National Brain Tumor Society

Network Inadequacy

Survey of Patients Diagnosed with Brain Tumors Finds that Narrow Provider Networks Impede Access to Specialized Cancer Care: Results, Discussion & Recommendations for Policy Interventions

SUMMARY: Results from a survey of patients with brain tumors found that healthcare insurance plans' use of narrow provider networks negatively impacts access to the continuum of care for enrollees, creating barriers to optimal treatment delivery.

INTRODUCTION

Patients with brain tumors need specialized medical services from diagnosis through anti-cancer treatment and palliative care. Among the necessary modalities of care, depending on the type of brain tumor, are surgery, oral medication, chemotherapeutic infusion, device therapy, and radiation, as well as rehabilitative care, surveillance, recurrence, survivorship, and end-of-life care. The most recent reclassifications of brain tumors by the World Health Organization (WHO) call for a diagnosis to include both histological and molecular profiling for a complete diagnosis[1], necessitating advanced biomarker testing for all patients. Additionally, the most up-to-date guidelines for treating malignant brain tumors include the stipulation that all patients receive the best management in clinical trials and the proposition that such studies should be considered as the first line of care[2]. Brain tumor clinical trials are typically clustered among top tertiary cancer centers, chiefly in many of the National Cancer Institute's Designated Cancer Centers (NCI DCCs)[3]. These types of specialized centers are also the most likely to offer advanced pathology services needed to meet the latest WHO standards for diagnostic integrity. However, previously published reports have indicated that NCI DCCs and their providers are largely **excluded from health plans that utilize narrow provider networks ("narrow networks")[4], particularly in plans sold on the Affordable Care Act (ACA) Health Insurance Marketplace[5 6 7]**.

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[1] Louis DN, Perry A, Wesseling P, Brat DJ, Cree IA, Figarella-Branger D, Hawkins C, Ng HK, Pfister SM, Reifenberger G, Soffietti R, von Deimling A, Ellison DW. The 2021 WHO Classification of Tumors of the Central Nervous System: a summary. Neuro Oncol. 2021 Aug 2;23(8):1231-1251. doi: 10.1093/neuonc/noab106.
[2] National Comprehensive Cancer Network Guidelines. https://www.nccn.org/guidelines/guidelines-detail?category=1&id=1425
[3] National Cancer Institute - Designated Cancer Centers https://www.cancer.gov/research/infrastructure/cancer-centers
[4] Yasaitis L, Bekelman JE, Polsky D. Relation Between Narrow Networks and Providers of Cancer Care. J Clin Oncol. 2017 Sep 20;35(27):3131-3135. doi: 10.1200/JCO.2017.73.2040.
[5] Schleicher SM, Mullangi S, Feeley TW. Effects of Narrow Networks on Access to High-Quality Cancer Care. JAMA Oncol. 2016;2(4):427–428. doi:10.1001/jamaoncol.2015.6125
[6] Kehl KL, Liao KP, Krause TM, Giordano SH. Access to Accredited Cancer Hospitals Within Federal Exchange Plans Under the Affordable Care Act. J Clin Oncol. 2017 Feb 20;35(6):645-651. doi: 10.1200/JCO.2016.69.9835. Epub 2017 Jan 9. Erratum in: J Clin Oncol. 2017 Jun 20;35(18):2100. PMID: 28068172; PMCID: PMC5455806.
[7] Center for Consumer Information and Insurance Oversight, CMS, 2025 Letter to Issuers in the Federally-facilitated Marketplaces (Apr. 10, 2024), Chapter 2, Section 3, Network Adequacy, available at: https://www.cms.gov/files/document/2025-letter-issuers.pdf

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The potential implication of this paradox is that many patients who have treatment at in-network hospitals with in-network providers may not receive care at facilities fully equipped to provide care up to the latest standards of brain tumor treatment needs. This potentially impedes the quality of diagnoses due to the lack of complete pathology, as well as advanced anti-cancer treatment opportunities offered by clinical trials, expanded access protocols, and experienced specialists in neuro-oncology, neuropathology, neurosurgery, and neuroradiology knowledgeable about the use of off-label medical approaches. Alternatively, they may need to self-pay for care at an out-of-network provider or facility, necessitating financially stressful out-of-pocket expenditures, while additionally exacerbating health care inequalities based on socioeconomic status.

