

Brain tumor patients' rights and the power of patient advocacy: The current international landscape

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Abstract

Across the globe, significant inequities in brain tumor treatment, care, and support perpetuate. Identifying and addressing these unmet needs in the context of patients' rights is crucial to reducing inequalities and improving outcomes for people living with brain tumors. Brain tumor patient advocacy addresses and influences gaps in healthcare provision, ensuring optimal treatment, care, and support for patients, their caregivers, and families. Therefore, the purpose of this review is to highlight the variety of challenges faced by brain tumor patients, caregivers, and advocates in various parts of the world and set a benchmark for improvements. Twenty-eight leading brain tumor patient/caregiver advocates from 18 countries in Asia Pacific, Sub-Saharan Africa, North America, Eastern Europe, and Western Europe collaborated to explore unmet and met needs in their countries. Virtual meetings were held with the 5 geographic groupings. Through a process of discussion based on a combination of patient advocates' informed expert opinion, published references, a survey (Asia Pacific) and the informal completion of a matrix of challenges by some of the advocacy organizations involved, agreement within the groupings was also reached regarding what rights within The Brain Tumor Patients' Charter of Rights they felt were being met and where there are still gaps. Acknowledging that some rights in The Brain Tumor Patients' Charter of Rights are aspirational, there still remain many areas of the world where even basic patient rights are not yet attainable. Patient advocacy organizations stand ready to help change this to achieve the best possible health and quality of life outcomes for adults and children living with brain tumors.

Keywords

advocacy | brain tumor/tumour | patient rights

Background

This foundational paper lays the groundwork for establishing an international baseline of patient advocacy activity and raising awareness of the vital requirement for more attention to the met and unmet needs of brain tumor patients and caregivers.

Between 2017 and 2020, leaders of brain tumor patient advocacy organizations around the globe established a document that

expressed aspirational care for brain tumor patients, resulting in the creation of The Brain Tumor Patients' Charter of Rights (the "Charter"; see [Supplementary Data](#) for all Charter references).

The Charter aims to inspire advocacy and collective action to improve the lives of people with brain and central nervous system (CNS) tumors. It provides an aspirational framework for improving healthcare systems and communications—goals that help reduce healthcare inequalities and support better outcomes.

Patient advocacy is key to supporting brain tumor patients and their caregivers. Advocacy contributes to progress in the field and inspires others to also engage in creating networks of support for people with brain tumors.

Advocacy encompasses a wide range of diverse areas of work and service including, but not limited to, research, government policy, health, financial, and patient/caregiver well-being. There is no established consensus on the definition of patient advocacy within the global brain tumor community. However, for the purpose of this review, patient advocacy comprises people or organizations working to improve outcomes for patients diagnosed with a brain or CNS tumor and their caregivers.

Brain tumor patient advocacy is nuanced and differs depending on a patient's or community's needs. The intense driver for patient advocacy derives from the devastating reality of a brain tumor diagnosis which is often associated with significant gaps in care and, in some instances, a lack of support from familial, societal, cultural, healthcare policy, and institutional standpoints.

Very little research and published evidence on the topic of brain tumor patient advocacy currently exist. In this review, the expert opinion of brain tumor advocacy leaders with many decades of experience in patient/caregiver support provides a snapshot of the met and unmet needs of brain tumor communities in various countries and regions around the world.

Twenty-eight leading brain tumor patient/caregiver advocates from 18 countries in Asia Pacific, Sub-Saharan Africa, North America, Eastern Europe, and Western Europe collaborated to explore unmet and met needs in their countries. Virtual meetings were held with the 5 geographic groupings. Through a process of discussion based on a combination of patient advocates' informed expert opinion, published references, a patient and caregiver survey (Brain Tumor Society Singapore) and the informal completion of a matrix of challenges by some of the advocacy organizations involved, agreement within the groupings was also reached regarding what rights within The Brain Tumor Patients' Charter of Rights they felt were being met and where there are still gaps.

Table 1. Areas of High Unmet Needs on the Brain Tumor Journey as Identified Through Discussions Between Expert Patient Advocates, Published References, a Patient and Caregiver Survey (Brain Tumor Society—Singapore) and the Informal Completion of a Matrix of Challenges by Some Patient Organizations Participating in this Review

Unmet Needs	Corresponding reference in The Brain Tumor Patients' charter of rights
Diagnosis	I shall have the right to:
Being given a prompt and accurate diagnosis	Acknowledgement and Respect (Clause 1h); Appropriate Investigations of Signs and Symptoms (Clause 2e); A Clear, Comprehensive, Integrated Diagnosis (Clause 3b), (Clause 3c), (Clause 3e), (Clause 3j)
Discrimination	I shall have the right to:
To not be discriminated against in the community and workplace because of a brain tumor diagnosis	Acknowledgement and Respect (Clause 1g)
Data collection	I shall have the right to:
Proper registration of all types of brain tumors (including all low grade brain tumors) in existing and future registries	Medical Information and Privacy (Clause 9a)
Sparsity of adequate surveillance data	Medical Information and Privacy (Clause 9a)
Access	I shall have the right to:
Access to functional radiotherapy machines and, if available in my country (and relevant to my treatment), access to proton facilities	Excellent Treatment and High-Quality Follow-Up Care (Clause 5c), (Clause 5d)
Access for all brain tumor patients to standard assays for molecular testing, appropriate safety regulations and adequate payor reimbursement for such tests	Excellent Treatment and High-Quality Follow-Up Care (Clause 5i)
Equitable access to effective treatments	A Clear Comprehensive, Integrated Diagnosis (Clause 3h); Appropriate Support (Clause 4b); Excellent Treatment and High-Quality Follow-Up Care (Clause 5c); The Care Relationship (Clause 6a); Rehabilitation and Well-Being (Clause 8a), (Clause 8c)
Access to second opinions	A Clear, Comprehensive, Integrated Diagnosis (Clause 3h); The Care Relationship (Clause 6d)
Access to a full range of appropriate services regardless of tumor type (ie low grade versus high grade, etc)	A Clear, Comprehensive and Integrated Diagnosis (Clause 3h); Appropriate Support (Clause 4c); Excellent Treatment and High-Quality Follow-Up Care (Clause 5a), (Clause 5c), (Clause 5d), (Clause 5j), (Clause 5l), (Clause 5o); Supportive/Palliative Care (Clause 7a), (Clause 7b); Appropriate End-of-Life Options and Care (Clause 10a)
Lack of uniform access to multidisciplinary care	Excellent Treatment and High-Quality Follow-Up Care (Clause 5j); Supportive/Palliative Care (Clause 7a)
Accessing treatments based on need and not the ability to pay for them	Excellent Treatment and High-Quality Follow-Up Care (Clause 5c);
Access to clinical trials	Appropriate Investigation of Signs and Symptoms (Clause 2c); Excellent Treatment and High Quality Follow-Up Care (Clause 5o)

