiding Principles for Adult CNS Tumor Treatment Programs in the United States

As a result of this group's efforts, the following Guiding Principles for Adult CNS Tumor Treatment Programs in the United States were drafted. These principles were designed to help patients and their loved ones identify the elements of specialized treatment as well as select the best care possible based on their individual needs.

1. **Dedicated program:** This medical institution offers a program dedicated to the treatment of adults with CNS (ie, brain, spine, cranial nerves, meninges) tumors. This program has specialist clinical staff trained in the diagnosis, treatment, and care of adult patients diagnosed with CNS tumors.
2. **Patient volume:** This CNS tumor treatment program treats at least 40 adult patients diagnosed with primary CNS tumors per year. If this program treats metastatic CNS tumors, at least 20 adult patients diagnosed with metastatic CNS tumors are treated per year.
3. **Multidisciplinary team:** This CNS tumor treatment program has a designated CNS multidisciplinary team which includes at least one of each type of the following specialists, each devoting at least 40% of their clinical hours to the treatment of CNS tumors: neuro-oncologist or medical oncologist who specializes in CNS tumors, radiation oncologist, neurosurgeon, specialist nurse (eg, neuro nurse, APN, NP, RN), and neuroradiologist. Each specialist must either be on-site or at a closely affiliated medical institution or practice.
4. **Molecular testing:** This CNS tumor treatment program performs either on-site or outsourced testing for molecular diagnostics to determine accurate tumor diagnosis, inform prognosis, and guide treatment. Testing is done in accordance with the latest World Health Organization (WHO) criteria and performed in an accredited laboratory.
5. **Clinical trials:** This CNS tumor treatment program offers clinical trials for CNS tumors and/or actively navigates patients to other medical centers that provide clinical trials for CNS tumors.

**Table 1.** Adult CNS Tumor Treatment Center Survey Data

Number of treatment centers contacted for survey data	107
Number of completed surveys	60
Response rate	56%
<i>Regional representation</i>	
Midwest	28.33%
Southeast	23.33%
West	20.00%
Northeast	20.00%
Southwest	8.33%
Percentage of treatment centers with a dedicated CNS tumor treatment program	100%
Average number of primary tumors treated in one year	190*
Average number of metastatic tumors treated in one year	182*
<i>Average number of specialists focusing on CNS tumors</i>	
Neuro-oncologists	2.3*
Medical oncologists	1.0*
Brain surgeons	3.9*
Spine surgeons	2.6*
Radiation oncologists	2.9*
Neuroradiologists	4.7*
Percentage of institutions with at least one neuro nurse on staff	100%
Percentage of institutions with at least one advanced practice nurse on staff	95%
Percentage of institutions offering clinical trials for CNS tumor patients	97%
Percentage of institutions with a clinical brain tumor board	100%
<i>Percentage of clinical supportive services and resources offered</i>	
Neuropsychological evaluations and/or cognitive rehabilitation services	98%
Inpatient or outpatient physical rehabilitation services	98%
Palliative care	100%
Nutrition services	100%
Survivorship services	96%
Caregiver support services	96%

\*Data excludes outliers.

include but are not limited to the following: neuropsychological evaluation, psychological intervention, cognitive rehabilitation, speech therapy, physical/occupational therapy, palliative care, oncology social work, patient navigation, brain tumor support group, survivorship service, and caregiver support service.

## Rationale Supporting the Development of the Guiding Principles

Several publications and guidelines served as evidence-based resources and provided rationale for the Guiding Principles listed above.

