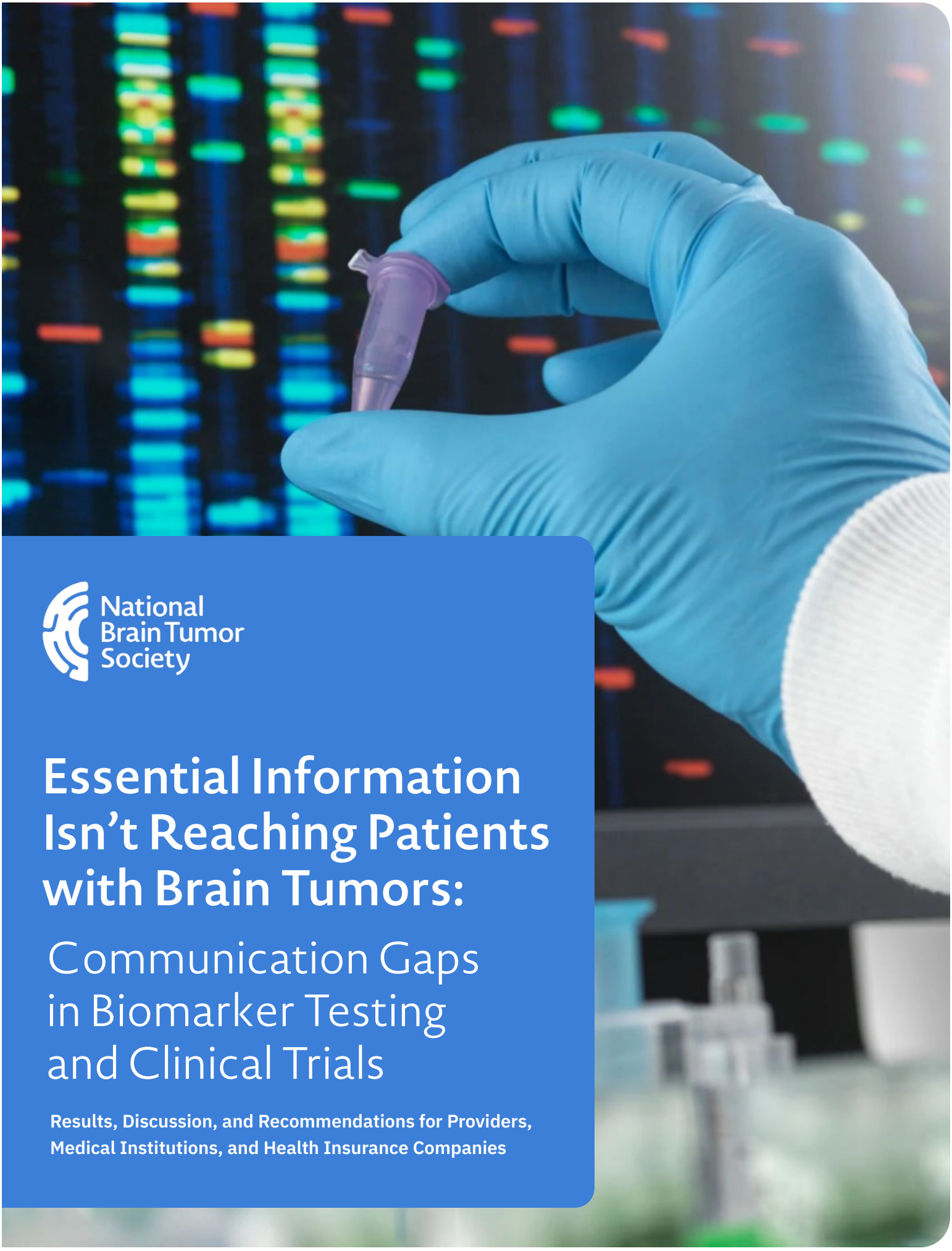

National Brain Tumor Society

Essential Information Isn't Reaching Patients with Brain Tumors:

Communication Gaps in Biomarker Testing and Clinical Trials

Results, Discussion, and Recommendations for Providers, Medical Institutions, and Health Insurance Companies

National Brain Tumor Society

Table of Contents

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Summary

Results from a survey of brain tumor patients and caregivers found that a lack of awareness and subsequent understanding of biomarker testing and clinical trials is linked to critical omissions during patient interactions with doctors and care teams. This deficiency in patient-provider dialogue and patient education negatively affects patients' understanding and views of these crucial components of their diagnosis and treatment planning, and limits access to potentially beneficial treatments.

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Introduction

More than 1.3 million Americans are living with a primary brain tumor. In recent years, significant advances have been made in neuro-oncology research, including new diagnostic techniques such as comprehensive biomarker testing and the development of targeted therapies. Despite these breakthroughs, the five-year relative survival rate for malignant brain tumors remains approximately 34.8%[1].

1.3 M+

Americans are living with a brain tumor

34.8%

Survival Rate for all patients with a malignant brain tumor

Biomarker testing, also called genomic or molecular profiling, is the analysis of tumor tissue or biological fluids to identify specific genetic mutations and protein alterations. Because every brain tumor possesses a unique molecular and genetic makeup, this testing is essential for establishing an integrated diagnosis that informs a tumor's expected behavior, growth rate, and treatment sensitivity. The World Health Organization (WHO) Classification of Tumors of the Central Nervous System now relies on this integrated diagnostic approach, combining histology with biomarker testing, to accurately diagnose brain and spinal tumors[2]. Beyond diagnosis, biomarker testing is the fundamental tool for determining targeted treatment options and eligibility for clinical trials. To put into contrast, without sufficient biomarker testing up to the latest WHO classification, it is possible that some patients with biomarkers for which there are approved on-label and off-label therapies might not be matched to those treatments, particularly patients with specific gene fusions.[3]

Traditional treatments, such as surgery, chemotherapy, and radiation, continue to be the standard of care for many of the more than 100 different types of brain tumors. Yet new treatment options are just beginning to emerge, with recent targeted therapy approvals and an expanding slate of clinical trials. FDA approvals began with TRK inhibitors for NTRK fusion-positive tumors in 2019[4], followed by dabrafenib plus trametinib for BRAF V600E-mutant gliomas in 2023[5], vorasidenib for IDH-mutant grade 2 astrocytoma or oligodendroglioma in 2024[6], and dordaviprone for H3K27M-altered diffuse midline glioma in 2025[7].

The pace of these approvals has accelerated. Three of the four targeted therapies above were approved between 2023 and 2025. Each requires biomarker testing to identify eligible patients. The communication and access gaps that this paper documents therefore carry higher stakes today than they did when the survey was fielded in 2023, and they are likely to continue compounding as additional biomarker-driven therapies move toward approval.

The National Comprehensive Cancer Network (NCCN) guidelines emphasize the importance of biomarker testing and recommend clinical trial enrollment as a top treatment consideration for eligible patients[8]. However, it remains unclear whether patients and caregivers are aware of these advancements, and to what extent doctors are incorporating them into clinical practice.

To better gauge patients' understanding and experiences with biomarker testing and clinical trials, NBTS conducted a survey of patients, their partners, and other individuals to assess current knowledge, identify gaps, and determine potential educational needs of this population. The survey results are reported here, along with specific perspectives from survey participants and recommendations to align provider practices and health insurance educational practices and coverage with current diagnostic and therapeutic standards.