Table 1. Continued

Unmet Needs	Corresponding reference in The Brain Tumor Patients' charter of rights
Shared decision-making (SDM)	I shall have the right to:
Shared decision-making not uniformly practiced	A Clear, Comprehensive and Integrated Diagnosis (Clause 3f); Appropriate Support (Clause 4a), (Clause 4b); Excellent Treatment and High-Quality Follow-Up Care (Clause 5b),
Information and support	I shall have the right to:
Referral of patients to regional and international patient information, support and advocacy organisations	Appropriate Support (Clause 4g)
Lack of good quality general information about all treatment options	Appropriate Investigation of Signs and Symptoms (Clause 2d), (Clause 2f); A Clear, Comprehensive, Integrated Diagnosis (Clause 3h); Excellent Treatment and High-Quality Follow-Up Care (Clause 5a); (Clause 5b), (Clause 5d), (Clause 5k), (Clause 5l), (Clause 5m), (Clause 5o);
Low health literacy	Currently outside of the remit of the Charter
Maintaining hope	Acknowledgement and Respect (Clause 1h);
Lack of standard protocols on how to convey information	Appropriate Investigation of signs and symptoms (Clause 2a); A Clear, Comprehensive, Integrated Diagnosis (Clause 3i); Appropriate Support (Clause 4a), (Clause 4d), (Clause 4e), Rehabilitation and Well-Being (Clause 8b); Medical Information and Privacy (Clause 9f)
Patient organizations	I shall have the right to:
Lack of patient advocacy organisations and support groups in some countries	Appropriate support (Clause 4f), (Clause 4g),
Survivorship	I shall have the right to:
Appropriate support and rehabilitation—there are particular gaps in care coordination, availability of information on legal issues, information about returning to work and school, and disability rights	Appropriate Support (Clause 4e); Supportive/Palliative Care (Clause 7a), Rehabilitation and Well-Being (Clause 8b)
Appropriate support particularly at initial diagnosis, discharge from hospital, at the time of follow-up MRIs and on tumor recurrence	Appropriate Investigation of Signs and Symptoms (Clause 2b); Excellent Treatment and High-Quality Follow-Up Care (Clause 5j); Supportive and Palliative Care (Clause 7a); Rehabilitation and Well-Being (Clause 8b), (Clause 8c)
Addressing aspects of survivorship such as neurocognitive, neuropsychological and physical impairments; access to community mental health services, addressing financial toxicity and employment	Excellent Treatment and High-Quality Follow-Up Care (Clause 5j); Supportive and Palliative Care (Clause 7a); Rehabilitation and Well-Being (Clause 8b), (Clause 8c)
Lack of care coordinators or navigators (ie a specialist nurse, social worker or other suitably trained person to support the patient and their family)	Appropriate Support (Clause 4c)
Clinical trials	I shall have the right to:
Availability and good quality information about clinical trials for brain and CNS tumors	Excellent Treatment and High-Quality Follow-Up Care (Clause 5o), (Clause 5p), (Clause 5q)
Better accrual for brain tumor clinical trials by finding solutions to the many barriers involved	Excellent Treatment and High-Quality Follow-Up Care (Clause 5o)
Palliative and end-of-life care	I shall have the right to:
Good palliative care and dignified end of life care including an effective referral system to palliative care	Supportive/Palliative Care (Clause 7a), (Clause 7b)
Research	I shall have the right to:
Absence of enough brain tumor tissue banks	Appropriate investigation of Signs and Symptoms (Clause 2e), (Clause 2f); A Clear, Comprehensive, Integrated Diagnosis (Clause 3b); Appropriate End-of-Life Options and Care (Clause 10g)
Institutional	I shall have the right to:
Lack of coordination across hospitals	Excellent Treatment and High-Quality Follow-Up Care (Clause 5r)
Lack of standardized timescales across institutions regarding delivery of MRI results to patients resulting in patients and caregivers suffering additional stress	Excellent Treatment and High-Quality Follow-Up Care (Clause 5r)
Important note: The unmet needs highlighted in this table vary across different regions and countries. This is a compilation of various unmet needs across the world.	

Asia Pacific

Australia, Japan, India, New Zealand, Pakistan, and Singapore

Countries in the Asia Pacific (APAC) region represent diverse landscapes, climates, populations, cultures, societies and economies. This diversity is reflected in the region's healthcare systems and the way brain tumor patients are cared for in each country.

Health expenditure and the level of healthcare resources is a contributing factor to this diversity. Of the 6 APAC countries covered in this review, 4 (Australia, Japan, New Zealand, and Singapore) are classified as high-income countries while 2 (India and Pakistan) are described as lower middle-income countries.