To better understand the potential impact of narrow health insurance networks, specifically on patients with brain tumors, in 2023, the National Brain Tumor Society (NBTS) surveyed patients, survivors, caregivers, and family members. The results of the survey are reported here, along with stakeholder perspectives on access to needed care in marketplace plans, and recommendations to address these issues.

SURVEY METHODOLOGY

NBTS conducted an online survey from 4/1/2023 to 6/1/2023, directed at current and former patients with brain tumors, caregivers, survivors, and family members. The survey was distributed through email, social media, and at an in-person event hosted by the National Brain Tumor Society.

The survey questions focused on the respondents' experience accessing major specialized cancer centers, ability to access clinical trials, and common barriers to accessing such care (e.g., prior authorization, clinician or cancer center was out-of-network, cost of care, delays in care, etc.) A specific skip logic was used to hone in on responses from participants on marketplace plans and their ability to access specialized cancer care.

RESULTS

There were 467 total survey respondents. Respondents represent a diverse group of patients and caregivers.

The survey asked respondents to indicate which program they receive care in. Respondents received care in Medicaid, Medicare Advantage, marketplace plans, and employer-sponsored plans.

Based on these responses, the following issues and supporting data emerged:

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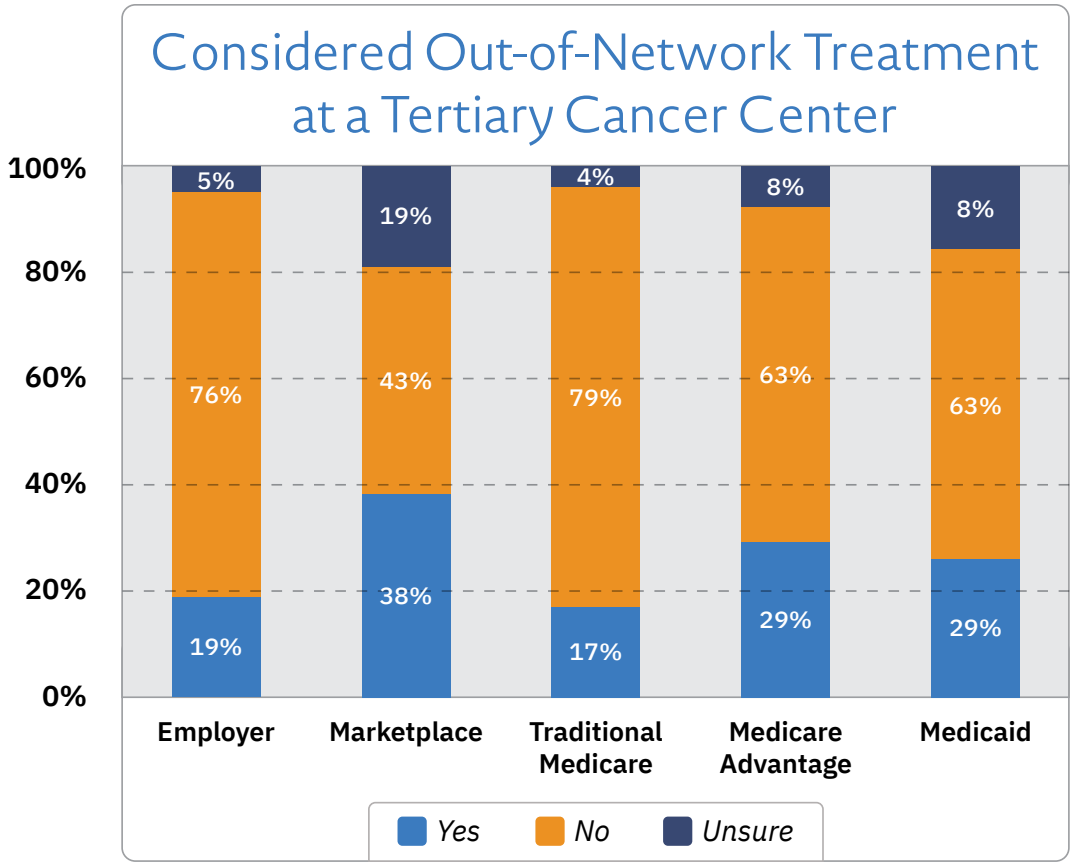