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Survey Methodology

NBTS conducted an online survey from June 23, 2023, to August 31, 2023, directed at patients with brain tumors and their caregivers. The survey was distributed through email, social media, and online search platforms such as Google search advertisements. The survey was split into four audiences for different members of the brain tumor community: patients, caregivers of current patients, caregivers of former patients (bereaved individuals), and other individuals.

The survey questions focused on patients' and caregivers' knowledge of, access to, and feelings regarding biomarker testing and clinical trials. A specific skip logic was used in the survey to ask participants appropriate questions based on whether they were a patient, current caregiver, former caregiver, or another person in the brain tumor community.

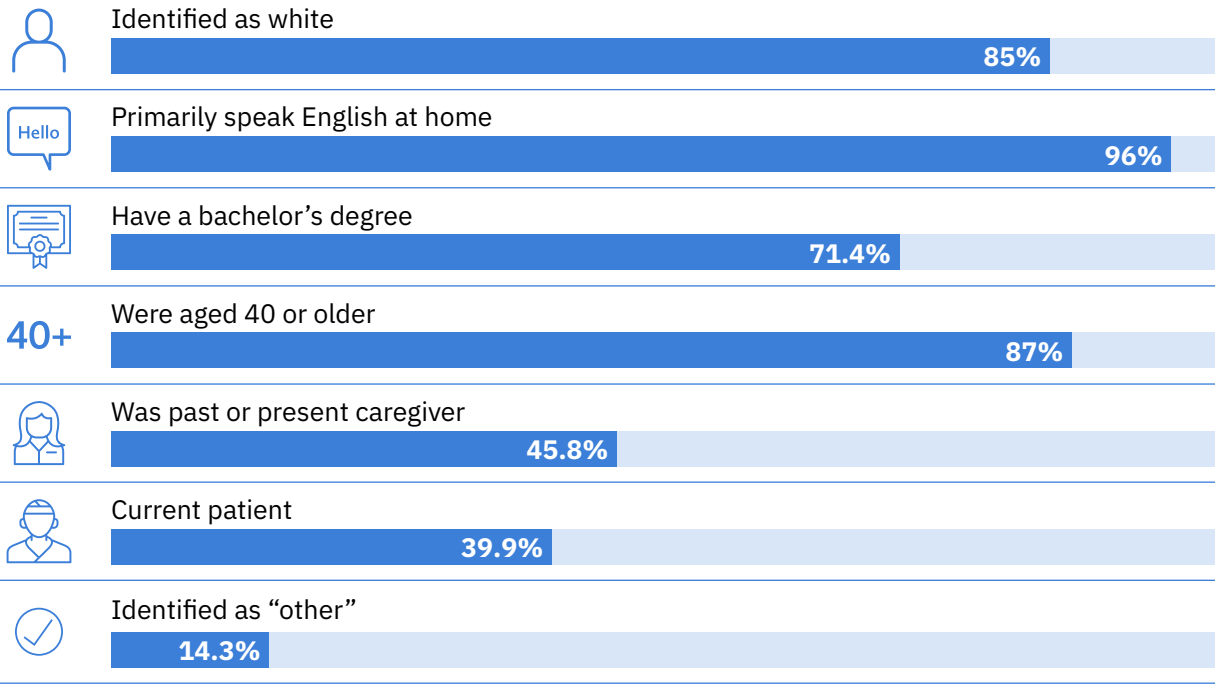
When reviewing these findings, it is important to note several limitations. Because respondents self-selected through online recruitment channels, the sample skews toward English-speaking, college-educated, and white participants. Additionally, brain tumors and their treatments can cause lasting cognitive impacts, and the profound stress of a diagnosis can affect how accurately a patient recalls specific clinical conversations. This cognitive factor may contribute to the differences in responses between patients and caregivers highlighted below. While these limitations require a cautious interpretation of any single statistic, they also suggest that the patterns documented here present a conservative view of the communication and access gaps in our community. These challenges are often even greater for individuals with fewer resources, those who navigate complex health information with difficulty, or those receiving care outside of major academic research centers.

National Brain Tumor Society

Survey Results

There were **1,256 total respondents** representing a range of perspectives within the brain tumor experience, including patients with brain or spinal cord tumors, caregivers of current patients, and caregivers of people who passed away. Regarding the demographics of these participants, 85% identified as white, 96% primarily speak English at home, and 71.4% have a bachelor's degree or higher. Among all respondents, 87% were aged 40 or older. The largest group was past or present caregivers (45.8%), followed closely by current patients (39.9%). 14.3% identified as "Other."

Respondents Demographics



All survey participants were asked questions pertaining to the following pertinent topics:

- Their familiarity with biomarker testing
- Whether the patient received biomarker testing
- Reasons why biomarker testing was not performed
- Whether clinical trials were discussed with patients and/or caregivers
- At what point clinical trials were discussed during their treatment
- Whether patients ever enrolled in a clinical trial
- Reasons for not enrolling in a clinical trial
- Overall feelings about clinical trials
- The resources they felt could help better educate patients and caregivers about biomarker testing and clinical trials

The following issues and supporting data emerged from the survey results.

There are Serious Yet Avoidable Gaps in Patient Awareness of Biomarker Testing

The most recent updates to the World Health Organization Classification on Tumors of the Central Nervous System in 2021 necessitate the use of biomarker testing in the diagnosis of brain tumors[9]. Biomarker testing is often needed to determine if a patient meets the inclusion and exclusion criteria of clinical trials for people with brain tumors. Overall, biomarker testing can help people identify tailored treatment options specifically for their unique tumor.

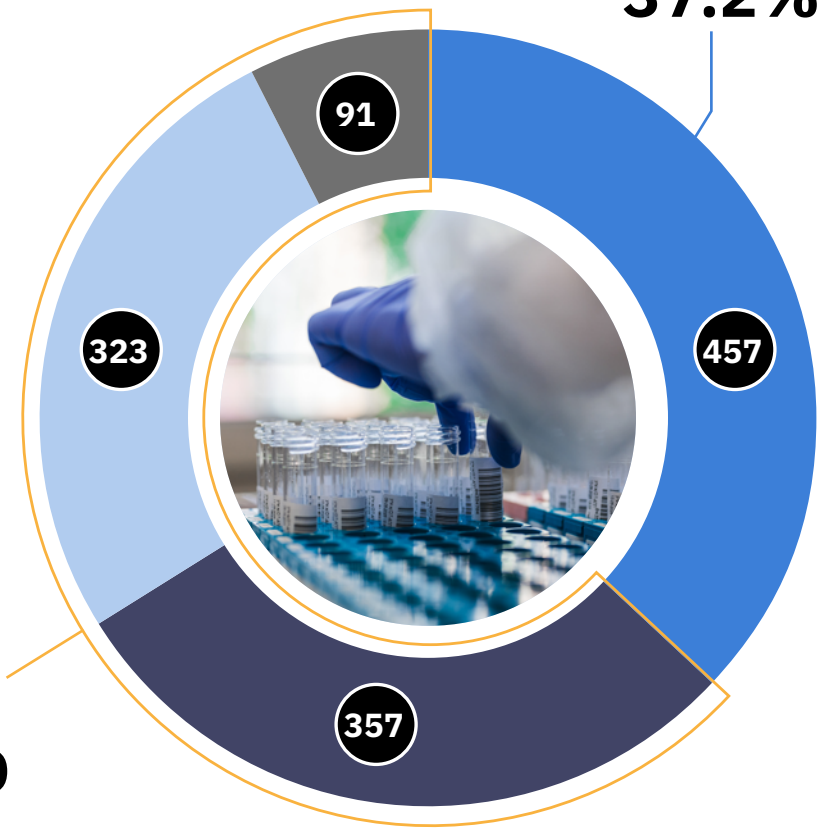
Familiarity with biomarker testing

ALL RESPONDENTS: 1228

Had at least a basic understanding of biomarker testing

37.2%

- Have heard of biomarker testing and have at least a basic understanding of what it is
- Have never heard of biomarker testing before
- Have heard of biomarker testing but don't know anything about it
- Weren't sure



62.8%

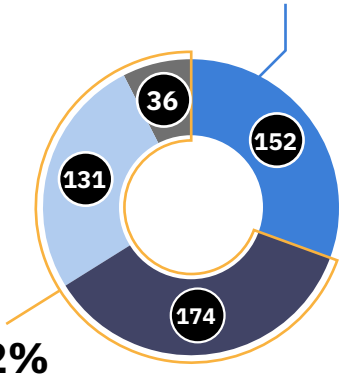
Didn't know anything about biomarker testing, never heard of the term before, or were unsure.