Cultural factors contribute significantly to diversity within APAC. People engage with their healthcare systems in Asian countries differently from those in the west. In many Asian societies, citizens tend not to question their doctors and fully accept their recommendations.¹ In LMICs, this is heightened due to lower literacy rates, with citizens from lower socioeconomic strata not feeling confident/equipped to question authority.

Patient groups advocate for timely care, support, and reintegration into society.² But in some APAC countries, the state imposes serious constraints on aspects of nonprofit advocacy.³ The concern of being investigated or charged with noncompliance may deter the development of patient advocacy organizations or lead to their adopting a more conservative approach.

Conversely, New Zealand and parts of Australia have state-directed or funded advocacy services.⁴ Having patient rights enshrined in law encourages the formation of patient advocacy organizations to promote specific causes.

The Brain Tumor Patients' Charter of Rights covers patients' rights to dignity, respect, privacy, treatment and to be treated as individuals without discrimination.⁵ Many of these basic rights were assessed (by expert patient advocate opinion) as being met in the majority of APAC countries included in this review, but with some exceptions.

In many Asian countries, Confucian culture prioritizes family over the individual.^{6,7} In India and Pakistan, treatment and end-of-life decisions are mainly made by immediate family members and patients are not privy to such discussions. Relatives are protective of their loved ones, feeling it is their duty to address such unpleasant issues themselves. A similar dynamic exists in Singapore, where it is common for younger, educated family members to represent their elders, persuading the patient to follow the family's preferred course of action.

"Not be discriminated against in my community or my workplace or indeed anywhere at any time because I have a brain tumor" is assessed by expert patient advocate opinion as unmet in 4 (India, New Zealand, Pakistan, and Singapore) of the 6 APAC countries in this review.⁸

The right to hope is also included in the Charter and rates (by expert patient advocate opinion) as a need which is only partially met, sending a firm message to the medical community that patients and advocates feel strongly that hope should be maintained whatever the diagnosis/prognosis.⁹

Section 9 of the Charter on Medical Information and Privacy scores highest among expert patient advocate opinion with the majority of the rights here being assessed as met by all 6 countries.¹⁰

One important right assessed as unmet was 9.a—"Have my brain tumor properly registered in my country's (and international) cancer registration records whether my brain tumor is so-called 'benign', low grade or high grade."

Most countries in the APAC region do not have dedicated brain tumor registries, and low-grade and nonmalignant brain tumors are not always included in existing cancer registries. The exception is Japan, where a national cancer registry, established in 2016, accounts for all adult and pediatric brain tumors, including nonmalignant tumors.

The right to appropriate support, rehabilitation, and well-being is assessed as the highest area of unmet need across the 6 APAC countries. Areas where support is lacking include right 4.c (care coordination); right 4.d (information on legal issues); and right 4.e (information about returning to work and school, and disability rights).¹¹

Patients and caregivers identify the need for support at several points along the brain tumor pathway: At initial diagnosis; returning home following hospital discharge; around follow-up MRIs; and on tumor recurrence. Many of these points occur in the outpatient setting requiring support services to be delivered outside the clinic.

This presents both a challenge and an opportunity for brain tumor patient advocacy organizations to close this gap. Advocates argue that maximal support services should be available in real-time rather than as an after-thought once treatment finishes. Patient advocates should work closely with healthcare teams so they can be actively involved with patients and their caregivers from the time of diagnosis.

Patient advocacy organizations are already making a positive impact establishing support groups/programs, delivered in person or online. In Australia and India, there are significant challenges in providing advocacy and support services across vast geographic areas. Rapid adoption of electronic technology by patients and caregivers has increased participation through online support groups.

The largest section of the Charter advocates for excellent treatment and high-quality follow-up care. This section elicited a variety of responses from expert patient advocates across the 6 APAC countries indicating that some aspects of medical care were well met while others were clearly unmet.¹²

The right to receive emergency treatment and be treated in a safe environment with the highest standards of ethical practice was largely met across the 6 APAC countries.¹³ The right to access treatments based on need and not the ability to pay was more problematic across the region, possibly reflecting the difficulty of some healthcare systems to fund standard-of-care treatments.¹⁴ In LMICs, patients unable to afford treatment themselves rely primarily on donations from charitable organizations and programs within private hospitals versus relying on government-funded healthcare.

The highest unmet needs across all 6 countries were those relating to clinical trials.¹⁵ There is a dearth of clinical trials in the APAC region compared with Europe and the United States. Australia, Japan, and Singapore fare slightly better than the other 3 countries. In Australia, brain tumor patients

can access clinical trials outside of their home state. The lack of brain tumor clinical trials is problematic for patients whose tumors have a poor prognosis and lack of effective treatments. The scarcity of clinical trials is a major focus of many patient advocacy organizations in the APAC region.

Sub-Saharan Africa

Zimbabwe

Although complexities associated with brain tumor treatment are universal, cutting across different global contexts, their impact is exacerbated in resource-limited countries by challenges stemming from sociocultural and economic factors. The nature of brain tumors necessitates the utilization of multidisciplinary healthcare professionals and highly specialized neurosurgical and oncological equipment, adding a layer of complexity to the provision of care in regions where access to such advanced medical resources is constrained. The cost of treatment can be substantial due to the need for advanced diagnostic procedures, intricate surgeries, and ongoing treatments. This is quite limiting to many people in Sub-Saharan Africa, particularly in Zimbabwe.