Patients with brain tumors experience health insurance network adequacy problems immediately upon trying to access top specialized cancer centers

A significant percentage of respondents who indicated they were insured through marketplace plans noted that when they initially sought out specialized care at a major cancer center they found that affiliated providers were out-of-network.

Patients across private employer plans, as well as Medicaid, in addition to marketplace plans, report access problems due to their cancer center of choice being out-of-network.

- **38%** of marketplace respondents found that a major specialized cancer treatment center was out-of-network.
- **26%** of Medicaid respondents found that a major specialized cancer treatment center was out-of-network.
- **19%** of private employer plan respondents found that a major specialized cancer treatment center was out-of-network.

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- **17% of traditional Medicare respondents reported issues accessing major specialized cancer treatment centers.**

Network adequacy problems hinder patients from diagnosis forward along the care continuum

Patients with brain tumors need access to many advanced services post-diagnosis, including surgery, advanced medical imaging, palliative care, molecular pathology, neuro-oncology, rehabilitative care, and clinical trials.

- **15%** of patients enrolled in private employer plans reported that while they were receiving treatment, their preferred specialist was out-of-network.
- **31%** of patients enrolled in Medicaid reported the same.
- **Notably, 33%** of patients enrolled in marketplace plans reported that while they were receiving treatment, their preferred specialist was out-of-network.

Network adequacy issues burdened patients with cost, time, and distance barriers that ultimately harmed access to best-in-class care

Survey results found that the impact of being out-of-network in marketplace and Medicare Advantage plans for a preferred center or provider for a patient with a brain tumor is costly, creates time and distance barriers, and reduces the likelihood of enrollment in potentially life-saving/life-prolonging benefits of clinical trials.

- Of respondents in **marketplace** plans reporting that their preferred hospital and/or provider were out-of-network, **83%** said that cost was a barrier to care, and one-third shared that distance to treatment was a barrier.
- Of **Medicare Advantage** enrollees, **40%** report that accessing clinical trials is a barrier, and **80%** had to get prior authorization from their health insurance plan to be able to see an out-of-network doctor or hospital.

Network adequacy issues forced patients to make difficult, often extraordinary decisions about their care across public and private health insurance plans

Many respondents indicated that they had to compromise some aspect of their care due to learning their preferred provider or center was out-of-network. Some chose to stay at their in-network hospital where they knew they were not getting the very best care. Others stated they are shouldering the financial burden by finding a way to pay out-of-pocket.

- **More than 30%** of respondents in marketplace plans who found their hospital/providers to be out-

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of-network said ***they had to find a way to pay the out-of-pocket costs to stay with their preferred provider***.

- **More than 40%** of the same group said they had to stay at their in-network hospital, even though they wanted to get into a more specialized center, due to cost.
- **33%** of respondents in marketplace plans reported that they experienced delays in appointments, scans, diagnostics, surgeries, etc. due to their preferred provider being out-of-network.
- **40%** of respondents in employer-sponsored health insurance plans reported they had to travel substantial distances to access care, after finding that their preferred hospital, medical center, or specialist was out-of-network.