Familiarity with biomarker testing

- Have heard of biomarker testing and have at least a basic understanding of what it is
- Have never heard of biomarker testing before
- Have heard of biomarker testing but don't know anything about it
- Weren't sure

493 PATIENTS

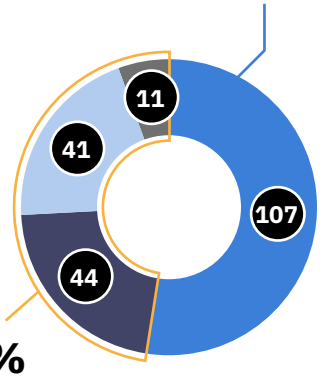
30.8%
Had at least a basic understanding



69.2%
Didn't know anything, never heard of it, or were unsure

203 CURRENT CARGIVERS

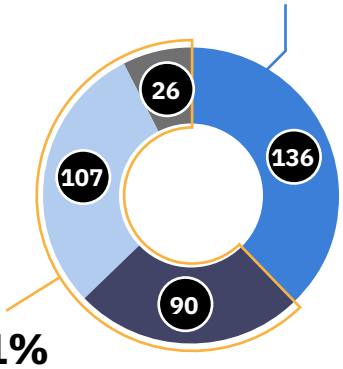
52.7%
Had at least a basic understanding



47.3%
Didn't know anything, never heard of it, or were unsure

359 FORMER CARGIVERS

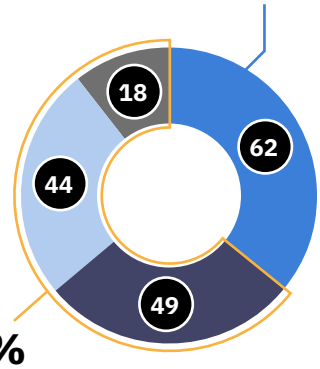
37.9%
Had at least a basic understanding



62.1%
Didn't know anything, never heard of it, or were unsure

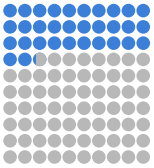
173 OTHERS

35.8%
Had at least a basic understanding



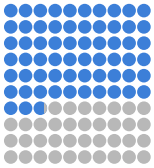
64.2%
Didn't know anything, never heard of it, or were unsure

There is a clear lack of awareness among patients and caregivers about the role of biomarker testing in brain tumor diagnosis and treatment. Across all groups, **less than half of people said they possessed at least a basic understanding of biomarker testing:**



37.2%

of people said they possessed at least a basic understanding of biomarker testing.



62.8%

either answered that they didn't know anything about biomarker testing, never heard of the term before, or were unsure.

When asked to explain in their own words the purpose of biomarker testing, many of the people who claimed to have a basic understanding provided incomplete, misinformed, or wholly incorrect answers:

"They're sort of the little connecting dots that make our cancer experiences unique and affect the way medicine/treatment works."

"Testing to see if a cancer is genetically linked."

"I thought with other cancers you can determine if you have or are prone to cancer based on biomaterial results but that there isn't a biomarker developed for brain cancer."

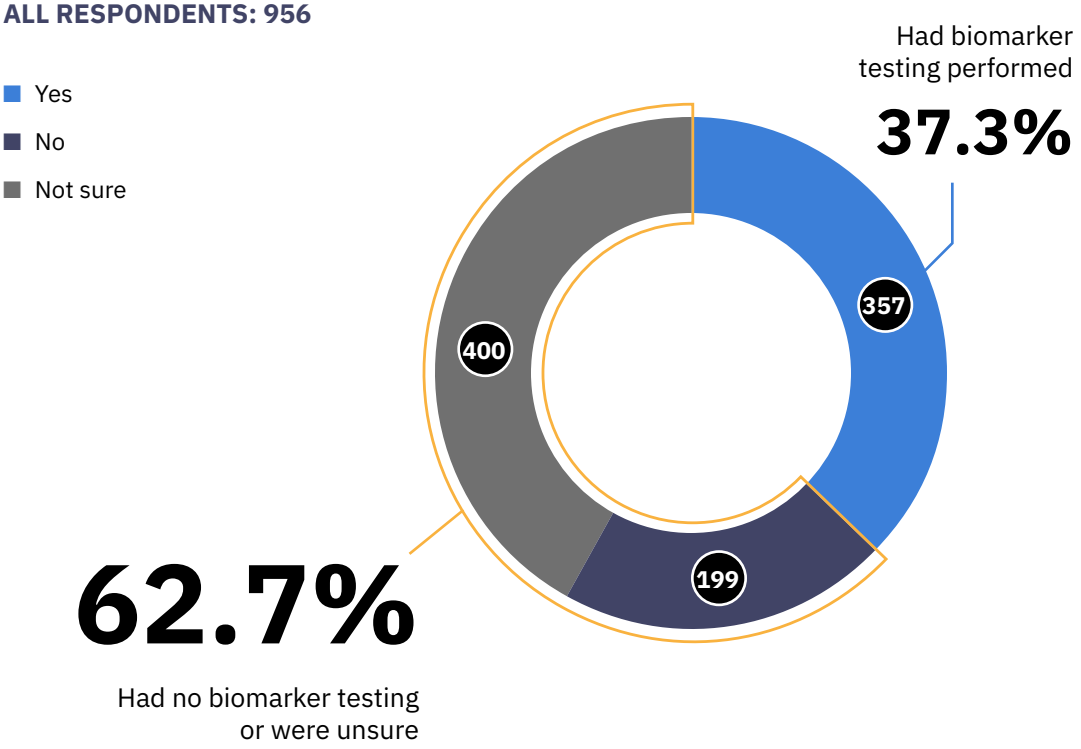
"It is helpful to detect tumors as early as possible. The sooner something is addressed, the easier it will be on the patient."

"Biomarker testing can test for new growth of tumor cells."

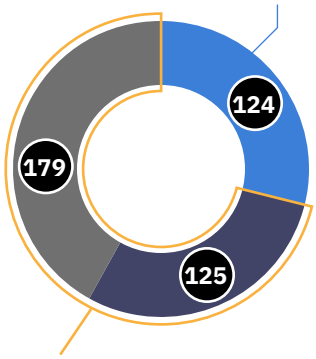
Furthermore, many brain tumor patients and their caregivers (**41.84%**) answered in our survey that they did not know whether or not they received this vital testing.

Biomarker testing may be performed after a biopsy or surgery. Have you ever had biomarker testing?

