



Patient Follow-up Form - Version 1.1

Thank you for participating in the Glioma Outcomes Project. To continue participating in this important project, **complete or correct** the following information.

This ____-month Patient Follow-up Form has been mailed directly to you by the Data Coordinating Center. A similar form will be mailed to you again in approximately 3 months.

Please print or type. Thank You!

Physician Information

Neurosurgeon _____
First Name Last Name

Hospital / Clinic _____

Patient Information

Patient Name _____

Social Security Number _____ (or Social Insurance Number in Canada)

Address _____

City _____ State _____ Zip / Postal Code _____

Telephone Number (____) _____ - _____ Alternate Phone Number (____) _____ - _____

Patient Contact Person Name _____ Relationship _____

Address _____

City _____ State _____ Zip / Postal Code _____

Telephone Number (____) _____ - _____ Alternate Phone Number (____) _____ - _____

The date of your **most recent** brain surgery was

____/____/____
month / day / year

If this is incorrect, please provide the date of your **most recent** brain surgery

____/____/____
month / day / year

Demographic Information

Date of Birth ____/____/____
month / day / year

Sex Male Female

Height ____ feet ____ inches

Are you Right Handed
 Left handed
 Ambidextrous (Both)

Ethnic Background (Please check all that apply)

- White/Caucasian
- Black/African American
- Hispanic
- Oriental/Asian, Pacific Islander
- American Indian, Eskimo/Aleutian
- Other (Specify _____)
- Prefer Not to Answer

1. Date of Completion (Today's Date)

___/___/___
month / day / year

2. Form filled out by

- Patient with no help
- Patient with help from family and/or friend
- Patient with help from health care provider
- Family member or friend
- Health care provider
- Other (Specify _____)

3. What is your weight? (Please use a weight taken within the last week)

___ Pounds

4. Compared to 3 months ago, has your weight gone

- Down
- Up
- Stayed the Same
- Don't know

5. Have you received chemotherapy for your brain tumor within the past 3 months?

- Yes
- No

6. Have you received radiation therapy for your brain tumor within the past 3 months?

- Yes
- No

7. Have you used any alternative treatments for your brain tumor within the past 3 months?

- | | Yes | No |
|-------------------------|--------------------------|--------------------------|
| High dose vitamins..... | <input type="checkbox"/> | <input type="checkbox"/> |
| Herbs..... | <input type="checkbox"/> | <input type="checkbox"/> |
| Macrobiotic diet..... | <input type="checkbox"/> | <input type="checkbox"/> |
| Shark cartilage | <input type="checkbox"/> | <input type="checkbox"/> |
| Antineoplastins..... | <input type="checkbox"/> | <input type="checkbox"/> |

7. (continued) Have you used any alternative treatments for your brain tumor within the past 3 months?

- | | Yes | No |
|--------------------|--------------------------|--------------------------|
| Hydrazine | <input type="checkbox"/> | <input type="checkbox"/> |
| Acupuncture | <input type="checkbox"/> | <input type="checkbox"/> |
| Faith healer | <input type="checkbox"/> | <input type="checkbox"/> |
| Meditation..... | <input type="checkbox"/> | <input type="checkbox"/> |
| Other..... | <input type="checkbox"/> | <input type="checkbox"/> |
| Specify_____ | | |

8. Have you enrolled in a formal clinical brain tumor trial (other than the GO Project) within the past 3 months?

- Yes (Specify _____)
- No
- Don't know

Glioma Outcomes Questionnaire

9. Please indicate how you felt during the past week (choose one answer on each line)

- | | Not at all | Some what | Quite a bit | Very much |
|---|--------------------------|--------------------------|--------------------------|--------------------------|
| a. I can remember new things..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| b. I have trouble with my vision ... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| c. I am able to find the right word(s) to say what I mean | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| d. I have trouble expressing my thoughts..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| e. I am able to put my thoughts into action | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| f. My personality has changed.... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| g. I have weakness in some parts of my body..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| h. I have trouble with my coordination..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| i. I have had seizures | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| j. I have had headaches..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| k. I get tired easily | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| l. I am slower to do things | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| m. I feel sick | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| n. I spend time in bed..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| o. I need help caring for myself (bathing, dressing, eating, etc) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