Zimbabwe is situated in southern Africa, with a population of 15.1 million.¹⁶ According to estimates by the Institute for Security Studies Africa Report, Zimbabwe grapples with substantial socioeconomic challenges.¹⁷ Approximately one-third of the population (around 5 million) experience extreme poverty, as defined by the globally recognized threshold of USD \$1.90 per day.¹⁷ Brain tumor patients and their families in the lower income bracket experience serious financial challenges, hindering access to treatment.

Poor brain tumor survival outcomes in Zimbabwe are primarily influenced by the delayed patient presentation for medical care, resulting in late-stage diagnoses, advanced disease progression, and limited treatment options. Contributing factors include limited awareness of early brain tumor symptoms, cultural beliefs, and inadequate access to healthcare services.¹⁸ It is not unusual for people to seek alternative, cheaper medicines instead of conventional, more expensive medicines, later accessing mainstream health services when they present with advanced disease, requiring palliative/end-of-life care.

As highlighted in The Brain Tumor Patients' Charter of Rights, access to good palliative care and dignified end-of-life care should not be exclusive to any particular region but rather should be delivered as a universal right for every brain tumor patient irrespective of their geographic location.¹⁹ This is a goal yet to be realized in resource-limited countries like Zimbabwe.

Despite improvements in access to healthcare professionals—there were only 3 neurosurgeons in Zimbabwe in 2000; in 2023 there were more than 20—there has not been any improvement in the survival rate of brain tumor patients in Zimbabwe.

Palliative care is fundamental to health and human dignity and is asserted as a basic human right.²⁰ However, for the patient, accessing these services is often associated with fear, myths/misconceptions, and a sense of

hopelessness, leading to delayed help-seeking behavior and reduced social support for patients and their families.²¹ Zimbabwe, like many countries in Sub-Saharan Africa, falls short of meeting international guidelines for the provision of palliative care (WHO, 2020). A brain tumor patient's experiences at the end of life include other challenges intrinsic to neuro-oncological disease. Notably, patients may present with increased intracranial pressure from their tumor necessitating corticosteroid use to manage disease-specific symptoms.²²

In Zimbabwe, patients experience unmet palliative care needs because:

- Economically disadvantaged brain tumor patients bear the brunt of treatment and medication expenses. Despite fee waivers for hospital services for children under 5 and adults over 65, recent developments have burdened families with the responsibility to procure their surgical sundries (ie, bandages and surgical gloves) and self-fund all medications, including pain management.
- The absence of a structured follow-up system for brain tumor patients post-hospital discharge (apart from scheduled outpatient appointments) exacerbates unmet palliative care needs and presents challenges in managing patients' holistic well-being.
- There is no formal referral system to palliative care services for brain tumor patients. Available palliative care is offered by private, self-pay, home hospice services. Other informal services are offered by families and the community. Most caregivers lack knowledge of how to care for palliative and end-of-life patients, but private hospice services offer training to caregivers. However, only a small number of caregivers have access to this training.
- At the time of writing, there are no functional radiotherapy machines in Zimbabwe, leading to a sense of despair and hopelessness among brain tumor patients reliant on this treatment for alleviating symptoms and reducing tumor burden.

North America

United States

The United States has several prominent patient advocacy organizations strategically prioritizing policy and program initiatives to address unmet community needs, filling critical gaps in care, and enhancing support systems within healthcare frameworks. Their efforts empower individuals affected by brain tumors and drive positive change. US brain tumor advocacy groups are particularly coalescing to push for a minimum standard assay of molecular testing, appropriate safety regulations, and adequate payor reimbursement for such tests. Brain tumor treatment decisions based on histology alone could lead to suboptimal treatment of an aggressive tumor. Molecular testing provides a more accurate diagnosis and better understanding of the level of tumor aggression as well as informs the choice of targeted therapies. Many brain and CNS tumors, as classified by the World Health Organization, require molecular

testing for accurate diagnosis and prognosis.²³ In line with The Brain Tumor Patients' Charter of Rights, all patients should receive copies of these test results and should be recognized as the "owner" of this data.²⁴

Molecular testing of brain tumors is not available at every hospital and clinic in the United States, particularly in the community setting (as opposed to major institutions in large cities).²⁵ Even so, there are vast differences in molecular profiling offered at major institutions. Patients are often rushed into surgery, without understanding the importance of their biomarker assay in making treatment decisions. The American Brain Tumor Association led a collaborative effort, together with other US brain tumor patient advocacy groups and 2 groups from Europe, to develop a set of United States-based "Guiding Principles for CNS Tumor Treatment Programs."²⁶ Guiding Principle #4 states that a CNS tumor treatment program should perform on-site or outsource testing for molecular diagnostics to determine accurate tumor diagnosis, inform prognosis, and guide treatment.

Advocacy for biomarker testing coverage is expanding, with comprehensive coverage currently available in 15 states. However, federal efforts to increase coverage have not succeeded. The Molecular Characterization Initiative, part of the National Cancer Institute's

(NCI) Childhood Cancer Data Initiative offers cutting-edge molecular characterization at diagnosis to aid treatment selection, initially focusing on CNS tumors.

Clinical trials increase the availability of treatment options for patients with certain poor-prognosis CNS tumors and limited treatment options beyond the standard of care. Trials can provide "a first-line treatment option for many people with glioma," yet many patients are not educated about the importance of clinical trial participation.²⁷ The Charter states that brain tumor patients shall have the right to be given "a clear explanation of the options for treatment" including clinical trials.²⁸ Access to clinical trials (Guiding Principle #5 of the Guiding Principles document) is considered an important part of quality cancer care.²⁹

Although brain tumor clinical trials are typically available at NCI-designated cancer centers, these government-funded clinical trials are only a portion of the potentially available studies and there are many barriers to accrual.³⁰ Efforts are being made by brain tumor advocacy groups, researchers, and clinicians to determine a roadmap that may help overcome these barriers in the future.³¹

US government support for brain tumor research has grown significantly due to dedicated advocacy efforts.³² Despite increased federal funding in the past decade, driven by grassroots initiatives and activism, no amount of funding can be considered adequate until a cure is discovered.

