

## Patient Demographics And Social Information

### Form filled out by:

	Brain (N=70)	Spine (N=81)	Brain & Spine (N=8)
Patient with no help	58 (83%)	71 (88%)	8 (100%)
Patient with help from family and/or friend	5 (7%)	4 (5%)	0
Family member or friend	6 (9%)	6 (7%)	0
Patient with help from healthcare provider	1 (1%)	0	0

### What is the patient's gender?

	Brain	Spine	Brain & Spine
Male	35 (50%)	37 (46%)	2 (25%)
Female	35 (50%)	44 (54%)	6 (75%)

### What is your current age?

	Brain	Spine	Brain & Spine
Mean	46	49	45
Median	45	48	47
Range	18-77	23-76	22-66

### What was your age at your original diagnosis?

	Brain	Spine	Brain & Spine
Mean	40	41	41
Median	40	39	42
Range	18-72	19-70	18-66

### Have you enrolled in a formal clinical trial (other than the EO Project)?

	Brain	Spine	Brain & Spine
No	60 (86%)	70 (86%)	6 (75%)
Yes	5 (7%)	3 (4%)	1 (13%)
Unsure	4 (6%)	6 (7%)	1 (13%)

**Marital status:**

	Brain	Spine	Brain & Spine
Never married	13 (19%)	8 (10%)	1 (13%)
Married	49 (70%)	58 (72%)	6 (75%)
Divorced	4 (6%)	12 (15%)	0
Widowed	1 (1%)	0	0
Separated	0	1 (1%)	0

**What is the highest grade you completed in school?**

	Brain	Spine	Brain & Spine
Some high school	2 (3%)	0	0
High school graduate	5 (7%)	7 (9%)	0
Some college	16 (23%)	17 (21%)	2 (25%)
College graduate	24 (34%)	27 (33%)	0
Any postgraduate work	21 (30%)	28 (35%)	4 (50%)

**Which of the following categories best describes your household's total income before taxes last year?**

	Brain	Spine	Brain & Spine
Less than \$20,000	6 (9%)	5 (6%)	0
\$20,000-\$39,999	3 (4%)	10 (12%)	1 (13%)
\$40,000-\$59,999	8 (11%)	10 (12%)	0
\$60,000-\$79,999	9 (13%)	6 (7%)	1 (13%)
\$80,000-\$99,999	11 (16%)	1 (1%)	1 (13%)
\$100,000 or more	23 (33%)	32 (40%)	4 (50%)
Prefer not to say	6 (9%)	13 (16%)	0

**Are you receiving home care services?**

	Brain	Spine	Brain & Spine
No	64 (91%)	74 (91%)	7 (88%)
Yes	4 (6%)	5 (6%)	0

### ***What health insurance provides your coverage?***

	<b>Brain</b>	<b>Spine</b>	<b>Brain &amp; Spine</b>
Medicare	18 (26%)	18 (22%)	0
Medex or Medicare supplement	7 (10%)	5 (6%)	0
Medicaid	5 (7%)	3 (4%)	0
HMO	7 (10%)	8 (10%)	0
BC/BS, other commercial insurance	32 (46%)	40 (49%)	5 (63%)
CHAMPUS (government)	2 (3%)	2 (3%)	0
Canadian Provincial Insurance	3 (4%)	2 (3%)	0
Other	15 (21%)	17 (21%)	1 (13%)
None	3 (4%)	0	

### ***In providing payment for the care of my ependymoma, my insurance company has been:***

	<b>Brain</b>	<b>Spine</b>	<b>Brain &amp; Spine</b>
N/A	6 (9%)	4 (5%)	0
Very helpful	54 (77%)	48 (59%)	6 (75%)
Somewhat helpful	7 (10%)	23 (28%)	1 (13%)
Unhelpful	1 (1%)	2 (3%)	0

### ***Are you currently working?***

	<b>Brain</b>	<b>Spine</b>	<b>Brain &amp; Spine</b>
No	39 (56%)	36 (44%)	2 (25%)
Full-time	23 (33%)	33 (41%)	3 (38%)
Part-time	5 (7%)	8 (10%)	2 (25%)

### ***Have you changed jobs since you were diagnosed with an ependymoma?***

	<b>Brain</b>	<b>Spine</b>	<b>Brain &amp; Spine</b>
Different job	7 (10%)	22 (27%)	1 (13%)
Same job	22 (31%)	26 (32%)	4 (50%)
Not working	37 (53%)	31 (38%)	2 (25%)

### ***Are you receiving disability benefits?***

	<b>Brain</b>	<b>Spine</b>	<b>Brain &amp; Spine</b>
No	40 (57%)	54 (67%)	5 (63%)
Yes	27 (39%)	25 (31%)	2 (25%)

***How knowledgeable do you feel about your ependymoma?***

	<b>Brain</b>	<b>Spine</b>	<b>Brain &amp; Spine</b>
Very knowledgeable	22 (31%)	32 (40%)	3 (38%)
Somewhat knowledgeable	41 (59%)	35 (43%)	4 (50%)
Need more information	2 (3%)	9 (11%)	0

***Which organizations have given you information or help with your ependymoma?***

	<b>Brain</b>	<b>Spine</b>	<b>Brain &amp; Spine</b>
American Cancer Society	16 (23%)	10 (12%)	0
American Brain Tumor Association	33 (47%)	7 (9%)	3 (38%)
National Brain Tumor Foundation	21 (30%)	4 (5%)	2 (25%)
Brain Trust	11 (16%)	4 (5%)	0
Spinal Cord Tumor Association	0	32 (40%)	0
Other	13 (19%)	15 (19%)	3 (38%)

