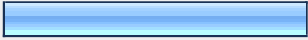

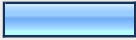






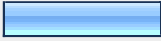
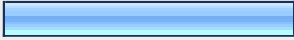

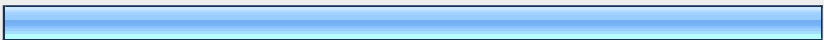


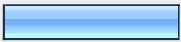
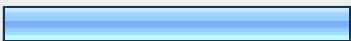
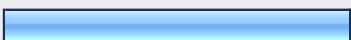



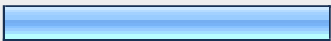


#2 Initial Patient Form

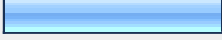

1. What is the highest grade you completed in school?			Response Percent	Response Count
Any postgraduate work			33.3%	14
College graduate			35.7%	15
Some college			14.3%	6
High school graduate			7.1%	3
Some high school			7.1%	3
8th grade or less			4.8%	2
		answered question		42
		skipped question		0

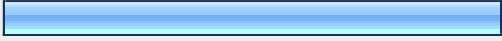
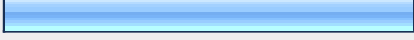
2. Which of the following categories best describes your household's total income before taxes last year? Please include income from all sources such as salaries and wages, Social Security, retirement income, etc.			Response Percent	Response Count
Less than \$20,000			4.9%	2
\$20,000 - \$39,999			9.8%	4
\$40,000 - \$59,999			14.6%	6
\$60,000 - \$79,999			17.1%	7
\$100,000 or more			31.7%	13
Prefer not to answer			22.0%	9
		answered question		41
		skipped question		1

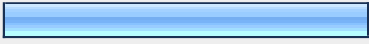
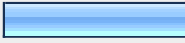

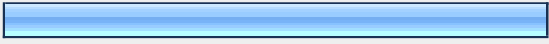
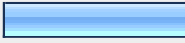
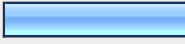
3. Form filled out by:			Response Percent	Response Count
Patient with no help			90.5%	38
Patient with help from family and/or friend			0.0%	0
Patient with help from healthcare provider			0.0%	0
Family member or friend			7.1%	3
Health care provider			0.0%	0
Other (please specify)			2.4%	1
			answered question	42
			skipped question	0


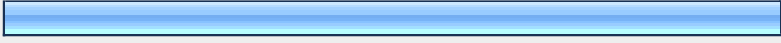

4. Since diagnosed with an ependymoma, has your weight gone:			Response Percent	Response Count
Down			19.0%	8
Up			38.1%	16
Stayed the same			38.1%	16
Don't know			4.8%	2
			answered question	42
			skipped question	0

5. My ependymoma is in my:			Response Percent	Response Count
Brain			35.9%	14
Spine			59.0%	23
Both			5.1%	2
			<i>answered question</i>	39
			<i>skipped question</i>	3

6. Have you received chemotherapy for your ependymoma?			Response Percent	Response Count
Yes			23.8%	10
No			76.2%	32
			<i>answered question</i>	42
			<i>skipped question</i>	0

7. Have you received radiation therapy for your ependymoma?			Response Percent	Response Count
Yes			54.8%	23
No			45.2%	19
			<i>answered question</i>	42
			<i>skipped question</i>	0




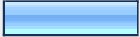

8. Have you used any alternative treatments for your ependymoma? (Please click on any and all that you have used)			Response Percent	Response Count
High dose vitamins			40.0%	6
Herbs			20.0%	3
Macrobiotic diet			13.3%	2
Shark cartilage			0.0%	0
Antineoplastins			0.0%	0
Hydrazine			0.0%	0
Acupuncture			60.0%	9
Faith Healer			20.0%	3
Meditation			20.0%	3
		Other (please specify)		5
		answered question		15
		skipped question		27


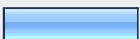


9. Have you enrolled in a formal clinical trial (other than the EO Project)?			Response Percent	Response Count
Yes			4.8%	2
No			85.7%	36
Unsure			9.5%	4
		answered question		42
		skipped question		0