Canada

The Brain Tumour Registry of Canada (BTRC), launched in May 2019, collects data on every primary malignant and nonmalignant brain tumor in Canada. Prior to its inception, Canadian researchers were restricted to malignant tumor data captured by the Canadian Cancer Registry, and demographic information from the United States. Brain Tumour Foundation of Canada (BTFC) worked with the University

of Alberta to prioritize the development of an accurate and comprehensive resource for brain tumor incidence, prevalence, mortality, and survival data throughout Canada.³³

Several surveillance reports have been published since the BTRC's launch, capturing the heterogeneous nature of brain tumors and addressing the sparsity of adequate surveillance data in Canada. Data on the frequency and distribution of brain tumors supports research planning, enabling the design of high-quality studies to help identify causes of brain tumors, develop life-saving treatments, and establish clinical guidelines and policies that facilitate improved patient outcomes.

A critical component of positive patient outcomes is timely, equitable access to effective treatments—an aim that patient advocates staunchly support.³⁴ Canada does not have a national health system so drug and treatment funding, including access to radiotherapy, varies widely by province and territory.^{35,36}

BTFC surveys of health professionals across Canada found that travel and wait times for treatments vary dramatically. Additionally, Canada is the only G8 country without a clinical proton facility so patients must travel to the United States or Europe for proton treatment.³⁷ The process for funding out-of-country procedures varies widely by province and territory, requiring many families to navigate non-medical costs and travel logistics on their own.³⁸

Although the federal and provincial/territorial governments are taking steps towards improved access and a national drug plan, there are still significant hurdles to overcome in implementation and delays persist. Patient advocacy in Canada is focused on better access to treatments and ensuring patient experiences are considered at the federal level.

A 2023 survey of the Canadian brain tumor community confirmed that better access to treatments was the community's top priority.³⁹ The community also wants to see increased awareness of the BTRC and survivorship needs addressed including neurocognitive, psychosocial, and physical impairments.^{40,41} A better understanding of post-treatment challenges experienced by brain tumor patients of all ages is necessary to develop tailored services that improve health-related quality of life amongst survivors, caregivers, and families.^{41,42}

Eastern Europe

Czech Republic

Being diagnosed with a brain tumor is a profoundly traumatic and unique experience. In the Czech Republic, during initial consultations when one is given their diagnosis, often a patient is not treated as an individual but rather as a sheer number. The quality of the information provided—mainly its clarity and unbiased, honest, comprehensive, and timely nature—varies. Certain conversations might be ambiguous such as what can and cannot be achieved surgically. Some of these issues are connected to a lack of detail about the management of tissue samples and the absence of brain tumor tissue banks.

Patients are not always encouraged to seek second opinions or be informed about all treatment options, including clinical trials. Access to comprehensive rehabilitation programs (ie, speech and language, occupational, neuropsychological, and physical therapies) to address cognitive, behavioral, and physical deficits caused by brain tumors is not standard. Often, patients must seek additional help independently.⁴³

Overall, the situation for a brain tumor patient in the Czech Republic is far from ideal. General information about this condition is scarce. Until recently, there was no brain tumor-specific support group in the Czech Republic, isolating this population of patients and caregivers even further. However, in 2019 the brain tumor patient advocacy organization Brain Czech was established to create a solid supportive community and disseminate knowledge.⁴⁴

One way to enhance patient experience is to produce a protocol for each hospital, describing information that should be provided at diagnosis. This protocol should include the potential risks of radiotherapy and chemotherapy, to help weigh treatment pros and cons; procedures that can and cannot be safely performed; and information regarding any lifestyle changes affecting nutrition, movement/mobility, sleep, mental health, etc. Details about any support groups for individuals with the same diagnosis, which can offer further information and a sense of community on a lonely journey; additional information regarding further treatment options, clinical trials, and palliative care (if applicable).

Standard protocols should be established on how to convey information. The manner in which a diagnosis is delivered can shape a patient's overall experience and affect further treatment. There must be constructive conversations with healthcare professionals. Furthermore, there is a need to remain open-minded and determined to communicate with the international brain tumor/neurological community, thus providing continuous education about the disease and support mechanisms.

Poland

According to the Polish National Cancer Registry, the incidence of primary malignant brain tumor cases in Poland was approximately 2500 in 2021.⁴⁵ The number of deaths was about 2900. The vast majority of brain tumor patients are adults (only about 5% of all cases are pediatric patients). Brain tumors, however, are the leading cause of cancer death among children.

There is one non-governmental organization in Poland—The Glioma-Center Foundation—whose assistance is specifically aimed at people of any age with brain tumors, particularly gliomas.

Once The Brain Tumor Patients' Charter of Rights was ratified in July 2020, the Foundation chose priorities from it that reflect the most important issues facing Polish patients.⁴⁶ These include the right to receive a prompt and accurate diagnosis (in line with the World Health Organization's most up-to-date classification) and supported with tissue analysis done by a neuropathologist (including biomarker assays); the right to request and access other opinions at any stage of treatment; and the right to be informed about all available, relevant treatment options.

The above-mentioned rights require an ongoing effort to ensure they are fairly respected throughout Poland. There are significant differences when it comes to honoring these rights. For example, typically the situation is better in large academic centers rather than in smaller community institutions.