***Do you feel that you have had access to all the healthcare you need for your ependymoma?***

	<b>Brain</b>	<b>Spine</b>	<b>Brain &amp; Spine</b>
No	11 (16%)	19 (24%)	0
Yes	57 (81%)	59 (73%)	7 (88%)

***In general, have you been satisfied with the medical care you have received for your ependymoma?***

	<b>Brain</b>	<b>Spine</b>	<b>Brain &amp; Spine</b>
Very satisfied	47 (67%)	32 (40%)	6 (75%)
Somewhat satisfied	16 (23%)	36 (44%)	1 (13%)
Not satisfied	4 (6%)	4 (5%)	0
Very unsatisfied	0	7 (9%)	0

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

	<b>Brain</b>	<b>Spine</b>	<b>Brain &amp; Spine</b>
No	9 (13%)	13 (16%)	0
Yes	58 (83%)	66 (82%)	7 (88%)

***Are you part of an ependymoma support group?***

	<b>Brain</b>	<b>Spine</b>	<b>Brain &amp; Spine</b>
No	51 (73%)	56 (69%)	6 (75%)
Yes	17 (24%)	23 (28%)	1 (13%)

## Diagnosis and Treatment Course

### What type of surgery did you first have for your ependymoma?

	Brain (N=70)	Spine (N=81)	Brain & Spine (N=8)
Biopsy (needle, stereotactic)	2 (3%)	3 (4%)	0
Craniotomy with part of tumor removed	22 (31%)	0	1 (13%)
Craniotomy with all of tumor removed	45 (64%)	1 (1%)	4 (50%)
Craniotomy for biopsy	1 (1%)	0	0
Spine surgery for biopsy	0	2 (3%)	0
Spine surgery with part of tumor removed	0	21 (26%)	0
Spine surgery with all of tumor removed	0	46 (57%)	3 (38%)
No surgery yet	0	2 (3%)	0

### What was the name of your first ependymoma tumor?

	Brain	Spine	Brain & Spine
Ependymoma	41 (59%)	46 (57%)	6 (75%)
Anaplastic ependymoma	15 (21%)	3 (4%)	0
Myxopapillary ependymoma	0	22 (27%)	1 (13%)
Subependymoma	4 (6%)	1 (1%)	0
Tanycytic ependymoma	2 (3%)	0	0
Giant cell ependymoma	0	1 (1%)	1 (13%)
Did not know name	8 (11%)	6 (7%)	0

### What was the grade of your first ependymoma tumor?

	Brain	Spine	Brain & Spine
Did not know the grade	20 (29%)	46 (57%)	1 (13%)
II	27 (39%)	24 (30%)	6 (75%)
III	14 (20%)	2 (3%)	0
Other	8 (11%)	7 (9%)	1 (13%)

***If your ependymoma was in the BRAIN, where in the brain was it located?***

	n	%
Left side	13	17
Right side	17	22
Midline	5	6
Bilateral	0	0
Frontal lobe	7	9
Temporal lobe	5	6
Parietal lobe	11	14
Occipital lobe	7	9
Cerebellum	17	22
Brainstem	38	49
Other	7	9
I don't know	1	1

***If your ependymoma was in the SPINE, where in the spine was it located?***

	n	%
Cervical	36	40
Thoracic	28	32
Lumbar	34	38
Sacral	17	19
I don't know	3	3

***What was the number of tumor sites for your first ependymoma tumor?***

	Brain	Spine	Brain & Spine
Single	57 (81%)	70 (86%)	7 (88%)
Multiple	5 (7%)	8 (10%)	1 (13%)
Did not know	6 (9%)	2 (3%)	0

***Did your first ependymoma tumor enhance on MRI?***

	Brain	Spine	Brain & Spine
Yes	52 (74%)	63 (78%)	6 (75%)
Did not know	17 (24%)	17 (21%)	2 (25%)

**At your first surgery, did you have any of the following symptoms?**

	Brain	Spine	Brain & Spine
Sleepiness	15 (21%)	11 (14%)	0
Headache	37 (53%)	12 (15%)	4 (50%)
Memory loss	14 (20%)	4 (5%)	0
Nausea/vomiting	30 (43%)	2 (3%)	1 (13%)
Trouble speaking or writing	14 (20%)	4 (5%)	1 (13%)
Personality change	10 (14%)	3 (4%)	0
Weakness	23 (33%)	39 (48%)	2 (25%)
Seizures	7 (10%)	1 (1%)	0
Problems thinking or completing tasks	16 (23%)	6 (7%)	1 (13%)
Numbness or tingling in the arms/legs/body	20 (29%)	51 (63%)	3 (38%)
Visual problems	32 (46%)	3 (4%)	2 (25%)
Back pain	5 (7%)	40 (49%)	0
Radiating back pain	3 (4%)	31 (38%)	0
Problems urinating	1 (1%)	16 (20%)	1 (13%)
Sexual dysfunction	1 (1%)	11 (14%)	1 (13%)

**Estimate the amount of time between your initial symptoms and your first surgery.**

	Brain	Spine	Brain & Spine
No symptoms	3 (4%)	2 (3%)	0
<1 month	16 (23%)	5 (6%)	0
1-2 months	8 (11%)	5 (6%)	1 (13%)
3-4 months	12 (17%)	8 (10%)	0
5-6 months	7 (10%)	4 (5%)	2 (25%)
7-11 months	6 (9%)	13 (16%)	1 (13%)
1-4 years	13 (19%)	26 (32%)	3 (38%)
>=5 years	4 (6%)	17 (21%)	1 (13%)

