

## Enrolment difficulties in Neurological Disorder Patients

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### DESCRIPTION

Adult patients with malignant brain tumours have poor prognosis and have seen very modest increase in survival over the previous few decades. Even though there are many reasons that contribute to this lack of development, inadequate clinical trial enrollment is a significant barrier to improving results. More than 50% of cancer patients often join in clinical trials when they are eligible and offered. However, a significantly smaller proportion of patients actually participate in clinical studies. Only 21.3% of patients with malignant gliomas participated in a clinical trial, according to data from 2002.

However, enrollment in neuro-oncology trials has been flat for the past ten years. Only 21% of brain tumour patients participated in a clinical trial, and only 24% of patients were told of clinical trials at the time of diagnosis, according to a 2016 survey of brain tumour patients by the National Brain Tumor Society (NBTS). Similarly, according to a 2018 report on the state of Glioblastoma (GBM) clinical trials, only 8-11% of newly diagnosed GBM patients join in these studies.

Based on this knowledge, the National Brain Tumor Society (NBTS), the Society for Neuro-Oncology (SNO), and the National Cancer Institute (NCI) collaborated on a survey of over 350 neuro-oncology providers in an effort to identify difficulties and barriers to clinical trial referral and participation. Less than 30% of all patients are referred for clinical trials, according to the survey's findings, but more than one-third of respondents indicated that their institution did not track clinical trial referral, making precise calculations challenging.

### Patient and community factors

Brain tumour patients are prevented from participating in clinical trials due to poorly understood patient and societal variables. Indeed, disease-specific study on these characteristics is crucial given the impact of the illness on cognitive function, behaviour, and motor abilities, which can affect patients' ability to make informed medical decisions, perform their jobs, and feel in control of their lives.

In order to identify opportunities for creating interventions to increase trial participation, this section assesses patient and community characteristics that may provide barriers to participation.

### Patient-specific factors

Clinical trial participation may be influenced by a variety of factors relating to brain tumour patients. Social disparities, linguistic or cultural hurdles, and advanced age are some of the aspects of oncology that adversely affect participation in brain tumour trials. Numerous aspects are specific to the community because of the disease's impact on neurocognitive function.

The time and method of discussing clinical trials with patients may have an effect on accrual, particularly if the patient has a poor understanding of the research and the medical professional finds it challenging to explain things to them. The ability of patients to decide whether to participate in clinical trials for various cancer types is known to be influenced by their level of education, which is a known barrier to clinical trial enrolment. Regardless of their educational background, patients and caregivers who are unfamiliar with clinical research methods or terminology may become overwhelmed by the explanation of complicated trial-related procedures by clinicians and long consent paperwork.

The nature of clinical research and associated processes, such as randomization, blinding, and biospecimens collection-as well as the additional time required as a study participant due to additional travel for clinic appointments-all add complications that may be viewed as unintended interventions outside of standard care. A new or recurring cancer diagnosis can also cause emotional and psychosocial distress, which is when clinical trials are often presented.

### CONCLUSION

Prior studies have found that increased oncology trial participation is correlated with better communication, a good patient-physician connection that develops trust, and a patient-friendly presentation of clinical trial information, underscoring the significance of these two criteria. Patients and caregivers considering a range of complex treatment options may find verbal, textual, video, and online review resources in addition to time allotted for questions and concerns to be of great use. The availability of financial or other supportive resources (such as travel reimbursement, cheap lodging, etc.) as well as sensitive consideration to trial complexity, such as the use of a placebo or blinded trial design, can also help promote trial participation.

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