



American
Brain Tumor
Association®

Providing and pursuing answers®

EXECUTIVE SUMMARY

Poll of Brain Tumor Constituents

May 1, 2015



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Introduction

This summary provides the results of a poll conducted by the American Brain Tumor Association, the first and now the only national organization committed to funding brain tumor research and providing information and education on all tumor types for all ages. To help identify the needs for brain tumor information and resources at the point of diagnosis and throughout the trajectory of the disease, the ABTA conducted this poll of brain tumor constituents consisting of patients, caregivers, survivors and individuals whom identified as “other”.

Study Methodology

The ABTA conducted a Web-based poll from February 24, 2015 through March 22, 2015 to obtain feedback from its constituents. ABTA staff assisted in questionnaire development, programmed the Web survey instrument, managed the data collection process and conducted data analysis. The final questionnaire used in this poll is provided on page eight.

The questionnaire was designed to collect feedback about the brain tumor diagnosis experience such as how long it took to receive a diagnosis; the most important thing respondents wished they would have known at the time of diagnosis; how much time they had to make treatment decisions, and whether they had sufficient information to make informed decisions, among other questions. Respondents also provided some demographic data.

Poll respondents were individuals who registered to receive emails from the ABTA, signed up for the ABTA’s online support community **Connections**, visited the ABTA website, and followed the ABTA via its social media channels (Facebook and Twitter). The ABTA used a list with the e-mail addresses of 84,236 individuals who registered to receive email communications from the ABTA and 3,972 individuals from ABTA Connections. On February 24, the ABTA sent an e-mail to its list inviting them to participate in the poll. The message contained an embedded link to the questionnaire; respondents were informed that they could begin answering the questionnaire by clicking on the link. On February 25, a message was posted to the ABTA Facebook page, and to the ABTA’s Twitter feed inviting followers to complete the questionnaire. Ultimately, 2,319 individuals completed the questionnaire.

Summary

Findings from the poll of 2,319 individuals showed that respondents felt they only had a few days to make treatment decisions, relied heavily on their physician recommendations, and turned to the Internet for more information. When asked what they wish they would have known at the time of diagnosis that they know now, the majority responded that they wish they would have known what questions to ask their healthcare team. The poll did not show any significant difference in answers based on timing of the diagnosis (less than 3 months to more than five years) or audience (patient, caregiver, survivor, other).

The sections below provide a summary report of the key findings obtained from the 2,319 individuals.