**Prior to your first surgery, did you have any of the following?**

	Brain	Spine	Brain & Spine
Depression	12 (17%)	13 (16%)	1 (13%)
Blood clot in leg	2 (3%)	0	0
Bleeding in the brain	3 (4%)	1 (1%)	1 (13%)
Infection	2 (3%)	0	0
Seizure	8 (11%)	1 (1%)	0
Stomach ulcer	4 (6%)	3 (4%)	0
Hydrocephalus	13 (19%)	0	3 (38%)
Problems thinking or completing tasks	16 (23%)	7 (9%)	0
Diabetes	2 (3%)	3 (4%)	0
Steroid myopathy	1 (1%)	16 (20%)	1 (13%)
Drug allergy	4 (6%)	5 (6%)	1 (13%)
Paralysis	1 (1%)	5 (6%)	0
Incontinence	1 (1%)	7 (9%)	1 (13%)
Recurrent urinary tract infections	0	7 (9%)	1 (13%)

**After your first surgery, how was your condition?**

	Brain	Spine	Brain & Spine
Better	43 (61%)	40 (49%)	5 (63%)
Worse	18 (26%)	30 (37%)	1 (13%)
Same	5 (7%)	9 (11%)	1 (13%)

**Did you have any of the following complications with the first surgery?**

	Brain	Spine	Brain & Spine
Infection	11 (16%)	4 (5%)	2 (25%)
Blood clot	5 (7%)	2 (3%)	1 (13%)
Bleeding in the brain	2 (3%)	0	1 (13%)
Seizure	7 (10%)	0	1 (13%)
Diabetes	1 (1%)	3 (4%)	1 (13%)
Drug allergy	2 (3%)	5 (6%)	1 (13%)
Weakness	23 (33%)	32 (40%)	5 (63%)
Paralysis	6 (9%)	20 (25%)	1 (13%)
Inability to urinate	5 (7%)	11 (14%)	1 (13%)
Incontinence	0	14 (17%)	2 (25%)
Sexual dysfunction	5 (7%)	20 (25%)	0

**After your first surgery, which of the following treatments did you receive?**

	Brain	Spine	Brain & Spine
Radiation therapy alone	27 (39%)	15 (19%)	2 (25%)
Chemotherapy alone	1 (1%)	0	0
Chemotherapy & radiation therapy	9 (13%)	5 (6%)	1 (13%)
Chemotherapy, radiation therapy & radiosurgery	1 (1%)	0	0
None	30 (43%)	53 (66%)	4 (50%)

**How many surgeries have you had for your ependymoma tumor?**

	Brain	Spine	Brain & Spine
0	0	2 (3%)	0
1	56 (80%)	47 (58%)	5 (63%)
2	6 (9%)	14 (17%)	2 (25%)
3	6 (9%)	8 (10%)	0
>3	1 (1%)	3 (4%)	0



**What type of doctor do you follow for your ependymoma?**

	Brain	Spine	Brain & Spine
Neurosurgeon	28 (40%)	47 (58%)	3 (38%)
Neuro-Oncologist	26 (37%)	18 (22%)	5 (63%)
Oncologist	4 (6%)	7 (9%)	0
Radiation oncologist	15 (21%)	8 (10%)	2 (25%)
Family doctor or internal medicine	10 (14%)	20 (25%)	1 (13%)

**How often do you have a MRI?**

	Brain	Spine	Brain & Spine
Every 2 months	10 (14%)	6 (7%)	0
Every 6 months	11 (16%)	17 (21%)	1 (13%)
Every year	11 (16%)	15 (19%)	5 (63%)
Every 2 years	1 (1%)	6 (7%)	0
>2 years since last MRI	2 (3%)	8 (10%)	0
Only when I have a concern	1 (1%)	3 (4%)	0
Other	25 (36%)	19 (24%)	2 (25%)

**At your last clinic visit, did your MRI show the tumor is:**

	Brain	Spine	Brain & Spine
Larger	4 (6%)	7 (9%)	0
Smaller	5 (7%)	3 (4%)	0
Unchanged	15 (21%)	23 (28%)	2 (25%)
Not present	36 (51%)	39 (48%)	6 (75%)
MRI not done	6 (9%)	7 (9%)	0

**Which of the following medications are you taking?**

	Brain	Spine	Brain & Spine
Anti-seizure	16 (23%)	13 (16%)	0
Antidepressant	14 (20%)	19 (24%)	2 (25%)
Corticosteroid	2 (3%)	4 (5%)	0
Pain	11 (16%)	35 (43%)	1 (13%)

**What is your current weight (in lbs)?**

	Brain	Spine	Brain & Spine
Mean	173	182	153
Range	95-353	112-380	72-210

***What is your current weight (in lbs)?***

	<b>Brain</b>	<b>Spine</b>	<b>Brain &amp; Spine</b>
Mean	173	182	153
Range	95-353	112-380	72-210

***Since diagnosed with an ependymoma, has your weight gone:***

	<b>Brain</b>	<b>Spine</b>	<b>Brain &amp; Spine</b>
Down	21 (30%)	15 (19%)	1 (13%)
Up	16 (23%)	36 (44%)	2 (25%)
About the same	27 (39%)	26 (32%)	3 (38%)
Did not know	2 (3%)	3 (4%)	0

***Have you received chemotherapy for your ependymoma?***

	<b>Brain</b>	<b>Spine</b>	<b>Brain &amp; Spine</b>
No	52 (74%)	68 (84%)	7 (88%)
Yes	18 (26%)	12 (15%)	1 (13%)

***Have you received radiation therapy for your ependymoma?***

	<b>Brain</b>	<b>Spine</b>	<b>Brain &amp; Spine</b>
No	22 (31%)	45 (56%)	4 (50%)
Yes	48 (69%)	36 (44%)	4 (50%)

