# Initial Patient Form - Version 1.0

**Thank you for participating in the Glioma Outcomes Project. To begin the process of participating in this important project, complete the following information.**

You should complete this form between hospital discharge and your first postoperative clinic visit (approximately 1 to 3 weeks after your surgery).

Please print or type. Thank You!

## Physician Information

Neurosurgeon _____ _____
First Name Last Name

Hospital / Clinic _____

## Patient Information

Patient Name _____ _____ _____
First Name MI Last 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 _____
First Name Last Name

Address_____

City_____ State_____ Zip / Postal Code _____-_____

Telephone Number ( __ __ __ ) __ __ __ - __ __ __ __ Alternate Phone Number ( __ __ __ ) __ __ __ - __ __ __ __

## 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. Since you were diagnosed with a brain tumor, has your weight gone**

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

**5. Have you received chemotherapy for your brain tumor?**

- ☐ Yes
- ☐ No

**6. Have you received radiation therapy for your brain tumor?**

- ☐ Yes
- ☐ No

**7. Have you used any alternative treatments for your brain tumor?**

| | Yes | No |
|---|---|---|
| High-dose vitamins | ☐ | ☐ |
| Herbs | ☐ | ☐ |
| Macrobiotic diet | ☐ | ☐ |
| Shark cartilage | ☐ | ☐ |
| Antineoplastins | ☐ | ☐ |

**7. (continued) Have you used any alternative treatments for your brain tumor?**

| | Yes | No |
|---|---|---|
| Hydrazine | ☐ | ☐ |
| Acupuncture | ☐ | ☐ |
| Faith healer | ☐ | ☐ |
| Meditation | ☐ | ☐ |
| Other | ☐ | ☐ |

Specify_____

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

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

## Glioma Outcomes Questionnaire

**9. Please indicate how you felt during the <u>past week</u> (choose one answer on each line)**

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

**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 | ☐ | ☐ | ☐ | ☐ |
| q. | I feel sad | ☐ | ☐ | ☐ | ☐ |
| r. | I am able to work (include work in home) | ☐ | ☐ | ☐ | ☐ |
| s. | I am able to drive | ☐ | ☐ | ☐ | ☐ |
| t. | I am able to enjoy my usual leisure pursuits | ☐ | ☐ | ☐ | ☐ |
| u. | I am content with the quality of my life | ☐ | ☐ | ☐ | ☐ |

## 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 1 year ago, how would you rate your health in general now? (choose one)**

- ☐ Much better now than 1 year ago
- ☐ Somewhat better now than 1 year ago
- ☐ About the same
- ☐ Somewhat worse now than 1 year ago
- ☐ Much worse now than 1 year 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. | Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports | ☐ | ☐ | ☐ |
| b. | Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf | ☐ | ☐ | ☐ |
| c. | Lifting or carrying groceries | ☐ | ☐ | ☐ |
| d. | Climbing several flights of stairs | ☐ | ☐ | ☐ |
| e. | Climbing one flight of stairs | ☐ | ☐ | ☐ |
| f. | Bending, kneeling, or stooping | ☐ | ☐ | ☐ |
| g. | Walking more than a mile | ☐ | ☐ | ☐ |
| h. | Walking several blocks | ☐ | ☐ | ☐ |
| i. | Walking one block | ☐ | ☐ | ☐ |
| j. | Bathing or dressing yourself | ☐ | ☐ | ☐ |

**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 amount of time you spent on work or other activities | ☐ | ☐ |
| b. | Accomplished less than you would like | ☐ | ☐ |
| c. | Were limited in the kind of work or other activities | ☐ | ☐ |
| d. | Had difficulty performing the work or other activities (for example, it took extra effort) | ☐ | ☐ |

**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 | ☐ | ☐ |
| b. | Accomplished less than you would like | ☐ | ☐ |
| c. | Didn't do work or other activities as carefully as usual | ☐ | ☐ |

**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? | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| b. | Have you been a very nervous person? | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| c. | Have you felt so down in the dumps that nothing could cheer you up? | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| d. | Have you felt calm and peaceful? | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| e. | Did you have a lot of energy? | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| f. | Have you felt downhearted and blue? | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| g. | Did you feel worn out? | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| h. | Have you been a happy person? | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| i. | Did you feel tired? | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

**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 | ☐ | ☐ | ☐ | ☐ | ☐ |
| b. | I am as healthy as anybody I know. | ☐ | ☐ | ☐ | ☐ | ☐ |
| c. | I expect my health to get worse. | ☐ | ☐ | ☐ | ☐ | ☐ |
| d. | My health is excellent. | ☐ | ☐ | ☐ | ☐ | ☐ |

**21. In the past year, 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 had 2 years or more in your life when you felt depressed or sad most days, even if you felt okay sometimes?**

☐ Yes
☐ No

**23. Have you felt depressed or sad much of the time in the past year?**

☐ Yes
☐ No

## Demographic and Social Information

**24. Marital Status**

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

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

☐ Yes
☐ No

**26. Are you receiving home care services?**

☐ Yes (Specify _____)
☐ No

**27. What health insurance provides your coverage?**

| | Yes | No |
|---|---|---|
| None | ☐ | ☐ |
| Medicare | ☐ | ☐ |
| Medex or other Medicare supplement | ☐ | ☐ |
| Medicaid | ☐ | ☐ |
| Health Maintenance Organization (HMO) | ☐ | ☐ |
| BC/BS or other commercial insurance | ☐ | ☐ |
| CHAMPUS (government) | ☐ | ☐ |
| Canadian Provincial Insurance | ☐ | ☐ |
| Other (Specify _____) | ☐ | ☐ |

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

☐ Very helpful
☐ Somewhat helpful
☐ Unhelpful
☐ Not applicable

**29. Are you currently working?**

☐ No
☐ Full-time
☐ Part-time

**30. Have you changed jobs since you were diagnosed with a brain tumor?**

☐ Same job
☐ Different job
☐ Not working

**31. Are you receiving disability benefits?**

☐ Yes
☐ No

**32. How knowledgeable do you feel about your brain tumor?**

- ☐ Very knowledgeable
- ☐ Somewhat knowledgeable
- ☐ Need more information

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

| | Yes | No |
|---|---|---|
| American Cancer Society..... | ☐ | ☐ |
| American Brain Tumor Association..... | ☐ | ☐ |
| National Brain Tumor Foundation..... | ☐ | ☐ |
| Others ..... | ☐ | ☐ |

Specify _____

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

_____
_____
_____
_____
_____
_____
_____
_____

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

_____
_____
_____
_____
_____
_____
_____
_____

**36. Are you part of a brain tumor support group?**

- ☐ Yes
- ☐ No

**37. 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

**38. 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

**39. 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

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

- ☐ Yes
- ☐ No

**41. 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

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

☐ Yes

☐ No

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

☐ Yes

☐ No (Reason:_____)

**44. Comments**

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

## Thank You for Completing This Questionnaire

Patient: Please give this form to your physician at the first clinic visit after your brain tumor surgery.

Physician: Please mail this form to

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