10. Please indicate how you felt in the past week:

	Not at all	Somewhat	Quite a bit	Very much	Rating Average	Response Count
I can remember new things	7.1% (3)	14.3% (6)	31.0% (13)	47.6% (20)	3.19	42
I have trouble with my vision	52.4% (22)	31.0% (13)	9.5% (4)	7.1% (3)	1.71	42
I am able to find the right word(s) to say what I mean	9.5% (4)	9.5% (4)	33.3% (14)	47.6% (20)	3.19	42
I have trouble expressing my thoughts	61.9% (26)	26.2% (11)	4.8% (2)	7.1% (3)	1.57	42
I am able to put my thoughts into action	4.8% (2)	16.7% (7)	31.0% (13)	47.6% (20)	3.21	42
My personality has changed	57.1% (24)	28.6% (12)	11.9% (5)	2.4% (1)	1.60	42
I have weakness in some parts of my body	19.5% (8)	26.8% (11)	26.8% (11)	26.8% (11)	2.61	41
I have trouble with coordination	23.8% (10)	33.3% (14)	23.8% (10)	19.0% (8)	2.38	42
I have had seizures	95.2% (40)	2.4% (1)	0.0% (0)	2.4% (1)	1.10	42
I have had headaches	50.0% (21)	38.1% (16)	4.8% (2)	7.1% (3)	1.69	42
I get tired easily	14.6% (6)	36.6% (15)	24.4% (10)	24.4% (10)	2.59	41
I am slower to do things	9.8% (4)	39.0% (16)	26.8% (11)	24.4% (10)	2.66	41
I feel sick	69.0% (29)	21.4% (9)	4.8% (2)	4.8% (2)	1.45	42
I spend time in bed	57.1% (24)	33.3% (14)	9.5% (4)	0.0% (0)	1.52	42
I need help caring for myself (bathing, dressing, etc.)	85.7% (36)	7.1% (3)	2.4% (1)	4.8% (2)	1.26	42
I get support from my family	17.5% (7)	12.5% (5)	30.0% (12)	40.0% (16)	2.93	40
I feel sad	39.0% (16)	31.7% (13)	19.5% (8)	9.8% (4)	2.00	41
I am able to work (include work at home)	24.4% (10)	14.6% (6)	14.6% (6)	46.3% (19)	2.83	41
I am able to drive	17.1% (7)	9.8% (4)	17.1% (7)	56.1% (23)	3.12	41
I am able to enjoy my leisure pursuits	9.5% (4)	33.3% (14)	28.6% (12)	28.6% (12)	2.76	42
I am content with the quality of my life	19.0% (8)	28.6% (12)	33.3% (14)	19.0% (8)	2.52	42

	<i>answered question</i>	42
	<i>skipped question</i>	0

11. In general, would you say your health is: (choose one)			Response Percent	Response Count
Excellent			12.2%	5
Very Good			22.0%	9
Good			43.9%	18
Fair			14.6%	6
Poor			7.3%	3
		<i>answered question</i>		41
		<i>skipped question</i>		1

12. Compared to 1 year ago, how would you rate your general health now? (choose one)			Response Percent	Response Count
Much better now than 1 year ago			14.6%	6
Somewhat better now than 1 year ago			14.6%	6
About the same			48.8%	20
Somewhat worse now than 1 year ago			17.1%	7
Much worse now than 1 year ago			4.9%	2
		<i>answered question</i>		41
		<i>skipped question</i>		1

13. 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?

	Yes, limited a lot	Yes, limited a little	No, not limited at all	Rating Average	Response Count
Vigorous activities such as running, lifting heavy objects, participating in strenuous sports	70.7% (29)	22.0% (9)	7.3% (3)	2.63	41
Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling or playing golf	34.1% (14)	39.0% (16)	26.8% (11)	2.07	41
Lifting or carrying groceries	24.4% (10)	34.1% (14)	41.5% (17)	1.83	41
Climbing several flights of stairs	39.0% (16)	29.3% (12)	31.7% (13)	2.07	41
Climbing one flight of stairs	19.5% (8)	22.0% (9)	58.5% (24)	1.61	41
Bending, kneeling or stooping	31.7% (13)	43.9% (18)	24.4% (10)	2.07	41
Walking more than a mile	43.9% (18)	24.4% (10)	31.7% (13)	2.12	41
Walking several blocks	31.7% (13)	34.1% (14)	34.1% (14)	1.98	41
Walking one block	22.0% (9)	17.1% (7)	61.0% (25)	1.61	41
Bathing or dressing yourself	7.3% (3)	17.1% (7)	75.6% (31)	1.32	41
	<i>answered question</i>				41
	<i>skipped question</i>				1