Regarding molecular testing and the reliability of the diagnosis, the Foundation randomly chose 15 molecular results shared by patients who approached the Foundation in 2023. These demonstrated that molecular diagnostics are not performed for all patients. If diagnostics are performed, the vast majority (75% of those surveyed) are only immunohistochemistry tests (IHC). There is no standard when it comes to particular biomarkers assayed. Almost all molecular testing results include GFAP and Ki67 assay and the vast majority include IDH1 (80%), while less than half include ATRX or p53. Other markers are available in about 10% of results. MGMT promoter methylation and 1p19q codeletion were labeled on only a quarter of the results.

Because of these gaps, patients in Poland considering participating in a clinical trial targeting a particular mutation frequently must obtain biomarker information at their own expense.

An EFPIA report (European Federation of Pharmaceutical Industries and Associations) analyzed access to molecular testing in Europe across all cancers. Results indicated that multi-biomarker testing in Poland is ranked as a low-access country.⁴⁷

Despite the fact that there are centers where doctors' attitudes have become more open during the past 5 years, there is still not widespread practice of the right to a second opinion. The situation is particularly difficult for adult patients diagnosed with glioblastoma IDH-wild type and children diagnosed with diffuse midline glioma. Given the unfavorable prognosis for these tumors, it has been noted that these patients complain that they are discouraged from seeking a second opinion or participating in clinical trials.

When it comes to the right to information, this is still an area for improvement.⁴⁸ The problem is particularly acute for patients with worst-prognosis tumors who, due to the lack of effective standard treatment, will desperately seek information about clinical trials because in-country options are limited. There are very few recruiting clinical trials for glioma patients in Poland. According to the clinicaltrials.gov database, at the time of writing, there is just one trial for children and 2 trials for adults in Poland. There are some trials which are not registered in this database, which makes the search for trials process even more challenging.

Over the last 5 years, there have been improvements in many areas of brain tumor treatment, care and support in Poland. However, not all the rights in The Brain Tumor Patients' Charter of Rights are yet guaranteed to every patient.

Western Europe

Ireland

According to the Irish National Cancer Registry (2018–2020), there are just over 800 people diagnosed with a brain or CNS tumor each year, with glioblastoma being

the most common malignant tumor.⁴⁹ Sixty-five children and young adults under the age of 20 are diagnosed each year, with 30 of those receiving a malignant brain tumor diagnosis.

Late diagnosis continues to be problematic. BrainTumor Ireland conducted an awareness campaign to educate general practitioners on some of the signs and symptoms of a brain tumor.^{50,51}

Once accurately diagnosed, treatment and care are of a very high standard in Ireland and the patient experience is generally very good. Difficulties arise once the patient returns home, with little in the way of community support. Often access to support depends on where the patient lives. It is vital to have a hospital-based, brain tumor patient navigator so the journey from diagnosis to treatment is less stressful and patients and their families feel supported at every stage.⁵²

People in Ireland with a low-grade tumor do not have access to the same range of services as those diagnosed with a high-grade tumor, despite the challenges faced by low-grade patients often being the same as those with a high-grade tumor. This needs more recognition.

Unmet needs in Ireland for the brain tumor community are improved early diagnosis, access to a full range of appropriate services regardless of tumor type, and clear signposting to reliable information and support.

United Kingdom

Shifting the United Kingdom's (UK) neuro-oncology landscape is a slow evolution as it is so complex. But a strength of UK advocacy is the empowered, unified, and proactive community of people living with a brain tumor who willingly share their stories to bring transformative change. Charities are key, providing a collaborative voice and clarion call for change. These aspects are exemplified by the All-Party Parliamentary Group on Brain Tumors (APPG-BT) which raises brain tumor issues at a political level.⁵³ This is underpinned by comprehensive, gold-standard UK data sets, with health, care, and cancer data united in one national institute.⁵⁴

The importance of education and empowerment in advocacy should never be underestimated.⁵⁵ For example, at the point of diagnosis, patients and their caregivers can feel lost and overwhelmed; yet this is the time when they need to step up and be advocates for themselves.⁵⁶ Unless the community understands the importance of patients advocating for themselves, the care pathway can be fragmented and isolating. Based on anecdotal reports, low-grade and nonmalignant brain tumor patients may not have access to nurse specialists, and may wait for scans and even longer for results so their anxieties about progression may be unaddressed.

The separate ("devolved") governments of Scotland, Wales, and Northern Ireland can result in a lack of parity of access between these nations and England to ongoing clinical care. Only 57% of centers in England have a dedicated clinic for people with a low-grade tumor and only 68% in England have neuropsychological attendance at multidisciplinary team meetings with a focus solely on discussing patients prior to an awake craniotomy. Smaller hospitals

often have general psychology teams but no qualified neuropsychology support. Community mental health services are sparse, with long wait times and teams which are not equipped to take on the complex needs of people with brain tumor.⁵⁷

Just as the clinical care pathway can be fragmented so is the research pathway. Every person with a brain tumor—from diagnosis to end of life—should be a potential research patient. Whole genome sequencing and flash-freezing of brain tumor tissue are fundamental. Whilst these are moving in the right direction, the pace is too slow.

Denmark

The Danish Brain Tumor Association, provides information for patients and caregivers, holds network support groups in the larger cities, provides advice and guidance, runs annual weekend seminars, and organizes webinars and publications to help ease the everyday life of people with brain tumors.

But in Denmark, people with low-grade tumors struggle to have similar services in the community as people with high-grade tumors. Awareness about the problem of healthcare professionals calling a low-grade tumor "benign" has been raised by patient advocates.⁵⁸

Delays in diagnosis and misdiagnosis are not uncommon, with patients told by their general practitioners that their headache, fatigue, and dizziness may be stress-related.^{59,60} The level of information and education of healthcare professionals, especially general practitioners, needs improvement and timely investigations of patients' symptoms need implementation.