ALL RESPONDENTS: 956

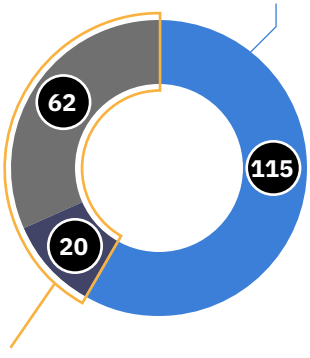


428 PATIENTS — **29%** Had biomarker testing



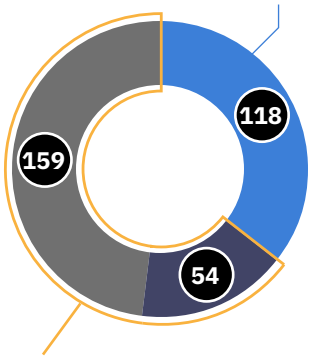
71% No biomarker testing or were unsure

197 CURRENT CAREGIVERS — **58.4%** Had biomarker testing

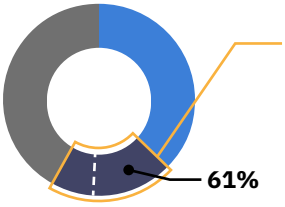


41.6% No biomarker testing or were unsure

331 FORMER CAREGIVERS — **35.6%** Had biomarker testing



64.4% No biomarker testing or were unsure

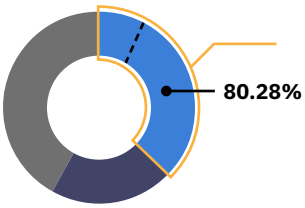


Approximately **21%** of survey participants confidently said biomarker testing did not occur. Among these answers, **most (61%) said biomarker testing was not performed because "the doctor or care team did not mention biomarker testing as an option."**

Two distinct issues are reflected in these responses. The first is whether comprehensive biomarker testing was performed at all on a patient's tumor tissue, a step that, in many cases, is determined within hospital pathology workflows rather than during a patient-facing conversation. The second is whether patients and caregivers were informed about the testing, its purpose, and its results in a way that empowered them to participate in treatment decisions. Both elements matter. A patient whose tumor was molecularly profiled but who was never told what the results mean is in a different position than a patient whose tumor was never tested at all — but neither individual is fully positioned to make informed decisions about targeted therapies or trial eligibility.

"It would have been nice to be able to talk to the doctor about this before my dad's first surgery."

"The biomarker testing was only discussed/ initiated after the recurrence of tumor and removal, not at the initial diagnosis. In retrospect, this was a negative situation. I believe all neuro-oncologists should discuss this opportunity and its benefits right away."



Some hopeful data did emerge from this section, however: **Of the 37.34% of people in the survey who confidently said they, or the patient they were caring for, had undergone biomarker testing, 80.28% said their doctor reviewed the results with the patient and/or caregiver.** This indicates that in institutions where biomarker testing is mentioned and offered, there is a dialogue with patients and caregivers regarding the information.

Opportunities Are Being Missed By Providers to Discuss Clinical Trials With Patients and Caregivers

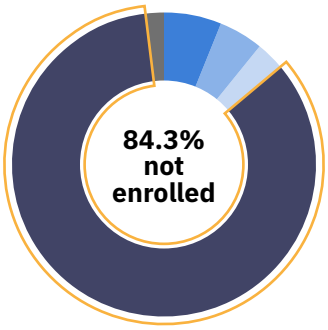
Despite the NCCN's recommendations to consider clinical trials early in brain tumor care, **84.3% of patients in the NBTS survey said they never enrolled in a clinical trial.**

Including caregivers, **77.9%** of respondents in the survey said they, or the patient they were caring for, have never participated in a clinical trial. Just **20.3%** reported they participated, or are participating, while the remaining **1.8%** were unsure.

These numbers mirror NBTS's previous survey in 2016, in which **21%** of respondents said they have participated in a clinical trial[10]. This low figure has been consistent across a large sample size spanning two separate surveys.

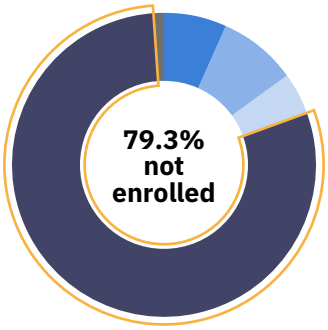
Patients enrolled in clinical trials

466 PATIENTS: Are you currently or have you previously been enrolled in a clinical trial for the treatment of your brain or spinal tumor?



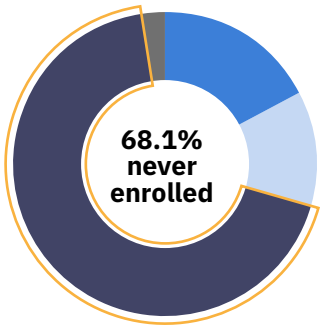
Yes, currently	29
Yes, previously one concluded	22
Yes, previously but withdrew early	14
No	393
Not sure	8

193 CURRENT CAREGIVERS: Has the patient ever been enrolled in a clinical trial for the treatment of their brain or spinal tumor?



Yes, currently	13
Yes, previously one concluded	16
Yes, previously but withdrew early	9
No	153
Not sure	2

332 FORMER CAREGIVERS: Did the patient ever enroll in a clinical trial for the treatment of their brain or spinal tumor?



Yes, had enrolled in a clinical trial that concluded	58
Yes, had enrolled but withdrew early	40
No, never enrolled in a clinical trial	226
Not sure, or don't recall	8

Patients and caregivers in the most recent survey indicated that their doctor or care team did not discuss with them clinical trials as a treatment option:

50.1%
said clinical trials never came up during conversations with doctors

45.09%
said clinical trials were mentioned

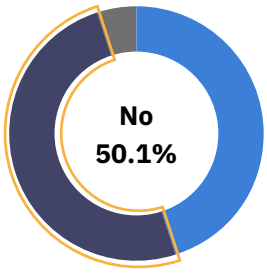
5%
were unsure

"I know nothing about clinical trials. Didn't know there was such a thing."

How many doctors discussed clinical trials

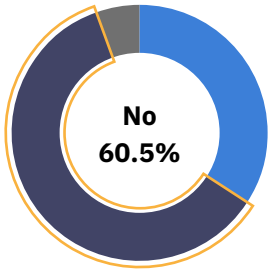
Has your doctor or care team ever discussed clinical trials as a treatment option for your brain or spinal tumor?