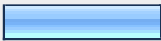
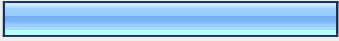
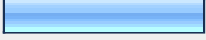
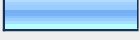

14. During the past week, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

	Yes	No	Rating Average	Response Count
Cut down on the amount of time you spent on work or other activities	48.8% (20)	51.2% (21)	1.51	41
Accomplished less than you would like	68.3% (28)	31.7% (13)	1.32	41
Were limited in the kind of work or activities	56.1% (23)	43.9% (18)	1.44	41
Had difficulty performing the work or other activities (for example, it took extra effort)	53.7% (22)	46.3% (19)	1.46	41
	<i>answered question</i>			41
	<i>skipped question</i>			1


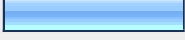
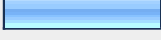
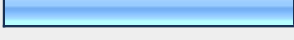


15. During the past week have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

	Yes	No	Rating Average	Response Count
Cut down the amount of time you spent on work or other activities	24.4% (10)	75.6% (31)	1.76	41
Accomplished less than you liked	31.7% (13)	68.3% (28)	1.68	41
Didn't do work or other activities as carefully as usual	19.5% (8)	80.5% (33)	1.80	41
	<i>answered question</i>			41
	<i>skipped question</i>			1

16. During the past week, to what extent has your physical health or emotional problems interfered with your normal social activities?

		Response Percent	Response Count
Not at all		17.1%	7
Slightly		36.6%	15
Moderately		22.0%	9
Quite a bit		14.6%	6
Extremely		9.8%	4
		answered question	41
		skipped question	1

17. How much bodily pain have you had during the past week?

		Response Percent	Response Count
None		24.4%	10
Very mild		19.5%	8
Mild		17.1%	7
Moderate		31.7%	13
Severe		7.3%	3
Very severe		2.4%	1
		answered question	41
		skipped question	1

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

		Response Percent	Response Count
Not at all		34.1%	14
A little bit		31.7%	13
Moderately		17.1%	7
Quite a bit		14.6%	6
Extremely		2.4%	1
answered question			41
skipped question			1

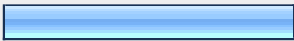
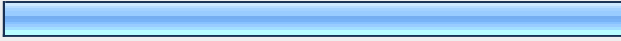
19. These questions are about how you feel and how things have been with you during the past week. How much of the time during the past week:


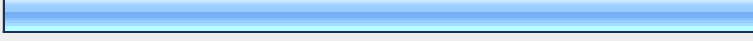
	All of the time	Most of the time	A good bit of the time	Some of the time	A little bit of the time	None of the time	Rating Average	Response Count
Did you feel peppy?	4.9% (2)	9.8% (4)	17.1% (7)	24.4% (10)	24.4% (10)	19.5% (8)	4.12	41
Have you been a very nervous person?	0.0% (0)	2.4% (1)	14.6% (6)	9.8% (4)	26.8% (11)	46.3% (19)	5.00	41
Have you felt so down that nothing could cheer you up?	0.0% (0)	2.4% (1)	12.2% (5)	9.8% (4)	7.3% (3)	68.3% (28)	5.27	41
Have you felt calm?	7.5% (3)	40.0% (16)	25.0% (10)	12.5% (5)	10.0% (4)	5.0% (2)	2.93	40
Did you have a lot of energy?	4.9% (2)	12.2% (5)	12.2% (5)	24.4% (10)	22.0% (9)	24.4% (10)	4.20	41
Have you felt blue?	0.0% (0)	12.5% (5)	7.5% (3)	12.5% (5)	37.5% (15)	30.0% (12)	4.65	40
Did you feel worn out?	5.1% (2)	12.8% (5)	30.8% (12)	30.8% (12)	10.3% (4)	10.3% (4)	3.59	39
Have you been happy?	4.9% (2)	29.3% (12)	22.0% (9)	19.5% (8)	14.6% (6)	9.8% (4)	3.39	41
Did you feel tired?	4.9% (2)	31.7% (13)	22.0% (9)	24.4% (10)	12.2% (5)	4.9% (2)	3.22	41


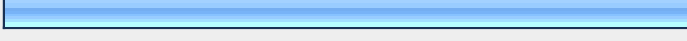
	<i>answered question</i>	41
	<i>skipped question</i>	1