***Have you used any alternative treatments for your ependymoma?***

	<b>Brain</b>	<b>Spine</b>	<b>Brain &amp; Spine</b>
High dose vitamins	3 (4%)	13 (16%)	0
Herbs	0	9 (11%)	0
Macrobiotic diet	1 (1%)	2 (3%)	0
Acupuncture	5 (7%)	12 (15%)	0
Faith healer	3 (4%)	5 (6%)	0
Meditation	6 (9%)	6 (7%)	0
Other	5 (7%)	10 (12%)	1 (13%)

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

	<b>Brain</b>	<b>Spine</b>	<b>Brain &amp; Spine</b>
No, definitely not	3 (4%)	5 (7%)	0
No, probably not	3 (4%)	6 (8%)	0
Yes, probably	6 (9%)	16 (22%)	0
Yes, definitely	53 (76%)	45 (62%)	8 (100%)

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

	<b>Brain</b>	<b>Spine</b>	<b>Brain &amp; Spine</b>
No, definitely not	0	1 (8%)	0
No, probably not	3 (17%)	1 (8%)	0
Yes, probably	3 (17%)	2 (17%)	1 (100%)
Yes, definitely	9 (50%)	8 (67%)	0

***If you had radiation therapy and could go back in time and make the same decision again, would you choose to have radiation therapy for your ependymoma?***

	<b>Brain</b>	<b>Spine</b>	<b>Brain &amp; Spine</b>
No, definitely not	4 (8%)	5 (14%)	0
No, probably not	2 (4%)	6 (17%)	0
Yes, probably	11 (23%)	6 (17%)	1 (25%)
Yes, definitely	30 (63%)	17 (47%)	3 (75%)

## Diagnosis and Treatment Course Data

### What was the time frame (in months) between diagnosis and the EOQ?

	Brain	Spine	Brain & Spine
Mean	69	96	54
Median	53	74	53
Range	1-458	2-456	7-96

### Number of presenting symptoms

	Brain	Spine	Brain & Spine
0-1	13 (19%)	19 (23%)	4 (50%)
2-5	41 (59%)	48 (59%)	4 (50%)
6-10	9 (13%)	10 (12%)	0
≥ 11	1 (1%)	1 (1%)	0
Mean	4	3	2
Median	3	3	2
Range	1-13	0-11	1-3

## Recurrence

### Has your ependymoma recurred?

	Brain (N=70)	Spine (N=81)	Brain & Spine (N=8)
No	46 (66%)	50 (62%)	7 (88%)
Yes	23 (33%)	28 (35%)	1 (13%)

### What was the name of your ependymoma tumor at recurrence?

	Brain	Spine	Brain & Spine
Ependymoma	9 (39%)	7 (25%)	1 (100%)
Myxopapillary ependymoma	0	13 (46%)	0
Anaplastic ependymoma	7 (30%)	3 (11%)	0
Subependymoma	1 (4%)	0	0
Did not know name	4 (17%)	4 (14%)	0

### How many recurrences?

	Brain	Spine	Brain & Spine
1	13 (57%)	12 (43%)	1 (100%)
2	5 (22%)	4 (14%)	0
>2	2 (9%)	9 (32%)	0

### Did it recur in the same location?

	Brain	Spine	Brain & Spine
No	7 (30%)	4 (14%)	0
Yes	15 (65%)	23 (82%)	1 (100%)

**What symptoms did you have the first time it recurred?**

	Brain	Spine	Brain & Spine
Sleepiness	3 (13%)	1 (4%)	0
Headache	6 (26%)	3 (11%)	0
Memory loss	0	4 (14%)	0
Nausea/vomiting	1 (4%)	1 (4%)	
Trouble speaking or writing	0	1 (4%)	0
Personality change	0	1 (4%)	
Weakness	0	17 (61%)	0
Seizures	1 (4%)	0	0
Problems thinking or completing tasks	1 (4%)	3 (11%)	0
Numbness or tingling in arms, legs or body	6 (26%)	16 (57%)	1 (100%)
Visual problems (double vision or loss of vision)	0	2 (7%)	0
Back pain	3 (13%)	15 (54%)	0
Radiating back pain	1 (4%)	12 (43%)	0
Problems urinating (incontinence or inability to void)	0	8 (29%)	0
Sexual dysfunction	0	6 (21%)	0

**What treatment did you receive after the recurrence?**

	Brain	Spine	Brain & Spine
Surgery only	2 (9%)	9 (32%)	0
Radiation only	4 (17%)	8 (29%)	0
Chemotherapy only	3 (13%)	1 (4%)	0
Radiation & chemotherapy	1 (4%)	1 (4%)	0
Surgery & radiation	3 (13%)	2 (7%)	1 (100%)
Surgery & chemotherapy	3 (13%)	2 (7%)	0
Surgery & radiosurgery	1 (4%)	0	
Surgery, radiation & chemotherapy	0	3 (11%)	0

## Quality Of Life

Please indicate how you felt in the past week:

### *I can remember new things*

	Brain (N=70)	Spine (N=81)	Brain & Spine (N=8)
Not at all	4 (6%)	6 (7%)	0
Somewhat	17 (24%)	10 (12%)	0
Quite a bit	19 (27%)	25 (31%)	3 (38%)
Very much	27 (39%)	37 (46%)	5 (63%)

### *I have trouble with my vision*

	Brain	Spine	Brain & Spine
Not at all	21 (30%)	49 (61%)	5 (63%)
Somewhat	29 (41%)	24 (30%)	2 (25%)
Quite a bit	8 (11%)	4 (5%)	1 (13%)
Very much	9 (13%)	2 (3%)	0