9. (continued) Please indicate how you felt during the past week (choose one answer on each line)

- | | Not at
all | Some
what | Quite a
bit | Very
much |
|--|--------------------------|--------------------------|--------------------------|--------------------------|
| p. I get support from my family.... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| q. I feel sad..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| r. I am able to work (include work in home)..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| s. I am able to drive..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| t. I am able to enjoy my usual leisure pursuits..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| u. I am content with the quality of my life..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

SF-36 Health Survey*

This survey asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities. Answer every question by marking the answer as indicated. If you are unsure about how to answer a question, please give the best answer you can.

10. In general, would you say your health is (choose one)

- Excellent
- Very good
- Good
- Fair
- Poor

11. Compared to 3 months ago, how would you rate your health in general now? (choose one)

- Much better now than 3 months ago
- Somewhat better now than 3 months ago
- About the same
- Somewhat worse now than 3 months ago
- Much worse now than 3 months ago

12. The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much? (choose one answer on each line)

- | | Yes,
limited
a lot | Yes,
limited
a little | No, not
limited
at all |
|---|--------------------------|-----------------------------|------------------------------|
| a. <u>Vigorous</u> activities, such as running, lifting heavy objects, participating in strenuous sports..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| b. <u>Moderate</u> activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| c. Lifting or carrying groceries..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| d. Climbing <u>several</u> flights of stairs..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| e. Climbing <u>one</u> flight of stairs..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| f. Bending, kneeling, or stooping..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| g. Walking <u>more than a mile</u> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| h. Walking <u>several blocks</u> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| i. Walking <u>one block</u> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| j. Bathing or dressing yourself..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

13. During the past week, have you had any of the following problems with your work or other regular daily activities as a result of your physical health? (choose one answer on each line)

- | | Yes | No |
|--|--------------------------|--------------------------|
| a. Cut down on the <u>amount of time</u> you spent on work or other activities..... | <input type="checkbox"/> | <input type="checkbox"/> |
| b. <u>Accomplished less</u> than you would like... <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| c. Were limited in the <u>kind of</u> work or other activities | <input type="checkbox"/> | <input type="checkbox"/> |
| d. Had <u>difficulty</u> performing the work or other activities (for example, it took extra effort) | <input type="checkbox"/> | <input type="checkbox"/> |

14. During the past week, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)? (choose one answer on each line)

- | | Yes | No |
|--|--------------------------|--------------------------|
| a. Cut down the amount of time you spent on work or other activities | <input type="checkbox"/> | <input type="checkbox"/> |
| b. <u>Accomplished less</u> than you would like .. | <input type="checkbox"/> | <input type="checkbox"/> |
| c. Didn't do work or other activities as <u>carefully</u> as usual | <input type="checkbox"/> | <input type="checkbox"/> |

15. During the past week, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups? (choose one)

- Not at all
- Slightly
- Moderately
- Quite a bit
- Extremely

16. How much bodily pain have you had during the past week? (choose one)

- None
- Very mild
- Mild
- Moderate
- Severe
- Very severe

17. During the past week, how much did pain interfere with your normal work (including both work outside the home and housework)? (choose one)

- Not at all
- A little bit
- Moderately
- Quite a bit
- Extremely

18. These questions are about how you feel and how things have been with you during the past week. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past week (choose one answer on each line)

- | | All of the time | Most of the time | A good bit of the time | Some of the time | A little of the time | None of the time |
|--|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| a. Did you feel full of pep?.. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| b. Have you been a very nervous person?..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| c. Have you felt so down in the dumps that nothing could cheer you up? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| d. Have you felt calm and peaceful? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| e. Did you have a lot of energy?..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| f. Have you felt downhearted and blue?.. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| g. Did you feel worn out?.... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| h. Have you been a happy person?..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| i. Did you feel tired? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

19. During the past week, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)? (choose one)

- All of the time
- Most of the time
- Some of the time
- A little of the time
- None of the time

20. How TRUE or FALSE is each of the following statements for you? (choose one answer on each line)

- | | Definitely True | Mostly True | Don't Know | Mostly False | Definitely False |
|--|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| a. I seem to get sick a little easier than other people..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| b. I am as healthy as anybody I know. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| c. I expect my health to get worse..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| d. My health is excellent. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

21. In the past 3 months, have you had 2 weeks or more during which you felt sad, blue, or depressed; or when you lost all interest or pleasure in things that you usually cared about or enjoyed?