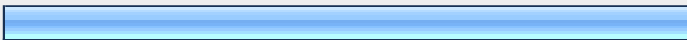


20. During the past week, how much of the time has your physical health or emotional problems interfered with your social activities?			Response Percent	Response Count
All of the time			2.4%	1
Most of the time			24.4%	10
Some of the time			29.3%	12
A little of the time			24.4%	10
None of the time			19.5%	8
			<i>answered question</i>	41
			<i>skipped question</i>	1


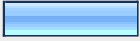
21. How TRUE or FALSE are each of the following statements for you?							
	Definitely True	Mostly True	Unsure	Mostly False	Definitely False	Rating Average	Response Count
I seem to get sick easier than other people	4.9% (2)	4.9% (2)	17.1% (7)	29.3% (12)	43.9% (18)	4.02	41
I am as healthy as anyone I know	14.6% (6)	39.0% (16)	12.2% (5)	19.5% (8)	14.6% (6)	2.80	41
I expect my health to get worse	4.9% (2)	19.5% (8)	58.5% (24)	4.9% (2)	12.2% (5)	3.00	41
My health is excellent	9.8% (4)	34.1% (14)	14.6% (6)	24.4% (10)	17.1% (7)	3.05	41
						<i>answered question</i>	41
						<i>skipped question</i>	1


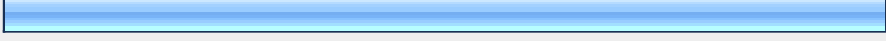
22. In the past year, have you had 2 weeks or more during which you felt sad, blue or depressed; or when you lost all interest or pleasure in things that you usually cared about or enjoyed?			Response Percent	Response Count
Yes			31.7%	13
No			68.3%	28
			<i>answered question</i>	41
			<i>skipped question</i>	1

23. Have you had 2 years or more in your life that you felt depressed or sad most days, even if you felt okay sometimes?			Response Percent	Response Count
Yes			19.5%	8
No			82.9%	34
			<i>answered question</i>	41
			<i>skipped question</i>	1

24. Have you felt depressed or sad much of the time in the past year?			Response Percent	Response Count
Yes			24.4%	10
No			75.6%	31
			<i>answered question</i>	41
			<i>skipped question</i>	1

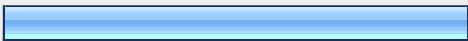


25. Marital Status				
			Response Percent	Response Count
Married			75.6%	31
Never Married			17.1%	7
Divorced			7.3%	3
Separated			0.0%	0
Widowed			0.0%	0
Prefer not to Answer			0.0%	0
			<i>answered question</i>	41
			<i>skipped question</i>	1

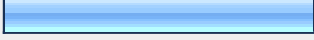

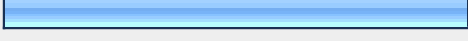
26. Do you live with someone who can help take care of you?				
			Response Percent	Response Count
Yes			85.4%	35
No			14.6%	6
			<i>answered question</i>	41
			<i>skipped question</i>	1


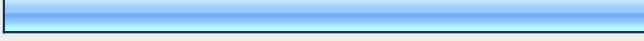
27. Are you receiving home care services?				
			Response Percent	Response Count
Yes			2.4%	1
No			97.6%	40
			If Yes, please specify	1
			<i>answered question</i>	41
			<i>skipped question</i>	1

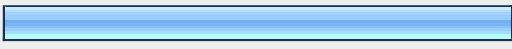
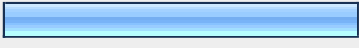

28. What health insurance provides your coverage?						
	Yes	No			Rating Average	Response Count
None	0.0% (0)	100.0% (11)	0.0% (0)	0.0% (0)	2.00	11
Medicare	28.6% (4)	71.4% (10)	0.0% (0)	0.0% (0)	1.71	14
Medex or other Medicare supplement	16.7% (2)	83.3% (10)	0.0% (0)	0.0% (0)	1.83	12
Medicaid	21.4% (3)	78.6% (11)	0.0% (0)	0.0% (0)	1.79	14
Health Maintenance Organization (HMO)	56.3% (9)	43.8% (7)	0.0% (0)	0.0% (0)	1.44	16
BC/BS or other commercial insurance	80.0% (16)	20.0% (4)	0.0% (0)	0.0% (0)	1.20	20
CHAMPUS (government)	23.1% (3)	76.9% (10)	0.0% (0)	0.0% (0)	1.77	13
Canadian Provincial Insurance	15.4% (2)	84.6% (11)	0.0% (0)	0.0% (0)	1.85	13
Other (please specify)						10
answered question						35
skipped question						7