### *I am able to find the right word(s) to say what I mean*

	Brain	Spine	Brain & Spine
Not at all	10 (14%)	9 (11%)	1 (13%)
Somewhat	15 (21%)	20 (25%)	1 (13%)
Quite a bit	18 (26%)	17 (21%)	1 (13%)
Very much	24 (34%)	33 (41%)	5 (63%)

### *I have trouble expressing my thoughts*

	Brain	Spine	Brain & Spine
Not at all	41 (59%)	47 (58%)	8 (100%)
Somewhat	12 (17%)	22 (27%)	0
Quite a bit	9 (13%)	7 (9%)	0
Very much	5 (7%)	3 (4%)	0

***I am able to put my thoughts into action***

	<b>Brain</b>	<b>Spine</b>	<b>Brain &amp; Spine</b>
Not at all	7 (10%)	8 (10%)	2 (25%)
Somewhat	17 (24%)	15 (19%)	1 (13%)
Quite a bit	16 (23%)	19 (24%)	0
Very much	27 (39%)	37 (46%)	5 (63%)

***My personality has changed***

	<b>Brain</b>	<b>Spine</b>	<b>Brain &amp; Spine</b>
Not at all	32 (46%)	39 (48%)	5 (63%)
Somewhat	28 (40%)	28 (35%)	2 (25%)
Quite a bit	6 (9%)	6 (7%)	1 (13%)
Very much	1 (1%)	6 (7%)	0

***I have weakness in some parts of my body***

	<b>Brain</b>	<b>Spine</b>	<b>Brain &amp; Spine</b>
Not at all	26 (37%)	11 (14%)	5 (63%)
Somewhat	25 (36%)	21 (26%)	1 (13%)
Quite a bit	9 (13%)	14 (17%)	2 (25%)
Very much	6 (9%)	33 (41%)	0

***I have trouble with coordination***

	<b>Brain</b>	<b>Spine</b>	<b>Brain &amp; Spine</b>
Not at all	20 (29%)	23 (28%)	3 (38%)
Somewhat	22 (31%)	25 (31%)	3 (38%)
Quite a bit	10 (14%)	15 (19%)	1 (13%)
Very much	15 (21%)	16 (20%)	1 (13%)

***I have had seizures***

	<b>Brain</b>	<b>Spine</b>	<b>Brain &amp; Spine</b>
Not at all	61 (87%)	72 (89%)	8 (100%)
Somewhat	3 (4%)	3 (4%)	0
Quite a bit	0	1 (1%)	0
Very much	2 (3%)	2 (3%)	0



### *I have had headaches*

	<b>Brain</b>	<b>Spine</b>	<b>Brain &amp; Spine</b>
Not at all	35 (50%)	43 (53%)	3 (38%)
Somewhat	18 (26%)	23 (28%)	5 (63%)
Quite a bit	2 (3%)	9 (11%)	0
Very much	11 (16%)	4 (5%)	0

### *I get tired easily*

	<b>Brain</b>	<b>Spine</b>	<b>Brain &amp; Spine</b>
Not at all	17 (24%)	8 (10%)	5 (63%)
Somewhat	22 (31%)	32 (40%)	1 (13%)
Quite a bit	15 (21%)	22 (27%)	0
Very much	13 (19%)	17 (21%)	2 (25%)

### *I am slower to do things*

	<b>Brain</b>	<b>Spine</b>	<b>Brain &amp; Spine</b>
Not at all	17 (24%)	12 (15%)	5 (63%)
Somewhat	23 (33%)	31 (38%)	1 (13%)
Quite a bit	14 (20%)	16 (20%)	0
Very much	12 (17%)	18 (22%)	2 (25%)

### *I feel sick*

	<b>Brain</b>	<b>Spine</b>	<b>Brain &amp; Spine</b>
Not at all	47 (67%)	54 (67%)	6 (75%)
Somewhat	10 (14%)	15 (19%)	2 (25%)
Quite a bit	6 (9%)	7 (9%)	0
Very much	4 (6%)	2 (3%)	0

### *I spend time in bed*

	<b>Brain</b>	<b>Spine</b>	<b>Brain &amp; Spine</b>
Not at all	42 (60%)	40 (49%)	6 (75%)
Somewhat	14 (20%)	23 (28%)	2 (25%)
Quite a bit	8 (11%)	8 (10%)	0
Very much	3 (4%)	7 (9%)	0

### *I need help caring for myself*

	<b>Brain</b>	<b>Spine</b>	<b>Brain &amp; Spine</b>
Not at all	55 (79%)	55 (68%)	7 (88%)
Somewhat	8 (11%)	9 (11%)	1 (13%)
Quite a bit	1 (1%)	8 (10%)	0
Very much	3 (4%)	6 (7%)	0

### *I get support from my family*

	<b>Brain</b>	<b>Spine</b>	<b>Brain &amp; Spine</b>
Not at all	8 (11%)	15 (19%)	2 (25%)
Somewhat	6 (9%)	13 (16%)	1 (13%)
Quite a bit	18 (26%)	18 (22%)	1 (13%)
Very much	34 (49%)	31 (38%)	4 (50%)

### *I feel sad*

	<b>Brain</b>	<b>Spine</b>	<b>Brain &amp; Spine</b>
Not at all	31 (44%)	24 (30%)	5 (63%)
Somewhat	17 (24%)	28 (35%)	2 (25%)
Quite a bit	15 (21%)	17 (21%)	0
Very much	2 (3%)	8 (10%)	1 (13%)