ALL 998 RESPONDENTS



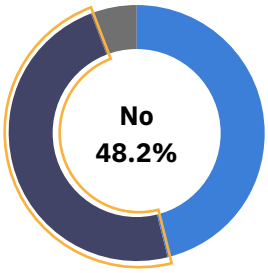
Yes	450
No	500
Not sure	48

468 PATIENTS



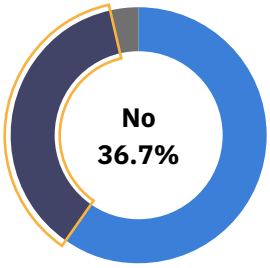
Yes	160
No	283
Not sure	25

197 CURRENT CAREGIVERS



Yes	91
No	95
Not sure	11

333 FORMER CAREGIVERS



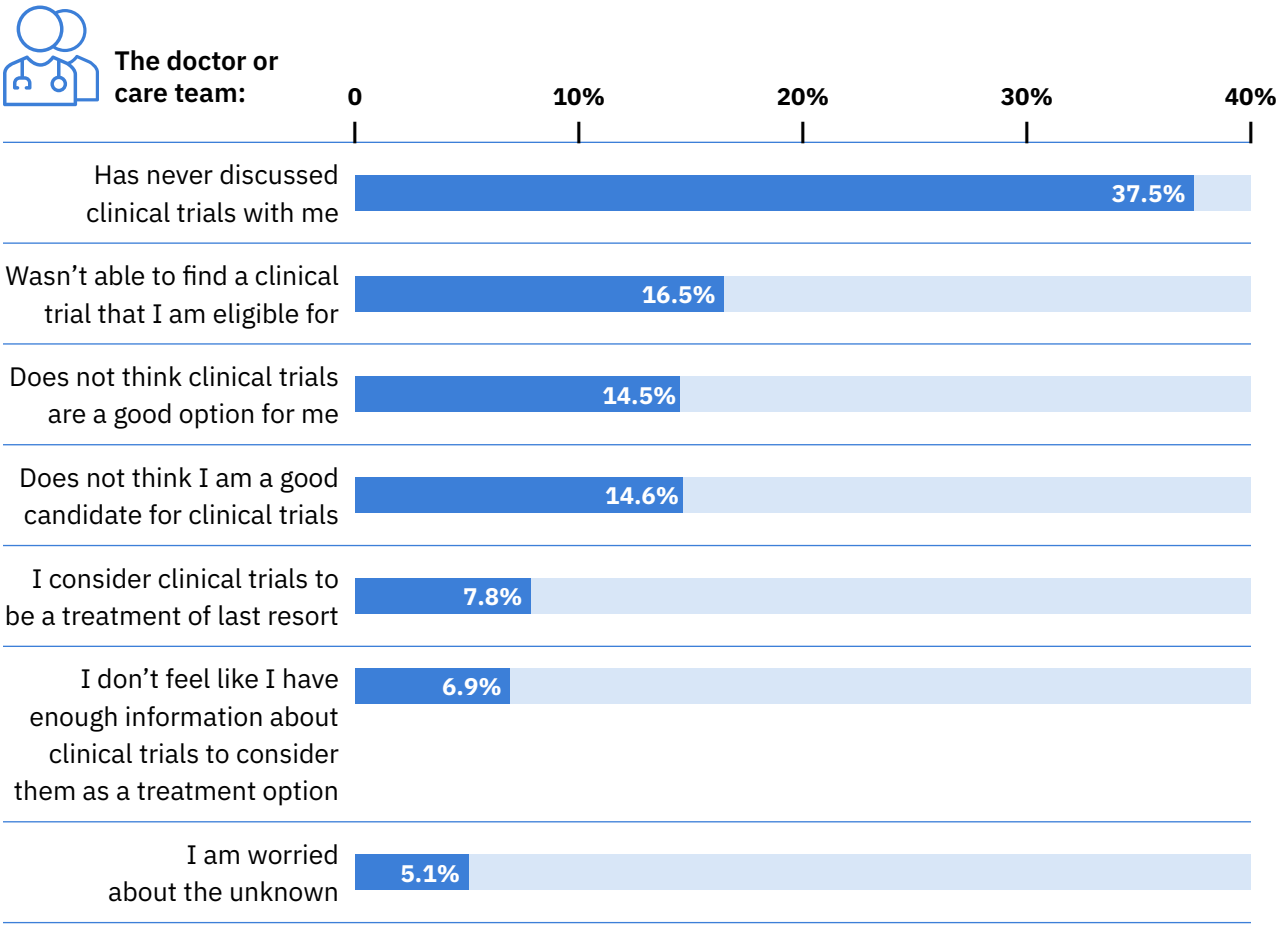
Yes	199
No	122
Not sure	12

The lack of consistent communication regarding clinical trials as a viable and even recommended treatment option is a major reason why some patients don't enroll in a study. **When asked why they or the patient they cared for did not enroll in a clinical trial, the most common answer (37.45%) was that the doctor or care team never discussed clinical trials with them.**

Patients Trust Their Doctors and Rely on Them for Guidance on Clinical Trials

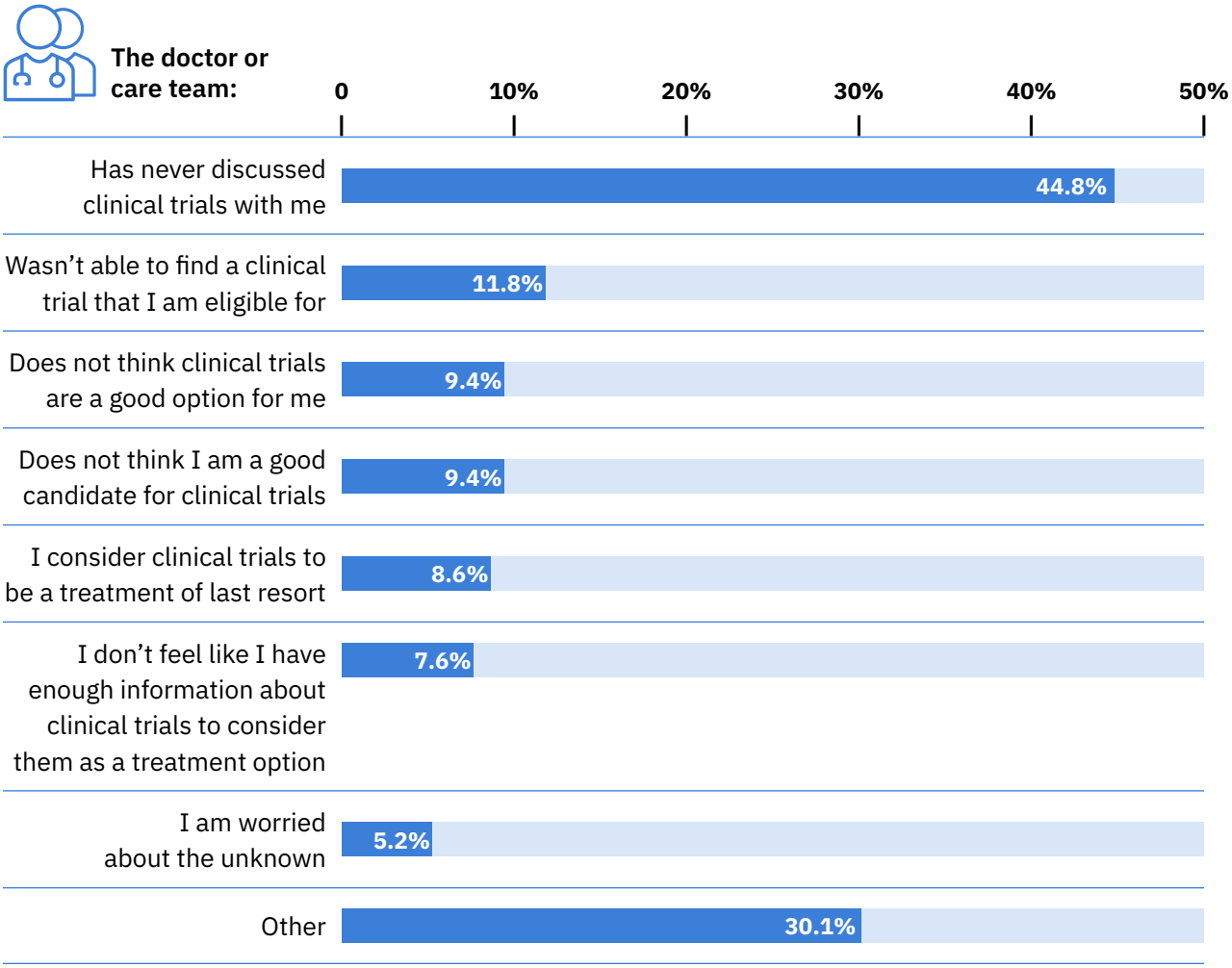
A patient's primary doctor for their brain tumor diagnosis and treatment is their most accessible medical expert – and therefore their most trusted source of information and guidance. It's expected that patients would rely on their doctors' knowledge and judgment when deciding on a treatment plan.