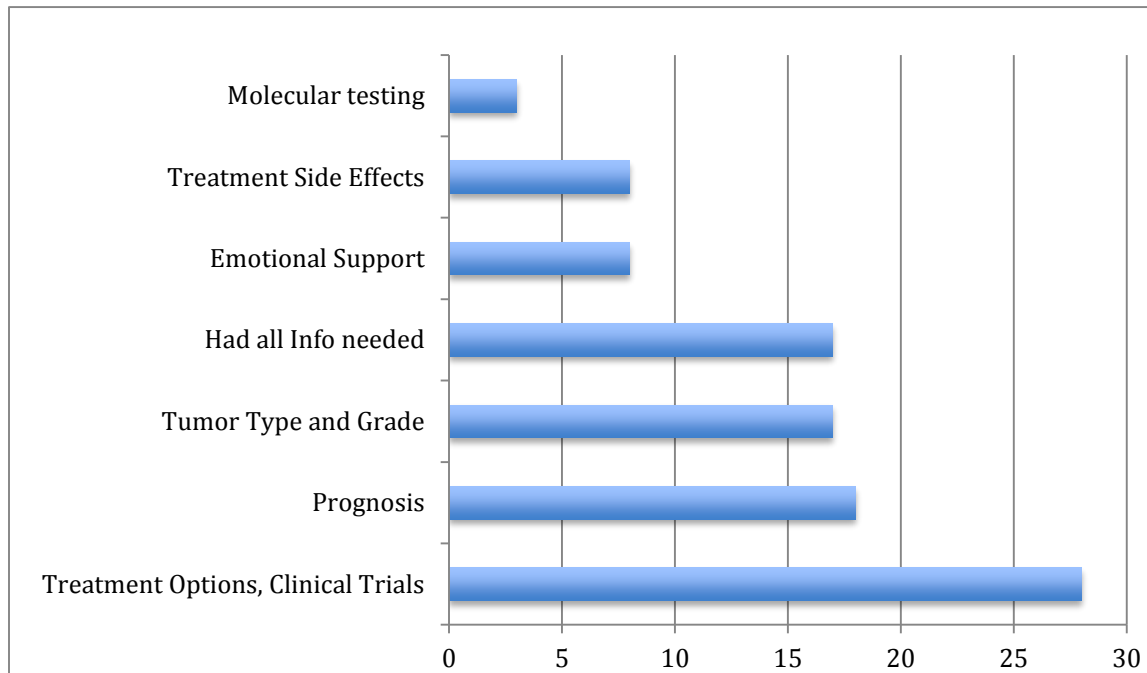


Length of time it took to receive a diagnosis

Thirty-four percent (34%) of respondents said that they received a brain tumor diagnosis within a few days or less from the time symptoms were first experienced. According to 27% of respondents, it took six months or longer to receive a diagnosis after symptoms were first experienced while 13% stated 3 months. Eleven percent (11%) answered that it took 2 weeks to receive a diagnosis after symptoms presented.



What information was needed at the time of diagnosis?



When asked about what one aspect of the diagnosis respondents felt they needed more information about, the majority (28%) answered that they needed more information about treatment options, including clinical trials. Interestingly, with precision medicine for the treatment of brain tumors gaining momentum, only 3% reported that they needed more information about molecular testing. Prognosis was the second highest response with 18% answering that they needed more information. Equal numbers (17%) answered that they received all the information needed at the time of diagnosis and 17% reported that they needed more information about their tumor type and grade. More information about emotional support was what 8% needed, and 8% stated that they needed more information about treatment side effects.

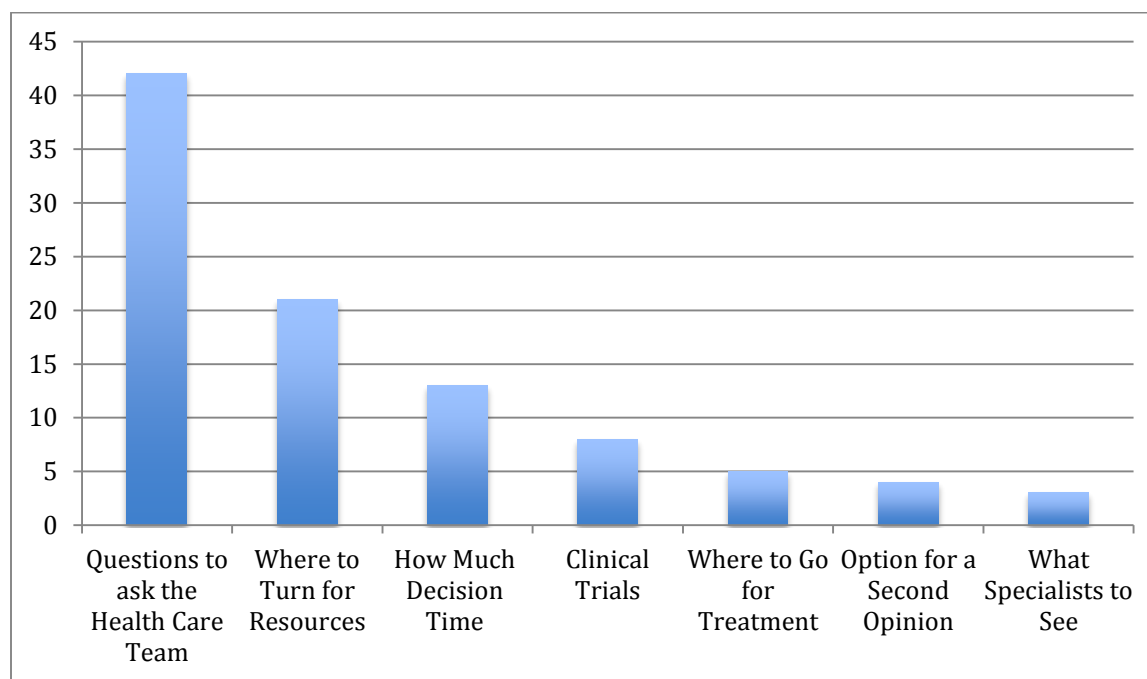
Referral to resources for more information