### Guiding Principle #1: Dedicated Program

There is documented evidence that specialized surgical care leads to improved outcomes for patients with different cancers, such as colorectal cancer<sup>5</sup> and breast cancer.<sup>6</sup> These improved outcomes include more frequently obtained diagnoses, greater collection of biopsies, healthy tissue conservation, lower recurrence rates, and improved overall survival.<sup>6</sup> For patients with brain tumors, such benefits may include more maximum safe resections, adequate and accurate tumor tissue sampling, availability of advanced molecular testing for more accurate diagnoses, advanced imaging techniques for more precise functional assessments, newer radiation methods, and access to newer investigational therapies which may not otherwise be available to these patients. Additionally, those diagnosed with glioblastoma receiving surgery at a specialized neuro-oncology care center experienced higher rates of complete resection, leading to significantly longer progression-free survival and overall survival.<sup>7</sup> The need for a dedicated medical program that specializes in a certain disease (or set of related diseases) is already recommended by advocacy groups and professional organizations representing several cancer-related fields including glioma,<sup>8</sup> melanoma,<sup>9</sup> and breast cancer.<sup>10</sup>

### Guiding Principle #2: Patient Volume

There is evidence in the CNS tumor field and other disease areas that superior outcomes are related to a program or center treating a high volume of cases.<sup>9,11,12</sup> The minimum numbers of CNS tumors treated per year by a CNS tumor treatment program, as listed in Guiding Principle #2 (40 primary tumors and 20 metastatic tumors), were not arbitrarily selected but were rather based on several data sets. One study showed superior outcomes for glioblastoma patients treated at high-volume facilities (defined as 15 or more cases per year).<sup>11</sup> Fifteen is significantly less than the 40 recommended in Guiding Principle #2 because Guiding Principle #2 is a recommendation for all primary tumors, not just glioblastoma. Additionally, the minimum numbers were informed by data collected by the ABTA from 60 different CNS tumor treatment programs in the United States, which reported the lowest values of primary and

- 6. Tumor board:** This CNS tumor treatment program has a multidisciplinary clinical tumor board that meets regularly, either in-person or virtually, to discuss and streamline patient care and the management of patients with CNS tumors.
- 7. Clinical supportive services and resources:** This CNS tumor treatment program (or its closely affiliated medical institution or practice) offers a range of clinical supportive services that are accessible to patients and their caregivers. Examples of clinical supportive services

metastatic CNS tumors treated per year as 50 and 20 respectively.<sup>4</sup> The working group agreed that the minimum numbers identified in Guiding Principle #2 are a modest entry point for community providers that focus on treating CNS tumors at a volume sufficient to suggest better outcomes for patients. The working group also recognizes that such numbers may not reflect the fact that there may be localized expertise for specific types of tumors that may still result in superior outcomes for patients with those tumors.

### Guiding Principle #3: Multi-disciplinary Team

The use of a multidisciplinary team of clinical specialists is suggested by several advocacy groups in the treatment of other diseases.<sup>3,8–10</sup> There is also evidence that having a multidisciplinary team can lead to better clinical outcomes for patients including improved survival.<sup>8,13</sup>

### Guiding Principle #4: Molecular Testing

Treatment decisions based on histology alone could lead to suboptimal treatment of a more aggressive tumor or over-treatment of patients with a more benign disease course. This is due to the potential for tumors viewed through the microscope to appear more aggressive or less aggressive than they are clinically. Molecular testing leads to a more accurate diagnosis and the clinical behavior of the tumor. The need for molecular testing is part of the standard classification of brain tumors. This is similar to the testing principles for diagnosis and treatment of other cancers, such as breast cancer<sup>10</sup> and non-small-cell lung cancer.<sup>14</sup> In addition, European<sup>3</sup> and American<sup>15</sup> clinical guidelines on treating CNS tumors incorporate the routine use of molecular testing to help guide treatment decisions. Furthermore, many CNS tumors, as classified by the World Health Organization,<sup>16</sup> require molecular testing for accurate diagnosis and prognosis.