FOR PEOPLE ANSWERING "NO":
TOP 10 PATIENT-IDENTIFIED REASONS FOR NOT PARTICIPATING IN CLINICAL TRIALS
ALL 753 RESPONDENTS



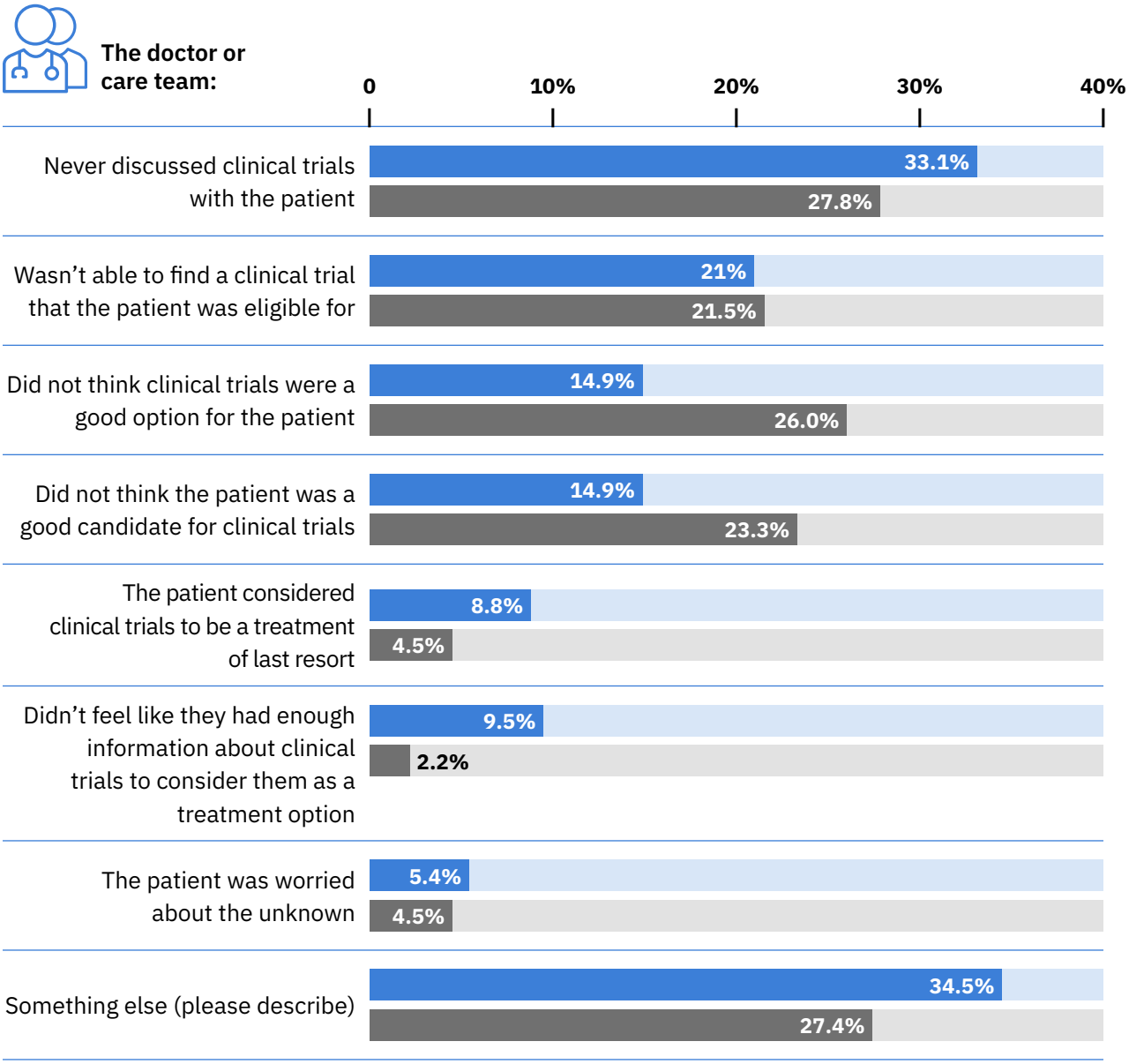
TOP 10 PATIENT-IDENTIFIED REASONS FOR NOT PARTICIPATING IN CLINICAL TRIALS

382 PATIENTS



TOP 10 PATIENT-IDENTIFIED REASONS FOR NOT PARTICIPATING IN CLINICAL TRIALS

■ 148 CURRENT CAREGIVERS | ■ 223 FORMER CAREGIVERS



For many patients with brain tumors, finding a matching clinical trial remains a significant challenge. While doctors strive to find the most appropriate treatment option, specific tumor characteristics and eligibility requirements mean that a suitable trial is not always available for every patient. When patients were asked in the survey why they did not enroll in a clinical trial, nearly half of respondents (45.6%) noted that their care team did not identify an available trial or did not recommend a trial as a treatment option:

- **14.61%** said the doctor or care team did not think the patient was a good candidate for clinical trials.
- **14.48%** said the doctor or care team did not think clinical trials were a good option for the patient.

Yet, many patients in the survey said they *would have* enrolled in a trial if their doctor endorsed this option, similar to the results published in "Barriers to accrual and enrollment in brain tumor trials" in *Neuro-Oncology*[11]. The responses below are just a few examples:

While this highlights a strong willingness to participate, it also emphasizes the critical role of the doctor's clinical judgment.

A little more than half of survey respondents indicated that when the conversations about clinical trials happened, they happened early in the treatment process, aligning with NCCN guidelines. Among those who had discussions with their doctor about clinical trials:

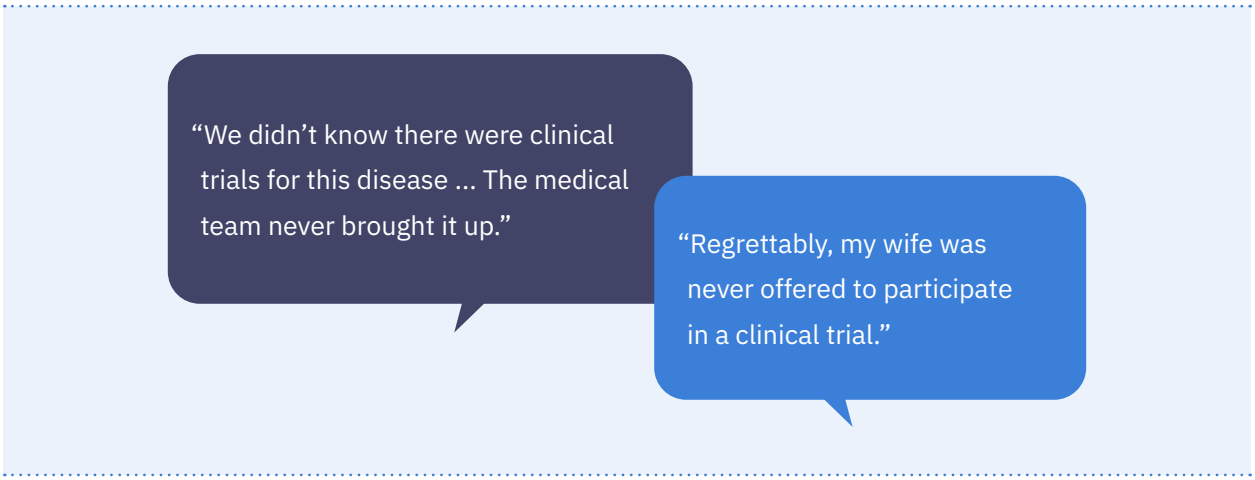
- **53.23%** said they first discussed clinical trials with the doctor around the time of diagnosis, or right before beginning radiation, chemotherapy, or other treatments.
- **28.51%** said the first mention of clinical trials happened after the patient's tumor recurred or started growing again after trying other treatments.