When asked whether their healthcare team referred them to resources for more information, 60% responded “no”, that they did not receive a referral to resources for more information about the diagnosis and treatment options.



Looking back, what was the most important thing to have known at diagnosis?

Recalling the time of diagnosis, 42% of respondents stated that the most important thing they wish they would have known at the time they were diagnosed was what questions to ask their healthcare team. 21% answered that they wish they would have known where to turn for comprehensive resources about brain tumors and navigating the healthcare system. Thirteen percent (13%) answered that the most important thing they wish they would have known was how much time they had to understand the diagnosis and make informed decisions about treatment options. Knowing about clinical trials was the most important thing to 8%. For 5% of respondents, knowing where to go for treatment was the most important thing they wish they would have known at the time of diagnosis. Only 4% felt the option for a second opinion was the most important thing they wish they would have known at the time of diagnosis, and 3% responded that they wish they would have known what specialists to see at the time of diagnosis.

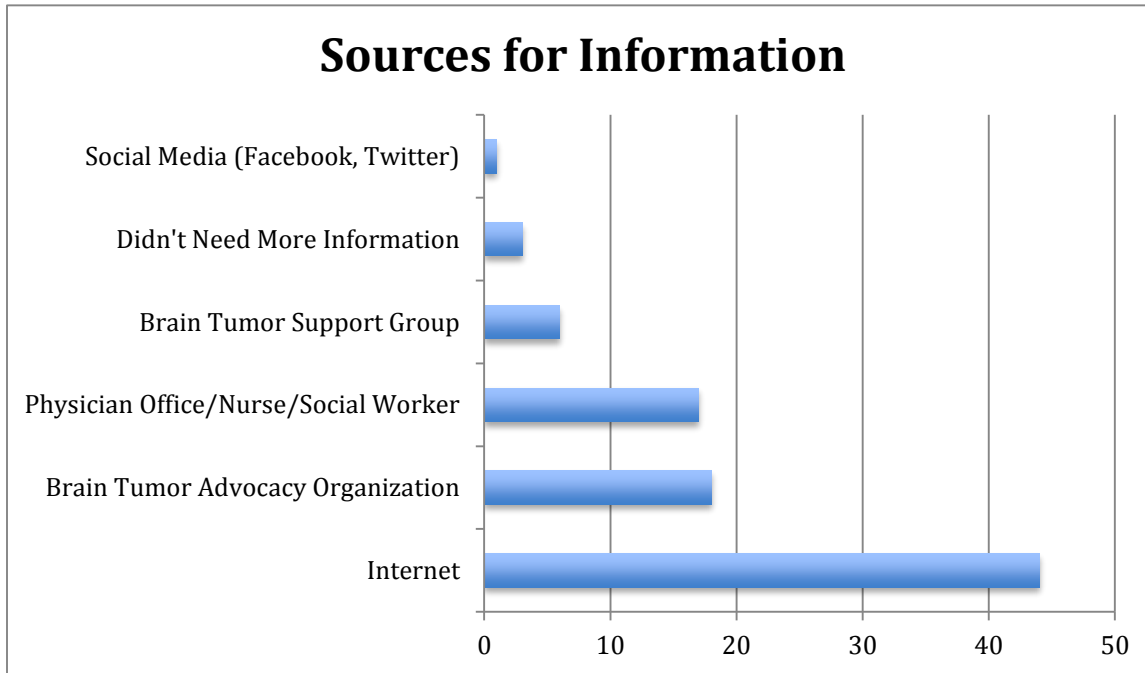


Informed Decisions

When asked if respondents had sufficient information about their diagnosis to make informed decisions, 40% stated “No”.