### Guiding Principle #5: Clinical Trials

Clinical trials increase the availability of treatment options for patients with certain CNS tumors that have poor prognoses and limited treatment options outside of the standard of care. US-based clinical guidelines for patients “recommend that everyone with a glioma consider joining a clinical trial for treatment.”<sup>15</sup> Access to clinical trials is considered an important part of quality cancer care<sup>17</sup> and is even required for accreditation in other oncological programs, such as breast cancer.<sup>10</sup>

### Guiding Principle #6: Tumor Board

Tumor boards, also known as multidisciplinary team conferences, are recommended in disease guidelines for glioma,<sup>8</sup> melanoma,<sup>9</sup> and other CNS tumors.<sup>3,18</sup> and accreditation guidelines for breast cancer treatment centers.<sup>10</sup> Tumor board meetings have been shown to influence clinical decision-making, leading to change in diagnosis and physician management decisions.<sup>19</sup>

### Guiding Principle #7: Clinical Supportive Services and Resources

Several guidelines for a variety of diseases, such as primary and metastatic brain tumors, melanoma, and breast cancer, advocate for the need for clinical supportive services and resources to provide a holistic approach to care. These include neurological rehabilitation,<sup>3</sup> psycho-oncology,<sup>9</sup> palliative care,<sup>9,10</sup> survivorship services,<sup>9,10</sup> neuropsychology,<sup>8</sup> and social work.<sup>8</sup>

### Limitations of Other Tools and Services that Identify Treatment Programs

The U.S. News & World Report Best Hospitals online search tool allows those diagnosed with a variety of health conditions to find top-ranked medical centers throughout the United States.<sup>20</sup> These medical centers are rated and ranked for quality based on institutions’ structural measures, processes, and performance outcomes. While this tool is an excellent resource for those who experience colon, lung, ovarian, and prostate cancer, it unfortunately does not evaluate CNS tumor programs’ level of expert, comprehensive treatment and care. The U.S. News & World Report rates and ranks the best hospitals for neurology and neurosurgery. While CNS tumors are often treated in neurology and neurosurgery departments of medical centers, many such departments specialize in other neurological diseases and conditions (eg, strokes, epilepsy) and do not have extensive experience with CNS tumors.

The National Cancer Institute (NCI) maintains a list of designated cancer centers that are recommended by the NCI for comprehensive treatment and care.<sup>21</sup> While this approach helps direct patients toward medical centers that offer high-quality care as determined by the NCI, some of these cancer centers do not offer comprehensive CNS-tumor treatment programs. Additionally, many patients cannot access these cancer centers due to geographic, financial, or other barriers, and many prefer to receive medical care in their local communities.

### Other Published Guiding Principles for Assessing CNS Tumor Program Quality

The UK-based Tessa Jowell Brain Cancer Mission, through its Tessa Jowell Centres of Excellence network, recognizes and awards CNS tumor treatment centers offering excellent patient care.<sup>22</sup> The Guiding Principles above have similar recommendations but, in a manner different from the Tessa Jowell Centres of Excellence, are designed to have a modest entry point to be more inclusive of community and academic programs throughout the United States. The Tessa Jowell Centres of Excellence program’s development in the UK supports the need for a similar system that measures the quality of CNS tumor treatment programs in the United States.

The European Cancer Organisation’s (ECO) “Essential Requirements for Quality Cancer Care (ERQCC): Glioma”



provides recommendations for high-quality care for patients diagnosed with glioma tumors.<sup>8</sup> This document is like the Guiding Principles above in that it offers a framework aiming toward high-quality treatment programs. It differs from the Guiding Principles because it is more robust and detailed. The Guiding Principles need more generalizability given the structure of the health system in the United States, which is very different from that in Europe. Another difference is that while the Guiding Principles are intended for all CNS tumor types, the ERQCC is specific only to glioma tumors.

The United States-based Joint Commission—whose vision is “that all people always experience the safest, highest quality, best-value health care across all settings”—provides disease-specific care certification for medical programs, including brain tumors.<sup>23</sup> This certification focuses on improving patient experience, program efficiencies, and organizational culture. The standards for certification are set relative to the program’s current level of operation. The Guiding Principles differ in that they are objective measurements intended to be applied to all CNS tumor treatment programs.