Discussion

There is a clear gap in awareness and knowledge among patients with brain tumors and care partners regarding the availability and purpose of biomarker testing and clinical trials. Survey responses indicate that communication on these topics is often insufficient, irregular, or not a routine part of standard operating procedures across many institutions and care settings.

These findings reflect system-level patterns rather than individual provider failures. The field of neuro-oncology has expanded faster than the systems built to support it. Testing infrastructure varies widely between academic and community settings, and health insurance coverage for molecular profiling remains inconsistent. Additionally, time-pressed appointments rarely accommodate detailed discussions of every emerging trial. The science itself has moved quickly enough that even attentive clinicians face challenges keeping pace with each new biomarker-driven approval.

Ultimately, this lack of consistent communication results in patients and caregivers being unfamiliar with the terms and concepts, being unsure whether they even had biomarker testing done, and not knowing to ask about biomarker testing and clinical trials. Similarly, low accrual numbers in brain tumor clinical trials, it can be deduced, is due at least in part to a lack of conversation about these options between patients and providers.



These obstacles and concerns can be addressed with more consistent communication on these two crucial topics from doctors and care team members to patients and their caregivers. To empower patients with brain tumors to become informed decision-makers, providers must proactively identify and discuss clinical trial options as a standard part of care.

Closing the communication and access gaps documented in this survey will require coordinated action across providers, medical institutions, insurance companies, advocacy organizations, and patient communities. National Brain Tumor Society (NBTS) includes itself among the parties responsible for leading this work.

One potential solution is for providers to focus on communicating pertinent information with caregivers, who can then deliver the information to patients at the appropriate time. Based on these survey responses, caregivers seem more knowledgeable of biomarker testing and have better memories than patients regarding past conversations with the care team. They also better understand the most effective time and method to deliver information to the patient.

Caregivers in the survey – both caregivers of patients who passed away, and caregivers of patients currently with a brain tumor – seemed more knowledgeable than patients regarding biomarker testing:

said they had at least a basic understanding of biomarker testing

Caregivers also better recalled conversations about clinical trials:

said the doctor or care team discussed clinical trials as a treatment option

From the survey responses, there seems to be a clear connection between a lack of provider-to-patient/ caregiver communication about clinical trials and low participation numbers:

said the main reason was that their doctor or care team did not bring the option up. This was the No. 1 reason people gave for not enrolling in a trial.

Collectively, patients indicated that a main reason why they did not enroll in a trial was simply because their doctor did not mention the option to them. Further, respondents were disincentivized if, when mentioning clinical trials, a provider did not portray the option as promising. This impacted treatment decisions, as patients understandably rely on their doctors and medical team for guidance when choosing treatment options.

The low percentage of trial participation could also be attributed to other causes, such as financial concerns. According to an article "Financial Toxicity in Cancer Clinical Trials: An Issue in Need of Clarity and Solutions" published in *The Journal of Clinical Oncology*[12], the extra requirements (more on-site visits for scans, blood draws, and treatment regimen) create concerns, especially for lower-income patients. The paper found that people enrolled in clinical trials travel to receive treatment on average twice as far as patients receiving standard treatment. This equals on average $600 per month in added nonmedical costs for patients. The NBTS survey found that 6% of patients who never enrolled in a trial said "cost and financial burden" was their main reason for not enrolling.

Other patients may be cautious about exposure to unproven treatments and the experimental nature of trials, which is especially pertinent among minority groups[13]. The article "Promoting Factors and Barriers to Participation in Early Phase Clinical Trials: Patients Perspectives" in the *Journal of Community Medical Health Education*[14] reports that many minority and underrepresented patient populations fear being the "guinea pig" in trials.

"I am most concerned about the cost and lack of insurance coverage help in the clinical trial."

Patient populations with lower education levels also have lower-than-normal clinical trial enrollment. The article "The impact of patient education on consideration of enrollment in clinical trials" in *The Journal of Community and Supportive Oncology*[15] said lower-education patient populations may not understand the science behind trials, and therefore do not trust them enough to enroll.

These sentiments were present in the NBTS survey. Approximately 12% of patients who never enrolled in a trial answered that the reason for this was that they were worried clinical trials are "not as effective" or "not as safe" as other treatment options, or that they consider trials to be "more beneficial for researchers than for patients." Another belief was that trials are intimidating. These attitudes can be the result of conversations – or lack thereof – with the care team.

"I'm intimidated by trials as I'm not familiar with the procedures."

"I have no idea what to expect from a clinical trial. My doctors have never brought it up to me."

The phrase "last resort" was used repeatedly among NBTS survey participants when describing clinical trials or their confidence in them working.

"I consider a clinical trial a last resort for treatment, I think there are so many changes to one's body caused during the trials."

"I think they can be lifesaving ... However, they can also do harm. I would need a lot of information before I participated in a trial. Or it would have to be a last resort."

National Brain Tumor Society

NBTS Institutional Recommendations

NBTS is proposing the following recommendations for medical institutions – which includes the doctors and care teams working directly with patients at these institutions and health insurance companies that provide educational materials to patients – to improve patient and caregiver education regarding biomarker testing and clinical trials:

> "Biomarker testing changed everything. By knowing my diagnosis and treatment options, I felt like I had a sense of control. It completely changed the trajectory of treatment and my life."
>
> **– HIGH-GRADE BRAINSTEM GLIOMA PATIENT**

- **Continue to promote comprehensive biomarker testing as a standard part of the diagnostic process and communicate this step to patients and caregivers.** Physicians must discuss biomarker testing with patients and their loved ones before and after testing to normalize this step and help them understand their tumor's molecular and genetic makeup. Biomarker testing, which classifies a tumor and informs how a tumor behaves and may react to treatment, is at least as important as a tumor's grade since patients can learn of and begin potential treatment options outside of the standard of care. Early conversations about biomarker testing allow patients to make informed decisions about their treatment plan.
  - **Note to health insurance companies:** Patients and caregivers (subscribers) will benefit from biomarker testing up to the latest WHO guidelines, and we urge that coverage policies support reimbursement of tests accordingly.
- **Ensure patient access to comprehensive biomarker testing (multi-gene panel testing).** Hospitals and treatment centers that do not have pathology programs with the capacity to conduct biomarker testing consistent with the latest WHO guidelines should establish arrangements to obtain comprehensive testing through CLIA-certified commercial laboratories or formal alliances with cancer centers that offer comprehensive biomarker testing panels, ensuring patients have timely access to testing that meets current national standards of care. This recommendation extends to both large cancer centers and to regional and community hospitals. There should not be any biomarker testing deserts just because a hospital is rural, a disproportionate share hospital, or is less focused on oncology.