### *I am able to work*

	<b>Brain</b>	<b>Spine</b>	<b>Brain &amp; Spine</b>
Not at all	17 (24%)	15 (19%)	2 (25%)
Somewhat	15 (21%)	20 (25%)	2 (25%)
Quite a bit	7 (10%)	13 (16%)	0
Very much	27 (39%)	29 (36%)	4 (50%)

### *I am able to drive*

	<b>Brain</b>	<b>Spine</b>	<b>Brain &amp; Spine</b>
Not at all	16 (23%)	14 (17%)	3 (38%)
Somewhat	4 (6%)	13 (16%)	0
Quite a bit	13 (19%)	6 (7%)	0
Very much	33 (47%)	45 (56%)	5 (63%)

*I am able to enjoy my leisure pursuits*

	<b>Brain</b>	<b>Spine</b>	<b>Brain &amp; Spine</b>
Not at all	10 (14%)	9 (11%)	3 (38%)
Somewhat	20 (29%)	32 (40%)	0
Quite a bit	13 (19%)	15 (19%)	1 (13%)
Very much	25 (36%)	21 (26%)	4 (50%)

*I am content with the quality of my life*

	<b>Brain</b>	<b>Spine</b>	<b>Brain &amp; Spine</b>
Not at all	9 (13%)	14 (17%)	3 (38%)
Somewhat	21 (30%)	30 (37%)	0
Quite a bit	18 (26%)	21 (26%)	0
Very much	20 (29%)	13 (16%)	5 (63%)

# Health Survey

**In general, would you say your health is:**

	Brain (N=70)	Spine (N=81)	Brain & Spine (N=8)
Excellent	13 (19%)	8 (10%)	2 (25%)
Very good	25 (36%)	11 (14%)	3 (38%)
Good	21 (30%)	35 (43%)	2 (25%)
Fair	4 (6%)	20 (25%)	0
Poor	4 (6%)	3 (4%)	1 (13%)

**Compared to 1 year ago, how would you rate your general health now?**

	Brain	Spine	Brain & Spine
Much better	7 (10%)	4 (5%)	2 (25%)
Somewhat better	10 (14%)	12 (15%)	3 (38%)
Same	35 (50%)	34 (42%)	3 (38%)
Somewhat worse	9 (13%)	20 (25%)	0
Much worse	5 (7%)	7 (9%)	0

**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?**

	Brain	Spine	Brain & Spine
<b>Vigorous activities such as running, lifting heavy objects, participating in strenuous sports</b>			
No	16 (23%)	4 (5%)	2 (25%)
Yes, a little	14 (20%)	11 (14%)	3 (38%)
Yes, a lot	39 (56%)	64 (79%)	3 (38%)
<b>Moderate activities such as moving a table, pushing a vacuum cleaner, bowling or playing golf</b>			
No	33 (47%)	19 (24%)	6 (75%)
Yes, a little	15 (21%)	31 (38%)	0
Yes, a lot	21 (30%)	29 (36%)	2 (25%)
<b>Lifting or carrying groceries</b>			
No	44 (63%)	27 (33%)	6 (75%)
Yes, a little	14 (20%)	33 (41%)	0
Yes, a lot	11 (16%)	19 (24%)	2 (25%)
<b>Climbing several flights of stairs</b>			
No	37 (53%)	22 (27%)	6 (75%)
Yes, a little	11 (16%)	25 (31%)	1 (13%)
Yes, a lot	21 (30%)	32 (40%)	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?**

<b><i>Climbing one flight of stairs</i></b>			
No	44 (63%)	41 (51%)	7 (88%)
Yes, a little	13 (19%)	17 (21%)	0
Yes, a lot	10 (14%)	21 (26%)	1 (13%)
<b><i>Bending, kneeling or stooping</i></b>			
No	41 (59%)	15 (19%)	5 (63%)
Yes, a little	15 (21%)	36 (44%)	2 (25%)
Yes, a lot	13 (19%)	28 (35%)	1 (13%)
<b><i>Walking more than a mile</i></b>			
No	37 (53%)	22 (27%)	7 (88%)
Yes, a little	11 (16%)	18 (22%)	0
Yes, a lot	21 (30%)	39 (48%)	1 (13%)
<b><i>Walking several blocks</i></b>			
No	41 (59%)	24 (30%)	7 (88%)
Yes, a little	12 (17%)	33 (41%)	0
Yes, a lot	16 (23%)	22 (27%)	1 (13%)
<b><i>Walking one block</i></b>			
No	49 (70%)	48 (59%)	7 (88%)
Yes, a little	9 (13%)	10 (12%)	0
Yes, a lot	11 (16%)	20 (25%)	1 (13%)
<b><i>Bathing or dressing self</i></b>			
No	54 (77%)	53 (65%)	6 (75%)
Yes, a little	12 (17%)	17 (21%)	2 (25%)
Yes, a lot	3 (4%)	9 (11%)	0

**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?**

	Brain	Spine	Brain & Spine
<b><i>Cut down on the amount of time spent on work or other activities</i></b>			
No	41 (59%)	38 (47%)	6 (75%)
Yes	27 (39%)	40 (49%)	2 (25%)
<b><i>Accomplished less than you would like</i></b>			
No	34 (49%)	23 (28%)	6 (75%)
Yes	34 (49%)	55 (68%)	2 (25%)
<b><i>Were limited in the kind of work or activities</i></b>			
No	35 (50%)	33 (41%)	6 (75%)
Yes	33 (47%)	44 (54%)	2 (25%)
<b><i>Had difficulty performing the work or other activities</i></b>			
No	34 (49%)	31 (38%)	6 (75%)
Yes	34 (49%)	47 (58%)	2 (25%)