Overall, these network adequacy problems forced patients into difficult decisions. One respondent offered, "I had to receive care from an in-network provider who was not well-versed in my tumor type and the care I received was substandard and unsatisfactory."

Several respondents with **employer-sponsored insurance** stated they had to switch jobs and insurance to gain access to PPO plans that cover the care they need. Others stated they had to utilize three separate insurance plans to ensure complete coverage for the care they needed, absorbing the associated higher monthly out-of-pocket costs with the additional plans.

Additionally, many respondents indicated that network inadequacy prevented them from getting to centers that offer clinical trials, even though they are a recommended part of clinical guidelines for patients with brain tumors *[see footnote 1]*.

"We never had the chance to even look at clinical trials because I had spent so much time on insurance-related issues," one respondent indicated. "My partner died 12 weeks after diagnosis."

DISCUSSION

The 2023 NBTS survey was the second such effort by the organization to better understand its constituents' access to specialized cancer centers, following a nearly identical survey in 2019. The results of the two surveys were very consistent. The results detailed in this white paper, combined with similar data from 2019 and outside research cited throughout this report, provide a strong basis from which to elevate concerns about how health insurance network adequacy impacts patients with brain tumors. Together, the available data and literature paint a disquieting picture — that too many patients with brain cancer are forced into a lose-lose situation when it comes to their care. They either have to face financial toxicity to go to top hospitals and providers highly trained in brain tumors, or they have to settle for health care delivery from hospitals and providers with less training, specialization, experience, facilities, and clinical research than by staying in an in-network hospital. These are bargains that patients dealing with a deadly and devastating

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cancer such as a malignant brain tumor should not have to grapple with when trying to save or extend their lives.

While these challenges were seen across health plan types, the impact of narrow networks on a patient's care seems particularly unpalatable in the context of government-backed safety net plans, including Medicare Advantage, Medicaid, and marketplace plans regulated under the Patient Protection and Affordable Care Act. It is well understood that there are complexities and differences in regulatory policy at the state and federal level that would make it difficult to solve network adequacy issues for cancer patients — or at least those with rare and recalcitrant cancers — with a singular policy change. However, we propose that addressing network adequacy within the Affordable Care Act's marketplace plans is the most logical, and potentially effective, avenue to start to serve patients and address health equity issues, particularly because these plans have been noted to frequently employ restrictive networks[8].

"My family moved from California to Texas so we could access a top tertiary cancer clinic so my wife could receive the highest quality care. In the middle of her chemotherapy treatment, they stopped accepting our marketplace plan. We ultimately had to resume treatment at a local hospital that did not provide as high-quality of care. Patients with brain tumors should not have to sacrifice quality of care due to out-of-network insurance status."

— Gary Citron, caregiver

Marketplace plans under the requirements of the ACA were meant to offer an additional safety net to individuals not eligible to receive other CMS programs, such as Medicaid, and who lack access to employer-sponsored insurance. It seems incongruous with the goals of the ACA that such plans should limit access to top specialized cancer centers, particularly ones that the federal government's own cancer authority, the National Cancer Institute, has officially designed as comprehensive cancer centers.

Beyond the mismatched nature of narrow insurance networks within plans created by legislation called the Patient Protection and Affordable Care Act, marketplace plans offer an opportune space for policy reforms. Additionally, Qualified Health Plans and marketplace plans are federally regulated. Action taken by the Consumer Information and Insurance Oversight Office (CCIIO) can have a nationwide impact.