29. In providing payment for the care of my ependymoma, my insurance company has been:			
		Response Percent	Response Count
Very helpful		56.1%	23
Somewhat helpful		36.6%	15
Unhelpful		0.0%	0
Not applicable		7.3%	3
answered question			41
skipped question			1

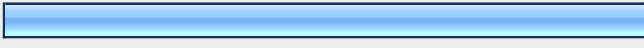
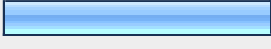
30. Are you currently working?			Response Percent	Response Count
No			51.2%	21
Full-time			41.5%	17
Part-time			7.3%	3
			answered question	41
			skipped question	1

31. Have you changed jobs since you were diagnosed with an ependymoma?			Response Percent	Response Count
Same job			34.1%	14
Different job			14.6%	6
Not working			51.2%	21
			answered question	41
			skipped question	1

32. Are you receiving disability benefits?			Response Percent	Response Count
Yes			29.3%	12
No			70.7%	29
			answered question	41
			skipped question	1

33. How knowledgeable do you feel about your ependymoma?			
		Response Percent	Response Count
Very knowledgeable		56.1%	23
Somewhat knowledgeable		39.0%	16
Need more information		7.3%	3
answered question			41
skipped question			1

34. Which organizations have given you information or help with your ependymoma?				
	Yes	No	Rating Average	Response Count
American Cancer Society	16.7% (4)	83.3% (20)	1.83	24
American Brain Tumor Association	44.4% (12)	55.6% (15)	1.56	27
National Brain Tumor Foundation	44.8% (13)	55.2% (16)	1.55	29
Other (please specify)				26
answered question				30
skipped question				12

35. Are you part of a ependymoma support group?			
		Response Percent	Response Count
Yes		70.7%	29
No		29.3%	12
answered question			41
skipped question			1

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

		Response Percent	Response Count
Yes, definitely		63.4%	26
Yes, probably		22.0%	9
No, probably not		2.4%	1
No, definitely not		2.4%	1
Not applicable		9.8%	4
		answered question	41
		skipped question	1

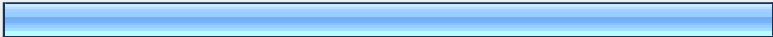
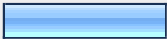
37. If you could go back in time and make the same decision again, would you choose to have chemotherapy for your ependymoma?

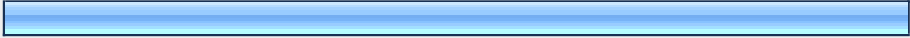
		Response Percent	Response Count
Yes, definitely		17.1%	7
Yes, probably		2.4%	1
No, probably not		2.4%	1
No, definitely not		17.1%	7
Not applicable		61.0%	25
		answered question	41
		skipped question	1

38. If you could go back in time and make the same decision again, would you choose to have radiation therapy for your ependymoma?			Response Percent	Response Count
Yes, definitely			31.7%	13
Yes, probably			9.8%	4
No, probably not			9.8%	4
No, definitely not			14.6%	6
Not applicable			34.1%	14
			answered question	41
			skipped question	1

39. Do you feel that you have had access to all the healthcare you need for your ependymoma?			Response Percent	Response Count
Yes			72.5%	29
No			27.5%	11
			answered question	40
			skipped question	2

40. In general, have you been satisfied with the medical care you have received for your ependymoma?			Response Percent	Response Count
Very satisfied			43.9%	18
Somewhat satisfied			43.9%	18
Not satisfied			7.3%	3
Very unsatisfied			4.9%	2
			answered question	41
			skipped question	1

41. Do you feel that the questions in this form are relevant to your health?			
		Response Percent	Response Count
Yes		85.0%	34
No		17.5%	7
<i>answered question</i>			40
<i>skipped question</i>			2

42. Do you plan to continue to participate in the EO (Ependymoma Outcomes) Project?			
		Response Percent	Response Count
Yes		100.0%	41
No		0.0%	0
If no, reason			0
<i>answered question</i>			41
<i>skipped question</i>			1