***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)?***

	Brain	Spine	Brain & Spine
<b><i>Cut down on the amount of time spent on work or other activities</i></b>			
No	48 (69%)	53 (65%)	6 (75%)
Yes	18 (26%)	25 (31%)	1 (13%)
<b><i>Accomplished less than you would like</i></b>			
No	41 (59%)	47 (58%)	6 (75%)
Yes	25 (36%)	31 (38%)	1 (13%)
<b><i>Didn't do work or other activities as carefully as usual</i></b>			
No	50 (71%)	52 (64%)	5 (63%)
Yes	16 (23%)	25 (31%)	0

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

	Brain	Spine	Brain & Spine
Not at all	23 (33%)	16 (20%)	5 (63%)
Slightly	17 (24%)	27 (33%)	1 (13%)
Moderately	12 (17%)	18 (22%)	1 (13%)
Quite a bit	7 (10%)	9 (11%)	1 (13%)
Extremely	7 (10%)	7 (9%)	0

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

	Brain	Spine	Brain & Spine
None	25 (36%)	7 (9%)	4 (50%)
Very mild	18 (26%)	15 (19%)	3 (38%)
Mild	4 (6%)	16 (20%)	0
Moderate	13 (19%)	21 (26%)	0
Severe	5 (7%)	13 (16%)	1 (13%)
Very severe	0	4 (5%)	0

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

	Brain	Spine	Brain & Spine
Not at all	37 (53%)	14 (17%)	6 (75%)
A little bit	9 (13%)	28 (35%)	1 (13%)
Moderately	12 (17%)	21 (26%)	0
Quite a bit	5 (7%)	11 (14%)	0
Extremely	2 (3%)	4 (5%)	1 (13%)

***These questions are about how you feel and how things have been with you during the past week.***

	Brain	Spine	Brain & Spine
<b><i>Did you feel peppy?</i></b>			
All of the time	4 (6%)	0	1 (13%)
Most of the time	18 (26%)	5 (6%)	2 (25%)
Good bit of the time	10 (14%)	13 (16%)	3 (38%)
Some of the time	11 (16%)	21 (26%)	0
Little bit of the time	15 (21%)	20 (25%)	1 (13%)
None of the time	9 (13%)	18 (22%)	1 (13%)
<b><i>Have you been a very nervous person?</i></b>			
All of the time	3 (4%)	3 (4%)	0
Most of the time	1 (1%)	3 (4%)	0
Good bit of the time	7 (10%)	5 (6%)	1 (13%)
Some of the time	11 (16%)	11 (14%)	1 (13%)
Little bit of the time	24 (34%)	20 (25%)	1 (13%)
None of the time	21 (30%)	36 (44%)	5 (63%)
<b><i>Have you felt so down nothing could cheer you up?</i></b>			
All of the time	0	2 (3%)	0
Most of the time	2 (3%)	3 (4%)	0
Good bit of the time	3 (4%)	6 (7%)	1 (13%)
Some of the time	9 (13%)	13 (16%)	0
Little bit of the time	5 (7%)	9 (11%)	3 (38%)
None of the time	48 (69%)	45 (56%)	4 (50%)
<b><i>Have you felt calm?</i></b>			
All of the time	7 (10%)	3 (4%)	1 (13%)
Most of the time	30 (43%)	24 (30%)	5 (63%)
Good bit of the time	14 (20%)	15 (19%)	2 (25%)
Some of the time	10 (14%)	21 (26%)	0
Little bit of the time	6 (9%)	9 (11%)	0
None of the time	1 (1%)	5 (6%)	0

**These questions are about how you feel and how things have been with you during the past week.**

	Brain	Spine	Brain & Spine
<b>Did you have a lot of energy?</b>			
All of the time	6 (9%)	2 (3%)	1 (13%)
Most of the time	15 (21%)	3 (4%)	3 (38%)
Good bit of the time	10 (14%)	16 (20%)	2 (25%)
Some of the time	12 (17%)	19 (24%)	0
Little bit of the time	11 (16%)	16 (20%)	0
None of the time	14 (20%)	21 (26%)	2 (25%)
<b>Have you felt blue?</b>			
All of the time	2 (3%)	2 (3%)	0
Most of the time	4 (6%)	8 (10%)	1 (13%)
Good bit of the time	3 (4%)	7 (9%)	0
Some of the time	13 (19%)	14 (17%)	1 (13%)
Little bit of the time	26 (37%)	30 (37%)	3 (38%)
None of the time	17 (24%)	16 (20%)	3 (38%)
<b>Did you feel worn out?</b>			
All of the time	3 (4%)	7 (9%)	0
Most of the time	12 (17%)	9 (11%)	1 (13%)
Good bit of the time	6 (9%)	18 (22%)	1 (13%)
Some of the time	14 (20%)	29 (36%)	2 (25%)
Little bit of the time	20 (29%)	11 (14%)	2 (25%)
None of the time	10 (14%)	3 (4%)	2 (25%)
<b>Have you been happy?</b>			
All of the time	12 (17%)	3 (4%)	2 (25%)
Most of the time	20 (29%)	23 (28%)	3 (38%)
Good bit of the time	13 (19%)	15 (19%)	2 (25%)
Some of the time	10 (14%)	21 (26%)	0
Little bit of the time	10 (14%)	14 (17%)	0
None of the time	3 (4%)	2 (3%)	1 (13%)
<b>Did you feel tired?</b>			
All of the time	9 (13%)	7 (9%)	1 (13%)
Most of the time	14 (20%)	20 (25%)	0
Good bit of the time	8 (11%)	17 (21%)	1 (13%)
Some of the time	13 (19%)	27 (33%)	2 (25%)
Little bit of the time	17 (24%)	7 (9%)	4 (50%)
None of the time	6 (9%)	0	0