- Yes
- No

22. Have you felt depressed or sad much of the time in the past 3 months?

- Yes
- No

Demographic and Social Information

23. Marital Status

- Married
- Never Married
- Divorced
- Separated
- Widowed
- Prefer not to Answer

24. Do you live with someone who can help take care of you?

- Yes
- No

25. Are you receiving home care services?

- Yes (Specify _____)
- No

26. What health insurance provides your coverage?

- | | Yes | No |
|--|--------------------------|--------------------------|
| None | <input type="checkbox"/> | <input type="checkbox"/> |
| Medicare..... | <input type="checkbox"/> | <input type="checkbox"/> |
| Medex or other Medicare supplement..... | <input type="checkbox"/> | <input type="checkbox"/> |
| Medicaid | <input type="checkbox"/> | <input type="checkbox"/> |
| Health Maintenance Organization (HMO)..... | <input type="checkbox"/> | <input type="checkbox"/> |
| BC/BS or other commercial insurance | <input type="checkbox"/> | <input type="checkbox"/> |
| CHAMPUS (government)..... | <input type="checkbox"/> | <input type="checkbox"/> |
| Canadian Provincial Insurance | <input type="checkbox"/> | <input type="checkbox"/> |
| Other (Specify _____)..... | <input type="checkbox"/> | <input type="checkbox"/> |

27. In providing payment for the care of my brain tumor, my insurance company has been

- Very helpful
- Somewhat helpful
- Unhelpful
- Not applicable

28. Are you currently working?

- No
- Full-time
- Part-time

29. Have you changed jobs within the past 3 months?

- Same job
- Different job
- Not working

30. Are you receiving disability benefits?

- Yes
- No

31. How knowledgeable do you feel about your brain tumor?

- Very knowledgeable
- Somewhat knowledgeable
- Need more information

32. Which organizations have given you information or help with your brain tumor?

	Yes	No
American Cancer Society.....	<input type="checkbox"/>	<input type="checkbox"/>
American Brain Tumor Association.....	<input type="checkbox"/>	<input type="checkbox"/>
National Brain Tumor Foundation.....	<input type="checkbox"/>	<input type="checkbox"/>
Others	<input type="checkbox"/>	<input type="checkbox"/>
Specify _____		

33. What additional information would you like to have about brain tumors?

34. What would you tell other patients and their families about brain tumors or their treatment?

35. Are you part of a brain tumor support group?

- Yes
- No

36. If you could go back in time and make the same decision again, would you choose to have your most recent brain tumor surgery?

- Yes, definitely
- Yes, probably
- No, probably not
- No, definitely not
- Not applicable

37. If you could go back in time and make the same decision again, would you choose to have chemotherapy for your brain tumor?

- Yes, definitely
- Yes, probably
- No, probably not
- No, definitely not
- Not applicable

38. If you could go back in time and make the same decision again, would you choose to have radiation therapy for your brain tumor?

- Yes, definitely
- Yes, probably
- No, probably not
- No, definitely not
- Not applicable

39. Do you feel that you have had access to all the health care you need for your brain tumor?

- Yes
- No

40. In general, have you been satisfied with the medical care you have received for your brain tumor?

- Very satisfied
- Somewhat satisfied
- Not Satisfied
- Very Unsatisfied

41. Do you feel that the questions in this form are relevant to your health?

- Yes
- No

42. Do you plan to continue to participate in the GO Project?

- Yes
- No (Reason: _____)

43. Comments

Thank You for Completing This Questionnaire

Please return the completed form in the envelope provided. If you lose the envelope and want another, call 1-888-820-7171. Our address is

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