In general, Danish neuro-oncology physicians treat patients with the respect they deserve and carefully give detailed information about surgery, prognosis, quality of life, side-effects and potential late effects of treatment, and probability of survival.⁶¹ But occasionally, patients experience shortcomings in their brain tumor care. This leaves patients and relatives in limbo, not knowing what to believe and expect. Therefore, concepts of patient participation and shared decision-making should be firmly prioritized and implemented throughout the whole patient pathway.

The following points in The Brain Tumor Patients' Charter of Rights are only partially met and should be addressed in future advocacy in Denmark. Patients have the right to:

- be respected as a significant partner in their own care and an expert in their own needs and experience;
- be given as detailed a prognosis as possible, if requested, which includes information regarding the quality of life, side effects of treatment, the potential for late effects of treatment, and probability of survival;
- access decision-making tools to enable patients to make the right choices for their situation;
- receive support from a care coordinator or navigator (ie, a specialist nurse, social worker, or other trained person);
- be offered information on legal issues that they may need to consider (ie, power of attorney, guardianship of children, living wills, advance directives, etc.);
- be offered appropriate information about returning to work or school and the laws in their country that govern employing or educating people with disabilities.

France

In France, patient advocacy is greatly supported by very favorable, specific legislation obliging all healthcare centers, public and private, to include official representation of patients, families, and caregivers in their governance.⁶²

This advocacy role is fulfilled by the "Réprésentants des Usagers" (RU), who are volunteers and members of organizations approved, on a national or regional level, by the French Ministry of Health.

Each French healthcare center must have its own Commission and representatives who sit on many national committees and bodies such as the High Authority of Health that strongly promotes and supports the inclusion of patients, families, and caregivers in the "Démocratie Sanitaire." This approach involves all health system stakeholders in the development and implementation of health policy.

Despite these good intentions and formal healthcare structures, brain tumor patients and their caregivers still have unmet needs in France. Not all patients have systematic support from a care coordinator or navigator such as a specialist nurse, social worker, or other trained person.⁶³ Nor are all brain tumor patients in France automatically told about local, regional, and international patient advocacy organizations to whom they can turn for advice and support.⁶⁴ Well-being programs that take into account particular, individual needs (family, employment, financial, and psychosocial requirements) are not always offered to brain tumor patients.⁶⁵

However, there have been significant improvements in communication between healthcare professionals, patients, and caregivers. Generally, patients are informed about all available, relevant treatment options whether (or not) the cost of delivering such treatments is reimbursed by national insurance or other parties.⁶⁶ Patients are usually provided with clear, unbiased, honest, comprehensive, and timely information.⁶⁷ Many patients seem to receive multidisciplinary care including support from physiotherapists, speech and language therapists, psychosocial therapists, social workers, occupational therapists, and others.⁶⁸

Italy

The past 4 decades in Italy have seen patient advocacy organizations playing a crucial role in prompting governmental bodies to enact legislation regarding patients' participation in their care and safeguarding of their rights. Patient advocacy is more advanced and dynamic in the northern-central regions of Italy compared to the southern-central areas.⁶⁹

Despite efforts and some very positive results, these organizations still find themselves excluded from decision-making forums which have the potential to yield significant outcomes in healthcare assistance and treatment. Patient associations are gaining increasing proficiency in many areas of healthcare and can actively contribute to the formulation and advancement of crucial health policies. One example is the 2016 Adoption of the Italian National Chronic Disease Plan, where involvement and engagement of patient advocacy organizations is strongly emphasized.⁷⁰

However, there is a crucial need for proactive support by the Italian government to incorporate the patient perspective

into healthcare decision-making processes. There should also be adequate and renewed ability on the part of doctors, institutions, and businesses to listen to the patient's voice. Patients themselves also require sufficient skills and training to actively participate in this collaborative approach.

Unmet needs in certain areas of Italy include the absence of multidisciplinary care; lack of a care coordinator/navigator; and poor communication with patients and caregivers regarding local, regional, and international patient advocacy organizations to which they can turn for further support and information about their disease.⁷¹

But there are success stories. For patients who do receive information, it is felt to be unbiased, honest, comprehensive, and timely.⁶⁷ Patients also need to be informed about all available, relevant, and reasonable treatment options (whether or not the cost of such treatments is reimbursed by the Italian national health service or insurance companies).⁶⁶ Continuity of care is vital throughout the patient pathway. In the pediatric brain tumor arena, continuity of care also involves transitioning to suitable adult follow-up care.⁷²

Germany

In Germany, there are a number of brain tumor patient organizations, awareness initiatives, and alliances. They provide reliable information in the form of regular face-to-face and online events, brochures, videos, magazines, and podcasts. Patients and their relatives can also contact experts directly via a specially-developed app which includes a brain tumor expert group.⁷³

To support brain tumor patient advocacy, The Brain Tumor Patients' Charter of Rights was translated into German in 2021 to help achieve comprehensive, high-quality care along the entire neuro-oncological disease trajectory.⁷⁴

Brain tumor patient advocacy groups in Germany cooperate with interprofessional and interdisciplinary healthcare professional teams. This collaboration is intended to ensure comprehensive, holistic care for patients in which medical, psychosocial, and policy aspects are given equal consideration so as to provide the best possible support and care.^{75,76}

With the establishment in 2018 of the first Patient Advisory Board for Cancer Research in Germany by the German Cancer Research Center (DKFZ), efforts are being made to involve patient advocates in developing cancer clinical trials in Germany which seek to ensure that the interests of patients are adequately embedded in research projects.⁷⁷ National funding agencies, such as the Federal Ministry of Education and Research (BMBF), also encourage the inclusion of patient representatives in research project proposals. It is standard practice in larger research studies in Germany to involve patient representatives, with dedicated budgets allocated for their participation in study development, execution, and analysis.⁷⁸

In recent years, patient representatives have played an active role in shaping guidelines for glioma treatment. Additionally, physicians are encouraged to refer patients to suitable support services. Given the limited availability of local support resources, patients should also be directed towards supra-regional support facilities.^{64,79}

Efforts are underway to standardize and certify major brain tumor centers under the auspices of the German Cancer Society. Certification criteria include access to

palliative care, psycho-oncological care, and social medical counseling. There is a growing emphasis on palliative care, encompassing symptom control, psycho-oncology, social medical issues, and spiritual support.^{80,81} Nevertheless, the demand for such services still exceeds the available supply.