- **Encourage doctors and care teams to partner with patient advocacy organizations to utilize reputable, easily accessible resources for educating patients and caregivers about biomarker testing and clinical trials.** The NBTS MyTumorID® campaign, for example, offers evidence-based tools for providers, patients, and caregivers to support awareness and advocacy for timely, comprehensive testing. Using resources from trusted advocacy groups can help providers explain how biomarker testing informs a diagnosis at the molecular level, and why it matters for treatment decisions.
  - **Note to health insurance companies:** We invite review and collaboration in the MyTumorID campaign to help fashion educational information for subscribers
- **Follow the NCCN guidelines and discuss clinical trials as an early treatment option.** Doctors should introduce the possibility of clinical trial participation at the time of initial diagnosis, and explain how trials can offer access to promising new therapies. Survey participants reported that clinical trials were often not mentioned, dismissed, or not explained in enough detail, leading to confusion and fear. Open, early conversations about clinical trials can help patients feel more confident and informed about their options.
- **Stay up-to-date on available clinical trials for patients with brain tumors.** Because clinical trial protocols and sites change frequently, no single provider can track all opportunities. The NBTS Clinical Trial Finder aggregates information from trial consortia nationwide and can help doctors identify suitable options for their patients, regardless of location. This tool is especially valuable for providers at institutions without active trials, ensuring that all patients have access to the latest opportunities.
- **Actively dispel common myths about clinical trials.** The persistent "last resort" framing reported by survey participants does not match how clinical trial appropriateness actually varies across an individual's care path. While some studies are designed specifically for individuals whose standard treatments have stopped working, others — including studies of new first-line therapies and biomarker-targeted approaches — are most appropriate at or near the time of initial diagnosis. Providers can help patients with brain tumors and their caregivers understand this variation by introducing clinical trials as one of several treatment categories to consider from the very beginning. Care teams can then revisit trial options at each decision point as the clinical picture evolves. Framing trial participation as a pathway to access cutting-edge precision medicine, where appropriate to the patient's situation, can help families feel hopeful and empowered. Doctors can use resources like the NBTS Myth-Busting Guide to address specific misconceptions and answer patient questions.
- **Partner with caregivers to share key information about biomarker testing and clinical trials.** Patients may have difficulty processing information after diagnosis, but caregivers often retain more details and recall conversations with the medical team. By working closely with caregivers, doctors can help ensure that important information is shared effectively and sensitively with patients, especially since caregivers best know how to deliver the information to their loved ones.

Conclusion

For decades, the established treatment options for cancer were chemotherapy, surgery, and radiation therapy. Targeted therapies and tumor-treating field devices have expanded the list of FDA-approved options, yet the stagnant survival rates for brain tumors continue to drive leaders in the field toward new treatment paradigms.

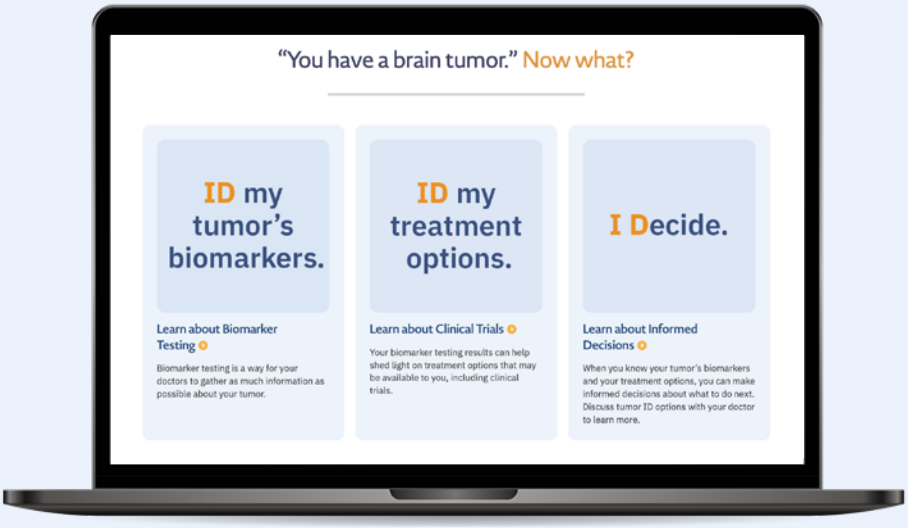
Part of the effort to improve treatment is better understanding the biology of brain tumors: the genetics, protein expressions, and more pertinent details that could predict how each treatment option will perform in each individual case. Biomarker testing is a vehicle to gain this knowledge and understand if a patient meets eligibility criteria for clinical trials, and it can help doctors form individualized treatment plans.

The answers to NBTS's survey indicate doctors are not consistently or sufficiently discussing these topics with patients and caregivers, evident by many of the incorrect definitions given for biomarker testing, as well as the majority of respondents unable to recall ever learning that clinical trials were an option.

However, the survey results, along with submitted open comments and existing literature, also indicate many patients firmly trust their doctor. Physicians possess the principal opinion in diagnosing the disease and determining the best course of treatment. This means that a doctor's omission of clinical trials in treatment conversations directly impacts patient enrollment in and access to promising therapies – and could be as impactful as other reported factors such as education level, income status, racial demographic, and general myths about clinical studies.

This level of trust also suggests that doctors can help reverse the reported trends of stagnant and low enrollment by affirming the validity and life-saving potential of trials in dialogue with patients and caregivers. The recommendations above can help providers at all institutions – from NCI-designated centers to rural community hospitals – align with the NCCN guidelines that clinical trials should be considered a preferred treatment option.

MyTumorID®



Doctors should not feel alone in the responsibility of educating patients about biomarker testing and clinical trials. The MyTumorID campaign, a public health and educational effort spearheaded by the National Brain Tumor Society, together with campaign affiliate organizations, is aimed at increasing awareness and literacy related to these topics within the brain tumor patient and caregiver community.[16] This initiative is the first of its kind in brain tumor patient education and advocacy.

In addition to offering easy-to-understand resources for patients and caregivers, the MyTumorID campaign includes materials for health care providers to join NBTS in sharing this potential life-saving information with their patients and the overall brain tumor community.

Organizations like NBTS also have online resources to help patients and providers search through an extensive list of active and recruiting clinical trials for brain tumors. These resources, including the NBTS Clinical Trial Finder, can be especially helpful for oncologists at rural hospitals – where clinical studies typically are not run – to help find trials fitting the patient's case at other medical institutions.

Making the most of these resources will empower doctors and others on care teams to effectively engage with patients and their loved ones about biomarker testing and clinical trial options. Furthermore, these recommendations empower patients and their caregivers to take an active role in their treatment and make informed decisions about their care.

National Brain Tumor Society

About the National Brain Tumor Society

As the largest patient advocacy organization in the U.S. dedicated to patients with brain tumors, and building on over 30 years of experience, the National Brain Tumor Society (NBTS) unrelentingly invests in, mobilizes, and unites the brain tumor community to discover a cure, deliver effective treatments, and advocate for patients and caregivers. Our focus on defeating brain tumors and improving the quality of patients' lives is powered by our partnerships across science, health care, policy, and business sectors. We fund treatment-focused research and convene those most critical to curing brain tumors once and for all. Join us at BrainTumor.org.

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Endnotes

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