Finally, the U.S. Department of Health and Human Services (HHS) and the Centers for Medicaid and Medicare's (CMS) Consumer Information and Insurance Oversight Office (CCIIO), which is charged with overseeing ACA reforms, have already indicated in recent Notice of Benefit Payment Parameter (NBPP) policies that improving network adequacy is one of their priorities[9]. However, in the 2025 NBPP final rule, CMS did not implement recommendations from commenters regarding additional provider and facility specialty types that should be

[8] Avalere Study Nov 2018: 73% of the ACA market has restrictive networks. "These narrow network plans may come at a lower price tag for consumers, but they may also limit consumer choice and access to specialist care." https://avalere.com/press-releases/health-plans-with-more-restrictive-provider-networks-continue-to-dominate-the-exchange-market

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subject to the time and distance standards that are in place to ensure access to in-network care.[10] CMS further noted that modifying time and distance standards would be "premature and may impose burdens" on plans that it has not fully evaluated[11]. Although CMS denied making policy changes regarding certain specialties, the agency acknowledged that it would research commenters' recommended changes to its time and distance metrics as well as their implications and may consider them in future rulemaking. CMS should continue to take steps to address network adequacy concerns and improve access to care.

NBTS POLICY RECOMMENDATIONS

Now is the time to improve network adequacy for cancer patients in marketplace plans as a first step to improvements across all insurance programs. NBTS is proposing the following framework for administratively reforming marketplace plans to ensure all patients with brain tumors have the necessary access to the specialized care their cancer requires.

- **Include NCI DCCs as Essential Community Providers.** NBTS encourages HHS to expand the definition of essential community providers to include those providers that are essential to the treatment of specialized cancers such as brain tumors. CCIIO recently strengthened network adequacy requirements for qualified health plans participating in federally facilitated marketplaces [see footnote 7]. However, these new requirements did not include NCI DCCs. Moving forward, we continue to encourage CCIIO to consider opportunities to require health plans in both federally facilitated marketplaces and state-based marketplaces to include at least one NCI DCC facility and the cancer providers at that facility in-network.

- **Implement NAIC Model Language to Include NCI DCCs as Out-of-Network Providers at the In-Network Out-of-Pocket Costs.** To address the costs of out-of-network providers, the National Association of Insurance Commissioners (NAIC) and several states have established protections for Qualified Health Plan (QHP's) enrollees who find themselves in a plan with an inadequate network. NBTS urges HHS to require that QHP issuers provide access to out-of-network services if an in-network provider is not available to meet their needs. The NAIC has embedded this policy in the "Health Benefit Plan Network Access and Adequacy Model Act."[12]

- **Address Access by Improving Oversight and Transparency Across Qualified Health Plans.** NBTS urges CMS to continue to actively conduct network adequacy reviews of QHPs in Federally Facilitated Marketplace (FFM) states and State Exchanges, and State-based Exchanges on the Federal platform

[9] CMS Final Notice of Benefit and Payment Parameters (NBPP) for 2024, https://www.cms.gov/newsroom/fact-sheets/hhs-notice-benefit-and-payment-parameters-2024-final-rule
[10] CMS Final Notice of Benefit and Payment Parameters (NBPP) for 2025, https://www.federalregister.gov/documents/2024/04/15/2024-07274/patient-protection-and-affordable-care-act-hhs-notice-of-benefit-and-payment-parameters-for-2025.
[11] CMS Final Notice of Benefit and Payment Parameters (NBPP) for 2025, https://www.federalregister.gov/documents/2024/04/15/2024-07274/patient-protection-and-affordable-care-act-hhs-notice-of-benefit-and-payment-parameters-for-2025.
[12] NAIC, "Health Benefit Plan Network Access and Adequacy Model Act," 2015. https://content.naic.org/sites/default/files/inline-files/MDL-074_0.pdf.

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(SBE-FPs) and to start to publicly report the outcomes of those reviews on an annual basis. Additionally, the Government Accountability Office should conduct a study of the adequacy of networks of hospitals and healthcare providers for cancer and brain cancer provided by QHPs in marketplaces regulated under the ACA, with particular emphasis on marketplace adequacy of inclusion of NCI DCCs and affiliated providers within QHP networks.

- **Ensure Health Plan Prior Authorization Policies Do Not Negatively Impact the Quality of Care for Patients With Brain Tumors.** Access to medically necessary, appropriate, and timely services for patients with brain tumors is essential to their overall care, health outcomes, and survivability. NBTS especially highlights the importance that the patients we serve place on timely access to appropriate cancer care.