Digital resources have significantly expanded the reach of brain tumor organizations, making it easier for brain tumor patients and their families to access information, support, and services. However, significant room for improvement remains in the realm of social support for brain tumor patients, particularly concerning legal assistance, reintegration into the workforce, engagement with navigators, and access to financial support.

The Netherlands

Treatment for brain tumors in the Netherlands is very far advanced and standardized throughout the country. Information about the different types of brain tumors is easy to find.

The patient's journey becomes more difficult when treatments are given across different hospitals, that is, surgery in one hospital, radiation in another, and chemotherapy in another. Under these circumstances, support from a brain tumor navigator for each patient and caregiver would be ideal, but this does not yet exist in the Netherlands.

Brain tumor patients and caregivers feel extremely lost during what is an intense journey with the disease. There are doubts, fears, uncertainties, and a desperate need for practical (ie, financial) and mental help. A professional patient organization supported by the government can help

fill this gap, not only helping patients and caregivers but also supporting healthcare professionals' work.

A 2021 survey carried out in the Netherlands by a Dutch brain tumor patient foundation, Sterk en Positief, examined the time span between a patient receiving a brain MRI and the patient receiving the results of their MRI.⁸²

Sixty-four percent of patients surveyed experienced extreme stress between the brain tumor MRI and notification of the result. More than 94% of patients surveyed experienced stress when hearing their scan results. The survey revealed that 2 hospitals gave the results to the patient on the same day as the MRI, while other hospitals took 2 to 7 days to inform the patient about their results. The time-scale between MRI and results should be standardized across institutions to provide MRI results to all patients as rapidly as possible.

While large cancer organizations in the Netherlands focus on cancer research, side effects, aftercare, and improving palliative care, it's vital to have a greater focus specifically on brain tumors.⁸³ Financial toxicity caused by a brain tumor diagnosis also needs a greater focus of attention.

Resulting Recommendations

A brain tumor diagnosis is devastating for anyone, no matter where they live in the world, and can present multiple major challenges even with access to best-in-class care. This paper presents a review based on the expert opinion of brain tumor patient and caregiver advocates. Some issues are repeatedly noted across geographic areas.

Table 2. Based on Common Themes From the Various Countries Contributing Expert Opinion to This Review, Solutions to Address the Unmet Needs Identified in this Paper Include Resultant Recommendations as Follows

Topic area	Recommendations
Addressing inequalities	There should be a greater focus of attention on healthcare inequalities in the treatment of brain tumor patients around the world, particularly regarding inequities in access to quality care in a timely manner.
Cultural factors	More information and clarity to better understand the importance of cultural factors in delivering appropriate care and supportive programs is needed.
Clinical trials	There should be increased clinical trial availability and more funding for research into the causes of and treatments for brain tumors. Additionally, patients need to be better informed about available clinical trials and provided with assistance in navigating this option.
Brain tumor patient advocacy organizations	Continued support is needed for existing brain tumor patient/caregiver organizations as well as encouragement/resources to establish brain tumor support groups/organizations in countries where they do not yet exist—these recommendations are vital to improve the patient and caregiver journey.
Education of healthcare professionals	Healthcare professionals should be taught about the importance of advocacy organizations and support groups at the residency stage of their training so they can be more proactive in referring patients to such groups and supporting these efforts at their institutions.
Low-grade and nonmalignant brain tumors	There should be greater attention and support focused on people with low-grade and nonmalignant brain tumors.
Navigator services for all	All brain tumor patients should have a navigator, no matter what type of tumor they have.
Brain tumor registries	There should be a greater and continuing emphasis on the need for brain tumor registries and collaborating with governmental organizations, researchers, clinicians, neuro-oncology societies and others to establish and manage such registries. Those running well-established, successful registries should guide/mentor others aiming to create registries in their countries.
International survey	A survey of the international brain tumor patient and caregiver community should be carried out to further highlight and establish evidence on their met and unmet needs.
Working together	A more unified, collaborative international brain tumor community needs to be created where all stakeholders come together and address the shortcomings which are preventing patients benefitting from the rights that should be theirs.

This review highlights inconsistencies across countries such as the availability of tumor registries and the need for more research, clinical trials, and navigators. A common theme across many countries is the lack of equitable care. The importance of fully supporting patients with low-grade and nonmalignant tumors as well as those with malignant tumors is also discussed.

The aspirational aims presented in The Brain Tumor Patients' Charter of Rights, if achieved in practice, would potentially meet many of the unmet needs of the international brain tumor patient and caregiver community, thus improving patient and caregiver quality of life.

Notes

Where possible (excluding direct quotes using the words "so-called benign" from The Brain Tumor Patients' Charter of Rights), the coauthors have used the words "low grade" and "nonmalignant" to denote what used to be referred to as "benign."

Additional Material

- We have submitted 2 tables—[Tables 1](#) and [2](#).
- We have submitted one item of [Supplementary Material](#) which is a copy of The Brain Tumor Patients' Charter of Rights which is intended to assist ease of reference when reading this review.

Supplementary material

Supplementary material is available online at *Neuro-Oncology Practice* (<https://academic.oup.com/nop/>).

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