**During the past week, how much of the time has your physical health or emotional problems interfered with your social activities?**

	Brain	Spine	Brain & Spine
All of the time	4 (6%)	6 (7%)	1 (13%)
Most of the time	12 (17%)	10 (12%)	0
Some of the time	11 (16%)	26 (32%)	1 (13%)
Little of the time	13 (19%)	19 (24%)	1 (13%)
None of the time	26 (37%)	15 (19%)	5 (63%)



**How TRUE or FALSE is each of the following statements for you?**

	Brain	Spine	Brain & Spine
<b><i>I seem to get sick easier than other people</i></b>			
Definitely true	7 (10%)	2 (3%)	1 (13%)
Mostly true	5 (7%)	6 (7%)	1 (13%)
Unsure	5 (7%)	8 (10%)	1 (13%)
Mostly false	17 (24%)	32 (40%)	4 (50%)
Definitely false	35 (50%)	30 (37%)	1 (13%)
<b><i>I am as healthy as anyone I know</i></b>			
Definitely true	18 (26%)	10 (12%)	3 (38%)
Mostly true	24 (34%)	25 (31%)	2 (25%)
Unsure	11 (16%)	12 (15%)	1 (13%)
Mostly false	9 (13%)	17 (21%)	1 (13%)
Definitely false	6 (9%)	14 (17%)	1 (13%)
<b><i>I expect my health to get worse</i></b>			
Definitely true	4 (6%)	7 (9%)	0
Mostly true	14 (20%)	15 (19%)	0
Unsure	20 (29%)	36 (44%)	1 (13%)
Mostly false	12 (17%)	8 (10%)	4 (50%)
Definitely false	19 (27%)	11 (14%)	3 (38%)
<b><i>My health is excellent</i></b>			
Definitely true	17 (24%)	6 (7%)	3 (38%)
Mostly true	24 (34%)	25 (31%)	2 (25%)
Unsure	13 (19%)	12 (15%)	0
Mostly false	7 (10%)	22 (27%)	1 (13%)
Definitely false	8 (11%)	13 (16%)	2 (25%)

***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?***

	Brain	Spine	Brain & Spine
No	48 (69%)	49 (61%)	4 (50%)
Yes	21 (30%)	27 (33%)	4 (50%)

***Have you had 2 years or more in your life that you felt depressed or sad most days, even if you felt okay sometimes?***

	Brain	Spine	Brain & Spine
No	54 (77%)	58 (72%)	6 (75%)
Yes	13 (19%)	21 (26%)	2 (25%)

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

	Brain	Spine	Brain & Spine
No	50 (71%)	53 (65%)	7 (88%)
Yes	18 (26%)	25 (31%)	1 (13%)

## Symptom Severity

We ask you to rate how severe the following symptoms have been in the last 24 hours ( 0 (symptom has not been present) to 10 (symptom was as bad as you can imagine it could be) .

### MDASI Core Items (Moderate to Severe Rating, $\geq 5$ )

	Brain (N=70)	Spine (N=81)	Brain & Spine (N=8)
Pain	13 (19%)	36 (44%)	1 (13%)
Fatigue	21 (30%)	36 (44%)	0
Nausea	7 (10%)	7 (9%)	0
Disturbed sleep	18 (26%)	29 (36%)	1 (13%)
Distressed/upset	17 (24%)	16 (20%)	0
Shortness of breath	7 (10%)	9 (11%)	0
Problems remembering things	20 (29%)	11 (14%)	0
Lack of appetite	8 (11%)	5 (6%)	0
Drowsiness/sleepiness	18 (26%)	23 (28%)	0
Dry mouth	10 (14%)	10 (12%)	0
Sadness	16 (23%)	15 (19%)	1 (13%)
Vomiting	3 (4%)	2 (3%)	0
Numbness/tingling	9 (13%)	40 (49%)	2 (25%)

### MDASI Brain Tumor Module Items

	Moderate to Severe (Rating $\geq 5$ )	
	Brain	Brain & Spine
Weakness	11 (16%)	0
Difficulty understanding	9 (13%)	0
Difficulty speaking	12 (17%)	0
Seizures	2 (3%)	0
Difficulty concentrating	16 (23%)	0
Vision	17 (24%)	0
Change in appearance	9 (13%)	0
Change in bowel pattern	4 (6%)	0
Irritability	12 (17%)	0

### MDASI Spine Tumor Module Items

	Moderate to Severe (Rating $\geq$ 5)	
	Spine	Brain & Spine
Radiating pain	31 (38%)	1 (13%)
Weakness	38 (47%)	0
Loss of control of bowel/bladder	18 (22%)	0
Change in bowel pattern	25 (31%)	0
Sexual function	33 (41%)	1 (13%)

### MDASI Interference Items (Moderate to Severe Rating, $\geq$ 5)

	Brain	Spine	Brain & Spine
General activity	26 (37%)	35 (43%)	1 (13%)
Mood	20 (29%)	22 (27%)	1 (13%)
Work	27 (39%)	35 (43%)	1 (13%)
Relations with others	13 (19%)	20 (25%)	0
Walking	25 (36%)	34 (42%)	0
Enjoyment of life	24 (34%)	26 (32%)	1 (13%)

### Module Overall Mean Severity (Range)

	Brain	Spine	Brain & Spine
MDASI Brain Tumor Module	2.13 (0-7.21)	--	0.71 (0-2.89)
MDASI Spine Tumor Module	--	2.96 (0-7.92)	0.73 (0-2.67)