- **Align Health Plan Policies on Access to Care for Patients With Brain Tumors with White House Cancer Moonshot Initiative Goals for Improving Clinical Treatment.** With the Biden Administration Cancer Moonshot moving forward at a rapid pace, CMS should ensure access to adequate, medically necessary cancer care is keeping up with clinical advances and new treatments. Access to the right medical providers, hospitals, and services should keep pace with the goal of the Cancer Moonshot and the updates made regularly by the National Comprehensive Cancer Network (NCCN), which publishes the standards of care in cancer.

CONCLUSION

In 2010, Vice President Joe Biden appropriately heralded the passage of the Affordable Care Act. Six years later, he launched the White House Cancer Moonshot initiative to end cancer as we know it. As president, he announced a "reignited Cancer Moonshot" in 2022, with the goals of reducing cancer death rates by at least 50 % over the next 25 years and improving the experience of living with and surviving cancer. The administration specifically noted aims to help achieve these goals, including focusing on "the most deadly and rare cancers, including childhood cancers," and addressing inequalities, specifically ensuring "that every community in America — rural, urban, Tribal, and everywhere else — has access to cutting-edge cancer diagnostics, therapeutics, and clinical trials *[see footnote 6]*."

Our research, based on existing literature and surveys within the brain tumor community, underscores the widely recognized patient access imperative and highlights a critical concern: inadequate provider networks within marketplace health plans and other types of health insurance programs, both public and private. These network limitations pose a significant threat to achieving the admirable and feasible goals outlined in the administration's – and many congressional – major policy and legislative initiatives. This issue is not only pressing for patients with brain tumors but also affects countless individuals battling various forms of cancer nationwide.

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At the macro-level, NCI Designated Cancer Centers are the loci of innovation in the world of cancer care. These centers offer access to diagnostics and cutting-edge trials that are often just not found at smaller, community-based hospitals. Access to these centers for patients with deadly cancer, such as most malignant brain tumors (where the overall five-year relative survival rate has hardly budged above 35% in decades), offers the best chance for optimal treatment outcomes[13] [14] [15]. Health plan provider networks that restrict access to NCI DCCs therefore stand in opposition to the administration's aims of ensuring essential health services through marketplace plans and advancing the Cancer Moonshot initiative.

At the individual patient level, no one with a deadly brain cancer should have to choose between paying exorbitant out-of-pocket expenses to gain access to an NCI DCC or forgoing the most appropriate cancer for them because their safety-net health insurance employs narrow provider networks.

The policy recommendations listed above represent common-sense, achievable reforms that the administration could take up in relatively short order.

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, healthcare, policy, and business sectors. We fund treatments-focused research and convene those most critical to curing brain tumors once and for all. Join us at BrainTumor.org.

[13] Wolfson JA, Sun CL, Wyatt LP, Hurria A, Bhatia S. Impact of care at comprehensive cancer centers on outcome: Results from a population-based study. Cancer. 2015 Nov 1;121(21):3885-93. doi: 10.1002/cncr.29576. Epub 2015 Jul 28. PMID: 26218755; PMCID: PMC4892698.
[14] Aulakh, S., DeDeo, M. R., Free, J., Rosenfeld, S. S., Quinones-Hinojosa, A., Paulus, A., Manna, A., Manochakian, R., Chanan-Khan, A. A., & Ailawadhi, S. (2019). Survival trends in glioblastoma and association with treating facility volume. Journal of Clinical Neuroscience, 68, 271-274. https://doi.org/10.1016/j.jocn.2019.04.028
[15] Johnson, K.J., Wang, X., Barnes, J.M. et al. Residential distance from the reporting hospital and survival among adolescents, and young adults diagnosed with CNS tumors. J Neurooncol 155, 353–361 (2021). https://doi.org/10.1007/s11060-021-03885-6