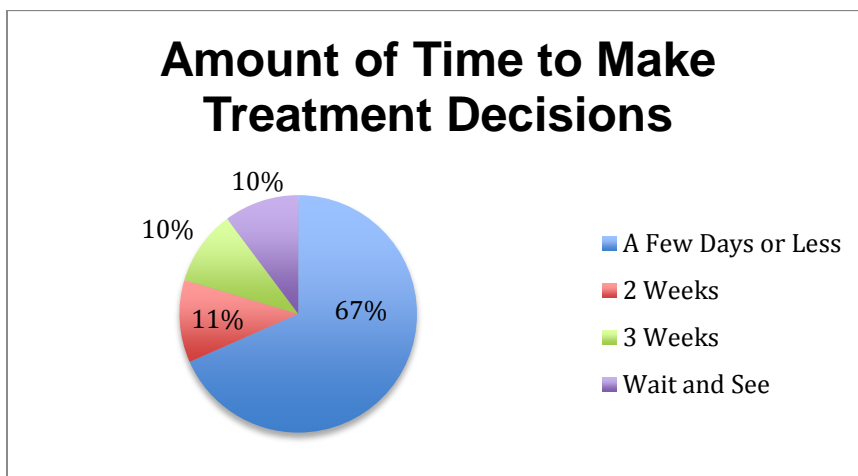


Poll respondents overwhelmingly turned to the Internet for more information



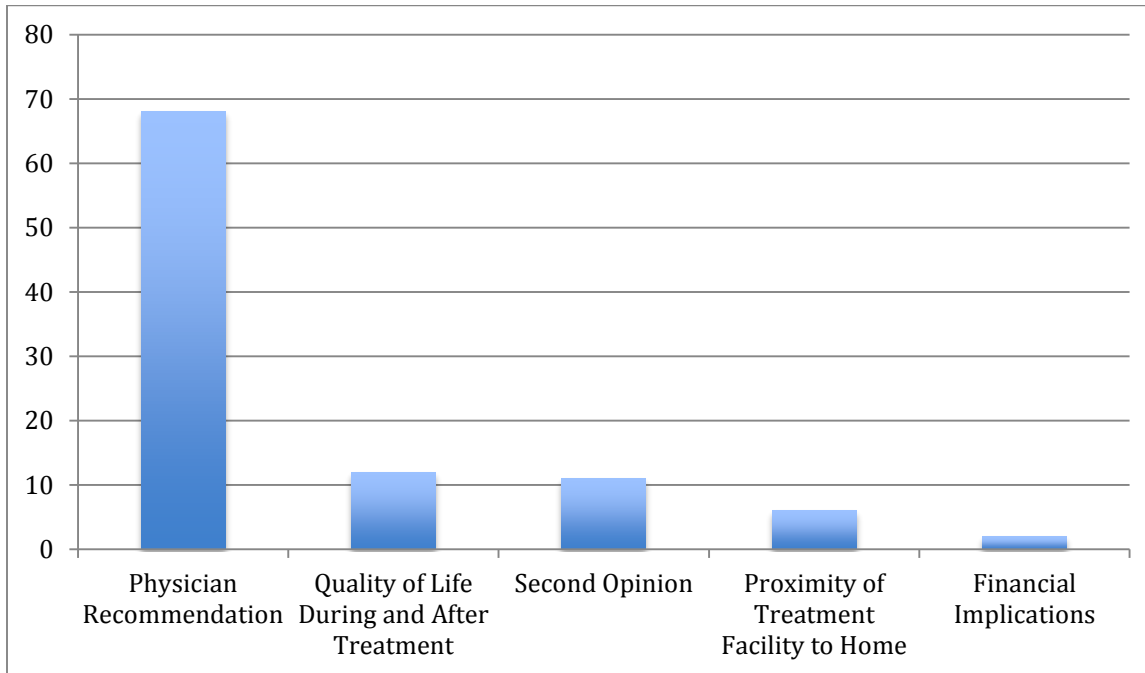
How much time was there to make treatment decisions

Sixty-seven percent (67%) of respondents answered that they felt they had a few days or less to make treatment decisions after receiving a brain tumor diagnosis. Only 11% reported that they felt they had 2 weeks to make treatment decisions after receiving the diagnosis, and 10 percent responded with the answer of 3 weeks. Ten percent (10%) reported that the treatment recommendation was to watch and wait.