## Considerations and Limitations

Although these Guiding Principles for CNS Tumor Treatment Programs are the first of their kind in the United States, there are several limitations to consider. First, the Guiding Principles are a framework for specialized and comprehensive CNS tumor treatment and care that does not account for patient outcomes. The Guiding Principles are intended to correlate with aspects of quality care, so adherence to them aims to suggest, rather than guarantee, that a treatment program provides quality CNS tumor treatment and care. Similarly, a program that does not adhere to all these Guiding Principles can still provide quality care. For some CNS tumor treatment programs, only certain elements of the Guiding Principles may be achievable at a certain time, while other elements may be aspirational. Finally, some programs that do not meet all these Guiding Principles may collaborate with other treatment programs to provide the most expert and comprehensive treatment and care possible. For example, a program that lacks a neuroradiologist may consult with another program whose neuroradiologist can review medical imaging and provide expert opinion. The authors encourage the brain tumor community to use the Guiding Principles as an aspirational framework, upon which treatment programs can build elements of specialized, comprehensive CNS tumor care.

Data collected through surveys by the ABTA on CNS tumor treatment programs were self-reported by participating institutions and hospitals. This creates a potential for error and biased reporting of data. Additionally, the dataset used to inform the creation of the Guiding Principles was a sample of convenience that was intended for other purposes and not collected in accordance with scientific research standards. Further, terms used in the ABTA survey could have been perceived as subjective. For example, the term “neuro-oncologist” generally applies to neurologists and medical oncologists who have completed a neuro-oncology fellowship and specialize in CNS tumors but has also been utilized by those who do not

have this experience, such as a neurologist who does an oncology fellowship, or a medical oncologist who worked in the field before the advent of neuro-oncology fellowships. Additionally, it is important to note that survey data was gathered between one month and two years before the time of analysis, rendering some of the data less current. Finally, most of the data received was primarily from larger academic institutions that tend to offer more clinical staff and resources for CNS tumor patients than many community-based treatment programs.

Lastly, if these guidelines are used for evaluating the extent to which a program offers specialized, comprehensive CNS tumor treatment and care, it could be challenging to verify whether the program strictly adheres to the Guiding Principles, given that there is not currently an organization that could verify adherence. If the Guiding Principles were used as a survey tool by an individual or organization, all information collected from a program would be self-reported, and, therefore, subject to error and bias. Also, these Guiding Principles themselves may need to be reassessed periodically for relevance in the rapidly changing medical environment with the advent of new technologies and data, which may provide new insights into the treatment and outcome of CNS tumors.

## Conclusion

While there are criteria and guidelines established for defining quality care, these Guiding Principles for Adult CNS Tumor Treatment Programs are the first tool of their kind in the United States that specifically identify elements of specialized, comprehensive treatment and care and are inclusive of community medical programs that treat people diagnosed with CNS tumors. Patient advocacy and not-for-profit organizations that support the CNS tumor population are encouraged to use these Guiding Principles to help patients and their loved ones make more informed decisions about where to seek treatment and care. These organizations are also encouraged to disseminate the Guiding Principles to CNS tumor treatment programs to promote greater awareness, adoption, and a framework to aspire to. It is hoped that, in the future, CNS tumor treatment programs will aspire to demonstrate their adherence to the Guiding Principles in a manner similar to disease-specific care certifications awarded by organizations such as the Joint Commission. Additionally, advocacy groups and nonprofit organizations can assist patients and their loved ones in making more informed decisions about their care by identifying specialized CNS tumor treatment programs that adhere to the Guiding Principles. It is also desired that by choosing treatment programs that adhere to the Guiding Principles, patients will experience better outcomes and improved quality of life.

## Keywords:

brain tumors | central nervous system tumors | medical centers | specialized treatment and care | spine tumors | treatment centers.

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