What influenced treatment decisions

Sixty-eight percent (68%) of respondents stated that physician recommendations most influenced their treatment decisions. Twelve percent (12%) responded that quality of life during and after treatment was the one factor that most influenced their treatment decisions. Eleven percent (11%) answered a second opinion; 6% proximity of treatment facility to respondent's home; and 2% financial implications



Poll Questions

1. Which most accurately describes you:
 - Patient
 - Caregiver/family member
 - Survivor (5+ years from diagnosis)
 - Other
2. How long has it been since your (your loved one's) diagnosis?
 - Less than three months
 - Three to six months
 - Six months to one year
 - More than one year
 - More than five years
3. How long did it take from the time symptoms were first experienced until you (or your loved one) received a brain tumor diagnosis?
 - A few days or less
 - 2 weeks
 - One month
 - Three months
 - Six months
 - More than six months
4. At the time of diagnosis, what one aspect of the diagnosis did you feel you needed more information about?
 - Tumor type and grade
 - Treatment options including clinical trials
 - Treatment side effects
 - Prognosis
 - Molecular testing
 - Emotional support
 - I received all the information I needed at the time of diagnosis
5. What is the most important thing you wish you would have known at the time of diagnosis that you now know?
 - The amount of time I had to understand the diagnosis and make informed decisions about treatment options
 - The option for a second opinion
 - Where to go for treatment
 - The type of specialist to see
 - Clinical trial options available
 - What questions to ask my healthcare team (for example, questions about my prognosis, quality of life implications, cognitive issues and other symptoms, molecular testing, progression/recurrence etc.)
 - Where to turn for comprehensive resources about brain tumors and navigating the health care system



6. At the time of diagnosis, did your healthcare team refer you to resources for more information about the diagnosis and treatment options?
 - Yes
 - No
7. Do you feel you had sufficient information about the diagnosis to make informed decisions?
 - Yes
 - No
8. Where did you turn for more brain tumor information and support?
 - A brain tumor advocacy organization (ABTA or other)
 - The Internet
 - Social media (Facebook, Twitter, LinkedIn)
 - Physician office/nurse/social worker
 - Brain tumor support group
 - Family/friends
 - I didn't need more information
9. After receiving the diagnosis, how much time did you feel you had to make treatment decisions?
 - Hours
 - A few days
 - Two weeks
 - Three weeks
 - The treatment recommendation was to watch and wait
 - I didn't have any time; I had surgery almost immediately
10. What one factor most influenced your treatment decision?
 - Physician recommendation
 - Getting a second opinion
 - Quality of life during and after treatment
 - Financial implications
 - Proximity of treatment facility to my home
11. Did the healthcare team talk about quality of life issues as they related to treatment options/decisions?
 - Yes
 - No



12. How did you learn about the ABTA?

- Healthcare team
- Internet search
- News media (newspaper article, TV show, radio)
- Social media (Facebook, Twitter, LinkedIn)
- Support Group
- Family member/Friend

13. Would being connected with someone who shares your brain tumor experience be of interest to you?

- Yes
- No

14. If you were having a difficult day, who would you most want to talk to, assuming all were available to you:

- Doctor
- Nurse/Social Worker
- Caregiver/spouse/family/friend
- Spiritual leader
- Someone who already had been through a brain tumor diagnosis and treatment
- Counselor at the ABTA Careline (800#)

15. Please indicate your gender

- Female
- Male

16. Please indicate your age range:

- 19 or under
- 20-34
- 35-44
- 45-54
- 55-64
- 65-74
- 75-84
- 85+

17. Please indicate where you reside (drop down of U.S. states)

18. Please share any additional information or comments (open field)

